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Are Social Networkers and Genome Testers One in the Same? The Limitations of Public Opinion Research for Guiding Clinical Practice

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Keywords

direct-to-consumer personal genome testing; public opinion research; physician-patient relationship

Several scholars have raised concerns about the potential ethical, legal and social implications of direct-to-consumer personal genome testing (PGT), particularly with regards to the clinical relevance of these tests and consumer-patients' expectations of healthcare providers to interpret test results (Hunter et al. 2008; McBride et al. 2008; McGuire & Burke 2008; Offitt 2008). As McGowan and Fishman (2008) have argued elsewhere, little is currently known about the actual consumer base for PGT, but as these services become more widely available and affordable, the need for empirical data regarding the uptake of PGT grows more important for evaluating the ethical, legal and social implications of this emergent technology. In order to assess whether the speculative concerns that have been raised about the clinical implications of these tests are substantive, it is imperative to track how early adopters interpret the results of these tests, whether and how the results inform healthcare decision-making, and how healthcare providers interpret and utilize these results in patient care. McGuire and colleagues' (year) study of potential consumer expectations regarding PGT moves towards filling this knowledge gap by assessing two significant ethical challenges posed by the availability of PGT: (1) why would-be consumers might be interested in using these services and (2) what they would do with their results, particularly whether and how PGT results would inform their healthcare decisions. Our commentary will focus on the usefulness and challenges of drawing upon a web-based survey of prospective users for evaluating these ethical concerns and informing the development of clinical guidelines regarding direct-to-consumer PGT.

In their findings, McGuire and colleagues report that “the majority (70%) of participants who would consider using PGT services reported they would ask for help interpreting their results from the company that conducted the analysis, but even more respondents (78%) would ask their physician to help interpret the results. Of those who have had PGT, 53% reported they discussed their results with their physician and 10% reported that they plan to” (page). From this finding, the authors hypothesize that “regardless of how PGT is marketed, potential consumers may still consider the information to be diagnostic and material to their healthcare decisions” (page). This hypothesis may sound an alarm concerning physician preparedness for PGT customers and their expectations regarding clinical interpretation of PGT results, however, the alarm may be muted by the methodological consideration of concern to us; that is, social networkers and genome testers are not necessarily one in the same.

Despite the authors' efforts to justify conflating these populations in the description of their sampling frame and their analysis of the potential uptake of PGT, as social scientists we are not convinced that users of a popular social networking website are necessarily the best

population to forecast the impact of the availability of these commercial services on the clinician-patient encounter. It is certainly plausible that some Facebook members may be PGT consumers, and market researchers would likely concur that the Facebook demographic of predominantly young, white, educated, insured, technologically-savvy individuals is more likely to purchase items on the Internet than nonusers of the Internet. But the selection bias resulting from using a social networking website to recruit participants does not account for the attitudes of the general public or necessarily those of early adopters of PGT. While it may be logistically challenging to find and survey early adopters of PGT on these issues, despite the challenges, the perspectives of early adopters would contribute much more to bioethical discourse and the development of clinical guidelines than the opinions of a convenience sample of social networkers, less than half of whom had any awareness of PGT before taking the survey. Ultimately, a bioethical assessment of a public opinion poll cannot move the debate over the potential clinical impact or utility of PGT services very far because neither the general public nor users of social networkers can capture the specificity of actual user and clinician perspectives on the potential clinical impact of these specialized services.

As a result, the use of a survey of a self-selecting group of social networkers limits the study's usefulness for medical professionals who may encounter actual consumer-patients of PGT because public interest in novel technologies may not necessarily translate to actual uptake nor accurately represent the motivations and health-related behaviors of early adopters of these techniques. As has been argued in reference to other novel and controversial medical technologies such as preimplantation genetic diagnosis (e.g. Ehrich et al. 2007; Franklin & Roberts 2006; Kalfoglou, Scott & Hudson, 2005; McGowan 2007), the personal experience and expertise on the everyday life of these technologies that consumer-patients and clinicians can provide lends nuanced insight into meanings of the technology specific to the most closely implicated constituencies. This, in turn, can inform the development of clinical guidelines and the framing of broader social implications in a way that public opinion research cannot.

Furthermore, the results of the study by McGuire and colleagues do not necessarily predict the behavior of the population of users of PGT, in part because the authors withheld a crucial piece of information which would likely greatly influence individuals' interest in using these services: the cost of PGT. The cost of these services, ranging from several hundred dollars to over two thousand dollars, might have figured importantly in consumer interest in these services, but because the authors did not include this information in the survey their hypotheses regarding consumer interest and behaviors may be overstated and thus diminishes the study's potential impact for informing clinical practice. The cost, availability and accessibility of PGT are all issues for which there is a need for empirical data, and assessment of the impact of these factors will be important for future research of consumer uptake and attitudes towards PGT.

While the aforementioned methodological issues are of concern, perhaps the most puzzling aspect of McGuire and colleagues' analysis and discussion was their decision to collapse and essentially ignore the data they collected from the small percentage (6%) of their participants that had actually used PGT. While the sample size of this group is small and may therefore limit the generalizability of the findings, the responses of 63 PGT users could have provided important baseline data profiling user perspectives on what they did with results of their test. While we recognize that the data collected from actual users of PGT was broken out from prospective users in the tables, we believe that the authors missed a key opportunity to provide more targeted insight for clinicians interested in preparing themselves for patients seeking advice on the results of PGT by collapsing data from actual early adopters of PGT with the responses of would-be users of PGT in their analysis and

discussion. The authors themselves acknowledged this limitation by indicating that “the attitudes and expectations of respondents who had not heard of these companies may not have been as informed as those who had” (page). However, it remains unclear why the authors did not capitalize on the available data from early adopters that could have provided a more robust representation of the clinical integration of PGT results since the authors did not provide an adequate explanation for why they felt it would be useful to analyze the perspectives of actual and would-be users together. The major shortcoming of this article is the missed opportunity which ultimately diluted the utility of these results for developing clinical guidelines and policy recommendations regarding PGT. It is unfortunate that the authors did not provide a rationale for analyzing actual and prospective users’ motivations together.

The authors end with a discussion of how the results of this study can be used to identify challenges to the clinical integration of PGT for clinicians preparing themselves for the arrival of PGT consumer-patients. Unfortunately, the authors have overstated the utility of this data for this purpose. Increasing physician education and establishing clinical guidelines for patients presenting with PGT results may ultimately be a constructive course of action, but insight into actual users’ attitudes and behaviors as well as clinicians’ attitudes, readiness and receptiveness to PGT will ultimately be more useful for the development of practice guidelines than is a survey of social networkers who may or may not ever use these services.

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