Addressing gaps in physician education using personal genomic testing

To the Editor:

Advances in genetic research have highlighted the need to expand physician education, especially among primary care physicians.^{1–3} This need is greater still with the recent emergence of direct-to-consumer (DTC) genetic testing products.^{4,5} The novelty of DTC products, coupled with their direct availability to patients, combine to suggest that in the near future, practicing physicians are likely to encounter patients wishing to discuss genetic test results with which those physicians have very limited familiarity.^{6,7}

To help address this gap in physician knowledge of genetics, several organizations have partnered with private sector companies that sell DTC testing products.^{8,9} Although the use of genetic testing in medical student teaching has been controversial,¹⁰ it is clear that innovative approaches will be necessary to address existing gaps in physician knowledge. A participatory approach to genetic education is also supported by data showing the effective-ness of interactive forms of medical education, especially pedagogical approaches that use some form of personal involvement.¹¹

As a way to increase physicians' familiarity with clinical genetics and personal genomic testing (PGT), in late 2008, Cleveland Clinic (CC) made anonymous PGT available to interested professional staff. The CC is located primarily in Cleveland, Ohio, and employs approximately 1800 salaried staff physicians under a group practice model. As part of this initiative, a commercially available DTC product was offered as a voluntary employee benefit, at no cost to physicians who chose to participate. Interested physicians were asked to attend a 90-minute educational session that discussed recent develop-

ments in clinical genetics and DTC genomic testing. At the end of the educational session, attendees were given a discount code that they could use to receive anonymous PGT through an independent service not affiliated with CC. Optional pre- and posttest counseling was available to those who participated.¹²

As this program presented a unique opportunity to characterize practicing physicians' opinions about the use of PGT as an educational approach, we developed a brief survey that was administered to attendees at the educational sessions. Survey items were developed through a review of relevant literature and refined by cognitive testing with CC physicians and research personnel. The final two-page instrument (available on request) consisted of five demographic items, 27 fixed-response items, and three open-ended items. This survey was approved by the Institutional Review Board at CC.

Two hundred twelve CC employees attended one of seven educational sessions held in early 2009. Attendees included 147 physicians, from whom we received 137 completed surveys (93% response). These physicians were predominantly male (68%), with an average age of 48 years (SD = 10.6). Half of these physicians were primary care specialists (general internal medicine, family medicine, obstetrics and gynecology, geriatrics, or general pediatrics).

The majority of physicians attending these educational sessions agreed that new findings in genetics were changing clinical practice in their areas of medicine (84%) and that increasing their familiarity with genetics would benefit their patients (97%). Fewer than half of physicians (39%) reported that they were familiar with recent genetic research affecting their patients. A similar proportion reported that their current knowledge of genetics was sufficient to answer their patients' questions (36%). Primary care physicians were more likely to strongly agree that increasing their familiarity with genetics would benefit their patients directly (67% vs. 43%, P = 0.006) and that to stay current in their area of medicine they needed to learn more about genetics (58% vs. 39%, P = 0.02).

Coding category	$n (\%)^{a}$	Illustrations
Better able to advise patients about the process of genomic testing, e.g., test procedures, diseases evaluated, and costs.	31 (53)	"Will make me aware of the process they will be going through.""Learning about the process will help in providing explanation and counseling to my patients.""I will be able to tell them about the preparation, counseling, and overall experience."
Better able to discuss genomic test results with patients, e.g., medical implications, potential utility, and potential limitations.	15 (26)	"Being able to explain limitations of results. Being able to know when to refer." "Can better explain results."
Better able to empathize or connect emotionally with patients who may be considering genetic testing	14 (24)	"Personal experience creates understanding and empathy, which will make me more able to be a better partner in my patients' decisions.""If I carry any high risk genes it would be easier to explain to a patient, having experienced the stress and decision making myself.""I will be able to personally empathize with the ambivalence that will accompany their decision-making process."
A general undefined appeal to the benefit of increased knowledge or direct personal experience with genetic testing	12 (21)	"I will be able to add another layer in the discussion—personal experience." "Personal experience dealing with genetic info."
No benefit	3 (5)	
Indeterminate	3 (5)	

Table 1 Written responses to the survey item "If you choose to pursue genomic testing, how do you think yourpersonal experiences will benefit your patients?"

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These findings reinforce previous findings about the educational needs of physicians.¹³

A majority of respondents (77%) felt that their personal experience pursuing PGT would benefit their patients directly. Written responses to the item "If you choose to pursue genomic testing, how do you think your personal experiences will benefit your patients?" were analyzed for content¹⁴ and are summarized in Table 1. Respondents often cited improvements in their ability to advise patients about the process of PGT (e.g., the procedures associated with ordering and the individual diseases evaluated) and increased ability to relate to patients' experiences interpreting genetic results.

We believe our study is the first attempt to characterize practicing physicians' interest in PGT as an educational experience. As an exploratory study, this study has several limitations. Participants were self-selected, and it is reasonable to assume that those who participated were more likely than other physicians to view additional training in clinical genetics as beneficial. Additionally, our sample was drawn from a single institution, and our findings may not be applicable to other medical settings. We also were not able to assess whether physicians' personal experiences with genomic testing resulted in a measurable improvement in genetic knowledge.

Our findings clarify what practicing physicians may find most valuable about the use of PGT as an educational tool. Future research should seek to clarify the extent to which these potential benefits are in fact achieved by educational initiatives that use PGT. Future research should also seek to compare the relative efficacy of educational interventions that do and do not include a participatory component. In addition to more traditional outcome measures, these studies should characterize the impact of PGT on physician empathy and interpretation of genetic risks.

Perhaps, the only consistent feature of human genetics has been its persistent challenge to traditional modes of thinking. As we consider the future educational needs of physicians, it will again be necessary to think creatively about genetics and the incorporation of genetics education into physician training. The participatory approach described herein represents a novel approach to educating physicians about clinical genetics and PGT. Although the utility of this approach has yet to be established, innovative educational approaches that include a participatory component may provide an effective way of increasing physicians' knowledge and awareness of clinical genetic testing.

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REFERENCES

- Guttmacher AE, Porteous ME, McInerney JD. Educating health-care professionals about genetics and genomics. *Nat Rev Genet* 2007;8:151– 157.
- Feero WG. Genetics of common disease: a primary care priority aligned with a teachable moment? *Genet Med* 2008;10:81–82.
- Burke W, Emery J. Genetics education for primary-care providers. Nat Rev Genet 2002;3:561–566.
- Eng C, Sharp RR. Bioethical and clinical dilemmas of direct-to-consumer personal genomic testing: the problem of misattributed equivalence. *Sci Trans Med* 2010;2:1–5.
- Salari K. The dawning era of personalized medicine exposes a gap in medical education. *PLoS Med* 2009;6:e1000138.
- Edelman E, Eng C. A practical guide to interpreting and clinical application of personal genomic screening. *BMJ* 2009;339:1136–1140.
- Offit K. Genomic profiles for disease risk: predictive or premature. JAMA 2008;299:1353–1355.
- Walt DR, Kuhlik A, Epstein SK, et al. Lessons learned from the introduction of personalized genotyping into a medical school curriculum. *Genet Med* 2011;13:63–66.
- Ormond KE, Hudgins L, Ladd JM, Magnus DM, Greely HT, Cho MK. Medical and graduate students' attitudes toward personal genomics. *Genet Med* 2011;13:400–408.
- Burke W, Evans JP. Teaching with single nucleotide polymorphisms: learning the right lessons. *Genet Med* 2011;13:17–18.
- 11. Mazmanian PE, Davis DA. Continuing medical education and the physicians as a learner: guide to the evidence. *JAMA* 2002;288:1057–1060.
- Edelman E, Eng C. A model for genomic counseling: one institution's experience in genetic counseling for post-direct-to-consumer 23andMe testing. J Genet Counsel 2009;18:689.
- Scheuner MT, Sieverding P, Shekelle PG. Delivery of genomic medicine for common chronic adult diseases: a systematic review. JAMA 2008;299: 1320–1334.
- Corbin JM, Strauss AL. Basics of qualitative research: techniques and procedures for developing grounded theory, 3rd ed. Thousand Oaks, CA: Sage Publications, Inc., 2008.