

The Importance of Patient Engagement

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WE READ WITH INTEREST TERRY'S recent editorial, "Don't Just Invite Us to the Table: Authentic Community Engagement" (Terry 2013). Terry makes the key point that there are merits to community engagement in developing policies affecting individuals and their families undergoing clinical exome and genome sequencing that can generate incidental findings. Managing incidental findings from genomic testing is an ongoing challenge, as evidenced by the volume and intensity of publications and debates examining the topic. We endorse Terry's call for purposeful patient, public, and professional interaction and opportunity for constructive discussion and debate on this topic. Broad proactive engagement creates an opportunity to develop guidelines and policies that not only identify and anticipate nuanced issues surrounding the disclosure of incidental findings but also identify and address salient issues. Perspectives of those who are healthy; have rare disorders or common chronic conditions; and are from diverse socioeconomic, ethnic, cultural, and regional backgrounds are needed.

This insight arose in our research (Daack-Hirsch *et al.*, 2013; Driessnack *et al.*, 2013) and that of others (Townsend *et al.*, 2012), namely, that members of the lay public not only want to be part of the health-related decision-making processes, such as the disclosure or nondisclosure of incidental findings, but also expect to be. Terry's editorial reinforces our understanding of procedural justice, that all stakeholders, including the public, have important contributions to make in addressing the challenges surrounding disclosure of incidental findings generated by genomic testing and therefore need to be contributing members at the table as guidelines and policy are created.

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References

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