


Terry, S. F., MA. (2011). Investing patients in the research and continuous improvement enterprise. *Patients charting the course: Citizen engagement in the learning health system: Workshop summary* (pp. 96-103) Institute of Medicine.


Horn E.J., Landy, D. C., Sharp, R. R., & Terry, S. F. (2010). Disease advocacy organizations may accelerate research through registries and biobanks. (poster). *2010 ACMG Annual Clinical Genetics Meeting, Albuquerque, NM.*, (March)


Khoury, Muin J., MD, PhD, McBride, C. M., PhD, Schully, S. D., PhD, Ioannidis, John P. A., MD, PhD, Feero, W. Gregory, MD, PhD, Janssens, A. Cecile J. W., PhD, et al. (2009). The scientific foundation for personal genomics: Recommendations from a national institutes of health-centers for disease control and prevention multidisciplinary workshop *Genetics in Medicine, 11*(8), 559-567.


Reed, K., Weaver, M., Chappelle, A., Furlong, P., Clapp, K., Miller, R., et al. (2009). Who said it? When did they say it? How did they know?: Deciding when to trust or trash genetics health information. (poster). *59th Annual Meeting of the American Society of Human Genetics.* (October)


Terry, S. F., Terry, P. F., Rauen, K. A., Uitto, J., & Bercovitch, L. G. (2007). Advocacy groups as research organizations: The PXE international example. Nature Genetics, 8


