HEALTH RESEARCH ABSTRACT SUBMISSIONS

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Title of Research *	Disclosure of incidental findings from genomic testing: A public perspective
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Introduction & Purpose *	Background: Incidental findings (IF) are clinical or research results unrelated to the reason or purpose for which a person is being tested. While guidelines are beginning to emerge re: disclosure of IF to patients and/or research participants, little is known about the issues and concerns arising from disclosure of genomic IF and even less is understood from the perspective of members of the public.
	Purpose: To explore the issues and concerns about disclosure of genomic IF in research and clinical settings from the perspective of members of the public.
Experimental Design *	Methods: This is an exploratory study, using qualitative description. Data are being collected using focus groups with a broad cross-section of different public groups. The first two focus groups have been conducted. The first focused on elderly adults, the second on parents of newborns with a new diagnosis of hearing loss. Focus group discussions were audio-taped, transcribed, and analyzed. N-Vivo was used for qualitative data management.

Results *

Results: Data collection and analysis are ongoing and consist of identifying descriptive categories of issues and concerns, both within and across the different groups. Findings from the first two groups suggest that individuals create personal contexts, drawing from personal experiences and clinical examples; however, personal experiences differed between the two groups. Elder participants tended to reflect on IF in the context of their past health care experiences and outcomes, while mothers of newborns with hearing loss tended to reflect on IF with respect to current/ongoing events whose outcomes were still uncertain and unknown. Despite these differences both groups indicted that they would want to be told about an IF as a result of genomic testing.

Conclusions *	Implications: Understanding the public perspective on disclosure of genomic IF is essential in development of disclosure guidelines and policies in both the clinical and research setting. Broad input is needed.
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