

# Broad Data Sharing in Genetic Research: *Views of Institutional Review Board Professionals*

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**Table 1.**  
**Participant Background Characteristics (N = 208)**

<i>Characteristic</i>	<i>Response</i>	<i>Percentage</i>
Degrees <sup>1</sup> (n = 198)	MA, MS, MSN, MBS, RN, MPH, MSW	44.4
	BA, BS, BSN	39.4
	PhD, ScD, EdD	18.7
	MD, DDS, /DMD, DO, DVM	12.1
	Other	17.7
Position <sup>1</sup> (n = 206)	IRB administrator/manager/director/staff	53.9
	IRB member	24.8
	Regulator/compliance coordinator/officer	19.9
	IRB chair	16.5
	HRPP administrator/manager/director/staff	14.6
	Other	71.4
Institution <sup>1</sup> (n = 205)	University	52.7
	Hospital	44.4
	Research center/institute	18.5
	Health system	18.1
	Medical center	16.6
	Nonprofit organization	15.6
	Other	78.0
Primary IRB panel (n = 204)	Biomedical	69.1
	Social, behavioral, educational	20.1
	Other	10.8
Areas represented on IRB <sup>1</sup> (n = 205)	Staff/administrative personnel	68.3
	Researcher, nursing/biomedical	12.7
	Researcher, social science	11.2
	Health care provider, physician	10.7
	Health care provider, nurse	7.3
	Other	29.3
Total years served on IRB (n = 198)	More than five years	59.6
	Three to five years	16.7
	One to two years	14.7
	Less than one year	9.1
Involved in substantive review of genetic studies (n = 208)	Yes	60.6

<sup>1</sup> Participants could select all that apply.

**Table 2.**  
**Need for Different Guidance for Genetic Research Studies**  
**Compared to Other Research Studies (N = 208)**

	<i>Yes Percentage</i>	<i>No Percentage</i>	<i>Not Sure Percentage</i>
Writing a consent form for genetic research (n = 203)	75.4	20.7	3.9
Designing procedures for recruiting participants for genetic research (n = 203)	42.9	41.4	15.8
Developing a genetic research study design (n = 201)	37.3	44.3	18.4
Developing a data repository or biobank that includes genetic data (n = 201)	65.7	23.9	10.5
Using large-scale data repositories containing genetic information (e.g., dbGAP)(n = 201)	60.2	28.9	11.0
Planning for sharing of genetic research data with other investigators (n = 202)	67.3	25.3	7.4