

Appendix 3: Methodology for the GPPC's Qualitative Evaluation of the Public's Knowledge, Beliefs, and Attitudes about Reproductive Genetics, 2003-2004

Abt Associates Inc. conducted focus groups and in-depth interviews for the Qualitative Evaluation of the Public's Knowledge, Beliefs, and Attitudes about Reproductive Genetics, sponsored by the Genetics and Public Policy Center. This study involved a collaborative, interdisciplinary research team that included five other researchers from academic institutions. The study populations included: (1) members of the general public, most of whom had little experience with genetic technologies, and (2) key informants who have more experience with genetic technologies, including families affected by genetic diseases, health care providers, and scientists. Data were collected from the general public through focus groups and data were collected from the remaining study populations through in-depth interviews.

All focus groups and interviews were audio taped and transcribed. The transcripts were then imported into NVivo, a qualitative data analysis software program. The research team developed the coding schemes, and Abt focus group moderators and interviewers coded the transcripts. The codes highlighted major themes that emerged from the data.

The study instruments and methodology were approved by the Institutional Review Boards of both Johns Hopkins University and Abt Associates Inc.

Focus Groups

Abt Associates Inc. conducted 21 2-hour focus groups with 181 members of the general public (8.6 people per group on average) between March 31 and April 22, 2003. Focus groups were conducted in five states (Massachusetts, Tennessee, California, Colorado, and Michigan) representing major U.S. geographic regions.

Fieldwork Inc., a national focus group vendor, provided facilities and recruited participants using a demographic survey. Each focus group facility maintains a database of potential focus group participants that contains contact and some demographic information on consumers by market area. People included in these databases have volunteered to participate in focus group research. They were recruited by word of mouth, telephone and the Internet. People were eligible to participate if they were fluent in English and had not participated in a focus group within the last 6 months. Participants received \$75 for their time. To ensure that the study participants had a broad range of perspectives on reproductive genetics, focus groups were homogeneous in terms of gender, age, race/ethnicity, religion, parental status, education and socioeconomic status. These demographic characteristics were associated with people's attitudes toward genetic technologies in the national telephone survey conducted by the Center in 2002. The characteristics of each focus group are shown in Table A-3a.

Table A-3a: Focus Group Characteristics

Group No.	No. of People	Location	Sex	Age	Parent?	Race/ Ethnicity	Religion	Education
1	8	Massachusetts	Mixed	25-40	N/A	N/A	N/A	N/A
2	7	Massachusetts	Female	35-45	N/A	N/A	Jewish	N/A
3	5	Massachusetts	Female	25-34	N/A	Mexican-American	N/A	N/A
4	7	Massachusetts	Mixed	25-34	N/A	N/A	N/A	N/A
5	9	Massachusetts	Male	25-34	N/A	African-American	N/A	N/A
6	6	Massachusetts	Female	25-45	N/A	N/A	Protestant	N/A
7	9	Tennessee	Female	25-34	N/A	African-American	N/A	College degree or >
8	9	Tennessee	Male	35-45	N/A	African-American	N/A	N/A
9	8	Tennessee	Male	18-25	No	N/A	N/A	N/A
10	10	California	Female	35-45	No	N/A	N/A	N/A
11	7	California	Female	35-45	N/A	Mexican-American	N/A	N/A
12	9	California	Male	35-45	N/A	Mexican-American	N/A	N/A
13	9	California	Male	35-45	N/A	N/A	N/A	< or = a high school diploma
14	9	California	Mixed	55+	Yes	N/A	N/A	N/A
15	7	California	Female	25-45	N/A	Chinese-American	N/A	N/A
16	11	Colorado	Female	25-34	N/A	N/A	Evangelical	N/A
17	11	Colorado	Female	18-25	No	N/A	N/A	N/A
18	8	Colorado	Male	25-34	N/A	Caucasian	N/A	College degree or >
19	10	Michigan	Female	35-45	N/A	Caucasian	N/A	< or = a high school diploma
20	11	Michigan	Female	35-45	N/A	African-American	N/A	< or = a high school diploma
21	11	Michigan	Female	25-34	N/A	Caucasian	Catholic	N/A

An experienced, trained moderator from Abt Associates Inc. facilitated each focus group using a discussion guide. The discussion guide was developed based on the research questions and objectives, concern about avoiding a limited pro-choice/pro-life discussion and cultural appropriateness. The guide consisted of a series of scenarios – realistic situations for fictitious couples involving choices about reproductive genetic technologies that might occur now or in the future -- and included questions to get participants to react to the situations. The scenarios were ordered in sequence, first presenting participants with the situations they were most likely to be familiar with and moving on to increasingly complex and/or futuristic stories. The sequence involved understanding an increasing amount about genetics and each scenario built on the previous one. The final guide included the following topics: carrier testing during and prior to pregnancy; prenatal genetic diagnosis for cystic fibrosis (sickle cell anemia was used for African-American groups, Tay-Sachs was used for the Jewish women’s group, and thalassemia was used for the Chinese-American group); preimplantation genetic diagnosis (PGD) for cystic fibrosis, late onset colon cancer, obesity and depression; genetic modification for cystic fibrosis, obesity, depression, and intelligence; and, finally, sperm sorting for sex selection to avoid an X-linked disease (Duchenne Muscular Dystrophy), family balancing and personal preference. The last section of the guide asked participants to reflect back on the technologies that had been described to them and to consider the social, regulatory, scientific, and ethical implications of the technologies. The moderator’s guide was pre-tested on three focus groups of Abt Associates employees.

The focus group moderators were assigned to groups according to their own personal characteristics to maximize cultural appropriateness whenever possible. Center staff trained moderators on genetic concepts related to the technologies in the discussion guide. Further details on methodology are available on the Center’s website www.DNAPolicy.org.

Interviews

Abt Associates Inc. conducted in-depth interviews with 61 families affected by genetic diseases, health care providers, and scientists between July 24, 2003 and March 4, 2004. Interviews were conducted over the telephone and lasted between 60 and 120 minutes (90 minutes on average). To ensure that participants with a broad range of perspectives on reproductive genetics were included, 12 types of families and providers were recruited (see Table A-3b). The types of genetic diseases were chosen in part based on convenience sampling but also to ensure that the diseases were moderate to severe.

Table A-3b Recruitment Sources and Criteria for Interview Populations

Group #	Special Population	# of Participants	Recruiting Source	Date Recruitment Started	Recruitment Criteria
People with a Genetic Condition in their Family					
1	Parents of a child with a genetic condition	5	Cystic Fibrosis Research Inc. listserv	9/03	Biological parent of child with cystic fibrosis
2	Adults with a genetic condition	5	Providers for people with achondroplasia or Marfan syndrome	8/03	Individuals with an autosomal dominant condition (achondroplasia or Marfan syndrome)
People with PGD Experience for Single-Gene Disorders					
3	Successful PGD outcome	3	PGD providers; Cystic Fibrosis Research Inc. listserv; Fanconi anemia informal network	11/03	Biological mother of child born after using PGD for single-gene disorder
4	Unsuccessful PGD outcome	6	PGD providers; Cystic Fibrosis Research Inc. listserv; Fanconi anemia informal network	11/03	Woman who was unsuccessful in using PGD to avoid birth of child with single-gene disorder (or male partner of)
5	Declined PGD	3	PGD providers; Cystic Fibrosis Research Inc. listserv; Fanconi anemia informal network	11/03	Woman who considered using PGD to avoid birth of child with single-gene disorder (or male partner of)
Providers					
6	Nurse midwives	5	American College of Nurse Midwives regional listservs for SE and Midwest regions	7/03	Certified nurse midwives who delivered more than 30 babies last year
7	Obstetrician-gynecologists	5	Obstetrician listserv: forums.obgyn.net	7/03	Delivered more than 30 babies last year
8	Family practice physicians	5	Family Practice Obstetrics listserv: famdel@lsv.uky.edu	7/03	Board-certified in family practice and delivered more than 20 babies last year
9	Assisted reproductive technology genetic counselors	5	National Society of Genetic Counselors ART Special interest group listserv: ART-L@LIFE.UAMS.EDU	7/03	Certified genetic counselors who specialize in reproductive genetics and counsel PGD patients
10	Prenatal genetic counselors	5	National Society of Genetic Counselors listserv: nsqclist@maelstrom.stjohns.edu	7/03	Certified genetic counselors who specialize in prenatal genetics and counsel prenatal patients
11	PGD Nurses	4	List of 62 nurses' emails from American Society for Reproductive Medicine	7/03	Nurses who provide care for patients using PGD for single gene disorders
12	PGD Specialists (physicians and/or scientists)	10	GPPC list of PGD specialists	7/03	Performs PGD for single gene disorders and/or provides clinical care for PGD patients
TOTAL		61			

GPPC=Johns Hopkins University Genetics and Public Policy Center

Abt Associates Inc.

Potential interview respondents were recruited primarily using the Internet beginning in July 2003 and ending in March 2004. All of the adults with a genetic condition had either achondroplasia or Marfan syndrome and were recruited via their providers, with whom one research team member was familiar. Parents of children with a genetic condition were recruited through a cystic fibrosis organization. PGD patients were recruited through either PGD providers or advocacy organizations that we were familiar with and that had listservs (the cystic fibrosis and Fanconi anemia organizations). Other conditions represented by the PGD patient interviewees included Fabry disease, hemophilia, and congenital adrenal hyperplasia. PGD specialists were identified by GPPC staff and recruited directly.

The research team developed separate interview guides for each group with the exception of nurse midwives, family practice physicians, and obstetrician-gynecologists, for whom only one interview guide was developed. Each guide consisted of a core set of questions based on scenarios from the focus group moderator's guide (in order to make comparisons between focus group participants and interviewees) as well as questions specific to their personal experience or clinical practices.

All interview groups first received a recruitment letter and a disclosure statement either emailed directly by the Center or their provider or posted on various listservs or websites for professional societies or support groups (after receiving permission from each group responsible for the listservs/websites). The recruitment letter described the study, eligibility criteria (such as fluency in English and recruitment criteria specific to each group), and directed interested potential interviewees to call a toll-free study hotline at Abt to find out more information about the study and to schedule an interview.

Interviews were conducted by one of three interviewers from Abt Associates who received training from Center staff on basic genetic concepts included in the interview guides. After the interview was complete and the audiotape was turned off, interview respondents were asked the same set of demographic questions asked of focus group respondents. All groups except the PGD providers (PGD specialists, PGD nurses, and ART genetic counselors), received \$50 for their time. PGD providers were not offered a monetary incentive because we assumed that they would be willing to discuss their experiences without compensation as a professional courtesy. Further details on methodology are available on the Center's website www.DNAPolicy.org.