Public perspectives on the use of preimplantation genetic diagnosis

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Abstract

Purpose To study the perspectives of the United States population towards the use of preimplantation genetic diagnosis (PGD) in various clinical scenarios.

Methods Online cross-sectional population based questionnaire of a nationally representative sample according to age, gender, race/ethnicity, income, education and religion.

Results A total of 1006 completed the questionnaire with an overall response rate of 94 %. A majority supported PGD for diseases fatal early in life or those causing lifelong disability (72.9 and 66.7 %, respectively); only 48.0 % supported PGD for diseases that manifest late in life. Respondents were more supportive of PGD for genetic diseases if they were aware of PGD prior to the survey (OR=1.64; CI=1.13–2.39). However, a small proportion were in favor of genetically-based trait selection: 21.1 % supported PGD for sex selection, 14.6 % for physical traits and 18.9 % for personality traits. Compared to

women, men were nearly two- to three-fold more supportive of PGD for sex selection (OR=1.65; CI=1.20–2.78), physical traits (OR=2.38; CI=1.60–3.48) and personality traits (OR=2.31; CI=1.64–3.26). Compared to Caucasians, Asians (OR=3.87; CI=1.71–8.78) and African Americans (OR=1.61; CI=1.04–2.74) were more supportive of PGD for sex selection.

Conclusions In a nationally representative sample, a majority supported PGD to identify early onset diseases. We noted significant variation in opinions by sex, race, and education. There was more support among those with prior knowledge of PGD suggesting that education about PGD may foster favorable opinions. This study identifies public knowledge and attitudes that may be used to shape future research hypotheses and clinical policies.

Keywords PGD · IVF · Public perspectives · Attitudes

Capsule Attitudes of the general public concerning the use of preimplantation genetic diagnosis vary by sex, race, and education.

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Introduction

Over 75 % of fertility clinics in the United States offer preimplantation genetic diagnosis (PGD), and approximately 4–6 % of IVF procedures utilize PGD annually [1]. While PGS can be utilized to screen for aneuploidy in patients undergoing IVF, PGD is also widely used to screen for specific genetic disorders. With modern technology, thousands of single gene defects that cause disease can be successfully identified, ranging from more common genetic diseases such as cystic fibrosis, muscular dystrophy and sickle cell anemia to rare diseases such as Denys-Drash Syndrome, Hurler Syndrome or Senior-Loken Syndrome.

The use of PGD to screen for genetic disorders has led to ongoing medical and ethical debates among healthcare providers both within the United States and internationally [2–4].

While the debates about the acceptability of PGD have included potential biologic impact as well as moral, political and religious values, these discussions rarely take into account attitudes of the general public. It is important to understand public perspective towards PGD, as these perspectives can be used to inform the development of recommendations, educational programs, and policies by professional medical organizations and fertility centers.

The majority of studies about attitudes towards PGD involve specific patient populations including those undergoing IVF, those with specific genetic disorders such as BRCA or thalassemia, or those seeking prenatal genetic counseling [5–10]. In general, these patients are both more likely to benefit from and more likely to utilize PGD. It therefore makes sense that these patients desire more reproductive genetic testing than is currently offered [5, 6] and believe that PGD is an excellent alternative to prenatal diagnosis [7, 8]. Similarly, couples at high-risk for genetic disease in their children favor legislation that permits the use of PGD [9] and are more likely to believe that offering PGD is considered ethical practice [10]. While there are limited studies on the attitudes of the general population, it seems that medical professionals may have more negative views towards genetic tests [11, 12].

In addition to the use of PGD to screen for genetic diseases, PGD could potentially be used to screen for both desired physical traits such as height, attractiveness or athleticism and personality traits such as intelligence, or humor. While some countries such as the UK, Canada, Germany and Switzerland ban PGD for non-medical use, other countries including the United States have become destinations for medical tourists seeking to take advantage of this new technology [13]. Sex selection may be the most common non-medical use of PGD. In the United States, over 80 % of fertility clinics that offer PGD will allow sex selection [1] yet a study in 2002 suggested that 70 % of the general population disapproved of PGD for sex selection [14]. As technology and our knowledge of genetics continue to evolve, the use of PGD to screen for certain desirable traits is increasingly becoming a possibility; there is limited information about public attitudes around this reality.

A survey conducted by the Genetics and Public Policy Center over a decade ago found that while only 24 % of the general public had heard of PGD, 74 % approved of PGD to screen for severe inherited diseases and 60 % approved of PGD to avoid a tendency to diseases like cancer [14]. The current study provides a more contemporary and comprehensive national public perspective on this widely utilized and rapidly evolving technology.

Materials and methods

The data for this survey were collected by Harris Interactive Service Bureau (HISB), a professional online survey company

with over six million participants. HISB recruited a panel of participants and then screened respondents with basic demographic questions to ensure a population corresponding to the most recent United States Census data. Respondents were selected to be representative of the U.S. population of adults based on sex, education, race/ethnicity, geography, religion and income. Eligible participants included male or female U.S. residents aged 18–75 years. The study was approved by the Human Research Committee of Brigham and Women's Hospital.

The questionnaire was distributed from December 10, 2013 to December 18, 2013. The questionnaire consisted of an introductory page that included a summary of the goals of the investigation as well as contact information both for the research team and for the institutional review board (see [Appendix 1: Questionnaire](#) for questionnaire). All of the participants provided socio-demographic information. Participants then were instructed to read a brief paragraph describing the process of PGD followed by 14 multiple choice questions: six on the utilization of PGD for genetic diseases and six on the utilization of PGD for personal traits. Participants were given the option to type descriptive text for questions that assessed a participant's reasoning behind answers selected. These freehanded responses were re-categorized into existing answer categories if the open-ended response was similar to or a paraphrase of an existing answer choice. All typed response not otherwise classified formed the "other" group.

Statistical analysis Descriptive statistics were calculated and reference groups were established as either the lower tail for the distribution for ordinal predictors or as the largest group for nominal predictors. Respondents who selected 'other' and entered a free response were reclassified into the appropriate category when applicable. Respondents were assessed in either their degree of opposition or degree of support in various clinical scenarios. Unadjusted and multivariable odds ratios (OR) and 95 % Wald confidence intervals (CI) were calculated using logistic regression. There was no evidence to indicate that there was confounding among the covariates, so any interaction between them was considered to be one of effect modification. The covariates in the multivariable model looking at support for PGD to screen for genetic diseases included number of biological children (0, 1–2, ≥ 3), religion (Christian-protestant, Christian-catholic, Jewish, atheist/agnostic, other), awareness of PGD prior to this study (yes, no), and personal acquaintance with someone requiring assisted reproductive technology to achieve a healthy pregnancy (yes, no) since these were all found to be significant in the univariate model. The covariates in the multivariable model looking at support for PGD to screen for genetic traits included gender (male, female), race (white, black or African American, Asian, other), number of biological children (0, 1–2, ≥ 3) and religion (Christian-protestant, Christian-catholic,

Jewish, atheist/agnostic, other) since these were also all found to be significant in the univariate model. For the main OR analysis, all covariates were treated as being either dichotomous or categorical, without taking into account any natural ordering. The OR was calculated separately for each category along with 2-sided Wald confidence intervals (95 %). In addition, with covariates for which there was a natural order in the way categories were defined, separately a trend value (p) was calculated. All reported P -values are based on two-sided tests. SAS 9.3 statistical software was used for all analysis.

Results

A total of 1226 respondents were initially recruited for the study. Among those recruited, 156 did not qualify for the survey because the quota of respondents with their given demographic characteristics had already been fulfilled. Exclusion of these respondents helped ensure a population that corresponded to the general United States population. Of the 1070 qualified respondents 1006 successfully completed the questionnaire for an overall response rate of 94 %. The distribution of participants across age, sex, income, geography, race/ethnicity and education largely matched the general United States Census with slightly fewer Hispanics/Latinos and slightly more college educated respondents among our cross-sectional participant population (Table 1) [15]. Among respondents, 49.5 % knew someone with a genetic or developmental disorder, 28.2 % knew someone who required assisted reproductive technology (ART) to achieve a healthy pregnancy and 27.7 % were aware of PGD before completing this study.

Support for PGD to screen for genetic diseases

A majority of respondents supported PGD to screen for genetic diseases: 72.9 % supported screening for ‘diseases that are fatal in the first few years of life,’ 66.7 % supported screening for ‘diseases that cause lifelong disability such as mental retardation or deafness’ and 48 % supported screening for

Table 1 Demographic characteristics of respondents ($n=1006$)

Characteristic	Frequency (%)
Gender	
Male	483 (48.0)
Female	523 (52.0)
Age	
18–29	143 (14.2)
30–39	168 (16.7)
40–49	205 (20.4)

Table 1 (continued)

Characteristic	Frequency (%)
50–65	246 (24.5)
65–69	142 (14.1)
70–75	102 (10.1)
Race	
White	834 (82.9)
Black or African American	111 (11.0)
Asian	26 (2.6)
Other / Multi-Racial	35 (3.5)
Ethnicity	
Hispanic or Latino	87 (8.7)
Not Hispanic or Latino	919 (91.4)
Geographic Region	
East	221 (22.0)
Midwest	268 (26.6)
South	342 (34.0)
West	175 (17.4)
Household income (annual)	
≤\$40,000	398 (39.6)
\$40,001–\$60,000	378 (37.6)
≥\$60,001	230 (22.9)
Education Level	
No college degree	490 (48.7)
College degree	416 (41.4)
Graduate or professional degree	100 (9.9)
Religion	
Christian – Protestant	481 (47.7)
Christian – Catholic	230 (22.9)
Jewish	42 (4.2)
Atheist or Agnostic	192 (19.1)
Other ^a	61 (6.1)
Number of biological children	
0	392 (39.0)
1 or 2	436 (43.3)
3 or more	178 (17.7)
Aware of PGD ^b before this study	
Yes	279 (27.7)
No	727 (72.3)
Personally know someone with a genetic or developmental disorder	
Yes	498 (49.5)
No	508 (50.5)
Personally know someone who required ART ^c to achieve a healthy pregnancy	
Yes	284 (28.2)
No	722 (71.8)

^a Those who responded ‘Other’ included individuals who were Hindu (0.5 %), Muslim (0.6 %), Buddhist (0.9 %), spiritual (1.1 %) and Wiccan (1.1 %)

^b PGD: Preimplantation genetic diagnosis

^c ART: Assisted reproductive technology

‘diseases that may not occur until later in life, such as diseases that place an individual at a high risk for cancer during adulthood’ (Table 2) Overall, respondents were more supportive of PGD for genetic diseases if they were aware of PGD prior to the survey (OR=1.64; CI=1.13–2.39) or if they knew someone who had required ART to achieve a healthy pregnancy (OR=1.46; CI 1.02–2.10). Compared to respondents with no children, those with three or more children were significantly less supportive of PGD for genetic diseases (OR 0.63; CI 0.41–0.96). Overall, atheists and agnostics were more likely to support PGD for genetic diseases (OR 1.89; CI=1.10–3.21) when compared to Christian-Protestants. The OR and the CI in multivariate models were similar to those in univariate models, indicating that there was no significant confounding among the covariates.

Analysis showed that respondents who supported PGD to identify genetic diseases were more likely to support PGD for trait selection (chi-square 2-sided p -value<0.001). Among the scenarios for genetically-based trait selection, 21.1 % supported PGD to screen for sex selection, 14.5 % for ‘physical characteristics such as height, eye color or athleticism,’ 18.9 % for ‘personality traits such as intelligence,’ and 13.3 % for sexual orientation. Compared to women, men were two- to three-fold more supportive of PGD for sex selection (OR=1.65; CI=1.20–2.78), physical traits (OR=2.36; CI=1.60–3.48) personality traits (OR=2.31; CI=1.64–3.26) and sexual orientation (OR=2.73; CI=1.82–4.09) (Table 3). Older respondents were less supportive of PGD to screen for physical traits when compared to those under 40 years old (respondents aged 40–64 had an OR=0.59; CI=0.39–0.88 and respondents 65 and older had an OR=0.33; CI 0.17–0.64). Compared to Caucasians, Asians were four times more supportive of PGD for sex selection (OR=3.87; CI=1.71–8.78) and African Americans were almost twice as likely to support PGD for sex selection (OR=1.64; CI=1.04–2.74). Similarly Catholic respondents were more likely to support PGD for sex selection (OR=1.56; CI=1.03–2.36) compared to protestants.

Respondents who agreed with the use of PGD in any of the clinical scenarios were presented with a number of reasons for their support; the responses are depicted in Table 4. Among respondents who supported PGD for genetic diseases, a majority thought that ‘couples should be able to make their own decisions about having a child’ and ‘PGD improves the chances that a couple will have a healthy child’ (66.2 and 62.1 % respectively). A minority of participants thought that ‘PGD will lower healthcare costs and may result in a better society’ (34.0 %). Similarly, among respondents who support PGD for trait selection, a majority supported PGD for genetic traits because they felt couples should have reproductive autonomy (75.1 %), while a minority thought it helped a child lead a successful life (37.1 %).

Opposition to PGD to screen for genetic diseases

Compared to Caucasians, African Americans were less likely to oppose PGD for late onset diseases (OR=0.45; CI=0.25–0.81), sex selection (OR=0.52; CI=0.34–0.80), physical traits (OR=0.51; CI=0.34–0.78), personality traits (OR=0.53; CI=0.35–0.81) or sexual orientation (OR=0.63; CI=0.41–0.95). Respondents with three or more children were approximately twice as likely to oppose PGD for diseases fatal early in life (OR=2.14; CI=1.25–3.68), diseases causing lifelong disability (OR=2.55; CI=1.54–4.21), or diseases with a late onset (OR=1.82; CI=1.19–2.77) than were those with no children. Those with a graduate degree were more likely to oppose PGD for sex selection (OR=2.36; CI=1.49–3.74), physical traits (OR=2.06; CI=1.28–3.31), personality traits (OR=2.72; CI=1.70–4.35) or sexual orientation (OR=2.10; CI=1.29–3.41) compared to those without a college degree. Respondents who knew someone with a genetic or developmental disorder were not more likely to oppose PGD for to screen for genetic diseases (OR=1.53; CI=0.99–2.37) but were more likely to oppose PGD for selection of sex (OR=1.89; CI=1.46–2.45), physical traits (OR=1.82; CI=1.39–2.37),

Table 2 Overall public perspectives on whether doctors should be allowed to perform preimplantation genetic diagnosis (PGD) in different clinical scenarios, n (%)

Indication for PGD	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
Diseases fatal in the first few years of life ^a	314 (31.2)	419 (41.7)	169 (16.8)	58 (5.8)	46 (4.6)
Diseases causing lifelong disability ^a	286 (28.4)	385 (38.3)	202 (20.1)	88 (8.8)	45 (4.5)
Diseases that do not occur until later in life	198 (19.7)	285 (28.3)	293 (29.1)	160 (15.9)	70 (7.0)
Screening for personality traits ^a	76 (7.6)	114 (11.3)	307 (30.5)	256 (25.5)	253 (25.2)
Screening for sex selection	76 (7.6)	136 (13.5)	276 (27.4)	258 (25.7)	260 (25.8)
Screening for physical traits	60 (6.0)	86 (8.6)	268 (26.6)	276 (27.4)	316 (31.4)
Screening for sexual orientation ^a	59 (5.9)	75 (7.5)	257 (25.6)	249 (24.8)	366 (36.4)

^a Due to rounding errors, some of the totals in individual rows total to more than 100 %

Table 3 Association between support of PGD with different demographic and personal characteristics ($n=1006$)

Characteristic	Relationship between support for PGD and select demographic characteristics, odds ratio (95 % confidence interval) ^a or p value for linear trend ^b						
	Diseases fatal early in life	Diseases causing lifelong disability	Diseases with onset late in life	Sex selection	Physical traits	Personality traits	Sexual orientation
Gender							
Male	1.19 (0.89–1.59)	1.13 (0.86–1.47)	1.53 (0.19–1.97)	1.65 (1.20–2.28)	2.36 (1.60–3.48)	2.31 (1.64–3.26)	2.73 (1.82–4.09)
Female	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.000 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
Age	$P=0.29$	$P=0.14$	$P=0.99$	$P=0.49$	$P<0.01$	$P=0.48$	$P=0.13$
18–39	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1000 (Referent)	1.00 (Referent)	1.00 (Referent)
40–64	1.03 (0.73–1.45)	0.89 (0.64–1.22)	0.99 (0.73–1.34)	0.89 (0.62–1.28)	0.59 (0.39–0.88)	0.81 (0.55–1.19)	0.74 (0.42–0.99)
>65	1.35 (0.89–2.06)	1.26 (0.85–1.87)	1.02 (0.71–1.46)	0.74 (0.47–1.21)	0.33 (0.17–0.64)	0.99 (0.60–1.63)	0.72 (0.40–1.27)
Race							
White	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
Black or African American	0.80 (0.51–1.24)	0.89 (0.58–1.36)	1.46 (0.97–2.19)	1.68 (1.04–2.74)	1.74 (1.00–3.02)	1.46 (0.86–2.46)	1.05 (0.56–1.97)
Asian	0.65 (0.27–1.55)	0.49 (0.22–1.10)	1.01 (0.46–2.23)	3.87 (1.71–8.78)	1.70 (0.67–4.30)	2.18 (0.91–5.19)	1.63 (0.61–4.30)
Other / Mixed Race	0.78 (0.37–1.65)	0.70 (0.35–1.41)	1.46 (0.73–2.90)	1.31 (0.60–2.89)	1.58 (0.68–3.69)	1.76 (0.81–3.82)	2.05 (0.88–4.75)
Education Level	$P=0.33$	$P=0.94$	$P=0.40$	$P=0.39$	$P=0.74$	$P=0.58$	$P=0.70$
No college degree	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
College degree	1.17 (0.86–1.58)	0.98 (0.74–1.30)	0.87 (0.66–1.14)	0.86 (0.61–1.20)	0.88 (0.59–1.30)	0.96 (0.68–1.36)	0.92 (0.62–1.37)
College or professional degree	1.45 (0.84–2.49)	0.92 (0.57–1.48)	0.77 (0.49–1.20)	0.70 (0.40–1.23)	0.83 (0.44–1.56)	0.73 (0.40–1.32)	0.75 (0.38–1.50)
Religion							
Christian - Protestant	1.00 (Referent)	1.00 (Referent)	1.000 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
Christian - Catholic	0.82 (0.57–1.17)	0.97 (0.69–1.37)	1.31 (0.94–1.82)	1.56 (1.03–2.36)	1.38 (0.82–2.31)	1.19 (0.76–1.86)	1.33 (0.79–2.24)
Jewish	1.73 (0.74–4.05)	1.53 (0.73–3.23)	1.33 (0.69–2.54)	1.34 (0.58–3.09)	1.86 (0.71–4.90)	1.12 (0.46–2.72)	2.23 (0.94–5.34)
Atheist or Agnostic	1.86 (1.14–3.01)	1.59 (1.03–2.45)	1.65 (1.13–2.43)	1.61 (1.01–2.57)	2.03 (1.20–3.44)	1.58 (0.98–2.54)	1.51 (0.87–2.62)
Other	1.05 (0.70–1.56)	0.89 (0.62–1.29)	1.23 (0.86–1.75)	0.97 (0.60–1.55)	1.33 (0.77–2.29)	1.06 (0.65–1.73)	1.29 (0.74–2.24)
Number of biological children	$P=0.06$	$P=0.16$	$P=0.08$	$P=0.43$	$P=0.26$	$P=0.01$	$P=0.54$
0	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
1 or 2	1.05 (0.76–1.46)	0.91 (0.67–1.23)	0.76 (0.57–1.00)	0.86 (0.60–1.22)	0.76 (0.50–1.14)	0.64 (0.44–0.93)	0.81 (0.53–1.24)
3 or more	0.67 (0.44–1.00)	0.69 (0.48–1.01)	0.71 (0.49–1.02)	0.73 (0.44–1.20)	0.66 (0.36–1.22)	0.51 (0.30–0.87)	0.76 (0.42–1.39)
Aware of PGD before this study							
Yes	1.77 (1.25–2.50)	1.25 (0.92–1.70)	1.12 (0.85–1.49)	1.23 (0.87–1.73)	1.10 (0.73–1.64)	1.18 (0.82–1.69)	1.17 (0.78–1.75)
No	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
Personally know someone with a genetic or developmental disorder							
Yes	1.10 (0.82–1.48)	1.04 (0.79–1.38)	1.04 (0.80–1.36)	0.97 (0.71–1.33)	0.92 (0.63–1.33)	1.06 (0.76–1.48)	0.87 (0.60–1.28)
No	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)

Table 3 (continued)

Characteristic	Relationship between support for PGD and select demographic characteristics, odds ratio (95 % confidence interval) ^a or p value for linear trend ^b						
	Diseases fatal early in life	Diseases causing lifelong disability	Diseases with onset late in life	Sex selection	Physical traits	Personality traits	Sexual orientation
Personally know someone who required ART to achieve a healthy pregnancy							
Yes	1.35 (0.97–1.88)	1.25 (0.92–1.69)	1.15 (0.87–1.52)	1.01 (0.71–1.44)	0.98 (0.64–1.49)	1.03 (0.71–1.49)	1.16 (0.76–1.76)
No	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)

^a Multivariable logistic regression was used to calculate the odds ratio and 95 % confidence intervals. The covariates in the multivariable logistic regression model for support for screening for genetic diseases include number of biological children (0, 1 or 2, ≥ 3), religion (Christian-Protestant, Christian-Catholic, Jewish, Atheist or Agnostic, Other), awareness of PGD prior to this study (yes, no), personal acquaintance with someone with a genetic or developmental disorder (yes, no), and acquaintance with someone who required ART to achieve a healthy pregnancy (yes, no). The covariates in the multivariable logistic regression model for support for screening for genetic traits include gender (male, female), race (white, black or African American, Asian, other), number of biological children (0, 1–2, ≥ 3) and religion (Christian-protestant, Christian-catholic, Jewish, atheist/agnostic, other)

^b In addition to the primary analysis for which all the variables were treated as dichotomous or categorical, a separate analysis of linear trend (p) was calculated for variables that had a natural order in the way the categories were defined (age, education level and number of biological children)

Table 4 Reasons for support or opposition to pre-implantation genetic diagnosis (PGD) ($n=1006$)

	PGD to screen for genetic diseases, n (%)	PGD to screen for traits, n (%)
Reason support	$n=1887^a$	$n=692$
Couples should be able to make their own decision	1250 (66.2)	520 (75.1)
Improves chances of having a healthy child	1172 (62.1)	n/a
Helps a child lead a successful life	n/a	257 (37.1)
May lower healthcare costs/ may lead to a better society	642 (34.0)	164 (23.7)
Can eliminate certain genetic diseases forever	682 (36.1)	0 (0.0)
Other	66 (3.5)	31 (4.5)
Reason oppose	$n=467$	$n=2234$
Unnecessary destruction of embryos	214 (45.8)	855 (38.3)
Promotes discrimination against groups of people	198 (42.3)	1221 (54.7)
Interferes with nature, allows doctors to play God	316 (67.7)	1399 (62.6)
Widespread use may lead to unforeseen consequences	217 (46.5)	1043 (46.7)
There is no regulation	104 (22.3)	537 (24.0)
Other	36 (7.7)	163 (7.3)

^a Numbers add to more than 1006, because participants were able to select multiple reasons for each scenario

personality traits (OR=1.84; CI=1.42–2.38) or sexual orientation (OR=1.77; CI=1.36–2.31).

Respondents who disagreed with the use of PGD were presented a number of reasons for their opposition. Among respondents who opposed PGD to screen for genetic diseases, 67.7 % thought ‘PGD interferes with nature and places doctors in the role of playing God,’ 46.5 % thought that ‘widespread use of PGD may lead to unforeseen consequences,’ 45.8 % thought that ‘PGD leads to the unnecessary destruction of embryos,’ and 42.3 % thought that ‘PGD promotes discrimination against people with certain characteristics.’ Nearly a quarter (22.3 %) opposed PGD for genetic diseases because ‘there is no regulation of PGD’.

Discussion

In a nationally representative sample, a majority supported PGD to identify genetic diseases. Similar levels of support for PGD have been seen in populations outside the United States including Europe and Asia [16, 17]. Although the majority of respondents supported PGD to identify genetic diseases, most did not support PGD for diseases that manifest late in life. The preferential support for genetic tests to identify diseases that manifest in childhood has been found in other

research studies that have looked at prenatal diagnosis. In a study by Hathaway, respondents were less supportive of prenatal diagnosis for diseases that presented in adulthood and support for such tests correlated inversely with the age of onset of the disease [6]. These results are particularly interesting, because PGD is commonly used to screen for autosomal disorders with adult onset, such as Huntington's Disease, early onset Alzheimer's or breast cancer [1].

As our understanding of the human genome continues to expand, it is more likely that new test panels utilized in PGD will incorporate an increased number of diseases with late-onset and diseases with incomplete or variable penetrance. Despite our increased understanding of the human genome, most traits have low heritability and there are substantial environmental factors that influence gene expression. For example, despite the discovery of BRCA1 and BRCA2, current genetic knowledge explains less than 30 % of breast cancer heritability [18]. There are few traits such as eye or hair color that have single nucleotide or well understood haplotypes that determine the trait, and most 'preferred' traits such as athleticism or intelligence are complex traits with multiple genetic, epigenetic and environmental factors. Even among traits with a strong heritability component, such as height, the genetic contribution has been difficult to understand.

Interestingly, our study seems to suggest that knowledge of PGD does not seem to have changed appreciably over the past decade [14] despite the increased utilization of PGD within IVF and advancements within the field. While awareness of PGD within the United States seems to be comparable to that in other developed countries [19], individuals familiar with PGD were more supportive of the use of PGD to screen for genetic diseases suggesting that further education and outreach may help inform the public and provide the knowledge upon which opinion can be formed more accurately.

Men were significantly more supportive of PGD for trait selection. Previous studies looking at the perspectives of specific patient populations towards PGD have failed to show a statistically significant difference in attitudes between male and female respondents but were limited by small sample sizes [2, 20]. >Lammens et al. looked at 119 families in the Netherlands at high risk for a familial cancer syndrome and found no difference in support of PGD between male and female respondents [20]. Van Lier et al. interviewed 61 Dutch patients at high risk for Peutz-Jeghers syndrome and again found no difference in support of PGD by gender. While recent studies looking specifically at PGD have not shown a difference in attitudes between genders, a random stratified sample study of 1967 members of the Finish population from 1993 by Aro et al. looked at concerns about theoretical genetic tests including tests that identified recessive genetic diseases. This study found that testing for recessive inherited genes was worrisome for 59 % of women but only 45 % of men [21, 22]. A follow up study with the same cohort found that men were

more likely to support a hypothetical DNA-test to determine the predisposition of their would-be children to severe cardiovascular disease, cancer or schizophrenia. More research is needed to further understand the different perspectives of men and women in regards to PGD and offspring trait preferences.

Our aim was to collect responses from a sample of participants that was representative of the overall United States population, however we recognize that utilizing a professional online survey company has some limitations. Our population had slightly fewer Hispanics/Latinos and slightly more college educated respondents than the United States population that might be due to the requirement that the survey was administered on-line and in English. Overall however, it is estimated that over 81 % of the United States population has internet access [23] and 95 % speak English "well" or "very well." [24] An additional limitation is that our study did not specifically describe the diseases or traits in each of the clinical scenarios and instead gave respondents the opportunity to formulate their own interpretation. For example, when we discussed screening for mental retardation, individuals may have different perceptions of the severity of disease based on personal experience with individuals with learning disabilities. Similarly, when discussing adult onset cancer, some respondents may interpret this as a treatable disease while others may interpret this as a fatal disease. Finally since only 27.7 % of respondents were aware of PGD prior to the survey, a brief paragraph as a precursor to the questionnaire might not be sufficient to help them fully understand the concepts involved.

At this time the majority of fertility centers offer PGD to screen for genetic diseases and over 40 % offer non-medical sex selection [1]. IVF centers should recognize that their practices may conflict with public opinion. We noted significant variation in opinions by gender, race and education. Despite the widespread use of PGD to screen for genetic diseases and the availability of screening for sex, many respondents support more limited applications. This study raises questions about public knowledge and attitudes that may indicate the direction needed for future research, educational programs, and clinical policies regarding PGD.

Conflict of interest There are no conflicts of interest for any of the authors

Appendix 1: Questionnaire

Section 1

When a woman's egg and a man's sperm join, they form a fertilized egg which then grows into an embryo and can

eventually lead to a pregnancy. This part of the survey asks you your opinions on whether doctors should provide genetic diagnosis of human embryos before pregnancy.

Preimplantation genetic diagnosis, or “PGD” is a procedure that takes place in a lab with test tubes and can be used to identify specific diseases in embryos before a woman gets pregnant. PGD can detect diseases that are fatal in the first few years of life as well as diseases that can cause significant disabilities throughout a person’s life. Patients who decide to undergo PGD must first agree to undergo in vitro fertilization where the woman’s egg and the man’s sperm are combined outside the human body in order to form a fertilized egg which then grows into an embryo. In PGD, one or two cells from an embryo are removed and tested for various diseases. If a specific disease is identified then the embryo is discarded. If there is no identified disease then the embryo is placed in the woman’s uterus with the ultimate goal of a healthy baby.

Questions

In the following questions, please indicate the answer that best reflects your own personal beliefs. There is no right or wrong answer.

1. Doctors should be able to perform PGD to screen for diseases that are fatal in the first few years of life.
 - a. Strongly agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly disagree
2. Doctors should be able to perform PGD to screen for diseases that cause lifelong disability such as mental retardation or deafness.
 - a. Strongly agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly disagree
3. Doctors should be able to perform PGD to screen for diseases that may not occur until later in life, such as diseases that place an individual at a high risk of cancer during adulthood.
 - a. Strongly agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly disagree
4. If you “agree” or “strongly agree” to questions 2, 3 or 4 that doctors should be able to perform PGD, which of the following statements best describes your reasons? (Please select all that apply)
 - a. Couples should be able to make their own decisions about having a child
 - b. PGD improves the chances that a couple will have a healthy child
 - c. PGD will lower healthcare costs and may result in a better society
 - d. PGD can eliminate certain genetic diseases forever
 - e. Other, please specify: _____
5. If you “disagree” or “strongly disagree” to questions 2, 3 or 4 that doctors should be able to perform PGD, which of the following statements best describes your reasons? (Please select all that apply)
 - a. PGD leads to the unnecessary destruction of embryos
 - b. PGD promotes discrimination against people with certain diseases
 - c. PGD interferes with nature and places doctors in the role of “playing God”
 - d. Widespread use of PGD may lead to unforeseen consequences
 - e. There is no regulation of PGD
 - f. Other, please specify: _____

Additional background information for participants

While PGD is a procedure that is most commonly used to identify diseases, in the future it potentially could be used to test for physical characteristics, personality traits, abilities, or sexual orientation. Again, please indicate the answer that best reflects your own personal beliefs. There is no right or wrong answer.

6. Doctors should be able to perform PGD for sex selection
 - a. Strongly agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree
 - e. Strongly disagree
7. Doctors should be able to perform PGD to screen for physical characteristics such as height, eye color or athleticism.
 - a. Strongly agree
 - b. Agree
 - c. Neither agree nor disagree
 - d. Disagree

- e. Strongly disagree
8. Doctors should be able to perform PGD to screen for personality traits such as intelligence or aggression.
- Strongly agree
 - Agree
 - Neither agree nor disagree
 - Disagree
 - Strongly disagree
9. Doctors should be able to perform PGD to screen for sexual orientation such as homosexuality
- Strongly agree
 - Agree
 - Neither agree nor disagree
 - Disagree
 - Strongly disagree
10. If you “agree” or “strongly agree” to questions 7, 8, 9 or 10 that doctors should be able to use of PGD for selection of ideal traits, which of the following statements best describes your reasons? (Please select all that apply)
- Couples should be able to make their own decisions about having a child
 - Selecting ideal traits will help a child lead a successful life
 - Selecting ideal traits will result in a better society
 - Other, please specify: _____
11. If you “disagree” or “strongly disagree” to questions 7, 8, 9 or 10 that doctors should be able to use of PGD for selection of ideal traits, which of the following statements best describes your reasons? (Please select all that apply)
- PGD leads to the unnecessary destruction of embryos
 - PGD promotes discrimination against people with certain characteristics
 - PGD interferes with nature and places doctors in the role of “playing God”
 - Widespread use of PGD may lead to unforeseen consequences
 - There is no regulation of PGD
 - Other, please specify: _____

Section 2

This section asks you for some basic background information. This information is for research reasons only. It will not be used to identify you in any way.

For each of the following questions, please select the answer that best describes you

- What is your gender?
 - Male
 - Female
- What is your age?
 - (Numerical values from 18 to 75)
- What is your ethnicity?
 - Hispanic or Latino
 - Not Hispanic or Latino
- What is your race? (select all that apply)
 - American Indian or Alaska Native
 - Asian
 - Black or African American
 - Native Hawaiian or Pacific Islander
 - White
 - Other
- In which state do you live?
 - (Dropdown menu of all 50 states)
- What is your approximate household income?
 - \$20,000 or less
 - \$20,000–\$40,000
 - \$40,001–\$60,000
 - \$60,001–\$80,000
 - More than \$80,000
- What is your religion?
 - Christian – Protestant
 - Christian – Catholic
 - Jewish
 - Muslim
 - Hindu
 - Atheist/Agnostic
 - Other, please specify: _____

- Which of the following best describes your level of education?
 - Some high school or less

- b. High school diploma or GED
 - c. Some college
 - d. College degree
 - e. Some graduate school
 - f. Graduate or professional degree
9. Prior to this study have you ever heard of preimplantation genetic diagnosis (PGD)?
- a. Yes
 - b. No
10. Do you personally know anyone with a genetic or developmental disorder?
- a. Yes
 - b. No
11. Do you personally know anyone who required the help of assisted reproductive technology to achieve a healthy pregnancy?
- a. Yes
 - b. No
12. How many biological children do you have?
- a. 0
 - b. 1
 - c. 2
 - d. 3
 - e. 4
 - f. More than 4

Thank you for taking the time to participate in our study.

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