

## A Web-based Instrument to Model Social Norms: NERD Design and Results

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### Abstract

Surveys and focus groups are well known methods for ascertaining public perceptions and opinion. The general view is that such tools provide reasonably accurate reflections of public values, and that the norms employed by people to make decisions are fixed. But what about issues where the public needs to consider novel choices where no prior experience can be drawn on? Do their preferences and beliefs change when presented with new options and new information? Recent evidence suggests they do. This paper describes an alternative way of gathering data,

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which takes into account the dynamic nature of social norms in response to new technologies and their applications. It also discusses the problem with traditional methods of generating information about public opinion and offers a possible solution. Our interdisciplinary research team, Norms Evolving in Response to Dilemmas, has developed a web-based survey instrument that is designed to bridge the gap between perceived and actual public opinion, which traditional surveys and focus groups are unable to capture. This paper will present some of our preliminary findings from the results of our first survey on the topic of Human Health and Genomics. We have found that there are differences in the way respondents answer which has not yet been accounted for in other participatory processes.

**Keywords:** Surveys, Focus Groups, Genetic testing, Deliberative Democracy, Social Norms, Public Opinion Polls

## 1 Introduction

Surveys and focus groups are common methods for ascertaining public perceptions and gauging public opinion. It is thought that such methods may provide reasonably accurate reflections of public opinion and values when the topic is familiar to respondents and when the heuristics used to make decisions are fixed. However, in the case of unfamiliar topics such as new technologies (i.e., genomics or biotechnology), it is difficult to determine whether these methods are sufficiently representative of public opinion to inform policy.<sup>1</sup>

Recent evidence suggests that social norms on issues involving breakthrough scientific advances (i.e., prenatal diagnosis and genetically-modified foods) are not as static as originally believed (George, 2004; BBC News, 2004). Preferences and beliefs change when the public is presented with new options, and when the consequences of their choices are unknown (Bornik & Dowlatabadi, 2004). This is of particular importance with issues concerning biotechnology, which is ethically complex in both its development and application, and demands the input of the public towards informing viable policy on its use. The science of biotechnology continues to evolve rapidly while our understanding of the science lags behind.

We are part of a larger research project, Democracy, Ethics, and Genomics (DEG): Consultation, Deliberation, and Modelling. In what follows, we compare our Norms Evolving in Response to Dilemmas (NERD) survey to the other DEG methods and propose applications of the NERD instrument that extend beyond public consultation. We then provide a detailed description of the NERD design (questions and advisors). Finally, we report on findings from our first survey, and address some of the challenges posed by our colleagues, including two sources of bias.

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<sup>1</sup>The theoretical context for this paper is also described in Danielson et al. (2004)

## 2 Background: Polls, Focus Groups, and Deliberative Democracy

Below, we provide a brief overview of three established methods for seeking public perspectives: polls, focus groups, and deliberative democracy. [Table 1](#), at the end of this section, addresses the strengths and weaknesses of each method by comparing them against a set of evaluative criteria, including recruitment, cost, and depth of engagement.

### 2.1 Polls

Polling is a popular consultation method because it can reach a large number of respondents and is thought to produce a representative sample. However, these polls tend to elicit a respondent's "raw" opinions concerning a particular issue. Critics have argued that such opinions merely elicit "top of the head" responses that may manufacture deceptive or phantom opinions ([Fishkin, 2000](#)). In addition, there is concern surrounding the statistical reliability of public opinion polls, because of the potential for self-selection in respondents. Polls that do not use representative sampling can produce misleading or distorted results that fail to represent the general public's actual views. In part, this originates in the increasingly high refusal rates, defined as the number of refusals divided by the total number asked. The Professional Marketing Research Society (PMRS) created the PMRS Response Rate Committee to deal with this issue by tracking and reporting on refusal rates for organizations that conduct telephone interviews. The Committee reported that in 1995, refusal rates for one-time telephone studies stood at 66%. In 1999, this rate increased to 68% and in 2002 the rate jumped to 78% ([PMRS Response Rate Committee, 2003](#)). They also noted that refusal rates correlated with the length of interviews. As might be expected, longer interviews tended to have higher refusal rates.

### 2.2 Focus Groups

Unlike most polls, focus groups can be used to capture social feedback during group interactions. Yet this method can cost anywhere from \$1,500 to over \$7,000 depending how difficult the sample is to assemble ([Prairie Research Associates, 2001](#)). Each respondent is typically paid for their time and there are generally 12–15 participants per group.<sup>2</sup> Some projects can use up to 40 groups in total. The moderators' skills are essential to this methodology. Moderators must ensure that opinionated individuals do not dominate group discussions and that all conversations are respectful and focused.

It can be argued that focus groups are a deliberative method of public consultation because respondents are given time to reflect on particular issues. However, while they may recruit members of the public randomly, the opin-

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<sup>2</sup>"Professionals" are usually paid more than randomly selected consumers.

ions of small groups of individuals do not necessarily represent the views of the general public.

### 2.3 Deliberative Democracy

James Fishkin, a proponent of deliberative democracy<sup>3</sup>, pursues consultation and decision-making through three methods: Deliberative Polling<sup>®</sup>, Online Deliberative Polling, and Deliberation Day. Each approach has the ability to harness expert opinion while engaging citizens in meaningful discussions. Deliberative Polling<sup>®</sup> was developed as a means of prompting discussions of public policy and electoral issues. The method has been used at more than 22 events worldwide, including in Britain, Australia, Denmark, Bulgaria, and the United States ([The Center for Deliberative Democracy, 2005](#)). Deliberative Polling<sup>®</sup> randomly selects up to 500 individuals, and provides them with background material representing each side of the specific issue.<sup>4</sup> Participants are broken into small groups who, over a weekend, discuss the issues and develop questions to be answered by a panel of experts. Portions of these discussions are televised. After the process is complete, individuals are asked original questions again and any changes in their views are tracked. Fishkin asserts that these deliberations typically produce “dramatic, statistically significant changes in views” ([Fishkin, 2005](#)).

The Centre for Deliberative Democracy has also developed an Online Deliberative Poll. The online version is intended to reduce costs and inconvenience for participants while maintaining many of the benefits of face-to-face Deliberative Polling ([Iyengar et al., 2004](#)). To overcome internet access problems, the randomly selected participants are offered free access by the researchers. Both the online and face-to-face versions use similar methodologies. However, weekly online meetings replace the face-to-face discussion and respondents may choose which online meeting to attend (group size = 12–21 people).

Finally, Deliberation Day is based on the same principles as the other methods, but aims instead to help individuals prepare for and turn out to vote. Arguments by proponents and opponents are televised and all citizens have the opportunity to participate in randomly assigned discussion groups a week before the vote occurs. These local discussion groups produce key questions to be addressed by competing parties during town meetings.<sup>5</sup> One obstacle to this option is the high cost of such an event. Fishkin asserts that participants must be paid for their time on Deliberation Day. A potential solution to minimizing these costs is to conduct Deliberation Day online.

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<sup>3</sup>Procedural conceptions of deliberative democracy engage citizens in decision making processes that are both thoughtful and inclusive.

<sup>4</sup>This information package is also made available to the general public, and may include a CD.

<sup>5</sup>It is unclear how competing voices will be reconciled during Deliberation Day as this method has never actually been tested.



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**Dr. Getwell**  
can answer your medical  
questions



**Rt. Hon. Funds**  
can speak to the public policy  
challenges



**Prof. Considerate**  
provides various ethical and  
religious perspectives



**Yes Advocate**  
reasons why you should say  
yes



**No Advocate**  
reasons why you should say  
no

## 1. Medical Research

### Facts:

A significant fraction of infant deaths in your country are known to be related to inherited disorders.

### Question: (1 of 12)

**Would you be in favour of a modest government research program to find a treatment for such disorders, which, if successful, could save an additional 5 infants for every 1000 live births?**

- a.Strong Yes
- b.Weak Yes
- c.Neutral
- d.Weak No
- e.Strong No
- f.Can't Answer

Should you be interested, please explain your answer:  
(500 character limit)

[Next question](#)

Figure 1: Typical NERD survey page.

### 3 NERD

Norms Evolving in Response to Dilemmas (NERD) is an easily accessible survey designed to stress-test normative decisions with social and technological change and social pressure. It offers respondents the opportunity to answer a carefully constructed set of twelve decision problems based on both historical fact and established science (Section A). For each question, the respondent has the option to seek information and advice from five well-informed advisors, since many respondents may have little prior knowledge or experience of the issue at hand. Figure 1 presents a typical survey page with the question and answer set on the central screen, and a list of clickable advisor icons to the left. The survey is designed to accommodate the dynamic nature of norms by leading participants through a series of questions in which the context becomes increasingly complex and “genomic.” There is neither social nor technical pressure for participants to hold firm to their values or preferences as they take the survey.

The NERD instrument provides depth to the analysis of public opinion. We not only record participants' answers to questions, but also the time they spend on each issue, their patterns of advice-seeking, and group dynamics. The findings of this research will be a critical first step towards a better characterization of the social science of public acceptance/rejection of novel technology and its applications.

NERD also has the advantage of attracting a large sample size (1042 participants in 5 months) while keeping expenditures low. The first survey cost 1/8<sup>th</sup> that of the cost of the other DEG methods (\$8,000<sup>6</sup> or \$7.80<sup>7</sup> per participant). Furthermore, the internet provides a vehicle to include, anonymously, a larger segment of the population.

While these features are not stand alone evaluative criteria, a public consultation method that can not affordably be scaled up to population sizes relevant to democracy faces a dilemma. Either a small sample subpopulation is presumed to serve as proxy for the whole population or the whole population can participate. In the former case, the public must accept the normative basis of sampling and projection, which is as unlikely as some of the original target policy issues. In the latter, cost constraints become clear barriers, as Fishkin admits in his Deliberation Day proposal. To presume that the voting age population could be paid to take a day off to deliberate is not compatible with real world incentives. We propose that NERD may gauge a 'deeper' public perspective, essential to informing public policy on novel technologies. Danielson et al. (2004) have described the NERD approach as "Deep, Cheap and Improvable." "Deep" signals the willingness to engage participants with both technological, policy, ethical, and social complexity. "Cheap" signals our ability to engage thousands of participants using the web. "Improvable" points to our development of standard, open-source tools, to allow more surveys with new features.

In addition to the obvious use of NERD online surveys as a means for gathering public input on important policy questions, there are other less obvious applications for the tool within the policy development and implementation process. For example, in Canadian governmental policy development, groups of experts are often brought together for on-site meetings to react to sets of questions prepared by civil servants. NERD surveys could be used to facilitate these meetings by asking experts either to answer questions ahead of time to establish a baseline, or, more interestingly, to compose some of the positions of the advisors. Thus, the actual face-to-face meeting would begin at a deeper level of engagement, and the resulting product could be used as a public consultation tool.

The features of NERD that recommend it in these policy arenas include: the NERD format, which includes advice from those with differing views and facilitates examining issues from different perspectives; the NERD structure, which

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<sup>6</sup>Costs can be broken down into: \$5000 for software design, \$0 for recruitment, and \$600/month for administration and maintenance. This overestimates cost by including the development of our web software, some of which will be spread over three surveys this year.

<sup>7</sup>Out of 1042 visitors, only 408 consented to have their answers saved, which if taken into account, brings up the cost per participant to \$19.60.

lends itself to dealing with a small number of questions seen through a large number of perspectives, and addresses objections from some that current policy making is excessively reductionist; the survey creation tool (i.e., Media Wiki), which provides a good vehicle for ‘pooling’ positions from disparate experts and other participants; and the NERD device, which has the potential to counter the charge that input from experts and other non-governmental participants is so heavily filtered that the input is more governmental than external. If a NERD survey were created as part of the process, the result might better represent the views of the participants who, after all, are the primary creators.

The ease with which NERD can be utilized allows for modifying the content so that surveys can be developed on a variety of topics. Our first survey, released July 2004, was about Human Health and Genomics, a topic which is both “close” and important to the public. Current surveys focus on food genomics (salmon, released April 2004) and non-food genomics (poplar, forthcoming). By evaluating parallel surveys across these three quite different domains, we can explore the proximity and context-dependent features of our results.

### 3.1 NERD-I: Human Health and Genomics

The content of NERD-I is modelled on a real-life case study involving the treatment and prevention of the hereditary disorder  $\beta$ -Thalassemia in Cyprus. This distinctive story is one in which rapidly evolving technology drove changes in the decision context amidst strong social and cultural norms. Over a 40-year time period,  $\beta$ -Thalassemia in Cyprus went from being peripheral on the public health agenda, to being a focal point for medical treatment, to being at the centre of a population-wide genetic screening and testing program. Norms concerning issues of treatment availability, abortion, and prenatal genetic testing were reshaped as emerging technologies and offered new options for solving Gordian knots.

NERD-I fictionalizes the Cyprus case study for a wider (international) and contemporary audience likely to have limited prior experience with the subject matter.<sup>8</sup> Rooting the survey in historical fact gave us a good foundation for the portrayal of the issue’s complexities when wording the questions and advisors, since much has been written on this topic from a variety of perspectives (i.e., [Angastiniotis, 1990](#); [Petrou & Modell, 1995](#); [Cao et al., 2002](#)). Our central hypothesis, based on what was historically observed in the Cyprus population, is that when technology offers participants new options for solving a given problem, the set of traditional positions in normative theory will prove inadequate to explain our data set (see [Keulartz et al. \(2004\)](#) for the general argument).

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<sup>8</sup>The hereditary blood disorder  $\beta$ -Thalassemia is prevalent in the Mediterranean Region, Middle East, Indian Subcontinent and Far East. While population movements have led to worldwide dissemination of this genetic defect,  $\beta$ -Thalassemia remains relatively uncommon in North America.



### 3.2 Design: Questions and Answers

The NERD survey tool consists of twelve carefully constructed question pages that engage participants in problems of increasing technological, policy, ethical, and social complexity (see [Appendix A](#) for complete list of questions). Questions are presented in a “ratcheted” form where participants cannot go back to a question they have previously answered, but are given the opportunity to reflect and comment on their answers at the end. Vocabulary and sentence structure were designed to meet a grade 10 level of comprehension (8.4 to 10.8, Flesch-Kincaid scale<sup>9</sup>) in anticipation of the range of education and backgrounds of our participants. The length of questions were compared and balanced to account for a projected average survey time of approximately 15–20 minutes.

Each question begins with a statement of one or more “facts” informing participants of the previous question’s outcome—for example, the decision taken by the government—and introducing any new technological advances. The fact set is followed by a short question with a number of multiple choice answers that range from Strong Yes to Strong No and Can’t Answer. Each question page also provides a space for written comments (500 character limit), should a participant be interested in explaining an answer. The comment-box feature has allowed us to collect a significant amount of qualitative data, which has not only helped us refine our survey tool, but also provides further data for analysis.

A unique feature of the survey instrument is that it records the amount of time each participant spends answering the questions. This gives us an opportunity to measure how long each individual took to complete the survey and each specific question. This feature also allows us to eliminate participants who took unfeasibly long amounts of time from the analysis. For those participants who answered all 12 questions (n=340) without interruption, the mean time spent on the survey was 17.5 minutes; standard deviation = 19.47 minutes (i.e., 143 participants finished in under 10 minutes).

### 3.3 Design: Advisors

Every question page includes links to fictional “advisors” who offer information and provide explanations of relevant scientific, health, financial, moral (and other) aspects of the issue. Using the advisors is neither compulsory nor necessary; the intent is to give participants the opportunity to make more educated decisions about issues with which they are likely to have limited prior experience while discouraging them from seeking external input and limiting the volume of material to prevent boredom.

Five advisors provide a balanced set of advice, ranging from scientific/health information to philosophical perspectives. “Dr. Getwell” explains medical and scientific terminology and procedures that may be referenced in the question. The “Rt. Hon. Funds” provides an opinion from within the public policy realm, weighing costs and benefits associated with the decision at hand. “Prof.

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<sup>9</sup>The Fleschmann-Kincaid scale, used by MS Word software to calculate a U.S. grade level, = .39(total words – total sentences) + 1.8(total words – total syllables) – 15.59.

Considerate” presents a variety of ethical and religious perspectives, discussing the consequences of a particular decision and other considerations that may not be obvious at first glance. “Yes” and “No” advocates represent more “every day” advice, similar to the type of advice that might be provided by friends, family, interest groups, or local newspapers.

By using gender-neutral names and symbols of balanced authority, we attempt to avoid biasing participants towards one advisor over another. Similar to the question design, the intent of the advisors is to provide only the necessary information in an accessible and easy to read manner. Given time constraints (e.g., attention span), we were unable to represent every relevant fact and opinion within our set of five advisors. However, we invited experts on social science experimentation, deliberative techniques, ethics and governance, and genetics to assist in the development and review of the survey.

The advisor feature in NERD allows us to collect “refined” data in the sense that it is a product of deliberation in which participants can choose to be informed about, and reflect on, competing considerations before reaching a decision. This approach can be contrasted with polling and focus groups, where participants are not provided with context-specific information in order to preserve the objectivity of the data. Our conceptual reservation about these methods is that we doubt the public is aware of their beliefs and preferences when the context and consequences of their choices are unknown.

### 3.4 Design: Feedback

An optional feature of NERD, central to the analysis that follows, is the bifurcation of participants; half receive aggregated feedback information on how other participants in this group answered each question and which advisors they consulted, while the other half does not. [Figure 2](#) shows the two forms of group feedback. The bar chart shows the distribution of answers of previous participants in the group, and the numbers of participants opting for advice are represented as percentages next to each advisor’s icon. The feedback feature allows us to discern whether participants deprived of information about others’ choices answer differently than those receiving that information, whether they seek more factual and ethical information, or whether they spend more time deliberating on their answers. By comparing answer modes and patterns of the two groups, we can also examine whether social feedback is influential enough to shape individual opinions against government decisions, or the prevailing story line.

## 4 Results

### 4.1 Findings

Only participants who consented to submit their responses were included in these analyses. In total, 682 respondents answered at least one question, 503

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25% **Dr. Getwell** can answer your medical questions



24% **Rt. Hon. Funds** can speak to the public policy challenges



25% **Prof. Considerate** provides various ethical and religious perspectives



23% **Yes Advocate** reasons why you should say yes



34% **No Advocate** reasons why you should say no

Percent figures show the proportion of your group that consulted each advisor.

### 1. Medical Research

**Facts:**

A significant fraction of infant deaths in your country are known to be related to inherited disorders.

**Question: (1 of 12)**

**Would you be in favour of a modest government research program to find a treatment for such disorders, which, if successful, could save an additional 5 infants for every 1000 live births?**

- a.Strong Yes
- b.Weak Yes
- c.Neutral
- d.Weak No
- e.Strong No
- f.Can't Answer

Should you be interested, please explain your answer: (500 character limit)

Next question

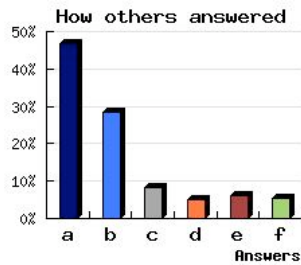


Figure 2: NERD survey page with feedback.

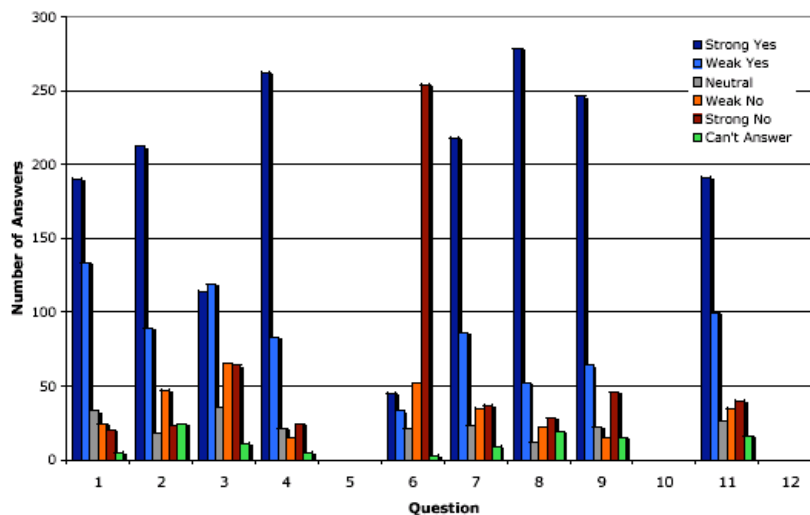


Figure 3: Summary of participant’s answers to NERD-I questions. Questions 5, 10, and 12 did not use the standard answer set (Section A) and so were not included in this figure (see text for description of these answers).

completed the full 12 questions, and of those, only 384 completed the 12 questions and the post-survey consent form. This limited our sample size considerably. We originally decided to locate the consent form at the end of our survey for recruitment purposes (i.e., we did not want to scare off potential respondents with a lengthy preliminary ‘contract’). However, low consent rates relative to survey completion rates indicate to us that a front-end consent process may have permitted us to include more valuable data in our analysis. Respondents who were uncomfortable with the survey would still have had the option to close the web browser, with no risk of attribution.

Figure 3 shows the results from the 12 questions in NERD-I (see Appendix A for a list of facts and questions from the survey). Of those questions that used the standard answer set (Strong yes to Strong no/Can’t answer), “Strong yes” and “Weak yes” were selected the most compared to “Neutral” and “Can’t answer,” which were chosen the least. The exception is Question 3 (Treatment Availability) which received much fewer “Strong yes” and more “No” answers than the other questions. In Question 6 (Pre-marital Screening), 62% (254/408) of respondents chose “Strong no” (Figure 3) and voiced their objections to infringing on people’s rights to marry, as observed in the written comments for this question (Appendix B).

The findings from Question 5 (Carrier Screening) show that most (45%, 175/393) respondents chose that a carrier screening program should be mandatory only for individuals with a family history compared to 21% (81/393) who

thought it should be mandatory for all. In Question 10 (Ethnic Differences), the answers were more evenly distributed over all five options. Screening the entire population was the most popular answer while focused screening on a minority carrier group was the least. As well, 12% (50/405) selected “Don’t know,” suggesting respondents were unsure which option was the best. Question 12 (Funding of Pre-implantation Genetic Testing) also received varied responses. Most respondents decided that funding should come from a combination of public health care and private money (36%, 145/406), although over half of the respondents were split between all public health care funding (23%, 94/406) and all private funding (28%, 113/406). Only two of the respondents thought that funding should come from the church, perhaps reflecting values in the demographic represented by these respondents.

## 4.2 Summary of Advisor Visits

The five advisors were developed to help respondents gain a more in-depth understanding of the topics and issues raised in the questions. As respondents made their way through the survey, the advisors they visited and length of time they spent at each advisor was recorded (Figure 4). The general trend shows that the most advice was sought in the first two questions and then steadily declined until Question 10 (Ethnic Differences) when there was a second peak, possibly indicating an area where respondents were less familiar with the subjects covered in the questions and sought more advice before answering.

The No advocate was the most popular advisor for seven of the 12 questions compared to the scientific and financial advisors, which were often the least visited. The exception to this is where the question was specifically about funding or research, for example Question 3 (Treatment Availability) and Question 12 (Pre-implantation Genetic Testing) where the financial advisor was the most visited and Question 11 (In-vitro Genetic Research) where the scientific advisor was the most visited. The ethicist and Yes advocate advisors were often moderately consulted, except in Question 9 (Termination of pregnancy) where the ethics advisor was visited the most.

Interestingly, while the No advocate was the most popular advisor, “Strong yes” was the most common answer. For example, of the questions with the standard answer set, respondents chose “Strong yes” seven out of nine times and of those, the No advocate was the most visited for five of them, and the second most visited for the other two. As well, for Question 6 (Pre-marital Carrier Screening Program) where “Strong No” was the most popular answer, the Yes advocate was the most visited. This suggests that participants sought out the opposing position prior to answering questions with an extreme response.

## 5 Feedback Effect

As previously mentioned, respondents in NERD-I were divided into two groups in order to test the effect of group dynamics on participant’s responses. The

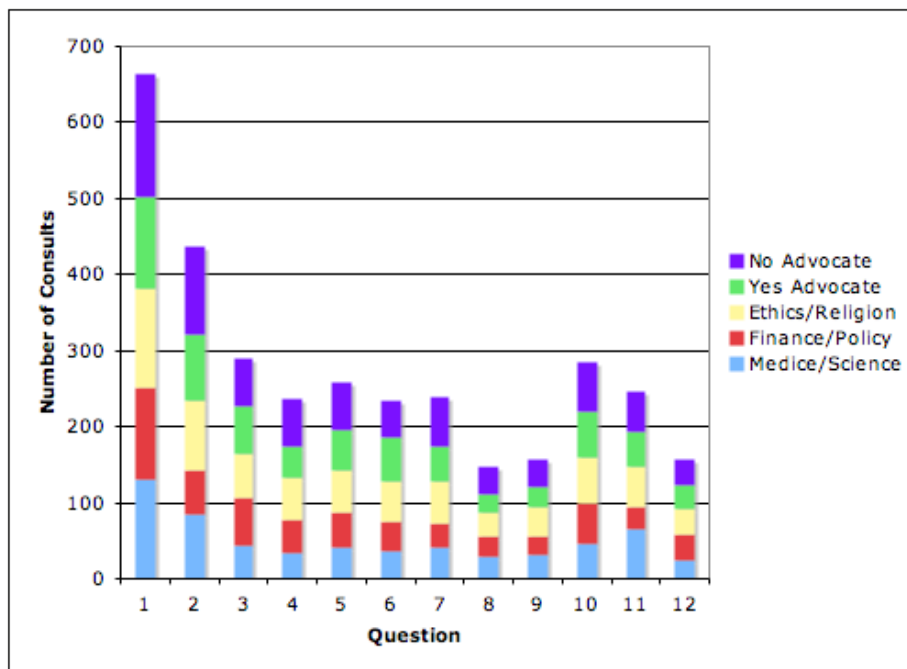


Figure 4: Total number of advisor visits for each question.

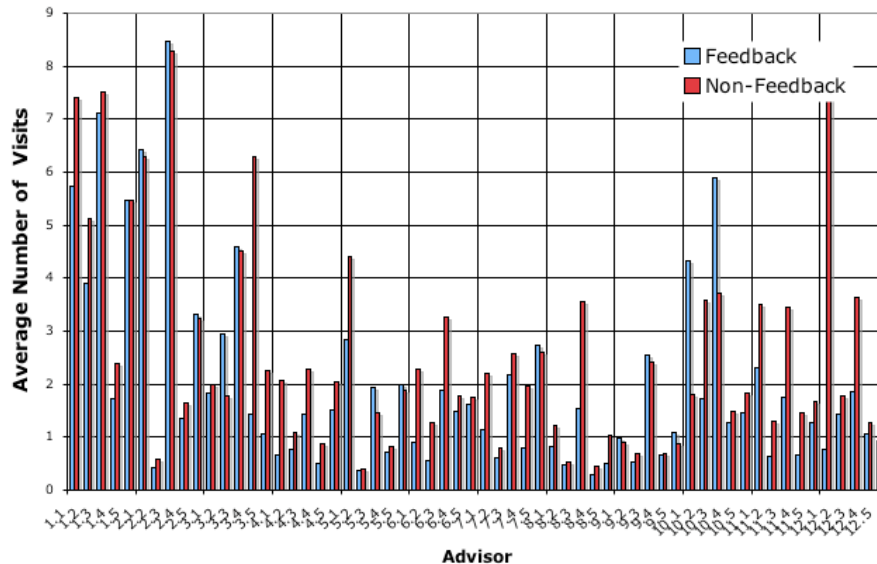


Figure 5: Number of advisor visits for feedback and non-feedback groups.

“feedback” group was shown the average responses of other respondents as they answered each question; the “non-feedback” group did not receive this information. The overall answer pattern between the feedback and non-feedback groups was the same across all questions. However, we found that the feedback group tended toward more Strong Yes answers than the non-feedback group, who responded with more Weak Yes and Neutral answers. This suggests that social feedback resulted in more extreme answers.

The general pattern in advisor visits was also similar for both groups; however, a non-parametric Mann Whitney U-test shows that respondents in the non-feedback group consulted advisors more often (Figure 5). This was particularly noticeable for Questions 4 (Genetic research), 8 (Prenatal Genetic Testing), 10 (Ethnic Differences) and 11 (In-vitro Genetic Research), which—aside from focused screening on ethnic groups—are mainly technology/research-based questions. The overall difference between the feedback and non-feedback groups was significant ( $p < 0.01$ ). In addition to the frequency of advisor visits, the non-feedback group spent more time consulting advisors than the feedback group for many of the questions (Figure 6). This difference was also found to be significant ( $p < 0.05$ ) based on a Mann Whitney U-test.

To examine whether the two groups sought different types of advice, advisors were divided into expert (scientific, financial, and ethics) and non-expert (yes and no advocates) classes and compared between the feedback and non-feedback respondents. Figure 7 shows that both groups consulted expert advice more

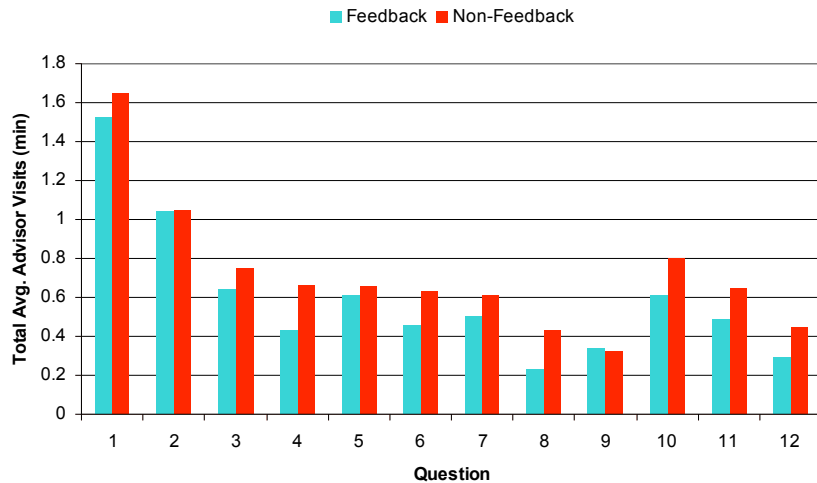


Figure 6: Duration of advisor visits for feedback and non-feedback groups.

often than non-expert, although this difference was more pronounced in the non-feedback group. Exceptions to this are Questions 2 (Medical Treatment) and 9 (Termination of Pregnancy), where the feedback group sought more expert advice than the non-feedback group.

Finally, we can see differences between the feedback and non-feedback groups by comparing their use of the optional text input box (Figure 8). We were surprised that many—almost one in four—participants answering a question contributed an optional textual response. The rate of response differed between the two groups, with non-feedback participants writing text more often. We conjecture that with no feedback indicating the expected response, non-feedback participants felt a greater need to provide a rationale for their choices.

## 5.1 Demographics

Participants were given the option, before exiting (regardless of the number of questions answered), of answering a set of questions about themselves (see Table 2). Most were designed to provide depth to our analysis of this survey and to compare it to other NERD surveys. Questions marked with ‘\*’ were asked for compatibility with the other methods studied in the Democracy, Ethics, and Genomics project.

Our participants are older and better educated than the Canadian population, if only because we were limited to participants 19 years old or older. In spite of our use of the internet to recruit and interact with participants, the sample is evenly divided by gender. They are well-informed about genetic diseases, often know someone directly affected, and are politically active.



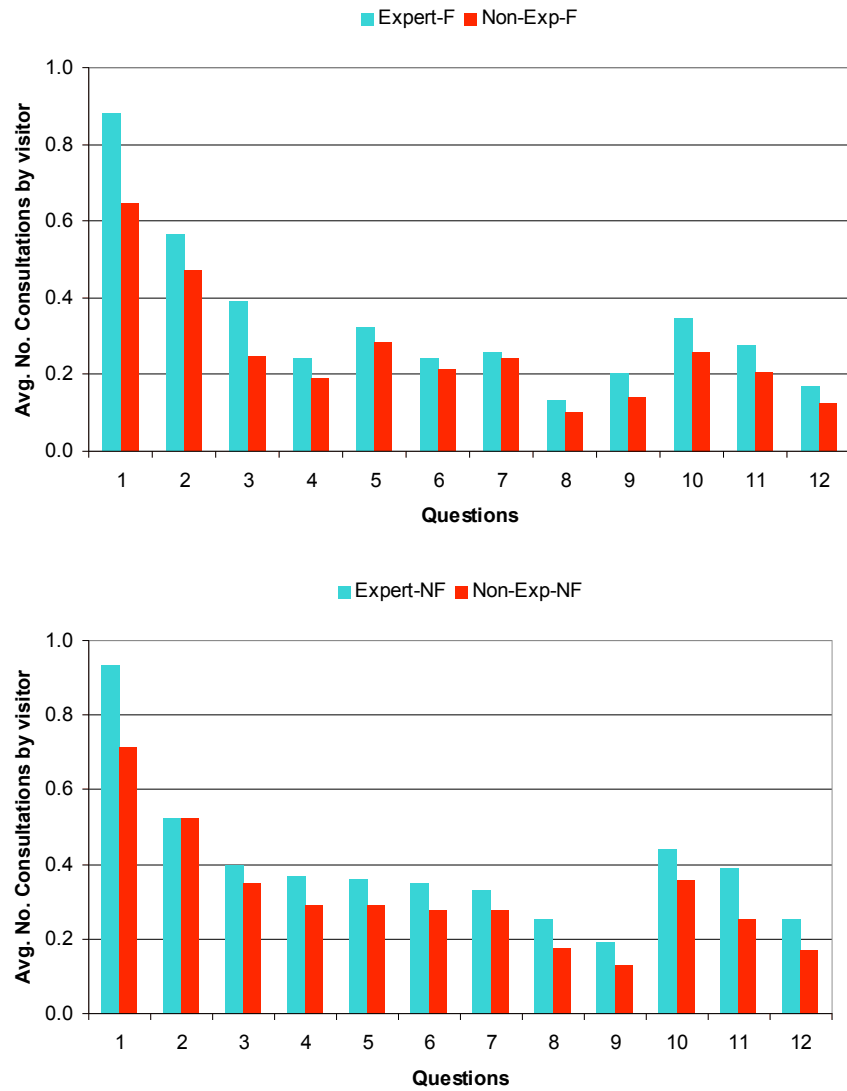


Figure 7: Feedback effect on expert and non-expert advisor consultations.

Table 2: Answers to Demographic Questions

Gender	female	189
	male	210
Age	19–29	149
	30–39	105
	40–49	82
	50–59	46
	above 60	18
Education	Secondary	9
	College/University	308
	Other	12
Involvement with genomics *	Uninvolved with no specific interest in genomic research	219
	Uninvolved with an interest in genomic research (e.g. at risk of a specific illness, member of an environmental non-governmental organization, taking a strong stance on specific aspects of genomic research)	123
	Directly involved in some aspect of genomic research (e.g. researcher, regulator, public or private funder)	57
Are you in a long-term relationship:	Yes	279
	No	118
Are you parent/guardian or otherwise responsible for another:	Yes	137
	Role = n	259
How active are you in public policy formation:	Active beyond voting	94
	Ongaged voter	248
	Infrequent voter	54
Have you known anyone who has sought genetic information to guide their personal decisions:	Know none	257
	Know someone	140
If yes, did they base a decision on that information?	Yes	84
	No	22
	Don't know	140
How familiar are you with genetically transmitted diseases?	First-hand experience	36
	In my circle of family/friends	116
	Have read about them	188
	Know they exist	50
	Other	8
If you are informed about genetically transmitted diseases, how much do you know about $\beta$ -Thalassemia ?	Very informed	20
	Somewhat informed	126
	Not heard of it	247

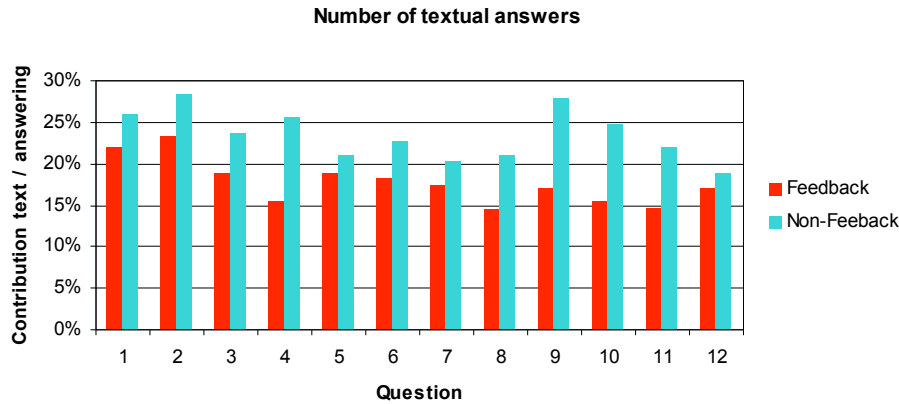


Figure 8: Feedback effect on text answers.

## 6 Discussion

NERD is a web-based and low cost alternative consultation method that incorporates the strengths of all three methods mentioned above in [Section 2](#). Like polls, NERD is capable of attracting a large sample size, can explore the role of social feedback similar to focus groups, and can provide respondents with the opportunity to examine expert advice like the methods proposed by Dr. Fishkin. We explore these claims in greater detail in the following paragraphs.

### 6.1 Large Sample Size and Selection Bias

In addition to the comparison of DEG methods outlined in this paper, our colleagues have challenged us to address a potential source of bias in NERD. Although NERD successfully attracts a large sample of respondents, we must address the possibility of selection bias inherent in any project which seeks to collect publicly representative opinions.

The use of an open internet survey supported by email advertising potentially biases the sample. Note first that our hypothesis on the feedback effect (see next section) was tested across a random partition of the population, which is not subject to selection bias. Second, selection bias is offset by our large sample size compared to the other established methods listed in [Table 1](#) simply because there will be more variance in our larger sample. None the less, analysis of demographic data in [Table 2](#) shows us that our sample was relatively old, highly educated, etc. In future version of NERD, this will be addressed by pooling participants solicited for a variety of topic areas (i.e., animal welfare, forestry, and biobanking) and creating a version for use in schools (as our NERD-1 was limited to those over 19 years by our research ethics certificate).

We argue that traditional selection methods can never be entirely random as

they fail to account for the random acceptance (or refusal) of participants. For example, participants self-select even in choosing to answer telephone polling calls (see [Section 2](#)).

## 6.2 Social Feedback

The NERD survey is an experiment designed to test hypotheses about the role of norms in important ethical decisions. Our hypothesis is that moral norms related to biotechnology are social—that is they are group dependent, and dynamic when they are modified under the effect of social and technological change. Consequently, we need to appeal to dynamic social norms to explain the decisions people make.

In our experiment, group feedback to one half of the participants is a proxy for social norms. In NERD-I, respondents were less affected by social feedback than we predicted. This may have had to do with the demographics of the sample, the level of confidence in their answers, and the nature of the topic (human health genomics). We hypothesize that familiarity with the issue and ‘proximity’ of the issue to the respondent, influences the degree of social dependence in ethical decision-making. Future iterations of NERD will allow us to test this theory by comparing results from human health genomics against food genomics and non-food genomics. Nevertheless, we observed some differences in NERD-I between the feedback and non-feedback groups’ answers, and significant differences between their duration of advisor visits, and the use of the text answer option.

We should note, briefly, that we have been successful, to date, in motivating a large group of people to take our survey and, apparently, quite seriously consider twelve hard questions. One measure of their seriousness is the time they spent completing the survey. Another is the amount of text they wrote discussing their decisions. That said, we must also address the possibility of question and information bias that proponents of focus groups charge limit the usefulness of web-based survey methods.

### 6.2.1 Framing Bias

A second source of bias in the NERD instrument is the framing effect of the questions asked and the set of advisors and advice provided. We do not deny this effect; it is impossible to ask neutral questions and provide neutral advice. Nor are we assuming that because we based our first survey on an historical incident, we escape the framing objection.

Indeed, the framing objection is one we embrace, as it supports our main hypothesis about the leading role of social norms. That is, if participants are influenced by the framing of the questions, they are responding to a social influence, a trend which is supported by our results from NERD-I. The way the storyline is presented, each question is, in effect, answered by the government as well as the participants. For example, in Question 2: “The government

decided to undertake the research program...,” indicates how the government responded to the problem in the previous question.

In NERD-I, the popular choice is always—with the outstanding exception of the pre-marital screening question—very close to the government choice. Since the government choice was pre-programmed (NERD-I is non-branching) this is not a sign of democracy in its most basic sense, of the government following the people. Rather, we should be concerned that participants’ choices (somehow) track what will be officially chosen. To test the strength of the government’s effect on the popular norm, we would need to re-write and re-run the survey with the government choosing at the other end of the scale, i.e., Strong No. We hypothesize that a reverse survey would produce very different answers from what we have seen from NERD-I. This experiment is underway.

### 6.3 Expert Knowledge

A key design choice that makes our survey ‘deeper’ than the alternatives is our use of optional advisors to provide rich information—scientific, policy, and moral. This moves our results away from shallow surveys, towards the deliberative approach, while maintaining a social structure that we can control as an experiment. By providing a variety of information from a variety of points of view, we give participants more choices, which we can analyse in depth, given our methods of collecting data.

In NERD-I, we observed a general declining trend in the use of advisors (both number and length of visits) over time. The high number of visits early on in the survey was suggestive of respondents familiarizing themselves with the feature and various forms of advice. Attention span and diminishing need for advice are possible explanations for the levelling off through Q3–9, and a renewed interest in advice for complex ethical questions at Q10 (Ethnic Differences) and Q11 (In-vitro Genetic Research).

However, the decline in advice-seeking may also be due to factors related to the usefulness, quality, and balance of advisor comments from the perspective of the respondent. Admittedly, we were unable to represent every relevant fact and opinion within our set of advisors. However, we did invite real experts to contribute to the perspectives presented in the survey.

A new application we hope to explore in order to bring our web-based survey closer to the level of real-life interaction with experts is broadening the sources for our advisors. First, we plan to incorporate real, dynamic advisors and have already begun experimenting with software (i.e., open-source Mediawiki and the Civicspace group content management system) for this phase. Third, we plan to move to dynamic advisors, with participants contributing advice, and employing democratic quality filters to provide focus.

## 7 Conclusion

Biotechnology is important to the public but difficult to comprehend, while ethical heuristics<sup>10</sup> quickly show their age under the pressures of rapid change.

By developing a web-based survey instrument, our interdisciplinary research team at the University of British Columbia has aimed to bridge the gap between perceived public opinion and actual responses. We maintain that neither surveys nor focus groups can adequately account for this challenge.

Therefore, we conclude first that there is a need for new instruments to improve public consultation on biotechnology. On one hand, we know very little about the social norms and other heuristics that people use in making decisions about important technologies. On the other hand, existing tools have evident shortcomings, especially in terms of cost, controlling for their own induced social structure, and motivating participations. Computer communication and modelling offer opportunities to improve the quality of public participation in all three of these respects and the NERD survey is a promising first step.

Second, we offer NERD as an instance of ethically informed design. From the onset, we aimed for an instrument that would respect our participants as partners in exploring ethically significant material. We hope that the design features needed to run our experiments interfere minimally with our participants.

Third, we offer an analysis of results that partially confirm our main hypothesis. The use of feedback as a proxy for social norms does show significant effects on participants' choices, advice-seeking, and contribution of optional comments.

## 8 Acknowledgements

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<sup>10</sup>An ethical rule of thumb (i.e., tell the truth, do not steal, etc...)

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## A NERD-I Facts and questions

The entire survey with all advisors and samples of feedback and the reversed government choice questions is available at <http://robo.ethics.ubc.ca/civicspace/?q=Survey1.pdf>

### 1. Medical Research

**Facts:** A significant fraction of infant deaths in your country are known to be related to inherited disorders.

**Question:** Would you be in favour of a modest government research program to find a treatment for such disorders, which, if successful, could save an additional 5 infants for every 1000 live births? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

### 2. Medical Treatment

**Facts:** The government decided to undertake the research program. It has been successful, and medical treatment is now available for  $\beta$ -Thalassemia, a hereditary blood disorder that leads to severe anemia and death of the child by age 8.

Treatment for  $\beta$ -Thalassemia involves monthly blood transfusions, and iron chelation therapy. This therapy involves a needle injection of drugs that requires the patient to be hooked up to a machine for 8–10 hours every day. These treatments can extend a person's life by up to 50 years.

**Question:** Would you use this treatment for your child if s/he had  $\beta$ -Thalassemia and the treatment was free? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

### 3. Treatment Availability

**Facts:** The life-time cost of medical treatment for a  $\beta$ -Thalassemia patient is \$1–2 million.

The average lifetime cost of public health care spending for an individual in your country is \$20,000. (Currently in Canada, the average lifetime healthcare spending is \$280,000)

**Question:** Assuming you were not a parent of an affected child, would you be in favour of publicly funding this treatment through the health care system? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

### 4. Genetic Research

**Facts:** The government has decided to provide free treatment to all  $\beta$ -Thalassemia patients.

Thalassemia is a recessive genetic disorder. This means that in order for a person to have the condition, they must have two copies of the



gene; one from each parent. If a person has only one copy of the gene, they do not have  $\beta$ -Thalassemia and are known as carriers. If two carriers have a child, their chance of producing a child with  $\beta$ -Thalassemia is 1 in 4, or 25%.

It may be possible to develop a technique that allows for the identification of carriers of genetic disorders like  $\beta$ -Thalassemia.

**Question:** Would you be in favour of a government-funded research program to find such a technique, in order to test and inform carriers about the risk of conceiving an affected child? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

#### 5. Carrier Screening

**Facts:** The research program was funded and has been successful, and carrier screening is now available for  $\beta$ -Thalassemia (beta-Thalassemia). The screening process will reliably detect carriers 99.5% of the time. Counselling informs potential parents of the risks they may face and their reproductive options.

**Question:** Are you in favour of a government-run, combined screening and counselling program that is: {Mandatory for all, Mandatory for those with family history, Voluntary, No program, Don't know}

#### 6. Pre-marital Carrier Screening Program

**Facts:** A voluntary screening and counselling program is in place. There are still concerns about providing blood and costly drugs to a rapidly growing number of  $\beta$ -Thalassemia patients.

**Question:** Would you favour a policy that marriage certificates are granted only if both people have agreed to screening and counselling? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

#### 7. Advanced Genetic Research

**Facts:** The policy to require pre-marital screening was passed by the government.

Research may deliver a prenatal test to inform parents if the fetus is unaffected, carries the gene for the disorder, or actually has  $\beta$ -Thalassemia.

The overall cost of a combined carrier screening and prenatal diagnosis program is projected to be much less than the overall cost of treating present and future  $\beta$ -Thalassemia patients in your country.

**Question:** Would you favour a research program to develop such a test? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

## 8. Prenatal Genetic Testing

**Facts:** Research has been successful and there is now a prenatal genetic test available at a cost of \$600.

The test has been proven to be accurate 99.6% of the time.

**Question:** Assuming you and your partner are both carriers, would you choose to have the test done for your fetus? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

## 9. Termination Of Pregnancy

**Facts:** A significant number of couples are choosing to have prenatal genetic testing for  $\beta$ -Thalassemia.

**Question:** Would you be in favour of a public policy that permitted abortion of fetuses testing positive for  $\beta$ -Thalassemia? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

## 10. Ethnic Differences

**Facts:** The number of carriers for  $\beta$ -Thalassemia is known to vary significantly across ethnic groups. In Cyprus, a country with a relatively homogeneous population 1 in 7 people carry the gene, making them a "majority carrier group."

In countries with diverse ethnic groups, such as Canada and the UK, an immigrant population from Cyprus would be considered a "minority carrier group" with higher prevalence rates than the national average.

**Question:** Would you be in favour of a public policy delivering focussed screening focussed on: {Entire population, Majority carrier group, Minority carrier group, Not at all, Don't know}

## 11. In-vitro Genetic Research

**Facts:** Public policy permitting abortion due to diagnosed severe genetic disorder has been enacted.

It may be possible to develop a technique that, when combined with in vitro fertilization (IVF), hold the promise of eliminating abortions due to the prenatal discovery of the  $\beta$ -Thalassemia trait.

**Question:** Would you favour such a research program? {Strong Yes, Weak Yes, Neutral, Weak No, Strong No, Can't Answer}

## 12. Pre-implantation Genetic Testing (PGD)

**Facts:** The research has been successful and there is now a pre-implantation genetic test available, which is conducted in the course of in-vitro fertilization (IVF).

This technique doubles the cost of IVF to approximately \$10,000 per course. Normally three courses are needed for a successful pregnancy. When both parents are carriers, use of IVF and PGD leads to children free of  $\beta$ -Thalassemia in 97% of the cases.

**Question:** Would you favour the use of this treatment by carrier couples, if the additional cost of PGD treatment was paid for by: {Public health care system, Privately, Church, Some combination of the above, Not at all, Don't know}

## B Sample of Qualitative Data from Question 6.

Answer to Q6 Text containing “right” (12 of 81 text entries for this question)

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5	An important part of living in a pluralistic society is respecting the rights of others to believe differently than I do. Just because I personally might try to avoid having a child with this condition (and I'm not sure I would!), I would be against requiring it of all. In addition, Prof. Considerate's point about stigmatizing children born out of authorized wedlock is an excellent one.
5	Infringement of human rights.
1	There are two poles here: collective rights (the general population agreeing through taxation to support all afflicted patients, at high cost) versus individual rights, whereby each couple decides on its own whether to risk having afflicted offspring. Would they make that choice if the public-funded treatment was not available? Their obligation is to consider more than themselves!
5	This is way too much intervention into people's lives and a violation of people's rights. Public education and outreach is a more suitable approach.
2	I hate to force anyone to do anything. As long as the government ultimately doesn't interfere with the couple's right to go ahead, marry and have children, I think screening and counselling is not a bad idea.
2	Ugh, tough question. As the question doesn't state that those who test positive can not then be married, I believe it to be a sound albeit infringing policy. I suppose the notion of having nothing to hide comes to mind and the fact that people have a right to live in ignorance only to the extent that it doesn't infringe on others. Not sure if this contradicts my last response but I believe not.
5	People have the right to marry whoever they want to. Like I said before, there is only 25% chances.
5	marriage and getting children is not the same!!! don't cut off human rights!!!
4	I think here there is a likelihood that the right of the individual to get married would be violated .
4	This impedes too heavily on personal rights. I prefer an appeal to all persons sense of responsibility in hopes of increasing voluntary participation and alternative reproduction planning.
5	Marriage is a right to everyone. There certainly should not be any restrictions pertaining to family hx of inheritable diseases/disorders or any other kind of discrimination (ie. gender). Besides, marriage is NOT a license to procreate nor has it been a prerequisite.
5	No Privacy and ethics issues related to mandatory testing are onerous and affect individual rights

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