



What Constitutes Informed Consent? Understanding Respondents' Need for Transparency

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- **In May 2015, proposed changes to the AAPOR Code of Professional Ethics and Practices regarding disclosure of survey sponsorship led to a heated discussion among AAPOR members.**
- **We conducted a survey among members of a probability-based online panel, which asked them what information is critical for them to make an informed decision about their participation in a survey.**
- **Disclosure about protection of privacy and personal information was the only piece of information deemed essential by most panelists.**

Proposed Wording: AAPOR Code of Professional Ethics and Practices (2015)



“We recognize the **right of potential participants to be provided with a description of our research sufficient to permit them to make a free and informed decision about their participation.** Such a description includes the purpose of the research, **who is conducting and sponsoring it,** a summary of risk of harm or benefit from participation, and how their personally identifiable information will be used and protected.”

“If we have valid reason to believe that providing potential participants certain information about the research would substantially bias results or endanger staff, **we will inform participants, in advance of their participation decision to the extent practicable, that they will be debriefed when the research is concluded.**”

Informed Consent



- **The notion of informed consent began in the medical field, where researchers are asked to disclose potential negative impacts of medical tests so patients can make informed choices about whether or not to participate.**

- **In general survey research poses little risk to participants, with disclosure of respondent identity being the primary risk.** (Presser, 1994)

- **Following an RDD telephone survey, only 13% of respondents said they could see any risks to being interviewed.** (Singer, 1984)
 - **54% of those who perceived a risk cited breaches of confidentiality as their primary concern.**

Survey Sponsorship

- **Disclosure of sponsorship can be problematic:** (Tourangeau et al., 2009)
 1. **May lead to nonresponse error** (e.g., Groves et al., 2012; Edwards, Dillman & Smyth, 2014)
 2. **May impact results/introduce bias due to preconceptions about sponsor** (e.g., Presser, Blair & Triplett, 1992; Tourangeau, Presser & Sun, 2014)

- **Disclosure of survey sponsorship was rated as less important than other types of information in an RDD telephone survey** (Singer, 1984)

	% Very Important
How the information was going to be used	71
Why the study was being done	62
Who is paying for a study	42

Current Survey

- **Research Questions:**

1. Do online panelists view taking surveys as risky?
2. What types of information do online panelists view as critical to make an informed decision?

- **Hypotheses:**

1. The majority of online panelists will view surveys as constituting minimal risk.
2. Three issues will emerge as essential to making an informed decision:
 - The topic of the survey
 - How much time the survey will take
 - What's in it for the respondent

Study Design



- **Used sample from GfK's KnowledgePanel®**
- **<5 minute survey on respondent motivation and informed consent**
 - Respondents were asked about their general experience taking online surveys and not strictly about their experiences with GfK.
- **Respondents had not been invited to complete a KP survey in the previous month**
- **Data were weighted to CPS benchmarks for age, sex, education, ethnicity, and income**



Possible Negative Impacts of Surveys



- 6% of respondents think taking an online survey could have a negative impact on their life.

“A survey company could have a data breach and my personal info could be leaked.”

“If the info generated is used improperly”

“I never know for SURE who has access to the info I reveal”

“If the people who created the survey use the information I give for purposes that are against my beliefs”

“If it’s done by a disreputable company or individual or if the survey company is hacked by unscrupulous people”

“I could become angry at the tricky way or the biased way in which a question was asked.”

“The survey could ask intrusive questions or raise uncomfortable topics.”

Online Surveys and Mental Health



- The majority of respondents think taking a survey constitutes no or only minimal risk to a person's mental health.

	%
No risk	70
Minimal risk	25
Some risk	2
High risk	3

Emotional Reactions to Online Surveys



- 23% of respondents have stopped taking one or more online surveys during the past year because a survey made them feel uncomfortable.
- And, almost as many report taking an online survey that made them feel very angry or increased their stress a lot.

Took an online survey that...	% experienced one or more times in the past year
Made you think more deeply about your life	48
Made you feel a lot better about your life	42
Made you feel very angry	19
Increased your stress level a lot	18
Made you feel a lot worse about your life	12
Made you feel deeply sad	8

What made you angry?



“Asking for my race and family income”

“Asking too much personal information.”

“Questions regarding Hispanic life style etc...”

“I was more annoyed than angry.”

“I am annoyed when there is not a chance for me to give the answer I would want to.”

“Political surveys seem to be slanted”

“The survey was just very, very long and extremely BORING!!!”

What increased your stress?



“answer selections didn’t apply to me so it was difficult to know how to answer”

“anything to do with my financial status/investments”

“Surveys that ask questions testing my knowledge, I find offensive.”

“Having to answer questions I know little about (politics, technology)”

“Health insurance. It is confusing. Expensive and can be overwhelming to think about”

“graphic ads featuring smokers with disfigurement”

“I completed most of the survey and then started reading the privacy statement and decided to not complete the survey because the privacy statement was too long to read & I didn’t want to take my chances in submitting it.”

Importance of Types of Disclosures



- Respondents were asked about the importance of finding out various types of information prior to their decision to complete a survey.

	% Essential
How personal information and privacy will be protected	79
Risks that exist	40
How long to complete	41
Topic	35
How results will be used	35
Money or points for completing	33
Why survey is being done	27
Company/organization conducting the research	23
Company/organization paying for the research	21
Description of types of questions	17
If will be entered into a sweepstakes (drawing)	15

Conclusions



- **In general, online panelists view surveys as low risk. Only 6% think taking an online survey could have a negative impact on their life, and 95% think taking a survey constitutes no or only minimal risk to a person's mental health.**
- **However, more than one in five have stopped taking a survey in the past year because they felt uncomfortable.**
- **About four in five online panelists feel that disclosure of how personal information and privacy will be protected is essential prior to making a decision about their participation.**
- **Only 23% feel it is essential to know the organization conducting the research, whereas 21% feel it is essential to know the organization paying for the research.**

Next Steps



- **This survey was conducted with respondents who have an ongoing relationship with an online panel. While many of the comments made it clear that respondents were considering their survey experience in total and not just GfK surveys, panelists may consider the panel as a first line of defense against breaches of privacy and as a way to screen survey sponsors.**
- **We will repeat the survey with respondents to an RDD telephone survey and compare the results to those found among online panelists to determine whether the need for disclosure differs among those who are not part of a panel.**

Approved Wording: AAPOR Code of Professional Ethics and Practices (2015)



“Participation in surveys and other forms of public opinion research is voluntary, except for the decennial census and a few other government surveys as specified by law. We shall provide all persons selected for inclusion with a description of the research study sufficient to permit them to make an informed and free decision about their participation. We shall make no false or misleading claims as to a study’s sponsorship or purpose, and we shall provide truthful answers to direct questions about the research. If disclosure could substantially bias responses or endanger interviewers, it is sufficient to indicate that some information cannot be revealed or will not be revealed until the study is concluded.”

Thank you!

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