

A Preliminary Exploration of the Effects of Informed Consent Language on Response Rates and Respondent Perceptions.

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Introduction

- Informed Consent information is essential to survey research
 - Provides respondents with important study information (risks, benefits, survey topic, length)
 - Required by Institutional Review Boards (IRBs)
 - Helps set the stage for the research and, we hypothesize, impacts success.
- Little guidance, however, is given as to how to best structure this important information



Background

- Most research on informed consent has been conducted in medical studies but issues raised are applicable to survey research:
 - Readability
 - Use of technical jargon and scary wording
 - For the perceived benefit of researchers only
 - Potential impacts on response rates
 - Zone-out of information
 - Potential impact on respondent information collected



Research Purpose

- Explore the effects of different informed consent scripts on response rates and respondent perceptions of consent language.
 - Do response rates vary?
 - Do respondents feel they were given adequate information to make an informed decision?
 - Do reports of consent understandings vary?
 - Does the information makes respondents feel their participation could have a negative consequence?
 - Did respondents feel their data would be handled responsibly?



The Real Purpose Here...

- Have empirical evidence to support our argument that:
 - Informed consent scripts, particularly in telephone surveys, should be short and simple
 - Longer response rates hurt response rates
 - Respondents feel just as consented with a short script as a long script.
 - Respondents tune out if they are read long sections of information



Data

- The Nebraska Annual Social Indicators Survey (NASIS), an annual state-wide telephone survey of 1,800 respondents
 - Currently, about half of data is collected (N=871)
 - Uses a directory listed sample
 - 31% response rate



Consent Scripts

Respondents are randomly assigned one of three scripts:

1. **SHORT**
 - basic and fairly short (traditionally used in NASIS)
 - 197 words, 10.2 Grade Level, 50.6 Reading Ease
2. **MEDIUM**
 - less lengthy, but including language from IRB template
 - 297 words, 11.3 Grade Level, 46.7 Reading Ease
3. **LONG**
 - lengthy statement based on IRB template
 - 388 words, 12.1 Grade Level, 39.1 Reading Ease

Flesch-Kincaid Reading Ease Score and Flesch Reading Ease Score used for evaluation

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Amount of Information

- Significant differences were found for reports of the information presented being “too much,” “too little, or “just right.”

Amount of Information *	Short	Medium	Long
Too much	4.1%	13.1%	18.7%
Too little	10.1%	9.0%	5.6%
Just right	85.8%	77.9%	75.7%

* $p < 0.001$

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Perceived Negative Outcome

- Respondents reported significant differences when asked if the information made them feel as though something negative could happen if they participated (but not quite in the way we anticipated).

Perceive negative *	Short	Medium	Long
Strongly Agree/Agree	6.9%	7.3%	5.8%
Neither Agree/Disagree	2.3%	5.9%	1.8%
Strongly Disagree/Disagree	90.8%	86.7% ←	92.3%

* $p < 0.05$

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Provided Information Needed

- No significant differences between the three consent scripts with regard to respondent perceptions of being provided the information needed to make an informed decision
 - 92.7% reporting agreement at the beginning
 - 96.1% at the end
- 36.4% changed their answers from beginning to end, most reporting more agreement at the end of the survey
 - Of those who became more agreeable, significant difference were found: 78.2% of medium, 63.9% of short, 63.2% of long



Non-Significant Findings

- No significant differences were found between the three consent scripts and respondent perceptions that the data would be handled in a responsible manner by the researchers
 - 95.8% agree or strongly agree
- Ratings for the ease/difficulty of understanding the informed consent script were not significantly different for the three groups.
 - Mean = 1.96 (1=easy, 5=difficult)
 - Social desirability?



Response Rate

- No significant effect of consent script on response rates
 - Short consent script (32.9%), medium (31.5%), long (29.4%), but nonsignificant.
- Anecdotally, interviewers perceive that there is a large difference in response rates.



Conclusion

- We would recommend the short script for use in telephone surveys
 - More respondents perceived it as providing the “just about right” amount of information
 - Respondents reported similar rates of being provided the information needed to make an informed decision
 - Respondents perceive data to be handled responsibly
 - The script is shorter – less burden on the respondent and the interviewer



Future Work

- Finish data collection
- Analyze open-end data
 - Follow-up question asking people who felt they were not given information needed to make an informed decision what information would be helpful
 - Respondent recall of informed consent information at the end of the survey
- Cognitive interviews
 - Examine the wording differences and length in more detail
- Research interviewer perceptions of response rates



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Short

Hello, this is _____ and I am calling from the research center at the University of Nebraska. We are interviewing people 19 years of age or older in the state of Nebraska as part of the Nebraska Annual Social Indicators Survey. This research asks questions about opinions, characteristics, and behaviors so we can find out more about how Nebraskans think, feel, and live. We need your help to make the study as accurate as possible. Any information obtained during this study which could identify you will be kept strictly confidential. Your telephone number was generated at random, and your participation is important so the study represents all types of Nebraskans. You are free to decide not to participate in this study or to withdraw at any time without harming your relationship with the researchers or the University of Nebraska. Your responses will not be linked to your phone number or any identifying information. You may choose not to answer any questions you wish. We will report the results only in summary form, so no individual data will be released. The interview may take about 25 minutes to complete, but we can complete it in more than one session if necessary. Can we begin now?

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Medium

Hello, this is _____ and I am calling from the research center at the University of Nebraska. We are interviewing people 19 years of age or older in the state of Nebraska as part of the Nebraska Annual Social Indicators Survey. This research asks questions about opinions, characteristics, and behaviors so we can find out more about how Nebraskans think, feel, and live. We need your help to make the study as accurate as possible. Any information obtained during this study which could identify you will be kept strictly confidential. Your telephone number was generated at random, and your participation is important so the study represents all types of Nebraskans. You are free to decide not to participate in this study or to withdraw at any time without harming your relationship with the researchers or the University of Nebraska, or in any way receive a penalty or loss of benefits to which you are otherwise entitled. Your responses will not be linked to your phone number or any identifying information. Information obtained in the study may be published or presented to the public or in scientific journals or meetings; however, we will report the results only as aggregated data. There are no direct or indirect benefits to you for participating in this study. There is a chance you might feel uncomfortable when answering questions, but you may choose not to answer any questions you wish. The interview may take about 25 minutes to complete, but we can complete it in more than one session if necessary. If you have questions concerning this research, I can provide you with a phone number for the Bureau of Sociological Research or the UNL Institutional Review Board. Completion of the interview implies your consent to participate in this research. Can we begin now?

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Long

Hello, this is _____ and I am calling from the research center at the University of Nebraska. We are interviewing people 19 years of age or older in the state of Nebraska as part of the Nebraska Annual Social Indicators Survey. This research asks questions about opinions, characteristics, and behaviors so we can find out more about how Nebraskans think, feel, and live. We need your help to make the study as accurate as possible. Any information obtained during this study which could identify you will be kept strictly confidential. The data will be stored on a secured server accessible only by Bureau of Sociological Research staff. Your telephone number was generated at random, and your participation is important so the study represents all types of Nebraskans. You are free to decide not to participate in this study. You can also withdraw at any time without adversely affecting your relationship with the investigators, the University of Nebraska, any other agent, or in any other way receive a penalty or loss of benefits to which you are otherwise entitled. Your responses will not be linked to your phone number or any identifying information. There are no direct or indirect benefits to you for participating in this study. There is a chance you might feel uncomfortable when answering questions about your attitudes, beliefs, and behaviors, but you may choose not to answer any questions you wish. Information obtained in the study may be published in scientific journals or in public media, or presented at scientific meetings or to the public, however, we will report the results only as aggregated data. We are asking you to participate in a telephone interview that may take about 25 minutes to complete, but we can complete it in more than one session if necessary. You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study. Or you may call the Bureau of Sociological Research at any time at (402) 472-3672. Sometimes study participants have questions or concerns about their rights. Also, they may wish to express problems, obtain additional information, or offer input. In that case you should call the University of Nebraska-Lincoln Institutional Review Board at (402) 472-6965. Completion of the interview implies your consent to participate in this research. Can we begin now?

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