

Appendix A: Advocate Interview Guide

Introduction and Informed Consent to Participate in Interview

Hello, my name is [INSERT NAME] and I am with NOVA Research Company. I will be conducting the interview today for the National Institutes of Health (NIH). Also on the telephone from NOVA is [INSERT NAME], who will be taking notes. We want to thank you for taking the time for this interview and would like to know if this is still a good time for you? [IF NOT, RESCHEDULE INTERVIEW DATE/TIME.]

I will briefly describe the purpose of this interview and will then ask if you have any questions before we start.

NIH would like to obtain information on its health communications efforts to more effectively communicate with its many interested audiences, including with the advocacy community.

Let me review some details about this call.

- Your participation in this call is voluntary and you can terminate it at any time.
- No one will know who said what because your opinions will be aggregated with that of others.
- The interview should take less than 30 minutes of your time.
- In order to help with the analysis of what was said, we need to audio-record the interview and have transcripts of it. Any identifiable information (e.g., name, organization represented) will be deleted from transcripts and only NOVA researchers will have access to these recordings and transcripts but if you don't want the interview to be recorded, we won't do it and will take notes.

Do you have any questions about this interview or data collection by the NIH now?

If you have any questions about this interview later on, please don't hesitate to contact either me or Dan Eckstein, who is NOVA's Project Manager for the contract under which this interview is being conducted. You may find our contact information in the letter of invitation we sent you and I am happy to provide it to you again if need be.

We would like to audio-record your verbal consent (or not) to this interview and audio-recording of your responses.

“Do you accept or decline to participate in the interview to gather information on communication efforts by the NIH?”

“Do you accept or decline to have the interview audio-recorded?”

Thank you. We are now ready to start.

Individual Interviews

Stakeholders: Disease-Oriented Advocacy Organizations and Industry and Professional Advocacy Organizations*

Public reporting burden for this collection of information is estimated to average 30 minutes. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN; PRA (0925-0648).

** There will be two different sets of interviews groups: (a) one with representatives from disease-oriented advocacy organizations; (b) the other with representatives from industry and professional advocacy organizations.*

Perceptions About NIH, Areas of Research, and Impact

1. What do you think is the unique role of the National Institutes of Health (NIH) with regard to biomedical and health research communication?

Collaborations

2. When are advocacy organizations, such as the one you represent, likely to work with NIH?
3. How do you view the extent to which institutions conducting biomedical and health research, including NIH, universities, health care organizations, the pharmaceutical industry and the nonprofit sector, collaborate with one another?

NIH Clinical Center

4. How familiar are you with the NIH Clinical Center?

NIH Health and Biomedical Research Information

5. What would you like to hear more about from NIH?