

Consent to Take Part in a Research Study

1. Title of research study: Understanding Meaningful Youth Engagement Study

2. Researcher: Dr. Alex Ezeh (Principal Investigator)

3. Concise Summary of Key Information: This study seeks to understand youth perspectives on engagement within youth advisory council/board/group, committee, or youth leadership group in order to produce recommendations on a model for meaningful youth engagement in research, programs, policies and practice, as well as identify and indicators for successful youth engagement. The survey and interview will ask you to answer on behalf of the organization you are affiliated with as a YAC member. You will be answering questions about your experience with youth advisory councils and what you believe are facilitators and barriers to youth-initiated participation. We are looking for your consent to participate in this study. Your participation in this research is completely voluntary. During the study, you will be asked a series of questions through an online survey and/or interview. The study will last the length of time that it takes you to complete the online survey and/or interview. The survey should take approximately 20 minutes and the interview should take 20-30 minutes. You may pause and resume the survey at any time. You may choose to stop responding to the survey and interview at any time. The results will be aggregated and will not include any organizational or individual identifying information. The potential risk of participating in this study includes breach of confidentiality. However, if you complete the survey and interview away from others this should minimize risk. You may choose to not participate in this study. There is no cost to you.

4. What you should know about a research study: This consent form provides an explanation about this research study. Whether or not you take part is up to you. You can choose not to take part. You can agree to take part now and change your mind later. If you decide to not be a part of this research no one will hold it against you. Feel free to ask all the questions you want before you decide.

5. Why you are being invited to take part in a research study? We invite you to take part in a research study because of your experience as a current or past member of a youth advisory council/board/group, youth member of a steering committee, youth board member or member of youth leadership group.

6. Why is this research being done? This research is being conducted to describe a model of meaningful youth engagement and identify indicators for successful youth engagement. We expect 60-100 participants will be in this research study.

7. How long will the research last? We expect that you will be in this research study for the length of time it takes to complete this survey and/or interview. For the survey, this should be approximately 20 minutes. For the interview, this should be approximately 20-30 minutes.

8. What happens if I say yes, I want to be in this research? If you would like to participate in the survey, you will start the survey by clicking on the link to complete an online Qualtrics survey. This survey should take approximately 20 minutes to complete. If you would like to participate in the interview, you will be scheduled for a 20–30 minutes Zoom interview. The interview will be recorded with your consent. The information will be analyzed to develop recommendations for a model of meaningful youth engagement and indicators for success.

9. What are my responsibilities if I take part in this research? Your responsibilities are to answer the questions asked in the online survey and interview as best as you can.

10. Is there any way being in this study could be bad for me? The potential risk of participating in this study includes breach of confidentiality. However, if you complete the survey and interview away from others this should minimize risk. Your name or organization will not be connected with any answers you give.

11. Do I have to pay for anything while I am on this study? There is no cost to you for participating in this study except for internet access.

12. Will being in this study help me in any way? There are no benefits to you as an individual for being in this study. However, possible benefits for your youth advisory council include better understanding of a model for meaningful youth engagement.

13. What happens to the information we collect? Efforts will be made to limit access to your personal information including your responses and demographic information to the research team. We cannot promise complete secrecy but will keep your responses confidential. Entities that may inspect and copy your information include the Drexel Institutional Review Board. We may publish the results of this research, however no individual-level information will be published. None of your responses will be linked to you or to your organization. Only authorized research team members will have access to the raw data. Names and email addresses will not be included in data collection forms. Contact information used for recruitment will be stored separately from your responses. All data will be stored on password-protected computers.

14. Who can you talk to about this research study? If you have questions, concerns, or complaints, or think the research has hurt you, you may contact the research team. The Principal Investigator is Dr. Alex Ezech, a Professor at Drexel University Dornsife School of Public Health. You can reach Dr. Alex Ezech at 267-359-6137 or email him at ace86@drexel.edu. This research has been reviewed and approved by an Institutional Review Board (IRB) at Drexel University. An IRB reviews research projects so that steps are taken to protect the rights and welfare of human subjects taking part in the research. You may talk to them at (267) 359-2471 or email HRPP@drexel.edu for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.

15. What happens if I do not want to be in this research? There are no consequences to you if you decide you do not want to be part of this research.

16. What happens if I say yes, but I change my mind later? If you agree to take part in the research now, you can stop at any time with no consequences. If you withdraw from the study, we will delete any data you may have provided up until that point

17. What else do I need to know? This research study is being done by members of the Lancet Commission on Adolescent Health and Wellbeing at Drexel University and is funded by the Bill & Melinda Gates Foundation. You will not be paid for taking part in this research.