Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Informed Consent-Survey

Title of Project: **Massachusetts Department of Public Health's Prevention for States Project - Ethnographic and Community Knowledge Survey-Ongoing (ECKS-O)**

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Opioid Policy Research Collaborative

Background

We are asking you to be in a research study. A research study is an organized way of collecting information to help learn and answer questions. Please read this form carefully. It will tell you what you should expect if you agree to be in the study. **It is your decision whether or not to join the study.** If you decide to participate, you will be given a copy of this form to keep.

The drug supply in Massachusetts is often changing. It is important to understand the impact of these changes on the lives and health of people who use drugs. This information can inform what resources should be made available and can improve care, prevention and other services in Massachusetts. Today you will be asked about your background, health care, housing, drug use, overdose, and more. **Your participation in this research study is completely voluntary and you may withdraw at any time.**

What is this study about?

Brandeis University is working with the Massachusetts Department of Public Health to distribute an anonymous survey in order to learn directly from people who use drugs about their health and needs. What we learn can be used to improve education, programs, and policies about substance use and overdose prevention. The survey will be available to answer once per year.

What Will Happen in This Research Study

You will be asked to answer questions on a survey on your own. You can also have a member of the study team ask you the survey questions if you wish. The survey will be provided to you on a tablet computer or paper copy by Brandeis research staff or a community partner organization. The survey will ask you about your background, the substances you use, your experiences with seeing or experiencing overdose, the ways you get and use drugs or alcohol, what you know and how you feel about ways to prevent overdose, your experiences with treatment for drug or alcohol use, and other topics. You will only be asked to complete this survey one time this year. The survey will take approximately 20 minutes to complete. **You may skip any question you don't want to answer. You may stop at any time.** If you don't understand a question or need help during the survey, you can ask the Brandeis Staff or the community organization staff for help.

If you are unable to complete a survey at this time, you may complete it at a later date. We can take down your contact information and reach out to you to schedule a time to complete the survey. Your contact information will not be shared with anyone outside of study staff. We will also ask your permission to retain your contact information (Name, contact number or email) to invite you to participate in future studies related to drug use. If you agree, the information you provide will be kept in a secure file that can only be assessed by study staff. If you are not interested in being contacted at a later date to complete the survey, there is no penalty.

Inclusion Criteria

People eligible to participate in the survey must be:

- Ages 18 years or over
- Be able to read and speak English or Spanish
- Have used illicit drugs or medications not prescribed to them in the past 30 days
- Live in a Massachusetts community

Risks and Discomforts

Some of the questions we will ask may be personal or sensitive in nature, and may cause stress or discomfort. **You can skip or refuse to answer any questions you don't want to answer.**

There is a risk that someone may find out you participated in the survey, however, we take special efforts to protect your privacy. To protect you from this risk, no information identifying you will be gathered on the survey and we ask that you not write any identifying information on electronic or paper surveys, like your name. The survey will be sent to Brandeis University and will not have any information with it that identifies you. Project staff will not tell anyone that you took the survey. Your survey will be stored securely in a computer program called Qualtrics and downloaded to a secure, password protected computer folder where access is restricted to study staff at Brandeis University.

Potential Benefits

You may not receive direct benefit from being in this study. You may gain more understanding into your own experiences related to drug use, harm reduction, and healthcare. Your answers to the survey may help public health and other people learn about drug use, housing, health care, how to improve overdose prevention efforts, and more.

Costs

There are no costs to you for being in this research study.

Payment

You will receive a payment of $20 for completing the survey.

Confidentiality

To help protect your privacy, this research is covered by a Certificate of Confidentiality. This means that the researcher may not disclose or use information or documents that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or proceeding, or be used as evidence – if there is a court subpoena, for example – unless you have consented to its use.

Information or documents protected by this Certificate cannot be disclosed to anyone who is not connected with the research unless you report to the researcher information concerning child abuse or communicable diseases; you have consented to the disclosure; or the information is used for other scientific research, as allowed by federal regulations protecting research subjects.

A Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you want your research information released to any other person not connected with the research, you must provide consent to allow the researchers to release it.

To keep your information secure, we will store any study-related paper files in locked filing cabinets and store electronic files in computer systems with password protection only accessible to the research team.

Future Use of Data

All deidentified data will be retained for future analyses by the research team.

We will share research results where we have removed anything that we think could show your identity (deidentified). Such sharing may include publishing results in journal, presentation, or for use of research data in future studies.

Subject's Rights

Participating in this study is completely voluntary. You can refuse to participate or quit at any time. You may also refuse to answer specific questions– simply skip them or ask the study staff to move on to another topic.

By consenting to be in this study you do not give up any of your legal rights. Consenting means that you have been given information about this study and that you agree to participate in the study. You will be given a copy of this form to keep, if you wish.

If you do not agree to be in this study or if at any time you stop the survey, you will not suffer any penalty. You will not lose any benefits to which you are entitled. Your participation is completely up to you. Your decision will not affect your ability to get health care or payment for your health care. It will not affect your enrollment in any health plan or benefits you can get.

Questions

A member of the research team will try to answer all of your questions. If you have questions or concerns at any time, call Dr. Traci Green at 781-736-2609.

If you have any questions about your rights as a subject in this study, would like to speak with someone other than the researchers about concerns you have about the study, or in the event the researchers cannot be reached, please contact the Brandeis University Human Research Protection Program at 781-736-8133 or hrpp@brandeis.edu.

By agreeing to be in this project, you are indicating that you have read this form, that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research.