

Title: TRANSLATE: Transgender and Gender Nonconforming Individuals' Access to Healthcare

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TRANSGENDER AND GENDER NON-CONFORMING INDIVIDUALS  
INFORMED CONSENT DOCUMENT

**Understanding and Reducing Health Disparities Faced by Transgender and Gender Non-conforming (TGNC)  
Individuals in Cleveland through TGNC-Directed Advocacy**

You are being asked to participate in a research study about the healthcare experiences of transgender and gender non-conforming individuals. You were selected as a possible participant because you use the LGBT Center of Greater Cleveland or you attended TRANS in the CLE in October of 2017 and you self-identify as transgender or gender non-conforming, are over the age of 18, and speak English fluently. Please read this form and ask any questions that you may have before agreeing to be in the research.

Researchers at Case Western Reserve University and the LGBT Center of Greater Cleveland are conducting this study.

**Purpose**

The purpose of this research is to work with transgender and gender non-conforming people to understand the barriers they face when accessing and using primary health care. We are interested in whether providing training in health literacy and meeting with healthcare providers in a safe, non-clinical setting makes it more likely for transgender and gender non-conforming people to use primary care services.

**Procedures**

If you agree to be a participant in this research, we would ask you to do the following things:

Fill out 2 surveys.

Attend 2 meetings a month over the course of 9 months. Each meeting will last approximately 90 minutes.

Work with other transgender and gender non-conforming people to identify what would be most helpful to you in getting access to health care, talk about your concerns about receiving health care, and receive a health literacy training based on your ideas.

Meet with healthcare providers 3 times (as part of the larger set of meetings) to discuss your thoughts, feelings, and suggestions with a trained facilitator.

Receive training on how to act as a peer mentor with other transgender or gender non-conforming people at the LGBT Center (as part of the larger set of meetings).

At the completion of the program, you can volunteer to give us a private interview about your experiences but this is not required. Additionally, if you have an experience with a healthcare provider you would like to share, you may volunteer to have a private interview about that experience without sharing any of your medical information as covered by HIPPA. Again, this is not required. If you want to do an interview or interviews, we would like to audio-record the interviews. You have the choice to have us take notes if you do not want to be audio-recorded.

You can choose to stop participating for any reason at any time. However, if you decide to stop participating in the study, we encourage you to tell the researchers. You may be asked if you are willing to complete some study termination activities.

**Foreseeable Risks and Discomforts**

There are no known risks, harms or discomforts associated with this study beyond those encountered in your daily life. Some of the activities we will ask you to complete might make you feel uncomfortable. You may refuse to answer any of the questions, take a break, or stop your participation in this study at any time. The possible risks and/or discomforts associated with the procedures described in this study include: feeling uncomfortable or anxious talking about healthcare experiences or other people potentially finding out you identify as transgender or gender non-conforming (if you are not out in all aspects of your life).

The researchers will keep your information confidential but because we will meet in a group setting, even with encouraging everyone to respect confidentiality, we cannot guarantee your identity or what you discuss will remain confidential. The researchers will keep their notes coded (not using your real name) and all data will be kept on a secure, encrypted server. You will not be identified, either by name or through identifying characteristics, in any reports or publications. If you feel uncomfortable or anxious, you may choose to not answer a question or respond to a discussion; leave the group for a little while or the rest of the meeting; or you can take advantage of the LGBT Center's resources in the form of their support groups or get a referral for counseling.

### **Anticipated Benefits**

The possible benefits you may experience from the participation in this study include increasing your knowledge about the healthcare system and getting to know individual healthcare providers.

Your participation could help other transgender and gender non-conforming people get better health care in the future and help educate healthcare providers on how to treat transgender and gender non-conforming people in an appropriate and respectful manner.

### **Compensation**

There will be no costs to you for study participation.

You will receive a \$25 Visa gift card for each meeting you attend. There are 18 total meetings. Total compensation for participation in this study is \$450. If you decide to withdraw from the study or are withdrawn by the research team, you will receive compensation for the visits that you have completed.

You will not be reimbursed for any out of pocket expenses, such as parking or transportation fees.

You will receive one \$25 gift card at the close of each meeting. If you decide to skip a meeting, you will not receive a gift card for that meeting. If you decide to withdraw from the study, you will stop receiving gift cards.

### **Voluntary Nature of the Study**

Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the University or the LGBT Center of Greater Cleveland. There is no penalty or loss of benefits for not participating or for discontinuing your participation.

You are free to withdraw from this study at any time. **If you decide to withdraw from this study you should notify the research team immediately.** The research team may also end your participation in this study if you do not follow instructions, miss scheduled visits, or if your safety or welfare are at risk.

If you withdraw or are removed from the study, the researchers may ask you to fill out a follow up survey and have a brief voluntary exit telephone interview.

If you elect to withdraw or are withdrawn from this research study, the researchers will discuss with you what they intend to do with your study data. Researchers may choose to analyze the study data already collected or they may choose to exclude your data from the analysis of study data and destroy it, as per your request.

## **Confidentiality**

The records of this research will be kept confidential. Any time information is collected, there is a potential risk for loss of confidentiality. Every effort will be made to keep your information confidential; however, this cannot be guaranteed. We ask that you respect the confidentiality of the group by not discussing specifics outside of the group. This will be reviewed at every meeting.

In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Research records will be kept in a locked file and access will be limited to the researchers, the University review board responsible for protecting human participants and regulatory agencies.

## ***Subject Identifiable Data***

Your name will be removed and replaced with a pseudonym in any fieldnotes or interviews. A list linking your name and your pseudonym will be kept separate from the research data until the end of the project. This is so we can track how your feelings change over time and track relationships.

## ***Data Storage***

Research data will be maintained in a secure location at CWRU and at the LGBT Center in a locked cabinet in a locked drawer. Only authorized individuals will have access to it.

Research data will be stored electronically on a secure, encrypted server that is password protected.

The audio recordings, if you choose to participate in a recorded interview, that can identify you will be:

- Stored in a secure location;
- Transcribed and erased as soon as possible

The researchers intend to keep the research data:

- Indefinitely, because the data are de-identified. Once the study is complete, we will destroy the master list linking your pseudonym to your name.

*This research is covered by a Certificate of Confidentiality (CC) from the National Institutes of Health. This means that we will not tell anyone what you tell us even if a judge tries to force us to identify you as a person in the study unless you give us permission. You should know, however, that we may tell local authorities if harm to you, harm to others, or if child abuse or neglect becomes a concern. Also, the government agency that has provided the money for this project may see your information if they ask for our records to ensure we were conducting the project correctly.*

## **Contacts and Questions**

The researchers conducting this study are Misty Luminais and Margaret McGuire. You may ask any questions you have now. If you have any additional questions, concerns or complaints about the study, you may contact them at [misty.luminais@case.edu](mailto:misty.luminais@case.edu) or 216-362-1329 or [margaret.mcguire2@case.edu](mailto:margaret.mcguire2@case.edu) or 216-368-0313.

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about; (1) questions, concerns or complaints regarding this study, (2) research participant rights, (3) research-related injuries, or (4) other human subjects issues, please contact Case Western Reserve University's Institutional Review Board at (216) 368-4514 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH 44106-7230.

You will be given a copy of this form for your records.

**[Permission to Record Voluntary Interviews]**

- [YES, I CONSENT to being audio-recorded. I also understand that I can change my mind.]*
- [NO, I DO NOT CONSENT to being audio-recorded. Please take notes.]*

**Statement of Consent**

Your signature below certifies the following:

- You are at least 18 years of age
- You have read the information provided above.
- You have received answers to all of your questions and have been told who to call if you have any more questions.
- You have freely decided to participate in this research.
- You understand that you are not giving up any of your legal rights.

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Signature of Participant:

Date: \_\_\_\_\_

\_\_\_\_\_  
Signature of Person Obtaining Consent:

Date: \_\_\_\_\_