IRB Use Only
Approval Date: July 18, 2019
Expiration Date: January 22, 2020

THE POPULATION RESEARCH IN IDENTITY AND DISPARITIES FOR EQUALITY (PRIDE) STUDY

INFORMED CONSENT FORM

****

FOR QUESTIONS ABOUT THE STUDY, CONTACT: Juno Obedin-Maliver, MD, MPH, MAS or Mitchell R. Lunn, MD, MAS by mail at 1701 Page Mill Road, Palo Alto, CA 94304, by telephone at 1-855-421-9991 (toll-free), or by e-mail at junoom@stanford.edu or lunn@stanford.edu.

DESCRIPTION: You are invited to participate in a research study (The PRIDE Study) about the physical, mental, and social health of lesbian, gay, bisexual, transgender, queer (LGBTQ), and other sexual and gender minority (SGM) people. The purposes of this study are to improve our understanding the physical, mental, and social health of LGBTQ and other SGM people, and to improve the lives of people in these communities.

We would like to keep track of your health status for as long as you remain in the study. Keeping in touch with you and checking on your health periodically over many years will help us look at how LGBTQ identity can influence physical, mental, and social health. This will also help us compare the health of LGBTQ people to the general population. We plan to do this by contacting you at least twice a year while you are in the study.

You will be asked to do a variety of tasks if you decide to participate in The PRIDE Study:

"My Profile" and "My Health"
After enrolling in The PRIDE Study, you will be asked to complete the "My Profile" and "My Health" sections. These section will ask a series of questions about you and your identity, race/ethnicity, medical problems, surgeries, medications, sexual history, and reproductive history (if applicable). These sections will take about 10-15 minutes to complete for most people.

You may be asked to update information in these section every six months or as your information (including your health) changes.

Surveys
If you agree to participate in The PRIDE Study, you will be asked to complete a series of surveys about your life and health. The surveys will ask about many things including, but not limited to: physical health, mental health, social health including your social supports, diet, exercise, alcohol, tobacco, experiences accessing health care, cancer screening, and costs associated with healthcare among many other topics. Some surveys may ask about sensitive information including illegal drug use, violence or trauma, and mental/behavioral health-related issues. Each survey that you are asked to complete will appear in "My Dashboard" and will include an estimated completion time for each survey.

IRB Use Only
Approval Date: July 18, 2019
Expiration Date: January 22, 2020

Hospitalization Assessment
Every three months, The PRIDE Study will contact you to ask if you have been hospitalized in the previous three months. If you have, you will be asked to complete a short four-question survey (about 2 minutes to complete) that asks details (*e.g.*, date, location, reason) for your hospitalization. If we are interested in learning more about the hospitalization, we may contact you to ask for your permission to obtain your medical records about the hospitalization.

Other Study Activities
As a participant in The PRIDE Study, you may be invited to participate in additional study activities, surveys, or modules of The PRIDE Study. Each of these studies may have a separate consent form and will be explained in detail so you may determine if you would like to be a part of it. Participation in these additional components will be optional. You can still be a participant in The PRIDE Study without participating in any of these additional components.

Reminders and Study Communications
When there is a study activity that we want you to complete or consider, we will contact you. The PRIDE Study will offer a variety of communication options (*e.g.*, e-mail, text) that you can choose from, so that you are contacted in the manner that you prefer.

Connecting an mHealth Device
Participants in The PRIDE Study who own a mobile health (mHealth) device – like a physical activity tracker – are given the option to connect their mHealth device account to The PRIDE Study. This will allow The PRIDE Study to have access to your mHealth device data. For example, The PRIDE Study would receive information about how many steps you walked, your blood pressure, etc. depending on the measurements that your mHealth device makes.

Other Studies
Occasionally, The PRIDE Study will be contacted by researchers who are not part of The PRIDE Study team. If these researchers are conducting valuable LGBTQ health research, we may list these other studies in the "Other Opportunities" section of The PRIDE Study site. It will be your choice if you want to join any of these outside opportunities. Additionally, we may contact you to inform you about valuable LGBTQ health research studies. At no time is your personal contact information ever shared with researchers outside of The PRIDE Study.

Follow-Up and Backup Contacts
Knowing about each participant in The PRIDE Study is important. If you remain enrolled in The PRIDE Study and we are unable to reach you via the contact information you provided, we may contact the Backup Contacts you listed to ask if you are still alive and how to reach you. If you have died, we may ask your provided Backup Contacts about who has power over your medical records. We may contact that person to request your cause of death, medical records (if you died in a hospital), and a copy of your death certificate.

IRB Use Only
Approval Date: July 18, 2019
Expiration Date: January 22, 2020

Future use of Private Information
Identifiers might be removed from identifiable private information and, after such removal, the information could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you.

RISKS AND BENEFITS: The risks associated with this study are that some of the survey questions may make you uncomfortable or upset, but you are free to not answer any questions you do not wish to answer. While unauthorized access of your health-related data is extraordinarily difficult and rare, there is a risk of loss of confidentiality should this occur. The benefits which may reasonably be expected to result from this study are that the information you provide may help health professionals learn more about the effect of sexual orientation and gender identity on physical, mental, and social health. The PRIDE Study team will create documents from the learnings of our study. We hope that society will benefit from your participation. By participating, you will help us have a better understanding of health issues that affect LGBTQ people. We cannot, and do not, guarantee or promise that you will receive any benefits from this study. Your decision whether or not to participate in this study will not affect your employment/medical care at Stanford University or Stanford University Medical Center.

TIME INVOLVEMENT: Your participation in this experiment will take approximately 60-90 minutes per year for most participants. For participants who are eligible for additional surveys and decide to complete them, the total time involvement may be longer. Each survey that you are invited to complete will include an estimated completion time.

PAYMENTS/REIMBURSEMENTS: You will receive no compensation as payment for your participation in The PRIDE Study. Some surveys that we conduct in The PRIDE Study may have be associated with a raffle (*i.e.,* a giveaway of a certain number of gift cards or other prize). For these surveys (which will be clearly marked), if you provide your contact information, you will be entered into a raffle to be conducted during the research for a gift/prize. Participation in The PRIDE Study or the specific surveys associated with the raffle is not required in order to participate in the raffle. You can enter the raffle if you do not start or complete the study task. The chance of winning a prize no worse than approximately 1 in 1000. The winner will be notified immediately by email and provided with information on how to receive the prize.

If any prize is worth $100 or more, the drawing may be limited to U.S. citizens, legal resident aliens, and those who have a work eligible visa. You may need to provide your social security number to receive payment.

PARTICIPANT'S RIGHTS: If you have read this form and have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

IRB Use Only
Approval Date: July 18, 2019
Expiration Date: January 22, 2020

The results of this research study may be presented at scientific or professional meetings or published in scientific journals. However, your identity will not be disclosed. You have the right to refuse to answer particular questions.

CERTIFICATE OF CONFIDENTIALITY

This research is covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers with this Certificate may not disclose or use information, documents, or biospecimens 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, for example, if there is a court subpoena, unless you have consented for this use. Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research except, if there is a federal, state, or local law that requires disclosure (such as to report child abuse or communicable diseases but not for federal, state, or local civil, criminal, administrative, legislative, or other proceedings, see below); if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protecting research subjects

You should understand that 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 an insurer, medical care provider, or any other person not connected with the research, you must provide consent to allow the researchers to release it.

IRB Use Only
Approval Date: July 18, 2019
Expiration Date: January 22, 2020

Authorization To Use Your Health Information For Research Purposes

Because information about you and your health is personal and private, it generally cannot be used in this research study without your written authorization. If you sign this form, it will provide that authorization. The form is intended to inform you about how your health information will be used or disclosed in the study. Your information will only be used in accordance with this authorization form and the informed consent form and as required or allowed by law. Please read it carefully before signing it.

What is the purpose of this research study and how will my health information be utilized in the study?

The purposes of this study are to improve our understanding the physical, mental, and social health of lesbian, gay, bisexual, transgender, queer (LGBTQ), and other sexual and gender minority (SGM) people, and to improve the lives of people in these communities. Health information that you provide will be utilized by researchers to examine how LGBTQ identity can influence physical, mental, and social health. It will also be used to compare the health of LGBTQ people to the general population.

Do I have to sign this authorization form?

You do not have to sign this authorization form. But if you do not, you will not be able to participate in this research study. Signing the form is not a condition for receiving any medical care outside the study.

If I sign, can I revoke it or withdraw from the research later?

If you decide to participate, you are free to withdraw your authorization regarding the use and disclosure of your health information (and to discontinue any other participation in the study) at any time. After any revocation, your health information will no longer be used or disclosed in the study, except to the extent that the law allows us to continue using your information (*e.g.,* necessary to maintain integrity of research). If you wish to revoke your authorization for the research use or disclosure of your health information in this study, you must write to: Juno Obedin-Maliver, MD, MPH, MAS or Mitchell R. Lunn, MD, MAS by mail at 1701 Page Mill Road, Palo Alto, CA 94304.

What Personal Information Will Be Obtained, Used or Disclosed?

IRB Use Only
Approval Date: July 18, 2019
Expiration Date: January 22, 2020

Your health information related to this study, may be used or disclosed in connection with this research study, including, but not limited to, information that you provide via "My Profile," "My Health," or surveys in The PRIDE Study about your health, diagnoses, experiences, and medications. The PRIDE Study does not access your medical records. All health information is provided directly by you to us for research purposes.

Who May Use or Disclose the Information?
The following parties are authorized to use and/or disclose your health information in connection with this research study:

- The Protocol Directors (Juno Obedin-Maliver, MD, MPH, MAS and Mitchell R. Lunn, MD, MAS)
- The Stanford University Administrative Panel on Human Subjects in Medical Research and any other unit of Stanford University as necessary
- Research Staff

Who May Receive or Use the Information?
The parties listed in the preceding paragraph may disclose your health information to the following persons and organizations for their use in connection with this research study:

- The Office for Human Research Protections in the U.S. Department of Health and Human Services
- Collaborators at other institutions (only after they have been approved by their Institutional Review Board for human subjects in research to receive protected health information)

Your information may be re-disclosed by the recipients described above, if they are not required by law to protect the privacy of the information.

When will my authorization expire?
Your authorization for the use and/or disclosure of your health information will end on December 31, 2050 or when the research project ends, whichever is earlier.

IRB Use Only
Approval Date: July 18, 2019
Expiration Date: January 22, 2020

WITHDRAWAL FROM STUDY

The Protocol Director may also withdraw you from the study without your consent for one or more of the following reasons:

- Failure to follow the instructions of the Protocol Director(s) and study staff.
- The Protocol Director decides that continuing your participation could be harmful to you.
- The study is cancelled.
- Other administrative reasons.
- Unanticipated circumstances.

CONTACT INFORMATION:

If you have any questions, concerns or complaints about this research study, its procedures, risks and benefits, or alternative courses of treatment, you should ask the Protocol Directors: Juno Obedin-Maliver, MD, MPH, MAS or Mitchell R. Lunn, MD, MAS by mail at 1701 Page Mill Road, Palo Alto, CA 94304, by telephone at 1-855-421-9991 (toll-free), or by e-mail at junoom@stanford.edu or lunn@stanford.edu. You should also contact them at any time if you feel you have been hurt by being a part of this study.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the Stanford Institutional Review Board (IRB) to speak to someone independent of the research team at (650)-723-5244 or toll free at 1-866-680-2906. You can also write to the Stanford IRB, Stanford University, 3000 El Camino Real, Five Palo Alto Square, 4th Floor, Palo Alto, CA 94306.

If you wish to participate in this study, please check the box that says "I have read, understand, and agree to the consent above." Then click the box that says "CONTINUE."

You can also download a copy of this consent form by clicking the link that says "DOWNLOAD A COPY OF THIS CONSENT."