CONSENT FOR RESEARCH

Template v. 09/09/2019

The Latiné Immigration and Health Study (LIHS): A longitudinal study exploring immigration, embodiment, and health within Latiné refugees/immigrants in the United States

You are being asked to participate in a research study that involves the collection of information regarding your immigration experience, experiences in the United States after immigrating, and a sample of saliva. Your participation is voluntary. Your decision whether or not to take part will have no effect on your life, livelihood, or citizenship status. Please ask questions if there is anything about this study that you do not understand.

What is the purpose of this research?

The purpose of this study is to understand how differences in journeys taken during immigration, experiences related to that journey, and experiences in the United States may manifest in differences in health, specifically biological aging, within Latiné refugees/immigrants that arrived in the United States since January 1, 2019. This is a longitudinal study, meaning that we will collect some information from you now and then follow-up with you in one year to collect new information based on your experiences living in the United States.

What does participation in this research involve?

Your participation in this research project involves:

- Providing 2 mLs of saliva (half a teaspoon)
- Answering a questionnaire asking for your demographic information, health information, mental health as it relates to anxiety, depression, and post-traumatic stress disorder, your experiences immigrating to the United States, and your experiences while living in the United States
- A subset of participants will participate in an audio-recorded semi-structured interview. If you are interested and are selected, you will be asked details about your life in your country of origin, your immigration story, and your experiences in the United States

Participation in the study involves being recontacted one year after the date of your first session to undergo a second session that will involve collecting the same information from you as listed above.

Are there any benefits to participating in this research?

There are no benefits to you should you decide to participate in this study. You may choose to receive a summary of the main findings of your genetic data. If you'd like to receive these findings, please contact Margarita Hernandez at Margarita.Hernandez@dartmouth.edu or at (954) 696-3502.

Are there any risks from participating in this research?
There is a risk of loss of confidentiality if your information or your identity is obtained by someone other than the investigators, but precautions will be taken to prevent this from happening. The confidentiality of your electronic data created by you or by the researchers will be maintained as required by applicable law and to the degree permitted by the technology used. Absolute confidentiality cannot be guaranteed.

Additionally, you may experience some distress related to answering the questions within the study. This could include recounting difficult experiences related to your life and your health. If you experience distress and need mental health services, please feel free to reach out the 988 Lifeline, the national Suicide and Crisis Hotline. This free hotline is available through call (988), text (988), or virtual chat (988lifeline.org). Trained professionals will provide you with the immediate care you need and connect you with resources for continued care.

There is one question that you will be asked during the questionnaire that pertains to thoughts of suicide. This question may be distressing and difficult to answer. If you express thoughts of suicide, I will ask you further questions to gauge whether you are at immediate risk of harming yourself. If you are determined to have an immediate risk of harming yourself, I will call the 988 Lifeline, which is a confidential Suicide and Crisis hotline that will be able to assist you. I will remain with you while you go through this process. Based on your answers, you may be referred to further mental health resources, either immediately in-person through a Mobile Crisis Clinic or through local authorities, or through the provision of mental health resources that you may follow up with on your own time. Please know that you will not be alone during this process. Your safety is the most important aspect of your participation in their research, and I will be there with you as you navigate these next steps during the interview, if needed.

How will my biological sample/s be analyzed for this study, and will I receive any results?
Your saliva sample will be kept and used for testing until study activities are completed. At that time, any unused saliva will be discarded. Your saliva will be used to generate genetic data on two markers that are known to change in people that experience stressful moments in their lives. These markers are called epigenetic methylation and telomere length. Both forms of genetic data are not identifiable to a specific individual, and therefore cannot be used to trace your participation in this research. Your data will not automatically be returned to you as part of the study. However, you may request to have your data sent to you at any time in the research process. Please contact Margarita Hernandez via email at Margarita.Hernandez@dartmouth.edu or at (954) 696-3502 at any time to request your data once they are generated. Please be aware that the results of this research study have no clinical significance. These results do not indicate if you are in better or worse health. Rather, they tell us if the experiences you have had in your life amount to predictable patterns of difference in your DNA.

If you take part in this study, what activities will be done only for research purposes?

If you take part in this study, the following activities will be done only for research purposes:

- Collection of saliva using a saliva collection kit
- Answering questions in a questionnaire asking about your physical health, mental health, and experiences coming to and living in the United States
- Answering questions during an audio-recorded interview regarding your experiences in your country of origin, your experience migrating to the United States, and your experiences in the United States
- You will be contact approximately one year after your initial participation to schedule your follow-up visit
- During the follow-up visit, you will provide the same information as listed above

Will my data be deidentified and used in the future for other purposes?

Your data will be stripped of identifiers and potentially used for future research. This is in line with the data sharing policies of the National Institutes of Health, the main funder of the study. The section below details what data will be available, the process of allowing others to access the data, and the protections you have as a participant of this research project.

Any future research that uses your data will be reviewed by the Committee for the Protection of Human Subjects at Dartmouth College, who will determine if the research requires your permission or may be properly done without further permission from you.

How will your privacy be protected?

The information collected as data for this study includes:

- Epigenetic and telomere length data generated from your saliva sample
- Demographic information
- Medical information (self-rated health score and health insurance)
- Anxiety, depression, and post-traumatic stress disorder information
- Pre-migration information (details about your experiences in your country of origin)
- Immigration history (details about your immigration journey)
- Post-migration information (details about your experiences in the United States)
- Social support information

Some of the data collected for this study will be made available for public use. These data will be de-identified, meaning they will not contain any information that could be traced back to you. This information includes: your survey responses, the transcripts generated from your interview, and the genetic data sequenced as part of the study. Once your audio file has been transcribed and deposited, it will be destroyed.

De-identified genetic data (methylation and telomere length data) will be deposited in the National Center for Biotechnology Information’s (NCBI) Database of Genotypes and

Phenotypes (dbGaP). Deidentified survey and ethnographic data will be deposited on Zenodo. Both groups of data will be deposited under controlled access. This means that data will only be available for reanalysis pending the submission of a written proposal summarizing the research project, how access to the data will meet the goals of the research project, and the intended analyses to be performed on the data. Access to methylation, telomere length, and ethnographic data will only be made available to scientists interested in studying health within Latiné populations. Margarita Hernandez will be responsible for reading through these summaries and granting access to investigators. Projects will be restricted to only scientific, not-for-profit research, and may involve other scientists in the United States and in other parts of the world.

This research is covered by a Certificate of Confidentiality from the National Institutes of Health. This means that the researchers cannot disclose information that identifies you to anyone not connected with the research. This protection also prevents this information from being used or disclosed for legal proceedings, such as being accessed through a court order. The Certificate of Confidentiality, however, does not prevent disclosures required by law, such as information about child abuse or neglect and harm to yourself or others. Also, your information may be disclosed in accordance with any consent you provide, including for your medical treatment or use in other research. Additionally, the Certificate of Confidentiality does not prevent your information from being disclosed to the National Human Genome Research Institute (NHGRI) for it to evaluate or audit the research, or prevent disclosures required to meet FDA requirements.

We are careful to protect the identities of the people in this study. We also keep the information collected for this study secure and confidential.

Efforts will be made to protect the identities of the participants, and the confidentiality of the research data used in this study, such as:

- All data will be stored on Dartmouth's Microsoft OneDrive account, which requires a Dartmouth ID and password for access and is under a Duo two-factor authentication system
- Data will only be accessed from computers that are password-protected
- Only individuals that are listed as authorized researchers as part of this project will have access to your identifiable information

Other important information you should know:

- **Leaving the study:** You may choose to stop taking part in this study at any time. If you decide to stop taking part, it will have no effect on your life, livelihood, or citizenship status.
- **Number of people in this study:** We expect 100 people to enroll in this study.

- **Funding:** The National Institutes of Health provides funding to Dartmouth College for this research.
- You may withdraw your information and saliva from use in this research at any time. If you wish to remove your saliva from use in the study, please contact the researcher in writing. If your saliva has not already been used up by the researchers, any saliva that remains will be destroyed.

Will you be paid to take part in this study?

You will be paid either $20 for providing a saliva sample and answering the questionnaire or $35 for providing a saliva sample, answering a questionnaire, and participating in an audio recorded semi-structured interview. You will be paid this same amount each time you participate: once during the baseline visit and once during the follow-up visit a year later. In total, you will receive $40 or $70 across two data collection sessions.

Whom should you call with questions about this study?

Questions about this study or concerns about a research-related problem or injury should be directed to the researcher in charge of this study: Margarita Hernandez, Margarita.Hernandez@Dartmouth.edu, (954) 696-3502

If you have questions, concerns, or suggestions about human research at Dartmouth College, you may call the Office of the Committee for the Protection of Human Subjects at Dartmouth College (603) 646-6482 during normal business hours.

Consent: I have read the above information and have been given an opportunity to ask questions. I agree to provide saliva for this study, *The Latiné Immigration and Health Study (LIHS): A longitudinal study exploring immigration, embodiment, and health within Latiné refugees/immigrants in the United States,* and I have been given a copy of this consent form for my own records.