Principal Investigator: Channing E. Tate, PhD, MPH
COMIRB No: 23-0899
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Study Title: **Underutilization of Hospice Care in Older Black Adults**

You are being asked to be in a research study. This form provides you with information about the study. A member of the research team will describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don't understand before deciding whether or not to take part.

Why is this study being done?

This study plans to learn more about older Black adults' knowledge and opinions of hospice.

You are being asked to be in this research study because you self-identified to Ipsos KnowledgePanel as a Black/African American adult aged 65 or older.

Up to 400 people will participate in the study.

What happens if I join this study?

If you join the study, you will be asked to complete 3 brief surveys to measure your thoughts and experiences around hospice and making medical decisions. These surveys will occur at your earliest convenience. After completing these surveys, you will be asked to review an informational booklet and complete follow-up surveys. The follow-up surveys will take place approximately 30 days after you complete the first set of surveys. You may also be asked to take part in a brief interview. Your study participation will last approximately one to three months.

What are the possible discomforts or risks?

Discomforts you may experience while in this study include feeling uncomfortable discussing this topic. You can stop the survey at any point if you feel uncomfortable.

Other possible risks include a risk of loss of confidentiality of your information that is used in this study. There may be other risks the researchers have not thought of.

Taking part in this study will have no impact on the care you receive or your access to hospice.

What are the possible benefits of the study?

This study is designed for the researcher to learn more about how older Black adults think and feel about hospice. This study is not designed to benefit you directly, but the information you give will provide important insights into the process of making decisions around hospice. If there are risks, these are described in the risks section of this document.

Who is paying for this study?

This research is being paid for by the Cambia Health Foundation.

Will I be paid for being in the study? Will I have to pay for anything?

You will be paid $5 for completing the first set of surveys and an additional $5 for completing the follow-up surveys. If you are selected to participate in the interview portion of the study, you will also receive a $25 gift card for completing the interview.

It will not cost you anything to be in the study.

Is my participation voluntary?

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you choose to take part, you have the right to stop at any time. If you refuse or decide to withdraw later, you will not lose any benefits or rights to which you are entitled.

If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them.

Who do I call if I have questions?

The researcher carrying out this study is Channing Tate, PhD, MPH. You may ask any questions you have now. If you have questions later, you may call Dr. Tate at 303.724.8985.

You may have questions about your rights as someone in this study. You can call Dr. Tate with questions. You can also call the Colorado Multiple Institutional Review Board (COMIRB). You can call them at 303-724-1055.

Who will see my research information?

The University of Colorado Denver | Anschutz Medical Campus (the University) and the health systems it works with have rules to protect information about you. Federal and state laws including the Health Insurance Portability and Accountability Act (HIPAA) also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it.
The institutions involved in this study include:

- University of Colorado Denver | Anschutz Medical Campus
- University of Colorado Health
- Ipsos (KnowledgePanel)

We cannot do this study without your permission to see, use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

We will see, use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside the University and its affiliate health systems may not be covered by this promise.

We will do everything we can to keep your records a secret. It cannot be guaranteed.

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by writing to the study's Primary Investigator, at the name and address listed below. If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in this study.

Channing E. Tate, PhD, MPH
Mail Stop F443 | 1890 North Revere Court | Aurora, CO 80045

Both the research records that identify you and the consent form signed by you may be looked at by others who have a legal right to see that information.

- Federal offices such as the Office of Human Subjects Research Protections (OHRP) that protect research subjects like you.
- People at the Colorado Multiple Institutional Review Board (COMIRB).
- The study doctor and the rest of the study team.
- Cambia Health Foundation, who is paying for this research study.
- Officials at the institution where the research is being conducted and officials at other institutions involved in this study who are in charge of making sure that we follow all of the rules for research.
- Ipsos (KnowledgePanel)

We might talk about this research study at meetings. We might also print the results of this research study in relevant journals. But we will always keep the names of the research subjects, like you, private.

Some things we cannot keep private. If you give us any information about elder abuse or neglect we have to report that to Adult Protective Services. Also, if we get a court order to turn over your study records, we will have to do that.

All information that we collect from you, including recordings and any personal health information, will be kept on password-protected computer systems on a secure university server. Any codes that link your study records to your name will be destroyed at the completion of the study.

You have the right to request access to any personal health information collected in this study from the Investigator.

Information about you that will be seen, collected, used and disclosed in this study:

- Name and Demographic Information (age, sex, ethnicity, address, phone number, etc.
- Research Visit and Research Test records
- Psychological (knowledge) tests

What happens to Data that are collected in this study?

Scientists at the University and the health systems involved in this study work to find the causes and cures of disease. The data collected from you during this study are important to this study and to future research. If you join this study:

- The data are given by you to the investigators for this research and so no longer belong to you.
- Both the investigators and any sponsor of this research may study your data.
- If data are in a form that identifies you, the University or the health systems involved in this study may use them for future research only with your consent or IRB approval.
- Any product or idea created by the researchers working on this study will not belong to you.
- There is no plan for you to receive any financial benefit from the creation, use or sale of such a product or idea.

Agreement to be in this study and use my data

I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I understand and authorize the access, use and disclosure of my information as stated in this form. I know that being in this study is voluntary. I choose to be in this study: I will get a signed and dated copy of this consent form.

Signature:_____ Date:_____

Print Name:_____

Consent form explained by:_____ Date:_____