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Participation in Medical Research: Reasons Provided in Cognitive Interviews of a Diverse Sample

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LOYOLA UNIVERSITY CHICAGO

PARTICIPATION IN MEDICAL RESEARCH:
REASONS PROVIDED IN COGNITIVE INTERVIEWS OF A DIVERSE SAMPLE

A THESIS SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Racial and ethnic minority groups are underrepresented in medical and health-related survey research, with implications for the generalizability across diverse populations of evidence gleaned from these studies. However, there is little known about the respondents' reasons for participating—or not—in medical research studies, and how these reasons might vary across race/ethnicity, age, gender and education. In this thesis, I extend previous research by looking at data collected from cognitive interviewing techniques to examine 1) participants' reported likelihood of participating in five increasingly invasive types of data collection, including research studies that ask participants to answer questions about themselves or provide samples of saliva, blood, tissue, or cerebrospinal fluid; 2) the reasons participants provide for participation; and 3) the reasons participants provided for non-participation. Cognitive interviews were conducted with 64 participants in a convenience quota sample crossing dimensions of race/ethnicity, gender, age, and education. I examined patterns in respondents' likelihood of participating in increasingly invasive medical research and examine whether these patterns vary across groups. I coded the reasons respondents provided for their likelihood of participation through an inductive, iterative, and systematic process, from the interview transcripts. The qualitative analysis consisted of identifying emerging themes throughout all cases. By focusing on respondents' explanations for participation-or not-in various types of medical research, I was able to establish reasons for participation-or not-in medical research studies that collect personal information and biomarkers such as saliva, blood, tissue samples, and cerebrospinal fluid, with specific attention to variations by age, gender, race/ethnicity, and education attainment.

INTRODUCTION

In 1993 the National Institutes of Health (NIH) mandated the inclusion of racial/ethnic minorities in medical research studies. Despite this mandate, underrepresentation of racial/ethnic minorities in medical research is still very common (Brown et al., 2015). Historical unethical medical experiments have created mistrust among racial/ethnic communities towards physicians, researchers, and medical research. This explanation has been used to explain racial/ethnic underrepresentation in medical research. For example, the notorious Tuskegee Study of Untreated Syphilis experiment is often referenced when examining mistrust among racial/ethnic minorities and medical researchers (Brown et al., 2015). Due to mistrust, racial/ethnic minorities are generally seen as not willing to participate in medical research and consequently low levels of participation. Low participation rates are a huge disadvantage for racial/ethnic communities and research due to health disparities that affect one group more than another and because it places an impediment on medical advances.

So far, there is little known about respondents' reasons for participating-or not-in medical research studies, therefore, this research study adds to the gap of knowledge that currently exists in the literature. This topic is extremely important to study, considering the recent research interest on minority participation in medical research studies. Specifically, the disparity between minority willingness to participate and actual enrollment rates of minorities in health research. Racial/ethnic minorities reported willingness to participate in medical research studies ranges from 40-95%, yet minorities represent less than 5% of participants in randomized clinical trials

(London, 2015). “Recruitmentology” is the study of factors associated with participation--or not--of hard-to reach populations for medical research studies (Epstein, 2011). Recruitmentology studies specifically look for low minority participation rates in medical research and develop interventions that help recruit and retain racial/ethnic minorities in medical research studies (Epstein, 2011). By looking at diverse responses from a diverse sample, this research focuses on respondents’ reasons for participating-or not-in a medical research study that asks its respondent to answer personal questions about themselves and to provide a biosample; such as saliva, blood tissue and cerebrospinal fluid. Therefore, this study will examine the factors that prevent or motivate participants from participating in medical research studies across all cases by social groups, such as race, ethnicity, gender, age, and educational attainment. Ultimately, this study will show us how these reasons might vary across race/ ethnicity, age, gender and education.

LITERATURE REVIEW

Approximately only 3% of the eligible participants for cancer clinical trials, participate, but the vast majority are White, middle-class, educated males. This indicates low participation rates and underrepresentation of women and racial/ethnic minorities (Robinson & William, 2007) this raises the concern of generalizability (Durant et al., 2011). Yet, the reasons for the underrepresentation of women and people of color in health research are complex. For a long time, the standard body examined for medical research were young to middle-aged, White men (Killien et al., 2000; Epstein, 2011). The results gathered from these studies were applied to women, people of color, children and older adults. The assumption was that these results could be generalized to the entire population, since that data generated from young White males would not be “tainted”. Women were excluded from medical research due to the belief that the women’s menstrual cycle would taint the data. However, this assumption was inappropriate since the medical conclusions deduced from young White males did not alleviate the health disparities of women and racial/ethnic minorities (Killien et al., 2000). As Epstein states, “differences do matter and we cannot just extrapolate medical conclusions from white people to people of color, from men to women, or from middle-aged adults to children or the elderly” (pg. 4). With these differences in mind, medical research and practices, in the U.S., redefined group differences and have divided social characteristics (age, gender, race/ethnicity, educational attainment, socioeconomic status, etc.) into distinguishable sub-populations (Epstein, 2011). To motivate researchers and to reduce health disparities affecting women and racial/ethnic minorities, the

NIH Revitalization Act of 1993, mandated the inclusion of racial and ethnic minorities, women, children and older adults in NIH funded health research (Robinson & William, 2007).

Due to the NIH mandate, researchers interested in NIH funding sought to recruit women and racial/ethnic minorities but struggled to recruit and retain these groups. The need for the inclusion of women and racial/ethnic minorities gave rise to recruitmentology, the study of factors responsible for low minority participation rates in medical research and development of interventions that help recruit and retain racial/ethnic minorities in medical research studies (Epstein, 2011). However, by doing this, there is an assumption that certain group identities correspond to a specific kind of body. For instance, people of color are more likely to have cardiovascular issues, like high blood pressure. Group identities are used to construct medically distinct bodies, leading to the assumption that medical differences and disparities can be improved by making medical research more inclusive, "through the study of the biology of race and sex" or race-based biology (Epstein, 2011, p. 4). This assumption gave rise to what Epstein calls the "inclusion-and-difference paradigm" (p. 6). Epstein explains the two substantive goals of paradigm: "1) the inclusion of previously underrepresented groups and 2) the measurement of differences across groups, in biological processes in relation to disease progression and treatment effects ameliorative drugs" (p. 6) (Duster, 2006). The Tuskegee Syphilis experiment was based on the assumption that there is a biological difference between Blacks and Whites and has been described as the "epitome of how racism is reflected in medicine and medical research as it is in the general society" (Killien et al., 2000, p. 1063). The Tuskegee experiment is just one of the major stories of unethical research on non-White bodies, unfortunately, there were more unethical studies and experiments that deceived, abused and exploited people of color and women, such as the experimentation of birth control on Puerto Rican women and the sterilization of African American and American Indian women (Duster 2006; Roberts, 2017; Killien et al., 2000).

For example, in the 1920s there was a big push for more modern means of birth control by the modern sexual revolution. The birth control movement was an “emblem reproductive liberty” for privileged white women but not for women of color (Roberts, 2017). Considering that the unethical development and testing of birth control was initially performed on women of color. During the mid-1950s and 1960s, Puerto Rican women were offered a “magic pill,” which prevented them from getting pregnant (Duster, 2006). These women were not informed that they were experimental human test subjects for the “world’s first birth-control pill” (Duster, 2006). Puerto Rico was not the only testing area, there were other test groups of poor women of color in Boston and other cities in the U.S. However, these studies did not last long due to the side effects of the pills, yet the testing continued in Puerto Rico. Puerto Rican women were given extreme dosages of birth control, three times as much as the hormone that is included in today’s birth control (Duster, 2006).

Consequently, White women had more choices as to whether and when they wanted to be a mother and have a family. However, women of color did not have an option in choosing motherhood, considering the massive sterilization among populations deemed “socially unfit” (Roberts, 2017). Such as the sterilization of Black and Puerto Rican women in the 1970s. It was reported that during this time, women of color were given unnecessary hysterectomies, often done without their consent and under false pretense, by publicly funded institutions in cities like Boston and New York (Roberts, 2017; Killien et al., 2000). In 1973, it was estimated that more than 150,000 poor women were sterilized under federally funded programs. Given all of this history, many people in the Black community saw federally funded, White operated clinics as an institutional form of racial genocide (Roberts, 2017). There was also the systematic sterilization of American Indian women between 1973 and 1976, in which 3,406 American Indian women were sterilization without their permission (Lawrence, 2000).

Due to the long history of unethical experiments, racial and ethnic minorities, in the U.S., it is widely believed that minorities are not as willing to participate in medical research studies and Non-Hispanic Whites (Benjamin, 2011; Wendler et al., 2005). The injustices that people of color have suffered at the expense of medical research has created feelings of distrust (Killien et al., 2000). Therefore, the underrepresentation of Blacks in health research has been attributed to lower willingness to participate, which in turn, has been attributed to distrust that stem from unethical studies like Tuskegee (Durant, 2011; Swell, 2015). Shavers et al.'s (2002) study indicated that compared to Whites, Blacks differ in their willingness to participate in medical research. The difference in willingness is thought to be due to differences in trust. Therefore, Blacks are less willing to participate in medical research because they have lower levels of trust than Whites.

However, this doesn't sound too different from what the infamous Tuskegee Syphilis experiment was doing, including Blacks into their research to measure the disease progression in the Black body. White physicians wondered if syphilis, a bacterial infection, progressed differently in African American bodies than it did in White bodies. The U.S. Public Health Service conducted the Tuskegee Study of Untreated Syphilis in the Negro Male in the 1920s, to answer this question. The study was originally going to last for only six months but ended up lasting for more than 40 years (Ahaghotu et al., 2016). The study looked at the natural progression of untreated syphilis in “black males … who were not treated with the available ameliorative drugs” (Duster, 2006). The Tuskegee experiment is just one of the major stories of unethical research, unfortunately, there were more studies and experiments that deceived and abused people of color and women. Such as the experimentation of birth control on Puerto Rican women and the sterilization of African American and American Indian women.

Minority representation in randomized clinical trials is below 5% (London, 2015). Kwiatkowski et al. (2013) reviewed clinical trial from 2001 to 2010 and found that only 2% of the participants enrolled were Latino. Much like the underrepresentation of Blacks, the underrepresentation of Latinos in health research has also been attributed to having less trust towards medical research (Swell, 2015). The abuse that people of color have endured at the expense of medical research has been associated with the general distrust that racial/ethnic minorities have towards medical research. Sewell noted that researchers often lump or categorize Latinos into the “other” category or do not include them into their studies at all. Therefore, due to limited research on Latinos, most research focuses on the difference between Blacks and Whites (Black-White differences). Sewell found that compared to Whites, Latinos and Blacks are less trusting, of physicians. However, the difference between Latinos and Whites was statistically and substantially significant, whereas the difference between Blacks and Whites was not. Therefore, in agreement with previous research, Blacks and Latinos are less trusting than Whites, but Latinos are less trusting than Blacks. Although, Sewell found that Latinos are the least trusting of physician, Wendler et al. (2005) and Mattews et al. (2009) found that there is no statistically significant difference in willingness to participate by racial/ethnic minorities. Therefore, racial/ethnic minorities are as willing to participate and likely to agree to participate in health research compared to Non-Hispanic Whites.

Even though historical unethical abuses like the Tuskegee Syphilis experiment lead minorities to distrust medical research, there are other factors that people take into consideration when deciding whether-or not-to participate, in medical research studies. The benefit-cost theory of survey participation explains how individuals take a certain course of actions before they decide to participate-or not-in survey questionnaires (Singer, 2016). When deciding whether-or not-to participate in surveys, people think about the benefits and costs; do the benefits of participating outweigh the costs? Overall, participation-or not-depends on the person's judgement of benefit and costs, if the cost outweighs the benefits, they are more likely to not participate. But if the benefits outweigh the cost, they are more likely to participate (Singer, 2016).

Therefore, if African Americans and Hispanics are as willing as Non-Hispanic Whites to participate in health research studies, why are we not seeing the same rates of willingness in enrollment or accrual rates? There is a gap between willingness to participate and actual enrollment rates, in health research studies. This is where “recruitmentology,” scientific-based evidence on the best methods to recruit and enroll hard-to-recruit populations into medical research studies comes into play (Epstein, 2011, p. 15). Recruitmentology studies specifically look at the barriers and facilitators to medical research studies. They look at the factors that prevent and motivate specific groups from participating in medical research studies. Based on these factors, researchers develop strategies and interventions that can help them increase recruitment and participation of hard-to-recruit population.

Facilitators to Participation

Facilitators to participation are factors that motivate individuals to participating in medical research studies or make the process of participating in medical research easier for that participant. Schmotzer (2012), Shavers et al. (2001), Cox and Mcgarry (2003), Hughes et al. (2015), and Roberson (1994) used content analysis, focus groups, and survey-based studies to identify and classify these facilitators into two different groups: altruistic factors and egoistic factors.

Altruistic Facilitators

Some of the facilitators that have been identified are associated with intrinsic and extrinsic factors, such as altruistic factors. These are personal factors that motivate individuals to participation in medical research studies because the individual has the desire to help others, the feeling that research is important, needed or necessary and will benefit others. Altruistic facilitators include: the desire to help others, contribution to scientific knowledge, and finding a cure (Cox and Mcgarry, 2003; Hughes et al., 2015; Roberson, 1994; Schmotzer, 2012; Shavers et al., 2001). This concept of altruism was applied when a participant chose to participate because it may benefit others (Killien et al., 2000, p.1065). Shavers et al.’s (2001) study showed that 56% of their participants would be willing to participate in medical research studies. Of those participants, 53% would be willing to help a friend or relative and 69% if it would benefit society.

Additionally, London et al. (2015) reported that 84% of Latina women, in their study, mentioned that they were willing to participate in a breast cancer preventive clinical trials under the lenient definition of intent: “maybe,” “probably” or “definitely.” Whereas, 43% of Latina women were willing to participate in clinical trials under the more stringent definition of intent: “definitely” and “probably.” Of the women Latina women who were willing to participate in a breast cancer preventive clinical trial, 83% of the women mentioned that they were willing if they could help a family member who had cancer.

Egoistic Facilitators

Whereas, egoistic facilitators are personal factors that also motivate individuals to participate in medical research studies because it will benefit them, personally. Egoistic facilitators include: access to health care, receive the best medical care, and compensation (Cox and Mcgarry, 2003; Hughes et al., 2015; Roberson, 1994; Schmotzer, 2012; Shavers et al., 2001). Shavers et al.’s (2001) data also showed that of the 56% participants that would be willing to participate in medical research studies, 78% of the participants mentioned that they would be willing if it would benefit them personally and 60% mentioned they would be willing to participate if they would learn more about their illness/disease/condition.

Barriers to Participation

Barriers to participating in medical research studies refer to the obstacles, physiological, psychological or psychosocial factors that prevent the respondents from participating in medical research studies. Previous studies have classified these barriers to participation into three different groups: systemic barriers, health-care provider barrier, and personal barriers (Grunfeld et al., 2002; Salman et al., 2015).

Systemic Barriers

Systemic barriers are systemic factors that prevent participants from participating in medical research studies. These barriers include the design of health research study, access to health care services, and health insurance (Grunfeld et al., 2002; Salman et al., 2015). Therefore, if researchers create a research study that does not include minorities, how are minorities supposed to participate? Sewell (2015) points this out when she mentioned that how researchers often lump or categorize Latinos into the “other” category or do not include them into their studies at all. Even if some research studies want to include minorities, they follow the same guideline that have always implemented with Non-Hispanic Whites. These guidelines do not work when recruiting minorities, therefore, if researchers are interested in recruiting minorities, new guidelines girded toward recruiting minorities should be implemented (Grunfeld et al., 2002; Salman et al., 2015). Yet, the greatest barrier today is the lack of health insurance among minorities. Physicians are the “gatekeepers” to health-related research information. Yet if minorities are not able to access their physicians, due to lack of health insurance, how are minorities going to access the information they have regarding health-related research studies (Grunfeld et al., 2002; Salman et al., 2015)?

Health-care Provider Barriers

Health-care providers as the "gatekeepers" to health-related research study information, physicians have a "direct influence on the participate rate of their patients" (Grunfeld et al., 2002; Salman et al., 2015). Some of the barriers attributed to health-care provider barriers are: physicians' attitudes, personal bias, communication, and lack of clinical trial awareness (Salman et al., 2015; Fisher and Kalbaugh, 2011). Due to historical unethical studies, physicians are less likely to ask minorities to participate in a health-related research study, than Non-Hispanic Whites (Fisher and Kalbaugh, 2011), either out personal bias or out of fear, of how the patient might react to the information.

Personal Barriers

Personal barriers are factors that prevent the respondents from participating in medical research studies (Fisher and Kalbaugh, 2011). Previous content analysis and survey based studies have identified personal barriers to participation in medical research studies, these include: fear of research, mistrust of research, general distrust, discomfort with unknown procedures, lack of information regarding the research study, attitudes, not want to be experimented on, and not wanting to feel like a "guinea pig" (Benjamin, 2011; Cox and Mcgarry, 2003; Grunfeld et al., 2002; Hughes et al., 2015; Roberson, 1994; Shavers et al., 2002; Schmotzer, 2012; Shavers et al., 2001). Fear, mistrust, distrust, attitudes, not wanting to be experimented on or the feeling of not wanting to be experimented on, like a "guinea pig" are personal barriers linked to historical occurrences involving unethical practices concerning minorities (Hughes et al., 2015). Lack of information regarding the research study refers to the lack of knowledge in several aspects related to understanding the research process, methods, and information needed to make an informed decision (Hughes et al., 2015). Fear related to research studies refers to the feeling of fear that is associated to some extent with the lack of knowledge and of the unknown (Hughes et al., 2015).

Shavers et al.'s (2001) data showed that 81% of the participants would not be willing to participate in medical research studies. Of these participants, 43% mentioned lack of trust in medical researchers, 43% mentioned not having time to participate and 17% mentioned lack of trust in physicians, as reasons for not being willing to participate. Mouton et al., (1997) found that negative attitudes towards cancer clinical trials and lack of trust were greater among Black women than White women. Compared to White women (71%), 56% of Black women had positive attitudes towards cancer clinical trials. Black women "agreed or strongly agreed that scientists cannot be trusted" 33% compared to 4% of White women. These finding support the possibility that lack of trust is a major impediment for racial minority participation in cancer clinical research.

Additionally, it is important to note that with the increasing diversity in our society, there will be a need for more multiethnic analyses that observe the crossing dimensions of race/ ethnicity, age, gender and educational attainment (George et al., 2014). It is currently estimated that 5.2 million Americans are currently being affected by Alzheimer's or other forms of dementia. Due to the advances in technology and medicine, this number is bound to increase in the years to come with the population increasing age and years lived (Hughes et al., 2015). African Americans are twice as likely to develop Alzheimer's or other forms of dementia compared to whites (Hughes et al., 2015). And even though minorities are as willing to participate in medical research studies as non-Hispanic whites (Fisher and Kalbaugh, 2011) minority participation rates continue to be low. Older adults, especially minority older adults, are underrepresented in medical research studies. This limits the generalizability and knowledge that there is on older adults (Hughes et al., 2015). Therefore, if minorities are just as willing to participate in medical research studies as Non-Hispanic Whites, and their willingness to participate not seen in actual enrollment rates one can argues that minorities and Non-Hispanic Whites weigh the costs and benefits differently.

No previous research specifically looks at barriers and motivators to participation in a medical research that asks its participants personal questions and to provide a biosample (saliva, blood, tissue and cerebrospinal fluid), with crossing dimensions of race/ethnicity, age, gender and education. Biosamples are increasingly being required and asked for by medical researchers, since there are promising factors that biological specimen provide for medical researchers. As Drake et al. (2015) state, “collecting biospecimens holds great promise for disease recognition, diagnosis, and preventions” (p. 51). The future of medicine and medical advancements is based on biological specimen that it is becoming common practice for research studies to ask for a participants’ biosample. Although Shavers et al. (2011), designed a similar study that looked African Americans’ willingness to participate in medical research studies across of race/ethnicity, age, gender and education. Shavers et al., concluded that “study participant did not significantly differ in their willingness to participate when stratified by gender, educational attainment, age group of income” (p. 234). By adding different dimensions of race/ethnic groups, this study expands upon prior research studies that focus on comparisons within Black participants.

Current Study

This study analyzes respondents' reasons for participating--or not--in a medical research study that asks its respondents to answer personal questions about themselves and to provide a biosample; such as saliva, blood tissue and cerebrospinal fluid. This research establishes participants' accounts of barriers and facilitators to participating in medical research studies that collect personal information and biomarkers such as saliva, blood, tissue samples, and cerebrospinal fluid, with specific attention to variations across social groups. Since there is little known about respondents' reasons for participating—or not—in medical research studies, this research study adds to the gap of knowledge that currently exists in the literature. This topic is extremely important to study, considering the recent research interest on minority participation in medical research studies. Specifically, the disparity between minority willingness to participate in health research and actual enrollment rates of minorities in health research. By looking at diverse responses from these cognitive interviews, this study can identify some of the factors that prevent or motivate participants from participating in a medical research study among racial/ethnic groups. Ultimately, this study will show us how these reasons might vary across race/ethnicity, age, gender and education.

METHODS

Study Design

The data upon which this research is based on, comes from the Voices Hear research project (Edwards, 2015; Garbarski et al., 2017). The goal of the Voices Hear project was to learn about the barriers to research participation by underrepresented groups (Voices Heard). Cognitive interviews were used to observe, measure and categorize participants' participants' responses and their reasons for participating-or not- in a medical research study that asks it participants to answer questions about themselves, or to provide a biosample; such as saliva, blood, tissue, cerebrospinal fluid. Cognitive interviews are a form of qualitative interviewing in which a set of questions allow for open ended responses (Waddington and Bull, 2007).

The survey used in the Voices Heard research project consisted of five main questions that increased in level of invasiveness, compared to the previous question, and a series of open-ended probe questions followed. It was important to use cognitive interviews because it allowed: access and retrieval of information from interviewees memory effectively; uncovered how participants formulated their answers; revealed any problems participants had in comprehending specific terms or questions; and documented issues participants faced in mapping their response onto the response categories provided. The open-ended probes of the cognitive interview protocol allowed for the documentation of participants' responses to these measures. Particularly, whether-or not-there were important differences among racial/ethnic groups, age, gender and educational attainment.

Recruitment

Participants were recruited through connections the members of the Voices Heard research team had built with leaders in specific racial/ethnic communities. These connections were established by visiting churches, community centers, attending events sponsored by specific racial/ethnic groups, such as pow-wows and by posting flyers located in main location individuals would see. Participants interested in the research were given a general description of the survey and were asked to come in for an interview. The survey was conducted by the Survey Center in University of Wisconsin-Madison. Therefore, recruiting was restricted to the southern part of Wisconsin, mainly around Madison and Milwaukee.

Sample

The data upon which this research is based, Voices Heard research project (Edwards, 2015; Garbarski et al., 2017), consisted of 64 interviews, were conducted within a year span, from 2012 to 2013, in two rounds. The study population and sample size consisted of a convenience quota crossing dimensions of race/ethnicity (Black, American Indian, White or Latino), gender (male or female), age (30-55 years of age or 56 years of age and older) and education (high school education or less or some college and/or more).

This sampling strategy produced nearly an equal number of participants from crossing dimensions of race, gender, age and educational attainment (2 participants per category) as seen on the table in Appendix A. The exception was the category of American Indian male age 30-55 with a high school education or less category. Instead of interviewing two participants, only one American Indian male age 30-55 years with a high school education or less was interviewed. To compensate for this, an additional American Indian male 30-55 year of ages with some college or more education was interviewed. Therefore, three American Indian males 30-55 years of age with some college or more were interviewed.

Interviews

In the Voices Hear project (Edwards, 2015; Garbarski et al., 2017), interviewers received a full day of training on cognitive interview protocol. This training required interviewers to complete a practice interview before obtaining their certification. This certification interviewers them to officially interview interviewees in the research project. The interviews were conducted at locations that were convenient for the participants. Such as, public libraries, the participants home, and places around the University of Wisconsin-Madison campus. The questionnaire was translated into Spanish, since eight participants elected to be interviewed in Spanish, while the rest, 56, participants elected to be interviewed in English. On average the interviews took approximately an hour to complete. Participants received a $30 minimum cash incentive for participating, but the amount was increased to $50 to decrease the likelihood of participants canceling appointments. As mentioned before the interviews were conducted within a year span, from 2012 to 2013, in two rounds. They were audiotaped and transcribed verbatim onto an Excel sheet, on a question-by-question format.

The reason the interviews were conducted in two separate rounds was because the format of the questions and response answer choices differed. The survey, regardless of round, consisted of five main questions that increased in level of invasiveness and followed-up with open-ended probe questions. For round one the cognitive interviews opened with, “The next questions are about what you would do if you were asked to participate in a medical research study. How likely would you be to participate in a medical research study that asked you to answer questions about yourself: not at all likely, a little likely, somewhat likely, pretty likely, or very likely?" (see Appendix B). Whereas for round two the cognitive interviews opened with "The next questions are about what you would do if you were asked to participate in a medical research study. If a medical researcher asked you to participate in a medical research study by answering questions about yourself, how likely would you be to participate" very likely, somewhat likely, neither likely nor unlikely, somewhat unlikely, or very unlikely" (see Appendix C). The questions stated above, for round one and two, were the first question of five main questions that were asked, the other four questions had the same structure except participants were asked to give a sample of their saliva, blood, tissue and cerebrospinal fluid (see Appendix B for round one and Appendix C for round two).

After each main question was asked, a series of open-ended probes followed, to uncover how the participant arrived at their answer. These probes included, "Tell me more about why you answered [ANSWER] for this question." If the participant gave the same response answer for two consecutive main questions, they were asked to explain why they had given the same response. The following probe question was asked, "So you answered that you would be [ANSWER] to answer questions about yourself /give a sample of your (BIOMARKER) and that you would be [ANSWER] to answer questions about yourself /give a sample of your (BIOMARKER). Can you tell me more about why you gave the answer of [ANSWER] for both of these?" However, if the respondent gave different response answers for two consecutive main questions, they were asked to explain why they had chosen different responses. The following probe question was asked, “So you answered that you would be [ANSWER] to answer questions about yourself /give a sample of your (BIOMARKER) and that you would be [ANSWER] to answer questions about yourself/ give a sample of your (BIOMARKER). Can you tell me more about why you would be more-or less- likely to answer questions/give a sample of your (BIOMARKER) than give a sample of your (BIOMARKER)?” (see Appendices B and C). These follow-up probe questions were asked after each main question, answer questions about self, give a sample of saliva, blood, tissue and cerebrospinal fluid (see Appendix B for round one and Appendix C for round two).

The difference between round one and round two are the format of the questions and response answer choices. Round one questions simply asked the participants likelihood to participate with a univariate response scale (not at all likely, a little, somewhat, pretty, and very likely). Whereas, round two questions posed the question as a medical researcher asking that participants their likelihood to participate with a bivariate scale (very unlikely, somewhat unlikely, neither likely nor unlikely, somewhat likely and very likely).

Analysis

The methods of this research project were inductive, iterative, and systematic. There was no hypothesis developed, instead I looked at the transcribed interviews for reoccurring themes throughout the cases. Having the interviews transcribed verbatim onto an excel sheet facilitated the line-by-line coding process. As I was coding the cases I developed a coding scheme and codebook to capture the reoccurring themes that emerged from the 64 cases. A code book is an organized document that included the codes, the categories and subcategories of the codes, the definitions of the codes and subcategories, and explicit examples where the codes could be applied (see Appendix E).

To help develop and refine the coding scheme, a “double coder” was trained and received the transcribed interviews and the codebook that was developed to develop her own coding scheme. An important part of developing such a coding scheme is to have someone who is not close to the data independently try to implement the coding scheme as it exists at that point in time. This process establishes the reliability of the coding scheme and would allow me to make further modifications in the code book to improve its validity.

Once the double coder finished applying the codes from the codebook onto the interviews, the double coder and I met several times to go over our own coding process. In these meetings the double coder and I went through our coding schemes from cell to cell to see if we applied the same codes to the interview transcripts. If the same codes were applied to the transcript, we would proceed onto the next cell. However, if the coded applied differed, we would explain discuss why we thought the code we used applied to the transcript. This process allowed me to make the necessary modifications to improve its validity of the codebook. The code book was revised numerous times. It was refined and updated each time, to capture the codes, the definitions and examples of when the codes could be applied to the interviews.

Once the code book was finalized, I used the final version of the code book to create a .do file, to create the commands necessary for STATA to run frequency tables and bivariate cross tabulations. The .do file contained the commands STATA needed to run the descriptive statistics of questions by response answers and questions by response answers by sociodemographic characteristics (age, gender, race/ethnicity and education). Through the commands on the .do file, STAT could also identify the primary codes, primary codes with specifications, or the specification without the primary code. This facilitated the formation of frequency tables of: primary codes by question, primary codes by question by sociodemographic characteristics and probe 1 by question by sociodemographic characteristics. It also facilitated the formation of bivariate cross tabulations of primary codes (i.e., prior knowledge) and associations among different primary codes (willing to contribute and prior knowledge). These frequency tables and bivariate tables were analyzed accordingly. The frequency tables and cross tables captured the number of times and percentage of each response answers or codes were recorded, throughout all the interview transcripts. Only the percentage is presented in results section, due to low number of participants the percentage is more descriptive than using the number of times a response answer or a code was recorded. Chi-square test was used to assess significant associations across sociodemographic characteristics and codes, codes by question for probe 1 and overlapping of codes. The descriptive statistics and cross tables are presented and discussed in detail in the results section.

RESULTS

The objective of this thesis was to discover the type(s) of populations that are willing-or not-to participate in medical research studies and their reasoning behind why they are willing-or not-to participate. The qualitative analysis of the data led to the identification of 32 codes, listed in Figure 1 and the classification of various facilitators (prior knowledge, previous experience and altruistic factors like benefit), conditional factors (depends and needs more information) and barriers (no prior knowledge, procedure unknown, no previous experience, fear, pain, procedure dangerous, distrust and invasive). The codes within each category (facilitators, conditional factors and barriers) will be discussed further below.

The quantitative analysis of the data led to the interpretation of substantive differences across groups, when looking at various different descriptive statistics of participants responses. When examining the differences across the groups, I looked at the percent point difference, an 8-10% or higher point difference is substantively meaningful because most relationships are not statistically significant across race/ethnicity, gender, age, and education using a chi-square test statistic (unless otherwise noted). The descriptive statistics of participants response answer by main questions (Q200-Q240) are reported below, according to rounds. Followed by descriptive statistics of response answers by gender, age, education and race. Unless otherwise noted, the descriptive statistics of response answers by sociodemographics follow the same pattern, by round, as the descriptive statistics of questions by response answer.

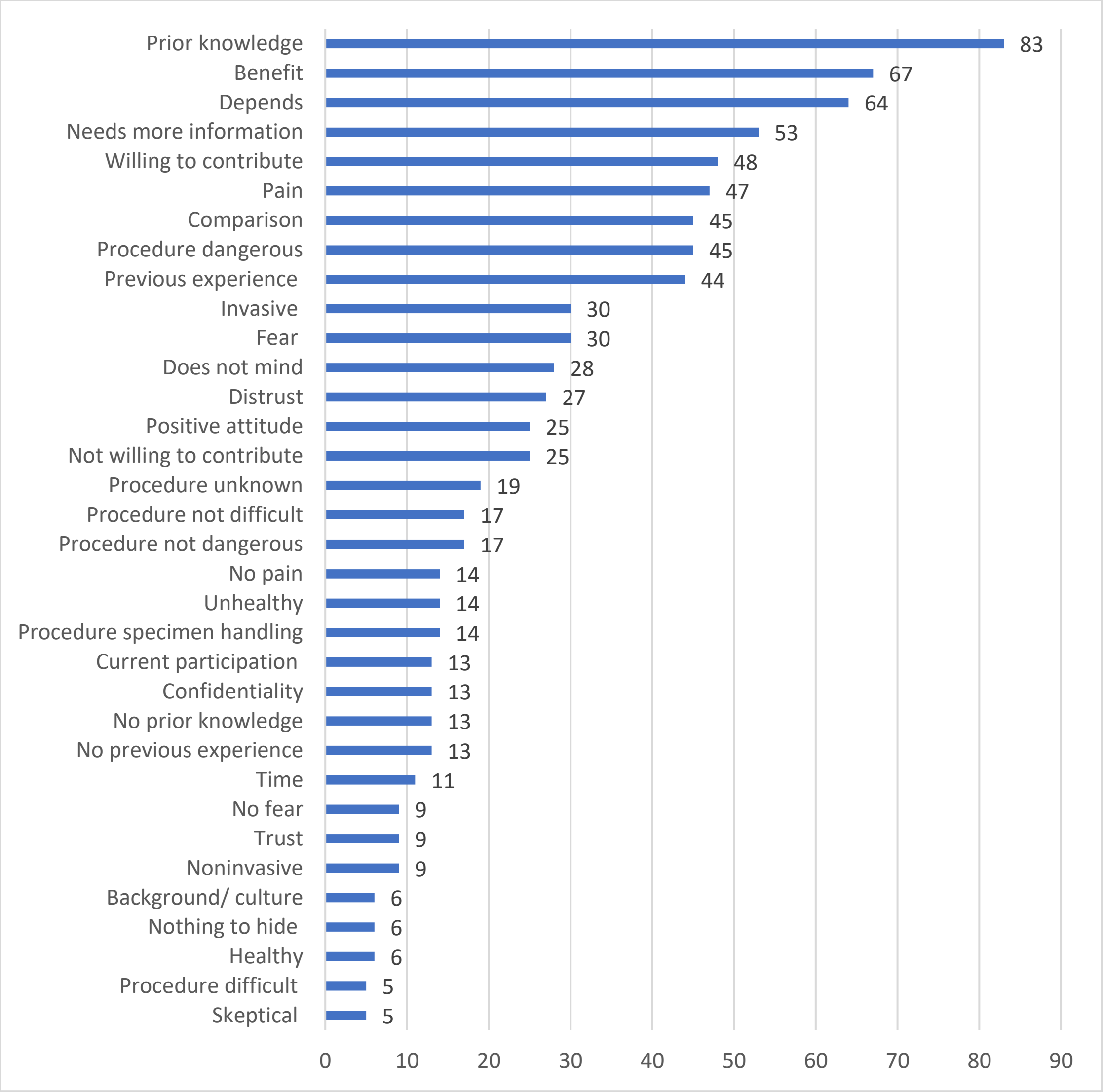

Figure 1. Percentage of Main Codes in any Probe for any Question (anywhere in probes 1, 11, and 12 for Q 200-240)

Descriptive Statistics of Questions

As mentioned in the methods section, the sample of this study consisted of 64 participants crossing dimension of race/ethnicity, age, gender and educational attainment. The 64 participants were split into two different groups-the format of the questions and answer scale changed (refer to Appendix with interview questions).

Descriptive Statistics of Questions by Response Answer

For round 1, participants in the sample were more likely to give an answer of “very likely” for questions 200 and 210-relatively less invasive procedures, like providing answers (41%) or saliva (39%). When participants were asked question 220 about providing a blood sample, they were more likely to state “pretty likely” to participate (29%). Yet, participants were more likely to answer “not at all likely” for question 230 and 240, which asked about more invasive procedures, like providing a tissue (30%) or cerebrospinal fluid sample (61%). Therefore, for this round, respondents were more likely to answer “very likely” for less invasive procedures, yet, as the level of invasiveness increased respondents were less willing to participate.

Table 1. Round 1-Descriptive Statistics of Questions by Response Answer

	Question				
Response	Q200	Q210	Q220	Q230	Q240
1: not at all likely	---	13%	16%	30%	61%
2: a little likely	3%	6%	13%	17%	10%
3: somewhat likely	22%	23%	16%	20%	16%
4: pretty likely	34%	19%	29%	13%	10%
5: very likely	41%	39%	26%	20%	3%
Total	100.00	100.00	100.00	100.00	100.00

For round 2, participants in the sample were more likely to provide the answer “very likely” to participate for questions 200-answering questions (47%), 210-providing a saliva sample (50%) and 220-providing a blood sample (39%). When respondents were asked in question 230 to provide a tissue sample, the most recorded answer was split between “somewhat likely” and “somewhat unlikely” (28%). Yet, participants were more likely to answer “very unlikely” for more invasive procedures like providing a cerebrospinal fluid sample (47%). Therefore, participants in this round were more likely to answer “very likely” for less and slightly invasive procedures, but split between “somewhat likely” and “somewhat unlikely” for second most invasive procedure, and “very unlikely” to participate when asked about the most invasive procedure.

Table 2. Round 2-Descriptive Statistics of Questions by Response Answer

	Question				
Response	Q200	Q210	Q220	Q230	Q240
-5: very unlikely	---	---	3%	6%	47%
-3: somewhat unlikely	3%	9%	10%	28%	19%
0: neither likely nor unlikely	13%	6%	13%	19%	16%
3: somewhat likely	38%	34%	35%	28%	9%
5: very likely	47%	50%	39%	19%	9%
Total	100.00	100.00	100.00	100.00	100.00

There are differences between round 1 and round 2 of descriptive statistics of questions by response answer, however, the only response answers that can be compared in both rounds are response answer 3 (somewhat likely) and 5 (very likely). Substantial differences are seen for all questions (Q200-Q240) for response answer 3 (somewhat likely), with round 2 having the higher percentages, with the exception of question 240. Yet, for response answer 5 (very likely) the differences are seen in questions 210 and 220, with round 2 having the greater percentages.

Descriptive Statistics of Questions by Response Answer by Gender

When looking at the descriptive statistics of respondent's answers for round 1 by gender, there was a substantive difference in Q200 between male and female responses for response answer 3 (somewhat likely), males were more likely to answer "somewhat likely" for question 200, compared to women. In Q210, there were substantive differences between male and female response answers 3 and 4 (pretty likely and very likely); females were more likely to answer "somewhat likely" for question 210, compared to males. Yet, males were more likely to state "pretty likely" for question 210, compared to females. In Q220 there were substantive differences between males and female response answers 2, 4 and 5 (a little likely, pretty likely and very likely). In Q220, females were more likely to answer "a little likely and pretty likely" compared to males. Yet, males were more likely to answer very likely, compared to males in question 220. In Q230 there were substantial differences between genders for response answers 1, 2 and 4 (not at all likely, a little likely and pretty likely). Females were more likely to answer "not at all likely," compared to males for question 230. Yet males were more likely to mention response answers 2 and 4 (a little likely and pretty likely) for Q230, compared to females. For Q240, the substantial differences between male and female response answers are 1 and 3 (not at all likely and somewhat likely). Females were more likely to mention "not at all likely," compared to males for question 240. Yet, males were more likely to report "somewhat likely" for question 240.

Table 3. Round 1-Descriptive Statistics of Questions by Response Answer by Gender

	Question									
	Q200		Q210		Q220		Q230		Q240	
Response	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
1	---	---	13%	13%	19%	13%	20%	40%	50%	73%
2	0 %	6%	6%	7%	6%	20%	20%	13%	13%	7%
3	31%	13%	19%	27%	19%	13%	20%	20%	25%	7%
4	31%	38%	25%	13%	25%	33%	20%	7%	13%	7%
5	38%	44%	38%	40%	31%	20%	20%	20%	0%	7%

Unlike round 1, which had substantial differences throughout all questions, round 2 descriptive statistics of response answers by gender only has substantial differences for questions 210, 220 and 240. In question 210, there were substantive differences among male and female response answers for -3 and 5 (somewhat unlikely and very likely). Males were more likely to state “somewhat unlikely” when asked to provide a sample of their saliva compared to females. Yet, females were more likely to state “very likely”, compared to males. In Q220, there were substantive differences among genders for response answer 3 and 5 (somewhat likely and very likely). Females were more likely to mention “somewhat likely”, whereas males were more likely to mention “very likely”, when asked to provide a blood sample. The substantive difference among gender in Q240 were seen in response answers 0 and -3 (neither likely nor unlikely and somewhat unlikely). Females, in this sample, were more likely to mention “neither likely nor unlikely”, whereas, males were more likely to mention “somewhat likely” when asked to provide a sample of their cerebrospinal fluid. The distribution of response answers for question 240 varies by gender and is statistically significant ($p < 0.10$).

Table 4. Round 2- Descriptive Statistics of Questions by Response Answer by Gender

	Question									
	Q200		Q210		Q220		Q230		Q240*	
Response	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
-5	---	---	---	---	0%	6%	6%	6%	50%	44%
-3	0%	6%	19%	0%	13%	6%	31%	25%	19%	19%
0	13%	13%	7%	6%	13%	13%	19%	19%	0%	31%
3	38%	38%	31%	38%	27%	44%	25%	31%	19%	0%
5	50%	44%	44%	56%	47%	31%	19%	19%	13%	6%

*p < 0.10

Descriptive Statistics of Questions by Response Answer by Age

Yet, when looking at the descriptive statistics of respondent's answers for round 1 by age, the substantive differences are seen in question 210, 220, 230 and 240. In Q210, the substantive differences among age are seen in response answers 3, 4 and 5 (somewhat likely, pretty likely and very likely). Participants 30-55 years of age (younger) were more likely to answer "somewhat likely" and "pretty likely", whereas, participants 56 years or older were more likely to answer "very likely" when asked to provide a sample of their saliva. The distribution of response answers for question 210 varies by age and is statistically significant ($p < 0.10$), therefore, this relationship can be seen in the population. In Q220, the substantive differences among age are seen in response answers 2, 3 and 5 (a little likely, somewhat likely and very likely). Younger participants (30-55 years of age) were more likely to answer "a little likely" and "somewhat likely," compared to older participants, when asked to provide a blood sample. However, older participants were more likely to answer "very likely", compared to younger participants, when asked to provide a blood sample. In Q230, the substantive difference among age are seen in response answers 1, 3, and 5 (not at all likely, somewhat likely and very likely).

Younger participants were more likely to answer “not at all likely,” when asked to provide a tissue sample, compared to older adults. However, older participants were more likely to answer “somewhat likely” and “very likely,” compared to younger participants, when asked to provide a tissue sample. And in Q240, the substantive difference among age is seen in response answer 1 (not at all likely), where males were more likely to answer “not at all likely” when asked to provide a cerebrospinal fluid, compared to women.

Table 5. Round 1-Descriptive Statistics of Questions by Response Answer by Age

	Question									
	Q200		Q210 *		Q220		Q230		Q240	
Response	30-55	56+	30-55	56+	30-55	56+	30-55	56+	30-55	56+
1	N/A	N/A	13%	13%	13%	19%	40%	20%	67%	56%
2	6%	0%	13%	0%	20%	6%	20%	13%	7%	13%
3	25%	19%	33%	13%	27%	6%	13%	27%	13%	19%
4	31%	38%	27%	13%	27%	31%	13%	13%	7%	13%
5	38%	44%	13%	63%	13%	38%	13%	27%	7%	0%

*$p < 0.10$

Round 2 descriptive statistics of response answers by age had substantial differences for all questions. In question 200, there were substantive differences among age is seen in response answers 3 and 5 (somewhat likely and very likely). Younger participants were more likely to answer “somewhat likely” when asked to provide answers to personal questions, compared to older participants. Yet, older participants were more likely to answer “very likely” when asked to provide answers to personal questions, compared to younger participants. In Q210, the substantive difference among age is seen in response answer 5 (very likely), where older participants were more likely to answer “very likely” when asked to provide a saliva sample, compared to younger participants. In Q220, the substantive difference among age are seen in response answers -3 and 3 (somewhat unlikely and somewhat likely). Younger participants were more likely to answer “somewhat unlikely”, when asked to provide a blood sample, compared to older participants. Whereas, older adults were more likely to answer “somewhat likely,” when asked to provide blood sample, compared to younger participants. In Q230, the substantive difference among age is seen in response answers 0 and 3 (neither likely nor unlikely and somewhat likely). Older participants were more likely to answer “neither likely nor unlikely” when asked to provide a tissue sample, compared to younger participants. Yet, younger participants were more likely to answer “somewhat likely” when asked to provide a tissue sample, compared to older participants. And in Q240, the substantive difference among age is seen in response answer 5 (very likely), where younger participants were more likely to answer “very likely” when asked to provide a cerebrospinal fluid sample, compared to older participants.

Table 6. Round 2-Descriptive Statistics of Questions by Response Answer by Age

	Question									
	Q200		Q210		Q220		Q230		Q240	
Response	30-55	56+	30-55	56+	30-55	56+	30-55	56+	30-55	56+
-5	---	---	---	---	0%	7%	6%	6%	44%	50%
-3	0%	6%	13%	6%	19%	0%	25%	31%	19%	19%
0	13%	13%	6%	6%	13%	14%	13%	25%	13%	19%
3	50%	25%	38%	31%	31%	40%	38%	19%	6%	13%
5	38%	56%	44%	56%	38%	40%	19%	19%	19%	0%

Descriptive Statistics of Questions by Response Answer by Education

The substantive differences are seen in all questions for the descriptive statistics of respondent’s answers for round 1 by education. In Q200, the substantive differences among education are seen in response answers 4 and 5 (pretty likely and very likely). Participants with some college or more were more likely to answer “pretty likely” when asked to answer personal question, compared to participants with a high school education or less. Yet, participants with a high school education or less were more likely to answer “very likely”, when asked to answer personal questions. For Q210, there are substantive differences throughout all response answers: 1, 2, 3, 4, and 5 (not at all likely, a little likely, somewhat likely, pretty likely and very likely). Participants with a high school education or less were more likely to answer “not at all likely” and “very likely,” compared to participants with greater education, when asked to provide a saliva sample. Yet, participants with some college or more were more likely to answer “a little likely,” “somewhat likely,” and “pretty likely,” compared to participants with less education. The distribution of response answers varies by education for question 210, which is statistically significant ($p < 0.10$). Respondents answers for question 220 in round 1 by education is the only descriptive statistic of responses that does not follow the same pattern as the descriptive statistics of questions by response answer. Table 7 shows the that “pretty likely” was the most recorded answer for Q220, yet the most recorded answers for this round by education was “pretty likely” and “very likely.” There were some substantive differences among education in Q220 as well. Participants with a high school education or less were more likely to answer “not at all likely” and “very likely” compared to more educated participants, when asked to provide a blood sample. Yet, participants with some college or more were more likely to answer “a little likely” and “pretty likely,” compared to participants with less education. For Q230, there were substantive differences throughout response answers: 2, 3, and 4, and 5 (a little likely, somewhat likely, pretty likely and very likely). Participants with a high school education or less were more likely to answer “a little likely” and “very likely,” compared to participants with greater education, when asked to provide a tissue sample. Yet, participants with some college or more were more likely to answer “somewhat likely” and “pretty likely,” compared to participants with less education. The distribution of response answers varies by education for question 230, which is statistically significant ($p < 0.05$). Lastly, the substantive difference in Q240 among age are seen in response answers 1 and 4 (not at all likely and pretty likely). Participants with some college or more were more likely to answer “not at all likely,” compared to participants with a high school education of less, when asked to provide a cerebrospinal fluid sample. Yet, participants with a high school education or less were more likely to mention that they would “pretty likely” provide a sample of their cerebrospinal fluid.

Table 7. Round 1-Descriptive Statistics of Questions by Response Answer by Education

	Question									
	Q200		Q210 *		Q220		Q230 **		Q240	
Response	H.S.	S.C.	H.S.	S.C.	H.S.	S.C.	H.S.	S.C.	H.S.	S.C.
1	---	---	21%	6%	21%	12%	31%	29%	57%	65%
2	0%	6%	0%	12%	7%	18%	23%	12%	7%	12%
3	20%	24%	14%	29%	14%	18%	0%	35%	14%	18%
4	20%	47%	7%	29%	14%	41%	8%	18%	14%	6%
5	60%	24%	57%	24%	43%	12%	38%	6%	7%	0%

*$p < 0.10$
**$p < 0.05$

The substantive differences among education found round 2 of description statistics of response answers are seen in questions 220, 230 and 240. In Q220, the differences are seen in response answers -3 and 3 (somewhat unlikely and somewhat likely). Participants with some college or more were more likely to answer “somewhat unlikely,” compared to participants with less education, when asked to provide a blood sample. Yet, participants with a high school education or less were more likely to answer with “somewhat likely,” when asked to provide a blood sample. In Q230, the differences are seen in response answers -5, 3 and 5 (very unlikely, somewhat likely and very likely). Participants with a high school education or less were more likely to answer “very unlikely” and “very likely,” compared with participants with some college or more, when asked to provide a tissue sample. Yet, participants with some college or more were more likely to answer “somewhat likely” compared to participants with less education. Lastly, the substantive difference in Q240 is seen in response answer -3 (somewhat unlikely). Participants with a high school education or less were more likely to answer “somewhat unlikely” compared to participants with more education, when asked to provide a cerebrospinal fluid sample.

Table 8. Round 2-Descriptive Statistics of Questions by Response Answer by Education

	Question									
	Q200		Q210		Q220		Q230		Q240	
Response	H.S.	S.C.	H.S.	S.C.	H.S.	S.C.	H.S.	S.C.	H.S.	S.C.
-5	---	---	---	---	0%	6%	13%	0%	44%	50%
-3	6%	0%	6%	13%	0%	19%	25%	31%	25%	13%
0	13%	13%	6%	6%	13%	13%	19%	19%	19%	13%
3	38%	38%	38%	31%	47%	25%	19%	38%	6%	13%
5	44%	50%	50%	50%	40%	38%	25%	13%	6%	13%

Now that I have looked at the substantive differences across groups through the various different descriptive statistics participants response answer by main questions (Q200-Q240) and by gender, age, education and race; I now look at the qualitative analysis of the data to show the classification of the codes along with their own descriptive statistics. Since the objective of this thesis was to discover the type(s) of populations that are willing-or not-to participate in medical research studies and their reasoning behind why they are willing-or not-to participate. The qualitative data analysis led to the identification of 32 codes, as seen in Figure 1, and the classification of various facilitators (prior knowledge, previous experience and altruistic factors like benefit), conditional factors (depends and needs more information) and barriers (no prior knowledge, procedure unknown, no previous experience, fear, pain, procedure dangerous, distrust and invasive). The factors within each category are reported below. The difference discussed below are substantial unless otherwise noted.

Sociodemographic Characteristics of Participants Willing to Contribute

Overall, 48% of the participants were willing to contribute throughout all cases for any question; anywhere in probes 1, 11, and 12 for any question Q200-240 (see Figure 1). Compared to the older participants, younger participants were willing and/or able to contribute/participate in medical research studies that ask questions and collect biomarkers. Male participants in this sample, were also more likely to mention that they were willing to contribute in medical research studies. The distribution of willing to contribute code varies by gender and is statistically significant ($p < 0.10$). American Indians were more likely to mention “willing to contribute” compared to Whites, but Blacks were more likely to mention that they were willing to contribute for medical research studies that gathers answer or biomarkers, compared to Whites and Latinos. Lastly, participants with some college of more education, were more likely to mention they willingness to contribute. The distribution of willing to contribute code varies by education and is statistically significant ($p < 0.05$)

Table 11. Willing to Contribute by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	59
56+	38
Gender *	
Male	59
Female	38
Race	
Black	63
American Indian	56
White	25
Latino/a	50
Education **	
High School or Less	32
Some College or More	64

*$p < 0.10$
**$p < 0.05$

Reasons for Participation

The reasons why the respondents in the sample would be willing to participate include: prior knowledge, previous experience and benefit.

Prior Knowledge

The most common main code coded was prior knowledge at 83%. Table 12 shows that compared to older participants, younger participants were more likely to state that they had knowledge regarding what they are being asked to provide, give or contribute. The distribution of prior knowledge code varies by age and is statistically significant ($p < 0.10$). Younger participants were more likely to report having prior knowledge of the procedure or sample in question. Participants with at least some college were more likely to report having prior knowledge compared to those with a high school education or less. Further analysis (see Appendix G) indicated that this trend remained mostly consistent when analyzed by probe 1 by the specific questions (Q200 is answering questions, Q210 providing a saliva sample, Q220 blood sample, Q230 tissue sample and Q240 a cerebrospinal fluid sample). The exception is seen in Q230 where participants with a high school or less educational attainment were more likely to mention that they had prior knowledge.

Table 12. Prior Knowledge by Age, Gender, Race and Education

Characteristics	%
Age Groups *	
30-55	91
56+	75
Gender	
Male	84
Female	81
Race	
Black	88
American Indian	88
White	81
Latino/a	75
Education	
High School or Less	77
Some College or More	88

*p < 0.10

An example of a case coded as prior knowledge is:
Case #1101
Probe Q240_P11

> I: Now you might've already answered this question, but just to, uh, um, go through all the questions, uh, for this interview, can you tell me more about why you would be more likely to give a sample of your cerebrospinal fluid than a sample of your tissue?
> R: Once again, the tissue would involve some kind of cutting out of something and, uh, the lumbar puncture, I've had them before, so it's, it's just like a needle, um, like drawing blood.
> I: Okay.

In Table 13, 51% of participants who mentioned that they had prior knowledge (in any probe for any question) also mentioned that they were willing to contribute/participate in medical research studies that ask questions and collect biomarkers. The only overlap recorded is the 6.25% overlap between willing to contribute and prior knowledge in probe one when respondents were asked to provide a tissue sample (Q230).

Table 13. Associations among Willing to Contribute, Previous Experience and Prior Knowledge Codes in any Probe for any Question (anywhere in probes 1, 11, and 12 for Q 200-240)

Codes	Willing to contribute	Previous experience	Prior knowledge
Willing to contribute	---	61% *	51%
Previous experience	---	---	47%
Prior knowledge	---	---	---

*p < 0.10

Previous Experience

Previous experience was coded for 44%, in any probe for any question. Table 14 shows that compared to Blacks, White and Latinos, American Indians were more likely to mention that they had previous experience. Blacks and Latinos were also more likely to mention that they had previous experience, compared to Whites. Therefore, in this sample, White participants were the least likely to report having previous experience regarding answering question or providing biomarker samples.

Table 14. Previous Experience by Age, Gender, Race and Education

Characteristics	%
Age Groups	
30-55	47
56+	41
Gender	
Male	44
Female	44
Race	
Black	44
American Indian	56
White	31
Latino/a	44
Education	
High School or Less	45
Some College or More	42

Further analysis (see Appendix G) indicated that this trend remained mostly consistent when analyzed by probe 1 for any question. In Q240, Blacks (instead of American Indians) were more likely to mention that they had previous experience compared to the other race and ethnicities. Table 13 shows that there was a 10% percentage point differences in associations between previous experience and willing to contribute (61%), compared to prior knowledge and willing to contribute (51%), despite prior knowledge being the most coded. The association between previous experience and willing to contribute is statistically significant ($p < 0.10$).

Furthermore, the only overlaps that were noted for probe 1 by questions was in Q200 and Q220 (answering questions and blood sample). There was a 20% overlap between previous experience and willing to contribute for probe 1 when respondents were asked to provide information about themselves for a medical research study and a 25% overlap when respondents were asked to provide a blood sample. It is not surprising that the only overlaps that are seen, when separated by question for probe 1 are Q200 and 220, considering that most individuals have participated in a survey that ask them to answer questions about themselves and have visited their doctor, where they are asked to answer questions about themselves and have had their blood drawn.

An example of a case coded as previous experience is:

Case #1101
Probe Q240_P1

> I: So tell me more about why you answered pretty likely for this question.
> R: Well, for one, I've had three lumbar punctures before, so I know about how those go. So I'd be pretty likely to do that.
> I: Okay.

Benefit

Benefit was coded for 67% in any probe for any question. Cases were coded as benefit because the participants stated that they were participating in the study because they expected and/or wanted something out of the medical research study. Table 15 shows that in comparison to Blacks and Latinos, Whites were more likely to mention their expectation of the medical research study. And participants with a high school education or less were also more likely to mention their expectations compared to those with some college or more education.

Table 15. Benefit by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	66
56+	69
Gender	
Male	66
Female	69
Race	
Black	63
American Indian	69
White	75
Latino/a	63
Education	
High School or Less	74
Some College or More	61

Further analysis (see Appendix G) indicated that this trend varied when analyzed by probe 1. There was no consistency for race/ethnicity since for Q200 and Q230 there was more than one race or ethnicity that had equal likeliness in mentioning their expectation. Yet, for Q210 and Q220 Blacks were more likely to discuss the expectation they had of the medical research study. Whereas in Q240 American Indians were more likely to mention their expectation of the medical research study. For all questions, except Q210, participants with a high school education or less were more likely to mention their expectation of the medical research study.

Lastly, 44% of the respondents that mentioned that they were willing to participate, they also mentioned their expectation of the medical research study or “benefit” code for any question, anywhere in probes 1, 11, and 12 for any question Q200-240. There was an overlap between willing to contribute and benefit for probe 1 in any question, expect for Q240, since there were no participants who mentioned they were willing to contribute their cerebrospinal sample. Q220 had the greatest overlap at 21%, between willing to contribute and benefit.

An example of a case coded as benefit is:

Case #3201
Probe Q230_P12

> I: You answered that you would be "somewhat likely" to give a sample of your tissue and that you would also be "somewhat likely" to give a sample of your blood. Can you tell me more about why you gave the answer of "somewhat likely" for both of these?
> R: Again, if it has anything to do with being beneficial for the future of medicine and finding out, you know, what works with what, like DNA or genetics or whatever, then I would be more than willing to help.

Conditional Factors

Conditional factors are neither facilitators nor barriers to participation that emerged from the data. These conditional factors have not been discussed in the literature, in terms of being “swing” factors. The conditional factors, depends and needs more information, were not categorized as barriers because the codes were created to capture the conditions under which participation of the respondent depended on. In other words, depending on the factor that the participant relies on to make their decision of participation -or not- can either influence the participant to participate or not, therefore, “depends” as a code is neither a barrier nor facilitator, but a conditional factor.

Depends

Depends was coded for 64%, throughout all the cases in any probe for any question. Cases were coded as depends because the participant explicitly stated that their participation depended or relied on something else. Table 16 shows that compared to older participants, younger participants were more likely to mention that their participation depended or relied on something else. It also shows that in comparison to American Indians and Latinos, Blacks and Whites were more likely to mention that their participation depended or relied on something else. And participants with some college or more education were more likely to mention that their participation depended or relied on something else, compared to those with high school education or less.

Table 16. Depends by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	72
56+	56
Gender	
Male	63
Female	66
Race	
Black	75
American Indian	56
White	81
Latino/a	44
Education	
High School or Less	58
Some College or More	70

Further analysis demonstrated that 74% of the cases coded for “depends” were also coded for “needs more information”. In other words, respondents who mentioned that their participation depended on other factors, requested more information. An example of a coded case is:

Case #3201
Probe Q210_P1

> I: Somewhat likely. Tell me more about why you answered "somewhat likely" for this question.
> R: It would just depend on what kind of a research they were actually doing and why they would need the saliva. But in my case I have nothing to hide, so I would feel that I would be okay with that.

Needs More Information

Overall, 53% of the cases were coded as needs more information because the participant explicitly stated that they were not informed, or that they need more information to make their decision on their likelihood of participating in medical research studies. Compared to older participants, younger participants were more likely to ask for more information. Females were also more likely to ask for more information, compared to males. Compared to Blacks, American Indians and Latinos, Whites were more likely to ask for more information. Participants with some college or more were more likely to ask for more information than participants with a high school education or less.

Table 17. Needs More Information by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	59
56+	47
Gender	
Male	63
Female	44
Race	
Black	50
American Indian	50
White	69
Latino/a	44
Education	
High School or Less	45
Some College or More	61

Further analysis of the code "needs more information" by age, gender, race and education for probe 1 by question demonstrates a statistically significant (*p < 0.10), the distribution of needs more information code varies by gender for question 230. However, the general descriptive statistics data for "needs more information" code and gender, show that females were also more likely to ask for more information, compared to males. Yet, this is not the case for question 230, instead males were more likely to ask for more information, when asked to provide a tissue sample, compared to women. When looking at the characteristics of race/ethnicity for "needs more information," Whites were more likely to ask for more information. However, racial/ethnic characteristics differed when looking at probe 1 by question. For question 200 American Indians and Latinos were more likely to ask for information, when being asked to answer questions. For question 210, Whites were more likely to ask for information, when asked to provide a saliva sample. However, for question 220 American Indians, Whites and Latinos, compared to Blacks, were more likely to ask for information when asked to provide a blood sample. In other words, Blacks were the least likely to ask for more information, when being asked to provide a blood sample. For question 230 Blacks, American Indians and Latinos were more likely to ask for more information, compared to Whites, when asked to provide a tissue sample. Therefore, Whites were the least to ask for more information when asked to give a tissue sample. Yet, in Q240 Whites, compared to the other race and ethnicities, were more likely to ask for more information when asked to provide a cerebrospinal fluid sample.

Table 18. Needs More Information by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	9%	3%	9%	22%	6%
56+	3%	6%	13%	22%	13%
Gender				*	
Male	6%	3%	13%	31%	13%
Female	6%	6%	9%	13%	6%
Race					
Black	0%	0%	0%	19%	6%
American Indian	13%	0%	19%	19%	6%
White	0%	13%	13%	3%	19%
Latino/a	13%	6%	13%	19%	6%
Education	**				
High School or Less	0%	3%	10%	19%	10%
Some College or More	12%	6%	12%	24%	9%

*p < 0.10
**p < 0.05

An example of a cases coded as needs more information is:

Case #2206
Probe Q200_P1

> I: Tell me more about why you answered neither likely nor unlikely for this question.

> R: Well, I mean, as, as a general matter, I don't have anything against participating in something like that, but I would need more information about what the study was going to be about, what it was going to be used for, um, you know, just more specifics, uh, to, uh, make an informed decision about whether I'd want to participate.

Once again, to reiterate, the objective of this thesis was to discover the type(s) of populations that are willing-or not-to participate in medical research studies and their reasoning behind why they are willing-or not-to participate. The qualitative data analysis led to the identification of 32 codes, as seen in Figure 1, and the classification of various facilitators (prior knowledge, previous experience and altruistic factors like benefit), conditional factors (depends and needs more information). The facilitators and conditional factors have been discussed above, barriers to participation that emerged from the date (no prior knowledge, procedure unknown, no previous experience, fear, pain, procedure dangerous, distrust and invasive) are reported below.

Sociodemographic Characteristics of Participants Not Willing to Contribute

Overall, 25% of the participants mentioned that they were not willing to contribute for any question or probe; anywhere in probes 1, 11, and 12 for any question Q200-240 (see Figure 1). Compared to the older participants, younger participants were not willing and/or able to contribute/ participate in medical research studies that ask questions and collect biomarkers. Female participants in this sample, were also more likely to mention that they were not willing to contribute/participate in medical research studies. Compared Whites, American Indians and Latinos, Blacks were more likely to mention that they were not willing to contribute for medical research studies that gather answer or biomarkers. Lastly, participants with some college or more were more likely to mention that they were not willingness to contribute, compared to participants with less education.

Table 19. Not Willing to Contribute by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	34
56+	16
Gender	
Male	19
Female	31
Race	
Black	38
American Indian	25
White	6
Latino/a	31
Education	
High School or Less	19
Some College or More	30

Reasons for Non-Participation

The reasons why the respondents in the sample would not be willing to participate include: no prior knowledge, procedure unknown, no previous experience, fear, pain, procedure dangerous, distrust and invasive.

No Prior Knowledge

Based on Figure 1, “no prior knowledge” was coded 13% throughout all cases regardless of probe or question. Compared to American Indians, Latinos were more likely to mention that they did not have any knowledge regarding what they are being asked to provide, give or contribute. Further analysis of “no prior knowledge” of race for probe 1 by question shows that

Latinos, compared to American Indians and Blacks are more likely to mention that they have no knowledge for question 230, regarding tissue and the process used to extract the sample.

An example of a case coded as no prior knowledge is:

> Case #4105
> Probe Q230_P1
>
> > I: Can you tell me more why you answered very likely for this question?
> > R: Uh, well, I don't know what's a tissue? Like, what? See, like that's the point for like people wouldn't, doesn't know a lot about the whole body, so that would be like a good thing to get more information about.
> > I: Yeah. That's good. That's actually our follow-up question here.
> > R: {L}.

Table 20. No Prior Knowledge by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	13
56+	13
Gender	
Male	9
Female	16
Race	
Black	13
American Indian	6
White	13
Latino/a	19
Education	
High School or Less	10
Some College or More	15

Procedure Unknown

Procedure unknown was 19% throughout all cases. When looking at the descriptive statistic by gender and race substantive differences can be seen. For instance, compared to males, females were more likely to mention a feeling of being subjected to an unknown procedure and/ or procedure with unknown outcomes. Although the participant might have some knowledge of what the biosample is but not know the procedure (site or method) in how the biosample will be obtained, the case would be coded as “procedure unknown”. Whites and Latinos compared to Black and American Indians were more likely to mention that the procedure was unknown. And when looking at the breakdown of by question for probe 1, Whites, compared to Blacks and American Indians were more likely to mention that they did not know the procedure for tissue sample extraction. An example of a case coded as procedure unknown is:

> Case #3101
> Probe Q230_P1
>
> > I: Okay. And then could you tell me more about why you would say somewhat likely to this question.
> > R: Yeah. I don't know, really know what's involved in that.
> > I: Okay.
> > R: A sample of my tissue, I don't know.
> > I: Okay.

Table 21. Procedure Unknown by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	19
56+	19
Gender	
Male	13
Female	25
Race	
Black	6
American Indian	13
White	25
Latino/a	31
Education	
High School or Less	16
Some College or More	21

No Previous Experience

No previous experience was coded for 13% throughout all cases, regardless of probe or question. The only substantive difference is seen in race, where Whites, compared to American Indian, were more likely to mention that they had no previous experience. When the analysis was broken down by probe 1 for all questions, the same difference between Whites and American Indians can be seen in question 240. Therefore, White participants were more likely to mention that they had no previous experience, when asked to provide a cerebrospinal fluid sample. An example of a case coded as no previous experience is:

> Case #3106
> Probe Q240_P1
>
> > I: And you might have answered this already, but can you tell me more about why you answered somewhat likely for this question?
> > R: Because I need more information about the procedure itself. I've never had it done.

Table 22. No Previous Experience by Age, Gender Race and Education

Characteristics		%
Age Groups		
	30-55	13
	56+	13
Gender		
	Male	16
	Female	9
Race		
	Black	13
	American Indian	6
	White	19
	Latino/a	13
Education		
	High School or Less	10
	Some College or More	15

Fear

Fear was coded 30% of the cases because participants expressed that they were afraid or have unpleasant feelings towards certain procedures, tools/equipment perceived as necessary to extract the biomarker. Table 23 shows that compared to older participants, young participants were more likely to express their fear. In comparison to American Indian and Latinos, Blacks and Whites were more likely to express their fear. Participants with some college or more were also more likely to their fear than participants with a high school or less education. The distribution of the code fear varies by educational attainment and was statistically significant ($p < 0.10$). An example of a case coded as fear is:

> Case # 3105
> Probe Q240_P1
>
> > I: And can you tell me more about why you answered a little likely for this question other than what you already said.
> > R: I'm afraid, I'm afraid it might be painful. That's why.

Table 23. Fear by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	34
56+	25
Gender	
Male	31
Female	28
Race	
Black	38
American Indian	19
White	44
Latino/a	19
Education *	
High School or Less	19
Some College or More	39

*p < 0.10

Pain

Figure 1 shows “pain” as the most coded barrier, at 47%. Compared to females, males were more likely to express physical discomfort associated with specific procedure(s) that are used to obtain the biomarker samples. Compared to Latinos, Blacks, Whites and American Indians were more likely to mention pain associated with specific procedure(s). Participants with some college or more, were also more likely to express pain, compared to participants with a high school education or less. The distribution of the code pain varies by education and is statistically significant (p < 0.01).

Table 24. Pain by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	47
56+	47
Gender	
Male	53
Female	41
Race	
Black	56
American Indian	50
White	50
Latino/a	32
Education ***	
High School or Less	29
Some College or More	64

***p < 0.01

Further analysis of “pain” looked at the breakdown of the code for probe 1 by question. Just like in the descriptive statistics of pain, throughout all cases, for probe 1 in question 240 males were more likely to express physical discomfort associated with specific procedure(s) that are used to obtain the biomarker samples. In Q220, compared to American Indians and Whites, Latinos were more likely to mention pain when asked to provide a saliva sample. Compared to participants with a high school education or less, participants with some college or more were more likely to mention pain when asked to provide a saliva sample. The distribution of the code pain varies by educational achievement for question 210, which is statistically significant ($p < 0.10$). In Q230, compared to Blacks, American Indians and Latinos, Whites were more likely to mention pain when asked to provide a tissue sample. The distribution of the code pain varies by race for question 230 (asking participants to provide a tissue sample), which is statistically significant ($p < 0.10$). In Q240, compared to Blacks, American Indians and Latinos, Whites were likely to express pain, when asked to provide a cerebrospinal fluid sample, compared to participants with a high school education or less. And participants with some college or more were more likely to mention pain when asked to provide a cerebrospinal fluid sample. The distribution of the code pain varies by educational achievement for question 240, which was statistically significant ($p < 0.10$). An example of a cased coded as pain is:

> Case # 2105
> Probe Q230_P11
>
> > I: Can you tell me more about why you would be less likely to give a sample of your tissue than a sample of your blood?
> > R: Um, because when I think of somebody wanting a tissue sample, they're cutting a piece of my tissue away. And that sounds like it'd be painful, so I wouldn't wanna participate in that.
> > I: Uh, so is it safe to say that, um, you know, pain is something that you're worried about in terms of, uh, samples of tissues?
> > R: Pain, discomfort, and scarring.

Table 25. Pain by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	---	---	6%	3%	28%
56+	---	---	3%	9%	19%
Gender					
Male	---	---	3%	6%	28%
Female	---	---	6%	6%	19%
Race				*	
Black	---	---	6%	6%	25%
American Indian	---	---	0%	0%	25%
White	---	---	0%	19%	38%
Latino/a	---	---	13%	0%	6%
Education			*		*
High School or Less	---	---	0%	3%	13%
Some College or More	---	---	9%	9%	33%

*$p < 0.10$

Procedure Dangerous

Overall, 45% of the case were coded as procedure dangerous. Compared to American Indians, Blacks, Whites and Latinos were more likely to mention that the procedure(s) may cause them harm or injury if they were to participate. Yet, compared to Blacks and Whites, Latinos were more likely to express that procedures were dangerous. The distribution of the code procedure dangerous varies by race, and is statistically significant ($p < 0.10$). Participants with some college or more were also more likely to mention a procedure being dangerous, compared to participants with a high school education or less.

Table 26. Procedure Dangerous by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	44
56+	47
Gender	
Male	44
Female	47
Race *	
Black	50
American Indian	19
White	50
Latino/a	63
Education	
High School or Less	39
Some College or More	52

*p < 0.10

Further analysis of “procedure dangerous” for probe 1 by question, show some of same associations mentioned above. In Q220, compared to Blacks, American Indians and Whites, Latinos were more likely to mention that the procedure for extracting saliva was dangerous. Yet, in Q230, Whites were more likely to mention the procedure for extracting tissues was dangerous. The distribution of the code procedure dangerous varies by race for question Q230, which was statistically significant ($p < 0.05$). In Q240 Blacks, Whites and Latinos were more likely to mention that the procedure for taking cerebrospinal fluid sample was dangerous, compared to American Indians. Lastly, participants with some college or more were more likely to state the procedure used to take a sample of cerebrospinal fluid is dangerous. An example of a case coded as procedure dangerous is:

Case #1104
Probe Q230_P1

> I: Tell me more about why you answered not at all likely for this question.
> R: Well, my personal fear of, uh, the danger of, uh, you know, some spine might be damaged or any little, oh, mishap, paralyze me or something.

Table 27. Procedure Dangerous by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	---	---	0%	6%	22%
56+	---	---	3%	3%	38%
Gender					
Male	---	---	0%	6%	28%
Female	---	---	3%	3%	31%
Race				**	
Black	---	---	0%	0%	38%
American Indian	---	---	0%	0%	6%
White	---	---	0%	19%	31%
Latino/a	---	---	6%	0%	44%
Education					
High School or Less	---	---	0%	3%	23%
Some College or More	---	---	3%	6%	36%

**$p < 0.05$

Distrust

Distrust was coded for 27% of the cases because the participant stated, hint at, or gave an example/scenario of lack of trust, regarding medical research. Table 28 shows that compared to young participants, older participants were more likely to state their distrust. American Indians and Whites were just as likely to mention their distrust, yet, compared to Latinos. Participants with some college or more were more likely to report their distrust, compared to participants with a high school education or less. The distribution of the code distrust varies by educational attainment was is statistically significant ($p < 0.05$). An example of a case coded as invasive is:

Case #1105
Probe Q200_P1

> I: And can you tell me more about why you answered not at all likely for this question.
> R: Um, because it's painful, number one, the main part. And the second part is because, um, I don't trust everybody's cleanliness when it comes to their blades, and, you know, things that can transmit other disease to other people.

Table 28. Distrust by Age, Gender, Race and Education

Characteristics	%
Age Groups	
30-55	22
56+	31
Gender	
Male	28
Female	25
Race	
Black	25
American Indian	31
White	31
Latino/a	19
Education **	
High School or Less	13
Some College or More	40

**$p < 0.05$

Invasive

The code invasive was observed in 30 % of the cases, as seen in Figure 1. Compared to older participants, younger participants were more likely to express that their participation involved the intrusion of privacy to collect answers or the introduction of medical instruments into the participant's body to collect a biomarker sample. Compared to males, females were more likely to state that their participation would involve the intrusion of privacy or body. Overall, Whites, compared to Blacks, American Indians and Latinos, were more likely to mention invasive when asked to participate in a medical study that either asked them question or to provide a biomarker (saliva, blood, tissue or cerebrospinal fluid) sample. Blacks were also more likely to mention invasiveness, compared to Latinos. Lastly, participants with some college or more were more likely to mention invasiveness, compared to participants with a high school education or less. The distribution of the code invasive varies by educational attainment and is statistically significant ($p < 0.05$)

Table 29. Invasive by Age, Gender Race and Education

Characteristics	%
Age Groups	
30-55	34
56+	25
Gender	
Male	25
Female	34
Race	
Black	31
American Indian	25
White	44
Latino/a	19
Education **	
High School or Less	16
Some College or More	42

**$p < 0.05$

Further analysis of the code “invasive”, for probe 1 by question shows that there is a statically significant association between age and mentioning invasiveness when asked to provide a tissue sample. Compared to older participants, younger participants were more likely to mention invasiveness when asked to provide a tissue sample. In Q200, Blacks were more likely to mention invasiveness when asked to provide answers to personal questions. In Q240, Whites compared to Blacks, American Indians and Latinos were more likely to mention invasiveness when asked to provide a cerebrospinal fluid sample. An example of a cased coded as invasive is:

> Case #1104
> Probe Q200_P1
>
> > I: Tell me more about why you answered somewhat likely for this question.
> > R: Well, I'd be kinda, you know, skeptical about the, you know, the, the invasions of my, uh, you know, my personal, you know, like, uh, the illness or conditions that I do have or possibly have.

Table 30. Invasive by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups				*	
30-55	0%	---	3%	9%	13%
56+	3%	---	0%	0%	6%
Gender					
Male	3%	---	3%	6%	6%
Female	0%	---	0%	3%	13%
Race					
Black	6%	---	0%	6%	6%
American Indian	0%	---	0%	0%	6%
White	0%	---	6%	6%	19%
Latino/a	0%	---	0%	6%	6%
Education					
High School or Less	3%	---	3%	3%	6%
Some College or More	0%	---	0%	6%	12%

DISCUSSION

To provide a more comprehensive understanding of the barriers and facilitators that certain populations face we need to look at the sociodemographic characteristics of the participants willing to contribute-or not-in medical research studies. Several sociodemographic characteristics were similar when comparing the characteristics of those who were willing to contribute, to those who are not willing to contribute. For instance, younger participants were willing-or not- to contribute/participate in medical research studies that ask questions and collect biomarkers. Males were more likely to report that they were willing to contribute, however, females were more likely to report that they were not willing to contribute. Interestingly, African Americans were more likely to mention willing to contribute-or not-compared to the other races and ethnicities. Participants with some college or more were also more likely to mention willing-or not-to contribute compared to those with a high school diploma or less. The statistically significant distribution of “willing to contribute” varied by gender and education ($p < 0.10$). There were no statistically significant associations involving “not willing to contribute”.

There are relatively few studies that look at age and willingness to participate in health research. Shaver et al. (2002) found that White females under the age of 65 with a high school education or more were more willing to participate in medical research studies. Another factor that has been examined in relation to willingness to participate is previous experience with clinical research. Kaplan et al. (2015) reported that compared to Whites, Latinos and Asians, Blacks were more likely to report prior participation in other types of research. Overall 65% of the men were willing to participate in a cancer clinical trial. Although, there was no statistical significant difference in willingness to participate by race, Latino men were the most willing at 79%, Blacks at 64%, Asians and Whites at 60% (p. 445).

Just like previous studies, Kaplan et al. (2015) found that that men with a college degree or more had greater scientific knowledge compared to those with less than a high school diploma (Shavers et al., 2002; Bak, 2001; Etzioni and Nunn, 1974; Mouton et al., 1997). Men who had prior participation in health research, were more likely to have above knowledge of clinical trials. Therefore, men with prior participation in health research were more willing to participate in prostate cancer clinical trials. These results contrast the popular belief that racial/ethnic minorities are less willing to participate in health research compared to Whites. They also indicate that compared Whites, Blacks and Latinos had the lowest level of clinical trial knowledge, despite this their willingness to participate in prostate clinical trials did not differ by race. Durant et al. (2011) data showed that Whites and Blacks were as likely to mention having previously participated in a clinical trial. Thus, there was no racial difference in willingness to participate in a clinical trial for those who have participated in a clinical trial.

Durant et al. (2011) and Igwe et al. (2016) have discussed how racial identity is not a significant indicator of willingness to participate in clinical trials. Considering that for this study, African Americans were the most likely to mention willing to contribute and not willing to contribute, it does not seem logic to focus on racial differences as indicators of willingness-or not-to participate in health research. Yet, previous studies have indicated that educational attainment is a significant indicator of willingness to participate (Shavers et al., 2002; Bak, 2001;

Etzioni and Nunn, 1974; Mouton et al., 1997). For instance, Shaver et al. (2002) concluded that only education was statistically significant in relation to willingness to participate in medical research. “Whites with less than a high school education were significantly less likely than those with more education to be willing to participate in a medical research study” (p. 254).

Bak (2001) and Etzioni and Nunn (1974) have reported that individuals with more education tend to be more supportive of science and those with less education. Therefore, education has been associated with the public’s attitude science; a higher level of education would indicate more support and a lower level of education would indicate less support. Etzioni and Nunn (1974) attributed a positive association between years of education and support of science to “the fact that more education yields more scientific knowledge, which increases trust in science” (p. 781). The deficit model has also been used to explain the public's understanding of science. It provides a simple version of how education, scientific knowledge and support for science are associated. Essentially, the more scientific knowledge a person has, the more inclined they are to appreciate and support science (Bak, 2001). The deficit model oversimplifies and magnifies the effect that education has on public attitudes towards science. However, by doing so it ignores other factors involved in relationship, like level of scientific knowledge. Years of education is not the only factor that can influence individuals attitudes towards science- the content of education or prior knowledge of health-related research studies may also be of influence.

Although, Bak (2001) found that at 16% education is the most important determinant of individuals attitudes towards science, gender only explained 3% and having scientific knowledge explained 11%. Thus, college graduates were more favorable towards science and those with a lower education. The study confirmed that people with more years of education support science more than those with less education. The reasons are because individuals with a bachelor's degree were more likely to believe that the “benefits are much greater than risks” (p. 791) than those without a high school diploma. The deficit model is too simple to explain complex relationships associated with attitudes towards science. Researchers cannot assume that individuals with more years of education will have more scientific knowledge and trust in science (p. 791). Based on the results and the percentage on each variable this study concludes that “neither lack of scientific knowledge nor limited education of attainment is the major factor behind public skepticism about controversial scientific research” (p. 793). Bak concluded that “gender is an important determinant of public attitudes towards politicized, controversial scientific research” as well (p. 793).

Even though knowledge of clinical trials does not count as formal education, it can be argued that knowledge of clinical trials is a form of education. Wallington et al. (2002) show that Latinas with greater knowledge of clinical trials have greater intentions to enroll. The data also demonstrated that compared to Whites, Latinos intended to participate at a similar rate, when asked to participate in a clinical trial. Although, there was not a statistically significant association between prior knowledge and race, there was a statistically significant association ($p < 0.10$) between prior knowledge and age. Other statistically significant associated with education include the following codes: fear ($p < 0.10$), pain ($p < 0.01$), distrust ($p < 0.05$), and invasive ($p < 0.05$). Future researcher should look at that association of prior knowledge and age to see if it’s similar to education; the more years of education or knowledge of health-related research, the more inclined the individual is to support and willing to participate in health research studies. Future research should also focus on the relationship of education and barriers (like fear, pain, distrust and invasiveness).

Furthermore, some of the reoccurring themes that emerged from the transcripts are consistent with other researcher’s results. Schmotzer (2012), Shavers et al. (2001), Cox and Mcgarry (2003), Hughes et al. (2015), and Roberson (1994) used content analysis, focus groups, and survey-based studies to identify facilitators to participation. These facilitators include the desire to help others, contribution to scientific knowledge, and finding a cure. Similar facilitators like benefit, and willing to contribute emerged from the data. Shavers et al. (2001) study showed that 56% of their participants would be willing to participate in medical research studies. Of those participants, 53% would be willing to help a friend or relative and 69% if it would benefit society. Additionally, London et al. (2015) reported of the women Latina women who were willing to participate in a breast cancer preventive clinical trial, 83% of the women mentioned that they were willing if they could help a family member who had cancer. Drake et al. (2015) also reported cases where men expressed altruistic motive for participating in tissue research; “most men held a common perception that the study would allow them to use their health experiences to improve health experience for close relative and future generation” (56).

Benjamin (2011), Grunfeld et al. (2002), Shavers et al. (2001, 2002), Schmotzer (2012), Cox and Mcgarry (2003) and Hughes et al. (2015) also identified barriers to participations, such as fear of research, distrust, discomfort with unknown procedures, lack of information regarding the research study, not want to be experimented on, and not wanting to feel like a “guinea pig.” Similar barriers like fear, distrust, and not willing to contribute emerged from the data. Drake et al. (2015) found that Black men were not willing to participate in tissue research, due to pain. However, contrary to Drake et al., Cottle et al. (2013) found that Blacks reported more willingness to participate in health research, even if it required blood or tissue samples. Overall, 95% if the participants were willing to provide a blood sample and 92% were willing to provide a tissue sample, if either was required. Of these participants, compared to Whites, Latinos, Asians and American Indians, Blacks were 91% interested in participation in health studies, with 83% willing to provide a blood sample and 77% willing to provide a genetic sample. These results contradict the studies that indicate that Blacks are less willing to participate in health/medical research studies and indicate that Blacks reluctance to participate in medical research due to Tuskegee is waning (Cottle et al., 2013).

Surprisingly, “needs more information” and “depends” were codes that emerged from the data and were later categorized as conditional factors. Research on these factors is limited as demonstrated with Igwe et al. (2016) their data shows that 29% of the women asked to participate in a randomized clinical trial, indicated that they would be willing to participate and did not ask for additional information about the trial. Whereas, 33% of the women agreed to participate in a random clinical trial after they were given more information about the clinical trial; like what was included in the trial. Although, there were no statistically significant associations related to “needs more information,” the emergence and the fact that more women were willing to participate in a clinical trial after they received more information about the trial

(Igwe et al., 2016), highlight the importance of including educational material pertinent to the research.

Although the goal was to gain sense of the reasons for participation-or not- in medical research studies. These findings can provide a framework for future research that look at the facilitators, conditional factors and barriers to participation in medical research studies that are not being addressed in the literature such as willing to participate associated with previous experience, prior knowledge and education, or the association of education and invasiveness, distrust, fear and pain and the association with not willing to participate. As mentioned throughout the text, focusing on racial/ethnic difference for willingness to participate in health research is not enough. Besides, there are a number of previous studies that indicate that willing to participate in health/medical research is not statistically significant by race. Instead, as researchers we have to look at the reasons behind why some individuals are willing to participate and why others from the same group are not. Taking Epstein's (2011) critique of the "inclusion-difference paradigm," as medical research becomes more inclusive, researchers become fixated with discovering differences that exist among different groups. Therefore, we cannot reduce the reasons for participation-or not-by simply by sociodemographic characteristics.

Although, the goal of the NIH mandate was to include racial/ethnic minorities and women into clinical trials, due low participation rates, it supported the inclusion-difference paradigm. We live in a racialized social system, differences across races/ethnicities are inscribed and foster deep and distinct ideologies of what groups of people should look like physically and medially. Therefore, race shape main components in our society-including medical research, it is time for a change. We need more research that challenges the status quo and as Cottler et al. (2013) put it, “work towards person-centered research to promote between health outcomes for all” (p. 1691). Even though there is an emphasis on reducing health disparities by including previously underrepresented groups in medical/health research, it is important that as researchers we do not perpetuate the same assumptions previous researchers have done (Cottle et al., 2013). Overall, racial and ethnic disparities in health research is not due to differences in preferences for participation, it is more complicated than looking at racial and ethnic barriers for explanations of low participation. Therefore, future research might want to look at other factors like previous participation, or prior knowledge of medical research, in relation to willingness to participate.

Limitations to this study include a small sample size. Although the sample size is small, considering the numerous variables that were analyzed, chi-square tests calculated for the associations among codes and sociodemographic characteristics could not be used to indicate a significant association among variable. However, the small sample size allowed for a comprehensive and in-depth study of the reasons that participants give for participating-or not-in medical research studies. Therefore, further research should focus on capturing the reasons with a larger sample size so that chi-square tests are reliable and demonstrate any significant associations among reasons and sociodemographic characteristics.

Also, this research study measures willingness to participate and not actual enrolment or accrual rates. Yet the approach of asking participants their willingness to participate in medical research is commonly used in survey research (Durant et al., 2011). Reason action theory is how individual’s behaviors are determined by their intention of performing the action, therefore, if participants are willing to participate, they will follow through. Although willingness to participate in medical research was measured throughout the survey/interview, it was not corroborated with actual participation rates. Therefore, future research on willingness to participate in health research should measure intent with accrual/enrollment rates in medical research studies.

CONCLUSION

In conclusion, this thesis focused on gaining a sense of the reasons for participation-or not- in medical research studies. Therefore, I looked at the reasons participants provided in cognitive interviews regarding participating-or nonparticipation- in medical research studies that ask participants personal questions and provide biomarkers like saliva, blood, tissue and cerebrospinal fluid samples. The involvement of racial/ethnic minorities in health research is crucial since preventions strategies, treatment efficacy and treatment effectiveness are created and tested in health research. Since racial/ethnic minority enrollment rates in health research remain low, it means that prevention strategies, treatment efficacy and treatment effectiveness are not being created for underrepresented populations in health research. By looking at the data for reoccurring and emerging themes, several codes that have been previously examined emerged, such as prior knowledge, previous experience, needs more information, fear, distrust, pain, willing to contribute and not willing to contribute. Based on previous studies and the results of this study, in terms of willing-or not-to participate in medical research by race, indicate that there are other factors that might have greater influence in participation of health research than sociodemographic characteristics. Therefore, identifying the main issues barriers to participation in medical research base on other factors like education, previous experience, prior knowledge of health-related research studies, and age can help prevent the perpetuation of race-based differences and race-based medicine (Benjamin, 2014). Some of the recurring themes that have emerged are facilitators, such as prior knowledge and previous experience, conditional factors like depends and needs more information, and barrier like no prior knowledge, procedure unknown, no previous experience, fear, pain, procedure dangerous, distrust and invasive.

APPENDIX A

SOCIODEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Number of Completed Interviews by Respondent Characteristics

	Male				Female				
	High School or Less		Some College or More		High School or Less		Some College or More		
	30-55 years	56+ years	30-55 years	56+ years	30-55 years	56+ years	30-55 years	56+ years	Total
Black	2	2	2	2	2	2	2	2	16
American Indian	1	2	3	2	2	2	2	2	16
White	2	2	2	2	2	2	2	2	16
Latino/a	2	2	2	2	2	2	2	2	16
Total	7	8	9	8	8	8	8	8	64

APPENDIX B

QUESTIONNAIRE ROUND 1

200. The next questions are about what you would do if you were asked to participate in a medical research study.

How likely would you be to participate in a medical research study that asked you <u>to answer questions about yourself</u>: not at all likely, a little likely, somewhat likely, pretty likely, or very likely?

○ NOT AT ALL LIKELY
○ A LITTLE LIKELY
○ SOMEWHAT LIKELY
○ PRETTY LIKELY
○ VERY LIKELY

○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2: In your own words, what did the phrase "medical research study" mean to you?

PROBE-3: In your own words, what did the phrase "answer questions about yourself" mean to you?

---

210. How likely would you be to participate in a medical research study that asked you <u>to give a sample of your saliva</u>: not at all likely, a little likely, somewhat likely, pretty likely, or very likely?

○ NOT AT ALL LIKELY
○ A LITTLE LIKELY
○ SOMEWHAT LIKELY
○ PRETTY LIKELY
○ VERY LIKELY

○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2a IF INDICATES BEING MORE OR LESS LIKELY FOR SALIVA THAN QUESTIONS: Can you tell me more about why you would be (more/less) likely to give a sample of your saliva than to answer questions about yourself?

PROBE-2b IF INDICATES BEING EQUALLY LIKELY FOR SALIVA AND QUESTIONS: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your saliva and that you would also be [ANSWER TO PREVIOUS QUESTION] to answer questions about yourself. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

---

220. How likely would you be to participate in a medical research study that asked you <u>to give a sample of your blood</u>: not at all likely, a little likely, somewhat likely, pretty likely, or very likely?

- ○ NOT AT ALL LIKELY
- ○ A LITTLE LIKELY
- ○ SOMEWHAT LIKELY
- ○ PRETTY LIKELY
- ○ VERY LIKELY
- ○ DON'T KNOW
- ○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2a IF INDICATES BEING MORE OR LESS LIKELY FOR BLOOD THAN SALIVA: Can you tell me more about why you would be (more/less) likely to give a sample of your blood than a sample of your saliva?

PROBE-2b IF INDICATES BEING EQUALLY LIKELY FOR BLOOD AND SALIVA: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your blood and that you would also be [ANSWER TO PREVIOUS QUESTION] to give a sample of your saliva. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

230. How likely would you be to participate in a medical research study that asked you <u>to give a sample of your tissue</u>: not at all likely, a little likely, somewhat likely, pretty likely, or very likely?

○ NOT AT ALL LIKELY
○ A LITTLE LIKELY
○ SOMEWHAT LIKELY
○ PRETTY LIKELY
○ VERY LIKELY

○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2: What did the phrase "sample of your tissue" mean to you in this question?

PROBE-3a IF INDICATES BEING MORE OR LESS LIKELY FOR TISSUE THAN BLOOD: Can you tell me more about why you would be (more/less) likely to give a sample of your tissue than a sample of your blood?

PROBE-3b IF INDICATES BEING EQUALLY LIKELY FOR TISSUE AND BLOOD: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your tissue and that you would also be [ANSWER TO PREVIOUS QUESTION] to give a sample of your blood. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

240. Cerebrospinal fluid is a fluid that surrounds your brain. It can be collected by inserting a small needle into your lower back, a procedure called a lumbar puncture or spinal tap.

How likely would you be to participate in a medical research study that asked you <u>to give a sample of your cerebrospinal fluid</u>: not at all likely, a little likely, somewhat likely, pretty likely, or very likely?

○ NOT AT ALL LIKELY
○ A LITTLE LIKELY
○ SOMEWHAT LIKELY
○ PRETTY LIKELY
○ VERY LIKELY
○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2a IF INDICATES BEING MORE OR LESS LIKELY FOR CEREBROSPINAL FLUID THAN TISSUE: Can you tell me more about why you would be (more/less) likely to give a sample of your cerebrospinal fluid than a sample of your tissue?

PROBE-2b IF INDICATES BEING EQUALLY LIKELY FOR CEREBROSPINAL FLUID AND TISSUE: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your cerebrospinal fluid and that you would also be [ANSWER TO PREVIOUS QUESTION] to give a sample of your tissue. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

PROBE-3: Were the answer choices – not at all likely, a little likely, somewhat likely, pretty likely, and very likely -- easy or hard for you to use to answer these questions?

PROBE-4: In your own words, what did the category "not at all likely" mean to you?

PROBE 4a IF NECESSARY: Does "not at all likely" mean the same thing to you as "never"?

APPENDIX C

QUESTIONNAIRE ROUND 2

200.INTERVIEWER: HAND PARTICIPANT CARD 1

Please use these categories to answer the next questions.

The next questions are about what you would do if you were asked to participate in a medical research study.

If a medical researcher asked you to participate in a medical research study by answering questions about yourself, how likely would you be to participate: very likely, somewhat likely, neither likely nor unlikely, somewhat unlikely, or very unlikely?

○ VERY LIKELY
○ SOMEWHAT LIKELY
○ NEITHER LIKELY NOR UNLIKELY
○ SOMEWHAT UNLIKELY
○ VERY UNLIKELY

○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2: In your own words, what did the phrase "medical research study" mean to you?

PROBE-3: What kinds of people did you think about when you heard the phrase "medical researcher?"

PROBE-4: In your opinion, are medical research studies good or bad things?

---

210. If a medical researcher asked you to participate in a medical research study <u>by giving a sample of your saliva</u>, how likely would you be to participate: very likely, somewhat likely, neither likely nor unlikely, somewhat unlikely, or very unlikely?

○ VERY LIKELY
○ SOMEWHAT LIKELY
○ NEITHER LIKELY NOR UNLIKELY
○ SOMEWHAT UNLIKELY
○ VERY UNLIKELY

○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2a IF INDICATES BEING MORE OR LESS LIKELY FOR SALIVA THAN QUESTIONS: Can you tell me more about why you would be (more/less) likely to give a sample of your saliva than to answer questions about yourself?

PROBE-2b IF INDICATES BEING EQUALLY LIKELY FOR SALIVA AND QUESTIONS: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your saliva and that you would also be [ANSWER TO PREVIOUS QUESTION] to answer questions about yourself. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

---

220. If a medical researcher asked you to participate in a medical research study <u>by giving a sample of your blood</u>, how likely would you be to participate: very likely, somewhat likely, neither likely nor unlikely, somewhat unlikely, or very unlikely?

○ VERY LIKELY
○ SOMEWHAT LIKELY
○ NEITHER LIKELY NOR UNLIKELY
○ SOMEWHAT UNLIKELY
○ VERY UNLIKELY

○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2a IF INDICATES BEING MORE OR LESS LIKELY FOR BLOOD THAN SALIVA: Can you tell me more about why you would be (more/less) likely to give a sample of your blood than a sample of your saliva?

PROBE-2b IF INDICATES BEING EQUALLY LIKELY FOR BLOOD AND SALIVA: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your blood and that you would also be [ANSWER TO PREVIOUS QUESTION] to give a sample of your saliva. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

---

230. Tissue is located in the human body and made up of cells. Small pieces of tissue can be taken from the body by a health care professional.

If a medical researcher asked you to participate in a medical research study <u>by giving a sample of your tissue</u>, how likely would you be to participate: very likely, somewhat likely, neither likely nor unlikely, somewhat unlikely, or very unlikely?

○VERY LIKELY
○SOMEWHAT LIKELY
○NEITHER LIKELY NOR UNLIKELY
○SOMEWHAT UNLIKELY
○VERY UNLIKELY
○DON'T KNOW
○REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2: What did the phrase "sample of your tissue" mean to you in this question?

PROBE-3a IF INDICATES BEING MORE OR LESS LIKELY FOR TISSUE THAN BLOOD: Can you tell me more about why you would be (more/less) likely to give a sample of your tissue than a sample of your blood?

PROBE-3b IF INDICATES BEING EQUALLY LIKELY FOR TISSUE AND BLOOD: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your tissue and that you would also be [ANSWER TO PREVIOUS QUESTION] to give a sample of your blood. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

---

240. Cerebrospinal fluid is a fluid that surrounds your brain. It can be collected by inserting a small needle into your lower back, a procedure called a lumbar puncture or spinal tap.

If a medical researcher asked you to participate in a medical research study <u>by giving a sample of your cerebrospinal fluid</u>, how likely would you be to participate: very likely, somewhat likely, neither likely nor unlikely, somewhat unlikely, or very unlikely?

○ VERY LIKELY
○ SOMEWHAT LIKELY
○ NEITHER LIKELY NOR UNLIKELY
○ SOMEWHAT UNLIKELY
○ VERY UNLIKELY

○ DON'T KNOW
○ REFUSED

PROBE-1: Tell me more about why you answered [ANSWER] for this question.

PROBE-2a IF INDICATES BEING MORE OR LESS LIKELY FOR CEREBROSPINAL FLUID THAN TISSUE: Can you tell me more about why you would be (more/less) likely to give a sample of your cerebrospinal fluid than a sample of your tissue?

PROBE-2b IF INDICATES BEING EQUALLY LIKELY FOR CEREBROSPINAL FLUID AND TISSUE: You answered that you would be [ANSWER TO CURRENT QUESTION] to give a sample of your cerebrospinal fluid and that you would also be [ANSWER TO PREVIOUS QUESTION] to give a sample of your tissue. Can you tell me more about why you gave the answer of [ANSWER TO CURRENT QUESTION] for both of these?

PROBE-3: Were the answer choices – very likely, somewhat likely, neither likely nor unlikely, somewhat unlikely, and very unlikely -- easy or hard for you to use to answer these questions?

PROBE-4: In your own words, what did the category "neither likely nor unlikely" mean to you?

APPENDIX D

MAIN THEMES LIST

1. noninv
    a. noninv-questions (noninv_qs)
    b. noninv-saliva (noninv_sa)
    c. noninv-blood (noninv_bd)
    d. noninv-tissue (noninv_te)
    e. noninv-lumbar puncture (noninv_lp)
    f. noninv-nonexperimental (noninv_nex)
    g. noninv-nonspecific (noninv_ns)
2. invasive
    a. invasive-compared (invasive_com)
    b. invasive-questions (invasive_qs)
    c. invasive-saliva (invasive_sa)
    d. invasive-blood (invasive_bd)
    e. invasive-tissue (invasive_te)
    f. invasive-lumbar puncture (invasive_lp)
    g. invasive-nonspecific (invasive_ns)
3. willing to contribute (wiltocont)
    a. willing to contribute-questions (wiltocont_qs)
    b. willing to contribute-saliva (wiltocont_sa)
    c. willing to contribute-blood (wiltocont_bd)
    d. willing to contribute-tissue (wiltocont_te)
    e. willing to contribute-cerebrospinal fluid (wiltocont_csf)
    f. willing to contribute saliva-commonly asked for (wiltocontsa_caf)
    g. willing to contribute blood-commonly asked for (wiltocontbd_caf)
    h. willing to contribute tissue-commonly asked for (wiltocontte_caf)
    i. willing to contribute-nonspecific (wiltocont_ns)
    j. willing to contribute-monetary incentive ((wiltocont_mi)
    k. willing to contribute-not a clinical trial ((wiltocont_nct)
4. notwill to contribute (notwiltocont)
    a. notwill to contribute-questions (notwiltocont_qs)
    b. notwill to contribute-saliva (notwiltocont_sa)
    c. notwill to contribute-blood (notwiltocont_bd)
    d. notwill to contribute-tissue (notwiltocont_te)
    e. notwill to contribute-cerebrospinal fluid (notwiltocont_csf)
    f. notwill to contribute-experimental (notwiltocont_ex)
    g. notwill to contribute saliva-not commonly asked for (notwiltocontsa_ncaf)
    h. notwill to contribute-nonspecific (notwiltocont_ns)
5. does not mind (doesnotmind)
    a. does not mind-questions (doesnotmind_qs)
    b. does not mind-saliva (doesnotmind_sa)
    c. does not mind-blood (doesnotmind_bd)
    d. does not mind-tissue (doesnotmind_te)

    e. does not mind-lumbar puncture (doesnotmind_lp)
    f. does not mind-nonspecific (doesnotmind_ns)
6. previous experience (prevexp)
    a. previous experience-questions (prevexp_qs)
    b. previous experience-saliva (prevexp_sa)
    c. previous experience-blood (prevexp_bd)
    d. previous experience-tissue (prevexp_te)
    e. previous experience-lumbar puncture (prevexp_lp)
    f. previous experience-other procedures/tests (prevexp_opt)
    g. previous experience-nonspecific (prevexp_ns)
7. no previous experience (noprevexp)
    a. no previous experience-questions (noprevexp_qs)
    b. no previous experience-saliva (noprevexp_sa)
    c. no previous experience-blood (noprevexp_bd)
    d. no previous experience-tissue (noprevexp_te)
    e. no previous experience-lumbar puncture (noprevexp_lp)
    f. no previous experience-nonspecific (noprevexp_ns)
8. prior knowledge (priorknowledge)
    a. prior knowledge-self (priorknowledge_sf)
    b. prior knowledge-questions (priorknowledge_qs)
    c. prior knowledge-saliva (priorknowledge_sa)
    d. prior knowledge-blood (priorknowledge_bd)
    e. prior knowledge-tissue (priorknowledge_te)
    f. prior knowledge-lumbar puncture (priorknowledge_lp)
    g. prior knowledge-other prior knowledge (priorknowledge_opk)
    h. prior knowledge-nonspecific (priorknowledge_ns)
9. nopr knowledge (nopriorknowledge)
    a. nopr knowledge-questions (nopriorknowledge_qs)
    b. nopr knowledge-saliva (nopriorknowledge_sa)
    c. nopr knowledge-blood (nopriorknowledge_bd)
    d. nopr knowledge-tissue (nopriorknowledge_te)
    e. nopr knowledge-lumbar puncture (nopriorknowledge_lp)
    f. nopr knowledge-nonspecific (nopriorknowledge_ns)
10. depends
11. needs more information
12. skeptical
13. distrust
    a. distru-organization (distru_org)
    b. distru-researcher (distru_res)
    c. distru-specimen handling (distru_sph)
14. trust
    a. trust-organization (trust_org)

    b. trust-researcher (trust_res)
    c. trust-specimen handling (trust_sph)
15. time
16. confidentiality/privacy (confidentiality)
    a. confidentiality/privacy-questions (confidentiality_qs)
    b. confidentiality/privacy-saliva (confidentiality_sa)
    c. confidentiality/privacy-blood (confidentiality_bd)
    d. confidentiality/privacy-tissue (confidentiality_te)
    e. confidentiality/privacy-lumbar puncture (confidentiality_lp)
    f. confidentiality/privacy-nonspecific (confidentiality_ns)
    g. confidentiality/privacy-other (confidentiality_oth)
17. nothing to hide
18. positive attitude
19. importance
20. background/culture (background)
21. pain
    a. pain-questions (pain_qs)
    b. pain-saliva (pain_sa)
    c. pain-blood (pain_bd)
    d. pain-tissue (pain_te)
    e. pain-lumbar puncture (pain_lp)
    f. pain-nonspecific (pain_ns)
22. nopn
    a. nopn-questions (nopain_qs)
    b. nopn-saliva (nopain_sa)
    c. nopn-blood (nopain_bd)
    d. nopn-tissue (nopain_te)
    e. nopn-lumbar puncture (nopain_lp)
    f. nopn-nonspecific (nopain_ns)
23. fear
    a. fear-questions (fear_qs)
    b. fear-saliva (fear_sa)
    c. fear-blood (fear_bd)
    d. fear-tissue (fear_te)
    e. fear-lumbar puncture (fear_lp)
    f. fear-needles (fear_ned)
    g. fear-nonspecific (fear_ns)
24. nofr
    a. nofr-questions (nofr_qs)
    b. nofr-saliva (nofr_sa)
    c. nofr-blood (nofr_bd)
    d. nofr-tissue (nofr_te)

- e. nofr-lumbar puncture (nofr_lp)
- f. nofr-needles (nofr_ned)
- g. nofr-nonspecific (nofr_ns)

25. procedure unknown (prounk)
    a. procedure unknown-questions (prounk_qs)
    b. procedure unknown-saliva (prounk_sa)
    c. procedure unknown-blood (prounk_bd)
    d. procedure unknown-tissue (prounk_te)
    e. procedure unknown-lumbar puncture (prounk_lp)
    f. procedure unknown -nonspecific (prounk_ns)
26. procedure dangerous (prodang)
    a. procedure dangerous-questions (prodang_qs)
    b. procedure dangerous-saliva (prodang_sa)
    c. procedure dangerous-blood (prodang_bd)
    d. procedure dangerous-tissue (prodang_te)
    e. procedure dangerous-lumbar puncture (prodang_lp)
    f. procedure dangerous-nonspecific (prodang_ns)
27. procedure not dangerous (pronotdang)
    a. procedure not dangerous-questions (pronotdang_qs)
    b. procedure not dangerous-saliva (pronotdang_sa)
    c. procedure not dangerous-blood (pronotdang_bd)
    d. procedure not dangerous-tissue (pronotdang_te)
    e. procedure not dangerous-lumbar puncture (pronotdang_lp)
    f. procedure not dangerous-nonspecific (pronotdang_ns)
28. procedure not difficult (pronotdiff)
    a. procedure not difficult-questions (pronotdiff_qs)
    b. procedure not difficult-saliva (pronotdiff_sa)
    c. procedure not difficult-blood (pronotdiff_bd)
    d. procedure not difficult-tissue (pronotdiff_te)
    e. procedure not difficult-lumbar puncture (pronotdiff_lp)
    f. procedure not difficult-nonspecific (pronotdiff_ns)
29. procedure difficult (prodiff)
    a. procedure difficult-questions (prodiff_qs)
    b. procedure difficult-saliva (prodiff_sa)
    c. procedure difficult-blood (prodiff_bd)
    d. procedure difficult-tissue (prodiff_te)
    e. procedure difficult-lumbar puncture (prodiff_lp)
    f. procedure difficult-nonspecific (prodiff_ns)
30. procedure specimen handling (prosph)
    a. procedure specimen handling-questions (prosph_qs)
    b. procedure specimen handling-saliva (prosph_sa)
    c. procedure specimen handling-blood (prosph_bd)

   d. procedure specimen handling-tissue (prosph_te)
   e. procedure specimen handling-lumbar puncture (prosph_lp)
   f. procedure specimen handling-nonspecific (prosph_ns)

31. benefit
    a. benefit-personal (benefit_per)
    b. benefit-others (benefit_oths)
    c. benefit-research (benefit_re)
    d. benefit-questioning (benefit_qsg)
32. healthy
    a. healthy-reason to participate (healthy_rtp)
    b. healthy-reason to not participate (healthy_rtnp)
33. unhlthy
    a. unhlthy-reasons to participate (unhlthy_rtp)
    b. unhlthy-reasons to not participate (unhlthy_rtnp)
34. comparison
35. current participation

APPENDIX E

CODE BOOK

Memo
Project Heading: Willingness of Underrepresented Groups to Participate in Medical Research Studies
Series Heading:
Memo Title: Codebook
File Name:
Date: July 2016
To:
From:

The purpose of this document to house our codebook.
At this point the examples that are included in the codebook are out of date and will be updated as the first set of cases are recoded again.

I. Primary Codes and Specifications

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
noninvasive	noninvasive		participation does not involve the intrusion of privacy to collect answers of the introduction of a medical instrument into the participant's body to collect biomarker				
					1101 Q200_P1 (5)	“nothing invasive”	
					1101 Q210_P1 (5)	“it's nothing, uh, intrusive or invasive”	
					4107 Q210_P1	“It's not an invasive”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
noninvasive	noninvasive	questions	participation that does not involve the intrusion of privacy when answering questions				
		saliva	participation that does not involve the introduction of medical instrument into the participant’s body to collect a saliva sample				
		blood	participation that does not involve the introduction of a medical instrument into the participant's body to collect a blood sample				
		tissue	participation that does not involve the introduction of a medical instrument into the participant's body to collect a tissue sample				
		lumbar puncture	participation that does not involve the introduction of a medical instrument into the participant's body to collect a cerebrospinal fluid sample				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
noninvasive	noninvasive	nonexperimental	participation that does not involve the introduction of a medical instrument (probing) into the participant's body to collect specimen or participation that does not involve experimental treatments or medication that have not been FDA approved				
		nonspecific	participation that does not involve the introduction of a medical instrument into the participant's body to collect specimen, specimen is not specified by the participant				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
invasive	invasive		participation involves the intrusion of privacy to collect answers or the introduction of medical instruments into the participants body to collect the biomarker				
				personal health conditions	1104 Q200_P1	“invasions of my, uh, you know, my personal, you know, like, uh, the illness or conditions”	
				person	1105 Q220_P2a	“invade my, my person”	
				skin	1105 Q220_P2a	“penetrate my skin.”	

Concept	**Primary Code**	**Specification**	**Definitions**	**Examples**	**Caseids (for examples)**	**Notes**	**DG notes**
invasive	invasive	compared-specific	the participant explicitly states a similarity or dissimilarity between two or more biomarkers that involve the introduction of medical instruments into the participants’’ body to collect the biomarker, biomarkers being compared by the participants must be stated	more invasive	1101 Q230_P3a (2)	Tissue sample extraction procedure is more invasive than the blood sample procedure “tissue is a little bit more invasive than just blood.”	
					1106 Q230_P1	“more invasive.”	
					1106 Q230_P3a	“tissue just seemed like it would be more invasive to me.”	
					1106 Q240_P1	“really invasive”	
					2102 Q230	“they're more hurtful or invasive” tissue sample is more invasive than giving a saliva or blood sample	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
invasive	invasive	compared-specific		more invasive	2102 Q240_P2b	“seem a lot more, I don't know, invasive or painful”	
					3102 Q240_P1	“a little bit more invasive.”	
					4101 Q230_P1	“a little more invasive”, tissue is more invasive	
					4107 Q240_P2a	“too invasive”	
						Cerebrospinal fluid is more invasive than giving a tissue sample	
				less invasive	2101 Q240_P1	Tissue is “less invasive than the spinal fluid.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
invasive	invasive	compared-specific		less invasive	3108 Q210_P2	Answering questions is less invasive than giving saliva samples “answering, because it doesn't seem as intrusive”	
					4107 Q220_P2a	“more invasive than spitting” Giving a blood sample versus a saliva sample	
		compared-nonspecific	the participant explicitly states a similarity or dissimilarity between two or more biomarkers that involve the intrusion of instruments into the participants’ body to collect the biomarker, but the participant is unclear or does not explicitly mention the biomarkers being compared	more invasive	2102 Q240_P2b	“seem a lot more, I don't know, invasive or painful”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
invasive	invasive	questions	participation involves the intrusion of participants' thoughts or privacy to collect answers				
		saliva	participation involves the intrusion of medical instruments into the participant's body to collect a saliva sample				
		blood	participation involves the intrusion of medical instruments into the participant's body to collect a blood sample				
		tissue	participation involves the intrusion of medical instruments into the participant's body to collect a tissue sample				
		lumbar puncture	participation involves the intrusion of medical instruments into the participant's body to collect a cerebrospinal fluid sample				
		nonspecific	participation involves the intrusion of a medical instrument into the participant's body to collect specimen, however the specimen is not specified, by the participant				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
willing to contribute to medical research	willing to contribute		participants are willing and/or able to contribute/participate in medical research studies that ask questions and collect biomarkers				that this could be questions or answer to questions anywhere
		willing to contribute-questions	the participant explicitly states that they are willing to participate in medical research studies that ask them questions	just questioning	2108 Q200 (5)	if the study is simply asking questions about the respondents’ opinion, than she/he would participate	
				"just" answering questions	1101 Q200_P1 (5)	answering questions for medical research	
					3103 Q210_P2	verses giving a sample	
				answer questions	3104 Q200_P1 (5)		
					1101 Q210_P3	“I can answer questions.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
willing to contribute to medical research	willing to contribute	willing to contribute-questions		"why not" answer questions	4107 Q200_P1 (5)	Respondent has previously participated in a research study where “parts” of their body were “touched”, “why not participate in something where” they can answer question	
				more personal	4101 Q210_P2	this respondent is less willing to provide answers for the survey portion of the research study, since answering the questions would deal with more personal information and emotion	
				Anonymous	4101 Q210_P2	“pretty anonymous, you know. It's like I just don't have that connection”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
willing to contribute to medical research	willing to contribute	willing to contribute-saliva	the participant explicitly states that they are willing to contribute/participate in medical research studies that collect biomarkers, specifically saliva				
				Saliva sample	1101 Q210_P1	“it's only saliva.”	
					1101 Q210_P3	“I can answer questions and give some saliva.”	
					1105 Q210_P2	“give a sample of my saliva”	
					4106 Q230_P3a	“saliva's are no big deal”	
					4109 Q210_P1	Not strenuous test “I don't think it would be a strenuous test.”	
		willing to contribute-blood	the participant explicitly states that they are willing to contribute/participate in medical research studies that collect biomarkers, specifically blood	Blood sample	2104 Q220_P1	“study my blood for some reason”	
					4106 Q230_P3a	“blood and saliva's are no big deal”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
willing to contribute to medical research	willing to contribute	willing to contribute-tissue	the participant explicitly states that they are willing to contribute/participate in medical research studies that collect biomarkers, specifically tissue	Tissue sample	2106 Q230_P1	“sample of the tissue would also help”	
		willing to contribute-cerebrospinal fluid	the participant explicitly states that they are willing to contribute/participate in medical research studies that involve spinal taps/ lumbar punctures and./ or studies that collect biomarkers, specifically cerebrospinal fluid	Cerebrospinal fluid	4107 Q240_P1	“I would only do it if it was to donate something to someone else”	
		willing to contribute saliva-commonly asked for	the participant states that they are willing to contribute/participate in a medical research because the saliva is commonly asked for or routinely done				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
		willing to contribute blood-commonly asked for	the participant states that they are willing to contribute/participate in a medical research because the blood is commonly asked for or routinely done				
		willing to contribute tissue-commonly asked for	the participant states that they are willing to contribute/participate in a medical research because the tissue is commonly asked for or routinely done				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
willing to contribute to medical research	willing to contribute	willing to contribute-nonspecific	the participant states that they are willing to contribute/ participate in medical research studies that collect biomarkers, but does not explicitly state which biomarker				
		willing to contribute-monetary incentive	the participant states that they are willing to contribute/ participate in medical research studies, if they are compensated for their time, by a monetary incentive				
		willing to contribute-not a clinical trial	the participant states that they are willing to contribute/ participate in medical research studies, if they are not being subjected to experimental treatments				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
not willing to contribute to medical research	not willing to contribute		participants are not willing and/or able to contribute/ participate in medical research studies that ask questions and collect biomarkers				
		not willing to contribute-questions	the participant explicitly states that they are not willing to contribute/ participate in medical research studies, that ask questions				
		not willing to contribute-saliva	the participant explicitly states that they are not willing to contribute/ participate in medical research studies that collect saliva as a biomarker				
		not willing to contribute-blood	the participant explicitly states that they are not willing to contribute/ participate in medical research studies that collect blood as a biomarker				
		not willing to contribute-tissue	the participant explicitly states that they are not willing to contribute/ participate in medical research studies that collect tissue as a biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
not willing to contribute to medical research	not willing to contribute	not willing to contribute-cerebrospinal fluid	the participant explicitly states that they are not willing to contribute/ participate in medical research studies that collect cerebrospinal fluid as a biomarker				
		not willing to contribute-experimental	the participant explicitly expresses that they are not willing to contribute/participate in medical research studies, if they are being subjected to experimental treatments and/or medications				
		not willing to contribute saliva-not commonly asked for	the participant expresses that they are not willing and/or able to give saliva as a biosample for medical research because saliva is not commonly or routinely done				
		not willing to contribute-nonspecific	the participant expresses that they are not willing to contribute/participate in medical research studies that collect biomarkers, but does not explicitly state which biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
does not mind	does not mind		the participants state that they do not mind and/or do not have a problem in participating in medical research studies that ask them questions or collect biomarkers				
		does not mind-questions	the participant states that they do not mind talking to others or answering questions for medical research studies	answering questions	1108 Q210_P3	“I don't mind answering questions about myself.”	
					4103 Q210_P2	“I don't mind doing both things.” both answering questions and giving a saliva sample	
				talking about self	4103 Q200_P1	“I don't mind talking about myself to other people”	
				participating in research	1107 Q230_P1	“I don't mind people doing research on me,”	
					3106 Q200	“I really don't have objections to health studies or anything.”	
					3106 Q200_P1	“I don't have a problem with doing studies”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
does not mind	does not mind	does not mind-saliva	the participant states that they do not mind giving saliva or DNA samples for medical research studies	giving saliva samples	1106 Q220_P2b	“it just doesn't seem like it would be anything that would really burden me. It's just saliva and blood”	
					1107 Q220_P1	“I don't mind, um, people researching my, you know, blood, saliva”	
					4103 Q210_P3	“I don't mind doing both things.” Giving a saliva sample and answering questions	
					3106 Q210_P1 DNA	“I don't have any problem giving samples of my DNA”	
		does not mind-blood	the participant states that they do not mind giving blood samples for medical research studies	giving blood samples	1106 Q220_P2b	“it just doesn't seem like it would be anything that would really burden me. It's just saliva and blood”	
					1107 Q220_P1	“I don't mind, um, people researching my, you know, blood,”	
					3101 Q220_P2b	“giving blood doesn't bother me”	
					3101 Q230_P3a	“it does not bother me to give blood.”	
					3106 Q210	“I have no problem with being here, you know, giving samples”	
					3106 Q220_P1	“I have no problems giving samples of blood.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
does not mind	does not mind	does not mind-blood			4101 Q220_P2b	“I give to a blood drive. I don't have any problems with that”	
					4103 Q220_P1 blood	“I wouldn't mind giving blood to”	
					4103 Q220_P2b	“I don't mind doing it”	
		does not mind-tissue	the participant states that they do not mind giving tissue samples for medical research studies				
		does not mind-cerebrospinal fluid	the participant states that they do not mind giving cerebrospinal fluid samples for medical research studies				
		does not mind-nonspecific	the participant states that they do not mind and/or have a problem, in participating in medical research studies that collect biomarkers, but does not explicitly state which biomarker		1106 Q220_P1	“I just wouldn't have a problem with it”	
					1107 Q200_P1	“I don't mind,”	
					1107 Q210_P1	“I don't have a problem”	
					3101 Q210	“That wouldn't be a problem to me.”	
					4107 Q210_P3	“I don't mind doing that.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
previous personal experience	previous experience		participants describe any previous personal experience that they have, regarding answering question or providing biomarkers				
		Previous experience-questions	the participant acknowledges that they have previous experience, with answering questions	survey questionnaire	2103 Q200_P1	“questionnaire and survey, I'm always doing that”	
					2109 Q200_P1	“I've been in the hospital quite a bit, so I always got teams of doctors coming around and these medical students want to sit and talk to you afterwards and ask you a bunch of things.”	
					4107 Q210_P3	“‘I’ve worked, uh, doing, um, interviews and doing surveys.”	
		Previous experience-saliva	the participant acknowledges that they have previous experience, with giving a saliva sample				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
previous personal experience	previous experience	previous experience-blood	the participant acknowledges that they have previous experience, with giving a blood sample	blood sample	2103 Q220_P1	"I'm used to just giving blood"	
					2106 Q220_P1	"I have given blood samples for tests, so I figure, you know, I've done it once, so I can do it other times."	
					4101 Q220_P2b	"blood drive, you know, I give to a blood drive"	
					4101 Q230_P3a	"I've done blood before"	
					4107 Q220_P1	"I went to donate blood"	
		previous experience-tissue	the participant acknowledges that they have previous experience, with giving a tissue sample	tissue sample	1_P103 Q240_P2a	"I gave a sample of my tissue before and it didn't hurt"	
		Previous experience-lumbar puncture	the participant acknowledges that they have previous experience, with the lumbar puncture procedure and/ or giving a cerebrospinal fluid sample	lumbar puncture/ spinal tap	1101 Q240_P1	"I've had three lumbar punctures before, so I know about how those go."	
					1101 Q240_P2a	"lumbar puncture, I've had them before"	

Concept	**Primary Code**	**Specification**	**Definitions**	**Examples**	**Caseids (for examples)**	**Notes**	**DG notes**
previous personal experience	previous experience	previous experience-lumbar puncture			1105 Q210_P1	Unlike other participants who have previous experience are willing to participate, this respondent is not. “I've had spinal taps before, and they are too dangerous to”	
					2109 Q240	“pretty likely, because I've had it done already”	
					4103 Q240_P2b	Has previous personal experience with the lumbar puncture procedure and would not do it again “I already have experience from it, so I wouldn't do it again.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
previous personal experience	previous experience	previous experience-lumbar puncture		lumbar puncture/ spinal tap	4101 Q240_P1	Has previous personal experience with a lumbar puncture, but unlike other participants, this respondent painful consequences and would not be willing to participate, due to the previous hurtful experience “then they just took a long needle like this and put it in my back. And now every time like I bend over for like 15, 20 minutes to straighten up, that I gotta slowly get up, because it hurts. So that's, that's why I wouldn't do it. I wouldn't do it again.”	
				epidural	1107 Q240	“but I've had an epidural before”	
					1107 Q240_P2a	“made it through the epidural,”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
previous personal experience	previous experience	previous experience-other procedures/ tests	the participant acknowledges that they have previous experience, with other types of procedures and medical examinations / tests				
				studies	2101 Q200_P1	“I've just done other studies before,”	
				colonoscopy	2109 Q230_P1	“I had to go have that done when I had a colonoscopy”	
				electrodes	4107 Q200_P1	“'I’ve already participated in one where it was pretty, it wasn't invasive, but it was where there were electroids”	
				Medical tests	4109 Q200_P1	“I have been on medical tests before”	
		previous experience-nonspecific	the participant acknowledges that they have previous experience, but does not specifically state the types of experience				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
no previous personal experience	no previous experience		participants state that they do not have any personal previous experience, regarding answering questions or providing a biomarker				
		no previous experience-questions	the participant states that they do not have any previous experience with answering questions				
		no previous experience-saliva	the participant states that they do not have any previous experience with giving a saliva sample				
		no previous experience-blood	the participant states that they do not have any previous experience with giving a blood sample	Blood draw procedure	1102 Q210_P2	"I've never given blood ever in my life either."	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
no previous personal experience	no previous experience	no previous experience-tissue	the participant states that they do not have any previous experience with giving a tissue sample	tissue sample	2103 Q230_P3a	“with the tissue, since I haven't had to do that”	
					4101 Q230_P3a	“I've never, I don't think I've ever given a tissue sample”	
		no previous experience-lumbar puncture	the participant states that they do not have any previous experience with lumbar punctures, spinal taps or giving a cerebrospinal fluid sample	lumbar puncture	2103 Q240_P2a	“I've never done it before.”	
					3106 Q240_P1	“I've never had it done.”	
					4101 Q240_P1	“I've never done it before,”	
					4109 Q240_P1	“never been, uh, introduced to anything like that”	
		no previous experience-nonspecific	the participant states that they do not have any previous experience, but does not mention the type of experience they do not have				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
previous knowledge on a subject or area	prior knowledge		the participant states that they have knowledge regarding what they are being asked to provide, give or contribute				
		prior knowledge-self	the participant has knowledge of self	health	3108 Q220_P1	"I have the most intimate knowledge of my own health"	
		prior knowledge-questions	the participant has prior knowledge regarding survey questionnaires or answering questions				
		prior knowledge-saliva	the participant has prior knowledge regarding the extraction procedure for saliva, what saliva is, the purpose of collecting saliva and/or the risks/consequences of the procedure				
		prior knowledge-blood	the participant has prior knowledge regarding the extraction procedure for blood, the purpose of collecting blood and/or the risks/consequences of the procedure				
		prior knowledge-tissue	the participant has prior knowledge regarding the extraction process for tissue, what tissue means, the purpose of collecting tissue and/or the risks/consequences of the procedure	sites of tissue extraction	4107 Q230_P3a	"I know the places that you can remove it from"	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
previous knowledge on a subject or area	prior knowledge	prior knowledge-lumbar puncture	the participant has prior knowledge regarding the extraction procedure for cerebrospinal fluid sample, lumbar puncture/ spinal tap, what cerebrospinal fluid is, the purpose for collecting cerebrospinal fluid and/or the risks/consequences of the procedure	spinal tap	1103 Q240_P1 4109 Q240_P2b		
		prior knowledge-other prior knowledge	the participant has prior knowledge regarding other information or procedures that are not asked in this study				
		prior knowledge-nonspecific	the participant has prior knowledge regarding the extraction procedure used to obtain a biomarker sample, what the biomarker is, the purpose for collecting the biomarker and/or the risks/consequences of the procedure, but the participant does not explicitly state the biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
no previous knowledge on a subject or area	no prior knowledge		the participant states that they do not have any knowledge regarding what they are being asked to provide, give or contribute				
		no prior knowledge-questions	the participant has no prior knowledge regarding survey questionnaires or answering questions				
		no prior knowledge-saliva	the participant has no prior knowledge regarding the procedure used to extract saliva or what saliva is				
		no prior knowledge-blood	the participant has no prior knowledge regarding the procedure used to extract blood or what blood is	blood sample procedure	4109 Q230_P3b	“the drawing of the blood. And the tissue samples, I, I don't know anything about how they do that.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
no previous knowledge on a subject or area	no prior knowledge	no prior knowledge-tissue	the participant has no prior knowledge regarding the process with giving a tissue sample or what tissue is	tissue sample procedure	4109 Q230_P3b	“, the drawing of the blood. And the tissue samples, I, I don't know anything about how they do that.”	
					4109 Q240_P2b		
					4109 Q230_P1	“I'm not familiar with, uh, tissue studies.”	
		no prior knowledge-lumbar puncture	the participant has no prior knowledge regarding the process with giving a cerebrospinal fluid sample, lumbar puncture, spinal tap or what cerebrospinal fluid is				
		no prior knowledge-nonspecific	the participant has no prior knowledge regarding the process with giving a biomarker or what the biosample is, but the participant does not explicitly state the biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
depending on the circumstances or conditions the respondent places	depends		the participant explicitly states that their participation depends or relies on something else this includes the verb *depend(s)* and derivate words, “such as”, “unless” etc.…				
				reasons for sample collection	1102 Q220_P1	“depends on what they would be using the blood for, would determine if I would do it or not.”	
				utilization of sample	1101 Q220_P1	“it depends on what they would be using the blood for”	
				purpose of study	1101 Q230_P1	“Depending on what the research is for, and, and, what it's going to be used for.”	
				time availability of respondent	1102 Q230_P1	“giving saliva would take five seconds. Tissue sample, five seconds. Blood, 20 minutes. It all depends how much they wanted.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
depending on the circumstances or conditions the respondent places	depends			time availability of respondent	2105 Q200_P1	“time issue being a student. I'm always busy, have to be here, be there, so, uh, I may not have time to sit down and, uh, participate, but, uh, if I did have time, I would.”	
					3106 Q200	“it's how much time available. You know, how busy I am at the time that these studies are going on,”	
				depth of study	1103 Q200_P1	“it depends on how in depth”	
				location of study	1103 Q200_P1	“where it was”	
				of questions	1103 Q200_P1	“what they were”	
				aftermath of results	1103 Q200_P1	“wanted to do with the answers”	
				setting	2105 Q200	“depending on the setting”	
				timeframe	2105 Q200	“depending on the setting and the timeframe”	
				level of invasiveness	1106 Q230_P1		
				what tissue is	4107 Q230_P1		

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
needs more information	needs more information		the participant explicitly states that they are not informed, or that they need more information to make their decision on their likelihood of participating in medical research studies				
				reason for research study	1102 Q240_P1	“would have to know more about why I'm doing that.”	
				risks associated with procedures	1103 Q240_P1 4106 Q240_P2b		
				lumbar puncture	1106 Q240_P2a		
				reasons for sample collection	2101 Q210	“I would wanna know what it was for	
					2101 Q210_P2	“like I would wanna know what it's for”	
					2101 Q230_P3b	“Why are you studying us?”	
					4107 Q230		

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
skeptical	skeptical		the participant states that they are skeptical	skeptical	1102 Q210_P1	“it makes me very skeptical” Due to the skeptical views that the respondent has, she or he is less willing to participate	
					1104 Q200_P1	“I'd be kinda, you know, skeptical”	
				sketchy		“it's a little sketchy.” Therefore, this respondent is less willing to participate	

Concept	**Primary Code**	**Specification**	**Definitions**	**Examples**	**Caseids (for examples)**	**Notes**	**DG notes**
distrust or lack of trust	distrust		the participant states, hints at, or gives an example/scenario of lack of trust, regarding medical research				
		distrust-organization	the participant states, hints or gives a scenario in which they do not trust the organization that is conducting the research				
		distrust-researcher	the participant states, hints or gives a scenario where they do not trust the researcher conducting the research, collecting the biomarkers and the information being collected				
		distrust-specimen handling	the participant states, hints, or gives a scenario where they do not trust the process of specimen handling (i.e. their biosample being used for other reasons)				
				researchers	1102 Q240_P2a		
					1105 Q230_P1	Specifically with septic procedure	
				Personal/ personality	4107 Q240_P1		

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
trust	trust		the participants state, hint at or give a scenario or example of trust, regarding medical research studies				
		trust-organization	the participant states, hints or gives a scenario that they trust the organization that is conducting the research and/or collecting the biosamples				
		trust-researcher	the participant states, hints or gives a scenario that they trust the researcher who is conducting the research, collecting the biosample and the information being collected				
		trust-specimen handling	the participant states, hints or gives a scenario where they trust the process of specimen handling (i.e. the biomarker will only be used for the appropriate reasons				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
time commitment/ time issue	time		the participant states, hints at or gives a scenario in which the time required for the medical research study would be an issue				Some of the examples under unwillingness below could fall under this category if we do away with unwillingness
				Distance proximity	4109 Q200 (4)		
				Availability	3106 Q200 (4)		
					2105 Q200 (4)		
				Procedure time	1102 Q230_P1 (3)	Amount of time that it takes to obtain the sample; therefore, more willing to give a saliva and tissue sample because it takes a shorter amount of time than giving a blood sample	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
privacy and confidentiality	confidentiality /privacy		the participants express concerns over confidentiality and privacy regarding their personal privacy and biomarker samples				
		questions	the participant express concerns over confidentiality and privacy regarding their personal and sensitive information when answering questions for a medical research study	Saliva sample	1104 Q210_P1	"about the confidentiality"	
					1104 Q210_P2	"the privacy and the confidentiality" Due to concerns for the privacy and confidentiality of the sample, the respondent is less willing to participate	
				Blood sample	1104 Q220_P1	"confidentiality, not knowing where it might end up"	
				Personal privacy	1104 Q220_P2b	"about the confidentiality"	
					2103 Q210_P2	"it just seems more, um, well, very personal"	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
privacy and confidentiality	confidentiality /privacy	saliva	the participant express concerns over confidentiality and privacy regarding their saliva sample				
		blood	the participant express concerns over confidentiality and privacy regarding their blood sample				
		tissue	the participant express concerns over confidentiality and privacy regarding their tissue sample				
		cerebrospinal fluid	the participant express concerns over confidentiality and privacy regarding their cerebrospinal fluid sample				
		nonspecific	the participant express concerns over confidentiality and privacy regarding a biomarker sample, but the participants does not explicitly state the biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
nothing to hide	nothing to hide		the participant states that they have nothing to hide from the researchers and/ or research	nothing to hide	1108 Q200_P1	"I don't feel that there's anything wrong with my health that I should try to shield from anyone."	
					1108 Q230	"I don't have anything to hide"	
					1108 Q230_P1	"I don't feel I have anything to hide"	
					1108 Q230_P3b	"I don't feel that I have anything to hide."	
					4101 Q210_P1	"I don't have anything to hide"	
					4101 Q220_P1	"I don't have anything to hide"	
					4104 Q210	"I don't have nothing to hide."	
					4104 Q210_P1	"I don't have nothing to hide"	
					4104 Q210_P3	"I don't have nothing to hide, and I don't have nothing to be ashamed of."	
					4104 Q230_P1	"there's nothing to hide"	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
personality and attitude towards research	positive attitude		participants have positive and good thoughts, beliefs, values and feelings toward medical research studies, in general				
				believes in research	2101 Q210_P2	“do it if I believed in the research”	
					2101 Q220_P2b	“if it's something that I believe in, then I'm more likely to do it”	
					2101 Q230	“I would have to really believe in the study”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
valuable and important	importance		the participants express that they find value and importance in contributing or participating in medical research studies				
				minority groups	4102 Q200_P1	“I think it's important for us to gather as much information for that specific, uh, minority group”	
				information out there	1102 Q200_P1	“information should be out there”	
					1107 Q200_P1	“I think it's good to get the information out”	
					1107 Q230_P1		
				research is important, generally	4107 Q210_P3		
				give samples	1107 Q230_P3b		
					Tissue		
					1107 Q230_P3b		

blood

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
background/ culture	background /culture		participants state that they have personal, educational, or social experiences that are unique and would like for researchers to be aware of	background	1102 Q200_P1	“I came from a unique background”	Move it as a primary code over Background/ culture To incorporate both of these things in one code.
					2101 Q200_P1	“because I'm Native.”	
					2108 Q220_P2b	“on my mother's side, I'm Philippino, Chinese, and Spanish. On my dad's side, I'm French and Indian,”	
				culture	2106 Q200_P1	“have people learn about you and your culture”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
pain associated with procedure (s)	pain		participants express that there is physical discomfort associated with specific procedure(s) that are used to obtain the biomarker samples				
		pain-questions	the participant states that there is physical discomfort associated with being asked questions and providing answers				
		pain-saliva	the participant states that there is physical discomfort associated with collecting a saliva sample				
		pain-blood	the participant states that there is physical discomfort associated with collecting a blood sample				
		pain-tissue	the participant states that there is physical discomfort associated with collecting a tissue sample				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
pain associated with procedure(s)	pain	pain-lumbar puncture	The participant states that there is physical discomfort associated with collecting cerebrospinal fluid through a lumbar puncture/ spinal tap	associated with spinal taps	1107 Q240 1103 Q240_P2a 1106 Q240_P1 1105 Q230_P1	“I've heard spinal taps hurt really bad”	
		pain-nonspecific	The participant states that there is physical discomfort associated with the collection of a biomarker, but does not specifically states the biomarker associated with the physical discomfort				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
no pain associated with the procedure used to extract sample(s)	no pain		participants express that there is no physical discomfort associated with specific procedure(s) that are used to obtain biomarker samples				
		no pain-questions	the participant specifically states that being questioned or answering questions does not cause them any physical pain or harm				
		no pain-saliva	the participant specifically states that giving a saliva sample does not cause them any physical pain or harm				
		no pain-blood	the participant specifically states that giving a blood sample does not cause them any physical pain or harm				
		no pain-tissue	the participant specifically states that giving a tissue sample does not cause them any physical pain or harm	Giving tissue sample	1103 Q240_P2a	“I gave a sample of my tissue before and it didn't hurt”	
		no pain-lumbar puncture	the participant specifically states that giving cerebrospinal fluid or undergoing a lumbar puncture/spinal tap does not cause them any physical pain				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
no pain associated with the procedure used to extract sample(s)	no pain	no pain-nonspecific	the participant states that the procedure or sample that they are giving does not cause them any physical pain, but does not specifically state the procedure or sample that does not cause them pain				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
fear associated with the procedure(s)	fear		participants express that they are afraid or have unpleasant feelings towards certain procedures, tools/equipment perceived as necessary to extract the biomarker				
				needles	1102 Q240_P2a		
					4109 Q220_P2a	“I don't care for needles.”	
				unknown	4109 Q240_P1	“I've never been, uh, introduced to anything like that”	
				spinal tap	1103 Q240_P1		
					1103 Q240_P2a		
				getting hurt	1103 Q240_P1		
				receiving other diseases	1105 Q230_P1		

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
fear associated with the procedure(s)	fear			sample comparison	1108 Q210_P3	"if you take my DNA and stuff, you go be trying to compare it to somebody else's" Less likely to participate is samples are to be compared to other people	
		fear-questions	the participant states that they are afraid or have an unpleasant feeling in being asked question and/or answering questions				
		fear-saliva	the participant states that they are afraid or have an unpleasant feeling in giving a saliva sample				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
fear associated with the procedure(s)	fear	fear-blood	the participant states that they are afraid or have an unpleasant feeling in giving a blood sample				
		fear-tissue	the participant states that they are afraid or have an unpleasant feeling in giving a tissue sample				
		fear-lumbar puncture	the participant states that they are afraid or have an unpleasant feeling in giving a cerebrospinal fluid sample and/or undergoing a lumbar puncture/ spinal tap				
		fear-needles	the participant states that they are afraid or have an unpleasant feeling towards needles				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
fearless	no fear		participants express that they are not afraid of and/or have unpleasant feelings towards procedures, or tools/equipment used to obtain the biomarker sample				
		no fear-questions	the participant specifically states that they are not afraid of being asked questions or answering questions				
		no fear-saliva	the participant specifically states that they are not afraid of the procedure or giving a saliva sample				
		no fear-blood	the participant specifically states that they are not afraid of giving a blood sample	fearless of giving samples	3108 Q220_P1	“not afraid to give blood”	
				fearless of needles	2101 Q220_P1	“I just don't really care for needles”	
					3101 Q220_P2b	“needles almost never hurt me {L}, so it's not an issue with me.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
fearless	no fear	no fear-tissue	the participant specifically states that they are not afraid of giving a tissue sample				
		no fear-lumbar puncture	the participant specifically states that they are not afraid of the procedure, lumbar puncture, or giving a cerebrospinal fluid				
		no fear-nonspecific	the participant states that they are not afraid of giving a biomarker or going through with the procedure to obtain the biomarker, but does not specifically mention which procedure or which biomarker they are not afraid of participating in				
		no fear-needles	the participant expresses that they do not have an unpleasant or discomfort feeling towards needles				

Concept	**Primary Code**	**Specification**	**Definitions**	**Examples**	**Caseids (for examples)**	**Notes**	**DG notes**
procedure	procedure unknown		the participant feels that they are being subjected to an unknown procedure and/ or procedure with unknown outcomes, participant might have some knowledge of what the biosample is, but not know the procedure (site or method) in how the biosample will be obtained				
		procedure unknown-question	the participant feels that they are being subjected to an unknown procedure and/ or procedure with unknown outcomes, when answering questions	drugs	2108 Q200 3102 Q200_P1	“as long as it didn't involve testing drugs I knew nothing about.”	
		procedure unknown-saliva	the participant feels that they are being subjected to an unknown procedure and/ or procedure with unknown outcomes, when giving a saliva sample				
		procedure unknown-blood	the participant feels that they are being subjected to an unknown procedure and/ or procedure with unknown outcomes, when giving a blood sample				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
procedure	procedure unknown	procedure unknown-tissue	the participant feels that they are being subjected to an unknown procedure and/ or procedure with unknown outcomes, when giving a blood sample				
		procedure unknown-lumbar puncture	the participant feels that they are being subjected to an unknown procedure and/ or procedure with unknown outcomes, when giving a cerebrospinal fluid sample				
		procedure unknown-nonspecific	the participant feels that they are being subjected to an unknown procedure and/ or procedure with unknown outcomes, when giving a biomarker sample, but does not specifically state the biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
procedure it not dangerous	procedure not dangerous		participant express that the procedure does not pose a threat to them				
		procedure not dangerous-questions	participant express that answering questions does not pose a threat to them				
		procedure not dangerous-saliva	participant express that giving a saliva sample does not pose a threat to them				
		procedure not dangerous-blood	participant express that giving a blood sample does not pose a threat to them				
		procedure not dangerous-tissue	participant express that giving a tissue sample does not pose a threat to them				
		procedure not dangerous-lumbar puncture	participant express that giving a cerebrospinal fluid sample does not pose a threat to them				
		procedure not dangerous-nonspecific	participant express that giving a biomarker sample does not pose a threat to them, but does not specifically state that biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
	procedure dangerous		participant expresses that procedure(s) may cause them harm or injury if they were to participate	lumbar puncture/ Spinal taps	1105 Q240_P1	“they are too dangerous to, um, just to participate in a study.”	
		procedure dangerous-questions	participant expresses that by answering questions may cause them harm or injury if they were to participate				
		procedure dangerous-saliva	participant expresses that giving a saliva sample may cause them harm or injury				
		procedure dangerous-blood	participant expresses that giving a blood sample may cause them harm or injury				
		procedure dangerous-tissue	participant expresses that giving a tissue sample may cause them harm or injury				
		procedure dangerous-lumbar puncture	participant expresses that giving a cerebrospinal fluid sample may cause them harm or injury				
		procedure dangerous-nonspecific	participant expresses that giving a biomarker sample may cause them harm or injury, but does specifically state the biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
	procedure not difficult		the state, condition or situation that a participant finds the procedure to not be difficult, therefore, it is relatively easily done				
		procedure not difficult-question	the participant finds that answering questions is not difficult				
		procedure not difficult-saliva	the participant finds that giving a saliva sample is not difficult				
		procedure not difficult-blood	the participant finds that giving a blood sample is not difficult				
		procedure not difficult-tissue	the participant finds that giving a tissue sample is not difficult				
		procedure not difficult-lumbar puncture	the participant finds that giving a cerebrospinal fluid sample, or undergoing a lumbar puncture/spinal tap is not difficult				
		procedure not difficult-nonspecific	the participant finds that giving a biomarker sample is not difficult, but does not specifically mention the biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
procedure	procedure difficult		the state, condition or situation that a participant finds to be difficult or not easily done	Blood procedure	1101 Q220_P2a	"it would involve a needle. It would involve, uh, a little procedure not just a swab of saliva."	
		procedure difficult-question	the participant finds that answering questions is difficult				
		procedure difficult-saliva	the participant finds that giving a saliva sample is difficult				
		procedure difficult-blood	the participant finds that giving a blood sample is difficult				
		procedure difficult-tissue	the participant finds that giving a tissue sample is difficult				
		procedure difficult-lumbar puncture	the participant finds that giving a cerebrospinal fluid sample, or undergoing a lumbar puncture/spinal tap is difficult				
		procedure difficult-nonspecific	the participant finds that giving a biomarker sample is difficult, but does not specifically mention the biomarker				

Concept	**Primary Code**	**Specification**	**Definitions**	**Examples**	**Caseids (for examples)**	**Notes**	**DG notes**
procedure	procedure specimen handling		participants express concern over how their answers or samples will be cared for and /or used/handled	2102 Q220_P2b	“that my blood or saliva would be used in a proper way,”		
		procedure specimen handling-questions	the participant expresses concern over how their answers will be handled				
		procedure specimen handling-saliva	the participant expresses concern over how their saliva sample will be cared, handled or used				
		procedure specimen handling-blood	the participant expresses concern over how their blood sample will be cared, handled or used				
		procedure specimen handling-tissue	the participant expresses concern over how their tissue sample will be cared, handled or used				
		procedure specimen handling-lumbar puncture	the participant expresses concern over how their cerebrospinal fluid sample will be cared, handled or used				
		procedure specimen handling-nonspecific	the participant expresses concern over how their biomarker sample will be cared, handled or used, but the participant does not state the biomarker				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
benefits that are expected of medical research	benefit		the participants state that they are participating in the study because they expect and/or want something out of the medical research study				Some of the examples from willingness to participate might fall under this code
		benefit-personal	the participant describes the specific outcome(s) that they expect will benefit them personally by participating in the medical research study	personal gain information about health -self	4105 Q200_P1	“, I would like to know more about like if I get sick what things to take or stuff like that.”	
					1103 Q210_P1	“something that would benefit me”	
					1103 Q210_P3	“better my environment”	
		benefit- others	the participant describes the specific outcome(s) that they expect will benefit others, by participating in the medical research study	find answers	2104 Q200_P1	“find some answers for things,”	
				benefit everyone	2108 Q200_P1 2108 Q200 (5)	“benefit everybody”	
					4104 Q200 (5)		

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
benefits that are expected of medical research	benefit	benefit- others		benefit everybody	1103 Q210_P1	"something that would benefit me and the community, I would do it."	
					1107 Q230_P3b	"if I could be of any benefit"	
					2101 Q220_P2b	"and it would benefit, um, benefit, then, yes, I probably would."	
					2108 Q200_P1	"benefit everybody"	
					3102 Q220_P1	"be beneficial to other people"	
					3102 Q230_P1	"was benefiting, uh, other, other people"	
					41014 Q200_P1	"I think it's for everybody's"	
				beneficial	2103 Q210_P1	"I don't mind because it's good for, uh, for future for, um, for planning for other people's health and the overall picture"	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
benefits that are expected of medical research	benefit	benefit-others		help	1101 Q210_P3	“if it's for medical research and if the possibility that it would help someone else”	
					2106 Q200 (5)		
					1103 Q210_P3	“help out to the research”	
					1103 Q220_P1	“I like to participate”	
					1106 Q200_P1	“I'm always willing to help.”	
					1106 Q210_P1	“would go towards research in helping”	
				Save a life	1108 Q200	“likely if it was going to save someone's life”	
					3103 Q220_P1	“save, actually, somebody's life”	
				Good cause	1103 Q210_P1	“pretty likely if it was used for good purpose”	
					1106 Q200_P1	“if it's for a good cause”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
benefits that are expected of medical research	benefit	benefit- others		cancer study	2104 Q230_P1	"some kind of cancer"	
					2109 Q230_P1	"agent orange I got, that's a cancer-causing thing"	
					3107 Q220_P2b	"it's more research for cancer cells"	
		benefit-research	the participant states that they are participating in the medical research study because they expect their contribution(s) to help research (create new medication, treatments or find a cure)				
		benefit-questioning	the participant questions the population who will be benefiting from the research that is being done	Question the benefitting population	2101 Q230_P3b	"who is it benefitting?"	
				Benefit the native population	2101 Q230_P3b	"if it's going to benefit Native populations, um, I'm much more likely to do the study"	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
state of health	healthy		the participant mentions their state of health, as being fit or healthy				
		healthy-reason to participate	the participant mentions their state of health as an indicator as why they participate in medical research studies	Healthy	1108 Q200_P1	“I don't feel that there's anything wrong with my health”	
					3101 Q200_P1	“I don't have any problems in talking about my health”	
					4101 Q220_P1	“I'm in good health”	
					4103 Q220	“I don't have any diseases”	
					4103 Q220_P1	“I don't have no diseases”	
		healthy-reason to not participate	the participant mentions their state of health as an indicator as why they would not like participate in medical research studies				

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
state of health	unhealthy		the participant mentions their state of health, as not being fit or healthy				
		unhealthy-reasons to participate	the participant mentions their state of health as an indicator as why they participate in medical research studies				
		unhealthy-reasons to not participate	the participant mentions their state of health as an indicator as why they would not like participate in medical research studies		4103 Q210_P1	“I'm not at all in good condition. I don't want to get other people sick”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
comparison	comparison		the participant states a similarity or dissimilarity between two or more biomarkers, procedures and/or risks/consequences associated with the procedure used to extract the biomarker				
				Saliva vs. Blood; personal	1101 Q220_P2a	"blood is a little bit more personal to give"	
				Level of difficulty	1101 Q220_P2a	“it would involve a needle. It would involve, uh, a little procedure not just a swab of saliva.”	
					1102 Q230_P1	“saliva is a very easy thing”	
				Level of risks associated	1102 Q240_P2a Less risks involved with saliva and tissue compared to blood and cerebrospinal fluid		
				Type of sample	1103 Q230_P1	“tissue probably, sample will probably give you a lot of insight on the person that you're interviewing or testing or what, so.”	

Concept	Primary Code	Specification	Definitions	Examples	Caseids (for examples)	Notes	DG notes
actively/ currently participating	current participation		the participant specifically states that they are currently participating in the research study or question whether it is not what they are already doing, participating or the participant states that they are willing to contribute the biomarker in question because it is part of the current research study				

APPENDIX F

ADDITIONAL TABLES

Table. Prior knowledge by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	3	28	13	31	28
56+	0	9	9	19	47
Gender					
Male	3	25	13	28	31
Female	0	13	9	22	44
Race					
African American	0	13	19	44	34
American Indian	0	38	0	19	50
Caucasian	6	13	13	25	31
Latino/a	0	13	13	13	31
Education					
High School or Less	0	13	13	23	29
Some College or More	3	24	9	27	45

Table. Previous experience by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	3	3	9	7	25
56+	13	9	16	7	13
Gender					
Male	3	6	6	9	16
Female	13	6	19	3	22
Race					
African American	0	0	6	0	31
American Indian	19	13	19	19	19
Caucasian	0	13	6	6	13
Latino/a	13	0	19	0	13
Education					
High School or Less	10	9	13	6	26
Some College or More	6	3	12	6	12

Table. Benefit by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	19	9	28	19	19
56+	19	25	16	9	13
Gender					
Male	22	6	19	13	6
Female	16	28	25	16	25
Race					
African American	13	31	38	13	0
American Indian	25	13	0	19	31
Caucasian	13	13	31	19	19
Latino/a	25	13	19	6	13
Education					
High School or Less	19	10	23	16	16
Some College or More	18	24	21	12	15

Table. No prior knowledge by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	---	---	---	13	0
56+	---	---	---	9	6
Gender					
Male	---	---	---	6	3
Female	---	---	---	16	3
Race					
Black	---	---	---	6	6
American Indian	---	---	---	6	0
White	---	---	---	13	0
Latino/a	---	---	---	19	6
Education					
High School or Less	---	---	---	10	3
Some College or More	---	---	---	12	3

Table. Procedure unknown by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	3	3	---	9	3
56+	0	0	---	13	0
Gender					
Male	0	3	---	6	3
Female	3	0	---	16	0
Race					
Black	0	0	---	6	0
American Indian	0	0	---	6	0
White	0	6	---	19	0
Latino/a	6	0	---	13	6
Education					
High School or Less	0	0	---	6	0
Some College or More	3	3	---	15	3

Table. No previous experience by Age, Gender, Race and Education for Probe 1 Question

	Probe				
Characteristics	Q200	Q210	Q220	Q230	Q240
Age Groups					
30-55	---	---	---	0	6
56+	---	---	---	3	6
Gender					
Male	---	---	---	0	9
Female	---	---	---	3	3
Race					
Black	---	---	---	0	6
American Indian	---	---	---	0	0
White	---	---	---	6	13
Latino/a	---	---	---	0	6
Education					
High School or Less	---	---	---	3	3
Some College or More	---	---	---	0	9

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