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An abstract of
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Abstract

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Genomic research holds many potential benefits for advancing clinical care, improving disease detection, and more. However, a significant underrepresentation of minority populations in genomic studies has resulted in limited applicability of genomic research findings. This underrepresentation stems from a variety of factors, including systemic racism, historical abuses, and a lack of knowledge/understanding about the benefits of genomic research, each contributing to skepticism and mistrust among minoritized communities. This study explores the role of trust in shaping college students' motivations and attitudes on participating in genomic research, with a large focus on historically underrepresented demographic populations. Through a hybrid deductive and inductive qualitative analysis of focus group interviews, this research found several key themes relating to trust that were discussed in interviews.

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Section I: Introduction

Ethical Dilemma in Genomic Research

The potential benefits of genomic research are numerous, including enhanced clinical care, early detection and treatment of diseases, and more effective treatments (Fatumo et al., 2022). However, a vast majority of genomics study participants are individuals of European descent and there is a significant underrepresentation of minority populations in genomic studies. As of 2021, 86.3% of individuals included in genome wide association studies were of European descent, compared to 5.9% East Asian, 1.1% African, 0.8% South Asian, and 0.08% Hispanic/Latino participants (Fatumo et al., 2022). Some reasons for the lack of inclusion of minoritized groups may include: systemic racism, historical abuses, and lack of knowledge on the benefits of this research (Lemke et al., 2022).This lack of diversity limits the applications of genomic research findings to non-European populations, thus excluding minority groups from the benefits of genomic research, such as improved clinical care, improved understanding of disease etiology, earlier diagnoses, and enhanced drug design. Further, this underrepresentation may hinder the discovery of population-specific clinically significant variants only discovered in understudied minority populations, highlighting the issue's reach that goes beyond strictly minority populations (Fatumo et al., 2022). For these reasons, a more nuanced understanding of peoples' views on genomic research may inform future recruitment efforts that focus on inclusivity in genomic research studies. Given the ethical and practical importance of diversifying genomic study participants, understanding how trust operates within marginalized communities is essential for developing culturally appropriate recruitment strategies and improving retention rates.

Evidence of Racism in Science

Considering the landscape of racism that backdrops genomic research is critical in understanding the inequities in genomic research and developing culturally appropriate recruitment and retention strategies. Racism is defined as an organized social system in which people are categorized by race and are prejudiced and systematically disadvantaged on this basis (Bonilla-Silva, 1997). Racism as a structure system then interacts with and is interdependent with other social institutions (i.e. healthcare systems, research institutions), reinforcing and perpetuating a racial hierarchy (Reskin, 2012). Scientific research, shaped by the structure system of racism, has historically perpetuated racial biases and injustices, exemplified in numerous situations.

Scientific Racism. Scientific racism is defined as a "historical pattern of ideologies that generate pseudo-scientific beliefs" (*Scientific Racism*, n.d.). Additionally, eugenics is the inaccurate theory that humans can be improved through selective breeding (*Eugenics and Scientific Racism*, n.d.). Though these pseudoscientific beliefs have been disproven, there is evidence of the persistence of scientific racism in research today. This includes the "belief that differences in disease outcomes are due to genetic differences between racialized groups" (Opara et al., 2022). The tragic legacy of scientific racism persists today, contributing to a potential skepticism and mistrust toward scientific institutions.

The Eugenics Movement. Eugenics is the scientifically erroneous and unethical theory of "racial and human improvement" which gained popularity alongside the ideology of scientific racism in the early 20th century (*Eugenics and Scientific Racism*, n.d.). Eugenicists deemed individuals, populations, and nations as inferior or superior based on biological and behavioral characteristics. This led to tragedies such as eugenics-based restrictions on immigration and involuntary sterilization of women of color and poor women deemed “unfit” (Chatters et al., 2022).

Tuskegee Syphilis Study. The United States Public Health Service (USPHS) Syphilis Study at Tuskegee University represents one of the most infamous examples of racism in science. This study aimed to “record the natural history of syphilis in Black people” and was titled “Tuskegee Study of Untreated Syphilis in the Negro Male.” (*About the USPHS Syphilis Study | Tuskegee University*, n.d.). Participants were misled and denied treatment, despite penicillin's newfound effectiveness and availability as a cure. The Tuskegee Syphilis Study remains in the minds of many African Americans today who voice concerns of mistrust in regard to research participation (Scharff et al., 2010).

Lasting Effects of Race. Although race emerged without a firm scientific foundation as a sociopolitical construct in part to justify the exploitation of groups deemed inferior, its legacy is an important predictor of societal rewards and a determinant of variations in health (Williams et al., 2019). Its lasting social implications have shaped people’s lives, from poor health outcomes, systemic inequities in access to resources, disproportionate exposure to environmental stressors, and disparities in medical care. These social determinants are intertwined with genomic research, further underscoring the necessity to extend the benefits of genomic research to those who have been historically underrepresented.

The effects of systemic racism extend beyond historical examples of injustices, and there is evidence that they may contribute to disparities in health care and outcomes today. However, by the time that is often takes for evidence of health damages to show, it is often difficult to decipher relevant implications and solutions (Braveman et al., 2022). Death rates from cancer, heart disease, and diabetes are significantly higher in ethnic minorities, and racial disparities in health care exist even when insurance status, income, age, and severity of conditions are similar (Nelson, 2002). Cultural context and systemic racism affect health in a number of ways, including driving societal policies that maintain inequitable structures, individual level unconscious biases, and stereotype threat (Williams et al., 2019).

This historic backdrop of scientific racism contributes to an environment that may lead to skepticism and mistrust among minority groups that persists today, which is seen in genomic research and is thus imperative to consider in scientific research. The history of the Eugenics movement, the Tuskegee Syphilis Study, and the enduring health disparities among racial/ethnic groups underscore the impact of racism in science. A study by the University of Georgia found that Black Americans living in Tuskegee, Alabama, were much slower to get their COVID-19 vaccines compared to white neighbors (Hou et al., 2024). Additionally, another study found that Black and Latino individuals are less likely to use genetic testing than non-Hispanic white individuals due to various barriers including disproportionate lack of knowledge or information provided by their physicians about genetic testing (Suther & Kiros, 2009).

Scientific Advancements/Efforts to Address Diversity Issue

In years following the Human Genome Project, a landmark scientific effort aiming to map and sequence the entire human genome, researchers found that genome sequences of human populations have changed significantly over time and that enough variation exists between populations groups that just a few genomes alone cannot represent global genetic diversity (*Participation in Genomic Research*, n.d.). To address this bias, the National Human Genome Research Institute funds the Human Pan Genome Reference Program to prioritize sequencing and assembling genomes from individuals of diverse populations. Efforts to reduce biases/underrepresentation in genomic research include genome-wide association studies (GWAS), and large representative data sampling approaches. Another effort to address this issue is through biobanking, in which large collections of biospecimens linked to relevant personal and health information are held. These samples can then be later used for facilitating access to underrepresented populations in research studies, instances where recruitment might not lead to an ideal diverse sample scenario. Biobanks and biorepositories serve as an effective means to increase diversity of ancestries in the genomic sample pool, and move toward a more accurate interpretation of the whole genome, establishing incidence of genetic variants across populations (Cohn et al., 2015). However, the current availability of genomic samples in biobanks remains predominantly of European ancestry, underscoring and circling back to a necessity for targeted recruitment of diverse individuals willing to donate genomic samples (Carress et al., 2021). Though there is evidence that suggests a high interest in returning information collected from genomic research samples to original participants, which may increase participation rates in genomic research (Vears et al., 2021), the problem with this strategy is that this is often cost-intensive, potentially inhibiting important research progress (Bledsoe et al., 2013). Another method of addressing inequities in genomic research is through increasing knowledge on genomic research, highlighted in the comprehensive measure of knowledge about genomic sequencing - the University of North Carolina Genomic Knowledge Scale (UNC-GKS) (Langer et al., 2017). However, a past study on issues of informed consent and subject motivation to participate in a large, population-based DNA research bank found that while most participants understood the overall goals of the project, many were uncertain about key details including duration of participation in the study, the fact that their DNA would be stored, and more (McCarthy et al., 2006). Genomic data sharing and privacy is complex, identifying, and enduring, presenting limitations and challenges for research participants and for researchers (Horton & Lucassen, 2023). These findings suggest that gaps in knowledge may further contribute to hesitancy amongst potential participants. As the field of genomics continues to work toward including a broader diversity of research participants, it is important to consider the factors that may deter individuals from participating in genomic research. This may benefit through examining this issue through the lens of trust. In a study on assessing trust in genomic data sharing among members of the general public in the UK, USA, Canada, and Australia, participants were most likely to trust their personal medical doctors, and least likely to trust company researchers (Milne et al., 2019). Several other studies identified trust as a critical influence on whether or not individuals would want to participate in genomic studies (Atutornu et al., 2022; de Vries et al., 2014; Milne et al., 2019, 2021; Passmore et al., 2020; Savić-Kallesøe et al., 2021; Ursin et al., 2020).

Protecting and Shaping Public Perception of Human Subjects Research: The Role of Trust

As a result of the National Research Act of 1974 and recognizing that science exists in a world fraught with a myriad of opinions and motivations for conducting research, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was established to protect the rights and wellbeing of human subjects involved in research conducted or supported by the U.S. Department of Health and Human Services (Protections (OHRP), 2010). Current human research practices in the U.S. are guided by ethical principles that emerged from the Belmont Report of 1976. The Belmont Report is a set of ethical principles that guide research involving human subjects and encompasses three dimensions that shape perceptions of trust. Overall, these activities in the U.S. have shaped perception of trust surrounding human research in serving as a reference for institutional review boards, helping to resolve ethical issues in human subjects research, and increasing the ethical standards set (*Genetic Information Nondiscrimination Act of 2008*, n.d.).

Trust plays an influential role in determining whether individuals feel secure in sharing sensitive genomic information with researchers (Atutornu et al., 2022). For example, trust resulting from inclusivity with the community under study, such as the extent that they are involved with the study and planning (i.e. are they stakeholders, do they have a direct benefit from the study, do they contribute and to what extent, how much are they informed, etc.) (Erlich et al., 2014). Further, when working to understand barriers to equity in research, trust is a critical component that often comes up (Bentley et al., 2017). In the context of understanding how trust influences participation in research studies, particularly among groups historically marginalized in scientific studies (Bentley et al., 2017), further understanding of the role of trust in the decision to participate in genomic research is crucial.

There is contradicting research relating to the role of trust/distrust in genomic research participation. For example, one study found that a majority of participants stated a willingness to participate in genomic research, distrust did not emerge as a dominant theme among participants, and that this willingness did not differ between patients based on racial demographics (S. Sanderson et al., 2013). Conversely, other studies find distinctions, particularly finding that non-Hispanic White people were significantly more likely than ethnic minorities to enroll in a biobanking study (Ridgeway et al., 2013), and that African Americans have expressed significant distrust surrounding discussions on biobanking participation (Halverson & Ross, 2012). Mistrust of researchers and research institutions may also be a notable barrier to research participation among African Americans (Halverson & Ross, 2012). For this project, trust was selected as the lens to analyze participant responses due to the sensitivity of genomic data as well as the legacy of systemic racism and unethical research practices.

The college student demographic is an interesting and important population to study due to the changes that come with this unique developmental period (Dahl, 2004; Evans et al., 2016). This period transitioning between impressionable adolescent to a young adult come with changes in neural systems of emotion and motivation, presenting an interesting population to study in this research context (Dahl, 2004).

Some past efforts to include college students in genomic research include allowing students to analyze personal genomic data via direct-to-consumer (DTC) genomic testing, in which users have in vitro diagnostics advertised to them directly and receive their results directly without the mediation or consult of health professionals (Research, 2023). This has shown resulting increased motivation and interest to learn about one's own genetic information, enhanced learning experience, and greater capacity for informed decision-making (S. C. Sanderson et al., 2013). However, these initiatives have raised several ethical concerns regarding classroom privacy, informed consent, some students reported a negative emotional impact related to regret, physiological distress, and uncertainty (S. C. Sanderson et al., 2015). This seemed to have been preceded by "experiencing conflict around the decision regarding whether to analyze their own genome in the first place and compounded by discovery of a variant of unknown significance several months after completing the course" (S. C. Sanderson et al., 2015). Relatedly, the California Department of Public Health opposed the University of California, Berkely's direct-to-consumer initiative, on the basis that students should not have been given access to test results (Sanders, 1 C.E.).

There is a gap in research involving American college students, particularly those from historically underrepresented groups in genomic studies. While previous studies have targeted specific subpopulations of college students studying genomics when implementing genomic testing in curricula, often excluding the broader college demographic and limiting generalizability (S. C. Sanderson et al., 2015). The present study addresses this limitation by intentionally recruiting a diverse group of college students from various majors and ethnic backgrounds, emphasizing the importance of unique perspectives and aiming to offer a more comprehensive and inclusive understanding of genomic research participation.

Research Goals

The goals of this study are to further the understanding of perspectives regarding the decision surrounding participation in genomic research, with a particular focus on historically underrepresented groups (African Americans, Asians, Hispanics/Latinos) and the role of trust in shaping these perspectives. Specifically, this project aims to:

1. Compare and contrast existing themes of trust in genomic research in literature (*a priori)* with emergent insights from the current focus group interviews.
2. Conceptualize trust by identifying and examining trust-related themes within the context of the focus group discussions.
3. Examine how trust-related themes from Aim 2 may influence motivations and decision-making regarding participation in genomic research in the broader context of the focus group interviews.

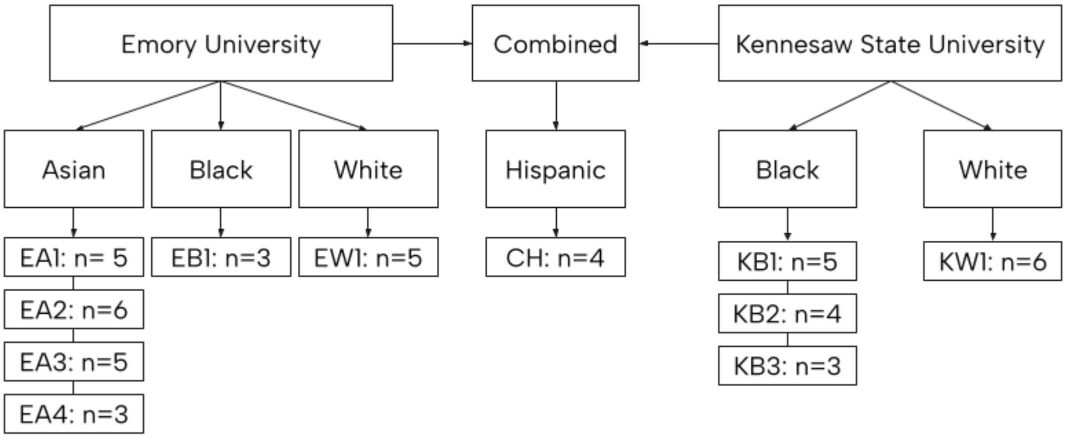
Section II: Method

Participants

The project used interview data transcripts and audio recordings collected from virtual focus groups of college students aged 18-25 at Emory University and Kennesaw State University from September 2020 to December 2020. These focus groups were conducted in the Behavioral Genetics of Addiction Laboratory at Emory University to study motives to participate in genetically focused research studies. A diverse group of students were intentionally recruited, prioritizing recruitment of historically underrepresented minority groups. Focus groups were employed to get student reactions to presented ideas on biobanking and volunteering genomic research, to stimulate discussions between participants grouped by race and school and explore similarities and differences in opinions among the groups (Bernard et al., 2017).

There were a total of 11 focus group interviews total with 49 participants across all groups were collected across Emory University and Kennesaw State University. Figure 1 depicts a breakdown of participant racial demographics within focus groups, and an overview of the populations analyzed in this study.

Figure 1. *Visual organization of focus groups.*



Note. Figure provides visual organization of focus groups depicting the number of participants in focus group interviews and breakdown of participant racial demographics. Abbreviations indicate Institution in first letter (E for Emory, K for Kennesaw State, and C for Combined Emory University and Kennesaw State University), Racial Demographic for the second letter (A for Asian, B for Black, W for White, H for Hispanic), followed by numeric designations within racial demographic groupings.

Focus group interviews were semi-structured in nature, with open-ended questions supplemented by follow up questions, clarifications, probes, and comments by interview moderators (DeJonckheere & Vaughn, 2019). These interviews consisted of open-ended questions to assess participant attitudes, opinions, and expectations on the topics of "Genomics", "Biorepositories/Biobanking", and 'Incentivizing Research".

Analytic Procedure

A mix of qualitative methodologies were employed in a hybrid approach to guide the analysis, namely template analysis, codebook thematic analysis, and reflexive thematic analysis. This hybrid approach complemented research aims through allowing for guidance and direction from existing literature through deducing *a priori* themes prior to coding, then allowing an inductive exploration of new potential themes through a data-driven thematic analysis approach (Fereday & Muir-Cochrane, 2006). *A priori* themes were identified prior to coding and were informed by existing literature on trust, systemic racism, and the historical context of participation in genomic research, and organization was emphasized through utilizing a codebook (Brooks et al., 2015). Thematic analyses were guided by Braun and Clarke's works for thematic analysis (Braun & Clarke, 2006) (Braun & Clarke, 2021). Through thematic analysis, we allowed for a line by line open coding to allow data to speak and explore ideas that did not necessarily come up in literature review (Braun & Clarke, 2021). Reflexive thematic analysis was beneficial for the independent research nature of this project through emphasizing the subjective skills of the researcher without the requirement of a research team for quality (Braun & and Clarke, 2021). Further, through this data-driven approach, there is opportunity for exploration of themes that bear little relation to the specific questions that were asked in the interview, relating to the post-hoc analysis nature of this project, as there was no discussion question explicitly addressing the idea of trust (Braun & and Clarke, 2006).

This study was grounded in a constructionist epistemology, in which meaning and experience were assumed to be socially produced, seeking to theorize the sociocultural context and structural conditions that lead to the accounts shared in the focus groups (Braun & and Clarke, 2006). The socially constructed nature of meaning and identity are shaped by the context of systemic racism and historical abuses (along with many other forces), which may then contribute to mistrust among underrepresented minority groups in genomic research. Within this framework, the recurrence of themes was not assumed to indicate importance, but instead prioritizes a deeper interrogation of the data to uncover meanings (Byrne, 2022).

A critical orientation to the data guided this study, focusing on how social structures and power dynamics influence individual experiences and perceptions of research. This approach aimed to uncover hidden meanings and inequalities embedded in the data, particularly in the context of trust and participation in genomic research.

Latent meanings were coded for, as patterns and underlying meanings in participant discussions on trust and motivations for participating in research were a focus. This allowed the study to explore the contextual and multifaceted nature of trust, which has often been discussed but rarely fully conceptualized in this context.

Phase 1. Familiarization of the Data: The MAXQDA software was used to analyze all focus group interview data (MAXQDA (Version 20)). Initially, a familiarization process was conducted, where the automated transcripts were imported into MAXQDA and cross-referenced with the audio recordings to address typos/missed words and phrases. Further, any transcripts that revealed identities of participants (i.e. aliases, etc.) were adjusted with aliases to maintain anonymity. As the data was already collected at the beginning of this project, all of the eleven transcripts were reviewed in this manner, with brief notes being collected along the way. Although this project focuses on the biobanking/ biorepository questions, the entire focus group interview was reviewed in this first read over.

Phase 2. Initial Coding Phase: Identification of *a priori* themes accompanied an open-coding approach in accordance with Braun & Clarke's thematic analysis was used to highlight and memo quotations that seemed relevant, especially in the context of the research question. A codebook was also utilized to organized themes, guided by template analysis recommendations. Instances of the word "trust" used were organized into a code as well, and words and phrases that were used to conceptualize trust-related ideas in the context of trust were coded to be analyzed later in accordance with the research goal of understanding how focus groups conceptualize/define "trust".

Phase 3. Reviewing Candidate Themes: A priori themes and the initial open-coding of transcripts were organized into candidate themes, visualized through a map. Provisional candidate themes were then reviewed and reassessed for fit to the data and viability to overall analysis accompanied by a second read through of transcripts (Braun & Clarke, 2021).

Phase 4. Refining and Defining Themes: Themes were then refined, defined, and named through a write-up of brief synopsis and creating names (Braun & Clarke, 2021).

Section III: Results

Research Goal I: Comparing and Contrasting Existing *A Priori* and Emergent Themes Relating to Trust

A Priori Candidate Themes

A portion of the literature review was dedicated to identifying and organizing *a priori* themes that guided the analysis of focus group interviews. Past research has explored various factors influencing trust in scientific and medical related research, particularly in the context of genomic studies. The following themes were drawn from existing models in the literature, and findings prior to delving into the current focus group interviews, serving as a foundation for analyzing college students' perspectives. Key ideas and potential/candidate themes from literature which guided the creation of the first version of the codebook were:

Transparency encompasses several dimensions, including who will access and use genomic data, how the data will be used, and who benefits from such research (Milne et al., 2021). Further, participants in genomic studies often express concerns about receiving transparent communication regarding genomic data control, privacy, and long-term use, particularly regarding potential secondary uses of their genomic information from biobanks without consent (Erlich et al., 2014). Transparency may also involve providing individuals with access to their own genomic data and ensuring clarity about whether their information will remain anonymous.

Overall, a lack of transparency has been identified as a leading factor in distrust and reluctance to participate in biobank research (Ursin et al., 2020).

Return of Results. The expectation of receiving personalized genomic findings is a significant motivator for some participants, however, there are some ethical concerns and implications of receiving uncertain or distressing results. The literature suggests that returning results can enhance participant trust when done responsibly and ethically (Vears et al., 2021). However, concerns may arise when results are not returned, overly complex, or are not communicated transparently, potentially contributing to distrust. Some participants expressed a desire/interest to receive personal health information from their participation.

Personal Experiences and Motives. An individual's prior personal experiences with healthcare, research institutions, and personal health concerns play a critical role in shaping their willingness to participate in genomic research. Studies show that those who have had positive interactions with medical and research institutions are more likely to trust the research process, whereas individuals with negative healthcare experiences or systemic discrimination may hesitate to engage (Milne et al., 2021). Participants also weigh personal benefits, such as potential health insights, against perceived risks when deciding whether to contribute their genomic data. Individual/personal experiences with healthcare, research, or personal/family history with genetic conditions were mentioned as playing a key role in several participants' willingness to engage with genomic studies.

Historical and Cultural Context. Trust in research is strongly influenced by historical and cultural factors, particularly for marginalized communities. Historical abuses, such as the Tuskegee Syphilis Study, have fostered deep-rooted distrust in medical and genomic research, especially among racial and ethnic minority groups (Bonilla-Silva, 1997; Reskin, 2012). Cultural norms and varying perspectives on genetic determinism, biomedical ethics, and communal versus individual decision-making further shape attitudes toward genomic research participation. The history of unethical research practices, particularly within marginalized communities, was acknowledged as a continued source of distrust for many participants. Some participants referenced cases such as the Tuskegee Syphilis Study or concerns about exploitation in medical research from a lens of justice. Further, some participants expressed not wanting to contribute to research participants did not agree with, which was also brought up in discussions.

Justice and Marginalization. Ethical concerns surrounding justice and equity in genomic research are especially relevant for marginalized and underrepresented groups. Participants may question whether research benefits all communities equally or if it primarily serves wealthy, privileged, or predominantly White populations (Milne et al., 2021). Some express concerns about structural inequalities in healthcare and research, fearing that their genomic data might be used without yielding direct benefits for their communities.

Commercialization and Economic Profit. One concern regarding genomic research participation is the potential commercialization of genetic data. Many individuals are wary that their genomic information could be sold for profit without their knowledge or consent (Erlich et al., 2014). For example, biobank participants who later discover their data have been used in commercial ventures may lose trust in the research process (Ursin et al., 2020). This highlights the need for clear policies on profit-sharing, ethical data use, and corporate involvement in genomic studies. This may also relate to private non-research companies who collect genomic information.

These *a priori* codes/themes were accompanied by a preliminary read through of the focus group transcripts. This initial interaction with the transcripts aided version I of the codebook.

Emergent Candidate Themes from Open-Coding Analysis

The following themes were not anticipated initially through the literature review and *a priori* theme development, but became evident through open coding of transcripts:

Confidence in Deidentification. Participants expressed concerns about whether their genetic data could be truly anonymized and whether it could be traced back to them in unintended ways.

Mistrust of the Unknown. Many participants were hesitant due to a general lack of understanding of genomic research and how their data might be used.

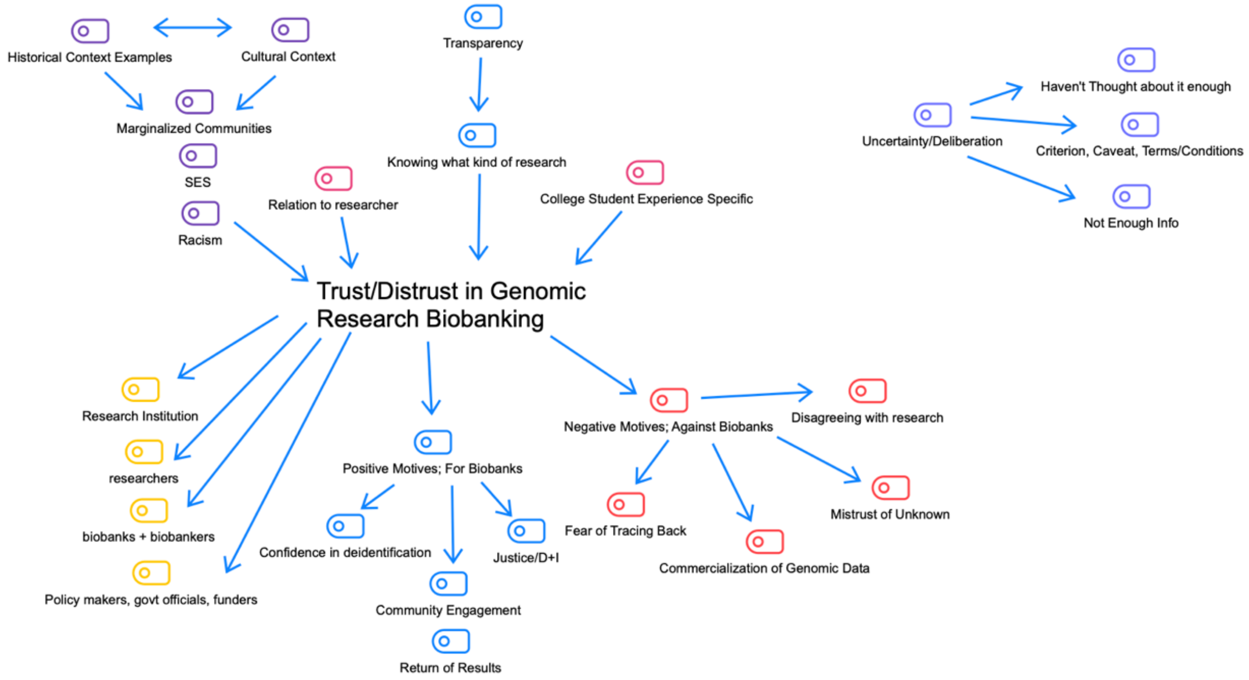
Uncertainty & Deliberation. Some participants were uncertain about their stance on participation, often because they had never been exposed to these questions before. Deliberation overlapped often with **Criterion, Caveat, Terms/Conditions,** as participants weighed in on specific conditions that would need to be met in order to decide to participate.

Ethics & Religious Beliefs. A few participants framed their concerns around ethical considerations or religious perspectives on genetic research and data sharing.

College-student-specific experience emerged as a potential theme. Given that college students represent a unique population with varying levels of exposure to research, institutional trust, and educational backgrounds, their trust-related concerns may differ from those of the public.

Further, college students are a unique population for increased susceptibility to risky behaviors and substance use, tying into the relevance for the MAPme study.

Figure 2. *Preliminary Organization of Initial Codes*



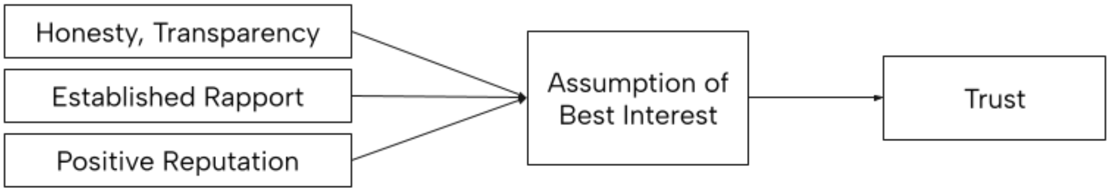
Note. Figure depicts a map organizing initial codes from first pass at coding transcripts. In this first version of the codebook, 37 different codes were organized into potential themes and subthemes.

Research Goal II: Conceptualizing Trust-Related Themes in Focus Group Interviews

Through focus group interviews, trust was expressed as an influential factor in decision-making on whether to participate in genomic research and biobanking. Though none of the discussion questions mentioned the word trust, the explicit use of the word "trust" (including contexts such as “mistrust”, “trustworthiness”, etc.) was mentioned 34 times across 10 of the 11 transcripts (all except for KSU Black #1). In the Emory Asian #3 transcript and Combined Hispanic transcript, “trust” was brought up by the moderator as a response to participant. In Emory Black #1 and KSU Black #2, “trust” was brought up by the moderator, but in response to participants bringing it up first and asking participants to expand on statements. In all other transcripts, “trust” use was introduced to the discussion candidly/naturally by participants in the context of the conversation.

In working to address aim 2 of this project, participant responses containing this explicit use of the word “trust” and relevant dialogue surrounding these responses were isolated and analyzed inductively, focusing on how it is participants were conceptualizing and defining the word “trust” in this genomic research participation context.

Figure 3. *Conceptual organization of trust themes surrounding “trust” use instances.*



Note. Participants conceptualized the opposing “Distrust” and “Inability to Assume Best Interest” similarly, mirroring themes of "dishonesty, deception; lack of rapport; negative reputation.

Table 1. *Table of subthemes surrounding conceptualizing trust with exemplary quotes for both “trust” and “distrust” discussion instances.*

Theme	**Trust Exemplary Quote**	**Distrust Exemplary Quote**
Transparency/ Honesty	“Moderator: is it is there, something that you don't trust about research or	“…**Like yes researchers can be transparent, but it's just like they**

	what in specific would deter you from having your de-identified information stored? Yellow Lion: **I’d just want to know what it's going to be used for honestly.** And just being told up front, or just along the way… honesty I guess.” Yellow Lion (Emory Asian 3)	**can still lie and deceive you.** So it's just like, regardless, like you can ask for all the facts, but they may not give you all the facts, so I think it's just like at the end of the day, I think, giving them, just like. What has happened, I think it just kind of just provides this like natural like apprehension and like distrust, so I think I would be like less inclined to provide like a DNA sample.” (Emory Black 1)
Rapport/ Relationship	“I definitely felt like the only reason I was able to feel comfortable donating blood for a research, study was because the person who was conducting the research was also providing me medical care so. I think. **I guess I had that trust already with them**.” (Emory Asian 1 Speaker: Steve)	Sorcha 1: “**I would feel a little bit uncomfortable. I would have to** check out the lab and talk to the doctors and basically **establish kind of trust.**” (KSU Black 2) “If I have a **good faith in our organization and trust in them**, then I’ll trust future researchers from the organization to test the same sample. (Combined Hispanic)
Reputation	“For me it's just knowing where the studies being conducted like if there was a way for people to opt in to receive alerts from a particular organization that way, you'd know it was a trusted study. **Like Emory has a good reputation in Atlanta.**” (KSU White 1)	“**I do not have complete trust and review boards and scientists**, because they are scientists. I think, like **through history, we can see a lot of examples of research being distorted.** And just false conclusions being drawn on like scientific data I wouldn't want to be part of any studies if they save my DNA that.” Emory White NH 1, Speaker: Coconut)

Note. Table expands on trust-related themes identified in Aim 2. Themes, which represent the contributing considerations that participants expressed shaped their ability to assume best interest and trust, are shown in the left column. The middle column provides exemplary quotes for trust instances, while the right-most column provides exemplary quotes for distrust instances.

1. **Transparency/Honesty**

   Participants emphasized the importance of clear communication by researchers in aiding their understanding how their genomic data would be used. Ideas of communication through honesty and transparency were discussed as influential in determining ability to trust researchers and institutions. Trust was communicated in contexts where researchers would provide clear and continuous information about the purposes of data collection, study aims, and future applications. Participants often brought up questions/concerns such as: What future research studies will involve my data? Who will have access to it? Will I receive any results in return? To what extent can I control/consent to how my data is used in future studies? Even when transparency was present, some participants expressed potential concern that researchers may selectively withhold critical information or deceive research participants. For example, one participant in the Emory Black 1 Focus Group noted, “Like yes researchers can be transparent, but it's just like they can still lie and deceive you. So, it's just like, regardless, like you can ask for all the facts, but they may not give you all the facts, so I think it's just like at the end of the day, I think, giving them, just like. What has happened, I think it just kind of just provides this like natural like apprehension and like distrust, so I think I would be like less inclined to provide like a DNA sample”, which exemplifies this concern.

2. Rapport/Relationship

For some participants, having some sort of built relationship/rapport with the researchers was expressed as an influential factor in building trust. Trust in research was often linked to having personal connections and previously established relationships that contribute to the ability to assume best interest. Having direct interactions with researchers and the opportunity to speak with them about specific study details and any concerns eased many participants' hesitation or unease. This theme was encapsulated in a participant in the Kennesaw State University Black 2 Focus Group who stated they would initially "feel a little bit uncomfortable. I would have to check out the lab and talk to the doctors and basically establish kind of trust." Similarly, a participant from the Combined Hispanic Focus Group explained, "If I have a good faith in our organization and trust in them, then I'll trust future researchers from the organization to test the same sample. Alternatively, not knowing researchers and a lack of established rapport made several participants hesitant expressing this ability to establish rapport or a relationship to be a criterion for establishing trust.

3. Reputation

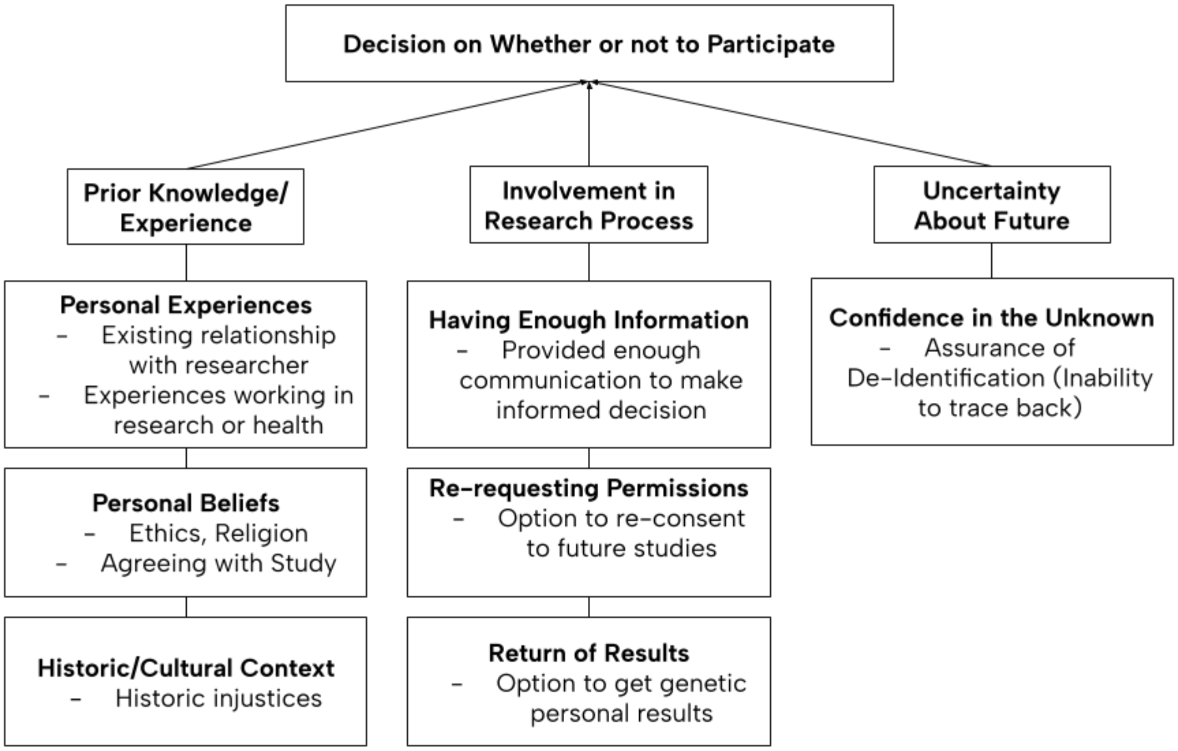
Reputation of researchers and institutions was also mentioned by some participants as playing a critical role in participant willingness to trust and engage with genomic studies. Reputation was implied through historic and/or existing information about the researchers/research institutions from outside sources. A participant from the Kennesaw State University White 1 Focus Group explained, "For me it's just knowing where the studies being conducted… you'd know it was a trusted study, like Emory has a good reputation in Atlanta, but an unknown research group just asking random people or even like having a club like a research club that was designed to promote research and promote critical thinking like people like being involved in student organizations and if I knew about that I probably wouldn't joined it.” Existing information included knowledge about the institutional review board and the regulations that are upheld through this. For example, a participant from the Emory White 1 Focus Group explained, “I trust that ethical review boards to dictate what is that the colon what's, not because I know that, particularly when using like human. subjects it's really, really strict protocols that you have to go through to get everything approved, so I would just kind of trust in that process to make sure that my DNA wasn't being used for anything behind.” Thus, trust was often granted to well-regarded research institutions, due to an understanding of ethical research that is screened by review boards. Conversely, distrust stemmed from personal and historical experiences of research conduct that lead to a perception of poor reputation of researchers. Some participants referenced historical scientific abuses where data had been misused unethically or distorted in misleading ways. For example, in the Emory White 1 Focus Group, one participant expressed, “I do not have complete trust and review boards. and scientists, because they are scientists, I think, like thorough history, we can see a lot of examples of research being distorted. And just false conclusions being drawn on like scientific data I wouldn't want to be part of any studies if they save my DNA”. This skepticism was more related to the broader scientific community, where instances of fraud, biased research, and unethical practices in research studies have diminished ability to assume best interest or trust institutions.

Research Goal III: Inferring How Trust-Related Themes May Influence Motives to Participate in Genomic Research

Participant responses from focus groups revealed that trust-related themes influenced their motives in complex ways. Findings from Aim 2 established a conceptual organization for understanding trust in the context of genomic research. However, trust may shape motivations and decision-making in ways that are not explicitly articulated. This research aim extends the analysis by re-examining and interact with focus group data holistically to identify how trust-related theme manifest in participant attitudes and choices surrounding genomic research participation, even in instances where "trust" was not explicitly mentioned.

Through applying ideas of trust developed in Aim 2, this section organized contributing factors that inform the decision on whether or not to participate in genomic research biobanking studies from the *a priori* and emergent candidate themes identified in Aim 1. Three key themes were identified, these being Prior Knowledge/Experience (perspectives that the participant brings), Involvement in the Research Process (the degree to which researchers communicate and are transparent, and provide opportunities for participants to be involved/have autonomy over own data in the research process), and Uncertainty about the Future (assurance that data is deidentified and cannot be traced back in the future).

Figure 4. *Refined Visual of Themes on Decision on Whether or not to Participate in Genomics Biobanking/Biorepository Research Studies*



Note. Provisional candidate themes were then reviewed and reassessed for fit to the data and viability to overall analysis in the context of trust through a second read through of transcripts.

Table 2. *Table of Themes and Subthemes Relating to the Decision on Whether or Not to Participate in Biobanking Genomic Research*

Theme	**Subtheme**	**Exemplary Quote**
Prior Knowledge/ Experience	Personal Experiences	"I'm always pretty happy to share because **I use biobank data for my research** so I'm like you know you're just contributing to the resources, so I am happy to do it." (Emory Asian 2)
	Personal Beliefs (Ethics, Agreeing/Disagreeing with Research Study)	**"**I would probably be opposed to. Criminal studies, because **I don't think that that is a valid use of time and resources** because I don't think that I don't I don't think that DNA... **I think it's a dangerous**

		path to go down to try and prove that DNA. Like, creates inclinations towards criminal activity? I think that there's a lot of biases involved that happen in those kinds of studies and, like in the past it's been used basically to justify. Like institutionalized racism, and so I thought that's probably the situation where I wouldn't feel like giving my DNA for that, because that doesn't seem like a. Like a that's not a research topic that I think needs more evidence." (Emory Asian 2)
	Historic/Cultural Context	"Well, part of me gets kind of concerned just because when I hear about DNA samples or whatnot, then I start, I don't know, for some reason, I think about, um, the **syphilis quote unquote experiment.** Yeah. Um, so my mind goes to it being used for something negative. Um, **it harming our community, it somehow coming back to me in a negative way, shape or form.**" (KSU Black 1)
Involvement in the Research Process	Having Enough Information	"I will say I agree with both of the statements there. I think there's a general consensus here that we prefer like we don't mind having our DNA used in specific experiments, but **as long as I'm aware of all of the terms.** I can't think of any specific types of procedures that I would be adverse to but you know as if I was more aware of, like the **exact procedures inside, then I can you know, make a decision based on that.**" (KSU Black 3)
	Re-requesting Permissions/Consent for Future Studies	"I'm comfortable with it being uh kept for the future but **before I do consent to giving my DNA for anything I would want to know the motivation of the study** what's the purpose of the study, because

		of course I would not want to participate in a study which I do not agree with." (Emory Asian 1) "I also wouldn't be okay with my DNA being stored for future **research I would want to know, like the only conditions under which I would be okay with it**. would be if I knew specifically what other studies that would be used for because I would want to like know that I would be okay, with what those studies are researching." (Emory White 1)
	Return of Results	"I don't like having my blood drawn, but like otherwise I feel generally willing to give a DNA sample, especially if there was some form of compensation and also like coconut said if with the possibility that **you could get the results of you know what your DNA said** or something that would be enticing to me." (Emory White NH 1)
Uncertainty About Future	Confidence in the Unknown	"I feel like especially like **you never know what medical science could turn into if someone's like storing my DNA.** You know who knows that one day that turns into like a clone of me or something like not saying like that's like impossible or like some like crazy out there idea… It sounds like very easy for these um like groups to like find a loophole and somehow be like unethical so that's kind of the only like hesitancy I have about it. (Emory Asian 4) "I feel like I **personally don't really like committing that far into the future**, so I probably would not give consent for them to store it and use it later on, I think." (Combined Hispanic)

Note. Table expands on themes relating to the decision on whether to participate in biobanking genomic research. Themes, which represent the contributing considerations that participants expressed shaped their decision on whether they would participate in biobanking genomic research are shown in the left column. The middle column provides subthemes. Exemplary quotes for subthemes are portrayed on the right-most column.

Prior Knowledge and Experience

This theme accounted for codes that represented the perspectives that participants bring to the research study due to prior knowledge and experience. Several participants attributed experiences working in research labs or in healthcare as motives for deciding to participate in genomic research. For example, one participant in the Emory Asian 2 Focus Group explained, “I'm always pretty happy to share because I use biobank data for my research, so I’m like, you know you're just contributing to the resources, so I am happy to do it.” Contrastingly, participants attributed experiences affiliating with certain historically stigmatized groups as influencers of distrust and hesitation to participate in genomic research. One participant from the Kennesaw State University White 1 Focus Group explained, “I know there's been a history of like pseudoscience, particularly in like Europe and America, like the 60s 70s 80s about linking certain genetic disorders and stuff like that to crime and, like a lot of it like Eurocentric idea of like, oh well, these racial ethnic groups are more likely to be convicted certain crimes, and I think a lot of that doesn't really have a lot of base it's a lot of like reaching and so, if I were like worried that a group might be using that against other ethnic group, that wouldn't really fly with me.” Prior knowledge and experience also involve an understanding of the reputation of researchers and institutions, a theme identified in Aim 2.

Involvement in the Research Process

This theme encompassed codes relating to the degree to which researchers involved participants in the research process. This begins with communication and transparency (ensuring that the participant has enough information to be able to make an informed decision and feel good about this) and encompasses the communication about research goals and the option to re-consent to future studies (if information is to be stored in a biobank/biorepository) and the option to certain results returned to participants. One participant from the Kennesaw State University Black 3 Focus Group explained, “I think there's a general consensus here that we prefer… like we don't mind having our DNA used in specific experiments, but as long as I’m aware of all of the terms.” Similarly, a participant from the Emory White 1 Focus Group stated that “I would probably be willing to like share my DNA samples if I knew what they would be used for and also if you'd be willing to share the results with me”. This theme is highly related to the themes “rapport/relationship” and “honesty/transparency” in Aim 2, as researchers involving the participants in conversations about the study establishes a relationship and rapport, influencing trust in the researchers, and increasing motivations to participate in genomic studies.

Indecisiveness & Uncertainty About the Future

While the theme of uncertainty initially seemed to appear more neutral, in the focus groups, it functionally resulted in the non-participation decision. Though responses initially coded under “Haven’t thought about it enough” within the larger theme “Uncertainty/Deliberation” were interpreted to have more of a neutral connotation/lack of decision on whether one would participate in a genomic study, this lack of decision in many ways has the same result as choosing to not participate. Adequate transparency and communication by researchers so that participants have enough information to decide was important for many participants. One participant explained, “I think I would also not necessarily be comfortable, I think, in the event trying new what type of research was being conducted and you know who would be, like who the research would be available to or who my DNA would be available to in the future, I think that would impact my decision, and I think like the ambiguity of not knowing would probably leave me to not agreeing to that situation” (Emory Asian 3). Therefore, in the absence of having enough information, inaction seemed to be the default.

Some participants struggled to articulate their stance due to lack of prior exposure or understanding of genomic research. One participant stated, “I don't really I don't know honestly, this is something I haven't thought about before and until that just you know, just this moment” (Emory White NH 1). Similarly, a participant from the Combined Hispanic Focus Group explained “I feel like I personally don't really like committing that far into the future, so I probably would not give consent for them to store it and use it later on, I think.” Factors such as insufficient previous knowledge about genomic research, which may speak to the importance of emphasizing transparency and communication in establishing trust and recruiting diverse participants.

Confidence or lack of confidence in the unknown was also a key topic of discussion for participants, as there were concerns regarding the reliability of deidentification and ensuring that the genomic information would not come back to detriment participants. This was also seen in the context of not wanting to be involved in studies that participants do not agree with.

Section IV: Discussion

Trust is uniquely relevant in the context of gaining perspectives on genomic research participation because it shapes how participants perceive the risks and benefits of involvement. Genomic research requires what may be perceived as a risk by participants in sharing highly personal information, despite deidentification. Analyzing trust in this context allowed this project to address questions such as how participants evaluate trustworthiness of researchers and institutions in the genomic research context and may inform future efforts for researchers to build and maintain trust in potential research participants, particularly among communities who have been historically excluded from this research. A previous study exploring components of trustworthiness in the decision to participate in genomic research participation for African Americans found that negatively assessed characteristics for participation could be mitigated by high communication of trustworthiness in the consent process, which may improve rates of research participation (Passmore et al., 2020). Overall, factors that contribute to establishing trust overlapped notably with factors that participants considered when deciding whether to participate in genomic biobanking/biorepository studies, affirming the importance of establishing trust when working to increase participation in genomic studies.

Research Goal I. Existing literature has identified several key themes regarding genomic research participation, including concerns about confidentiality, trust in researchers and institutions, the role of healthcare providers, and racial/ethnic differences in trust dynamics (Trinidad et al., 2010). Our findings both support and extend these established themes by incorporating new perspectives from focus group discussions. Participants expressed confidence in deidentification, agreement with research goals (i.e. justice), and community engagement/return of results as reasons for participation in genomic research. On the other hand, participants expressed mistrust of unknown/lack of confidence in deidentification, disagreeing with research, and commercialization of genomic data as reasons against participation in genomic research. These participation attitudes were shapes by the historic and cultural context relating to genomic research and healthcare and influenced by the level of transparency provided by researchers. Oftentimes, participants expressed a conditional willingness to participate, which was coded as “Criterion, Caveat, Terms/Conditions” where certain conditions would need to be met for the participant to consider research participation. These conditions were often related to establishing relationships between researchers and participants, providing transparent and honest communication.

Research Goal II. The specific analysis of explicit “trust” use instances in focus group interviews revealed additional nuances through the organization of trust related themes. This revealed insights on the ways in which participants built a contextual definition of trust through discussions on honesty/transparency, relationship/rapport, and positive reputations implicated ability to assume the best of researchers (especially in situations such as biobanking/biorepositories where genetic information may be used in future studies without participant approval) and the ability to trust researchers. In a study on assessing trust in genomic data sharing among members of the general public in the UK, USA, Canada, and Australia, participants were most likely to trust their personal medical doctors, and least likely to trust company researchers (Milne et al., 2019). This relates to ideas of preconceived reputations and also relates to rapport/relationships that were affirmed through focus group findings, as likelihood of trust for medical doctors diminished for any medical doctor as opposed to one’s own (Milne et al., 2019).

Research Goal III. While trust was explicitly mentioned and discussed in some areas of focus groups, there were also instances in which trust-related themes were identified in ways that were not always directly articulated as "trust". Influences on motivations to participate in genomic research identified in Aim/Research Goal I were organized under 3 larger themes: Prior Knowledge/Experience, Involvement in the Research Process, and Confidence in the Unknown. Prior knowledge and experiences encompassed participant's personal experiences, personal beliefs, and the historic/cultural context that shape their perspectives. Involvement in the Research process spoke to the degree to which participants were involved. A past study found that careful implementation of community engagement benefitted the development of a relationship based on trust between researchers and various stakeholders (Staunton et al., 2018). Focus group participants often expressed a desire to get involved/engaged in the research process, supporting this idea. Lastly, participants spoke to a confidence in the unknown, or concerns about deidentification, data misuse, and more. Together, these factors/influences on genomic research participation overlapped with the factors that shape participant trust, underscoring the interconnected nature and importance of trust in shaping genomic research participation.

Limitations

Though the aim of qualitative research is not to produce generalizable findings, it is important to consider some limitations of the study that influence the data and analysis. First, participants were recruited from only two institutions in Georgia (Emory University and Kennesaw State University), potentially limiting the applicability of findings to broader populations. The nature of the study recruitment also biased responses in that we may have missed individuals who did not trust research as a whole and would not even want to participate in this focus group study. This may be a useful area of focus for future studies. Further, this project was conducted in a post-hoc analysis where the focus group transcripts had been collected prior to the development of these research aims. Though this allowed for an analysis of the theme of trust which naturally came up in focus group discussions, discussion prompts were not specifically designed to examine trust, and trust-specific topics were not examined on a deeper level. Lastly, due to the independent research nature of this thesis, this project was conducted without forma multiple-coder validation. However, this same dataset has been analyzed by other researchers conducting a broader study, and discussions between these researchers were consistently held throughout the research process.

Summary and Conclusions

This study supports existing literature that demonstrates that trust in genomic research is complex and has been shaped by a variety of factors. Research findings may contribute to efforts to address the inequity in genomic research through targeted recruitment strategies, increasing transparency, and initiatives to build trust in historically underrepresented groups and work toward equitable access to the benefits of genomic research. Future efforts and initiatives to increase participant trust in researchers may contribute to increased recruitment of diverse populations in genomic studies and research. Initiatives may include transparent and accessible communication ad education about research studies and consent processes, community-driven engagement and relationship building, emphasizing ethical data use and participant protections, and greater involvement of trusted healthcare providers in recruitment.

Future Directions

This study aimed to provide an overview of attitudes and perspectives across all demographics, with a focus on historically marginalized communities. However, due to the organization of focus groups by demographics, there may be opportunity to take a closer look at how these attitudes/perspectives may differ by participant demographics. Past studies have observed trends stratified by demographic groups, such as finding that Hispanic participants more commonly stressed the importance of having a close and trusting relationship with a provider in facilitating access to research opportunities whereas Asian participants more frequently described cultural barriers to communication (Young et al., 2022). Another study found that Black and Latino individuals are less likely to use genetic testing than non-Hispanic white individuals due to barriers they face including disproportionate lack of knowledge or information provided by their physicians about genetic testing (Suther & Kiros, 2009). Next steps may include taking a closer look at each demographic group in isolation from one another, to observe if there are differences in how participants conceptualize trust. Additionally, as the initial focus group discussions did not explicitly place a focus on the idea of trust, a future study may be designed with trust in mind and center discussion questions around gaining a deeper understanding of insights identified in this analysis.

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