DIVERSITY IN RESEARCH: A NEW LOOK AT AN OLD PROBLEM

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DIVERSITY IN RESEARCH: A NEW LOOK AT AN OLD PROBLEM

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EXECUTIVE SUMMARY

DIVERSITY IN RESEARCH: A NEW LOOK AT AN OLD PROBLEM

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Historically minorities have been underrepresented in research studies and new research has emerged describing how important it is to diversify the research pool in genomics especially and to provide equitable treatment to all people. My goal was to examine current programs at a local hospital that is an advocate for children's well-being and strives to be the voice for public policies surrounding health, safety, and security for all children. This hospital is dedicated to research that develops treatments and cures for children and they are customer focused and determined to make families their top priority. Within this hospital, I examined research studies from a progressive translational department that has flourished over the past five years. This department has paved the way in patient disease management, has refined diagnoses, has provided information on prognosis, and has assessed genomic profiles for possible enrollment on clinical trials or use of targeted therapies. This department unfortunately has the same issues of under-enrolling diverse populations, therefore semi-structured interviews were conducted with healthcare workers intimately involved in these studies to provide insights into how this historic problem can be changed.

Dedicated to my husband and dogs.

ACKNOWLEDGEMENTS

Special thanks to my committee chairs at the University of Dayton, Drs. Olive, and Essex for always providing their time and feedback throughout this journey.

I would also like to express my gratitude to Dr. Wilson who allowed me to continue this journey even after I was no longer an employee at this organization. I appreciate your mentorship and patience.

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CHAPTER ONE: INTRODUCTION

Statement of the Problem/Topic

The topic of this study includes the complex system of organizations, individuals, processes, policies, and factors that may perpetuate potential implicit bias and structural racialization. Opportunities to confront possible barriers and to promote health equity in research studies may lead to more inclusive and equitable ways of behaving and reacting.

The Problem of Practice

The purpose of this study is to examine potential implicit bias or structural racialization among healthcare professionals who nominate patients to genomics studies at a local hospital. Implicit bias refers to the psychological notion that people may develop unconscious attitudes or stereotypes towards certain populations (Chapman, 2013 p. 1504). Since these attitudes are oblivious to that person, behaviors may be affected that go ignored during patient appointments. The word racism refers to the beliefs that people have against certain individuals based on their membership of a certain racial or ethnic group. To create successful programs, an organization must be examined to exploit cycles of racism and implicit bias. According to Powell (2013), “Structural Racialization is a set of processes that may generate disparities or depress life outcomes without any racist actors” (p.1). Structural racialization is a concept that may unknowingly proceed implicit bias in the fact that healthcare professionals may limit opportunities for underrepresented populations (Kempf, 2020, p.115). The existing problem is that historically minorities have been underrepresented in research across the United States. For my literature review, I focused on the Black and African American community to gain insight into historic and societal issues with research. To my knowledge, this issue has not been studied at this hospital. Therefore, this study aims to understand blind spots that can jeopardize healthcare for underrepresented populations and focuses on championing diversity.

Justification of the Problem

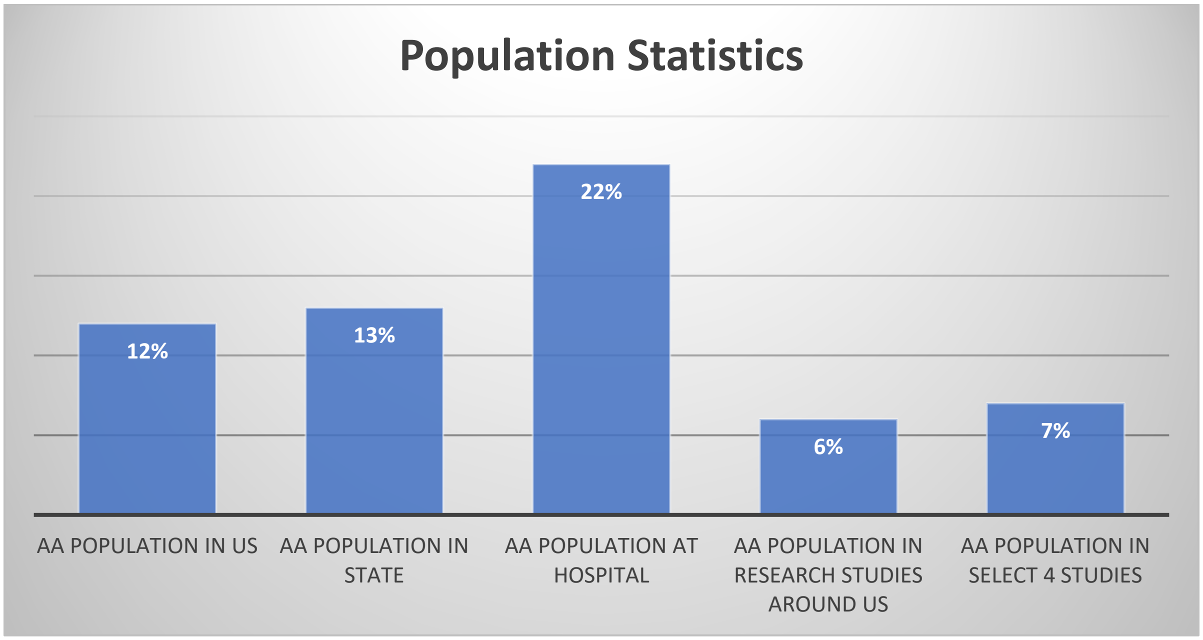
Konkel (2015) described the Black and Latino population as being more than 30% in the United States yet make up less than 6% of clinical trials (p.299). The Konkel (2015) article also stated:

> Research shows that many individuals of racial and ethnic minorities are as willing to participate in research studies as whites when given the opportunity and when research objectives are translated into a culturally relevant context. It's not that minorities are hard to reach but that they're hardly reached. (p.299)

The National Institutes of Health instituted the Revitalization ACT in the 1990's that aimed to include women and minorities in research studies (National Institute of Health, 2020). "Since the passage of the Revitalization Act in 1993, less than 2% of more than 10,000 cancer clinical trials funded by the National Cancer Institute included enough minority patients to meet the NIH's own criteria and goals" (Oh, 2015, p.3). According to the 2019 census, the Black or African American population represents approximately 13% (figure 1) of residents in the state being studied (U.S. Census Bureau, 2020). After sampling four research studies at the hospital, the Black or African population averaged 7% (figure 1) in genomic studies within the department where this research occurs.

Figure 1

Patient Population



Deficiencies in the Organizational Knowledge Record

The Hippocratic oath requires healthcare professionals to eliminate personal biases and develop into an ally for underrepresented populations (Chapman, 2013 p.1504). Healthcare professionals are typically placed in a fast-paced, time-sensitive environment where learned social stereotypes may impact decisions made while treating a patient (Mitchell, 2021, p. 1). According to Chapman, "As with any behavioral change, individuals need to become aware of their habitual engagement in an undesirable behavior and be provided with strategies to increase self-efficacy to engage in a new desirable behavior" (Chapman, 2013, p.1508). This hospital (anonymous website, 2022) has had a long-standing desire to make strides in diversity and inclusion and not until the death of George Floyd in 2020 did hospital leadership mandate change. This revolutionary context led the hospital to solicit feedback from employees and local families and used this 2020 crisis to strengthen their diversity and inclusion programs. The hospital hired new diversity and inclusion staff, created unconscious bias training for management, and developed seven pillars that aim to create equitable change (figure 1). The health equity movement helps identify ways to develop antiracism programs and it provides a framework to build diversity and inclusion efforts at the hospital. However, based on conversations with hospital employees, the research and outcomes pillar is still extremely underdeveloped.

Figure 2

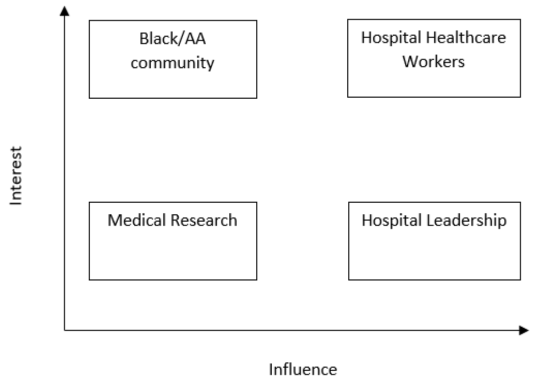
Health Equity Model

Audience

Dumlao (2018) thought that “audience analysis involves figuring out what information matters most to the other person or group and what channels might be most effective for sharing that content” (p.90). Therefore, by using the ideas of Stringer and team (2020), stakeholder engagement will be based on interest and influence (figure 2). Low interest, low influence stakeholders will be communicated with, if necessary, by publishing findings in medical journals. High interest, low influence groups will be kept satisfied by bringing results and change to community leaders as needed. Low interest, high influence leaders will be invited to any meetings and well-informed during data collection and analysis. High interest, high influence members will be briefed weekly via email or in meetings, so they can understand what is always going on to ensure buy-in. The goal for these stakeholders is to encourage them to be change agents and feel empowered to support organizational transformation.

Figure 3

Stakeholder Matrix



This research study may be important to the hospital, hospital healthcare professionals, medical research, and the Black or African American community. In a qualitative study with 40 physicians and 269 patients by Cooper, et al. (2012), it was discovered that physicians were not communicating effectively with minority patients, therefore this gap may lead to unequal care (p.979). This article also went on to state that strategies to “increase clinicians’ awareness and understanding of the basis of bias and help them develop cultural sensitivity, patient-centered communication, and partnership-building in the patient clinician relationship will enable clinicians to reduce their reliance on social categories when clinically irrelevant” (Cooper, 2012, p.985). By widening research populations at the hospital, other treatment teams may also benefit by understanding diverse cultures and learning how to treat underrepresented populations.

Local Hospital

Hospital leadership includes internal stakeholders that have committed to diversity in research and may potentially benefit by receiving additional funding to support diverse research in the future and may be able to hire more diverse staff. Hospital leadership members are considered secondary stakeholders based on the Stringer (2020) text, stating that “secondary stakeholders are affected by or can influence those who directly experience the problem” (p.99). Hospital leadership will not be involved in the evaluation; however, this evaluation could lead to organizational change. Therefore, keeping them well-informed will be critical throughout the evaluation due to their high interest.

Hospital Healthcare Professionals

Hospital healthcare professionals are internal stakeholders that may benefit by becoming more self-aware of their thought process, may feel more empowered to share experiences, and may become more creative and innovative when thinking about health care. Hospital healthcare professionals are primary stakeholders because “they are directly affected by the research problem” (Stringer, 2020, p.99). The physicians and healthcare professionals may have the highest interest because they are the people that are most impacted by this evaluation and have the most influence to create change. Engaging healthcare professionals continuously will be important to ensure they support outcomes and give their buy-in.

Medical Research

The medical research community may benefit because diversity in research can lead to the generalizability of research findings and the accuracy of analyses by removing reporting bias. The medical research community is an external associated stakeholder that when informed may be able to use these findings for future research, but they have no direct effect on my research study. If changes are made at the hospital, this may contribute to new knowledge in the medical community, may produce more articles, and may generate new knowledge. The medical community may have little interest in our evaluation, however keeping them informed may be valuable for future studies. If diversity is increased in research, population databases may become more robust and usable to the medical community.

Black or African American Community

The Black or African American community are external associated stakeholders that may benefit in many ways and based on a quote from Corbie-Smith (1999), “Young participants described their desire to access state-of-the-art medical care, obtain free medications, and discover alternatives to standard therapy. Older participants described the benefits of research for their extended family and the broader society” (p. 540). The Black or African American community of stakeholders may have high interest in this type of a study because this evaluation may ultimately affect their healthcare. However, the Black or African American community will have little influence on the decisions made at a hospital organizational level. Nevertheless, the Black or African American community may benefit by participating in research by having health care equity and access to cutting edge therapies.

Overview of Theoretical Framework/Methods/Research Question(s)

Theoretical Framework

According to Conyers (2021), racism is embedded in U.S. organizations and is a systemic practice that can lead to diminished inclusion in research studies for certain populations in the healthcare system (p.484). Using the Critical Race Theory (CRT) as a theoretical framework in this study may help guide the process of addressing implicit bias in healthcare employees. CRT is a multidisciplinary concept that examines the intersection of race and law (Conyers, 2021 p. 492). CRT is an idea that addresses structuralized racialization by exposing power dynamics and focusing on dominant cultures mindset. The CRT framework was used while interviewing healthcare professionals and helped to navigate the dialogue by analyzing the unconscious thoughts surrounding patient selection for genomic studies. According to Conyers (2021), "By placing race and racism at the center of analysis, CRT is utilized as an instrument to reveal and identify institutional racial paralysis in organizations" (p. 491).

In Tara Yosso's (2005) article, she outlines the theory of CRT, addresses the social assets of a person, and proposes a new framework where leaders may be able to empower individuals. Yosso (2005) defines "CRT in education as a theoretical and analytical framework that challenges the ways race and racism impact educational structures, practices, and discourses" (p.74). Yosso (2005), discusses that culture impacts our society and her premise is based on schools, but can be applied to any context. In summary, Yosso (2005) places the emphasis on cultural strengths and by using CRT one can use this lens to build relationships with minoritized communities.

As a conceptual component to the CRT theoretical framework, Glenn Singleton (2015), defined three critical factors necessary for systems to eliminate racial gaps: passion, practice, and persistence (p.14). Courageous conversations are defined by Singleton (2015), to be dialogues designed to engage teams, to listen deeply, and to continue conversations even when difficult (p.26). Courageous Conversations were used during interviews to build strategies to address and impact change when it comes to implicit bias and structural racialization. Using Singleton's (2015) three critical factors when talking about race, a focus on passion, practice, and persistence were key. Passion is a strong desire for equity and is imperative when comforting the challenges of race or oppression. However, one needs to go beyond passion and act as seen in this action research study. Understanding the gaps and talking about what people need to fulfill potential is a central theme. Lastly, persistence is dedicating time to keep the topic moving and not letting the subject diminish. When combining CRT and courageous conversations, Yosso (2005), thought that change may arise when discussions occur to understand struggles and the mindset of those who are limiting opportunities are expanded (p.73). As the researcher and using this thought process, I questioned healthcare professionals, while being "engaged, speaking my truth, experiencing discomfort, and except and accept non-disclosure" (Singleton, 2015, p.27).

Methods

To understand the research problem, I used a qualitative action research design that gained insight from healthcare professionals on their thought process while nominating patients to genomic studies. The first step was to review demographic data from four genomic studies at the hospital to understand what discussion points could be used for interviews. Using descriptive statistics, I charted these demographic data from patients consented on genomic studies and examined the gaps in diversity from a visual perspective. A semi-structured interview process consisting of a series of open-ended questions was utilized to get feedback from healthcare professionals that nominate patients to internal hospital genomic studies.

A qualitative action research approach allowed different perspectives and further investigation of trends, as well as details of the research problem and an understanding how the research pool can be diversified. With CRT on the forefront of my mind during interviews, I used these tools to frame interview questions that may address a possible unjust system.

Research Question

Therefore, my research question seeks to understand if there is an unconscious bias towards certain groups of people that is leading to a gap in research studies?

Limitations

Set in a neighborhood in the Midwest, this hospital serves approximately 22% Black or African American patients and families (figure 1). Based on those data, these research findings may be limited, or not be applicable to other institutions like this hospital or other hospitals in the Midwest. Also, as stated previously, to narrow my scope for this DiP, I only did literature searches based on the Black or African American population versus opening this to all minority groups.

Becoming self-aware could be a limiting factor when discussing implicit bias. Since implicit bias may be seen as negative, I was open and sensitive about the topic when conducting interviews. Finally, developing concrete and objective training may be an obstacle while promoting change since there is sparse literature surrounding implicit bias in healthcare professionals.

Review of Related Literature

The focus of this study was to examine the mindset of healthcare professionals that nominate participants to genomic studies at a local hospital. Due to a lack of diversity in study demographics it was important to understand if there is an unconscious stereotype towards certain groups of people. A review of related literature was completed to examine other organizations and issues they may encounter.

Theoretical Framework(s) Informing the Study

While there has been literature affirming systemic and historic barriers that have led to a lack in research participation of the Black or African American community (Oh, 2015, p.6), moving towards a framework where cultural stereotypes are challenged may lead to bias-reducing strategies with healthcare professionals. According to Blessett (2021), “Critical race theory (CRT) allows scholars to examine issues (e.g., legal, educational, institutional, societal) with a clear understanding of the ways in which the system of racism acts as a form of oppression for Black, Latino, and Indigenous People in the United States” (p.456). CRT was used to confront the unconscious social practices that may be occurring at the organization by examining the thought process of healthcare professionals. The goal of using CRT in this study was to understand the social construct of potential implicit bias and eliminate embedded structural racism (Yosso, 2005, p.81).

Related Research

This literature review focused on three main themes which included racial disparity in research, implicit bias in healthcare, and CRT. The goal for this literature review was to explore historical articles on diversity in healthcare and search for solutions that may be implemented. Once those objectives were met, I explored the theoretical framework of CRT and how it may be used to combat unconscious thoughts that could eliminate disparities.

Racial Disparity in Research

The authors in this section examined societal, historical, and other barriers in non-participation in research by minority populations. According to the Oh (2015), "Minorities would likely to be as willing to be involved in research as whites if problems of diversity could be better addressed" (p.4). Oh (2015), went on to state that there was a need to engage community members due to a lack of awareness and fear of experimentation. The article also discussed the need to include minorities in research due to it providing opportunity to understand "ancestral influences, environmental exposures, and social factors" (p.2). With this literature in mind, it was important to understand if healthcare professionals are excluding Black or African American populations based on historical participation.

The Hughes (2017) article is a research study that aimed to assess barriers and design better recruitment strategies for Black or African Americans and improved approaches for study retention. Hughes (2017) used a non-probability technique to recruit 64 people to participate in focus groups to understand the lack of research participation and provided questionnaires to all participants to gather basic information about the subjects. Based on the focus groups, the theme of recruitment strategies was a major focus that included:

> The need to educate community members about the various aspects of research, the importance of conveying how research programs have benefited individuals, groups and communities, the importance of providing personal stories that enable community members to understand the potential benefits of research, and having research discussed by an individual that the audience can identify with or trust. (Hughes, 2017 p. 354)

Overall, Hughes and team (2017) teased out the need for more education, suggested ideas for recruitment and retention in research studies, and provided evidence that historic barriers are passed down from the previous generations and need to be continuously addressed (p.356). Therefore, by utilizing this knowledge, creating strategies to support healthcare professionals was at the forefront of conversations.

Implicit Bias in Healthcare

Chapman (2013) discussed the Implicit Association Test (IAT) that is used to measure implicit bias in healthcare professionals. In this article, the IAT "found significant pro-White bias despite no explicitly reported preference for Whites over Blacks" (Chapman, 2013, p.1505). The Chapman (2013) article compiled a list of studies that used the IAT with physicians and found that physicians have a quantifiable implicit bias. Chapman (2013) concluded that there is implicit bias in physicians that may lead to unequal treatment in patients, but it can be combated if physicians make conscious efforts to understand their own beliefs.

Raphael and team (2020) stated that "In health care, implicit biases function to the disadvantage of vulnerable populations, including racial and/or ethnic minorities, immigrants, sexual minorities, and those with disabilities" (p.1). The Raphael article

(2020) assessed pediatric emergency departments and notes the heuristics may be used by physicians to quickly examine patients to be able to move on to the next child. However, by using this technique, Raphael (2020) suggested that this may lead to discrimination in minority populations if not addressed. Overall, Raphael (2020) suggested training in empathy, perspective taking, and employing various forms of social cognitive methods to reduce implicit bias.

Critical Race Theory

Blessett (2021) stated that "CRT is rooted in primary basic assumptions that argue: (1) racism is ordinary, not an aberration, but ingrained within the ordinary practices of society; (2) interest convergence is at play in U.S. systems" (p. 456). According to Blessett, (2021), interest convergence is the idea that an interest will be supported if the majority is aligned (p.456). Therefore, by using CRT with healthcare professionals I remained mindful and united to ensure we could create change. Blessett (2021) thought that CRT acts as a theory of awareness in the community, instead of an area of avoidance. Blessett (2021) suggested that CRT may help address systemic thought processes in healthcare professionals by teaching them to become mindful in the moment.

Conyers (2021) suggested that the crux of the CRT framework is to expose structuralized racialization which leads to the collective and lasting inequalities linked to race. Conyers (2021) stated that "CRT provides an operative race-conscious lens to critically examine the degree to which race impacts institutional racial paralysis (IRP) in organizational culture" (p. 485). Conyers (2021) recognized that organizations become idle in their lack of activity, may fail to divulge misconduct, may operate in a habitual way, and these activities may lead to widespread IRP.

Action Research Design and Methods

Positioning

This participatory action research (PAR) study involved a hands-on approach where members are committed to the transformation of the sociocultural environment. PAR aims to involve both the researcher and the participants and emphasizes growth for the community and to the lives of others (Mertler, 2020, p.19). By using PAR, the goal was to empower healthcare professionals at the hospital by giving them a voice and understanding if there are unconscious stereotypes that may be entering their practice. This personal growth may lead to a psychological change in attitudes and principles.

The purpose for choosing PAR was to address social issues that may lead to the suppression of marginalized communities and to strive for open communication that may open the door for change and equity (Creswell, 2019). According to Creswell (2019), "PAR is a social process in which the researcher deliberately explores the relationship between the individual and other people" (p. 593). Emancipatory action research has the objective of integrating conscious thinking and creating practical bridges to facilitate change and was utilized in this research study.

Site

This hospital is a nationally ranked healthcare facility in the Midwest. The main campus is in the downtown area of the city and includes twelve different specialty buildings, four of which serve as research centers. This hospital has thirteen off site buildings, which are community-based facilities, spanning the entire state. According to the hospital website (2022), in 2020, they served over 1.3 million patients from 49 states and 43 different countries. This study took place via Zoom and focused on the healthcare professionals at the main campus of the hospital.

Population Selection

To address the possibility of implicit bias at this hospital, ten healthcare professionals were chosen based on a non-probability or purposive sampling technique. A purposive sample technique is where the "researcher selects samples based on the particular research question as well as consideration of the resources available to the researcher" (Hesse-Biber, 2017). Due to the small number of healthcare professionals that select patients to be on these protocols, I aimed to ensure gender, race, area of expertise, and age are represented in this study. The current demographics (table 1) of all healthcare professionals that nominate to genomic protocols is currently at 57 employees all with differing backgrounds and experience.

Table 1

Healthcare Professionals that Nominate to Genomic Studies

Sex	
Male (n=29)	51%
Female (n=28)	49%
Age	
50-55 (n=15)	26%
45-49 (n=10)	18%
40-44 (n=12)	21%
35-39 (n=13)	23%

30-34 (n=7)	12%
Education	
Doctoral Degree (n=48)	84%
Professional Degree (n=8)	14%
Master's Degree (n=1)	2%
Race	
White (n=42)	74%
Black (n=2)	4%
Bi-racial/multi-racial (n=13)	23%
Ethnicity	
Hispanic or Latino (n=3)	5%
Not Hispanic or Latino (n=54)	95%
Area of Expertise	
Oncology (n=34)	60%
Genomics (n=15)	26%
Behavioral Health (n=8)	14%

Researcher Role and Positionality

My former title at this hospital was Clinical Research Operations Manager in the department where research studies were completed. My role within this department was to execute clinical research genomic projects from an operations standpoint. I worked directly with healthcare professionals, genetic counselors, pathologists, surgeons, and clinical research coordinators. In this role, I had no direct influence over any participants and none of these participants ever reported to me as a manager. My role for this research study was participant as observer, meaning I was in the field interacting with people while taking notes about the interviews. My role was also interviewer and data analyst. To gain access to participants, I was given permission by the executives who lead the department to contact healthcare professionals that nominate to genomic studies.

As the researcher, to build rapport with interviewees I focused on being welcoming, attentive, and encouraging by nodding, affirming statements, and kept a steady voice tone. I ensured that anonymity would be maintained by changing names on any transcripts and adding pseudonyms as needed. To mitigate bias, I employed trustworthiness by member checking and confirmability of the interview transcripts once they were complete. During interviews I utilized an Interpretative phenomenological Analysis (IPA) thought process, I reserved judgment and created a safe space for research participants to discuss topics (Alase, 2017, p. 13). By journaling after each interview, I became aware of any biases as the researcher and continually monitored my own subjectivity by using reflexive behaviors to reflect on my own expectations, beliefs, and feelings (Creswell, 2019, p.18). According to Peshkin (1988), when researcher subjectivity is unconscious, it may skew research projects data. Peshkin (1988) “advocates for the enhanced awareness that should result from formal, systematic monitoring of self” (p. 20). Therefore, by journaling between research interviews I was able to think about biases during that interview process and write down themes that emerged.

Ethical and Political Considerations

The first ethical consideration for this qualitative action research project was anonymity of the interviewees. At the beginning of each Zoom call, I asked each participant if a voice recording was acceptable and since these interviews were recorded and transcribed, participants were asked to use fake names and then I used pseudonyms when saving files. If real names were used, after transcription, I cleared out any names with XXX prior to saving. The interviewee files are stored on a password protected personal computer that is stored at home.

Another ethical consideration is informed consent or the invitation to participate memo (appendix A). The invitation to participate document was approved by the University of Dayton's Institutional Review Board in 2022 and was sent to each participant via email when soliciting participation. At the beginning of each interview, I discussed voluntary participation, stressed confidentiality, and guaranteed there was no deception in this research study.

The last consideration was sensitivity of the research topic. Impartial treatment by healthcare professionals is a controversial topic. Therefore, I applied strategies to ensure objectivity by asking the subjects all the same questions and regulating emotions by not giving opinions to ensure participants felt comfortable giving honest answers.

Data Collection Methods

For this research study, I opted for a qualitative research methodology to examine themes related to implicit bias and communication. Prior to the interviews, participants that healthcare professionals that nominate to genomic protocols were contacted via email from a list that was vetted by the department's leadership team to inquire about participation. Once the potential interviewee list was confirmed, informed consent forms or invitation to participate forms (see Appendix A) were emailed to participants with a standard email template and discussed via Zoom call.

According to Creswell (2013), in a phenomenological research study, “the process of collecting information involves primary in-depth interviews with as many as 10 individuals” (p.161). Therefore, fifteen healthcare professionals were sent a standard email to participate with the goal of interviewing at least ten participants. Once participants agreed, 20-30-minute individual interviews were conducted through the Zoom platform. To maintain confidentiality, interviews were recorded via phone by using a voice memo application. To understand different vantage points, three participants from different departments with varying demographics were recruited to participate but fell short in one department by only recruiting one participant from behavioral health. Creswell (2013) stated that “It is essential that all participants have [similar lived] experience of the phenomenon being studied” (p. 155).

During the interview, a semi-structured approach was used to address questions relating to potential implicit bias. Thirteen questions (Appendix B) were prepared with the understanding that all questions may not be discussed due to the open-ended nature of the interview and the assurance of staying on time. While in the interview, I asked for clarification on answers that were vague and asked interviewees to expand on topics or thoughts that strengthened the discussion. During the interview process, personal biases were reserved to “enable participants to express their concerns and make their claims on their own terms” (Smith, 2009, p. 42). Smith et al. (2009) indicated that “A qualitative research interview is often described as ‘a conversation with a purpose’” (p. 57).

Therefore, being engaging during interviews and expanding on sensitive topics was critical.

Data Analysis Procedures

Once all interviews were complete, Otter.ai was purchased and voice memos were uploaded to the online transcription tool. An inductive approach using IPA to understand the participants' social world was applied. Alase (2017), stated that the IPA approach was "flexible enough and 'participant-oriented' enough to get to the real 'lived experiences' of the research participants" (p.9). In the Alase article (2017), they suggested that a preliminary review of the data should be conducted to understand and organize the content. Therefore, the transcripts were read several times and transcripts were cleaned to ensure readability and any real names were anonymized. After review, the transcripts were sent to each participant for feedback to guarantee accuracy of the interview.

Once the interviews were checked by all participants for correctness, the coding process was conducted in the Otter.ai system. Notes were created in the transcripts to uncover any common themes or concepts related to the participants' experience. According to Creswell, (2019) by coding, I scanned the interviews several times to look for five to six concepts related to my topic. Once complete, I color coded the related themes and created statements about these combined themes (Alase, 2017, p.17). By using the IPA method, my goal was to create a storyline of each participants' world and accept or reject my research question.

Trustworthiness/Validity/Credibility/Transferability

Credibility.

To establish trustworthiness, credibility was taken into consideration to ensure the findings are consistent with the collected data. Due to this being a sensitive topic I ensured participants that confidentiality will be maintained by saving files with pseudonyms and de-identifying anything in writing. Alase (2017) stated that “protecting the right and privacy of the research participants is the most honorable thing that any research methodology (and traditions) can do to show, at a minimum, some kind of credibility and respect for their research studies” (p.18). Member checking was also utilized to ensure that what was discussed in the interview accurately depicts the viewpoint of the participant. Transcripts were sent to each participant for review and confirmation of correctness of the interview record.

Transferability.

Thorough and detailed descriptions of the setting, interview pool, and demographics of the participants were provided to ensure transferability (Shenton, 2004, p.70). Showing that the findings and participant population are applicable in other settings is key. This issue is not unique to this hospital and should provide enough evidence to be able to replicate this type of study that may lead to more social change in research.

Dependability.

Due to the different times and situations for the Zoom interviews, as the researcher, I utilized operational definitions during data collection in this study. While interviewing, I attempted to ask each question as stated and if follow up questions occur while interviewing, I wrote down differences in my journal and evaluated the effect once the interview was complete (Mertler, 2020, p.141). To ensure that the transcripts are accurate and not based on my beliefs, I employed reflexivity. By using reflexivity in this process, I was able to understand and document my own bias and isms. I would journal after each interview to reflect upon the lessons being taught and how my lens may impact this study (Creswell, 2019, p. 18).

Confirmability.

To establish confirmability and ensure statements were accurate, I used direct quotes from interviewees in this paper to ensure that the information is representative of the participants. By using the transcription software (Otter.ai) as well as my voice memos while coding the interviews, I was able to compare these two data sets objectively to ensure they matched (Shenton, 2004, p.72).

CHAPTER TWO: RESULTS OF RESEARCH

Reporting Qualitative Results

The purpose of this qualitative action research study was to examine potential implicit bias or structural racialization among healthcare professionals at a local hospital. Through semi-structured interviews, I explored the thought process of why healthcare professionals select certain patients for genomic research studies.

Population

The interviewees chosen for this study all hailed from the main hospital campus and varied from different backgrounds, experience, and demographics (table 2). A solicitation email was sent to fifteen participants and ten responded. All participants but one interviewed via the Zoom platform within one month. The last interviewee was interviewed 2 months later due to a conflict of scheduling. Once all interviews were complete, the pseudonyms of interviewee 1-10 were given to each participant in order of interview date.

Table 2

Healthcare Professionals Interviewed

Sex	
Male (n=5)	50%
Female (n=5)	50%
Age	
56-60 (n=1)	10%
50-55 (n=1)	10%
45-49 (n=1)	10%
40-44 (n=3)	30%
35-39 (n=2)	20%
30-34 (n=2)	20%
Education	

Doctoral Degree (n=7)	70%
Professional Degree (n=2)	20%
Master's Degree (n=1)	10%
Race	
White (n=5)	50%
Bi-racial/multi-racial (n=5)	50%
Ethnicity	
Hispanic or Latino (n=0)	0%
Not Hispanic or Latino (n=54)	100%
Area of Expertise	
Oncology (n=4)	40%
Genomics (n=5)	50%
Behavioral Health (n=1)	10%
Years of Experience at Hospital	
13-16 (n=1)	10%
9-12 (n=2)	20%
5-8 (n=5)	50%
1-4 (n=2)	20%

Present Findings

Interview Results

Once I received approval for this qualitative research study from the University of Dayton’s Institutional Review Board (IRB), I solicited interviews via emails and then scheduled these Zoom calls using my personal email account. Interviewees did not receive any specific questions prior to the interviews but were sent a copy of the invitation to participate which included the topic and purpose of this study. To prepare for interviews, I thought back to my theoretical framework and the works by Blessett (2021) and the critical race theory. By understanding the historical context of racial inequities and unconscious racism, “CRT is used to examine the manifestations of institutional racism through the four-stages of IRP: idleness, concealment, evolving modus operandi, and pervasive" (Blessett, 2021, p. 457). Therefore, thoughtful conversations were imperative to ensure that questions could be adequately addressed.

A semi-structured approach was taken during the one-on-one interviews and each interview was recorded via phone (voice only) to facilitate confidentiality. During Zoom interviews, I used a participatory action research (PAR) position to ensure I was addressing the improvements that were needed regarding this social issue. Appendix B captures the questions asked during each interview and if follow up questions were required, I would journal after each interview to capture those additional comments or questions. Transcripts were also reviewed several times to guarantee transferability to have a clear picture of the situation (Mertler, 2020). Once all interviews were complete, I purchased Otter.ai (transcriptions software) and uploaded each interview recorded from my phone. During the first interview, a central theme began to emerge surrounding communication, or the lack of tools provided to explain these studies to patients. Therefore, I asked a follow up question after question five with interviewees two-nine about communication tools that aid in healthcare professionals' decision to decide to nominate.

Since I used a purposeful sampling technique by selecting experts in the field of genomics, most participants (70%) stated that their level of knowledge in genomics was excellent. By utilizing this technique, credibility was established "to address issues that are not easily explained" (Mertler, 2020, p. 141). Once the transcripts were reviewed a table (table 3) was created to understand if the characteristics had no effect, little effect, or a large effect on why these healthcare professionals nominate to genomic protocols. To distinguish between little and a large effect, I decided that if one reason was given then it was due to little effect and if more than one reason was given then it was due to a large effect based on the Mertler (2020) idea of "grouping responses into similar categories" (p.146) during open ended interviews.

Table 3

Interview Question Responses

What is your knowledge of Genomics?	
Excellent (n= 7)	70%
Excellent/Good (n=1)	10%
Good (n=1)	10%
Fair (n=0)	0%
Poor (n=1)	10%
Very Poor (n=0)	0%
Extent of Genomic Knowledge Affect Decision Making?	
No affect on Patients Treated (n=0)	0%
Little Affect (n=4)	40%
Large Affect (n=6)	60%
Ancestry	
No affect on Patients Treated (n=7)	70%
Little Affect (n=2)	20%
Large Affect (n=1)	10%
Non-English Speaking	
No affect on Patients Treated (n=2)	20%
Little Affect (n=6)	60%
Large Affect (n=2)	20%
Parental Profession or Education	
No affect on Patients Treated (n=10)	100%
Little Affect (n=0)	0%
Large Affect (n=0)	0%
Parental Absence	
No affect on Patients Treated (n=3)	30%
Little Affect (n=7)	70%
Large Affect (n=0)	0%

Parental or Family Religious Beliefs	
No affect on Patients Treated (n=5)	50%
Little Affect (n=5)	50%
Large Affect (n=0)	0%

Themes

Three themes emerged from the ten interviews with genomic professionals at this hospital, which included the need for aids to communicate with patients about these studies, the desire to have scripts during appointments, and the lack of forms to recruit diverse patients. Therefore, follow up questions were asked during the interviews about the types of tools needed to arm healthcare professionals and discussions with the executives of the genomic department occurred to create these tools. While none of these tools specifically are aimed at recruiting more Black or African American participants specifically, they can be used to open doors in genomic appointments for all populations.

Aids to Communicate.

Amendola (2018) stated that “although knowledge of genetic testing is increasing in diverse communities, social and cultural context can be expected to influence the success of genetic services” (p.324). Interviewee one stated that “there was the lack of tools or diagrams that could be used during visits to discuss these studies”. Therefore, a follow up question was added to subsequent interviews to see if there was a desire to have a diagram or communication tools during appointments. All interviewees but one stated that having a diagram or work aid during appointments would be helpful with all families and would encourage them to nominate more diverse populations. Interviewee eight stated that she “often uses diagrams during appointments and these visual aids are very helpful”. Therefore, the need to arm these healthcare professionals with tools to communicate effectively is critical.

Develop Communication Scripts.

Another concern from several interviewees was that there was no standard way to discuss studies with patients. Perez-Stable (2018) mentioned that “Although challenging, effective communication between clinicians and patients is essential to improved healthcare per numerous ethical and professional guidelines such as the American Medical Association’s Principles of Medical Ethics” (p.18). Therefore, the idea of creating a script for healthcare professionals and/or translators was developed. Interviewee two stated that they didn’t like to use translators because in an appointment “the translator used the word cure when I used the word treat”. Therefore, a standard script may help the translator use universal language when discussing these studies with patients. The other issue that came from these interviews was that in some languages there are no transferable words for genetic terms to describe the procedures and results to patients. If English is not the primary language, then using words in a script that are like genomic terms and standardized may be helpful when describing these studies. Perez-Stable (2018) suggested that the shared decision model (SDM) may be effective in patient-centered situations. Therefore, to combat poor communication skills “it is imperative that in language discordant encounters the interpreter be professionally trained with standard quality control (Perez-Stable, 2018, p. 15).

Lack of Tools.

When I asked about communication with non-English speaking families it was unanimous concern because we do not have short forms or translated consent forms for these studies. Seventy percent of the participant's said ancestry does not influence their decision to nominate and two of the participants mentioned that there is an issue with a lack of diversity in the genomic databases and the need to expand research populations. However, all stated that they simply cannot nominate due to a lack of IRB approved forms in patients' native language. Amendola et al (2018) stated that "additional challenges for genomic medicine implementation research in underserved groups include a lack of diversity in the scientific community, smaller sample sizes, and the analytical challenges faced when studying participants of mixed ancestry" (p.320). Interviewee eight stated that "due to a lack of diversity in our clinical records, we receive generic results that are not applicable to our patient and then we have wasted the patient's time and money". Therefore, creating short forms in the top ten languages may be critical in diversifying our population.

Overall, the interviews seemed to focus on communication and the lack of tools to be able to successfully explain genomic studies to certain populations. By using the CRT lens, the ideas of implicit bias and structural racialization were examined and while overt biases were not expressed, underlying communication issues can still lead to unconscious actions. Perez-Stable (2018) suggested that "select patient (i.e., language proficiency, health and digital literacy) and clinician (i.e., cultural competency, communication skills, unconscious bias) factors that may contribute to poor patient- clinician communication" (p.7) and are "interconnected in complex ways and rarely can be considered in isolation" (p.7).

Action Plan

To understand the research problem, I used a qualitative action research design to gain insight from healthcare professionals on their thought process while nominating patients to genomic studies. By leveraging my theoretical framework of CRT, I took the works of Conyers (2020) and wanted to create an action plan surrounding the numerous ideas that address why marginalized populations are not present in research studies. "CRT is utilized as a tool to explain the existence, persistence, and pervasiveness of IRP" (Conyers, 2021, p. 485). One theme that surrounded all interview questions was the notion of communication, meaning there were no tools for communication and there seemed to be a lack of being able to communicate with diverse patients. Therefore, after additional literature review, developing a verbal, nonverbal, and written communication plan seemed to be an important step in this action research study.

CHAPTER THREE: DESCRIPTION OF ACTION/INTERVENTION/CHANGE PROCESS

Description of Action/Intervention/Change Process

According to Joseph, et al (2019), “Gaps in effective communication (where all parties share a common understanding) are widely recognized as a major contributor to health disparities (p.358). If communication between healthcare providers and minority patients is occurring, then that could lead to the gaps of nomination to research protocols. This action research plan is not solely focused on the Black or African American community but aims to champion diversity for all communities seeking genomic information.

According to Alase (2017), by utilizing the IPA paradigm “the researcher has positioned himself or herself to capture and represent the ‘core essence’ of the ‘lived experiences’ of the research participants without distorting or misrepresenting the ‘core essence’ of what the participants have experienced” (p.16). To do that, strategies were developed to provide communication tools to healthcare workers during genomic appointments.

Three goals described in the action planning models (see tables 4 and 5) include creating a diagram or work aid to be used in patient appointments, designing a script for the ease of discussing genomic studies, and the development of short forms which are translated informed consent forms. To reach these goals, steps were developed to ensure stakeholders buy in and that goals to expand diversity in genomic studies at this hospital are achieved. These included discussion of genomic tools with hospital healthcare workers and peer debriefing.

Goal One: Create and Use a Diagram or Work Aid in Appointments to Describe Genomic Studies

During interviews, a challenge in communication was described as exacerbated by limited proficiency or low health literacy (Perez-Stable, 2014, p. 8). Perez-Stable (2018) stated:

> Among American adults 53% have intermediate and 22% have basic health literacy levels. However, race/ethnic minorities disproportionately had limited health literacy with 24% of Blacks, 41% of Latinos, 13% of Asians/Pacific Islanders, and 25% of American Indians/Alaska Natives compared to 9% of Whites. (p.8)

In an article that focused on communication of genetics for patients with breast cancer, van der Giessen (2020) indicated:

> In general, limited health literacy is associated with lower genomic related knowledge and it effects patients' understanding of print and oral communications about genetic and genomic information, so adapting communication to patients with limited health literacy is important in different settings of genetic counseling. (p.288)

To create a diagram or work aid that could be used during patient appointments to describe genomic studies to all populations, constructing an action plan from Stringer (2020, p.201) was implemented. First, I started off deciding what the major issues were and what components needed to be included in the communication diagram. Next, I wrote down a list of topics that are explained during a genomics appointment. For example, a high-level explanation of genomics, how do we test, what can we find, what will happen next, and how will this help me and my family. After that, I organized these issues on a PowerPoint document and created visuals to describe each step by using Microsoft PowerPoint Icons. After speaking with former colleagues, they suggested using The Greenwood Genetic Counseling Aid (Greenwood Genetics Center, 2022) as a resource to create pictures for a communication tool since it is a highly regarded center in the genetic counseling field. The Greenwood Genetic Counseling Aid has been designed to be used by healthcare professionals in many settings and uses updated graphic designs to help explain genomics (Greenwood Genetics Center, 2022). A purchased visual aid from Greenwood Genetics (Greenwood Genetics Center, 2022) was included to illustrate examples of cancer syndromes in different sections of the body. These steps were then arranged in order of the discussion flow, starting with understanding how genomics affect a person's health and ending with a questions section. Included in the questions section, a chart indicating a person's chance for developing a genetic disorder was created by using the Icon Array tool (2022). The Icon Array tool (2022) can be manipulated and downloaded at any time to display outcomes for a study, disease, or treatment.

While creating this work aid, I wanted to avoid jargon by using plain language while ensuring I included all the important topics that could potentially be discussed. To assess readability of the document, the Flesch/Flesch Kincaid formula (2023) was utilized to ensure words chosen for the work aid were understood by most readers. By using the Flesch (2023) reading ease score, words on the PowerPoint were added to a word document to assess readability. Scores on the Flesch reading ease scale range between 1 and 100. Scores between 70-80 represent an 8th grade US school grade level with 100 being the highest readability (Readable, 2023). According to the word document, the

Flesch reading ease score was 95.4. The Flesch Kincaid score (2023) indicates the reading level from basic to skilled with a score between 0-18. According to the word document, the reading level from my work aid was 0.8, indicating it is at the basic reading level for the US grade level of education (Readable, 2023). By using the Flesch/Flesch Kincaid formula I felt more confident in the accessibility of this work aid (appendix C), and this is a tool that most IRB's recognize.

Goal Two: Create a Script

The overarching goal of creating a script for healthcare professionals was to provide a high-level tool that can be used during appointments while describing research studies to patients. Elwyn (2012) and colleagues noted that it was best to request the level of knowledge that the patients have and clarify if it is correct, describe options, offer choices, provide support for any decisions, and review these decisions. Therefore, by using the work aid in appendix C and the potential script in appendix D, healthcare professionals may be better equipped to discuss these studies with all patients. A shared decision model (SDM) was utilized from the Perez-Stable (2018) article that stated that the "SDM has been associated with improved health outcomes and seems to be most helpful in "toss-up" decisions or when there are clear similar options on management decisions" (p.10). Since the healthcare professional's role becomes secondary in a SDM paradigm, communication by creating scripts will be helpful to ensure healthcare professionals are communicating in an impactful way (Perez-Stable, 2018). To create a SDM model and a subsequent script for healthcare professionals, Elwyn (2012) described three crucial stages to decision making.

Choice talk, option talk, and *decision talk* create a stepwise process for healthcare professionals to support decisions. Choice talk ensures that patients know all the options and can be completed in person, by email, or telephone (Elwyn, 2012). With choice talk we can script the options for patients and offer background information for patients to review. Option talk is getting more into the details about the options, this would include in-person discussions to check one's knowledge (Elwyn, 2012). The last step in the SDM model is decision talk which leads the team to a decision about treatment (Elwyn, 2012). Elwyn stated that "The model outlines a stepwise process, although it is important to recognize that the model is not prescriptive clinical interactions are by necessity fluid (Elwyn, 2012, p. 1363). To create this script, a word document was created and by using the flow of steps from the diagram/work aid a script was drafted. Jargon and medical terms were kept to a minimum to achieve a Flesch reading ease (2023) score of 75.5, which means we are in line with what an average adult can read. The Flesch Kincaid (2023) grade level score was 6.6 which is equivalent to approximately a 6th grade reading level and according to readable (2023), "aim for grade 8 to ensure your content can be read by 80% of Americans". Therefore, with this reading level, the script should be useful while discussing genomic studies to patients.

Since action research is a cyclical process (Mertler, 2020), engaging stakeholders early in the script process will be important. During interviews, several other healthcare professionals were identified as being good communicators and may be used for peer debriefing. Therefore, once the script is complete by utilizing the SDM model, the document will be examined by the healthcare professionals and edited as needed. Once these scripts are vetted then they will be sent to the hospital IRB for approval. After the script is IRB approved, healthcare professionals can start using this document during appointments. When in practice, we will discuss how the scripts work with healthcare professionals, reflect on what changes need to be made, and collect objective data by reviewing patient ancestry (figure 4).

Figure 4

Action Research Stages

Goal Three: Create Short Forms

To reach non-English speaking individuals, short forms or summarized informed consent forms will be created in ten languages. The top ten languages in this area according to the U.S. Census Bureau (2020), outside of English are Spanish, Amharic (Somali), Chinese, Arabic, Yoruba (Western Africa), Nepali, French, Hindi, German, and Telugu. Since Participatory Action Research (PAR) holds the view that “PAR is reflexive and focused on bringing about change” (Creswell, 2019, p.593), a reflection step will be applied to ensure these short forms are being translated appropriately and that they are effective. Therefore, the first two languages of Spanish and Amharic will be translated and then utilized during appointments with patients. If no issues are discovered, then the next two consent forms will be translated and tested to ensure there are no concerns with usability. Mertler (2020), suggested that "in order to develop adequate rigor, it is critical to proceed through a number of cycles, using earlier cycles to help inform how to conduct later cycles" (p.27). Adding in a reflection stage (Mertler, 2020) once the first two forms are utilized, will help to address the effectiveness of these forms. Once these short forms are designed, amendments to the hospital IRB will be created and then once approved will be sent to healthcare professionals that nominate to genomic protocols for use while discussing genomics with patients.

Table 4

Outcomes and Objectives

Objectives and Outcomes (What)	**Tasks (How)**	**Person(s) (Who)**	**Time (When)**	**Location (Where)**	**Resources**	**Funds**
Objective 1: Develop strategies to explain genomic	A. Create a diagram or work aid for communication with patients by	Researcher, Hospital staff	10/2022-12/2023	A. Via PPT B. Via email and zoom.	A. PPT B. Zoom C. IRB at hospital	A. The researcher paid for the Greenwood Genetic

research studies. Outcome 1: Provide IRB approved tools to healthcare professionals to explain genomic studies to patients	using the Iconarray website and tools from the Greenwood Genetics genetic Counseling Aids B. Take the diagram or work aid to stakeholders for review. C. Get diagram or work aid IRB approved for use in studies.			C. IRB portal		Counseling Aids

Objective 2: Develop communication skills and plans to explain genomic research studies based on a Shared Decision-Making Model (Perez-Stable, 2018) Outcome 2: Create an IRB approved script for healthcare professionals to use when	A. Reach out to fellows and other staff that have been good communicators to understand strategies in good communication with potential patients. B. Create a script for healthcare professionals to communicate with patients by	Researcher, Hospital staff	10/2022-12/2023	A. Via PPT B. Via email and zoom. C. IRB portal	A. PPT B. Zoom C. IRB at hospital	NA

explaining genomic studies	using a shared decision-making model (Perez-Stable, 2018)					
Objective 3: Identify short forms for non-English speaking patients. Outcome 3: Create IRB approved short forms for non-English speaking families to	A. Work with hospital translators to create short forms for 10 ten languages in the area. B. submit to hospital IRB for approval	Researcher, Hospital staff	10/2022-12/2023	A. Via email B. IRB portal	A. Word	Potential cost of using translational services

communicate genomic studies in their native language.						

Analysis of Implementation to Date and/or Future Implementation

Communication of Action Plan

To carry out this action plan, an evaluation model was created (table 5) to "represent the logic model components, evaluation questions, indicators, and targets by logic model strategies, early and immediate objectives, and long-term goals" (Giancola, 2021, p.155). The goals and objectives for this action plan are rooted in the notion that health care professionals have a lack of tools to communicate with diverse patients, which in turn leads to a lack of diversity in research studies at this hospital. Strategies to combat a lack of communication were developed and will be discussed with all stakeholders involved. Fortunately, this hospital has culturally responsive leaders who embrace change and these ideas will be challenged in a positive way to introduce the transformation of studies. Bryk stated that "change ideas are tested and refined based on evidence from what actually happened, both intended and otherwise" (Bryk, 2017, p.9). Three objectives were created that focused on print communication (diagram or work aid), oral communication (script), and culturally sensitive communication (translated short consent forms). This logic model was created to graphically understand how communication will be delivered to stakeholders and what inputs and outputs will be needed to reach the outcome goals. Engagement with stakeholders will be ongoing and as such need specific communication strategies and timelines which have been outlined. Using these SMART goals for communication will provide a realistic picture for this plan. With a logic model set up, an assessment of this logic model was created to gauge the process and progress of each objective. Once assessments are complete, continuous feedback from the stakeholders will be utilized to see if the tools are successful in recruiting diverse patients.

Table 5

Evaluation Matrix

Logic Model Component	**Evaluation Questions**	**Indicators**	**Targets**	**Data Source**	**Data Collection**	**Data Analysis**
Strategies/Activities and Implementation	Are we recruiting diverse patients by using these diagrams or work aids?	Review Hospital studies	Day 1, 6 months, 1 year evaluation	Excel spreadsheets from database	Internal database	Descriptive statistics

Strategies/Activities and Implementation	Have we successfully been able to communicate by using scripts based on the SDM model?	Discuss with healthcare professionals	6 months and 1 year evaluation	Hospital Healthcare professionals	Semi-structured Interviews	Coding
Strategies/Activities and Implementation	Are the short forms successful in explaining studies to non-	Discuss with healthcare professionals	Annually at IRB review	Hospital Healthcare professionals	Semi-structured Interviews	Coding

	English speaking patients?					

Potential Barriers While Implementing Plan

While creating these communication tools additional articles were reviewed to ensure effectiveness and to search for potential barriers. Canedo, et al. (2020) created focus groups in diverse populations to address knowledge and awareness for the term's genes, genetics, and personalized medicine. Most subjects in these focus groups knew about genes and understood they were related to human traits, however "None of the focus group participants mentioned that doctors or other healthcare providers had explained to them what genes are" (Canedo, 2020, p. 5). Furthermore, the article stated that participants that understood the word gene had little knowledge of the word genetics. Canedo (2020), stated that "Different terms used for new healthcare approaches, such as precision medicine and individualized/personalized medicine create concern, confusion, and fear among people in marginalized socioeconomic and cultural groups" (p.10). This fear stemmed not only from illness, but also from fear of losing insurance, access to healthcare, financial liability, and the novelty of the field of precision medicine. In a separate study, Diaz, and colleagues (2014) discussed genomic studies with diverse subjects and discovered that "individuals may not be aware of terms such as 'personalized' or 'genomic' medicine, but after a brief explanation can recognize how genes can play an important role in medical care" (p.5). Therefore, not only is there an issue with terminology but potentially an issue with awareness and understanding of the benefits of genomic sequencing. The scripts include several different terms meaning the same concept and explanations of what those terms need to be included.

With these known barriers, a plan "B" or a follow up plan will need to be considered. Eggly (2022) and team designed a training module for healthcare professionals to review effective and ineffective strategies during clinical appointments. A series of videos were created with input from stakeholders, oncologists, and cancer survivors. Their aim was to provide "more frequent and higher-quality communication about clinical trials, especially with the diverse patient populations who stand to benefit most" (Eggly, 2022, p. 5). This was a pilot study, however, early evidence suggested that this was an effective training to enhance communication skills for healthcare professionals. The Cancer Health Assessments Reaching Many also known as CHARM (2021) study evaluated several interventions that related to disparities in healthcare and as a part of their study provided robust training to genetic counselors and interpreters. Early results from the CHARM (2021) study were positive and provide some guidelines for training if a plan B is needed.

Analysis of Organizational Change & Leadership Practice

Organizational Change

According to Hatch (2018), incremental change is "deep and lasting cultural change that occurs only when a strategy is different, but not incompatible with existing assumptions and values" (p. 212). Providing these tools to our organization seems to be in line with the foundation created to incorporate change and eliminate systemic racism.

These tools can be modified and used more widely in other studies throughout this hospital. This action research study may provide more awareness surrounding the need for more simple language while describing research studies and the local IRB may require more translated consents in the future. By utilizing an emergent process, the organizational leaders should challenge the research institute to incorporate these approaches to create lasting change. Stringer and team (2020) discussed the need for action research processes to evolve within an organization for change to last. “The purpose of courageous conversations is not only to accomplish gradual change in our systems, but to urgently and radically embrace the possibility of eliminating racial achievement disparities” (Singleton, 2015, p.227). Glenn Singleton (2015) described the need for courageous conversations throughout the whole organization and thought that administration needed to set the standards to achieve change goals. Once better standards are implemented throughout this hospital then hopefully gaps in diversity will decline.

Reflection

Initially positioning myself as a transformational leader during this action research project enabled me to “initiate, develop, and carry out significant changes in organizations” (Northouse, 2019, p.201). This hospital has clear values and norms and my role as a leader was to understand deficiencies in the system that may lead to unseen racism. My goal for this action research project was to understand the thought process of healthcare professionals, build trust, and collaborate with colleagues to transform our system. When I began this journey, I thought I was going to uncover structures of implicit bias that lead to the discrimination of marginalized communities. Based on the advice from Creswell (2013), after each interview, I reflected on the process to separate my personal views from the data. I listened to the recordings several times with the theory of critical race on the forefront of my mind and challenged myself to focus on the ideology of racism (Yosso, 2005, p.5). By using CRT, it allowed me to "bring racial paralysis from the personal to the institutional level" (Conyers, 2021, p.493). Not one interviewee displayed any type of overt implicit bias but did convey that they had a lack of tools to work with all populations. With this eureka moment, I assumed an adaptive leadership style and stepped back to find perspective (Northouse, 2019). I shifted my focus and started researching literature involving the lack of communication surrounding medicine, healthcare, and genomics. I was surprised to discover a sparse amount of literature describing these communication issues but found more recent articles that are starting courageous conversations and collecting data to pinpoint the issues. Once these ideas were on paper, peer debriefing (Mertler, 2020, p.143) was utilized to critique and reflect on my action research goals.

Implications for Practice & Future Research

Populating Databases and Informing Health Disparity

In the past 20 years, genetic testing and research has significantly increased, yet trends of gaps in diversity have continued and awareness of this issue needs to be addressed in all settings. Historic data surrounding the disparity in research with Black or African Americans suggests that "the most common barriers to participation included fear and mistrust of research due to multiple factors, such as lack of information about research and prevailing knowledge of historical occurrences" (Hughes, 2017, p.348). Therefore, by equipping healthcare professionals with as many communication tools to discuss and describe genomic studies to an array of people may lessen this historic gap.

This study revealed that although healthcare professionals at this hospital have an extensive knowledge of genomics, they may not be fully armed with genomic educational material to speak with the public and do not have the tools to discuss studies with diverse populations.

Diversifying research may have many benefits to the Black or African American and all minority communities. For example, Hendricks-Sturrup and team (2020) discussed that the underrepresentation of Black or African Americans in genomic research has led to underdiagnosed fatal genetic conditions like "transthyretin (TTR)-related hereditary cardiac amyloidosis, a genetic disease that warrants treatment with tafamidis, a pharmacogenomic drug that is Food and Drug Administration (FDA)-indicated for the TTR biomarker" (p.2). Without generating diverse population databases, these potentially treatable genomic disorders may go undiagnosed, untreated, and may lead to unnecessary death. Hendricks-Sturrup and team (2020) also thought that the effectiveness of genetic testing could be quantified if researchers are actively depositing diverse genetic information into public databases. Even as early as 2002, Harold Varmus discussed the importance of populating genomic databases and stated that "genomes are natural entry points for teaching many of the principles of biological design, including evolution, gene organization and expression, organismal development, and disease (p.1). Another example of the importance of genomic testing as pointed out by Rotimi (2012) is the survival rates for certain cancers like childhood acute lymphoblastic leukemia (ALL). Childhood ALL has approximately a 90% 5-year survival rate, yet Black non-Hispanic patients have approximately a 62% 5-year survival rate (Zhao, 2021). Zhao at team (2021) suggested that this was because there was a lack of participation in clinical trials, no access to trials, and the lack of insurance. Recognizing limitations and barriers while implementing this type of relatively new precision medicine will be key as we are trying to improve population databases to inform healthcare.

Future Research

Future research depends on many facets, but can start with funding resources, and local IRBs requiring certain standards of diversity in clinical studies. The Clinical Sequencing Evidence-Generating Research (CER) consortium that Amendola (2018) described, aimed to recruit at least 60% of patients from non-European ancestry and focused on the opportunities and challenges while presenting genomic medicine to diverse populations. The Amendola (2018) article suggested several opportunities for change, that included offering genomic training to non-academic institutions or physicians, developing relationships with the community to receive feedback and recommendations, engage stakeholders that are non-English speaking or have limited literacy to understand appropriate terms, and to utilize a shared decision model with patients to understand their needs.

The genomic department discussed in this study has many opportunities to incorporate communication tools into practice while also considering a more global impact. Leaders from this department should assess effectiveness or make appropriate updates where needed and if successful should share data with the research departments at this hospital and should encourage similar practices. Goals for this study included the assessment of implicit bias in clinical care and ended up with a different sort of conclusion. If there is disparity in other research departments, implicit bias should still be assessed with an open mind and tactics to combat these racial gaps should be addressed.

Conclusion

Overall, this research study aimed to assess blind spots in healthcare and understand how diversity can be increased in genomic studies at this hospital in the Midwest. A qualitative research study consisting of ten interviews with genomic professionals was conducted with a theoretical framework of the critical race theory and a conceptual framework of courageous conversations. The ten healthcare professionals openly discussed the need for communication tools while discussing these studies and the limitations they endured while working with diverse populations. Therefore, three main processes were created to help broaden the population in genomic studies and provide healthcare professionals with the communication skills needed to discuss these difficult studies. By using the action research stages and steps, plans will be set and procedures to reflect on the process and implement changes as needed will be created. Continuous review of all three processes will be conducted at fixed time points and stakeholder engagement will be conducted at every step. The benefits of this study include changes to practice that may lead to improved outcomes for diverse populations and may inform set-up, processes, and review of all research studies in the future.

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APPENDIX A: Invitation to Participate in Research Form Provided by the University of Dayton's IRB

INVITATION TO PARTICIPATE IN RESEARCH

Surveys and Interviews

Research Project Title: Black and African Americans Participating in Research Studies: A New Look at an Old Problem

You have been asked to participate in a research project conducted by Kristen Leraas from the University of Dayton, in the Department of Education and Health Sciences.

The purpose of the project is: The purpose of this study is to examine potential implicit bias or structural racialization with healthcare professionals who nominate patients to genomics studies at XXXX hospital.

You should read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

- Your participation in this research is voluntary. You have the right not to answer any question and to stop participating at any time for any reason. Answering the questions will take about 30-60 minutes.
- You will not be compensated for your participation.
- All of the information you tell us will be confidential.
- If this is a recorded interview, only the researcher and faculty advisor will have access to the recording and it will kept in a secure place.
- If this is a written or online survey, only the researcher and faculty advisor will have access to your responses. If you are participating in an online survey: We will not collect identifying information, but we cannot guarantee the security of the computer you use or the security of data transfer between

that computer and our data collection point. We urge you to consider this carefully when responding to these questions.

- I understand that I am ONLY eligible to participate if I am over the age of 18.

Please contact the following investigators with any questions or concerns:

Kristen Leraas, Leraask1@udayton.edu, Phone Number:937-750-0624

James L. Olive, Ph.D., Jolive1@udayton.edu, Phone Number:937-229-3177

If you feel you have been treated unfairly, or you have questions regarding your rights as a research participant, please email IRB@udayton.edu **or call (937) 229-3515.**

APPENDIX B: List of Interview Questions

Hospital Healthcare Worker Translational Study Survey

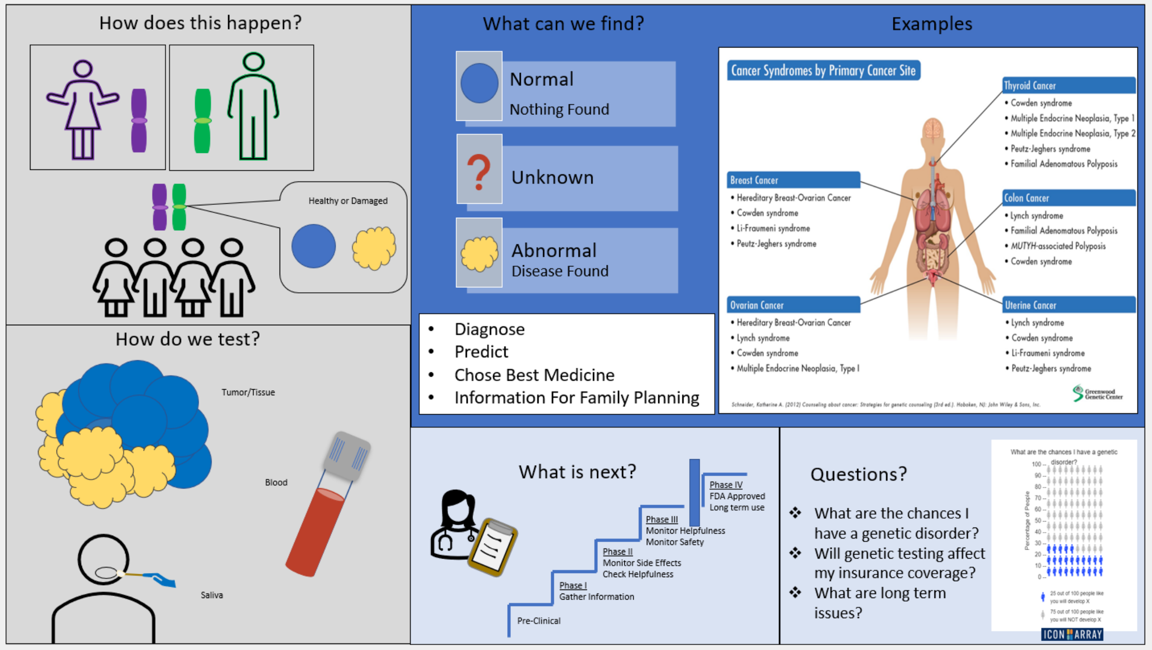
1. What is your knowledge of genomics?

   Excellent Good Fair Poor Very Poor

2. To what extent does your knowledge of genomics effect your decision to nominate patients to genomic protocols?
3. Tell me how your ancestry influences the patients you treat?
4. How do the different ancestries in your department effect the population of patients they treat?
5. If a patient (or family) is non-English speaking and need an interpreter, how does that effect the care you give to a family? Would you nominate that patient to a genomics study?
6. How does parental profession or education level influence your decision to nominate patients to genomic studies?
7. How does the absence or low level of parental involvement during visits or hospitalization impact your decision to nominate patients to a genomics protocol?
8. When recruiting patients for genomics studies, how does a patient's ancestry effect your decision to nominate?
9. If religious beliefs are known, how does that effect your decision to nominate patients to a genomics protocol? (For example if a patient was unable to give blood due to religion)
10. How do you envision genomics impacting the health and life of a child?

11. If a patient is nominated to a genomics study and there is a somatic or germline finding that could be clinically confirmed (with charges to the patient), what influences your decision to proceed with clinical confirmation?
12. Are there any other reasons your patients are not referred to genomics studies?

APPENDIX C: Diagram/Work Aid Describing Genomic Studies



How does this happen?

How do we test?

What can we find?

Normal
Nothing Found

Unknown

Abnormal
Disease Found

- Diagnose
- Predict
- Chose Best Medicine
- Information For Family Planning

Examples

Cancer Syndromes by Primary Cancer Site

Thyroid Cancer
- Cowden syndrome
- Multiple Endocrine Neoplasia, Type 1
- Multiple Endocrine Neoplasia, Type 2
- Peutz-Jeghers syndrome
- Familial Adenomatous Polyposis

Breast Cancer
- Hereditary Breast-Ovarian Cancer
- Cowden syndrome
- Li-Fraumeni syndrome
- Peutz-Jeghers syndrome

Colon Cancer
- Lynch syndrome
- Familial Adenomatous Polyposis
- *MUTYH*-associated Polyposis
- Cowden syndrome

Ovarian Cancer
- Hereditary Breast-Ovarian Cancer
- Lynch syndrome
- Cowden syndrome
- Multiple Endocrine Neoplasia, Type I

Uterine Cancer
- Lynch syndrome
- Cowden syndrome
- Li-Fraumeni syndrome
- Peutz-Jeghers syndrome

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Greenwood Genetic Center

What is next?

Pre-Clinical

Phase I
Gather Information

Phase II
Monitor Side Effects
Check Helpfulness

Phase III
Monitor Helpfulness
Monitor Safety

Phase IV
FDA Approved
Long term use

Questions?

- ❖ What are the chances I have a genetic disorder?
- ❖ Will genetic testing affect my insurance coverage?
- ❖ What are long term issues?

APPENDIX D: Potential Script for Describing Genomic Studies

Can you tell me what you know about your situation or illness?

- Add details as needed

Have you heard of the word genes or genomics?

- Yes, please tell me what genes or genomics is or isn't?
- No, genes or genomics is a process that looks at the material in your body and helps to make decisions about what we can do next.

Get work aid

Have you heard of DNA or RNA?

- Yes, please explain
- No or follow up, when parents have children, they pass down material in their body to a child. Sometimes the material can be damaged or become damaged and this leads to issues down the road.

We can test this by getting a small sample during surgery, some blood or we can swab the inside of your mouth and collect saliva.

We can find that everything is normal and there may be other answers. There is a chance that the answer will still be unknown. We could also find something in your DNA or RNA that could help us diagnose, predict, or choose the best medicine.

If we decide to do this, it could be helpful for your family as well because we may have other people we would want to test.

Here are a few examples of what could be going on in your body ***show chart***. There could be other items too that we will need to discuss if we decide to do this testing.

If we do find something there is a chance that you may qualify for clinical trial ***show stages of trials***

Do you have any questions so far?

There are a few questions that patients ask, one is about my chances of having something in my genetic material ***show IconArray Chart***. You do have a 25% chance of having something in your material that we need to look at.

Another question is about insurance. As of right now, the tests we would complete are on a research basis and the hospital would cover costs. If we do find something, then we may have to submit it to the insurance company. Typically, they cover the cost, but every now and then they do not, and we can work with you to look at those costs.

Lastly, the long-term issues could include knowing that you have something, and you want to make future plans or that your family members may be affected.

Here are our options for the next steps. ***have informed consent ready***