ABSTRACT

Title of Thesis: EVALUATION METHODS FOR A COMMUNITY-CENTERED HUMAN SUBJECTS PROTECTIONS AND RESEARCH ETHICS TRAINING: YOUR RIGHTS IN RESEARCH

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Any research project that involves human subjects requires ethical considerations and protections for individuals who enroll as participants. However, because the responsibility of these protections is often entrusted to the researchers, participants may not be aware of, and fully understand the rights to which they are entitled. The proposed training takes a preventative approach to increase awareness of protections available to individuals before they enroll in future research. The training also consists of an evaluation component to assess the extent to which the training program affects Prince George's County residents' decision-making ability regarding future research participation. The overarching goal of the project is to equip Prince George's County residents so that they are able to make informed decisions about research participation that ultimately preserve, optimize, and protect their health and quality of life to the fullest extent possible.

EVALUATION METHODS FOR A COMMUNITY-CENTERED HUMAN SUBJECTS PROTECTIONS AND RESEARCH ETHICS TRAINING: YOUR RIGHTS IN RESEARCH

by

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1. INTRODUCTION

Research involving human subjects requires ethical considerations to protect participants' rights and well-being. The responsibility of these protections is often entrusted to the researchers, which can leave participants without a thorough understanding of research processes including informed consent and data privacy and security.

The proposed project consists of two parts. The first part includes all implementation aspects of a previously designed training to increase participants' knowledge and self-efficacy regarding research processes and decision-making, as detailed in the companion piece to this work (Jordan, 2020). The second part proposes an evaluation method to assess training outcomes and understand the extent to which aims were met. The author intended to implement both the training and evaluation method at several community locations in Prince George's County, Maryland. However, due to unforeseen circumstances caused by the coronavirus pandemic, the investigator was unable to execute the full project. Thus, all materials and methods discussed are for a proposed training program for future implementation.

1.1 Project Overview

The proposed training, which consists of three three-hour training sessions on the rights and protections to which human subjects are entitled, is designed to be delivered at the following locations: College Park Academy, the First United Methodist Church in Hyattsville, and the Susan D Mona Center for Health and Wellness in Temple Hills, MD. Sites were selected because they offer services to vulnerable populations in Prince George's County. Each training session delivers the same content, regardless of location.

In order to assess training implementation process and impact, the project includes a pre-post evaluation study design with paper surveys to be administered to participants in each session prior to and upon training completion.

1.2 Research Question and Specific Aims

The project aims to address the following question: How does an ethical human subjects protections training affect community members' decision-making ability regarding research participation?

All aspects of training implementation and evaluation support the following aims:

Aim 1: To increase Prince George's County residents' knowledge of rights and protections to which participants in human subjects research are entitled

Aim 2: To enhance Prince George's County residents' sense of self-efficacy with regard to decision-making about human subjects research participation.

2. LITERATURE REVIEW

2.1. Program Implementation

Several themes emerged in the literature regarding program implementation and evaluation methods. Best practices for implementation include tailoring communication to the population of interest and considering the role of power in community relationships. Communication is examined in the context of recruitment, informed consent, and the importance of plain language. In terms of power, the literature emphasizes strengths and limitations of an empowerment approach, which can be instrumental in facilitating increased self-efficacy among training participants so that they are able to make the most appropriate and informed decisions regarding research participation.

2.1.1 Communication

One of the most important themes that emerged in the literature on effective implementation of research ethics programs for community members, was the role of communication. Several successful training programs developed best practice recommendations, which were grounded in effective communication.

2.1.1a Recruitment

Regarding recruitment methods, programs advocated for tailored efforts to reach individuals who are affected by health disparities (Coats, Stafford, Thompson, Javois & Goodman, 2015). To operationalize this recommendation, programs used a variety of recruitment methods, which included placing advertisements in local newspapers and on radio shows, holding informational sessions prior to the training, and reaching out to community organizations to utilize their network capacities (Coats, Stafford, Thompson,

Javois & Goodman, 2015; Goodman, Dias & Stafford, 2010). One program also accounted for those whose learning styles and abilities deviated from traditional norms by recommending that trainings be conducted on a platform that is accessible to unconventional learners (Goodman, Dias & Stafford, 2010). When defining the purpose of training, the same program advocated for the establishment of a common language to facilitate empowerment and provide a foundation for more equitable and collaborative partnerships in future (Goodman, Dias & Stafford, 2010).

2.1.1b Informed Consent

Communication is also an integral part of the informed consent process in public health research. A recent study conducted among African American and Latino community members revealed that participants preferred having more than one interaction with researchers and other participants and being able to take away information from those meetings (Quinn et al., 2012). Regarding the actual consent forms, participants prioritized visual aids, and brief and plain language (Quinn et al., 2012). When surveyed on their beliefs and perceptions about informed consent, the majority of participants (85% Latino, 84% African American) correctly reported that signing a consent form confirmed understanding of, and agreement to participate in the study. However, the majority of participants falsely believed that giving consent meant they were not allowed to sue the research entity and that consent was a form of protection for that entity rather than for individuals (Quinn et al., 2012). These misunderstandings could impede attempts to build trust between researchers and participants, which has implications for the relationship between researchers and participants. Therefore, these

methods and findings demonstrate how clear and considerate communication is crucial to facilitating understanding and delivering an effective community training.

2.1.1c Plain Language

In terms of communication methods, using plain writing and considering the reading level of the primary audience increases understanding of written materials (Plainlanguage.gov, "What is plain language?", n.d.). In concordance with the Plain Writing Act of 2010, the federal government has created a checklist to assist with plain writing standards (Plainlanguage.gov, "Checklist for Plain language", n.d.). These include using the active voice and using second person writing to increase readability (plainlanguage.gov, "Checklist for Plain Language"). Using this checklist to evaluate and edit materials is critical for accessibility, as described in the informed consent section.

2.1.2 Empowerment

Most research ethics trainings in the literature are designed to educate researchers while entrusting them with the responsibility of protecting study participants. While historical precedent rightfully justifies the designation of this responsibility, it is important to consider the implications of the authority researchers wield over participants and how such a power imbalance may affect the ability to forge meaningful partnerships and conduct mutually beneficial research. Even in initiatives that attempt to empower community members and prioritize their needs, those intentions may not translate or accomplish their intended goal from participants' perspectives.

Empowerment includes processes and outcomes that have been studied across various disciplines including psychology, sociology, public health, and social work (Zimmerman, 2000; Perkins & Zimmerman, 1995). In previous literature, empowerment

theory serves as a framework to guide the development and implementation of research and interventions (Zimmerman, 2000; Perkins & Zimmerman, 1995). An empowerment approach is strengths-based, meaning that it focuses on identifying existing resources and maximizing their capacity rather than assessing risk factors, needs, and deficits (Perkins & Zimmerman, 1995). In terms of the proposed project, empowerment is embedded in **Specific Aim 2**, which facilitates community members' ability to make informed-decisions about research participation.

2.1.2a Empowerment Theory Constructs

Empowerment theory is based on three overarching constructs. The first involves intrapersonal aspects that center on the extent to which an individual perceives control over their own life (Zimmerman, 2000). The second construct is interactional and focuses on the degree to which one maintains a critical awareness about social, political, and cultural determinants and how those impact the surrounding environment (Zimmerman, 2000). The final construct is behavioral and assesses the extent to which an individual is civically engaged in their community. Examples of civic engagement include participating in social and collective action and volunteering (Zimmerman, 2000). When considering empowerment process and outcomes through the lens of the social ecological model, the current project aims best align with measures at the individual-level. Specific empowerment processes of interest for the project include learning decision-making skills and collaborating with others while outcomes of interest include critical awareness and sense of control, which directly relate to self-efficacy, one of the project's main outcome measures (Zimmerman, 2000).

2.1.2b Empowerment Limitations

While an empowerment approach can be advantageous in promoting equity among specific populations and in particular contexts, there are several challenges to consider. A recent article that draws attention to these limitations argues that empowerment is inherently paradoxical in nature (Weidenstedt, 2016). Weidenstedt's argument is supported by three main claims, which counteract the goal of empowerment (2016). The first claim draws attention to the implications associated with underlying power differentials. At its core, the process of empowerment implies a transfer of power. This assumes an initial power differential exists between the two parties. Weidenstedt argues that as long as this power differential exists, it is impossible for the empowerer to completely overlook this discrepancy and thus will view the empoweree as inferior, regardless of their intentions (2016).

The second limitation is based on the idea of reciprocity and posits that empowerees might be distrustful of, and hesitant to accept the one-sided help being offered by the empowerer even if the intention is completely altruistic. Such hesitations among empowerees may also evoke a need to reciprocate out of social obligation (Weidenstedt, 2016). The final claim emphasizes the paternalistic nature of empowerment (Weidenstedt, 2016). More specifically, the author suggests that the act of empowerment can be compared to presenting a "gift" to the empoweree, yet the gift is given on the terms of the empowerer, which serves to perpetuate rather than diminish the power imbalance between the two parties (Weidenstedt, 2016). For these reasons, it is necessary for researchers to consider the implications and perceptions attached to initiatives that use an empowerment approach to ensure that goals are most meaningful

and respectful of participants' autonomy. In terms of the current project, the investigator accounts for these limitations by proposing a program that caters to potential participants, considers their experiences in research, and aims to build upon those experiences by providing knowledge to help them make fully informed decisions about research participation.

2.2 Evaluation Methods

The existing literature highlights several aspects of evaluation practices that warrant consideration in relation to ethics training programs. A recent review that examined the utility of evaluation procedures for ethics training programs focused on study design and measures as two of the most important determinants in the evaluation process (Steele et al., 2016). In terms of study design, a pre-post design with a control group was found to be most advantageous in assessing ethics training programs, followed by a pre-post test, and then a post-only design (Steele et al., 2016). Without a control group, authors note that causal effects of the training cannot be inferred to the same degree (Steele et al., 2016).

Regarding measures, the most prominent framework in the evaluation literature was developed by Kirkpatrick (1996). Kirkpatrick's system focuses on four main criteria including reaction, learning, behavior, and results (1996). The most commonly used measure of the four is reaction, which encompasses items that assess participant experiences and perceptions of the training (Kirkpatrick, 1996). Learning measures knowledge, attitude, and skill acquisition as a result of the training. Behavior refers to practices that are transferred and applied beyond the training context (Kirkpatrick, 1996). Results assesses training impact on an organizational level (Kirkpatrick, 1996). While

reactions and learning can be measured as immediate outcomes, behavior and results are long-term outcomes and must be assessed beyond the training context (Steele et al., 2016; Kirkpatrick, 1996).

Upon reviewing evaluation studies of research ethics training programs that cater specifically to community members, several themes emerged. Most studies applied a pre-post design and collected a combination of qualitative and quantitative data from participants to assess training sessions (Cadman et al., 2014; Coats, Stafford, Thompson, Javois & Goodman, 2015; Goodman, Dias & Stafford, 2010; Rivera & Borasky, 2009). Open-ended survey items were commonly used to measure participant reactions to the training and elicit suggestions for improvement (Cadman et al., 2014; Coats, Stafford, Thompson, Javois & Goodman, 2015; Goodman, Dias & Stafford, 2010). Two community program evaluations assessed content retention and knowledge acquisition to evaluate learning outcomes. In terms of analytic strategies, paired t-tests and Wilcoxon Signed-Rank tests were used to measure changes in pre- and post-survey scores (Coats, Stafford, Thompson, Javois & Goodman, 2015; Goodman, Dias & Stafford, 2010).

3. METHODS

3.1 Training Program Implementation

The training program, which consists of a three-hour session as detailed in Jordan, 2020, will be implemented at each of the three community partner sites. Trainings at the Mona Center and at First United Methodist Church of Hyattsville are designed around existing meal service times to maximize participation. The training at College Park Academy is designed for a weekend morning as parents had indicated that this time was convenient during another training session.

3.1.1 Sampling Methods

The researcher will use convenience and snowball sampling methods to recruit participants. A potential benefit of snowball sampling in this population is that participants will have a social connection attending the training, and thus will be more likely to participate and to have access to transportation. Inclusion criteria require the individual to be a legal adult and speak English. Language is a constraint based on proficiency and resources allotted to the investigator.

3.1.2 Recruitment

After receiving approval from the Institutional Review Board (IRB), participants will be recruited from the community partner sites: College Park Academy, The First United Methodist Church of Hyattsville, and the Mona Center (see **Appendix A. Budget and IRB Approval**). The investigator designed a flier that contains logistic information to be given to potential participants (see **Appendix B. Recruitment Materials**). At both the church and the Mona Center, the investigator will approach individuals in-person, share the flier, discuss the study, obtain written informed consent, and complete

registration with potential enrollees upon initial contact. At the school location, the investigator will rely on the school's communication methods to send out the flier and notify parents about the upcoming training. Interested parties will then contact the investigator to give written informed consent and complete registration for the training via an online survey in Qualtrics. The investigator aims to enroll 20 participants per location.

3.2 Evaluation Measures and Survey Development

To understand the degree to which the program supported the project's specific aims, the investigator developed a pre-post evaluation. The pre-post design is advantageous because it allows the investigator to establish a baseline and to assess change in participant knowledge, attitude, and skill acquisition upon training completion. The outcomes of interest are (1) content retention and (2) participants' self-efficacy level as it relates to their ability to make informed decisions about research participation (see **Specific Aims**).

3.3 Measures

Measures are designed based on outcomes of interest as well as content and materials presented during the training program. The content retention measures consist of seven items that ask participants to indicate the extent to which they think or know a statement to be true or false using a 5-point Likert Scale with response options ranging from "I know this is false" to "I know this is true". Measures relate directly to information shared during the training. Content measures are scored by summing the responses for all items and dividing by the total number of items to calculate an average score for each participant (see **Appendix C. Evaluation Materials**).

Self-efficacy measures include the New General Self-Efficacy Scale (NGSES) and a novel Research Decision-Making Efficacy Scale (RDMES) (Chen, Gully & Eden, 2001). Chen and colleagues' New General Self-Efficacy Scale (NGSES) (2001) is an eight-item measure that has been validated for the project's population of interest, which includes low income African American adults and Latinx adults (Chen, Gully & Eden, 2001; Roman et al., 2009; Businelle et al., 2013). The scale is developed to match a 6th grade readability level. The NGSES, which asks participants to indicate their level of agreement using a 5-point Likert Scale with response options ranging from "strongly disagree" to "strongly agree", is used to establish a baseline for participants' general self-efficacy levels (Chen, Gully & Eden, 2001). The scale is scored by summing the response options for all items and dividing by the total number of items to calculate an average score for each participant (see **Appendix C.**).

Due to a lack of accessible and validated measures for evaluating research efficacy, the investigator designed the novel RDMES to assess participants' self-efficacy levels with regard to decision-making about research participation, using the same 5-point scale as the NGSES (Chen, Gully & Eden, 2001). Development of the novel RDMES was informed by, and adapted from the NGSES, the Research and Knowledge Scale, and the current project aims (Chen, Gully & Eden, 2001; Powell et al., 2017). This scale is also scored in a similar manner to that of the NGSES for consistency (see **Appendix C.**).

3.4 Registration Survey Development

During registration, the investigator will collect demographic data and previous research participation history in order to shorten the length of the pre- and post-surveys.

Demographics are selected to understand participants' backgrounds without eliciting emotional distress. To avoid this, the investigator omitted questions related to preferred language and citizenship status given the current tensions around immigration in the United States. Previous research participation is also included in the survey to better understand individuals' past experiences and how this may affect their opinions of research (see **Appendix C.**).

3.5 Pre- and Post-Survey Development

Participants will be asked to fill out two surveys prior to and upon training completion. The surveys are designed to take 20 minutes each to limit the amount of training time spent on the surveys and to reduce form intimidation among participants. The pre-survey includes content retention measures, the NGSES, and the RDMES (Chen, Gully & Eden, 2001). The post-survey contains the same content retention measures and the RDMES (see **Appendix C.**). The NGSES is only included on the pre-survey to establish a baseline for participants' general self-efficacy levels. To account for participant literacy, both surveys are designed at an eighth-grade reading level.

3.6 Data Collection

3.6.1 Registration Data

Upon obtaining written informed consent from participants, the investigator will administer the registration survey to collect demographic data. At the church and the Mona Center, the survey will be available on paper. For College Park Academy, the registration survey will be administered online via Qualtrics.

3.6.2 Evaluation Data

Hard copies of the pre-survey and post-survey will be available to ensure collection and prevent missing data from online surveys. The investigator also recognizes that some participants will not have access to a device or an Internet connection, so paper copies are included to address accessibility concerns.

3.7 Data Storage and Analysis

To begin analysis, the investigator will enter the pre-survey and post-survey data into Microsoft Excel. Paper surveys and registration forms will be kept in a locking folder for transportation and storage. Electronic data will be stored on box.umd.edu, a confidential and secure cloud storage system. Participant identifying information will be kept confidential and will only be known to the author and advisors.

The investigator will conduct all data analyses in SPSS. Frequency distributions will be reported for demographic information collected on the registration form and for each measure on pre- and post-surveys. Mean scores and standard deviations for each survey item as well as an aggregate mean score will be calculated and reported for both the pre- and post-survey. Change from pre to post-survey scores for each item as well as change from pre- to post-survey aggregate scores will be assessed using the Wilcoxon Signed-Rank test, which was selected over the paired t-test because it is non-parametric.

Table 1. Success Criteria by Measure

Domain	Measure (based on specific items in surveys)	Criteria for Success
Research Efficacy	Percent reporting a 4 or higher on "I feel like I understand research studies"	Seventy-five percent of participants will improve in score from pre- to post-survey.
	Percent reporting a 4 or higher on "If I were asked to be in a study, I would know what questions to ask"	
	Percent reporting a 4 or higher on "I feel confident in my ability to refuse if I did not want to be in a study"	
	Percent reporting a 4 or higher on "If I wanted to leave a study, I feel confident that I could"	
	Percent reporting a 4 or higher on "If I became uncomfortable during a study, I would say something"	
	Percent reporting a 4 or higher "Keeping my personal information private is important to me"	
Content Retention	Percent reporting 1 or better on "All research projects involving human subjects are checked by ethical review boards before they happen"	Seventy-five percent of participants will improve in score from pre- to post-survey.
	Percent reporting 1 or better on "If I agree to a study, I can't back out. I have to stay in for the whole study"	
	Percent reporting 1 or better on "Researchers can't public my name or anything else that can be used to identify me without my permissions"	
	Percent reporting 1 or better on "Government records like birth certificates can't be used by researchers without my permission"	
	Percent reporting 1 or better on "If I give my DNA (like a blood sample or spit) to one research study, my DNA can't be used in any other research studies"	
	Percent reporting 1 or better on "If I am worried about problems with a study, I can call the university or organization to get my concerns addressed"	
	Percent reporting 1 or higher on "Informed consent means that I know what the study is asking of me and that I agree to participate"	

3.8 Evaluation Criteria for Success

As seen in **Table 1**, the overall content retention measure is based on a 5-point spread ranging from a possible mean score of -2 to 2. The criterion for success threshold was selected to ensure that the majority of participants who attend the training increase their scores from pre- to post-survey completion. The overall research efficacy measure is based on a 5 point-spread ranging from a possible mean score of 1 to 5. The criterion for success threshold was selected to be consistent with the content retention criterion.

3.9 Strengths and Limitations

There are several methodologic strengths of the proposed program. For instance, implementation efforts include a discussion of informed consent with participants as well as varying the locations of the training program to reach a diverse portion of the population in Prince George's County, MD. In terms of training evaluation, the pre-post design is advantageous because it allows the investigator to establish a baseline and to assess change in participant knowledge, attitude, and skill acquisition upon training completion. The investigator limited the length of both pre- and post-surveys and tailored survey language to ensure it is appropriate for the population of interest. Measures are also designed specifically to reflect training content.

The main limitation of this project involves time constraints. Due to the time requirements and deadlines associated with the MPH thesis project, the investigator was unable to conduct a systematic literature review, institute a needs assessment in the community of interest, offer longer or multiple training sessions, and conduct an extensive evaluation. In terms of measures, there was a lack of validated measures for research efficacy for the primary population. Thus, the investigator developed novel

measures to evaluate research efficacy. Further studies should be conducted to evaluate and validate the novel measure. Since this project is a pilot study, enrollment will be relatively low and results will likely not be generalizable to the site populations or to residents of Prince George's County. Results from the study will also be fairly limited, as the investigator curtailed the amount of training time spent on pre- and post-survey completion to maximize training time.

4. PROCESS AND RECOMMENDATIONS

4.1 Timeline of project

The proposed program, Your Rights in Research, was a nine-month long endeavor beginning in late August 2019 and carrying through April 2020. The project was developed in response to a concern by the investigator about the increase in research activity in the area surrounding the University of Maryland. The training idea was proposed to faculty in early September and underwent further development to make the concept more specific and attainable. The investigator started reviewing literature in September to understand previous programs developed for community-oriented research literacy.

The investigator began selecting potential sites and developing community partnerships in October. The investigator visited the Mona Center to view the site and begin talking with leadership about use of the space for the training session. In October, the investigator identified funding available to University of Maryland students through the Do Good Institute and wrote a funding application. The application was accepted and the project received a grant of $500 (see **Appendix A.**). The investigator also made contact with the College Park Academy and began their partnership at this time.

The investigator developed a thesis proposal and defended it in November. Feedback from committee members was incorporated into the final proposal. The committee made recommendations for survey development, which included limiting the length of surveys and using validated measures whenever possible.

In January, the investigator began volunteering with the Mona Center and the First United Methodist Church in order to start building an authentic connection and to

better understand the population of interest. These locations offer free meals to the community at specified times during the week. The project was submitted for IRB review in February and the final amendment was accepted in mid-March (see **Appendix A.**). In March, surveys underwent additional modifications including further community tailoring and a final review of readability scores. The investigator conducted one successful recruitment day in March, but shortly after, received confirmation that the training sessions would not take place due to University of Maryland's shift to remote learning in response to COVID-19.

After the university's shift to an online environment, the investigator developed a new strategy with faculty advisors. Although unable to continue with training implementation, the investigator was still able to present the materials and recommendations for such a program to be implemented in the future. Modification of final materials took place through the end of March.

4.1.1 Time logistics

The original proposed concept was reduced in response to time constraints. In order to fully implement a similar project, the investigator recommends that preparations begin a full year before program implementation.

The investigator recognizes that a community assessment would have been a valuable tool prior to identification of participants and selection of training topics. Interviews with subject matter experts and community partners would have also greatly improved the quality and relevancy to the specified population. If there had been more time, the investigator would have pursued a qualitative component concerning important considerations for the program and selection of training topics.

In terms of logistics, time constraints prevented the investigator from implementing the program in alternate settings and with groups that may have also benefited from the training including members of the healthy volunteer program at the National Institutes of Health or other such recruitment sites. The investigator recommends further investigating implementation at other locations.

4.2 Partnerships

As stated in the timeline overview, the investigator began interacting with two of three potential community partner sites in October 2019, five months before the intended training implementation. The investigator added and made contact with the third community partner site in February due to concerns about obtaining adequate participation. Sites were selected based on their existing relationships with the University of Maryland and because they served vulnerable populations in Prince George's County, MD. Partnerships were essential during training development. The investigator used information from the literature review, recommendations from faculty members, partner feedback, personal observations from site visits, and comments from community members to tailor materials.

4.2.1 Building Trust

For the training program, the investigator recognized the utility of conducting community-based participatory research, which advocates for a long-term approach to partnership building (Horowitz, Robinson & Seifer, 2009). The investigator was also mindful of helicopter research endeavors and sought to minimize activities that mimic those practices. Thus, the investigator volunteered on a weekly basis to support the meal services at two partner sites. This repeated interaction helped to build a strong foundation

of trust with site organizers as well as with community members who visited these locations regularly. The investigator relied on this foundation when recruiting for the training program. People were more willing to consider the study because they recognized the investigator from weekly involvement at the sites. It is important to note that service and volunteer activities were not pursued primarily as a recruitment tool. Building meaningful connections with the people served as sufficient motivation to continue volunteering during meal services.

4.2.2 Feedback and Community Modifications

In discussing the proposed training with community partners, the investigator received feedback on several different issues including logistics of the training, the role of trust, and communication tactics.

4.2.2a Logistical Concerns

Although the investigator had selected potential times as described in the **Methods** section, community partners offered alternatives based on location availability, staffing, and their perceived attendance. Scheduling was a difficult endeavor based on the tight timetable for the investigator. Ideally, participants would select from several scheduled times to maximize convenience and attendance but given the limited time frame this was not possible. The investigator recommends securing the site and date as early as possible to avoid conflicts. In-person meetings are also preferable in order to further the relationship and better allow for questions.

4.2.2b Client Vulnerabilities

Community partners had concerns about how the investigator would approach their clients and share information. Some locations preferred posting fliers as a more

passive approach, but they were not comfortable with the investigator approaching people directly. Two partner locations had concerns about the original title of the training "Nobody's Guinea Pig: Your Rights in Research". They felt it would be offensive to individuals and requested that it be changed. In response, the investigator altered the title to simply "Your Rights in Research". Another location wanted the name to be more immediately clear. For this location, the investigator titled it "Community Workshop: Your Rights in Research".

A partner also expressed concerns over specific groups of clients, including undocumented immigrants. They felt that the data collection forms might frighten them into no longer trusting the location. For this reason, the location declined to host the training. They also noted they thought the topic would not have been of interest to their clients and that there would be low attendance. The investigator fully respected their concerns and refusal to participate.

This feedback also matches an identified limitation of the project: The accessibility of the topic at a surface level glance. Since research participant exploitation is not a commonly discussed health issue, the investigator often had to expand upon the content and rationale for the training program.

4.3 Training Program Delivery

Training session length was kept to a minimum to be respectful of participant's time. Selection of training times was based around other activities that participants were already attending, such as the free meal services. The programs were also planned to allow full attendance at those activities, timed either before or after the meal.

In terms of recruitment, individuals cited time and transportation as significant barriers to attendance. Altering their schedule to arrive early seemed to be difficult, with one participant explaining that in order to get to the program, she would need to leave three hours early to fit the bus schedule. Others cited a regular ride that was able to transport them to the meal service, but not to the earlier session times. Further consultation with people at these locations could provide alternative times or methods to attend.

Alternative opportunities were explored for offering an online training with modified activities in place of discussion. The surveys were also developed as electronic versions if participants preferred to fill out the form on their smartphones. However, the investigator observed great variation in technological access among participants, and so this idea was not further explored. Had an online training been implemented in place of in-person trainings, it would have likely created selection bias towards those who were able to attend the virtual training.

4.3.1 Compensation

Compensation for the training included twenty dollars in cash for completion of all surveys and the training session. Provision of a meal was also offered for the College Park Academy training, as a meal was available at the First United Methodist Church. In these two groups there was an observable difference in socioeconomic status. This difference could lead to differential motivation for participation, as some might participate solely for the incentive and some might be more motivated to talk about the topic or attend the training for other reasons. These motivations could have an impact on the results and knowledge retention which might create biased sample groups.

4.3.2 Considerations around Power

As previously discussed, positions as researchers and 'the researched' can create a powerful dynamic that can mimic and reinforce systems of oppression. One notable observation about this was some people's reaction to the word "research". Even though the investigator only conducted one day of recruitment, there were several relevant conversations about research and the perception of research.

The investigator had a conversation with an older African American woman. The researcher began the conversation using language similar to the recruitment script (see **Appendix B.**). By the time the investigator had said both the words "workshop" and "research" she was resolutely shaking her head no. The woman expressed that she had no interest in taking part in research and implied that researchers would not have her best interests at heart. She told the investigator that she currently receives primary care at the NIH in Bethesda, remarking that it was like a "castle". She made a statement that the NIH was always kept very nice and clean and that she had never seen any homeless people there. Her phrasing and tone insinuated that there is a line between the people at NIH and people like her. Through the conversation, the woman implied that research is something that happens to you, rather than an equal process. She agreed with statements concerning a lack of transparency in data use and seemed to have low trust in the researchers she had met. The statement that troubled the investigator was that she stated she received primary care at the NIH, but to the investigator's knowledge, the NIH does not offer care that is not research-related. The investigator inquired about the woman's knowledge concerning her rights in the situation, but she did not seem to believe there was a way to prevent her information from being used, even when told about human

subject protections. She acknowledged that her medical records probably were being used in research but was not interested in learning more about human subject rights.

Another conversation of note happened shortly after with a different woman, also an African American grandmother. The investigator began the conversation about the training, stating that the topic involves health research. The woman replied back “What are you going to take from me?”. The investigator understood the question’s implications and tried to answer honestly, saying that they were interested only in her opinion. The two women talked about their perceptions of research briefly, and both declined to participate.

These conversations were powerful reminders of the importance of building trust between community members and researchers. The researcher tried to be reflexive in the moment and truly listen to and accept the experiences that individuals had, rather than trying to ensure recruitment for the training. The researcher also recognizes that some of these comments were shared openly because of previous conversations and connections the researcher had with these women. Recruitment strategies often aim for optimum enrollment and low refusal rates, however, reasons for non-participation can lend rich and crucial information for the project. These comments were valuable and will be taken in consideration as course material is made and recruitment is re-evaluated.

5. SIGNIFICANCE AND INNOVATION

Most research ethics training programs in the literature are designed for researchers. Thus, the proposed project is innovative because it aims to equip community members with knowledge of their rights prior to enrolling in research in order to facilitate their ability to make informed decisions about research participation. While innovative, this approach may limit the degree to which the training program is effective as the population of interest has not specifically indicated an intent to participate in research. In terms of long-term impact, the proposed initiative is innovative because it lays the foundation and sets the tone for future collaborations between community members and researchers on subsequent research projects that take place at each of the partner sites.

In future, the investigator recommends piloting the program at each of the community partner sites to understand the effectiveness and utility of the trainings for the population of interest. The investigator acknowledges that program implementation is an iterative process and recommends incorporating participant feedback into subsequent training sessions to ensure they provide relevant, accessible, and applicable information.

6. CONCLUSION

The proposed project aims to implement and evaluate an interactive training program to increase participants' knowledge about the rights and protections to which human subjects are entitled before they choose to participate in research. As demonstrated through the literature and investigator's experiences conducting the project, building community partnerships, considering the role of power, tailoring communication, and accounting for accessibility are essential components of a successful training program that leverages participants' autonomy. The University of Maryland has laid the groundwork for collaboration and service to the surrounding community and this project would not have been possible without that foundation. Implementation of the training program and evaluation serves to further strengthen the relationship between university researchers and community members in an equitable and just manner. Most importantly, this program is intended to benefit the community so that they are able to use the knowledge and skills gained in the training to be active and informed decision-makers about research participation.

Please refer to the companion piece to this work, Jordan, 2020, for the theoretical foundation of the program and for the development of training materials for the Your Rights in Research workshop.

7. APPENDICES

7.1 Appendix A. Budget and IRB Approval

7.1.1 Budget

Your Rights in Research (YRR) Line Item Budget				
Operating Costs	**Unit**	**Cost**	**Total Proposed Amount**	**Justification/Type of Contribution**
Community Cafe, First United Methodist Church of Hyattsville	2.5 hours	$100	$250	In-Kind Donation (FUMC)
High School Room, College Park Academy	2.5 hours	$100	$250	In-Kind Donation (CPA)
Food (one meal- College Park Academy training)	20 participants	$10	$200	YRR* (100% Do Good)
Cash incentive	40 Participants	$20	$800	YRR* (37.5% Do Good; 62.5% YRR)
Equipment				
Printed Handouts and Fliers	100	$0.50	$50	HPM Dept, UMD SPH
Writing Utensils	40	$0.13	$5	HPM Dept, UMD SPH
Printed Survey materials	80	$0.10	$8	HPM Dept, UMD SPH
Source of Contributions				
College Park Academy			$250	In-Kind Donation
First United Methodist Church of Hyattsville			$250	In-Kind Donation
Do Good Institute			$500	(~32% of final cost)
Health Policy and Management Department, University of Maryland School of Public Health			$558	(~35% of final cost)
TOTAL			$1,558	

7.1.2 Funding Approval: Do Good Institute

DO GOOD INSTITUTE

DATE: November 7, 2019
TO: Your Rights and Research Project, Meg Jordan
FROM: Do Good Institute
2105 Susquehanna Hall
University of Maryland
College Park, MD 20742
RE: Award Notification Letter: Fall 2019 Do Good Mini-Grants

Dear Meg,

Congratulations on the selection of **Your Rights and Research Project** as a Fall 2019 Do Good Mini-Grant recipient!

To receive your award, you must complete an Award Disbursement Form via Terp Link on the Do Good Institute organizational account. If you are a University of Maryland student, you automatically have a Terp Link account. You will need to "Sign In With Campus ID" using your Directory ID and password to access your account and fill out this form. You will select one of the three fund disbursement options listed below. Once you have selected an option and submitted the Award Disbursement Form, we will create and send you an Official Award Letter. The Official Award Letter will need to be signed and submitted to the Do Good Institute before award disbursement can begin.

You must complete the Award Disbursement Form via Terp Link within 15 days of receiving this letter. Failure to do so may result in forfeiture of the award back to the Do Good Institute.

Fund Disbursement Options

1. State Issued Check (EIN)

- Organizations that are established with an Employer Identification Number (EIN) may request a payment via a state issued check.
- In order to create an official award letter, a W9 must be submitted with your business or nonprofit [such as an individual/sole proprietor, LLC, S Corporation, or 501(c)(3)] information and EIN.
- This fund disbursement option can take up to six weeks once you have signed and submitted the official award letter.
- State issued checks may be subject to taxation. Recipients could be required to report the award as income on their tax returns. DGI staff is prohibited from providing tax advice of any kind. It is recommended that any recipient receiving an award payment consult with a tax professional.

2. Student Organization KFS Account

- You must be a student team that applied for an award on behalf of/as part of a SGA-recognized student organization.
- If you are currently an SGA-recognized student organization, you must have received funding from the SGA during their funding allocation in order to have an assigned KFS account. If you are a SGA-recognized student organization, but have not received funding from the SGA, you will not have a KFS account and will need to select a

different fund disbursement option. Additionally, applying to become a SGA-recognized student organization does not guarantee that you will receive funding from the SGA nor does it guarantee that you will receive a KFS account. For questions about how student organizations access and use their funds, contact the Student Organization Resource Center.

- If you are unsure about your status, or if you would like to become an SGA-recognized student organization, contact Student Organization Resource Center.
- If you are a student who is a member of a student organization, but your proposal is solely your own, and not on behalf of/as part of your student organization, you will need to choose a different fund disbursement option.
- In order to create an official award letter, a KFS account number must be provided.
- This fund disbursement option can take up to five business days once you have signed and submitted the official award letter.

3. Sponsoring Office KFS Account

- You will use this option if you do not select option #1 or #2.
- You must identify a faculty/staff advisor in a sponsoring office/department/unit, or college with the ability to initiate financial transactions.
- The disbursement and handling of your funds will be at the discretion of your sponsoring office.
- In order to create an official award letter, the name and contact information of your faculty/staff advisor must be provided.
- This fund disbursement option can take up to five business days once you have signed and submitted the official award letter.

Again, make sure you select one of these options in the Award Disbursement Form via Terp Link within 15 days of receiving this letter.

On behalf of the Do Good Institute and all of our sponsors, we want to express how excited we are to be supporting your work. If you have any questions, please feel free to contact us. Congratulations once again and please stay in touch!

Sincerely,

Cali Moore
Program Coordinator, Do Good Campus
Do Good Institute, School of Public Policy

7.1.3 IRB Approval

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE:	March 10, 2020
TO:	M Jordan
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1492191-2] Master's Thesis: Community Knowledge of Research Participant's Rights
REFERENCE #:	
SUBMISSION TYPE:	Amendment/Modification
ACTION:	APPROVED
APPROVAL DATE:	March 10, 2020
EXPIRATION DATE:	March 3, 2021
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # 7

Thank you for your submission of Amendment/Modification materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

This project has been determined to be a MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of March 3, 2021.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Please note that all research records must be retained for a minimum of seven years after the completion of the project.

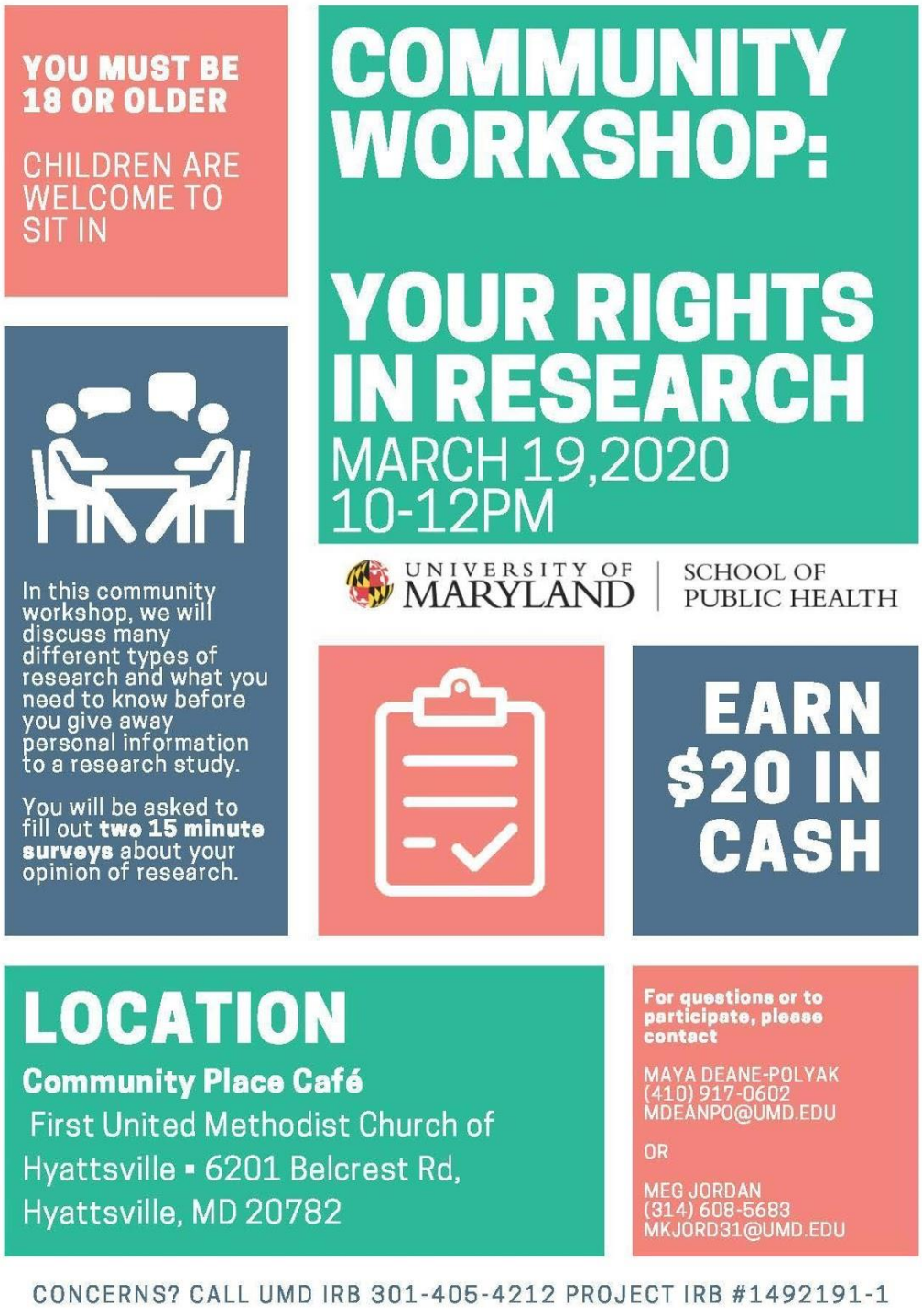
If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

7.2 Appendix B. Recruitment Materials

7.2.1 Recruitment Flier: College Park Academy

7.2.2 Recruitment Flier: First United Methodist Church of Hyattsville



7.2.3 Recruitment Script

Hello, I hope you are doing well today. My name is (Meg Jordan/Maya Deane-Polyak) and I'm a student at the University of Maryland School of Public Health.

Opening questions

- Do you mind if I ask: What have you heard about research, just in general?
- Have you ever participated in research before?
    - (If they say yes) What did you think about it?
    - (If they say no) Have you ever been curious about research?

We are going to be offering a two-hour workshop here at (location) on (date and time). If you're interested, we are going to be talking about science, research, and what you need to know should you choose to participate in research. If you're interested in the workshop, we will ask you to fill out a short registration form today, a 15 minute form before the workshop and a 15 minute form at the end. If you do all three, you will get $20 in cash.

Please feel free to bring your children, we will have an area designated for them to play.

Follow up question (chosen based on how the conversation is going)

- Does this sound like something you would be interested in?
- Do you have any questions about the workshop?
- Would that time work for you?

We will be calling/texting you to remind you about the workshop the week before and the day before (if recruited less than a week before, they will receive one call/text the day before the workshop)

If you have any further questions about the project, please contact us.

Meg Jordan
mkjord31@umd.edu
(314) 608-5683

Maya Deane-Polyak
mdeanepo@umd.edu
410-917-0602

7.2.4 Consent Form: College Park Academy (IRBnet package: 1492191-2)

Building Trust: Your Rights in Research

This study is being conducted by Meg Jordan and Maya Deane-Polyak. We are testing our newly written program "Building Trust: Your Rights in Research". In this program, we are offering a two-hour information session that will discuss the inner workings of science and research projects. In the DMV area there are a lot of opportunities to join research studies, but it isn't always clear what the project is doing or what it wants from you. In this workshop, we will discuss how to talk to researchers about their work to see if you want to participate. If you are interested in the workshop, we will ask you to fill out a survey before and after the two hour workshop. Food will also be provided as part of participation.

Who can participate in the study?
Anyone over the age of 18 can be part of the study.

What will I be asked to do in the study?
1. Register for the workshop: If you want to come to the workshop, first you need to fill out a registration form. You will be asked which time you are coming and some basic personal information. We will ask for your phone number or email in order to contact you.

We will only use your contact information to call or text to remind you one week before the workshop. We will also call or text the day before as another reminder.

2. Attend the workshop: Come to the workshop location and time you signed up for

3. Complete the pre- and post-surveys: You will be asked to complete two surveys- one given before the training and one given after the training. Each survey will take about 15 minutes to complete and includes questions about information you learned in the workshop and your thoughts on research participation. You will have 20 to 25 minutes to complete the surveys.

What will you do with this information?
All of the information that you give to us in the registration form, pre-survey, and post-survey will be kept strictly confidential. At no time will any of the information you give to us be shared with your name attached. Once we have all of the surveys, we will remove your name and any other information that could be used to trace your identity. We will give your surveys an ID number rather than use your name. The only people who will have access to your information will be Maya Deane-Polyak and Meg Jordan.

Surveys will be kept in a folder that locks during and after the workshop. After the training is over, your answers to survey questions will be typed up and kept in a secure online cloud storage system called Box. Only Maya Deane-Polyak and Meg Jordan will have access to the online storage. The paper surveys will be kept for three months in a locking file cabinet, and then shredded afterwards.

We will use the information you give us to see what you learned and to make further improvements to the workshop. The information will also be presented to professors and students at the Maryland School of Public Health.

If you have any questions about how your information will be kept private, please ask Maya Deane-Polyak or Meg Jordan.

Are there any risks of being in the study?

There is a low risk of harm from this study. There is a small chance of an accidental breach of confidentiality, but this is very unlikely because of how we will protect your information. This includes never storing your responses with your identity and reporting overall responses without any of your information attached.

The workshop will also cover some topics which can be upsetting. If you want to talk to someone after the workshop, you can call us or any of the numbers below:

The Lifeline Network: 1-800-273-8255 (Español: 1-888-628-9454) The Lifeline is available for everyone, is free, and confidential. A skilled, trained crisis worker who works at the Lifeline network crisis center closest to you will answer the phone. This person will listen to you, understand how your problem is affecting you, provide support, and share any resources that may be helpful. Or chat online at: https://suicidepreventionlifeline.org/talk-to-someone-now/

Crisis Text Line: Text HOME to 741741. This service is available 24/7 and provides free crisis support and information via text.

Substance Abuse and Mental Health Services Administration (SAMHSA) Hotline: (800) 662-4357. This service is available 24/7 and provides education, support, and connections to treatment.

What do I gain from this study?
If you fill out the registration form, attend the workshop, and fill out both surveys, you will receive $20 in cash. There will also be food provided.

Participation Procedures:
You can leave this study at any time and for any reason. In the surveys, you may skip any questions that you do not want to answer. If you wish to leave, please let us know. Your information will not be used in the final study.

Contact Information:
If you want to leave the study, have any questions, concerns or complaints, please contact Meg Jordan or Maya Deane-Polyak at mkjord31@gmail.com or 410-917-0602.

If you have any questions about your rights as a research participant, please contact the University of Maryland College Park Institutional Review Board Office at **irb@umd.edu** or **301-405-0678**.

Signature:
By signing below, you affirm that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form for your records. If you agree to participate, please sign below:

_____

(Print Name) (Signature) (Date)

7.2.5 Consent Form: First United Methodist Church of Hyattsville (IRBnet package: 1492191-2)

Community Workshop: Your Rights in Research

This study is being conducted by Meg Jordan and Maya Deane-Polyak. We are testing our newly written program: "Community Workshop: Your Rights in Research". In this program, we are offering a two-hour information session that will discuss the inner workings of science and research projects. In the DMV area there are a lot of opportunities to join research studies, but it isn't always clear what the project is doing or what it wants from you. In this workshop, we will discuss how to talk to researchers about their work to see if you want to participate. If you are interested in the workshop, we will ask you to fill out a survey before and after the two hour workshop.

Who can participate in the study?
Anyone over the age of 18 can be part of the study.

What will I be asked to do in the study?
1. Register for the workshop: If you want to come to the workshop, first you need to fill out a registration form. You will be asked which time you are coming and some basic personal information. We will ask for your phone number or email in order to contact you.

We will only use your contact information to call or text to remind you one week before the workshop. We will also call or text the day before as another reminder.

2. Attend the workshop: Come to the workshop location and time you signed up for

3. Complete the pre- and post-surveys: You will be asked to complete two surveys- one given before the training and one given after the training. Each survey will take about 15 minutes to complete and includes questions about information you learned in the workshop and your thoughts on research participation. You will have 20 to 25 minutes to complete the surveys.

What will you do with this information?
All of the information that you give to us in the registration form, pre-survey, and post-survey will be kept strictly confidential. At no time will any of the information you give to us be shared with your name attached. Once we have all of the surveys, we will remove your name and any other information that could be used to trace your identity. We will give your surveys an ID number rather than use your name. The only people who will have access to your information will be Maya Deane-Polyak and Meg Jordan.

Surveys will be kept in a folder that locks during and after the workshop. After the training is over, your answers to survey questions will be typed up and kept in a secure online cloud storage system called Box.

Only Maya Deane-Polyak and Meg Jordan will have access to the online storage. The paper surveys will be kept for three months in a locking file cabinet, and then shredded afterwards.

We will use the information you give us to see what you learned and to make further improvements to the workshop. The information will also be presented to professors and students at the Maryland School of Public Health.

If you have any questions about how your information will be kept private, please ask Maya Deane-Polyak or Meg Jordan.

Are there any risks of being in the study?

There is a low risk of harm from this study. There is a small chance of an accidental breach of confidentiality, but this is very unlikely because of how we will protect your information. This includes never storing your responses with your identity and reporting overall responses without any of your information attached.

The workshop will also cover some topics which can be upsetting. If you want to talk to someone after the workshop, you can call us or any of the numbers below:

The Lifeline Network: 1-800-273-8255 (Español: 1-888-628-9454) The Lifeline is available for everyone, is free, and confidential. A skilled, trained crisis worker who works at the Lifeline network crisis center closest to you will answer the phone. This person will listen to you, understand how your problem is affecting you, provide support, and share any resources that may be helpful. Or chat online at: https://suicidepreventionlifeline.org/talk-to-someone-now/

Crisis Text Line: Text HOME to 741741. This service is available 24/7 and provides free crisis support and information via text.

Substance Abuse and Mental Health Services Administration (SAMHSA) Hotline: (800) 662-4357. This service is available 24/7 and provides education, support, and connections to treatment.

What do I gain from this study?
If you fill out the registration form, attend the workshop, and fill out both surveys, you will receive $20 in cash.

Participation Procedures:
You can leave this study at any time and for any reason. In the surveys, you may skip any questions that you do not want to answer. If you wish to leave, please let us know. Your information will not be used in the final study.

Contact Information:
If you want to leave the study, have any questions, concerns or complaints, please contact Meg Jordan or Maya Deane-Polyak at mkjord31@gmail.com or 410-917-0602.

If you have any questions about your rights as a research participant, please contact the University of Maryland College Park Institutional Review Board Office at **irb@umd.edu** or **301-405-0678**.

Signature:
By signing below, you affirm that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form for your records. If you agree to participate, please sign below:

_____

(Print Name) (Signature) (Date)

7.3 Appendix C. Evaluation Materials
7.3.1 Registration Survey

Your Rights in Research Registration Form

Hello! Thank you for your interest in participating!

Please fill out the information below to register for the workshop.

What is your name? (First and last)

_____

Phone Number

_____

Email

_____

How do you want to be contacted for workshop reminders?

☐ Call

☐ Text

☐ Email

Will you be bringing your children with you?

☐ If yes, how many _____

☐ No/ I don't have children

What zip code do you live in (or spend the most time in)?

_____

Have you ever participated in a research project before?

☐ No

☐ Yes, once

☐ Yes, more than once

What type of research was it? (Select all that apply)

☐ Online or in person survey

☐ Medical research in a doctor's office or hospital

☐ Genetics research where I gave a sample

☐ An interview with a researcher

☐ No, I have never participated

☐ Other _____

Have you ever wanted to participate in research before this?

☐ Yes

☐ Not sure

☐ No

Do you have any questions or concerns about the workshop?

What is your age? _____

Are you of Hispanic, Spanish, or Latina ethnicity?

☐ No, not Hispanic, Spanish, or Latina

☐ Mexican, Mexican American, or Chicana

☐ South American

☐ Puerto Rican

☐ Cuban

☐ Central American

☐ Other Spanish, please specify _____

☐ I prefer not to answer

What is your race? (Please check all that apply)

☐ White

☐ Black, African American

☐ American Indian or Alaska Native

☐ Asian Indian

☐ Asian Other than Asian Indian

☐ Native Hawaiian or Pacific Islander

☐ Other (please specify) _____

☐ I prefer not to answer

How many years of education have you completed?

- ☐ 8th grade or less
- ☐ Some high school
- ☐ High school graduate
- ☐ Some college
- ☐ College graduate
- ☐ Some graduate school
- ☐ Have a graduate degree
- ☐ I prefer not to answer

Do you consider yourself to be

- ☐ Heterosexual or straight
- ☐ Gay or Lesbian
- ☐ Bisexual
- ☐ Other _____

How do you describe yourself?

- ☐ Man
- ☐ Woman
- ☐ Trans Man
- ☐ Trans Woman
- ☐ Non-binary/Genderqueer
- ☐ Other _____

7.3.2 Pre-Survey

Building Trust: Your Rights in Research Pre-Survey

Please rate how much you agree with each of the following statements:

	+1	+2	+3	+4	+5
	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I will be able to achieve most of the goals that I set for myself.	1	2	3	4	5
2. When facing difficult tasks, I am certain that I will accomplish them.	1	2	3	4	5
3. In general, I think that I can obtain outcomes that are important to me.	1	2	3	4	5
4. I believe I can succeed at most any endeavor to which I set my mind.	1	2	3	4	5
5. I will be able to successfully overcome many challenges.	1	2	3	4	5

	+1 Strongly disagree	+2 Disagree	+3 Neither agree nor disagree	+4 Agree	+5 Strongly agree
6. I am confident that I can perform effectively on many different tasks.	1	2	3	4	5
7. Compared to other people, I can do most tasks very well.	1	2	3	4	5
8. Even when things are tough, I can perform quite well.	1	2	3	4	5

Please rate how much you agree with each of the following statements:

	+1	+2	+3	+4	+5
	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I feel like I understand research studies	1	2	3	4	5
2. If I were asked to be in a study, I would know what questions to ask	1	2	3	4	5
3. I feel confident in my ability to refuse if I did not want to be in a study	1	2	3	4	5
4. If I wanted to leave a study, I feel confident that I could	1	2	3	4	5
5. If I became uncomfortable during a study, I would say something	1	2	3	4	5
6. Keeping my personal information private is important to me	1	2	3	4	5

Please rate the extent to which you think/know each of the following items to be true/false.

	-2	-1	0	+1	+2
	I know this is false	**I think this is false**	**I'm not sure**	**I think this is true**	**I know this is true**
1. All research projects involving human subjects are checked by ethical review boards before they happen	1	2	3	4	5
2. If I agree to a study, I can't back out. I have to stay in for the whole study (R)[1]	1	2	3	4	5
3. Researchers can't publish my name or anything else that can be used to identify me without my permission	1	2	3	4	5
4. Government records like birth certificates can't be used by researchers without my permission (R)	1	2	3	4	5
5. If I give my DNA (like a blood sample or spit) to one research study, my DNA can't be used in any other research studies (R)	1	2	3	4	5

[1](R) indicates that the item is reverse-coded, meaning that a response of "I know this is false" would be scored as +2, and "I know this is true" would be scored as -2.

	-2 **I know this is false**	-1 **I think this is false**	0 **I'm not sure**	+1 **I think this is true**	+2 **I know this is true**
6. If I am worried about problems with a study, I can call the university or organization to get my concerns addressed	1	2	3	4	5
7. Informed consent means that I know what the study is asking of me and that I agree to participate	1	2	3	4	5

7.3.3 Post-Survey

Building Trust: Your Rights in Research Post-Survey

Please rate the extent to which you agree with each of the following statements:

	+1	+2	+3	+4	+5
	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I feel like I understand research studies	1	2	3	4	5
2. If I were asked to be in a study, I would know what questions to ask	1	2	3	4	5
3. I feel confident in my ability to refuse if I did not want to be in a study	1	2	3	4	5
4. If I wanted to leave a study, I feel confident that I could	1	2	3	4	5
5. If I became uncomfortable during a study, I would say something	1	2	3	4	5
6. Keeping my personal information private is important to me	1	2	3	4	5

Please rate the extent to which you agree with each of the following statements:

	-2	-1	0	+1	+2
	I know this is false	**I think this is false**	**I'm not sure**	**I think this is true**	**I know this is true**
1. All research projects involving human subjects are checked by ethical review boards before they happen	1	2	3	4	5
2. If I agree to a study, I can't back out. I have to stay in for the whole study (R)[1]	1	2	3	4	5
3. Researchers can't publish my name or anything else that can be used to identify me without my permission	1	2	3	4	5
4. Government records like birth certificates can't be used by researchers without my permission (R)	1	2	3	4	5
5. If I give my DNA (like a blood sample or spit) to one research study, my DNA can't be used in any other research studie (R)	1	2	3	4	5

[1] (R) indicates that the item is reverse-coded, meaning that a response of "I know this is false" would be scored as +2, and "I know this is true" would be scored as -2.

	-2	-1	0	+1	+2
	I know this is false	**I think this is false**	**I'm not sure**	**I think this is true**	**I know this is true**
6. If I am worried about problems with a study, I can call the university or organization to get my concerns addressed	1	2	3	4	5
7. Informed consent means that I know what the study is asking of me and that I agree to participate	1	2	3	4	5

Would you have preferred this workshop to be in Spanish? Yes No

What can we do to make this workshop better?

What did you like best about the workshop?

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