Providing Public Engagement Training to Build Connections Between the Community and Research Ethics Professionals: A Pilot Project

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Abstract

There is growing interest for research ethics professionals to engage with members of the public, yet they often lack the training needed to engage effectively. The STEM Ambassador Program provides a promising framework for training research ethics professionals to form authentic community connections and carry out effective engagement activities based on shared interests and values. The experiences of ten research administrators who participated in a pilot of the STEM Ambassador training for research ethics professionals are presented. Post-training surveys of the research administrators indicate that they valued the training and the skills obtained, and intend to continue with public engagement activities with support of their leadership.

Keywords

public engagement in research, communication in research, ethics communication, science communication. professional development and training in public engagement, research ethics, public engagement in ethics

Introduction

The growing need for and interest in broadening participation in science, as well as enhancing societal impacts of scientific research, has fostered burgeoning efforts by scientists to make authentic and synergistic connections with members of the public (Besley et al., 2016, 2018a; Sacco, 2014). Science administrators have recognized that a critical component for these efforts to succeed are trainings in public engagement for scientists (Leshner, 2007). An increasing number of public engagement trainings are being offered to scientists at universities and through scientific societies. These are making inroads in enhancing the societal impact of science.

This same interest is now emerging for research ethics professionals, such as members and employees of Institutional Review Boards (IRBs) and offices, as well as employees and faculty in Human Research Protection Programs (HRPPs). The roots of these efforts have been present for decades in their professional mandates. Federal regulation and guidance specifies that an IRB must be "sufficiently qualified" (Protection of Human Subjects, 2017) to assess research according to the social and cultural attitudes and norms of the potential subject population (Johnson & Kasimatis Singleton, 2022). The purpose of such a requirement is so that the foundational ethical principles of the Belmont Report (1979) can be applied in contextually focused ways, making the research better suited to the needs, predilections, and values of the community in which it is conducted. Fundamentally, an IRB must understand the public's desire to be informed and their preferred methods of obtaining information in order to ensure an informed consent process will be effective; an IRB must understand the public's perceptions of risk and benefits in order to properly determine how to protect research participants from such risks and increase the potential benefits; an IRB must understand the conditions in a community that may result in unfair treatment in order to ensure that research procedures are just.

There is also value in establishing basic research ethics literacy among members of the public, allowing them to have greater understanding of their rights and protections other than through an informed consent document. Many current issues affect human subject research, including inadequate clinical trial participation (Krutsinger et al., 2020; Nathan, 1999; Nipp et al., 2019); diversity, inclusion, and equity (Strauss et al., 2021); and public distrust for and misinformation about science (Feine & Jakubovics, 2021; Kabat, 2017). Efforts to make science, research, and research

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protections more accessible and understood by the general public through education and engagement are critical to inform and potentially help resolve these complex issues.

One potential method for achieving these goals is through public engagement activities, in which the IRB, HRPP, and the community can exchange knowledge, ideas, and a sense of their held values. Community engagement as a tenet of ethical research is valued by the research ethics community (Dickert & Sugarman, 2005; Holzer et al., 2014; King et al., 2014) and many research-related organizations, including National Science Foundation (n.d.), the National Institutes of Health (Hood et al., 2010), Council for International Organizations of Medical Sciences (2016), and the Association for Accreditation of Human Research Protection Programs (2019). Though IRB voting members have the formal authority to make determinations regarding the conditions for approval of research, IRB and HRPP staff are critical to the day-to-day assurance that administrative and ethical practices are implemented, and often have more direct interaction with research teams and potentially research participants when it comes to studyspecific conduct and issues. Both types of research ethics professionals can contribute meaningfully to exchanges with the community they serve, as well as gain feedback and insight from the community that can directly impact their perspective on the conditions for approval of research. Additionally, gaining and using community feedback at the IRB- and HRPP-levels, instead of an individual study-level, allows for positive input to applied across many studies reviewed by the IRB, increasing the impact it can have.

However, public engagement has not often been directly implemented by IRBs and HRPPs, and outcomes from such activities have rarely been evaluated. IRBs and HRPPs have generally not been resourced to conduct activities beyond those specifically described in the Federal regulations for research review and oversight, resulting in limited connection and communication between the IRB and the community it serves, other than the federally-mandated connection of IRBs to unaffiliated, non-scientific representation within their membership (Protection of Human Subjects, 2017). Although financial and personnel resources could be devoted to IRBs and HRPPs for this purpose, another barrier stems from IRBs" and HRPPs" lack of training in effective methods for engaging with the community. In general, staff and members of IRBs and HRPPs are trained in the review and oversight of research, but do not receive guidance and resources for establishing community connections, learning about their cultures and values, delivering engagement activities, and reflecting upon and evaluating the impacts of these activities.

We propose that for research ethics professionals to engage, two key outcomes would need to be observed, based on a 2018 study by Besley, Dudo, Yuan that identified key predictors for scientists to take part in engagement activities. First, they must feel capable of performing the community engagement activities given their skills and time constraints. Second, they must believe that they can make a difference through engagement and perceive the engagement activity to be enjoyable and personally or professionally valuable (Besley et al., 2018b).

The purposes of this paper are to (1) present how a public engagement training program might provide a conceptually suitable framework for training research ethics professionals and establishing public engagement capabilities within an IRB and HRPP; and (2) report on the experiences of ten research administrators employed by an IRB and HRPP who participated in an engagement training program and the ideas for engagement activities that were pursued. We describe the rationale for these trainings and the specific procedures used for two pilot trainings of IRB and HRPP staff at one university that conducts biomedical, social, behavioral, and educational research. We also discuss the potential value and applications for this training for other IRB and HRPP offices in academic settings.

Methods

The STEM Ambassador Program (STEMAP) is a training program that originally focused on training scientists to carry out innovative public engagement activities. The Program guides trainees (referred to as "Ambassadors") to draw on their professional and personal experiences to form authentic community connections and engage in nontraditional learning venues (Nadkarni et al., 2019; Weber et al., 2021). Ambassadors participate in a series of workshops where they learn to design and implement engagement activities that are informed by the community they seek to engage and carried out in that community's gathering places (e.g., cooking class, church, public park). In addition to conveying knowledge content, Ambassador engagement activities also aim to build trust by demonstrating that scientists (a) are high in integrity; (b) are willing to listen; (c) care about the community; and (d) have shared values with the community (modified from Besley et al., 2018a). Over 150 scientists (graduate students, postdoctoral researchers, and faculty) at six academic institutions have participated in STEMAP between 2016–2021.

STEMAP trainings are structured as as a cohort-based, semester-long program comprised of five sequential workshops (Figure 1 and Table 1). STEMAP staff—a faculty advisor, program manager, and program coordinator—facilitate the training with accompanying worksheets, readings, and discussion. Ambassadors practice applying engagement skills by carrying out an engagement project. Participation in STEMAP is approximately a 30 h time committment. Ambassadors first each participate in an interview to reflect on their personal and professional experiences to identify communities, or "focal groups," that they wish to engage. The purpose of this exercise is to identify opportunities for mutually beneficial exchanges between the



Figure 1. Schematic depicting the five STEMAP training modules.

Ambassadors and focal groups. Connections to a focal group can be made based on an Ambassador's personal interests (e.g., an Ambassador who is a parent might wish to connect with a parenting group around a shared experience) or a professional interest (e.g., an Ambassador who studies birds might wish to connect with members of a birdwatching club around a shared interest in birds) or a combination of both. This first step helps Ambassadors identify engagement opportunities that they will find personally or professionally valuable. Second, the Immerse Workshop sees the Ambassadors deepen their knowledge of the focal group they seek to engage. Immersion may include reading public information about the focal group, visiting the focal group's location, understanding processes or procedures used by the focal group, and having conversations with focal group representatives. Third, the Design Workshop helps Ambassadors set their engagement objectives and draw on what they've learned about the focal group during the immersion to develop an appropriate engagement activity. Ambassadors write an insight statement to narrow their focus and brainstorm activities in small groups. The insight statement is drafted with the following format in mind: How might I engage with [description of what was learned about the focal group during the immersion] to [engagement objectives]. For example: How might I engage with parents whose children are experiencing illness and are often invited to participate in medical trials to show that I care about their concerns and to provide information on parental permission to participate in research? Fourth, the Engage Workshop prepares the Ambassador with the basic communication skills needed

to execute the activity and fulfill the planned engagement with the focal group. Fifth, the Reflect Workshop allows Ambassadors an opportunity to consider the results of their engagement activity and evaluate their observations and any feedback they received from the focal group.

In 2020, leaders of the University of Utah IRB and HRPP proposed a pilot project to apply the STEMAP objectives and methodology for training human research administrators to engage focal groups on topics of human research ethics. This proposal was accepted by the STEMAP faculty and staff. The IRB and HRPP leaders recruited ten research administrators (two cohorts of five individuals each) to receive STEMAP training, with the goal of increasing the research administrators" ability to engage with the community and become research ethics Ambassadors. The two cohorts participated in the training in the fall semester of 2020 and the spring semester of 2021. Training was presented to research ethics Ambassadors with only minimal modifications in terminology to encourage participants to draw on personal and professional interests, rather than personal and research interests, for engagement. The research ethics Ambassadors were all female and their experience in working in the HRPP and/or IRB ranged from one to fifteen years. All workshops were adapted from an in-person format and conducted in a virtual setting. Ambassadors were encouraged to consider remote opportunities for focal group engagement due to COVID-19 pandemic restrictions. A postworkshop survey (Supplemental Appendix A) was administered to the Ambassadors to determine whether Ambassadors built new skills after participating in the program and evaluate their interest in continuing to carry out public engagement

Workshop theme	Workshop objective	Workshop outcomes	
Connect	ldentify opportunities for exchange with a focal group.	Ambassadors develop their impact identity (Risien & Storksdieck, 2018) by responding to a series of interview questions related to their professional interests, personal interests, and experiences. Ambassadors then identify focal groups that may be open to engagement opportunities that align with the Ambassador's impact identity.	
Immerse	Apply empathetic design strategies to learn about the focal group.	Ambassadors initiate contact with the focal based on scripts (for telephone, email, or social media) provided by STEMAP staff. After initiating contact, the Ambassador explores opportunities for exchange by carrying out an "immersion visit" to the venue either in person or virtually, in which the Ambassador interacts with the focal group member(s) to help the scientist discern the focal group's shared values, traditions, and activities that will inform engagement tactics. The Ambassador also learns about the focal group by reviewing the group's authorities (e.g., texts, journals, websites), and making observations during in-person immersion visits.	
Design	Apply insights from immersion visit to design engagement activities that take place in the focal group venue.	Insights from the immersion process are incorporated into the design of the engagement activity by applying a design-thinking approach traditionally used by design professionals to develop user-centered products and solutions (Goldman, 2017; McDonagh & Thomas, 2010). The Ambassadors write an "insight statement" to focus on precise interests and focal groups. The insight statement is drafted with the following format in mind: "How might I engage with [specific focal group] to [describe the connection to be made over the specifc shared interest]?". The Ambassador then shares proposed engagement activity ideas with STEMAP cohort members and with focal group representatives for feedback.	
Engage	Engage with focal groups using best practices in science communication.	The Ambassador applies insights gained in the immersion visit and best practices in science communication to engage with the focal group, highlightoing shared identities or interests, imbeding questions to facilitate exchange, sharing narratives to create a connection with the group and invites group members to share their expertise and experiences (Selvakumar & Storksdieck, 2013).	
Reflect	Reflect on and report outcomes.	Ambassadors request and incorporate participant feedback for future engagement activities. If administering formal surveys is not feasible, they make observational notes on how they perceive their activities were received. They share outcomes via informal discussions with other research ethics professionals through meetings, the scientific or education literature, newsletters, and social media.	

Table I. Overview of STEMAP Training Workshop Outcomes for Research Ethics Professionals.

activities. Six out of ten Ambassadors responded to the survey. The survey included Likert scale rating questions, as well as questions with open-ended responses.

Results

Every Ambassador in each cohort participated in all five workshops. All Ambassadors were able to successfully identify a novel focal group they wished to engage, that was closely aligned with their professional and personal interests and deepen their knowledge of the group through an immersion. All Ambassadors were able to conceptualize and design an engagement activity for a specific focal group. We provide an overview of this work for a subset of the Ambassadors, outlining the Ambassadors" focal group connections, insight statements, and proposed engagement activities (Table 2).

Two Ambassadors were able to successfully engage with a focal group and conduct an engagement activity within the semester timeframe. Two more Ambassadors were able to conduct their engagement activities in subsequent semesters and within one year of their completion of the workshops. Two additional Ambassadors were able to schedule their engagement activities to be conducted beyond one year of workshop completion.

Some Ambassadors had existing relationships with the focal groups, while others initiated contact with focal groups where they did not have a previous relationship. Occasionally focal groups were not responsive to the Ambassador's request for possible connection and engagement. In these cases, Ambassadors reached out to a different focal group that they had generated during the Connect workshop. Additionally, some Ambassadors proposed engagement activities that ultimately were not accepted by the focal groups, most often because the focal group had other priorities. For example, one Ambassador submitted an article proposal to a sewing magazine that was not accepted; another Ambassador could not arrange for an appropriate virtual venue with a rare disease support group due to the focal group's shifting priorities amidst the COVID-19 pandemic.

The STEMAP staff conducted the Reflect Workshop with all Ambassadors, even though most had not completed their engagement activity prior to this final workshop. Ambassadors were expected to reflect on their lessons learned during the workshop series and how they could move forward with engagement activities after the workshops were completed. Ambassadors continued to report their progress to IRB and HRPP leaders, which encouraged the completion of more engagement activities after the workshops had ended.

All ten Ambassadors anecdotally reported during the Reflect Workshop that they valued and learned from their training experience. Of the Ambassadors who chose to respond to the post-workshop survey (n=6), they rated the overall value of their experience in the STEMAP training as "very valuable." All survey respondents agreed or strongly agreed that through the training they increased their interest in public engagement; gained new skills to design and build relationships for engagement activities; learned how to connect with focal groups based on shared values, interests, and experiences; acquired new skills in effective questioning techniques; wished to do more engagement activities; and would like to reach out to new audiences. In addition, all respondents rated themselves as likely or highly likely to continue to engage. Responses to open-ended questions on what was most beneficial from participating in the STEMAP training included comments such as the following:

"Discovering skills I didn't know I had."

"That all experiences are valid and beneficial for different people."

"It reignited my interest in community engagement."

"It helped me get back to the roots of my job and how to relate it to others."

"It gave me tools for exploring community engagement and talking about the IRB and our work to people outside of the research world."

Discussion

STEMAP was developed to increase access to science and build trust between scientists and members of the public. The STEMAP faculty and staff originally sought to do this by training academic scientists to carry out public engagement activities. Expanding to include research ethics professionals enhanced the work of both STEMAP, the IRB, and the HRPP. The pilot STEMAP trainings for two small cohorts of research ethics professionals suggest that they have an interest in and a desire to be involved in the work of public engagement and recognize the value it contributes to their work of protecting human subjects. The STEMAP trainings may be a useful process for such professionals to expand their roles into public engagement. It serves as an open door to the research ethics community for establishing more educational opportunities and conducting more assessment of the impacts that IRBs and HRPPs may have when performing public engagement.

There are expected limitations to the findings of this pilot project. First, with a small and homogenous sample the conclusions cannot be confidently extrapolated to the broader population of research ethics professionals either nationally or internationally. Second, because of the restrictions imposed by the COVID-19 pandemic at the time this project was conducted, we were not able to understand the impact of this project outside of the virtual setting. Third, we were unable to gain firm evidence that those in the focal groups valued their experiences as well. These limitations encourage us toward additional research in this area, described subsequently.

Best Practices

This effort revealed three best practices for implementation of these activities in the future, and in different institutions. First, allowing IRB and HRPP Ambassadors to identify their own engagement interests and apply STEMAP training to explore these interests helped participants to stay motivated as each new workshop brought them one step closer to fulfilling their engagement goals. Presenting the training as a series of workshops with opportunities to apply new skills between meetings was important in helping Ambassadors learn an engagement process that they could repeat throughout their careers. With a structured, effective training program for research ethics professionals to gain skills and experience with public engagement, HRPPs can feel confident supporting expansion of the IRB and HRPP responsibilities into this realm.

Second, we observed that support from and active participation of the HRPP leadership was key to the success of the Ambassadors in our research ethics cohorts. This involved the provision of financial support from and direct participation of the Director of the IRB and HRPP. These actions appeared to "give permission" to the

Ambassador's selected personal & research ethics interests	Focal group	Ambassador's insight statement summarizing details from immersion and engagement objectives	Proposed engagement activity
Sewing and textile arts; morality and societal value systems	Adults who sew and/or create textile arts and take classes through an adult continuing education program	How might I engage with adult students who are taking a textile arts class to learn about research ethics and how our shared values can be expressed through textile art?	 Teach a textile arts workshop through an adult continuing education program, where students will: evaluate their personal values as well as different value systems and codes of ethics (including research ethics) in their society; create and explore artistic designs that represent a personal value they would like to convey; and make a garment out of fabric that is printed with their artistic design.
Social justice; access to education; advocacy for vulnerable community members; ethics	Youth in custody / teenage incarcerated youth	How might I engage with teenage students in custody in an age and situationally appropriate way to build trust and increase their awareness of and interest in research ethics?	 Present virtually to incarcerated students in their existing science classes, with an engagement activity to: build trust and connect with the students; highlight shared values of justice and fairness; convey knowledge about the IRB and the basic principles of research ethics; and engage with students in a mock-IRB activity where they have the opportunity to consider whether or not to approve research studies based on the principles learned.
Children; parenthood; creative writing; consent and parental permission in research and other situations	Parents who subscribe to or consume media from an online parenting resource	How might I engage with parents who are interested in or concerned about the elements of parental consent in general societal situations and relate that to parental permission in research?	 Write an article or web post on parental decision-making on behalf of children for a parenting website, organization, blog, or publication that includes: a comparison of general prinicples of consent to the elements of research consent.
Popular culture; gaming; movies; ethical human subject research	Local gaming community	How might I engage with the local gaming community that exists largely online and is suspicious of authority figures and researchers, to a) build public trust, b) increase awareness of the IRB, c) generate curiosity about ongoing research?	 Host a panel at a comic/fan convention where attendees will join a group of experts as they do a explore famous (and infamous) scientists from movies and video games and review: the ethicality of research methods, address potential complaints; and discuss what kind of penalties these scientists would face in the real world.

Table 2. Examples of Proposed Engagement Activities Generated by STEMAP Trainings, Including the Ambassador's Research Ethics and Personal Interests, the Focal Group Identified, the Insight Statement, and the Proposed Engagement Activity.

Ambassadors to allocate time and fully participate. In previous cohorts of scientists, the STEMAP staff pushed for engagement activities to be completed in a semester while Ambassadors had the benefit of support from staff and other Ambassadors. However, the IRB and HRPP leadership continued to provide this kind of support even after the training had concluded, which not only ensured that engagement activities could be achieved, but opened the door for Ambassadors to take on larger, longer-term, and more impactful projects. This observation has informed the STEMAP staff that in the future they can encourage larger scale projects if the Ambassador has external support in their professional setting for engagement activities. Thus, we view active institutional support as a central tenet for public engagement performed by research ethics professionals.

Third, providing a flexible time frame to design, implement, and evaluate the public engagement events is necessary. Although the original STEMAP training was structured around a traditional semester-long timeframe, we came to understand that professional staff, in some cases, required a longer time frame to execute their engagement events, and that this flexibility resulted in outcomes that fulfilled training objectives with no loss of quality.

Educational Implications

This project demonstrates a potentially transformative educational opportunity for learning and supporting the research ethics community, as this area of education for research ethics professionals has remained largely unexplored. This project may be helpful to those searching for public engagement training options, as well as educators who may be developing future content and pedagogical approaches for such trainings.

In this pilot project, STEMAP training was presented with minor modification to the research administrators. STEMAP cohorts have traditionally consisted of scientists from a range of disciplines, most of whom had not worked together previously. Scientists occasionally chose to collaborate on engagement projects, but many worked independently towards a range of communication goals. In contrast, the research administrators entered STEMAP as colleagues who were working towards the shared professional goal of ensuring research is conducted in an ethical manner. This dynamic presents a unique opportunity to explore whether STEMAP training could be modified in the future to better support Ambassadors in leveraging their unique focal group connections to achieve shared communication goals, such as broadening participation in clinical trials by listening to community concerns and building trust. This might serve to increase the impact of IRB engagement activities going forward. Additionally, the ability for research administrators to work together on engagement activities is fitting for their professional setting in an HRPP or IRB, where they are already collaborating on many aspects of their work and resources can be maximized with fewer individual projects.

These pilot trainings also revealed an opportunity for research ethics professionals and scientists to work collaboratively on engagement projects. In 2021, STEMAP trained two cohorts in parallel-one consisting of the research administrators and another of scientists. Two participants in the scientist cohort were assisting high school students with a community service project on vaccine awareness. The students were working to prepare a brochure on vaccines in both English and Spanish for their community. The scientists were able to support the students in locating and interpreting technical information related to vaccines, but they lacked expertise in language translation. STEMAP connected the scientists to a member of the research ethics cohort who was a professional translator. This individual helped Spanish-speaking students with the translation, shared career opportunities in language translation, and engaged with the students on values shared in the field of research ethics. STEMAP, like many science communication programs, originally focused on training research scientists to engage with the public. Yet this pilot with research ethics professionals brought the realization that science depends on more than just the researchers.

Furthermore, this project has educational implications for the general public. As research ethics professionals become trained to perform engagement activities, they open a door to the community for learning about priniciples of research ethics. Research ethics professionals can become competent educators to build community awareness and understanding for the priniciples and accompanying practices of respect for persons, beneficence, and justice, so that individuals are better able to engage as potential research participants and harness the protections that are in place for them.

Research Agenda

We continue to carry out exploratory, or early-stage research (Institute of Education Sciences, 2013) in three ways. First, we are looking into ways in which we can scale up the STEMAP training for cohorts of research ethics professionals within our institution and at other universities and IRBs. We forsee a need to expand the research and evaluation for this work to document the factors that influence the willingness of research ethics professionals participate in public engagement activities. to The STEMAP staff have implemented pilot trainings for scientists at five other institutions by guiding faculty and staff at those universities to deliver some or all of the workshops, and are evaluating the outcomes from those efforts. There is also value in continuing to explore ways to include other fields and build in opportunities for collaboration between scientists and other related professionals to increase the impact of engagement projects.

Second, we foresee the need to carry out future research to measure and understand focal group perspectives after they have taken part in a research ethics engagement activity. Benevolence, competence, integrity, and openness have been identified as four key dimensions of trust (Besley et al., 2021). These dimensions align with the core ethical principles to which IRBs ascribe—respect for persons, beneficence, and justice—as they provide oversight to ensure that scientific research is carried out with integriy and competence. As a result, research ethics professionals may be well positioned to build public trust, not just in IRBs, but also in the research they oversee. Future trainings and engagement activities should collect participant feedback to better understand public perception of both research ethics and science more broadly.

Lastly, we require short- and long-term research on assessing the impacts that engagement, built relationships with the public, and collaborations with scientists and other IRB Ambassadors have on research ethics professionals and their review process. Were future research to show a direct and positive change in the conditions IRBs require for the approval of research, based on sound perspectives and feedback from the public, the fulfillment of the core ethical principles—respect for persons, beneficence, and justice—would be strengthened. As such, it would behoove IRBs and HRPPs to ensure sustained resources for these engagement activities.

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Supplemental material

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