

Launching Myeloma Link into the World of New Media:

Addressing the National Disparity in Oncology Care and Black Blood Cancer Patients Through Health Communication, in Partnership with the Leukemia and Lymphoma Society

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Introduction

The primary purpose of this thesis project is to formulate a health communication intervention plan for the Leukemia and Lymphoma Society's Myeloma Link program. Currently, Myeloma Link exists as a volunteer lead outreach program in twelve major US cities. The Leukemia and Lymphoma Society has performed outreach in historically Black churches and conducted “lunch and learn” events with community health workers. This intervention aims to expand upon this outreach by providing a communication plan and use of new media to disseminate vital health information.

This intervention will be using the theory and steps outlined in part three of *Health Communications: From Theory to Practice* by Dr. Renata Schiavo.^[1] The Health Communications Planning model has four main components: a situation and audience analysis, communications objectives and strategies, an action plan, and finally, an evaluation plan.

The complete intervention will also utilize Health Belief Theory and the Elaboration Likelihood Model to inform its communication tactics and messaging channels.

Situation and Audience Analysis

Multiple Myeloma in the United States

Multiple Myeloma (MM) is a form of blood cancer that is characterized by the uncontrolled division of plasma cells within one's bone marrow.^[2] According to the National Institutes for Health (NIH), in 2017, over 140,000 people in the United States were living with multiple myeloma with a 53.9% survival rate over five years.^[3] Due to these statistics, it is estimated that in 2020 there will be around 32,000 new cases of MM and 12,800 related deaths.^[3]

Multiple Myeloma and the Black Community

Multiple myeloma is the most common blood cancer among Black Americans, these patients being 2 to 3 times more likely to be diagnosed than their White counterparts.^[2] This disparity is unique to Black Americans, especially Black men. According to the NIH, 16.5 per 100,000 Black men will be diagnosed with MM and 7.3 of 100,000 will die of MM per year in the United States, compared to 8.8 and 4.1 respectively of all other races.^[3] Similarly, 12.0 per 100,000 Black women per year will be diagnosed and 5.1 Black women will die of MM, compared to 5.7 and 2.6 per 100,000 women of all other races.^[3]

Age Range

In addition to the increased incidence among Black men, there is a specific age range of patients that are diagnosed with multiple myeloma. MM is most commonly diagnosed between the ages of 65 and 74, and one third of related mortalities occur between the ages of 75 and 84.^[3] This age pattern is important when considering the intervention population and will inform communication strategies and techniques to advance health literacy.^[4]

Audience: Primary

Myeloma Link's primary audience are current multiple myeloma patients or those who may have it and remain undiagnosed. In particular, Myeloma Link is meant to reduce racial disparities in cancer care. This audience is comprised of Black Americans that are over the age of 40. Myeloma Link Member cities include: Atlanta, Baltimore, Birmingham, Cleveland, Dallas, Detroit, Houston, New York City/The Bronx, Oakland, Philadelphia, Raleigh-Durham, St. Louis and Washington D.C. Participants of current programming reside in these major cities or within their greater reach.

Audience: Secondary

The secondary audience is divided between caregivers of myeloma patients and oncology professionals.

A caregiver is a role that can be filled by a number of different people. They assist the patient with treatment and provide support. This caregiver will absorb information as well as pass it on to the patient. A caregiver can be a spouse, a parent, a sibling, a daughter or a son, a close friend, or anyone that actively assists in the patient's well-being. This caregiver role is less easily narrowed as they may not be the same age, race or ethnicity as the patient. Caregivers want the best for the patient, so effective communications will build trust and a sense of authority to catch a caregiver's attention.

The oncology provider is also a much more broadly defined audience type. They could include every type of professional from physician, nurse, licensed clinical social workers, patient navigators, community health workers, and more. The only defining characteristics between this

audience is that they are likely above the age of 18, they have professional education, and they have invested interest in healthcare. Parameters such as race and gender and heterogenous and will not be employed to segment oncology providers.

Current Programs

As of 2021, the only other program specialising in the health disparities among Black Americans and Multiple Myeloma is I Can Even the Odds. This program consists of an informational website provided by Amgen Oncology. The site is divided into three categories: *This is Progress*, *You First*, and *Help You May Need*. The categories link to single web pages that explain treatment options, meditation skills and other aid organizations respectively. The *Help You May Need* tab contains a short description of both the International Myeloma Foundation and the Leukemia and Lymphoma Society (LLS). As far as an intervention goes, I Can Even the Odds serves as an informational hub and a tool to improve health literacy for patients performing web searches. While information is present in text and infographics, there are no direct links to resources or tools.

Other preexisting programs include the current LLS Myeloma Link program. As of 2020, Myeloma Link has functioned in 13 cities, provided 250 educational programs and reached 30,000 people according to LLS statistics.^[5]

The primary programs consist of “ministry moments” and “lunch and learn” events. Ministry moments have occurred in partnership with the National Black Churches Collective and Myeloma link volunteers. Essentially, the outreach volunteer is invited to a church service, gives a brief overview of a pre-written ministry moment script at some point during the sermon and tables in the church space after the service. The primary takeaways align with symptom

recognition and building community awareness. It also serves as an opportunity for patients with a diagnosis to meet a representative and connect to patient programs. There is currently one national volunteer who travels to provide ministry moments and some small teams of volunteers in some of the member cities.

Myeloma Link has also done “lunch and learn” events, where an oncology trained speaker gives a talk about disparities associated with myeloma treatment to a group of community health workers, nurses, licensed clinical social workers, or other health professionals that may offer referrals to LLS programs. These events are carried about by local patient and community outreach coordinators, volunteers and guest speakers.

In addition to educational programs, Myeloma Link has developed a distinct brand as part of LLS. During March, Myeloma Awareness Month, LLS sends out related newsletters, social media postings, and has a greater emphasis on myeloma related information on high traffic web pages. Myeloma Link also has its own educational booklet and pdf available in print and online. Lastly, LLS has a number of giveaways and items branded with Myeloma Link and LLS messaging. The items include pens, chapstick, stress balls, and other novelties of that nature. They are commonly distributed at the educational programs as a form of subliminal messaging and brand outreach.

A Legacy of Abuse

Distrust in the Black community for clinical trials and medical research has been a reality due to events such as the Tuskegee Syphilis trials and the brutal history surrounding experiments performed on enslaved women by J. Marion Sims.

The Tuskegee Syphilis Trials study occurred in 1932, in Macon County Alabama.^[6] Researchers gathered a cohort of Black men with Syphilis, isolated them from receiving outside medical care, and watched the disease run its course through their bodies, completely untreated. This resulted in many men dying from syphilis and the surviving participants suffering in the name of “science.” Informed consent was not given nor received. Researchers believed that Black men were biologically different than their White peers. These researchers in particular chose neurosyphilis because they believed Black men to be sexually uncontrollable and neurologically inferior.^[6] This false belief of biological difference served as the hypothesis behind the research. As a result, the men studied had no ethical protections in place and were left vulnerable to medical abuse. While many people outside of medical or historical fields do not remember Tuskegee, as a singular event, it has undoubtedly added to the context of racism in medical care and is a part of what shaped racial differences in medical distrust.^[7]

In addition to the atrocities committed in Alabama disguised as a clinical trial project, an infamous doctor named J Marion Sims used the bodies of enslaved Black women to further his medical research. Sims is often coined as “the father of modern gynecology.” He performed a number of extremely painful experimental procedures, without anesthesia, on enslaved women during the 1840s.^[8] Historians report that Sims would often perform up to 30 experiments over four months on a single patient, remarking how they could handle the pain due to the assumed “biological differences” between White and Black folks.^[8] Due to these experiments, he founded a number of modern gynecological procedures that are now widely used. While Sims received praise and statues in various US states to commemorate him, the women he tortured, who bore the whole of the pain and sacrifice, received no recognition or reparations. While these atrocities

are not commonly included in modern history books, many Americans have not forgotten about the Black women who unrightfully suffered at the hands of the US medical system.

In modern times we still see racism present in patient and provider interactions. For example, consider Serena Williams and the complications she faced after giving birth. Williams paved the way for the conversation about Black maternal mortality and the racial correlations associated with maternal outcomes after she shared her story on numerous news fronts. With all of this in mind, historical trauma combined with modern neglect, it is no surprise that studies find a significant increase in expressed medical districts among Black participants.^[7]

This coupled with the underrepresentation of non-white patients in clinical trials creates an issue with proper treatment research and with reduced treatment options for Black MM patients. A review of 128 published MM trials revealed that racial and ethnic minorities were underrepresented and often not even reported in numerous studies even though racial disparity in diagnosis is an enormous public health characteristic of MM.^[9] In order to increase the quality of treatment for Black MM patients, public health professionals must connect patients to clinical trials and actively work to earn the trust of a population that has been historically abused by the medical system. Without addressing clinical trials, it is unlikely that outcomes will improve for Black MM patients as research progresses.

Other Barriers

In addition to the issues surrounding medical racism, the age range of the primary audience also poses some barriers to a one-size-fits all communication approach. When dealing with an older population and a complex health issue, use of accessible language is vital to engage patients and caregivers appropriately. Barriers for older adults and cancer literacy include but are

not limited to: cognitive decline related to aging, loss of vision, hearing loss, the ability to access appropriate information, memory loss, reduced social interactions, and language barriers..^[4] A health communication plan addressing health literacy and engaging older cancer patients will address these barriers effectively.

Lastly, Covid-19 has made in person meetings, especially for cancer patients, difficult to impossible. As a result Myeloma Link programs have been greatly slowed from March 2020 to March 2021. To overcome this barrier, creating digital options and platforms for outreach is vital. These platforms need to be easy to find and smartphone friendly as well.

Communication Objectives and Strategies

Program Goal

To increase the engagement of Black blood cancer patients and caregivers with Leukemia and Lymphoma Society's financial aid programs, emotional support programs and clinical trial support center in all Myeloma Link program cities by 40% by 2026

Primary Audience Outcome Objectives

Behavioral:

- By the year 2026 we will see a 30% increase in self identifying Black blood cancer patients utilizing the Clinical Trial Support Center.
- By the year 2026 we will see a 50% increase in self identifying Black blood cancer patients utilizing LLS support groups
- By the year 2026 we will see a 30% increase in self identifying Black blood cancer patients utilizing the copay assistance program, patient aid program, travel assistance program and urgent need program.

Social:

- By the year 2026 we will see a 15% increase in First Connection volunteers that have reported engaging with Myeloma Link

Secondary Audience Outcome Objectives

Behavioral:

- By the year 2026 we will see a 15% increase in Myeloma patient caregivers utilizing LLS support groups

- By the year 2026 we will see a 50% increase in Myeloma patient caregivers reporting that they have accessed educational resources online
- By the year 2026 we will see a 35% increase in Myeloma patient caregivers utilizing the Information Specialist hotline
- By the year 2026 we will see a 45% increase in provider referrals of Myeloma patients to LLS programs

Social:

- By the year 2026 we will see a 50% increase in Myeloma patient caregivers reporting that they have accessed educational resources online
- By the year 2026, five Op Eds pertaining to racial disparities and blood cancer, treatment access, and related issues will be published and circulated in the academic community

Organizational Objectives

- By the year 2026, LLS will have salesforce profiles on 30% more self identifying Black patients
- By the year 2026, LLS will have salesforce profiles on 30% more Myeloma patient caregivers
- By the year 2026, LLS will forge collaborations with at least three organizations regarding Myeloma Link programs and information

Primary Audience Communication Objectives

- 80% of patients engaged with Myeloma Link programing will be able to understand and recognize at least three symptoms of Multiple Myeloma

- 75% of patients engaged with Myeloma Link programing will be able to identify where they can access information on LLS emotional support programs
- 75% of patients engaged with Myeloma Link programing will be able to identify where they can access information on LLS financial support programs
- 60% of patients engaged with Myeloma Link programing will be able to locate the phone numbers for the Information Specialist and the Clinical Trial Support Centers

Primary Audience Communication Strategies

The main strategies to engage patients include: a new Myeloma Link webpage, a support group for Black identifying patients, and a digital storytelling campaign. These strategies will engage the patients by providing information, encouraging communication around blood cancer, building community, and providing a source of advocacy. Patients with blood cancer will be engaged in secondary and tertiary prevention, which corresponds to disease recognition and treatment respectively. These prevention strategies and intervention components are informed by the Health Belief Model, which is widely used in the creation of public health interventions..^[10]

The Health Belief Model

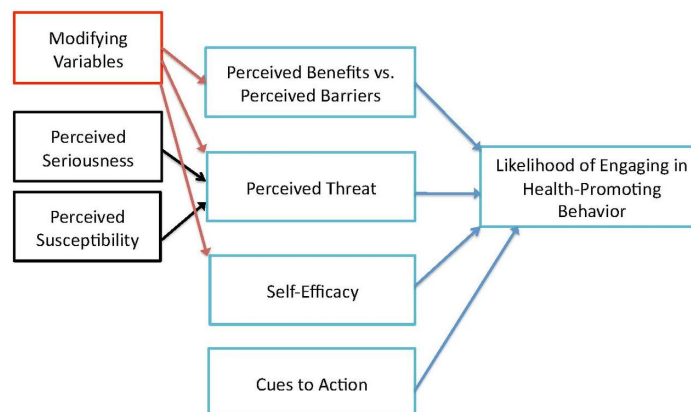


Figure 1. Health Belief Model. From *Health Education Monographs* by I.M. Rosenstock; 1974.^[10]

The Health Belief model aims to engage in behavior change by analyzing the components that lead to design making. The health behavior for our primary population is to either: get proper blood tests if they are presenting symptoms of Multiple Myeloma, engage with LLS emotional, educational and financial resources if they have a diagnosis, or to seek treatment and clinical trials options with the help of LLS resources.

To ensure these changes, we must increase perceived seriousness and susceptibility for patients in the secondary prevention phase. We can achieve this attitude change by building symptom awareness and increasing overall Myeloma awareness in the broader community. Both the webpage and digital storytelling campaigns serve as useful tools to build an increased sense of perceived threat. They may also increase self efficacy by providing patients with

communication tools so that they are able to speak with physicians about blood cancer and request a full blood panel if necessary.

Patients in the tertiary stage will need information to connect with resources and seek proper treatment. The webpage, digital storytelling campaign and the support group will create a space for current patient dialogue around issues of access and oncology related health literacy. The primary goal is to reduce and lessen perceived barriers to treatment and increased quality of life. Having the information available as well as creating a dialogue has the purpose of educating and encouraging patients in various stages of the cancer journey. This speaks heavily to the self efficacy and perceived barriers vs benefits portion of the model. Normalizing conversations around blood cancer and promoting trustworthy education is key to empowering the patient to access resources as well as advocate for clinical trial participation and treatment options. By creating a Myeloma Link hub and talkspace, we will be able to increase both perceived benefits and self efficacy in carrying out these health behaviors.

Secondary Audience Communication Objectives

- 60% of caregivers engaged with Myeloma Link will know how to sign up for a support group
- 75% of caregivers with Myeloma Link programing will be able to identify where they can access information on LLS financial support programs
- 60% of patients engaged with Myeloma Link programing will be able to locate the phone numbers for the Information Specialist and the Clinical Trial Support Centers
- 95% of providers engaged with Myeloma Link programing will know how to refer a patient ot LLS

- 75% of providers engaged with Myeloma Link programming will report gaining a greater understanding of racial disparities around blood cancer

Secondary Audience Communication Strategies

Our secondary audience consists of caregivers and oncology providers. Both of these groups are diverse and broad, however it is vital to target both to reach a developed communication plan.

In a similar strategy as targeting patients themselves, we aim to communicate to caregivers through a Myeloma Link webpage, support group space, and a digital storytelling campaign.

The webpage will essentially contain resources specific for caregivers and educational elements, as they are often making treatment decisions with or for cancer patients. This population group may have varied levels of health literacy, so all information should be written clearly, with subheaders, and contain a link to email or call the LLS Information Resource Center.

The support group also has a similar function to caregivers as it does patients. The main purpose is to let participants create the space that they need and build a sense of emotional support and resilience together. Caregivers typically can participate in the other LLS support groups, so the new group will follow the same norms and formatting.

The last aspect for caregivers is the digital storytelling campaign. This will help provide information and experience from other patients and caregivers in their own words. The stories aim to build a sense of shared experience and allow caregivers to discover the challenges and joys that others have experienced in their health journeys. This is also vital to build trust and

community as the stories will be told in the words of the patients and caregivers themselves in order to facilitate authenticity and integrity. It allows LLS to spread information and experience, giving control over the narrative to those it belongs to.

When appealing to providers, the use of an opinion editorial series and webinar series will appeal to the population using principles of the Elaboration Likelihood Model (ELM).

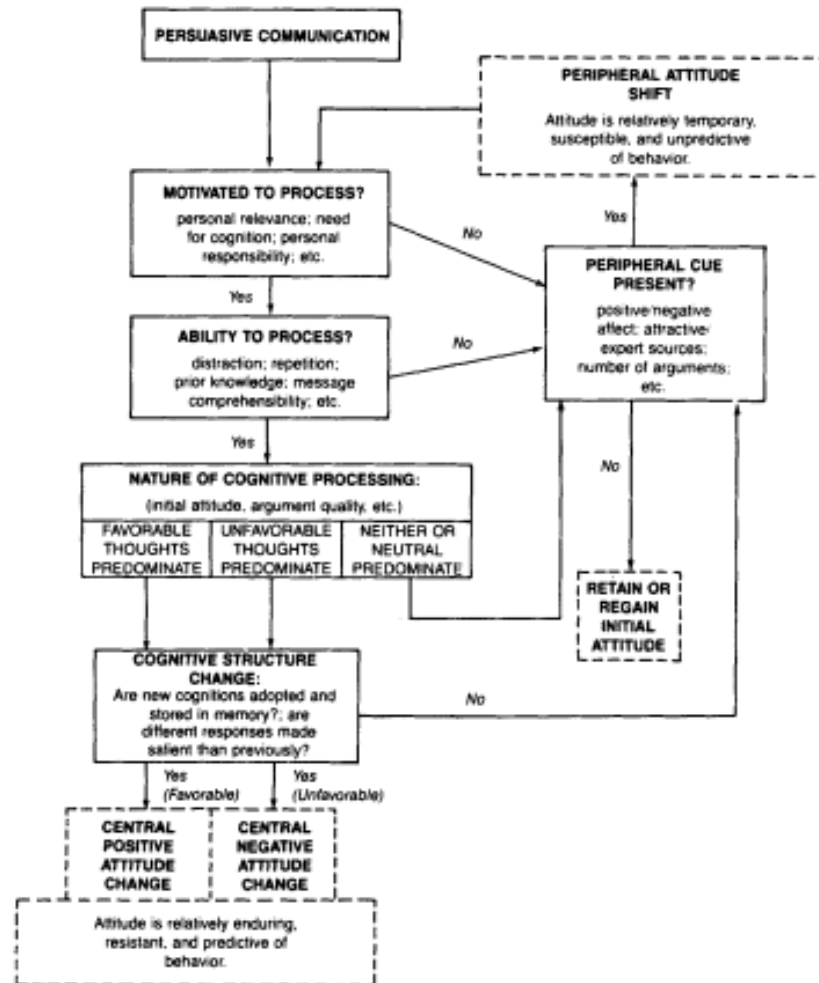


Figure 2. The Elaboration Likelihood Model of Persuasion From *Advances in Experimental Social Psychology* by Petty R. E., and Cacioppo J.T. 1986.^[11]

ELM is a psychology model that hypothesizes two different routes for information processing from a communication channel: a central route, characterized by thoughtfulness and desire for information and a peripheral route; which is characterized by inactive engagement with the communication and subliminal messaging.^[11] This strategy is ideal when working with providers of different disciplines and differing levels of interest in principles of health equity.

Both the Op Ed series and Webinar series appeal to the central and peripheral routes. An Op Ed will move centrally when the population actively reads and engages with the piece. The desire for information can be met with statistics, stories, emotionality, and extended resources. Providers with knowledge of medical racism will remember the messaging and engage with it further. This is the same for the webinar. The participants that attend voluntarily or have a desire to attend will actively engage. For this reason, the webinars will have a space to ask questions and engage in dialogue with participants.

For providers that are more inclined to the peripheral route, the Op Eds and webinars are also valuable tools for communication. For readers engaging with the Op Ed, a strong title, subheadings, and featured sentences are key in formatting. For example: providers may see an Op Ed titled: “Medical Racism and Multiple Myeloma Care: How Physicians are Failing Black Blood Cancer Patients.” Even if the reader does not actively read all of the article, they will still register that there is a health disparity in multiple myeloma Care and that there may be something that they can do about it. Some messaging in a visible place is always impactful over having no messaging at all. This also applies to providers engaging in the webinar series that may be participating for a job requirement. LLS can bring in more peripheral participants by working with the appropriate health organizations to give the webinars a continuing education or professional development credit. While folks may attend out of obligation, they will still be

exposed to information and learn more about the topics at hand. Building up these associations of multiple myeloma, racism, health disparities, blood cancer, and other key phrases teach those exposed over time and develop another type of learning. The final step to reinforce subliminal messaging would be to send an email to all registered webinar participants two weeks after the conclusion of the series. This will serve as a reminder and push them to process the information presented even more.

Action Plan

Webpage- For Patients and Caregivers

Within the past fifteen years, a large number of studies have determined that cancer patients often search for health information online and that it is vital for oncology professionals to ensure that truthful information is easily accessible over the web.^{[12][13][14]} In addition to this, the information found also profoundly affects the kinds of conversations and treatment information that a patient or caregiver will speak to an oncologist about.^[15] Even patients that don't have access to physical computers are still able to search for health information online. A 2017 study found that Black Americans have high rates of smartphone ownership when compared to other racial groups, feel as though the internet improves their access to health information, and were willing to enroll in mobile research programs.^[16]

Recent studies have also shown that Black cancer patients receive less Autologous Stem Cell Therapy (ASCT) and novel therapies than their white counterparts, and this negatively affects five year survival rates as a result.^{[17][18]} The best way to make information on treatments available is through an easy-to-find webpage. That is where LLS has the potential to reach and educate new patients.

While LLS has an accessible website stocked with information, it can be difficult and overwhelming for an older patient or caregiver to navigate without assistance. To increase Myeloma Link visibility, a spinoff webpage or an entirely new, individual website would increase visibility and highlight only the most vital information for a myeloma patient. For example, the Know Your Girls campaign by Susan G Komen developed an exciting webpage to

increase specific outreach for Black women and breast cancer.^[19] The webpage contains everything from screening information, patient stories, risk screening, healthcare affordability and more. The primary organization webpage is provided as a resource, but Know Your Girls is simplified and curated to make it easier to locate vital information. LLS should do the same, creating a webpage for Myeloma Link that is easy to find and specifically curated to Black Americans with blood cancer. In order to be readable to older adults with limited health literacy, the information should be kept between a fifth grade and eighth grade reading level. When this is not possible, the content page should clearly display the phone number for the Information Resource Center at the top and an invitation to call with questions.

Some vital subpages include: stem cell transplant information, myeloma information pamphlets and links to the LLS online library, clinical trial information and the Clinical Trial Support Center, financial aid programs, emotional support services including First Connection and LLS support groups, and relevant podcasts, webinars, or other patient facing information with an emphasis on multiple myeloma, health disparities, or standard treatments. The webpage must also have a location with the patient story collection, which will be explained further in following sections.

Being Black with Blood Cancer: Online Support Group - For Patients and Caregivers

The Leukemia and Lymphoma Society currently offers support groups in each of the chapter locations. The groups are intended for both patients and caregivers and are sometimes segmented by early diagnosis or survivorship. As Covid-19 arrived in the United States in March of 2020, all of the support groups have moved online. These online groups and chat room options are hosted by an oncology professional.

With the new Myeloma Link programming, it would make sense to provide a support group option for Black identifying caregivers and patients. In 2007, statisticians estimated that if racial disparities were eliminated, 37% of premature cancer deaths for patients aged 25 to 65 could have been prevented that year.^[20] Due to the health disparities associated with being Black in the United States and cancer outcomes, there is no denying that Black patients have a unique experience with blood cancer. A support group specified for that intersection will create a safe place and a sense of community. Patients and caregivers can share their challenges, successes, worries, and joys in a place where they can build a sense of resilience together. Creating this space with a Black facilitator will also likely reduce microaggressions. Participants can share their frustrations openly that may be associated with racism within healthcare without feeling the need to explain or defend themselves. It creates a climate of understanding and a common goal of survivorship, even though each person's experience is likely quite different.

This support group should be offered once a month, just as all other support groups are, and open to the entire LLS patient community. The time and date should not conflict with existing LLS groups. As the pandemic ceases and in person events begin once again, the location for this support group should be easily accessible by bus, metro and other forms of local public transportation.

My Story: Digital Storytelling Campaign- For Patients and Caregivers

Digital Storytelling is the creation of a video to record and present someone's story with the purpose of sharing it. The story can be presented in an interview style, with the storyteller on film speaking to the camera. It can also be a voice over with animation, photographs, art or any other visuals that correspond to the script. Digital storytelling methods have grown in popularity

as forms of health promotion and communication in the public health community over the past ten years.^[21] In a similar manner to photovoice practices, digital storytelling allows patients and caregivers to share their stories and control their narratives.

A 2021 article published in the Journal of Cancer education asserts that storytelling is a valuable tool to improve health literacy, and a sense of resilience among African American cancer patients.^[22] This storytelling may also contain biblical elements, which can be used with current Black church outreach efforts as many services have moved online during the Covid-19 pandemic.^[22]

These digital stories should be available on Youtube, reposted on the Leukemia and Lymphoma Society's Instagram IG TV, and housed in the new Myeloma Link webpage. The stories will be three to five minutes long, which translates to scripts three to five pages in length. Storytellers can be recruited from First Connection volunteers and current Myeloma Link volunteers. LLS has a style guide that all of their content fits into and it should be applied to the editing and stylization of each video. To create connection and humanization, the digital stories should be filmed with the storyteller speaking to the camera. Pictures and other visual elements can be included, but in this circumstance building representation by filming the storyteller will make the content more powerful and emotionally compelling. Within a year and a half of program launch, Myeloma Link should have three patient and two caregiver stories ready for posting. Trying to choose storytellers that vary in age, gender, and treatment experiences will also improve the impact of the stories.

Webinar Series- For Oncology Providers

Currently, Myeloma Link has engaged various oncology providers through events called “Lunch and Learns.” Essentially, LLS provides free lunch to community health workers, clinical social workers, nurses or physicians that attend an informational talk on Myeloma Link. These events have typically occurred in person before the Covid-19 pandemic reached the United States. While this has been a great tool in the past, for Myeloma Link to continue, to build capacity and to expand reach, transitioning “Lunch and Learn” events into webinars is the most appropriate next step; as many social events are now digital.

LLS has provided numerous webcasts for patients and caregivers. These are available if searched for on the general webpage. Using the same software and formatting, LLS already has the tools required to make a series specific to Myeloma Link and intended for providers. When creating the content, LLS can work with hospitals or organizations to incentivize the webinars as continuing education or professional development programs, which are required events for many health professionals. This would increase the reach overall. The webcasts are also helpful as they can be nationally held rather than a chapter-specific lunch and learn event. They are able to reach a greater number of people using less resources.

A vital aspect to keep in mind during the development of the series is to have time for debrief and questions either as a follow up program or part of the main programming in each session. To start there should be four major sessions. The general outline should be as follows: 1. An Introduction to Racial Disparities and Blood Cancer, 2. Modern Blood Cancer Treatments, Clinical Trials and Referral Resources, 3. Communicating With Blood Cancer Patients and Caregivers, and finally 4. Increasing Blood Cancer Health Literacy with Parents and Caregivers. Each session should emphasize the LLS referral form and how to complete it as well.

By focusing on both the reality of disparities and increasing communications, the webinars will both educate and train providers in addressing disparities. These communication skills have been proven through a number of studies to improve patient outcomes and adherence to treatment.^[23] Guidelines to communications can be found and reinforced by the American Society of Clinical Oncology.^[23]

Op Ed Series- For Oncology Providers

The last major action step for Myeloma Link is to encourage and ask physician volunteers or hire a handful of freelance medical writers to write and submit Op Eds for publication. It may be up to the author to choose the exact focus of the piece and the submission location, but the Op Eds should have some relation to the Myeloma Link mission: addressing racial disparities and blood cancer care. Op Eds increase conversion in the medical community. They also serve as a source for advocacy. Typically, an Op Ed contains emotions and anecdotal evidence, which appeals to a more feeling centered side of healthcare and the human experience that is lost in scientific writings. They are also more accessible than the average journal article and have a greater reach. The primary goal of an Op Ed campaign is to make the space for a greater conversation within the medical community.

When supporting the authors with editing, questions, and content the advocacy branch of LLS staff would be the most helpful to engage. Within two years of program launch, LLS should aim to have around five Op Eds written and in the submission or publishing process. Each Op Ed should conclude with a brief explanation of the Myeloma Link program and the commitment LLS has made to improving health equity. This in turn will encourage Myeloma Link visibility in

a channel that isn't solely patient facing and establish the program as a source for advocacy as well as direct engagement.

Partnerships

Strategic partnerships will help to build Myeloma Link capacity, reach, and involvement. Some potential organizational level partnerships include: I Can Even the Odds, the International Myeloma Foundation, Black Nurses Rock, Melnated Social Workers, and the Black Cancer Podcast.

I Can Even the Odds is an informational website by Amgen Oncology that provides statistics on health disparities and some resources for multiple myeloma Patients. They mention LLS on a page detailing aid organizations, however there is no link or button to redirect. A possible collaboration could engage them with the creation of a link and give them access to the forms for patient referral that LLS gives to providers. This way LLS has greater span on web information and has an increase in referrals.

Next, the International Myeloma Foundation has access to patients and providers that LLS may not. Collaborating on a webinar for providers or patient centered events would allow LLS to reach patients that are associated with them, but not yet in the LLS Salesforce database. This partnership could also help LLS gather speakers from the International Myeloma Foundation's team or volunteers for future programs.

Black Nurses Rock (BNR) is a Non-Profit that supports Black nurses all over the United States and internationally. Many of the board members are searchable and contactable through LinkedIn. A partnership with BNR would give LLS access to more healthcare providers in order

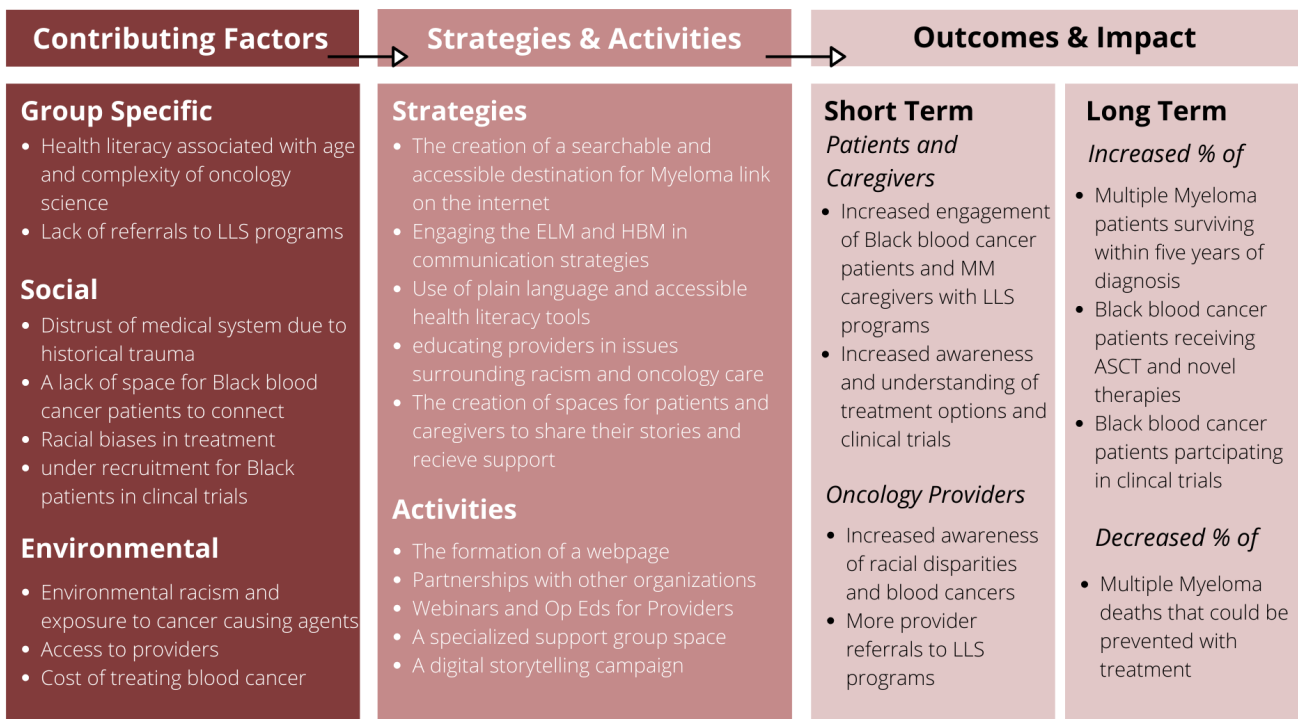
to increase referrals, patient engagement, and attendance to educational webinars. LLS may also be able to attain Myeloma Link Volunteers and guest speakers through a collaboration.

Next, Melanated Social Workers has reach through an Instagram account and a podcast. It serves as a social media community for social workers of color striving to make their work more equitable. A feature on Instagram and a guest slot on the podcast could provide LLS with Myeloma Link volunteers working in clinical social work and increase the reach of new patient referrals. The easiest way to reach out would be over Instagram or through the contact form on their website.

In a similar way, a guest spot on the Black Cancer Podcast would create an opportunity to increase communication channels. It would also benefit LLS to have the host, Jodi-Ann Burey, be a guest on an LLS podcast or webinar. This would increase LLS reach and myeloma awareness. Myeloma Link could contact Ms. Burey over email at blackcancerpodcast@gmail.com, over the Black Cancer Podcast instagram page, or on her LinkedIn page.

Evaluation Plan

Logic Model



In order to guide the evaluation, the logic model above was created. This illustrates the thought process behind the intervention steps and the intended consequences of its implementation.

Webpage

As the webpage is rolled out, using a domain such as squarespace, hubspot or wordpress will give the Leukemia and Lymphoma Society access to real time, monthly analytics. An additional analytics program can be purchased to access more detailed information.

To evaluate the process portion of the webpage, we will look primarily at website traffic to get an idea of reach. How many visits is the site getting? Where are visitors located geographically? What pages on the site are receiving the greatest amount of clicks? Answering

and summarizing these questions from month to month will give LLS an idea of how the Myeloma Link website is performing in reach and dose. Myeloma Link can also use website analytics to see how often links are taking visitors to the main organizational webpage or what workbooks are being downloaded and how often from the educational pages.

Outcome evaluation for the webpage will be divided two ways. First, Salesforce patient and caregiver profiles should be updated to include a box to check that indicates if the new contact was retrieved through Myeloma Link web programming. This would be a simple, optional checkmark and would not create additional work for Patient Outreach Coordinators, volunteers, Information Resource Center staff, financial assistance staff, or anyone else that is trained and approved to add contacts through Salesforce. This box will create a list within the database that can be further specified by chapter of new LLS contacts received through the Myeloma Link webpage. It is a simple additional question that can be asked anytime as information is collected on contacts.

The second outcome evaluation would be to incorporate a link to a learning measure survey on the webpage near the top where it is visible and easy to click. To encourage website readers to take the survey, LLS can send free caregiver workbooks to each completed survey entry, as they are typically ordered through the main webpage. The survey will measure self efficacy and perceived learning on a five point likert scale. These surveys can be quantitatively analyzed and used to measure short term outcomes of interaction with the Myeloma Link webpage. A sample survey of this type can be found in Appendix A.

Being Black with Blood Cancer: Online Support Group

For the support group, information should be collected from both the participants and the facilitator. The primary goal is to create community and a safe space for patients to share, so it is imperative that the support groups are maintained as such.

A process evaluation for the support group should contain two primary measures. First, tracking attendance numbers from the first meeting to each following meeting will give LLS an idea of reach and overall adherence. Secondly, requiring facilitators to record a reflection after each meeting will give Myeloma Link coordinators an idea of what is working and how to support facilitators to make the meetings better. This helps to ensure that the nature of the space created within the group is what was intended.

An outcome evaluation would be best measured with a survey that is sent to participants via email after their third group meeting. This survey will measure if they perceive that they are benefitting from the support group. The results of the survey will be collected on a likert scale and can be analyzed quantitatively. A sample survey containing types of questions can be found in *Appendix B*. To increase response rate of the survey, evaluators can provide incentive by creating a raffle for a basket of Myeloma Link giveaway items and a collection of additional information booklets. These items, such as chapsticks, rubber bracelets, sticky notes and similar objects are already available to each Patient and Community Outreach Coordinator in the twelve Myeloma Link member cities.

Digital Storytelling Campaign

Evaluating the digital storytelling campaign will be very similar to the process of evaluating the Myeloma Link webpage.

To measure a process evaluation, analytics on video views, comments, likes, shares, and completions are available to view on Youtube, Facebook, and Instagram's IG TV feature. This will give LLS a sense of reach and scope and can be monitored monthly or every three months.

To measure outcome or impact of the videos, a quantitative survey and qualitative measure can be employed. To measure the quantitative impact the same survey in Appendix A can be shared as a link in the video caption; once again in exchange for a Caregiver workbook. This survey will be abbreviated: containing only the demographic information and the set of questions pertaining to the Myeloma Link: *My Story* campaign. Qualitative information can be gained by providing an email address in the caption and video credits (ie:mystory@lls.org) where viewers can ask questions and share their thoughts and feelings. This provides LLS with a more emotional response and the potential to quote viewers on the impact the campaign had on them personally.

Webinar Series

The main goals of the webinars are to build awareness around health disparities to healthcare providers and give them tools to better communication with patients and caregivers. To evaluate the series, focusing on provider motivation to use the materials and their satisfaction with the program, will give LLS a sense of whether or not the series was informative and helpful.

A process evaluation can be measured by how many participants register for the webinar, how many attended the webinar at the start, and how many stayed until the end. This will measure reach and dose of the information for each event. The numbers can be both analyzed separately or collectively after the conclusion of the four part Myeloma Link series.

An outcome evaluation should employ a survey sent to all participants. Once again, this survey can be administered at the completion of each event or at the end of the series. A sample survey containing webinar specific questions can be found in *Appendix C*. Questions will measure perceived learning, perceived helpfulness, and whether or not the providers intend to use the information learned in their work.

Op Ed Series

The last action item to evaluate is the Op Ed series. This may be the most difficult, as it is published on platforms with analytics to which LLS has limited access. It is also much more difficult to quantify the overall effect on advocacy efforts and the conversations surrounding health inequities in the United States.

To gather some feedback and data, Myeloma Link can request data on article views from the organization in which the Op Ed is published. From there, evaluators can also perform social listening techniques by searching the title of each piece on Twitter and Facebook. This will provide insight into public shares and comments. At least one written report on social listening patterns should be performed three months after each publication and recorded. These reports can be simple and consist of observations from who is interacting with the material and what kinds of responses it is generating.

Final Thoughts and Considerations

Budgeting

The major budgeting considerations for the Myeloma Link program relate to the creation and maintenance of each action step.

For the web page, creating and maintaining a domain costs anywhere from five to fifteen dollars a year depending on the platform. Google Analytics has a free and a paid version, depending on what information Myeloma Link needs long term. The paid version, Google Analytics 360, would amount to \$150,000 per year. When choosing the domain and analytics plan, LLS may be able to use the same plan, domain and analytics software for their main site and add the Myeloma Link site into the account. This would save the organization time and funds in this respect. Other costs include hiring a web page designer. This position could be freelance, volunteer, or the tasks could be given to current LLS staff. Hiring a new website designer would amount to fifty-five thousand dollars per year in salary.

In addition to the creation of the website, a freelance video editor should be hired to film, edit, brand and produce the digital stories. A freelance videographer would earn around thirty dollars an hour for their services or seventy thousand dollars for a year of work. LLS could also work with Story Center, which is a digital storytelling focused Non-Profit Organization, and engage existing staff and volunteers in free workshops on creation and editing of digital stories. Budgeting options around the digital story project remain flexible based on organizational capacity and resources.

For the online support groups, the major costs are facilitator salary and online meeting platform. A premium Zoom Meetings account costs fifteen dollars a month or one hundred and fifty dollars per year. This platform is reliable and widely used, so it would be easy for most

participants to engage with. The link would also stay the same each month, making it a reliable destination. For the facilitator, they may be paid staff or a volunteer that receives an honorarium for their time. An appropriate salary would be thirty dollars per meeting, which would equate to three hundred and sixty dollars per year, per chapter specific Myeloma Link support group. This is also flexible based on volunteerism and the previous practices LLS employed when hosting in person groups.

Similarly to costs of support groups, online webinars require a platform, speaker salary or honorarium, and a content planner. Most webinar platforms cost less than a hundred dollars a month. LLS currently uses a platform for patient centered webcasts. It makes the most sense to use and expand upon those existing resources. A speaker would also cost no more than forty dollars an hour for salary or honorarium if the speaker is a volunteer. LLS could also gather new speakers and platforms through collaborations with the organizations listed under the partnerships section. Finally, Myeloma Link should either engage current national chapter education coordinators in the development of webinar content and other Myeloma Link related educational content or hire a Myeloma Link specific health education specialist. The salary for hiring a new national staff member in that position would equate to roughly sixty five thousand dollars a year based on experience and full-time vs part-time work.

For the Op Ed portion of the intervention, authors can either be volunteers or freelance writers. For the use of freelance writers, Myeloma Link should expect to pay three thousand dollars per Op Ed, which would amount to fifteen thousand dollars total within the first five years of Myeloma Link roll out. Like the majority of other budget items, this is flexible if assigned to existing staff or active volunteers.

Lastly, the final major budgeting consideration for Myeloma Link lies within the need for a full time evaluator. This evaluation project can be delegated between chapter outreach coordinators and national staff, or LLS could hire a freelance program evaluator. This salary would amount to around seventy five thousand dollars a year depending on experience level. Hiring an evaluator would strengthen evaluation design and produce a program report without the bias that comes from using staff within the organization.

Each of these budget considerations is flexible based on LLS budgeting, grant availability, and collaboration capacity. Over time it may make sense to switch to the use of freelance employees as the program grows. This is up to the discretion of the national office and Myeloma Link coordinators.

Long Term Considerations

Overall, successful roll out of the new Myeloma Link design will inevitably impact the entirety of the Leukemia and Lymphoma Society. With increased reach and engagement we expect each member chapter to see an increase in workload on the patient services side. As the program grows, overtime LLS should monitor the workload of Information Resource Center staff, the Clinical Trial Support Center staff, and the Financial Aid Hotline staff so that they can hire more associates or recruit more volunteers as necessary. Long call hold times are stressful for staff members and a major deterrent for patients seeking services. LLS should also look into recruiting more chapter-specific patient outreach volunteers and interns to assist Patient and Community Outreach Coordinators in their chapters as LLS grows and engages with more populations.

Lastly, a commitment to Myeloma Link ideals does not end within the patient services sector of LLS. As the program grows in time, LLS will need to include its advocacy and research arms into the fight for health equity. Myeloma Link stands as a health intervention now, but it is also a small piece of what kinds of work and commitments define the overall organization. The Leukemia and Lymphoma Society aims to make lives better, and Myeloma Link has the opportunity to expand and strengthen that core mission.

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Appendix A. Web Page Evaluation Sample Survey

The following questions will ask you a bit about yourself. Please answer to the best of your ability.

1. What is your gender?
 - Male (1)
 - Female (2)
 - Other (3)

2. Which of the following best describes you?
 - Asian or Pacific Islander (1)
 - Black or African American (2)
 - Native American or Alaskan Native (3)
 - Hispanic or Latino (4)
 - White or Caucasian (5)
 - Multiracial or Biracial
 - A race/ethnicity not listed here (6)
 - I prefer not to say (7)

3. What is your age in years?
 - 18-25 (1)
 - 26-35 (2)
 - 36-45 (3)
 - 46-55 (4)
 - 56-65 (5)
 - 66-75 (6)
 - 76-85 (7)
 - 85+ (8)

4. What is your interest in blood cancer?
 - Non-patient/ exploring my health (1)
 - Diagnosed patient (2)
 - Primary caregiver of patient (3)
 - Family or friend of patient (4)
 - I know someone with blood cancer but I do not provide them care (5)
 - Community health worker, nurse, physician, social worker, or other health professional (6)
 - I want to volunteer (7)
 - Generally interested individual (8)

5. If you checked yes to “diagnosed patient” or “caregiver,” what is your/ the patient’s diagnosis?
 - Acute Lymphoblastic Leukemia ALL (1)
 - Acute Myeloid Leukemia AML (2)
 - Chronic Lymphocytic Leukemia CLL (3)
 - Chronic Myeloid Leukemia CML (4)

Multiple Myeloma MM (5)
 Hodgkin Lymphoma HL (6)
 Non-Hodgkin Lymphomas NHL (7)
 Myelodysplastic Syndromes MDS (8)

How much do you agree or disagree with the following statements about the material you just viewed?

1. I found the information on MyelomaLink.LLS.org to be helpful
1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

2. I would consider this website to be accessible
1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

3. I would consider this website to be easy to navigate
1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

How much do you agree or disagree with the following statements about your experience on MyelomaLink.LLS.org:

1. I am likely to apply to a financial aid program through LLS
1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

2. I am likely to utilize the information resource center hotline
1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

3. I am likely to register for a support group or request a first connection
1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

If you visited the Clinical Trial Page, please answer the following questions:

1. I have a better understanding of what a clinical trial is

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

2. I understand the next steps I can take to get involved with a clinical trial

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

3. I am considering using the Clinical Trial Support Center's services

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

If you watched any of the *My Story* videos, please answer these questions:

1. I felt emotionally impacted by the video or connected to it in some way

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

2. I feel the story or stories I watched and other patient stories should be shared

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

3. I feel a greater sense of community after watching the story

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

4. I feel compelled to share the story I watched

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

5. I learned something I did not know before from watching the story

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

Appendix B. Support Group Sample Survey

1. I felt overall better after attending the support group

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

2. I felt listened to and respected within the space

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

3. I would recommend this group to other patients and caregivers

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

4. I would not consider this group to be a safe space

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

5. I was given the opportunity to speak or listen

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

6. This group has made an impact on my journey as a patient or caregiver

1	2	3	4	5
(strongly disagree)	(Somewhat disagree)	(Neutral)	(Somewhat agree)	(strongly agree)

Appendix C. Post Webinar Sample Survey

7. Other providers would benefit from the X webinar.

1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

8. The X webinar was relevant to my personal experience.

1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

9. The X webinar will have an impact on my work in the future

1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

10. The X webinar made me think differently than before

1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

11. I learned something new from X webinar

1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)

12. I felt encouraged to ask questions in the X webinar.

1 **2** **3** **4** **5**
 (strongly disagree) (Somewhat disagree) (Neutral) (Somewhat agree) (strongly agree)