

PROJECT REPORT

Cancer Screening for immigrants and BIPOC Communities in Lewiston and Auburn, Maine



2023

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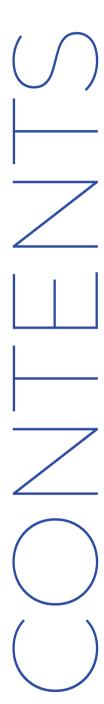
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EXECUTIVE SUMMARY

AK Health and Social Services (AKHSS) has received funding from the Maine Cancer Foundation to conduct a comprehensive needs assessment with the aim of improving our understanding of cancer screening rates among adults in immigrant, refugee, asylum seeker, and BIPOC communities. Our primary objectives for this project were to evaluate breast, cervical, colorectal, and lung cancer screenings within these communities.

This funding has enabled us to address a significant knowledge gap regarding cancer screening rates among vulnerable populations. By focusing specifically on immigrant, refugee, asylum seeker, and BIPOC communities, our intention was to identify potential disparities and barriers to cancer screenings in these groups. The insights gained from this needs assessment will be instrumental in shaping future grant applications that specifically address the issue of cancer screenings within Maine's immigrant, refugee, asylum seeker, and BIPOC communities.

Our approach involved the collection and analysis of data through various methods, including surveys, interviews, and community engagement. We worked closely with community organizations and stakeholders to ensure that the assessment was culturally sensitive and inclusive. By actively involving the target communities, our goal was to establish trust, foster meaningful connections, and gain valuable insights into the factors influencing cancer screening rates.

AK Health and Social Services (AKHSS) is dedicated to promoting health equity, advocating for social justice, and addressing the unique healthcare needs of vulnerable populations. With the support of the Maine Cancer Foundation and the findings from this project, we are committed to making a meaningful impact on cancer screening rates within immigrant, refugee, asylum seeker, and BIPOC communities in Maine.

In conclusion, AKHSS is grateful for the funding provided by the Maine Cancer Foundation, which has enabled us to conduct a comprehensive needs assessment. Through this project, we aim to develop targeted interventions that will improve cancer screening rates. By focusing on breast, cervical, colorectal, and lung cancer screenings within immigrant, refugee, asylum seeker, and BIPOC communities, we strive to create lasting positive change in Maine's healthcare landscape.

COMMUNITY BACKGROUND

Lewiston and Auburn, located in the heart of Maine, have become vibrant and diverse communities that have welcomed immigrants, refugees, and asylum seekers from various parts of the world. Over the past few decades, this region has experienced significant demographic changes, contributing to the cultural richness and economic growth of the area.

Historically, Lewiston and Auburn were predominantly populated by people of European descent, with a strong French-Canadian presence. However, in recent years, the region has witnessed a notable increase in the number of immigrants and refugees settling in the area.

According to the American Community Survey 2019 data, the foreign-born population in Lewiston and Auburn is estimated to be around 10.5%, higher than the statewide average of Maine. This indicates the significant presence of immigrants in the community. Furthermore, the survey reveals that the most common countries of origin for immigrants in the area include Somalia, Democratic Republic of Congo, Sudan, Iraq, and Afghanistan.

The influx of immigrants and refugees to Lewiston and Auburn can be traced back to the late 20th century. In the 1990s, Lewiston experienced a significant wave of Somali immigrants, many of whom were fleeing civil unrest and violence in their home country. They sought safety and stability in Maine, eventually making Lewiston their new home.

This initial migration opened doors for more immigrants and refugees to settle in the area. Over the years, Lewiston and Auburn have also welcomed individuals and families from other regions affected by conflict and persecution, such as Sudan, Democratic Republic of Congo, Iraq, and Afghanistan. he community responded to the growing diversity by establishing support systems and services to aid immigrants, refugees, and asylum seekers in their settlement process.

The impact of immigrants and refugees on the local economy has been significant. Many individuals have become entrepreneurs, establishing small businesses that cater to the specific needs and preferences of their communities. These businesses not only provide employment opportunities but also contribute to the cultural vibrancy and diversity of the area.

While the community has made significant strides in welcoming and integrating newcomers, challenges remain. Language barriers, access to healthcare, and employment opportunities continue to be areas of concern that require ongoing support and resources. However, the collective efforts of community organizations, educational institutions, and residents have helped address these challenges and create an inclusive environment that values diversity and promotes social cohesion.



In conclusion, Lewiston and Auburn, Maine, have experienced a demographic shift as a result of increased immigration, refugee resettlement, and asylum-seeking populations. The communities have embraced the presence of immigrants and refugees, recognizing the value and contributions they bring. With ongoing support and efforts, Lewiston and Auburn continue to evolve as inclusive and welcoming places where individuals from diverse backgrounds can find a new home and contribute to the fabric of the community.

HISTORY OF AKHSS



AK Health and Social Services was established in 2020 with a mission to address the unique challenges faced by immigrants and refugees. Founded by a former refugee, the organization is driven by a deep understanding of the experiences and needs of these communities. AK Health offers a range of services, including public health education and outreach, advocacy, and initiatives aimed at reducing barriers and challenges for immigrants and refugees.

As a founding member of the AK Collaborative, a coalition of five immigrant-led nonprofit organizations, AK Health works in partnership with Her Safety Net, Masjid Salaam Mosque, LA Family Support Services, and Care for All. Together, they primarily serve immigrants and BIPOC communities in Maine. The AK Collaborative implements various programs, including Health Education and Outreach, training and deployment of Community Health Workers, civic engagement activities, case management services, food security initiatives, spiritual care services, and support for victims of domestic violence among immigrant women and young girls.



Beyond the AK Collaborative, AK Health strives to establish partnerships with other service providers catering to the needs of immigrant and BIPOC communities, such as hospitals, schools, law enforcement agencies, and housing authorities. By fostering these collaborations, AK Health aims to enhance the support available to its target population and create a more comprehensive and integrated network of services.

TECHNICAL REPORT

INTRODUCTION

AK Health and Social Services (AKHSS) is a community-based nonprofit organization serving immigrants, refugees, asylum seekers, New Mainers, and BIPOC communities in Maine. Through direct engagement, conversation, and collaboration with the community and partners, AKHSS strives to understand what inequities and barriers exist between the Lewiston-Auburn community and their health. For this project, AKHSS received a grant from the Maine Cancer Foundation to investigate the community's trust and understanding of cancer screenings and to identify what social and cultural barriers prevent community members from getting regularly screened.[1] Between April-May 2023, AKHSS distributed 150 anonymous surveys collected via Survey Monkey both in person and over the phone. Community partners for this project included Her Safety Net, Masjid Salaam Mosque, and LA Family Support Services. Healthy Androscoggin was another community partner who assisted in reviewing the surveys. The survey contained a total of 22 questions with the first 8 questions identifying demographic information including gender, age, race, identity group, and religion. Baseline cancer screening questions aimed at identifying respondent's awareness of cancer screening and family history related to cancer. The remaining questions were asked to gauge respondent's trust, confidence, and emotional awareness of how getting screened for cancer made them feel and what preexisting knowledge they may or may not have.





Bates College students Caitlin Chan '24 and Amy Townend '24 were hired by AKHSS to assist with the data analysis and technical report. Caitlin's role in the project as project manager was to coordinate and facilitate meetings with community partners, create questions for the survey, and contribute to the technical report. She is a rising senior double majoring in mathematics and gender & sexuality studies with a concentration in Chinese language. This summer, Caitlin will be interning with Palladium's Data Science team in Washington, D.C. Amy's role in the project as data analyst involved working with the respondent data in RStudio to produce data visualizations for an analysis of cancer screening awareness and inequities. She is a rising senior majoring in economics with a minor in digital and computational studies. This summer, Amy will be interning as a summer analyst at Protagonist in Washington, D.C.

METHODOLOGICAL APPROACH

In order to conduct our analysis, we utilized the programming language R to build visualizations that help represent our data. R was a good choice for this project as it has a broad range of visualization libraries and was designed to display statistical analysis results. The survey result CSV file was imported into RStudio so we could run R. RStudio is an integrated development environment for R.

In order to build visualizations, we first had to "clean" or "tidy" the data. This process allows us to streamline the data and alter it into a usable set. We utilized Excel during this process as it was a larger data set with multiple columns and rows and Excel is able to apply formulas to data more smoothly than R. For example, when investigating how religion affects cancer screening, we had to merge the religion columns so we had one column that listed the religion for each person. This made building visualizations much easier as we only had to access one column instead of five. The cleaning process takes a lot of time and can appear unnecessary but it helps both the analysts and the programming language better sort the data. This survey is very vital to improving the cancer screening resources in the community so we had to pay close attention to confidentiality while striving for reflexive analysis of the population.

DATA ANALYSIS

Respondents participating in the survey identified themselves as either male or female and ranged from age 18-64. Most respondents identified themselves as African American followed by Asian, Alaskan native, and White. One question asked respondents to select as many options that applied to their situation and status as a resident of the Lewiston-Auburn community. The main analysis of this project utilizes a Likert scale which is "used to measure respondents' attitudes to a particular question or statement."[1] Respondents had options ranging from "Strongly Disagree" to "Strongly Agree." The survey was distributed via Survey Monkey, transferred to an Excel spreadsheet, and then imported into RStudio for data cleaning and coding. The analysis was conducted separately by gender and age to recognize the presence of any patterns by demographic groups. The following section contains highlighted findings from the Likert scale section extracted by themes and there is a visualization gallery included toward the end of the report.

[1] University of St. Andrews, "Analysing Likert Scale."

FINDINGS

Motivation for this project was to identify barriers that Lewiston-Auburn community members face when getting screened for cancer. After distributing the survey and conducting an analysis of the findings, it is evident that several themes exist in categorizing and describing feelings of hesitancy and uncertainty the community faces. Questions used in the assessment were from the Likert scale portion of the survey unless otherwise specified.

Trust

Trust is a key component of any relationship. One hypothesis our team developed prior to any of our research was that there existed a disparity between the Lewiston-Auburn and healthcare communities. In fact, "Medical mistrust is a cultural construct, that in general, has historical relevance and is deeply rooted in minority populations."[1] Given many of our respondents identified themselves as immigrants, refugees, asylum seekers, and New Mainers, we wanted to assess their level of comfort and ability to understand what resources are available to them and how healthcare providers can also play a role in their health. Previous research on tobacco usage and COVID-19 vaccine hesitancy conducted by AKHSS has shown there exists a certain level of mistrust that minority communities living in the Lewiston-Auburn have experienced when it comes to their relationship with their primary care and healthcare providers. In the statement, "I trust the information I receive from health providers about cancer screening," over 75% of all age groups were in some level of agreement. Respondents aged 25-54 showed the highest levels of disagreement around 10% each. In terms of gender, females (22%) tended to hold greater trust in health providers than males (14%) did. Trust was ultimately high across gender and age groups, however, we cannot exclude the respondents who did not agree with the statement and perhaps have had previously poor experiences with receiving medical advice.

[1] Gamble, "Under the shadow," in Bynum et al., "Unwillingness to."

Access

Question 6 asked respondents if it was easy to get a screening for cancer. The aim of this question was to identify whether or not respondents could easily get a screening for cancer regardless of whether or not they would get the screening done for themselves. Questions 20 and 21 were asked as follow-ups and asked where that information might be found or if their healthcare providers had previously spoken to them about cancer screenings. Respondents across all age groups and both genders did not find it easy to get screened for cancer. 18-24 and 55-64 year-olds tended to agree it was easy to get screened for cancer with 65% responding strongly in agreement. In comparison, respondents in the age groups of 25-35 and 36-54 found it more difficult with only 48% agreeing. However, the distribution of male and female respondents was almost identical at 62% agreeing.

In a later section addressing the theme of "Confidence," it would perhaps be beneficial to consider whether a relationship between confidence and access to cancer screening are at all related. In other words, perhaps the respondent's confidence is not as high because they are unsure or unaware of where they are able to access information on cancer and the importance of getting screened regularly.

Risk Perception

Risk perception refers to "subjective judgements of risk and are often to deviate from numerical risk estimates."[1]Factors including "uncertainty, fairness of risk distribution in society, and emotional reactions to risks also contribute to risk perception."[2] Questions asked during the survey strove to understand reasons for not getting screened for cancer which we believed might have been due to hesitancy, misunderstanding, or personal beliefs.

Questions 14 and 15 asked respondents to consider if getting diagnosed with cancer was a concern for them and if they were worried about the cancer screening process. Across both age and gender demographics, there was an overwhelming lack of concern about the possibility of getting diagnosed and the cancer screening process. In fact, nearly 70% of males and 82% of females were neutral or had some level of disagreement with the statement "Getting diagnosed with cancer is a concern for me." Regarding the cancer screening process, 85% of males were neutral or had some level of disagreement with the statement "I am worried about the process of getting screened for cancer" while females was a bit lower at 82%. Respondents who took the survey generally seemed to have a low risk perception of being diagnosed with cancer or getting screened.

- [1] Kortenkamp and Moore, "Psychology of Risk Perception."
- [2] Ibid.

Confidence

In accordance with risk perception, we wanted to assess levels of confidence in the community in regards to their knowledge of cancer screening. Lack of confidence in cancer screening knowledge might point to how we can strengthen accessibility and willingness to seek out resources that will benefit the health of the community. Given that many of our respondents have identities coming from a variety of social, cultural, and economic backgrounds, we recognize their ability to understand where and how to access these resources might vary. Therefore, their confidence level in knowledge they have regarding cancer screening might also vary as well.

3 of the 4 age categories had at least 75% of some level of disagreement to the statement "I am confident in my knowledge of cancer" with those aged 55-64 showing the highest levels overall at 90%. As knowledge and research increases regarding the importance of detection and screenings for early onset diseases as one ages, that could potentially explain the slightly lower levels of disagreement for those in the 18-24 age category at 47%. In terms of gender, again, both the male and female categories were nearly identical with slightly more females disagreeing with their confidence in knowledge of cancer than males. Both gender categories were slightly over 75% in disagreement of the statement.

Beliefs

Along with assessing the community's confidence and trust in their knowledge of cancer and cancer screenings, we also wanted to gauge their personal thoughts and emotions on the subject matter. Participants were overwhelmingly willing to get screened for cancer and agreed with the importance of getting screened. Nearly 75% of 18-35 year olds and over 75% of 36-55 year olds agreed they would get screened for cancer. Similarly, over 75% of all age groups agreed that it was important to get screened for cancer. While knowledge of cancer and the reasons for getting screened might not be totally understood, community members seem to recognize that regular screenings are a necessary component of their health and lifestyle.

To build stronger relationships founded upon trust, a better understanding of the community and their own personal needs by public health professionals and healthcare providers is crucial. Another question asked if getting screened for cancer was against any cultural or community beliefs and was overwhelmingly disagreed with by all age groups. It was noted that the largest percentage of those who agreed came from the 18-24 category at almost 100% disagreeing.

CHALLENGES AND LIMITATIONS

This survey was conducted between April-May 2023 which allowed 150 applicants to fill out the survey. We would hope to run this survey on a larger scale in order to get a better understanding of the community and the feelings towards cancer screening. If the survey was only filled out by a certain area of the community, the results can't be applied to the general population. When we started to run demographics, we did see that about 55% of the respondents were female which might reflect a bias in our results. In order to evaluate if we did have a bias in our results, we would want to evaluate if this gender split is reflected in the overall population that AKHSS serves.

Our study was limited to the community members that chose or had access to take the survey which also could introduce bias into our results. Those that actively participated in the survey might be a bigger advocate for healthcare and would create a false positive effect for us. In order to get a larger sample size, we would hope to advertise the survey in more areas of the community in order to get to those that aren't typically in medical centers and wouldn't normally see the survey. This study was also done during a small time period with limited data abilities so we would hope to expand both the time and resources for this project.

FUTURE RECOMENDATIONS

In our brief study which we conducted in hopes of better understanding perceptions the community had of getting screened for cancer, we have developed several recommendations for future studies and suggestions the healthcare community might consider. Alongside the technical report, we hope to distribute pamphlets around the community in an effort to make information on cancer screening understandable, equitable, and most importantly, accessible for anyone in the near future.

Community members seem to have a strong understanding that getting screened for cancer is important but their lack of confidence in their knowledge of cancer is an opportunity for outreach. As pointed out in an earlier paragraph regarding the demographics of the community that we surveyed, many of our respondents come from backgrounds that have placed them in the unfamiliar space of Lewiston-Auburn, Maine. Thus, it is the responsibility of the healthcare providers and public health organizations to understand how they can best serve these minority communities. Our research has identified that community members may have very general and at times limited knowledge of cancer screening. Cancer has the potential to play a huge role later in their lives if they are not aware of the precautions they need to take early on.

Greater levels of community outreach and involvement are key to bettering the understanding and health of these communities. Specifically, greater measures to ensure that community members are visiting primary care providers for routine health checks and screenings could play a role in benefitting their long term health.[1] Additionally, increasing circulation of awareness of the services offered at the Dempsey Center could also potentially help breach that gap between the community and health workers.[2] On top of increasing the community's overall knowledge, this could also simultaneously strengthen those relationships while building trust between the Lewiston-Auburn community and healthcare providers.

Lastly, a future study investigating the role of risk perception and fear amongst the community has great potential to pinpoint specific motivations for understanding why hesitancy exists. Our survey was distributed to identify and cultivate an understanding of general levels of screening amongst the community and what barriers they might face. The Lewiston-Auburn community would surely benefit from a study allowing public health professionals to learn what gaps in knowledge exist and how to better mitigate their hesitancy or reluctance. We can only hope to help the future health of our communities if we can understand the complex nature of their identities and the needs of their community.

CONCLUSION

Through our research, we have found that the way people view cancer screening can be influenced by emotions such as feelings of fear, confidence, and trust. Cancer is a frightening possibility to anyone, especially those with limited access to resources or knowledge. Women are more likely to get screened for cancer compared to males in both nationwide surveys and our survey by a margin. When we began our delve into the data, we created visualizations that focused on the demographics of our survey respondents in order to evaluate the data accurately. We found a large number of respondents to be females between the ages of 36-54 who are Muslim. This preliminary search helped guide our research and let us focus on the most pressing questions.

We found that the majority of the survey respondents had some level of trust in the medical community when regarding cancer screening which is an improvement from a previous study that investigated tobacco use. However, when questioned whether they would get screened for cancer, we saw a large drop to only half the respondents agreeing they would get screened. When it came to evaluating respondent's confidence in cancer information, we saw a higher percentage of agreement in the older age groups when compared to 18-24. This is similar to nationwide surveys that reflect older populations are more educated as they are at higher risk.

There was an overwhelming majority that agreed it was very important to get screened for cancer and that getting screened for cancer doesn't go against their beliefs. This was an important question in order to help AKHSS understand how to encourage people to get screened for cancer.

As mentioned previously, this study gives us a glimpse into the stigma around cancer screenings in the Lewiston-Auburn community. While the majority agree it is important to do so, it is still a struggle to get people in to be screened for cancer due to many reasons. With this study, we hope that we have a better understanding of people's feelings about cancer screenings and can use this information to increase access to cancer screenings in the future.

VISUALIZATION GALERY

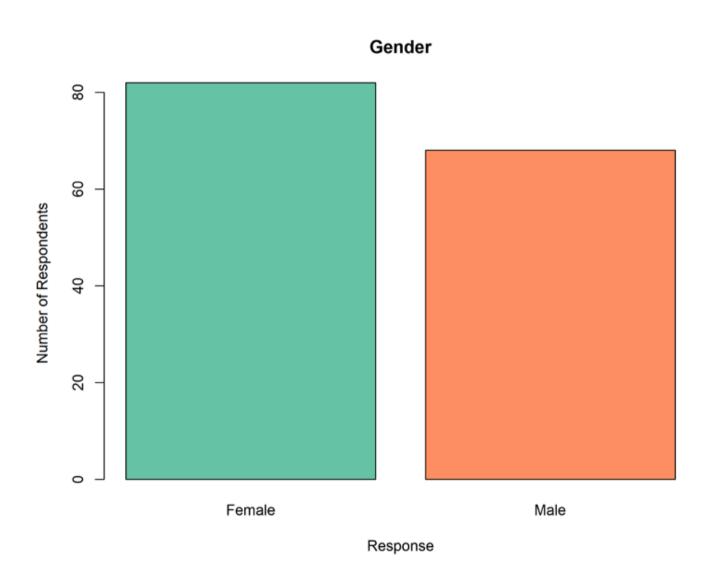


Figure 1: Response rate of survey by gender

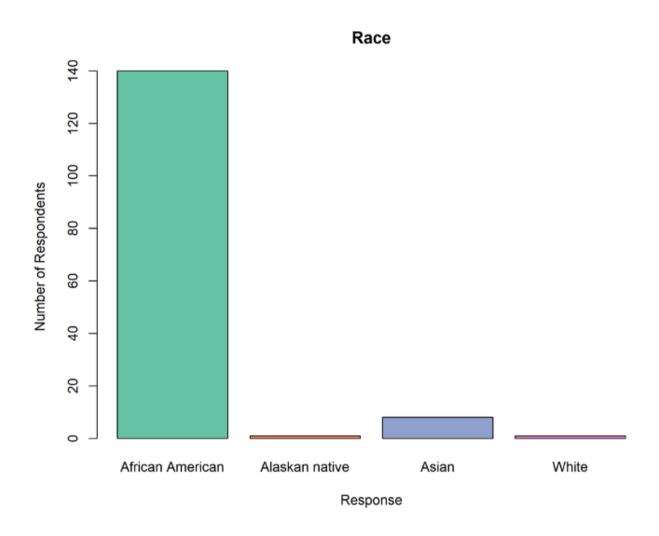
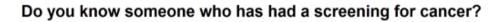


Figure 2: Response rate of survey by race



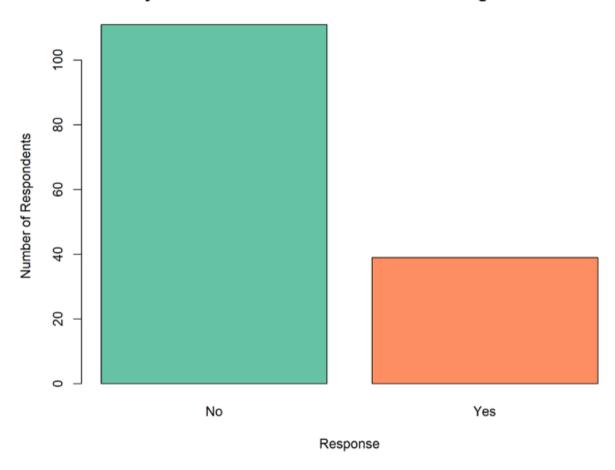


Figure 3: Number of respondents who know someone who has previously been screened for cancer

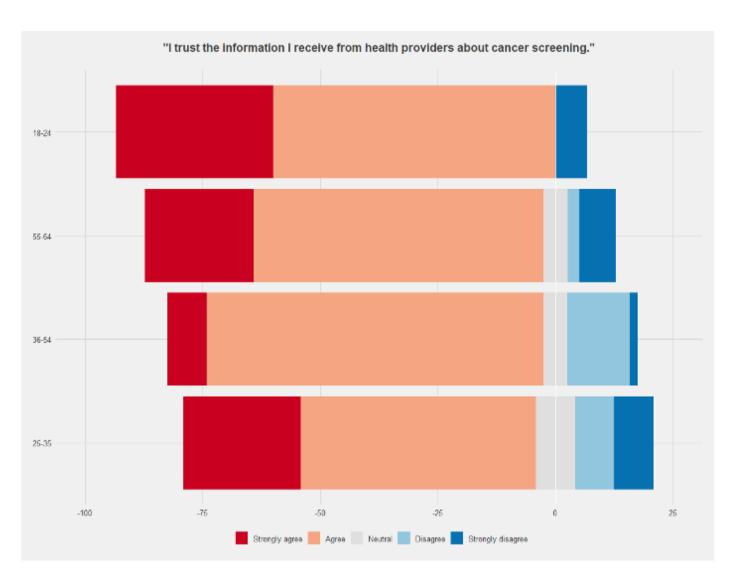


Figure 4: Question 8 percent response rate by age (Trust)

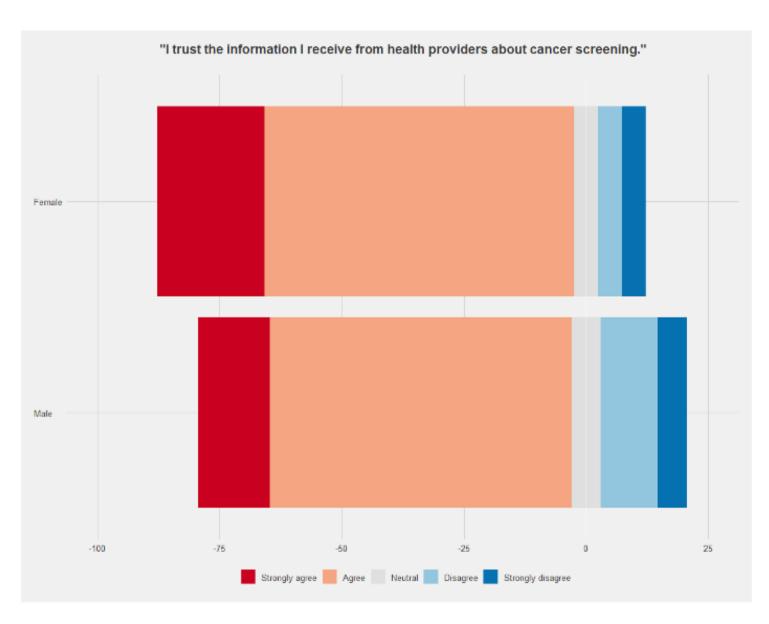


Figure 5: Question 8 percent response rate by gender (Trust)

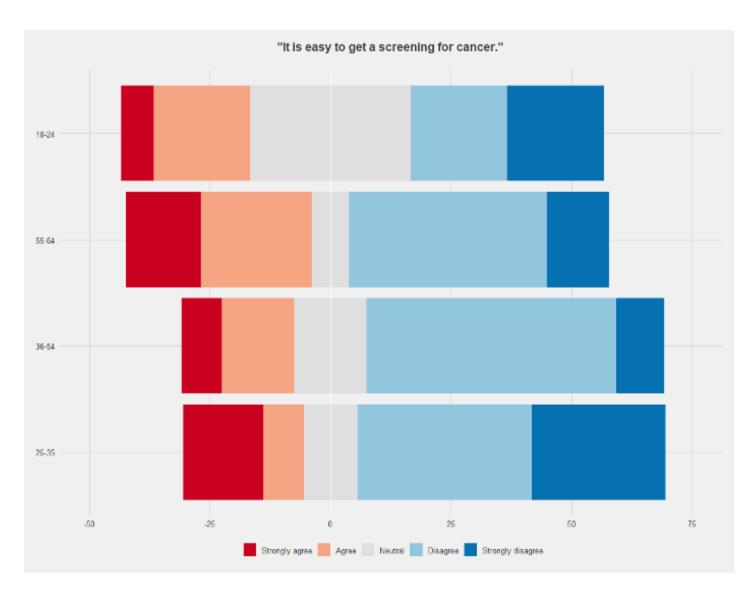


Figure 6: Question 6 percent response rate by age (Access)

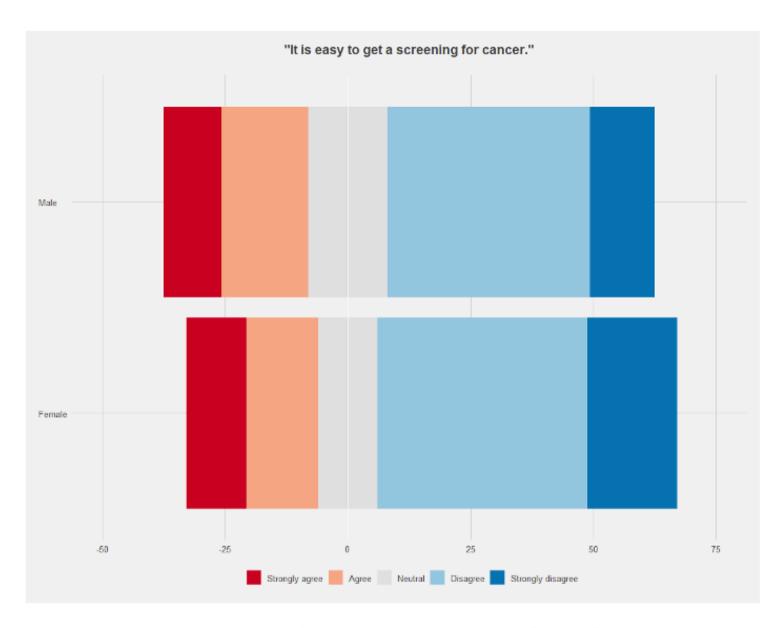


Figure 7: Question 6 percent response rate by gender (Access)

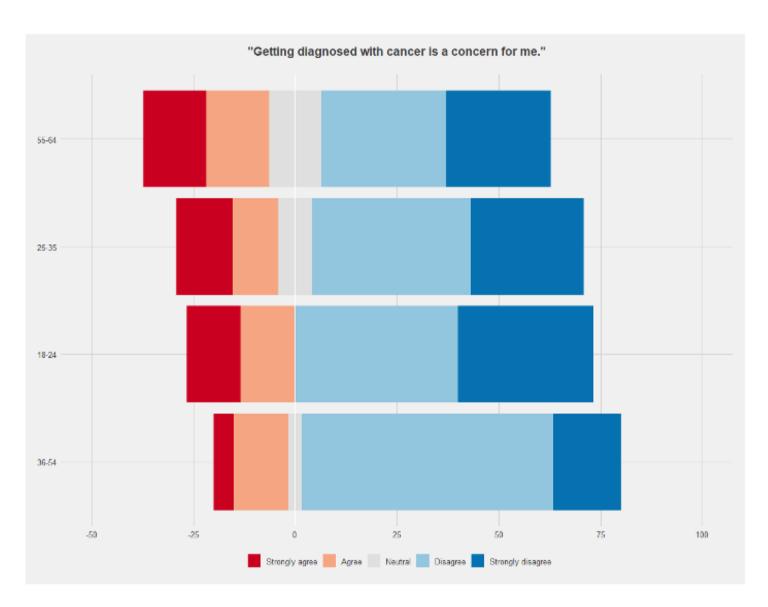


Figure 8: Question 3 percent response rate by age (Risk Perception)

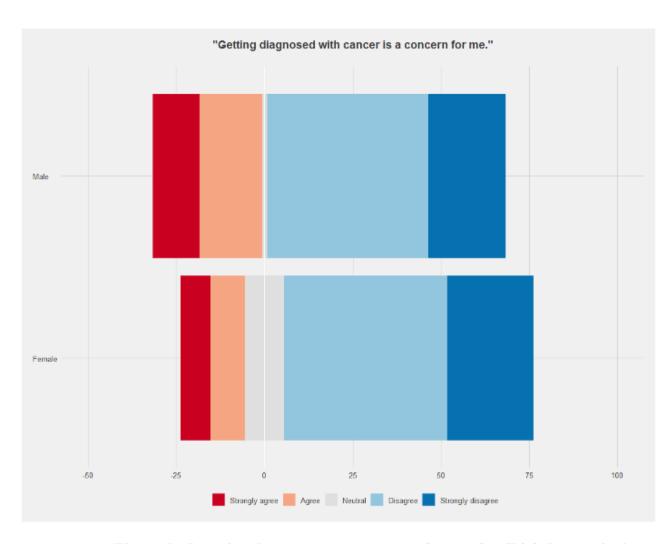


Figure 9: Question 3 percent response rate by gender (Risk Perception)

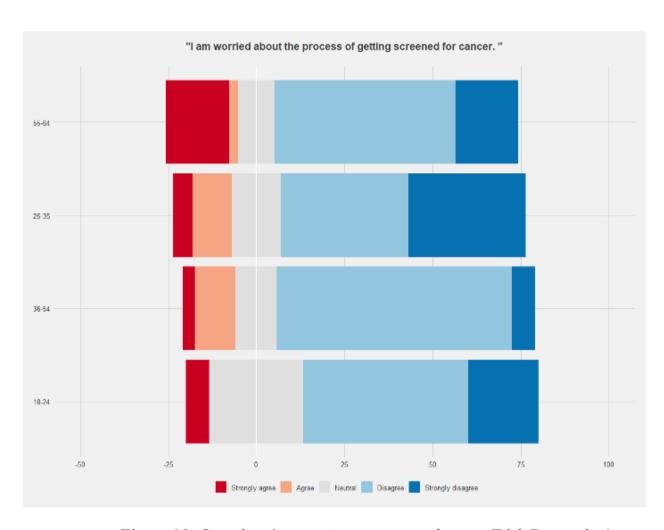


Figure 10: Question 4 percent response rate by age (Risk Perception)

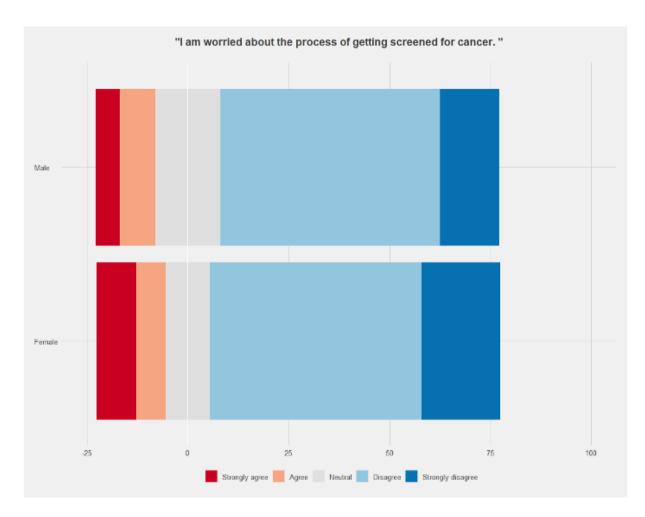


Figure 11: Question 4 percent response rate by gender (Risk Perception)

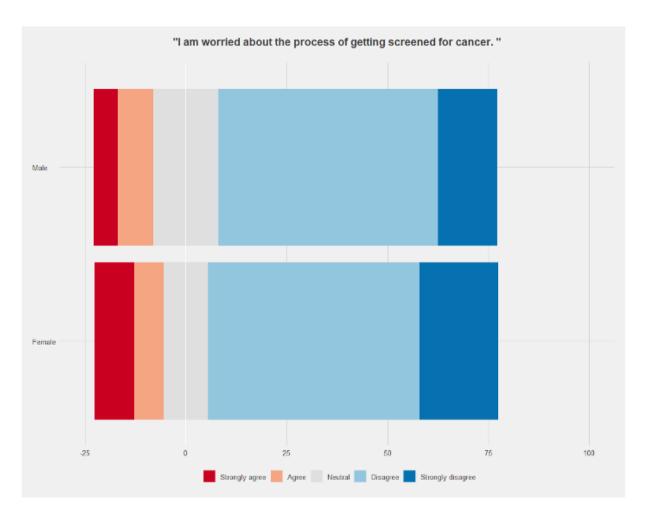


Figure 11: Question 4 percent response rate by gender (Risk Perception)

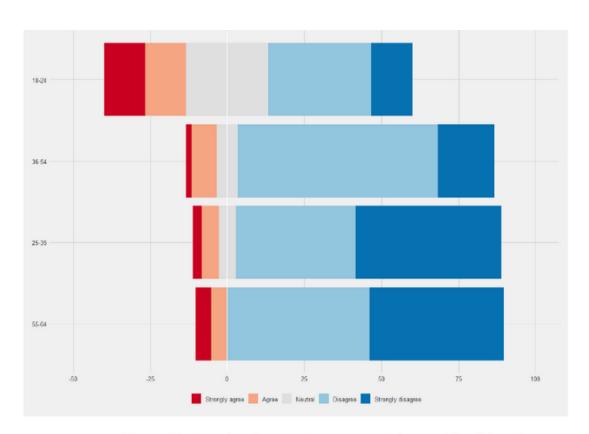


Figure 12: Question 5 percent response rate by age (Confidence)

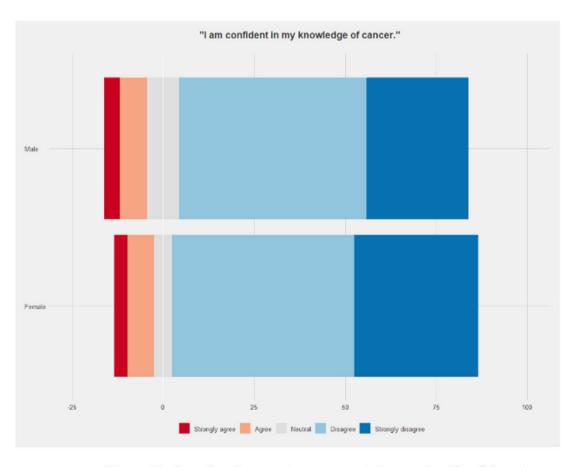


Figure 13: Question 5 percent response rate by gender (Confidence)

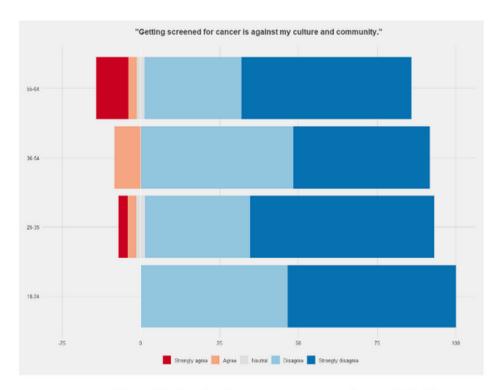


Figure 14: Question 7 percent response rate by age (Beliefs)

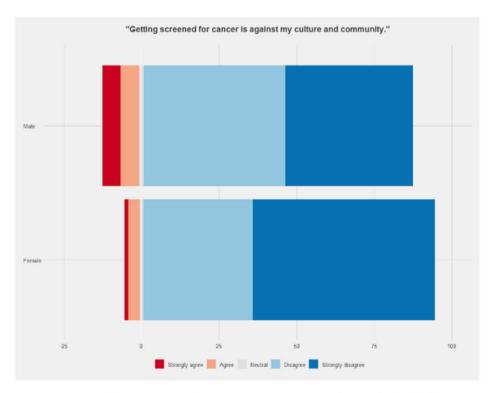


Figure 15: Question 7 percent response rate by gender (Beliefs)

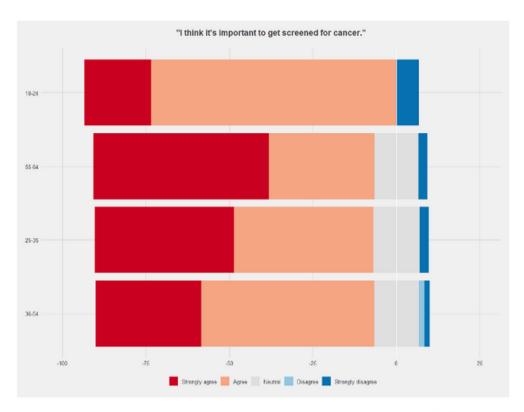


Figure 16: Question 2 percent response rate by age (Beliefs)

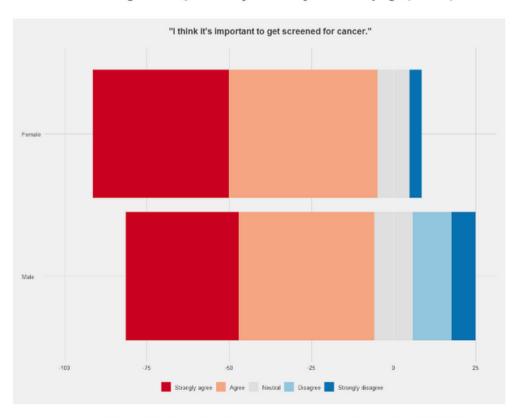


Figure 17: Question 2 percent response rate by gender (Beliefs)

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WE WOULD LIKE TO EXPRESS OUR HEARTFELT APPRECIATION TO THE MAINE CANCER FOUNDATION FOR THEIR GENEROUS SPONSORSHIP OF THIS PROJECT. FURTHERMORE, WE EXTEND OUR GRATITUDE TO THE FOLLOWING INDIVIDUALS AND ORGANIZATIONS FOR THEIR INVALUABLE SUPPORT, WHICH PLAYED A VITAL ROLE IN MAKING THIS PROJECT A REALITY.

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AMINA HASSAN- HER SAFETY NET
AHMED ALI- LA FAMILY SUPPORT SERVICES
CATILIN CHAN- AK HEALTH AND SOCIAL SERVICES
NADIFA MOHAMED- MASJID SALAAM MOSQUE
ZAHARA NOOR- HER SAFETY NET
MOHAMED NOOR- HER SAFETY NET
DR LYNN WALKIEWICZ
CANDACE JOHNSON
AMY TOWNEND- BATES COLLEGE

AND THE ENTIRE AK HEALTH TEAM
ABDIKHADAR SHIRE, ABSHIRO NOOR, CAITLIN CHAN,
RYAN DENBOW, ANTONIO MELGAR, AMARACHI ALOZIE,
NIMCO HASSAN, HURIO EDEN, YASMIN EDEN AND SUUDI
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