Exploring Best Practices in Recruiting Rural Maine Cancer Patients and Their Families to Participate in Focus Groups

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Capstone Report

Exploring Best Practices in Recruiting Rural Maine Cancer Patients and Their Families to Participate in Focus Groups

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INTRODUCTION

The purpose of this capstone project was to explore best practices in recruiting rural Maine cancer patients and their families for focus groups by developing, implementing, and reflecting upon a recruitment protocol using an Evidence-Based Practice framework. The basis of this project was a partnership between the Dempsey Center and the Muskie School of Public Service at the University of Southern Maine (USM). This partnership was developed to explore ways to connect underserved (especially rural) and uninsured Maine cancer patients and their families to free cancer support services and resources. To help achieve this goal, USM researchers planned to conduct two focus groups with cancer patients and family members/caregivers who live in rural areas of Androscoggin, Franklin, and Oxford counties and who have never used cancer support services from an organization like the Dempsey Center before.

This project is important because rural residents may be underserved by the existing cancer support systems and learning more about their experiences may help the Dempsey Center and others connect them to valuable services. In addition, recruiting rural residents to participate in focus groups is challenging due to barriers like distance and mistrust, so identifying the best recruitment strategies for this population is important to learning about and addressing the disparities they may be facing. The underlying goals of this project were: to recruit 12-16 rural Maine cancer patients and/or their family members to participate in the focus groups, to use evidence from the literature and suggestions from experts in the field to guide the recruitment process, and to reflect upon this process to offer suggestions for recruitment of this population in the future. Reflection on the recruitment process has provided some valuable insights that will be shared in this report.
BACKGROUND

In 2015, cancer was the leading cause of death in Androscoggin and Oxford counties and ranked as the second leading cause of death in Franklin County (United States Department of Health and Human Services, 2016). County Health Rankings also reports that Androscoggin County ranks 13th for health outcomes in Maine, while Oxford and Franklin rank 10th and 6th, respectively (2017). These health outcomes rankings are based on a number of length and quality of life measures. Further, the Maine Shared Community Health Needs Assessment indicates that Androscoggin, Franklin, and Oxford counties perform poorly on measures of socioeconomic status (SES) (2015). SES, along with other social and environmental factors, contributes significantly to the health disparities in these counties. Numerous articles in the literature indicate that SES is a predictor for an individual’s risk of developing cancer and the likelihood that they will survive cancer. For example, a 2012 study by Doubeni et al., found that people who had a low educational level or lived in a low socioeconomic status (SES) neighborhood had a higher risk of colorectal cancer relative to the highest SES groups, even after accounting for other risk factors. Another review and meta-analysis of twenty-three papers found that patients with lung cancer who held a lower socioeconomic position were significantly less likely to receive any type of treatment, surgery, and chemotherapy (Forrest, Adams, Wareham, Rubin, & White, 2013). These differences remained even after accounting for differences in stage and for both universal and non-universal health care systems (Forrest et al., 2013).

Considering the literature and Androscoggin, Franklin, and Oxford County’s reported disparities, it is important that organizations like the Dempsey Center expand their service reach to individuals living in these counties who are currently disengaged. Free complementary cancer support services (e.g. massage therapy, acupuncture, support groups) like those provided by the
Dempsey Center are an important option for individuals and their families impacted by cancer in these counties. Individuals impacted by cancer at any point from diagnosis to treatment, recovery, and beyond are eligible for services at the Dempsey Center.

In an effort to expand its reach to underserved, especially rural and uninsured, populations, the Dempsey Center applied for, and was awarded funding through a small Maine Health Access Foundation (MeHAF) grant to conduct focus groups, and to undertake additional data collection activities. The purpose of the focus groups was to gather information from patients and family members about their knowledge of, access to, and barriers to using free support services provided by the Dempsey Center. The recruitment for these focus groups was viewed as critical because well-attended focus groups return the most useful and representative data. From the start, the researchers knew the recruitment process would be difficult because the target population is disengaged from the support system. Finding creative ways to reach this population is important to addressing the health disparities they face because their lack of involvement with the existing support services makes them difficult to reach.

**SIGNIFICANCE**

This project is important because of the current disparities and rates of cancer in the target counties. The hope for this project was to talk with individuals affected by cancer living in rural areas to see how the Dempsey Center could better reach them and other rural, underserved individuals with resources and services. Although this aspect of the project is not yet complete, the lessons learned about focus group recruitment in this population can give the Dempsey Center and other interested organizations valuable insights on how to recruit rural Mainers for focus groups.
LITERATURE REVIEW

Rural Participant Recruitment

Recruiting for focus groups, especially with rural participants, is extremely difficult. Members of rural communities have unique perspectives and barriers that require responsive recruitment strategies. The literature includes numerous sources that explore barriers, motivators, challenges, and strategies for the recruitment of this distinct population.

Goodsell, Ward, and Stovall present an interesting perspective on adapting focus groups to a rural context where they insist on “seeing the rural” to ensure validity of focus group findings (2009). The article includes details on some potential challenges of conducting focus groups with people living in rural areas, namely problems with distance, mistrust of outsiders, weather, poor road conditions, and rural lifestyles (Goodsell et al., 2009). Smith, Blake, Olson, and Tessaro echoed many of these challenges in a rural case study where researchers entered into small communities to learn about conducting rural focus groups (2002).

Many of the other articles in the literature that explore the recruitment of rural research subjects involve clinical trials. Challenges presented in these articles include: inconvenience of times or sites, a desire for independence, having to drive more than 30 miles, transportation issues, confusion over study components, potential stigma, and limited time (Das Nair, Orr, Vedhara, & Kendrick, 2014; Friedman, Foster, Bergeron, Tanner & Kim, 2015; Pribulick, Williams, & Fabs, 2013). These resources reflect on recruitment for clinical trials, but the barriers to focus group recruitment are likely comparable.

A number of strategies to address these challenges have been presented in the literature. One frequently suggested strategy is to use family, friends, and trusted community members as recruiting intermediaries (Friedman et al., 2015; Goodsell et al., 2009). Similarly, Smith et al.
argue that research needs “local legitimacy”, which can be achieved by involving local agencies and community leaders and asking them to endorse the project and share it with other gatekeepers in the community (2002). Other sources suggest that, to address these challenges, researchers should: consult with local informants, invite potential participants in person, reimburse or provide travel, place meeting sites in the rural community, use multiple local advertising sources, and work with churches, schools and other community organizations (Friedman et al., 2015; Goodsell et al., 2009; Pribulick et al., 2013; Smith et al., 2002). In addition to these suggestions, Friedman et al. observe that financial incentives are the most effective motivator, but the opportunity to help friends and families may also persuade rural individuals to participate (2015).

Further, a review article by Shaghaghi, Bhopal, and Sheikh introduces other potential sampling strategies that may help boost recruitment for this project (2011). The review describes snowball sampling, respondent-driven sampling, and indigenous field worker sampling, all of which could help recruit “hard-to-reach” populations (Shaghaghi et al., 2011). In snowball sampling, the initial subjects for the study are asked to give referrals to recruit additional subjects, while respondent-driven sampling uses a similar method, but includes incentives for those individuals who recruit their peers (Shaghaghi et al., 2011). These strategies build trust between research subjects and researchers because new participants are recruited by someone they know. Finally, with indigenous field worker sampling, people working in the target communities are trained for the study so they can track down and recruit participants (Shaghaghi et al., 2011). This strategy could be especially valuable in rural focus group recruitment, but may not be feasible for small or time-constrained projects. This long list of strategies was considered when developing the recruitment plan for this project.
Cancer Patient Recruitment

Recruiting cancer patients and their family members adds unique challenges upon which the literature offers additional insights. Ford et al. conducted a systematic review to examine recruitment barriers for cancer clinical trials in which they found that, in addition to the barriers listed above, a lack of awareness about the project, sociodemographic characteristics like higher age and lower income, and a lack of culturally appropriate information hindered recruitment (2008). Looking specifically at rural patients in cancer clinical trials, other important factors impacting recruitment include physician opinions about the study and monetary burden (Virani, Burke, Remick, & Abraham, 2011). Other studies on cancer clinical trial recruitment have found that patients were too unwell, wanted to focus on treatment, had too many medical appointments, or did not feel the need to participate (Balogun et al., 2011; Sygna, Johansen, & Ruland, 2015). These challenges, although found for clinical trials, may be similar to those that come up in focus group recruitment, making the target population for this project even more difficult to reach.

To address the challenges of recruiting cancer patients for research studies, several resources share insights. An article sharing the perspective of a clinical research associate found that the most important factors in cancer patient recruitment to clinical trials were physician involvement (including the physician’s view that the trial has merit), the patient’s sense of personal benefit, and successful information transfer in the consent process (Wright, Crooks, Ellis, Mings, & Whelan, 2002). Das Nair et al. presented similar findings, namely that invitation to a clinical trial should come from general practitioners (2014). In addition to these suggestions, Sygna et al. tested a number of specific recruitment strategies in a randomized controlled trial (2015). These researchers found that on-site recruitment was the most successful recruitment method because it eases registration and builds trust, but the problem with this method is that it is
time consuming and researchers may not know who is eligible (Sygna et al., 2015). In comparison, they found that relying on hospital providers for recruitment was successful, but recognized that relying on someone else who has limited time to do recruitment is a downside to this method (Sygna et al., 2015). These researchers also noted that newspaper advertisements reached a large number of people and recruited genuinely interested participants, but, because the patients needed to take action, few participants were recruited this way (Sygna et al., 2015). Similarly, they found that social media advertisements have a large reach and require little effort, but low response rates resulted from the need for patient action and the overload of information on the Internet (Sygna et al., 2015). Although these strategies address clinical trial recruitment, they were important to consider when developing a focus group recruitment plan because limited literature exists on strategies for focus group recruitment among this population.

Older Adult Recruitment

Although cancer patients and their families may be of all ages, generally, cancer affects an older population, which means that the strategies for recruitment in this project need to be geared to this group. Dibartolo and McCrone suggest strategies for recruiting rural community dwelling older adults, which include using gatekeepers, increasing personal contact by the researchers who are attentive to the needs of older adults, and other media approaches like the newspaper, radio, tv, and church bulletins (2003). These strategies may be tailored to specific rural communities when community based organizations become engaged in the process, although accessing older adults may still be difficult due to lower literacy rates, transportation issues, and distrust of outsiders (Dibartolo & McCrone, 2003). Clearly, given all of the challenges presented in the literature, recruiting focus group participants with cancer from rural areas is difficult, so finding the best ways to engage them was important to this project.
PROJECT OBJECTIVES

1. To identify the biggest challenges to focus group recruitment of cancer patients and their families who live in rural Maine.
2. To identify the most effective focus group recruitment strategies in recruiting cancer patients and their families who live in rural Maine.
3. To recruit 12-16 cancer patients and/or their family members who live in Androscoggin, Franklin, or Oxford county to participate in a focus group on their knowledge of, attitudes toward, barriers to, and access to free cancer support services provided by the Dempsey Center and other organizations.
4. To develop recommendations for researchers looking to recruit rural Mainers and other rural dwellers for future focus groups.

METHODS

As this project was done in coordination with a grant-funded research project directed by a USM Muskie School researcher, she submitted the original protocol for IRB approval, which the IRB granted on December 27, 2017. Although the student was not involved in the original IRB submission, she amended the protocol twice to submit recruitment materials. The resubmission of the materials was not required for IRB approval, but was due to additional feedback from the Dempsey Center. The recruitment materials received final approval from the IRB on February 26, 2018.

The student included a short literature review in the project proposal, but she conducted a more in depth review of the literature between January 14, 2017 and January 28, 2017. She identified nine new sources and included them in the final literature review of this capstone
project. The strategies and barriers identified in the literature were then considered when developing the recruitment plan for this project.

After reviewing the literature, the student identified two individuals who have worked on rural focus group recruitment in the Maine Rural Health Research Center as experts in the field and contacted them for interviews. These researchers worked on recruitment for the Maine Lung Health Study (MLHS) focus groups. These focus groups targeted men and women over forty living in one of three rural Maine counties who were current or former smokers and were disengaged from the health care system. Although this population seems different from the target for this project, they were pursuing an older group of people living in rural Maine who were disengaged from the health care system, so the input from the two key informants was extremely relevant. Rather than completing two separate 30-45 minute interviews as was originally planned, the interviewees opted to partake in a single one-hour interview, so they could talk through the project together. The interview followed a semi-structured interview protocol, which can be found in Appendix A. The student used the insights from this interview to supplement what she learned from the literature search and to help give some insights into how to recruit in Maine specifically.

After completing the literature review and the interview, the student reached out to a public health coalition of organizations that she thought may serve the target population. The coalition consisted of public health, cancer support, and healthcare organizations serving the three target counties (Androscoggin, Franklin, and Oxford) and included: the Cancer Resource Center of Western Maine, Dempsey Center, DFD Russell Medical Center, Healthy Androscoggin, Healthy Community Coalition of Greater Franklin County, Healthy Oxford Hills, Oxford County Wellness Collaborative, and Stephen’s Memorial Hospital. The student identified
and asked eight staff at these organizations to share insights about places they would go in their community to recruit this population for focus groups. She did this to help tailor the recruitment plan to individual communities by identifying specific places to go for recruitment. In addition, she asked the public health coalition staff if their organizations would help disseminate recruitment materials on their website, Facebook, in office, or otherwise, so they could serve as recruiting intermediaries, a step suggested in the literature.

Using the information obtained in these steps, the student developed the recruitment materials. Before creating the materials, she reviewed USM IRB’s PRISM training and used it as a source for guidance. The recruitment materials for this project can be found in Appendix B. Appendix B contains two flyers and a descriptive paragraph that could be posted with the flyers on the Internet. The first flyer is an electronic version, for posting and sharing online, while the second was for posting flyers in person because it has pull tabs with the study phone number along the bottom. After the student developed the materials, she received feedback from a number of individuals including the principle investigator for the project, representation from the Dempsey Center, and multiple non-researchers. Using this input, she edited the materials and submitted them for IRB approval, which was granted on February 26, 2018.

After approval, the student distributed the materials according to the recruitment plan she developed for this project. She started by reaching out to the community organizations who she engaged earlier in the project to ask them to post materials to their website, calendar, newsletters, or Facebook. After contacting these organizations, she reached out to health centers and hospitals in the target areas to see if they would be willing to share the information or post flyers in their locations. Next, she visited individual communities to talk with people, hang flyers, and spread the word. This piece of the process took several days as she drove through the target
communities stopping at town offices, libraries, laundromats, post offices, banks, restaurants, corner stores, and any other locations that might be able to get the word out. During this phase, she also enlisted the help of a relative who lives in a rural part of Oxford County and owns a corner store. This relative helped expand the recruitment reach by: sharing the flyers and information with her own local connections, hanging up flyers in her community (including her store), and posting the flyer on her store’s Facebook page.

After visiting these communities and meeting people in them, the student reached out to a number of community Facebook groups and forums, especially in those communities she had not been able to drive through, to ask if they would share the flyer with their followers. She also contacted local newspapers in the target communities to see if they would run an article or ad on the project. Finally, during the last week of recruitment, the student asked the organizations that shared flyers and information online to repost the flyer about the focus groups to encourage one last wave of recruitment. The index of locations where recruitment materials were shared or posted, by county, can be found in Appendix C. This list includes only those places where recruitment materials were successfully posted. A number of organizations and people did not respond to requests or would not post the materials.

After disseminating the flyers and spreading the word, the researchers waited for potential participants to call in. The materials advertised the student’s Muskie School phone number and prompted individuals to call if interested in participating. The student recorded a voicemail in case calls came in while she was not in the office. The voicemail script, inclusion and exclusion criteria, and sample phone scripts can be found in Appendix D. Three individuals called to participate in the focus groups, so the student screened them for eligibility and scheduled them for one of the two focus groups. The snowball sampling strategy was used with
each caller to see if they knew anyone else who might be eligible to participate. All three were eligible because they were 18 or older, had been impacted by cancer, had never used services from a free-standing cancer support center like the Dempsey Center, and lived in Androscoggin, Franklin, or Oxford county.

    The plan was to have both focus groups on March 20, 2018. One from 12:00-1:30 PM at the Cancer Resource Center of Western Maine in Norway and the other from 5:00-6:30 PM at the Dempsey Center in Lewiston. Each participant would receive a $30 Hannaford gift card for participating along with refreshments during the session. Unfortunately, due to low numbers, the researchers cancelled the focus groups. The student called the scheduled participants on March 20, 2018 to notify them of the change and to ask if they might be interested in a telephone interview instead. The project team is currently developing a plan to satisfy the funder’s needs that will likely include phone interviews with these participants.

    **STUDY FINDINGS**

    Although the number of participants recruited to the focus groups was not as high as the researchers had originally hoped, this project is still important because it provided opportunities for lessons learned. The first big lesson learned, which was no surprise, was that focus group recruitment is extremely difficult, especially when recruiting individuals from a rural population. The many remaining lessons came in different forms, starting with findings from the key informant interview, working with public health coalition staff, and, finally, implementing the recruitment plan.

    **Key Informant Interview**

    As described above, the MLHS target population was similar to the population for this project, so the researcher’s insights were valuable. One thing was clear during the interview:
focus group recruitment is difficult and requires a lot of effort. The researchers mentioned that they had to change the recruitment parameters several times to increase the number of people who were eligible for the focus groups. Overall, the biggest challenges that they had were getting the information to the “right ears” and people not calling until the last minute. This was surprising, so it was important to know before beginning recruitment for this project.

The MLHS recruitment was successful, so it was helpful to learn about the strategies they used to reach people. Their most effective strategies were: using word of mouth at community events, contacting community organizations, town or community Facebook pages, online community calendars, local newspapers, and local radio stations. Interestingly, they also added that there seemed to be a level of trust built between participants and Zach, who was fielding the calls. Both interviewees noted that simply putting “Call Zach” on the poster worked well and people were friendly when they met in person since they felt like they knew Zach already. Similarly, the interviewees also indicated that being warm, authentic, friendly, and letting people know you aren’t interested in changing their minds, but want to hear what they have to say helped with recruitment. Overall, the interview was useful because it showed that recruitment would be difficult, but that there are ways to be successful. The strategies discussed in this interview guided this project’s recruitment strategy.

**Working with Public Health Coalition Staff**

Working with public health coalition staff was another learning experience in this project. Overall, they were wonderful to work with and provided some helpful guidance on where to go to promote the project. They did a fantastic job sharing the information in any way they could with their community. Even with these positive takeaways, there were a lot of factors that influenced communication with community partners that should be noted.
First, community partners have a lot going on, so promoting an outside project can be hard to fit onto a priority list. There were some people who indicated that they would help on first contact, but, in the end, they were too busy and weren’t able to be as helpful as they originally indicated. Second, vacations, weather, illness, and a full email inbox can seriously delay communication. Throughout the recruitment process, multiple snowstorms meant people wouldn’t be in the office or people were out for a variety of other reasons like sickness or vacation. These factors made it difficult to get recruitment materials out as quickly as planned. Therefore, it is important to recognize that more time is better and is necessary for recruitment, especially during the Maine winter. Finally, after reflecting on these experiences, it’s clear that to get the necessary information for recruitment, you need to be extremely direct. In this project, there was an effort to be direct with the community partners when asking where to go to do recruitment, but asking for more specifics about individual events or places to go to would be even more beneficial. For example, there was a suggestion to go visit beano halls, but local beano halls do not advertise online, so in small communities in rural Maine it is extremely difficult to figure out when and where to go. Therefore, asking for more specific details from community partners at the start could improve the recruitment process.

**Barriers to Recruitment**

Actually implementing the recruitment plan and reflecting on it revealed a lot of barriers that likely prevented successful recruitment. Many of these barriers may be related to a small target population and a limited budget, although there are a number of other factors that were also influential.

The most significant barrier to recruitment was probably the limited budget for the project. Due to the budget constraints, the locations of the focus groups were set in Norway and
Lewiston, each of which already has their own free-standing cancer support center with the Cancer Resource Center of Western Maine in Norway and the Dempsey Center in Lewiston. These locations made this project financially feasible by limiting travel and providing a free room, but they also hindered recruitment because the target population included only those individuals who have never been to a free-standing cancer support center. Where the locations of the focus groups were in communities that already have a cancer support center, many people affected by cancer in these areas may have used services in the past, making them ineligible for the study. Chances are that the people who have not used these services live further outside of town, which would mean that to participate in the focus groups they might have to travel a significant distance. For example, no one called from Franklin County, likely because the travel distance to Norway or Lewiston was too far.

Besides location, another potential barrier to recruitment that stemmed from the budget was the timing. Both focus groups were scheduled for the same day to lessen the impact of travel on the researchers (who received no travel reimbursement), but some participants may not have been available on that day, which would make it impossible for them to participate. It is likely that some potential participants may have seen the information about the focus groups, but did not bother calling because of travel distance or inconvenient times. Further, an added budget issue that was likely a barrier to participation was not having a large enough incentive. Fortunately, the Dempsey Center was generous enough to provide a $30 Hannaford gift card as an incentive for this project, but this may not have been enough to overcome many of the other barriers to recruitment for this project.

Another barrier to recruitment that undoubtedly influenced the outcomes of this project was weather. Weather was a factor in communication with community partners, but it also likely
prevented potential participants from joining the focus groups. During the first two weeks of March, just before the focus groups, there were three large snowstorms. This much snow brings poor road conditions and consumes attention. People are worried about cleaning up the snow and staying safe rather than going out and thinking about participating in a focus group. Therefore, the weather was probably an influential factor that limited focus group participation.

Finally, as the literature review indicated, cancer can be a difficult topic to recruit for. Many people feel too unwell to be involved in research, while others simply don’t like to talk about cancer, especially after the loss of a loved one. This was the case with at least one potential participant. One of Mary’s friends who lives in Androscoggin County recently lost a loved one to cancer. Although, as a friend, she was not eligible to participate, she shared that one of her relatives might be interested. Later, upon follow up, the friend shared that her relative was not interested in joining the focus groups because, “She doesn’t like to talk about it.” This is another potential reason for low interest in the focus groups because talking about cancer can be difficult, especially after experiencing it firsthand.

**Successful Strategies**

Although the student only recruited three participants for this project, their willingness to join shows that some of the recruitment strategies worked and reached the target audience. Two of the participants saw flyers in local places that they frequent, specifically a library and a convenience store. The third participant saw the information in a Facebook post shared by her town.

Based on the research and expert interviews, it is surprising flyers in local places generated two-thirds of the recruitment for this project. One factor that likely helped recruitment in these places was that the student talked to people and explained the project when distributing
flyers, rather than simply putting them up. Many people were intrigued and thought it was a great idea. Generally, most people seemed willing to point the flyer out to people they knew who might be eligible and who visit their place of business. This probably helped generate interest in the flyers, which could be why the majority of recruitment came from this source.

The other source of successful recruitment was Facebook. Where this was a strategy recommended in the interview and the community organizations were acting as gatekeepers sharing the focus group information with rural community members, this was not surprising. In fact, it was surprising that there were not more calls generated by social media outreach. There were a number of shares and comments about people being interested in the project, even one comment that said, “I’m going to call tomorrow.” Unfortunately, people forget and social media has so much information that it’s easy to lose a post you meant to go back to, which may be what happened with these individuals. Multiple follow-ups should be posted to ensure people remember to call when recruiting online.

Lastly, it is important to note that all three participants lived relatively close to one of the focus group locations, within 30 minutes. Therefore, placing focus group locations in the target communities is an important strategy when holding focus groups with a rural population. Clearly, this is one of the most important factors for focus group recruitment because the recruitment strategies that were successful for this project only worked on those individuals who lived close to the focus group locations. The flyers at popular community locations and Facebook posts will likely only have limited success if used too far from the focus group location. Other strategies that were not noticeably effective for this project included local newspaper articles, health center and hospital promotion, and snowball sampling. Only a couple of newspapers and health centers agreed to share articles or flyers and these were advertised only
one to two weeks before the focus groups. This limited reach and timespan could be why these strategies were not successful. Additionally, the snowball sampling was likely not effective because only three people were asked if they knew anyone else who would be eligible, which is a small sample size.

**RECOMMENDATIONS**

Based on the experiences recruiting for this project, the student has developed these five recommendations for the focus group recruitment of rural Mainers:

1. When recruiting rural Mainers to focus groups, location is critical. Without a significant incentive, chances are low that potential participants will agree to travel further than 30 minutes. Focusing recruitment in a relatively small geographic area around the focus group location may be beneficial to allow for the most thorough recruitment effort possible.

2. Give yourself extra time for recruitment! Weather, illness, and vacation can all delay recruitment because people may not be available to respond to messages as quickly as you would hope. In addition, it takes a lot of time to go into communities, connect with people, and spread the word. Take this into account if you plan on doing any in-person recruitment.

3. Get in touch with local people and community organizations. Talking to people, explaining what you are doing and why, and being open to suggestions can help tremendously with recruitment. Not all people will have the time to help, but those that do can help spread the word in important ways.
4. Try to hold focus groups in the spring, summer, or fall in Maine. Unpredictable winter weather can delay progress and likely discourages people who may be eligible from participating.

5. Social media recruitment can be effective, but several follow ups need to be done to ensure that those folks who are interested remember to call.

These recommendations can also be found on the handout in Appendix E titled, “Focus Group Recruitment in Rural Maine: Recommendations for Researchers.”

**LIMITATIONS**

There are a number of limitations to this study that should be considered. Most notably, due to unexpected changes and time constraints for project completion, the recruitment effort was only three weeks. Given more time, the recruitment effort would have likely been more comprehensive and the end results may have been more successful.

Next, the budget for this project was a clear limitation because it dictated a number of decisions like focus group location, date, and time. These factors all influenced recruitment and make it difficult to assess how successful individual recruitment strategies were. In addition, the focus group recruitment effort was relatively small, as it was for only two focus groups, but it covered a large geographic area. The large geographic area for recruitment is beneficial because more people are eligible to participate, but where one person completed the entire recruitment process, it was difficult to sufficiently recruit in the entire region. Therefore, the strategies that were successful for this project may not speak to what strategies would be successful in a larger recruitment effort with more resources.
CONCLUSIONS

Overall, recruitment for this project was not as successful as the researchers had originally hoped, but the challenges faced set the stage for a number of lessons learned. Specifically, that location is critical, extra time will be needed, connecting with community organizations is helpful, and delaying focus groups until winter is over may be worthwhile. Future work of this nature should explore the most effective recruitment strategies further by eliminating barriers like time frame, location, and weather to isolate and determine which recruitment strategies are most effective. Specifically, other work in this area should consider how effective in person recruitment is as well as strategies that were not tested in this project like indigenous field worker sampling and respondent driven sampling. This project makes it clear that recruiting rural Maine cancer patients and their family members for focus groups is extremely challenging and more effective strategies still need to be tested and developed.

REFERENCES


Appendix A. Key Informant Interview with Rural Recruitment Experts
Planning for Dempsey Center Focus Group Recruitment

Thank you for agreeing to be interviewed today. As you know, I’m helping Anush with the recruitment for the Dempsey Center project and I’m looking for insights that might help me with the recruitment process. Before we start, I should ask, Is it okay with you if I record our conversation?

Great, thank you.

First,

1. Could you tell me about the population you were recruiting in the MLHS study?

2. What challenges were difficult to overcome in recruiting this population to participate in the MLHS study or other studies you have done with similar recruitment needs?
3. What strategies worked best for recruitment in the MLHS study or others like it?

   a. About how long was the lag time between when you put out recruitment materials and started receiving calls?

   b. Do you have any suggestions on the best ways to talk to this population when recruiting them?

4. What big “lessons learned” would you pass on to me as I begin the recruitment process for the Dempsey Center project?
Okay, I have one last question.

5. Is there anything else that you would like to share with me that you think will help me recruit for these focus groups?

Okay, that’s all I have for you. Thank you so much for your time.

Interviewer Notes/Observations
Appendix B. Recruitment Materials

Recruitment Paragraph (posted with electronic flyers)

“Has cancer affected you? Come talk with researchers from the University of Southern Maine about cancer support services in Maine!

They are looking for adults who live in Androscoggin, Franklin or Oxford County, who have been affected by cancer, and who have never used services from a cancer support center like the Dempsey Center to participate in a 90-minute group conversation. They will give you a **$30 Hannaford gift card** (and snacks!) for participating! Joining this study is voluntary and you may back out at any time. They only want to hear what you have to say!

If you are interested, please call Mary at (207)-780-5836 to learn more. For specific questions about this research study, you may also contact the Principal Investigator, Anush Hansen at (207)-228-8217 or anush.hansen@maine.edu.

If you know anyone impacted by cancer who has not yet used the services of the Dempsey Center or another cancer support center, please share this information with them!”
HAS CANCER AFFECTED YOU?
COME TALK WITH US!

IF YOU:
1. Are 18 years or older
2. Live in Androscoggin, Franklin, or Oxford County
3. Have ever been told you have cancer OR have a family member who has cancer
4. Have NEVER used services from a cancer support center like the Dempsey Center or the Cancer Resource Center of Western Maine

ABOUT THE PROJECT
Researchers from the University of Southern Maine are doing a study to learn about rural Mainers’ knowledge of, access to, and thoughts about cancer support services in Maine.

You may be eligible to join the conversation about Cancer Support Services in Central and Western Maine!

To learn more contact Mary at: (207) 780-5836

WHAT WILL HAPPEN IF I JOIN?
You will take part in a 90-minute conversation about your thoughts on free cancer support services in the area.

1. We will give you a $30 Hannaford gift card.

Joining this study is VOLUNTARY. You may back out at any time. You do NOT have to answer any questions that you are uncomfortable with. We only want to hear what you have to say.

4. We will provide snacks during the conversation.

DATES, TIMES, AND LOCATIONS

Tuesday, March 20
5:30-7:00 PM
The Dempsey Center, Lewiston, ME

Tuesday, March 20
12:00-1:30 PM
Cancer Resource Center of Western Maine, Norway, ME

For specific questions about this research study, you may contact the Principal Investigator, Anush Hansen, at (207)228-8217 or anush.hansen@maine.edu
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## Appendix C. Index of Locations where Recruitment Materials were Posted or Shared, by County*

<table>
<thead>
<tr>
<th>County</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Androscoggin</td>
<td>Androscoggin Bank, Lisbon</td>
</tr>
<tr>
<td></td>
<td>Androscoggin Bank, Turner</td>
</tr>
<tr>
<td></td>
<td>Aubuchon Hardware, Lisbon</td>
</tr>
<tr>
<td></td>
<td>B &amp; A Variety</td>
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<tr>
<td></td>
<td>Bear Pond Variety</td>
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<tr>
<td></td>
<td>Bretton's Variety</td>
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<tr>
<td></td>
<td>Chummy's Diner</td>
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<td></td>
<td>Cumberland Farms, Mechanic Falls</td>
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<td></td>
<td>Dad's Place</td>
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<td></td>
<td>Deli Joe's</td>
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<td></td>
<td>Dempsey Centers (Facebook)</td>
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<tr>
<td></td>
<td>Depot Square Hardware</td>
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<tr>
<td></td>
<td>DFD Russell Medical Center</td>
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<tr>
<td></td>
<td>Five County Federal Credit Union, Lisbon</td>
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<tr>
<td></td>
<td>Food City, Lisbon</td>
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<td></td>
<td>Food City, Turner</td>
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<tr>
<td></td>
<td>Future Foods, Mechanic Falls</td>
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<td></td>
<td>Gulf Station, Lisbon</td>
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<tr>
<td></td>
<td>Hannaford, Turner</td>
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<tr>
<td></td>
<td>Healthy Androscoggin (Facebook)</td>
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<tr>
<td></td>
<td>Lisbon Community Credit Union</td>
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<tr>
<td></td>
<td>Lisbon Post Office</td>
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<td></td>
<td>Lisbon Town Office</td>
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<tr>
<td></td>
<td>Livermore Falls Advertiser (In Print)</td>
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<td></td>
<td>Long Green Variety</td>
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<tr>
<td></td>
<td>Mechanic Falls Post Office</td>
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<tr>
<td></td>
<td>Minot Country Store</td>
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<tr>
<td></td>
<td>Minot Post Office</td>
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<tr>
<td></td>
<td>Northeast Bank, Poland</td>
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<tr>
<td></td>
<td>Poland Post Offices (2)</td>
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<tr>
<td></td>
<td>Poland Town Office</td>
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<tr>
<td></td>
<td>Rich Bader Physical Therapy</td>
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<td></td>
<td>Ricker Memorial Library</td>
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<td>Sam's Italian Foods, Lisbon</td>
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<td>Slattery Farm &amp; Maple Syrup Co.</td>
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<td></td>
<td>Uncle Andy's Digest (Facebook)</td>
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<td></td>
<td>Valetone Cleaners</td>
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<tr>
<td></td>
<td>Village Pizzeria</td>
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<tr>
<td></td>
<td>Village Trading Post</td>
</tr>
</tbody>
</table>

*Note: Locations may vary and are subject to change.*
| Franklin | Kingfield Community Forum (Facebook)  
The Original Irregular (In Print and Website) |
|----------|------------------------------------------------------------------------------------------|
|          | Aubuchon Hardware, Rumford  
Betty's Laundry  
Blaisdell's Variety  
Cancer Resource Center of Western Maine  
(Newsletter and Facebook)  
Canton Town Office  
Canton Variety  
Catalyst Paper Mill, Rumford (Lunchroom)  
Citgo, Mexico  
Community Quik Stop  
Dixfield Library  
Dixfield Town Office  
Ellis Variety and Diner  
Franklin Savings Bank, Rumford  
Hannaford, Rumford  
Healthy Oxford Hills (Facebook)  
M & K Laundromat  
Mallard Mart  
Mexico Post Office  
Mountain Valley Variety  
Mrs. B’s Village Store (In Store and Facebook)  
Norway Post Office  
Norway Town Office  
Otisfield Town Office  
Oxford County Wellness Collaborative (Facebook)  
Oxford Federal Credit Union, Mexico  
Oxford Town Office  
Paris Farmer's Union  
Paris Town Office  
Rumford Hospital Oncology Department  
Rumford Library  
Rumford Post Office  
Rumford Town Office  
Sacopee Valley Health Center  
Save A Lot, South Paris  
Sunday River  
Sunday River, South Ridge Lodge  
Swift River Health Care  
Towle's Corner Store  
Town of Norway (Facebook)  
Town of Paris (Facebook) |

*Please Note: This is only a list of where materials were successfully posted. There were many locations and organizations who did not respond to requests or would not post materials.*
Appendix D. Phone Materials for Recruitment

Table 1. Focus group inclusion and exclusion criteria.

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 18 or older</td>
<td>Under 18 years of age</td>
</tr>
<tr>
<td>Have ever had a cancer diagnosis AND/OR have a family member who has had a cancer</td>
<td>Have not had a cancer diagnosis AND/OR are not an adult family member of a person with</td>
</tr>
<tr>
<td>diagnosis</td>
<td>a current or former cancer diagnosis</td>
</tr>
<tr>
<td>Live in one of the study counties (Androscoggin, Franklin, or Oxford)</td>
<td>Do not live in one of the study counties (Androscoggin, Franklin, or Oxford)</td>
</tr>
<tr>
<td>Have NEVER used services from a free-standing cancer support center like the</td>
<td>Have received free-standing cancer support services from an organization like the</td>
</tr>
<tr>
<td>Dempsey Center</td>
<td>Dempsey Center</td>
</tr>
</tbody>
</table>

Voicemail Script

“Hello. This is Mary Caron of the University of Southern Maine. If you are calling about the Cancer Support Study, please leave a message after the tone with your First Name, your phone number and if I can leave a message for you at that number, and the best time to reach you. I am only in the office part-time Wednesday through Friday, so I will return your call as soon as I can. Thank you!”

Sample Phone Script – Returning a Call

“Hi, could I please speak to (name)?” “Hi (name) this is Mary with the cancer support study at USM returning your call. How are you today?”
“Great, I’m happy to hear you’re interested in the Cancer Support Study! Before we go any further, would you mind if I ask you a few screening questions to see if you’re eligible to participate?”

“Wonderful, thank you! First, are you at least 18 years old?”

“Do you live in Androscoggin, Franklin, or Oxford County?”

“Okay, Have you been impacted by cancer? In other words, have you ever been told you have cancer or have you ever had a family member who has had cancer?”

“Thank you. (insert appropriate sympathy given details). Finally, have you ever used services from a free standing cancer support center such as the Dempsey Center, the Cancer Resource Center of Western Maine or the Cancer Community Center?”

“Okay, great, thank you so much for calling – you meet all of our eligibility requirements to participate in the study. I’ll give you a quick overview of what to expect and then we can talk about your questions and scheduling if that’s alright?”

*(IF THEY DO NOT MEET THE REQUIREMENTS)*

“Thank you for answering those questions for me. Unfortunately, you are not eligible to participate in this study, but thank you for calling in!”
“Okay, to participate in this study you will be asked to participate in a 90 minute focus group – which is basically a group conversation with 6-8 people where Anush Hansen (the principle investigator) and I will ask questions about your thoughts on free cancer support services in the area. We will provide refreshments during the focus group and you’ll also get a $30 Hannaford gift card for joining us.

You won’t have to answer any questions you don’t want to and we are not going to try to convince you of anything. We simply want to hear what you know about the services, what prevents you from using them, and how you feel about them. If you agree to participate, your agreement will be voluntary and you will be allowed to back out at any time. All of your personal information will be kept private- we will only use first names. What questions do you have for me about this study?”

*Answer any and all questions*

“Excellent, thank you! I’m happy to hear you would like to participate. Can we discuss scheduling?”

“Are you able to attend a session at the Dempsey Center in Lewiston from 5:30 PM to 7 PM on March 20th? Or a session at the Cancer Resource Center of Western Maine in Norway from 12 to 1:30 PM on March 20th?”

“Great, thank you. I’ll put you down for (session). The address for your session location is: (address).”
IF NO: “Okay, thank you for calling – if for some reason the schedule changes, would you be interested in hearing from me to see if you could make another time?”

“Finally, just so you’re aware. I’ll give you a call one or two days before the focus group to remind you of the time, date, and location. Can I leave a voice message if you miss my call? Or can I leave a message with whomever might answer?”

“Great, thank you so much for agreeing to participate! I’ll see you soon!”

End call
FOCUS GROUP RECRUITMENT IN RURAL MAINE
RECOMMENDATIONS FOR RESEARCHERS

1. LOCATION IS CRITICAL.
   - Hold focus groups in the target community.
   - Limit travel to 30 minutes or less and provide compensation.
   - Recruit thoroughly in a relatively small geographic area.

2. TIME, YOU'LL NEED EXTRA.
   - Prepare for delays due to weather, illness, vacation, etc.
   - Set aside extra time to connect with people in communities, it's a long process.

3. COMMUNICATE WITH LOCALS.
   - Talk to local people and community organizations. They can help spread the word.
   - Explain what you're doing and ask for suggestions.

4. 4. PICK THE RIGHT SEASON.
   - Hold your focus group in the spring, summer, or fall in Maine.
   - Avoid winter. Poor weather is a huge recruitment barrier.

5. SOCIAL MEDIA, FOLLOW UP.
   - Use social media, it can help with recruitment.
   - Follow up! Post several times and in many places to ensure that people remember to call.

PRESENTED BY: MARY CARON, MUSKIE SCHOOL OF PUBLIC SERVICE