



Cancer Information Resources:

Preferences among health professionals
serving American Indian Communities
in Minnesota, North Dakota, and Wisconsin





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Executive Summary

Background

The primary purpose of this project was to identify the cancer information resources used by health professionals in tribal health departments or Indian Health Service clinics serving American Indian communities in Wisconsin, Minnesota, and North Dakota. The project also evaluated the use of *Cancer Information Resources for Native Americans*, a notebook published by the University of Wisconsin Comprehensive Cancer Center (UWCCC) in 1999.

Methods

Spirit of EAGLES (SOE) staff drafted the specific survey questions with the assistance of the UWCCC Survey Research Shared Service. The survey consisted of fourteen questions that were formatted as yes/no items or used Likert scaling. The SOE program director identified an initial pool of 31 health professionals serving facilities visited by him between January 2001 and December 2003. Two of the original 31 potential respondents declined to participate, each suggesting a colleague they thought would be more appropriate to the survey's focus on cancer. These two health professionals were notified by letter, and added to the pool, bringing it to a total of 33 potential respondents. Twenty-five (76%) of the potential respondents participated in the survey.

Results

The following three points are most noteworthy in the survey results: 1) there was a low level of interest in the topic of cancer clinical trials, 2) there was a low level of familiarity with the UWCCC notebook, and 3) there was a distinction between what cancer information resources the respondents used for themselves versus those to which they referred clients. Over 90% of respondents used websites for themselves, and nearly 70% said they used websites most frequently. When referring clients to cancer information, over 90% of respondents used brochures/booklets and local medical personnel, and almost 50% used brochures/booklets most frequently. In addition, there was a high degree of respondent interest in the survey as evident in the number of post interview comments and the volume of information volunteered when questions included an "other" category.

There were limitations to this survey. First, the respondents were selected for participation in the survey; second, they represent a very specific group of health professionals; and third, the small number of respondents (25) limits the applicability of the findings.

Conclusion

Both health professionals serving American Indian populations and their clients would benefit from greater availability and ease of access to American Indian specific cancer information. A website containing resources and links for the health professional, as well as downloadable brochures for clients, would aid in meeting the primary resource preferences identified in this survey.

Full Report

Background

The purpose of this project was to identify cancer information resources used by health professionals in tribal health departments or Indian Health Service clinics serving American Indian communities in Wisconsin, Minnesota, and North Dakota. A phone survey was conducted of health professionals in these communities. The primary question addressed was what cancer information resources were preferred by participating health care professionals. The project also assessed the utilization of a cancer information notebook, distributed by the North Central Spirit of EAGLES (SOE) project director from January 2001 through December 2003.

This project was supported by SOE, and operated through the University of Wisconsin Comprehensive Cancer Center (UWCCC). The survey was conducted by project assistant Kristian Knutsen under the supervision of SOE project director Rick Strickland and senior research specialist Jackie Matloub. SOE also received survey assistance from the UWCCC Survey Research Shared Service.

Methodology

The project was initiated by SOE project staff as a means of evaluating the usefulness of a notebook entitled *Cancer Information Resources for Native Americans*, published by the University of Wisconsin Comprehensive Cancer Center in 1999. As the questionnaire was developed, the survey was broadened to evaluate general cancer information seeking behaviors of health professionals serving American Indian communities in the three state region.

SOE staff drafted the specific survey questions with the assistance of the UWCCC Survey Research Shared Service. The survey consisted of fourteen questions that were formatted as yes/no items or used Likert scaling.

The SOE program director identified a pool of 31 health professionals serving American Indian populations in three states, Minnesota, North Dakota, and Wisconsin. These health professionals included health educators, clinic administrators, public health directors, nurses, physicians, and other health professionals.

The initial 31 potential respondents were mailed a letter in late August 2004 explaining SOE interest in conducting this survey and requesting their participation. The letter included basic information about the survey's focus on cancer, the focus on the three-state area, and the overall pool of health professionals as potential respondents. The letter also included the following explanations about the project:

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- This mailing will be followed by a telephone call to determine willingness to participate, obtain informed consent orally, and conduct or schedule the interview.
 - Trained student interns and/or program assistants will conduct the survey with the Spirit of EAGLES (SOE) project under direct supervision by Jacqueline Matloub, a SOE research specialist. General supervision will be provided by Rick Strickland, SOE project manager and Patrick Remington, PI.
 - The questions asked of the respondents are not personal, focusing rather on the health information seeking behavior of health professionals. The only risk to subjects in this project is potential breach of confidentiality, but this risk is minimal. Disclosure of their information seeking preferences would not be a personal or professional risk to the respondents.
 - The respondents' confidentiality will be protected by not linking this information to the data recording sheets, nor in any computer database. This information will be destroyed after the last interview is conducted and a total number of respondents determined.
 - While this study has program evaluation and quality improvement objectives, the aggregate findings may be published in an aggregate manner.

Results

Conducting the Interviews

The initial interview was conducted on September 7, 2004. Most interviews were completed by late September 2004, with the final interview conducted on October 15, 2004. Multiple telephone contacts were made to a majority of respondents in order to arrange and conduct the interview.

During the interview process, two of the original 31 members of the respondent pool declined to participate because they considered themselves inappropriate respondents for the survey. They each suggested a colleague they thought would be more appropriate to the survey's focus on cancer. These two colleagues were contacted by letter inviting them to participate, and were added to the pool, bringing it to a total of 33 potential respondents.

A total of 25 of the 33 potential respondents participated in the survey. Four of five potential North Dakota participants responded, nine of ten potential Minnesota participants, and twelve of eighteen potential Wisconsin participants.

Professional Functions

Respondents were asked to describe whether their professional position entailed one or more of the following roles: administrative, clinical, and/or educational. Among the 25 respondents, sixteen stated that their position included an administrative function, thirteen a clinical function, and nine an educational function. As shown in Table 1, the stated professional functions of the respondents were as follows: nine were solely administrative, one was administrative and clinical, two were administrative and

educational, six were solely clinical, two were clinical and educational, one was solely educational, and four reported themselves as functioning in all three roles.

Table 1: Professional functions of survey respondents

Professional Functions	#
Administrative only	9
Administrative and Clinical	1
Clinical only	6
Clinical and Educational	2
Educational only	1
Administrative and Educational	2
Administrative, Clinical, and Educational	4

Professional Experience

Fourteen out of 25 (56%) survey respondents had between ten and twenty years experience in their present professional position. An additional five respondents had between five and ten years experience. See Table 2.

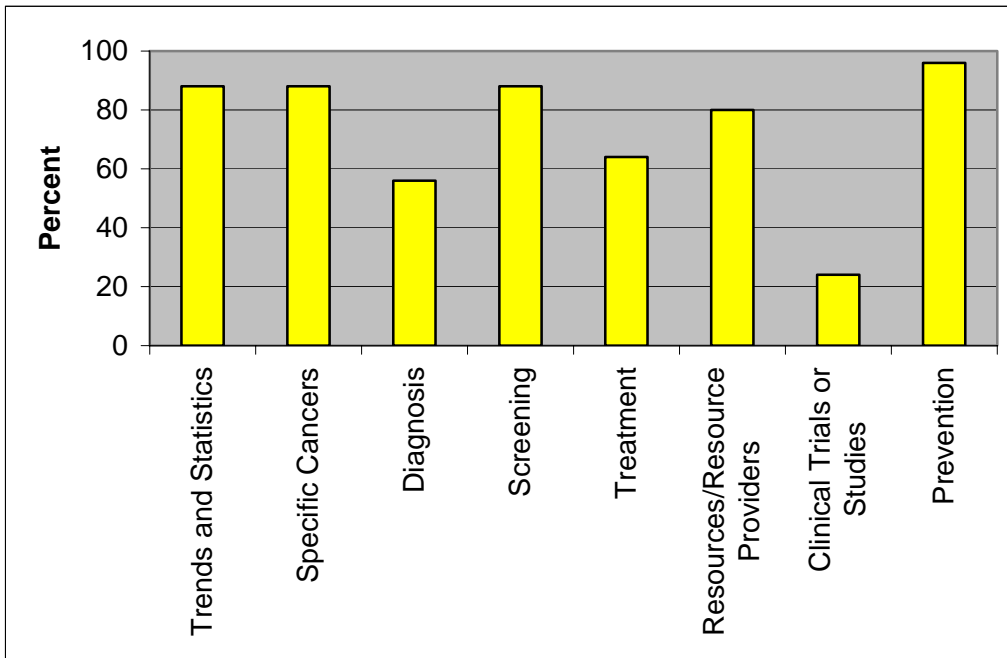
Table 2: Amount of time in current position

How long has respondent worked in current position?	#
<1 year	1
>1 year and <5 years	5
>5 years and <10 years	5
>10 years and <20 years	14
>20 years	0

Interest in Broad Cancer Topics

Survey participants were asked if, within their professional roles, they sought information on eight broad cancer topics. The topics and their responses, in descending order, were prevention (96%), trends and statistics (88%), specific cancers (88%), screening (88%), resources/resource providers (80%), treatment (64%), diagnosis (56%), and clinical trials or studies (24%).

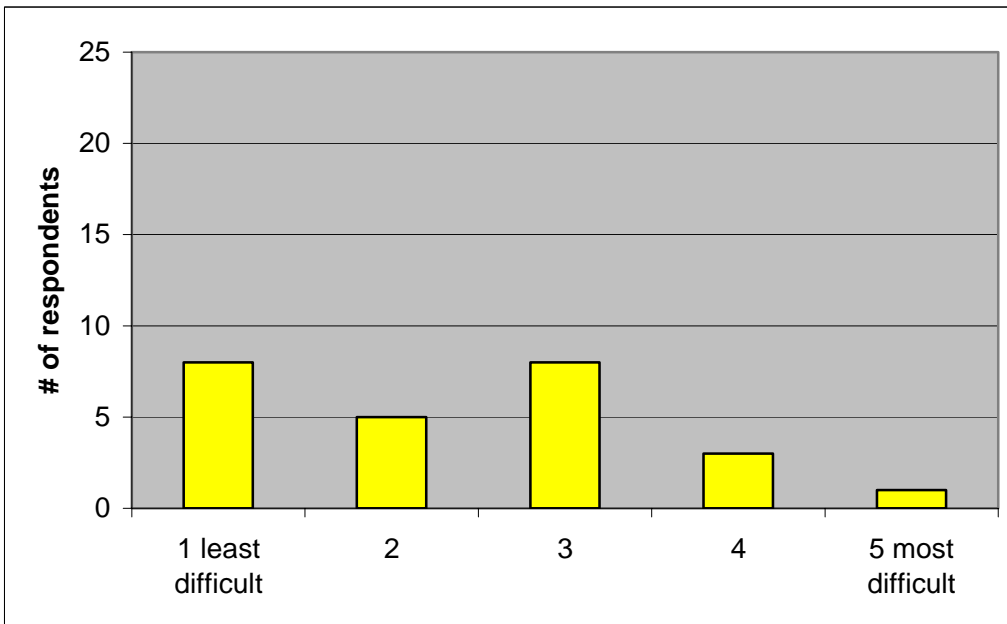
Figure 1: Level of interest in specific cancer topics



Difficulty of Finding Cancer Information

Respondents were asked on a scale of one to five (one, least difficult, and five, most difficult) the relative difficulty of finding cancer information for their professional use. Eight respondents reported little difficulty in finding cancer information, one reported a great deal of difficulty, and the remainder fell between as seen in Figure 2. The mean of all responses was 2.36.

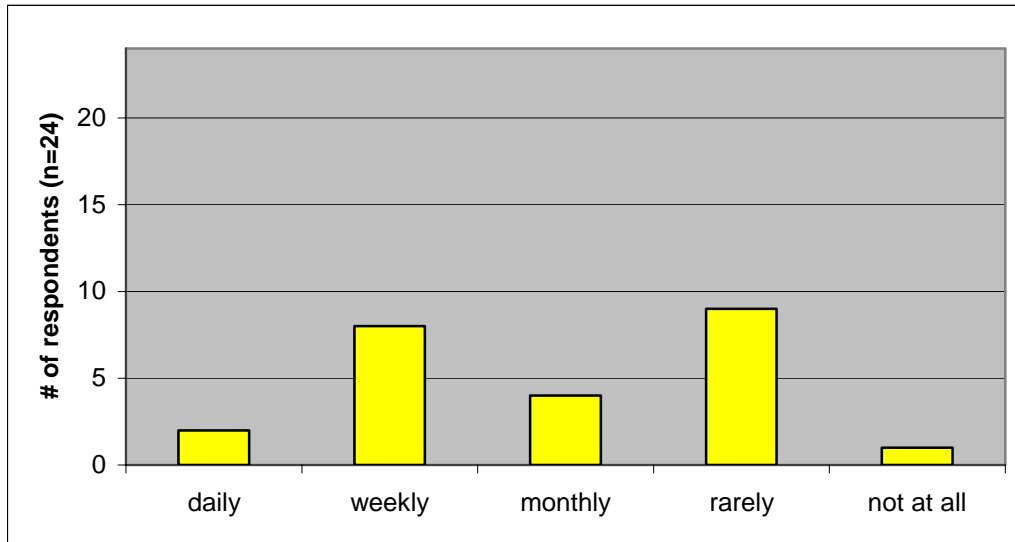
Figure 2: Respondents' difficulty in finding cancer information



Frequency of Cancer Inquiries

Respondents were asked how often members of the population they serve requested information about cancer. Respondents were given the option of five possible responses and answered as follows: daily (2), weekly (8), monthly (4), rarely (9), and not at all (1). The responses approximate a bimodal distribution. About two-fifths of the respondents noted that they are asked about cancer on a daily or weekly basis, and another two-fifths noted that they are asked rarely or not at all.

Figure 3: How often clients asked respondents about cancer



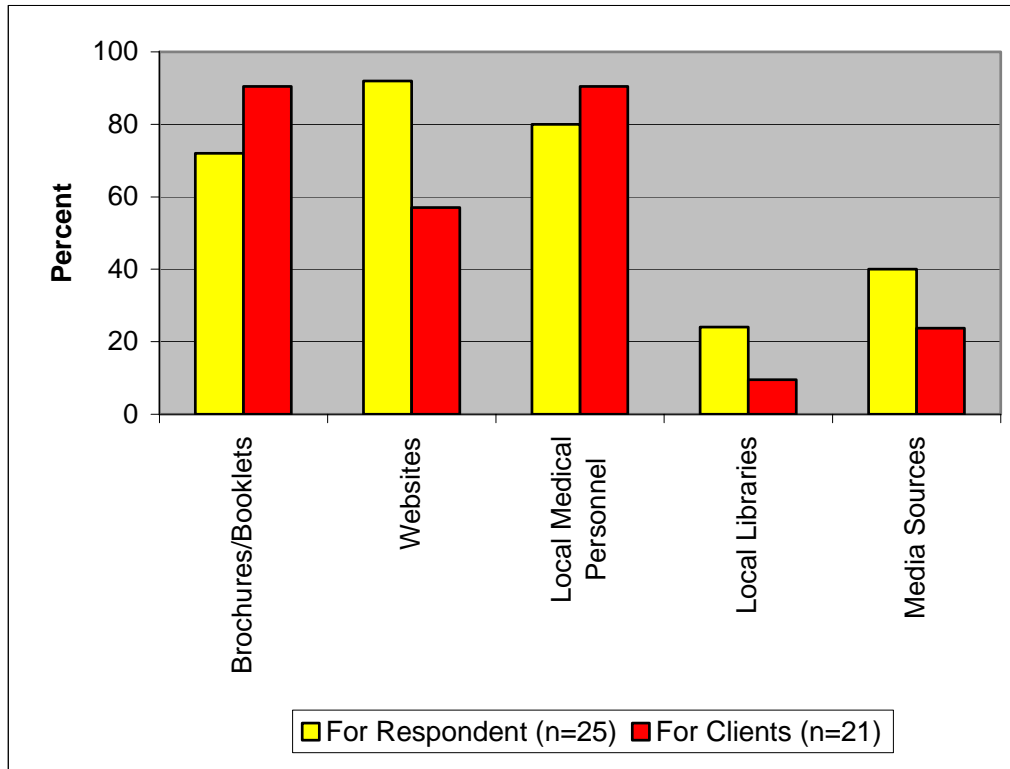
Cancer Information Resources

Respondents were asked about sources of cancer information they used for themselves professionally. The information sources and results are shown in Figure 4. The respondents used websites (92%), brochures/booklets (72%), local medical personnel (80%), media sources (40%), local libraries (24%), and “other” sources.

They were also asked to what sources of cancer information they referred their clients. Their responses, as shown in Figure 4, were brochures/booklets (91%), local medical personnel (91%), websites (57%), media sources (24%), local libraries (10%), and “other” sources.

All respondents (25) answered with regards to themselves, while twenty-one respondents answered with regards to clients. Four respondents noted that they did not have direct contact with community members regarding cancer issues, and did not answer that segment of questions. Each of these four respondents had positions that included an administrative function.

Figure 4: Sources of cancer information used by respondents for themselves and for clients



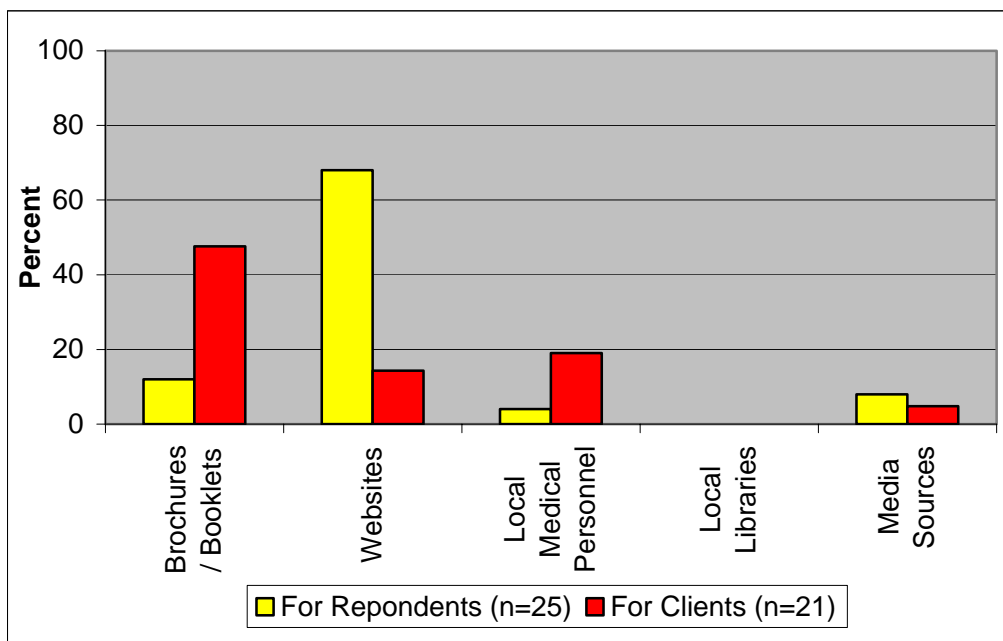
The responses to the “other” sources option were classified into broad groups during analysis for reporting purposes.

When seeking cancer information for themselves, the “other” sources identified by respondents were books, medical journals, and other publications (32%), other medical personnel (20%), state health department programs (4%), specific cancer centers (4%), and pharmaceutical representatives (4%).

When referring clients to sources of cancer information, the respondents identified “other” sources as follows: other medical personnel (10%), 1-800 numbers (10%), specific cancer centers (5%), state health department programs (5%), cancer survivors (5%), and workshops/conferences (5%).

As a follow-up to the preceding questions, respondents were asked to select which one cancer information source they preferred to use most often, both for themselves as well as when referring clients. Figure 5 shows that websites was the respondents’ preferred source for themselves. When referring patients/clients, Figure 5 shows a primary preference for brochures/booklets and a secondary preference for local medical personnel and websites.

Figure 5: Sources of cancer information used **most** by respondents for themselves and for clients



Two respondents identified “other sources” when choosing the cancer resource they use most often for themselves. One response (4%) was classified as other publications, books, and medical journals, while the other (4%) was classified as other medical personnel. One respondent (5%) chose “other sources” as what they used most often in referring clients; this source was a state health department cancer program.

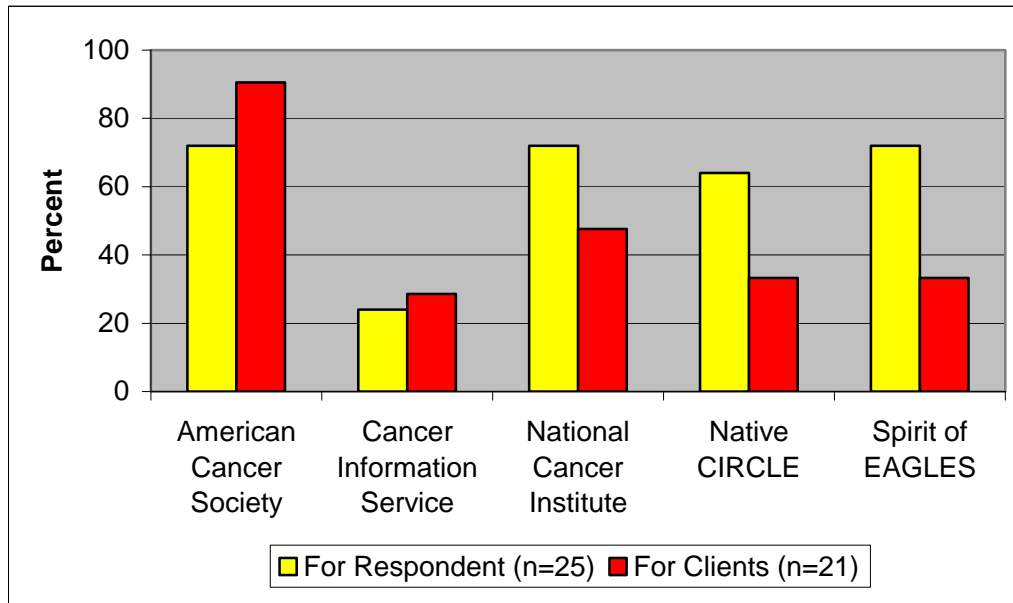
Cancer Resource Organizations

Respondents were asked whether they consulted any of five cancer-focused organizations for information. Two of the five were American Indian specific. Respondents were also asked to note “other” organizations that they used for the same purpose. Again, this question was asked with regards to the respondents seeking information for themselves, and for referring clients. See Figure 6.

The five organizations, and the percent of respondents who reported using them for themselves were as follows: the American Cancer Society (72%), the National Cancer Institute (72%), Spirit of EAGLES (72%), Native CIRCLE (64%), the Cancer Information Service (24%), and “other” organizations.

When referring clients, the respondents identified the American Cancer Society (91%), National Cancer Institute (48%), Native CIRCLE (33%), Spirit of EAGLES (33%), Cancer Information Service (29%), and “other” organizations.

Figure 6: Cancer resource organizations used by respondents for themselves and for clients



When asked about “other” organizations used as resources for themselves, respondents cited specific cancer centers (24%), state health department programs (20%), the Indian Health Service (12%), the Centers for Disease Control and Prevention (12%), the American Lung Association (4%), the National Health Information Center (4%), and the Great Lakes Inter-Tribal Council (4%). The respondents stated that they found these organizations useful sources of cancer information, though, with the exception of specific cancer centers, these organizations were not exclusively focused on cancer. Respondents also cited several “other” organizations that they referred their clients to when they have questions regarding cancer. These were specific cancer centers (10%), the Centers for Disease Control and Prevention (5%), and state health department programs (5%).

Use of Cancer Resource Notebook

Respondents were asked about their familiarity with and use of a native-specific cancer resource notebook titled Cancer Information Resources for Native Americans, developed and distributed by the UWCCC in 1999. All potential respondents in the original survey pool were identified for participation because their facilities received a copy of this resource notebook from the North Central SOE program director during an on-site visit.

Only nine of the twenty-five respondents were familiar with the notebook, and of those, only two had ever used it. Of the nine who were familiar with the notebook, five found it helpful, seven found it easy to understand, and eight found it credible.

Post-Interview Comments

There were fourteen respondents who volunteered post-interview comments when asked for any comments at the end of the survey. The comments are listed below, and if a comment was made more than once, the number of times was noted in parentheses.

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- Little information about cancer was necessary for their current professional responsibilities (3 respondents)
 - More cancer resources are generally needed
 - Not enough AI cancer-specific resources are available
 - This survey/project is useful in eliciting cancer information needs in AI communities
 - American Indian communities have a history of medical research abuses with regards to clinical trials/studies
 - Rural location makes websites invaluable for health providers
 - Patients/clients are not referred to websites due to access issues (2 respondents)
 - The Office of Native Cancer Survivorship is an important resource
 - The website healthfinder.gov (from the Office of Disease Prevention & Health Promotion, part of the USDHHS) is an important resource
 - Women's Way is an important resource
 - The UWCCC cancer handbook is too old, and thus not helpful
 - Unfamiliar with the UWCCC cancer handbook (2 respondents)
 - Interested in the UWCCC cancer handbook (3 respondents)

Discussion

Several important patterns emerged from this study regarding the participants' cancer information seeking preferences. The respondents' roles can generally be assigned to two broad groups: the first group is largely administrative, with less contact with their facility's user population, and the second is largely clinical/educational, with greater contact with the facility's user population. The extended length of time most survey respondents have worked in their current position suggests they constitute a very stable workforce with significant levels of experience.

When asked about seeking information on specific cancer related topics, the responses roughly fall into high, moderate, and low use categories. Five topics were highly used: prevention (96%), trends and statistics (88%), specific cancers (88%), screening (88%), and resources/resource providers (80%). Two topics were moderately used – treatment (64%) and diagnosis (56%) – and one topic, clinical trials or studies (24%), was only sought by six out of the twenty-five respondents.

Lower information seeking levels for treatment, diagnosis, and clinical trials or studies may reflect the number of respondents with an administrative function. In the case of clinical studies, the history of research abuse among American Indian populations may impact the lower level of interest/use. This concern was specifically noted by one respondent as a general comment at the end of the interview.

The specific cancer topics queried were subject to interpretation by the respondents. This factor may be a reason that information on diagnosis and treatment was sought less frequently. Another contributing factor may be that thirteen of the twenty-five respondents reported a clinical component to their job, which corresponds to the

percentage that sought information on diagnosis and treatment. While administrators and educators may be interested in cancer trends or prevention, cancer diagnosis and treatment may be of more limited interest to them. It is also worth noting that the respondents generally worked in ambulatory clinic settings that do not treat cancer, but rather referred cancer patients for treatment in regional and specialized centers. Of the three physicians interviewed, two responded that they sought information on cancer diagnosis and treatment, and one did not.

When asked to gauge their difficulty in finding such information on a five point scale, roughly one-third (32%) selected option 1, designating the lowest level of difficulty, while the same percent selected the midpoint, option 3. More than four-fifths (82%) considered finding information about cancer to be from moderately easy to very easy.

The bimodal distribution of how often respondents were asked by clients about cancer may reflect respondent professional functions. Those responding that they were asked rarely or not at all may have less direct contact with community members, while those responding that they were asked daily or weekly might have more direct contact.

The cancer information resources used by respondents – both for themselves and for referring clients – were classifiable into two groups. The first, composed of brochures/booklets, websites, and local medical personnel, were used more frequently. The second, composed of local libraries, media sources, and other sources, were used to a lesser extent. The resource used most by respondents for themselves was websites (at 92%), with brochures/booklets and local medical personnel used by more than 70% as well. The resources used most for referring clients were brochures/booklets and local medical personnel (both at 91%). The respondents referred others to websites to a lesser extent (57%), but this level of use was still considerably higher than the other three categories. When asked to name the one resource used most, almost half (48%) of the respondents selected brochures/booklets as the resource used most when assisting clients, and nearly 70% of respondents selected websites as their preferred resource when educating themselves about cancer.

The frequency of use of online resources for referring patients varied among the respondents. Almost three-fifths of the respondents reported that they referred their clients to websites as a source of information about cancer. However, three respondents commented independently that not many members of their user population had Internet access, and they felt it was not useful for health professionals to refer their clients to cancer websites.

It is also worth noting that one resource option, local medical personnel, differed from the others in that it was a human resource as opposed to an informational medium. When there was a human option available for seeking information, there was significant interest by respondents, both for their own use, as well as when referring clients. The high number of responses volunteered by participants when given the option to identify

other resources also indicates they were forthcoming and engaged in the content of the survey.

Among cancer resource organizations, the American Cancer Society was a frequently used resource, for respondents themselves, and especially for others. On the other hand, the Cancer Information Service was used to a considerably lesser extent, and less than the other identified organizations in the survey question. For self-use, about two-thirds of the respondents identified the National Cancer Institute, Native CIRCLE, and Spirit of EAGLES. However, they did not refer their clients to these organizations to a similar degree. Clients were referred to the National Cancer Institute by a little less than half of the respondents, while only one-third referred clients to the two native-specific groups.

Among the comments given at the end of the survey, three indicated respondent interest in the topic of cancer information. One respondent noted more cancer resources were generally necessary, while another said that there were not enough American Indian-specific cancer resources. A third commented that the application of this research would be useful in identifying cancer information needs in American Indian communities.

It is important to recognize the limitations of this survey and particular group of respondents. First, the respondents were selected for participation in the survey. Second, they represented a very specific group of health professionals working in tribal and Indian Health Service facilities serving American Indians in Minnesota, North Dakota, and Wisconsin. Third, the small number of respondents (25) also limits the general applicability of the findings.

Also, it should be noted that this survey was conducted and identified as a Spirit of EAGLES project; consequently, respondent use of SOE may be inflated (halo effect). Again, the high level of volunteered responses to the “other” resource option indicated the respondents regularly used other sources than those pre-identified in the survey, and that they were engaged in the content of the survey. Finally, since the survey was affiliated with the UWCCC, there may have been a halo effect among the questions regarding the notebook, Cancer Information Resources for Native Americans.

Conclusion

The major findings that emerged from this study included; 1) a low level of interest in the topic of cancer clinical trials, 2) a low level of familiarity with the UWCCC notebook, and 3) a distinction between what cancer information resources the respondents use for themselves versus those that they refer to clients. When looking for cancer information for themselves, more than 90% of respondents used websites, and nearly 70% of them said they used websites most frequently. When referring clients to cancer information, more than 90% of respondents used brochures/booklets and local

medical personnel, and almost 50% said they referred clients to brochures/booklets most frequently.

In addition, the survey results suggested that web-based information was useful for rural health professionals, but not as useful for community members, partially due to access reasons. Also, certain organizations, such as the American Cancer Society, were definitely used more than others. Moreover, respondents were actively engaged in the survey, as shown by the number of post interview comments and the information gathered in the “other” categories.

In addition to surveying a larger and broader sample of respondents, there are several avenues for future research: examine and differentiate the level of respondent interest in the general cancer topics relative to their professional roles; use broader Likert scaling; move beyond identifying which resources are used and examine “how” health professionals used them; and most importantly, examine the ease of locating American Indian-specific cancer information by health professionals working in American Indian communities.

However, based upon these results, it appears both American Indian health professionals and their clients may benefit from greater availability and ease of access to American Indian specific cancer information. A website containing resources and links for the health professional, as well as downloadable brochures for clients, would meet the primary resource preferences identified in this survey