

Three two-hour focus groups were conducted on 3/19/14 at the New Mexico Cancer Council (NMCC) meeting to explore: (a) how members are using the plan, (b) the extent to which evidence-based practices are being implemented in the community, (c) the extent to which the inclusion of a section on implementing the Cancer Plan in Native American Communities impacts programs and interventions, and (d) ways in which access to culturally and linguistically competent care can be provided.

A total of 22 Cancer Council members participated in the focus groups representing a variety of agencies and organizations such as the Albuquerque Area Indian Health Board, American Cancer Society, Cancer Services of New Mexico, Cancer Support Now, CAPPED, Casa Esperanza, Health Insight New Mexico, Leukemia and Lymphoma Society, New Mexico Cancer Care Alliance, People Living Through Cancer, University of New Mexico Cancer Center, and University of New Mexico School of Medicine.

Many of the focus group participants hold director or manager level positions in their organizations. Participant titles/positions include: Executive Director, Program Director, Project Director, Director, Associate Director, Protocol and Outreach Coordinator, Patient Access Manager, Program Specialist, Associative Professor, Board Member, Grassroots Manager, Government Relations Director, Project Director, Founder/Past President, and Retired CEO.

A summary of findings from the focus groups are presented below for each key area (i.e., Cancer Plan Use, Evidence Based Practices, Cancer Plan Supplement on Considerations for Implementing the NM Cancer Plan in Native American Communities, and Access to Competent Cancer Care). A complete list of focus group questions is included in Appendix A.

Cancer Plan Use

1) Ways Organizations Use the Plan: Participants indicated that their organizations utilize the Cancer Plan numerous ways. The most frequently mentioned uses of the Cancer Plan were related to grant writing/reporting and ensuring that agency specific programs and activities align with the goals articulated in the plan. Many of the participants talked about using the plan to help focus their work, set organizational priorities, and make sure they are “on track.” They said they use the plan for educational purposes with community members, community health representatives, educators, staff, trainers and legislators, and to inform research areas, as well as a variety of services related to advocacy, outreach, navigation, survivorship, and addressing disparities and access to care. Participants also mentioned using the Cancer Plan as part of workgroup activities and during networking opportunities.

1a) How the Plan Enhances Missions/Programs: Over one-third of the participants agreed that the Cancer Plan enhances their current mission/program. Others clarified that the plan helps their organizations increase alignment rather than specifically “enhance” their organizations’ missions/programs. In all three of the focus groups, participants mentioned that the plan helps increase the legitimacy of their presentations and talking points with groups such as community members, board members, Rotarians, legislators, treatment groups, and oncologists statewide. Participants emphasized that they let people know that they were involved with the development of the plan and that their organizations’ missions/programs align with the plan. As one participant put it, “[The plan] gives us backing in New Mexico.” Participants also mentioned that the plan enhances their missions/programs because it helps them obtain funding for expanding services and helps them understand what is available.

“The implementation plan shows value to communities and what they want to work towards.”

2) Influence on New Initiatives: Over three-quarters of the participants indicated that their organizations brought about new initiatives during the past year. Participants talked about new initiatives related to a travel assistance program, outreach for primary care, capacity development initiatives for tribal community health workers, smoking cessation, research studies about access, quality of life and survivorship, new presentations and trainings such as the community clinical linkages training and “Everything Counts” presentation, text messages to reduce weight, testing in underserved populations, and a new quality of care focus/evaluation. When asked how the Cancer Plan influenced these new initiatives, participants explained that although their new initiatives are consistent with the Cancer Plan, the plan did not necessarily drive their decisions related to implementing the new programs/activities. Instead, the new initiatives tended to be designed on a national level (e.g., Outreach to Primary Care initiative) or based on the organizations’ own research specific to the communities they serve. One participant suggested that the Council’s Executive Committee might have additional insight on how new initiatives are influenced by the Cancer Plan since they are involved with selecting priorities.

3) Influence on Reducing Disparities: Many of the participants indicated that their organizations have worked to reduce disparities in their communities during the past year. They used New Mexico cancer incidence data from the plan, as well as county level data provided online, to help write grant proposals to fund this work. Some participants were not sure if low-income/education was added to the plan to address inequities but then found a reference to it on pages 22-24. Related to this, a participant in one group indicated that 50-60% of their one-on-one smoking cessation meetings are with low-income families. During this discussion, one participant shared that he/she does not feel the plan guides enough.

4) Influence on Increasing Access: Nearly all of the participants agreed that their organizations worked to increase access to cancer services in their communities during the past year, with many adding that their organizations are well aligned with the plan in this area. They talked about increasing access to screening, survivorship care plans, information for patients/survivors/caregivers, communication about cancer in the Native American community, clinical trials, lodging, and other cancer programs, services and resources in New Mexico. Participants said they used the plan to help increase access by:

- Using language from the initial portion of the plan for grant writing to obtain funds for increasing access.
- Applying talking points about policies specific to pain management care (e.g., palliative care).
- Using the plan as a backing when explaining to legislators that access is an important issue to New Mexico.
- Continually thinking of the diversity of New Mexico when making services available (i.e., culturally, linguistically, geographically and socio-economically).
- Expanding access to clinical trials in Roswell, Carlsbad and Hobbs.
- Conducting outreach in rural communities through working with federal clinics to create links to their cancer center.
- Increasing tribal participation in state programs (e.g., free screenings if eligible).
- Having local hospitals and social workers ensure insurance coverage to increase access to services.
- Increasing integrated services and programs related to lodging and resource programs.

5) Sharing the Plan: Over half of the participants indicated that they have shared the Cancer Plan with others such as their board, advisory committee, upper management, staff (new and existing), legislators, partner organizations, state health councils, quality improvement organizations, and funders. Below are examples of how/why the plan was shared.

- Reminded the board of the organization’s role within the plan and how much time went into working on the plan.
- Shared the plan with the new Executive Director, which helped her see how different groups are working toward similar goals.
- Gave copies of the plan to staff at a meeting so they could see how their work is interconnected with other agencies.
- Shared the plan with the advisory committee for patient services to show them the work being done and their role in that work.
- Brought copies of the plan to presentations and a legislative breakfast.
- Discussed the plan with upper management during weekly reports.
- Talked about the plan with partnering organizations in conversations about collaboration.

“It’s part of our mission to collaborate with other agencies so staff need to see how the work is interconnected.”

6) Influence on Educating the Community: When asked how and in what ways the Cancer Plan goals and objectives are used to educate the community, one of the focus groups listed examples related to specific goals supported by their organizations’ cancer work. These responses are summarized below.

- Goal 3, Improve the quality of life for New Mexicans living with cancer throughout the cancer journey: through peer support (one-on-one and in groups), educational workshops, conferences and policy work.
- Goal 4, Ensure equal access to pain management, palliative care, complementary and alternative services with proven evidence based efficacy, and end of life services: through policy work, education for volunteers, and community outreach.
- Goal 5, Increase culturally and linguistically competent and effective education about appropriate screening services for the early detection and/or prevention of cancer among New Mexicans: through language and cultural sensitivity and education via storytelling, digital media and illustrations.
- Goal 8, Reduce disparities and inequities in access to appropriate and effective cancer prevention, screening, diagnosis, treatment, care and survivor services: through survivorship services, support groups, conferences, and workshops (e.g., tobacco cessation workshop).
- Goal 9, Improve cooperation, coordination, and collaboration among organizations and federal, state, tribal, county and local governments engaged in community-oriented cancer control: through working closely with prostate cancer group, trainings, workshops, and sharing information.

Another group discussed examples of how they used the plan for educational purposes more generally. Some participants talked about bringing the plan and using it during various meetings and events with groups such as the ACC workgroup, PR workgroup, legislators at the balloon breakfast, Board of Education in Otero County, national and local programs (e.g., relay process involving schools), and other community partners. They also said the plan was used to inform a data sheet developed for legislators, to expand support groups, health fair participation and an annual conference, and encourage community partners to implement evidence-based practices. Participants in the third group did not feel that their specific organizations use the cancer plan this way and suggested asking the Council’s Executive Committee about how the goals and objectives are used to educate the community.

7) Most Helpful Components of the Plan: Participants listed several components of the plan that they find most helpful. Responses are bulleted below in order from most to least frequently mentioned.

- Information about barriers (pages 24-25)
- Overview and disparity information (e.g., more general population information) (pages 12-29)
- Section on considerations for implementing the plan in Native American communities (pages 35-43)
- Goals and objectives (list of goals on page 7; goals related to cancer control on pages 14-21)
- Executive summary (page 7)
- Evidence-based activities (pages 45-53)
- “At a glance” items (no specific page)

Evidence Based Practices

8) Evidence Based Practices Implemented: Participants reviewed pages 45-53 of the Cancer Plan to determine which evidence based cancer control interventions listed in the plan are being implemented by their organizations. Participants from two of the groups indicated the following evidence based practices/programs from the plan (listed in order of most to least frequently mentioned): QUIT NOW, National Institute of Health Resources, BCC Program, Agency for Health Research and Quality (AHRQ) Innovations and Tools, Sun Safe, ALIVE!, and Body & Soul. Participants from the third group said that they are not currently using any of the listed practices. Instead, they implement their own programs/activities tailored to the specific needs of their communities. They said they create their own programs based on their own evidence and data.

9) Other Evidence Based Practices Implemented: Next participants were asked what other evidence based cancer control interventions their organizations have implemented. The following interventions/resources were discussed by the participants (in order of most to least frequently mentioned): US Preventative Services Task Force Guides, American Cancer Society (Guidelines, Screening, Survivorship), Nutrition Guidelines, Physical Activity for Prevention and Survivors, NCCN Oncology Care Guidelines, Managing Chronic Disease Program from Stanford University, Aging in Australia – Peer Support Cancer Groups, Patient Caregiver Support, Coleman Care Transitions Model, Cancer 101, Promoting Health Equity, Physical Activity and Nutrition Program, and Access to Counseling.

Some participants also discussed specific ways they collect evidence (i.e., data) to inform, develop and refine their interventions. They indicated using client surveys, intake and exit interviews, follow-up questionnaires, focus groups, and a statewide survey of cancer patients and loved ones. The statewide survey is called the New Mexico Cancer Services Survey. It is completed by 500 respondents and used to identify gaps and develop tailored programs and services in the state of New Mexico.

10) Intervention Choice: All of the participants in one of the focus groups agreed that the Cancer Plan helped informed their choice of intervention. They said they used the goals and objectives to inform their scope of work, as well as specific programs related to early detection and screening, sun safety, and tobacco cessation (i.e., QUIT NOW). Participants in the other groups clarified that the plan shows alignment with the work they are already doing. Participants from one of these groups also reiterated that they use their own data and specific programs/interventions not the ones listed in the plan.

11) Other Practices Seen in the Community: The last question in this section asked participants what else they have seen implemented in the community. Participants discussed the following: Step Into Cuba model, Mobile Farmers Markets, Use of National Directories/Objectives (e.g., screening guidelines), Traditional/Alternative Healing Methods, Storytelling, Digital Storytelling, Mindfulness, Curanderos (Herbal Healers), Text Message Study (to increase physical activities and chemotherapy adherence), Indoor Tanning Information Related to Skin Cancer (including it in contracts/agreements at workplaces and in gyms), Addressing Youth Access to E-Cigarettes, Fear Appeal Messaging to Youth (smoking),

Addressing Smoking in Permitted Areas in Casinos, and Genetic Counseling (referrals/education). Participants also talked about new health care implementations and how they are affecting enrollment, screening, preventive care, survivor care, and palliative care.

Cancer Plan Supplement: Considerations for Implementing the NM Cancer Plan in Native American Communities

12) Implementation of Considerations for Native American Communities: When asked which of the practical ideas and examples in the “Considerations for Implementing the New Mexico Cancer Plan in Native American Communities” (pages 37-43) has your organization implemented, some participants discussed implementing particular goals (e.g., goal 1 through life style changes; goal 3 to improve quality of life; goal 8 to decrease disparities and increase access through treatment, screening, diagnosis, etc.). Participants also mentioned some specific examples of programs/activities they are implementing in Native American communities. For example, one participant said his/her organization included a Native Healer as part of their Cancer Retreat; this was very popular and increased participation in the event. Another participant talked about conducting a capacity development initiative for tribal community health workers. The participant explained that this work is focusing on mobilization at a larger scale; he/she also emphasized the importance of including Native voices.

Other programs/activities included providing one-on-one tobacco cessation for pueblos, holding a facilitator training for peer support groups, conducting outreach activities for Native American communities (e.g., health fairs, workshops and conferences), and coordinating a cancer focus group with a council of tribal leaders. In one of the groups, participants mentioned that there had been previous discussions about one of the workgroups, possibly the Native American workgroup, doing something related to addressing the diversity of clients. Participants said they would like to see this happen or receive an update on related activities.

13) Impact of Considerations for Native American Communities Section: Participants were also asked to discuss the impact of the “Considerations for Implementing the New Mexico Cancer Plan in Native American Communities” supplement has had on their programs and interventions. Participants mentioned positive attributes of this part of the plan. For example, one participant said, “There is good content that could provide a framework in this section.” Others talked about the interventions being culturally sensitive and adaptable for groups and individuals. Participants specifically mentioned that the Native American groups they work with prefer face-to-face meetings (e.g., they don’t use the 1-800 number) and that one-on-one smoking cessation meetings have been more effective than group meetings with this population. The participants also indicated various impacts of this part of the plan. Themes from the discussion are provided below in order of most to least frequently mentioned.

Participants said that the “Considerations for Implementing the NM Cancer Plan in Native American Communities”:

“It validates community knowledge by having it documented.”

- Increases education and awareness about issues.
- Reinforces and increases value (e.g., value of health and incentive to be a part of the group).
- Enhances collaboration and access to these communities.
- Increases visibility (e.g., helps develop a work plan/next steps and create more extensive education opportunities).
- Acknowledges these groups as citizens of the state – not just a federal issue.
- Increases community ownership (e.g., is less intimidating, more relevant to the community).
- Motivates the creation of supplements for other populations.

Access to Competent Cancer Care

14) Issues with Access to Competent Care: The last few questions focused on access to competent care. First the participants were asked to describe issues with regards to access to culturally and linguistically competent cancer care. Participants across the three groups most frequently talked about issues related to six key themes: (1) communication barriers, (2) cultural divide, (3) shortage of providers, (4) lack of transportation, (5) lack of integrated services, and (6) insufficient resources and other competing issues. Examples related to each key theme are discussed below.

Communication Barriers. The participants discussed communication issues between patients, family, facility staff, and physicians. They were not sure how many Native languages are available through translation services, and mentioned that it can be difficult to translate medical terms. They also

“Materials are not inclusive for those with little education.”

discussed challenges with Spanish translations (e.g., sometimes family members/children translate). Participants also noted that English is not the first language for many oncologists, which can add to communication problems. Negative messaging in translation from one culture to another can also be an issue. Participants suggested that translated messages be worded positively; instead of saying “use tobacco and die” the message can be positively phrased to say “be healthy, make better choices and live.”

Cultural Divide. Participants discussed a cultural divide or lack of awareness of different spiritual values, customs and traditions among health care professionals. Participants explained that “systems are not necessarily open or culturally aware” which compounds communication issues. For example, they said Hispanic patients tend to not ask doctors questions; if more doctors knew this it would change doctor/patient relationships. They also said that in some cultures trust issues exist with going to “outsiders” (i.e., people outside their community) for care. In addition, some people have attitudes that prevent them from seeking care. They may think “if I don’t go to the doctor then I’m not sick” or “if I have cancer it’s my fault so I don’t deserve treatment.” Participants also talked about the role stereotypes play in patients receiving culturally competent care.

Shortage of Providers. Many participants talked about there being a shortage of cancer care providers in New Mexico. They indicated that both attaining and retaining trained providers was an issue, especially in rural areas. In one group participants said there is a lack of services for the “forgotten rural communities.” They specifically mentioned a lack of care for children with cancer and a lack of Native American providers. Similarly, in another group, participants discussed a shortage of providers who are reflective of the populations they serve. Participants also talked about how the shortage of providers impacts waiting time to get into appointments and overall access to quality of care.

Lack of Transportation. Participants discussed a lack of resources for both long distance and local travel for cancer care in the state of New Mexico. They mentioned that many cancer patients must travel huge distances for care and to so do they need guides, housing, information and transportation. Participants also mentioned that for some patients, even if they have resources available for travel, they still may not be able to leave their jobs to come to the city for treatment.

Lack of Integrated Services. Participants emphasized that navigating the health care system can be confusing for patients for a number of reasons, one being a lack of integrated services. They explained that there is a lack of coordination among different settings (e.g., I.H.S. patients going to cancer centers). Some mentioned that the implementation of the Patient-centered Medical Home Model/Continuity of Care may help in this area, along with increased patient navigation services.

Insufficient Resources and Other Competing Issues. Participants discussed how a lack of resources and other competing issues, such as drug addiction and poverty, impact community members' ability to access competent care. They talked about issues related to a lack of financial resources, housing, insurance, internet, education/literacy, pharmacies for medications, equipment, and availability of healthy foods. Participants explained that cancer patients may be dealing with a multitude of problems and that "cancer may not be their biggest issue."

15) What Competent Care Looks Like: Next participants were asked what culturally and linguistically competent cancer care looks like. Participants came up with the following list (in order of most to least frequently mentioned).

Competent care means having:

- Easy access to care
- A holistic view of the patient
- Someone in charge who the patient trusts (e.g., an advocate, navigator or point person)
- Providers who are reflective of the populations they serve
- An integrated system working together (e.g., Patient-centered Medical Home Model)
- More transportation (e.g., providing mobile services for rural communities)
- Informed decision making (e.g., understanding benefits and risks; this information must be accessible - not all written, available in different languages and culturally appropriate)
- Cultural humility (e.g., willingness to learn, no assumptions about partnerships, no judgments)
- Individualized care
- Access to complementary and alternative care
 - More than one choice of where patients can go
 - Affordable health care
 - Optimal care, not sub-optimal (e.g., valuing quality)
 - Providers that understand differences in spiritual values, customs and traditions
 - Patient centers that engender trust (e.g., centers that focus on the needs and preferences of the patient)

"It's not just about the cancer. It's about the person and how do we improve quality of life overall?"

"Treat people the way THEY want to be treated."

16) What Cancer Control Professionals Can Do: The final focus group question asked participants for their thoughts on what cancer control professionals can do to ensure access to culturally and linguistically competent cancer care. Participants discussed suggestions related to the following eight key themes (in order of most to least frequently mentioned): (1) patient navigation services, (2) practitioner beliefs/cultural awareness, (3) patient support programs and resources, (4) communication plans, (5) workforce development and retention, (6) partnerships/community-clinical linkages, (7) policy and systems level change, and (8) population specific recommendations. Suggestions related to each key theme are provided in Table 1.

Table 1 - Suggestions for Ensuring Access to Competent Care

Theme	Suggestions	Example Quotes
Patient Navigation Services	<ul style="list-style-type: none"> • Increase patient navigation services (e.g., provide resources for more health care advocates and patient navigators). • Work collaboratively to increase patient navigation/advocacy – this is one of the four council priorities (i.e., access); however, there has been a lack of structure/leadership for this workgroup and not a lot of progress. • Dedicate the July council meeting or annual conference to the topic of patient navigation (representation from the medical community, leadership and planning is needed to make this happen so the conference would probably be a better fit than the July council meeting). • Invest in and value “navigators” so they can be effective (currently can’t bill for this). • Use accreditation/reimbursement of treatment centers to drive systems level change related to increasing resources for hospital patient navigators. 	<p>“It’s not about just having them [patient navigators], but investing in them and valuing them.”</p> <p>“People need an advocate. They may not know what questions to ask ... their brains shut down when they hear the C word.”</p> <p>“We have volunteers willing to be patient navigators and patients who need the services but no funding for this piece.”</p>
Practitioner Beliefs/ Cultural Awareness	<ul style="list-style-type: none"> • Take a holistic view of the person. • Change culture around talking about death. • Encourage personal responsibility from providers and patients. • Increase cultural humility (e.g., no labeling based on supposed cultural awareness). • Provide training on cultural intelligence (e.g., spiritual values, customs and traditions). 	<p>“As a culture we don’t talk about death ... we need to start to change this over time as practitioners in the field.”</p>
Patient Support Programs and Resources	<ul style="list-style-type: none"> • Refer patients to peer support programs (providers do not do this very often because of time/other priorities). • Use talking points for patients developed by survivorship committee (these do not get handed out by providers). • Use the directory of resources so people know where services are available (this is related to a gap identified by the statewide survey). • Expand the transportation network for both long distance and local travel – a council member wanted to start a transportation initiative backed through the oil industry but participants are not sure what happened with 	<p>“There is help and assistance programs but patients don’t know about them.”</p> <p>“I have only heard of one or two cases where providers suggest these types of programs [support programs].”</p>

Theme	Suggestions	Example Quotes
	this.	
Communication Plans	<ul style="list-style-type: none"> • Develop communication plans for individual hospitals/clinics – this should be a strategic plan and process that goes over tools/services; the planning should happen over time and incorporate a team approach. • Start a discharge plan for patients upon arrival/check-in – this should be part of the patient planning process and include emotional and financial components, as well as re-entry to the family. • Improve communication. 	“Families need to know they have the right to sit down and have a plan.”
Workforce Development and Retention	<ul style="list-style-type: none"> • Keep up to date. • Start with medical schools for changing structure and improving emotional intelligence and family practice. • Encourage providers to stay in New Mexico. 	“Encourage providers to stay in New Mexico.”
Partnerships/Community Clinical Linkages	<ul style="list-style-type: none"> • Bring community and professional/clinical providers together. • Increase partnerships between communities. • Learn from other chronic diseases (e.g., diabetes) on topics such as community-clinical linkages. 	“Tribes are left out of the political/research process.”
Policy and Systems Level Change	<ul style="list-style-type: none"> • Support health care workforce policy development. • Create systems level change (e.g., create an advocacy system outside of medical system treatment). • Support the Patient-centered Medical Home Model/Continuity of Care. 	“[We need] health care workforce policy development.”
Population Specific	<ul style="list-style-type: none"> • Increase mechanisms to help the low-income population get diagnosed. • Use priority funding for priority patients (e.g., spend on Spanish population rather than translate; value the expertise of population members). 	“Use priority funding for priority patients.”

Appendix A: Interview Guide for New Mexico Cancer Council Members

Cancer Plan

1. Describe how your organization utilizes the Cancer Plan?
 - a. How does this enhance your current mission/program?
2. Has your organization brought about any new initiatives this past year? If so, how did the use of the Cancer Plan influence those initiatives?
3. Has your organization worked to reduce disparities in your community this past year? If so, how did the use of the Cancer Plan help?
4. Has your organization worked to increase access to cancer services in your community this past year? If so, how did the use of the Cancer Plan help?
5. How and in what ways does your organization share the Cancer Plan?
6. How and in what ways are the goals and objectives in the Cancer Plan used to educate the community?
7. What components of the Cancer Plan do you find most helpful?

Evidence Based Practices

8. Which of the evidence-based cancer control interventions listed in the 2012-2017 NM Cancer Plan (page 45) are being implemented by your organization?
9. What other evidence-based cancer control interventions has your organization implemented?
10. How did the plan inform your choice of intervention?
11. What else have you seen in the community?

Cancer Plan Supplement

12. Which of the practical ideas and examples in the “Considerations for Implementing the NM Cancer Plan in Native American Communities” (pp.37-43) has your organization implemented?
13. Describe the impact this supplement has had on programs and interventions.

Access

14. Describe some of the issues with regards to access to culturally and linguistically competent cancer care.
15. What does culturally and linguistically competent cancer care look like?
16. What are your thoughts on what cancer control professionals can do to ensure access to culturally and linguistically competent cancer care?