

Cancer Community Action Plan:

Community recommendations for wellness on Navajo Nation

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**BRIGHAM AND
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Cancer Community Action Plan (“Action Plan”)

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Cancer Community Action Plan (“Action Plan”) Objectives:

The purpose of this community-led Action Plan is as follows:

- 1) To describe the **process** of community-led stakeholder engagement implemented to create the recommendations in this document;
- 2) To identify **priorities** for improving cancer care on Navajo Nation; and
- 3) To recommend **actions** designed to empower communities affected by cancer throughout their Wellness Journey on Navajo Nation.

Introduction.

This Action Plan is only understood on the foundation of understanding the current context in which cancer patients, families, and providers are existing. This background serves to outline this context. American Indians and Alaska Natives (AI/ANs) have the lowest cancer survival rates of any racial group in the United States. These poor outcomes extend to the Navajo Nation which is the second largest federally recognized tribal nation. A major barrier to care across the cancer care continuum in Navajo Nation is the complexity of the tribal healthcare system. Navajo Nation is sovereign and runs the Navajo Nation Department of Health (NNDOH). Within the NNDOH there are 14 programs focused mainly on public health and outreach. The Indian Health Service (IHS) is a separate health care delivery system and is responsible for providing the majority of clinical care to people living in Navajo Nation. Although both organizations are focused on improving health on Navajo Nation, tribal programs often function separately from clinical care provided through the IHS. Furthermore, cancer treatment is only available outside of the IHS system at regional cancer centers located off the Navajo reservation, often hundreds of miles away from a patient’s community. There is often little communication among the different providers and programs involved in cancer treatment and public health programs. Fragmented healthcare delivery programs like these have a negative impact on health outcomes, especially among older AI/AN patients with cancer. In addition to the complex network of services, health insurance coverage is strikingly low in Navajo Nation. Although the Affordable Care Act has improved enrollment into Medicaid, many people served by IHS are uninsured. Specialized care like cancer treatment requires contracted services, and services such as transportation and nursing home care are often difficult to obtain.

Another challenge to cancer care on Navajo Nation has been the lack of culturally appropriate education materials and treatment programs. Although materials are now in development, the lack of these materials previously, combined with stigma, have led to little or no open discussions about cancer on Navajo. One such example of difficulty talking about cancer on Navajo is the traditional Navajo belief that if you speak about negative possibilities directly they may become real. Another example is that many Navajo individuals are uncomfortable speaking about death. Such nuances make preventive, screening, and palliative services difficult to deliver, especially by providers who are not from the community. This also makes raising awareness about cancer, validating the survivor experience and discussing what is needed to improve cancer outcomes (including research, programmatic interventions, etc.) difficult to address. A few promising programs to increase patient education and awareness in AI/AN populations have begun to de-mystify cancer in AI/AN communities. One important common theme among such programs is the fact they are community led.

The COPE Cancer Community Engagement Initiative captures COPE's attempt at addressing this need and building on community assets on Navajo Nation. Community Outreach and Patient Empowerment (COPE) is a programmatic initiative of Brigham and Women's Hospital (BWH) and Partners in Health (PIH) based in Gallup, New Mexico. Founded in 2009, COPE's mission is to eliminate health disparities and improve the wellbeing of AI/AN. COPE believes that the power to overturn long-standing, historical health inequalities lies inherently in Native communities themselves. Recognizing that solutions for improving cancer outcomes in Navajo Nation must be patient-centered and culturally relevant, this project has built on COPE's strong foundation of partnerships and trust to effectively engage community members who have been affected by cancer. Specifically, the project established a cancer Patient and Family Advisory Committee (PFAC) and formalized and expanded the previously nascent COPE Cancer Coalition (CCC).

The purpose of the PFAC is to elevate the voice of cancer survivors and frame all dialogue within the cultural context of Navajo communities. Patients must be brought together with key stakeholders to increase collaboration, learn about Patient-Centered Outcomes Research (PCOR), share experiences, and generate a collaborative and patient-centered strategy to guide future research oriented toward improving cancer outcomes.

The PFAC is comprised of 14 patients and family members who received training and technical assistance covering a variety of topics to strengthen their understanding of research and current standards of care across the cancer care continuum. The trainings also formalized the PFAC's advocacy and engagement skills with other stakeholders, including health professionals, program leaders, and policy makers who compose the CCC. Throughout this engagement process COPE helped to deepen community participation in research by training PFAC members to have the skills to design and carry out evidence-based research in future efforts.

The project's overall goal is to increase capacity, collaboration, and coordination among stakeholders to carry out patient-centered program and research activities, with the long-term aim of improving cancer care and cancer outcomes in Navajo Nation.

Objectives:

The project's overall goal is to increase capacity, collaboration, and coordination among stakeholders to carry out patient-centered research activities, with the long-term aim of improving cancer care and cancer outcomes in Navajo Nation. Our specific objectives for the proposed project are as follows:

1. Establish and support the Patient and Family Advisory Committee (PFAC) focused on improving cancer care and cancer outcomes in Navajo Nation.
2. Conduct a series of workshops. Workshops were built on the foundation of co-learning principles.
3. Formalize and Expand the COPE Cancer Coalition (CCC) to include PFAC members and

broader stakeholders focused on improving cancer care in Navajo.

4. Support the CCC to develop a Cancer Community Action Plan that outlines recommendations for community-led interventions to improve cancer care and outcomes on Navajo Nation.

Methods:

Established the Patient and Family Advisory Council (PFAC). Based on community feedback there was a need for effective patient and family member engagement. The council consists of patients and family members of different ages and from different areas within Navajo Nation. The goal was to be comprised of at least 10 members referred by clinic and community based providers as well as word of mouth among patients. The PFAC has developed its own governance structure, and set its own vision and mission. Based on feedback, PFAC meetings were held regularly (6-8 times per year). PFAC members have been partners in setting the agendas for the meetings.

The PFAC met alone for the first eight months in order to provide time to develop the PFAC vision, mission, and identity as well as a culture of advocacy, education, and sharing. This also provided robust time for the PFAC to become particularly comfortable with concepts of research. The PFAC participated in workshops ranging from patient advocacy, basics of epidemiology, cancer epidemiology in Navajo, research methods, case management, health system strengthening, and hypothesis generation, and monitoring and evaluation. In the ninth month, the PFAC was then integrated into CCC meetings. The integration of the PFAC voice into the larger CCC created a strong patient- and community-centered voice with which to develop recommendations for future interventions to improve cancer care and cancer outcomes on Navajo Nation.

Formalized and Expanded the CCC. The CCC was founded in 2012 and consists of clinic and community-based providers including doctors, nurses, pharmacists, and social workers in Indian Health Service and tribally led clinics and community-based providers including community health workers and health educators. Additionally, tribal programs serving cancer patients and community members are involved as well as other local, regional and national partners/stakeholders. With feedback from CCC members, we formalized the schedule of quarterly in person meetings and held conference calls in between.

Held regular in-person PFAC and CCC workshops. These workshops are meant to develop and support patient empowerment and increase knowledge of cancer on Navajo and research methodology. All travel costs and time were compensated. The PFAC and CCC set the schedule of meetings and workshops and helped establish the agenda and identify speakers. Speakers were invited to participate in meetings based on their area of expertise and willingness to engage with members of the PFAC and CCC. Although the PFAC joined the CCC for some meetings starting in the ninth month of the project, the PFAC continued to have separate meetings to ensure PFAC members were supported, continued to feel a strong identify and sense of empowerment, and were able to have an element of peer support and engagement.

Expanded engagement to include the broader community. Both the PFAC and CCC supported the planning and implementation of the COPE-Navajo Cancer Survivorship Conferences which engaged a broader audience. The conferences not only provided an opportunity to offer support and education to patients and family members not part of the PFAC but it served to provide a platform to increase the discussion about cancer and cancer survivors and obtain additional buy-in from stakeholders for further resources, research, and interventions to support patients and family members affected by cancer.

Developed a Cancer Community Action Plan. The Cancer Community Action Plan (“Action Plan”) was the culmination of two years of engagement of the PFAC and CCC. The Action Plan was co-created by the PFAC, CCC, and COPE and outlines community-led recommendations for interventions to improve cancer care and cancer outcomes on Navajo Nation.

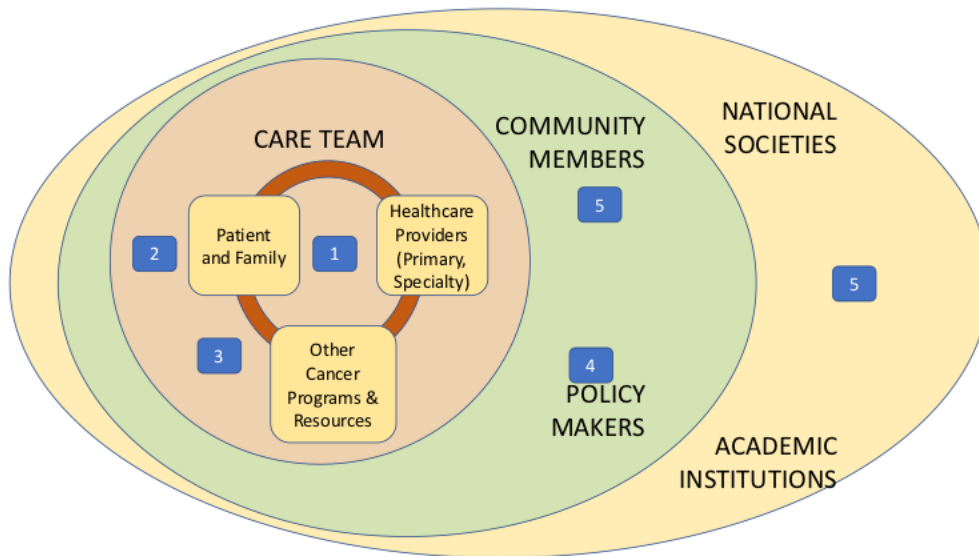
Engagement Process: Lessons Learned

- Two coalitions (1. healthcare professionals-CCC and 2. cancer survivors, patients, and caregivers-PFAC) were established with complementary roles;
- A convening team played a core role in recruiting, organizing sessions, and facilitating discussions;
- The PFAC and CCC met separately to address specific needs and interests of each group, but also worked together on deliverables and community events.

Understanding stakeholder relationships:

From this community-led, iterative engagement process consisting of PFAC and CCC meetings, discussions, and feedback, several important recommendations emerged. In order to better understand the context in which these recommendations were developed, Figure 1 provides a description of how key stakeholders are related to each other. These stakeholder categories include the following: 1) cancer patients and family members, 2) healthcare providers (including primary care providers as well as specialty providers) and 3) other cancer programs & resources on Navajo. These three core components are referred to as the “Core Care Team.” That “Core Care Team” is situated in a larger sphere that is comprised of 4) community members and 5) policy makers who also play a vital role in affecting patients, families, and providers. In the final concentric circle are national organizations (i.e. the American Cancer Society) as well as supporting academic institutions. The organizations in this circle impact the smaller circles and even extend out to other communities, with a broader reach and impact. It is important to understand how the different stakeholders interact with and influence each other. Understanding these interactions and influence are key to effective advocacy efforts.

Figure 1.



Overarching recommendation:

The comprehensive recommendation from the PFAC and CCC is to develop a culturally and linguistically appropriate patient-centered health care system for cancer patients. And, a system that has key components such as patient navigation and other support for cancer patients.

Key components of this vision include the following:

- 1. Improve care coordination and healthcare delivery:** Because the current healthcare delivery system on Navajo Nation is fragmented it is important to understand how care coordination can be improved to improve cancer care. Table 1 identifies the current patient experience, root causes, and recommended solutions.

Table 1.

Patient Experience	Root Cause	Solution
Burden on patient and caregiver, including exhaustion of personal resources and delays in care due to patient / family barriers	Care coordination relies heavily on patient	* Improve care coordination by hiring case managers and /or patient navigators * Healthcare system should assume responsibility of data transfer through provider-provider referrals and communication * Minimize in-person encounters for patients by using virtual and community-based care whenever possible
Patient and caregivers are frustrated, lose trust in healthcare system and cannot participate effectively in their own care decisions	Health information and care processes are not communicated to patient	Communicate transitions of care (e.g. change in provider) and test results to patients in a proactive, timely manner
Patients experience disruption and delays in their care, diagnosis and start of treatment may be delayed with poorer treatment outcomes	Healthcare system is under-resourced, including high provider turnover, vacancies	* Reduce provider turnover and understaffing if possible * Create a core team of stable inter-professional providers to deliver cancer care at each facility, including patient navigators and care coordinators, to improve care continuity
Patient may have limited treatment options, may not know their insurance options, and can experience delays and compromise in their cancer care	Healthcare options through Medicaid, Insurance, and Contract Health are limited and confusing; approval processes by middleman adds delay and complexity	Inform patients of their insurance options, including MCOs, Medicaid. Reduce delays in approval of services.
Providers, case managers, CHRs, and patients may not know the treatment plan, or status / follow-up plan after completing treatment.	Coordination between primary care team and cancer care team is challenged by poor communication and documentation	Increased communication between primary care team, patient and caregivers, and cancer center via shared platform access to medical records

- 2. Enhance access to and coordination of culturally integrated care:** The majority of providers on Navajo Nation are not from Navajo. This introduces barriers to care including language and culture which ultimately impacts trust. Additionally, many patients on Navajo Nation seek integrated wholistic care. Table 2 the current patient experience, root causes that create that patient experience and recommendations for improvement.

Table 2.

Patient Experience	Root Cause	Solution
Patient and family members feel confused and that they don't have the right information	Diagnosis or goals of care are sometimes given without an interpreter present or when the patient is alone	* Offer services of certified Navajo Interpreters to patients and families especially when having difficult conversations like diagnosis or Goals of Care * Communicate transitions of Care (e.g. change in provider) and test results to patients in a proactive, timely manner
Burden on family and clinical staff to explain information they may not be comfortable with or know the Navajo medical terminology for	Health facilities often have to rely on clinical staff or families to interpret instead of certified interpreters	*Hire certified Navajo interpreters to improve culturally appropriate care * Create a specialized training mentorship with certified interpreters to give them the extra training and coaching they need to translate Navajo cancer terminology and convey complexities in cancer care * Provide debriefing services to interpreters to give them the psychosocial support they need, recognizing dealing with these type of situations can take an emotional toll on the interpreter as well
An opportunity is lost to provide culturally appropriate psychosocial support and resources for those who may be interested	Lack of Navajo Traditional Services for patients	Increase referrals offered to office of Native Medicine, continue funding for Office of Native Medicine Departments - create these offices in health facilities that do not have them
Patient may not be offered any psychosocial support options because of the high demand and limited availability of culturally-sensitive providers	Lack of culturally appropriate psychosocial support options	* Develop training materials to expand pool of providers and peers who can deliver support to patients and family members in a culturally-appropriate manner, e.g. peer support groups, psychosocial providers with training in cancer care * Develop culturally-sensitive resources for grief and grieving
Cancer can be diagnosed at later stages than in other populations	Colon and Cervical Screening rates are low	Increase understanding of what barriers exist to screening and patient perceptions, increase communication and outreach to increase screening uptake

3. Strengthen communication and care coordination between providers and different delivery systems:

As outlined above, the healthcare delivery system on Navajo Nation is fragmented and more can be done to close gaps in care and rely less heavily on patients and family members to provide their own care coordination. Recommendations in this area includes the following:

i. 1. Cancer Centers

- A. Improve communication between cancer centers and patients/families. For example, developing materials for each center that outlines what to expect and provide information about local resources to contact for additional questions and concerns.

- B. Improve communication systems among providers. This includes improved communication between cancer centers, primary care providers, case managers, and outreach workers (CHRs). The communication should include clinical information and plans and should be used to develop local care coordination plans for both clinic as well as community-outreach purposes.
 - ii. 2. Coordination of programs/outreach: There are a variety of diverse community programs on Navajo Nation such as programs through the Indian Health Service and under the Navajo Nation Department of Health or other nonprofit or private hospital services. Duplication of services can sometimes develop, thus,
 - A. Developing a system for comprehensive cancer patient care coordination plans will allow each provider to follow-up through on a specified aspect of a particular patient's care
- 4. **Streamline early advanced care planning:** Given the challenges talking about stigmatized issues such as cancer and end-of-life combined with the cultural distance between a patient and his/her provider, advanced care planning is not optimized on Navajo Nation. Table 3 summarizes recommendations in this area.

Table 3.

Patient Experience	Root Cause	Solution
Patients and caregivers are sometimes surprised by a prognosis or don't have the time to plan and understand what the options are for their own goals of care	Advanced Care Planning doesn't systematically take place with all individuals who could benefit from information, guidance, and discussion, to make future plans.	Create systems and consistency with regard to advanced care planning discussions (i.e. EHR notifications) * Develop resource materials including cultural guidance and facility-based protocols to providers, as well as training / coaching from providers who are comfortable having these conversations * Providers can then have conversations like DNR early and keep this in a patient's chart Develop similar patient specific resources that include information about DNR and advanced directives
Patients and family members have a difficult time completing the forms, which can make it difficult for the family and providers	Forms for DNR, Advance Directives, etc. are very complicated and not culturally appropriate or consistent across states	Connect stakeholders across health facilities to create culturally appropriate less complicated DNR, Advance Directive Forms

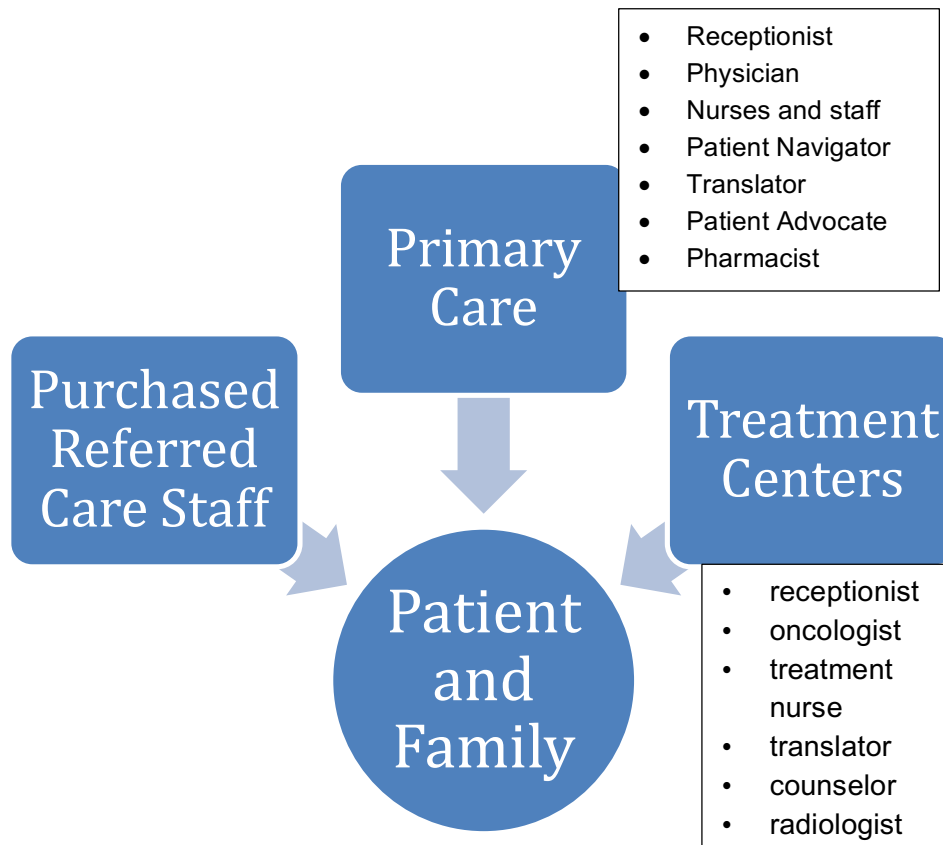
5. Develop orientation materials for health professionals treating cancer patients:

- a. PFAC should guide the development of training materials for new and returning providers including the following topics:
- i.
 - cultural sensitivity
 - community details (i.e. community tour)
 - conversation guide regarding Care (i.e. how do you feel about chemo? How do you feel about your diagnosis? Do you have concerns about recovery?)
 - Key referrals needed for cancer patients
 - Outlining key community resources

6. Deliver respectful and friendly patient interactions at all levels of care:

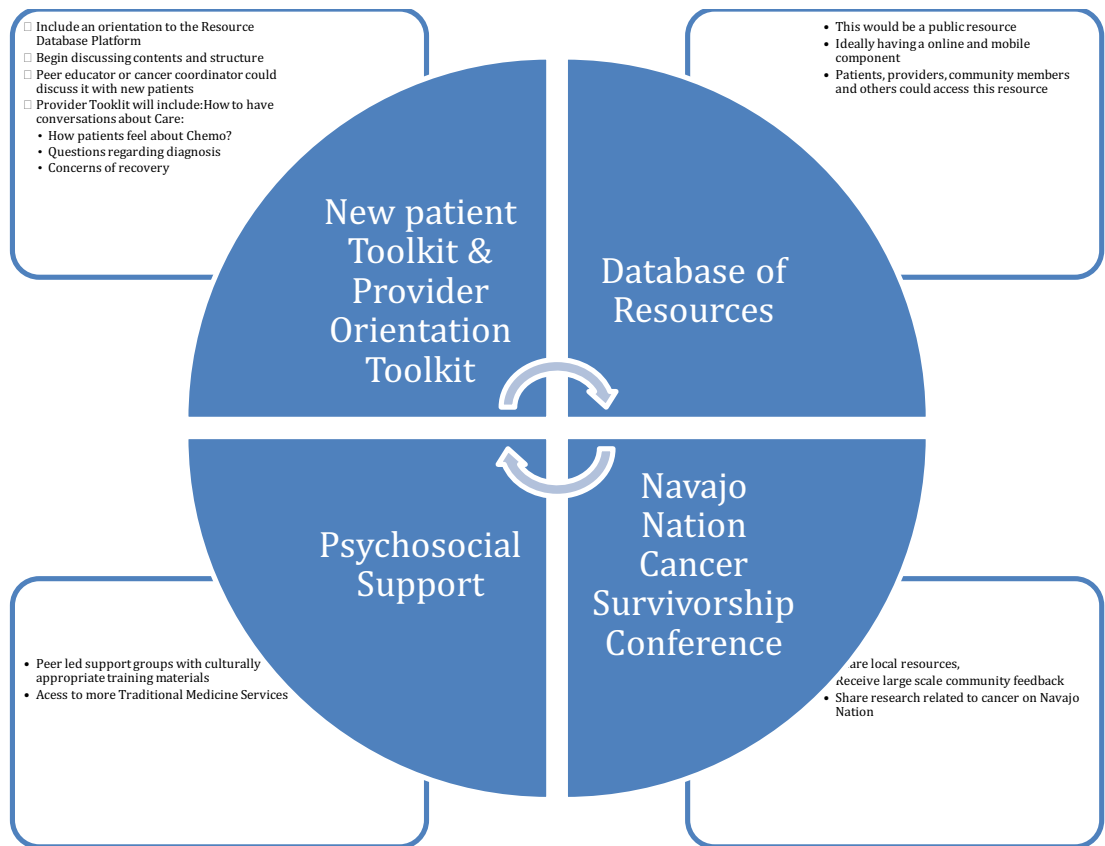
Because a patient and family's interactions with anyone along the cancer care continuum can greatly impact the way they feel about their treatment and care and the trust they have in the system and with individual providers, it's important for there to always be friendly, supportive, and respectful interactions at all levels of care across all individuals in contact with patients and family members.

Figure 2.



7. **Develop culturally appropriate resources and support for individuals, families, and communities affected by cancer:** As can be observed in Figure 3, the development of resources will be supportive to the majority of recommendations in the Action Plan. These resources will support the recommended interventions to improve the cancer patient experience and outcomes on Navajo Nation.

Figure 3.



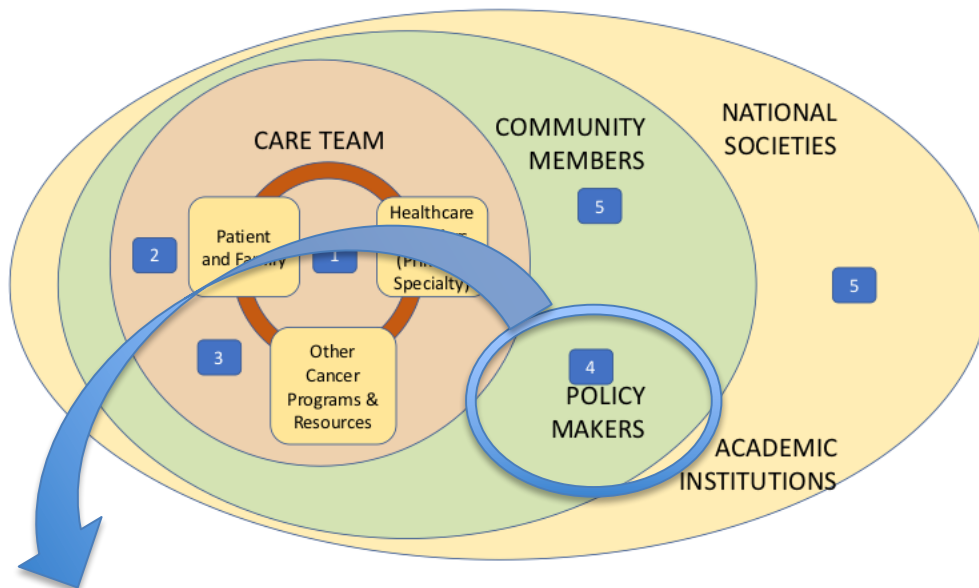
8. ***Make legal-aid accessible to all cancer patients:*** Because of the complex systems cancer patients are navigating combined with the fact that they often are not fully aware of their rights as a patient, making legal-aid accessible to all cancer patients is important. Additionally, because cancer can be an intense financial burden on patients and families, legal-aid consults are able to provide additional support and resources for already taxed individuals and families.

Table 4.

Patient Experience	Root Cause	Solution
Patients and caregivers are not able to make the best-informed decisions and/or access needed resources; providers are often uninformed and can't provide the best advice	Many legal challenges often accompany cancer – (job loss, medical bills, denial of insurance due to a preexisting medical condition, housing, etc.)	<p>* Train providers and patient navigators on how they can address the legal concerns *</p> <p>Discuss advanced planning prior to emergency situation, possibly at health-check visit *</p> <p>* Develop and support more Medical-Legal Partnerships across Navajo Nation health facilities</p> <p>* A good example: the Medical legal partnership in Shiprock with respect to cancer care *</p> <p>* Develop informational resources on: Family Medical Leave Act, Requirements (varies by state) for wills, POA, code status, etc., Video for DNR/DNI</p>

9. **Address larger system issues / Health Systems Policy:** Many of the recommended interventions within the Core Care Team will only be possible with larger system level change as outlined below.

Figure 4.



System/Policy Challenges:

Working on the grassroots and local levels, there are many challenges that will require advocacy to address system issues such as:

- Hospital/clinic underfunding
- Understaffing
- Provider vacancies
- No available home health services
- Moratorium on genetic research

Outcomes:

- These larger system issues can have a huge impact!
 - Patients pay a lot of money out of pocket, some may have to sell cars, possessions, etc. to be able to travel to treatment.
 - Other families are stuck calling EMS because there is no home health/hospice services.
 - The system breakdown ultimately leads to a lack of trust in the system and patients disengage from their care. This can have devastating effects on health outcomes.
 - The moratorium on genetic research has led to ineffective screening approaches so cancers are caught later than they should be. Additionally, this has led to families affected by Lynch Syndrome to feel isolated and helpless.

Solutions:

- Identify sources for greater financial support to patients
- Increase coordination with Community Health Representatives for home-based care and follow-up, getting information from the treatment facilities when they are sending a patient back into the community setting.
- Expand reliable, high-quality options for home-based care

10. Increased communication, support and community outreach

a. Increase outreach to people affected by cancer to overcome isolation:

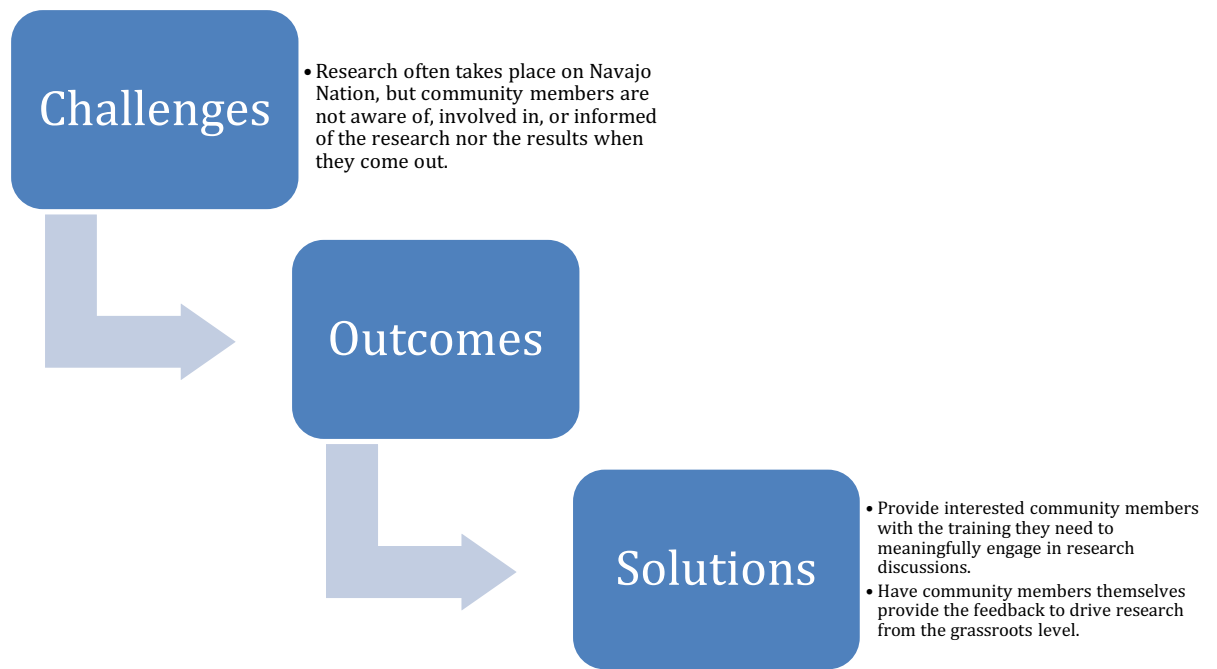
Individuals need to know that they are not alone. They need to know about available to support them. In some cases, additional resources need to be developed. For example, peer-led support groups.

b. Strengthen outreach to Navajo community to increase awareness, reduce stigma and increase cancer prevention and screening

- Increased sharing of the Navajo Nation Epidemiology Center's Cancer Among the Navajo Report to the communities across Navajo Nation.
- Since cancer is the second leading cause of mortality on Navajo Nation, there should be more awareness raised to address cancer, especially because it affects a large number of people.
- The new Diné Terminology Glossary should be shared AND used to shift the perception of cancer to a more positive perspective. The old word "the sore that doesn't heal" should not be used any longer.
- Straight forward information materials that explain Genetic Counseling, and the genetic components involved in cancer screening, treatment, and care should be developed.
 - o Including: what services are provided by health facilities in regard to genetic counseling, screening, and prevention

11. Increase patient and family-driven research: More research is needed to better understand cancer among Navajo and evaluate interventions. This research will be more effective and have more buy-in the more it is drive by patients and family members affected by cancer as outlines in Figure 5.

Figure 5.



In summary, priorities identified by the Patient and Family Advisory Council and the COPE Cancer Coalition include the following:

Short-Term Priorities
Disseminate the Cancer Community Action Plan
Develop & Adapt Culturally Appropriate Education Materials for Patients
Continue Annual Cancer Survivorship Conferences
Increase Cancer Awareness through Communications and Digital Stories
Intermediate-Term Priorities
Create a resource map /database for patients and for providers to use
Pilot a Support Group network
Need for continual patient input into healthcare delivery system at every level
Create mentorship resources for medical interpreters and integrate into healthcare delivery system
Adapt cultural orientation materials for providers
Create and implement curriculum on advance directives for patients and providers
Establish a Patient & Family Advisory Council at each delivery site to provide guidance specific to cancer care to that health facility
Long-Term Priorities
Fund positions for a Referral Specialist, Patient Navigator, and/or Care Coordinator at each Health Facility
Fund positions for Office of Native Medicine at each health facility
Increase staffing at health facilities, fill vacancies of nursing, emergency department and urgent care