

COMMUNITY FORUMS

COMMUNITIES SPEAK ON THE *TEXAS CANCER PLAN*



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Texas Cancer Council

Texas Comprehensive Cancer Control Coalition

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Abilene
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Executive Summary

Report on Community Forums

Communities Speak on the *Texas Cancer Plan*

Background

The Texas Cancer Council is a state agency whose mission is to reduce the human and economic impact of cancer on Texans. The Council achieves its objectives through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control. The roadmap used to guide these activities is the *Texas Cancer Plan*. The Texas Cancer Council's decisions regarding the cancer control activities it chooses to recommend, promote, fund, implement or support are very strongly guided by the *Plan*. SUMA/Orchard Social Marketing, Inc. was contracted to seek the guidance of cancer control professionals statewide for the update of the *Plan*. To gather input, two-hour community forums were organized in eight Texas locations representative of the ethnic and geographic diversity of Texas. The locations included:

- ◆ San Antonio
- ◆ Nacogdoches
- ◆ Laredo
- ◆ McAllen
- ◆ Abilene
- ◆ Houston
- ◆ Ft. Worth
- ◆ Midland

In total, 113 participants provided input. Professions represented include:

- ◆ Physicians
- ◆ Dentists
- ◆ Nurses or Nurse Practitioners
- ◆ Radiology Technicians
- ◆ Nurse Educators
- ◆ Social Workers
- ◆ School Health Professionals
- ◆ Hospital Administrators
- ◆ Patient Navigators
- ◆ Texas Cooperative Extension Agents

For each goal, progress made since the *Plan's* publication in 1998 was discussed, and objectives and strategies were reviewed and probed for continuing relevance in the new *Plan*. The group also generated new strategies to address cancer control.

The recommendations for the *Plan* presented in this report are the synthesis of participants' recommendations, continuous themes in discussion, and researcher qualitative analysis and observation.

Findings Goal I: Prevention Information and Services

Participants in all communities were highly interested in prevention and offered a wide range of strategy recommendations under Prevention and Information Services, including enhancement of public relations and education, and activity in areas of public policy.

Recommendations for Prevention Information and Services

Produce more Spanish-language educational audiovisual and print materials, along with guidance in using the appropriate media or distribution channels for specific audiences. The increase in Texas of a Spanish-dominant population necessitates the production of more Spanish-language materials. Some participants noted that offering information in Spanish does not guarantee understanding by all Texas Hispanics. Linguistic complexities, regional differences among Spanish speakers as well as the use of culturally appropriate terms rather than direct translations must be considered. In addition, many participants noted that production of print matter is not enough. Many Hispanics use other media such as radio and TV as their primary mode of gathering information, and even more than media, they use personal or community relationships.

Emphasize messages for educational materials that are culturally appropriate and targeted by gender. Participants reported limited availability of culturally appropriate materials for minority communities including African American, Asian, and Hispanic. Materials must respond to gender expectations and beliefs within cultures. For instance, many Hispanic forum participants noted that Hispanic male concern about spousal privacy and gender roles can delay or prevent breast and cervical cancer screening and treatment. They recommend that these barriers be acknowledged and addressed in educational messages that persuade individuals to seek cancer screening and their family members to support them.

Offer technical assistance with the “how-to and where-to” of materials distribution. Many participants reflected the need to disseminate materials through more non-traditional, creative avenues, in order to effectively reach underserved communities such as working with churches in the African-American community or *promotoras* in the Hispanic community.

Offer technical assistance for communicating with local media. Participants reported varying levels of media competency and success, often related to the size of the community, the level of personal media sophistication, and staff support for disseminating messages to the media. Community-based agency

representatives know that effective dissemination of prevention and screening messages can make a life-and-death difference for local residents.

Address public policy areas that enhance cancer prevention through state or local funding and enforcement. Existing tools for cancer prevention are not fully utilized. Participants expressed dissatisfaction in the lack of funding or implementation oversight for Senate Bill 19 requiring thirty minutes of daily physical activity in elementary schools and the general failure to strongly enforce regulations preventing youth tobacco usage.

Assist local communities with advocacy. The expressed need for advocacy at local, county, and state levels led to requests for advocacy training and assistance.

Build support from school administrators for youth-based educational programs. Many participants believe schools are the logical places to disseminate prevention messages but share frustration that many schools are focused on meeting state testing requirements to the exclusion of promoting healthy behaviors and awareness.

Offer comprehensive guides to assist communities in networking, needs assessment and locating programs. The forums' end conversations and "card swaps" underscored participants' interest in maintaining contact with those they had met, many for the first time, during the forum. Participants know their collective effectiveness is strengthened by collaboration and networking, especially in isolated areas where professional fraternization opportunities are limited or nonexistent. Specific requests were made for best practices information and a clearinghouse for materials, programs and strategies.

Findings Goal II: Early Detection and Treatment

All groups acknowledged that, since 1998, enormous strides have been made in early detection and treatment with breast and cervical cancer screening, and colorectal cancer screening. *Promotoras* and patient navigators have been a major positive change in improving the continuum of cancer control, especially within communities experiencing healthcare disparities. There was a clear call for more concentrated funding for these kinds of activities.

The greatest challenge is providing access to care after cancer diagnosis, especially for the uninsured or underinsured. Access issues pervaded the forum during discussions of early detection and treatment.

Recommendations for Early Detection and Treatment

Provide more outreach and education for minority populations and the uninsured or underinsured about screening and diagnosis, with information about access to treatment for those who with a cancer diagnosis (e.g. funding for breast cancer treatment if screened by BCCCP).

Increase funding for patient navigator and *promotora* programs.

Increase funding for diagnosis and treatment infrastructure (especially in places with long waiting periods for few providers/or those who accept Medicaid).

Promote continued education to primary care physicians to recommend routine cancer screening for their patients.

Findings Goal III: Professional Education and Practice

The huge strides in technological capability to disseminate information through the Internet, teleconferencing, and other innovations have led to tremendous progress in the area of professional education and practice since 1998. The Nurse Oncology Education Program (NOEP) in particular, and also the Physician Oncology Education Program (POEP) received high marks from many participants who are part of their target audiences.

However, nurses and physicians still face barriers to continuing education. Barriers mentioned in multiple forums centered on time, motivation, cost and access to the necessary technologies. Most recommendations about continuing education focused on creating opportunities for other professionals such as mid-level providers, school nurses and social workers in ancillary cancer fields.

Physicians are more likely than nurses to use the many Internet continuing education options, with nurses often preferring face-to-face educational opportunities. Some participants felt that online continuing education opportunities should be rated for accuracy and timeliness.

Recommendations for Professional Education and Practice

Educate general/family practitioners about the value of effective risk assessment and provide them with assessment tools. They should be encouraged to consistently recommend screening and to follow-up with patients to ensure that screening is received.

Provide cancer screening and treatment education for mid- to lower level healthcare professionals.

Provide cancer prevention and information educational opportunities for professionals from non-medical disciplines, such as educators, social workers, or community-based workers, so that they can more fully participate in prevention and early screening initiatives.

Provide communities with templates and training for implementing a team approach managing a cancer diagnosis. Metropolitan areas with large cancer centers tend already to integrate a team approach, as do some smaller forum communities where clear leadership and vision are evident, and a team approach happens organically. In communities with competing hospitals or lack of a safety net hospital, little had taken place to encourage the team approach.

Provide continuing education opportunities about pain management.

Findings Goal IV: Cancer Data and Planning

The scarcity of accurate data is viewed as a major problem. Participants shared a general agreement that while the state Cancer Registry has improved, it is still not adequate to meet the needs of the cancer control community. For participants seeking funding, specific information about their population and the lack of accurate and current data is a continuing source of frustration.

Inadequate data hampers local planning, according to many participants. Another issue is the perceived lack of resources available for community collaboration in needs assessment and planning. Judging from many participants' post-forum interest in continuing to meet, the forum events themselves planted the seeds of local cancer control coalitions.

Recommendations for Cancer Data and Planning

Improve the quality and timeliness of cancer data through training.

Certify local cancer data registries. Local registry sites with highly trained registrars increase the likelihood that local data can be gathered more systematically and with more accuracy.

Provide a "Guide to Local Planning," or collaborate with the American Cancer Society to adapt its E-Tool to the *Texas Cancer Plan*. The concept of local collaboration and information sharing emerged at each forum. Tools for community needs assessment, a galvanizing force for community organization

around the issue of cancer control, and actual coalition building are areas that were touched upon and agreed to be desirable.

Findings: Survivorship

The updated *Texas Cancer Plan* will include survivorship as a new goal area. The Lance Armstrong Foundation defines survivorship as, “living with, through and beyond cancer.” Forum participants noted that cancer survivorship begins with diagnosis. Increasingly successful cancer treatment equals more long-term cancer survivors, including more children who survive cancer, grow to adulthood, and face issues as they plan their families. Other cancer patients and their families need support as they face end-of-life issues.

Recommendations for Survivorship

Provide survivors with knowledge of resources about how to survive, with additional emphasis on the psychosocial aspects of survivorship. Access to clinical drug trials, access to mental health care, pain management, and advice about exercise and nutrition were named as important information areas.

Expand opportunities and reduce barriers to participating in support groups. Some forum participants talked about the difficulty of getting people to support groups, especially in rural and border areas. For some, transportation is an issue, for others, the hospital or office environment is not as comfortable as a neighborhood setting or a church, among peers.

Provide survivors with information on the long-term economic impact of cancer. Living with and through cancer can effect a family’s economic stability. Expensive medications and continued screenings, coupled with the difficulty in getting health insurance after a cancer diagnosis, may be compounded by a disruption in the continuity of care that often results from changes in insurance.

Target information on survivorship to age-specific groups, including young adults and children.

Provide families with education about a wide range of issues relating to supporting a family member with cancer, from how to make end-of-life decisions to risk assessment for future generations.

Help health care providers, patients and families understand genetic implications of cancer and know how to assess risk for the family.

Forum Findings and the Texas Comprehensive Cancer Control Coalition

The formal purpose of the community forums was to gather input to the updated *Texas Cancer Plan*. Fortuitously, strategies emerged that can help guide the Texas Comprehensive Cancer Control Coalition as it seeks to encourage collaboration, strengthen its role in statewide cancer control, and further define its purpose.

Recommendations for Enhancing the Texas Comprehensive Cancer Control Coalition

Spread the state coalition model to local communities. Provide technical support in the way of a trainer and continuous guide, a toolkit and a written guide that enables local cancer control professionals from all areas related to the *Texas Cancer Plan* to build a local cancer control coalition. The eight communities visited could represent the seeds of the first eight local coalitions.

Host an annual statewide forum for local coalition participants. An annual summit of cancer control representatives from local coalitions should facilitate networking, information sharing, and advocacy.

Enhance Texas Comprehensive Cancer Control Coalition membership with local representation that matches the ethnic and geographic diversity of Texas. Local “stand-outs,” visionaries or strong voices for the underserved should be tapped to become quasi-permanent members of the state coalition.

Conclusion

The *Texas Cancer Plan*, to date largely unknown within the cancer control community, can become an educational, organizing and planning tool in every community, when coupled with local cancer care providers and stakeholders. An anonymous survey distributed at the end of each forum was completed and returned by 90 participants. In response to a question about the usefulness of the *Texas Cancer Plan* to local efforts, fifty-seven percent (57%) said it would be very useful; twenty-four percent (24%) responded that it would be somewhat useful. Very few thought the *Plan*, in any form, was irrelevant.

The *Plan* continues to be very relevant to cancer control issues. Recent successes in prevention education and early screening have created new urgency in the areas of treatment and survivorship, and the *Plan* should reflect those needs. Increased attention to cultural sensitivities and diversity is critical to reducing cancer among those who most seldom receive early cancer screening and timely cancer treatment. Increased attention to improving data timeliness, accuracy and availability will have a wide and positive impact on cancer control in Texas for generations to come. Survivorship is becoming a way of life for a larger percentage of the Texas population, and the *Plan* should anticipate the decision-making and daily living needs of this group.

As the gap widens between families facing cancer and access to early and successful treatment options, health disparities should draw renewed attention across all *Plan* goals.

Report on Community Forums

Communities Speak on the *Texas Cancer Plan*

Introduction

The Texas Cancer Council is a state agency whose mission is to reduce the human and economic impact of cancer on Texans. The Council achieves its objectives through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control. The roadmap used to guide these activities is the *Texas Cancer Plan*. By state legislative mandate, the Texas Cancer Council is charged with the very critical task of developing and implementing the *Plan* and keeping it current.

The Texas Cancer Council's decisions regarding the cancer control activities it chooses to recommend, promote, fund, implement or support are very strongly guided by the *Plan*. To receive the input and guidance of cancer control professionals statewide, SUMA/Orchard Social Marketing, Inc. was contracted to seek community input to the *Plan*.

Forum Participants

To gather community input for the updated *Texas Cancer Plan* from cancer control professionals living in diverse geographic areas of Texas, SUMA/Orchard Social Marketing, Inc. organized community forums in eight Texas locations:

- ◆ San Antonio
- ◆ Laredo
- ◆ McAllen
- ◆ Abilene
- ◆ Nacogdoches
- ◆ Houston
- ◆ Ft. Worth
- ◆ Midland

Forum participants were recruited through the recommendations of state and local cancer control professionals. Participants were identified as stakeholders for a variety of reasons, including participation in the Texas Cancer Council either as a board member or grantee and involvement with the Texas Comprehensive Cancer Control Coalition. Participants represented many agencies actively engaged in cancer control, including the Texas Department of Health and local health districts; education service centers; local medical and community-based organizations; academic and research institutions; the Breast and Cervical Cancer Control Program; American Cancer Society; Susan G. Komen Foundation as well as other non-profit and community-based organizations, legislator offices, and hospices. Forums lasted about 2 hours each and included lunch.

A total of 113 participants represented these professions:

- ◆ Physicians
- ◆ Dentists
- ◆ Nurses or Nurse Practitioners
- ◆ Radiology Technicians
- ◆ Nurse Educators
- ◆ Social Workers
- ◆ School Health Professionals
- ◆ Hospital Administrators
- ◆ Patient Navigators
- ◆ Texas Cooperative Extension Agents

Prior Familiarity with the *Texas Cancer Plan*

Prior to each forum, participants were mailed a copy of the 1998 *Texas Cancer Plan*, along with a letter asking them to review the goals, objectives and strategies for each of four goal areas, including prevention and information services, early detection and screening, professional education and practice, and cancer data and planning. They were also informed that a new goal area, survivorship, is expected to be addressed in the updated *Plan*.

After the discussions, participants completed an anonymous written survey about their prior familiarity with the *Texas Cancer Plan*. Of the 90 participants who completed the survey, thirty percent (30%) said they had not seen it prior to the forum activity. Another forty-two percent (42%) had heard of it or briefly skimmed it in the past, but had no real familiarity with it. Sixteen percent (16%) were familiar with it, and nine percent (9%) had actually used the *Plan*. The remainder of the respondents, three percent (3%), were Coalition or Texas Cancer Council Board members, and indicated a high familiarity with the *Plan*.

Areas of Discussion

During the forums, moderators asked participants for their insights and opinions about each goal area. Progress made since the *Plan's* publication in 1998 was discussed. Objectives and strategies were reviewed for continuing relevance, and recommendations were sought for inclusion in the updated *Plan*. The remainder of this report describes findings from all the forums.

Analysis. Forums were tape-recorded and transcribed verbatim. Researchers read and coded the transcripts, looking for common themes and categories of need. The results of this qualitative analysis are not definitive, but they may be considered directional inasmuch as participants from across the state often related similar ideas and expressed the same needs.

Verbatim quotes from participants appear in italics throughout the report. The basis used for selecting quotes for this report was that they best captured sentiments expressed by many. Ellipses indicate that extra verbiage was skipped for brevity and/or clarity. The author of this report made every effort to provide a representative sampling of voices from different parts of the state, and representing various points of view.

Prevention Information and Services

Progress Since 1998

Forum participants from all parts of the state agreed that there has been some progress in the areas of prevention information and services since 1998. Great strides have occurred in the areas of disseminating prevention practices for breast cancer, awareness of sun safety issues, and the benefits of prostate and colorectal cancer screening. Progress in tobacco prevention initiatives was also noted, with many participants talking about local efforts. Expanded awareness of the need for physical activity and good nutrition was mentioned as culminating with the passage of Senate Bill 19. Participants in a few locations also mentioned that there had been progress in their community collaborations as a result of prevention information initiatives. The acknowledgement of progress was usually tempered, however, by the expressed need for more. The following quote reflects the sentiments of many participants.

I still think there is a paucity of appropriate materials for specific target audiences, but I think there has been a big change since '98 in what is available electronically and the ability to adapt quickly and change electronic materials for target audiences, is a wonderful feature.

Recommendations for Prevention Information and Services

Participants in all areas offered a variety of recommendations for strategies to be included in the updated *Texas Cancer Plan*, under the goal of enhancing prevention information and services. The following reflects the broad categories mentioned by participants across multiple sites.

Produce more Spanish-language educational audiovisual and print materials, along with guidance in using the appropriate media or distribution channels for specific audiences. The increase in the Spanish-dominant population necessitates the production of more Spanish-language materials. However, many participants noted that production of print matter is not enough. Many Hispanics use other media as their primary mode of gathering information, and even more than media, they use established personal or community relationships. According to many, this is an area that needs attention.

I think that in Laredo and being Hispanic, it is my belief that we are more of an oral culture. I think that ... Spanish radio stations, Spanish TV has one of the strongest effects...we see it in our clinics. We go on

Spanish radio and we get tremendous calls. It has been fabulous for increasing prostate cancer screening.

It's not just the radio, not just the TV, it's literally having classes...support groups, understanding. A population health type of process, where you are talking about it.

Get those kids educating their parents and grandparents, because they are the ones that go back from school.

Emphasize messages for educational materials that are culturally appropriate, and targeted by gender. Participants reported limited availability of culturally appropriate materials for African American, Asian, and Hispanic communities. Some participants noted that Spanish language print media does not guarantee understanding by all Texas Hispanics. Linguistic complexities and regional differences among Spanish speakers are serious challenges. Different word usage to describe the same idea is not uncommon among regional dialects. For example, one participant related a story of locating Spanish-language end-of-life educational materials in New York, only to find that her Mexican American patients in South Texas did not understand something written by a Puerto Rican writer.

I was looking for research that was done on end-of-life issues and palliative care, and almost nothing is done for Hispanics and practically everything I found is from New York and is for Puerto Ricans or Cubans...Even the words are different, not even the same from a literal standpoint ... A lot of times, a lot of folks truly don't understand and it's not for lack of education. It's a lack of understanding.

Materials must respond to gender expectations and beliefs within cultures. For instance, many Hispanic forum participants noted that Hispanic male concern about spousal privacy and gender roles can delay or prevent breast and cervical cancer screening and treatment. They recommend that these barriers be acknowledged and addressed in educational messages that persuade individuals to seek cancer screening and their family members to support them.

Hispanic men and going to get prostate screenings....it is like pulling teeth. They don't know how important it is.

.... there are also some cultural norms. We have a group of Hispanic ladies that we work with and we talk about that a lot when they come in for their healthy women check ups, their husbands come with them. And if that physician goes to do a clinical exam on their breast, they

are like, 'you are not touching my wife.' We have to get past that culturally. We have a lady that for a year and a half described problems that she is having and I'm sitting there cringing because you need to get in there and you need something done. She finally came in when her husband was off at work and they are going to run a mammogram on her.

Offer technical assistance with the “how-to and where-to” of materials distribution and message delivery. Many participants spoke about the need to disseminate materials in alternative ways, in order to effectively reach different communities. They described their search and dissemination efforts as those of trial and error: looking for and finding materials, wondering how to disseminate, and the occasional surprise when they find the right distribution channel. In the African American community, working with churches or within the spiritual community is important to successful material dissemination and message delivery.

You need to get outside of the box. We've increased the awareness among African-Americans in Gray County. Testing has doubled and it is just blown off the top. And the doctors have to put on extra GIs in order to meet the demand of the people who are getting screened. And I will tell you how we did that. It is the radio. We started advertising on gospel radio.

I think there are great materials out there and I think they are readily available on the Web... we just might not be very good at getting it to the people who need it.

One of our biggest gaps is minorities in the underserved population. The white population has been great in getting information out there in traditional avenues and they watch the ACS commercials on television and they read the ad in the paper. We are not reaching the minorities and the uninsured and medically underserved population. They still have the highest cancer rate of any population, the African-Americans and Hispanics, and trying to get that information out to those populations, it does not work in the traditional way as when we reach the white populations.

I have to say that I spoke at a convention this weekend and I was truly impressed, and I'm not in the sorority but I spoke in Houston at the AKA sorority. This is all black women and they had a whole section on health. And there were more than 3000 women there and several of them had to go to one session on health. It varies from oncology to

other topics, so again, there are links in our communities with our minorities that we do not know about.

Offer technical assistance for communicating to the media. Participants indicated varying levels of media competency, depending upon the size of the community or the level of sophistication or staff support for disseminating messages to the media. Some participants said they did not understand how to achieve successful collaboration with media outlets.

The ACS nationwide has a company that cuts newspaper clippings of each cancer story in each area. And they send that to us on a quarterly basis. I am surprised that every time I get the email, that there is one everywhere in the State of Texas. Quite a few clippings in newspapers and TV, where they are promoting screening and prevention measures. And I look at the Valley and there are none, absolutely none. One of our biggest problems is getting the local media involved.

Address public policy areas that enhance cancer prevention through state or local funding and enforcement. Communication about public policy was identified as an issue clearly distinct from cancer prevention messages. Participants in all locations had participated in local coalition efforts to ensure the passage of Senate Bill 19, which requires thirty minutes per day of physical activity in elementary schools. Having passed the bill, however, several expressed dissatisfaction with the lack of funding and oversight for its implementation.

...basically the three main components of Senate Bill 19 were that schools required 30 minutes a day of physical exercise, activity, or 135 minutes a week. The second component was that each school was to have a school health advisory council to address school health issues. The third one is that each school by 2007 would implement a coordinated approach to child health....those were not funded and also they're not being regulated.

Other public policy issues, such as “putting teeth in enforcement efforts” to prevent adult and youth tobacco usage were mentioned.

I think this city has a certain responsibility in that we are still allowing smoking in public places. It's kind of hard to tell a child not to do it when we are not adhering to our own policies. If we are not abiding by state policy in our local businesses, how can we tell a child, don't buy a pack of cigarettes?

Assist local communities with advocacy. The need to advocate for public policy change in an effort to work on prevention usually led to discussions of the need for advocacy training and assistance. Advocacy at the state level was an acknowledged need during most forums, and participants in some communities said they could also use help locally.

I don't really see that advocacy has been directed in a sustained fashion with the city and the county that can help provide for indigent care in an adequate fashion.

I have spoken to commissioners at commissioner's court, I have worked with the Hospital Association for the state, I have sat down with a couple of representatives myself and talked to them. Even at a national level, our corporation is talking, but it is not just us talking to them as a for-profit entity, because that is the way they look at us. It has to come from these type groups [community]...Advocacy needs to be brought to the local level by state leaders because you get a lot of local people hesitating to put any pressure on them, and yet that is where the pressure should be.

Work to garner support from school administrators for youth-based educational programs. Many participants acknowledged that schools are the logical places to disseminate prevention messages for a myriad of reasons. However, participants share frustration that many schools are more focused on meeting state requirements concerning Texas Essential Knowledge and Skills (TEKS), leading to the Texas Assessment of Knowledge and Skills (TAKS), and do not necessarily address these prevention objectives. Participants noted that schools are not as fertile a ground as they could be for receiving and encouraging the dissemination of these messages. A few participants suggested that a positive climate for collaborative efforts to encourage healthy behaviors could best be set at the state level through the Commissioners of the overseeing state agencies.

We deal with kids in sixth, seventh, and eighth grade that is our biggest target and we had one school district tell us, "You have to be crazy to come in here and talk to kids about sun and skin cancer. We have more important things to do."

School-age kids, there is a lot of curriculum out there, various sorts and types, but getting teachers to actually use in schools and stuff is very difficult I think. Their time constraints in teaching the TAKS test to my kids at least, they do not have much time to do anything else.

We might want to consider working with TEA and the Texas Education Association and the Department of Agriculture.

Offer comprehensive guidance to assist communities in networking, needs assessment, locating materials, program models and funding. One event common to every forum was the “card swap” occurring at the meeting’s end. Participants in all locations requested that moderators generate a list of participants, and indicated a great interest in maintaining contact with those they met during the forum, many for the first time. The expressed desire for more networking was generally qualified by a desire to understand what others have done, what works and “how to.” This was particularly true for those working in isolated areas where opportunities for professional fraternization are limited, or nonexistent. The following recommendations represent what many participants believe should be strategies offered in the new *Texas Cancer Plan*.

◆ **Produce a *Guide to Best Practices* so “we don’t have to reinvent the wheel.”**

There is a need for information about best practices. ...If we want to implement something in Nacogdoches and someone in some other part of the state had a really awesome program with a population similar to ours, I would never know that unless I happen to be in the room like this and somebody said it. ...We do not have a central place where best practices are recorded, so everyone else in the state can learn about that.

I learned a whole bunch going to one of the TCC Program Directors meetings that they had, from the Austin director of the American Cancer Society. They had put together practices on reaching at-risk populations particularly African-Americans. We all sat around that round table and I was just like, oh my God, I mean you do not have to try to reinvent something I can take it from there.

◆ **Offer a clearinghouse for access to educational materials, programs and strategies.**

There needs to be more initiative to get people to work together. We have a wealth of people with experience. But we have our Walk Across Texas, while TDH has Walk Texas. Duplicity. We have people in every county to provide leadership. It’s difficult to get people interested in prevention. If we can foster an initiative to work together, especially in prevention, that would help people get behind it.

Early Detection and Treatment

Progress Since 1998

I just have to have one patient to see what it costs to treat a patient with colon cancer versus the cost of a colonoscopy. It is unbelievable.

The words of this physician reflect the sentiments of many physicians and nurses who participated in the community forums. Since 1998, enormous gains have been made in early detection and treatment. All groups acknowledged that great strides had been made with breast and cervical cancer screening, and colorectal cancer screening.

BCCCP with the Medicaid Act has been a major plus. We are just thrilled that Medicaid will now pay for breast treatment for these ladies diagnosed in our program. We are really having to make an effort to let our physicians know that, let us get the diagnosis and then we want to catch them before they have a biopsy.

We had huge progress in terms of mammography and cervical screenings. Awareness of colorectal cancer screenings and early detection is now where these used to be, I don't know, a decade ago. Now we know we can prevent it, we can cure it. In the past 5 years we're seeing a lot more early detection of colon cancer.

Years ago breast cancer was stage 3 and 4, most now are TIS or Stage 1. We need more of the same. I encourage the Council to stay fast, get funding to small communities. Funds are amazing. You hear about red tape and hoops, but I see that no money is wasted here. We see it earlier, and frankly most oncologists would prefer getting by on something else if we can get rid of cancer.

In several communities, participants described the introduction of *promotoras* (health promotions outreach workers working within their own communities) and patient navigators into the healthcare continuum as a positive change. These health workers provide much needed services, especially in communities with known health disparities. There was a clear call for more concentrated funding for these kinds of activities.

We see a lot of promotoras going out to the colonias. They're doing an excellent job because it is a female in their community. They are very comfortable with her. The promotoras are very non-threatening. People aren't worried they are going to get reported if they are illegal.

I think the navigators ... are a fantastic use of resources. And we are using what they call promotoras and are getting ready to expand that program to reach outside Hispanic community and doing house parties, anything that we bring a group of women together who do not routinely access services and make them aware of what services are out there.

Patient navigators are also related to the progress [in this area] ... not just the aggressive case management, but the growing acknowledgement and use of lay health advisers or whatever you call them, those facilitators are helping get people from beginning to end and following through. It seems to be something that federal agencies are agreeing to fund now. They are making wonderful progress trying to get to that endpoint.

Continuing Barriers to Early Detection and Treatment

Many challenges remain after early detection. For the majority of participants, the greatest challenge is providing access to care after diagnosis, especially for the uninsured or underinsured. In fact, during the forums, the impulse to dwell on frustration about the serious problems of access to care, prevailed in all groups. The following access issues pervaded forum discussions about early detection and treatment; the quotes selected reflect what many participants said.

- ◆ **Fear of diagnosis because of actual or perceived lack of access to treatment options after diagnosis.**

I have a colorectal grant here in the Valley that is for help raising the awareness level for the people as to what colorectal cancer is and try and find resources for them to go. So they can, with their limited insurance, be screened and diagnosed and treated. And the major problem that we are finding is when people finally let us talk about it, it is where can we go and get it for free?

- ◆ **Disparities in treatment options for the uninsured, those with Medicaid/Medicare or those who live in medically underserved areas.**

If we do a huge outreach to all these people in the whole wide world in Texas whatever it may be, then you are going to open a whole new can of worms because they are going to be diagnosed early but there'll be no way to treat all these people. So it is kind of a Catch-22.

I mean our surgeon that does breast biopsies and localizations. We have a six-month waiting list for those needle localizations and we have 213 people just waiting to get an appointment. So we have women with abnormal mammograms that we are looking at waiting sometimes up to a year.

Going forward is very difficult when you are talking about 78,000 uninsured in the community. Where are they supposed to get the care? How can you afford to provide the care at a cost to the facility or a cost to the doctor?

Underserved, majority are in latter stages, simply because many hear they have a problem, need a biopsy, they need \$500. They go home until they're in last stages of cancer.

....we are in rural east Texas, and we get those patients unfortunately on hospice who are at their last stage. And they could have received treatment, and had some sort of intervention, had they known who to go to what area to be directed toward.

- ◆ **Disparity includes access to clinical trials.** Some participants working directly in cancer care remarked that clinical trials are often open only to those with certain kinds of health insurance. As drugs reach the approval stage, the drug companies want to enroll paying patients. Participants suggested that this disparity should be noted and acted upon if possible.

Clinical research trials...are getting harder and harder to come by. We have huge clinical research, but the issue I am hearing from so many people is that unless you have the ability to pay for yourself, you are not a candidate. Insurance will not pay for it.

- ◆ **Even if care is accessible, many patients and healthcare providers don't know it.** The fact that Medicaid now pays for treatment after screening from a BCCCP program is unknown to some, including healthcare providers. One surgeon was dismayed to learn that he had turned away patients seeking his services who would have qualified for care under the Medicaid Treatment Act. The following exchange between two participants illustrates the concern expressed by many about making people aware of expanded access opportunities.

Participant 1: With Medicaid Treatment Act, they get it immediately for BCCCP, it has been so important. In the past, women didn't want

to know because they couldn't do anything about it. Now we can do something about it. They need to know treatment is there if they're diagnosed.

Participant 2: So many who don't know about it have no clue about it.

Participant 1: I haven't done press releases to put it out because I didn't have enough money to do mammograms for women. We're coming up for competitive bid, and I'm trying to get all the money I can. We serve a lot of under and uninsured. That population is growing.

For example, in Smith County we have the Komen grant plus the BCCCP and depending on which program they are in, if they get diagnosed with one, and the services end, they cannot jump to the other. So it is a Catch-22 and you get locked in. Another gap is a surgeon will call, or a gynecologist will call, [and say] "I have this lady here I have just done a biopsy and she has breast cancer or cervical cancer," and we (BCCCP) can't take them because it is too late. You have to be diagnosed through the funded program.

◆ **Family practitioners do not consistently advocate for screening.**

We just need more, if anything I would say we need more in the way of public awareness and professional education to get people on board for the screenings. We can prevent so many deaths.

I would say that general practitioners need a little more education on cancer.

We have been working our butts off for colorectal cancer screening with the hospital and ... [is] doing all that she can to educate as many people as we can, but we can't do it without physicians and that is where a big hole is. Because they go back to their primary care provider and they say, hey, I heard this on the radio. I heard this talk and they said I need screenings and that physician goes, 'Don't worry,' checks the card, that's it. A lot of these guys don't even know what the requirements are...

Recommendations for Early Detection and Treatment

Conduct outreach and education for minority populations on screening and diagnosis, with information about access to treatment for those with a cancer diagnosis (e.g. funding for treatment if screened by BCCCP).

Increase funding for patient navigator and *promotora* programs.

Increase funding for diagnosis and treatment infrastructure (esp. in places with long waiting periods and few providers/or those who will accept Medicaid).

[The] community needs to be educated about values of early detection. Put it in dollars and cents, show the bottom line. That's how decisions are made, net bottom line. It shouldn't be, but decisions are made that way.

What if you encourage local community health councils, patterned after state council to bring all players together to address the disparity. Funding is only going to go down if Medicare is the marker; you're going to have to address it locally with state guidance. There is going to have to be more "tithing" to explore additional ways to fund free care.

Promote continued education to primary care physicians to recommend routine cancer screening for their patients.

Professional Education and Practice

Professional Education and Practice Progress Since 1998

Huge strides in technological capability to disseminate information through the Internet, teleconferencing, and other innovations have led to tremendous progress in the area of professional education and practice since 1998. The Nurse Oncology Education Program (NOEP) in particular, and also the Physician Oncology Education Program (POEP) received high marks from many participants who are part of their target audiences.

Respondent #1: The programs are great. I think the only issue is they cannot be everywhere. In the rural area with a nursing shortage, if you do not have a NOEP program right there in your hospital there's not much chance that those nurses are going to get the time off to go to it. That is just the reality of nursing today, that people are just very shorthanded and cannot get off.

Respondent #2: But NOEP looks for places to post their workshops, if you have that demand in your area, they will set it up. They did that with me one time...they did a good job and they had a full house.

The best program for education is funded by the Cancer Council which is the Physician Oncology Education Program.The problem is finding local hosts and getting people to get the doctors together to have the programs. That is really the limiting factor.

Barriers to Continuing Education

Most agree that they have ample access to educational opportunities, and that NOEP and POEP programs are well constructed. However, nurses and doctors still face barriers to continuing education. Barriers mentioned in multiple forums centered on time, motivation, cost and access to the necessary technologies.

Nurses and doctors can't go offsite. They're looking for easy access. I heard yesterday that sometimes people don't take advantage. People don't know where to find it. It's getting easier to find what you need, but not real easy yet. Make it more accessible to rural areas.

If hospitals can't offer distance learning, several colleges will offer it at night, or when it is convenient. We have a nursing coalition for rural counties, and they're working together on diabetes education, but they're also trying to increase their knowledge. Distance learning is an option.

I think what happens is that people are busy, but it is required to maintain a license, right? So what usually happens is people will be late, delay and delay it, and when they're going to reapply for the license, one month before they decide, how? I don't have that. They pick up the phone and see that there is a big conference in Corpus Christi. And people go there for two or three days...They just do it because it is the requisite, and you have to do it to maintain a license.

You take an hour for lunch and by the time you get back, it's over an hour. Yes, you have to take it on your free time. It is not included as part of your work. Nobody pays, nobody covers it.

While many Internet options are available for continuing education credits, many participants agreed that doctors are more likely than nurses to use that learning option, with nurses often preferring face-to-face educational opportunities. Others mentioned that the wide choice of Internet and electronic options were of questionable value, and felt that they should be monitored for accuracy and timeliness.

A lot of what is on the Web is old or outdated. I wish a group like POEP or NOEP could jury what is on the Web so we know if it is good or not.

Recommendations for Professional Education and Practice

Most participants who were healthcare providers expressed relative satisfaction with the opportunities for continuing education available to them. Most participant recommendations pertained to other professionals working in ancillary fields. In addition to general and family practitioners, mid- to lower-level healthcare providers, such as physician assistants, licensed vocational nurses, school nurses and medical assistants were recommended targets for additional education. Professionals like teachers, social workers and community-based outreach workers were also included in the list of those who could join the cancer control effort, particularly in the areas of Prevention and Information Services and Early Detection and Treatment. Their recommendations include:

Educate General/Family Practitioners and provide them with tools to assess risk. Enhancing the general or family practitioner's ability to promote cancer prevention, information and screening efforts was considered an important area for activity. Some participants recommended that practitioners should be paid for prevention to encourage their support. They also suggested the creation of risk assessment forms for use during annual check-ups. Educational efforts

should encourage them to be more consistent in recommending screening, and also in follow-up with patients to ensure that they actually do receive screening.

Primary care physicians, they are the gatekeepers not just for HMOs but for patients, and it really has to be up to them to do the screening to keep up with the screening to make sure that it gets done. And you talk about funding that is not something that, as a family physician that is going to put them out of pocket. Males beginning at 50 years old there are two things you have to worry about; prostate cancer and colorectal cancer screening and those things won't cost a physician anything. And if anything if they just educate the person and their patients, I mean they're going to send those out to have their screenings done or they are going to do the hemacult cards, which is nothing. So those screenings can be done, but it is definitely neglected, and that is probably the biggest gap we have.

Participant #1: There are so many checklists. It would be great if the Cancer Council gave health information sheets to give to MD's and supplied it. I wonder if they would use it. Would they pull it off the Web? Will they print it out?

Participant #2: A lot of that stuff has been tried, and there are a lot of barriers to getting it to work. Not the least of which is there is no reimbursement for preventive care. Everyone agrees it should happen, but there are a lot of reasons why it doesn't happen.

I think the primary care physicians, everybody's impacted by cancer not just the oncologist and there is so much for primary care doctors to know about that I think it is overwhelming, but everybody works with cancer patients particularly in small communities where we are in very rural areas, sometimes that primary care doctor is that main doctor for that patient.

I think for those who will not get access to go back and see their oncology specialist for checks, we need better education for primary care physicians for signs and symptoms. I cannot tell you how many breast cancer patients have recurred. They had pain and their primary caregiver told them it was arthritis. The physician missed the early warning signs of a recurrence.

Provide cancer screening and treatment education for mid-to-lower level healthcare professionals.

There is a group of mid-level providers and practitioners physician assistants, who do a lot of preventive care. That is an additional avenue for enhancing education practice, nurse practitioners. You know, some offices are set up with the physician to see the more seriously ill and the mid-level to see more of the preventive care. I guess what I'm saying is that they do not need special materials. They probably just need special attention.

I'm having trouble locating it [continuing education] for the lower levels like medical aides and PA's. It is not just about getting credit. It is also about finding things that are kind of important.

Professional education should reach beyond doctors and nurses to LVN's and school nurses and promotoras.

School nurses ... are really the health champions of their school. Sometimes they are the only person in their school who is mentioning anything that has to do with health. A lot of times they are just looked at as, hey hey, this is not a priority. I really look for continuing education priorities to offer school nurses on various topics.

Provide educational opportunities for professionals from other disciplines, such as educators, social workers, or community-based workers, to learn about cancer prevention and information so that they can more fully participate in prevention and early screening initiatives.

I think one of the areas that is missing is that we have physicians, we have nurses, but there is no social work. In Texas that is not just a priority and you cannot deal with a cancer patient and not deal with their psychosocial issues. It is a big gap that we have and that is not a priority in Texas for us to deal with those psychosocial issues. Social workers are in a lot of these areas, especially the Metro areas, but, the AOSW, the Association of Oncology Social Workers is the only group that is really specialized for social workers. They have a national conference that we can go to, but there is nothing in Texas that you can go to get your continuing education on oncology.....what I was thinking about is when NOEP came down to do our workshop, everything was geared toward medical. It would be great if it had been some credits allowed for social work.

As far as the [Education] Region Service Center, a catalog goes out with our offerings to every single campus. So that campus has the opportunity to come for professional development. If you want screening, every school nurse within the Region could have the opportunity to have access to that professional development. Plus we have a website, and we have a list serve.

Provide communities with templates and training for implementing a team approach to managing a cancer diagnosis. During discussions about the various roles medical and non-medical professionals play in the overall picture of cancer control, it emerged that some communities desire and need training and technical assistance in implementing a team approach. Metropolitan areas with large cancer centers tend to already integrate a team approach. Anecdotally, it appeared that in some small forum communities, where clear leadership and vision were evident, a team approach happened organically. However, in communities with competing hospitals or lack of a safety net hospital, little had taken place to encourage the team approach.

As a patient advocate, I got into a discussion with the recovery nurse the other day. I could not understand the faxed x-ray reports and so I said, "He wants to know if the patient can go to the floor." I was looking and I cannot read the report and he said, "Well neither can I." Well, how am I going to decide? Could you call the radiologist and find out? Well, why don't you do that? I hit the roof. Don't you care? ... Why call it a healthcare team if you are not functioning as a team?

...on basic cancer stuff, of working on patients with cancer and deciding what to do with them with a group of people deciding, instead of whoever gets to them first. If the radiation therapy guy gets them first, then he got them, man. If the surgeon gets them first, then out it comes.

Provide continuing education opportunities about pain. A number of forum participants mentioned that healthcare professionals need training in pain management. The following quote illustrates the sentiment of many.

The pain portion of that is still terrible...All treatment, adequate treatment of pain, which is one of the components of palliative care is still a big issue. Nausea and stuff with chemotherapy has gotten better with some of the newer drugs, but some of the newer drugs insurance companies do not pay for.

Cancer Data and Planning

“The Catch 22”: The Need for Accurate and Timely Data

Without accurate data how can we prove that we are making a difference or that there is a problem?

Generally, people don't understand why data gathering is so important.

These two quotes illustrate the two directions taken in community forum discussions about cancer data. There was general agreement that while the Registry has improved, it is still not adequate to meet the needs of the cancer control community. For those seeking funding or looking for specific information to better serve their population, the lack of accurate data is a continuing source of frustration.

I can tell you we are so delayed on statistics that it is very difficult. If you lack that information it is very difficult to try to get grants and to try to get people to give monetary help. I've got to tell you it is very discouraging to do research nowadays... if you do not have the data to actually say, "This is a problem," it is very difficult to convince NIH and federal type of funding to come in and help you, or even a philanthropy type of foundation.

I depend on data because I have to show how many screens were done, what the cancer rate is in the final project we submit to TCC, I go over to the Registry and I get information on accounting. The only problem with that is, it is not current, it is about a year or two years past time.

Trying to get the Registry up to speed is very important because a lot of research funding that potentially could come to the state is contingent upon having accurate and up-to-date data. That's kind of the Catch-22. If we can do more research, and could fund the Registry better, but we cannot do more research because the Registry is not working. Bridging that gap has been sort of the sticking point.

I'll give you another Catch-22 on this. If you have done a good job of increasing awareness and getting people to get screens, it is going to show that you are having a higher incidence, that you are not reducing the rate. You're showing increases because more people are going to get screens so you are not doing your job of decreasing the rate of cancer.

Local communities need local data. The need for localized data specifically emerged in several forums. At least one community had its own “rogue” statistician, who had gathered cancer data and catalogued it by zip code in his home town. Most, however, find the scarcity of accurate data a problem.

It's an issue trying to get the number of reports that are distributed throughout the state up to mid-level, to get their systems so that they can report it quickly to identify patients proactively through new mechanisms and through pathology reports and through other reports before they are reported on death certificates.

It's difficult to get data reported on a local level. It is so broad you may have it for the state, but if someone is seeking funding for the community those statistics are not helpful. It would be great if we can get that wonderful data somehow available on more local level.

The Texas-Mexico border presents unique challenges in data gathering.

The porous nature of the border area and the free flow of the population from healthcare provider to healthcare provider across borders offer unique challenges for those providers. This challenge is augmented by migrant workers who not only go from country to country, but from state to state within the United States.

As far as data, the Rio Grande Valley is a very difficult area to find correct data, because we have so many people from Mexico. We do not know how many people really do have breast cancer. And we have people that migrate to the North.

We are taking care of two countries and that makes it very difficult to collect the data.

Planning

The negative impact of inadequate data on local planning was often described.. Inasmuch as the lack of data is a planning issue, so is the perceived lack of resources available for communities to coalesce to assess their needs in cancer control, and plan accordingly. Anecdotally, moderators noted the end-of-forum “card swaps” as the precursors to additional meetings where community needs assessment and planning could take place: the seeds for local cancer control coalitions.

Recommendations for Cancer Data and Planning

Improve the quality and timeliness of cancer data through training. Overall, those who had a grasp of the issue expressed the need for training for more registrars.

Collection of data is only as good as those that are providing it.

Certify local data registries. Local registry sites with highly trained registrars increase the likelihood that local data can be gathered more systematically and with more accuracy.

...hospitals could be certified as a Registry site or try and get that certification-that they are certified Registry Center....and part of that could be that the people who are doing your tumor registry have to be certified people.

Provide a “Guide to Local Planning,” or adapt the American Cancer Society’s E-Tool to the Texas Cancer Plan. The idea of local collaboration and information sharing emerged to different degrees at each forum. In some locations, collaboration is already happening; in others, it is not. Tools for community needs assessment, a galvanizing force for community organization around the issue of cancer control, and actual coalition building are areas that were touched upon and agreed to be desirable. Only one forum discussed the existence of the American Cancer Society “E-Tool.” For the most part, the E-tool and its uses remain untapped. Many participants were unaware of its existence, even though it seems that it could answer some of the needs expressed. This lack of awareness among participants could possibly be explained by the fact that the E-Tool is disseminated through local ACS chapters to volunteers, and these forums were populated largely by professionals. In addition to a tool for community needs assessment, the need for a template for forming local cancer control coalitions was evident, as was the strong call for technical assistance from the Texas Cancer Council in the area of advocacy both at a state and local level.

Because these gaps are going to be bigger, funding is going to go down if the Medicare system is any marker for how healthcare funds, so it is going to go down. You’re going to take on more of these things locally with direction from state agencies or federal agencies but there is going to have to be more giving in the community of healthcare. You are going to have to get more, or everybody's going to lose. So I think patterning some type of local community council to address these issues is important.

Survivorship

A diagnosis of cancer is not immediate death. You know, because that is still what is thought out there. It needs to be known that research is there, the treatment is there, hope is there. Cancer is not a death sentence.

The updated *Texas Cancer Plan* will include a new goal area of survivorship. The Lance Armstrong Foundation defines survivorship as “living with, through and beyond cancer.” According to forum participants, cancer survivorship begins with diagnosis. A cancer patient in treatment is a survivor; a patient in remission is a survivor. Medical advancements in the treatment of cancer mean there are more long-term cancer survivors. More and more children survive cancer and grow to adulthood, and face issues as they plan their families. While some survivors are cured, others face end-of-life issues and their families need support.

The faces of survivorship are diverse, and their issues are unique. Participants in these forums, particularly those working in hospice, social work or medical ethics, talked about topics ranging from palliative care and pain management for those at end-of-life (see section on Professional Education), to housing and hospice. Those in treatment may need assistance in navigating the system (see section on Early Detection & Treatment); frequent changes in health insurance often disrupt the continuity of care. Long-term survivors may have difficulty getting or keeping health insurance. And all survivor families need support, whether they face end-of-life or treatment issues, or whether after the death of a loved one they need help in assessing their own genetic risk.

The following areas were mentioned by forum participants as those worthy of consideration for the formation of objectives and strategies corresponding to the goal of survivorship.

Recommendations for Survivorship

Provide survivors with knowledge of resources about how to survive, with additional emphasis on the psychosocial aspects of survivorship. Forum participants discussed the need for cancer patients to know what resources there are to make the journey through treatment easier and to enhance the quality of life. Clinical drug trials (see Section on Early Detection and Treatment), mental health care, pain management, and advice about exercise and nutrition, are all resources that people need to know about.

I do agree that we need psychosocial services for cancer patients from diagnosis all the way to after treatment and end-of-life. I think that is one of the shortfalls that we do have in this community.

I have been looking at this thing [the Plan] all weekend and there is a huge gap because it does not mention psychosocial issues. You cannot deal with cancer and not deal with psychosocial issues, mental health, emotional and financial.

I think living with cancer is something that is so important, because you know, just trying to let them live as normal a life as possible. You know, letting them go about their daily activities while living with cancer, so that everything doesn't come to a screeching halt. Try to help them cope and keep on going.

If you're in so much pain, you're not really living. There has to be attention to surviving. It can go into remission one time, and if they never go back to get it checked, it can recur. People need continuous treatment.

You have some psychological effects that go along with cancer patients. I think that is one of the biggest issues as far as survivorship. Improving the quality of life and letting them know that there are resources that are available to them for patient services after their treatment is over.

...Their dietary habits change, their taste buds change so, here are some recipes to change things and also what physical activities are still important and try and keep up to the best of your ability.

You have to be with patients, mind, body and spirit...hospice does that very well. Mentally, what is in their minds, what do they see and feel physically. The nutrition, the diet, the quality of life, it all has to be dealt with. A lot of times, we deal with one or two components, and leave one or two out. It has to be complete.

Expand opportunities and reduce barriers to participating in support groups.

In rural and border areas especially, some forum participants talked about the difficulty of getting people to attend support groups. For some, transportation is an issue; for others, the hospital or office environment is not as comfortable as a neighborhood setting or a church, among peers.

Most support groups are going to be at a hospital or the American Cancer Society, and a lot of these people can't get there...I would like

to see materials developed that laypersons can use, volunteers or paraprofessionals, because we can go to people's homes. Flip charts and things like that.

Support groups reach a small number of people in a limited amount of time. You want to get out there and promote to the whole public the idea of survivorship.

They need to have support groups of their own age. Some of them want to be able to have a family and they want to let it be known that there is a possibility that the treatment is going to make them sterile...This is a whole new concept, and these young survivors are different than the older cancer survivors. So we have many levels of survivorship, and some of them haven't been touched.

Provide survivors with information on the long-term economic impact of cancer. Living with and through cancer impacts a person's long-term economic situation. The costs of medications and continued screenings, coupled with the difficulty in obtaining health insurance after a cancer diagnosis, may be compounded by a disruption in the continuity of care that often results at the very least, from changes in insurance after cancer. Forum participants discussed these issues, and recommended that information be more readily available.

What is the cost of survivorship? I mean, for the families with the economic factors? Medication, additional exams and indirect costs.

If you are diagnosed with cancer, a lot of people really do not want to know a lot of these things because it affects the insurance coverage. There are people who are out there that are really scared of this information. But when people are looking and seeking medical insurance, they can say, you know that if you have this, forget it. You have all these complications. I'm not going to insure you.

They are stuck with their job, if they're lucky enough to have had one and kept it, because they are certainly not going to get insurance anywhere else, or their insurance is dropping them. So that's an issue, too.

...continuity of care is an issue too. The primary healthcare provider is not the same person for a long time now, people switch insurance companies all the time now and doctors drop on and off the plans. You may be on the fifth physician on that plan in two years.

Target information on survivorship for age-specific groups, including young people and children. In several forums, participants noted the high rate of survivorship among children, and discussed the implications for cancer survivors who grow to adulthood.

I just met with the young coalition survivors group. And those are people under the age of 30 that have survived generally breast and cervical cancer and their needs are very different because they said for a five-year survival rate means nothing to them. So they're going to be 31. It's a whole lot different someone that is 55 five years along the way. So their needs have not even really been introduced.

About 60% of kids who are treated with cancer survive. Of all the groups they have the highest survival rate. These kids are having issues with education access to teachers that they need and the different set of services.

What about collecting data? Long-term effects of cancer treatment. As we have more children survivors now, I would suspect that things may crop up that we haven't known about in the past that are a result of the therapies.

Provide families with education about a wide range of issues relating to supporting a family member with cancer, from how to make end-of-life decisions to risk assessment for future generations. As previously discussed in the section of this report detailing Early Diagnosis and Treatment, lacking proper information about cancer care or the realities of a diagnosis, many family members of cancer patients cannot offer the most appropriate support to their loved ones. Some forum participants discussed how this lack of information, together with cultural beliefs or norms, can lead to additional suffering for patients and their families.

We still get calls from family members two, three, four years after a loved one has died and they are still going through it in their heads, you know, "What is new in lung cancer treatment? My husband died four years ago and I was wondering" They are stuck. "What could I have done differently? What about my kids? What does this mean to them? What should I be telling them? Are they at risk? Should we have our genes tested?"

You also need to include the whole family. Especially the spouse or partner and for children the parents. A lot of times we forget about the support system but the support system will affect the patient potentially.

One of the problems we have with educating our dying patients and families is that for the physician it is very overwhelming and time-consuming because ... each of the individuals wants to speak to the doctor, all 20 family members, and sometimes we can't do that. The other thing is that we tell the families and immediately they say, well, "He doesn't know what he's doing, he does not know my mom or my dad, can we transfer to Houston or San Antonio?"

Help healthcare providers, patients and families understand genetic implications of cancer and know how to assess risk for the family. In a few forums, visionaries who monitor the progress in human genome mapping and/or who have fielded enough questions from studious patients and families or the press, mentioned a concern that as knowledge of genetic risk becomes part of popular science and current events, more and more questions will arise about genetics and risk. In the view of these participants, healthcare providers in general need to be prepared to answer these questions.

The other concern we have is, especially with the genome project, everybody is wondering; well, what does this mean to my kids. So the genetic implications of cancer in cancer survivorship are very important.

So that family is aware of where these cancers are showing up and what generations and what degree of relations. And that could probably tie in with the genealogy. It is going in the Cancer Registry.

There is a message for the public and I think it is just to keep it in perspective that only five to 10% of cancers have a strong inherited component. But it is very important for everybody to keep as accurate a family health tree as they can. Who had what? And when? And that is something they can start in school. That information is something that needs to be discussed with their personal healthcare provider to decide if there is a risk or not.

Health Disparities

The burden of cancer is unequally borne by different population groups in the United States. African-American men are twice as likely to die from prostate cancer than white men. African-American and Hispanic women have higher death rates from cervical cancer. People from lower socioeconomic status have higher death rates than those with means. Social position, economic status, literacy level and environment will impact health throughout the life of an individual.

The fact and consequences of health disparities among Texans who happen to be lower income Hispanic or African-American, or who happen to reside in remote rural areas that are medically underserved, or of any ethnicity who possess lower literacy skills, and above all, who may have the misfortune of being uninsured or underinsured, rang clearly throughout these forums. Whether articulated or labeled “health disparities,” or not, the consequences are the same. Participants agree that those with the least access to information need it the most; those with least access to healthcare are less likely to be screened for cancer or to have the benefit of early detection. Once diagnosed, they have the poorest prospect of survival and the greatest loss of quality of life. Many of their recommendations in all goal areas address health disparities.

One of the most obvious causes of health disparities in Texas is the lack of health insurance or access to affordable care. This is a problem that cannot be solved without a willingness to acknowledge it. With limited funding for Medicare, Medicaid and the Children’s Health Insurance Program, programs created to ensure that most lower income Texans have access to health care, communities must band together to take responsibility for their most vulnerable citizens. If the Texas Cancer Council and the Texas Comprehensive Cancer Control Coalition want to reduce health disparities, they must find a way to educate the public and the legislature about the devastating cost in lost potential and human suffering in failing to address these pressing issues. To bridge the gap, effectively, strong advocacy is not optional; it is required.

Every goal of the *Texas Cancer Plan*, including survivorship, holds potential for designing objectives and strategies to address health disparities. “Addressing Health Disparities,” is not a separate goal area in and of itself. Like malignancy, health disparities spread to every area touched, and like a malignancy, must be treated aggressively.

Implications of These Findings for the Texas Comprehensive Cancer Control Coalition

While it was somewhat beyond the scope of these community forums, this report's findings have some fortuitous implications for the Texas Comprehensive Cancer Control Coalition, funded by a grant from the Centers for Disease Control and the Texas Department of Health, and managed by the Texas Cancer Council and its subcontractors, who also authored this report. Concepts emerged that can help guide the Texas Comprehensive Cancer Control Coalition as it seeks to encourage collaboration, strengthen its role in statewide cancer control, and further define its purpose.

In an anonymous survey at the end of each forum, participants were asked how useful they thought the *Texas Cancer Plan* would be to their local efforts. Of the 90 responding participants, fifty-seven percent (57%) said it would be very useful; twenty-four (24%) responded that it would be somewhat useful. Few if any thought the *Plan*, in any form, was irrelevant. Given that almost fifty-eight percent (58%) of these 90 participants had either never seen the *Plan* or had little familiarity with it, and that they all thought it would be useful, the Texas Cancer Council, with the help of the Coalition, needs to ensure that the updated *Plan* is distributed as widely as possible throughout the State of Texas.

Anecdotally it was noted that participants who did not previously know each other often lingered after the sessions had ended and planned to continue their discussion. The meeting was acknowledged by many as a positive development, and one that should continue for the purposes of networking, sharing information, team building and when needed, advocacy. The etchings of local replications of the Texas Comprehensive Cancer Control Coalition became obvious.

Recommendations for Enhancing the Texas Comprehensive Cancer Control Coalition

- 1) Ensure that the *Texas Cancer Plan* is distributed widely and in a targeted way to all Texas cancer control communities.**
- 2) Spread the state coalition model to local communities.** Provide technical support in the way of a trainer, a tool kit and a written guide that enables local cancer control professionals to build a local cancer control coalition. The eight communities visited could represent the seeds of the first local coalitions.

3) Provide local coalition representatives with an annual statewide forum. The Texas Comprehensive Cancer Control Coalition should sponsor an annual summit of cancer control representatives from local coalitions for the purposes of networking, information sharing and assistance with advocacy.

4) Enhance Texas Comprehensive Cancer Control Coalition membership with local representation that matches the ethnic and geographic diversity of Texas. Local “stand-outs,” visionaries or strong voices for the underserved should be tapped to become members of the state coalition. At least one state Coalition spot, and possibly more, should be dedicated to ensuring that these voices become part of all the discussions.

Appendix A Invitation to Forums



March 25, 2004

Dear Dr. Foxhall,

Because you have been identified as a strong voice for cancer control in your community, you are cordially invited to participate in a facilitated discussion about the *2004 Texas Cancer Plan*, on Wednesday, March 31, 11:00 a.m.– 1:00 p.m. at the Hendrick Medical Center on 2000 Pine Street in Abilene. Lunch will be provided.

This facilitated discussion is sponsored by the Texas Cancer Council and supported by the Texas Cancer Control Coalition. Our discussion will heavily focus on ways in which the 1998 *Texas Cancer Plan* has worked to this point and how it should be revised to reflect new information and trends in cancer control. If you have not had the opportunity to familiarize yourself with the 1998 *Plan*, we would like to suggest that you review it prior to the meeting. A copy of the report is enclosed for your convenience.

Our mission at the Texas Cancer Council is to reduce the human and economic impact of cancer on Texans. We achieve our objectives through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control. As the agency mandated by the Texas Legislature to develop and implement the *Texas Cancer Plan*, we provide cancer control stakeholders with a definitive roadmap to guide statewide cancer control activities. To produce a relevant *Plan* that can be implemented to reduce the cancer burden in Texas, we need to hear the voices of those on the front lines in the fight to control – and ultimately conquer – cancer.

Meetings will be facilitated by professional moderators from SUMA/Orchard Social Marketing, Inc. You may expect a telephone call in the very near future from their staff to confirm your participation. Should you be unable to attend, we request that you designate another individual to attend in your stead.

We look forward to meeting you and to hearing your ideas on March 31 as we work together on our *Plan* to conquer cancer.

Sincerely yours,

Mickey L. Jacobs
Executive Director, Texas Cancer Council

Lewis Foxhall, M.D.
Chair, Comprehensive Cancer Control Coalition

Appendix B
LEND YOUR VOICE TO THE TEXAS CANCER PLAN 2004
TEXAS CANCER COUNCIL
GUIDE FOR COMMUNITY FORUMS

Introduction to the Discussion

(The following introduction may be offered by TCC staff member present at the forum or, if a staff member is not present, by a TCC Board member. If Staff or Board Member from TCC is not present, the moderator must read the following script prior to starting the discussion in order to convey the weight and uniqueness of the task at hand.)

Why are we here? The Texas Cancer Council is a state agency whose sole mission and reason for being is to reduce the human and economic impact of cancer on Texans. The Council achieves its objectives through the promotion and support of collaborative, innovative, and effective programs and policies for cancer prevention and control. The roadmap used to guide these activities is *Texas Cancer Plan*. By state legislative mandate, the Texas Cancer Council is charged with the very critical task of developing and implementing the *Plan* and keeping it current. You are here today to lend your ideas and your voice to that effort.

Why is this important? Quite simply, the Texas Cancer Council's decisions regarding the cancer control activities it chooses to recommend, promote, fund, implement or support are **very strongly guided** by the roadmap provided by the *Plan*. For that reason, the Council values cancer data and the voices of people like you, who are experienced and dedicated to cancer control. The *Plan* will be written with a strong regard for empirical cancer data and also for the spoken ideas and directions known to be so critical to our success by those of you who are "where the rubber meets the road."

Finally: While the Texas Cancer Council is responsible to the executive and legislative branches of state government, its ultimate responsibility is to all Texas citizens. Through its funded initiatives and programs, we strive to efficiently and effectively apply allocated funds to reducing the human and economic impact of cancer on Texans. The Council also responds rapidly to the requirements and needs of the Governor and Texas Legislature.

We thank you for your participation. We would like to honor your time, and so as your moderators, we may occasionally redirect conversations in order to stay on task. In order to insure that everyone feels comfortable, we ask that you follow a few basic ground rules.

I. Introduction of Texas Cancer Council/Process

Ground rules: Our goal here today is to gather input from cancer control professionals about two things: the state of cancer control in Laredo and surrounding areas, and your input into the next *Texas Cancer Plan*.

- ◆ Time is short; you are busy; we want to honor your time. A few ground rules will help.
- ◆ We will guide you through the discussion with a prepared guide. We will designate approximately 15 minutes to each area under discussion. Susan will be our time keeper and if she stands up, watch out.
- ◆ We ask that you speak one at a time, and with respect for one another should you disagree. Please limit side conversations.
- ◆ A stronger cancer plan will result from an honest and open discussion. Please feel free to speak your honest opinion.
- ◆ Restrooms are....

II. Introduction of Participants/Icebreaker (10 minutes)

*(On the flipchart or board, a table should be drawn with the following categories: **Prevention & Information, Early Detection, Professional Education, Cancer Data & Planning, and Survivorship**. Response to the question of what is perceived to be the greatest need for cancer control should be categorized under one of these areas).*

- ◆ Please tell us who you are, your role in cancer control and recognizing that there is never enough funding, tell us the thing you perceive to be the greatest need for cancer control—other than money--in your community.

(After each participant has introduced him/herself, moderator should recap the areas of need perceived by the group and draw broad consensus).

III. Discussion of Goal I: Prevention Information and Services

Direct people to page 11. Recap aloud what the objectives and strategies have been. More funded efforts to prevent tobacco have occurred, along with progress in awareness of good nutrition and state mandated physical activity. Progress is being made in obesity prevention and sun safety.

- ◆ What has happened in your community?

- ◆ What needs to happen to meet the goal of greater information about prevention?

IV. Discussion of Goal II: Early Detection and Treatment

Direct people to page 69; recap the objectives and strategies. More resources have been designated for mammography and colorectal cancer. We know that early detection can mean a higher survival rate because cancer is arrested at a time when it is more treatable. We also have seen progress with physicians managing cancer as a chronic disease, rather than a death sentence.

- ◆ What progress has been made in the community in this area?
- ◆ What still needs to happen to meet the goal of early detection & treatment?

V. Discussion of Goal III: Professional Education and Practice

Turn to p. 111 and recap. As you know, many new advances have been made in the technological capability to offer and receive continuing education. Online conferences, satellite conferencing technologies and distance learning have all increased.

- ◆ By a show of hands, how many are required to receive continuing education?
- ◆ How many provide that education, or supervise folks who need it?
- ◆ What barriers exist to receiving continuing education?

VI. Discussion of Goal IV: Cancer Data and Planning

Please turn to 141; recap. Since 1998, awareness has grown about the importance of the Registry data. There are several groups of concerned people currently out there trying to get more money for cancer data, including the American Cancer Society, our Health Commissioner Dr. Eduardo Sanchez, and others who are trying to get a tobacco tax designated for data keeping. You may also know that there is a new unfunded mandate to improve record keeping.

- ◆ How are you affected by data in your work?
- ◆ What access do you have to local data?
- ◆ What information do you have about replicating and disseminating similar programs?
- ◆ Thinking about the second objective, planning, what has happened here and in surrounding areas with regard to community-based planning for cancer control?
- ◆ What do you think needs to happen?

VII. Survivorship

For the next *Plan*, survivorship will become its own goal. The Texas Cancer Council has borrowed the words from the Lance Armstrong Foundation in that the goal is to live with, through and beyond cancer.

- ◆ Overall, what should the objectives be for survivorship?
- ◆ What would be some ways to reach those goals?

VIII. Conclusion

The Texas Cancer Control Coalition is an organization of cancer control providers seeking ways to fight cancer in cooperation or collaboration with each other. Membership costs nothing. Active membership includes quarterly meetings to help participants create opportunities for cooperation. Associate membership offers access to information and networking through mailing and the Coalition e-newsletter. (Pass out sign-up sheet)

Thank you for your time.

Appendix C

Anonymous Forum Participant Survey

Thank you for your participation in today's discussion about the 2004 Texas Cancer Plan. We appreciate your taking a few extra moments to answer these questions. Answers are anonymous and confidential. Your honesty is greatly appreciated.

1. Please estimate the hours you donated in support of this project, including time spent reviewing the *plan*, travel to meetings, and time in attendance here today.

2. Choose the best description of your knowledge of the *Texas Cancer Plan* prior to being invited to this meeting.

I had never heard of it or seen it before.

I have seen it and skimmed through it in the past, but was not all that familiar with it.

I was very familiar with the *Plan*.

I have been part of efforts that have used the *Plan* in our local planning and budgeting.

Other _____

3. After reviewing the *Plan* and participating in this discussion, how useful do you believe this document could be to your local cancer control efforts?

Very useful

Somewhat useful

Not very useful

Irrelevant

Please feel free to add your comments or suggestions for creating a useful and relevant *Texas Cancer Plan*.



Appendix D Recording Instrument

GOAL 1: PREVENTION AND INFORMATION SERVICES

OBJECTIVE	PROGRESS SINCE 1998	POTENTIAL NEW ADDITIONS
Increase availability & effectiveness of materials & programs		
Encourage children to adopt risk reduction habits		
Promote policies & programs aimed at reducing tobacco use		
Increase awareness of & protection from carcinogens in the environment		

GOAL 2: EARLY DETECTION AND TREATMENT

OBJECTIVE	PROGRESS SINCE 1998	POTENTIAL NEW ADDITIONS
Increase knowledge of screening & detection services		
Increase access to and use of treatment & services.		
Reduce barriers to services.		
Enhance quality of existing services.		
Enhance regional planning, development & coordination of services.		

GOAL 3: PROFESSIONAL EDUCATION AND PRACTICE

Barriers to professionals gaining continuing education:

OBJECTIVE	PROGRESS SINCE 1998	POTENTIAL NEW ADDITIONS
<p>Enhance health care professionals' knowledge, skills & practices in areas like early detection, telemedicine, training & resource needs.</p>		
<p>Enhance knowledge, skills & practices for cancer care guidelines, alternative & complementary therapies, supportive service referrals, palliative care.</p>		

GOAL 4: CANCER DATA AND PLANNING

Access to data and helpful data that may be missing:

OBJECTIVE	RELEVANCE TODAY	POTENTIAL NEW ADDITIONS
Design & implement a comprehensive data system.		
Ensure the <i>Texas Cancer Plan</i> is useful and up-to-date.		

GOAL 5: SURVIVORSHIP

OBJECTIVES/STRATEGIES FOR REACHING GOALS FOR SURVIVORSHIP