

What Is Happening to Real People: Findings

At each of its seven regional meetings, the Panel posed the question: “*Why don’t all Americans get the best available cancer care?*” The numerous issues, barriers, and contributing factors raised in testimony provided to the Panel by cancer patients and survivors, family caregivers, representatives of state health departments, state and local program administrators and staff, physicians, nurses, hospice providers, outreach workers, advocates, and volunteers fall broadly into two categories—access and information. In addition, behaviors and decision-making by both health care providers and the public that stem from perceived differences among populations and individuals can influence greatly the type and quality of cancer care that people receive.

What Barriers Limit or Prevent Access to Care?

Access barriers include those related to the organization and operation of the health care system itself, financial barriers to care, and physical barriers that reduce or prevent access. These categories are not always mutually exclusive, however. For example, certain barriers that appear to be related to physical distance from care may be mediated by financial factors that have influenced the distribution of health care facilities, resources, and personnel. Speakers at the regional meetings and town halls across the country attested to the complexity and interrelated nature of these cancer care barriers.

System and Financial Barriers

System and financial issues are inextricably linked. Fiscal concerns have shaped, and continue to shape, both the private and public components of the health care delivery system.



“The health care system and reimbursement system is terribly broken...it’s incentivizing

all the wrong behaviors. Preventive care is not reimbursable, really. Outreach is not reimbursable. Procedures are reimbursable...We need a system that fixes the basic overall funding of health care and that’s the key.”

Sharon Anderson, administrator, Delaware

“It is time for the nation’s public health work force to accept responsibility for leadership and coordination in the war on cancer. They should be the hub of activity at state and local levels. Voluntary groups cannot do the job alone.”

Lois J. Hall, screening project director, Ohio



“Every person who dies while we’re looking for care for them, or for whom we find care too

late to make a difference, only makes it more difficult for us to convince the family and friends of the benefits of screening.”

Mawuna Gardesey, administrator, Delaware



“Assistance programs seem to be based on the political popularity of the specific disease...

Once the diagnosis of lymphoma was established for Lucinda, I spent weeks calling programs that offer assistance to people with cancer. One program only assisted people with leukemia. Another, only people with breast cancer. How does one say to a patient, ‘If you had this type of cancer, I could get help for you but I can’t get help for your type of cancer.’”

Susan Garrett, clinical coordinator, Maryland

Issues Related to the Structure and Focus of the Health Care System

Speakers from across the country, including program administrators, providers, and patients, emphasized that the current health care system focuses on acute care over prevention and allocates cancer funding by disease site. Both approaches, they stated, are counterproductive to the provision of comprehensive cancer care and the development of effective cancer control programs.

Currently, public health resources and leadership are insufficient to create consistent community goals and programs for cancer control, including cancer education and cancer prevention. Perhaps the most glaring example in this regard concerns tobacco control; while some states have devoted significant resources to this effort, other state programs are minimal. Early detection programs for cancer are likewise uneven. Nearly every state has a CDC-funded Breast and Cervical Cancer Detection Program, and in some states, adjunctive local programs targeting these cancers. Testimony heard across the country made clear that without Federal funding, few states attempt to screen for other cancers. It also was noted that although the breast and cervical cancer screening programs exist, most are reaching only a small fraction of eligible women. A variety of factors, including funding restrictions and cultural barriers, appear to be responsible for such limited success. States have struggled with the problem of finding funds and providers to pay for the treatment of people whose cancer is diagnosed through Federal government-sponsored screening programs. The Breast and Cervical Cancer Treatment Act of 2000 now provides supplemental Medicaid funding to pay for treating women whose breast or cervical cancer is detected through the CDC-funded screening effort, however, states must apply for and match these funds and some states may elect not to do so. Moreover, people whose cancer is detected through other screening initiatives may still find themselves with diagnosed cancer and no source of treatment.

Several state health department representatives described the difficulty of trying to fashion comprehensive cancer control programs with piecemeal and often tenuous funding. If a state or Federal grant for a particular service program is not renewed, those services are likely to be discontinued unless alternative funding can be found. In addition, each grant comes with its own documentation requirements and restrictions on how the funds may be used, even when multiple grants are from the same agency, such as the CDC.

These restrictions often prevent states and localities from organizing and delivering services in the most logical and cost-effective manner. A few states have funding designated for a comprehensive cancer control program, but these relatively new efforts are not yet well established. Other states indicated that while they have or are developing cancer control plans, no funding has been committed to implementing these plans.

Intervention, demonstration, and other research projects funded by the Federal government, academic centers, foundations, or other private sources further complicate the picture by providing needed services for the three to five year period of the grant, only to disappear when the grant period concludes because provision is seldom made to sustain the program in the community once it has been shown to be beneficial. The community is abruptly faced with a gap in much-needed care, often just as residents have come to trust and depend on the providers of these services. This grant-based funding also hampers efforts to recruit and retain cancer care providers, particularly in underserved areas.

Lack of coordination among public payers was another issue cited repeatedly in discussions of how the health care system itself creates barriers to care. Some patients are eligible for cancer care coverage through more than one program, such as Medicaid, Medicare, the Veterans Administration (VA), and the Indian Health Service (IHS). Administrators of these programs do not appear, as a matter of course, to assist patients in determining how best to access all of the coverage to which they are entitled. In too many cases, according to testimony provided to the Panel, patients are treated like “hot potatoes,” with payers seemingly competing to avoid paying for care. The most consistent examples described involved the IHS; according to a member of the Cheyenne tribe in South Dakota, “*they make sure that when we’re ill and we come to them, that they are a payer of last resort and that we understand that.*” Similarly, a physician related the case of an older veteran who was encouraged to use his Medicare benefits instead of his veteran’s benefits to cover his cancer care. Unable to afford the Medicare Part B premium for all physician and outpatient care, he unwittingly paid out-of-pocket for services that would have been covered under the VA system. Even with Part B coverage, he still would have been subject to a 20 percent copayment not required for the same services under the VA benefit program.

“I had two female friends who in their late 40s died of cancer...both of their husbands were physicians...we complain that poor people sometimes don’t get adequate care, and yet these people were neither poor nor uneducated and they really didn’t get the care they needed. Even the insured and the privileged are not immune to the delay or the misdiagnoses and death.”

Mary Ann Andreis, family caregiver, Rhode Island



“I refinanced my home, which was paid for... I had to sell one of my cars. And it just bankrupted us. I didn’t have any more money. The copayments were so high it ate me up...Yes, I had Medicare and I have Medicare supplement. I’m very grateful that we have. I don’t believe in charging anything that I can’t pay. After I used up all my money then I [felt] like I have to have some help. So I went to Medicaid... I was making too much money. So you have to be almost starving to death before you can get Medicaid.”

Alan Hebert, prostate and colon cancer survivor, Louisiana



“...we don’t accept any money from [Medicare] because when you do that then you get restrictions...

but because we don’t do that we aren’t limited to [the] six months [benefit period]. When someone is dying, they don’t do it on time...Is it life threatening? We’ll help you out. Do we have to leave if you don’t die on time? No, because there’s nobody who is going to slap our hands and say, ‘You didn’t spend our money the right way.’”

Kathleen Dietsch, voluntary hospice provider, Maryland



“My insurance actually will only pay \$5,000 towards my leg...which might be okay if, like,

my leg was amputated from the ankle or something, but since my leg is amputated from the hip, I require a relatively large artificial leg that includes a lot of parts... if we go for the absolute baseline of everything, it’s still \$11,000, and we’re fortunate that we can afford that but we can’t go beyond that, and so that’s kind of discouraging sometimes, not being able to get better equipment that would make it easier for me to walk and more comfortable for me in my day-to-day living.”

Joshua Sundquist, age 17, Wilms tumor survivor, Virginia

For people with employer-sponsored or other private health insurance, fragmentation of care, gatekeepers who control access to screening and specialists, and limitations or exclusions on specific drugs and services, including clinical trials, were the system-related barriers to cancer care most often described. Insured patients detailed situations in which they were denied care despite suspicious symptoms and/or a strong family history of cancer because they did not fit screening guidelines or the typical patient profile; this was particularly true for younger patients. Those with diagnosed cancer recounted having to battle their health plan continually to gain access to specialists, medications, and testing they needed. In some cases, physicians did not know the most appropriate care for a patient’s disease.

Several speakers emphasized that the current system discourages appropriate end of life care. Some public payers (e.g., IHS, VA) have hospice benefits, but according to speakers, do not refer patients to hospice or have insufficient service capacity for the beneficiary population. Medicare beneficiaries can receive hospice benefits only if their life expectancy is projected to be six months or less. Physicians testified that it is exceedingly difficult to predict how long some patients with advanced disease may live.

Many physicians wait too long to refer to hospice, fearing that if they refer too soon, the patient may outlive the benefit period. As a result, many dying patients and their families are deprived of much of the comfort and care that hospice could provide. Another system barrier to hospice care is Medicare’s requirement that the patient must have a primary caregiver living in the home; those who cannot meet this requirement often are forced to die in institutional settings. In addition, patients can receive regular Medicare benefits or hospice, but not both. Under Medicare, hospice patients may not receive palliative chemotherapy or radiation; hospice providers emphasized that many patients could benefit greatly from care that controls pain and other symptoms but does not have a curative intent or prolong life.

Financial Issues Affecting Patient Access to Care

Throughout the testimony in every region of the nation, from providers and patients alike, there was a consistent call for an equitable system of health insurance that would assure patients access to cancer preventive and therapeutic care when needed. Clearly, issues remain to be resolved as to what level of care should be considered the minimum

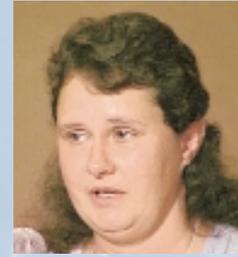
expected care for specific conditions. However, numerous speakers voiced the same moral tenet:

No person in America with cancer should go untreated, experience insurance-related diagnosis or treatment delays that jeopardize survival, or be bankrupted by a cancer diagnosis.

For people with cancer and their families, health care system issues that can be explained logically by current fiscal and economic realities often translate into a personal reality that includes family bankruptcy, needless suffering, loss of dignity, and loss of life. Inadequate insurance, or a total lack of health insurance, were the financial barriers to cancer care most frequently experienced by testifying survivors and most often noted by state health department and local program officials. State health officials reported that uninsured rates are as high as 25 percent in some states for the non-Medicare population, with some states reporting markedly higher uninsured rates in rural and frontier regions compared with urban areas. The underinsured population is difficult to quantify in most states.

Many people discover after a cancer diagnosis that their employer-sponsored or individual private health insurance does not cover many of the costs of cancer care. Those with only catastrophic coverage typically have extremely high deductibles, but even those with fairly comprehensive coverage or Medicare find themselves faced with significant, unanticipated out-of-pocket costs. As numerous survivors and family members recounted, Medicare and many private health plans do not provide reimbursement for orally administered chemotherapy drugs; supportive medications such as those to control pain, nausea, and anemia; or chemopreventive drugs. Such out-of-pocket costs, plus deductibles, copayments, and the costs of laboratory and other tests, office visits, supportive care, and other denied or excluded services add up quickly.

Some providers demand full payment at the time of service, and slow reimbursements from the health plan strain cash flow even further. For example, a mother whose son died of leukemia recounted being asked by her local pharmacy to charge thousands of dollars a month on her credit card to pay for his medications because the pharmacy was unwilling to wait for reimbursement by the insurer. Such costs constitute an especially heavy burden for patients whose income is reduced or lost; even more costs are incurred by a spouse, significant other, or parent who is caring for the patient



“We were both working at the time and we made \$22,000 but it was too high... I was told that the only way

I could get a medical card was to be 100 percent disabled, pregnant (after having a hysterectomy, which wasn't going to happen), or to separate from my husband. My husband and I seriously discussed the option of separation so that I could pay for my treatments.

From the time [the doctor] recommended the hysterectomy until the time we found someone to do it [on a payment plan] was nine months. During that time I felt that my life was only worth a 2x3 inch health card. I knew the cancer was there. I knew it was growing and multiplying. I felt I would not live to see my son grow up... These feelings are with me every day.”

Pamela Rutherford, cervical cancer survivor, West Virginia



“Each one of us at some point in our lives can come to the point that we've lost everything without

thinking we could. But the system as it is now does not allow us to receive care when we are in need... You make too much for Medicaid. You sold a home that is an asset, so you cannot have Medicaid. You have not had the disease [long] enough to get disability or SSI. You are not old enough for Medicare. You're not insurable because you have a pre-existing condition. So you're in a hole.”

Gerardo Midence, oncologist, Montana



“...I had to get in my vehicle after having surgery, two surgeries back to back, and drive three

counties trying to find a doctor that would take my insurance (Medicaid)...We found a doctor that would take it but I would have to sit out for three months before they could start my treatment. In the meantime, the doctors are telling me I can't put this off...My question to the doctor was, 'Why is it so hard for me to find a doctor to take my insurance?' They said, 'Because they're slow payers or they don't pay'...and because of that I was denied treatment.”

Sherry Davis, breast cancer survivor, Florida



“It's heart-breaking to understand that...they're processing the claim and all my medical records was

at the same location. The doctors are right there. It takes a phone call or a fax or e-mail and you can get the information from the doctor but yet it still takes a year [to process a VA disability application] and that does not make any sense, and it's contrary to what I could ever believe.”

David Dalton, non-Hodgkin's lymphoma and lung cancer survivor, Maryland

and consequently must take time off from work. These and other non-covered costs, such as transportation, child care, and medical supplies can rapidly drain personal and family savings, causing some patients to sell whatever assets they may have, including the family home, farm, or business, or to go without care.

Should a patient or spouse lose the job providing health insurance, the family can face a quick descent into indigent care and family bankruptcy. To qualify for Medicaid, patients may be forced to give up any remaining assets, including the car needed to reach the hospital for treatment.

If they are well enough to return to work after treatment but have had a break in insurance coverage in excess of two months, cancer survivors may find they are subject to a waiting period of up to one year for coverage of pre-existing conditions under a new employer's health plan.⁴⁵ Survivors or family members (e.g., a spouse with cancer) who return to work at jobs that do not offer health insurance may be able to obtain private coverage, but often only at prohibitively high cost, and in some cases, excluding coverage for any services related to cancer. For example, a breast cancer survivor testified that she lost her insurance when she and her husband divorced; the only insurance she has since been able to secure excludes coverage for care in any way related to breast cancer, including screening mammography.

The unemployed poor, the working poor, and self-employed middle-income people are in an even more precarious position, since they are unlikely to have any health insurance at all. The poorest poor are the most likely to qualify for Medicaid or obtain care through hospital charity care systems. However, speakers described such long delays in obtaining Medicaid approval that they were faced with more advanced disease by the time they were able to begin treatment. In one such case, a cervical cancer survivor recounted beginning her quest for Medicaid approval when her disease was at a precancerous stage; by the time she was approved, she had advanced invasive cancer. Moreover, she lost her Medicaid eligibility as soon as her initial treatment was completed, leaving her with no coverage for needed follow-up care. Other survivors indicated that although they had secured a Medicaid card, it took weeks or months to find a provider who would accept Medicaid payment and provide needed care.

Many of the cancer survivors and family caregivers providing testimony were self-employed—farmers, ranchers, small

business owners, and other independent workers. As these speakers indicated, they seldom can afford even basic health insurance, though they make enough money to support themselves and their families. The working poor may hold two or three jobs, none offering health benefits. Both groups are likely to lack both health insurance and the financial reserves to see them through an extended illness. Upon being diagnosed with cancer, however, these patients often find that they make too much money to qualify for Medicaid. If they stop working in order to become eligible for Medicaid, they may not have enough income to support themselves and their families. This wrenching predicament was described by many of the survivors providing testimony to the Panel. One such case involved a self-employed cancer survivor from the District of Columbia, who was the sole source of support of her elderly mother. Though her mother was a Medicare beneficiary, her medications, costing \$450 to \$3,500 per month, were not covered by any insurance. Despite a family history of cancer, the daughter had chosen to forgo health insurance for herself in order to pay for her mother's medicine. When she was diagnosed with cancer, the daughter applied for Medicaid but was denied because her income exceeded the maximum allowable amount. Yet she could not give up her income to qualify for Medicaid without depriving her mother of needed medication.

People with cancer who are unable to work due to their disease may qualify for Social Security Income (SSI); however, one must have a diagnosed disease for at least 12 months before an application can be submitted, and it is quite common for applications to be denied two or more times before approval. Speakers reported that SSI income often exceeds state Medicaid income ceilings; the result is that patients may regain income to help meet living expenses, but lose their access to cancer care. Patients who are approved for Social Security Disability Income (SSDI) also become eligible for Medicare, but only after having a totally disabling disease for two years.

Knowing they cannot pay for care, some uninsured patients avoid screening that might result in a cancer diagnosis, and if diagnosed, refuse care in order to avoid what one presenter described as the “roller coaster” that leads to bankruptcy, or accumulating debts they fear might be left to family members to pay. It was suggested that those with incomes at 100 to 250 percent of the poverty level are most quickly wiped out financially by a cancer diagnosis.



“I am on disability; therefore, I have Medicare and Medicaid. I know that if I were to be on Medicaid

alone and told I had cancer, I would have no choice but opt for no treatment. Living on \$495 a month, no possibility of going back to work, no spouse to help with work or other expenses, the copayment on the Medicaid —because I’ve seen my hospital bills—would be so astronomical that there is no hope of ever being able to pay them.”

Pat Myers, cancer survivor, South Dakota



“I am on the two-year waiting list for Medicare... Six months ago, though, I had to go through a

reapproval process [for state medical assistance]. In January, the government, Social Security, gave me a \$15 raise a month. I went from \$599 to \$614. I was 66 cents over the limit and they took away my medical insurance.”

Catherine Danielson, stage IV throat cancer survivor and single mother of four, Arizona



“Well, last month I come home from my chemo treatment and there was a message on my machine

to call [the state of West Virginia] where I work...and the girl in the personnel office regretted to inform me that the state will no longer provide my medical coverage... I pay \$600 a month now for my insurance to keep me going so I can receive my treatments. There’s no help available. I’ve called as many people as I can... I still have the Veterans [Administration] to go through yet because I’m a two-time Vietnam veteran...

We depleted our Christmas club and our savings account. I do receive Social Security disability. That’s \$1,087 a month. When you subtract \$600 a month from that, it doesn’t leave very much for food and bills and other things. And I also have one drug that I get 16 shots a month between chemo treatments, that’s for the white blood cells...and the copayment for that drug is \$1,176...and my copayment for the pain medication is \$130 a month. And my nausea medication, which I do have to take...five pills, my copay is \$36. And sometimes those five pills run out in a week or sometimes they run out in less than a week.”

Edward Chisholm, colorectal cancer survivor, West Virginia

Many uninsured patients struggle to pay out-of-pocket for their care, often amassing debt equal to several years’ wages, even when providers have discounted services and arranged for donated medications. To pay these bills, patients and family members take on second jobs, give up their homes and possessions, exhaust savings, and accept loans and donations from friends. A survivor of childhood cancer, now age 26, indicated that his family is still paying hospital bills incurred following his diagnosis at age ten. A man whose wife had cancer and died is working three jobs to pay more than \$100,000 in bills for her care—though his wife did not survive, he felt she had received the best possible care and felt a responsibility to see that her doctor and hospital did not go uncompensated. Other patients whose creditors will not accept installment payments are forced to declare bankruptcy.

Financial Issues Affecting Health Care Providers

As health care payers and purchasers struggle to contain health care costs, financial pressures on health care providers continue to increase, affecting the care available to people with cancer and those in need of screening, diagnostic, and preventive services. Survivors and family members reported widely varied experiences with the provider community in terms of willingness to accommodate patients’ lack of insurance or full insurance coverage. Some patients were told to “pay what you can, when you can;” others were able to negotiate reduced rates and payment plans with their hospitals and physicians; and some providers donated their time and services. In other cases, however, providers asked for advance payments of \$20,000 to \$100,000 before initiating treatment. These highly divergent responses to patients in need appear in some instances to reflect the extreme and intensifying conflict between some providers’ commitment to render care as needed and a range of financial pressures that threaten the solvency, vitality, ethics, and integrity of health care institutions and individual providers alike.

Providers at nearly every regional meeting reported steadily increasing payer-related paperwork, regulatory requirements, and other administrative responsibilities. Both institutional and office-based cancer care providers have been forced to hire staff whose sole job is to negotiate with payers to secure approvals for patient treatment and subsequently to try to obtain payment. These substantial administrative costs have been coupled with steadily falling reimbursement rates for drugs and services.

Many of the providers and advocates who testified before the Panel expressed grave concern about the effects that Medicare's Ambulatory Payment Classifications (APCs, also known as the Hospital Outpatient Prospective Payment System, or HOPPS) will have throughout the cancer care system. For example, the cost of chemotherapy administration (e.g., nursing staff time, monitoring equipment, supplies) is not reimbursed in the office setting, and providers have previously covered these costs through margins on drug acquisition reimbursements. With severe drug cost reimbursement cuts, in some cases below acquisition cost, providers indicated they will have little choice but to absorb chemotherapy administration costs or stop providing office-based chemotherapy. As speakers pointed out, the solution to this problem is not necessarily reinstatement of higher drug reimbursements, but fair reimbursement for both chemotherapy administration and drug acquisition costs.

The hospital outpatient reimbursement scheme likewise threatens an already fragile balance. Many smaller community hospitals are going out of business, worsening access problems for rural patients. Even in large metropolitan areas, hospitals are struggling to maintain both services and solvency in the face of shrinking reimbursements by Medicare, Medicaid, and private payers. However, while demand for indigent care is increasing, decreased total revenues are reducing hospitals' ability to absorb the direct and indirect costs of uncompensated care. Other casualties of these fiscal changes are nursing, pharmacy, social work, education, outreach, tumor registry, and other supportive care personnel, clinical research, and training programs for the next generation of cancer care providers.

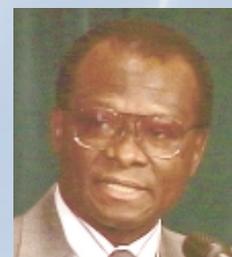
Relative to differences in the cost of doing business, reimbursements for identical care are inappropriately inconsistent both across the nation and between urban and rural areas (even within the same state), with substantially lower reimbursements for the same items in rural areas. These payment differences have serious effects on the quality and type of care available in rural localities. As a radiation oncologist from the Midwest pointed out, *"It costs the same amount of money for me to buy a linear accelerator as it does for somebody in New York City."* Radiotherapy and other complex medical equipment is extremely expensive and has a limited useful life as treatment techniques become more sophisticated. Supplies, such as the radiation sources required to operate specific pieces of equipment, may cost in excess of \$30,000 and last only months—whether they are used or not.



“All of the clinical research in the world will be of no use to patients... if their hospitals cannot

afford to own the equipment and pay the personnel needed to deliver these high-tech, labor-intensive treatments safely and efficiently.”

Cassandra Foens, radiation oncologist, Iowa



“Lupron® is an injection that is given for patients who have prostate cancer. It doesn't take

more than two minutes to administer Lupron®. If [it] is administered in one of the rural clinics, the reimbursement is \$50. It costs us \$650 to acquire the Lupron®. So for all the times that we are giving somebody a Lupron® injection, we are taken by a \$600 deficit. The only way we can recoup our costs would be for the patient to come to [Bismarck], travel the hundreds of miles to get to us.”

Ferdinand Addo, physician, North Dakota



“We’ve had several medical groups go under because the funding and reimbursement is

so bad that many physicians really cannot make a living. I mean, there are some physicians who are working 100 hours a week and taking home \$50,000 a year. And, you know, they’ve got families, they’ve got school loans, and they can’t do it. And they’re starting to drop a lot of patients that have Medicaid or Oregon Health Plan or HMOs where the reimbursement is even less than you get from Medicare.”

Nathalie Johnson, surgeon, Oregon



“When you’re a cancer victim already and you’re not supposed to live and you’re surviving each day, it’s a fear

of ‘they didn’t catch me the first time, told me it wasn’t cancer because I have pain,’ and it turned out I had two massive tumors, both different, and carried them for four years and wasn’t diagnosed. And now here I go again...

...they run you in and out so quick and you can’t ask questions a lot of times, you have to be there and be your own doctor and say, ‘Now, look, I think I have this and will you please do something? I’m not leaving here today. I have pain in my cheek. You’ve taken it out twice. I had pain in my breast and no one listened and this time I’m not going anywhere.’”

Elnora Marsh, breast and skin cancer survivor, Pennsylvania

Lower reimbursements for the same care provided in rural areas also has meant that instead of increasing efforts to take state-of-the-art cancer care to rural sites, many metropolitan cancer centers bring rural patients to the city for care. This approach constitutes a physical and financial hardship for many fatigued and ill patients, who incur travel, lodging, food, and child care costs to obtain care, especially if they must be accompanied by a spouse or companion. Oral medication, even if available for an individual’s condition, is not an alternative, since Medicare and many private plans do not cover the cost of “take home” drugs. Thus, some patients drive hundreds of miles just to receive an injection, then return home the same day.

Some providers are attempting to establish viable rural oncology clinic networks, but the combination of recently reduced reimbursements for drugs, lower patient volumes, and lack of reimbursement for chemotherapy supplies and administration are making financial survival questionable. The CEO/oncologist of such a network in Alabama described the situation this way: *“We don’t have as many patients per nurse, per vial of Taxol®, per square foot of building, to dilute fixed cost...it doesn’t take long for the private sector to ratchet right down to many of the Medicare fee schedules, and the margins that are allowed are just unsurvivable in the private doctor’s office.”*

Another concern expressed was that Medicare APCs will reimburse for older drugs and treatment regimens, but not for newer anti-cancer agents and therapies. A related, ongoing issue is that Medicare-approved drug lists are not kept current, causing providers to engage in often lengthy negotiations with Medicare contractors for approval of newer treatments. Physicians reported instances in which paperwork and approval-related delays were so protracted that the patient’s disease advanced beyond the point at which the recommended treatment might have been curative, or even possible.

Speakers maintained that Medicare and Medicaid reimbursement cuts have “downstream” effects that are increasing the gap between state-of-the-art care and its implementation for all people. And as noted above, Medicare reimbursement levels and policies often are quickly adopted by the private health insurance industry. Reimbursement reductions under the APC payment schedule are of concern to all providers, including those whose patient population may be insured principally by private sector payers.

Testimony indicated that one effect of diminishing reimbursement levels is growing pressure on physicians in office and institutional settings alike to see more patients per day. Payers specify the maximum allowable reimbursement for office visits of various durations and the diagnosis codes that may warrant extensive office visits. Physicians who spend too much time with each patient risk a greater percentage of denied or reduced claims and may be dropped from health plan provider lists if they are judged to be inefficient. Physicians may also face penalties if they perform too many expensive tests or biopsies, even when these are deemed necessary.

While the effect on the provider may include reduced revenues and greater professional and personal stress, effects on the patient may include inadequate discussion of medical history and all relevant health issues; inadequate patient education; missed opportunities for preventive care; failure to be offered clinical trials or other care that requires lengthy explanation, monitoring, or additional paperwork; and in the worst cases, misdiagnoses.

Physical Barriers

Distance from Care

Testimony provided to the Panel suggested that residence in rural or frontier areas poses a special set of problems that comprise a vastly underappreciated barrier to cancer care access. It is estimated that one-fourth of the U.S. population of 281 million in 2000⁴⁶ live in areas designated as rural (i.e., fewer than 2,500 people per town boundary) and frontier (i.e., fewer than 6.6 people per square mile). In fact, roughly 45 percent of the U.S. land mass is frontier, and half of all states have frontier regions.⁴⁷

Excessive distance from cancer care is due in part to the concentration of health care personnel and resources in urban areas, the lack of public transportation systems in rural and frontier areas, and the fact that many residents of these areas lack the resources to travel to care.

Uneven Distribution of Cancer Care Resources and Personnel

The scarcity of health care providers and resources in rural and remote areas is a longstanding problem that Federal and State governments have tried to address over many



“After my surgery, for seven weeks I drove every weekday 100 miles to Minneapolis and 100 miles

home for 45 seconds of radiation a day... there is no sarcoma support group in Minnesota, to my knowledge, and certainly not in my community, because I’m the only sarcoma patient there...it took me six months to find out that a sarcoma support group did exist. It’s on the Internet.”

Barbara Ingalsbe, soft tissue sarcoma survivor, Minnesota



“We in Montana are a proud people. So whether it’s coming from generations of Native peoples or

the pioneer spirit, we tend to suck it up and make do. But we shouldn’t have to make do with inadequate cancer care.”

Kerry Dewey, breast cancer survivor, Montana



“My cancer center is very lucky. We have an excellent reputation, and live in an area of the country that

people want to move to. If I'm having this difficulty [finding oncology nursing, radiology, and dosimetry staff], you know that in more rural settings, in some less desirable parts of the country, that they are experiencing an even greater problem. These problems compound the access issues already faced by people in rural communities.”

Deborah D. Hood, cancer center administrator, Colorado

years (e.g., through the National Health Service Corps, rural and migrant health centers, and other mechanisms). Yet the number, type, and distribution of cancer care providers, treatment facilities, and treatment technology remains seriously inadequate in large areas of the country. In many underserved areas, there also are few primary care providers—in some counties, none at all. Where there are no primary care physicians, patients cannot get referrals to specialty care. As a result, people living in these areas frequently are misdiagnosed or diagnosed at late stages of disease. It was suggested that some cancers in these populations are never diagnosed.

Lower reimbursements for care provided in rural and frontier regions and the limited grant funding available in sparsely populated areas continue to hamper efforts to recruit and retain oncologists and other cancer care professionals and are a major contributor to the uneven distribution of cancer care services across the country. A young physician testified that he would like to practice in a rural setting, but feared he would not make enough money to repay his educational loans. Speakers called for programs and incentives to attract rural and minority individuals to cancer care professions and help them sustain careers in underserved areas.

A number of speakers noted that both oncology nurses and other nursing staff are in short supply nationwide and that their number is shrinking. The average oncology nurse in practice is 40 to 45 years old, and the number entering the field is decreasing because of health system changes. Most importantly, hospitals attempting to reduce costs in the face of shrinking reimbursements are replacing oncology nurses with nurses who are not specially trained to care for cancer patients. Apart from their specific training to manage cancer care regimens and treatment side effects, these nurses are critical to patient and family communication throughout the treatment process. Some nurses are leaving the profession because they are consistently being asked to care for too many patients at one time and these patients tend to be quite ill. In the current health care environment, inpatient care is reserved for the sickest patients and the most difficult treatment regimens. Concerns were expressed that such heavy caseloads may jeopardize patient safety. In addition, with fewer applicants, oncology and other nurse training programs are closing. Similar patterns are being observed among other cancer-related health professions. These trends bode ill for the future, as the elderly population and the

number of cancer patients and survivors grows, and cancer care becomes increasingly complex.

Some services cannot be taken easily to remote areas. One such service is radiation oncology. Providers testified that the lack of radiation facilities in rural and frontier areas results in more surgical treatment for breast and prostate cancer (due to both physician recommendation and patient choice) because the nearest radiation facility is too far away for patients to make daily round trips for several consecutive weeks. Physicians have tried to establish rural radiation facility networks, but these are proving to be barely self-sustaining. It likewise has proven difficult to sustain home hospice services in rural areas; a provider of these services indicated that a nurse may spend two hours traveling to make a one-hour home visit.

Speakers also noted that disabled patients face unique physical barriers to care. People with disabilities such as mobility, spasticity, and mental problems may require special equipment or specially trained personnel to enable them to receive cancer screening and care.

Transportation Issues

In rural and remote areas, there are virtually no public transportation systems. Patients reported driving up to 300 miles one way for screening or treatment. Some patients may be too ill, either from their disease or from treatment side effects, to make trips of this duration. Those with compromised immune systems utilize at their peril the van services a small number of communities have established. In some areas, volunteer transportation assistance programs help people reach treatment, but these too are limited.

Native Americans, particularly those living on reservations, frequently drive long distances to an IHS hospital or clinic and wait all day to be seen, only to be turned away and told to return the next day. This situation is so discouraging that some people avoid seeking care for symptoms until they require emergency care. According to the director of a screening program for Native American women, only 11 mammography machines are available to serve all 566 recognized Native American tribes. Even women with symptoms may wait months for a mammogram, and outreach and education efforts can create a demand for services that outstrips already limited capacity.

Most managed care enrollees and VA beneficiaries are required to obtain care only from providers with which



“We’re in a remote area and we have a lack of public transportation. We just don’t have any. If you

don’t know somebody with transportation you’re not going anywhere, if you don’t have it yourself...I transport [patients] to and from the VA hospital in my personal vehicle. I make two or three trips—it’s a hundred miles to Oklahoma City—a week. And as I said, I’m a volunteer.”

William “Budd” Phillips, prostate cancer survivor, Oklahoma



“If you have to drive 200 miles in an unreliable car for a Pap smear or a breast exam, and when

you get to the IHS clinic, you may not be seen, how apt are you to go?”

Mary Alice Trapp, program director, Minnesota



“Because the cancer was so rare, there was no one in Rapid City who was qualified to do the surgery...

so she was sent to Portland, Oregon... unfortunately, there wasn't funds available to help her with the transportation and everything. So there was fund raisers that had to be done. So it took almost five months to get enough money together to get her up to the hospital and her husband to stay there with her. And after the surgery the doctor came in and said 'I hate to tell you this; if you had been here four months ago, we could have gotten it all and you would be free from cancer. But it's too late now and you have a year to live.'”

Dolly Randles, cancer survivor, South Dakota, describing her daughter's cancer experience

contracts have been negotiated. In many cases, rural patients must travel considerable distances—sometimes to a distant city or another state in the case of VA-approved treatment sites—to reach these providers. In some cases, they literally drive past equivalent treatment facilities near home on their way to the contracted provider.

Poor rural patients, particularly the elderly, often are not considered for clinical trials because of their physical isolation, transportation problems, and fixed income. In addition, clinical trial protocols are often rigid, not allowing monitoring and treatment schedules to be coordinated so as to minimize patient travel. This lack of flexibility results in additional long-distance travel for rural patients who do enroll in trials, discouraging participation.

Often, neither the patient nor his or her friends or family has a car that is sufficiently reliable to make long trips to the treatment facility; they also may not have the money for fuel and tolls. Many older Americans do not have anyone who can drive them to care and cannot afford to pay for transport. Since relatively few treatment centers are able to help patients with food or lodging expenses when they must remain near the treatment site for outpatient chemotherapy or radiation treatment, some patients end up sleeping in their cars, in homeless shelters, or on chairs in the hospital or clinic. In some cases, the time required to raise money to pay for transportation to treatment can mean the difference between life and death.

Transportation-related barriers and associated costs are difficult for rural and frontier area residents, but they are particularly onerous for patients in isolated regions like Alaska, Hawaii, the Virgin Islands, Puerto Rico, and the Pacific Territories. Often, the only way to reach screening or treatment of any kind is by air or boat. In Puerto Rico, for example, a poor cancer patient who misses the last ferry home following a chemotherapy treatment is faced with sleeping in the town square; most have no money and there is no other means of transportation. In Alaska, the cost to fly from a remote village to a medical facility providing colonoscopy may exceed the cost of the test itself. For those in areas that also have harsh winters, reaching cancer care may become impossible for weeks at a time when country and mountain roads become impassable due to snow. As speakers noted, such conditions can delay diagnosis of suspected cancer and seriously disrupt cancer treatment regimens.

Transportation also is an issue for many inner city residents who may not own cars or be able to afford bus or subway fares needed to reach screening or treatment facilities. Moreover, some urban patients are too sick to undertake a trip that may cover relatively few miles, but involves multiple bus transfers and considerable walking.

Technologies exist, or are emerging, that could help relieve some of the transportation problems faced by rural, frontier, geographically isolated, and inner city residents. Telemedicine has been tested in a number of rural settings and has shown considerable promise for bringing state-of-the-art diagnostic and other care to those at great distance from metropolitan cancer centers. Tumor boards, consultations, and continuing medical education are among the possibilities telemedicine may offer. Effective October 1, 2001, Medicare reimbursement for “telehealth” services will expand to include consultation, office visits, individual psychotherapy, and pharmacologic management delivered via specified telecommunications systems.

What Barriers to Cancer Care Are Related to Information and Education?

Lack of information or education, not knowing how to find or evaluate information, not believing or acting appropriately on available information, not knowing how to get needed care within the health system—all can constitute barriers to cancer care. Singly or in combination, they affect both health care providers and people who seek cancer information and care.

Provider-Related Barriers Related to Information and Education

Information and education barriers related to health care providers take several forms; these can seriously affect the care cancer patients receive and ultimately, affect disease outcome.

Lack of information about cancer and cancer care was the provider-related barrier most commonly described by those providing testimony at the regional meetings. The need to better educate primary care providers about cancer was emphasized repeatedly. Initial decisions about care can be a critical determinant of the patient’s outcome. Primary care providers, especially in rural and remote areas, often make these crucial referral and treatment choices.



“I called [an esophageal cancer patient’s] HMO...and they said he was noncompliant with his

care. Well, what happened was, it was a 45-minute bus ride to the center to receive the Ethyol® medication prior to getting his radiation, then it was another 30-minute bus ride over to the radiation center, and by the time he completed this after a few months he was too exhausted and too tired to make this continual trip.”

Mary Emma Middleton, palliative care coordinator and nurse, District of Columbia



“I said, ‘Well, how would you treat this if I do have [prostate] cancer?’ He said, ‘Well,

we’ll just cut that fellow out.’ And I said, ‘What about nerve-sparing surgery? Because, you know I’m kind of a young man, I still like to do some things with my wife.’ He said, ‘Well, you don’t worry about that, just take everything out so you won’t have the cancer. You want to be alive, right?’...I can see that if a person wasn’t educated as to what’s out there they would say this is the end of my sexual life.”

Noah Lewis, kidney and prostate cancer survivor, Louisiana



“Even if [teens] are diagnosed, often because of their age the doctors send them to local oncolo-

gists or try and treat them themselves... one of my very good friends, C.B. Wolford, didn't even get a fighting chance to battle his cancer because doctors at home kept telling his parents he was having growing pains and was just getting lazy when he complained he was very sore and very tired...that he was probably developing breast tissue because of puberty [and] that if he started producing breast milk to come back and they'd run more tests. His parents immediately took him to the University of Kentucky Medical Center where he was diagnosed swiftly with advanced sarcoma. Right before C.B. died two years ago, he had a chance to meet with [the] President...and tell him of his concerns.”

Jarrett Mynear, age 11, cancer survivor, Kentucky

Likewise, oncology professionals may not be aware of all available treatment options for a given type of cancer, and considerable confusion exists in the provider community about the strength of supporting evidence for and the validity of sometimes conflicting published screening and treatment guidelines. More broadly, there is confusion among providers, payers, and patients as to what constitutes quality care for cancer. Speakers suggested that more universal acceptance of guidelines and consensus statements could make it easier to practice consistent, high quality cancer care, and also could decrease the time needed to obtain treatment approvals and process claims. Clearer and more widely publicized guidelines also would help patients make more informed treatment decisions.

Staying abreast of the latest research in all aspects of cancer care is challenging for any practicing provider in the current health environment, but speakers indicated that clinicians in rural and other geographically isolated areas are at a particular disadvantage in this regard. Most continuing education programs and professional meetings are held in urban areas, and many rural providers also have no local network of peers with whom to exchange ideas and information. Nurses at many Native American health sites work entirely alone. It was suggested that information be provided in a format that can be quickly and easily absorbed. In addition, speakers encouraged the development of distance learning approaches for continuing medical education and computer linkages to help connect isolated providers.

The lack of reliable, up-to-date cancer care information, or a failure to change practice patterns based on new evidence, can have serious repercussions for patients. For example, the surgeon of a breast cancer survivor refused to discuss the option of lumpectomy, saying that all of his patients who had chosen breast conservation surgery had died within a year. Regional variations in the use of breast conserving treatment have been well documented, and have been attributed to a number of factors, including provider age, practice patterns, and bias.⁴⁸ Other cancer patients reported that their providers expressed pessimism about their prognosis; in addition to robbing patients of hope, this attitude appeared to influence the treatment options that were offered. Many community providers are mistrustful of and do not understand clinical trials; in particular, few primary care providers have received any training about how clinical research is conducted. Providers also may unduly influence treatment choice through body language, to which anxious

patients are highly, if not consciously, attuned. Provider education is needed on clinical trials and on communicating information about treatment choices.

Lack of information also results in misdiagnoses and late diagnoses. For example, one testifier indicated that her physician performed a mastectomy for what he diagnosed as aggressive breast cancer; in fact, it was a spindle cell carcinoma that did not require such drastic surgery. Late diagnosis was particularly common among younger patients whose physicians dismissed or misattributed their symptoms to other causes. Several of the breast cancer survivors who testified, even those with symptoms and/or family histories of cancer, were told they were too young to have the disease; the same was true of younger patients with colon cancer. When these patients asked for screening or other tests, they often were denied because they did not fit screening guidelines or the typical patient profile. A woman with throat cancer testified, *“I went from doctor to doctor, and I was told I was overreacting, that I needed professional counseling, that I wanted attention...and even worse, I was told I was a drug addict, because I had to keep working to support my family and I was asking for something to treat the [severe ear and jaw] pain.”*

Speakers further suggested that providers are more likely to miss signs of cancer in patients with other chronic illnesses (e.g., diabetes, hypertension). They also may miss major health problems like depression in cancer patients, a problem recently documented in the literature.^{49,50} This problem may stem in part from the limited time physicians usually have to spend with each patient, since only the most urgent or newest presenting health issue may be assessed. Lack of provider knowledge also may contribute to this problem.

Many oncologists are not knowledgeable about hospice and instead are likely to refer terminal patients to intensive care, where end of life issues tend not to be addressed. In addition, many physicians are uncomfortable with and unskilled at discussing end of life care. Hospice providers indicated that referral to intensive care rather than hospice sometimes reflects an unwillingness on the part of the physician, the family, or both, to give up aggressive treatment of terminal patients.

Another problem described by speakers is a lack of provider information or education about cultural differences that affect the way patients need to receive information and how they perceive disease and treatment. This was distinguished from instances of bias, and from a more common lack of



“We have one computer for all the medical staff. That is not good. Tele-conference we only use

for teaching once a week if we get good reception...we have the mammogram that cannot be serviced and CT scan.”

Aloiamoa Anesi, internist, American Samoa

“Poor palliative care delivery is the most powerful barrier to cancer care, the most powerful barrier to cancer screening, the most powerful barrier to cancer research and cancer treatment, because of the lack of confidence untreated suffering creates in the system as a whole.”

Gregory G. Marino, hematologist-oncologist, Alaska



“A week later I returned to the clinic for the results. We walked in. And I greeted the doctor,

saying, ‘Well, how you doing, doc?’...He responded, ‘I’m okay, but you’re not. You have cancer.’”

Ron Zeno, head and neck cancer survivor, California



“There are survivors, but you hear about the non-survivors more...and once it’s hit your family,

taken a few, it has a tendency to look that way.”

Kay Perkins, family caregiver and community volunteer, Vermont

communication skills and compassion (“bedside manner”) that seemed to be at the root of unnecessarily blunt communications about diagnosis and prognosis.

Finally, an information problem cited by many providers involves the serious deficiency of existing medical data systems, including patient monitoring and tracking systems to help improve patient care and ensure that no one “falls through the cracks.” One physician observed that, “*Medicine currently is less computerized than Wal-Mart.*” Community providers related instances in which patients were referred for testing or treatment but did not receive it due to lack of transportation, lack of money, fear, or other reasons. With no monitoring or reminder systems in place, the providers sometimes did not realize that the additional care was not received until the patient returned months later with more advanced disease. One provider noted that whereas reminder cards and telephone calls for checkups and other appointments are commonly used by the dental profession—and even in nonmedical settings such as auto maintenance—to help ensure continuity of care and compliance with recommended treatment, such systems seldom are employed in cancer screening and cancer care programs.

Information and Education Barriers Faced by Patients and the Public

The lack of accurate cancer-related information that is readily available, understandable, clear, and delivered in a sensitive and culturally acceptable manner is a major contributor to the inability of patients and the public to obtain the most appropriate cancer prevention, treatment, and supportive care.

Cancer is perhaps the most feared of diseases. Few people have not been touched by cancer, seeing family members, friends, or co-workers succumb to some form of the disease. These experiences can be galvanizing lessons, particularly when they are not balanced by the experience of seeing people who not only survive, but live full and productive lives after having cancer. Fear of cancer can cause people to reject cancer prevention messages, avoid cancer screening, delay or avoid treatment if diagnosed, and have difficulty understanding and choosing among treatment options or following treatment regimens.

Across many populations and cultures, fear related to cancer takes the form of fatalism, fear of treatment and its costs, fear of pain and disfigurement, and fear of rejection by one’s partner, family, or community. In addition, myths

related to cancer persist in many populations, including beliefs that cancer is contagious, that surgery and exposing cancer to air causes it to spread, and that mammograms cause cancer. Overcoming these cancer-related fears and myths is a major challenge to those who provide cancer education and cancer services.

For some Americans, cancer-related information is simply unavailable. In remote regions and high poverty areas, thousands lack telephones. Some remote areas even lack radio or television reception. Library access is limited in many rural areas as well as some inner city areas. Few of the poor own computers or have access to the Internet. Many lower-income people without health insurance do not go to the doctor or to other sites where cancer information is most commonly found. Cancer educators and cancer control providers must learn where and how to reach such hard-to-reach populations. For example, it was suggested that cancer information should be made available at social welfare departments and other organizations that provide financial, housing, food, and other assistance. Health fairs, churches, and established community events have proven effective for reaching underserved populations. Some communities are making Internet information more accessible to populations that are unlikely to have such access at home or at work by having open computer hours at community health centers and holding free computer lessons for seniors.

For other Americans, cancer information may be readily available but entirely unusable due to literacy or language issues, or it may be presented in ways that are culturally unacceptable. Low literacy appears to be an underappreciated barrier to cancer information and appropriate cancer care. In a few states, as much as a third of the population cannot read. Low literacy seriously limits the ability to locate and comprehend information about cancer risk, prevention, early detection, or treatment options. Patients who cannot read may have difficulty following medication regimens or other physician instructions, and literacy level has been shown to be a factor in late stage diagnosis of cancer.⁵¹ Print materials available from government and voluntary organizations, health care organizations, and in newspapers and magazines are typically written at high school reading levels or above. Informed consent forms likewise are written at too high a reading level for many; these forms are intimidating even for many well-educated patients. Speakers reported some attempts to shorten and simplify both educational materials and consent forms for low literacy populations.



“My first experience with [a] cancer patient was a Cambodian older man who [had]

stomach cancer. And he was...very lonely in his pain. And his family is a large family but they never went to help him...and so one day I asked the family, ‘Why don’t you do anything for him? Why don’t you touch him? Why don’t you talk to him? He’s going to die pretty soon.’ And they cried and they said they want [to] so much but they had to stand behind a glass door, they’re afraid that he will give them his cancer.”

Yung Krall, program director, Georgia



“There are people who are so afraid of the treatments...that they decide to leave it in God’s hands.

I, myself, am a very strong believer, but I also believe that God has given us the medical establishment of which you must take advantage. Let us teach them that it’s okay to go to the doctor with God.”

Mavis A. Alleyne, cervical cancer survivor, New Mexico



“...a lot of people does not even go to a store from month to month, much less go to an education program [that] is in town...[we need] more outreach workers.”

Joyce Hudson, breast cancer survivor and outreach liaison, South Carolina



“The doctor would give me the bad news first and I would have to translate to my parents. Out of respect

for them I would try to soften the news as much as possible, you know, and telling them, ‘Oh, everything will be okay...just another hurdle that we have to face’...to be a 12-year old facing cancer as it is, is already difficult enough. However, having the news given to you first by the doctor without somebody softening the blow for you is even worse and I remember those moments and I will never forget those moments.”

Jarvis Kuo, age 26, steogenic sarcoma survivor, Virginia

Language barriers are a growing challenge to effective communication about cancer as the current wave of immigration continues. In Hennepin County, Minnesota, for example, the county hospital emergency department has used 91 languages to communicate with patients; in Los Angeles County, California, more than 120 languages are spoken. With so many languages (and distinct dialects of some languages) in use, hospitals and other health care providers are finding it extremely difficult to provide adequate interpreter services. In some cases, translation is provided by non-medical hospital workers or other strangers. Neighbors, friends, and even the children of patients are called upon to translate, which can be an embarrassing and awkward situation for all involved and may cause the patient to withhold important information. Moreover, the physician or other health care provider may not be able to assess whether information is being translated accurately.

Written materials in numerous languages are costly and time consuming to produce. Speakers emphasized that many health-related materials translated from English versions are inadvertently translated either in the wrong dialect or at too high a literacy level. Some recent immigrants are not literate either in English or in their native language; for some population groups, picture books are needed to convey essential cancer information. Translation to certain languages is particularly challenging: in languages spoken by certain Alaska Native populations, there is no word for cancer, and in the native language spoken in the Northern Mariana Islands, there is no translation for “prostate cancer.” Disabled populations also may have special information needs; for example, the visually impaired may need large print or audio materials, and the hearing impaired may require sign language interpreters. Some local programs have developed tailored communication materials for specific populations. But with the exception of a small NCI-funded program to facilitate distribution of educational materials targeting Native American populations, there appears to be no established mechanism for collecting and disseminating such materials to others who may be able to use or adapt them for other population groups.

In addition to being understandable, clear, and in the right language, information must be presented in culturally sensitive and appropriate ways. The myriad cultures of the nation complicate attempts to provide cancer information, but cultural considerations must be incorporated into communication efforts. When the positive aspects of culture are

woven into the design and presentation of cancer information, the message is far more likely to be accepted. A program director described how her staff helped to make cervical cancer screening relevant for a group of Native American women: “...they thought ‘cervix’ is a really strange word... [we said] think of it like this: ‘it’s the doorway to the world for your babies and grandchildren.’ And all of a sudden Pap smears became important to these women.”

Regardless of their educational level, most people need help to evaluate and prioritize information about cancer risk, prevention, and all aspects of cancer care. Just as too little information can lead to poor treatment choices, too much information also can lead to less than optimal care. Cancer information is now available from multiple sources, including print media (e.g., newspapers and magazines, pamphlets and other materials from research and advocacy organizations and health centers), television and radio, and the Internet. However, this material is presented at varying levels of detail, is of highly variable quality, and often contains conflicting recommendations. The Internet in particular is rife with persuasive information about untested alternative treatments. Information that is intended to be helpful can have unintended effects. For example, confusion about conflicting screening guidelines causes some people to avoid screening entirely. Inconsistent messages about cancer prevention discourage beneficial behavior changes. Media coverage of clinical trials that emphasizes problems rather than successes can contribute to fear of trials and discourage participation.

People newly diagnosed with cancer also are likely to be bombarded with information from family, friends, and health care providers. The physician’s role is changing from the principal provider of information to an interpreter of information. Many patients now arrive at the doctor’s office with information obtained from the Internet or other sources. Physicians and patients indicated that some physicians find this threatening, while others welcome the active involvement of patients in their care. Yet even with assistance, patients who choose to be involved in decisions regarding their care may themselves making life-altering, and even life or death choices with little confidence that they have received the best advice. In large measure, this is due to the fact that for the majority of cancers, the most effective care is not known. A Massachusetts sarcoma survivor who faced the dilemma of inconsistent recommendations from doctors who rendered second opinions about her care, observed that physicians’ recommendations are subject to the individual provider’s



“One of the things we learned is we can’t go in with our western medical style and do educational

programs. You can’t walk in, unpack your little suitcase, set up, do a few things, pack your suitcase up, and walk out. You have to know the people. You have to come in and have hands-on things, things that they can touch, feel, see, all those things, but not the western style. It didn’t work with our Native American people.”

Delores Fallsdown-Geiger, outreach educator, Montana



“Programs or education efforts should be community-based, not just community placed. In

other words, the [focus group] participants talked about having someone that looks like them, someone that can relate to their lives, talk to them on a level that they are familiar with. And they also wanted to do it in familiar community settings.”

Shauna Dominic, health department official, South Carolina

judgment based on the information available; patients ultimately have to go with their “gut feeling” in making treatment choices. At the other end of the continuum, it also was noted that in the Vietnamese medical system, doctors customarily do not explain to the patient why he or she is sick, or with what disease. They simply dispense medication and send the patient home. It has become part of the culture to not know the cause or to expect information about one’s illness.

Customary patterns of seeking health-related information can be a significant barrier to reaching people with accurate cancer information. For example, men of many cultures are uncomfortable discussing personal health issues, and so are unlikely to talk with each other about health problems or seek information in ways or in places that might disclose such problems. Therefore, as community program planners indicated, they are less likely than women to accept cancer education or screening efforts at the workplace. Targeting spouses and significant others to transmit colon and prostate cancer screening information and motivate men to obtain screening has proven effective in improving screening rates among at-risk men.

Seeking information through written material is a largely American and Western European cultural practice. Some cultures instead have a tradition of seeking health information from a trusted person in the community; however, such persons may not be knowledgeable about cancer. Several speakers described local programs designed to address this issue in which community members, usually women, are trained to provide cancer education, outreach, and support to peers. Various known as community health representatives, lay health educators, *promotoras*, church health aides, or by other titles, these community members reach their neighbors—often through one-to-one communication or events held in homes or churches—with accurate and culturally acceptable cancer prevention and screening information.

Going beyond the need for information alone, however, patients and providers alike emphasized the critical importance of providing assistance in navigating the complex and fragmented cancer care system. The Panel heard testimony about several programs in which patients are assisted by individuals (e.g., patient navigators, ambassadors, patient advocates, case managers, patient liaisons, social workers) from entry into the screening process through definitive diagnosis and treatment of a detected abnormality and follow-up care. These navigators often help patients find out

about financial and medical assistance for which they may qualify, help complete the required documentation, advocate for the patient with payer agencies, arrange transportation and child care, accompany patients to appointments, help obtain referrals and treatment approvals, find appropriate support groups, and provide emotional support to the patient and family. Importantly, the fiscal support of the programs described varied from small, purely volunteer efforts by grassroots organizations and churches, to grant-supported activities, to hospital system-wide programs funded by endowments. While the need for such programs for insured and uninsured patients at all educational and socioeconomic levels was unquestioned, the tenuous stability of these often fledgling programs was also underscored. An administrator from an endowment-supported hospital program that provides a case manager to every cancer patient upon entry into the system noted that due to reimbursement reductions, the hospital system has operated at a deficit for the past three years and the future of the program is now uncertain.

Information Barriers to Effective Cancer Control Planning and Implementation

Cancer surveillance is grossly underfunded in many areas of the country, and numerous presenters described protracted—and sometimes failed—efforts to secure state funding for these activities. They noted with frustration that funds for cancer, other health issues, or other non-health activities too often are based on institutional and political preferences or misperceptions of need rather than on data.

Without adequate information on the extent and nature of the cancer burden, states cannot identify high risk groups, focus their planning efforts, develop targeted prevention and cancer control efforts, or evaluate their success. Nonetheless, many states are pressing ahead with developing cancer control programs despite inadequate data on the cancer burden borne by populations within the state and lacking fundamental information on the care available and community needs. Some states, particularly those supported by NCI's Surveillance, Epidemiology, and End Results (SEER) program or the CDC's equivalent cancer registry program, have population-based registries. Other state cancer registries are not population-based, since only hospitals may be required to report. Even this hospital data may be less than complete; speakers noted that with many hospitals struggling just to stay open, cancer data reporting is not a priority. Moreover, a speaker pointed out that in



“The [tumor] on my neck had grown so large that I didn't know what to do... I was embar-

assed because I didn't have insurance. I was overwhelmed because I wasn't getting anywhere [trying to find information and a source of treatment]...I wanted to give up...there's people out there like myself in the crack or in the corner, whatever you want to call it, that don't know where to turn.”

Albert Calloway, head and neck cancer survivor, Pennsylvania

independent-minded mountain states, it is difficult to mandate anything, including data reporting.

A positive development has been the recent expansion of SEER coverage through contracts to four additional states. This expansion effort, jointly funded by NCI and CDC, nearly doubles coverage of the U.S. population to over 65 million people and substantially enhances data collection on populations that bear a disproportionate cancer burden and about whom limited data currently exist.⁵² In addition, the recently developed state and county cancer mortality maps available on the Internet (<http://cancer.gov/atlas>) now provide state and local planners with data at a level of detail not previously available. However, many presenters emphasized the importance of detailed incidence, treatment, and survival data on local populations for guiding cancer control planning and implementation efforts, and data at this level remain sorely lacking in most states.

The lack of data for effective cancer control planning leaves most states and communities with a difficult dilemma. They recognize the importance both of devoting greater resources and effort to surveillance activities and of allocating scarce screening and treatment resources to data-driven interventions. Yet data on cancer patterns and trends may take years to develop, and surveillance activities should not supplant action to address readily apparent cancer screening, diagnosis, treatment, and support problems.

The Impact of Culture and Bias on Cancer Care

The population of the United States is becoming more diverse with each passing day. Elements of diversity (i.e., individual and population characteristics) include ethnicity, race, culture, religion, nation of origin, native language, literacy level and educational attainment, income level, gender, and age. In many important respects, these differences among people enrich the collective life of the nation, and the country has made strides in fostering a positive appreciation of and reducing bias based on diversity, particularly in the areas of employment, housing, education, and sport. Yet as a Nation, we still have far to go to understand and be fully respectful of individual and population differences.

Combinations of characteristics attributed to individuals or populations often are spoken of broadly as culture, including

characteristics attributed to perceived race. Culture also can be thought of as largely implicit frameworks of shared ideas, beliefs, social expectations, or habits of mind—one’s mental software.⁵³ These frameworks, and our ideas about who and what we are, develop from our social environment, which in turn is influenced by history and chance. Importantly, these frameworks (or world views, or mindsets) exist for the most part below the surface of the individual’s conscious mind. People are seldom called upon to become conscious of or re-examine them unless confronted with mindsets that are substantially different, or when it is important to understand the mindset of another to achieve an objective.⁵⁴

Thus, people bring their cultural mindsets with them to all of the experiences of their lives, including seeking cancer information and cancer care, or providing such information and care. Aspects of individual or group culture may contribute positively to these pursuits. However, to the extent these mindsets cause people to make health-related decisions not in their self-interest or in the interest of those who could be harmed by their decisions, the effect of culture is bias with negative outcomes.

Issues of Culture and Bias Originating With Health Care Providers

The cultural mindset of the health care provider has the potential and has been demonstrated to affect behavior and decision-making not related to an individual patient’s medical condition. As noted earlier in this document, to date; such disparities in treatment and disease outcome have been studied most intensively as they relate to care provided to African Americans compared with white Americans. Similar disparities also have been documented in the care of Latino populations, the elderly, women, and other population groups.

Health care providers have a special responsibility to be aware, in the immediacy of their contact with patients, of the potential negative impact of failing to understand and accommodate cultural differences—both their own and those of the patient. This responsibility extends to hospital and health plan administrators and other non-medical personnel who make decisions affecting patients’ access to information and care. This is especially true because of the power and authority many patients confer upon or accept from health care providers, particularly physicians.

Provider bias may be overt, but more often it appears to be both unintended and transparent to the health care provider,



“My gynecologist had retired, and so I found a new one. I told him of my complaints. He checked me

and asked me whether I had any STDs [sexually transmitted diseases] in my younger life, to which I said no. He almost insisted that it had to be so...I was given the diagnosis of a urogenic bladder and I was treated for that with no improvement... my situation got so bad that I called the doctor, complained so strongly, that I was eventually sent for an MRI scan, which revealed a large cancer, which had invaded my pelvic organs...You see, the learned opinion that all black women have STDs prevented a correct diagnosis for my disease, which took three years to do... and I do not call this racism, because I do not think it was done intentionally.”

Mavis A. Alleyne, cervical cancer survivor, New Mexico



“There’s institutional racism, sexism, classism, provider biases at all levels of the

system... there’s this belief that it isn’t there, but I don’t know how people believe that folks can behave one way outside and then get inside a hospital or something and act differently. It doesn’t happen.”

Patricia McManus, program director, Wisconsin



“I’ve seen among my colleagues, where patients are not offered certain services or the

ultimate in care because they feel that they can’t follow through, they won’t understand. And those differences are made really on the physician’s bias...and I practiced with people that, you know, will tell me they’re sending me someone who’s a real person. By that they mean a middle-class white working person. And they’re not prejudiced because they’re telling it to me. I really think they honestly don’t recognize their own bias...we have to learn how to make people more sensitive to this.”

Nathalie Johnson, surgeon, Oregon

agency, or institution.⁵⁵ Speakers from the gay community testified to pervasive and often overt provider bias against gay and lesbian patients that causes these patients to avoid screening and care, to avoid disclosing their sexual orientation to providers, and to have few support services available to them. As a result, speakers maintained that lesbian cancer patients in particular are at greater risk of late diagnosis and poorer outcome. In addition, hospital policies often exclude the partners of gay and lesbian cancer patients from family discussions of or participation in the patient’s care.

Patients with disabilities may be denied screening or other cancer-related care because providers focus only on health problems related to the disability. Speakers suggested that this is particularly true for patients with mental, mobility, and spastic disorders.

In an instance of apparently unintended bias, an African American prostate cancer patient who held degrees in physics and mathematics, recounted that he was not told his Gleason score (a measure of tumor aggressiveness expressed as a number on a scale of two to ten) by his white physician because the doctor assumed he would not understand it.

Bias at the provider and institutional levels may also occur when assistance, referrals, treatment, and other services are offered more readily to more educated or white patients compared with less educated or minority patients, even when they have equivalent resources, or lack of them.

Speakers also suggested that some provider behaviors may reflect a lack of understanding and respect for cultural practices that are key to the effective treatment of specific patients. For example, physicians may refuse to allow patients or their families to accommodate traditional practices such as prayers or ceremonies in the hospital setting, even though doing so would not interfere with treatment and would be comforting to the patient. Speakers indicated that under these conditions, some patients reject further treatment.

In other cases, provider behaviors that impede the care process may stem from a simple lack of education about other cultures and their customs. To illustrate, a speaker explained that in many Native American cultures, people are always addressed by their first names regardless of station or situation. A non-Native health care provider who believes he or she is showing respect by addressing a patient more formally (e.g., Mr. Jones) is likely to be immediately dismissed as someone who does not understand the patient’s culture and world view.

Issues of Culture and Bias Originating With Patients and the Public

Culture and bias are not just issues for health care providers. As the paragraphs above suggest, cultural values and beliefs affect how—or even if—people approach and interact with the health care system and with individual providers. They also affect the ways in which people perceive illness, how they develop and act on medical and caregiver preferences including folk healing methods, how they explain and tolerate pain, and what they perceive to be quality care. Diverse cultural values and beliefs therefore can be a barrier to the most effective information and care if they cause people to make choices that result in less favorable medical and/or quality of life outcomes.

Fatalism about cancer pervades many cultural groups and affects the extent to which people are receptive to information about prevention and early detection, and their willingness to seek cancer care. Speakers noted that fatalism about cancer is widespread among Native Americans since people living on reservations with poor health care access have long observed that virtually everyone diagnosed with cancer dies from it. This view has engendered a disinterest in screening that educators about the benefits of early detection are challenged to change. Fatalism about cancer also is common among African American, Latino, and some Asian populations who believe that if one gets cancer it is God's plan, a punishment from God, or the result of bad karma. Similarly, representatives from Appalachian states indicated that fatalism about cancer is common among this population, but rather than being seen as a punishment, the prevailing view is that everyone has to die from something, so it is pointless to seek screening or treatment.

The grinding circumstances and resultant culture of poverty profoundly affect the information and care seeking behaviors of the poor. Crucial daily activities such as finding and keeping employment, providing food and shelter, meeting transportation and child care needs, and remaining safe in sometimes hazardous environments leave little time for preventive health care, exercise, or other health promoting behaviors. In addition, since a great many of the poor are uninsured, few adults receive regular medical check-ups and are unlikely to take time off from work to seek care except for medical emergencies. These conditions, and the culture that accompanies them, are a major factor in the late diagnosis and limited survival of many poor cancer patients.



“Around the same time there was a baseball player that was diagnosed with [non-

Hodgkin's lymphoma], too. [Almost] the next day he was operated on...I still haven't gotten any answer of every time that I ask how come it took four months for them to start treating me. So I've got to think that it was probably because I was not famous or maybe because I was Spanish... four months after they give you five years at the most. So why do they wait so long?”

Aide Montoya, non-Hodgkin's lymphoma survivor, Maryland



“Poverty was what was on the minds of the people, and daily survival: how am I going to feed my kids today?

How am I going to get out to the house in a four-wheel drive and back into town? Or how am I going to go to work and get my kids to day care? All of those daily survival things were a priority, not being screened for a disease that wasn't even bothering them—it was unthinkable to do that.”

Delores Fallsdown-Geiger, outreach educator, Montana



“...the gynecologist told me that I had cancer, cervical cancer, but he said that, ‘It’s just at the begin-

ning, don’t worry.’ So since he said don’t worry—I don’t know much about health—so I just let it go past. The years was passing and passing. My stomach was growing. So I went to the doctor, not the same doctor... and he said that ‘You have a tumor that’s like a tennis ball size.’ And, well, I did not have much money. I did have some money saved for my son because I was planning to send him to the college. And I said, well, what can I do in this case? It doesn’t bother me. It doesn’t do anything. Only my stomach is growing. So when I went back later on to the doctor—another doctor—she said, ‘You have to have an operation.’ I have no health insurance...and for a living I do housecleaning on my own...finally what I did is I took all the money with me two years later. I took all the money with me to Peru. I had the operation over there...”

*Trinidad Ayque, cervical cancer survivor,
District of Columbia*

Speakers also pointed out that rural residence and agricultural lifestyle comprise a distinct culture in which it is rare to seek medical care unless one is in significant pain. Rural pride dictates that medical services are not sought out unless one can pay the bill; since many farmers and other rural residents lack health insurance, care is likely to be deferred. People in small towns and farm areas also place a high value on privacy, and may avoid seeking care if it will mean disclosing one’s income or health problem. Some rural residents will only accept care if they can obtain it in another town where they are not known and have a means of transportation to get there.⁵⁶ Speakers from rural states attested to the rigor of farm life, in which taking time to go to the doctor can mean postponing tasks whose timing is critical to a successful harvest. Women, it was noted, are essential to the day-to-day operations of the farm, and are unlikely to interrupt farm routines to seek health care even when they have symptoms. A similar tendency to minimize or hide their own health needs was noted among Asian populations. For example, a study comparing treatment choice for early stage breast cancer between Chinese, Japanese, and Anglo-American women⁵⁷ found that the Asian American women were less likely to choose breast conservation (rather than mastectomy) because it would inconvenience others to take them to their radiation therapy or chemotherapy and prevent them from most rapidly resuming their family responsibilities. In addition, Asian women in the study tended not to choose oral chemotherapy not fully covered by insurance, since doing so would mean taking money out of the family’s savings, an expense deemed inappropriate unless it offered a clear survival advantage. This cultural view also was expressed movingly by a speaker from Hawaii, who recounted discovering by accident her mother’s ulcerated breast cancer that her mother had kept secret because she did not want to leave her children with bills. Her mother died shortly thereafter. Her daughter, also a cancer patient, indicated that if she did not have health insurance, she would do the same thing.

Provider-patient relationships built on familiarity and trust are crucial to effective education and medical care for some populations. Speakers indicated that trust relationships with providers are particularly important to Native Americans, yet patients at IHS facilities seldom see the same doctor. The same is true in other health facilities that tend to be staffed by temporary, rotating medical staff. Many of these facilities serve large numbers of patients who are new immigrants from cultures that also place a high value on a personal relationship with the provider.

For minority populations, issues of trust extend more broadly to a distrust of the health care system as a whole, which in many respects reflects a fear of mistreatment by people who have power, knowledge, and influence. African Americans in particular bear an enduring distrust of the health system, due in part to the infamous Tuskegee syphilis experiments and to a long history of substandard and disrespectful treatment that is shared by Latino and Native American populations. These experiences reinforce the fear of cancer treatment, including clinical trials, and are a significant barrier to care.

In some cases, resistance to entering the health care system and difficulty navigating it, is undergirded by cultural traditions concerning appropriate personal interactions. For example, Latino culture discourages challenging authority figures; among Native Americans, it is considered rude to be assertive or aggressive. Therefore patients from these cultures are less likely to be strong self-advocates.

Speakers testified to the critical need for health care providers from minority and underserved populations. Patients from these populations express a strong preference to be seen by providers from their same sociocultural group, but such providers are unavailable in most areas. As one speaker pointed out, there are only two Native American oncologists in the United States. In addition, more female providers are needed, since in Latino, Moslem, and Vietnamese cultures, for example, it is forbidden for a woman to be seen or touched by a man other than her husband. Thus, in Latino and other cultures in which men are the decision makers, women may be prohibited from going to male physicians for gynecologic examinations. Further, female providers are needed to help overcome issues of modesty common among older African American, Latina, and other women.

Presenters also described the special difficulty of reaching the Amish population with cancer education or cancer care. In this highly private and self-secluded culture, women are relatively uneducated and seldom receive cancer screening. These cultural barriers are not well understood.

In some Asian and other cultures, and particularly among newer immigrants from these cultures, it still is considered undesirable or inappropriate to disclose life-threatening illness to the patient⁵⁸ because it may cause the patient to lose hope and die sooner. In strongly patriarchal cultures, the elder male family member typically makes all important family decisions, including those concerning health care. Though such practices often change with increasing acculturation, they may deprive



“Rural women, especially older women, perceive themselves as last in the pecking order of life’s priorities.”

Linda Jackson, health promotion specialist, Washington



“When my father was diagnosed my parents told no one...they were very conservative, private

Filipinos who did not want people to know that cancer had invaded our lives. My father was also ashamed. He was afraid that we’d be ostracized by our very tight-knit Filipino community.”

Lourie Campos, endometrial cancer survivor, California

the person with cancer of the chance to achieve closure in personal relationships or otherwise prepare for death and can cause significant stress for younger-generation family members who do not agree with traditional practices.

Until relatively recently, discussing cancer was taboo in mainstream America. People spoke in hushed tones about “the big C” and cancer patients typically were said to have died “after a long illness.” As many speakers testified, prohibitions on discussing or disclosing cancer remain strong in many cultures. For example, many Native Americans believe that speaking aloud about cancer will bring it upon the reservation, and it is common for patients to keep their disease secret even from family members. Latina and African American women may hide their cancer because they fear rejection by their partners. In some Asian cultures, there is a strong fear of being shunned by both family and community. In relatively closed rural, Asian, and other communities that value self-reliance and privacy, there is a belief that emotional support should come from within the family, and that outside support is not necessary. If the culture also dictates that cancer is to be hidden even from family members, the person with cancer may die not only without treatment, but without the comfort and solace of family support. Taken together, these varied cultural beliefs create a “code of silence” that prohibits discussion of cancer, the result of which is delayed care or lack of care, needless suffering, personal isolation, and in many cases, preventable death.

Conclusion

The Panel is acutely aware that most of the issues and problems described in this document are not being expressed for the first time. Indeed, the very fact that these problems—faced by real people with cancer every day, in every corner of the nation—remain so prevalent makes concrete, achievable action to resolve them that much more urgent. **We have heard these voices of our broken health care system—now we must answer.**