

Examining Rural Cancer Prevention and Control Efforts from the National Advisory Committee on Rural Health and Human Services - 01/21/20

Kristine Sande:

Good afternoon, everyone. I'm Kristine Sande and I am the program director for the Rural Health Information Hub. I'd like to welcome you to today's webinar Examining Rural Cancer Prevention and Control Efforts. We're happy to be collaborating with the National Advisory Committee on Rural Health and Human Services for today's webinar.

Now I'll quickly run through some housekeeping items before we begin. We do hope to have time for your questions at the end of the webinar today. If you have questions for our presenters, please submit them at the end of the webinar using the Q&A button on the bottom of your screen. We've provided a PDF copy of the presentation on the RHlhub website, accessible through the URL on your screen. We have also sent the link via the Chat function. If you have technical issues during the webinar, please visit the Zoom Help Center at support.zoom.us. Now to tell us a bit more about the National Advisory Committee on Rural Health and Human Services and give us some background on today's speakers, I would like to introduce Paul Moore.

Paul Moore currently serves as the Executive Secretary for the National Advisory Committee on Rural Health and Human Services. He is also a Senior Health Policy Advisor at the Federal Office of Rural Health Policy. Paul brings a lifetime of experience related to rural healthcare from both his family heritage and more than thirty years in community and hospital pharmacy. His experience reaches beyond pharmacy as he has also been the CEO of a County Healthcare Authority, consisting of one of the nation's earliest critical access hospitals, the County EMS, a physician clinic and a Home Health Agency. Paul is also a Past President of the National Rural Health Association. And with that, I am going to turn it over to Paul.

Paul Moore:

Thank you, Kristine. Good to be with you today. I'd like to take the opportunity to welcome the audience again to today's webinar Examining Rural Cancer Prevention and Control Efforts by the National Advisory Committee on Rural Health and Human Services. Now in this webinar, we will provide an overview of the Committee, highlight rural-urban disparities across rural cancer prevention and control, and hear about the committee's site visit and policy recommendations.

I would like to now provide some brief background on the Committee, especially for those joining today's webinar who may not know who we are. The Committee is a federally chartered independent citizens' panel whose charge is to advise the Secretary of the U.S. Department of Health and Human Services on health care challenges that affect rural Americans. The Committee consists of 21 members, including the chair, and the experiences and the expertise they bring reflects a wide variety of rural issues in public health, medicine, nursing, human service delivery, hospital administration, child care, research, finance, law, and business. They're a pretty diverse group, we're fortunate to have them.

The Committee was formed in the late 1980s in response to a large number of rural hospital closures. Since then, the Committee has continued its work to address and examine pertinent issues that affect the health and well-being of rural Americans and to also hear directly from rural stakeholders. Following its meetings, the Committee produces policy briefs to the HHS Secretary with recommendations on policy or regulatory matters under the Secretary's purview.

For its 85th convening that we held in April 2019, the Committee met in Sacramento, California and focused on examining rural cancer prevention and control efforts as one of two topics. During the meeting, the Committee examined the underlying factors that affect a rural patient's ability to access critical health care services to prevent and to detect cancer, or to fully engage in a comprehensive care treatment plan once the cancer has been diagnosed. Over the two-and-half-day meeting that we held, the Committee first heard from subject matter experts—two of whom you will hear from during this webinar. The subcommittee tasked with this issue then visited Northern Valley Indian Health Inc in Willows, CA.

We have hyperlinked on this slide here to the brief if you click on the cover of this policy brief. You can also find it, along with others, at the link provided at the bottom of the slide.

So the question might be asked then, why rural cancer prevention and control, necessarily. Well, cancer is the second leading cause of death in the US, and despite a downward decline in national cancer mortality, our research demonstrates a distinct disparity in cancer mortality between rural and urban populations.

Compared to urban areas, rural counties have higher mortality rates for several of the preventable cancers specifically, lung, colorectal and cervical cancers. Furthermore, the mortality rates for cancer are slow to decrease in rural counties, further widening the gap between urban and rural areas. Now, this disparity in death rates between rural and non-rural counties is attributable to several factors.

In general, rural populations experience higher rates of poverty, have less access to health care services and things like transportation and are more dependent on public health insurance programs such as Medicare and Medicaid.

Now given the confluence of these challenges, an understanding of the underlying factors that affect a rural patients' ability to access critical health care services to prevent and detect cancer will be helpful for The Federal Office of Rural Health Policy, for Health and Human Services, and for other stakeholders to address issues of rural cancer prevention and control.

So, to transition us into learning more about rural cancer prevention and control, I want to briefly introduce the rest of the team presenting on today's webinar.

First, we will hear from Dr. John Rochat. Dr. Rochat is an oncologist in Fort Bragg, California and he has long been affiliated with hospitals in that area. He received his medical degree from University of Mississippi School of Medicine and has been in practice for more than 20 years. Dr. Rochat shared with the committee at the meeting in Sacramento regarding his management of multiple clinics: Oncology, Hematology and Anticoagulation, and some of the specific challenges in accessing specialist for rural residents in Northern California.

Following Dr. Rochat will be Peggy Wheeler, a former committee member. Peggy is the Vice President of the Rural Healthcare Center (RHC) at the California Hospital Association (CHA). RHC represents small and rural hospitals and other members of the sponsoring organizations who provide service to rural populations in the State of California and Peggy does a great job of making sure they have representation too. It is acknowledged as the primary body for rural healthcare policy on behalf of its members there, in California. Peggy is responsible for developing, advocating and executing public policies, legislation and regulations on behalf of rural hospitals at the state and national levels.

And so with those two brief introductions, I will turn it over to Dr. Rochat. Dr. Rochat, it's good to have you with us today.

John Roachat:

Thank you very much, Paul. Paul I threw you a couple of curveballs there, because things have changed for me since I met you guys last April. While I am an oncologist, and actually this year is my 30th year since graduating from Ole Miss, I am now working as an internal medicine specialist. I've changed my cloaks a little bit, I also work an hour south of Fort Bragg now at an FQHC Anderson Valley Health Center, and as I went through this slide set to make it more pertinent since last April, it almost looks prescient, I have to say.

So, Mendocino county is a large county, territory wise, since 1850. We're California's wine growing area, we're 88,000 people, .2 percent of California. We're considered mostly urban by the U.S. Census because most of our population lives in our three bigger towns, our biggest town is Ukiah city with 15,000 people, so it's not that big.

But I want to start with what Paul had kind of mentioned about MMWR Surveillance Summaries suggesting, or actually indicating, that there was a huge disparity between metropolitan and nonmetropolitan cancer deaths from 2011 to 2015, but that's not a lot of help as to why this is happening. So, look at those disparities. Otherwise, as Paul also suggested, there's a lot of differences even between insurance, but about 19 percent of Americans are rural.

This next slide is important, only 3 percent of oncologists work in rural areas, so you can tell patients are moving to urban areas to be treated, etc. Again, there is 81% that own their own homes, sometimes we're a little bit older, we're a little bit more Caucasian, we're actually not bad on the underinsurance, but a lot of Medicare.

Unger and Jama Network looked a little bit further at this to say what could be the root causes, and looked at clinical trial data of nearly 40000 people from 1986 to 2012 up through January of 2018, looking at 17 different cancer specific cohorts, and looked at these in rural versus urban continuum codes. Any guesses as to how that might turn out?

This is kind of unusual, especially if you look at Southern California there. I promise you the eastern part of Southern California is extremely rural, but there's only two counties across the base of California so they get designated as urban, I think that's probably the best example there. Also, the counties outside are quite rural. If we look at those clinical trials, patients they were more likely to be older, they were more likely to be Caucasian, male, from all geographic regions, and their prognostic factors for having cancer were actually very similar.

There was only one cancer that stood out, that was triple-negative breast cancer, had worse overall survival.

But no other statistically significant differences for overall progression-free or cancer-specific survival. They looked at this eight different ways of defining rurality, I give lots of kudos for doing that, so parse these eight different ways and you get the same answers.

This kind of reminds me of the Indian parable of the six blind men who approached an elephant and saw a different thing, our usual conclusion is we're missing the big picture. We're also missing the part that each one of those blind men is not wrong. What their experience is must be listened to. What we learn from clinical trials rigidity, is that equal applications of standards of care, have the greatest impact on outcomes in clinical trials. How do the rest of us do this?

We've long known that when clinical trials leave academic institutions, the outcomes aren't quite as good. These are national comprehensive cancer network participating organizations, I've put Fort Bragg, where I previously worked, up in red on the far left coast, the next stop is Japan. So these are 17, I believe it is, institutions that are integrally involved in trying to

standardize cancer care. I want to encourage anyone to look at their site, you can access it for free as a healthcare provider. There are cancer screening guidelines in there as well.

So what about the real-world outcomes outside of clinical trials, again the regimen may be standardized the delivery of that regimen is not always the same. NCCN more recently has made a big push to assess patients for distress, I'm going to come back to that in more details. Then resources, Paul also mentioned it can be difficult in rural areas, you need a team to do this. But you'll notice I finished that list with primary care and I did it last April. What does NCCN's "Assess for Distress" mean for rural patients?

Traveling is very disruptive. It is four hours to Stanford, it is 3 and a half hours to UCSF, about four hours to UC Davis for our patients in this area. That pretty much kills the day, if not more, overnight. Those cities are not cheap to stay in, so public transportation up here is very limited in rural areas. Finances – lots of incidental expenses are not covered. Employment – people have work to keep, as you all know, I don't think this is unique to our area. Grandparents are raising grandchildren. If you have older patients having cancer evaluations, they have to take care of grandchildren too. In our rural areas, we have many farms, farms are not forgiving to schedules. And finally, amongst our list of difficult resources is mental health support.

Primary care cancer challenges? Primary care is horribly understaffed; we have tremendous dependence on independent mid-level providers. In California, mid-level providers must work with a physician, that's not the same in all parts of the United States. But they're the gatekeepers to screening and early detection. We have a large bias in differentiating age from performance status, yet we said rural patients are older. We have difficulty with what I call, "community self-esteem," I have not trademarked this, feel free to use it. We have self-esteem problems with our community, we don't think we can do this well, we also have a high opinion of urban areas, which may or may not be deserved. We have great difficulties with electronic health records systems, we're smaller institutions, we may not be compatible with what the academic institutions can send us. HIPAA remains a major obstruction to communication between systems.

Rural oncology care challenges? NCCN is one ability to standardize what we're doing, unrelated to rurality. No typical "tumor board" or local clinical trials, there is very poor support and collaboration from academic centers, we're not on their radar. We're a referral source, but if they were to put a pin on the map, they probably couldn't find us. The first thing I did when I moved to this part of Northern California, was I put a map of California on my wall. EHR incompatibility again, HIPAA obstruction again. Online library/journal access is cost prohibitive, those of you who practice in rural areas are very aware of this if we're not connected to an academic institution. Staffing is difficult, expensive and transient, continuity is difficult. And as we have the national discussion about net neutrality, the internet is the great leveler, which we may not have.

Academia collaboration? My mother likes to say, "There are two ways to have the biggest house in town. You can build on to yours, or tear your neighbors down." Rural providers need the help of academic providers, we're no threat, that's for certain. And we're here to try and take care of our patients as well.

Oncology in the rural community, helps the entire medical system. We maintain and increase a volume of services for laboratory, imaging, pathology, pharmacy. We retain regional revenues, both direct and indirect. We create jobs for nurses, et cetera. We keep patients and families at their jobs, that's probably the most critical.

And this is the way I left this last April, it gave me quite a chuckle recently. My “Primary” suggestion... we don’t necessarily need a whole lot of new oncologists...that’s not what the oncologist does.

My other suggestions were encouraging NCCN use, encouraging that standardization. The American Society of Clinical Oncology guidelines are not very user friendly and they’re not always current or up to date. We need to educate all providers about performance status – how well you are versus how old you are. Chronologic age is not as predictive, I’m proud of oncology over decades for pointing that out. Few of our guidelines actually look at chronologic age, we want to know how well you are. We need to make HIPAA user-friendly in this country, I recognize the idea behind HIPAA, I think we all do. We must encourage academic support and collaboration. Again, are not a threat, they’re educated, and our rural patients are different. Back to one of my earlier slides, if you work in an urban area, you have a really good chance of running into rural patients, so you need to be aware of what those patients are like and what the circumstances are. We need better access to data for rural providers, I don’t suppose that’s just oncology providers, there’s not that many of us, but it is obstructive for doctors to stay current. And rural reimbursement rates, it is more expensive for us to deliver what we deliver. I hope that all makes sense and obviously I will be available for your questions. Thank you for interest in this meeting.

Peggy Wheeler:

Thank you, John for providing that context and your experience with the differences in providing rural cancer prevention, control, and treatment. To everyone on this webinar, this is Peggy Wheeler, I welcome everyone who’s joining us today to hear about the Committee’s recommendations on rural cancer care. I am delighted to present the committee recommendations as a former member of the Committee myself, I was happy that the meeting was convened in my hometown, Sacramento. Before we go over the recommendations, I would like to talk more about the site visit that took place on the second day of that national advisory meeting.

So, to learn more about local efforts in cancer prevention and control, the Committee traveled to Willows, CA to visit one of the Northern Valley Indian Health, Inc locations. Willows is a small community with a population of just over six thousand, about 75 miles southeast of Sacramento. The Northern Valley Indian Health (NVIH) Inc., established in 1971, is a non-profit, tribal organization that was founded by a group of California tribal representatives from the region who were “seeking to reestablish health services for Indians in California.” At each of its seven locations in northern California—Chico, Red Bluff, Willows, and Woodland (they have several clinics in some of those)—NVIH clinics provide quality, patient-centered primary care, dental, behavioral health, and community health services to Native and non-Native patients. As of 2016, UC Davis’ Comprehensive Cancer Center developed a relationship with NVIH clinic in Willows. In 2018, UCDC was one of the 21 National Cancer Center designated centers to receive supplemental funding. Since then, the UCDC-NVIH partnership has focused on developing a HPV vaccination program to prevent cervical cancer.

At the site visit, the Committee consistently heard about the need for better communication between rural providers and specialists, John talked a little bit about that in his presentation. The NVIH Staff and stakeholders emphasized the important role that patient navigators play in bridging communication challenges and strengthening care coordination for rural patients.

Yet, issues of definition cancer patient navigation and differentiating patient navigators from other public health workers (such as community health workers and community health representatives) surfaced in our discussion.

I'd like to move on to the policy recommendations that the Committee came up with that will be submitted to the Secretary.

Over the course of the meeting and site visit, the Committee was able to acknowledge that comprehensive, strategic approaches are needed to address the magnitude of multiple intersection access-to-care barriers that limit rural cancer patients from engaging in the full continuum of care.

In an attempt to tackle these barriers and ultimately reduce rural cancer mortality disparities, that's what we're trying to do here, the Committee presents these recommendations.

For the first recommendation, the Committee recommends the Secretary support combined funding from the CDC, HRSA and the National Cancer Institute to develop, implement, and evaluate a rural patient navigation program to enhance care coordination, particularly in tribal communities and persistent poverty counties.

In the context of cancer care, patient navigation refers to "individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality health and psychosocial care through all phases of the cancer continuum." Research on cancer patient navigation programs—similar to the research conducted for Community Health Workers (CHWs)—has shown to be effective in addressing barriers and improving access to care across the continuum. However, much like CHWs, patient navigators rely on several sources of public and private funding that may not be sustainable for the long-term. Given the growing interest and promise in patient navigators and other frontline public health workers, the Committee encourages HHS agencies to invest in them as well as find ways to sustainably integrate them into the current healthcare infrastructure.

For the second recommendation, the Committee recommends the Secretary work with Congress to increase funding to expand the National Cancer Institute's Rural Cancer Control Program and partnerships with rural and tribal providers in implementing cancer control projects.

The Committee commends the innovative and collaborative work of the National Cancer Institute and believes NCI should continue building upon its efforts to advance rural cancer control by expanding its reach to further strengthen and improve partnerships with local health clinics, like Northern Valley Indian Health. Due to the numerous barriers rural communities can face in accessing health care it's important for there to be increase funding to programs that focus on improving, really moving the needle on care coordination in rural areas.

For the third recommendation, the Committee recommends the Secretary and HHS implement a national campaign. That national campaign would promote cancer-related clinical information and resources, be supported by the Department to improve the delivery of cancer care for providers and clinicians practicing in rural and underserved areas.

During the meeting, the Committee members heard Dr. Rochat and he spoke about the lack of access to new evidence from clinical literature. Through a national campaign, relevant clinical information and resources to providers practicing in rural areas would truly help enhance cancer care. Moreover, this campaign would serve to decrease existing rural cancer disparities, which may encourage innovative public-private partnerships and reduce the disease burden. Lastly, as part of this effort, the committee believes the National Network of Libraries of Medicine should become involved.

For the fourth recommendation, the Committee recommends CMS conduct more targeted outreach for rural providers on how to use existing Medicare codes for cancer care coordination.

The Committee sees value in HHS, specifically CMS, revisiting the previous FORHP and CMS-led Chronic Care management campaign conducting specific outreach to inform rural providers how to use existing Medicare codes to properly bill for care coordination. As referenced earlier, under the current Physician Fee Schedule, Medicare reimburses for Chronic Care Management services furnished to Medicare beneficiaries with two or more chronic conditions. The Committee believes rural providers should have the relevant information on how to accurately bill for services in order to better support cancer care coordination.

For the fifth recommendation, The Committee recommends that CDC require states, territories, and tribes to assess rural-urban cancer mortality rates as part of their cancer control plans and, where appropriate, develop and implement rural-focused cancer control goals, objectives, or strategies, particularly in areas with high rural cancer mortality rates.

The CDC's National Comprehensive Cancer Control Program oversees the development and implementation of strategic, coalition-driven, sustainable cancer control plans. Since the National Comprehensive Cancer Control Program grantees are not required to report the geographic population makeup of their jurisdictions, grantees reference "rural" into each of their cancer control plans. The Committee believes that the grantees can bring greater awareness and attention to rural cancer mortality and address rural access-to-care challenges. Therefore, the Committee believes the inclusion and integration of rural-specific objectives and strategies to cancer control plans, would further advance the goals of NCCCP while reducing the disease burden on our rural and underserved populations.

Thank you all for listening to the Committee's experience and our recommendations and Paul, I'll turn it back to you.

Paul Moore:

Thank you, Peggy, appreciate that information and for sharing the recommendations the Committee put together. For more information, well these are the Committee's recommendations that you've seen, but I invite you to access the Committee's website, and I encourage you to read the Policy Brief in full for further details. You can access the brief, along with additional information about the Committee at the link on this slide. To help us with the time of questions and answers, and ask both Peggy and Dr. Rochat to hang around and answer maybe some of the questions directed to them. So, Kristine?

Kristine Sande:

Alright, thank you everyone. So we will open the webinar to questions now and down at the bottom of your screen there's a little button that says Q&A. You may need to hover your mouse toward the bottom of the screen to activate that bar, with those options to able to activate the Q&A. So we do have one question that we will start with and it says please explain why it is more expensive to deliver prevention care in rural areas. Anyone want to take that one?

John Rochat:

I could say a few things about this, this is Dr. Rochat again, it's not always necessarily the cost of the procedure itself. It is the cost of getting there, back and forth, so those fees for certain screening tests

not always 3 hours for a colonoscopy, if that sounds crazy enough. But there are a lot of other cost involved besides the fees, the other difficulty we wind up with is that free market is not so free when our patients have fewer options. So we have some providers that charge quite a bit more sometimes. Not for Medicare obviously, but

- Peggy Wheeler:** Hi John its' Peggy, I think you hinted at it, the rem expenses lend itself to why more money, but as you know if rural areas when people need to leave their jobs or rely on family members to take care of their familial responsibilities so they can spend time somewhere else. There is a cost to that and that may be harder to put a dollar figure on but we recognize it can be a barrier to people getting the kind of treatment they need in a timely manner.
- John Roachat:** I will actually see it in the patients eyes when I recommend screenings. You can see the wheels turning it becomes a deterrent, it's a not starter. A lot of patients don't even try to do this because they start adding up the cost is gonna be and they will say "I can't do that."
- Kristine Sande:** Thank you so another question is how to we account for the disparities in reimbursement for rural cancer care? Can it be attributed to inappropriate billing and coding, maybe fewer uninsured patients or rather fewer insured patients? Any thoughts on that?
- John Roachat:** My personal experience like a lot of other specialties in medicine is billers and my personal experience is that our billers have not always been asked to use current CMS coding and I hope that also includes billing staff.
- Paul Moore:** I was going to point out that it is multifactorial. A lot of times healthcare costs more in rural areas is just a matter of the small in. you have fixed resources that have to be there whether you are seeing 10 patients or a hundred, but as the questioner pointed out it's a number of things.
- John Roachat:** And I might want to respond again to our first question, from the providers' perspective and cost there's a lot of delivery charges for getting chemotherapy drugs delivered. Same day air does not exist in rural areas; we all chuckle when someone says we'll send that you next day. That doesn't happen. When we had the large fires in CA Fort Bragg had no mail for 3 days. We weren't in the fire but he tricks couldn't get through.
- Kristine Sande:** This question is: Rural cancer centers are by nature more isolated, are there specific strategies on the table to invite these programs to partner in the programs being proposed?
- Paul Moore:** We have seen great collaboration between FORHP and our partners over at NIH National Cancer Institute. It has been enhanced by the CDC looking at the disparities in their MMWR. Showing that there is such a disparity in rates and in mortality when you compare urban to rural. Just to highlight that data by cutting it rural/urban showed that we aren't doing as well as we think we are; because you know how averages work, they work great for people on one end curve and not on the other. So we are enjoying a great partnership with the national cancer institute. They are reaching out to their cancer centers, many of which are urban in nature, but they are working in rural areas and their funding these centers to do that their requiring outcomes as part of the continued funding so we are appreciative of the collaboration that is taking place in order to increase both the cancer control but also the preventive efforts in rural areas. We're appreciating the attention at this point.
- Kristine Sande:** It looks like another question did come in. It says, you mentioned transportation issues affecting patients, what strategies have been utilized to address this ongoing issue?
- John Roachat:** So to offer local cancer care I recall a Stanford provider that there was a patient from my town driving to Stanford for the same regimen that I could give right there locally. That came back to that community self-esteem issue of not feeling that a standard regimen could not be given locally. Could I save that patient 8 hours of travel per cycle? Absolutely. So really one of the transportation issues is offering more care locally instead of having to driver for hours. Other than that increasing the counties transportation is not going to happen.

Paul Moore: I am so grateful that there are communities that have done what Dr. Rochat is talking about. When it is a situation where it's easier to move the therapy to the community than the community members to the therapy that's good. So often that's not the case especially in the case that the treatment is radiologic and it doesn't matter whether you're urban or rural, cancer is a significant challenge to anybody that needs to deal with it no matter where they live. But it is particularly challenging in rural areas.

Kristine Sande: How is telemedicine being considered to help keep care in rural areas? Is there any movement in making telemedicine more sustainable? Most models of reimbursement for telemedicine require that local primary care provider to be in the practice also no shows have the cost of both providers with no reimbursement. So any thoughts on telemedicine related to cancer care?

John Rochat: Physical exam is very important in oncology and telemedicine to lend itself to that unfortunately. We must rely on lab evaluations and there isn't a substitute for an actual visit. And if you look back at one of my earlier slides I quote that 23.8% of rural patients have no internet access so keep that in mind.

Kristine Sande: In our Rural Models and Innovations we do have at least on rural model related to cancer care via telemedicine so that might be something that people may want to check out.

I don't see any other questions so I think we will wrap up our webinar for today. I would like to thank our speakers for being with us today and sharing this great information and for the great conversation that we've had. I would like to thank our participants for joining us.

The slides used in today's webinar are currently available at www.ruralhealthinfo.org/webinars. In addition, a recording and transcript of today's webinar will be made available on the RHlhub website and sent to you by e-mail in the near future so you can listen again or share this presentation with your colleagues. Thank you again and have a great day!