Good afternoon and welcome again to can't send a grand rounds. We're really fortunate to have an invited speaker in an area that is certainly not only a priority for our Cancer Center. But for the National Cancer Institute. But I rather than issues the speaker. I'm going to introduce the introducer. So I'm pleased to introduce the host for today’s Speaker Doctor Melinda Irwin's you know.

Welcome everyone uhm. I'm delighted to welcome doctor. Lorna mcneal today to give grand rounds. I'm into present. Her research entitled community. Engaged research with faith based communities and how to create long standing partnerships.

Doctor MacNeil is Professor and chair of the Department of Health disparities research at MD. Anderson Cancer Center. Ann she's also the colon trust healthcare chair and health disparities research. She directs the Center for community engaged translation. TLE research at the MD Anderson, which is focused on working with MD. Anderson faculty to develop collaborations with underserved communities, with a focus on conducting high quality relevant cancer prevention. Research and her research in particular focuses on the elimination of cancer related health disparities.
In minority populations that take place in minority in underserved communities such as public housing developments. Black churches community based clinics in low income neighborhoods. She’s been continuously funded receiving grants from NIH and foundations to better understand and design, innovative solutions to address Health Inequities. Currently, she’s the P of several community based studies primarily working with African American churches to identify reasons for cancer health disparities.

So welcome Doctor McNeil.

Simple.

Thank you.

OK.

Great let me um get my timer on because I'm already over time before I've even started a function of too many slides so thanks so much for this invitation specifically from Melinda come in give grand rounds today and it really is. A pleasure to share a little bit about what I've been doing specifically at MD Anderson and the city of Houston.

So we know that there are patterns of cancer incidence mortality and survivorship. They vary widely across the United States population and very often, so when we talk about those patterns and how they differ. There’s a we generally term those as cancer disparities. We want to see how it’s cancer distributed across a population and where do we see cancer incidence mortality survivorship? That is disproportionate in terms of?

The population that is bearing the brunt of that cancer burden.
And so when you look at cancer incidence rates. This is showing kids in this race from 2011 to 2015 and general. We know that men have the highest cancer incidence rates of between men and female and then black men in particular, have the highest cancer incidence rates and then we looked at cancer death rates by race, ethnicity see a similar pattern men still have the highest cancer death rates, but African American men also.

Have a higher cancer death rates as well. I want to mention here was white women have slightly higher cancer incidence rates, but black women have higher cancer mortality rates.

When we look at the state of Texas, which is where I live our Texas population. This is projected for 2018. Texas is now I know the 2nd largest state in the United States with about 28.7 million population and it is a majority minority state were 58% of the population are racial ethnic minorities. Compared to 42% being non. Hispanic whites, but in terms of newly diagnosed cancer cases in the state of Texas and this is.

From the cancer registry from 2015. You’ll see that more whites are getting cancer in the state of Texas than our racial ethnic minorities. Such that cancer in general is a disease of elderly and the aging and the white population in Texas are more in populous in the state even though the distribution in terms of population is a little bit more diverse, so you’ll see more cancer cases among whites in the state.

But we do have some unique concerns in our state as a relates to who is getting cancer dying from cancer and these trends and unique concerns. So just in general. These are what are cancer distribution looks like in terms of new cancer cases and incidents breast cancer followed by long prostate the major cancers that you probably see in most States and similarly you’ll see a distribution here in terms of death, except this peak here for liver can’t understand that you also experiencing higher level cancer cases.

Texas is number one in terms of the incident of new liver cancer cases and that’s largely driven by larger incidents Spanish population in our state and that’s crying here, along the Rio Grande Valley border with Mexico. We also have a significant increase in cervical cancer mortality that also exists along with other non board as well. This is looking at some trends
in our cancer cases and this is where we’re improving getting better and these are some of the cancers in which we are.

NOTE Confidence: 0.910303711891174

00:07:32.750 --> 00:07:48.300 The rates are rising and that as a Cancer Center. We want to focus on I mean, you’ll see that liver cancer is where we are seeing a significant increase, an the next coming 5 years want to be on the forefront of addressing that.

NOTE Confidence: 0.915114641189575

00:07:49.140 --> 00:08:20.390 This looks looks at where cancer is distributed within the state and so these are pointed out are larger major cities. Dallas Austin, San Antonio and Houston sits right here, but sort of in armor. NE section of the state is where you’ll have most of the highest incident and this happens to be the rule areas of of the state of Texas, where most of the cancer incidence is occuring and then if you look at the cancer mortality rates. You’ll see a similar pattern there.

NOTE Confidence: 0.922113120555878

00:08:20.390 --> 00:08:53.760 Some challenges that we uniquely have is that we are ranked 4th nationally and the number of newly diagnosed cancers as well as number one nationally and the number of uninsured as well as total number of people that are under short so come from a state that did not do Medicaid expansion and so therefore lots of large majority of our population doesn’t have insurance. And so as a Cancer Center that we’ve represents unique challenge about how we’re going to address that and make sure that we’re meeting the needs of the population that were serving 30% of our newly diagnosed cancers and 34% of deaths occur.

NOTE Confidence: 0.914238393306732

00:08:53.760 --> 00:08:59.620 Actually, I think minorities and women comprise about 50% of cancer incidence and death as well.

NOTE Confidence: 0.91653174161911

00:09:00.330 --> 00:09:32.780 So cancer mortality more cancer distribution disparities also defers by where you live. We very often tend to focus on racial ethnic minorities and looking for disparities from that perspective, but you want to look at disparities. Comprehensively not just focus on racial ethnic groups. But lots of other categories of populations such as distribution disparities insects socioeconomic status and also geographic location.

NOTE Confidence: 0.910282790660858

00:09:32.780 --> 00:10:04.010 And I like this particular slide because it looks at cancer death rates by race, ethnicity as well as sex. I mean, I’ve added state here to show that it matters where you get cancer and where you where you might receive your cancer care so if you look at white males and black women
and white women. This is across the United States, Texas Harris County, which is where Houston is located and then this is the state of New York essentially cancer mortality.

NOTE Confidence: 0.921618342399597

00:10:04.030 --> 00:10:35.460 Is is equally distributed distributed amongst of those particular groups? But if you look at black men you can see that it’s not within the state of Texas has much higher rates and then Houston here is County High rates for black males. But in the state of New York black men have the same mortality profile that white men do across the United States and across on geographic location. So Geograph geography matters. In matters sort of policies and programs and promotions and outreach into various communities.

NOTE Confidence: 0.924301266670227

00:10:35.460 --> 00:10:40.800 In order to be able to impact these types of cancer statistics.

NOTE Confidence: 0.91132777929306

00:10:41.450 --> 00:11:13.020 So when we look at what is causing those dis- parities was driving them we tend to focus on these risk factors below genetic and biological factors are definitely although not the major determinant of what we see in terms of cancer despairs with there are some cancers where they’re likely is a more of a genetic and biological determinant. For example, such as trickum triple negative breast cancer. While that might be occurring more among younger, women or African American women for example, health care. Access is very important. I know there was a published.

NOTE Confidence: 0.905279994010925

00:11:13.020 --> 00:11:43.080 Paper here from the Cancer Center that was show- ing that Medicaid expansion across the country definitely help to reduce or delay improve the state of presentation of cancer such that it may not affect cancer incidence. But definitely effective mortality because people had access to care that they previously didn’t. Social economic factors poverty is across Energon and that being poor put you at greater risk for worse outcomes than if you are financially.

NOTE Confidence: 0.496357351541519

00:11:43.080 --> 00:11:43.510 Hum.

NOTE Confidence: 0.90658301115036

00:11:44.010 --> 00:12:16.220 A wealthy or have financial means and then chemical and physical exposures diet and physical activity or some of our normal cancer prevention. Determinants that we want to look at an address and we want to think about cancer disparities and then when you look at that distribution of various types of cancer sites. You’ll see various groups at our greater higher risk than others. Such that African American women are nearly twice as
likely as white women triple negative breast cancer higher kidney cancer among American Indian elated skins.

And same pattern for liver cancer and I mentioned for Hispanics in the state of Texas is what we see you’re probably very familiar with larger death rate from prostate cancer incidence among black men cervical cancer in Rule areas for women and then multiply myeloma for example.

When we look at Texas cancer risk factors risk factors in the state of Texas we are 42nd in terms of tobacco use and that is a bad number is not a higher is not better in this case with three point three million adults smokers 14th in obesity and 47th and HPV vaccination range, which is really unfortunate because we were one of the earliest states that on a statewide level had adopted a law that mandated vaccination of all young girls and then there was uproar.

And our community after the governor signed that law and it was reversed and now we find ourselves 47th in the nation in terms of HPV vaccination rates. So these are some of our priority areas. Some of the cancer risk factors that we are working on when we think about how we address. Those most of the research that we have historically done looking at disparities puts us in this green box looking at these biological and genetic pathways.

Biological responses individual risk factors, which I just mentioned and looking at disparities from a demographic perspective, but moving for we want to try to focus more of our research what I will call sort of in upstream factors and that is having a stronger focus on the role of the social and community. Contexts and how where you live work and play really does influence your cancer incidence cancer mortality.

And quality of life in terms of surviving cancers and that would be to look at things like neighborhoods in which our populations are living in an how that varies in terms of people’s chances of getting an answering from getting cancer and die from cancer. The kinds of relationships that were involved in this kind of support. That’s provide all the way up to of course, public policies that dramatically impact sort of that cancer distribution such as Medicaid expansion for example.
All of this is particularly important because in order to another important mechanism to addressing those disparities from my perspective is an NCIS as well is to involve the populations that have these higher. Despart rates and the innovative Cancer Research. That’s taking place at RNC a NCI designated can’t comprehensive cancer centers. But there are barriers for the same populations that were trying to reach to enrolling in the cancer trials.

That we are conducting and so this is data from the NCI cooperative trial group that was published several years ago and it’s looking at trial. Enrollment for minorities versus White, according to various cancer types and what I’ve just highlighted is for example, for breast cancer black and Hispanic women are less likely than white women to participate in clinical trials. A similar story is for colorectal cancer and lung cancer. The one cancer side that African Americans overrepresented we prostate cancer for African American men.

That’s a great thing, and makes sense to see that type of active participation. But in general, Blacks and Hispanics as well as older. Adults are likely to less likely to roll an R cancer clinical trials and there’s some evidence that that enrollment is declining overtime.

So how do we reduce these disparities that I’ve just discussed an increase participation in clinical trials. So my major thesis for the rest of the day is going to be a focus on community engagement that communication is is powerful and can increase the participation in an the relevance of our Cancer Research to the population in the communities that we’re trying to solve So what are those berries to participating in clinical trials by the groups that were trying to include in them? Well, you can look at it from various factors but.

And from a research respect if we look at berries that exist on the role of the participant or the patient and then institutional. There’s our study design barriers that prevent people from enrolling in those trials and so many of you are probably very familiar with the Tuskegee syphilis study for example, but these types of studies that were conducted historically in the United States that were unethical and resulted in great harm to some populations, particularly African Americans still.

Have a lot of mistrust and fear of the medical centers medical complex. The notion that at the end of the day. We are still
using people as Guinea pigs, even though you know all of our ethical standards have been dramatically increase time since that time, but some of those that fear and perception still exists and we need to address that there’s often information overload when it comes time to invite people to participate in clinical trials. So I do work with breast cancer survivors and you know the day that you get diagnosed with Stage 3 breast cancer.

NOTE Confidence: 0.909584641456604

00:17:29.660 --> 00:17:59.900 Is the day that we want to enroll you in the next innovative cancer trial that’s going to impact your trajectory, but it may not be the right time for that person to be able to receive the information about whether or not. This is the right decision for them to make not all clinical trials are free. Some of them have copays and cause an often if you don’t have insurance. You may not be able to participate in the trial and then there’s things like lack of Transportation and find connectional constraints communication barriers. All these kinds of things exists on the individual depth or juice their ability to participate.

NOTE Confidence: 0.907392263412476

00:18:00.380 --> 00:18:31.810 Clinical trial, but was known in the literature an work that we’ve done in Houston shows that partly is lack of awareness about what clinical trials are available. ’cause patients aren’t uniformly inconsistently being invited to ask to participate in these clinical trials or why aren’t they being asked well there’s lots of institutional barriers to that consistent practice of inviting everyone to participate in a trial provider time constraints multiple and competing clinical trials in terms of prioritization.

NOTE Confidence: 0.916261434555054

00:18:31.810 --> 00:19:03.900 Of those studies whether or not. This particular patient may be good for one study over another study in terms of physician preference for a specific therapy exists communication Bears on both sides from institutional perspective. Restrictive eligibility criteria very often. There are clinical trials that will exclude people if they have hypertension or exclude you if you have diabetes. So you know like to say that if you have a trial that excludes diabetics and Hypertensives and.

NOTE Confidence: 0.919274091720581

00:19:03.900 --> 00:19:34.310 You don’t want any African Americans anger trial that’s not what you’re thinking when you’re designing that study. But that is an unintended consequence of these types of eligibility. Criterion so more thoughtful conversation needs to take place about what is necessarily really required for that clinical trial and what might be excluding people an unintentionally study complexities you know trials people have to come back every single day or come back weekly go through multiple tests, there might be some populations that may be able to.
Adhere to that type of study complexity in other populations that make it more challenging and against this systematically not asking patients, as well. And so these types of factors can exclude up to 50% of minority patients, meaning before they might even be enrolled in a study where you can. Invite them to roll in this study have already excluded them from being eligible to participate.

So there’s a big difference when we think about research from research. That’s being done on populations and communities ones that they are being done in populations of communities and those are being done with populations and communities and of course, my main premise is that we should be doing research with populations and communities because we’re all part of a community if you think at some point in your life your patient probably a patient right now got some kind of condition families our communities.

Non profit organizations are cultural groups are faith based organizations. The public is a community but very often. We think about in engaging the community within our studies groups are we generally think of racial ethnic minorities. And when you think of it from that perspective that group is other that group is other than me. My point is that we are all part of a community today, an if you were being you know, someone was doing a clinical trial and is in the community that you are a part of you might want to be included or involved.

And that trial that you might want someone to come to you and ask you is this the right way to approach the community that you are a part of and so I think it’s important to recognize that we are all part of communities. Yes, we focus on racial ethnic minorities because they’re they’re have disproportionate participation. But keep that in mind that we’re all part of a community and might want to be engaged in a similarly ethical an engaged way in order to better learn how to engage in the research that is being conducted.

So there’s a continuum of partnerships and collaboration, you can go all the way on this side to just some form of community involvement from outreach and how you might provide the community with some information and then it gets more involved overtime from consulting the community involving collaborating all the way through more of a shared leadership model of what we might consider community based Participatory Resource. Not every single research study needs to be on this level, but I argue that.
Each one does need to have some kind of outreach in some form of engagement with the communities in the populations that we’re seeking to enroll in our clinical trials. So I’m going to spend the next portion to give you a brief case study of work that I’ve been doing around engaging African Americans in this research that we’re doing at MD understand using that as a model for learning how to collaborate with and engage various different population groups.

So African American churches have promoted Health, Education, business political activity with this within the African American community historically because they were excluded from other mainstream ways to kind of get this. These services in this information. And so the Black Church became the place that everything was provided so while they do care about the spiritual health of the population in the community. They also care about the physical health of the population and community.

They’ve been affected partners for health promotion efforts, including cancer diet and physical activity. So I’m trained in public health and got my Masters of public health at UNC Chapel Hill and that was one of the first one of the Ground Zero of really doing a lot of research with African American churches in engaging them as research partners in cancer prevention. Efforts and so I learned a lot in that setting 7770% of African Americans regularly attend church. This is data from the Pew Internet research.

Centers and in general families are part of churches for generations. So that depending on the kinds of studies that you want to do or you need to follow people. Follow people overtime. This may be an opportunity for you to find people that seem to be hard to reach are lost to follow up to be able to locate the parses and later years, so when I first came to MD. Anderson about 14 years ago as a bright eyed bushy tail assistant professor wanting to do community engaged research.

You know, we wanted to implement a research study that was going to look at cancer health disparities. An address it more from that holistic perspective to look at individual factors. But try to look at more upstream factors when I suggested that we partner with African American churches. I have been trained in terms of working with African Americans through churches on my whole karere. Plus, I’m originally from New York. We are with Cindy and Jamaican and my mother grew up.
Going to church, my whole entire life. I say that I’ve gone to church way more than their probably most people have and then I have me and God have a really special relationship as a result of that. But it’s also very familiar setting to me. I know a little bit about the people in the culture from a church based perspective and thought that they would be good partners for engaging in this research. So we started a partnership in a collaboration that we call project church, it stands for creating a higher understanding of Cancer Research and community health.

Was part of a research study, but we wanted to investigate the role of biological behavioral social environmental factors that might already helping cancer disparities among African Americans in the Houston area. The long-term goal is to use the data and the knowledge that we derived in order to improve quality life improve the cancer risk profile for African Americans to engage them in Cancer Research. But to create a long-term mutually beneficial partnership focused on doing Cancer Research.

So when you look at wanting to partner with people we all do a collaborative or team based science. Everyone has strengths that they bring to the table and so from the churches perspective. This particular church that we initially partnered with had a very large diverse congregation. So there’s about about 2.5 million people that live in the city of Houston and Houston is home of the Mega Church. So if any of you have heard of Joel Olsteen or you know, kind of like.

Where his churches former basketball stadium you know we routinely have churches that have 5000 people in them and so they have access to the populations in the communities that were interested in engaging in our research. They’re committed to reducing cancer in African Americans longstanding community relationships from ambient ocean perspective we bring knowledge of cancer cancer disparities an and knowledge about how to conduct.

Doctor assertion culturally competent way, so project charge had 5 Ames and I’m going to only touch on these really briefly, but please. Feel free to ask me questions about how we did anything in depth when it’s done but the first thing was to develop the research collaboration, the second aim. We focus on to doing a cohort study together. We’re going to try to recruit about 1500 African Americans and follow them for 3 years. We’re going to aim three share. The findings back with the church committee aim for
was to provide referrals for health related services and do some cancer French
in programming.

NOTE Confidence: 0.896414875984192

00:27:08.860 --> 00:27:20.920 Within the church setting and then to 5 was de-
veloped an evaluate interventions that we’re going to improve the health profile
so from the data that we received where do we need to target and focus on in
terms of to reduce cancer risk.

NOTE Confidence: 0.917901158332825

00:27:21.550 --> 00:27:53.100 So, in terms of aim one developing the collabora-
tion for any of you who do work within African Americans and focus on church
based settings. You may know that that relationship really begins with the
pastor they are an important gatekeeper of that particular church community
and usually when they endorse something the church body and the members
generally come along side of him to support those types of decisions so for me,
it was meeting this particular pastor of this church.

NOTE Confidence: 0.918408870697021

00:27:53.100 --> 00:28:23.670 And we had at least 4 meetings over 2 years.
When I first got there and questions that he would ask me in these meetings
where for example? How does his church benefit from their participation in this
particular partnership? Why was his church selected as opposed to others will
his congregation get care at MD Anderson that was a really important issue. I
just showed you the uninsured rates in the state of Texas and not very different in
the in the city of Houston as well. This collaboration confer additional benefits
is population.

NOTE Confidence: 0.922978758811951

00:28:23.670 --> 00:28:53.760 And in essence what he was trying to find out
is you know can I trust you right so I look like him in terms of being African
American, but I’m not like him? I’m a woman. That’s number one, but I’m
also from New York, an I don’t know anything about Texas in culture and I
definitely don’t know anything about his church in the culture that exists there.
So I have to learn that he needs to bet me to make sure that this is going to
be something that is going to be appropriate for his church and so I attended
church services whenever possible and provide information was requested.

NOTE Confidence: 0.922070145606995

00:28:53.760 --> 00:28:59.450 And the whole point of that was to reduce the
barrier of trust within this particular community.

NOTE Confidence: 0.906782627105713

00:29:00.010 --> 00:29:30.160 Sorry it’s a double slide focus on here we developed
a community Advisory Board and their job is to share the identity and the
history and the symbols and language in the culture of that particular target
population in this case, it was the church population. So it was populated with ministry leaders. There is also cancer survivors. Their parents in the elderly that the pastor had appointed to serve on this particular Advisory Board. They helped identify challenges and various implementing the study, but it.

NOTE Confidence: 0.914380609989166

00:29:30.160 --> 00:30:01.410 Assisted in advise on all aspects of the study that we were doing in the partnership such as the informed consent process recruitment intention and one thing they were really concerned about was an ethical conduct and confidentiality of when people were providing their data. You know where is it going to go? Where is it going to be stored? Who is going to have access to it things of that nature that I would not have known that maybe rose to a level of making a decision whether or not you were or were not going to participate. It might have rested on whether or not the data. We're going to be kept confidential. These are some of the things that they were.

NOTE Confidence: 0.910346686840057

00:30:01.410 --> 00:30:31.960 Sharing with us to let me know what was really important in terms of how we recruited the 1500 participants was very common is on a Sunday morning. You know the past, so maybe talks about this particular partnership in front of the church congregation. What he also did was allowed me to address the congregation as well to talk about this partnership in this study that we were doing and they wanted to do a health fair, which I hate health fairs. I mean, we all know that there not evidence based we do them anyway.

NOTE Confidence: 0.905533909797668

00:30:32.070 --> 00:31:03.240 And I might have one I wanted to resist that but the Advisory Board was telling me know. We know our people. We know what’s going to work 500 people signed up to participate in the study on one day, um when we rolled it out doing in the way that which we’ve done and I’ll show you a little bit more about how that was done video announcement during churches. People handout recruitment cars, but one of the major things that we were able to do was get space within the church so that we can enroll people in our cohort study so.

NOTE Confidence: 0.905268609523773

00:31:03.240 --> 00:31:28.760 Instead of asking people to come to the Medical Center, which no one wants to come to any Medical Center because it’s tedious and you have to park and it cost so much money you get lost. Instead we came to where the people were an set up a office within the church so this is an example of our project church office. When people walked in what the setup was some health education information that was there for example.

NOTE Confidence: 0.916786670684814
So, in terms of aid to developing the focusing on the research. We focused on doing a prospective longitudinal cohort study. One we wanted to investigate. These particular factors but it’s also the design that was going to reach as many people as possible. And so our goal was to 1500 church members. I can tell you a little bit more about how benefits that the church and the participants received for participating In addition to compensation.

In those first three years we were going to do annual data collection, you’re one with the baseline survey and then subsequent years added an optional procedure. So, your two we collected DNA for Biobanking and about 12191 of the original 1500 agreed to participate in that and so that was a 92% participated of that, but that’s all the people who came back and then in the year 3 want to collect objective measures of physical activity, Belinda Melinda would love to see that.

So there’s about 280 questions over all these are some of the categories.

And that you’ll see. We tried to keep it as comprehensive as possible with focusing on burden as well. So the older you were the longer took because you had to ask answer a whole bunch of questions about screaming. The younger you were it was more. It was quicker for you to complete the survey and then with the Advisory Board. We talked about adding additional questions. In subsequent years of things that they were interested in and wanted to learn more about within the Congregation for example.

So, in subsequent years we added 2 additional churches. The first one. We started with his church a an then church be in church. See is I’ve label them. These were smaller churches. But overall our final sample size, overcome all of the data collection for what we call project church was about 2338. This just shares some demographic data. One what the population look like is about 75% seventy 4%.

Female this is very common in terms of the distribution that exists in churches is very dominated by women mean age was about 46 years old. This was not a very low income low. SES groups all make that
be known about 45% were college graduates. But 61% reported one or more medical conditions. About 5% were cancer survivors and 4054% were obese. If I included this distichs on overweight. It was 70% were overweight and obese.

NOTE Confidence: 0.89057582616806

Very common as well, amongst African Americans and then this just shows you the distribution of some of the cancer risk factors within the population. Services fruits, vegetables, smoking status. Depressive symptoms have been getting prostate cancer screening colorectal cancer an not comment on current on their mammogram and what you’ll likely see is that church be stands out that was purposely recruited to be lower income lower SES.

NOTE Confidence: 0.897025525569916

And you can see that when you do that. You’ll start to see more more poor cancer prevention. Behavior is being performed in that particular.

NOTE Confidence: 0.901705324649811

Group, but what you’ll see is even in sort of moderately educated sample. You’ll see a great number of women that network current on their mammogram. You would expect to find you might expect to find lower. But we didn’t high numbers of age appropriate. People that have never been screened for colorectal cancer and even higher rates of smoking status. Usually find at least self reported smoking and alcohol used to be lower among faith based populations are because they don’t actually do it.

NOTE Confidence: 0.903878390789032

Or they don’t want to disclose that they do it. Either way, but you still see sort of higher rates here is a reminder wash not as reminded is a reminder to me. I’m telling you for the first time. This was not a representative sample and so, if you want to know how this sample relates to the larger Houston area. But we had done more of a random sample that it does look slightly different. But some of the factors do look similar and I can point out some of those as well.

NOTE Confidence: 0.907353043556213

In terms of sharing findings back with the community. This is an important tenant of doing collaborative research. We cannot be seen as the researchers that are coming to collect data from people and never sharing back what they find that is a strong pet peeve of communities. But as scientists were never trained to share findings back with anybody is published in a Journal and maybe it changes practice. But the people that we the people that we enroll in our studies that bills. The findings that we have is not uh.

NOTE Confidence: 0.921925067901611
A common practice is so we need to change that paradigm and share what we were learning with the community. So these are reports that we developed that in aggregate would share some of the data that I just showed earlier back with the community. The research participants and then with the larger community. So they could get an understanding of what we were finding and then what we were doing.

We also developed Ancillary Studies Committee, who would evaluate we want others to be able to use. This data that were collected to learn more about African American community and then identify a potential interventions to help support that so the committee assesses whether or not the research is a value to African Americans. Anne these data have been used to contribute to several Jiwa studies nationally. We have several papers published around the various cancer prevention behaviors.

And how’s literacy for example, a name for? We provided referrals to and focus on cancer prevention program. So to the extent that we were identifying people who needed cancer screening. We’re obligation to figure out how to get them screen to extend that we were identifying church members who did not have a usual source of care we’re obligated to figure out how to connect them to the source of care Anderson didn’t have to provide the care, but we do need to navigate them.

To a source of care and so that’s one of the major things that we spend our time doing and over 100 referrals were provided and in terms of cancer prevention. Activities this for example, is like to increase physical activity maintain body weight was a salsa class that we paid for an instructor to deliver and this was with like the Singles Ministry for example, and so they wanted to engage in more physical activity smoking cessation, we developed.

Newsletter that was specifically focused on major cancer risk factors and then in about the 3rd year. The Advisory Board was hearing back from the church community says OK this is good, but you still can do better and what they wanted to know was what is my individual cancer profile look like? am I at risk for developing cancer and as we know that those are very individual factors. We look at things on a population level, but we could do is perhaps provide them date about there.

Home question their own answers to survey questions so how are they doing in terms of fruit and vegetable consumption?
Well, they obtaining at least 5 servings a day for example, or what? How many minutes of physical activity where they’re getting what was their BMI. So we developed an individual. A feedback on that. We call the health assessment that broke down. Those specific areas are computers were able to calculate you know sort of their scoring and then provide that data back to them in that meant that particular need So what do we achieve so we definitely developed the collaboration under the name of the church that had mentioned before was with you?

Windsor village United Methodist Church. We met the research goals. We partner with two additional churches later and we weren’t able to recruit 1500 and follow them for 3 years. The first cohort of 1500 took about 6 months to enroll and we did a fourth data collection points are retained about 80% of folks over the course of 4 years, so not super labor intensive. They had to come back every year and complain annual and complete a survey, but nevertheless.

And actually it took 6 months to recruit 1500. We probably could have done it in 4 months. We weren’t prepared actually for the positive response from the community members who wanted to particularly participate in this research in this partnership and so we were actually understaffed but nonetheless those either the learning lessons about sort of engaging communities in the right way, and the response that you can get so you know the models. If you engage them You know they will participate similar if you build it will they come?

In this case you know, my experience over many years now working with African Americans in this way is the answer is yes.

We asked on one of the follow-up surveys on a closed ended way. An open ended you know? Why do people choose to participate and they know that the strong church involvement the endorsement by their pastor the formation of the Advisory Board who was able to communicate positive messages about the benefits of participating this. Many had a personal or family. History of cancer. I didn’t. I don’t know if I shared that statistic. But over 50% had noted a family history of cancer.

There’s lots of altruism service to God and mankind that this may not benefit me personally, but maybe it’s going to
benefit my children and my grandchildren. There’s something that I can do to see that they don’t get cancer in the future are also Golden job was to introduce participating in clinical research and very positive way where we were providing the utmost customer service. And so they noted that as well. But all the research staff was very knowledgeable and.

NOTE Confidence: 0.893314123153687

00:41:33.290 --> 00:41:57.770 It was very clear you do not have to participate in the will lose no benefits to you at MD. Anderson have any time you choose not to participate. Things of that nature and then these are some of the quotes from open ended perspective, that people are mentioned but basically we tried to reduce the barriers and increase the trust of that community in order to have participation in a stickler research.

NOTE Confidence: 0.895454883575439

00:41:58.300 --> 00:42:29.630 Then in terms of aim 5? How do we leverage it So what do we do when we got that data and how? Is it now benefiting we started this in about 2008 in terms of the first participant being enrolled you know. So where are we now 10 years later this is just a sample of some of the grants that have been received I am some of the pie of some of them. Another faculty other pies of them as well, but leverage that partnership in that infrastructure.

NOTE Confidence: 0.90106463432312

00:42:29.630 --> 00:43:00.660 In order to continue this particular research and so we when we do research within the project charge framework and there’s a grant the church is always a subcontract on that, grant if there’s any financial benefits that come they receive financial benefits to participate. We’ve done studies with them. Where we build up their capacity to conduct research and so have hired and trained research coordinators that sit at the church who also can help facilitation of enrollment in 2.

NOTE Confidence: 0.894224584102631

00:43:00.660 --> 00:43:01.740 Research as well.

NOTE Confidence: 0.88083690404892

00:43:02.370 --> 00:43:33.500 So we work together to identify a bring. The scissors on board. I mentioned the churches of Co lead. I have a grant least to the Cancer Center for non health educator. I believe you have one here as in yell as well. That person is situated within our church network. They provide this ongoing health education to the church committee community even though the research portion has now concluded.

NOTE Confidence: 0.895389258861542

00:43:33.500 --> 00:44:03.530 And these are some of the populations just a snapshot that had been enrolled in various studies over over that time by most ambitious one is a family obesity study that on the PC over. I’m going to
recruit 900 family African American families out into a study so please pray for me. This is done intervention work. You know that recruitment is you know the hardest thing ever, but I’m fully confident that I can do it is a 3 are randomized control trial.

NOTE Confidence: 0.906297981739044

00:44:03.530 --> 00:44:05.290 We’re going to recruit 24 churches.

NOTE Confidence: 0.880958557128906

00:44:05.860 --> 00:44:38.330 And this is recruiting one parent and one child, an we’ve developed. This study in this grant that we see for American Cancer Society to focus on Houston area churches and then I recently received an R21 from an ion are that’s going to use a similar infrastructure an engagement plan to focus on Hispanics focus on Hispanic churches in Houston as well. Another faculty member that has utilized this infrastructure is Karen Batson quiz. She also does physical activity research focused on on breast cancer cancer survivors and she had done on evidence program.

NOTE Confidence: 0.917271256446838

00:44:38.330 --> 00:45:12.360 That was a Tim prove quality of life among breast cancer survivors and then she got funding from Sebring to do to place this program and community based settings now as she wanted to focus on African Americans so she utilizes the project church network of churches for collaboration. My team provides her team with training and ongoing technical assistance about how to work with African American churches, thus far. The churches and the members that have the members that participated in this particular program, she’s seeing 6071%.

NOTE Confidence: 0.905988156795502

00:45:12.360 --> 00:45:23.920 Follow Ray switch from her perspective is very good compared to other communities where she’s been trying to implement this and of course, those that participate have the same kind of program outcomes as anybody else.

NOTE Confidence: 0.891427576541901

00:45:24.690 --> 00:45:56.900 And then Lastly I’ll mention utilizing this in kuna engage framework about engaging other communities as well. Other Dispur communities. And so we recently got a supplement to our Cancer Center support grant to focus on rural populations in the state of Texas and roll NE where I told you all the incidents in the mortality is that we’re going to start to go and focus on tobacco. They have high the highest rates of lung cancer incidence more child in a state of Texas and want to definitely be influential helping him bring that down.

NOTE Confidence: 0.905464887619019
But we’re going to use this same type of framework in order to build collaborations and partnerships and that particular area. Other additional communication strategies. I want to briefly touch on I direct the Center for communications relational research that Melinda talked about and basically what we do is facilitate collaboration between Indian researchers and the community and so we have over 50 local partners that they serve 1,000,000 people. But those are the partners that we go to whenever a faculty and researchers are there within RC TS?

OK, or within MD understand what to do more research on the community will tap into those networks who why does it keep moving forward anyway an Cedar has supported over 46 research studies that have brought in over 77 million dollars and we discuss clinical trial. Participation within the community on a widespread basis. We also have a community scientist program and I believe you have a program similar here that is your community bassador program.

Um where we have trained community members to give rapid feedback to researchers about their science and so community members already come with natural advocacy skills. They advocate on behalf of whatever community. They represent we also train them in research fundamentals, so that they can share their insights and first hand knowledge based on their lived experiences with our research faculty, so they advised on study design recruitment informed consent language.

You can come with just an idea so while many of our faculty within MD. Anderson an then Utah school public health utilized our community. Scientists pool our postdoctoral fellows and now, even some of our doctoral students are able to present their research in front of this community panel. The great thing about it is, you may not be able to have time to develop your own Advisory Board. You know spent 2 years developing trust in relationships that I did now you can do it in a more quick fashion by sharing some of your ideas with our community scientist.

Also, there are clinical trial clinical trial patient navigators. You may be familiar with clinical trial. Navigators more from a patient perspective? How to reduce people, making sure people come back for appointment if they have normal paths to make sure that they would come back to the clinic to get seen will now clinical trials. Navigators are as an evidence
based approach in order to increase the accrual of women and minorities to clinical trials as well. They help people understand what clinical trials are and increase there.

NOTE Confidence: 0.897956073284149

00:48:36.660 --> 00:49:07.140 Interesting clinical trials and basically help to reduce barriers to help them join and stay within clinical trials. This is data from UAB where MD Anderson was part of a consortium of cancer centers who are testing out. These clinical trial Navigators to see if they increase enrollment and trials and found that patients will accept the navigation when offered it resulted during increases an clinical trial. Participation and they were 4 times more likely to complete the trial compared to people who.

NOTE Confidence: 0.893420577049255

00:49:07.620 --> 00:49:37.990 Access to the clinical trial Navigator as well so this is a new program that we had been doing as part of the study in MD Anderson for many years, it went away and now in our renewal clear we’re going to be deploying clinical trial navigated super specific disease size that have lower or cruel to particular trials and neat that particular health and of course can’t forget this is an opportunity for a student research opportunity, so over 7 five student trainees. The majority of which are racial ethnic minorities.

NOTE Confidence: 0.894638001918793

00:49:38.650 --> 00:50:09.040 Um have participated within this project church infrastructure. They come from various disciplines and education levels high school through Postdoc Fellows, but also from historically black colleges universities in minority serving institutions. Students gain experience in community based participatory swords for servers, cancer prevention. Health disparities students published papers. Anas in those churches that are enrolled in Project Church. They all we also have a summer program where those students come to MD Anderson for the summer.

NOTE Confidence: 0.896223127841949

00:50:09.040 --> 00:50:41.510 Thinking research experiences, so too particular training grants that I have that I have again utilized this infrastructure and that we draw from is assume. It's Susan G Komen training grant to reduce cancer disparities received that grant in 2017 and we have 4 doctoral students who are participating in that and then we have a P 20 grant from NCI that is a collaboration between MD Anderson and the University of Houston, which is a minority is Hispanic, serving institution.

NOTE Confidence: 0.899893939495087

00:50:41.550 --> 00:50:55.890 In order to develop Cancer Research partnership, so we also got that grant in 2017. We met provide mental research experiences to students and then our students also do community outreach and education as part of their training.
And the last thing I’ll mention is the notion of a community mentor, so whereas we are very familiar with research mentors. An research mentors help guide us through the research process and how to be calm develop into a researcher and generate a knowledge base community mentors are people who can serve in that same way. An I would argue that alongside of research mentor that many of our students should have community mentors whose job it is to provide access to Munich humanity.

Mentors talk to real effective people engaging community meetings in networks and so engage in learning from a different perspective. Yes, we learn hands on in the lab perspective, but the community is also allowed for that perspective where they need to gain hands on experience as well. They provide a bigger picture and impact for why the research. We’re doing is as important and these are Coleman scholars and this is our Cullman mentor who is helping to facilitate those relationships, so future research and health disparities in community engagement.

You know, we need to develop and evaluate trans-lational teens that includes community perspectives, engaging sort of the Canadian scientists program clinical trials navigator. I believe the notion that altruism is a very strong motivating factor in the communities in which we want to serve. It’s just the way that we approached them engage them in that, but that can be useful in terms of gauging in the research project process consider the impact of age in sections sexual and gender identity in.

Focus on cancer risk and cancer outcomes, so um, including only the necessary and relevant relevant eligibility criteria, including Spanish speaking populations at us as a minimum. My I’m on a quest that it can be interesting we cannot keep saying that we cannot enroll his Spanish speakers because we don’t know one of my team speak Spanish. No, we have a whole infrastructure that can translate conformance. Long consent documents. I sent that I have can provide that kind of translation, but this becomes a common.

Um um framework that is being used as an excuse. I think for not being able to gauge in those cut population. So we’re going to get rid of that overtime and using common visions beyond race ethnicity.

To collect those data because it allows for pooling and sharing of data so if we’re all collecting race ethnicity in the same way so she
economic status in the same way issues around acculturation disability status. And so forth that you might have a single trial that focus on one population. But we may be able to pull our data in order to have more power to look at some of the disparities that we’re interested in one single study that you may not be able to do that, so the implications are cancer disparities. Research is not a novel method can be engagement is not an now NCI recognizes.

NOTE Confidence: 0.879798531532288

00:53:44.380 --> 00:54:15.830 As well, but it does work to bring the communities as alongside of us as we’re trying to better their cancer health profile. There’s a focus on communication principles research methodology intervention development in suiting training and it’s replicable. I have a query grant that just ended where we were using a similar module process for Asian Americans not in church based setting but still using some of those principles.

NOTE Confidence: 0.865951061248779

00:54:15.830 --> 00:54:46.620 And I mentioned Hispanics around Catholic churches, alright, so last slide is that communication is powerful and it can increase participation in relevance for Cancer Research. Hopefully my talk did convince you of that and then I’d like to thank all of the projects for churches that participated. Thank you. That was great. Thank you what a great infrastructure, you created for.

NOTE Confidence: 0.907716453075409

00:54:46.620 --> 00:54:50.590 So many more studies going forward to really wonderful Roy.

NOTE Confidence: 0.843865573406219

00:54:52.680 --> 00:55:22.740 That’s an amazing amount of work I’m graduations on that you showed this slide. Clinical trials and their low clinical trials accrual for everyone. Then certainly from minorities. And while this is a grassroots type thing, and you’re probably working with many people who don’t have cancer. I guess one of the metrics would be prevention trials, which I know you do great deal of having been there. But what do you expect that you’ll see some impact when the CCSG grant is presented in Indiana you able to show at any point now that your number of minority patients and.

NOTE Confidence: 0.889105021953583

00:55:22.740 --> 00:55:54.180 I’m trousers, increasing yes, so there are 2 factors that relate to participate in clinical trials. 1st I have to be a patient. They have to come in the door. Then, when they get in the door are they on trials at a comparable way what we struggle with more at MD. Anderson is getting you know sort of more diverse patients in the door. But when patients do come to Indy Anderson and we have almost you know in terms of the proportion of the population represent representation on therapeutic trials, non Interventional trials, we have very.
Participation rates we have is accessing folks into the Cancer Center and once we do go through the culture of the place plus some of these other kinds of programs that I’ve mentioned that we have in place can see you know proportionate representation of many other hospitals in Texas. Yes, so within the city of Houston, we have sort of.

We call them Houston area location sites and there is a clinical trial infrastructure for those particular sites in the community to enroll those an roll folks there an trials. Those locations do not tend to be in very diverse areas so it increases clinical trial participation, but actually makes us look worse from minority participation in clinical trials because those are participating primarily are white because that’s where the those locations are.

Locate it, you probably know the MD. Anderson is you know on a world quest for world domination. So you’ll see us in New Jersey and in Florida and I don’t know we might show up down the street any day, now. I’m just joking. I hope not only are things like just you know, those sites are not included in our cancer trial data.

It’s really wonderful work and I have a similar question, but from a different perspective and I’m wondering whether you’re able to measure within your project church participation group.

Delta changes in attitude about therapeutic clinical trials before and after participating and or whether there’s actually enough. You know malignant disease developing within this cohort, which is a couple 1000 people, and whether there’s been any measurable output in terms of whether people go on trials because now they have less skepticism. So you know as you know developing and maintaining real Cohort Studies is very expensive so.

I think the initial thought was to engage the community in research. Through this cohort design and follow them overtime. But once the relationships were developed to be able to do other things, so maintaining the cohort and continuing to follow people is not something that we’ve done to be able to show the data that you were talking about hindsight, being 2020. Of course wish. We had done that because I get that question and you know can’t demonstrate it from from from that perspective.
Oh yeah, thanks for that, really interesting and rich talk. I had to sort of separate questions. One is we know that regular church attendance is associated with a quite a significant lower mortality rate all cause mortality rate. An I think also depression rate, and I was wondering if in any of your studies. You’ve been able to look at that within the different churches in terms of the the breadth and depth of participation and whether that does have an impact.

On health and whether people in the churches were interested in that point and then the other question was whether there was talk of bringing the clinic to the church like in a big church with 5000 people. There could be like health clinics right in the church with screenings and so forth that would maybe avoid a lot of the barriers of people getting there and getting in and etc. So House I’ll tackle the latter I first screening is always a really big.

Issue because it’s hard to sort of universally screen and then people. Find the cancer and then there’s no follow-up care that you can you know sort of link them, too, so I think that that’s great that you’re in the state of Connecticut that theoretically people have access to care due to Medicaid expansion so that you can be in the community in more of that strong way in order to be able to link them to care. When something is diagnose so that we do have a mammography van and have some secret grants to try to increase colorectal cancer screening.

But it’s within a low income clinic context. So we’re working with FQH CS in order to identify their own patient populations that aren’t current and then provide the screening there and then navigate them back to the clinic and don’t do as much of that from a community based expect perspective ‘cause. We need a place for them to follow up care as a relates to sort of the improved health outcomes necessarily for mortality. Other ways within a church context and lower sort of let’s say perceived stress.

And uh a depressive symptoms. I mean, there was a fair number. I don’t know how it how it relates to the national average in terms of report of depressive symptoms. But high enough there that to your point that you may think might look slightly. It might have a different profile so people were willing to still endures depressive symptoms. You know, I mean in this particular 30% who completed the survey that’s very, very high so there are some benefits to you know sort of being in a church setting or
Being spiritual or having faith, but it’s unclear from these data sort of where the benefits you know begin and end there’s still a lot of cancer risk in psychosocial health that needs to be addressed in that community, regardless of the fact that they attend church.

NOTE Confidence: 0.956863641738892