

INNOVATIONS CONFERENCE -- HIGH PLAINS RESEARCH NETWORK

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NORMAN: Well, I'll go ahead and start. I'm Ned Norman. I'm a member of the High Plains Research Network's Community Advisory Council.

And if you ever wanted to know what the -- what the public looks like out of their silo...

(LAUGHTER)

I'm a farmer and a rancher. I don't work in healthcare. I don't work in research. I'm not a doctor. So this is, of course, an unusual thing for me to do. A much more engaging audience than my cattle tend to be...

(LAUGHTER)

It's appropriate for me, I think, to -- to talk about grassroots organizing and to talk about it from a rancher's perspective. In the area where I live if you -- if you ask a farmer what he raises, he'll say, oh, I raise wheat or I raise corn, maybe sugar beets. And I harvest that crop with a combine and market it.

Now, if you ask a rancher what he raises, he might say beef or cattle. But the -- the wise ranchers, the ones that have been there a long time and run a good -- a good operation will say -- they'll say that they raise -- they'll say that they raise grass. And they harvest it with their cows.

Because they understand that -- that the crop is the grass. That is -- that's where their wealth and their livelihood comes from and that if they have healthy grass, healthy pastures, healthy grassroots, then that will support their cattle in the same way it'll support the information transfer you're talking about with your communities.

It'll support research projects, progress, change, getting these discussions going on these platforms. It's all about having the roots activated, having all that stuff working. You can't just be top-down.

So with that context, I think HPRN, which is the High Plains Research Network, has done a really good job of grassroots organizing because they have fully committed to this idea of community engagement, which is what's led me here.

It was started, in 1997, by Dr. Jack Westfall, who is a family medicine doc who works out of C.U.'s Department of Family Medicine in Denver. He was born and raised in Yuma, Colorado, which is one of the communities. It's about two hours from Denver. It's in the network.

And the network does practice-based research and community-based participatory research in a way that oftentimes people don't think would work.

So this map is of Colorado. And it shows in the yellow area the region of Colorado that High Plains Research Network covers. That's a 16 county area. And just to give you a sense of reference, that covers 33,000 square miles. Maryland is 12,000 square miles.

Of those 16 counties, 9 are considered frontier counties, population of less than 7 people per square mile. The rest are rural. No frontier counties in there. So it's a huge, wide-open area and nobody lives there.

So what you have are lots of very small, dispersed communities that don't know each other but share a lot of commonalities.

So Sergio is gonna tell you about how the Community Advisory Council came to be.

SANCHEZ: Good morning, well, good afternoon, guys. How are you guys? I gotta tell you that I was really interested in your guys' technical stuff. That's pretty cool stuff you guys got going on. I got to tell you that I really like that.

I manage a hardware store. It's a two-store chain. And I'm always trying to encourage my guys to use more technology to get more efficient, to get cleaned up and start making things. You make more money if you do that.

I think a lot of the concepts that I saw in the marketing and how you were trying to get people involved, it's the same kind of stuff. It's just you're talking patients, I'm talking hammers and screwdrivers.

So that being said, how HPRN came to be as a -- a -- an advisory council, it was formed in 2003. The real experts on here are really the people that are living in the grassroots. The guys that live in that 33-mile zone or that -- that -- that one-third of Colorado that really is uninhabited.

They're the ones that have a different kind of lifestyle. Their lifestyle is more based off of gotta go to work, get up to school, get the kids out there -- there's -- gotta get to church, you know, there's a bake sale going on, there's a auction going on somewhere. We gotta go, somebody's selling.

Right now people -- Ned, it's really crazy for Ned to be here right now because he's supposed to be harvesting. And I don't know why he's here.

(LAUGHTER)

NORMAN: Taking a break.

SANCHEZ: He's taking a break.

Our group is made up of all of the unusual suspects. You really aren't gonna find a bank president on our board. You're not gonna find a college president, wealthy business owners, what you're gonna find is, I think, what makes us really strong, OK?

It's gonna be just that we're all really diverse -- there we go -- makes us very diverse because of all of the different kinds of personnel that are involved in this group that we have.

It's about 14 to 15 people that are in there and they range from 17 all the way to 81, if you really look in there. But there are -- everybody there has a life other than this. You know, this isn't where our paycheck comes from. This isn't where we're involved.

We do it because we're passionate about it, about our community, and we want to make things work. But that being said, it has to work. We don't have time to wait for all of the mumbo-jumbo that goes on to try to get something to come across.

Sometimes when I hear the, it takes three years to get out something good, I go, that sucks. I -- I -- I go, you know, by that time somebody else in my field would of came out with a better fertilizer, better hammer -- I'm losing business waiting for everybody and we're having all of this discussion.

So for me, these are the real experts. These are the ones that are there hitting it -- hitting it all the time and making it happen for Jack and actually the team that we have.

And on Jack's end and Linda's end, from the college side of it, they're very good leaders. What they've done is they've really thought about this in a whole circle, in a big, big rounded start-to-finish kind of area.

What they've done is they looked at, when they picked people out they had to be somehow connected to the community. They had to be people of interest. I mean, you go to the hardware store, you're gonna see my mug sitting in there.

But then also, a couple key traits that we did was, we have husband and wife teams. So then really the discussion after our meetings doesn't end after the meeting on the drive back home. And if you look at the distances that some of us drive, there's a lot of discussing going on when we go home.

It's after we eat. It's like we gotta get ready for this. So this has been really one of the phenomenal traits that have made us very strong right now.

And this was formed by Jack and I think it started with, around 2001, with -- with AHRQ. I think there was a -- now, make sure I get all my acronyms all right and all of that because that's one thing that I found with all you guys, is there's a lot of acronyms.

(LAUGHTER)

It -- it's the RFA that put out, I guess, a feeler out there for some mechanics on a community involved organization or something and I guess that was our push. Wow, that's how we ended up starting here.

But for all of that being said, one of the things that happened for us in a small -- in a small community are that where our clinicians, or our doctors I guess we would say, when they live in a small town, they live a different life.

As soon as the doctors are done with their 9-to-5, if that's what you would call it, they really still don't get to shut it off. We get to see them at the grocery store. We see them at the game. I see them at the hardware store, hopefully a lot, you know.

(LAUGHTER)

And -- and that's, you know, part of being this group here, you know, that-- that we're all intermingled.

NORMAN: Well, there's a picture of our motley crew, some of the motley crew at a conference in Montreal, NAPCRG conference, which I've been to now maybe seven years in a row, to this NAPCRG conference, which is the North American Primary Caregivers Research Group where we do presentations, poster sessions -- everybody knows us there.

We're the people that wear crazy t-shirts, apparently. We'll come back to that slide later.

So now I'm gonna run you through a large project we did called Testing to Prevent Colon Cancer in rural Colorado. And I'm gonna go through it trying to accentuate how we did grassroots organizing and tried to involve as many people as possible.

Because I want you to understand that our group is not like a focus group. High Plains Research doesn't call us up and say, come spend an hour with us. Let us run some things by you; check some surveys and then go home.

They might like to do that at this point but they don't get to.

(LAUGHTER)

We are, you know, deeply and systemically involved now in what we they do.

So this project was a four-year CDC funded research study. And it aimed to increase the screening rates for colon cancer in our community. Eastern Colorado has very low screening rates, within the state of Colorado and nationally.

So it -- it was a CDC funded idea that came to us as opposed to us looking for this one, which we've also done. We agreed to do it when we discovered the severity of that problem and that need for us.

So you can see where there's the 10 CAC members, that's our core group at the time. The first thing we'd do is we typically grow the group a little bit bigger so we added another 13 people who are also community members but they tend to be health professionals in this case, not all.

Increasing the size of the group, of course, means more creativity and energy. And in going back to the onion analogy this morning, if the 10 members of the CAC are the one percent, then the nine percent would be like one of these joint planning commissions, these extra docs from C.U., extra staff from HPRN, people from CDC.

They come together for a shorter period of time, do a project, but then they go back to their communities and their lives when that project is over.

So we -- we came up with our message for this intervention and then the community itself came up with the message, not HPRN. We used HPRN as a resource to talk to doctors to learn the medicine, to learn what we should and should not

recommend.

We sculpted this message, which has four points. I actually wrote them down because Jack would be upset if he knew I forgot them: colon cancer is the second leading cause of cancer death, colon cancer is preventable, testing is worth it, and talk to your doctor today.

Because what we were after, we weren't telling people what to do medically, we were trying to get a dialogue started, raise awareness of this issue and get people to go to their doctor and say, what's all this thing about colon cancer?

So those messages were the core of all the material and intervention ideas that we had for this campaign.

And so then you can see where it bifurcates out into a lot more people. And -- and in an area of -- of that magnitude, with such a low population, this is a lot of people. You gotta trust me on this.

So as you can see, there were -- some of the materials were what we considered active materials. You had to pursue them. You had to go to a talk. You had to spend some time actively digesting information.

Some of the other materials were more passive. Traditional newspaper articles -- you just pick them up and read them and you set them down. The palm cards here -- there's the green one that actually shows Sergio.

We originally met Sergio and his wife Norah as what we considered photo talent because in -- in his...

(LAUGHTER)

In his town we needed local people who were recognizable to be in newspaper pictures and to be on this palm card. The idea being you could pick these cards up at stores, the feed shop, you know, when you went to buy your tractor parts you could pick up these palm cards.

The palm cards said here are the four main messages I read to you. The palm cards said, hand this card to somebody and ask them about colon cancer. Take an action. Do something.

The palm card also said, if you just simply call your clinic and tell them that you have a palm card, you can go in and pick up one of these beautiful stainless steel coffee mugs for free.

We didn't want to overwhelm the clinic with you have to make an appointment because they don't want that. So just call them. And the staff was thrilled to do this.

The mugs have "Got polyps?" on it -- conversation starter.

(LAUGHTER)

Inside the mug is another palm card and some of the -- I think some of them had a free cup of coffee.

SANCHEZ: Yeah.

NORMAN: So you could pass that out, give it to your friend. They're like, hey, that's a cool mug. What does "got polyps" mean, but I'm gonna go get one.

So it just -- we tried to sort of saturate our environment, as big as it was, with all these sort of cues.

You can barely see it but there's one of them called the Farm Auction Flyer. This was our guerrilla tactic. In a small town rural community like this at certain places around town you will see these stacks of auction flyers nailed up to the wall.

They have pictures of farm equipment and basically junk for sale, old tractors, old combines, old cars, fence posts, that kind of thing. And they tend to be really tech -- they're really information dense with the facts about the combines and the facts about the implements and the facts about the guns

that are for sale.

So what guys do, especially 50 and 60 year old males, who you really want to have get tested for colon cancer, is they just -- they pull one of those off the wall. They wad it up. They take it home because they think, man, I gotta call about that combine.

And then they got home and opened it up and discovered that all the information on there, even though it looked like an auction flyer, was all about colon cancer.

(LAUGHTER)

And it freaked a lot of them out. We had a sheriff...

(LAUGHTER)

We had a sheriff who was upset because he really wanted the combine.

(LAUGHTER)

So at every level we used local people to pass these materials out, hang them up. We used local people to give personal, I mean, to give talks at the gun clubs, the churches, the Rotary, and they were always matched -- a -- a -- a talk was always matched, the local person with a clinician to make sure that you had legitimacy and medical knowledge, but a local person so that others would listen.

So by the time we were all done with this project, we'd involved 230 people in implementing the project and that's not who saw it. So the entire system was generated through grassroots organizing.

SANCHEZ: All right. Now, to add on to that, when we did another project here, it was our asthma toolkits. It was called Community Air.

I must be getting nervous. My legs are shaking.

And it was a two-year quality improvement program funded by the Caring of Colorado -- the nice part about this is that we followed the exact same thing that, the format, that Ned just talked about. We did the exact same thing here.

This one was really beautiful, though, because what it did was it started to create its own amazing little web here. What it started to do was that Jewish National came up to us and said they've done all of the footwork. They did the first side of this, right down -- if you look over here onto the left.

And they put this beautiful box together and they'd had all of this information. What was really was inside of there was spirometers and a lot of training material encouraging people to go down and go get checked and, you know, the emphasis being you can live with this -- I think we came up with that.

But they -- they put all this together. They had all of their brain trust all together and they came back to us because I -- I think what they ended up doing was they tried to put this out by themselves and it wasn't working well.

They -- they -- it didn't go as good as they wanted so they came to us and they talked to Jack. And Jack said I don't know if you really want these guys involved because they do things a little bit different and all.

(LAUGHTER)

NORMAN: And -- and just to give you an -- just to give you an idea of how this works, they talked to Jack. Then Jack said, sure you can come to the meeting. That means you can drive two and a half hours from Denver and you're welcome to sit at our meeting and ask my Community Advisory Council if they're interested.

SANCHEZ: Yeah. That's right. And what ended up happening is...

NORMAN: And we were.

SANCHEZ: We were. We were more than happy. Like I said, you know, all of them experts that we talked about earlier, they want to help. They always really want to help.

But they want to find things that are actually applicable to where we're at, things that make sense, you know. You -- you get too big -- too big of a word going on -- I mean, we're just country folk, I guess, you know.

What will end up happening, though -- what ended up happening here is that we accepted, they brought us their box and like I said earlier, I don't know if they were really ready for us because we started tearing into it.

We looked at it and we go, you know, we wouldn't use this. This is junk, you know. The information was well but really what we looked at was not junk to the point of the information that was in there. It was just the way it was presented.

We pulled out a book that looked like a manual to probably one of the combines that -- that -- that we were just talking about. It was about this thick and we went, that doesn't make me get inviting about wanting to come in and do anything with that.

I go, wow, this is so disconnected that, what are you doing? You know, make it simple. Give me the -- give me the facts, you know. Put a coloring book inside of there. You're gonna try to get kids inside of here.

We almost redesigned the whole box and literally to the point of we just didn't change the outside, you know.

NORMAN: I -- I think they already had so much money invested in it that they didn't let us.

SANCHEZ: But I mean, the fun part about that is that once they came to us, we did that change and it sounded like it was something that we were gonna be able to go ahead and tackle and -- and make part of our -- our -- our resume, I guess you would say, a -- a project that we're going through now.

And what we ended up doing was we were trying to encourage people to go ahead and go back to their doctors and get an asthma check, you know.

Go ahead and check yourself, you know, to make sure, if you think you have this, because a lot of times it was getting misdiagnosed with allergies -- it was a hard one to diagnose, especially where we're at.

There is wind always blowing in the northeastern part of Colorado and more often than not you probably have asthma or had asthma and they probably were told that it was allergies or something.

So what we were trying to encourage was, you know, you can live with this. Go get checked. You know, go do what you have to do. Go talk to your doctor. They'll give you an asthma toolkit.

And as we were going through that, we wanted -- we wanted to emphasize the -- the -- the younger adults in our -- and -- and high schoolers in -- in our community.

So what we started to think about was we tried to break off who do we want to attack with this message? Who are we going after right now?

So we started thinking about kids that, you know, really can go on and play baseball because everybody's really, ooh, you know, something's gonna happen if you have asthma and all.

And we were trying to get there and say, you know, you can live with this and still do an everyday kinda deal, you know, be out and work or go to school and play sports.

So what we needed was -- the web started to grow that went from National Jewish and it came to the HPRN and it came to us. And we were a little stifled there on how we're gonna get this word out.

How are we gonna get this out to the high schoolers and -- and to the junior colleges? We had to bring them in.

So our -- our web grew bigger. We ended up we had two high school kids that -- that -- Chris and Jessica that were on our board and they were actually the ones that came up and said put it all together. Send it out to us. We're gonna get the FFA involved, the FBLA, all the sport agencies, we're gonna put all of them -- we're gonna let them own it.

And what we said is, OK, then we'll message -- we'll -- we'll -- we'll hang out on the message that we're gonna try to get out.

So instead of cups, we ended up focusing on some shirts that had some key, important people on it, like JFK that had asthma, you know. And we had them on their names -- (inaudible)...

NORMAN: T-shirts.

SANCHEZ: T-shirts, yep, that had them and it -- it -- the kids sort of made that fun. That was part of their distribution, you know. You could see them walking around with these t-shirts all over town and it was sort of fun to see, you know, because you could see the word was getting around.

But then we didn't only, only focus on that, we also focused, for the kids, we got them to take that and say, you distribute this. You make this happen. You be -- you be, through the schools, get this all out to everybody -- be our distribution, I guess, for us. And it -- it worked out well.

On the other hand, what we ended up still working on was we worked on dust masks to show how well they didn't work for asthma. If you're sitting out there and you're putting these out especially if you're out cleaning in a rural area and all of that, you'll -- usually you'll see them with just a regular dust mask on and we ended up finding out that doesn't work as well as what you need it to be.

The t-shirts, like I said, for the kids and then we ended up doing posters that -- the posters that we put had very good information inside of it. You know, to get you that -- inspirational things that would say, you know, you can live with asthma.

But the nice part about it is we used local kids on it, you know. So we put them on there so now they're a little more hero when you put it in the -- we got those into the elementary schools. And they could see the big football star, you know, wow, look at him and what he's doing.

And -- and we were able to generate some more involvement there from, I guess, this web that had just started. We didn't know that it was gonna get this big.

And I think on ours, on the bottom it said about 688 people were involved in trying to implement this one, you know, from the top, not just people that saw it.

But that is pretty big from where we were at and the nice part about it was that we learned that even our kids are interested in this. Even the young group will get into it.

If you pick the right ones, it's really -- you gotta look at what your information is gonna be, what are you trying to sell or trying to get them to get involved in.

And really, in reality, this is -- this was a fantastic one because to this day, I think he is going to school to be a rocket scientist...

NORMAN: Who, Chris ?

SANCHEZ: Chris. Yeah, literally, I mean, we sat in there and I mean...

NORMAN: It's our high school members of our group.

SANCHEZ: Yeah, and I mean, this worked out fantastic on his end and I -- I really believe that the legacy will grow on. It'll just keep going on.

So then if anything maybe later on, you know, down the road, you know he gets into and he buys into the community involvement, make your community bigger, maybe going back to the rural area because that is one of the things that we run into, that it's not very service -- I don't know, that's not very

good -- it's not serviced well.

You know, it -- it's just is it's hard to get information to us fast enough or good enough, you know, agencies to be able to come out and say this is being done right, you know, and -- and you usually end up finding out at the end that it's not.

So this kind of community involvement on our end I believe is very beneficial to us. I think it benefits my kids. It's worth my time. You know, I flew a long way to come out here to turn around and go back to work tomorrow.

So with that ...

NORMAN: What's great about a project like this is we had this method all worked out, design with messages, design these materials and we had all these great ways to put it in these communities.

When we got to this trying to reach a younger crowd than it was normally represented on our group and we got kind of stifled. Well, the young kids on the group said, well, that's easy. Just give us the materials. We'll go to the schools. Here's who you talk to.

And sort of deputized people within each of those smaller communities and let them customize that intervention for however it works in their little tiny small town or their football team or their junior college.

And so we didn't expect that at all but we were, like, well, of course, you know, a bunch of 40 year old farmers can't tell high school kids what's gonna make this cool. Let them do it.

So if you're committed to the process and -- and just be patient with it, it will take off and run by itself for a while. So this always brings the next question. Why does the community keep coming back? Why do we do this?

Well, this is my ninth year as a member of this Community Advisory Council. And the joke in our group is the only way you can stop is by moving away or dying.

(LAUGHTER)

SANCHEZ: And that's true.

NORMAN: And it is true so far, sadly...

(LAUGHTER)

... on both counts. But it is fulfilling. It's purposeful work. We feel like we're doing something great and helping our community out.

For me personally, it's a lot more interesting than being just a member of the PTA or just going to your typical sort of board meeting once every six months. It's a bigger investment, a bigger commitment.

It truly is fun. We have a great time even though they're all day meetings when you have them. It's a long drive, when we have a meeting. People drive two, three, sometimes four hours for an all day meeting for our group.

We always make the people from the front-range come out. They always meet in the eastern half of the state, which means that all the C.U. people have to drive at least two hours.

We have a loyalty to the HPRN family. And, you know, there's loyalty and trust there but that's because of the way the situation has been -- has been taken care of for us.

And the work provides added mental stimulus. You hear this a lot but you have a lot of people out there who might have simple jobs or they're retired. They want to chip in. They want to help. They need something to do.

And you don't have to dumb it down and make it simple like draw a poster, you know. Make it hard. Make it complicated. Make it -- ask for them to give of themselves and they'll do it.

You get a lot of respect in the community. You get to help the community out. And as I've said before at other talks and people don't believe me, but there are always members of these communities who are just sort of waiting to be engaged.

They're ready to be activated but you have to go find them and ask them to do it. And then you just kinda have to step back out of the way because they will.

We've had -- at NAPCRG conference -- I showed that picture, years ago we would go to this conference. People would come up to Jack and say, you know, how do you put a group like this together? And we would -- we would give a presentation or a talk and we'd have a meeting with them.

A few years later they would come to us and say, "Well, I have a group. What do I do with them?"

(LAUGHTER)

Because they didn't know how to make that jump to going from focus group to getting them involved. And -- and I think we're pretty close to the point where -- and I think Jack's probably done this a few times -- he's at, "How do I stop them?"

(LAUGHTER)

Because there have been times when we were -- we've done projects, and there's been a portion of the intervention that's been tedious and complicated and he was gonna ax it and we said, "No, you can't. You gotta keep doing it. You gotta spend the time and the money."

So we keep doing it because it's working and because we feel like it's -- because we feel like we're worthy and because they make us feel like we're experts in our community.

So that's how you get the community engaged.

Thank you.

(APPLAUSE)

END