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The uh standard three-minute delay has been observed i'm thrilled to be here to

welcome you to the next uh treats talk our series of talks on translational research ethics applied

topics as you know these are about 20 30 minute introductions to the

basic ethics issues related issues in research or regulation around important central topics and

translational research today we are very pleased and honored to have dr

catherine head with us today Katie Head who's an associate professor of communication studies and director of

the health communication PhD program here at iupui

and i should say her topic on engaging in research within rural communities i'm sure she'll say more

about how important a topic this is it has always been important i think it is now

uh gaining the recognition for the importance and the great harm that has been done by researchers failing to

access rural communities adequately in the past and here in indiana we have an amazing opportunity to do that uh even

more than we are now and i look to dr head for guidance on doing that ethically and effectively again we are

very she's not a one of our fast members in the bsap program often these are given by faculty from the BSAP program

the bioethics program of the ctsi um but she is a close friend and uh and

colleague to bsap i'm working on a number of projects including a few with doctor with Jane Hartsock uh on

communication in genetics um a different area that will probably invite her back again sometime to do a treats talk on

so over to you Dr. Head again thanks for being here thank you so much um i am going to ask

everybody to participate just a little bit here at the beginning um if you want to turn your at least

turn your cameras on um i would like you to raise your hand or use the little

emojis that zoom provides how many people grew up in a rural area

raise your hand or all right um Dr. Beckman i'll pick on you will you

unmute yourself i didn't realize this was a part of it okay

uh Dr. Beckmann what did you like about growing up in a rural area

i was a small town and everybody knew everybody um that was great too to an extent

um from a healthcare perspective you sort of had your doctor you know your entire

life from for many um i don't live there anymore but but i think sort of the small town feel knowing everybody

grandparents right next door you know kind of a thing what uh if you could use one word to

describe your town that you grew up in one word that encapsulates kind of

a really important thing what would it be comfortable

looking back now as a very educated person who studies health herself what would you think are sort of the

major health issues looking back in your community that you guys grew up with

um specifically very low vaccination rates resistance to

fluoride in the water wow there you go there are two big ones

yeah definitely all right thank you thank you so much i won't pick on you anymore anybody else who grew up in a

rural area do you want to tell me something about your town that you loved or looking back that you reflect on now

i saw some other hands Tasha did you say you grew up in a rural area

yes i grew up in a small town um the thing that i liked about it the bet

well the best is like she said everybody knew everyone no one really leaves so the same families have been there for

forever yeah if you could look back and maybe pinpoint maybe a really hard issue

in that town growing up something that people struggled with what would it be

struggled with is probably education the socioeconomic status and the

thought that most people never leave means there's not a high priority on education

thank you thank you for sharing that i wanted us to start today thinking about those of

us who come with sort of our own knowledge about growing up and living in rural areas and

the importance of listening to people who are from those rural areas as we think about what the problems are and

what the strengths are in those communities so i'm going to share my screen

i like i always say this i like on zoom how we um narrate what we're doing so everybody knows what we're supposed to

be seeing um the title of my talk is engaging in research within rural

communities i am from a rural community and my research career has touched on

several different rural projects so it's been a theme that's run throughout a lot of my research and it's one of my

passions so i'm really grateful to Dr. Schwartz and to the center for asking me

to do this talk and i hope i can leave you with some guidance and some thoughts about doing this work some of you might

be brand new to it or thinking about kind of breaking into it some of you may already be doing this

work and i welcome your own expertise and thoughts on some of the perspectives that i'm going to share

today so i want to start um with the idea that

people who live in rural communities are already starting out with a lot of

health disparities so if we look at some of the statistics that are out there we know that access to MDs and other

specialty health care is lacking in rural areas we know people in rural areas are

have higher rates of being uninsured or under insured

people live in rural areas often face poverty and low income and a lot of the things that come

along with that they often tend to be older and increasingly rural populations are

becoming more racially diverse we also know that people who live in

rural engage areas some health behaviors that put them at increased risk so we know people in

rural areas tend to smoke more they tend to have higher diabetes and coronary heart disease

we know mental health care is really lacking in rural areas

the suicide rate for young men in rural areas is much higher than it is for the general population

one of the big rural projects i worked on very early in my career was with the department of veteran affairs and sort

of the south central united states and we went around to the different community-based outpatient

clinics which are always associated with a va medical center to interview mental health care providers out in rural areas

most people don't know but most young service men and women and veterans are from rural areas and they're returning

to rural areas after you know Afghanistan and Iraq often when we went out to interview

mental health care providers in these community-based outpatient clinics there were no

psychiatrists usually there was not a psychologist the main mental health care provider we encountered were social

workers which do great work great social workers do amazing work but they are

usually not trained to provide the type of mental health care that some of our veterans need so there are

access issues to health care in general but mental health care in particular the digital divide is something that has

to be mentioned when we talk about rural health and doing research in rural health the digital divide is not just

that people don't have access to internet is that they don't have access to good broadband quality internet

my mom lives in a little rural town in Texas and she lives three quarters of a mile from the

end of the road where the internet stops and it doesn't matter how many times she calls the internet company

how many times her neighbors call they can't get the internet extended down to their houses so this is a very

real problem that people in rural areas face we also know that people in rural areas

have transportation challenges um there is very rarely public transportation in

rural areas even though rural residents usually need to depend on it more

so we know that these stats on rural health are pretty grim when it comes to

health disparities our neighbors are facing a lot of different struggles but

rural areas as we heard from some of our attendees when we started are also full

of just really rich wonderful cultures that provide a really wonderful place to

go in and do research and try to tackle some of these health disparity issues

so today during this talk i want to talk about sort of four pillars

that have guided my own research in rural health that i learned from my mentors and that helps influence how i

approach this kind of research and i've labeled the talk research within

rural communities because i want us to focus on that with as much as the in

so these four pillars that i want to talk about will be kind of the main points of my talk are the use of gatekeepers when we're

doing rural research the focus on trust with our research participants in our communities

the focus on relevance the relevance of our research topics to our participants

and not surprisingly as a communication professor i'm going to focus a little bit on communication

i have worked on a number of research projects in rural areas but today i want

to use a research project that i worked on when i was at the university of Kentucky

um and i'm going to use it as a little bit of a case study i'm going to spend some time introducing it and then as we go through these four pillars i'll kind

of give examples from that project so the project i'm going to talk about

is a big CDC-funded prevention research center that was situated in eastern Kentucky

it was called the rural cancer prevention center and it was focused on cervical breast and colorectal cancer

among residents in this little eight county region you can see highlighted on

your screen it's called the crad Kentucky river area development district

this eight county region has some of the worst health statistics that you're going to see across the country but

particularly when it comes to these three cancers my main area of working on this project

was focused on cervical cancer screening and hpv vaccination women in that area have a 40

higher likelihood of dying from cervical cancer compared to the national average so we knew there were some serious

health disparities around cancer in this area um this

project was situated in an area that was very

different from where the university was located in the city of Lexington this was part of the university of Kentucky

and one of the things that we spent a lot of time doing was getting to know our community and getting to know

Appalachia and getting to know this eight county region there's a really wonderful article and i

know as part of the talk i can share some resources but this article does a good job of helping

us think about how place and the cultural values and

history and um you know employment opportunities

and social aspects of the community plays a role in health and one of the

best quotes i love from this article is that the mountains shape these people's lives both literally and figuratively

and we took that approach as we approached this project and we were working to tackle these cancers

now it's important to remember that any time you are working with marginalized populations you have to consider

your own biases of what this community is like especially

especially if you are not a member of this community and so around the time that we were

doing this project Diane Sawyer who likes to say she's from Kentucky and she understands these

people by the way she's from Louisville which is about as far from Appalachia as you can get did a 2020 special called

hidden America children of the mountains where she followed people in Appalachia

and some of the footage was from this eight-county region and it was

a very harsh look now there was a lot of it that wasn't false but there was a lot

of it that she didn't portray and so this sort of um media coverage about

this marginalized group shapes how we think about them shapes how we think about the kind of research or the kind

of people that we're going to be working with another thing that's really important about rural research and any research

where you're going into a culture or group that you are not a part of is learning how people

talk about themselves and learning about what's important to the people who live there and their identity that's tied to

that place and so one of the

wonderful things you learn about going to Appalachia is you have to know what to call it so i'm going to share a quick

little video real quick and um Peter Emily since your cameras are on let me know if you can hear the sound

the safest way to say is Appalachian and i have to explain this to people

because when i go off on book tours i find myself being appointed as cultural ambassador and i will get somewhere west

of the Mississippi people will say Appalachia i will correct them and they will say well that's how we say it around here so i finally had to come up

with a story to explain to them why it's not um

optional if you're in if you're in Ireland in the north of Ireland and you start out in Donegal

that city on the west coast and you're headed for Belfast it will take you most of a day to get all the way across

Ireland and you'll be driving on the coast road where if it's a clear day you look off your left you'll see Scotland

in the distance well about halfway between Donegal and Belfast there's a walled city which is hundreds

of years old it was built by the Irish and they named it the Irish word for oak

tree which is dairy but a few hundred years ago the British

conquered Ireland and they changed the name of that town to London ferry

so it is one town with two names and so if you stop at a little store along the way and ask directions on how to get

from the walled city you can walk in and tell the man behind the counter that you want to go to Derry

where you want to go to Londonderry and either way he will tell you how to get there

but you need to know that when you choose what you're going to call that city you have told that man whether or not he

can trust you you're talking your religion

which side you're on and how open he can be with you in one word

because dairy is what the Irish call it and Londonderry means you sympathize with the British

Appalachia and Appalachia work exactly the same way Appalachia is the

pronunciation of condescension the pronunciation of the imperialists the pronunciation of people who do not want

to be associated with the place and Appalachia means that

you are on the side that you trust

so as we think about working with different groups and for those of you who are researchers on the call

and do this kind of work you know this kind of stuff happens all the time even single words we use to describe people

or to describe their experiences hold weight words have meaning what we

label people has meaning and these are the things we have to think about and know

if we're going to go into these communities and engage with them in our research so i set up Appalachia as a bit of a

case study because of my experience there and because i think it's an interesting cultural area

and i'm going to talk about this rural cancer prevention center project as we go through those four pillars and

i'll bring up examples from that to sort of highlight all right so the first pillar or

perspective on rural research that i want to talk about is gatekeepers sometimes call cultural

ambassadors they're referenced in many different ways in the literature but the definition is just individuals groups or

organizations that act as intermediaries between researchers and participants

it's important to understand that when we work with populations there's a very big difference between access to a

population and cooperation and gatekeepers as that intermediary can

play an incredibly important role in doing research in a community or doing

research with a community and we always want to try to strive for the width for

the cooperation sometimes though thinking about um what some of the literature calls the simple

exchange perspective or approach can be problematic just finding someone or an

organization to give you access right is not always going to be the best approach

and especially if it's a long-term project a multi-county project where you're thinking about doing long-term

intervention work maybe we really have to think

thoughtfully about who our gatekeepers are and what role they play um we have to consider the different

mechanisms that enhance or hinder that relationship and also enhance or hinder

the research for example you know an individual gatekeeper an organization or a group

they have their own motives and their own issues around the health issue that you're trying to tackle

when we worked in Appalachian Kentucky we actually didn't partner very much with churches which is a very common

thing in other research and other community-based approaches and one of the reasons was because um

cervical cancer is caused primarily by a sexually transmitted infection and working with

churches in a very conservative area to try to tackle a cancer caused by STIs

was not something that we found was um going to be helpful for the research

right and so that was not a direction that we went um instead i want to spend a little bit

of time talking about a gatekeeper we did work with and for anybody from a rural area you're going to recognize

this person in my description we were really lucky to get connected with uh a man named Wallace bates

Wallace lived in that eight-county region he owned property in that region his family had lived there for years

he was the vice principal of the junior high he coached the women's basketball

team he had a real estate license he was an elder in his church he mentored young men who were coming

out of the juvenile detention center and on the weekends he and his brother made moonshine in his garage which he then

used as part of the barter system there in their community which is really common barter it for

you know lumber or car parts or things like that Wallace was an excellent gatekeeper he

was an excellent partner in our research because he was so much a part of that community that if he brought us to a

meeting or he brought us to a school and he vouched for us there was a lot of trust that was

already there if Wallace trusts them and he thinks their motives are good then i'm on board so our gatekeepers our

cultural ambassadors have to be the people who um who care about the

research and care about the people remember gates and this sort of analogy

of a gatekeeper gates not only keep people out but they protect the people that are inside and so we have to really

respect the role of a gatekeeper when we're working in these communities so how are some ways you can get started

thinking about identifying gatekeepers in a rural area well the first is you need to go to that community and you

need to start meeting with stakeholders in the community maybe it's you set up a meeting with a local pastor or a local doctor or the

mayor or a business owner or the vice principal who's also the coach and the real estate agent and

but start with meeting with people just getting to know people if you've been to a rural area if you're from a rural area

you can't just come in right blazing you have to build those relationships and you have to start with just getting to

know each other all right the second pillar that i want to talk about or approach is building

trust especially when we're working with marginalized groups engaging in efforts

focused on building trust and rapport is incredibly important sometimes that takes time

and effort that we often don't think about sort of factoring into our research projects but they're very

important endeavors that relationship building is key to make sure that that research can happen

there's also an important distinction about the difference between the trust of the researcher and the trust of the

research institution so if you are a researcher from iu from

iu school liberal arts from iu school of medicine and you are going into a rural area in Indiana to do work

you have to think about what does that say how do people perceive iu how are

people perceiving me are they mixing up the two university of Kentucky which is where we

were all based has a pretty positive relationship in the state of Indiana with different

communities i mean you know it is the state school but there had been a little bit of a

history of researchers from UK going out to Appalachia and doing research and then going back to their ivory tower

so having that perception of well there's much more uk people coming out to study us

right with something that we encountered and it was something that we had to work to build that relationship and

build that trust and say yeah i am from UK but i'm katie and i'm here and we're

working together and i'm really interested in your perspective and you know tell me about your lives and those

sorts of things so you have to consider um who you are and who your institution

is and how that might be perceived particularly maybe how your previous colleagues have set a reputation

positive or negative um there's also throwing back to sort of the

Aristotelian view of phronesis where we have to think about this idea that through experience through good mentors

through training we can develop this sort of practical value informed wisdom

that as we are navigating these rural communities and these rural networks of people and these research studies that

we want to do we have to make sure that we have on that sort of value-informed hat as well

and that if we don't have the trust and the and the buy-in from our participants

not only is that right not good for our research study that's not good for anybody that's not something we should

be doing so how can we get started with building trust well i think the first place is to

start with acknowledging your own positionality and your research and your own motives and that's something that we should all

be doing in our research on an everyday basis but i think it's something that's particularly important to do

if you are going into a community that you're not a member of and you're trying to develop those relationships and that

trust all right the third and then we've got

one more is relevance one of the things that you'll

find with a lot of communities and particularly rural communities is that

feeling like the research topic and the research approach is relevant and has a

direct benefit to them are important factors for whether these rural community members will even

participate in your research so if they don't find it relevant but they don't think it's going to benefit them they're

not going to waste their time and that's you know logical and so i would contend that we have to

make sure that both our research questions and our outcomes have to be co-produced

with our community members i'm not saying everybody needs to take on a full-blown cbpr approach to every

project that they do but i do think that there are a lot of principles within the cbd cbpr approach

that helps us understand that any focus has to begin with a research topic that has importance to the community

so if we go back to the example of the rural cancer prevention center we identified that cancer was a problem

it was a big problem people were dying people were getting sick it was causing all sorts of other ripple

effects that was the health issue we wanted to address but we spent

months years getting to know the community getting to know our stakeholders doing formative

research and focus groups and interviews and community events learning what the community thought were

the solutions and how they wanted to approach solving this health disparity

so while we may have come in both identifying what the health issue is that we know we need to

address everything else was co-produced with the community to try to solve that

problem um so i think one place to start with this is

again it goes back to you it's doing that perspective taking and doing that reflective

listening on what the community even thinks the problem is in the first place so understanding why they think

cancer might be an issue or why they think women don't come in and get pap tests regularly

one of the things we found out is that in one of the first of all there's not a lot of clinics in the in the crad the

eight county area um but one of the things we found was that um there was one county

where there was like a women's health clinic that everybody knew was where you went to get birth control

and so it had a separate entrance from the other part of the clinic and women told

us well if somebody sees your car parked out there they know why you're in there right they know why you're doing

something bad you need to get birth control or you've got an STI or something like that so it wasn't that they didn't think

cancer was important or they didn't think these screenings were important it was sort of the privacy and everybody

knows everybody everybody's in everybody's business so just suggesting that we have a common

entrance to the clinic was something that our community members suggested we went to the clinic and worked with them

and were able to solve that problem did that solve every problem no but it's an example of listening to your

community members to identify what is the what is the solution here how do we need

to approach this all right the last is communication

and what do i mean when i say communication and research you know i know the irb tells us we have to have in

our informed consent in our study information sheet and i hope peter has some experience in

working in that in that area with consent forms but what i mean is separate from that i mean a clear

conversation about what the study purpose is you know as researchers sometimes we develop our elevator talk where we're

like here's the 30-second breakdown of what i do and what you know i'm trying to accomplish what's

the elevator talk for your research study that you can meet with participants and tell them what you're trying to do

how can you explain in layman terms the methods that will be used and and why you know why am i using focus groups

what does that mean why did i make that choice why am i asking you to come and be a part of this focus group

and the outcomes and the findings are incredibly important to communicate back to the community

this communication has a couple of attributes that need to be checked off it needs to be clear it needs to be

regular it can't just be we come in we tell you everything about the project we do the project and we leave

and it also needs to be accessible it can't be hidden in a journal article

on you know some journal website it can't be hidden on some sub web page of the CDC that nobody's

going to ever go look at um of all of these things though i think one of the things that we as researchers

you know we do a pretty good job of being you know communicative with our participants throughout the study but

communicating research results and what we do with those outcomes and findings is often missing from that story

and so i'm going to put kind of a big quote up here on the on the board but i really like it and it notes that

participants have a right to know the outcome of the research this is especially important for participants

with a direct interest in the findings for whom knowledge can be power

reporting back to participants is part of the discipline of transparency that keeps researchers honest and accountable

it fits within that responsibility that we have to foster public understanding and make

patient and public involvement a core part of our health research i just really like that quote because i

think it leaves us all with some important reminders about what we need to do

so where can we start well one of the things we can start with is a lay summary or an abstract and

increasingly grant funding agencies are asking for this because they know it's incredibly important there are lots of

great resources out there my dear colleague Krista Hoffman Longton whose office is right behind this wall

does a lot with this with the Alan Alda center and communicating science but figuring out a way to take a brief

summary of your abstract and turn it into something that lay people can understand

is a really good place to start because it gives you a framework for thinking about how to talk about this in ways

that's not research centric right all right so in closing um i think

when we think about research with and in rural communities i would argue and i would um

support the idea that these four pillars are what we need to be thinking about as we approach that research

we need to go in with topics that have relevance to the community

through these respected gatekeepers who help us ethically go through those gates to

access our populations and work with our populations we need to focus on relationship

building that centers trust and respect and we need to communicate the process

and the findings along the way um i think it needs to be considered

that we need to take the viewpoint that we're making an investment in these communities we do more harm if we just

go in and do a one-off study and we come back to our ivory tower and we publish it who is that helping except that single

researcher who gets a publication and i mean that and i think we all need to examine ourselves if we think that we're

going to be doing that ourselves instead let's think about the investment in these communities that we can make

i want to end with a quote from one of my mentors from Kentucky who now works at nci and she's just one of my heroes

when it comes to cancer and rural health um she said you know we can learn a lot

about rural areas and there are a lot of commonalities but just like any research community that we work with

if you've visited one rural place you've visited one rural place so we can't just

read about rural areas and go in and start swinging we have to get to know each individual community

thank you so much oh my gosh okay got your head wonderful

i'll let you field your own questions from the from the room such as it is the virtual room and i've got my own but i'm going

to wait because i can ask you later if everybody else wants to have questions how wonderful thank

don't you shy

hi doctor head uh i just wanted to say thank you and um i'm actually i actually uh just moved

back to Indianapolis from Kentucky and i worked with the center on drug and alcohol research at UK so i did

some research in Lexington and surrounding area so it was it was really cool to hear about that project

in Kentucky

i think matt put up his virtual hands so oh yes yeah

oh you're still muted got my picture there forgot to unmute hi

Dr. Head thank you very much i'm Matt Ritelly from Eli Lilly and um how do you handle it when you're trying

to identify that gatekeeper and maybe even in your example where there's maybe multiple gatekeepers that have very

different interests and so how do you make sure you're really getting at the right ones

that represent that that community um i mean i think that's trial and error but i think one of the most important

things is starting with that investment and getting to know the community you don't want to align yourself from day

one with an organization that four weeks into the project you realize nobody in the community trusts and they have a bad

reputation right and that could have been avoided with just meeting with multiple stakeholders and meeting with multiple

groups and trusted leaders in the community um

you know Indiana is a very rural state um

i'm not from here but when people ask what the state's like i'm kind of like well there's Indianapolis and then kind of everywhere else um

but there are a lot of great statewide organizations that have really good

reach and have really good investment in both urban and rural communities and sometimes those

organizations are a good place to start because if they are truly a community based organization they're going to be

able to suggest people in those communities so for example i work really closely with

um the Indiana immunization coalition so i do a lot of vaccination research and their reach

is across the whole state so i know if i want to go into accounting i start with them who should i reach out to who

should i talk to sometimes those organizations can just provide those good people to talk to

um so i don't know if that answers your question but i think it would be just approach with

with you know caution and be um you know just like the first day of high school you don't want to sit at the

first table that has a seat you want to get to know and kind of lay the lay of the land um so you know who you want to

align yourself with thank you

i have a question for you um Dr. Head um

question it has to do with the return of results and they're sort of um

i want to draw a distinction between return of results so you have so there's one

um stage of that where like maybe a patient undergoes some kind of cancer screening or STI screening as part of

their participation in research and so you what you return to them is their results

but the second stage of that would be what i think you're talking a little bit more about which is

a discussion with the community about what the reach research showed about the community

which is a different thing and is something i don't think a lot of researchers do and

so my question about that is um to sort of probe the controversy of that a little bit

what do you do when what your research shows about a community is likely to break the trust that the

community has with you like eg um you know uh

iv drug use induced HIV is a problem in your community um or something like that where the

community might respond and say no it's not no it's not we don't want to hear that well i i think i'd counter that and say

your community knows what their problems are whether they want to admit it or not and building that trust and working with

them to identify what the research topic is from the start is going to help you

you know it's going to help you do that i mean like i said on the royal cancer prevention center one of the biggest

areas i worked on was the cervical cancer stuff and it was um

one of the first times that i realized how important health literacy was

it wasn't just that people had a maybe a little misunderstanding about how something worked this was um women who

did not understand their own reproductive health right there were multiple focus groups where we had to

stop the focus group just to offer a basic anatomy lesson so that we could understand i don't just mean where the cervix is

but how many i remember a woman was talking and um

she was like wait how many holes do we have down there right and i just remember leading that focus group i was

with my faculty mentor at this time and realizing wow right we have to we have to reframe how we're how we're

thinking about this and address things that might seem silly to us um i'm getting a little bit off track

but i i think um part of the idea where i say we have to

build trust and build relationships and have relevant topics and make an investment in the community is that even

though we're pulling back the curtain on these problems we're invested in helping those communities try to solve those

problems so are women dying from cervical cancer and colorectal cancer and breast cancer and

lung cancer even though these are preventable things yes but oh gosh here are some ways we can do it and can we

help you and what people should we be talking to and those sorts of things so it's a it's a give and take but i think

it's that investment in the community where people are like okay we're ready to work with you to try

to solve this problem thank you that's our really helpful answer in terms of i think reframing the

research as the first step in providing

oh i think you muted but sorry in terms of providing help to the community yes yeah

on the other hand so i was calling myself again i've had this a great talk and two things i want to say something last

question so first thing is this is a Creston wave thank gosh i mean i think that i'm asking you can have various

in response to that that cbpr was sort of a corner of research and i would call the idea of working collaborate with

with any community is becoming more and more central it's uh NIH topic it's

pcori one of my funders and as a researcher who was sort of dragged

picking and screaming to do it i i'm a convert i've drunk the kool-aid because i guess what i'd

say is i like jane's example because that's the fear i'd say that was my fears i'll lose

control and i'll be pissing people off of what i'm finding and then my experience was the opposite

it was that uh if you had a relationship no truth was a problem it was always

received it's my experience very positively and jane's example it's wonderful because it

reminded me like oh wow that's right that was a danger this was what i was afraid of at the beginning so i'd say

this um if this is the future i think it is now the present of research to do cvpr

deep collaboration with your communities throughout research including rural two questions one is what is the number one

barrier like what is holding this up still number one number two if you want to say i guess i'd say also like are there

hopes for getting over those barriers and last one is is this especially hard and rural like is this something you're

seeing like we can do it in our urban communities which again are as far as far from the ivory tower as some rural

communities or is it is it is it just um what is it different is it just is

it just a different you said every community is different so you have to do it differently everywhere i guess i would say what is the barrier

here because i feel like we're still struggling to make it happen yeah i think there's i think there's two

barriers let's think about your question as you're asking it um i think one is

um researcher ego right i think we do want to have control

and we want to pose our clean hypotheses and do our study and have our journal that we're going to publish and those

sorts of things and um cbpr approaches sorry community based

participatory approaches that's what cbpr stands for and you have to say it five times fast before they let you

practice it um it uh it's a little bit of an interesting term

because people throw it around but they're not always really doing it and peter kind of alluded to that people throw it in their grants and then the

grant reviewers are like you're not really doing this but um i think cbpr approaches which just centers that

co-production of research the collaboration with your participants researcher ego can be one of the most

important barriers right because we as researchers are really not trained to do that i mean we're only a few decades

away from calling our research participants subjects right i mean so we have to reframe how we think about

the research process and to teach it different we have to mentor it different i think the second

major barrier and this is probably not a surprise to anybody is just the way we reward research in academia right and so

um i did not really fully realize how lucky i was to be at a place like iupui until

i went out for tenure and that i could have my community-based partners write letters of support and i

could take some of my public scholarship which i didn't publish a journal article on right but i helped design and you

know implement theory-based you know messaging and clinics and you know offer

expertise here and there um and so our university systems and our reward and promotion systems have to

privilege that sort of um and there's different terms you know public scholarship translational research i

mean just throw them all in a hat and pick one out but if you're doing that kind of work you have to work within a system that

rewards that and allows for that and we are incredibly lucky to be at a place that does that because not every place

is going to do that um is are rural areas particularly hard places to do cbpr i would say it's one

of the easiest places to do cbpr especially if you go in with you know

that take your ego out of it and you're going in with pure motives and building partnerships

one of the defining features of most rural areas is community right and

working together and tackling problems together these people have often lived

for generations in this area they know each other they know their neighbors um they're in everybody's business right

so um i would argue um it doesn't come without its

challenges peter but i think rural areas are particularly primed

to be not only open to but you almost necessarily have to take a cbpr approach

to do good research with those communities

other questions there is anybody working on rural research that you want to talk to us about or we could problem solve if

you're having an issue right now

you know sometimes doing rural research doesn't necessarily mean you're in that rural community

every day i work really closely with my colleague Greg Zimmett on identifying urban-rural differences in

vaccination and different vaccination attitudes and behaviors and beliefs and we spend a lot of time serving and

interviewed parents surveying and interviewing providers across the state working with state agencies

and so sometimes that research does happen at a little bit of a higher level but it's always about how do we get to

that dissemination and implementation eventually and we do that through our community partners that we work with

yeah i'm going to make people talk by threatening them having to listen to me talk oh there you go it worked yeah i know so go and match back into it

i'll be quiet now Karen how about that Dr. Head you may have addressed this in

the very beginning i was called out to chat with my i.t person um at the

beginning of your talk but i did want to ask you know how are you defining rural versus urban such

as in the study that you just um described yeah Karen that's a really good question i don't have a clear

answer for you in our in our in our survey research um we ask

participants you know where how they would classify the area that they live in um urban rural suburban

um we can use zip codes to do um NIH has a

it's like a 10 category continuum from you know sort of how small the

metro area is to you know to how you know how dense the population is um so you can do it on that kind of

continuum i don't really have an answer for you i think um sometimes i think how people

identify their community is incredibly important and thinking about how rural it is but um

there is no i you know there are so many definitions of how we define rural that i don't really think there is a clear

answer i can provide do you do you have a perspective no i just was curious because i know

that's such a um difficult you know in our past experience again with p

i'm a project coordinator working with peter um and so and i know in past projects we were trying to define that

and i know Purdue i guess the extension service has fairly in-depth um i guess

metrics although clearly they have disclaimers that it's just their

position i guess whether you look at population whether you look at population density or whether you look

at services but yet you know i live in what i would consider now a rural area but my internet is pretty good and after

our ops meeting when was that Wednesday where Peter and Heather who i would consider live in a very urban area had

horrible internet service um and back to you know health care um

folks and you know greenwood and some of the southern Indianapolis areas really don't have access to hospital care um

which is you know amazing and they are very much in an urban area so anyway um

just it's just incredibly muddy and to try to categorize someone as urban

versus rural is just so difficult um so difficult it really is um where i

grew up in Texas you were rural if you didn't have a Walmart

that was how we kind of categorized it so you didn't have a Walmart you were you were really in the sticks

but you can go to some very affluent areas in this country that do not have

Walmarts or any box stores that are you know have every service imaginable at their fingertips um so

they would absolutely blow that definition um yeah so

thanks now um are there any special considerations

around either you know sharing the data with others or secondary research when it

comes to these communities because especially if the community itself is defined like you know you get all this

trust through your research and then someone can come along and even if it's de-identified or whatever do

something that maybe could just blow that apart

yeah well i mean there are a lot of sort of de-identified data sets right where

we're able to sort of draw some of these conclusions that we have about these higher level health disparities and

things like that but yeah i think you know i think to your point i i think if we're going to build trust with these

communities and that they trust their data with us we need to explain how that data is

really going to be used and if something changes we need to you know alert the community so

i think that just goes back to that um you know Aristotle's phronesis we have

to as we're navigating these different situations we have to sort of inject

some values in our decisions and how we approach things and make decisions about things

and we should right we shouldn't leave all of the sort of ethical considerations of our research

to that IRB approved it so we're good to go and let's just do whatever we want from here

not that any of us would do that but i think that's sort of the you know all right we've protected our human subjects

let's do our project now so something in the chat

Russo was McDonald's yes Emily we didn't have a McDonald's or a Walmart it did

have a Sonic because every Texas town has a Sonic which is one of the saddest things about Indy is that i think

there's a

Sonic and it's way on that oh Emily you know where it is you'll have to take me there someday

i'll be respectful of time for you doctor and also the rest of our participants i will say one thing about the co-production

aspect of what you were describing i would say that in my experience that was as with a

researcher's ego just you know that that's the fear like oh my god i can't do what i want to do

and then from my experience it was again an urban environment here it was actually

in some ways being surprised at how natural it was maybe as maybe your cancer case showed as well it's like boy

are we on the same page like if you're doing the right kind of research you won't find it hard to find co-production because

um you're not asking to be scientists but you also ask them to give you insight on their experience and it

really can work as with all relationships it's work and it takes time and their frustrations and

annoyances um but that's also the greatest playoffs possible there was a time when

my my early research product walked into the community group saying i'm giving up on this i don't think it's important anymore and they said no it is important

um this is my experience it's how it's important for this my experience so okay we should go forward with it and we got

the grant we did the project but i really look back at that as a case where i was very fearful as you said number

one barrier fearful of sharing the planning and the direction

and then i learned that it was actually it was safe and it was actually a good experience so yeah i like to build on

that to build on that co-production idea i i and talking about you know

kind of checking your ego at the door and approaching it as a partnership i i always let my participants know like

here's the expertise i bring to the table i'm a communication professor i do this kind of research here's some of the

stuff i've done in the past you are the experts on this is that right what other expertise do you bring

to the table so we have a little bit of a moment of uh we're going to level the field here before we start this

interview or this focus group or the stakeholder meeting because i am not the end-all be-all right i don't know

everything that's going on that's why i'm here and you bring really valuable expertise um

that's a really important um strategy that i was taught as a grad student like you know if you're

conducting focus groups or interviews to really get your participants to open up and then i realized wait that's actually

true right it's actually true that shouldn't just be a strategy that that is incredibly true and so um i always

try to approach it that way it's a lovely note to end on um unless

any last comments thanks again Dr. Head and everybody for being here nice i really enjoyed the conversation too so

um this all gets posted on the treats website um i'll send links uh

we can sit next to everybody at this meeting they're also Dr. Head mentioned there are some resources she may be able

to share maybe i'll guide guidance if you're taken by this topic and you want to uh do more or learn more we can provide

those resources also you can always get a consultation from the bioethics group our group from ctsi or i'm guessing

that Dr. Head accepts emails as well and is happy to help people with questions so thanks all and um thanks

again Dr. thank you