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uh we're welcoming you to another um event in the treats series treats as you

know stands for translational research ethics and applied topics and today we

have the great pleasure of any privilege of hearing from Dr. Lauren Nephew

Dr. Nephew is an assistant professor of medicine in the division of gastroenterology and hepatology at iu

she is particularly interested in understanding the barriers to liver

transplantation that exist for vulnerable populations and

looking at the impact of social and structural determinants of health on the outcome of patients with liver disease

and especially disparities of care in the in the care of patients with

hepatocellular carcinoma she trained in her residency at mass general

hospital and did fellowships at the university of Pennsylvania

she also went to case western reserve for medical school and completed a master's program in bioethics

and while at the same uh at the university of Pennsylvania she completed a master's of science in clinical

epidemiology she is a health equity champion and we are so honored that

you're here today dr nephew i think you're going to be talking about diversity and clinical trials but take

it away all right thank you so much for that kind introduction i am going to

share my screen

and hopefully then share my slide deck

as everyone seeing my title slide in slide mode hopefully

yes okay all right well i'm really excited to be here to talk to you all about this topic

of clinical trial diversity um and who is accountable as someone who does clinical research

this is a topic that's just really important to me and i'm also excited to

put on my bioethics have a little bit today so we'll cover

three questions in this talk and hopefully have some conversation around these

three questions at the end so why is clinical drought diversity

important so why should we care why is it something that we should all

be striving for um and that's important because you want to know the why why

should you be putting your efforts towards this and so we'll talk about that first and then we can talk about

how pervasive the problem is um so what is the problem how pervasive is it

um and why um do i think it's an issue where does the issue stem form and what are the

issues that are kind of driving this problem and then of course we want to talk about

solutions and so are there solutions to this problem

of disparities in clinical trial enrollment um if there are solutions um

who's accountable for those solutions who's responsible for making sure

they are seen through um and so those are where we will go today those are

questions that i hope we can answer today so why is clinical trial diversity important

well um there are uh therapeutic goals of research um

certainly um we do research because we want to advance uh and

undergo promotion but mostly our goals are to improve the outcomes of the patients that we

serve and we want to come up with effective therapies and if we don't have diversity

in our clinical trials then we are really unable to generalize the therapies that we have to a diverse

population and specifically you know we think about some of the challenges we face with

difficult to treat populations with high blood pressure or autoimmune hepatitis or some of the

more challenging conditions that often plague vulnerable populations

and if they are not enrolled in the clinical trials then um it's really tough to know how they respond to

therapy so we really want to know um if we um can come up with effective

therapies for these groups we need to have the most challenging groups with the most challenging conditions

in these studies similarly we want to minimize side effects so when we're coming up with

medications we want them to be effective and we want them to have a few side effects and we want to make sure we're

minimizing side effects in all groups and so without having

diverse clinical trials we don't have safety data in a diverse population

and again if we have certain populations where we're maxing out therapies then we have

a real potential to also be maximizing uh poor side

poor effects and having maximum side effects and so that is certainly not a goal

that we want to be striving for so we want to minimize side effects and we need to have diverse clinical trials to

be able to do that and then finally one of our goals of research of course is to be seeking good outcomes for our

patients and many of the best and kind of newest drugs

are really accessed through clinical trials and so we want to be able to reduce

health disparities and we can't do that if vulnerable populations can't access clinical trials or don't access clinical

trials and so a therapeutic goal certainly is to

have our vulnerable populations be able to access those investigational new exciting drugs

and if they if we don't have diverse clinical trial enrollment then certainly

we aren't able to do that and so why is clinical trial diversity important

it's important because we need to reach these therapeutic research goals um

it's also um notable that there's differences in exposure and

response for diverse groups we know that

there can be underlying differences in genetics these may be minimal

between racial and ethnic groups but there's certainly differences in comorbidity burden renal disease hepatic

dysfunction diabetes differences in socio economic situations

geography people's lived environment differences in drug metabolism

and these things affect drug response and how effective these medicines are

going to be in different groups and what their side effect profile is going to be

and so if we don't have diverse populations in these studies again we

don't have a real good understanding of how effective the medicine is going to be

and again we aren't able to minimize those side effects

in addition to our therapeutic goals of clinical research we have an ethical imperative right um

and so that that's an additional reason um why uh diversity in clinical trials

is so important um and so we have an ethical imperative to kind of uphold these principles um until the Belmont

report um in 1974 was written um and summarized for us what our ethical

imperatives were um and certainly um we know that there is respect for person

which says that we should have autonomy for patients in our clinical trials um and that we need to protect those who

have diminished autonomy um and certainly we always think about do no harm that's a maxim

in medicine as well as in clinical research and we want to minimize harm to patients and clinical trials but

justice i think sometimes gets a little bit of a kind of swept under we don't think about

this principle as much but it is also important and something that we need to be thinking

about um certainly um in 1974 they were thinking about justice a little bit

differently they were thinking about how to protect

the vulnerable from being involved and kind of

just being easily accessed from making sure that we weren't exploiting prisoners we want to just exploiting a

poor we weren't just researching on people who were easily accessible but certainly we also need to be

thinking about the benefits and the burdens on the other side um right so if research is

supported by public funds and we want to develop therapeutic devices and procedures

using those public funds then everyone should be able to benefit who has supported those public funds and so

everyone should be able to access that that clinical research would be a part

of that clinical research and she'll should be able to also benefit and so not only do we need to think

about the burden of burdening vulnerable populations but also some of the benefits that come

along with being a part of clinical research that people may not be able to access when we leave them out of

clinical trials

so how pervasive is the problem of racial disparities in clinical trial enrollment um and why do i think um

it's an issue well racial disparities in clinical trial enrollment it's pretty uh

it's pretty pervasive unfortunately so um this is a snapshot of the us

population um and you can see here um in the turquoise

that Americans are black uh persons make up about 12 of the U.S. population

and Hispanic Americans make up about 16 of the population this is a little bit dated it's probably about 18 to 20

percent now and if you look at clinical trial enrollment just kind of taking overall

clinical trials for kind of all types of um medicine drugs interventions

you can see the representation and clinical trials is much lower than that and and this has gone up slightly

since this figure but not much still less than what would be expected based on the

numbers of persons in the U.S. population

and so why is this an issue and certainly mistrust is something that comes to

people's mind immediately the reason why racial and ethnic minorities are non-violent and clinical trials is

mistrust and certainly that is a big reason and so i say we tackle that one first

and one of the first things that i think is important to think about when you think about mistrust

is that it's an earned mistrust okay this is not something that's just uh made up in people's minds

this is something that happened and it was it's real and it is not remote um this is an

illustration of Dr. Marion sims he is um often coined as the

founding father of gynecology um and he performs experiments on enslaved black

women without anesthetics 20 to 30 procedures at a time

on them to perfect his surgical procedures

and this is this is something that is widely kind of talked about

in communities of color many will say well that was a long time ago the people who that happened to um

are no longer alive well this is a picture of a

a person who was alive from the Tuskegee

or the U.S. public health service experiment at Tuskegee um and this is president Clinton

who is apologizing uh to one of the descent or one of the survivors of that

experiment um and i like this picture because it's very modern we all know

president Clinton we all know president gore and it just centers for you that these are not things that happened 100

years ago these are things that happened recently and this is someone who this happened to

and so people sit around the table in the south and they have lived this and

talk about this and so this is something that is a lived experience for people's

relatives um and so it is certainly an earned mistrust

however it is not the only barrier to people participating

in research and there are a lot of other barriers that i think are much likely

driving people's participation or lack of participation in research and so there are patient

centered barriers like access related barriers just access to providers with knowledge about trials

where people get care and the community at health centers that may not be

academic health centers and they may just not have access to providers who really know about these clinical trials

they don't have transportation uh to and fro um to be able to

go to enroll in a clinical trial that requires five study visits

they don't have opportunity and awareness about trials and they don't have providers who are willing to refer

them to clinical trials again there's mistrust and there's fear about side effects

there's research literacy issues there's a misunderstanding about randomization and placebo and what that means

and there's a belief that clinical trials really may not have any benefit to them at all and are just for the benefit

of the system um and the pis and then their cultural issues around

excluding family members and a lack of patient provider relationship

which becomes really big when you are sending someone to be enrolled in a trial

at a center where they don't know really anybody and they don't really have a relationship with that provider

there are provider barriers where providers in the community really don't have information about trial sites

about the PIs who are enrolling they have lack of familiarity with the inclusion criteria

they don't believe that patients will adhere to protocols they believe the patients aren't interested

they're concerned that they're going to lose their patients which is a really big and probably valid

concern quite honestly to the clinical practice if they refer patients to clinical trials at academic

centers there are logistical issues about lack of time to discuss clinical

trials when there's so many other competing interests that are real that need to be discussed

and then just the distance of getting to clinical trial sites um so there are many other

real patient and provider barriers in addition to just earned mistrust that prevent

racial ethnic minorities from really being able to participate in clinical trials

despite the mistrust issue there is a willingness among racial and

i think minorities participate in trials so this is an older study but i like

it because it begins to describe this kind of willingness of racial and ethnic minorities to

participate in trials and it's termed it was called the Tuskegee legacy project

and it was a minister to a little over 1100 persons around the united states

and it measured fear really around research studies and yes indeed black participants had

almost twice the likelihood of being afraid to be in research studies but

there was no difference in self-reported willingness to participate and many of us can think about

situations where we're afraid to do stuff but you still do it okay so people have fear people have mistrust but they

were still willing to participate particularly if their physician was doing the research which really speaks

to that patient-provider relationship and there's plenty of data

to support that this is true this is some phase 1 study data

just looking at participants in the northeast and the south just

looking at the diversity of participation in phase 1 trials you can see here um

that 42 of uh participants and phase one trials in the northeast were black 54 in the

southwest were Hispanic um how are they able to do this in these phase one trials

well most phase one trials occur in the private sector there's limited physician investigator

involvement um they use trained recruiters many are bilingual um they're trained in um how to read how to recruit

they're located in urban areas right so they're located where people are

facilitating access to diverse populations and they provide financial incentive for

participation so if you can overcome some of these social determinants of health language

money location you really can see that some of this mistrust

is there but people are willing uh you will may say well everybody will

participate in a phase one trial right that's not that big a deal um they're not that many risks

but this is some data looking at surgical intervention studies um and you can see

um there are a number of studies here um this is seven thousand um patients were

offered enrollment um the consent rate uh for non-Hispanic white patients versus all minority groups was uh

similar excuse me but the off array only 5.1 in minority

groups so they're not getting asked if you don't ask people how do you expect them to enroll um so this just looks at some

of the provider bias um and barriers to providers even asking

minorities about enrolling in clinical trials

even more recent data looking at phase three study enrollment for participation in the covet vaccine

trials this data is looking at Pfizer's and Moderna

phase three studies and you can see that the Black and Latina Latinx

Hispanic participation was fairly high black participation approaching nearly

what it is in the U.S. population and Hispanic and Latinx participation at or nearly over what it

is in the U.S. population and they were able to do that by leveraging

many of the um

mechanisms that they did in the phase one studies that we talked about earlier placing trial sites in urban areas

having weekend enrollment leveraging community partnerships

really investing in some of the strategies

translators to overcome some of those social determinant and logistical barriers that

prevent people from participating so again people want to participate if we can make it happen

um so are there solutions to the problems of racial disparities in clinical trial enrollment um and if so

who is accountable so

there is a you know a problem recognition um by the ecosystem the ecosystem i say is kind of

the stakeholders um the milieu of people who are involved in this

recognize that there's a problem and they have began to come out with guidance and

statements around this which i think is a great first step so the FDA issue guidance on enhancing

the diversity of clinical trial populations in November of 2020. it's a really well written document and i have

it kind of boxed as one of the places to go if you are enrolling patients and you're

having difficulty and you're trying to figure out kind of what are some of the things that

i can do to help in this area um and i think that their document is well

written um even more detailed and um a really amazing document um is the Brigham and

Wiggins hospital and a multi-click regional clinical

trial working group document that was published in 2020 in their toolkit

this document is not for the fainting heart over 200 pages it is more of an encyclopedia

but it is fabulous and also gets their strategies for clinical trial enrollment and the

toolkit is also very nice pharma has also come out

with their first ever kind of problem recognition strategy document in 2020 they came together and

came up together with kind of a strategy document and as well as the national academy of science

and so i think my point here is to say that people um stakeholders the ecosystem they recognize that there is

an issue um they've put together working groups they're investing time which is kind of the first um investment

i think in this problem and coming up with some solutions um on

paper um to how we can move forward but i think

the next step probably is needed this started happening around

2020 uh 2021 and i would say that the next step probably to me

um is a little bit more accountability as a solution um so accountability is

the obligation to explain justify and take responsibility for one's actions right um so they're we're explaining

we're kind of justifying we're coming up with some explanations but at some point somebody's got to take

responsibility for these things happening there are lots of explanatory documents out here now um but who's

going to on up and take responsibility for these things actually um being accomplished um and i think

that um i'm interested to see if that happens um and who is accountable i think that

there are a few groups who could take responsibility and be accountable

the food and drug administration pharmaceutical companies and funding agencies and then us in the scientific

community i think the onus is on us as well and i'll talk a little bit more

specifically about our accountability in this as well

and so our current challenges um i think lack of accountability

is where we are now i think that's a good place to be um in 2017 we were farther back than that

right we didn't even have any solutions kind of written down now we've got some solutions we've got some guidebooks now

we've got to have somebody say okay how can we be accountable now that we've got some guidance about how to do these

things um so i think in terms of accountability um i think the FDA um could step up um

they've written this really nice statement it's strong but i think they could put some mandates

um in place about diverse enrollment that this is what we expect to see

this is um what we expect um given the population

here in the united states for enrollment if they put that in paper people would

follow suit pharma and funders would allocate money um specifically for the

goal um to make this happen because if drugs were not going to be approved if they

did not have diverse enrollment then people would have to um fund strategies for enrollment right um

because they knew their drugs would not get um through the pipeline um and so

uh and then they would also require PIs to kind of write strategic plans um

and deliverables based on the money that they allocate us because they would expect it but they

wouldn't just give us money right we would have to write a plan for what we do with that money to make these things happen and then i think scientific

journals should require race and ethnicity data be reported and explain

uh if we don't uh report it why and if we have low enrollment in our

clinical trials what happened you may do everything in the world and it sometimes just doesn't work out that's fine what

what happened and what's the implication for your study um i think that if this kind of

accountability happened everything downstream could fall into place infrastructure could be built

for clinical trials in underserved communities we can invest in that infrastructure

so that there could be clinical trial sites in non-traditional locations not just in academia at fundamentally funded

healthcare locations so that we weren't just dependent on enrolling at iu

so that patients could be enrolled where they are we can engage in community partnerships then we can educate where

people are share research findings and trust build i think that providers need to work on

exclusionary clinical trial design many times we just very quickly write clinical trial

designs that exclude people with chronic kidney disease extrude people with diabetes exclude people with this

this is this it makes our analysis a lot easier but we often end up then excluding a lot of vulnerable

populations and so i think we need to consider that and who we're excluding with our exclusion criteria

and then i think we all need implicit bias training for our full research staff and then finally i think at the patient

level there are lots of logistic issues that keep people from being able to participate

and i think that if we have funding from the top that came down these things

could be um could be budgeted in

and these things could be dealt with and so we could do share rides and

lifts and weekend hours and translators and all the things that i wish that i could pay for

in my studies but don't quite have the budget for so in conclusion

why is clinical trial diversity important we need to achieve all those therapeutic goals and it's an ethical imperative to do so

it is the just thing to do how pervasive is the problem of racial disparities in clinical trial enrollment

why is it an issue it's pretty pervasive um and there's an earned distrust but

there's willingness and an interest in participating if we can overcome the social and structural

barriers to participation and are there solutions to the problem of racial disparities in clinical trial

enrollment and who is accountable yes i think there are solutions but they require recognition

there's a problem with fixing a willing ecosystem which i think we have financial time and investment and

accountability which we don't quite have um at multiple levels to ensure this happens

i like to thank everybody for your time these are the two references that were boxed that i think

are quite nice guidance documents about how to increase clinical trial enrollment

and i will pause here

thank you so much Lauren that was just terrific um would you be willing to take some

questions if people of course give me one second to get off of um

to fix my technology hold on because i'm trying to figure out how to

make the screen bigger and stop share but um let's see

oh here we go stop share okay there you are here i am okay great

excuse me i have to step away just for a minute keep going

excuse me i have a question um i am wondering um Dr. Nephew about when i

approach people about research and i can tell

that there is lack of trust might be people of color and they heard the word research and i can just tell they shut

down do you have any recommendations on how to approach people in a way that makes

them feel safer yeah

i find that if people they know can approach them first

is helpful so if so if

if we're going to enroll patients who we don't know and i can get their provider to even mention

um that we're going to enroll um i can even say you know hey i really you know i

really want to enroll your patient in our research studies anyway you can let them know my coordinator is outside the room

um even if that can get them to make the introduction um because when

i think when people of color have no connection of who you are you just kind of catch them in a waiting room and

you're just like hey you know will you be in my research study they're

very leery of new people and no relationship so i think if you can get someone they know

to make even the briefest introduction someone they do trust not to go over the

whole research study because they don't have time for that but just to say hey one of my colleagues is going to talk to you about their research study that

those 10 words go a long way thank you thank you

Lauren Mary i'm in adolescent medicine in the center for bioethics so first thank you

for a phenomenal talk i learned a ton i'm super excited about it um one of the

things i struggle with in epidemiologic research is how to handle reporting of

race and ethnicity like as a social construct i want to see like you know is

there a hypothesis because this isn't a biological factor like how do i handle

it do i include it in the analysis not included in the analysis um i think it you know because including

it in the analysis sort of perpetuates um a lot of these false stereotypes and so

i'd love for you to talk a little bit about like sort of you were talking this is a lot on the front end of inclusion

but on the back end um in terms of like analysis and reporting results oh the struggle is such a

struggle on the data analysis side um so um

i am always struggling with that right um i'm a i'm a firm believers race is a

social construct um but as a social construct it has had biological consequences often um that i have um you

know that are deeply embedded um i am very careful about putting race

into models now much more careful than i was two years ago even um

and so um i will often

um i'm so careful about it i mean it's a very thoughtful question that i will

um stratify sometimes instead of putting in it as a multi-variable

um to kind of just see um you know what the

with the odds ratio would be um for each race um just to kind of get

it depends on kind of what the question is but i'm very careful about just throwing it in a model now um

so i think in a table one fine i mean you just want to know what your population is but in terms of multivariable model

building um i think you know it's probably you know

often best as like an effect modifier or kind of stratifying by race

i'm careful about just throwing it in the model um but again it depends sometimes it may be okay it may be appropriate it kind of

depends on what the what the hypothesis is but i think you have to be really thoughtful and then

really thoughtful about it in your discussion about what it means you know if you did put in the model

would it look like without it would it meant with it um

and i think if you can tell people kind of you know if you can tell people that um

you know it can be helpful i don't know if that answered your question but i think you know i think thinking about it

looking at it as a you know both ways with and without it and stratifying by it can sometimes really tell a story

you're muted though no i'm sorry i'm on an editorial board for the journal of pediatrics and we've been talking about

like how to handle reviews of papers and thinking about like is there a hypothesis around

race um have they looked have they do do they do any exploration of mediating factors

for this social construct um instead of like making white the reference race do they have like a

population mean that they may use as a reference because we now have like better statistical techniques than we

had 30 years ago and you know so i've been i'm you know your your sort of off-the-cuff answer is very

similar to some of the things that i've been looking at and thinking about in my role on an editorial board so thank you

well lauren i i just have a sort of a more personal question about so how are things at indiana

how how is the diver diversification within our

clinical trial i mean how receptive are people to uh what you're doing and and um

anyway depends on the trial um

my um i am currently enrolling for a

you know a pretty easy study about you know social determinants

and liver cancer and our enrollment rate for um

um black and Hispanic patients is like 80 you know um but they don't have to come they

don't have to come back you know what i mean they do everything on that first study visit it's a lot of paperwork but we pay them

and they don't have to come back um we've got another study we're enrolling for alcohol associated hepatitis

there's got a lot of study visits and we can't enroll anybody regardless of

race so

i would say and then i hear other investigators um

it's mixed so it depends on the study i think um i think it really um if there are a lot

of study visits it can be challenging for anybody but i think we see

um barriers more logistical barriers than overall research like distrust

altogether i see people really are kind of

interested in being involved in research i don't find a lot of people who are just kind of shut me down altogether um

because i again we have 80 approach you know 80 percent enrollment of the people in Brooklyn that we

approach thank you and i see that Dr. Schwartz has arrived

[Laughter] well i'm a shameless person that you know

even though i didn't hear the talk but i'm not that shameless i'm sorry lauren i had another

i'll defer to others warren i'm struck by the finding that

investigators are not offering clinical trial participation to

um for me it would be like adolescents and families um

from minoritized groups and i'm wondering if you have like really specific

recommendations that you can give investigators around this

you know i think i think people have a

false idea that people are going to that people are going to say no um

i think they just uh i even think that sometimes

um you sometimes just have this um thought you know that you know

they've just got too much going on they've got you know um you know kids just too many barriers

like you know they're going to say no um but they don't

so i think there's just a um misconception that

um you know that there's this and there is mistrust though right i mean it's not

like that's not true there is there is there that is there but i think um depending on who's asking people will

say yes especially if they know you um so when i ask patients they often say

yes but you know if i'm asking people i know um but i think providers don't really

know that and they get nervous um that nobody likes rejection right

um and so um i mean bias is biased but

you know in terms of what's driving that nobody wants to hear no

when we hire research coordinators we're always looking for those people who are okay with that no right

because if you're not willing to get in there if you're scared of rejection and you're not going to be a good research

coordinator um and so um if you're scared that a black patient

or Hispanic patient is going to say no you may just not ask um and if somehow you've been tuned to

think that they're going to say no you may just not ask um so i think just some kind of

re-education around that belief um

um and then you know um and helping

patients to understand what the benefits are um i think patients of color don't often

you know if they know what the benefits are if a provider they know is asking them

i think those two things together help them to say yes um

and so i i mean that may be true of any patient but i think that patients of color um

you know as long as they need to feel like it's not just something the system is doing

to advance it itself but that is something that could be a

benefit not just to them but to other people who look like them who have the disease that they have

and if they can understand those things um and it's somebody they know and trust

that those things together will help them to say yes and if providers can understand if they're

willing to say yes and that they aren't going to be rejected any more than anybody else

i think that we may get somewhere

well in the absence of any more questions i'm uh maybe i i've just Meg is letting it go she's

about to talk about um discomfort right there's silence on the line Peter Schwartz gets nervous and

starts to think well maybe it's time to end um uh and again i didn't have the benefit

of listening i'll see it on recording meg is waving her hand though well this is i'm not a researcher Lauren i

mean clinical research um except in the conscience project but i

will i would just the echoing the um sense of the mistrust so my clinical

practice was at Richard Eskenazi and that health centers and i found that and i and

i was there for a long time and had lots of patients with whom i became close

but sometimes even with those patients whom i knew i would say something like we have this new drug you

know i was dermatology so skin stuff so i said you know we have this new drug and i really think it and i could see

this look on the face and it's just like experiment

i go no not an experiment you know so but and once we

then the um i think most often that the patient felt much better i didn't mean it as an

experimental drug i was excited because it was something new that we could offer for

example psoriasis or even a new antibiotic um but so it's just interesting to think about the

words that we use uh and then to stay in the conversation as you're saying um so

you don't just like okay never mind anyway

yeah i think you know um people don't want to feel like

they're uh perhaps that that they're um

they're being experimented on for the benefit of

you know benefit of

everyone at badaphra to benefit them perhaps um and i think you know

um that they're being exploited um and um

and there's this fear that i'm being used i'm being used or they're going to use me they're using me for their benefit

and i'm not getting anything out of this really but they're really just using me um

and i can't get god like and i have to always be on the lookout

for a situation where um i may be um

you know there may be something someone out to get me because um

you know um so which you know um

because someone had been not together because somebody had that so um so i've got to have this kind of extra defense

up um to kind of you know be on the lookout so um

like you know and you these were people you knew um and they still had their kind of ears up like whoa she said no

it was for me it was very um important that was a really um

important and i was grateful for the for the conversation i it made me much more

sensitive to what the patient was hearing which was not at all what i was intending uh and so i was anyway it's

it's interesting thank you again see now i've heard enough to ask another question so i'm sorry but

but i'll pick up on this discussion you're having please just stop me if it's something you covered earlier um

Lauren um that that um you know i teach actually i

taught a thing about um uh diversity and enroll in enrollment recruitment uh to the kl2

scholars if you remember we were talking about doing that with Lauren to Bangla and um

uh Linda DiMaggio um and one thing we thought was payment for

like step one for phase one trials you know so many examples of phase one trials where

you know that worry meg you mentioned of being taken advantage of because risks maybe

haven't been described or payment actually has been inadequate you know because we don't pay

or whatever and so actually i almost think like a patient who distrusts you is almost the patient who's more reasonable the

patient who does trust you in some ways the challenge is to live up to the skeptical patient

um and to i mean the session i ran we talked about paying people better for phase one where

there's no real reasonable benefit to the individual except for the pay as well as you know it's nice if they

can help but the actual benefit of the individual is really only the pay and so we should pay better we should

pay actually a lot more than we've ever been comfortable paying and that's a that's a response in some ways to a skeptical patient who says why

should i do this whereas before we a patient said oh yeah maybe i should because i feel obligated or something

and that latter case that's very nice to have so much trust and i hope we've earned it with some groups

i don't know if any groups really should trust us that much to out to um to volunteer in a phase one trial you

know we're being given a untested medication and you're a healthy person who couldn't benefit from the medication

so i don't know i think that's almost a healthy skepticism um now of course having sat in clinic and

trying to convince patients to get the vaccine i know the line that gets crossed from healthy

skepticism to um to very hurtful skepticism for their own health do you think about that

Lauren if you speak about this in the talk i'm sorry that i'm gathering late and just just tell me that a little bit about

phase one trial enrollment um and um

and some of the reasons that um minority enrollment is actually really good in phase one trial

enrollment um and um and some of the reasons for that is the

fact that they're often located in urban areas they're often not run by academic

centers they often use recruiters

some of the phase one sites do pay well um and those things can be coercive um but

um i think the risks tend to be fairly low for phase one um and so people

i think in general are willing to participate because they can kind of the trial sites are where they live then

they get paid and the risks are relatively low as opposed to phase three which are often at academic centers

um are run by physicians um

um and are kind of barriers because they aren't really in the communities

where people live um logistically and um don't really pay as well quite frankly

um but um so we talked we didn't talk about that here

but we i talked about a little bit in the talk but

that's fascinating it is fascinating um

i've never been a healthy subject in a um in a phase one but

um i know people sign up for them because they feel like they're kind of low-risk high-reward um

yeah okay so i will defer to you in terms of whether

we should go on or well then meg's wavy so i'll go

ahead and thank you lord i guess so much for doing this Dr. Nephew i appreciate it so much i'm sorry for the scheduling i

couldn't be here but i will be logging off now and watching the recording probably as soon as Emily Varan can get

it to me so thanks again so much for doing it all these talks as meg probably mentioned are available online uh on our

tweets page on the center for bioethics website um uh it's under our ethics

uh resources section and so this will be immortalized now no

including my on my asking a question after i didn't after talk i didn't see uh so and along with there'll

be some references to that um Dr. Nephew spoke about in the talk you can you can click on

those there for content um so again thanks everybody for being here and thank you especially Dr. Nephew for

speaking and thank you meg for saving my butt as usual and filling it

thank you thank you Lauren it was wonderful to see you i hope we get to teach together again sometime

thank you everybody thank you for having me i appreciate the invite