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Okay and then I'm going to introduce myself my name is Mary Ott I'm a

professor of pediatrics in adolescent medicine in a pediatric ethicist at the IU Center

for Bioethics and I'm going to talk today I'm going to give a TREATs talk on the ethics of virtual engagement and

this is a the first of what I hope will be several treats talks where we deal

with research ethics issues specific to conducting research during a pandemic

I do have disclosures my spouse is an

employee of Eli Lilly and I've provided expert consultation on adolescent

contraception for Merck and bear

in my objective for this talk is to think about like what I call key ethics

benchmarks for virtual research in a pandemic setting and I'm going to Heather

it looks like we'll be May at Mont and Manning the chat so please feel free to

enter questions into the chat box and I will just let people know I just got a

message that my internet was unstable so if I disappear I will real aughh in so

my I started thinking about this topic about ethical issues in virtual

engagement as a part of a consulting job

that I had in Uganda with investigators from Colombia and we were interviewing

young people about HIV research experiences and the question was with

the onset of the pandemic and social distancing could we transfer these

in-person surveys to phone surveys and the surveys are being done in rural

villages very high poverty settings but most families did have a phone at least

one per household in the organization International initiative for impact

evaluation had just published this commentary on the use of caution and

phone surveys and they are thinking about in high poverty settings what role does a phone play and a family

what other stressors to family Hamleys have as a result of the pandemic and

would the phone survey advance the health and well-being of the individuals

that you're serving and so it got it it had me start thinking about what does

it mean for what are the ethics issues for virtual engagement for our own

research here in the US so when I want to start with talking

about what virtual methods includes I mean there's a huge range of virtual methods there are a lot of specific

methods they range from surveys to social network analyses and adolescent

HIV we're seeing a lot of online clinical trials looking at behavioral risk reduction it can include social

media research cyber ethnography focus groups interviews Delphi studies so a

whole range of methods can be done virtually it can be quantitative or

qualitative and these methods virtual methods can be done via phone video

online social media email texts so if you can think about a way to communicate

you can think about a method to deliver virtual research and finally it can be synchronous or asynchronous so you know

a survey might be asynchronous where you're sent a link and you can just follow the link to the survey and do it

whenever you'd like to a focus group could be either synchronous or asynchronous where you could get everybody on zoom together and do a

focus and in-person or virtual in-person focus group or it could be asynchronous

where people are given links and have a series of questions and they can see other people's replies to the questions

and they have a time period where they reply so there's a variety of different

methods that are included in virtual methods it's a big umbrella and so the

first thing my first sort of thinking about benchmarks and this is adapted from work Ezekiel Emanuel had done

thinking about benchmarks for research in general but the first one is scientific rigor and virtual methods and

you may say well scientific rigor that's like science that's not ethics but

scientific rigor it turns out is like the first ethical hurdle that research

has to go over because research that's not scientific rigorous really shouldn't

be done because we're taking participants time their energy we're setting expectations for them or

exposing them to harms so if we're if our participants are

taking on this burden then we really have an ethical obligation to make the research that we're doing as

rigorous as possible so that so that it can change and improve individuals

well-being and there are certain aspects of virtual methods that are where rigor

tends to fall off and I'd like to in and I'd like to talk about those a little

bit one of them is recruitment and a lot of times there's let's round up the

usual suspects for recruitment and there's reaching out to people that we

know to groups that we know to existing groups and that may or may not be okay I mean we really need to ask ourselves is

who is present who is missing so if we

are doing Facebook ads who doesn't have access to a Facebook social media

account what's the denominator our participants who they say they are and I

have some examples of these there can be barriers to participation that would

affect recruitment so particularly device and Wi-Fi access so our colleagues that do work with

older adults I still have many older adults that have flip phones that use

landlines and not devices people that have very limited or no Wi-Fi access

thinking about generalizability or in the case of qualitative methods transferability of the research and then

have we thought carefully about adapting methods for virtual engagement so

thinking about surveys if someone's doing a survey on a phone on a small handheld device and they're sort of more

limits to the number of questions that you can ask if they're following a link on a computer to redcap if someone is

participating in a focus group and we'd like to move the focus group to online you know what does it mean for

participating in the focus group zoom for example only allows one person to talk at a time can you do

combinations of zoom and chat you know can you think thinking about like what

what are the limitations of the technology how can and how can we

overcome these limitations of technology so I think about thinking about scientific rigor so a colleague of mine

did an online survey many years ago about pro-ana and pro-miamia are

pro-anorexia probe bulimia website use and the investigator recruited 18 to 26

year olds her IRB did not want her to

recruit younger participants because they were concerned about minor consent

and harm so what proportion said they lied about their age and I can actually

see chat so if people want to throw in some guesses and chat that would be

great the other question is like thinking

about recruiting I'm working with a colleague and we're thinking about like

in she's looking at recruiting young adults for a study of sexual health access from Facebook ads and thinking

about who's missing and I'm going to go back to the first one because we have like oh wow people are like 40% 20% 30%

so it turns out that it's like 10 to 20% which I thought was like a huge number

so thinking about who they are they who they say they are so that the recruiting young adults for a study of

health access from Facebook ads and the one thing my daughter pointed out to me where I was wondering about Facebook for

young adults she said mom you know Facebook actually owns Instagram so so

who's missing from this study who's not in the study so thinking through these questions like does the person have a

social media account do they routinely use social media accounts are there you

know what are the biases that you get in a social media account and then you know if you're thinking about it what's your denominator with the social media

account and finally I had a colleagues that have done a lot of really innovative work on HIV

out of Chicago and they assembled a virtual focus group of 20 LGBTQ adolescents to discuss HIV risk you know

the question came up is how generalizable are their results in

thinking about you know do does their group of 20 how who do they represent

who did they recruit you know did they

is it generalizable to the entire population of adolescents with who are

gender or sexual minority does it can it you know does it like is it limited to P

kids that have access to their recruitment you have adequate Wi-Fi who have devices who have you know so

thinking about what does it mean and who you're recruiting ends up being really important so there are also scientific

pitfalls in terms of implicit bias and structural racism and you know so

pandemics we all know that pandemics make fear much worse I gave a talk to

the International School faculty on the effects of the pandemic on adolescents

and one of their biggest concerns were Chinese exchange students and how to

handle the discrimination that they were seeing that was happening in the racism that these young people were experienced

in the early weeks two months of the corona virus structural racism is

something that we need to keep in mind but particularly in times of social and

economic stress because when we're in

times of stress it it makes the effects of structural racism worse and so

thinking about like what is our thinking about our research questions our recruitment strategies sort of who's

there who's not there how we're asking the questions and you know are there any aspects of

what we're doing that would actually worsen structural racism or are our methods such that they would address

issues around structural racism so the

second piece is social value and that sort of builds on this issue of you know

are we addressing something that's going on right now so as I said before pandemic conditions cause high levels of

distress and does the research itself address either like the health the

economic or social well-being effects of koban 19 and if it doesn't

is it an additional burden on individuals who are already struggling to deal with pandemic conditions people

who you know beyond sort of the illness and the health effects of the corona virus itself thinking about what's

happening in terms of jobs and job loss distancing from family and support

systems so are we adding additional burden to participants and is this research that absolutely has to be done

right now is there social value to the research and will it worsen levels of

distress that people are feeling

informed consent and this is something thinking like as much in a virtual

setting as in a pandemic setting but thinking about the economic and social stressors these types of things

interfere with people's cognitive processes we think differently when we're stressed scarcity also changes

people's responses so people having difficulty putting food on the table might look at a research study really

differently than not people who aren't putting food on the aren't stressed about putting food on the table and then

finally thinking about is there any undue influence and in what's happening

and this is something that gets bandied about a lot I mean for something to be

undue influence it has to be an excessive offer so a $20 survey versus a

$200 survey versus thousand dollars for a survey it has to be something that exposes that would

make the person make a choice that a normal person wouldn't make under that

he wouldn't make under other circumstances and then it would have to be something where that where it engages

high levels of risk so the excessive offer making a choice you wouldn't

otherwise make in excessive levels of risk and that's really it takes a lot to do that but I mean as we think about

different methods thinking about is there any possibility that this could happen and finally thinking about

virtual privacy and confidentiality so like on the left hand side I mean this

is you we're not seeing this now this is like a Starbucks table a coffee shop table with people sort of sitting and

working together but if thinking about having like a family of four in a

two-bedroom apartment like you're interviewing the mom about sensitive issues like where is she physically at

is there someone nearby her is she able to be private so in privacy are people

knowing a participant's business so thinking about and then from a research like from an SOP perspective are there

things that you can do to assess privacy our psychology colleagues in clinical

care oftentimes have like standard procedures where they check are you in a room who else is in the room with you

are you able to be in a room alone is there a door that closes can other people hear you how long will you have

this level of privacy so that in thinking about that from a research and building that into our SOPs

confidentiality has to do with protecting personal information and really is more about data security and I

just put up like the Forbes article on hacking zoom but thinking about as we

move forward with our methods like what are our data security procedures is something HIPAA compliant is like sort

of what you know like what is our sort of chain of data as it moves electronically through the system

thinking of if you're having focus groups setting it up so that there are passwords and things like that so you don't get sort

of zoom bombed but thinking about these types of things as we move to virtual

things that we take for granted and in-person work the other thing that's

more complicated than just sort of setting up an SOP around making sure the person has a private space or setting up

electronic protections for data our thinking about this blurred distinction

between public and private in social media a lot of research and recruitment

is done nowadays through social media but you know I'd like a you know I sort

of ask the question if you are if you're analyzing social media is one person

snapping photo to another person is that public domain is that private domain is

it public domain if it's elite is that a legal question or is it a question of people's perceptions you know Facebook

has really been sort of determined to be by and large sort of public domain but a lot of times particularly when you have

groups Facebook groups people may feel that it's more private and that they're

sending it to a smaller number of people so thinking about this as your if you're using social media approaches for

particularly for research methods or for gathering data thinking about this like sort of like the distinction between

public and private potentially talking to some users and doing some outreach

around it to see how people feel like the people that you're studying would feel about it in keeping in mind that

well like distinctions are often very clear in terms of like access and the law they're oftentimes very blurry in

terms of people's own perceptions so I

would be protecting virtual participants so we talked about privacy and confidentiality but you know there's a

lot of the things are really stressful right now how in if you're collecting

qualitative data from individuals how do you handle disclosures of abuse

of interpersonal violence of suicidality and I have some examples on the next

slide so in a virtual advisory board one of the young people say that they're

having trouble getting up in the morning they cry all the time and they wonder if life is worth living like what's our

ethical obligation to this participant you know what can we offer this young

person and what do we need to think about ahead of time before we do a virtual focus group or a virtual

advisory board if we get this type of disclosure you know we see this in

qualitative research but you can also see it in quantitative research a lot of work that people are doing is are

including measures of mental health of distress of just depression in one

Qualtrics survey of reproductive health access the investigator included a phq-9

to screen for depression several participants scored very high like what

are our ethical obligations to these individuals do we report do we not report you know and you know at what

point do we take action this is something where I would say like as an adolescent provider and adolescent

researcher I'm much more commonly in the camp of reporting because our reporting

requirements with minors and young people are much more stringent than reporting requirements for things like

domestic violence or are are for adults but also thinking like ahead of time

what does this mean for your SOP what does this mean for your research procedures what do you put in the

consent form so thinking about like can these considerations need to go in upfront in terms of like how to handle

people in distress what are what are what are the the the procedures that the

research staff member will take and while this is like a standard part of research I think when we're thinking about a pandemic situation we really

need to consider that these things may happen more often

the other safety thing is thinking about the importance of phones and all low-income settings both international

but also domestic any phones are frequently shared devices so thinking

about confidentiality thinking about like families access so for many

families it's the only source of communication or contact they may need the phone to receive calls they need me

the phone to apply for jobs and benefits so like what role does the phone play in

their household and you know what does it mean to be tying up a phone for

research time and then are there costs that are hidden that we should take into account when we're working with people

in low-income settings so that they have limited minutes or do they have a limited data plan so and then the final

thing would be thinking about engaging affect affected community so thinking

about like our research like all research should be done in ways that

elevate the dignity enhance the empowerment of the individuals that we're serving and so thinking about like

who's our target population what's the health issue that we're studying who are the individuals most affected by it and

then looking at our virtual procedures and we are we treating individuals with dignity are we valuing and

respecting their time and their efforts are we empowering them and partnering

with them thinking about shared goals and responsibilities and so thinking of

like and this would be certain aspects of it issues around safety issues around privacy getting community input would be

very important truth-telling providing communities with facts letting them

determine good and harm so it may be that a survey that's not specifically on

kovat but is on something related to mental health may be actually really

appreciated in communities and then thinking about sustainability and ongoing benefit so are your participants

going to benefit not just from this like say interaction where they might have like

get reimbursement or access to other goods but as there will your work sort

of be sustainable and in an ongoing way and these are more generic types of best

practices and community engagement but I think particularly in pandemics situations we need to keep them at the

front of our mind and then I'm done so that's our little treats talk for today

and I'm open to questions so I'm going to actually unsure my screen so people

can see me and you can either ask questions or put them in chat I'm Mary

Peter Schwartz here how are you I'm good ok good that was a beautiful talk just

wonderful really enjoyed it and definitely raised a lot of important

issues the one I was wondering about was the question of whether

enrolling people in research now will impose harms and burdens that wouldn't

usually as you know and we talked about a lot together sometimes you know IRB

ease and others worry of the research is more burdensome sometimes in other

settings then we think it is we think actually participating research can be a benefit to an individual I know it's a

mere work you've done with sensitive topics and adolescence people have worried about the burdens on adolescents

participating but you've seen benefit to them does that apply here as well I was gonna link that's the question of paying

participants which again you raised as well which is you know this can be a source of some income for some people

and about you talk about issues perhaps stresses that that maybe need to be

addressed should know can be expressed and listened to in a way that is not happening otherwise so I totally respect

a lot of things you raised I had not even thought about it specially about sharing phones and privacy in the home you would think I would have thought of

that given the lack of privacy in our own home where I am now where you're probably a

child before I finish this question but my video is off you don't want to see me right right now but I wondered whether

there are some benefits that maybe should be taken to account as well and

maybe a special benefits in this situation yeah I can get Peter thank you for that question I think that there may

be benefits in certainly thinking about like all of my work with adolescence is

with adolescence and there are absolutely no summer jobs now and like thinking about you know is there a

research opportunity while young people are out of school that they could participate in

that's something pro-social that they could be reimbursed for so thinking about this as like a pro-social thing

you could also see this helping communities thinking about like looking

at like Reproductive Health Access has in in some areas of reproductive health than almost completely shut off and even

like ERS are our like sort of safety net for reproductive health access and

because of kovat and related fears there are more barriers to going to an ER so

like this might be something like a study of reproductive health access under pandemic conditions might be

something that women young women of reproductive age may actually want to see and may think feel that is

beneficial to them but I think the key piece would be like thinking about your

you know like thinking about engaging to test this to engage communities and

thinking about like how does the community feel about it how do the people that you're going to be working with feel about it and that would be and

I probably didn't link my last slide on community engagement as explicitly as I

as I should but it's really sort of a solution can I just follow up with one

more question Mary again excellent response also I was thinking about the

issue of focusing our research right now on you know like you raised that in

terms of the focus of research in this setting where we have you know a number

one number two and number three health problem our code there's a danger perhaps of you know

forgetting other health problems and losing traction and momentum on other issues again without taking away

from the from the incredible pressing need to do the best we can with Co vid but also looking at other things is

there it is the ethics of choosing a topic you don't think it's all Cove it all the time now obviously is there a

change though in prioritizing research areas

Peter I was really thinking about like using virtual methods to engage like

marginalized and minoritized populations and I just wanted to put it up as a you

know these are we looking at a group of individuals that's really stressed right now like covid and uh is theirs and

I think this question of is there social value to the research so if you're doing like research on children with cancer

caregivers of children with cancer then you know like I think thinking about like what's the social value now what

does your population say about it I think that this is a population of families that would want to participate

in one to have the research going on if we're doing research on a topic that's

not related to what's going on now then and we're doing it with a population

that's been thinking about like what's the burden to the population in terms of not just kovat as a disease but the

social and economic effects I think it's like one of these things thinking about like social value what does the

engage community say but I would I I don't want my slides to be an absolute

yet like stop you can't do this I just want them to be to be sort of let's ask

this question and make sure it's still a relevant question outstanding

outstanding Mary thank you any

additional questions I'm happy to take them in chat I'm happy to have people just sort of yell out a question

so there's a wonderful comment in chat like from Zeynep solely about thinking

about issues with not being able to notice emotional responses of participants and not able to respond in

virtual interviews and I think this is a really important point like we lose nuance in particularly if

you're doing it by phone where you can't actually see the person and this may be

something like this is would be again sort of a consideration as you go from

in-person interviews to virtual interviews particularly if you're doing work like Zeynep doing where Zeynep as

am unit ologist does a lot of work with like parents of extremely high-risk newborns and so not being able to gauge

emotional responses ends up being really important and being able to engage emotional responses is important to the

to the interview so I think this is a key thing some of the things about would be like sort of setting it up as ground

rules like if the person feels that they're not able to answer a question if

they feel choked up if they feel like the question is intrusive having them giving them permission to say I need a

little bit of time or I'm not comfortable answering that question and perhaps being very explicit about it

rather than having it be something that you notice and go along and again sort of these are the types of things like

ideally we could all think through before we do the flip to virtual to a virtual method

additional questions you are all welcome

to email me separately if anything comes up what we'll do there's a question

about slides and I will send my slides to Tah Yogo who is the center manager and

he will make sure that people have access to slides potentially posting them with the top can I jump in again

and just yes thanks again Mary for an excellent talk and so

topical and so thanks I'm so thankful for it the Center for Bioethics is also

opening a web site on Kovach ethics issues especially related

to Indiana and one of our topic areas is research ethics in this in its time

Mary's talk will be posted there as well as to the treats page against is the

monthly talk on the translational research ethics applied topics so they'll be posted there along with

possible references including what I assume is the paper that Mary will write and will be published in a very high I'm

not actually not kidding I think that's really I haven't seen this discussed and I got feedback from people when your

title was announced Mary saying this is a such an important topic and something has to be addressed so um thanks again

and that's just what I make sure people knew that there's this opportunity to

see things related to ethics we'll be posting that live probably early next week along with all the other ethics

topics yeah thanks to everybody for dialing in being a part of the

conversation