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okay hi everybody thanks welcome to our next episode of translational research ethics applied topics

i'm Peter Schwartz i'm the director of the center for bioethics and of the bioethics and subject advocacy

program of the indiana ctsi and this is a

speaker series a series we've done uh for a bunch of years now to give a short introduction to

uh ethics issues and research that are coming up in translational research especially the focus of the indiana ctsi

and the attempt the goal is to give a short introduction as you know this is painful to me speaking for a short period of time goes

against everything i stand for but i will try to do it uh so 30 minutes is our goal maybe even less

and then conversation discussion for about 30 minutes the goal of these uh talks is to give

people a quick introduction uh to the topic so they can come to us for more information

and they can actually see it the talk not just today with all of you here which is wonderful to have you

but also we archive these things online in fact let's see if this works i'm going to try to

oh it's going to let me look at this great so here is our online

archive of these talks the translational research ethics topics talks to treats talks this is on

the center for bioethics website you can also get there through the ctsi website and here you go you can see the most

recent talks going back in time this is from recent to pack or

you can see it as an a to z listing by topic it goes from advocacy

or authorship a great talk by Jane recently uh professor Hartsock i should say all

the way down to wearable technology and this one really should be called uh quality improvement uh should be in

the queues but it's down here for some reason we also have recently again when you go to these pages

take authorship for instance you can see the talk you can get a little short introduction to it there's a video this one has a

picture at the very beginning of it and then references to go and find out more about the topic if you want so that is our

goal and we now actually have just added under the treats talk a core section so

you can go and see core topics if you just want a general introduction to core topics and research ethics

and responsible cognitive research you can go through here and actually this is one that i've done before we've lost the

video for the time i did it before and we decided to re to redo it so we

have an updated version uh on this topic uh this topic's been coming up a lot i should say

uh we'll go back to the first page paying research participants i hear about it on national meetings i go to i hear about

it as an ethics issue that a lot of programs face it seems to be a central topic and here at iu there's actually a group

led by Brenda Hudson through the ctsi i believe John's involved in that group i know i saw Mary

Ott on the phone and she's involved in that group too on this topic and i actually saw their draft document

and it stimulated me to get to want to do this talk so i hope this is helpful and like i said speaking quickly

speaking quickly is second nature speaking for a short period of time is against everything i stand for

uh our goal with these talks is give a short introduction if you're watching this online and then you can call us for a consultation or for uh

go to one of our classes so i'm going to start with my oh well i'm

Coercion Undue Influence

going to start by revving my engine i'm sitting here on a motorcycle i thought i'd do that first okay that was the FedEx truck so here you go

so i want to know i want you i'm going to focus on one part of this and it has to do with the

ideas of coercion and undue influence and this is something actually some very smart ethicists much smarter than myself

have been writing about and i am smart enough to understand what they're saying and to convey it to you guys and i hope to the world of research that

basically we have been misthinking and i believe in some cases completely misunderstanding ideas of coercion and

under influence as they apply to research ethics actually i'm not going to accuse the IRB of this i think our IRB is excellent at

this topic i've had conversations with them uh the leadership there but i think some researchers actually

are confused they hear the word coercion they hear the word undue influence and they and they uh they run and this is a topic

therefore that a philosopher like myself a jointly trained philosopher with medicine

person uh can maybe help with so the take-home point is we may be worrying

about overpaying research participants due to this general idea of interfering with voluntariness

um and i think we should worry less about it we still have to worry of course but i think there's been a misplaced

emphasis again i'm following some very good emphasis on this which i'll explain more about and we have to think more about the

dangers of underpaying research subjects and participants which i would call exploitation again

these are all philosophically loaded terms and i'm going to go through each of them and so it's a perfect topic for me um

i put here right the philosopher wants to let you know like should i cut these the

joke there is that when i was in surgery as a medical student when you were on your surgery rotation you always asked the surgeon do you want

these surgery sutures cut too long or too short because they were never right if you cut them one way it was too long cut it

shorter it's too short and i think with painting of research subjects we make it in the same mindset where we may be paying them too much or

too little and i want to think about how to approach that notice as a philosopher i'd like to walk you through some of these notions which

float around but which philosophers and ethics have been thinking about very carefully and we hope to help you think about in a

practical way there'll be no simple formula here but i'm going to be recommending some approaches

again my interest here is partly because of the interesting philosophy behind it i think the questions of what is coercion and what is in undue influence

in general are fascinating questions and i think this is the case though where we can use these notions to

improve research ethics and the responsible concept of research i will be following a excellent paper

mostly there are a bunch of good papers out there but the paper i really like is by Emily Largent and Holly Fernandez

lynch about paying research participants a paper that appeared a couple years ago actually 2017 in the

hastings center's ethics of research journal

Purpose of Research

okay i'm going to go back to the beginning uh the purpose of research uh so as you know and we do inform

consent for research participants generally um and we uh we

think informed consensus is very important informed consent to the short uh picture here of how we think about

informed consent for research versus clinical care is that when we talk about risks of participating in research

and participating and getting clinical care describing those risks in the informed consent form

is not all that different in the two cases you have to describe risks that are important that are

significant enough to be material to a reasonable person and so when i think of

consent in both those cases and i evaluate consent forms consent discussions i think description of risk is actually

pretty similar the burden on the on the researcher and on the clinician two very different

characters uh is similar you have to explain the risks that are relevant to a reasonable person

benefits however could not be more different in case of receiving clinical care you're you're there to to receive help for your

health either to treat a an illness uh to to address perhaps suffering caused by an illness or to

prevent illness or disease in research the reason for the interaction the reason why you're there

is to advance science and medicine there are still uh ethical obligations of course

important ones of the researcher towards you but the goal of their interaction with you and their

primary purpose you could say is not to improve your health it is to advance science and medicine

so while it's very clear why a person goes for health care it is has always been a puzzle in

research ethics why exactly a person is there and if they are there for different reasons

which of these reasons are okay and payment for participation is going to be one of those reasons

there's been a bit of a confusion and difficulty with the notion of whether it is okay for a person to be

there just for the money is that okay so Hans Jonas one of the great early

bioethicists wrote about the reasons for human subjects to be involved in

in research and from his view in the view of similar bioethicists from that time the goals

of the research subject the reason why they had come in the benefits to them were really benefits to others so that's

called altruism it was a gift from the participant to the society to the future members

and perhaps it was actually engaging in a partnership with the researchers so the participant

is not designing the research perhaps it's not conducting the research but they are contributing with a shared goal with the researchers

of achieving certain ends now i will say the last part of this has been become much more prominent

as we think about community-based research we think about patient-centered research we think about

the partners that we have in our research so this is not all out of date but this is how it's thought about first

now from this perspective and i'd say coming up to the modern day we can separate the reasons for giving

money to participants uh into four categories roughly you could probably do different ones

here they are first you might be reimbursing people for just their expenses of coming and participating in research

so that would be something like you know their parking fees uh second we might be wanting to reimburse

them to make them whole if they were injured in some way then you might think that we should be reimbursing them with money

to help them get better uh you those of you who are involved in research know that often we just say

well your health insurance will cover that if you're injured but this is a reason for monetary compensation you could think about

even with those old Hans Joseph Jonas categories right somebody comes out of the goodness of their heart they're participating help

future signs but they get injured you could imagine of course that's part of how you would you would pay them

and you might just be showing your thankfulness right that's another way to say we really appreciate your coming out here and making the sacrifice

for the future of research and the future of knowledge and we'd like to give you this hundred dollars to say thank you

and there's a very different model the fourth thing actually the wage model where we see the money as being an

inducement to participate we're giving higher pay for instance four higher time commitment effort discomfort

uh and for risk we're saying we're paying you to do this like we pay people when they are working

in other settings right so one through three we're all consistent with the idea of research

participation as a purely altruistic act number four isn't so much number four says no this is one of the benefits

we were looking for the reason why people participate in research here's one we're going to do and give them money and i would say

the research ethicists like researchers and other leaders in the research world have been a bit conflicted about the

fourth model now what does the common rule say the regulation here says that informed

consent should be carried out in ways quote that minimize the possibility of coercion or undue influence

ah so here are these notions that have befuddled and somewhat confused us uh the regulation says

we should be minimizing the possibility of coercion and undue and undue influence so what does that mean when does payment

cause coercion and undue influence and how should IRBs or research ethicists for

instance guiding researchers or yes researchers themselves how should they act in response

What is Coercion

so the first question would be what is coercion so i do this with a class i actually ask

the students to respond in the interest of time just go through this here are the four cases

just four cases really off the top of my head i'm a parent right i say to my child you can't watch

tv until you finish your homework i want you to think about each of these are they coercion

right is this coercive when i give my son a statement like that

or my wife uh says to me when i say let's just stay home tonight she says if you want to stay home fine

fine my brother used to teach me it's a four letter word i know what she means she's saying i'm going to be irritated

if we really are going to tangle in the house the way you want to do and work on your papers that's not going to make me happy is that coercion that she's telling me

she's going to be irritated to my employee i say if you're late one more time i'm going to fire you

you will be fired i have the right to do that and i will do that to my contractor i say okay interesting

estimate you're going to clean my gutters for 200. i don't accept that offer i'll give you 125.

do it for that price or go to your next house

so are any of these coercion when i ask students or actually i once did this before with research

coordinators i think i had some people say that each of these are coercion i had at least somebody in the audience

argued that each of these are coercive right they they come off maybe seeming a little mean

and kind of hard right i'm going to argue that these are not

coercion and i'll give you a definition for why that is these are fair bargaining i i you may have noticed

my first two were familial you might say peter there's something wrong with you to use familial examples

when you're trying to think about coercion but i think actually the home life the personal life is of course always central to thinking about

ethical behavior and i would call these fair bargaining

here's what's not fair bargaining here is true coercion robbed at gunpoint someone points a gun

at you and says your money or your life in the old fashioned way and i said gee how old are you get robbed by a 65 year

old right this is like an old man robbing you um because that's an old saying your money or your wife

right that is coercion to an employee right the same employee

case as if you're late one more time i'll tell the company you've been stealing you haven't but i will lie to them

to a contractor i say i know i agreed to pay you 125 for the guttys

but i won't pay you for that if you you better if you don't resurface my driveway i'm not paying you anything i'm going to renege on my offer so what's

special about those cases is they are coercion by this definition a coercion is a threat

to violate someone else's rights or to fail to satisfy an obligation to someone in order to obtain compliance in

situations where that person has no reasonable alternative but to comply go back here actually do i do it next i

think i've got some more slides here yeah no i don't so let me just go back

here i'm going to go backwards right so look i'm telling my child you can't watch tv to finish homework i'm not violating any of his rights

i'm not treating him unjustly i'm just telling him how it is because i am the parent i have that right my spouse can be irritated to me she

often is i don't blame her right to an employee if you're late you don't fulfill your obligations

then there are consequences for that which are fair and will probably explain to you when you first came to work

negotiation with a contractor i have a price i want to pay for this if you don't want to do it for my price that's called the free market what's

wrong with being robbed at gunpoint is that what i am threatening to do is to is to hurt you with the gun

and that is to violate your rights that is to be unjust towards you it is too it is to assault you

by the way i'm realizing it's very quiet so i hope i have not somehow frozen i've been talking for 20 minutes on my own so

um Aubrey i can see you can you give me some i can see your dog picture give me some

sun yes good okay good just went off you're fine okay but Aubrey i'm counting on you to let me know if i if i go bad and i've

got my phone here too in case i do go bad it is kind of lonely when you're talking on zoom by the way i will mention

the treats talks we'll be returning to in person in august so at least the speaker will be in the room

even though we'll still probably allow zoomer anyway and to the contractor when i lied and said i'd pay him

for the gutters but now i'm demanding more that's violating my my promise to him

and therefore what i've done is i've failed to satisfy my obligation

so now let's move to research back to research i should say what if i have a simple survey i'm doing

Research Examples

for a study and it takes 10 minutes to do and there's no real risk to it and i'm

not offering to pay i'm just asking people as they walk by on the street to fill it out it's certainly not coercive if i

if i don't pay them what if i were from five dollars it's a pretty good money for filling out a survey but am i

violating their rights in some way or failing to fulfill an obligation to them by offering them money

of course not what if i gave them a thousand dollars

this is the kind of case i think some reasons think about when they worry about overpaying their subjects it's not that the research is so risky

it's just a survey but i'm paying an insane amount and i think for some people they think well

that's sort of too good an offer to refuse and so what i am doing is that i'm

failing i'm giving them no reasonable alternative but to comply it's such a good offer a thousand

dollars for a five-minute survey nobody in our right mind turns that down so this is somehow coercive

because it is very convincing and the answer is it is not by this notion of coercion

right because although it is true it's an offer that's too good to refuse what i'm doing is i'm not violating

their rights with that offer i'm not um failing to fulfill an obligation to them

i am truly given an offer that's too good to turn down they can still vote and if they do turn it down

none of their rights will be will be violated they will walk away just as well as they were when they came

again okay so let's get back to a little more so now it's a phase three randomized trial now there's a little

bit of risk again no pay i'm going to say not exploitative to offer people the chance to

participate to be randomized to stay two different anti-hypertensive drugs and they can do it if they want

they don't have to do what they don't want i'm one of them fifty dollars right now that's not that seems like a that's

something probably wouldn't die or be nobody no researcher would even uh would even wonder about ah again overpay

once again i'm going to argue that overpaying here is not coercive it is very convincing

it's a bad use of your research money and the NIH should come to you and say you're paying too much we didn't we

don't giving the money away this is ridiculous um but it's not on a coercive offer

to a research subject because they're participating in a trial that really wouldn't have been unjust to enroll them for no pay

again we have not violated someone's rights or failed satisfy obligation to them in

order to obtain their compliance uh phase one trial with some risk again no pay

money okay so here's their argument which again i am trying to convince you to accept

Undue Influence

and i am happy to discuss in our discussion but the idea is excessive payment if a lower payment would not be

coercive then excessive payment is not coercive so what is wrong with overpaying

participants if it's not coercion you might say okay Peter we get it not coercive it's

still wrong and maybe it's going to fall on this category of undue inducement

undue influence

once again you think about that phase one trial right you're encouraging them to participate in phase one trial

i don't think it would be unethical to enroll them if they offered to do it altruistically

now you're often a thousand dollars maybe it's not coercive what if i had extremely high risks

what if i offered you a thousand dollars to run across the street with your eyes closed this is a scene in a movie it's a murphy

movie called Bowfinger one of his lesser known movies at one point i forget why he does it but he closes

his eyes and runs across the street um that is a horrible decision to make

whether it works out or not i use it in my decision making classes a bit but um it would be

i would say concerning maybe ethically questionable i'd say i would say absolutely wrong to

pay somebody a thousand dollars to run across the street with our eyes closed that's interesting i'm not coercing them

but what am i what how do we describe what's going wrong there what's wrong is that the individuals

doing something has a very high probability of causing harm or extreme discomfort which is not worth it

even for the money offered again we can have a long discussion about this these treat stocks are not like a class where

we could really delve into this but the idea is the money is blinding the person to the dangers involved

you aren't coercing them but you're acting unethically and this gets the idea of undue influence it's an offer to provide an

excessive reward that results in bad judgment meaning it results in a choice that's unreasonably

against the offeree the participants self-defined values and interests

i think in the case of the person running across the street with their eyes closed you can see how that would be that um you know a person just they

wouldn't do it for fun they wouldn't do it for a hundred dollars but they will take this insane risk which is a

horrible risk to take you know i don't and i got to tell you i don't even care how hard up you are for the money you

guys can argue with this in a class we'd have a great discussion about it this is an unethical offer to somebody

and the idea of undue influence is probably closer to what researchers worry about now this phrase though an offer to

provide an excessive reward that results in bad judgment

so the person accepts it even though it is not in their self-interest this does raise some very

good and deep questions which of course we can't solve today come to our classes for the right what

are an individual's self-defined values and interests i mean Eddie Murphy in that movie i can't

remember much about the movie i should re re-watch it before i talk about it in talks i guess it's you know it's part of my research

you might think i sit at home and read books and run my studies and come to the office occasionally but

actually it's the movies i have to watch to catch up on my references you can see i don't do that enough though i can't remember why he does it

but right what are how do we know the person who does this crazy thing either phase one trial

or run across the street with their eyes closed what are their self-defined values of interest i can tell you from a

researcher in this area it's very hard to pin that down and how do we know if the choice was

consistent with those interests um a case that large and lynch go through in that

article i quite like is that um your next door neighbor Kate uh is friendly with you there's a big

snowstorm i know it's hard to imagine right now that's what talking can only do in the uh in the winter time but there's

a snowstorm and uh she offers to shovel your walk

because she knows that you're feeble perhaps and it's certainly a nice thing to do i

wouldn't call it unethical in any way and let's say i offer her ten dollars to do it and she does she would do it for ten dollars

and again i overpay her same thing it's not coercive and doesn't look like undue influence to overpay her here either she might

she might do us a favor but now imagine Kate has a heart condition that makes it extremely difficult and

dangerous for her to shovel your walk now it's going to look more like the case of running across the street

if she does it as a favor i guess we can live with it she's choosing for whatever reasons

to do this dangerous thing as a help to you if i give her a reasonable amount of

money for that work again i think we can live with it ethically but here's the time that the

overpayment looks bad right i'm going to overpay or do something very dangerous and i might

be tempting her into doing something which is really not a good idea for her and so this is sort of the kind of case

that we have in mind um so the question is does this come up

in research cases right is the case of Kate with the heart condition shoveling or eddie murphy running across

the street in Bowfinger are these cases ones where um

where a person's has great is facing great risk and is being induced unduly to take that risk larger than

lynch are going to say that actually this should not apply because the IRB is not supposed to approve studies ever

that carry this kind of high probability of causing harm or extreme discomfort actually Amy and Beth who are two

leaders in our regulatory world and john of course uh you are all happy to weigh in i'm

going to keep on going like a freight train here to try to get through in my close to my 30 minutes i'm going to be over

as you can see but um but i'd be interested in your thoughts at the end of this talk about this or anybody else on the call

about is that right the IRB basically uh is not supposed to

allow studies that are high risk of this sort high probability of causing harm or extreme discomfort or another way to put

it and again more specifically i think this is right but supposed to judge whether the risks

to the participants have been minimized right their design is such that the goals are being achieved in the minimal risks of participants and

if there are additional risks that they're justified by the social value of the knowledge to be gained

and benefits to participants that do not include payments so now this is where again the payments

are rearing their head if you were an IRB considering a study that put people at great risk we said oh

don't worry about i'm going to pay them five thousand dollars that is not supposed to be the use of a payment the risks cannot be

justified based on that they can be based on the very very high value of the research

the fact the risks have been absolutely minimized and a war or benefit to the participants

like a person i guess going through a chemotherapy trial where the drug is their last chance

um again this gets back to our idea of what we're paying people for when we pay them when they participate

in research studies let's see where i'm going here

um okay so the wage model is going to be okay in some cases but again with very high

risks the wage model is not going to apply when we pay people in some jobs take very high risks for very high pay

think of the test pilot i guess we are not looking that kind of

situation for research subjects but again for researchers who are nervous about this topic might be watching this or might be reading

something the idea is unless there are those high risks and there's a concern that we're actually getting people to act against

their best interests the worries about undue influence probably are not primary so what are the dangers there are still

Dangers

some dangers of allowing higher payments right first of all if you were allowing

uh researchers to overpay and to pay somebody a thousand dollars for a participating phase one trial um there

is the danger that the IRB will forget its obligation to not count that in

considering risk so what if regulators allowed trials to occur which with risks were not minimized where the

benefits there were no benefits to participants that were non-monetary um and the social value of the

information was not high but it's all well at least it's a lot of money it's that makes it okay that would be a danger let's assume that

would not happen not happen there is a danger of course when you pay too much you may get

some problems in how people uh and how you apply the exclusion and inclusion criteria and

the danger here is that if you're paying so much then there is a danger people will conceal

their personal history that will exclude them from the study and especially if that's one that would put them at higher risk

so here's a phase imagine this case again it comes from larger than lynch's paper it's a phase one trial where people with

a history of previous malignancy are not eligible because the treatment or the in the study uh

procedures would put them at high risk if they had a previous malignancy if you're overpaying for participation

that study someone with that history of previous malignancy even told they should not participate

might choose to conceal that malignancy in order to participate in this case they are incurring a risk

that the irb did not approve that would not be appropriate but they're hiding it because of the high payment

so this is a big risk of higher payments this is the risk

uh that actually lynch and larger sort of admit to there are two sides of it there's a side about giving people risks that they

should not have to incur they should not be allowed into the study because they will be incurring those high risks there's also a scientific uh issue that

they might be giving into the study again concealing aspects that would make the study less valid for their participation

and these are the risks of higher payments that lynch and largent want to um acknowledge

and if that's the reason for limiting the payment then that's right if you're a researcher you're concerned about paying too much

for these reasons that's a good reason the one i'm throwing called water on is the idea that you're just afraid you're exploiting

or unduly influencing in the case for people being truthful now what's the danger of not allowing

higher payments right if there is if there is a danger of allowing higher payments what's the danger of not

allowing higher payments and the answer there is very clear and sadly i think very common so here's

exploitation the danger is exploitation again a favorite philosophy word exploitation occurs when one party do a transaction

insufficiently benefits or assumes an unfair share of burdens relative to other parties in a transaction right the classic case is

the sweatshop right so you're paying people a penny to work 12 hours because they are desperate you are not

paying them a reasonable wage uh that is not a fair payment and so you're exploiting them they're agreeing

to it but that doesn't make it okay you're not paying them what you should be paying them now

i have friends in the philosophy world who think that actually even that should be considered the sweatshop that's still fair because

people have freely chosen to do it and they're still pursuing their own self-interest it's a bad situation that

they have to work for 12 hours for one penny but it is not um it is not harming them they are not

worse off at the end of it i'll leave those arguments again for another day but if there is such a thing called exploitation i believe there is then

underpaying people for their work below a reasonable pay is is exploitation and it's unethical

within medical research of course we know about cases international research where this has happened where

the research was actually located internationally in order to find people who are desperate and would be willing to take low risks

um the general idea of this petition is you really could have consensual

exploitation that's the second bullet point again the sweatshop or other unemployed uh underpaid employment

so consent doesn't the fact that somebody agree doesn't make something or even that they agree to their own free will does that make

something um non-exploitative so if you can see i'm concerned about

exploitation and i'm concerned about the fact that when participants are asked to do things that may be burdensome or even risky

and they're not paid a fair rate something that would seem fair to cover their participation to reimburse

them or at least compensate them for their work maybe what you might consider a fair wage then they're being exploited

there's that danger they're being they're being treated unfairly and again as a philosopher and as a

thoughtful emphasis i will say that of course the notion of exploitation is even if you believe in it as i do

it is a squishy notion right what determines what's a fair rate especially what would a fair rate be in

a research setting and again this is my libertarian

philosopher friends you know i say how do you Peter Schwartz and your like-minded liberal-minded philosophers

criticize a transaction where a person makes an informed choice ends up better off and you think they

were underpaid they say Peter you're being your classic paternalist

uh lint larger than lynch think yeah sure these are these are complicated but the irb has this this concern to

defend our participants not just from unnecessary risks or undue influence undue influence

but uh to protect them from exploitation so when the resources are there for sure

um to pay them appropriately uh lynch and larger and people like me

who want participants to be paid higher we point also to things like if you underpay

you have the risk of not recruiting sufficiently and therefore the entire project becomes unethical because it's

not achieving its research goals um

uh you may actually only attract people with lower socioeconomic status you may fail to attract people from a wider range of

socio-economic backgrounds and there's a scientific benefit to that and i would say an ethical benefit a justice

benefit to involving a wider range of people in research if you overpay you will get some of the poor middle

class and upper class if you really do stick to the lowest payment possible you may get people who are only willing to do it for a

lower wage okay so i am at the end we want to offer

payment that fits the time and the burden involved uh you probably can consider risks as well but be careful adjusting payment

for that in case you are getting into the realm of undue influence where you're encouraging people to take high risks

that were not minimized perhaps because you're paying them a lot avoid that overpayment therefore when you're

concerned about undue influence avoid underpayment due to the danger of exploitation and the dangers of limited uh

recruitment and explain your rationale to the IRB and any regulators or involved researchers or certainly on

grant applications as clearly as possible the least controversial justifications are the ideas of reimbursement

appreciation and paying the fair wage for burden and time i should mention there's some topics here i did not cover

Other topics

uh you know there's a question of how to it's the same that is the same truck

that was here before or this is a duplicate um there's the question of uh

when to stop paying a participant who perhaps fails to complete a study or

violate some other expectation of participants in a study and those are written in and that's another side of paying

participants of course when we determine payment amounts there are all kinds of things you might take into account like cost of

living wages people argue that different parts of our country may have different uh payment amounts for the same research

participation there's a fascinating question actually the question i asked Amy and Beth about last week is the question of whether you

can pay people different amounts based on their expertise um you know

if i'm interviewing doctors in my study and i know i'll get no doctors to participate if i don't pay them a

hundred dollars each for their hour of their interview but i know i can get lay people for the same price for a very similar interview

then i have been told and i think it's interesting that we should we cannot pay them separate amounts we

should pay them the same amount because we're asking the same of them and if we are paying even on the wage

model the fact that somebody has an md is not itself a reason to be paid more just because you need them to participate

uh Amy and Beth both helped me think through also the question of what you're asking from them

if they're perhaps providing specialized knowledge there could be a justification for paying more to a specialist a highly

trained person but again these are the sort of things you have to think through in terms of your fairness um there is there are some strict rules

about how you describe your payments to two people on advertisements you don't put them first i believe

uh and so we always follow that on our rules that we do not make it the number one thing that is said

although again i think that's an interesting side of how we think about payment and research uh there are other issues on paying

children and their families when uh people less than the age majority participate in research

there are special issues there i'm not going to talk about today and there are taxation responsibilities that are practical i should say that

there's part of the reason i'm thinking about those and i've recently been reminded of those additional issues is this ctsi recruitment optimization

project that um Brenda Hudson is leading a lot of my friends are involved that i'm involved in somewhat

and i'm i'm eager to see what they provide i hope that this talk can be of help to researchers

who might have questions about these topics too although i know i went very fast uh feel

free to come to bsap the bioethics subject advocacy program for consultation or just conversation we

love thinking about these issues i promise i won't lecture too much about exploitation we'll just think it through

uh we have this webpage i showed you where you can request a consult and you can also just email me or

ty yoga who's our program manager or just the bsap iu.edu

and now i blissfully both for you and for me get to stop talking and i get to hear what you

Participants

think so i will open i'm going to stop the full share do that good

and now i'm going to do participants and really with this number we only have 36 people you're really welcome to open

your mic and ask a question if you want to raise your hand and go in that order i can see the participant list here

i'll pull that over to this screen please feel free and thank you for being here thank you for your attention

Carol Robertson Plouch you are unmuted sure i put a message in the

chat but i'll just uh vocalize it here uh verbalize it here um

so to thinking about the wage model i think it's a very interesting

thing to think about and probably could be a whole separate discussion in and of itself

because what is the reasonable wage then is it today's minimum wage is it

the minimum wage post the current uh proposal which it doubles it or is it a

professional wage or is it some place in between so you know is it is it eight dollars an hour is it fifteen dollars an

hour is it a hundred dollars an hour is it three hundred dollars an hour you know you know they said how do we

even determine that i know it's crazy right so let me tell you what i learned as i came up the ranks as

a you know as a professor now is that they actually set wages at iu by looking at other universities

right they say like okay how much you pay a doc here how much you pay a new surgeon here well look at what they're paying in Cleveland and what they're paying at

iu health and so it is kind of a funny game right how much is fair is probably based on just what other

people do and you didn't have a reason for paying them this amount and now they don't but you still you know you're um

benchmarking your amount by their amount so there are some funny numbers that seem like they're standard numbers in research participation and i go by those

numbers when i'm writing studies like 30 for an hour generally for an interview with a patient or 50 if i can get away

with it um and anyway in further answer your question i now call on Amy Waltz and Beth

Johnson to answer your question hi this is Beth i would say for the last

several years we've been seeing about 15 usually for much longer than it's been in the political

discussion realm that's been pretty standard 15 per hour

yep and how about how about more than that what if somebody wants to pay 30 an hour is that sure yep that's okay too but at

least 15 yeah i would say excellent thank you Beth you're brave and helpful thank you

for being here i said i wouldn't need you but i did yeah no so that's interesting so with the wage model would be by the hour

lucy has her hand up lucy yeah i'm just thinking about this with

kids too and parents do we um do we compensate kids and reimburse parents

um or what do you think about that so this is interesting these are i'm

going to again i said i was not going to talk about kids in fact sorry we'll put Mary Ott on this on the

stand uh to answer either now or in a future talk but i know that the recruitment optimization

program has been thinking about this and what's the best method for paying for pediatric participation

because we generally don't pay five-year-olds you know big money or even small money we give it they're

they're below the age of majority actually lucy i know you practice in the pediatric realm so what do you do is it

is it a matter of paying the family it is so what we tend to do is um we pay the

participant um so we pay five-year-olds we pay two-year-olds um and then uh it's just a matter of

reporting is a little bit different but we usually pay the participant if the participant is the whole family

then we what we tend to do is go ahead and give the give the payment to whoever the adult is

at the visit and then how they want to divvy it up as a family is up to them and we i usually at least for me

communicate to that to everyone at the same time what that what that plan is for me but

um just trying to you know there's no set a set rule or set um guideline

guidelines i think for us too it's just what each individual group does outstanding i i that sounds

very reasonable what you're saying and actually if anybody else wants to comment on that or criticize it feel free but

that sounds like you have a good approach it is complicated when you're paying a child for anything like paying him for

cleaning his room you know i mean i parents pay children um i pay my children they did very good

work last weekend very impressively heavy work actually and i paid them a fair wage i think i overpaid

them they think i underpaid them which means it must have been the right amount okay john you've come off mute i've got to let you go so i

this has been very interesting thank you peter and everyone else who's made comments or raised

Market driven reimbursement

questions so you know sometimes when you're in the process of conducting research

you know you're it it's fairly easy to get the first say 60 of your subjects but then as it gets

later and later in the project it gets harder to find the remaining subjects that you

might want to see want to obtain uh what is what are people's thoughts about you know almost a market driven

reimbursement process in which at a certain point in order to finish off your successful

recruitment you feel like you need to up the amount that you're giving them

which means now you're giving people more than you gave three months ago this is the true wage

model right why are wages going up now we have a shortage of lifeguards so the lifeguard wage has

gone up in my local place so um thoughts on this uh that that doesn't make the wage module um

model i see Amy has come on camera Amy so we i think we're kind of talking

about this when you asked us this question earlier this week peter um and i think the issue

really is the comparison of the two groups because as you mentioned if you put in two

different protocols and said i'm going to pay them thirty dollars and in the second protocol i'm

going to pay them fifty dollars an IRB would look at those and it would be unlikely that

they would say that that was coercive i think it's only when the comparison happens that um

IRBs start to get a little bit uneasy with that um and i would say that you know

uneasy is not um just because you're uneasy or just because it feels a little weird

um doesn't mean that it goes against the regulations or that it actually is coercive um so it's an interesting question but i

you know if i were an IRB member i think i would support that yeah i mean it's what's

fascinating is i really understand what you and Beth said Amy about how and this may apply to what john's saying

is how um uh you know if i'm asking different things of them i'm asking for lay experience which is

commonly shared across society versus asking for doctor experience which is not commonly shared that's much

much more rare and relies on specialized training then i can justify paying them more

no but that was not that was not my question my question is the subjects are exactly are no

different from one another but in order to successfully recruit you have to raise the ante if you will

right either late in the study the way you said john or because my study needs mds and providers and i'm just doing it

because i need to get them and i can't get them if i don't pay them enough and that's basically the wage model right i basically i've got a problem

i've got high paid specialists for research purposes that are reasonable i need them to talk to me

and i cannot get them to talk to me if i only pay them 30. so i'm going to pay them 100 even though i'm going to pay the lay

people 30 for the same interview but i can get lay people for 30. i can't get uh doctors for

for less than 100. i think you might make an argument and poor old Amy and Beth have to actually be the deciders

but i would support the argument that you can pay them different amounts based on this wage model but john do you

not like that answer no i think there's a practicality that makes it almost necessary to answer that way

Will people hold back

actually i would if it seems to me that if you were going to do that you would have to kind of go

back and retroactively pay the rest of the folks that the same wage and and there's a

couple things that just come to my mind about it one is if we start to do that regularly all

your trials i can assure you are going to have a hard time enrolling until the prices go way up

and it's so i think it'd be better to again you know look at the trial as a whole try to come up with what's going

to be the right thing to do and then stick with it and then if you do have to make a change because it's not working to be fair in

terms of how you make that change it'd be i guess the advice i would think about

i'm going to introduce matt matt's the lead of the bioethics at Lilly corporation thank you matt for being out thanks for

that thought right so people will they hold back it's kind of like the worry i think we have here about paying for vaccination i think the governor said that he said

well we're afraid of paying because people will wait uh to to get vaccine till they see the price go up or they go to see the

the lottery gets richer of course you know matt that could be a practical concern but not an ethical one right it

could basically in the end undermine your ability to recruit if the price of participation that people are expecting goes up um and

they're going to hold back and see if later in the study they can get more dollars that's of course the problem with paying people more effort

right if we start paying lifeguards more this year because we have a shortage then gosh darn it JCC membership is going to go up because

they're paying people more i think the fairness is the ethical issue though right if it's

if it's if you're asking for the same stuff from the same people you should pay the same if i hire lifeguards

i only have seven lifeguards i need nine if i have if i pay the last two lifeguards i hire a higher fee the first

seven are going to quit unless i go back and raise their fee too so actually again it does seem to fit

here a bit on that wage model we're not asking people i assume in these studies to do something dangerous like run across a road

it's been the sort of thing the IRB approves is minimizing risks not being ridiculously high risks in that case

i think actually going to the wage model and think of the costs and benefits of paying higher wages is not wrong i think it's a useful way

to think about things and i see lucy's come off come off oh wait a few people have come off oh no she's come on camera

please just raise your hand if you want to talk i still have my participant thing open i was going to say there was zainab um

sally came on the chat to say that she was giving they did uh want to

increase an incentive because they were not recruiting enough and they increased um and uh they were worried about

telling patients about it at the beginning they would be coercive but again zainab my whole talk so far is to say telling

people what you are going to pay them is not and it being a good fee that people will actually respond to

and choose to participate because you are paying them that amount is not coercion i don't think that

should ever make you think of coercion i think of overpayment as being nice and

having certain dangers but nothing like coercion dangers unless there's some other things about the study you want to tell me which that

you're exposing them to risk the IRB should never have approved or something like that and so Zaynab i'm

just part of my point of this talk of picking on you for this great question is that i want to highlight that i want

people to walk away from this being more suspicious of this question a lot of researchers have of

if i pay more and keep coercive i know i went fast at that part of the talk because i just can't do everything in an

hour but i hope you think about that go ahead yeah so can you hear me Peter i can hear you

okay perfect so my question was yes the research is telling the participants they are going to

be getting a gift card but she said she told me she wouldn't tell them much i said why not because

this is the reason why we raised this incentive from 25 to 100

i mean why don't you so she was hesitant she said this would be coercion so i wonder if telling the amount is

okay or not well this is great xana because i'm thinking it should be fine to say it right up front it's not again assuming there's nothing

else about this that we should be concerned about but now i'm going back to Amy and Beth again which i do believe the rules still are

that when you advertise a study you cannot put the dollars in big numbers in big text and then put the

rest of the study appreciation small attacks and john of course you i'm sorry i keep guys i didn't bother you before the talk so Amy and Beth are my people

i'm picking on but john you're in too i see you've come off mute that i thought you were not allowed to put that advertisement at the very top

kind of like your RA there uh saying apple said i'm not going to say it first i'll say it but i won't say it first John Amy Beth

i'll let Amy and Beth answer okay thanks John

Increasing the incentive

hi yeah i agree um you know you don't want to start with hey get paid for participating in this

research study but you know you can say it as your second sentence your third sentence that's fine they can say it as part of

that initial recruitment unless the IRB has expressly you know approved something else as the recruitment plan

but i would i actually came off mute because i wanted to ask a question when the IRB approved you

increasing the incentive to go back to the comment that Matthews raised did they make you go back in and

compensate already participating subjects more or they just did it as a market process if you will

right we did this actually twice that's what first time we increased it was few years ago

uh and this this is the second time they didn't ask us to go back and be accomplished because this

would be very cumbersome and to me and to me i don't think it makes a big difference

in the end if the pastor wants to participate in that in my kind of research they would or not you know

but for some people it might be for example it might be a reason but they didn't ask us to go back

and pay the pay the rest more i think that highlights the limitations of irb

review you know IRB review is based in ethics but we are not charged with uh covering

everything that might be ethical we still have regulations that tell us which portions of the study we should be

reviewing and what our standards are and so i think that would go a little bit beyond what our charge is

in the common role personally yeah we are not an ethics review right

Discussion

well wait so i want to go to Howard uh Howard you have your hand up and you asked a question in chat which i didn't

get to yet please go ahead and ask that question or another if you'd like no i'm going to skip the one in chat because i think you addressed it

uh whether or not you pay someone a lot of money you can't ask them to do something that's ridiculously dangerous

now i wanted to push back briefly on Matthew's comment about retroactive payment using your

example uh if you change the payment from a lifeguard from eight dollars to ten

dollars clearly the other people you're recruiting at the same time ought to get paid that you don't go back the last 50 years and

pay everyone who used to used to be a lifeguard that makes no sense

what's great Howard it's great this is a deep philosophical question when does somebody's participation in the study end

is it that the study is still ongoing so they're like the lifeguards you already have you know they they've done their

participation but they're still sort of part of the same study or has their participation ended kind of like your example of going back to the lifeguards

from last year matt do you have a thought on this well let me chime in my quick answer first on that because

i i think it ends when their part when their physical or intellectual participation

ends i don't keep paying technicians when they leave just because the grant goes on

excellent response yeah i mean well so first of all before i went back to graduate school i

used to lifeguard now i would love to get uh recompensated for the 50 years since i did

for the difference in wages now um yeah i think there's i mean i guess it's

not black and white but i do think you could run into problems if and of course your participants aren't supposed to talk but you know

i i think if i was currently in a study and i found out that somebody else who was in it was getting more than me

i would maybe have some questions about that i think you have a good point about once you've completed

the study um you know maybe it's done so i that and that's the thing why it raises

questions of fairness i do think though this is also just another thing before i was too

quick to change the pricing i would really want to dig in to understand what are the barriers to enrollment

maybe there is something in the inclusion exclusion maybe there are parts of the study that

are more burdensome than what you had anticipated and it could be that maybe you need to pay more for that

but it could be maybe you can you can simplify your study or make other changes that might make

more sense than just increasing the payment rate so that is a great

comment i think it brings the talk actually full circle i'm going to take advantage of that i if i'm as a burning question i'll

entertain it but matt as you know and as many of the researchers know we are in a new age

of research participation where the participant is considered differently we used to say you know um they're a

subject right we used to say now we say participant and actually the group i am funded by recently is

Pcori and they call them partners right they want to think of them as being partners almost going back to that Hans Joseph and Joe Jonas uh conception

of sharing a goal and therefore your contributions being the scientists their contribution is participating and

you're working together towards a common goal and so payment always has been sort of an awkward part of that

and i would say this like you're saying man if you think about the other benefits of participation being included being communicated with

hearing about results that affect you or perhaps if results that affect society having that open and honest exchange of

communication i think is the goal for research ethics now and probably the picture for the future and so i agree that talking about money

you know filthy looker as we say in Latin you know um uh is a little off-putting

because it almost takes us away from that i would say however i want to actually make this point that it's actually making sure we pay

people as well as we can without getting distracted by a i believe a red herring

of coercion or of undue influence in most cases is actually a way of of showing that

partnership again we're not just trying to get the biggest bang for our littlest buck right unless we really have to i've done

studies that were pilot studies run on shoestring where i was paying people out of my own pocket really i shouldn't say that is that against the rules

and that was way back when not currently but you know i was paying you know it was real i wasn't there was there was no grant now there's a grant

and of course you have to budget a grant responsibly and your funder will of course watch that but actually paying well as well as you

can is i think part of our respect issues it's not to replace treating your uh participants as partners

but it's a way to respect them as partners as well as you can last questions i guess it is one o'clock

holy cow we're on time and under budget under budget getting back to the payment issue

i'm going to go ahead and stop please feel free to email us you have the emails that we put up on the

uh on the things you now know how to get to us by the web we'd love to talk more about this thank

you all for being here and we'll see you in a month for our next treats talk