Hello everybody today for the IU bioethics

Grand rounds I get to introduce myself see it's a special treat to me and thank you for being here thank you for people

being online I don't see the number but there you go Al so we have a few people online thank you for all being here uh

we do have CME credit for today's activity T text that number to that

number and you'll get an hour of CME credit we'll come back to that slide later

I have to show the disclosure that's our accreditation statement I have no Financial

conflicts okay and um as a official activity of the IU Center for bioethics

I get to advertise our many wonderful events both today and coming up we have

a treat seminar on December 5th that's a translational research ethics led by the wonderful Andrew Brightman on students

as subjects we have a few uh Grand rounds scheduled for the spring term in February we have Lauren nephew on liver

transplantation in March we have Megan Haley hiy Haley hiy from Stanford who will be

talking about genomics and rare diseases in April we have our Silvers annual

lecture on Holocaust bioethics and uh genocide and that'll be presented by

Amber comr uh in may we have Paul Han from the NCI coming in to speak about

clinical uncertainty and he'll be doing medical Grand rounds the next day uh finally we do have some more treats

seminars to to schedule which we'll announce soon I want to say a couple words again because I am the center

director and this is a wonderful activity of the center I'm proud of our Center for now having a grand rounds

seminar series that's well attended wonderful speakers and I think a contribution to this community um and so

this the center for bioethics is strong I am I am thrilled to be a part of it and to have chance to collaborate with

many of these wonderful people um I am as Nick poor Nick Oliver our program

manager knows I'm a little obsessed with our events page which you can go to anytime including you see today's event

on the upper left there but also nonu events so things online you might be interested in a lot of us in bioethics

and the you know working world of bioethics are are on these list serves and things so we always hear about these

talks but we wanted the rest of the community to get a chance to and here are the wonderful people of the

center for bioethics look at those smiling faces we caught them all on good days when they were smiling sometimes

we're all frowning we all work hard but we look more tired than in those pictures but but it's a wonderful group

to work with and I'm honored to to lead them to the degree to which I do so today I'm going to talk about

evaluating oh say may I'm Peter Schwarz from the director for the center for bioethics I'm also professor of medicine and professor of bioethics at the med

school and professor of philosophy at IU Indianapolis um so that's who I am um

the title we announced was evaluating patient decisions how when and why and

in my mind I have my little personal title title which is what is decision quality and why I guess I should have

put here too why does it matter um here's a here's a sketch a

little graphical sketch of our talk of the talk I'll present today starting

with bioethics of course course and uh autonomy and consent such such Central concepts for the field of uh

bioethics um that leads to Concepts like shared decision-making and patient- centered care which have been widely

adopted in medicine there are then fields that

study the the the progress and the distribution the provision of medical

decision- making and health communication in fields with those names and specialized journals

once you are doing science and you're trying to measure these these Concepts and whether these things are going on

you need measures of something I'll call just roughly decision quality U and and my warning today is these measures have

real problems and I want us to think about what uh decision quality is in

part uh in in light of how hard it is to measure it doesn't mean it's a useless

concept but it means our understanding of it may need to shift um and I I will um describe and try to engage you in a

conversation about the goals of bioethics uh in light of these sort of limitations on what we can

measure I've written about this with Greg Sachs I want to uh thank Greg for

our conversations about this and for participating this paper with me that was about a year and a half ago in the Hing Center uh we're proud of that work

and in this talk I'll try to bring you up to speed with some of our thoughts in that paper and maybe engage you in a

conversation about next steps so

how do we think about this field well how do we think about this issue I'll date the beginning of modern

bioethics to the 1960s as a really a civil rights and and and advocacy

movement that was anti- paternalism in medicine and pro- patient rights we can all argue over when bioethics started of

course hypocrates is a reasonable place in the west but for the modern bioethics

movement it's appropriate perhaps to put it in the 1960s then we should think then that

that led to very clear articulations of the goals of respect for persons and patients and the autonomy of of patients

and persons and then the concept of informed consent like I mentioned where we agree and have accepted in a way that

probably was not accepted before the 1960s and or 1970s the competent patients can reject or choose any

medical intervention even when it's potentially life-saving and I have the J cat's book cover up here it's a

wonderful book if you want a good read um I my students often have to read it it uh and and and he has a wonderful

statement of it including he also had made the next step by the 1980s when he publish that book to share

decision-making from Simply Having the the ability to approve or deny a

proposal from your doctor or the provider to a shared process of decision- making where you're there

together choosing the next step in the patient's care and here's a title by

Mike Barry and a CO co-author from New England general journal about about how important that is

the model of shared decision- making is is complex and we could spend the whole hour talking about that here's one model

to get your head around the clinician brings technical understanding right she knows a lot of

medical facts she knows science she knows about the medical research she can't convey all those all that

information but she can convey key information about the possible diagnoses involved and a lay understanding of what

that means the treatment options and the risks and benefits of each in this conversation then the patient brings

values and preferences right in discussion with the provider they consider the options and risks and benefits of each they evaluate the

chance of good and bad outcomes and how good or bad those would be and they choose one option as optimal the sort of

idea is the clinician brings the facts the patient brings the values they Converse and choose something

together and what are the limits of it well there are there are many challenges

limits we sort of know it's not going on in the way we might ideally hope limits

in patient understanding and misunderstanding limited time for discussion limited ability of clinicians

to to talk and to listen and limited inclination in many cases the complexity

is a tremendous challenge for doing shared decision- making it's the requires why we do it but it's also a

tremendous challenge to doing it um the widespread difficulty in handling probability is every medical decision is

about chances in the future and trying to affect those and people have trouble thinking about that we say patients have

trouble but yes uh doctors and other providers do too uh clinicians don't really

understand what their patients value a lot of things point that out patients are reluctant to speak up for themselves

to challenge recommendations and often patients in the situation will say uh just just

decide for me looks like the death of shared decision-making when a patient would do that on the other hand some

have argued that not the death effect maybe we should accept and and endorse a a model where a patient could just say I

don't want to be bothered just choose for me take care of me would that be shared decision-making these are all

challenges I'm going to say now I'm gonna take a little pause here I almost cut these slides out this morning in

fact but I'm going to keep them it's a little bit of a detour but I think we have time because the talk comes in about 35 minutes so I think we have time

um which is when you think about decisions you think about the kind of decisions people are making of course there's an infinite number I'm of course

not today talking about some of the really hard decisions those of you who come to the Fairbank Center for Medical

ethics call this morning we had based medical decisions with competency questions and you know real um life and

death questions I guess my uh Concepts I think some of these things I'm going to talk about today would apply there but

maybe the decisions we'll think about are a little simpler but but in among relatively more simple decisions

consider recommended choices where there's a strong recommendation towards one option so antibiotics for pneumonia

mamogram for a 60y old woman Co oh yeah I'll take that one off okay covid vaccine right strong medical advice to

do this thing then there's preference sensitive choices cases where even doctors and

health professionals don't really know what's the best choice and say you have to decide patient you have decide what

fits better with your life we call these preference sensitive choices this might be mammograms in an older woman or

perhaps a younger woman like 40 masectomy after a braa mutation perhaps versus other ways of monitoring and

anticoagulation in certain cases of ant of atrial fibrillation like how do you balance the the goals the benef possible

benefits the possible risks we say it's up to you we can tell you what the right thing is some cases we think we can

antibiotics quitting smoking in other cases we can't in fact someone say there's a whole range here two

Dimensions maybe more of like as the treatment risk goes up and the medical

uncertainty of what we think you should do goes up more and more importance for two people to sit together and make a

shared decision about it so a little bit about the realm of decisions though of course this just scratches the surface

how are we going to improve shared decision- making and decision- making in medicine there are all kinds of things

tried right do we train providers in communicating and conversing with patients do we modify the clinical

experience to have people actually have more time and maybe more you know encouragement to actually talk do we

provide patients with information we call these decision AIDS which explain options they help the patients decide

what they want and they help them talk to their to their providers those are often designed around preference

sensitive cases cases where we really feel the patient and the provider have to talk to find out what the patient

wants there have been hundreds of Trials of these randomized controled trials the

latest review which I just found while preparing for this talk do you know there a new one 2024 Stacy came out with her newest one um 200 randomized trials

Stacy's her last name um 100,000 participants whole range of clinical scenarios used by patients independently

and sometimes with their providers so it's a whole field of work uh funded by the NIH and other institutions do they

improve decision- making are they making a making a dent the the decision AIDS or the other

interventions well how would we know well we're going to do randomized trials like I mentioned in the in the in the

Cochran review right randomized trial by the way I forgot to say something at the beginning I'm take a little break here

people who are online and there are a bunch of you I guess I don't see exactly the number but feel free to type questions in the question box and at the

end we're GNA stop and we're gonna open up so everybody's mic is open and Nick

may call on people in order of questioning or maybe he'll pick some questions and then everybody else is welcome to join in too so just just just

so you know if you're sitting there bored online that you can talk we might take our first couple questions from the

room where people are just to let you know online people are noshing on Donuts and uh and coffee so sorry you're

missing out I was going to hold the donnut up at the beginning I decided not to because okay so how are we going to

do this randomize trials so randomized trials uh compare for example any some

intervention like a decision Aid to usual care or they might compare decision AIDS this is actually the work that my team does um these are two

articles we published uh the last few years where we did randomiz Trials of decision AIDs that were designed in

different ways one had numbers one didn't one gave population information one gave personal level information one

included a nudge one didn't so this is kind of work we do and that a lot of people do to try to figure out how best

to improve decision- making in in the clinic so remember because these are

preference sensitive decisions in many cases there's not a single medically preferred option so we can't just

measure oh did we get people to do this thing like if you're studying smoking sensation you just want people to quit smoking you almost don't care why in

these cases that's not the situation we want people to make a choice that's good for them how do we measure that how do

we know whether we they've made a medically informed or a good choice a choice with good decision quality we

want to improve the quality of decision made we want to improve the quality of the decision- making process um we want

to know whether it was shared how are we going to measure these things there have been hundreds of measures developed in this area not to scare you we'll go over

each one no in the 30 minutes we have about 25 minutes left I think um we'll go over three groups that I'll I'll tell

you about so what are these measures trying to measure what are they actually

measuring and again getting back to that first question if we're trying to measure the thing called decision

quality what is that okay the three approaches I'll go over check my time it is now 12:13 I'm

exactly on time very good I'm G take it that that allows me to take a drink of water it always lets me go over and grab a cup of coffee which I'll do during the

question okay three approaches it's G to go by quick I'm happy to go back during the discussion they're pretty

straightforward to my mind but I know they're new to some people watching so that's okay my my my research team is

here too and it's not new to them they they're very familiar with these measures okay subjective approaches they ask the

patients feelings or opinions of about about the decision or the decision-making process sometimes

looking backwards often looking backwards I'll talk about that one first

the most famous one is the decisional conflict scale it's been used in hundreds of studies in more than 10

languages a lower score is the desired and that means this lower decisional

conflict you've eliminated conflict which means patient that's been associated in studies with making

decisions more quickly being more satisfied with the care they get and having less

regret um in the scale itself it's 16 questions in the full form there are

shorter forms like 10 and one which is it just four forms four four questions they answer each question on a liky

scale in the full form agreeing to disagreeing with each statement and

there are subscales that can be looked at about in how whether they're informed whether they feel that they have clarity

about their values whether they feel supported and whether they have uncertainty and whe they feel effective

in implementing their decision here are some samples of the kind of statements they agree or disagree with the informed

subscale says I know which option are available to me agree to disagree I know

the benefits of each option again I know the risks and side effects of each option and the values Clarity subscale

this one of the statements is I know which benefits matter most to me I'm clear about which risks and side effects

matter most to me support I have enough support from others to make a choice I'm choosing without pressure uncertainty

subscale I'm clear about the best choice for me or I feel sure about what to choose now look these are important

Concepts it's nice when people agree with them what kind of problems am I going to raise for this kind of approach

well here you go let's look at the informed subscale where the patient asserts that they know which options are

available to them they know the benefits of each option they know the risks and side effects of each option the problem

is that when patients feel good let's start there they think they do know they

may not right they say they know but they don't that's all very well and good it's a nice feeling but doesn't

necessarily reflect very good decision- making if they don't actually know their options they may feel their doctor must

have told me everything the things they told me I I understood but maybe the doctor didn't tell them everything

second of course is the opposite where people feel like I don't think I know everything but they actually do they're they're reaching for straws they're

reaching for more but they actually do know a lot so that's a limitation on asking them their

feelings values Clarity or uncertainty are they clear about what benefits matter what risks and side effects

matter what's their best choice they say they do feel good about that or they say they don't and remember their score is

worse when they say they don't feel good about that they don't know which benefits matter they don't know which risk they're confused their decisional

conflict is higher that's not a good thing that's a sign of a bad decision or is it or is it the sign of a

bad decision isn't that the sign of a good decision sometimes right there there are hard choices dang I don't know what I what to

do I don't really know how to think through this doesn't mean that they've made a bad choice maybe it means they're

actually struggling with a hard Choice um and it can be good be part of good decision-making in fact it could be

an improvement in decision- making to be unclear how to balance the risks and benefits and what to

do here's another quick example from the subjective SC area the Liker scale again

sorry decision regret scale it again uses a Liker type answers um it's asked

after the decision they're asked to agree or disagree with it was the right decision I regret the choice I made I

would go for the same choice if I had to do it again Etc measures of regret

so is a regret a good thing to measure again I can see the attraction but here are some problems right patients may

make a good decision they may have chosen very well but they may regret it maybe it had a bad outcome unfortunately

even though it was the best choice or maybe it was just incredibly unpleasant they they look back wish I never got

involved in that or they may make a poor decision and fail to regret it I'd say this one's even more dangerous right

that uh the regret the regret scale actually has this problem that people feel pretty good looking back at their decisions even if they were pretty maybe

ones we would really criticize right maybe it worked out fine they didn't know any of their options they didn't

know much about them they they just did what they what they felt like or something or they they were talked into something that they' never have chosen

if they knew more but it worked out okay so in some sense pretty bad decision

other sense I'm glad they did well but but it's it's not necessarily a very sensitive measure of whether the

decision or the decision-making process was good or bad observational approach is the second

approach you'll see it's very different the idea is that somebody looks and rates the conversation between the

provider and the patient uh the elements of informed decision-making scale by conis bradoock

the observing patient involvement decision- making the option scales by elowin we'll talk about option option

five it's called where two individuals listen to a recording of a medical visit and rate Five areas um that are covered

by the provider the five areas are whether the provider Drew attention to

alternative treatment or management options whether they reaffirmed their support for the patient whatever they

choose giving information and checking understanding asking basically what the patient wants and trying to include

those preferences in the in the choice each area is scored right zero

means they didn't try at all in that area one means there was a little bit two means some quick comments three was

a longer conversation four was a really long deep exploration of that topic and you can get zero to four points for each

of five areas for a score from zero to 20 the advantage of this is that it's objective it's an objective observation

to look at what the conversation was like not just what the patient remembered about what they or what they felt about what they what they

heard the problem is maybe a problem you were thinking of when I was talking

about those quick decisions before sometimes a good decision might have a quick discussion right sometimes a quick

discussion doesn't go over everything at least on one occasion might be an okay discussion take this example so um you

know if a woman considering mammograms let's take the preference sensitive choice of a maybe 80y old woman

considering continuing with mammograms versus not again Mavs are not recommended Beyond age 75 they're

offered um just because the data for benefit is is limited um the areas of

course these five areas and the scores are there if you think about a conversation in a provider and a patient

who know each other maybe it's the annual meeting maybe she's already decided to do mammograms between ages 75

and 80 so she's been already moving into the elderly age where she's continuing mammograms it's clear how she feels the

conversation could be pretty quick right if people who know each other and there's a established clinical

relationship well it like maybe on these areas you might get ones or twos right

now you might say Peter you're being too kind that discussion has to be hit every year in these detailed you know ways

that that the option five rewards I don't know I mean there you really have

to think about whether that's a good use of time um given that they do understand

each other she knows the doctor's going to offer it she knows what she wants to do he knows she knows what she wants to

do they move on you might say Peter okay fine fine Peter look at more decisions you know look look at look at all those

meetings they've been having and try to rate through all of those how much they've talked about mammograms well I

wish right that's exactly what these measures are not able to do is something like recording all the visits between a

provider and a patient and rating those the only this is just the thing that's used in research is one meeting usually

and this is the limitation one of the many one one of the significant ones down to my last measure so again

I'm not saying these are useless I'm just violating their limitations in fact we use them so they

can't be useless my my research uses them concordance uh the informed concordance

uh the values concordance approach which uh is a very popular uh influential one

where what we're trying to measure is whether the patient's informed in their a Knowledge Test not just asking if they

feel informed but measuring whether they're informed and whether the what they got the care they got matches what

they want what matches their values the goal of a preference sensitive

Choice uh some examples are the multi-dimensional measure of informed consent by Marto and the decision

quality interest by sauka so just to the people in this room

um certainly know about this maybe not everybody online but the idea of concordance can be a little hard to get your head around I'll take a minute to

review it the idea is that people have values that make different sorts of care appropriate for them so some people have

values that are appropriate make aggressive care more appropriate or certain kinds of aggressive care some

have values that favor other kinds of that's that's one of the ideas behind this let's go back to the mammograms

again so some people have values that would support continuing with mammograms into an older age or starting younger

and some people have values that that are against that and so the idea is in medical decision- making to figure out

which one you are right to let you have a choice of deciding what your values are and how you want to apply them to

this decision that would be the ideal and concordance is trying to capture that have we given you what fits your

values so again I maybe I'll belabor this but you know if your values support

getting mammograms you should get a mamogram if your values support not getting mammograms you don't want any more trouble it's the risk is not the

benefits not high enough then you should not get mammograms like it's sort of a basic idea Discord and Care would be the

opposite right your values are for mammograms but nobody's giving them to you or vice versa you really don't want

them that doesn't fit with what you want out of your life but how you're you're getting them decision only counts as a

good one if the patient had adequate knowledge they passed the knowledge test and they got value Concord care the

advantages are I hope pretty clear it's an objective Knowledge Test rather than some kind of thing about how they feel

um so we know whether they're informed and it assesses whether the treatment was appropriate for the patient not just

looking at the process like we did an option we were trying to record the conversation and see whether it was good now we're actually looking at the

outcome fact sometimes people writing about this saywell those first two approaches are

really about the process and this is about the decision I I don't know if it's that clear ah problems you know I'm

G to raise problems okay first what is adequate knowledge so an enormous amount

of information is relevant to any medical decision of course people are not going to understand all of it but we

have to set a line and everybody in this room look at the room we've written knowledge tests so we know how hard it

is what goes on the knowledge test and what kind of question what do people have to pass in order in order to be

counted counter as knowledgeable um it may vary on situations and patients uh Josh reger's

here me have written a paper with others on our group Karen about you know what

kind of knowledge has been asked on these knowledge tests around the colon cancer area that we colon cancer screening area that we work in and the

answer is all kinds of Knowledge Questions I mean they are amazingly varied what people decide is essential

that's one problem maybe you know a problem not the end of the world how can we determine whether a

person's values are consistent with the treatment they receive and does it even make sense to try that's a depressing

ass question let me ask it here so consider the mamogram case again right what are the values in favor of

continuing with your mammograms extending life avoiding dying of breast cancer avoiding getting Advanced Breast

Cancer the values opposed of course are avoiding discomfort of mammograms avoiding anxiety of undergoing the test

and a waiting result avoiding possibly unnecessary treatment because you'll find cancers that treated that never would have caused a

problem so I think everybody in this room holds

all of those values right whether you're a mamogram person or you're a colon cancer person right like colon cancer

screening person like that's these are the values you have got to balance everybody's got the values it's a matter of how much do you weight them how do

you balance them and that's that's pretty hard thing to calculate in fact you've got to weight

values which is a hard thing to do personally and certainly as a researcher in fact and this is a interesting fact

psychologists argue the idea that we have these values that lead us to make decisions is um maybe misleading so we

sort of imagine it this way right I've got my values I walk into my doctor's office just like in that original model

right and I think H here are my values here's my situation I'm G to apply my values

well right psychologists argue it's actually the other way right often you don't know your values because got them

all and they're all a jumble you don't know how to wait them in fact it's not till you make the decision that you

actually prioritize and and rank order and combine those values you actually there's not like there's a there's a

fact of how your values should make you go it's more like the other way what you decide will help you figure out your

values and there was no fact about them before anyway philosophical point which why I get excited and somebody's not

Elizabeth nodding vigorously which I like that's what I did too when I first heard that thought that's the coolest fact I've read this week or this month

or maybe this year okay so we actually speaking of discordance and the problems of measuring it in our studies we

actually don't try to figure that out about values we actually ask people what they want we see if they're informed we ask them what they want and then we see

if they got that that's a poor man's way of trying to do this did people get what they want we can't sort of calculate it

from their values let's just ask them what they want that's what a lot of people in this field do so in the study

though we looked at the people who said they wanted one type of colon cancer screening but they got the other and in

our study looking for when K and I put this together in the beginning we asked an additional question which said you

know why wait is that that is that here oh no right we asked them why' you do

that why' you get that test and if they had switched from beginning to what they got we said why' you switch what's up

and so we looked back at these in this paper that uh Josh Karen and I wrote here were the here were the five

areas six areas that that that it looked like there reasons fell into sometimes

they said yeah you know I really wanted to fit it's a stool test but I got a colonoscopy because you know that stool

test isn't really that good I sort of thought more about that or I switched from the colonoscopy to the easier stool

test because that prep for that big test just put me off I decided to switch or

they switch because of the benefits of the alternative test like well I was going to get that stool test but I wanted the best test I wanted a

colonoscopy that's so much more accurate or I was going to get colonoscopy but I just couldn't go through with it so I got a F test sounds like somebody I know

okay so um cost maybe they said it was too expensive they found out about cost

right maybe maybe they had a discussion with families or friends maybe they talked to that provider who made a recommendation maybe some health issue

arose where they for example switched because they had some rectal bleeding when we looked back then we try to figure out which of these reasons are

bad Reasons by the way the reviewers of this journal hated this um that we kept saying these were this looks like they

were pressured into you don't know if they're right if they made a choice they changed their mind that's actually good

decision- making a decision doesn't happen at a single moment right maybe on six months earlier they thought they

wanted one they Swit that's actually not this discordance between what they said they wanted and what they eventually wanted got is not a m a problem it looks

like discordance it gets a bad score on the informed concordance scale but it's not really bad um some of these

discussions with families and friends and some of those were the ones that were suspect right where it said my

doctor just said he wouldn't give me a fit I had to get a colonoscopy that sounds like what we were looking for

what we were afraid of in discordance but it wasn't all of the cases at all so

at the very least we have to look into the reasons for discordance discordant care may not

always indicate a poor decision or poor decision making okay that's it for my talking about measures those of you

who've been struggling through a lot of technical stuff there I hope it wasn't too technical but now some

conclusions there were three that I'm going to highlight they're the same three as in our paper no measure and I'm

gonna say no combination of my measures but look at each measure individually can reliably indicate the overall

quality of a decision or a decision-making process so each measure

as we saw has something to be said for it they're looking at important features better scores on one measure

doesn't mean that it was a better decision you could have a great score on the decisional conflict scale but it

could be uninformed and truly Discord and Care the bad kind of course even within one approach

let's say the subjective approach there are multiple different scales and they may have different answers so even if you say well you know I'm just looking

at subjective feelings well there's the regret scale which may give you a great score and the decisional conflict scale

which gives you a poor score um this is not special to looking at quality of decision- making um how do

we measure quality of Health Care say provided by a clinic or a Health Care System you could look at the experience

you know how do patients feel good about their experience at Clinic did they feel like the provider listen to them they

could you could look at process you know calls are answered on time or not you can look at outcomes you could look at you know whether patients in that clinic

have good blood pressure control or or heart attacks or not no one of these will reflect the full quality of the

clinic you need probably all of them and maybe more quality of life actually in medicine and economics medical economics

we measure quality of life a lot and of course there are an infinite number of ways to do that it' be an easier argument even to make about that you can

measure all kinds of different things and researchers do those of us who teach know that when you grade students you're

not really grading the quality of them maybe the quality of their thinking the quality of their understanding there are a million ways to do that they aren't

the same some students will do better on one way and not the other so we know in the heart of hearts there's no sort of

single fact of the quality of thinking or understanding for a specific student so that leads to a some what

skeptical philosophical conclusion for those of you who like to think about whether it's a thing are we measuring a

thing called quality is that looks like maybe not um I always when I think of

that go back to one of my favorite books a novel called Zen In The Art of Motorcycle Maintenance even if you hate

this talk and you do not want to ever think about it again it's a great book a bestseller from the 70s uh Richard

gunderman taught me that also it's the book that had the most rejections before being published

and then became a bestseller 162 rejections for those of you who have papers that you can't get published

don't worry you could be like Robert pers and write one of the most important books of the 70s in it he talks about

the struggle of trying to measure quality and how that upends in his mind much of the philosophical understanding

of the world that he Associates with the classical thinkers but also with all of the Western World um this question about

how to measure things that are hard to measure applies in of course areas outside of quality consider psychological States such as aggression

anxiety or depression right you can choose a single measure well does just

say it's you know how do you measure aggression what depends how you measure it right there are many different ways to measure aggression many different

features of aggression you might measure same for depression uh you can choose a single

measure you can buy measures for a specific purpose so I you certainly can use measures they they give you

something the idea is a signal magnitude there lurking is somehow I would say we probably have to make sure we're not

falling in for maybe you listening or saying Peter I never fell for that that was just you in your philosophical mind

okay if there is something there it's vague it's not precise it's my our second conclusion my second conclusion

it probably makes more sense to categorize the quality of a decision broadly as good satisfactory or poor for

instance not as having a number um the measures may be relevant for trying to come up with that

categorization and good scores on all measures that's a good thing right that's certainly going to point towards the good category a bad score H I don't

know what it means as well right maybe it means decision was poor maybe it

doesn't maybe a bad score and decisional quality actually is not a bad thing maybe the decisional decision quality

decisional process was actually not bad a bad score on option Five May indicate an appropriately abbreviated

conversation um any final evaluation going from those measures to a final

evaluation of course is going to call on judgment and qualitative judgment that is not a quantitative measure or a

measure of combining these these a matter of combining these measures in some um a clear uh way algorithm it'll

involve judgments about autonomy deliberation rationality and preference third and final conclusion

researchers in this area and bioethicists certainly who are con committed to improving quality of decisions should focus on addressing and

identifying so identifying addressing areas of problem s that's actually an important thing not to forget if you use

those measures they really most helpful for finding problems that you might be able to address

so uh bad scores could point out to something important our motto here my

motto here is identifying solve problems with decision- making rather than moving the needle on decision quality measures

the mistake that I'm trying to um head people off from is thinking that um you

know if these are the bad features of some of the worst cases we should use

them to sort of build a scale that somehow there's a decision quality that we're trying to change up or down better

to find the problems and fix them here's the analogy I I'll finish with this so

we often see unjustice Injustice in the world and we we make those judgments

based on things like oppression and exploitation and discrimination in those settings uh we actually then decide that

those kinds of problems are in place by looking at maybe measures right living

measures uh resource distribution ethnic or racial representation those might be measures we use to identify these bad

features but of course even though we're looking at these measures and we're deciding when there's Injustice present

we don't try to create a scale of like justice level right maybe the Justice

League has to do that no justice level we don't like say oh well this is Justice level 52 and it's got to move up

to Justice level 55 it's that you want to find the areas of Injustice and the final punchline is that actually working

to improve decision quality and mag medicine weeding out those bad cases is actually not that not an analogy right

it's actually a case of Injustice right so when a patient is not treated appropriately when a decision is made

without their appropriate involvement or understanding um that's Injustice right that's that's unjust care that's

unethical care that's why we focus on it that's why the field of bioethics started here and you know the modern

field to try to improve and address these problems improving metalis is part of

bioethics quantitative measures of course are important but uh the measures

are mostly just tools to identify problems and promising Solutions and we must always avoid any danger of thinking

we know what decision quality is and we can somehow you know incrementally change

it right oh right well I'll finish with a couple more things patients certainly

have to have the option of learning and participating but they of course may not want to as as Carl Schneider pointed out

um I will say this leads into a discussion of nudges I decided not to put a whole section of the talk on that

I'm actually hitting my time exactly of 12:38 so I'll finish here but um there's all kinds of things you can talk about

people talk about the ethics of nudging patients different directions it probably comes back to some of these thoughts about what is a good and a bad

decision the patients might might make thanks to the men I decided not to try to list all the people I've bored

with my thoughts on this topic of course all my mentors uh at the med school and before all my research team as we try to

actually puzzle through the kind of research we do to actually measure and improve decision- making and that is it

let me go back and give you the CME code in case you are eager to send that in and we can also now talk so first of all

in the room any questions we have I've got to show you online this incredible thing what going on in this room

this is a block it has the IU thing on it and it is a block you can talk

into so now when people want to talk we can just throw them Sam watch out how amazing is that this is

brilliant we used to have to run around I used to whenever I taught I would run around with a with a microphone like like the Olympic torch I was always my

joke was like now I can't do that okay questions in the room and then Nick will'll take

care of uh asking questions from do we have some online questions one so far one so far first in the room and then

the one online in the room gets priority because they came for donuts which I'm gonna go get so if you don't see me

here can you yeah this is great um thank you Dr

Schwarz this was fascinating I can't tell if this is super loud or okay picks you up too um so I thought

this was really interesting I'm very uh fascinated by the question of how you determine whether like what the quality

is of the decision uh practically uh and I was reminded of some of your work on

informed consent uh in biobanking and how it drew on bca's kind of expert

consensus model on determining what is and isn't uh a good decision or a good

outcome um what's adequate knowledge which was one of your questions um and it really is I think this is like the

constitutive uh the kind of the constitutive problem

is determining what's adequate knowledge for all of this and I was wondering um

you were I think getting kind of close to this you probably didn't say it because it's a bad idea but I was wondering kind of from a pragmatic

approach if there is a way of taking the outcomes if uh from the patient's

perspective so the patient looks at the outcome says whether the outcome aligned with their Valu is or not and then

seeing what information was necessary to get that patient to that outcome irrespective of whether the experts

thought that was a good outcome and irrespective of whether the experts would have thought that those aspects of

uh knowledge or those pieces of information were relevant to the decision yeah I know it's good good set

of questions I don't know where to start it we could definitely take another hour so I'll start now no um the best Scout

case he's talking about is actually a fascinating case if you're interested in quality of decision- making the best Scout group at Vanderbilt um put

together an adequate Knowledge Test for patients who were participating in biobanks 10 questions I think 11 maybe I

think it was 11 might have been 21 and we cut it down to anyway it's a certain number they really decide what do people really need to know to make an informed

Choice kind of the discordant care thing the values concordance measure and then

they tried it out and patients didn't pass they've been given great information and they did horribly and

bcal went back to her credit and her colleagues and they uh Beck with was

back with who was her call Co co-author and um they went back and they asked their experts who had made it and

their their patients and you know blade people who had made it and said what should we do with these people who didn't know and they said half of them

said they shouldn't be part of the biobank they didn't know enough and the other half said you know what they chose

not to learn it they had the information in front of them we know we gave they chose to participate based on trust

maybe and they basically were stuck like they basically didn't know what to do so it's a fascinating question about what to do with an adequate Knowledge Test in

that setting getting back to Carl Schneider again May rest in peace he's been gone a year and a half now and I I

I really respect what he brought up here what are we to do with people who choose

not to learn should we say it was a poor decision they chose to make a poor decision or do they choose to make a

perfectly good decision which was their choice how much should it person learn that's up to them

we've done some work uh TJ Casper BAU and I and now Tom and I have done work and we ran a public deliberation with as

you said lay people to ask them what do you need to know and the answer is all over the place but they get hung up on

the same problem we do which is is it right to require them to know anything

because a person might be given information and say Doc tell me what I should do or they

might say I you biobank Indiana biobank I want to help I don't even need to know

any of this stuff and as long as the provider or the researcher are actually

acting in a trustworthy way and protecting the participant or the patient and serving their interest in the case of healthcare maybe it's good

enough maybe the whole idea of that being a bad decision is wrong there's still bad decisions which are the

Badness the Badness of them is based on lack of understanding but a person who chooses not to learn where the

information is provided and chooses not to be the one to make the choice it's probably not so clear that it should be

dinged as being a failure and then you would say what kind of measure are you looking for Then Pete like you know like

you don't want to measure their knowledge you want to see whether they want the knowledge it gets it gets more complicated and so it again gets us to

these questions about what is a good decision that's not a full answer to your question but let's do an online one

unless somebody else hear burning question in the room just so we can throw the phone block around oh Elizabeth's going it to cayb

no he's using okay so we have an online question

it says uh how can you ever judge a decision is bad when we can never know what outcome the opposite decision would

have brought about that's from Heather penwell who asked it did he say Heather penwell okay great question so so so so

right so the unbearable lightness of being right says we don't know the value of anything we do because we don't know

what would have happened if we' done the other thing we just don't know so um I I respect what you're saying it's somebody

decides to not get screened and they come down with cancer we say oh that was a horrible choice they should have been

screened but it turns out if you did go back in time and did the other decision

which we never get to do um we see that the screening test actually would have missed the cancer or maybe the screening

test would have led to its own problems and this person would have still died of cancer like how do we know what's a good

decision well this is partly why we don't look just at outcomes right because it's not actually

about which decision ends up with some outcome and

this gets back to Colin's question a little bit about what outcomes matter um bad decisions can have good outcomes uh

my favorite example of that is the wonderful and underappreciated movie bow finger where uh Eddie Murphy on a dare

closes his eyes and runs across a a a highway it's actually not a dare he's

he's coerced into it horrible decision the worst decision in the world

injust incredibly dangerous horrible the outcome is fine right he actually

survives it it's a movie but he actually survives it and gets the job I think it was for an acting job he was doing it

more like so you might say well okay like pretty good decision you know Eddie Murphy or the character he's playing no

horrible decision anyway right we look at the features and the factors before

to identify whether people are making good choices it's not just about whether

it works out I feel that way later like boy that worked out I'm I'm happy about it I would call that a different notion

of goodness of it being a good choice like good thing I closed my eyes and ran across that highway I got the job my

action career was made in some sense sure you won in other sense that's a

horrible Choice more I have a question

um on slide 14 you have a a slide that says Contin of

decisions love it I love slide 14 I almost took it out I'm so glad you're bringing it up go on I know slide 14 that's this one

right yeah um so when you were talking about the relationship between medical

and I have a poster of this graph in my room no but I'm going to put it up there go ahead man uh when you're talking

about the relationship between medical uncertainty and the treatment risk level I had two thoughts the first of which is

that it seems like a high-risk decision where there's one clear best choice might still have high uncertainty if

depending on the patient's values and so it seems to me like we might be passing the buck on the importance of the

decision to the patient in higher risk situations to avoid personal responsibility for that

decision okay Fair Point Fair Point right so you could have a so you're

thinking of high risk level with where there's where we think

there's one best choice so it's up in the upper left corner there it's over it's over here and so it's not in the

zone of decision making so what to say about

that let me tell you a story I love stories it's a long story

know it's a short story so uh a uh a uh an executive a young business walked

into the Eskenazi emergency room with chest pain and the intern was you know

running the usual tests and things and said by the way if you your heart does stop we want to know if you want CPR or

not it's a perfectly healthy guy young just had some chest pin and the guy went like what are you talking about am I

dying like what's going on and when you think about that question it's a fair question he's kind of asking the

question in that zone he's like we know what we want to do you're a young man with chest pain we're going to check you out and we have to know what to do in

case you have a a heart attack your heart stops but the other hand it's a very bad question because we kind of know what this person wants unless they

come in saying I hate health care I'm ready to die even though I'm young and healthy unless he starts flagging all of

that it's almost inappropriate to ask like to see whether he has some I would call them unusual I'd say weird values

and so it's it's almost a mistake to sort of explore that realm with him

unless you have all the time in the world you have a way of presenting it that won't be very scary and you have a real reason to to to worry that maybe he

has some some strange values like you said the values that would now I put up I know I put up covid vaccine sort of as

a joke um in the case of effective decision-making because that's maybe one where where we actually think there's

more of a debate right just the way our society is standing right now and I'm thinking of the covid vaccine in 2021

not right now um you know obviously some people felt that even though medical professionals and we believe that the

data was very good um they they just they didn't want it and so maybe they're in that realm too they see it as

something which is risky and we should respect that and give them the chance to say no of course um I wouldn't say this

is a graph of whether to ask patients anywhere anything it's more a graph about the importance of exploring their

values and I agree with you it may always be important but in cases where there are a range of well-known common

values that may make an impact on a high risk medically uncertain Choice then

that's really where we have to be focusing our attention not to say we shouldn't focus it anywhere else it's a roundabout way to answer your question

though I think another way of putting it is like that is ah speak to the phone block oh

there's multiple oh it's right another way of um I guess answering that is like that is the distinction between informed

decision-making and shared decision- making that on that top category where the treatment risk level is very high

whether or not you have one choice or multiple choices the the the threshold for being informed would me need to be

much higher which is what I think you're sort of getting at which is I think what Simon Whitney effectively argued in in

this paper right um so uh it's it's a important thing and I think this that

distinction falls apart clinically often um but I think it does also point to the

fact that we do a very poor job of defining when something is preference sensitive and knowing when shared

decision- making is the most important not that you can't do it when it's not preference sensitive but you see this

like General Trend towards more and more things are preference sensitive and sometimes that is because our evidence

is not as good as we thought it was and we're actually acknowledging the uncertainty in a lot of our

recommendations but um uh you you see that more and more and I think that's actually one of the uh really important

messages here is that it's like not done all the time and when we find the instances in which it's really important

it gets even harder um to sort of know if we're doing it well or not and by the way no one does well in the option five

scale you can look at all the papers they all look terrible it seems like it's never being done and the option

five they they they get poor scores always literally every everyone y again

this is this is kind of the fun fun um funny hard thing is that you know

the the claim by many Fair claim and not not dumb it's just I think

simple-minded is that is that is that taking back a criticism no I called them simple-minded not dumb um you know is to

say that because this model of extensive discussion is not happening these must

be bad choices and that's that I think is not right I think that again as K

Schneider I think was very good at arguing some people may choose to not have that discussion and as long as it's

an option it's available maybe that they know it's available but they choose not not to have it that probably needs a lot

of credit for making progress and actually maybe even achieving exactly what bioethics has been trying to

achieve since its modern Inception right if we got to that stage where people could choose how much involvement they

wanted and choose how much guidance they wanted I think we'd be there even if the

option five scale was not registering success so I think that's a good good thing to point out

Josh other comments or are we done online this is your chance in oh Nick currently are not any

more online questions but I have a follow-up question if no one else here does oh thank you yeah well I was I was

gonna ask are you making an argument for a mixed methods approach to

understanding decision- making really in any Intervention basically showing that we need these quantitative measures we

need our qualitative measures and we therefore need to triangulate decision quality using mixed

methods approaches and that might be actually the only way yeah no that's

that's a fair proposal I think mixed methods and kind of is exactly right you can use the numbers but you've got to

then look back at them the second part is that final point about you know worry about the

Injustice um make sure you make the case before you do a research study trying to

improve decision- making that this is a case where there's something really disturbing about what's happening here

maybe in terms of what interventions are being done ter of people's understanding you you can probably pull on one of the

measures but you should have a bigger Global picture of why this is a problem Beyond just you know the option five

scale was was registering very low it it requires a more complex um evaluation

again as in all areas of quality right where there's going to be no good measure so I guess what I'd say is yes

mixed methods but actually I think the deeper question of what did even means for there to be a good decision made is

an open question and one which is never going to be solved so be aware of that kind of problem and if you're going to

focus your efforts probably focus on areas where you think is the biggest problems for example in healthare

prostate cancer screening you know is one area you might argue for I think colon cancer is one too where people

were not being offered both choices or the option to think about both choices and we've been working on that one Co

cancer screen is a great one too because so many men were being defaulted with no discussion to being screened um I have

no problem with being screened good choice for many people but certainly not a good choice if you don't know there's

a good case to be made for no screening and you know that continued or the

lessened set of concerns about the provision of healthc care is one that I

think should attract attention to decision makers because it's about the quality of healthare provided now of course say Peter you just now relied on

the word quality again and and you're right Nick you get the last question

thank you Josh for that question thank thank you all for your questions um so following up on my previous question

when is it appropriate to begin discussions with a patient on shared

decision- making like what are there specific criteria that you can look for are there like case specific information

what what are the because I think Josh said that it's very difficult to know when it's important to involve shared

decision- making so how can you I guess standardize that decision-making process or can you even do that let's go back to

the graph but you know there's no answer to your question it's a wonderful question the um let me wrap up with

another quote so the graph I was going to say you half joke you know it's um as

you get into higher levels of risk and higher levels of medical uncertainty certainly it's

time to to start thinking about at least offering people and making it possible people make choices for themselves

absolutely so maybe that's a short answer um in the jcats book which I showed the cover of earlier uh one of

and maybe we'll make it's available on the web page when we put up the recording one of the most beautiful

quotes in there is Jay Catz he says well you know what we call for and share decision-making is understanding right

that the patient is understood by the provider and their wishes Maybe maybe

about the nature of decision- making but also about their goals in life are understood and shared there's a communication there and so that's our

goal he said but then how are you doing in your personal relationships at that goal right much less with your doctor

like does your loved one understand your dreams and hopes in a good way or is it

not so like if we hope for it in medical care and 15minute visits with your doctor how's it going in your home okay

that's one and then and this is the kicker me and I can finish the talk on this how you doing with

yourself right do you understand your own goals do you understand your own wishes you know what you want out of

life oh how's that going Pete and I sit there trembling as I'm reading the book going not well I don't know what I want

so anyway that's that's uh a final depressing end to to this topic um but

thank you all for being here and thanks for coming