JB: Welcome to Listen to THIS where we have conversations with people taking all sorts of approaches to studying how to improve the quality of healthcare. I’m Jenni Burt, Senior Social Scientist at the Healthcare Improvement Studies Institute.

Today we’re talking a close look at how philosophical thinking can help improve healthcare. Anyone providing or studying healthcare knows that it’s fraught with ethical questions, for example, at the frontline of healthcare provision lies a relationship between providers and patients and within that relationship issues like confidentiality, consent and transparency are really central. And I’m sure everyone would agree that there are always improvements to be made in areas such as that.

Like any other challenges in healthcare, it’s rather helpful if any efforts to improve are backed by evidence as well as some super clear thinking. Which rather neatly brings me onto my guests today who are both very well practised at super clear thinking [laughs] on these issues.

So, first, I’m delighted to be joined today by Richard Holton. Richard, you’re Professor of Philosophy at the University of Cambridge and you specialise in ethics and moral psychology. Your studies are applicable to all sorts of different contexts but I’d like you to tell us how you became interested in the ethics of healthcare?

RH: One of the intriguing things about healthcare is that you have so many issues knotted up together. So, I really don’t feel the philosopher’s job is to come in and tell people what the right thing to do is and what the wrong thing to do is. I think our primary job is to come in and tease apart this knot of difference issues, lay out the different strands and get them to a position where we can start to think about those individually. And I think medical issues are absolutely fascinating in that respect.

JB: Okay, look forward to unknotting some things later. I’m also delighted to welcome Zoe Fritz. Zoe, you’re a consultant physician in acute medicine at Addenbrookes Hospital, you’re also a Wellcome Fellow who is working on empirical ethics. You’re based at THIS Institute as well, I should say.

When it comes to ethics of healthcare you’ve got both an academic hat on but also a very practical perspective and what advances do you think that brings?

ZF: I think doctors and other healthcare professionals do all kinds of things in medicine all the time because they have always been done that way and they don’t necessarily question why they are doing them in that way. And they also don’t necessarily transmit to the rest of the world or make open why they’re doing them in that kind of way and I think that it is important to question the premises of the behaviours we have and, as a clinician, I am an embedded anthropologist, if you like.

JB: [Laughs]

ZF: I’m in at the deep end watching all the things that go on, but at some po,int in my training I had a kind of click moment where I started questioning why it was we were doing things this way.

So I continue to be an active clinician, I do medical on-calls, I work on the wards, but I have at some point decided to really actively question the way patients and doctors interact, the way we make decisions about what information we’ll give patients and what we won’t, and to try and make my colleagues aware of what is often called the moral discomfort, so this idea of when is it that we do something that doesn’t feel quite right?

And if something doesn’t feel quite right instead of just ignoring that and pushing it under the carpet and saying, well, that’s what everyone does and we do it because there are time pressures or we do it because that’s the way it’s always been done, to actually say, well, it probably wasn’t designed this way, it’s probably become this way in reaction to the needs of certain people and those needs have probably…most often healthcare professionals are not the other actors in the interaction and so we should perhaps be questioning or really being aware of that moral discomfort and saying, where are the places that we can change medical practice to improve care for patients?

JB: Lots of issues to pick up on as we talk today but I want to bring you back to my reaction when I was thinking about bringing both of you together here today, I had a possibly slightly disturbing image of Aristotle in scrubs being chucked into an A&E department [laughs] on a Friday night and being told to deal with patients, philosophy, acute medicine.

Because on the one hand, Richard, you’re a professor of philosophy at Cambridge which, in the nicest possible way, sounds like it couldn’t get any more ivory towers and, Zoe, you’re a doctor at the sharp end dealing with what’s walking through those doors. So, it could seem that you were absolutely worlds apart in what you were concerned with.

So, help me out, what are the common concerns that link your work, your thoughts together?

ZF: Richard and I meet and we talk about what I have just seen in hospital, so we have a kind of an ongoing often with a Fitzbillies Chelsea bun, if I’m allowed to make a plug for Fitzbillies.

JB: [Laughs].

ZF: But often with a Fitzbillies Chelsea bun we meet and talk about what it is that I have seen in hospital that perhaps has bothered me or that I have thought I could have made any one of three or four decisions in, for example, what information I gave a patient. What were the things that were guiding me in making those decisions and should we be considering other factors outside the obvious ones of time pressure and some of the things that we are taught at medical school in terms of quite basic ethical framework?

JB: Okay, and then, Richard, what do you do with that information you’re [laughs] given by Zoe

RH: So, first, just about philosophy in general, I think philosophy has changed actually over the last 20 or 30 years, so I think there was a time when it was a very, very a priori discipline and I think it has changed a lot. So nowadays if you do philosophy of mind you need to know the psychology, if you do philosophy of language you need to know the linguistics. I think it is an engaged discipline in a way it probably wasn’t some years ago.

JB: Okay, which prompts me ask a really basic question about what do you mean when you say philosophy and, for example, what’s the difference between philosophy, ethics, we also see the word bioethics, all of those terms?

RH: Okay, so I don’t think there are sharp distinctions and I think philosophy is at the more conceptual end of a field. So, I think when you’re doing this with a clinician like Zoe, she talks about very concrete things that have happened and very immediate issues come up about how you should interact with a patient. And I tend to think a bit more in terms of what the structure of the responsibilities there are, what the structure of the rights of the patient, the welfare of the patient, but also the concerns of the doctor, concerns of the other medical staff involved.

So, I don’t think we’re really doing a different thing and I think historically, you go back to Aristotle, a scientist as much as a philosopher, and what’s happened since is we’ve specialised, we’ve had to specialise because knowledge has become harder won and more complicated. But there’s a risk also of losing the connections that I think are naturally there between a more conceptual take on what’s going on and a more evaluative take where you’re concerned explicitly with the evaluative issues and not just with implementation issues, how you achieve something, but what the right thing to achieve here is.

JB: Where’s ethics and bioethics in this?

RH: So, ethics is just the philosophy of the normative, it’s the philosophy around what one should do, what one has a right to do, what one may do, those sorts of issues.

JB: Okay, and bioethics?

RH: Bioethics is just that as applied to the biomedical sciences.

JB: Okay, so we’re getting somewhere. So, philosophy on the conceptual end of the spectrum, ethics around what we do.

RH: Not just descriptive questions, questions about what you ought to do, are entitled to do.

JB: Okay.

RH: I actually think it’s a mistake to put it all in terms of ought, I think there’s no one way of thinking which is the right way and there are lots of issues which turn out to involve a normative dimension in less explicit ways. So, if you talk about respect or you talk about honesty or something like that those are all notions which have an ethical dimension to them but they also have a more descriptive dimension to them.

ZF: So, you were asking how it was that we combine front end with philosophy, while I am clearly a clinician, I have had a good stab at trying to understand at least ethical and philosophical concepts and learnt how to read a philosophy paper. That was a big step for me, I have to admit.

RH: And how to write a philosophy paper.

ZF: And how to write a philosophy paper. And Richard has had to learn a lot of the medical language.

One of the things that’s been really important about our collaboration is in saying there have been silos of people who’ve been looking at things. So there have been medics who’ve been looking at how to improve things without necessarily stepping back and saying, what is the right thing to do for all actors involved? And there have been plenty of philosophers pontificating on what doctors should do without necessarily having full insights into them.

And what Richard and I have tried to do over the last…it’s actually nearly four or five years now, is learn each other’s language a bit and learn each other’s approaches, and that, I think, has been quite rewarding in terms of being able to say, here’s something that happened in the hospital, and Richard doesn’t need to ask 30 questions about what I mean about how the clinic works and what would happen next. And we then can discuss what the issues are and work out what questions should be asked next.

And in terms of the overall what would be the game plan, why are we doing it? It’s really fun but is there anyone else that’s going to benefit from our conversations? Well, the hope is that we will be able to continue to have new ideas that then can be added to, for example, medical school teaching to guidance for doctors to establishing a new approach which could then be evaluated with some kind of quite hard outcomes in terms of seeing how you can improve care.

RH: Yeah, coming back to something Zoe said earlier, I think you really lose track of how particular your take on the world is, you think that what you’re saying is just absolute common sense and everybody thinks that way and it’s only when you talk to someone from another discipline that you realise, no, you have a very particular specialised take on the world. And you have to step out of that and start to engage with the other ways of other people are thinking about things.

JB: Thinking about an average shift for you, Zoe, in acute care what are the kind of questions that are popping up for you, could you give us some practical examples?

ZF: So, a lot of them were easily accessible medical ethical issues that doctors can find are those surrounding end of life. How does a medical professional make decisions about what treatments should or shouldn’t be given at the end of life, how can we sensitively involve patients and their relatives in those decisions, when might having discussions produce harm, how much should decision making be the responsibility of the clinician, the patient and relative?

And all of those I think people who are listening will immediately be able to empathise with as being difficult ethical decisions but they actually stretch much beyond those ones just at the end of life and stretch, for example, to all of the interactions we have when we, a doctor, are processing what might be wrong with the patient in front of us. And how much should we tell the patient about what we’re thinking at that particular time and is there an ethnical component to that decision making which is almost subconscious?

So, for example, if a patient comes in to see me with anaemia and some back pain, an elderly patient, they probably have anaemia because they’re not eating enough iron and back pain because they’ve got slightly crumbly bones, that’s the most likely thing. But there’s a disease called multiple myeloma which could be the reason that they have back pain and anaemia, presented those things, and that is tested for very easily with a blood test and a urine test.

Now a blood test and urine test aren’t invasive, most patients are quite happy to provide a bit of blood and give a urine test without necessarily wanting to know the details of exactly what you’re testing.

And so if I’m doing these tests on this patient do I say to them, well, I don’t know what’s causing your anaemia we’ll just do some blood and urine tests and I’ll get back to you shortly? Or do I say, the most likely thing is that you’re not eating enough iron and your bones are a bit crumbly but there are other things and I should test them. Or do I say the whole lot, the most likely thing is you’re probably not having enough iron, your bones are a bit crumbly but it could be a cancer of the bone marrow and I will test for that as well?

So that’s an immediate set of options that I have and I think there is an ethical dimension to how much I tell that patient and how much that in telling that patient is offloading the responsibility of following up those investigations and how much of it is me wanting to make sure that I’m being really open? So, what are the different factors in making those decisions?

JB: That’s expressed in very lay terms and every day and, as you said, everyone listening can probably understand why that’s something that you’re questioning. Richard, what’s going on?

RH: One of the movements that there’s been over recent years is the idea that informal consent provides this kind of touchstone of ethically acceptable medical approach. So, a patient can’t be treated unless they’re consenting to the treatment and that consent needs to be done given full information, hence informed consent.

And one of the things that these kinds of issues I think they bring out is that there are lots of different levels to which a patient can be informed, and then you start thinking, well, it would be a bit of a fetish if you thought just giving them more and more information was the only criteria, what about the anxiety, what about the confusion that you provoke?

And we’ve got lots of empirical studies which say that human beings in general are very bad at manipulating probabilistic information, overestimate small probabilities, we underestimate large ones, we’re not designed to cope with probabilistic stuff. When a doctor comes up with a differential diagnosis, with a set of different things it could be, this is the most likely, these are possible, these are possible, is it really a useful thing or is it a right thing to give all that to the patient?

Now obviously you don’t want to think you shouldn’t give any of it to the patient and you don’t want to go back to the sort of pre-informed consent days where we just thought that the doctor knows best but, equally, it feels that we need to understand what the relationship between the doctor and the patient should be such that the doctor can be respecting the needs that the patient has for information there in order to make the decisions.

So, I think these are lovely cases that Zoe’s been outlining where you think, well, yeah, I could just give more information here, but to some degree that might be losing the responsibility of the doctor to look after that stuff by just dumping it on the patient, and that doesn’t look to be the right way forward.

So, then I think we have to unpick these different issues it’s to do with, it’s to do with welfare, it’s also to do what’s right, it’s to do with respect and autonomy and those kinds of things but also just looking at the reality of what the patient’s life is like and how much…saying, well, there’s a 5 per cent chance of something absolutely awful happening to you and let me tell you all about that. Whether that’s the right thing to do in many of these cases.

ZF: If I take that back and look at this example when I was talking about a patient with anaemia and some back pain and I was talking about how, ultimately, you might be able to provide some guidance, I laid out three options and then there’s another option to say, I’m going to do some tests, there are various things I can tell you about these tests or would you like me to just on with it?

So that’s another option where you are explicit that there is more information you’re not giving and you’ve got to kind of opt out if you don’t want to, other than just explicitly…rather than waiting for a patient to ask you more.

And I have had experience of trying out these different things because this doesn’t feel like a controlled trial where I needed to test them out, I’m just seeing how my communication with patients works, so this is not proper empirical medicine, this is just my day to day experience. And I had a patient who I basically said, I’m going to do some tests, do you want me to tell you what they are? And she said, yes. And I told her this example and she said, oh, I wish I hadn’t asked now.

JB: [Laughs].

ZF: And, as it happens, she was really distressed about it and I phoned her to tell her, unfortunately, the urine sample went missing, anyway, it was just anaemia and back pain, two weeks later when I spoke to her said, I’ve never had two weeks of such anxiety in my life.

Now this is an N of 1 and I’m a scientist and I am not suggesting that all patients will have had huge anxiety by telling them this, but I do think it identifies this risk that offering too much information…oh, I’ve just made a normative judgement that it’s too much information.

JB: [Laughs].

ZF: But offering all of the information has the potential to cause harm. And I guess I’m using this example as one where you’re saying there may not be a right amount of information for every single patient because clearly there’s variety in patients, but there may be a way of, first, making people sensitive to the fact that they need to consider how much information they’re giving, second, being open on a kind of wider level to patients that there are variations in how much information they might get given and that they have the risk to ask for more if they want but their doctors aren’t telling them everything.

And probably patients know doctors aren’t telling them everything but we’re not explicit about that. So, is that in itself a question? And then should we be providing some kind of guidance to medical students and doctors about how you might phrase those things.

JB: How do we study these issues and how do you actually…you say, okay, let’s design a research study about this?

RH: There are two things that come in then, one is a question about experimental design, how do you design an experiment to answer the questions you want answered? But then there’s also this issue of, well, what are the questions? And here you’ve got an interaction in those questions between this empirical issue, how much do people get upset when they’re told information like that, and these more ethical issues about how much are you sharing the responsibility between the patient and the doctor and are there ways where that’s important?

So, one possibility is move the consent up a level here, effectively that’s what Zoe was outlining. So rather than saying, I’m going to tell you everything, you get consent for not telling you everything. Now that’s a more philosophical distinction that you make there but then you might think, okay, now let’s try and design some experiments around that and see how much if you offer that to patients, patients welcome it, are the outcomes better as a result of that?

No, that’s stuff we need and the plan is to do some of that down the line, but I think seeing those possibilities is something where thinking about the ethical issues actually helps you to see where the experimental design will have to be.

JB: Does it start with some super clear thinking about that N of 1?

ZF: The N of 1 provided the example of the person who was super stressed by it. So, I joked about being an embedded anthropologist, so I have, whatever, 18 years of medical experience, of watching how my colleagues and I share information and how patients appear to react. And that’s what we’ve then gone off and talked about in order to be able to say, well, as Richard said, should this consent be brought to a different level, should we be more open about what information we are and aren’t giving and how might we assess what impact that has?

So, one thing might be causing anxiety is a problem, let me get from N of 1, another thing might be that by giving information we’re empowering parents which you might argue is the right thing to do inherently because then they may be able to have more control over what tests they get, what they’re doing with their time, whether they want a second opinion. So, then that’s another thing that we might end up testing when we’re looking at different ways of sharing information.

So, Richard alluded to the fact that we’ve been working out how to look at this empirically and so the Wellcome funded study that I’m doing at the moment on diagnosing diagnosis is exactly doing that, it’s saying, well, the first thing we need to do is instead of just relying on my personal experience we’re going to go to three trusts. And we’re going to look at how doctors communicate differential diagnosis, differential diagnosis being the list of things that might be wrong, to patients, how they communicate the uncertainty in that, is there a normal way of doing that? We’ve got a couple of anthropology colleagues who are going to be helping with that and then…

JB: And just to jump in again, I’m sorry, but for those who don’t know that basically means, as I call it, constructive lurking, sitting around and watching.

ZF: I mentioned at the beginning that actually what medicine does is a little bit of a closed book and there are a lot of secrets in it. I mean I don’t think we’re actively trying to keep it secret; we don’t think of ourselves as a secret society but the way things work there’s an awful lot that isn’t open to the rest of the world. And there are things that we don’t question and there’s variation in practice that we don’t even know about because you end up working in your own hospital for a long time.

So, one of the things we’re trying to do is say, well, what is the variation in practice, what do doctors do? And then we’re going a step further and we’re going to interview the doctors about why it was that they chose to tell some patients some things and some others, we’re going to dig a little bit deeper about whether they feel comfortable about it.

And then, and this is kind of exciting, we’re also going to interview the patients and see what they heard in what they were saying. So, the doctors may have thought that they were describing uncertainty and the patients may not have heard that.

JB: [Laughs].

ZF: So, I’ve got another example of that where I had a patient with a headache who I had gone through very clearly where I didn’t think she had a brain tumour and why I didn’t think she had a bleed on her brain and I thought she probably had a cluster headache, was the exact language I used, I said, I think you probably have a cluster headache. And when I spoke to her a few days later she said to me, the doctor told me I had a cluster headache. And I said, no, I was that doctor [laughs], I did not say, I said I thought you probably had and there are still things we need to do.

So, when we describe uncertainty which we think is inherent in the language, I thought you probably had, that that might not be heard as uncertainty because of the authority that a doctor carries.

So we’re going to interview the patients to hear what uncertainty they have perceived and then we’re going to phone them up two weeks later as well and talk to them to see what they remember of the consultation and whether they ended up having any questions and whether they felt anxious or whether they felt calm or any other words that we end up deciding we’re going to look into in order to be able to spread from our N of 1 or 2 to a slightly wider idea of what impact conveying or not conveying uncertainty might have.

RH: I think actually there’s a profound difference between the way that science, including medicine, views the world and the way that probably most ordinary people view the world. So, science has moved very much into a probabilistic framework. Right, so it’s not that you think this is how things are, you think, well, there’s this probability of this, there’s this probability of that and so on.

That’s the method of science now and statistics is a way of calculating that in an accurate form and you come forward on the basis of that.

I think our native way of thinking of the world, and there’s a lot of empirical work based on that, does not look like that. We just have a view of what the world’s like. And we might, at times, be a bit uncertain and we’re fishing around wondering which one but then we just go for one.

So, I think you get this problem where the scientific world hits the way that most people think about things, that you give a differential diagnosis and the patient really just wants to know, well, no, don’t give me all that rubbish, right, I want to know what’s wrong with me, what do you think the issue is? Can terminology, which Zoe reports time and again?

So, there are different ways you can handle this, one way is to keep bashing patients over the head [laughs] with the thought that the best we’ve got here is just a set of probabilities. The other is to say, well, maybe…especially a patient who’s sick, this is the worst time to be trying to have a fundamental, cognitive shift.

JB: [Laughs].

RH: So maybe what we should be doing here is, to some extent, accommodating the tendency that patients have to see the world in a rather more black and white way and to say, look, maybe there’s a division of labour here, maybe the doctor can look after some of that uncertainty and we can make sure that we keep track of the little probabilities whilst giving you a narrative that basically lets you go forward saying this is what we think it is.

And I think there’s been very little investigation of whether that is an ethnically okay way, whether it’s actually helpful to patients, whether they would be reassured by it, whether they would be unnerved by it, whether that is patronising, whether it takes away the right to know or whether, on the other hand, it provides a way of accommodating the natural ways people have of thinking about things at a point where they’re not really ready to change.

JB: And that kind of question seems to be entirely absent from the whole shared decision making, kind of, literature where we’ve had a pendulum which has swung from that paternalistic, doctor knows best, all the way to at every level throughout every healthcare encounter we need to make sure that decisions are shared, are joint decisions.

RH: We have to think that there can be, as I put it earlier, a division of labour, some people are better at doing some things than other people are in this case. I mean if you’ve got a lot of the emotional stress that’s on you when you’re ill adding then this kind of further complexity of having to think in these ways which are rather foreign to you might not be welcome, it might be something which just unnerves you further.

I think there may be a problem in both directions, both the problem of giving too much probabilistic stuff and also perhaps a problem of doctors, kind of, hiding behind that probabilistic stuff.

I was talking to someone just the other day who had been working in geriatric wards with diagnoses of various forms of dementia and he was saying that he thought there was, on the other extreme, you had a tendency of doctors to use the uncertainty to just hid behind it. So, the doctors would actually have a much better idea of what was really going to happen than they were prepared to communicate because, again, they were thinking, well, formerly there were quite a few different possibilities. Whereas, in fact, if they had to put any money on it, they would probably have thought this is going to be the outcome.

And he thought there were problems there as well so, for instance, he was saying about the issues around power of attorney. I know it may well be that it’ll be really useful for many patients who are starting, who are in the early stage of dementia, to arrange for power of attorney for their relatives so that they can take over certain things if need be.

But unless you’re told that there’s a real chance of this and you really…this is something, a possibility you really should take seriously patients were not putting those into place early enough. And then, of course, once dementia really sets in getting power of attorney established can be very difficult because the patient’s no longer got the ability to consent to it. They should be saying actually this is a much more likely outcome and this is really the thing you should be focussing on.

ZF: You were saying a second ago about the pendulum swinging and I think obviously you’re completely right that if you look even 50 years ago it was absolutely common practice not to tell patients they were dying.

Now that now seems a complete anathema, like the idea that we wouldn’t tell a patient they were dying but it was common accepted medical practice 50 years ago, maybe 60, and it was considered that it would cause someone too much distress to tell them they were dying. And they would often tell the relatives but not the patient.

And then that was questioned and obviously practice changed and I think the idea that you wouldn’t have informed consent for surgery, let alone for research also, I mean really just 60 years ago that that wasn’t the case. Clearly not telling patients what was going on with them and not giving them the right to be involved in care decisions that were being made was inappropriate. Has it gone too far and my view is that it has gone without questioning what the unintended consequences of that might be.

And that’s where Richard was talking about the division of labour and this diversion of labour idea is very much one of the things that came from the conversation, this is a fruit of the interdisciplinary conversations we’ve been having.

JB: The one that’s fuelled with Chelsea buns?

ZF: Chelsea buns, yeah. Because we were saying maybe there is some work, some emotional labour, of worrying about what might be going on. And maybe what we need to say is part of the therapeutic relationship is in taking on that work and in saying, don’t worry, I’m going to look after you, or, don’t worry, we’re going to find out what’s wrong.

And maybe even being explicit about that and saying, there are all kinds of things it could be, I don’t think it’s anything serious but I’m going to make sure it’s not. Allowing yourself to hand over that worry might be part of what allows you to get better, the kind of laying on…I was going to say the laying on of hands, the explicit articulation of, I’m going to look after you, might be quite important.

And I think that we should not just be focussing on the individual interaction, we should be saying, is this a change in practice that we need to actively be propagating? We don’t want to do that unless we have some [laughs] evidence that we should be doing it, but we certainly should be investigating it.

Because at the moment most of our changes in practice have been reactive and that pendulum swing, I question whether it’s gone too far and whether if you insist on telling patients and involving patients every step whether you might be diminishing the power of the therapeutic relationship.

JB: I think the pendulum swing is really interesting and I certainly think that, to go back to the shared decision debate, the bandwagon seems to have just gone, there’s now talk about shared decision making being assessed and mandated and all of these things without us actually, I think, understanding, as you said, the unintended consequences.

ZF: And I think one of the reasons, and Richard and I talked about ethical frameworks versus philosophical constructs, I don’t know the right word but the next bit. But medical students are taught an ethical framework of the four principles which are autonomy, the ability to have power over yourself, maleficence and doing good, non-maleficence, not doing bad, and justice, being fair.

So, it’s Beauchamp and Childress, and actually Beauchamp is actually American and called himself Bo-champ but all the English people call him Beauchamp which is very funny, anyway, that aside. So, they are the people that came up with this framework, it is the framework, as I say, medical students and, therefore, junior doctor are using. They were saying when you’re making any medical decision you need to balance these things, you need to make sure, and the justice issue actually then is that you’re not just dealing with the individual but you’re thinking, well, how does this affect societally, what is the resource implication and all the rest of it?

But at some point, in the last maybe 15 years, the autonomy gained primacy and also people stopped trying to think outside the four principles, I would say, because it just was a very nice, easy framework to use. And people stopped thinking about other issues.

JB: And how long has that been around for, that framework?

ZF: Nineteen 80s, 1990s, I would have to go and check when the first paper was. So, a historical perspective, I qualified in 2001 and medical ethics wasn’t formally taught to me in 2001 as a doctor then.

JB: Well, these are pretty big things that we’re talking about here.

ZF: [Laughs].

RH: Hmm mm.

JB: And I’m sitting here thinking about obviously when we’re trying to think about improving healthcare we tend to be thinking about the system, we have lots of individuals and lots of individual encounters within a very complex system. And so, to engineer change you need to think about the whole system level.

RH: Yes.

JB: And I’m thinking, okay, if your work around how you communicate diagnosis comes up with some kind of suggestion of how you do present those options to patients how do you get that piece of individual behaviour to happen within a very complex system? You’re looking at change at lots of different levels.

RH: Zoe was mentioning that kind of medical ethics training that people get does tend to lay down a certain categorisation and probably many of those doctors will never go back to read any ethics stuff thereafter, right. So, Keynes talked about people being slaves of the dead economist, right. Well, here maybe people are slaves of the dead bioethicists.

ZF: I think he’s alive [laughs].

JB: [Laughs].

RH: At times. And you get that kind of framework and it just goes on. So, I think probably two things here, one is just to make sure that framework is as good and as flexible as possible. And I think one risk when you have a very definite framework is that it kind of sets it in stone. People don’t realise, no, this was just someone’s attempt to try and get it right once and we need to keep revisiting this, it’s not…it’s in the nature of ethics that it’s more complicated than any framework that you might try and capture it in.

The other thing possibly is to try and make sure that, as much as possible, we keep those conversations about these ethical issues in such a place that doctors will keep hearing them thereafter.

Now I think doctors are busy [laughs], right, and they’re not going to spend all their time reading ethics journals but insofar as we can just make sure that those conversations keep happening. And also, that doctors think of them as being useful, helpful things rather than these kinds of outside authorities just coming in and imposing a new set of categories, God, we had enough checklists to go through and now we’ve got some extra ethics ones as well.

I mean that would be absolutely the worse thing. What you want is this sense that, ah, here’s something. So, as we were saying, people feeling uncomfortable, yeah, well, let’s help people with that discomfort, let’s bring out some of those themes and try and articulate them for you and help you to think through something that is already worrying you in some way.

ZF: Exactly, so it’s taking not only trying to improve the care for patients but trying to nudge doctors into behaviours which are inherently better for patients which then actually will make the emotional load for the doctor less.

JB: Absolutely.

ZF: So, there is…

JB: As well as you could argue probably more efficient use of resources, better outcomes, knock on effects.

ZF: You absolutely could. So, I’m going to do a slight tangent briefly about the work I’d done before on resuscitation decision. So, I think this is an example of where there was moral discomfort widely felt about the way we made decisions about resuscitation, that’s whether or not you attempt CPR on someone whose heart has stopped, and how you discuss that decision and how you document that decision.

Someone whose heart has stopped unexpectedly has a reasonably good chance of having their heart restarted because it’s something that’s happened to their heart all of a sudden and if you see someone collapsed you absolutely should attempt CPR.

If, on the other hand, the heart has stopped, as I like to say, as the final common step of the dying process, if your heart has stopped because you have a metastatic malignancy or because one of your other organs is failing or because you’re just very old and frail and your heart has worn out, then attempting to start it, A, probably won’t be successful and, B, might be quite damaging in that it could bring an individual back from what had been a peaceful death to a brief period of being aware of being surrounded by lots of people attempting to get them back and then dying. Which probably isn’t good for the patient, isn’t good for their relatives, isn’t good for the team that has had to do this invasive procedure and it probably isn’t good for other patients on the ward.

I have no problem in saying there are definitely examples of where attempted CPR can be harmful.

So, the question is how do you make sure that those decisions are made in a consistent and ethical way with the involvement of the patient, because we’ve accepted that we probably shouldn’t make those decisions without telling the patient those decisions are being made. There is now an explicit legal need to have those discussions of patients unless you think it’s going to cause physiological or psychological harm.

And so, the issue was that they were documented on red pieces of paper that was put in the front of the notes in order to make sure that in an emergency someone would know that CPR shouldn’t be attempted. And nobody liked having these discussions, so doctors didn’t like having them because it’s not very nice going up to a patient and saying, by the way, if your heart stops, we’re not going to try and restart it. I mean no-one actually said it that way but that was the general content of the conversation because, ultimately, it is a medical decision that you don’t think someone’s going to have a successful CPR attempted.

Patients didn’t like bringing it up, as a society in general we’re not very good at approaching our own mortality, although I think that’s getting a lot better. And there was another ethical problem that actually these red forms are being misinterpreted to mean other care shouldn’t be given, which was a substantial problem.

So, we did some empirical research…

JB: Constructive lurking.

ZF: Constructive lurking. We saw what the variation in practice was and we then had lots of focus groups of doctors and patients, what approach could be different? And, ultimately, we decided that the thing to do was to make sure that the CPR decision was always contextualised within goals of care, what are we going to try and do, instead of just talking about not doing something we were going to talk about what we’re going to try and do in trying to make someone better or trying to make sure that they were comfortable.

And before we even did that, we were going to make sure that we all had a shared understanding of what was wrong with the patient. We slowly, and it felt like 11 years, developed this new approach which is now called ReSPECT, recommended summary plan for emergency care and treatment, and that is a process where you get a shared understanding of what is wrong with the patient, you make sure you understand what the patient prioritises in terms of what outcomes they value and what outcomes they fear. And then as a clinician you can say, well, now that I’ve understood that these are the treatments that I think you would benefit from and one of them either is or isn’t CPR depending on the patient’s situation.

And then we tested it and we’ve shown that it improves not only the experience but probably improves outcomes.

The reason that I’ve gone into that long spiel about that is because it’s an example where we recognised a problem, did research, introduced it and actually doctors have found the approach much, much, much more comfortable.

JB: Are there particular challenges in trying to bring different disciplines together, are there potentials for misunderstandings?

RH: I think there always are but I think that’s why you can’t do this kind of work by just saying, okay, we’ll have an afternoon and we’ll sort it out, because it’s got to come from disciplines understanding each other.

So, I do a lot of work with psychologists as well and you just have to go to conferences and talk to people and read the papers and hang around and you have to become close enough to a native speaker of the other discipline to be able to do it. And I think that’s…I mean I think that is what’s happening with medical ethics now, it’s much less that people are just coming and saying, okay, well, philosophers just have discovered this, here’s the stuff you need, and much more of this constructive lurking amongst each other’s professional practices.

JB: So, I did want to ask, we’ve talked about focussing the philosophical lens on communicating diagnosis and also on agreeing treatments really with the CPR example. Are there any other big issues or challenges that you’d like to be taking this approach to?

RH: You mentioned earlier joint decision making so, yeah, this has become the great thing, every journal you open is full of all this joint decision making stuff. But I think there there’s a wealth of different things you might mean by that.

So, one is the kind of joint decision making where the thought is everybody’s in on everything and we do everything equally and whatever, the other is that you come to an agreement that this is how we’re going to divide up the decision making, this is what you need to look after, this is what you need to look after, right. The patient has to keep an eye on how their symptoms are progressing, the doctor’s not going to be there to do that, these are the ones that it’s important for them to look at, these are the ones they’d better get back to you quickly if there’s something going wrong here.

But equally, the doctor’s going to be getting the results of various tests and so on, maybe the thought is that they can be making just autonomous decisions along the way because you’ve jointly agreed that this is the way forward.

So, I think there’s a host of different things that can come under that heading, I think in some ways it’s a very useful heading to think under but I think, again, we’re at risk of seeing it in much too simplistic a way.

JB: So, anything you’d like to…

ZF: I am also working on how we share other kinds of information, so how we share written information with patients, so access to medical records, I think that needs to be questioned. So, doing some work on looking at there’s a kind of assumption, well, maybe patients should have access to all of their records but what would that have? I mean you can say that’s tightly linked to what we’ve already been talking about but could we empower patients better by giving them a quick summary on the post hit ward round.

So, we’ve honed down on diagnosis and differential diagnosis but the meta question is how much responsibility should we be handing over to the patient, how much should we be keeping for ourselves? And Richard Layman at Birmingham talks…instead of about shared decision making he talks about the shared understanding. And I think that’s saying clearly, we want a shared understanding of medicine, obviously we should make sure that it’s not an opaque world where patients don’t know what they don’t know, we should be in a world where people have a better understanding of how things work.

I think we should be being really open about the processes that go on but I think then we should also be being open about when some of those might be better to be managed by people who are used to managing them, that might actually be beneficial to patients.

RH: On this responsibility issue I find this really useful actually to think about the philosophical notions here because people normally talk about responsibility meaning are you to blame for something? But there’s this other notion which Zoe just alluded to of taking responsibility for something. So, if I take responsibility for looking after the catering maybe that I’m to blame if the catering goes wrong, right. But it’s more to do with the idea that I’m the person who’s doing the management of that and other people can be agreeing that that responsibility is properly taken by me.

And I think we haven’t thought very much about responsibility in that sense. Interestingly, there’s very little philosophical discussion of that, that in a clinical relationship there can be some responsibilities which fall on the physician, some which fall on the patient, those are not going to be identical. And we should be thinking about responsibility in that way which is, in a way, a much more constructive way, right.

I mean the other way of thinking is who carries the can when it all goes wrong? Basically, you’re looking at the whole thing through the eyes of disaster, whereas this is saying, no, in the ongoing process, the mundane management of illness which the medical establishment is basically concerned with that there can be this kind of division of responsibility in that sense.

JB: I do have a question again about systems, I’m obviously sounding slightly obsessed by systems but, Zoe, as a clinician you gave the example of, again, the CPR changing practice, do you think there are clear routes to feed these kinds of insights through at all of these levels into altering practice and improving care?

ZF: I do and I think some of it comes back to medical student and junior doctor training, that comes at an even bigger level. So, you said what am I still interested in, I think we need to be teaching our junior doctors and our medical students to question the premises of what they see. My students get taught that all the time, that, in itself, changes practice if you just don’t assume that you do things just the way that you saw someone else do it.

But I think there are other tools in terms of doctors are very good at following guidelines [laughs] because we have to because you can’t keep everything in your head all the time. And having a guideline is helpful but, as Richard said, you don’t just want another job that has to be done. And the best possible change you can make is a suggested change that actually not only intuitively improves care for the patient but makes the way that you’re delivering care easier.

That’s the nirvana, that’s what we’re trying to get to because then you don’t have to enforce it, that is then what people want to do and if we can find a way of saying, and it has to be evidence based because…

JB: N of 1 doesn’t get us anywhere.

ZF: [Laughs] no, no, no, so if you can find that there is a way of doing something and then you can say, look, this is what we discovered, have a go. And then as soon as doctors have a go at doing it that way they go, oh, well, that was a much easier consultation and my patient left much happier and it was much less stressful and I’m not going home wondering about whether I gave the right information to patients or whether I should have told them more. Because we do all take that, all the decision making we take home and keep on thinking about. If it can make that more comfortable and make the patient feel better, then it will have a system change.

I don’t think that there is a change that can be imposed that will make things better, I think the answer is in doing enough really good philosophical thinking and empirical work to come up with the change that will improve care for patients, experience for doctors and then that will just be taken on.

JB: I think what I’ve taken from the discussion today is how important it is to question what we think are fundamental principles, but actually might be things that have wormed their way in and probably need to be tipped over and given a good examination as to whether they’re still fit for purpose and whether we shouldn’t be using different things.

That this kind of philosophical thinking isn’t just confined to the micro, to the individual interactions and that actually it can explode all the way up to the system level to make big changes in care.

And I think asserting that idea of the flow, that if you’re observing what’s not working using these philosophical approaches to guide what we should be doing instead that then if it just fits it fits. So, I can that has so many opportunities for improving caring, more natural, not forced ways and that you can do amazing things if you eat enough Chelsea buns.

Thank you so much, Richard, for coming in today, thank you, Zoe, for giving up your time as well.

ZF: Thank you.

JB: And I am Jenni Burt, thanks for listening to this.

**End of transcript**