

[Steve:

Hello and thank you for this opportunity to speak at your conference.

I apologise for not being there in person, but I do have my first grandchild due at any minute, and being on the other side of the planet when she arrives would make it very hard to be as indulgent as I intend to be.

Let me just do the proverbial sharing of the screens so we can begin the presentation.

There we go.

So my name is Steve Trumble. I'm Professor of General Practice, Education and Curriculum at Deakin University in Geelong, Victoria. I've previously been head of medical education at the University of Melbourne and I've edited several journals relating to general practice and medical education. I've been chair of the EIDO International Editorial Board now for nearly 20 years I think. For those of you who know Australia and Melbourne, I'm actually an hour and a half to the southwest at Aireys Inlet, down on the South Coast and on the picturesque Great Ocean Road. Very nice place to be, although at the time I'm recording this, the temperature is 35°. So we are heading into another hot summer and a high Bush fire risk in this part of the world.

As is the custom in Australia, I acknowledge that I am on the unceded lands of the Wadawurrung people and I pay my respects to their elders, past, present and emerging. I also acknowledge that I am paid an annual stipend for my editorial work with EIDO International.

I've been in this role as chair of the editorial board, as I mentioned, for nearly 20 years. I'm not a surgeon or any other kind of clinical proceduralist. I am definitely not a lawyer I'm, although I know there's a number of lawyers there and they may well find my presentation reasonably superficial, but I'm presenting it as a clinician would view this particular topic. As a General practitioner by training and by nature, I've always had an academic interest in my work and I've had a lifelong career in academia. Particularly involving the doctor patient relationship, and how better communication can

improve the quality and safety of the patients experience, while also reducing the doctor's risk of complaints and litigation.

As doctors, we work in our field where our customers frequently have an outcome, or even just a clinical experience, that is not what they're expecting. I can't remember where I first heard it, but medical practice has been described as 'the management of disappointment', and there is something in that. It's no surprise that the frequent flyers with the medical regulators and claims departments and indemnity providers down here tend to be doctors who over promise and under deliver, or if not under deliver, fail to give their patient a realistic expectation of what their clinical skills can achieve.

For example, the plastic surgeon at the cosmetic end of that speciality spectrum, who was sued by a patient for an adverse surgical outcome, when their real complaint is that their partner continues their infidelities despite the expensive and painful cosmetic procedures the patient is endured. It's unrealistic for that patient to expect their deep seated relationship issues to be resolved in theatre with a scalpel, but some surgeons encourage that sort of magical thinking and need to pull back to what is reasonable and respectful to expect. This is where patient information aids can help to make sure that the patient is properly informed and gets the help that they really do need.

It's not just procedures that are more a purchase commodity than a medical treatment where this risk of unmet expectations is high. Many of you will be aware of the high rate of dissatisfaction said to exist amongst recipients of total joint arthroplasties. Patient dissatisfaction with the outcome of total knee replacement is often quoted as being 20 to 30% with this 1990, sorry this 2022 systemic review.

Where is it?

Down the bottom right hand corner there. Placing the figure at about 10%, noting that it's reduced over more recent years, studies conducted in more recent years and that may have been due to better preoperative preparation. While there's another study down the bottom left hand

corner there. 2023, on decision regret following hip or knee replacement, which concluded with the words 'the use of decision aids to reduce postoperative decision regret in joint replacement patients should be examined, especially for knee replacement patients'. That's just one example.

The one above it is from just down the road from you at Addenbrooke's near Cambridge, and it was another systematic review and it identified the patients whose preoperative expectations were met were less likely to be satisfied, I'm sorry, were more likely. I'll try that again. Patients whose preoperative expectations were met, were more likely to be satisfied with their clinical outcome, which is no great surprise. Although I suppose it is a reminder that while we do everything we can to get the possible, best possible clinical outcome, we also need to make sure that the patient's expectations of that outcome are reasonable. Otherwise we're setting the person up for disappointment and setting ourselves up for complaint.

So it really all comes back to what information we provide to patients about their healthcare and how we present it. I will confess to being a massive fan of improved patient information, which is why I've been involved with editing this library of resources for so many years. Big developments are coming in the way that information is provided to patients with online versions that allow easy dissemination, animations to make better sense of complex concepts, live information that allows patients and their families to dig deeper into topics about which they're particularly curious, as well as tracking of usage to make sure that the information is getting to patients, being read and most importantly, understood. Things are definitely due for a change. Here's just a short piece of video showing a public hospital patient in the UK being given information about his impending laparotomy.

*[Doctor in Video:]*

Now you just lie still old fellow. I'm just going to discuss your case with these young doctors here. Take his pyjamas off sister. you! Examine his abdomen.

Take that grubby fist away. The first rule of diagnosis, gentlemen. Eyes first and most, hands next and least, and tongue not at all.

Now Look!

Have you looked?

*[Junior doctor in video:]*

Yes, Sir.

*[Doctor:]*

See anything?

*[Junior doctor:]*

No, Sir.

*[Doctor:]*

Very good. Carry on. Gently, man, Gently! You're not making bread! Don't forget, to be a successful surgeon, you'll need the eye of a hawk, the heart of a lion and the hands of a lady. Have you found it?

*[Junior doctor:]*

Yes, Sir.

*[Doctor:]*

Well, what is it?

*[Junior doctor:]*

A lump.

*[Doctor:]*

Well, what do you make of it? Is it kidney? Is it spleen? Is it liver? Is it dangerous? Don't worry my good man, you won't understand our medical talk.

You, What are we going to do about it? Cut it out, man, Cut it out! Where should we make the incision? Nothing like large enough. keyhole surgery, Damnable. Couldn't see anything. Like this. I don't bite, this is nothing whatever to do with you.

Now you. When we've cut through the skin, what's the first substance we shall find?

*[Another junior Doctor in the video:]*

Subcutaneous fat, Sir.

*[Senior Doctor in the video:]*

Quite right. And then we come across the surgeon's worst enemy. Which is what? Speak up, man! Blood! you numbskull! You cut a patient, he bleeds until the processes of nature form a clot and stop it. This interval is known scientifically as the bleeding time.

You! what's the bleeding time?

*[Another junior Doctor in the video:]*

Ten Past Ten sir.

*[Steve:]*

OK, so I'm sure some of you have seen that video before, and apologies to any other speaker who's planning on using it today because it is a bit of a classic in the field. It amuses me hugely. Exactly. Quite a lot of that stuff still goes on, I must confess. Unfortunately, the look of bewilderment on the patient's face as he was discussed and dissected in public is still quite common in some places.

Our challenge, of course, is to present patients with the information they need, in a format that suits them. Occasionally I do some work with an orthopaedic surgeon who has a collection of video clips of himself explaining the common procedures he performs. There's actually not that many when you specialise in feet. His receptionist passes the patient an iPad after their consultation and they sit in the waiting room watching the relevant video. The receptionist then takes the iPad back and hands them a ten item multiple choice exam, on which they have to score 100%, before signing the consent form and lining up for surgery.

My colleague is quite delighted with the system as he has a clear record of what the patient was told and that they understood the

information as evidenced by the perfect marks in their exam, High distinction. He seems baffled when he gets negative feedback from some patients who felt subjugated into knowledge rather than educated. And I've also observed another GP colleague in Singapore, who does perianal surgery in his rooms, and who proudly showed me his patient information videos which display the actual procedures close up and in glorious, living Colour. He makes people watch the relevant video while he sees his next patient, and he couldn't figure out why some would be unconscious on the floor when he came back into the room. They were truly grizzly, graphic videos. We cannot abdicate responsibility for informing patients about their proposed treatment onto documents or videos or whatever. It has to be done in a person centred way.

Of most interest to me is the consent conversation. The educational resources can support, not replace. I must emphasise 'support'. When I was a surgical intern way back in 1985 in my long white coat, a large part of that job is being dispatched by the registrar to consent that 'nothing casualty', or make sure you also consent that termination for a 'lap-steri' while we're there. Looking back, the depersonalisation caused by referring to people as their procedures was deplorable. As was sending a very junior and rather thick headed intern off to obtain a signature on a piece of paper, for a procedure he was in no way competent to explain, let alone perform. The consent process definitely needed to change. In Australia, as elsewhere in the world.

If the COVID pandemic has taught me one thing, it's that even the most entrenched behaviours can be changed if the disruptive blow is hefty enough. But they do creep back in. From a medical education perspective, the virus drove the major change we've been trying to bring about for decades. It rendered our lecture theatres obsolete overnight and it socialised us to using communication technology, such as this to make learning more accessible, timely and convenient. A legal meteor struck Australia in the early 1990s and provided the disruption needed to bring about major change in the way we speak with patients. A seminal court case made its way to the Australian High Court that has forever altered medical practice, both here and in the UK, when it comes to failure to warn and gaining informed consent for

medical treatments. And I'm sure this will be discussed further and more competently today.

But in summary, many of you would be aware I think of the Rogers and Whitaker case which was in 1992 in which a former nurse, Marie Whitaker, successfully sued an ophthalmologist Chris Rogers, when she developed sympathetic ophthalmia, or ophthalmoplegia in her left eye after he'd operated on her right. Now, she'd been blind in the right eye since penetrating trauma as a child age of nine, and she remained bothered by the cosmetic appearance of the scarred eye. The procedure was largely to improve the appearance of that eye, but the doctor had also said he hoped to be able to restore significant vision. So it wasn't just for cosmesis she was going through the procedure, as someone can say.

Unfortunately, vision in the damaged eye did not improve post-operatively, and the operation led to that very rare complication of sympathetic ophthalmia, which damages vision in the good eye. Which the court received evidence occurs in approximately 1 in 14,000 such procedures, although nobody's quite sure where that figure came from and what literature underpins it, and it continues to be disputed. But whatever, it's a very small risk and several, highly reputable experts were summoned to the courts to give evidence and they gave evidence that they would not have warned Miss Whitaker about the risk if she'd been their patient. The High Court decided how, I should say that as you were probably aware, under the bottom principle, if the profession believes that to be the standard, that is generally accepted by the courts as their appropriate standard for information provision and practice in general.

But the High Court on this occasion decided that Miss Whitaker had asked lots of questions about the operation which had clearly demonstrated that she was worried about the procedure and that she had a particular concern about losing sight in her good eye. So the Justices rejected the long standing Bolan principle of the being up to the medical profession to decide what reasonable practice and instead ruled that it was, and here we go, 'the doctor's duty to disclose to the patient any material risk inherent in the proposed treatment, with the risk being considered material if, in the circumstances of a

particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it. Or if the medical practitioner is or should reasonably be aware that the particular patient, if warned, would be likely to attach significance to it'.

OK. In other words, if there was a particular thing that that patient would need to know about, the doctor has a particular duty to warn the patient of that.

Now you will recognise many of those words from the United Kingdom's own case, 'Montgomery', where a child sustained a hypoxic brain injury said to be due to shoulder dystocia, which occurred in a mother who was of short stature and who had diabetes. And she successfully sued that she was not warned of the possibility of shoulder dystocia or informed of alternatives to vaginal delivery. With the obstetrician saying that he believed that if he had warned her or had informed of the of the option of caesarean, she would have taken it and that wouldn't have been the best choice for her. And again, I suspect this case will be discussed by others sometime today.

Anyway, in both cases the profession was criticised for being paternalistic, or doctor centred, in deciding what information to pass on and what to withhold. In return in Australia at least, a lot of surgeons feared the sky was falling and they would be spending *hours* with each patient explaining every vanishingly small risk, as well as all the alternative procedures that could be done but were really not the best clinical choice. In reality, things settled down and we were left with two, clear questions to ask ourselves when informing patients about their treatment.

'What does any person reasonably need to know about this particular treatment?' and 'what would this specific person want to know about it?'. Now really, 'what does any person need to know?' can be delegated to other resources like patient information sheets, videos, as long as they're comprehensive. But then what do you need to tailor specifically to the needs of that person? Now the second question sometimes led to the querulous response from doctors. 'How would I know what the

particular patient needs to know?' to which the best response seems to be, Ask them.

It did become apparent that patients quite like doctors anticipating their questions by having the basic information clearly presented, as well as tailoring the details to suit them and their specific needs. It demonstrated consideration, empathy, caring and concern, all of the things that patients understandably want their doctors to sincerely demonstrate. Most importantly, perhaps, this new approach turned medical consent from something we did to patients as a procedure, into a conversation we have with patients.

Many doctors end up being quite surprised to discover that answering a patient's questions is considerably more efficient than delivering a much practiced, long spiel, a great deal of which is of no interest or relevance to the patient. We can leave the standard information to the information sheet, as I've said, and instead spend more time effectively and efficiently focusing on what's particularly important to this patient having this treatment on this occasion. I've said that so many times, but it's the nub of the whole thing.

Now I must confess I'm not sure what the future holds as far as electronic consent resources go, although as I did mention earlier, there's no question they can make distribution and tracking so much more efficient and reliable. My interest is in what information can be presented in which the patient has agency in choosing to view, rather than just being sent a one size fits all document.

The one thing I will ask though, as we move further into that realm of electronic patient information, is to always have the facility for the doctor to customise the information, to electronically underline or circle this bit, to cross out that bit, to jot a risk percentage next to the mention of an adverse event about which the patient is particularly concerned. That gives the patient the experience of having a personalised concierge approach, which is exactly what's required these days.

And that's not just to leave a trail for the lawyers should things go wrong. It's to keep the consent conversation as a personal interaction

between two people who share a common interest in achieving the best possible outcome. It's a conversation that really should conclude with the doctor's question 'Is there anything further you'd like to know?' being answered by the patient saying 'no doctor, I've got all the information I need.'

So really it is all about anticipating the information needs of a patient and making sure they're met, asking patients what else they particularly want to know and making sure that question or those questions are answered, and basically giving patients information they need.

So thank you for your attention despite this remote means of communication, which has definitely been a one way conversation only. I'm sorry that something has let us down technologically or personally, that I can't give you this presentation live. And most particularly, I'm disappointed that we can't have questions and discussion now because it's such a fascinating topic.

You've got a fabulous group of resources, human resources, live resources in the room with you there today. So I hope you will enjoy the conversation today, learn a lot from each other, and all the best for what lies ahead.

Thank you very much

[End of Transcript]