






# Ann Single - Transcript

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**Richard:** So welcome and thank you for joining us on Rare Cancers Australia Thought Leader Series.



**Ann:** Good to be here. Thanks.



**Richard:** Because of your background and because of your expertise, we're obviously going to talk today a lot about health technology assessment and that my simple definition is that's the process by which we decide what we bring into Australia to treat patients with. But could you give us a slightly more sophisticated explanation to get us going so that our viewers can understand?



**Ann:** Yeah, I'll do my best to elaborate on that. And you're absolutely right because it's the system we use in Australia to decide what we're going to fund on the PBS or the MBS. So what will get subsidised in Australia? But health technology assessment is really just a way of determining the value of things called health technologies, which always makes them sound, you know, highly futuristic and developed sometimes. You know, health technology could be a band aid, it could be a medicine, it could be a health program, it could be a screening program. It could be a hip replacement, health technologies, any intervention. So it could be for prevention or diagnosis or treatment. And it's just a way of determining what is good value. And usually we say what is good value for money because we think about cost effectiveness. And as you know in the Australian system, cost effectiveness is central to it and governments are interested in that cost effectiveness bit because they've got to manage a budget.

Health Technology Assessment came out of assessing technologies, and it came out of the States in the seventies, and it was really in response to seeing all these technological developments come into society and saying, shouldn't we be a bit thoughtful about what comes in and what the consequences of these things are? Shouldn't we think about different scenarios for how they might change our society rather than just blindly accepting everything that comes through? And so it was adapted from that to look particularly at medicines and medical services. But it still can be all about value.



**Richard:** That's a brilliant definition. Before we go do your background is as a writer and as a journalist, as I understand it. It's an interesting, interesting leap into the world of health technology assessment and being, you know, surrounded by health economists and other types of bureaucrats and analysts. How did you get there?



**Ann:** I'll try and do a short and sensible story to make this make sense. So I do I love writing. I love finding out stuff. And I really wanted to be a journalist and I wanted to be a radio journalist. And I briefly got that opportunity. And for a number of reasons, I didn't make it work. And one of them, I would say, is because I didn't actually ask good questions. So that's sort of been a lifelong quest to ask better questions. But I also was really always frustrated by the basis of the claim when you do journalism. So, you know, if you're a really good journalist, you get to spend quite a bit of time researching and finding out your facts and what's what. But when you're starting out, you have to just grab bits and pieces of the story. And I was constantly frustrated by that thought about, you know, what basis are you saying that? And there wasn't often time to check. And obviously if I'd been a good journalist, I would have developed that. But I wandered off into science communication because I was interested in in the basis of the claim, like, why are we saying that? And on what authority?

So I got interested in that and I went down sort of working in communications for research areas, and I was over in Scotland working and I got a job with this new body called the Health Technology Board for Scotland. And I admit I went to the interview thinking I'll have a little practice interview for when I see a job that I really want. And when I was doing the research for the interview, I was just fascinated by it. I thought, this is really this really speaks to me, this thing about trying to work out whether something is good value that's really interesting and on what basis you would do that. And so I went to the interview and I found them to be really interesting people to speak to, and they were very generous answering all the questions. But I'm not sure if I ever answered theirs.

And when I came, you know, and suddenly being in Australia, I really wanted Australia to have, you know, a health technology assessment system that's for patients. That's I know the definition of it is that it's for the health system. But I really wanted us to have something that was about great outcomes for patients because I thought if we got these great outcomes for patients, wouldn't that just revive our whole health system? Wouldn't clinicians and nurses and researchers, wouldn't we all, you know, get out of bed with a bit more spring in our step if we thought we were really making a difference?



**Richard:** Yeah, I think that is that's a hell of a journey. But it's a very it's a very appropriate one. I wonder if we could go through a little bit the this breakdown of patient experience versus patient participation versus whatever else that you might you might think appropriate there. But it's definitely not just, you know, do you feel a pain in your left side? Therefore, we have patient engagement.



**Ann:** It is. It's a lot more than that. If you think about stepping back to what health technology assessment is, what is it? It's a question or a series of questions, really. And we might reduce it down to saying what is good value, you know, is this good value for patients? But of course, there's a series of questions that sit underneath that. And then when you ask those questions, you then use a certain type of evidence to answer it, and then you have to interpret that evidence and decide the answer to your questions. But the point is that, you know, depending on your perspective, you're going to ask different questions. And so that's why it's not just about a patient's experience of a technology, it's what sort of things a patient would value. You know, what sort of questions would they ask? What sort of questions would their family ask? We have this tendency to think about patients as answering the questions where we can't find other evidence. And that's valuable. Don't get me wrong, don't stop doing that. But that's just one type of involvement. There's also the who gets to ask the questions, and that's something that I think patients should have a say in what sort of questions we're asking and then what sort of evidence are we using.

It's not that everyone has input to give but to get a more diverse community and to find ways to hear that more diverse community, that would be that would be something we could build

on. But I think for most Australians it's a black box, it goes on behind doors. We don't know who does what and we get an outcome and we often don't know why. And that's not a process that's that belongs to the people, is it?



**Richard:** No, it's not a process. And those people are in the case of cancer patients, which is our area of interest, dying. Yeah. And if they're going to be denied a life extending lifesaving treatment, it seems not unreasonable that someone explain to them why and not just say it's too expensive or whatever, because we end up in this perpetual discussion around cost. But the cost happens. And I guess this is one of the interesting aspects of health technology assessment. It happens with comparison to existing treatments or a comparison to possible treatments, but there's always a comparison. But I was talking to someone this morning and I said, what we never do is take a medicine and compare it to the cost of a tank or a jet fighter. Why don't we have all of government technology assessment and see whether, for example, and I know we and heaven help me what the Defense Department will do for this, but they bought a whole bunch of tanks a few years ago. And I don't think I don't know if they've ever been out of the garage and they've certainly never been fired. We've never had an enemy to fire them at. But they cost billions.



**Ann:** And look, I have no understanding of defense budget, but I look at buying submarines for 30 years' time and I think; we're making a lot of assumptions about the next 30 years. But we wouldn't do that in health technology assessment. We would look for ways to model that and to understand it.

And I'm not convinced that we always have enough information to make the decisions that we do. And I'm not convinced that they're always in line with our societal values and that we have enough public dialogue about that. You know, one of the things I do like about what happens in the UK is this dialogue sits on the front of the paper most days. You know, you are constantly challenged on it. You are constantly asked by the media, you are asked by people in the street, you are asked by politicians to defend what you've done. And I think that's appropriate. I don't think anyone in our committees makes decisions lightly. I expect they probably bend over backwards to try and make things happen. But I think the system shouldn't require them to bend over backwards. I think the system should be more in keeping with the sort of values we have. And I also think we have this tendency sometimes to ask all of society what they think about funding expensive medicines. And I'm not sure if that's fair, because the difference between going through and being a patient and hitting a wall or seeing a family member hit a wall.



**Richard:** We did an interview last year with a chap from the US who was clearly very, very supportive of the US system, shall we put it that way? And his comment was. It's a question of what you're prepared to pay in America. 90% of all drugs that are registered with the Food and Drug Administration as being effective and safe are available to patients within 2 to 3 months. In Australia, 40% of medicines that are registered as effective by the TGA out here are available somewhere in the space of 2 to 3 years. And he simplified it down by saying that the difference is what you're prepared to pay. I'm interested in what you might think about that.



**Ann:** One of the things is we don't always know what other places are paying for things, right? My understanding is maybe when they come to Australia it's already been rolled out in the big markets. We're a tiny market. Maybe they're less expensive down here and that seems good because if they don't cost as much, maybe we can buy more. I think every system needs a process of determining whether something's good value. I don't think it all has to be the same process for everything. I think the nuances of the circumstances and how we determine the value could differ. But I do think if you want a well society, you make a decision to invest in that.



**Richard:** Yeah, there are there are circumstances if we get the value right. I think the other element when we talk about value is if we go back to our nuclear submarines, which is perfect,

is that we've ordered them. And the only way we'll know whether we got value is 20 years' time based on in the context of health speak real world evidence. So if they're floating around somewhere and they prevent us being invaded in 2044, we'll all say that was money well spent. But we can't assess it right now. No, no, but that doesn't stop us going forward. But in a lot of circumstances, sometimes we put a barrier up because we can't see the value today. Do you think how we might deal with that, not 40 years out, but better real world evidence in the future.



**Ann:** And some of these really innovative ones, you know, they could be life changing. We don't know what happens in the longer term. And I think, you know, there's naturally a safety issue that everyone's thinking about with some of these things. And that's right.

That's appropriate. But there seems to be something that's potentially really valuable here and we're not going to have enough information by the time it gets to HTA, but actually there's people who are dying or whose condition is degenerating, waiting and we should bring that forward and capture evidence about it because we want to learn about it. We want to know it may be that we do that for a couple of years and we go, you know, that's there's now something better or whatever, but this is what other countries are doing. They're saying there's a lot of uncertainty. That's the words they use a lot of uncertainty around this. We are not going to have enough information to be certain even when it gets to health technology assessment. But the communities need is so great and the potential benefit of this is exciting. I'm sure that's not the word they'd use. That's a word I would use. Let's bring it through now and let's capture good data about it and let's have patients involved in deciding what we're going to capture about it. And let's put that in with international databases as well. Because often these ones are in rare. Let's capture this in a sensible way so that we really get a handle on this and let's feed that back into the system again for future innovation, rather than sit here through phase two, phase three, roll out at FDA, go over there to UK, come through Europe, sitting patients, watching, watching, waiting, go through our process. Oh, there's not enough evidence. Maybe it needs a different process. You know, let's do it at that...



**Richard:** ...stage, because the reality in our world is that patients aren't sitting, watching, waiting. They're dying.



**Ann:** Yeah, exactly. Exactly.



**Richard:** I'd like to talk about a couple of other things that you do because you do a lot and I think you're chair of the Patient and Citizen's Involvement in Health Technology Assessment Committee of Health Technology Assessment International.



**Ann:** Well done. It's the world's longest title.



**Richard:** It's pretty impressive, I've got to say. And so to international, it's a society.



**Ann:** It's a society. And I think it was formed it was originally called something else. And then it was reformed in the early 2000s. And it was for anyone working in the field of H-2A, which was taking off rapidly around the world in the nineties, late nineties. And I guess originally people there were HTA body researchers and staff industry and it's grown. I mean now we have we have a strong patient representation. It in our last meeting annual meeting I think out of the 800 attendees, 75 were patients who were given grants to come in. But yeah, the interesting thing about it is it's multidisciplinary and I think as you alluded to before, how has this this core methodology around it and this core definition around it, but it looks a bit different everywhere that it happens. And so it's a great space for learning. And I mean my interest in it has been one to push to say HTA has to have patients perspective. H-2a is meaningless without patients perspective, but my other area of interest in it is just to learn what people are doing and to learn not just about the patient involvement area, but to learn how they're doing health technology assessment, and just to try and think about what that means for the patient.



**Richard:** And the other initiative that occupies you is that you're on the advisory committee and you're a coordinator for the Patient Voice Initiative in Australia. And I just wondered if you could just take a few minutes to explain what it's doing, what it hopes to do, I should say for transparency, I'm on its management committee.



**Ann:** Absolutely, absolutely. So the patient voice initiative is led by patient advocate Jessica Bean, who most people will know. And she's a very hands on chair. She gets involved in the detail, which is fabulous. And look, it came out of this series of workshops, which, Richard, you know more about because you were involved. I came in at the end of that series of workshops and met them travelling around this multi stakeholder group travelling around Australia in 2016. Really asking people, patient communities is what they expected in terms of involvement from HTA and from that, you know, a report was written up bringing together all those recommendations and shortly after that we became an incorporated association. And initially, you know, I think Jessica and I were just very happy to volunteer for it and I was really happy because I felt like I was sort of running around doing stuff to progress this in in international spaces. And I wanted to see more of it within my own environment. And so we're still quite lean, we're still a multidisciplinary team. We have wonderful people involved with us and, and really our work sits in two areas. Now we, we take quite a practical approach to advocacy where a lot of our work is around capacity building. So with the system as it is now, what could you do as a patient or someone who loves a patient to be heard and have your experience heard within the process? And then beyond that, we want to drive the discussion on what happens in this space, what could HTA be for me that's what is for patients and I appreciate the definition says what is HTA is something for the health system, but for me HTA is for patients.

So how can we drive that dialogue and show people what's possible and encourage others in the patient communities to not only have a voice in the current HTA system, but to have a voice about what it can be in the future. So that's really the work we're doing.



**Richard:** Yeah. So one final question. The Federal Government has initiated a review of HTA processes and the system in Australia. And you have been appointed?



**Ann:** I think so.



**Richard:** As you've been appointed, to the best of our knowledge, you've been appointed as one of the consumer patient representatives on that. Are you optimistic? Are you ambitious? How do you, do you think that there's an opportunity there to amplify all elements of patient involvement?



**Ann:** Yeah, I wouldn't have said yes to it if I wasn't optimistic and ambitious. I don't know whether I should be, but I don't see, you know, I think go big or go home. You know, we've all been doing this for a very long time. Others, longer than me, have been working hard at this. I just think regardless of what everyone thinks it says, I think everyone thinks their strategic agreement says something slightly different. To my mind. It says, here's an opportunity to get to for patients. And we may not, you know, quite reasonably, we won't get everything. And we won't get this perfect system out of this review. But I was really interested this year at the annual meeting how people were talking about HTA is learning and I thought exactly. It's about learning about the health technologies, it's about learning about patients, communities needs and HTA has to constantly learn. And if we could set up a system that meant that our HTA system in Australia was learning with patients and would continually improve, I think that would be I don't think that's unrealistic. I think it just needs goodwill on everyone's part to make it work.

So I am optimistic about it. And look, talk to me in 12 months I might feel differently, but I hope I can back that up with action. I'm not going there to give them the doctrine of an...I hope that we have a process that brings in patient communities into this process and that they can be heard in. I think we don't want processes where we draft documents and send them out to people.

When asked for comment, I don't see that as working. To review HTA I think there will be a diversity of opinions across our patient communities and I think we need to have them and hear them. I don't think we have to pitch ideas against each other. I think it can be a both/and sort of growth thing. So I am optimistic and I guess I'm optimistic because to me it's just obvious that it should be better. I've got lots of respect for the people who do HTA. I think it's tough. It's not that I don't respect their expertise. I just think we could do something more wonderful with it.



**Richard:** So you've obviously dealt with lots and lots of patients, patient groups. I guess one of the questions that flows through my mind is what would they have taught you? How has it changed from when you started? What have you learnt from them, from their experiences and their anguish and, and the day-to-day experience.



**Ann:** Um, the first thing you learn is that they're all different. So you're going to have to just keep learning. You won't be able to put a tick on that one. You were just going to keep learning and, and, and different answers at different times. And I think that's really important because what that reminds you of is that you're dealing with humans, not machines, and you're going to have to be responsive to that. The other big thing I think, that stood out straight away for me was they taught me about how many assumptions are made. And that's why you always still have to ask questions I guess, the other big area, they've taught me that you can work in health for a long time and not know it from a patient perspective because it looks really, really different when you're a patient. And we've all seen the stories about the doctor who became a patient and that. But, I think always remembering that. And so I guess the thing patients have taught me the most is to question and to not make assumptions about their lives and what they want.



**Richard:** Great things. One of the things I remember most strikingly about you and your your talks when I've been present is I think it happened in a meeting in Rome. And you said that you thought the patient experience was the lens through which the HTA process should see the spreadsheets. And it made enormous sense to me at the time. But when I think back on it now, I wonder if it's too passive a way to see patient engagement and or whether, in other words, it's not just a lens, it's actually part of the process. That's where I was.



**Ann:** Yeah, I think it's interesting and sometimes interesting to hear what you've said somewhere.



**Richard:** It was such a beautiful line.



**Ann:** I think we tend to look at aged care. We tend to look through the lens of the technology, particularly in a system like Australia where the trigger point is the technology so high begins when we get a technology coming system. So in other systems, HTA might start because of patient need, there might be a need that's identified and that triggers a particular type of health technology assessment. I still think if you started from the position of the patient, you would frame everything slightly differently. But we tend to frame it either from the technology or from the health system. But yeah, I agree. It does sound a bit passive to me now, and I think my views about the agency of patients have probably developed since then. I think I've probably even since that meeting, that was quite a trigger for thinking about who sets the rules. I remember writing something like that down on the plane, going home. So it's possible that I am now thinking about a much more empowered patient than I was even in 2017.



**Richard:** Yeah, it's really interesting because I would be in the same boat because I walked away thinking that that was...and I used it for years. I stole it and I used it. That was the best description of why the patient experience and the patient voice, if you like, was so important in the process. And then as time has gone by, I've started to think about it and I don't want to use the word more militant patient involvement, but to a certain extent that's it's more active.



**Ann:** And there's something on the back of that that I think and I've fluctuated a bit on this

over time, but at the moment where I am is I don't see the patient in charge of this and that might be different to other people. I see them as an equal empowered player and they're in charge of what is a good outcome for patients. They're in charge of that. They're in charge of their space. But over the years, I've fluctuated a bit on this because I've watched how people have marginalised the knowledge of patients and marginalised the experience of patients. And sometimes I've pushed back quite hard and said, you know, they should be in charge of this thing. And now I'm kind of like maybe the world is looking a bit different, maybe co-design is looking a bit different, but I wouldn't want to lose the expertise of people who have to run the hospitals and make it work. And I wouldn't want to lose the clinicians, but I do think if we are not first stopping to think about what matters to the patient, then we are heading off in the wrong direction.



**Richard:** Yeah. And I think it's absolutely true. Well, thank you very much for joining us on the Thought Leader Series. And I think on behalf of every patient, every patient group, I should also say thank you for everything that you do. I've got to take a wild guess and say, I don't think you're doing this for the money. And we would be we would be much, much poorer without you. Thank you.



**Ann:** Well, and thank you to all the patients who and patient communities who get involved. Because hasn't that been transformative? And thank you for what you do.



**Richard:** Thanks.