

Dr Tessa Copp; Is women's health tech empowerment or exploitation?

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SPEAKERS

Tessa Copp, Joyce Harper

Joyce Harper 00:01

Welcome to my podcast. Why didn't anyone tell me this? With my guests, we are exploring health issues and questions you may have about your health. And today it's a real privilege to be discussing with Dr. Tessa Copp is women's health check, empowerment or exploitation. Now Tessa is a postdoctoral research fellow in the University of Sydney School of Public Health. Her research focuses on the psychosocial impacts of disease labels over diagnosis and evidence based reproductive health care for women. Her PhD research examined the benefits and harms of a polycystic ovary syndrome diagnosis, and has been published in high impact journals in the field. Welcome, Tessa.

Tessa Copp 00:52

Thanks so much, Joyce. Thanks for having me. It's it's great to be here. I'm discussing this with you.

Joyce Harper 00:58

Now, this is a hot topic, and we're going to get into some controversial discussions. But before we do that, I would love to hear from you too. So about what made you decide to be a scientist and work in this particular field?

Tessa Copp 01:15

Thanks, Joyce. I guess I was I was very lucky to hit the jackpot with my supervisors during my psychology honours year. So yes, Anson and QC McCaffrey, they were actually based in the School of Public Health and introduced me to the fascinating and controversial field of overdiagnosis, low value care. And I made the connection with polycystic ovary syndrome or PCOS as all of a sudden, lots of lots of people I knew around my age were being diagnosed. So I started digging into the literature on how the diagnostic criteria had been expanded. And with the help of many experts in diagnosis PCRs I turned it into a PhD, which was, which was an amazing experience. And since then, I've been kind of examining inappropriate medicalization of women's reproductive health. Yes.

Joyce Harper 02:16

Yes, and you've got lots to research on, because it's something that I've been delving into as well. Now, before, before we get into some of the nitty gritty, let's have some definitions. How would you define Women's Health Tech? What does it mean, sometimes called FEM tech?

Tessa Copp 02:32

What does it mean? Yeah, so I guess I see it as digital health products for health technology that's focusing on women's health, whether that be to monitor and track signs or symptoms, measure signs or you know, some even claim to provide solutions. In certain areas of women's health, whether the fertility pregnancy, menstrual cycle sexual wellness, you know, it's really has expanded under this banner of FEM tech to many different interviews and comes in the form of sensors, online questionnaires, or monitors.

Joyce Harper 03:19

And it is a it is a very large growing area. And I assume that health tech companies have two aims. And I, I hope that their number one aim is to improve health. But obviously, they are a company they are in the corporate world. So the aim is to also make money. And what do you think about that? Is that a problem trying to juggle those two?

Tessa Copp 03:47

Yeah, I think, absolutely. I think, you know, most, I think do have the best of intentions, you know, they are aiming to improve women's health and some definitely a targeting, you know, really important and needs or, you know, areas that desperately need more attention and care for women, but with these competing interests, different conflicts of interests that come into play, can set certain agendas and cloud judgments. So you know, perhaps pressure from shareholders to make a profit, that pressure can be greater overshadow the need to pay close attention to the evidence. And even though I feel like most probably arise originally from good intentions, it seems like some almost seem to purposefully conceal the evidence to spin their product in the name of profits. So for example, with familiar with hormone or NMH test, you know, there's very clear evidence has been for several years and it's not predictive of fertility. Yet, you know, there's many companies out there selling the test explicit At least claiming it can predict a woman's chances of conceiving. So

Joyce Harper 05:05

yeah, we're gonna we're gonna delve into AMH testing in a lot more detail. But before we do that, if, if a health tech company came to you, and said, We want to develop a test for something and say, if you agreed with it, what advice would you give to them and expect them from their development of their new tech, I'm at an event next week, about women's health tech, and I'm on a panel with a company I do some work with, or Gedeon Richter, and we're talking about how pharma and startups in women's health tech could work together. And my advice would be that academia needs to be in there as well, because we're not out to make money. And we are there for evidence based medicine. But what advice would you give to a new health tech company?

Tessa Copp 05:58

Yeah, well, that's exactly Joyce, I think, ideally, they'd want to involve, you know, multiple stakeholders with as little bias of vested interests as possible to try and reduce the conflicts of interest that jeopardize

the interpretation of the evidence or, you know, hijack the agenda away from helping women in favor or making money. So there's that but also don't further don't think it's too big of an ask to have solid defensible evidence of behind the claims. extended team and dopes, they're just not good enough. Yeah, yeah,

Joyce Harper 06:41

we're gonna we're going to delve into that a bit more. What I mean, what, let's talk about what is evidence based medicine. So I wrote quite a lot about this in my book, Your fertile years, because when I wrote that book, I genuinely I seem to be spending a lot of time debunking myths that people take on board. And, you know, you and I have done a lot of studying to understand evidence based medicine and understand what a clinical trial is and what a randomized control trial is. But I totally understand that journalists and the public do not understand what that means. And so their interpretation of some of the published work that we get, unfortunately, in, in the literature, in the scientific literature, might not be good science might be bad science. So what would what do you consider evidence based medicine? If you were a company and you said a product was going to come onto the market? What would you like to see that company? You talked about anecdotal evidence, and we'll talk about marketing towards the end. But I see so many companies that on their website, it's just full of testimonials, testimonials from women saying yes, I love this. It was wonderful. That's, we know, that's not evidence based medicine. Tell us about evidence based medicine.

Tessa Copp 08:07

Yeah, I mean, I mean, it's exactly that. And I think there's so many people who aren't familiar with the weighting that should be applied to certain study designs and types. And often people think expert opinion, is the gold standard, when really actually it's at the bottom. And so I think, ideally, we want to see, you know, randomized clinical trials examining this before products are implemented into practice. But if that's not possible, then there needs to be transparency, first and foremost, about the lack of the lack of evidence here or the potential limitations. But you know, really, yeah, I think, to me, it doesn't seem to be given us to, to wait for the evidence before rolling out because there's a strong risk that, you know, there could be substantial harm, you know, you might assume that there's going to be benefits there might be no benefits, you know, real harm that can result. And so I think that was one of kind of the arguments that we grappled with. When writing our piece that we will probably discuss further down, womens health is so underfunded, and under research, and there's so many knowledge gaps, and there's such a big need need for, you know, intervention needs and knowledge. You know, why don't we just implement these things so that women can keep up the same places. But there's a huge risk that you could actually be further disadvantaging women often in an assumption that benefit doesn't necessarily play out in the evidence on the Bitcoin bounce your question Yeah, No, that's

Joyce Harper 10:00

great. So just for our listeners, I have written about this in my book. But if you don't know what a randomized control trial is, this is where you would normally have two groups that are randomized. And you'd have one group. So for example, if there was a treatment that you do, you would have one group that would be randomized into the group that would have the treatment. And the other people would be randomized into the group that don't have the treatment, and you would decide what you were trying to look for. So for example, in fertility treatment, we're going to talk later about IVF add ons, which I spend

a lot of my time talking about, these are a whole suite of treatments that clinics will say, will improve your chance of getting having a baby, we're not getting better at having a baby. So the endpoint of the study would be having a baby. So if there's what's called a live birth rate, and the two groups would be one having the adults and one group not having the add on at the end of the study, and we need hundreds of people ideally, in this study, you would have a look and see if the delivery rate was different between the two groups. And that that's a standard delivery of a randomized control trial. Sorry. I wanted to take that up about companies running with tech and then being biased about it before they really have developed it. And I was at a health check event this week. And someone said, well, with companies, what they often do is fake it till you make it. And apparently that's quite a well known term in Silicon Valley, which I found a bit worrying fake it till you make it. And so basically, if you got an idea, and it's not quite working yet, just, you know, you want to be out there, you want to be the first so get out there and do it. And it does remind me of Elizabeth Holmes, and I've been really criticized for talking about Elizabeth Holmes. But she was the founder of Theranos. And they had a great idea, she had a great idea. And she was very, she's very bright, very dynamic. And her idea was to have a blood testing machine that you just do on a finger prick test. And she wanted people to have easy access to a whole range of tests that could improve their health and make an early diagnosis of various disorders. So as we said earlier, she's got a great idea, she really did want to save the world. But you need to make sure that this actually is deliverable. And it didn't work. It wasn't possible to do was it possible to do some of these tests even on a large amount of blood and run by the fingerprint. But she was very convincing. And I think she usually mentioned the term hijacked I think she got hijacked along the way. And, and he just seemed to have got all out of control. It's a great drama are on at the moment on TV about what happened for Elizabeth Holmes, it was really captivating. And there was a big culture of secrecy and suing. And obviously, she got millions and billions actually in funding for something that didn't work. But now she's in prison for fraud. And she's not the only company. She's anyone I know is in prison. I know a couple of people in prison. Not personally. But I am aware of other companies, there was a company in the fertility field called molecular biometrics years ago that said that they could help predict the best embryo transfer in fertility treatment. And, again, they were running before they could walk. And I had many discussions with this company set up by someone I know very well, it didn't work, the tech, I kept saying to them, your tech doesn't work. And then finally, the company went under. So what's your view on fake it till you make it?

Tessa Copp 14:04

Yeah, I think, you know, this is such a big issue and just so, so dangerous in the health space, in particular, I mean, I still find it unbelievable that medical interventions and tests can be, you know, rolled out and put into practice before they're backed by evidence. And, you know, I do really worry about companies concealing the results that will hurt the profit margins behind the scenes and you wonder how often it's happening. But I also think now, it's not just industry that, you know, probably do this. I think scientists aren't immune to this. And there's other conflicts of interests aside from financial at play by professional or personal. Reporting. A negative result is never fun, especially when you've spent years working on something unless you have been So much funding energy put into something, you know, I know the findings, still really important, should still be applauded, you know, no matter how disappointing, you know, it reminds me of the, you know, cervical cancer screening trial. That's, that's just finished. And, you know, after 20-30 years, or however long it was, you know, didn't actually prevent more deaths. It was so disappointing. That, you know, they were so honest about it was, you

know, I think we should really applaud those efforts, still, just because, you know, it was still so important to know that this is making happen in this instance. So vital knowledge. So,

Joyce Harper 15:49

yeah, I do think along the way, scientists, including some academics, I've heard of that they've just got out of their depth. And I think that I will I wonder whether they, you know, they wish they could turn turn the clock back. Do you think we can regulate this in any way? Is there any regulation that we could do? I mean, they should be. But it doesn't seem to be that this new tech has been regulated at all.

16:21

No, yeah, I think even you know, in countries where there is regulation, it seems to barely scratch the surface. So, for instance, in Australia, we've got the TGA. Think they're concerned about using the example of AMH testing, they're concerned by the language test measures what it claims to measure which is anti Mullerian hormone does Okay, tick. That's all they're concerned about. It's not necessarily the greater context in which it's been recommended on the recommendations of actions based off the test results. Yes, I think there's also the issue, that it's very reactive, it's dependent on clinicians or the public making a complaint about the company, and then it's investigated. So I think there's a lot of a lot of things that probably slipped through the gaps. So definitely, just missed that misses the mark. To time, we definitely need better regulation in next week.

Joyce Harper 17:25

I and the regulation does sometimes say it so it will, it will license a test. So people see Oh, it's a license test. So like the AMH testing, it can get licensed. So yes, the regulator's check that the company can do the test, and it's doing what it says. But that, that doesn't mean the test is going to achieve anything. So I think that's a big problem for the public. They see a license test. It's got, you know, the right markings on it, you know, the FDA approval, etc. But it just means that the company aren't doing that test, if that test has any use for the public to take is a totally another question, isn't it?

Tessa Copp 18:09

Yeah, well, yeah, that's exactly right. And it might be useful in some circumstances doesn't mean it's going to be useful and others, so it's kind of extrapolated out to lots of different situations or retires to way more people than would actually benefit. Us.

Joyce Harper 18:31

Do you think? If we have bad women's health tech, it can actually be dangerous to a woman's health or is it just dangerous to her finances? So she might be paying for a test? That's not valid, but do we need to worry Could any of the data or the results that she gets actually be bad for her?

Tessa Copp 18:52

Yeah, absolutely. It can be so dangerous, especially in the form of over testing, misdiagnosis, overdiagnosis and overtreatment, as a medical interventions aren't without harm, and without warranted in the first place. The outcomes can be significant. And I think people often don't see the link between what can seem like a harmless test, you know, it's only \$100. It's just the test, you know, to the potential downstream consequences. So, for example, getting an AMH test under the false premise that

can it can predict your chance of conceiving. Now, this can lead to false reassurance about delaying pregnancy if you get a good result, then really age is the most important factor or unwarranted anxiety which can place a lot of pressure to conceive earlier than wanted or, you know, pressure women to undergo costly and unneeded fertility procedures, you know, which can have substantial side effects, as well as the significant financial costs

Joyce Harper 20:01

Yeah, you've really summarized it there about the AMH testing, I think there are going to be I mean, when I've everything I've got, so everything I've listened to about the test is, so I'm just going to cover it very early in the morning, I'm not quite awake yet. So the AMH testing, as you said, it's, it's supposed to be it's it says on the tin, that it will predict your fertility. But it doesn't as we as you said, it doesn't do that. So that I'm really worried about those women who if the result says your fertility is okay, and you might be 31 or 32, and it's selling your fertility, okay, you might delay, as you said, delay your fertility. And then I think they're going to be women, who then totally missed the boat on having children, because they've got this result from this AMH. And they think they're okay. And then, as you said, there's women having costly egg freezing procedures. So I think that's very, very dangerous to women. And I also think we end up with what we call a worried well, and you've talked about the anxiety, which I just think that is unacceptable, it is dangerous. And yet we people have to be very, very careful. And a major concern I have is that these health tech companies are trying to replace a visit to the doctor that I see more and more now offering a suite of tests. And I'm really worried about the advice that they give, they're often not the doctor. And, again, talking about this word well, and for years, and I do as well, if we're feeling unwell, we go and google something, and we listened to Dr. Google. But then what we'd normally do is go to see our doctor and say, Okay, I've Googled it, I think I've got this or that, and then the right tests and treatment are going to be done. But now we've got this other layer of health tech, where people are then deciding they're not going to the doctor, and then they're deciding what tests they're going to have with the company. And I just think that this is getting more and more confused, and more and more dangerous. So what's your thoughts about that?

Tessa Copp 22:18

Yeah, I couldn't agree more. And I think it's, it's such an issue. And, you know, tying back to the AMH test again, because it's where most of my research is focused on but, you know, online companies, some of them offer a doctor consult after giving the test results, you know, saying no, we're providing adequate counseling, and you know, they're seeing qualified doctor. But I think that's too late after you've gotten the test results, because, you know, counseling about the test limitations, and reasons for getting it should come before the test is ordered. You know, once you get that result, and experience the emotional reaction to you can't undo that you can't unknow and know the result. You know, people really underestimate the impact they can have on people, you know, diagnostic labels can really change the way people think about themselves. And in self esteem, it changes their behavior. You know, there's numerous studies looking at the impact of a diagnosis of hypertension on number of sick days, you know, it can really change the way people live their lives. And so they, they really shouldn't be buried. And lastly,

Joyce Harper 23:33

many years ago, I did the 23andme test. And I can't remember how many years ago it is now. But I chronicled it on BBC Radio. So when I was living everyone, I was doing the tests. And then they came round one Sunday evening and recorded me opening the tests. So you open this test on your own on your, you know, you just open an email, and there's your data. And there was no doctor that as you said, it could have it could have been very stressful. And there were some things on there I didn't agree with it said I was lactose intolerant. I don't think I am there, but there were also tests on there. They were assessed on there for outsiders breast cancer. And I spent I literally spent about three days before I got the results really delving deeply into what they said they were offering. And a lot of the mutations, specific tests they were doing the mutations they were looking at, were for Ashkenazi Jewish population, not for someone of my genetic background. So the tests weren't there. They were problematic. But I had blocked the outside because I felt so I was in my family and I don't want to know if I'm going to get it because no treatment but to unlock it to unlock it as far as I have Were was just two clicks, you clicked on it, and you said, Are you sure you want to unlock it? And then you clicked again and it unlocked it. So imagine on a Sunday evening with the BBC Radio, your interviewer in my house, opening that, and then finding out I had a risk of breast cancer outside was that is just unacceptable. But that, you know, we've got to understand that there are people at the end of this, for sure. Absolutely. Awesome. So let's, let's go into your terrific paper. I was so so pleased when you sent when I saw this paper, and lots of people sent it to me and said, You're going to love this paper. Now. It's titled, marketing, empowerment, how corporations Co Op feminist narratives to promote non evidence based health interventions. And I'll put a link to this it is behind a paywall, unfortunately, but you can read the beginning of it. But we're going to talk about it now. So I want to ask you many questions about the paper. But tell us overall, what were your key messages of why you wanted to write this? And what did you find in the paper? Yeah,

Tessa Copp 26:14

so this paper paper really focuses on how language around increased knowledge and women's empowerment and enhancing autonomy. This language is being used by commercial entities to market new technologies, tests and treatments that are not backed by robust evidence. And so it was just something that me and my colleagues, they kind of noticed this rhetorical often being used to kind of sell products and kind of using the guys or, you know, portraying themselves as socially progressive notes, by women, for women, and you know, knowledge is power and empower yourself with, with information to make informed decisions about your reproductive health. It's so persuasive. And, you know, it really makes you feel like you've got to act, you've got to do something. Except, you know, the products they're selling, don't have evidence of benefit, or they've got, you know, good evidence that they don't work. And, you know, this marketing, I think it's so persuasive and really risks harming women, you know, through inappropriate medicalization and system of treatment. And, you know, often these health technologies, tests and treatments, we're not arguing against the use of them per se, because they are beneficial to some women in certain situations. But it's about the way that the commercial marketing and efforts push these interventions to a much larger group of women who will then who are likely to benefit without being explicit about the limitations. So yeah, so we kind of looked at, you know, it's not just companies and industry, but also mass media, and even well intentioned advocacy groups, using this kind of simplistic phrasing, to push these products that, you know, just don't have any evidence of benefit, so goes against the empowerment being sought.

Joyce Harper 28:18

And, as you said, it the AMH test is useful for some women. But for those, it's, it's useful for needed for, they can go to their doctors, at least I think in Australia, as well. And certainly in the UK, they can go to their doctor and get that test for free, rather than and get proper advice rather than pay a company to do a test and then go through this very odd system of medical advice. So, you know, that's, that seems absolutely crazy to do this online when you can go to your doctor.

Tessa Copp 28:55

Yeah, so I think the AMH test does have a small cost. Sometimes it depends what state you're in, but it's a lot cheaper to get it from your doctor then through an online company. And yet certainly useful in in particular situations, mainly in assisted reproduction. So if you're, you know, you've decided to undergo fertility treatment, it can. So basically, there you might test its associate with a number of eggs in the ovaries so roughly indicates the number of eggs that might be retrieved in a stimulated cycle when undergoing IVF or egg freezing, so it's certainly not perfect. You can still get a number that you don't expect, might help in some expectations, many cycles you might need and the cost and the cost of that to get a good enough number of eggs to freeze or, you know, to understand your chances. So, in terms of IVF.

Joyce Harper 30:00

If you if you were a 25 year old woman who were not thinking of getting pregnant for for many years, is there any use of you having an AMH test?

30:14

No, stay away from the AMH test. I think it's yeah, it's not useful at all in a situation because it's not predictive of current or future fertility. Unfortunately, there is no magic or reliable test of fertility except for trying to get pregnant. Don't let it save yourself the money and angst. Yeah, yeah.

Joyce Harper 30:43

And, yeah, it's, it's, as I said earlier, it's I'm more worried about the 30 year old who gets it and is that they're told one of two things they told are, your fertility is fine. So they might delay trying to get pregnant, or your fertility is not fine. We think you should freeze your eggs. And as we both said earlier, we think that both of those are dangerous. So it would worry me more about that. And also, when I when I was, wrote this section, in my book, I was really careful. I sent it to lots of clinicians to make sure I got the wording right. And that I wasn't just being unconsciously biased against this test. I just wanted to be sure, and I was careful with the wording. But also, fertility is not just about one person, it's about your partner as well. So just looking at your fertility in sight, even if there was a test that could do that. It's your partner's fertility as well. And the two of you together, you know, you could be super fertile with one person and not with another for various reasons. We won't we won't go into what why do you think companies and fertility clinics, we must say it's not just online companies, also, fertility clinics market this as a valid test? And I've heard so many women say, Oh, I've got to get the fertility test. They also say we've got to get the menopause test, and there's no menopause test. But they they have become obsessed with wanting these tests. And I think you said before we started, did you say there was 27 companies that you found that were offering an AMH test? Why? Why would they want to do this?

Tessa Copp 32:21

Yeah. So I think for the fertility clinics, I think, you know, years ago, when the tests first came out, it looks like a really promising model. Fertility was relatively stable across the menstrual cycle. I think it was very quickly adopted into practice and fertility clinics, and it was kind of now become a routine test in the workout. VF. As soon as evidence has emerged that really questions its usefulness aside from helping to set expectation as retrieval is. So does, it's like once something is implemented, it's it's so hard to do. And you know, I wonder we did a kind of analysis of the information on fertility clinic websites, you in Australia. And, you know, we found that there was a lot of kind of misleading information. It made me question how often these clinics are updating the information on their websites, because science is constantly evolving, information goes out of date so quickly. And so that the doctors might have been some inaccurate website certainly weren't. But you know, the online companies, however, so you mentioned the 27. Companies we found, so this is company selling the test direct to consumer, so they had an Add to Cart option where you could automatically buy the temps. You know, they're much more recent, and it's hard for me to see how they've missed the strong recommendations in the guidelines not to use this test outside of fertility treatment settings. So for me, that kind of seems more of a blatant disregard of the evidence. And so

Joyce Harper 34:13

yeah, which we are going to move slightly away from AMH testing. We don't want to just talk about image so stick it the last thing to say, ah, testing, as you said, looks at the quantity of your eggs, but what's really important about your egg as well as the quality of your egg, and it tells you nothing about the quality of your, but in your paper, you mentioned the book feminists forever and it did make me smile and chuckle. It's a book we've talked about a lot. In the UK, there's maybe we're risking getting sued on this one. I don't know. But there's someone that promotes this book and says it's a great book for women's health. And there's many of us who criticize the book. and use it as an example of not being empowerment for women. I know the problem with this book, can you tell us? What's the problem with the author of this book?

Tessa Copp 35:09

Oh yeah, so I think now I'm in no way an expert in menopause. But we wanted to show how the hijacking of feminism has been happening for many years, you know, long before FemTech was a theme. And so this book was written by a gynecologist who argued that menopause is an issue and deficiency disease that needed to be treated. On my replacement therapy was a cure for women to maintain their femininity, attractiveness. And they really push this narrative that the HRT was key to women's liberation, through enabling greater control over their bodies and things. What wasn't widely known at the time was that he was funded by the HRT. Industry. And so that you probably know a lot more about that. If

Joyce Harper 36:09

I'm honest, I haven't read the whole thing. I don't think I I try not to do things now that upset me. But there are still people today. So I think we should bring this in, you know, there are really still reputable scientists. And I've mentioned I do do some work with some companies, I always declare it. I whenever I give a talk, I have a slide with all the companies listed that have ever paid me for consultations, I think it's important as a an academic to try and help companies who are trying to develop new technology.

And I get messages every week from someone with new tech, saying, Could you be involved, I think it's really good. But we need to declare it. If we're if we are taking a commission, or getting a conference trip or whatever from a company, then we need to make that clear so that people are aware of that I don't think that happens. And let's move on to period tracking apps also something that I've we've mirrored our research a lot. I've also looked at fertility clinic websites as well and how they miss market things. But let's look at you've mentioned in your paper period tracker apps. And my main issue with these, I think I think they're great. If I had periods, I would use one. But our research shows so many of them that just look at dates, they don't measure anything, any what we call markers of ovulation, such as luteinizing hormone, which is right rises just before you ovulate. So many of them tell women tell women the day of ovulation, so they're just looking at period dates, you just put in the date of your period. And then what they what will happen, it will tell you normally in 14 days or 13 days, for some of them, it will say you are ovulating. And I think this is really inaccurate and dangerous use of health check. Because I think I've been told that there have been pregnancies, where women who were trying not to get pregnant, the app told them they'd ovulate it so they thought that they were now not at risk of getting pregnant unprotected sex. And I also know people who are trying to get pregnant and are using these apps. And our research into this with with one of the companies I fully disclose I work with natural cycles who do measure a mark of ovulation, they measure your change in your body temperature. And we found and other studies since looking at big data have found that ovulation is not on day 14, it can really vary between different women. And on average, it's nearest day 16. So tell us more about your thoughts about these period tracker apps.

Tessa Copp 38:58

Yeah, no, that's I mean, that's so that's really great to hear. And I think probably one positive that's coming out of them is that we're now finally getting population level data on what a regular menstrual cycle even is. Because we don't have that data. And you know, I think, you know, you said absolutely, you know what you've said absolutely, yes, you know, they can be incredibly depending on how February their predictions or believe can have such serious, serious consequences. And they do include the caveats and limitations in small print. But that's not what you see when you see the big circle ovulation. Three or you're going to ovulate in three days. There's none of that caveats in in the end, I think, you know, they I must admit, I have a period Tracker app and I love it. But, you know, I think Awesome, some good benefits that are coming through them. So I think, you know, they do a really good job of normalizing things like discharge, you know, being a teenager girl, and being really stressed and anxious about, you know, whether this is normal positives, in addition to having better. So it's great that you're partnering, you know, to do do stuff and this. Now, alongside the issues, you've mentioned, some from them being mostly in that period, some of them have also introduced what they're calling, you know, pre diagnostic tools, where they, you know, if if your cycle isn't deemed regular, you know, despite the fact that we don't really know what regular even even is. So, you know, you might have PCOS, do this questionnaire. And then based off that result, they give you a diagnosis, which is really interesting, as a pre pre diagnosis, you know, there's caveats saying, you know, this isn't a diagnostic tool, but they're basically labeling women with PCOS. Based off, you know, nothing really, and, you know, there's such serious harms that can result from this, you know, my PhD, I looked into the benefits and harms of receiving a diagnosis of PCOS. And it really doesn't take much for women to develop their fertility, and it can have serious, you know, psychological, emotional and real consequences.

Joyce Harper 41:30

It's, it's really, I find it really, really frustrating. And I don't understand. So to me, there's a lot of bad science out there, I, I'll bring this up. Now, I also know that there is a culture of threatening to sue people I've been threatened to be sued, maybe will be threatened to be sick after this. And you know, some of these companies have a lot of money. And they threatened to sue, you know, a scientist who has no means of dealing with this, and they cause us lots of stress doing that. And I just don't understand why we've got this bad culture of bad science happening by people who are who are really reputable. And really, you know, many, many of them who I admired in the past. And then they sort of unusual Toby and hijacked along the way. And another example of this is the IVF add ons. So I've mentioned this many times before, but the infertility treatment, fertility treatment is big, big business. It's a multi billion dollar business, we charge in most countries, we charge patients crazy amounts to try and help them have a baby. And it's there's a lot of IVF millionaires. I always joke about the clinicians or driving around in their Maserati's, and some of them have Maserati's. And they're making money off of people and the, the vulnerable public, who are trying to get pregnant. And I've done a lot of work on IVF add ons, which is treatments that are claiming to help your chance of having a baby, as I said earlier, and with the human fertilization and embryology authority, we, I was part of the group that developed a traffic light system to help people understand the complexities of these treatments, because you would think in and I know, it's a big problem in Australia as well, you think with our regulated boards, that because it's regulated, these are fertility treatments very regulated in our countries, you would think that the regulators could say, you can't do treatments that are not evidence based. But unfortunately, that's not the case. And the HFEA has even given some of these treatments or red signal saying, you know, these are not evidence base, etc, etc. You think they could just say, well, the clinics can't do it anymore. But they don't they don't say that. And we wrote a paper last year with a big European group by work with ESHRE giving some recommendations about this. But I, I just that they these treatments are still there, they're still being offered. And what worries me is that we publish our papers and tell people I know you've got the paper coming out about giving women information about Hmh before they consider the test. And you know, the results were good that they you know that there was useful information there but people still ignore the guidance from you know, the main society for example, in the UK, the British menopause society make clear statements about use of HRT, etc, but it gets ignored because I think social Media and the propaganda and the great slick marketing of some of these companies just overshadows raising and also the promotion by celebrities here it's, you know, celebrities promote lots of these things. Another another controversial areas glucose monitoring, which I won't get to I'm sure I'll get sued. But you know, the celebrities are out there for the public get bombarded with this amazing marketing. And it's, it's just a mess out there. What do you what do you think? Is there a solution? How can we help the public get through?

Tessa Copp 45:44

Yeah, I mean, I mean, you're exactly right, everything you said very strongly. And it's such a mess, and I don't have a solution. But, you know, I think it's really it's not fair to place the responsibility on women to, to navigate these health messages and understand all the potential benefits and harms. In order to make an informed decision. The responsibility has to be placed on the company's marketing these health interventions. But as you say, you know, there's even with regulations and guidelines and, you know, awesome traffic system. You know, it's still happening, I feel like the government has a

responsibility to do more, I think can counter conventionally driven messages and more strongly regulate the marketing of unproven health interventions. current regulations are just not. Not working.

Joyce Harper 46:50

Yeah, in my last podcast was with Dame Lesley Regan, our women's health ambassador, and she made a program in 2009, called Professor Reagan investigates. And she was looking at how some companies were using science to sell. And I've seen some of some of these companies actually mount many of the companies they say, backed by science. And I think we're in a much worse position than we were in 2009, when Leslie did her program, and go back to that the IVF add ons that the HFEA. Government for today fertility treatment in the UK, but they have a limited power. And they actually have been sued before by a number of clinics, and the clinics always win. Because the clinics that have got lots of money, they have a much better lawyer. And they had to bring in the competition's marketing authority to try and help with the bad marketing, as you said earlier, such as fertility clinic websites, etc. But the authority mate, the marketing authority made a great report and they it was really robust that they said they were going to sue company. So su clinics if they made misinformation on their website, but nothing happened. It's still there. So what do we do? Well,

Tessa Copp 48:10

so depressing. Yeah,

Joyce Harper 48:15

it's a lot in the last question about your paper, you've said isn't more information or knowledge always power? So I want to finish on that note, is it it's not always power? Is it? What can we do again, about?

Tessa Copp 48:33

Yeah, and, you know, we're not arguing that women shouldn't be informed, you know, we want to support stronger women's autonomy about their bodies and health decisions. But I guess we're wanting kind of more awareness about the issues with this simplistic phrases and sayings and the way they kind of used to downplay or conceal the limitations or exaggerate and downplay the plans. So the marketing and campaigning for interventions and provision of information without setting the limitations or unclear evidence of benefits really risk causing more harm than good. You know, the positive spin emphasis on that discussing the harms, it's the opposite of and it's using them. So I think just being aware of simplistic messaging in such slick marketing, cuz there's always more to the story. So if there's any

Joyce Harper 49:37

health tech companies out there that want to sue Tesla right after to say please don't sue us. It's freedom of speech. We were giving our personal view on this. So I'm making that caveat. Now. It's our personal views, and we should be able to have freedom of speech hopefully. And Theresa my last question is I asked all of my guests Um, this podcast is called Why didn't anyone tell me this? Have there been questions that you've come across where people have said to you, especially women have said to you? I didn't know this? Why didn't anyone tell me this before? And if so, what is the main question they've said?

Tessa Copp 50:19

So a great question. I guess something that, you know, I, I found really fascinating when I first got into this field was I didn't realize that medicine wasn't black and white. And, and I didn't realize that disease definitions were based off pathological findings, they often, you know, just a group of experts who come together and decide what the definition should be in science and medicine is gray. And it's a continuum of, you know, severity, so arbitrary where the line is drawn between normal and normal. So, I guess, yeah, knowing that it's not black and white, and, you know, kind of looking at the rationale and reasoning, to see evidence before kind of patiently accepting a diagnosis or, or, you know, a recommendation. But, yeah, in terms of that image, I guess, um, you know, I think there needs to be a lot more awareness and education. And, you know, simple things about futurity. And in this in high school, often all we're taught taught is how not to get pregnant. And that's obviously so important, because you are so fertile when you're when you're a teenager, but knowing that, you know, it's actually not always all that simple. And, you know, more wins in an age and fertility with being alarmist, because obviously, it's, it's often you know, it's not often a choice. Children is one of societal factors play. Yeah, I think probably, probably those two things.

Joyce Harper 52:22

That's a great place for me to comment that the work we're doing, we set up an international reproductive health, education, collaboration, where I've got together some of the world's experts who have been teaching and doing research on education. And we have the great team in Australia, you, you've had a website, a government led, I believe, website, Karin Hammerberg, and others have been working on giving free advice about fertility to the public. And we, the the international group, we work with ESHRE, who I mentioned before, and we want to give people empowerment through education. So that's where we think empowerment comes, we want to make sure that everybody right from school is informed not as you said, not just how not to get pregnant, but how to get pregnant how to have a healthy pregnancy. We feel if we educate about the limitations of apps and tech, and testing and AMH testing and menopause testing, and all these other things, if we educate the public, then they can make an informed decision. But we are at battle with social media, which as I said, shouts very loudly. And when you've got a professor or society telling you one thing, but then you've got a celebrity who you really admire telling you something different and you get bombarded on social media. Unfortunately, that that's now it's a battle that we have to try and get things back to evidence based level so it will keep working on that. And the last few questions, what makes you happy and where is your happy place?

Tessa Copp 54:13

So these days is probably hanging out with my little eight month old boy Jasper. But I also love cycling with my girl gang and playing soccer. my happy place is going to be on the north coast of New South Wales a little place called Red Rock. If you ever come to Australia, I'd recommend it. It's a it's a beautiful place in the world.

Joyce Harper 54:36

Brilliant. I'm so glad that I've asked all my podcast guests this because now this is my next book. I'm doing a big study with 50 women over all over 50 I know you're a long way away from that. And we're it's all about good health and happiness. And I think it's so inspiring to hear different people's views on what makes them happy and their their happy place if they Thank you for sharing that. And congratulations on your little boy. They grow very quickly. Um,

55:07

yeah, I've seen that already.

Joyce Harper 55:11

Um, the very last question, what advice would you give your younger self?

Tessa Copp 55:15

So great question. I guess it would be probably not stressing, don't stress about not knowing what career you want or where you want to be in 10 years, you know, just take each opportunity as it comes and follow your interests and hunches as pop up and trust that they'll lead somewhere interesting as they almost always happens. So that's,

Joyce Harper 55:42

that's great. And so many people. I've asked that question to have said, you know, don't stress. And then we've talked today about tests that could make you more stressed. That's come around. Tessa, thank you so much. It's been very early for me very late for you with our time difference. Thank you for your brilliant work. And please keep it up. We've got an ongoing growing problem. So I think your work is really essential. And so many people and I told them I was interviewing you said, brilliant. And thank you very much for your time. Jessa

Tessa Copp 56:24

thanks so much, Joyce. It's been it's been awesome to chat to you. Thank you. Thank you.