

KATE BRIAN, PATIENT REPRESENTATIVE - WHAT DO PATIENTS WANT FROM A REGULATOR? - HFEA ANNUAL CONFERENCE 2008 - SESSION 1: MAKING BETTER REGULATION HAPPEN

Speaker	Transcript
S1	<p>And our final speaker in this session is Kate Brian. Kate is a former IVF patient and she is ideally placed to give first hand insights into the information needs and priorities of patients throughout the different stages of that challenging journey through ART treatment. Kate is a writer and journalist and I'm in the interest of giving you some time to speak, I'm not going to run to your stellar career, but just to allow you to take the podium.</p>
S2	<p>Hello, I wanted to start by thanking you for inviting me here today, I'm delighted that you are actually interested in patient's perspective on this once again, I am a former patient, I've also written books from a patient's perspective about infertility and treatment, and I'm a trustee of Infertility Network UK. I must admit I am completely daunted by the title of this speech, what the patient want from Regulator, because the reality as your all know, is the patient is actually only want one thing, that's all they are thinking about when they come to a fertility treatment. Regulator is not something that we start out thinking about, but actually, I think as patients, we probably expect quite a lot from the HFEA without ever realizing it, we take it for granted that clinics are being monitored, and that they are being inspected, and they started working for starting guidelines, but for the most part of the only real contact we have with the HFEA is when we want to know information and 56% of those currently going through treatment who are actually considering treatment have visited the HFEA website. They want information about treatment, about what's involved, they want to find clinics in their area, but mostly they want to know about success rates, and for many patient I would say that the publication of success rates is probably at the moment is one of the most important things from their perspective that the HFEA does, whatever you may think about the league tables, patients are using them to choose connections for them that is a really important function, but what the patient actually think that a regulator should be doing, well, fortunately for me the HFEA put the question to the panel of patients so that they set up fertility views which is used to consult patients and get feed back, and the two most important things were regulating the quality of service and information and guidance. So, again we see that information as absolutely is the absolutely crucial thing and also the fact that they want to, if they're going to a</p>

licensed clinic, they can feel safe that certain standards will be upheld. They're also concerned about the safety of treatment, patient's safety, and they want the HFEA to monitor the treatment options that are available to keep an eye on the latest developments, and to help the patients to assess their values. And I know that as a patient that could be a really difficult thing, when one consultant is telling you that some new development is the best thing since sliced bread, and another one is telling you that something they wouldn't touch with a barge of pole, how on earth do we meant to know? And for the HFEA to provide that information would be fantastic, but actually it isn't always and it is always quite clear as possibly as it could be. They also wanted to regulate, to formulate policy and to meet the patient's satisfaction which can be very hard, because I think it's obviously a very subjective thing, but I think again the patient panel helps that. So in the overall things, the patient seems to be concentrating on is safety and information. One really important thing, there is the feeling that if something does go wrong, they will be made aware of that, and they would like to know when the clinic's license is taken away, they like to know if the HFEA is taking regulatory action, or if changes are made to a license, or if a clinic is licensed for a new treatment. Now, patients on the panel are actually asking for that information to be published. You know, some of that is, you can't find that information out, and part of the problem for the patients is not always clear why these things are happening, and it is pretty pointless having this information if we don't understand why. Some of this information is actually in the clinic inspection report and that was one of the things that patients were asked about, what they are like to see in inspection report. Interestingly, the main request, 83% was something on the patient's experiences, which we thought actually is quite interesting. The other thing that they wanted is about clinical nursing laboratory procedures. They wanted to be made aware of any problems found during inspection, and they also wanted information on staff, premises, equipment, and other facilities. Now, it's quite interesting because I think that the patient experiences, patient can find in lots of other places. If you log-on to any of the fertility websites, there's an awful lot about different clinics and what patients think about them, but I think the reason why patients quite like some of that in an inspection report, that it is terribly subjective, and it is terribly hard to assess from a patient's perspective, whether this is someone who just had a particularly hard time at one clinic or whether actually it is a real problem. So, I think patient would like more of that in a more kind of balanced way. The thing I think there is a problem with inspection report, is when it comes to schools, when it comes to Ofsted, inspection reports, parents read them avidly before choosing a school, every parents would have been through them before making a decision about the school, and I have interviewed dozens of patients about why they

choose a clinic that they've been to and I can tell you that not any single one of them ever mentioned an inspection report. So, why is that? For the main reason, is because they are completely full of chuck, and I look at some the other day, I couldn't understand half of them, you know, how a patient meant to know, is it important if it's not fitted with alarms or if the background area in the laboratories are not grade D, and what is C-mark, I mean, I don't know any of this things. It's completely not user friendly at all, and I actually want to know if there is any point in publishing them, if you're going to publish them in this kind of way in which for patient is completely incomprehensible, and perhaps, if there was some lay summary at the end of the inspection that will make them a little more meaningful. So, what is the HFEA actually doing well at the moment in patient size? Well of course, most importantly as I already said is providing information on treatments, that's a really important part of the service, publishing success rates, and getting patient's views. I think, we recognise all of these things are being done well, and patients also felt that the safety of medical treatments and scientific developments is another area that the HFEA is doing well in, but there were some areas that they were less happy about. And, one main thing from a patient's perspective is absolutely no regulation of the cost of treatment, and from the patient's perspective when DNA test provision is still so patchy, that's a really, really crucial thing. Treatment here is incredibly expensive, and when we did a survey on the Infertility Network UK and I became a trustee we did a survey asking patients what their reasons were considering going abroad for treatment? One of the major things that came up is actually the cost of treatment in the UK, and a lot of patients do feel now that they can get just as good treatment with sometimes higher success rates for a lot less money going overseas, and at the time when we're going to some sort of financial crisis, I think, more and more people are going to be considering that, if there is no kind of regulation of how much people have to spent here. Another thing that came out of people that they are not happy about, is paying fees with the HFEA when you've got a large bill already. It is not necessarily clear from a patient's perspective what exactly fees are for and where exactly they are going. And the final statistics which I thought that actually is interesting from one of the infertility views panels, is that slightly less than half of the patients who responded, for the HFEA to protect the interests of the patients, and I wondered why that was, is it partly the fees again? Is it to do with the kind of sometimes controversial publicity that the HFEA has had over the years? One thing, if you look on the forums the patient is often moaning about, is interference from the HFEA, and you know, single embryo transfer have been deeply unpopular in some sections of the patient's population, but I speculate that partly it comes from the attitudes of those treating them. Actually, I have been shocked that a few patients have told me over

	<p>the last years that all of my consultants don't agree with the HFEA about the single embryo transfer, you know, that's the message the patients are getting from their consultants, then patients will never again feel that way about the HFEA, and I think that sometimes that's what is making the difference, is the message from those treating them that is influencing patients use of Authority. So, is regulation working for patients? Well, I think it's very reassuring for patients. We know that clinics have to comply with certain regulations and rules, and we're very happy on the whole information we can get from the HFEA. We know that clinics are monitored, and we know that they are inspected, but I think it is true that patients don't always feel like the HFEA is entirely on their side, but more than anything, what patients really want from a Regulator is to be able to feel safe and to feel that certain standards will be maintained. When you are working in a clinic everyday, which I know lots of you are, you kind of forget how scary is for patients who are going through IVF, we are going out leaving you with our eggs, our embryos, our sperm, at the end of the day that's our future children that we are leaving in your hands, we want to know if they are being looked after properly, and that's why I feel that from a patient's perspective, regulation is so essential.</p>
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