

## Research, production ethics, and trust

**Dr Anna Claydon, University of Leicester, and Professor Pratap Rughani,  
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Duration of video clip: 2 minutes and 30 seconds

**Pratap Rughani:** So the question's about research ethics?

**Anna Claydon:** Yes, and production ethics.

**Pratap Rughani:** I mean it's an area that really interests me and typically in a documentary film we work with the notion of consent, and even informed consent, and that has an important history that goes back to the Nuremberg trials and the dispensation at the end of the Second World War, and allocated the detail and the philosophy of that but it basically means that there needs to be some kind of bond of trust between makers and subjects. You know typically you work with this notion of informed consent. Well when I was approached to think about this what really interested me, was how do you work in terms of consent, - how do you work with the notion of consent with somebody who's not able to give their consent in a way we would normally understand it. And that seemed a really really important question and it made me think well why don't I see much work - by work I mean films media stuff in the public square - about people like Justine. She has advanced neurological disorders so that is very important to me that we don't name her in terms of her medical conditions. So then that was the challenge I suppose, was ethically how do you then work when on the basis hopefully of connection with somebody but you're not able through language anyway to check out with them what's going on and to reach notions of informed consent, in the way that the law would understand it. The law would say, I mean we obviously satisfied all the legal requirements, the law would say, well you go to the parent or guardian get their consent and then you're done. Okay well that might deal with the law but in a way that only takes you so far. Justine is not her mom, or her brother, or her dad, all those wonderful people around her - she's her own person. How could film start to intuit and respond to the experience of another, when we don't yet have an example with consent - a legal framework to really talk about how to work with people with what's called, you know who are not wired in the same way as the so called "neurotypical". So that that really interested me and it made me wonder is that one of the reasons why these sorts of experiences are all but excluded certainly from what you see in mainstream broadcast documentary practice.