

# Thank you for taking part!

## ConnecteDNA Stakeholder Workshops

**ConnecteDNA Stakeholder Workshops**

**Watermark and Introduction to the project**

- 2 strands - 1) how are people using the data and why? 2) legal perspective - are the laws changing?
- Connections come often through relatives - can be challenging
- It can bring out secrets
- Emotions can be difficult to manage
- Everyone's experience is different but...
- New secrets can be born (don't tell your siblings)
- Can be upset that parents didn't explain
- Lack of longer-term follow up
- Not many young people are joining
- often feel an obvious pressure to join
- 16 donors
- 24 donor-conceived
- 20 parents
- 2 relatives
- Dr Ling Ting
- Dr Leah Gilman

**Key Concerns:**

- click wrap + browse wrap
- click means you accept!
- cookies - pop-ups. Share your info
- Data protection
- Some company terms + conditions are not so good, I've been looking at small print
- They make it very hard to complain
- Discussions often began without much consideration of the child's perspective
- Donor anonymity
- Sweden - banned from 1985
- Netherlands - banned from 2004
- Australia - retrospective release from 2016
- UK - banned from 2005
- No consistency about what age a child can access info
- Dr Caroline Bell

**Socio-Legal Work**

- In Australia that group is more vocal, which gives us a warning into their opinions
- It's a limitation but not vitally important
- Some companies terms + conditions are not so good, I've been looking at small print
- They make it very hard to complain
- Discussions often began without much consideration of the child's perspective
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**Break-out Workshops**

- Imagine scenarios and how they would be affected
- Many parents opt into from choice and pass it on before the child is 16
- These companies are at Fisher Fairs now
- Liberty House had social media would undermine the rules
- There needs to be accountability
- Donor conceived person
- "Why don't I look like any parent?"
- What if a parent gets ill? Will I get this too? It would be nice to know before the test
- You might have blood tests at school
- What about meeting a partner could feel attraction because of DNA link?
- The points might disclose of some stage
- I know someone who disclosed when their child went to university they suddenly had their own GP
- Should I tell my girlfriend?
- Donors

**FEAR of the unknown**

- How will people react?
- The scenarios are different but so many of the issues are the same
- My favourite quote "Data is not anonymous"
- New YOU are no longer anonymous
- They must have had an inkling of the issues...
- In the long term everything comes out in the wash!
- Like Uncle Albert in Only Fools + Horses!
- It would have to be based on families, not children - you can't control multiple births
- I would want to control the number of offspring possible
- What would a great version of aftercare be?
- Information could be provided with the DNA provision kit
- You can't give all the info into, but sign positivity is important
- How do you know what you need is truly - you might not be clear, but I adapted? Extra-marital affair?
- You might see warnings but not realise they are relevant to you
- You don't know all your info
- I'd really like the issue to have a higher profile in the media
- People need to feel able to talk about it more widely
- But we need shared positive scenarios
- It's still very much a taboo subject
- People can feel shame that they make help to create a child
- It's very mixed up with masculinity + femininity
- Attitudes to sperm donors are different to egg donors
- Just seeing examples of other people in your situation is so important
- In so sorry - we really need to stop so you can have some lunch!
- You have to consider the social parent though
- Both options could be a good point to engage discussion between fertility + sociality
- DISCUSSION
- It's already easier for young people - they are used to conversations about gender
- We really need to tap into that!
- Who pays for counselling?
- I paid £50 for an hour
- via the DCA you get 2 free sessions
- But it's so much bigger
- We need peer to peer support
- Where desperately short of counsellors

**Discussions around changes to the laws**

- What is the role of the law in DNA testing?
- How could the law support service users better?
- What age do you think it's appropriate for children's access to official channels of information?
- It's a global thing, wider than UK legislation
- There should be restrictions on how they are marketed
- The status quo is simply not realistic
- Stigma minorities can have different attitudes which make it even more challenging
- You need awareness campaigns so donors can update their details
- People need to realise the potential life-long experience of being a donor
- What we have is not practical
- The parents hold all the cards
- Laws need to be more based on the rights of the child
- Maybe you need an opt out button so you can choose when you want to know what
- But that it would be a similar deal - base a number would work best still
- AFCA should have all the information - not be in the hands of commercial organisations
- I worry about future insurance implications so I opted out
- There isn't an age restriction on any of these sites
- We need standardisation of terminology across the different websites
- The whole thing should be child-focused
- In what other circumstances would we not put the child first?
- They need educating. They need support.
- Do you think some parents just don't have the skills?
- The making has the moral duty from the idea of creating a person, that said do you want a new handbag? It's targeted as an income stream!
- I seriously considered donating but I thought about the implications of a future 18 year old turning up on my doorstep
- You are creating a human being!