Fertility conundrum: UK IVF clinics have genetic health information about egg and sperm donors. Are they obliged to share this with patients?

ECS [expanded carrier screening] is a reproductive genomic test, used prior to conception, that can identify whether a potential parent or donor carries any of the hundreds of genetic mutations associated with recessive genetic conditions.

While UK fertility clinics rarely use ECS to screen gamete donors recruited in the UK, many gametes offered in both NHS and private clinics are imported from banks in Europe and the USA, where donors – especially sperm donors – are often screened using ECS. This means that when a patient selects (or is matched with) a donor from one of these banks, the clinicians treating them in the UK may be aware of the donor’s carrier status and need to decide what to do with this information.

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Can they allow the recipient to use this donor? Are they obliged to inform the recipient about the potential risks of transmission, possibly prompting them to reject that donor? If they do not tell, whose responsibility is if the future child ends up developing the condition? Should the recipient be tested too and if so, who should pay for the test and provide counselling? And what happens if the recipient does not want to take the test? These are just some of the novel and important questions clinicians are increasingly facing in their practice.

This is an excerpt. Read the original post here