Post print

This is an author-produced PDF of an article published in *BioNews*. The definitive publisher-authenticated version is: Newson, A. (2014) "Whose genome is it anyway? Ethics and whole genome sequencing before birth", BioNews 782, 1 Dec 2014, available at http://www.bionews.org.uk/page_474185.asp. Published with permission, 2014.

Whose genome is it anyway? Ethics and whole genome sequencing before birth

01 December 2014

Dr Ainsley Newson, Centre for Values, Ethics and the Law in Medicine; University of Sydney, Australia

Geneticist Razib Khan's decision to obtain the whole genome sequence of his partner's fetus in utero shows us that genomics is no longer a fantasy. While it would be a mistake to use this one example to condemn the entire practice of whole genome sequencing (WGS) prior to birth, I will suggest here why we should look before we leap regarding prenatal WGS.

If you lean towards the permissive with respect to genomics, this sequencing event may not be a big deal. Genomic sequencing technology is now fast and cheap. Long-held paradigms such as non-directiveness and respecting children's future autonomy may no longer apply when sequence information is becoming almost mundane and is striding into new healthcare domains. Presumptions of bodily integrity and reproductive autonomy in pregnancy may further diminish concerns – after all, we have very few justifiable thresholds for interfering in decision-making during pregnancy and the harm to the future child that may occur here would be unlikely to reach them.

I think a bit differently to this and advocate a (future) child-centred approach; one which rejects technological imperatives to obtain whole sequences before birth just because we can. WGS will soon be cheaper than testing for one or a few genes and this is certainly a welcome development. But while high throughput methods might be chosen, they should not necessarily dictate the information that is provided. Genomics will bring a significant change in the volume of information received and we won't know for some time what it all means. Genomics also won't ever be able to tell us everything about our health. While Khan may have been able to analyse his son's own genome, this skill will not be within everyone's reach. And while genome sequencing is cheap, interpretation and data storage are not.

Current practice regarding the provision of predictive genetic information to children is helpful. Generally, carers are dissuaded from obtaining information irrelevant to health in early childhood, before the child herself can participate in decision-making. This position is based on considerations such as the future autonomy of the child to decide for herself, the child's future being as 'open' as possible and other welfare-based considerations.

I also claim that the current presumptions in prenatal testing, which distinguish between serious and minor conditions and include a commitment to shared decision-making, can still serve as a useful guide. They are certainly not perfect, but can and should remain relevant as we enter the genomics era. So before we seek a whole genome in a fetus, I'd suggest the following points for reflection:

- Why do we want to know this information? What is its utility in the prenatal context?
- What benefit will this information have during pregnancy? Why test now?

- Is there a medical indication for testing?
- Would it be in the future adult's interests for his or her genome to be determined now?

Obtaining whole genomes may well be valuable and important to global health. However the prenatal context is not the only time this can be done. If sequencing (ideally due to medical indication) is undertaken, analysis can be limited and the sequence can then be destroyed. An individual can then decide whether to be re-sequenced, once she has the capacity to do so (1).

Are these claims proving too much? That is, in advocating that a genome should belong to the future adult that this fetus will become, will the result be that a woman or couple should not be able to make any decisions that affect a fetus, including termination of pregnancy?

In a forthcoming paper, my colleagues and I address this issue (2). We claim that it is possible to be both pro-choice and seek to place limits on the information that a couple can obtain about a child prior to birth, particularly in cases like Khan's where there seemed no intention to terminate the pregnancy (as the information was obtained in the third trimester). If a woman or couple intends to continue a pregnancy regardless of the information received, then the above claims can apply. The fetus is, all being well, destined to become a future adult who will have rights and interests. This does not mean that a fetus will always have rights that override those of its parents, but in circumstances such as WGS for information only they are relevant and may override those of the couple.

My position of caution and child-centredness over prenatal WGS is not absolute and is consistent with others working in the field (3). The presumption should be against prenatal WGS, but justifications for testing reached using the above points for consideration, together with consideration of sound evidence and after appropriate discussion with an inter-disciplinary team could lead to testing going forward.

Children born into the WGS age will have the rest of their lives to come to grips with their genomes, at an appropriate time and with sound clinical oversight. Let's preserve these opportunities as best we can.

SOURCES & REFERENCES

1) Clarke AJ. (2014) 'Managing the ethical challenges of next generation sequencing in genomic medicine'.

British Medical Bulletin, 2014, 1–14. |

2) Deans Z, Clarke A, Newson AJ. (forthcoming) 'For your interest? The ethical acceptability of using non-invasive prenatal testing to test "purely for information".'

Bioethics |

3) Donley G, Hull SC, Berkman BE. (2012) 'Prenatal Whole Genome Sequencing. Just Because We Can, Should We?'

Hastings Center Report, 42(4): 28-40 |