Doctor, parents, or future child: Who has rights to an embryo's genome?

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.

Read full, original article: Whose genome is it anyway? Ethics and whole genome sequencing before birth