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Personal Genomics as an Interactive Web Broadcast

Newson, A.J. (2009)

Personal genomics and whole-genome sequencing are rapidly becoming established on the spectrum of genomic research and service provision. It appears that we do in fact possess curiosity about our genomes, enough to prompt many to purchase DTC testing and more to consider it. McGuire and colleagues' study (2009) and Lee and Crawley's reflection (2009) provide a useful snapshot of emerging issues in personal genomics. Yet the momentum of these technologies suggests we need to act quickly in deliberating their implications.

This commentary will draw out and provide some initial reflection on some of the key ethical issues arising in DTC genomics. This will incorporate an analysis of an online personal genomics broadcast that has recently taken place in the United Kingdom: the Routes Game. Additionally, a claim is advanced that further empirical reflection on DTC genomics should rest on a strong theoretical ethical foundation.

DTC genomics is not yet as visible in the United Kingdom as it is in North America. Nevertheless debates over DTC genomics are ongoing and the Human Genetics Commission has made recommendations about so-called 'over the counter' testing that focus on the problem of mis-selling (Human Genetics Commission 2007). A prominent science journalist has had his genome sequenced and pointed out the pitfalls of DTC interpretation (Henderson 2008a; 2008b). In 2009, DTC genomics and its interpretation have gained an increased online presence courtesy of the "Routes game" (Channel 4 2009).

Routes, which ran for 8 weeks in early 2009, was an online educational package designed to take the concept of personal genomics to an adolescent audience and in the process to teach them about genetics, evolution and the human genome. It was developed collaboratively by the education department of a public broadcaster and a scientific research charity. The site focuses on developments in genomics, including personal genomics, and encourages its audience to start thinking about the impact it will have. The site is interactive and is linked to social networking sites Facebook and MySpace, social bookmarking service Delicious and social news site Digg.

The Routes DTC genomics story was personified by Katherine Ryan, a Canadian comedian living in London. Katherine, aged 23, is a survivor of melanoma, is pregnant and has the autoimmune disease lupus. She volunteered to take herself on a very public journey through her own genetic makeup by obtaining a DTC test from a commercial company, after receiving counselling from an independent genetic counsellor. This was summarized each week by a themed video to document the testing process and the results she obtained (YouTube 2009).

DTC genomics both raises new issues and offers new nuances to previous debates. It challenges current models of clinical service provision and could re-shape professional-patient relationships, not least what constitutes a 'professional' health care provider. No matter how often companies providing DTC testing claim that this is not health information, it is certainly being interpreted as such (McGuire et al. 2009). This gives rise to a prima facie responsibility on DTC providers to ensure that this information is correctly framed and contextualized, perhaps via ongoing clinical support. This is not yet happening—Katherine's results, and those of the United Kingdom science journalist, were provided by e-mail without further clinical input. Both then sought further expert help to interpret them. Katherine commented:

You'd have to get, like, Greg [a scientist friend of hers] or someone to look at it, because it's like ... weird numbers that don't mean anything ... Oh, I have a really elevated risk of prostate cancer. Wow! This is pretty accurate, this test. No, but maybe it might mean other things. See, that's the thing with this. It just means, like ... not a lot to us (YouTube, 2009, Week 2: Sick).

The lack of clinical integration in DTC genomics is under-explored and warrants further consideration. No matter how a service is marketed, if consumers are interpreting this information as health-related it will impact on clinical services (McGuire et al. 2009). Even though clinicians are effectively bypassed by most DTC genomics services, they will no doubt be approached afterwards for interpretation and follow-up, potentially creating a drain on resources and problems of specialist education.

Linked to the issue of ongoing clinical support is the presumption of DTC genomics providers that recipients of results will be active consumers of the information that is provided. However not all consumers are going to appreciate the difference between absolute and relative risk, assuming these are even accurate. DTC testing for serious later-onset diseases should be offered with at least a degree of counselling, as professional experience constantly shows that this protects people's well-being in the longer term. DTC companies may well reject this as paternalistic but a counter-argument is that this either does not constitute paternalism or that if it does, it is justifiable.

Personal genomics is also spearheading a shift in the management of patient information, as patients will become the new guardians of their data. This will no doubt be framed by the companies who market these tests as empowering for individuals and their future choices. But with this choice will come the task (and perhaps, in the longer term, the responsibility) to manage this information and interpret it in light of further developments in the field. Who will update this information over time? The potential burden arising from this task should not be underestimated.

The concept and rhetoric of 'empowerment' promoted by DTC genomics companies, highlighted by McGuire and colleagues (2009) and Lee and Crawley (2009), also requires further exploration and debate. Was Katherine 'empowered' by this information, or merely bemused? What does empowerment mean from a moral perspective? Is this a 'good' thing for DTC genomics? How does this empowerment sit with existing models of professionals and consumers (not always patients, as the majority accessing DTC genomics will be well)? What might the practical applications be? Empowerment may not be intrinsically good, as reframing recipients of this information as advocates may come at a cost to other domains of their medical care. This possible trade-off requires conceptual and practical exploration. As Lee and Crawley (2009) state, we should be wary

of recasting this information as 'fun' given that its pleiotropic nature could quickly change its meaning in the future.

Creating new social networks based on DNA also grates against more traditional presumptions of privacy and familial communication of genetic information. While sharing of appropriate data with other potentially at-risk individuals should occur, careful consideration should be given to the impact of this information on relatives. Ill-considered or poorly framed information sharing can cause psychological harm. A decision to share information about a risk for a particular genetic condition is therefore usually a considered decision made in collaboration with a clinical team. Information from DTC testing will, in contrast, be much greater in volume and of uncertain significance. While a great deal of this information will be inert for relatives, some genetic risks will emerge particularly as more gene-disease relationships and environmental interactions become known. DTC recipients should give careful consideration to whom and how they share this information as it may not be universally welcomed by all.

Despite these concerns, it is also worth bearing in mind that professionals and academics, who have been absorbed in analysing issues in Mendelian genetics for so long, could be over-interpreting the ethical concerns arising from DTC genomic information. Consumers may not be the vulnerable group that we often worry they are. They may be perfectly capable of taking DTC genomic information and its limitations into due consideration when conceiving their overall health. As Katherine stated:

Like, what can they tell me in the genetic testing that's going to be worse than the day someone said, "You have cancer"? Not "You could have cancer." Not "You have the genome for cancer (YouTube, 2009, week 2: Sick).

In a later video, she also comments in response to an incorrect prediction about her food preferences:

I really like the fact that the genetics didn't predict what you like. ... I mean, for me that's very reassuring that we can't learn everything from science (YouTube, 2009, Week 6: Tasty).

DTC information could therefore increase people's overall health awareness, even if it does seem to be an expensive way to be told to eat more greens and do more exercise. Lee and Crawley (2009) also correctly point out that this information could lead to the creation of new ties between individuals, groups and organizations. Social networks may therefore be used to create new kinds of communities or to re-connect individuals. These benefits should be carefully monitored.

In reading both DTC articles in this issue, as O'Connor (2009) recognizes it is slightly frustrating that they both undertake to map the ethical landscape, but neither of them use this to advance a position as to how personal genomics should proceed. There is therefore a pressing need for further theoretical reflection on the ethical issues arising from DTC genomics to create a robust foundation for ethical discourse and further empirical investigation. The manner in which empirical results should influence theoretical debate also requires deliberation, as other commentaries have highlighted. Empirical follow-up for individuals who have already had testing is also required.

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