Gnome medicine: what does genomic medicine mean to our patients and us?

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“Gnome medicine did you say?” With more than a hint of incredulity, this was the response from my (SF) mum when I talked to her about my work. We then went on to laugh about the misunderstanding. I use this example, not to humiliate my mum (she has given permission for me to use her response) but to highlight the divide between clinicians, scientists and the everyday person.1,2 My mum is not alone in her response. In the UK there is an engagement project “Socialising the Genome” funded by Genomics England, the Wellcome Trust and the Wellcome Trust Sanger Institute, which aims to “explore what people already understand about DNA and genomics—even if they think they know nothing—and how they are currently talking about it.”

In their letter, Parry and Middleton discussed how some genomics professionals “argue fiercely that the public should be educated to use and understand technically precise genomics terminology.”1 However, Parry and Middleton went on to say that they felt that insisting on such an approach would present “a marked barrier to communication and also creates an unhelpful power differential of expert versus other.”

Genomic medicine, sometimes also known as personalised medicine, is a way to customise medical care to your body’s unique genetic makeup—where treatment plans can be tailored to the individual.3 Rather than looking at one gene, genomic medicine looks at all of the genes, using techniques such as next-generation sequencing. It takes into account family health history and environmental factors. A key aspect of the success of genomic medicine is related to public acceptance;4–6 in particular around collecting family health histories and the development of biobanks that contain large numbers of individuals’ genomic DNA, linked with other health, lifestyle and administrative data4—–which raises significant, and as yet unresolved, consideration around governance, caretaking, informed consent and sharing (or not) findings with family members.6,9

Genomic medicine is poised to transform patient care, and it will become more common as genomic medicine is being mainstreamed (ie, no longer a specialist service).3 But as one of the investigators from the socialising the genome project stated, “We don’t yet know how to make genomics an everyday conversation for people currently unconnected to it”. If the people that genomic medicine is intending to benefit are excluded from the dialogue as this technology advances, the divide will only widen and it will remain inaccessible (and distrusted) on many different levels.

How about health providers? The uptake of genomic technology into clinical practice will depend on providers’ perspectives of its utility in patient care. Currently we don’t have a good handle on what these are, nor on the educational needs.10 If we look overseas, evidence barriers to adopting genomic medicine are cited as many, with “variable knowledge and comfort with genetic concepts” being leading concerns.10

The rise of direct-to-consumer testing (DTC) with kits such as 23andMe will likely increasingly reach our practices, as patients may turn up for help interpreting their health report, as an example, because they have been found to have the ε4 variant in the APOE gene associated with late onset Alzheimer’s disease.11

As health researchers, medical sociologists and practitioners, we would like to highlight a gap in our engagement and education
around genomic medicine in Aotearoa New Zealand with both our patients and providers. We don’t know what messages about genomics are meaningful to people (our patients) in Aotearoa, nor do we know what practitioners want and need to deliver it. Are we genome ready? We would contend not really, and we would welcome the opportunity to work with health providers, stakeholders and researchers to become so.

**Competing interests:**
Nil.

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