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Do the Public Need a Good Understanding of Genomics?

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Genomics has become a vastly growing field, with scientists of differing backgrounds dabbling in the subject, or jumping on its prolific bandwagon. As a biologist, you would be hard pushed to attend a conference without hearing the word 'genomics' sandwiched between scientific jargon. In the last decade alone, new technologies and data management have boosted the use of genomic research, to the point where genetic testing is now almost commonplace in many healthcare settings for a range of diseases. But the question is, what is the public's understanding of genomics and why is this important?

Last month, the Festival of Genomics hosted an engaging and popular panel discussion about genomics in 2017, which quickly navigated in the direction of public understanding. Panellist Dr Anna Middleton was very much 'pro' public understanding and education, highlighting that its good for the general population to be in tune with genomics and genetic testing, considering the vast amount of inherited conditions that people may be at risk of.

Dr Middleton works at the Sanger Institute researching the impact of genomics on the general public (1). During the discussion, she

highlighted that her research has indicated that the public hasn't actually heard of the word genomics *per se*, and when asking the public about genetic testing, it was clear that their understanding was mostly based on representation of genetics in the media – for example, forensic testing in CSI, the Angelina Jolie *BRCA* story. But this isn't necessarily a bad thing.

The 'Angelina Jolie Effect' did wonders for raising public awareness to the *BRCA* predisposition genes seen in some inherited breast cancers, leading to a huge spike in women coming forward for genetic inheritance testing. Through her research over the years, Dr Middleton believes that 'the public can have very sophisticated conversations about genomics without the scientific jargon'; cutting out every day scientific terms can make genomics seem much more accessible. Her research is now striving to work alongside filming and advertising to get basic scientific messages to the masses.

So, now we must question whether the public NEED an understanding of genomics? Overall, public knowledge can have a huge and longstanding effect on attitudes and interest in scientific principles. A prominent problem that scientists are facing today is the willingness of patients to share and donate their biomedical data; one may question whether, with greater understanding of the application of genomics and data privacy, the public may become more 'on board' with sharing their genetic information. If people are unaware of how something may affect themselves, or a family member, they are unlikely to engage with it.

It is also interesting to consider the juxtaposition of data privacy and sharing across different areas. When it comes to sharing genomic data, overall, people are very reluctant to do so. However, most people are happy to share all sorts of information on social media, without understanding how, or even who, could be using their data. Why are people so hesitant to share when it comes to genomics? Perhaps it is the daunting, 'futuristic' nature of genomics, or unsettling feeling of unfamiliarity?

Additionally, although genomics shows exceptional promise for the future, it is a package deal with social, ethical and legal considerations (2). Greater public understanding of genomics has the ability to be of great benefit to society, not only by affecting personal and public health, but also by influencing policymakers. Hence, greater public understanding and awareness of these things can help them to make informed decisions, which ultimately will affect the public and scientists alike.

On the flip side, other panellists argued that it isn't always necessary for the public to have a full understanding of complex scientific principles like genetics – the analogy that 'we all have cars, but we don't all know how to fix them' was used here. There are many aspects of health that the public does not necessarily need a full understanding of – for example, most people are happy to take regular pills or pharmaceutical drugs, but are unaware of how they work.



*Dr Anna Middleton speaking at the Festival of Genomics
London 2018*

However, Dr Middleton's study published in 2015 found that 98% of people would like to know as much as they can about their genetic information in a healthcare setting; when it comes to disease, people want to know if they are at risk (3). Although, too much information can be distressing and not always helpful to all patients. This illustrates the sheer impact that genomics has when being integrated into healthcare, and achieving the correct balance here is tricky.

In light of all of this, how do we engage the public when genomics is moving so fast? The primary issue is that the majority of the public are unaware of the future IMPACT of genomics. As it stands, diagnostic laboratories mainly use genetic testing for rare genetic diseases, for example, cystic fibrosis, which affects a handful of the population (2). By highlighting that in the future, genomics may help diseases with high prevalence in the population, such as cancer, diabetes, and cardiovascular disease, this may encourage the public to engage with the field, making it seem real, and extinguish the idea of genetics being a futuristic tool used only in sci-fi movies.

Another way to engage with the public is to start

with the younger generation. Science is a core subject in schools, and the principle of DNA being the building blocks of all life is taught universally. However, the novel applications of genetics and genomics need to be homed in on, so pupils have a grasp of how genetics can be used to treat their family, or friends, or even themselves in the future.

It is clear that there is a disconnect between scientists and the public when it comes to genomics, and that patients are more willing to learn about their own DNA than first thought. As scientists, it is our responsibility to educate the public, and disseminate knowledge in the media, to achieve an equilibrium between what is necessary and what is helpful for patients.

References

1. <http://www.sanger.ac.uk/people/directory/middleton-anna>
2. <https://www.ncbi.nlm.nih.gov/books/NBK83754/>
3. <http://www.frontlinegenomics.com/news/937/data-shows-people-want-to-know-whats-in-their-genome/>

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