Development and mixed-methods evaluation of an online animation for young people about genome sequencing

LEWIS, Celine, SANDERSON, Saskia C., HAMMOND, Jennifer, HILL, Melissa, SEARLE, Beverly, HUNTER, Amy, PATCH, Christine <http://orcid.org/0000-0002-4191-0663> and CHITTY, Lyn S.

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Section	Animated video topics
1. Genetics: the basics	• Bodies made of millions of cells which contain DNA
	• Our DNA act like set of instructions and control how our body works
	• A genome is a person's complete set of DNA
	• Genome made up of 6 billion chemical 'letters' AGTC
	• Order of DNA is your genome sequence
	• Each person's genome sequence is unique
	• Variation in the DNA sequence can cause body not to function properly and may cause a genetic condition
	• Genes are short sections of DNA
	• Inherit our genes from our parents
	• Humans have about 20,000 genes
	• Genes code for proteins which do most of work in body
	• Genes packaged on chromosomes
2. What is whole genome sequencing?	• Procedures
	○ Genome sequencing is a technology that involves sequencing or writing down exact order of all the As Cs Gs and Ts
	○ Other genetic tests only look at certain sections of the DNA in your genome, WGS looks at almost all of it
	○ Blood test or saliva sample
	○ Amount of blood will depend how old you are but varies between 6-12ml (1-2 teaspoons)
	○ Blood sent to laboratory where DNA is extracted using chemicals
	○ Use very high powered machines to read the DNA sequence
	○ Interpret sequence by comparing it to a reference sequence
	○ Other close relatives (usually parents) may also be tested for comparative purposes
	○ Timeframe for getting results
	○ How you will receive the results
	○ Test accuracy
3. What results you may receive?	○ Identify genetic cause of you/your child's condition
	○ Additional findings about risk of disease such as cancer or other rare genetic conditions
	○ Carrier status
	○ Variants of unknown significance
	○ Your likely response to therapeutic drugs
	○ You can choose whether you want to know about these additional findings
4. Making your decision	• Benefits
	○ Getting a diagnosis. Find out 'cause' for you/your child's condition
	○ If you get a result might help identify treatment/monitoring/prevention
	○ Reproductive decision-making
	○ Alert other family members of potential health risks
	○ Psychological/social benefits of diagnosis e.g. end of 'diagnostic odyssey', connecting with people with same condition
	○ Contribute to genomics research and improve health of future generations
	• Risks
	○ Might not always find a genetic cause for condition – can be disappointing
	○ Blood test so might feel slight sting and leave some bruising
	○ Worry if find out something unexpected
	○ Potential loss of privacy
	○ Concerns around insurance
	• Limitations
	○ Interpretation of DNA sequence may not provide any information about your condition
	○ Technology is still in its infancy so much we still can't interpret
	• Privacy
	○ Genome sequencing is voluntary
	○ Results are confidential