

**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
<b>1. Genetics: the basics</b>	<ul style="list-style-type: none"> <li>• Bodies made of millions of cells which contain DNA</li> </ul>
	<ul style="list-style-type: none"> <li>• Our DNA act like set of instructions and control how our body works</li> </ul>
	<ul style="list-style-type: none"> <li>• A genome is a person's complete set of DNA</li> </ul>
	<ul style="list-style-type: none"> <li>• Genome made up of 6 billion chemical 'letters' AGTC</li> </ul>
	<ul style="list-style-type: none"> <li>• Order of DNA is your genome sequence</li> </ul>
	<ul style="list-style-type: none"> <li>• Each person's genome sequence is unique</li> </ul>
	<ul style="list-style-type: none"> <li>• Variation in the DNA sequence can cause body not to function properly and may cause a genetic condition</li> </ul>
	<ul style="list-style-type: none"> <li>• Genes are short sections of DNA</li> </ul>
	<ul style="list-style-type: none"> <li>• Inherit our genes from our parents</li> </ul>
	<ul style="list-style-type: none"> <li>• Humans have about 20,000 genes</li> </ul>
	<ul style="list-style-type: none"> <li>• Genes code for proteins which do most of work in body</li> </ul>
	<ul style="list-style-type: none"> <li>• Genes packaged on chromosomes</li> </ul>
<b>2. What is whole genome sequencing?</b>	<ul style="list-style-type: none"> <li>• Procedures</li> </ul>
	<ul style="list-style-type: none"> <li>○ Genome sequencing is a technology that involves sequencing or writing down exact order of all the As Cs Gs and Ts</li> </ul>
	<ul style="list-style-type: none"> <li>○ Other genetic tests only look at certain sections of the DNA in your genome, WGS looks at almost all of it</li> </ul>
	<ul style="list-style-type: none"> <li>○ Blood test or saliva sample</li> </ul>
	<ul style="list-style-type: none"> <li>○ Amount of blood will depend how old you are but varies between 6-12ml (1-2 teaspoons)</li> </ul>
	<ul style="list-style-type: none"> <li>○ Blood sent to laboratory where DNA is extracted using chemicals</li> </ul>
	<ul style="list-style-type: none"> <li>○ Use very high powered machines to read the DNA sequence</li> </ul>
	<ul style="list-style-type: none"> <li>○ Interpret sequence by comparing it to a reference sequence</li> </ul>
	<ul style="list-style-type: none"> <li>○ Other close relatives (usually parents) may also be tested for comparative purposes</li> </ul>
	<ul style="list-style-type: none"> <li>○ Timeframe for getting results</li> </ul>
	<ul style="list-style-type: none"> <li>○ How you will receive the results</li> </ul>
	<ul style="list-style-type: none"> <li>○ Test accuracy</li> </ul>
<b>3. What results you may receive?</b>	<ul style="list-style-type: none"> <li>○ Identify genetic cause of you/your child's condition</li> </ul>
	<ul style="list-style-type: none"> <li>○ Additional findings about risk of disease such as cancer or other rare genetic conditions</li> </ul>
	<ul style="list-style-type: none"> <li>○ Carrier status</li> </ul>
	<ul style="list-style-type: none"> <li>○ Variants of unknown significance</li> </ul>
	<ul style="list-style-type: none"> <li>○ Your likely response to therapeutic drugs</li> </ul>
	<ul style="list-style-type: none"> <li>○ You can choose whether you want to know about these additional findings</li> </ul>
<b>4. Making your decision</b>	<ul style="list-style-type: none"> <li>• Benefits</li> </ul>
	<ul style="list-style-type: none"> <li>○ Getting a diagnosis. Find out 'cause' for you/your child's condition</li> </ul>
	<ul style="list-style-type: none"> <li>○ If you get a result might help identify treatment/monitoring/prevention</li> </ul>
	<ul style="list-style-type: none"> <li>○ Reproductive decision-making</li> </ul>
	<ul style="list-style-type: none"> <li>○ Alert other family members of potential health risks</li> </ul>
	<ul style="list-style-type: none"> <li>○ Psychological/social benefits of diagnosis e.g. end of 'diagnostic odyssey', connecting with people with same condition</li> </ul>
	<ul style="list-style-type: none"> <li>○ Contribute to genomics research and improve health of future generations</li> </ul>
	<ul style="list-style-type: none"> <li>• Risks</li> </ul>
	<ul style="list-style-type: none"> <li>○ Might not always find a genetic cause for condition – can be disappointing</li> </ul>
	<ul style="list-style-type: none"> <li>○ Blood test so might feel slight sting and leave some bruising</li> </ul>
	<ul style="list-style-type: none"> <li>○ Worry if find out something unexpected</li> </ul>
	<ul style="list-style-type: none"> <li>○ Potential loss of privacy</li> </ul>
	<ul style="list-style-type: none"> <li>○ Concerns around insurance</li> </ul>
	<ul style="list-style-type: none"> <li>• Limitations</li> </ul>
	<ul style="list-style-type: none"> <li>○ Interpretation of DNA sequence may not provide any information about your condition</li> </ul>
	<ul style="list-style-type: none"> <li>○ Technology is still in its infancy so much we still can't interpret</li> </ul>
	<ul style="list-style-type: none"> <li>• Privacy</li> </ul>
	<ul style="list-style-type: none"> <li>○ Genome sequencing is voluntary</li> </ul>
	<ul style="list-style-type: none"> <li>○ Results are confidential</li> </ul>