

## **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.

Available from Sheffield Hallam University Research Archive (SHURA) at:

<https://shura.shu.ac.uk/26521/>

---

This document is the Supplemental Material

### **Citation:**

LEWIS, Celine, SANDERSON, Saskia C., HAMMOND, Jennifer, HILL, Melissa, SEARLE, Beverly, HUNTER, Amy, PATCH, Christine and CHITTY, Lyn S. (2020). Development and mixed-methods evaluation of an online animation for young people about genome sequencing. *European Journal of Human Genetics*, 28 (7), 896-906. [Article]

---

### **Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>

### Review of online existing information sources 3.12.15

## Search strategy

## Search engines: Google, Bing & You Tube

Search terms: 'whole genome sequencing', 'genome sequencing' 'genomics'

Produced by	URL	Information delivery	What is covered	Strengths and Limitations
National Genetics and Genomics Education Centre	<a href="http://www.geneticseducation.nhs.uk/">http://www.geneticseducation.nhs.uk/</a> <a href="http://www.geneticseducation.nhs.uk/mededu/genetics-to-genome">http://www.geneticseducation.nhs.uk/mededu/genetics-to-genome</a> <a href="http://www.geneticseducation.nhs.uk/genomic-healthcare">http://www.geneticseducation.nhs.uk/genomic-healthcare</a>  <a href="http://www.geneticseducation.nhs.uk/">http://www.geneticseducation.nhs.uk/</a>	<p>Online text Clinical images, animations and videos</p> <p>Information divided into the following sections: I'M LEARNING I'M TEACHING I'M IN CLINICAL PRACTICE GENOMIC HEALTHCARE RESOURCES</p>	<p>Whole section on genetics (genes to genome): DNA, genes, chromosomes, genetic code, inheritance patterns</p> <p>Section on genomics in healthcare:</p> <ul style="list-style-type: none"> <li>○ Translational genomics: the path from genomic insight to clinical applications</li> <li>○ Examples of genomic healthcare</li> <li>○ Refining diagnosis</li> <li>○ Individualising clinical care</li> <li>○ Predicting drug effects</li> <li>○ Developing new therapies</li> </ul> <p>Video of Leslie Biesecker discussing whole genome sequencing</p> <p>Clinical images, animations and</p>	<p>Quite high level –it is aimed at healthcare professionals rather than patients.</p> <p>A lot of information to go through. Not focused on patient perspective</p>

	<a href="http://action.nhs.uk/for-healthcare-educators/clinical-images">action.nhs.uk/for-healthcare-educators/clinical-images</a>  <a href="https://vimeo.com/78906181">https://vimeo.com/78906181</a>  <a href="https://www.flickr.com/photos/119980645%40N06/?rb=1">https://www.flickr.com/photos/119980645%40N06/?rb=1</a> (free image library)	Video animation series: Introduction to genomics	videos <ul style="list-style-type: none"> <li>○ Animated videos on inheritance patterns,</li> <li>○ Using genomic information to predict the effect of drugs</li> <li>○ Using genomic information to predict and prevent adverse drug reactions</li> </ul> How can your genome affect your health?	
NHS England Genomics Education Programme	<a href="https://www.genomiceseducation.hee.nhs.uk/resources/videos">https://www.genomiceseducation.hee.nhs.uk/resources/videos</a>	Video – Introducing genomics in healthcare  Video – Rare	Intro to genetics/genomics How it is being used Stratified/personalised medicine Diabetes/cancer Genome sequencing of MRSA Molecular ‘lab in a box’ 100,000 Genomes Project Health Education England  Discussed 1 particular rare	Aimed at healthcare professionals Talks about 100,000 Genomes project  Talks about 100,000 Genomes Project

		disease, a families journey	disease patient and how 100,000 Genomes Project is helping	
Genomics England	<a href="http://www.genomicsengland.co.uk/taking-part/participant-stories/">http://www.genomicsengland.co.uk/taking-part/participant-stories/</a>  <a href="http://www.genomicsengland.co.uk/the-100000-genomes-project/understanding-genomics/">http://www.genomicsengland.co.uk/the-100000-genomes-project/understanding-genomics/</a>	<p>Video – participant stories</p> <p>Understanding genomics – infographic, animated infographic and video</p>	<p>Stories from patients who have taken part in the 100,000 Genomes Project</p> <p>What is a genome? (infographic) How do you sequence a genome? (infographic) Genomics in healthcare (video – same as above) What happens to the data in the project? (animated infographic)</p>	Aimed at patients
23 and Me and Khan academy - Genetics 101	<a href="https://www.youtube.com/watch?v=ubq4eu_TDFc&amp;list=PLF9969C74FAAD2BF9">https://www.youtube.com/watch?v=ubq4eu_TDFc&amp;list=PLF9969C74FAAD2BF9</a>	Animation	<p>What are genes? What are SNPs? What are phenotypes? Why not Y?</p>	Had over half a million views. Appears to be aimed at young people. Uses animated images. 810/855 'likes' Doesn't specifically address genome sequencing
Genes and health	<a href="http://www.genesandhealth.org/syl/node/63">http://www.genesandhealth.org/syl/node/63</a>	<p>Online information with images &amp; animation.</p> <p>2 videos</p>	<p>Genes and your health – genes made easy Easy explanation of genes and science Genes, chromosomes, where do your genes come from, how do genes affect your health, genetic conditions, personalised medicine</p> <p>Watch the YourGenome from DNA to protein video to see how it all works Zoom in on your genome</p>	Explains basic genetic concepts but not much information on genomics.

<p>Your Genome – Wellcome Trust Sanger Institute</p>	<p><a href="http://www.yourgenome.org/facts/what-is-a-genome">http://www.yourgenome.org/facts/what-is-a-genome</a></p> <p><a href="http://www.yourgenome.org/videos/">http://www.yourgenome.org/videos/</a></p>	<p>What is a genome? Webpage</p> <p>‘Zoom in on your genome’ animated video</p>	<p>Explanation of: Gene, genome, DNA, chromosome, inheritance</p> <p>An array of short films giving insight into what is happening in genomics and how it is helping in the fight against human disease. Animations show how we sequence DNA and other techniques. Includes “my career in genomics”, “the human genome project”, “DNA sequencing”,</p>	<p>Clear and concise explanations</p> <p>Video ‘zoom in on your genome’ provides a good short explanation</p> <p>Some of the videos quite complex. Some of the videos aimed at graduates</p> <p>Good summary of human genome project</p> <p>Some of the animations e.g. ‘how the human genome was sequenced’ do not have audio – only wording</p>
<p>Sanger survey on genomics</p>	<p><a href="https://survey.sanger.ac.uk/genomics/">https://survey.sanger.ac.uk/genomics/</a></p>	<p>Survey with embedded videos</p>	<p>Sharing of Pertinent Findings</p> <p>Sharing of Incidental Findings</p> <p>Categorizing Incidental Findings</p> <p>Relations with Risk</p> <p>Raw data</p> <p>Duty of Genomic Researchers</p> <p>Filter of Genomic Information</p> <p>Consent for genomic research</p>	<p>Focused mainly on some of the ethical issues associated with genomic research studies and incidental findings. Doesn’t include background information about genomics</p>
<p>Icahn School of Medicine</p>	<p><a href="https://www.youtube.com/watch?v=IXamRS85hXU&amp;hd=1">https://www.youtube.com/watch?v=IXamRS85hXU&amp;hd=1</a></p>	<p>“Whole genome sequencing and you” video</p>	<p>Genetics: the basics</p> <p>What is whole genome sequencing – physical traits, ancestry, risk of common diseases and psychiatric disorders, genetic disorders, carrier status, VUS, pharmacogenetics</p> <p>Making your decision – benefits,</p>	<p>Has undergone formal review process with adults (18-89 years) and was well received</p>

			risks and limitations, privacy	
National Human Genome institute	<a href="http://www.genome.gov/18016863">http://www.genome.gov/18016863</a>	Fact sheet – A brief guide to genetics	DNA, Genes and Genomics DNA sequencing The Human Genome Project Implications of Genomics for Medical Science	Doesn't address whole genome sequencing
PHG Foundation	<a href="http://www.phgfoundation.org/file/10365/">http://www.phgfoundation.org/file/10365/</a>	4 page summary leaflet of main report	Whole genome sequencing – clinical impact and implications for health services	Aimed at health professionals
Learn Genetics Utah	<a href="http://learn.genetics.utah.edu">http://learn.genetics.utah.edu</a>	online animated videos	Tour of basic genetics Human health Cell biology	Doesn't specifically address whole genome sequencing
Genetics Home Reference	<a href="http://ghr.nlm.nih.gov/handbook.pdf">http://ghr.nlm.nih.gov/handbook.pdf</a>	Help me understand genetics handbook – 203 pages.	1 chapter on genomic research SNPs GWA studies HapMap project ENCODE project Pharmacogenetics Advances in DNA sequencing	Very dense Does not provide a summary Text based
Illumina website – Genetics 101	<a href="http://www.everygenome.com">www.everygenome.com</a>  <a href="http://www.illumina.com/clinical/illumina_clinical_laboratory/genomics-101.html">http://www.illumina.com/clinical/illumina_clinical_laboratory/genomics-101.html</a>	Video  Webpage – Genomics 101	Case study of a patient with a rare disease who benefited from WGS. Page itself aimed at clinicians.  Reading the genome DNA as genomic encyclopaedia Genomes and inherited disease DNA changes	Video gives a good example of how WGS can help patients, but doesn't give much information about WGS itself and what it is. The genomics 101 page is patient friendly
Genes in Life	<a href="http://www.genesinlife.org">http://www.genesinlife.org</a>	What is whole	What is whole genome	Seems to be written for patients as

	<a href="https://www.genetics.gov.uk/testing-services/testing-genetic-conditions/whole-genome-sequencing">g/testing-services/testing-genetic-conditions/whole-genome-sequencing</a>	genome sequencing? Webpage	sequencing? How can I be tested? What do the test results mean? Questions to consider Also has a Genetics 101 and Genes and Your Health section on the website	language is very clear and simple.
How to sequence the human genome	<a href="https://www.youtube.com/watch?v=MvuYATH7Y74">https://www.youtube.com/watch?v=MvuYATH7Y74</a>	Ted Ed		Relatively complex some useful analogies