

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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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]

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Questions identified by school pupils & young people in the 100,000 Genomes Project about whole genome sequencing

Genetics - the basics

- What is DNA?
- What is a gene?
- What is a genome?
- What does our genome do?
- Do our genomes all look the same? Are they the same as our parents?
- Why does our genome affect our health?

What is whole genome sequencing

- What is whole genome sequencing?
- How do you do whole genome sequencing? What is the process?
- Will you always get an answer from genome sequencing?
- How accurate are the results?

Questions around the process of genome sequencing

- What do they do with the blood? Who does the test?
- How long will it take to do the test? How long will it take to get the results back? How will I get the results back?
- How many times do you do the test to make sure it's right?
- Do I have to have the test?

What results you might receive

- What could be the possible result? What information might I get back?
- Can you get results for other things in addition to the main genetic conditions?
- What if you find something? What are the consequences if I find out I have a genetic condition?
- What happens after I get the result? What is the treatment?

Benefits

- What are the benefits?
- In what ways will it benefit me? Will it benefit other people?

Risks, limitations, uncertainties

- What are the risks? What are the disadvantages?
- Will you always get an answer from genome sequencing?
- Is it safe?
- How many people have had it done?
- Will it work for everyone, because everyone's genes are different?
- Can the information be used against me in any way?