Let’s talk DNA: a story about co-designing an animation with young people

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What is co-design?

A *democratisation* of the design process

users/stakeholders  designers/researchers

Slide: Dr Penny Hagen
https://www.slideshare.net/pennyhagen/hagen-rowlandcodesign-ux-australiaupload
Background: What was the problem we were trying to solve?

1. 75% of rare diseases affect children - vast majority have genetic cause
2. New genomic technologies increase diagnostic yield by 25%-40%
3. Young people want to be engaged in decisions about genomic testing
4. Information aimed at young people in their preferred format, currently missing
Co-designing an animation aimed at 11-16 years
Phase 1: Content development
What should we include in an animation about genome sequencing?
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What should we include in an animation about genome sequencing?
What is a genome?

How does whole genome sequencing work?

Will you always get an answer from genome sequencing?

Why do some people have genetic conditions?

How do you do the test and does it hurt?

In what ways will it benefit me?
Phase 1: Content development
How best to explain genomics?
Phase 1: Content development
Checking in the advisory team
Phase 2: Script & story development
Phase 2: Script & story development
Phase 2: Voice-over
Phase 3: Animation testing
Development of a measure of genome sequencing knowledge for young people: The kids-KOGS

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Abstract
Genome sequencing (GS) is increasingly being used to diagnose rare diseases in pediatric patients; however, no measures exist to evaluate their knowledge of this tech-
Fig. 1 Change score by age in sample overall.
Lessons learn

• How much fun co-design is
• Iterative process is time-consuming! Start to finish ~18 months
• Good relationship & building trust – with interviewees, schools, YPAG, animator etc