

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

Dr Celine Lewis
Senior Behavioural Scientist
NIHR Advanced Fellow



What is co-design?



users/stakeholders



designers/researchers

A **democratisation** of the design process

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?



NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust

Phase 1: Content development

What should we include in an animation about genome sequencing?



NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust



What is a genome?

How does whole genome sequencing work?

Will you always get an answer from genome sequencing?

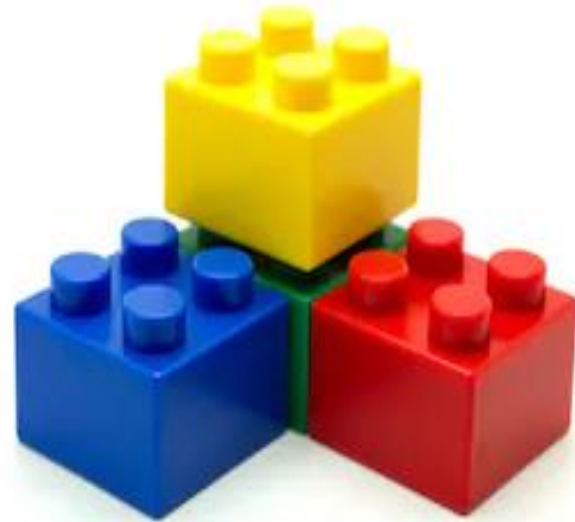
Why do some people have genetic conditions?

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

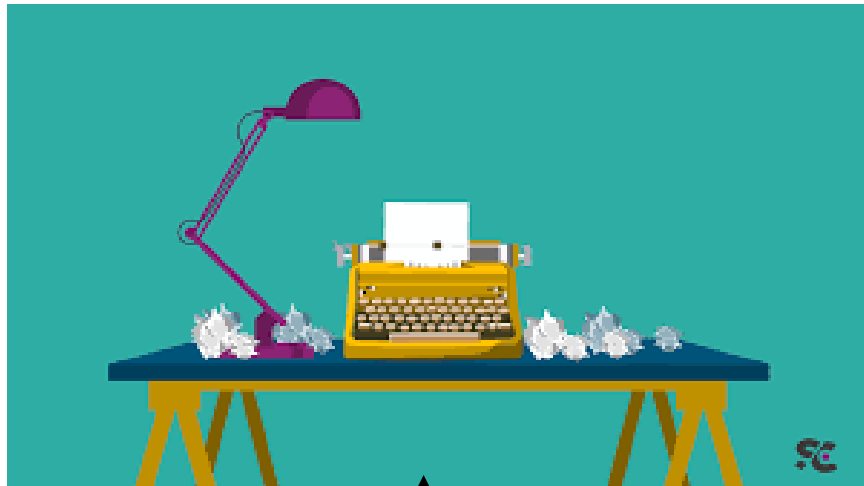


NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust



Phase 2: Script & story development



WONKY Films

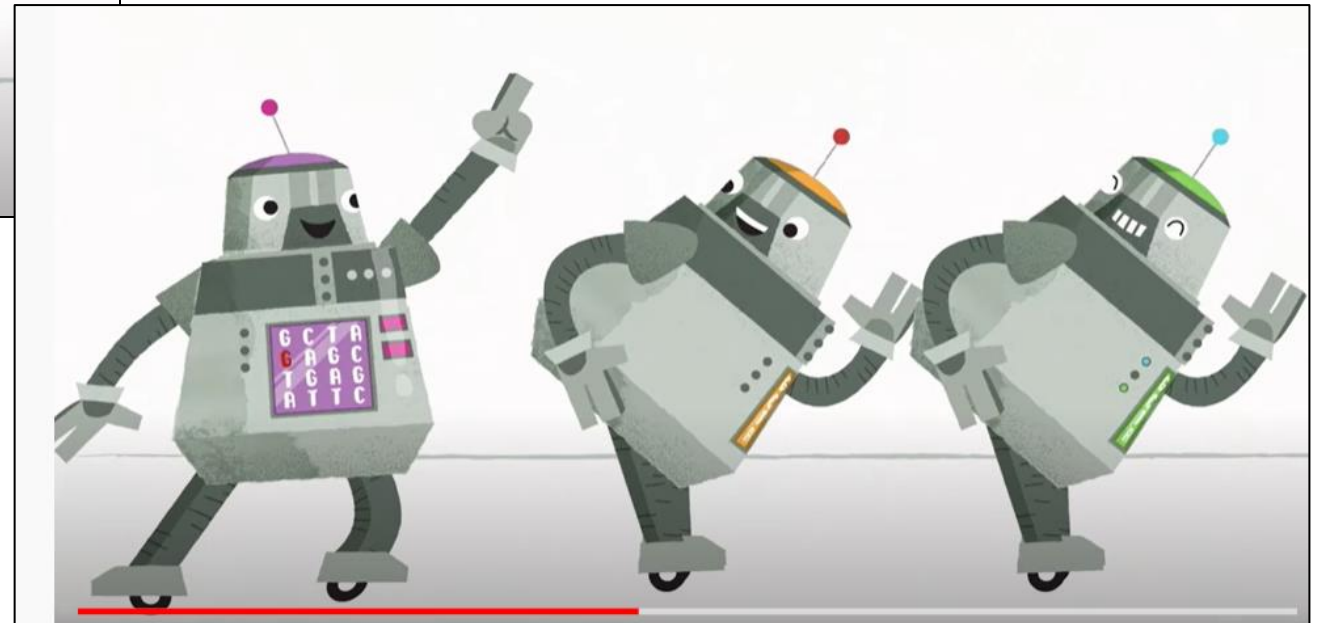
Content With Character for Animation, Illustration & Digital

WONKY are an award-winning full service, high-end UK animation and illustration studio who creates content with character for multiple platforms. Based in the UK (Bristol) we work with clients both nationally and internationally. Our aim is to collaborate closely and efficiently with our clients so that we feel more like their very own in-house animation department. Specialising in character-based animation and illustration, we cover 2D, mixed media and stop motion animation. We work with an eclectic mix of talented creatives ranging from illustrators and model makers to writers and musicians allowing us to develop a bespoke approach for every job.

Featured Projects



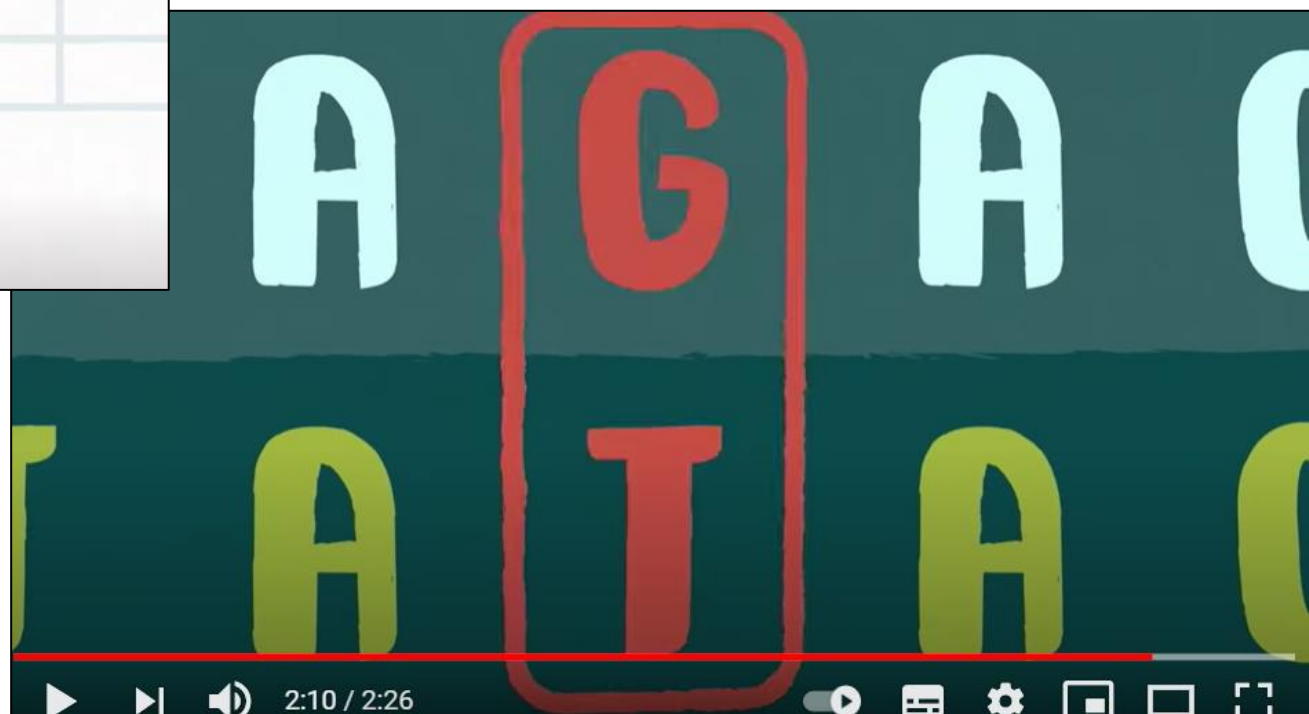
Phase 2: Script & story development



Phase 2: Voice-over



Phase 3: Animation testing





MY GENOME SEQUENCE




Received: 1 April 2019 | Revised: 10 July 2019 | Accepted: 16 July 2019

DOI: 10.1111/cge.13607

ORIGINAL ARTICLE

CLINICAL
GENETICS | WILEY

Development of a measure of genome sequencing knowledge for young people: The kids-KOGS

Celine Lewis^{1,2}  | Bao S. Loe³ | Chris Sidey-Gibbons⁴ | Christine Patch^{5,6,7} |
Lyn S. Chitty^{1,2} | Saskia C. Sanderson^{1,8}

¹North East Thames Regional Genetics Services, Great Ormond Street Hospital NHS Foundation Trust, London, UK

²UCL Great Ormond Street Institute of Child Health, London, UK

Abstract

Genome sequencing (GS) is increasingly being used to diagnose rare diseases in paediatric patients; however, no measures exist to evaluate their knowledge of this tech-

902

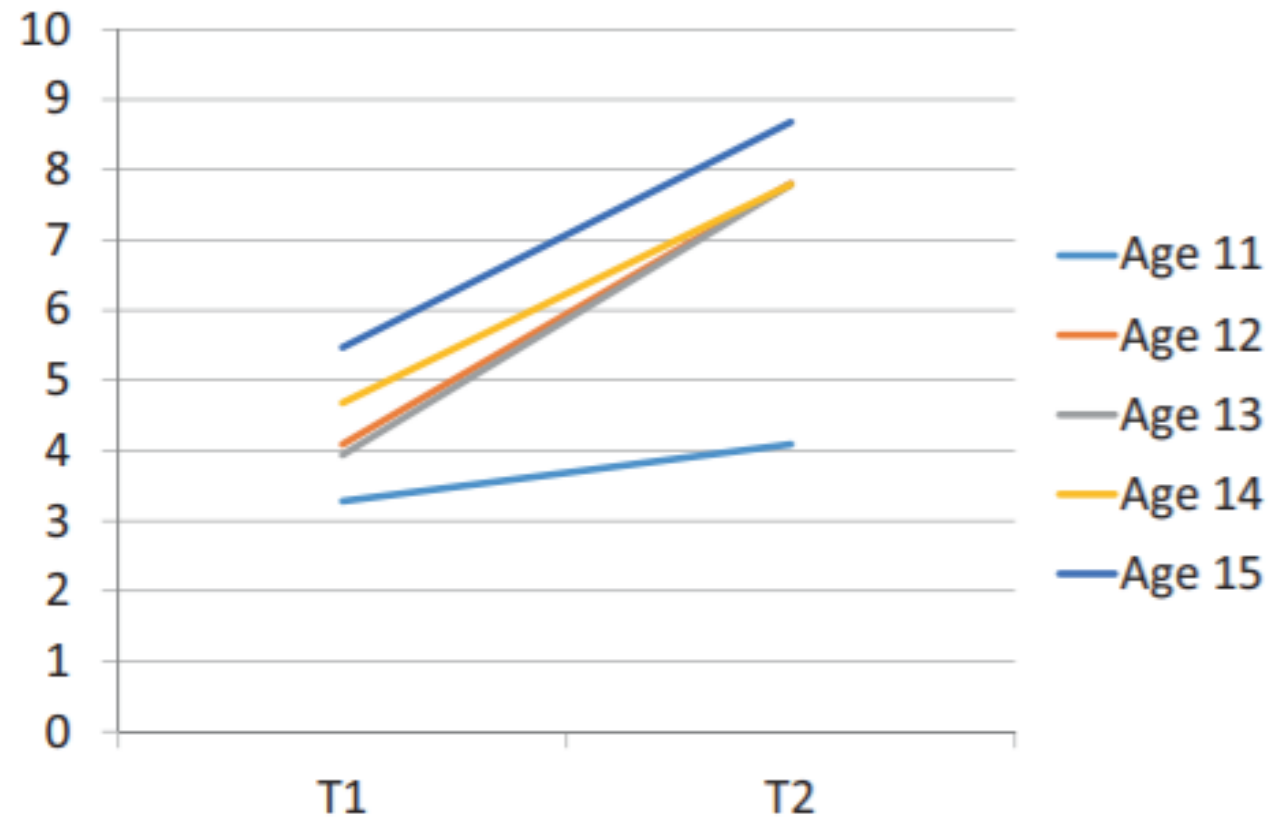


Fig. 1 Change score by age in sample overall.

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