

# Socialising the Genome



Dr Anna Middleton  
Head of Society and Ethics Research  
Wellcome Genome Campus  
Cambridge, UK







HiSeqX<sup>2</sup>  
Do not load  
Monday 12th Oct  
21.10.15

illumina  
HiSeqX2













How to start a  
conversation  
about  
genomics





### Genome British Columbia Intro Video

1,063 views · 11 months ago

Genome British Columbia is a catalyst for the life sciences cluster on Canada's West Coast and manages a cumulative program of genomics research projects and technology platforms. We work with academia and industry across forestry, fisheries, agriculture, mining and human health to generate social and economic benefits for British Columbia and Canada. [Read more](#)



You are more beautiful than you think.



### Dove Real Beauty Sketches



doveunitedstates

[Subscribe](#) 48,413

64,399,829

[+](#) Add to [Share](#) [...](#) More

[151,303](#) [3,886](#)







We explored....

**How** to start a conversation  
about genomics with people who  
know nothing about genomics



We explored...

How to get simple messages out  
on a large scale?

Do the messages work?

# Your challenge...

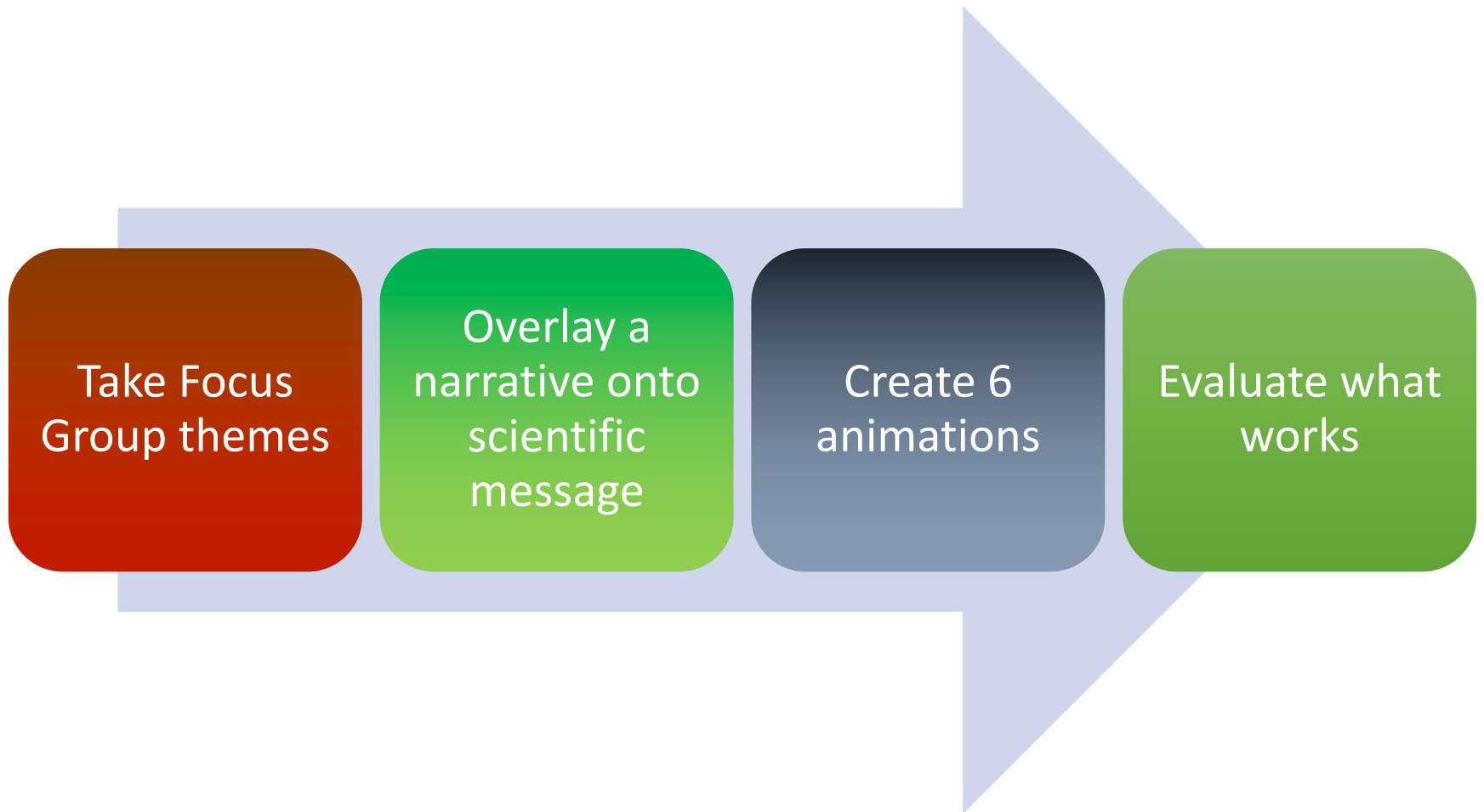
- To create an animation that explains what a mutation is
- Without using any scientific terms
- Using natural language
- In a way that keeps people's attention
- In about 1 minute



Glitch to explain pathogenic variant



# Process





# Focus Groups (7-10 in each)



Parents (mixed cultures)



'Women's group' – women from the Hertford Women's Guild



'Men's group' – curry club



Young people - choir



Council estate residents

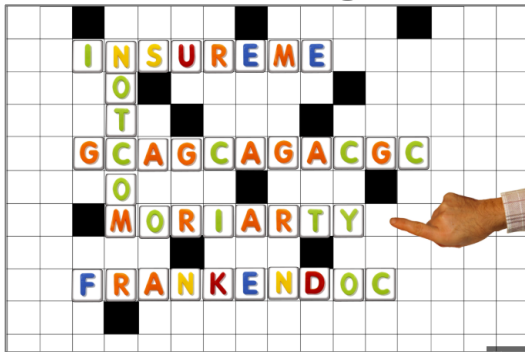
# Core Themes

- There is a lot of juggling and weighing up of information– ‘risk of disease’
- No idea what ‘genome’ means; is it to do with gnomes?
- Some want light-hearted approach –‘spreading genes around!’
- Insurance and exploitation are a fear



# The six films animations

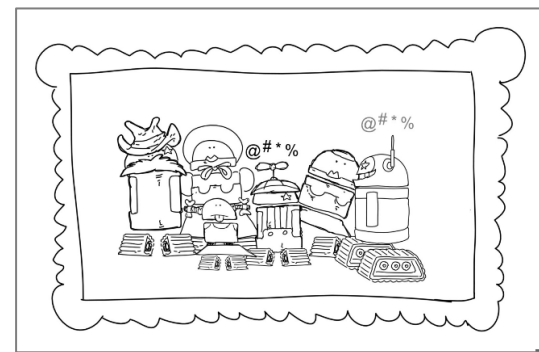
DNazing



Gene Deck Shuffle



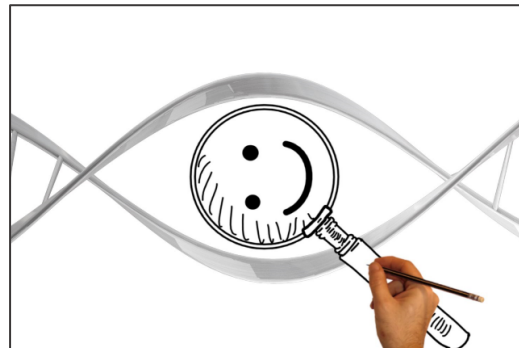
Glitch



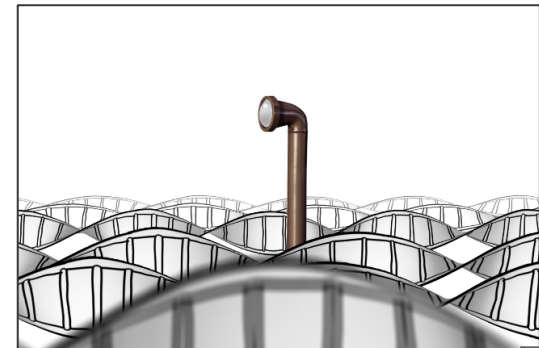
Gnome



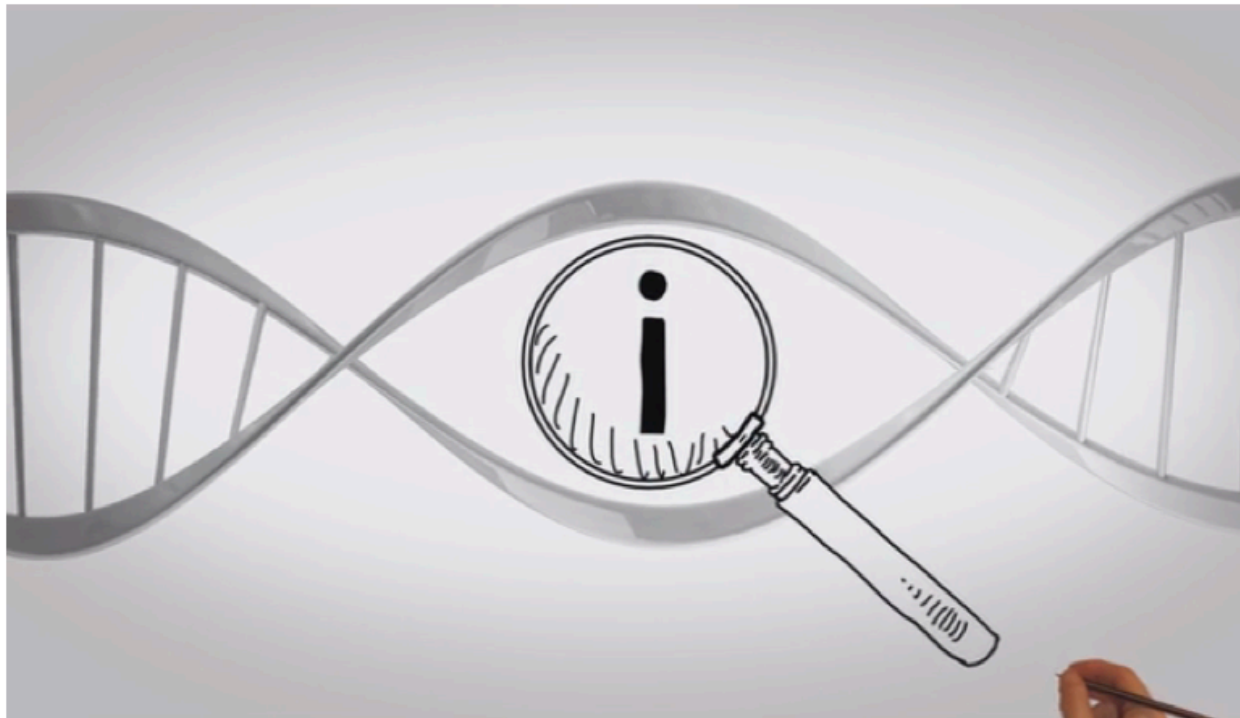
Reasons to be Cheerful



Search Me



Welcome to genetube – a space dedicated to shaping fresh, informative, surprising and shareable bite sized insights about DNA and genetics. Not for profit; just for humankind.



Thanks for all your help, please feel free to watch again and share the videos.

f Share via Facebook

t Share via Twitter



#reasonstobecheerful



#DNAZING



#genedeckshuffle



#mygenome



#glitch



#searchme





# Feedback

- 500 representative British public – data presented
- Web based survey from 1,800 people (same results, but biased to higher education)





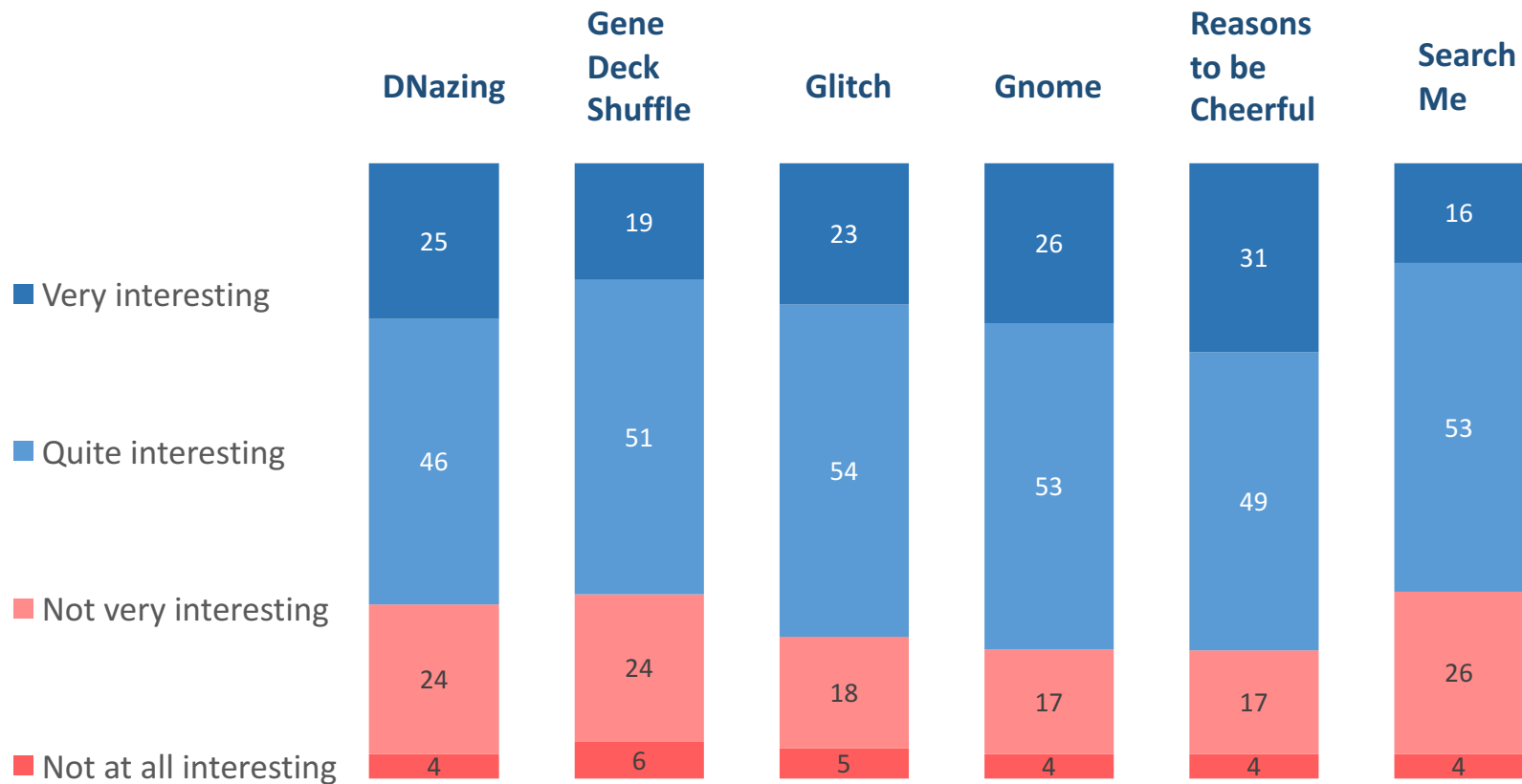


Search Me – using the search engine as a metaphor for sequencing





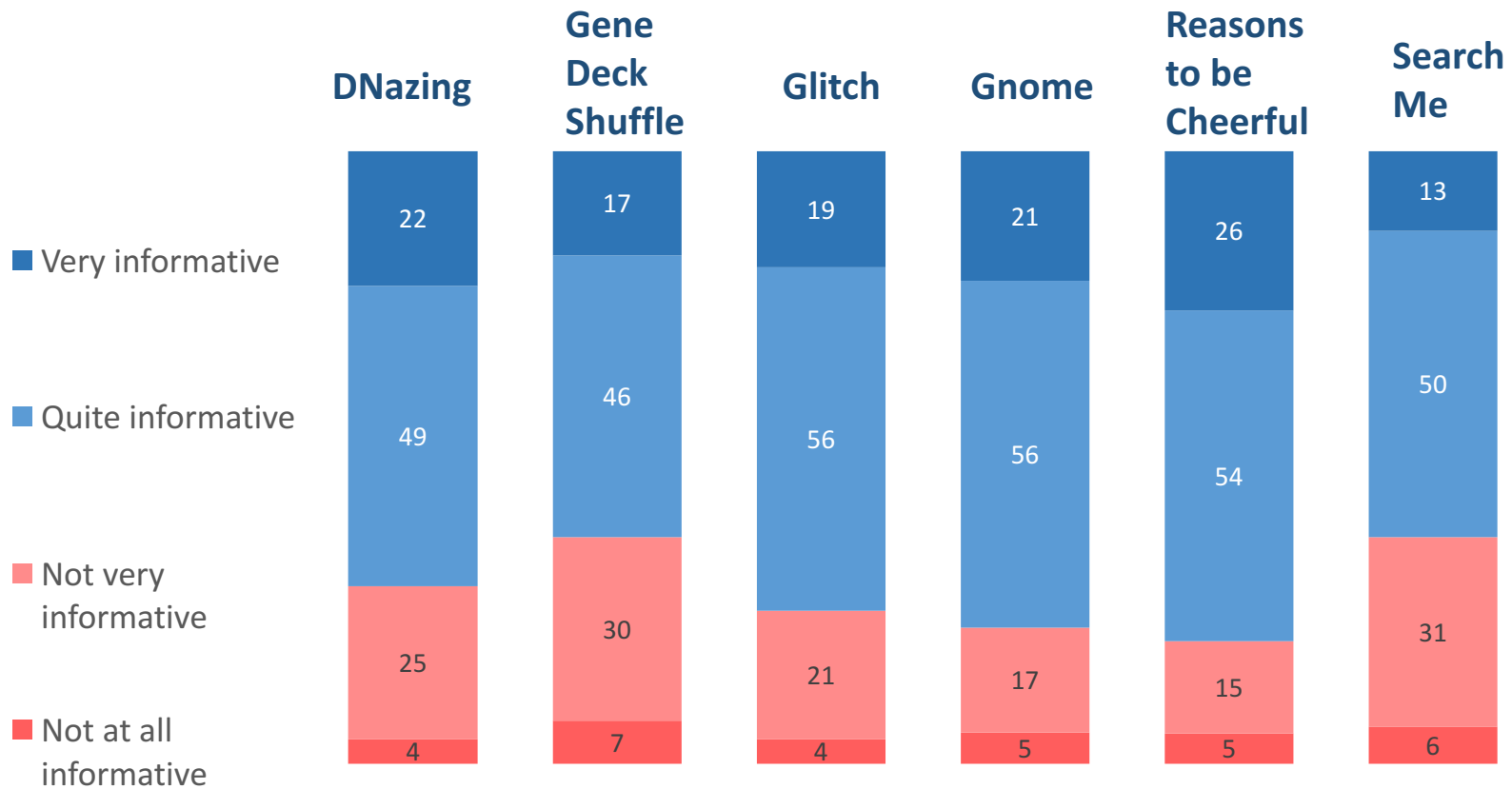
# The majority of respondents found the films interesting



Using the fishing gnome as a metaphor for sequencing



# The majority of respondents found the films to be informative

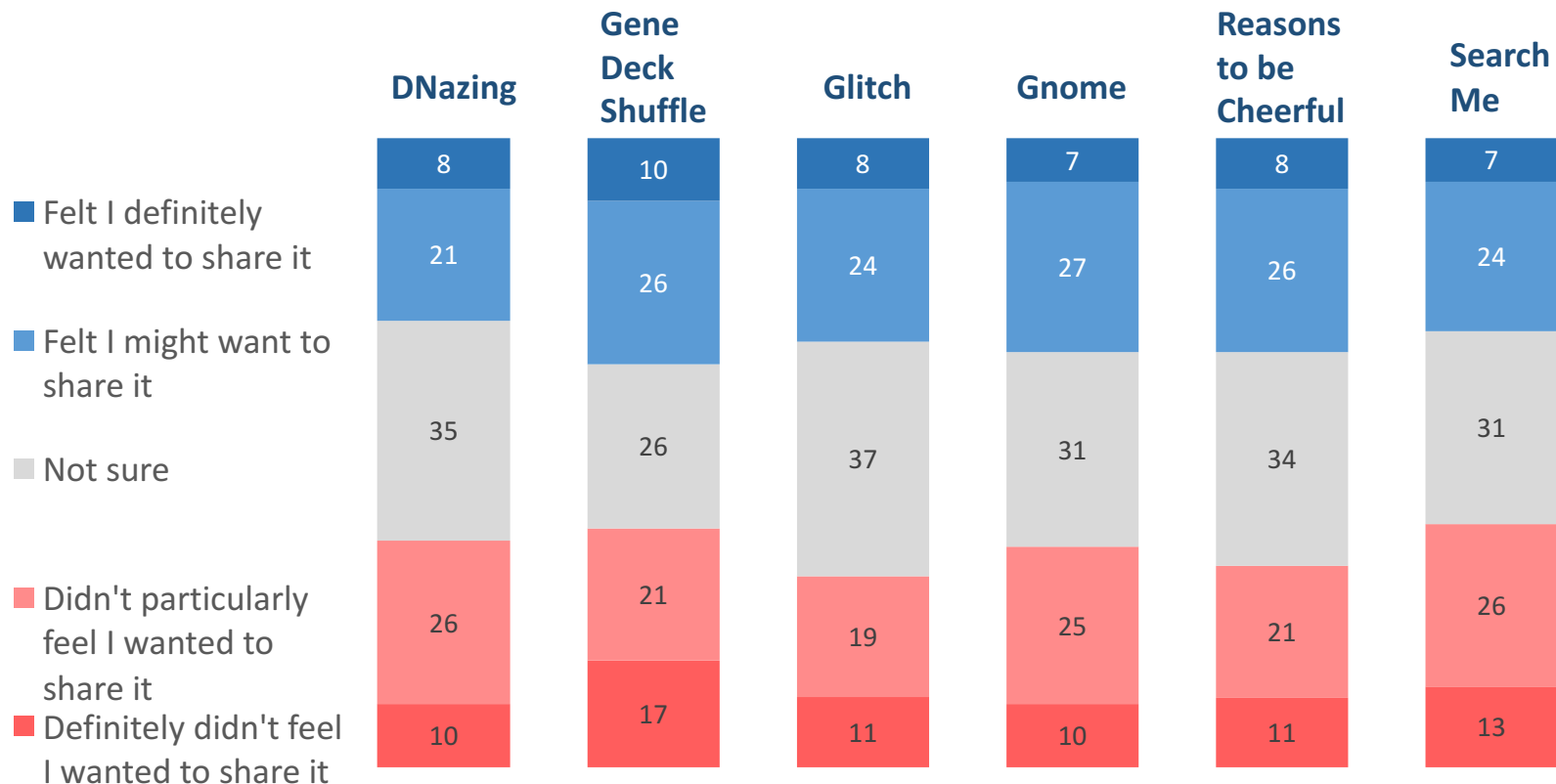




## Addressing fears about insurance as a conversation starter



# Sharability (e.g. via talking to someone about it, or via social media)



# Summary

- Have found some **new, evidence-based public engagement methods**, to build on
- Quirky works ('gnome', 'glitch', sex, etc)



## THE LANCET

Online First Current Issue All Issues Special Issues Multimedia Inform

All Content

[< Previous Article](#) Volume 389, No. 10079, p1603–1604, 22 April 2017

Correspondence

---

### Socialising the genome

Vivienne Parry, Anna Middleton



Annual Report of the  
Chief Medical Officer 2016

Generation Genomics



## Chapter 1

### About Genomics

A gene is a piece of DNA with a code for a specific instruction – like whether you have blue or brown eyes. A genome is an organism's whole set of DNA. When the human genome was sequenced for the first time, scientists assumed that there would be at least 100,000 genes. In fact, there were around 20,000 – the same as a starfish has. They also found that only 1% of the genome was comprised of genes; in the past the rest was assumed to be 'junk' DNA. It is now known to be incredibly important, with a vital role in controlling and regulating how your body works. That's why the whole genome is sequenced.

The study of all the DNA in the genome together with the technologies that allow it to be sequenced, analysed and interpreted is collectively called genomics, or genomic medicine.

### Glitches that make you, you

About 99.8% of our DNA is the same as other human beings. But the 0.2% that is different – about 3 to 4 billion letters – is what makes each of us unique. Some variation between genomes is perfectly healthy but some is not and it is these unhealthy differences that the 100,000 Genomes Project is looking for. You can think of them as spelling mistakes or missing paragraphs and pages in your instruction manual.

### Comparing the visible you with the invisible you

Information about exactly how an illness is affecting you is the focus of precision medicine. This includes the symptoms you have or what you can see. The 'phenotype' is an observable characteristic or trait that an organism has as a result of its genotype and the environment. Genomics relies on a better understanding of the genetic basis of disease to help predict and prevent phenotypic outcomes.

# FUTURE PROJECTS

Having a genomic test can be confusing







# Acknowledgements

## **Socialising the Genome Research Group**

- Julian Borra
- Vivienne Parry
- Kat Nevin-Ridley
- Amy Sanders
- Julian Rayner



**WELLCOME  
GENOME  
CAMPUS**  
**SOCIETY AND  
ETHICS RESEARCH**

