Socialising the Genome

Dr Anna Middleton
Lead Principal Social Scientist
Genetic Counsellor
Cambridge, UK
Acknowledgements

**Research Group**
- Anna Middleton
- Julian Borra
- Vivienne Parry
- Kat Nevin-Ridley
- Amy Sanders
- Julian Rayner

**Fabrika team**
- Steven Hess
- Toni Biočić
- Igor Savic

**Research Now**
- John Madell

**Funding – 3 way partnership (120k)**
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
You are more beautiful than you think.
Process

- Take Focus Group themes
- Overlay a narrative onto scientific message
- Create 6 animations
- Evaluate what works

www.GeneTube.org
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.

Share via Facebook

Share via Twitter

#reasonstobecherful
#DNAZING
#genedeckshuffle
#mygenome
#glitch
#searchme

www.GeneTube.org
Feedback

• 500 representative British public – data presented

• Web based survey from 1,800 people (same results, but biased to higher education)
The majority of respondents found the films interesting.
The majority of respondents found the films to be informative.
Sharability (e.g. via talking to someone about it, or via social media)

<table>
<thead>
<tr>
<th></th>
<th>DNazing</th>
<th>Gene Deck Shuffle</th>
<th>Glitch</th>
<th>Gnome</th>
<th>Reasons to be Cheerful</th>
<th>Search Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt I definitely wanted to share it</td>
<td>8</td>
<td>10</td>
<td>8</td>
<td>7</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Felt I might want to share it</td>
<td>21</td>
<td>26</td>
<td>24</td>
<td>27</td>
<td>26</td>
<td>24</td>
</tr>
<tr>
<td>Not sure</td>
<td>35</td>
<td>26</td>
<td>37</td>
<td>31</td>
<td>34</td>
<td>31</td>
</tr>
<tr>
<td>Didn't particularly feel I wanted to share it</td>
<td>26</td>
<td>21</td>
<td>19</td>
<td>25</td>
<td>21</td>
<td>26</td>
</tr>
<tr>
<td>Definitely didn't feel I wanted to share it</td>
<td>10</td>
<td>17</td>
<td>11</td>
<td>10</td>
<td>11</td>
<td>13</td>
</tr>
</tbody>
</table>
Summary

• Have found some new, evidence-based public engagement methods, to build on

• Quirky works (‘gnome’, ‘glitch’, sex, etc)

• Next project – larger filmed materials, building on metaphors
Welcome

- Welcome
  - Online footprint
  - Data access by others
  - Access by medical doctors
  - Access by non-profit researchers
  - Access by for-profit researchers
  - Perceived harms
  - Expectations of information
  - Trust
  - Socio-demographic questions
  - Submit your response

www.YourDNAYourSay.org