

Your interests; your opinions: Survey for research project: "Family communication and genetics"



Thank you for taking part in my survey. My name is Jonathan Roberts. I am a genetic counsellor who is carrying out some research at King's College London and the Wellcome Trust Sanger Institute.

I am trying to find out new ways to engage people in the story of DNA, inheritance and genetics. I am keen to do this by using people's own interests and knowledge and I am particularly interested in how families talk about inheritance. As part of this project it would be helpful to know some things such as what TV shows and films you like, what books you read and what you enjoy doing in your spare time.

All responses to this questionnaire will remain anonymous. However if there are any questions you do not wish to answer you can just skip them and move on.

I am interested in your thoughts and opinions so there are no right or wrong answers in this survey. By completing this survey you consent to the terms and conditions found in the information sheet which can be **found here** (<http://www.characterofdna.com/#!/project-and-survey/ajj9o>).

Your interests; your opinions: Survey for research project: "Family communication and genetics"



1. This questionnaire is the first part of a research project. The second part of this project will involve focus groups discussing films and TV programs related to inheritance. If you want to be contacted about this part of the project please provide contact details (either phone number or email address)

If you do not want to provide your contact details this is fine, you can still continue the survey.

2. Listed below are some different types of book. Please tick those you like reading. You can tick as many or as few you like.

- | | | | |
|--|---|---|--|
| <input type="checkbox"/> Science Fiction | <input type="checkbox"/> Cooking | <input type="checkbox"/> Horror | <input type="checkbox"/> Religion |
| <input type="checkbox"/> Adventure | <input type="checkbox"/> Fiction (stories and novels) | <input type="checkbox"/> Mind and Spirit | <input type="checkbox"/> Romance |
| <input type="checkbox"/> Comic/graphic novel | <input type="checkbox"/> Health | <input type="checkbox"/> Crime/Detective | <input type="checkbox"/> Popular Science |
| | | <input type="checkbox"/> Nonfiction (Fact | |

- Biographies History books) Home and Garden
 Comedy/humour Fantasy Poetry Other (please specify):

3. Listed below are some different types of film. Please tick those you like watching. You can tick as many or as few you like.

- Period Drama War Films Comedy Animation
 Science Fiction Bollywood Documentary World Cinema
 Musicals Westerns Action and Adventure Other (please specify):

4. Listed below are some different types TV programmes. Please tick those you like watching. You can tick as many or as few you like.

- History Crime/Detective News Talk show
 Comedy Reality TV Action and Adventure Sport
 Science Fiction Drama Documentary Other (please specify):
 Music Animation

5. How often do you watch/listen to the following? This can be on TV, radio or online.

	Never	A bit	A lot
Films	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Documentaries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Soaps	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TV dramas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comedy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. What interests do you have. Please tick as many or as few as you like.

- | | | | |
|---|--|---------------------------------------|---|
| <input type="checkbox"/> Computer Games | <input type="checkbox"/> Gardening | <input type="checkbox"/> Pets/animals | <input type="checkbox"/> DIY |
| <input type="checkbox"/> Reading | <input type="checkbox"/> Cooking | <input type="checkbox"/> Music | <input type="checkbox"/> Mechanics |
| <input type="checkbox"/> Watching TV | <input type="checkbox"/> Handicrafts/knitting
/sewing | <input type="checkbox"/> Board Games | <input type="checkbox"/> Politics |
| <input type="checkbox"/> Going to the
cinema | <input type="checkbox"/> Sports/exercise
/health | <input type="checkbox"/> Computers | <input type="checkbox"/> Other (please
specify): |
| <input type="checkbox"/> Social Media (e.g.
Twitter, Facebook) | <input type="checkbox"/>
Science/engineering | | <input type="text"/> |

7. Listed below are some different activities. Please tick those that you enjoy. You can tick as many or a few as you like.

- | | |
|--|---|
| <input type="checkbox"/> Cinema | <input type="checkbox"/> Theme parks |
| <input type="checkbox"/> Car boot sales | <input type="checkbox"/> Concerts |
| <input type="checkbox"/> Sporting events (e.g. football match, racing) | <input type="checkbox"/> Religious centres (e.g, Church, Mosques) |
| <input type="checkbox"/> Museums | <input type="checkbox"/> Betting centres/betting website |
| <input type="checkbox"/> Art Gallerys | <input type="checkbox"/> Playing sport |
| <input type="checkbox"/> Festivals (e.g. music, food, science,) | <input type="checkbox"/> Other: |
| <input type="checkbox"/> Zoo/aquariums | <input type="text"/> |

8. Are there any films, books, or TV shows you can think of that have used genetics as part of the story?

Your interests; your opinions: Survey for research project: "Family communication and genetics"



**WELLCOME
GENOME
CAMPUS**

9. Which, if any, of these films have you seen?

- | | | |
|--|---|---|
| <input type="checkbox"/> Jurassic Park | <input type="checkbox"/> The Boys from Brazil | <input type="checkbox"/> Films from the 'Spider Man' series |
| <input type="checkbox"/> Jurassic World | <input type="checkbox"/> Still Alice | <input type="checkbox"/> Harry Potter |
| <input type="checkbox"/> GATACCA | <input type="checkbox"/> Frankenstein | <input type="checkbox"/> The Hunger Games |
| <input type="checkbox"/> Films from the 'X Men' series | <input type="checkbox"/> Blade Runner | <input type="checkbox"/> The Fly |

10. Are you interested in how genetics relates to any of the following?

	Not interested	A bit interested	Very interested
Pets/animal breeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetically modified food	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Evolution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ancestry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forensic evidence/solving crimes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	1 Totally genetic	2	3	4	5 Totally environmental	Don't know
Sporting ability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intelligence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. Have you ever chatted with other family members about whether any of the following traits might be inherited in your family?

- | | | |
|--------------------------------------|---|--|
| <input type="checkbox"/> Hair colour | <input type="checkbox"/> Musical ability | <input type="checkbox"/> Academic ability |
| <input type="checkbox"/> Eye colour | <input type="checkbox"/> Artistic ability | <input type="checkbox"/> Sporting ability |
| <input type="checkbox"/> Height | <input type="checkbox"/> Sense of humour | <input type="checkbox"/> Other (please specify): |
| <input type="checkbox"/> Weight | | <input type="text"/> |

16. Please tick the answer that most closely fits with your view on the following statement.

"If there was an inherited disease in my family, I would find it easy to discuss with my relatives"

- Strongly Disagree
- Disagree
- Uncertain
- Agree
- Strongly agree

17. Which of the following best describes your gender.

- Male
- Female
- Transgender

18. How old are you

19. What education have you completed

- School
- Undergraduate degree
- Postgraduate
- Apprenticeship
- Other professional qualification
- Other (please specify):

20. Please tell me about your current employment

- I am in full time education
- I am currently out of work
- Your current job/most recent job

21. Which newspaper to you regularly read (you may tick multiple boxes)

- Sun
- Mirror
- Daily Express
- The Times
- Daily Mail
- Guardian
- Independent
- Metro
- Telegraph
- None
- Local paper
- Other (please specify):

22. What is your postcode

- Prefer not to say

Comments:

23. Which ethnic group do you belong to?

- White
- African American, Black
- Hispanic
- Indian

- East Asian (e.g.Chinese, Japanese)
- Arabic, Central Asian
- Pakistani
- Bangladeshi
- Please specify if you would prefer

24. Would you say you are

- A religious person
- Not a religious person

Comments:

Appendix 2 Calculating the classes the LCA analysis

https://onepoll.com/wp-content/uploads/2019/01/Panel_Overview_2018.pdf

The first step of the LCA was to generate a manageable number of variables from the data that could be used to carry out LCA. These variables were generated using the survey responses to the questions about participants interests and cultural preferences.

Responses regarding cultural participation and interests were looked at in three ways. First, the ways in which the content is qualitatively similar was considered. For example, an interest in science and engineering is similar in content to reading popular science. In a similar way, cultural activities that could broadly be described as 'spiritual' can be put together (reading religious books, mind and spirits, attending religious centres). Resources that could be described as 'factual' can also be brought together, documentaries, non-fiction, biographies and history books.

Second the responses were also assessed on how they are valued – how 'elite' they are ('highbrow' or 'lowbrow'). This approach primarily draws on work by Bennet, Savage et al., (2013) who used multiple correspondence analysis to assess the value attributed to 'highbrow' and 'lowbrow' culture in the United Kingdom. They provide empirical evidence that, while the ability to consume a wide range of culture has become a form of distinction (the "cultural omnivore"), this does not mean all culture is regarded as equal. There is strong evidence, they argue, that old divisions between 'low' and 'high' culture still remain. Evidence of this comes from patterns of cultural participation, where powerful class divisions in cultural practices remain. 'Elite' practices - going to museums, opera and art galleries, liking classical music and reading more – are still primarily the preserve of those from higher socio-economic class. So-called 'low brow' activities – enjoying soaps, liking musicals and watching more TV are more commonly enjoyed by people from lower socio-economic class (Bennett, Savage et al., 2009 p. 180).

Finally, it was possible to consider correlations between different responses in the data. For example, to assess if likening documentaries was correlated with enjoying biographies.

Variables were created by assessing the response based on the criteria outlined above, namely

1. The content of the knowledge – like goes with like
2. The criteria by which they were ‘legitimate’ is opposed to ‘low brow’
3. Correlations between answers

Using these criteria, six variables were generated that encompassed participants enjoyment and interest in: Science Related Cultural Capital (e.g. liking popular science books) Factual media (e.g. documentaries, new programs) ‘Legitimate’ culture (e.g. art galleries, museums) ‘non-legitimate’ cultural e.g. soap operas, watching TV), familiarity with genetics in fiction and Health.

The next step to was to assess whether a participant will be analysed have high interest or low interest in across variables. Let’s take the example of ‘legitimate culture’. This was made up of questions regarding participants’ interest in: Poetry, world film, politics, art galleries, museums and reading. The question to answer was: how many of these would a participant have indicated they were interested in to be rated as having high levels of legitimate culture? Of course, this process creates binary categories (high interest or low interest) and in only allowing for participation to be rated as ‘low’ or ‘high’ some nuance lost. However, steps were taken to try retain some of the complexity in the way participants were sorted into high and low categories. This was done by exploring the correlation matrix between the responses that made up each variable. If there was a strong correlation it would suggest that the categories were homogenous. If the correlation were weaker this would mean the categories were more diffuse. For more diffuse variables participants would be required to tick more options, thus ensuring there was a genuine similarity amongst those rated ‘high’ and those rated ‘low’.

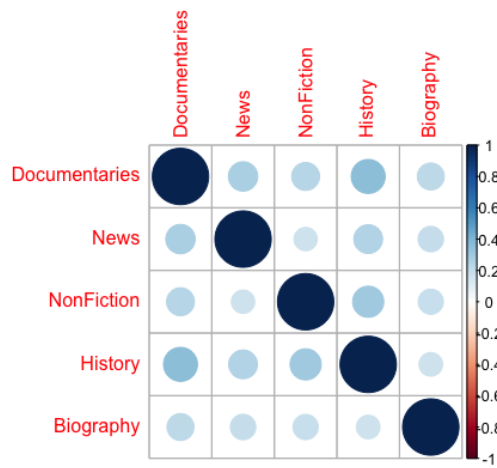
The variables were as follows:

Factual: Documentaries, news, non-fiction, history and biography (participants were rated as 'High' if they selected 3 or more)

High interest in factual media: 66%

Low interest in factual media 34%

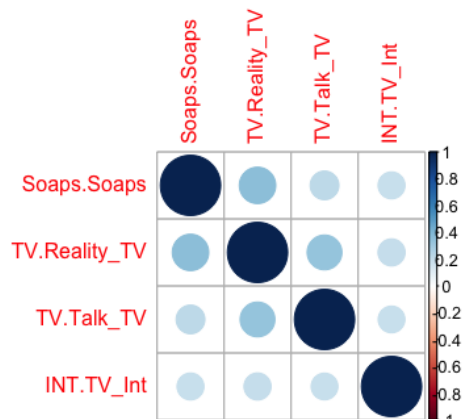
Correlation Matrix:



'Non-legitimate' culture: Soaps, Reality TV, talk show, Interest in TV (High = two or more)

High: 52%

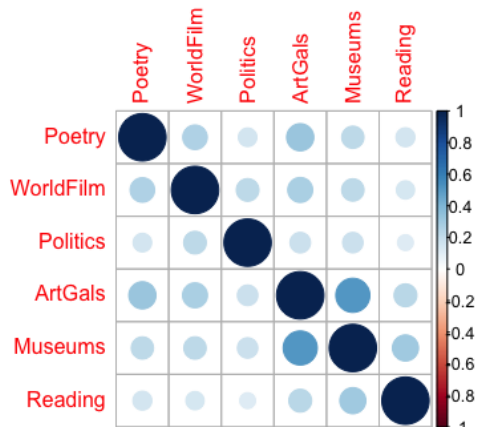
Low 48%



‘Legitimate’ culture: Poetry, world film, interest in politics, visit art galleries, visit museums, interest reading (High = three or more)

High: 38%

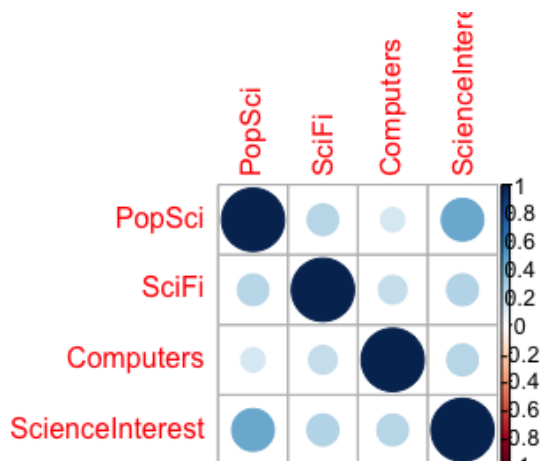
Low 62%



Science Related Cultural Capital: Popular science books, Science Fiction, Interest in computers, Interests in Science (high = three or more)

High: 32%

Low 68%



Familiarity with Genetics in pop culture (based on familiarity with following films: Jurassic Park, Jurassic World, Boys from Brazil, Frankenstein, Spiderman, Hunger Games, X -Men, Still Alice, GATACCA and Blade Runner. (Participants were rated as High if they had seen over 50% of these films)

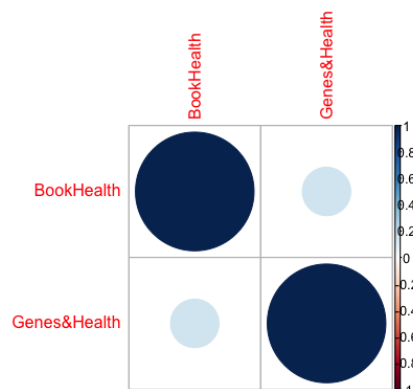
High: 38%

Low:62%

Health: Health books, interested in health and genetics (High = one or more)

High 50%

Low 50%



It should be noted that there is a significant amount of interpretation on the researcher's part in generation these variables. This is not unusual in LCA (Waitkus and Groh-Samberg 2017). As such, I have tried to make the generation of the variables robust and transparent, recognising that they represent assumptions and interpretation on the part of the researcher.

In R the PO-LCA package was used to calculate the latent classes. I choose a three-class model on the basis of the sample share (a model producing a class containing less than 10% of the sample was discarded) as well as the Bayesian information criterion, which is minimised at three classes.

Table Model fit statistics:

Number of Classes	BIC
1	11271.51
2	11039.55
3	10998.77
4	11028.08
5	11049.52
6	11092.62

Appendix 3 Familiarity with genetics terminology

The survey asked participants about their familiarity with eight genetic terms. Mirroring other survey research, the majority of participants were familiar with genetic terminology. Participants were generally familiar with the terms DNA (98%), genetics (96%), evolution (95%), gene (95%), cloning (95%), chromosomes (93%), and mutation (92%). Replicating findings from other research (Middleton 2017) 'genomics' (38%) was the most unfamiliar term.

As a guide to participants' familiarity with genetics terms, 38% participants had heard all these terms (8), 48% all except cloning (7) and 14% had heard of 6 or fewer. For clarity, I divide these groups up into 'high', 'medium' and 'low' in reference to their familiarity with genetic terminology, as measured in the survey.