Genetics: International Public Knowledge, Perceptions and Engagement

Robert Carroll Chapman

Department of Psychology
Goldsmiths, University of London

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Declaration

I declare that the work presented in this thesis is my own. All experiments and work detailed in the text of this thesis are novel and have not been previously submitted as part of the requirements of a higher degree.

Signed: _____ Date: _____

Abstract

Advances in genetics not only have implications for health, but also in areas such as law, society, education and philosophy. There is a scarcity of research focusing on population levels of genetic knowledge and opinions outside of medical domains. As such, little is known about what people generally know, think and feel about genetics. The main objectives of this doctoral thesis are therefore: to develop a novel measure of genetic knowledge and opinions (the International Genetic Literacy and Attitudes Survey – iGLAS); to evaluate the results of that measure (N=10090); and to experimentally investigate the relationship between genetic knowledge, opinions, the media and education (N=33-126). iGLAS results indicate poor levels of genetic knowledge, with variation based on factors such as religion, political affiliation, education level, profession and nationality. Different aspects of genetics showed differences in how well they were understood, and by whom. Genetic knowledge was found to be positively associated with attitudes to important applications of genetics. Experimental studies indicated that genetic knowledge and views on genetic destiny appeared to be relatively unchanged by small manipulations in media exposure and educational interventions. More involved programs of study were found to be much more effective. Public engagement activities were conducted in parallel with this thesis. Attendees of these events reported considerable enjoyment and were keen to learn more about genetics. These events also provided material related to the research aims above. For example, during one event participants were found to have relatively polarised and intransigent views on the use and sharing of genetic information. The findings of this thesis indicate the importance of addressing poor genetic knowledge in the public, especially for key stakeholders such as educators and lawyers. Such endeavours are likely to be met with considerable enthusiasm, especially if they are engaging and encourage open discourses.

Statement of Authorship

The work presented in this thesis is original and my own. The data management, input, cleaning and all analyses have been completed by me.

Data collection using the International Genetic Literacy and Attitudes Survey (iGLAS) is ongoing. The measure was developed and implemented by me, with support from the team at The Accessible Genetics Consortium (TAGC) and InLab. The student collections in iGLAS reported in Chapter 4 were managed and promoted by: Mammarella Irene Cristina of the University of Padova, Italy; Juan José Madrid Valero at the University of Murcia, Spain; Olusegun Ogundele of the Tai Solarin University of Education, Nigeria; and Daria Matsepuro of Tomsk State University who has been instrumental in aiding collections across Russia. Fatos Selita organised much of the data collection in the UK. Translations were undertaken by several international collaborators. Thanks particularly go to Maxim Likhanov who worked on the Russian translation and facilitated a great deal of data collection.

Chapter 5 reports results from an experimental study into media framing. This formed part of the third year undergraduate project of Lucy Gallop, who I co-supervised with Professor Yulia Kovas. That project resulted in a publication on which Lucy Gallop and I are joint first authors:

Gallop, L., Chapman, R., Selita, F., & Kovas, Y. (2017). Effects of Education and Media Framing on Genetic Knowledge and Attitudes. *The European Proceedings of Social & Behavioural Sciences EpSBS*, *33*, 121–141.

Chapters 2, 3 and 6 utilise data from papers on which I was the lead author:

Chapman, R., Likhanov, M., Selita, F., Smith-Woolley, E., & Kovas, Y. (2017, December 13). *Genetic Literacy And Attitudes Survey (Iglas): International Population-Wide Assessment Instrument*. 45–66. https://doi.org/10.15405/epsbs.2017.12.6

Chapman, R., Likhanov, M., Selita, F., Zakharov, I., Smith-Woolley, E., & Kovas, Y. (2018). New literacy challenge for the twenty-first century: Genetic knowledge is poor even among well educated. *Journal of Community Genetics*, 1–12. https://doi.org/10.1007/s12687-018-0363-7

Chapman, R., Devereux, J., Nanau, V., Smereczynska, V., Matsepuro, D., & Selita, F. (2018). To Tell or Not to Tell: The Ethics and Law of Disclosing Health-Related Genetic Information to Family Members. *Psychology in Russia: State of the Art*, *11*, 68–78.

The ‘Genes & Tonic’ public engagement events discussed in Chapter 6 were planned and co-ordinated by me but would not have been possible without the phenomenal team at InLab, including considerable contribution from Emily Smith-Wooley, Tomasz Bloniewski, Teemu Toivainen and Maxim Likhanov. Funding for these events was provided by the Graduate School and Public Engagement Offices at King’s College and Goldsmiths, University of London. The 4th ‘Genes & Tonic’ event GEkNOwME was conducted as part of the Economic and Social Research Council’s (ESRC) Festival of Social Science 2018 and part funded by the ESRC.

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One of the most fulfilling experiences of my time at Goldsmith's has been working with InLab. In my many years with this research team I have worked with more excellent collaborators than I can count. In particular, I should like to thank Elaine White, Maxim Likhanov, Margherita Malanchini and Tomasz Bloniewski for providing guidance and support from the very outset of my PhD. I should like to thank the colleagues I have worked so closely with on some excellent and interesting research papers, particularly Fatos Selita and Juan Jose Madrid Valero. A special thanks goes out to those students whose third year projects I co-supervised: Lucy Gallop, Lava Ahmed, Vanessa Smereczynska and Victoria Nanu. I learnt so much from each of you. Above all, I should like to offer my sincere thanks to Teemu Toivainen. You are an inspiration, a great friend and a wonderful distraction, I know ours is a friendship and collaboration that will go on for many years.

On a more personal note, I should like to thank my wonderful friends and family. All of you have done more than you will ever know. Thank you especially to Lisa Miller who all those years ago taught me that wonderful things happen when you take a leap. To Joanne Davies and Joanna Hooper, the love and stability you provide has been more than I could ever have asked for. To Robert Maxwell-Marsh, thank you for reminding me there is a life outside of my PhD. To Charlotte Donachie, for keeping my mind open. And finally, to Emma Martin, for all the above and so much more.

Statement on Accessibility

Accessibility has been kept in mind in the production of this thesis, with the hope that this project on public engagement with genetics might be accessible to any interested readers and not only experts in the area.

A glossary of terms is included at the end of this document. The first mention of a new technical term is presented in the text in **bold**.

Where possible, and to maximise access by readers with visual impairments, graphs have been presented with both colour and texture coding.

To aid the visual inspection of results, where appropriate to the data, tables have been shaded so that cells with higher numbers are tinted. The higher the number, the more intense the tinting.

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Chapter 1: Introduction

We live in an era of advanced and advancing genomics research (Collins, 2010). Genetics is starting to touch all aspects of human life and experience, from genetically modified food (Lang, 2016) to reproduction choices (Roberts & Wasserman, 2009), medicine (Davies, 2017), law (Selita et al., 2019) and education (Asbury & Plomin, 2013). As we move further into the genomic era there will be increasingly important implications for ethics, society, law and philosophy. As such, it is important that all people are equipped with sufficient knowledge of genetics to engage effectively in this new era.

Previous research in the area of public knowledge and opinions about genetics has primarily focused on prenatal, medical and disease aspects (e.g. Morrow et al., 2016; Olesen et al., 2016a, 2016b; Tang et al., 2017). The first area in which to evaluate and develop genetic knowledge is medicine. Medical applications of genetics offer the first substantial benefits to people's health and health choices. The research on public engagement in these areas is vital, but other areas have not been as well studied. When it comes to the genetic knowledge of patients and those engaging with health services it can reasonably be expected that advice and guidance will be available from healthcare professionals and genetic counsellors (Harper, 2010), especially as genomic medicine becomes more integrated to general healthcare practices (Davies, 2017). It is not clear what, if any, channels will be available for knowledge transfer outside of these settings. Additionally, genetic research is not constrained to medical domains. Ethical issues of medical genetics are not limited to patients but also have implications for family members and society. For these reasons, it is vital to gain a better understanding of what people know, think and feel about all aspects of genetics, where their information comes from and how their opinions are formed. Only then can appropriate and effective public engagement and educational programmes be developed. This thesis presents a systematic investigation of genetic knowledge and opinions in a broad range of areas impacted by advances in genetic research and technology. It also evaluates attempts to engage people in these areas.

The first full human **genome** sequence was announced as complete in 2003, an endeavour estimated to have cost between USD$500 million and USD$1 billion (Collins et al., 2003). It now costs as little as USD$2000 to sequence the human genome (Schwarze et al., 2018). This reduction in cost, and the increasing efficacy of genomic sequencing technology, means that there has been a proliferation of research and findings in recent years, both inside and outside medicine.

Genetic relatedness means that what one individual might learn about their genome has implications for their family members. For example, if a genetic test reveals that someone will develop Huntington's Disease (HD) (Dayalu & Albin, 2015), should they be morally obliged to share this information with family members? Should health care providers be legally obliged to share this information? This particular example is based on a real-life court case (*ABC v St George's Healthcare NHS Trust & Ors [2015] EWHC 1394 (QB)*, 2015) and is explored in Chapter 6.

When making such decisions at the individual level there are important genetic concepts that need to be understood and considered. For example, antagonistic **pleiotropy** means that a genetic variant that may bestow a protective or desirable outcome on one trait, may pose risks to other traits (e.g. Cheng et al., 2015). Genetic influences are also overwhelmingly **polygenic** (i.e. related to considerable numbers of interacting genes) and probabilistic, rather than monogenic (the product of a single gene) and deterministic. Is this something that is well understood by people? At the sociological level, consideration needs to be given to factors such as disability rights, the rights of future generations and the richness associated with genetically varied (**heterogeneous**) communities. Genetic knowledge is therefore not only important at the level of individual choices, but also on a larger sociological level, especially if debates in these areas are to be accurate and fruitful. As such, it is important that genetic knowledge is improved at the population level.

Genetic Knowledge vs Genetic Literacy

Genetic literacy is a common term within the literature and has been defined as "sufficient knowledge and appreciation of genetic principles to allow informed decision-making for personal well-being and effective participation in social decisions on genetic issues" (Bowling et al., 2008). However, some controversy surrounds the use of this term. For example, there is an organisation in the USA called the 'Genetic Literacy Project' -GLP (https://geneticliteracyproject.org/). This organisation works to disseminate genetic findings in the areas of human genetics and agriculture. However, there have been controversies about the relationship between the GLP and the American agrochemical and agricultural biotechnology industry (Kaskey, 2015). For example, the GLP published a series of articles from academics which were funded by the agricultural company Monsanto, without declaring this potential conflict of interest. Another issue with the term is the existence of a measure called the Rapid Estimate of Adult Literacy in Genetics (REAL-G) (Erby et al., 2008), which assesses familiarity with terms related to genetics. It is presented as a reading list of words of increasing complexity and so can be considered more a measure of literacy, rather than an evaluation of the understanding of genetic concepts.

To avoid any confusion in the current project it has been decided to mostly use the term 'genetic knowledge', rather than 'genetic literacy', although the fundamental principles of genetic literacy as defined by Bowling are still applicable and, in fact, the term 'literacy' is used in the name of the novel measures of genetic knowledge developed as part of the present project.

Why Study Genetic Knowledge?

People's views on science are formed under a myriad of influences, including religion (Allum et al., 2014, 2017) and politics. For example, studies have identified that people at different ends of the political spectrum have interests in different types of science (Shi et al., 2017). This study found that individuals with more liberal political views on average prefer books on basic scientific principles such as astronomy, physics and zoology. Those of a more conservative

ideology on average tend towards more applied and commercial sciences such as criminology, medicine and geophysics. Further research has identified that opinions in certain fields cannot be explained by a lack of knowledge. Instead, knowledge was found to confer a polarising effect (e.g. Kahan et al., 2012). For example, in relation to climate change, those participants already sceptical of climate change were more sceptical when more knowledgeable, and vice versa (Kahan et al., 2012). Some researchers (e.g. Klintman 2019), suggest that people's resistance to scientific facts and their necessary implications form for social, economic and evolutionary reasons. This contradicts the 'deficit model', which suggests that people hold their views because they do not have sufficient information about the science in question (Brown, 2009).

The applicability of the deficit model is not clear in relation to genetic knowledge and opinions. Some studies have identified more favourable opinions about genetic technology in those with better genetic knowledge (Allum et al., 2014; Pardo et al., 2002). Others have found no link between knowledge and attitudes towards genetics (Gottweis, 2002; Henneman et al., 2004; Sturgis et al., 2010). One study suggested a negative link (Jallinjoa & Aro, 2000).

Unlike certain areas of science, most notably the sciences of climate change (Linden et al., 2017) and vaccination (Kata, 2012), there are arguably no necessary immediate or obvious implications of genetic research. In the case of climate change and vaccinations, the preponderance of the evidence suggests certain actions should be taken at the individual and state level. There is a 'correct' conclusion intrinsic in the scientific evidence. In many areas, this is not the case with genetic research. Genetic research is providing new insights every day, with considerable benefits already being realised in medical domains. However, what is done with many of these insights is for society to decide. For example, should family members have a right to the genetic information of their first-degree relatives? Should genetic information be used in court cases? What might genetically informed educational reform look like and how might it work? The answers to such questions are unlikely to be directly indicated by genetic research in the same way as for climate change and vaccination research. As such, there is no 'correct' view to align public opinion with. Therefore, whilst attempts to engage the public with

genetics should follow the good principles of engagement rather than instruction (as suggested by the deficit model), it is also important that people are supported in improving their genetic knowledge. To this end, it is important that levels of genetic knowledge are evaluated and understood. After all, if people believe that we should or should not utilise genetic research in areas such as medicine, legal and educational reform, they should have a fuller and more accurate understanding of exactly what such reform might look like, and what might be possible. Without this knowledge, their arguments cannot be fully developed, and their voices cannot be properly heard.

As well as considering what people know and think about genetics, it is also important to consider where that knowledge comes from and how opinions are formed. Previous research has suggested two main avenues through which non-scientists access scientific knowledge; education and the media (Falk, Storksdieck, & Dierking, 2007; Wellington, 2001, 1994). As such, it may be that poor genetic knowledge results from outdated or incomplete instruction at school and persists because of similar issues in media coverage. For example, an Introductory book *Genetics for Beginners* from 1994 states of the human genome that "There's still a hundred thousand or so genes to be found before even the main landmarks in the map have been sorted out" (Jones, 1994, p. 123). We now know that the human genome consists of about 20,000 genes (Strachan & Read, 2018), but this misinformation may still be exerting and influence. Similarly, there may be perseverating impacts from how genetics is and was covered in the media. These issues will be covered further in chapter 5.

Review of research on genetic knowledge

The rapid advancement of genetic research means that studies on public knowledge of genetics can become quickly dated. Here I briefly summarise the results of the comprehensive review, conducted as part of this thesis, of studies related to genetic knowledge published in the last five years. The search of the relevant papers was conducted using Web of Science and the following search term: TITLE: (genet*) AND TOPIC: (knowledge OR literacy) AND TOPIC: (Attitude*

OR opinion* OR think) NOT TITLE: (*natal OR nurse* OR disease* OR counse* OR cancer* OR syndrome* OR PKU OR sickle*) NOT TOPIC: (algor* OR hierar*) Timespan: Last 5 years. Indexes: SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI. Further details are available from the author upon request.

The review identified that the recent trend in studies related to genetic knowledge has been focused on the application of this knowledge in specific domains such as *BRCA1* and *BRCA2* mutations (e.g. Tang et al., 2017) and attitudes towards pre-implantation genetic screening and other prenatal considerations (e.g. Morrow et al., 2016; Olesen, Nor, & Amin, 2016; Olesen, Nor, & Amin, 2016). As the current project is interested in genetic knowledge outside of medical domains, the search term was constructed to exclude several medically salient terms from the search criteria (natal, nurse, disease, counselling, cancer, syndrome, PKU, sickle). Even with these exclusion criteria applied, most papers (43% N=88) related specifically to genetic knowledge and opinions in clinical contexts and/or in relation to specific traits (typically diseases). There has also been considerable recent interest in people's attitudes towards Genetically Modified Organisms. See Table 1 for the results of the 205 studies identified in this review.

Table 1. Categorisation of results from a systematic review of 205 articles related to public knowledge and engagement with genetics

Theme	Article N	Description
GMO	48	Knowledge, views and opinions about genetically modified organisms, including in the human food chain
Trait	46	The genetics of specific traits, typically disease traits
Clinical	42	Clinical, medical, family and natal applications of genetics
Other	27	These papers did not focus on a specific sample, condition or application of genetics.
Industrial	20	Non-human aspects of genetics (methodologies of genetic research, farming and ecological applications etc.)
Education	15	Genetics in education. Including how genetics is taught and the views of parents and teachers on genetics
DCGT	7	Direct to consumer genetic testing
Total	205	

These studies employed very different paradigms (qualitative, quantitative, experimental, focus groups, surveys etc.) and most conducted research with specific populations such as parents and patients. The results of these studies, as well as some key studies more than 5 years old, are

inconsistent. Some suggest good levels of genetic knowledge (Dar-Nimrod et al., 2018; LePoire et al., 2019). Others suggest that genetic knowledge is insufficient (Bowling et al., 2008; Lanie et al., 2004; Miller et al., 2006; Mills Shaw et al., 2008). For example, only 34% of 62 respondents, recruited through a random digit dialling method in the continental United States, knew that genes are stored in every cell of the body (Lanie et al., 2004). These inconsistencies are not surprising. The rapidly changing field of genetics means that old information becomes outdated quickly. With any measures such as these it is also difficult to categorise responses as 'good' and 'bad'. There is no statistical tipping point at which an individual's ability to discuss genetics shifts from incompetent to competent. Furthermore, it is not clear which components of knowledge have utility. For example, does a good conceptual understanding need to be built on concrete factual knowledge, or can people engage with important genetic debates without, for example, knowing how many base pairs there are in the human genome, or the basic 'alphabet' of DNA (TAGC)?

The Aims of the Present Thesis

The overarching aim of the present thesis is to expand the previous research into genetic knowledge so as to move the conversation out of primarily medical domains and to involve a broader scope of participants.

Many of the studies presented in this thesis have utilised the International Genetic Literacy and Attitudes Survey (iGLAS) – created and validated as part of this thesis research. iGLAS was designed to be an adaptive measure, intended to give a fast and engaging tool for evaluating functional genetic knowledge and opinions. The current version of iGLAS consists of 5 sections: Demographic details, Genetic Knowledge, Opinion items, Vignettes, and 2 items on Neuromyths. See Chapter 2: 'iGLAS Versions' and Appendix 1 for further details of the different versions of iGLAS.

iGLAS is distinguished from other measures of genetic knowledge for two reasons. First, it provides feedback to participants on their performance as well as further information at the item

level (see Appendix 2). Secondly, it includes multiple choice questions rather than the true/false options seen in most other measures of genetic knowledge.

iGLAS can also be used for further in-depth projects using skip logic. For example, a study is currently underway that uses skip logic to present additional items to those participants who report that they either work in a legal profession or study law. These items will not be addressed in the current study but are being utilised in 3 additional projects. Chapter 2 of this thesis describes the development and validation of iGLAS.

Chapter 3 presents the research that used iGLAS to evaluate general levels of genetic knowledge and how these differ based on demographic details, such as political and religious affiliation. Educational, employment and international differences are also explored in relation to genetic knowledge. Chapter 3 also considers some of the implications of genetic knowledge.

Chapter 4 explores the errors participants make in iGLAS. This analysis provides additional insights into sources of misinformation and possible reasons for this misinformation. The chapter presents results from the total iGLAS sample, as well as from targeted collections with students in Italy, Nigeria, Russia, Spain and the UK.

Chapter 5 presents results from iGLAS on genetic knowledge and media engagement as well as two experimental studies and a focus group discussion. The first experimental study considers the impact of how genetics is portrayed in the media; the second considers the efficacy of educational interventions. These studies are particularly focused on genetic knowledge, education, the media and how these relate to views on genetic determinism.

Chapter 6 goes beyond approaching the issues hypothetically through research. The chapter describes and evaluates 4 public engagement events that formed a fundamental aspect of this project. Focus is given to a project that combined public engagement and research to provide an ecologically valid insight into public opinions about the ethics of genetic data sharing.

Chapter 7 provides an overall discussion of the findings, as well as of the limitations of the conducted research. The chapter also outlines suggestions for future directions.

Chapter 2: Development and Validation of the International Genetic Literacy and Attitudes Survey (iGLAS)

Abstract

The International Genetic Literacy and Attitudes Survey (iGLAS) was developed to move the discussion of genetics out of medical domains, where previous research had been focused. iGLAS continues to evolve in response to changes in genetic technology and to accommodate specific research interests. The evaluation presented here indicates that iGLAS is a reliable and valid measure of genetic knowledge and opinions. The breadth of demographic data collected also allows for varied analyses within and between different groups. iGLAS is currently available in 7 languages, with 3 further translations underway, and this has augmented its use as an international measure. In addition to testing genetic knowledge, iGLAS also provides feedback on performance as well as additional information about each knowledge item. This is evidently appreciated by participants, many of whom report finding iGLAS both educational and enjoyable. Requests are regularly received from outside the central research team to use iGLAS for research and education - a further indication of the utility of this measure. iGLAS is a broad, adaptive, enjoyable and educational research tool that is available for use internationally. It has already amassed a cleaned dataset of >10000 participants and collections are ongoing with the current version (v. 3).

Introduction

Previous studies of genetic knowledge and opinions have mainly focused on medical domains/personal well-being, with less attention paid to other applications of genetics (e.g. Carver, Castéra, Gericke, Evangelista, & El-Hani, 2017; Erby, Roter, Larson, & Cho, 2008; Fitzgerald-Butt et al., 2016; Hooker et al., 2014; Hott et al., 2002; Jallinoja & Aro, 1999; Molster, Charles, Samanek, & O'Leary, 2008; Pearson & Liu-Thompkins, 2012; Saul, 2013). They have also largely focused on well-defined populations such as patients, undergraduate students and young adults. This research is limited, as it does not provide a comprehensive picture of genetic knowledge and attitudes in the population, nor does it consider how people

relate to genetics outside of medical domains, for example in areas such as law and education. Therefore, more comprehensive assessment instruments are required to capture the different aspects of genetic knowledge and opinions and their application across different socio-demographic groups and in non-medical contexts. This chapter describes the development of a new measure of genetic knowledge, attitudes and opinions.

At the outset of this thesis it was decided it would be necessary to develop a novel measure of genetic knowledge, one that would be appealing and engaging for participants, and which was not constrained to only medical aspects of genetics. I therefore began development of this new measure from the very beginning of my studies, co-ordinating, constructing and evaluating all elements of the International Genetic Literacy and Attitudes Survey (iGLAS). Fundamental to this process was an initial meeting (02/03/2015) of behavioural geneticists, psychologists, educationalists, lawyers and ethicists. These experts met to discuss issues related to applications of genetics and genetic communication (a transcript of this meeting is available from the author upon request). The collaboration led to the identification of key areas to be assessed by iGLAS, including knowledge related to genetic differences within and across populations; gene/environment interplay; and determinism. The collaborative team then worked on compiling a list of specific items to be included in the instrument, leading to 81 initial items grouped into: 28 items on genetic knowledge; 8 items on heritability estimation; 17 items on opinions/attitudes; and 28 items on demographics and additional information. These items were evaluated, and the majority were selected for inclusion in the first version of iGLAS.

Demographics and Additional Information

19 questions related to demographics of interest were included in the initial pilot study. The selected demographic information was: gender, year of birth, level of education (GCSE or equivalent/A-level or equivalent/undergraduate/postgraduate), in which country respondents grew up, ethnicity, religion, religiosity, spirituality, political ideology, social media use and popular science areas participants are interested in. Participants were also asked to rate how likely they are to provide a DNA sample for genetic research; how confident they are in their

genetic knowledge; how confident they are discussing science generally; how important self-awareness and self-improvement are to them; sources of guidance they may access (counselling support, advise of a psychic, private genetic testing, courses on mindfulness); and their likelihood to have genomic sequencing if there were no/moderate/definite history of a debilitating disease in the family. Finally, participants were provided with some commonly held concerns about genetics, and asked to tick any that applied to them, with the option to add their own additional concerns.

Genetic Knowledge items

At the time of the initial focus group it was identified that the methods of evaluating genetic knowledge in previous studies (e.g. Christensen et al., 2010; Jallinoja & Aro, 1999; Molster et al., 2008) tended to include true/false responses. For example: *"Genes are inside cells – True/False"*. As such, a score of 50% correct would be expected by chance. To reduce the influences of chance, and in an endeavour to make iGLAS more engaging, each member of the focus group was asked to supply questions they felt would evaluate a reasonable (non-specialist) level of genetic knowledge in a multiple-choice format, including one correct and up to three incorrect response options.

All items were evaluated, and any duplicates were combined into a single item. This resulted in 28 initial items assessing Genetic Knowledge. Previous research established 6 main concepts and 43 sub concepts as benchmarks of genetic content for non-major degree level courses in the USA (Hott et al., 2002). As shown in Table 2, each of the items selected to measure genetic knowledge in the first iGLAS pilot were mapped onto these 6 main concepts.

Table 2. Number of questions in the first iGLAS pilot that map onto each of the genetic concepts established by Hott et al. (2002)

Concept	Corresponding items in iGLAS-P1
Nature of genetic material	9
Transmission	1
Gene expression	9
Gene regulation	2
Evolution	1
Genetics and society	3

Previous measures of genetic knowledge (e.g., Hott et al., 2002; Bowling et al., 2008) tend to discuss genetics in medical and pathological (disease) terms. iGLAS is intended to also capture public perception and understanding of the more behavioural and sociological aspects of genetics, which to date have been poorly studied. As can be seen from Table 2, the first pilot of iGLAS focused on the nature of the genetic material, gene expression, and genetics and society. This reflects the more applied and sociological focus of iGLAS and the move away from individual health aspects of genetics such as transmission from parent to offspring.

Questions were formatted in ways to help reduce the effects of Common Method Variance (Lindell & Whitney, 2001). The formats of the questions were: Yes/No, multiple choice, Likert scales (vertical and horizontal presentation), slider scales, dropdowns, radio buttons, checkboxes and free text.

Contrary to some measures developed since iGLAS (e.g. Carver et al., 2017; Fitzgerald-Butt et al., 2016), it was decided not to include ‘don’t know’ options for the genetic knowledge questions in iGLAS. Research has indicated that inclusion of a ‘don’t know’ option can encourage participants to disengage from a study (Oppenheim, 2000). Additionally, Mondak & Davis (2001) identified that, when not given a ‘don’t know’ option, participants answer at an above chance level, even if they do not think they know the correct answer. Except for questions related to ethics, participants of iGLAS could leave blank any items they did not wish to answer.

With a multiple-choice format, it is expected that score ranges will be restricted as participants are provided with only limited options for their responses. For example, a multiple-choice question with 3 wrong and 1 right option will be right 25% of the time, even if answered randomly. However, the influences of chance are less in this scenario than with True/False questions. This chance level is also taken into consideration in the interpretation of results throughout this thesis.

Heritability Estimates

8 items evaluating participant knowledge about the heritability of common traits were included in the first draft of iGLAS. Heritability is a population based statistic that estimates the relative influence of genes and environments (**shared** and **non-shared**) on complex traits (Plomin et al., 2013). It is typically reported on a scale of 0% to 100% heritable. Estimates for a vast number of complex traits can be identified in the literature (see http://match.ctglab.nl/#/home). As heritability is a population based statistic it can change as a function of time and geography. However, international studies produce robust replications for most traits – showing similar heritabilities in different populations (Plomin et al., 2016).

Traits included in iGLAS were chosen to reflect an interest in common variance within the population: Height, Weight, IQ, Eye Colour, Depression, Motivation, School Achievement and Sexual Orientation. Previous studies that have asked questions about the heritability of such traits have used restricted scales. For example, in one study participants were asked to classify various traits and health conditions (e.g. eye colour, cystic fibrosis, heart disease) as being either entirely genetic, entirely environmental or a mixture of both (Molster et al., 2008). It was not thought appropriate to use such a restricted measure for the traits of interest in iGLAS, as research has consistently shown that all complex human traits are influenced by both genes and environments (Collins, 2010; Plomin et al., 2016). In one recent study participants were initially asked to estimate the genetic influences of common traits on a 10-point Likert scale (0: Environment is most important to 10: Genes are most important) (Carver et al., 2017). On consultation with experts, the authors revised this to a 5-point scale, as it was felt that a 0-10

scale too closely reflected heritability estimates. However, the authors do not clarify why this was considered problematic. For iGLAS it was decided to provide participants with a 100-point scale, so that responses could be directly compared to scientific heritability estimates of the traits of interest. The term 'heritability' was not used in the phrasing of this question as this was considered too specialist, instead the concept was described, and participants were asked to respond to this concept. For each trait, participants were asked: 'On a scale of 0-100 how important are genetic differences between people in explaining individual differences in the following traits:'.

Opinions

Members of the focus group were asked to provide questions that would evaluate what people think and feel about genetics, resulting in 17 items. Each item was evaluated on a 7-point Likert scale appropriate to the wording of the question (e.g. strongly disagree to strongly agree; very unlikely to very likely).

After repeated phases of screening, the first version of iGLAS was implemented using Qualtrics software (Qualtrics, Provo, UT). The validation then proceeded in 4 stages: Pilot 1 (iGLAS-P1) and Pilot 2 (iGLAS-P2) were followed by test-retest analyses and comparison with another recently developed measure of genetic knowledge and opinions (Carver et al., 2017).

Development and Piloting

iGLAS went through various stages of development and piloting (Chapman et al., 2017). Root-mean-square Error of Approximation (RMSEA) and parallel factor analyses on two sets of pilot data revealed no viable factorial structure to the genetic knowledge items in iGLAS. As a single factor model did not fit the data, neither McDonald's Omega nor Cronbach's Alpha could be used to evaluate the internal reliability of the measure (Dunn et al., 2014). Instead, an evaluation of the items, based on the responses, was conducted in consultation with behavioural genetics experts. Guiding principles in the selection and refinement of items were clarity of language and precision of items. Another consideration was utility of knowledge. iGLAS is intended to

evaluate how equipped participants are to discuss genetics in a meaningful way, rather than evaluate their specific knowledge of complex genetic, genomic and **epigenetic** processes.

Validity and Reliability

It is important that any newly developed measure is evaluated for validity and reliability. Various analyses were conducted with iGLAS to evaluate its reliability and validity.

Criterion Validity

As work on iGLAS was ongoing, another team of researchers (Carver et al., 2017) was also developing a measure of genetic knowledge and opinions, primarily intended for use with young adults and university students. This measure, the 'Public Understanding and Attitudes towards Genetics and Genomics (PUGGS)' consists of 25 questions related to genetic knowledge. For each question, the response options are true/false/don't know, with the instruction that participants should only chose 'don't know' if they did not understand the statement. According to the PUGGS codebook, only correct responses are scored (1). Incorrect responses and don't know are not scored (0).

The genetic knowledge questions in PUGGS are divided into two sections 'Determinism questions/gene-environment interaction' (9 questions) and 'Knowledge about modern genetics and genomics' (16 questions). In both sections, many items ask specifically about medical aspects of genetics, and this is the general remit of the second section. For example, in the first section, 7/9 items included the term 'disease' or are related to specific disorders. Furthermore, the opinions element of PUGGS consists of the following sections:

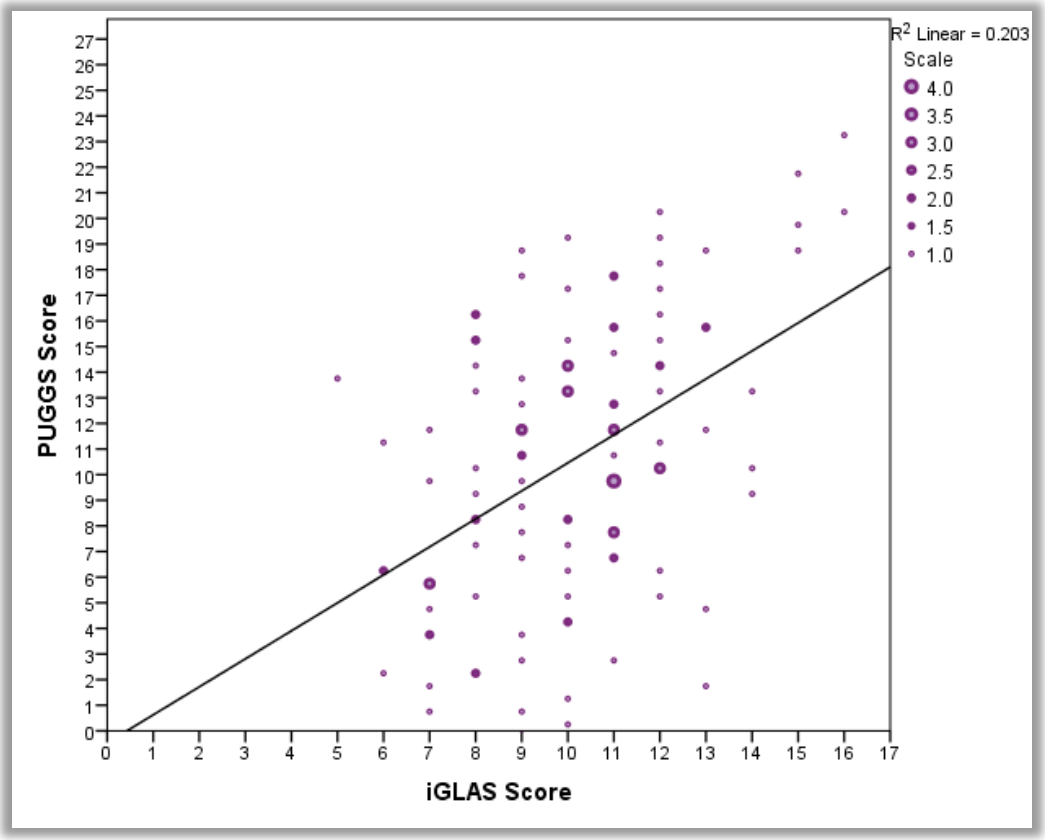
- Gene therapy
- Genetic testing
- Prenatal genetic testing
- Personalised medicine and pharmacogenomics

PUGGS can therefore be taken as having a focus on medical aspects of genetic knowledge and opinions. iGLAS is intended to evaluate a much broader range of knowledge and opinions about genetics, and comparisons between these two measures should be treated within this context.

On 16th November 2017, first year undergraduate psychology students at Goldsmiths, University of London completed both iGLAS and PUGGS (N = 115; 100 female /15 male; age: M = 20.87, SD = 4.50, range 18-42). The collection was managed using Qualtrics, with all students first completing iGLAS then PUGGS during a single testing session. Within the constraints of the testing session it was not possible to randomise the order of these measures.

The version of iGLAS used in this study (iGLAS 2.2) consisted of 17 items related to genetic knowledge. The full version of PUGGS was used (25 Items). In iGLAS, participants achieved a mean score of 10.10 (SD = 2.26, Range 5 to 16). This equates to an average correct score of 59.41%. The average score on the knowledge section of PUGGS for these same participants was 42.24% (Mean = 10.57, SD = 5.47, Range = 0 - 23). On average, participants scored higher on iGLAS than on PUGGS (see Figure 1).

Figure 1. Correlation matrix of performance in the knowledge sections of iGLAS and PUGGS



Note. Elements have been binned for ease of interpretation. Larger circles indicate a higher proportion of respondents at that point.

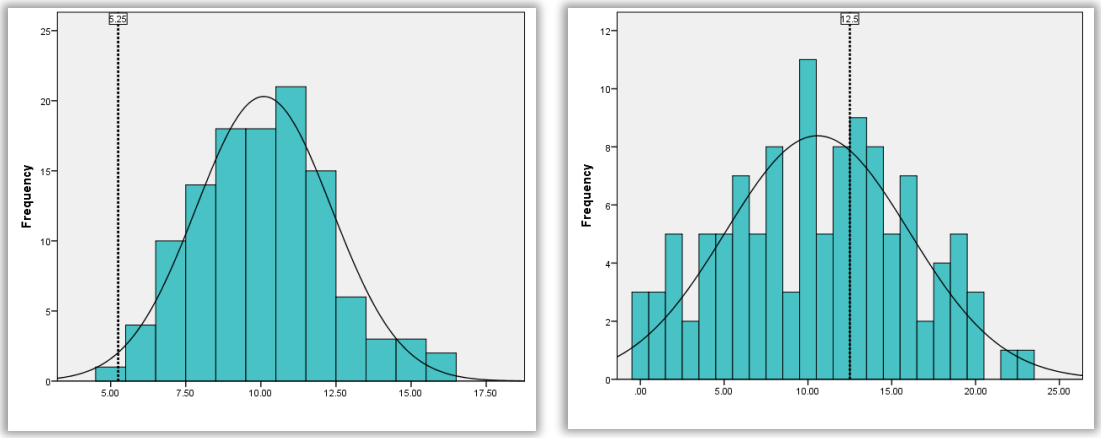
A Pearson product-moment correlation coefficient was computed to assess the relationship between PUGGS and iGLAS genetic knowledge scores. There was a positive correlation between the two measures, r = .45, N = 115, p <. 001. Participants tended to perform better on iGLAS than on PUGGS. However, the PUGGS codebook notes that 'don't know' responses should be coded as 0, the same as incorrect answers, rather than excluded from analysis. Across PUGGS genetic knowledge items, between 10.2% (N = 14) and 48.2% (N = 66) of participants opted for 'don't know' for different items, which may be deflating the scores in PUGGS.

Both PUGGS and iGLAS provide participants with response options for each genetic knowledge item. In PUGGS, the options were 'true' 'false' and 'don't know'. It might reasonably be expected that participants wishing to maximise their score in PUGGS would exclude 'don't know' as a possible response. This being the case, each item therefore has a .5

(50%) chance of being responded to correctly, even if responses are given at random. PUGGS consists of 25 items in total, so an average chance score of 25 x .5 = 12.5 (50% correct) would be expected. Incorporating the 'don't know' response would result in an average correct score of 25 x .33 = 8.25 (33.3% correct) by chance. In iGLAS, 13 items were presented with 1 correct and 3 incorrect response options, giving a chance level of .25 for these items. 4 items had 1 correct and 1 incorrect option, giving a chance level of .5. The overall average chance score for iGLAS was therefore calculated as follows: (13 x .25) + (4 x .5) = 5.25 (31%).

As can be seen from Figure 2, almost all participants scored above chance level in iGLAS, but the majority performed below chance in PUGGS. As such, whilst participants may have been trying their hardest in both measures, in PUGGS it is not possible to distinguish this from a response pattern that could have been generated by chance responses. This adds further validity to the choice to give multiple responses in iGLAS and to exclude a 'don't know option'.

Figure 2. Frequency responses to the genetic knowledge items of iGLAS (left) and PUGGS (right).



Note. Reference lines denote the point at which responses would be expected by chance alone (5.25 for iGLAS, 12.5 for PUGGS). This was calculated by dividing the possible number of responses by the possible correct responses. PUGGS's chance level is higher than iGLAS as it only consists of true/false questions.

Participants in PUGGS were also asked to estimate the heritability of 16 complex traits. Both iGLAS and PUGGS included estimates for height, intelligence and depression. Depression was described as 'severe' in PUGGS and 'clinical' in iGLAS. In PUGGS the question about intelligence stipulated 'in adults', iGLAS did not include this stipulation as knowledge about the

changes in the heritability of intelligence across the lifespan was thought too complex for a simple measure of perceptions of heritability. In iGLAS, participants were asked to estimate heritability on a scale of 0 to 100. In PUGGS, the scale was 1 (only environment) to 5 (only genetic). For results, see Table 3.

Table 3. Means and standard deviations of heritability estimates for the three traits included in both iGLAS and PUGGS. Scientific estimates of heritability are also provided.

Trait	PUGGS score Mean (SD): *%**	iGLAS score Mean (SD): *%*	Scientific estimate
Height	3.97 (.77): *74.1%*	70.31 (22.37): *70.3%*	70.5% (Jelenkovic et al., 2016)
IQ	2.94 (.64): *48.5%*	58.24 (21.49): *58.2%*	50% (Kovas et al., 2013)
Depression	3.03 (.58): *50.8%*	54.65 (21.62): *54.7%*	42% (Lohoff, 2010)

Note. *For PUGGS, mean scores were multiplied by 25 to place scores on a range of 25-125 (original 1 –5); 25 was then subtracted to give scores on a scale of 0 – 100 (%) - the same scale as iGLAS and heritability estimates from the literature. Where possible, the Scientific estimates were taken from meta-analyses. Where not available, large scale studies conducted with reputable samples were utilised.

To see if responses to heritability estimates in PUGGS and iGLAS differed significantly from each other, the scores from iGLAS were also placed on the same scale as PUGGS (1-5) so that 0-20 became 1; 21-40 = 2; 41-60 = 3; 61-80 = 4; and 81-100 = 5.

Paired samples t-tests revealed that heritability estimates of height in PUGSS (M = 3.94, SD = .77) and iGLAS (M = 3.93, SD = 1.11) did not differ significantly from each other; t (114) = .32, p = .75. Heritability estimates of Depression in PUGGS (M = 3.03, SD = .57) and iGLAS (M = 3.18 SD = 1.05) also did not differ significantly from each other; t (112) = -1.66, p = .101. However, heritability estimates for IQ in PUGGS (M = 2.94, SD = .64) and iGLAS (M = 3.34, SD = 1.10) did differ significantly from each other; t (113) = -4.16, p <. 001.

Heritability estimates are population based, and so are specific to the time and population they study. The heritability of some traits, including intelligence, are different in children and adults, with heritability higher for adults (~80%) than children (~20%) (Plomin & Deary, 2015). In the

case of intelligence, different components have also been found to have different average heritabilities, e.g. 60% for verbal tests, 50% for spatial and speed-of-processing tests and 40% for memory tests (Plomin et al., 1994). In terms of both differences across the life-span, and differences between sub components of intelligence, the average heritability of intelligence is 50%, as reported in Kovas et al., (2013) and given in Table 3. This range of heritabilities means that any over or underestimation made by participants must be treated with caution. However, PUGGS states particularly that participants are asked to estimate the heritability of intelligence in adults (~80%), and the average heritability estimate for intelligence in PUGGS (48.5%) do not reflect a good understanding of this. This difference is perhaps best explained by the different scales used in iGLAS and PUGGS. PUGGS constrained participants to 1 of 5 options. In PUGGS 69.6% of participants responded '3 = Both genetic and environmental differences contribute to the same extent to the trait' (i.e. 50%). iGLAS is free of such constrictions and so is thought to provide a more valid tool for evaluating people's heritability estimates.

The differences in wording between iGLAS and PUGGS meant it was not possible to compare responses on opinion items.

Overall, the results suggest that despite the different focus in PUGGS, the relevant estimates are similar for iGLAS and PUGGS. Therefore, iGLAS demonstrates a good degree of criterion validity – to the extent that it could be evaluated given the limited overlap in content. As mentioned above, the goal of iGLAS is to provide a broad, fast and engaging evaluation of genetic knowledge greater in scope than only health and disease – in different populations.

Test-Retest Reliability

Two studies were conducted to evaluate the test-retest reliability of iGLAS. The first utilised a small number of undergraduate psychology students with a lapse of several months between testing phases. The second reports data from a much larger number of students, but the testing phases were only 20-30 minutes apart.

Test-Retest: Study 1

As described in the previous section, data collection for iGLAS-P2 included the administration of iGLAS to 112 undergraduate psychology students in a single testing session. Students were then invited to complete the survey again 2 to 4 months later. These were first year Psychology students who had not received any genetics instruction between testing phases. Only 14 students provided sufficient identification and responses to allow for a test/retest analysis of iGLAS-P2. Although these numbers did not allow for a robust statistical analysis, the changes in responses were evaluated to see if refinements to iGLAS could be made. For example, test/retest correlations were calculated for the opinions section of iGLAS-P2.

The overall Pearson's test-retest correlation for the genetic knowledge section was .67 based on the summed genetic knowledge scores, which is thought to be good, given the time that elapsed between the testing phases. There were no significant differences in genetic knowledge scores between Phase 1 (M = 12.14, SD = 2.54) and Phase 2 (M = 12.79, SD = 2.55), t (13) -1.147, p = .272. However, it must be noted that this study was underpowered due to low participant numbers. As only 14 participants completed this first test-retest analysis, presentation of the results as a scatter graph would not be informative.

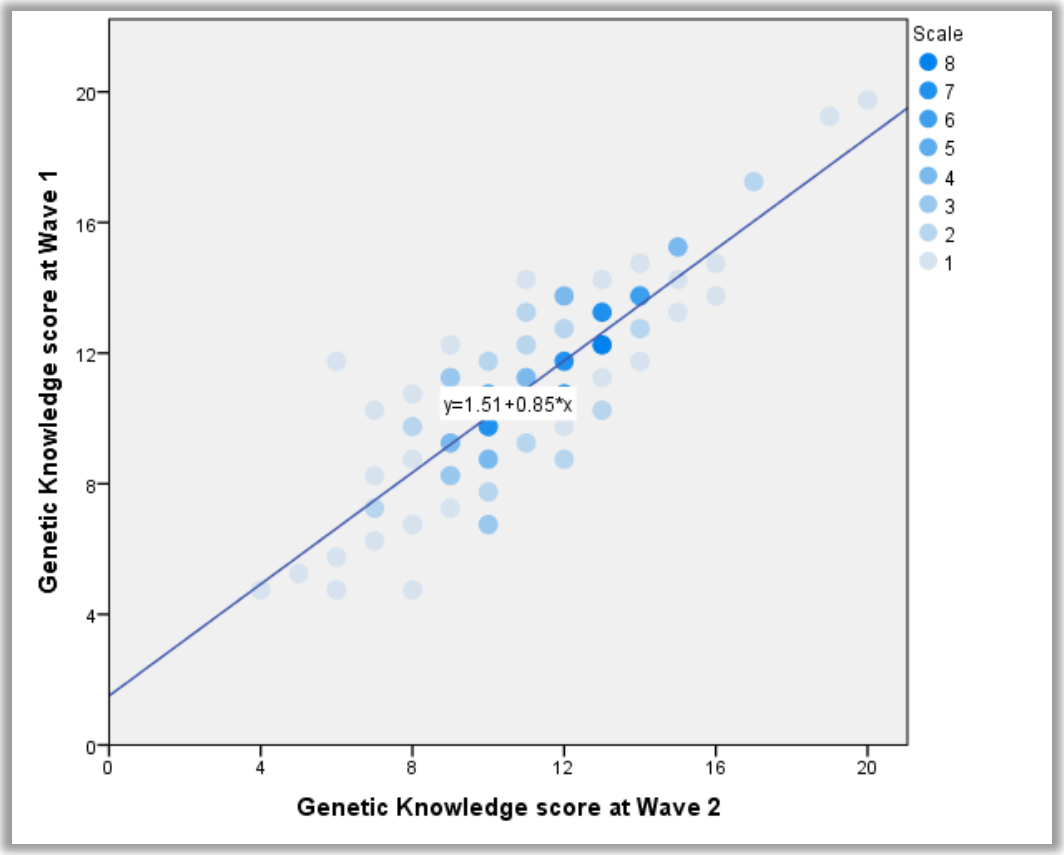
The overall test-retest correlation for the opinions section was .55. One item, 'We should use genetic research to learn how best to adapt environments to people's needs, for example through individualised health advice', was slightly negatively correlated (-.056). As for most of the opinion items, this was measured on a 7-point Likert scale, from strongly disagree to strongly agree. This negative correlation is likely a product of the complexity of the language in the question. With this item removed, the test-retest correlation for the opinion section increased to .582. This item was removed from subsequent versions of iGLAS. Another item, 'Scientific development is essential for improving people's lives', had a low test-retest correlation (.168) and showed poor variance in iGLAS-P2 (96.3% of participants agreed with this statement to some degree; responding 5, 6 or 7 on the Likert scale where 4 was 'neither agree nor disagree'. Of these, 74.4% marked 7 - agreeing strongly). With this item also removed, the test-retest

correlation became .61. This item was retained in iGLAS as it was thought to be an important measure to evaluate the way participants think about science in general when compared to genetics in particular. The observed restricted scale of responses on this item may also have been the product of collecting data with Psychology students as they might reasonably be expected to have a higher than average view on the importance of science, given that they were all studying for a Batchelor of Science degree.

Test-Retest: Study 2

An experimental study was conducted on 29/11/2018, with a new cohort of 140 first year Goldsmiths psychologist students (108 female, 31 male, 1 non-binary; age M = 19.64, SD = 2.83, range = 18 – 36). This study was intended to see if providing students with information about polygenicity and gene/environment interplay would affect their levels of genetic knowledge and views on determinism (see Chapter 5). Students were separated into groups and given one of three pieces of information to read: that eye colour is monogenic (group 1), that eye colour is polygenic (group 2) and that eye colour is polygenic and susceptible to gene environment interplay (group 3). Prior to these manipulations, participants were asked to complete the 20 genetic knowledge items from the current version of iGLAS (v3) as well as the opinion item "I believe my destiny is written in my genes". After the manipulation, which only took 2-3 minutes, participants were asked to repeat these measures. The manipulation was unsuccessful as participants genetic knowledge and views on genetic determinism showed no significant change as a result of the three experimental conditions. The conclusion therefore was that these manipulations were ineffective in changing genetic knowledge and opinions. Given this, these data are being presented here as an evaluation of the consistency of responses between each testing phase.

Figure 3. Correlation matrix of genetic knowledge scores in waves 1 and 2 of testing with iGLAS (Test-Retest: Study 2)



Note. Elements have been binned for ease of interpretation. More intense colours indicate a higher proportion of respondents at that point.

A Pearson product-moment correlation coefficient was computed to assess the relationship between iGLAS genetic knowledge responses at two waves approximately 20 minutes apart. There was a positive correlation between the two phases, r = .85, N = 140, p <. 001 (see Figure 3). There were no significant differences in genetic knowledge score between Phase 1 (M = 11.10, SD = 2.68) and Phase 2 (M = 11.22, SD = 2.59), t (139) -0.99, p = .322.

To sum up, the number of participants in the first test-retest analysis was small, but the time between testing phases was relatively large (2 to 4 months). As such, participant responses at phase 2 were unlikely to have been informed by their responses at phase 1. In contrast, the number of participants in the second test-retest analysis was larger, but the time between testing phases was very short. Taken together, the results of the two studies suggest an acceptable test-retest reliability in iGLAS.

Participant Feedback

In all versions of iGLAS participants had the opportunity to provide feedback on the measure at the end of the survey. This feedback has been used to refine iGLAS at various stages. For example, earlier versions of iGLAS included 2 questions about **'variable' DNA**. A number of participants commented that this was a confusing term. On evaluation of this feedback it was decided to remove both items and replace them with one item that still evaluated the concept of variable DNA without using that specific term. In some instances, participants who self-identified as genetics experts commented that some of the options available in iGLAS could be more technically precise. For example, one noted that the response options for the question 'What is the main function of all genes?' needed to be revised. Again, this feedback was reviewed and adjustments made where appropriate. However, it was always maintained that iGLAS is a measure of public knowledge, not expert knowledge, which occasionally necessitated items being broadly correct rather than necessarily technically accurate.

Of those 645 participants to date who have opted to provide free-text feedback on iGLAS, 298 (46.2%) commented that the measure was enjoyable and/or educational (original transcripts of qualitative feedback are available from the author). This is by far the most common response by proportion and is taken as a strong indicator that iGLAS is meeting its specified goals.

iGLAS Versions

iGLAS is intended to be a dynamic and responsive tool, able to accommodate additional items related to specific research interests. iGLAS has therefore been through a number of updates and is currently in its 10th version (iGLAS 3). Table 4 shows a timeline of versions of iGLAS from its inception. The Master data dictionary for all versions can be found in Appendix 1.

Table 4. Versions of iGLAS: N of participants completing each version; data collection dates; and the number of items in each version of iGLAS

iGLAS version	Collection dates	N participants	Number of items*				
			Demographics	GK	H2 estimates	Opinions	Vignettes
1.1	31/10/16 01/02/17	713	20	18	8	16	2
1.2	08/12/16 01/02/17	6359	21	18	8	17	2
1.3	14/02/17 28/09/17	134	21	18	8	17	2
2.1	17/08/17 15/10/17	216	17	18	8	17	2
2.2	21/09/17 02/01/18	250	18	17	8	17	2
2.3	30/12/17 09/06/18	763	18	18	8	19	2
2.4	16/05/18 07/08/18	2661	17	19	14	13	2
2.5	19/06/18 07/08/19	1595	17	20	14	13	2
2.6	08/08/18 02/04/19	536	17	20	14	13	2
3	02/04/19 On going	> 77	17	20	11	13	2

Note. The items (e.g. Demographics, Opinions etc.) shown here are for the basic version of iGLAS. From version 2.1 onwards certain participants, such as educators, medical and legal practitioners are presented with additional items. A short 10 item personality measure was included in iGLAS 1.1 – 1.3 (Rammstedt & John, 2007, p. 5). 14 items related to common neuromyths were included in iGLAS 2.3. Two items from this list were retained in all subsequent versions of iGLAS.

GK = Genetic knowledge; H_2 = Heritability.

In some instances, the changes between versions were minor. For example, the only differences between iGLAS 3 and its predecessor, iGLAS 2.6, is the removal of 3 items related to the heritability of sleep which were added to iGLAS 2.6 for a specific research project. In other instances, the changes were more considerable. For example, iGLAS 2.1 (previous version 1.3) included an additional 12 items specifically targeted to law students and legal practitioners.

From iGLAS 2.1 onwards more detailed questions about employment were also included for certain professions (education, medicine and law). For example, if a participant identified that they work in education, they are also asked in what capacity (teacher, administrator etc.), what level (primary, secondary, university) and how long they have been in post. Teachers were also asked what subjects they teach and if they have any responsibility for students with special

educational needs. Skip logic is utilised with all these additional questions so that they are only asked when relevant. From iGLAS 2.1 onwards participants have also been provided with feedback on their performance in the genetic knowledge section of iGLAS. This takes the form of an overall score (e.g. 15/20) as well as whether they got each item correct or not. Further information on each item is also provided (see Appendix 2).

Translation

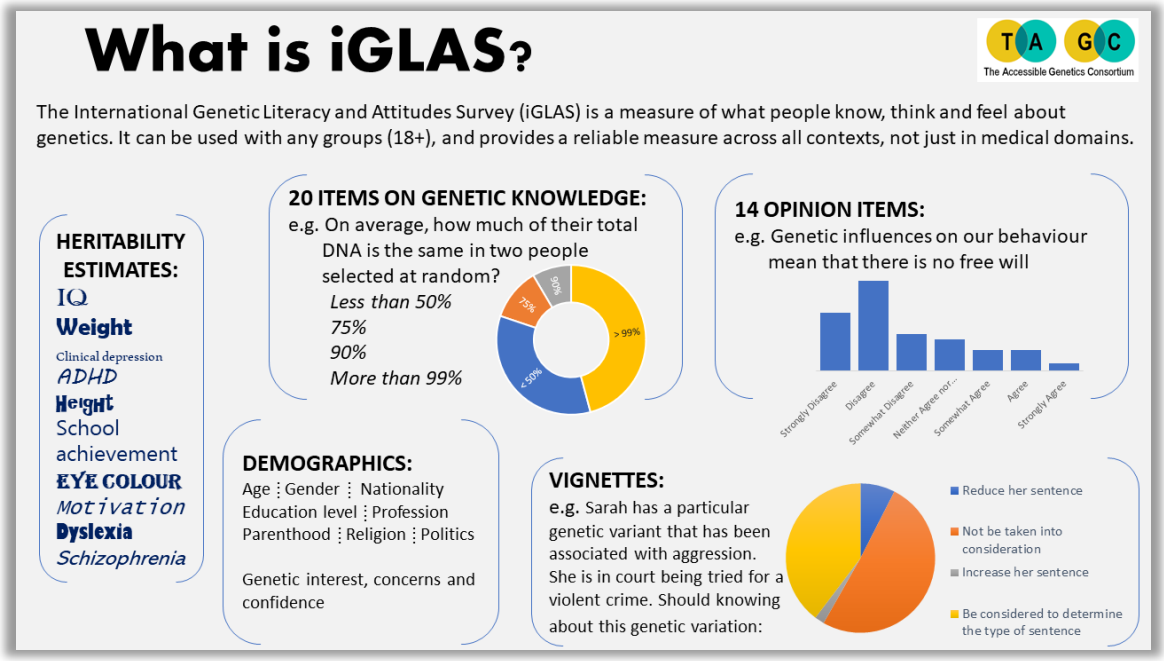
Since its inception, iGLAS has been available in both English and Russian, with all items first developed in English. Translations have been added for subsequent collections, and iGLAS is currently available in Albanian, English, French, Italian, Romanian, Russian and Spanish. Translations are also underway for Indonesian, Chinese and Farsi (Persian).

In all instances, the same protocol was followed for translations. A native speaker of the target language, a member of InLab or of InLab's collaborative network, was provided with a document containing all items of iGLAS. Next to this was a column for the translation. A final column was included so that the translator could provide comments or feedback on their translation. Where appropriate, specific guidance at the item level was also provided. For example, in the list of subjects that students might study, translators were asked to translate the subject of 'English' to the school subject appropriate for the language they were translating into. Once this initial translation was completed, the original text was removed, and the translation was given to a second native speaker for back translation. All documentation was then checked for any inconsistencies and if any were found, these were resolved with both translators. The translation was then added to Qualtrics and made live. Qualtrics defaults to the appropriate language for the country in which a participant takes the study. E.g. someone completing iGLAS in France will be presented with the French language version. However, there is also the option to change this manually on each screen of the survey.

The Current Version (iGLAS 3)

An overview of the current version of iGLAS can be seen in Figure 4. The 12 items specifically targeted to law students and legal practitioners are not shown in this figure.

Figure 4. A summary of the current version of iGLAS (version 3)

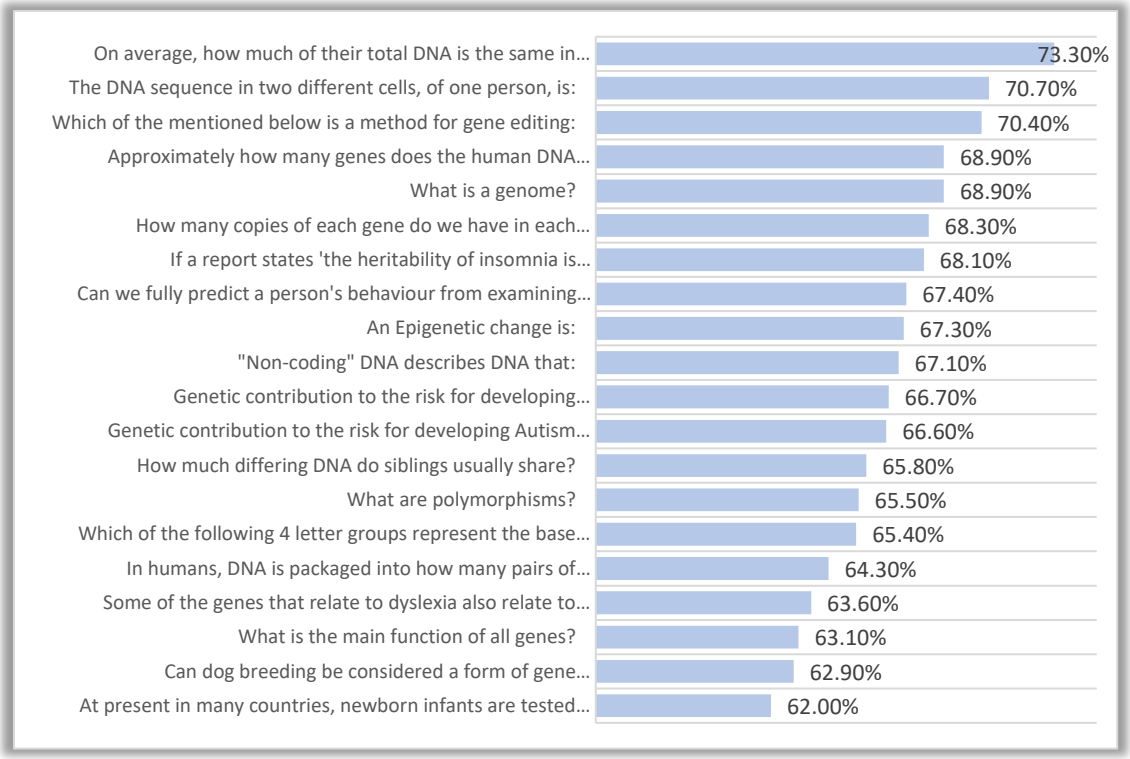


The current version of iGLAS can be found at:https://goldpsych.eu.qualtrics.com/jfe/form/SV_6nStWV7qjArYNgh. A PDF version of iGLAS in any of the available languages can be provided by the author upon request.

iGLAS v3 consists of 20 questions related to genetic knowledge. Each item was evaluated to see how difficult it was. Items with binary responses (true/false) could simply be ranked, with those most often answered correctly indicating easier items. However, this is not thought to be a reliable method with multiple response items as an equal difference between correct and each incorrect response cannot be assumed. For example, an item that asked "When did the second world war end" would be more likely to attract correct responses if the options were 1645/1745/1845/1945 than if they were 1st/2nd/3rd/4th September 1945. The latter would require a better level of knowledge about the second world war if it is to be answered correctly. As

such, it is not thought appropriate to rank each iGLAS item on how many participants got it correct and consider this a measure of the ease of the genetic concept being measured. Instead, each item in iGLAS was evaluated to find the average overall genetic knowledge score for those participants who answered correctly. Those individual items that were correctly answered by participants with lower overall genetic knowledge scores are taken as being easier items. Those that required a better general level of genetic knowledge to be answered correctly are considered more difficult (see Figure 5).

Figure 5. Genetic knowledge items in iGLAS v3 ordered by item difficulty with the most difficult items at the top



Note. Some item descriptions are truncated due to limited space. Full item descriptions and further details can be found in Chapter 4 and Appendix 1. Scores relate to the average genetic knowledge score of participants who responded correctly to each item.

For participants who do not identify themselves as either law students or legal professionals iGLAS takes approximately 10 to 15 minutes to complete. For lawyers and law students iGLAS tends to take between 15 and 20 minutes.

Merging and Production of the Final Dataset

Each version of iGLAS includes different numbers of items. Because Qualtrics has limited options for how items are named, producing the final master dataset (merging all iGLAS collections) presented a challenge. It was decided that each item should be renamed so that item names were consistent across all versions of iGLAS. Merging was managed using SPSS Syntax and Excel spreadsheets. Conditional formatting and extensive cross-checking were employed to ensure the veracity of the final master dataset. Further information, including datasets and scripts are available from the author.

The genetic knowledge items in iGLAS needed to be scored during iGLAS completion, so that participants could be provided with feedback on their performance. As such, Qualtrics automatically produced a variable of summed genetic knowledge for each participant. However, as there were different numbers of genetic knowledge items in different versions of iGLAS this statistic could not be used for comparison of genetic knowledge across different versions. An averaged genetic knowledge score (correct score divided by the total number of items in the particular version of iGLAS) was generated for each participant. For each participant a score was also calculated based only on those 13 genetic knowledge items that had remained unchanged in all versions of iGLAS.

Where appropriate, for example with the personality measures (versions 1.1 – 1.3), items were reverse coded and summed according to established protocols (Rammstedt & John, 2007). Data dictionaries were produced for each version of iGLAS using the standardised variable names. A master data dictionary, that lists all items ever included in iGLAS, their response options and which versions they are included in can be found in Appendix 1. A copy of the data dictionary for the current version of iGLAS (v3) is available from the author. These procedures have resulted in a master dataset and supporting material for iGLAS that can easily be used by interested collaborators.

Data Cleaning

In order to ensure consistency of results across all analyses of iGLAS data, both within the research team at Goldsmiths and for international collaborators, a standard procedure of data screening and cleaning was developed. Qualtrics generates the statistic 'progress', which reports how far through a survey each participant progresses. This is a crude measure, as it would be possible for someone to click through all the pages of iGLAS but only respond to those items where they are forced to do so in order to progress. Such participants would record a 'progress' of 100% despite having only answered 3 or 4 questions. However, it is unlikely that many participants would do this, and so this variable was one of the tools utilised in cleaning the data.

In total, 13227 participants are included in the current iGLAS master dataset. 73.2% (N = 9754) fully progressed through iGLAS according to the Qualtrics generated statistic. The possibility of only retaining those participants who had completed 100% of iGLAS was considered. However, participants were given the option of excluding any items they did not wish to answer, and it was felt that their responses to the items they did wish to answer were valid and important. Analysis of frequency responses at each percentage of completion suggested a parsimonious cut off at 70%, and this was applied to the dataset. This left 79.9% of participants in the master dataset who had progressed through at least 70% of iGLAS. 70% progress was considered a productive midpoint for excluding participants who were not engaged with the measure but retaining those who may have opted to leave some items incomplete.

Most items in iGLAS are independent of each other. For example, each opinion item is treated independently. The exception to this is the genetic knowledge section of iGLAS, where each participant is given a summed score across the genetic knowledge items available in whichever version of iGLAS they completed. As such, for the master dataset, it was felt important to only include participants who had made a good attempt at genetic knowledge items. 69.2% (N = 9154) attempted all genetic knowledge items. 78.6% (N = 10399) attempted at least three-quarters of the items, and 81.3% (N = 10748) attempted at least half. In order to remove participants who were likely disengaged with the study but retain those who had made a good

attempt at the genetic knowledge items, it was decided to remove any participants who had not attempted at least 75% of the genetic knowledge items.

In early versions of iGLAS participants were asked to give their year of birth rather than their age. This resulted in some participants having inviable ages. For example, 14 participants had resulting ages between 97 and 116 and were statistical outliers. With these participants removed there remained only one statistical outlier at 3 interquartile ranges from the mean. This participant was also removed. 107 participants chose a year of birth that related to an age between 13 and 17. The versions of iGLAS reported here have been developed for use with participants over 18 and so these participants were also removed. An alternative version of iGLAS has been developed for use with children and young adults but will not be addressed in the current thesis. In more recent versions of iGLAS participants are asked to report their age, rather than their birth year, thus removing this issue.

This data cleaning protocol has resulted in a master dataset of 10090 participants, all of whom are taken to represent an engaged sample for use in statistical analyses. This number will increase as further collections are added to the master dataset.

Conclusion, Limitations and Future Directions

From its inception, iGLAS was intended to be an adaptive measure of genetic knowledge and opinions. It seeks to move the discussion of life in the genomic era away from purely medical domains by asking questions about free will, destiny, education, law, ethics, rights, responsibilities and autonomy. iGLAS faces many of the limitations of on-line data collection, such as respondents requiring the economic and educational resources to access the internet, but attempts have been made to ameliorate these. For example, iGLAS is available in different languages and is formatted so that it can be completed on tablets and mobile phones as well as computers. With some adjustments, iGLAS can also be used to collect data with pen and paper.

Rather than being a static measure, iGLAS is adaptive and responsive. It can change to keep pace with advances in genetic sciences, as well as to accommodate the specific interests of researchers. Previous measures have tended to be immutable and static. This may be appropriate for certain psychometric measures, or tools intended to assess participant knowledge on relatively established and static scientific topics. However, in the rapidly advancing field of genetics it is important that a tool evaluating public knowledge and opinions is adaptable.

iGLAS has been through 10 revisions to date. Some of these revisions are minor, for example, the addition of 2 to 3 items related to a specific research project, other changes have been more substantial. One such change was the inclusion of more fine-grained employment details for educators, legal and medical professionals. Where vignettes, knowledge and opinion items have been added or amended, small pilots have been conducted to ensure these items show appropriate variance. Each new item has also been developed, scrutinised and/or adjusted (where necessary) by relevant experts. Work is underway on the development of the 11th version of iGLAS (v4). Given the time that has elapsed since the original development of iGLAS, this version will undergo full statistical evaluation of validity and reliability as described above. These measures ensure that iGLAS continues to be a relevant and productive tool.

Perhaps one of the greatest assets of iGLAS is that it is available for use in collaborative projects (https://tagc.world/iglas-collaboration/). 5 such projects are currently underway, with 2 being initiated from within the research team at Goldsmiths. Additionally, researchers entirely unconnected to Goldsmiths have also made requests to use iGLAS in their own studies. This includes researchers in Italy, Mexico, Nigeria and the USA. Researchers from the World Health Organisation have recently expressed interest in using iGLAS. iGLAS is also attracting attention as an educational tool, with academics in the USA wishing to use it to inspire and frame discussions about genetics amongst their students.

The analyses presented here indicate that iGLAS is a robust, reliable and valid measure of genetic knowledge and attitudes. To date 3 papers reporting results from iGLAS have been

published (Chapman, Likhanov, et al., 2018; Gallop et al., 2017; Selita et al., 2019). 3 more papers are in preparation, with many more planned. iGLAS has also been promoted through a piece for *The Conversation* "We're not prepared for the genetic revolution that is coming"(https://theconversation.com/were-not-prepared-for-the-genetic-revolution-thats-coming-96574). This article has had 177209 reads to date (02/02/2020) and was republished in various outlets including Scientific American, IFL Science and the Independent. This resulted in several communications from interested professionals and members of the public, including the Pulitzer prize winning journalist David Cay Johnston.

iGLAS was also promoted through the Naked Scientist podcast (https://www.thenakedscientists.com/articles/interviews/robert-chapman-public-gene-knowledge), and a Reddit Science AMA. Presentations based on iGLAS have been given at conferences of the American Psychological Association; the International Society of Intelligence Researchers; and the European Society of Human Genetics. iGLAS has also been promoted through the 'Science Show off' stand-up comedy festival.

The development and promotion of iGLAS has resulted in it gaining international interest. These factors, coupled with the feedback from participants that iGLAS is important, educational and enjoyable, are perhaps the strongest indicators that it has achieved its intended goals. iGLAS is an adaptive, efficient, broad, enjoyable and educational tool.

Chapter 3: Individual and Group Differences in Genetic Knowledge, and the Relationship of this Knowledge to Attitudes About Genetics

Abstract

We live in an age of rapidly advancing genetic research. This research is generating new knowledge that has implications for personal health and well-being. The present study assessed the level of genetic knowledge and personal engagement with genetics in a large sample (N = 5404) of participants. Participants received secondary education in 78 countries, with the largest samples from Russia, the UK and the USA. The results showed significant group differences in genetic knowledge between different countries, professions, education levels and religious affiliations. Overall, genetic knowledge was poor. The questions were designed to assess basic genetic knowledge. However, only 1.2% of participants answered all 18 questions correctly, and the average score was 65.5%. Genetic knowledge was related to people's attitudes towards genetics. For example, those with greater genetic knowledge were on average more willing to use genetic technology for their personal health management.

Introduction

As demonstrated in Chapter 1, having a good basic level of genetic knowledge is becoming increasingly important. The first step towards improving engagement in the genomic era is to evaluate people's genetic knowledge and attitudes towards genetics. Although there have been several studies looking at genetic literacy, these have focused on medical genetics, biology and evolution (Carver et al., 2017), and mostly explored undergraduate populations (Bowling et al., 2008; Carver et al., 2017). The results of these studies suggest that genetic knowledge is insufficient in the general population (Lanie et al., 2004) and in non-science undergraduate students (Bowling et al., 2008). As these studies have been comparatively small scale and targeted to particular cohorts, they have not been able to consider group differences in levels of

genetic knowledge. They have, for example, been unable to ask questions about differing levels of genetic knowledge across different professions, or to see if there are associations between genetic knowledge, politics and religion.

The present study sought to address these limitations by evaluating levels of genetic knowledge through use of the International Genetic Literacy and Attitudes Survey (iGLAS) with a large sample of participants from diverse demographic backgrounds, stratified for analyses by: age, education, occupation, country of residence and of secondary education, and religious and political affiliations. To lay groundwork for future research, group differences were considered in relation to Genetic Knowledge (GK). Investigation was also made to consider some of the implications of genetic knowledge, both in abstract / philosophical terms (views on genetic determinism) and in relation to the currently most salient application of genetics – genetic medicine – and willingness to engage with this.

Based on previous research, the following 9 hypotheses were formulated:

Genetic Knowledge (GK)

Hypothesis 1: Average GK, as evaluated by iGLAS, will be poor.

Previous research has provided inconsistent results on public levels of genetic knowledge (Bowling et al., 2008; Dar-Nimrod et al., 2018; Lanie et al., 2004; Miller et al., 2006; Mills Shaw et al., 2008). However, the majority of these suggest that genetic knowledge is poor.

Hypothesis 2: Participants' estimates of heritability for different traits will be under- or over-estimated, mirroring misconceptions about control over traits.

A wealth of findings demonstrate that intuitive views on heritability (the proportion of variance in a trait in a population due to inherited genetic factors) are often wrong (Kovas et al., 2016). Errors that people make in heritability estimates are unlikely to be random. Based on much experience of public engagement events, it is expected that participants will underestimate the

heritability of traits which are seen to be under conscious control and more changeable (e.g. weight, motivation, achievement). In contrast, they will overestimate the heritability of traits, which are often considered more fixed (e.g. eye colour, height, IQ).

GK by Demographic Characteristics

Hypothesis 3: Average GK will differ across countries.

Problems with genetics education have been identified in a number of countries (Challen et al., 2005; Dougherty et al., 2011), and there are cross-country differences in secondary education curricula and policies. There are also differences across countries in relevant legislative provisions and in media coverage of genetic findings. It is therefore hypothesised that genetic knowledge will vary across countries.

Hypothesis 4: Levels of GK will vary as a function of an individual's profession/occupation.

Previous studies have shown that representatives of some professions, such as nursing (Calzone et al., 2010) are able to implement genetics knowledge to improve their daily practice. Out of the five occupations considered in this study (doctors, lawyers, teachers, university lecturers and office workers), doctors are expected to have the highest levels of genetic knowledge.

Hypothesis 5: Higher levels of education will be associated with greater GK.

Research has shown that education levels and scientific literacy interact with opinions about contentious science topics in complex ways, often related to political and religious affiliations, but that higher general education levels usually correlate with higher scientific literacy (Drummond & Fischhoff, 2017; Funk, 2017).

Hypothesis 6: Participants who identify with a religious faith will, on average, show poorer GK than those who do not.

Since the publication of "On the Origin of Species by Means of Natural Selection" (Darwin, 1859), there has been contention about the relationship between evolution, genetics and religion (Allum et al., 2014, 2017; Curry, 2009). For a full discussion on this topic, see Clark (2014). Previous research has also established a negative link between religiosity and science literacy (Sherkat, 2011).

Hypothesis 7: There will be an average difference in the level of GK between people identifying as politically left or right.

A recent study identified that conservative people on average are more likely to purchase literature on applied, commercial sciences (e.g. medicine and climate change), while liberals are on average more attracted to fundamental science (e.g. physics and zoology) (Shi et al., 2017). Therefore, it could be expected that liberals would have higher levels of GK. However, liberals have also been found to show greater resistance to the consensus over the positive benefits of genetically modified food (Berezow, 2014). Liberals may also be more likely to reject the notion of genetics playing a role in individual differences, especially in education ('The Rise and Fall of the Meritocracy - BBC Radio 4', 2017).

GK and Views on Genetics

Hypothesis 8: Participants with greater GK will consider genetic effects less deterministic.

Based on previous research (Shaw et al., 2008), popular media outlets around the world continue to report genetic findings in binary and deterministic terms, often with misleading headlines – a damaging practice in an era of scrolling news (Condit et al., 2001) (see O'Neill (2015) for an example). People with better genetic knowledge may be less susceptible to such misinformation.

Hypothesis 9: Participants with greater GK will on average be more willing to undergo genetic testing.

There has historically been strong resistance to gene testing and therapy in humans (see Davies (2017) for a discussion). However, there is evidence that people are becoming more accepting of genetic testing in certain contexts, presumably with increased relevant knowledge. For example, in one previous study 85% of 2000 respondents from a Russian urban population expressed positivity towards undergoing predictive genetic testing for preventable health conditions (Makeeva et al., 2010).

Methods

The genetic knowledge section of these versions of iGLAS (v 1.1 – 1.3), the focus of the current study, consisted of 18 questions. An abbreviated version of each genetic knowledge question and percentage correct answers for each question are presented in Table 5, for the total sample used in this study (N = 5040) and for different demographic groups.

Participants were also asked to rate how heritable, on a scale from 0 (no genetic influence) to 100 (entirely genetically influenced), the following traits were: height, weight, IQ, eye colour, clinical depression, motivation, school achievement and sexual orientation.

The attitudes section of iGLAS included 14 items asking participants about their views on various aspects of genetics. This chapter presents data for six of these items.

Demographic questions allowed stratified analyses by the following characteristics: *sex, education level, employment,* parental status (number of children), *country of secondary education*, country of residence, *religious affiliation, religiosity level*, spirituality level, *political ideology*, social media use, self-improvement and sources of guidance (e.g. counselling, self-help literature, religious guidance, consulting a psychic). This chapter presents data for 8 of the items presented in italics above. These demographic characteristics were selected as they were

felt to be the most salient for international comparisons. For example, the concept of ‘spirituality’ varies across countries, with colleagues in Russia pointing out that it is effectively meaningless to Russian speakers. Similarly, access to social media cannot be assumed to be equal across countries or different Social Economic Statuses (SES). Further research is already underway on the analysis of additional demographic data.

Data collection took place in both English and Russian internationally. Data used in this paper was collected using Qualtrics software (Qualtrics, Provo, UT).

Table 5. Percentage correct responses to each item in iGLAS versions 1.1 to 1.3 for the total sample who completed this collection and specific demographic groups

Question (shortened/rephrased for this table)	Total sample (5310)	Christian (1093)	Atheist (1349)	Legal Practitioner (90)	Teachers (244)	UG Psychology* (112)	Men (1919)	Women (3301)
What is a genome?	53%	47%	58%	54%	61%	55%	58%	50%
What 4 letter groups represent the base units of DNA?	76%	68%	82%	54%	67%	66%	83%	73%
In humans, DNA is packaged into how many pairs of chromosomes?	82%	76%	86%	73%	84%	89%	84%	80%
What is the main function of all genes?	99%	98%	99%	100%	98%	91%	99%	99%
What is variable DNA?	57%	51%	62%	43%	58%	58%	58%	60%
On average, how much of their total DNA is the same in two people selected at random?	60%	43%	76%	47%	50%	35%	79%	49%
How many copies of each gene do we have in each cell?	46%	40%	54%	34%	49%	45%	51%	42%
What is an epigenetic change?	72%	68%	78%	62%	66%	66%	74%	72%
The DNA sequence in two different cells of one person, is how similar?	74%	72%	79%	70%	66%	38%	79%	72%
On average, how much of the variable DNA is the same in siblings?	31%	31%	33%	21%	34%	71%	30%	32%
Approximately how many genes does the human DNA code contain?	45%	40%	50%	44%	44%	24%	47%	45%
How many copies of each gene do we have in each cell?	46%	40%	54%	34%	49%	45%	51%	42%
What is an epigenetic change?	72%	68%	78%	62%	66%	66%	74%	72%
The DNA sequence in two different cells of one person, is how similar?	74%	72%	79%	70%	66%	38%	79%	72%
On average, how much of the variable DNA is the same in siblings?	31%	31%	33%	21%	34%	71%	30%	32%
Approximately how many genes does the human DNA code contain?	45%	40%	50%	44%	44%	24%	47%	45%
How many copies of each gene do we have in each cell?	46%	40%	54%	34%	49%	45%	51%	42%
Total	66%	61%	72%	58%	64%	60%	70%	64%

Note. To aid visual inspection, each cell has been coloured such that higher proportions of responses are in a darker shade of green. Numbers of participants for some groups do not add up to the total sample size due to missing data. For example, Men (1919) and Women (3301) do not sum to the total sample size because some participants opted for 'non-binary' or 'prefer not to say'. The questions are short versions of the actual questions, retaining the essence but not the wording. Some questions have been rephrased here as their meaning was only clear in the context of the provided answers (see Appendix 1 for actual items)

*this study included a dedicated data collection with a sample of undergraduate psychology students who all completed collection at the same time. This is the same sample invited to complete the test-retest analysis reported in Chapter 2.

Participants

The total sample was 5405 participants. 845 (417 females; Age: M=32.51, SD=12.8) completed the English language versions of iGLAS; and 4559 (2887 females; Age: M=30.43, SD=8.0) completed the Russian language version. Participants had to be 18 or over, with no upper age limit. The English and Russian language samples were comparable in terms of age (English M=32.51, SD=12.77: Russian M=30.43, SD=8.00), sex and education level. The number of participants varied across different analyses due to missing data, as not all participants answered all questions. Despite the large sample, participants were not fully representative of the countries in which they reside/received their secondary education: iGLAS was disseminated online, and so all participants were computer literate and had access to the internet; 88% of all respondents were educated to degree level or higher.

Participants were reached through social media (https://facebook.com and https://vk.com); Reddit AMA (https://www.reddit.com/r/AMA/); and by emailing teachers in the UK via school circulars. A subsample included 112 undergraduate Psychology students from the University of London.

Participants from the USA were primarily recruited through an online science forum (Reddit Science AMA), and so respondents might reasonably be expected to have greater GK based on their engagement with such forums. However, analysis revealed no significant differences in GK between USA educated participants, whether they were recruited through the science AMA (N = 200) forum or not (N = 156), $t = 1.059$, $p = .291$. In addition, participants from the USA were similar to participants outside the USA in level of education ($t (5215) = -.289$, $p = .773$); and religiosity ($t (3995) = -.022$, $p = .983$).

Informed consent was implemented at the beginning of the survey. The study was approved by the Goldsmiths Department of Psychology Ethics Committee and the Ethics Committee for Interdisciplinary Research of Tomsk State University, Russia.

Results

Results showed unexpected sex differences, with men on average scoring higher on GK (M = 12.30, SD = 3.07, Range 3-18) than women (M = 11.23, SD = 3.15, Range 2-18), t (5218) = 11.84, $p < 0.001$, Cohen's d = 0.34. These differences were not explained by age or education. Data for men and women were normally distributed and covered almost the entire range of scores (see Table 5). For all inferential analyses, sex was regressed out.

Hypothesis 1: Overall Knowledge

The GK section of the iGLAS questionnaire presented each question with 1 correct option and either 1 or 3 incorrect responses (see Chapter 2 and Appendix 1). The average GK was 11.8 (SD = 3.13, Range 2-18), translating to an average correct score of 65.5%. Only 1.2% of participants got all the knowledge questions correct, and 3% of people achieved at or below the chance level of 5 correct answers.

Evaluation of individual items revealed some interesting gaps in knowledge (see Table 5). For example, less than 50% of participants knew the approximate number of genes in human DNA, or the degree of genetic relatedness between family members. Approximately 30% of participants considered complex conditions, such as autism and schizophrenia, to be a product of a single genetic variant (for more on this see Chapter 4).

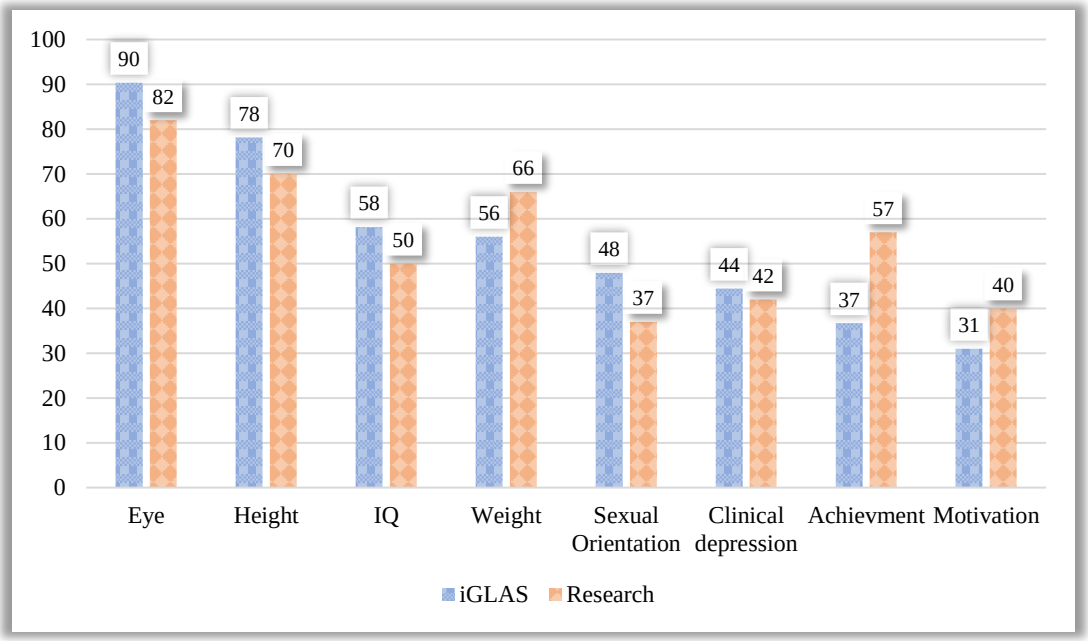
Hypothesis 2: Estimates of Heritability

Participants indicated the strength of genetic effects on 8 common traits, using a sliding scale from 0 (not heritable) to 100 (entirely genetically determined).

As presented in Figure 6, participants' estimates were close to the estimates established by behavioural genetic research. The pattern of under- and over-estimations was not random and confirmed the prediction: people tended to underestimate the heritability of weight, motivation

and school achievement, but overestimate heritability of intelligence, height, eye colour and sexual orientation.

Figure 6. Average heritability as estimated by iGLAS participants vs. heritability from reputable genetic studies



Note. iGLAS N ranged from 4803 to 5234 for different traits. The estimates came from the following meta analyses or reputable papers that report large and representative samples: eye colour (Larsson et al., 2011); height (Jelenkovic et al., 2016); weight (Liu et al., 2015); school achievement (Rimfeld et al., 2015); IQ (Kovas et al., 2013); clinical depression (Lohoff, 2010); motivation (Kovas et al., 2015); sexual orientation (LeVay, 2016). In some instances, e.g. IQ (see Chapter 2) and sexual orientation, these figures represent an averaged heritability score from different studies reported in the above sources.

Hypothesis 3: Cross-Country Differences

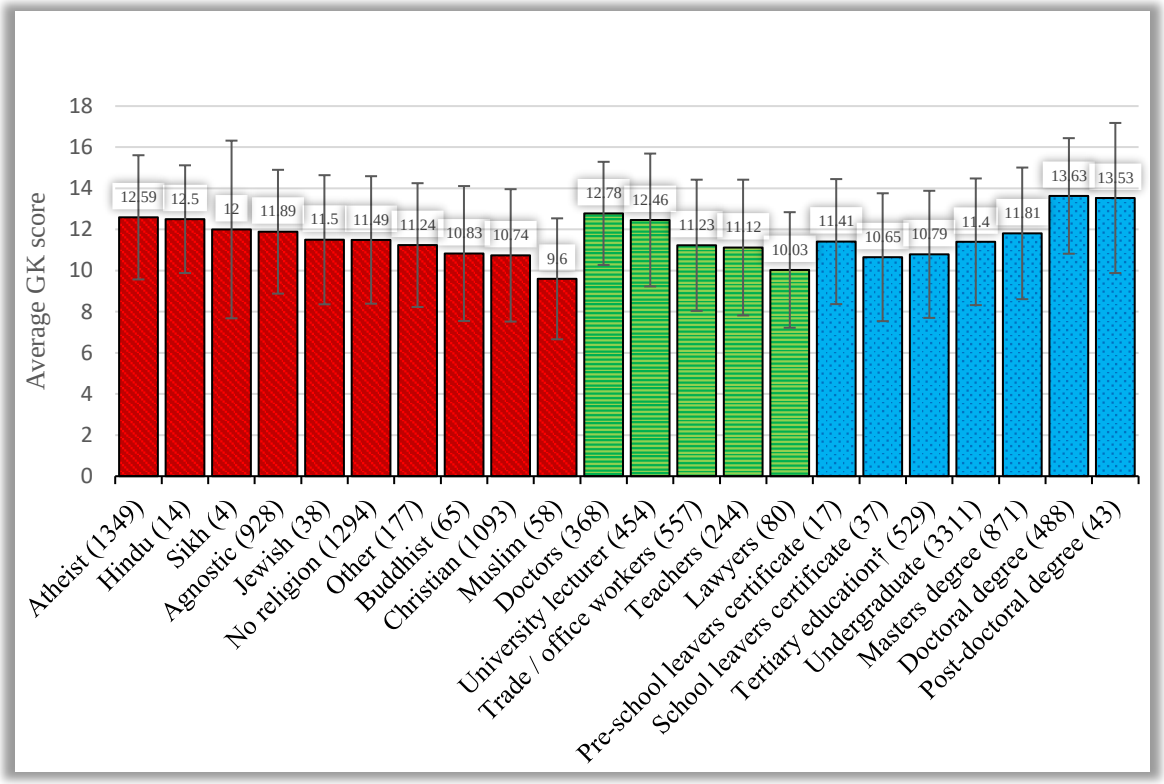
Participants received their secondary schooling in one of 78 different countries, with 71.4% of the sample (3731 people) educated in Russia; 7.2% (375) in the UK; 6.1% (317) in Ukraine; and 4.9% (255) in the USA. These four countries were represented in sufficient numbers for statistically meaningful comparisons. Levene's test indicated equal variances across country groups ($F = 2.14$, $p = .093$). The results of an ANOVA revealed significant differences in the level of knowledge between the four countries: $F (3, 4630) = 37.06$, $p <. 001$. However, the differences were small, with country of secondary education explaining only 2.3% of the variance in GK ($\eta_p^2 = 0.023$). Post hoc analysis revealed that people who received their secondary schooling in the USA ($M = 13.66$, $SD = 2.84$) scored on average significantly higher

than participants educated in the other three countries; and that those educated in Ukraine (M = 11.11, SD = 3.26) scored significantly lower than those educated in Russia (M = 11.57, SD = 3.1). Participants educated in the UK (M = 11.22, SD = 3.17) differed significantly only from the USA participants.

Hypothesis 4: Occupation

Five professions/occupations were reasonably represented in this sample (see green horizontally striped bars in Figure 7) and were included for analysis. Doctors and lawyers both had smaller variance than the other three groups: ranges were 5-18 for doctors; 5-17 for lawyers; 3-18 for university lecturers; 2-18 for office workers; and 3-18 for teachers. The lawyers' data showed negative skew and the doctors' data showed positive skew. Levene's test indicated unequal variances ($F = 8.89$, $p < .001$). Therefore, Welch's ANOVA was conducted (Field, 2013) and revealed significant differences in the level of knowledge among the five professions: $F (4, 436) = 32.43$, $p <. 001$. However, the differences were small, with occupation explaining 6.6% of the variance in GK ($\eta_p^2 = 0.066$). Post hoc analyses revealed that doctors and university lecturers had similar scores, but all other groups differed significantly from each other (Figure 7).

Figure 7. Mean GK scores for each group (number of participants in brackets) represented in this study



Note. †Tertiary education here refers to a level of study between the completion of compulsory schooling (school leavers' certificates) and undergraduate studies. This is not applicable for all countries, but in the UK, tertiary education is referred to as further education, and is known as continuing education in the USA. Such education may be academic, practical and vocational or combinations of the three.

Hypothesis 5: Educational Levels

As expected, there was a significant positive correlation between education level and GK ($r = .210$, $N = 5310$, $p < .001$). As can be seen in figure 7, there are differences in levels of genetic knowledge between participants who have completed different levels of education. Participants with higher levels of education tend to have higher genetic knowledge on average. The small number of participants who did not complete school certificates (17) are unlikely to truly represent the genetic knowledge of others that did not complete school. These participants were sufficiently interested in genetics to engage with and complete iGLAS.

Hypothesis 6: Religion

Participants identified their religious affiliation (see red diagonal striped bars in Figure 7) and rated their religiosity on a scale from 0-100, with 0 being a complete absence of religiosity. 'Agnostic', 'Atheist', 'No religion' and 'Christian' groups were represented in sufficient numbers for statistically meaningful comparisons.

Levene's test revealed heterogeneity of variance for the four groups ($p = .021$). A one-way Welch ANOVA revealed that there was a significant difference in GK across the four groups, $F(3, 2491.74) = 60.12$, $p <. 001$. However, the differences were small, with faith explaining 3.7% of the variance in GK ($\eta_p^2 = 0.037$). Games-Howell post hoc analyses revealed that each of the four groups differed significantly from the others ($p < .05$), with the biggest mean difference ($p < .001$) between Christians ($M = 10.74$, $SD = 3.22$, Range 3-18) and Atheists ($M = 12.59$, $SD = 3.02$, Range 2-18).

Participants were then grouped into either "believers" (Christian, Buddhist, Hindu, Jewish, Muslim, Sikh and other; $N = 1402$) or "non-believers" (Agnostic, atheist and no religion; $N = 3492$). Levene's test revealed heterogeneity of variance for the two groups ($p = .029$). A one-way Welch ANOVA revealed that there was a significant difference in GK between believers ($M = 10.80$, $SD = 3.20$, range 3-18) and non-believers ($M = 12.01$, $SD = 3.08$, range 2-18); $F(1, 2601.93) = 124.193$, $p < .001$. However, the differences were small, with belief explaining 2.5% of the variance in GK ($\eta_p^2 = .025$). This indicates that not all religious and non-religious groups show the same pattern of GK, with some religious groups likely outperforming non-religious groups, as can be seen in Figure 7.

For the entire sample, religiosity (measured on a scale of 0 to 100) was normally distributed (skew = 1.2, kurtosis .581). There was a significant weak negative correlation between religiosity and GK, $r = -.124$, $N = 4297$, $p <. 001$. Additional analyses were performed within the religious groups. Religiosity was normally distributed within the Christian group (skew = -.015, kurtosis = .695), and was not correlated with GK ($r = -.007$, $N = 1079$, $p = .825$).

Therefore, poorer GK is associated with self-identifying as Christian, not the level of one's religiosity (devotion to Christianity). A similar intra-faith correlation pattern was seen for Muslim ($r = .040$, $N = 58$, $p = .766$), and Buddhist ($r = -.113$, $N = 65$, $p = .370$) participants. Analyses were not conducted for other religious groups due to the small sample sizes. This may indicate that there is a very weak association between religiosity and GK which is only identifiable from the large size of the entire sample.

Hypothesis 7: Political Views

Participants rated their position on a political spectrum from 0 (left /very liberal) to 10 (right/very conservative). Although the concept of a left/right political spectrum is less applicable to the Eastern European concept of political affiliation (Đorić & Filipović, 2010), the concept of liberal vs. conservative is comparable for the English and Russian speaking participants. On this spectrum, 49.9% of participants identified as left (answering 0-4), 26.7% as centre (answering 5) and 23.4% as right (answering 6-10). A large proportion of participants identified as extreme left (17.3% scoring 0-2) and extreme right (5.9% scoring 8-10). There was a weak but significant negative correlation between political ideology and GK: those to the left of the political spectrum had slightly better GK than those to the right, $r = -.053$, $N = 3861$, $p < .001$.

Hypothesis 8: Genetic Knowledge and Determinism

Next, analysis was performed to assess whether higher levels of GK are associated with less deterministic views of genetics – examining a correlation between GK and 2 'determinism' questions: 'I believe that my destiny is written in my genes' and 'If genes influence our behaviour then there is no free will'. These two questions were measured on a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). Visual inspection showed that both questions were positively skewed (though skewness was less than 2 in both instances). Most of the participants (70.7%) disagreed that their destiny is written in their genes; 25.5% reported that they agree; 3.7% neither agreed nor disagreed. For the statement 'If genes influence our

behaviour then there is no free will', 85.5% of participants disagreed; 9% agreed to some extent; and 5.5% neither agreed nor disagreed.

A weak negative correlation (r = -.052, N = 5301, p <. 001) was found between GK and the belief that one's destiny is written in one's genes. Similarly, a weak negative correlation (r = -.120, N = 5295, p <. 001) was found between GK and belief that genetic influences result in there being no free will. As this question is negatively phrased, this indicates that greater GK was associated with less deterministic views.

Hypothesis 9: Genetic Knowledge and Genetic Testing

iGLAS included 4 items about willingness to undergo genetic testing: 'If genetic testing allowed you to have improved treatment (for example, medication with fewer side effects) how likely would you be to take that test?' measured on a 7-point Likert scale (strongly disagree – strongly agree); 'In each of the scenarios below, please indicate how likely you would be to take up the offer to have your genome sequenced?: If there were (no/moderate/definite) history of debilitating disease in your family.' In this question, each participant was asked to respond based on each of the scenarios in parentheses above. This question was measured on a 100-point slider scale (not at all likely to very likely).

Most participants (88.6%) expressed willingness to undergo genetic testing if it were to improve their treatment. In the condition of high familial risk (disorder/illness running in the family), 43% of participants expressed extreme likelihood to undergo personal genetic testing; the percentages were 33.7 and 23.7 in the medium and low familial risk conditions, respectively.

There was a weak, but statistically significant, positive correlation between GK and each of the four items (p < .001). Higher GK was associated with greater willingness to undergo testing: r = .208 (N = 5304) for improved treatment; r = .229 (N = 4709) for low familial risk; r = .253 (N = 4859) for moderate familial risk; and r = .219 (N = 4830) for high familial risk.

iGLAS also included 2 items tapping into trust in research institutions and suspicion about genetic research. Trust and suspicion were measured with 2 items: 'I do not trust research institutions in my country because they might misuse the data obtained from participants'; and 'I feel suspicious about genetic studies; hidden political/economic agendas may be behind them' both measured on 7-point Likert scales (1 = strongly disagree to 7 = strongly agree). Some degree of suspicion (i.e. above neutral on the testing scale) towards genetic studies was reported by 19.1% of people, and 12.3% of participants reported a lack of trust in the research institutions in their country by responding below neutral.

A simple linear regression was conducted to examine whether willingness to undergo genetic testing for improved treatment was associated with GK, trust in research institutions and suspicion about genetic research. The model explained a small but significant proportion of variance in willingness to undergo testing, $R^2 = .079$, $F (3, 5282) = 151.121$, $p < .001$. GK and suspicion of genetic studies significantly predicted willingness to undergo genetic testing ($B = .175$, $t (5282) = 13.03$, $p <. 001$; $B = -.192$, $t (5282) = -13.19$, $p < .001$, respectively). Trust in research institutions did not significantly predict willingness to undergo genetic testing scores ($B = -.002$, $t (5282) = -.168$, $p = .886$).

Discussion

This study used the International Genetic Literacy and Attitude Survey to assess genetic knowledge and attitudes of 5404 participants from diverse backgrounds. The average score on basic genetic knowledge was 11.62 out of 18 (65.5%). This indicates poor genetic knowledge, considering the multiple-choice format which increases the chances of correct responses, even from people with minimal knowledge (Wilkinson & Shaw, 2015). iGLAS was also developed to evaluate a non-specialist level of genetic knowledge. Therefore, scores close to 100% correct are expected from people with a good basic knowledge of genetics. Furthermore, 87.6% of the respondents were educated to degree level or higher – a significantly greater proportion than in

the represented populations. For example, as of 2015, 38.7% of European citizens had studied until at least degree level (Eurostat, 2015). For the USA, 33.5% of 25 to 29 year olds hold at least a Batchelors degree (Rampell, 2013). It is therefore likely that population average levels of genetic knowledge are even lower than found in this study. This is concerning as iGLAS questions included genetic concepts that are fundamental for understanding how genes affect our lives.

The results suggested a weak positive correlation between education level and GK. As this sample is skewed towards higher education, it is reasonable to expect an even stronger correlation between education and knowledge in the general population. However, with increasing numbers of school leavers attending university, factors other than educational attainment (years in education) may contribute to GK: the quality of education, educational achievement, the types of degree and if/when/how genetics was included in the school curriculum.

The study also revealed specific gaps in genetic knowledge. For example, ~30% of participants thought that schizophrenia and autism were the product of a single genetic mutation, when in fact research has consistently shown that they stem from multiple genetic factors (Bergen & Petryshen, 2012; van Eijk et al., 2015), which also interact with environments. For more on this see Chapter 4. Discovery of the polygenic nature of most human traits, including many common diseases and disorders, is of great importance. The shift towards understanding that traits are polygenic (and not caused by a single mutation), represents a fundamental qualitative change in the way a person views genetic effects and the traits themselves.

Overall, participants provided reasonably accurate estimates of heritability – the extent to which genetic factors contribute to individual differences in traits. However, people on average underestimated genetic influences on weight, motivation and school achievement. In contrast, they overestimated the heritability of eye colour, height, sexual orientation and IQ. This contradicts the findings of Morin-Chassé (2014) as iGLAS participants did not over estimate

physiological traits, nor did they underestimate for behavioural traits. This pattern of under- and over-estimation is likely driven by an erroneous intuition that certain traits are more easily controllable or malleable than others, and therefore are under weaker genetic control. A powerful example of this is the common belief that educational achievement is less heritable than IQ, as evidenced in this study. Research, however, has shown that for school children, heritability is greater for academic achievement than for intelligence (Kovas et al., 2015; Krapohl et al., 2014).

The analyses stratified by different demographic characteristics revealed some interesting findings. Lack of knowledge and misconceptions were evident across all occupation groups, including medical doctors, teachers, lawyers, university lecturers and office workers. This lack of knowledge raises cause for concern because of the importance of genetic awareness for the roles these professions play: teachers and lecturers - in education; medical doctors - in health and well-being; and lawyers - in legal representation and reform. Office workers were included in the analyses as a control sample, but their results also highlight weaknesses in genetic knowledge in general.

The differences in levels of genetic knowledge between different educational levels and different job sectors were small. For education, the mean scores differed by <3 points between the lowest and highest education levels. For employment, mean scores also different by <3 points between the lowest and highest scoring groups (lawyers and doctors respectively). This suggests that factors other than just educational level and employment sector (and, by extension SES) are accounting for variance in genetic knowledge. Such factors could include the content of school curricular, media coverage and interest in genetics. These factors will be explored in more detail in Chapter 5.

The relatively low level of genetic knowledge was also evident across all belief groups, with slightly lower average scores for individuals who identified as religious than those who

identified as non-religious. Those who identified as more conservative, had on average poorer genetic knowledge than those identifying as more liberal.

With regards to attitude towards genetics, this study identified that 88.6% of participants would consider undergoing genetic testing to access improved health care. This is in line with a previous study, in which 85% of participants responded positively towards a question about their own willingness to undergo predictive genetic testing for preventable health conditions (Makeeva et al., 2010).

The results also suggest that people with greater genetic knowledge are more likely to benefit from genetic advances, such as greater willingness to opt for genetic testing for medical reasons. As suggested by the negative correlation between GK and determinism, people with greater GK are likely to have a more realistic view on the sources of individual differences. However, the correlation was weak, indicating that many factors beyond knowledge influence genetics related deterministic views.

The results of this study also indicate that the GK of a population may depend on such factors as curricula, policy, legislation and the media. For example, the observed higher rates of GK in the USA may result from the insurance-based healthcare system there, the passing of the Genetic Information Non-discrimination Act (GINA) and media coverage of genetic topics such as BRCA mutations (Abrams et al., 2016; Jolie, 2013).

Understanding more about genetic knowledge and the errors participants are making, should prove fruitful in the development of specific strategies to improve general levels of genetic knowledge. Continuing data collections with iGLAS will allow many more questions to be asked in relation to genetic knowledge and opinions and the implications of these.

Chapter 4: iGLAS – Genetic Knowledge, How and Why are Errors Being Made, and by Whom

Abstract

Having a good basic understanding of genetics may help all people engage in the genomic era: to make better decisions about their personal health and lifestyle and enable richer and more productive debates about the ethical use of genetic data and technology across all aspects of society. Exploratory evaluation of the genetic knowledge items in the current version of iGLAS, particularly in relation to errors, has identified some national differences and similarities in genetic knowledge in student samples, which may be the result of cultural and educational differences between those countries. Analyses on the total sample have also identified that knowledge seems particularly weak in relation to fundamental concepts including the gene, the genome, non-coding DNA, heritability, heredity, polygenicity, and epigenetics. Misconceptions in these areas were found to be associated with such outcomes as views on determinism and attitudes to personal healthcare. The current chapter presents and discusses these results and provides suggestions for addressing these misconceptions in public engagement activities.

Introduction

The Genetic Knowledge section of iGLAS differs from other recently developed measures of genetic knowledge/literacy (Carver et al., 2017; Dar-Nimrod et al., 2018) as it includes items with multiple responses rather than just binary (yes/no; true/false) questions. This approach was taken to reduce the effects of chance responses, to make the measure more engaging for participants, and to allow for the evaluation and investigation of errors as well as correct responses.

This chapter will consider the responses to the 20 genetic knowledge items in the current version of iGLAS (v3). A detailed exploration of responses to these items will provide new

insights that may allow for the development of educational and public engagement strategies, as well as the formation of hypotheses to inform future studies.

As well as evaluating the total responses to iGLAS, each question will be looked at within 5 international student samples (Italy, Nigeria, Russia, Spain and the UK). Student samples have been chosen to increase **homogeneity** across samples. Degree level students can be considered to be relatively well educated and have completed compulsory schooling, thus reducing the confound of variable educational levels. Focus on this group should also help reduce confounds such as professional experience with genetics and wide age ranges; thus allowing for a closer scrutiny of international differences. Previous studies have identified international differences in the understanding of genetic concepts (Kılıç et al., 2016). There are several hypothetical explanations for these international differences. For example, media coverage of genetics in different countries may relate to general levels of interest and engagement with genetics. Legal and healthcare systems may also explain some of these differences, as may differences in culture and school curricular.

Students will be in the vanguard of the genomic era and are most likely to be faced with important decisions about the use of genetic data in their own health and family planning decisions. They are also part of the generation(s) making important contributions to debates at the legal, ethical, political and societal levels about how genetic data should be used. As such, it is particularly important to have a clearer understanding of their conceptions and misconceptions about important genetic ideas. To allow for cross country comparisons, student samples from Italy, Nigeria, Russia, Spain and the UK are being investigated. International differences are expected due to differences in school curricular, media coverage of genetics, culture, legal and health service provision differences in those countries. For example, the UK leads the world in genomic health implementation (Davies, 2017) and so participants may reasonably be expected to have better genetic knowledge due to higher exposure to genetic information when compared to other countries. Europe wide differences have also been identified in attitudes towards different applications of genetic technology (Gaskell et al., 2000).

Participants were able to complete iGLAS in their native language (i.e. English (UK and Nigeria[1]), Italian, Spanish or Russian) The stringency of the translation process (see Chapter 2) means that any international differences are very unlikely to be explained by the different languages participants may have completed the study in.

Methods

The present chapter analyses responses for all participants on the genetic knowledge section of iGLAS, looking at both correct and incorrect responses. 13 of these questions have been present since the first version of iGLAS and have been completed by more than 10000 participants from around the world. The number of responses to the remaining 7 items are lower as these have been introduced or edited in later versions of iGLAS. Responses to each item for the whole group are given in the first row of the tables in each section below, this includes students and non-students. Focus is then given to selected student samples in countries where targeted collections of iGLAS have been completed.

Participants

iGLAS was completed by students currently resident in 80 countries. However, for some of these countries, only 1 or 2 students provided responses. Targeted collections of iGLAS took place in 5 countries: Italy, Nigeria, Russia, Spain and the UK. In Italy, Spain, Nigeria and the UK, these collections were targeted by researchers working within different degree specialisation (i.e. Biology in Nigeria, Psychology in Italy and Spain, Law in the UK). The exception to this is Russia, where students were recruited from across different subject areas. Russian participants, therefore, could be taken as being more representative of the Russian population, than the other student samples are of their populations. This is particularly likely to be the case as Russia also has one of the highest international graduation ratios[2] (70.29 in 2017).

[1]English is the lingua franca in Nigeria.
[2]Number of graduates from first degree programmes (at ISCED 6 and 7) expressed as a percentage of the population of the theoretical graduation age of the most common first degree

This is higher than the UK (52.71 in 2014), Spain (43.55 in 2017) and Italy (37.34 in 2016)[3]. Figures were not available for Nigeria. Samples from other countries may be more representative of their area of subject specialism (e.g., psychology students), rather than their country. Consideration of this is made in all the following evaluations and interpretations. In addition to their degree specialisation, students were also asked their age and to identify if they were undergraduate or postgraduate and in which year of their programme they were at the time of completing iGLAS (year 1, year 2 or year 3+). Descriptive statistics for these student samples can be seen in Table 6. In each student sample there are different breakdowns of first, second and third year students. For example, 73.5% of Nigerian students, most of whom were studying Biology, had completed at least one year of teaching. This compares with 95% for Italian, 75.7% for Russian, 42.4% for Spanish, and 54.4% for UK students.

Table 6. Five student samples used for analyses of genetic knowledge errors

Country	N	Mean Age	Undergraduate %	Number of different subjects	Main subject and %	1st year	2nd year	3rd + year	Average GK score
Italy	123	22.5	86.1%	8	Psychology 90.2% (N = 111)	5.0% (N = 6)	31.4% (N = 38)	63.6% (N = 77)	64%
Nigeria	1030	21.9	81.8%	15	Biology 85.1% (N = 804)	26.6% (N = 238)	26.3% (N = 235)	47.2% (N = 422)	55%
Russia	1196	20.3	95.6%	31	Media 16.7% (N = 199)	24.3% (N = 290)	24.1% (N = 287)	51.6% (N = 615)	50%
Spain	134	22.1	88.1%	15	Psychology 74.4% (N = 99)	57.6% (N = 76)	7.6% (N = 10)	34.8% (N = 46)	65%
UK	211	25.0	57.8%	16	Law 72.0% (N = 152)	45.6% (N = 88)	22.8% (N = 44)	31.6% (N = 61)	56%

"Number of different subjects" represents the total number of different degree specialisms represented for that country. Numbers and proportions are also given for students in their first, second and third (or more) years of their degrees. "GK" = genetic knowledge.

Results

The average genetic knowledge score for the full sample was 63%. Scores for student populations in Italy, Nigeria, Russia, Spain and the UK can be seen in Table 6.

programme.https://datacatalog.worldbank.org/gross-graduation-ratio-first-degree-programmes-isced-6-and-7-tertiary-education-both-sexes

[3] Statistics taken from http://uis.unesco.org/. Most recent available data are reported.

Genetic Knowledge and Views on the Importance of Science

It may also be that general attitudes to science explain any international differences in genetic knowledge scores. To test this hypothesis, analysis was conducted on the collected data. iGLAS included the opinion item 'Scientific development is essential for improving people's lives' (Likert scale 1 = strongly disagree – 7 strongly agree). Across all countries endorsement of this statement was high (> 6). However, this was lowest in the Nigerian sample of students, it was also lower in students from the UK. Welch's ANOVA revealed a significant model when comparing all 5 countries on this measure $F (4, 994.20) = 34.47$, $p <. 001$; η_p^2 .02. Games-Howell post-hoc analyses revealed that Nigeria (N = 1037, M = 6.01, SD = 1.31) differed significantly from Italy (N = 271, M = 6.45, SD = 0.85), Russia (N = 4861, M = 6.44, SD = 1.07), Spain (N = 294, M = 6.57, SD = 0.79) and the UK (N = 766, M = 6.23, SD = 0.97), all at $p <. 001$. The UK differed from Russia and Spain at the $p <. 001$ level, and Italy at $p = .006$. No other significant pairwise comparisons emerged. This may explain the lower genetic knowledge scores seen in these groups. However, this does not hold for the Russian students who had high endorsement of this item but low genetic knowledge scores.

The following sections present the responses for all 20 items of the genetic knowledge section in the current version of iGLAS. Questions have been ordered and presented thematically, rather than in the order in which they appeared to participants. The results for each question are presented in a separate table. Correct response options are highlighted in bold. Statistical analyses will be applied to items where this might provide further illumination on the observed patterns.

Question 1: What is a genome?

The term 'genome' refers to the entire sequence of DNA in any living organism (Brosius, 2009); as such, it consists of both coding (genes) and non-coding regions.

Table 7. Frequency responses to 'What is a genome?'

	A sex chromosome	**The entire sequence of an individual's DNA**	All the genes in DNA	Gene expression
Total sample N = 10064	323 3.2%	**5434** **54.0%**	3926 39.0%	381 3.8%
Italy N = 123	5 4.1%	**68** **55.3%**	29 23.6%	21 17.1%
Nigeria N = 1020	159 15.6%	**539** **52.8%**	215 21.1%	107 10.5%
Russia N = 1195	60 5.0%	**364** **30.5%**	747 62.5%	24 2.0%
Spain N = 134	2 1.5%	**69** **51.5%**	48 35.8%	15 11.2%
UK N = 210	11 5.2%	**134** **63.8%**	43 20.5%	22 10.5%

Within the full sample, and across different student populations, most participants identified the correct definition of the genome. The exception to this was Russia, where 62.5% of participants incorrectly responded that the genome only consists of genes. To investigate this further, the responses from Russian participants who did not identify themselves as current students were considered. The same pattern emerged. 51.1% (N = 1845) thought that the Genome consisted only of genes, 48.0% (1733) correctly identified the definition of the genome and <1% (30) selected the remaining options.

Interestingly, Russian students were also least likely to identify the definition of non-coding DNA when compared to the other student samples (Question 9). Russian students were also the student sample most likely to erroneously believe that complex disorders (in this case: autism and schizophrenia) can be monogenic (Questions 15 and 16).

A considerable proportion of those surveyed in iGLAS showed a fundamental misconception about the term 'genome', wrongly identifying this as only consisting of genes (protein-coding regions). Such errors may have implications. For example, people who believe that a genome only consists of genes are unlikely to be able to make informed decisions if having to choose between whole genome and whole exome sequencing. The former sequences all 3 billion base pairs of DNA, the latter focuses only on protein-coding regions (genes) (Bick & Dimmock, 2011).

In more conceptual terms, this misconception may suggest that individuals have a poor understanding that the genome has many functions other than to store information for protein synthesis.

Question 2: Which of the following 4 letter groups represent the base units of DNA?

DNA is constructed of repeating patterns of 4 bases: Adenine (A), Thymine (T), Cytosine (C) and Guanine (G). The order in which these bases are read relates to the functioning of the Genome (Egholm et al., 1992). The erroneous options for this question ('GHPO', 'HTPR', 'LFWE') were chosen at random to provide a pure evaluation of whether participants had accurate knowledge of this item.

Table 8. Frequency responses to 'Which of the following 4 letter groups represent the base units of DNA?'

	GHPO	HTPR	**GCTA**	LFWE
Total sample N = 9705	1031 10.6%	1176 12.1%	**7250** **74.7%**	248 2.6%
Italy N = 121	2 1.7%	8 6.6%	**111** **91.7%**	0 0.0%
Nigeria N = 1007	120 11.9%	197 19.6%	**680** **67.5%**	10 1.0%
Russia N = 1177	220 18.7%	223 18.9%	**691** **58.7%**	43 3.7%
Spain N = 132	6 4.5%	7 5.3%	**119** **90.2%**	0 0.0%

UK N = 210	36 17.1%	25 11.9%	**147** **70.0%**	2 1.0%

Participants had a good knowledge of the 4 bases of DNA, especially students from Italy and Spain. In both countries, most students were studying psychology. Nigerian students performed worse than the total sample on this question. As these students were mostly studying biology, this increased error rate is surprising. It may be that the observed international differences relate more to differences in compulsory schooling curricula between those countries, rather than degree level subject. Differences in media coverage may also explain these international differences, although the specifics of DNA base pairs are unlikely to be of interest to the media.

To investigate the hypothesis that degree subject may not explain the observed differences in responses, the data from Russian students was scrutinised in more detail. For this sample, 31 different degree specialisms were represented in the data, with numbers spread more evenly across all subjects than for other countries. Evaluation across these subjects invariably revealed the same pattern of responses. 'GCTA' was the most popular response and 'LFWE' the least popular. 'GHPO' and 'HTPR' were each selected by about 15-20% of participants. The exception to this was the 15 Russian biology students who completed iGLAS, all of whom selected the correct option.

The erroneous responses do not appear to be random. In all instances 'LFWE' was rarely chosen by participants, with 'GHPO' and 'HTPR' accounting a similar amount for most errors. When iGLAS was designed, all 4-letter groupings other than 'GCTA' were chosen at random and so it is not clear why this pattern has emerged. HTPR may have been subliminally appealing to participants as it is similar to 'HTTP' (Hyper Text Transfer Protocol), used to denote website addresses. In the case of 'GHPO' participants may have thought the 'G' stood for genetic. If this is the case, then a similar number of participants may have selected 'GCTA' without having concrete knowledge that these letters represent the base pairs of DNA. Further research is

required to better understand this seemingly systematic pattern of responses to ostensibly random erroneous options.

Question 3: In humans, DNA is packaged into how many pairs of chromosomes?

Human cells have 23 pairs of chromosomes, consisting of 22 pairs of autosomes and 1 pair of sex chromosomes (Venter et al., 2001).

Table 9. Frequency responses to 'In humans, DNA is packaged into how many pairs of chromosomes?'

	23 pairs	48 pairs	10 pairs	27 pairs
Total Sample N = 10063	**8392**	1280	139	252
	83.4%	12.7%	1.4%	2.5%
Italy N = 123	**120**	2	0	1
	97.6%	1.6%	0.0%	0.8%
Nigeria N = 1028	**834**	134	39	21
	81.1%	13.0%	3.8%	2.0%
Russia N = 1195	**927**	209	25	34
	77.6%	17.5%	2.1%	2.8%
Spain N = 134	**132**	1	0	1
	98.5%	0.7%	0.0%	0.7%
UK N = 211	**184**	15	4	8
	87.2%	7.1%	1.9%	3.8%

Overall, most participants responded correctly to this item. This was especially the case for students in Italy and Spain. When mistakes were made, participants were likely to opt for 48 pairs. 10 pairs and 27 pairs were rarely chosen. The incorrect options for this question were chosen at random, and so no particular pattern of erroneous responses was expected. Further investigation, possibly using qualitative methods, should consider why '48 pairs' was a more commonly erroneously selected option than either '10 pairs' or '27 pairs'. As chromosomes come in pairs, human cells actually contain 46 separate chromosomes (44 autosomes and 2 sex chromosomes). It may be that participants were confused, thinking that there were 46 autosomes, with 2 additional sex chromosomes (totalling 48 single chromosomes).

Question 4: Approximately how many genes does the human DNA code contain?

Based on genomic research in other organisms, it was expected that the human genome would contain a considerable number of genes, with some researchers anticipating up to 2 million (Kauffman, 1969). However, it is now known that the human genome contains approximately 20,000 genes (Willyard, 2018).

The erroneous response options for this question were chosen to a) provide a wide variation (2,000 to 3 billion); b) to see if participants can distinguish base pairs (3 billion) from genes (20,000); and c) to see if participants assume a high number of genes (1 million or 3 billion) – reflecting similar assumptions to early genetic researchers.

Table 10. Frequency responses to 'Approximately how many genes does the human DNA code contain?'

	2,000	1 million	3 billion	**20,000**
Total sample N = 9822	886 9.0%	2135 21.7%	2647 26.9%	**4154** **42.3%**
Italy N = 118	10 8.5%	45 38.1%	27 22.9%	**36** **30.5%**
Nigeria N = 1020	96 9.4%	232 22.7%	180 17.6%	**512** **50.2%**
Russia N = 1187	164 13.8%	404 34.0%	354 29.8%	**265** **22.3%**
Spain N = 133	6 4.5%	36 27.1%	58 43.6%	**33** **24.8%**
UK N = 210	13 6.2%	60 28.6%	81 38.6%	**56** **26.7%**

This item clearly presented difficulties for participants, especially student populations in Russia, Spain and the UK, where more participants opted for 3 billion than the correct response of 20,000. This suggests that participants have some confusion between the concept of the 'gene' and the number of base pairs in the human genome – approximately 3 billion (Venter et al., 2001). In all instances, the option of '2,000' genes was rarely chosen. Errors were fairly evenly spread between '1 million' and '3 billion'. Whilst it seems likely that participants who opted for '3 billion' may have confused genes with base pairs, it is not immediately obvious why some

participants opted for '1 million'. It may be that these participants selected this response as it represented an approximate midpoint between the two extreme values (2,000 and 3 billion), a response choice sometimes associated with multiple-choice items (Attali & Bar-Hillel, 2003). Alternatively, it may be that participants assumed a high number of genes (but not as high as 3 billion) based on the idea that the human genome must be complex due to the degree of human phenotypic complexity. This being the case, it may be that individuals who opted for 1 million and 3 billion genes have a poor understanding that more complex organisms are not necessarily the product of more genes, but that his complexity can arise from other genetic differences that impact the reading of genes and the regulation of protein production. This reflects the expectations of early molecular geneticists and warrants further investigation as it seems these early misconceptions may perseverate in the general population.

Question 5: How many copies of each gene do we have in each autosome cell?

Each autosome cell contains two copies of each gene. Understanding this fact is important in understanding heredity - how traits are transmitted between generations (Grafen & Ridley, 2007, p. 69).

Response options were chosen to see if a) participants are aware that humans are **diploid** (2 copies) rather than **haploid** (1 copy); b) to see if participants are confusing genes with chromosomes (23 copies); and c) to identify participants who might simply be guessing (5 copies)

Table 11. Frequency responses to 'How many copies of each gene do we have in each autosome cell?'

	1 copy	**2 copies**	23 copies	5 copies
Total sample N = 4256	835 19.6%	**2100** **49.3%**	1180 27.7%	141 3.3%
Italy N = 123	17 13.8%	**75** **61.0%**	31 25.2%	0 0.0%
Nigeria N = 1018	68 6.7%	**492** **48.3%**	433 42.5%	25 2.5%
Russia	291	**486**	331	81

N = 1189	24.5%	**40.9%**	27.8%	6.8%
Spain N = 133	36 27.1%	**75** **56.4%**	22 16.5%	0 0.0%
UK N = 194	38 19.6%	**86** **44.3%**	59 30.4%	11 5.7%

In all instances, more participants selected the correct response to this item, rather than any specific incorrect response; however, only about half the participants got this item right. Participants rarely selected '5 copies'. A substantial proportion of participants in all 5 countries selected '23 copies'. These participants were presumably thinking of the number of chromosomes that DNA is packaged into. It is possible that some participants who selected 'one gene' may have thought that the question related to sex cells or that they believe humans to be haploid rather than diploid. However, this seems unlikely, as any participant with sufficient biological knowledge to make this distinction would have been likely to select the correct response.

Whilst participants may have knowledge of some salient terms and figures in genetics (e.g. 23), this item suggests that this knowledge is being misapplied. The fact that almost 20% of participants opted for 1 copy, suggests that any attempts to communicate important genetics concepts may need to focus on distinguishing haploid and diploid cells / organisms.

Question 6: The DNA sequence in two different cells, for example a neuron and a heart cell, of one person, is:

With the exception of mature red blood cells, every cell in the human body contains DNA (Kabanova et al., 2009). In healthy individuals (e.g. those without cancer or other de novo mutations) each cell contains the entire sequence of an individual's DNA. The DNA sequence found in a heart cell is the same as that found in a neuron or any other somatic cell. Their differences in form and function result from epigenetic processes during cell formation (Goldberg et al., 2007).

Table 12. Frequency responses to 'The DNA sequence of two different cells, for example a neuron and a heart cell, of one person is:'

	Entirely different	About 50% the same	More than 90% the same	**100% identical**
Total sample N = 4274	747 17.5%	973 22.8%	910 21.3%	**1644** **38.5%**
Italy N = 120	7 5.8%	21 17.5%	24 20.0%	**68** **56.7%**
Nigeria N = 1026	356 34.6%	316 30.8%	203 19.8%	**151** **14.7%**
Russia N = 1192	197 16.5%	430 36.1%	286 24.0%	**279** **23.4%**
Spain N = 132	13 9.8%	22 16.7%	30 22.7%	**67** **50.8%**
UK N = 194	26 13.4%	35 18.0%	59 30.4%	**74** **38.1%**

Participants had considerable difficulty responding to this item. Only amongst Italian and Spanish students did at least half the participants correctly identified that every somatic cell in an individual's body contains the same DNA. UK, Russian and Nigerian students were more likely to get this item wrong than right. This is surprising amongst Nigerian students as most were studying biology. Further evaluation of iGLAS data revelated that non-Nigerian biology students (N = 75; various countries) were more accurate in this item: 55 (73.3%) got this item correct; 6 (8%) responded 'entirely different'; 2 (2.7%) 'about 50% the same'; and 12 (16%) 'more than 90% the same'. These results indicate that even biology students may hold fundamental misconceptions about DNA.

Participants who thought that the DNA in different cells is entirely different may consider that differences in cell structure and function result from differences in the DNA they contain, rather than from epigenetic processes when the cell was formed.

It is unclear what mechanisms for cell differentiation could be ascribed to the views of the remaining participants. It may be that those respondents who opted for 'about 50% the same'

and ‘more than 90% the same’ were of the view that most cellular structure is invariant across cells, and that a small proportion of DNA variation between cells results in cell differentiation.

The analysis presented in Chapter 2 identified this to be the second most difficult item in the Genetic Knowledge section of iGLAS. Most participants have very poor knowledge about the relationship of DNA in different cells. They appear to not understand that different cell types result from how DNA is read rather than from different DNA contained in different cells. This would suggest a poor understanding of epigenetics and may have implications for how individuals understand molecular genetic findings and personal genomic results.

Question 7: An Epigenetic change is:

‘Epigenetic’ refers to non-genetic processes related to gene expression. Epigenetic processes are involved in the production of biological material and relate to cell differentiation. In some plants and animals, epigenetic markers can be passed through the generations, but this is extremely rare in mammals due to germline reporgramming, and there is little evidence for truly transgenerational epigenetic inheritance (Heard & Martienssen, 2014). In recent years there have been a number of popular science, spiritual and esoteric publications proposing that humans can take conscious control of their DNA through epigenetic processes (e.g. Akhtar & Khan, 2017; Lipton, 2015), a view unsupported by empirical science.

Table 13. Frequency responses to ‘An Epigenetic change is:’

	A change in gene expression	A change of the genetic code itself	A process by which human beings can consciously change their DNA	Gene splicing
Total sample N = 9747	**6332** **65.0%**	2003 20.5%	732 7.5%	680 7.0%
Italy N = 122	**85** **69.7%**	20 16.4%	4 3.3%	13 10.7%
Nigeria N = 1025	**554** **54.0%**	185 18.0%	246 24.0%	40 3.9%
Russia N = 1180	**552** **46.8%**	385 32.6%	126 10.7%	117 9.9%

Spain N = 132	**92** **69.7%**	32 24.2%	6 4.5%	2 1.5%
UK N = 210	**114** **54.3%**	70 33.3%	15 7.1%	11 5.2%

Most participants in the general sample and each student sample got this item correct. However, a number of participants got this item wrong and the concept of epigenetics seems to be quite poorly understood, especially amongst students from Nigeria, Russia and the UK. Those who responded that epigenetic changes related to 'a change in the genetic code itself' and 'gene splicing' are likely to have simply been unfamiliar with the term. However, several participants (732; 7.5% of the total sample) responded that epigenetics is 'A process by which human beings can consciously change their DNA'. Further analysis of 3 opinion items explored whether this response was a true belief in the pseudoscientific notion that humans can consciously alter their DNA and if this view has implications for health management. Participants who believed that epigenetic processes can be consciously controlled were expected to be more likely to use alternative medicine when unwell and when diagnosed with a severe condition, and less likely to have a genetic test for improved treatment. Mean responses to these three items for each of the four responses to the epigenetics question are presented in Table 14.

Table 14. Average endorsement of health items based on different responses to the item 'An Epigenetic Change is…' (Likert scale: 1 = very unlikely – 7 = very likely)

		N	Mean	Std. Deviation
iOp05 When feeling unwell (e.g. common cold, headache), how likely are you to turn to alternative medicine (such as homeopathy) rather than seeking treatment from conventional medicine?	A change in gene expression	2357	2.89	1.96
	A change of the genetic code itself	1015	2.95	1.85
	A process by which human beings can consciously change their DNA	512	3.75	2.02
	Gene splicing	282	3.07	1.87
	Total	4166	3.03	1.95
iOp06 If diagnosed with a severe condition such as cancer, how likely are you to turn to alternative medicine (such as homeopathy) rather than seeking treatment from conventional medicine?	A change in gene expression	2357	2.64	2.00
	A change of the genetic code itself	1015	2.81	2.00
	A process by which human beings can consciously change their DNA	512	3.64	2.10
	Gene splicing	281	2.69	1.98
	Total	4165	2.81	2.03
iOp02 Would you take a genetic test if it allowed you to have improved treatment (for example,	A change in gene expression	2101	5.71	1.52
	A change of the genetic code itself	862	5.53	1.65

medication with fewer side effects)?	A process by which human beings can consciously change their DNA	472	5.35	1.73
	Gene splicing	238	5.62	1.75
	Total	3673	5.61	1.60

All three predictions were supported by analyses of variance and appropriate post-hoc testing. Full inferential analyses are available from the author. When compared to all other groups, participants who responded that an epigenetic change relates to human conscious control of DNA were significantly more likely to pursue alternative rather than conventional medicine ($p < .001$), even when severely ill ($p < .001$). They were also less likely to engage with genetic testing for improved treatment when compared to participants who got this item correct ($p < .001$) and those who thought an epigenetic change was gene splicing ($p = .035$). However, all effect sizes were small. The largest overall effect was found in relation to severe illness where understanding of epigenetics explained 2.5% of the variance ($\eta_p^2 < .025$).

Question 8: What is the main function of all genes?

The conceptualisation of the 'gene' has changed over time (Gericke & Hagberg, 2007). One of the currently accepted working definitions of a gene is 'A locatable region of genomic sequence, corresponding to a unit of inheritance, which is associated with regulatory regions, transcribed regions and/or other functional sequence regions.' (Pearson, 2006). This definition, whilst it may be of use to geneticists, is too specialised for common use. As iGLAS was developed for use with general populations, this question was written to acknowledge that storing information for protein production is not the only function of genes but is the main one.

Table 15. Frequency responses to 'What is the main function of all genes?'

	Storing information for protein synthesis	To provide energy to the cell	To clear out waste from the cell	To repair damage to a cell
Total sample N = 10065	**9572**	224	57	212
	95.1%	2.2%	0.6%	2.1%
Italy N = 123	**121**	1	0	1
	98.4%	0.8%	0.0%	0.8%
Nigeria	**893**	62	13	53

N = 1021	**87.5%**	6.1%	1.3%	5.2%
Russia N = 1195	**1143** **95.6%**	25 2.1%	11 0.9%	16 1.3%
Spain N = 133	**132** **98.5%**	0 0.0%	0 0.0%	2 1.5%
UK N = 194	**186** **88.2%**	12 5.7%	2 0.9%	11 5.2%

As can be seen from Table 15, participants have a good understanding of the main function of genes, and this pattern generally holds for student samples in the different countries evaluated. The strong performance in this item, coupled with poor performance in other areas, for example knowing approximately how many genes the human genome contains, and that it consists of many other regions and functions, some of which are involved in regulation, suggests that participants might have quite a simple mapping concept between genes, proteins and phenotypes.

Question 9: ‘Non-coding’ DNA describes DNA that:

Approximately 98% of the human genome does not lead to the production of proteins (Elgar & Vavouri, 2008). Historically, these regions were known as ‘Junk DNA’ (Ohno, 1972). This term fell out of favour as more was learnt about these regions of the genome, but some researchers have started to reclaim the term (Carey, 2015; Palazzo & Gregory, 2014). However, for this question, it was decided to use the more accurate and less leading term ‘Non-coding’.

Table 16. Frequency responses to 'Non-coding DNA describes DNA that:'

	Is removed when passed from parent to offspring	**Does not lead to the production of proteins**	Is non-human DNA	Is not composed of nucleotides
Total sample N = 9966	1850 18.6%	**6883** **69.1%**	341 3.4%	892 9.0%
Italy N = 121	14 11.6%	**101** **83.5%**	2 1.7%	4 3.3%
Nigeria N = 1021	294 28.8%	**437** **42.8%**	108 10.6%	182 17.8%
Russia N = 1195	418 35.0%	**569** **47.6%**	57 4.8%	151 12.6%
Spain N = 132	16 11.9%	**110** **82.1%**	0 0.0%	6 4.5%
UK N = 194	35 16.6%	**141** **66.8%**	9 4.3%	26 12.3%

Responses to this item were particularly inconsistent across the international student samples. The majority of students in Italy, Spain and the UK got this item correct. This was not the case for Russia and Nigeria: only 569 (47.6%) and 437 (42.8%) got this item correct in these countries. However, the correct option was the one most often chosen in all countries. In all instances the selection of incorrect responses followed the same pattern: 'Is removed when passed from parent to offspring' > 'Is not composed of nucleotides' > 'Is non-human DNA'. Based on the wording of this item, this pattern of responses seems to suggest that participants may have been applying logical reasoning to their responses. For example, participants may have thought that the term 'non-coding' DNA relates to genetic information which is not passed from parent to offspring (e.g. the 50% of the genetic data that is not present in the chromosomes of each gamete). As such, it may be surmised that a proportion of those participants who got this item correct were also applying such logical reasoning rather than demonstrating factual knowledge about the definition of 'non-coding' DNA.

Question 10: What are polymorphisms?

Polymorphisms are points of genetic variation found throughout the human genome. Polymorphisms account for much of the variance seen between individuals (Karki et al., 2015).

Table 17. Frequency responses to 'What are polymorphisms'

	Building blocks of the DNA	Proteins found in the brain	**Points of genetic variation**	Deoxyribonucleic Acid
Total sample N = 9913	1866 18.8%	439 4.4%	**7391** **74.6%**	217 2.2%
Italy N = 120	18 15.0%	5 4.2%	**97** **80.8%**	0 0.0%
Nigeria N = 1026	278 27.1%	120 11.7%	**583** **56.8%**	45 4.4%
Russia N = 1192	295 24.7%	98 8.2%	**735** **61.7%**	64 5.4%
Spain N = 133	7 5.3%	5 3.8%	**121** **91.0%**	0 0.0%
UK N = 210	35 16.7%	25 11.9%	**145** **69.0%**	5 2.4%

Approximately three-quarters of the total sample got this item correct. Participants tended to correctly identify the definition of 'polymorphism'. Some may have been applying logic to the word (poly = *many*; morph = *form*) to ascertain its meaning. There is some variation amongst international student samples. Students in Nigeria, Russia and the UK performed more poorly than the total sample, Italy and Spain. In each of the student samples, as well as the total sample, the pattern of erroneous responses is the same: Building blocks of DNA > Proteins found in the brain > Deoxyribonucleic Acid. These errors would seem to follow something of a logical pattern. Participants who understand that DNA stands for Deoxyribonucleic Acid would recognise this to be the wrong answer, and this is likely why it was the least popular. It is less clear why participants opted for 'proteins found in the brain'; such participants may have just been guessing. The term 'building block' is often used to describe single bases of DNA (e.g. https://www.genome.gov/about-genomics/fact-sheets/Deoxyribonucleic-Acid-Fact-Sheet). Participants may have been thinking of such information when responding to this item.

Question 11: On average, how much of their total DNA is the same in two people selected at random?

Human beings share more than 99% of their DNA. Variation in the remaining <1% accounts for much of the difference in traits seen between individuals.

Table 18. Frequency responses to 'On average, how much of their total DNA is the same in two people selected at random?'

	Less than 50%	75%	90%	**More than 99%**
Total sample N = 10073	3457 34.3%	1144 11.4%	855 8.5%	**4617** **45.8%**
Italy N = 123	102 82.9%	4 3.3%	9 7.3%	**8** **6.5%**
Nigeria N = 1030	419 40.7%	252 24.5%	107 10.4%	**252** **24.5%**
Russia N = 1195	891 74.6%	152 12.7%	75 6.5%	**74** **6.2%**
Spain N = 134	59 44.0%	19 14.2%	7 5.2%	**49** **36.6%**
UK N = 211	108 51.2%	26 12.3%	21 10.0%	**56** **26.5%**

When looking at the total sample, most participants were able to identify the degree of genetic relatedness in unrelated individuals. However, a sizable minority thought that two random individuals share less than 50% of their total DNA. Across all countries, students were more likely to make this error, with Russian and Italian students especially prone. A surprisingly high proportion of participants, especially in Nigeria (24.5%), thought that unrelated individuals share 75% of their DNA.

The variation in responses to this item, especially the frequency of the "Less than 50%" option, suggests that participants have great difficulty with the concepts of total and variable DNA.

Question 12: People differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?

All human beings share almost all of their genetic information, but there is a small proportion in which we vary (Variable DNA:<1%). Of this <1%, siblings share 50% on average. Second-degree relatives (e.g. cousins) share 25%. The average proportion of this genetic relatedness reduces as the degree of relatedness becomes more distant (Jacquard, 1974).

Table 19. Frequency responses to 'People differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?'

	75%	**50%**	.01%	99.9%
Total sample N = 4273	1043 24.4%	**2013** **47.1%**	331 7.7%	886 20.7%
Italy N = 122	34 27.9%	**69** **56.6%**	4 3.3%	15 12.3%
Nigeria N = 1024	233 22.8%	**562** **54.9%**	63 6.2%	166 16.2%
Russia N = 1194	450 37.7%	**482** **40.4%**	88 7.4%	174 14.6%
Spain N = 133	21 15.8%	**56** **42.1%**	23 17.3%	33 24.8%
UK N = 194	43 22.2%	**96** **49.5%**	16 8.2%	39 20.1%

The correct answer was most often chosen in the total sample and all student samples; however, errors were also common. These tended to follow the same pattern: *75%>99.9%>.01%*. The exception to this was Spain (*99.9%>.01%*> 75%). In Russia, responses were almost evenly split between 50% and 75% sibling relatedness. 75% genetic similarity on average could only result from extreme consanguinity (e.g. siblings reproducing). In cultures that allow consanguineous marriages, this is most typically between first or second degree cousins. This would increase genetic relatedness, but not typically as high as 75% (Hamamy, 2012). It therefore remains unclear why participants chose this option. It seems unlikely they were considering the children of consanguineous couples, especially as such unions are uncommon outside the Middle East (Hamamy, 2012). It seems possible that those participants who responded '0.01%' and '99.9%'

are confusing total DNA and variable DNA. This confusion with the concept of 'variable DNA' was also found in the validation stages of iGLAS, were participants reported difficulties responding to items that included the term. Altering these items to avoid this specific term has revelated that the concept of variable DNA is poorly understood as its distinction from total DNA.

Question 13: If a report states 'the heritability of insomnia is approximately 30%' what would that mean?

Heritability is an important and much misunderstood concept. It considers trait variation in a population and evaluates what proportion of that variation can be explained by genetic factors. If a trait is found to be 40% heritable, then 40% of the variation in a particular population is due to genetic variation. The remaining 60% can be subdivided into shared and non-shared environments (Plomin et al., 2016).

Table 20. Frequency responses to 'If a report states "the heritability of insomnia is approximately 30%" what would that mean?'

	If someone has insomnia this is approximately 30% due to their genes	Approximately 30% of people will experience insomnia at some point in their lives	**Genetic influences account for approximately 30% of the differences between people in insomnia**	There is an approximately 30% chance that someone will pass insomnia onto their children
Total sample N = 1606	274 17.1%	188 11.7%	**386** **24.0%**	758 47.2%
Italy N = 115	8 7.0%	3 2.6%	**29** **25.2%**	75 65.2%
Nigeria N = 698	137 19.6%	146 20.9%	**162** **23.2%**	253 36.2%
Russia N = 6	2 33.3%	1 16.7%	**0** **0.0%**	3 50.0%
Spain N = 130	25 19.2%	6 4.6%	**6** **27.7%**	63 48.5%
UK N = 27	7 25.9%	1 3.7%	**13** **48.1%**	6 22.2%

Note. This item was only added after targeted collections in Russia and the UK had largely completed, hence the low number of participants in these groups.

Analysis of the responses to this item indicate that there is persistent confusion about the concept of heritability. This item was only recently added to iGLAS, as such, participant numbers from Russian (N = 6) and UK (N = 27) students are small. The responses from student participants in Italy, Nigeria and Spain follow the pattern of the general sample: about a quarter of participants identified the correct definition of heritability. Participants are more likely to think that the term heritability relates to the chance of passing a complex trait to one's offspring. This suggests that heritability is being confused with heredity. Additionally, it seems that the concept of heredity is also poorly understood by iGLAS participants. Sexual reproduction produces offspring with genetic information from both parents. It would not be possible to place a percentage risk of one parent passing on a complex trait as this would depend on numerous other factors, including risk alleles in the other parent; random crossing over in zygote formation; and gene-environment interplay.

Participants completed iGLAS in several languages other than English. It is possible that the distinction between heritability and heredity does not translate well. However, all the translators were native speakers with expertise in behavioural genetics. They were asked to comment on any translation issues, and none reported concerns with this item. The fact that similar errors are being made in the English (Nigerian), Italian and Spanish language versions of iGLAS suggests that these errors are unlikely to relate to issues of translation.

Further analyses: Knowledge of heritability and ability to estimate heritability

Further analyses were conducted to see if those respondents who got this item correct were more accurate in estimating the heritability of the complex traits discussed in the previous chapter. Error scores were calculated for 8 traits (height, weight, eye colour, school achievement, IQ, clinical depression, motivation and sexual orientation). The error score is taken as each participant's estimation of genetic influences in that trait, minus the best current heritability estimate from scientific research. Therefore, if a trait were 40% heritable, the range of possible scores would be -40 (not heritable at all) to +60 (100% heritable). Someone who

estimated the heritability of this trait to be 30% would have an error score of -10. Participants scoring 0 would have estimated the heritability correctly. Each of these error scores were summed and divided by 8 to give an average accuracy in estimating heritability across traits. With this method, over estimation on some traits and underestimation on others may occlude actual error rates in some participants. However, the overall heritability estimate error score showed the full range of possible responses and did not differ from normality in terms of skew (-.04) or kurtosis (.29). As such, it was thought to be a viable dependent variable for use in this analysis.

Table 21.Overall summed heritability estimate error scores for each of the response options for the genetic knowledge item related to the definition of heritability.

	If someone has insomnia this is approximately 30% due to their genes	Approximately 30% of people will experience insomnia at some point in their lives	**Genetic influences account for approximately 30% of the differences between people in insomnia**	There is an approximately 30% chance that someone will pass insomnia onto their children
N	251	178	**372**	738
Mean	1.43	-.97	**1.71**	-.57
SD	13.94	16.40	**14.69**	14.76

Analysis of variance showed an overall significant model F (3, 1535) = 2.90, p = .034. However, the η_p^2 (.01) suggests an extremely small effect size. Post hoc analyses revealed no specific group differences in heritability estimates in any pairwise comparisons. Those who correctly identified the definition of heritability were no better at estimating heritability.

The description used when asking for heritability estimates was: 'On a scale of 0-100 how important are genetic differences between people in explaining individual differences in the following traits:'. Having already provided such estimates clearly did not then lead to participants identifying the correct definition of heritability, even those participants who were able to identify the correct definition of heritability were no better at estimating the heritability of complex traits.

Question 14: Can we fully predict a person's behaviour from examining their DNA sequence?

Advances in molecular genetics, especially in recent years and with the development of Genome Wide Polygenic Scoring (Dudbridge, 2013) are allowing for increased accuracy in predicting complex traits from DNA, including educational (e.g. Selzam et al., 2017) and behavioural (e.g. Peyrot et al., 2014) traits. However, such methods will never allow for full prediction as human behaviour is the product of complex interactions between genes and environments.

Table 22. Frequency responses to 'Can we fully predict a person's behaviour from examining their DNA sequence'

	Yes	**No**
Total Sample N = 10068	3209 31.9%	**6859** **68.1%**
Italy N = 122	4 3.3%	**118** **96.7%**
Nigeria N = 1030	691 67.2%	**337** **32.8%**
Russia N = 1194	357 29.90%	**837** **70.10%**
Spain N = 133	7 5.2%	**127** **94.8%**
UK N = 211	19 9.1%	**190** **90.9%**

Overall, about 70% of participants were able to correctly identify that it is not possible to fully predict an individual's behaviour by examining their DNA. However, international differences emerged. Participants from Italy and Spain, the majority of whom were studying psychology, were almost unanimous in recognising that behaviour cannot be predicted from DNA alone. This presumably reflects their understanding of the complexity of human behaviour. A similar pattern can be seen for UK students, most of whom were studying law.

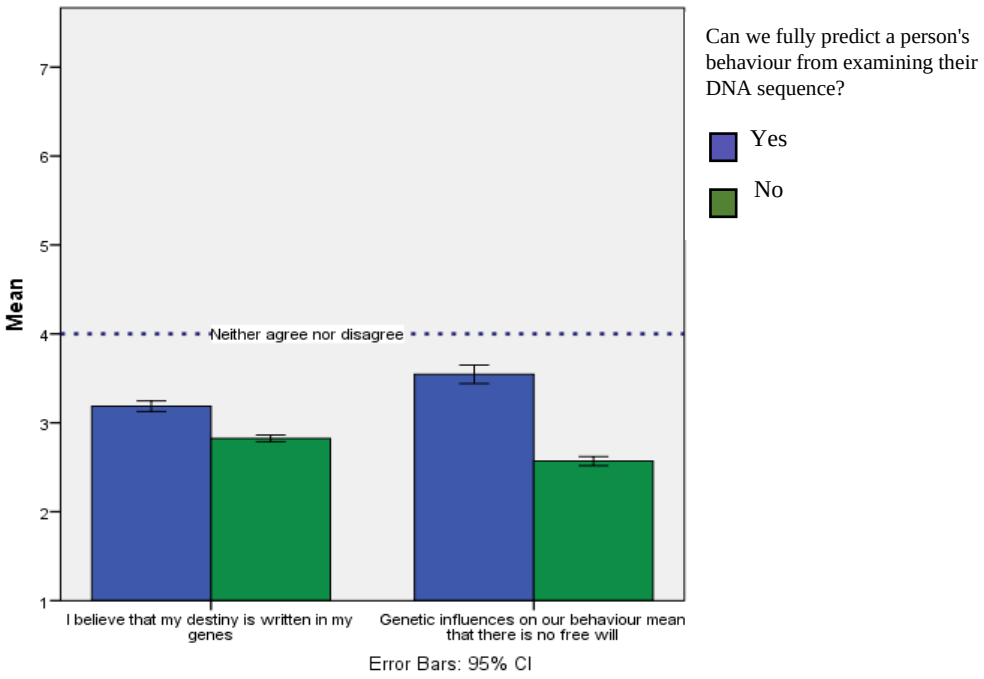
Again, the pattern of responses from Nigerian students is particularly interesting, as the majority thought that full behavioural prediction from DNA was possible. This may be the product of most of these students studying biology. However, this seems unlikely, as biology students

might reasonably be expected to have a good understanding of the complexity of gene/environment interplay. To test this assumption, the responses of non-Nigerian biology students (N = 79) were scrutinised, regardless of the country in which they were studying. 93.7% (N = 74) of these students correctly identified that behaviour cannot be fully predicted from DNA alone.

Miscomprehensions about this item may have implications for how participants think about genetic influences on trait variability within populations. An independent-samples t-test was conducted to compare overall heritability estimate error scores in participants who thought that behaviour could be fully predicted from DNA alone (IV level 1: Yes), and those who did not (IV level 2: No). There was a significant difference in the scores between Yes (M = 2.06, SD = 15.00) and No (M = -1.97, SD = 13.78); t (5630.94) = 12.74, p <. 001; Cohen's d = 0.28. Participants who thought behaviour could be fully predicted from DNA alone (Yes) tended to overestimate heritability, those who recognised this is not possible (No) tended to underestimate it. This analysis was repeated for only Nigerian students and no significant differences emerged. However, Nigerian students tended to overestimate the heritability of traits in both conditions (Yes, M = 3.90 SD = 15.30; No, M = 4.88 SD = 16.27).

Further analyses were conducted to compare opinions on free will and destiny (two opinion items included in iGLAS) of those participants who thought behaviour could be fully predicted from DNA alone and those who did not (see Figure 8).

Figure 8. Mean responses on 1-7 Likert scale items (strongly disagree to strongly agree, where '4' is neither) by responses to the item "Can we fully predict a person's behaviour from examining their DNA sequence?"



An independent-samples t-test was conducted to compare views on the iGLAS item 'I believe that my destiny is written in my genes' in participants who thought that behaviour could be fully predicted from DNA alone (IV level 1: Yes), and those who did not (IV level 2: No). There was a significant difference in the scores for Yes (M = 3.19, SD = 1.71) and No (M = 2.83, SD = 1.57); t (5684.19) = 10.04, p <. 001; Cohen's d = 0.22.

A further independent-samples t-test was conducted to compare views on the iGLAS item 'Genetic influences on our behaviour mean that there is no free will' in participants who thought that behaviour could be fully predicted from DNA alone (IV level 1: Yes), and those who did not (IV level 2: No). There was a significant difference in the scores for Yes (M = 3.55, SD = 1.85) and No (M = 2.57, SD = 1.50); t (1856.86) = 16.60, p <. 001; Cohen's d = 0.58.

In summary, participants who thought behaviour could be predicted from DNA alone were also more likely to endorse the statements that 'Genetic influences in our behaviour means there is no free will' and 'I believe that my destiny is written in my genes'. However, with the midpoint of this scale being 4 (neither agree nor disagree) it is worth noting that even this group tended to

disagree with this notion, just to a lesser extent than those who correctly identified that behaviour cannot be predicted from DNA alone.

Question 15: Genetic contribution to the risk for developing Schizophrenia comes from (one or many genes):

Schizophrenia is a complex mental health disorder characterised by various positive and negative symptoms, not all of which need to be present for a diagnosis (Tsuang, 1975). Schizophrenia is associated with various genetic influences (polygenicity). As with all complex traits, schizophrenia is the product of interacting genetic and environmental influences (Owen et al., 2016).

Table 23. Frequency responses to the item 'Genetic contribution to the risk for developing Schizophrenia comes from':

	One gene	**Many genes**
Total sample N = 10037	3301 32.9%	**6736** **67.1%**
Italy N = 123	44 35.8%	**79** **64.2%**
Nigeria N = 1028	415 40.4%	**613** **59.6%**
Russia N = 1188	580 48.80%	**608** **51.20%**
Spain N = 133	58 43.6%	**75** **56.4%**
UK N = 208	77 37.0%	**131** **63.0%**

The pattern of responses to this item were broadly consistent across different samples, with most students correctly identifying that Schizophrenia is not the product of a single gene (i.e. that it is polygenic, not monogenic). However, a large number of participants reported this erroneous view.

In more recent versions of iGLAS participants were asked to estimate the heritability of schizophrenia, in addition to the 8 traits included since the first version of iGLAS. An

independent-samples t-test was conducted to compare schizophrenia heritability estimate error scores in participants who thought that schizophrenia is monogenic (IV level 1), and polygenic (IV level 2). There was a significant difference in the scores for monogenic (M = -24.08, SD = 28.30) and polygenic views (M = -19.64, SD = 25.45); t (2049.22) = -4.47, p <. 001; Cohen's d = 0.16. In both instances' participants were underestimating the heritability of schizophrenia, particularly those who thought schizophrenia to be monogenic.

Cross-tabulations revealed that participants who understood that schizophrenia is polygenic, were also more likely to understand that behaviour cannot be predicted from DNA alone. X^2 (1, N = 10017) = 173.44, p< .001. For distributions see Table 24.

Table 24. Cross tabulations for Can we fully predict a person's behaviour from examining their DNA sequence? and *Genetic contribution to the risk for developing Schizophrenia comes from:*

		Can we fully predict a person's behaviour from examining their DNA sequence?	
		Yes	No
Genetic contribution to the risk for developing Schizophrenia comes from:	One Gene	1341	1954
	Many Genes	1858	4864

Further analyses: Views on determinism and free will

2 x independent-samples t-tests were conducted to compare views of participants who thought schizophrenia was monogenic/polygenic on the iGLAS opinion items (Likert scale: 1 = strongly disagree – 7 = strongly agree)

1) *I believe that my destiny is written in my genes*
2) *Genetic influences on our behaviour mean that there is no free will*

There was no difference (t (9932) = 0.77, p = .901) in how strongly participants believed that 'destiny is written in their genes' between those who thought that schizophrenia was monogenic (IV level 1; M = 2.96, SD = 1.63), compared with those who thought it was polygenic (IV level 2; M = 2.93, SD = 1.62).

In relation to this item, significant differences emerged in how strongly participants felt genetic influences negated free will (t (4538) = 7.23, p <. 001; Cohen's d = 0.23). Participants who thought that schizophrenia was monogenic had higher endorsement of this statement (M = 3.08, SD = 1.64), than those who thought it was polygenic (M = 2.71, SD = 1.65).

Question 16: Genetic contribution to the risk for developing Autism comes from (one or many genes):

Autism is a complex neurodevelopmental condition characterised by a triad of impairments. Repeated studies have indicated that autism is highly heritable (70% - 80%) (Ramaswami & Geschwind, 2018). As with any complex trait, many genetic variants are likely to be associated with autism, and many complex polygenic, pleiotropic and epigenetic processes are likely to be involved. Believing that such complex traits are (or can be) the product of a single gene is therefore likely to be indicative of a fundamental misconception about the relationship of genetic and phenotypic variants.

Table 25. Frequency responses to 'Genetic contribution to the risk for developing Autism comes from:'

	One gene	**Many genes**
Total sample N = 10015	3383 33.8%	**6632** **66.2%**
Italy N = 122	36 29.5%	**86** **70.5%**
Nigeria N = 1021	416 40.7%	**605** **59.3%**
Russia N = 1191	703 59.0%	**488** **41.0%**
Spain N = 133	55 41.4%	**78** **58.6%**
UK N = 211	92 43.6%	**119** **56.4%**

Overall, the total sample and each student sample identified that autism is associated with more than one genetic variant; the exception to this was Russia where more participants (59%)

thought that autism was the product of a single gene. The breadth of fields of study/subjects of degrees represented in the Russian student sample suggests this sample is more likely to be representative of the general Russian population. The Italian student sample had the highest proportion of correct responses, but even here, almost 30% of participants got this item wrong. These results suggest generally poor conceptualisation of the complex relationship between genes and traits, especially in the student populations sampled here, and particularly amongst Russian students.

As with schizophrenia, cross-tabulations revealed that participants who understood that autism is polygenic, were also more likely to understand that behaviour cannot be predicted from DNA alone. X^2 (1, N = 9995) = 123.45, p< .001. Distributions for this item are presented in Table 26. iGLAS did not ask participants to estimate the heritability of autism, and so the analyses presented for schizophrenia above cannot be replicated for this item.

Table 26. Cross tabulations for 'Can we fully predict a person's behaviour from examining their DNA sequence?' and 'Genetic contribution to the risk for developing Autism comes from':

		Can we fully predict a person's behaviour from examining their DNA sequence?	
		Yes	No
Genetic contribution to the risk for developing Autism comes from:	One Gene	1322	2055
	Many Genes	1866	4752

Further analyses: Views on determinism and free will

2 x independent-samples t-tests were conducted to compare views of participants who thought autism was monogenic/polygenic on the iGLAS items:

3) *I believe that my destiny is written in my genes*
4) *Genetic influences on our behaviour mean that there is no free will*

As with schizophrenia, there was no significant difference in the scores for monogenic (M = 2.90, SD = 1.62) and polygenic (M = 2.96, SD = 1.6) views; t (9911) = 0.50, p = .052 in the item related to destiny. However, there were significant group differences on the item related to genetic influences and free will. Those with a monogenic view of autism were more likely to

think that genetic influences negate free will (M = 3.04, SD = 1.61) than those who understood that it was polygenic (M = 2.72, SD = 1.67); t (4533) = 6.34, p <. 001; Cohen's d = 0.20.

Question 17: Some of the genes that relate to dyslexia also relate to ADHD:

The Generalist Genes hypothesis postulates that cognitive abilities and disabilities are influenced by many of the same genetic variants (Plomin & Kovas, 2005). Such pleiotropic genetic effects have been demonstrated in educational outcomes (Rimfeld et al., 2015). For example, studies have identified shared genetic factors for ADHD and dyslexia (Couto et al., 2009; Loo et al., 2004; Plourde et al., 2015).

Table 27. Frequencies of responses to the question 'Some of the genes that relate to dyslexia also relate to ADHD:'

	True	False
Total sample N = 3721	**2921** **78.5%**	800 21.5%
Italy N = 123	**93** **78.8%**	25 21.2%
Nigeria N = 1030	**853** **83.7%**	166 16.3%
Russia N = 935	**610** **65.20%**	325 34.80%
Spain N = 134	**110** **84.0%**	21 16.0%
UK N = 42	**33** **78.6%**	9 21.4%

Note. This item was only added after collections in the UK had largely been completed, hence the low number of participants in this group

The pattern of results here suggests that individuals have a good understanding that genetic influences in one trait (e.g. dyslexia) can also relate to other traits (e.g. ADHD). This pattern generally holds in different countries. In combination with other results, this may suggest that participants think that 2 traits may be influenced by one single gene. However, the fact that the item is worded in the plural 'Some of the genes' suggests this may not be the case.

Question 18: At present in many countries, newborn infants are tested for certain genetic traits.

It is now common practice for new-born infants to be tested for certain rare genetic disorders. For example, in the UK, blood is drawn from a heel prick shortly after birth, and the following conditions are tested for: sickle cell disease, cystic fibrosis, congenital hypothyroidism, phenylketonuria (PKU), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1) and homocystinuria (pyridoxine unresponsive) (HCU) (Davies, 2017). Each of these conditions has a known **aetiology** and clear and effective treatment options are available.

The number of conditions tested for varies globally, typically from 2 to 20 (Bodamer et al., 2007), but such testing happens in most countries, including Italy Nigeria, Russia, Spain and the UK (Therrell et al., 2015).

Table 28. Frequency responses to 'At present in many countries, newborn infants are tested for certain genetic traits.'

	True	False
Total Sample N = 10035	**8172** **81.4%**	1863 18.6%
Italy N = 123	**90** **75.6%**	29 24.4%
Nigeria N = 1030	**955** **92.9%**	73 7.1%
Russia N = 1194	**937** **78.50%**	256 21.50%
Spain N = 133	**124** **92.5%**	10 7.5%
UK N = 211	**155** **73.5%**	56 26.5%

Statistically, this was the easiest Genetic Knowledge item in iGLAS (see Chapter 2), and respondents were largely accurate. Differences in the availability of newborn screening may explain international differences in awareness of its availability. For example, such screening is routine in the UK and so not often discussed as it is not a contentious issue. This may explain

why the UK sample of students had the lowest proportion of correct response. However, newborn screening is largely unavailable in sub-Saharan Africa (Nnodu et al., 2018). The prevalence of Sickle Cell Disease is high in Nigeria and could be included in newborn screening, and there is strong support for such programs (Nnodu et al., 2018). The unavailability of such screening in Nigeria may explain why so many Nigerian students are aware that such screening is available in many countries.

Question 19: Can dog breeding be considered a form of gene engineering?

Selective breeding, a form of gene engineering, is a practice that goes back to the earliest days of farming (Buffum, 2008). Across generations, crops and livestock are meticulously bred for increasing yield and other desirable outcomes. In the early 1990s, technological advances meant that such outcomes could be engineered using molecular techniques, rather than intergenerational breeding (Redenbaugh, 1992; Redenbaugh et al., 1994). The term 'genetic engineering' can be considered to only relate to biotechnological manipulation of genes, and so would not include selective breeding. As such, the term gene engineering was used to evaluate whether participants understood that differences between dog breeds result from deliberate genetic manipulation.

Table 29. Frequency responses to 'Can dog breeding be considered a form of gene engineering?'

	Yes	No
Total sample N = 4279	**3376** **78.9%**	903 21.1%
Italy N = 123	**81** **65.9%**	42 34.1%
Nigeria N = 1028	**840** **81.7%**	188 18.3%
Russia N = 1192	**888** **74.50%**	304 25.50%
Spain N = 132	**104** **78.8%**	28 21.2%
UK N = 194	**160** **82.5%**	34 17.5%

This was the second easiest Genetic Knowledge item in iGLAS (see Chapter 2). Most participants understood that selective breeding is a form of gene engineering. Knowledge was highest in the UK and lowest in Italy.

Further Analyses: Opinions about the safety of consuming Genetically Modified (GMO) food

Much research has been conducted on attitudes to Genetically Modified Organisms (GMOs). For example, Utkualp, Ozdemir, Bicer, & Ozdemir (2016) identified generally unfavourable views of GMOs amongst university students, especially in relation to the safety of consumption. More recently Fernbach, Light, Scott, Inbar, & Rozin (2019) have identified that increased concerns about GMOs are inversely related to knowledge about science and genetics. This study also identified that those with the least knowledge of GMOs perceived their knowledge to be very high. Those who know the least, worry the most and think they know the most.

A t-test was conducted on the total iGLAS sample (N = 4279) to see if responses to this item related to varying views on the safety of consuming GMO food. No significant differences were found between participants who responded correctly (M = 4.36, SD = 1.89) and incorrectly (M = 4.28, SD = 1.90) to this item; t (4197) = 1.11, p = .266. This suggests that views on GMO safety are not related to the knowledge that selective breeding is a form of genetic engineering.

Question 20: Which of the mentioned below is a method for gene editing:

CRISPr (Clustered Regularly Interspaced Short Palindromic Repeats) is a recently developed method for extremely accurate editing of DNA sequences (Cong et al., 2013).

Table 30. Frequency responses to 'Which of the mentioned below is a method for gene editing'

	ERP	**CRISPR**	CERN	PCR

Total sample N = 4134	514 12.4%	**2126** **51.4%**	744 18.0%	750 18.1%
Italy N = 103	22 21.4%	**25** **24.3%**	8 7.8%	48 46.6%
Nigeria N = 1019	141 13.8%	**457** **44.8%**	213 20.9%	208 20.4%
Russia N = 1176	190 16.2%	**378** **32.1%**	353 30.0%	255 21.7%
Spain N = 114	17 14.9%	**39** **34.2%**	17 14.9%	41 36.0%
UK N = 192	24 11.4%	**80** **37.9%**	47 22.3%	41 19.4%

Note. CRISPR is more commonly abbreviated as CRISPr. It was decided to present the acronym in all capital letters to provide parity of presentation across all items.

Statistically, this was the most difficult Genetic Knowledge item in iGLAS (see Chapter 2). In the total iGLAS sample (N = 4134) the correct response (CRISPR) was the most popular, but even here, the error rate was quite high and evenly dispersed across the incorrect options. Students in Italy were more likely to opt for PCR. Amongst other things, PCR stands for Polymerase Chain Reaction, a process involved in molecular genetic testing (Bartlett & Stirling, 2003). Across all countries and in the total sample, this was the most popular erroneous option. The other options ERP (Event Related Potential)(Luck, 2014) and CERN (https://home.cern/) were selected for inclusion in iGLAS so that all options for this question would represent actual scientific processes and endeavours.

The poor performance on this item, coupled with no clear pattern of erroneous responses suggests that CRISPr, an emerging technology, is unknown by many of the participants in iGLAS, even in Italy and Spain, where other areas of genetic knowledge seem to be better understood.

Discussion

In the interpretation of the results in this chapter, several factors have to be taken into account. iGLAS collections were targeted to students in Italy, Nigeria, Russia, Spain and the UK. This resulted in several important implications for interpreting results. Firstly, students were

recruited by academics and researchers with an interest in genetic knowledge. This interest may have been communicated to students, especially if being taught by the academics involved in the collaborations. The student samples are also relatively small and cannot be taken as indicative of all students in their respective countries. The sample comparisons are further complicated by the fact that most students from each country were studying for particular degrees (e.g., biology), with the exception of the sample in Russia, which was the most diverse in terms of students' degrees. Moreover, the samples differed in composition in terms of year of study (e.g., most students (57.9%) in Spain were in the first year of their degrees; and a large proportion of students in the UK (42.2%) were studying at postgraduate level). Student samples were selected to reduce the influence of confounding variables such as age, education level and professional experience with genetics. However, the differing rates of university attendance in different countries as well as the different levels of study (undergraduate vs postgraduate) and subject areas will have reduced this homogeneity.

It must also be noted that the total sample, whilst not systematically targeted for collection, all had internet access and sufficient interest to engage with a study such as this. This self-selection also limits the generalisability of the results.

The international student samples showed some interesting differences. The highest overall levels of genetic knowledge were seen in the Spanish (65%) and Italian (64%) participants. This is even though Spanish students were more likely to be in the first year of their studies when compared to Italian students. Overall scores were similar in the UK (56%) and Nigeria (55%). Russian participants had the lowest overall scores (50%). General attitudes to the importance of Science varied, although were generally very high. Students in Nigeria, who were almost all studying Biology, were least likely to endorse this notion. However, this was highly endorsed in Russia. As both Russian and Nigerian students had the poorest genetic knowledge, it seems that general attitudes to science are unrelated to genetic knowledge.

Each student sample had mean ages between 20.3 and 25.00. As such, each sample can reasonably be taken to represent participants who have recently completed their compulsory schooling. With differences emerging in student samples, it seems likely that the content of school curricular may explain these international differences.

Nigerian students, the majority of whom were studying biology, had a surprisingly low average score in genetic knowledge. There was often less consensus in their responses when compared to students in other countries. There was evidence of errors in some fundamental genetic concepts especially in relation to the degree of genetic relatedness between two cells, and two strangers. Many Nigerian participants also struggled with the concepts of epigenetics, non-coding DNA, polymorphisms and heritability. The Nigerian students sampled were the only group where a majority thought that human behaviour can be fully predicted from DNA. They were also more likely to consider complex disorders (autism and schizophrenia) as monogenic when compared to the full iGLAS sample. Several of these patterns were not replicated when investigated in non-Nigerian biology students. For example, non-Nigerian biology students were better able to identify the genetic similarity of two cells in one body, and more knew that full behavioural production is not possible from DNA alone. Research has identified that biology in general and genetics in particular are seen as difficult subjects by Nigerian students (Etobro & Fabinu, 2017). iGLAS's key research collaborator in Nigeria, Dr Olusegun Ogundele (personal communication December 16, 2019), has indicated that biology is no longer a compulsory subject in the later stages of secondary schooling in Nigeria and that even when covered, genetics is not taught until the final semester of the final year and is often not covered in great detail. These would seem to be strong explanatory factors for the observed underperformance in Nigerian participants.

Russian students in this study had the lowest levels of overall genetic knowledge (50%). They tended to hold a more monogenic view of autism and schizophrenia when compared to other student samples. They were also the sample least likely to agree that there are pleiotropic effects between dyslexia and ADHD. Many Russian students struggled with the term 'genome' and

showed evident difficulty distinguishing between coding and non-coding regions of the genome, even though the majority knew the main function of genes. Russian students also demonstrated confusion about the genetic relatedness of cells, siblings and strangers. However, they generally did well in identifying that behaviour cannot be fully predicted from DNA alone. Within this study, the Russian student sample was the most diverse in terms of their degrees/subjects studied. They therefore represent a sample that is not necessarily engaged in genetics or topics allied to genetics such as biology and psychology. The Russian sample is also likely to be the most representative of the general population given the high proportion of Russians that complete degree level studies.

Italian and Spanish students in this study, most of whom were studying psychology, tended to have similar patterns of responses. They had the highest average genetic knowledge scores (64% and 65% respectively). Further analysis of the iGLAS dataset revealed that the average genetic knowledge score of psychology students not currently resident in Italy or Spain (N = 165) is 59%. The average genetic knowledge scores for non-psychology student residents of Italy (N = 12) and Spain (N = 34) are 65% and 67% respectively. Although these participant numbers are too small for meaningful analysis, this may suggest that the scores of the Italian and Spanish students in the sample are more representative of their nationality than the fact they are psychology students.

The average genetic knowledge score for the sampled UK students was 56%, lower than an average UK score of non-students of 72%. Most students in the sample (N = 152; 72.0%) were studying law. As demonstrated in the previous chapter, lawyers and law students tend to underperform in tests of genetic knowledge, and so the scores in this sample may be more reflective of the fact that this sample was largely made up of law students, rather than the fact that they are studying in the UK.

Overall Patterns of Responses

Several interesting patterns of results emerged in the total iGLAS sample and within and between the five student samples.

It appears that many participants in iGLAS have some good basic information about genetics. For example, three quarters of the total iGLAS sample were able to identify the base units of DNA (Question 2), within the student sample this ranged from 58.7% in Nigeria to 91.7% in Italy. Most also knew how many chromosomes DNA is packaged into in the human genome (Question 3). However, there were areas in which participant knowledge was poorer. 27.7% of the total sample thought that somatic cells contain 23 copies of each gene (Question 5). The figure '23' may have particular salience for participants if they were taught this at school or because of the major direct-to-consumer genetic testing company 23 and Me (Goetz, 2007). However, it seems that a considerable proportion of respondents were unable to associate this figure to the correct genetic concept.

Many participants seemed to struggle with some fundamental genetic concepts. For example, many participants could not identify the correct description of the genome (Question 1). A large proportion of respondents, particularly students in Russia and Spain, thought that a genome consists of only genes. This is an understandable error as the word 'genome' includes the root gen-, but it demonstrates a generally poor understanding of what a genome is. Participants also seemed to show a high degree of confusion between base pairs and genes. The question 'Approximately how many genes does the human DNA code contain?' (Question 4) proved particularly difficult for many participants. This may have real world implications as participants who cannot distinguish between genome and exome sequencing may be disadvantaged when choosing genetic testing, be this for medical or recreational (direct to consumer) purposes.

Further investigations also indicate that participants of iGLAS may have difficulties correctly interpreting personal genomic information. For example, approximately half the participants did not understand the degree of genetic relatedness in family members (Question 12). This lack of

knowledge may, for example, have implications if/when discussing shared familial risk for genetic diseases, and/or the implications of results from direct to consumer genetic testing.

It was not uncommon for participants to report that two human beings selected at random share 50% of their total DNA (Question 11). Human beings share more than 99% of their DNA, but variance in the remaining <1% contributes to observed human variation. This is not an uncommon issue (e.g. https://www.newscientist.com/letter/mg17523584-000-people-arent-bananas/).

Most participants were able to correctly identify a description of epigenetics (Question 7). However, a small minority thought epigenetics corresponded to 'A process by which human beings can consciously change their DNA'. Those who held this pseudoscientific view were less likely to engage with conventional medicine, preferring alternative medicine even when severely ill. They were also marginally less likely to engage with genetic testing, even if it allowed improved treatment such as medication with fewer side effects. Tackling such pseudoscientific misconceptions may have positive implications for the way people chose to manage their own health.

Participants of iGLAS also showed difficulties with the concepts of heritability and heredity (Question 13). Only a small proportion were able to identify the correct definition of heritability. These participants were no better at estimating heritability in practice. In most instances for this item, participants were more likely to select an option more aligned with the definition of heredity: 'There is an approximately 30% chance that someone will pass insomnia onto their children'. However, this is not an accurate or viable definition of heredity, and so there is also evident confusion about this term.

Many participants demonstrated misunderstandings about **genotype**/phenotype relationships. A large proportion (31.9%), especially amongst Nigerian students (67.2%), thought that behaviour could be fully predicted from an individual's DNA (Question 14). These participants tended to

overestimate the heritability of traits when compared to those who identified that behaviour cannot be fully predicted. They were also more likely to endorse statements aligned with a deterministic view of genetic influences.

It appears that participants may have a better understanding of pleiotropy than polygenicity. The majority were correctly able to identify that genetic influences on dyslexia can also influence ADHD (Question 15). However, a large proportion of respondents reported monogenic views of complex conditions (schizophrenia and autism – Questions 15 and 16). This monogenic view was associated with greater endorsement of the idea that genetic influences negate free will. However, there was no such relationship in response to an item about destiny being written into our genes.

Across items, participants often seemed to use logical reasoning to arrive at correct responses. For example, the frequency of responses to the item 'Non-coding DNA describes DNA that…' (Question 9) seemed to follow a pattern of diminishing logic, such that the least logically viable response 'Is non-human DNA' was chosen the least frequently. This is supported as some participants of iGLAS volunteered feedback that they had applied logic to guess some responses. The patterns seen suggest that most participants were able to do this effectively, supporting the notion that, when pressed, participants tend to respond above chance level when not provided with a 'don't know' option (Mondak & Davis, 2001).

For two of the genetic knowledge items the order of responses was invariant across different samples. In all samples, the proportion of responses to the question 'Non-coding DNA describes DNA that:' (Question 9), always followed the pattern: 'Does not lead to the production of proteins' > 'Is removed when passed from parent to offspring' > 'Is not composed of nucleotides' > 'Is non-human DNA'. Stable patterns of responses were also evident for: 'What are polymorphisms?' (Question 10). These items relate to molecular genetics concepts and these consistent patterns of response in multiple samples may warrant further investigation. Building

on such logical reasoning may prove fruitful in any programs designed to improve genetic knowledge.

Conclusion

The analyses presented here have identified some interesting international differences and similarities in genetic knowledge and misconceptions. Several applied and abstract implications of these misconceptions have also been identified in the present chapter.

Across all questions and samples, there appear to be some common misconceptions. It seems likely that participants have a simplistic and confused conception of the relationship between the genome and phenome, and that people may be working at a simple conceptual level – Genes make proteins, proteins make us. It therefore seems that people are lacking an appropriate framework for thinking about how the information encoded in DNA is accessed and used. In particular, it seems that the people surveyed here might be thinking about genetics in primarily static (and possibly deterministic) rather than dynamic ways. Chapter 5 identifies that genetics is often taught in a 'static' (e.g. Mendelian, punnet squares, dominant and recessive alleles etc.) way in schools in the UK; and the same may hold for the international samples. This is likely to be a strong factor in explaining the persistence of this insufficient framework when thinking about actual genetic effects. There also seems to be a great deal of confusion about inter- and intra-individual genetic variation: that the genome of one person is a unique intact entity, that genomes are proportionally almost invariant between people, but that a lot of phenotypic variation can arise from this relatively small proportion as it still accounts for many million points of genetic variation, all of which interact with each other and the environment.

The results presented in this chapter should be interpreted with caution. However, some patterns emerged in the data which warrant further investigation. These results should also be useful in informing strategies for improving public engagement with genetics. In general, the following topics would seem to particularly need addressing:

- Genetics in numbers: Understanding some of the important facts and figures of genetics and applying these consistently and knowledgeably. This is especially important when it comes to proportions in genetics, particularly in relation to total and variable DNA.
- Genome, gene and junk: Better understanding of the construction of the human genome.
- Distinguishing heritability and heredity: The genetics of us (heritability) and the genetics of me (heredity).
- Pleiotropy and Polygenicity: Using pleiotropy, which participants seemed to understand better, to explore polygenicity, which was poorly understood.
- Addressing new technologies and pseudoscience: Dispelling myths and detailing emerging technology.

Each of these topics should prove fruitful avenues in developing a framework to support non-scientists in gaining a fuller and more accurate understanding of genetics, which in turn should allow people to engage more accurately and effectively in the genomic era. This will allow them to make more informed personal decisions and will also improve the quality of public discussions and debates about the ethical and legal use of genetics in all aspects of society. Promoting improved genetic knowledge in students should be considered a priority.

Future Directions

Further research is required to consider the relationship between factual knowledge/recall (e.g. the base pairs of the human genome) with more conceptual understanding (e.g. inter and intra-personal genetic variation). This will be a focus for revisions to iGLAS v4.

Chapter 5: Influences of Education and the Media on Genetic Knowledge and Opinions

Abstract

Previous chapters have demonstrated deficits in public levels of genetic knowledge; it is therefore important to consider the ways in which people access information about genetics. Two primary avenues have been identified: formal education and media reporting. This chapter presents the results from four studies. Study 1 identified a relationship between genetic knowledge and media exposure to genetics. Study 2 found no significant effect of 'media framing' – the presentation of salient information in the media – on views on genetic determinism. Study 3, extending the research of Jamieson & Radick (2017), identified that a brief experimental intervention did not significantly affect genetic knowledge or views on determinism in a cohort of undergraduate Psychology students. However, comparisons between first year and third year students identified that studying a psychology degree is associated with improvements in genetic knowledge and changing views on genetic determinism. First year students reported generally low endorsement when asked if they believe their destiny is in their genes. This endorsement was higher in third year students who generally neither agreed nor disagreed with this notion. The likely explanation of this is a move from a more environmentalist explanation of human behaviour to an appreciation of gene/environment interplay. Study 4 - a focus group study - identified that, whilst participants who have studied behavioural genetics may be less environmentalist in their views, they do not believe that genetic effects negate free will. Whilst media reporting may be an important factor in views on genetic determinism, the results in this chapter show that short interventions do not appear to make a significant difference. More involved educational interventions might be more effective in improving genetic knowledge and the ways people think about genetic determinism.

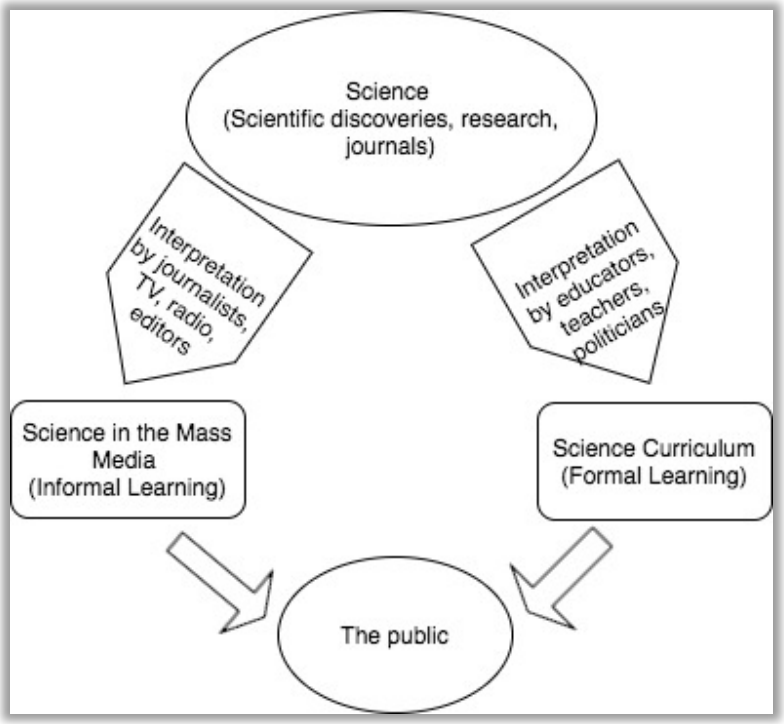
Introduction

Results from the previous chapters add support to the idea that levels of genetic knowledge in the general population are insufficient for meaningful engagement in the genomic era. It is

therefore important to consider ways in which genetic knowledge can be improved in the general population. This will help counter misinformation as well as erroneous beliefs (for example, that complex traits can be the product of a single gene). Attempts to improve general levels of genetic knowledge should help all people engage more accurately and robustly in important philosophical and sociological debates, as well as instances where genetics relate to them personally.

Research has identified mass media and formal education as two of the main gateways of scientific information from the scientific community to the public (see Figure 9; and also Falk, Storksdieck, & Dierking, 2007; Wellington, 2001, 1994).

Figure 9. A visual presentation of the science communication filtering system between the scientific community and the public. Adapted from Wellington (2008).



This chapter presents four studies. Study 1 uses the total iGLAS sample to evaluate if there is a relationship between genetic knowledge and media use. Study 2 evaluates the relationship between knowledge, views on genetic determinism and the media, specifically media framing.

Study 3 considers educational interventions, genetic knowledge and views on genetic determinism. Study 4 reports the results from a focus group discussion of the concepts of genetic determinism, destiny and free will.

Ethical approval for the four studies presented in this chapter was provided by Goldsmiths, University of London.

Genetic Determinism, Destiny and Free will

Advances in genetics and genomics have generated the understanding that complex traits form under the influence of a myriad of genetic and environmental factors (Bubb & Queitsch, 2016; Plomin et al., 2016). Consequently, the science community has adopted a more probabilistic, rather than deterministic, understanding of the relationship between genes and phenotypes (observed traits), with the 'nature versus nurture' debate becoming outdated (Castéra & Clément, 2014; Levitt, 2013). Despite recent advancements undermining the very premise of determinism, a wealth of literature suggests that genetic deterministic beliefs are prevalent in the population (Dar-Nimrod & Heine, 2011; Gericke & Smith, 2014; Gould & Heine, 2012).

Several studies have attempted to quantify the concept of genetic determinism and to develop tools for its measurement (Aikenhead & Ryan, 1992; Castéra & Clément, 2014; Keller, 2005; Paulhus & Carey, 2011). The number of items included in these measurements ranges from 16 (Castéra & Clément, 2014) to 27 (Paulhus & Carey, 2011). Rather than providing a detailed analysis of targeted aspects of genetic knowledge and opinions, iGLAS was developed to provide a broad overview covering a variety of aspects. As such, it was decided not to include such lengthy measures related to genetic determinism in iGLAS. Instead, participants were asked to indicate their endorsement (scale 1-7 strongly disagree to strongly agree) of two key statements: 'I believe my destiny is written in my genes' and 'Genetic influences on our behaviour mean that there is no free will'. In earlier versions of iGLAS this second item was phrased differently ('If genes influence our behaviour then there is no free will'). On reflection, it was decided that this item was too difficult to interpret and respond to. Participant's responses

may have reflected disagreement with the conjecture "If", rather than their opinions about genetics and free will. As such the results presented later in this chapter are from the rephrased item only.

Genetics and the Media

Research has found the mass media to be the public's second major source of scientific information, following formal education (Condit, 1999; Eyck & Williment, 2003; Holliman, 2004). Similarly, the Wellcome Trust Monitor (Ipsos, M. O. R. I., 2016) found that, whilst public interest in genetics remains high, most people access genetic information passively rather than actively. Research has also shown that the informal presentation of genetic information, used by the media, is often inaccurate (e.g. Lanie et al., 2004). This highlights the importance of the requirement for a standard of quality and quantity of scientific information in the mass media. The media often creates simplified accounts of genetic research placing a stronger emphasis on genetic (rather than gene-environment) explanations. These explanations are in line with a typical lay-person's intuitive essentialism, which is often an incorrect belief about how genes function (Bubela & Caulfield, 2004; Dar-Nimrod & Heine, 2011; Young et al., 2008).

Academics have expressed concerns about deterministic and discriminatory public attitudes towards genetics as a result of media coverage (Lynch et al., 2008; van Dijk, 1998). For example, research identified that genetic misconceptions in children as young as 10 paralleled themes from their media activity (Donovan & Venville, 2012). Additionally, research into lifelong science education has found that informal methods of learning (such as the mass media) take precedence over formal education in some contexts (Rundgren et al., 2012). University science students have been found to have poor evaluation and interpretation of the quality of typical science media reports (Norris et al., 2003). Interestingly, even the highest performing science students struggled with this skill. Overall, such findings have led to a number of investigations into how to educate students to be able to critically evaluate mass media science reports (e.g. McClune & Jarman, 2010).

Media Framing

In recent years, a concept of "media framing" in science communication has attracted research interest. A "media frame" is the result of critical words, phrases, metaphors and other forms of textual materials manifesting in media content (Carver et al., 2014). Entman's (1993) description clarifies that media framing is based on selection and salience; it is the selection of certain aspects of a perceived reality and an enhancement of their salience via communicative text. Media framing has been found to be an important factor in affecting accuracy of transmission of science information to the public (Nisbet & Mooney, 2007; Reis, 2008). Research into public interpretation of media framing in news articles tends to merge the effect of the headline and accompanying article. However, research suggests that these should be viewed as having independent contributions. It is easy to see how such headlines as "Schizophrenia gene remains elusive" and "Crime in the family tree" can lead to a deterministic interpretation of the material (Hubbard, 1999).

Lower knowledge on a subject can lead readers to engage less with material and rely more on their own heuristics, emotions and values. It has been suggested that disengaged audiences are particularly prone to how scientific information is framed when it is communicated, not least of all as they are more likely to be exposed to media frames that reflect their existing opinions and values (Bubela et al., 2009; Scheufele & Tewksbury, 2007).

Study 1: Genetic knowledge and media exposure to genetics

Chapter 3 demonstrated that genetic knowledge is positively related to education level. The total iGLAS sample (N = 10090) was explored to see if there is a relationship between independent engagement with genetics and genetic knowledge. In iGLAS, participants are asked if and how they engage with genetics. For example, they are asked to indicate if they work in the field or are currently studying genetics and if they follow genetics topics through their own studies and/or social media. Significant differences were found in the genetic knowledge of participants

who reported not seeking out information (N = 6938, GK = 60.3%), those who self-studied genetics (N = 619, GK = 69.3%,) and those that followed genetics topics on social media (N = 2025, GK = 69.2%). Participants who reported either self-studying genetics or following genetic topics on social media did not differ from each other (p = 1.00), but those who reported both (N = 508, GK = 76.6%) had significantly higher levels of genetic knowledge than all 3 other groups. All differences were significant at the p <. 001 level. This provides strong evidence for a relationship between media exposure, especially of different types, and genetic knowledge.

Study 2: Media Framing

The study was conducted to see if media framing would influence self-reported deterministic attitudes towards genetics.

Method

A between participants design was used. Participants were split into one of two groups. The first saw a media frame associated with high genetic determinism; the second saw a media frame related to low genetic determinism. All participants then completed iGLAS, and their responses to the question 'I believe my destiny is written in my genes' (Likert scale 1 – strongly disagree; to 7 – strongly agree) were evaluated. Participants were debriefed after the testing session. They were advised about the manipulation and the content and findings of the sources paper (Rimfeld et al., 2015). After the experimental manipulation, the participants were also given a teaching session about psychometrics and questionnaire design. These steps were taken to avoid participants leaving the testing session with misconceptions about the subject matter.

Participants

This study was conducted with a sample of 126 undergraduate students; 96 female, 28 male, and 2 non-binary participants, aged between 18-51 (M = 20.89 years, SD = 5.66 years). All participants were first year Psychology undergraduate students who were recruited via the Psychology Department Research Participation Scheme in exchange for a course credit. All

testing took place in one session on 17th November 2016. Participants were debriefed at the end of the testing session to eliminate any effects of exposure to deterministic reporting.

Materials

Investigation of skim readers is important as this is a style of reading often adopted by Internet users (Duggan & Payne, 2011), and as the Internet is often a source of over-simplistic genetic concepts (Condit, 2007). To try and capture this method of media engagement it was decided to present participants with word-clouds based on newspaper articles, rather than asking participants to read full articles. Word-clouds are a visual representation of the frequency tabulation of the words in a selected piece of text (Miley & Read, 2011). The word-cloud method was employed in this study to increase the salience of high frequency words (as suggested by Condit et al., 2001), much like an interpretation from skim reading (Fatmawati, 2014). Two word-clouds were generated using online newspaper articles (See Figure 10), with the most repeated words from each article appearing as larger words in the cloud. Online newspaper articles were chosen as the mass media platform for the experiment, as they are a widespread, relatively in-depth source of information for the public (McClune & Jarman, 2010). To retrieve genetics related articles, a search for "genes online article UK" was conducted. Only national broadsheet papers were considered because they address broader society and are representative of genetic information being presented to society. Two broadsheet articles were selected for being similar in topic and length: "Genes influence academic ability across all subjects, latest study shows" (Guardian); and "Genetic screening of pupils would herald a Huxleyan nightmare" (Telegraph). Both articles were ostensibly reporting on the same scientific paper entitled 'Pleiotropy Across Academic Subjects at the End of Compulsory Education' (Rimfeld et al., 2015). The Telegraph article fitted the hypothetical deterministic media frame: seeing genes as the definite cause for a trait (e.g. Marks, 1995). The Guardian fitted the hypothetical gene/environment media frame (e.g. Condit, 2007).

Figure 10. Word-clouds for the high determinism and low determinism conditions.

High Determinism (Telegraph) Low Determinism (Guardian)

Note. Telegraph article (left): https://www.telegraph.co.uk/news/science/11760729/Genetic-screening-of-pupils-would-herald-a-Huxleyan-nightmare.html Guardian Article (right) https://www.theguardian.com/science/2015/jul/23/genes-influence-academic-ability-across-all-subjects-latest-study-shows

The Word-clouds were created on www.wordclouds.com. From the Telegraph text, "Brave New World" was removed as social familiarity may lead to response bias. Brave New World (Huxley, 2007) is a 1932 novel about a dystopian future in which there is an intractable genetic class system. Participants with familiarity with this novel, referenced in the Telegraph article, are likely to have attributed higher determinism to the article than those without familiarity. As media framing requires a certain exposure time to be effective (Buturoiu & Corbu, 2015), each participant was presented with their word-cloud for exactly 60 seconds.

Prior to the experiment, a manipulation check was carried out on a separate group (N = 8) of a similar demographic profile, to test whether the two Word-clouds were significantly different in their level of determinism (as suggested by Condit et al., 2001). Participants were asked to answer for both Word-clouds: 'what word best describes the authors conclusion about the relationship between genes and intelligence', on a scale of 1 to 4, where 1 = unrelated, 2 = associated, 3 = predisposing and 4 = cause. The two clouds were found to be significantly different ($t = 7.94$, $df = 7$, $p < .05$): high determinism: $M = 3.38$, $SD = .52$ – suggesting a more

causal association between genes and intelligence; low determinism: M = 1.50, SD = .54 – suggesting a less causal association or no association.

Results

A one-way between participants ANOVA was conducted to compare the effect of word-cloud on genetic determinism, in the high-determinism (N = 60; M = 3.03, SD = 1.45) and low-determinism (N = 67; M = 2.76, SD = 1.42) conditions. No significant effect of word-cloud on genetic determinism was found (F (1, 125) = 1.14, p = .287). On average, participants in both conditions reported low endorsement of the idea that their destiny was not written in their genes. These results suggest that post-exposure attitudes were not more deterministic in those who were exposed to the high-determinism word-cloud than in those who were exposed to the low-determinism word-cloud.

Limitations

Whilst this finding is in line with previous literature (e.g. Condit et al., 2001; Lynch et al., 2008), its generalisability must be considered against several limitations. In particular, the presentation of the news article, using a word-cloud, was not a typical method of communication, particularly not for a newspaper article. Furthermore, the samples available to this study would only be able to detect a large effect size (Cohen's d > .5), at an acceptable level of power (.8). The participants who completed study 2 were all undergraduate Psychology students in the first year of their programme. With a mean age of 20.89 years, many of the participants would have recently completed their previous education, and their opinions are likely to have already been developed to some extent. Repeating this study with a larger sample of participants who have not so recently studied genetics at school, should be considered.

Discussion

The use of Word-clouds was chosen as a means of presenting fewer more salient words, much like the interpretation one would expect from a skim-reader (Rayner et al., 2016). The results of

Study 2 suggest that this form of 'media framing' does not have a significant or sizable effect, at least on views of genetic destiny. However, the direction of the results, i.e. that those who viewed the 'high' determinism media frame had higher endorsement of the statement 'I believe my destiny is written in my genes', suggests that weak but significant effects may exist, with further better powered research needed. Moreover, media framing may have led to other effects not explored in this study. Accurate media portrayal of genetics is important for raising genetic literacy and potentially for alleviating misconceptions and deterministic views.

Study 3: Educational Interventions

It is important to find ways, beyond media reporting, to address fundamental genetic misconceptions and limitations in knowledge. In the UK, genetics is taught as part of the sciences curriculum at secondary school, meaning that all school children attending state schools are theoretically introduced to the topic of genetics. However, the approach taken is inconsistent. At GCSE level (the end of compulsory schooling in the UK), most students study 'Combined Science' (Biology, Chemistry and Physics), with guidelines for the teaching of these subjects provided by the Department for Education[4]. These guidelines indicate a clear focus on single gene inheritance, with numerous examples and consideration of different aspects of monogenic inheritance. These guidelines only indicate that students should be able to 'recall that most phenotypic features are the result of multiple genes rather than single gene inheritance', but activities related to this are not suggested and considerations of the complexity of this aspect of inheritance are absent. There is no indication that topics such as gene environment interplay are covered at all.

GCSE exams are set by various boards across the UK. This focus on monogenicity is reflected in the teaching materials provided by GCSE exam boards such as AQA[5] and Edexcel[6], neither of which propose material related to the teaching of polygenicity and more complex

[4] https://www.gov.uk/government/collections/gcse-subject-content
[5] https://filestore.aqa.org.uk/resources/biology/specifications/AQA-8461-SP-2016.PDF
[6] https://qualifications.pearson.com/content/dam/pdf/GCSE/Science/2016/Specification/GCSE_CombinedScience_Spec.pdf

genotype/phenotype relationships. The Cambridge International Examinations board syllabus for 2019-2021[7] includes no mention of inheritance or DNA, and the only mention of genetics is in relation to predictors of coronary heart disease and a/sexual reproduction. Even at Advanced (A) levels, the Department for Education's guidance of subject content[8] makes no mention of polygenicity, pleiotropy or any other complex aspects of gene environment interplay. Evaluation of numerous GCSE and A-level examination papers indicate that coverage of anything other than **Mendelian** patterns of inheritance is entirely absent. This focus on Mendelian inheritance, monogenicity and disease, and the absence of more complex aspects of genetics in the school curricular may be partly responsible for genetic misconceptions observed in the UK samples. It is possible that school curricular in other countries have similar gaps in relation to genetics.

A recent study (Jamieson & Radick, 2017) sought to tackle the problem of genetic determinism by developing a genetics curriculum that emphasised developmental contexts and their relationship to phenotypic variability, rather than following a more traditional Mendelian approach to the teaching of genetics (as for the GCSE and A-level curricular). This case/control study compared views on genetic determinism in a group of UK university students studying a standard 'Mendelian' approach to introductory genetics (the 'comparison' group N = 28), with those studying a novel 'Weldonian' approach (the 'intervention' group N =28).

A curriculum was developed for the intervention group based on the work of W. F. R. Weldon, a critic of early Mendelism, who felt that Mendel's research was too reductive and did not take proper account of environmental contexts (Weldon, 1902a). He also repeated Mendel's pea plant experiments and concluded that the peas that were produced did not fall into binary categories of yellow/green and smooth/wrinkly, but varied on a continuum (Weldon, 1902b). Jamieson & Radick's (2017) study was intended to see whether a Mendelian curriculum,

[7] https://www.cambridgeinternational.org/Images/329756-2019-2021-syllabus.pdf
[8] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/593849/Science_AS_and_level_formatted.pdf

focusing on single gene inheritance and binary traits, and a less binary and more context dependent Weldonian approach resulted in differing views on genetic determinism.

Despite several limitations, the study found that the intervention (Weldonian) group showed a reduction in genetic determinism at the end of the 10 x 50-minute lecture intervention. There was no such reduction in the comparison group. The paper does not report effect sizes, nor does it report standard deviations, only means, and so effect sizes cannot be calculated. However, the approach to genetic instruction was thought worthy of further exploration.

Building on this paper, Study 3 sought to address three research questions:

Research question 1: Could improvements in genetic knowledge and reductions in views on genetic determinism be realised based on a much less intensive intervention than used by Jamieson & Radick (2017)? I.e. would there be group differences in views on genetic determinism between students in 3 experimental groups:

- Group 1. Students provided with information about dominant and recessive alleles in relation to eye colour, consistent with the monogenic approach prominent in the GCSE and A-level curricular.
- Group 2. Students provided with the above information plus information about polygenicity in eye colour.
- Group 3. Students provided with the same information as for groups 1 and 2 and information about gene environment interplay in relation to eye colour.

Research question 2: Would final year BSc Psychology students (who had selected the third year optional module "Behavioural Genetics") on average have better genetic knowledge and report different views on genetic determinism in the first week of their third year than first year Psychology students in the first few weeks of their degree? I.e. does studying Psychology for 2 years have any relation to genetic knowledge and views on genetic determinism. Additionally,

would third year psychology students show any change in their genetic knowledge and views on genetic determinism having studied a 10-week optional module in Behavioural Genetics?

Research question 3: Would any of the manipulations result in a better understanding that complex traits are rarely the product of single genes?

In addressing these questions, it is hoped that teaching interventions for the improvement of genetic knowledge and the reduction of genetic determinism can be developed.

Methods

Procedure

This study consisted of two independent groups, each completing two collections. First year psychology students completed testing and were then assigned to one of three intervention groups. They completed the testing again after the intervention. Third year psychology students completed the survey at the start of the first lecture in their optional "Behavioural Genetics" module in term one of their third (final) year; and then again in the last teaching week – 10 weeks later. Third year students were provided with overall feedback about their performance after the first wave of collection, i.e. their total score on the genetic knowledge items. At the second wave of collection they were again provided with this score but also with detailed feedback at the item level. Third year students were asked to provide their email so that feedback could be supplied. Emails were also used to match wave 1 and 2 collections before being substituted for anonymous identifiers.

The first year student cohort was relatively large, which allowed random allocation to different test conditions. The collection was completed electronically via Qualtrics. Collection with the third year students was completed with pen and paper at both waves. Data from the third year students were entered initially into Excel spreadsheets so that feedback on performance could be provided through a Mail Merge. A second researcher spot checked the first wave of data collection and found no errors. Wave 2 data was double input and conditional formatting was

used to identify any incongruous cells between both inputs. Of 1353 data points, 13 were incongruous (<1%). The original data sheets were checked, and the primary database amended accordingly.

Participants

First year student group

144 first year students (109 female, 33 male, 2 non-binary; age M = 19.76, SD = 3.22, range = 18 – 39) completed this study on 29/11/2018 during a first term lecture. Qualtrics was used for data collection with participants assigned randomly to one of three experimental conditions. The experimental group sizes were: Mendelian = 36; Polygenic = 52; Gene/Environment = 56.

Third year student group

60 participants completed the first wave of collection on 02/10/2018 (44 female, 16 male; age M = 22.49, SD = 4.61, range = 20 – 47). 40 participants completed the second wave of collection on 11/12/2018 (30 female, 10 male; M = 23.05, SD = 5.50, range = 20 – 47). 27 participants completed wave 1 but not wave 2. 7 participants completed wave 2 but not wave 1. 33 participants completed both waves 1 and 2.

Materials

Materials used in all collections

Test material was drawn from the International Genetic Literacy and Attitudes Survey – iGLAS (Chapman et al., 2017). Participants were presented with 20 items related to genetic knowledge. Each item was presented with one correct and either one or three incorrect options. Performance on these 20 items was summed to give a total genetic knowledge score. At each collection participants were also asked to respond to the following item: ‘I believe that my destiny is written in my genes’. Responses were collected on a 7-point Likert scale from ‘strongly disagree’ to ‘strongly agree’, with 4 being ‘neither agree nor disagree’. Demographic information was also collected: age, gender, previous genetic studies and interest in genetics.

First year intervention material

Having completed the above measures, the first year students were randomly assigned to one of three experimental groups. Each group was provided with the following information:

> Genetic information is passed from parents to offspring. For each trait, such as eye colour, a child will receive one set of instructions from their father, and another from their mother.
>
> But this information isn't treated equally. One instruction will dominate over the other. One trait is dominant, the other is recessive.
>
> In the case of human eye colour, BROWN is dominant, and BLUE is recessive.
>
> Someone with blue eyes will be homozygous recessive. Someone with brown eyes might be homozygous dominant or heterozygous: they will have brown eyes but carry the gene for blue eyes.
>
> There will be 2 phenotypes and 3 genotypes.

In addition, Group 2 was also provided with the following:

> However, almost all human traits show influences from multiple genes. 1 gene results in 3 genotypes. 2 genes result in 10 genotypes.
>
> In the case of eye colour, 16 genes have been identified. This results in 43,046,721 different genotypes.
>
> This is why we see such diversity in human eye colour.

In addition to the above, those in group 3 were also shown:

> In fact, it is even more complex than that. Eye colour shows a very high genetic influence but can also be affected by the environment. For example, eye colour can change as we age or as a result of certain diseases.

For clarity of reference in this report, each of these test conditions will be labelled.

- Group 1 = Mendelian
- Group 2 = Polygenic
- Group 3 = Gene/Environment

Having read the above information, participants were then asked to complete the initial test items again.

Results

Descriptive statistics for overall genetic knowledge and views on determinism for both groups and each collection can be seen in Table 31.

Table 31. Means (Standard Deviations) and ranges for Genetic Knowledge (possible range 0-20) and Views on Determinism (possible range 1-7) for each data collection.

	Genetic knowledge	Views on genetic destiny
1st years: Baseline (full sample)	11.00 (2.77) *1-20*	3.02 (1.34) *1-6*
1st years: Mendel	11.00 (2.07) *6-15*	2.72 (1.26) *1-5*
1st years: Polygenic	11.13 (3.00) *5-20*	3.37 (1.36) *1-6*
1st years: Gene/Environment	10.88 (2.95) *1-19*	2.89 (1.32) *1-5*
3rd years: Wave 1	13.62 (3.50) *3-20*	4.04 (1.30) *1-6*
3rd years: Wave 2	16.71 (1.91) *10-19*	4.24 (1.22) *1-6*

Research question 1: Could improvements in genetic knowledge and reductions in views on genetic determinism be achieved by a simple educational intervention? Paired samples t-tests revealed no significant differences in views on determinism in any of the first year collections based on the experimental manipulations. Nor were there any significant differences in genetic knowledge for each of these groups between the first and second collections.

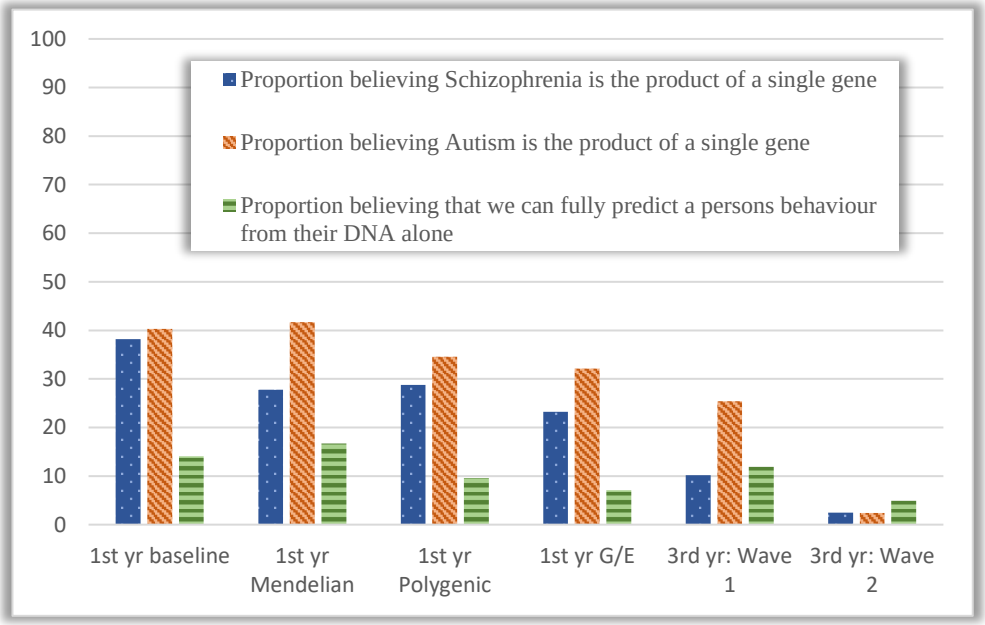
Research question 2: Does studying Psychology for 2 years have any relation to genetic knowledge and views on genetic determinism: An ANOVA revealed that there were significant differences in Genetic Knowledge between the three levels (First year baseline; Third year wave 1; Third year wave 2). The test of Homogeneity of Variance was significant (Levene (2, 242) 7.29, P = .001) and so equal variance cannot be assumed. Welch's ANOVA revealed overall significant differences between the three groups F = 114.12 (2, 104.47), p <. 001. Dunnett post-hoc analysis revealed significant differences between all levels at p < .001. In particular, the average genetic knowledge scores of third year students were more than one standard deviation higher at the second collection than at the first collection.

An ANOVA revealed that there were significant differences in Views on Determinism between the three levels (First year, Third year wave 1, Third year wave 2). The test of Homogeneity of

Variance was non-significant (Levene (2, 235) .50, P = .606) and so equal variance is assumed. The ANOVA revealed overall significant differences between the three groups F = 20.63 (2, 235), p <. 001. Tukey HSD post-hoc analysis revealed significant differences between first years and both third year collations (both at p < .001), but not between the two waves of collection in the third years.

Research question 3: Would any of the manipulations result in a better understanding that complex traits are rarely the product of single genes? Two items from the Genetic Knowledge section of iGLAS specifically relate to the polygenicity of complex traits and one asks whether we can fully predict a person's behaviour based on their DNA alone. Responses to these items across all collections are given in Figure 11.

Figure 11. Proportional responses to genetic knowledge items about monogenicity and behavioural prediction from DNA



Note. Proportions are shown for ease of comparison across groups due to different sample sizes in each group.

Limitations

Qualtrics was used for data collection with the first year cohort. The test conditions were set to display the experimental manipulations randomly but were not constrained to have equal numbers of participants in each condition. This resulted in different sample sizes in each group

and this may have affected the results. However, the mean differences between the three groups were so small that this is unlikely to have had an impact.

In all instances, participants were asked to respond to the item: 'I believe my destiny is written in my genes', and this item was used as a proxy for genetic determinism.

Discussion

The manipulation administered with first year psychology students did not influence genetic knowledge or views on determinism (Research question 1). Some changes were observed in response to specific items about the polygenicity of complex traits and the ability to fully predict behaviour from DNA alone (Research question 2). These warrant further and more direct investigation.

The genetic knowledge of third year students in the first week of their final year was significantly higher than that of the first year students (Research question 3). This suggests that studying Psychology for 2 years (in the case of this degree programme) increases genetic knowledge. Indeed, several modules in the first and second year of the psychology degree include information about genetic influences on behaviour. Moreover, the group of students in this study have chosen to study the Behavioural Genetics module in the third year, which indicates interest in this subject. Further improvements in knowledge were seen in these students between the first and last week of the module.

Third year students reported higher endorsement for the statement 'I believe my destiny is written in my genes', when compared to first year students. On average, first year students disagreed with this statement somewhat (M = 3.02). Prior to the commencement of the optional Behavioural Genetics module, third year students had a slightly higher score (M = 4.04, where 4 in the scale is neither agree nor disagree). This increased slightly but not significantly by the end of the Behavioural Genetics module. Studying psychology would seem to be associated with a

reduction in purely environmentalist explanations of psychological traits and individual differences, with participants more likely to also consider genetic influences on our destinies.

The manipulation between waves 1 and 2 of the third year students – attending a module in Behavioural Genetics – significantly increased their genetic knowledge but made no difference to their response to the item 'I believe my destiny is written in my genes'. However, third year students showed higher average endorsement of this statement than the first year students. Whilst this may be taken as an indication of an increase in genetic deterministic thinking, it must be remembered that the score chosen by third year students averages as 'neither agree nor disagree' and may be an endorsement of more complex views, such as 'destiny' depending on genetic and environmental factors. The difference seen between first and third years in this item is more likely to reflect the fact that first year Psychology students will most likely have been exposed to primarily environmental explanations of trait variation during their previous psychology instruction. For example, as described earlier, the Department for Education's recommendation for GCSE Psychology[9] only makes one passing references to genetics.

Third year students, who had already been introduced to the concept of heritability by the time of the first wave of data collection, may have a more accurate idea of how genes influence our behaviour when compared to first years.

The item 'I believe my destiny is written in my genes' is very open ended. However, someone adhering to an entirely **Cartesian** '**tabula rasa**' notion of the self would likely answer 'strongly disagree', whereas **fatalists** may be more likely to 'strongly agree'. Therefore, a response at the midpoint may be reflective of a balanced understanding of the relative contribution of both genes and environments to trait variation. This interpretation is supported as, at the second wave of collection, the third year students demonstrated a good understanding that genetic influences

[9] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/485228/Psychology_GCSE_final.pdf

in complex traits are typically polygenic, and that behaviour cannot be fully predicted from DNA alone.

Study 4. Genetic Destiny and Free will

To investigate views on free will and determinism further a follow up study was conducted (15/08/2019). 18 undergraduate students (4 x first years, 10 x second years, 4 x third years) were invited to take part in a focus group pertaining to these issues. Each participant was asked to respond to the items: 'I believe my destiny is written in my genes' and 'Genetic influences on our behaviour mean that there is no free will'. Participants were also asked to reflect on their responses and given the chance to make any changes they wished following that reflection. Measurements were taken on a 7-point Likert scale from strongly disagree to strongly agree. In addition, participants were also asked what the terms 'destiny' and 'free will' meant to them. Having provided these responses, an open-ended discussion was conducted to further explore these concepts.

Participants in this focus group were all Psychology students at Goldsmiths, University of London during their 2-month Erasmus+ internship at Tomsk State University in Russia. They had all received instruction in genetics, both as part of their degree programme and through a specific half-day workshop developed and delivered by the author of this thesis. This workshop was developed to provide an overview of behavioural genetics and was delivered three weeks prior to the focus group. Numerous informal conversations about behavioural genetics were also held with students on various occasions between 22/07/2019 and 03/08/2019. As such, even students who were in the first and second years of their course had rather intensive exposure to issues related to behavioural genetics.

Overall, the results from these participants broadly reflected the findings of the previous study (above) for the item related to genetic destiny (M = 3.83 SD = 1.29, range 1 to 5). The results suggest that individuals with at least some instruction in behavioural genetics tend to report higher endorsement of genetic destiny. This can be seen in Table 32, where frequencies from

the focus group are compared to those of the above study, as well as the general collection of iGLAS data.

Table 32. Frequency of responses to the question 'I believe my destiny is written in my genes' for the total sample of iGLAS, first and third year BSc Psychology students and focus group participants.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
Total iGLAS sample	2285 22.90%	2607 26.10%	1800 18%	632 6.30%	2154 21.60%	390 3.90%	118 1.2%
1st years (baseline)	18 12.50%	41 28.50%	35 24.30%	21 14.6%	28 19.40%	1 0.70%	0 0%
3rd years wave 1	2 3.80%	5 9.40%	12 22.60%	8 15.10%	22 41.50%	4 7.50%	0 0%
3rd years wave 3	1 2.40%	4 9.80%	4 9.80%	11 26.80%	17 41.50%	4 9.80%	0 0%
Focus group	1 5.60%	2 11.10%	4 22.20%	6 16.70%	8 44.40%	0 0%	0 0%

For third year Psychology students and those involved in the focus group, the most frequent response was somewhat agree. Members of the focus group were asked to reflect on their responses, and several common themes emerged. Primary amongst these was the argument that gene/environment interactions mean that 'destiny' is not written into the genome in a deterministic way. Several participants also commented that genetic influences are important in certain traits, but do not determine them.

Participants in the focus group were also asked to respond to the item 'Genetic influences in our behaviour means there is no free will'. When compared to the item on genetic destiny, participants in the focus group were less likely to endorse this notion (M = 2.17, SD = 0.86, range = 1 to 4). 17 members of the focus group (94.4%) disagreed to some extent (responding 1-3) with the notion that genetic influences negate free will. The remaining participant responded at the mid-point in the scale (4) so neither agreed nor disagreed. As such, none of the members of this focus group agreed with the idea that genetic influences negate free will. This question was not asked of participants in the first/third year teaching intervention study but was included in recent versions of iGLAS. In the total sample of iGLAS, 3187 (69.8%) disagreed to some extent, 545 (11.9%) neither agreed nor disagreed and 834 (18.2%) agreed to some extent.

The reflections on free will were generally more complex, metaphysical and reflective. Some participants acknowledged that, whilst behaviours may be heritable, this does not prevent us from making our own decisions:

> "Disagree: Genetic influences may have a strong effect on how we behave etc, however they do not dictate our lives removing free will"

> "Strongly disagree: Free will is different from the result or outcome of an event, because free will is the action leading to an outcome (rather than the outcome itself). So, whilst genetic influences may affect the likelihood of an outcome occurring, it doesn't change the notion that free will exists to allow us to aim for that outcome."

Interestingly, in both instances, and despite most participants acknowledging the importance of gene/environment interplay and the complex relationship between the genome and phenome, several focus group members used deterministic language. For example, the term "written into our genes" was used by two participants. Three participants talked about genetics 'determining' a trait even whilst acknowledging that genetics are not deterministic. This may suggest that 'deterministic' language when discussing genetics does not necessarily reflect deterministic beliefs. It also suggests that such a vernacular may have been engrained through years of exposure to such language.

Participants in the focus group were asked to reflect on their responses to these two items and then given the opportunity to change their responses if they wished. 3 participants opted for this. There was no consistent pattern to response changes, and these rarely shifted more than one point in either direction. Whilst this may suggest that initial responses may be less valid than considered ones, the small proportion of participants who opted to change, and the minimal changes they made, indicate that initial responses can be taken as a fair indication of participants' perspectives.

These results suggest that increasing awareness of the complexity of the relationship between genes and traits, from studying psychology in general, and behavioural genetics in particular, is associated with an increase in views on the importance genetics plays in shaping who we are. However, this is not associated with a reduction in the belief in free will. Indeed, participants in the focus group were less likely to endorse the notion that genetics negate free will when compared to the total iGLAS sample. This is in line with the theoretical framework proposed by Stroessner & Green (1990), that determinism and free will can be independent of each other. I.e., that they are not opposites on a single bipolar dimension.

Conclusion from the 4 studies

The results from these studies suggest that genetic knowledge and opinions may be quite robust to simple manipulations of media reporting, but that seeking out information about genetics in the media, especially through different channels, is associated with higher levels of genetics knowledge. Studying a degree in Psychology, which includes information about gene environment interplay, is associated with improved genetic knowledge, especially in participants who complete an optional module in Behavioural Genetics. Studying Psychology also appears to be associated with a more balanced, and less environmental, view of gene/environment interplay in shaping who we are. The focus group, which further investigated this finding, suggests that understanding the importance of genetic influences in shaping who we are, is not necessarily associated with a reduction in belief about our free will. The concepts of genetic determinism, destiny and free will are complex. It is proposed that the views reported by members of the focus group indicate a balanced view of these factors that would allow them to engage in fruitful and productive debates about how genetics should be used across society.

How genetics is reported and discussed in the media is important, however, carefully considered educational interventions may prove more productive in equipping the general population with the tools to engage effectively in the genomic era. One avenue which is likely to be productive would be a re-evaluation of how genetics is taught as part of compulsory school curricular.

Chapter 6: The Accessible Genetics Consortium, and 4 Public Engagement Activities; Development, Reception and Evaluation

Abstract

Chapter 5 suggested that public opinions and knowledge about genetics tend to be resistant to relatively brief interventions, but that structured educational programs can have a more marked impact. This chapter discusses the development and scope of "The Accessible Genetics Consortium" (www.tagc.world) a tool designed to improve public engagement with genetics. It also considers 4 public engagement activities delivered under the brand 'Genes & Tonic'. These events were designed and conducted by me in collaboration with The Accessible Genetics Consortium and InLab (past and present members) and evaluated as part of this PhD project. Each event was informed by feedback from the previous one. From the outset, these events were developed to engage the public in a discourse, rather than being a simple knowledge transfer. This arguably reached a peak with 'Genes & Tonic 3: Know Thy Father', in which participants acted as medical ethicists in a complex real-life case of privacy in the genomic era. 'Genes & Tonic: GEkNOwME' specifically sought to engage people might not normally express interest in genetics. Feedback from each event suggested that these endeavours were extremely successful. Future events, based on the findings of this thesis, are planned. In particular, an interactive knowledge exchange activity for teachers and trainee teachers is under development.

Introduction

Previous chapters have demonstrated that the general population that has engaged with iGLAS have generally low levels of genetic knowledge. This is also the case within specific student samples. However, participants who are studying psychology and particularly those who have studied behavioural genetics, seem to have better genetic knowledge. Chapter 6 also indicated that studying behavioural genetics can affect the way people think about genetics, especially in terms of destiny and free will. It was a fundamental aspect of my PhD programme to try and

improve the way genetics is communicated to the public through engaging and accessible activities.

The 'deficit model' of science communication (Sturgis & Allum, 2004) suggests that members of the public do not hold certain opinions about important science topics simply because they lack information about those topics but that views are influenced by other factors, including political partisanship (Hart & Nisbet, 2012) and the need to avoid social exclusion (Frimer et al., 2017). This thesis demonstrates the importance of knowledge, and supports the idea that members of the public are not simply empty vessels to be filled with information that they are currently deficient in. This has been a guiding principle in the development of The Accessible Genetics Consortium (www.tagc.world) and a number of public engagement activities and endeavours, including the 4 reported in this chapter.

From the outset of my PhD, my colleagues and I have produced and maintained "The Accessible Genetics Consortium" (www.tagc.world).This consortium exists to provide information about genetic research in accessible and understandable ways. More information about the goal and scope of TAGC can be found in the following promotional video https://www.youtube.com/watch?time_continue=5&v=42mOWfiMBdU&feature=emb_logo. In addition to on-line resources, TAGC has organised a number of working groups, focus groups, conferences; and produced 4 public engagement events under the identifying brand of 'Genes & Tonic'. This branding was chosen to reflect the open and non-academic nature of the events.

The current chapter presents overviews and reviews TAGC's activities, including the four 'Genes & Tonic' events, showing how they have evolved from primarily deficit models of science communication to fully immersive and engaging events. Particular focus will be given to the third of these events: 'Know Thy Father', which resulted in some important findings about the opinions and attitudes of attendees in relation to how genetic data should be used and shared in healthcare settings.

TAGC – The Accessible Genetics Consortium

The Accessible Genetics Consortium is primarily a collection of world leaders in the areas of genetics, behavioural genetics, legal and ethical implications of genetics research and public communication. Details of the activities of TAGC can be found at www.tagc.world and a brief selection of screen shots can be seen in Appendix 5. TAGC includes review articles on recent genetic studies and advances. These can be searched thematically so that articles are easy to find for interested readers. There is also a glossary of common genetic terms. Details of recent publications and projects from its collaborators are also given on TAGC. Planned and past public engagement events can be found on TACG as well as details of the bespoke training, teaching and Continuing Professional Development (CPD) that can be supplied. TAGC is also host to the Working Group on Legal, Ethical and Societal Implications of Genetics (LESIG). This group aims to produce specialist proposals, through multidisciplinary work and international collaborations and exchange, for regulating genetic information. The TAGC website is available in both Russian and English and is updated regularly.

Genes & Tonic 1 (3rd March 2016 18:30 – 21:30)

The first TAGC 'Genes & Tonic' event took place in central London on the evening of March 3, 2016. The event was advertised through social media, communications by collaborators with their peers and students and via posters displayed in the Student Unions of local universities (e.g. Goldsmiths, the Institute of Education, New York University in London, Birkbeck and the School of Oriental and African Studies). In total, 83 attendees signed up for the event. 64 of these attended, with an additional 5 people attending who did not sign up.

The event was free, but attendees were asked to complete a short survey when booking their place. The aggregated anonymous results of this survey were then presented on display screens during the event. The intention behind this was to allow attendees to reflect on their own knowledge and opinions and to discuss these with their fellow attendees, rather than be passive

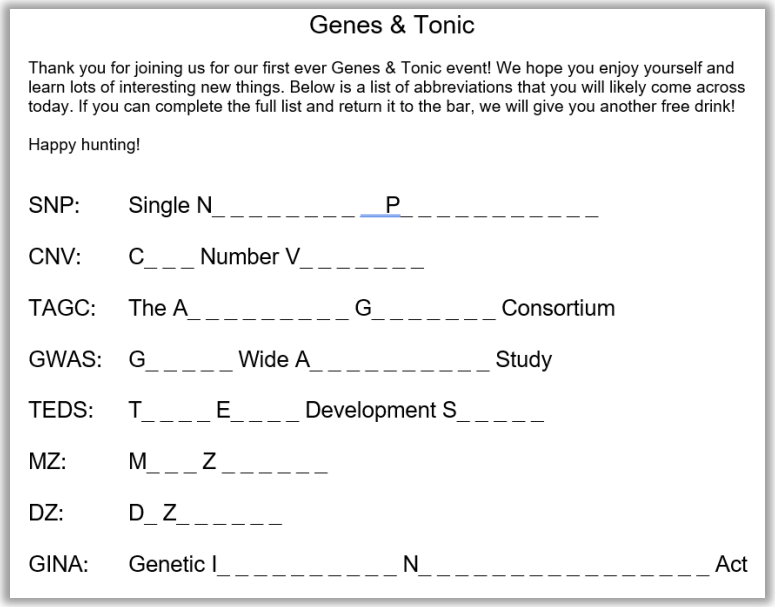
receivers of information. The speaker's contributions were fee-free. Refreshments were sponsored by InLab. These and other costs associated with the event were also support by the public engagement small grant scheme at King's College London.

The event consisted of short talks from expert researchers in the area of behavioural genetics. Talks were scheduled for between 15 and 20 minutes, with time for questions. Endeavours were made to make these talks accessible to a general audience, but feedback on the event suggested that some contained too much technical information. This was addressed for future events.

Fatos Selita, a world leading expert in genetics and the law (Selita et al., 2019; Selita & Kovas, 2018), was also present at the event and gave several question and answer sessions, which were very well received.

In addition, there were a number of stalls and activities. For example, attendees were able to conduct supervised DNA extraction. This activity proved so popular that it was included in the next two events. There were stalls at which attendees could produce paper DNA origami and DNA bracelets whilst informally discussing genetics with an expert. To further encourage engagement in the event and communication with the speakers, attendees were presented with a task to complete (see Figure 12).

Figure 12. Abbreviations activity



Genes & Tonic

Thank you for joining us for our first ever Genes & Tonic event! We hope you enjoy yourself and learn lots of interesting new things. Below is a list of abbreviations that you will likely come across today. If you can complete the full list and return it to the bar, we will give you another free drink!

Happy hunting!

SNP: Single N_ _ _ _ _ _ _ _ _ P_ _ _ _ _ _ _ _ _ _ _

CNV: C_ _ _ Number V_ _ _ _ _ _ _

TAGC: The A_ _ _ _ _ _ _ _ _ G_ _ _ _ _ _ _ Consortium

GWAS: G_ _ _ _ _ Wide A_ _ _ _ _ _ _ _ _ _ Study

TEDS: T_ _ _ _ E_ _ _ _ Development S_ _ _ _ _

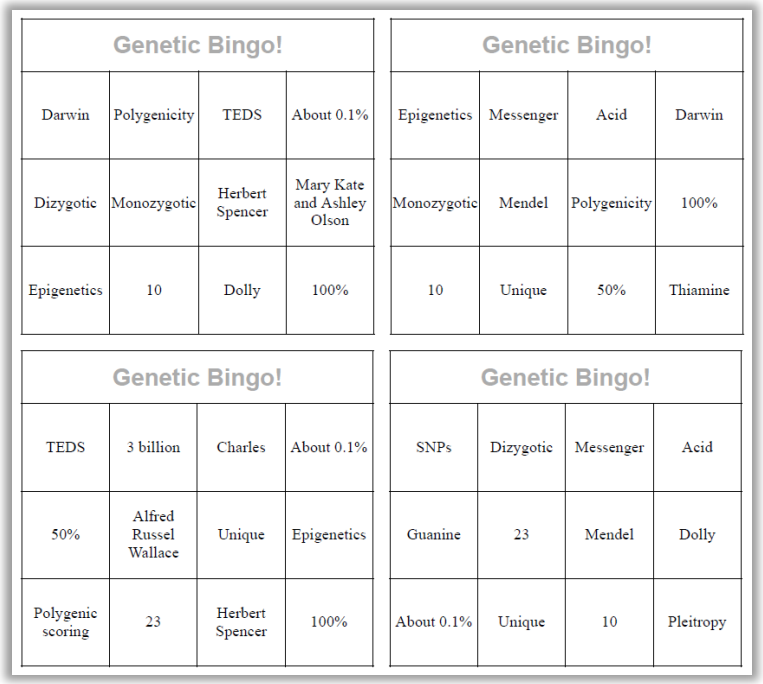
MZ: M_ _ _ Z _ _ _ _ _ _

DZ: D_ Z_ _ _ _ _ _

GINA: Genetic I_ _ _ _ _ _ _ _ _ _ N_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ Act

Attendees were free to move about during the event, attending those aspects that most interested them. To provide a sense of cohesion, all attendees were involved in the final activity. Prior to the event, the expert speakers were asked to provide information about their talks. This information was then turned into quiz questions. For example: ‘The scientific term for identical twins is…’. A random ‘Bingo’ card generator was then used to produce 4 x 3 grids that contained a random selection of answers to these questions (Figure 13). At the end of the event, all attendees were gathered. I then called out the questions in a random order, and attendees searched their Bingo card to see if they had the corresponding answer. Prizes were awarded for the first participant to achieve: a full horizontal line; two full horizontal lines and a ‘full house’. This activity provided an excellent and cohesive conclusion to the event. It also allowed attendees to reflect on their own learning and experience.

Figure 13. Examples of Genetic Bingo cards



Genetic Bingo!			
Darwin	Polygenicity	TEDS	About 0.1%
Dizygotic	Monozygotic	Herbert Spencer	Mary Kate and Ashley Olson
Epigenetics	10	Dolly	100%

Genetic Bingo!			
Epigenetics	Messenger	Acid	Darwin
Monozygotic	Mendel	Polygenicity	100%
10	Unique	50%	Thiamine

Genetic Bingo!			
TEDS	3 billion	Charles	About 0.1%
50%	Alfred Russel Wallace	Unique	Epigenetics
Polygenic scoring	23	Herbert Spencer	100%

Genetic Bingo!			
SNPs	Dizygotic	Messenger	Acid
Guanine	23	Mendel	Dolly
About 0.1%	Unique	10	Pleitropy

Attendees were contacted shortly after the event and asked if they would like to provide feedback. 21 attendees completed feedback, which was overwhelmingly positive. On a scale of 1 (not at all) to 5 (very), 95.2% felt the event was interesting, and 100% thought the activities were enjoyable (responding 4 or 5). When asked what they enjoyed about the event, participants' comments included: "New knowledge, great atmosphere"; "TED like presentations. Well structured"; "The genetic bingo!"; and "The amazing and talented organisers who provided us much knowledge about Genetics."

One participant commented that they would have preferred more optional activities at the same time as the Genetic Bingo. Other than this, feedback focused on aspects, such as room size and temperature. One participant suggested that there should be more people to talk with, and that there should be some material that can be taken home. Action was taken on this feedback in the planning of the next event.

Genes & Tonic 2 (11th November 2016 18:00 – 21:30)

The second 'Genes & Tonic' event followed a similar format to the prior event. In this instance, 120 people booked and 79 (66%) attended. Whilst not a poor ratio, consultation with the

communications team at Goldsmiths suggested that people are less likely to attend events they book if they do not have to pay. For the next event, it was decided to add a small booking fee (£4.00).

The feedback provided from the previous 'Genes & Tonic' was used to plan improvements for the second event. Firstly, attendees were provided with a programme for the event which detailed which talks were happening at which times. Each talk was accompanied by a description and biographical details of the speakers/panel members. Attendees were able to take these home if they wished. It was decided not to have concurrent talks, so that all attendees could attend all talks if they wished. The room sizing issues were tackled by having live streaming of talks in other rooms. Interactive stalls were again available, and the evening concluded with another game of Genetic Bingo. To encourage attendees to engage with the organisers and invited speakers, each TAGC member wore a lanyard that described their expertise (e.g. "I'm a psychologist, ask me about genetics in the public domain"), this was in addition to their name badge.

It was decided to include feedback as part of the event, rather than request this via email afterwards. This was primarily to increase the proportion of attendees who provided feedback. This initiative worked, as more people completed feedback, but the depth of that feedback was reduced when compared to the previous method. However, feedback was again overwhelmingly positive. As previously, some attendees still felt that the level of technical information was pitched a little too high and that more introductory material would have been useful. This was taken as a primary issue to be tackled in future events.

Genes & Tonic 3: Know Thy Father (9th February 2018 18:30 – 21:30)

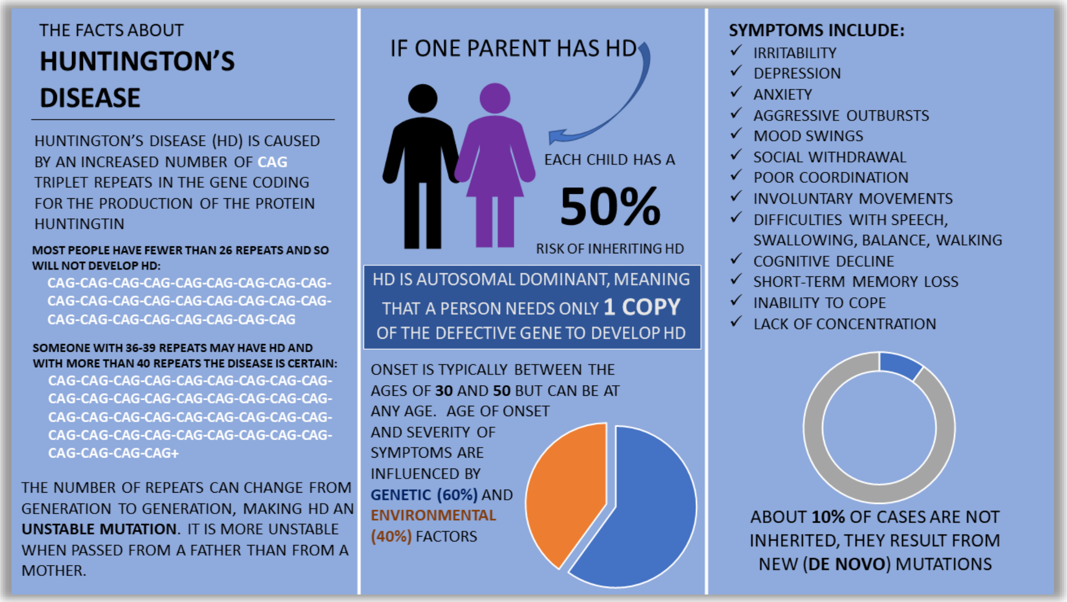
The third 'Genes & Tonic' event combined a public engagement event with data collection for a research project related to the ethical use of genetic data in healthcare systems. This resulted in

a published paper (Chapman, Devereux, et al., 2018). The following section draws on that paper and is structured accordingly.

Introduction

The importance of actively engaging attendees was made of paramount importance in the development of our third event. For ‘Genes & Tonic’ 3, attendees were cast in the role of medical ethicists and presented with a real-life case to consider. The case of ABC v the NHS (*ABC v St George’s Healthcare NHS Trust & Ors [2015] EWHC 1394 (QB)*, 2015). In this case, action has been brought against the UK National Health Service (NHS) by a patient on the basis that the NHS owed a duty of care to disclose her father’s Huntington’s Disease (HD) diagnosis to her (see Figure 14 for an infographic on HD). The daughter asserts that, had she been informed of the risk, and her own diagnosis was confirmed, she would have terminated her pregnancy. The High Court struck out her claim on the grounds that there was no reasonably arguable duty of care owed to the daughter by the NHS. The decision of the High Court was appealed by the daughter, and the Court of Appeal reversed the High Court’s decision, remitting the case for trial. The differing decisions of the UK courts reflect the complexity of the moral, ethical, and legal issues in such cases.

Figure 14. Information about Huntington's Disease



Method

During the event, attendees heard talks by a geneticist, a lawyer, and a genetic counsellor, and engaged in activities during which data were collected. Refreshments were provided twice during the event. As with previous 'Genes & Tonic' events, the evening included interactive activities including DNA extraction, an activity related to monogenicity and polygenicity, and a short quiz element (with prizes). A professional photographer and professional pianist were engaged for the event, which was held at Goldsmiths, University of London. Funding for this event was provided by InLab, the Graduate School and Public Engagement teams at Goldsmiths.

Participants

Recruitment for this event was via www.tagc.world, social media and through friends and family of the organisers. Data were recorded for 35 participants (22 female) of a median age of 31.88 (SD =14.1, range 18 to 80). 14 participants had only secondary school education, 10 had completed undergraduate university degrees, and 11 had completed postgraduate studies. All participants provided written consent for the use of their data in this research. The research was approved by the Goldsmiths University Psychology Department Ethics Committee.

Measures and Procedure

Upon arrival, participants were provided with a welcome pack and a unique identifier number. This pack contained a programme and forms for participants to provide responses to specific questions asked throughout the event, as well as questions to capture demographic information: age, sex, occupation, and highest educational level achieved. Throughout the event, participants were provided with details drawn from the above-mentioned court case concerning Huntington's Disease. Participants were asked to give their opinions three times during the event, as progressively more details about the case, as well as other information, were released to them in successive waves.

At the outset of the evening, participants were provided with background information about the symptoms, progression, prognosis and current treatment options for HD. They were also presented with the following overview of the case notes (people's names were fabricated for the event):

- 2007: Having shot and killed his wife, a man (Fred) was sentenced to a hospital order and a restriction order (related to mental illness). In connection to this, his adult children attended family therapy at the same hospital.
- January 2009: Fred's doctors first suspected that he might have HD. They urged him to tell his family; he informed his brother but refused to tell his three daughters.
- 2nd September 2009: Fred received a confirmed diagnosis of HD through genetic testing.
- December 2009–January 2010: Healthcare professionals repeatedly urged Fred to disclose his diagnosis to his daughters. Fred withheld consent.
- 23rd August 2010: One of his daughters (Claire) was accidentally told by Fred's doctor that her father was diagnosed with HD.
- Late 2010: Claire began the process of suing the NHS for not providing this information officially at the time of diagnosis.

Participants at the event were also advised of the familial risk to Claire and her sisters, i.e. that they each had a 50% risk of developing HD. The fact that HD can impair cognitive function, and that this might have had an impact on the father's ability to understand his and his family's situation, was not emphasised to the participants, although some did comment on this in their feedback. Participants were then asked to give their opinions on a 7-point scale (1=not at all to 7=definitely) on the following three statements:

1) The patient (daughter) had a right to know about her father's diagnosis.
2) The National Health Service (NHS) should have been legally obliged to provide this information to the daughters.
3) The father had a moral responsibility to provide this information.

Participants were also invited to provide written feedback and comments during each wave of data collection.

The second wave of data collection was preceded by the additional information that the daughter (Claire) was pregnant at the time her father's diagnosis was confirmed. The participants were also informed that she attested that, if she had known of her father's diagnosis, she would have terminated her pregnancy given her own risk of developing HD and the risk to her unborn child. The participants' opinions were collected again as described above.

The third wave of data collection was preceded by additional information. This time participants were given a hypothetical scenario that a cure for HD had been discovered but was only effective if begun before symptoms appeared. In this scenario, genetic testing for HD by the NHS was still only available to patients exhibiting symptoms, or to those with a known family history of the disorder. As such, the daughter would only have been able to access the cure if she knew about her father's diagnosis. The participants' opinions were collected for the third time as described previously. It was made clear to them that the scenario was hypothetical (no cure for HD currently exists), but that this is an active area of research.

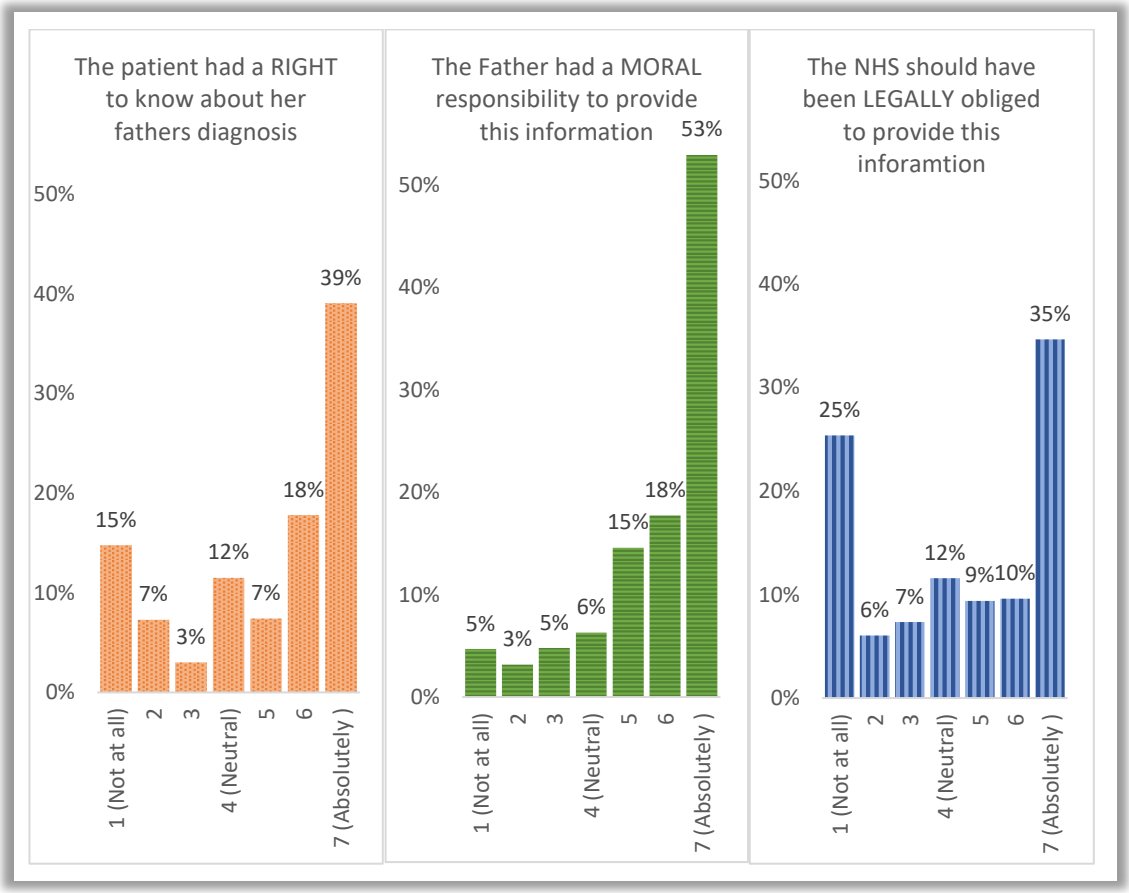
Participants were asked to record their unique ID on each form they submitted during the evening. Unfortunately, not all participants provided this information which led to missing data on some aspects of the analyses (those involving all three waves).

Participants were also asked whether they had ever had a genetic test, if they knew anyone with a genetic condition, or if they had such a condition themselves. They were also asked how influential religion was in informing their opinions and decisions (not at all, somewhat, or greatly influenced) and how confident they were in their genetic knowledge on a scale of 0 (none) to 100 (entirely confident).

Results

As can be seen in Figure 15, there was a consensus (86% of participants agreeing to some extent) that the father had a moral obligation to provide information to his daughter about his diagnosis. However, opinions were slightly more divided when it came to the daughter's right to such information (64% agreeing to some extent, 25% disagreeing and 11% neutral). Participants' responses were even more polarised when they were asked whether the NHS should be legally obliged to disclose genetic information when consent has been withheld. Even following the final wave of information, when participants had been advised that the daughter was pregnant, and that, hypothetically, there was a cure for HD, 22% of participants still felt that there should be no legal obligation placed on the NHS to disclose the father's diagnosis to the daughter.

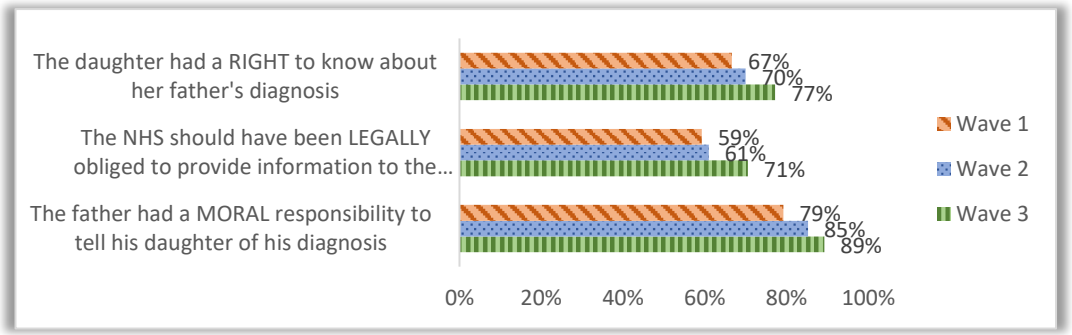
Figure 15. Summed percentage (across the 3 waves) of participants' responses to the 3 statements.



Note: Percentage of responses (rather than participant numbers) are reported

As can be seen in Figure 16, participants' opinions remained relatively stable throughout the event, with only small increases for each statement across the three waves of data collection.

Figure 16. Average score on a scale of 1-7 represented as percentages for each wave and each question



Some potential group differences emerged, although the sample was underpowered to test these statistically. Men tended to be more inclined toward mandating disclosure of the genetic information than women, particularly in relation to the daughter's rights and the NHS's

obligations (Figure 17). Participants who had a genetic condition, either themselves or in their family, were also more inclined towards disclosure (Figure 18). As only four participants (11.5% of the sample) stated that their opinions were influenced by religion to some degree, group analyses of religion are not presented.

Figure 17. Average score on a scale of 1-7 for men (N =9) and women (N =13) for each question.

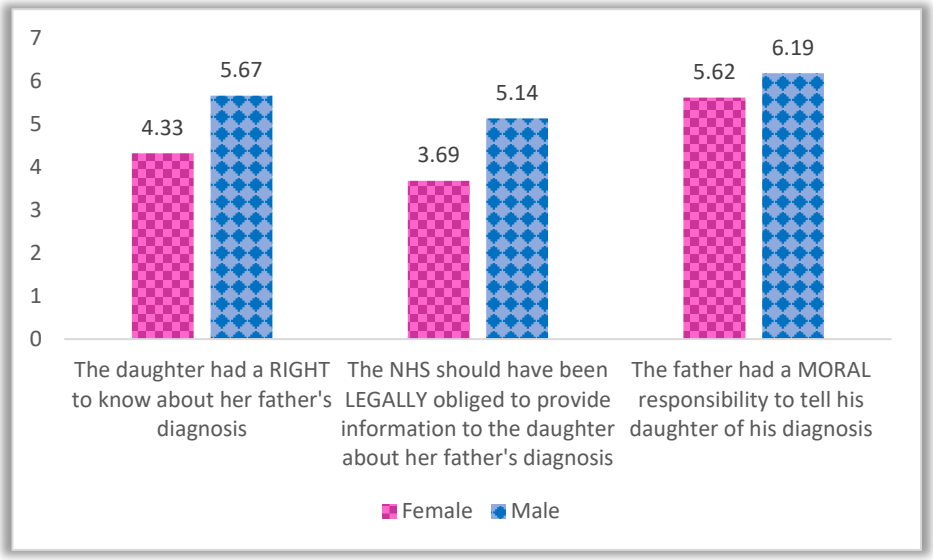
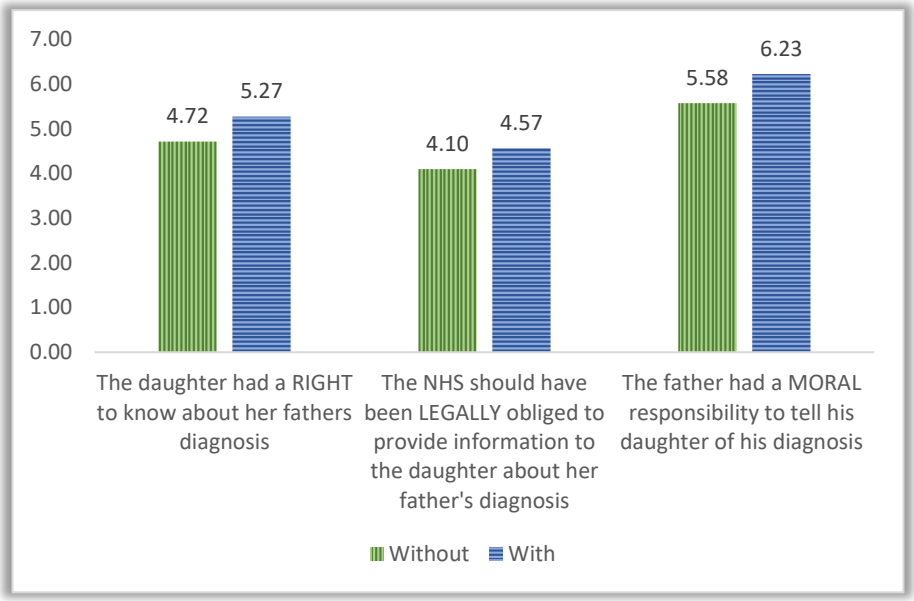


Figure 18. Average score on a scale of 1-7 for participants without (N=17) and with (N=5) a genetic condition, either themselves or in the family.



The open responses provided by participants clearly demonstrate their strong and polarised views. For example, when in favour of a patient's privacy, participants made such statements as: "If your DNA isn't your own, what is?"; "It remains Fred's right alone. Regardless of consequences."; and "The NHS were refused permission by the father, a violation of this goes against doctor-patient confidentiality." When in favour of disclosure of the information to relatives, participants said, for example: "Any information to do with genetics like this must be shared."; "Families need careful genetic counselling to deal with Huntington's. It leads to early death therefore families need to know because of their children."; and "Fred is now responsible for 2 lives, so is under a lot of moral obligation. It's the woman's choice if she wants to terminate, not Fred. #Prochoice." The full collection of responses is available upon request.

Conclusion

The opinions expressed during 'Genes & Tonic' 3 demonstrate that people hold strong and polarised views on the issue of confidentiality, and the moral and legal duty to disclose genetic information to family members. In particular, participants disagreed about the legal obligations on healthcare providers to disclose a person's genetic information to relatives, even when withholding information could have adverse impacts on the health, well-being, and life choices of those relatives. This polarity in opinions may reflect conflicting expectations of healthcare providers: a) that patient privacy will be respected; and b) that disease will be prevented whenever possible. Indeed, it is this very issue that is at the heart of the ABC v NHS case. The polarity in opinions represented here suggests that the debate is far from over and will likely be very difficult to resolve.

Although the study sample size was small, it captured a wide range of ages, professions, and educational backgrounds. Conversely, the sample was also homogeneous in that all participants were interested in genetics and had intentionally attended a genetic science engagement event. Over half of the participants were students and 60% had completed degree-level studies, indicating high levels of educational attainment within the sample. The fact that such a diversity

of views is present within this sample suggests that the issue of privacy and disclosure of genetic information is complex and divisive.

The results also showed that exposure to the same information, including expert talks on genetics, law, and genetic counselling, did not lead to significantly increased similarity in participants' views. A bigger and more representative study is needed to further explore demographic and other factors that may influence people's views on these matters. For example, the results indicated that having a genetic condition in the family may lead to viewing disclosure of genetic information to family members more favourably.

The case discussed during this event was relatively simple, as there is a single known genetic cause for HD. There are numerous medical conditions for which a single genetic variant or group of variants have been identified, and much is often known about the link between these variants and how diseases develop. This information can help inform treatments and interventions as well as provide information about the risk of parents passing the same condition to their children. Even with these known genetic risks, there can complex factors at play (e.g. pleiotropy, mutations, gene environment interplay) leading to a wide variation in outcome. Most diseases have much more complex aetiologies, with a mixture of genetic and environmental factors potentially contributing. This aetiological complexity makes risk estimates much harder, since genetic information is highly probabilistic. With this increased uncertainty, deciding on ethical and legal responsibility becomes even more complicated.

The data presented here only represent the views of a small number of participants who presumably were already engaged enough with genetics and genomics to attend the event. The numbers were insufficient to allow for meaningful inferential analyses and this should be addressed in future studies. However, the open and engaging way in which data were collected during a public engagement event reflects a high degree of ecological validity. Given this, the fact that opinions were found to be polarised and somewhat stable would suggest a reliable result that warrants further investigation.

Genes & Tonic 4: GEkNOwME (9th – 10th November 2018)

'Genes & Tonic' 1, 2 and 3 were constructed so that participants had to sign up to attend. This resulted in the events being attended by individuals already interested in genetics. Whilst this is a valid way of promoting engagement events, it was a passionate desire of mine that we also produce events that appealed to people who were not already engaged with the subject matter. 'Genes & Tonic' 4 was approached to specifically address this issue.

Goldsmiths, University of London has a gallery space in an old shopfront on New Cross Highstreet. It was decided to host an exhibition of genetically informed artwork within this space. This event was incorporated into the Economic and Social Research Council's Festival of Social Science. Timings for the event were chosen so that the exhibition would be open as pedestrians commuted home on Friday and as they did their shopping on Saturday. The exhibition was clearly branded with window displays and a board promoting the event outside the venue. In this way, it was hoped to attract audience not normally engaged with genetics. There was no charge for this event.

Art pieces were produced by members of TAGC. There was also an open call for students, staff and alumni of Goldsmiths, University of London to contribute pieces in response to three broad aspects of genetics that had been identified as being important areas to address in public engagement activities. Below are the titles and concluding comments for each brief. Further information about each brief as well as details of the prizes, terms and conditions, can be found in Appendix 3:

Mendel and More

Understanding that all human traits are influenced by multiple pieces of information coded into our DNA, rather than being caused by just one piece of information, is essential to understanding how genes influence (rather than determine) who we are.

Many Genes, Small Effects

In the vast majority of cases, genes have tiny and cumulative effects. Even though we have gene editing technology available now, changing just one gene is very unlikely to have an impact on the trait we want to improve or correct. We also don't know very much at all about how genes actually influence complex traits, so changing just one gene may impact a whole variety of traits other than the one we are interested in. Far better to look at improving people's environments, rather than tinkering with their genomes.

Gene and Environment Interplay

Even when genes exert an influence on a trait, they need an environment in which to flourish. Knowing that genes are very important for a trait does not mean that environments aren't. Indeed, some diseases which are highly genetic can be controlled by entirely environmental means. It is not a case of Nature vs Nurture, or Genes vs Environments. It is Nature and Nurture always working together that makes us who we are.

Ten separate pieces of artwork were produced, each of which responded to one of the above briefs. These included a 7-foot tall knitted DNA Helix, a replica of the Human Genome bookcase exhibited at the Welcome Gallery, a piece by the Goldsmiths Alum and artist Alex Keays, and an interactive exhibition using umbrellas and ink to frame a discussion of gene/environment interplay. The artwork was installed within the space to make maximum visual impact and to allow space to freely walk around the installations and talk with the curators. The event was continuously curated by me and other members of TAGC. Attendees were free to walk through the exhibition themselves, or to ask for a guided tour/more information on any of the pieces. Further details of each piece, including images and item descriptions, can be seen in Appendix 4.

Feedback for this event was collected using forms supplied by the ESRC. 28 attendees completed these forms. 2 attendees reported attending the event for work related reasons, 14 as they were students and 22 as members of the public. Attendees heard about the event in a number of ways including: Social media (9), ESRC material (2), local press and radio (2), Invitation (5) and the TAGC website (3). One participant noted that they attended after seeing the event as they were passing by. This breadth of attendees, and the different avenues that brought them to the event suggests that a wider audience was reached than in previous events. However, as only one person reported that they were 'passing by' GEkNOwME cannot be taken as fully meeting its intended goals. This suggests that art exhibitions, even when free and in accessible gallery spaces, may not be an effective way of engaging disengaged audiences; not because the exhibitions do not work, but because people do not see them. This will be kept in mind in the development of future events.

The content of the exhibition seems to have been very effective. On a scale of 1 (strongly disagree) to 5 (strongly agree), participants reported strong interest in the social sciences (4.46). They also reported that they would use/share the things they learnt at the exhibition (4.25) and that they were inspired to learn more about the topic (4.46). Comments included: "Superb ideas to gain conceptual knowledge of complex science ideas"; "Well laid out, imaginative way to portray notions related to genetics"; and "Great artwork! Loved the knitted DNA!". In these regards, 'Genes & Tonic: GEkNOwME', can be taken as a great success.

Conclusion

The Accessible Genetics Consortium (TAGC) continues to provide up to date information about importance advances in genetics, as well as details of taking and using iGLAS, public engagement and speaker activities and the work of LESIG. It is maintained by me, in collaboration with associate members of TAGC, particularly Fatos Selita and Daria Matsepuro. Engagement with TAGC as well as the responses to the public engagement events discussed here clearly demonstrate that members of the public are very interested in genetics and are

responsive to endeavours to improve information transfer. Feedback suggests that fundamental principles should be communicated before more complex topics are addressed, but that activities that encourage engagement and discourse are appreciated. The results of 'Genes & Tonic 3: Know Thy Father' suggest that members of the public do not hold their views simply because they lack information, as all participants were provided with the same information during the event. Their opinions remained largely unchanged and relatively divergent and are likely the product of complex experiences and expectations. This suggests that the deficit model of science communication is not sufficient when discussing issues related to the ethical use of genetic information. More broadly however, the attendees of these events were keen to improve their knowledge of genetics and indicated that they would share this knowledge with others.

The Genes & Tonic events took place between 3rd March 2016 and 10th November 2018. Some attendees of these events were friends and family of the organisers. However, the time between events, and the rolling nature of the team that has worked on these events means that even these 'known' participants were different between events. Different events were also targeted to different groups. For example, Genes & Tonic 1 and 2 included students from New York University in London (different cohorts); this was not the case for Genes & Tonic 3 and 4. Different styles of delivery and the anonymity of attendee records does not allow for accurate evaluation of people who attended multiple events, but a reasonable estimation would be 80%-90% novel attendees at each event. Each Genes & Tonic event was designed for novel audiences and did not assume prior knowledge of genetics. As such, this rate of 'new' attendees is thought to be a strength of the events. It also adds validity to the feedback provided as this should represent a broad range of opinions.

Future events are planned and will be informed by the findings presented in this thesis, especially those in Chapters 4, 5 and 6. In particular, an event targeted to teachers and trainee teachers is being developed. By targeting these professionals, it is hoped there will be a trickledown effect of knowledge transfer and an encouragement of interest in this vital area of social engagement and change.

Chapter 7: General Discussion, Implications and Future Directions

The present thesis set out to investigate knowledge and opinions about genetics in varied samples of the general population; to see if there are international differences in genetic knowledge and if this varies based on career, education level, political ideology and religion. Investigation was also made of the response patterns, and, in particular, of potential sources of errors and misconceptions about genetics. This thesis also investigated some of the implications of genetic knowledge, how knowledge is acquired and possible ways of improving knowledge transfer and public engagement.

The 'deficit model' postulates that the public hold certain opinions because they lack sufficient knowledge relevant to a particular topic. Studies have identified that this is not always the case, indeed, in some areas, more information about a topic can lead to even more polarised opinions (e.g. Kahan et al., 2012). This is a concern in certain scientific areas where the preponderance of the evidence suggests certain courses of action. For example, steps need to be taken to reduce and curtail human impacts on the climate (Schellnhuber et al., 2006), and vaccination is important for individual and group health (Anderson & May, 1985). Studies have identified that opinions contrary to those suggested by scientific research in these fields are not necessarily caused by a lack of knowledge or information.

The findings of this thesis suggest that people's opinions in relation to genetics are formed for similarly complex reasons, and not simply as a result of lack of knowledge about genetics. However, good genetic knowledge is associated with opinions and is therefore important, especially for informed and productive sociological debates. These debates are essential if advances in genetic technology are to be realised and used in productive and non-damaging ways. Even in medicine, where there have already been benefits in individual treatments, **epidemiological** issues are complex and need to be debated. For example, should decisions about reproductive choices be left solely to parents, or should society establish parameters for

these choices? What responsibilities should be placed on health care professionals to communicate information about familial risk for genetic disorders? In order for people to engage with an informed and productive debate, they need to have a good basic knowledge of genetics. As such, the need to improve general levels of genetic knowledge is paramount.

Chapter 1 identified that recent measures of genetic knowledge have been restricted to predominately medical domains, and most often to specific diseases, although there has also been some recent interest in Genetically Modified Organisms (GMOs) and Direct to Consumer Genetic Testing (DCGT). The present thesis extended this research out of medical contexts motivated by two main reasons. First, people are unlikely to have access to professional advice when presented with genetic information and options outside of medical domains, for example when receiving results from Direct to Consumer Genetic Testing (DCGT). Second, the ethical, legal and practical implications of genetic research become more complex outside of medical domains. As a first step in tackling these issues, it is important to evaluate and understand general levels of genetic knowledge. This led to the development of the International Genetic Literacy and Attitudes Survey (iGLAS). Chapter 2 details the development of this measure and provides evidence for its validity, reliability and efficacy. Perhaps the element of iGLAS that I am most proud of is that participants seem to find it educational and enjoyable, and that educators wish to use it in their teaching practice.

Chapter 3 identified some interesting group differences. As might be expected, medical doctors had the highest levels of genetic knowledge, but even they did not achieve perfect scores. Lawyers were found to have relatively low levels of genetic knowledge. This is something of a concern as legal professionals will be advocating in court systems, which are likely to become more informed by genetics as research continues. As well as differences between professions, this chapter also indicated a relationship between genetic knowledge and general education. Unexpected gender differences in genetic knowledge were also identified.

This chapter also identified that participants were quite accurate in estimating heritability, although there was no relationship found between this ability and whether participants knew the correct definition of 'heritability' (Chapter 4). Participants tended to underestimate the heritability of traits such as school achievement and weight and overestimate for traits such as height and IQ. This suggests that genetic influences are considered more marked in traits that are seen as 'fixed' and underestimated in more 'malleable' traits.

iGLAS is a measure that goes beyond testing literacy in the purest sense – the ability to identify genetically relevant terms (Erby, Roter, Larson, & Cho, 2008). iGLAS has been able to shed light on conceptual understanding, even if participants might not know the specific term. For example, participants showed a good understanding of the concept of pleiotropy, even though they may not have been able to correctly identify the meaning of this term.

Genetic knowledge was found to be related to positivity towards applications of genetic technology, especially in relation to personal health management. Furthermore, Chapter 4 identified that participants who hold pseudoscientific beliefs about epigenetics were more likely to turn to alternative medicine, even when severely ill, and they were also less likely to engage with genomic medicine.

Chapters 3 and 4 identified international differences in genetic knowledge. It seems that this knowledge is generally high in the USA but may be weaker in Russia and Nigeria (genetic knowledge levels were found to be low in samples of Russian and Nigerian students). Possible explanations for these differences might include school curricular, legal provisions and media coverage in different countries. These country differences may also partly stem from the sample differences. For example, Spain and Italy differed in the number of first and third year students, and Chapter 5 showed that third year students had better genetic knowledge when compared to first year students. In addition, the Russian sample of students was the most diverse in terms of fields of study and may have, therefore, been the most representative of the general population, particularly as a high proportion of Russian's have completed degree level studies. The

evaluation of errors in Chapter 4 identified that salience is also likely to be an important factor. For example, the Nigerian students sampled in Chapter 4 had generally low levels of genetic knowledge but almost all of them knew that genetic testing was provided at birth in a number of countries. Such testing is not routine in Nigeria but is greatly needed due to the high proportion of individuals affected by Sickle Cell Disease. It is therefore likely that this issue is present in the zeitgeist and media in Nigeria. In the UK, where testing is routine, there were relatively low levels of knowledge of such testing. As such, how genetics is covered in the media is important. This is supported by the preliminary analysis presented in Chapter 5 that showed participants who seek out information on genetics have higher knowledge than those who don't, especially if they engage with different media types.

The 'media frame' manipulation in Chapter 5 was not effective as it did not lead to any changes in views on genetic determinism. Brief educational interventions were also found to be ineffective on overall genetic knowledge and views on genetic destiny. However, even with the small manipulation of providing information that eye colour is a) polygenic and b) subject to gene environment processes, resulted in some participants shifting from monogenic to polygenic views of autism and schizophrenia. The participants in these experimental conditions, especially those who received information about polygenicity and gene environment interplay, were also less likely to think that behaviour can be fully predicted from DNA alone. This may suggest that targeted information can lead to related changes in knowledge and warrants further investigation.

Chapter 5 also identified that protracted/intensive educational interventions are likely to have an impact on genetic knowledge and opinions. Students at the outset of the third year of their BSc Psychology degree had better levels of genetic knowledge than students at the outset of their first year. Knowledge levels increased further by the end of an optional third year module in Behavioural Genetics. Interestingly, the surveyed third year students reported higher endorsement of the statement 'I believe my destiny is in my genes' when compared to first year students, although the average endorsement of this statement in this cohort was 'neither agree

nor disagree' and should not be taken as an indication that these students believe in genetic determinism. Rather it seems that studying a Psychology degree, which includes some instruction in behavioural genetics, may result in a more balanced and nuanced view of the importance of gene/environment interplay in shaping who we are. This was further supported by a focus group conducted with students who had received training in behavioural genetics. These focus group members reported similar scores to the third year students. They also confirmed this was related to a better understanding of gene/environment processes. However, they did not feel that these processes negated free will.

Chapter 6 discussed various strategies to improve public engagement with advances in the genetic sciences, primarily through The Accessible Genetics Consortium (TAGC) the 'Genes & Tonic' events series. Four events were described. The first two included expert talks as well as hands on activities and games. The response to these events was excellent, although some attendees felt that more introductory information would have been useful.

The third of these events, 'Genes & Tonic: Know Thy Father', cast attendees in the role of medical ethicists. Participants were presented with details of a real-life court case in which a woman was suing the NHS for not telling her of her father's diagnosis of Huntington's disease. They were asked their views on whether the daughter had a right to such information, whether the father should have been obliged to disclose his condition and whether the NHS should have been placed under a legal obligation to provide this information. Attendees views tended to be polarised and intransigent. There was considerable disagreement on the legal obligations that should be placed on the NHS to disclose a patient's genetic diagnosis to his relatives. Attendees' opinions did not become more similar as a result of the expert talks they attended. It therefore seems that the opinions expressed by attendees are formed for reasons other than their knowledge about relevant genetic and legal considerations. Although the sample size in this study was small, the results indicate a need to better understand the origins of people's opinions.

Limitations

The studies presented in this thesis faced many of the limitations common to this type of work. iGLAS was disseminated online and so participants required the economic and educational resources to access the internet. Attempts were made to ameliorate these issues, for example by translating iGLAS into several different languages and formatting it so that responses could also be completed on tablets or smart phones.

88.4% (N = 8824) of the participants who completed iGLAS reported that they were either studying for or had completed at least degree level studies. The studies reported in Chapter 5 were all conducted with BSc Psychology students. 60% (N = 21) of the participants reported in the study based on ABC v the NHS (Chapter 6) had completed university education. Studies reporting data largely collected with student samples and those educated to at least degree level have advantages and disadvantages. Student samples offer some degree of homogeneity but may not be especially generalisable to the population. The inclusion of so many Russian students addresses this issue to some extent as Russia has one of the highest rates of degree completion in the world, therefore making Russian students more representative of the Russian population. The sample of Russian students was also diverse in the subject areas they were studying, which should further improve generalisability. During 'Genes & Tonic: Know Thy Father' attempts were made to collect particularly ecologically valid data, and this worked to some degree. Future studies should address these limitations as a priority.

Several of the items in iGLAS presuppose a basic level of maths literacy, the ability to understand important maths concepts such as variance, central tendencies, risk and ratios (Paulos, 2000). For example, being able to evaluate the meaning of the sentence "If a report states the heritability of insomnia to be 30%, what would this mean" requires understanding of the concept of heritability and variance. Future versions of iGLAS will include even more items

– e.g. polygenic scoring (Selzam et al., 2017) – that may be confounded by poor maths literacy, and so will also measure this.

Future Directions

iGLAS

The results of this thesis have identified 3 avenues which should prove interesting to investigate further:

- **Direct to Consumer Genetic Testing (DCGT):** An interesting and timely new direction is to explore public knowledge and opinions in relation to Direct to Consumer Genetic Testing (DCGT). Commercial applications of genetic information are growing, and a better understanding of the relevant issues will help people not to become victims of fraud and misinformation. Future versions of iGLAS should include a question about whether participants have engaged with DCGT and in which capacity.
- **Personal experience of genomic medicine:** 'Genes & Tonic: Know Thy Father' identified the impact of having a diagnosis of a genetic condition oneself or in a close relative in the formation of opinions about genetic data sharing. Questions related to this should also be included in an updated version of iGLAS.
- **Emerging genetic technology – particularly Genome Wide Polygenic Scoring (GPS):** Chapter 4 identified that participants seem to have particularly low knowledge of emerging genetic technology (e.g. CRISPr). Genome-wide Polygenic Scoring (GPS) is likely to be increasingly used in all areas of genetics and it will be important to consider knowledge and opinions about this technology.

A working group of TAGC members will be presented with the above options so that additional items can be considered for inclusion in the next version of iGLAS. Proposed items have already been developed and are available from the author upon request.

iGLAS has also been adapted for use with children. Data from the pilot study of this measure will need to be analysed and this measure refined so that a suitable tool can be developed and implemented.

An adapted measure, the International Genetic, Legal and Ethical, Literacy and Attitudes Survey (iGLELAS) has been developed and is undergoing piloting. A similar measure is also being developed for use with teachers and educators.

Publications and Collaborations

Four papers are currently being prepared in the areas broadly covered in this thesis, with several of these specifically looking at legal aspects of genetic knowledge, opinions and data use.

There continue to be on-going international collaborations with research teams outside Goldsmiths. Further publications of results and promotion of iGLAS should foster exciting and productive new endeavours, which I look forward to working on.

Public Engagement

Finally, the findings reported in this thesis should enable the development of even more effective public engagement activities. The intention is to run several such programs in two streams. One accessible to the general public under the 'Genes & Tonic' brand, the other through training and engagement days with targeted professionals, particularly teachers and legal practitioners. Work is also underway on the development of a Massively Open On-line Course (MOOC) on genetics.

Conclusion

Members of the public surveyed in this thesis tended to have low levels of genetic knowledge. This was expected for several reasons. First, due to the innate complexity of genetic information (both in terms of the genetic code itself and the related fields of research). Second, due to the

way that genetics findings are sometimes conveyed in the media. Third because genetics is such a fast-paced science with information quickly becoming outdated. Fourth, unlike areas such as climate change, genetic research does not point to a unitary socially salient message. The fact that genetic research does not unambiguously lead to one (or a few) 'take home messages', and findings can be interpreted in a variety of ways depending on, for example, political and philosophical preferences, is also likely to be adding to confusion and differing opinions.

Some of the findings presented here suggest that people may have conceptual understanding, even in the absence of factual / technical knowledge. For example, most participants understood the concept of pleiotropy, but may have struggled to identify the term (although this was not tested). Similarly, participants tended to be accurate in estimating heritability, but there was no relationship between this accuracy and the ability to correctly identify the definition of heritability. These findings should help inform further evaluation of the relationship between factual and conceptual understanding in genetics for non-scientists.

Genetic knowledge was found to be associated with attitudes towards genetics in both abstract / philosophical terms (e.g. genetic determinism) and in real life applications such as the likelihood to engage with genomic medicine. However, the opinions people hold also seem to be formed by other factors including gender, experience with genetic conditions and susceptibility to beliefs in pseudoscience. The findings of this thesis indicate numerous other factors that might be relevant in understanding these differences of opinion and will be explored in future research. Those factors that have been identified in this thesis should prove invaluable in guiding such further research.

Genetic data is already forming an important part of medicine and healthcare, and its effects will increasingly be felt in other domains including law, privacy, psychology and education. Whilst opinions about genetics seem to be quite robust to relatively small interventions, more involved engagements seem to be effective. However, further research needs to be conducted to see just how involved such engagements need to be. The final manipulation presented in chapter 5 was a

10 week (20 hours) module in Behavioural Genetics, and it remains to be seen if a similar impact can be achieved by a shorter course (such as a day course). Several key insights have been identified that should help retain the efficacy of longer interventions in shorter courses. These include: providing a framework to think effectively about factors such as total and variable DNA; genetic relatedness within and between individuals and the implications of this; and the complexity of gene environment processes as being dynamic rather than static. With such insights, it should be possible to produce programmes and activities to help improve public knowledge about, and engagement with, genetics.

There is good reason to think that such endeavours should be well received. Participants seemed to enjoy engaging with questions and issues related to genetics, especially when there is an open discourse. Given this, it is thought especially important to encourage key stakeholders to get more involved with genetic research, discussions and debates. In particular, it is suggested that programs are targeted to teachers and trainee teachers as they should be instrumental in encouraging further engagement across society.

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Appendices

Appendix 1: The International Genetic Literacy and Attitudes Survey (iGLAS) MASTER Data Dictionary

iGLAS began development in late 2015 and has been used for data collection for over 3 years. It has progressed through 9 different versions and is currently on version 3. iGLAS is intended to be a flexible measure of public knowledge of and attitudes towards genetics. It is flexible and responsive to specific research questions and includes branching and skip logic to present additional items to specific participants (e.g. lawyers and law students).

This data dictionary covers all versions of iGLAS, from 1.1 through to 3. If you have any questions please contact the lead researcher, Robert Chapman at r.chapman@gold.ac.uk

The validation paper for iGLAS (Chapman et al., 2017) can be accessed at https://www.futureacademy.org.uk/files/images/upload/ICPE2017F6.pdf.

Where there is a correct response, as is the case with the Genetic Knowledge Section, the correct response is underlined. Variable values are shown in **bold**.

To find particular items please use CTRL F (cmd F on Mac) to search this document.

Demographic details

Variable name	Item/Question	Response/Answer	Comments	Versions									
StartDate	Start Date		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
EndDate	End Date		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
Status	Response type		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
IPAddress	IP Address		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
Progress	Progress		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
Duration__in_seconds_	Duration (in seconds)		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
Finished	Finished		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
RecordedDate	Recorded Date		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
ResponseId	Response ID		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
RecipientLastName	Recipient Last Name		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
RecipientFirstName	Recipient First Name		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
RecipientEmail	Recipient Email		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
ExternalReference	External Data Reference		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
LocationLatitude	Location Latitude		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
LocationLongitude	Location Longitude		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
DistributionChannel	Distribution Channel		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3

UserLanguage	User Language	**1** English **2** Russian **3** Romanian **4** French **5** Spanish		Qualtrics generated	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
Collection	Collection Wave	**1** iGLAS 1.1 **2** iGLAS 1.2 **3** iGLAS 1.3 **4** iGLAS 2.1 **5** iGLAS 2.2 **6** iGLAS 2.3 **7** iGLAS 2.4 **8** iGLAS 2.5 **9** iGLAS 2.6 **10** iGLAS 3		This data is not collected from participants but input when responses are compiled into the master database										
Sub_Collection	Sub collection	**1** iGLAS 2.3 for G&T Prize Draw **2** iGLAS 2.3: Group 1 (Fatos) **3** iGLAS 2.3: Group 3 (Fatos) **4** iGLAS 2.3: Group 4 (Fatos) **5** iGLAS 2.3: Prize draw for Genes & Tonic event **6** iGLAS 2.4: NIGERIAN **7** iGLAS 2.4 VLADIVOSTOK – Social Scientists **8** iGLAS 2.4 VLADIVOSTOK – Law (Group A) **9** iGLAS 2.4 VLADIVOSTOK – Law (Group B) **10** iGLAS 2.4 VLADIVOSTOK – Medical Students **11** iGLAS 2.5 NIGERIAN **12** iGLAS 2.6 ITALIAN		This data is not collected from participants but input when responses are compiled into the master database										
iEthics01	My participation in this study is voluntary				1.1	1.2	1.3	2.1						
iEthics02	I am over 18				1.1	1.2	1.3	2.1						
iEthics03	I may withdraw				1.1	1.2	1.3	2.1						
iEthics04	I may omit				1.1	1.2	1.3	2.1						
iEthics05	Data confidentiality				1.1	1.2	1.3	2.1						
iEthics06	Code for data removal				1.1	1.2	1.3	2.1	2.2					
iEthics07	I wish to have the option of withdrawing the information I								2.2					

	have provided the study on my request.												
iEthics_Combined	Collated ethics item		Participants are asked to accept the following statements: • My participation in this study is voluntary • I am over 18 • I may withdraw from this research at any time and for any reason • I may omit any questions I do not wish to answer • All data will be treated with full confidentiality and, if published, it will not be identifiable as mine.					2.2	2.3	2.4	2.5	2.6	3
iID	If you have been provided a unique identifier for this study, please type this in the box below:		This item has been included to facilitate collaborations with other researchers who might ask participants to provide an ID.										3
iDgender	Gender	**1** Male **2** Female **3** Non-binary **4** Prefer not to say		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDage	Age		Age range 18 to 100: iGLAS v1.1-v1.3 asked for year of birth. This was converted into an age score for the master data set.				2.1	2.2	2.3	2.4	2.5	2.6	3
iDyear	In what year were you born?		This score is interpreted into an age in the data set	1.1	1.2	1.3							
iDint01	I've studied genetics as a part of a school curriculum		These items are all presented as responses to the question. Please select any of the below that apply to you: Participants are able to select multiple responses		1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDint02	I've studied genetics as a part of my university degree				1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDint03	I have worked in the field of genetics				1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDint04	I have studied genetics myself (watched documentaries, attended short courses, read genetics books etc.)				1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDint05	I am currently studying genetics				1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDint06	I follow genetics topics on social media				1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3

iDint07	I have never studied genetics				1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDint08	I have no interest in the topic				1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDedu_level	What is your highest level of education, either achieved or that you are working towards?	**1** Pre-GCSE **2** GCSE **3** A-level **4** Undergraduate **5** Master's **6** Doctoral **7** Post-doctoral		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDstyn	Are you a current university student?	**1** Yes **2** No					2.1	2.2	2.3	2.4	2.5	2.6	3
iDst1	Chose the area that is most applicable to your study:	**1** Art and Design **2** Ancient History and Archaeology **3** Biology **4** Chemistry **5** Classics **6** Communication, Advertising and Marketing **7** Economics and Business Studies **8** Education **9** Electronics, Engineering, Computing and ICT **10** English **11** Environmental Sciences **12** Genetics **13** Geology **14** Geography **15** Government and Politics **16** Health and Social Care **17** History **18** Languages **19** Law **20** Mathematics **21** Media Studies **22** Medicine **23** Music **24** Performance and Theatrical Arts **25** Philosophy, Religion and Ethics **26** Physics **27** Psychology **28** Sociology **29** Sports and Exercise Science **30** Statistics and research methods **31** Travel and Tourism	Item only presented to participants who answered yes to being a student (iDstyn)				2.1	2.2	2.3	2.4	2.5	2.6	3

		32	Other											
iDst2	What year of your course are you currently in	**1** **2** **3** **4** **5** **6**	1 2 3 4 5 6+	Item only presented to participants who answered yes to being a student (iDstyn)						2.3	2.4	2.5	2.6	3
iDst3	Please provide the title of your degree programme, including award (e.g. BSc Psychology)			Item only presented to participants who answered yes to being a student (iDstyn) This is a free text item where participants can type in their degree programme				2.1	2.2	2.3	2.4	2.5	2.6	3
iDwork	If you are in full or part-time employment, please chose the sector that is most applicable to your profession: - Selected Choice	**1** **2** **3** **4** **5** **6** **7** **8** **9** **10** **11** **12** **13** **14** **15** **16** **17** **18** **19** **20**	Not Applicable Charity Sector Construction and maintenance Education Engineering, Computing and ICT Farming and agricultural Finance Government employee Housing and accommodation Law Management Medicine Retired Sales and office work Science and Research Other Academic (university lecturer) University student Unemployed Service sector					2.1	2.2	2.3	2.4	2.5	2.6	3
iDworkOTHER_text	If you are in full or part-time employment, please chose the sector that is most applicable to your profession: - Other - Text			Free text where participants can provide more information about their employment				2.1	2.2	2.3	2.4	2.5	2.6	3
iDwork01	Not Applicable				1.1	1.2	1.3							
iDwork02	Charity Sector				1.1	1.2	1.3							
iDwork03	Construction and maintenance				1.1	1.2	1.3							
iDwork04	Education				1.1	1.2	1.3							
iDwork05	Engineering, Computing and ICT				1.1	1.2	1.3							

iDwork06	Farming and agricultural			1.1	1.2	1.3							
iDwork07	Finance			1.1	1.2	1.3							
iDwork08	Government employee			1.1	1.2	1.3							
iDwork09	Housing and accommodation			1.1	1.2	1.3							
iDwork10	Legal practitioner			1.1	1.2	1.3							
iDwork11	Management			1.1	1.2	1.3							
iDwork12	Medical practitioner			1.1	1.2	1.3							
iDwork13	Retired			1.1	1.2	1.3							
iDwork14	Sales and office work			1.1	1.2	1.3							
iDwork15	Science and Research			1.1	1.2	1.3							
iDwork16	Other			1.1	1.2	1.3							
iDwork17	Academic (university lecturer)			1.1	1.2	1.3							
iDwork18	University student			1.1	1.2	1.3							
iDwork19	Unemployed			1.1	1.2	1.3							
iDwork20	Service sector			1.1	1.2	1.3							
iDwork_Title	What is your specific job role (e.g. teacher)			1.1	1.2	1.3							
iDlaw01	Lawyer		Item only presented to participants who indicate that they work in law (responding **10** to iDwork) Participants can select more than one response. I.e. barrister and lecturer				2.1	2.2	2.3	2.4	2.5	2.6	3
iDlaw02	Barrister						2.1	2.2	2.3	2.4	2.5	2.6	3
iDlaw03	Solicitor						2.1	2.2	2.3	2.4	2.5	2.6	3
iDlaw04	University lecturer /researcher						2.1	2.2	2.3	2.4	2.5	2.6	3
iDlaw05	Legal assistant						2.1	2.2	2.3	2.4	2.5	2.6	3
iDlaw06	Judge							2.2	2.3	2.4	2.5	2.6	3
iDlawDURATION	How many years have you been in this role? (Law)	**1** Less than 1 year **2** 1 to 4 years **3** 5 to 10 years **4** 11 to 20 years **5** 21 or more years	Item only presented to participants who indicate that they work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDmedAREA	Please select the most appropriate description of your role (medicine)	**1** Medical doctor **2** Nurse **3** Administration and reception **4** Health care management	Item only presented to participants who indicate that they work in medicine (responding **12** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDmedDURATION	How many years have you been in this role? (medicine)	**1** Less than 1 year **2** 1 to 4 years **3** 5 to 10 years **4** 11 to 20 years **5** 21 or more years	Item only presented to participants who indicate that they work in medicine (responding **12** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed01	Accident and Emergency		Item only presented to participants who indicate that they are medical doctors (responding **1** to iDmedAREA)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed02	Anaesthesia						2.1	2.2	2.3	2.4	2.5	2.6	3

iDmed03	Audiology		Participants can select more than one response. E.g.. Dermatology and Paediatrics				2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed04	Cardiovascular						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed05	Chornic pain						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed06	Dentistry						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed07	Dermatology						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed08	Endocrinology						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed09	Eye care						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed10	General Practice						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed11	Geriatric						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed12	Gynaecology						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed13	Maternity						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed14	Neonatal						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed15	Neurology						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed16	Oncology						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed17	Paediatrics						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed18	Plastic Surgery						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed19	Psychiatry and mental health						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed20	Renal						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed21	Respiratory medicine						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed22	Rheumatology						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed23	Trauma and orthopaedics						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed24	Urology						2.1	2.2	2.3	2.4	2.5	2.6	3
iDmed25	Other						2.1	2.2	2.3	2.4	2.5	2.6	3
IDmed25_text	Other Text						2.1	2.2	2.3	2.4	2.5	2.6	3
iDnurse	Please provide the area of your specialism: (Nurses)	**1** Adult **2** Child **3** Dentistry **4** District nursing **5** Mental health **6** Midwifery					2.1	2.2	2.3	2.4	2.5	2.6	3

		7 **8** **9**	Oncology Trauma Other											
iDnurse_text	Other text									2.3	2.4	2.5	2.6	3
iDeduAREA	Please select the area you work in: (education)	**1** **2** **3**	Primary school Secondary school University	Item only presented to participants who indicate that they work in education (responding **4** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDeduDURATION	How many years have you been in this role? (Education)	**1** **2** **3** **4** **5**	Less than 1 year 1 to 4 years 5 to 10 years 11 to 20 years 21 or more years	Item only presented to participants who indicate that they work in education (responding **4** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDeduSEN	Do you have any particular responsibility for students with special educational needs (e.g. dyslexia, autism)?	**1** **2**	Yes No	Item only presented to participants who indicate that they work in education (responding **4** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDedu01	Please select your role (primary)	**1** **2** **3** **4**	Teacher Head teacher Teaching assistant Office and admin	Item only presented to participants who indicate that they work in a primary school (responding **1** to iDeduAREA)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDedu02	Please select your role (secondary)	**1** **2** **3** **4**	Teacher Head teacher Teaching assistant Office and admin	Item only presented to participants who indicate that they work in a secondary school (responding **2** to iDeduAREA)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDedu03	Subject taught	**1** **2** **3** **4** **5** **6** **7** **8** **9** **10** **11** **12**	English Maths Science Languages History Geography Physical Education Art and Design Music ICT Drama Other	Item only presented to participants who indicate that they work in a secondary school (responding **2** to iDeduAREA)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDedu03_text	Subject taught Other Text			Item only presented to participants who indicate that they work in a secondary school (responding **2** to iDeduAREA) Free text option				2.1	2.2	2.3	2.4	2.5	2.6	3

iDhe01	Please select your role: academic/non-academic	**1** **2**	Academic Non-academic	Item only presented to participants who indicate that they work in a university (responding **3** to iDeduAREA)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDhe02	Subject area (academic)	**1** **2** **3** **4** **5** **6** **7** **8** **9** **10** **11** **12** **13** **14** **15** **16** **17** **18** **19** **20** **21** **22** **23** **24** **25** **26** **27** **28** **29** **30** **31** **32**	Art and Design Ancient History and Archaeology Biology Chemistry Classics Communication, Advertising and Marketing Economics and Business Studies Education Electronics, Engineering, Computing and ICT English Environmental Sciences Genetics Geology Geography Government and Politics Health and Social Care History Languages Law Mathematics Media Studies Medicine Music Performance and Theatrical Arts Philosophy, Religion and Ethics Physics Psychology Sociology Sports and Exercise Science Statistics and research methods Travel and Tourism Other	Item only presented to participants who indicate that they are an academic (responding **1** to iDhe01)				2.1	2.2	2.3	2.4	2.5	2.6	3
iDhe02_text	Other Text			Item only presented to participants who indicate that they are an academic (responding **1** to iDhe01) Free text option						2.3	2.4	2.5	2.6	3

iDhe03_text	What is your subject/research area?		Item only presented to participants who indicate that they are an academic (responding **1** to iDhe01) Free text option				2.1	2.2	2.3	2.4	2.5	2.6	3
iDkids01	How many children do you have	**0** 0 **1** 1 **2** 2 **3** 3+		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDkids02	Are any of your children under 16?	**1** Yes **2** No		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDcountry01	In which country did you receive your secondary education?		Please see Appendix one for list of country codes	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDcountry02	In which country do you currently live?		Please see Appendix one for list of country codes	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDCountry03	In which city do you now live?				1.2								
iDrp01	The next few questions are about religion and politics. Are you happy to answer these questions?	**1** Yes **2** No			1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDrp02	What is your religion? - Selected Choice	**1** Agnostic **2** Atheist **3** No religion **4** Christian **5** Buddhist **6** Hindu **7** Jewish **8** Muslim **9** Sikh **10** Other	Only presented if participants respond yes (**1**) to iDrp01	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDrp02_text	Other text		Only presented if participants respond yes (**1**) to iDrp01 Free text response to religion question	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDrp03	Please rate your religiosity on a scale from 0 to 10 - Religiosity	**Likert scale 0-10**	Only presented if participants respond yes (**1**) to iDrp01 In earlier versions (1.1-1.3), this item was presented on a 100-point scale. Later versions were 0-10. To convert all onto the same scale the following formula was applied to earlier versions:	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3

			(Score/10)										
iDrp04	What is your political orientation? 'Liberal' is intended to include the Left, progressives, and in some countries socialists. 'Conservative' is intended to include the Right, traditionalists etc. Please rate your political ideology on the following scale Economically	**Likert scale 1-7 (Liberal – Conservative)**	Only presented if participants respond yes (**1**) to iDrp01						2.3	2.4	2.5	2.6	3
iDrp05	What is your political orientation? 'Liberal' is intended to include the Left, progressives, and in some countries socialists. 'Conservative' is intended to include the Right, traditionalists etc. Please rate your political ideology on the following scale Socially	**Likert scale 1-7 (Liberal – Conservative)**	Only presented if participants respond yes (**1**) to iDrp01						2.3	2.4	2.5	2.6	3
iDrp06	Please rate your religiosity on a scale from 0 to 100- Religiosity	**100-point scale**		1.1	1.2	1.3							
iDrp07	Please rate your spirituality - Spirituality - 100 point scale	**100-point scale**	To bring this in-line with the religiosity scale, the following formula was applied to shift from 0-100 to 0-10: (Score/10)	1.1	1.2	1.3							
iDrp08	Here is a 10-point scale on which the political views that people might hold are arranged from extremely liberal (left) to extremely conservative (right). Where would you place yourself on this scale? - Political Ideology	**10-point scale**		1.1	1.2	1.3							

iDrp08.5	On the scale below, please rate how you identify politically, from extremely liberal (left) to extremely conservative (right).	**10-point scale**					2.1	2.2					
iDsm01	On average, how many hours do you spend on social media each day (excluding for work purposes)?	**0** 0 **1** 0-1 **2** 1-2 **3** 2-3 **4** 3-4 **5** 4+		1.1	1.2	1.3							
iDsm02	I worry that information shared on social media can be misused by other people and/or the service provider?	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3							
iDguidence01	How likely would you be to pursue one of the following: Counselling	**Likert scale 1-7** (very unlikely to very likely)	In earlier versions (1.1-1.3), this item was presented on a 100 point scale. Later versions were 1-7. To convert all onto the same scale the following formula was applied to earlier versions: (Score/100)*6+1	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDguidence02	How likely would you be to pursue one of the following: The advice of a psychic	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDguidence03	How likely would you be to pursue one of the following: Seek genetic testing through a private company	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDguidence04	How likely would you be to pursue one of the following: Attend a course in mindfulness and self-awareness	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDguidence05	How likely would you be to pursue one of the following: Seek religious guidance	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDguidence06	How likely would you be to pursue one of the following: Refer to self-help literature	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDguidence07	How important is self improvement to you?	**Likert scale 1-7**(not at all to extremely important)		1.1	1.2	1.3							
iDtesting01	If there were no history of debilitating disease in your family	**Scale 1-7** (very unlikely to very likely)	In earlier versions, this item was presented on a 100 point scale. Later versions were 1-7. To convert all onto the same scale the following formula was applied to earlier versions:	1.1	1.2	1.3	2.1	2.2	2.3				
iDtesting02	If there was a moderate history of debilitating disease in your family	**Scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3				

iDtesting03	If there was a definite and clear history of debilitating disease in your family	**Scale 1-7** (very unlikely to very likely)	(Score/100)*6+1	1.1	1.2	1.3	2.1	2.2	2.3				
iDconcern01	I don't know who will have access to that information?		These items are presented in response to the question: In deciding whether to take a genetic test, which of the considerations below apply to you? Participants are able to select multiple responses	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern02	I don't know whether the data will be stored securely?			1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern03	I would rather not know of any potential debilitating diseases in my future			1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern04	I'm not interested			1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern05	I'm worried that I might find out something I would rather not know about myself			1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern06	I would not want to be labeled as having any deficiency			1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern07	I'm worried some information about my physical or mental health could be used against me (e.g. employment; legal matters; obtaining insurance)			1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern08	I am concerned my data will be used for other purposes without my knowledge						2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern09	Other			1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcern09_text	Other Text		Text response to the question: In deciding whether to take a genetic test, which of the considerations below apply to you?	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDgkConfidence	How confident are you in your genetic knowledge	Likert scale from 0 to 100		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3

Genetic Knowledge items

Variable name	Item/Question	Response/Answer	Comments	Versions									
iH2_height	Heritability of Height	**0-100**	Participants are asked "On a scale of 0-100 how important are genetic differences between people in explaining individual differences in the following traits"	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_weight	Heritability of Weight	**0-100**		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_IQ	Heritability of IQ	**0-100**		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_eye	Heritability of Eye colour	**0-100**		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_SlQuality	Heritability of sleep quality	**0-100**								2.4	2.5	2.6	

iH2_ClinDep	Heritability of Clinical depression	**0-100**		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_Motivation	Heritability of Motivation	**0-100**		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_Achievement	Heritability of School Achievement	**0-100**		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_SexualO	Heritability of Sexual Orientation	**0-100**		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iH2_Insomnia	Heritability of Insomnia	**0-100**								2.4	2.5	2.6	
iH2_ADHD	Heritability of ADHD	**0-100**								2.4	2.5	2.6	3
iH2_dyslexia	Heritability of Dyslexia	**0-100**								2.4	2.5	2.6	3
iH2_Schiz	Heritability of Schizophrenia	**0-100**								2.4	2.5	2.6	3
iH2_slLength	Heritability of Sleep length	**0-100**								2.4	2.5	2.6	
iGK01	What is a genome?	**1** **2** **3** **4**	A sex chromosome <u>The entire sequence of an individual's DNA</u> All the genes in DNA Gene expression	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK02	Which of the following 4 letter groups represent the base units of DNA?	**1** **2** **3** **4**	GHPO HTPR <u>GCTA</u> LFWE	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK03	How many copies of each gene do we have in each autosome cell?	**1** **2** **3** **4**	1 copy <u>2 copies</u> 23 copies 5 copies						2.3	2.4	2.5	2.6	3
iGK03.5	How many copies of each gene do we have in each cell?	**1** **2** **3** **4**	1 copy <u>2 copies</u> 23 copies 5 copies	1.1	1.2	1.3	2.1	2.2					
iGK04	People differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?	**1** **2** **3** **4**	75% <u>50%</u> .01% 99.9%						2.3	2.4	2.5	2.6	3
iGK04.5	On average, how much of the variable DNA is the same in siblings?	**1** **2** **3** **4**	75% <u>50%</u> .01% 99.9%	1.1	1.2	1.3							

iGK04.5.5	All human's differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?	**1** **2** **3** **4**	75% <u>50%</u> .01% 99.9%					2.1	2.2						
iGK05	What is the main function of all genes?	**1** **2** **3** **4**	<u>Storing information for protein synthesis</u> To provide energy to the cell To clear out waste from the cell To repair damage to a cell		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK06	On average, how much of their total DNA is the same in two people selected at random	**1** **2** **3** **4**	Less 50% 75% 90% <u>More than 99%</u>		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK07	Genetic contribution to the risk for developing Schizophrenia comes from:	**1** **2**	One gene <u>Many genes</u>		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK08	In humans, DNA is packaged into how many pairs of chromosomes?	**1** **2** **3** **4**	<u>23 pairs</u> 48 pairs 10 pairs 27 pairs		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK09	An Epigenetic change is:	**1** **2** itself **3** beings DNA **4**	<u>A change in gene expression</u> A change of the genetic code A process by which human can consciously change their Gene splicing		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK10	Approximately how many genes does the human DNA code contain?	**1** **2** **3** **4**	2,000 1 million 3 billion <u>20,000</u>		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK11	Genetic contribution to the risk for developing Autism comes from:	**1** **2**	One gene <u>Many genes</u>		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK12	What are polymorphisms?	**1** **2** **3** **4**	Building blocks of the DNA Proteins found in the brain <u>Points of genetic variation</u> Deoxyribonucleic Acid		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK13	The DNA sequence in two different cells, for example a neuron and a heart cell, of one person, is:	**1** **2** **3** **4**	Entirely different About 50% the same More than 90% the same <u>100% identical</u>							2.3	2.4	2.5	2.6	3

iGK13.5	The DNA sequence in two different cells, for example a neuron and a liver cell, of one person, is:	**1** **2** **3** **4**	Entirely different About 50% the same More than 90% the same 100% identical		1.1	1.2	1.3	2.1	2.2					
iGK14	Non-coding DNA describes DNA that:	**1** **2** **3** **4**	Is removed when passed from parent to offspring Does not lead to the production of proteins Is non-human DNA (3) Is not composed of nucleotides (4)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK15	Can dog breeding be considered a form of gene engineering?	**1** **2**	Yes No							2.3	2.4	2.5	2.6	3
iGK16	Which of the mentioned below is a method for gene editing:	**1** **2** **3** **4**	ERP CRISPR CERN PCR							2.3	2.4	2.5	2.6	3
iGK17	Can we fully predict a person's behaviour from examining their DNA sequence?	**1** **2**	Yes No		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK18	At present in many countries, new born infants are tested for certain genetic traits.	**1** **2**	True False		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK19	Some of the genes that relate to dyslexia also relate to ADHD:	**1** **2**	True False								2.4	2.5	2.6	3
iGK20	If a report states that 'insomnia is approximately 30% heritable' what would that mean?	**1** **2** **3** **4**	If someone has insomnia this is approximately 30% due to their genes Approximately 30% of people will experience insomnia at some point in their lives Genetic influences account for approximately 30% of the differences between people in insomnia There is an approximately 30% chance that someone will pass insomnia onto their children									2.5	2.6	3
iGK21	What is variable DNA	**1** **2**	DNA that can differ amongst people Junk DNA		1.1	1.2	1.3							

		3 course **4**	DNA that can change in the of a person's life Gene therapy											
iGK22	Genetic Modification is:	**1** **2** **3** **4**	Selective breeding Genetic engineering Both of the above Neither of the above		1.1	1.2	1.3	2.1	2.2					

Opinion items

Variable name	Item/Question	Response/Answer	Comments	Version									
iOp01	I believe that my destiny is written in my genes	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iOp02	Would you take a genetic test if it allowed you to have improved treatment?	**Likert scale 1-7** (very unlikely to very likely)								2.4	2.5	2.6	3
iOp02.5	If genetic testing allowed you to have improved treatment (for example, medication with fewer side effects) how likely would you be to take that test?	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3				
iOp03	I do not trust institutions in my country because they might misuse data obtained from participants	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iOp04	Consuming genetically modified (GMO) food is perfectly safe	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iOp05	When feeling unwell (e.g. common cold) how likely are you to turn to alternative medicine?	**Likert scale 1-7** (strongly disagree to strongly agree)							2.3	2.4	2.5	2.6	3
iOp06	If diagnosed with a severe conditions such as cancer how likely are you to turn to alternative medicine?	**Likert scale 1-7** (strongly disagree to strongly agree)							2.3	2.4	2.5	2.6	3
iOp07	Genetic information should be used to adapt environments to people's needs, for example through individualised health advise	**Likert scale 1-7** (strongly disagree to strongly agree)					2.1	2.2	2.3	2.4	2.5	2.6	3

iOp07.5	We should use genetic research to learn how best to adapt environments to people's needs, for example through individualized health advice	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3							
iOp08	I believe that genetic manipulation, such as gene editing, should be allowed for the prevention and treatment of disease	**Likert scale 1-7** (strongly disagree to strongly agree)					2.1	2.2	2.3	2.4	2.5	2.6	3
iOp09	I believe that parents should be allowed to opt for gene editing in order to improve/select specific traits in their children	**Likert scale 1-7** (strongly disagree to strongly agree)					2.1	2.2	2.3	2.4	2.5	2.6	3
iOp10	I feel suspicious about genetic studies; hidden political/economic agendas may be behind them	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iOp11	Scientific development is essential for improving people's lives	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iOp12	Genetic influences on our behaviour mean that there is no free will	**Likert scale 1-7** (strongly disagree to strongly agree)					2.1	2.2	2.3	2.4	2.5	2.6	3
iOP12.5	If genes influence our behaviour then there is no free will:	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3							
iOp13	Would you be willing to give a sample of your DNA for scientific research if your data are stored anonymously?	**Likert scale 1-7** (very unlikely to very likely)							2.3	2.4	2.5	2.6	3
iOP13.5	How likely would you be to give a sample of your DNA for scientific research if your data are stored anonymously?	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2					
iOp14	In the same way as there is socio-economic disadvantage, there is genetic disadvantage	**Likert scale 1-7** (strongly disagree to strongly agree)	From version 2.4 onwards this item was only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3

iOp15	We should make provisions (legal and policy) to buffer the effects of genetic disadvantage on individuals (e.g. tailored education)	**Likert scale 1-7** (strongly disagree to strongly agree)	From version 2.4 onwards item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOP16	Breaches of genetic data should be made a criminal offence (2.1)	**Likert scale 1-7** (strongly disagree to strongly agree)	For versions 2.3 this item was shown to all participants. Other than this it was only presented to participants who indicated that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1		2.3	2.4	2.5	2.6	3
iOp17	Current laws in your country are sufficient to protect individuals from misuses of genetic data by: - Insurance companies	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOp18	Current laws in your country are sufficient to protect individuals from misuses of genetic data by: - Employers (e.g., for hiring or firing purposes)	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOp19	Current laws in your country are sufficient to protect individuals from misuses of genetic data by: - Selective/private schools (e.g., for admission)	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOp20	If we find that people with certain genetic mutations have a propensity for violence, the state should use this information for prevention of crime:	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOp21	Insurance companies should be allowed to request genetic data prior to issuing health and/or life insurance.	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOp22	Employers should be allowed to use genetic data for hiring:	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3

iOp23	Schools should be allowed to use children's genetic data to create individualized educational programmes for them:	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOp24General	From a DNA sample taken at birth we already can predict, with a degree of probability, future behaviour (such as school performance). The precision of prediction is continuously increasing. Moreover, sequencing is already routinely conducted for medical research and other purposes. When should relevant laws (e.g. data protection, privacy, discrimination, insurance, employment) be updated/introduced accordingly?	**1** Now (asap) **2** After some cases in the areas have been brought to courts **3** After we are certain of the scale of the risk **4** No need to do so as the current laws are sufficient	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1		2.3	2.4	2.5	2.6	3
iOP24_1	Data protection: From a DNA sample taken at birth we already can predict, with a degree of probability, future behaviour, such as school performance. The precision of prediction is continuously increasing. Moreover, sequencing is already routinely conducted for medical research and other purposes. When should the following laws be updated accordingly?: - Data protection and privacy laws	**1** Now (asap) **2** After some cases in these areas have been brought to courts **3** After we are certain of the scale of the risk **4** No need to do so as the current laws are sufficient	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2					

iOP24_2	Discrimination: From a DNA sample taken at birth we already can predict, with a degree of probability, future behaviour, such as school performance. The precision of prediction is continuously increasing. Moreover, sequencing is already routinely conducted for medical research and other purposes. When should the following laws be updated accordingly?: - Discrimination laws (e.g. education, health benefits, race)	**1** **2** **3** of **4**	Now (asap) After some cases in these areas have been brought to courts After we are certain of the scale the risk No need to do so as the current laws are sufficient	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2					
iOp24_3	Insurance Laws: From a DNA sample taken at birth we already can predict, with a degree of probability, future behaviour, such as school performance. The precision of prediction is continuously increasing. Moreover, sequencing is already routinely conducted for medical research and other purposes. When should the following laws be updated accordingly?: - Insurance laws	**1** **2** **3** of **4**	Now (asap) After some cases in these areas have been brought to courts After we are certain of the scale the risk No need to do so as the current laws are sufficient	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2					
iOP24_4	Employment Laws: From a DNA sample taken at birth we already can predict, with a degree of probability, future behaviour, such as school performance. The precision of prediction is continuously increasing. Moreover, sequencing is already routinely conducted for medical research and other purposes. When should the following laws be updated accordingly?: - Employment laws	**1** **2** **3** of **4**	Now (asap) After some cases in these areas have been brought to courts After we are certain of the scale the risk No need to do so as the current laws are sufficient	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2					

iOp25	Genetic findings rely on data from large numbers of people. If companies are allowed to patent findings, then related treatments may become very expensive. Do you agree that companies should be allowed to patent genetic findings?	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOP25.5	Genetic findings rely on data from large numbers of people. Once findings are patented, the benefits from the findings can become unaffordable for most. Should patenting of genetic findings be allowed?	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1						
iOp26	If people have access to their genetic data, whereas health insurers do not, these insurers are likely to be disadvantaged (e.g. pay-outs surpassing collected premiums). Insurers should be allowed access to genetic data of those applying for insurance.	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOp27	In the genomic era (we now live in), governments should provide health insurance to people: - Without consideration of medical records or genetic data	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOp28	In the genomic era (we now live in), governments should provide health insurance to people: - Considering medical records, but not genetic data	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOp29	In the genomic era (we now live in), governments should provide health insurance to people: - Considering age only	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOp30	In the genomic era (we now live in), governments should provide health insurance to people: - Equally, not	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3

	considering age, genetic data, medical records or lifestyle												
iOp31	As genetic science has been progressing very fast, laws and policy must be updated as soon as possible to protect individuals' rights.	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1		2.3	2.4	2.5	2.6	3
iOp32	Considering the highly sensitive and permanent nature of genetic data as well as the increasing availability of whole genome sequencing, those who commit genetic data breaches should face criminal punishment:	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2	2.3	2.4	2.5	2.6	3
iOp33	According to the latest genetic findings, human behaviours are a product of multiple gene-environment processes, often beyond an individual's control. - This information should be taken into account in deciding the form of sentencing (e.g. compulsory therapy or education, community service, prison sentence)	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOp34	According to the latest genetic findings, human behaviours are a product of multiple gene-environment processes, often beyond an individual's control. - This information should be taken into account in deciding the length of punishment	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOp35	Information about gene-environment processes should be included in judges' training:	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3

iOp36	Findings show that within any population there is a very large variability among people, including in terms of ability, personality and level of education. To provide justice for all, the legal system should accommodate this variability, including in terms of procedure and resources. For example, providing accessible jargon free information and making court proceedings people friendly.	**Likert scale 1-7** (strongly disagree to strongly agree)	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)					2.2	2.3	2.4	2.5	2.6	3
iOp37	Pharmacological		Participants are asked to respond to the question "When treating rare disorders which are entirely caused by genetic influences, which of the following treatments are likely to be used (tick as many as you think appropriate)" Participants may give multiple responses							2.4	2.5	2.6	3
iOp38	Talking therapies									2.4	2.5	2.6	3
iOp39	Life style changes									2.4	2.5	2.6	3
iOp40	Surgery									2.4	2.5	2.6	3
iOp41	Genetic Engineering									2.4	2.5	2.6	3
iOp42	Understanding how certain genes influence academic achievement is important for understanding how to best tailor education to individuals.	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3				
iOp43	Understanding how certain environments influence academic achievement is important for understanding how to best tailor education to individuals	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3				
iOp44	Second language learning should be mandatory throughout compulsory education	**Likert scale 1-7** (strongly disagree to strongly agree)	This control item was included to counter Common Method Variance, but did not perform to task and so was removed	1.1	1.2	1.3							
iOp45	When you are ill, how likely are you to turn to alternative medicine (such as homeopathy) rather than seeking treatment from conventional medicine?	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2					
iOp46	Studies showing genetic influences on mental health	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3	2.1	2.2	2.3				

	problems (depression, schizophrenia, bi-polar disorder etc.) lead to increased stigma for people with those conditions:													
iOp47	I believe that, if it is possible to manipulate DNA to improve health and happiness, it should done	**Likert scale 1-7** (strongly disagree to strongly agree)		1.1	1.2	1.3								
iOp48	Schools should be allowed to use genetic data for admissions.	**Likert scale 1-7** (strongly disagree to strongly agree)					2.1	2.2						

Vignettes

Variable name	Item/Question	Response/Answer	Comments	Version									
iV01	Bill was adopted at birth, both his biological parents have served jail time for violent crimes, as did his paternal grandfather. His adopted parents have no such convictions. How likely do you think it is that Bill will also have a tendency towards violence?	**Likert scale 1-7** (very unlikely to very likely)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iV02	Sarah has a particular genetic variant that has been associated with aggression. She is in court being tried for a violent crime. Should knowing about this genetic variation:	**1** Reduce her sentence		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
		2 Not be taken into consideration		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
		3 Increase her sentence		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
		4 Be considered to determine the type of sentence (e.g. mandatory labour, psychological therapy)						2.2	2.3	2.4	2.5	2.6	3
		5 Be considered but make no difference to her sentence		1.1	1.2	1.3	2.1	2.2					
iV03.1	Pharmacological	**Likert scale 1-5** (Not effective at all to Extremely effective)	Robert is suffering from insomnia. He thinks it is probably because his job is so stressful and he has a lot else going on in his life. Robert is keen to seek help for his disturbed sleep. Estimate how effective you think the following treatments might be (from not at all effective, to very effective).								2.5	2.6	3
iV03.2	Talking therapies										2.5	2.6	3
iV03.3	Therapy										2.5	2.6	3
iV03.4	change in lifestyle										2.5	2.6	3
iV04.1	Peter (genetic explanation): Pharmacological	**Likert scale 1-5** (Not effective at all to Extremely effective)	Peter is suffering from insomnia. He thinks it is probably because of his genes								2.5	2.6	3

iV04.2	Peter (genetic explanation): Talking Therapies			– after all multiple family members suffer terribly with sleep too. Peter is keen to seek help for his disturbed sleep. Estimate how effective you think the following treatments might be (from not at all effective, to very effective).								2.5	2.6	3
iV04.3	Peter (genetic explanation): Gene Therapy											2.5	2.6	3
iV04.4	Peter (genetic explanation): A change in lifestyle											2.5	2.6	3
iV05	It is now 2020. Using genetic data for insurance is prohibited. Mary's genome shows that she has a propensity for a particular type of cancer. She has received very high health insurance quotes, which she could not afford. It is admitted that due to earlier data breaches by the national health service, Mary's genetic data had fallen into the possession of insurance companies, but denied that this data have been used for the quote. Mary is now ill and facing very high medical bills. Based on this scenario:	**1** Mary, **2** **3** **4**	The NHS should compensate because data were in their possession. The Government should compensate Mary for not having updated the relevant laws to regulate use of information obtained from genetic data. The insurance company should compensate Mary even though their claim is that the data were available online. No one is responsible.	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)						2.3	2.4	2.5	2.6	3
iV05.5	It is now 2020. Mary's genome shows that Mary has a propensity for a particular type of cancer. Due to earlier data breaches by the national health service, Mary's genetic data had fallen into the possession of insurance companies, from untraceable sources. Mary had applied for health insurance, and had received very high quotes (her genetic propensity not given as a reason), which she could not afford. Mary is now ill and facing very high medical bills. Based on this scenario:	**1** Mary, **2** research **3** their available 4 the	The NHS should compensate because data were in their possession. The Government should compensate Mary for not having updated the laws when it became apparent that genetic sequencing was becoming a routine for and other purposes. The insurance company should compensate Mary even though claim is that the data were online. No one is responsible, because Mary should have opted out of research programme.	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)				2.1	2.2					

iV06	It is 2020. It has now become possible to predict, with significant precision, an individual's performance from DNA alone. The laws were recently updated, making genetic data breaches a criminal offence, and hiring on genetic data is not allowed. Employers are headhunting based on genetic data, that were available due to NHS data breaches before laws were updated. Employers admit that the had access to the data, but deny that they use them. People have an action against:	**1** Employers **2** The Government for not updating the laws in time to prevent genetic data breaches **3** No-one **4** The NHS, even though the breaches occurred before laws were updated	Item only presented to participants who indicate that they either study law (responding **19** to item iDst1) or work in law (responding **10** to iDwork)						2.3	2.4	2.5	2.6	3
iV06.5	It is 2020. It has now become possible to predict (with a much greater degree of certainty) an individual's performance from DNA alone. The laws are now updated, making genetic data breaches a criminal offence. However, numerous genetic data breaches had occurred before laws were updated. Employers, who got hold of the data through unknown sources (due to previous breaches), without declaring the basis of the selection, started headhunting people whose genetic codes showed that they would be better performers. People have an action against:	**1** The employers **2** The Government for not updating in time the laws to prevent genetic data breaches **3** No-one, as it is the right of employers to choose the most suitable people for the job **4** No one, because hiring on genetic data produces similar outcome to hiring on test results and curriculum vitae (CV), and is a more efficient way.					2.1	2.2					

Neuromyths

Variable name	Item/Question	Response/Answer	Comments	Versions									
iNm01	We only use 10% of our brain	**1** Correct **2** Don't know **3** Incorrect							2.3	2.4	2.5	2.6	3
iNm02	Individuals learn better when they receive information in their preferred learning style (for example, visual, auditory or kinaesthetic)	**1** Correct **2** Don't know **3** Incorrect							2.3	2.4	2.5	2.6	3
iNm03	Short bouts of co-ordination exercises can improve integration of left and right hemispheric brain function	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm04	Children are less attentive after sugary drinks and snacks	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm05	Differences in hemispheric dominance (left brain or right brain) can help to explain individual differences amongst learners	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm06	Drinking less than 6 to 8 glasses of water a day can cause the brain to shrink	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm07	Learning problems associated with development in brain function cannot be remediated by education	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm08	We have an evolutionary old part of the brain that is responsible for emotions and subconscious decision making	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm09	New nerve cells form throughout life	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm10	Glutamate in food is dangerous for your brain	**1** Correct **2** Don't know **3** Incorrect							2.3				
iNm11	The left brain hemisphere is responsible for logical reasoning, while the right hemisphere is responsible for creativity	**1** Correct **2** Don't know **3** Incorrect							2.3				

iNm12	A bigger brain size is linked with higher IQ	**1** **2** **3**	Correct Don't know Incorrect							2.3					
iNm13	Fine motor skills development in early childhood predicts the level of cognitive abilities in adulthood	**1** **2** **3**	Correct Don't know Incorrect							2.3					
iNm14	Playing chess makes you smarter	**1** **2** **3**	Correct Don't know Incorrect							2.3					

Personality Measures

Variable name	Item/Question	Response/Answer	Comments	Versions									
i5reserved	How well do the following statements describe your personality? - I see myself as someone who is reserved	**5-point Likert Scale** (Disagree strongly – agree strongly)	Extraversion: To be reverse coded	1.1	1.2	1.3							
i5trusted	How well do the following statements describe your personality? - I see myself as someone who is generally trusted	**5-point Likert Scale** (Disagree strongly – agree strongly)	Agreeableness:	1.1	1.2	1.3							
i5lazy	How well do the following statements describe your personality? - I see myself as someone who tends to be lazy	**5-point Likert Scale** (Disagree strongly – agree strongly)	Conscientiousness: To be reverse coded	1.1	1.2	1.3							
i5stress	How well do the following statements describe your personality? - I see myself as someone who is relaxed, handles stress well	**5-point Likert Scale** (Disagree strongly – agree strongly)	Neuroticism: To be reverse coded	1.1	1.2	1.3							
i5artistic	How well do the following statements describe your personality? - I see myself as someone who has few artistic interests	**5-point Likert Scale** (Disagree strongly – agree strongly)	Openness: To be reverse coded	1.1	1.2	1.3							
i5outgoing	How well do the following statements describe your personality? - I see myself as someone who is outgoing, sociable	**5-point Likert Scale** (Disagree strongly – agree strongly)	Extraversion:	1.1	1.2	1.3							
i5fault	How well do the following statements describe your personality? - I see myself as someone who tends to find fault with others	**5-point Likert Scale** (Disagree strongly – agree strongly)	Agreeableness: To be reverse coded	1.1	1.2	1.3							
i5thorough	How well do the following statements describe your personality? - I see myself as someone who does a thorough job	**5-point Likert Scale** (Disagree strongly – agree strongly)	Conscientiousness:	1.1	1.2	1.3							
i5nervous	How well do the following statements describe your personality? - I see myself as someone who gets nervous easily	**5-point Likert Scale** (Disagree strongly – agree strongly)	Neuroticism:	1.1	1.2	1.3							
i5imgaination	How well do the following statements describe your personality? - I see myself as someone who has an active imagination	**5-point Likert Scale** (Disagree strongly – agree strongly)	Openness:	1.1	1.2	1.3							
i5reserved_R	Reverse coding Reserved		Generated in SPSS once master data set compiled										
i5lazy_R	Reverse coding of Lazy												
i5stress_R	Reverse coding of Stress												

i5artistic_R	Reverse coding of Artistic													
i5fault_R	Reverse coding of Fault													
i5Extraversion	Average: i5reserved_R + i5outgoing		Generated in SPSS once master data set compiled											
i5Agreeableness	Average: i5trusted + i5fault_R													
i5Conscientiousness	Average: i5lazy_R + i5thorough													
i5Neuroticism	Average: i5stress_R + i5nervous													
i5Openness	Average: i5artistic_R + i5imgaination													

Genetic scoring and free text

To generate iGKtotalAVE and iGKtotalALL each Genetic knowledge question was scored as either correct or incorrect, with the suffix TF added to the end of the item. E.g. iGK01 becomes iGK01TF etc.

Variable name	Item/Question	Response/Answer	Comments
iFree	Please use this section if you would like to make any general comments		Participants are able to provide any additional information in this section
iGKtotalRAW	Sum of GK score		This is the total score as calculated by Qualtrics based on the score coding of the 20 True/False multiple-choice Genetic Knowledge Items
iGKtotalAVE	Average GK score = total score/number of items presented		This is the averaged GK score across different versions of iGLAS taking into account the varying number of genetic knowledge questions asked in different versions
iGKtotalALL	Sum of GK scores for only those items presented at all waves of collection		Sum of correct responses for: iGK01, iGK02, iGK05, iGK06, iGK07, iGK08, iGK09, iGK10, iGK11, iGK12, iGK14, iGK17, iGK18

Scores generated post-collection

Variable name	Item/Question	Response/Answer		Comments	Versions									
iGK01TF	What is a genome?	**0** **1** **0** **0**	A sex chromosome The entire sequence of an individual's DNA All the genes in DNA Gene expression		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK02TF	Which of the following 4 letter groups represent the base units of DNA?	0 **0** **1** **0**	GHPO HTPR GCTA LFWE		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK03TF	How many copies of each gene do we have in each autosome cell?	**0** **1** **0** **0**	1 copy 2 copies 23 copies 5 copies							2.3	2.4	2.5	2.6	3

iGK03.5TF	How many copies of each gene do we have in each cell?	**0** **1** **0** **0**	1 copy 2 copies 23 copies 5 copies		1.1	1.2	1.3	2.1	2.2					
iGK04TF	People differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?	**0** **1** **0** **0**	75% 50% .01% 99.9%							2.3	2.4	2.5	2.6	3
iGK04.5TF	On average, how much of the variable DNA is the same in siblings?	**0** **1** **0** **0**	75% 50% .01% 99.9%		1.1	1.2	1.3							
iGK04.5.5TF	All human's differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?	**0** **1** **0** **0**	75% 50% .01% 99.9%					2.1	2.2					
iGK05TF	What is the main function of all genes?	**1** **0** **0** **0**	Storing information for protein synthesis To provide energy to the cell To clear out waste from the cell To repair damage to a cell		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK06TF	On average, how much of their total DNA is the same in two people selected at random	**0** **0** **0** **1**	Less 50% 75% 90% More than 99%		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK07TF	Genetic contribution to the risk for developing Schizophrenia comes from:	**0** **1**	One gene Many genes		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK08TF	In humans, DNA is packaged into how many pairs of chromosomes?	**1** **0** **0** **0**	23 pairs 48 pairs 10 pairs 27 pairs		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK09TF	An Epigenetic change is:	**1** **0** itself **0** beings DNA **0**	A change in gene expression A change of the genetic code A process by which human can consciously change their Gene splicing		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK10TF	Approximately how many genes does the human DNA code contain?	**0** **0** **0**	2,000 1 million 3 billion		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3

		1	20,000											
iGK11TF	Genetic contribution to the risk for developing Autism comes from:	**0** **1**	One gene Many genes		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK12TF	What are polymorphisms?	**0** **0** **1** **0**	Building blocks of the DNA Proteins found in the brain Points of genetic variation Deoxyribonucleic Acid		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK13TF	The DNA sequence in two different cells, for example a neuron and a heart cell, of one person, is:	**0** **0** **0** **1**	Entirely different About 50% the same More than 90% the same 100% identical							2.3	2.4	2.5	2.6	3
iGK13.5TF	The DNA sequence in two different cells, for example a neuron and a liver cell, of one person, is:	**0** **0** **0** **1**	Entirely different About 50% the same More than 90% the same 100% identical		1.1	1.2	1.3	2.1	2.2					
iGK14TF	Non-coding DNA describes DNA that:	**0** **1** **0** **0**	Is removed when passed from parent to offspring Does not lead to the production of proteins Is non-human DNA (3) Is not composed of nucleotides (4)		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK15TF	Can dog breeding be considered a form of gene engineering?	**1** **0**	Yes No							2.3	2.4	2.5	2.6	3
iGK16TF	Which of the mentioned below is a method for gene editing:	**0** **1** **0** **0**	ERP CRISPR CERN PCR							2.3	2.4	2.5	2.6	3
iGK17TF	Can we fully predict a person's behaviour from examining their DNA sequence?	**0** **1**	Yes No	"fully was added during wave…"	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK18TF	At present in many countries, new born infants are tested for certain genetic traits.	**1** **0**	True False		1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iGK19TF	Some of the genes that relate to dyslexia also relate to ADHD:	**1** **0**	True False								2.4	2.5	2.6	3
iGK20TF	If a report states that 'insomnia is approximately 30% heritable' what would that mean?	**0**	If someone has insomnia this is approximately 30% due to their genes									2.5	2.6	3

		0 point **1** **0**	Approximately 30% of people will experience insomnia at some in their lives Genetic influences account for approximately 30% of the differences between people in insomnia There is an approximately 30% chance that someone will pass insomnia onto their children											
iGK21TF	What is variable DNA	**1** people **0** **0** course **0**	DNA that can differ amongst Junk DNA DNA that can change in the of a person's life Gene therapy		1.1	1.2	1.3							
iGK22TF	Genetic Modification is:	**0** **0** **1** **0**	Selective breeding Genetic engineering Both of the above Neither of the above		1.1	1.2	1.3	2.1	2.2					
i5reserved_R	REVERSED personality item - reserved	**5-point Likert Scale** (Disagree strongly – agree strongly)			1.1	1.2	1.3							
i5fault_R	REVERSED personality item - fault	**5-point Likert Scale** (Disagree strongly – agree strongly)			1.1	1.2	1.3							
i5lazy_R	REVERSED personality item - lazy	**5-point Likert Scale** (Disagree strongly – agree strongly)			1.1	1.2	1.3							
i5stress_R	REVERSED personality item - stress	**5-point Likert Scale** (Disagree strongly – agree strongly)			1.1	1.2	1.3							
i5artistic_R	REVERSED personality item - artistic	**5-point Likert Scale** (Disagree strongly – agree strongly)			1.1	1.2	1.3							
iDconcernTOT	Sum of all iDconcern items, excluding iDconcern04 as this item states “not interested” and so is not a concern. The item iDconcern08 was also not included as this is the “other” item.			An additional iDConcern item was added from iGLAS 2.1 onwards. Therefore, the total for iGLAS 1.1, 1.2 and 1.3 is out of 6. All versions since iGLAS 2.1 are out of 7.	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3
iDconcernAVE	iDconcernTOT/total number of concern items. I.e. 6 in all versions of iGLAS 1 and 7 in all versions of iGLAS 2.				1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	2.6	3

Country codes

Country List									
Code	Country	Code	Country	Code	Country	Code	Country	Code	Country
1	Afghanistan	40	Costa Rica	79	Indonesia	118	Myanmar	157	Slovenia
2	Albania	41	Côte d'Ivoire	80	Iran, Islamic Republic of...	119	Namibia	158	Solomon Islands
3	Algeria	42	Croatia	81	Iraq	120	Nauru	159	Somalia
4	Andorra	43	Cuba	82	Ireland	121	Nepal	160	South Africa
5	Angola	44	Cyprus	83	Israel	122	Netherlands	161	Spain
6	Antigua and Barbuda	45	Czech Republic	84	Italy	123	New Zealand	162	Sri Lanka
7	Argentina	46	Democratic People's Republic of Korea	85	Jamaica	124	Nicaragua	163	Sudan
8	Armenia	47	Democratic Republic of the Congo	86	Japan	125	Niger	164	Suriname
9	Australia	48	Denmark	87	Jordan	126	Nigeria	165	Swaziland
10	Austria	49	Djibouti	88	Kazakhstan	127	Norway	166	Sweden
11	Azerbaijan	50	Dominica	89	Kenya	128	Oman	167	Switzerland
12	Bahamas	51	Dominican Republic	90	Kiribati	129	Pakistan	168	Syrian Arab Republic
13	Bahrain	52	Ecuador	91	Kuwait	130	Palau	169	Tajikistan
14	Bangladesh	53	Egypt	92	Kyrgyzstan	131	Panama	170	Thailand
15	Barbados	54	El Salvador	93	Lao People's Democratic Republic	132	Papua New Guinea	171	The former Yugoslav Republic of Macedonia
16	Belarus	55	Equatorial Guinea	94	Latvia	133	Paraguay	172	Timor-Leste
17	Belgium	56	Eritrea	95	Lebanon	134	Peru	173	Togo
18	Belize	57	Estonia	96	Lesotho	135	Philippines	174	Tonga
19	Benin	58	Ethiopia	97	Liberia	136	Poland	175	Trinidad and Tobago
20	Bhutan	59	Fiji	98	Libyan Arab Jamahiriya	137	Portugal	176	Tunisia
21	Bolivia	60	Finland	99	Liechtenstein	138	Qatar	177	Turkey
22	Bosnia and Herzegovina	61	France	100	Lithuania	139	Republic of Korea	178	Turkmenistan
23	Botswana	62	Gabon	101	Luxembourg	140	Republic of Moldova	179	Tuvalu
24	Brazil	63	Gambia	102	Madagascar	141	Romania	180	Uganda
25	Brunei Darussalam	64	Georgia	103	Malawi	142	Russian Federation	181	Ukraine
26	Bulgaria	65	Germany	104	Malaysia	143	Rwanda	182	United Arab Emirates
27	Burkina Faso	66	Ghana	105	Maldives	144	Saint Kitts and Nevis	183	United Kingdom of Great Britain and Northern Ireland
28	Burundi	67	Greece	106	Mali	145	Saint Lucia	184	United Republic of Tanzania
29	Cambodia	68	Grenada	107	Malta	146	Saint Vincent and the Grenadines	185	United States of America
30	Cameroon	69	Guatemala	108	Marshall Islands	147	Samoa	186	Uruguay
31	Canada	70	Guinea	109	Mauritania	148	San Marino	187	Uzbekistan
32	Cape Verde	71	Guinea-Bissau	110	Mauritius	149	Sao Tome and Principe	188	Vanuatu
33	Central African Republic	72	Guyana	111	Mexico	150	Saudi Arabia	189	Venezuela, Bolivarian Republic of...
34	Chad	73	Haiti	112	Micronesia, Federated States of...	151	Senegal	190	Viet Nam
35	Chile	74	Honduras	113	Monaco	152	Serbia	191	Yemen
36	China	75	Hong Kong (S.A.R.)	114	Mongolia	153	Seychelles	192	Zambia
37	Colombia	76	Hungary	115	Montenegro	154	Sierra Leone	193	Zimbabwe
38	Comoros	77	Iceland	116	Morocco	155	Singapore		
39	Congo, Republic of the...	78	India	117	Mozambique	156	Slovakia		

Appendix 2: Item Feedback provided to iGLAS Participants

Upon completing iGLAS participants are presented with the following information. Scoring and display logic is also used to inform participants whether they got each individual item correct or not:

Congratulations on completing the Genetics Knowledge section of iGLAS. In total, you scored: **xx/20**

What is a genome? **Correct/Incorrect**
Having taken more than 10 years and huge international efforts, the human genome was sequenced in 2003.

Which of the following 4 letter groups represent the base units of DNA? **Correct/Incorrect**
DNA is made of 4 base pairs. Guanine and Cytosine which always pair together, and Thymine and Adenine which are also always paired.

How many copies of each gene do we have in each cell? **Correct/Incorrect**
We have two copies of each gene in every cell of our body, one from our mother and one from our father. The exception to this is the sex cells, where we have just one copy of each gene which has been shuffled together from our parents DNA.

People differ in the amount of DNA they share. How much of this differing DNA do siblings usually share? **Correct/Incorrect**
Brothers and sisters share an average of 50% of the proportion of genes that make each human different from everyone else.

What is the main function of all genes? **Correct/Incorrect**
Although geneticists differ in their definitions of what a gene is, it is accepted that all genes have a role in protein synthesis. Proteins are the building blocks of all our cells.

On average, how much of their total DNA is the same in two people selected at random? **Correct/Incorrect**
All humans share more than 99% of their DNA. We share about 98% of our DNA with chimpanzees and about 50% with a banana.

Genetic contribution to the risk for developing Schizophrenia comes from one gene or many genes? **Correct/Incorrect**
Schizophrenia is an incredibly complex condition with many differing traits (phenotypes) which can include paranoia, delusions and hallucinations. A great number of genes relate to each of these traits.

In humans, DNA is packaged into how many pairs of chromosomes? **Correct/Incorrect**
Humans have 23 pairs of chromosomes. The 23rd pair, or sex chromosomes, differ between men (XY) and women (XX).

An epigenetic change is: **Correct/Incorrect**
Epigenetics is a relatively new and complicated area of genetic research. It relates to how and when DNA is read and so regulates gene expression.

Approximately how many genes does the human DNA code contain? **Correct/Incorrect**
Human DNA contains approximately 20,000 genes. Based on other living organisms, this is a lot fewer than was expected.

Genetic contribution to the risk for developing Autism comes from one gene or many genes **Correct/Incorrect**
Autism is a very complicated neurodevelopmental condition that has many different genetic and environmental components

What are polymorphisms **Correct/Incorrect**
Polymorphisms relate to one of the ways in which DNA can vary between people. Very rare polymorphisms are sometimes known as mutations.

The DNA sequence in two different cells, for example a neuron and a liver cell, of one person, is how similar? **Correct/Incorrect**
Within each of us, our DNA does not differ from cell to cell. We have different cell types because of how and when our DNA is read (epigenetics).

"Non-coding" DNA describes DNA that... **Correct/Incorrect**
Approximately 98% of human DNA falls outside of genes and does not directly code for proteins. This used to be known as junk DNA. Today we know that this non-coding DNA also has its own functions.

Can dog breeding be considered a form of gene engineering? **Correct/Incorrect**
Humans have been using genetic modification techniques on animals and plants through selective breeding for millennia. Now modifications can also be made with much more precision through genetic engineering.

Which of the below is a method for gene editing? **Correct/Incorrect**
CRISPR is a relatively recent gene editing technique that utilises a natural mechanism found in viruses to edit very specific parts of a genome.

Can we fully predict a person's behaviour from examining their DNA sequence? **Correct/Incorrect**
Genes interact with each other and the environment in complex ways. Because of this we will never be able to look at someone's DNA and make fully accurate predictions about their behaviour.

At present in many countries, newborn infants are tested for certain genetic traits? **Correct/Incorrect**
Many countries conduct a small number of genetic tests on new-borns (the heel prick test) to see if they have any particular genetic mutations, linked to specific diseases. Some of these genetic diseases can be managed through environmental intervention. For example, PKU can be managed through diet, if it is caught early enough. If this test is not done and the baby starts a normal diet they will get sick very quickly.
Some of the genes that relate to dyslexia also relate to ADHD: **Correct/Incorrect**
Studies have identified that genes that contribute to one trait often relate to others. For example, children who perform well in maths are also likely to perform well in reading in comparison to their classmates. This is because many of the genes that contribute to reading ability also influence maths. These genetic influences unravel through different processes including attention, working memory, motivation etc.

If a report stated 'insomnia is approximately 30% heritable' what would that mean? **Correct/Incorrect**
In most languages, "heritability" relates to how much of the differences we see in the people around us are explained by genetic differences across those people. This is not the same as "heredity" which tells us the patterns of inheritance from parent to child.

Appendix 3: Collaborator Recruitment Details and Terms &Conditions for 'Genes & Tonic: GEkNOwME'

Design Briefs

We now live in the Genomic Era. It takes about 30 minutes and less than $1000.00 to sequence the entire genome of one person. As technology advances and costs reduce, genetic testing will become a routine part of health management. Millions of people have already opted to investigate their own genomes through private companies like 23andMe. Although doctors and nurses will pass on important information about how DNA works to their patients, no such guidance will be available in other areas, such as education, law and home DNA tests. For these reasons, there need to be real efforts to interest everybody with genetics, so they have a good understanding of what their DNA can really tell them.

That's where you come in!
The Accessible Genetics Consortium, based at Goldsmiths, will be curating an exhibition about genetics, with the aim of getting people more interested and involved with their own DNA. We are looking for talented Goldsmith's students to produce original artwork in response to one of three specific design briefs related to an important genetic concept. Successful applicants will:

- Have their work exhibited as part of the prestigious and national ESRC Festival of Social Science
- Be considered for a place on the highly competitive Erasmus Scheme: offering full funding for 2 months of foreign study
- Have their work entered for a prize draw, with a grand prize of £200
- Have a budget of up to £50 for artistic materials upon having their design proposal accepted

The exhibition will be running on 9th and 10th November 2018. Proposals will need to be submitted by 1st October. If you are then selected for the exhibition you will have to submit your completed work by 1st November 2018.
Each piece of proposed artwork should address one of the following briefs (or could cover multiple briefs):

Mendel and more
Gregor Mendel was a 19th century monk who discovered how genetic information is passed from parents to children. For each trait, such as eye colour, blood type, height and personality traits, each child inherits some genetic information from their mother, and some from their father. The information from one parent may dominate over that of another parent. To really understand this we need to look a bit closer at the experiments Mendel conducted. Mendel did much of his research with pea plants. He noticed that:

- Some plants had green peas, even when they were bred from plants with yellow peas
- Some plants with yellow peas only ever produced offspring with yellow peas, although there would sometimes be plants with green peas in future generations
- Breeding from plants with green peas never produced plants with yellow peas

He concluded that pea colour (yellow or green) was determined by just one point of information in DNA, with each new plant getting one instruction for pea colour from their father, and another instruction from their mother. If both parents passed down information to make yellow peas then the offspring would have yellow peas. If one parent passed down information to make yellow peas, and the other provided information to make green peas, the plant would make

yellow peas but be a carrier for green peas (meaning that it might then have offspring of its own with green peas, if bred with another plant that either had green peas or was also a carrier). Only if a plant received instructions to make green peas from both parents, would it make green peas. All this is explained really well in this video.

Rather than the information from parents being mixed together, Mendel concluded that one set of instructions took dominance over the other set. In the case of Mendel's peas, yellow is dominant and green is recessive.

In simple organisms, like pea plants, many traits are influenced in this way. In more complex organisms, like humans, most traits (except for some rare diseases) aren't influenced by just one piece of DNA information, but by many different pieces of information.

Let's think about eye colour in humans. If eye colour was influenced by just one piece of genetic information we would expect everybody in the world to have one of two eye colours (let's say blue and brown). We would also expect to see more of the dominant eye colour (let's say brown), than of the recessive colour (blue). Two blue eyed parents would only ever have blue eyed babies. Brown eyed parents would have mostly brown eyed babies, but might occasionally have a baby with blue eyes -if they were both carriers for blue eyes.

But eye colour in humans is much more varied than just blue and brown. There are different shades of blue and brown. Some brown eyes are so dark they appear black, some blue are so light they almost seem white. There are also green and grey eyes, and any combination of these colours. All with different patterns. At the best current estimate, eye colour is influenced by as many as 16 different bits of information from parental DNA.

Ironically, eye colour is often chosen as a way of explaining Mendel's principles in high school science lessons by talking only about blue and brown eyes. Research has suggested that understanding genetic influences on traits in such a binary, on/off, dominant/recessive way can lead people to misunderstand and over estimate the influence of genes in complex traits.

Understanding that all human traits are influenced by multiple pieces of information coded into our DNA, rather than being caused by just one piece of information, is essential to understanding how genes influence (rather than determine) who we are.

Many genes, small effects

As all complex human traits are influenced by lots of different genes (pieces of DNA encoded information) – see *Mendel and More* above – each gene tends to have a very tiny influence on a trait. Even though some genes have been found to be associated with human traits, at best these can explain only about 1% of variation in that trait. It is much more common for genes to have even smaller influences.

Twins studies are very useful for looking at the relative influences of genes and environments in what makes each of us different and unique. By looking at certain traits in twins', scientists have found that genetic influences account for between 40% and 80% of trait differences seen in any given population.

Now that we are able to look directly at the genome, scientists are starting to make use of an exciting new technique called Genome-wide Polygenic Scoring (GPS). To do this, they look for the thousands of genes most associated with a particular trait and then sum these together to give a GPS. This GPS can then be used to make predictions about other traits. One such GPS (EduYears) has recently been used to predict school achievement. Students with the highest EduYears score typically achieved one whole grade higher than students with the lowest

EduYears score. These predictions will never be perfect as the environment is so important, but they do help us understand the relationship between our genomes and who we are. As our DNA does not change, these GPS scores can theoretically be tested as soon as we are born.

Genes have tiny and cumulative effects. Even though we have gene editing technology available now, changing just one gene is very unlikely to have an impact on the trait we want to improve or correct. We also don't know very much at all about how genes actually influence complex traits, so changing just one gene may impact a whole variety of traits other than the one we are interested in. Far better to look at improving people's environments, rather than tinkering with their genomes. Using GPS scores could really help with this.

Genes and Environments interplay

Genes do not exert their influences in a bubble, unaffected by the world around them. They interact with the environment. Imagine this, you were born into a musical family. Your father is a concert pianist and your mother composes jingles for TV adverts. Her parents both played in an orchestra and his parents were jazz musicians. The traits that make them great musicians: perfect pitch, rhythm, creativity, physical dexterity, determination etc. are likely to be passed on to you. In part, these traits will be passed on genetically through the DNA information your parents pass down, but they will also be passed down through the environment. Your home will be full of music, books about music, instruments to try, conversation about music etc. You will inherit music both genetically and environmentally.

Imagine now that you were adopted at a very young age and your adoptive parents had no particular musical ability or interest. You grew up in a home with no music, or books about music, or instruments to try, but you still got all the genetic gifts of great musical ability from your biological parents. It may be that those gifts never get to flourish, or are directed elsewhere, maybe into poetry or creative writing. However, there is a good chance your environment will respond to your genetic musical ability. A teacher at school may notice that you sing very well in assembly and suggest you join the choir. Your enjoyment of music and strong sense of rhythm may make you turn saucepans into a drum kit or ask your parents for a guitar.

Even when genes exert an influence on a trait they need an environment in which to flourish. Knowing that genes are very important for a trait does not mean that environments aren't. Indeed, some diseases which are highly genetic can be controlled by entirely environmental means. It is not a case of Nature vs Nurture, or Genes vs Environments. It is Nature and Nurture always working together that makes us who we are.

Terms & Conditions

TAGC: GeKnoWme (the "Competition") is an art concept competition run by The Accessible Genetics Consortium ("TAGC"), with funding from the ESRC Festival of Social Sciences (“ESRC”). The theme of the competition is around the communication of genetic concepts through art. Work will be displayed as part of the GeKnoWme exhibition (the “Event”)

1. Terms of Entry
    a. Entrants must read and abide by these terms and conditions (the “Terms and Conditions”).
    b. By submitting an Entry, each Entrant agrees to the Terms and Conditions, and warrants that their entry complies with the requirements set out here.
    c. Any entry found not to comply with the Terms and Conditions will be disqualified.
    d. Winning entries will be considered for exhibitions at the Event. TAGC reserves the right to refuse to display specific works and this decision will be at the organisation’s discretion.
    e. The decision of TAGC on all matters relating to the Competition is final and binding.

2. The Schedule and the Prize
    a. The Schedule:
        i. The Launch Date: midday Monday 17th September 2018. Entries are accepted from the Launch Date.
        ii. The Deadline: 23:59 on Monday 8th October 2018. Entries accepted until the Deadline.
        iii. Announcement of winners: 5pm on Wednesday 10th October 2018. Up to six Entries will be chosen by the judging panel (the "Panel") based on their concept, these winning artist(s) will be informed by email after the panel has met on the evening of 10th October and awarded £50 (the “Award”) for the development of their artwork (the "Work").
        iv. The Completion Date: Thursday 1st November 2018. By accepting the award, the artist(s) agree to commence production of their Work, and complete and deliver it to TAGC by the Completion Date. TAGC agrees to assist with delivery of works to the best of their ability.
        v. Review process: Monday 5th November. After the Completion Date, the Work(s) will be reviewed by TAGC for final approval, so they may form part of the Event.
        vi. The Event: Friday 9th and Saturday 10th November 2018. Work(s) passing the final review by TAGC will form an exhibition at 310 New Cross Road, A reception will be held on Friday, with prizes being announced at the close of the exhibition on Saturday. Address: 310 New Cross Road, London, SE14 6AF
        vii. The End Date: Sunday 11th October 2018. Artists are asked to collect their works the Sunday after the exhibition. If this is not possible work can be stored for up to a week after the event.
    b. TAGC reserves the right to substitute the Award with an award of equivalent or higher value, in the event of circumstances outside of its control.
    c. By accepting the Award, the artist(s) agree not to sell their work or copies of their work before the End Date, without first receiving prior written consent from TAGC.
    d. By accepting the Award, artists agree to make themselves available to attend the Launch Event listed in the Schedule.

e. TAGC reserves the right to substitute the Prize with a prize of equivalent or higher value, in the event of circumstances outside of its control.

3. Entering the Competition
    a. The Competition is open to all students and alumni of Goldsmiths, University of London.
        i. Artists may enter as an individual or part of a group.
        ii. Entry is limited to one per individual artist or collective group. However, Entrants that have entered as individuals may also form part of a group Entry, providing the two pieces are distinctly different.
    b. Before submitting their concept, artists should consider the limitations listed here:
        i. Art cannot hang from the ceiling in the gallery so all work must be suitable for display on a plinth or a wall
        ii. Performance pieces are unfortunately not eligible for this competition
        iii. Sound-based pieces will be considered for exhibition in an annex to the main gallery. No equipment for sound-based pieces can be provided by TAGC.
        iv. Entrants should submit a PDF version of their completed application form via email to: r.chapman@gold.ac.uk by the Closing Date as listed in the Schedule. Any entries received after this time will not be eligible for inclusion in the Competition.
        v. TAGC cannot be held responsible for submissions that do not arrive due to an entrant email security settings or restrictions placed by their Internet Service Provider.

4. Judging the Competition
    a. The Panel will be appointed by TAGC and will include experts in genetics, aesthetics and science communication.
    b. The Panel will judge Entries as concepts, not as final works.
    c. The Panel will judge the Entries on the selection criteria including originality and creativity. Decisions of the judges are final and binding and no correspondence will be entered into surrounding this decision.
    d. All Competition Entries will be judged anonymously: names will not be provided with the Entries during the judging process.

5. The completion of work
    a. The artist(s) will commence their works upon acceptance of the Award.
    b. The artists will, to the best of their ability, carry out the production of the Work according to the concept and specification detailed in their Entry.
    c. The artist(s) agree(s) to send an initial progress update to Robert Chapman (r.chapman@gold.ac.uk) by midday Monday 22 October 2019, and when requested thereafter, up to the Completion Date.
    d. The artist(s) agree(s) to the size limits here:
        i. For 2D Work, the maximum size is 1.5 x 1.5 m.
        ii. For 3D Work, the maximum size is 1.5 x 1.5 x 1.5 m.
    e. The artist(s) Work must be the original work of the entrant, and must be willing to sign a form stating that the completed digital, 2D or 3D Work is entirely their own.

6. Ethical standards

a. If TAGC suspects that any entry or final work has been achieved through the use of illegal or unethical practices, the entry will be disqualified and TAGC reserves the right to report the entrant to the applicable authorities.

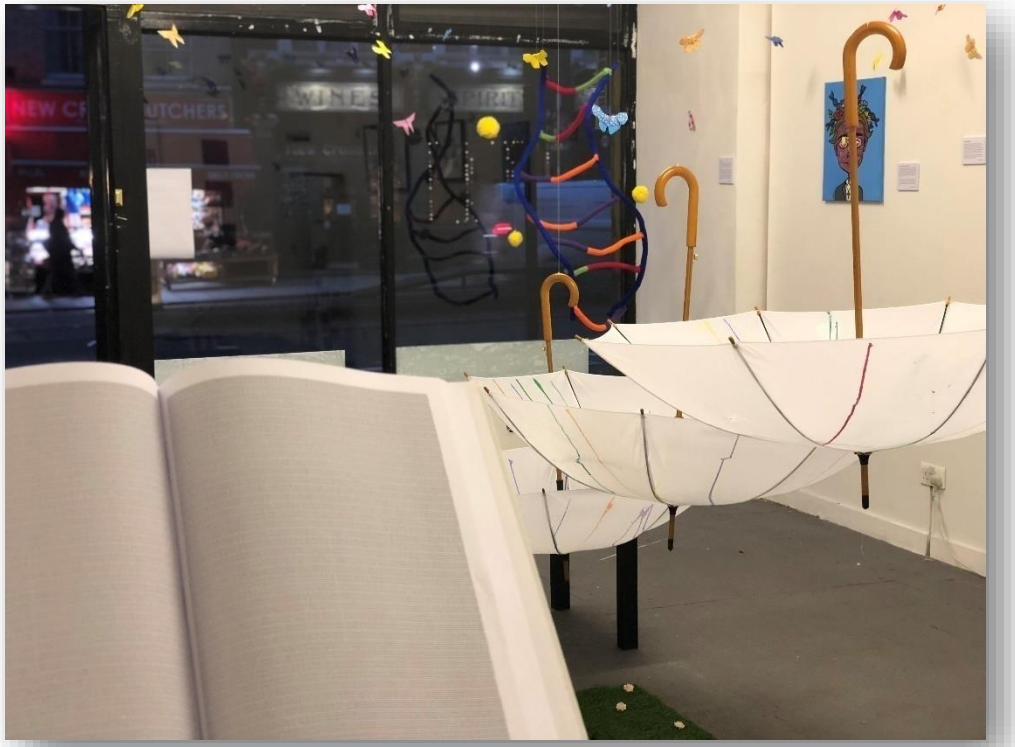
7. Copyright, reproduction and publicity
    a. The intellectual property of any submitted concepts and/or completed Works remains solely with the artist(s).
    b. By entering the Competition, the Entrant(s) warrant(s) that their Entry is their original work and does not infringe the rights of any other party.
    c. All Entries will be considered Confidential.
    d. Upon acceptance of the Award, the artist(s) agree to the use (subject to agreement by the copyright owners) of details from their Entry, their name, images and recordings of their final works for the purposes of advertising, promotion and publicity of TAGC and the Competition on both internal and external channels, and to display their work in the exhibitions listed in the Schedule, without additional compensation.
    e. Upon acceptance of the Award, the artists agree to take part in promotional activities, including potential media interviews, which may occur in relation to the Competition, up to the End Date.

8. Liability
    a. Proof of electronic submission of Entries is not proof of receipt by TAGC.
    b. TAGC does not accept liability for the misuse of Entries by and/or failure of any third party to comply with the Competition's guidelines.
    c. TAGC does not accept any liability, to the fullest extent permitted by law, for any loss or damage suffered by any Entrant in relation to the Competition.

9. Data protection
    a. The personal data of entrants will be managed by TAGC in accordance with the principles of the General Data Protection Regulation (GDPR) (EU) 2016/679.
    b. TAGC will collect personal data about entrants from their Registration and Consent Form and as otherwise provided in order to administer the Competition and/or all publication and uses of the Competition Entries.
    c. Entrants may contact TAGC at any time to update their details, via Robert Chapman (r.chapman@gold.ac.uk)

10. Organiser's details The Accessible Genetics Consortium, c/o Psychology Department, Goldsmiths, University of London 8 Lewisham Way, New Cross, London SE14 6NW Main contact: Robert Chapman Email: r.chapman@gold.ac.uk

Appendix 4: Genes & Tonic 3: GEkNOwME Exhibition Materials



GEKNOWME

In November 2018 The Accessible Genetics Consortium (TAGC) curated an exhibition as part of the ESRC Festival of Social Science. The exhibition was extremely well received. Should you have any questions please contact r.chapman@gold.ac.uk

TAGC

The Accessible Genetics Consortium

I Am a Product of My Everything

The piece uses acrylic paint on 16x20 inch canvas and depicts Gregor Mendel (a monk who discovered the basic principles of heredity through his experiments on pea plants), with plants and DNA helixes coming out of the top of his head. This represents how we are a complex product of the interaction between our genes (DNA helixes) and our environments (the plants).

For some time, there has been a debate of whether our nature or nurture influences our behaviour and traits, however we now know that the two work together in complex ways, and almost everything about us is the product of both nature and nurture.

Vanessa Smereczynska

That Lived in Feel

Our physical attributes, our qualities, and our tendencies are the result of a complex give-and-take relationship between our inherited genes and our environments.

These quilts consider used denim (taken from the designer, her friend, and her mother) as a material that embodies both inheritance and chance. Associated with working-class Canadiana, it is both the ‘given’ (what we are born with or born into) and the malleable that changes with day-to-day use. Creating the quilts involves forcing fabric that has become inconsistent and stretched with wear into a plan that, while drawing attention to points of interest, flattens it and removes it from its context.

Invoking personal themes of identity and legacy alongside ideas of structure versus chance and probability, these pieces serve as a response to the intertwined factors that influence our understanding of who we are.

Alex Keays

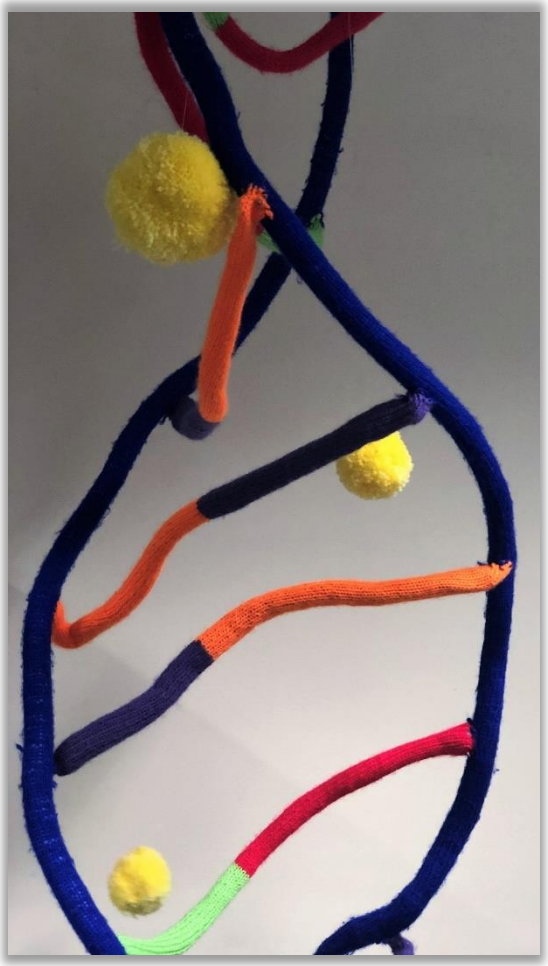
DNA Helix

DNA is found in every cell of every living organism. It carries the information that guides development. This information is stored in a language of 4 letters A (Adenine), T (Thymine), C (Cytosine) and G (Guanine), represented here by 4 different colours of wool.

Approximately 2% of human DNA falls within genes and is involved directly in the production of proteins. The remaining 98% has many other functions including the regulation and activation of genes. One method for this regulation is the application of methyl to either stop or attenuate gene expression. In this exhibition methyl is represented by yellow pom-poms. Methylation is one of the fundamental processes of epigenetics and can be affected by the environment as well as other genes.

Materials: Wool and wire

Robert Chapman



Mendel and More

Gregor Mendel (see: I am a product of my everything) discovered the way in which information is passed from parent to offspring. A child inherits information from both their mother and their father. In many cases, one set of information dominates over the other and leads to a trait being expressed. Rarer traits, known as recessive, are only expressed when a child inherits instructions for that trait from both parents.

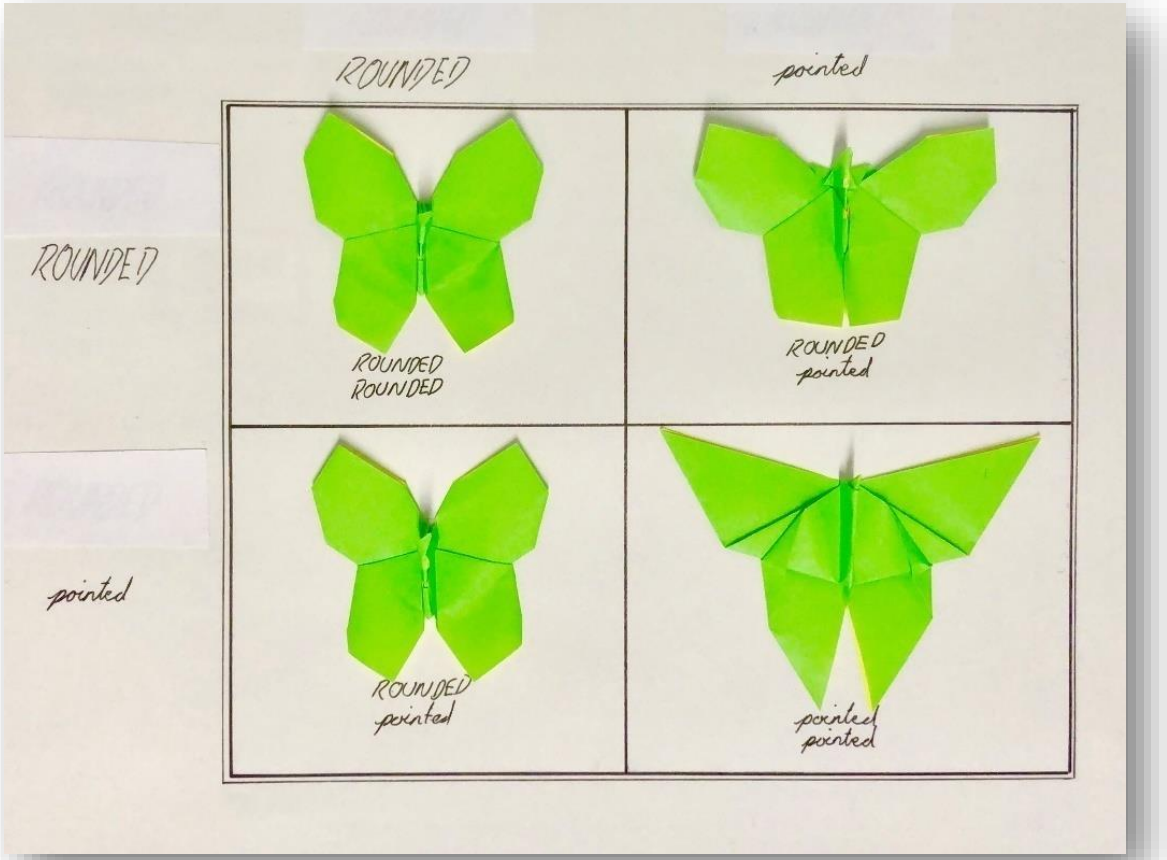
This exhibition consists of three parts as well as the butterflies scattered throughout the gallery.

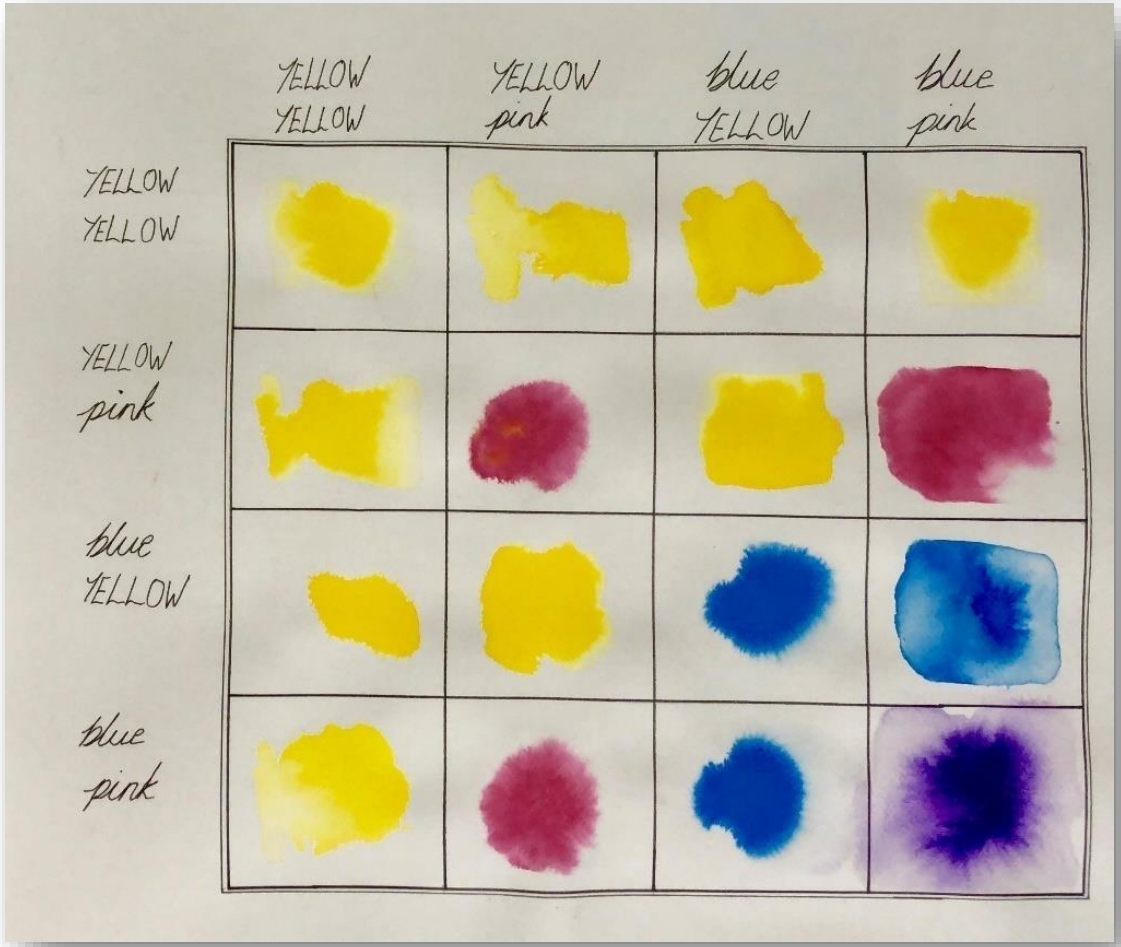
Robert Chapman

A Punnett Square #1

Used to demonstrate the ratio of offspring that show dominant and receive traits. In this case, only one gene is associated with the trait; wing shape. The parents, represented on the sides of the grid, have rounded wings, but are carriers of pointed wings. On average, three of their off spring will have rounded wings (of which two will carry pointed wings) and one has pointed wings.

Robert Chapman





A Punnett Square #2

Here we see a trait (wing colour) that is influenced by two genes. When two genes are involved there are 4 possible trait variations (phenotypes). In this case: Yellow, Pink, Light Blue and Purple, in the ratio 9:3:3:1. With two genes involved there are 10 different genetic combinations (genotypes).

Robert Chapman

The Eyes have it

The best current estimate is that human eye colour is influenced by at least 16 genes. This results in 43,046,721 different genotypes. As can be seen in this photo exhibition, eye colour is extremely varied. The images also demonstrate that human characteristics are extremely varied, and genes have an influence to play in these too.

Robert Chapman

Prediction

Humans have always been fascinated by prediction. Be this through arcane methods such as the tarot and horoscopes or the pseudoscientific ideas of phrenology – that character traits can be predicted by feeling bumps on the head.

Genomic sequencing, using gene chips, allows for prediction of individual differences in all sorts of traits, both physical and psychological, but only with a degree of probability.

From Oedipus and Macbeth we know how dangerous predictions can be, especially when not fully understood and treated as immutable. This is the same for genetic prediction. For each of us, knowing more about genetics will become increasingly important as we progress further into the genomic era, where genetic prediction may become part of our everyday lives.

Teemu Toivainen

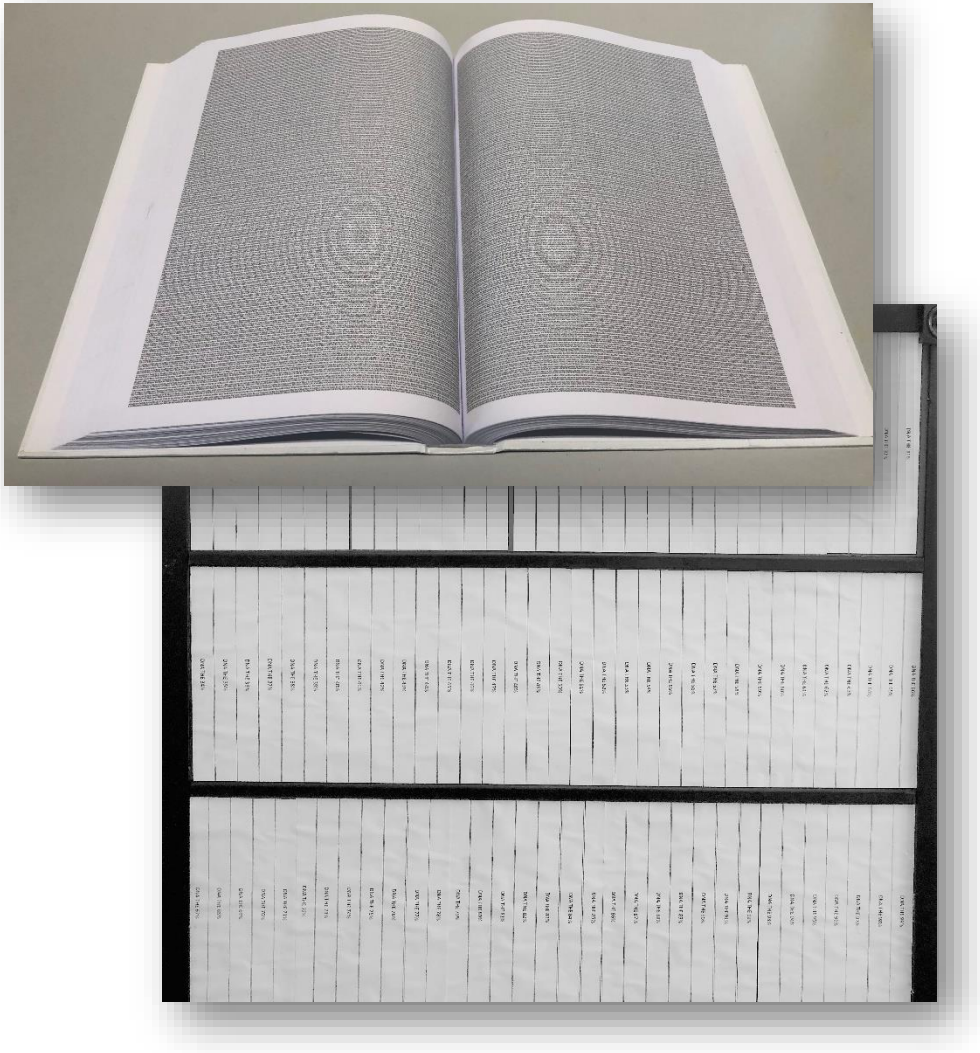
The Language of Life

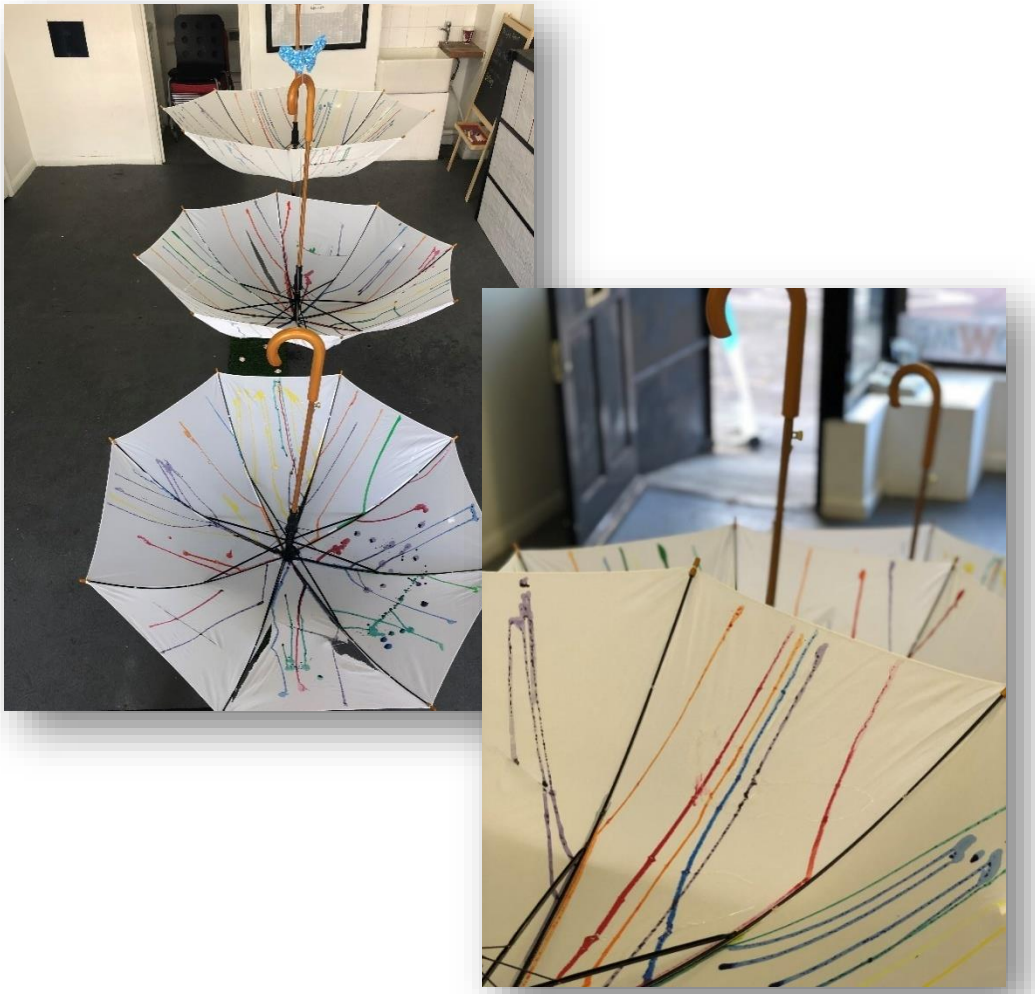
The human genome consists of roughly 3 billion base pairs. We share approximately 50% of our DNA with a banana and more than 98% with chimpanzees.

The open book represents 1% of the human genome - 30,000,000 base pairs. The remaining 99 books are represented on the shelves below. Although all humans are more than 99% genetically identical, there is still a lot of opportunity for variation.

If you were to read the human genome aloud at a rate of one base pair per second, it would take just over 97 years to finish.

Teemu Toivainen





Gene environment interactions

The effects of genes do not exist in a vacuum, they interact and relate to the environment. For example, a person with genetic predispositions for perfect pitch and rhythm will never become a concert pianist if they never have access to a piano.

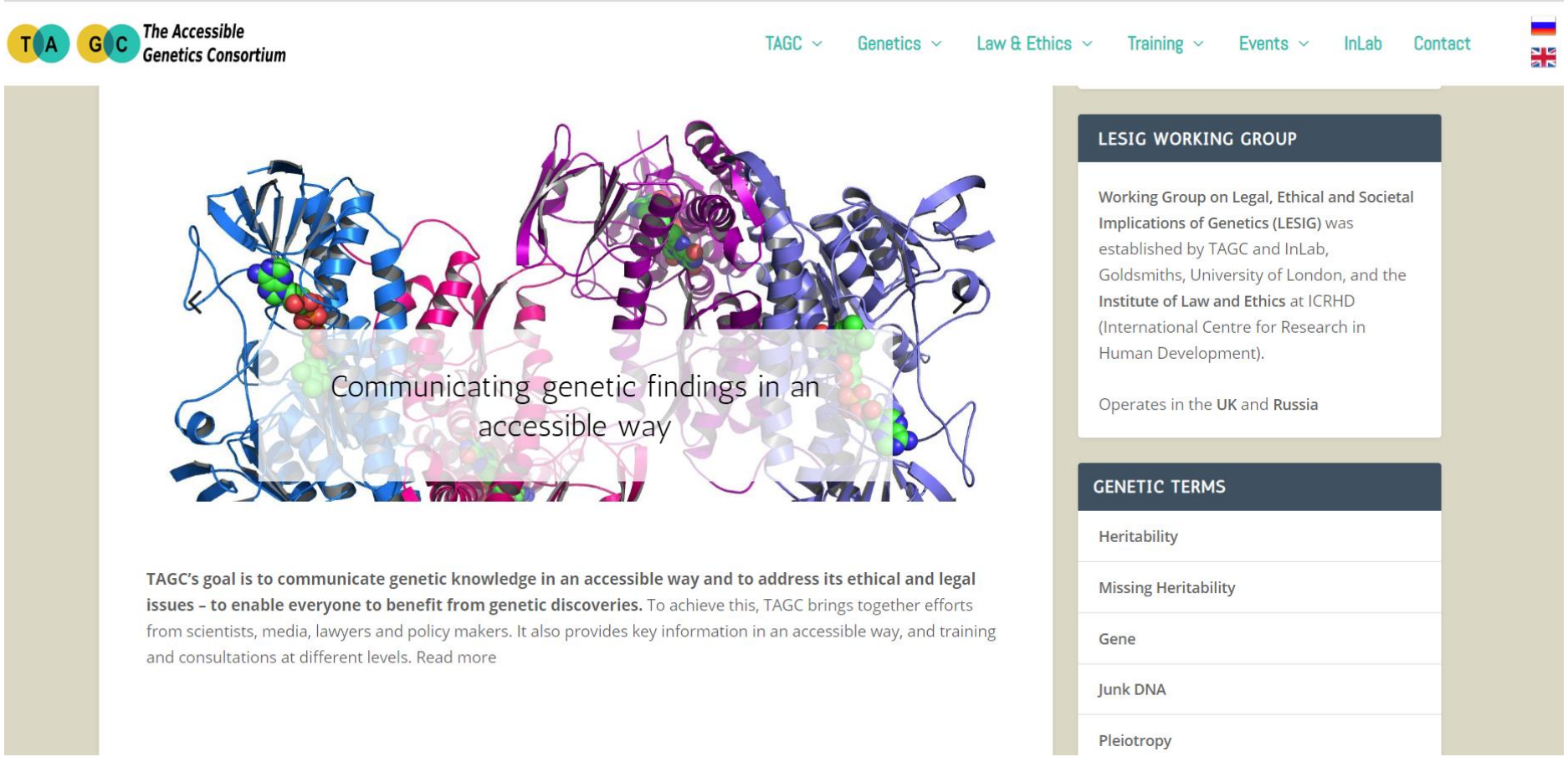
Measuring genetic influences is extremely complex, measuring environmental influences is no less so. Studying how genes and environments interact is arguably even more difficult.

In this interactive exhibition the ink represents genetic influences, the umbrellas represent the environment.

Robert Chapman

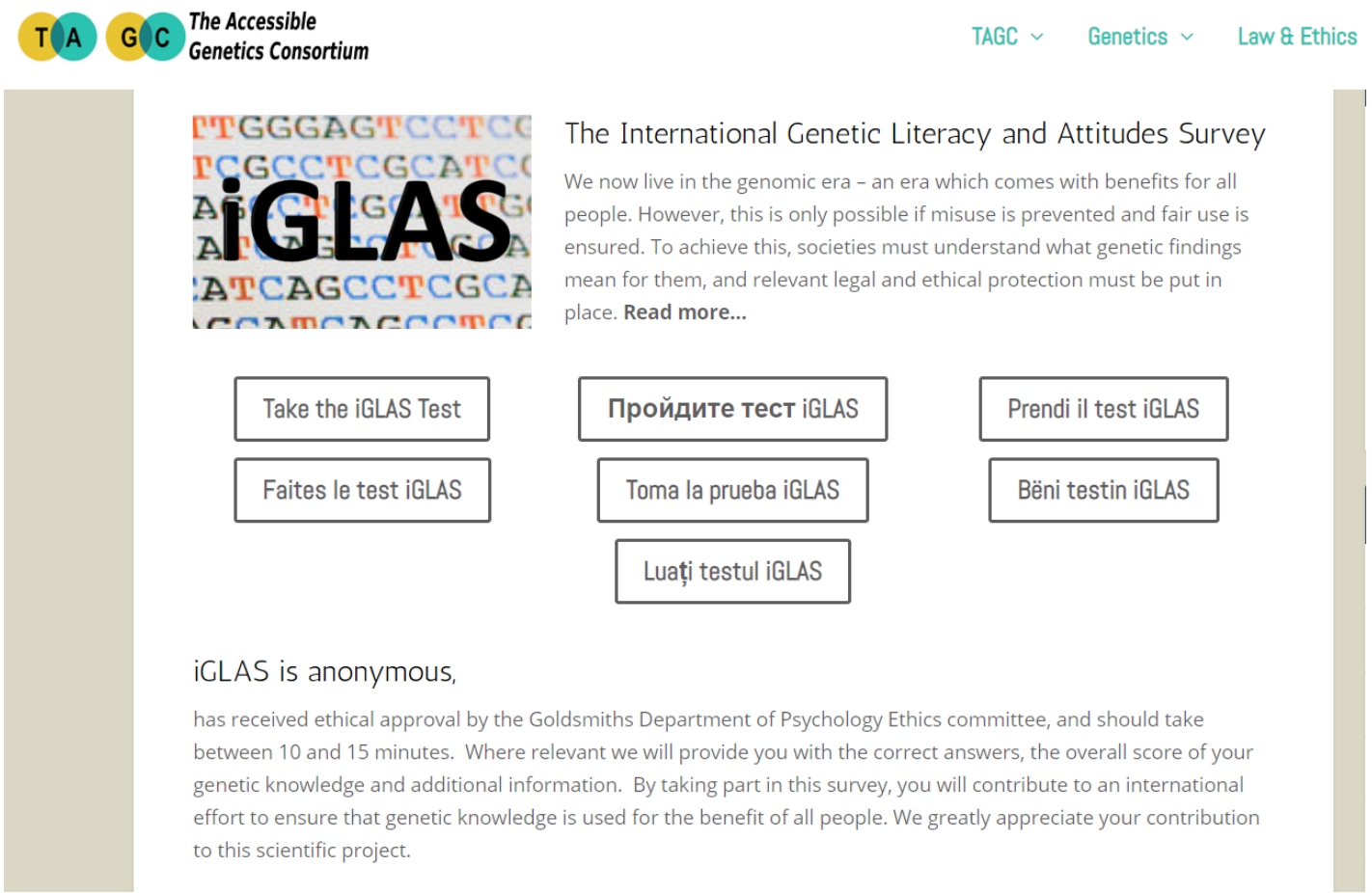
Appendix 5: Example Screenshots from TAGC's website (www.tagc.world)

Homepage
https://tagc.world/



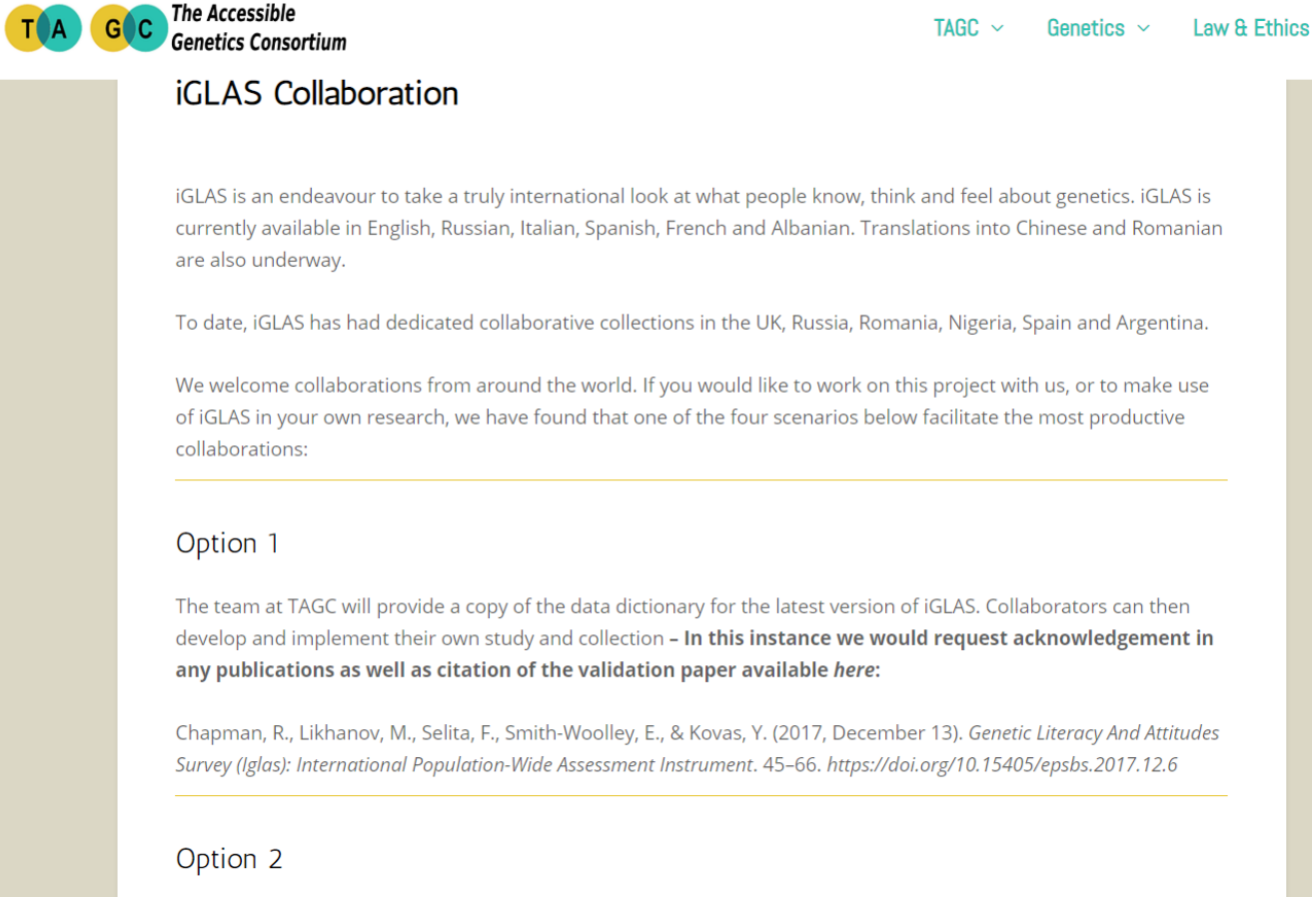
The International Genetic Literacy and Attitudes Survey – Including Links to all Available Languages

https://tagc.world/iglas/



Details of Collaboration Options for New Research Projects Using iGLAS

https://tagc.world/iglas-collaboration/



Details of Training and CPD from TAGC

https://tagc.world/training/

The Accessible Genetics Consortium

TAGC Genetics Law & Ethics

Providing training to individuals and organisations in matters related to genetic findings and their practical application, legal issues and ethical concerns.

Genetics findings and their practical application

Knowledge on genomic findings and their practical application are now essential for medical professionals and policy makers, and are becoming essential for lawyers, educationalists/teachers and other related fields of practice. Training is tailored to the professional needs.

Using genetics in health care and education

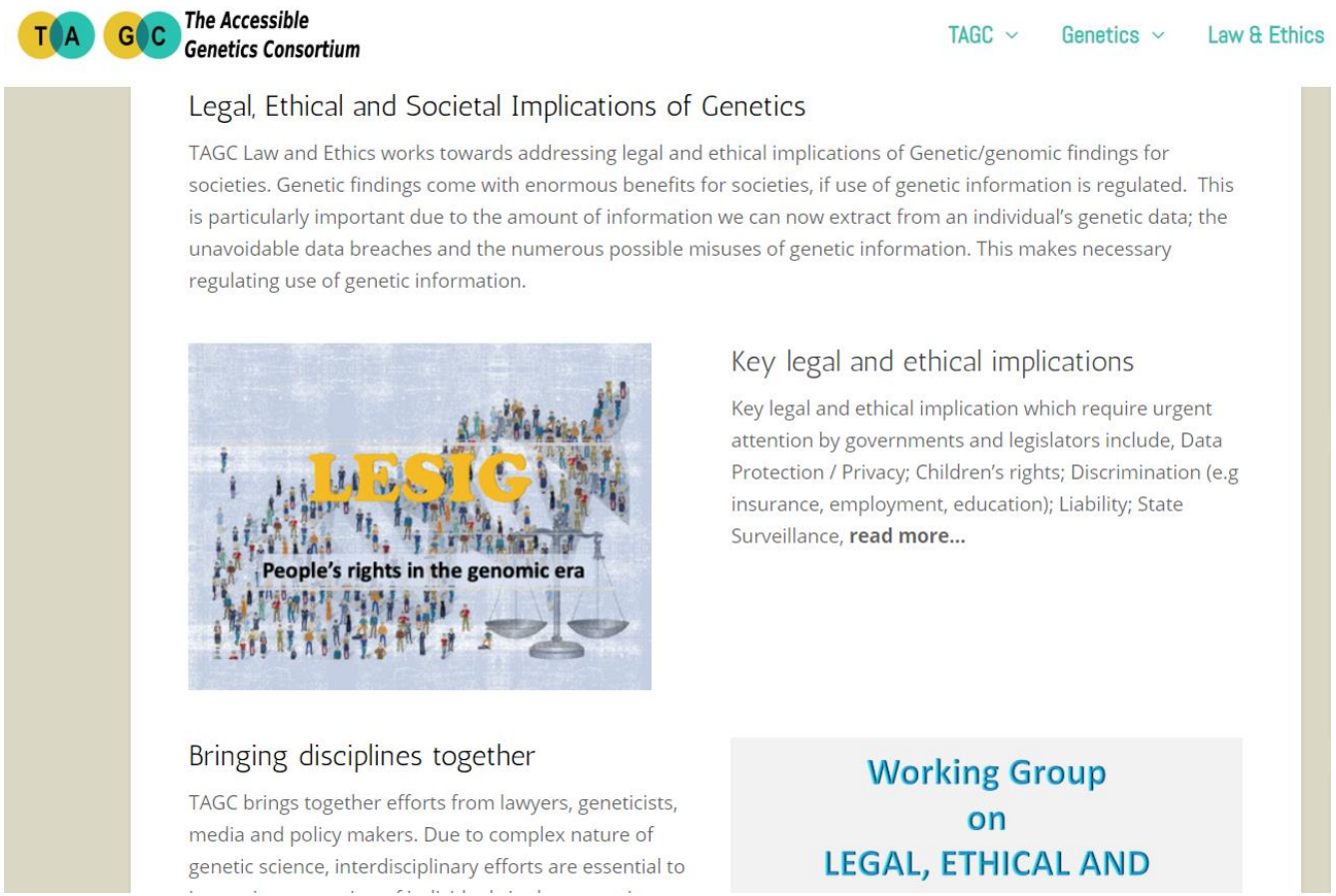
Latest advancements are now important in health care and education and it is important to use these advancements effectively for the benefit of people.

Legal and ethical implications of genetic findings

Knowledge of ethical and legal issues related to genomic findings, and of their impact on societies and science, are essential to ensuring positive use of these findings for the benefit of all people, as well as to maintain public trust in science. Our training in this area includes:

Details of TAGC's work on the Legal, Ethical and Social Implications of Genetics Research

https://tagc.world/law/



Glossary

Aetiology	The origin or reason for something
Cartesian	Relating to the philosophy of René Descartes. Descartes thought that the human mind was essentially different to the human body. Existing in a different sphere and governed by different laws.
Diploid	Cells or nuclei that contain two complete sets of paired chromosomes, one from each parent.
Environments: Non-shared	Those environments which lead to increased differences in monozygotic (identical) twins. This also includes measurement error.
Environments: Shared	Those environments which lead to increased similarity in monozygotic (identical) twins
Epidemiology	The study of the distribution and control of disease and health in populations
Epigenetics	Changes in an organism that relate from changes in gene expression rather than the genetic code itself
Fatalism	The philosophy that all events and actions are predetermined
Genome	The entire sequence of an organism's DNA
Genotype	The specific genetic construction of an individual organism (person)
Haploid	Cells or nuclei that have one set of unpaired chromosomes
Heritability	The proportion in trait variation in a population that can be explained by genetic variation
Heterogeneous	Characterised by high variation
Homogeneous	Characterised by low variation
Mendelian	The pattern of inheritance that is seen in rare disorders and traits that relate to a single genetic variant.
Monogenic	Human traits (usually diseases) that are the product of a single genetic variation
Phenotype	An organisms observable or measurable characteristics resulting from the interaction of its genes and environments.
Pleiotropy	One Gene affecting many traits
Polygenic	Many genes affecting one trait
Polygenic Scoring	A method that uses weighted and summed points of genetic variation in the genome to predict trait variants. When related to disease, these are often known as Polygenic Risk Scores (PRS)
Tabula rasa	Literally 'blank slate'. The idea that people are born without any inherited personality or characteristics etc. and that these are entirely formed by experience and the environment
Variable DNA	The proportion of DNA that varies within a species and accounts of phenotypic differences
Weldonian	A theory of genetic inheritance that includes evaluation of environmental context in an organisms development.