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# GENETIC LITERACY AND ATTITUDES SURVEY (IGLAS): INTERNATIONAL POPULATION-WIDE ASSESSMENT INSTRUMENT

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#### Abstract

Genetics represents the fastest developing discipline in the history of scientific enquiry. Genetic advances have implications for individuals and society, including matters related to law, ethics, education, medicine and philosophy. As such, it will be important for all people to be able to engage with genetic research, not just at the point that it becomes personally applicable, such as in medical treatment, but also more generally across many social domains. Given the ever-increasing impact of genetics on daily life, it is important to have a tool to evaluate what people know, think and feel about genetics and for this tool to be applicable across society. Previous studies have mainly focused on genetic literacy in medical domains with less attention paid to other applications. They have also largely focused on well-defined populations, such as undergraduate students and young adults. To overcome these limitations of previous research in this area, a consortium of psychologists, geneticists, lawyers, educationalists and ethicists have developed the International Genetic Literacy and Attitudes Survey (iGLAS). This paper presents the development, piloting and validation of this instrument. The resulting iGLAS provides a flexible, informative and quick tool for evaluating public knowledge and perceptions of genetics. In particular, it provides a tool that can be used across all demographics, allowing for tailored research with specific groups of interest.

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## 1. Introduction

We live in an era of advanced and advancing genomics research (Collins, 2010). It now takes approximately 30 minutes and less than \$1000.00 to sequence an entire genome of a person. As the price and time for genetic testing continue to reduce, market forces suggest that whole genome sequencing will become routine practice for screening for genetic conditions in new born infants (Berg et al., 2017). Routine sequencing will also allow for identification of many more single mutation disorders that could be nullified or partially managed through environmental manipulations. Additionally, it will also reveal a great deal of probabilistic information about each person's physical, educational, emotional and psychological development.

With the rate of genomic sequencing increasing, people will need to become genetically literate. 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). For example, genetic literacy would mean a good grasp of the concept of heritability. Heritability is a population based statistic estimating the relative influences of genetic factors on complex traits such as personality, physical and mental health, and education. Quantitative genetic studies, using twin, adoption and other family designs, have found all complex human traits to be heritable to some degree. For example, school achievement is substantially heritable, with genetic differences accounting for approximately 60% of the variation among primary school students (e.g., Kovas et al., 2013).

Genetic literacy also means understanding how an individual's DNA sequence provides probabilistic predictive information about behaviour and health. With increasing computer processing power and the cost of genomic sequencing reducing, greater precision has become possible. A recently introduced Genome-wide Polygenic Scoring (GPS) technique allows for thousands of genotyped markers in a person's DNA to be aggregated together to predict different traits. For example, in a recent study using this method, DNA information alone could explain 10% of the variation in school achievement of high school students (Selzam et al., 2017). Further research using GPS is likely to achieve even greater predictive power in many domains (Spiliopoulou et al., 2015).

Genetic literacy also includes understanding that for all complex traits, genetic variability within a population is so vast that two randomly selected individuals within a population can be more genetically different from each other than two randomly selected individuals from two diverse populations (Jorde & Wooding, 2004; Witherspoon et al., 2007). Moreover, any differences within and between populations can be due to environmental and/or genetic differences. For example, genetically identical orchids will thrive in a hothouse, but not in the desert; it is the environment that explains the differences in these populations, not genetics. As such, observed population differences at the phenotypic level cannot automatically be attributed to genetic differences between these populations. However, this concept seems to be poorly understood and is likely to be the source of much resistance to genetic research in areas such as education and intelligence.

The need to be genetically literate therefore extends beyond the medical domain and has relevance in many other areas, including education, law, social policy and philosophy. If genomic sequencing becomes routine, many important questions will need to be addressed. For example, who should have access to genomic data? Should parents be faced with vast amounts of probabilistic information about their new born child? Should the state have access to this information? What if something is indicated in a DNA test that a child might not want other people to know, such as the likelihood of their sexual preferences? Such questions are pressing, particularly as deciphering the genome is far from being complete. We know more today than we did yesterday, and will know considerably more tomorrow. As such, decisions about genetic testing not only relate to what is known now, but to potential future knowledge emerging during a lifetime.

Such information also rarely pertains just to the individual being tested. Genetic relatedness between family members invariably means that an individual's decision to have their genome sequenced will have implications for family members. Discovery of a rare genetic disorder in one individual increases the chances of that condition being found in family members. For example, if someone finds out that they have a genetic disorder, are they morally and/or legally obliged to share this information with their siblings? In May 2015, a pregnant woman found out via her hospital that her recently deceased father had Huntington's disease; a debilitating genetic condition that results in the death of brain cells, with symptoms usually beginning between the ages of 30 and 50. Huntington's is an autosomal dominant condition (Dayalu and Albin, 2015), with a 50% risk for the child of inheriting the disease if just one of their parents has the condition. In this case, the woman's father had refused to let doctors inform her of his condition, as he worried that she may commit suicide or terminate her pregnancy. However, his diagnosis was released to the daughter accidentally. Her own screening then revealed that she too would develop Huntington's disease. The woman reported that she would have terminated her pregnancy had she been notified of the risk in time. She attempted to sue the National Health Service in the UK for not disclosing this information about her father, but a High Court Judge ruled that her case had no chance of success and struck it out (Dyer, 2015). Such issues will become significantly more common as genetic testing becomes more routine.

Further questions arise as genetic testing can be done just a few days after conception, with preimplantation genetic diagnosis becoming more routine in fertility treatments (Sermon et al., 2004). If such screening becomes routine for natural conception, then conditions such as Cystic Fibrosis, Huntington's disease, Phenylketonuria and Sickle Cell Anaemia could theoretically be eradicated within a few generations. Whilst eradication may seem to be a desirable outcome, eradicating genetic diseases will likely result in complications. For example, people with Sickle Cell disease are resistant to malaria, as are carriers of the sickle cell trait (Eichner, 2007). Furthermore, many genes are pleiotropic - they influence a number of different traits. One recent study has identified a genetic variation in East Asians that is known to protect from coronary heart disease, but to increase risk for age related macular degeneration (Cheng et al. 2015). Certain traits, that are usually conceptualised in disease terms, such as Schizophrenia (Horrobin, 2001), would be selected against in successive generations if they were solely detrimental. However, such traits persist, suggesting some possible evolutionary advantage. Most importantly, genetic variation is essential for evolution, with reduction in variation in a species hindering its ability to adapt to dramatic changes in the environment.

The ability to select for and against traits therefore presents ethical and practical dilemmas. If parents select for traits they feel will be beneficial to their children, might this limit the diversity and

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richness of society? If parents decide to continue with a pregnancy of a child who will require extensive and expensive health care for the entirety of their life, should they be allowed to and should the state have to pay for that care? Should the child be allowed to sue their parents for not terminating the pregnancy, or selecting for better traits? Finally, will everyone be able to afford genetic tests and have access to the relevant advice, guidance and genetic counselling? Will healthcare and educational establishments be sufficiently resourced to use this information beneficially for individuals?

As a first step towards addressing the multitude of genetics related issues, it is necessary to evaluate the level of genetic literacy and attitudes towards genetics across the population.

#### 2. Problem Statement

Previous studies of genetic literacy have mainly focused on genetic literacy in medical domains/personal well-being, with less attention paid to other applications of genetics (e.g. Erby, Roter, Larson, & Cho, 2008; Hooker et al., 2014; Hott et al., 2002; Molster, Charles, Samanek, & O'Leary, 2008; Pearson & Liu-Thompkins, 2012; Saul, 2013). They have also largely focused on well-defined populations such as undergraduate students and young adults (Carver et al., 2017; Fitzgerald-Butt et al., 2016). This research is limited, as it does not provide a comprehensive picture of genetic literacy in the population. Therefore, more comprehensive assessment instruments are required to capture the different aspects of genetic knowledge and its application across different socio demographic groups. The ultimate goal of this research is to aid the development of training and information tools to improve people's genetic literacy. This will allow people to: become more engaged with important genetic developments; make informed decisions about their own health and that of their family; and engage in social debates about how genetic information should be stored, accessed and used in various domains such as law, education and society.

## 3. Research Questions

To overcome limitations of previous research, a consortium of psychologists, geneticists, lawyers, educationalists and ethicists (The Accessible Genetics Consortium – TAGC) have developed the International Genetic Literacy and Attitudes Survey (iGLAS). iGLAS has been designed to evaluate what people know, think and feel about genetics and its multiple applications, including law, ethics, education and medicine. iGLAS is designed for population-wide administration, including different ages, occupations and education levels. iGLAS has multiple applications, including to identify: areas in which people have poor genetic knowledge; potential differences in knowledge across different demographic groups; and sources of information and misinformation and their impact on people's knowledge and opinions.

# 4. Purpose of the Study

The present study has two major aims: (1) to develop, pilot and validate the international population-wide assessment instrument – the International Genetic Literacy and Attitudes Survey (iGLAS); and (2) to make iGLAS available as a resource for research and educational purposes.

## 5. Research Methods

Development of the iGLAS instrument began in April 2015, as a collaborative venture between behavioural geneticists, psychologists, educationalists, lawyers and ethicists. These experts met to discuss issues related to applications of genetics and genetic communication. The collaboration led to the identification of key areas to be assessed by iGLAS, including knowledge related to 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 (GK); 8 items on heritability estimates; 17 items on opinions/attitudes; and 28 items on demographics.

**5.1. Genetic Knowledge:** Each member of the focus group was asked to supply questions that they felt would evaluate a reasonable (non-specialist) level of genetic knowledge. As the survey was to be disseminated online, questions had to be in a multiple-choice format with 1 correct and up to 3 incorrect options. All items were evaluated and any duplicates were combined into a single item. This resulted in 28 initial items assessing Genetic Knowledge (GK). Previous research established 6 main and 43 sub concepts as benchmarks of genetic content for non-major courses in the USA (Hott et al., 2002). As shown in table 1, each of the items selected to measure GK in the first iGLAS pilot were mapped onto these 6 main concepts.

**Table 01.** 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

Many of the concepts established in previous research (e.g., Hott et al., 2002; Bowling et al., 2008) 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 1, the first pilot of iGLAS focused on the nature of the genetic material, gene expression, and genetics and society.

It was decided not to include "don't know" options for the GK 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, when pressed, participants answer at an above chance level even if they do not think they know the correct answer (Mondak and Davis, 2001).

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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 4

options will be right 25% of the time, even if answers are given randomly.

5.2. Heritability Estimates: 8 items evaluating participant knowledge about the heritability of common

traits were included in the first draft of iGLAS. Traits were chosen to reflect iGLAS's interest in common

variance within the population and were: Height, Weight, IQ, Eye Colour, Depression, Motivation,

School Achievement and Sexuality. Previous studies that have asked questions about 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). However, 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 a combination of 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, this was revised to a 5-point scale,

as it was felt that a 0-10 scale too closely reflected heritability estimates - conventionally measured on a

scale of 0% to 100%. 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. For each

trait, participants were asked: "On a scale of 0-100 how important are genetics in the variability of the

following traits".

**5.3.** 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. These items are summarised in a table in Appendix 1.

**5.4.** 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 they 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.

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After several phases of screening, the first version of iGLAS was implemented using Qualtrics software (Qualtrics, Provo, UT). The validation then proceeded in 3 stages: Pilot 1 (iGLAS-P1), Pilot 2 (iGLAS-P2) and a test-retest analysis (iGLAS-P3).

## 6. Findings

#### 6.1. Pilot 1: iGLAS-P1

iGLAS-P1 was disseminated on line, primarily through social media (e.g. Facebook). Participants had to be 18 years or older, with no upper age limit. Participation in this pilot was restricted to those who had at least a degree level qualification.

**6.1.1.** iGLAS-P1 - Demographics: 78 participants completed iGLAS-P1(55 female). One participant identified as gender non-binary and one participant chose not to disclose their gender. The mean age of participants was 31.49 (SD = 10.15 Range 18 – 67). Most participants (79.5%) grew up in the UK, and the rest in 14 other countries. The following ethnicity categories (used in the UK national census) were reported by the participants: 76.9% -White (British/Irish/Other); 7.7% - Asian / British Asian; 5.1% - Black/African/Caribbean/Black British; 6.4% - mixed/multiple ethic groups; and 2.8% - other.

The following occupations were represented: 7 university lecturers; 38 university students; 14 parents; 2 primary care givers; 5 legal practitioners; 4 medical practitioners; 5 teachers; 8 government employees. Participants could select more than one option, so respondents may have been both parents and university lecturers, for example. This item was found to be too restrictive and so was addressed for iGLAS-P2. A section focusing on careers was included in iGLAS-P2. Several broad categories were presented to participants, with the option to add their own specific job role. To identify parents, participants were also asked if they had any children, and if so, if any of them were under the age of 16. The majority of the remaining demographic information was retained unchanged in iGLAS-P2. However, the item about ethnicity was excluded from iGLAS-P2, as it was felt this may alienate some participants, particularly given the sometimes-contentious relationship between genetics and race in previous literature (e.g. Herrnstein & Murray, 1996).

Level of Education: The categories used in iGLAS-P1 were selected as suitable for UK participants. For iGLAS-P2 these were revised to be more internationally applicable. Categories were added for pre-school certificate and tertiary education (further education in the UK, continuing education in the USA). Postgraduate education was subdivided into masters, doctoral and post-doctoral categories, resulting in 7 educational categories in iGLAS-P2.

One item in iGLAS-P1 ("In which country did you grow up") was judged by the participants to be vague. Instead, two separate items were included in iGLAS-P2. "In which country did you receive your secondary education" and "What is your current country of residence".

Based on the results of iGLAS-P1 and feedback from participants, for the question about sources of guidance, additional options were added for iGLAS-P2: "Seek Religious Guidance" and "Refer to self-help literature".

In iGLAS-P1 items related to religiosity, spirituality and political ideology were represented on slider scales. Participants who opted not to answer these items would have had responses recorded as zero, which would have indicated a meaningful score. To eradicate possible complications related to this, skip logic was added to iGLAS-P2, so that participants could opt out of answering questions about religion, spirituality and politics. The item on which popular science topics participants are interested in was shown to provide little useful data within the scope of iGLAS, and so was removed from iGLAS-P2. The question about confidence to discuss science topics participants did not feel they were experts in was also removed from iGLAS-P2, as it could not be corroborated with actual scientific knowledge.

6.1.2. iGLAS-P1 - Genetic Knowledge: The average GK score, as evaluated by iGLAS-P1, was 19.69 (SD = 4.41, range 11 to 28). This equates to an average correct score of 70.32%. Only one participant achieved 100%, and 3 achieved the lowest score of 11 (39.29% correct). For iGLAS, which includes multiple choice items with 1 correct and either 1, 2 or 3 incorrect options, the chance level for correct responses was 29% (approximately 8 correct answers). The lowest score of 39.29% suggested that this first draft of iGLAS included several times that were too easy as none of the respondents achieved at or near the chance level of 29%. Three items were identified as being too easy and showing poor variance. What is another way to describe monozygotic twins? (4 possible responses) 92.68% correct; What method can be used to collect a sample of someone's DNA? (4 possible responses): 97.53% correct; In what part of cells is DNA found? (4 possible responses): 91.46% correct.

Analysis was conducted on the pilot data to see if the GK scores fitted a single factor model. A Root-mean-square Error of Approximation (RMSEA) of 0.084 (90% confidence intervals 0.048 – NA) indicates a poor fit to a single factor model; a value of .06 or less is indicative of an acceptable model (Brown, 2015). Further, a parallel factor analysis revealed potentially 5 factors in the data, when compared to simulated data. Therefore, the questions included in iGLAS-P1 do not support any underlying factorial structure.

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. Instead, an evaluation of the items, based on the responses, was conducted in consultation with several 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: items aimed to evaluate how equipped participants are to discuss genetics in a meaningful way, rather than evaluate their knowledge of complex genetic, genomic and epigenetic processes.

For iGLAS-P2 16 items were removed (see table in Appendix 1 for justifications); 3 items were retained unchanged; 11 items were rephrased for clarity and to reflect that iGLAS-P2 would be conducted internationally; and 4 new items were added. This resulted in 18 GK items.

**6.1.3. iGLAS-P1 - Heritability Estimates:** For iGLAS-P1, participants were asked to estimate the heritability of 8 common traits. Apart from eye colour, each item showed acceptable limits for kurtosis, and all items had acceptable skew (see Table 2).

Table 02. Heritability Estimates from iGLAS-P1

Trait	N	Mean	Standard Deviation	Minimum	Maximum	Skew	Kurtosis
Height	78	78.4	12.5	49	100	-0.6	0.2
Weight	78	58.4	18.2	1	90	-0.6	0.6
IQ	78	29.8	21.7	0	100	-0.7	0.5
Eye Colour	77	90	14.3	30	100	-1.9	4.1
Depression	77	50.1	19.7	0	88	-0.2	-0.1
Motivation	77	34.3	22.2	0	100	-0.2	-0.4
School Achievement	78	39.2	22.3	0	84	0	0.5
Sexuality	77	46.4	29.1	0	100	-0.1	0.5

Note. Means represent the mean heritability estimate for each trait included in iGLAS-P1.

For 3 items (IQ, Motivation and Sexuality), responses included the full range of heritability estimates, suggesting these items may be quite divisive and that some participants saw these traits as either entirely genetic or entirely environmental.

For iGLAS-P2 it was felt that the term "heritability" was too easy to misinterpret. Therefore, the principle question in this section was reworded to: "On a scale of 0-100 how important are genetic differences between people in explaining individual differences in the following traits:" For clarity, sexuality was reworded to sexual orientation. To allow comparison with heritability estimates in the scientific literature, depression was more specifically defined as clinical depression.

**6.1.4. iGLAS-P1** - **Opinions:** Of the items included in the opinions section (see table in Appendix 1), two items: Learning about the relationship between our genes and illness is important for prevention and treatment and Learning about how exposure to certain environments may influence disease is important for prevention and treatment showed negative skew with 98.7% and 97.5% agreement respectively (above the neutral midpoint of "neither agree nor disagree"). Due to this lack of variation these items were excluded from iGLAS-P2. All other items had acceptable levels of skew and kurtosis, but several were reworded for clarity in iGLAS-P2 (see Table Appendix 1).

It was felt that having all items in this section on the same scale (1-7) would increase the chance of common method variance (Lindell and Whitney, 2001). Where appropriate to the question, some scales were altered and a marker variable, specifically intended to address common method variance was included: *Second language learning should be mandatory throughout compulsory education*. For iGLAS-P2 3 items were retained unchanged; 6 were rephrased for clarity (including one item being split in two); 5 items were removed; and 5 new items were added. These additional items included two vignettes intended to evaluate how people think genetics should be used in court cases and how influential they believe genetic influences are in the perseverance of violent tendencies in the absence of environmental influences (see table in Appendix 1). These vignettes were included to make iGLAS more engaging and thought provoking.

**6.1.5. iGLAS-P1** - **Conclusion:** The content of iGLAS was evaluated based on the results of iGLAS-P1, including statistical analysis, feedback from participants and consultations with behavioural genetics experts. Some participants commented that the instrument was too long and too difficult. It was

thought especially important to address the issue of length and difficulty, given that iGLAS was developed to provide a quick, easy and enjoyable tool for collecting information pertaining to what people know, think and feel about genetics. iGLAS-P2 consisted of: 18 Genetic Knowledge items; 8 heritability items; 18 opinion items; and 20 demographic items. An item was added, allowing participants to provide any feedback they wished.

**6.2. Pilot 2: iGLAS-P2:** iGLAS- P2 included English and Russian language versions. The English version was translated and back translated into Russian. The Russian version then underwent several stages of editing by experts, internal and external to the project. Two items were identified as possibly being poor candidates for inclusion in the Russian language study: the concept of spirituality was thought to have different connotations for English and Russian speaking populations; and concerns were raised that a left/right political spectrum may lack saliency for a majority of Russians. However, it was decided to retain these items for iGLAS-P2.

iGLAS-P2 was disseminated online via social media (e.g., https://facebook.com, https://vk.com and https://www.reddit.com/r/AMA). Participants were also recruited through an undergraduate research participation scheme at the University of London, with 112 students completing iGLAS-P2 at the same time on 17/11/2016.

**6.2.1.** iGLAS-P2 - Demographics: 5404 participants completed iGLAS-P2 (3304 female; 1923 male; 41 gender non-binary; 49 chose not to disclose their gender). The mean age of participants was 30.76 (SD = 8.96 Range 18 – 80). 71.4% of participants received their secondary schooling in Russia; 7.2% in the UK; 6.1% in Ukraine; and 4.98% in the USA. In total, 78 countries were represented in iGLAS-P2.

Table 03. iGLAS-P2 career responses

Occupation	N
Academic	480
Charity sector	853
Construction and maintenance	166
Education	40
Farming	73
Finance	240
Government employee	190
Housing and Accommodation	1522
Legal practitioner	92
Management	599
Medical doctor	384
Retired	45
Sales and office work	581
Unemployed	392
University Student	1126

From the free text option in the careers section it was evident that an option for Engineering, Computing and ICT was missing, and this was added to the final version of iGLAS.

1785 participants were parents: 936 had one child; 642 had 2 children; and 207 had 3 or more children. 1462 parents reported having children under the age of 16; 329 reported that their children were not under the age of 16; giving a total of 1791. Therefore, 6 participants did not report having children, but then reported the age of their children. Skip logic was applied to the final version of iGLAS, so that participants were only asked how many of their children were over 16 if they selected yes to having children.

With the exception of the item asking participants whether they might seek guidance from a psychic (Skew = 2.44, Kurtosis = 5.68), all opinion items showed suitably normal distributions. All items were retained in the final iGLAS.

**6.2.2. iGLAS-P2** - **Genetic Knowledge:** iGLAS-P2 included 18 GK items. The average GK score, as evaluated by iGLAS-P2, was 11.62 (SD = 3.17, range 2 to 18). This equates to an average correct score of 64.56%. 66 participants (1.2%) scored 100%, and 2 achieved the lowest score of 2 (0.04%). For iGLAS-P2 the chance level for correct responses was 29.17% (5.25 correct answers). 96 participants (6.2%) scored below this chance level. This resulted in a slight negative skew (-.233), suggesting that none of the items in iGLAS-P2 were too easy.

Analysis was conducted to see if the GK scores from iGLAS-P2 fitted a factor model. A Root-mean-square Error of Approximation (RMSEA) of .034 (90% confidence intervals 0.032 – 0.036) suggested a good fit to a plausible model. However, when compared to 20 simulations of random data, Eigenvalues suggest loadings onto 7 factors. As such, the questions included in iGLAS-P2 do not support any underlying single factor to genetic knowledge. This is to be expected, as GK is likely to represent a diverse knowledge base rather than a unitary construct, especially for those who have not specifically studied genetics. For example, parents may have a better understanding of genetic relatedness in siblings than non-parents, but are no more likely to be able to identify the base units of DNA.

**6.2.3. iGLAS-P2** - **Heritability:** With the exception of eye colour (skew = -2.77; kurtosis = 7.66), all heritability estimates in iGLAS-P2 showed normal distribution. Eye colour is often used as an example when Mendelian inheritance is taught at school, which might lead to a limited range of estimations. Therefore, divergence from normality might be expected for this item.

A whole range of responses emerged for heritability of all traits, with importance of genetic factors rated from 0 to 100% (see Table 4).

**Table 4.** Number and percentage of participants in iGLAS-P2 estimating trait heritability as either entirely genetic or entirely environmental

Trait	0% heritable	100% heritable
Height	31 (.6%)	905 (17.3%)
Weight	62 (1.1%)	225 (4.3%)
IQ	87 (1.6%)	239 (4.4%)
Eye Colour	86 (1.6%)	3242 (62.2%)

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Clinical Depression	227 (4.5%)	113 (2.2%)
Motivation	484 (10.1%)	56 (1.2%)
School Achievement	308 (6.3%)	51 (1.1%)
Sexual Orientation	419 (8.7%)	446 (9.3%)

All heritability items were included unchanged in the final iGLAS.

**6.2.4. iGLAS-P2** - **Opinions:** For iGLAS-P2, except for 2 items, all opinion items showed acceptable levels of skew and kurtosis. The 2 exceptions were: *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?* Skew = -2.45; Kurtosis = 6.93; *Scientific development is essential for improving people's lives*: Skew -3.41; Kurtosis = 13.76.

The first of these items was included to evaluate how likely participants are to engage with personal medical genetics. This is thought to be a key question in relation to engagement with genetics and so was retained for the final iGLAS. The item related to scientific development was excluded from the final iGLAS.

In iGLAS-P2 one item was included to evaluate Common Method Variance: Second language learning should be mandatory at school. This item was selected as it was thought to have no theoretical correlation with the other opinion items. However, it showed significant correlation with 13 items at <.05, indicating that this item was not performing to task. Alternatives were considered, such as the inclusion of several items asking respondents to select a designated response so that demand characteristics could be evaluated. However, iGLAS is intended to be a quick and accessible measure of genetic knowledge and opinions, and inclusion of several such items would be too disruptive in such a short measure. To reduce the effects of common method variance, iGLAS uses varied presentations of questions: multiple choice, Likert and slider scales.

- **6.2.5. iGLAS-P2 Conclusion:** Results from iGLAS-P2 indicated that most of the revisions from iGLAS-P1 were effective. To evaluate this further, additional test-retest analysis was conducted (iGLAS-P3).
- **6.3. iGLAS-P3: Test-retest Analysis:** 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. 14 students provided sufficient responses to allow for a test / retest analysis. The second wave of data collection was available to students between 2 and 4 months after the initial data collection. This is thought to be sufficient time to remove any confounding carryover effects.
- **6.3.1. iGLAS-P3 Genetic Knowledge:** The overall Pearson's R test-retest correlation for the GK section was .667 based on the summed GK score, which is thought to be good, given the time that elapsed between testing phases. The test-retest correlations for individual items can be found in Table 4. Although not significant t(13) -1.147, p = .272, there was a slight increase in GK between testing phases (Phase 1: M = 12.14, SD = 2.54; Phase 2: M = 12.79, SD = 2.55). At the retest phase participants were

invited to comment if they thought their GK had improved since the initial testing phase due to their studies or own interest. None of the participants noted any external variables that might have affected the test-retest correlation.

6.3.2. iGLAS-P3 - Opinions: The average test-retest correlation for the opinions section was .547. One item, We should use genetic research to learn how best to adapt environments to people's needs, for example through individualized health advice, was slightly negatively correlated (-.056). As for most of 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 this section increased to .582. 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. Based on this, it was decided to remove both items from the final iGLAS measure.

**6.3.3. iGLAS-P3** - **Conclusion:** The strength of the test-retest correlations from iGLAS-P3 suggests that iGLAS is a reliable and valid measure of what people know, think and feel about genetics.

**6.4. iGLAS-Final:** The final version of iGLAS takes approximately 15-20 minutes for most participants to complete. The structure of the final measure can be seen in Table 5. Display logic is employed, with some items presented only to the relevant participants (e.g., those who identified as having a particular occupation).

Table 5. The structure and content of the final version of iGLAS

Section	Content	Completion Time
Instructions and ethical	Description of the study, including items about	
agreement	data storage, use and deletion	1-2 minutes
Demographics and additional information	15 items; additional items are presented for parents and specific career paths (e.g., 2 items for legal professionals)	4-6 minutes
Genetic Knowledge (GK)	8 heritability estimate items; 17 multiple choice and true/false statements	4-6 minutes
Opinions	17 Likert scale items; 10 additional items for legal professionals	4-7 minutes
Vignettes	2 items; 3 additional items for legal professionals	2-5 minutes
Feedback	Total score for the GK section along with information about item response	

Two items from the GK section of iGLAS-P2 and iGLAS-P3 were combined into a single item. Participants' ability to answer the question 'On average, how much of the variable DNA is the same in siblings?' was dependent on their ability to answer the prior question 'What is variable DNA'. Instead, the following single item was included in the final version of iGLAS: All humans differ in the amount of

DNA they share. How much of this differing DNA do siblings usually share? The final iGLAS measure therefore consists of 17 genetic knowledge questions. The test-retest evaluation suggested that simply completing iGLAS does not lead to significant increases in genetic knowledge. To make iGLAS more attractive and useful to participants, it was decided to provide feedback for each of the GK items in iGLAS, as well as an overall GK score - directly on completion of the questionnaire. This feedback not only includes information about whether the participant's response was correct, but also some additional information about the concept being assessed through that item.

The two vignettes were removed from the opinions section of the Final version of iGLAS and presented separately. Two additional items were added to the final iGLAS opinions section: *I believe that genetic manipulation, such as gene editing, should be allowed for the prevention and treatment of disease* and *I believe that genetic manipulation, such as gene editing, should be allowed so that people can improve themselves and / or their children.* These items were included after further consultation with genetic experts as it was felt that previous versions of iGLAS did not cover these important topics.

To be able to investigate certain groups further, the final iGLAS includes additional items for selected occupations: Law, Education and Medicine. These more in-depth assessments add additional 2-5 minutes to the total testing time. Further items can be added to explore other groups of interest in-depth. Display logic was employed so that such items would only be presented to participants who had identified the appropriate career. For example, if a participant identifies their career as "education", they are then presented with questions about their specific role, with teachers being asked whether they work in primary or secondary school and their years of employment as a teacher. Secondary school teachers are then asked which subject(s) they teach, but primary school teachers are not. Details of this tailoring, which can be added to as research develops, can be found in Figure 1.

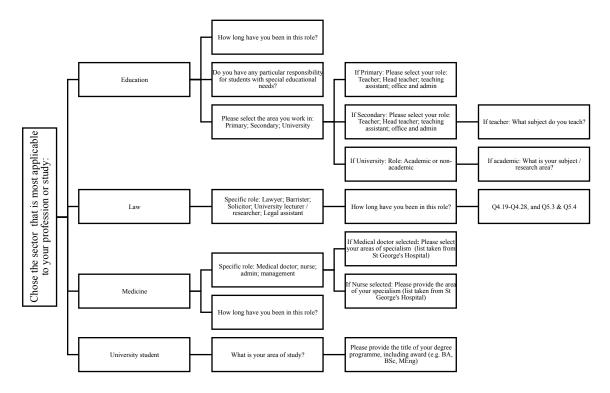


Figure 01. iGLAS display logic for specific career and educational paths.

The demographic section of the final iGLAS consists of 14 base questions. Parents are asked to identify how many of their children are under the age of 16. The opinions section of iGLAS consists of 17 items, of which 15 were retained from iGlAS-P2. The following 2 items were added after consultation with experts in legal and ethical genomics, both assessed on a 7-point Likert scale from Strongly disagree to Strongly agree: (1) In the same way as there is socio-economic disadvantage, there is genetic disadvantage; and (2) We should make provisions (legal and policy) to buffer the effects of genetic disadvantage on individuals (e.g. tailored education).

The final iGLAS is designed for flexible use, by adding items tapping into knowledge or opinions of specific groups of interest. For example, we developed a version of iGLAS that focuses on ethical and legal implications of genetics. This version is currently being tested with participants who identify their career as "Law", who complete several additional items and vignettes. Further developments of iGLAS can include additional specific items for other career paths of interest, such as medicine and education. Specified career paths also include additional demographic items as indicated in Figure 1.

#### 7. Conclusion

The present study was intended to develop a tool for evaluating the general public's awareness of genetics. iGLAS does not just focus on medical applications, as has often been the case in previous studies, but also assesses general and social applications of genetics. iGLAS also evaluates what people think and feel about genetics and personal genomics. The genetic knowledge section of iGLAS provides a quick and usable evaluation of what people understand about genetic concepts that are necessary for engagement in contemporary debate. The opinions section of iGLAS covers a broad array of contemporary issues and the demographic details allow for useful stratification, so that appropriate interventions and educational tools can be used for different groups (e.g., professionals, students). The provision of an overall genetic knowledge score and feedback on each item should help participants learn from their engagement with this study and improve their ability to engage in genetics research and debates.

The flexibility of iGLAS is its particular strength. Previous studies on public engagement with genetics have targeted specified populations, most often undergraduate students and young adults. iGLAS can be applied effectively to diverse populations. In addition, it allows for tailoring, to enable research with specific groups, including those previously poorly represented. The design of iGLAS also accommodates new adaptations in response to rapid advances in genetic research and related societal issues.

## **Using iGLAS**

The final version of iGLAS is available here:

https://goldpsych.eu.qualtrics.com/jfe/form/SV 0oG9w9iDMrJ9l2t

iGLAS is free to use and is available on request from the authors. We welcome collaborations, including adaptations to other languages and joint data analyses.

To cite iGLAS, reference this paper and include the following link:

https://goldpsych.eu.qualtrics.com/jfe/form/SV 0oG9w9iDMrJ9l2t

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Table Appendix 1. Items from Pilot 1 and 2 with reasons for inclusion and exclusion

	Genetic Knowledge	2	
Pilot 1	Pilot 2	Reason for Exclusion	Reason for inclusion/amendment
What is a genome?	=		Unchanged
Which of the following 4 letter groups represent the base units of DNA?	=		Unchanged
In what part of cells is DNA found?	-	Lack of variation. 91.46% got this item correct	
How many chromosome pairs do we have in our cells?	AMENDED In humans, DNA is packaged into how many pairs of chromosomes?		Reference to "cells" was thought to be confusing as this would have included gametes.
What is the main function of DNA?	AMENDED What is the main function of all genes?		Item rephrased as much of the DNAs function is not protein synthesis
On average, two people selected at random will share how much of their DNA?	AMENDED On average, how much of their total DNA is the same in two people selected at random		Rephrased for clarity
Each of us has complex differences to each other. What is the most likely reason for this?	-	Lack of variation. 82.93% identified this as a combination of genes and environments.	
How many copies of each gene are there in our body?	AMENDED How many copies of each gene do we have in each cell?		Rephrased for clarity
	+ What is variable DNA		This item was included to establish if participants had an understanding of variable DNA
On average, how much of the DNA that varies between humans do non-identical twins share?	AMENDED On average, how much of the variable DNA is the same in siblings?		Rephrased to reflect the above item
What is heritability?	-	In English, there is a distinction between heritability and heredity, this distinction is not applicable to all languages.	
When something is heritable it means that genetic information is:	-	In English, there is a distinction between heritability and heredity, this distinction is not applicable to all languages.	
What is the function of epigenetics?	AMENDED An Epigenetic change is:		The term "Function" was thought to be too teleological.
Who coined the term the "Selfish Gene"	-	This item was not felt to assess useful GK. I.e., it did not reflect an ability	

		to usefully discuss genetics	
What is a Deoxyribonucleic Acid?		Item removed for lack of variance (82.5% of responses were correct)	
It is estimated humans have how many genes?	AMENDED Approximately how many genes does the human DNA code contain?		Rephrased for clarity
When it comes to genetics, human traits such as sexuality are usually influenced by:	-	This item was added to the heritability scale	
	+ Genetic contribution to the risk for developing Schizophrenia comes from:	This and the following item were included to see if participants saw complex conditions as the product of a single genetic variation and to see if responses differed for psychopathological and neurodevelopmental conditions	
	+ Genetic contribution to the risk for developing Autism comes from:	This and the previous item were included to see if participants saw complex conditions as the product of a single genetic variation and to see if responses differed for psychopathological and neurodevelopmental conditions	
Who wrote: On the origin of species by means of natural selection	-	This item was not felt to assess useful GK. I.e., it did not reflect an ability to usefully discuss genetics. Also 98.78% of responses were correct.	
What are polymorphisms?	= What are polymorphisms?		Unchanged
What method can be used to collect a sample of someone's DNA?	-	97.53% correct responses. This item was not felt to assess useful GK. I.e., it did not reflect an ability to usefully discuss genetics	
	+ The DNA sequence in two different cells, for example a neuron and a liver cell, of one person, is:		Item included to evaluate if participants are aware that DNA is stored in every sell of the body
Which two scientists are credited with discovering the structure of DNA	-	This item was not felt to assess useful GK. I.e., it did not reflect an ability to usefully discuss genetics. 81.48% correct	
What is another way to describe monozygotic twins?	-	Insufficient variation 92.68% correct	
Approximately 85%-92% of the human genome does not code for protein. This is correctly known as:	AMENDED "Non-coding" DNA describes DNA that:		Item reworded as there is contention between the terms Junk/non-coding DNA.

Artificial genetic modification is only possible now that DNA can be manipulated directly?	AMENDED Genetic Modification is: (Selective Breeding/Genetic Engineering/Both/neither)		Rephrased for clarity
Someone's genes can accurately predict complex behaviors and traits regardless of one's environment:	AMENDED Can we predict a person's behaviour from looking at their DNA sequence?		Rephrased for clarity.
At present in the UK new born infants are tested for certain genetic traits.	AMENDED At present in many countries, new born infants are tested for certain genetic traits.		Changed to reflect international dissemination of iGLAS
What do you think influences the DIFFERENCES seen in siblings raised in the same family?	-	Insufficient variation in the data. 87.8% of responses correct. This is also an opinion not a knowledge item.	
What do you think influences the SIMILARITIES seen in siblings raised in the same family?	-	Insufficient variation in the data. 82.72% of responses correct. This is also an opinion not a knowledge item.	
For most traits, genetic influences remain stable across the lifespan:	-	This item was judged too ambiguous as "most" traits was not defined.	
	Opinions		
Pilot 1	Pilot 2	Reason for exclusion	Reason for inclusion
If genetic testing could allow you to have improved treatment (for example, medication with fewer side effects) how likely would you be to take that test?  7 point Likert Scale	AMENDED 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?  7 point Likert Scale		Reworded for clarity
Preventing health problems is preferable to curing health problems?  7 point Likert Scale	-	Lack of variation in response. 92.4% agreed to some extent.	
Learning about how exposure to certain environments may influence disease is important for prevention and treatment 7 point Likert Scale	-	Lack of variation in response. 97.5% agreed to some extent.	
Understanding how genes influence motivation and academic achievement is important for understanding how to best tailor education to individuals 7 point Likert Scale	Understanding how certain genes influence academic achievement is important for understanding how to best tailor education to individuals.  7 point Likert Scale		Unchanged
Understanding how certain environments (classroom size, teacher qualification etc) influence academic achievement is important for understanding how to best tailor education to individuals 7 point Likert Scale	AMENDED Understanding how certain environments influence academic achievement is important for understanding how to best tailor education to individuals 7 point Likert Scale		Item rephrased so that wording was more like the item above. Presentation of these two items was separated.
How would you rate the political stability of your country of residence?  7 point Likert Scale	-	This item was thought too volatile, not only due to changes in local political stability, but also as	

	T		<del> </del>
		respondents may not have lived in their country of	
		residence for a long	
		period.	
Do you agree that your government		Item removed for	
prioritizes its citizens best interests?	_	ambiguity as	
7 point Likert Scale		governments are	
-		multifaceted.	
How effective is DNA analysis in predicting someone's behaviour?	_	Item was replaced with	
7 point Likert Scale		the two Vignettes below	
	+		
	Bill was adopted at birth,		
	both his biological parents		Included to
	have served jail time for		provide variety to
	violent crimes, as did his		the survey and to evaluate whether
	paternal grandfather. His adopted parents have no		participants
	such convictions. How		consider violence
	likely do you think it is that		to be influenced
	Bill will also have a		by genetic factors.
	tendency towards violence?		
	7 point Likert scale		
	Sarah has a particular		
	genetic variance that has		
	been associated with		
	aggression. She is in court		
	being tried for a violent		Included to
	crime. Should knowing		provide variety to
	about this genetic variation?		the survey and to
	4 options:  • Reduce her		evaluate how
	sentence		participants feel genetic
	Not be taken into		information
	consideration		should be used in
	<ul> <li>Be considered but</li> </ul>		legal cases
	make no		
	difference to her		
	sentence • Increase her		
	sentence		
	AMENDED		
Research institutions in your	I do not trust research		Initial item was
country of residence are properly	institutions in my country		too abstract.
regulated and accountable?	because they might misuse		Rephrased to be
7 point Likert Scale	the data obtained from participants?		more precise.
	7 point Likert Scale		
	=		
Consuming genetically modified	Consuming genetically		
food is perfectly safe?	modified food is perfectly		Unchanged
7 point Likert Scale	safe		
	7 point Likert Scale		
When you are ill, how likely are	When you are ill, how		
you to turn to alternative medicine	likely are you to turn to		
(such as homeopathy) rather than	alternative medicine (such		Unchanged
seeking treatment from	as homeopathy) rather than		3
conventional medicine? 7 point Likert Scale	seeking treatment from conventional medicine?		
/ point Likert Scale	7 point Likert Scale		
Studies showing genetic influences	AMENDED		Item rephrased for
in mental health difficulties	Studies showing genetic		clarity. Previously
(depression, schizophrenia, bi-polar	influences on mental health		negatively
etc.) help to reduce stigma:	problems (depression,		phrased, which

7 point Likert Scale	schizophrenia, bi-polar disorder etc.) lead to increased stigma for people with those conditions: 7 point Likert Scale	can be confusing for participants.
I believe that genetics studies should be used only to understand how nature works and not to manipulate it, even if it is to improve people's health and quality of life.  7 point Likert Scale	AMENDED I believe that, if it is possible to manipulate DNA to improve health and happiness, it should be done. 7 point Likert Scale	Initial question separated into two (see below) to provide further information.
	We should use genetic research to learn how best to adapt environments to people's needs, for example through individualized health advice 7 point Likert Scale	Initial question separated into two (see above) to provide further information.
I feel suspicious about genetic studies; hidden political/economic agendas may be behind them.  7 point Likert Scale	I feel suspicious about genetic studies; hidden political/economic agendas may be behind them.  7 point Likert Scale	Unchanged
Scientific development is essential for social progress 7 point Likert Scale	AMENDED Scientific development is essential for improving people's lives: 7 point Likert Scale	Social progress was thought to be ambiguous in this context. Item rephrased
	+ I believe that my destiny is written in my genes: 7 point Likert Scale	Included to evaluate if participants feel that genetics are deterministic
	+ If genes influence our behaviour then there is no free will: 7 point Likert Scale +	Included to see how participants feel about genes and free will
	Second language learning should be mandatory throughout compulsory education 7 point Likert scale	Item included to help control for common method variance.
	How likely would you be to give a sample of your DNA for scientific research if your data are stored anonymously?  7 point Likert scale	Included to see how willing participants are to engage with genetic research
Note: '=' indicates item included	+ How confident are you in your genetics knowledge? 100 point slider scale	Included to evaluate knowledge calibration

Note: '=' indicates item included unchanged from Pilot 1; '-' indicates item excluded after Pilot 1; '+' indicates item added after Pilot 1; 'AMENDED' indicates item amended from Pilot 1.