D2.5: Public views on genetics, genomics and gene editing in 11 EU and non-EU countries

WP 2 – Human genetics and genomics: ethical, legal and social analysis

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[1]The University of Uppsala, as work package 2 leader, developed the content of the questionnaire, own the data and plan to further analyse and contextualise the data for publication in academic journals. While UU helped to edit this report, they cannot take responsibility for this report.

[2] The University of Twente as coordinator of SIENNA is the official entity who sub-contracted the work for this report from Kantar.

This report has been developed as a part of the SIENNA project funded by the European Commission; for the period October 2017 to March 2021 (http://www.sienna-project.eu). SIENNA involves the study of the ethical, legal and social issues (ELSI) of three different technology areas, namely Artificial Intelligence/Robotics, Human Enhancement and Human Genomics. The ELSI study of each of these technology areas was predominantly conducted by performing seven distinct tasks presented in as many reports. Herein is presented the results of one of these tasks, namely the quantitative investigation of public views and awareness of the three SIENNA technologies.

This report has been predominantly developed by a social and policy research company, Kantar (www.kantar.com/public), which was subcontracted to conduct this task for each technology area. Kantar conducted the fieldwork (e.g. pilot questionnaire, conduct telephone survey), while the academic partners provided, to varying degrees, the content for the questions for the telephone survey. Kantar performed the analyses and were responsible for the reports.

Important context: Obtaining lay publics' views on novel technologies poses many challenges; trying to obtain views on the ELSI of novel technologies is even more difficult and while the exercise may provide some insights on non-expert views it also has important limitations. First, challenges are related to the use of empirical approaches in Bioethics, which unfortunately often lack strong underlying methodology and critical review given the inter- and multidisciplinary nature of the field. This is particularly true here, as all three technological areas are large and ELSI studies are by definition multidisciplinary. Second, these characteristics also make the scientific and ethical issues discussed challenging to grasp to the broader public. Thirdly, using telephone interviews (aimed to last approximately 15 for all three technology areas) meant that very little time was available for obtaining respondents' answers (in some cases, five minutes or less were available for one technology area). Hence, due to time constraints, participants may not have had the time required to reflect on the questions posed. This should be considered when interpreting the results of this survey.

Due to space constraints, not all methodological details could be included to necessarily satisfy readers with different areas of expertise. To fully understand the results and their meaning, further analysis is needed, and it may be conducted by one of the academic partners in the project and communicated through academic publications.

Finally, it is important to emphasize that the results of empirical research about publics' views and preferences are not meant to answer policy questions, and we caution against the over-interpretation of these results outside of the research context. Indeed, we see such results as being able to inform policy questions (refine them, add to them, guide them) but not as answers per se since this is not the context in which the questions were posed.

Prof. Philip Brey, SIENNA Coordinator

Abstract

Based on a telephone survey of 1,000 people in each of 11 countries (*EU*: France, Germany, Greece, the Netherlands, Poland, Spain, Sweden; *non-EU*: Brazil, South Africa, South Korea, USA), this report provides a snapshot of awareness, understanding and opinions on human genetics and genomics in 2019. Most respondents, in all countries, had at least heard of both genetics or DNA and gene editing in humans. However, there was variation between countries in the proportion of respondents who said they had seen or heard a lot or a fair amount about these areas. The majority of respondents in all countries felt that it was important for people to understand more about genetics or DNA. Opinions regarding experimenting on human embryos differed based on the purpose of the research. Generally, it was thought of as unacceptable to carry out research on human embryos for 'any purpose' or to 'increase human intelligence'. However, the majority of respondents thought this would be acceptable if the purpose of this research was to understand 'how to treat or cure severe health conditions. Respondents were split on whether researchers understood the health risks and benefits of changing an unborn baby's DNA, as well as on who should be responsible for decision making about how genetic technologies are used. Opinions varied between countries on whether all babies should have their all DNA analysed at birth. In some countries, a majority agreed with this statement and in other countries, a majority disagreed with the statement. In all countries, a majority of respondents agreed that the termination of pregnancies as a result of genetic tests would lead to disabled people becoming less accepted in society, and that parents would come to feel pressured to have genetic tests on their unborn babies if the practice becomes more common.

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Information in this report that may influence other SIENNA tasks

Linked task	Points of relevance
Task 2.7: Proposal for an ethical framework	Survey results will be consulted in the development of the ethical framework
Task 5.2: A code of responsible conduct for researchers in human genomics	Survey results will be consulted in the development of the Code.
Task 6.5: Reconcile needs of researchers and the legitimate concerns of citizens	The survey results will be used as input for task 6.5.

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Executive summary

Introduction

As part of the SIENNA project, an exploratory telephone-survey of the publics' views and opinions was conducted in 11 countries, including seven EU countries (France, Germany, Greece, the Netherlands, Poland, Spain and Sweden) and four countries outside Europe (Brazil, South Africa, South Korea and the USA).

The survey aimed to obtain information about the publics' perceptions of genomics in relation to a range of applications as well as self-reported levels of awareness of genomics. In particular, the survey addressed genomic sequencing, and gene editing (also known as genome editing).

Self-reported awareness of genetics (or DNA)

Based on an all country average[3], 94% of respondents reported having heard or read at least something about genetics or DNA. Overall, 17% said they had heard or read 'a lot', 33% 'a fair amount', 33% 'a little' and 12% 'hardly anything'.

Results varied by country. Respondents in Germany (68%) and South Korea (68%) were most likely to report having heard or read a lot or a fair amount about genetics or DNA. Those in South Africa (36%), Poland (34%) and Spain (32%) were least likely to report having heard or read a lot or a fair amount about this.

More than four in ten respondents in South Africa (43%) said they had heard or read hardly anything or nothing about genetics or DNA, a far higher proportion than in any other country.

Across all countries, those with university degrees were more likely to say they had heard or read a lot or a fair amount about genetics or DNA than those without degrees.

Public perception on the need to know more about genetics

Based on an all-country average, 87% of respondents said it was important for the public to understand more about genetics. This was the case for at least eight in ten respondents for all countries surveyed. Those in South Africa were most likely to say this was important (94%).

Responses to this question are associated with how much people had heard or read about genetics, with those who had heard or read more being more likely to say it was important for the public to understand more about genetics.

Basic knowledge about genetics

Respondents were asked three true or false questions regarding genetic tests and changing DNA in human cells.

[3] The average result across the 11 countries surveyed. This means that all 11 countries surveyed contribute equally towards the average, regardless of the number of surveys completed in that country or the population total of the country.

In all countries, the majority of respondents (55% to 98%) answered each of the three questions correctly. Based, on an all-country average, the highest proportion responded correctly to the statement 'Genetic tests can help diagnose a disease', with 91% selecting this as true.

Overall, 84% of respondents correctly responded to the statement 'Genetic tests can predict whether an unborn baby will be born with Down's Syndrome' as being true. A slightly smaller proportion (76%) correctly said that 'Researchers are working on changing the DNA in human cells to treat diseases' was true.

For all three statements, respondents in South Korea and South Africa were least likely to be correctly answered, though the majority still selected the correct answer in each case.

Those with university degrees were more likely than those without degrees to answer each of three questions correctly.

Based on an all country average, two thirds of respondents answered all three true or false statements correctly (62%). Respondents in Spain (75%) were most likely to answer all three statements correctly with those in South Africa (35%) least likely.

Perceptions of consequences of increased prenatal testing on persons with disabilities and on prospective parents

Respondents were asked to consider the likelihood of two hypothetical scenarios in relation to genetic testing during the prenatal period:

- How likely did they think that disabled people would be less accepted by society if more and more women choose to terminate their pregnancy due to the result of a genetic test, and
- How likely did they think that parents would feel pressured to have a genetic test done on their unborn baby if genetic testing on unborn babies becomes increasingly common.

Based on an all-country average, two-thirds of respondents (67%) said it was likely (33% said very likely and 34% said fairly likely) that disabled people would be less accepted by society if more and more women choose to terminate their pregnancy due to the result of a genetic test. The majority of respondents in all survey countries felt this would be likely.

Again based on all countries, eight in ten respondents (79%) said it was likely (39% saying both very likely and fairly likely, respectively) that parents would feel pressured to have a genetic test done on their unborn baby if genetic testing on unborn babies becomes increasingly common. At least two thirds of respondents said this would be likely in each of the 11 countries surveyed.

Perceptions on analysing all genes/DNA at birth

Respondents were asked how much they agreed or disagreed that all babies should have all their genes/DNA analysed at birth.

Based on an average across all survey countries, just over four in ten (43%) agreed that all babies should have their genes analysed at birth, with 22% strongly agreeing and 22% tending to agree. Just under four in ten (36%) disagreed, with 17% tending to disagree and 19% strongly disagreeing.

There was substantial variation between countries. Respondents in South Africa (75%) were most likely to think that all babies should have their genes analysed at birth; respondents in Germany (22%) were least likely to think this.

In half the countries? most countries, men were more likely than women to agree with this statement.

Self-reported awareness of gene editing

Based on an all country average, 80% of respondents reported having heard or read at least something about gene editing in humans. Overall, 6% said they had heard or read 'a lot', 18% 'a fair amount', 31% 'a little', and 25% 'hardly anything'.

Looking at those saying they had heard or read a lot or a fair amount about gene editing in humans, self-reported awareness was highest in Germany (40%) and South Korea (39%) and lowest in Poland (9%), Spain (13%) and Sweden (14%).

As with self-reported awareness of genetics, those with university degrees were more likely to have heard or read a lot or a fair amount about gene editing in all countries apart from Spain and Germany.

Public perception of what experts know about gene editing

Respondents were asked how well they thought researchers understood the health risks and benefits of changing an unborn baby's DNA.

Opinions on this issue were divided. Based on an all-country average, 48% and 46% thought that researchers understood this well and not well respectively.

In France, Germany, Poland, Spain and South Africa respondents were significantly more likely to say they thought researchers understood the risks and benefits well compared with not well. Respondents in the USA, Brazil and Sweden were significantly more likely to say that researchers did not understand this well (in the USA 67% said not well, compared with 28% saying they understood the risks and benefits well). In the Netherlands, Greece and South Korea, opinions were split fairly evenly.

Perceptions regarding research with embryos

All respondents were presented with three statements regarding conducting laboratory experiments on human embryos and asked how acceptable they considered each to be.

Responses varied based on the purpose of the experiments. Based on an all-country average, the majority of people felt it was unacceptable to 'use human embryos in laboratory experiments for any purpose' (60% unacceptable) and to 'conduct laboratory experiments on human embryos to understand how to increase human intelligence' (65% unacceptable). However, most said it would be acceptable to 'conduct laboratory experiments on human embryos to better understand how to treat or cure severe health conditions' (65% acceptable).

Men and those saying religion was not important to them were more likely to see each of these uses of human embryos as acceptable in most countries.

Responsibility for decision-making in genetics

Respondents were asked who they felt should be most responsible for making decisions about how genetic technologies are used.

Based on an all-country average, opinions were divided over who should hold most responsibility. Scientists were most commonly mentioned (25%) but 19% of respondents selected medical doctors, 16% patients with a genetic disease, 15% the government, 12% the public, and 9% someone else.

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List of acronyms/abbreviations

Table 1: List of acronyms/abbreviations

Abbreviation	Explanation
CATI	Computer Assisted Telephone Interviewing
DNA	Deoxyribonucleic acid
EC	European Commission
EU	European Union
RDD	Random digit dialling
SIENNA	Stakeholder-informed ethics for new technologies with high socio-economic and human rights impact

Glossary of terms

Table 2: Glossary of terms

Term	Explanation
All country average	The average result across the 11 countries surveyed. This means that all 11 countries surveyed contribute equally towards the average, regardless of the number of surveys completed in that country or the population total of the country.
CATI surveys	A survey conducted by telephone (CATI stands for 'Computer Assisted Telephone Interviewing').
Cognitive testing	A qualitative questionnaire testing technique that examines how well questions perform when asked of respondents. It aims to explore how respondents understand, mentally process and respond to questions and identify where problems are experienced.
Confidence interval	The range of values that is likely to include the true population value of a survey estimate. For example, if a survey estimate is 50% and a confidence interval is +/-4%, then based on a 95% confidence interval, we can be 95% certain that the true population value is between 46% and 54%. The size of the confidence interval is impacted by the size of the survey sample and the impact of weighting on the results.
Demographic subgroup	A sub-sample without the overall survey sample based on demographic characteristics – for example, women, 35 to 54-year olds or people with a university degree.
Design effect	A value which shows the impact of weighting on the survey results.
Design weighting	A stage of weighting that corrects for different probabilities of selection. For this survey this was based on telephone types the respondent had access to (landline/mobile) and the number of adults aged 18+ living in the household.
DNA	A molecule which contains genetic information. It is made of nucleotides, each of which contains a deoxyribose sugar, a phosphate and one of four bases (adenine, guanine, thymine, or cytosine). The order of the nucleotides is a DNA sequence

Term	Explanation
Dual frame design	A telephone survey sample design that includes both landline and mobile phone numbers.
EU average	The average result across the 7 EU countries surveyed. This means that all 7 EU countries surveyed contribute equally towards the average, regardless of the number of surveys completed in that country or the population total of the country.
Gene	A gene is a sequence of nucleotides, a fragment of DNA or RNA, which is a functional unit of inheritance. A gene usually contains information about the sequence of amino acids in a protein or polypeptide, however, it may have a function of controlling expression of other genetic material
Gene editing	Approaches of introducing modifications to a genome
Genetic tests	This was defined in the survey questionnaire as follows: "We are now going to ask you about genetic tests – these are also known as DNA tests. These tests are done by analysing samples of blood, saliva or body tissues. They can determine whether you, a family member, or an unborn baby carries genes for certain inherited features, including genetic diseases, or traits like height and eye colour."
Genomics	A field of biology focused on studying genomes. It uses high-throughput technologies, which produce large quantities of data, mainly sequencing data. Traditional genetics focuses on studying a few genes at a time; genomics meanwhile, provides insights into whole genomes thanks to advanced technologies, such as next generation sequencing
Human embryo	The survey questionnaire introduced a human embryo to respondents as follows: "An embryo is an unborn baby at a very early stage of development, up to eight weeks after conception. Scientists sometimes use human embryos in medical research."
Pilot	A fieldwork test of the survey with a small number of respondents conducted prior to the main fieldwork period.
Random digit dialling (RDD)	A method for selecting people for involvement in telephone surveys by generating numbers at random (for this survey, using country numbering plans as a frame).
Response rate	The number of respondents to complete a survey divided by the total sample of phone numbers attempted (excluding any numbers known to be eligible).
Rim weighting	A stage of weighting that adjusts key sample demographics (e.g. age band, gender, level of education) to be reflective of the target population.
Rizzo method	An approach to select one adult at random in sampled households commonly used in telephone surveys.
Significance test	A statistical test which determines whether relationships (e.g. differences) observed between two survey variables or groups are likely to exist in the population from which the sample is drawn.
Weighting	An adjustment to the survey data to account for different probabilities of selection and differences in likelihood to complete the survey between different population groups.

1. Introduction

1.1 Background: overview of the SIENNA project

SIENNA (Stakeholder-informed ethics for new technologies with high socio-economic and human rights impact) is a three-and-a-half-year project (October 2017 – March 2021) that has received funding under the European Union's H2020 research and innovation programme under grant agreement No 741716. It has 11 core partners and 2 associate partners. The project focusses on ethical and human rights challenges posed by human genomics, human enhancement and AI and robotics.

While technologies used in human genomics, human enhancement and AI and robotics might offer significant benefits to individuals and society, they also present significant ethical challenges, e.g., in relation to human autonomy, equality, personal liberty, privacy, and accountability. In collaboration with a variety of stakeholders, SIENNA is identifying and assessing the ethical and socio-economic issues, public opinions, legal and human rights implications of each of these technology areas.

SIENNA will produce a framework for each of the three technologies that will form the basis for the development of research ethics protocols, professional ethical codes, and better ethical and legal frameworks. Before developing their recommendations, the partners are gathering views of experts and citizens towards the three technologies in four ways: (1) a major survey of citizens in 11 countries within and outside the EU; (2) panels of citizens in five countries; (3) interviews with experts and stakeholders; (4) workshops with stakeholders including scientists, ethicists, research ethics committees, professional organisations, civil society organisations, industry and policy makers. This report presents the results of the survey.

1.2 Objectives of the survey

A key feature of the SIENNA project is that stakeholders, including the general public, will be engaged throughout the process. The involvement of the general public is particularly important; research and innovation into new and emerging technologies carries an ongoing risk of being in tension with public concerns. It is therefore crucial to gain insights into and consider such concerns. One method of exploring the general publics' views of the SIENNA project is through empirical research.

SIENNA commissioned Kantar to conduct telephone public opinion surveys in 11 countries.[4] This included seven EU countries (France, Germany, Greece, Netherlands, Poland, Spain and Sweden) and four countries outside of Europe (Brazil, South Africa, South Korea and the United States). The survey aimed to obtain information about the publics' perceptions of human genomics, human enhancement and AI and robotics in relation to a range of applications as well as self-reported levels of awareness. In human genomics, the survey addressed genomic sequencing, and gene editing (also known as genome editing).

[4] We explain the reasons for selecting these 11 countries in section 2.2.

1.3 Structure of the report

This report sets out the findings from the public opinion survey on genomics across 11 countries. The report is structured as follows:

- In section 2, we provide an overview of the survey methodology.
- In section 3, we look at self-reported awareness genetics.
- In section 4, we look at public perceptions on the need to know more about genetics.
- In section 5, we look at basic knowledge about genetics.
- In section 6, we look at perceptions of the consequences of increased prenatal testing on persons with disabilities and prospective parents.
- In section 7, we look at public perceptions on analysing all genes or DNA at birth.
- In section 8, we look at self-reported awareness of gene editing.
- In section 9, we look at public perceptions of what experts know about gene editing.
- In section 10, we look at perceptions regarding research with embryos.
- In section 11, we look at perceptions regarding responsibility for decision making in genetics.
- In section 12, we draw conclusions from the results across all sections of the survey.

1.4 Scope and limitations

The survey was designed to deliver information in relation to human genomics. While data was successfully obtained from 11,000 respondents, there were limits to the scope and approach of the survey that should be considered when interpreting the results:

- Some of the topics and questions planned for inclusion in the survey were felt to be too complex based on current levels of public understanding. This was found in the cognitive testing phase conducted in the Netherlands, Poland and South Africa (see section 2.3), with several changes made to simplify question content following this. While simplifications were made to the questionnaire following testing, and definitions were added to help guide respondents, we cannot fully assess how well respondents understood all of the concepts and questions covered in the final questionnaire. Furthermore, the need to simplify the survey content may have resulted in questions lacking details or specificity. This should be considered when judging the use of the results for any policy-oriented work.

- Due to the budget allotted to the empirical work (approx. €1 million for both the panels, reported in D2.6, and the surveys reported here), the target questionnaire length to cover all three technology areas was very short (an average of 15 minutes in total and 5 minutes per technology area). In such a short time, we could only cover a few areas of use and for each use we could only ask a few relatively simple questions with simple close ended answers.

- The questionnaire was originally drafted in English and translated into each of the languages used for the survey. While attempts were made to ensure equivalent understanding of terms between languages (for example, providing translators with notes to convey the meaning of certain terms), we cannot be sure that all questions and response options were interpreted in completely comparable manner between languages.

- While attempts were made to deliver a representative sample in each country (see section 2.4), it is possible that those with more interest or awareness of the survey topics were more likely to agree to participate and to complete the survey. For example, we found in most countries that the proportion of the surveyed sample with a university degree was higher than we would expect for a nationally representative sample. Any observable bias in the surveyed sample was corrected through weighting (see section 2.6).

- As shown in section 2.5, the responses rates achieved in each country ranged between 2% and 8%. While these response rates are similar to those achieved for similar surveys, they do show that only a minority of those selected to take part in the survey chose to do so. This may limit the extent to which the results can be seen as representative of the views of the adult population in each country.

- The survey was conducted by telephone in all countries. This meant that responses needed to be provided immediately in response to the survey questions and respondents could not spend much time considering their options.

- "Don't know" and "Refused" options were available at every question but were not read out to respondents. They were therefore only selected by interviewers when respondents offered these responses spontaneously. Levels of "Don't know" and "Refused" responses were low for most survey questions. However, it is possible that this partly reflects the way these response options were administered, and the levels may have been higher if the options were read out to respondents.

- Any 'all country' results included in the report are based on averages across the 11 countries included in the survey. These figures should be interpreted in this way and not as global results, as we cannot generalise these results to other countries not included in the survey. We have also included an EU country average for each question. This reflects the SIENNA project being funded by the EU and, as such, the EU level results being of particular interest. As with the 'all country' results, the EU average results are based on an average of the EU countries included in the survey and cannot be generalised to other EU countries.

- The objective of this report is to provides a descriptive overview of the survey findings. As such, it does not follow common academic standards for publishing survey results. For example, it does not include introduction and discussion sections, which contextualize the results with relevant academic literature in order to further understand the meaning of the results for the field. There is scope to analyse the results more deeply to fully understand their meaning and how this pushes our understanding of public views toward genetics and genomics further. Such further analysis may be conducted by academic partner Uppsala University.

2. Methodology

This section provides insights on the methodology for the survey. This includes information about:

- The collection methodology
- The countries surveyed
- The questionnaire development
- The sampling
- The fieldwork method
- The weighting

2.1 Data collection methodology

The survey was conducted by Computer Assisted Telephone Interviewing (CATI) across all countries. It was decided to adopt a CATI approach for a number of reasons:

- It reflected the objective to attempt to deliver a representative sample of adults in each country. An online approach would have excluded people without internet access. Telephone samples have the advantage of being unclustered, unlike face-to-face designs.
- A CATI approach was more cost effective compared with face-to-face interviewing. If a face-to-face approach was adopted, the number of survey countries and/or respondents to survey per country would have needed to be reduced. An online survey would have been cheaper but would not be feasible for some of the countries included in the survey given lower levels of internet access in some countries.
- It was important to adopt a single mode of data collection for all 11 countries, to support comparative analysis. This consistency would have been difficult to achieve based on alternative modes: for example, face-to-face surveys are rarely conducted in the United States and South Korea.

2.2 Countries surveyed

The survey was conducted in 11 countries; in each country, the target sample size was 1,000 adults aged 18 or over. These countries were selected to include a range of cultures, financial standing and geographic locations across the EU, as well as being countries where consortium members worked and where Kantar could conduct the surveys. Due to the purpose of the research, which is aimed at informing the development of an ethical framework at the European level, seven of the surveyed countries were within the European Union:

- France
- Germany
- Greece
- Netherlands
- Poland
- Spain
- Sweden

The remaining four countries were selected in different regions of the world, to provide comparative insights:

- Brazil
- South Africa
- South Korea[5]
- USA

Kantar Public Division surveyed at least 1,000 adults across all 11 countries. The number of completed surveys in each country at an overall and demographic sub-group level can be found in section 2.5.

2.3 Survey development

The questionnaire development was an iterative process done in collaboration between Kantar UK Public Division and the SIENNA consortium. The questions were developed taking into consideration: 1) the results of a scoping review of surveys on genetics and genomics published to date (the review was conducted by UU), 2) the experience of UU team members in ethical, legal and social issues in genetics and genomics, 3) and technologies and applications as well as related social and ethical issues identified during the work on the SIENNA task 2.1. The questions are presented in Appendix 2. As well as the questions, short explanations of a technology or applications were also included and read out for some sections.

The specific wording of the questionnaire and some content was further informed by cognitive testing and a pilot. The cognitive testing was conducted face-to-face by local Kantar teams in the Netherlands, Poland and South Africa. The budget could not cover cognitive testing in all countries. These three

[5] Originally, the plan was to conduct the surveys in countries where SIENNA is represented by partners. However, because of new legislation in China that prohibits conducting surveys for social purposes without prior governmental consent, it was decided to conduct the Asian survey in South Korea instead.

countries were selected to provide a mix of cultures and geographies while also being countries where Kantar has experience in cognitive testing. In each of these countries, 10 participants were selected across a mix of gender, age and education level. The purpose of the cognitive testing was to assess understanding of the questions and terminologies used in the countries.
Following the cognitive testing, the questionnaire was amended, and tested again during the pilot.

The pilot was conducted using the same approach as outlined for the main survey elsewhere in this section (see sections 2.4 and 2.5). As such, it was conducted by telephone using a Random Digit Dialling sample design (more information about this methodology can be found in section 2.4 of the report). The pilot consisted of 30 completed surveys conducted in each of the 11 countries. Following the pilot fieldwork, the Kantar team in each country provided feedback in the form of a written report including recommendations. Further changes to the questionnaire were made based on this feedback.

The translation of the questionnaires was managed by the Kantar team in Brussels. All translators were native speakers in the language in which the survey was to be translated. Verification of the translation followed a two-step process. First, each translation was proofread by a second translator before being reviewed by a project manager. The final translation was then "back-translated" into English by a third translator and this version was verified against the original English version by a fourth translator to ensure they match. Verifications of the translations were made by members of the Kantar teams in each survey country, who reviewed the translations against the original English questionnaire.

The final questionnaire included sections for each of the three technology areas and demographic questions. The order that the three technology areas were included was randomised between respondents, with each area being included 1st, 2nd and 3rd in approximately a third of all surveys completed. Within each section, questions were always presented to respondents in the same order. In a few places, the order of statements was randomised in batteries. This is noted in the questionnaire (see Appendix 2).

2.4 Sampling

The survey used a dual frame (mixed landline and mobile) Random Digit Dialling (RDD) sample design in all countries. This was to ensure full coverage of the population (mobile only, landline only and dual phone users) and to help minimise observable biases seen in the responding profiles of dual phone users by responding phone. By this we mean the propensity for dual phone users to respond to a survey by their mobile or landline phone differs by observable characteristics such as gender, age, working status and education.

In all countries, we generated a random sample of numbers using as our frame of the country numbering plans. Prior to generating the samples, the landline frame was stratified by region and the mobile frame by operator. Within each region and operator stratum, a random samples of telephone numbers were generated such that the final landline sample was proportionally representative by region and mobile sample by operator.

Using the country numbering plans as the frame from which to generate our samples ensures full coverage of the phone owning population in each country. The telephone owning population make up more than 95% of the total 18+ population, with most countries being much closer to 100%.

The target percentage of the achieved sample from the landline and mobile frames is provided in Table 3. These ratios are designed to optimise the representativeness of the sample with respect to the following demographics: age, gender, working status and phone ownership.

Table 3: Target landline and mobile sample ratios per country

Country	Target landline %	Target Mobile %
Brazil	20%	80%
France	50%	50%
Germany	50%	50%
Greece	50%	50%
Netherlands	40%	60%
Poland	70%	30%
South Africa	5%	95%
South Korea	20%	80%
Spain	40%	60%
Sweden	30%	70%
USA	20%	80%

In all countries except South Africa, these targets were met or were very close to being met (within a few percentage points). The landline sample in South Africa was problematic, with a much higher percentage of numbers than expected being non-active. Whilst every effort was made to obtain the target number of completed surveys through the landline frame, it was clear that this was not going to be feasible in South Africa. Therefore, the decision was taken to reach all respondents through the mobile frame.

This change in approach is unlikely to have any significant impact on the results in South Africa, partly due to the very small target of 5%, but also due to the fact that our design may have over-estimated the percentage of the residential (non-business) South African population with a landline phone given the very high inactive rates we observed.[6]

In all 11 countries, a minimum of five call backs were made to numbers with non-final outcomes. Calls were made at different times and on different days of the week to maximise the chances of making contact. Most calls were made in the evening and at the weekend to avoid biasing the sample towards the non-working population. To maximise acceptance, appointments were made if needed to allow individuals contacted an opportunity to take part even if they were unavailable during the initial call.

[6] For South Africa, we had used the International Telecommunication Union (ITU) statistics on landline and mobile subscribers to help determine the sample design. In 2016, the ITU estimated there were just over 3.5 million landline subscriber and almost 77 million mobile subscribers (this figure is higher than the population of South Africa and reflects that some people have multiple phones as well as including phones used for business as well as personal use). However, what isn't clear from these figures is what percentage of the landline subscriber count is for business phones. This could also help explain the low productivity as these were not in scope for this study.

The person answering the phone was asked to participate in the mobile sample. In landline households one adult aged 18 or over was randomly selected from all adults in the household, based on the Rizzo method.[7] Only the selected person could participate; no replacement was permitted.

No incentives were offered for participation in the survey in any of the countries.

2.5 Fieldwork

Fieldwork was conducted over a period of approximately six weeks in March and April 2019.

Fieldwork teams from each country were briefed by the lead UK-based team prior to the start of fieldwork. They then briefed their interviewers on the survey background and requirements.

After contact was made with respondents, interviewers read out a brief introduction to the survey and asked the respondent for their consent to participate. The introduction included the approximate survey length and a statement that respondents could choose not to answer any questions they did not wish to.

Table 4 shows number of completed surveys (overall and split by landline and mobile sample frames) and response rates achieved in each country. The response rate is the percentage of completed surveys from all eligible phone numbers attempted.

Table 4: Survey numbers and response rates achieved by country

Country	Completed surveys	Completed by landline	Completed by mobile	Response rate
Brazil	1,000	167	833	2%
France	1,002	501	501	4%
Germany	1,002	495	507	2%
Greece	1,001	491	510	4%
Netherlands	1,011	399	612	7%
Poland	1,070	264	806	7%
South Africa	1,000	0	1,000	3%
South Korea	1,000	200	800	3%
Spain	1,000	394	606	4%
Sweden	1,000	294	706	8%
USA	1,002	200	802	2%

The target average survey length was 15 minutes. The median length across all completed surveys in each country slightly exceeded this in all countries, ranging from a minimum of 16 minutes in Greece to 22 minutes in Sweden. The median length of each section across all completed surveys was: 4.2

[7] https://www.webdepot.umontreal.ca/Enseignement/SOCIO/Intranet/Sondage/public/exemples_public/Rizzo_Minimally_intrusive_method.pdf

minutes for AI and robotics; 5.5 minutes for human enhancement; and 6.3 minutes for human genomics.[8]

2.6 Weighting

The survey data for each country were weighted to account for different probabilities in selection and non-response (e.g. where certain demographic groups were more or less likely to participate in the survey). Weights were calculated using two stages.

The first stage of weighting (design weighting) corrected for the different probabilities of selection based on the telephone types the respondent had access to and the number of adults in the household. This weighting also adjusted for the overlapping landline and cell frames and the relative size of each frame and each sample.[9]

A probability weight was calculated based on the probability of selections from the landline and mobile frames and then standardised by taking the mean of the probability weights to give the design weight.[10]

The second stage of weighting (rim weighting) adjusted key sample demographics to be reflective of the population using the design weight as a pre-weight and rim weighting on the key demographics.[11]

The key demographics for non-response were identified as being age by gender (12 bands – see table below), educational attainment (2 bands – university degree or above vs. other) and working status (2 bands – working vs. non-working). Population targets for the key demographics were sourced from official population sources for each country.[12]

Respondents were rim weighted to the population based on these key demographics using the design weight as a pre-weight at a country level. All countries were weighted to the same total weight, meaning that all countries contribute equally to the 'All country average' results included in this report.

[8] In addition to these sections, a median time of 1.4 minutes was spent introducing the survey and carrying out a person selection (where required) and 1.0 minutes was spent collecting demographic information.

[9] A design weight is used to account for differences in the probability of being selected into the sample. With dual frame telephone surveys, a respondent who owns a mobile and fixed line phone has a higher chance of being selected than a person who just has a fixed line phone or just a mobile. Also, a person living in a household with multiple eligible people has a lower probability of selection than a person living on their own. We need to account for these differences in the probability of selection through our design weight.

[10] By this we mean that the design weights were recalibrated so that they had a mean of 1 and summed to the total sample size prior to running non-response weighting.

[11] Rim (or post stratification) weighting is a method for calculating weights that ensure the marginal totals match population targets. It is a standard method to weight survey data where you are using multiple variables to weight on, e.g. age, working status, educational attainment, region. Rim weighting uses an iterative proportional fitting method to calculate a weight for each respondent that ensures the survey data when weighted replicates the population targets e.g. the % of people aged 18-24 is the same in the sample as the population. For further information, please refer to: https://www.europeansocialsurvey.org/methodology/ess_methodology/data_processing_archiving/weighting.html

[12] For further information on weighting of dual frame telephone surveys please refer to: http://www.aapor.org/Education-Resources/Reports/Cell-Phone-Task-Force-Report/Weighting.aspx and https://surveyinsights.org/?p=5291

Tables 5 and 6 includes a comparison of the demographic of the achieved survey sample in each country against the population profile in that country.

Table 7 includes the overall design effect for each country and maximum confidence interval for estimates based on the full sample in each country and at a 95% confidence level.

The design effect is calculated based on the impact of weighting on the survey results for each country; the larger the design effect, the larger the confidence interval around the survey results. The maximum confidence interval is based on an estimate of 50%.[13] For example, if 50% of people in Brazil gave a particular response to a question, we can be 95% confident that the true population value is between 46% and 54%.[14]

[13] The confidence interval reduces as estimates get closer to 0% or 100%. For example, the confidence interval for an estimate of 10% or 90% in Brazil is +/- 2.4%, compared with +/- 4.0% for an estimate of 50%.

[14] The design effect due to weighting is calculated using the Kish approximation. (Reference: Kish, L. (1990). Weighting: Why, when, and how? Proceedings of the Joint Statistical Meetings, Section on Survey Research Methods, American Statistical Association, 121-129. Kish proposed the "design effect due to weighting" as a measure to quantify the loss of precision due to using unequal and inefficient weights.)

Table 5: Profile of achieved sample versus population – age by gender

	Survey %												Population %											
	M 18-24	M 25-34	M 35-44	M 45-54	M 55-64	M 65+	F 18-24	F 25-34	F 35-44	F 45-54	F 55-64	F 65+	M 18-24	M 25-34	M 35-44	M 45-54	M 55-64	M 65+	F 18-24	F 25-34	F 35-44	F 45-54	F 55-64	F 65+
Brazil	7%	17%	12%	9%	6%	4%	8%	12%	11%	8%	7%	3%	8%	11%	10%	8%	6%	5%	8%	11%	11%	9%	7%	7%
France	4%	7%	9%	10%	10%	12%	2%	5%	6%	7%	10%	17%	5%	7%	8%	9%	8%	11%	5%	8%	8%	9%	8%	14%
Germany	5%	8%	8%	11%	11%	12%	4%	5%	7%	8%	10%	11%	5%	8%	7%	9%	8%	11%	4%	7%	7%	9%	9%	14%
Greece	5%	9%	12%	11%	7%	7%	4%	8%	11%	13%	7%	5%	4%	7%	9%	9%	7%	12%	4%	7%	9%	9%	8%	15%
Netherlands	4%	6%	7%	10%	11%	16%	2%	4%	5%	9%	9%	15%	6%	8%	7%	9%	8%	11%	5%	8%	7%	9%	8%	13%
Poland	6%	12%	12%	6%	5%	8%	5%	9%	9%	6%	8%	13%	5%	9%	10%	7%	8%	8%	5%	9%	9%	8%	9%	13%
South Africa	15%	22%	10%	5%	3%	2%	12%	15%	7%	5%	2%	1%	9%	14%	11%	7%	5%	4%	9%	14%	10%	7%	5%	5%
South Korea	4%	15%	14%	12%	11%	8%	5%	11%	7%	5%	5%	4%	6%	8%	10%	10%	9%	8%	5%	7%	9%	10%	9%	10%
Spain	4%	7%	11%	13%	6%	5%	4%	7%	10%	13%	12%	6%	4%	7%	10%	10%	8%	10%	4%	7%	10%	10%	8%	13%
Sweden	3%	7%	9%	11%	8%	19%	2%	4%	8%	8%	6%	16%	5%	9%	8%	9%	7%	12%	5%	8%	8%	8%	7%	13%
USA	6%	8%	7%	8%	12%	16%	3%	4%	5%	5%	7%	16%	6%	9%	8%	8%	8%	9%	6%	9%	8%	8%	9%	12%

Table 6: Profile of achieved sample versus population – educational attainment and working status

	Educational attainment				Working status			
	Survey %		Population %		Survey %		Population %	
	Degree or above	Other	Degree or above	Other	Working	Not-working	Working	Not-working
Brazil	33%	67%	20%	80%	64%	36%	54%	46%
France	61%	39%	32%	68%	53%	47%	52%	48%
Germany	40%	59%	26%	74%	67%	32%	60%	40%
Greece	60%	39%	27%	73%	61%	34%	43%	57%
Netherlands	42%	57%	32%	68%	56%	41%	62%	38%
Poland	50%	49%	25%	75%	62%	36%	55%	45%
South Africa	36%	64%	11%	89%	49%	49%	43%	57%
South Korea	76%	23%	36%	64%	71%	28%	61%	39%
Spain	45%	55%	32%	68%	63%	37%	50%	50%
Sweden	64%	36%	23%	77%	60%	39%	63%	37%
USA	61%	38%	32%	68%	55%	42%	59%	41%

Table 7: Design effects for each country

Country	Design effect	Maximum confidence interval
Brazil	1.69	+/- 4.0%
France	1.78	+/- 4.1%
Germany	1.29	+/- 3.5%
Greece	2.40	+/- 4.8%
Netherlands	1.33	+/- 3.6%
Poland	1.63	+/- 3.8%
South Africa	1.93	+/- 4.3%
South Korea	3.63	+/- 5.9%
Spain	1.39	+/- 3.7%
Sweden	2.31	+/- 4.7%
USA	1.92	+/- 4.3%

2.7 Notes on analysis and interpretation

In this report we present the results from all survey questions based on an overall (all countries) and individual country level. As noted above, the overall results are based on the average results across all countries. This means that all countries contribute equally towards the average, regardless of the number of surveys completed in that country or the population total of the country. The same applies to the EU average results; these are based on the average across the seven EU countries surveyed, regardless of the number of interviews achieved in each country.

Results are also compared between demographic sub-groups. The results at all questions were analysed by gender, age group, and level of education. Selected questions were also analysed based on working status, importance of religion and parental status. We only include comparisons between demographic subgroups in this report where there were significant differences based on two criteria. First, that there was a significant difference in results at an 'all country' level: for example, on average across all countries, men were more likely to hold a certain view than women. And second, that these significant differences hold for the majority of countries surveyed (at least 6 out of the 11 countries). Where one or both of these criteria do not hold, we do not include the subgroup comparisons in the report. If a significant difference holds for most, but not all, countries, we note the exceptions in the report.

Significance tests (t-tests) were conducted on the country level and demographic subgroup results based on a 95% confidence interval. This means we can be 95% certain that any significant differences reported between countries or demographic subgroups reflect true differences in the populations.

Any differences reported are significant at a 95% confidence level.

Due to rounding, charts may not always add to 100%.

3. Self-reported awareness of genetics

Respondents were asked how much they had heard or read about genetics or DNA:

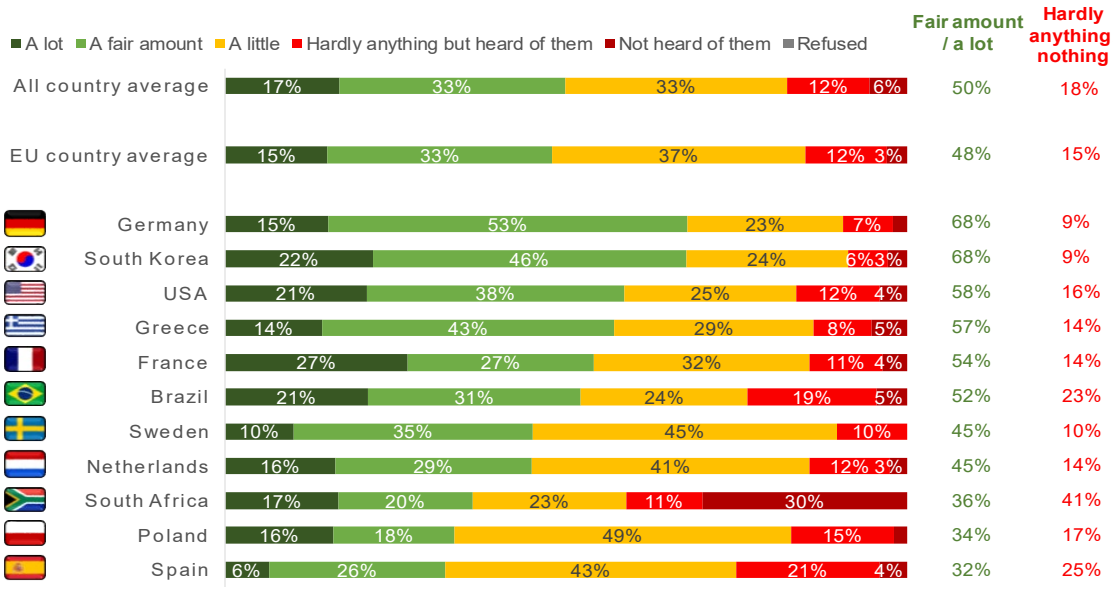
"Before today, how much, if anything, had you heard or read about genetics or DNA?"

Overall, an average of 94% of respondents across all countries (and 97% in the surveyed EU countries) had heard or read at least something about genetics or DNA, while 6% (3% in the surveyed EU countries) had not heard of these terms. Based on an all country average, 17% said they had heard or read 'a lot', 33% 'a fair amount', 33% 'a little' and 12% 'hardly anything'. Within the surveyed EU countries, 15% said they had heard or read 'a lot', 33% 'a fair amount', 37% 'a little' and 12% 'hardly anything'.

Awareness of genetics or DNA varied by country. Focusing on the top two categories of this self-reported measure, that is those who had heard or read at least a fair amount about genetics or DNA, those in Germany (68%) and South Korea (68%) had heard or read the most. Between five in ten and six in ten respondents said they had heard or read a lot in the USA (58%), Greece (57%), France (54%) and Brazil (52%). In Sweden and the Netherlands, 45% of respondents said they had heard or read a lot about genetics or DNA. The countries with the lowest levels of awareness based on this measure were South Africa (36%), Poland (34%) and Spain (32%).

The proportion of respondents who had heard or read hardly anything or nothing about genetics and DNA was highest in South Africa (41%, compared with 25% or lower in all other countries).

Figure 1: Awareness of genetics or DNA



Q058: GEN_Q1 Before today, how much, if anything, had you heard or read about genetics or DNA?
Base: all respondents.

Those with university degrees were much more likely than those without degrees to say they had heard or read a lot or a fair amount about genetics or DNA (63% versus 45%). This was the case for all countries surveyed.

Discussion points

There are different factors which may influence awareness about genetics, including, how advanced the genetic research and medicine is in a given country, to what extent issues related to genetics are covered by local mass media, and how much time is given to this topic in education programmes at schools.

It is important to keep in mind that self-reported awareness may not mirror the actual awareness and is context dependent. For example, having read a fair amount of information on a given topic may reflect very different actual amounts of text, depending, among others, on how much people read on average in a given group.

4. Public perceptions on the need to know more about genetics

All respondents were asked: *"How important do you think it is for the general public to understand more about genetics or DNA?"*

Based on an average across all survey countries, just under nine in ten respondents (87%) felt it was important (fairly important or very important) for the general public to understand more about genetics or DNA, with almost half (44%) stating it was very important. One in ten (11%) said it was not very or not at all important for the public to have more of an understanding about genetics or DNA.

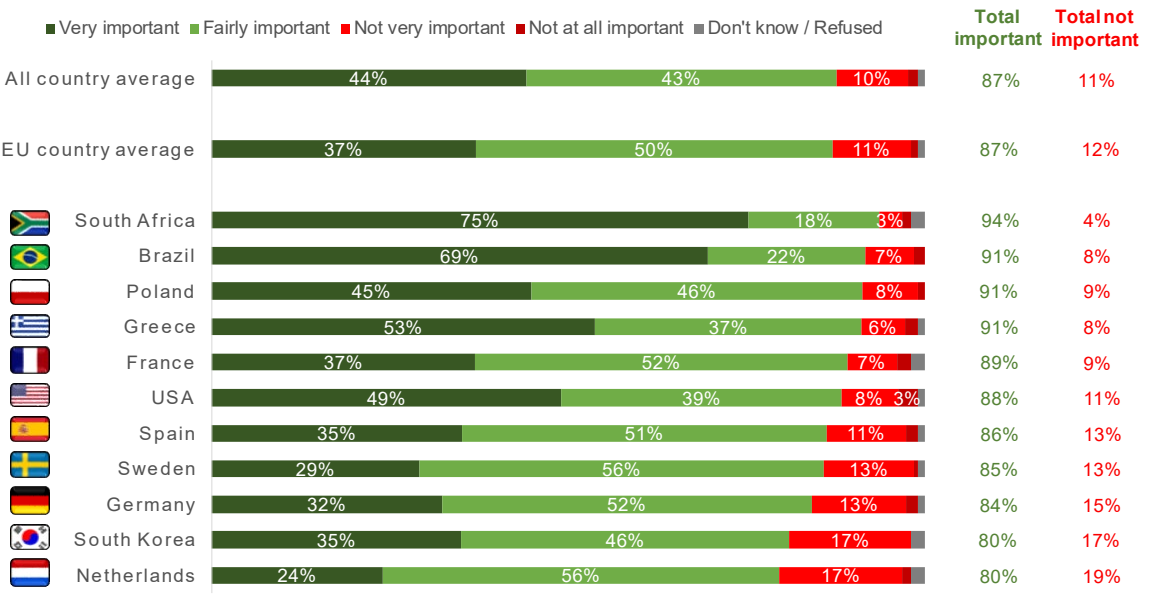
Based on an average across all EU survey countries, again, just under nine in ten respondents (87%) felt it was important for the general public to understand more about genetics or DNA, with 37% stating it was very important. One in eight (12%) said it was not very or not at all important for the public to have more of an understanding about genetics and DNA.

In all countries, at least eight in ten respondents felt it was very or fairly important for the public to understand more about genetics or DNA. However, this rose to over nine in ten for South Africa (94%), Brazil (91%), Poland (91%) and Greece (91%).

There were substantial differences between countries, and compared with the all-country average, when focusing on just those who said it was *very important* for the public to understand more. Respondents in South Africa (75%) and Brazil (69%) were most likely to say this was very important, while respondents in the Netherlands (24%) were least likely to respond in this way.

We should note that responses to this question are likely to relate to how much respondents perceive the general public in their country to currently understand about genetics. For example, respondents in South Africa were most likely to say they knew hardly anything or nothing about genetics, which may partly explain why they perceive it to be very important for people there to learn more about this.

Figure 2: Perceived importance of public understanding of genetics



Q059: GEN_Q2 How important do you think it is for the general public to understand more about genetics or DNA?
Base: all respondents.

As noted above, there was a relationship between responses to this question and awareness of genetics and DNA. Based on an equal-weighted country average, respondents who said they had heard or read a lot or a fair amount about genetics or DNA were more likely than those with less self-reported awareness to say it was very important for the public to understand more about genetics or DNA (51% versus 35% of those who had heard or read a little about genetics and DNA and 40% of those who had heard or read hardly anything or nothing about this).

Based on an all-country weighted average, women were more likely than men to think it important for the general public to understand more about genetics and DNA (90% versus 84%). This was the case in all countries, except the Netherlands, Greece, South Africa, South Korea and Brazil, where there was little difference between men and women's results.

Discussion points

Vast majorities of the respondents (ranging from 80 to 94% depending on the country) thought that it was important for the general public to understand more about genetics and such a view was more prevalent among those who had higher awareness of genetics. It should be kept in mind, however, that the group which decided to participate in this study (only 2-8% of those contacted, depending on the country, see Table 4) may be more interested in the topics addressed in survey than general population. The perceived importance of understanding more about genetics may be lower in the general population.

5. Basic knowledge about genetics

All respondents were asked three true or false questions regarding genetic tests and changing DNA in human cells (*"For each of the following statements, please say whether you think it is true or false. It doesn't matter if you don't know, just say so and we'll go on to the next one"*). As with other questions in the survey, the "Don't know" and "Refused" codes were not read to respondents and so were only selected when respondents spontaneously gave these responses.

5.1 Whether genetic tests can help diagnose a disease

The first question was whether they thought it was true or false that **'genetic tests can help diagnose a disease'**. Based on an average across all countries, the vast majority of respondents (91%) correctly answered this statement (true).

Respondents in Spain and Poland were most likely to say this statement was true with almost all respondents in these countries (98% and 97% respectively) selecting this. Respondents in South Africa were least likely to say the statement was true with just over three quarters (77%) selecting this. Sixteen per cent of respondents in South Africa thought this statement was false, compared with 6% or lower in all other countries.

In all other countries, around nine in ten respondents believe this statement to be true (between 93% and 89%).

Table 8: Understanding that genetic tests can help diagnose a disease – This statement is…

	True	False	Don't know / Refused
All country average	91%	5%	4%
EU country average	94%	3%	3%
Spain	98%	2%	-
Poland	97%	1%	2%
Sweden	93%	4%	2%
Greece	92%	4%	4%
Netherlands	92%	5%	3%
Brazil	92%	4%	3%
USA	91%	5%	4%
Germany	91%	4%	5%
France	91%	4%	5%
South Korea	89%	6%	5%
South Africa	77%	16%	7%

The statement respondents were asked about here is true.
Q060: GEN_Q3 For each of the following statements, please say whether you think it is true or false.. 'Genetic tests can help diagnose a disease'
Base: all respondents.

5.2 Whether genetic tests can predict whether an unborn baby will be born with Down's Syndrome

Respondents were then asked whether they thought it was true or false that **'Genetic tests can predict whether an unborn baby will be born with Down's Syndrome'**

Based on an average across all countries, 84% of respondents correctly believed this statement to be true, with the highest levels in Spain (92%) and Greece (91%). The EU surveyed-country average for this was 87%. Respondents in South Korea and South Africa were least likely to say this statement was true (78% and 73% respectively). Those in South Africa were almost twice as likely to select this statement as false compared with those in all other countries (18% versus 10% or lower elsewhere).

Table 9: Understanding that genetic tests can predict whether an unborn baby will be born with Down's Syndrome – This statement is…

	True	False	Don't know / Refused
All country average	84%	8%	7%
EU country average	87%	7%	6%
Spain	92%	3%	4%
Greece	91%	4%	5%
Poland	88%	5%	6%
Brazil	87%	8%	4%
Sweden	85%	9%	5%
Germany	85%	7%	7%
Netherlands	84%	10%	6%
France	83%	8%	9%
USA	81%	9%	10%
South Korea	78%	9%	13%
South Africa	73%	18%	9%

The statement respondents were asked about here is true.
Q060: GEN_Q3 For each of the following statements, please say whether you think it is true or false. 'Genetic tests can predict whether an unborn baby will be born with Down's Syndrome'
Base: all respondents.

5.3 Whether researchers are working on changing the DNA in human cells to treat diseases

Respondents were then asked whether they thought it was true or false that '**Researchers are working on changing the DNA in human cells to treat diseases'.**

Based on an average across all countries, three quarters of respondents (76%) correctly believed this statement to be true. Across the EU countries surveyed this was 79%. This was a lower level compared with the previous two statements.

The proportion of respondents selecting this statement as true was fairly similar in nine of the eleven countries. As with the other statements, respondents in South Africa (57%) and South Korea (55%) were least likely to correctly select this statement as being true. Over a quarter of respondents in both countries (26% South Africa and 27% South Korea) said the statement was false, compared with 12% or lower in all other countries.

Table 10: Understanding that researchers are working on changing the DNA in human cells to treat diseases – This statement is…

	True	False	Don't know / Refused
All country average	76%	12%	12%
EU country average	79%	9%	12%
Brazil	85%	8%	7%
Poland	82%	6%	13%
Spain	82%	9%	9%
Germany	81%	8%	10%
USA	80%	8%	13%
Sweden	80%	12%	8%
Greece	78%	10%	12%
Netherlands	78%	10%	12%
France	76%	8%	17%
South Africa	57%	26%	17%
South Korea	55%	27%	17%

Note: the statement respondents were asked about here is true.
Q060: GEN_Q3 For each of the following statements, please say whether you think it is true or false. 'Researchers are working on changing the DNA in human cells to treat diseases'
Base: all respondents.

Discussion points

The answers to these "true/false" questions, testing the actual (as opposed to self-reported) knowledge of genetics, indicate that vast majority of respondents have a very basic level of knowledge about genetics, namely, most respondents understand that genetic tests are used in diagnostics (91% of respondents) and for prenatal testing to determine if a child has Down syndrome (84% of respondents). A high number of respondents (76%) (however lower when comparing to answers to the previous two statements) answered correctly that researchers are working on changing the DNA in human cells to treat diseases, suggesting that there may be lower overall knowledge on this issue, which would be expected given the more recent scientific progress in gene editing.

The differences in knowledge about genetics between countries may be related to factors, such as level of education in biology/genetics, media coverage of related issues, accessibility and uptake of genetic services in healthcare, and others.

6. Perceptions of consequences of increased prenatal testing on persons with disabilities and on prospective parents

Respondents were asked to consider the likelihood of two situations. First, how likely it was that disabled people would be less accepted by society if more and more women choose to terminate their pregnancy due to the result of a genetic test. And second, how likely it was that parents would feel pressured to have a genetic test done on their unborn baby if genetic testing on unborn babies becomes increasingly common.

Before being asked these questions, respondents were given the following introduction regarding genetic tests:

"We are now going to ask you about genetic tests – these are also known as DNA tests. These tests are done by analysing samples of blood, saliva or body tissues. They can determine whether you, a family member, or an unborn baby carries genes for certain inherited features, including genetic diseases, or traits like height and eye colour."

6.1 Perception of influence of increased uptake of prenatal testing on persons with disabilities

"Suppose that over time more and more women choose to terminate their pregnancy due to the result of a genetic test.

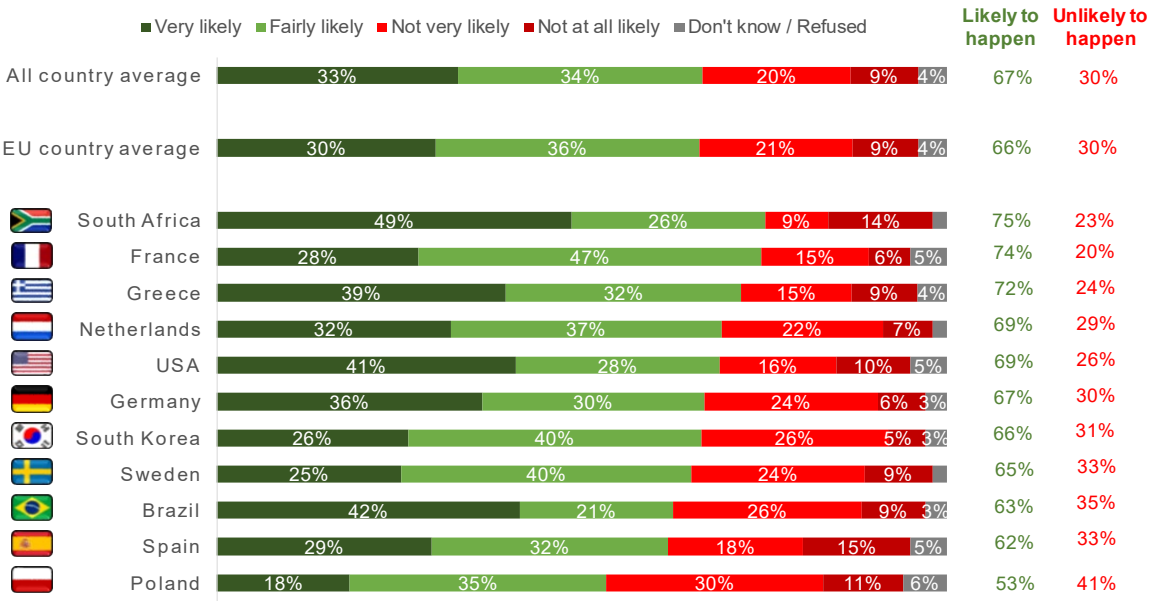
How likely do you think that this would result in disabled people being less accepted in society?"

Based on an average across all survey countries, two thirds of respondents (67%) said it was likely that disabled people would be less accepted by society if more and more women choose to terminate their pregnancy due to the result of a genetic test. This was split evenly into one third who said this would be very likely (33%) and a further third thinking it would be fairly likely (34%). Overall, 29% said this would be unlikely to happen: 20% not very likely and 9% not at all likely.

Based on an average across all EU surveyed countries, the breakdown is very similar to that of the average across all countries. Two thirds of respondents (66%) said it was likely that disabled people would be less accepted by society if more and more women choose to terminate their pregnancy due to the result of a genetic test. This was split into 30% who said this would be very likely and a further 36% thinking it would be fairly likely. Overall, 30% said this would be unlikely to happen: 21% not very likely and 9% not at all likely.

There was some variation in responses across survey countries. However, in all countries the majority of respondents said that it would be very or fairly likely that disabled people would become less accepted by society if more women choose to terminate their pregnancy due to genetic test results. South Africa (75%), France (74%) and Greece (72%) had the highest proportion of respondents thinking this would be very likely. The lowest proportion was Poland (53%), though still more respondents there thought this was likely rather than unlikely to happen

Figure 3: Perception of the likelihood that disabled people would become less accepted in society as a result of more women choosing to terminate their pregnancies due to the results of a genetic test



Q064: GEN_Q7 Suppose that over time more and more women choose to terminate their pregnancy due to the result of a genetic test. How likely do you think that this would result in disabled people being less accepted in society?
Base: all respondents.

6.2 Perceptions of consequences of increased prenatal testing on prospective parents

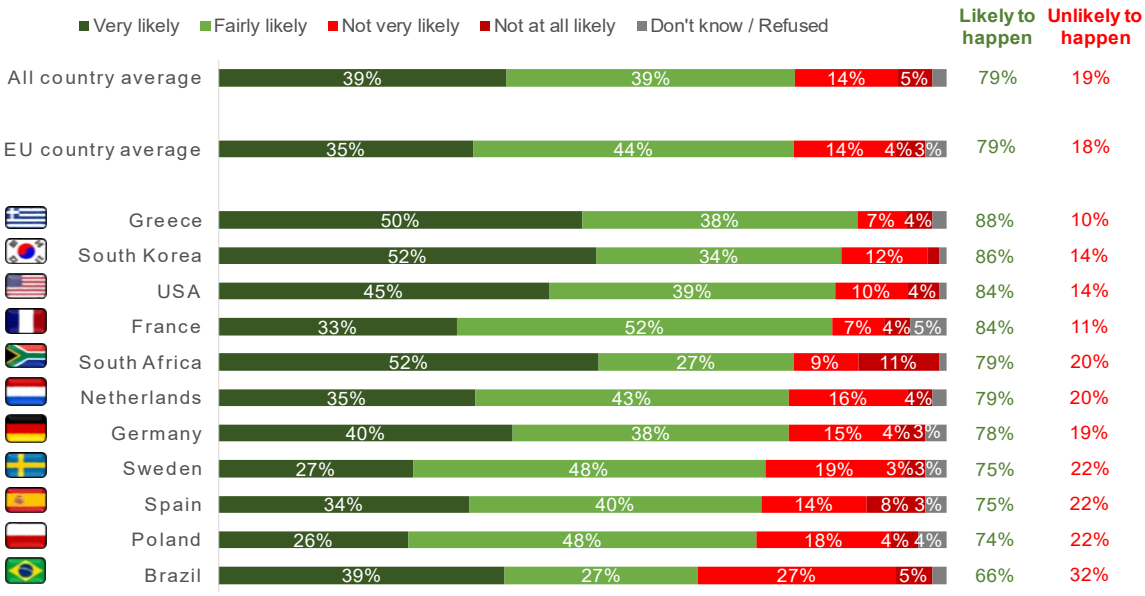
"Now suppose that genetic testing on unborn babies becomes increasingly common. How likely do you think that this would result in parents feeling pressured to have genetic testing done on their unborn baby?"

Based on an average across all survey countries, eight in ten respondents (79%) said it was likely that parents would feel pressured to have a genetic test done on their unborn baby if genetic testing on unborn babies becomes increasingly common. Four in ten (39%) said this would be very likely and a further four in ten (39%) said that it was fairly likely. Overall, 19% said this was unlikely to happen: 14% said it was not very likely and 5% not at all likely.

Based on an average across all EU surveyed countries, the breakdown is very similar to that of the average across all countries. Eight in ten respondents (79%) said it was likely that parents would feel pressured to have a genetic test done on their unborn baby if genetic testing on unborn babies becomes increasingly common. Over three in ten (35%) said this would be very likely and under half (44%) said that it was fairly likely. Overall, 18% said this was unlikely to happen: 14% said it was not very likely and 4% not at all likely.

Greece (88%), South Korea (86%), the USA (84%) and France (84%) had the highest proportions of respondents saying that this was likely to happen. This proportion was lowest in Brazil but still there two thirds of respondents (66%) said it was likely that this would result in parents feeling pressured to have genetic tests done on their unborn baby, double the proportion that said this would be unlikely (32%).

Figure 4: Perceptions of the likelihood of parents feeling pressured to have genetic testing done on their unborn baby due to genetic test becoming more common



Q065: GEN_Q8 Now suppose that genetic testing on unborn babies becomes increasingly common. How likely do you think that this would result in parents feeling pressured to have genetic testing done on their unborn baby?
Base: all respondents.

Discussion points

The answers to questions about potential increase in an uptake of prenatal genetic testing and terminations of pregnancies based on genetic test results indicate that majority of respondents in all the countries perceive negative consequences of these practices as likely to occur, namely, pressure on parents to undertake prenatal genetic testing, and decrease in acceptability of disabled people, respectively.

Both practices of pregnancy termination based on genetic test and prenatal testing, have been taking place for decades, with prenatal testing becoming increasingly common due to, among others, the availability of non-invasive prenatal testing in the last few years. Perception that these practices may have negative impact reported by such a large group of respondents highlights potential need for an ethical framework which would take into account these concerns as well as further research investigating social impact of prenatal testing.

7. Perceptions on analysing all genes/DNA at birth

All respondents were asked how much they agreed or disagreed that all babies should have all their genes or DNA analysed at birth.

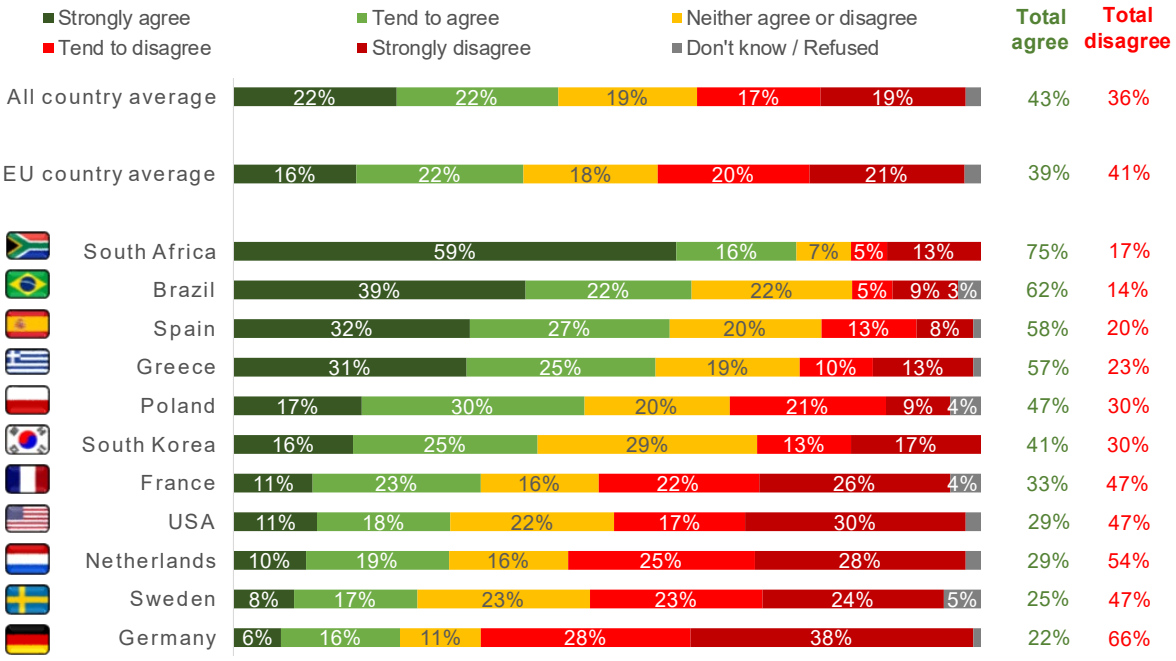
Based on an average across all survey countries, just over four in ten (43%) agreed that all babies should have all their genes analysed at birth and just under four in ten (36%) disagreed with this statement.

Across the surveys EU countries, an average of just under four in ten (39%) agreed that all babies should have their all genes analysed at birth and just over four in ten (41%) disagreed with this statement.

There was substantial variation between countries in response to this statement. Respondents in South Africa (75%) were most likely to agree that babies should have all their genes analysed at birth. In each of Brazil, Spain and Greece, over half of respondents agreed with this statement (62%, 58% and 57% respectively). Respondents in Poland and South Korea were also more likely to agree with this statement than disagree with it.

Respondents in Germany were most likely to disagree that all babies should have their genes analysed at birth (66%), with almost four in ten (38%) strongly disagreeing with this. Respondents in Sweden, the Netherlands, USA and France were also more likely to disagree than agree with the statement.

Figure 5: Agreement with all babies having their genes or DNA tested at birth



Q066: GEN_Q9 Some tests can analyse all of a person's genes or DNA at the same time. This genetic data can then be stored for health purposes, or for medical research. How much would you agree or disagree that all babies should have all their genes or DNA analysed at birth?
Base: all respondents.

Based on an equal-weighted country average, men were more likely than women to agree that all babies should have their genes analysed at birth (47% versus 40%). This was the case for all countries except Germany, Greece, the Netherlands, Poland and Spain, where responses were similar between men and women. The largest gender difference in response to this question was in Sweden, where men were almost twice as likely as women to agree that babies should have their genes or DNA analysed at birth (32% versus 17%).

Discussion points

The issue of whole genome sequencing of newborns, based on the answers to this survey, seems to be a contentious topic, and respondents are divided in their views. The level of development and uptake of medical genetics services, which is also likely related to familiarity with risks and benefits of genetic testing, the history of misuses of knowledge about inheritance may all potentially have influenced the view on this issue. A hypothesis that higher awareness and/or understanding of genetics influences this view could be tested.

8. Self-reported awareness of gene editing

Respondents were presented with the following information about gene editing:

"Researchers are currently looking into how we can change someone's DNA to treat or eliminate certain diseases. This is known as 'gene editing'. Some people are also interested to use gene editing to change non-disease features such as intelligence, strength or eye colour."

Following this definition, they were asked: *"Before today, how much, if anything, have you heard or read about gene editing in Europe"?*

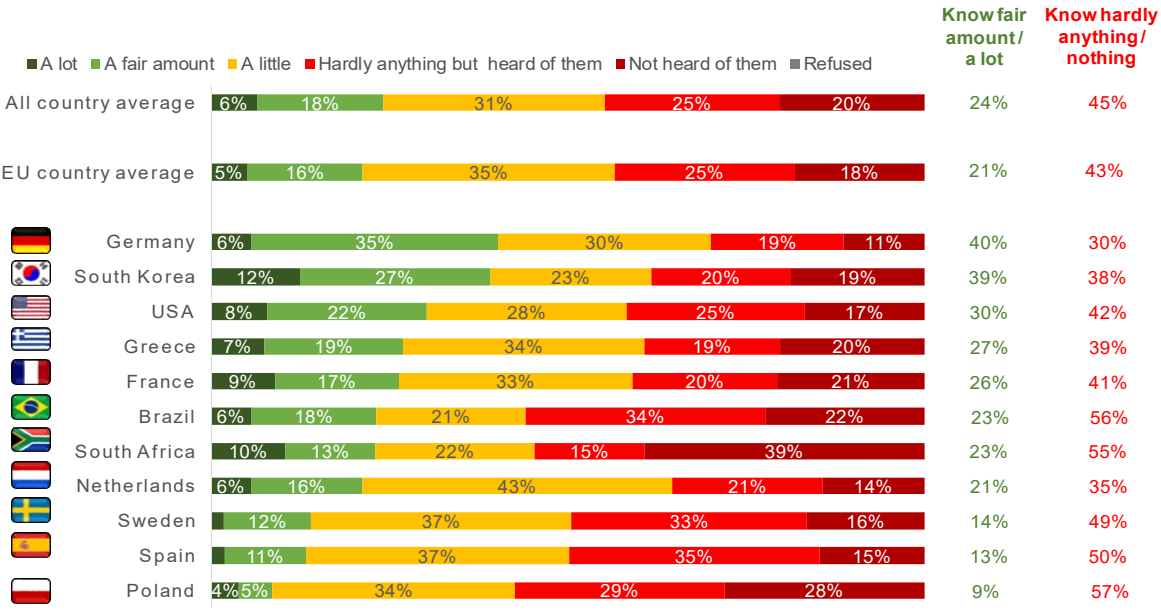
Overall, an average of 80% of respondents across all countries reported having heard or read at least something about gene editing in humans, while 20% had not heard of this. Based on an all country average, 6% said they had heard or read 'a lot', 18% 'a fair amount', 31% 'a little' and 25% 'hardly anything'.

Across the surveyed EU countries, an average of 82% of respondents reported having heard or read at least something about gene editing in humans, while 18% said they had not heard of this. Across these countries, 5% said they had heard or read 'a lot', 16% 'a fair amount', 35% 'a little' and 25% 'hardly anything'.

Respondents in Germany and South Korea had the highest levels of self-reported awareness, with four in ten respondents saying they had heard or read 'a lot' or 'a fair amount' about gene editing in humans (40% and 39% respectively). Between two in ten and three in ten of respondents reported having heard a lot or a fair amount about gene editing in the USA (30%), Greece (27%), France (26%), Brazil (23%), South Africa (23%) and the Netherlands (21%). Respondents in Poland (9%), Spain (13%) and Sweden (14%) were least likely to say they knew a lot or a fair amount about gene editing.

As with awareness of genetics or DNA, respondents in South Africa were more likely than those in other countries to say they had not heard of gene editing (39%, versus 28% in Poland and 22% or lower in all other countries).

Figure 6: Awareness of gene editing



Q068: GEN_Q11 Before today, how much, if anything, have you heard or read about gene editing in humans?
Base: all respondents.

As with awareness of genetics and DNA, based on an equal-weighted country average, those with university degrees were more likely than those without degrees to say they had heard or read a lot or a fair amount about gene editing (33% versus 21%). Spain and Sweden were exceptions to this, with a relatively even split between those with and without university degrees.

Discussion points

As with awareness of genetics in general, there are different factors which may influence awareness about gene editing, including, whether gene editing experiments are conducted and covered by press in a given country.

It is important to keep in mind that self-reported awareness may not mirror the actual awareness and is context dependent. For example, having read a fair amount of information on a given topic may reflect very different actual amounts of text, depending, among others, on how much people read on average in a given group.

9. Public perception of what experts know about gene editing

All respondents were asked how well they thought researchers understood the health risks and benefits of changing an unborn baby's DNA. Based on an average across all countries, only 13% of respondents believed researchers understood the risks and benefits very well and 34% fairly well (total 48%). A similar proportion thought researchers understood the risks and benefits not too well (34%) or not at all well (12%) (total 46%). Six per cent said they did not know or refused to answer this question.

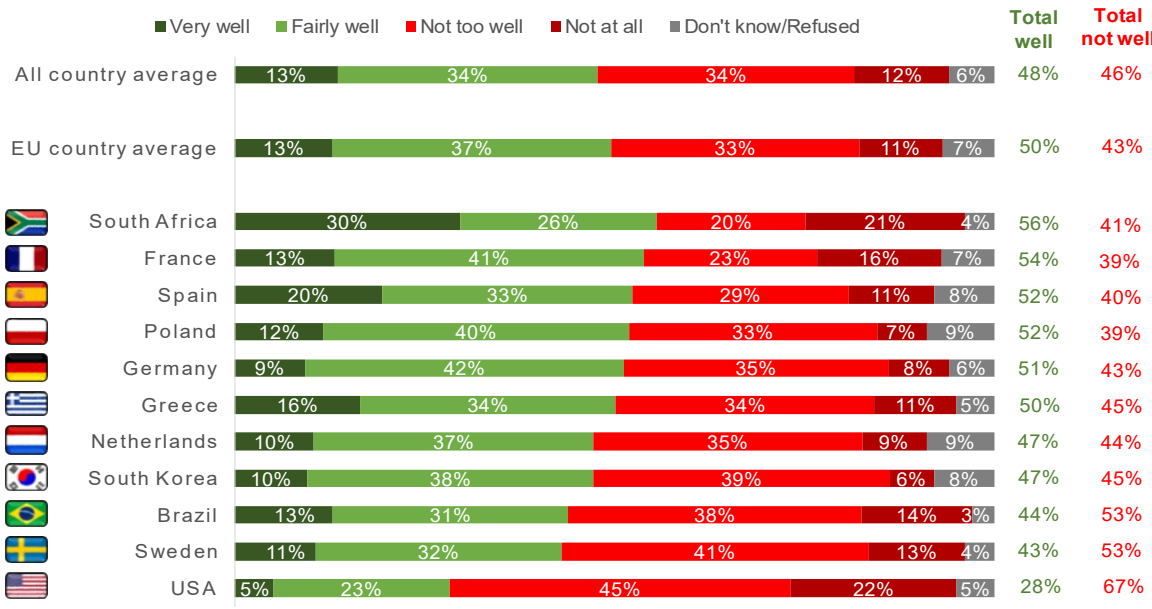
Across the surveyed EU countries, half of respondents believed researchers understood the risks and benefits very well or fairly well (50%) and slightly less felt they understood the risks and benefits not too well or not at all well (44%).

There were some notable differences between countries in response to this question. For all countries apart from Brazil, Sweden and the USA (where the reverse was true), respondents were more likely to say that researchers understood the risks and benefits very or fairly well than not too well or not at all well.[15] However, even in these countries, respondents were divided; the country where the highest proportion of respondents thinking that researchers understood the risks and benefits very or fairly well was South Africa but even there the proportion was below six in ten (56%).

More respondents in Brazil, Sweden and the USA thought researchers understood the risks and benefits not too well or not at all well compared with very or fairly well. In the USA, two thirds of respondents (67%) felt that the risks and benefits were not understood too well or at all well compared with 28% saying they were understood very or fairly well.

[15] The difference between the proportion saying the risks were understood well and not well was not significant in the Netherlands, Greece and South Africa.

Figure 7: Perceptions of researchers understanding of health risks and benefits of changing an unborn baby's DNA



Q070: GEN_Q12 How well do you think researchers currently understand the health risks and benefits of changing an unborn baby's DNA?
Base: all respondents.

Discussion points

It seems that there is no general trend among all the countries in respondents' opinions on how well researchers understand the health risks and benefits of changing an unborn baby's DNA; the number of respondents who answered "well" to this question ranges from 28% to 56%. A hypothesis could be tested whether those who have *low general knowledge* about gene editing research (see section 5.3), perceive that researchers understand *well* the risks and benefits of changing DNA of an unborn baby. Further statistical analysis would have to be performed to answer this question.

Interestingly, the USA and Sweden have the lowest number of respondents (28% and 43%) who perceive that researchers understand well (fairly well or very well) the risks and benefits of prenatal applications of gene modification technologies. Both the USA and Sweden are among few countries where research on embryos involving gene editing is performed. Such studies likely attract local media attention and coverage; therefore, public opinion may be better informed on related issues, including, uncertainties of potential applications of gene editing in clinic than publics in the countries where such research is not conducted.

10. Perceptions regarding research with embryos

Before the next three questions were asked, the following information on human embryos was read out:

"An embryo is an unborn baby at a very early stage of development, up to eight weeks after conception. Scientists sometimes use human embryos in medical research.

The law in many countries states that embryos used for research can only be used in the laboratory and cannot be placed into a woman's womb to grow a baby. These laws also require that embryos are used for up to 14 days after conception after which they must be destroyed."

All respondents were presented with three statements regarding human embryos and asked "*how acceptable do you consider each of the following to be"*:

- *"Using human embryos in laboratory experiments for any purpose"*
- *"Conducting laboratory experiments on human embryos to understand how to increase human intelligence"*
- *"Conducting laboratory experiments on human embryos to better understand how to treat or cure serious health conditions"*

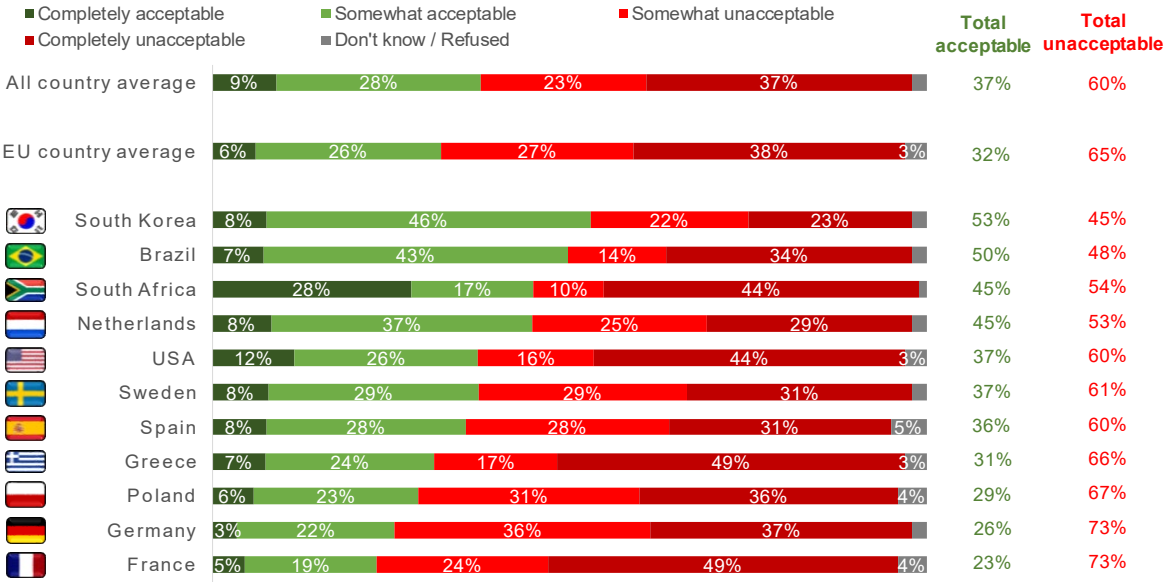
10.1 Using human embryos in laboratory experiments for any purpose

Based on an average across all survey countries, 37% answered that it was acceptable (9% completely acceptable and 28% somewhat acceptable) to use human embryos in laboratory experiments for any purpose while 60% felt this was unacceptable (37% completely unacceptable and 23% somewhat unacceptable).

Based on an average across all surveyed EU countries, 32% felt that it was acceptable to use human embryos in laboratory experiments for any purpose while 65% felt this was unacceptable.

The majority of respondents in most countries felt this was unacceptable. The only exceptions to this were South Korea (where 53% of respondents felt this was acceptable compared with 45% unacceptable) and Brazil (50% versus 48%). Those in France (73%), Germany (73%), Poland (67%) and Greece (66%) were most likely to say it was unacceptable to use human embryos in laboratory experiments for any purpose.

Figure 8: Acceptability of conducting laboratory experiments on human embryos for any purpose



Q071: GEN_Q14 How acceptable do you consider each of the following to be? 'Using human embryos in laboratory experiments for any purpose'
Base: all respondents.

Overall, based on an all-country average, there were a number of notable differences between groups in perceived acceptability of using human embryos in laboratory experiments for any purpose.

Men were more likely to think it acceptable for human embryos to be used in laboratory experiments than women (43%, versus 32% of women). This difference held for all countries, except Germany and South Africa, where there was little difference between men and women.

Those saying religion was not important to them were also more likely to think it was acceptable for human embryos to be used in laboratory experiments than those who said religion was important to them (45% versus 33% of those saying religion was important). This difference held for all countries except South Africa and South Korea where there was little difference between the two groups.

Non-parents were more likely to think it acceptable for human embryos to be used in laboratory experiments than parents (44% vs 34%). This held true in all countries, except for France, South Africa, South Korea and Spain, where there was little difference between parents and non-parents.

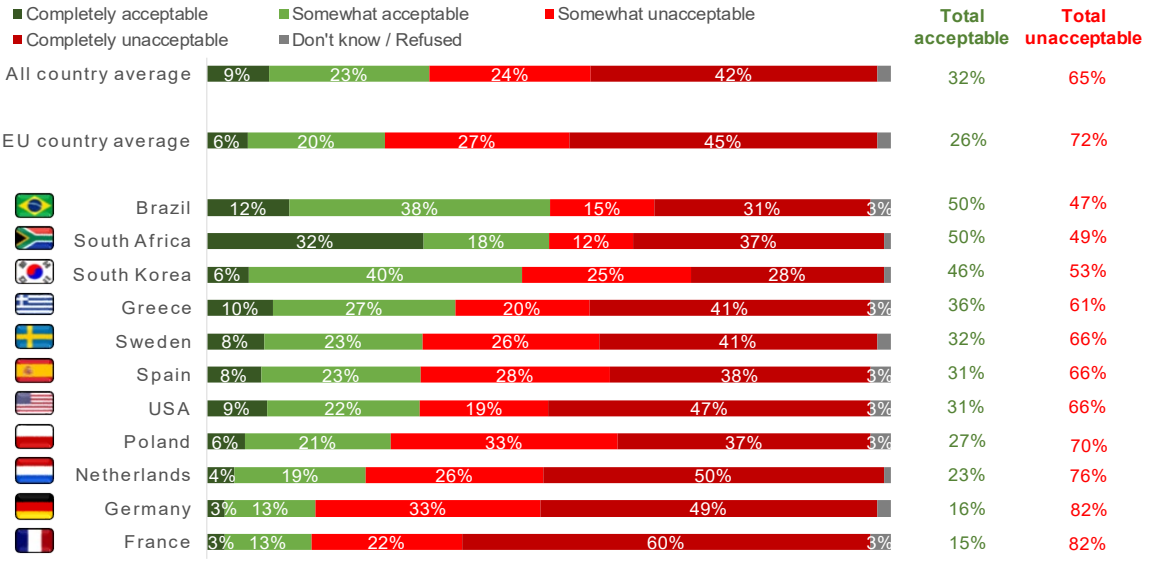
10.2 Conducting laboratory experiments on human embryos to understand how to increase human intelligence

Based on an average across all survey countries, 32% said it was acceptable to conduct laboratory experiments on human embryos to understand how to increase human intelligence, while twice as many (65%) said this was unacceptable.

Similarly, based on an average across all EU surveyed countries, 26% said it was acceptable to conduct laboratory experiments on human embryos to understand how to increase human intelligence, while more than twice as many (72%) said this was unacceptable.

As with the previous statement on human embryos, respondents in Brazil and South Africa were most likely to see this as acceptable (both 50%). Respondents in France (82%), Germany (82%), the Netherlands (76%) and Poland (70%) were most likely to consider conducting experiments on human embryos to understand how to increase human intelligence as unacceptable.

Figure 9: Acceptability of conducting laboratory experiments on human embryos to understand how to increase human intelligence



Q071: GEN_Q14 How acceptable do you consider each of the following to be? 'Conducting laboratory experiments on human embryos to understand how to increase human intelligence'
Base: all respondents.

Overall, based on an all-country average, there were gender and age differences based on whether it was seen to be acceptable to conduct laboratory experiments on human embryos to understand how to increase human intelligence.

Men were more likely than women to think it acceptable to conduct laboratory experiments on human embryos to understand how to increase human intelligence (39%, versus 26% of women). This difference held across all countries, except Greece and South Africa where results for men and women were relatively similar.

Those aged 18-34 were more likely than those aged 55+ to think it acceptable to conduct laboratory experiments on human embryos to understand how to increase human intelligence (42% versus 27%). This difference held in all countries apart from South Korea, Spain, Greece, Brazil and France, (where there was little difference between the two age groups).

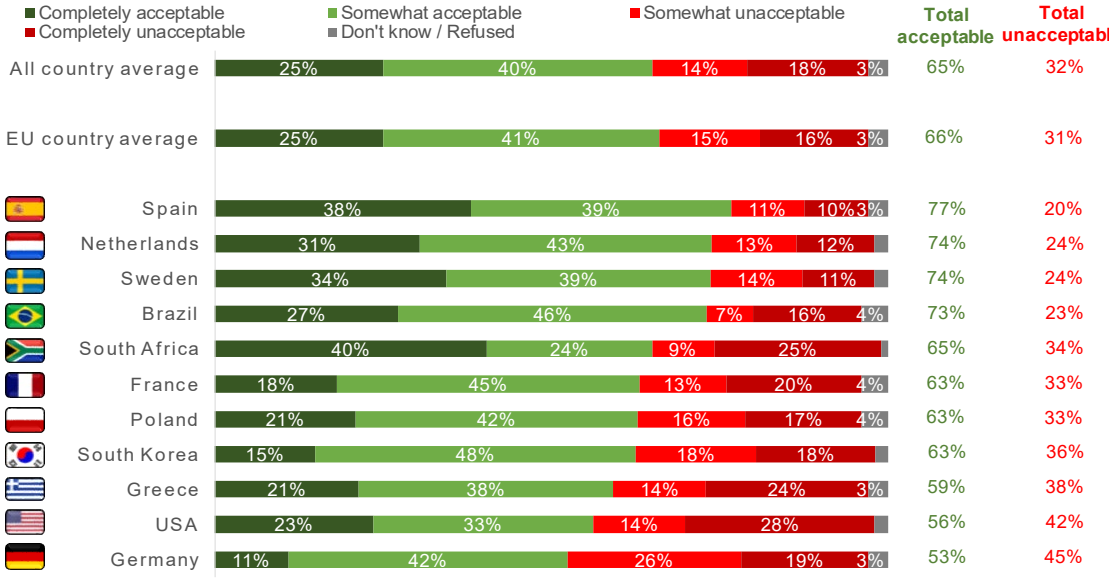
10.3 Conducting laboratory experiments on human embryos to better understand how to treat or cure serious health conditions

As noted above, the majority of respondents in most countries felt that the proposed use of human embryos for any purpose and to help understand how to increase human intelligence were unacceptable. However, when use of human embryos was linked to better understanding how to treat or cure serious health conditions, most respondents deemed this to be acceptable. Based on an average across all survey countries, 65% said it would be acceptable to conduct laboratory experiments on human embryos to better understand how to treat or cure serious health conditions, while 32% said this was unacceptable.

Similarly, based on an average across all EU surveyed countries, 66% said it would be acceptable to conduct laboratory experiments on human embryos to better understand how to treat or cure serious health conditions, while 31% said this was unacceptable.

Respondents in all countries were more likely to say that this use of embryos was acceptable than unacceptable. Those in Spain (77%), the Netherlands (74%), Sweden (74%) and Brazil (73%) were most likely to deem this acceptable. Respondents in Germany and the USA were most likely to say that this use of human embryos was unacceptable, though still a little over half felt it was acceptable.

Figure 10: Acceptability of conducting laboratory experiments on human embryos to better understand how to treat or cure health conditions



Q071: GEN_Q14 How acceptable do you consider each of the following to be? 'Conducting laboratory experiments on human embryos to better understand how to treat or cure serious health conditions'
Base: all respondents.

Overall, based on an all-country average, men were more likely to feel it was acceptable to conduct laboratory experiments on human embryos to better understand how to treat and cure serious health conditions, when compared to women (71%, versus 60% of women). This difference held across all countries, except Spain, Greece, France and South Africa where there was little difference between men and women.

Those saying religion was not important to them were also more likely to feel it was acceptable to conduct laboratory experiments on human embryos to better understand how to treat and cure serious health conditions than those who considered religion to be important to them (74% versus 60% of those saying religion was important). This difference held in all countries apart from South Africa and Greece, where those saying religion was important to them had relatively similar results to those saying it wasn't important.

Discussion points

The answers to the questions about research on embryos suggest that it may be a contentious topic; concerns of public regarding this should be taken seriously when considering ethical framework for human genomics.

Some explanations as to why the acceptability of experiments on embryos was lower among women and among those who answered that religion was important to them can be envisaged.

11. Responsibility for decision-making in genetics

Respondents were asked *"who do you think should be most responsible for making decisions about how genetic technologies are used"* from a list including the following groups:

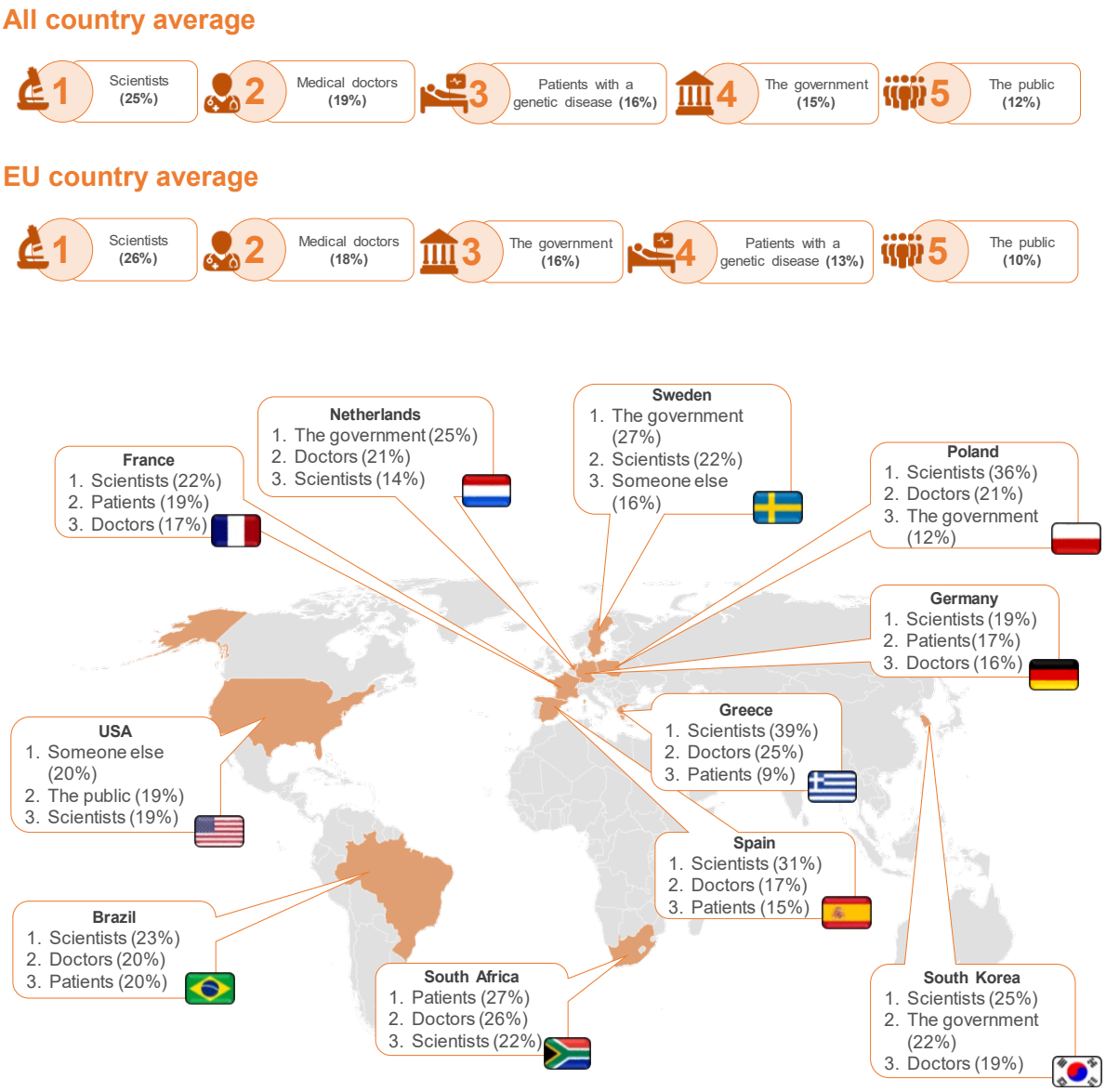
- Scientists
- Medical doctors
- The government
- The general public
- Patients with a genetic disease
- Someone else

Based on an average across all survey countries, there was no one group which stood out as having a huge majority over the others to shoulder the responsibility to make decisions on the use of genetic technologies. Scientists were most commonly chosen (25%), whilst 19% of respondents selected medical doctors, 16% patients with a genetic disease, 15% the government, 12% the general public, and 9% someone else.

As with the overall average, based on an average across the EU surveyed countries, scientists (26%) and medical doctors (18%) were most commonly selected. This was followed by the government (16%), patients with a genetic disease (13%), and the general public (10%).

There were some differences between countries on who it was felt should have most responsibility for making decisions about how genetic technologies are used. Respondents in Greece (39%), Poland (36%) and Spain (31%) were by far most likely to select scientists (and all three had another biomedical expert (medical doctors) in the 2nd position). For most other countries, responses were more mixed. However, respondents in the Netherlands (25%) and Sweden (27%) were slightly more likely to say the government should be responsible compared with other groups. Those in South Africa placed patients and doctors (27% and 26%) first and second respectively. In the USA, 20% of respondents said that someone else (other than the groups listed) should be responsible, with 19% selecting the public and 19% scientists. Only one other country had "someone else" listed in the top 3 (Sweden, in 3rd position).

Figure 11: Perceptions of who should be most responsible for making decisions about how genetic technologies should be used



Q072: Who do you think should be MOST responsible for making decisions about how genetic technologies are used?
Base: all respondents.
A full breakdown of answers and sample sizes can be found in the appendix.

Discussion points

The opinions on who should be most responsible for making decisions about how genetic technologies are used were divided. On average, the scientists, medical doctors and patients with genetic diseases were chosen most often. The fact that only few surveyed (12% average) indicated that public should be most responsible for making decisions about how genetic technologies are used may be related to relatively low awareness about genetics (around half of the respondents (51%) reported that they had heard or read only a little, hardly anything or nothing about genetics).

12. Conclusion

Self-reported awareness of genetics/DNA and gene editing

Across most countries, self-reported awareness of genetics or DNA was high. Based on an all-country average, more than nine in ten respondents had heard or read at least something about genetics or DNA. Respondents in South Africa were least likely to have heard of genetics or DNA, with three in ten unaware (compared with less than one in ten in all other countries). Around half overall said they had seen or read a lot or a fair amount about genetics or DNA, with some significant variation between countries in these results. Respondents in Germany and South Korea were most likely to have seen or read a lot or a fair amount about genetics or DNA with those in Spain, Poland and South Africa least likely.

Self-reported awareness of gene editing was a little lower. Based on an all-country average, eight in ten respondents had heard or read at least something about this. Again, respondents in South Africa were least likely to have heard of gene editing, with four in ten unaware. Based on an average across all countries, just a quarter said they knew a lot or a fair amount about gene editing. These results also varied significantly between countries, with the proportion claiming to know a lot or a fair amount about gene editing ranging between one in ten in Poland and four in ten in Germany and South Korea.

Public perceptions on the need to know more about genetics

The survey results suggested that people thought it was important for the general public to learn more about genetics or DNA. More than eight in ten respondents in all countries, and over nine in ten in some countries (South Africa, Brazil, Poland and Greece), felt it was very or fairly important for the public to learn more about this. Respondents in South Africa were the most likely to think that people should learn more about genetics and DNA, which may reflect the current lower level of awareness of these areas in this country.

Basic knowledge about genetics

In all countries, the majority of respondents answered each of three basic true or false statements regarding genetics correctly. Based on an all-country average, around nine in ten respondents were aware that genetic tests can help diagnose a disease, over eight in ten aware that genetic tests can predict whether an unborn baby will be born with Down's Syndrome, and just under eight in ten aware that researchers are working on changing the DNA in human cells to treat diseases. Respondents in South Africa and South Korea were least likely to answer these questions correctly.

Perceptions and consequences of increased prenatal testing on persons with disabilities and on prospective parents

Two hypothetical situations were posed to respondents in their survey to determine opinions on the impact the widespread use of genetic tests on unborn babies could have.

First, they were asked how likely it was that disabled people would be less accepted by society if more and more women choose to terminate their pregnancy due to the result of a genetic test. Based on an

all-country average, two thirds of respondents thought this was likely to happen. The majority of respondents in each of the 11 countries surveyed also thought this would be likely.

Respondents were then asked how likely it was that parents would feeling pressured to have genetic tests done on their unborn baby if genetic testing on unborn babies becomes increasingly common. The proportion of respondents seeing this as likely was higher than the previous scenario: an average of eight in ten across all countries and at least two thirds of respondents in all countries saw this as likely.

Perceptions on analysing all genes or DNA at birth

It is becoming increasingly common for genetic tests to be carried out on babies at birth to test for potential genetic diseases. The survey measured public opinion on whether all babies should have all their genes or DNA analysed at birth. Based on an average across all countries, respondents were fairly evenly divided on this issue. However, there were substantial variations between countries, with those in South Africa most likely to agree that all babies should have their genes or DNA analysed at birth and those in Germany most likely to disagree.

Self-reported awareness of gene editing

Self-reported awareness of gene editing was a little lower than awareness of genetics or DNA. Based on an all-country average, eight in ten respondents had heard or read at least something about this. Respondents in South Africa were least likely to have heard of gene editing, with four in ten unaware. Based on an average across all countries, just a quarter said they knew a lot or a fair amount about gene editing. These results also varied significantly between countries, with the proportion claiming to know a lot or a fair amount about gene editing ranging between one in ten in Poland and four in ten in Germany and South Korea.

Public perceptions of what experts know about gene editing

Respondents were divided on whether they thought researchers understood the health risks and benefits of changing an unborn baby's DNA. Based on an average across all countries, respondents were roughly equally likely to say that researchers understood this well and not well. This was also the case for most of the country level results, with respondents on most of the surveyed countries divided on this issue. The United States was the one notable exception to this, with respondents there far more likely to think the health risks and benefits were not understood well.

Perceptions regarding research with embryos

Respondents were posed with three scenarios regarding research on human embryos and asked to rate the acceptability of each of these. The results suggest that public acceptability of conducting laboratory experiments on human embryos is dependent on the purpose of the experiments. Based on an average across all countries, the majority of respondents thought it would be unacceptable to conduct laboratory experiments on human embryos for any purpose and to understand how to increase human intelligence. Respondents in Germany and France were most likely to see these scenarios as unacceptable.

The reverse pattern was true when the purpose of the experiments was to better understand how to treat or cure heath conditions, with the majority of respondents in all 11 countries thinking this would be acceptable.

Women were less likely to see each of these scenarios as acceptable compared with men. Those saying religion was important to them were also less likely to see two of the three scenarios as acceptable compared with those saying religion was not important to them.

Responsibility for decision making in genetics

Respondents were asked who they thought should have most responsibility for making decisions about how genetic technologies should be used. Based on an average across all countries, respondents were divided regarding who should have most responsibility, though scientists and medical doctors were slightly more likely to be selected than the other options (patients with a genetic disease, the government, the general public, or someone else). There were a number of differences between countries in who people thought should hold most responsibility. Respondents in Greece, Poland and Spain were most likely to select scientists; those in the Netherlands and Sweden were more likely to select the government; and respondents in South Africa thought patients and doctors should have most responsibility.

Final remarks

Importantly, all the above presented results should be interpreted keeping in mind the limitations of this study, such as low response rate (2-8%), no time for thinking about the response (since it was a telephone survey), and potential issues related to translation of the questions or concepts in different countries.

Notwithstanding, the results of the survey highlight a few issues, which seem to be of concern to the respondents. Specifically, a large number of respondents indicated that:

- using embryos for laboratory research is not acceptable (in case of research for any purpose: 60% average; to understand how to increase human intelligence: 65%; to better understand how to treat or cure health conditions 32%);
- genomic sequencing should not be performed on all newborns (36% average);
- increased numbers of termination of pregnancies based on a genetic test would likely result in disabled people being less acceptable in society (67% average); and
- increased uptake of prenatal genetic testing would likely result in parents feeling pressured to have genetic testing done on their unborn baby (79% average).

These concerns can be taken into account when developing ethical framework for human genomics in the task 2.7.

Furthermore, around half of the respondents (51%) reported that they had heard or read only a little, hardly anything or nothing about genetics. It may be that for this reason only few surveyed (12% average) indicated that public should be most responsible for making decisions about how genetic technologies are used. Yet, importantly, the vast majority (87%) indicated that it is important that general public understands more about genetics. These are important indications to consider in further SIENNA work.

Appendix

Appendix 1: Sample for routed questions

Q072: Who do you think should be MOST responsible for making decisions about how genetic technologies are used?

Base: all respondents (n=11088).

Country	Surveyed country average	Surveyed EU country average	Brazil	France	Germany
Sample size	11088	7086	1000	1002	1002
Scientists	25%	26%	23%	22%	19%
Medical doctors	19%	18%	20%	17%	16%
The government	15%	16%	10%	12%	14%
The general public	12%	10%	19%	11%	14%
Patients with genetic disease	16%	13%	20%	19%	17%
Someone else	9%	10%	4%	10%	12%
No one should be responsible	1%	1%	-	2%	1%
Don't agree with genetic technology at all	-	-	-	-	1%
Refused	-	-	1%	1%	1%
Don't know	4%	5%	2%	6%	4%

Country	Greece	Netherlands	Poland	South Africa
Sample size	1001	1011	1070	1000
Scientists	39%	14%	36%	22%
Medical doctors	25%	21%	21%	26%
The government	9%	25%	12%	12%
The general public	8%	13%	5%	10%
Patients with genetic disease	9%	12%	12%	27%
Someone else	7%	11%	7%	1%
No one should be responsible	1%	1%	-	-
Don't agree with genetic technology at all	-	-	-	-
Refused	-	-	-	-
Don't know	2%	2%	6%	2%

Country	South Korea	Spain	Sweden	USA
Sample size	1000	1000	1000	1002
Scientists	25%	31%	22%	19%
Medical doctors	19%	17%	12%	17%
The government	22%	11%	27%	5%
The general public	11%	14%	6%	19%
Patients with genetic disease	17%	15%	9%	15%
Someone else	3%	8%	16%	20%
No one should be responsible	-	-	-	1%
Don't agree with genetic technology at all	-	-	-	-
Refused	-	-	-	-
Don't know	3%	4%	7%	3%

Appendix 2: Questionnaire

Q001 - Q001: INTRODUCTION — **Single coded**

Not back

Good morning / afternoon / evening. My name is ... and I am calling from [NAME OF NATIONAL INSTITUTE] on behalf of Kantar Public, an independent research company. We are conducting a global survey funded by the European Union about some technologies and their impact on society.

IF NEEDED: The European Union is an organization comprising 28 European countries and governing over their economics, social and security policies.

Your participation in this survey is entirely voluntary. You can choose not to answer any questions if you do not wish to. Your answers will remain confidential.

IF ASKED: The survey will take about 15 minutes.

IF NECESSARY: If now is not convenient, I can call back at another time, but it would be helpful if I could ask you a couple of questions now, to check if you are the person we need to speak to.

IF NECESSARY: If you would like any more information about the survey, please contact [INSERT NAME, EMAIL AND PHONE NUMBER OF LOCAL KANTAR FIELD TEAM MEMBER].

[EACH COUNTRY SHOULD ADD ANY RELEVANT ADDITIONAL LOCAL INFORMATION SUCH AS GDPR PRIVACY NOTICES.]

INTERVIEWER: CONFIRM RESPONDENT IS AGED 18 OR OVER. IF NOT, ASK TO SPEAK TO SOMEONE AGED 18+, MAKING AN APPOINTMENT IF NECESSARY. IF NO ONE AGED 18+ LIVES IN HOUSEHOLD OR PHONE BELONGS TO SOMEONE AGED UNDER 18, CODE AS UNPRODUCTIVE OUTCOME.

May I ask you a few questions?

CODE OUTCOME FROM LIST BELOW
DO NOT READ OUT

Normal

1	Continue
2	Book appointment
3	Refuses to participate [GO TO OUTCOMES]

Q083 - Q083: **Text**

Not back

For quality control and training purposes this interview may be monitored.

Q002 - Q002: Landline or mobile sample - dummy — **Single coded**

Not back | Dummy

Landline or mobile sample

Normal

1	Mobile
2	Landline

Ask only if **Q002 - Q002**,1

Q007 - Q007: M1 **Single coded**

Not back

For safety reasons, could you please confirm that you are not driving and that you are in a safe position to answer the survey?

DO NOT READ OUT UNLESS NECESSARY – IF NEEDED, READ OUT 'YES' OR 'NO'

Normal

1	Yes, the respondent is in a safe position to answer the survey
2	No, the respondent is not in a safe position to answer the survey [GO TO OUTCOMES]

Ask only if **Q002 - Q002**,1

Q008 - Q008: M2 **Single coded**

Not back

Is this your phone?

INTERVIEWER: SELECT 'YES' IN CASES WHERE RESPONDENT SAYS THIS IS A WORK PHONE THEY USE.
DO NOT READ OUT UNLESS NECESSARY

Normal

1	Yes
2	No

Ask only if **Q008 - Q008**,2

Q009 - Q009: M3 **Open**

Not back

INTERVIEWER: ASK FOR PERSON WHO THE PHONE BELONGS TO. IF NOT AVAILABLE, ARRANGE TO CALL BACK.

Ask only if **Q002 - Q002**,2

Q011 - Q011: S1 **Numeric**

Not back | Max = 100

How many people aged 18 or over currently live in your household **including yourself**?

INTERVIEWER: ENTER NUMBER. CHECK THE FOLLOWING IF NECESSARY:

INCLUDE:
- People who normally live at this address, but are away for less than 10 weeks.
- People away at work for whom this is the main address.
- Boarders and lodgers.

EXCLUDE:
- People away for 10 weeks or more
- People who live elsewhere due to work/study
- Spouses who are separated and no longer resident

ENTER NUMBER

Scripter notes: Scripter notes: ***SCRIPTING NOTE: MAKE SELECTION USING RIZZO METHOD HERE***

RIZZO METHOD WORKS AS FOLLOWS:

- NUMBER OF PEOPLE TO SELECT FROM = NUMBER ENTERED AT S1
- ALL HAVE AN EQUAL PROBABILITY OF SELECTION
- PERSON INTERVIEWING IS SPEAKING TO COUNTS AS 'PERSON 1'
- THE DATA SHOULD STORE THE PERSON NUMBER OF THE SELECTED PERSON

Q012 - Q012: S2 **Single coded**

Not back

To make sure we speak to a good cross section of the public, we are using a random method to select who takes part. On this occasion someone else has been selected to take part. Could I speak to the person aged 18 or over, not yourself, who has the most recent birthday?

INTERVIEWER NOTE: THIS DOES NOT INCLUDE THE PERSON YOU ARE SPEAKING TO, IT MUST BE ANOTHER MEMBER OF THE HOUSEHOLD.

IF NECESSARY, SAY THE PERSON WITH THE MOST RECENT BIRTHDAY IS SELECTED TO ENSURE WE ACHIEVE A NATIONALLY REPRESENTATIVE SAMPLE OF ADULTS.

DO NOT READ OUT – IF NEEDED, READ OUT 'YES' OR 'NO'

Normal

1	Yes, available
2	No, not available [BOOK APPOINTMENT]
98	Refuses to participate [GO TO OUTCOMES]

Scripter notes: ROUTING CONDITIONS: ASK IF S1 > 2 AND PERSON 1 NOT SELECTED

Q013 - Q013: S3	Single coded

Not back

To make sure we speak to a good cross-section of the public, we are using a random method to select who takes part. On this occasion it is the other person that I would like to speak to. May I speak to that person?

IF NECESSARY, SAY WE NEED TO MAKE A RANDOM SELECTION TO ENSURE WE ACHIEVE A NATIONALLY REPRESENTATIVE SAMPLE OF ADULTS

DO NOT READ OUT

Normal

1	Yes, available
2	No, not available [BOOK APPOINTMENT]
98	Refuses to participate [GO TO OUTCOMES]

Scripter notes: ROUTING CONDITIONS: ASK IF S1 = 2 AND PERSON 1 NOT SELECTED

Q014 - Q014: S4	Single coded

Not back

Is it okay to continue with the interview now?

DO NOT READ OUT

Normal

1	Respondents willing – CONTINUE
2	Book appointment
98	Refuses to participate [GO TO OUTCOMES]

Scripter notes: ROUTING CONDITIONS: ASK IF PERSON 1 SELECTED

Ask only if **Q012 - Q012**,1 or **Q013 - Q013**,1

Q015 - Q015: S5 **Single coded**

Not back

Good morning / afternoon / evening. My name is ... and I am calling from [NAME OF NATIONAL INSTITUTE] on behalf of Kantar Public, an independent research company. We are conducting a global survey funded by the European Union about some technologies and their impact on society.

IF NECESSARY: The European Union is an organization comprising 28 European countries and governing over their economic, social, and security policies.

Your participation in this survey is entirely voluntary. You can choose not to answer any questions if you do not wish to. All your answers will remain confidential.

IF ASKED: The survey will take about 15 minutes.

IF NECESSARY: If now is not convenient, I can call back at another time, but it would be helpful if I could ask you a couple of questions now, to check if you are the person we need to speak to.

ADD IF NECESSARY: If you would like any more information about the survey, please contact [INSERT NAME, EMAIL AND PHONE NUMBER OF LOCAL KANTAR FIELD TEAM MEMBER].

[EACH COUNTRY SHOULD ADD ANY RELEVANT ADDITIONAL LOCAL INFORMATION SUCH AS GDPR PRIVACY NOTICES.]

Can we continue?

CODE OUTCOME FROM LIST BELOW

Normal

1	Continue
2	Book appointment
98	Refuses to participate [GO TO OUTCOMES]

Ask only if **Q012 - Q012**,1 or **Q013 - Q013**,1

Q085 - Q085: **Text**

Not back

For quality control and training purposes this interview may be monitored.

Ask only if **Q014 - Q014**,1 or **Q015 - Q015**,1

Q016 - Q016: S5a **Text**

Not back

Thank you for agreeing to participate.

THEN PROCEED TO INTERVIEW

B001 - B001: SECTION 1 - CONTACT SCRIPT **End block**

B002 - B002: SECTION 2 - DEMOGRAPHICS PART 1 **Begin block**

Q017 - Q017: Q3 **Single coded**

Not back

Before we start, can you confirm whether you are…

READ OUT

Normal

1	Male
2	Female
3	Or identify in another way
98	Refused (DO NOT READ)

B005 - B005: SECTION 5 - GENOMICS **Begin block**

Q058 - Q058: GEN_Q1 **Single coded**

Not back

[TEXTFILL IF FIRST IN ROTATION: This first section is about**; IF SECOND IN ROTATION:** We are now moving onto the second part of this survey. This section is about**; IF THIRD IN ROTATION:** We are now moving onto the last part of this survey. The final section is about**]** genetics and DNA.

Before today, how much, if anything, had you heard or read about genetics or DNA?

READ OUT

Normal

1	A lot
2	A fair amount
3	A little
4	Hardly anything but I have heard of it
5	I have not heard of this
98	Refused [DO NOT READ OUT]

Q059 - Q059: GEN_Q2 **Single coded**

Not back

How important do you think it is for the general public to understand more about genetics or DNA?

READ OUT

Normal

1	Very important
2	Fairly important
3	Not very important
4	Not at all important
99	Don't know [DO NOT READ OUT]
98	Refused [DO NOT READ OUT]

Q060 - Q060: GEN_Q3 **Matrix**

Not back | Number of rows: 3 | Number of columns: 4

For each of the following statements, please say whether you think it is true or false. It doesn't matter if you don't know, just say so and we'll go on to the next one.

Rows: Normal | Columns: Normal

Rendered as Dynamic Grid

	True [ONLY READ IF NECESSARY]	False [ONLY READ IF NECESSARY[	I don't know (DO NOT READ OUT)	Refused [DO NOT READ OUT]
Genetic tests can help diagnose a disease [READ OUT]	❍	❍	❍	❍
Genetic tests can predict whether an unborn baby will be born with Down's Syndrome [READ OUT]	❍	❍	❍	❍
Researchers are working on changing the DNA in human cells to treat diseases [READ OUT]	❍	❍	❍	❍

Q061 - Q061: GEN_Q4: GENETIC TESTING INTRO **Text**

Not back

We are now going to ask you about genetic tests – these are also known as DNA tests . These tests are done by analyzing samples of blood, saliva or body tissues. They can determine whether you, a family member, or an unborn baby carries genes for certain inherited features, including genetic diseases, or traits like height and eye colour.

READ OUT

Q063 - Q063: GEN_Q6: GENETIC TESTING OF BABIES INTRO **Text**

Not back

A Genetic test can be carried out on unborn babies, to find out whether a baby might be born with a genetic disease like Down Syndrome. Some countries allow for a termination of pregnancy when a disease is suspected in an unborn child.

READ OUT

Q064 - Q064: GEN_Q7 **Single coded**

Not back

[READ SLOWLY]

Suppose that over time more and more women choose to terminate their pregnancy due to the result of a genetic test.

How likely do you think that this would result in disabled people being less accepted in society?

READ OUT

Normal

1	Very likely
2	Fairly likely
3	Not very likely
4	Not at all likely
99	I don't know [DO NOT READ OUT]
98	Refused [DO NOT READ OUT]

Q065 - Q065: GEN_Q8 **Single coded**

Not back

Now suppose that genetic testing on unborn babies becomes increasingly common. How likely do you think that this would result in parents feeling pressured to have genetic testing done on their unborn baby.

READ OUT

Normal

1	Very likely
2	Fairly likely
3	Not very likely
4	Not at all likely
99	I don't know [DO NOT READ OUT]
98	Refused [DO NOT READ OUT]

Q066 - Q066: GEN_Q9 **Single coded**

Not back

Some tests can analyse all of a person's genes or DNA at the same time. This genetic data can then be stored for health purposes, or for medical research.

How much would you agree or disagree that all babies should have all their genes or DNA analysed at birth?

READ OUT

Normal

1	Strongly agree
2	Tend to agree
3	Neither agree or disagree
4	Tend to disagree
5	Strongly disagree
99	I don't know [DO NOT READ OUT]
98	Refused [DO NOT READ OUT]

Q067 - Q067: GEN_Q10: GENE EDITING INTRO **Text**

Not back

Researchers are currently looking into how we can change someone's DNA to treat or eliminate certain diseases. This is known as 'gene editing'. Some people are also interested to use gene editing to change non-disease features such as intelligence, strength or eye colour.

READ OUT

Q068 - Q068: GEN_Q11 **Single coded**

Not back

Before today, how much, if anything, have you heard or read about gene editing in humans?

READ OUT

Normal

1	A lot
2	A fair amount
3	A little
4	Hardly anything but I have heard of it
5	I have not heard of this
98	Refused [DO NOT READ OUT]

Q070 - Q070: GEN_Q12	Single coded

Not back

How well do you think researchers currently understand the health risks and benefits of changing an unborn baby's DNA?

READ OUT

Normal

1	Very well
2	Fairly well
3	Not too well
4	Not at all
99	Don't know [DO NOT READ OUT]
98	Refused [DO NOT READ OUT]

Q069 - Q069: GEN_Q13: EMBRYOS INTRO	Text

Not back

The next question is about human embryos. An embryo is an unborn baby at a very early stage of development, up to eight weeks after conception. Scientists sometimes use human embryos in medical research.

The law in many countries states that embryos used for research can only be used in the laboratory and cannot be placed into a woman's womb to grow a baby. These laws also require that embryos are used for up to 14 days after conception after which they must be destroyed.

READ OUT

Q071 - Q071: GEN_Q14 **Matrix**

Not back | Number of rows: 3 | Number of columns: 6

How acceptable do you consider each of the following to be?

Rows: Random | Columns: Normal

Rendered as Dynamic Grid

	Completely acceptable [ONLY READ IF NECESSARY]	Somewhat acceptable [ONLY READ IF NECESSARY]	Somewhat unacceptable [ONLY READ IF NECESSARY]	Completely unacceptable [ONLY READ IF NECESSARY]	Don't know (DO NOT READ OUT)	Refused [DO NOT READ OUT]
Using human embryos in laboratory experiments for any purpose *Fixed [READ OUT]	❍	❍	❍	❍	❍	❍
Conducting laboratory experiments on human embryos to understand how to increase human intelligence [READ OUT]	❍	❍	❍	❍	❍	❍
Conducting laboratory experiments on human embryos to better understand how to treat or cure serious health conditions [READ OUT]	❍	❍	❍	❍	❍	❍

Q072 - Q072: GEN_Q15 **Single coded**

Not back

Who do you think should be MOST responsible for making decisions about how genetic technologies are used?

READ OUT

Random

1	Scientists
2	Medical doctors
3	The government
4	The general public
5	Patients with genetic diseases
6	Someone else (ASK TO SPECIFY) *Open *Fixed
7	No one should be responsible [DO NOT READ OUT] *Fixed
8	Don't agree with genetic technology at all [DO NOT READ OUT] *Fixed
99	Don’t know [DO NOT READ OUT] *Fixed
98	Refused [DO NOT READ OUT]

B005 - B005: SECTION 5 - GENOMICS **End block**

B006 - B006: SECTION 6 - DEMOGRAPHICS PART 2 **Begin block**

Q073 - Q073: DEM_INTRO **Text**

Not back

We are nearly done with the survey, thank you very much for your time. Before we finish, we have a couple of questions about you.

READ OUT

Q074 - Q074: DEM_Q1 **Numeric**

Not back | Min = 16 | Max = 99

What is your age?

TYPE IN

Q075 - Q075: DEM_Q2 **Single coded**

Not back

Which of these age bands do you belong to?

READ OUT

Normal

1	18-24
2	25-34
3	35-44
4	45-54
5	55-64
6	65-74
7	75+
98	Refused (DO NOT READ)

Scripter notes: ASK IF DEM_Q1 = REFUSED

Q076 - Q076: DEM_Q3 **Single coded**

Not back

What is the highest level of education you have successfully completed?

READ OUT

Normal

1	University degree or above (or equivalent)
2	High school/senior school (or equivalent)
3	Below high school/senior school (or equivalent)
4	No educational qualifications
98	Refused (DO NOT READ)

Q077 - Q077: DEM_Q4 **Single coded**

Not back

What is your main current status. Are you...?

READ OUT

INTERVIEWER: IF 2+ ACTIVITIES, CODE THE ONE WHICH RESPONDENT SPENDS MOST TIME DOING

Normal

1	Working full-time or part-time
2	Unemployed
3	Retired
4	Full time student
5	Or doing something else (IF NECESSARY: for example looking after home/family, sick/disabled) [ASK TO SPECIFY] *Open *Fixed
99	Don't know (DO NOT READ)
98	Refused (DO NOT READ)

Q078 - Q078: DEM_Q5 **Single coded**

Not back

Have you ever been the parent of a child?

IF NECESSARY – IF SAY NO: Please include adult children, and any step-children or adopted children

READ OUT

Normal

1	Yes
2	No
98	Refused (DO NOT READ)

Q079 - Q079: DEM_Q6 **Single coded**

Not back

[GERMANY ONLY] The next question asks about the importance of religion in your life. You do not have to answer should you not wish to.]

How important, if at all, is religion in your life?

READ OUT

Normal

1	Very important
2	Somewhat important
3	Not very important
4	Not at all important
99	Don't know (DO NOT READ)
98	Refused (DO NOT READ)

B006 - B006: SECTION 6 - DEMOGRAPHICS PART 2 **End block**

Ask only if **Q002 - Q002**,1

Q081 - Q081: END_M **Single coded**

Not back

Do you have a working landline telephone at home?

READ OUT

Normal

1	Yes
2	No
99	Don’t know (DO NOT READ)
98	Refused (DO NOT READ)

Ask only if **Q002 - Q002**,2

Q082 - Q082: END_L **Single coded**

Not back

Do you have a working cell phone?

READ OUT

Normal

1	Yes
2	No
99	Don’t know (DO NOT READ)
98	Refused (DO NOT READ)

Q080 - Q080: END **Text**

Not back

That's the end of the interview. Thank you very much for your time.