D2.6: Qualitative research exploring public attitudes to human genomics

WP2 – Human Genomics – ethical, legal and social analysis

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Abstract

The SIENNA project - *Stakeholder-informed ethics for new technologies with high socio-economic and human rights impact (website: http://www.sienna-project.eu/)* – is a European Union (EU) funded project which is part of the Horizon 2020 research and innovation programme under grant agreement no. 786641. It deals with three emerging technology areas: human genomics, human enhancement, and artificial intelligence (AI) and robotics. This report presents findings from qualitative research which involved a day-long workshop in five countries comprising three two-hour discussion sessions, with one session focused on human genomics. The overarching aim of this qualitative research was to engage a range of citizens to consider issues raised by the three technology areas. The specific objectives for the genomics sessions were to explore citizen awareness, understanding, views and concerns about genomic sequencing and modification, specifically about: prenatal genome screening, storage and use of whole genome sequences (which was referred to as a "genomic passport" during the workshops to help participant understanding of the concept), somatic genome editing, and germline genome editing. Workshops were held in 5 countries: France, Germany, Poland, Greece, and Spain. Each workshop consisted of 50-53 participants (total n= 253) including a minimum of 10 participants from pre-specified vulnerable groups. This report outlines initial participant associations with the technologies and perceived benefits and concerns for their use, and provides some very early insights into what mitigation measures citizens may want to see in place to address their concerns.

This qualitative research was conducted by a social research agency rather than academics. There are a number of important limitations to this research, which include referencing, methodological, sampling and analytical limitations. The results in this report should be read with reference to and in the context of these limitations. The results serve as indicative findings about public attitudes to this technology area and should be treated as a starting point for further academic research and analysis to build from. They should not be read in isolation and should be read with reference to the other reports that have been produced as part of the SIENNA project.

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Executive summary

Overview of the research

The SIENNA project - *Stakeholder-informed ethics for new technologies with high socio-economic and human rights impact* – is a European Union (EU) funded project which is part of the Horizon 2020 research and innovation programme. It concerns three emerging technology areas: human genomics, human enhancement, and artificial intelligence (AI) and robotics. This report presents the findings from qualitative research exploring public attitudes to human genomics.

The overarching aim of this qualitative research was to engage a range of citizens to begin to consider issues raised by the three technology areas. The primary research objectives were to:

- Obtain insights into awareness and understanding of the technologies and their applications
- Explore and improve understanding of citizens' views of the technology areas in general, and particular uses and applications
- Explore citizens' concerns about the three technologies (and specific applications) and how they would like these concerns to be addressed

The specific objectives for the genomics sessions were to begin to explore citizen views and concerns about genomic screening and modification technologies, including the following applications: prenatal genomic screening (PGS), "genomic passports", somatic genomic editing, and germline genomic editing. The results serve as indicative findings about public attitudes to this technology area and should be treated as a starting point for further academic research and analysis to build from.

This qualitative research - which was conducted by a social research agency (not academics) to explore public attitudes to human genomics - comprised three two-hour discussion groups which were held as part of day long workshops in five countries. Qualitative research enables some discussion about complex, sensitive and/or contentious topics on which it is important to gain a public view. The workshops were a chance to introduce citizens to the technology areas and provide their initial responses to stimulus materials introducing the technology areas. Qualitative research does not aim or allow for statistical analyses; the data is neither representative nor generalizable and is not meant to be used to provide statistically significant results. The findings are one way to further understand why and how individuals perceive the technology areas, notably what concerns them about their development and use. The findings cannot be taken to be indicative of wider views within each country.

Full day qualitative workshops were held in 5 countries: France, Germany, Poland, Greece, and Spain. These countries were selected by the SIENNA consortium to represent different geographical regions, modes of socioeconomic development, and cultural, political and religious identity. Each workshop (lasting 8.5 hours) included three two-hour sessions, one covering each of the three technology areas. All workshops were held on a Saturday between 6th and 27th April 2019 and consisted of 50-53 participants (total n= 253 participants). Each workshop included a minimum of 10 participants from pre-specified vulnerable groups. Vulnerability, in this context, was defined as groups who might be at greater risk of disadvantage or of being adversely affected by the development and use of one or more of the three technology areas in their society (some criteria were more relevant to some technology areas than others). The vulnerability categories included the following: chronic health conditions; mental health conditions; genetic conditions; disabilities (including impairments to vision, hearing, mobility, breathing or dexterity and learning difficulties); those aged 70+; and immigrants (1st and 2nd generation). Some categories were more relevant to some technology areas than others.

Three to four members from the SIENNA consortium and their colleagues attended each of the workshops and were available to answer questions from participants during the discussions.

This research follows the more descriptive and interpretive traditions in qualitative research and is based on established qualitative analytical techniques used in social research agencies (rather than those typically used in academia). The analysis has focused on identifying key themes from within the accounts recorded by notetakers of the accounts provided by participants and should be understood within the limitations of the research and analysis context through which they were produced.

The report first outlines the research design (chapters 1 and 2) and then presents the findings about participant response to the stimulus materials introducing genomic screening technologies (chapter 3) and then the genomic modification technologies (chapter 4). The discussion section presents key themes that emerged about public attitudes towards these human genomics technologies.

Summary of limitations

There are a number of important limitations to this research which are outlined in Section 2.4, including referencing, methodological, sampling and analytical limitations. The results in this report should be read with reference to and in the context of these limitations. The results serve as indicative findings about public attitudes to this technology area and should be treated as a starting point for further academic research and analysis to build from. They should not be read in isolation and should be read with reference to the other reports that have been produced as part of the SIENNA project.

Most importantly, this project has been conducted by a social research agency and not academic researchers. This therefore limits the degree to which the research conforms with academic analysis and writing approaches and has not been referenced to the extent that would be expected in academic publications. It lacks introduction and discussion sections which contextualize the results with relevant academic literature to further understand the meaning of the results for the field.

This qualitative research involved a day-long workshop in each country comprising three two-hour discussion sessions, with one session focused on human genomics. It was not possible within the time and budget constraints to conduct discussions to the point of saturation, as might be expected in some types of academic research. The limited length of the discussion sessions also means that this exercise cannot claim to have uncovered 'in depth' views of the public, but rather associations and initial responses to introductory materials about the three technology areas. Further to this, it is important to recognise that the results presented here can only be understood within the context of the stimulus materials that were presented to the participants. Furthermore, the project originally sought to understand public attitudes towards and concerns about the three technology areas and how citizens wanted to see their concerns mitigated. The discussions about mitigation were restricted to a limited amount of time and the presentation of these results should be viewed as limited and as an indication of participant views – they should not be used to inform decision-making about regulation of these technologies but rather a starting point for further research to build upon.

Small (qualitative) sample sizes mean the workshops were not representative of the local population, and cannot be taken to be indicative of wider views within each country. Where references are made to views in countries in this report, this should be understood as references to the views expressed in the workshop in that country. Qualitative research does not aim or allow for statistical analyses; the data is neither representative nor generalizable and are not meant to be used to provide statistically significant results. Considering the data as such would be an invalid and misleading representation of qualitative data.

This report makes reference to results that were obtained from pre and post event questionnaires completed by participants. We note that these should be read with caution. The questionnaires were conducted as a

workshop activity and should not be interpreted or treated as a robust survey methodology as this is not what they were intended to be. This project was not conceived or designed to investigate whether and how views about these technologies change, which would not be possible through this methodological approach, and the questionnaire results should be approached accordingly.

Finally, this report should also be read within the context of the limitations in which the analysis was conducted – namely time and budget restrictions. The analysis has been conducted to the standard that was possible within these constraints, but may not meet with academic expectations for qualitative research analysis. Again, we reiterate that it should therefore be treated as a starting point for further analysis.

Summary of findings

Overall, there was **low awareness and understanding** of genomics technologies as this was not an area the public was generally familiar with. Lack of familiarity and low levels of understanding drove anxiety and concern among participants, particularly when they could not understand the purpose of a technology, how it worked, or what the limit of the technology might be in the future. This is crucial when considering the acceptability of technologies involved with areas the public see as central to the essence of our 'humanity', which was the case for human genomics.

Human genomics technologies (screening and modification technologies) were seen as more **beneficial and acceptable** when:

- they were voluntary and only affected the individual;
- they were more familiar;
- they provided a solution to a serious medical condition or improved a patient's quality of life;
- they provided certainty rather than probability of a condition;
- there were lower perceived risks of unforeseen medical consequences;
- they were less seen to likely result in negative social implications (notably inequality and discrimination).

In summary, **the main concerns raised about genomic screening technologies** across the five workshops were:

- The technologies **being made mandatory** by the state or private companies and this leading to discrimination in a variety of sectors;
- **Non-medical use of the technologies** for cosmetic or social purposes, and this leading to 'designer babies' and a drive for 'perfect' humans and less diversity in society as a result. There was concern that this could lead to lead to greater anxiety, inequality, and more intolerance and discrimination in society;
- The **provision of probabilistic and uncertain information** – particularly about chronic conditions that could emerge later in adult life – leading to increased stress and anxiety and lower quality of life for people. There was also concern about whether people would be able to understand and engage with probabilistic information;
- **Data privacy –** who would be able to access the data and for what purpose - and whether sufficiently accessible information would be provided to people to enable them to give informed consent with regard to data use;
- **Data security** – and whether data could be stored securely to avoid theft and hacking.

In summary, **the main concerns raised about genomic modification technologies** across the five workshops were:

- **Side effects and unforeseen consequences** – for the individual and their descendants - and whether editing could lead to new diseases or 'mutants and monsters' in the future;
- **Parents giving consent on behalf of children and their descendants** who could be negatively affected by any medical and social implications in the future – but had not given their consent for this;
- **Whether those who have been edited would need to be monitored** their whole life and how intrusive this would be for them;
- **Non-medical use** – for cosmetic or social purposes – and this leading to 'designer babies' and a drive for 'perfect' humans, and more anxiety and less diversity in society as a result. There was concern that this would lead to greater inequality, and more intolerance and discrimination in society as a result;
- **Data privacy and security** – there was concern about who would have access, how they could use the data, whether consent processes would be clear, and how secure storage would be.

Overall there was a mixed response to the materials about human genomics technologies, with the response overall being quite cautious and apprehensive. There was some positivity about the idea that editing could potentially provide a solution to serious medical problems rather than just information about a problem, as was the case for screening technologies, which might reduce a patient's quality of life due to anxiety as a result, particularly where the information was probabilistic and/or there was not an established cure or treatment. Responses to genomic technologies were commonly emotional, with some participants equating it with 'playing God', questioning the nature of humanity, and potentially causing serious unforeseen consequences for individuals and descendants in the future who did not consent to the editing process. There were also many questions raised about the kinds of impacts these technologies may have on equality and relations in our societies, and there was a need for all these concerns to be balanced against the potential medical benefits associated with genomic technologies.

List of tables

List of acronyms/abbreviations

Abbreviation	Explanation
ELSI	Ethical, legal and social issues
EU	European Union
GM	Genomic modification
Passport	Genomic passport
PGS	Prenatal genomic screening
UN	United Nations
WGS	Whole genome sequencing
WHO	World Health Organisation

Table 1: List of acronyms/abbreviations

Glossary of terms

Term	Explanation
Whole genome sequencing	An approach in which high throughput sequencing is applied to obtain nearly the entire genome sequence. Whole genome sequencing is currently being used for different reasons, including the molecular diagnosis of rare genetic conditions.
Prenatal genomic screening	Sequencing and analysis of large parts of fetal DNA to see whether there is a genetic risk for certain conditions. The positive results of such screening usually have to be confirmed in a diagnostic test which can give definite diagnosis of a disease.
“Genomic passport”	A metaphoric term for whole genome sequence, which is stored and used for healthcare and potentially other purposes throughout someone’s life. Whole genome sequence is unique to each person; an individual can be identified by his genomic sequence. To introduce and explain this aspect of whole genome sequence to workshops’ participants we used the term “genomic passport”.
Genome modification or gene editing	Approaches used to introduce changes to the genome, so changes to the DNA sequence, for example to correct a disease-causing gene
Somatic gene editing	Approaches of introducing changes to DNA in the cells of the body other than germline cells, such as blood cells, skin, heart etc. DNA changes introduced in such cells are not heritable.
Germ line gene editing	Approaches of introducing changes to the populations of cells that may pass on their genetic material to the progeny; examples are: gametes, zygote and embryonic cells

Table 2: Glossary of terms

1. Introduction

1.1 Introduction to SIENNA

The SIENNA project - *Stakeholder-informed ethics for new technologies with high socio-economic and human rights impact* – is a European Union (EU) funded project which is part of the Horizon 2020 research and innovation programme (grant agreement No 741716). It concerns three emerging technology areas: human genomics, human enhancement, and artificial intelligence (AI) and robotics.

These technology areas may offer benefits for both individuals and society - but also raise ethical challenges. SIENNA will address the ethical, legal and social issues (ELSI) covering these rapidly emerging technological fields and in particular the areas that may become more relevant to the publics' lives. It is therefore important and timely to develop ethical frameworks that will try to address both current and future ELSI.

The University of Twente (UT) leads a consortium of 11 international partners for this work. The project includes the following for each technology area: (1) review of the state of art; (2) analysis of legal and human rights issues; (3) a survey of normative documents; (4) ethical assessment; (5) surveys of citizens in 11 countries; (6) workshop s in 5 countries; and (7) the proposal of an ethical framework. This work will then be used to contribute to suggestions for enhancement of current ethical and legal frameworks in each technology area as well as propose codes of conducts for stakeholders and offer additional guidance for research ethics committees.

A key feature of the SIENNA project is that stakeholders, including the general public, will be engaged throughout the project. Kantar (Public Division) was commissioned to conduct public opinion surveys and qualitative research to assess public awareness, understanding and perceptions of the three technology areas. This report presents the findings from the workshop discussions about human genomics.

Further information about SIENNA project can be found on the SIENNA project website: http://www.sienna-project.eu/.

1.2 Aims of the citizens workshops

The overarching aim of the qualitative research was to engage a range of citizens to begin to consider issues raised by the three technology areas. The primary research objectives were to:

- Explore citizens' views of the technology areas in general, and particular uses and applications
- Explore citizens' concerns about the three technologies (and specific applications) and how they would like these concerns to be addressed

More specific secondary research objectives were used to structure the sessions and to try to achieve a level of consistency across the technology areas, whilst still allowing for divergence and flexibility as required by the area leads and their priorities. They were to explore:

- Awareness of the technology area and sources of awareness
- Feelings about the use of the technology
- Associations with and levels of understandings of the technology area
- Benefits, hopes and aspirations for the technology
- Risks and concerns about the technology – and what was driving these concerns
- Whether there should be a limit to use of the technology
- How citizens would like to see their concerns mitigated and who is seen to be responsible for the mitigation of public concerns
- Overall level of acceptability of / comfort with the development and use of the technology.

The specific objectives for the genomics sessions were to begin to explore citizen views and concerns about genomic screening and modification technologies, including the following applications: prenatal genomic screening (PGS), “genomic passports”, somatic genome editing, and germline genome editing.

The results serve as indicative findings about public attitudes to this technology area and should be treated as a starting point for further academic research and analysis to build from. They should not be read in isolation and should be read with reference to the other reports that have been produced as part of the SIENNA project.

2. Methodology

2.1 Research design

2.1.1 Qualitative research: full day workshops comprising three two-hour discussion sessions (one of which focused on human genomics)

Qualitative research was conducted by a social research agency (not academics) to explore public attitudes to human genomics. The research comprised three two-hour discussion groups which were held as part of day long workshops in five countries. Qualitative research of this nature at Kantar is primarily informed by the approach to research described in Ritchie and Lewis (2003)[1]. Full day workshops were held in five countries: France, Germany, Poland, Greece, and Spain (listed in the order the workshops were held). Each day (8.5 hours) included and introductory plenary session and three two-hour sessions, one covering each of the three technology areas (these were rotated as shown in Table 3 below). All workshops were held on a Saturday between 6th and 27th April 2019 and consisted of 50-53 participants (total n= 253 participants).

Qualitative research of this nature enables some discussion about complex, sensitive and/or contentious topics on which it is important to gain a public view. The workshops were a chance to introduce citizens to the technology areas and provide their initial responses to stimulus materials introducing the technology areas. The workshops gave members of the public the opportunity to begin to consider issues and express opinions on topics of interest. The limited length of the discussion sessions means that this exercise cannot claim to have uncovered 'in depth' views of the public, but rather associations and initial responses to introductory materials about the three technology areas. In-depth exploration of the topic was also limited by the consortium's preference to ask participants to explore multiple examples of each type of technology, rather than a more focused selection for deeper discussion.

The qualitative research performed herein used purposive sampling. Quotas were set with the aim of including a broad range of demographics and the likely diversity of views in each of the five countries. However, we note that we cannot be sure this is the case or that the variables chosen constitute all those that may be relevant to informing views about these technologies. Small (qualitative) sample sizes mean the workshops were not representative of the local population, and cannot be taken to be indicative of wider views within each country. Where references are made to views in countries in this report, this should be understood as references to the views expressed in the workshop in that country. Qualitative research does not aim or allow for statistical analyses; the data is neither representative nor generalizable and are not meant to be used to provide statistically significant results. Considering the data as such would be an invalid and misleading representation of qualitative data. The findings should be taken as one way to further understand why and how individuals perceive the technology areas and their uses, notably what concerns them about their development and use in their societies. Whilst the workshops enabled more detailed discussions than a survey, the depth of insight is limited due to the short time available to discuss three complex topics (120 minute per topic, and all three topics were done in one day) and the fact that a wide

[1] Ritchie, Jane., and Jane Lewis, *Qualitive Research Practice: A Guide for Social Science Students and Researchers*, Sage, London, 2003

range of examples and applications were included in each session. It should also be kept in mind, that while moderators who led the discussions were prepared for this task through a telephone briefing by the central research team, they were researchers from a social research agency and not experts in the technology areas, nor in the ethical, legal or social issues of the technology areas. Furthermore, group dynamic issues should be considered, such as some people feeling less able to express unpopular opinions in a group situation. Further detail about the limitations of this methodological approach are detailed in Section 2.4.

2.1.2 Description of the workshops

Here we offer a general description of all workshops and the way in which they were conducted. This is then followed in 2.1.3 by the specific details of the process for human genomics.

The five day-long workshops were held in Paris, Hamburg, Warsaw, Athens, and Madrid and were conducted in French, German, Polish, Greek and Spanish, respectively. The workshops in Paris and Hamburg were held on Saturday 6 April 2019, followed by Warsaw and Athens on Saturday 13 April, and Madrid on Saturday 27 April. The topic guide for the workshops, outlining the structure of the day and the topics for discussion posed, can be found in Appendix 1. Three to four SIENNA members with knowledge of, or expertise, in philosophy, (bio)ethics, law, or one of the three technology areas attended each of the workshops to observe or participate in the discussion (their role is outlined in detail below). Their names, affiliations, status, and which workshop they attended is provided in Appendix 2.

The design, topic guide, and stimulus materials for the workshops were developed by Kantar, with assistance from experts in the technology areas from the consortium. The overall design and structure of the day was reviewed and agreed by the consortium in Autumn 2018. In Spring 2019, the consortium experts informed Kantar what topics they wanted each discussion session to focus on and provided examples and applications for each technology area to be used as tangible examples for the participants. Kantar then wrote the detailed topic guide (Appendix 1), which was reviewed at least twice by the consortium experts for each topic area. Kantar also developed the stimulus materials which were reviewed at least twice and signed off by the consortium, to ensure that the materials were accurate, up to date and balanced. In the case of genomics, much of the text in the stimulus materials was written by the consortium experts, although this was reviewed by Kantar to consider usability and the participant perspective. There was not sufficient time available to cognitively tests the stimulus materials for the public to ensure their accessibility which is a limitation of the design. The topic guide and stimulus materials were translated into the languages in which the workshops were held by the Kantar Brussels' translation unit. The translations were reviewed and signed off by members of the consortium.

Each workshop followed the same format: an initial plenary session involving all 50-53 participants and then break out groups comprised of 10-11 participants. Before the workshop began, participants were asked to complete a short pre-task activity to explore hopes and concerns about technology more generally and a short two question questionnaire to ascertain familiarity with the technologies and feelings about them. After the workshop, a short two question follow up activity was conducted to see how they then felt about the technology area (Appendix 3). The questionnaire responses are provided in Appendix 3. We note that the findings from the questionnaires in this report should be read with caution. They were conducted as a workshop activity and should not be interpreted or treated as a robust survey methodology as this is not what they were intended to be. Participants were asked to answer two questions before and after the workshop, to give an indicative suggestion as to whether and how views might have shifted about the technologies during the workshop. This project was not conceived or designed to investigate whether and how views about these technologies change, which would not be possible through this methodological approach, and the questionnaire results should be approached accordingly.

The 20-minute introductory plenary session involved a presentation from the lead moderator from Kantar and informed participants about the SIENNA project, purpose of the research, aims of the workshops, and the structure of the day. Participants were then organised into moderated break out groups to encourage more in-depth discussions and to try to enable all participants to participate and contribute their views. Participants were randomly allocated to break out groups to try to achieve a mix of demographics in each group as this encourages exchange between participants with different perspectives or experiences. This was done through the distribution of coloured stickers at registration.

The workshop then consisted of three two-hour sessions, one for each of the technology areas. Division of workshops into three sessions facilitated somewhat more focused discussions on each topic as well as even distribution of time across the technology. Each break out group was led by a Kantar moderator experienced in conducting qualitative research for a social research agency (we note they were not academic researchers nor did they have any expertise in the topic area) - to set the parameters for the discussion, to strive for an open and respectful exchange of views, that everyone felt able to contribute to as far as possible, and that the flow of the discussion remained relevant and covered the agreed topics as far as possible. An agreed topic guide was used to – as far as possible - facilitate consistent coverage of topics and framing of questions across the five countries (Appendix 1). The order of the technology areas was rotated across the countries, to counter any ordering effects and ensure each technology area had the opportunity to be the first discussed.

Rotation of technology areas across the workshops

	Paris 6 April 2019	**Hamburg 6 April 2019**	**Athens 13 April 2019**	**Warsaw 13 April 2019**	**Madrid 27 April 2019**
ORDER OF SESSIONS					
SESSION 1 (2 hours)	Enhancement	AI & robots	AI & robots	Genomics	Enhancement
SESSION 2 (2 hours)	Genomics	Enhancement	Enhancement	AI & robots	Genomics
SESSION 3 (2 hours)	AI & robots	Genomics	Genomics	Enhancement	AI & robots

Table 3: Rotation of technology areas across the workshops

Although the exact structure of the two-hour sessions for each technology area varied according to the priorities identified by each work package leader, all sessions covered awareness and associations and understandings of the technology area, as well as some discussion about how to mediate/mitigate any citizen concerns raised where time allowed - and we note that mitigation was not covered for all topics by all break out groups due to time constraints. Basic information was introduced to inform the discussion, followed by some limited further materials on the tangible applications and benefits, risks and ethical issues associated with the specific subjects outlined by work package leaders for each technology area (see Appendices 1&4). The materials were in the format of paper handouts. They were read through by the participants with the assistance of their moderator as required. The handouts were translated into the language in which the workshop was being conducted. There was not sufficient time in the project timeline to cognitively test these materials before they were used, which is a limitation of the approach. However, in addition to this guide, discussions were always led by the priorities, interests and concerns of the participants.

The workshop closed with a short reflective plenary session, bringing all the participants together to reflect on how their views had developed over the course of the day. This also provided the SIENNA members

present the opportunity to pose any final questions they had to the participants and participants to ask questions.

A small number of changes were made to the guide based on experiences at the first two workshops in Paris and Hamburg to help the smooth flow of the further events. This included increasing the amount of introductory time in the break out groups to maximise the opportunity to establish rapport before the first session began and a reduction in length of the final plenary session, which was felt to be less productive at the end of lengthy day for participants. No changes were made to the stimulus materials due to lack of time to have these translated. The amount of stimulus material for the genomics session was reduced by half, as described below.

2.1.3 Description of the human genomics session

The human genomics session explored views about and concerns with the development and use for two areas:

1- high-throughput sequencing, (i.e. whole genome sequencing, WGS) and in particular WGS during the prenatal period,
2- genome editing (also known as gene editing or genome modification) including both somatic and germ line (i.e. heritable) gene editing.

The tables below provide an outline summary of the structure of the session to show what topics were discussed.

Structure and general content of the human genomics session

	Timing	Name of stimulus used
Awareness **Sources of awareness** **Associations and understanding**	10 mins	
Views about WGS **Views about PGS**	60 min	SCREEN STIM
Views about "genomic passports"	20 min	SCREEN STIM
Views about oversight and decision making and who is responsible for this	30 mins	

Genomic modification

	Timing	Name of stimulus used
Awareness **Sources of awareness** **Associations and understanding**	10 mins	
Views about somatic modification **Views about germline modification**	80 mins	MODIF STIM
Discussion about perspectives of vulnerable citizens	10 mins	
Views about regulation of genomic modification	20 mins	

Table 4: Structure and general content of the human genomics session

During the workshops, participants first discussed their awareness, associations, and understanding of genetics, genomics, and WGS. They then explored stimulus materials on the use of prenatal genomic

screening (PGS), discussing acceptability of the technology and in what circumstances they were more and less comfortable with its use, what types of diseases should be screened for, whether we should be able to screen for non-disease traits, and the benefits and concerns about its use. Participants then reviewed information about "genomic passports" and discussed perceived benefits and concerns about their use, views about the impact they might have on society, and comfort with them being used for research purposes. The workshop concluded by exploring participants' views about what oversight should be in place for the use of WGS technologies, what role parents should have, what measures should be in place to mitigate participant concerns, and who is responsible for addressing citizen's concerns. It should be noted that there was limited time for discussion of oversight and mitigation and therefore these findings should be taken as tentative and do not indicate recommendations from Kantar or SIENNA – as these topics are better placed to be taken forward by those with expertise in the technologies.

The human genomics section explored public attitudes towards the use of human genomic modification (HGM) technologies, including somatic and germline genomic modification. The workshops explored awareness, associations, and understanding of 'gene editing', 'genetic modification', and 'genomic modification'. The workshops explored responses to somatic modification and germline, including their acceptability and the circumstances with which participants were most and least comfortable with their use (including clinical and research use), and benefits and concerns associated with each. In the germline section, views about egg procurement from women and the destruction of embryos 14 days after fertilization were discussed. The session concluded by briefly discussing participant views about what oversight should be in place for the use of HGM technologies, what measures should be in place to mitigate participant concerns, and who is responsible for addressing citizen's concerns. It should be noted that there was limited time for discussion of oversight and mitigation and therefore these findings should be taken as tentative and do not indicate recommendations from Kantar or SIENNA - – as these topics are better placed to be taken forward by those with expertise in the technologies.

Due to the complexity of the subject areas in human genomics, and the fact that during the first two focus groups (in Paris and Hamburg) there were clear signs that participants were struggling to understand the material (e.g. how WGS works in practice), and that moderators also seemed in need of additional guidance, some changes were made. An additional explanatory document was prepared by the experts in ELSI of genomics at UU for the moderators to use (Appendix 6). Furthermore, to increase time for each subject and to try to help participant understanding of the topics, each break out group in Warsaw, Athens, and Madrid only discussed either whole genome sequencing or genome modification (see Table 3), rather than both topics as had been the case in Paris and Hamburg (Appendix 1).

Number of break out groups discussing each genomics topic

	Whole Genome Sequencing	Genome modification
Paris	5	5
Hamburg	5	5
Warsaw	2	3
Athens	3	2
Madrid	2	3
TOTAL	**17**	**18**

Table 5: Number of break out groups discussing each genomics topic

2.1.4 Role of SIENNA consortium members in the workshops

Three to four members from the SIENNA consortium and their colleagues attended each of the workshops. Not all were experts in the ethics of the technology areas, but each had a degree of knowledge and/or expertise in at least one of the following areas: law, political science, philosophy, bioethics or the technology area and ranged in experience from doctoral students to professors.

All SIENNA consortium members were provided with a written and telephone briefing before the workshops to ensure they were informed of best practice at the workshops. They were given the opportunity to contribute to one hour telephone de-brief sessions afterwards with the Kantar research teams which gave the chance for them to talk about their main take-aways from the workshop. The full list of expert attendees and their affiliations can be found in Appendix 2.

The purpose of their attendance was to enable participants to ask questions and for them to provide accurate, up to date, and balanced information as far as possible. Whilst they sat with the break out groups, there was a limit to how much participants could engage with them due to time restrictions during the workshops due to the amount of material to be covered. However, participants were able to interact with the experts during the breaks, ask questions at the break out tables, and ask any outstanding questions in the final plenary session.

2.1.5 Ethics and data protection

Kantar Public Division adheres to the following standards and industry requirements: Market Research Society (MRS) and ESOMAR (the global voice of the data, research and insights community) professional codes of conduct, ISO 20252 international market research quality standard, ISO 9001 international standard for quality management systems and the Data Protection Act 2018. Ethics approval was not required by Kantar for this research in any of the five countries where the workshops were conducted, but the MRS code of conduct was followed which provides ethical guidelines for the industry[2]. Furthermore, the coordinating university, University of Twente, obtained ethics approval from the SIENNA project.

Participants took part voluntarily and provided informed consent for participation; this was ascertained through the use of a recruitment screener which informed participants about the SIENNA project as the project commissioner for the research, aims and purpose of the research, how data would be used, and what participation would involve. Further information was provided via a Participant Information Sheet. The participants were informed that members of the consortium would be present at the workshops. They were able to withdraw from participation at any point during the workshop. As vulnerable groups were involved in the workshops, extra measures were taken to support their participation in the research: most of the discussions took place in break out groups with staff from Kantar moderating the groups; vulnerable groups were dispersed among the break out groups to avoid stigmatization; and accessible venues were chosen to accommodate vulnerabilities and sufficient time for extra breaks was allowed as required. Permission was also obtained from the participants – during recruitment and at the workshop itself – for the SIENNA

[2] Market Research Society, "Code of Conduct 2019".
https://www.mrs.org.uk/pdf/Draft%20MRS%20Code%20of%20Conduct%202019%20-converted.pdf

consortium to audio record the discussions for use for their own analysis. A GDPR compliant consent from was used to gain permission from the participants. The consortium is the data controller for these recordings.

2.2 Sampling and recruitment

The workshops were held in Germany, France, Poland, Greece and Spain. The consortium selected these countries based on different geographical regions within Europe, modes of socioeconomic development, and cultural, political and religious culture. The choices were influenced by the requirement that these countries should also have partner representation in the project (some EU partners in the project were themselves chosen in part to reflect geographic, economic and cultural diversity in the project).–While the consortium would have preferred a greater variation in religious traditions (as is, three of the five countries are predominantly Catholic and one is Greek Orthodox) this was not achieved and is a limitation of the research.

The workshops were held in the capital/large cities of Paris, Hamburg, Warsaw, Athens, and Madrid to best ensure successful recruitment, easy travel for participants, and the availability of suitably sized and equipped venues to hold these events. It was not feasible within the scope of the project to include participants from different regions of the countries, as we would not expect research participants to travel for more than an hour to attend a day-long event and there was not sufficient budget for travel and accommodation. Whilst a minimum number of three participants from more rural areas were included in each workshop, the urban locations and bias towards city-based experiences should be noted as a limitation of this methodology.

A total of 253 participants took part in the research, with 50-53 attending in each location. Each workshop included a minimum of 10 participants from pre-specified vulnerable groups, to include the views of these audiences in this research. A full break down of the achieved sample can be found in Appendix 5.

2.2.1 General composition of the workshops

Quotas were set with the aim of including a broad range of demographics and the likely diversity of views in each of the five countries. However, we note that we cannot be sure this is the case or that the variables chosen constitute all of those that may be relevant to informing views about these technologies. Minimum quotas were set to ensure the inclusion of a range of participant characteristics. However, it is important to note that small sample sizes mean the workshops were not representative of the local population, and cannot be taken to be indicative of wider views within each country. Qualitative research does not aim or allow for statistical analyses; the data is neither representative nor generalizable and are not meant to be used to provide statistically significant results. Considering the data as such would be an invalid and misleading representation of qualitative data. The findings should be taken as one way to further understand why and how individuals perceive the technology areas and their uses, notably what concerns them about their development and use in their societies.

Quotas were set for gender, age (from aged 18 and including a minimum for those 70+), education level, work status (including students and retirees), occupation type, ethnicity, whether religious or not, character of their area of residence (urban or more rural), parents and non-parents, and comfort with technology. Occupation was established by asking what is/was the participant's last main paid occupation and selection was based on minimum quotas assigned for different categories (see appendix 5). Ethnicity was established by asking participants how they would describe their ethnicity. However, due to legal restrictions in France, participants were not asked for their ethnicity but were instead asked 'whether they feel they belong to a minority group due to the country they or their parents were born in'. Minimum quotas were set for areas of residence to include views from more rural locations in the research and higher rural quotas were set for Madrid and Warsaw as it was deemed easier for participants to travel in from more rural locations in these cities (although we note the urban bias of the workshops as discussed above). Venues were chosen to, as far as possible, accommodate those travelling from outside of the city. Comfort with technology was established

by asking proxy questions about how comfortable participants were using the internet to buy goods and services; change energy supplier, and complete banking transactions. A refusal code was available for every question.

A quota was not included for socio-economic group due to the lack of availability of an agreed definition that could be applied consistently across the countries.

2.2.2 Vulnerable groups

A minimum of ten participants from vulnerable groups attended each workshop to attempt to allow diversity of views in the research. No vulnerable person included had severe disabilities or conditions that prevented them from joining the other participants, so they were included across the break out groups, rather than separated from the general population, also to avoid stigmatisation.

Vulnerability groups, in this context, were defined as groups who might feel they are at greater risk of disadvantage or of being adversely affected by the development and use of one or more of the three technology areas in their society. The vulnerability categories included the following: chronic health conditions; mental health conditions; genetic conditions; disabilities (including impairments to vision, hearing, mobility, breathing or dexterity and learning difficulties); aged 70+ (potentially including those living in nursing/care homes); and immigrants (1st and 2nd generation).

Lists of some of the most common conditions in Europe were provided for categories 1-4, but recruitment was not limited to these as 'Other - specify' codes were available to record other possible conditions. Due to the low prevalence of rare genetic conditions, participants were asked if they or a close relative had 'a condition which has a genetic component (e.g. that can or will be passed from parents to children)' – and this included cancer and diabetes – or 'had ever been concerned that either you or a close family member has an illness which has a genetic component (even if this turned out to **not** be the case)'. Immigrants also needed to meet vulnerability criteria which were defined as one or more of the following: refugee or asylum seeker; not fluent in the main language of the country (but skilled and confident enough to participate); not confident reading or writing in the main language of the country; age 60+, low educational attainment, unemployed, semi or unskilled jobs; or a minority ethnic group.

We note that in Warsaw, the number of participants classified as vulnerable was substantially higher (40). While the general recruitment was conducted in the same way as in the other four countries, there were more participants who had chronic health conditions, relatives with cancer, and vision impairments among older participants.

The sample excluded some vulnerable groups for whom participation would have been too great a burden. The sample did not include individuals who had mental impairments that rendered them unable to give valid informed consent (e.g. dementia, Alzheimer's). The agreed screener document monitored for people's level of comfort in participating (by describing the event to them and what they will be asked to do and giving a choice as to whether they felt able to participate or not) and any extra needs those who did feel able to participate had, to ensure participants were fully informed of what the workshops entailed. Where it was not possible to include some vulnerable groups, and to boost these perspectives in the research, options were given to include close relatives of vulnerable groups to represent their experiences. 'Close relative' was defined as a partner, a parent / grandparent, a child or step child, a sibling, or a family member who had lived with a vulnerable person. Some participants were recruited on this basis and this is detailed in Appendix 5.

2.2.3 Recruitment

54 participants were invited to each workshop, including an over-recruitment of four in anticipation of an 8% drop out rate. A screening questionnaire was used during recruitment to ensure a consistent approach was taken across the countries, which was reviewed and signed off by the consortium.

At recruitment, to support the informed consent process, all participants were provided with information about the SIENNA project, the purpose of the research, the aims of the workshops, what participation in the workshop would involve, and how their data would be used. Furthermore, a detailed description of the workshop was provided to aim to inform participants what would be asked of them. Participants were also provided with a Participant Information Sheet (PIS), giving more detailed information about what the workshop would involve and contact details if they wanted further information.

Recruitment for the workshops was conducted by experienced, local qualitative recruiters in each of the countries. It was carried out in accordance to the screening document agreed with the consortium and to be compliant with GDPR and Market Research Society standards. A variety of recruitment approaches were taken across the five countries and were dependent on the networks and databases that were available there, meaning it would not be possible for further research to replicate this process which is a limitation of the approach. In France, participants were recruited via a national database of c.250,000 people which is refreshed on a monthly basis. Participants opted in by responding to a questionnaire and were then telephoned if they were eligible. In Germany, the recruiter recruited from a panel of over 10,000 people, first using email and then re-contacting via phone. In Greece, Kantar Greece's panel involving over 20,000 participants across the country was used (aged 10-70). In Poland, recruitment was done face to face in the city centre, with five recruiters stopping citizens in the street for 25 days between them. In Spain, a recruitment agency was used which recruited via telephone from a database of over 30,000 people. Participants were offered a financial incentive to thank them for their time and participation and to cover travel and childcare costs, the amount being in line with local guidelines and norms (150 EUR in Germany; 200 EUR in France; 120 EUR in Spain; 100 EUR in Greece; and 300 PLN in Poland).

2.3 Analytical approach: thematic qualitative analysis

2.3.1 Raw data collection

The raw data was collected through the one-day workshops described in section 2.2. Three types of raw data were collected at the workshops; (1) audio recordings of the sessions; (2) notes taken by the note-takers; and (3) pre and post event questionnaires completed by the participants.

The workshops were conducted in hotels; in some cases, in one room and in others the groups were spread into smaller rooms, as the space allowed. The plenary sessions were led by a Kantar moderator experienced in conducting qualitative research for a social research agency (we note they were not academic researchers). The break out groups were each led by a Kantar moderator (with experience of conducting research in a social research agency context), who audio recorded the discussions. A member of staff from Kantar also took notes throughout the sessions. In Germany and Greece, the notetakers recorded into a structured template which mirrored the order of the discussion points in the topic guide. In France, Poland, and Spain, the note takers took notes in blank documents as this was their preference for recording the most accurate notes possible.

2.3.2 Analytical approach

This report should also be read within the context of the limitations in which the analysis was conducted – namely time and budget restrictions. The analysis has been conducted to the standard that was possible

within these constraints but may not meet with academic expectations for qualitative research analysis. Again, we reiterate that it should therefore be treated as a starting point for further academic analysis.

This research follows the more descriptive and interpretive traditions in qualitative research (Spencer et al: 2003). It presents what participants mean and understand about the technology areas, analysing the 'situated accounts' provided within the workshops (Kvale:1996). The analysis for this report has focused on identifying themes from within the accounts recorded by the notetakers of the accounts provided by the participants in the workshops (Ritchie and Lewis:2003. The project did not seek to force a consensus; while it focuses on aggregate level results, it has sought to explore the diversity of views present across the sample as far as was possible within the limitations of the analytical approach which were defined by the budget available. We remind the reader that the results of qualitative analysis are to some extent subjective (to those conducting the analysis) and should be understood within the limitations of the research context through which they were collected which were taken into account as far as possible within the analysis; e.g. group dynamics, uneven coverage, the influence of other views, and within the limits of the information that was provided to participants and the questions that were asked to them (Ritchie and Lewis:2003) - as well as the fact that the analysis was conducted from notes and not verbatim transcripts meaning that nuances will have been lost in the analysis process.

2.3.3 Analysis process

This section outlines the analysis process undertaken to provide transparency about how the data was managed and interpreted so that comprehensive coverage of the dataset was achieved within the limited time and budget available for this project. Analysis consisted of two stages, firstly management of the data and then interpretation of it to produce a descriptive account afterwards. The analytical process consisted of the following:

- In the workshops, three types of raw data were collected: (1) audio recordings of the sessions; (2) notes taken by the notetakers; and (3) pre and post event questionnaires completed by the participants. We note that the audio recordings were not transcribed, a decision made by the consortium due to budget limitations – and this should be noted as a limitation of the analytical process because it means that nuances have been lost in the process and means the analysis reported here was an analysis of accounts recorded by notetakers of accounts provided by participants. Recordings were reviewed by the lead moderators in order to collect illustrative quotations for the country level reports (by listening to relevant sections highlighted in the note taker notes, they were not reviewed in their entirety). Notes were recorded as accurately as possible into a blank document in all countries except Germany and Greece, where note takers used a structured template which reflected the order of the discussion topics in the topic guide. The notes were not translated, again due to budget constraints. The variety of approaches taken to recording the notes also limits the extent to which comparison between the countries has been possible.
- The audio recordings, notes, and questionnaires responses – all in the language in which the workshop was conducted – were reviewed by the lead moderators (experienced in qualitative research conducted in a social research agency environment rather than an academic environment) to produce five country level reports. They did this by reading the notes, and entering common themes identified into a structured country level report template provided by the project team.
- The country level reports were provided to Kantar Public UK approximately two weeks after the final workshop in Spain in a highly structured template, which closely mirrored the discussion points in the topic guide and asked the country lead moderators to draw out thematic findings for each discussion point (e.g. associations, awareness, response, reported benefits and risks/concerns associated with each technology area, how concerns should be mitigated and who is responsible for

this). The template also instructed the lead moderators to include quotations to illustrate the findings, because the purpose of the quotations is to illustrate the key themes identified. The use of this structured country report template meant that the analysis was not a bottom-up, grounded approach.

- The analysis process also included 1-3-hour telephone de-brief sessions one week before and one week after the reports were submitted, led by the Kantar UK project lead or project director. These focused on and were used to draw out the key themes for each discussion point for each technology area (meaning those which were discussed mostly commonly across the groups). One hour telephone de-brief sessions were held with the lead moderators in each country after each workshop with the Kantar UK team. The lead moderators reported key findings for each discussion topic for each technology area. The Kantar UK team noted these to keep track of key themes emerging during the fieldwork period. One hour de-brief phone calls were held with some of the SIENNA members who attended the Paris, Hamburg, Warsaw, and Madrid workshops who also contributed their thoughts to this process.
- After the five country level reports were submitted to the team in Kantar UK, a final two-hour telephone based de-brief session was held with all the lead moderators to discuss the key themes to try to ensure they were consistent with their experiences in the workshops – before the final reports were drafted. A one-hour telephone de-brief was then held with the experts from the SIENNA consortium to check the headline findings were consistent with the observations and experiences of those who attended the workshops and to enable other consortium members to request what areas they wanted the further analysis to focus on.
- Kantar UK staff then spent more time reading the country level reports to produce report outline structures for each of the three reports. They identified key themes for each discussion topic for each technology area across the five countries – key themes being those that emerged most strongly across the break out groups. The report outline structures were provided to and agreed with the SIENNA leads to ensure the report structures took into account the interests of the technology leads.
- The final phase of the analysis was then conducted by Kantar UK staff and involved reviewing the five country level reports to identify more detailed themes and sub themes for each discussion topic for each technology area. This was done by reading and annotating the country level reports where themes were reoccurring. Quotations were selected which supported and illustrated key findings in the reports at this stage. It is important to note the distance this final report has moved away from the original accounts provided by the participants, as the analysis has involved multiple layers of interpretation, beginning with the notetaker, the country lead who wrote the country level report, and then the final report authors.

Verbatim quotes are used throughout this report to illuminate and bring to life key findings and are attributed as follows: *"Quote."* (Location).

2.4 Limitations

In this section we consolidate the limitations of this research exercise, which include referencing, methodological, sampling and analytical limitations. The results in this report should be read with reference to and in the context of these limitations. The results serve as indicative findings about public attitudes to this technology area and should be treated as a starting point for further academic research and analysis to build from. They should not be read in isolation and should be read with reference to the other reports that have been produced as part of the SIENNA project.

2.4.1 Referencing limitations

Most importantly, this project has been conducted by a social research agency and not academic researchers. This therefore limits the degree to which the research conforms with academic analysis and writing

approaches and has not been referenced to the extent that would be expected in academic publications. This report does not follow common academic standards for publishing qualitative research exercise results. It lacks introduction and discussion sections which contextualize the results with relevant academic literature to further understand the meaning of the results for the field. This decision was made by Kantar and the consortium to meet the time and budget constraints within which the project was conducted. Clearly, each discussion group could and should be more deeply analysed to fully understand their meaning and how this pushes our understanding of public views toward human genomics further. Ideally such further analysis will be conducted by academic partners through academic publications.

2.4.2 Methodological limitations

This qualitative research involved a day-long workshop in each country comprising three two-hour discussion sessions, with one session focused on human genomics. Qualitative research of this nature at Kantar is primarily informed by the approach to research described in Ritchie and Lewis (2003)[3].

Originally the research was conceived of as a piece of deliberative research. However, time and budget constraints meant that this approach could not be employed as it was not possible to fund a study which would allow the reconvening of participants or enough time for discussion which would allow the level of reflection required for deliberative research. The research follows the standards and conventions used in social research agencies. It was not possible within the time and budget constraints to conduct discussions to the point of saturation, as might be expected in some types of academic research.

The limited length of the discussion sessions also means that this exercise cannot claim to have uncovered 'in depth' views of the public, but rather associations and initial responses to introductory materials about the three technology areas. In-depth exploration of the topic was also limited by the consortium's preference to ask participants to explore multiple examples of each type of technology, rather than a more focused selection for deeper discussion.

Further to this, it is important to understand that the results presented here can only be understood within the context of the stimulus materials that were presented to the participants. All three technology areas are complex, and participants commonly had little to no previous awareness and understanding of the technologies. Therefore, discussion was limited to their response to the high-level introductory materials they were exposed to. It is particularly important to note the limited definitions that were provided to participants and the large number of examples that participants had to comprehend within a limited time frame. Furthermore, the project originally sought to understand public attitudes towards and concerns about the three technology areas and how citizens wanted to see their concerns mitigated. The discussions about mitigation were restricted to a limited amount of time and the presentation of these results should be viewed as limited and as an indication of participant views – they should not be used to inform decision-making about regulation of these technologies but rather a starting point for further research to build upon.

[3] Ritchie, Jane., and Jane Lewis, *Qualitive Research Practice: A Guide for Social Science Students and Researchers*, Sage, London, 2003

It should also be kept in mind that while moderators who led the discussions were prepared for this task through a telephone briefing by the Kantar project team, they were not experts in the technology areas, nor in the ethical, legal or social issues of the technology areas.

2.4.3 Sampling limitations

As well as the design of the exercise, it is important to understand the limitations of the sampling approach taken in this qualitative exercise. Quotas were set with the aim of including a broad range of demographics and the likely diversity of views in each of the five countries. However, we note that we cannot be sure this is the case or that the variables chosen constitute all of those that may be relevant to informing views about these technologies.

Small (qualitative) sample sizes mean the workshops were not representative of the local population and cannot be taken to be indicative of wider views within each country. Where references are made to views in countries in this report, this should be understood as references to the views expressed in the workshop in that country.

Qualitative research does not aim or allow for statistical analyses; the data is neither representative nor generalizable and are not meant to be used to provide statistically significant results. Considering the data as such would be an invalid and misleading representation of qualitative data. The findings should be taken as one way to further understand why and how individuals perceive the technology areas and their uses, notably what concerns them about their development and use in their societies. We also note that it is not possible to carry out sub group analysis through this style of qualitative research, as there are not sufficient numbers to represent sub groups, moderators are not able to accurately allocate participants in their group to sub groups, and because this is not possible within the dynamics of a group research setting where some voices may be more dominant than others.

Recruitment for the workshops was conducted by local qualitative recruiters in each of the countries. It was carried out in accordance to a screening document agreed with the consortium and to be compliant with GDPR and Market Research Society standards. A range of recruitment approaches were taken across the five countries and were dependent on the networks and databases that were available there. It would not be possible for further research to replicate this process.

This report makes references to results that were obtained from pre and post questionnaires completed by the participants. We note that these should be read with caution. The questionnaires were conducted as a workshop activity and should not be interpreted or treated as a robust survey methodology as this is not what they were intended to be. Participants were asked to answer two questions before and after the workshop, to give an indicative suggestion as to whether and how views might have shifted about the technologies during the workshop. This project was not conceived or designed to investigate whether and how views about these technologies change, which would not be possible through this methodological approach, and the questionnaire results should be approached accordingly.

2.4.4 Analytical limitations

Finally, this report should also be read within the context of the limitations in which the analysis was conducted – namely time and budget restrictions. The analysis has been conducted to the standard that was possible within these constraints but does not meet with academic expectations for qualitative research analysis. Again, we reiterate that it should therefore be treated as a starting point for further analysis. We remind the reader that the results of qualitative analysis are to some extent subjective (to those conducting the analysis) and should be understood within the limitations of the research context through which they were collected; e.g. group dynamics, uneven coverage, the influence of other views, and within the limits of

the information that was provided to participants and the questions that were asked to them (Ritchie and Lewis:2003).

The approach follows in the descriptive and interpretive traditions for qualitative research (Spencer et al: 2003). However, it does not conform with academic standards for grounded or thematic analysis. For example, there was not sufficient budget available for the transcription of the audio files which would be required for a purist implementation of these approaches. The analysis in this report has been conducted based on the notes taken by note takers for each of the discussion groups which were collated into country level reports (according to a structured template) and then comparison was made between these country level reports and themes drawn out accordingly – rather than robust and systematic thematic analysis being conducted as may be expected in academia.

There are three final limitations to be noted. The results are presented as an aggregate of the dataset comprising of the material across the five countries. Whilst we acknowledge that the five countries have different political, economic, social and cultural contexts (and indeed were chosen by the consortium for this reason), it is not possible to draw any conclusions about the impact of these differences on the results within the limits of the design. It is also not possible to compare the results of the three technology areas as the analysis process does not allow for systematic comparison between the technology areas. Finally, where technologies are referred to as being most and least acceptable in these reports, this refers to them appearing to be acceptable through the discussions in the workshops and should not be taken to imply statistical significance as is established through quantitative research.

3. Results and discussion: Whole Genome Sequencing Technologies

This section reports on participant responses to the stimulus materials presented about the development and use of whole genome sequencing (WGS) technologies - focusing on prenatal genomic screening and storage and use of whole genome sequences (which was referred to as "genomic passports" in the materials and workshops to make this concept clearer for participants and therefore this term is used throughout this chapter for consistency with that approach).

3.1 Introduction

During the workshops, the following definitions of terms were provided to participants and the findings should therefore be interpreted with reference to these. All the materials presented and given to participants are provided in Appendix 4 and the discussion flow is described in the methods chapter.

- A **genome** is all the genetic material (DNA) of an individual.
- **Genetics** is the science of studying genes and their effects on individuals. Traditionally, genetics only studied one or a few genes at a time. New technologies mean we can now study hundreds to thousands of genes at a time - this is called genomics.
- **Genomics** is useful in diagnosing diseases and in some cases helping to decide the right treatment. Some very rare genetic diseases can be almost certainly predicted by a genetic test. For other more common diseases, genetic information can give a *probability* of developing the disease in the future (e.g. breast cancer or cardiovascular diseases). However, factors like lifestyle, diet, exercise, and stress often play a very important role in developing and preventing diseases.

It emerged from the analysis process that awareness, knowledge and understanding of WGS was low. Participants were provided with information about the technologies and input from experts to support a more informed debate (Appendices 1,2,4) but often struggled to understand the material, which limited their ability to provide informed responses. This should be noted as a limitation of the findings and underlies the results presented in this report.

3.2 Whole genome sequencing

During the workshops, the following definition was provided to participants and the findings should therefore be interpreted with reference to it:

- **Whole genome sequencing (WGS) -** is **a readout of all of a person's DNA / genome**. It contains information about someone's health and non-health related traits. Some genetic information revealed by DNA sequencing may not be expected by the patient. It is difficult to predict what will be found and what it could mean. The significance of some of genetic information to disease is currently not known. WGS has so far mainly been used by researchers rather than by doctors. In a few places it is slowly being introduced as part of healthcare services

There were limited introductory conversations about WGS and the information was provided as background information for the rest of the session, which focused on prenatal genomic screening and "genomic passports". Therefore, the findings presented below should be read as highly preliminary, indicative and in need of further research.

3.2.1 Awareness, associations and understanding – spontaneous and prompted

Based on self-reported awareness and understanding, there was low awareness and understanding of **WGS** across the five countries. Pre-workshop questionnaires showed participants were most commonly 'not familiar at all' (Appendix 3). Furthermore, when asked to 'describe how you feel about each of the technologies', participants said they felt 'neutral' about the technology. After the provision of information, participants' responses showed they commonly still found it difficult to understand the process, purpose, and value of WGS and this drove fear and anxiety about the application. This is likely to be due to the complexity of the topic but also the complexity of the materials provided to the participants and the short amount of time in which they had to digest this information and respond to it.

There was wide familiarity with the term **'genetics'** across the five countries. It was associated with terms and ideas such as: DNA, stem cells, and chromosomes; teaching in science subjects at school (notably biology); traits and diseases being inherited; and new medical cures. 'Genetics' was also associated with genetically modified food amongst participants in Germany and Poland. Whilst there was wide awareness of the term 'genetics', there was little understanding of what it meant. Participants cited learning about it at school or via the news through stories about Dolly the Sheep and coverage of Angelina Jolie's preventative cancer surgery. Whilst generally feeling 'neutral' towards the term, in some countries participants also associated genetics with 'scary' topics such as cloning and eugenics (France) and designer babies (Germany).

> *" Yesterday I watched a movie with Keanu Reeves where he reproduces his family." (Poland)*
>
> *"Genetics is the science that might bring cure for diseases that now are incurable, like the medical use of stem cells." (Greece)*
>
> *"I have an older son with a heart defect. My cousin's son has it [too], even though none of his parents does. A genetics doctor drafted out for us [an explanation about) who could possibly have the defect. It was twenty some years ago, and we were told that once the boy was born, he would have that illness, and if it was a girl, she wouldn't. But that generation is not here yet." (Poland)*

There was low awareness of the term **'genomics'** and confusion emerged about the difference between this and 'genetics'. Participants assumed that associations would be similar to genetics – particularly the inheritance of genes. They had a sense that 'genomics' might be to do with having more 'control' over genes (amongst participants in Greece and Spain), and this evoked fear for participants in Spain that it might be 'playing God'.

> *"I can't really tell the difference between genetics and genomics. Are they really two different things?" (Greece)*

There was no awareness of the term **'whole genome sequencing'** – except among a small number of participants in France who had scientific backgrounds. Some participants in Germany guessed that WGS was about the passing of genetic sequences between generations. There was widespread confusion about whether WGS was about screening or modification. After being provided with the stimulus materials, participants generally understood WGS related to the shape and structure of DNA and all of a person's genetic material. However, some remained confused about the term, notably participants in Germany and France before the workshop session was modified to allow more time for explanation of key terms to the participants.

> *"[Is WGS to] understand and see the position of genes?" (France)*
>
> *"[Is WGS about] taking the genome, and repairing and sequencing it; to determine the illnesses you could have?" (Spain)*

"One can also 'knock out' different areas [using WGS], then the disease is no longer present, or the disease is intensified, or determine what the child looks like." (Germany)

3.2.2 Response to whole genome sequencing

From the very limited discussion on this topic, there was **a highly mixed response to WGS** and no consensus emerged before participants explored prenatal genomic screening and "genomic passports". Responses were emotionally driven and participants tended to find the concept of WGS intimidating and tended to be quite anxious about it. The post-workshop questionnaire indicated participants most commonly thought WGS would have a 'neutral' impact on society, and there was a mixed range of feelings towards WGS (including 'curious', 'hopeful' and 'neutral'). There was a somewhat more positive response amongst participants in Poland where people more commonly saw WGS as the natural progression of the field of medicine.

The discussions indicated that participants tended to find WGS somewhat **more acceptable when it identifies serious genetic conditions for which there is a treatment and improves survival rates**. However, there was widespread concern across the five countries that WGS may identify health problems, notably chronic conditions and those that occur later in life, but not provide a solution to them. There was some concern that WGS would identify conditions for which long term life style changes would be required to make a difference, and there was a concern that these would be difficult to follow and achieve. As a result, participants tended to be unsure whether they would want this information, claiming it could lead to greater anxiety and therefore a lower quality of life.

3.3 Prenatal genomic screening

During the workshops, the following information and definitions about prenatal genomic screening (PGS) were provided to participants and the findings should therefore be interpreted with reference to them:

- In **prenatal genomic screening (PGS)**, it is proposed that large parts of the unborn baby's DNA or entire genome be sequenced and analysed to find out if it has or will develop genetic diseases. For many diseases, the information only provides a **probability** of developing the disease – not certainty. The DNA readout may reveal information about diseases which will appear in adulthood and non-health traits (e.g. eye colour). Prenatal genomic screening is not currently offered in routine prenatal care.

3.3.1 Awareness, associations and understanding

There were **self-reported higher levels of awareness and understanding** of PGS than during the initial discussions about WGS, but it seems this may have been due to the availability of a familiar frame of reference, as participants tended to compare PGS with current pregnancy screening, which had also been presented in the materials and with which they were widely familiar. This greater sense of familiarity meant there was generally a higher level of comfort with PGS than WGS.

"[it is] normal, science is progressing; [the] subject is familiar, it has been for 20 years that research has been carried out on the subject." (France)

Despite reported greater familiarity with the term, participants had **low levels of understanding** of how PGS works. Participants were unclear about the range of conditions that could be screened for and diagnosed. PGS was widely associated with the early detection of serious genetic conditions in foetuses, most commonly with reference to Downs Syndrome and also a type of anaemia amongst participants in Greece.

"It's the identification of genes that could cause malformations or genetic diseases." (France)

"Foetal examination to detect anomalies, disorders, diseases." (Poland)

3.3.2 Benefits

Overall, **participants could identify some benefits of PGS that were important to them**, although to a lesser degree in Spain where there was greater concern about the implications of this technology.

PGS was seen as **more beneficial when it could provide information which could lead to treatment of genetic conditions**, particularly serious ones, or reduce infant mortality rates. It was also seen as beneficial where it could identify chronic conditions for which there are established treatments (e.g. diabetes). In Spain and Greece, participants were enthusiastic when PGS could lead to an issue being fixed before birth.

> *"Yes for when it's serious like paralysis, illnesses that might not have a treatment later. The more common might have more solutions." (Spain)*
>
> *"It's a good thing it exists in case there are problems." (France)*
>
> *"If the disease is curable while the embryo still in womb, I would like to know and proceed with cure as the baby won't be born ill." (Greece)*

PGS was also seen as beneficial **when it could help parents to prepare to look after a disabled child or child with a serious genetic condition** – therefore potentially improving the quality of life for the child and parents. In this way, it was viewed positively that PGS could provide parents with greater choice. Downs Syndrome was the condition most commonly referred to across the five countries, and there was also discussion amongst some participants in Germany about whether it was appropriate to see and describe this condition as a 'disability'.

> *"I'd put it there and whoever wants to can request it. It's about making decisions more freely. The more you know, the freer you are" (Spain)*
>
> *"I think it is important to know and then be able to make decisions, but it's very sensitive" (Spain)*

PGS was seen to be **more beneficial when diagnoses were certain rather than probabilistic** because people are more able to utilise this information in decision making. There was concern across the countries that people would not understand or know how to react to probabilistic information and that it could create anxiety for expectant parents.

The use of PGS for **research stood out and was seen as beneficial by some participants**, when the procedure could contribute to the discovery of cures for other conditions.

> *"This might bring the cure for uncurable diseases, if researchers use the results for humanity's best interest and not for earning more money." (Greece)*

3.3.3 Concerns

Despite identifying some benefits, **there were widespread concerns about the development and use of PGS**. Some participants were more nervous about this technology – despite the potential for health benefits – where they feared a 'darker' side to the area of genetic medicine – driven by lack of information or certainty about where this technology will go and whether there is an 'end' to it. There was some fear about the **pace of development**. Some participants saw PGS as science advancing 'too far' and stepping into the realm of 'playing God' (in Germany) and 'intervening in nature' (in Greece).

> *"We give ourselves rights or influence we should not have – who's to decide and why? … you play sorcerer's apprentice." (France)*
>
> *"It's like intervening in nature." (Greece)*

> *"I find it's excessive to do a complete screening, it's against nature [to] before birth already make an inventory of all the diseases that the child could potentially develop. It's scary if you hear there is 30% chance he develops this illness and 20% chance that he will develop that illness, you will only be thinking about that and you will be in a very negative mode." (France)*

There was concern that PGS would be used to **provide information about conditions for which there is not a solution** and that this would lead to anxiety and lower quality of life. There was therefore greatest concern about the provision of probabilistic diagnoses of conditions that could appear in later life. Some participants said that PGS should only be available for conditions where there is a cure or way to improve quality of life.

> *"On the other hand, if I have a baby, I'll keep thinking that it might get cancer – I would not want to know that. The whole life in fear." (Poland)*

> *"The thing is that it's talking about probabilities, not certainties, and you make momentous decisions based on probabilities." (Spain)*

> *"Feelings of uncertainty that are not solved because you only know about a percentage, a probability. It's not sure. If you do not do the test it's unsure but with the test it's still not sure." (France)*

> *"I don't want to live my whole life in fear in case the disease would not appear. I can't live my life based on possibilities." (Greece)*

Concerns were raised that the identification of issues through PGS could affect a child's **health insurance premiums** and could lead to discrimination in this area. Some participants also had concerns about children who may get a disease in the future being treated differently and 'mothered' or isolated in society (in Germany).

There was widespread concern that PGS could be **used to create 'designer babies'.** Screening of non-medical traits was seen as unacceptable and as 'unnatural' and 'artificial'. In Poland, participants feared this would lead to parents aiming to create the 'perfect' child and children 'on demand and to order'. Participants in Greece were concerned this could lead to trying to create 'super humans' and participants in a number of countries were concerned about a 'supreme' race . The fact that the notion of creation of babies/humans was raised in the discussion about sequencing highlights the potential extent of participant misunderstanding (between sequencing and modifying the genome). While sequencing would technically be needed to modify humans (should that be possible), the way we presented it, it was about sequencing to diagnose disease and we did not link this to modification of the genome (which came as a topic later on for participants in France and Germany but would not have been discussed for the other break out groups that addressed this in the other countries).

There was concern amongst participants across the five countries about screening for gender, eye and hair colour and skin tone –in Greece, Spain and Germany. There was concern about gender selection in France, where participants made reference to gender selection in India and expressed desire to avoid this.

> *"At the touch of a button and on request orders [of babies] should be prohibited." (Germany)*

> *"Ethically wrong … It looks like we're looking for a superior race." (Spain)*

> *"Already today, a doctor can tell whether the child will be tall or not. I was surprised, I did not know, but carrying out analysis to know whether my son will have the muscles of Naymar, please no!" (France)*

There was widespread agreement that PGS should not be used for non-medical purposes, and participants in Poland also did not want to see it used for matching people with life partners, which was seen as 'unnatural'.

> *"And what about meeting somebody and falling in love? – everybody will start from checking the genes." (Poland)*

There was concern that society would become **less diverse and less tolerant and less accepting of disability, disease, and difference more generally through the use of PGS** (amongst participants in France and Germany) – and this point was prompted in the stimulus materials. There was greatest concern about loss of diversity in society in France, where participants had a fear of 'standardizing' society. There was concern that disabled people would face greater discrimination and become more isolated as a result of this. Participants also questioned how children whose parents chose not to screen them would feel in a society where this was more common if they subsequently had a medical condition, and how parents who chose not to screen would feel and be treated by society as a result. There was a desire to prioritise education about disability and support in society amongst some participants in Germany.

> *"It would be your fault as a mother for not preventing your child from being born with a disability." (Germany)*

> *"Search for the perfect human being […] It could cause a potential risk of discrimination of people who differ from the norm. Would the world be better with or without people suffering from Down syndrome?" (France)*

> *"It raises ethical concerns for me. Are we creating a society of super humans, with no tolerance on differentiation and diversity?" (Greece)*

There was also widespread concern about **data privacy and security.** Participants questioned who would have access to PGS data, how they could use it, where and how it would be stored and whether it would be secure. Concern was exacerbated by reported lack of information about this issue, what the potential problems could be, and what solutions are available to address these issues. There was widespread concern and cynicism about whether and how PGS data would be kept private, with concern about sale to private companies (notably private healthcare and insurance companies). Participants in Spain had a desire that insurance companies should not get access to the data because this would lead to discrimination in this market and greater inequality in society as a result.

> *"I'd suggest that the data is only used for health purposes, not that someone could steal it." (Spain)*

> *"If they're already listening to us right now through our mobiles, this even beats it." (Spain)*

There were some concerns raised by participants about **access to this technology and whether uneven access could contribute to greater inequality** in society if it was only or predominantly available to wealthier citizens (especially in France). Some participants in Poland were somewhat more accepting of the idea that access to technology could be uneven and that wealthier people are likely to have more and earlier access to new technologies. There were discussions about who would pay for the technology and whether this should be paid for by the state or parents, which remained unresolved.

Some concern was raised amongst participants in Greece about the safety of the procedure itself and the level of risk to the mother and baby and said that PGS should not be allowed where there is significant risk.

> *"I believe that it might be dangerous for the mother, as they have to use a huge needle to puncture the belly of the mother." (Greece)*

Some concern was raised across the five countries about the **potential increase in abortion rates due to the use of PGS,** particularly amongst participants in Greece. However, we note that the workshop context and limited time available meant that discussions on this sensitive topic were incomplete. Increase in abortion rates was a concern and some participants suspected there may be greater levels of concern in more rural and less cosmopolitan locations where the workshops were held. Concern was raised by some participants in France that women may have abortions for conditions for which cures and treatments are then discovered later in their life. There was some concern raised that women may seek illegal and/or unsafe abortions in light of PGS results, if these were not available in their country when PGS was.

> *"I think that doctors would suggest abortion just because they detected an indication of a disease. Human lives will be sacrificed based on an indication that is scary." (Greece)*
>
> *"I am afraid that more and more abortions will take place, for no reason at all." (Greece)*

3.3.4 Level of (un)acceptability

Overall, there was **a mixed response to the acceptability of PGS**. For some participants, particularly in Poland, PGS was seen to be an evolution of current technologies that participants were already familiar with (i.e. pregnancy screening). However, PGS was less acceptable and more contentious amongst participants in Spain.

The level of acceptability of PGS seemed to vary according to the following themes:

- Use must be **voluntary and follow fully informed consent from parents** – participants in all five countries felt that it would not be acceptable to make PGS mandatory. Participants in Germany also mentioned that they would want parents to be able to decide the level of information they would want access to.
- Use of PGS was o**nly acceptable for medical purposes. Non-medical trait screening was widely seen as unacceptable** (notably of eye, hair and skin colour; and for intellectual capabilities for participants in France)
    - Screening for **serious genetic conditions was the most acceptable use** of PGS – particularly for those that lessen life expectancy or mean a life of dependence on carers – where screening could prevent or treat the condition or lessen suffering
    - Screening for conditions that start **prenatally or in childhood was more acceptable** than those that appear in later life
    - PGS was seen to be more acceptable where it was able to **provide (more) certain predictions**, and less acceptable where it provided less certain probabilities
- It was only acceptable for the procedure to be **carried out by trained medical professionals**
- PGS was seen as more acceptable for participants where there is assurance that the **data is stored safely and securely**, and where there is strict data protection laws in place (especially Germany and Spain)
- Some participants in Greece felt that the use of PGS was seen as **more acceptable for older mothers** – where risk of genetic diseases might be higher.

3.4 "Genomic passports"

During the workshops, the following information and definition for the storage and use of whole genome sequences – or "genomic passports" - were provided to participants and the findings should therefore be interpreted with reference to them. This approach was referred to in the materials and workshops as "genomic passports" and therefore this term has been used in this report for consistency.

"Genomic passports" are when a whole genome sequence is stored in a database and could be used by healthcare professionals throughout a person's life to see if they are likely to develop a disease or react to a treatment. The goal is for doctors to use this information to give more tailored advice to patients. This currently does not exist in most healthcare systems. There are significant costs and logistical issues to resolve to ensure the information is securely stored, and that doctors know how to analyse the DNA readout. Researchers may want to access the information to conduct research.

3.4.1 Awareness, associations and understanding

There was **no awareness of "genomic passports"** among participants across all five countries and they therefore had no associations with the term. However, it appeared they were able to understand the concept of "genomic passports" when this was explained via the stimulus materials through their further discussion of the approach. This term was not included in the pre and post questionnaire.

3.4.2 Benefits

Across the five countries, **participants generally struggled to identify benefits of "genomic passports" that were valuable and important** to them and the discussions on this approach skewed towards concerns about it. Participants in Poland were less concerned than in the other countries, again more commonly seeing "genomic passports" as the progression of medical science.

> *"If we were so fearful, there would be no people signing up for bone-marrow transplant." (Poland)*

"Genomic passports" were seen as beneficial where they can **improve diagnosis of medical conditions,** particularly of rare conditions and those where this is currently difficult or takes a long time (allergies were provided as an example of this in France) and where use of this approach improves survival and treatment rates. "Genomic passports" were seen as beneficial for those with serious hereditary conditions in their families, where their use would enable people to get up to date information about new solutions and options for them.

> *"When new things appear, I swipe the passport through the reader, and if it applies to me, I sign up for it, if not, I don't." (Poland)*

"Genomic passports" were seen as **most beneficial when they provide a certain result** and can be used throughout your life to identify health conditions for which there is a **cure or treatment** and for which early detection makes a difference to survival rates, treatment, and quality of life.

"Genomic passports" were also seen as beneficial when they can help doctors **identify a treatment more easily**. In France, some participants were enthusiastic about the idea of a more collaborative approach between doctors and patients which "genomic passports" could facilitate. Participants in France saw these as beneficial when they can be used to plan more effective treatment in advance, particularly if people need to adapt their way of living. Participants in Germany and Poland were more commonly positive about the idea of more 'personalised' and 'customised' treatment and care being available through the use of a "passport".

> *"[Passports would be] a super good help for doctors, to improve treatments. I understand that it gives them more information than they currently have – more sophisticated information" (Spain)*

Research use of "genomic passports" was generally seen as beneficial when it can help to find cures for diseases, particularly serious genetic diseases and cancer. However, for any research use of "passports" to be acceptable, the data must be collected and held **on a voluntary, confidential and anonymous basis**.

"I think that is positive for medical study as to find cure for diseases like cancer." (Greece)

"It is important to keep your anonymity and not be stigmatised for life." (Greece)

3.4.3 Concerns

Whilst some benefits were identified, the discussions about "genomic passports" were heavily skewed towards concerns and participants generally found the 'permanence' of this highly sensitive data 'unnerving'.

"It is like a record for life, that will determine who we are without being able to get out of it." (Greece).

As with WGS and PGS, **concern was raised about the provision of probabilistic results**, particularly for conditions which may develop in later life. Participants were concerned that this would lead to worry and anxiety, therefore decreasing overall quality of life – particularly in cases where the condition then does not develop and this means the decline in quality of life due to stress that was unnecessary. In France and Germany, participants had some concern that people could end up taking unnecessary treatments or taking unnecessary preventative measures, particularly where these might have negative side effects.

"Yes, I'd also prefer not to know so much and not be conditioned. Knowing that my son is going to have liver cancer at 40 seems to me to be gratuitous suffering." (Spain)

"You no longer live life. People then live with the fear of this disease." (Germany)

There were widespread and **high levels of concern about data privacy,** especially for participants in Germany and Greece. Participants were concerned about who will have access to the data and how they could use the information. These concerns were driven by a sense that others could use the information to 'control' you in the future. It was seen as essential that any data sharing must be voluntary and follow fully informed consent, but **participants were sceptical this would be the case and were concerned that people would not be able to understand complex data privacy/sharing agreements and understand the implications of these**. Participants wanted any data sharing to be on an **anonymous basis but were unsure whether this was possible**.

"Who will have access to these data, huge interests might use it to control people in the future." (Greece)

"Do you want to release your DNA to the whole population?" (Germany)

There were also **high levels of concern about data security** and whether the information could be hacked or stolen and how it could be used by those with malign intentions. In Germany, some participants had concerns that stolen "genomic passport" data could be used for cloning or identity theft. In Poland, some participants were concern about the use of "passport" data for cyber-attacks and that there could be a black market of data trading.

"Every piece of information can be obtained, like in the case of WikiLeaks… It shows that there is no secure data base." (Poland)

There was also **widespread concern about the use of "genomic passports" for non-medical purposes**. Limiting use to medical applications was fundamental for "passports" to be seen as acceptable. Participants did not want non-medical companies to have access to "genomic passports" data, as they could not conceive of a way this would be beneficial to citizens. They did not want to see their data used for research into non-medical trait issues. In Greece, some participants had some concern that private companies would try to

create a 'supreme' human from the data. In France, some participants were also concerned about citizens being able to upload their "passport" to dating sites and that this could lead to discrimination.

As with the other screening technologies, there was concern that use of "genomic passports" **could lead to a change in social norms**, where 'perfection' becomes the norm and those with disabilities or deviations face discrimination in society. Amongst participants in France, there was concern that life, and a 'perfect' life would become seen like a 'product' you can buy. This suggests there remained some misunderstanding of what the technology could achieve.

> *"It's like those people who use a surrogate mother and order what they want their child to be like." (France)*

There was concern across the countries about the ways in which "genomic passports" could **make people vulnerable to discrimination and stigmatisation** in society. There was concern about whether people could face discrimination in education, work and their social life if their "passport" said they were more likely to develop a condition in later life (especially amongst participants in Greece). There was widespread concern about increased health insurance premiums for those whose "passport" identified chronic conditions and participants did not want insurance companies to have access to the data or to be able to request it mandatorily (particularly amongst participants in Spain, Greece, and Germany). In France, Germany, and Poland participants were concerned about workplace discrimination and whether those with identified conditions would be able to get jobs. Amongst some participants in France and Poland, there was concern about discrimination in the financial sphere, and whether those with conditions would be refused loans if they were identified as a repayment risk. In France, some participants were concerned that people could be refused health treatment or charged more for it – if they were deemed less 'worthwhile' to treat if their "passport" suggested they would have a lower life expectancy.

> *"Discrimination exists, and the more information you have the more there is. We're very selfish" (Spain)*

Some concern was raised across the five countries about whether "genomic passports" could **contribute to greater social inequality** – and whether people would face discrimination and stigmatisation based on how 'good' or 'normal' their data was perceived to be. In Greece, participants had concern that use of these "passports" could create a more divided society, split between more and less 'advanced' humans through use of the "passport" to improve and 'fix' people. Likewise, participants in Germany were concerned about the creation of new 'classes'.

3.4.4 Level of (un)acceptability

Overall, there was **a generally quite negative response to "genomic passports"** across the five countries and there were lower levels of acceptance of the development and use of this approach. This stemmed from participants' struggle to see the value of "genomic passports", and the benefits they did ascertain generally did not outweigh their concerns about data privacy and security.

The level of (un)acceptability of "genomic passports" depended on the following themes and varied according to the following conditions:

- It was widely seen as only acceptable to use "genomic passports" for medical purposes. Use for non-medical purposes was seen as unacceptable.
- Use of the approach was widely only acceptable by medical professionals, and participants did not want to see use by private companies and organisations outside of the healthcare system (unless this was to develop new medical cures through research).

- Acceptance of the approach depended on it being voluntary – it was not seen as acceptable for this to be made mandatory either by the state or medical professionals
- Acceptance depended on informed consent being provided either by the individual or the parent of a child.
- Use of "genomic passports" was more acceptable where they were able to provide more certain results.
- Use was more acceptable if "genomic passports" were used to identify conditions for which there is a cure or treatment in place and less acceptable where this is not the case.

There were **mixed views about the use of "genomic passports" for research**. This was only acceptable in the context of seeking medical cures but participants across the five countries had concerns about data privacy and security in this context. There was general agreement amongst participants that use for research would need to be on an anonymous basis (particularly in Greece). In France, some participants wanted to see state control and oversight of this research due to distrust of private companies who they did not believe would provide sufficient oversight and safeguards. In Germany, some participants suggested that only small parts of a "genomic passport" should be released for research rather than the whole dataset, to protect anonymity and reduce the risk of misuse of the data.

3.5 Participant views on mitigation of concerns about whole genome sequencing

This section reports on discussions held with the participants about what measures they wanted to see in place to address their concerns about whole genome sequencing approaches. We note that these findings are limited due to the short amount of time allocated to this discussion and the findings should therefore be read as highly tentative. We also note that these views are not presented as Kantar (Public Division) or SIENNA's recommendations, but as reporting of participant views.

Overall, there was a sense across all five countries that regulation is needed in the area of whole genome sequencing, and that it needs to be strict and tight to give citizens the confidence that the technology should be developed and used in their societies. There was a sense amongst participants that regulation should prioritise the safety and privacy of the individual first, ahead of the state and private companies, especially in Spain.

Across the five countries, participants were able to express some preferences for what regulations should look like and these reflected the factors and issues that shaped the acceptability of the sequencing approaches discussed. There was a sense that regulation should ensure that:

- Use of sequencing must be **voluntary** and cannot be mandated by the state, employers, or companies (e.g. insurance companies)
    - **Parental consent would be required** for children under 18 – and as to whether data is used for clinical and/or research purposes
        - In Germany, participants had more mixed views on whether doctors could decide without parental consent in clinical settings; for example, in cases where parents were neglectful. Participants in France also raised the issue in relation to discussion about parents deciding not to vaccinate children who then may be at risk
        - In France, some participants suggested that children aged 13+ could request use of these technologies for clinical use
        - In Germany, some participants considered whether children under 18 should be able to destroy their "genomic passports" if they wanted to but no consensus was reached
        - In Greece, some participants suggested that children aged 15+ should be actively involved in the decision making about these technologies.

"In the case of unborn babies, if the doctor thinks the baby has a huge problem, they can take a closer look at it and the parents can decide whether they want to do it or not. But I would like to have several levels." (Germany)

- Whole genome sequencing should **only be available for medical use by medical practitioners** – not for cosmetic use or other non-medical reasons (e.g. gender selection). There was a sense for participants that non-medical use should be banned and those using/practising otherwise should face tough legal penalties (particularly in Spain).
- There are **strict data privacy and security regulations** in place which prioritise the individual rather than companies and that there are strict penalties for breaches and misuse.
    - There is clear and accessible information about access and usage of data that citizens can understand in order to give informed consent for access and use.

There was a wide sense across the five countries that **government** is responsible for mitigating participants' concerns, but it was widely agreed that medical experts needed to be involved in creating, implementing, and overseeing regulation. More specifically, participants in Poland identified the Ministry of Health as responsible for addressing citizen concerns. In France, some participants said the government needs to set the scope and limits for researchers to work within and some suggested the need for a specialised committee providing oversight of organisations using the technologies. However, a minority of participants also said that there is a role for **international regulation** of this issue, because people would be able to travel to access the technologies if they could not in their own country.

4. Results and discussion: Human genomic modification technologies

This section reports on participant responses to the stimulus materials presented about the development and use of human genomic modification (HGM) technologies, focusing on somatic and germline editing.

4.1 Introduction

During the workshops, the following information and definitions of key terms for this chapter were provided to participants and the findings should therefore be interpreted with reference to them:

- **Modifying genes or genomes** means making changes to DNA. Gene editing tools can change pieces of DNA, like changing a letter in a word on a computer (e.g. luke to lake). New methods of gene modification allow for **precise, fast, efficient and cheaper modification**. They are widely used in research on different organisms, including human cells, to study what genes do and to correct disease-causing genes.

It should be noted that awareness, knowledge and understanding of HGM technologies was low. Participants were provided with information about the technologies and input from experts to support a more informed debate (Appendices 3-5) but often struggled to understand the material, which limited their ability to provide informed responses. This should be noted as a limitation of the findings.

4.2 Awareness, associations and understanding of genomic modification

Across the five countries, there was **some awareness of 'genetic editing'**, but low levels of knowledge and understanding of this term. Some participants **claimed awareness of 'genomic modification' –** but where it was familiar, it tended to be conflated with genetically modified foods (and Monsanto amongst participants in France) and modification of animals (Dolly the Sheep and farm animals) rather than human genomic modification. The pre-workshop questionnaire indicated that participants tended to most commonly be 'not very' or 'not at all familiar' with 'genomic modification' and most commonly felt either 'neutral' or 'curious' about it.

> *"For a child to have blue eyes or for a plant to be more drought-resistant. I've heard something about children modified in order to be more immune to diseases." (Poland)*

> *"Everything is genetically modified nowadays when it comes to food. It makes us mutate, it's dangerous." (Poland)*

Awareness had mostly been gained via the news, TV shows, and sci fi films and books as well as the internet (including via YouTube and science websites) and documentaries. In Greece, some participants reported gaining information from religious groups, and reported that this tended to be from a negative perspective.

> *"We don't take much interest in it. We find out about it from the Internet, TV, radio." (Poland)*

There were **low levels of understanding of genetic editing and modification**, and they were commonly confused and conflated. This lack of understanding drove fear and anxiety about the technology area among participants. Some participants understood the technology as being able to change genetic traits. Some participants continued to struggle with understanding after exposure to the stimulus materials.

> *"It is something that I can only imagine…" (Greece)*

> *"It is about changing the genetic code…it will change only you and not the offspring." (Greece)*

"It is about changing the DNA sequence in order to modify the human genetic code." (Greece)

"We hear a lot about it, but understanding it is a different story." (Poland)

Genetic **editing and modification were commonly spontaneously associated** with genetically modified foods, Dolly the Sheep, and 'designer babies' by participants (France, Germany) – and these associations drove fear of the technology because they associated it with mistakes, errors, and negative consequences for society (such as being able to 'shop' for a perfect person). Participants gaining awareness from sci-fi sources in Greece and Germany had led to association of editing and modification with mutants and clones.

"Is it still a fully-fledged human being or an experiment what you can just kill if something goes wrong?" (Germany)

"This is a nightmare…if someone can change all these then one becomes God! I feel unsure to trust another human and credit him with such power." (Greece)

There was also some **association with 'fixing' problematic genes and curing inherited diseases** and this prompted some initial positivity for some. In Poland, some participants associated genetic editing and modification with speeding up other selection processes that already exist, with reference to agriculture. In Greece, some participants associated it with IVF and this was seen to be a positive framing when the technology helps parents struggling to conceive children. It was also associated by some participants with a range of other scientific processes, such as fusion and animal experiments (France, Poland), cloning of pets (France), and dog breeding (Poland).

"It is like eugenic… acting on the primary human material in order that humans do not suffer from diseases or to improve human characteristics." (Greece)

"This is like nuclear power…it is dangerous for humans." (Greece)

"Dog breeds have been modified, selected." (Poland)

" I've heard that scientists try to edit monkey brains, placing a part of human gene in them." (Poland)

4.3 Somatic editing

During the workshops, the following information and definition for somatic editing was provided to participants and the findings should therefore be interpreted with reference to them:

- Somatic cells include any cells in your body other than egg cells and sperm. Somatic gene editing involves changing the DNA of cells that are not passed on to the person's children. It is currently being tested as a treatment in clinical trials (e.g. to treat blood disorders, some types of cancer, and HIV)

4.3.1 Awareness and associations

There was **no recognition or awareness of the term 'somatic editing'** in the workshops and no further associations beyond those discussed above. The pre-workshop questionnaires indicated that participants were largely either 'not very' or 'not at all' familiar with 'somatic cell gene therapy'. There was a wide range of feelings towards it, but most commonly 'neutral' or 'curious'.

4.3.2 Benefits

Overall there was **quite a positive response to somatic editing** across the five countries. This response was driven by somatic editing being seen as beneficial because it provides **potential cures for serious illnesses**

and could therefore help prevent serious suffering and improve quality of life for people. There was particular interest in somatic editing being used to cure cancer and other fatal conditions, and long-term degenerative diseases (e.g. Multiple Sclerosis) and disabilities (e.g. Downs Syndrome) that impact on the patient's life but also those who care for them.

> *"In my opinion, everything should be done in harmony with nature. But as long as I know that cancer will come, I'll do anything. I went through chemo, I went through treatment. If I did not take medications, I would not be here. I would agree to have gene replacement done to survive." (Poland)*

> *"Every hereditary illness will be eradicated…This is particularly good when there is no cure." (Greece)*

> *"If it can prolong the life of people who are going to die shortly; they have nothing to lose." (France)*

To some extent, somatic editing was seen as more beneficial than screening technologies because it **provides a solution to a problem,** particularly when it cures serious genetic conditions. The ability to increase survival rates and/or improve quality of life was seen as highly beneficial. Across the five countries, there was **wide acceptance that somatic editing may only be relevant to a small portion of the population,** because relevant conditions can seriously affect quality of life for those people and their loved ones. In Greece, some participants noted that these treatments could also lead to improved mental health and well-being in society more widely, by reducing fear of disease and aid a more carefree approach to life. For some participants in Greece and Poland, somatic editing was also seen as beneficial because it gives people more choice of treatments and greater security by having options and greater control over their health. For some participants in Greece, there was positivity about the potential to have more control because this means you don't have to worry about being a burden to your family or society and this improves peoples' dignity and self-respect.

> *" It is a great comfort to have the sense of security, like in the case of HPV vaccines. It would be good if it was available, if there was a choice." (Poland)*

Research use of somatic editing was seen as beneficial because this can contribute to **curing serious illnesses** for others, and some participants only wanted to see research being done which would have a clinical application (in France).

4.3.3 Concerns

Few concerns about somatic editing were raised and discussions tended to focus more on the benefits and aspirations for this technology. However, some concern was raised about the **potential for side effects**, but participants assumed that individuals would know they were taking this risk and would be able to make this decision themselves. There was also some concern among some participants in Greece about negative unintended consequences, such as the accidental creation of new illnesses and diseases. In Poland, some participants were more accepting than in other countries that there are trade-offs and unintended consequences of scientific developments more widely.

> *"Why not if it's for people who have AIDS or cancer. Patients decide for themselves. It may work out, like it may not work out." (France)*

> *"That's the way it is with technology, it's got its bright and dark sides. Like the atomic fission. We have power plants and power, but also atomic bombs which can wipe out a city." (Poland)*

" Absolutely, that's the next step, like penicillin. Everything has pros and cons. Penicillin can be a killer, but it also saves lives." (Poland)

"And what if we eliminate cancer and suddenly something more severe emerges, making the cancer seem less scary, like tonsillitis, which used to be a big problem in the past but is currently under control." (Poland)

"I am sceptical since we do not know the impact it may have." (Greece)

"A gene that alters DNA may create other problems." (Greece)

"if you manipulate one cell, what does it mean for another? We have too little information and we know nothing about the long term." (France)

Following this, some **concern was raised by participants in Spain about parents providing consent** for somatic editing for their children because the child would be the one who would suffer any negative side effects. Some participants also discussed the issue of psychological impacts on children and them feeling potentially like an 'experiment' for the rest of their life. In Greece, some participants were more comfortable with this prospect, assuming parents are best placed to make the best choice for their children.

"There are a lot of ethical problems... I have to decide if I want them to research on me... why create a life that will be marked by something all their life, that child will grow up and when you tell them: You're being researched." (Spain)

There was **concern about somatic editing being used for non-medical purposes**, and agreement that this should not be permitted. There was rejection of the idea of cosmetic use because this was seen to be 'unnecessary'.

"I think about the cost to the population. Everything that is for curing should be funded by the state. But not for frivolous issues (cosmetic matters). The thing is this is important." (Spain)

"There is a difference between medical science and ordering a blond child with blue eyes. This is a hot potato." (Greece)

"It is like an experiment on a living human being. It should be done only to those that cannot be cured." (Greece)

There was **some concern raised across countries about accessibility** and whether uneven access to somatic editing could contribute to growing inequality and more discrimination in society if only the wealthy have access to it, especially in Germany and Spain where participants reported fearing the creation of a two-tier society. However, participants in Poland were more relaxed about this risk and accepting that there is already uneven access to advanced technologies.

"I wouldn't have a problem with the highest class using it and benefiting from it. If they were the guinea pigs and it worked on them and then if they shared that, I'd be up for it." (Poland)

4.3.4 Level of (un)acceptability

Overall, participants had **a quite positive response to and quite high levels of acceptance of somatic editing**. It was widely seen quite positively as another step forward in medical science (especially by participants in Poland). The post-workshop questionnaires found a mix of responses but most commonly 'quite positive' or 'neutral' in terms of the anticipated impact of somatic editing on society, and participants most commonly felt 'hopeful', 'curious' or 'neutral' about it – having begun most commonly feeling 'neutral'. However, it was less acceptable to those who perceived it as 'unnatural' and 'playing God'.

"Overall, the medical field should keep advancing over time. In the past a painful arm used to be cut off, and now heart transplants are done." (Poland)

"We have plenty of other diseases which we cannot influence and where there is no cure. It is not moral for me. For me, the difficulty is that it does not only remain in research and that too much is experimented on humans." (Germany)

The level of (un)acceptability of somatic editing depended on the following themes and varied according to the following conditions:

- **Use must be voluntary**. The wide acceptance of somatic editing was driven by the nature of the technology meaning that use is the individual's choice. The decision and risk are theirs to make and take and they will be affected by consequences, rather than future generations who do not have a choice as is the case with germline editing. There would need to be parental consent for use with children, although some concerns were raised about this as discussed above.

  " If they are not passed on to children, that's good. It's better that they practise on grown-ups." (Poland)

  "That sounds good because you work on cells, but you don't go any further than changing a person. There's no effect on other people. Only pure symptoms of a disease are treated." (Germany)

  "It is something positive since there is no impact in future generations and it contributes to stop an illness." (Greece)

- **Use should follow fully informed consent**; participants wanted to see research into the risks and ensure that people are provided with accessible information about this to make a decision before undergoing treatment (especially in Germany)

  "People with incurable illness who are sure to die shortly and who have given their express conscious consent to go ahead." (France)

4.4 Germline editing

During the workshops, the following information and definitions for germline editing were provided to participants and the findings should therefore be interpreted with reference to them. We note that this was a large volume of highly technical information provided to participants in a short space of time and therefore there were limitations to the extent to which they were able to meaningfully respond to the material.

- **An embryo** is an early unborn baby (up to 8 weeks after conception).
- **Gene editing in embryos in research -** Research on this approach is being done in some countries. Embryos, sperm or egg cells are used in laboratories to study biological processes like infertility, and how to correct disease-causing genes. Legally, these embryos **must** be destroyed 14 days after fertilization. Some of these studies involve egg cell donation by volunteers, which is a risky procedure for women. In some studies hundreds of embryos are created specifically for that study and will be eventually destroyed.
- **Gene editing in embryos -** Gene editing could technically be used on human embryos that have disease-causing genes, when the embryo is created through In Vitro Fertilisation in a laboratory. This procedure would require the creation of a few embryos in laboratory and not all of them would be used to establish pregnancy. Some embryos would be frozen or destroyed. The safety and side-effects for the prospective child and for that person's future offspring are currently unknown; a person whose DNA had been edited as an embryo would be participating in a life-long experiment

as they would need to be monitored for the effects of the gene editing. Gene editing in embryos to be used for pregnancy is illegal in most places, including Europe and the USA, and there are numerous ethical concerns about it. Most scientists and regulators agree that the tools are not yet ready for use in humans and some say they should never be used in patients. However, a case of use was recently reported in China.

- **Alternative techniques -** An alternative technique currently being used is where embryos are tested *before* being implanted into the womb but are **not** edited. Only embryos without disease-causing genes are used to establish the pregnancy. Alternatively, parents who do not want to pass on a genetic disease may consider adopting or not having children.

4.4.1 Awareness, associations, and understanding

There was **low awareness of the term 'germline editing'**. The pre-workshop questionnaire found participants were largely 'not familiar at all' with 'germline gene therapy' and most commonly felt 'neutral' or 'curious' about it. Where there was some low-level awareness, this has been gained from the news. There were low levels of understanding of the concept.

Germline editing was **a more sensitive and controversial topic** than somatic editing. It sparked more heated debates across the countries and there was less consensus and a wider diversity of views expressed.

> *"Religious people would say it's God who decides how he creates people. We are not allowed to touch his creation." (France)*
>
> *"Those who defend gene editing in embryos, they deserve to go to prison." (France)*
>
> *"I acknowledge that there is a cultural factor that makes this type of research unacceptable in Arabic countries, but it's better accepted in France. We give a higher priority to the evolution and progress of science." (France)*

4.4.2 Benefits

There was a wide range of views expressed about germline editing and individual participants tended to have mixed views, as well as across the break out groups and countries. However, some perceived benefits emerged from these discussions. In Germany and Poland, some participants hypothesised that people with genetic conditions would probably be more positive about the potential of the technology but those with disabilities may be less positive if they fear discrimination.

> *"I feel a bit of discomfort, but I understand it perfectly and in the end, there are more things that weigh on the balance of the positive. If not, no progress is made. We have to advance and it's the only way, to experiment with real cases." (Spain)*
>
> *" Those people may feel unhappy about the fact that it had not happened earlier." (Poland)*

Participants were able to identify some benefits associated with germline editing. It was seen to be beneficial when it **provides a solution to serious medical conditions,** where it increases survival rates, provides a cure, and improves quality of life for children and families who need to care for them. As with somatic editing, participants tended to be positive about the nature of germline editing meaning that this technology provides a solution to a problem, rather than just identifying it like screening technologies. Across the countries, some participants identified other related benefits such as savings for the public healthcare system in the long term (Spain), and improved mental health in society due to a reduction in anxiety for patients and their families (Greece).

"If there is guarantee that my baby will not have any disease, they can do anything" (Greece)

There was acceptance that germline editing is likely to only benefit a small number of people, because it was seen to be able to make a significant impact for them and improve society as a result. However, some participants in France and Germany were less positive about clinical use and expressed a preference for germline editing to remain a research tool, at least while there are so many unknown implications for the technology.

Research use of germline editing was generally seen as beneficial, because it contributes to curing medial conditions for a range of people, but participants were keen to ensure that this would be on an anonymous basis.

"Research is done to achieve a purpose, the purpose is for healthy people to be born, although it isn't permitted now." (Spain)

"It could be used to find a cure for cancer, which is a current problem. When I was little, people talked about test tube babies (in-vitro fertilisation), that would be an experiment and it has led to many people being able to have children." (Spain).

"It doesn't really harm anyone to research with embryos." (Germany)

4.4.3 Concerns

Whilst some participants were able to identify some benefits, **there was widespread concern about the use of germline editing** across the five countries, and there were mixed views for individuals as well as across the break out groups and countries. Across the issues raised, there was an underlying concern that this technology could be used in ways to 'control' people, particularly by companies or states (notably in Greece).

The most common concern raised was that it is **unclear now what the future social implications could be** of using germline editing. There was concern that we do not know how far this technology could go and where it will stop and about the pace of development and unknown destination of progress in this area, and where and how limits will be established.

"The problem with science is that no one knows exactly where this is going. I do not think it is a good thing to decide on research." (Germany)

"I do not know what I would do, what are the limits! I should have to fight with demons, ones that I am not currently aware of." (Greece)

"What happens when that life is born and it is discovered that it has a defect, will they let it live? Because it's already a life, what's going to happen with that. I think that the limit is at birth, I mean how we go from the 14 days to the 5 months, when is the limit for a genetic experiment and now it's a life." (Spain)

There was **concern about the lack of choice for the individual themselves.** Unlike with somatic editing, parents would be making choices for their children and for future generations without their consent, which was concerning if something goes wrong during the procedure. In Spain and Germany, some participants questioned whether those edited would need to be monitored their whole life and whether this would be invasive, inconvenient, and worrying for them. There was some concern about this in Poland too, but participants noted that people with chronic and genetic conditions have to undergo regular monitoring anyway (e.g. for diabetes, vision issues, high blood pressure etc).

"It reduces the right to free will, self-determination choice…" (Greece)

There was also concern about whether there could be **unknown long-term side effects associated with germline editing,** for the individual or future generations ahead of them. Concern was raised across the five countries about whether germline editing could lead to the production of 'monsters' and 'mutants' in future generations or accidentally produce other new diseases by mistake. As a result, in Spain, some participants had a preference for investment in other technology instead if possible.

> *" And we don't want somebody to create monsters." (Poland)*
>
> *" Disease knows no void. If we find the cure for one (disease), another will appear." (Poland)*
>
> *"We may wish to control something that we know about but what about things we do not know well, and we may create something even worse than before? What about the general causes of diseases such as pollution, out daily way of life, etc?" (Greece)*

As with the other genomic technologies discussed in this report, there was **concern about the creation of 'designer babies'** and a strong sense that germline editing should only be used for medical purposes, not to alter cosmetic or social traits. Concern was raised that use of germline editing would increase a drive for people to be 'perfect' and lead to greater anxiety and mental health issues (especially amongst participants in Germany).

> *"I don't think it's right for this to be used to say I'm going to get pregnant and I want my child to be blond with blue eyes, not for that, but to prevent a type of cancer developing, perfect." (Spain)*
>
> *" If it's to save lives, yes, but when it comes to sex, hair colour and height, no." (Poland)*
>
> *"Why should I choose or change the sex of my child, why should I interfere with it? If we are talking about Greece, most children would be boys." (Greece)*

As with the other genomic technologies, some participants had concerns that germline **editing could lead to greater homogenisation and loss of diversity in society,** especially in Greece and Germany where participants expressed a need for variety in society. There was concern that this change could also lead to **greater discrimination** for disabled people and those with genetic conditions. It could lead to exclusion of those with these conditions who have not been edited. However, participants ruminated on the idea that stigmatisation could occur for either group depending on how this technology develops and is perceived in society; it could either be those who have, or have not, undergone editing. In Germany, some participants were particularly fearful about stigmatisation for children edited where something goes wrong and this is visible to society.

> *"We hope that such technologies will not fall into the wrong hands, like wrong institutions, wrong governments. They could consciously make a sub-group worse. Then people will be exploited." (Germany)*
>
> *"Because it's beautiful that the human being is imperfect. Everybody is different, and there is beauty in that diversity." (Poland)*
>
> *" I can't imagine that in a year or two everybody suddenly would look the same. I'd go to the store and I see somebody looking just like me." (Poland)*
>
> *" I see the risk of the in-vitro people becoming a better kind of people, (the risk) of the development of a new race somehow." (Poland)*

There was also concern raised, as with the other genomic technologies, about **access** to the technology and whether uneven access could contribute to greater social **inequality**. In Germany, some participants were concerned it could lead to a two-tier society. Those who have been edited and those who have not. Again,

participants in Poland were less concerned about this, seeing uneven access to new technology as 'normal', and because they assumed it will become cheaper over time like other technology. They appreciated that there needs to be early adopters to improve the technology before it is rolled and used more widely.

Meanwhile, in Spain, participants were **concerned about the motivations of private companies** who might develop and use germline editing, and that they may benefit disproportionately contributing to greater social inequality. Participants in Germany and Greece were more widely concerned about profit making from this technology.

> *"The genetic scientists will get rich…" (Greece)*

> *"Such modifications will be expensive and paid by rich people. There will be two categories of humans. The ones that can afford and those who cannot afford it." (Greece)*

Some participants raised concerns about **data privacy and security** during these discussions in Germany and Greece, and this was important to those who raised the issue, but this overall issue was less prominent in discussions than for the other technologies.

> *"Who will have access to the information about the genes?" (Greece)*

4.4.4 Response to the destruction of embryos 14 days after fertilization

There was wide acknowledgement by participants that the destruction of embryos is likely to be a **controversial topic and highly sensitive for some people** in their societies. The discussion groups generally did not come to a consensus and there was a diversity of views within and between them. **There were highly mixed views,** but overall tended towards lower levels of concern about this issue where participants thought the benefits were worth the cost (although there was greater concern for participants in Poland and Spain). Some participants were against this, where they saw an embryo as human and therefore felt that this should not be allowed.

> *"It's a terrible abuse. Imagine human beings could be created just for the organs that would be delivered to an organ bank." (France)*

Whilst some participants had negative views, it was more common not to see embryos at 14 days as 'human'. Although participants anticipated this was more likely to be the case for religious groups and those outside of cosmopolitan areas, even if not for themselves. We note there was limited scope for this debate within the context of this research and that some religious groups may have felt less able to deviate from the growing consensus and this should be seen as an important limitation of the research.

> *"It's more a religious than an ethical issue." (Spain)*

> *" I think that a 14-day old embryo is not a human being. It's a living organism, but not a human." (Poland)*

> *"It's acceptable because an embryo cannot be accepted yet as human life, it's not yet a human being." (France)*

> *"You're going to sacrifice something that doesn't suffer for a person who can suffer (later)" (Spain)*

> *"If I have to donate an embryo, I'd feel sorry, I hope it won't have to be that way because I'd imagine it as a little person and I don't like it, but I understand that it's the only way." (Spain)*

> *"Is a cell cluster already potential life? I am torn back and forth. "(Germany)*

"I have not made up my mind if killing of an embryo is murder or not." (Greece)

"Human is evolving by his nature but from a religious point of view any experiment on embryos cannot be accepted." (Greece)

4.4.5 Response to concerns about implications for female egg donors

Overall, participants were **quite comfortable with the risks associated with women donating eggs** for germline editing research. There was some concern about the pain of extraction for women, but it was generally seen as acceptable as long as women are fully informed of the risks and give informed consent for the procedure. There was some concern by a small number of participants about whether there would be a risk to their future fertility and some concern about unknown health/fertility risks in the future.

Mixed views emerged about whether women should be paid for egg donation. Some participants found it acceptable to compensate women for undergoing pain and risk whereas other participants in Germany and Greece worried that women may feel financially 'forced' or feel forced by the state – particularly women from lower socio-economic grades and those in financial difficulties.

"As long as the volunteer is aware that there are risks. My partner donated eggs, and everything went perfectly." (Spain).

" Everybody decides for themselves, so she would not do that if there was no need for it or if she did not want to do that." (Poland)

" They should not be able to do that out of extreme poverty." (Poland)

"When it becomes a business, it will become a problem." (Greece)

"It is dangerous for women…they produce a certain number of eggs in their life and if they donate them they will not be able to have own children." (Greece)

4.4.6 Level of (un)acceptability

Overall there was a **highly mixed response to the use of germline editing across the countries**. Those who found it less acceptable tended to cite reasons with reference to life being 'sacred' and that this was too much human interference, 'unnatural' and 'playing God'. Those who tended to be more accepting saw it as the natural progression of medical science and direction of advancement in society. There was greater positivity about germline editing amongst participants in Poland (where it was more commonly associated with the progression of medical science), and least positivity about it amongst participants in Greece where there was greater concern about the access and social implications. The division between these two points of view was most pronounced by participants in France. The post-workshop questionnaire indicated that participants most commonly thought 'germline gene therapy' would have a 'neutral' or 'quite positive' impact on society and by the end participants mostly commonly felt 'hopeful', 'neutral' and 'curious' about it – where they began most commonly feeling 'neutral'.

"If it is legal, it is ethical.' (Spain)

Any use of germline editing technology would have to be **in the context of curing a serious medical condition, and non-medical use was unacceptable**. Germline editing was more acceptable where it is seen to provide a solution to serious genetic conditions and relieve pain and suffering for individuals and their families. However, there were serious and widespread concerns about: lack of choice for the individual; fears about unknown side effects in the future; and about potential increased homogeneity of society and increasing intolerance - which lower levels of acceptability of the technology.

4.4.7 Participant views on mitigation of concerns about genomic editing technologies

This section reports on discussions held with the participants about what measures they wanted to see in place to address their concerns about genomic modification technologies. We note that these findings are limited due to the short amount of time allocated to this discussion and the findings should therefore be read as highly tentative. We also note that these views are not presented as Kantar (Public Division) or SIENNA's recommendations, but as reporting of participant views.

There was a sense that **there needs to be very strict rules and regulations in place** for genomic modification technologies. Participants wanted to see clear legal and ethical frameworks in place for all organisations involved with developing and using these technologies and there needs to be oversight and control of development and use; although participants generally struggled to determine what exactly needed to be regulated and controlled beyond the ideas below. More specific ideas were suggested by some participants in France, where participants wanted to see regulations for the number of embryos that can be created and destroyed to enforce limitations on this issue. In Greece, some participants did not want to see the use of technologies that affect other generations and there were wide discussions held across the tables about the impact these technologies have on what it fundamentally means to be human.

> *"I think changes should not be passed onto next generations […] It is something unknown. Like Pandora's box." (Greece)*

It was widely agreed that that any use of genomic modification technologies must be **voluntary and involve fully informed consent,** although there were, as discussed, concerns about the fact future generations were unable to provide this. In Poland, some participants wanted regulation to be in place to stop those who are unable to consent and those with mental health conditions being able to use the technologies. In France, Spain and Greece, participants wanted to see more information about this topic available to educate the public and said that this needs to be accessible for a wide range of members of the public. In Greece, participants wanted to see more public participation in discussion of these issues in civil society.

> *" Everybody has to give their own consent, nobody can sign consent on behalf of somebody else." (Poland)*

There was agreement that these technologies should **only be available for medical use and by medical professionals;** and participants wanted to see strong punishments in place for those who administer these for non-medical purposes. Participants did not want germline editing to be used to create 'designer babies', particularly where modifications to eye and hair colour and height were made.

There was wide agreement that there is a need for **strict data privacy regulations** which prioritise the individual rather than companies and/or the state; but some participants were fatalistic about whether this was possible.

In Germany, some participants also wanted a high degree of **transparency** about what was being done and by whom to control illegal activity and potential illegal global trading of this technology.

> *"We've realized that research can't be stopped. We should rather take the offensive and make it transparent before everything is done in the background. Otherwise the process will be slowed down because it is being made illegal. Transparency is better then." (Germany)*

A small number of participants discussed the issue of access, wanting to see the technology **widely available** for those who need it, rather than restricted to those who can afford it - although this was less of a concern initially amongst participants in Poland than other countries. In Poland, one group discussed wanting all countries, even smaller ones, to be able to contribute to the research.

> *" I think that all countries should partially contribute to genetic research, not just the rich ones. Information about research and the developed research methods should be available to everybody." (Poland)*

The **government was seen to be responsible for mitigating participants' concerns** about germline editing. However, it was widely agreed that scientists and medical experts needed to be involved in creating and implementing regulations. In Greece, some participants were also keen for lawyers and religious organisations to be involved in the development of regulations. In France and Germany, some participants suggested a body of experts or ethics committee to oversee activity and advise and intervene where necessary and that this should be interdisciplinary in nature. In Poland and Germany, participants noted that public opinion should be taken into account, but that ultimately decisions about regulation should be made by experts who understand the technology in detail. However, in Greece, some participants were keen to see those with genetic diseases and their families involved in creating regulations and that their views are taken into account.

> *"Surveys and public opinion questionnaires would be good, in order to check what people know. The opinions should be taken into consideration but should not play a determining role." (Poland)*

> *"In the beginning there should be regulation to apply it. It should only be done by people who have a lot of experience. The state institution doing this should include all relevant social groups. But not the general public should decide about it, because they have too little knowledge." (German)*

> *"Carl Popper once said that belief is prevails to science and religion. Therefore, lawyers should have the final say about this." (Greece)*

> *"It is important to address those that actually have the diseases, their relatives; they are the ones who live by these." (Greece)*

It was generally agreed that there is also a role for **international and global regulation of germline editing** because people would be able to travel to access the technologies if they could not in their own country, such as the UN and WHO. Participants in Germany and Greece most strongly felt that this issue needs to be addressed at the global level.

> *"There should be a globally accepted legislation." (Greece)*

5. Results and discussion

The results in this report should be read with reference to and in the context of the limitations set out in Section 2.4. The results serve as indicative findings about public attitudes to human genomics and should be treated as a starting point for further academic research and analysis to build from. They should not be read in isolation and should be read with reference to the other reports that have been produced as part of the SIENNA project. This project has been conducted by a social research agency and not academic researchers. The report lacks contextualization of the results with relevant academic literature to further understand the meaning of the results for the field. Clearly, each discussion group could and should be more deeply analysed to fully understand their meaning and how this pushes our understanding of public views toward human genomics further. Ideally such further analysis will be conducted by academic partners through academic publications.

5.1 Summary of findings

Overall, there was **low awareness and understanding** of genomics technologies as this was not an area the public was generally familiar with. Lack of familiarity and low levels of understanding drove anxiety and concern among participants, particularly when they could not understand the purpose of a technology, how it worked, or what the limit of the technology might be in the future. This is crucial when considering the acceptability of technologies involved with areas the public see as central to the essence of our 'humanity' which was the case for human genomics.

The conditions under which human genomics technologies (screening and modification technologies) were seen as more **beneficial and acceptable** were similar and can be summarised as when they:

- Were more familiar;
- Were voluntary and only affected the individual;
- Provided a solution to a serious medical condition or improved a patient's quality of life;
- Provided certainty rather than probability of a condition;
- Presented lower perceived risks of unforeseen medical consequences;
- Were less seen to potentially contribute to negative social implications (notably inequality and discrimination).

In summary, **the main concerns raised about genomic screening technologies** across the five workshops were:

- The technologies **being made mandatory** by the state or private companies and this leading to discrimination in a variety of sectors;
- **Non-medical use of the technologies** for cosmetic or social purposes, and this leading to 'designer babies' and a drive for 'perfect' humans and less diversity in society as a result. There was concern that this could lead to lead to greater anxiety, inequality, and more intolerance and discrimination in society;
- The **provision of probabilistic and uncertain information** – particularly about chronic conditions that could emerge later in adult life – leading to increased stress and anxiety and lower quality of life for people. There was also concern about whether people would be able to understand and engage with probabilistic information;
- **Data privacy –** who would be able to access the data and for what purpose - and whether accessible enough information would be provided to people to enable them to give informed consent with regard to data use;
- **Data security** – and whether data could be stored securely to avoid theft and hacking.

In summary, **the main concerns raised about genomic modification technologies** across the five workshops were:

- **Side effects and unforeseen consequences** – for the individual and their descendants - and whether editing could lead to new diseases or 'mutants and monsters' in the future;
- **Parents giving consent on behalf of children and their descendants** who could be negatively affected by any medical and social implications in the future – but had not given their consent for this;
- **Whether those who have been edited would need to be monitored** their whole life and how intrusive this would be for them;
- **Non-medical use** – for cosmetic or social purposes – and this leading to 'designer babies' and a drive for 'perfect' humans, and more anxiety and less diversity in society as a result. There was concern that this would lead to greater inequality, and more intolerance and discrimination in society as a result;
- **Data privacy and security** – there was concern about who would have access, how they could use the data, whether consent processes would be clear, and how secure storage would be.

Overall, there were mixed views about human genomics technologies, with the response overall being quite cautious and apprehensive. There was some positivity about the idea that editing could potentially provide a solution to serious medical problems rather than just information about a problem, as was the case for screening technologies, which might reduce a patient's quality of life due to anxiety as a result, particularly where the information was probabilistic and/or there was not an established cure or treatment. Responses to genomic technologies were commonly emotional, with some participants equating it with 'playing God', questioning the nature of humanity, and potentially causing serious unforeseen consequences for individuals and descendants in the future who did not consent to the editing process. There were also many questions raised about the kinds of impacts these technologies may have on equality and relations in our societies, and there was a need for all these concerns to be balanced against the potential medical benefits associated with genomic technologies.

5.2 Seven key themes

Overall, there seemed to be a somewhat greater acceptance of the development and use of somatic editing and prenatal genomic screening and less acceptance of "genomic passports" and with germline editing being the most controversial and problematic of the genomic technologies explored in the workshops.

From review of the benefits and concerns associated with each of these technologies and the discussions about how acceptable their development and use were across the five countries, **seven key themes emerged regarding levels of acceptability** of human genomic technologies. The analysis process which identified these themes -along with the limitations of this - is described in section 2.3 and should be read with reference to this. Whilst acknowledging the limitations and weaknesses of the analysis process, the identification of these themes can help us begin to understand why some of the human genomics technologies were more acceptable than others. This section serves as a starting point for further academic analysis to build upon.

1. **Consent:** the use of genomic technologies was more acceptable when voluntary and informed consent was provided

The extent to which it was possible for voluntary and informed consent to be provided shaped how acceptable a human genomic technology was seen to be. There was widespread agreement that use of genomics technologies must be voluntary and should not be made mandated by the state, medical professionals, private companies (e.g. health and insurance companies), or employers. There was agreement that informed consent must be provided before use, and participants wanted accessible information to be provided to enable all citizens to provide this regardless of educational attainment. This factor is important

in understanding why germline editing was seen as less acceptable than the other technologies, because parents would be giving consent on behalf of the child and their future descendants who would not have provided consent and would be the ones to suffer any adverse side effects or unknown consequences in the future. Conversely, somatic editing was more acceptable because only the individual who gave informed consent would be affected by any immediate negative consequences.

2. **Familiarity:** the use of genomic technologies tended to be more acceptable the more familiar it was to participants

The level of familiarity participants had with a genomic technology tended to shape how acceptable they found it. Greater familiarity tended to mean that participants had greater understanding of the purpose and value of a technology and to some extent how it worked. In some cases, having a frame of reference could make a technology feel more familiar even if the technology itself was not – namely prenatal genomic screening.

3. **Necessity:** the use of genomic technologies tended to be more acceptable the more their use was seen to be medically necessary

Genomic technologies were more acceptable where their use was seen to be 'necessary', and necessity was equated with medical use, particularly with the treatment of serious genetic and fatal health conditions. Genomic technologies were seen to be most beneficial and acceptable where they were 'fixing' serious genetic and other medical conditions. They were least acceptable, and generally unacceptable, when it was suggested they could be used for non-medical purposes, such as selecting cosmetic and social traits to select or creating 'designer babies' or 'super humans'.

4. **Nature of service provided:** the use of genomic technologies tended to be more acceptable where they provided a solution rather than just information about a problem

Genomic technologies were more acceptable where they provided a solution to a medical problem, rather than just information about a problem. There was more enthusiasm for the idea that genomic editing technologies were seen to 'fix' a problem, as opposed to screening technologies which provided information about conditions, particularly when this was about conditions which may appear later in adult life and would require difficult life style changes as a result.

5. **Certainty:** the use of genomic technologies tended to be more acceptable where they provided certainty rather than probabilistic information

Genomic technologies were more acceptable where they provided more certain information about whether or not a condition would emerge. This was particularly the case for conditions which would emerge in later life as there was concern that this could lead to unnecessary stress and anxiety for people.

6. **Level of medical risk:** the use of genomic technologies tended to be less acceptable where there was seen to be a greater risk of known or unknown medical risks

Genomic technologies were less acceptable where participants had greater levels of concern about side effects and the potential for unknown future implications of their use. This was an important reason why there was concern about germline editing, because participants were worried about whether new diseases or 'mutants' could be accidentally created that would emerge later or in future generations. In this sense, screening technologies were less risky than editing technologies.

7. **Level of risk of negative social implications:** the use of genomic technologies tended to be less acceptable where there was seen to be a greater risk of negative social implications

Genomic technologies were less acceptable where participants had greater levels of concern about potential negative social implications associated with the development and use of genomic technologies. Genomic technologies were less acceptable where there was greater concern that they could cause greater social inequality and/or greater discrimination in technology. These concerns were raised about all of the genomic technologies but were of particular concern where they could be used to select or change cosmetic or social traits or future generations (notably gender, hair and eye colour).

Consideration of these themes individually and in combination can help us begin to understand why some of the human genomics technologies were more acceptable than others. This report serves as a starting point for further analysis.

Appendix 1 – SIENNA Qualitative workshops - Topic Guide

Logistics

Location	Date	Timings	Location
Hamburg	Saturday 6th April	09:00-17:30	ms Teststudio, Ute Fehling, Mönckebergstraße 18, 20095 Hamburg
Paris	Saturday 6th April	09:00-17:30	LE PAVILLON DE CHESNAIE, Route de la Pyramide, 75012 Paris
Warsaw	Saturday 13th April	09:00-17:30	Centrum Konferencyjne Golden Floor Tower, ul. Chłodna 51; 00-867 Warszawa
Athens	Saturday 13th April	10:00-18:30	DIVANI CARAVEL HOTEL, 2 Vassileos Alexandrou ave. 16121 Athens
Madrid	Saturday 27th April	09:00-17:30	Hotel Puerta de América, Avenida de América, 41, 28002 Madrid

Topic guide

Background

Aim

- The aim of the panels is to engage citizens in deep consideration of the issues raised by three technologies (Human genetics and genomics; Human enhancement; and Artificial intelligence and robotics)

Primary objectives

- To explore and understand citizens' views of the technology areas and particular uses and applications
- To explore citizens' concerns about the three technologies (and specific applications) and how they would like these concerns to be addressed

Methodology

- Full-day Saturday citizens panels in five countries - held in the (main) national language
- Citizen panels provide a forum for discussion and deliberation of complex, sensitive and/or contentious topics on which it is important to gain a public view. They give members of the public the time, space and information they need to consider issues and express confident opinions.
- Deliberation begins by providing background information and obtaining participants' initial views. Over the course of the panel, experts provide information, informing participants' discussions. Discussions will build incrementally – first introducing basic principles, then looking at potential applications and issues of ethical and legal regulation. Discussions will start from the point of view of participants, allowing them to frame content, raise questions and identify concerns or areas of uncertainty. Stimulus materials will be used to encourage discussion and provoke debate.
- The day includes both plenary sessions and breakout group discussions where participants are split into five groups of 10 participants. The breakout groups will each comprise participants from a range of demographic groups and discuss each of the topics and respond to provided stimulus materials.
- Each panel will be moderator by x5 local KP moderators, with an additional x5 KP notetakers, with one moderator and one notetaker in each breakout group.
- 2-5 experts will attend each workshop

Materials

X1 Leader pack:

Client Research Observation and Monitoring Confidentiality Agreement	X1 (A4, black and white, single side)
Expert name badges	As required
Participant SIENNA audio recording consent forms	X54 (A4, black and white, single side)
Stickers	X54 (x5 different colours)
Incentives and signature sheets	X54
Participant questionnaires booklets	X54 (A4, colour, doubled sided, stapled)
Laptop and connector cable with the introductory presentation pre-loaded	X1
Flip chart pens	X3
Audio security confirmation form	X1 (A4, black and white, single side)

X5 Moderator packs <u>each</u> with:

Encrypted GDPR-compliant audio recorder	X1
Laptop with note taker template pre-loaded (for notetaker to use)	X1
Flip chart pens	X3
Pens	X11
Fictional segments	X11 (A4, colour, single sided)
Stimulus materials	X11 copies (A4, colour, doubled sided) EACH **SUB TOPIC** SHOULD BE SEPARATELY STAPLED (e.g. 'DRONES' should be **separate stapled** pack)

Topic guide

ALL TIMINGS MUST BE MOVED FORWARD BY ONE HOUR FOR ATHENS WORKSHOP TO START AT 10:00

1. 07:30 – 08:15: Set up by local Kantar team (45 mins)

2. 08:15 – 08:30: Kantar lead to brief expert(s) (15 mins)

PLENARY	**Timing**	**Stim**

2.1 Kantar local lead to brief experts
 	
• Introduce the venue (e.g. toilets, fire exit)
• Sign Observation agreement (Kantar lead to talk through requirements)
• Collect name badges
• Briefing points
  ○ Ask them to give a short introduction in the introductory plenary (4.1)
  ○ X1 experts to observe each break out group
  ○ Experts to circulate around the break out groups throughout the day
  ○ Experts only to answer questions during break out sessions when invited by the moderator
  ○ Experts should provide unbiased accurate, and up to date information and provide succinct answers and avoid the use of jargon and complex / academic language
	15 mins	**Name badges**
		
		Client observation agreement

3. 08:30 – 09:00: Participants arrive (30 mins)

REGISTRATION AREA – with coffee and biscuits (to be left out)	**Timing**	**Stim**
3.1 Registration • Register and receive incentive • Give a random sticker to allocate to a break out group (use 5 colours to ensure each group has a mix of demographics) • Sign consent form • Hand out questionnaire booklet ○ Ask participants to complete Section 1 (pre-task) and Section 2 (pre-questionnaire) before the workshop starts	**30 mins**	**Signature sheet** **Incentives** **SIENNA audio recording cons**

		ent forms **Stick ers** **Quest ionna ire bookl et**

4. 09:00 – 09:20: Introductory plenary (20 mins)

PLENARY	**Timing**	**Stim**
4.1 Introduction • Welcome from Kantar lead moderator • Kantar local lead to give introductory presentation (USING SLIDES PROVIDED) • Experts to introduce themselves (name, role, university, area of expertise) • Introduce 'burning issues board' (where unresolved issues are written up to draw on-going conversations to a close) • Participants join their break out group (indicated by their sticker) • **KP moderator to check all participants have completed their pre-workshop questionnaire before they join their break out group**	**20 mins**	**Introductory presentation slides**

5. 09:20 – 09:40 Introductions (20 mins)

- **Experts split across the break out groups – they will observe and help answer any questions only when indicated by moderators**

BREAK OUT GROUPS	**Timing**	**Stim**
5.1 Moderator introduction • Moderator introduction – name, role • Reassure participants there are no right or wrong answers, this is not a test, and that we are interested in their views • Check whether they have any questions about the introductory presentation • Reiterate ground rules ○ Take turns, do not speak over each other, respect each other's views	**10 mins**	

• Check permission for Kantar audio recording and begin audio recording • Confirm participants give permission for the SIENNA experts to record the discussions and for them to analyse the data for academic publications. **5.2 Participant introductions** • Participants to briefly introduce themselves ○ First name, who they live with, any jobs or hobbies		

TOPIC ORDER TO ROTATE AS FOLLOWS:

	Paris	Hamburg	Athens	Warsaw	Madrid
TOPIC 1	Enhancement	AI & robots	AI & robots	Genomics	Enhancement
TOPIC 2	Genomics	Enhancement	Enhancement	AI & robots	Genomics
TOPIC 3	AI & robots	Genomics	Genomics	Enhancement	AI & robots

ROLE OF EXPERTS DURING THE BREAK OUT GROUPS:

- **One expert per group - where there are <5 experts – experts rotate between (not during) sessions**
- **Observe and help answer any questions only when indicated by moderators**

6. 09:40 – 11:40 Topic 1 (120 mins) – BREAK OUT GROUP

7. 11:40 - 12:00: BREAK (20 mins)

REGISTRATION AREA – with coffee and snacks (to be left out)	**Timing**	**Stim**
• Experts circulate and allow participants to ask them questions	**15 mins**	

8. 12:00 – 14:00 Topic 2 (120 mins) – BREAK OUT GROUP

9. 14:00 - 14:50: LUNCH (50 mins)

REGISTRATION / PLENARY AREA (venue dependent) – food and drinks to be left out	**Timing**	**Stim**
• Experts circulate and allow participants to ask them questions	**45 mins**	

10. 14:50 – 16:50 Topic 3 (120 mins) – BREAK OUT GROUP

11. 16:50 - 17:05: BREAK (15 mins)

REGISTRATION AREA – with coffee and snacks (to be left out)	**Timing**	**Stim**
• Experts circulate and allow participants to ask them questions	**15 mins**	

12. 17:05 – 17:20 Reflective session (15 mins)

- **Experts to observe and help answer any questions <u>only</u> when indicated by lead moderator**

PLENARY	**Timing**	**Stim**

KP TO RECORD THE PLENARY SESSION AND KEEP NOTES FOR THE ANALYSIS
 	
Set up x1 flipchart for each technology area and Kantar lead moderator to flip chart:
 	
• Any final questions **to experts**
  ○ Kantar moderator to ask experts if they have any response to the issues on the burning issues board
 	
• Briefly reflect on **key hopes and concerns** for each of the 3 technology areas [**REVERSE** the order you have discussed the topics today]
  ○ Briefly reflect on whether any of the four fictional segments may have different / additional concerns
 	
• Reflection on how they would like to see their concerns for each area mitigated
  ○ **Whose responsibility** it is to mitigate citizen concerns
  ○ **Whether and what role there is for the EU regarding regulation in these areas**
	20 mins	

• Overall – what are participants' **main concerns** about the development of technology in our society more generally	**5 mins**	
• Opportunity for experts to ask any final questions **to participants**	**5 mins**	

13. 17:20 – 17:30 Close (10 mins)

PLENARY	Timing	Stim
13.1 Close • Thank participants • Final questions • Confirm everyone has incentives	**2 mins**	
13.2 Questionnaires • Ask participants to complete the SECTION 3 (post questionnaire) of their questionnaire booklet (ASK PARTICIPANTS TO RETURN THESE TO THEIR BREAK OUT MODERATOR FOR ANALYSIS)	**8 mins**	Questionnaire booklet

14. 17:30 – 18:00 De-brief and clean up (30 mins)

	Timing	Stim

• Kantar lead moderator to lead de-brief with experts
  ○ What were the most interesting findings for each technology area
  ○ What, if anything, surprised them
  ○ What, if anything, will they do differently as a result of attending the workshop
  ○ Whether any changes need to be made to the guide or materials for future sessions
	15 mins	

• Kantar team clean up • Ensure that questionnaire booklets are returned **to the break out group moderator / notetaker** to be analyzed with their notes/recordings	**15 mins**	

IF AUDIO RECORDERS ARE NOT PASSWORD PROTECTED AND ENCRYPTED – TRANSFER AUDIO FILES TO ENCRYPTED LAPTOP AND KP LEAD TO SIGN THE AUDIO SECURITY FORM AND SCAN AND EMAIL THE FORM TO KP UK

Genomics (120 mins) – BREAK OUT GROUPS

IN THIS SECTION – MODERATORS PLEASE READ THROUGH EACH TEXT BOX ON EACH PIECE OF STIMULUS MATERIAL WITH THE PARTICIPANTS AND THEN GET THEIR RESPONSE TO IT – TO ENSURE THERE IS CLEAR UNDERSTANDING DURING THE DISCUSSIONS

SECTION 1: GENOMIC SCREENING

WARSAW – X2/5 BREAK OUT GROUPS TO DO THIS TOPIC (AND NOT MODIFICATION)
ATHENS – X3/5 BREAK OUT GROUPS TO DO THIS TOPIC (AND NOT MODIFICATION)
MADRID – X2/5 BREAK OUT GROUPS TO DO THIS TOPIC (AND NOT MODIFICATION)

120 MINS	**Timing**	**Stim**

1.1 AWARENESS AND ASSOCIATIONS
 	
• Have you ever heard of the terms:
  ○ Genetics
  ○ Genomics
  ○ Whole genome sequencing
• Check sources of awareness
• What do you understand by:
  ○ Genetics
  ○ Genomics
  ○ Whole genome sequencing
• What, if anything, do you know about 'genomic screening':
  ○ Prenatal genomic screening
	10 mins	

1.2 VIEWS ABOUT PRENATAL GENOMIC SCREENING MODERATOR TO HAND OUT X1 COPY OF SCREEN STIM TO EACH PARTICIPANT AND TALK THROUGH Moderator to reiterate that a readout of all the DNA of an **unborn** baby can be obtained but that this is not **currently** done for babies. • How would you **feel** if a readout of all the DNA of unborn babies would start being obtained in our country? • How acceptable/unacceptable do you find obtaining a readout of all	**60 mins**	**SCREEN STIM**

the DNA of an unborn babyand why? ○ In which circumstances are you MOST and LEAST comfortable with this and why? ▪ To assist with future disease management *(to inform parents, and potentially offer treatments if any are available prenatally* ▪ To decide whether to terminate a pregnancy ○ What types of diseases should be screened for and why? ▪ Serious versus common (what do you understand by these terms?) ▪ Those which develop prenatally and in children, versus those which develop in adulthood ▪ Those where tests can predict with a higher degree of certainty whether a disease will develop, versus those where tests can only predict with lower probabilities (e.g. 60% likely) ○ Should we be able to screen for non-disease traits (e.g. height, hair colour, muscle mass); why / why not • What are the benefits of obtaining a readout of all the DNA prenatally? ○ Who might be more positively affected? • What are your concerns about obtaining a readout of all the DNA prenatally and why? ○ Who might be more negatively affected? • Do you think that obtaining a readout of all the DNA prenatally would raise any issues for society more widely?		
1.3 PASSPORT Moderator to explain that obtaining a readout of all DNA prenatally would mean children would have a **'genomic/genetic' passport**. • What are the benefits of this? • What are your concerns about this – and why? • What impact might this have on society more widely? • How comfortable would you feel about these data being used for research purposes? ○ And by companies outside of the health system?	**20 mins**	

1.4 OVERSIGHT/DECISION MAKING
 	
• Thinking about all the concerns you have: (MODERATOR TO REMIND PARTICIPANTS OF THE KEY CONCERNS DISCUSSED):
  ○ Do you think this is a sensitive topic?
  ○ What would you like to see done to address your concerns
  ○ Do you think there should be more regulation?
  ○ Who should be responsible for this regulation?
 	
• What role should parents have in deciding:
  ○ Whether screening happens
  ○ Whether data is used for health research (along with other health data)
  ○ What role should children have in this (and when they reach 18?)
 	
  ○
	30 mins	

SECTION 2: GENOMIC MODIFICATION

WARSAW – X3/5 BREAK OUT GROUPS TO DO THIS TOPIC (AND NOT SCREENING)
ATHENS – X2/5 BREAK OUT GROUPS TO DO THIS TOPIC (AND NOT SCREENING)

MADRID – X3/5 BREAK OUT GROUPS TO DO THIS TOPIC (AND NOT SCREENING)

120 MINS	**Timing**	**Stim**

2.1 AWARENESS AND ASSOCIATIONS
 	
• Have you ever heard of the terms
  ○ Gene editing
  ○ Genetic modification
• Check sources of awareness
• What do you understand by:
  ○ Gene editing
  ○ Genetic modification
• How aware are you of ‘genomic modification’?
	10 mins	

○ Sources of awareness		
2.2 INFORMATION MODERATOR TO HAND OUT X1 COPY OF MODIF STIM TO EACH PARTICIPANT AND TALK THROUGH • Explore any initial responses to the material	**80 mins**	**MODIF STIM**
2.3 SOMATIC MODIFICATION Moderator to explain that in somatic cell gene therapy, changes to genes are only made in some cells and these **<u>are not passed on</u>** to the person's children. • How acceptable do you find the use of somatic cell gene therapy and why? • Which circumstances are you MOST and LEAST comfortable with somatic cell gene therapy being used and why? ○ In a lab in a research context ○ For clinical use (i.e. as a healthcare treatment) • What are the benefits of somatic cell gene therapy? ○ Who might be more positively affected? • What are your concerns about somatic cell gene therapy and why? ○ Who might be more negatively affected?		
2.4 GENETIC MODIFICATION IN EMBRYOS Moderator to explain that in genetic modification in embryos, changes made to genes in cells **<u>are passed on</u>** to the person's children. Modification may be done for clinical or research purposes. • How acceptable do you find the use of genetic modifications in embryos and why? • Which circumstances are you MOST and LEAST comfortable with genetic modification being used in embryos and why?		

○ For research purposes in embryos that are not used for pregnancy afterwards – which is already happening ○ For clinical purposes – as a healthcare treatment where embryos would be used for pregnancy – which is not happening now • What are the benefits of genetic modification in embryos? ○ Who is more likely to benefit? ○ Does it matter to you that it is likely only a narrow group of people will benefit? • What are your concerns about genetic modification in embryos and why? ○ Who might be more negatively affected? Moderator to explain that in research, egg cells need to be removed from women for this use • How comfortable / uncomfortable are you with this and why? Moderator to explain that in research, embryos are destroyed 14 days after fertilization. • How comfortable / uncomfortable are you with the use and destruction of embryos and why?		
2.5 Other perspectives *IF not already discussed*: • Explore whether and how they think these people might feel differently about the technologies discussed ○ Genetic conditions ○ Disabilities ○ Health conditions • And how they might feel about: ○ Any specific applications / uses – why? ○ Any of the benefits and concerns associated with the technology – why? ○ Any additional concerns they may have	**10 mins**	
2.6 REGULATION Throughout, moderator to check whether there are different views about genetic somatic modification and modification in embryos:	**20 mins**	

• Thinking about all the concerns you have: (MODERATOR TO REMIND PARTICIPANTS OF THE KEY CONCERNS DISCUSSED): ○ Do you think this is a sensitive topic? ○ What would you like to see done to address your concerns ○ Do you think there should be more regulation? ○ Who should be responsible for this regulation? ○		

Appendix 2 – Experts attendance at the workshops

Germany – Hamburg	France – Paris	Poland – Warsaw	Greece – Athens	Spain – Madrid
Lisa Tambornino, European Network of Research Ethics Committees (EUREC)	**Bernard Reber**, Sciences Po	**Zuzanna Warso**, Helsinki Foundation for Human Rights	**Maria Bottis**, Ionian University	**Javier Valls Prieto**, University of Granada
Saskia Nagel, University of Twente	**Roberto Gianni**, Sciences Po	**Emilia Niemiec**, Uppsala Universitet	**Maria Papaioannou**, Ionian University	**Ana Valverde**, University of Granada
Philipp Hoevel, European Network of Research Ethics Committees (EUREC)	**Alexandra Soulier**, Uppsala Universitet	**Konrad Siemaszko**, Helsinki Foundation for Human Rights (Observer)	**Marilena Siahou**, Ionian University	**Oscar Huertas**, Freelancer Communiation Granada Emprende
	Anaïs Rességuier, Trilateral Research (Observer)		**Martha Ioanna Stroumpou**, National Printing House in Athens	**Patricia Saldaña**, University of Granada

Appendix 3 – Pre and Post Questionnaire Results

The SIENNA Project Citizens' workshop: Pre-workshop questionnaire results

Q1 **How familiar are you with the technology? PLEASE TICK**								
	Very familiar	Quite familiar	Not very familiar	Not familiar at all	Excluded	No response	Total participants	**Valid participants**
Genomic screening								
France	2	7	18	22	0	4	**53**	**49**
Germany	0	5	10	33	0	2	**50**	**48**
Poland	3	2	10	33	0	2	**50**	**48**
Greece	1	8	13	28	0	0	**50**	**50**
Spain	2	3	10	35	0	0	**50**	**50**
TOTAL	**8**	**25**	**61**	**151**	**0**	**8**	**253**	**245**
Whole genome sequencing								
France	3	5	15	26	0	4	**53**	**49**
Germany	1	3	9	36	0	1	**50**	**49**
Poland	0	5	10	32	0	3	**50**	**47**
Greece	1	3	14	32	0	0	**50**	**50**
Spain	3	5	11	30	0	1	**50**	**49**
TOTAL	**8**	**21**	**59**	**156**	**0**	**9**	**253**	**244**
Genomic modification								
France	1	6	15	27	0	4	**53**	**49**
Germany	1	4	14	30	0	1	**50**	**49**
Poland	1	3	13	31	0	2	**50**	**48**
Greece	1	8	12	29	0	0	**50**	**50**
Spain	3	5	11	31	0	0	**50**	**50**
TOTAL	**7**	**26**	**65**	**148**	**0**	**7**	**253**	**246**
Somatic cell gene therapy								
France	0	4	16	29	0	4	**53**	**49**
Germany	0	4	9	37	0	0	**50**	**50**
Poland	0	5	7	37	0	1	**50**	**49**
Greece	1	7	15	27	0	0	**50**	**50**
Spain	2	4	10	34	0	0	**50**	**50**
TOTAL	**3**	**24**	**57**	**164**	**0**	**5**	**253**	**248**
Germline gene therapy								
France	0	0	15	34	0	4	**53**	**49**
Germany	0	0	10	39	0	1	**50**	**49**
Poland	0	3	9	37	0	1	**50**	**49**
Greece	3	8	13	26	0	0	**50**	**50**
Spain	3	2	10	35	0	0	**50**	**50**
TOTAL	**6**	**13**	**57**	**171**	**0**	**6**	**253**	**247**

Q2 Which of these words describe how you feel about each of the technologies? PLEASE TICK										
	Excited	Hopeful	Curious	Neutral	Anxious	Scared	Angry	No response	Total participants	**Valid participants**
Genomic screening										

France	6	8	11	18	2	1	2	5	53	**48**
Germany	1	4	7	26	9	2	0	1	50	**49**
Poland	4	3	14	19	6	1	1	2	50	**48**
Greece	1	7	14	17	5	8	1	0	50	**50**
Spain	5	7	13	20	2	1	2	0	50	**50**
TOTAL	**17**	**29**	**59**	**100**	**24**	**13**	**6**	**8**	**253**	**245**
Whole genome sequencing										
France	4	8	9	21	2	2	2	5	53	**48**
Germany	1	4	7	24	9	6	0	0	50	**50**
Poland	5	1	11	17	10	0	3	3	50	**47**
Greece	2	7	13	18	4	7	3	0	50	**50**
Spain	5	13	10	17	2	2	1	0	50	**50**
TOTAL	**17**	**33**	**50**	**97**	**27**	**17**	**9**	**8**	**253**	**245**
Genomic modification										
France	4	3	10	16	7	5	4	4	53	**49**
Germany	1	2	7	21	13	6	0	0	50	**50**
Poland	5	3	14	16	7	1	1	3	50	**47**
Greece	3	5	16	11	6	12	3	0	50	**50**
Spain	6	10	12	13	3	5	1	0	50	**50**
TOTAL	**19**	**23**	**59**	**77**	**36**	**29**	**9**	**7**	**253**	**246**
Somatic cell gene therapy										
France	2	4	15	21	2	1	3	5	53	**48**
Germany	0	6	4	25	10	5	0	0	50	**50**
Poland	5	1	14	16	7	1	4	2	50	**48**
Greece	9	17	9	9	3	4	3	0	50	**50**
Spain	5	7	12	17	2	4	3	0	50	**50**
TOTAL	**21**	**35**	**54**	**88**	**24**	**15**	**13**	**7**	**253**	**246**
Germline gene therapy										
France	1	1	13	26	3	1	2	6	53	**47**
Germany	0	2	3	29	10	5	0	1	50	**49**
Poland	5	1	15	15	7	1	4	2	50	**48**
Greece	9	20	9	9	0	5	1	0	50	**50**
Spain	6	6	11	20	1	3	3	0	50	**50**
TOTAL	**21**	**30**	**51**	**99**	**21**	**15**	**10**	**9**	**253**	**244**

The SIENNA Project Citizens' workshop: Post-workshop questionnaire

Q1 What kind of impact do you think each of these technologies will have on society? PLEASE TICK									
	Very positive	Quite positive	Neutral	Quite Negative	Very negative	Excluded	No response	Total participants	**Valid participants**
Genomic screening									
France	6	19	18	5	0	0	5	53	**48**
Germany	2	17	18	9	2	1	1	50	**48**
Poland	5	20	17	6	1	0	1	50	**49**
Greece	4	16	13	11	6	0	0	50	**50**
Spain	10	23	11	5	1	0	0	50	**50**
TOTAL	**27**	**95**	**77**	**36**	**10**	**1**	**7**	**253**	**245**

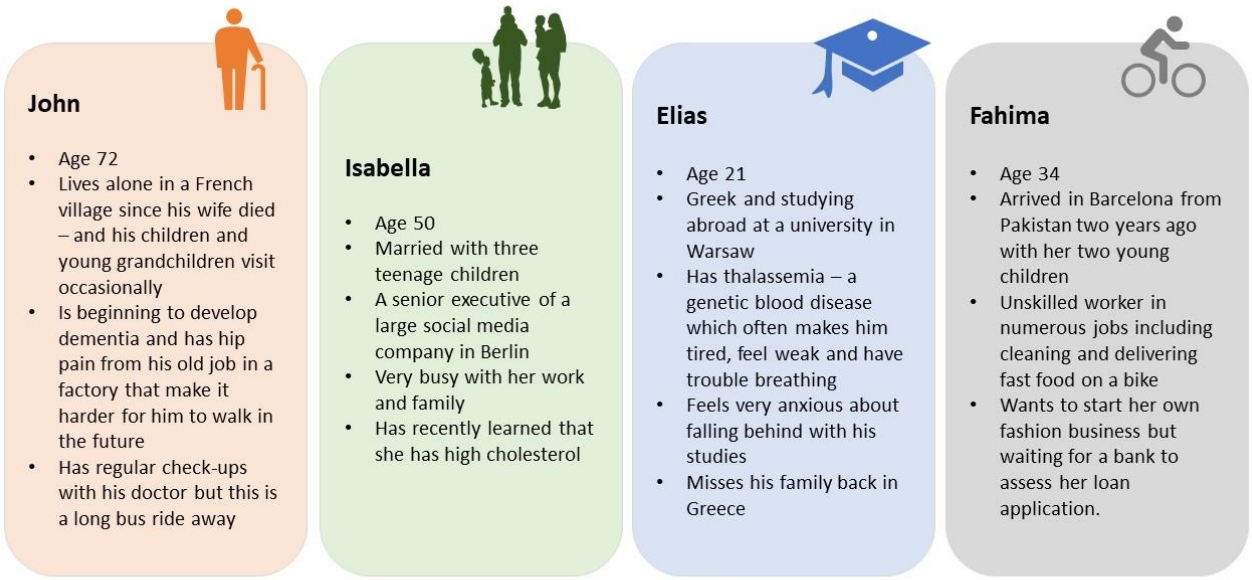
Whole genome sequencing									
France	6	15	20	7	0	0	5	53	**48**
Germany	2	10	26	7	3	1	1	50	**48**
Poland	4	17	17	9	2	0	1	50	**49**
Greece	2	15	17	13	3	0	0	50	**50**
Spain	10	24	12	3	1	0	0	50	**50**
TOTAL	**24**	**81**	**92**	**39**	**9**	**1**	**7**	**253**	**245**
Genomic modification									
France	1	10	12	13	11	0	6	53	**47**
Germany	1	8	20	11	7	1	2	50	**47**
Poland	3	20	12	12	2	0	1	50	**49**
Greece	4	9	14	14	9	0	0	50	**50**
Spain	12	15	16	6	1	0	0	50	**50**
TOTAL	**21**	**62**	**74**	**56**	**30**	**1**	**9**	**253**	**243**
Somatic cell gene therapy									
France	4	15	17	9	3	0	5	53	**48**
Germany	3	9	21	8	7	1	1	50	**48**
Poland	5	17	14	9	3	0	2	50	**48**
Greece	9	21	10	5	5	0	0	50	**50**
Spain	5	22	17	5	1	0	0	50	**50**
TOTAL	**26**	**84**	**79**	**36**	**19**	**1**	**8**	**253**	**244**
Germline gene therapy									
France	3	11	19	10	4	0	6	53	**47**
Germany	2	5	26	9	6	1	1	50	**48**
Poland	4	16	14	11	3	0	2	50	**48**
Greece	10	21	12	4	3	0	0	50	**50**
Spain	7	20	16	6	1	0	0	50	**50**
TOTAL	**26**	**73**	**87**	**40**	**17**	**1**	**9**	**253**	**243**

Q2 Which of these words now describe how you feel about each of the technologies? PLEASE TICK										
	Excited	Hopeful	Curious	Neutral	Anxious	Scared	Angry	No response	Total participants	**Valid participants**
Genomic screening										
France	5	9	17	4	7	2	1	8	53	**45**
Germany	1	10	11	14	6	6	1	1	50	**49**
Poland	3	12	9	14	7	2	2	1	50	**49**
Greece	4	11	11	11	7	9	3	0	50	**50**
Spain	7	13	16	4	4	4	0	2	50	**48**
TOTAL	**20**	**55**	**64**	**47**	**31**	**23**	**7**	**12**	**253**	**241**
Whole genome sequencing										
France	6	8	17	10	6	1	0	5	53	**48**
Germany	2	7	13	12	8	7	0	1	50	**49**
Poland	2	11	13	11	5	3	4	1	50	**49**
Greece	2	12	12	10	6	8	4	0	50	**50**
Spain	8	16	12	5	4	3	0	2	50	**48**
TOTAL	**20**	**54**	**67**	**48**	**29**	**22**	**8**	**9**	**253**	**244**

Genomic modification										
France	2	4	12	7	13	6	3	6	53	**47**
Germany	2	5	11	10	8	10	3	1	50	**49**
Poland	2	15	9	7	8	5	3	1	50	**49**
Greece	2	9	11	6	5	11	10	0	50	**50**
Spain	5	14	13	7	4	2	3	2	50	**48**
TOTAL	**13**	**47**	**56**	**37**	**38**	**34**	**22**	**10**	**253**	**243**
Somatic cell gene therapy										
France	3	9	12	11	6	5	1	6	53	**47**
Germany	4	6	11	13	8	6	1	1	50	**49**
Poland	4	12	9	10	9	2	3	1	50	**49**
Greece	8	18	7	6	5	8	1	0	50	**50**
Spain	4	22	8	5	5	4	0	2	50	**48**
TOTAL	**23**	**67**	**47**	**45**	**33**	**25**	**6**	**10**	**253**	**243**
Germline gene therapy										
France	3	5	11	11	9	7	1	6	53	**47**
Germany	3	4	7	19	8	9	0	1	50	**49**
Poland	4	13	8	11	7	3	3	1	50	**49**
Greece	10	19	8	8	3	4	2	0	50	**50**
Spain	4	17	10	8	3	6	0	2	50	**48**
TOTAL	**24**	**58**	**44**	**57**	**30**	**29**	**6**	**10**	**253**	**243**

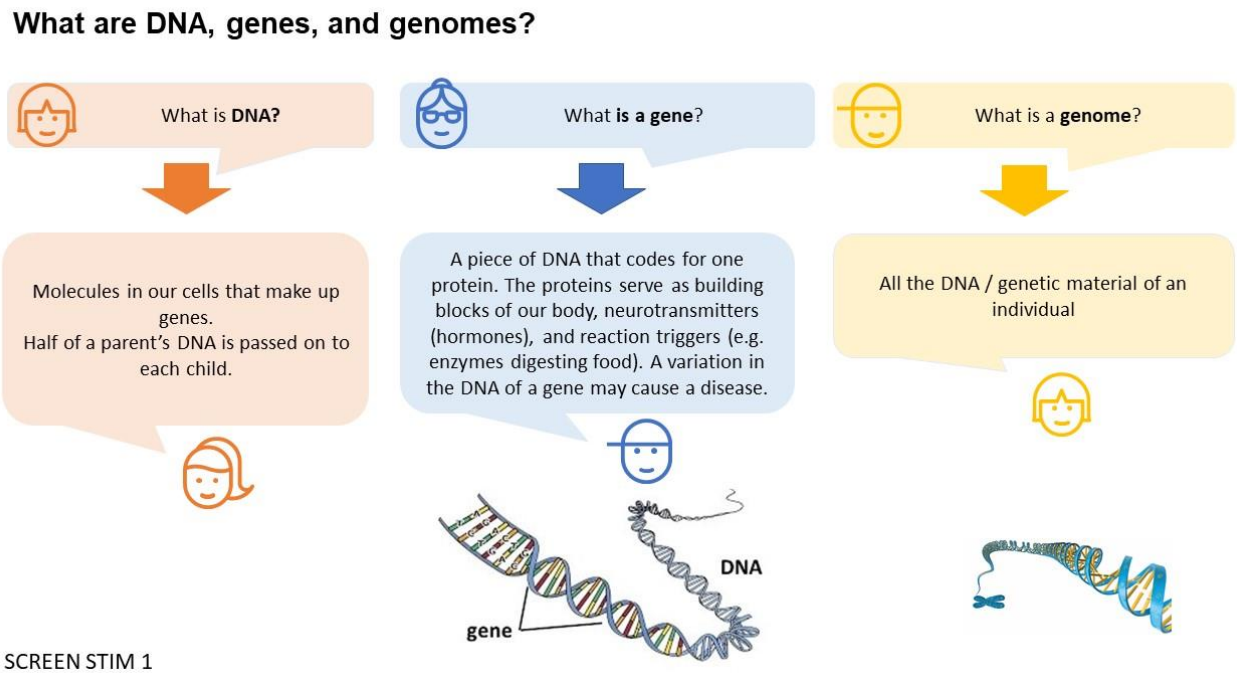
Appendix 4 - Stimulus Materials

5.1 Fictional segments

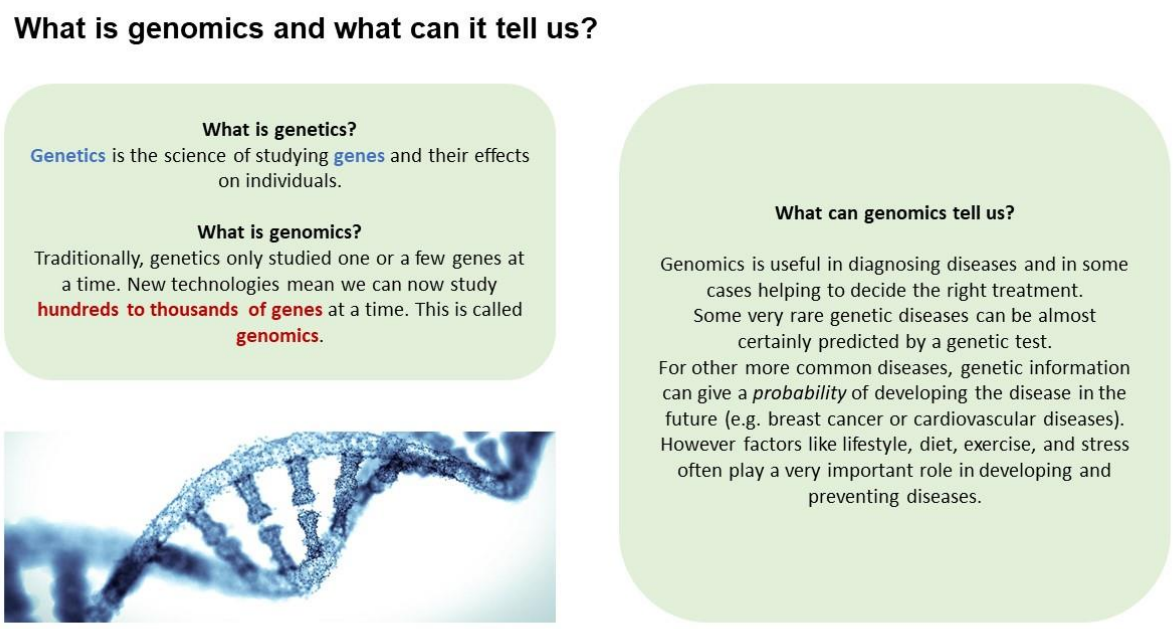


FICTIONAL SEGMENTS

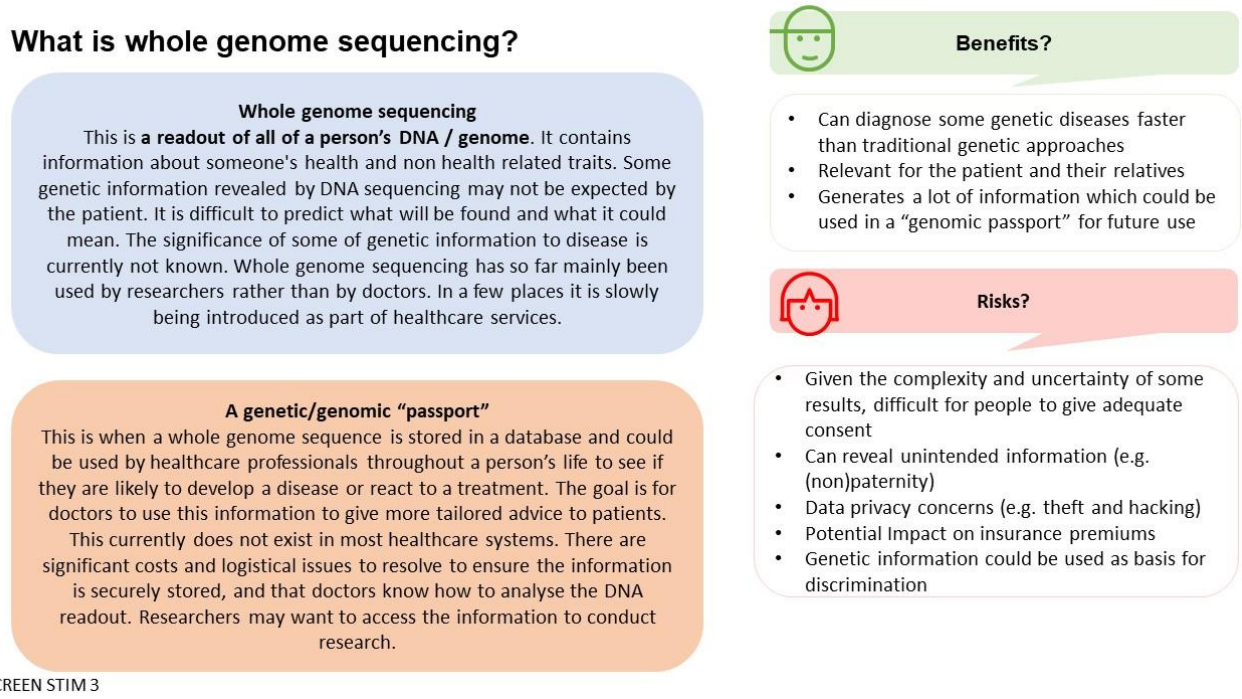
5.3 Genomic screening



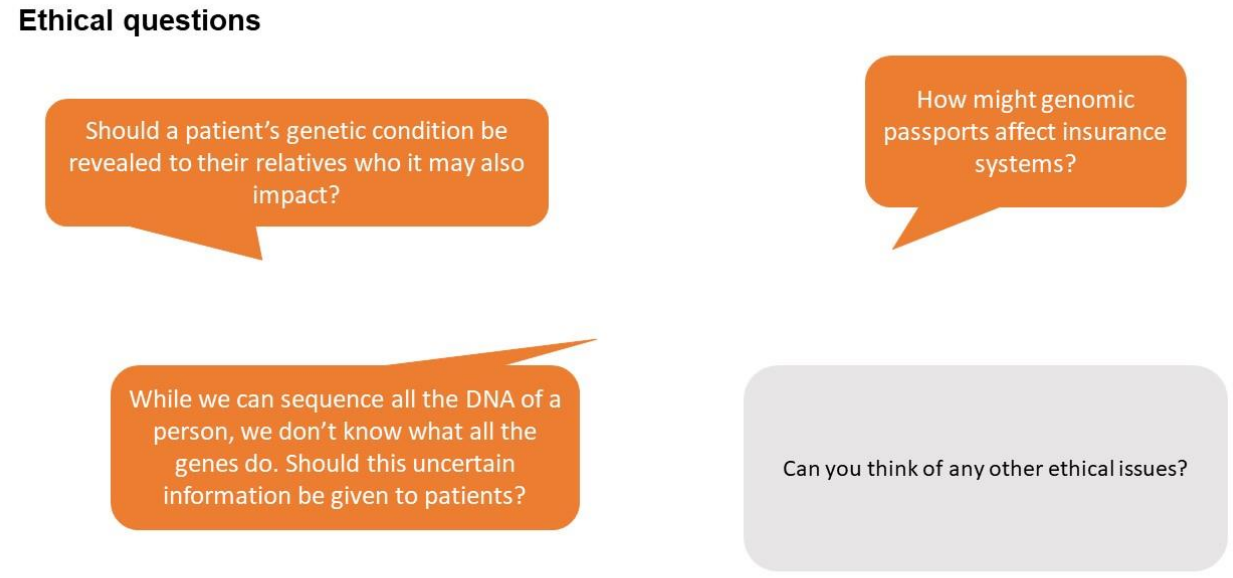
SCREEN STIM 1



SCREEN STIM 2



SCREEN STIM 3



SCREEN STIM 4

What is prenatal screening?

What is prenatal screening?

Procedures done during pregnancy to determine whether a baby is **likely** to have a disease.
Procedures include testing the mother's blood, ultrasound, measurements of the foetus, and DNA tests of the foetus.
Screening is usually offered to all pregnant women or those above a certain age or with specific risks.
Screening **provides the probability** that a condition exists.
Additional tests are required to provide a **more definitive** answer, but would not be offered to everyone.
In some countries, certain diseases are the basis for termination of pregnancy.

How can genomics be used in prenatal screening?

In prenatal **genomic** screening, it is proposed that large parts of the unborn baby's DNA or entire genome be sequenced and analysed to find out if it has or will develop genetic diseases.
For many diseases, the information only provides a **probability** of developing the disease – not certainty.
The DNA readout may reveal information about diseases which will appear in adulthood and non-health traits (e.g. eye colour).
Prenatal genomic screening is not currently offered in routine prenatal care.

SCREEN STIM 5

What are the implications?

Ethical questions

- What types of disorders are "acceptable" to screen for?
- Could this lead to less acceptance of people with disabilities?
- Would parents feel pressured to undergo screening and/or abortion?
- Should we be able to screen for non health related traits? (e.g. eye and hair colour)
- Should termination of pregnancy/abortion be allowed when a disease is detected in an unborn baby?

Benefits?

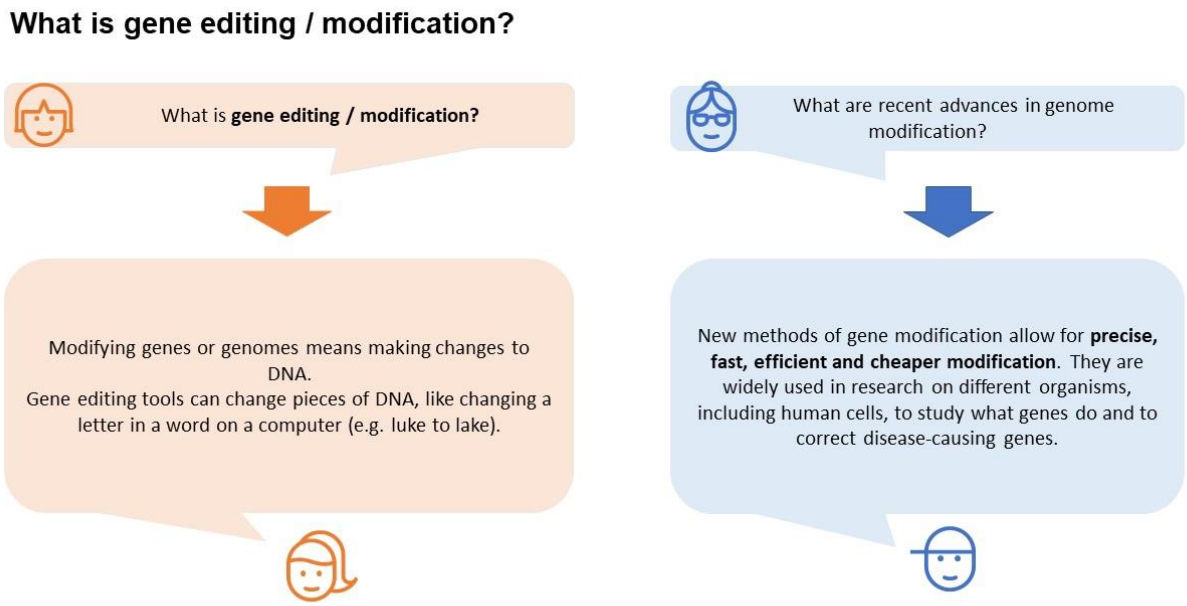
- If there is a treatment, this can be started at the earliest possible time (in the womb or soon after birth)
- The DNA readout could be used as a genomic passport to determine predisposition to other diseases in the future (e.g. cancer)

Risks?

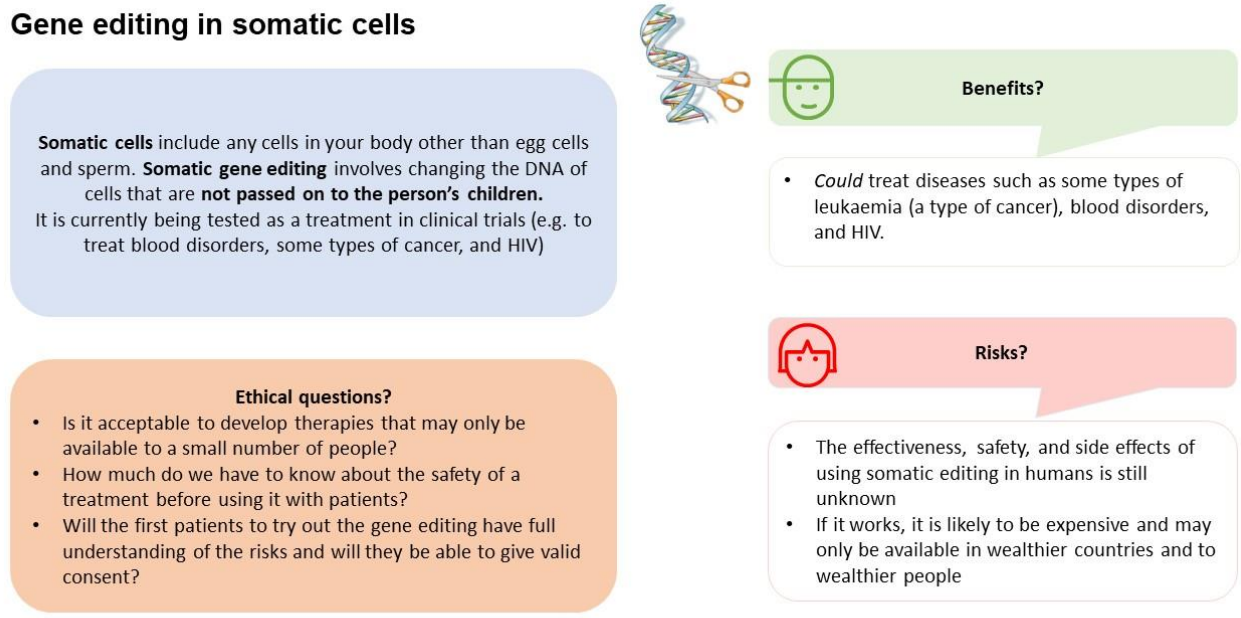
- Misunderstanding of results, especially those that are probability based.
- Increase in number of abortions/termination of pregnancies for non-serious and/or adult onset diseases
- Risk of rising intolerance toward disabled and ill people
- Revealing paternity

SCREEN STIM 6

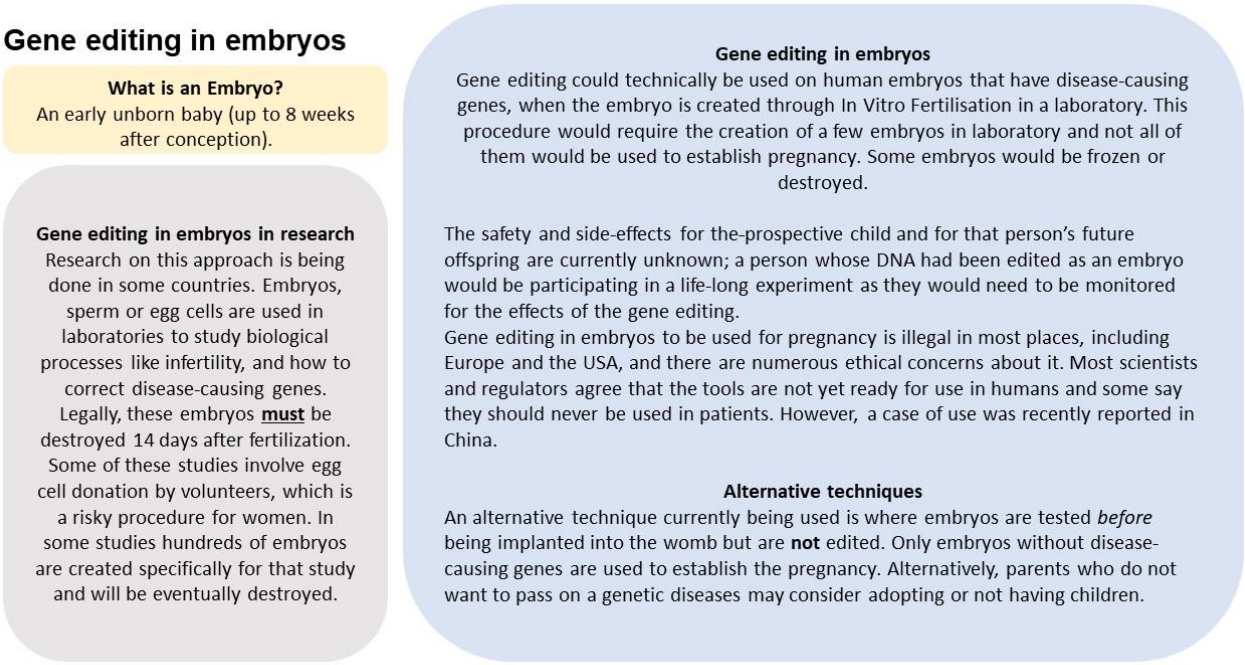
5.4 Genetic/genomic modification



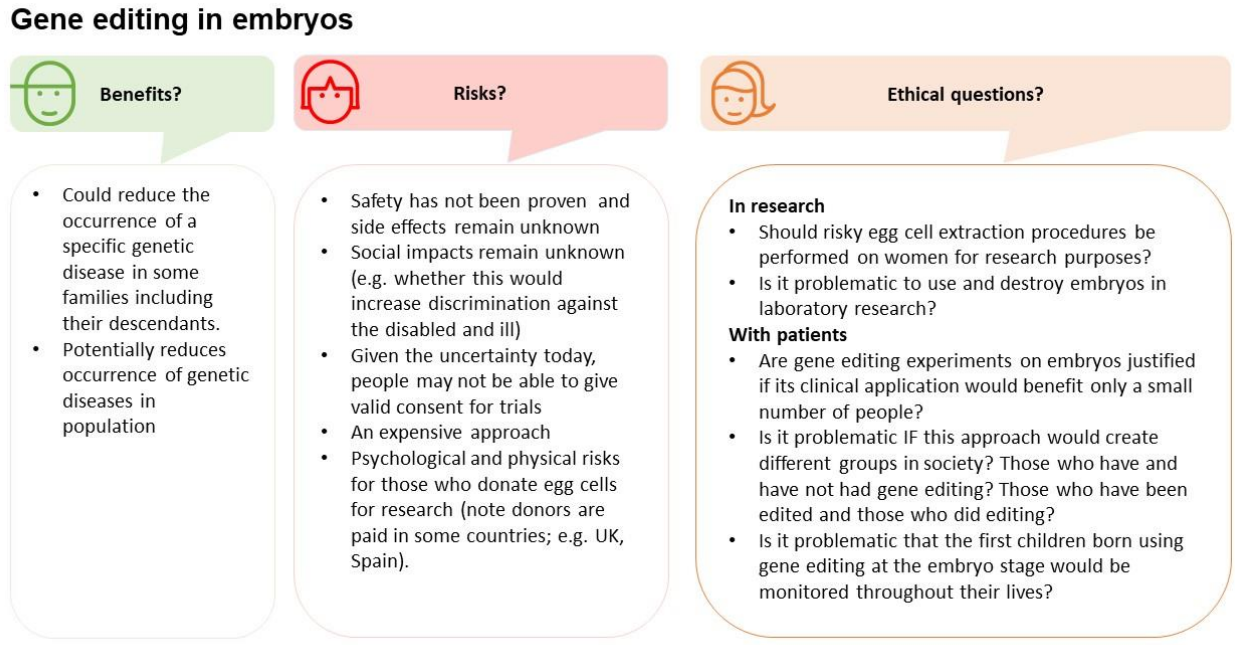
MODIF STIM 1



MODIF STIM 2



MODIF STIM 3



MODIF STIM 4

Appendix 5 – Achieved Sample

	OVERALL TARGET	PER COUNTRY TARGET	PARIS	HAMBURG	WARSAW	ATHENS	MADRID	TOTAL
TOTAL								
5 workshops of 50 participants (OVER RECRUIT TO 54)	250	50	53	50	50	50	50	253
GENERAL POPULATION QUOTAS								
GENDER								
Female	Min 100	20	29	21	25	24	25	124
Male	Min 100	20	24	29	25	26	25	129
Other / prefer not to say								
TOTAL	Min 200	40	53	50	50	50	50	253
AGE								
18-24	Min 25	5	9	10	12	10	11	52
25-34	Min 25	5	15	11	8	8	12	54
35-49	Min 25	5	14	9	11	12	11	57
50-59	Min 25	5	7	9	10	10	9	45
60-69	Min 15	3	7	7	6	8	5	33
70+	Min 10	2	1	4	3	2	2	12
TOTAL	Min 125	25	53	50	50	50	50	253
EDUCATION LEVEL								
University degree or above (or equivalent)	Min 50	10	29	21	17	19	21	107
High school/senior school (or equivalent)	Min 50	10	17	18	21	23	19	98

Below high school/senior school Inc. vocational qualifications (or equivalent)	Min 50	10	7	11	10	8	9	45
No educational qualifications			0	0	2	0	1	3
TOTAL	Min 150	30	53	50	50	50	50	253
WORK STATUS								
Student	40	8	8	8	10	10	8	44
Working	75	15	30	23	24	25	27	129
Not working	40	8	8	10	8	7	9	42
Retired	40	8	7	9	8	8	6	38
TOTAL	195	39	53	50	50	50	50	253
OCCUPATION								
Professional, managerial or administrative job managing people	25	5	18	13	8	6	6	51
Professional, managerial or administrative job not managing people	25	5	13	8	11	20	14	66
Skilled manual job	25	5	7	8	9	7	5	36
Semi-skilled or unskilled manual job	25	5	7	13	10	8	16	54
Other			8	8	12	9	9	46
TOTAL	100	20	53	50	50	50	50	253
ETHNICITY								
White			[redacted]	44	44	49	41	178
Non-white (Inc. Roma)	20	Min 5 Germany, Min 7 Spain, Min 3	[redacted]	6	6	1	9	22

		Poland, Min 5 Greece						
TOTAL	20	Min 3		50	50	50	50	200
MINORITY GROUP (FRANCE ONLY)								
Feel they belong to a minority group due to the country they or their parents were born in	7	Min 7 France	7					7
TOTAL	7	Min 7	7					7
RELIGION								
Catholicism	100	20	22	1	32	0	29	84
Orthodox Christianity			1	0	5	42	0	48
Protestantism			1	0	0	0	0	1
Islam			2	3	3	1	3	12
Judaism			1	0	0	0	0	1
Sikhism			0	0	0	0	0	0
Hinduism			0	0	0	0	0	0
Buddhism			2	1	0	0	0	3
Other			2	17	1	0	0	20
No/Agnostic/atheist	25	5	22	28	9	7	18	84
TOTAL	125	25	53	50	50	50	50	253
AREA OF RESIDENCE								
Urban (city)	Min 25	Min 5	16	32	33	30	29	140
Suburban (suburbs of city)	Min 25	Min 5	27	13	7	19	14	80

Rural/Semi rural (town or village)	Min 19	Min 3 France, Min 3 Germany, Min 3 Greece, Min 5 Spain, Min 5 Poland	10	5	10	1	7	33
TOTAL	Min 69	Min 3	53	50	50	50	50	253
LIFE STAGE								
Not parent	25	5	34	29	22	27	27	139
Parent	50	10	19	21	28	23	23	114
Total	75	15	53	50	50	50	50	253
INTERNET SCALE								
More negative (1-3)	60	12	10	12	12	12	12	58
Medium	60	12	10	16	12	17	13	68
Positive	60	12	33	22	26	21	25	127
TOTAL	180	36	53	50	50	50	50	253
VULNERABLE GROUPS QUOTAS								
10 Participants from Vulnerable Groups	50	10	19	15	40	10	10	94
CHRONIC PHYSICAL CONDITIONS								
Heart disease	5	1	0	1	2	0	0	3
Stroke			0	0	0	0	0	0
Chronic Obstructive Pulmonary Disease (COPD)			0	6	2	0	0	8

Emphysema and other respiratory conditions			0	0	0	0	0	0
Arthritis (including gout or fibromyalgia)			0	0	3	0	0	3
Asthma			0	0	1	0	0	1
Cancer			1	0	2	1	1	5
Osteoporosis			0	0	2	0	0	2
Kidney and or liver conditions			0	0	1	0	0	1
Epilepsy			0	0	0	0	0	0
High blood and or high cholesterol levels			0	0	8	1	0	9
Lupus			0	0	0	0	0	0
Glaucoma			0	0	2	0	0	2
Thyroid condition			1	0	2	0	0	3
Other			0	0	4	0	0	4
TOTAL	5	1	2	7	29	2	1	41
MENTAL HEALTH CONDITIONS								
Anxiety	5	1	1	0	2	0	0	3
Depression (including post-natal depression)			2	6	5	1	0	14
Panic attacks			1	0	0	0	0	1
An eating disorder			2	0	2	0	0	4
Obsessive Compulsive Disorder (OCD)			4	0	0	0	0	4
Asperger's Syndrome			0	0	0	0	0	0
Post-Traumatic Stress Disorder (PTSD)			0	0	0	0	0	0
Phobia(s)			1	0	0	0	0	1
Bipolar or other personality disorder			0	1	0	0	0	1
Schizophrenia and psychosis			0	0	2	0	1	3

Self-harm			0	0	0	0	0	0
Suicidal thoughts or attempted suicide			0	0	0	0	0	0
Other			0	0	2	0	0	2
TOTAL	5	1	11	7	13	1	1	33
PLEASE NOTE HERE WHO HAS EACH CONDITION (participant, partner, parent, child, step child, sibling, family member living at home at the time of the condition) (e.g. anxiety = participant, depression = participant's sibling)	**Paris:** 1 x participant = depression (themselves), OCD (themselves); 1 x participant = depression (relative), panic attacks (relative) OCD (themselves);1 x participant = anxiety (themselves), eating disorder (themselves), phobia (themselves) ; 1 x participant = OCD (themselves), eating disorder (themselves); 1 x participant = OCD (themselves) **Hamburg:** 1 x participant = bipolar disorder (themselves); 1 x participant = manic depression (themselves) and cardiac insufficiency (themselves); 1 x participant = depression (themselves), Multiple Sclerosis (themselves), Diabetes (themselves), Skin allergy (themselves); 1 x participant = depression (themselves) and Crohn's disease (themselves); 1 x participant = depression (themselves), arthrosis (themselves); 1 x participant = depression (themselves); 1x participant = depression (themselves) **Warsaw:** 1 x participant = depression (participant), depression (partner); 1 x participant = Eating disorder (child), 1 x participant = Autism (child); 1 x participant = Anxiety (participant), eating disorder (child), Schizophrenia (relative); 1 x participant = Autism (child); 1 x participant = Anxiety (parent), depression (parent); 1 x participant = depression (participant); 1 x participant = depression (relative); 1 x participant = depression (child); 1 x participant = schizophrenia (sibling) **Athens:** 1 x participant = depression (themselves) **Madrid:** 1 x participant = schizophrenia (son), psychosis (son)							
GENETIC DISORDERS								
Cancer	5	1	0	2	11	0	1	14
Type 1 Diabetes			0	1	5	0	0	6
Cystic Fibrosis			0	0	0	0	0	0
Crohn's Disease			0	0	0	0	0	0
Haemophilia			0	0	0	0	0	0
Down's Syndrome			0	0	0	1	0	1
Thalassemia			0	0	0	0	0	0

Sickle Cell Anaemia			0	0	0	0	0	0
Huntingdon's Disease			0	0	0	0	0	0
Tay-Sachs			0	0	0	0	0	0
Angelman Syndrome			0	0	0	0	0	0
Type 1 Neurofibromatosis			0	0	0	0	0	0
Tuberous Sclerosis			0	0	0	0	0	0
Autosomal Dominant Polycystic Kidney Disease (ADPKD)			0	0	0	0	1	1
Duchenne Muscular Dystrophy			1	0	0	0	0	1
Fragile X Syndrome			0	0	0	0	0	0
Edward's Syndrome			0	0	0	0	0	0
Patau's Syndrome			0	0	0	0	0	0
Turner Syndrome			0	0	0	0	0	0
Klinefelter's Syndrome			0	0	0	0	0	0
Other			1	1	0	0	0	2
TOTAL	5	1	2	4	16	1	2	25
PLEASE NOTE HERE WHO HAS EACH CONDITION (participant, partner, parent, grandparent, child, step child, sibling, family member living at home at the time of the condition) (e.g. diabetes = participant, cancer = participant's parent)	**Paris:** 1 x participant = myopathy (child), myopathy (child's father); 1 x participant = Duchenne muscular dystrophy (niece) **Hamburg:** 1 x participant = Meniere's disease (themselves); 1 x participant = cancer (other person); 1 x participant = factor V Leiden thrombophilia (themselves); 1 x participant = diabetes (other person) **Warsaw:** 1 x participant = cancer (participant), type 1 diabetes (parent); 1 x participant = cancer (parent), cancer (siblings); type 1 diabetes (relative); 1 x participant = cancer (partner); 1 x participant = cancer (parent); 1 x participant = cancer (parent); 1x participant = cancer (parent); 1 x participant = cancer (partner), type 1 diabetes (partner); 1 x participant = cancer (participant) cancer (parent), cancer (siblings); 1 x participant = cancer (partner); 1 x participant = cancer (relative); 1 x participant = type 1 diabetes (parent); 1 x participant = type 1 diabetes (parent); 1 x participant = cancer (parent) **Athens:**1 x participant = Down's Syndrome (child)						

	Madrid:1 x participant = cancer (themselves); 1 x participant = Crohn's disease (themselves), Autosomal dominant polycystic kidney disease (child)							
GENETIC CONCERN								
Cancer			0	2	6	1	0	9
Type 1 Diabetes			0	1	2	0	0	3
Cystic Fibrosis			0	0	0	0	0	0
Crohn's Disease			0	0	0	0	0	0
Haemophilia			0	0	0	0	0	0
Down's Syndrome			0	0	0	0	0	0
Thalassemia			0	0	0	0	0	0
Sickle Cell Anaemia			0	0	0	0	0	0
Huntingdon's Disease			0	0	0	0	0	0
Tay-Sachs			0	0	0	0	0	0
Angelman Syndrome			0	0	0	0	0	0
Type 1 Neurofibromatosis			0	0	0	0	0	0
Tuberous Sclerosis			0	0	0	0	0	0
Autosomal Dominant Polycystic Kidney Disease (ADPKD)			0	0	0	0	0	0
Duchenne Muscular Dystrophy			0	0	0	0	0	0
Fragile X Syndrome			0	0	0	0	0	0
Edward's Syndrome			0	0	0	0	0	0
Patau's Syndrome			0	0	0	0	0	0
Turner Syndrome			0	0	0	0	0	0
Klinefelter's Syndrome			0	0	0	0	0	0
Other			0	1	0	0	1	2
Total			0	4	8	1	1	14

PLEASE NOTE HERE WHO THE CONCERN WAS ABOUT (participant, partner, parent, grandparent, child, step child, sibling, family member living at home at the time of the condition) (e.g. diabetes = participant, cancer = participant's parent)	**Hamburg:** 1 x participant = cancer (other person); 1 x participant = cancer (other person); 1 x participant = diabetes (other person); 1 x participant = other (other person) **Warsaw:** 1 x participant = cancer (child); 1 x participant = cancer (participant); 1 x participant = cancer (participant); 1 x participant = cancer (partner), type 1 diabetes (parent); 1 x participant = cancer (participant); 1 x participant = cancer (participant); 1 x participant = type 1 diabetes (parent) **Athens:** 1 x participant = cancer (partner) **Madrid:** 1 participant = autism (son)							
DISABILTIES								
Vision (e.g. impaired vision, macular degeneration, blindness)	10	2	0	1	10	0	1	12
Hearing loss			1	0	3	0	0	4
Learning difficulties (including dyslexia and dyspraxia)			1	4	4	1	0	10
Impaired mobility			0	0	5	1	0	6
Breathing problems (reduced stamina, severe fatigue)			0	0	1	0	0	1
Dexterity			0	0	0	0	0	0
Other			0	0	1	0	1	2
TOTAL	10	2	2	5	24	2	2	35

PLEASE NOTE HERE WHO HAS EACH CONDITION (participant, partner, parent, grandparent, child, step child, sibling, family member living at home at the time of the condition) (e.g. impaired vision = participant's grandparent; hearing loss = participant's grandparent; impaired mobility = participant's sibling)	**Paris:** 1 x participant = hearing loss (themselves); 1 x participant = learning difficulties (themselves) **Hamburg:** 1 x participant = arthropathic (themselves); 1 x participant = walk with walking stick (themselves); 1 x participant = slipped disc (themselves); 1 x participant = arthropathic (themselves) 1 x participant = other (themselves) **Warsaw:** 1 x participant = vision (participant); 1 x participant = vision (participant), hearing loss (participant); 1 x participant = vision (participant); 1 x participant = cerebral palsy (child); 1 x participant = learning difficulties (child), breathing problems (partner); 1 x participant = vision (participant); 1 x participant = vision (participant); 1 x participant = learning difficulties (participant); 1 x participant = vision (participant); 1 x participant = vision (parent), learning (child), impaired mobility (child); 1 x participant = impaired mobility (participant); 1 x participant = impaired mobility (relative); 1 x participant = vision (participant); 1 x participant = impaired mobility (child); 1 x participant = learning difficulties (sibling); 1 x participant = vision (participant); 1 x participant = impaired mobility (participant); 1 x participant = hearing (parent); 1 x participant = vision (participant); 1 x participant = hearing loss (participant) **Athens:** 1 x participant = learning difficulties (participant), dyslexia (participant); 1 x participant = Impaired mobility (participant) **Madrid:** 1 x participant = retinitis pigmentosa (child); 1 x participant = Disabilities caused in childbirth (child); 1 x participant = Polio (relative)

IMMIGRATION								
At least one of my parent was born outside of this country	10	2	2	16	2	3	2	25
Born outside of this country	5	1	5	1	10	3	4	23
TOTAL	15	3	7	17	12	6	6	48
BASIS OF VULNERABILTY								
I am a refugee or asylum seeker	15	3	0	0	0	0	0	0
I am not fluent in the main language of this country			1	0	0	0	0	1
I do not feel fully confident reading or writing in the			0	0	1	0	1	2

main language of this country								
60+ years old			1	0	0	0	0	1
Low educational attainment			0	4	3	1	0	8
Unemployed			0	4	3	1	0	8
Semi-skilled or unskilled job			0	0	2	1	1	4
From a non-white ethnic group (Germany, Poland, Spain, Greece)				0	6	0	1	7
Feel they belong to a minority group due to the country they or their parents were born in (France only)			6					6
From a minority religious group in this country			2	2	3	0	0	7
TOTAL	15	3	10	10	18	3	3	44

Appendix 6 – Genomics Expert Briefing document

SIENNA- Human Genomics:

Assistance sheet for moderators

There is a lot of information contained in the genomics material and it may be overwhelming for both you and the participants.

We are asking you to really look carefully at the material concerning genomics before taking charge of the group. Please, read it several times orally to make sure that you can convey this material in a meaningful way.

If participants ask a question, always start by responding:

- ⇨ **what does the group think about it?**

As a second step, if the discussion can not move forward, you can ask an expert for help. Hopefully, you will find answers to the participants' questions in this assistance sheet, but if you do not, just explain that we do not need to know all the technicalities to discuss ethical issues and go back to the script.

1. Please make a pause after each page and check that participants have understood.
   - ⇨ **Ask : Have you all understood information displayed on this page. do you have any questions?**

2. You need to make a pause after each bubble and check that participants have understood.
   - ⇨ **Ask : Have you all understood information conveyed in this bubble. do you have any questions?**

3. On slide 13 (gene editing in embryos), this is the proper order of reading:
   i. Yellow: What is an embryo

   Embryo and foetus are terms used to describe different stages of development of human life. Embryo refers to human life from the conception until the 9th week; from the 9th week we use the term foetus to describe it. In the ninth week of pregnancy, a fetus have arms, fingers, heart formed which will continue to develop in the weeks to come. A fetal heartbeat may be detectable as early as 5 1/2 to 6 weeks.

   ii. Grey: Genetic modification of embryos in research
   iii. Blue: Genetic modification of embryos

   Participants may not understand this slide perfectly so you have to be prepared to re-explained the basics on this page :

   - **In vitro fertilisation (IVF)** is a procedure in which allows to have biological children to couples who are not able to conceive a child in a natural way. Eggs are extracted from a prospect mother in a surgical procedure and fertilized by sperm in a laboratory, in a dish, under microscope. Embryos which look healthy are then transferred in uterus/womb to establish pregnancy.

- **Egg extraction** – is a procedure in which eggs are retrieved from women for the purpose of research or to create embryos (by IVF) which will develop into children. Egg extraction involves taking medication by women so that her eggs mature quicker and can be retrieved in high number. Egg extraction is an invasive and surgical procedure. The whole procedure involves serious risk and discomforts, e.g. hyper stimulation syndrome (affects up to 10% of egg donors) which may result in infertility or even death. Less serious but more common risks and discomforts include nausea, headache or constipation. Long-term risks of the procedure are not well investigated, however there are some results suggesting that risks of breast cancer may be increased in egg donors.
- **Genetic modification of embryos in research**
  - ⇨ Embryos used in research have two origins (Grey):
    - either they are made in the lab by researchers with given oocytes/eggs and sperm
    - or they have been given to researchers by couples who went through IVF, had several embryos made, some of which have not been implanted and were thus given to research with the parents' consent
  - ⇨ These embryos have been experimented upon and they cannot, by law, be used for a pregnancy/ develop into babies. Once experimented upon, they have to be destroyed.
- **Genetic modification of embryos (Blue)**
  - This procedure is currently theoretical and is not currently legal in the EU
  - This procedure would be for parents who are suspected to give birth to sick children. In this case, the procedure would rely on several steps:
    - We would use the eggs and sperm of the parents to create embryos in the lab (in vitro)
    - A disease-causing gene in the embryo would be corrected by gene editing in the laboratory
    - Embryos would be tested to determine if gene editing worked well
    - An embryo which has corrected gene would be implanted into the uterus of the mother
    - Embryos that have not be implanted/used for a pregnancy can either be stored, if the parents want more children ; destroyed or given to research where they will be experimented upon and eventually destroyed.

4. To end both sessions on genome sequencing and genome editing, the question is "how can your concerns be addressed ?" What we want to know is: if and how they see the field should be. You can thus ask the question in this way:
   - Do you think certain type of research/uses of genomics should be prohibited?
   - If yes, whom do you think should decide about this?

Somatic gene editing – additional information

Somatic gene editing is performed on a given tissue, cells or organ to correct a disease-causing gene. For example gene editing therapy would be delivered to lungs to treat a lung disease by inhalation. To treat a blood disease, a blood would be drawn and the gene editing would be performed on blood cells in the laboratory. Blood cells with edited genes would be delivered back to the patient.

References

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