



Public attitudes to life sciences research in six European countries



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EXECUTIVE SUMMARY

This report is part of ORION (Open Responsible research and Innovation to further Outstanding kNowledge), a European project funded under the Science with and for Society (SwafS) work programme within Horizon 2020. As part of Work Package 2 (Analysis and Benchmarking), a survey involving 6,000 respondents in Czechia, Germany, Italy, Spain, Sweden and the United Kingdom (UK) has been conducted. Building on existing knowledge regarding public attitudes to science,

the objective has been to develop new knowledge on the general public's attitudes towards life sciences research and, more specifically, genome editing. The survey was directed towards the general public and revolved around three themes: (i) interest and confidence in life sciences research, (ii) views on personal involvement on life sciences research, and (iii) awareness and concerns about genome editing. A selection of the results is summarised below.

INTEREST AND CONFIDENCE IN LIFE SCIENCES RESEARCH

- ▶ Interest in life sciences research is generally high with the number of respondents being fairly or very interested ranging from 52 percent (Czechia) to 91 percent (Italy).
- ▶ Levels of interest depend more on country of origin than any other demographic variable (age, gender, level of education, or a job related to research).
- ▶ The respondents are most interested in finding out more about research findings, practical applications of research findings and the methods used in research.
- ▶ Respondents with high levels of interest in life sciences research also express high levels of confidence.
- ▶ Age and level of education had only marginal effect on confidence levels.

PERSONAL INVOLVEMENT IN LIFE SCIENCES RESEARCH

- ▶ Respondents saying that it is fairly or very important for the general public to be involved in life sciences research ranges from 68 percent (Czechia) to 93 percent (Italy). The positive views hold through all demographic variables.
- ▶ Fewer respondents would consider personal involvement in life sciences research, ranging from 39 percent (Czechia) to 84 percent (Italy).
- ▶ Men tend to be more interested in being personally involved in research than women.
- ▶ Respondents aged between 60 and 79 years are less willing to consider personal involvement in research than younger respondents across all countries.
- ▶ Respondents with a high interest in life sciences research are much more willing to be personally involved.
- ▶ The most attractive ways to be involved in research include several activities associated with citizen science projects: collaborating in data collection, giving opinions on research questions/topics, collaborating in data analysis and donating research material.
- ▶ The two most interesting topics that would motivate involvement are to understand the impact of lifestyle on health and that of DNA on health and disease.

AWARENESS AND CONCERNS ABOUT GENOME EDITING

- ▶ Fifty-five percent of the respondents have previously heard of genome editing. By country, this number ranges from 45 percent (Czechia and Germany) to 74 percent (Sweden).
- ▶ Men have heard of genome editing to a higher extent than women in all of the countries.
- ▶ There is higher awareness of genome editing among higher educated people in all of the countries except Czechia, where no substantial differences among educational groups were found.
- ▶ Respondents with high confidence in life sciences research have higher awareness of genome editing.
- ▶ The three most desired purposes for using genome editing in all of the countries are: prevention or cure of diseases, prevention of disabilities and organ transplantation.
- ▶ Respondents with higher levels of interest and confidence are more supportive of all purposes of genome editing.

- ▶ The largest concerns associated with genome editing are that the technique might be misused or that it might come with unexpected side-effects in humans.
- ▶ Levels of concern are only marginally affected by respondents having a job related to research.
- ▶ All levels of concern decrease with rising age.
- ▶ Higher levels of concern are expressed with increasing interest in life sciences research.

1. INTRODUCTION

INTRODUCTION TO ORION AND OPEN SCIENCE

ORION (Open Responsible research and Innovation to further Outstanding kNowledge) is a European project funded under the Science with and for Society (SwafS) work programme within Horizon 2020¹. The objectives of the project are to trigger evidence-based, institutional, cultural and behavioural changes in Research Funding and Performing Organizations (RFPOs) targeting researchers, management staff and high-level leadership. The long-term vision of the project is to embed Open Science (OS) and Responsible Research and Innovation (RRI) in RFPOs (RRI principles include *ethics, gender, governance, open access, public engagement and science education*). One of the ways that the project seeks to implement its objectives is to design, execute and evaluate co-creation experiments with relevant stakeholders, including the general public. In order to efficiently design such activities and adapt them to local audiences, knowledge of the attitudes among the general public is crucial. Citizens of the countries that are part of ORION (Czechia, Germany, Italy, Spain, Sweden and the United Kingdom (UK)) will be involved in several activities planned later in the project (e.g. public dialogue workshops and citizen science projects).

Open Science is a broad term encompassing several assumptions concerning the future of

knowledge creation. The transition towards OS is meant to make research more accessible, applicable, transparent and responsible for the benefit of both RFPOs and society at large (e.g. Cribb & Sari, 2010; Fecher & Friesike, 2013). Components that are commonly associated with OS are *open access, open data, open methodology, open source, open peer review, open science policies* and *stakeholder engagement* (e.g. in the form of citizen science) (Cribb & Sari, 2010; Nosek et al., 2015).

The European Research Area (ERA) has named ‘optimal access to and circulation and transfer of scientific knowledge’ as one of its main priorities (ERA, 2015, p. 1). This statement highly overlaps with the ideas of OS, which is illustrated by its focus on accessibility of research findings, availability of information to researchers in the public domain, and the cutting of costs of accessing knowledge for smaller and less-advanced countries, institutions, and enterprises. Carlos Moedas, European Commissioner for Research, Science and Innovation, defined Open Innovation, Open Science, and Openness to the World as the three strategic priorities of European research in a speech entitled *A new start for Europe: Opening up to an ERA of Innovation*². These priorities were adopted and elaborated on by the European Commission in the report

¹ Grant Agreement No. 741527.

² The speech can be accessed in its entirety at: http://europa.eu/rapid/press-release_SPEECH-15-5243_en.htm

called *Open Innovation, Open Science, Open to the World – a vision for Europe* (2016) and were formally endorsed by the EU member states at a Council meeting in May 2016³. Ongoing work with implementing the OS principles is realised through, for example, the Open Science Policy Platform⁴ and the European Open Science Cloud⁵.

Open Science has a high potential to influence the practices of researchers, funding institutions and the public. The implementation of open access to research publications is of crucial importance to make scientific literature available to interested individuals outside academia (incl. policymakers, general public etc.). Open data has the potential of making science production more effective as it enables verification, replication as well as expansion of research results (Bull, Roberts & Parker, 2015). However, there are also challenges associated with open data. These include, among others, privacy and confidentiality issues (e.g. Bull et al., 2015; Destro Bisol et al., 2014). Involving citizens in the actual research process, for instance through citizen science, is another element of OS in which there is increasing interest. Participants can be involved in data collection, in the formulation of research questions, as well as in assisting with data analysis. It is argued that this may improve science-society-policy interactions and lead to a more democratic research process (Hand, 2010; Societize/European Commission, 2013).

For the purpose of the ORION project, the consortium has decided to focus on three key challenge areas situated in life sciences research. These are:

1. Opening up the research engine
2. Identifying risks and opportunities presented by disruptive technologies
3. Running citizen science in fundamental research

The first challenge relates to the fact that, since research affects nearly everyone, RFPOs need to become more attentive to receiving input from stakeholders commonly left outside the research processes. *The second challenge* is about novel technologies such as CRISPR-Cas9 (see e.g. O’Connell et al., 2014), that are revolutionising the ways that we can interact with and edit our genomes. Risks and opportunities associated with these techniques will be explored from several perspectives together with multiple stakeholders. *The third challenge* will explore how citizen science can be taken one step further and explore its potential in fundamental research within life sciences and biomedicine. Benefits and risks with engaging different stakeholders throughout the research process (including hypothesis generation, data collection, analysis and further exploitation) will be carefully explored within the ORION project.

In order to approach these areas, managing stakeholder expectations is of crucial importance. To be able to fulfil its objectives, the ORION project therefore needs updated knowledge on the attitudes and views connected to the challenge areas of both the general public and RFPO-employees within the countries collaborating in the ORION project. For this purpose, knowledge from previous studies has been gathered and synthesised to inform the survey that is the subject of this report. This survey was conducted as a telephone survey among the general public in the six countries of the ORION project partners to gather updated and comparable data on citizens’ attitudes. In the survey, the citizens were asked about their general interest and confidence in life sciences research, their willingness to be involved themselves in such research endeavours, as well as specific questions to investigate their knowledge and attitudes towards techniques involving genome editing. The findings are presented in this report.

3 <http://data.consilium.europa.eu/doc/document/ST-9526-2016-INIT/en/pdf>

4 <https://ec.europa.eu/research/openscience/index.cfm?pg=open-science-policy-platform>

5 <https://ec.europa.eu/research/openscience/index.cfm?pg=open-science-cloud>

PREVIOUS STUDIES OF PUBLIC ATTITUDES IN RELEVANT AREAS

To date, no public survey explicitly targeting OS has been conducted. Recently, two expert working groups on Skills and Rewards, respectively, appointed by the European Commission, have completed dedicated surveys on OS⁶. However, one of these surveys targets researchers and the other is aimed at funding agencies in addition to researchers.

However, studies concerning various aspects of public confidence, knowledge and/or attitudes in relation to science and technology have been performed for many years. In the case of genome editing, a recent survey carried out over eleven countries showed that applications, rather than the technology itself, is a critical issue for the general public. For example, genome editing receives consistently more support when applied to therapy rather than enhancement and to adults rather than prenatals (Gaskell et al., 2017). The following sections present further results from previous surveys that explore public attitudes to ORION-related aspects in science and technology. First, results from several Eurobarometers, conducted on behalf of the European Commission, are presented. These are followed by an account of several national surveys, which have been conducted in countries represented by the ORION partners.

Eurobarometer surveys

The Eurobarometer is a public opinion survey conducted by the European Commission. Each survey consists of approximately 1,000 interviews per country and includes all member states of the European Union. The surveys address a variety of topics and are designed to compare opinion trends among member states. Special Eurobarometers are performed to provide in-depth thematic studies on

various topics of interest for the European Commission and the member states of the European Union. Several Special Eurobarometer surveys have had a distinct focus on issues associated with public perceptions of and/or engagement with science and technology⁷. These surveys are therefore of unique relevance to the ORION project, since the results give a good, European-wide, understanding of the awareness and interest in science and scientific processes, and the public's engagement in these issues. However, the scope of these Eurobarometers dedicated to science is often on science and technology in general. It is therefore not always possible to relate the results from these specifically to life sciences research, which is the focus of ORION. In addition, given the rapid development of knowledge and techniques in life sciences, public knowledge and attitudes cannot be expected to be stable over time. Hence, novel investigations, situated within a life sciences context and encompassing questions related to RRI and OS, are of value to the project.

In 2013, the public's interest in developments in science and technology was measured in *Special Eurobarometer 401: Responsible Research and Innovation (RRI), Science and Technology* (European Commission, 2013). A majority of the European citizens answered that they were very interested (13 percent) or fairly interested (40 percent). Notably, fewer people (40 percent) said that they felt informed about developments in science and technology (6 percent felt very well informed, 34 percent fairly well informed). However, large national differences did emerge among the countries participating in the ORION project (Figure 1 on page 14).

In Special Eurobarometer 401, the respondents were also asked about the level of involvement they

6 The reports from these surveys can be accessed through: <https://ec.europa.eu/research/openscience/index.cfm?pg=open-science-policy-platform>

7 See e.g. Special Eurobarometers numbers 9, 11, 43, 76, 154, 224, 340, 401, 419.

believed citizens should have in decision-making about science and technology. More than half of the Europeans (55 percent) were of the opinion that public dialogue is needed when it comes to decisions about science and technology. On a European average, four out of ten (39 percent) thought that citizens should be consulted and that their opinion should be considered regarding decisions about science and technology. Twelve percent of the Europeans believed that citizens should have an active role in decision-making on science and technology, and four percent even thought that the citizens' opinion should be binding. Figure 2 on page 15 shows how citizens in the countries participating in ORION responded to this question. The Eurobarometer also demonstrates a positive relationship between how informed a citizen feels about science and technology and the opinion that public dialogue is required in decision-making about science and technology (in the sense that the more informed the respondents feel, the more they believe that public dialogue is required).

Europeans' views on open access were also examined in Special Eurobarometer 401. A vast majority (79 percent) of the respondents was of the opinion that results from publicly funded research should be made available online free of charge (ei-

ther to the general public, to other researchers or to industries). Ten percent of the European citizens responded 'no' and an additional ten percent responded 'don't know'.

In 2010, issues related to life sciences were investigated in Special Eurobarometer 341. This survey was conducted with a specific focus on European citizens' awareness of, and attitudes towards, biotechnology (European Commission, 2010; Gaskell et al., 2011). The results show that, on average, 53 percent of the Europeans believed that biotechnology and genetic engineering would have a positive effect on the way of life for the following 20 years. Among the ORION countries, the positive responses ranged from 42 percent in Germany to 72 percent in Sweden. A number of questions were dedicated to genetically modified foods. These revealed an overall suspicion towards this technique with 70 percent agreeing that genetically modified food is unnatural and 61 percent feeling uneasy about the subject. Further, there were mixed views towards genetic engineering. Forty-three percent agreed and 45 percent disagreed with the statement that introducing resistance genes into plants (from different species) is a good idea. Among the ORION countries, those in agreement ranged from 39 percent (Italy) to 52 percent (UK). The proportion of posi-

Figure 1: Interest and sense of being informed about developments in science and technology as responded by citizens in ORION-collaborating countries. Based on data from Special Eurobarometer 401 (European Commission, 2013).

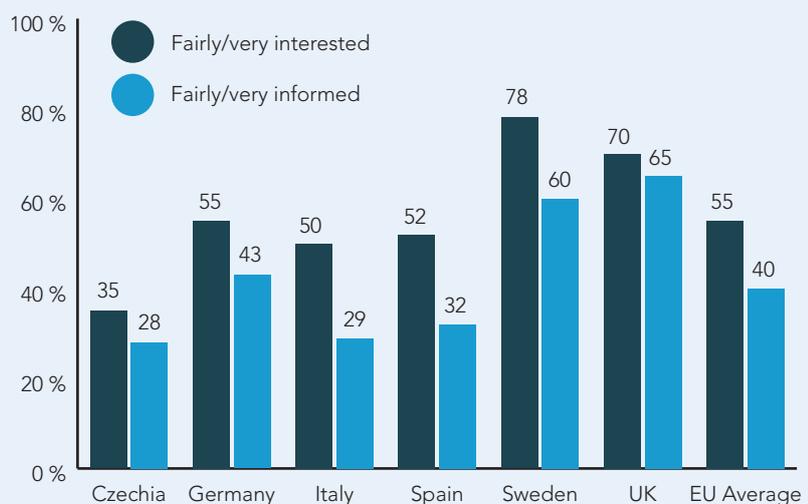
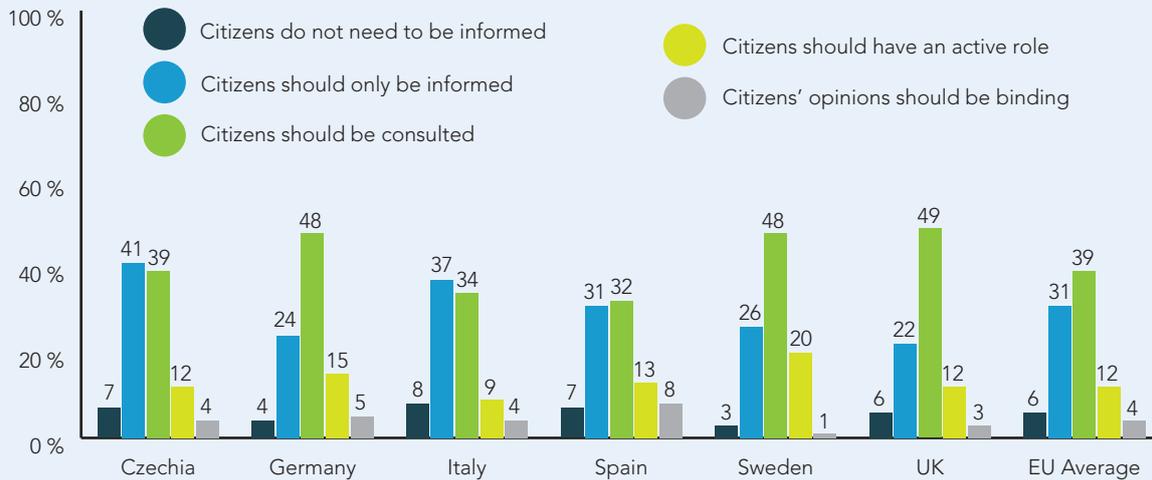


Figure 2: Level of involvement citizens should have when it comes to decisions made about science and technology, as responded by citizens in ORION-collaborating countries (non-valid responses and 'Don't know' are not shown). Based on data from Special Eurobarometer 401 (European Commission, 2013).



tive citizens decreased with rising age. The respondents were also asked about what issues on synthetic biology that they would like to know more about. The topics of most interest were all related to what the risks and benefits are and who will bear them.

In *Special Eurobarometer 224: Europeans, Science and Technology* (European Commission, 2005), the Europeans were asked about their ways of accessing information on issues related to science and technology.⁸ According to the results from the survey, the Europeans seem very keen on informing themselves about science and technology, mainly by reading articles on science in newspapers, magazines or on the internet. Nineteen percent of the Europeans claim to do this on a regular basis, and 40 percent do this occasionally. Another way to become informed about science and technology is through visiting sci-

ence and/or technology museums, which 16 percent of the respondents had done over the past year. The same question was asked to the European public in surveys 2001 (European Commission, 2001) and 2002 (European Commission, 2003). These surveys show a slight increase in the number of people that visited science and/or technology museums annually, from 11 percent in 2001 and 8 percent in 2002, to 16 percent in 2005.

National surveys

The Eurobarometers mentioned above provide comparable results across the European national contexts. Moreover, there are national surveys in several European countries, including most (but not all) of the countries participating in the ORION project.

⁸ Note that this survey was performed over ten years ago and that the results, due to the changing media landscape, should be interpreted with caution.

These surveys bring up important findings of relevance for the development of future project-related activities within ORION. Results of particular relevance to ORION (related to interest, confidence and/or involvement in science), from surveys that have been conducted in the participating countries, are presented below.

Public attitudes to science is a series of studies looking at attitudes to science, scientists, and science policy among the public in the UK. The latest survey was conducted in 2014 and was preceded by similar studies in 2011, 2008, 2005 and 2000. The survey from 2014 (Castell et al., 2014) consisted of a representative sample (1,749 answers) of the UK population aged 16 and up, together with a booster survey of 315 16–24-year-olds.

UK citizens have a positive view on science and see it as an important contributor to society. A vast majority (81 percent) agrees with the statement ‘On the whole, science will make our lives easier’. Half of the population (55 percent) agrees, and 16 percent disagrees, with the statement that ‘the benefits of science are greater than any harmful effects’. However, more than half of the UK population thinks that ‘people shouldn’t tamper with nature’, and a third (34 percent) thinks that ‘science makes our way of life change too fast’.

The UK survey also investigates the public’s opinions on being involved in science. The results strongly indicate that UK citizens are keen on becoming involved in science and there is a desire for more public participation in dialogues about science and technology issues. An overwhelming majority (88 percent) agrees with the claims that ‘those who regulate science need to communicate with the public’, and that ‘scientists should listen more to what ordinary people think’ (69 percent). It is also worth mentioning that, even though a vast majority want to see more dialogue and more public influence on decision-making in science and technology, far from everybody wants to get involved personally. Forty-three percent say that they

would like the public to be involved in decision-making about science issues but would not like to be involved themselves, while an additional quarter (24 percent) are not interested in being involved personally.

The German survey *Wissenschaftsbarometer* has been conducted annually since 2014 by the German non-profit organisation Wissenschaft-im-Dialog. The latest survey from 2017 included a question on whether the German public believe it is important that citizens are involved in the formulation of research questions. More than half of the respondents (56 percent) agreed on this. In accordance with the results from the UK, fewer people would like to be personally involved in science. Forty percent of the respondents said that they would like to participate in a research project (Wissenschaft im Dialog/Kantar Emnid, 2017).

In Sweden, the non-profit organisation Vetenskap & Allmänhet, VA (Public & Science)⁹ has conducted annual surveys on the public’s attitudes to science and technology since 2002. The results are published in the annual *VA Barometer* and are based on a representative sample of the Swedish population aged 16–74. The Swedish surveys show that confidence in researchers is high in Sweden. Nine out of ten Swedes have fairly or very high confidence in researchers at universities (six out of ten gave a similar response for researchers working in companies). Swedish citizens also have a positive view on how the scientific and technological developments impact society. Ever since the first survey in 2002, approximately eight out of ten respondents think that the scientific and technological developments in the last 10–20 years have made life better for ordinary people. The *VA Barometer 2016/2017* (Vetenskap & Allmänhet, 2016) confirms the previously mentioned Eurobarometer findings that interest in science is higher than the self-perceived knowledge.

In the *VA Barometer 2014/2015* (Vetenskap & Allmänhet, 2014) and the *VA Barometer 2015/2016*

9 VA (Public & Science) is one of the partner organisations in the ORION project.

(Vetenskap & Allmänhet, 2015), Swedish citizens were asked about potential involvement in research and innovation processes. Nine out of ten Swedes considered it important to involve the public in research, and approximately six out of ten would like to be personally involved. Here we can also see the effect of level of education, where two-thirds of the university graduates believe public involvement in science to be important (and would also like to be personally involved), but only half of those with compulsory-level or upper secondary education share this opinion.

The Italian research centre *Observa Science in Society* publishes annual data on public perceptions on science and technology in *Annuario Scienza Tecnologia e Società* (Bucchi & Saracino, 2017). In the edition from 2017, 1,002 citizens aged 15 years and older were surveyed through a combination of telephone- and web-based interviews. The survey found that almost three quarters of Italian citizens agree with the statement that science and technology change our lifestyle too quickly. However, eight out of ten Italians have a positive view on the research and innovation taking place in national universities. When asked about different research areas where they would like to see more funding to be spent, biomedical research is most highly ranked (40 percent of the respondents). The positive views towards biomedical research were more pronounced in the lower educated groups and increased with rising age.

Seven out of ten (73 percent) of Italians agree with the claim that citizens do not understand the importance of research. Consequently, a majority of the respondents thought that the scientific community should make their own decisions regarding scientific issues, such as which areas of research need more investment. However, a third of the respondents still believed that all citizens should be part of these decisions, based on the reason that research is financed by taxes.

Since 2002, the Spanish foundation for science and technology (FECYT) has been conducting a bi-annual survey called *Percepción social de la ciencia y la tecnología*, measuring Spanish citizens' perceptions on different issues in science and technology. The latest survey was conducted in 2016 and con-

sisted of 6,357 face-to-face interviews with citizens aged 15 years and above (FECYT, 2017). When asked about their interest in science and technology, 40 percent responded that they were fairly or very interested. This result is almost ten percentage points lower than the Spanish result from Special Eurobarometer 401 (Figure 1). A positive perception of science was more common among men from 25 to 54, citizens with a higher education level and residents of cities with 50,000 to 500,000 inhabitants. A majority (54 percent) of Spanish citizens considered that the benefits of science and technology are greater than the detriments, while only six percent thought that the damages are greater than the benefits. However, when asked specifically about genetically modified plants and cloning, a majority believed that the damages outweighed the benefits.

Regarding public involvement in science and technology, 65 percent of Spanish citizens agreed strongly or quite strongly that decisions on matters of general interest related to science and technology are better left to the experts. However, when it comes to decisions about science and technology that directly affect citizens, 52 percent agreed strongly or quite strongly that citizens should have a more important role.

Implications for the present study

The overview of existing surveys illustrates that some information of relevance for ORION (such as public views on involvement in research) has previously been investigated in surveys based in one or several of the participating countries, or in previous Eurobarometers on science and technology. Several of the mentioned surveys focus on people's hopes and expectations on science, and opinions on whether science and technology have the ability to contribute positively to the future development of society. The results show that the general public has an optimistic perception of what science and technology can do for humanity, often in terms of medical developments, improvements to the quality of citizens' lives and the prospects for forthcoming generations.

Many surveys also show that there are generally high levels of confidence in scientists, especially

for those based in universities. Several surveys also identify a strong correlation between confidence in science and level of education, where citizens with a higher level of education tend to have higher levels of confidence in science and technology.

Based on the outcome of Special Eurobarometer 401, there is no doubt that the citizens of Europe think that public involvement in science is an important issue and that open and productive dialogues are desired. This is confirmed in national surveys from both Sweden, Germany and the UK. Furthermore, more than one out of ten Europeans is of the opinion that citizens should have an active role in decision-making about science and technology.

Even though the findings from previous surveys strongly support the view that citizens put hope into science and technology, and that the confidence in scientists is high, there is also a concern that scientists' influence on future development can be misused or even dangerous. Over the last few years, vast developments in life sciences have raised general concerns among the public about the applications of genomics in certain fields, such as the ability to alter the genome of organisms. Further in-depth studies are needed to explore how these concerns can be efficiently discussed.

To be able to properly implement ORION's objectives, the project needs updated knowledge of

citizens' views on life sciences research in general as well as a more detailed understanding of their opinions on personal involvement in life sciences research. Moreover, the data need to be comparable across all six national contexts to allow for reproducibility in upcoming activities. To accomplish these objectives, four research questions were formulated to guide the design of the survey:

1. What levels of (a) interest and (b) confidence do the citizens in the participating countries have towards life sciences research?
2. What do citizens in the participating countries want to know more about regarding life sciences research?
3. To what extent and under which circumstances do citizens in the participating countries want to be personally involved in life sciences research?
4. What hopes and concerns do citizens in the participating countries have towards genome editing?

2. METHOD

DEVELOPING THE QUESTIONNAIRE

The public survey of the ORION project aims to expand the existing knowledge of public preferences on engagement with life sciences research. The questionnaire used in the public survey partly builds upon existing data and literature on public engagement with science (see previous chapter). Moreover, it addresses several gaps in existing knowledge, for instance by including items asking about public preferences on involvement in life sciences research processes, or opinions about the highly topical technique of genome editing. The items in the questionnaire were developed in multiple stages in collaboration with all institutions involved in the ORION project and were centered on attitudes towards, and public engagement with, life sciences research.

The questionnaire (see Appendix B for all language versions) consists of three main parts. The first part includes questions on sociodemographic characteristics and general attitudes to life sciences research. These questions collected information about respondents' age, gender, level of education, interest and confidence in life sciences research, and whether the respondents' job is related to research. The second part contains questions on preferences on personal engagement with science regarding different topics and stages of research. The third part investigates citizens' familiarity with genome editing and opinions on future developments of this technique. The response items were rotated when the nature of the question allowed for it.

DATA COLLECTION

The data collection in all six countries involved in ORION (Czechia, Germany, Italy, Spain, Sweden, and the UK) was carried out by Nio Field Service, a field service institute based in Germany. The company was involved in the preparation of the questionnaire in local language versions. The English master questionnaire was translated into five languages and all language versions were a) reviewed and finally approved by an expert panel including native speakers, and b) piloted on at least five re-

spondents from a given country (in Germany, 30 pilot interviews were conducted).

Nio Field collected data through Computer-Assisted Telephone Interviewing (CATI) conducted on six nationally representative samples of respondents chosen by Random Digit Dialling (RDD). Proper ratio of landlines and mobile phones and margined quota on age, gender, and level of education were specified for each country. Common ethical standards were followed during

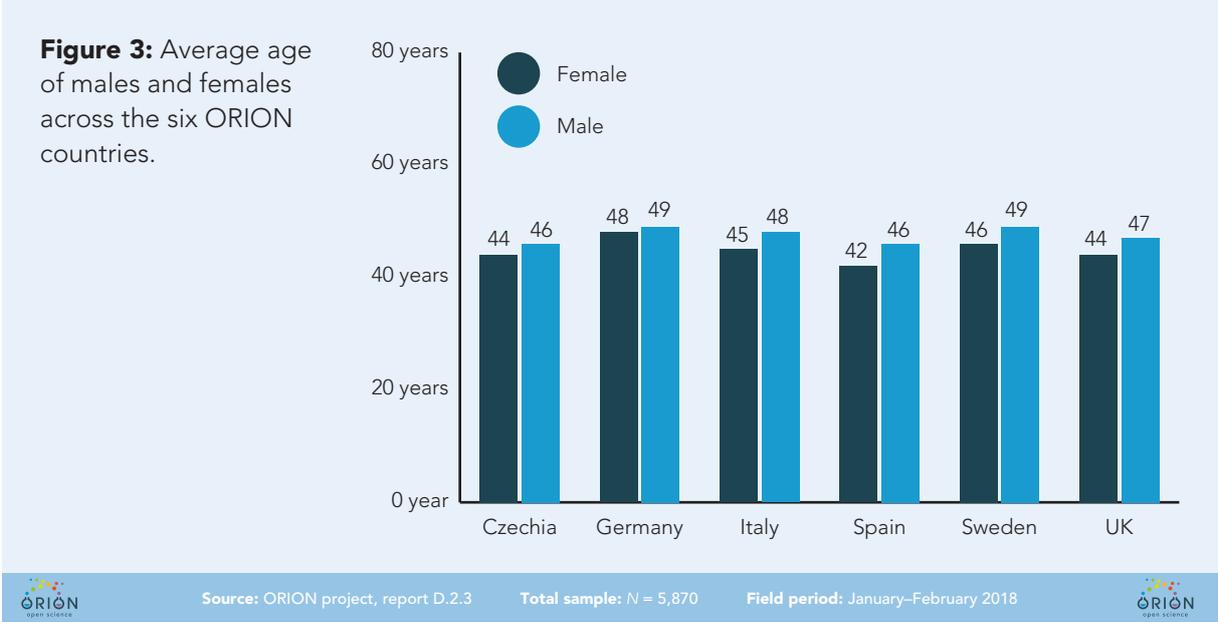
the data collection – each respondent was free to end the interview at any time and had an opportunity to skip any question (which was the main source of missing values). Telephone interviews were conducted between 25 January and 28 February 2018. The agency delivered exactly one thousand completed interviews for each country. These data were cleaned by the ORION project team. In this process, data from 130 cases were excluded due to their tendency to use the same answers through the whole interview. Subsequently, the final dataset contains data from 5,870 respondents. A more detailed description of the sample follows in the next section.

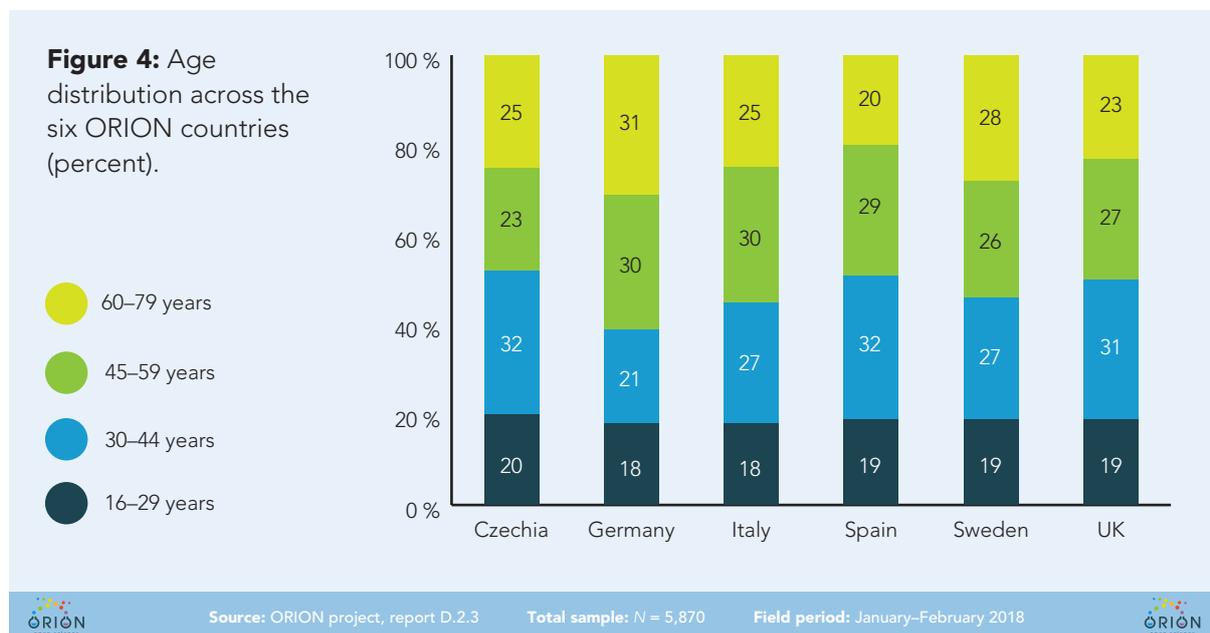
In short, the employed procedures in terms of sampling (combining RDD and population quota), validation of translations, piloting of national versions, and data collection were conducted by the same agency in the same way for all countries. This procedure ensured that results based on the delivered data could a) be generalised to national samples and b) be used for investigating differences between countries. However, it should be kept in mind that due to the heterogeneous character of the ORION countries, the findings for the pooled sample cannot always be generalised across the nations. Neither is it possible to generalise the findings on Europe as a whole.

SAMPLE

In total, the final sample consisted of data from 5,870 respondents which comprise representative national samples from six European countries. The distribution across countries is as follows: Czechia $n = 997$ respondents (corresponding to 17 percent of the total

sample), Germany $n = 986$ (17 percent), Italy $n = 970$ (17 percent), Spain $n = 961$ (16 percent), Sweden $n = 992$ (17 percent) and the UK $n = 964$ (16 percent). The distribution of major individual characteristics, namely gender, age, level of education and whether





the respondents have a job related to research, are described for each country.

Gender

The distribution across gender was roughly equal and almost identical to gender ratios of the target populations aged 16–79. More precisely, there were slightly more women in Czechia (53 percent), Spain (51 percent), and Sweden (53 percent), while the other countries had a 50/50 gender distribution.

Age

The average age of respondents ranged from 44 to 48 years across countries (Figure 3), with a minimum of 16 years and a maximum of 79 years. Specifically, the average age of Czech respondents was 45 years, of German respondents 48, of Italian respondents 46, of Spanish respondents 44, of Swedish respondents 47, and of respondents from the UK 45. In all countries, men were slightly older than women.

The respondents were clustered into four age groups: 16–29 years; 30–44 years; 45–59 years; and

60–79 years. The percentage distribution of these groups (Figure 4) did not differ substantially across country and all differences from the target population were within the range of pre-defined margins.

Level of education

The sample consisted of 1,487 respondents with primary education as the highest completed level of education, 2,712 respondents with secondary education, and 1,671 respondents with tertiary education. These three categories were derived from country-specific types of education according to ISCED categorisation. The respondents chose from all country-specific categories of education (Appendix C) and were clustered into three levels afterwards.

Figure 5 shows the distribution of the levels of education across the sample. Most respondents in Czechia, Germany, and Sweden obtained secondary education (varying from 48 to 68 percent), whereas primary education prevailed in Italy and Spain (42 and 46 percent respectively), and tertiary education (42 percent) in the UK. Hence, national samples were quite heterogeneous in terms of education level.

Figure 5:
The highest levels of education across countries (percent).

- Tertiary
- Secondary
- Primary

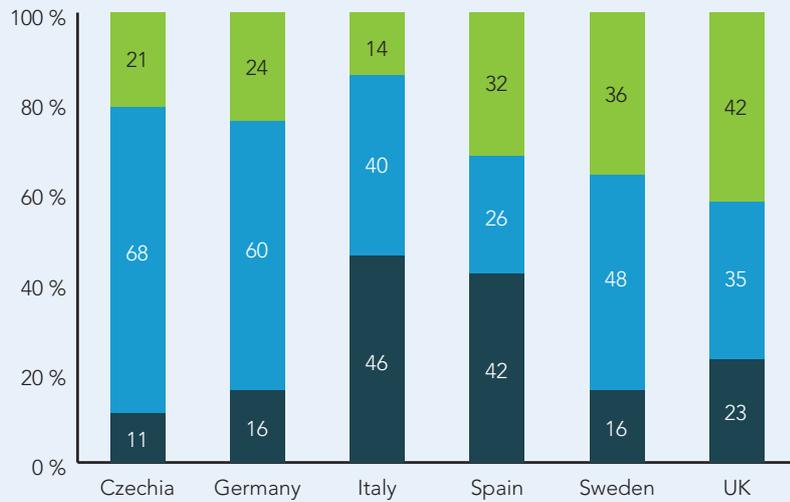


Figure 6: Whether respondents have a job related to research (percent).

- No
- No, but it has been in previous positions
- Yes, my work is related to research, but I am not a researcher
- Yes, I work as a researcher



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



Job related to research

The respondents were asked the question ‘Is your work related to research?’ and chose from categories of working as a researcher (meaning various academic positions); work related to research (publisher, funder, research-based industry, professional organisation); and previous work related to research. The majority of respondents (from 84 to 96 percent) did not have a job related to research (Figure 6). Only a small number of respondents currently worked as researchers (from 0 to 5 percent across

countries), or their work was related to research in a current (from 1 to 6 percent across countries) or previous position (from 2 to 6 percent across countries). The number of respondents with a job related to research substantially differed across countries, with the highest percentage (16 percent) in the UK and lowest (4 percent) in Czechia. Altogether, two groups based on this variable are used in the analysis – 553 respondents (9 percent) with a job related to research in some way and 5,317 respondents (91 percent) without a job related to research.

STATISTICAL PROCEDURES

This report provides descriptive analyses focused on people's interest and willingness to engage with life sciences research as well as perceptions of the genome editing technique. All basic results are sorted by country. Some more complex analyses are presented for the whole sample together, but country-specific results are produced whenever it is feasible and the same procedure is recommended to other users of the data¹⁰. As noted in the previous section, it is not always meaningful to generate the overall results and generalise them to Europe or even the group of six different countries. Moreover, if mea-

ningful, results have been structured according to selected individual factors, including gender; age; level of education; job related to research; interest in life sciences research; and confidence in life sciences research. The findings are presented predominantly as percentage distributions. Due to the large sample size, which affects the p-values, we do not report results of significance tests (for instance, differences as small as three percentage points were found to be significant). Our intention is to focus on the substantial meaning of the results rather than introducing an additional layer of statistical tests.

10 The ORION project participates in the Open Research Data Pilot of Horizon 2020, and in consequence the data generated by this survey will be made freely available through a research data repository hosted by the ORION coordinator CRG, Centre for Genomic Regulation, in Spain.

3. FINDINGS

In this chapter, the results of the ORION survey will be presented. Questions related to *interest and confidence in life sciences research* are presented in the first section. This is followed by findings related to citizens' views on *personal involvement in life sciences research*. Finally, citizens' *awareness and concerns related to genome editing* are presented. As explained in the methods chapter, the results are presented in a straightfor-

ward way focusing on substantial meaning rather than statistical tests. However, all differences highlighted in the report are statistically significant. All figures are cleared from missing values (which varied from 60 to 250 for different questions), and thus all categories such as 'yes' and 'no' together result in 100 percent. More detailed results for each individual country are presented in dedicated country sheets in Appendix A.

INTEREST IN, AND CONFIDENCE ABOUT, LIFE SCIENCES RESEARCH



First a question on how interested you are in life sciences research.

Are you ...

- ▶ Very interested
- ▶ Fairly interested
- ▶ Neutral
- ▶ Not very interested
- ▶ Not at all interested

General interest

Interest in life sciences research is generally high in all countries, with the majority of respondents being fairly (38–48 percent across countries) or very (14–43 percent across countries) interested (see Figure 7). The highest level of interest is found in Italy with 91 percent being fairly or very interested in life sciences research, which is only true for 52 percent of the Czech respondents.

It can be noted that the small proportion of respondents with a job related to research are consid-

erably more interested in life sciences research than those who do not have a job related to research – 53 percent of people with a job related to research are very interested compared to 24 percent of those without a job related to research. This tendency is found within all national contexts.

Gender

The whole sample taken together, respondents' interest in life sciences research does not differ between women and men or between age groups. However, the same analysis broken down by country reveals higher interest among men in the UK, Sweden, and Czechia (the respective differences between very and fairly interested men and women are seven, eight and ten percent), while gender differences seem smaller in Germany, Italy and Spain. Additional analyses show that this difference cannot be explained by differences in level of education or by having a job related to research.

Figure 7: Interest in life sciences research across countries (percent).

- Very interested
- Fairly interested
- Neutral
- Not very interested
- Not at all interested

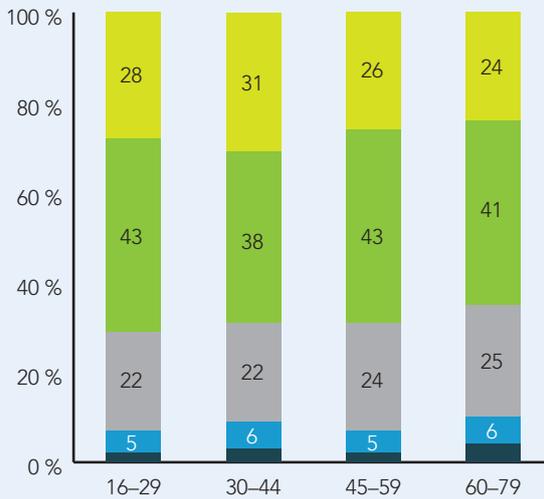
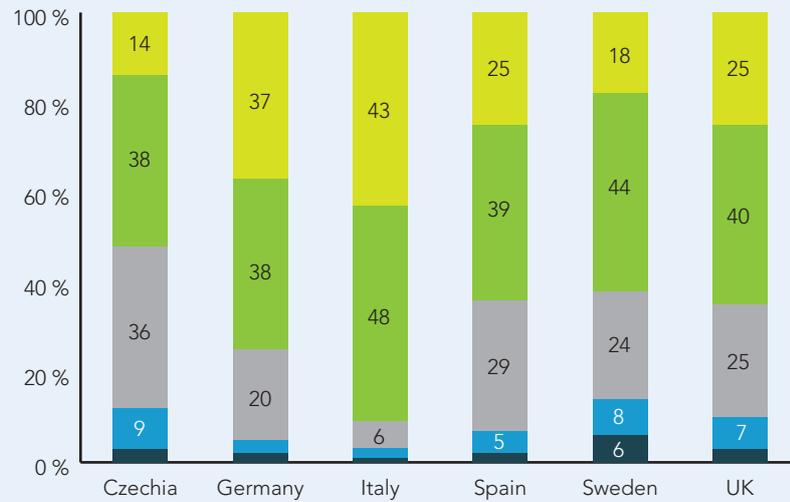


Figure 8: Interest in life sciences research in relation to age (percent).

- Very interested
- Fairly interested
- Neutral
- Not very interested
- Not at all interested



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



Age

As seen in Figure 8, the age group with the highest interest in life sciences research is 30–44-year-olds, whereas the least interested age group is the oldest (60–79-year-olds). Although these results are statistically significant, Figure 9 and additional statistical tests show that country of origin has a stronger effect on respondents’ interest than age. Furthermore, the oldest group is as interested as younger age groups in Italy and even more interested in Czechia.

Level of education

When it comes to level of education, the respondents with a tertiary education show a slightly higher interest in life sciences research (77 percent, compared to 65 percent for respondents with an upper secondary education and 66 percent for those with primary-level education, see Figure 10).

When the figures are broken down to show differences between countries and between levels of education, the results are more diverse, as illustrated by Figure 11. Compared to the differences

Figure 9: Interest in life sciences research in relation to age and country (percent).

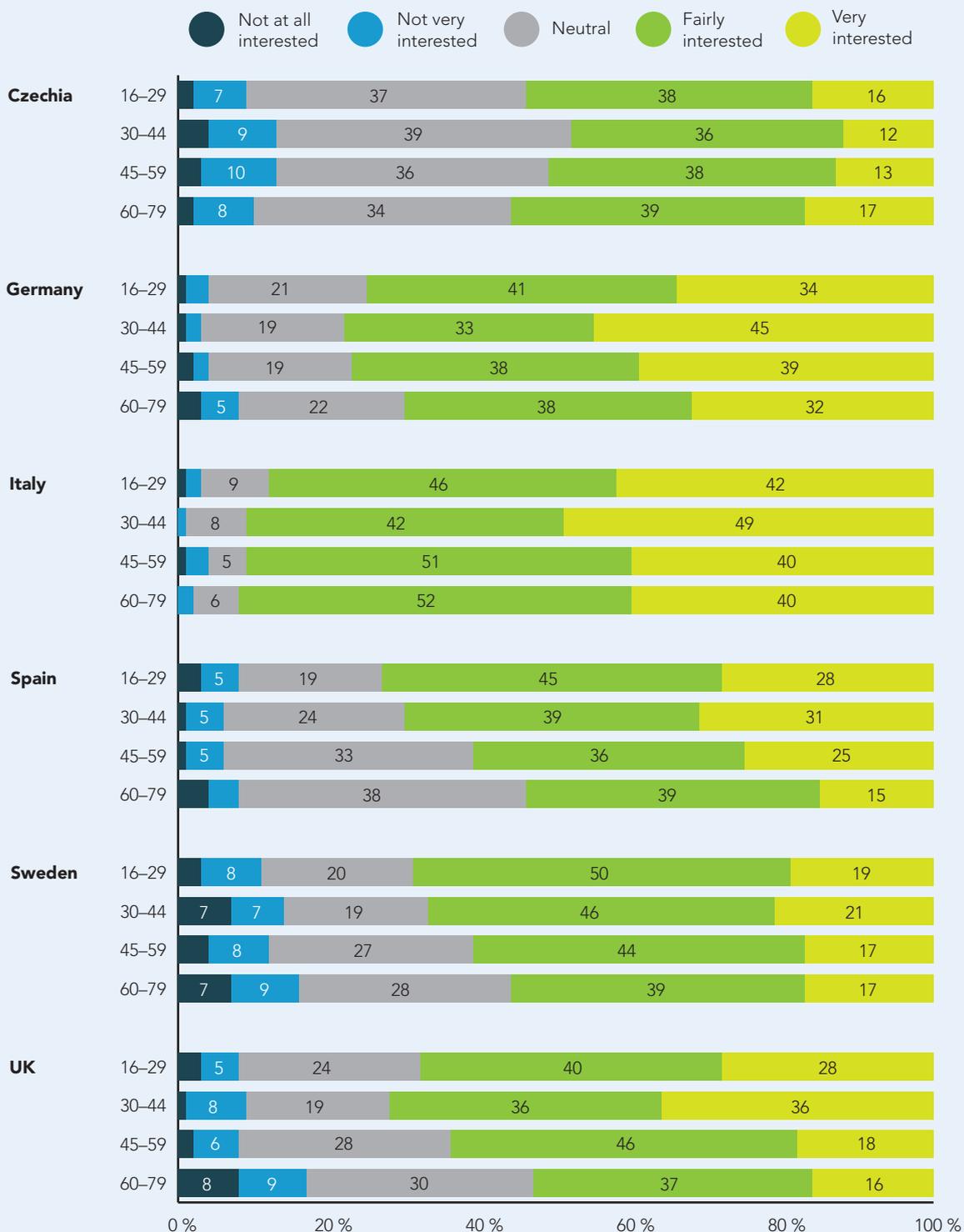
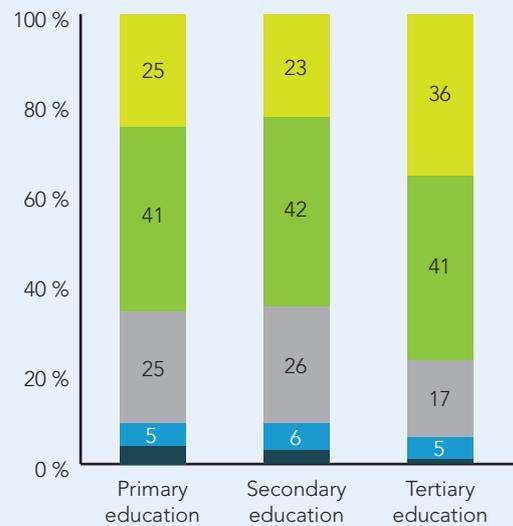


Figure 10: Interest in life sciences research in relation to level of education (percent).

- Very interested
- Fairly interested
- Neutral
- Not very interested
- Not at all interested



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



among age groups, differences based on education are weak in Italy and reversed in Czechia. These findings show that interest and confidence in life sciences is shaped differently across some European countries with citizens of Czechia and Italy having different views to those from the other four countries.

Interest in specific topics



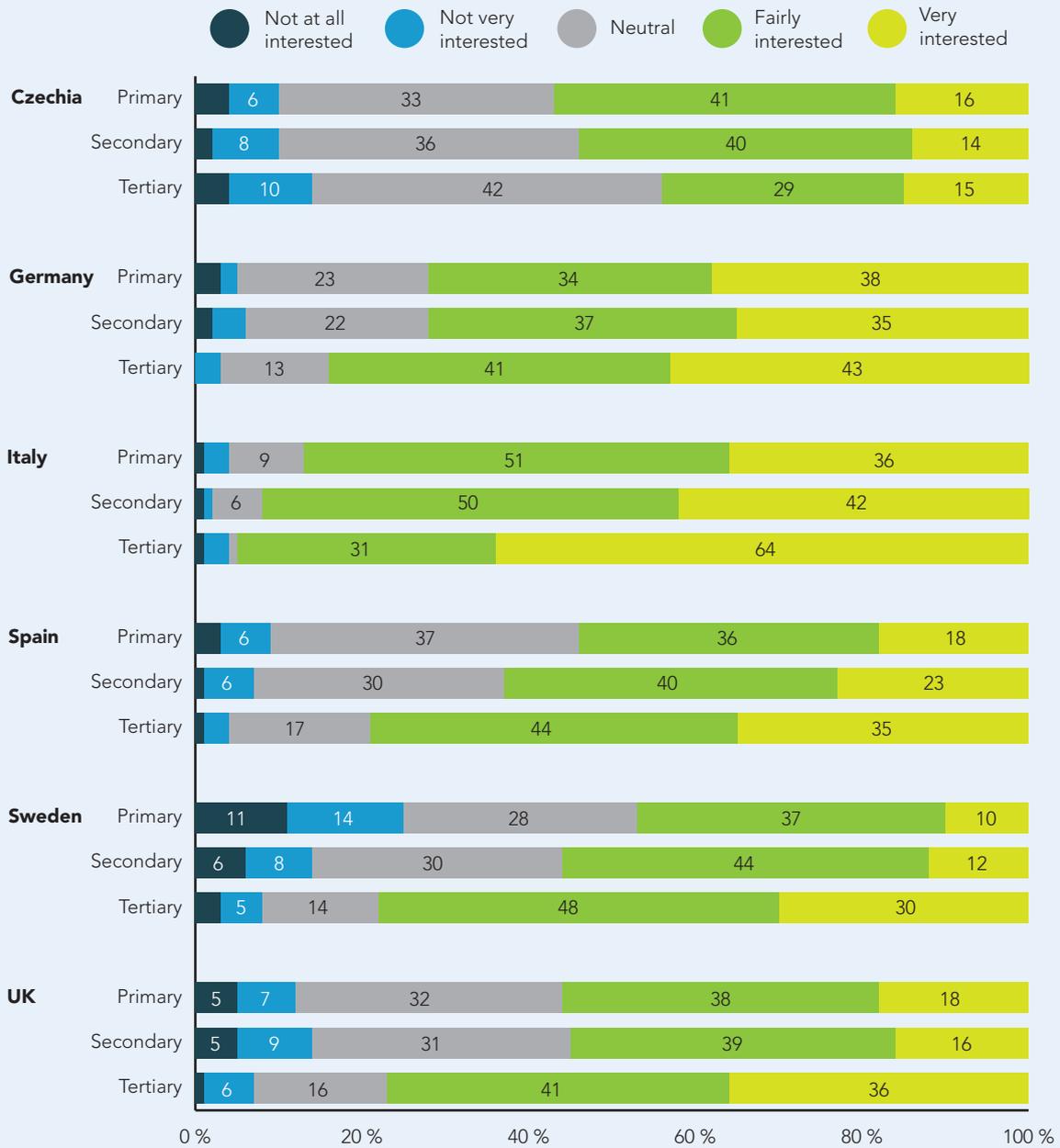
Is there anything you would like to know more about research in life sciences? (Yes/No for each option.)

- ▶ How research topics are selected
- ▶ The methods used in research
- ▶ Research findings
- ▶ Practical applications of research findings
- ▶ Ethical issues connected to the research
- ▶ The researchers themselves
- ▶ How research is funded
- ▶ How research is communicated to society
- ▶ Other

Respondents were asked ‘Is there anything you would like to know more about research in life sciences?’ with a list of items following the question. In general, respondents want to know more about research findings (87 percent); their practical applications (80 percent); research methods (76 percent); how research is communicated to society (74 percent); and how research topics are selected (70 percent). Furthermore, respondents show interest in ethical issues connected to the research (68 percent); research funding (67 percent); and researchers themselves (53 percent). Thus, the findings indicate a clear interest in opening life sciences research.

There are no large differences among countries, gender, age groups, or education, but a few points can be highlighted. Firstly, respondents from Spain and Italy show greatest interest in all categories (Figure 12). Secondly, the largest difference among countries is related to interest in researchers themselves, ranging from 40 to 78 percent. Thirdly, the smallest difference among countries is related to ethical issues connected to the research (63–77 percent) and to research findings (77–94 percent). Fourthly, there are only negligible differences between women and men as well as among age groups, with only 0–5 percent difference. Finally,

Figure 11: Interest in life sciences research in relation to level of education and country (percent).



Source: ORION project, report D.2.3 Total sample: N = 5,870 Field period: January–February 2018

as presented in Figure 13, respondents with tertiary education show greatest interest in all categories (53–88 percent), with the exception of the topics of research methods and the researchers themselves.

Figure 14 shows the proportions of very or fairly high interest in specific topics among people with different interest in life sciences. Citizens with lower interest in life sciences research score lower in all

Figure 12: Interest in specific topics across countries (percent of 'yes' answers).

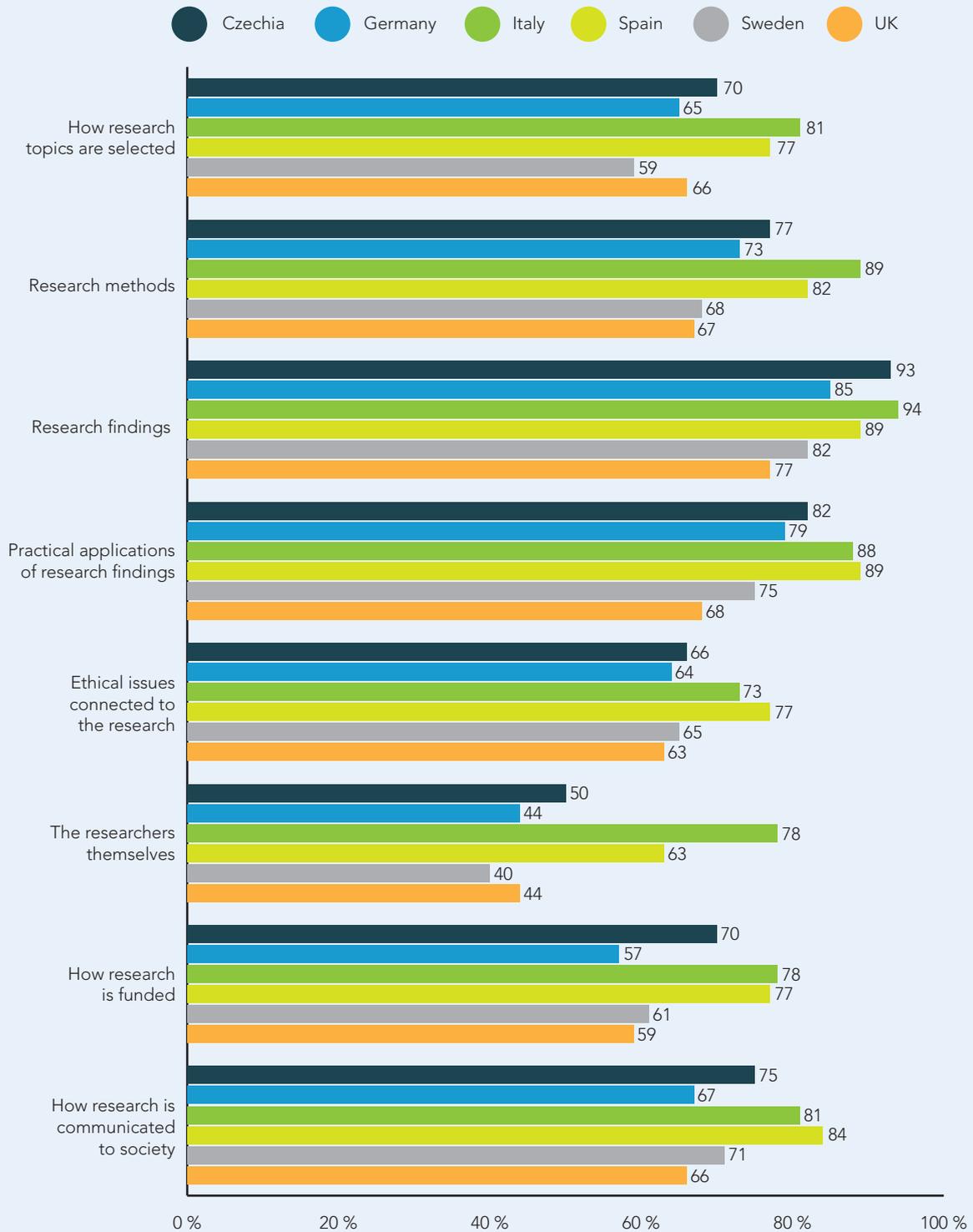


Figure 13: Interest in specific topics in relation to the level of education of respondents (percent of 'yes' answers).

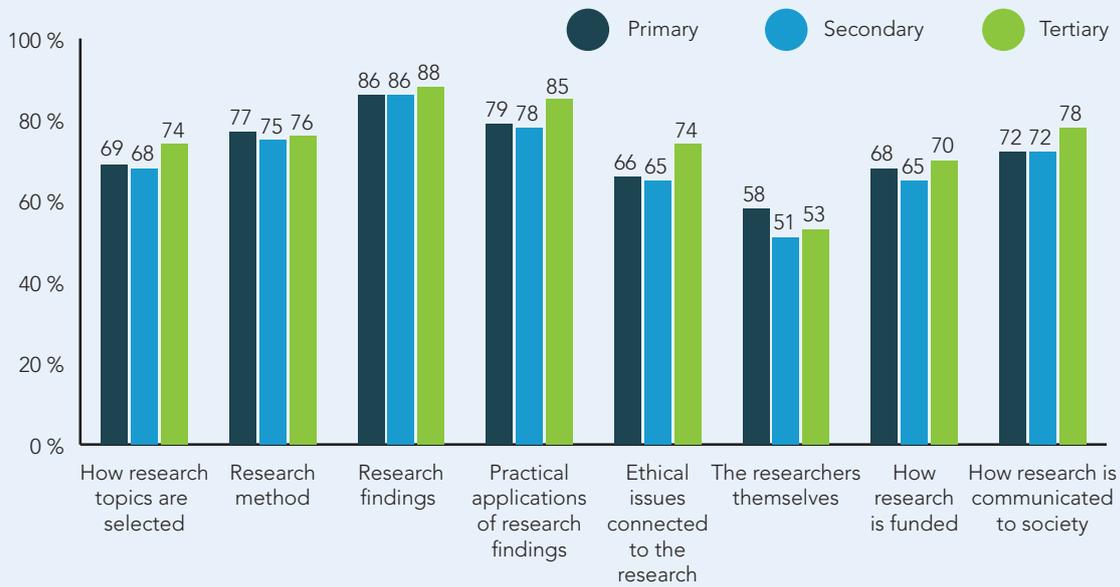
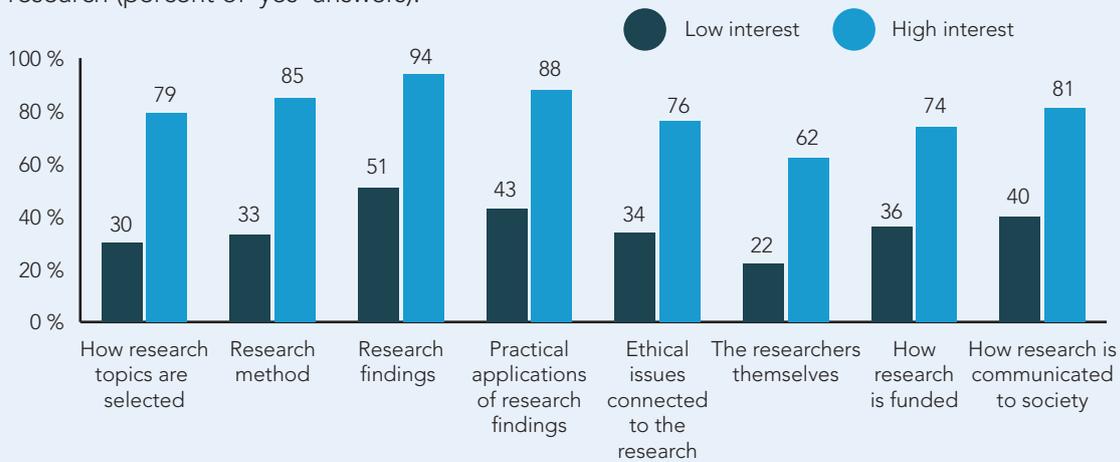


Figure 14: Interest in specific topics in relation to interest in life sciences research (percent of 'yes' answers).



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



included topics, but express a relatively higher interest in how research is communicated to society and how research is funded (third and fourth rank) than the overall sample. Hence, these two topics are relatively more attractive to those who are less interested, while those that are more interested prioritise

the stages of research such as research methods or selection of research topics (third and fifth rank, see Figure 14). Nevertheless, research findings and their practical application are the most important for people regardless of their interest in life sciences research.

Confidence



How much confidence do you have in life sciences research? Do you have ...

- ▶ Very high confidence
- ▶ Fairly high confidence
- ▶ Neutral
- ▶ Fairly low confidence
- ▶ Very low confidence

Confidence in life sciences research is generally high in all countries, with the majority of respondents being fairly (from 39 to 56 percent) or very (from 11 to 35 percent across countries) confident (see Figure 15). Italy has the greatest proportion of respondents being confident in life sciences research (91 percent) and Czechia the lowest proportion (50 percent).

Figure 16 shows that confidence in life sciences is connected to a job related to research. Eight out

Figure 15:

Confidence in life sciences research across the six ORION countries (percent).

- Very high confidence
- Fairly high confidence
- Neutral
- Fairly low confidence
- Very low confidence

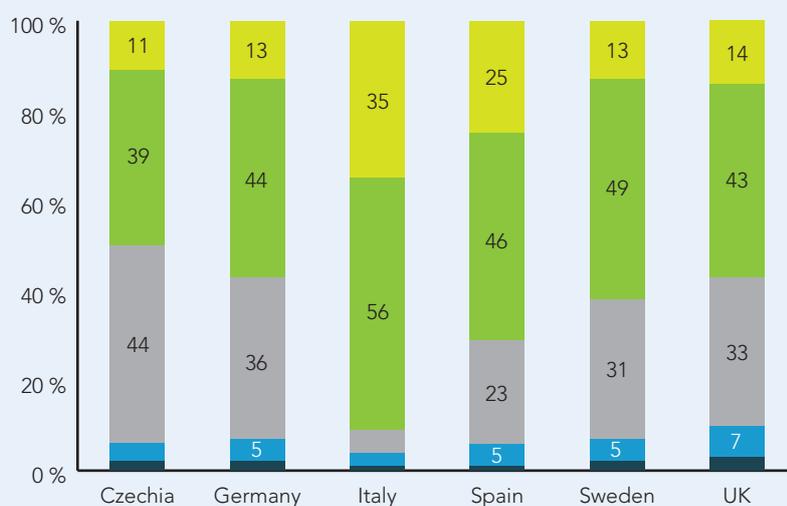
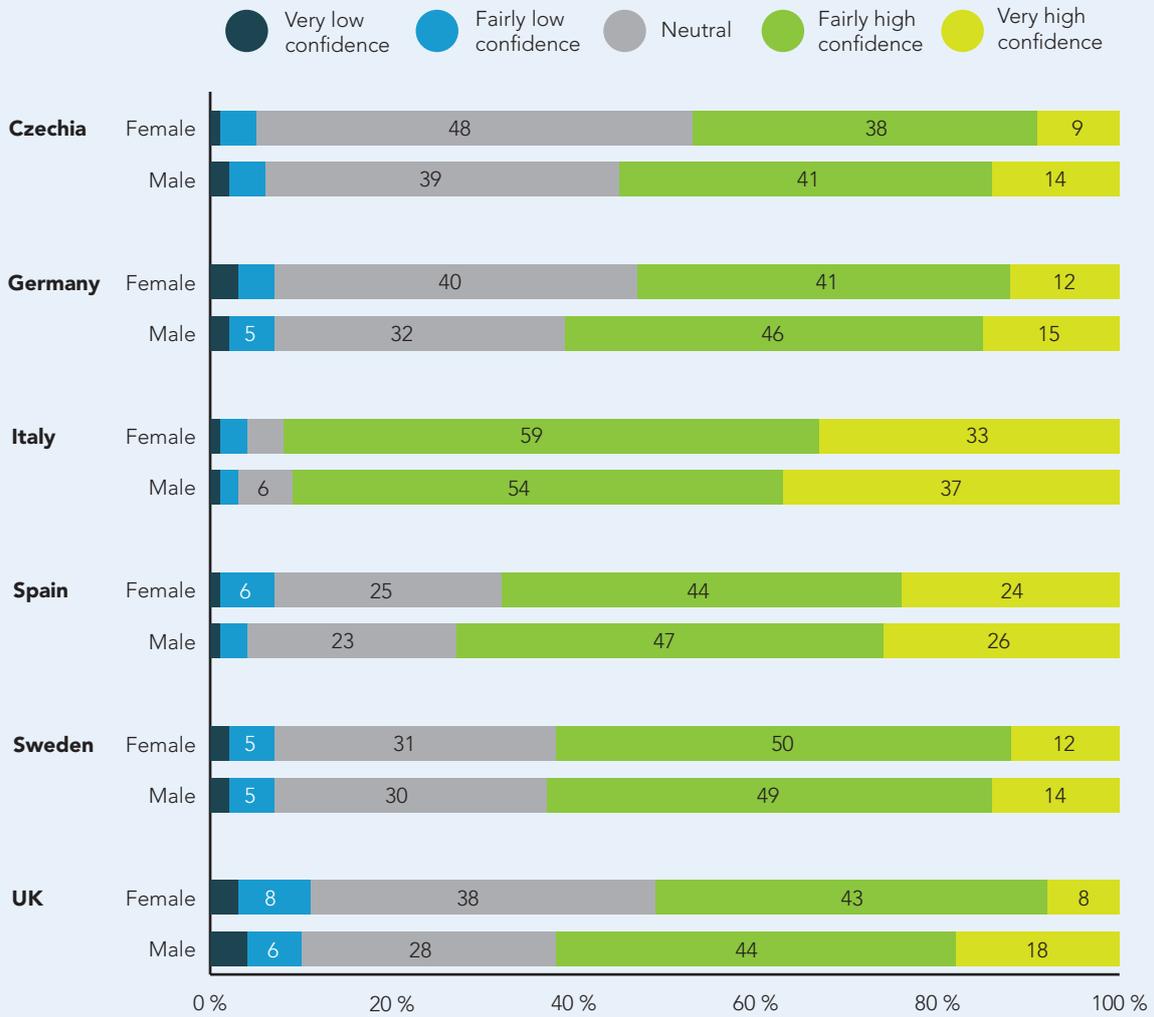


Figure 16:

Confidence in life sciences research according to respondents that either have a job related to research or not (percent).

- Very high confidence
- Fairly high confidence
- Neutral
- Fairly low confidence
- Very low confidence

Figure 17: Confidence in life sciences research in relation to gender across countries (percent).



Source: ORION project, report D.2.3 Total sample: N = 5,870 Field period: January–February 2018

of ten (82 percent) with a job related to research are fairly or very confident, but only 63 percent of those without a job related to research have fairly or very high confidence.

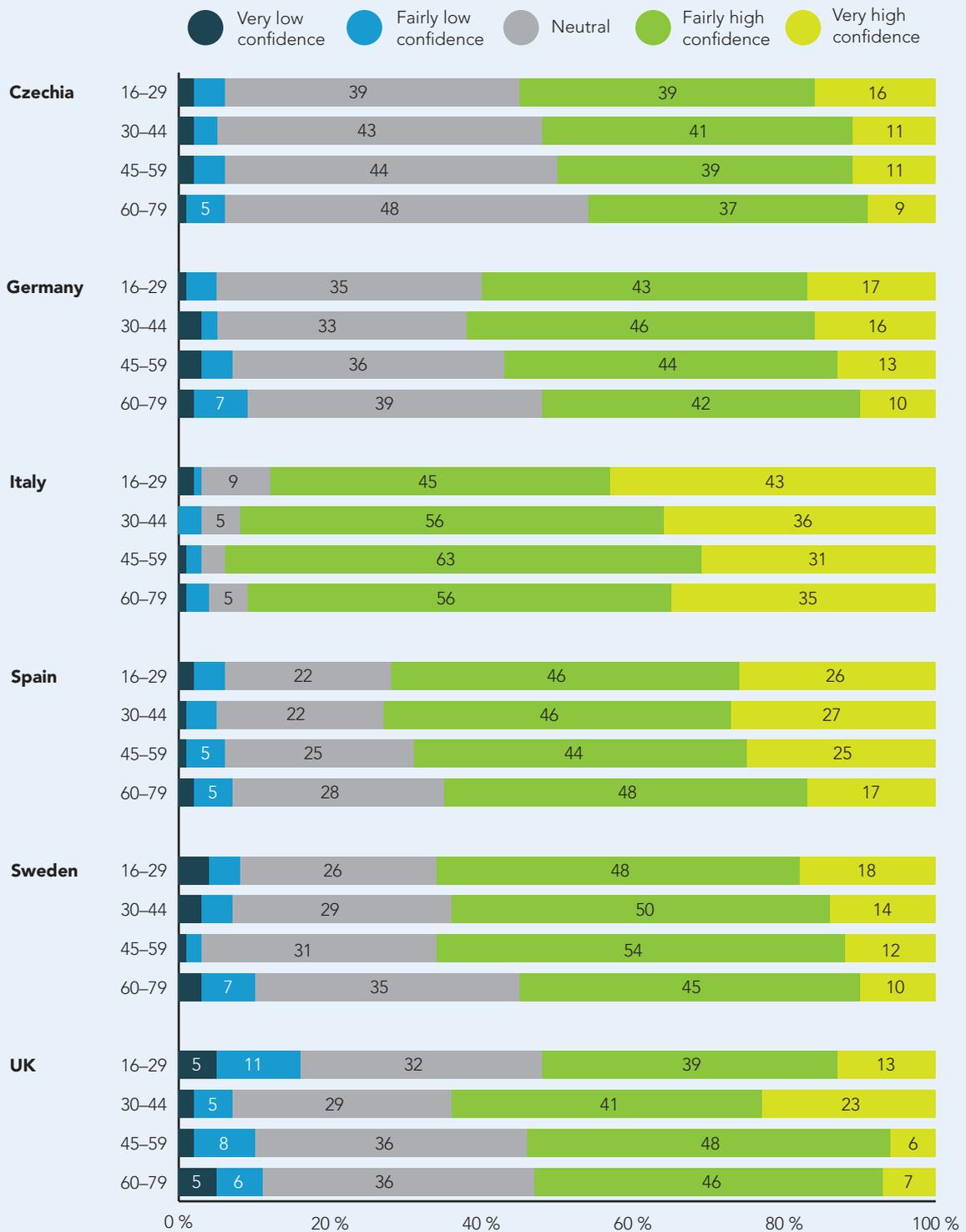
A closer look at these results also indicates that this difference is much smaller in Italy (where lay people are also very confident) and Czechia (where people with a job related to research express less confidence) than in the other four countries.

Confidence in life sciences research is slightly

higher among men (68 percent) compared to women (62 percent). The difference between gender is significant and found in all countries except for Sweden and Italy (Figure 17). Confidence is also higher among those with a job related to research in all countries except Italy.

In general, respondents' confidence in life sciences research does not differ among age groups or level of education. Still, these two characteristics play some role within country populations. Figure 18 shows that

Figure 18: Confidence in life sciences research in relation to age across countries (percent).



older people are less confident than younger people in Czechia, Germany, and Sweden, while the youngest group is the least confident in Italy. Furthermore, people with higher education have higher confidence

in life sciences research in all countries apart from Germany and Czechia (Figure 19).

Finally, respondents with a high interest in life sciences research also show high confidence in life

Figure 19: Confidence in life sciences research in relation to level of education across countries (percent).

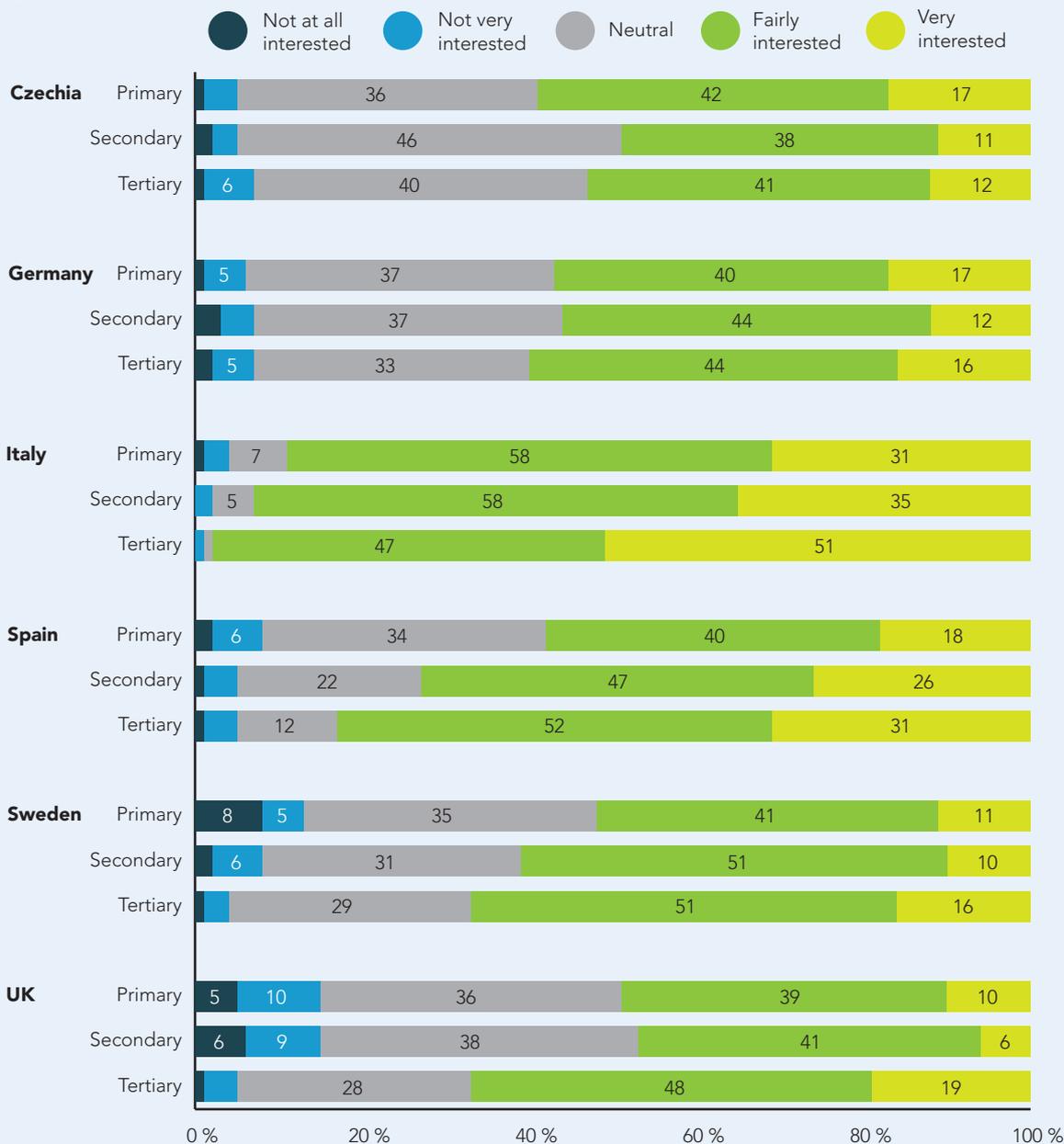
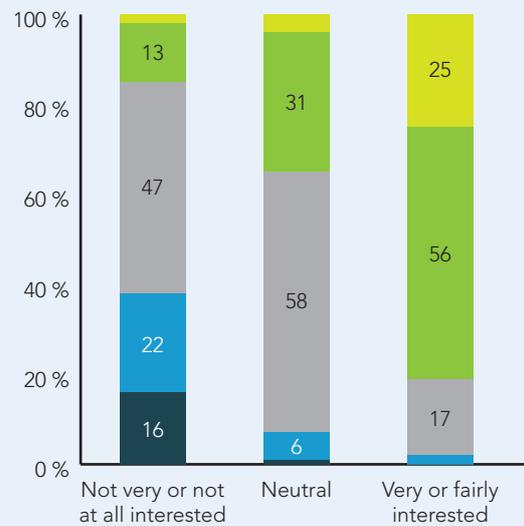


Figure 20: Confidence in life sciences research in relation to interest in life sciences research (percent).

- Very high confidence
- Fairly high confidence
- Neutral
- Fairly low confidence
- Very low confidence



Source: ORION project, report D.2.3 Total sample: N = 5,870 Field period: January–February 2018

sciences research (Figure 20). This result was expected, but its strength is notable: 81 percent of people with a high interest have fairly or very high

confidence compared to 15 percent of those with a low interest.

PERSONAL INVOLVEMENT IN LIFE SCIENCES RESEARCH

One aspect of Open Science is that various stakeholders, including citizens, are to be actively involved in the research process. In order to examine attitudes towards the involvement of the general public in life sciences research, we asked whether the respondents consider it important that the public gets involved, and also if they would consider being involved themselves.

? In your opinion, how important is it that the public gets involved in life sciences research?

- ▶ Very important
- ▶ Fairly important
- ▶ Neutral
- ▶ Not very important
- ▶ Not at all important

Is it important that the public gets involved?

The question starting this section of the questionnaire asked ‘In your opinion, how important is it that the public gets involved in life sciences

research?’ For the most part, respondents think it is fairly (37–49 percent) or very (26–52 percent across countries) important that the public gets involved in life sciences research (Figure 21). The greatest proportion of these responses is found in Italy (93 percent) and the lowest in Czechia (68 percent), which

is analogous to that of confidence in life sciences research, although Germany is placed relatively higher and Spain lower here. There were no substantial differences between women and men or age groups in any of the countries. In Sweden and UK, public involvement is seen as more important among the higher educated.

It is clear in Figure 22 that respondents with a job related to research find it more important for the public to get involved (91 percent) than respondents without such a job (79 percent). This positive relationship between a job related to research and the opinion that the public should get involved could be found in all countries except Germany and Italy.

Figure 21: Importance that the public gets involved across countries (percent).

- Very important
- Fairly important
- Neutral
- Not very important
- Not at all important



Figure 22: Importance that the public gets involved according to respondents that either have a job related related to research or not (percent).

- Very important
- Fairly important
- Neutral
- Not very important
- Not at all important

Respondents' interest in getting personally involved



Would you consider being involved personally in life sciences research?

- ▶ Yes
- ▶ No

Personal involvement of citizens in research (notably through citizen science) is an important aspect of Open Science. Respondents were asked about their willingness to be involved by the question 'Would you consider being involved personally in life sciences research?' (Figure 23). The proportion of those who believe that public involvement is important is higher than those who want to be personally involved in the research process. The number of respondents that would consider personal involvement is higher in Italy (84 percent) and Spain (77 percent), while it is lower in Czechia (39 percent). These country differences follow the same pattern as levels of interest and confidence in life sciences research within the countries.

People with a job related to research are more likely to consider personal involvement in life sciences research, which is not surprising, as they are often involved already. The differences between researchers and other citizens vary between 12 percent in Italy and 25 percent in Czechia.

Figure 24 indicates that men are more willing to engage personally than women in Czechia and the UK (differences are 11 and 7 percentage points respectively), while the differences in other countries are negligible. These results are in accordance with the higher interest in life sciences research among men in these countries.

Figure 25 illustrates that 60–79-year-olds are less eager to be personally involved (from 31 to 71 percent of them across countries agree on this matter). No clear pattern appears when comparing other age groups and there are only slight differences between these. However, in Czechia, it was found that 16–29-year-olds are willing to be involved more often than other age groups (48 compared to 39 percent).

There is no clear pattern across countries when the respondents' level of completed education is considered (Figure 26). The willingness to be involved in life sciences research decreases with education in Czechia, does not change much in Germany and Italy, and increases in Spain, Sweden, and UK. These cross-national patterns are similar to differences in interest in life sciences.

Figure 27 shows the willingness to be personally involved in the research process in relation to the respondents' views on public involvement in general. The two questions are clearly connected one to another. Those who think that involvement of the general public is fairly or very important would consider personal involvement in 72 to 86 percent of cases across countries (with the exception of Czech respondents whose corresponding number is 49 percent). In contrast, people who do not believe it is important that the public gets involved are less willing to be involved (53 percent in Italy and 9 percent in Czechia and Germany).

According to Figure 28, those interested in life sciences research are more willing to be personally involved in research. The differences in involvement between interested and uninterested citizens span from 47 percent (Czechia) to 64 percent (Sweden).

Reasons for personal involvement



People can get involved in research for different reasons. What, if any, of the following would motivate you? (Yes/No for each option.)

- ▶ Monetary or material incentives
- ▶ Public recognition
- ▶ If people I know were involved
- ▶ A belief that my involvement would help society
- ▶ If the research topic was interesting to me

Life sciences research needs to engage with various types of citizens. This can be facilitated by a more thorough knowledge of the functional motivations to participate in research among different groups

Figure 23:

Interest in getting personally involved across countries (percent of 'yes' answers).

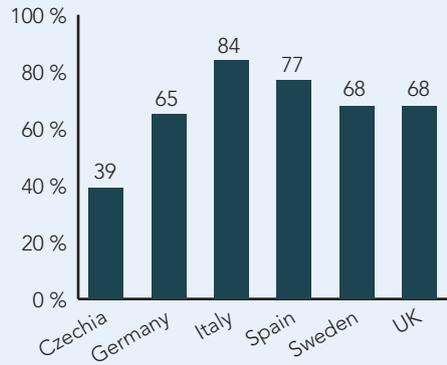


Figure 24:

Interest in getting personally involved in relation to gender across countries (percent of 'yes' answers).

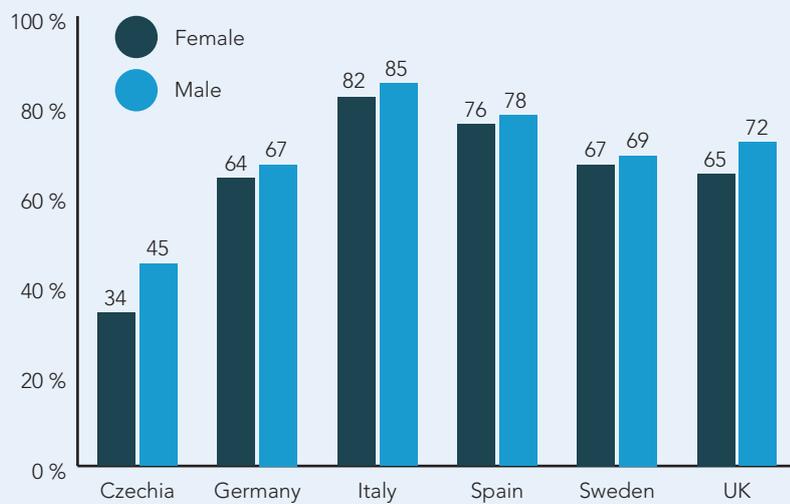


Figure 25: Interest in getting personally involved in relation to age across countries (percent of 'yes' answers).

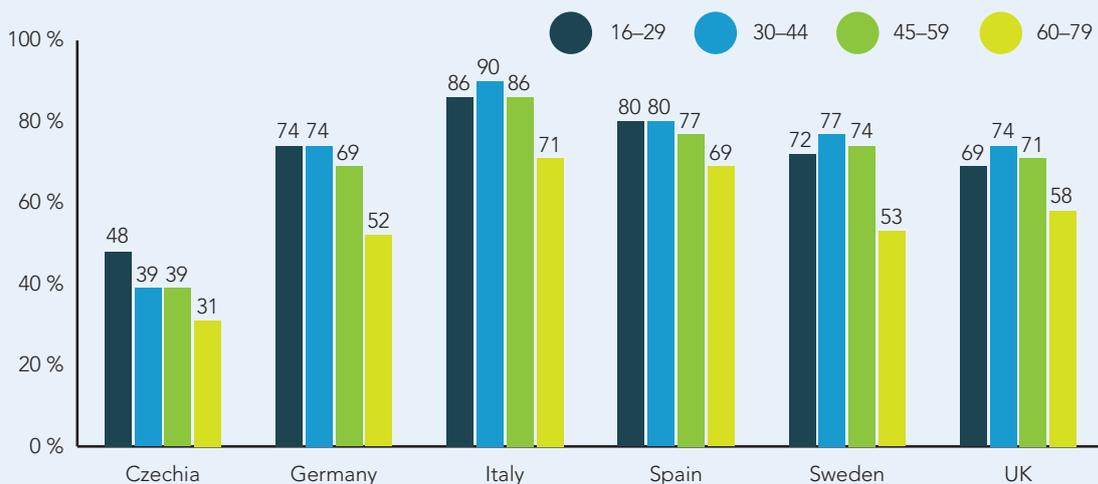


Figure 26: Interest in getting personally involved in relation to the level of completed education across countries (percent of 'yes' answers).

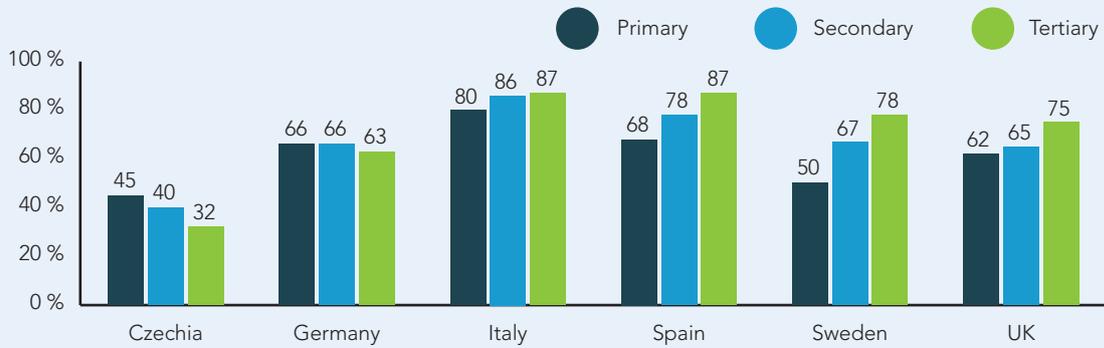


Figure 27: Interest in getting personally involved in relation to the importance of public involvement across countries (percent of 'yes' answers).

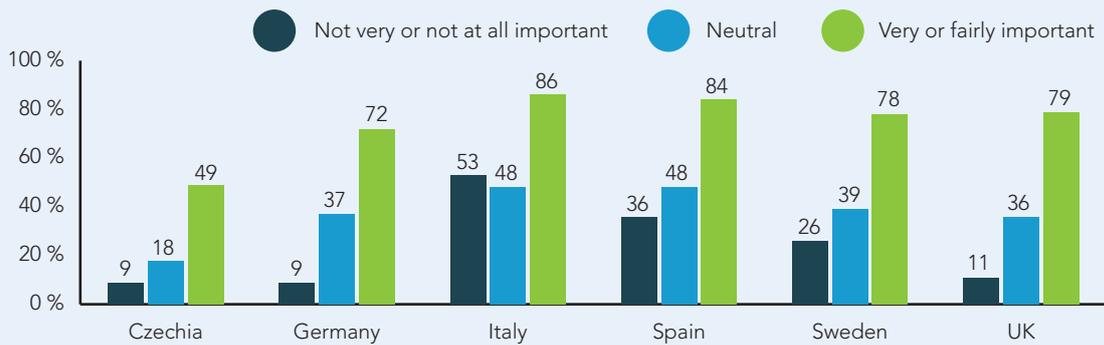
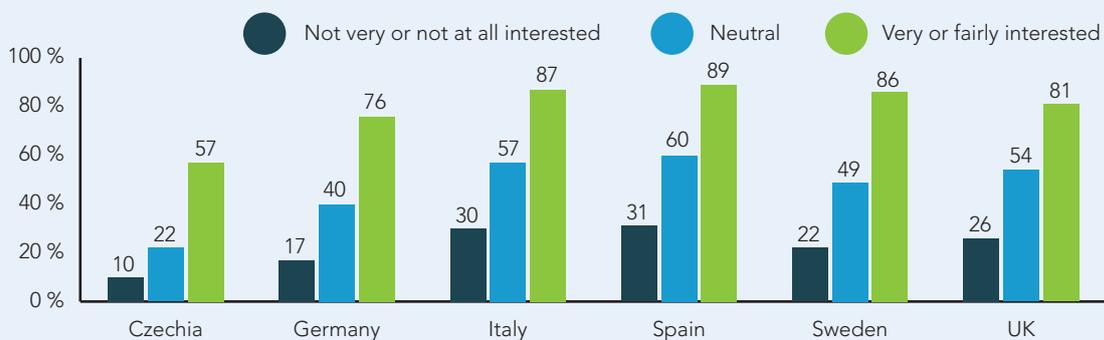


Figure 28: Interest in getting personally involved in relation to interest in life sciences across countries (percent of 'yes' answers).



of individuals. The relative importance of different reasons to participate in research is indicated by the question ‘People can get involved in research for different reasons. What, if any, of the following would motivate you?’ The respondents could answer ‘yes’ or ‘no’ for each option.

The answers did not differ much across countries (Figure 29), but Czech, Spanish, and Italian citizens feel more motivated by most reasons compared to Swedish and UK citizens. Generally, a belief that personal involvement would help society (74–89 percent across countries) and interest in the research topic (85–93 percent across countries) are more important reasons, while a public recognition is considered less important (29–44 percent across countries). The remaining reasons are somewhere in between – monetary or material incentives received 59 to 78 percent ‘yes’ answers across countries and involvement of people known by the respondents received 48 to 61 percent ‘yes’ answers across countries.

Neither gender nor education have an effect on how the different options are prioritised by the respondents. However, certain differences are found for age (Figure 30). Young people would be motivated if people they knew were involved, more often than older people. The differences between the youngest and the oldest respondents are 18 percentage points for monetary or material incentives, 32 percentage points for public recognition, and 17 percentage points for involvement of people the respondents know beforehand. No age differences for helping society and interest in the research topic have been found.

Figure 31 shows that citizens interested in life sciences stress all reasons more than those who are not interested; the average difference is over 20 percentage points. In order to attract the attention of the non-interested segments of the public, it is obvious that the research topic must be perceived as of personal interest, or that their personal involvement would benefit society.

Figure 29: Reasons to get involved in life sciences research across countries (percent of ‘yes’ answers).

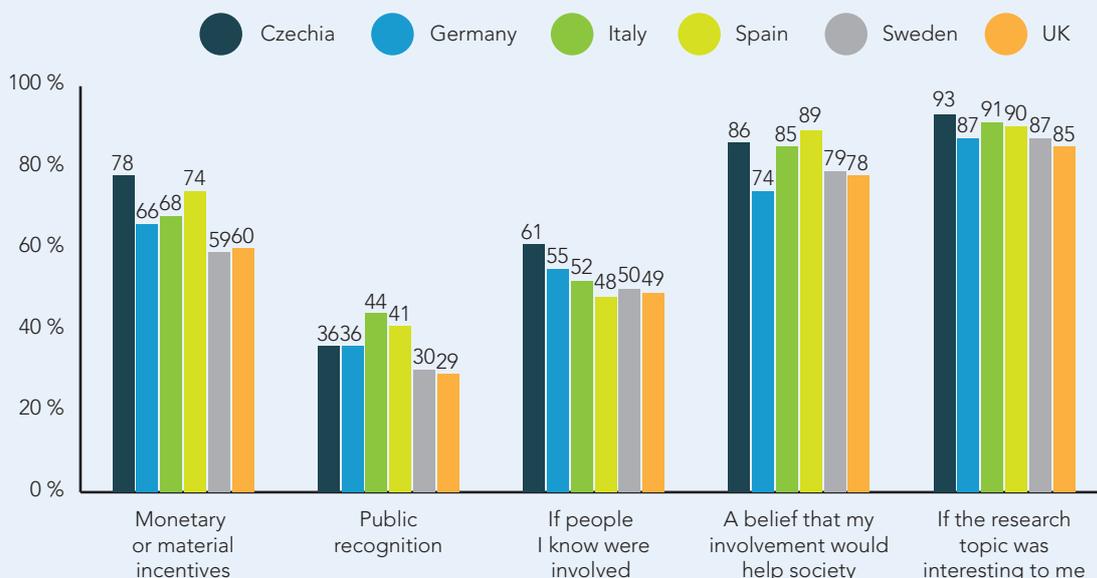


Figure 30: Interest in getting personally involved in relation to level of education across countries (percent of 'yes' answers).

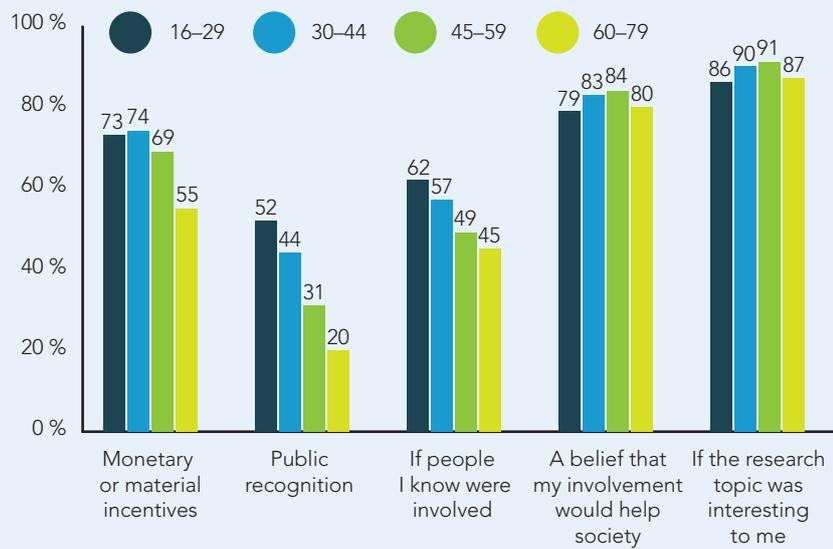
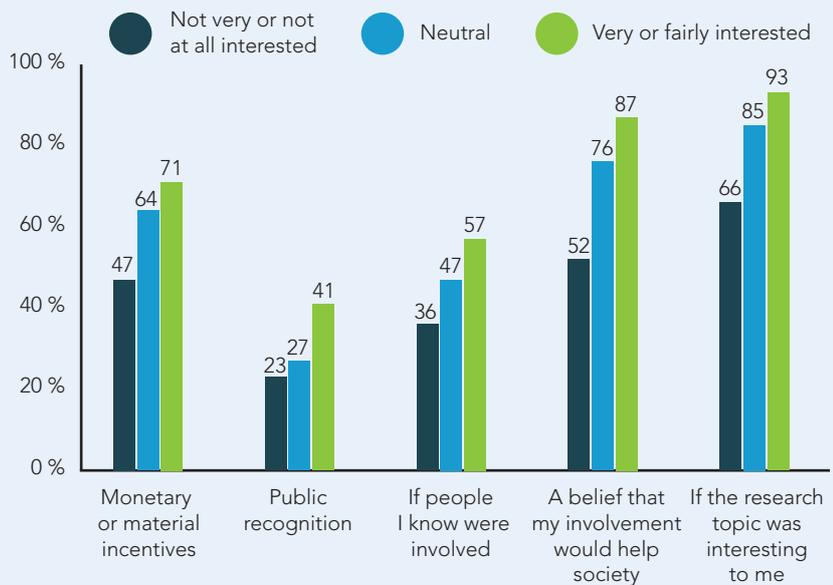


Figure 31: Reasons for involvement in relation to personal interest in life sciences research (percent of 'yes' answers).



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



How do the respondents want to be involved?

The respondents further expressed in what way they would consider being involved in life sciences research. The question was asked to those who said they were interested in being involved ('In what of

the following ways would you prefer to be involved?' with the possibility to answer 'yes' or 'no' for each alternative). It was also asked in a hypothetical way to those who had answered that they would not want to get involved ('You answered that you would not want to be involved. Please, try to imagine that you

were to be involved. Would you prefer any of these options?').

The responses to these questions are presented in the following two subsections. First, we present findings from those who are willing to get involved in life sciences research, and thereafter from those who are not.

Ways of involvement for respondents who are willing to get involved

? In what of the following ways would you prefer to be involved? Would you prefer any of these options? (Yes/No for each option.)

- ▶ Giving my opinion about which research projects should be funded
- ▶ Giving my opinion about what could be looked for or asked in a research study
- ▶ Giving my opinion about what methods and procedures to use or not to use
- ▶ Giving my opinion on how to use the findings
- ▶ Contributing to the funding of research projects, e.g., through helping to raise money
- ▶ Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)
- ▶ Collaborating with scientists to get data (e.g., helping to sort images of birds)
- ▶ Donating material needed for biomedical research (e.g., hair or saliva)

Responses to the question 'In what of the following ways would you prefer to be involved?' provide information on how the respondents would like to be involved. The information gained from this question may prove useful when various groups of citizens are to be involved in life sciences research. This part of the analysis includes 3,909 respondents (67 percent of the sample).

As shown in Figure 32, four items related to giving opinions at several stages of the research

process received about 60 to 80 percent positive answers across the six countries. The least popular alternative is to contribute to the funding of research, for instance by helping to raise money (39–59 percent across countries). In contrast, at least 70 percent of respondents across all countries are positive to helping to collect or analyse data, and to donating research material (e.g., hair or saliva). There are some differences between countries, in the sense that Spanish citizens tend to prefer more ways of involvement and Swedish citizens fewer ways.

Women positive to personal involvement tend to prefer to assist with data collection and donating research material with differences of about seven percentage points compared to male respondents. The other gender differences are negligible.

Regarding age differences examined in Figure 33, 60–79-year-olds are less interested than younger age groups, with the exception of giving opinions on how to use the findings, collaborating in data collection, and donating material needed for biomedical research. People aged between 16 and 59 years old displayed similar preferences in the ways they would be willing to get involved in life sciences research.

The effect of level of education is generally weak.

If we relate the answers to the level of interest in life sciences research, we see a much stronger association (Figure 34). People who are interested in life sciences research are generally more willing to participate, and their difference from those not interested is between 6 and 24 percentage points. The results also indicate how respondents who are neutral or uninterested are willing to get involved; the pattern is similar, but with overall lower scores. Confidence in life sciences has an overall moderate effect on the number of preferred ways of involvement; the difference is around ten percentage points between respondents who are confident and those who are not confident.

Figure 32: Preferences for personal involvement of respondents *willing to get involved* across countries (percent).

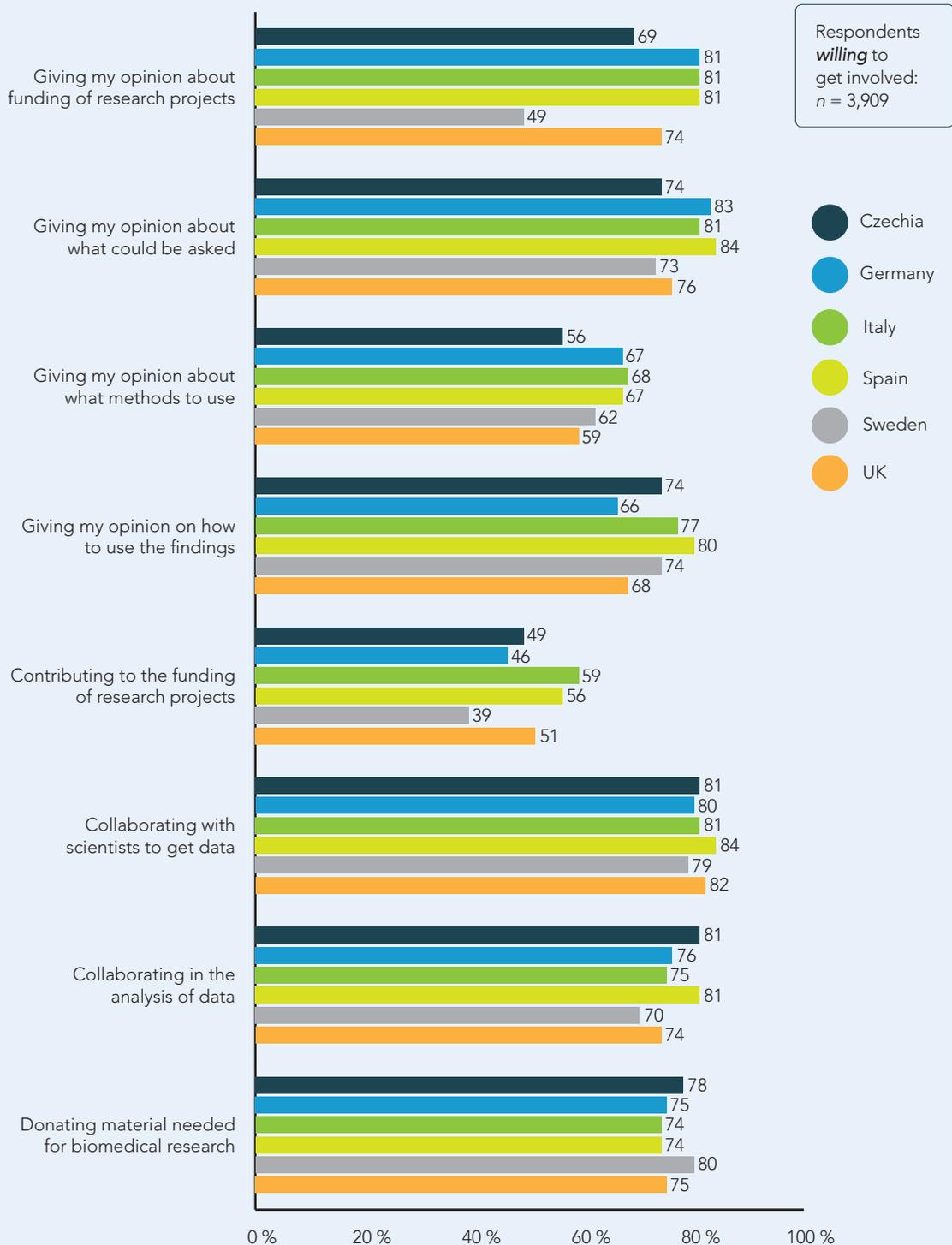


Figure 33: Preferences for personal involvement of respondents *willing to get involved* in relation to age (percent of 'yes' answers).

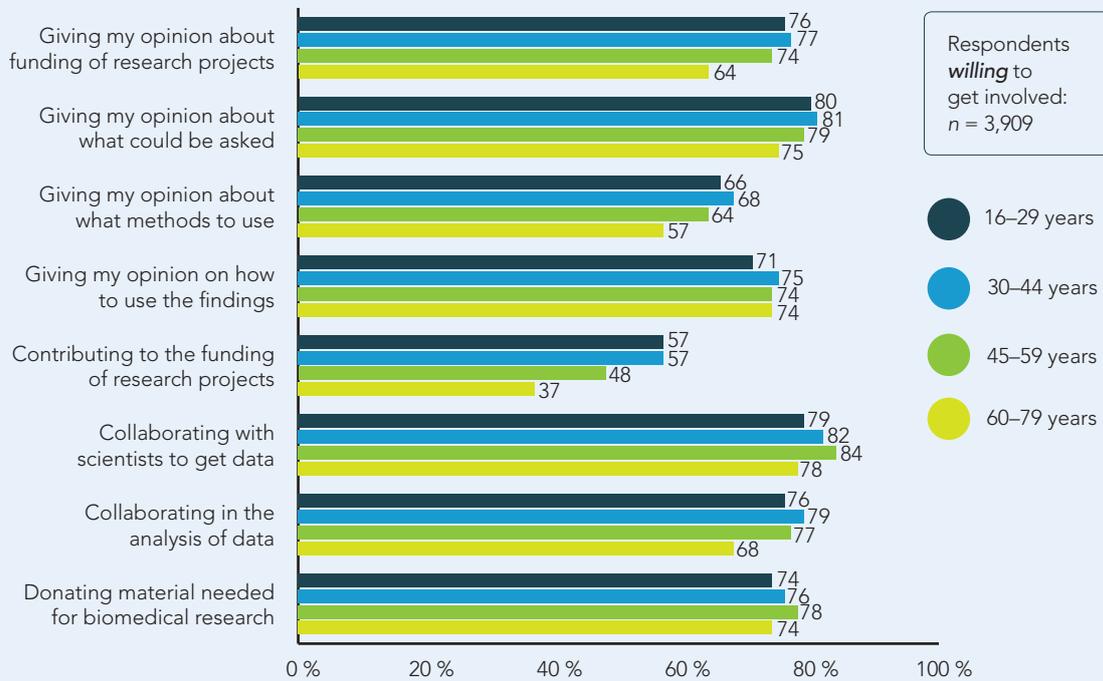
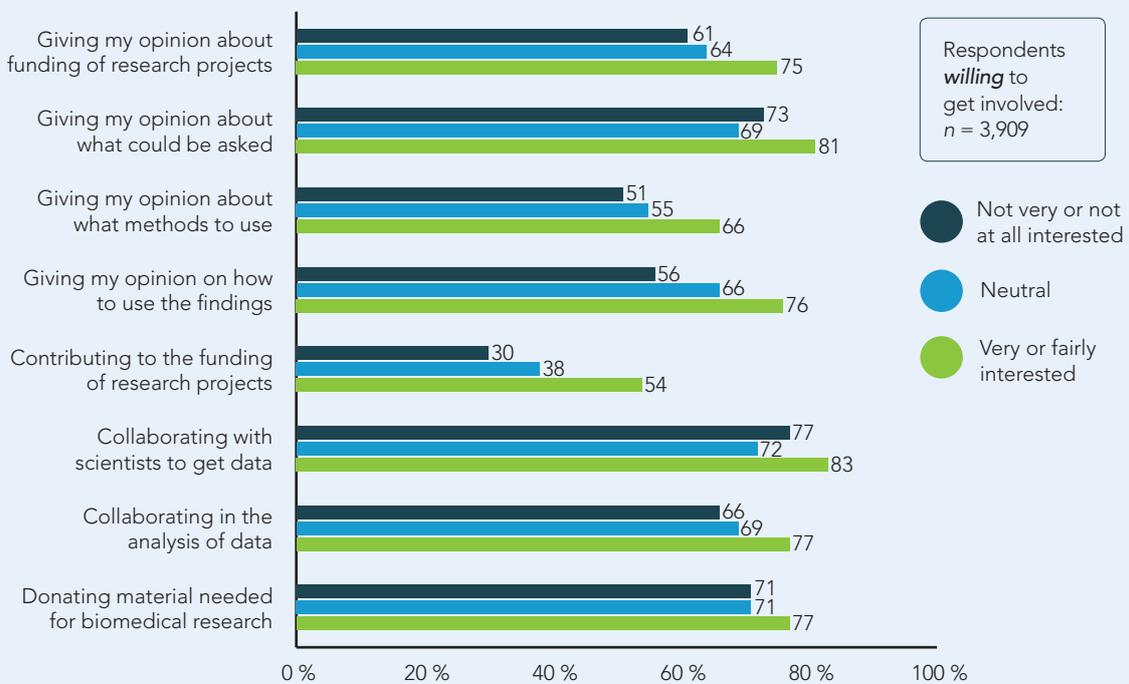


Figure 34: Preferences for personal involvement in relation to respondents' level of interest in life sciences research (percent of 'yes' answers).



Ways of involvement for respondents who are unwilling to get personally involved



You answered that you would not want to be involved. Please, try to imagine that you were to be involved. Would you prefer any of these options? (Yes/No for each option.)

- ▶ Giving my opinion about which research projects should be funded
- ▶ Giving my opinion about what could be looked for or asked in a research study
- ▶ Giving my opinion about what methods and procedures to use or not to use
- ▶ Giving my opinion on how to use the findings
- ▶ Contributing to the funding of research projects, e.g., through helping to raise money
- ▶ Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)
- ▶ Collaborating with scientists to get data (e.g., helping to sort images of birds)
- ▶ Donating material needed for biomedical research (e.g., hair or saliva)

The set of items asking about ways of involvement were also asked hypothetically to 1,945 respondents (33 percent of the sample) who would not wish to be personally involved in life sciences. These two groups of answers have been analysed separately. The purpose of these hypothetical answers was to examine which ways of involvement would be acceptable even to those who are not eager to participate and how this willingness is structured by other characteristics.¹¹

Figure 35 displays the country differences in this hypothetical involvement, which are significantly larger than the differences among the people who were willing to get involved. Respondents from Spain prefer most of the activities more than those residing in Sweden and the UK, with an average difference of about 20 percentage points. Furthermore, Czech respondents prefer three specific ways of involvement

more than any other nation (collaborating with data collection, collaborating in data analysis, and donating research material), all of them 13–14 percentage points above the average score.

Women are inclined to engage more in data analysis and donating research material (differences of 8 percentage points and 7 percentage points, respectively), while interest in other types of involvement is not affected by gender. Interestingly, the same pattern of gender differences is found among those willing to be personally involved.

The oldest age group prefer to discuss how to use the findings (54 percent) compared to other age groups, but are less willing to contribute to research funding (18 percent), see Figure 36. The youngest age group is overall more positive about ways of being involved than the other age groups, except towards collecting research data (11 percentage points less than 30–44-year-olds).

Similarly to those who are willing to be involved, the differences based on level of education are negligible.

Interest in getting involved in different topics

These questions aimed to compare how respondents view different topics within life sciences as interesting to be involved in. Their exact formulations were ‘Are you interested in getting involved in the following research topics?’ for people willing to be involved and ‘If you were to be involved in any way, would any of the following research topics be of interest to you?’ for those not interested in being involved.

Figure 37 presents responses from those who are interested in being personally involved in life sciences research (3,909 respondents), while Figures 38–39 show results for citizens who are not interested in being personally involved (1,945 respondents). Similarly to the ways for being involved, the findings from these questions are presented in the following two subsections. First, we present topics of interest to those who are willing to get involved, and thereafter from those who are not.

¹¹ It could have been expected that people not interested in being personally involved in life sciences research would refuse to answer these questions, but this was true only in 77–147 cases for particular items.

Figure 35: Preferences for personal involvement of respondents *not willing to get involved* across countries (percent).

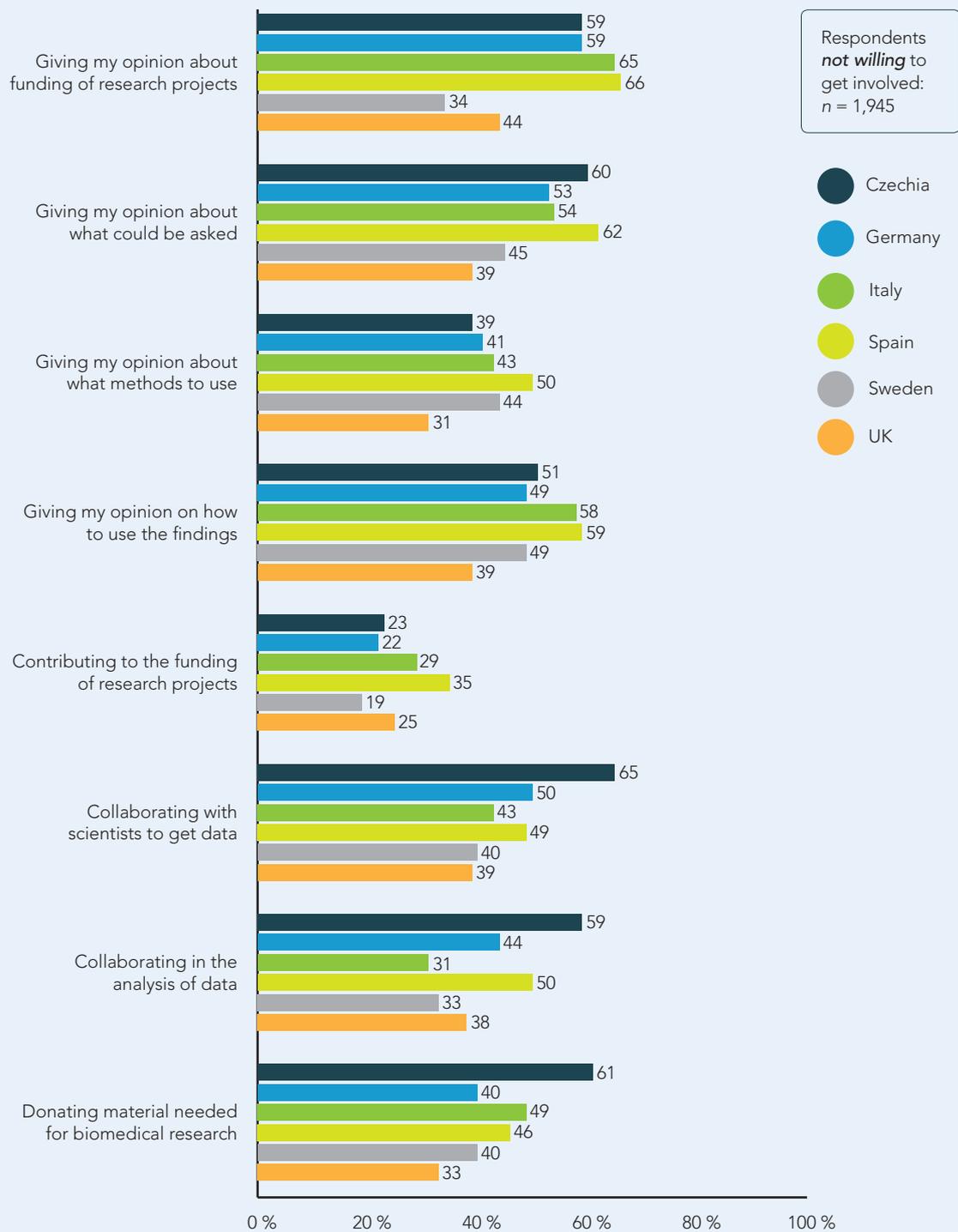
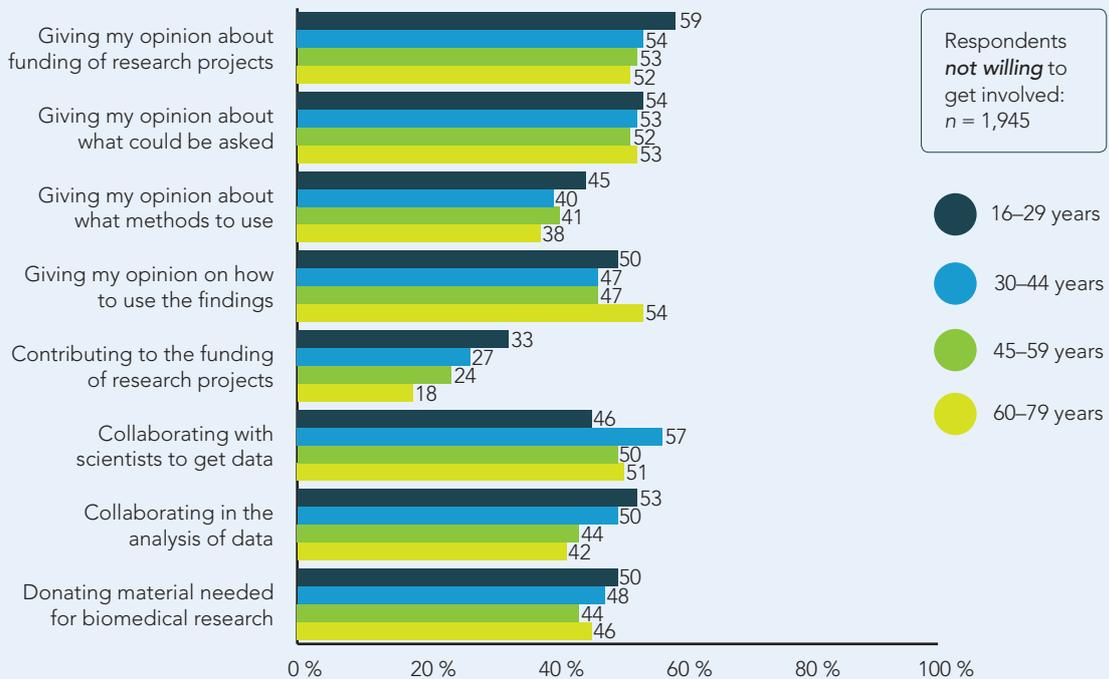


Figure 36: Preferences for personal involvement of respondents *not willing to get involved* across age groups (percent of 'yes' answers).



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



Topics of interest to those who are willing to get involved

? Are you interested in getting involved in the following research topics? (Yes/No for each option.)

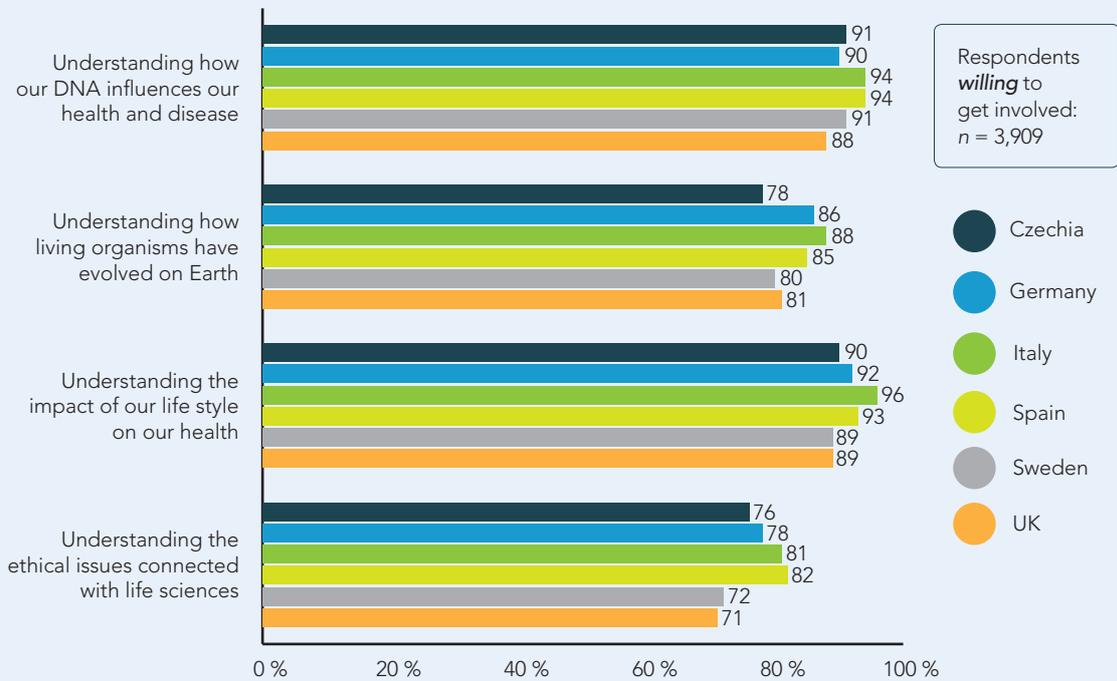
- ▶ Understanding how our DNA influences our health and disease
- ▶ Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth
- ▶ Understanding the impact of our life style on our health
- ▶ Understanding the ethical issues connected with life sciences

Figure 37 indicates that all four topics of life sciences research are of interest and most of those who

are interested in personal involvement would consider all of them. Understanding both the influence of DNA and the impact of our lifestyle on our health and disease are the topics of most interest (88–94 percent and 89–96 percent of positive answers for each country). Involvement in research on how living organisms have evolved on Earth and research on ethical issues in life sciences is less attractive (78–88 percent and 71–82 percent across countries), but still of interest to the majority of the respondents. With regards to countries, Italy scored about 10 percentage points higher than Czechia, Sweden and the UK for all research topics.

Interest in involvement in research on particular topics is unaffected by both gender and level of education. The only noticeable difference relates to age, in the sense that the oldest age group is less interested in the evolution of living organisms. This shows that those willing to engage with life sciences

Figure 37: Interest in involvement in different topics of respondents *willing to get involved* across countries (percent of 'yes' answers).



Source: ORION project, report D.2.3 Total sample: N = 5,870 Field period: January–February 2018

research are interested in all four topics, regardless of their personal individual characteristics.

Topics of interest to those who are not willing to get involved

? If you were to be involved in any way, would any of the following research topics be of interest to you? (Yes/No for each option.)

- ▶ Understanding how our DNA influences our health and disease
- ▶ Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth
- ▶ Understanding the impact of our life style on our health
- ▶ Understanding the ethical issues connected with life sciences

Figure 38 shows that even people not interested in being personally involved in life sciences research would hypothetically engage with some scientific topics. This group of people favours the same topics as those who are willing to participate, namely the influence of DNA and the impact of our lifestyle. The country differences were more pronounced here, as the frequency of positive responses in Czechia, Italy, and Spain is about 20 percentage points higher compared to those for Sweden and the UK.

Women are more interested in some topics than men (Figure 39), especially with regard to the influence of DNA and how our lifestyle impact on health and disease (8 and 7 percentage points higher respectively).

In contrast, age and level of education do not affect preferences concerning interest in involvement in research topics.

Figure 38: Interest in involvement in different topics of respondents *not willing to get involved* across countries (percent of 'yes' answers).

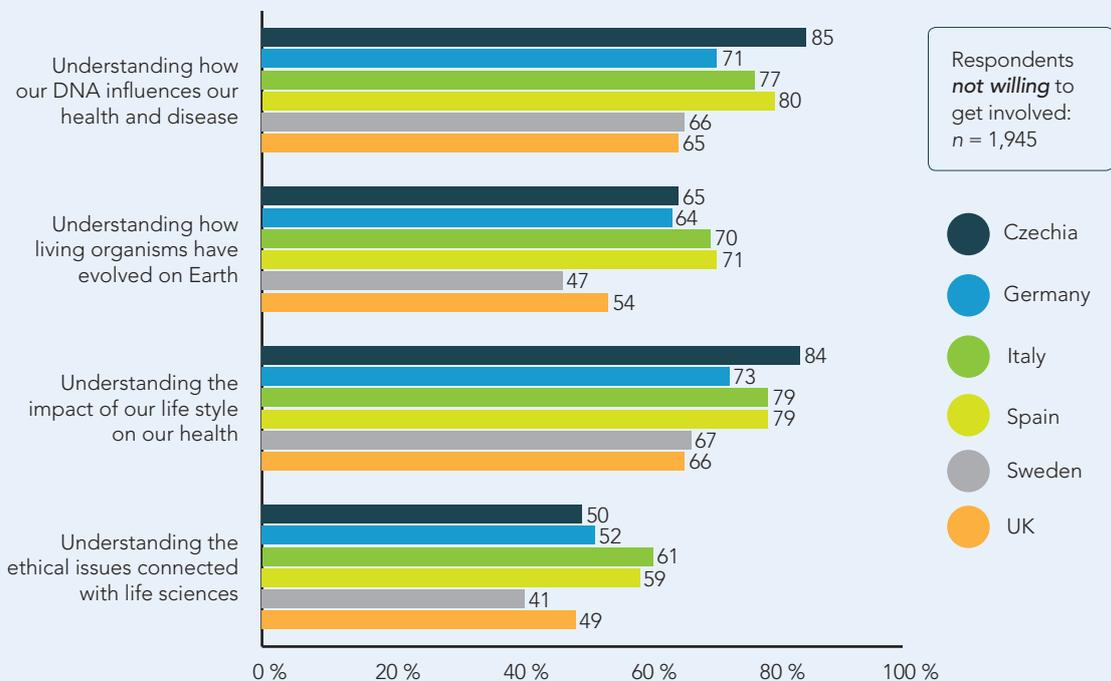
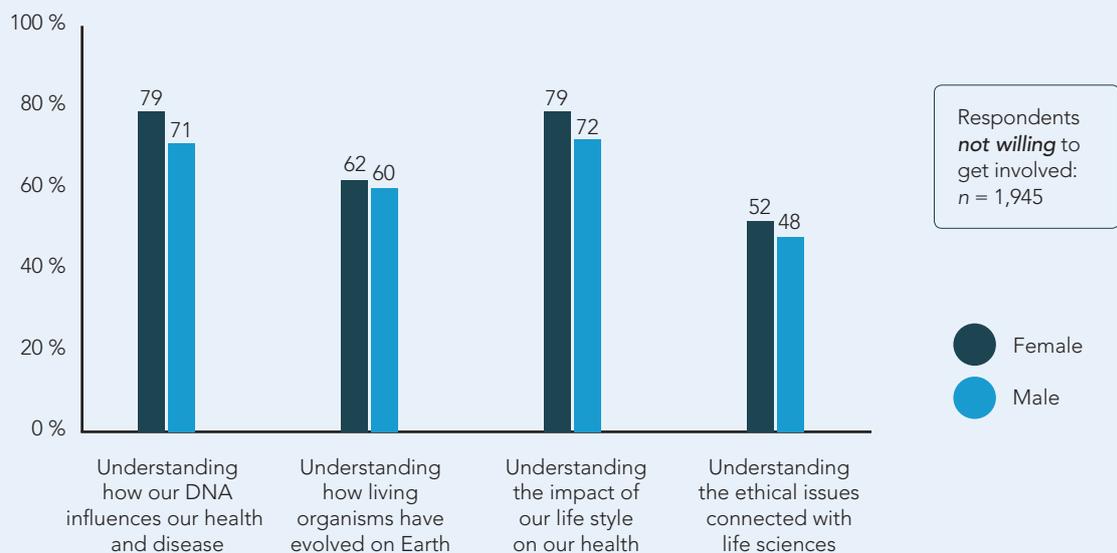


Figure 39: Interest in involvement in different topics of respondents *not willing to get involved* in relation to gender (percent of 'yes' answers).



GENOME EDITING – AWARENESS AND CONCERNS

The last part of the questionnaire had a specific focus on genome editing, and people’s awareness and concerns with regard to this highly topical and potentially disruptive technique. The respondents were asked three questions: whether they had heard about the genome editing technique, for what purposes they believed it should be used, and whether they had any concerns about the technique.

Awareness of the existence of genome editing

? Have you ever heard of the technique that enables the modification (insertion, deletion or replacement) of sections of DNA in cells and living organisms? This technique is called genome editing.

- ▶ Yes
- ▶ No

Figure 40: Awareness of genome editing across countries (percent of ‘yes’ answers).

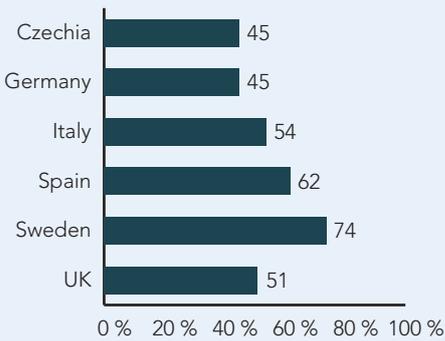


Figure 41: Awareness of genome editing across countries (percent of ‘yes’ answers).

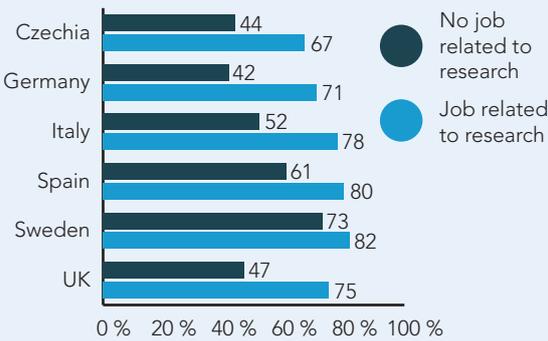
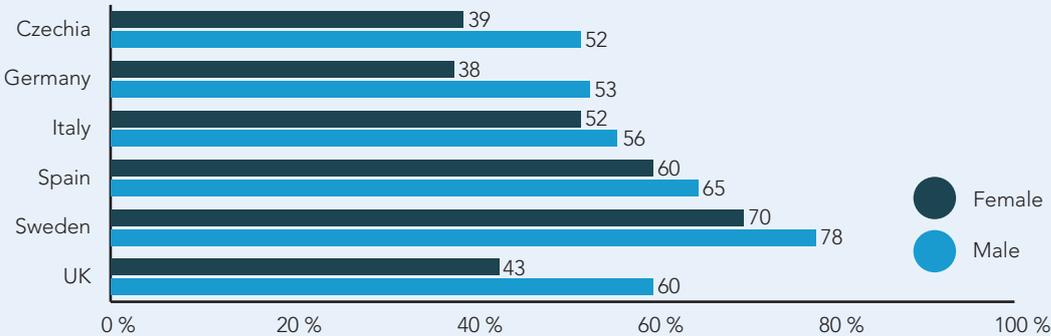


Figure 42: Awareness of genome editing in relation to gender (percent of ‘yes’ answers).



Firstly, respondents were asked about their awareness of the genome editing technique. On average, 55 percent of the respondents have heard about genome editing before.

As Figure 40 shows, there is a difference between countries: 74 percent of the Swedes have heard about genome editing compared to 45 percent of the Czech and German population.

Respondents with a job related to research have a higher awareness of genome editing. This was found in all of the countries with differences ranging from about 10 to 30 percentage points (Figure 41). The lowest difference was found in Sweden, where this technique was widely known even by the lay public (73 percent of persons without a job related to research).

Figure 43: Awareness of genome editing in relation to age (percent of 'yes' answers).

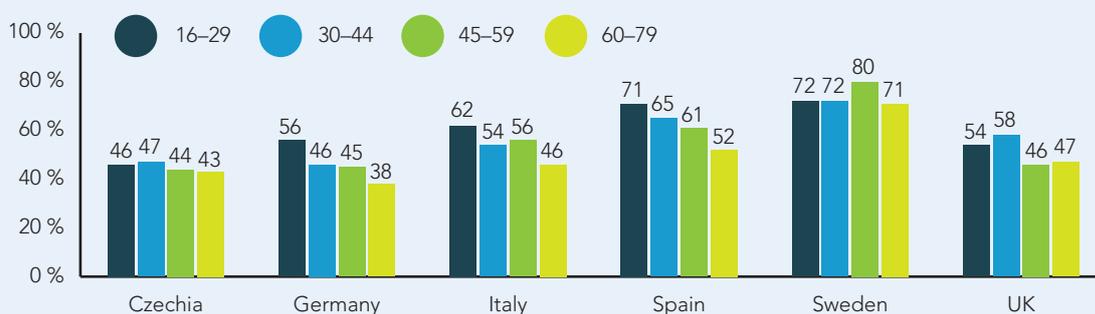


Figure 44: Awareness of genome editing in relation to level of education (percent of 'yes' answers).

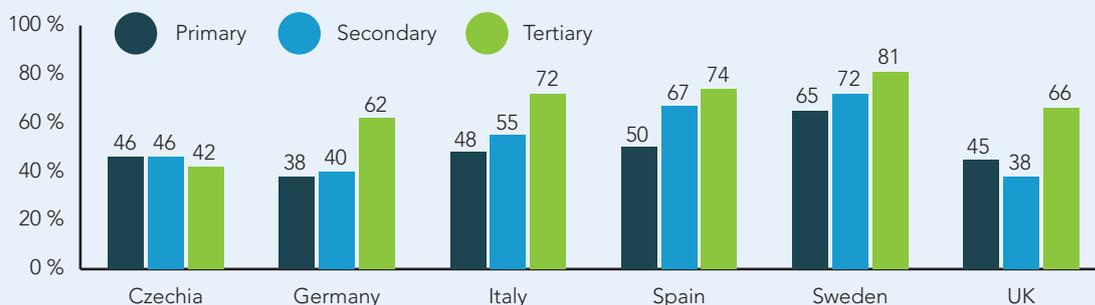


Figure 45: Awareness of genome editing in relation to respondents' confidence in life sciences research (percent of 'yes' answers).

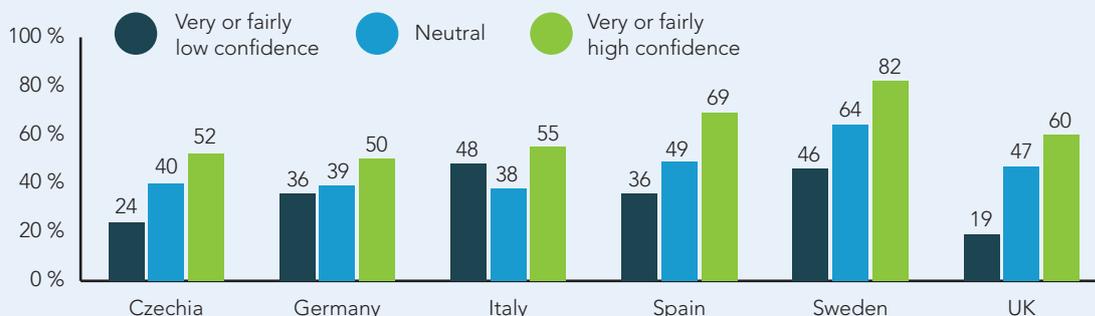


Figure 42 indicates that it is more often men that have heard about genome editing than women with particularly high differences in the UK (17 percentage points), Germany (15 percentage points), and Czechia (13 percentage points).

Younger age groups are aware of genome editing to a larger extent than older age groups in all of the countries apart from Czechia and Sweden (Figure 43). In fact, 80 percent of Swedes between 45 and 59 years of age have heard of this technique, the highest number among age groups in all countries.

As Figure 44 suggests, awareness of genome editing is positively related to level of education in five countries with differences of between 16 and 24 percentage points between primary and tertiary education. In contrast, this relationship appears reversed in Czechia, although the difference of four percentage points is not statistically significant.

Respondents with high confidence in life sciences research are more aware of genome editing, a result which is consistent in all of the countries (Figure 45).

The purposes of genome editing

For what purpose do you think genome editing should be used? Should it be used ... (Yes/No for each option.)

- ▶ For organ transplantation
- ▶ For prevention or cure of diseases
- ▶ For prevention of disabilities
- ▶ For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)
- ▶ For improvement of plant production
- ▶ For improvement of livestock production

Figure 46: Public support across countries for use of genome editing for different purposes (percent of 'yes' answers).

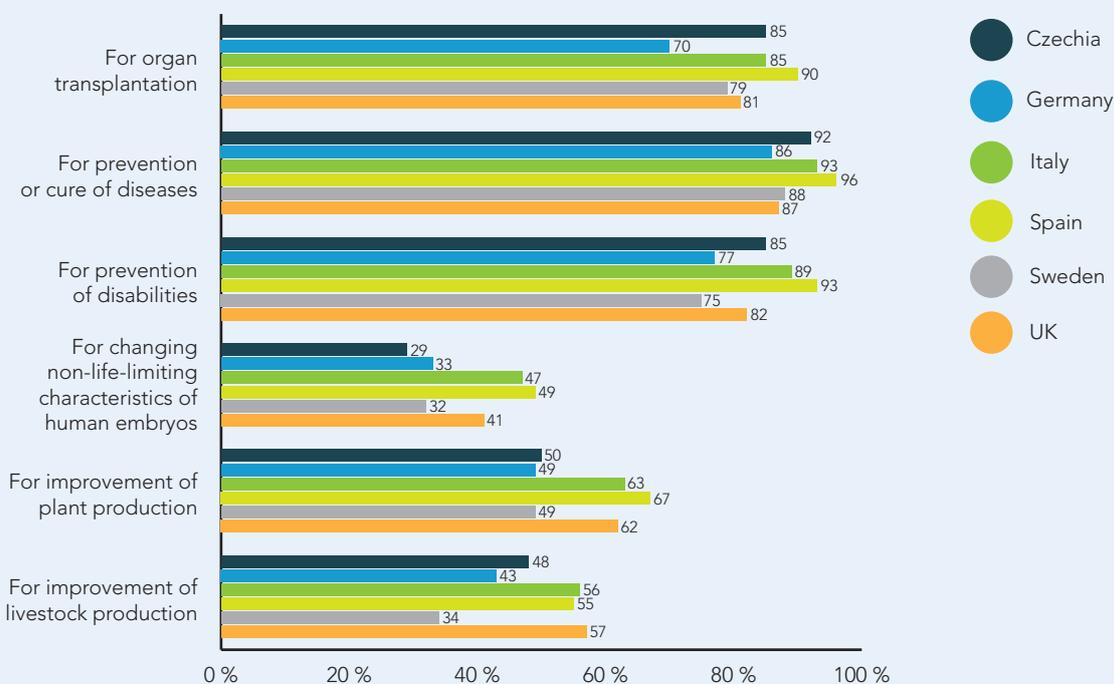


Figure 47: Public support for use of genome editing for different purposes and its association with a job related to research (percent of 'yes' answers).

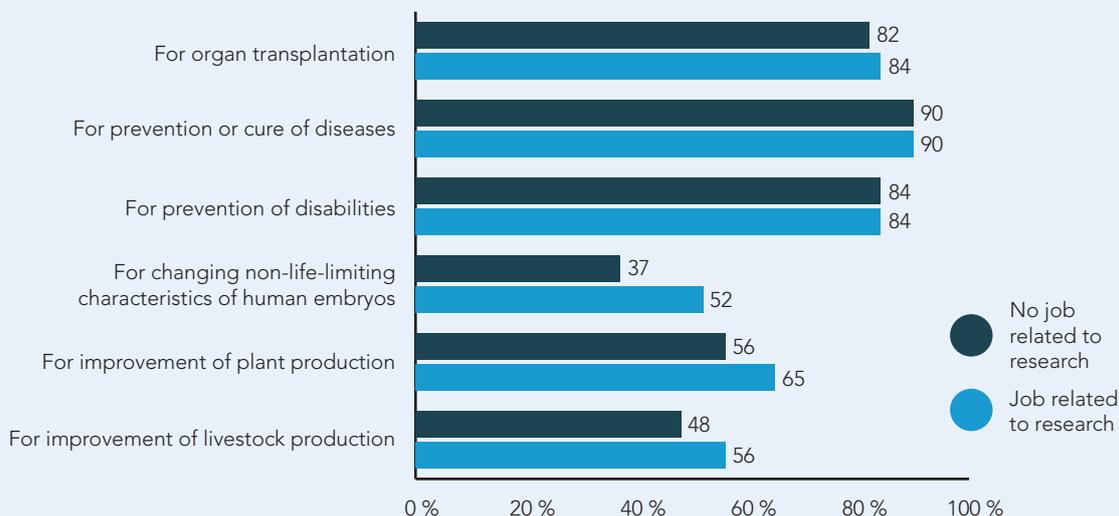
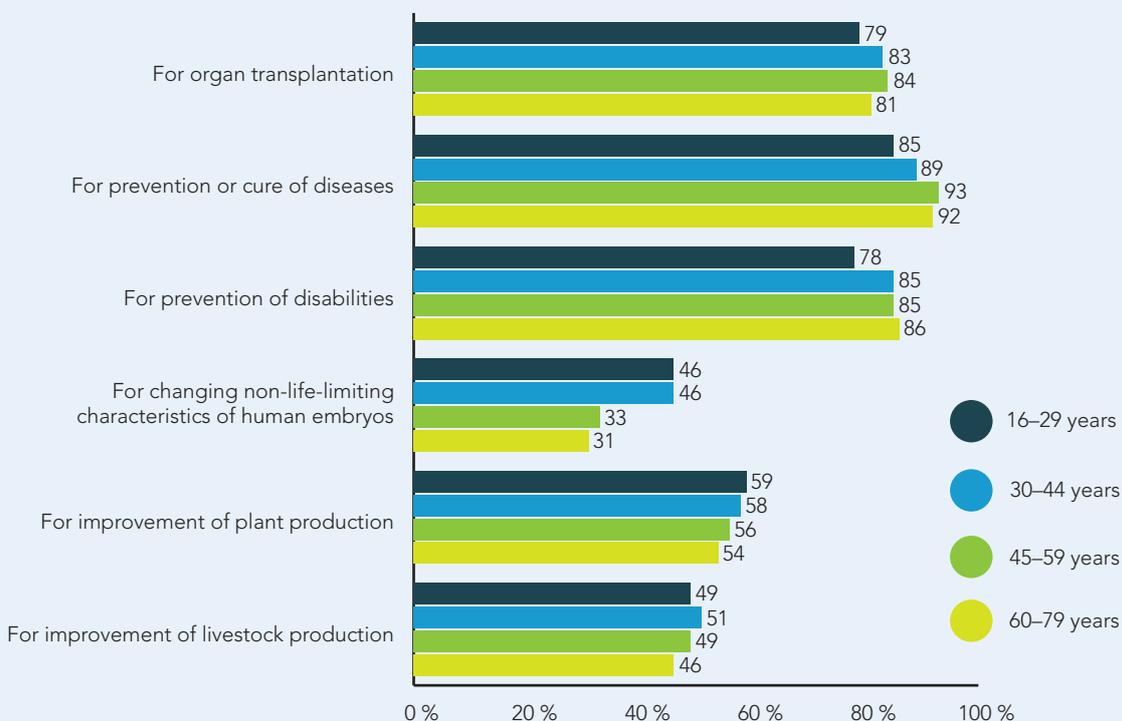


Figure 48: Public support in relation to age for use of genome editing for different purposes (percent of 'yes' answers).



The respondents were also asked for what purpose they think genome editing should be used. The response items illustrate a number of usages for genome editing, and the responses indicate in what situations genome editing is acceptable to the general public.

According to the respondents, the most accepted purposes of genome editing are related to human health: prevention or cure of diseases (86–96 percent across countries), prevention of disabilities (75–93 percent), and organ transplantation (70–90 percent).

The least preferred usages are changing non-life-limiting characteristics of human embryos (29–49 percent across countries), improvement of livestock production (ranging from 34 to 57 percent across countries) and improvement of plant production (49–67 percent).

As can be seen from Figure 46, respondents from Italy and Spain generally accept reasons for genome editing to a higher degree than respondents from Germany and Sweden.

Gender and job related to research

Regarding the use of genome editing for different health purposes, there are no substantial differences among respondents with or without a job related to research.

However, respondents with a job related to research are more supportive towards genome editing being used for changing non-life-limiting characteristics of human embryos, for the improvement or plant production and for the improvement of livestock production. They are more supportive of these three techniques than respondents that do not have a job related to research (differences of 15, 9, and 8 percentage points, respectively) (Figure 47).

The same pattern can also be seen in relation to gender, where women are less likely than men to support genome editing being used for the reasons mentioned above with respective differences of 10, 5, and 6 percentage points.

Figure 49: Public support for use of genome editing for different purposes in relation to respondents’ interest in life sciences research (percent of ‘yes’ answers).

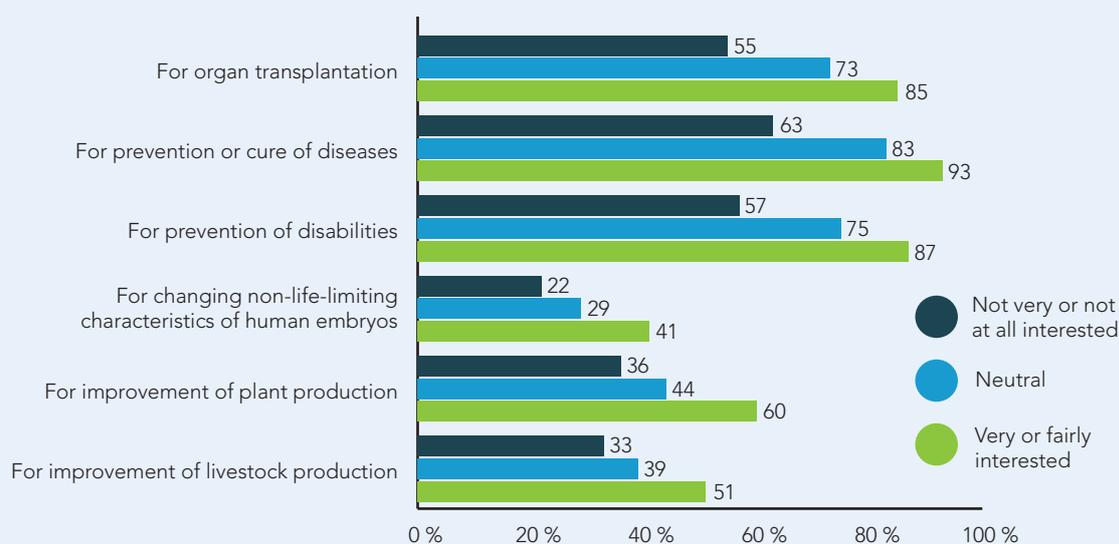
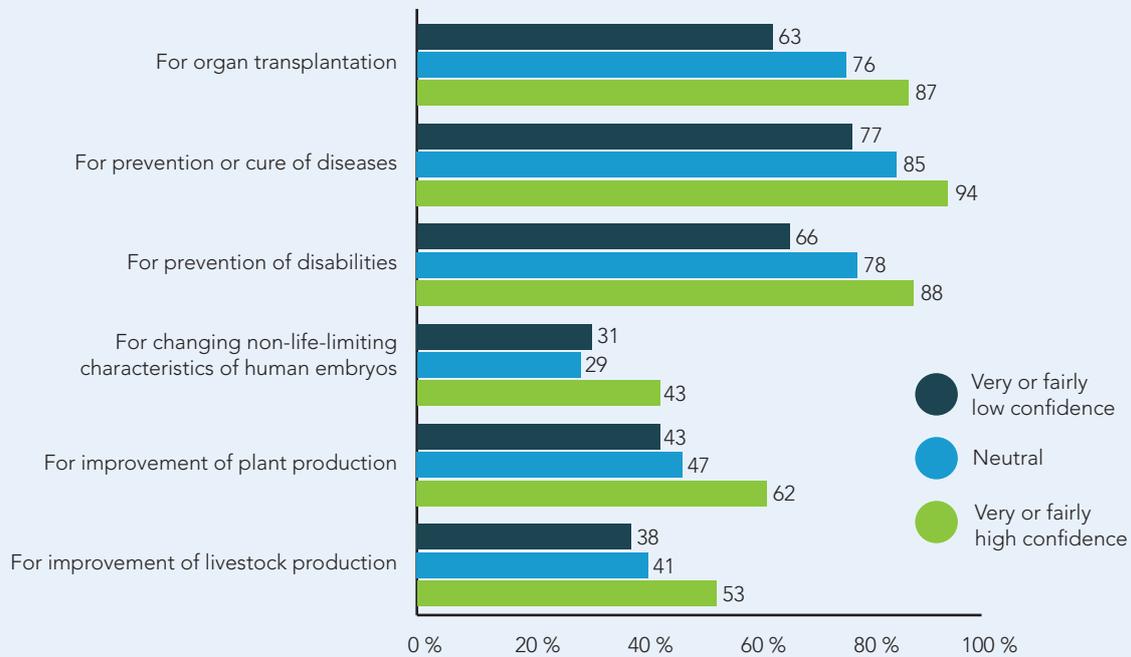


Figure 50: Public support for use of genome editing for different purposes in relation to respondents' confidence in life sciences research (percent of 'yes' answers)



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



Education and age

There are no substantial differences regarding views on purposes of genome editing based on the respondents' level of education. Figure 48 suggests that older respondents (aged from 45 to 79) are 15 percentage points less supportive of genome editing being used for changing non-life-limiting characteristics of human embryos. This was the only larger age difference in relation to the uses of genome editing.

Interest and confidence in life sciences research

Respondents with high interest and high confidence in life sciences research are more inclined to believe that genome editing should be used for all of the listed purposes, in comparison to respondents with low interest and confidence.

The effects of interest and confidence were consistent with citizens expressing a neutral opinion being found between respondents who are interested/confident and those who are not interested/not confident (Figures 49 and 50).

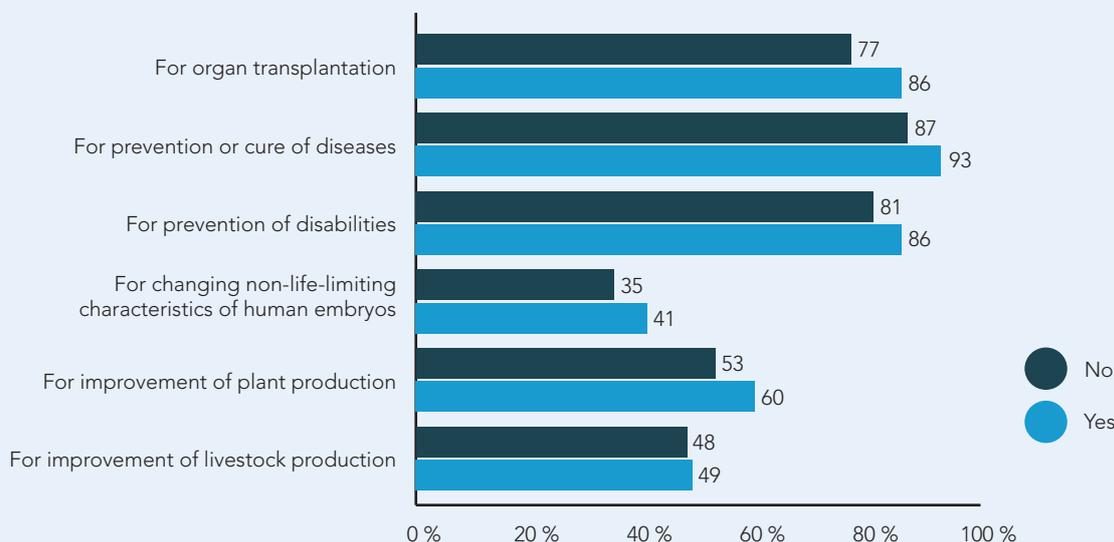
Finally, people who had heard about genome editing before the survey can have different attitudes to those people who heard about the technique for the first time in relation to the survey.

The latter group's opinion had just been formed and is likely to be more unstable. The views among these groups are compared in Figure 51.

People who were already aware of genome editing are more open to all purposes of its use except of improvement of livestock production.

The differences for these two groups vary between 5 and 9 percentage points.

Figure 51: Public support for use of genome editing for different purposes in relation to respondents' awareness of genome editing (percent of 'yes' answers).



Source: ORION project, report D.2.3

Total sample: N = 5,870

Field period: January–February 2018



Concerns with genome editing

? Regarding genome editing, how concerned are you about any of the following? Please, tell me if you are very concerned, fairly concerned, neutral, not very concerned, not at all concerned.

- ▶ That sufficient regulation is not in place
- ▶ The ethical implications regarding any use of this technology
- ▶ That the technology could be misused
- ▶ That the technology may come with unknown side-effects in human beings

The respondents were asked about their levels of concern regarding four different aspects of genome editing.

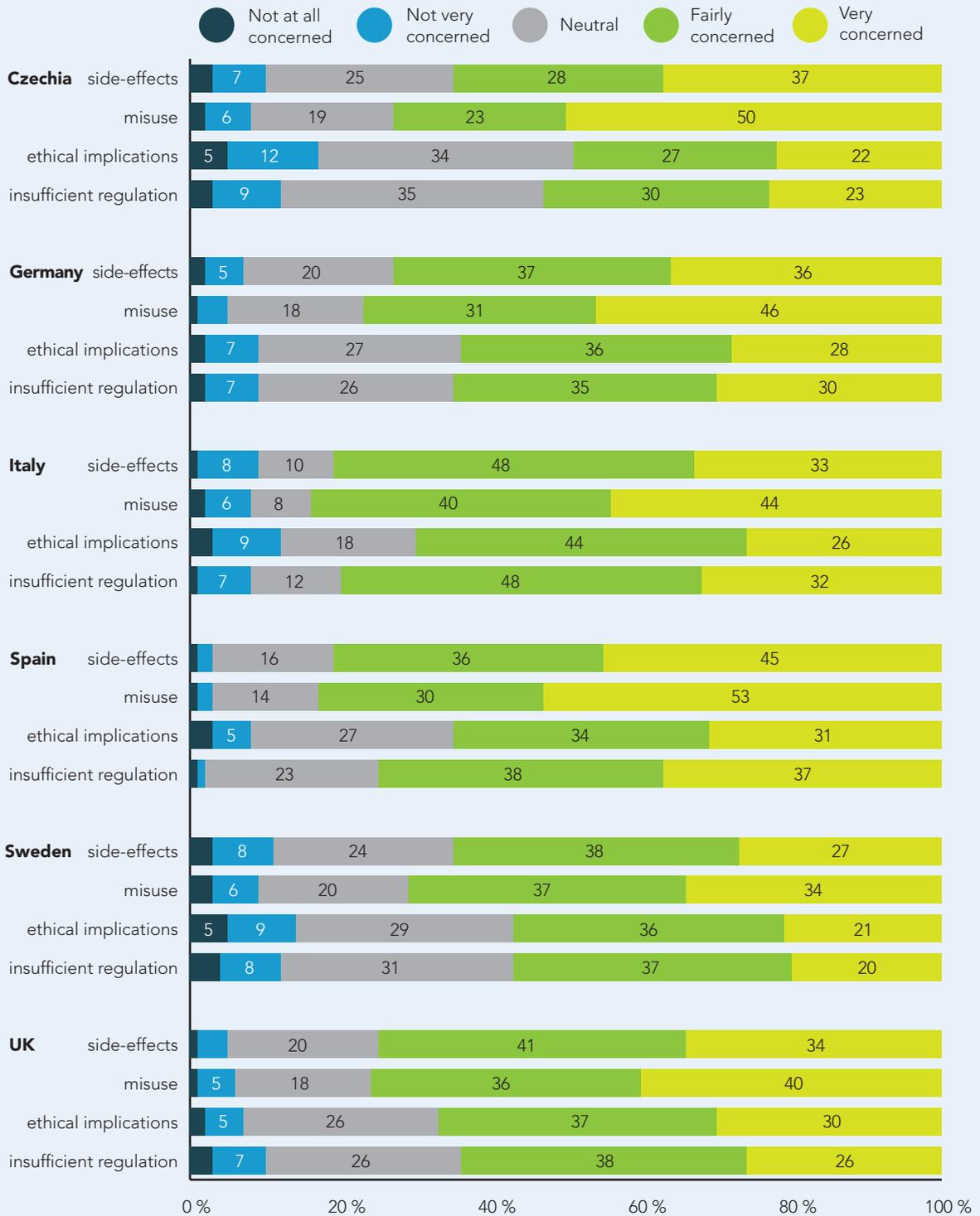
Country of residence

The respondents' answers according to their country of residence are given in Figure 52. In general, respondents are mostly concerned about side-effects and misuse of genome editing in all of the countries.

The number of respondents very or fairly concerned about these two topics is higher in Spain (81 and 83 percent respectively) and Italy (81 and 84 percent respectively) in comparison to Czechia (65 and 73 percent respectively) and Sweden (65 and 71 percent respectively).

Czech respondents show low concerns especially regarding ethical implications (with 49 percent being very or fairly concerned) and insufficient regulation (with 53 percent being very or fairly concerned).

Figure 52: Potential concerns regarding genome editing across countries (percent of 'yes' answers).



Gender and job related to research

Slightly higher concerns about several areas of genome editing use are observed among respondents with jobs related to research in comparison to those without jobs related to research. As can be seen in Figure 53, these respondents showed higher concerns

about ethical implications (seven percentage points difference), and insufficient regulation (six percentage points difference). There were also minor differences in relation to gender, with women showing slightly higher concerns about genome editing use (Figure 54).

Figure 53: Potential concerns regarding genome editing in relation to a job related to research (percent of 'yes' answers).

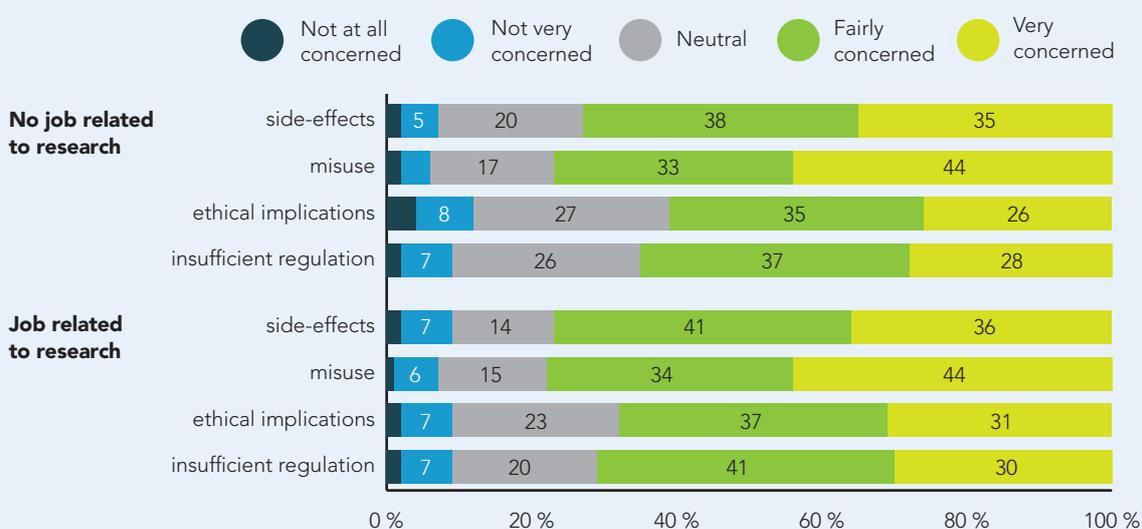


Figure 54: Potential concerns regarding genome editing in relation to gender (percent of 'yes' answers).

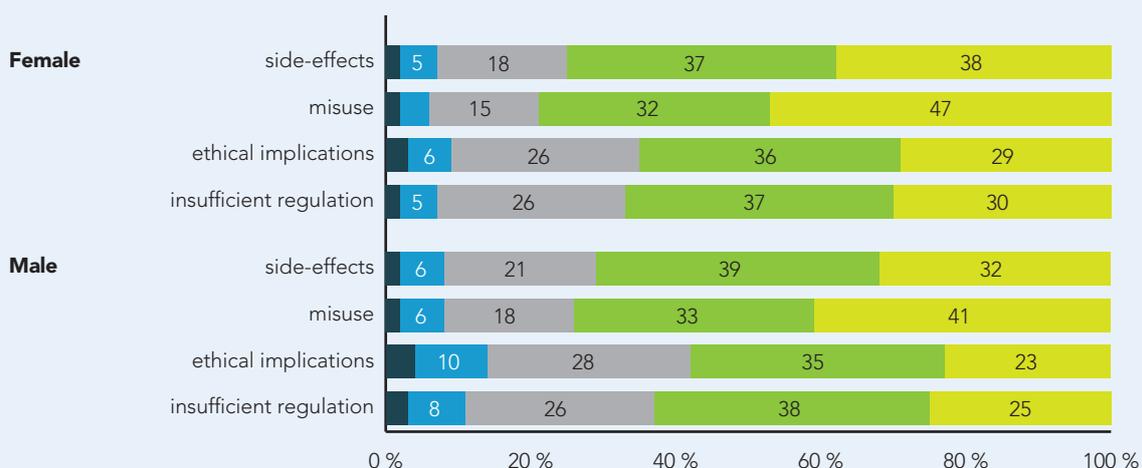
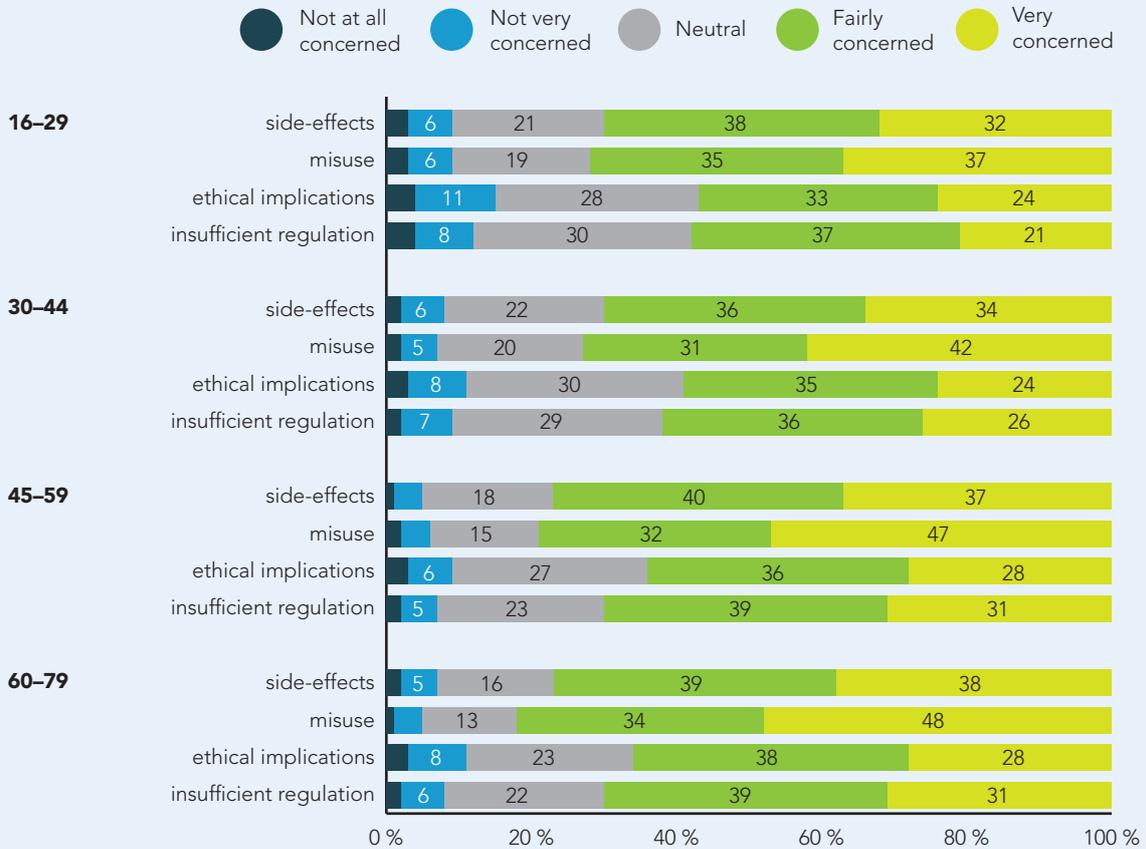


Figure 55: Potential concerns regarding genome editing in relation to age (percent of 'yes' answers).



Source: ORION project, report D.2.3 Total sample: N = 5,870 Field period: January–February 2018

Age, education and interest in life sciences research

Regarding the age of the respondents, concern about genome editing use slightly rises with age. Respondents aged from 16 to 29 show relatively low concerns among all areas of genome editing use. On the contrary, respondents over 45 show higher concerns among all areas of genome editing use in comparison to younger age groups (Figure 55). Furthermore, the respondents' level of education is not related to concerns about genome editing use. Finally, an interesting finding is that those who are very or fairly interested in life sciences research express higher concerns about genome editing (Figure 56).

Concerns related to awareness of genome editing

Figure 57 implies that people with previous knowledge of genome editing are more concerned about three of the four areas. The differences in their concern from people not aware of the technique are eight percentage points for insufficient regulation, eight percentage points for ethical implications, and seven percentage points for potential misuse. The results thus suggest that awareness of genome editing is connected to both higher acceptability of most purposes but also higher awareness of potential threats. This interesting finding should be taken into account in the preparation of any event addressing this topic.

Figure 56: Potential concerns regarding genome editing in relation to the respondents' level of interest (percent of 'yes' answers).

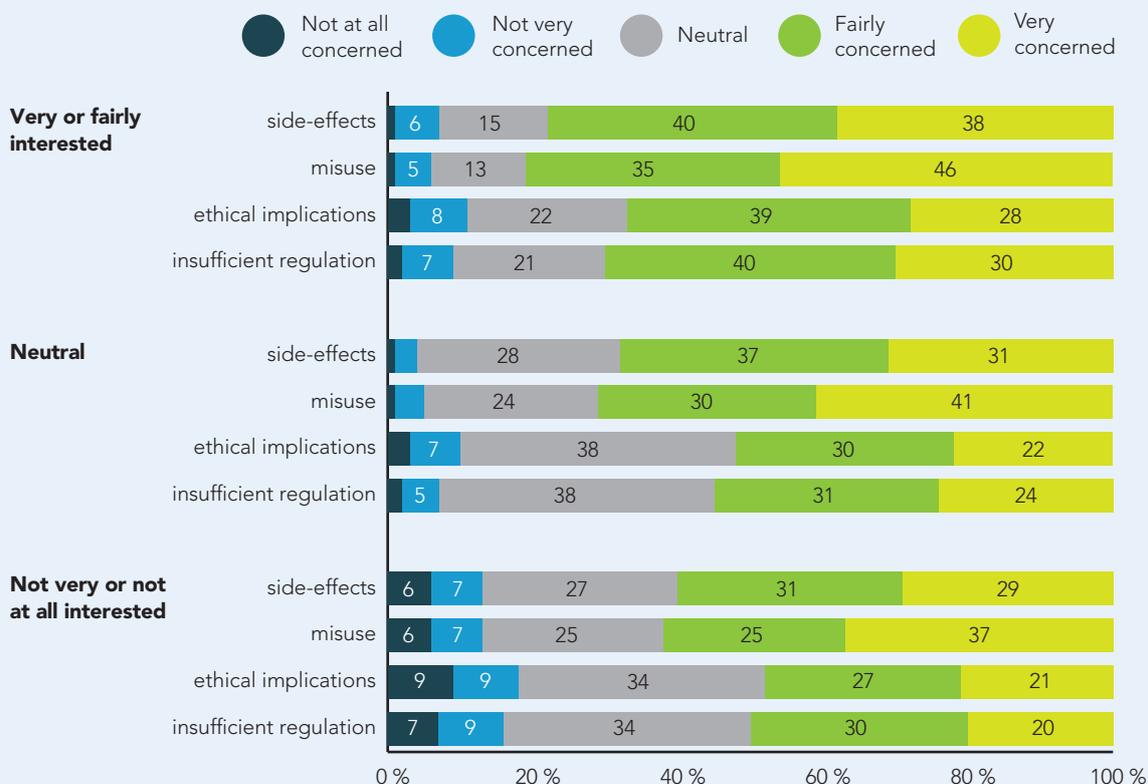
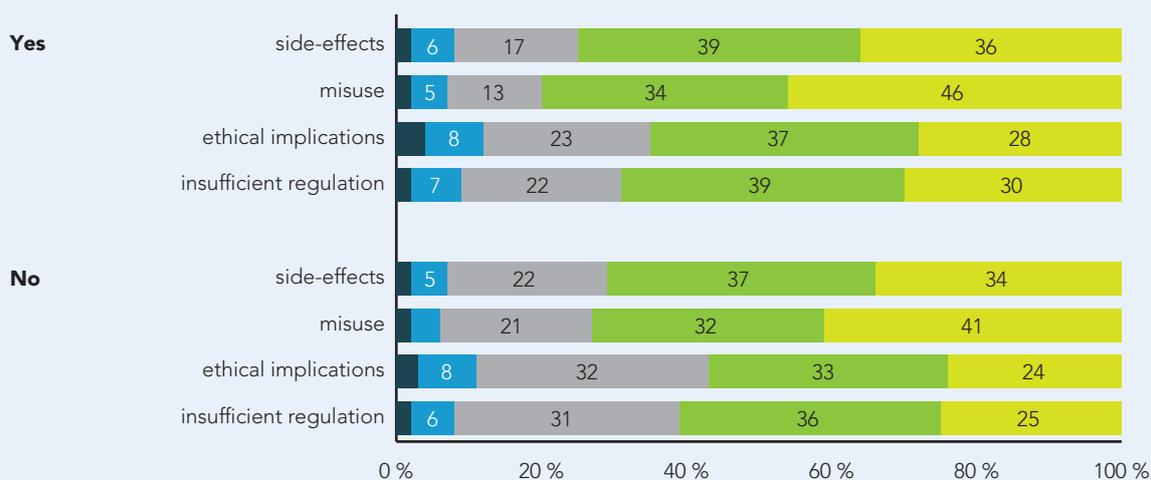


Figure 57: Potential concerns regarding genome editing in relation to the respondents' awareness of genome editing (percent of 'yes' answers).



4. SUMMARY AND CONCLUSIONS

In this chapter, a selection of the results are summarised under three themes: (i) public interest and confidence in life sciences research, (ii) public views on involvement in life sciences research and (iii) public views on genome editing. The focus will be on findings that are of potential use for future project activities, although the issue of how the data feeds into

future work packages will receive more attention in a future report (Deliverable 2.4) of the ORION project. A general reflection is that, although several differences can be discerned among the participating countries and demographic groups, the patterns are still remarkably similar across the heterogeneous groups of respondents.

PUBLIC INTEREST AND CONFIDENCE IN LIFE SCIENCES RESEARCH

Interest in life sciences research varies between residents of the participating countries with the highest interest found in Italy and the lowest interest found in Czechia. The high level of interest in Italy compared to Sweden and UK is somewhat surprising in light of previous surveys, such as the VA Barometer that has revealed high levels of interest in research (in general) among Swedish citizens (e.g. Vetenskap & Allmänhet, 2015; 2016). In relation to the other ORION countries, the relatively high interest among the Italian sample is also substantial when compared to the findings from Special Eurobarometer 341 (European Commission, 2010). Although the national Italian survey reveals that biomedical research is prioritised by Italian citizens (Bucchi & Saracino, 2017), that survey also indicates a general skepticism toward science and technology among Italians that could not be confirmed by our data.

The only demographic difference among the Italian sample in our survey is that there is a higher proportion of people with primary level of education compared to people with tertiary education. However, all of these groups expressed a higher level of interest in life sciences than the same groups in the other countries. Hence, the positive views among the Italian sample cannot be explained through any of our background variables but need to be sought in factors not addressed by the data.

According to the data, country of origin is more related to levels of interest than any other demographic variable. The second variable that is related to interest levels is whether respondents have a job related to research. Age and gender have less influence on interest whereas the effect of education level seems to differ among countries. When only considering educational level in a pooled sample, those

who have completed tertiary education are more interested in life sciences research. Among the Italian sample, 95 percent of those with tertiary education and 87 percent of those with only primary education are very or fairly interested in life sciences research whereas the corresponding number for Czech respondents with tertiary education is 44 percent, a lower number than Czech respondents with secondary education (54 percent). The surprising results indicate that more educated, but also younger Czechs, are highly critical towards life sciences research. The higher level of education in all other countries is connected to higher interest in life sciences research.

When asked about their interest in knowing more about specific topics connected to life sciences research, the trend looks largely similar across all demographic variables. Spanish and Italian

respondents show greater interest overall and the topics found to be most interesting are research findings, practical applications of research findings and the methods used in research. Notably, an average of 87 percent wants to know more about research findings providing evidence of a public desire for open access and open data. The least interesting topic in all of the countries, except for Italy, is knowledge about the researchers themselves.

Confidence levels towards life sciences research to a large extent reflects levels of interest with respondents having high levels of interest also expressing high levels of confidence. Italian respondents have the highest confidence and Czech respondents the lowest. Age or level of education does not seem to have any substantial influence on confidence levels.

PUBLIC VIEWS ON INVOLVEMENT IN LIFE SCIENCES RESEARCH

On a general level, respondents from the ORION countries believe that it is important for the general public to be involved in life sciences research. Respondents saying that it is fairly or very important ranged from 68 percent in Czechia to 93 percent in Italy. The positive views on involvement held through all demographic variables (age, gender, level of education and job related to research).

On the question of whether the respondents would be interested in being personally involved, the proportion of positive responses is lower. Citizens from Italy and Spain are most prone to consider personal involvement (84 and 77 percent, respectively), whereas Czech citizens are the least positive toward personal involvement (39 percent). Men tend to be interested in personal involvement to a higher extent than women across all six countries with the largest difference between the two sexes in Czechia (eleven percentage points). This seems connected to men's higher interest in life sciences rather than their higher level of education.

Looking at age differences, the oldest age group

(60–79-year-olds) are least eager to consider personal involvement across all countries. The other age groups show slight differences except for the youngest age group (16–29-year-olds) in Czechia, who were more positive towards personal involvement than other age groups. Other strong correlates for considering personal involvement in research are an interest in life sciences and the opinion that it is important in general for the public to be involved in life sciences research. However, the proportion of respondents expressing the latter opinion is consistently higher than those considering personal involvement. This finding is in line with previously conducted British and Swedish national surveys (Castell et al., 2014; Vetenskap & Allmänhet, 2015).

What are the motivations for involvement in the research process? Although the exact numbers differ between countries and other demographic variables, the order of the options is consistent. The most important motivation for citizens to be involved is that the research topic is interesting to them. This is followed by a belief that they are helping society;

monetary or material rewards; if they know persons involved in the project; and lastly public recognition. The largest difference found in the demographic breakdowns is that the youngest age group would be more motivated by public recognition than people in the oldest age group (a 32 percentage point difference). All of the incentives were more appealing to those respondents who were interested in life sciences research than those who were neutral or not interested.

There are different ways in which citizens could be involved in life sciences research. In the survey, we asked about possible ways of involvement, both to respondents who previously responded that they would be interested in being involved, and as a hypothetical question to those who would not be willing to be involved in the research process. Among those who are positive about involvement, the most attractive methods of involvement are: collaborating with scientists in data collection, giving opinions on research questions/topics, collaborating in data analysis and donating material (such as hair or saliva) in biomedical research. The least attractive ways of involvement are contributing to, and giving opinions about, funding of research projects (specifically among Czech respondents) and giving opinions

about what methods to use in research. Slight differences emerged between gender and age groups (for example, the oldest age group is less inclined to be involved in most of the ways) but the overall pattern is stable and most of the ways of involvement have a relatively high level of acceptance.

For citizens who would not consider personal involvement, and thus responded hypothetically to the question on different ways of being involved, the pattern of responses is a lot more diverse with citizens from different countries as well as age groups preferring different ways of involvement.

When asked about specific research topics that would interest respondents to become involved, a similar pattern (with different numbers) emerges across the demographic variables. All of the topics are of high general interest (ranging from 92 to 77 percent among those who were positive toward personal involvement). The two topics of most interest are understanding the impact of lifestyle on health and that of DNA on health and disease. These are followed closely by understanding the evolution of life and ethical issues connected with life sciences. The pattern is similar among those who would not be interested in personal involvement in the research process.

PUBLIC VIEWS ON GENOME EDITING

On average, over half of the respondents have heard of genome editing. However, awareness ranges from 45 percent in Czechia and Germany to 74 percent in Sweden. It is hard to conclude whether these differences are due to, for example, media coverage or public debates. But considering that interest and confidence in life sciences is higher in both Spain and Italy compared to Sweden, it is insufficient to refer to different levels of interest to explain these results. Men have heard of the technique to a larger extent than women in all of the countries. Respondents from all of the countries except Czechia who had completed tertiary education have heard of

the technique to a larger extent than those who had completed only primary or secondary education. As previously mentioned, Czech respondents with tertiary education are also less interested in life sciences research than those with primary or secondary education, which could explain why they are less aware of genome editing – the difference of four percentage points is neither significant nor substantial. Another finding is that people who previously replied that they are fairly or very confident in life sciences research have heard of genome editing to a larger extent than those who are neutral or do not have confidence. Whether this correlation is because con-

confidence leads to awareness, or the other way around, presents an intriguing future research question.

With regard to purposes for using genome editing, the pattern was similar (although the numbers differ) across the demographic variables. Prevention or cure of diseases, prevention of disabilities and organ transplantation are the three most desired purposes, whereas improvement of plant production, livestock production and changing non-life-limiting characteristics of human embryos ranked lower. Spanish respondents are more positive in general whereas more doubts on specific purposes are found among respondents from Germany (organ transplantation), Sweden (livestock production) and Czechia (improvement of human embryos). The largest difference between genders is found for changing characteristics of human embryos with 44 percent of men supporting this purpose compared to 34 percent of women. As levels of interest and confidence rise, respondents in all of the countries tend to increasingly support genome editing for all purposes. The purpose of genome editing that divides opinion the most is changing non-life-limiting characteristics of human embryos, with perceptions varying strongly across countries, age groups, gender, job related to research, and both interest and confidence in life sciences research.

The largest concern associated with genome editing is that the technique could be misused. The respondents claiming to be very concerned about this range from 34 percent in Sweden to 53 percent in Spain. The second largest concern is that the technology could come with unknown side-effects in humans. Interestingly, levels of concern are only mar-

ginally affected by whether the respondents' job is related to research. Women are slightly more concerned about the potential side-effects and the risk of misuse whereas men are more concerned about insufficient regulation and ethical implications of the technology. All levels of concern seem to decrease with rising age. An intriguing finding is that level of interest in life sciences research seems to be negatively correlated with concerns about genome editing in the sense that the more interested an individual is, the higher the level of concern that is expressed. This result can be found across all four options of concern (side-effects, potential misuse, ethical implications and insufficient regulation).

The results of this survey offer important insights into how the general public in the six countries participating in the ORION project perceive life sciences research, and, more specifically, genome editing. Public attitudes on the OS dimension of 'stakeholder involvement' have also been investigated. These results will now feed into the development of public dialogues and training (for the scientific community), which are at the core of the ORION project. In parallel to this survey directed to the general public, the project has also investigated opinions within the project's partner organisations, by way of interviews with people in leading positions and a survey distributed to the staff working at the RFPOs involved (ORION Deliverable D2.2). The objective has been to get an overall picture of attitudes and practices relating to Open Science within the organisations. Taken together, these parallel studies will lay an important foundation for the rest of the ORION project.

5. REFERENCES

- Bucchi, M., & Saracino, B. (2017). Scienza, tecnologia e opinion pubblica in Italia nel 2016. In B. Saracino (Ed.), *Annuario Scienza Tecnologia e Società 2017* (pp.11–37). Società editrice il Mulino: Bologna.
- Bull, S., Roberts, N., & Parker, M. (2015). Views of Ethical Best Practices in Sharing Individual-Level Data From Medical and Public Health Research: A Systematic Scoping Review. *Journal of Empirical Research on Human Research Ethics*, 10, 225–238.
- Castell, S., Charlton, A., Clemence, M., Pettigrew, N., Pope, S., Quigley, A., ... & Silman, T. (2014). *Public attitudes to science 2014: Main Report*. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/348830/bis-14-p111-public-attitudes-to-science-2014-main.pdf
- Cribb, J., & Sari, T. (2010). *Open science: Shaking knowledge in the global century*. Collingwood: CSIRO Publishing.
- Destro Bisol, G., Anagnostou, P., Capocasa, M., Bencivelli, S., Cerroni, A., Contreras, J., ... & Boulton, G. (2014). Perspectives on Open Science and scientific data sharing: An interdisciplinary workshop. *Journal of Anthropological Sciences*, 92, 179–200.
- European Commission. (2001). *Eurobarometer 55.2: Europeans, science and technology*. Retrieved from <https://ec.europa.eu/research/press/2001/pro612en-report.pdf>
- European Commission. (2003). *Candidate Countries Eurobarometer 2002.3 on Science and Technology*. Retrieved from http://ec.europa.eu/commfrontoffice/publicopinion/archives/cceb/2002/2002.3_science_technology.pdf
- European Commission. (2005). *Special Eurobarometer 224: Europeans, science and technology*. Retrieved from http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_224_report_en.pdf
- European Commission. (2010). *Special Eurobarometer 341: Biotechnology*. Retrieved from http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_341_en.pdf
- European Commission. (2013). *Special Eurobarometer 401: Responsible Research and Innovation (RRI), Science and Technology*. Retrieved from http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_401_sum_en.pdf
- European Commission. (2016). *Open Innovation, Open Science, Open to the World – a vision for Europe*. Retrieved from <https://publications.europa.eu/en/publication-detail/-/publication/3213b335-1c6c-11e6-ba9a-01aa75ed71a1>
- European Research Area. (2015). *Assessment of progress in achieving ERA in Member States and Associated Countries*. Retrieved from http://ec.europa.eu/research/era/pdf/era-communication/era_final_report_2015.pdf

- Fecher, B., & Friesike, S. (2014). Open science: One term, Five schools of thought. In S. Bartling & S. Friesike (Eds.), *Opening science* (pp. 17–47). Springer: Cham.
- FECYT. (2017). *Percepción social de la ciencia y la tecnología 2016*. Retrieved from: <https://www.fecyt.es/es/publicacion/percepcion-social-de-la-ciencia-y-la-tecnologia-en-espana-2016>
- Gaskell, G., Allansdottir, A., Allum, N., Castro, P., Esmer, Y., Fischler, C., ... & Wager, W. (2011). The 2010 Eurobarometer on the life sciences. *Nature Biotechnology*, 29(2), 113–114.
- Gaskell, G., Bard, I., Allansdottir, A., da Cunha, R. V., Eduard, P., Hampel, J., ... & Zwart, H. (2017). Public views on gene editing and its uses. *Nature Biotechnology*, 35(11), 1021–1023.
- Hand, E. (2010). Citizen science: People power. *Nature*, 466, 685–687.
- Nosek, B. A., Alter, G., Banks, G. C., Borsboom, D., Bowman, S. D., Breckler, S. J., ... & Contestabile, M. (2015). Promoting an open research culture. *Science*, 348, 1422–1425.
- O’Connell, M. R., Oakes, B. L., Sternberg, S. H., East-Seletsky, A., Kaplan, M., & Doudna, J. A. (2014). Programmable RNA recognition and cleavage by CRISPR/Cas9. *Nature*, 516, 263–266.
- Socientize Consortium / European Commission. (2013). *Green paper on Citizen Science for Europe: Towards a society of empowered citizens and enhanced research*. Retrieved from <https://ec.europa.eu/digital-single-market/en/news/green-paper-citizen-science-europe-towards-society-empowered-citizens-and-enhanced-research>
- Vetenskap & Allmänhet. (2014). *VA Barometer 2014/2015*. Retrieved from <https://v-a.se/downloads/201412-VA-barometern2014-english.pdf>
- Vetenskap & Allmänhet. (2015). *VA Barometer 2015/2016*. Retrieved from https://v-a.se/downloads/varapport2015_6_eng.pdf
- Vetenskap & Allmänhet. (2016). *VA Barometer 2016/2017*. Retrieved from https://v-a.se/downloads/varapport2016_4_eng.pdf
- Wissenschaft im Dialog/Kantar Emnid (2017). *Science Barometer 2017*. Retrieved from https://www.wissenschaft-im-dialog.de/fileadmin/user_upload/Projekte/Wissenschaftsbarometer/Dokumente_17/Einzelgrafiken/Sciencebarometer2017_brochure_web.pdf

APPENDIX A: COUNTRY SHEETS

This appendix includes 'Country sheets' with all data relating to each of the participating countries.

	Total	Male	Female
No. of respondents	997	465	532
Interest in life sciences research (%)			
Very interested or fairly interested	52	57	47
Confidence in life sciences research (%)			
Very or fairly high confidence	51	56	48
Is there anything you would like to know more about in life sciences? (% yes)			
How research topics are selected	70	65	75
The methods used in research	77	73	80
Research findings	93	90	95
Practical applications of research findings	82	78	85
Ethical issues connected to the research	66	58	73
The researchers themselves	50	49	52
How research is funded	70	68	72
How research is communicated to society	75	72	79
Other	23	22	23
How important is it that the public gets involved in life sciences? (%)			
Very or fairly important	69	68	68
Would you consider being involved personally in life sciences research? (%)			
Yes	39	45	34
Would you prefer to be involved in any of these options? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Giving my opinion about which research projects should be funded	63	65	61
Giving my opinion about what could be looked for or asked in a research study	65	63	67
Giving my opinion about what methods and procedures to use or not to use	45	46	44
Giving my opinion on how to use the findings	60	61	60
Contributing to the funding of research projects, e.g. through helping to raise money	33	30	36
Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)	71	68	74
Collaborating in the analysis of data (e.g., helping to sort images of birds)	68	62	72
Donating material needed for biomedical research (e.g., hair or saliva)	67	63	71
Would any of the following research topics be of interest to you? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Understanding how our DNA influences our health and disease	87	86	89
Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth	70	69	71
Understanding the impact of our life style on our health	87	83	90
Understanding the ethical issues connected with life sciences	60	56	64
What, if any, of the following would motivate you to get involved in research? (% yes)			
Monetary or material incentives	78	79	78
Public recognition (e.g. if my name was mentioned in the project)	36	39	33
If people I know were involved	61	58	63
A belief that my involvement would help society	86	84	88
If the research topic was interesting to me	93	92	94
Have you ever heard of the technique called genome editing? (%)			
Yes	45	52	39
For what purpose do you think genome editing should be used? (% yes)			
For organ transplantation	85	83	87
For prevention or cure of diseases	92	90	93
For prevention of disabilities	85	85	84
For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)	29	31	28
For improvement of plant production	50	49	50
For improvement of livestock production	48	48	47
Regarding genome editing, how concerned are you about any of the following? (% very or fairly concerned)			
That sufficient regulation is not in place	53	49	55
The ethical implications regarding any use of this technology	49	46	52
That the technology could be misused	73	69	75
That the technology may come with unknown side-effects in human beings	65	62	68

AGE				HIGHEST LEVEL OF EDUCATION			JOB RELATED TO RESEARCH	
16-29	30-44	45-59	60-79	Primary	Secondary	Tertiary	In any possible way	No
195	318	233	251	109	677	211	43	954
54	48	52	57	57	54	44	66	51
56	52	51	47	60	49	53	56	51
69	66	70	76	69	70	70	84	70
77	81	75	73	74	78	74	91	76
92	93	90	95	94	93	91	93	93
79	80	80	87	82	82	81	93	81
65	61	61	71	64	65	68	66	66
55	51	51	47	53	50	48	46	50
63	68	68	76	58	71	74	72	70
67	73	73	80	71	76	75	81	75
29	22	22	21	24	22	23	40	22
70	64	70	72	70	69	66	75	68
48	39	39	31	45	40	32	63	38
66	64	61	61	71	60	68	70	63
66	67	65	64	70	66	61	88	64
55	46	44	37	55	44	46	63	44
57	63	55	65	53	60	63	83	59
42	34	32	26	38	30	39	50	32
68	74	71	71	65	72	72	83	71
71	71	65	64	66	68	69	83	67
69	66	64	71	66	66	71	86	67
86	88	86	89	90	86	89	95	87
73	78	63	65	74	70	69	84	69
88	85	84	90	91	86	86	95	86
60	61	57	62	59	60	62	71	60
84	82	80	67	84	78	74	81	78
58	42	24	21	52	36	27	48	35
71	63	53	56	68	61	57	63	60
81	87	88	88	80	87	86	100	85
90	93	94	93	90	94	90	98	93
46	47	44	43	46	46	42	67	44
81	86	87	86	78	87	83	90	85
85	93	92	95	85	92	93	93	92
79	86	82	89	77	86	83	95	84
38	36	21	23	35	29	29	49	28
51	49	48	52	44	49	55	68	49
44	50	46	50	40	48	52	60	47
47	49	58	56	48	51	58	54	52
48	43	51	56	47	48	54	47	49
67	69	75	79	66	73	73	74	72
63	62	66	70	59	65	69	70	65

	Total	Male	Female
No. of respondents	986	495	491
Interest in life sciences research (%)			
Very interested or fairly interested	75	75	74
Confidence in life sciences research (%)			
Very or fairly high confidence	57	61	53
Is there anything you would like to know more about in life sciences? (% yes)			
How research topics are selected	65	62	68
The methods used in research	73	73	73
Research findings	85	84	85
Practical applications of research findings	79	81	77
Ethical issues connected to the research	64	62	67
The researchers themselves	44	44	44
How research is funded	57	59	55
How research is communicated to society	67	66	67
Other	24	21	26
How important is it that the public gets involved in life sciences? (%)			
Very or fairly important	83	84	83
Would you consider being involved personally in life sciences research? (%)			
Yes	65	67	64
Would you prefer to be involved in any of these options? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Giving my opinion about which research projects should be funded	73	72	75
Giving my opinion about what could be looked for or asked in a research study	73	73	72
Giving my opinion about what methods and procedures to use or not to use	58	59	58
Giving my opinion on how to use the findings	60	61	59
Contributing to the funding of research projects, e.g. through helping to raise money	38	38	38
Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)	70	69	71
Collaborating in the analysis of data (e.g., helping to sort images of birds)	65	61	70
Donating material needed for biomedical research (e.g., hair or saliva)	63	62	64
Would any of the following research topics be of interest to you? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Understanding how our DNA influences our health and disease	84	81	87
Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth	78	79	78
Understanding the impact of our life style on our health	86	87	84
Understanding the ethical issues connected with life sciences	69	69	69
What, if any, of the following would motivate you to get involved in research? (% yes)			
Monetary or material incentives	66	66	66
Public recognition (e.g. if my name was mentioned in the project)	36	38	34
If people I know were involved	55	58	52
A belief that my involvement would help society	74	74	74
If the research topic was interesting to me	87	86	87
Have you ever heard of the technique called genome editing? (%)			
Yes	45	53	38
For what purpose do you think genome editing should be used? (% yes)			
For organ transplantation	70	71	70
For prevention or cure of diseases	86	88	85
For prevention of disabilities	77	78	77
For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)	33	37	30
For improvement of plant production	49	53	44
For improvement of livestock production	43	47	39
Regarding genome editing, how concerned are you about any of the following? (% very or fairly concerned)			
That sufficient regulation is not in place	65	62	67
The ethical implications regarding any use of this technology	64	59	69
That the technology could be misused	77	74	80
That the technology may come with unknown side-effects in human beings	73	70	77

AGE				HIGHEST LEVEL OF EDUCATION			JOB RELATED TO RESEARCH	
16–29	30–44	45–59	60–79	Primary	Secondary	Tertiary	In any possible way	No
178	203	295	310	151	594	241	98	888
75	79	77	70	72	72	83	90	74
61	62	58	52	60	49	53	73	55
69	69	67	58	60	64	70	77	64
75	81	74	66	71	73	74	87	71
85	86	87	82	84	84	88	92	84
76	81	79	79	75	76	88	86	78
59	66	67	63	55	63	73	71	64
45	49	47	39	45	43	47	57	43
51	60	59	57	49	56	65	73	56
65	67	66	68	58	65	75	72	66
26	30	22	20	24	26	18	27	23
83	84	84	82	85	82	84	83	83
74	74	69	52	66	66	63	85	63
79	74	76	67	76	73	72	75	73
78	73	73	69	75	70	77	83	72
65	56	63	52	63	57	58	67	57
68	56	61	58	62	59	63	67	60
46	47	37	28	36	38	38	53	36
65	74	75	66	67	69	74	86	68
68	71	69	56	64	68	58	71	65
69	65	66	55	66	62	62	67	62
80	87	82	85	86	83	84	85	84
78	82	79	76	79	79	76	88	77
84	85	86	87	85	85	88	92	85
71	68	71	67	70	66	75	80	68
82	72	65	53	62	70	56	64	66
53	46	33	21	36	38	30	41	35
63	55	55	51	57	55	54	61	55
74	75	75	73	72	75	74	80	74
84	88	88	85	81	87	88	93	86
56	46	45	38	38	40	62	71	42
73	72	70	68	71	70	71	77	70
84	85	87	87	86	86	86	82	87
78	79	76	78	82	75	82	74	78
50	42	25	26	36	32	34	42	32
48	48	48	49	53	46	51	54	48
49	41	43	40	48	41	46	47	42
56	54	68	72	58	63	72	64	65
57	56	68	70	57	63	72	66	64
73	66	81	84	80	75	83	73	78
71	66	77	77	71	72	78	73	74

	Total	Male	Female
No. of respondents	970	483	487
Interest in life sciences research (%)			
Very interested or fairly interested	90	91	90
Confidence in life sciences research (%)			
Very or fairly high confidence	92	91	93
Is there anything you would like to know more about in life sciences? (% yes)			
How research topics are selected	81	78	85
The methods used in research	89	86	91
Research findings	94	95	94
Practical applications of research findings	88	87	89
Ethical issues connected to the research	73	71	74
The researchers themselves	78	76	81
How research is funded	78	77	78
How research is communicated to society	81	79	84
Other	36	34	38
How important is it that the public gets involved in life sciences? (%)			
Very or fairly important	94	92	95
Would you consider being involved personally in life sciences research? (%)			
Yes	84	85	82
Would you prefer to be involved in any of these options? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Giving my opinion about which research projects should be funded	79	79	78
Giving my opinion about what could be looked for or asked in a research study	77	79	76
Giving my opinion about what methods and procedures to use or not to use	64	67	61
Giving my opinion on how to use the findings	75	76	73
Contributing to the funding of research projects, e.g. through helping to raise money	55	52	57
Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)	76	74	78
Collaborating in the analysis of data (e.g., helping to sort images of birds)	69	65	72
Donating material needed for biomedical research (e.g., hair or saliva)	71	66	75
Would any of the following research topics be of interest to you? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Understanding how our DNA influences our health and disease	92	91	92
Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth	86	88	83
Understanding the impact of our life style on our health	94	93	95
Understanding the ethical issues connected with life sciences	78	76	80
What, if any, of the following would motivate you to get involved in research? (% yes)			
Monetary or material incentives	68	69	67
Public recognition (e.g. if my name was mentioned in the project)	44	45	43
If people I know were involved	52	54	50
A belief that my involvement would help society	85	85	85
If the research topic was interesting to me	91	90	92
Have you ever heard of the technique called genome editing? (%)			
Yes	54	56	52
For what purpose do you think genome editing should be used? (% yes)			
For organ transplantation	85	86	84
For prevention or cure of diseases	93	93	93
For prevention of disabilities	89	89	90
For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)	47	51	42
For improvement of plant production	63	62	64
For improvement of livestock production	56	54	59
Regarding genome editing, how concerned are you about any of the following? (% very or fairly concerned)			
That sufficient regulation is not in place	80	78	81
The ethical implications regarding any use of this technology	70	67	73
That the technology could be misused	84	82	85
That the technology may come with unknown side-effects in human beings	81	80	83

AGE				HIGHEST LEVEL OF EDUCATION			JOB RELATED TO RESEARCH	
16-29	30-44	45-59	60-79	Primary	Secondary	Tertiary	In any possible way	No
173	259	296	242	447	383	140	78	892
88	91	91	84	87	92	95	94	90
88	92	94	91	89	93	97	95	91
80	84	83	78	80	81	86	93	80
92	87	90	87	89	88	88	88	89
94	93	95	95	95	94	96	94	95
87	85	89	91	87	89	88	87	88
62	72	77	76	70	74	77	76	72
75	75	81	80	76	81	78	81	78
69	76	82	81	79	77	78	73	78
74	85	83	80	81	81	84	78	82
34	40	40	28	36	36	36	47	35
91	96	95	92	92	96	94	96	94
86	90	86	71	80	86	87	95	83
82	84	79	71	76	79	89	93	78
79	84	77	69	75	78	85	86	77
60	72	66	56	61	64	72	83	62
68	77	79	71	71	76	82	80	74
54	63	55	45	49	57	65	65	54
77	83	77	66	73	78	79	82	75
71	77	69	56	65	70	77	80	68
70	72	74	65	67	72	77	78	70
88	92	95	90	89	94	94	93	91
83	87	89	82	85	86	86	91	85
91	96	94	93	92	95	97	96	94
75	77	84	75	77	79	82	80	78
73	71	74	55	69	67	70	76	67
58	51	47	26	43	44	50	61	43
53	56	54	44	52	51	56	64	51
75	89	88	86	84	88	85	88	85
89	93	92	89	89	92	92	96	90
62	54	56	46	48	55	72	78	52
79	84	86	89	85	86	82	80	85
86	92	96	96	94	94	90	88	94
84	90	89	94	88	90	92	85	90
53	55	41	40	45	47	53	58	45
68	65	61	61	63	60	71	68	63
61	57	55	54	55	56	61	58	56
71	78	84	82	77	81	82	83	79
64	69	72	71	69	68	75	74	69
81	80	86	87	82	86	82	79	84
76	80	84	84	81	83	80	83	81

	Total	Male	Female
No. of respondents	961	471	490
Interest in life sciences research (%)			
Very interested or fairly interested	65	66	70
Confidence in life sciences research (%)			
Very or fairly high confidence	70	73	67
Is there anything you would like to know more about in life sciences? (% yes)			
How research topics are selected	77	76	78
The methods used in research	82	82	82
Research findings	89	88	89
Practical applications of research findings	89	89	89
Ethical issues connected to the research	77	77	76
The researchers themselves	63	65	62
How research is funded	77	76	78
How research is communicated to society	84	84	84
Other	51	51	52
How important is it that the public gets involved in life sciences? (%)			
Very or fairly important	82	82	82
Would you consider being involved personally in life sciences research? (%)			
Yes	77	78	76
Would you prefer to be involved in any of these options? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Giving my opinion about which research projects should be funded	78	80	76
Giving my opinion about what could be looked for or asked in a research study	79	80	79
Giving my opinion about what methods and procedures to use or not to use	63	64	63
Giving my opinion on how to use the findings	76	77	74
Contributing to the funding of research projects, e.g. through helping to raise money	51	53	50
Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)	76	77	75
Collaborating in the analysis of data (e.g., helping to sort images of birds)	74	73	74
Donating material needed for biomedical research (e.g., hair or saliva)	67	70	66
Would any of the following research topics be of interest to you? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Understanding how our DNA influences our health and disease	91	92	91
Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth	82	82	82
Understanding the impact of our life style on our health	90	90	90
Understanding the ethical issues connected with life sciences	77	78	76
What, if any, of the following would motivate you to get involved in research? (% yes)			
Monetary or material incentives	74	77	72
Public recognition (e.g. if my name was mentioned in the project)	41	46	36
If people I know were involved	48	52	5
A belief that my involvement would help society	89	89	88
If the research topic was interesting to me	90	90	89
Have you ever heard of the technique called genome editing? (%)			
Yes	62	65	60
For what purpose do you think genome editing should be used? (% yes)			
For organ transplantation	90	90	90
For prevention or cure of diseases	96	96	95
For prevention of disabilities	93	93	93
For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)	49	57	42
For improvement of plant production	67	71	64
For improvement of livestock production	55	59	51
Regarding genome editing, how concerned are you about any of the following? (% very or fairly concerned)			
That sufficient regulation is not in place	75	74	75
The ethical implications regarding any use of this technology	65	64	65
That the technology could be misused	83	82	83
That the technology may come with unknown side-effects in human beings	81	79	82

AGE				HIGHEST LEVEL OF EDUCATION			JOB RELATED TO RESEARCH	
16-29	30-44	45-59	60-79	Primary	Secondary	Tertiary	In any possible way	No
182	312	276	91	401	250	310	87	874
74	70	61	54	54	64	80	91	63
72	74	69	66	58	73	84	93	68
77	79	77	72	71	76	85	90	76
79	85	82	79	77	84	87	90	81
87	88	89	90	86	90	90	91	88
83	89	92	90	84	89	94	94	88
73	77	79	76	72	75	84	87	75
59	65	65	62	59	66	67	70	63
73	77	78	78	75	74	81	87	76
82	82	87	83	79	86	88	86	83
54	53	52	46	51	51	53	49	52
84	82	80	82	77	87	86	94	81
80	80	77	69	68	78	87	95	75
81	81	77	70	75	78	81	83	77
83	82	81	69	74	79	87	80	78
66	70	61	55	61	62	68	74	62
72	81	72	76	71	78	80	86	75
61	54	52	35	43	57	57	63	50
76	80	74	71	69	78	83	91	75
75	76	75	68	68	75	81	81	73
67	71	68	62	61	73	71	69	67
90	90	93	91	89	90	95	92	91
82	85	80	81	78	87	84	91	81
89	89	93	90	88	90	94	94	90
76	76	80	75	73	79	81	86	76
78	76	73	70	70	78	77	79	74
58	46	34	29	40	41	43	58	40
59	53	41	41	46	49	51	62	47
85	88	91	90	85	90	92	89	89
89	89	92	88	88	90	91	89	90
71	65	61	52	50	67	74	80	61
86	89	94	90	88	94	90	90	91
92	95	97	97	94	97	97	99	95
87	93	97	93	91	95	94	96	93
47	52	49	46	49	48	50	63	48
69	68	69	63	65	64	73	75	67
50	52	59	57	55	55	54	59	54
72	73	77	74	67	80	76	74	75
67	63	62	69	63	67	64	65	65
81	79	85	87	80	84	84	83	82
79	78	81	86	79	85	79	77	81

	Total	Male	Female
No. of respondents	992	462	530
Interest in life sciences research (%)			
Very interested or fairly interested	63	67	59
Confidence in life sciences research (%)			
Very or fairly high confidence	63	63	63
Is there anything you would like to know more about in life sciences? (% yes)			
How research topics are selected	59	62	57
The methods used in research	68	68	68
Research findings	82	84	81
Practical applications of research findings	75	78	72
Ethical issues connected to the research	65	61	69
The researchers themselves	40	41	39
How research is funded	61	64	59
How research is communicated to society	71	73	69
Other	13	14	13
How important is it that the public gets involved in life sciences? (%)			
Very or fairly important	78	76	80
Would you consider being involved personally in life sciences research? (%)			
Yes	68	69	67
Would you prefer to be involved in any of these options? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Giving my opinion about which research projects should be funded	45	52	38
Giving my opinion about what could be looked for or asked in a research study	65	65	65
Giving my opinion about what methods and procedures to use or not to use	56	53	59
Giving my opinion on how to use the findings	67	64	69
Contributing to the funding of research projects, e.g. through helping to raise money	33	35	31
Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)	67	69	65
Collaborating in the analysis of data (e.g., helping to sort images of birds)	59	59	58
Donating material needed for biomedical research (e.g., hair or saliva)	67	63	71
Would any of the following research topics be of interest to you? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Understanding how our DNA influences our health and disease	83	81	86
Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth	70	71	68
Understanding the impact of our life style on our health	82	80	85
Understanding the ethical issues connected with life sciences	63	62	64
What, if any, of the following would motivate you to get involved in research? (% yes)			
Monetary or material incentives	59	64	55
Public recognition (e.g. if my name was mentioned in the project)	30	32	27
If people I know were involved	50	50	51
A belief that my involvement would help society	79	77	80
If the research topic was interesting to me	87	86	88
Have you ever heard of the technique called genome editing? (%)			
Yes	74	78	70
For what purpose do you think genome editing should be used? (% yes)			
For organ transplantation	79	80	79
For prevention or cure of diseases	88	88	88
For prevention of disabilities	75	79	72
For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)	32	40	26
For improvement of plant production	49	55	44
For improvement of livestock production	34	40	29
Regarding genome editing, how concerned are you about any of the following? (% very or fairly concerned)			
That sufficient regulation is not in place	57	56	59
The ethical implications regarding any use of this technology	57	49	64
That the technology could be misused	71	66	75
That the technology may come with unknown side-effects in human beings	65	62	68

AGE				HIGHEST LEVEL OF EDUCATION			JOB RELATED TO RESEARCH	
16-29	30-44	45-59	60-79	Primary	Secondary	Tertiary	In any possible way	No
191	264	256	281	156	474	362	93	899
69	67	61	56	48	56	78	92	60
66	65	66	55	53	62	68	78	61
61	61	60	57	53	57	65	74	58
70	68	72	64	68	68	69	73	68
82	82	87	79	76	79	89	90	82
69	70	79	80	67	71	84	78	75
65	65	67	64	63	61	73	74	64
38	43	42	37	42	37	43	52	39
58	63	62	61	57	57	69	72	60
69	70	68	74	65	68	77	79	70
19	17	14	6	14	13	14	17	13
74	78	80	79	70	76	84	94	77
72	77	74	53	50	67	78	87	66
49	49	48	34	36	44	49	63	43
64	67	67	61	57	61	73	87	62
59	60	58	49	53	57	57	77	54
65	66	67	68	59	62	75	82	65
43	40	34	18	36	32	33	46	31
61	72	73	61	58	65	74	80	66
61	64	63	48	54	59	60	73	57
67	72	71	60	66	67	68	73	67
81	87	86	80	79	83	86	85	83
72	72	75	61	68	68	73	82	68
83	83	87	77	78	80	88	88	82
58	67	67	58	61	59	68	71	62
59	76	62	42	47	56	68	66	59
43	39	30	11	32	27	32	46	28
66	58	47	36	48	49	54	57	50
77	83	81	73	74	75	85	92	77
86	89	89	85	79	86	92	92	87
72	72	80	71	65	72	81	82	73
74	82	81	78	74	78	84	83	79
84	88	90	89	86	87	89	91	87
67	78	78	76	69	74	80	86	74
37	41	27	25	35	30	34	44	31
53	55	48	43	54	48	49	60	48
33	40	34	29	38	31	36	48	33
47	54	59	68	50	57	62	62	57
47	54	60	65	49	55	63	63	57
63	66	73	79	64	70	75	71	71
58	60	71	71	65	63	69	67	65

	Total	Male	Female
No. of respondents	964	483	481
Interest in life sciences research (%)			
Very interested or fairly interested	65	68	61
Confidence in life sciences research (%)			
Very or fairly high confidence	56	63	51
Is there anything you would like to know more about in life sciences? (% yes)			
How research topics are selected	66	68	64
The methods used in research	67	68	65
Research findings	77	78	77
Practical applications of research findings	68	72	64
Ethical issues connected to the research	63	64	62
The researchers themselves	44	44	44
How research is funded	59	59	59
How research is communicated to society	66	65	67
Other	17	18	15
How important is it that the public gets involved in life sciences? (%)			
Very or fairly important	78	79	77
Would you consider being involved personally in life sciences research? (%)			
Yes	68	72	65
Would you prefer to be involved in any of these options? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Giving my opinion about which research projects should be funded	65	66	64
Giving my opinion about what could be looked for or asked in a research study	64	65	63
Giving my opinion about what methods and procedures to use or not to use	51	54	47
Giving my opinion on how to use the findings	59	62	57
Contributing to the funding of research projects, e.g. through helping to raise money	43	45	41
Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)	69	68	70
Collaborating in the analysis of data (e.g., helping to sort images of birds)	63	63	63
Donating material needed for biomedical research (e.g., hair or saliva)	62	60	63
Would any of the following research topics be of interest to you? (% yes) <small>Pooled results for respondents who would, and would not, consider personal involvement in life sciences research</small>			
Understanding how our DNA influences our health and disease	81	78	83
Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth	73	75	71
Understanding the impact of our life style on our health	82	81	83
Understanding the ethical issues connected with life sciences	65	68	61
What, if any, of the following would motivate you to get involved in research? (% yes)			
Monetary or material incentives	60	63	57
Public recognition (e.g. if my name was mentioned in the project)	29	35	24
If people I know were involved	49	50	47
A belief that my involvement would help society	78	76	79
If the research topic was interesting to me	85	84	86
Have you ever heard of the technique called genome editing? (%)			
Yes	51	60	43
For what purpose do you think genome editing should be used? (% yes)			
For organ transplantation	81	80	82
For prevention or cure of diseases	87	86	87
For prevention of disabilities	82	82	82
For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)	41	46	36
For improvement of plant production	62	65	59
For improvement of livestock production	57	63	51
Regarding genome editing, how concerned are you about any of the following? (% very or fairly concerned)			
That sufficient regulation is not in place	64	62	67
The ethical implications regarding any use of this technology	67	64	69
That the technology could be misused	76	75	77
That the technology may come with unknown side-effects in human beings	75	73	79

AGE				HIGHEST LEVEL OF EDUCATION			JOB RELATED TO RESEARCH	
16-29	30-44	45-59	60-79	Primary	Secondary	Tertiary	In any possible way	No
182	303	256	223	223	334	407	154	810
68	72	65	53	56	55	78	91	60
52	64	54	54	50	47	68	84	51
65	72	64	60	58	61	74	80	63
69	67	67	64	62	63	72	73	65
75	77	78	80	73	75	82	83	76
66	68	70	69	61	63	76	73	67
65	65	60	61	55	58	70	70	61
51	46	43	37	41	38	51	56	42
65	53	61	61	57	56	63	75	56
67	69	63	65	60	64	71	71	65
23	21	11	12	14	15	19	25	15
78	80	81	72	74	74	84	92	75
69	74	71	58	62	65	75	88	65
72	71	61	54	66	56	71	79	62
68	69	62	58	61	60	70	76	62
56	56	47	43	50	46	55	68	47
64	58	60	55	57	56	63	66	58
58	54	34	25	41	38	48	57	40
70	68	75	63	69	67	71	74	68
72	66	61	53	63	57	67	72	61
61	62	65	58	56	61	66	68	60
85	81	83	75	76	80	84	81	81
81	77	70	64	69	71	76	82	71
83	84	80	81	79	81	84	88	81
73	71	62	52	54	62	72	79	62
63	69	62	45	55	56	66	70	59
45	42	18	13	31	23	34	47	26
60	56	43	36	47	47	51	64	46
79	75	82	75	73	77	81	81	77
79	85	90	86	77	85	90	90	84
54	58	46	47	45	38	66	75	47
77	80	83	84	79	81	83	87	80
80	82	92	93	83	88	88	91	86
75	78	85	90	78	86	81	80	83
50	51	32	31	40	35	47	52	39
64	64	60	60	56	57	68	67	61
59	60	55	53	52	55	61	64	56
54	61	71	71	59	62	70	79	62
61	68	71	64	55	64	75	77	64
67	75	77	82	70	73	81	85	74
70	74	77	82	71	73	81	85	74

APPENDIX B: QUESTIONNAIRES

Appendix B contains all of the questionnaires in the same order as the results presented in the graphs: Czechia, Germany, Italy, Spain, Sweden and the UK. The English questionnaire was used as a master

questionnaire, English being the working language of the ORION project, and the other language versions were translated based on the final English version.

CZECHIA

Introduction from the interviewer

Dobrý den, jmenuji se xxx.
Volám v rámci Evropského projektu ORION, jehož cílem je zajistit, aby veřejnost byla lépe informována o výzkumu věd o živé přírodě. Tyto vědy zkoumají živé organismy, tedy lidské bytosti, zvířata, rostliny nebo bakterie, a zahrnují biologii, genetiku, neurovědy a medicínu. Bylo by velmi užitečné slyšet vaše názory na to, jak se lidé mohou výzkumu věd o živé přírodě zúčastnit. Vaše odpovědi budou anonymní a průzkum bude trvat přibližně 10 minut. Jste ochoten/ochotna se zúčastnit?

Background variables

Q1. Věk:

bez odpovědi (prosím, nečtěte)

Q2. Pohlaví:

muž

žena

bez odpovědi (prosím, nečtěte)

Q3. Jaká je vaše nejvyšší dosažená úroveň vzdělání?

Bez ukončeného vzdělání

Základní škola

Praktická škola

První čtyři roky osmiletých SŠ

První dva roky šestiletých SŠ

Střední škola s maturitou

Střední škola bez maturity

Pomaturitní jazyková škola

Vysoká škola – bakalářské

Vysoká škola – magisterské

Vysoká škola – doktorské

Vyšší odborná škola

bez odpovědi (prosím, nečtěte)

Q4. Souvisí nějak vaše práce s výzkumem?

- a) Ano, pracuji jako výzkumný pracovník/ výzkumná pracovnice
- b) Ano, má práce souvisí s výzkumem, ale výzkumný pracovník/ výzkumná pracovnice nejsem
- c) Ne, ale bylo tomu tak v předchozích pozicích
- d) Ne

bez odpovědi (prosím, nečtěte)

Poznámka pro tazatele, v případě že respondent potřebuje vysvětlení.

Alternativy pro a) může být PhD student/ka, postdoc, hlavní řešitel/ka, profesor/ka, lektor/ka.

Alternativy pro b) může být vydavatel/ka, sponzor, práce ve firmě související s výzkumem, profesní organizace

General questions (interest, confidence, etc.)**Q5. Napřed bychom se vás zeptali, nakolik vás výzkum věd o živé přírodě zajímá. Zajímá vás...**

- a) Velmi
- b) Celkem dost
- c) Tak napůl
- d) Celkem málo
- e) Vůbec

bez odpovědi (prosím, nečtěte)

Q6. Jak velkou důvěru ve výzkum věd o živé přírodě máte? Máte...

- a) Velmi velkou důvěru
- b) Celkem velkou důvěru
- c) Středně velkou důvěru
- d) Celkem malou důvěru
- e) Velmi malou důvěru

bez odpovědi (prosím, nečtěte)

Q7. Je něco z následujících věcí, o čem byste v souvislosti s výzkumem v oblasti věd o živé přírodě chtěl/a vědět více?

Ano, ne, bez odpovědi (prosím nečtěte)

- a) Jak se témata výzkumu vybírají
- b) Jaké jsou metody používané při výzkumu
- c) Jaké jsou výsledky výzkumu

- d) Jaké jsou praktické aplikace výsledků výzkumu
- e) O etických otázkách souvisejících s výzkumem
- f) O samotných výzkumnících
- g) Jak je výzkum financován
- h) Jak se o výzkumu informuje společnost
- i) O něčem jiném

Personal engagement

Lidé mohou získávat informace o výzkumu, ale také mohou k výzkumu přispět sdílením svých vlastních nápadů, znalostí nebo zkušeností. Mohou se účastnit diskuzí o otázkách a metodách výzkumu, rozhodovat o jeho financování. Také se mohou přímo účastnit sběru nebo analýzy dat nebo darovat výzkumný materiál.

Q8. Jak důležité podle vašeho názoru je, aby se veřejnost do výzkumu věd o živé přírodě zapojila? Je to...

- a) Velmi důležité
 - b) Celkem důležité
 - c) Středně důležité
 - d) Celkem nedůležité
 - e) Naprosto nedůležité
- bez odpovědi (prosím, nečtěte)

Q9. Uvažoval/a jste o tom, že byste se do výzkumu věd o živé přírodě osobně zapojil/a?

- a) Ano
 - b) Ne
- bez odpovědi (prosím, nečtěte)

Q10. Kterým z následujících způsobů byste se chtěl/a zapojit?

OR

Q11. Odpověděl/a jste, že se zapojovat nechcete. Zkuste si ale prosím představit, že byste se do výzkumu zapojil/a. Chtěl/a byste se zapojit některými z následujících způsobů?

Ano, ne, bez odpovědi (prosím nečtěte)

- a) Poskytnutím názoru na to, které výzkumné projekty by měly být financovány

- b) Poskytnutím názoru na to, co by se ve výzkumu mělo zjišťovat nebo na co se ptát
- c) Poskytnutím názoru na to, jaké metody a postupy použít a jaké ne
- d) Poskytnutím názoru na to, jak využít výzkumná zjištění
- e) Příspěním k financování výzkumných projektů, například pomáhat se sháněním finanční podpory
- f) Spoluprací s vědci při sběru dat (například počítat ptáky na vaší zahradě)
- g) Spoluprací při analýze dat (například pomáhat třídít obrázky ptáků)
- h) Darováním materiálů potřebných pro biomedicínský výzkum (např. vlasy nebo sliny)

Q12. Máte zájem zapojit se do výzkumu na následující témata?

OR

Q13. Pokud byste se nějakým způsobem měl/a zapojit do výzkumu, zajímala by vás některá z následujících témat?

- Ano, ne, bez odpovědi (prosím nečtěte)
- a) Zkoumání toho, jak naše DNA ovlivňuje naše zdraví a nemoci
 - b) Zkoumání toho, jak se živé organismy (viry, bakterie, zvířata nebo lidé) na zemi vyvíjely
 - c) Zkoumání důsledků našeho životního stylu na naše zdraví
 - d) Porozumění etickým otázkám souvisejících s vědami o živé přírodě

Q14. Lidé se do výzkumu mohou zapojit z nejrůznějších důvodů. Motivovaly by některé z následujících důvodů vás?

- Ano, ne, bez odpovědi (prosím nečtěte)
- a) Finanční nebo hmotné odměny
 - b) Veřejné uznání (například, kdyby v projektu bylo uvedeno mé jméno)
 - c) Kdyby se také zapojili lidé, které znám
 - d) Pokud bych věřil/a, že moje zapojení pomůže společnosti
 - e) Kdyby pro mě téma výzkumu bylo zajímavé

Q15. Už jste někdy slyšel/a o vědecké metodě, která umožňuje úpravy (to znamená vkládání, odstraňování nebo nahrazování) částí DNA v buňkách a živých organismech? Tato metoda se nazývá editace genomu.

- a) Ano
 - b) Ne
- bez odpovědi (prosím, nečtěte)

Q16. K čemu myslíte, že by se editace genomu měla používat? Měla by se používat...

- Ano, ne, bez odpovědi (prosím nečtěte)
- a) Pro transplantaci orgánů
 - b) Pro prevenci nebo léčení chorob
 - c) Pro prevenci postižení
 - d) Pro změnu charakteristik; lidských embryí, které nejsou přímo ohrožující pro zdraví (například výběr barvy očí nebo zlepšení imunity)
 - e) Pro zlepšování rostlinné výroby
 - f) Pro zlepšování živočišné výroby

Q17. Co se týče editace genomu, nakolik jste znepokojen/a následujícími možnostmi?

- Prosím řekněte mi, jestli jste velmi znepokojen/a, celkem znepokojen/a, středně znepokojen/a, málo znepokojen/a nebo, nejste vůbec znepokojen/a.
- a) Tím, že tato metoda není dostatečně regulována
 - b) Etickými důsledky spojenými s použitím této metody
 - c) Tím, že by tato metoda mohla být zneužita
 - d) Tím, že by tato metoda mohla mít nezamýšlené vedlejší účinky na lidi

Děkuji vám za odpovědi na tyto otázky. Pokud vás zajímá náš projekt, jehož cílem je vědu více přiblížit veřejnosti, můžete navštívit naše webové stránky www.orion-openscience.eu

GERMANY

Introduction from the interviewer

Hallo, ich heiße...

Ich rufe im Auftrag eines europäischen Forschungsprojekts an, das sich ORION nennt und das Ziel hat, die Bevölkerung besser darüber zu informieren, was aktuell in den Lebenswissenschaften passiert. Forschung in den Lebenswissenschaften versucht Lebewesen wie Menschen, Tiere, Pflanzen oder Bakterien zu verstehen und umfasst Biologie, Genetik, Neurowissenschaften und Medizin. Wir sind daran interessiert zu erfahren, wie ihrer Ansicht nach die Bevölkerung über die Forschung in den Lebenswissenschaften informiert werden sollte oder sogar selbst in die Forschung mit eingebunden werden kann. Ihre Antworten werden anonymisiert und die Umfrage dauert ungefähr 10 Minuten. Sind Sie bereit teilzunehmen?

Background variables

Q1. Alter

Keine Antwort (bitte nicht vorlesen)

Q2. Geschlecht

männlich

weiblich

Keine Antwort (bitte nicht vorlesen)

Q3. Welches ist Ihr höchster abgeschlossener Bildungsstand?

Kein Abschluss

Noch in Schulausbildung ohne Abschluss

Hauptschulsabschluss

Realschule / POS

Fachabitur

Abitur / EOS

BOS

Abgeschlossene Berufsausbildung

Fachschulausbildung (z.B. Techniker,

Betriebswirt, Meister, Fachwirt)

Fachhochschulstudium

Berufsakademie

Hochschulstudium

Promotion

Keine Antwort (bitte nicht vorlesen)

Q4. Hat Ihre Arbeit etwas mit Forschung zu tun?

a) Ja, ich arbeite als Forscher

b) Ja, meine Arbeit hat mit Forschung zu tun, aber ich bin kein Forscher

c) Nein, aber in der Vergangenheit schon

d) Nein

Keine Antwort (bitte nicht vorlesen)

Bemerkung für den Interviewer, im Falle dass der Proband eine Erläuterung benötigt.

Alternative für a) kann Doktor, Postdoktorand, Doktorand, Untersuchungsleiter/Prüfer, Professor, Lektor/Dozent sein.

Alternative für b) kann Verleger, Förderberater, forschungsbasierte Industrie, Fachorganisation sein.

General questions (interest, confidence, etc.)

Q5. Zunächst eine Frage, wie sehr Sie an Lebenswissenschaften interessiert sind. Sind Sie ...

a) Sehr interessiert

b) Einigermaßen interessiert

c) Neutral

d) Nicht besonders interessiert

e) gar nicht interessiert

Keine Antwort (bitte nicht vorlesen)

Q6. Wie viel Vertrauen haben Sie in die Lebenswissenschaften? Haben Sie ...

a) Sehr großes Vertrauen

b) Einigermaßen großes Vertrauen

- c) Neutral
 - d) Kein sehr großes Vertrauen
 - e) Sehr wenig Vertrauen
- Keine Antwort (bitte nicht vorlesen)

Q7. Gibt es irgendetwas zum Thema Lebenswissenschaften, über das Sie gerne mehr erfahren möchten?

- Ja, Nein, Keine Antwort (bitte nicht vorlesen)
- a) Wie Forschungsthemen ausgewählt werden
 - b) Methoden, die in der Forschung angewandt werden
 - c) Forschungsergebnisse
 - d) Praktische Anwendungen von Forschungsergebnissen
 - e) Ethische Fragestellungen im Zusammenhang mit der Forschung
 - f) Die Forscher selbst
 - g) Wie Forschung gefördert wird
 - h) Wie Forschung der Gesellschaft vermittelt wird
 - i) Andere

Personal engagement

Die Bevölkerung kann Informationen über Forschung erhalten, aber auch selber mitwirken indem man Ideen, Wissen oder Erfahrungen teilt. Die Leute können teilnehmen indem sie über Forschungsfragen und Methoden mit diskutieren, über die Förderung von Forschung mitbestimmen oder noch direkter, indem sie Forschungsmaterial sammeln, analysieren oder spenden.

Q8. Wie wichtig ist es Ihrer Meinung nach, dass die Öffentlichkeit in die lebenswissenschaftliche Forschung eingebunden wird?

- a) Sehr wichtig
 - b) Einigermaßen wichtig
 - c) Neutral
 - d) Nicht sehr wichtig
 - e) Überhaupt nicht wichtig
- Keine Antwort (bitte nicht vorlesen)

Q9. Könnten Sie sich vorstellen selbst in die lebenswissenschaftliche Forschung eingebunden zu werden?

- a) Ja
 - b) Nein
- Keine Antwort (bitte nicht vorlesen)

Q10. Auf welchen der folgenden Wege würden Sie gerne eingebunden werden?

OR

Q11. Sie haben geantwortet, dass Sie nicht eingebunden werden wollen. Bitte versuchen Sie sich vorzustellen, dass sie eingebunden wären. Würden Sie eine dieser Optionen vorziehen?

- Ja, Nein, Keine Antwort (bitte nicht vorlesen)
- a) Meine Meinung einbringen, welches Projekt gefördert werden soll
 - b) Meine Meinung einbringen, wonach in einer Forschungsstudie geforscht oder gefragt werden sollte.
 - c) Meine Meinung einbringen, welche Methoden und Verfahren angewendet oder nicht angewendet werden sollten
 - d) Meine Meinung einbringen, wie die Fördermittel eingesetzt werden sollten
 - e) Bei der Förderung mitwirken, z.B. durch Hilfeleistung beim Einwerben von Geldern
 - f) Mit Wissenschaftlern zusammenzuarbeiten um Daten zu generieren (z.B. Vögel in Ihrem Garten zählen)
 - g) In der Datenanalyse mitzuwirken (z.B. dabei unterstützen, Bilder von Vögeln zu sortieren)
 - h) Material für biomedizinische Forschung stiften/spenden (z.B. Haare oder Speichel)

Q12. Sind Sie interessiert an der Einbindung in eine der folgenden Forschungsthemen?

OR

Q13. Wenn Sie auf irgendeine Weise eingebunden sein sollten, wäre eines der folgenden Forschungsthemen für Sie interessant?

Ja, Nein, Keine Antwort (bitte nicht vorlesen)

- a) Verständnis darüber, wie unsere DNA unsere Gesundheit und Krankheiten beeinflusst
- b) Verständnis darüber, wie sich Lebewesen (Viren, Bakterien, Tiere, Menschen, ...) auf der Erde entwickelt haben
- c) Verständnis über den Einfluss unserer Lebensweise auf unsere Gesundheit und das Wohlbefinden
- d) Verständnis über ethische Fragestellungen in Verbindung mit Lebenswissenschaften

Q14. Die Bevölkerung beteiligt sich aus verschiedenen Gründen an der Forschung. Würde einer der folgenden Punkte Sie auch motivieren teilzunehmen?

Ja, Nein, Keine Antwort (bitte nicht vorlesen)

- a) Finanzielle oder materielle Anreize
- b) Öffentliche Anerkennung (z.B. wenn mein Name in einem Projekt erwähnt wird)
- c) Wenn Personen aus meinem Umfeld beteiligt wären
- d) Die Auffassung, dass mein Engagement dem Wohle der Gesellschaft dient
- e) Wenn das Forschungsthema für mich interessant ist

Q15. Haben Sie jemals von einem wissenschaftlichen Verfahren gehört, welches die Veränderung (Einsetzen, Entfernen oder Ersetzen) von DNA-Abschnitten in Zellen und Lebewesen ermöglicht? Dieses Verfahren heißt Genome-Editing (Genomveränderung).

- a) Ja
- b) Nein

Keine Antwort (bitte nicht vorlesen)

Q16. Für welchen Zweck, glauben Sie, sollte Genome-Editing (Genomveränderung) angewendet werden? Sollte es...

Ja, Nein, Keine Antwort (bitte nicht vorlesen)

- a) Für Organtransplantationen
- b) Zur Vorbeuge oder Heilung von Krankheiten
- c) Zur Vorbeuge von Behinderungen
- d) Für die Veränderung von Eigenschaften im menschlichen Embryo, die nicht lebensverkürzend sind (zum Beispiel Augenfarbe oder Stärkung des Immunsystems)
- e) Zur Verbesserung der Pflanzenzucht
- f) Zur Verbesserung der Viehzucht

Q17. Bezüglich des Genome-Editing (Genomveränderung), wie besorgt sind Sie über die folgenden Punkte?

Bitte sagen Sie mir, ob Sie sehr besorgt, etwas besorgt, neutral, nicht sehr besorgt, überhaupt nicht besorgt sind.

- a) Dass keine ausreichenden Regulierungen getroffen sind
- b) Die ethischen Folgen jeglicher Anwendung dieser Technologie/ dieses Verfahrens
- c) Dass diese Technologie/ dieses Verfahren missbraucht werden kann
- d) Dass diese Technologie/ dieses Verfahren eventuell zu unbekanntem Nebenwirkungen im menschlichen Körper führt

Danke für die Antworten auf diese Fragen. Wenn Sie mehr über unser Projekt erfahren möchten, welches das Ziel hat, Wissenschaft zugänglicher für die Öffentlichkeit zu machen, können Sie uns gern auf der Webseite <http://www.orion-openscience.eu/> besuchen.

ITALY

Introduction from the interviewer

Buongiorno, il mio nome è xxx.

La chiamo su incarico del progetto europeo ORION, che ha l'obiettivo di assicurare che il pubblico sia meglio informato sulla ricerca nel campo delle scienze della vita. La ricerca in questo campo mira a capire gli esseri viventi, quali l'uomo, gli animali, le piante e i batteri, e comprende la biologia, la genetica, le neuroscienze e la medicina. Sarebbe per noi di grande aiuto conoscere la Sua opinione su come migliorare la partecipazione delle persone alle attività di ricerca nel campo delle scienze della vita. Le Sue risposte saranno anonime e l'intervista durerà circa 10 minuti. È disponibile a partecipare?

Background variables**Q1. Età**

nessun

a risposta (per favore, non leggere)

Q2. Sesso

Maschile

Femminile

nessuna risposta (per favore, non leggere)

Q3. Quale è il Suo titolo di studio?

Senza istruzione complete

Scuola primaria

Scuola secondaria di primo grado

Istruzione professionale

Istruzione artistica

Istruzione Tecnica

Istruzione liceale

Corso serali/intergrativo

Corso di Laurea

Corso di Laurea Magistrale

Dottorato di Ricerca

Corsi di Alta Formazione Artistica Musicale e

Coreutica

nessuna risposta (per favore, non leggere)

Q4. Il Suo lavoro ha a che fare con la ricerca?

a) Sì, lavoro come ricercatore

b) Sì, la mia attività lavorativa ha a che fare con la ricerca, ma non sono un ricercatore

c) No, ma in occupazioni precedenti sì

d) No

nessuna risposta (per favore, non leggere)

Nota per l'intervistatore nel caso che l'intervistato abbia bisogno di chiarimenti.

Per a) sono possibili le seguenti alternative:

dottorando, ricercatore, responsabile di un progetto di ricerca, professore, docente.

Per b) sono possibili le seguenti alternative: editore, finanziatore, settore della ricerca, associazione di categoria

General questions (interest, confidence, etc.)**Q5. Innanzitutto Le vorrei chiedere quanto le interessa la ricerca nel campo delle scienze della vita. Lei è ...**

a) Molto interessato

b) Abbastanza interessato

c) Indifferente

d) Non molto interessato

e) Per niente interessato

nessuna risposta (per favore, non leggere)

Q6. Quanta fiducia ha nelle scienze della vita?

Ha ...

a) Molta fiducia

b) Abbastanza fiducia

c) Indifferente

d) Poca fiducia

e) Molto poca fiducia

nessuna risposta (per favore, non leggere)

Q7. C'è qualcosa che Le piacerebbe sapere di più nel campo delle scienze della vita?

Sì, No, nessuna risposta (per favore non leggere)

- a) Come vengono scelti gli argomenti della ricerca
- b) I metodi di ricerca utilizzati
- c) Risultati della ricerca
- d) Applicazione pratica dei risultati della ricerca
- e) Questioni etiche collegate alla ricerca
- f) La ricerca in quanto tale
- g) Come viene finanziata la ricerca
- h) Come la ricerca viene comunicata alla società
- i) Altro

Personal engagement

Le persone possono ricevere informazioni sulla ricerca, ma anche contribuire alla ricerca mediante lo scambio di idee, conoscenze o esperienze. Possono partecipare discutendo sugli argomenti e sui metodi della ricerca, decidendo sul finanziamento oppure più direttamente con la raccolta, l'analisi o la donazione di materiale per la ricerca.

Q8. Secondo la Sua opinione, quanto è importante che il pubblico venga coinvolto nella ricerca nel campo delle scienze della vita?

É...

- a) Molto importante
 - b) Abbastanza importante
 - c) Indifferente
 - d) Non molto importante
 - e) Per niente importante
- nessuna risposta (per favore, non leggere)

Q9. Sarebbe disposto a prendere in considerazione la possibilità partecipare ad attività di ricerca nel campo delle scienze della vita?

- a) Sì
 - b) No
- nessuna risposta (per favore, non leggere)

Q10. In quale dei seguenti modi preferirebbe essere coinvolto?

OR

Q11. Lei ha risposto che non vuole partecipare ad attività di ricerca. La prego però di immaginare, invece, di aver deciso di essere coinvolto in questa attività. Quale delle seguenti opzioni preferirebbe?

Sì, No, nessuna risposta (per favore non leggere)

- a) Esprimere la mia opinione su, quali progetti di ricerca debbano essere finanziati
- b) Esprimere la mia opinione su, ciò che potrebbe essere cercato o chiesto in uno studio di ricerca
- c) Esprimere la mia opinione su, quali metodi e procedure utilizzare e quali no
- d) Esprimere la mia opinione su, come utilizzare i risultati
- e) Partecipare al finanziamento di progetti di ricerca , ad es. aiutando a raccogliere fondi
- f) Collaborare con ricercatori nella raccolta dati (ad es. contando gli uccelli che visitano il mio giardino)
- g) Partecipare all'analisi dei dati (ad es. la classificazione di foto di uccelli)
- h) Donare materiale per la ricerca biomedica (ad es. capelli o saliva)

Q12. Ha interesse a partecipare ai seguenti temi di ricerca?

OR

Q13. Se Lei fosse coinvolto in una qualsiasi forma, quali dei seguenti temi di ricerca Le interesserebbero?

Sì, No, nessuna risposta (per favore non leggere)

- a) Comprendere, come il nostro DNA influenza la nostra salute e le nostre malattie
- b) Comprendere come gli esseri viventi (virus, batteri, animali o esseri umani) si siano evoluti sulla Terra
- c) Comprendere gli effetti del nostro stile di vita sulla salute
- d) Comprendere le questioni etiche connesse con le scienze della vita

Q14. Esistono vari motivi per cui le persone si interessano alla ricerca. Quali dei seguenti costituirebbero una motivazione per Lei?

Sì, No, nessuna risposta (per favore non leggere)

- a) Incentivi monetari o materiali
- b) Riconoscimento pubblico (ad es. menzione del Suo nome in un progetto di ricerca)
- c) La partecipazione di altre persone che conosco
- d) La convinzione che la mia partecipazione sia utile alla società
- e) Se mi interessasse l'argomento della ricerca

Q15. Ha mai sentito parlare di un metodo scientifico con cui è possibile modificare (mediante inserimento, cancellazione o sostituzione) sezioni del DNA in cellule e in esseri viventi? Questo metodo viene chiamato "genome editing".

- a) Sì
- b) No

nessuna risposta (per favore, non leggere)

Q16. Secondo la Sua opinione, per quali scopi dovrebbe essere utilizzato il genome editing? Dovrebbe essere utilizzato per...

Sì, No, nessuna risposta (per favore non leggere)

- a) Il trapianto di organi
- b) La prevenzione e la cura di malattie
- c) La prevenzione di disabilità
- d) La modifica di caratteristiche dell'embrione umano che non limitano la vita (per esempio il colore degli occhi ed il rafforzamento del sistema immunitario)
- e) Per il miglioramento della produzione vegetale
- f) Per il miglioramento della produzione animale

Q17. In riferimento al genome editing, quanto La preoccupano i seguenti temi?

La prego di dirmi se Lei è molto preoccupato, abbastanza preoccupato, indifferente, non molto preoccupato oppure per niente preoccupato.

- a) Mancanza di una sufficiente regolamentazione
- b) Conseguenze etiche relative a qualunque utilizzo di questa tecnologia
- c) Possibilità di abusi di questa tecnologia
- d) Possibilità di effetti collaterali sconosciuti di questa tecnologia per l'uomo

La ringrazio per aver risposto alle mie domande. Se Le interessa il nostro progetto con cui si cerca di rendere più accessibile al pubblico la ricerca scientifica, può visitare il nostro sito internet www.orion-openscience.eu/

SPAIN

Introduction from the interviewer

Hola, mi nombre es xxx.

Le llamo en nombre de un proyecto europeo, ORION, cuyo objetivo es asegurar que la sociedad esté mejor informada sobre las ciencias de la vida. Este ámbito de la ciencia trata de entender a los diferentes tipos de organismos vivos, como los seres humanos, los animales, las plantas o las bacterias, y abarca las disciplinas de la biología, la genética, la neurociencia o la medicina. Sería de mucha ayuda para el proyecto conocer sus puntos de vista sobre cómo la gente podría participar en investigaciones de ciencias de la vida. Sus respuestas serán anónimas y la conversación durará 10 minutos aproximadamente. ¿Está interesado en participar?

Background variables**Q1. Edad**

NS/NC (no leer)

Q2. Sexo

Hombre

Mujer

NS/NC (no leer)

Q3. ¿Cuál es su nivel más alto de estudios?

Sin Educación Completa

Educación Primaria

Educación Secundaria Obligatoria

Segundo ciclo de Educación

Secundaria (Bachillerato)

Ciclo Formativo de Grado Medio

Certificado de Profesionalidad

Diplomatura Universitaria – Grado

Diplomatura Universitaria – Máster

Diplomatura Universitaria – Doctorado

Licenciatura Universitaria

Ciclo Formativo Superior

NS/NC (no leer)

Q4. ¿Su trabajo está relacionado con la investigación?

a) Sí, trabajo como investigador

b) Sí, mi trabajo está relacionado con la investigación pero yo no soy investigador

c) No, pero lo ha estado en puestos anteriores

d) No

NS/NC (no leer)

Nota para el entrevistador, en caso de que el entrevistado necesite alguna aclaración.

Alternativas para a) podría ser Doctorado, postdoctorado, profesor universitario, conferenciante.

Alternativas para b) podrían ser editor, financiador, empresa de investigación, asociación profesional

General questions (interest, confidence, etc.)**Q5. Primera pregunta sobre cuán interesado está usted en la investigación de las ciencias de la vida. ¿Le interesa....?**

a) Mucho

b) Bastante

c) Normal

d) No demasiado

e) Para nada

NS/NC (no leer)

Q6. ¿Cuánto confía en la investigación de las ciencias de la vida? ¿Le interesa...?

a) Mucho

b) Bastante

c) Normal

d) No demasiado

e) Para nada

NS/NC (no leer)

Q7. ¿Le gustaría saber más sobre alguno de estos aspectos del estudio de las ciencias de la vida?

Sí, No, NS/NC (no leer)

- a) Cómo se seleccionan los temas de investigación
- b) Los métodos utilizados en investigación
- c) Hallazgos de investigaciones
- d) Aplicación real de hallazgos de investigaciones
- e) Temas éticos relacionados con la investigación
- f) Los propios investigadores
- g) Cómo se financia la investigación
- h) Cómo se comunica la investigación a la sociedad
- i) Otros

Personal engagement

La sociedad puede recibir información sobre una investigación pero también puede contribuir a la investigación compartiendo sus propias ideas, conocimientos o experiencias. Puede participar en debates sobre cuestiones científicas y métodos de estudio, decidir sobre su financiación o, más directamente, recopilando, analizando o aportando material de investigación.

Q8. En su opinión, ¿qué importancia tiene para usted que la sociedad participe en estudios sobre las ciencias de la vida? Es...

- a) muy importante
 - b) bastante importante
 - c) normal
 - d) poco importante
 - e) nada importante
- NS/NC (no leer)

Q9. ¿Se plantearía participar personalmente en un estudio sobre ciencias de la vida?

- a) Sí
 - b) No
- NS/NC (no leer)

Q10. ¿De cuáles de las siguientes maneras le gustaría participar?

OR

Q11. Usted contestó que no le gustaría participar en la investigación en ciencias de la vida. Por favor, trate de imaginar que sí le gustaría participar. ¿Preferiría alguna de estas opciones?

Sí, No, NS/NC (no leer)

- a) Opinando sobre qué proyectos de investigación deberían financiarse
- b) Opinando sobre qué se podría estudiar o cuestionar en un estudio de investigación
- c) Opinando sobre qué métodos y procedimientos se deberían utilizar o no
- d) Opinando sobre cómo utilizar los resultados
- e) Contribuyendo a la financiación del proyecto de investigación, p.ej., ayudando a recaudar fondos
- f) Colaborando con los investigadores a recoger datos (p.ej., contando el número de pájaros que visitan su balcón)
- g) Colaborando en el análisis de los datos (p.ej., ayudando a clasificar imágenes de pájaros)
- h) Donando material necesario para la investigación biomédica (p.ej., pelo o saliva)

Q12. ¿Está interesado en participar en los siguientes temas de investigación en ciencias de la vida?

OR

Q13. Si tuviera que participar en cualquier caso, ¿le interesaría alguno de los siguientes temas?

Sí, No, NS/NC (no leer)

- a) Cómo nuestro ADN influye en nuestra salud o en nuestras enfermedades
- b) Cómo los organismos vivos (virus, bacterias, animales o humanos) han evolucionado en la Tierra
- c) El impacto de nuestro estilo de vida en nuestra salud
- d) Los aspectos éticos relacionados con las ciencias de la vida

Q14. La gente puede participar en la investigación por diversos motivos. ¿Cuál de los siguientes si fuera el caso, le motivaría a usted?

Sí, No, NS/NC (no leer)

- a) Incentivos económicos o materiales
- b) Reconocimiento público (p.ej., si se me mencionara en el proyecto)
- c) Si participa gente que conozco
- d) La convicción de que mi participación pudiera ayudar a la sociedad
- e) Si el tema de investigación fuera de mi interés

Q15. ¿Ha oído hablar de la técnica científica que permite modificar (insertar, eliminar o sustituir) secciones del ADN en células y organismos vivos? Esta técnica se denomina edición del genoma.

a) Sí

b) No

NS/NC (no leer)

Q16. ¿Con qué fin considera que debe utilizarse la edición del genoma? ¿Debería utilizarse...

Sí, No, NS/NC (no leer)

- a) para trasplantes de órganos
- b) para prevenir o curar enfermedades
- c) para prevenir discapacidades
- d) Para modificar en embriones características genéticas que no limitan la vida (por ejemplo, cambiar el color de los ojos o fortalecer el sistema inmunológico).
- e) para mejorar la producción de plantas
- f) para mejorar la producción de ganado

Q17. Considerando la edición del genoma, ¿cuánto le preocupan las siguientes afirmaciones? Diga si le preocupan mucho, bastante, normal, no mucho o no le preocupan para nada.

a) Falta de regulación

b) Las consecuencias éticas a partir de cualquier uso de esta tecnología

c) El mal uso de la tecnología

d) El hecho de que la tecnología pueda tener efectos secundarios desconocidos en seres humanos

Gracias por responder a estas preguntas. Si está interesad@ en nuestro proyecto, que pretende abrir más la ciencia a la sociedad, puede visitar nuestra página web www.orion-openscience.eu

SWEDEN

Introduction from the interviewer

Hej, jag heter xxx.

Jag ringer på uppdrag av det europeiska projektet ORION, som arbetar för att allmänheten blir bättre informerad om forskning inom livsvetenskap. Det här är forskning som strävar efter att förstå levande organismer, som människor, djur, växter eller bakterier. Den innefattar forskningsfält som biologi, genetik, neurovetenskap och medicin. Det skulle vara till stor hjälp att få höra dina åsikter om hur allmänheten kan engageras i livsvetenskaplig forskning. Dina svar kommer att vara anonyma, och enkäten tar ungefär tio minuter att gå genom. Kan du tänka dig att delta?

Background variables**Q1. Alder**

inget svar (läs ej upp)

Q2. Kön

Man

Kvinna

inget svar (läs ej upp)

Q3. Vilken är din högsta avslutade utbildning?

Utan avslutad grundskoleutbildning

Grundskola

Grundsärskola

Specialskola

Sameskola

Arbetsmarknadsutbildning / Arbetsförmedlingen

Folkhögskola

Gymnasieskola

Komvux

Yrkesteknisk högskoleutbildning <2 år

Kvalificerad yrkesutbildning, <2 år

Högskoleutbildning – Bachelor/Kandidat

Högskoleutbildning – Master/Magister

Forskarutbildning – doktorsexamen

Kvalificerad yrkesutbildning, 2–3 år

inget svar (läs ej upp)

Q4. Är ditt arbete relaterat till forskning?

a) Ja, jag arbetar som forskare

b) Ja, mitt arbete är relaterat till forskning, men jag är inte forskare

c) Nej, men har varit det tidigare

d) Nej

inget svar (läs ej upp)

Kommentar till intervjuaren, ifall respondenten behöver en förklaring.

Alternativ för a) kan vara doktorand, postdoktor (postdoc), försöksledare/PI (principal investigator), professor, lektor.

Alternativ för b) kan vara utgivare, finansiär, forskningsbaserad industri, professionell organisation

General questions (interest, confidence, etc.)**Q5. Först en fråga om hur intresserad du är av livsvetenskaplig forskning. Är du ...**

a) Mycket intresserad

b) Ganska intresserad

c) Varken eller

d) Inte särskilt intresserad

e) Inte alls intresserad

inget svar (läs ej upp)

Q6. Hur stort förtroende har du för livsvetenskaplig forskning? Har du ...

a) Mycket stort

b) Ganska stort

c) Varken eller

d) Ganska litet

e) Mycket litet

inget svar (läs ej upp)

Q7. Finns det någonting du skulle vilja veta mer om när det gäller livsvetenskaplig forskning?

Ja, Nej, Inget svar (läs ej upp)

- a) Hur man väljer vad man ska forska om
- b) Vilka metoder som används inom forskningen
- c) Forskningsresultat
- d) Praktisk tillämpning av forskningsresultat
- e) Etiska frågor kopplade till forskningen
- f) Forskarna själva
- g) Hur forskningen finansieras
- h) Hur forskningen kommuniceras till samhället
- i) Något annat

Personal engagement

Människor kan få information om forskning, men även bidra till forskningen genom att dela med sig av egna idéer, kunskaper eller erfarenheter. De kan delta genom att diskutera forskningsfrågor och metoder, besluta om finansiering eller mer direkt genom att samla in, analysera eller donera forskningsmaterial.

Q8. Hur viktigt är det enligt dig att allmänheten involveras i livsvetenskaplig forskning? Är det ...

- a) Mycket viktigt
 - b) Ganska viktigt
 - c) Varken eller
 - d) Inte särskilt viktigt
 - e) Inte alls viktigt
- inget svar (läs ej upp)

Q9. Kan du själv tänka dig att bli involverad i livsvetenskaplig forskning?

- a) Ja
 - b) Nej
- Inget svar (läs ej upp)

Q10. På vilket av följande sätt skulle du föredra att bli involverad?

OR

Q11. Du svarade att du inte vill bli involverad. Försök föreställa dig att du ändå skulle bli involverad. Skulle du föredra något av följande alternativ?

Ja, Nej, Inget svar (läs ej upp)

- a) Tycka till om hur forskningsprojekt bör finansieras
- b) Tycka till om vad man bör titta på eller fråga efter i en forskningsstudie
- c) Tycka till om vilka metoder man bör eller inte bör använda
- d) Tycka till om hur man bör använda forskningsresultaten
- e) Bidra till finansieringen av forskningsprojekt, t.ex. genom att hjälpa till att samla in pengar
- f) Samarbeta med forskare vid insamling av data (t.ex. genom att räkna antalet fåglar i den egna trädgården)
- g) Samarbeta i analysen av data (t.ex. genom att hjälpa till att sortera bilder på fåglar)
- h) Donera material som behövs för biomedicinsk forskning (t.ex. hår eller saliv)

Q12. Är du intresserad av att involveras i något av följande forskningsområden?

OR

Q13. Om du på något sätt skulle bli involverad, skulle i så fall något av följande forskningsområden intressera dig?

Ja, Nej, Inget svar (läs ej upp)

- a) Att förstå hur vårt DNA påverkar vår hälsa och sjukdomar
- b) Att förstå hur levande organismer (virus, bakterier, djur eller människor) har utvecklats på jorden
- c) Att förstå hur vår livsstil påverkar vår hälsa
- d) Att förstå vilka etiska frågor som uppstår i livsvetenskaplig forskning

Q14. Människor kan bli involverade i forskning av olika anledningar. Vilka, om några, av följande anledningar skulle kunna motivera dig?

Ja, Nej, Inget svar (läs ej upp)

- a) Ekonomiska eller materiella incitament
- b) Offentligt erkännande (t.ex. om mitt namn nämndes i projektet)
- c) Om personer jag känner var involverade
- d) En tro på att mitt bidrag skulle hjälpa samhället
- e) Om forskningsämnet skulle intressera mig

Q15. Har du någonsin hört talas om en vetenskaplig teknik som gör det möjligt att modifiera (infoga, avlägsna eller ersätta) DNA-segment i celler och levande organismer? Denna teknik kallas genmodifiering.

a) Ja

b) Nej

inget svar (läs ej upp)

Q16. För vilka ändamål anser du att genmodifiering bör användas? Bör det användas ...

Ja, Nej, Inget svar (läs ej upp)

- a) För organtransplantationer
- b) För att förebygga eller bota sjukdomar
- c) För att förebygga funktionsnedsättningar
- d) För att ändra icke livsbegränsande egenskaper hos mänskliga embryon (till exempel ögonfärg eller för att stärka immunförsvaret)
- e) För att förbättra produktionen av grödor
- f) För att förbättra produktionen av boskapsdjur

Q17. När det gäller genmodifiering, hur oroad är du för något av följande? Ange om du är mycket oroad, ganska oroad, varken eller, inte särskilt oroad, inte alls oroad.

- a) Att det saknas tillräcklig lagstiftning
- b) De etiska konsekvenserna gällande all användning av denna teknik
- c) Att tekniken kan missbrukas
- d) Att tekniken kan ge okända biverkningar hos människor

Tack för att du svarade på frågorna. Om du är intresserad av vårt projekt, som strävar efter att göra vetenskapen mer öppen för allmänheten, kan du besöka vår webbsida på www.orion-openscience.eu/

UNITED KINGDOM

Introduction from the interviewer

Hello, my name is xxx.

I am calling on behalf of a European project ORION, which aims to ensure that the public is better informed about life sciences research. This research tries to understand living organisms such as human beings, animals, plants or bacteria and includes biology, genetics, neuroscience or medicine. It would be very helpful to hear your views on how people can be involved in life science research. Your answers will be anonymous and the survey will take approximately 10 minutes. Are you willing to participate?

Background variables**Q1. Age****Q2. Gender****Q3. Level of education (3 levels: primary, secondary, tertiary)[ML1]**

Which is your highest completed level of education?

Note to the interviewer – use country-specific categories of education.

Q4. Is your work related to research?

- a) Yes, I work as a researcher
- b) Yes, my work is related to research, but I am not a researcher
- c) No, but it has been in previous positions
- d) No

Note to the interviewer, in case the respondent needs clarification.

Alternatives for a) can be PhD, postdoc, Principal Investigator, professor, lecturer.

Alternatives for b) can be publisher, funder, research-based industry, professional organisation

General questions (interest, confidence, etc.)**Q5. First a question on how interested you are in life sciences research. Are you ...**

- a) Very interested
- b) Fairly interested
- c) Neutral
- d) Not very interested
- e) Not at all interested

Q6. How much confidence do you have in life sciences research? Do you have ...

- a) Very high confidence
- b) Fairly high confidence
- c) Neutral
- d) Fairly low confidence
- e) Very low confidence

Q7. Is there anything you would like to know more about research in life sciences?

YES/NO for each alternative

- a) How research topics are selected
- b) The methods used in research
- c) Research findings
- d) Practical applications of research findings
- e) Ethical issues connected to the research
- f) The researchers themselves
- g) How research is funded
- h) How research is communicated to society
- i) Other

Personal engagement

People can receive information about research, but also contribute to research by sharing their own ideas, knowledge or experiences. They can participate by discussing research questions and methods, decide about funding or more directly by collecting, analysing or donating research material.

Q8. In your opinion, how important is it that the public gets involved in life sciences research? It is...

- a) Very important
- b) Fairly important
- c) Neutral
- d) Not very important
- e) Not at all important

Q9. Would you consider being involved personally in life sciences research?

- a) Yes -> go to Q10 and Q12
- b) No -> go to Q11 and Q13

Q10. In what of the following ways would you prefer to be involved?

OR

Q11. You answered that you would not want to be involved. Please, try to imagine that you were to be involved. Would you prefer any of these options?

YES/NO for each alternative

- a) Giving my opinion about which research projects should be funded
- b) Giving my opinion about what could be looked for or asked in a research study
- c) Giving my opinion about what methods and procedures to use or not to use
- d) Giving my opinion on how to use the findings
- e) Contributing to the funding of research projects, e.g. through helping to raise money
- f) Collaborating with scientists to get data (e.g., counting the number of birds visiting your garden)
- g) Collaborating in the analysis of data (e.g., helping to sort images of birds)
- h) Donating material needed for biomedical research (e.g., hair or saliva)

Q12. Are you interested in getting involved in the following research topics?

OR

Q13. If you were to be involved in any way, would any of the following research topics be of interest to you?

YES/NO for each alternative

- a) Understanding how our DNA influences our health and disease
- b) Understanding how living organisms (viruses, bacteria, animals or humans) have evolved on Earth
- c) Understanding the impact of our lifestyle on our health
- d) Understanding the ethical issues connected with life sciences

Q14. People can get involved in research for different reasons. What, if any, of the following would motivate you?

YES/NO for each alternative

- a) Monetary or material incentives
- b) Public recognition (e.g. if my name was mentioned in the project)
- c) If people I know were involved
- d) A belief that my involvement would help society
- e) If the research topic was interesting to me

Q15. Have you ever heard of the scientific technique that enables the modification (insertion, deletion or replacement) of sections of DNA in cells and living organisms? This technique is called genome editing.

- a) Yes
- b) No

Q16. For what purpose do you think genome editing should be used? Should it be used...

YES/NO for each alternative

- a) For organ transplantation
- b) For prevention or cure of diseases
- c) For prevention of disabilities
- d) For changing non-life-limiting characteristics of human embryos (for example eye colour or strengthening the immune system)
- e) For improvement of plant production
- f) For improvement of livestock production

Q17. Regarding genome editing, how concerned are you about any of the following?

Please, tell me if you are very concerned, fairly concerned, neutral, not very concerned, not at all concerned.

- a) That sufficient regulation is not in place
- b) The ethical implications regarding any use of this technology
- c) That the technology could be misused
- d) That the technology may come with unknown side-effects in human beings

Thank you for answering these questions. If you are interested in our project that aims to make science more open to the public, you can visit our webpage www.orion-openscience.eu/

APPENDIX C: CATEGORIES OF THE LEVEL OF EDUCATION BY COUNTRY

	Primary education , i.e. less than primary, primary, and lower secondary education (ISCED 2011 levels 0-2)	Secondary education , i.e. upper secondary and post-secondary non-tertiary education (ISCED 2011 levels 3 and 4)	Tertiary education (ISCED 2011 levels 5-8)
Czechia	Bez ukončeného vzdělání Základní škola Praktická škola První čtyři roky osmiletých SŠ První dva roky šestiletých SŠ	Střední škola s maturitou Střední škola bez maturity Pomaturitní jazyková škola	Vysoká škola – bakalářské Vysoká škola – magisterské Vysoká škola – doktorské Vyšší odborná škola
Germany	Kein abschluss Noch in Schulausbildung ohne Abschluss Hauptschulabschluss Realschulabschluss/POS	Fachabitur Abitur/EOS BOS Abgeschlossene Berufsausbildung	Fachschulausbildung (z.B. Techniker, Betriebswirt, Meister, Fachwirt) Fachhochschulstudium Berufsakademie Hochschulstudium Promotion
Italy	Senza instruzione completa Scuola primaria Scuola secondaria di primo grado	Istruzione professionale Istruzione artistica Istruzione Tecnica Istruzione liceale Corso serali/intergrativo	Corso di Laurea Corso di Laurea Magistrale Dottorato di Ricerca Corsi di Alta Formazione Artistica Musicale e Coreutica
Spain	Sin Educación Completa Educación Primaria Educación Secundaria Obligatoria	Segundo ciclo de Educación Secundaria (Bachillerato) Ciclo Formativo de Grado Medio Certificado de Profesionalidad	Diplomatura Universitaria – Grado Diplomatura Universitaria – Máster Diplomatura Universitaria – Doctorado Licenciatura Universitaria Ciclo Formativo Superior

	Primary education , i.e. less than primary, primary, and lower secondary education (ISCED 2011 levels 0-2)	Secondary education , i.e. upper secondary and post-secondary non-tertiary education (ISCED 2011 levels 3 and 4)	Tertiary education (ISCED 2011 levels 5-8)
Sweden	Utan avslutad utbildning Grundskola Grundsärskola Specialskola Sameskola Arbetsmarknadsutbildning/ Arbetsförmedlingen	Folkhögskola Gymnasieskola Komvux Yrkesteknisk högskoleutbildning <2 år Kvalificerad yrkesutbildning, <2 år	Högskoleutbildning – Bachelor Högskoleutbildning – Master Högskoleutbildning – PhD Kvalificerad yrkesutbildning, 2–3 år
UK	Without completed education Primary school Adult literacy, numeracy and language	Secondary school 6th form Diploma – Foundation Diploma – Higher Diploma – Advanced NVQ Level 1 NVQ Level 2 NVQ Level 3	NVQ Level 4 NVQ Level 5 HNC HND Diploma of Higher Education Foundation degree University education – Bachelor’s degree University education – Master’s degree University education – Doctorate

