

June 2018

# **Genomics England Polling**

Ipsos MORI

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# Introduction

### What is Genomics?

You have a complete set of genes in almost every healthy cell in your body. One set of all these genes, (plus the DNA between the genes), is called a genome. Genomics is the study of the whole genome and how it works, including how particular features or diseases are inherited from one generation to the next. Genomics is also about the way that the genome is interpreted and the technologies that have been developed to help do this.

### Who are Genomics England?

The Department of Health & Social Care set up Genomics England in 2013 to deliver the 100,000 Genomes Project. This is a project which aims to sequence 100,000 human genomes, with an initial focus on cancer and rare diseases. This ultimately aims to improve cancer care for NHS patients by improving treatment and outcomes through personalised medicine<sup>1</sup>. Genomics England commissioned Ipsos MORI to undertake this survey which asks the public about their knowledge of genomics and genomics medicine (including the 100,000 Genomes Project). In addition, this survey asks participants about their attitude to genomics and concerns about potential ethical and data protection issues.

### Methodology

On behalf of The Department of Health and Social Care, Ipsos MORI undertook 1,926 online interviews with a representative sample of adults aged 16 – 75 across England. The questions were placed on Ipsos MORI's Online Omnibus and fieldwork took place between Friday 25<sup>th</sup> and Tuesday 29<sup>th</sup> May 2018. A quota sample of adults was interviewed with quotas set by age within gender, region, social grade and working status. The survey data were weighted to the known population proportion of those in this audience. The questions asked, subgroups analysed and a guide to Social Grade are provided in full in the Appendices.

Where differences between subgroups are discussed as significant, this refers to a statistical significance level of 0.05. Where percentages are based on a small base size this is indicated with an asterisk following the base in the figure legend (\* for a base size <30 and \*\* for a base size <100).

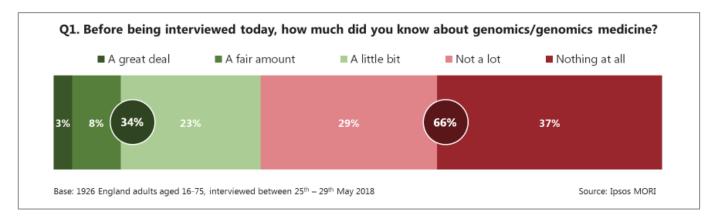
18-039340-01| Version 1 | Public | This work was carried out in accordance with the requirements of the international quality standard for Market Research, ISO 20252, and with the Ipsos MORI Terms and Conditions which can be found at http://www.ipsos-mori.com/terms. © Genomics England 2018

<sup>&</sup>lt;sup>1</sup> https://www.genomicsengland.co.uk/about-genomics-england/how-we-work/

# 1. Knowledge of genomics

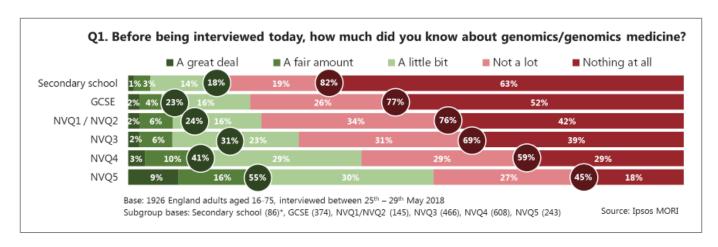
Knowledge of genomics and genomics medicine is generally low; when asked about their knowledge of genomics, the majority of participants state they know not a lot or nothing at all (66 per cent). As shown in Figure 1.1, around a third (34%) per cent feel they know a great deal, a fair amount or a little bit.

Figure 1.1



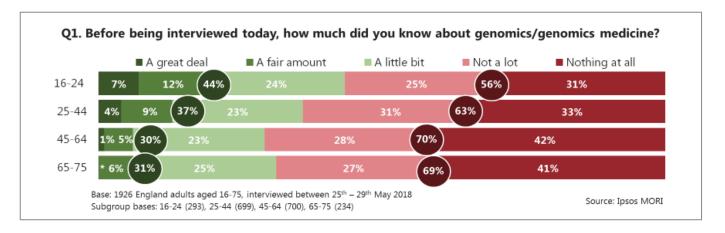
Reported knowledge of genomics varies by the demographic groups of social grade, region, age and education. Those in social grade ABC1 are significantly more likely to state they are knowledgeable (39 per cent feel they know a great deal, a fair amount or a little bit compared to 28 per cent of those in grade C2DE). This is also reflected in the participants level of education which is likely to overlap with social grade. Of those with an NVQ5 or post-graduate diploma, 55 per cent feel they know a great deal, a fair amount or a little bit, which is higher than those with lower levels of qualifications, as shown in Figure 1.2.

Figure 1.2



Participants living in Greater London are more likely to state they are knowledgeable compared to those in other regions (40 per cent feel they know a great deal, a fair amount or a little bit compared to 31 per cent, 32 per cent and 31 per cent in the West Midlands, East Midlands and South East of England respectively. As shown in Figure 1.3, those aged 16-24 are significantly more likely to state they know a great deal, a fair amount or a little bit (44 per cent) compared to those in any other age group.

Figure 1.3



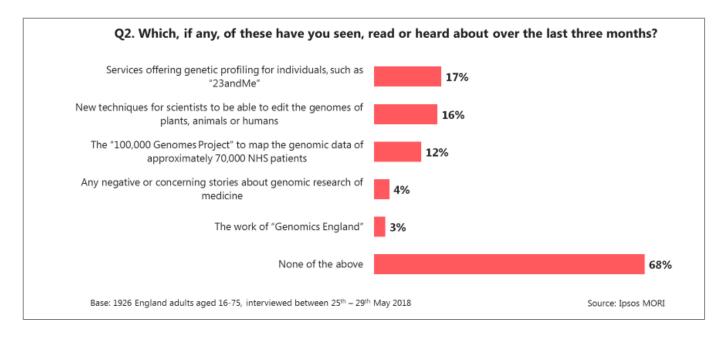
Finally, awareness of genomics may be linked to a positive attitude towards this field. Those with a positive attitude towards genomics are significantly more likely to state they are knowledgeable (68 per cent answered a great deal, a fair amount or a little bit), compared to 52 per cent of those who feel negatively towards this field.

In addition to asking about general knowledge of genomics or genomic medicine, participants were asked if they had seen, read or heard about any of the following over the last three months:

- Services offering genetic profiling for individuals, such as "23andMe"
- New techniques for scientists to be able to edit the genomes of plants, animals or humans
- The "100,000 Genomes Project" to map the genomic data of approximately 70,000 NHS patients
- Any negative or concerning stories about genomic research of medicine
- The work of "Genomics England"

As shown in Figure 1.4, awareness is low and the majority of participants have not seen, read or heard of any of these five aspects of genomics (68 per cent). However, the most commonly recalled are services offering genetic profiling (17 per cent), new techniques for scientists to edit genomes (16 per cent) and the "100,000 Genomes Project" (12 per cent). Participants are less likely to recall any negative or concerning stories about genomics (4 per cent) or the work of Genomics England (3 per cent).

Figure 1.4



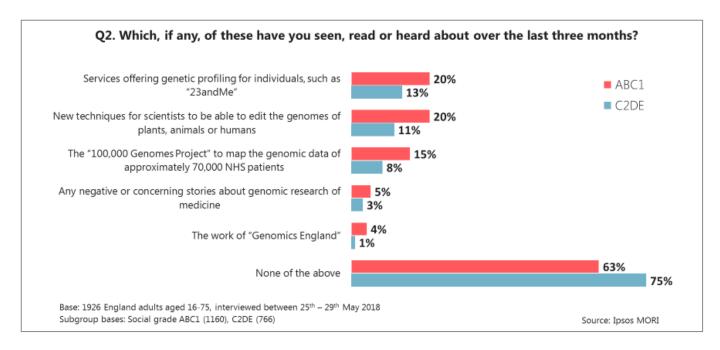
Again, several demographic subgroup differences exist. Females are significantly more likely to not be aware of these five aspects of genomics (70 per cent) compared to males (66 per cent).

Participants aged 45-64 are significantly less likely to have seen, read or heard about several of the examples provided. Fourteen per cent recall services offering genetic profiling (compared to 21 per cent aged 16-24 and 19 per cent aged 25-44). Similarly, 13 per cent recall new techniques for scientists to edit genomes (compared to 21 per cent of those aged 16-24 and 19 per cent of those aged 65-75. They are also less likely to recall the "100,000 Genomes Project" (9 per cent compared to 15 per cent aged 16-24 and 14 per cent aged 65-75) or the work of Genomics England (2 per cent compared to 7 per cent aged 16-24 and 4 per cent aged 25-44).

While the number reporting awareness of any negative or concerning stories about genomic research of medicine is very low, it is significantly higher amongst the youngest age groups. Those aged 16-24 are more likely to recall something (7 per cent) compared with 3 per cent aged 25-44, 5 per cent aged 45-64 and 3 per cent aged 65-75.

As shown in Figure 1.5, differences in knowledge also exist by social grade, as those in social grade ABC1 are significantly more likely to be aware of all the examples provided.

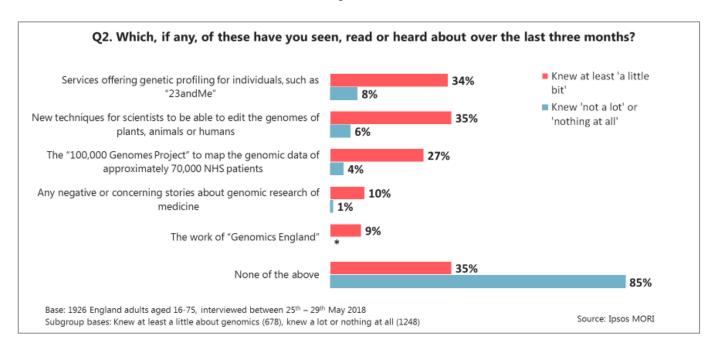
Figure 1.5



Similarly to general knowledge about genomics, generally those with a higher level of education are more likely to have seen, read or heard of the examples given. For example, 27 per cent of those with an NVQ5 or post-graduate diploma recall the "100,000 Genomes Project". Knowledge is lower in the other education categories of NVQ4 (13 per cent), NVQ3 (10 per cent), NVQ1/NVQ2 (7 per cent), GCSE (6 per cent) or secondary school (3 per cent).

As expected, those who report knowing at least 'a little bit' about genomic medicine are more likely to recall each of the five aspects of genomics (Figure 1.6).

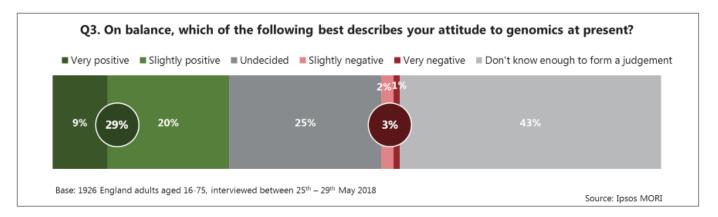
Figure 1.6



## 2. Attitude to genomics

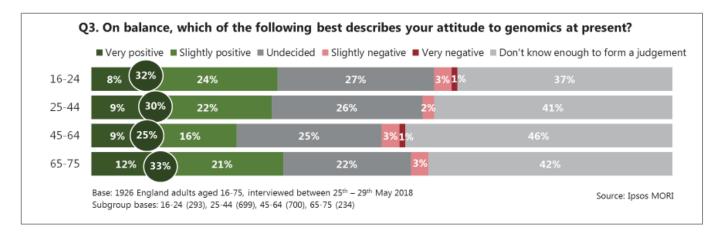
As shown in Figure 2.1, the majority of participants do not feel they know enough to form a judgement on their attitude to genomics (43 per cent) or are undecided (25 per cent). This low level of familiarity is reasonable, as members of the public would be unlikely to have had contact with this area of medicine. However, around three in ten (29 per cent) feel very or slightly positive, and a very small minority are very or slightly negative (3 per cent). This suggests participants are overall more positive than negative towards genomics, with a net positivity score of 26%.

Figure 2.1



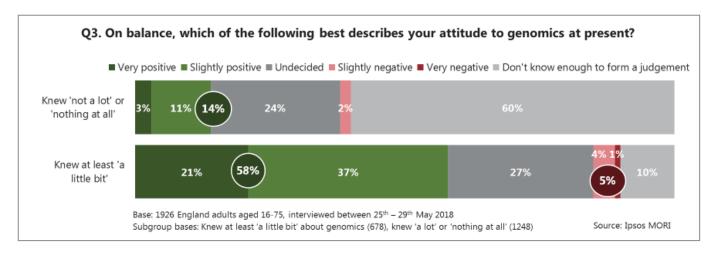
Those in social grade ABC1 are also more likely to be positive (32 per cent state they are very or slightly positive compared with 25 per cent of those in social grade C2DE). Those in social grade C2DE are more likely to state they do not know enough to form a judgement (48 per cent compared to 38 per cent). As shown in Figure 2.2, those aged 45-64 are significantly less likely to be positive about genomics compared to any other age group.

Figure 2.2



Finally, those who know at least 'a little bit' about genomics or genomics medicine are more likely to feel positively (58 per cent) compared with 14 per cent of those who state they know not a lot or nothing at all. Whereas those who state they know not a lot or nothing at all are more likely to respond they do not know enough to form a judgement (60 per cent) compared to those who know at least a little (10 per cent) (Figure 2.3).

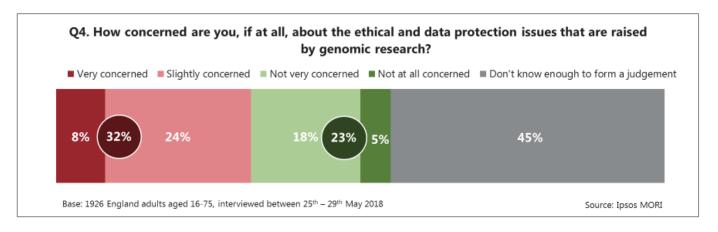
Figure 2.3



# 3. Ethical and data protection concerns

As shown in Figure 3.1, around a third of participants (32 per cent) have some concerns about ethical and data protection issues raised by genomic research, whereas a quarter (23 per cent) are not very or not at all concerned. Almost half of participants (45 per cent) state they do not know enough to form a judgement (45 per cent).

Figure 3.1

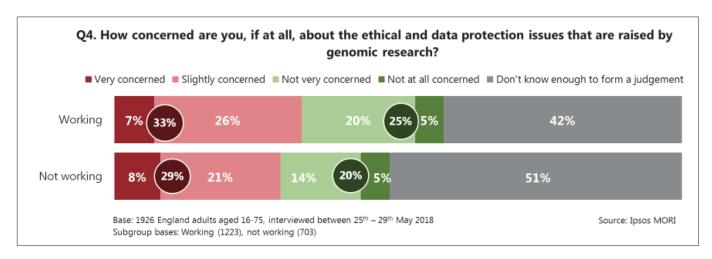


Those in higher social grades are the most likely to report they have concerns. Around a third (34 per cent) of ABC1s reported they are very or slightly concerned compared with 28 per cent of those in grade C2DE.

Participants in the youngest age category are the least likely to report feeling concerned about ethical and data protections issues raised by genomics research. Around a third (33 per cent) state they are not very or not at all concerned compared with 24 per cent aged 25-44, 21 per cent aged 45-64 and 18 per cent aged 65-75.

As shown in Figure 3.2, participants who are not working are less likely to have concerns (20 per cent) compared with those working (25 per cent). Those who are not working are more likely to state they do not know enough to form a judgement (51 per cent) compared with those working (42 per cent).

Figure 3.2



# **Appendix**

### **Appendix 1: Omnibus Questions**

#### What is Genomics?

You have a complete set of genes in almost every healthy cell in your body. One set of all these genes, (plus the DNA between the genes), is called a genome. Genomics is the study of the whole genome and how it works, including how particular features or diseases are inherited from one generation to the next. Genomics is also about the way that the genome is interpreted and the technologies that have been developed to help do this.

#### 1. Before being interviewed today, how much did you know about genomics/genomic medicine?

- A great deal
- A fair amount
- A little bit
- Not a lot
- Nothing at all

#### 2. Which, if any, of these have you seen, read or heard about over the last three months?

- The work of "Genomics England"
- The "100,000 Genomes Project" to map the genomic data of approximately 70,000 NHS patients
- Services offering online genetic profiling for individuals, such as "23andMe"
- New techniques for scientists to be able to edit the genomes of plants, animals or humans
- Any negative or concerning stories about genomic research or medicine
- None of the above

#### 3. On balance, which of the following best describes your attitude to genomics at present?

- Very positive
- Slightly positive
- Undecided
- Slightly negative
- Very negative
- I don't know enough to form a judgement

#### 4. How concerned are you, if at all, about the ethical and data protection issues that are raised by genomic research?

- Very concerned
- Slightly concerned
- Not very concerned
- Not at all concerned
- I don't know enough to form a judgement

### Appendix 2: Omnibus Demographic Categories

#### Gender

- Male
- Female

#### Age

- 16-24
- 25-44
- 45-64
- 65-75

#### Region

- North East
- North West
- Yorkshire and the Humber
- West Midlands
- East Midlands
- East of England
- South West
- South East
- Greater London

#### Working Status

- Working
- Not Working

#### Education

- Primary School
- Secondary school (age under 15 years old)
- GNVQ / GSVQ / GCSE/ SCE standard
- NVQ1, NVQ2
- NVQ3/ SCE Higher Grade/ Advanced GNVQ/ GCE A/AS or similar
- NVQ4 / HNC / HND / Bachelor's degree or similar
- NVQ5 or post-graduate diploma

## Appendix 3: Guide to Social Classification

In this report, references are made to social grade. The following table contains a brief list of social grade definitions as used by the Institute of Practitioners in Advertising. These groups are standard on all surveys carried out by Ipsos MORI.

Social Grade	Social Class	Occupation of Chief Income Earner
A	Upper Middle Class	Higher managerial, administrative or professional
В	Middle Class	Intermediate managerial, administrative or professional
C1	Lower Middle Class	Supervisor or clerical and junior managerial, administrative or professional
C2	Skilled Working Class	Skilled manual workers
D	Working Class	Semi and unskilled manual workers
Е	Those at the lowest levels of subsistence	State pensioners etc., with no other earnings

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