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Science Education Tracker: Young people's attitudes towards biomedicine

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Science Education Tracker:

Young people’s attitudes towards biomedicine

Rebecca Hamlyn, Peter Matthews and Martin Shanahan

Kantar Public

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This project was carried out in compliance with our certification to ISO 9001 and ISO 20252 (International Service Standard for Market Opinion and Social Research)

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Executive summary

Introduction

- This report presents findings from the biomedicine module which was conducted as part of the 2016 Science Education Tracker (SET) survey. The SET survey is a survey of young people conducted by Kantar Public on behalf of the Wellcome Trust and supported by the Royal Society, the Department for Business, Energy and Industrial Strategy (BEIS) and the Department for Education (DfE).
- The core content of the SET survey is designed to provide evidence on a range of key indicators for science engagement, education and career aspirations among young people in England. The biomedicine module specifically focuses on young people's interest in and attitudes towards biomedical science.
- The SET survey is based on a nationally representative sample of 4,081 young people in school years 10 to 13 (aged 14-18) attending state-funded education in England. The biomedicine module was addressed to a random half sub-sample of this population, a total of 2,037 young people.
- Fieldwork was conducted online between June 29th and August 31st 2016.

Key findings

- A half (51%) of young people expressed some interest in medical science or medical research; 13% said that they were "very interested". Interest was highest among young females and those with: Asian ethnicity; strong family science connections; a high science quiz score; experience of a serious genetic condition within the family; and experience of a serious illness or disability within the family.
- Key areas of interest for young people were how the brain works (52%), mental health issues (47%) and how the body works (42%). Females were considerably more likely than males to show interest in mental health issues (62% compared with 32%).
- Two in five young people (43%) had sought information about medical advice such as cures and symptoms while 17% had sought information on medical careers. Females were more likely than males to look up information on medical advice (51% compared with 36%) and medical careers (23% compared with 11%). Almost all students looking for information of this type used online channels (92%). Other channels used to search for information included doctors (24%), teachers (22%) and books (19%).
- Overall 73% said that they would be willing to share their medical records for the purposes of medical research; a slightly lower proportion (64%) said they would be willing to share information from their genes/DNA for this purpose. More scientifically able students with a

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high quiz score were much more prepared to share medical records (85%) and DNA (77%) compared with students with a low quiz score (60% and 51% respectively).

- A quarter of young people (23%) had some concerns about sharing their DNA for medical research purposes. Among those who had concerns, the nature of concerns centred around knowing what the research was going to be used for (71%), confidentiality (65%) and having sufficient knowledge about the research (55%).

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Introduction

Background

Wellcome is interested in understanding and tracking the public's awareness, interest, knowledge and attitudes in relation to biomedical science and research. Previous research conducted by Wellcome (the Wellcome Monitor - see below) concentrated on attitudes towards biomedicine among adults and, to a more limited extent, among young people. Developing a greater understanding of young people's attitudes towards biomedical research will help Wellcome to shape its related policy, education and public engagement work.

The Science Education Tracker

The Science Education Tracker (SET) is a new survey of young people in Years 10 to 13 attending state-funded education in England. The survey was conducted by Kantar Public on behalf of Wellcome with support from the Royal Society, the Department for Business, Energy and Industrial Strategy (BEIS) and the Department for Education (DfE). The survey provides evidence on key indicators for science engagement, education and career aspirations among young people in England.

The SET survey has built on two previous studies conducted on behalf of Wellcome: the Wellcome Monitor Waves 1 and 2 conducted in 2009 and 2012.[1] The first two waves of the Wellcome Monitor were large-scale face-to-face surveys of adults and young people aged 14+. Each of these studies included a sample of around 400 young people aged 14-18. From 2015 (Wave 3), the Monitor focused on adults aged 18+ only and a bespoke Science Education Tracker survey was established to focus on understanding young people's experience of science inside and outside of school and how this influences decision-making around science-based subject and career choices. The survey represented a departure from the Monitor surveys in several respects: the survey moved from face-to-face interviewing to online self-completion; the sampling frame changed; and the young person's sample size was substantially increased to allow more detailed analysis by school year cohorts and population subgroups.

The Biomedicine module

As an addition to the core content of the SET survey, two supplementary modules were included: a short module on attitudes towards biomedical science funded by Wellcome (reported here) and a short module on awareness and attitudes towards machine learning funded by the Royal Society.[2]

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[1] https://wellcome.ac.uk/what-we-do/our-work/public-views-medical-research

[2] The findings for the machine learning module can be found at: https://wellcome.ac.uk/what-we-do/our-work/young-peoples-views-science-education

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Each module was asked of a randomly selected half of the main sample. The biomedicine module is based on a sample of 2,037 out of the 4,081 respondents who completed the SET survey.

The Wellcome Monitor surveys (waves 1, 2 and 3) included a number of questions on attitudes towards biomedical research. A smaller biomedicine module was developed as part of the SET survey. The questions were developed using the Monitor survey questions as a starting point, although the questions were adapted to suit the context of the SET survey instrument.

The SET survey included questions on the following:

- Interest in medical research
    - Level of interest and specific areas of interest
    - Information sought on medical issues and channels used
- Willingness to participate in medical research that involves use of medical records or DNA
    - Concerns about this.

A note about comparisons with the Wellcome Monitor

It is important to note that the sample design and the mode of data collection of the SET survey differ from those of the Wellcome Monitor surveys (waves 1 and 2) which also covered samples of young people. Therefore, while the Science Education Tracker has built upon the knowledge collected from the previous waves of the Wellcome Monitor, caution must be exercised in making comparisons between the two and drawing conclusions about changes over time.

In addition to changes in wording and sampling, we would also expect some differences in responses due to the placement and context of the questions in the two surveys. The Wellcome Monitor was specifically focussed on biomedical issues and therefore it is possible that respondents in the Monitor survey were more engaged in the topic of medical science when answering questions about levels of interest and engagement. In the SET survey on the other hand, the questions were not as closely related to other topics in the survey.

SET Survey Methodology

Further information about the survey background and methodology can be found in the Technical Report, available from the UK Data Archive while the reports are on the Wellcome website. Key details are as follows:

- The sample is a random sample of young people in school years 10 to 13 (aged 14-18) attending state-funded education in England. It was drawn from a combination of the National Pupil Database (NPD) and the Individualised Learner Record (ILR).
- All sampled individuals were sent a letter inviting them to take part in a survey; for young people aged under 16 correspondence was directed via parents. Respondents then completed the survey online.

- Respondents were asked questions about a range of topics including their experience of science education, their plans for the future and their attitudes towards science-related careers. The questions drew on existing surveys such as the Wellcome Monitor, as well as newly developed questions for this survey. The questionnaire wording and content was also informed by focus groups with young people commissioned by Wellcome at the outset of the project. All new questions were cognitively tested with young people prior to administration.
- A field pilot of c. 200 online completions was conducted before the main survey to test and pilot survey procedures.
- Respondents were able to complete the survey on any online device, including PCs, laptops, tablets, and mobile phones.
- 4,081 respondents completed the survey between June 29th and August 31st 2016, representing a response rate of 50%[3]. Questions related to the September 2015-July 2016 school year which respondents had recently completed.
- This response rate was achieved after sending an initial invitation and up to three reminders. Reminders were targeted at groups with the lowest response rates in order to maximise the representativeness of the sample. The achieved sample closely matched the population on a range of demographic variables; data were weighted to ensure that the sample profile fully matched the population profile.

Linking survey responses to administrative data

All respondents were asked their permission for administrative data from the NPD to be linked to their survey answers: 83% gave permission for their data to be linked. This administrative data included (amongst other data):

- eligibility status for free school meals
- whether English is the young person's first language
- academic results from Key Stage 2 and Key Stage 4[4].

The 17% of respondents who did not consent to data linkage were asked some additional questions about qualifications achieved to cover some of the items that would have been drawn from the NPD.

Science quiz

In the Wellcome Monitor, respondents were asked a series of true / false questions relating to knowledge of different areas of science such as genetic modification, DNA, electrons and mass. A very similar knowledge quiz was used in the Science Education Tracker.

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[3] Response rate is calculated as: number of completed interviews / number of cases issued. This corresponds to Response Rate 1, as calculated by the American Research Association for Public Opinion Research (AAPOR, 2016, Survey Outcome Rate Calculator 4.0).

[4] Key Stage 4 data was only available for young people who had already completed these exams. This was primarily young people in Years 12 and 13.

Respondents were classified into one of three groups based on their score from the knowledge quiz:

- Low (23% of respondents) – 0-5 correct answers
- Medium (57% of respondents) – 6-8 correct answers
- High (20% of respondents) – 9-10 correct answers.

Throughout this report, the knowledge quiz scores are used as a measure of scientific knowledge and as a proxy for attainment in science. For respondents in Years 12 or 13 who had agreed to link NPD data to their survey answers, we were able to compare knowledge quiz scores with achieved Key Stage 4 science results. A moderate Pearson's correlation coefficient of 0.5 was observed between quiz score and Key Stage 4 results, indicating that there is some overlap with qualifications.

Family Science Connection Index (FSCI)

In the Science Education Tracker we developed a Family Science Connection Index (FSCI) to help measure and explain the variation in family connections to science. The index was constructed by combining responses to three questions which asked:

- How many people you know with a medical or science-related job that you can talk to about health, medicine or other scientific issues outside of school.
- Whether your parents are interested in science.
- Whether any family member works as a scientist or in a job using science or medicine.

This produced a scale from zero to six. Scores were then banded into three categories: those with low family science connections (score of 0); medium family science connections (1-3); and high family science connections (4-6). The measure is used to classify young people into groups according to the strength of family science connections they hold within their family and wider networks.

Structure of report

The report is structured as follows.

- Chapter 1 considers the level of interest in medical science and medical research among young people, focusing on areas of interest, information sources and channels used.
- Chapter 2 explores young people's willingness to allow their medical records and DNA to be used for the purposes of medical research. It looks at overall levels of willingness, how this varies by different subgroups and the types of concerns they have about participating in such a project.

Reporting conventions

All differences commented on in this report are statistically significant at the 95 per-cent level of confidence. All percentages reported are weighted to account for differential nonresponse.

Where percentages do not sum to 100 percent or to net figures, this will be due to either rounding or questions which allow multiple answers.

Respondents were able to refuse to answer any question by selecting ‘prefer not to say’. Where a respondent refused an answer, they have not been included in the analysis for that question. ‘Don’t know’ responses are included in all questions reported except where otherwise specified.

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1. Interest in medical research

This chapter considers the level of interest in medical science and medical research among young people, focusing on specific areas of interest, sources of information and channels used.

1.1 Overall level of interest

Overall half (51%) of young people expressed some interest in medical science or medical research; 13% said that they were “very interested”. This level is broadly in line with the proportion of young people aged 14-19 expressing an interest in the 2012 Wellcome Monitor (Clemence *et al*, 2013) where the overall level of interest was 58%. Level of interest among young people in the SET survey does however remain lower when compared with the adult population: 77% of adults aged 18+ in the Wellcome Monitor 2015 (Huskinson *et al*, 2015) expressed interest in this topic.

As shown in Figure 1.1, subgroups most likely to express an interest in medical science or research include:

- female students
- students with an Asian background
- students with strong family science networks
- students with a higher science knowledge level, as measured by the science quiz
- students affected by a serious genetic condition (themselves or within the family)
- students affected by a serious disability (themselves, close family member or close friend)

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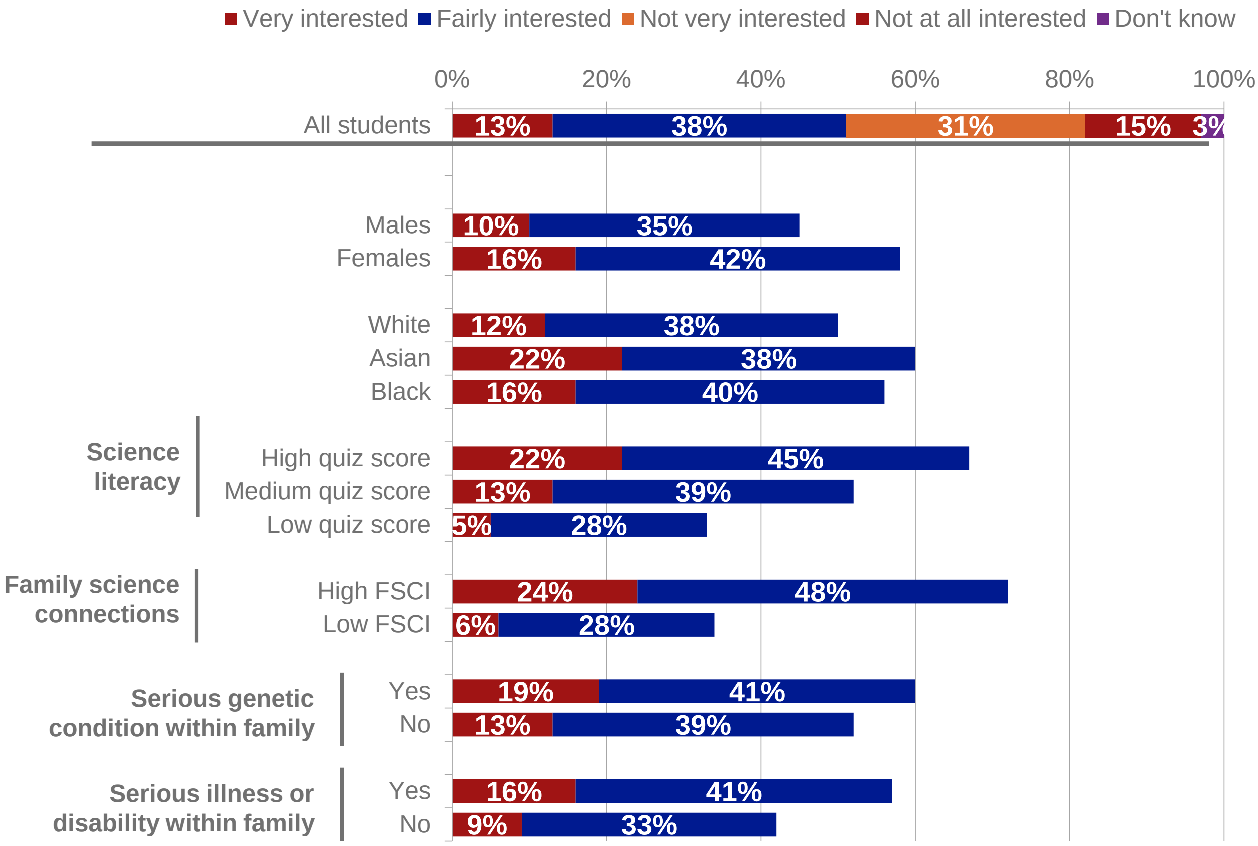
Figure 1.1: Interest in medical science by demographic and health-related subgroups

Q. In general, how interested are you in medical science and medical research?



Base (All respondents):Total (2,024), Males (964), Females (1,046), White (1,575), Asian (215), Black (83), High quiz score (423), Medium quiz score (1,202), Low quiz score (399), High FSCI score (365), Low FSCI score (508), Serious genetic condition within family (223), No genetic condition with family (1,365), Serious disability/illness within family (1,234), No disability within family (790)

1.2 Specific areas of interest

Figure 1.2 displays the level of interest among young people in different biomedical topics. Some young people who said they were not interested in medical science and research in general (as discussed above), nevertheless identified areas of interest when presented with more specific topics; overall 80% expressed in interest in at least one of the topics presented, as shown in Figure 1.2.

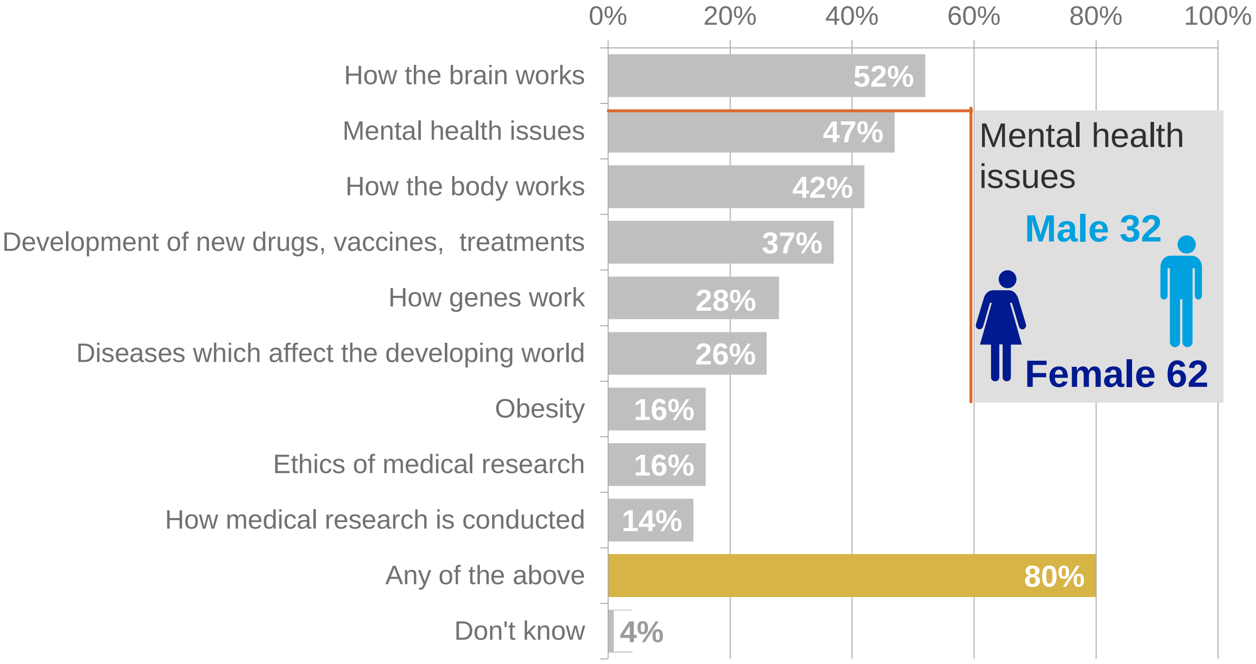
The key areas of interest among young people were how the brain works (52%), mental health issues (47%), workings of the body (42%) and development of new drugs and treatments (37%). Findings cannot be compared with the 2012 Young Person's Wellcome Monitor as a slightly different list was presented which will affect relative frequencies. However, it is worth noting that the top three factors in the Monitor overlapped with the key areas of interest in the SET survey: in the 2012 Monitor young people were mainly interested in new drugs/treatments; how the body works and how the brain works (mental health issues were not included in the Monitor question).

The inclusion of mental health in the SET survey question clearly signposts this as a key area of interest for young people. Female students were more interested than male students in all issues, with the sole exception of development of new drugs and treatments where there was no gender difference. However, there was a particularly marked gender difference in relation to mental health issues. Females were around twice as likely to cite this as an area of interest (62% compared with 32% of males).

Students with experience of genetic conditions within the family were particularly likely to be interested in how the brain works (66 % compared with 52% of those without such experience); and how genes work (37% compared with 28%).

Figure 1.2: What areas of medical research interest young people?

Q. Are you interested in any of these areas of medical research?



Base (All respondents):Total (2,017), Males (959), Females (1,046)

1.3 Information sources

Half (53%) of young people had sought information about an area of medicine, as displayed in Figure 1.3. While 43% had sought information on medical advice, a lower proportion sought information on medical careers (17%) or medical research projects or trials (15%).

There was a strong gender divide in relation to seeking information: females were much more likely than males to look up information on medical advice (51% compared with 36%) and medical careers (23% compared with 11%). Students with experience of illness or disability within the family had a higher propensity to seek out information on medical advice (49%) compared with students with no such experience (35%).

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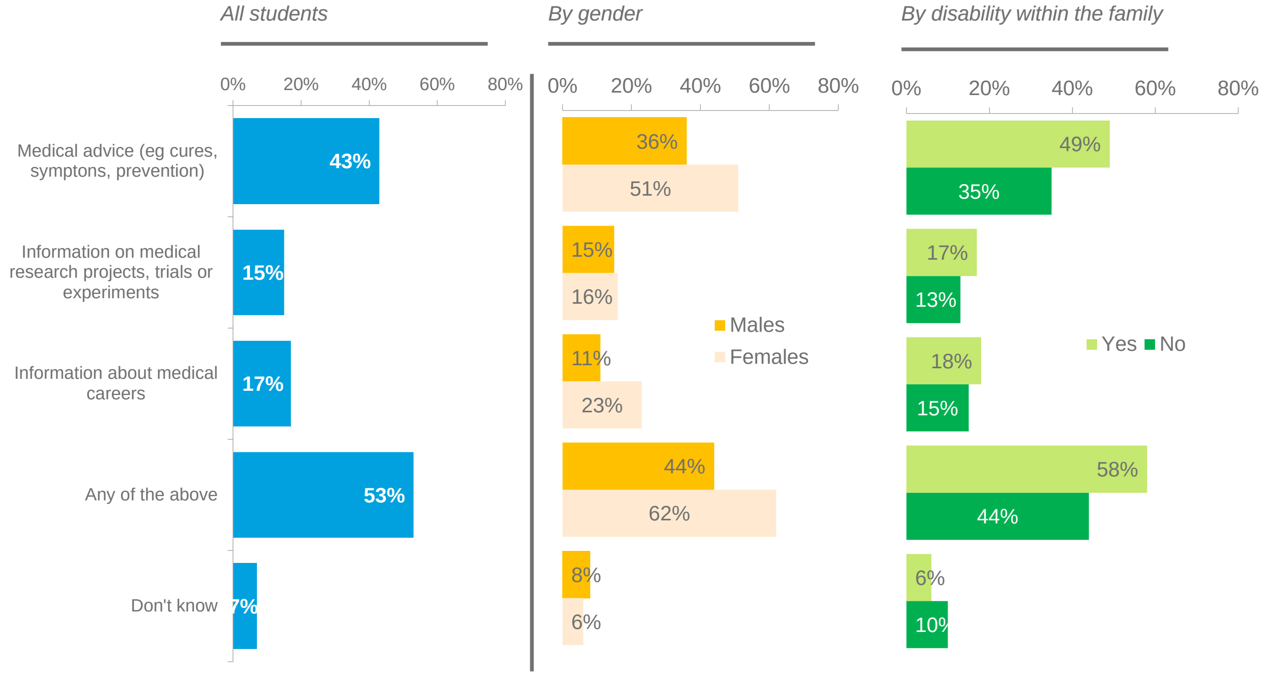
Figure 1.3: Information sought on medical issues

Q. In the past year, have you tried to find out any information about any of the following?



Base (All respondents):Total (2,011), Males (956), Females (1,042), Serious disability/illness within the family(1,229), No disability within the family (782)

Students who had sought information on any of the topics in Figure 1.3 were asked about channels used for this purpose. Online resources were used almost unanimously by young people seeking information (92%) while at least one in five of this subgroup consulted doctors (24%), teachers (22%), other people (29%) and books (19%). See Figure 1.4.

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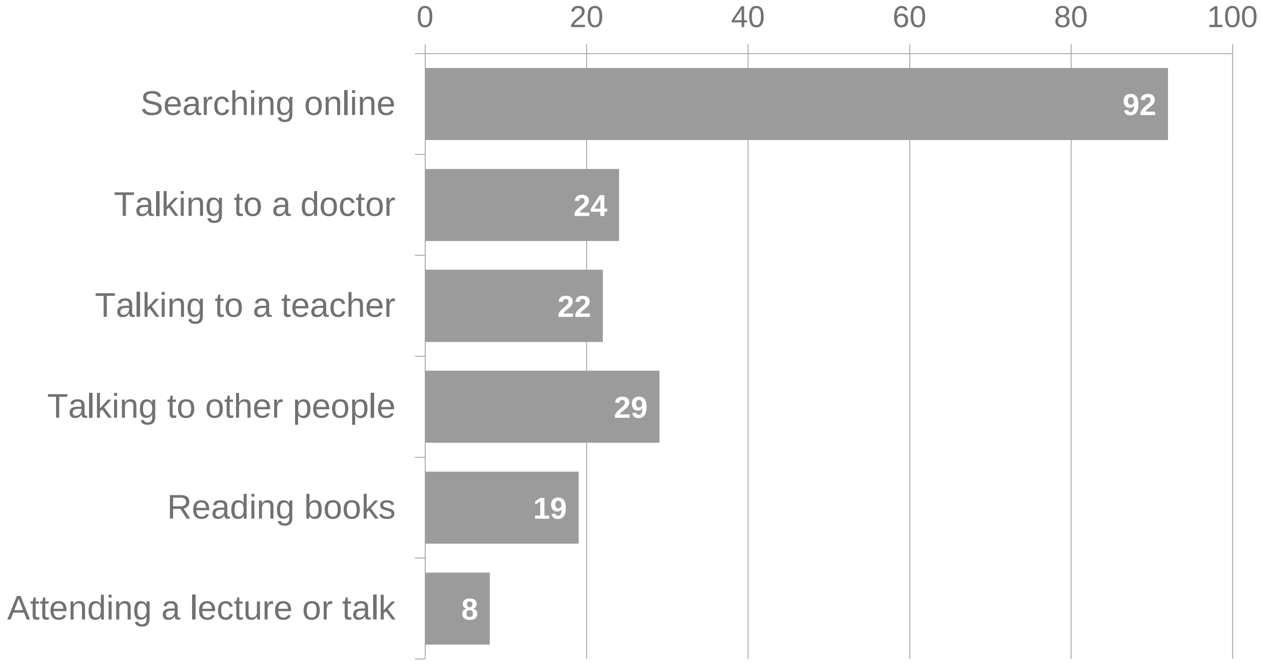
Figure 1.4: Channels used to seek information on medical issues by those who have looked for information

Q. How did you look for this information?



Base (All respondents who looked for medical science information):Total (1,087)

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2. Willingness to share medical records or DNA for medical research

This chapter explores young people's willingness to allow their medical records and DNA to be used for the purposes of medical research. It looks at overall levels of willingness, how this varies by different subgroups and the types of concerns young people have about participating in such a project.

2.1 Level of willingness

Young people were asked about their willingness for their patient data to be used for the purposes of medical research: first in the context of using their medical records; and second in the context of using their DNA.

The findings in Figure 2.1 indicate that most young people are willing to participate in medical research in this way: overall 73% said that they would be willing to share medical records and a slightly lower proportion (64%) were willing to share information from their genes/DNA. However, only around one in four young people said that they would "definitely" share medical information of this nature in each of these scenarios. It is also worth noting that the level of "don't know" responses is relatively high (11% and 14% for medical records and DNA respectively)

A similar (though not identically worded) set of questions was asked of adults in the 2015 Wellcome Monitor survey[5] (Huskinson *et al*, 2016) and here around three quarters (77% for medical records and 75% for DNA) were in favour of sharing their data for research purposes. Thus the rate of young people's willingness to share medical records was similar to the rate among adults, although the rate of willingness to share DNA was slightly lower among young people.

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[5] The equivalent question in the Wellcome Monitor survey addressed to adults stated that medical records would be anonymised; this clarification was not included in the SET survey version of the question.

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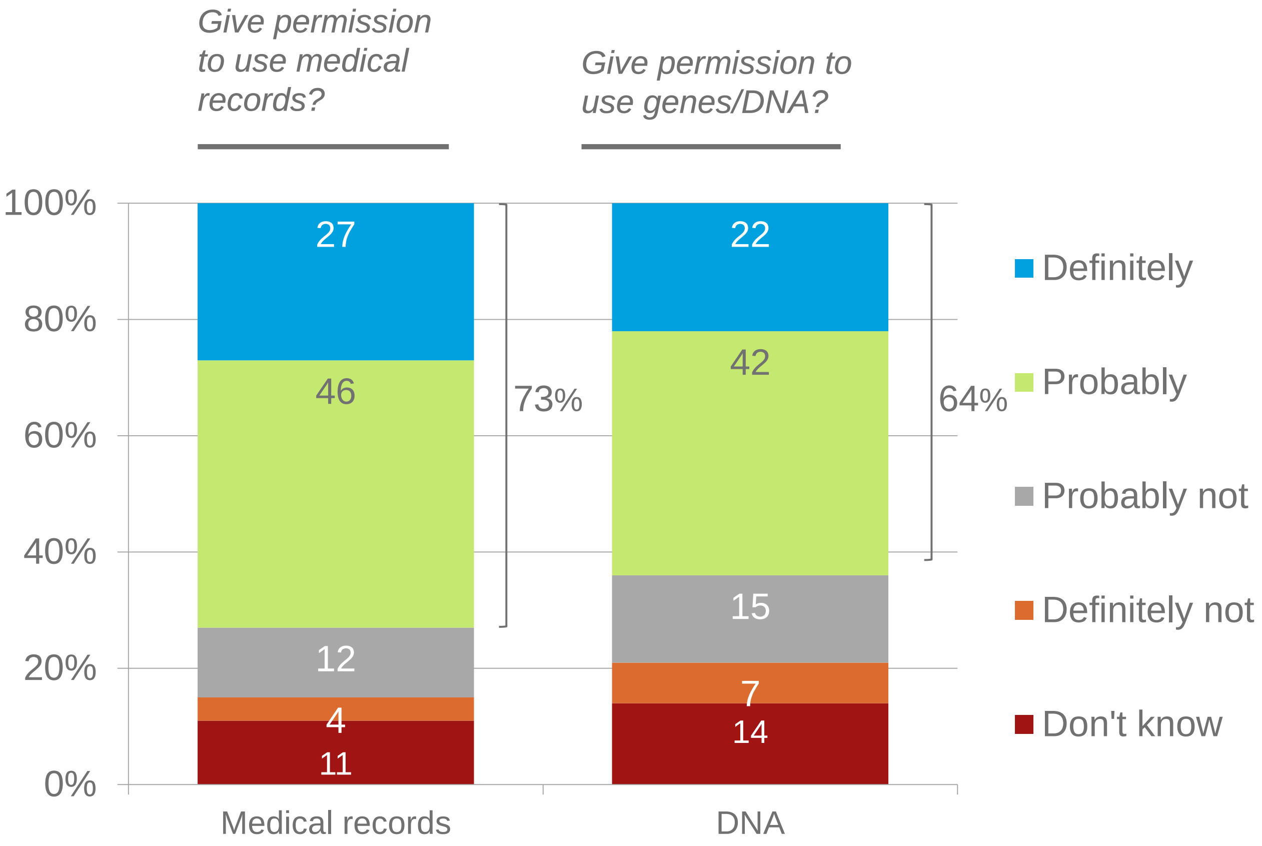
Figure 2.1: Willingness to use your medical records or DNA in a medical research study?

Q. Imagine a doctor asks your permission to use your medical records in a medical research study. Would you give permission?
Q. Now imagine a doctor asks your permission to use information from your genes/DNA in a medical research study. Would you give permission?



Base (All respondents):Total (Medical records: 2,011, DNA: 2,009)

Young people’s willingness to share records or DNA does not vary by gender. However there are some subgroups that were more prepared to share data for medical research purposes (see Figure 2.2). For both sharing medical records and DNA the following groups were most willing to participate:

- Young people with stronger family science connections
- Young people from a white ethnic background (compared to those from an Asian background)
- Young people with experience of illness or disability in their family
- Students with a high science quiz score (which serves as a proxy for science knowledge). The difference between those with a high quiz score and those with a low quiz score was partly explained by a greater reluctance to share data among those with a low quiz score, and partly by a greater level of “don’t know” responses among this group.

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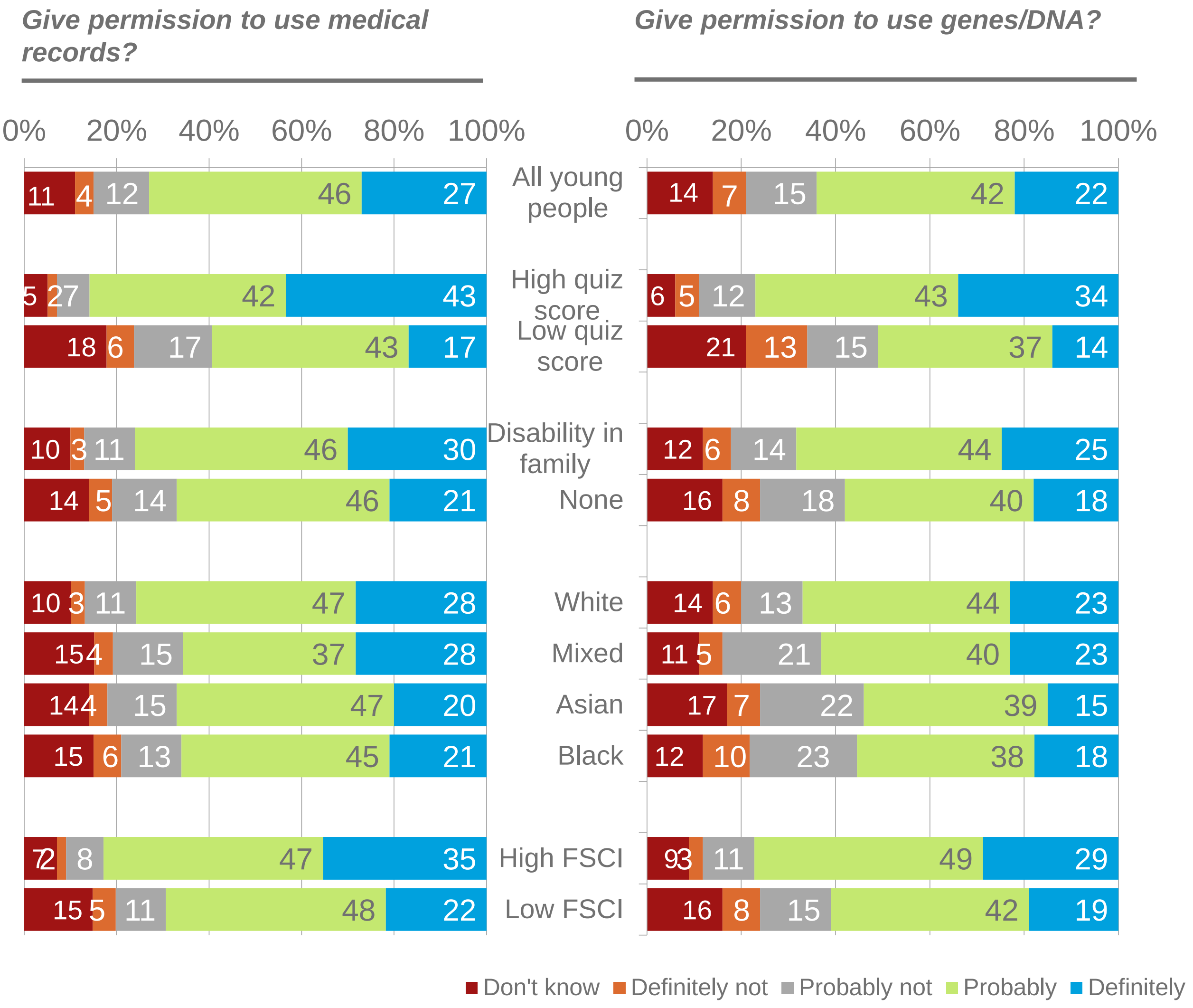
Figure 2.2: Willingness to share data for medical research purposes

Q. Imagine a doctor asks your permission to use your medical records in a medical research study. Would you give permission?

Q. Now imagine a doctor asks your permission to use information from your genes/DNA in a medical research study. Would you give permission?



Base (All respondents):Total (2,011), High quiz score (423), Low quiz score (392), Serious disability/illness within family (1,230), No disability within family (781), White (1,565), Mixed (87), Asian (214), Black (81), High FSCI score (366), Low FSCI score (502)

2.2 Concerns about sharing DNA

Around a quarter of young people (23%) had some concerns about sharing their DNA for medical research purposes while a further quarter (26%) did not know if they would have concerns. Unsurprisingly, the rate of reporting concerns was strongly related to willingness to share DNA:

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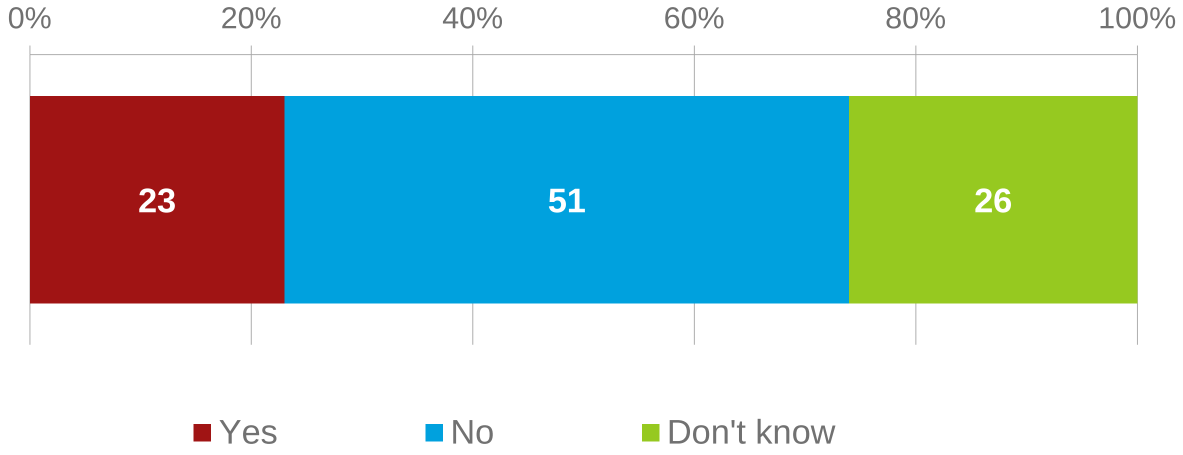
48% of those who were probably or definitely unwilling to share their DNA for research purposes cited concerns compared with only 13% of those who were probably or definitely willing.

In addition, those with experience of a genetic condition within the family were more likely to have concerns than those without such experience (29% compared with 22%). See Figure 2.3.

Figure 2.3: Whether young people have concerns about information from their genes/DNA being used in a medical research study

Q. Would you have any concerns about information from your genes / DNA being used in a medical research study?



Base (All respondents): Total (1,995)

Among those who said they had concerns, respondents were presented with a list of issues and asked which concerns they might have (see Figure 2.4). The nature of the concerns cited reflected a desire to know more about what was involved before committing to participation. For example, 71% would be concerned about what the research would be used for, 55% had concerns about the nature of the research, 45% would want more information on how genetic information would be collected and 38% were concerned they would not understand the research. Other concerns mentioned were confidentiality (65%) and lack of trust in organisations conducting such research (52%).

Sample sizes are too small for detailed subgroup analysis.

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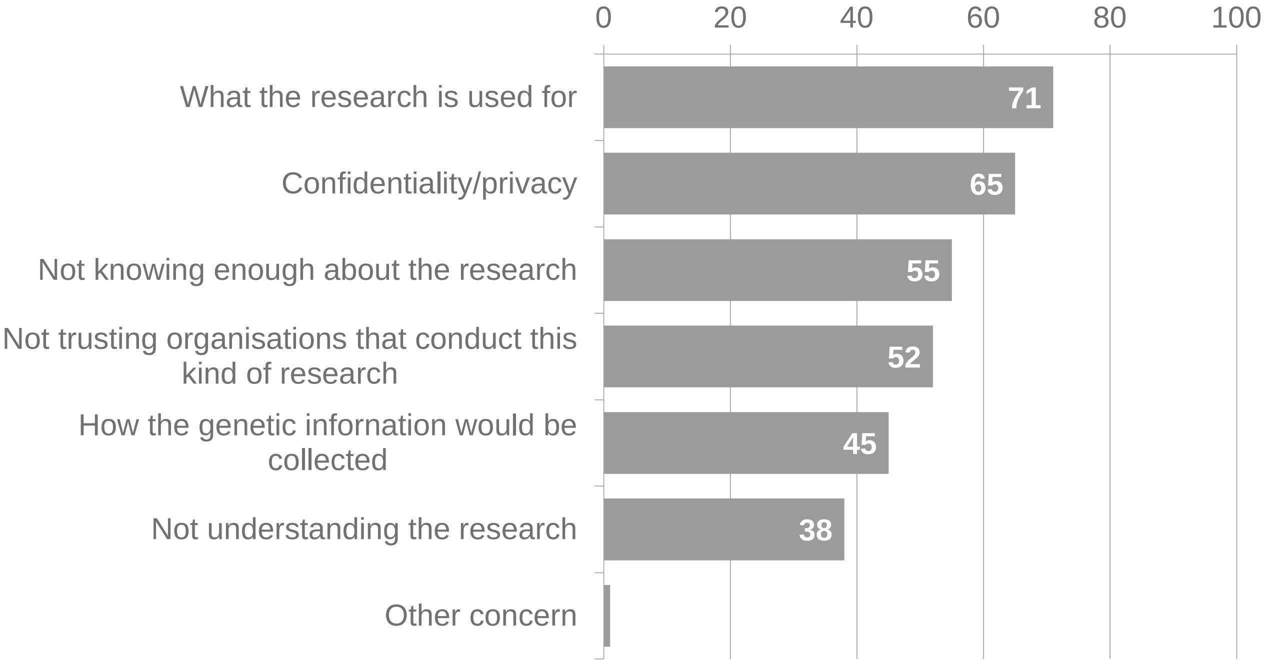
Figure 2.4: What concerns do young people have about information from their genes/DNA being used in a medical research study

Q. What concerns would you have?



Base (All respondents with concerns): Total (453)

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