

NatCen

Social Research that works for society

Wellcome Monitor 2020

How the British public engage with
health research



Authors: Sylvie Craig, Curtis Jessop, Pri Perera, Ethan Greenwood

Date: February 2021

Prepared for: Wellcome

At NatCen Social Research we believe that social research has the power to make life better. By really understanding the complexity of people's lives and what they think about the issues that affect them, we give the public a powerful and influential role in shaping decisions and services that can make a difference to everyone. And as an independent, not for profit organisation we're able to put all our time and energy into delivering social research that works for society.



NatCen Social Research
35 Northampton Square
London EC1V 0AX
T 020 7250 1866
www.natcen.ac.uk

A Company Limited by Guarantee
Registered in England No.4392418.
A Charity registered in England and Wales (1091768) and Scotland (SC038454)
This project was carried out in compliance with ISO20252

Contents

Executive summary	1
1 Introduction	4
1.1 Background.....	4
1.2 Methodology	5
2 Public appetite for health research.....	7
2.1 Interest in using health research	8
2.1.1 How interested are people in hearing about health research and health-related information?	8
2.1.2 What areas of health research are people interested in?	12
2.2 Interest in informing health research	17
2.2.1 Playing a role in health research.....	17
2.2.2 Setting priorities for health research	19
2.3 Perceived value of health research	21
3 Engaging with and accessing health research.....	24
3.1 Engaging with health-related information.....	25
3.2 Accessing health-related information	28
3.2.1 Making decisions about your health.....	28
3.2.2 Experiences accessing health-related information	29
4 Involvement in health research	39
4.1 Participation in health research.....	39
4.1.1 Activities done in the past 5 years.....	39
4.1.2 Interest in participating in health research in the future	43
4.2 Empowerment in health decision-making	44
5 Segmenting the population	50
6 Conclusion	59
Appendix A. Health issues which people think it is most important for researchers to work on	62
Appendix B. Details of population segments	67

Tables

Table 5:1	Percentage trusting health related information from different sources completely or a great deal by health research attitudes and behaviours segment	57
Table 5:2	Percentage that have taken up spread-prevention behaviours by health research attitudes and behaviours segment	58
Appendix table A:1	Health issues which people think it is important for researchers to work on, by sex.....	62
Appendix table A:2	Health issues which people think it is important for researchers to work on, by age group	63
Appendix table A:3	Health issues which people think it is important for researchers to work on, by ethnic group.....	64
Appendix table A:4	Health issues which people think it is important for researchers to work on, by education level.....	65
Appendix table A:5	Health issues which people think it is important for researchers to work on, by financial circumstances.....	66
Appendix table B:1	Use of health-related information by health research attitudes and behaviours segment	67
Appendix table B:2	Trust in health-related information by health research attitudes and behaviours segment	69
Appendix table B:3	Value of health research by health research attitudes and behaviours segment	69
Appendix table B:4	Informing health research by health research attitudes and behaviours segment	70
Appendix table B:5	Demographics by health research attitudes and behaviours segment	71

Figures

Figure 2:1	Interest in health-related information.....	8
Figure 2:2	Proportion who actively seek out news, information and events related to health, by ethnic group	9
Figure 2:3	Whether hear and see too much, the right amount, or too little health-related information	10
Figure 2:4	Whether hear and see too much, the right amount, or too little health-related information	11
Figure 2:5	Which of these areas of health research are you interested in?	12
Figure 2:6	Proportion interested in mental health issues, by age group	13
Figure 2:7	Interest in the health implications of climate change, 2009 to 2020.....	14
Figure 2:8	Which health issues are most important to you personally for researchers to work on?	16
Figure 2:9	How important do you think it is for the public to be able to play a role in health research?	17
Figure 2:10	Given the opportunity, how likely or unlikely would you be to play a role in health research?	18
Figure 2:11	Proportion likely or very likely to take part in health research, by age	19
Figure 2:12	Proportion that think group should probably or definitely be involved in informing/setting priorities for health research – 2018 and 2020	20
Figure 2:13	Whether agree or disagree that scientists are interested in the views of the public when considering the priorities for research and how it is produced	21
Figure 2:14	How beneficial, if at all, would you say health research has been for people like you?	22

Figure 2:15 Thinking about recent health research, what impact, if any, has it had on how you live your life?	22
Figure 3:1 Engagement with health-related information, 2018 and 2020	25
Figure 3:2 Proportion who did at least once 'socialising' activity, by age group.....	27
Figure 3:3 Actions taken when making decisions about health	28
Figure 3:4 Actions taken when making decisions about health, by age group.....	29
Figure 3:5 How often look up health information, 2018 and 2020	30
Figure 3:6 Proportion looking for health-related information several times a day or on most days, by ethnicity	31
Figure 3:7 Clarity of and ease of access to health information	32
Figure 3:8 Trust the health-related information you find	33
Figure 3:9 Proportion with very little or no trust in health-related information normally find, by ethnicity	34
Figure 3:10 Sources of health information, 2020 and 2018.....	35
Figure 3:11 Proportion who use social media or online forums to get health-related information, by how getting by financially	36
Figure 3:12 Online sources of health-related information.....	37
Figure 3:13 Activities done at least once a month by those who use social media....	38
Figure 4:1 What does 'participating in health research' mean to you?	40
Figure 4:2 Activities done in the last 5 years or would be interested in doing.....	41
Figure 4:3 Whether participated in any health research activity including and excluding use of app, by age group	42
Figure 4:4 Confidence in making health decisions	45
Figure 4:5 Confidence in making health decisions, by qualification level	46
Figure 4:6 Whether confident making decisions about health, by ease of access to health-related information, how clear find health-related information and trust in health-related information.....	47
Figure 5:1 Segments of the population based on health research attitudes and behaviours	51
Figure 5:2 Use: Relationship with health-related information & clarity of health-related information by health research attitudes and behaviours segment.....	52
Figure 5:3 Trust: Trust in health-related information you find by health research attitudes and behaviours segment	53
Figure 5:4 Value: Impact of health research on how you live your life by health research attitudes and behaviours segment	53
Figure 5:5 Inform: Likelihood of playing a role in health research by health research attitudes and behaviours segment	54
Figure 5:6 Percentage in age group by health research attitudes and behaviours segment	55
Figure 5:7 Percentage with different levels of qualification by health research attitudes and behaviours segment	56

Executive summary

The following were the views and experiences of the British public between 30th March and 26th April, at the start of the government lockdown in response to the coronavirus outbreak. This report explores the complex nature of people's relationships with health information in the early stages of a public health crisis, building on findings from previous Wellcome Monitor surveys conducted in 2009, 2012, 2015, and 2018.

Public appetite for health research

Most people were interested in health research and around half felt they hear or see the right amount.

- People from BAME groups, those with higher qualifications and younger people were more likely to actively seek out health research.
- People were more likely to be interested in hearing directly from scientists than they were in 2015.
- Mental health remains the area people were most interested in, but there has been an increase in interest in the health implications of climate change.

A majority of people thought it was important that the public play a role in health research and would be likely to do so themselves, given the opportunity.

- Younger people and those with degrees were more likely to be willing to play a role in health research.
- More people thought that members of the public should be involved in setting priorities for health research than in 2018.
- People still felt that scientists in universities and government should be more responsible for setting priorities for health research than the public.

Most people viewed health research as beneficial to people like them and as having had a positive impact on their lives.

- One in three people, however, said that health research had had no impact, or a negative impact, on the way they live their lives.
- People in BAME groups, aged under 50, and with worse financial circumstances were less likely to view health research as valuable.

Engaging with and accessing health research

More people had engaged with health information than in 2018.

- Those with lower qualifications and finding it harder financially were less likely to engage with health-related information (for example, by having a conversation or reading an article about a health topic).
- There has been a small increase in the proportion of people who had participated in health research than in 2018.

When making decisions about health, most people followed the advice of a health professional and very few followed the advice in the media.

-
- Older people were particularly likely to say they followed the advice of a health professional, whereas younger people were more likely to look up information, base a decision on their previous experience, or follow the advice of friends and family.

The proportion of people who looked for health information on most days increased since 2018.

- Younger people and people finding it difficult financially, from BAME groups, and with higher qualifications, were more likely to try to find health-related information more often.
- Most people found health information easy to find and clear, but people without qualifications, with more difficult financial circumstances, and older people were more likely to find it difficult to access or less clear.
- People from BAME groups were less likely to trust the health information they found, with nearly one in five Black people reporting very little or no trust in the health-related information they usually find compared to four per cent of White people.

Involvement with health research

Most people thought that participating in health research means taking part in medical trials.

More people said they had participated when prompted with other ways they may have participated in health research, but this was still under half.

- Most people reported taking part in health research activities where they were a “data subject” rather than those where they would play an active role.
- Most people said they would be interested in participating in health research in the future, particularly younger people and those with higher incomes.

A large majority of people were confident making decisions about their health.

- People who found it difficult to find health-related information, found it unclear, or trusted it less were less likely to be confident making decisions about their health.
- Younger people and people from BAME groups were less likely to be confident making health decisions.
- Yet people with no qualifications were more likely to be very confident making decisions about health.

Segmenting the population

Based on their use of health-related information, their trust in it, their role in informing it, and the extent to which they value health research, we find the population splits broadly into four groups: the ‘Core engagers’, ‘Dormant engagers’, ‘Unsupported enthusiasts’, and ‘Under-served’.

- Around one in seven people are core engagers and one in four are in the under-served group, who are respectively consistently positive and negative across the four dimensions.
- The largest group are the unsupported enthusiasts (two in five) who are broadly positive about health information and research but are less confident making decisions about their health, trust the information they access less and find it less clear.

-
- One in five people are dormant engagers who are not especially engaged or disengaged with health research or information, although they think it is beneficial. However, when they do try to find health information, they find it clear and easy to find, and are confident making decisions about their health.

1 Introduction

1.1 Background

The Wellcome Monitor is a longstanding study of the British adult population's attitudes towards, and engagement with, science and health research, conducted by The Wellcome Trust.

Wellcome supports science to solve urgent health challenges for everyone. The three global challenges Wellcome are taking on are Mental Health, Global Heating and Infectious Disease. Wellcome's Public Engagement team connect people and science to help solve these health challenges together. Given it is the public at large that face these challenges, they are placed at the heart of this mission – the public are whom science is for. Understanding the public perspective and how people engage with health research is thus critical to ensure urgent health challenges are solved for everyone, and that science and health research meet people's needs.

To achieve this requires enabling and understanding how the public trust, use, and inform science and health research. The Wellcome Monitor helps provide an understanding of the societal context in which science and health research operate, and how this context is changing over time. Since 2009, the Monitor has provided high quality estimates of public attitudes towards science and health research, with surveys also run in 2012, 2015 and 2018.

In March 2020, the fifth wave of the Monitor was conducted by NatCen, just as Britain was entering into the first national lockdown as a result of the coronavirus pandemic. The original aims of the Wave 5 Monitor, as with previous waves, was to collect high-quality evidence on people's changing attitudes and experiences with health information and research to support the work of Wellcome's Public Engagement team. Whilst the survey was being prepared for launch, it became evident that the pandemic was likely to have an impact not just on attitudes to health and science, but life in general.

This report describes changing or persisting patterns in the way people relate to and perceive health research and information. Where possible, it explores how some of these changes may relate to experiences of the Covid-19 pandemic in its early stages. For example, findings about what role the public see scientists as having and whether they are seen as caring about the views of the public, have taken on a new dimension at a time when public health officials and scientific advisers are more visible than ever.

The first Wave 5 report looked more directly at the public's experiences of the Covid-19 pandemic and their views on health information during lockdown¹. Wellcome's long-term aims of understanding who in the population is engaging and benefiting from health research, and who isn't, have proved to be particularly pertinent at a time where connecting the public to science and health research has rarely been of more importance.

¹ <https://wellcome.org/reports/wellcome-monitor-2020-covid-19-study>

1.2 Methodology

Fieldwork

Fieldwork for this wave of the Wellcome Trust Monitor was conducted using the random-probability NatCen Panel. The NatCen Panel is formed of people recruited from the British Social Attitudes (BSA) survey, a high-quality, random probability face-to-face survey. Respondents interviewed as part of BSA were asked at the end of the interview to join the Panel. Those agreeing to join the Panel are then invited to take part in additional short surveys covering a range of different topics either online or over the phone. By using a probability-based sample and allowing those without internet access to take part, this design reduces the risk of bias compared to online-only surveys (which exclude those who do not have access to, or are less confident using, the internet) and surveys using convenience samples (which are more likely to include people who are more 'available' or particularly want to express their views).

The survey also included a 'boost' of participants from Black, Asian, and minority ethnic (BAME) groups², allowing analysis of the experiences of people with BAME backgrounds to look at more detailed groups, although small sample sizes still limit the statistical power to detect differences.

Panellists were initially invited to take part online, before being contacted by telephone if they had not completed the survey after one week. A £5 gift card was sent as a 'thank you' to those who participated. Fieldwork for this study began on the 30th of March 2020 and ended on the 26th of April 2020. Fieldwork was therefore conducted within the context of the start of the Covid-19 outbreak. During this time, the context changed dramatically, with the number of deaths as a result of the coronavirus increasing from around 1,700 to around 24,000. Also in this period, a number of senior politicians were diagnosed with coronavirus, which is likely to have impacted people's attitudes to public health-related topics.

A total of 2,651 people took part in the survey, of whom 2,330 (88%) completed online and 321 (12%) completed on the phone. For the main sample, 2,403 of the 4,058 panel members invited took part, giving a 59% survey response rate³. Taking account of non-response at the BSA interview and at the point of recruitment to the panel, the overall response rate was 15%. Forty-six per cent of panel members invited to take part as part of the ethnic boost did so.

Analysis

Data have been weighted to be representative of the adult (18+) GB population, including accounting for the over-sampling of people with BAME backgrounds. The weights account for non-response in the survey used for recruitment (the BSA survey), refusal to join the panel at the end of that interview and non-response in the survey of panel members itself. All differences between groups presented in this report have been tested for statistical significance at the 95 per cent level, and all are statistically

² In this report we use the term 'BAME' to describe participants of Black, Asian, and Mixed/Other ethnicity. While this grouping is useful to explore the collective experience of racialised minority groups, it has limitations, treating different ethnic groups as a single category and potentially missing important differences. We use it as a term and grouping widely used across the higher education and public sectors which enables comparison with other studies. As important differences could be present across different ethnic groups, we look in more detail where statistically meaningful.

³ The remaining 248 cases were included as part of the boost sample

significant unless otherwise stated. Some percentages may not sum to 100 due to rounding.

The Wellcome Monitor moved from a cross-sectional face-to-face interview design to a web/telephone interview with a probability-based panel sample in 2018. While this report looks at changes over time, comparisons between the 2009, 2012, or 2015 and the 2018 or 2020 Monitor waves should be interpreted with caution.

Equivalised household income

In this report we refer to figures for 'monthly household incomes'. These figures are based on banded household income estimates which have been adjusted to account for the number of adults and children living in the household to make them comparable between different household structures. This measure is designed to be used as a broad indicator of a person's financial circumstances relative to others, rather than a precise estimate of their financial situation.

Latent Class Analysis

Latent Class Analysis (LCA) is a statistical method for identifying related cases (or 'latent classes') who share patterns of responses across multiple variables. LCA was used here to segment the population by identifying sub-groups whose members share similar characteristics with regards to health attitudes and behaviours.

2 Public appetite for health research

This chapter explores the overall level of interest people have in health research and health-related information. It also covers the extent to which people are interested in hearing directly from scientists, and the areas of health research people are most interested in and think are most important for researchers to work on.

It then looks at whether, and to what extent, people are interested in *informing* health research. We identify the demographic groups who are most likely to think it is important for the public to play a role in health research and whether they are also most likely to do so themselves. We also look at which groups people think should be responsible for setting the priorities for health research.

Finally, we look at the value people feel that health research brings to their lives – has it been beneficial for people like them and has it had a positive or negative impact - and which groups are more and less likely to report finding health research valuable.

Key findings

- Most people were interested in health research, but fewer people sought it out unless they needed it.
 - People under 60, people from BAME groups and people with higher qualifications were more likely to actively seek it out.
 - Around half of people thought they hear the right amount of health information, with equal amounts feeling they hear too much or too little.
 - People were more likely to be interested in hearing directly from scientists than in 2015.
 - Mental health remained the area in which most people were interested in, but there has been a longer-term increase since 2015 in the proportion of people interested in the health implications of climate change.
- A majority of people thought it is important that the public play a role in health research and stated they would be likely to, given the opportunity.
 - Younger people and those with degrees were more likely to say they would play a role in health research.
 - The proportion of people who thought members of the public should be involved in setting priorities for health research has increased since 2018, but people were still more likely to say they should be set by scientists.
 - People continued to be unsure whether or not scientists are interested in their views.
- Most people viewed health research as beneficial to people like them and believed it had a positive impact on their lives.
 - One in three people said that health research had had no impact, or a negative impact, on the way they live their lives.
 - People in BAME groups, aged under 50, and with worse financial circumstances were less likely to view health research as valuable.

2.1 Interest in using health research

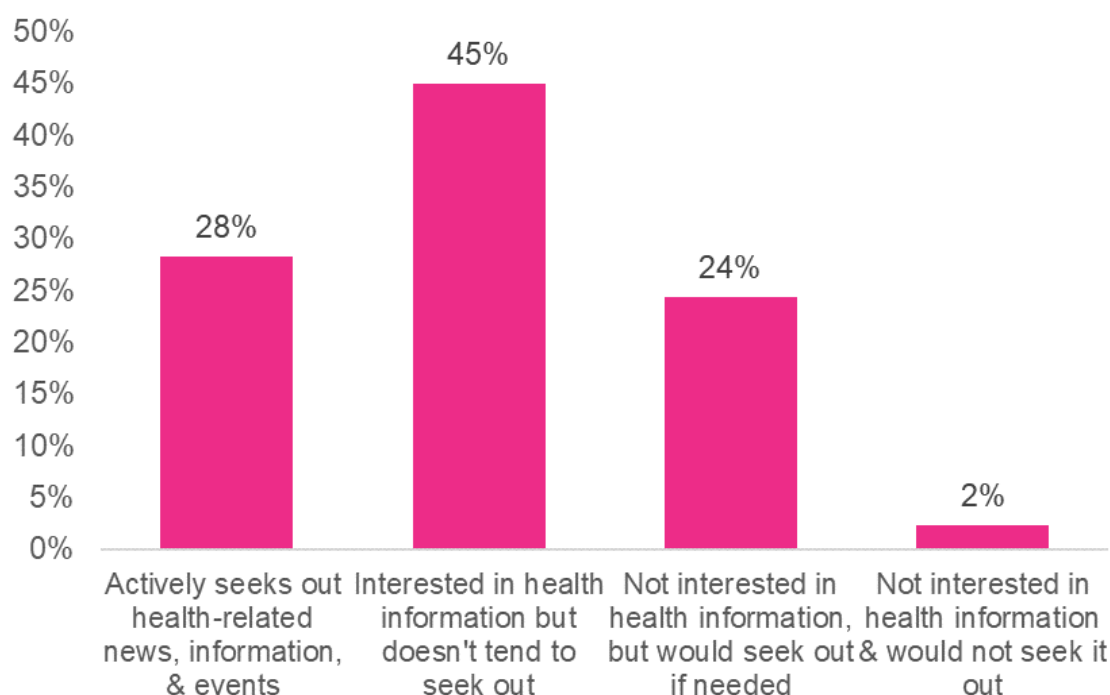
One of the most common ways the public use health research is through engaging with health-related information, for example by having a conversation or reading an article about a health topic. Before looking at the different ways the public engage with health-related information and their experiences accessing it (section 3), this section explores how interested the public were in hearing about health-related information, what areas they were interested in, and how this varied across different demographic groups.

2.1.1 How interested are people in hearing about health research and health-related information?

Most people were interested in health information, but fewer sought it out unless they needed it

Respondents were asked to select a statement which best reflected their relationship with health-related information. Figure 2:1 shows that most people reported being interested in health-related information (73%) but only a minority sought it out actively (28%).

Figure 2:1 Interest in health-related information



Which of these statements best describes your relationship with health-related information? Base: All GB adults (18+): 2645

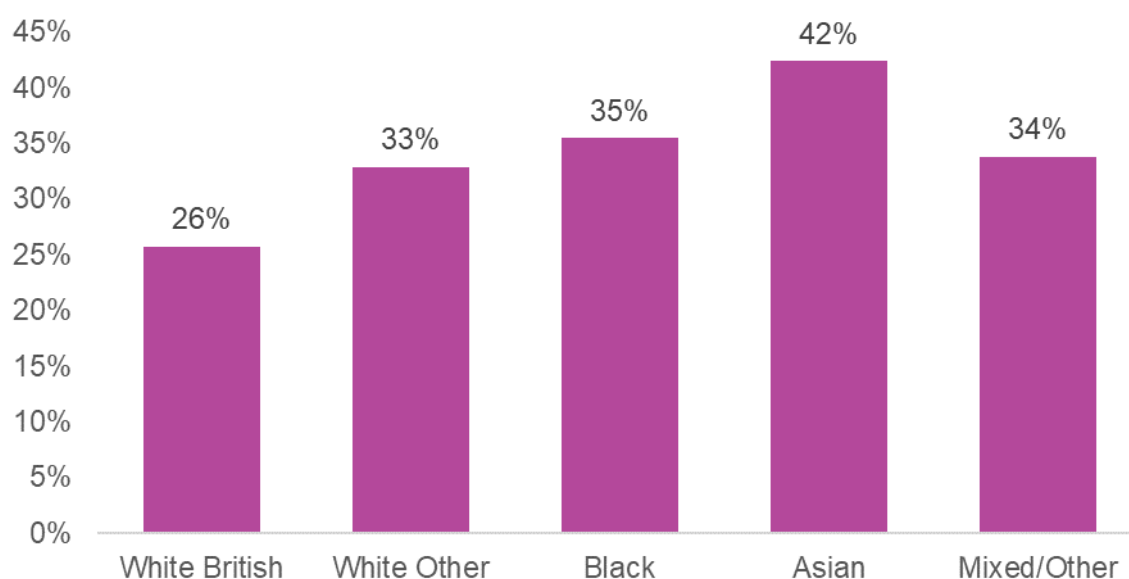
People under 60, in BAME groups and with higher qualifications were more likely to actively seek out health information

There was no significant variation in the proportion of people that actively seek out health-related information by sex or financial circumstances. However, people aged under 60 were more likely to say that they actively seek out health information (31%) than those aged 60 or over (22%).

People in BAME groups were also more likely to say they actively seek out news, information, and events related to health (39% compared to 26% of White people). This reflects a similar pattern seen in 2018, when respondents were asked how interested they were in health research. Less than a quarter (24%) of White people said they were 'very interested', compared to 40% of people from BAME groups.

In 2020, Asian people were particularly more likely to say that they actively seek out health-related information than other groups (Figure 2:2).

Figure 2:2 Proportion who actively seek out news, information and events related to health, by ethnic group



Which of these statements best describes your relationship with health-related information? Base: All GB adults (18+): White British (2061), White Other (145), Black (99), Asian (174), Mixed/Other (106).

We also find that people with higher educational qualifications were more likely to say they actively seek out health information (36% of people with a degree, compared to 25% of people with other qualifications and 21% of people with no qualifications).

Finally, we see that people living in London were more likely to say they actively seek out news, information, and events related to health (35%, compared to 28% in other urban locations and 23% in rural locations). This relationship (as well as others found throughout between urban/rural location and other health attitudes) is likely to be driven by other demographic factors, such as age, education, ethnicity. For that reason, in what follows we mostly focus on the demographic factors and do not comment on differences across region or urban/rural status.

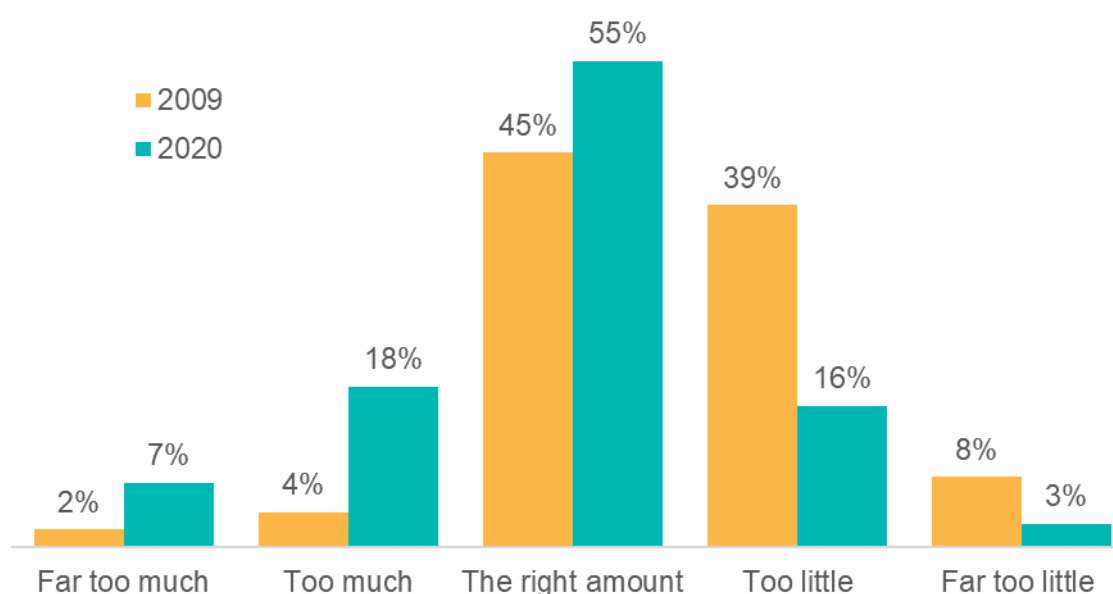
Around half of people felt they get the right amount of health information

Respondents were also asked whether they felt they hear or see the right amount of health information. Most people felt they get the right amount of health information, with around one in five people (19%) wanting more and around one in four people (26%) wanting less (Figure 2:3).

This is substantially different to 2009 when fewer people (six per cent) said they were getting far too much or too much information, and more people said they were getting

too little or far too little (47%)⁴. This may reflect a longer-term trend but also is likely to reflect the experiences of the public at that specific point in time (the first few weeks of lockdown, in which there was a great deal of uncertainty about the virus and its effects, and daily briefings from the government). This is supported by an association between finding it clearer on what to do to minimise the risk of getting or spreading the coronavirus and reporting hearing/seeing the right amount of information. People who said that they saw too little health information were least likely to say they were ‘very clear’ on how to minimise coronavirus risks (58%, compared to 67% of people who saw too much information and 73% who said they saw the right amount).

Figure 2:3 Whether hear and see too much, the right amount, or too little health-related information



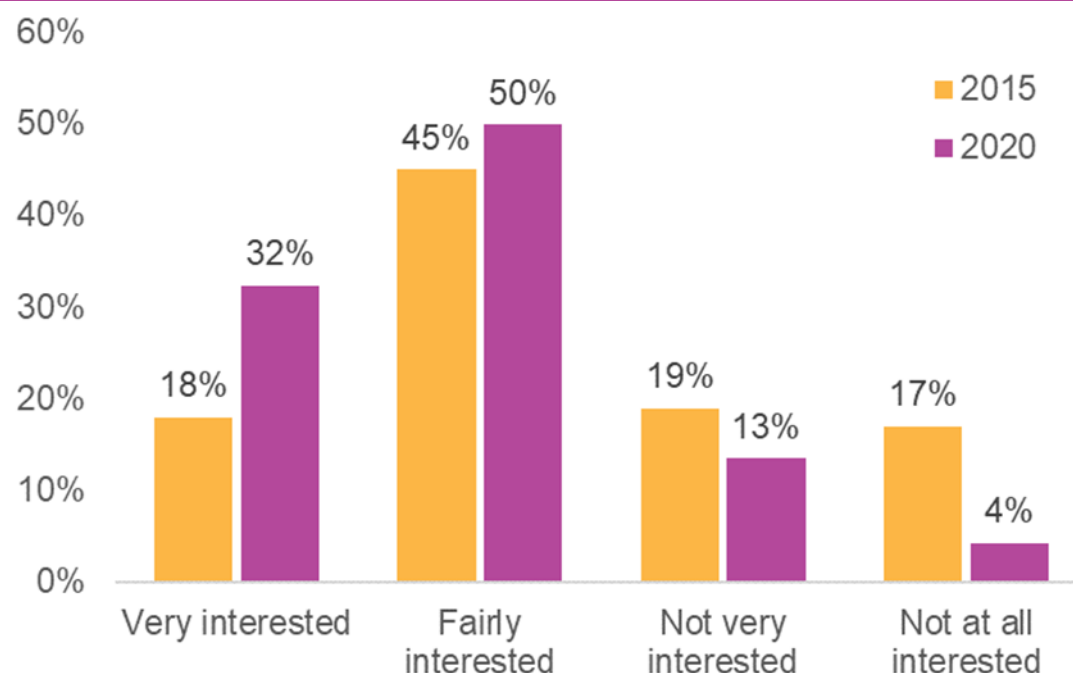
Which of the statements do you most agree with? These days I hear and see... too much/the right amount/too little health-related information. Base (2020): All GB adults (18+) 2641. Base (2009): All UK adults (18+) 1179.

⁴ The precise differences should be treated with caution due to the change in fieldwork design.

The public are more likely to be interested in hearing directly from scientists than they were in 2015

Respondents were asked to what extent they were interested in hearing directly from scientists about the research they are conducting. Overall, a large majority (82%) of people reported being very or fairly interested - an increase from 63% in 2015⁵. As above, while this may reflect a longer-term trend, it is likely to reflect the context of the Covid-19 pandemic, with people more used to hearing from scientists during daily briefings from the government.

Figure 2:4 Whether hear and see too much, the right amount, or too little health-related information



To what extent, if at all, are you interested in hearing directly from scientists about the research they are conducting?. Base (2015): All UK adults (18+) 1524 Base (2020): All GB adults (18+) 2650.

Unlike the preceding measures of interest in using health research, there was little variation in how interested people were in hearing directly from scientists between different groups: there was no significant variation in the proportion of people who were very interested in hearing directly from scientists by age, ethnicity or financial circumstances. However, we found that men were more likely to be very interested in hearing from scientists (36%, compared to 29% of women), as were people with degrees (41%, compared to 26% of people with other or no qualifications).

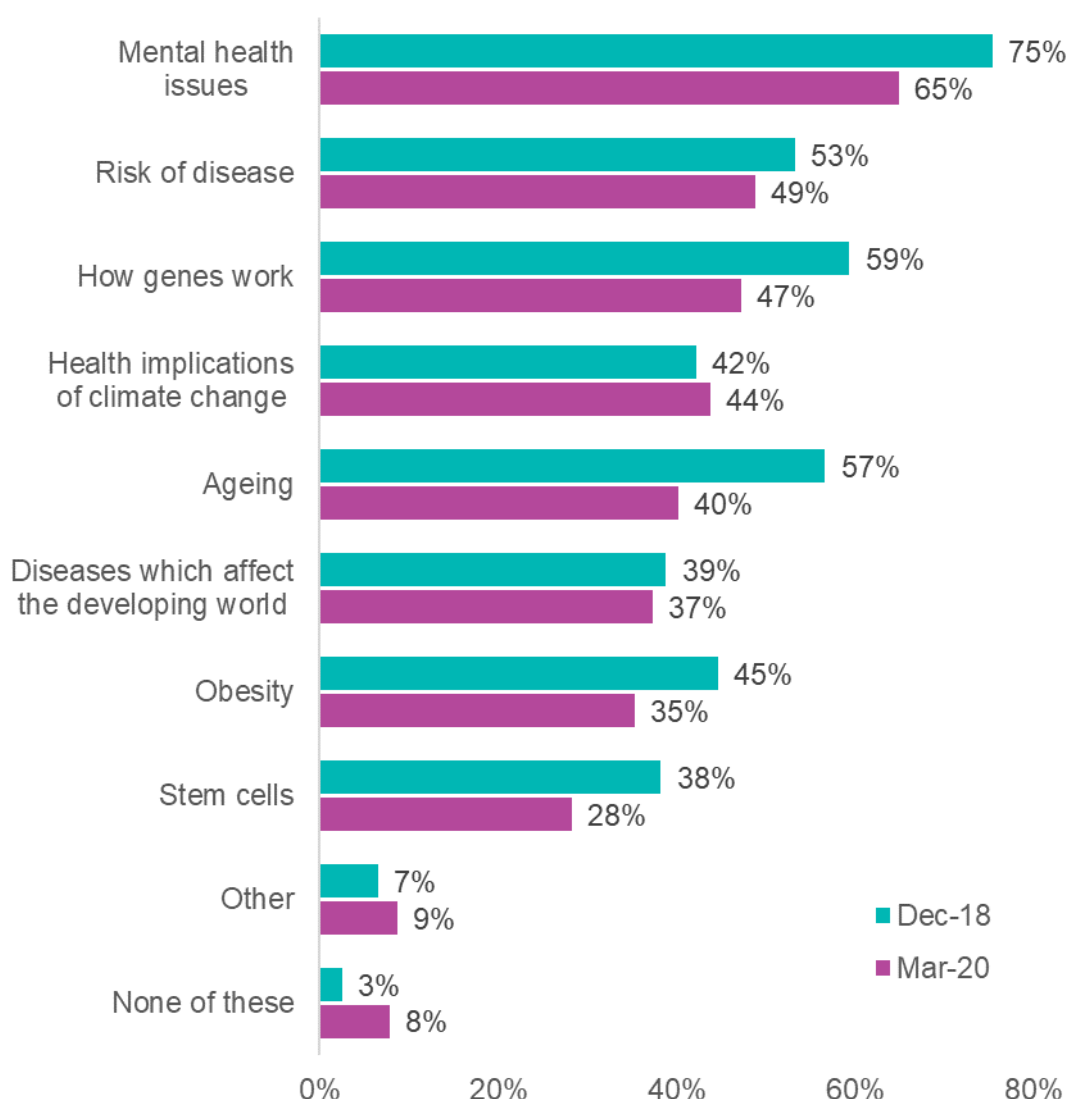
⁵ The precise differences should be treated with caution due to the change in fieldwork design.

2.1.2 What areas of health research are people interested in?

People were most interested in health research related to mental health

Respondents were asked to select areas of health research they were interested in from a list. Reflecting patterns seen in 2018, people were most likely to select mental health issues as an area of interest (Figure 2:5). Relatively few people (eight per cent) said they were interested in none of the areas – including any other area.

Figure 2:5 Which of these areas of health research are you interested in?



Which of these areas of health research are you interested in...? Base: All GB adults (18+) (2020) 2649. Base (2015): All UK adults (18+) 2708

While mental health is the area of health research the public continued to be most interested in, Figure 2:5 also shows that, while there has been an increase since 2015 in interest in hearing directly from scientists about health research generally, interest in hearing about a variety of more specific health areas has decreased since 2018 (including mental health, risk of disease, how genes work, ageing, obesity, and stem

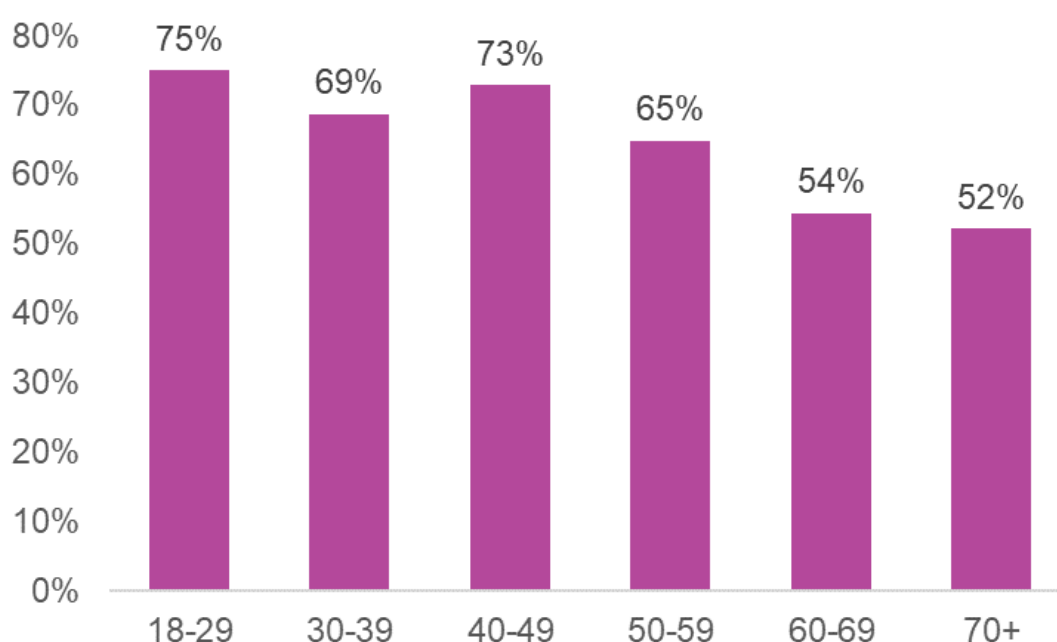
cells). This may be because coronavirus has become dominant in the public's perception of what matters in health at the moment.

Interest in mental health was higher among women, younger people, BAME groups, and those struggling financially

Mental health was the most commonly selected area of interest of those listed, but interest varied between demographic groups, with women, younger people, people with longstanding conditions, people in BAME groups, people finding it more difficult financially, and people living in London all more likely to be interested in mental health as an area of research. These are all groups more likely to have experienced mental health problems during lockdown⁶, according to the Covid-19 Study published as part of this Monitor series⁷. However, there was no variation by highest educational qualification.

Sixty-eight per cent of women, compared to 61% of men, were interested in mental health. Looking across age groups, seven in ten (70%) of people aged 18 to 59 were interested in mental health, compared to just over half (53%) of people aged 60+ (Figure 2:6).

Figure 2:6 Proportion interested in mental health issues, by age group



Which of these areas of health research are you interested in...? Base: All GB adults (18+) 2649. 18-29 (220), 30-39 (430), 40-49 (475), 50-59 (508), 60-69 (509), 70+ (498)

⁶ Participants were asked questions in this survey which enabled us to calculate both a GAD-2 score, for which a score of 3 points or more is an indicator of possible generalised anxiety disorder, and a PHQ-2 score, for which a score of 3 points or more is an indicator of major depressive disorder. We found that women were more likely to have a GAD-2 score of 3 or higher, as were younger people (under 40), those with longstanding conditions, people from BAME groups and people with lower household incomes. Similar patterns were seen looking at PHQ-2 scores, apart from women were no more likely than men to have a score of 3 or more.

⁷ Longitudinal research comparing mental health indicators before and during the first lockdown have shown that the negative impact of national lockdowns on mental health have been profound and widespread. See 'Mental health before and during the Covid-19 pandemic: a longitudinal probability sample survey of the UK population' [https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(20\)30308-4/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30308-4/fulltext)

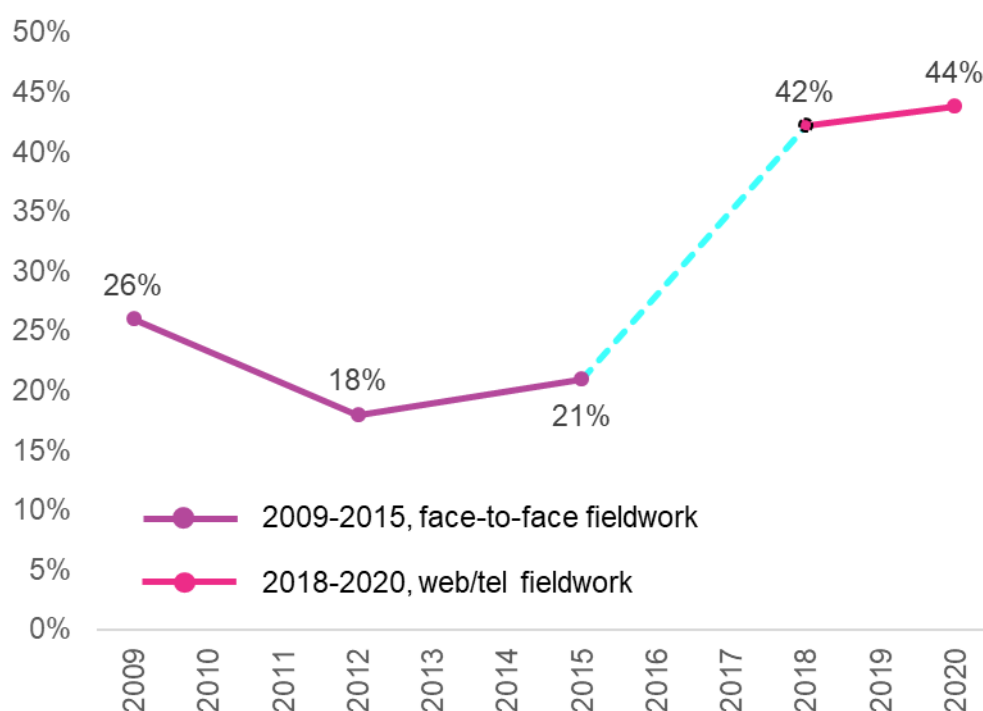
People in BAME groups were more likely than White people to be interested in mental health (78%, compared to 63%). People finding it more difficult to get by financially were also more likely to report being interested in mental health - 77% of those finding it quite or very difficult were interested, compared to 69% of people just about getting by and 60% of people doing alright or living comfortably.

Finally, people with a longstanding condition that affects everyday life were also more likely to say they were interested in mental health (75%, compared to 66% with a condition that doesn't affect everyday life and 62% without a condition).

An increase in interest in the health implications of climate change since 2015 has been sustained, despite a decline in interest in other areas

The health implications of climate change stands out because, unlike most other areas, there has not been a decline in interest since 2018. There also appears to have been a long-term increase in interest in climate change relative to other topics that has been sustained. In the first wave of the UK Wellcome Monitor in 2009, it was the least selected of these topics, and it is now the fourth most commonly selected. Figure 2:7 suggests that over the last eleven years, interest in this area has risen substantially⁸.

Figure 2:7 Interest in the health implications of climate change, 2009 to 2020



Which of these areas of health research are you interested in...? Base: 2020: All GB adults (18+) (2649), 2018: All GB adults (18+) (2708). 2015: All UK adults (18+) (1,524). 2012: All UK adults (18+) (1,396). 2009: All UK adults (18+) (1179).

There was little variation between key demographic groups in interest in the health implications of climate change or risk of disease – also key strategic areas for

⁸ Changes should be treated with caution given the change in fieldwork design. In 2009 to 2015 (represented by the purple line in Figure 2:7), the survey was conducted face-to-face. In 2018 and 2020 the survey was conducted on the NatCen Panel, meaning participants took part online or over the phone (Section 1.2).

Wellcome⁹. There was no significant variation in interest in the health implications of climate change when comparing men and women, age groups, ethnic groups, and people in different financial circumstances. However, people with higher qualifications were more likely to be interested in the effects of climate change on health (52% of people with a degree compared to 40% with other qualifications and 36% of people with no qualifications), as were people living in London (55%, compared to 42% of people living outside of London).

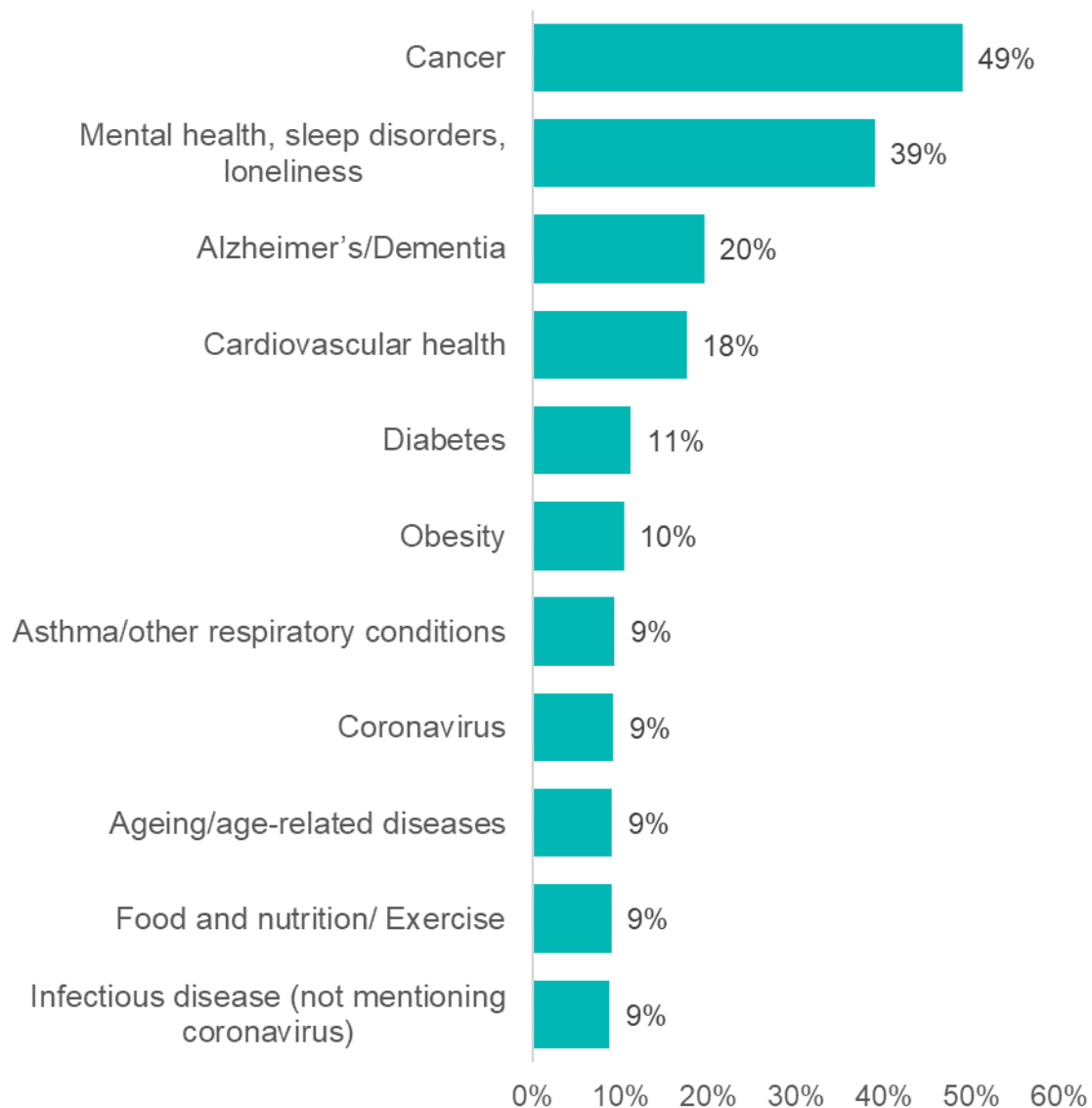
Similarly, interest in risk of disease also varied little between demographic groups. There was some variation by age, with people aged 60 or over more likely to be interested in risk of disease (54%, compared to 46% of people aged under 60). However, there was no significant variation when looking at sex, ethnicity, financial circumstances, education, whether or not someone has a long-standing health condition, or whether or not they live in London.

Cancer and mental health were the health issues people feel are most important for researchers to work on

Respondents were also asked, in an open question, which three health issues were most important to them personally for researchers to work on. People mentioned a wide range of health issues, ranging from addiction to cancer to diabetes. The most common answers mentioned diseases and health issues that affect large proportions of people across the population. Cancer was the most commonly mentioned issue (the leading cause of death for women aged 50 to 79), with half of people mentioning this. Next was mental health (suicide being the leading cause of death for people aged 20 to 34), followed by Alzheimer's/Dementia (the leading cause of death for those 80 and over) and cardiovascular health (with heart disease being the leading cause of death for men aged 50-79) (Figure 2:8). There was a 'long tail' of responses covering other areas. Perhaps surprisingly, relatively few people (nine per cent) mentioned Covid-19 as one of the three most important areas for researchers to work on.

⁹ <https://wellcome.org/about-us/strategy>

Figure 2:8 Which health issues are most important to you personally for researchers to work on?¹⁰



What three health issues are most important to you personally for researchers to work on...? Base: All GB adults (18+) 2441

We found some variation in areas of interest by demographic characteristics (Appendix A). Of the more commonly selected options, younger people were more likely to mention mental health and obesity, whereas older people were more likely to mention Alzheimer's, cardiovascular health, asthma, and ageing. People in their 50s were most likely to mention cancer.

Those finding it harder to get by financially were more likely to mention mental health conditions, while those more comfortable were more likely to mention cancer, Alzheimer's and ageing.

People from BAME backgrounds were more likely to mention infectious disease (15% compared to 8% of White people), whereas White people were more likely to mention cancer, Alzheimer's, cardiovascular health and asthma.

¹⁰ Answers given by less than seven per cent of the population are not included in this chart.

2.2 Interest in informing health research

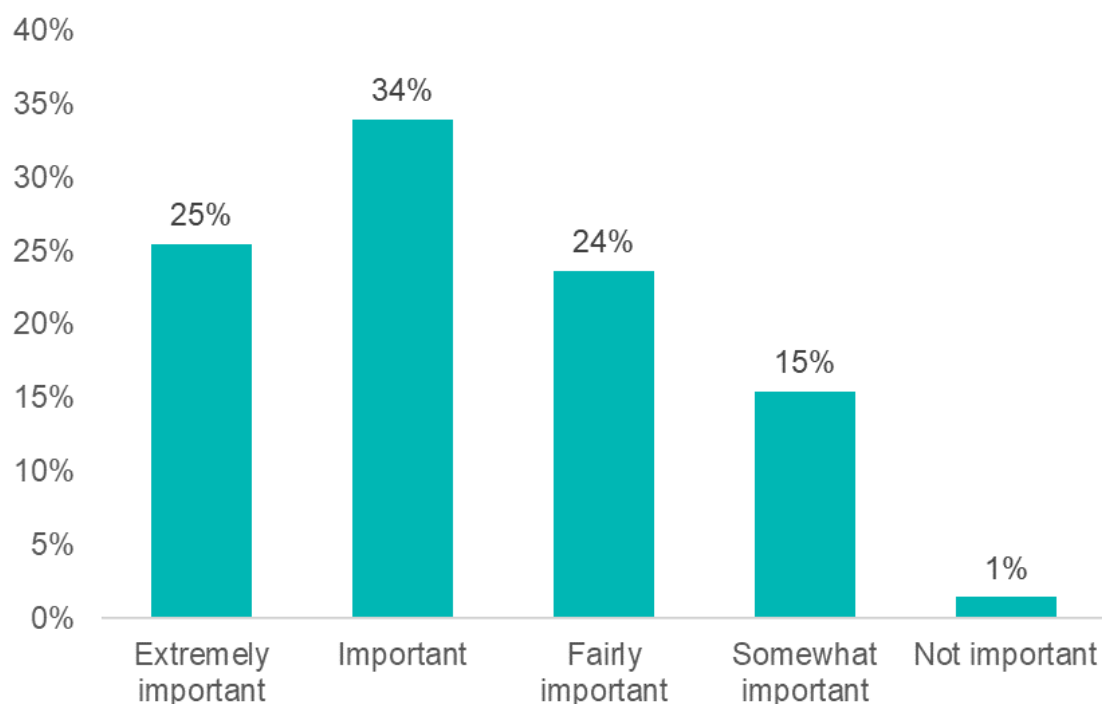
While it is more common for the public to use health research through its findings and its translation into products, public engagement often seeks to involve the public in the production of health research as well. This involvement enables the public to play a role in informing the process of health research as well as its outcomes. This could include discussing health studies with researchers, helping shape what questions should be asked, ensuring the design of studies is ethical, taking part in clinical trials, supporting researchers to collect and analyse data as part of citizen science efforts, helping researchers communicate their findings to others, and many more activities. In this section we explore the public's interest in playing such a role and informing health research.

2.2.1 Playing a role in health research

A sizeable majority thought it is important that the public play a role in health research and would be likely to, given the opportunity

Respondents were asked how important they think it is for the public to be able to play a role in health research. Overall, most people (59%) said it was important or extremely important (Figure 2:9).

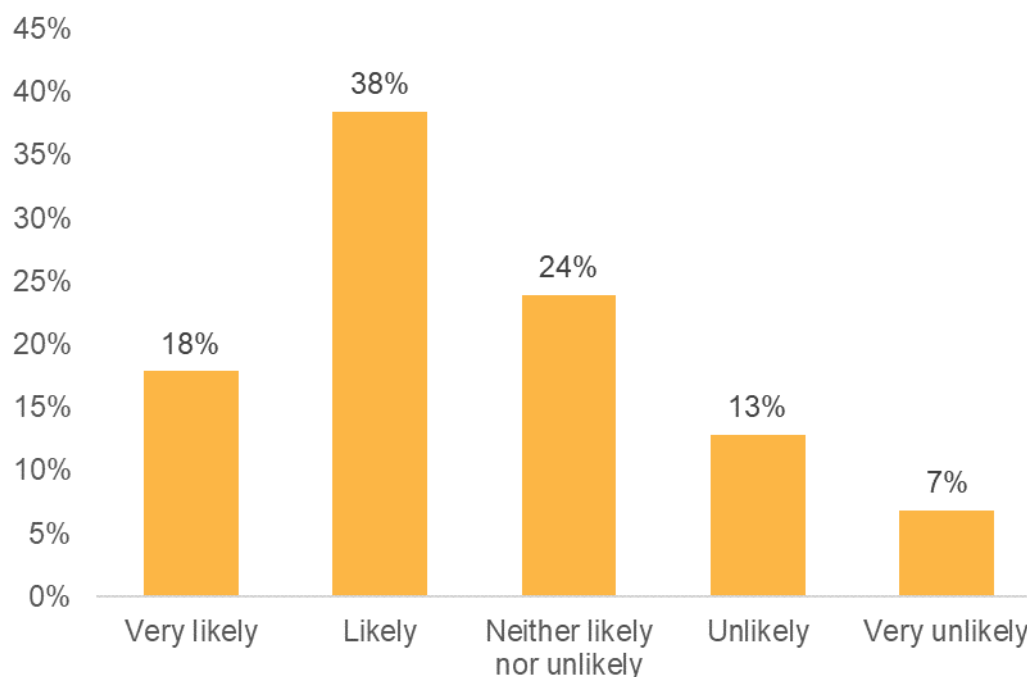
Figure 2:9 How important do you think it is for the public to be able to play a role in health research?



How important do you think it is for the public to be able to play a role in health research? Base: All GB adults (18+) 2646

We also asked respondents, given the opportunity, how likely they would be to play a role in health research. Again, most people (56%) said they would be likely or very likely to play a role (Figure 2:10).

Figure 2:10 Given the opportunity, how likely or unlikely would you be to play a role in health research?



Given the opportunity, how likely or unlikely would you be to play a role in health research? Base: All GB adults (18+) 2644

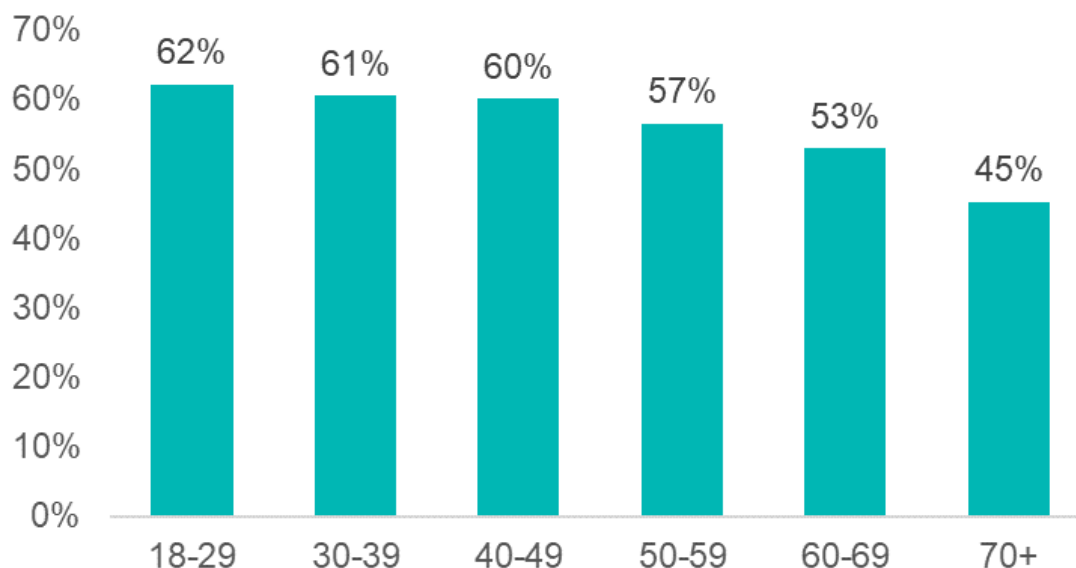
How likely people would be to play a role in health research was associated with how important they felt it was for the public to play a role. Nearly three in four (72%) people who said that that it was extremely or very important for the public to play a role said they would be likely or very likely to play a role, compared to 39% who said it was fairly important, and 26% who said it was somewhat or not important. Twenty-eight percent of people who said they think it is important the public play a role would not be likely to do so themselves given the opportunity.

Younger people and people with degrees were more likely to be willing to play a role in health research

There was little significant variation in perceived importance of the public playing a role in health research, or willingness to do so given the opportunity, by demographic group, suggesting support is widespread. While more people with a degree thought it was important or extremely important (65% compared to 57% of people with other qualifications and 53% of people with no qualifications) or said they would be likely or very likely to play a role (64% compared to 57% of people with other qualifications and 37% of people with no qualifications), there was no significant variation by people's sex, ethnicity, or financial circumstances.

While there was no significant variation in the perceived importance of the public playing a role in health research, younger people were more likely to say they would be very likely or likely to take part (Figure 2:11).

Figure 2:11 Proportion likely or very likely to take part in health research, by age



Given the opportunity, how likely or unlikely would you be to play a role in health research? Base: All GB adults (18+) 18-29 (220), 30-39 (430), 40-49 (475), 50-59 (508), 60-69 (507), 70+ (496)

2.2.2 Setting priorities for health research

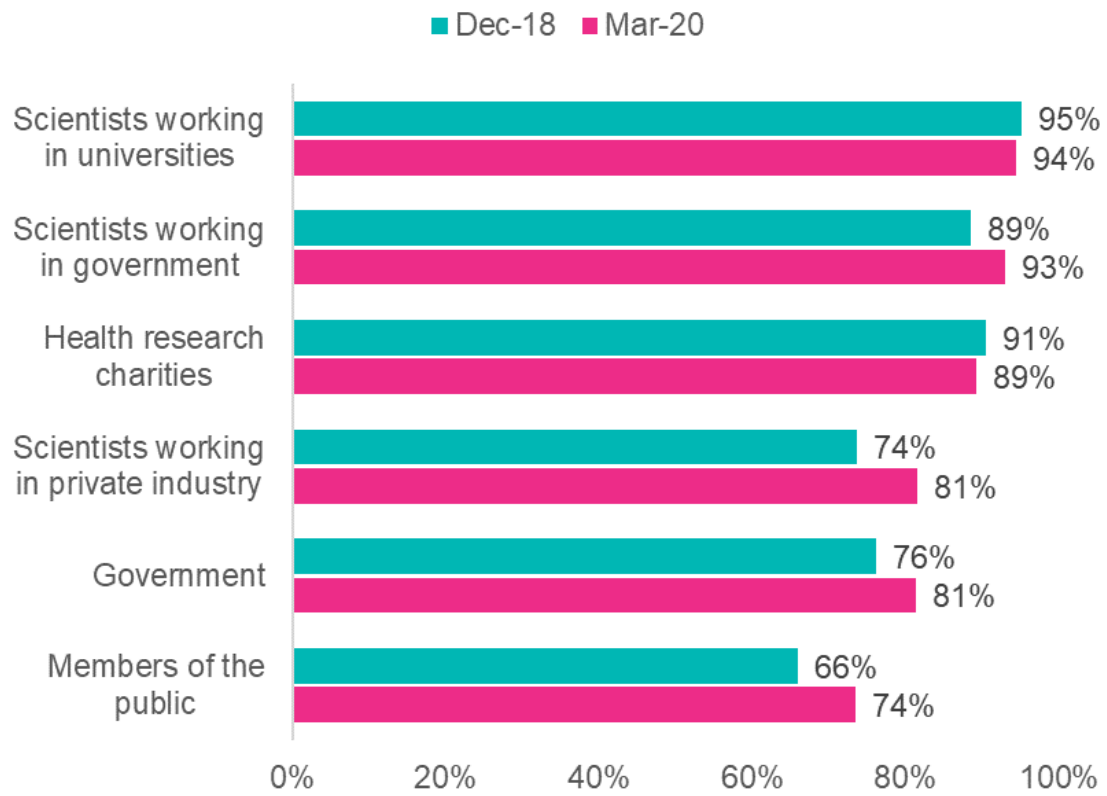
People were more likely to think members of the public should be involved in setting priorities for health research than in 2018

Respondents were asked to what extent different groups should be involved in setting or informing priorities for health research.¹¹

Figure 2:12 shows that the proportion of people who said they think that members of the public should definitely or probably be involved in setting priorities increased to almost three quarters from two-thirds in 2018. This is perhaps related to changing attitudes during the Covid-19 pandemic, during which decisions about public health priorities have had considerable impacts on the public.

¹¹ In this wave, we conducted an experiment to test two ways of wording this question. A random half of respondents were asked about 'informing priorities' and the other half were asked about 'setting priorities'. No significant differences were found between the two versions.

Figure 2:12 Proportion that think group should probably or definitely be involved in informing/setting priorities for health research – 2018 and 2020



To what extent do you think each of the following groups should, or should not, be involved in informing/setting priorities for health research?

Base (2018): All GB adults (18+). Scientists working in universities (2686). Scientists working in government (2693) Health research charities (2691). Scientists working in private industry (2677) Government (2683). Members of the public (2686). Base (2020): All GB adults (18+). Scientists working in universities (2643). Scientists working in government (2643) Health research charities (2639). Scientists working in private industry (2641) Government (2643). Members of the public (2643).

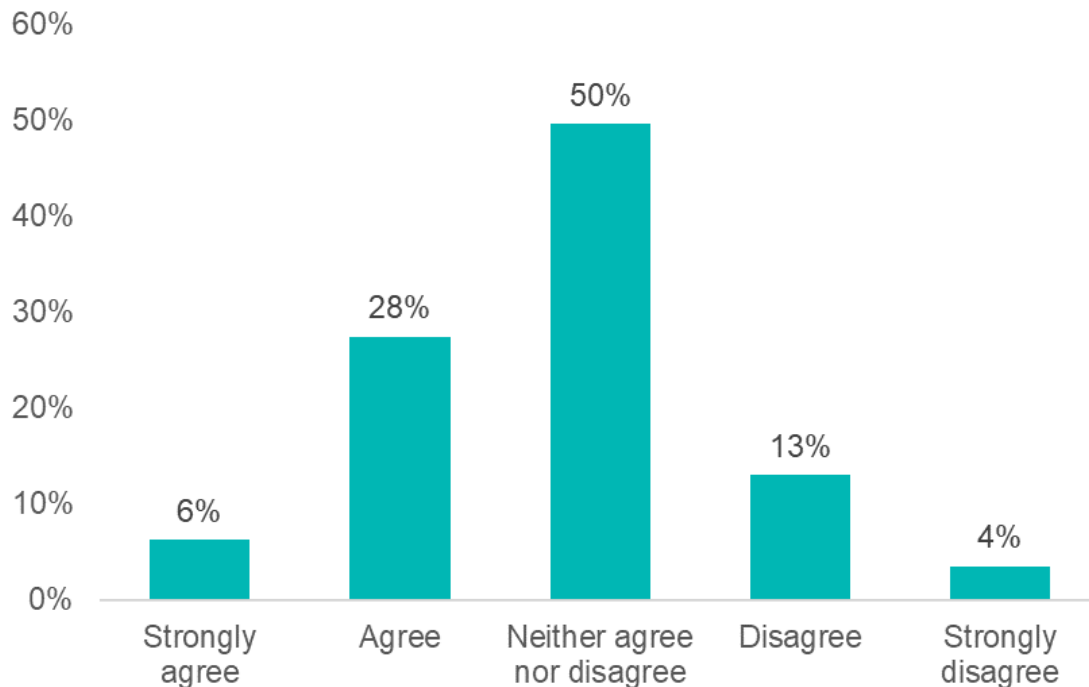
There was no significant variation in the proportion of people who thought members of the public should be involved in setting priorities for health research by sex, ethnicity, financial circumstances, education, or whether or not someone had a longstanding health condition.

Despite this increase, Figure 2:12 also shows that people were still least likely to say members of the public should be involved in setting priorities for health research. People were most likely to say that scientists in universities or in government should be involved, followed by health research charities, government and scientists in private industry, and lastly members of the public.

People were uncertain whether scientists are interested in their views

Despite an increased desire for public involvement since 2018, the majority of the public did not believe that scientists were interested in their views. We asked respondents to what extent they agreed that scientists are interested in the views of the public when considering the priorities for research and how it is produced. Reflecting patterns seen in 2018, we found that more people agreed (35%) than disagreed (17%), but most took a neutral position (50%) (Figure 2:13), suggesting people felt they did not have a strong position on the issue.

Figure 2:13 Whether agree or disagree that scientists are interested in the views of the public when considering the priorities for research and how it is produced



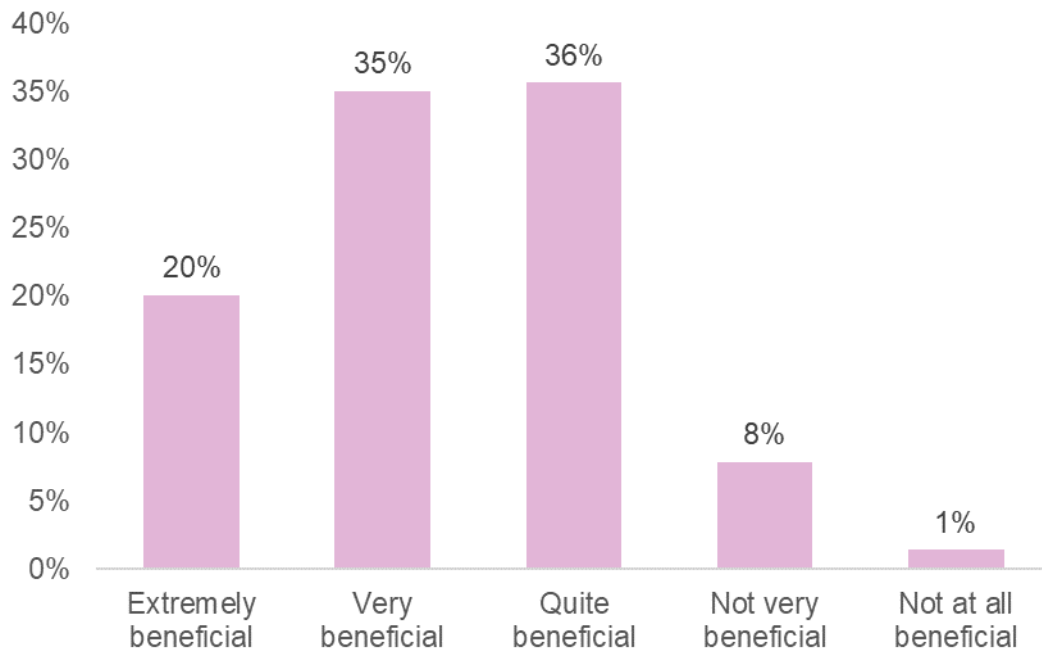
To what extent do you agree with the following statement...? Scientists are interested in the views of the public when considering the priorities for research and how it is produced. Base: All GB adults (18+): 2432

2.3 Perceived **value** of health research

Most people viewed health research as beneficial to people like them and having a positive impact on their lives

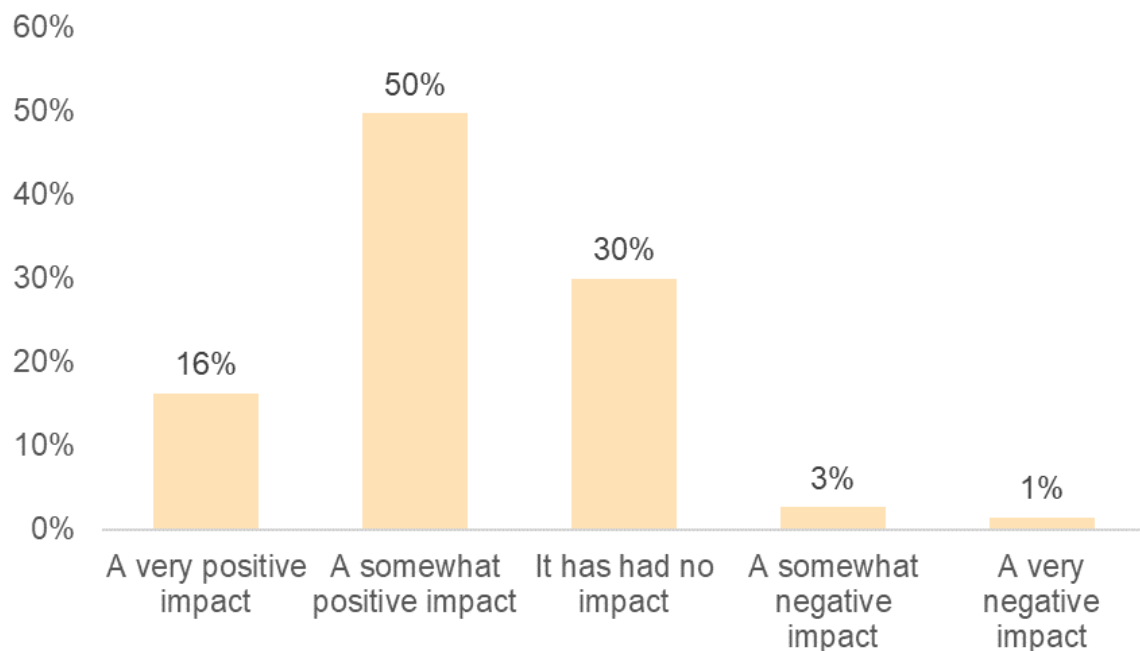
Respondents were asked two questions about the value of health research: how beneficial they felt it had been to people like them and, thinking about recent health research, what impact it has had on how they live their life. Most people viewed health research as valuable: 55% of people said that health research had been extremely or very beneficial to people like them (Figure 2:14), and 66% said it had had a very or somewhat positive impact on their life (Figure 2:15). However, one in three (34%) said that health research had had no impact, or a negative impact, on the way they live their lives.

Figure 2:14 How beneficial, if at all, would you say health research has been for people like you?



How beneficial, if at all, would you say health research has been for people like you? Base: All GB adults (18+): 2639

Figure 2:15 Thinking about recent health research, what impact, if any, has it had on how you live your life?



Thinking about recent health research, what impact, if any, has it had on how you live your life? Base: All GB adults (18+): 2622

White people and people aged over 50, with a longstanding health condition, in better financial circumstances or with higher qualifications were more likely to value health research

Perceived value of health research varied between demographic groups. Reflecting the patterns seen with interest in using health research identified in Section 2.1, people with degrees were more likely to say health research was beneficial to people like them (62% compared to 51% of people with other or no qualifications). Similarly, 72% of people with a degree felt that health research had had a positive impact on their lives compared to 64% of people with other qualifications and 59% of people with no qualifications.

In contrast, while people who actively sought out health information were more likely to be aged under 60 and from BAME groups, it was older people and White people who were more likely to say that health research had been beneficial. Half (50%) of 18-49 year olds said health research had been beneficial compared to 60% of people aged 50 or over, and 71% per cent of people aged 50 or over felt health research had had a positive impact, compared to 61% of people aged under 50.

While the majority of White people said that health research had been beneficial to people like them (57%), less than half of BAME people said the same (44%). Conversely, seven per cent of people in BAME groups felt that health research had had a *negative* effect, compared to three per cent of White people.

We find that people in better financial circumstances were more likely to say health research had been beneficial. Fifty-nine per cent of people living comfortably or doing alright said health research had been beneficial for people like them, compared to 50% of people just about getting by or finding it difficult. In fact, we see that eight per cent of people finding it difficult financially thought health research had had a negative effect compared to five per cent of people just about getting by and three per cent of people living comfortably or doing alright.

We also find some associations between finding health research beneficial and experience of poor health. People with longstanding conditions were more likely to say that health research had been extremely or very beneficial for people like them (59% of people with a condition that affects day-to-day life, compared to 66% of people with a condition that does not affect day-to-day life, and 51% of people without a condition). People with longstanding conditions were also more likely to say that health research had had a positive impact on the way they live their life, particularly those with a condition that does not affect everyday life (75%, compared to 66% of those with a condition that affects everyday life and 64% of those without a condition).

The perceived value of health research is, then, associated with people's interest in it. People who actively sought out health-related information or were interested in it were more likely to think health research is beneficial, compared to those who were not interested in it (70% of those who actively sought out information, compared to 54% who were interested but didn't seek it out, and 36% who weren't interested). Similarly, 83% of people that actively sought out health-related information felt recent health research had had a positive impact on their lives, compared to 67% of people who were interested but didn't seek it out, and 46% of people that were not interested.

3 Engaging with and accessing health research

This chapter looks at the ways in which people engage with and access health information, and the barriers they face in doing so. We first explore different types of engagement and consider how the Covid-19 pandemic may have affected behaviours. We then look at the actions people take when making decisions about their own health, and their experiences accessing health information – how often they do it and the sources they use. Finally, we identify the groups who face difficulties: either in accessing and understanding health information or finding information they trust.

Key findings

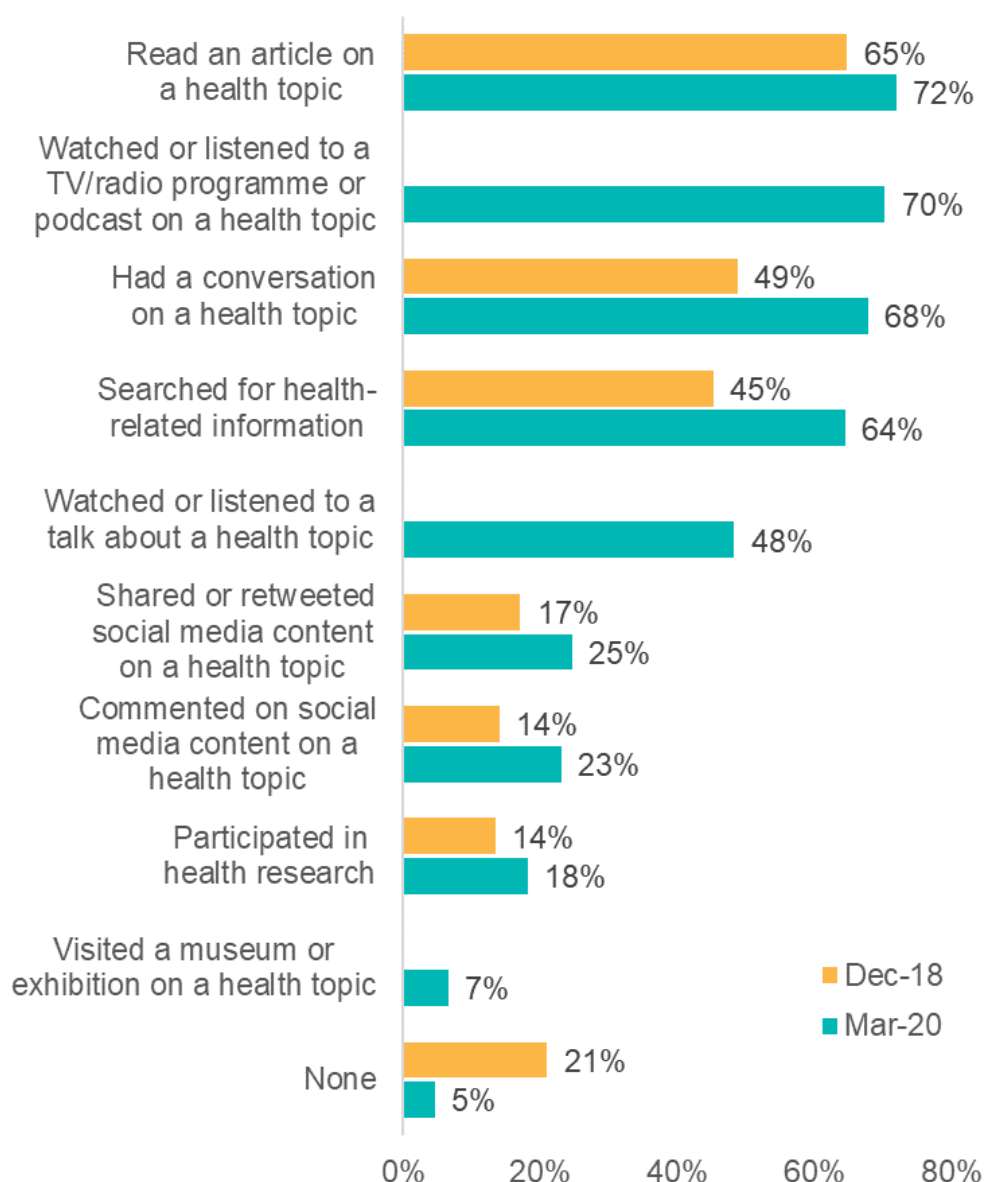
- More people engaged with health information than in 2018, but certain groups – those with fewer qualifications and those finding it harder financially – were less likely to have engaged.
 - The most common ways of engaging with health-related information were reading articles, watching or listening to a TV, radio programme or podcast, and having a conversation.
- When making decisions about their health, most people followed the advice of a health professional, but many looked up information and used their own experience.
 - Older people were particularly likely to say they followed the advice of a health professional, whereas younger people were more likely to look up information, base a decision on their previous experience, or follow the advice of friends and family.
- The proportion of people looking up health information on most days increased since 2018, but most people still only tried to find health-related information once or twice a month or less often.
 - Younger people and people finding it difficult financially, from BAME groups, and with higher qualifications, were more likely to try to find health-related information more often.
 - Most people found health information easy to find and clear, but people without qualifications, finding it more difficult financially, and older people were more likely to find it difficult to find or unclear.
 - People from BAME groups were less likely to trust the health information they find, with nearly 1 in 5 Black people reporting very little or no trust in the health-related information they usually find, compared to four per cent of White people.
- Most people looked for health information online.
 - Only a minority used social media to find health information, but younger people, people in BAME groups and people finding it difficult financially were more likely to have done so.

3.1 Engaging with health-related information

More people had engaged with information about health than in 2018

Respondents were asked to select activities they had done in the last year from a list of ways people engage with information about health. Figure 3:1 shows that the proportion who had engaged with health-related information in each of the listed ways increased since 2018, in particular the proportion who had a conversation about a health topic or searched for health-related information. These increases are likely to reflect the pervasiveness of information and news about the Covid-19 crisis at the time of the survey¹².

Figure 3:1 Engagement with health-related information, 2018 and 2020



Which of the following health-related activities have you done in the last year...? Base (2020): All GB adults (18+) 2646. Base (2018): All GB adults 18+ (2708).

¹² Changes should be treated with caution as new answer options were added to the list in 2020. In addition, the question in 2018 asked about a 'conversation on health research' rather than 'a conversation on a health topic', the latter of which could be more broadly interpreted.

People were more likely to have engaged with information about health passively than actively

Despite these changes, Figure 3:1 also shows the pattern of which activities were done has remained similar to in 2018. Respondents were most likely to have read an article, watched or listened to a TV/radio programme or podcast, had a conversation on a health topic or searched for health-related information in the past year. Fewer people had watched or listened to a talk on a health topic, online or in person, followed by sharing or retweeting, or commenting on, social media content on a health topic. Finally, a relatively small group had participated in health research or visited a museum or exhibition on a health topic in the past year. Only five per cent of people had done none of these activities.

People with the lowest incomes and with no qualifications were less likely to have engaged with health information

The list of activities was categorised into three groups, according to the way that the health information was engaged with. Overall, 93% had **used** health information, 74% had **socialised** health information in some way, and 18% had **participated** in health research (an increase from 14% in 2018).

Participated	Participated in health research
Socialised	Shared or retweeted health research on social media
	Commented on health research on social media
	Had a conversation about health research
Used	Visited a museum or exhibition on a health topic
	Searched for information related to health research
	Read an article about health research
	Watched or listened to a talk about a health topic, online or in person
	Watched or listened to a TV/radio programme or podcast on a health topic
None	None

Using these categories, we find some variation in the ways that demographic groups engaged with health information. We do not find any variation in by sex or ethnicity, however, people with higher incomes and level of qualification were more likely to ‘use’ and ‘socialise’ health information, and to participate in health research. Eighty-seven per cent of people with monthly household incomes of £800 or less had done any of the activities related to ‘using’ health information, compared to 95% of people with household incomes of more than £800. Similarly, 84% of people with no qualifications had done any of the activities related to ‘using’ health information, compared to 95% of people with any qualifications.

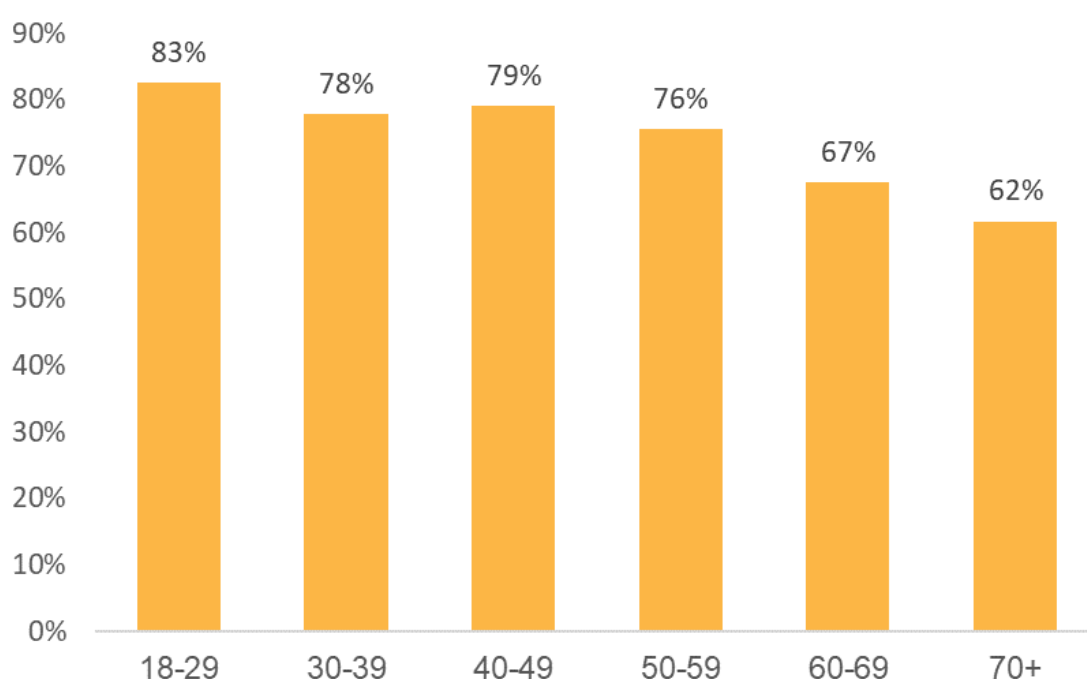
Looking at ‘socialising’, differences were not just seen between the group with the lowest household income and the rest of the population. Eighty-two per cent of people with monthly household incomes of more than £1,250 had done any of the activities related to ‘socialising’ health information, compared to 71% of people with household incomes of £801 to £1,250 and 62% of people with incomes of £800 or less. Similarly, 85% of people with degrees had done any of the activities related to ‘socialising’, compared to 73% of people with other qualifications and 51% of people with no qualifications.

Finally, the people most likely to have taken part in health research were also those with higher educational qualifications and higher household incomes. Twenty-three per

cent of people with a degree reported having participated in health research in the past year, compared to 15% of people without a degree, and 20% of people with monthly household incomes of more than £1,250 reported having participated in health research in the past year, compared to 15% of people with household incomes of £1,250 or less.

While we do not find any significant variation in 'use' of health information by age, younger people were more likely to have done any of the activities related to 'socialising' (Figure 3:2). This is in part due to younger people being substantially more likely to use social media (two of the three 'socialising' activities involve social media). However, the pattern remains when just looking at whether young people had had a conversation about a health topic. Seventy-six per cent of 18-29 year olds had had a conversation about a health topic, compared to 72% of 30-49 year olds, 67% of 50-59 year olds, 62% of 60-69 year olds and 59% of people aged 70 or older.

Figure 3:2 Proportion who did at least once 'socialising' activity, by age group



Which of the following health-related activities have you done in the last year...? Base: All GB adults (18+) 18-29 (220), 30-39 (431), 40-49 (473), 50-59 (508), 60-69 (508), 70+ (498).

We also see that younger people were more likely to have reported participating in health research in the past year: Twenty-two per cent of people aged 18-39, compared to 18% of people aged 40-59 and 15% of people aged 60+.

Finally, while we do not find any significant variation in 'use' of health information by whether or not someone has a long-standing health condition, we find the proportion that had done any of the activities related to 'socialising' health information or had participated in health research did. Sixty-nine per cent of people with a long-standing condition that affects their day-to-day life had done any of the activities related to 'socialising', compared to 78% of people with a condition that does not affect their day-to-day life, and 74% of people with no long-standing condition. Similarly, 19% of people with a long-standing condition that affects their day-to-day life had participated in health research in the past year, compared to 24% of people with a condition that does not affect their day-to-day life, and 16% of people with no long-standing condition.

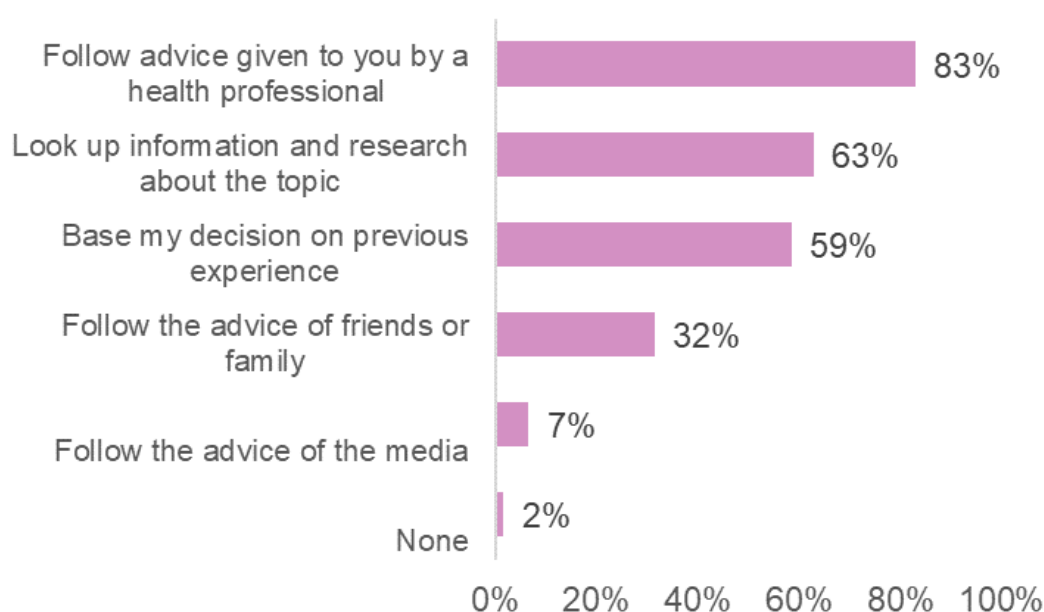
3.2 Accessing health-related information

3.2.1 Making decisions about your health

Over three in five people looked up information when making decisions about their health

Respondents were asked to select from a list of things they do when making decisions about their own health, including when they felt ill but also their mental health and general wellbeing. Figure 3:3 shows that following the advice of a health professional was the most common action but many also looked up information or based decisions on previous experience. A smaller proportion followed the advice of friends and family and few people followed the advice of the media.

Figure 3:3 Actions taken when making decisions about health



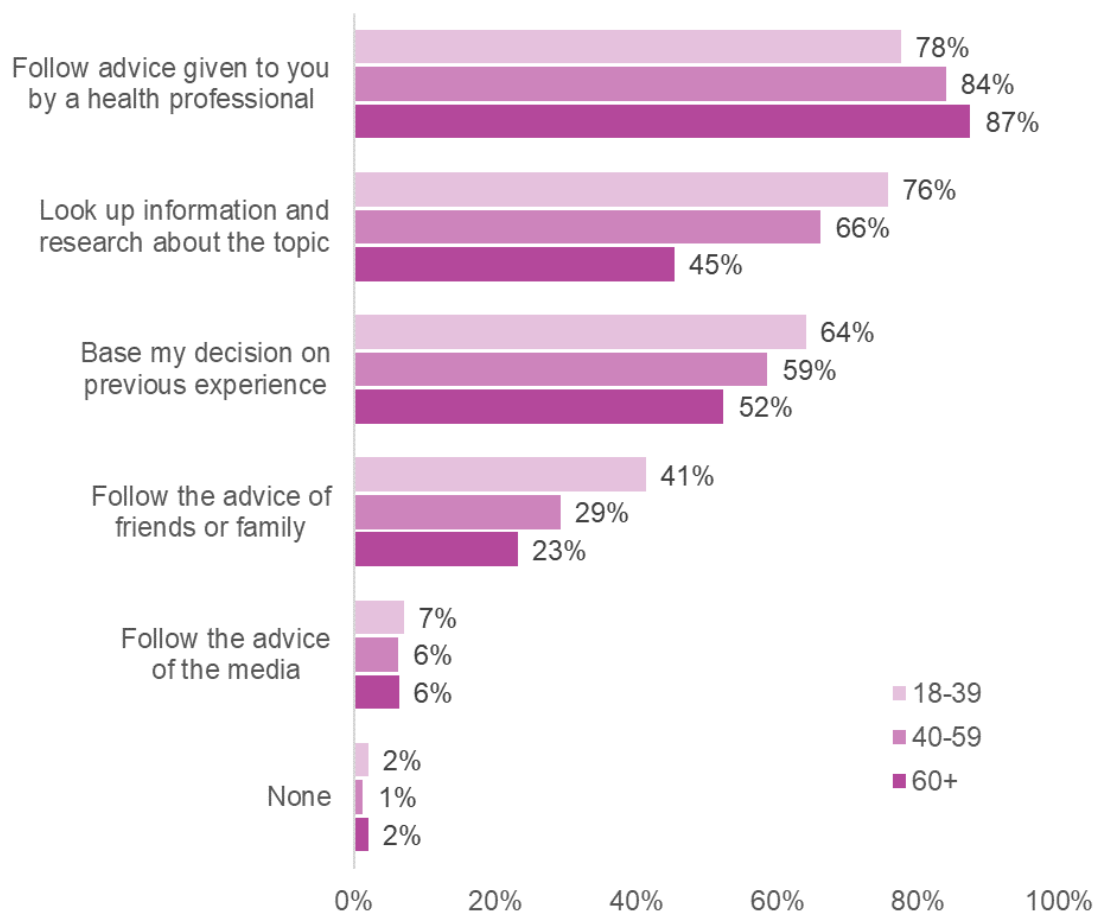
When making decisions about your own health, including when you feel ill, but also your mental health and general wellbeing, which of the following do you do...? Base: All GB adults (18+) 2648.

Older people were more likely to follow the advice of health professionals, whilst younger people were more likely to follow advice of friends and family

The proportion of people that followed advice from a health professional when making decisions about their health did not vary significantly by sex, ethnicity, financial circumstances, or education.

However, Figure 3:4 shows that older people were more likely to follow the advice of a health professional than younger people. In contrast, younger people were more likely to look up information, base a decision on their previous experience, or follow the advice of friends or family. This could perhaps reflect the different nature of health problems experienced by different age groups, or perhaps younger people being more confident looking up information.

Figure 3:4 Actions taken when making decisions about health, by age group



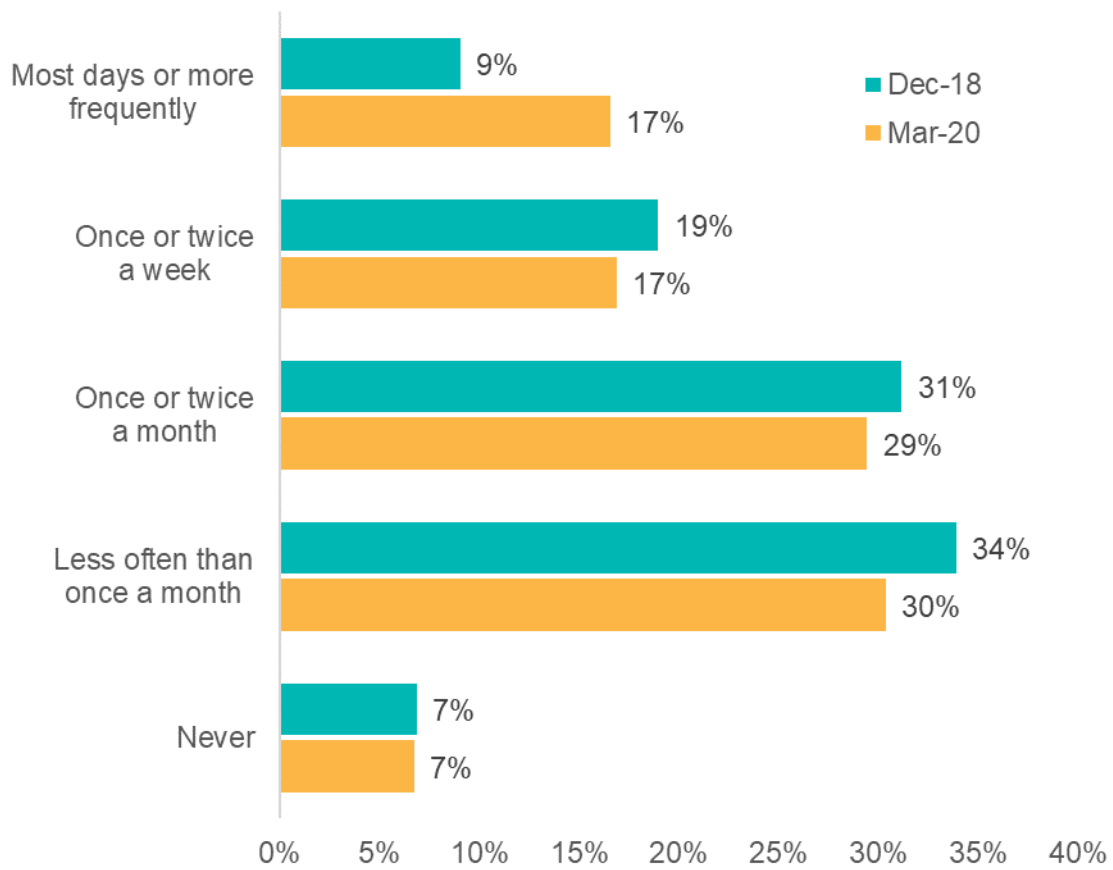
When making decisions about your own health, including when you feel ill, but also your mental health and general wellbeing, which of the following do you do...? Base: All GB adults (18+). 18-39 (651), 40-59 (982), 60+ (1005)

3.2.2 Experiences accessing health-related information

The proportion of people who looked up health-related information on most days increased since 2018

Respondents were asked approximately how often they try to find health-related information. Around one in six people (17%) reported trying to find health-related information on most days or several times a day, increasing from one in ten (9%) in 2018 (Figure 3:5). This repeats the changes seen in Section 3.1, and likely reflects the context of the Covid-19 pandemic. Despite this, and similarly to 2018, most people (67%) still reported only trying to find health-related information once or twice a month or less often.

Figure 3:5 How often look up health information, 2018 and 2020



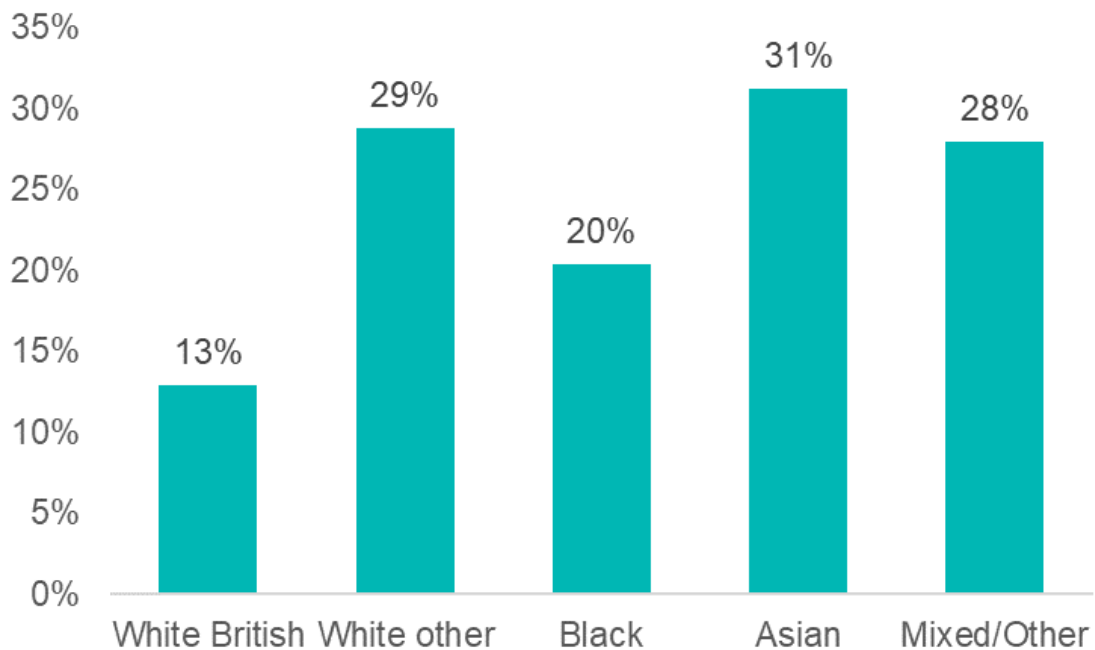
Approximately how often do you try to find health-related information? Base: All GB adults (18+) (2020): 2649. Base (2018): All GB adults 18+ (2704)

Younger people and people finding it difficult financially, from BAME groups, and with higher qualifications, were more likely to try to find health-related information more often

The proportion of people trying to find health-related information on most days or several times a day varied by a range of demographic characteristics. One in five people aged 18-39 (20%) tried to find health-related information several times a day or on most days, compared to 18% of people aged 40-59 and 10% of people aged 60+.

People from BAME groups were also more likely to look up health-related information several times a day or on most days (28% compared to 14% of White people). This difference was also seen in 2018, when 22% of people from BAME groups looked up health-related information several times a day or on most days, compared to 7% of White people, suggesting the difference between White and BAME groups in 2020 is not entirely attributable to different levels of concern about the effects of Covid-19. Looking more closely at ethnicity shows further variation. Asian people and people in mixed or other minority ethnic groups were particularly likely to try to find health-related information on most days or several times a day (Figure 3:6).

Figure 3:6 Proportion looking for health-related information several times a day or on most days, by ethnicity



Approximately how often do you try to find health-related information? Base: All GB adults (18+). White British (2063), White Other (146), Black (99), Asian (174), Mixed/Other (106)

People finding it more difficult to get by financially were more likely to look for health-related information more frequently. Sixteen per cent of people living comfortably or doing alright and 15% of people just about getting by looked for health-related information several times a day or on most days, rising to 22% of people finding it quite difficult or very difficult.

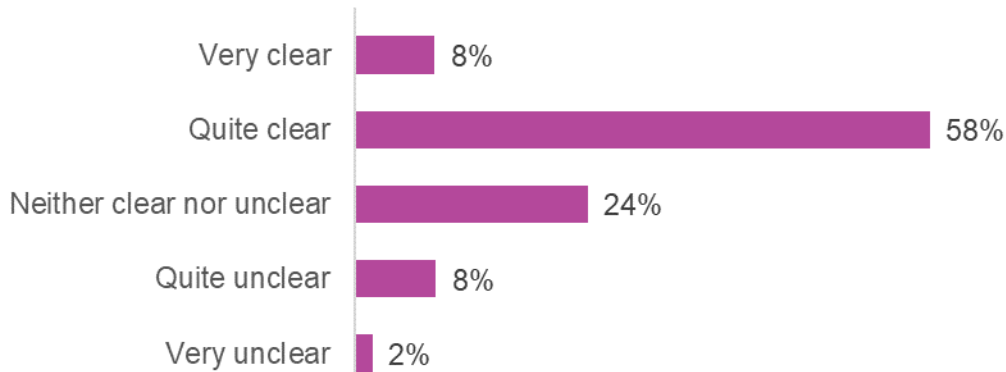
Finally, graduates were also more likely to try to find health-related information on most days or several times a day (24% compared to 12% of people with other qualifications and 10% of people with no qualifications).

Of people who tried to find health-related information, only a minority found it difficult to find or unclear

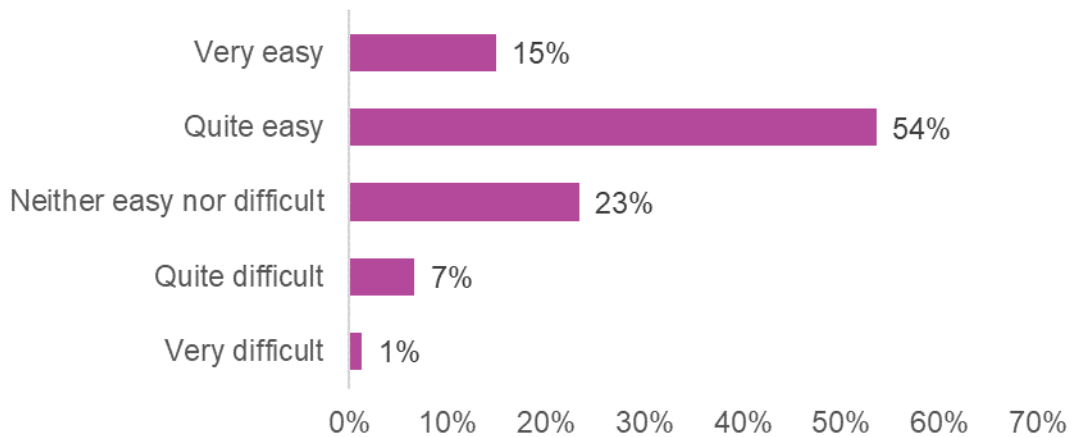
Respondents who ever tried to find health-related information were asked how easy or difficult it was to find the health information they wanted and how clear the information they found was. Figure 3:7 shows that only eight per cent of people said it was quite difficult or very difficult to find the information they wanted, and only ten per cent found the information quite or very unclear.

Figure 3:7 Clarity of and ease of access to health information

How clear or unclear is the information that you find?



How easy or difficult is it for you to find this information?



Thinking about the health-related information you normally want, how easy or difficult is it for you to find this information? Base: All GB adults who ever look for health information (18+) (2514)
Still thinking about the health-related information you normally want, how clear or unclear is the information that you find? Base: All GB adults who ever look for health information (18+) (2510)

People without qualifications or finding it more difficult financially, and older people were more likely to find health information difficult to find or unclear

Among people who tried to find health-related information, some groups were more likely to find it difficult to find health-related information they wanted or find it unclear. Eighteen per cent of people with no qualifications reported finding health information very or quite difficult to find compared to seven per cent of people with any qualifications, and 17% said they found it very or quite unclear, compared to nine per cent of people with any qualifications.

People finding it more difficult financially were more likely to find it difficult to find health related information. Only seven per cent of people living comfortably, doing alright or just about getting by found finding health-related information quite or very difficult, compared to 13% of people finding it quite or very difficult financially. Older people were also more likely to find it difficult to find health-related information. Eleven per cent of people aged 60 or over found it quite or very difficult to find health-related information, compared to seven per cent of people aged 18 to 59. However, there was

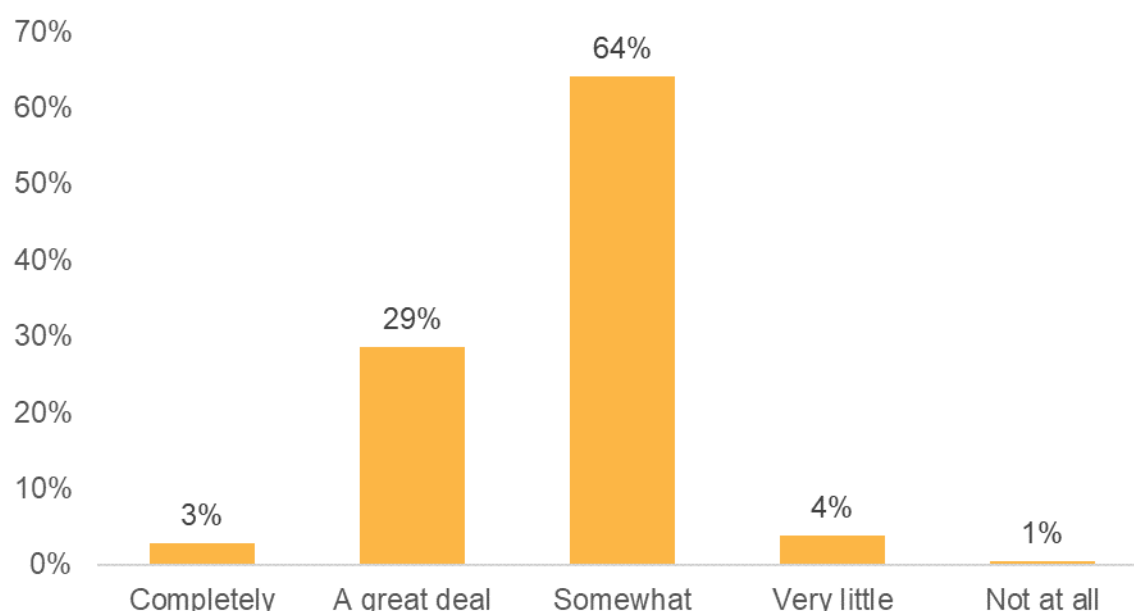
no significant variation in how clear people found health-related information by financial circumstances or age.

We also find that people with a condition that affects everyday life were more likely to report finding it very or quite difficult (15%, compared to 7% of the rest of the population), and more likely to find it very or quite unclear (14%, compared to nine per cent of the rest of the population). There was no significant variation in the proportion of people finding health-related information quite or very difficult to find or quite or very unclear by sex or ethnicity.

Most people trusted the health-related information they find but people from BAME groups and people with lower incomes were less likely to trust the information

Respondents were asked how much they normally trust the health-related information that they find. Most people (93%) trusted the health information they find a great deal or somewhat, but few trusted it completely, very little, or not at all (Figure 3:8).

Figure 3:8 Trust the health-related information you find

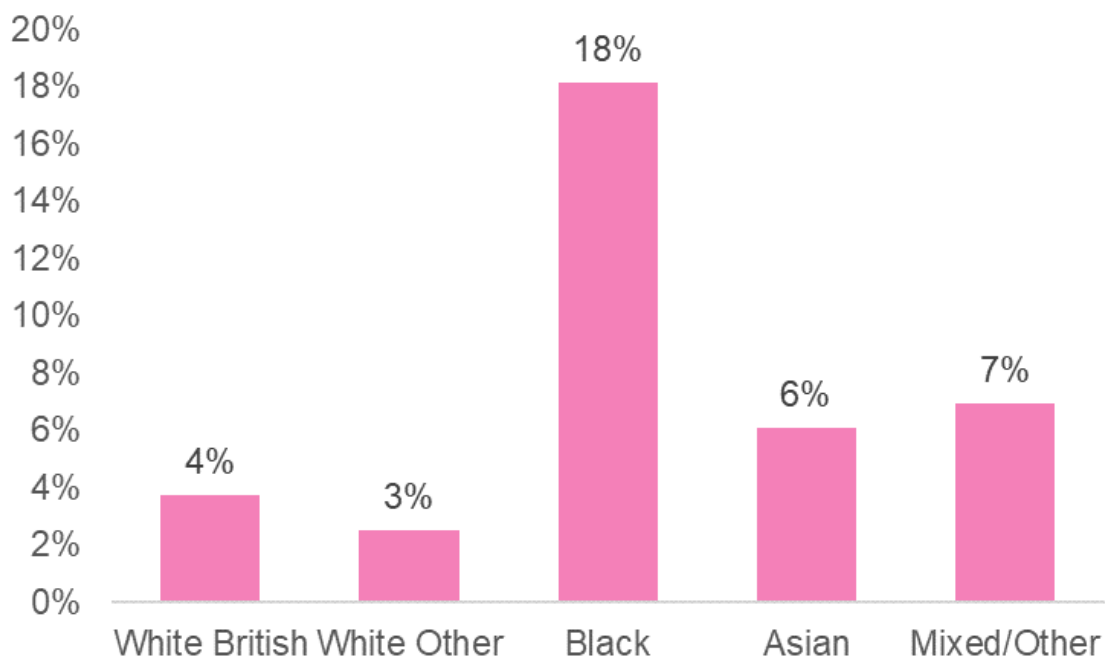


How much do you normally trust the health-related information that you find? Base: All GB adults who ever look for health information (18+) (2513)

There was no significant variation in how much people trust the health-related information they find by sex, age or whether or not they have a longstanding condition. Although people from BAME backgrounds were more likely to actively seek out health information (Section 2.1.1) and looked for it more often (Section 3.2.2), they were twice as likely to say they had very little or no trust in the information they find (nine per cent, compared to four per cent of White people). This difference was mostly accounted for by the relatively high proportion of Black people with low trust (Figure 3:9). This reflects the pattern seen when looking at trust in information about coronavirus from certain sources, which showed that those from Black and Mixed/Other groups were significantly less likely to trust information about coronavirus from health scientists and government scientific advisers¹³.

¹³ <https://wellcome.org/reports/wellcome-monitor-2020-covid-19-study>

Figure 3:9 Proportion with very little or no trust in health-related information normally find, by ethnicity



How much do you normally trust the health-related information that you find? Base: All GB adults who ever look for health information (18+). White British (1943), White Other (142), Black (97), Asian (170), Mixed/Other (101)

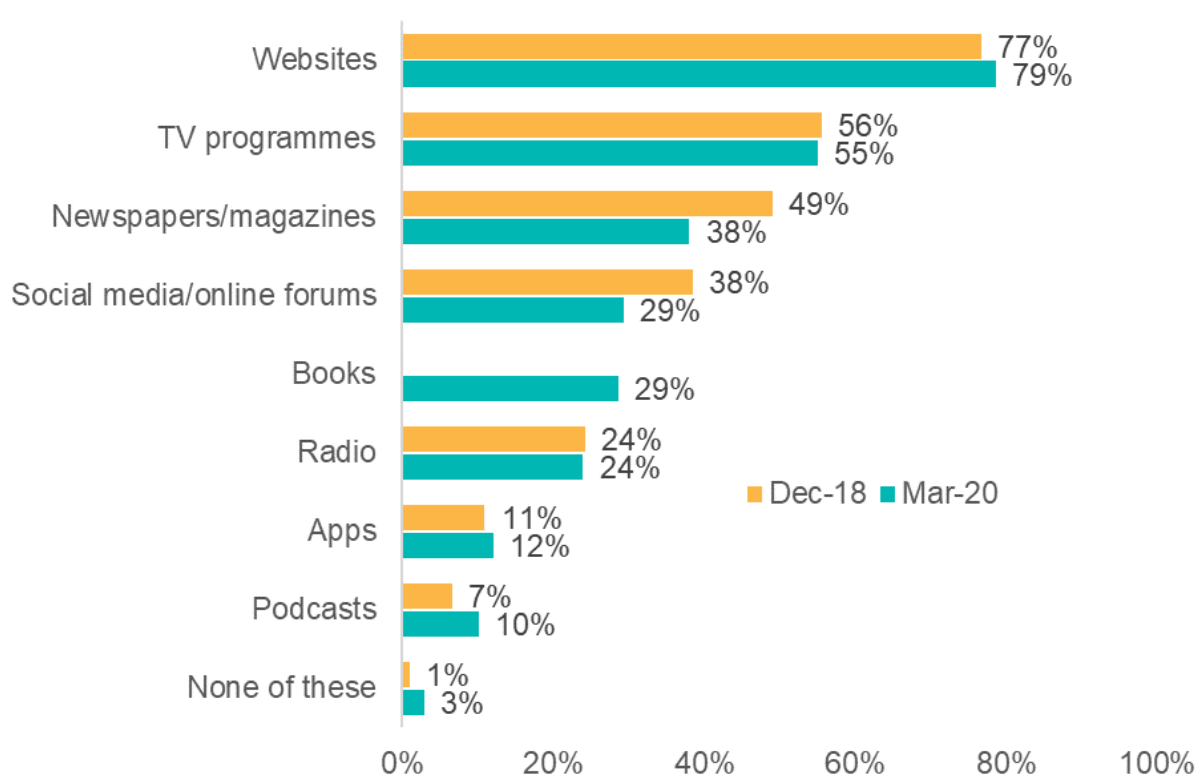
People finding it harder to get by financially were also more likely to say they had very little or no trust in the information they find. Nine per cent of people finding it quite or very difficult had very little or no trust in the health-related information they find, compared to three per cent of people living comfortably, doing alright, or just about getting by. Again, this reflects the findings about trust in information about coronavirus, which saw that people finding it harder financially had significantly less trust in scientists about coronavirus.

Most people got their health-related information online, but traditional media still played a substantial role

Respondents were asked to select from a list what sources they get their health-related information from. Figure 3:10 shows that people were most likely to get their health-related information from websites, followed by TV programmes, newspapers and magazines, social media sites or online forums and books, radio, and finally apps or podcasts. This is a similar overall pattern as seen in 2018¹⁴. However, Figure 3:10 also shows there was a slight drop in the proportion of people getting health-related information from newspapers/magazines and from social media compared to 2018.

¹⁴ Books were added to the list for the 2020 survey

Figure 3:10 Sources of health information, 2020 and 2018



From which of the following sources do you get health-related information...? Base (2020): All GB adults who ever look for health information (18+) (2513). Base (2018): All GB adults who ever look for health information (18+) (2563).

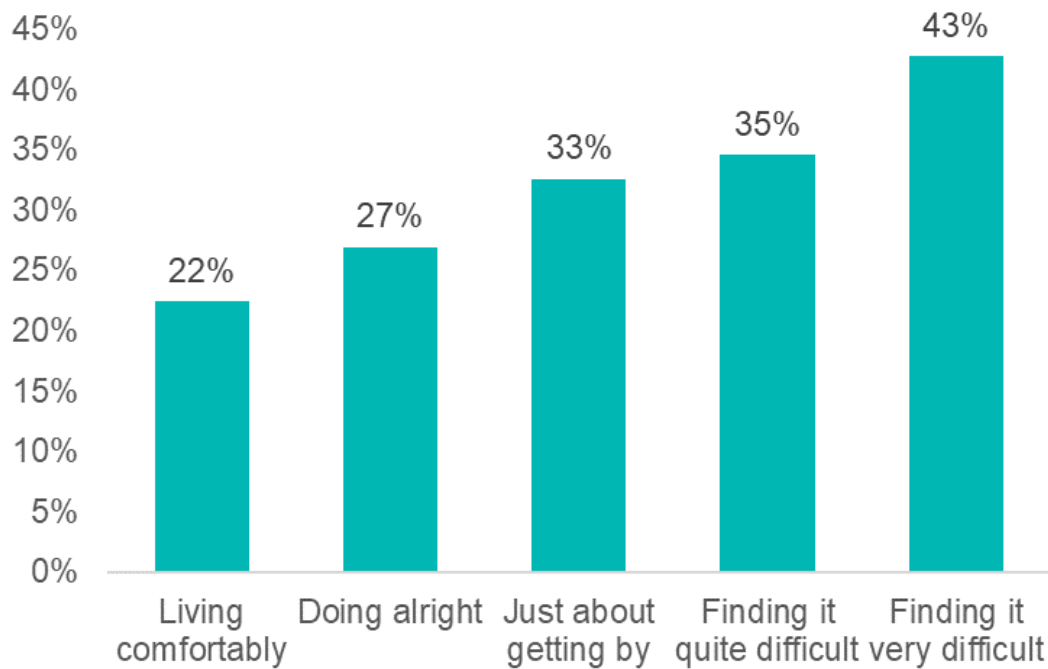
Younger people, people in BAME groups, and people finding it difficult financially were more likely to get health information from social media

As might be expected given higher internet use amongst this group, younger people were more likely to get their health information from social media or online forums. Thirty-nine percent of 18-39 year olds, 32% of 40-59 year olds, and 16% of people aged 60+ got health information from social media.

There were substantial differences in the proportion of people getting health-related information from social media between different ethnic groups. Half (49%) of people from BAME groups got their information from social media, compared to 28% of White people. Asian people were most likely to get information from social media or online forums (58%), followed by Black people (45%), people from other White backgrounds (36%) people from mixed/other groups (32%) and people from White British backgrounds, who were least likely (25%).

People finding it harder to get by financially were also more likely to get health-related information from social media or online forums (Figure 3:11). There is no significant variation by sex or highest qualification.

Figure 3:11 Proportion who use social media or online forums to get health-related information, by how getting by financially

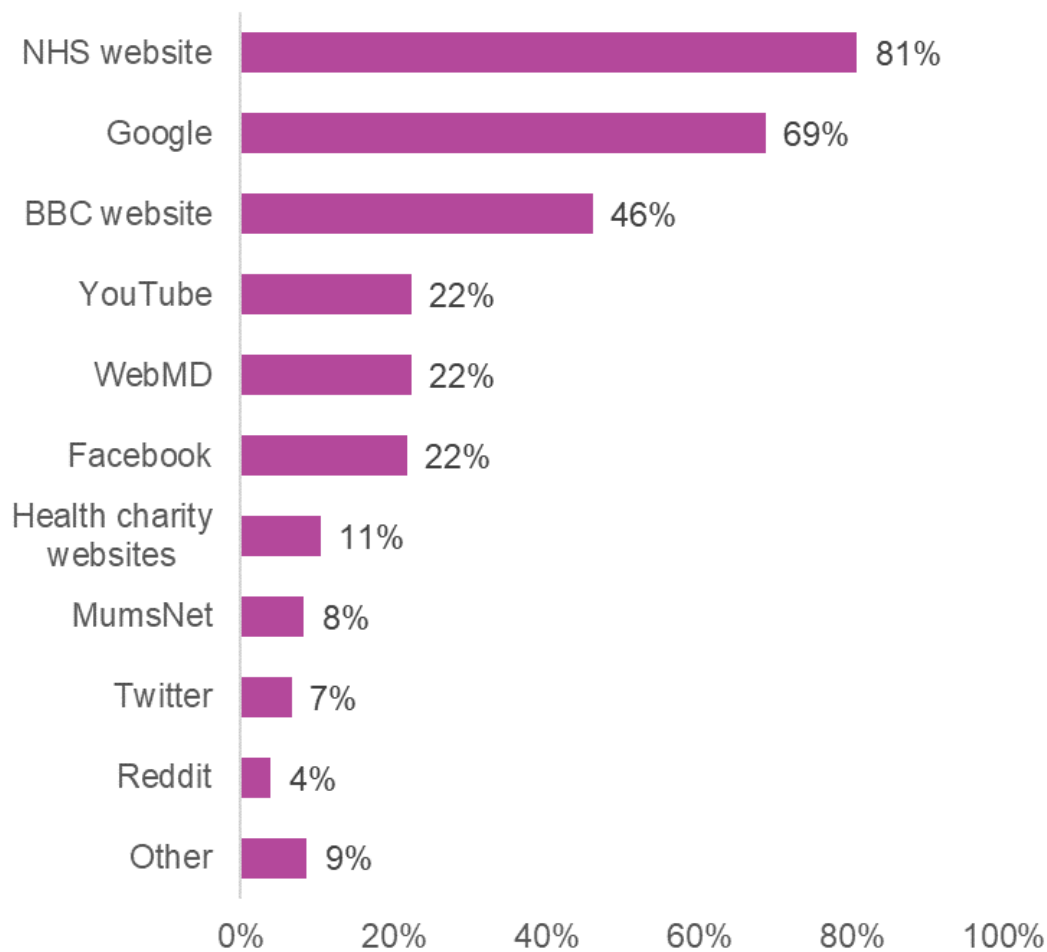


From which of the following sources do you get health-related information...? Base: All GB adults who ever look for health information (18+). Living comfortably (542), Doing alright (993) Just about getting by (620) Finding it quite difficult (221) Finding it very difficult (129)

NHS website was the most commonly used online source, followed by Google and then the BBC website

Respondents who said they got health-related information from websites, apps, or social media sites or online forums were asked to choose which ones they used from a list. Figure 3:12 shows that, reflecting the patterns seen previously, most people got their health-related information online from websites, with the NHS website, Google, and the BBC website being the most common. However, a significant minority (43%) still used at least one social media site (of YouTube, Facebook, MumsNet, Twitter or Reddit) for health-related information.

Figure 3:12 Online sources of health-related information

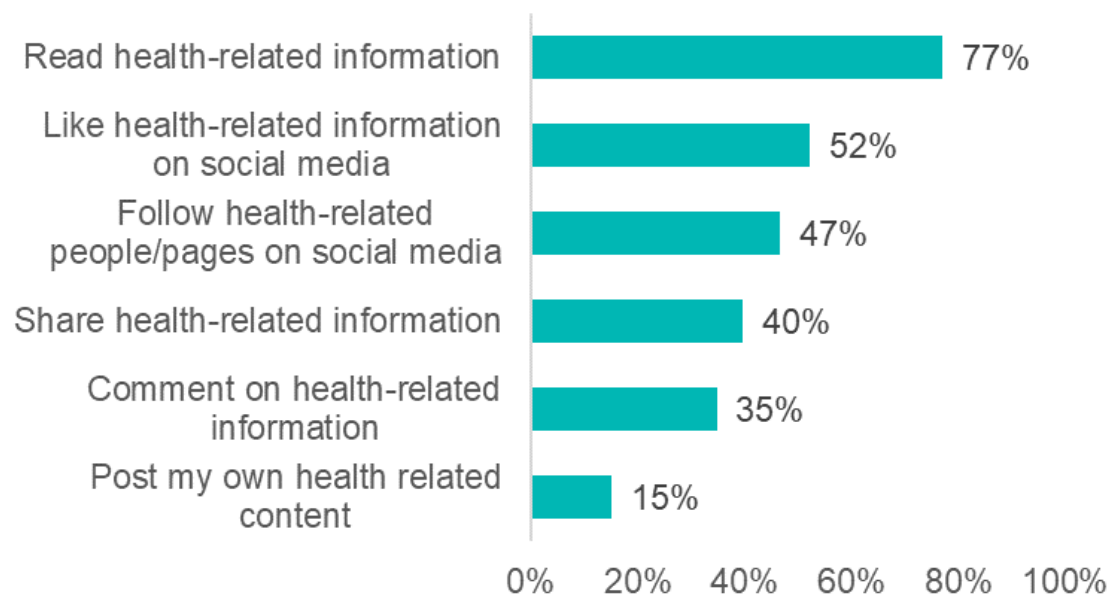


From which of the following websites, apps, social media sites or online forums do you get health-related information? Base: All GB adults (18+) who tried to find health-related information on social media or online forums (2265)

How are these social media platforms used?

Respondents who said they got health-related information from social media sites or online forums were asked how often they did a number of different activities. Of those using social media platforms for health-related information, most had 'consumed' health-related content via social media platforms, with fewer engaging or sharing and fewer still posting their own content (Figure 3:13).

Figure 3:13 Activities done at least once a month by those who use social media



How often do you do each of the following on social media sites or online forums...? Base: All GB adults (18+) who tried to find health-related information on social media or online forums (54)

4 Involvement in health research

In Chapter 3 we found that more people had participated in health research than in 2018. In this chapter, we take a closer look at what people understand by participation in health research. We then explore the extent to which people are interested in participating in health research in a variety of ways, and how that varies between different groups.

In the second part of this chapter, we then explore the extent to which different groups feel confident making decisions about their health, and how this is related to barriers to accessing health information.

Key findings

- Most people had a narrow conception of what it means to participate in health research, revolving around taking part in medical trials, and providing data.
- When taking an expanded view of what constitutes participation, we observe a higher rate of participation, but still a minority.
 - Most people reported taking part as a “data subject” rather than playing an active role.
 - Most people said they would be interested in participating in health research in the future, particularly younger people and those with higher incomes.
 - People who thought the public playing a role is important, and who valued health research were more likely to say they would take part.
- A large majority of people were confident making decisions about their health.
 - However, younger people and people from BAME groups were more likely to lack confidence.
 - People who found it difficult to find health-related information, found it unclear, or trusted it less were less likely to be confident making decisions about their health.
 - People with no qualifications were more likely to be very confident making decisions about health.

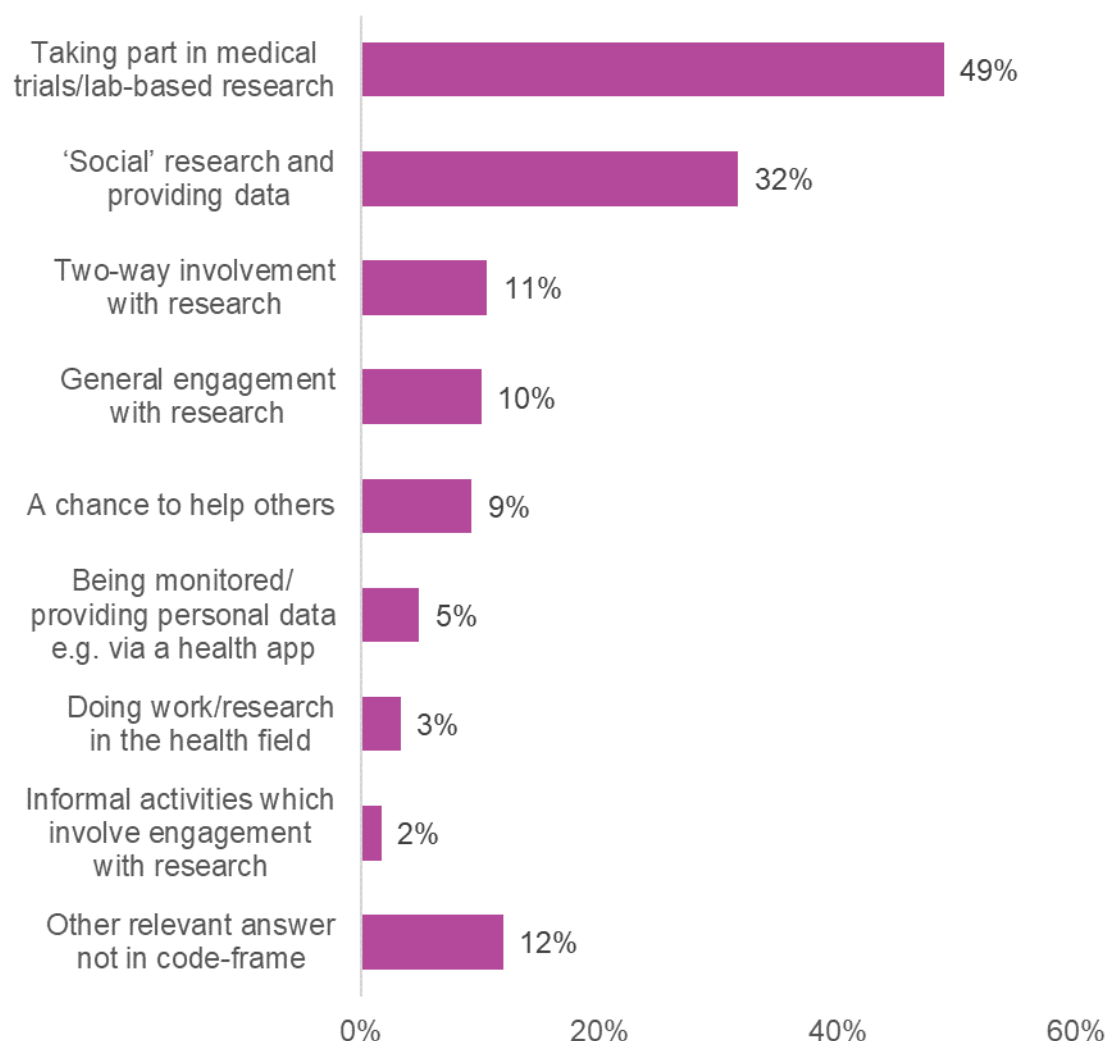
4.1 Participation in health research

4.1.1 Activities done in the past 5 years

Most people thought of participation in health research as taking part in medical trials

Findings reported in Section 2.1 suggest a slight increase in participation in health research: 18% of people said they had participated in health research in the past year, compared to 14% in 2018. Respondents were asked to give an open answer about what ‘participating in health research’ meant to them. We found that most people mentioned medical trials and/or lab-based research when thinking about participating in health research, with some thinking more about ‘social research’, but fewer talking about ‘two-way involvement’ (for example “*A two way exchange of information and views*”) or a sense of helping others.

Figure 4:1 What does 'participating in health research' mean to you?



What does 'participating in health research' mean to you? Base: All GB adults (18+) (2126 open-text answers given)

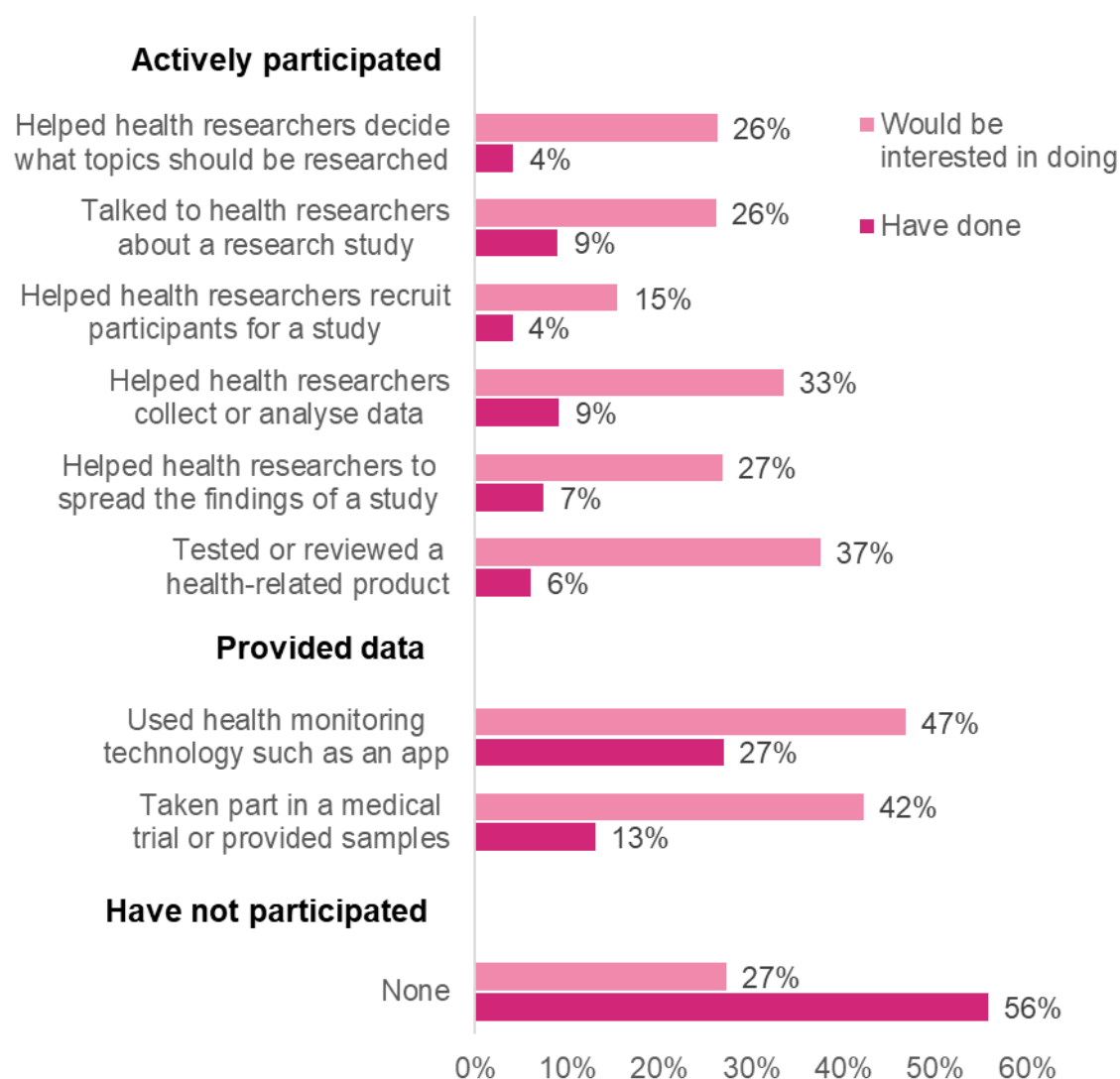
Most people had not participated in health research in the past 5 years, and most who had did so by providing data

Respondents were also asked to select from a list ways they had participated in health research in the last five years. The list was designed to reflect broader opportunities for participating in health research than might otherwise be considered.

Figure 4:2 shows that a large minority (44%) had done at least one of the listed 'participation' activities in the last five years – substantially higher than the 18% when asked in general. This will partially reflect the longer timescale, but also that the public were not necessarily including all the listed activities as participation in health research. Of those who had participated, a minority did so 'actively' (45%) and of those, a minority had done so at an early stage of, or during, the research process (36%).

From this list, people were more likely to have selected activities where they were the 'data subject' (providing data through an app¹⁵ or taking part in a trial), rather than playing a more active role in a research project. There was not significant variation in whether people had taken part in specific activities earlier (e.g. helping decide what topics should be researched) or later (e.g. helping to spread the findings of the study) in the research cycle.

Figure 4:2 Activities done in the last 5 years or would be interested in doing



Which of the following activities have you done in the last five years? Base: All GB adults (18+): 2646
And which of the following activities would you be interested in doing in the future? Base: All GB adults (18+): 2638

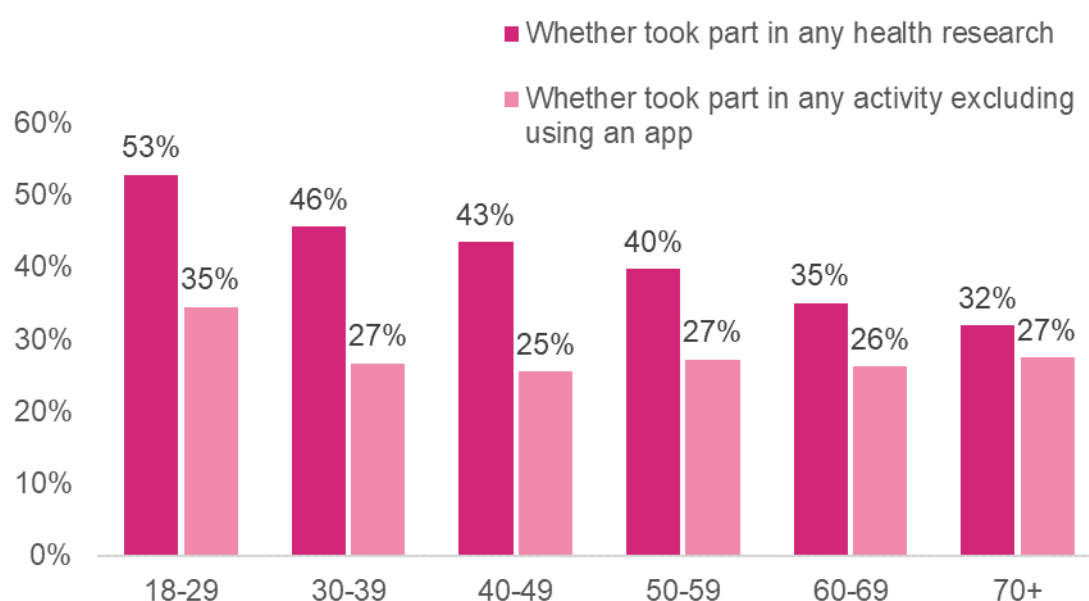
¹⁵ Though the NHS Covid-19 contact tracing app has now been widely downloaded across Britain, this was not released until September 2020 so will not account for the levels of participation through an app seen here.

Younger people and people with higher incomes were more likely to have participated and this difference was driven by use of health monitoring technology

Whether or not people had participated in health research through any of the listed activities in the last five years did not vary significantly by sex, ethnicity, or whether or not they had a health condition.

Figure 4:3 shows that younger people were more likely to have done any of the activities in the last five years. However, when excluding using health monitoring technology, there was no longer any significant variation.

Figure 4:3 Whether participated in any health research activity including and excluding use of app, by age group



Which of the following health-related activities have you done in the last five years...? Base: All GB adults (18+): 18-29 (220), 30-39 (431), 40-49 (473), 50-59 (508), 60-69 (508), 70+ (498)

Similarly, people with a monthly household income of £1251 or higher were more likely to have taken part than those with an income of £1,250 or lower (48% compared to 40%). However, this difference also disappeared when excluding using health monitoring technology (both 28%) suggesting that use of this technology was the key driver of higher participation amongst those on higher incomes.

In contrast, people with higher qualifications were more likely to have participated in health research irrespective of whether or not using health monitoring technology is included. Half of people with a degree (52%) had done any of the activities in the last five years, compared to 42% of people with other qualifications and 35% of people with no qualifications.

Finally, people who considered it more important that the public play a role in health research were more likely to have done any of the activities in the last five years. However, we still see that only half of those who thought it was important had taken part (49% of those who thought it was important or extremely important compared to 37% of those who thought it was fairly, somewhat, or not important).

4.1.2 Interest in participating in health research in the future

Most people said they would be interested in participating in health research in the future

Figure 4:2 also shows the proportion of people that said they would be interested in doing activities related to participating in health research in the future. Reflecting patterns seen in Section 2.2, a majority (73%) said they would be interested in doing at least one of the listed activities.

As with the activities people reported having done in the last five years, people were most likely to report being interested in activities where they were the 'data subject' relative to being more actively involved. Taking part in a medical trial or reviewing a health-related product were the activities where there was the largest gap between the proportion of people who had done them in the last five years and would be interested in doing them in the future.

Younger people and people with higher incomes were more likely to be interested in participating in the future

Whether or not people were interested in participating in health research in the future through any of the listed activities did not vary significantly by sex, ethnicity or whether or not someone has a health condition, but did again vary by age, income and highest qualification.

Younger people were more likely to be interested in doing any of the activities. Seventy-seven per cent of people aged 18-39 and 75% of people aged 40-59 were interested in doing at least one of the activities, compared to 34% of people aged 60 or older. Similarly, people with a monthly household income of £1251 or higher were more likely to be interested in doing any of the activities than people with an income of £1,250 or lower (76% compared to 70%).

Finally, people with higher qualifications were more likely to be interested in participating in health research. Eighty-two per cent of people with a degree would be interested in doing any of the activities, compared to 70% of people with other qualifications and 42% of people with no qualifications.

People who thought it is important for the public to play a role in health research, and would be likely to do so given the opportunity, were more likely to be interested in participating in health research

Again reflecting patterns with history of participation, people who considered it more important that the public play a role in health research and would be more likely to do so themselves given the opportunity, were more likely to do any of the activities in the future.

Eighty-four per cent of people who thought it was important for the public to play a role in health research said they would be interested in doing any of the activities related to participation in health research in the future, compared to 60% of people who said it was fairly important, and 50% of people who said it was somewhat important or not important.

Similarly, 92% of people who said they would be very likely or likely to play a role given the opportunity said they would be interested in doing any of the activities, compared to 60% of people who were neither likely nor unlikely and 34% of people who would be unlikely or very unlikely.

People who valued health research were more likely to be interested in participating in it

Finally, we find that people's interest in participating in health research is associated with the extent to which they valued it. Seventy-nine per cent of people who said that health research had been extremely or very beneficial for people like them said they would be interested in doing any of the activities, compared to 69% of people who said it had been quite beneficial and 53% of people who said it had been not very or not at all beneficial.

Similarly, 80% of people who said recent health research had had a very or somewhat positive impact on how they live their lives said they would be interested in doing any of the activities, compared to 61% of people who said it had had no impact and 51% of people who said it had had a somewhat or very negative impact.

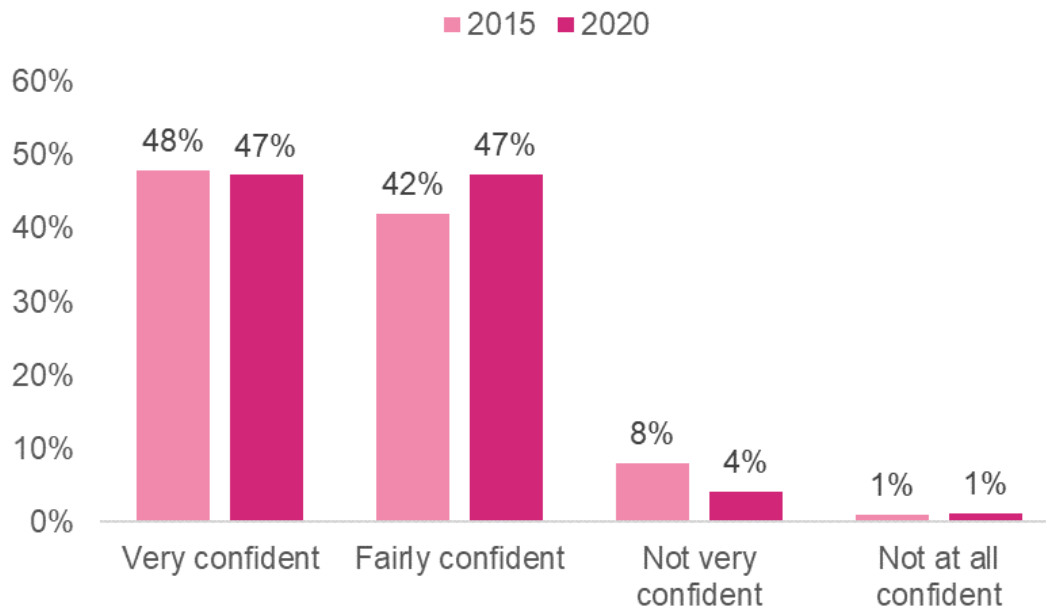
4.2 Empowerment in health decision-making

A large majority of people were confident making decisions about their health

Respondents were asked how confident they are making informed decisions about their health, for example whether to have a flu jab, or whether to make a doctor's appointment when they are feeling unwell. Figure 4:4 shows that a large majority of people (95%) were very or fairly confident making decisions about their health, a slight increase compared to the 90% seen in 2015¹⁶.

¹⁶ Comparisons should be treated with caution given the change in fieldwork design.

Figure 4:4 Confidence in making health decisions



How confident, if at all, would you say you are making informed decisions about your health, for example whether to have a flu jab, or whether to make a doctor's appointment when you are feeling unwell? Base: 2020: All GB adults (18+) 2648. Base: 2015: All UK adults (18+): 1524.

Younger people, and people from BAME groups or finding it more difficult financially were less confident about making decisions about their health

People finding it more difficult financially were less likely to be confident making health decisions. Thirteen per cent of people finding it very difficult financially said they were not confident making informed decisions about their health, compared to eight per cent of people finding it quite difficult, six per cent of people just about getting by, five per cent of people doing alright and two per cent of people living comfortably.

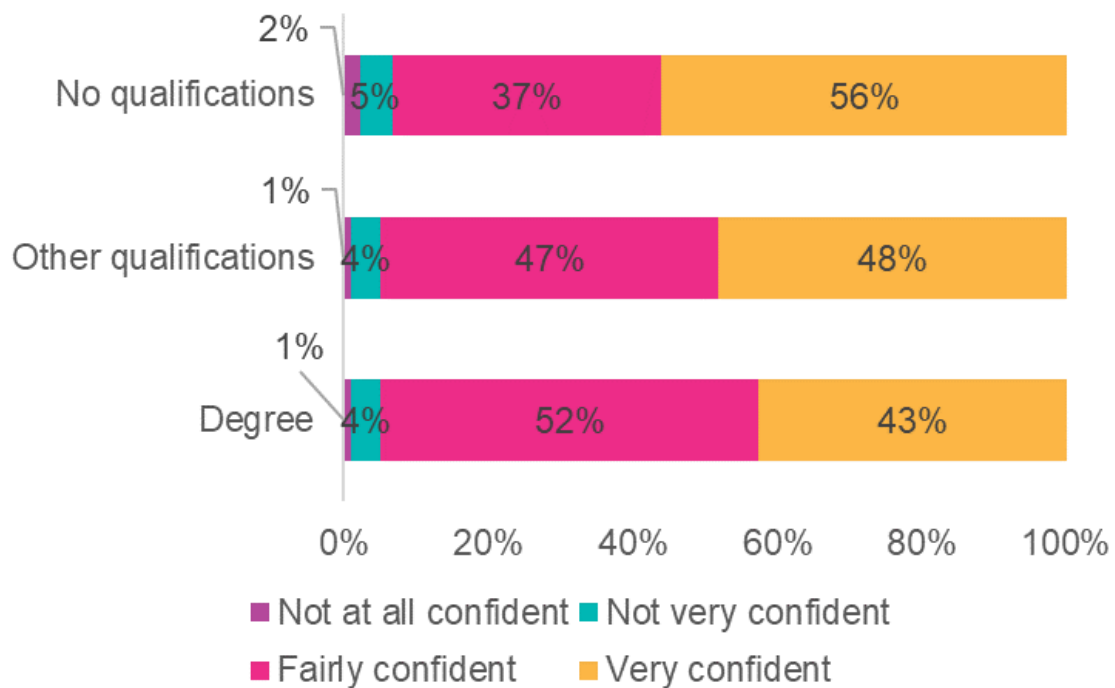
Similarly, people from BAME backgrounds were three times as likely to say they were not very or at all confident making informed decisions about their health (12%, compared to four per cent of White people).

We also find that younger people were less likely to be confident making decisions about their health. Eight per cent of people aged 18 to 39 were not very or at all confident making decisions about their health compared to four per cent of people aged 40 or over.

People with no qualifications were more likely to be very confident making decisions about their health

Contrary to what might be expected, the proportion of people who were not confident making decisions about their health did not vary significantly by education. However, as Figure 4:5 shows we do find that those with lower qualifications, or none, were more likely to say they were very confident making decisions.

Figure 4:5 Confidence in making health decisions, by qualification level



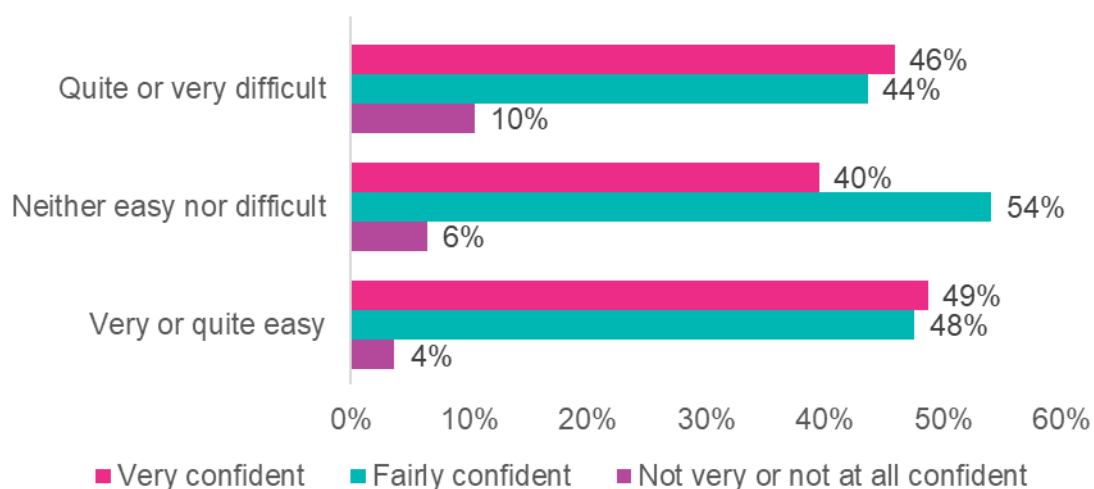
How confident, if at all, would you say you are making informed decisions about your health, for example whether to have a flu jab, or whether to make a doctor's appointment when you are feeling unwell? Base: All GB adults (18+). Degree or above (1197), Other qualifications (1163), No qualifications (280)

People who found it difficult to find health-related information, found it unclear, or trusted it less were less likely to be confident making decisions about their health

People's confidence making decisions about their health was also associated with their experiences trying to find health-related information. Figure 4:6 shows that, among people who tried to find health-related information, those who found it harder to do so, found that information less clear, or trusted that information less, were more likely to lack confidence making health decisions.

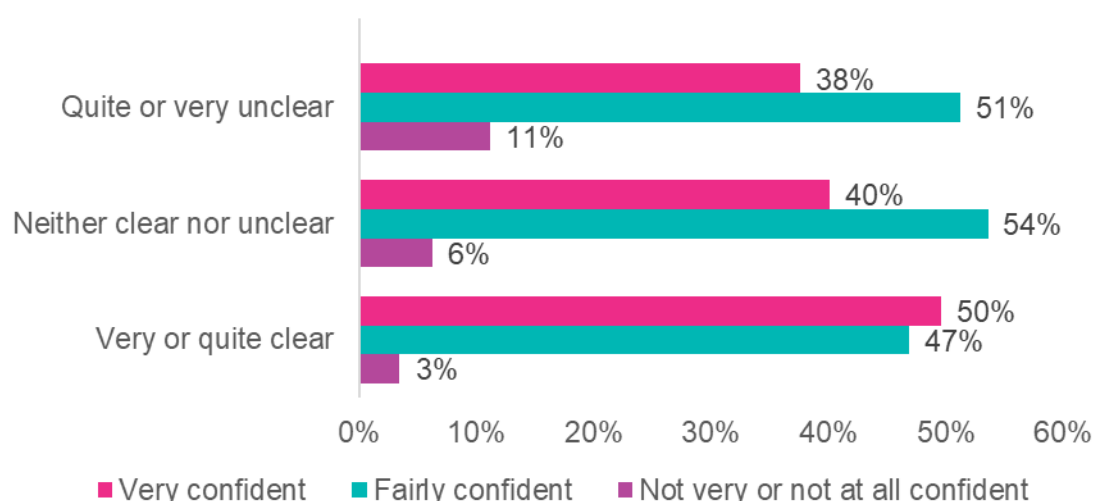
Figure 4:6 Whether confident making decisions about health, by ease of access to health-related information, how clear find health-related information and trust in health-related information

How easy or difficult is it for you to find this information?



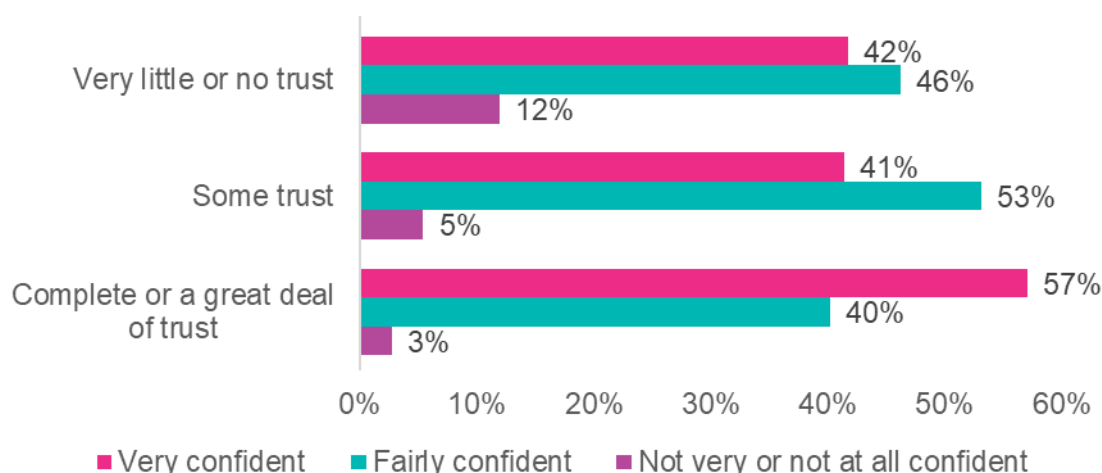
How much do you normally trust the health-related information that you find? Base: All GB adults who ever look for health information (18+) Quite or very difficult (162), Neither easy nor difficult (564), Very or quite easy (1788)

How clear or unclear is the information that you find?



Thinking about the health-related information you normally want, how easy or difficult is it for you to find this information? Base: All GB adults who ever look for health information (18+). Quite or very unclear (204), Neither clear nor unclear (576), Very or quite clear (1732)

How much do you normally trust the health-related information that you find?



Still thinking about the health-related information you normally want, how clear or unclear is the information that you find? Base: All GB adults who ever look for health information (18+). Very little or no trust (88), Some trust (1604), Complete or a great deal of trust (821)

People who had not engaged with health research, or valued it less, were less likely to be confident making decisions about their health

People who had not engaged with health research in any of the ways outlined in Section 3.1 were significantly more likely to lack confidence making health decisions. Nearly a fifth (19%) of people who hadn't engaged with health research in any of the listed ways said they were not very or not at all confident making decisions about their health, compared to four per cent of people who had done any of the activities. However, people's confidence making decisions about their health did not vary significantly by whether or not they had participated in health research through any of the activities outlined in Section 4.1.1 in the past five years.

Finally, people who said that health research was not very or not at all beneficial were substantially more likely to say they were not very or not at all confident making health decisions (18%, compared to seven per cent of people who said it was quite beneficial and two per cent of people who said it was very or extremely beneficial). A similar pattern was seen when looking at impact. Sixteen per cent of people who said recent health research had had a somewhat or very negative impact on their lives said they were not very or at all confident making health decisions, compared to seven per cent of people who said it had had no impact and four per cent of people who said it had had a very or somewhat positive impact.

5 Segmenting the population

The previous chapters of this report have found that it is not always the same groups that were 'positive' or 'negative' in their views and experiences of health research. For example, people from BAME groups were more likely than White people to try to find health-related information more often but were also less likely to trust it.

In this section, we look at the links across different dimensions of people's relationships with health research and health-related information – their **use** of health-related information, their **trust** in it, their role in **informing** it, and the extent to which they **value** health research. We explore how people's answers on these topics group together and how we can segment the population based on them using Latent Class Analysis. This chapter looks at the groups that this analysis creates and their demographic differences and similarities, before looking at how they differ in terms of their attitudes and behaviours in the context of information about Covid-19 during the first lockdown.

Key findings

- Based on their attitudes and behaviours across the four dimensions, the population splits broadly into four groups: the 'Core engagers', 'Dormant engagers', 'Unsupported enthusiasts', and 'Under-served'.
- Around one in seven people (14%) are core engagers. This group were consistently positive across all four dimensions, and tend to be slightly younger than the population as a whole, and well-educated.
- In contrast, one in four people (27%) are in the under-served group and were consistently negative across the dimensions. This group tends to be older than the population as a whole and are more likely not to have any qualifications.
- The largest group are the unsupported enthusiasts, making up two-fifths of the population (40%). They were broadly positive about health information and research, although not as much as the core engagers. However, they were relatively less confident making decisions about their health and had more difficulty when accessing health information. This group is slightly younger than the population as a whole.
- Finally, the dormant engagers make up one fifth of the population (19%). Unlike the other groups, they were not especially engaged or disengaged with health research, although they viewed it as beneficial. However, when they did try to find health information, they found it clear and easy to find and were more confident making decisions about their health.

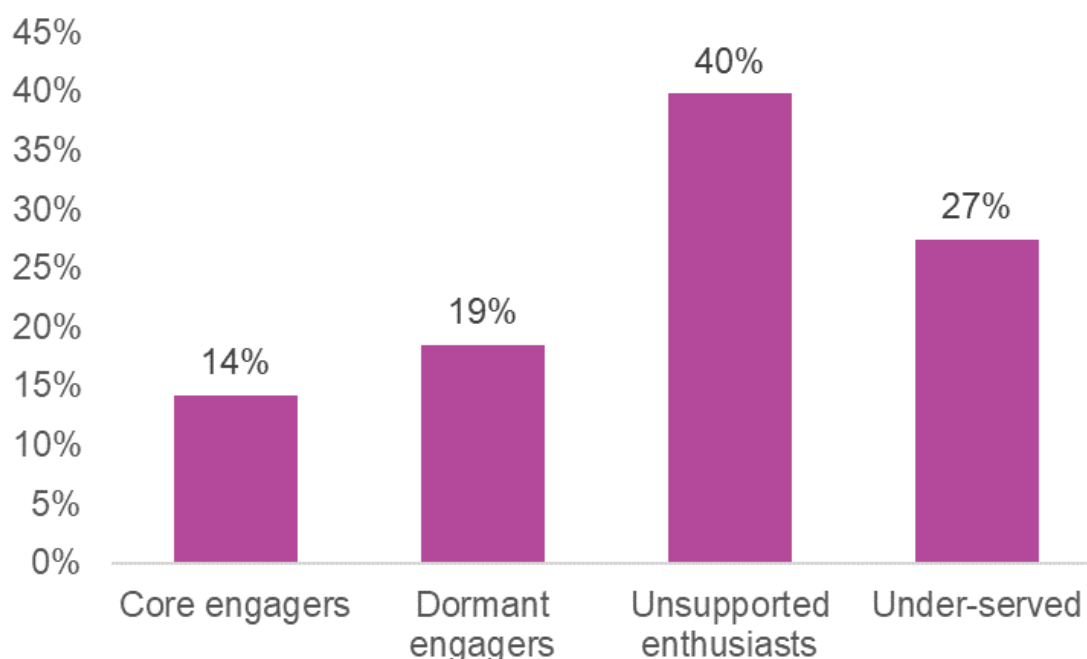
The population splits into four groups based on their views and engagement with health research

The segmentation was conducted by using 'Latent Class Analysis', an analytical technique which groups together people based on their answers to a pre-defined set of questions. For this analysis, the population was segmented based on a range of questions covering four key areas within which Wellcome's Public Engagement team seeks to strengthen the connection between the public and science: people's **use** of health research (for example their interest and engagement experiences accessing health information, and health decision-making), their **trust** in health-related information, their role in **informing** health research (including their participation and

views on the role of public), and the extent to which health research provides **value** to their lives. No socio-demographic variables were used when creating the groups.¹⁷

Based on this analysis, we find the population segments into four broad groups¹⁸: the 'Core engagers', 'Dormant engagers', 'Unsupported enthusiasts', and 'Under-served'. Figure 5:1 shows that the largest group is the unsupported enthusiasts, followed by the under-served, and then the dormant engagers and core engagers.

Figure 5:1 Segments of the population based on health research attitudes and behaviours



Base: All GB adults (18+): 2651

Core engagers and the under-served were consistently positive & negative about health research, but dormant engagers & unsupported enthusiasts had a more complex relationship with health research

The tables in Appendix B show the profiles of the different segments across the variables included in the analysis. There are two clear groups that were consistently positive or negative about health research: the core engagers and the under-served. In-between, the unsupported enthusiasts were generally positive about health research (albeit not as much as the core engagers) but were less trusting of it and find it less clear, while the dormant engagers trusted and valued health research, but tended to engage less.

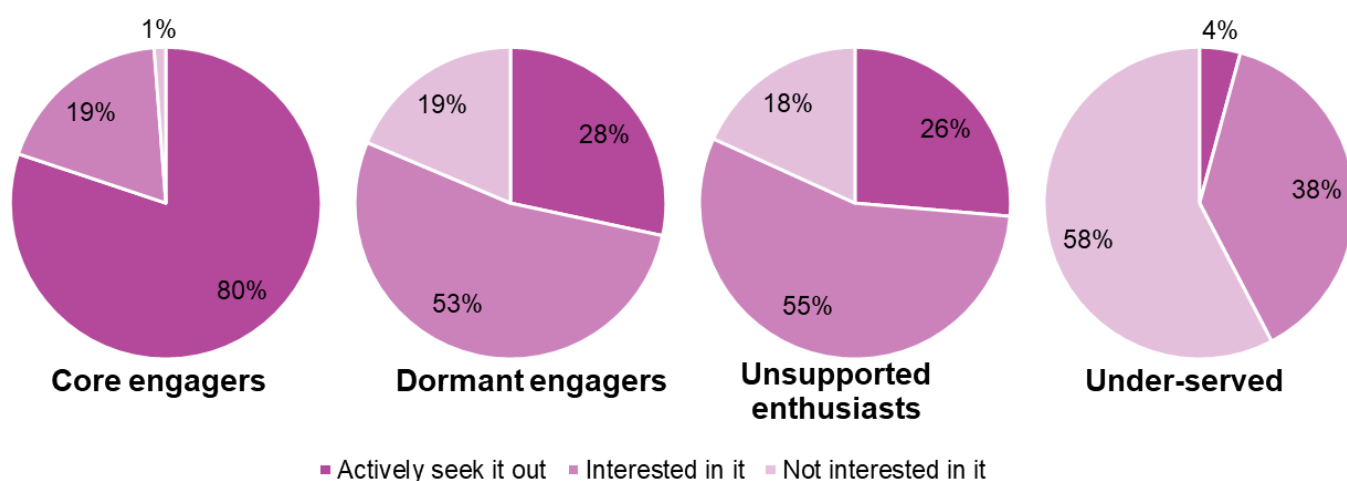
¹⁷ More information on the questions used in the analysis can be found in Appendix B

¹⁸ Models were run with two, three, four, and five clusters. The four-cluster model was found to best map on to the dimensions of interest and had the smallest classification error and best model fit of the four approaches.

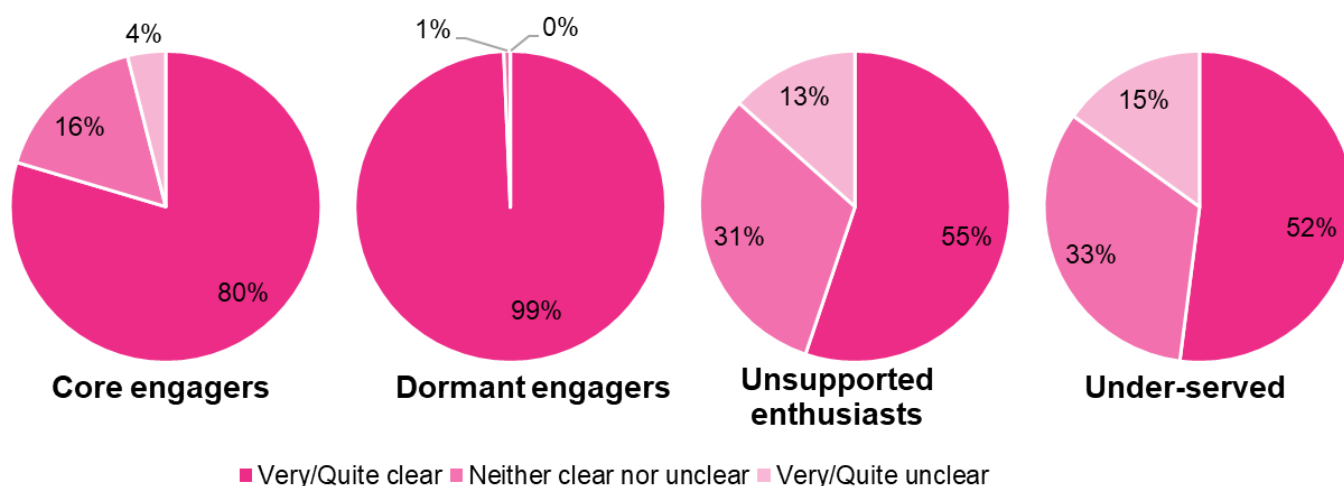
Figure 5:2 begins to illustrate this pattern showing core engagers were more likely to actively seek out health-related information, and find it clear, while the under-served were more likely to be uninterested in health-related information, and less likely to find it clear. However, while dormant engagers and unsupported enthusiasts were both similarly interested in health-related information on this measure, the dormant engagers were more similar to the core engagers in how clear they find information (in fact, almost unanimously finding it very or quite clear), while the unsupported enthusiasts are similar to the under-served.

Figure 5:2 Use: Relationship with health-related information & clarity of health-related information by health research attitudes and behaviours segment

Use: Relationship with health-related information



Use: Clarity of health-related information you find



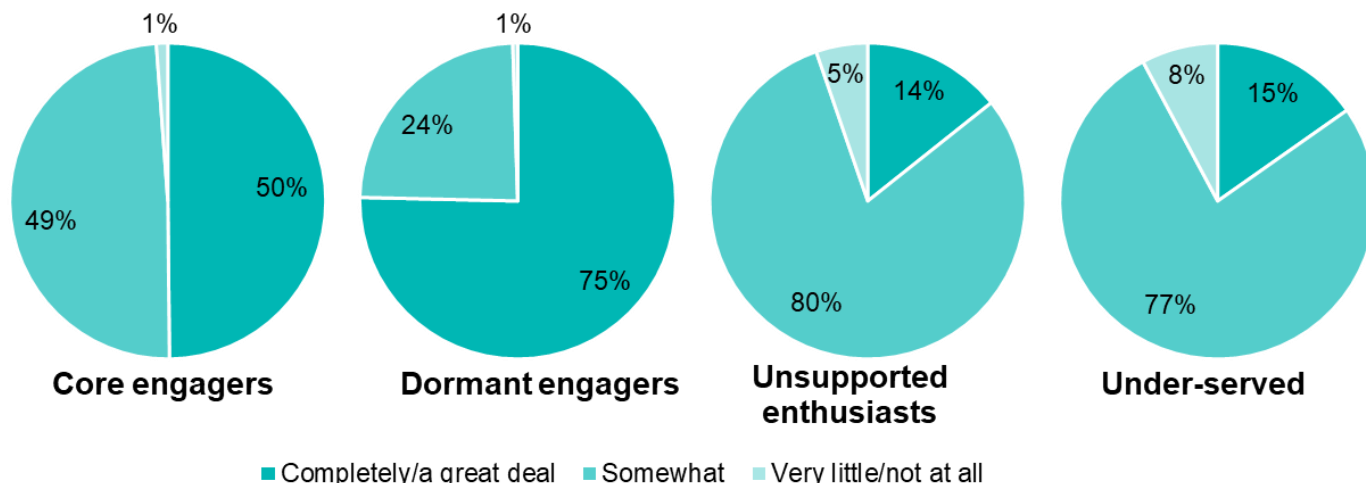
Which of these statements best describes your relationship with health-related information? Base: All GB adults (18+): Core engagers (416); Dormant engagers (511); Unsupported enthusiasts (1,099); Under-served (619).

Still thinking about the health-related information you normally want, how clear or unclear is the information that you find? Base: All GB adults (18+) that ever try to find health-related information: Core engagers (416); Dormant engagers (494); Unsupported enthusiasts (1,087); Under-served (515).

This pattern continues in Figure 5:3, where the dormant engagers are more similar to (and if anything more trusting than) core engagers, while the unsupported enthusiasts, like the under-served, were less likely to trust the health-related information they find.

Figure 5:3 Trust: Trust in health-related information you find by health research attitudes and behaviours segment

Trust: Trust in health-related information you find

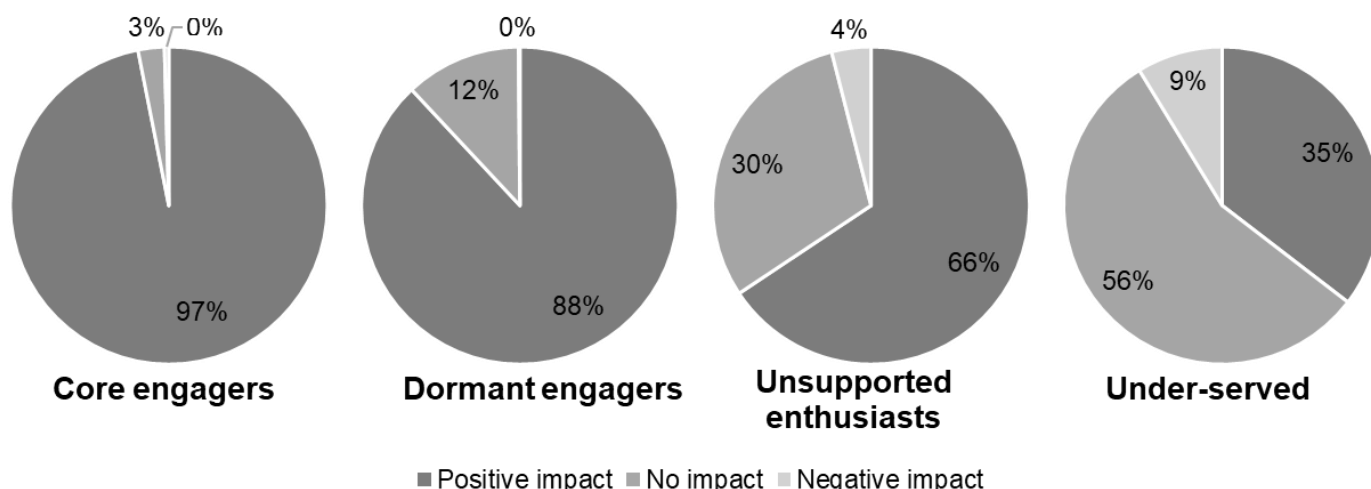


How much do you normally trust the health-related information that you find? Base: All GB adults (18+) that ever try to find health-related information: Core engagers (416); Dormant engagers (495); Unsupported enthusiasts (1,086); Under-served (517).

However, this pattern begins to shift when we look at the different segments' views on the value provided by health research. Figure 5:4 shows that, while unsupported enthusiasts felt they get less value from health research (compared to how core engagers and dormant engagers feel), they were still much more likely to say it had a positive impact on how they live their lives than the under-served.

Figure 5:4 Value: Impact of health research on how you live your life by health research attitudes and behaviours segment

Value: Impact of health research on how you live your life

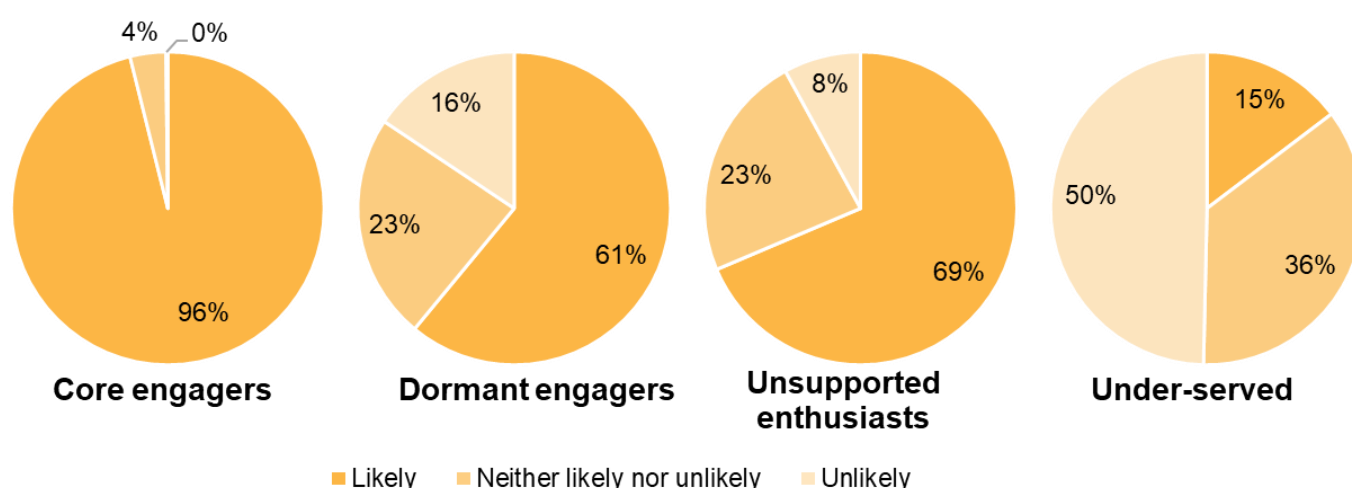


Thinking about recent health research, what impact, if any, has it had on how you live your life? Base: All GB adults (18+): Core engagers (417); Dormant engagers (504); Unsupported enthusiasts (1,090); Under-served (611).

Finally, we see an important distinction when we look at the different segments' views on informing health research. Figure 5:5 shows that the unsupported enthusiasts were more likely than the dormant engagers to say they would be likely to play a role in health research, despite finding health-related information less clear, being less trusting of that information, and being less likely to feel it has had a positive impact.

Figure 5:5 Inform: Likelihood of playing a role in health research by health research attitudes and behaviours segment

Inform: Likelihood of playing a role in health research



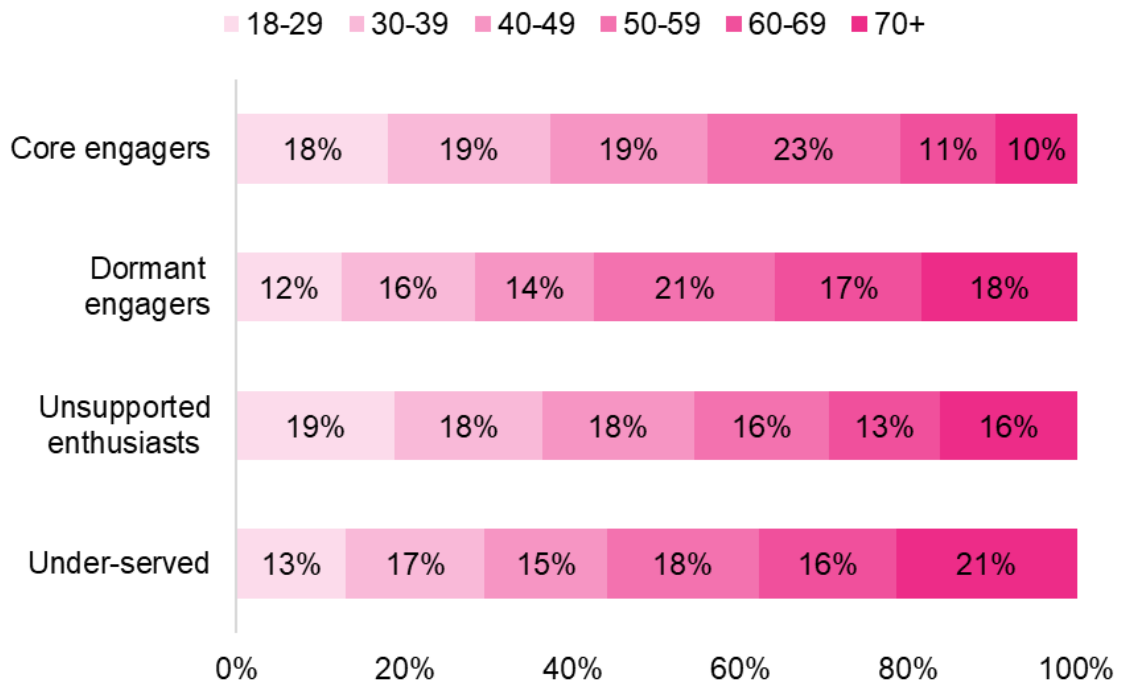
Given the opportunity, how likely or unlikely would you be to play a role in health research? Base: All GB adults (18+): Core engagers (417); Dormant engagers (510); Unsupported enthusiasts (1,097); Under-served (620).

The four groups varied by age and levels of education, but little else

The four groups were created purely on the basis of their attitudes and behaviours with respect to health information and research. The tables in Appendix B outline how the demographic profile of these groups varied. These tables suggest that, for the most part, there is relatively little significant variation in the demographic profile of the four groups: there is no significant variation by sex, ethnicity, financial circumstances, whether or not someone has a longstanding health condition, and whether or not someone lives in London or in an urban or rural area.

However, the groups do differ from one another in terms of their age and highest qualifications. Looking firstly at the core engagers and under-served, Figure 5:6 shows that the consistently more positive core engagers are more likely to have been under 60, while people in the under-served group were more likely to have been aged 60+. The unsupported enthusiasts have a younger age profile similar to core engagers, while the dormant engagers have an older profile more similar to the under-served.

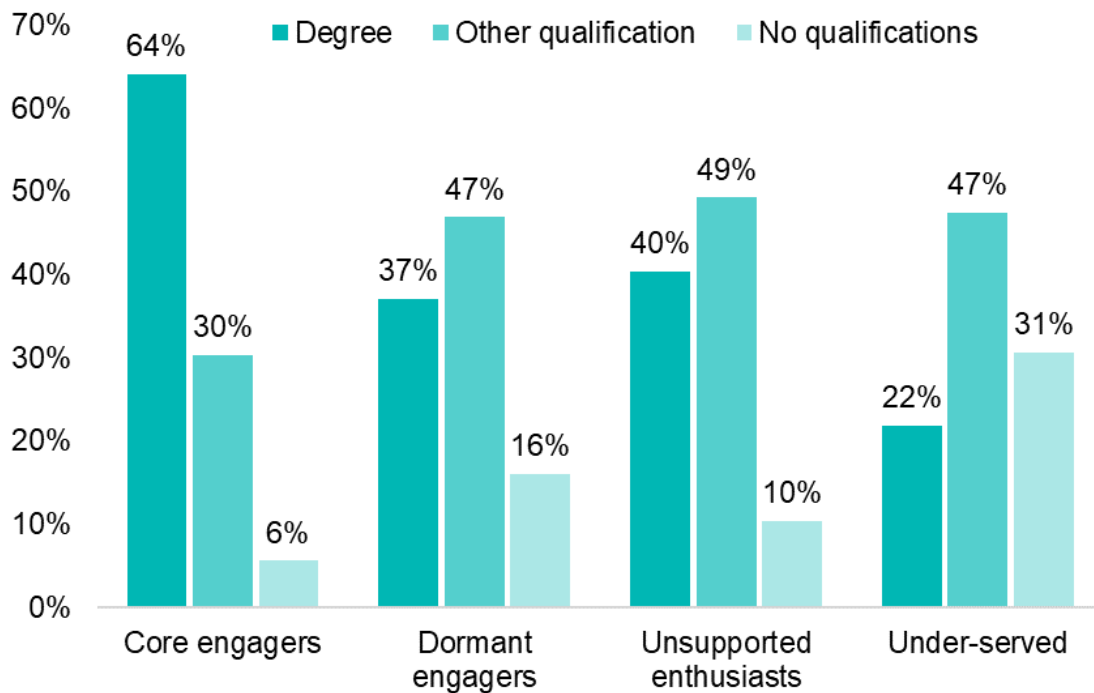
Figure 5:6 Percentage in age group by health research attitudes and behaviours segment



Base: All GB adults (18+); Core engagers (415); Dormant engagers (511); Unsupported enthusiasts (1,097); Under-served (619).

There are also differences between these groups in terms of their education. As well as being relatively young, core engagers are substantially more likely to have had a degree, while people in the under-served group were more likely to not have had any qualifications (Figure 5:7). The dormant engagers and unsupported enthusiasts, however, are not substantially different from the population as a whole in terms of their education, which may be surprising given the differences in their experiences in ease of accessing health information.

Figure 5:7 Percentage with different levels of qualification by health research attitudes and behaviours segment



Base: All GB adults (18+): Core engagers (417); Dormant engagers (509); Unsupported enthusiasts (1,098); Under-served (619).

The four groups experienced information about Covid-19 differently during the first lockdown

Given the complex demographic patterns we have seen between different chapters in this report it is perhaps unsurprising that we do not see substantial variation in the demographic profile of the four groups. However, by looking at the data collected about people's experiences of Covid-19 at the start of the first UK lockdown in 2020, we can see how these clusters of views are associated with behaviours.

Firstly, we can see that the segments varied in how clear they found information about what to do to stay safe and minimise risk during the coronavirus outbreak. Matching the patterns seen in Figure 5:2, dormant engagers were most likely to find it very clear (81%) compared to 64% of unsupported enthusiasts and 67% of the underserved. Perhaps surprisingly, the core engagers were also less likely to find the information very clear (68%).

The trust in information about coronavirus among these population groups also mirrored the patterns seen earlier. Table 5:1 shows that core engagers were generally more likely, and the under-served less likely, to trust information from all sources (except the Prime Minister, friends & family and religious leaders). Like the under-served, unsupported enthusiasts were also less likely to trust information from most sources, though it is note-worthy that they were more likely than the under-served to trust information from health scientists and researchers, while dormant engagers were most likely to trust information from most sources.

Table 5:1 Percentage trusting health related information from different sources completely or a great deal by health research attitudes and behaviours segment

	Core engagers	Dormant engagers	Unsupported enthusiasts	Under-served
Health sector sources				
The NHS	89%	93%	81%	79%
Healthcare professionals	88%	89%	84%	81%
Health scientists & researchers	85%	79%	73%	60%
The WHO	79%	75%	68%	57%
Government sources				
Public Health England	77%	78%	64%	62%
Government scientific advisers	72%	73%	60%	54%
Prime Minister	51%	53%	44%	49%
UK government	56%	61%	49%	47%
'Everyday' sources				
Your employer	59%	45%	41%	42%
Friends & family	28%	36%	23%	29%
Religious leaders	11%	14%	10%	11%
Journalists & the media	19%	17%	10%	9%

Base: All GB adults (18+): Core engagers (412-417); Dormant engagers (493-511); Unsupported enthusiasts (1,081-1,101); Under-served (607-621). 'Your employer': All GB adults (18+) in employment: Core engagers (224); Dormant engagers (241); Unsupported enthusiasts (553); Under-served (271).

These patterns of clarity and trust translate through into perceived effectiveness of spread-prevention measures, with the core engagers and dormant engagers consistently more likely to perceive activities as very effective than unsupported enthusiasts and the under-served. For example, 90% of core engagers and 89% of dormant engagers perceived avoiding social activities as very effective, compared to 86% of unsupported enthusiasts and 81% of the under-served. Similarly, 14% of core engagers and 13% of dormant engagers perceived wearing a mask as very effective, compared to nine per cent of unsupported enthusiasts and eight per cent of the under-served.

However, when we then look at the actual take-up of spread-prevention behaviours, this pattern does not continue. Part of this may be that some the activities were legally enforced by the lockdown (e.g. avoiding social activities). However, Table 5:2 shows that where this is not the case (for example touching your face less) the unsupported enthusiasts, despite finding guidance less clear, trusting information on coronavirus less, and perceiving measures to be less effective, were as likely as the dormant engagers, and more likely than the under-served, to take up the behaviours.

Table 5:2 Percentage that have taken up spread-prevention behaviours by health research attitudes and behaviours segment

	Core engagers	Dormant engagers	Unsupported enthusiasts	Under-served
Avoiding social activities	99%	99%	100%	97%
Washing your hands with soap & water often/thoroughly	99%	98%	98%	97%
Avoiding closed public spaces	98%	96%	97%	96%
Avoiding open public spaces	86%	84%	87%	90%
Staying home from work/school/university	84%	82%	85%	84%
Cleaning surfaces that you touch more regularly	84%	79%	81%	77%
Touching your face less	82%	77%	76%	66%
Using alcohol-based hand sanitizer	70%	64%	70%	62%
Wearing a face mask	21%	17%	15%	14%

Base: All GB adults (18+): Core engagers (414-417); Dormant engagers (508-511); Unsupported enthusiasts (1,094-1,011); Under-served (611-621).

6 Conclusion

This report has explored the ways in which the British public utilise, engage with, and participate in health research, and examined how these attitudes and behaviours vary between different groups in the population. At the time of fieldwork in April 2020, Covid-19 will have been very much at the forefront of people's minds and is likely to have had a strong influence on people's answers. As the Wellcome Monitor has collected data on many of these topics in the past, this report provides a first look at what impact the pandemic may have had on people's attitudes and behaviours, at least in the short-term.

As might be expected, it seems that there has been an increase in people's engagement with health-related information. Chapter 3 shows that the proportion of people engaging with health-related information and participating in health research increased since 2018, and this is mirrored by an increase in the proportion of people who were looking up health information on most days or more frequently. However, at the same time, Chapter 2 shows that there was a decrease in the proportion of people who are interested in specific areas of health research beyond Covid-19, raising questions about what, if any, long-term effects the pandemic might have on public engagement across other areas of science and health research. Mental health remained the health research area of most interest across the population, particularly amongst those experiencing mental health difficulties themselves (difficulties that we now know have been widely exacerbated by Covid-19 and associated lockdowns)¹⁹. We also see, however, that interest in the health implications of climate change has been steadily increasing since 2009. This is likely to be in part due to the increased focus climate change has received in recent years, via high-profile international summits like COP21 in 2015, during which the Paris Agreement was formed, but also wider coverage in media and popular culture from figures like David Attenborough and Greta Thunberg, as well as activist groups like Extinction Rebellion.

We also see that the proportion of people interested in hearing directly from scientists about the research they are conducting increased since 2015, potentially reflecting people being more used to hearing from scientists during daily briefings from the government. However, this was lower among women and those without degrees, and was not matched by an increase in the belief that scientists care about the views of the public, which people seem to still be uncertain about. People also tended to think of the public role in health research as limited to being involved in medical trials, rather than other types of involvement where they might inform the health research process, engage in dialogue with researchers, or contribute to the research through, for example, citizen science initiatives.

Together these findings suggest that there is still considerable room for the research community to broaden both its appeal, and the conception of public involvement in health research. This is particularly pressing during a time where the need for scientists to have an effective public voice and the need for the public to play a role, have never been more important.

Reflecting the complexity seen in changing attitudes and behaviours, our analysis also finds that it is not always the same groups that were 'positive' or 'negative' in their views and experiences of health research. For example, people from BAME groups were more likely than White people to say they actively seek out information, but they were also less likely to feel health research benefited people like them. Mirroring what we found more specifically in our Covid-19 report, people from BAME groups were also

¹⁹https://journals.lww.com/psychosomaticmedicine/Abstract/9000/Mental_health_during_COVID_19_lockdown_in_the.98497.aspx

less likely to trust health information (with lack of trust particularly pronounced amongst Black people). This is likely to reflect historical disparities in healthcare provision and beyond: according to research commissioned by the Parliamentary Joint Committee on Human Rights, over 60% of Black people in the UK do not believe their health is as equally protected by the NHS compared to White people.²⁰ We also found that people from BAME groups were less likely to be confident making decisions about health, as were younger people. Recent findings from ONS showed that only half (49%) of Black adults would be likely to get a Covid -19 vaccine, compared to 85% of White adults, a finding which is important to consider within the wider context of how attitudes to and experiences to health provision vary across ethnic groups.²¹

This study finds that it is also BAME groups and younger people, as well as those with more financial difficulties, who were more likely to use social media to get health information. The pandemic brought about a need to consider alternative approaches for engaging the public with health information and has increased usage among people who normally wouldn't have used the internet to such extents. As the internet has, in certain ways, fewer barriers to entry, it could be a fruitful source of information for older people and those without degrees (who were among those who found it difficult to access health information or find it clear). However, despite presenting a promising opportunity for wider and more diverse engagement, the greater risk of exposure to misinformation and disinformation means engagement efforts will have a chequered information environment to navigate.

The varying patterns we find are not necessarily contradictory, and our segmentation analysis in Chapter 5 shows that while around two fifths of the population fall into groups that are more consistently 'positive' (the core engagers) or 'negative' (the under-served) in their behaviours and attitudes related to health-related information and research (when it comes to using, trusting, valuing, and informing it), many do not. Core engagers made up 14% of the population, the under-served 27%. Dormant engagers (19% of the population) were more likely to find health-related information clear and trust and value it but were not especially likely to actively seek it out or wish to participate themselves. In contrast, the unsupported enthusiasts (who made up the largest group, 40% of the population) did not find health-related information clear, and were less likely to trust or value it, but despite this they were not less likely to be interested in it and were actually more likely to say they would play a role given the opportunity. These differences in health engagement generally were found to relate to attitudes and behaviours around staying safe and minimising risk from Covid-19 more specifically.

Overall, these findings suggest that the Covid-19 pandemic has increased the general public's engagement with health-related information and research, with an increased interest in health research. However, at the same time, the opportunity to engage and the value health research brings is disparate across the population. It is yet to be seen whether this increased engagement will last and translate into an engagement more broadly with science and health research beyond Covid-19 or a greater desire to play a role in guiding that research themselves. Nevertheless, it remains an opportune time for the research community and public engagement practitioners to consider different

²⁰: Celine Henry, Kenny Imafidon and Dr Niamh McGarry, 2020. The Black Community & Human Rights, <https://publications.parliament.uk/pa/jt5801/jtselect/jtrights/correspondence/The-Black-Community-Human-Rights-Report.pdf>

²¹

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/coronavirusandthesocialimpactsongreatbritain/29january2021#attitudes-to-covid-19-vaccination-by-different-sub-groups-of-the-population>

approaches that enable a broader and more diverse public to engage with health research.

Appendix A. Health issues which people think it is most important for researchers to work on

This section summarises variation in health issues which are personally important for researchers to work on by sex, age, ethnicity, education level and financial circumstances. Variation is statistically significant in highlighted rows.

Sex

Appendix table A:1 Health issues which people think it is important for researchers to work on, by sex

<i>Base: GB adults (18+)</i>	<i>Male</i>	<i>Female</i>	<i>Total</i>
	%	%	%
Cancer	49	49	49
Mental health, sleep disorders, loneliness	36	41	39
Alzheimer's/Dementia	18	21	20
Cardiovascular health	18	17	18
Diabetes	12	11	11
Obesity	9	11	10
Asthma/other respiratory conditions	8	10	9
Coronavirus	9	9	9
Ageing/age-related diseases	11	7	9
Food and nutrition/ Exercise	8	9	9
Infectious disease (not mentioning coronavirus)	11	6	9
Other	45	55	50
None	5	3	4
<i>Unweighted bases</i>	1046	1447	2493

Age

Appendix table A:2 Health issues which people think it is important for researchers to work on, by age group

Base: GB adults (18+)	18-29	30-39	40-49	50-59	60-69	70+	Total
	%	%	%	%	%	%	%
Cancer	49	48	45	58	48	46	49
Mental health, sleep disorders, loneliness	56	46	47	37	25	23	39
Alzheimer's/Dementia	17	14	18	23	23	22	20
Cardiovascular health	7	14	18	20	26	21	18
Diabetes	7	8	12	15	14	11	11
Obesity	13	12	14	12	7	5	10
Asthma/other respiratory conditions	5	7	6	10	12	15	9
Coronavirus	7	12	10	10	9	6	9
Ageing/age-related diseases	6	4	6	9	12	17	9
Food and nutrition/ Exercise	9	10	10	9	10	6	9
Infectious disease (not mentioning coronavirus)	11	8	8	10	7	7	9
Other	45	55	47	47	53	48	48
None	4	3	4	2	4	8	4
Unweighted bases	199	392	444	492	484	477	2493

Ethnic group

Appendix table A:3 Health issues which people think it is important for researchers to work on, by ethnic group

<i>Base: GB adults (18+)</i>	<i>White</i>	<i>BAME</i>	<i>Total</i>
	%	%	%
Cancer	53	26	49
Mental health, sleep disorders, loneliness	39	37	39
Alzheimer's/Dementia	22	7	20
Cardiovascular health	19	11	18
Diabetes	11	12	11
Obesity	10	14	10
Asthma/other respiratory conditions	10	5	9
Coronavirus	9	9	9
Ageing/age-related diseases	10	6	9
Food and nutrition/ Exercise	8	11	9
Infectious disease (not mentioning coronavirus)	8	15	9
Other	49	56	50
None	2085	354	4
<i>Unweighted bases</i>	1046	1447	2493

Education level

Appendix table A:4 Health issues which people think it is important for researchers to work on, by education level

<i>Base: GB adults (18+)</i>	<i>Degree or equivalent, and above</i>	<i>Other qualifications</i>	<i>No qualifications</i>
	%	%	%
Cancer	49	53	39
Mental health, sleep disorders, loneliness	35	41	42
Alzheimer's/Dementia	25	19	9
Cardiovascular health	15	20	18
Diabetes	13	10	12
Obesity	11	10	10
Asthma/other respiratory conditions	7	9	17
Coronavirus	10	10	5
Ageing/age-related diseases	11	8	7
Food and nutrition/Exercise	10	9	6
Infectious disease (not mentioning coronavirus)	11	9	4
Other	57	45	45
None	1	5	10
<i>Unweighted bases</i>	1154	1087	247

Financial circumstances

Appendix table A:5 Health issues which people think it is important for researchers to work on, by financial circumstances

<i>Base: GB adults (18+)</i>	<i>Living comfortably</i>	<i>Doing alright</i>	<i>Just about getting by</i>	<i>Finding it quite difficult</i>	<i>Finding it very difficult</i>	<i>Total</i>
	%	%	%	%	%	%
Cancer	54	52	48	43	26	49
Mental health, sleep disorders, loneliness	31	37	42	50	51	39
Alzheimer's/Dementia	28	22	13	16	13	20
Cardiovascular health	17	19	17	14	17	18
Diabetes	11	10	15	9	8	11
Obesity	9	9	10	16	16	10
Asthma/other respiratory conditions	7	9	11	10	14	9
Coronavirus	9	8	8	12	13	9
Ageing/age-related diseases	13	9	9	4	6	9
Food and nutrition/ Exercise	10	9	9	10	9	9
Infectious disease (not mentioning coronavirus)	11	8	8	9	11	9
Other	47	53	48	52	43	50
None	3	4	5	5	3	4
<i>Unweighted bases</i>	<i>545</i>	<i>988</i>	<i>615</i>	<i>216</i>	<i>124</i>	<i>2493</i>

Appendix B. Details of population segments

This section summarises the profile of the four population segments created by the latent class analysis discussed in Section 5 using the variables included in the model and demographic variables.

Variables used in the segmentation

The following tables summarise the profile of the population across the four dimensions: use, trust, value, and inform. All variables were used in the model, although for questions marked with an asterisk only the 'none' value was used.

Appendix table B:1 Use of health-related information by health research attitudes and behaviours segment

	<i>Core engagers</i>	<i>Dormant engagers</i>	<i>Unsupported enthusiasts</i>	<i>Under-served</i>
Which of these statements best describes your relationship with health-related information?				
I actively seek out news, information, and events related to health	80%	28%	26%	4%
I am interested in health-related information but don't tend to seek it out	19%	53%	55%	38%
I am not interested in health-related information, but I would seek it out if I or someone I know needed it	1%	17%	18%	50%
I am not interested in health-related information and would not seek it out	0%	1%	0%	7%
Which of the statements do you most agree with? These days I hear and see...				
Far too much health-related information	8%	6%	6%	11%
Too much health-related information	14%	17%	19%	20%
The right amount of health-related information	56%	62%	52%	56%
Too little health-related information	16%	14%	20%	12%
Far too little health-related information	6%	1%	3%	1%
To what extent, if at all, are you interested in hearing directly from scientists about the research they are conducting?				
Very interested	73%	32%	35%	8%
Fairly interested	26%	55%	58%	47%
Not very interested	1%	10%	7%	33%
Not at all interested	0%	4%	1%	11%
Which of the following have you done in the last year...? *				
Had a conversation on a health topic	88%	69%	76%	44%
Commented on social media content on a health topic	50%	19%	25%	8%
Shared or retweeted social media content on a health topic	52%	23%	28%	7%
Searched for health-related information	89%	65%	76%	35%

Appendix table B:1 Use of health-related information by health research attitudes and behaviours segment				
Participated in health research	47%	16%	18%	5%
Read an article on a health topic	94%	80%	78%	46%
Watched or listened to a talk about a health topic, online or in person	82%	45%	57%	20%
Visited a museum or exhibition on a health topic	19%	5%	7%	2%
Watched or listened to a TV/radio programme or podcast on a health topic	88%	73%	77%	50%
None	0%	1%	0%	16%
Which of these are you interested in...? *				
Obesity	49%	35%	39%	23%
How genes work and how they affect health and diseases	67%	46%	56%	25%
Ageing	56%	40%	45%	25%
The health implications of climate change	58%	42%	51%	27%
Mental health issues	73%	64%	73%	50%
Stem cells	49%	30%	31%	12%
Risk of disease	62%	51%	54%	33%
Diseases which affect the developing world	52%	38%	42%	23%
Other	18%	8%	9%	4%
None	1%	7%	1%	22%
When making decisions about your own health, including when you feel ill, but also your mental health and general wellbeing, which of the following do you do...?				
Look up information and research about the topic	80%	67%	69%	41%
Follow advice given to you by a health professional	91%	88%	85%	73%
Follow the advice of the media	12%	6%	7%	3%
Follow the advice of friends or family	35%	29%	35%	26%
Base my decision on previous experience	70%	60%	64%	44%
None	1%	0%	0%	5%
How confident, if at all, would you say you are making informed decisions about your health, for example whether to have a flu jab, or whether to make a doctor s appointment when you are feeling unwell?				
Very confident	69%	69%	35%	40%
Fairly confident	30%	30%	59%	51%
Not very confident	1%	1%	5%	6%
Not at all confident	0%	1%	1%	3%
Approximately how often do you try to find health-related information?				
Several times a day	14%	2%	2%	0%
On most days	40%	11%	13%	1%
Once or twice a week	25%	18%	20%	7%
Once or twice a month	17%	36%	39%	18%
Less often than once a month	2%	28%	23%	56%

Appendix table B:1 Use of health-related information by health research attitudes and behaviours segment

Never	0%	5%	2%	18%
Thinking about the health-related information you normally want, how easy or difficult is it for you to find this information?				
Very easy	24%	42%	4%	6%
Quite easy	59%	54%	54%	48%
Neither easy nor difficult	16%	3%	29%	35%
Quite difficult	1%	0%	11%	7%
Very difficult	0%	1%	1%	3%
Still thinking about the health-related information you normally want, how clear or unclear is the information that you find?				
Very clear	13%	29%	1%	2%
Quite clear	67%	70%	55%	50%
Neither clear nor unclear	16%	1%	31%	33%
Quite unclear	3%	0%	12%	11%
Very unclear	1%	0%	2%	4%

Base: All GB adults (18+): Core engagers (416-417); Dormant engagers (494-511); Unsupported enthusiasts (1,087-1,102); Under-served (515-620).

Appendix table B:2 Trust in health-related information by health research attitudes and behaviours segment

	<i>Core engagers</i>	<i>Dormant engagers</i>	<i>Unsupported enthusiasts</i>	<i>Under-served</i>
How much do you normally trust the health-related information that you find?				
Completely	4%	10%	0%	1%
A great deal	46%	65%	14%	14%
Somewhat	49%	24%	80%	77%
Very little	1%	1%	5%	7%
Not at all	0%	0%	1%	1%

Base: All GB adults (18+): Core engagers (416); Dormant engagers (495); Unsupported enthusiasts (1,086); Under-served (517).

Appendix table B:3 Value of health research by health research attitudes and behaviours segment

	<i>Core engagers</i>	<i>Dormant engagers</i>	<i>Unsupported enthusiasts</i>	<i>Under-served</i>
How beneficial, if at all, would you say health research has been for people like you?				
Extremely beneficial	54%	36%	11%	5%
Very beneficial	40%	45%	36%	24%
Quite beneficial	6%	17%	46%	49%
Not very beneficial	0%	1%	7%	18%
Not at all beneficial	0%	0%	1%	3%
Thinking about recent health research, what impact, if any, has it had on how you live your life?				
A very positive impact	46%	29%	8%	4%

Appendix table B:3 Value of health research by health research attitudes and behaviours segment

A somewhat positive impact	51%	59%	57%	32%
It has had no impact	3%	12%	30%	56%
A somewhat negative impact	0%	0%	3%	5%
A very negative impact	0%	0%	1%	3%

Base: All GB adults (18+); Core engagers (417); Dormant engagers (504-508); Unsupported enthusiasts (1,090-1,102); Under-served (611-612).

Appendix table B:4 Informing health research by health research attitudes and behaviours segment

	<i>Core engagers</i>	<i>Dormant engagers</i>	<i>Unsupported enthusiasts</i>	<i>Under-served</i>
How important, if at all, do you think it is for the public to be able to play a role in health research?				
Extremely important	62%	29%	23%	8%
Important	31%	42%	40%	20%
Fairly important	6%	20%	23%	36%
Somewhat important	1%	7%	13%	32%
Not important	0%	2%	1%	3%
Given the opportunity, how likely or unlikely would you be to play a role in health research?				
Very likely	60%	13%	17%	1%
Likely	36%	48%	52%	14%
Neither likely nor unlikely	4%	23%	23%	36%
Unlikely	0%	12%	5%	31%
Very unlikely	0%	4%	2%	19%
To what extent do you think each of the following should, or should not, be involved in informing/setting priorities for health research...?				
Government	49%	58%	43%	42%
Scientists working in universities	87%	74%	72%	67%
Scientists working in government	72%	73%	61%	63%
Scientists working in private industry	51%	50%	39%	39%
Health research charities	59%	57%	54%	47%
Members of the public	40%	33%	28%	24%
Which of the following activities have you done in the last five years...?				
Helped health researchers decide what topics should be researched	12%	3%	4%	1%
Talked to health researchers about a research study, for example commenting on how to communicate with study participants or on the ethical acceptability of the research	26%	6%	9%	2%
Helped health researchers recruit participants for a study	13%	3%	4%	1%
Used health monitoring technology such as an app to monitor sleep or diet or worn devices such as a step or heart-rate monitor	48%	25%	31%	12%

Appendix table B:4 Informing health research by health research attitudes and behaviours segment				
Taken part in a medical trial or provided samples (e.g. blood or tissue) for a health study	27%	9%	16%	4%
Helped health researchers collect or analyse data, for example by recording what you see or categorising images – be it online, in a game, or in a laboratory	29%	4%	10%	1%
Helped health researchers to spread the findings of a study or make them easier for the general public to understand	25%	6%	6%	1%
Tested or reviewed a health-related product	19%	4%	6%	1%
None	17%	60%	50%	80%
Which of the following activities would you be interested in doing in the future...?				
Helped health researchers decide what topics should be researched	56%	23%	31%	6%
Talked to health researchers about a research study, for example commenting on how to communicate with study participants or on the ethical acceptability of the research	53%	27%	31%	5%
Helped health researchers recruit participants for a study	38%	12%	17%	3%
Used health monitoring technology such as an app to monitor sleep or diet or worn devices such as a step or heart-rate monitor	67%	47%	59%	18%
Taken part in a medical trial or provided samples (e.g. blood or tissue) for a health study	67%	44%	50%	17%
Helped health researchers collect or analyse data, for example by recording what you see or categorising images – be it online, in a game, or in a laboratory	62%	32%	41%	8%
Helped health researchers to spread the findings of a study or make them easier for the general public to understand	56%	26%	30%	8%
Tested or reviewed a health-related product	61%	39%	46%	12%
None	1%	26%	11%	66%

Base: All GB adults (18+); Core engagers (377-417); Dormant engagers (448-511); Unsupported enthusiasts (851 -1,100); Under-served (419-620).

Demographic characteristics

Appendix table B:5 Demographics by health research attitudes and behaviours segment				
	Core engagers	Dormant engagers	Unsupported enthusiasts	Under-served
Sex				
Male	52%	46%	46%	50%
Female	48%	54%	54%	50%
Age group				

Appendix table B:5 Demographics by health research attitudes and behaviours segment				
18-29	18%	12%	19%	13%
30-39	19%	16%	18%	17%
40-49	19%	14%	18%	15%
50-59	23%	21%	16%	18%
60-69	11%	17%	13%	16%
70+	10%	18%	16%	21%
Whether has long-standing condition that affects day-to-day life				
Yes - affects day-to-day life	14%	20%	17%	19%
Yes - does not affect day-to-day life	18%	20%	18%	13%
No	68%	59%	65%	68%
Ethnicity				
White (Total)	81%	89%	86%	88%
BAME (Total)	19%	11%	14%	12%
White British	70%	80%	78%	85%
White - Other	11%	9%	7%	3%
Asian or Asian British	11%	5%	8%	6%
Black or Black British	3%	3%	3%	4%
Mixed or other ethnic group	5%	3%	4%	3%
How managing financially				
Living comfortably	18%	20%	19%	17%
Doing alright	43%	39%	38%	41%
Just about getting by	23%	29%	28%	27%
Finding it quite difficult	10%	8%	10%	7%
Finding it very difficult	6%	4%	5%	8%
Equivalised household income				
£800 or less	22%	23%	24%	30%
£801 to £1250	19%	22%	17%	24%
£1251 to £2000	23%	26%	23%	20%
More than £2000	36%	30%	36%	26%
Highest qualification				
Degree	64%	37%	40%	22%
Other qualification	30%	47%	49%	47%
No qualifications	6%	16%	10%	31%
Whether lives in London/urban/rural area				
London	19%	14%	13%	12%
Not London - Urban	64%	66%	68%	67%
Not London - Rural	18%	20%	19%	22%

Base: All GB adults (18+): Core engagers (392-417); Dormant engagers (479-511); Unsupported enthusiasts (1,035 -1,102); Under-served (575-621).