

This report has been funded by Genomics England

# Attitude towards health and medical research within the Muslim community

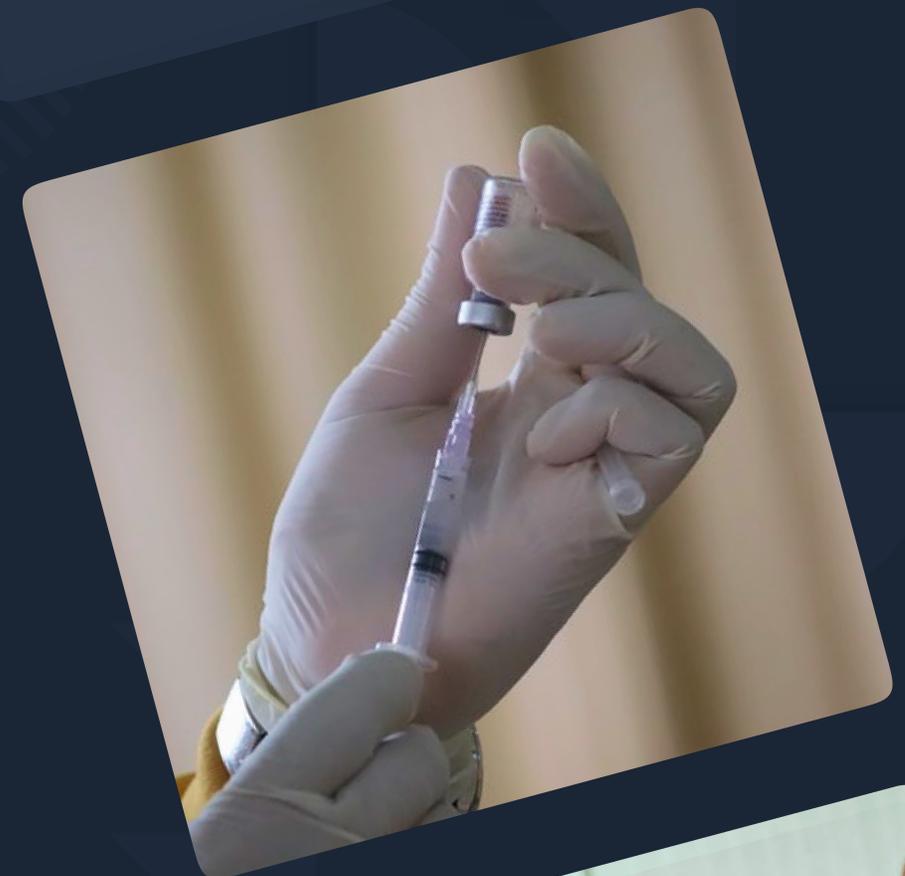


# Introduction

Studies of genetic diseases are largely based on European ancestry, with ethnically diverse people being massively underrepresented – Mils and Rahal<sup>1</sup> found that 88-90% of studies only include white European individuals therefore representing just 16% of the population. This has huge implications for the development of science – it means the application of research findings to ethnically diverse populations could be dangerous if it leads to an underassessment of the risks involved<sup>2</sup>. However, previous mistreatment and manipulation of minorities has led to a distrust in healthcare<sup>3</sup>, which might partly explain the lack of minority participation in medical research.

Indeed, studies have suggested that ethnic minorities tend to have different views about genomics and are less engaged with health research generally, despite researcher's apparent efforts to include more ethnic minorities in their health research. There is also not much known about where Muslims seek health information from, and whether this is more likely to be rooted in religious community rather than mainstream, scientific sources.

Muslim Census surveyed 1,007 Muslims aged 18-65+ living in the UK to understand whether these pre-conceptions about Muslim's attitudes towards health research and genomics more broadly, as well as health information, are based in fact. Our aim is for the findings to help explore how to engage with Muslims to increase Muslim representation in genetic research.



# Methodology and limitations

This research was conducted via an online survey that was distributed to our dedicated subscriber base and across our social media channels. The survey was live between 1st February and 8th March. Overall, 1,007 Muslims living in the UK responded to the survey.

Results of any sample are subject to sampling variation. The margin of error varies based on the size of the sample. In this particular study, the chances are 95 in 100 that a survey result does not vary, plus or minus, by more than 3% from the result that would be obtained if interviews had been conducted with all persons in the universe represented by the sample.

The data has been weighted by age, gender and ethnicity according to the UK Census data of 2011 to increase the accuracy of the overall results. However, controlling for all variables is challenging. An example being that our sample appears to be at a higher education level compared to the overall Muslim population. Another limitation is the exclusively online collection of our responses. Also, Muslims who have previously engaged with health research are more likely to have responded to the survey, therefore our results are more likely to show a positive perception of health research and genomics.

Overall, however, given the large sample size, we can be confident that this provides valuable insight into the sentiments of Muslims with regards to healthcare and genomics.

# Information seeking behaviour

Muslims turn to the NHS website and their GP at a rate more than 2.5 times higher than the next 3 options combined, making the NHS as a whole the most trusted source within the community. 73% of Muslims listed the NHS website as one of their go to sources of medical information.

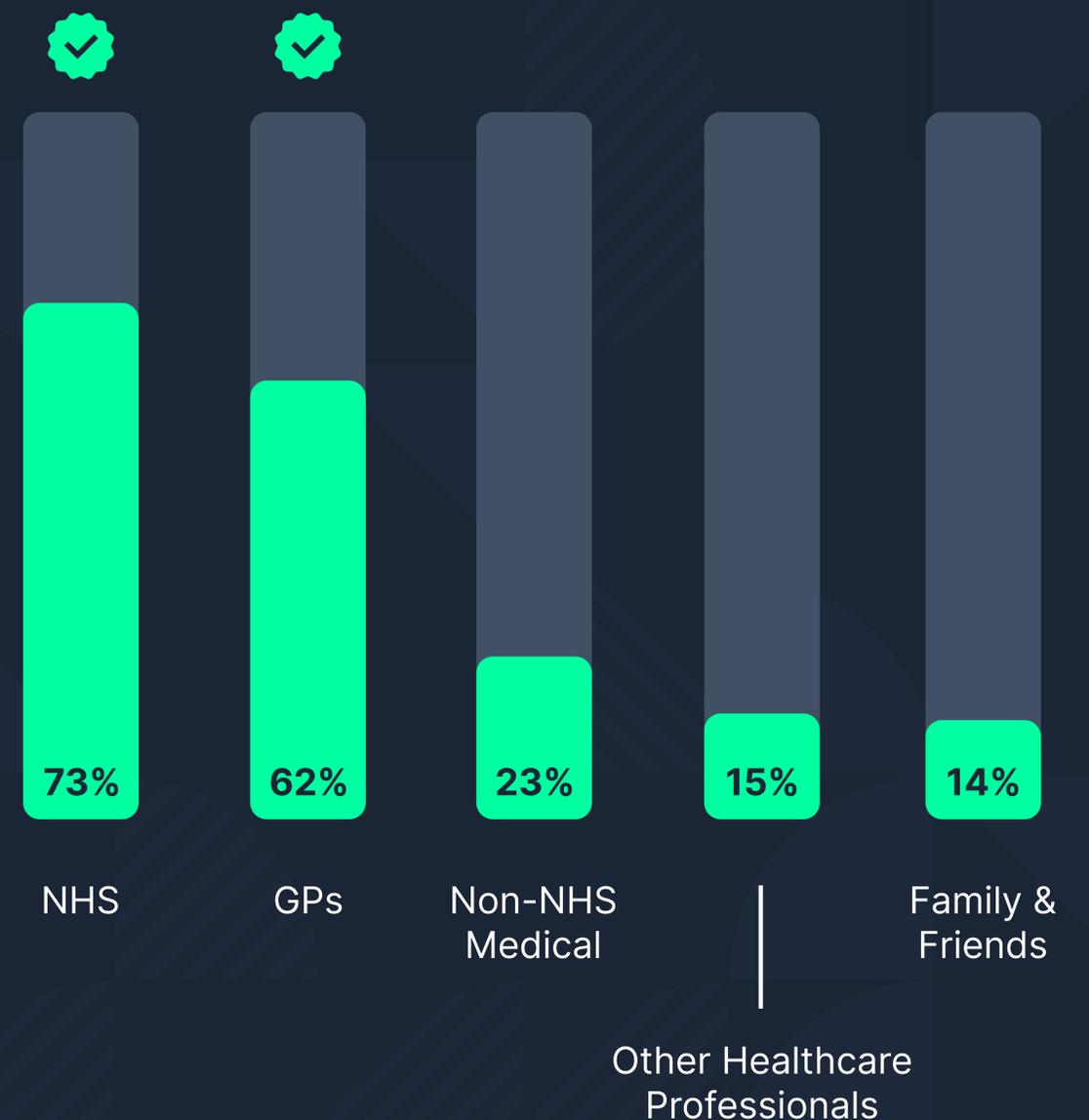
Muslims also rated online sources of information relatively highly, locking down the #1 and #3 most trusted sources with the NHS website and other medical sites respectively. Arab Muslims preferred online sources 11% more than the Muslim population more generally.

Black Muslims were more than a third less likely than other Muslims to consult GPs when looking for medical information, with only 42% reaching out compared to 62% of the overall Muslim population. This effect was especially strong among younger Muslims. In the 18-24 age bracket, this effect was especially stark, with only 29% of Black Muslims reaching out to their GPs.

Whilst younger Muslims tended to use online sources more, older Muslims were more likely to turn to family and friends – around 2 times more than those younger than 35. This was particularly pronounced within the South Asian community.

Muslims highlighted trust as the main factor for why they chose a source of healthcare information.

## Muslims are more likely to trust mainstream, verified sources



# Attitudes towards health research

**A large majority of Muslims think that health research is important, with 86% stating it's very important.** This is in line with the general population whereby an NHS study found that 83% of the population think health research is very important<sup>4</sup>.

There were limited differences between ethnicities, age and gender but the overall sentiment was consistent across Muslims - most results are clustered within a range between 82% and 90% of Muslims surveyed. In terms of ethnicity, the lowest proportion of Muslims that deemed health research very important was Indian Muslims at 82%, and the highest was Asians Muslims of other ethnic origin at 92%.

The strongest trend was generational - younger Muslims rated health research as more important than those older than them. 90% of those aged 18-24 rated health research as very important, compared to 79% of those aged over 45. Most of the rest (19%) still saw health research as fairly important however.

# Participation in health research

## 22% of Muslims have previously taken part in health research.

The UK has a thriving health research environment. Each year, more people take part in research studies<sup>5</sup> and medical research remains one of the top five causes supported by British people through charitable donations<sup>6</sup>.

Public participation in health research translates into better care for patients and service users as well as helps to influence policy and practice that aids in advancing healthcare and treatment techniques.

Yet, data on participation of ethnic minorities is inaccurate or not easily available as ethnicity data is not routinely collected in studies including current COVID-19 studies.

There is increasing recognition of the need for health research to be more representative of the general population, which includes ethnic minorities. Ethnic inequalities in health and social care have been well documented in published research, becoming even more prevalent during the COVID-19 pandemic where it became clear that individuals ethnic minority groups were disproportionately affected by the coronavirus infection<sup>7</sup> emphasising the need for need to obtain good quality research information from these groups<sup>8</sup>.

22% of Muslims from our sample have previously taken part in health research. Those from a professional medical background or had genetic diseases present in themselves and/or their families were more likely to participate in health research compared to their counterparts. Muslims aged between 35-44 were also most likely to have taken part in health research before at 27%, whilst Arab Muslims had the highest participation in health research compared to all Muslim ethnic groups, at 33%.

Those who had taken part in health research gave a range of reasons for taking part. Some participated because they were paid for it whilst others were 'aware of how beneficial the information is in order to improve healthcare'. Most said they wanted 'to support scientific developments' as many worked in the field so were 'passionate about research' and thus understood the importance of establishing 'new innovation and better targeted services and care'. Many answered that they felt it was their 'duty' to do so to benefit their 'community', 'medical development' and 'advancements' as well as participating for 'the greater good it may bring society'. This relates to Muslims mentioning that they would attain spiritual benefits from participating, citing their 'duty' as Muslims to help others and increase knowledge.

## Muslims view health research positively and a large proportion are open to participating.



**90% of whom said they had taken part in health research before would do so again.**

Almost 70% of Muslims said that they have not taken part in health research. Muslim men were less likely to have taken part in health research before, as 72% of them responded 'no' compared to 67% of Muslim women. Of those that had not participated in health research before, Bangladeshi Muslims were least likely out of all ethnic groups to have not participated, at 74%.

# Willingness to participate in health research

**Muslims generally had a positive response to participating in health research, with 56% saying they would be willing to take part in health research if asked to do so.**



61% of Indian Muslims and Asian Muslims of other ethnic origin stated they would participate in health research if asked to do so. Muslim men overall were more likely to participate at 59% compared to 54% of Muslim women. Muslim women were also more likely to be uncertain about participating as 34% said they were unsure if they would participate in health research.

Black Muslims were least likely to take part, at 20.9%. This ethnic group was also the highest (35.8%) to have expressed uncertainty regarding their participation in health research.

This is consistent with findings from NHS Race & Health Observatory, which looked at 12 papers and studies related to attitudes to help-seeking in which Black African and Caribbean individuals stated that a prevalent reason for their lack of willingness to participate was due to racism, healthcare professionals not understanding what racism is, and its subsequent negative impact on participating or help-seeking<sup>9</sup>.

There was a significant difference between each age group's willingness to participate. Older Muslims aged 45 and above were more likely to be willing to participate in health research, at 61%. 53% and 50% of younger Muslims aged 18-24 and 25-34 were willing to participate, and 35% and 30% were unsure, respectively.

When asked about why respondents might be unwilling to participate in health research if offered to do so, 81% of respondents had concerns about the risk of taking part in medical research and felt like they did not know enough about what is involved in health research to take part. 62% of respondents chose lack of time as the reason for their unwillingness. Interestingly, 76% of respondents who were unwilling to participate in health research stated that they do not know enough about what is involved in health research to take part.

Muslim men were more concerned about the risks of taking part in medical research as were Muslims aged 25 and above and Muslims of African or Caribbean descent, whilst older Muslims stated lack of time as their reason for not participating. A majority of Arab Muslims and Indian Muslims would not trust those doing the research to have their best interests at heart compared to Pakistani Muslims and Muslims of mixed, English or other ethnicities felt uninformed about health research procedures therefore highlighting a lack of educational awareness amongst those ethnic groups.

The differences between each minority group's reasons, as well as the variance of willingness amongst different age groups, suggests there are a multitude of barriers to participation and that ensuring full representation of different ethnic groups is not just a case of encouraging individuals to take part.

Cultural competency – the importance of understanding, communicating and interacting with people from across and within cultures – is a key aspect of participation in health research. There is also a responsibility that health care researchers and staff should approach each ethnic minority group with bespoke appropriate solutions to promote appropriate engagement and inclusion at all stages of health research.

# Increasing ▲ research participation

**Muslims would be more likely to participate in health research if they were familiar with the institution conducting the research, if the research study had been reviewed by a research ethics committee and if the study benefited the development of medicine in society more broadly.**

More Muslim women prioritised familiarity with the institution as their main factor that would encourage their participation compared to Muslim men. All ethnic groups apart from Black African, Black Caribbean and Asian Muslims of other ethnic group had high confidence in participation if health research study was conducted by an institute they were familiar with, such as the NHS or medical universities. Black African and Caribbean Muslims gained confidence in participation if the study had been reviewed by a research ethics committee whilst Asian Muslims of other ethnicities would be more likely to participate if the health study benefitted themselves or their family.

Interestingly, Muslims tended to select factors based on positive collectivist outcomes as opposed to individualistic reasons. This suggests that whilst a majority of Muslims may not have previously participated in health research, there is a strong foundation on which ethnic minority participation can be built on.

This is in line with the general population. Research by the NHS found that a vast majority of respondents indicated high levels of confidence to take part in health research if they knew it had been funded by the public sector including the NHS and been reviewed by a research ethics committee<sup>10</sup>.

To improve participation in health research, it is vital that inter and intra-cultural and ethnic diversities are considered and explored when designing and reporting research to ensure that research studies serve and represent British communities widely and accurately.

# Data consent

**The majority of Muslims were happy to allow the NHS to use their data for healthcare research, with more than 63% willing to share.** Arab Muslims were especially open to the idea, with more than 72% trusting the NHS with their data in this way.

On the other hand, Black Muslims were less likely to share their data, with less than 55% willing to turn it over to the NHS. Not being able to trust that their data would be kept safe or that it would be used for the right causes was a common concern; in the words of one young black woman from our sample, 'I don't trust organisations to use your data only in the way you agree to, i.e they may sell your info; data leaks'.

Black Muslims were not alone here. Of those who had explicit concerns, themes of trust, confidentiality, data misuse, and data security were common. Specifically, fears revolved around personal data being made public and/or being sold on to third parties, with a substantial number of respondents specifically citing that as a concern.



**More than a fifth of Muslims don't trust that their data will be held securely by any institution, highlighting how important the issue is to the community.**

While the NHS were relatively well trusted, with 55% of Muslims vouching for them, pharmaceutical companies and the Government were almost universally distrusted, with less than 6% and 15% of Muslims trusting them with their data respectively.

Muslim men are more free with their data than Muslim women, with 59% of Muslim men were willing to give their consent to the NHS to use their data for healthcare research, as compared to 51% of Muslim women. When it came to other institutions, this pattern holds up, with more men trusting the Government (17% of men to 12% of women), universities (30% to 22%), scientific institutions (27% to 23%), and Muslim-led health organisations (42% to 37%).

As a counterpoint to this, Muslim women and men were roughly as likely to be unwilling to share their data with any institutions, 24% of women compared to 23% of men. This suggests that women were more discriminating with who they trust their data with, rather than being opposed to sharing it on principle. This might be because historically medical research has discriminated against women with female medical conditions understudied and dismissed by doctors and researchers. It might also be because society has attached more stigma to basic female bodily functions, making it more risky for women to have their personal medical information leaked.

Older Muslims, especially those over the age of 45, were more likely to trust institutions with their data across the board. Less than 20% were completely unwilling to share their data, compared to 30% of 25-34 year olds. Older Muslims were also more likely than the overall population to trust the Government (26% to 14%), the NHS (67% to 55%), scientific institutions (29% to 21%), and pharmaceutical companies (10% to 6%).

# Attitudes to Genomics

Most Muslims have a **positive attitude** towards Genomics research and development



68%



28%



4%

Studies of genetic diseases are generally largely based on European ancestry, with ethnically diverse people being massively underrepresented. This has largely been attributed to institutional biases, a lack of engagement from Muslims, and perhaps more mistrust in science and development more broadly.

However, our survey found that one in five Muslims tend to be familiar with DNA, genetics or genomics, with most viewing the study and research of DNA, genetics or genomics in healthcare positively.

22% of Muslims stated they are familiar with DNA, genetics or genomics. This is broadly similar to the general population, where around 25% of people in the UK are familiar with genetics/genomics<sup>11</sup>. Clearly, more work needs to be done to engage the general public on genomics, but our findings suggest Muslims are similar to the mainstream.

Whilst familiarity was fairly consistent across age and gender, there was reasonable divergence amongst ethnicities. Just 14% and 15% of Bangladeshi and Indian Muslims were familiar with genomics, compared to 33% of Arabs, and 34% of ethnicities in the “Other” category – mostly comprised of Mixed and White populations.

The proportion of Muslims slightly familiar with Genomics saw even more divergence, with 33% and 35% of Indians and Black Africans respectively were slightly familiar compared to 58% of Asian Muslims of other ethnic origin and 50% of Arabs.

Most Muslims have a positive attitude towards Genomics research and development, with 68% of Muslims viewing the study and research of DNA, genetics or genomics in healthcare positively (40%) or slightly positively (28%). The data suggests a positive correlation between familiarity with genomics and attitude – Muslims familiar with genomics were more likely to view the study and research of genomics as positive. One study of the general population found that around 82% of respondents were positive about using genome editing to treat life-threatening conditions, and 73% were positive about its use for non-life-threatening conditions. The difference in questions, and sample representation, means the two studies can not be directly compared but this does provide a useful indication that Muslims attitudes to genomics are broadly in line with the general population.

Again, gender and age differences were negligible but there were substantial differences in opinion across ethnicities. Asian Muslims of other ethnic origin (47%) and Black African (45%) Muslims were more likely to have a positive attitude to Genomics whilst Indians and Bangladeshis were least likely to have a positive attitude towards Genomics at 30% and 34% respectively.

# Genomics information seeking behaviour

**When seeking information about genomics, Muslims mostly trusted mainstream, verified sources.** 55% said they'd turn to the NHS website, followed by their GP (41%) and healthcare professionals (28%). The most important reason respondents noted for their chosen information source was trustworthiness and reliability. Some respondents noted that they preferred to access sources that had been verified and written by experts in the field such as scientists, doctors. Accessibility and ease of use was the second reason identified by respondents.

12% of respondents relied on family and friends although this was largely in cases whereby the respondent's family members were doctors, or health professionals themselves.

A minority of respondents (3%) went to religious figures although this was largely to enquire about Islamic rulings whilst the detailed, scientific knowledge was accessed from more mainstream sources.

Some respondents were more likely to trust sources of information they deemed independent, with limited incentive for financial gain.

<b>Trust</b>	33.33%
<b>Reliable</b>	25.61%
<b>Accessibility</b>	24.39%
<b>Easy to use</b>	8.54%
<b>Convenient</b>	3.25%
<b>Written by scientists</b>	2.85%
<b>Independent</b>	1.22%
<b>No financial gain</b>	0.81%

# Genetic research

**4% of Muslims have taken part in genetic research and 80% of respondents highlighted a need for trust and transparency to increase engagement with Muslims in genetic research.**

Although only a small sample of our respondents had taken part in genetic research, we found that Arab Muslims (8%) were twice as likely to take part as Pakistani and Bengali Muslims. Indian Muslims and Black Muslims were least likely to take part with only 1% and 2% of respondents, respectively, taking part in genetic research.

Similar to general health research, 83% of Muslims had a positive sentiment towards genetic studies. This pattern was fairly consistent – 60% of Muslims had similar views regarding health research and genetic research, suggesting any lessons learnt from increasing engagement with health research can be applied to genomics research. Younger Muslims were more likely to view genomics research similarly to healthcare with 65% of 18–24-year-olds, and 70% of 25–34-year-olds having similar views, compared to about 50% of Muslims 35+. There was limited difference in opinion between ethnicities.

A survey conducted by the Health Research Authority found that 25% of the public did not feel confident that their data would be held securely in health research. However, over 80% of the Muslims in our study raised this as one of their main concerns as to why they are cautious in taking part in this type of research. Muslims have a distrust in healthcare due to how they have historically been treated, many comments include “trust is something we lack in our community. This needs to be rectified before expecting more trust for research like this amongst our communities”.



**When it comes to taking part in genetic research, over 80% of Muslims are concerned about data security, compared to 25% of the overall population.**

# Recommendations

72% of Muslims were interested in, and 74% were hopeful about where developments in science and technology are heading. Clearly, Muslims are very engaged with health research and recognise its benefits - it is therefore for the scientific community to increase engagement with Muslims in order to improve representation in health and genetic research.

The most important step identified by respondents to increase Muslim engagement in health research is raising awareness about the benefits and importance of genetic research alongside FAQs, followed by how to get involved. This was encouraged via social media infographics, short videos in different languages given the ethnically diverse nature of the Muslim population, local events at mosques and University Islamic Societies or using personal stories and anecdotes to debunk health myths.

Other suggestions include ensuring that the research is conducted by Muslims, collaborations with Islamic scholars and Muslim-led organisations, and providing incentives. Given Muslims tend to value collectivist factors when it comes to participating in research, engaging with the community is essential to ensuring Muslims are reached by the scientific community.

Finally, a common factor in almost all answers was the need for trust and transparency between the organisation carrying out the research and those participating. This is particularly pertinent given more than a fifth of Muslims don't trust that their data will be held securely by any institution. Scientific institutions, especially those outside of the NHS, need to gain the trust of the Muslim community, and ensure they can demonstrate individual's data will be held securely, particularly given the current political context.

# Sample Splits

Age	Weighted Sample (Responses)
18 - 24	33% (333)
25 - 34	19% (196)
35 -44	22% (217)
45+	26% (261)

Gender	Unweighted Sample (Responses)
Female	60% (605)
Male	39% (396)
Prefer not to say	0.7% (7)

Ethnicity	Weighted Sample (Responses)
Bangladeshi	25% (254)
Pakistani	33% (329)
Indian	11% (108)
Black African	8% (84)
Arab	5% (48)
Asian Other	6% (59)
Other	12% (129)

NHS Regions	Weighted Sample (Responses)
London	40% (405)
Midlands	17% (175)
North West	14% (139)
North East & Yorkshire	10% (100)
South East	8% (81)
East of England	4% (45)
South West	3% (27)
Wales	2% (19)
Scotland	2% (16)

# References

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