

Survey of the general public: attitudes towards health research 2017

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National Institute for Health Research

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Foreword

The Health Research Authority (HRA) and National Institute for Health Research (NIHR) are committed to strengthening UK health research culture in ways that ‘protect and promote the public interest’.

As organisations we actively involve and engage the public. The NIHR has an expectation that research partners support this approach, while the HRA places public involvement as a central requirement of research projects receiving ethical approval. There is now increasing evidence of the beneficial impact public involvement and engagement has on research excellence. In future, we anticipate that there will be very little research done in the UK that has not benefited from public insight and experience.

Understanding public attitudes to research is an important component of this work, informing research policy and practice. Tracking attitudes over time can identify issues where further effort is needed to build a relationship of trust with the ultimate beneficiaries of research – patients, carers and the public. While we have both carried out surveys in the past, this is the first time we have jointly commissioned a survey of the public, demonstrating how high it sits on both organisations’ agendas.

We welcome the fact that this year’s survey once again highlights the public’s strong support for health research and their high level of confidence in the way research is conducted. The vast majority of people continue to be confident their data would be held securely if they take part in a research study. Knowing that research has involved the public in its design and been reviewed by an ethics committee increases people’s confidence in a study.

The survey showed people associate research in the NHS with access to better quality of care. But our survey also found that most people did not believe or were not aware of research taking place in their local hospital. This suggests much more needs to be done to raise public awareness of research in the NHS if people are not to miss out on the opportunity to test potentially better treatments as part of their care.

In view of its contribution to life sciences and the health and wealth of the nation, it is of concern that the pharmaceutical sector is viewed more negatively than other funders of research. However, for one-third of people, confidence in the pharmaceutical industry increases if they know it works closely with the NHS. It is a glimmer of light as to how the reputational issues of this sector might be addressed in the future. Further work is clearly needed.

The most important theme in this public attitudes work is the less positive perception of research among lower socio-economic groups and ethnic minorities. Only 35% of ethnic minority respondents believe they would be treated with dignity and respect in research compared to 52% of white respondents. And only 26% of ethnic minority respondents were very confident about the security of their data compared to 37% of white respondents.

Such negative perceptions are a potential barrier to these groups in our society accessing and taking part in research that could enhance their life chances and those of their family, friends and neighbours. The knock-on consequences for health research, its relevance to our increasingly diverse population, and its ability to produce outcomes that people want and need is an issue requiring urgent and collective action by all research organisations. We are in agreement that this work will be a priority for both our organisations in the coming years, and something we will be raising with stakeholders and partners.



Simon Denegri
NIHR National Director for Patients
and the Public in Research



Teresa Allen
Interim Chief Executive
Health Research Authority

Executive Summary

1. This executive summary shows the top-line findings of a survey conducted by Ipsos MORI and commissioned by the Health Research Authority (HRA) and the National Institute for Health Research (NIHR). Face-to-face interviews were held with 1,014 adults aged 15 years or more across the UK.
2. 83% of respondents said that health research is very important.
3. There were a number of statistically significant differences in responses from different subgroups related to ethnicity, social class and working status. For example, 52% of white respondents were very confident that they would be treated with dignity and respect if they took part in a health research study in the UK compared with 35% of ethnic minorities. Similarly confidence levels varied by socio-economic group; 59% of those in social class AB were very confident in health research as opposed to 39% of those in social class DE. Educational level also had a significant impact on confidence; 56% of people who had completed a degree or higher were very confident in comparison with just 36% of people with no formal qualifications. These variations in confidence by demographic characteristics occur throughout the survey.
4. 91% of respondents said that they would be confident that they would be treated with dignity and respect if they were asked by their doctor to take part in a health research study in the UK. This compares with 82% in 2013 and 89% in 2014.
5. A similar rise in confidence was also found in relation to sharing patient data. In 2013 72% respondents said that they would be confident that their personal data would be held securely if they were asked by their doctor to take part in a health research study in the UK; by 2017 this had risen to 80%. In 2013, 26% said they would not feel confident whereas by 2017 this figure had dropped to 18%.
6. 83% of all respondents would be confident about taking part in a health research study if they knew that it had been reviewed by a Research Ethics Committee.
7. Involving patients in helping to ensure that clear information is given to participants in a health research study can help to increase confidence in a study; 52% of respondents said that involving patients in this way would increase their confidence in a study. However 43% said it would not impact on their confidence in a study either way.

8. Respondents have the greatest confidence in health research funded by the public sector including the NHS, closely followed by research funded by major health charities. Respondents had less confidence in health research studies undertaken by the pharmaceutical industry. This difference in opinion by funder has been consistent since our first survey in 2013.
9. Knowing that pharmaceutical companies work closely with the NHS in running research studies increased the confidence in 38% of respondents in studies funded by the pharmaceutical industry. This percentage has grown significantly since 2013 (26% in 2013 and 30% in 2014).
10. 48% of respondents think that patients receive a better quality of care if the hospital they attend also carries out research into new medicines or treatment of patients.
11. 44% of respondents think that patients receive a better quality of treatment if the hospital they attend also carries out research into new medicines or treatment of patients.
12. When asked if their local NHS hospital currently offer patients and carers the opportunities to take part in health research, only 22% said yes. 32% said opportunities were not offered and almost half did not know.
13. Respondents were asked to suggest future topics for research from a menu of items. 58% of respondents favoured 'improving the quality of care/services people receive' followed by:
 - developing new drugs and treatments (56%)
 - devising ways to prevent ill-health (49%)
 - understanding the underlying causes of ill-health (49%).
14. Awareness of the NIHR has grown slightly from 17% in 2014 to 20% in 2017, whilst awareness of HRA is steady at 18%. Just to put this in context, a fictitious organisation in the same list achieved an awareness level of 14%.

Introduction

The HRA and the NIHR commissioned Ipsos MORI to conduct a general public omnibus survey in 2017 to understand the range of opinions held by the public about health research. The survey built heavily on [previous general public omnibus surveys](#).

The results of the three surveys are shown side by side in this report for easy comparison. The findings from this general public survey will be used to enable the HRA to make informed decisions on the strategy for the management of health and social care research in the UK. It will also inform the NIHR's future strategy on public involvement, engagement and participation, building on the work that is already underway.

Methodology

On behalf of the HRA and the NIHR, Ipsos MORI interviewed 1,014 adults across England, Scotland and Wales as part of an omnibus survey. All interviews were carried out by Ipsos MORI interviewers in-home, using CAPI (Computer Assisted Personal Interviewing) based on a representative sample.

The respondents were all aged 15 years or older and the survey was confined to England, Scotland and Wales. The fieldwork was undertaken in the general public omnibus commencing 12 April 2017. The data were weighed by the region, social grade, age, working status and gender to make the survey results representative of the adult population. The weighted demographics of the survey respondents are shown in appendix 1. The questions that people were asked are shown in appendix 2.

Statistical Analysis

The sample has not been randomly drawn, it has been selected to be representative of the population. With a sample size of 1,014 the margin of error is plus or minus 3.2% at a 95% confidence level. This means that if the survey shows, for example, that the answer to one question is 50%, we can be 95% confident that the true answer in the wider population is 50% plus or minus 3.2% (that is between 46.8% to 53.2%).

In the report findings we describe differences between sub-groups in gender, age, social class etc. The report notes where differences between sub-groups are statistically significant; this means the difference is not likely to have happened according to chance. We have indicated this by stating the difference is significant at $p=0.05$ or less; this means there is a one in 20 probability of this difference being according to chance.

Survey Findings

Where the same question has been asked in previous years, the results from all relevant years are shown. Some additional questions were asked solely in 2014 or 2017 and so only data for that year is shown.

Public confidence in health research

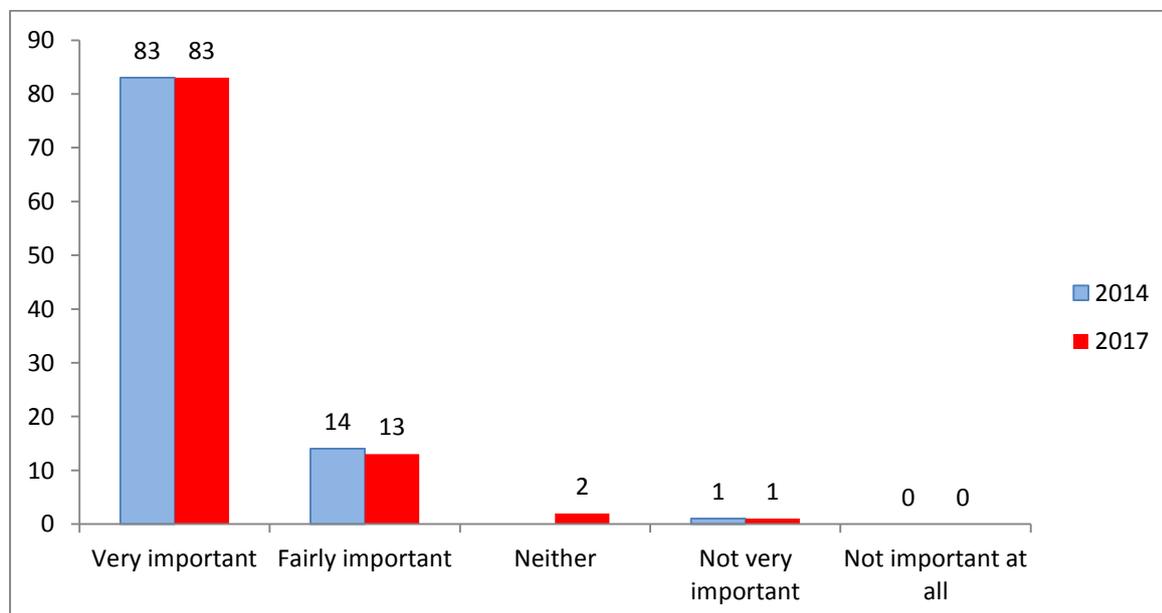
Q1. How important do you think health research is?

Table 1 - Importance of health research

	2014 %	2017 %
Very important	83%	83%
Fairly important	14%	13%
Neither		2%
Not very important	1%	1%
Not important at all	*	-
Don't know	1%	-
Total	100%	100%
Base:	1,324	1014

*less than 1%

Figure 1 – Importance of health research (2014 vs 2017)



In 2017 96% of respondents regard health research as important. Those in higher social classes or with educational qualifications are more likely to think that health research is very important. 89% of people in social classes AB rate health research as very important compared with 77% of those in DE. Similarly 74% of those with no formal educational qualifications rate health research as very

important in comparison with 86% with a degree or above. There was also a significant difference by ethnicity with 84% of white respondents rating health research as very important compared with 75% of ethnic minorities.

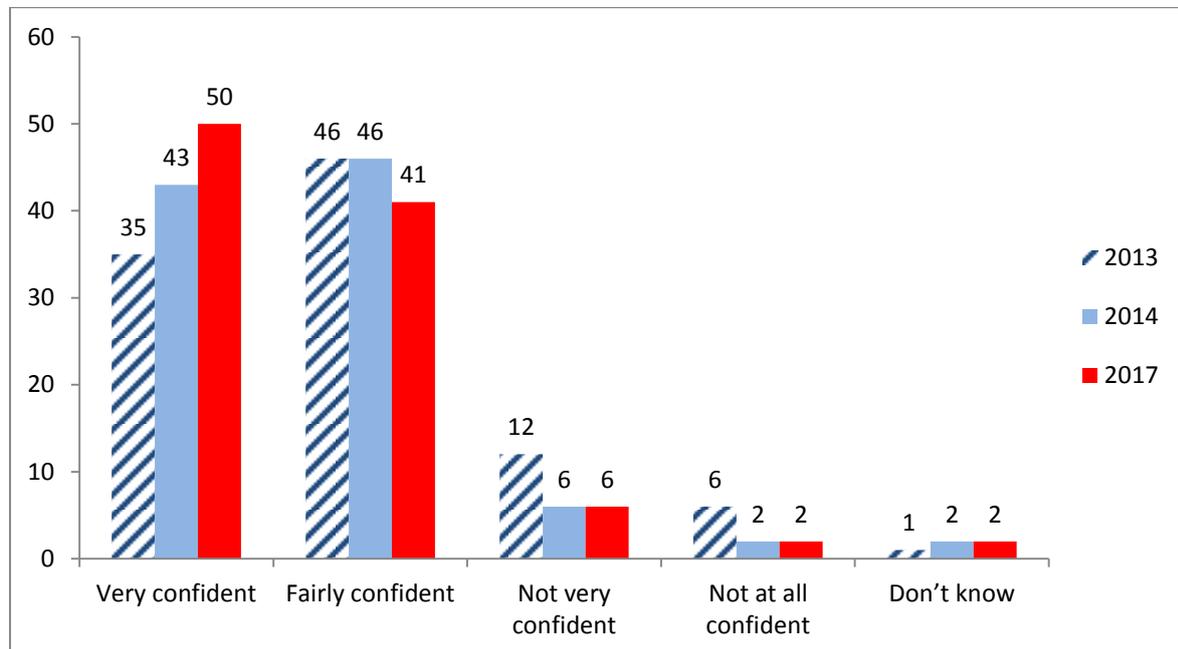
All respondents were asked two questions about their confidence in taking part in a health research study; the first focusing on dignity and respect and the second concerned the security of personal data.

Q2. If you were asked by your doctor in the NHS to take part in a health research study in the UK how confident would you be, if at all, that you would be treated with dignity and respect?

Table 2– Confidence that you would be treated with dignity and respect

	2013	2014	2017
Very confident	35%	43%	50%
Fairly confident	46%	46%	41%
Not very confident	12%	6%	6%
Not at all confident	6%	2%	2%
Don't know	1%	2%	2%
Total	100	100	100
Base:	1295	1324	1014

Figure 2– Confidence that you would be treated with dignity and respect



In 2017 91% were confident that they would be treated with dignity and respect (50% were very confident and 41% were fairly confident). 8% did not have confidence; with 6% saying they were not very confident and just 2% were not confident at all. Overall confidence has grown since 2014 and

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the growth of those stating that they would be very confident has grown significantly from 35% in 2013 to 50% in 2017.

Although overall confidence in being treated with dignity and respect is high, there are significant variances. There were wide variations by social class, with people in social class AB being more likely to express confidence about the way they would be treated. 59% of those in social class AB were very confident as opposed to just 39% of those in social class DE. Similarly only 36% of people with no qualifications were very confident compared with 56% of people with a degree or above. People aged 55-64 years were the most confident that they would be treated with dignity and respect.

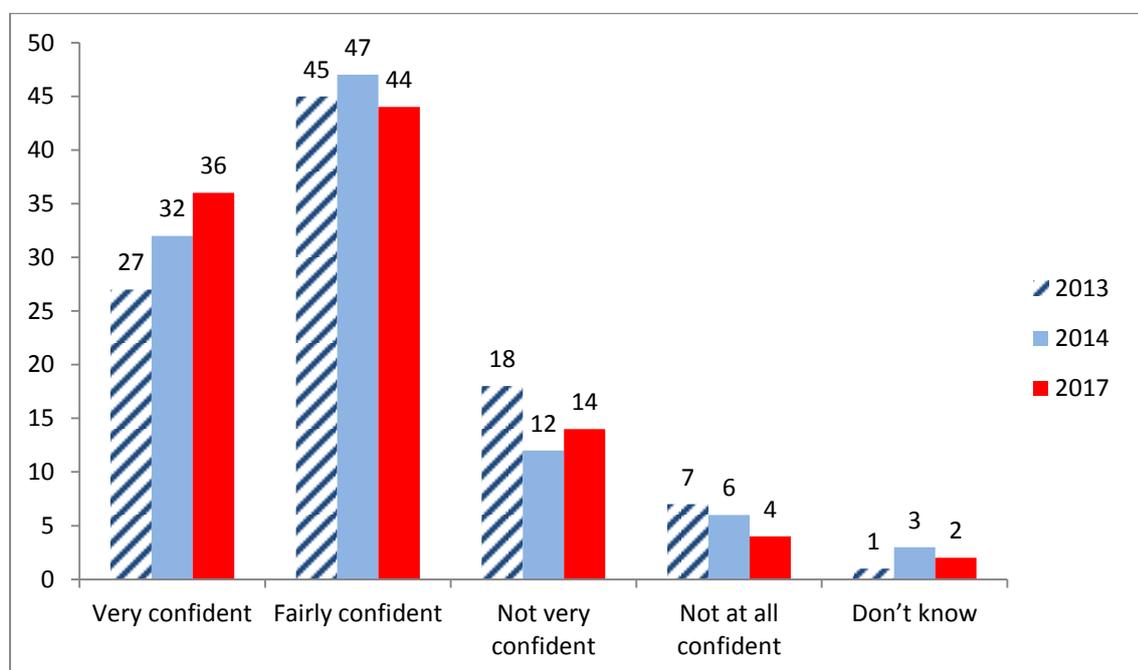
Confidence that they would be treated with dignity and respect varies by ethnicity, with white respondents being more likely to have confidence that they would be treated with dignity and respect than respondents from an ethnic minority. 52% of white respondents were very confident that they would be treated with dignity and respect compared with just 35% of ethnic minorities. This difference was statistically significant at $p=0.05$.

Q3. If you were asked by a doctor in the NHS to take part in a health research study in the UK how confident would you be, if at all, that your personal data would be held securely?

Table 3 – Confidence that personal data would be held securely

	2013	2014	2017
Very confident	27%	32%	36%
Fairly confident	45%	47%	44%
Not very confident	19%	12%	14%
Not at all confident	7%	6%	4%
Don't know		3%	2%
Total	100	100	100
Base:	1295	1324	1014

Figure 3– Confidence that personal data would be held securely



Confidence that personal data will be held securely has increased over time with four fifths of those surveyed (80%) confident that their personal data would be held securely throughout the study compared with 72% in 2013. Over a third (36%) were very confident and just under half were fairly confident (44%). 18% were not confident; 14% were not very confident and 4% were not confident at all. Confidence that their data would be held securely decreased with age with the highest levels of confidence amongst the 15-34 age group.

Respondents from ethnic minorities were less likely to have confidence that their data would be held securely than white respondents - 26% of respondents from an ethnic minority were very confident as opposed to 37% of white respondents (statistically significant at p=0.05).

Public perception of Research Ethics Committees

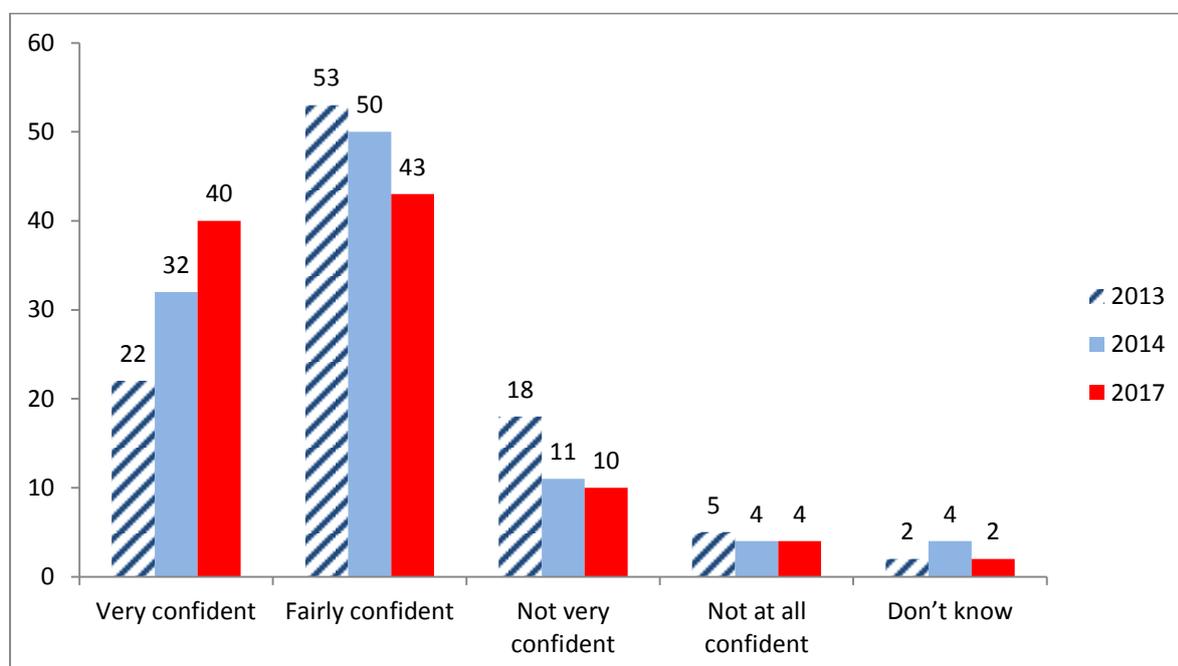
Q4. All health research that involves patients has to be reviewed by an ethics committee before it takes place. An ethics committee is composed of roughly 18 people; two thirds are experts from the NHS and one third members of the public. The aim of the ethics committee is to protect the rights, safety, dignity and wellbeing of patients taking part in a health research study.

If you knew that a health research study had been reviewed by an ethics committee, how confident would you feel about taking part in it?

Table 4 – Confidence in taking part in a health research study, if you knew it had been reviewed by a Research Ethics Committee

	2013	2014	2017
Very confident	22%	32%	40%
Fairly confident	53%	50%	43%
Not very confident	18%	11%	10%
Not at all confident	5%	4%	4%
Don't know	2%	4%	2%
Total	100	100	100
	1295	1324	1014

Figure 4 – Confidence in taking part in a health research study, if you knew it had been reviewed by a Research Ethics Committee



In 2017 83% said they would feel confident about taking part in a health research study if they knew that the study had been reviewed by an ethics committee, similar to 2014. At a more detailed level,

year on year we can see more support for those saying that they are 'very confident'; rising from 22% in 2013 to 40% in 2017. [Public dialogue work](#) supports these findings; people in the workshops commissioned by the HRA¹ (both the general public and patients) expressed confidence in the ethical review of health research studies conducted by Research Ethics Committees.

The number of people expressing a lack of confidence in research reviewed by an ethics committee has fallen since 2013. In 2017 14% said they would not feel confident compared with 23% in 2013. Responses did not vary by age or gender but did change according to social class, ethnicity, working status and income level.

As with other questions in this survey, those in social class AB had a higher level of confidence than those in social class DE. The variation by social class was quite marked with 52% of respondents in social class AB stating that they were very confident compared with just 29% of those in social class DE. This difference was statistically significant at $p=0.05$. Respondents from an ethnic minority were a lot less likely to state that they would be very confident to take part than white respondents (28% of ethnic minorities compared with 42% of whites). This difference was statistically significant at $p=0.05$.

Non-working respondents had lower levels of confidence in research reviewed by an ethics committee than those in work (88% of those in full-time work had confidence in research knowing it had been reviewed by an ethics committee compared with 79% of those not in work).

Similarly there were also significant differences by income, with those in the higher income bands expressing higher levels of confidence in taking part in a study than those in low income bands (47% of those in the highest income band £25K plus said they were very confident compared with 29% of those in the lowest band i.e. less than £6,499).

Patient and public involvement

Patient and public involvement in health research can take many forms, such as:

- suggesting ideas for research
- reviewing research proposals to ensure they are feasible and meet the needs of patients
- informing the development of outcome measures so that they are meaningful to patients
- ensuring that any communication with patients is easily understood.

It was not possible to ask a question about patient and public involvement which covers all these aspects and the question for this survey needed to be one that members of the public could grasp quickly without lots of explanation. Consequently this question focused on the involvement of patients in the design of information for patients in a study.

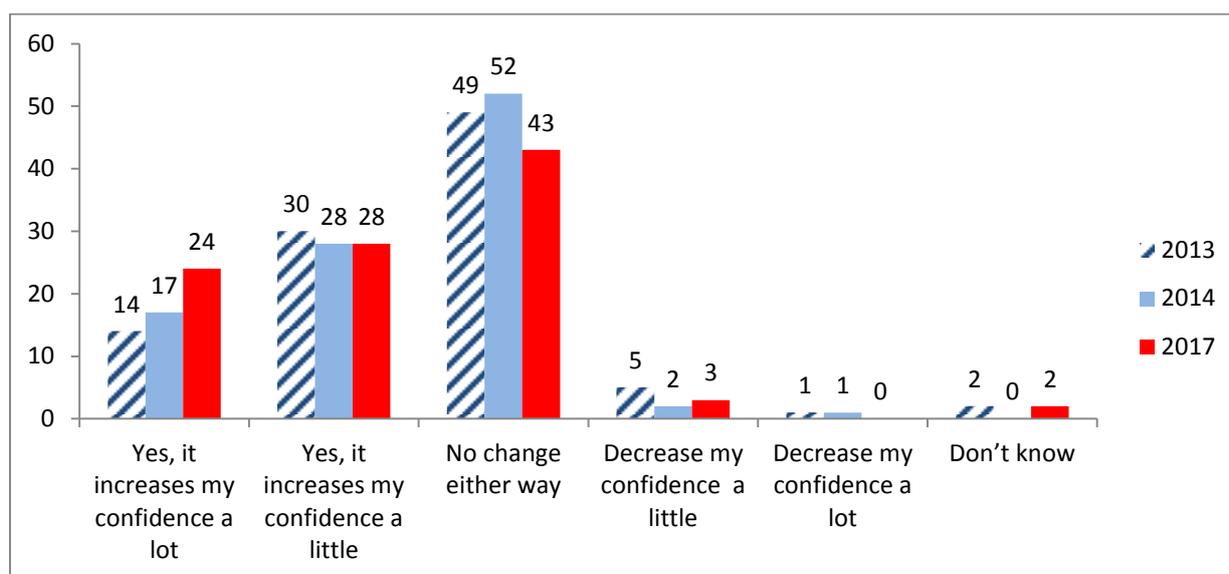
¹ Public dialogue workshops were part funded and supported by [Sciencewise](#).

Q5. Sometimes researchers work with groups of patients who have a particular condition to ensure that the information given to patients in a health research study is easily understandable and meaningful. If you were told that patients had been involved in this way, what impact would this have on your confidence in the study?

Table 5 - Impact of patient and public involvement on confidence in the study

	2013	2014	2017
Yes, it increases my confidence a lot	14%	17%	24%
Yes, it increases my confidence a little	30%	28%	28%
No change either way	49%	52%	43%
Decrease my confidence a little	5%	2%	3%
Decrease my confidence a lot	1%	1%	-
Don't know	2%		2%
Total	100	100	100
Base:	1295	1324	1014

Figure 5 - Impact of patient and public involvement on confidence in the study



52% said knowing about patient involvement would increase their confidence in the study compared with just 3% who said it would decrease their confidence in the study. 43% said it would not impact on their confidence either way.

As before there was no difference by age or gender but the impact on confidence did vary by social class, educational level, ethnicity, and working status.

63% of respondents from social class AB said that knowing that patients had been involved in this way would increase their confidence in the study as opposed to just 45% of those in social class DE. This difference is statistically significant at $p=0.05$.

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Similarly respondents of working status were more likely to state that knowing about patient involvement would increase their confidence in the study than respondents who were not working (88% of those in full-time work versus 79% of those not working). This was statistically significant at $p=0.05$.

The influence of patient involvement on confidence also varied by educational level. Confidence rose with higher levels of education. 62% of those with a degree or higher said knowing about patient involvement would increase their confidence a lot in comparison with 45% of those with no qualifications.

The confidence of white respondents in research was boosted by patient involvement with 26% stating that if they were told about patient involvement in this way, it would increase their confidence in the study compared with 17% of ethnic minorities. This was statistically significant at $p=0.05$.

Public perception of the funders of health research

In the HRA’s public workshops, the participants had largely made negative comments in relation to research conducted by the pharmaceutical industry. The question below was designed to quantify this issue in comparison with other funders of health research.

Q6. To what extent would you feel confident or not about taking part in a health research study if you knew it was funded by:

- a) the public sector including the NHS
- b) a major health charity
- c) a pharmaceutical company.

Survey participants were asked to rate their confidence score out of 10 where 0 means not confident at all and 10 is very confident.

Table 6 – Confidence in taking part in a health research study depending on funding source (2013)

	Public sector Inc. NHS	Medical Health Charities	Pharmaceutical Company
	%	%	%
0 – Not confident at all		5	11
1	2	2	4
2	2	3	6
3	3	4	8
4	4	4	8
5	13	13	20
6	9	8	9
7	15	14	11
8	19	19	9
9	10	10	5
10 - Very confident	18	16	7
Mean score	6.74	6.67	4.95
Don't know	1	1	1
Total	100%	100%	100%

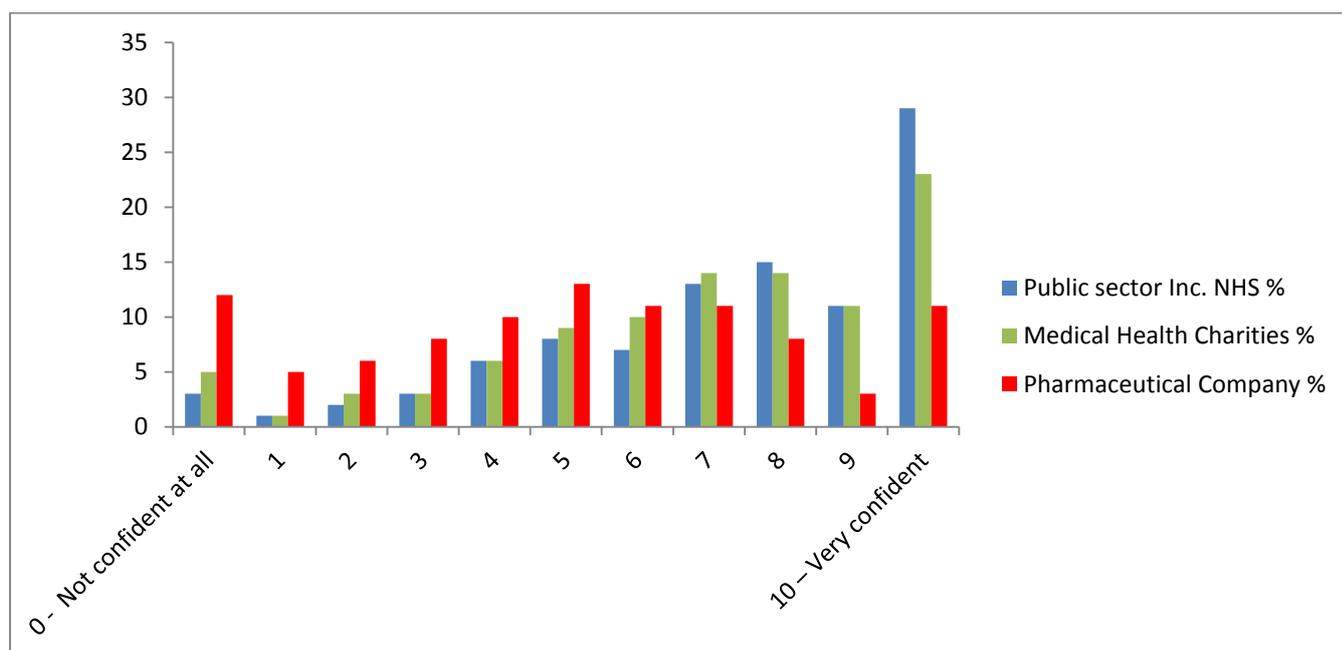
Table 6 – Confidence in taking part in a health research study depending on funding source (2014)

	Public sector Inc. NHS	Medical Health Charities	Pharmaceutical Company
	%	%	%
0 – Not confident at all	3	4	9
1	1	1	2
2	2	1	5
3	2	2	6
4	3	2	8
5	14	15	21
6	10	10	12
7	17	18	13
8	17	17	10
9	10	8	4
10 - Very confident	19	18	8
Mean score	7.03	6.88	5.28
Don't know	3	3	3
Total	100%	100%	100%

Table 6 – Confidence in taking part in a health research study depending on funding source (2017)

	Public sector Inc. NHS	Medical Health Charities	Pharmaceutical Company
	%	%	%
0 - Not confident at all	3	5	12
1	1	1	5
2	2	3	6
3	3	3	8
4	6	6	10
5	8	9	13
6	7	10	11
7	13	14	11
8	15	14	8
9	11	11	3
10 – Very confident	29	23	11
Mean score	7.23	6.89	4.91
Don't know			
Total	100%	100%	100%

Figure 6 – Confidence in taking part in a health research study depending on funding source 2017



In 2017 studies funded by the public sector including the NHS were regarded as the most trustworthy with a mean score of 7.23. Studies funded by a major health research charity achieved a similar level of confidence with a mean score of 6.89. Studies funded by the pharmaceutical industry engendered the least confidence with a mean score of 4.9.

It was clear in public dialogue workshops that the general public were unaware that the pharmaceutical industry works together with the NHS to conduct their clinical trials. The next question was therefore designed to ascertain whether knowing this made a difference to their perception of the research studies funded by the pharmaceutical industry.

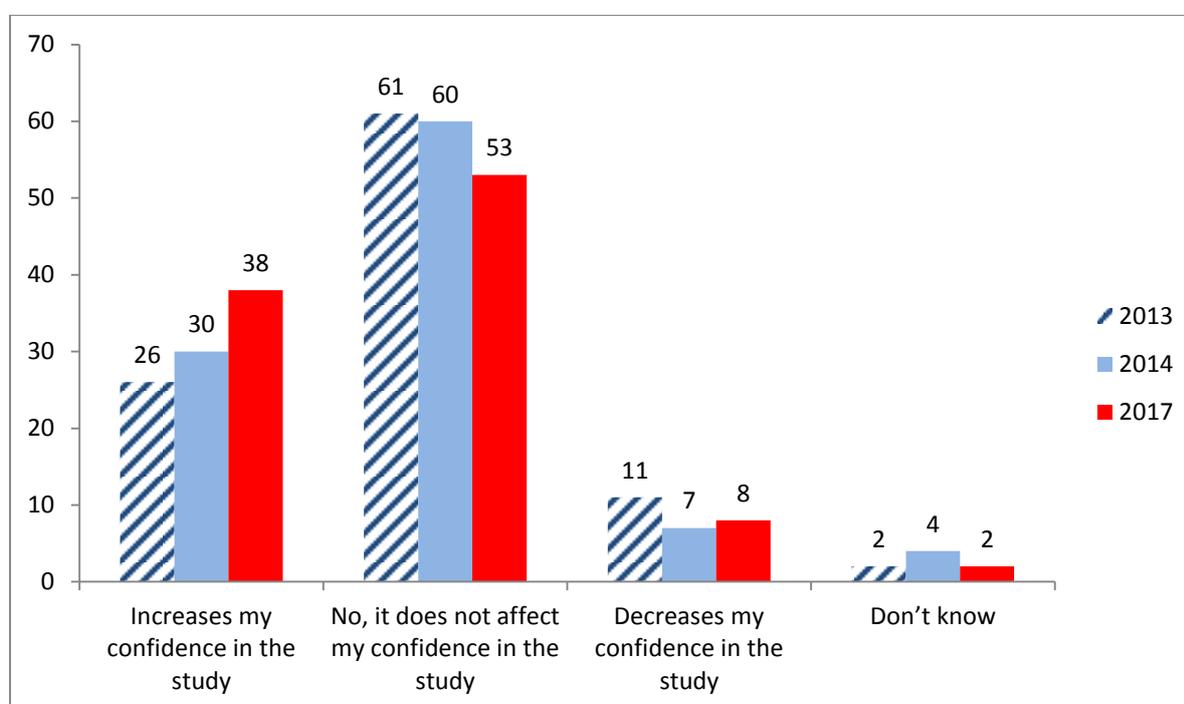
As with previous questions, confidence levels are lowest amongst those in social class DE, those with no formal qualifications and ethnic minorities.

Q7. Most pharmaceutical company research studies with NHS patients take place in NHS settings and are run locally by NHS. Does knowing this make a difference to the way you feel about research funded by pharmaceutical companies or not?

Table 7 – Impact on confidence in research funded by pharmaceutical companies

	2013	2014	2017
Yes, it increases my confidence in the study	26%	30%	38%
No, it does not affect my confidence in the study	61%	60%	53%
Yes it decreases my confidence in the study	11%	7%	8%
Don't know	2%	4%	2%
Total	100	100	100
Base	1295	1324	1014

Figure 7 – Impact of awareness of NHS integration of pharmaceutical studies with NHS on confidence



The majority of people (53% in 2017) upon being informed about NHS involvement in commercially funded studies did not change their opinion about research funded by pharmaceutical companies. However 38% said that knowing about the links with the NHS would increase their confidence. Roughly one in ten cases (10%) thought that knowing about the links with the NHS would decrease their confidence in a study. Over time we can see that the percentage of people who are reassured by demonstrating the link between pharmaceutical companies and the NHS in relation to research funded by the former has increased from 26% in 2013 to 38% in 2017.

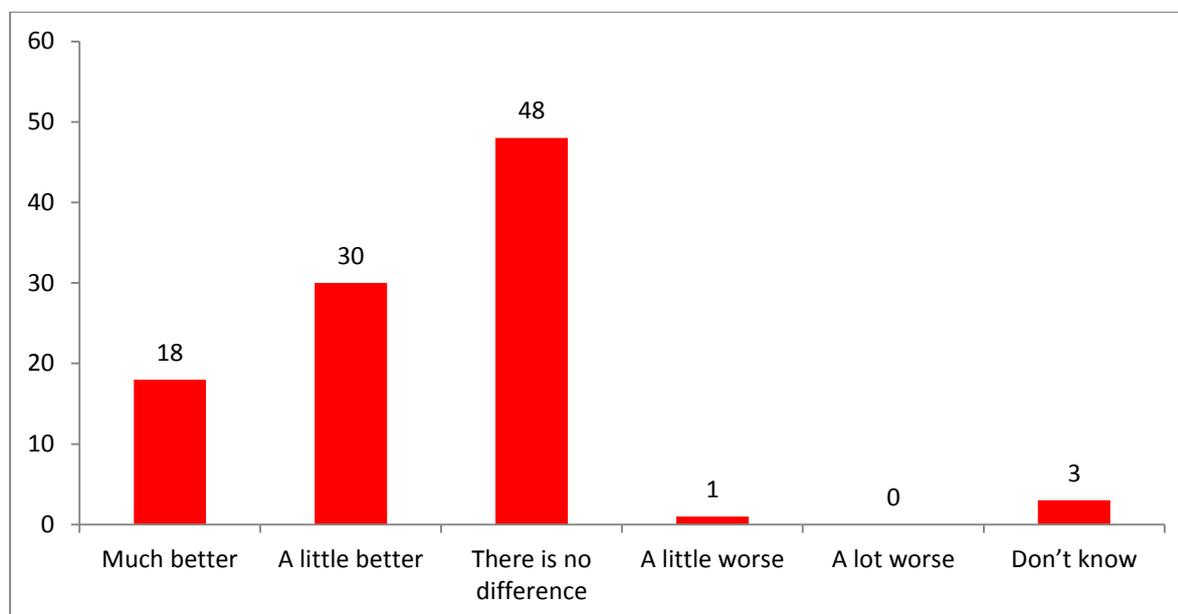
New questions in 2017: perception of research

Q8. Overall do you think that patients receive better or worse quality of care if the hospital they attend also carries out research into new medicines or treatment of patients? Or do you think there is no difference?

Table 8 - Impact of hospital research on patient care

Much better	18%
A little better	30%
There is no difference	48%
A little worse	1%
A lot worse	-
Don't know	3%
Total	100
Base	490

Figure 8 – Impact of hospital research on patient care



Overall we can see that almost half of all respondents (48%) thought that patients would receive better quality of care if the hospital they attend also carries out research into new medicines or treatment of patients. The same percentage thought there would be no difference. Just 1% thought that this might make patient care worse.

Respondents with a degree or above were more likely to think that hospital care would be better if they also carried out research into new medicine than those with GCSEs or A-levels.

Respondents were asked why they thought this was the case and the main reasons given for thinking care would be better were as follows:

- level of expertise/ greater knowledge
- medical research advances medical care/leads to better treatments

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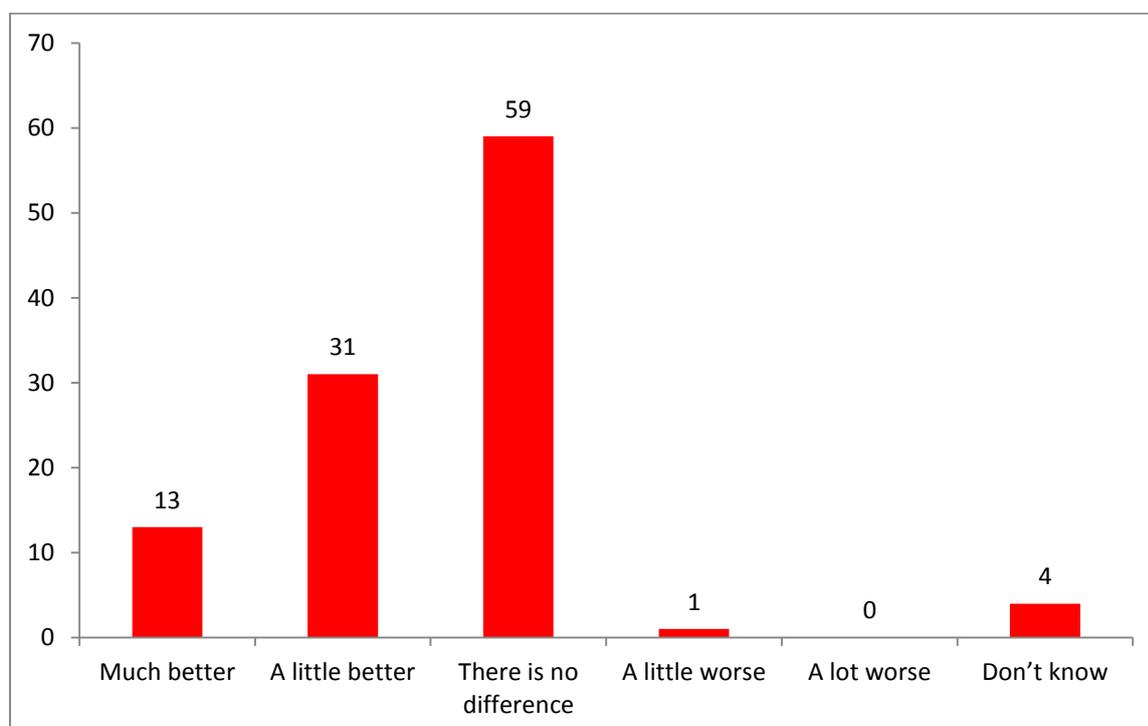
- more interest in/engagement in patient health when research is done
- more treatment options/more up to date treatment
- medical research provides more information
- more funding
- medical research is regulated/monitored
- might have access to new treatments more quickly
- better facilities/technology.

Q9. Overall, do you think that patients receive better or worse quality of treatment if the hospital they attend also carries out research into new medicines or treatment of patients? Or do you think there is no difference?

Table 9 - Impact of hospital research on patient treatment

Much better	13%
A little better	31%
There is no difference	59%
A little worse	1%
A lot worse	-
Don't know	4%
Total	100
Base	524

Figure 9 – Impact of hospital research on patient treatment



This second new question focused on the impact on patient treatment rather than patient care.

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44% thought that patients would receive better quality treatment if the hospital they attend also carries out research into new medicines or treatment for patients. However 59% thought there would be no difference. Again just 1% thought that this might make patient care worse. Overall, respondents thought that a patient attending a hospital where research takes place might lead to better quality of care but were slightly less convinced that this would lead to better treatment.

Views differed according to social class and qualifications. So, for example, the percentage assuming that the quality of treatment would be better if they also carry out research was 56% for social class AB but fell to 36% for social class DE. Similarly 53% of those with a degree or above think quality of treatment would be better compared with 40% of people with GCSEs or no qualifications.

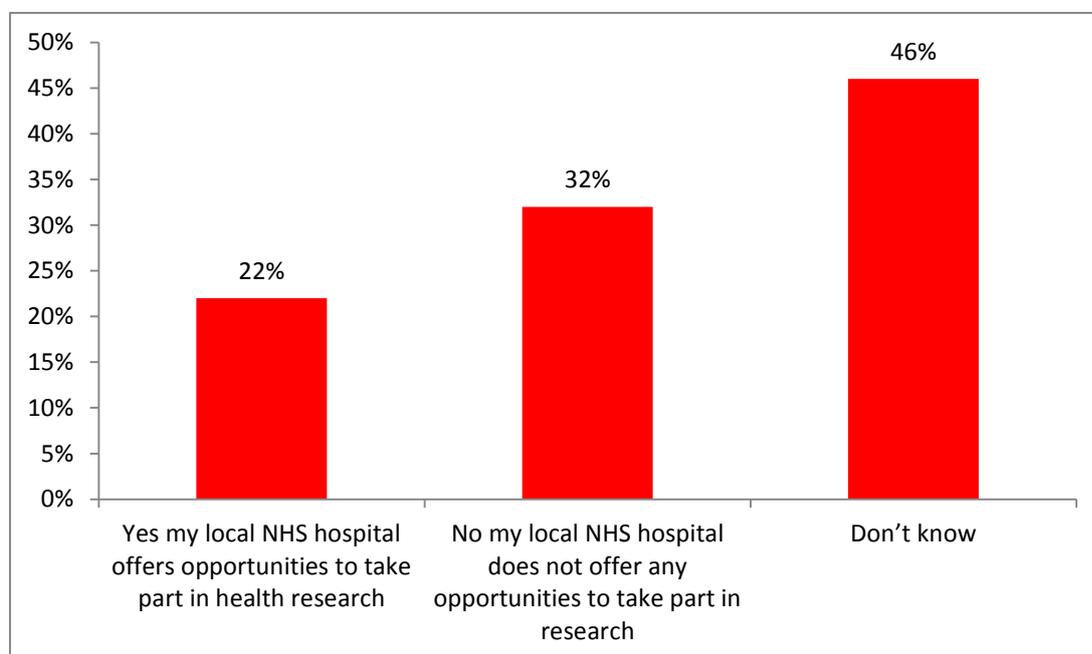
The reasons given for this were similar to those cited in the question above.

Q10. Does your local NHS hospital currently offer patients and carers the opportunities to take part in health research? When we say carers, we mean people caring for someone with a disability or serious impairment.

Table 10 – Does your local hospital offer research opportunities

Yes my local NHS hospital offers opportunities to take part in health research	22%
No my local NHS hospital does not offer any opportunities to take part in research	32%
Don't know	46%
Total	100
Base	1014

Figure 10 – Does your local hospital offer research opportunities



Clearly almost half of all respondents simply did not know if their local hospital offered opportunities to take part in health research and almost a third (32%) thought that no such opportunities were offered. A fifth (22%) thought opportunities to take part in health research were offered and this seems to echo the findings of a survey carried out in 2012 by the NIHR in which 21% of people surveyed were aware that carrying out research was a key activity for the NHS.

Respondents were asked what topics researchers should focus their efforts on. The first four categories listed were pre-coded and shown to the respondents. Respondents were also asked to suggest topics of their own.

Q11. Which, if any, of the following do you think health researchers should focus their efforts in the future?

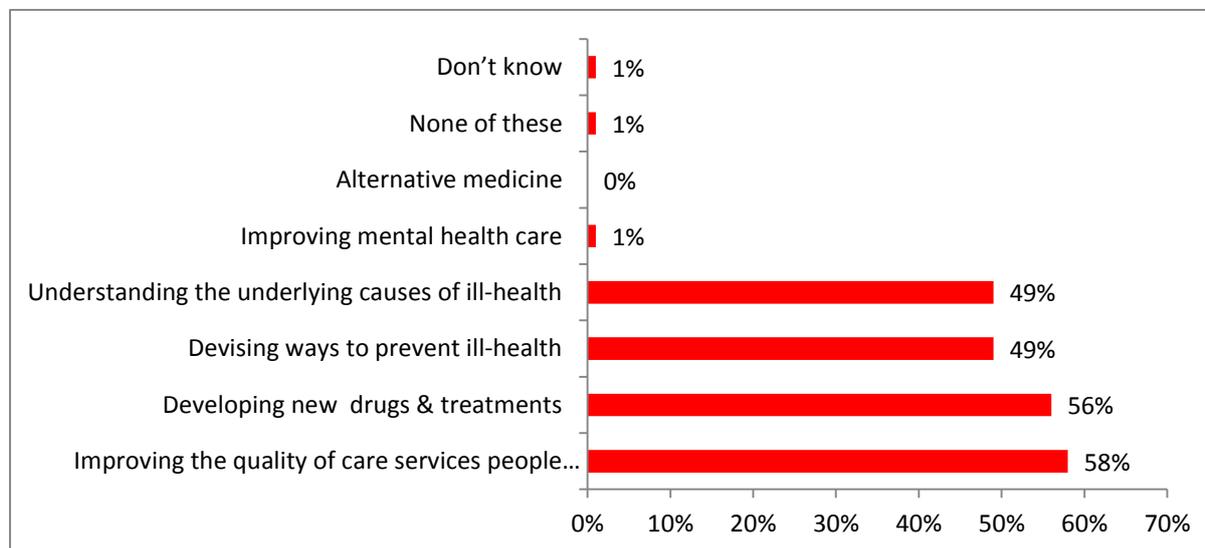
Table 11 – Future focus of research

Improving the quality of care/services people receive	58%
Developing new drugs & treatments	56%
Devising ways to prevent ill-health	49%
Understanding the underlying causes of ill-health	49%
Improving mental health care	1%
Alternative medicine	*
None of these	1%
Don't know	1%
Total	100
Base	1014

*less than 1%

N.B. Respondents were allowed to pick/suggest more than once answer

Figure 11 – Future focus of research



Broadly speaking support for the four proposed categories was roughly similar with 'improving quality of care/ services that people receive. The number of people suggesting other topics was very small with just 1% suggesting mental health and less than 1% suggesting alternative medicine. Respondents in social class AB or with a degree or above were more likely to select or suggest a topic. Respondents from an ethnic minority were significantly less likely to select 'Understanding the underlying causes of ill-health' than white respondents at a statistically significant level.

Awareness of the NIHR and HRA

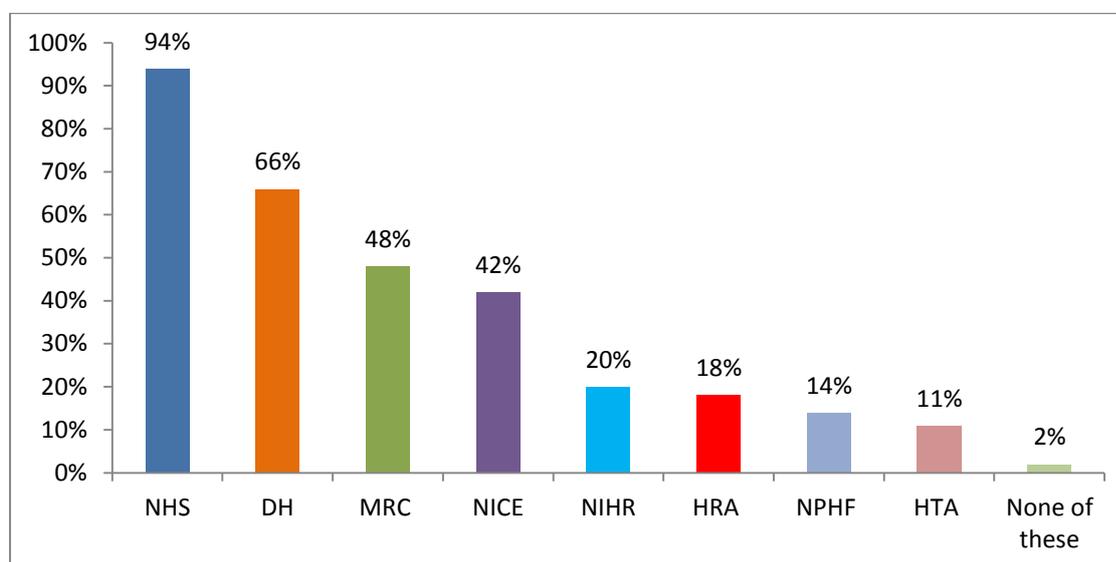
A list of organisations was read out in full to respondents and they were asked which ones they had heard of. It should be noted that one of the organisations on the list (National Public Health Foundation – NPHF) is a made up name. This fictitious name was included to control for respondents falsely claiming to be aware of an organisation.

Q12a. Here are various organisations which deal with health research, which, if any, have you heard of?

Table 12 – Awareness by organisation

Heard of:	2013	2014	2017
NHS (National Health Service)	88%	94%	94%
DH (Department of Health)	61%	71%	66%
MRC (Medical Research Council)	38%	41%	48%
NICE(National Institute of Health and Care Excellence)	33%	38%	42%
NIHR (National Institute for Health Research)	13%	17%	20%
HRA (Health Research Authority)	14%	19%	18%
NPHF (National Public Health Foundation – fictitious)	10%	14%	14%
HTA (Human Tissue Authority)	9%	12%	11%
None of these	7%	3%	2%
Total	100	100	100
Base	1295	1324	1014

Figure 12 – Awareness by organisation 2017



Rank order of the organisations has remained the same over time. The NIHR saw a small increase in recognition at 20% compared with 17% in 2014 and HRA remained broadly similar at 18%. However it should be noted that 14% also claimed to be aware of the National Public Health Foundation (NPHF) which was a fictitious name.

Survey of the general public: attitudes towards health research

In general awareness of most organisations is higher amongst the older age groups, social class AB and those with a degree or above. There was wide disparity in recognition between white respondents and those from an ethnic minority except in relation to the NHS which almost everyone seems to have heard of.

Q12b. The system for approving health research in England is the responsibility of an organisation called the Health Research Authority. Had you heard of the Health Research Authority before today?

Yes	28%
No	72%
Total	100

Q13. How confident, if at all, are you in the way that health research is managed by the Health Research Authority?

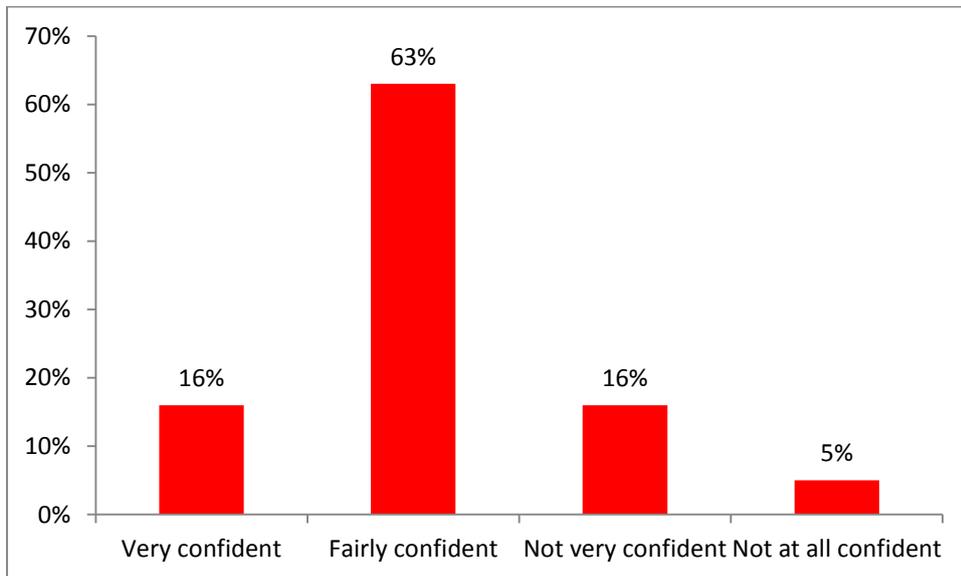
Table 13a – Confidence in the HRA

	2013	2014	2017
Very confident	7%	9%	11%
Fairly confident	51%	40%	44%
Not very confident	19%	10%	11%
Not at all confident	3%	3	3%
Don't know	19%	37%	30%
Total	100	100	100
Base:	1295	1324	1014

Table 13b – Confidence in the HRA (excluding don't knows)

	2013	2014	2017
Very confident	15%	9%	16%
Fairly confident	66%	63%	63%
Not very confident	14.5%	24%	16%
Not at all confident	4.5%	4%	5%
Total	100	100	100
Base:	1048	834	715

Figure 13 – Confidence in the HRA



All respondents were asked how confident they were of the way that the HRA manages health research regardless of whether they were aware of the HRA. Despite low awareness of the HRA, 79% of respondents said that they were confident in the way that health research is managed by the HRA. Roughly one in five (21%) was not confident in the way the HRA manages health research.

It should be noted that confidence in the HRA does not vary according to social class, qualification or ethnic origin.

Conclusions

Overall confidence in health research is high and also appears to have grown consistently since 2013. A large majority of respondents believe they would be treated with dignity and respect if they were invited to take part in a health research study in the UK. Similarly a large majority believe that their personal data would be held securely if they were invited to take part in a clinical trial although a significant minority would not. This was supported by the views derived from the public dialogue workshops where confidentiality of personal data in the NHS was regarded as a given. This was reinforced by public engagement work conducted by Wellcome² which indicates the public have faith in the safety of their health data but do have concerns about the security of their personal data in other spheres. This emphasises the importance of continuing to communicate the safeguards that are in place around personal information in health research and the NHS in general in order for this confidence is to be maintained.

This survey has given the HRA and the NIHR the opportunity to track public opinion over time and explore some of the issues that have been previously identified by the patients and the public. For example, in public dialogue workshops, members of the public commonly show distrust of the pharmaceutical industry but have shown considerable trust in research conducted by the NHS. The survey findings confirm that this view holds for the wider population. Following on from this, it was apparent in the public workshops that most people thought that pharmaceutical research took place in isolation. However as the survey demonstrates when the closer working relationship between the NHS and the pharmaceutical industry is described, levels of confidence increase.

Although respondents could only be given a limited explanation of what a Research Ethics Committee is and what they do in the context of a structured interview survey, knowing that an ethics committee has had a role in review of research boosts public confidence.

The survey demonstrates the impact that demographic differences have on levels of confidence in research. Confidence in health research was consistently higher amongst those with a degree or higher, those in social class AB and white respondents. Those in lower socio-economic groups, those with no formal qualifications and people from ethnic minorities consistently recorded lower levels of confidence in health research. This finding is reflected in other surveys on the topic of health research³ and has implications for future engagement with different sections of the public and the communication methods employed.

² <http://www.wellcome.ac.uk/About-us/Publications/Reports/Public-engagement/WTP053206.htm>

³ NIHR Public survey OnePoll 2012

Appendix 1

Survey demographics

Gender

The respondents were split almost 51% male and 49% female.

Age

	%
18 – 24	15
25 – 34	16
35 – 44	16
45 – 54	17
55- 64	14
65+	22
Total %	100
Weighted Base	1022

Social Class

	%
AB	26.5
C1	27.5
C2	21
DE	25
Total %	100
Weighted Base	1022

Highest educational level

	%
No formal qualifications	15
GCSE or equivalent	27
A-level of equivalent	20
Degree or above	31
Total %	93
Weighted Base	1022

Survey of the general public: attitudes towards health research

Working Status

	%
Working	56
Not working	44
Total %	100
Base	1022

Ethnicity

	%
White	86
Non-white	14
Total %	100
Base	1022

Working status

	%
Full-time	43.5
Part-time	13
Not working	43.5
Total %	100
Base	1022

Income

	%
Up to £6,499	2.5
£6,500 – 11,499	8
£11,500 – 17,499	9
£17,500 – 24,999	7
£25,000 +	41
Total %	67.5
Base	1022

Disability

	%
Yes	14
No	83
Total %	97
Base	1022

Appendix 2

Ipsos MORI questionnaire

SAMPLE: 1000 Adults aged 15+

I am now going to ask you some questions about health research in the NHS. Health research includes different types of research, for example testing a new medicine or treatment with patients to see how well it works, or research in laboratories, or simple interviews with people or patients in clinics and in the community, to help understand diseases or conditions and how to treat or prevent them.

Health research is carried out by scientists, researchers and NHS staff working in universities, hospitals and institutes. It's paid for by different funders, including the government, medical research charities such as Cancer Research UK or the British Heart Foundation, and pharmaceutical companies.

These scientists and NHS staff are supported by the NHS to conduct their research. This support might be to find the right patients to take part. The following questions are about health research in the UK.

ASK ALL

Q01

How important do you think health research is?

1. Very important
2. Fairly important
3. Neither important nor unimportant
4. Fairly unimportant
5. Not at all important

ASK ALL

Q02

If you were asked by a doctor in the NHS to take part in a health research study in the UK how confident would you be, if at all, that you would be treated with dignity and respect by those undertaking the study?

1. Very confident
2. Fairly confident
3. Not very confident
4. Not at all confident

ASK ALL

Q03

If you were asked by a doctor in the NHS to take part in a health research study in the UK how confident would you be, if at all, that your personal data would be held securely throughout the study?

1. Very confident
2. Fairly confident
3. Not very confident
4. Not at all confident

ASK ALL

Q04

All health research that involves patients has to be reviewed by an ethics committee before it takes place. An ethics committee is composed of roughly 18 people, two thirds are experts from the NHS and one third members of the public. The aim of the ethics committee is to protect the rights, safety, dignity and wellbeing of patients taking part in a health research study.

If you knew that a health research study had been reviewed by an ethics committee, how confident or not would you feel about taking part in the study?

1. Very confident
2. Fairly confident
3. Not very confident
4. Not at all confident

ASK ALL

Q05

Sometimes researchers work with groups of patients who have a particular condition to ensure that the information given to patients in a health research study is easily understandable and meaningful. If you were told that patients had been involved in this way, what impact would this have on your confidence in the study?

1. Increase my confidence a lot
2. Increase my confidence a little
3. Not change it either way
4. Decrease my confidence a little
5. Decrease my confidence a lot

ASK ALL

Q06a

To what extent would you feel confident or not about taking part in a health research study if you knew it was funded by the public sector including the NHS? Please could you give me an answer between 0 and 10 where 0 means that you would not feel at all confident and 10 means that you would feel very confident.

- 0 Not at all confident
- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10 Very confident

ASK ALL

Q06b

To what extent would you feel confident or not about taking part in a health research study if you knew it was funded by a medical research charity? Once again, please could you give me an answer between 0 and 10 where 0 means that you would not feel at all confident and 10 means that you would feel very confident.

0 Not at all confident

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9

10 Very confident

ASK ALL

Q06c

To what extent would you feel confident or not about taking part in a health research study if you knew it was funded by a Pharmaceutical company (that makes and sells medicines)? Once again, please could you give me an answer between 0 and 10 where 0 means that you would not feel at all confident and 10 means that you would feel very confident.

0 Not at all confident

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9

10 Very confident

ASK ALL

Q07

Most pharmaceutical company research studies with NHS patients take place in NHS settings and are run locally by NHS doctors. Does knowing that they take place in NHS settings make a difference to the way you feel about health research studies funded by Pharmaceutical companies, or not?.

1. Yes, it increases my confidence in the study
2. Yes, it decreases my confidence in the study
3. No, it does not affect my confidence in the study

ASK ALL – SPLIT HALF SAMPLE V1a – c.500

Q08

Overall, do you think that patients receive better or worse quality of care if the hospital they attend also carries out research into new medicines or treatment of patients? Or do you think there is no difference?

1. Much better
2. A little better
3. There is no difference
4. A little worse
5. A lot worse

ASK ALL – SPLIT HALF SAMPLE V1b – c.500

Q09

Overall, do you think that patients receive better or worse quality of treatment if the hospital they attend also carries out research into new medicines or treatment of patients? Or do you think there is no difference?

1. Much better
2. A little better
3. There is no difference
4. A little worse
5. A lot worse

ASK ALL

Q09b

Why is that?

ASK ALL

Q10

Does your local NHS hospital currently offer patients and carers the opportunities to take part in health research?

When we say carers, we mean people caring for someone with a disability or serious impairment.

1. Yes, my local NHS hospital offers opportunities to take part in health research to patients or carers
2. No, my local NHS hospital does not offer any opportunities to take part in health research to patients or carers.

ASK ALL

Q11

Which, if any, of the following do you think health researchers should focus their efforts in the future?

1. Developing new drugs and treatments
2. Improving the quality of care services people receive
3. Devising ways to prevent ill-health
4. Understanding the underlying causes of ill-health
5. Other (please specify)

ASK ALL

Q12a

Here are various organisations which deal with health research. Which, if any, have you heard of before today?

1. DH (Department of Health)
2. HRA (Health Research Authority)
3. HTA (Human Tissue Authority)
4. MRC (Medical Research Council)
5. NHS (National Health Service)
6. NICE (National Institute for Health and Care Excellence)
7. NIHR (National Institute for Health Research)
8. NPHF (National Public Health Foundation)

ASK ALL

Q12b

The system for approving health research in England is the responsibility of an organisation called the Health Research Authority. Had you heard of the Health Research Authority before today?

1. Yes
2. No

ASK ALL

Q13

How confident, if at all, are you in the way that health research is managed by the Health Research Authority?

1. Very confident
2. Fairly confident
3. Not very confident
4. Not at all confident