

# Survey of the general public: attitudes towards health research

Author: Amanda Hunn



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## Executive Summary

1. This executive summary shows the top-line findings of a survey conducted by Ipsos MORI and commissioned by the HRA. Face-to-face interviews were held with 1,295 adults aged 18 years or more across England.
2. 82% 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.
3. 74% all 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. 25% said they would not feel confident.
4. 77% 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.
5. 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; 44% of respondents said that involving patients in this way would increase their confidence in a study. However 49% said it would not impact on their confidence in a study either way.
6. 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.
7. Knowing that pharmaceutical companies work closely with the NHS in running research studies increased the confidence in 27% of respondents in studies funded by the pharmaceutical industry. However it had no impact on the 61% of respondents.
8. 33% of respondents would be very happy for their GP to access their patient records to see if they might be suitable to join a health research study. 25% would be very happy for a hospital consultant to access their records and 18% would be very happy for an NHS doctor who does not provide their care but is doing research to access their records.

## Introduction

The Health Research Authority (HRA) has an ambitious programme of work to streamline and simplify the research approval process. The approval system covers all types of health research that involves patients across England including clinical trials. It is important for the HRA to understand public attitudes towards health research. The HRA has already commissioned a series of public dialogue workshops which were facilitated by Ipsos MORI. In addition the HRA has conducted a number of dialogue workshops with patients and Phase 1 participants. Both the patient and public dialogue workshops were supported and funded by Sciencewise.<sup>1</sup> The results of this patient and public dialogue work can be found on the HRA website at [www.hra.nhs.uk/](http://www.hra.nhs.uk/)

This survey has enabled some of the findings which had emerged from the public dialogue workshops to be quantified in the wider population. The findings from this survey and the public dialogue work will be used to enable the HRA to make informed decisions on the strategy for the management of health research in the UK.

## Methodology

Ipsos Mori was commissioned by the HRA to conduct a face to face survey of the general public. Ipsos MORI interviewed 1,295 people on behalf of the HRA as part of a wider omnibus survey. All interviews were carried out by Ipsos MORI interviewers in-home, using CAPI (Computer Assisted Personal Interviewing). The Ipsos MORI Capibus is a weekly, face-to-face omnibus survey of a nationally and regionally representative sample.

The respondents were all aged 18 years or more and the survey was confined to England. The fieldwork was undertaken in the week commencing 12 April 2013. The data were weighed by the region, social grade, age, working status, tenure and ethnicity of adults in England. The weighted demographics of the survey respondents are shown in the appendix.

It should be noted that Questions 11 – 13 on who can access patient records to identify suitable people to join a research study were repeated with a different sample of the general public from 30<sup>th</sup> August to 5<sup>th</sup> September 2103 with three additional options for comparison. This is explained in more detail in the findings section. The repeated questions were administered by Ipsos-MORI to a sample of 868 people across England.

Details of the MRI Capibus survey can be found at: <http://www.ipsos-mori.com/omnibusservices/capibus.aspx>

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<sup>1</sup> The UK's national centre for public dialogue in policy making involving science and technology issues. Visit [www.sciencewise-erc.org.uk](http://www.sciencewise-erc.org.uk) for more information and guidance.

## Statistical Analysis

Although the sample has not been randomly drawn, it has been selected to be representative of the population. With a sample size of 1,295 the margin of error is plus or minus 2.9% at a 95% confidence level. This means that if the survey shows, for example, that the answer to one response is 50%, we can be 95% confident that the true answer in the wider population is 50% plus or minus 2.9% (that is between 47.1% to 52.9%).

In the report findings we describe differences between sub-groups in gender, age, social class etc. The report notes where differences between sub-groups as 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. Where  $p = 0.05$ , this means there is a one in 20 probability of this difference being according to chance. Where the probability is shown as a figure smaller than  $p=0.05$ , the likelihood of the difference being due to chance is even lower.

## Survey Findings

### Public Confidence in Health Research

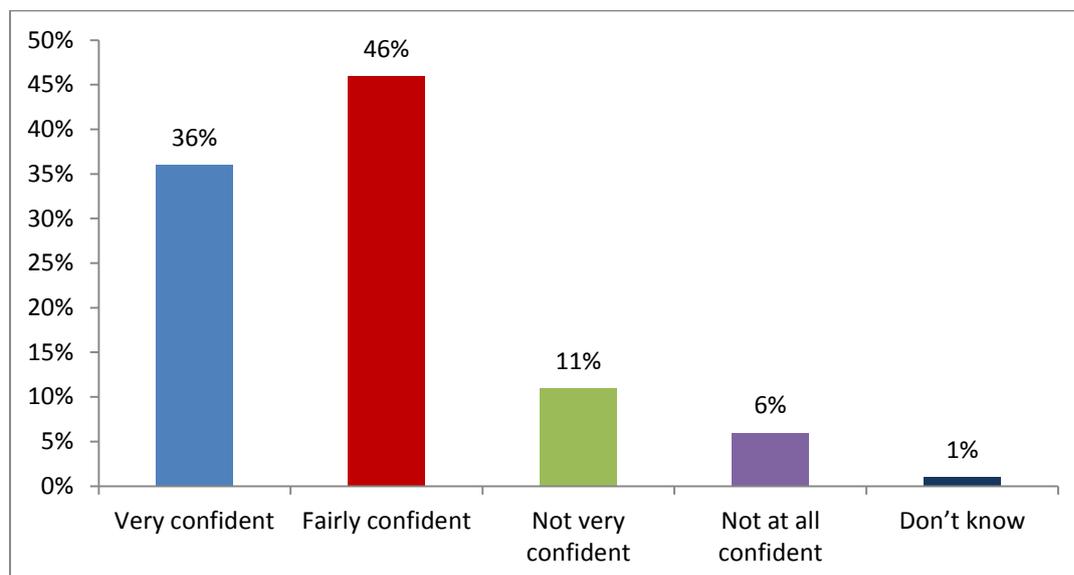
All respondents were asked two questions about their confidence in taking part in a health research study; the first focusing on dignity and respect and the second concerned the security of personal data.

**Q1 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 1– Confidence that you would be treated with dignity and respect**

	No.	%
Very confident	467	36%
Fairly confident	593	46%
Not very confident	138	11%
Not at all confident	79	6%
Don't know	18	1%
Total	1295	100

**Figure 1– Confidence that you would be treated with dignity and respect**



82% were confident that they would be treated with dignity and respect (36% were very confident and 46% were fairly confident). 17% did not have confidence; with 11% saying they were not very confident and 6% were not confident at all.

People aged 55-64 years were the most confident that they would be treated with dignity and respect. The variation by age group is statistically significant at  $p=0.002$ . Social class also correlated with confidence, with people in social class AB being more likely to express confidence about the way they would be treated. There was also a significant difference by ethnicity, with white respondents being more likely to have confidence that they would be treated with dignity and

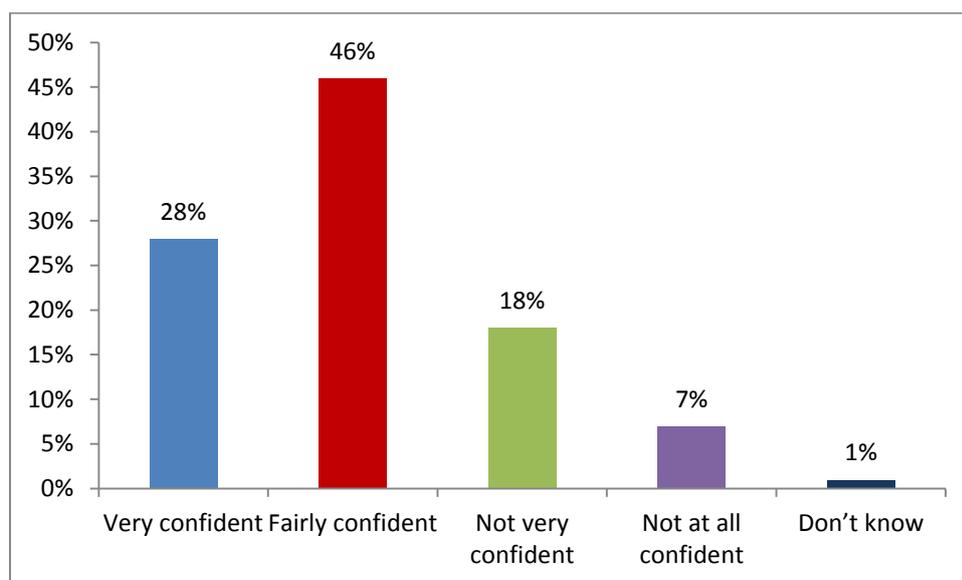
respect than non-white respondents. 38% of white respondents were very confident that they would be treated with dignity and respect compared with just 23% of non-white respondents. This difference was statistically significant at  $p=0.000$ .

**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 your personal data would be held securely?**

**Table 2 – Confidence that personal data would be held securely**

	No.	%
Very confident	359	28%
Fairly confident	596	46%
Not very confident	236	18%
Not at all confident	88	7%
Don't know	15	1%
Total	1295	100

**Figure 2– Confidence that personal data would be held securely**



Almost three quarters of those surveyed (74%) were confident that their personal data would be held securely throughout the study; over a quarter (28%) were very confident and just under half were fairly confident (46%). One in four (25%) were not confident; 18% were not very confident and 7% were not confident at all.

Respondents from higher social classes are most likely to have confidence that their data would be held securely (sig at  $p= 0.001$ ); 34% of respondents in social class AB were very confident that their data would be held securely compared with 25% of those in social class DE. Non-white respondents were less likely to have confidence that their data would be held securely than white respondents - 22% of non-white respondents were very confident as opposed to 29% of white respondents (sig at  $p=0.05$ ).

## Public perception of Research Ethics Committees

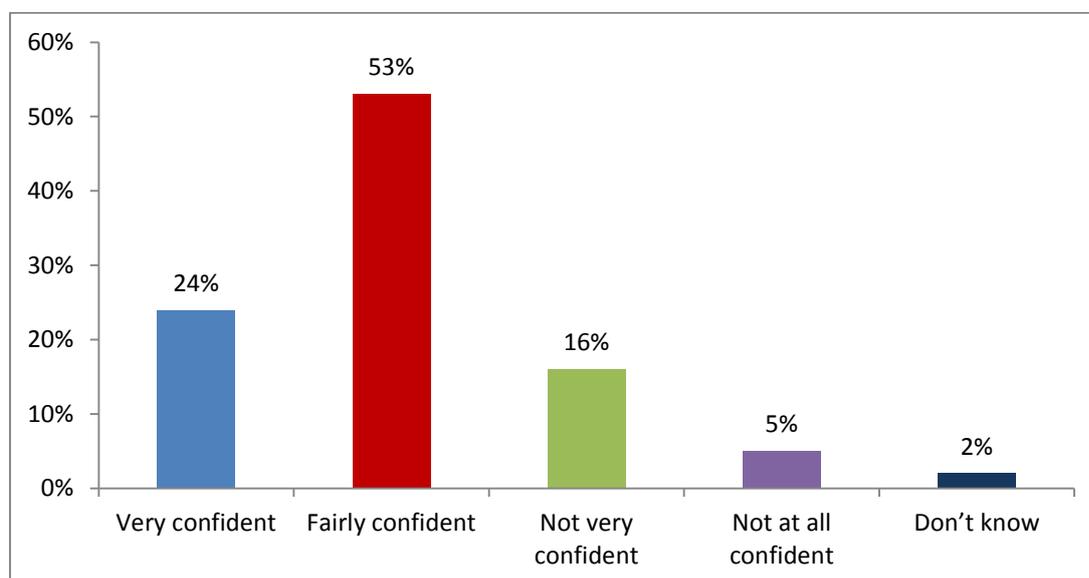
**Q3 All health research that involves patients has to be reviewed by an ethics committee before it takes place. An ethics committee is composed of roughly 18 people; two thirds are experts from the NHS and one third members of the public. The aim of the ethics committee is to protect the rights, safety, 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 3 – Confidence in taking part in a health research study, if you knew it had been reviewed by a Research Ethics Committee**

	No.	%
Very confident	309	24%
Fairly confident	681	53%
Not very confident	213	16%
Not at all confident	69	5%
Don't know	24	2%
Total	1295	100

**Figure 3– Confidence in taking part in a health research study, if you knew it had been reviewed by a Research Ethics Committee**



Just over three quarters of all respondents (77%) 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. Recent public dialogue work supports these findings; people in the workshops (both the general public and patients) expressed confidence in the ethical review of health research studies conducted by Research Ethics Committees.

Approximately one in five (21%) said they would not feel confident. Responses did not vary by age or gender but did change according to social class and ethnicity. As with other questions in this

survey, those in social class AB had a higher level of confidence that those in social class DE. The variation by social class was quite marked with 37% of respondents in social class AB stating that they were very confident compared with just 16% of those in social class DE. This difference was statistically significant at  $p=0.000$ . Non-white respondents were a lot less likely to state that they would be very confident to take part than white respondents (11% compared with 26%, respectively) This difference was statistically significant at  $p=0.000$ .

Respondents with internet access were also more likely to show a higher level of confidence in taking part in a health research study if it has been approved by a Research Ethics Committee; 25% of those with internet access said they would be very confident in taking part compared with just 15% of those without internet access.

## 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.

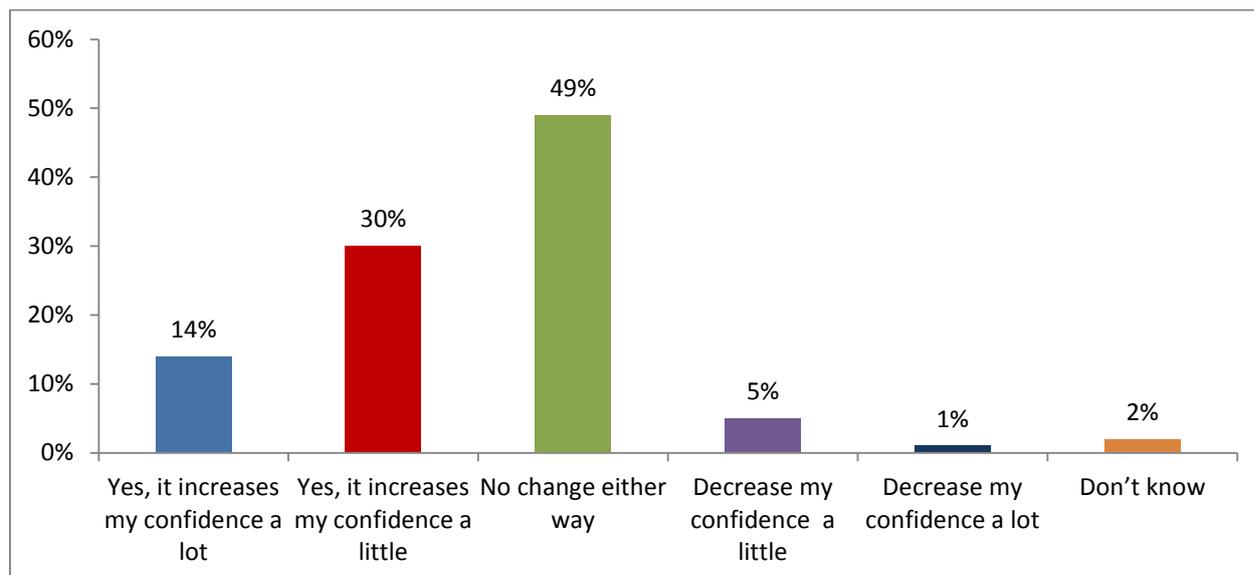
It was not possible to ask a question about patient and public involvement which covers all these aspects and the question for this survey needed to be one that members of the public could grasp quickly without lots of explanation. Consequently this question focused on the involvement of patients in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

**Q4 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 4 - Impact of patient and public involvement on confidence in the study**

	No.	%
Yes, it increases my confidence a lot	176	14%
Yes, it increases my confidence a little	385	30%
No change either way	639	49%
Decrease my confidence a little	60	5%
Decrease my confidence a lot	13	1%
Don't know	22	2%
Total	1295	100%

**Figure 4 - Impact of patient and public involvement on confidence in the study**



44% said knowing about patient involvement would increase their confidence in the study compared with just 6% who said it would decrease their confidence in the study. Just under half (49%) 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, ethnicity, working status and internet access.

55% 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 36% of those in social class DE. This difference is statistically significant at  $p=0.000$ . Similarly respondents of working status were more likely to state that knowing about patient involvement would increase their confidence a lot in the study than respondents who were not working (17% of those in work versus 10% of those not working). This was significant at  $p=0.000$ .

Non-white respondents were particularly dismissive of patient involvement in the study with 14% stating that if they were told about patient involvement in this way it would decrease their confidence in the study compared with 4% of white respondents. This was significant at  $p=0.000$ .

Respondents with internet access were much more positive about the impact of patient involvement on their confidence in a study than those without internet access. 15% of those with internet access said that knowing about patient involvement would increase their confidence a lot compared with just 5% of those with no internet access.

## Public Perception of the funders of health research

In the 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.

**Q5 To what extent would you feel confident or not about taking part in a health research study if you knew it was funded by:**

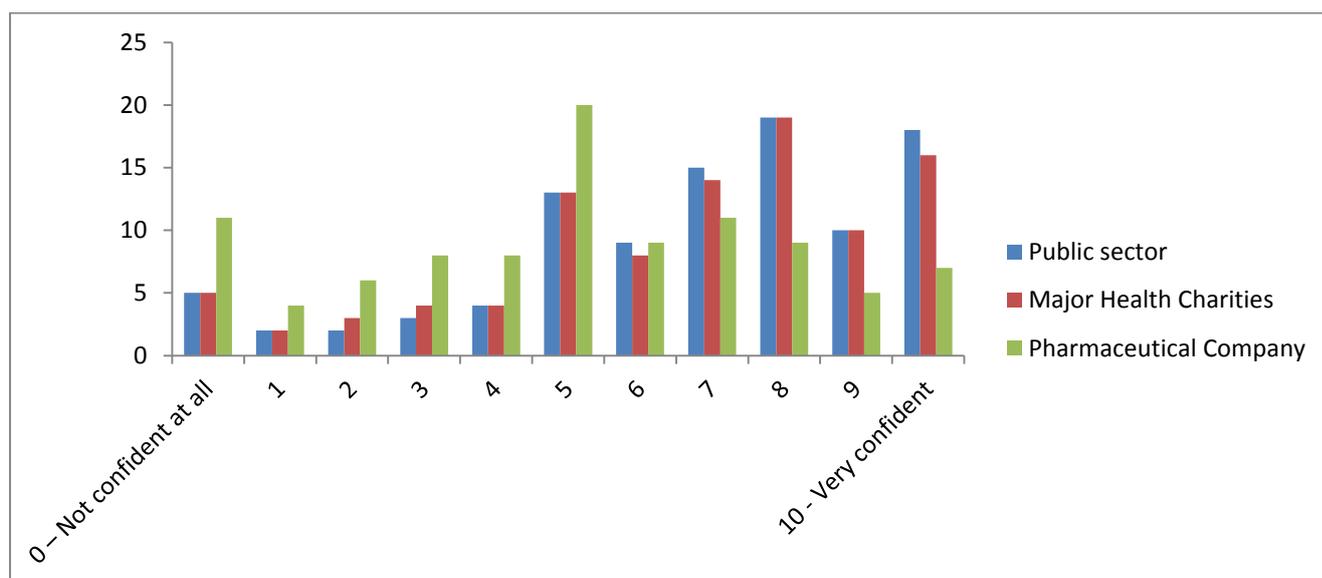
- a) the public sector including the NHS
- b) A major health charity
- c) A pharmaceutical company.

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 5 – Confidence in taking part in a health research study depending on funding source**

	Public sector Inc. NHS	Major Health Charities	Pharmaceutical Company
	%	%	%
0 – Not confident at all	5	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
<b>Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

**Figure 5 – Confidence in taking part in a health research study depending on funding source**



Studies funded by the public sector including the NHS were regarded as the most trustworthy with a mean score of 6.74. Studies funded a major health research charity achieved a similar level of confidence with a mean score of 6.67. Studies funded by the pharmaceutical industry engendered the least confidence with a mean score of 4.95. This lack of confidence is mirrored in the public dialogue workshops also conducted by Ipsos MORI which showed that the public were suspicious of the motivations of the pharmaceutical industry.

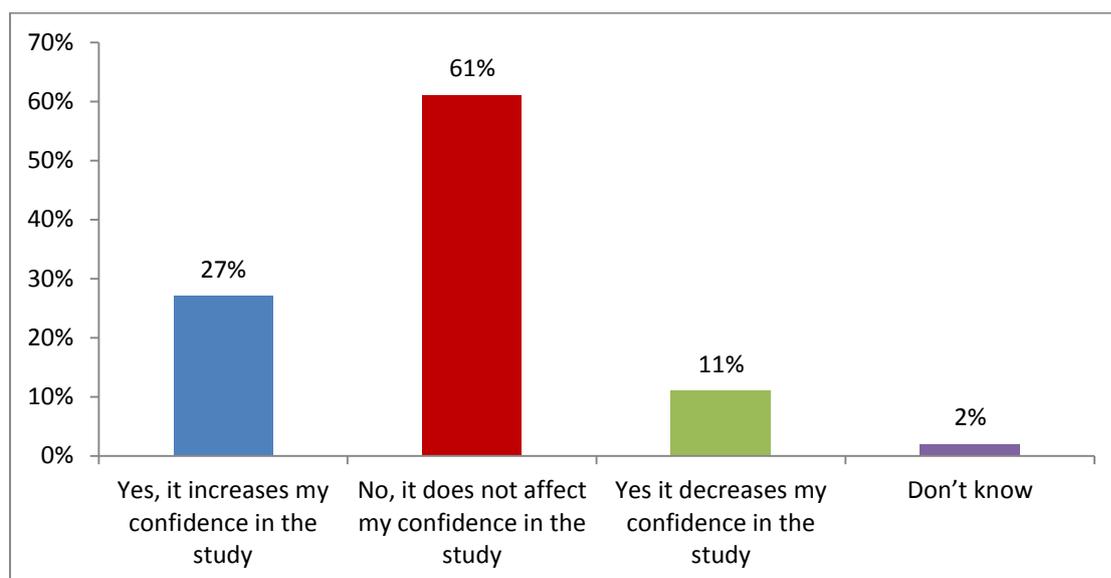
It was clear in the public dialogue workshops that the general public did not understand how the pharmaceutical industry works together with the NHS to conduct their clinical trials. The next question was therefore designed to ascertain whether knowing this made a difference to their perception of the research studies funded by the pharmaceutical industry.

**Q6 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 6 – Impact on confidence in research funded by pharmaceutical companies**

	No.	%
Yes, it increases my confidence in the study	352	27%
No, it does not affect my confidence in the study	785	61%
Yes it decreases my confidence in the study	137	11%
Don't know	20	2%
Total	1295	100

**Figure 6 – Impact of awareness of integration of pharmaceutical studies with NHS on confidence**



The vast majority of people (61%) upon being informed about patient involvement did not change their opinion about research funded by pharmaceutical companies. 27% said that knowing about the links with the NHS would increase their confidence. Roughly one in ten cases (11%) thought that knowing about the links with the NHS would decrease their confidence in a study. There was no statistical variation with age, gender, social class, ethnicity or working status.

## Public perception of who could access their patient records to find suitable patients to join health research studies

Respondents were asked a hypothetical question about how happy they would be about people in different roles being able to access their patient records with a view to finding patients who might be suitable to join a particular health research study.

**Q7 Patient records are sometimes used to find patients with particular conditions who might be suitable to join a health research study. How would you feel about any of the following people accessing your patient record to see if you might be suitable for joining a health research study:**

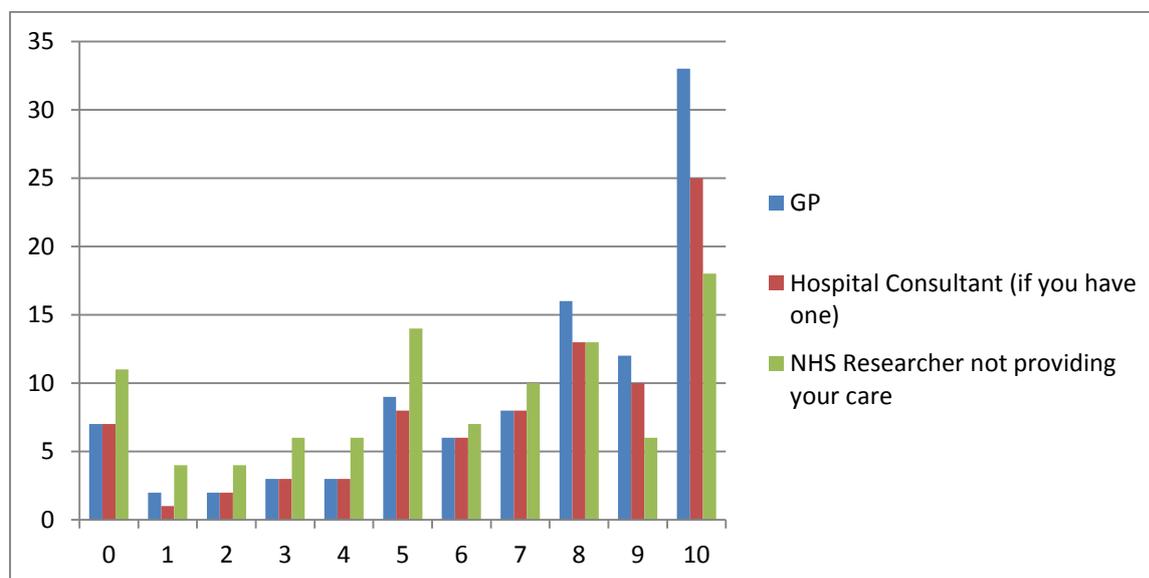
- a) your GP?
- b) your hospital consultant (if you have one)?
- c) an NHS doctor who is doing research but is not providing your normal care?

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

**Table 7 – Public views on who could access patient records to find suitable patients for health research studies**

	GP	Hospital Consultant (if you have one)	NHS Researcher not providing your care
	%	%	%
0 – Not happy at all	7	7	11
1	2	1	4
2	2	2	4
3	3	3	6
4	3	3	6
5	9	8	14
6	6	6	7
7	8	8	10
8	16	13	13
9	12	10	6
10 – Very happy	33	25	18
Mean score	7.28	6.94	5.79
Don't know	1	1	2
Not applicable	-	10	-
<b>Total %</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>
<b>Base</b>	<b>1295</b>	<b>1165</b>	<b>1295</b>

**Figure 7 – Public views on who could access patient records to find suitable patients for health research studies (April 2013)**



As the graph above shows the general public are happiest with the concept of their GP accessing their records to see if they might be suitable to join a health research study. A third of all respondents (33%) would be very happy for their GP to access their records and just 7% would not be happy at all. Most members of the public would not be under the care of a hospital consultant so it is not surprising that they are less happy with the idea of a hospital consultant accessing their data; 25% of respondents would be very happy for a hospital consultant to access their records and 7% would not be happy at all.

Roughly one in five respondents (18%) would be very happy for an NHS doctor who is doing research but not providing their normal care to access their records and 11% would be not at all happy.

Overall levels of happiness about access to their patient records increased with both social class and with age. Non-white respondents were less happy with anyone having access to their patient records than white respondents.

This question was repeated approximately four months later with three additional options. In addition to the existing options of 'your GP', 'your hospital consultant' and 'and NHS doctor who is doing research but is not providing your normal care', we added the following options:

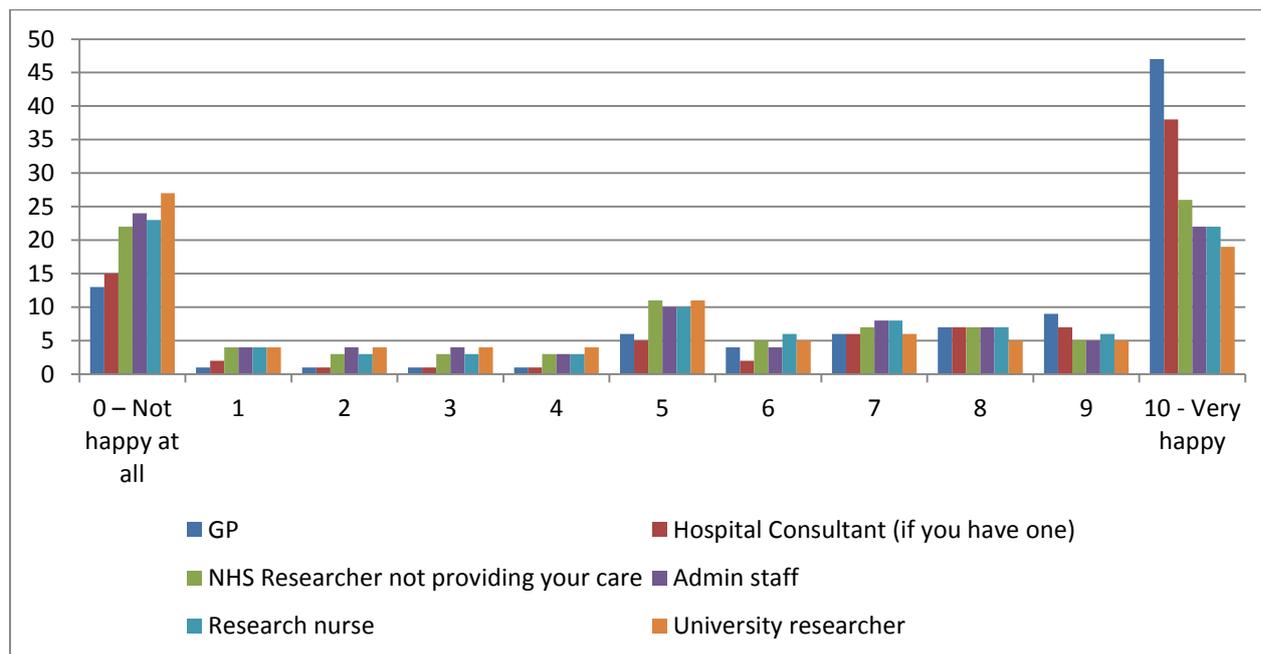
- Administrative staff employed by either your GP or your hospital consultant
- A research nurse, that is a nurse employed by the NHS who specialises in research and does not provide your care
- A health researcher employed by a local university.

The table and chart below shows the responses for all six options.

**Table 8**

	<b>GP</b>	<b>Hospital Consultant (if you have one)</b>	<b>NHS Researcher not providing your care</b>	<b>Admin staff employed by either your GP or your hospital consultant</b>	<b>A research nurse, that is a nurse employed by the NHS who specialises in research and does not provide your care</b>	<b>A health researcher employed by a local University</b>
	%	%	%	%	%	%
0 – Not happy at all	13	15	22	24	23	27
1	1	2	4	4	4	4
2	1	1	3	4	3	4
3	1	1	3	4	3	4
4	1	1	3	3	3	4
5	6	5	11	19	10	11
6	4	2	5	4	6	5
7	6	6	7	8	8	6
8	7	7	7	7	7	5
9	9	7	5	5	6	5
10 – Very happy	47	38	26	22	22	19
Mean score	7.38	6.94	5.51	5.16	5.25	4.69
Don't know	3	15	6	4	5	6
<b>Total %</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>
<b>Base</b>	<b>1295</b>	<b>1165</b>	<b>1295</b>	<b>868</b>	<b>868</b>	<b>868</b>

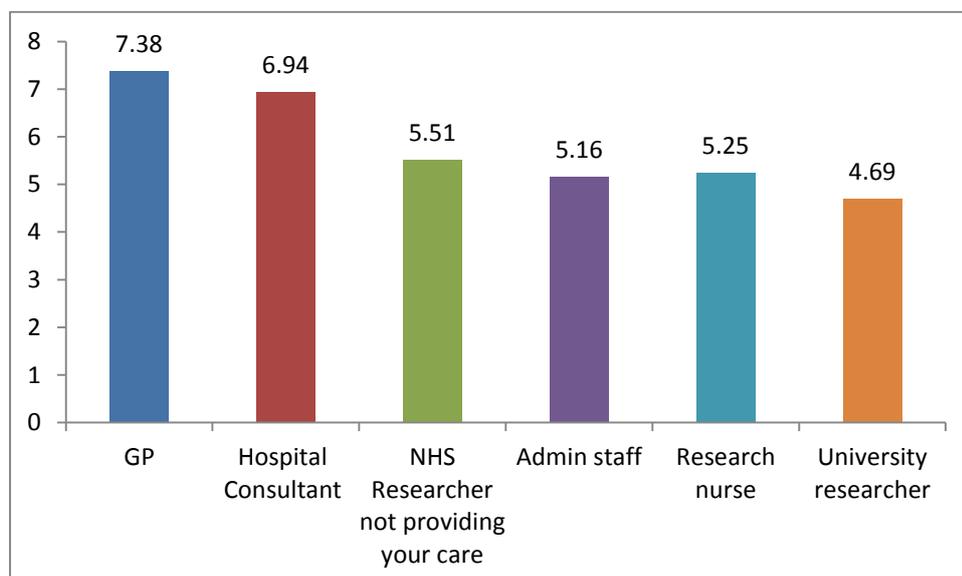
**Figure 8 – Public views on who could access patient records to find suitable patients for health research studies (August- September 2013)**



Essentially where the options are the same as last time, the results are more polarised with higher numbers saying they are either not very happy or very happy but the mean scores remain more or less the same. The public have the most faith in their GP, followed by their hospital consultant. Researchers employed by the local university are held in the least regard followed by admin staff employed by GPs and consultants. Interestingly research nurses are perceived as negatively as admin staff. The health researcher from the local university is seen as the most negative option.

In order to make comparison easier, the chart below shows the mean average score for each option.

**Figure 9**



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Based on overall mean average scores, the research nurse is seen as a more popular option than administrative staff but only by a small amount.

We know from our public dialogue workshops that there was a lot of support amongst the general public for the GP to have access to patient records for the purpose of finding suitable people to join health research studies. Conversely we also found that patients under the care of a hospital consultant were generally happy for the hospital based care team including the research nurse to have access to their records to find suitable patients.

## Conclusions

This survey has given the HRA the opportunity to quantify some of the issues that were identified in the public and patient dialogue workshops. For example, participants in the public workshops were consistently critical of the pharmaceutical industry but had 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. The survey results show that informing the public about the close working relationship with the NHS has a positive impact for a proportion (27%) of the population but no impact on the majority (61%).

Overall confidence in health research seems to be reasonably high. 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 recent public engagement work conducted by Wellcome<sup>2</sup> 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.

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, the vast majority (77%) of respondents indicated that they would feel confident to take part in a health research study if they knew it had been reviewed by a Research Ethics Committee. This mirrors the findings of the public dialogue workshops which suggested that the public had a high level of trust in the Research Ethics Committee system.

The survey findings in relation to patient involvement were also supported by the patient and public dialogue workshops. Whilst experienced patients have a clear understanding of the positive outcomes of patient and public involvement, the public dialogue suggested that lay membership of Research Ethics Committees was not fully appreciated. The survey findings suggest that the benefits of patient and public involvement are not intuitively understood and require further explanation and clear demonstration of benefits. Members of the public attending the workshops called for the HRA to do more to promote the role of the HRA and the Research Ethics Committees.

Confidence in health research was consistently higher amongst those with access to the internet, those in social class AB and those in work. This finding is reflected in other surveys on the topic of health research<sup>3</sup>. This has implications for future communication and the communication methods employed.

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

<sup>3</sup> NIHR Public survey OnePoll 2012

# Appendix 1

## Survey Demographics

### Gender

The respondents were split roughly 50:50 male and female.

### Age

	%
18 – 24	12%
25 – 34	17%
35 – 44	17%
45 – 54	18%
55- 64	15%
65+	21%
Total %	100
Base	1,295

### Social Class

	%
AB	27%
C1	27%
C2	22%
DE	23%
Total %	100
Base	1,295

### Working Status

	%
Working	57%
Not working	43%
Total %	100
Base	1,295

### Ethnicity

	%
White	86%
Non-white	14%
Total %	100
Base	1,295

### Internet Access

## Survey of the general public: attitudes towards health research

	%
Yes	88%
No	12%
Total %	100
Base	1,295

### **Newspaper Readership**

	%
Quality	13%
Mid market	12%
Popular	30%
Total %	100
Base	1,295

## Appendix 2

### Public opinion: HRA research approval process

**PREAMBLE: The following questions are about health research in the UK. Health research covers a wide range of different types of studies from simple interviews and surveys about health issues through to clinical trials used to test new treatments. Please answer all the questions as best you can.**

ROTATE QUESTIONS Q1-Q2

Q1-2 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 ...

- 1) you would be treated with dignity and respect?
- 2) 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
5	Don't know

Q3. 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?

1	Very confident
2	Fairly confident
3	Not very confident
4	Not at all confident
5	Don't know

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Q4. 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

Q5- Q7. To what extent would you feel confident or not about taking part in a health research study if you knew it was funded by ...

- 5) the public sector including the NHS?
- 6) a major health research charity?
- 7) a Pharmaceutical company (that makes and sells medicines)?

Please give your answer on a scale of nought to ten where nought means you would not be at all confident and ten means you would be very confident.

0 = not at all confident

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

10 = very confident.

Don't know

Q8. Most pharmaceutical company research studies with NHS patients take place in NHS settings and are run locally by NHS doctors. Does knowing this make a difference to the way you feel about health research 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
5	Don't know

Survey of the general public: attitudes towards health research

Q9 - 11. Patient records are sometimes used to find patients with particular conditions who might be suitable to join a health research study. How would you feel about any of the following people accessing your patient record to see if you might be suitable for joining a health research study:

9) your GP?

10) your hospital consultant (if you have one)?

11) an NHS doctor who is doing research but is not providing your normal care?

Please give your answer on a scale of nought to ten where nought means you are not at all happy and ten means you are very happy.

0 = not at all happy

1

2

3

4

5

6

7

8

9

10 = very happy.

Don't know

Not applicable – Q12 ONLY

The later question run in August/September 2013 repeated questions 11 – 13 with three additional options:

- Administrative staff employed by either your GP or your hospital consultant
- A research nurse, that is a nurse employed by the NHS who specialises in research and does not provide your care
- A health researcher employed by a local university.