

# Engaging for increased research participation

Public and healthcare professionals' perceptions



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## 1. Executive summary

See section 15 for summary findings and specific recommendations for increasing clinical research participation.

### 1.1.1 People are positive about research and participation

The Wessex population views research in the NHS positively and a large proportion are open to participating: 90% of respondents think that it is important for the NHS to support research into new treatments, whilst 47% think it likely they would be willing to participate in clinical trials in the future.

Those that have participated have positive perceptions, and they will likely have a significant influence on others' future participation: 80% of people who have taken part in clinical research would recommend taking part to a friend or family member, whilst around half (44%) of people who know someone who has taken part in clinical research said that they are more likely to participate now because of their experience.

### 1.1.2 The critical conversations are not happening

Only 15% have had clinical research discussed with them by a healthcare professional in their lifetime, whilst only 5% of those who have seen healthcare professional in the last 12 months had clinical research discussed with them.

#### Recommendation 1:

**Communications supporting participation in interventional trials should be focussed on enabling effective clinical conversations, with a reduced emphasis on broad public awareness approaches.**

### 1.1.3 Healthcare professionals perceive major barriers to involvement

The healthcare professionals interviewed were broadly positive about research; however they cite workload, time and lack of local trial information as constraints on discussion of research with patients. Better trial information was also identified as something that would increase the likelihood of discussing trial options with patients.

Clinicians self-segregate themselves into 'researchers' (an academically orientated minority) and 'practitioners', with the latter positive about the benefits of clinical research and open to research referrals/facilitation but unlikely to have direct involvement in, or lead their own, research.

Direct involvement in research by clinicians is limited by lack of programmed/sanctioned time within work plans, perceptions of excessive bureaucracy and lack of support.

#### Recommendation 2:

**Local Clinical Research Networks, local research infrastructure and Trusts' senior leadership should support NHS clinicians' engagement with local clinical trials, and to explore management and education interventions to make communication with patients about trials a routine part of all NHS consultations.**

### 1.1.4 The public need information, of immediate relevance to their health

Public participation motivations centred on potential benefits to one's own health or that of close friends and family, whilst perceived risk of harm and receiving the 'unknown' alongside concerns over time commitments and time off work were the biggest barriers to participation.

Only 9% of respondents reported that they felt they understood clinical research very well, with this group the least likely to agree that risk was a significant barrier to participation. Generic online searches, condition-specific online sources of information and healthcare professionals were the primary sources of information, with a high degree of trust in the information provided by professionals.

#### Recommendation 3:

**Public communications and engagement should have a greater emphasis on informing and empowering people at the point of care or enquiry, to enable discussion of trials with clinicians.**

### **1.1.5 Time and fitting participation into life is a concern**

Concerns over time commitments needed to participate in studies, including taking time out of work and fitting such activity into daily/family life were significant barriers to participation.

#### **Recommendation 4:**

**Changes to clinical research delivery to improve convenience and flexibility for participants, alongside interventions that lower the practical threshold to participation should be investigated and evaluated.**

## 2. Introduction and Methodology

### 2.1 Introduction

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The partnership between University Hospital Southampton NHS Foundation Trust (UHS) and the University of Southampton enables clinical-academics to perform clinical research through quality assured support, facilities and resources embedded at the heart of a major teaching hospital trust.

This partnership hosts, and participates in the National Institute for Health Research Clinical Research Network Wessex (NIHR CRN:Wessex), one of 15 regional CRNs that coordinate and support clinical trial activity across the UK on behalf of the NIHR.

Participation in clinical research by the public, patients and clinicians is essential to advancing medicine and care, and access to such trials is a right conferred to patients under the NHS constitution<sup>1</sup>. Because of this, recruitment to trials is the primary measure by which NIHR manages performance of CRNs and their member organisations.

Rapid, complete recruitment to open trials remains challenging for Trusts and CRNs nationwide, indicating a significant issue relating to public and patient engagement with trial treatment options and research participation.

Against this background UHS, with match-funding from NIHR CRN:Wessex, commissioned Alterline Research Ltd. to conduct a programme of market research to better understand the perceptions, motivations and barriers to participation in clinical research across the region. This research is intended to inform more effective communication and engagement aimed at increasing participation, primarily focussed on interventional clinical research.

### 2.2 Key objectives

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The research was conducted with three audiences:

- **The public** (18 years and older across all demographics and geographies)
- **Primary care professionals** including GPs and community nurses across the region.
- **Hospital clinical staff** including consultants, nurses, midwives and allied health professionals across the region's trusts.

The research outputs are intended to provide an evidence base to help:

- Shape and inform effective engagement strategies with these audiences
- Build an evaluation framework against which engagement can be assessed and developed for greater efficacy
- Ensure coherence and commonality in engagement approaches and messages across Wessex
- Provide a reference point and baseline data for long-term tracking and evaluation.

### 2.3 This report

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This report details findings of the research with the public and healthcare professionals, exploring their attitudes towards clinical research, their likelihood to participate and the drivers and barriers to increasing participation and recommending actions for increasing research participation.

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<sup>1</sup> NHS Constitution, 2013 <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf>

## 2.4 Method

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### **Review of literature and pilot**

A review of the existing literature was conducted to help inform the design of research materials including the quantitative and qualitative questionnaires.

### **Quantitative questionnaire development**

A questionnaire comprising predominantly closed questions and a small number of open-ends was developed in partnership with the Trust.

### **Quantitative public survey by telephone**

In total 1101 interviews were completed by telephone using specialist computer assisted telephone interviewing (CATI) software and an automated dialler system.

The interview sample for the telephone survey was sourced from a specialist data provider using relevant postcodes. In order to ensure a representative survey sample of the Wessex population interview completions were monitored by key demographics such as gender, age and location. See appendix one for details of the demographic sample.

### **Public depth survey**

Following the quantitative survey, key emerging themes were used to develop a qualitative, in-depth survey which was administered by telephone. In total, 30 people took part in in-depth interviews including a mix of men and women, different ages and geographies.

### **Clinician depth survey**

To explore perceptions, motivations and barriers of clinicians, an in-depth survey was designed and administered by telephone. In total, 25 healthcare professionals took part in the survey, including 6 GPs, 10 nurses, and 9 hospital consultants.

### **Analysis**

The quantitative survey data was exported to SPSS (Statistical Packages for Social Sciences) where it was quality checked. Frequencies and cross-tabulations exploring differences between respondents were produced and key questions were charted and included in this report.

Demographic differences have been included in this report following the application of tests of statistical significance. Open-ended data was themed, with key verbatim quotes pulled out and included in the report.

The in-depth interviews were audio recorded and transcriptions were made. Key themes were identified from the focus group transcripts and representative verbatim quotes have been pulled out and included in the report.

## 3. Review of the literature

### 3.1 General background

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Clinical research is central to advancing medicine, developing and evaluating medications, treatments, and practices. The purpose of this review is to examine perceptions of clinical research, willingness to participate and motivations and barriers to taking part. As the research in the area is limited, it will also look at motivations and barriers to taking part in related, voluntary activities (i.e. giving blood and organ donation) in order to identify any commonalities.

Generally, reports in the literature show support for clinical research to be high. The Wellcome Trust notes that 95% of adults and 93% of 13-18 year olds think that medical research should be supported<sup>2</sup>. Further 88% of those surveyed by the National Institutes of Health<sup>3</sup> in the USA think that clinical trials are important for advancing knowledge about treating disease. A 2011 UK national survey of 990 adults by IPSOS-MORI, commissioned by the Association of Medical Research Charities, reported similarly strong public support for research with 97% believing the NHS should support research into new treatments, whilst 93% wanted their local NHS to be encouraged or required to support research. These figures are corroborated by a 2014 national survey of 3,000 adults commissioned by the National Institute for Health research, indicating that 95% of people said it was important to them that the NHS carries out clinical research<sup>4,5</sup>.

Reported willingness to participate in research is also strong. In a monitor of people's views on science and research, 60% said they would be willing to take part in clinical trials<sup>6</sup>. 72% of those polled in the 2011 AMRC survey would want to be offered opportunities to be involved in trials of new medicines or treatments if they suffered from a health condition that affects their day-to-day life; 80% would consider allowing a researcher confidential access to their medical records, and 88% would be happy to be asked to talk to researchers about their family history or give a sample of their blood for laboratory testing. 89% of people surveyed in the 2014 NIHR national survey would be willing to take part in clinical research if they were diagnosed with a medical condition or disease, with only 3% saying they would not consider it at all<sup>5</sup>. Comis *et al*<sup>7</sup> report that, in relation to cancer trials, 32% of adults would be willing to take part and 38% would potentially be interested, but would hold some reservations. Further, willingness to participate is not static and much depends on the nature of the trial. For example, 74% of people would be willing to allow access to their medical records, whereas only 30% would be willing to test a new drug<sup>2</sup>.

These figures showing positive perception and willingness to participate are however in stark contrast to reported and actual participation rates. In two monitors by the Wellcome Trust, lifetime participation varied from 10%<sup>6</sup> to 23%<sup>2</sup>, whilst a further 10% of people have a family member who has taken part<sup>6</sup>. These findings support National Institute for Health Research official figures indicating that annual recruitment to clinical trials in the English NHS stands at 0.94% of the English population (2013-14 figures)<sup>8</sup>, with CRN Wessex reporting recruitment of 1.15% of the regional population in the same period<sup>9</sup>.

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<sup>2</sup> Butt, S., Clery, E., Abeywardana, V., Phillips, M. (National Centre for Social Research). Wellcome Trust Monitor 1. London: Wellcome Trust; 2010

<sup>3</sup> National Institutes of Health, National Cancer Institute. (1997). Results from Quarterly Omnibus Survey: Clinical Trials Questions-April 22, 1997. Bethesda: National Cancer Institute.

<sup>4</sup> IPSOS-MORI / Association of Medical research Cahrities J11-02572 Public support for research in the NHS, <http://www.ipsos-mori.com/researchpublications/researcharchive/2811/Public-support-for-research-in-the-NHS.aspx>

<sup>5</sup> National Institute for Health Research, 2014, <http://www.crn.nihr.ac.uk/blog/news/nine-out-of-ten-people-would-be-willing-to-take-part-in-clinical-research/>

<sup>6</sup> Clemence, M., Gilby, N., Shah, J., Swiecicka, J., Warren, D. (2013). Wellcome Trust Monitor Wave 2: Tracking public views on science, biomedical research and science education. London: Wellcome Trust.

<sup>7</sup> Comis, R.L., Miller, J.D., Aldige, C.R., Krebs, L. and Stoval, E. (2003). Attitudes toward participation in cancer clinical trials. *Journal of Clinical Oncology*. 21: 830-835.

### 3.2 Why do people take part in clinical research?

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By far, the most reported reason for taking part in clinical research in the literature was a sense of altruism and helping others. Mattson et al<sup>10</sup>, found that 65% of participants took part for altruistic reasons. Rosenbaum et al<sup>11</sup> noted that 46% of people who participated in clinical research reported altruism as the reasons for doing so. Of those people, just under half (45%) provided an altruistic reason as their only motivation. Those who gave altruistic reasons were more likely to have higher levels of social support, have a college education, and were less likely to say they had a disability.

Specifically in cancer trials, altruism is often reported as a reason for taking part<sup>12</sup>. Jenkins et al<sup>13</sup> report that 23% of those who consented to take part in clinical research did so because others would benefit from their participation.

Many people also said that they took part because of healthcare professionals. Some report that this was because of a recommendation from their doctor<sup>3</sup> and others report that it was through the doctor's influence that they decided to take part<sup>14</sup>. Jenkins et al<sup>13</sup> looked solely at people who had decided to take part after being asked by their doctor. Of those who were asked, 72% decided to take part, of which 21% said it was because they trust their doctor.

Further, it is apparent that some people also take part in clinical research because of the benefit that it will have to them. Such motivations include a hoping that there will be a therapeutic benefit or because there is no other treatment available<sup>12</sup>. Further, in Mattson et al<sup>10</sup> 74% of participants for aspirin and beta-blocker trials said they were motivated by non-altruistic motivations. These motivations included better medical monitoring and reassurance, physical improvement and preventions of further illness.

### 3.3 What stops people from taking part in clinical research?

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A concern about side effects and risks present a significant barrier to participation in the literature. Looking into cancer trials, a fear of making the cancer worse presented a significant barrier when being asked to participate<sup>15</sup>. Further, when testing a new drug, 93% of those with concerns in the Wellcome Trust study said they were worried about the possible risk to their own health from participating<sup>2</sup>. As with many factors, concerns about the side effects and risks of a trial are not stable across all groups. Basche et al<sup>16</sup> spoke to seniors who were asked to participate in cancer trials. They found that those ages 65–75 were more likely to participate in the trial when the side effects were likely, than those aged over 75.

Further, many studies report that issues related to the time commitment of clinical research and logistical difficulties also present a significant constraint on participation. A quarter of people asked about their attitudes to participation in clinical research said that they did not have the time to participate<sup>17</sup>. Further, a third of people in Basche et al<sup>16</sup> said that they were concerned about the time commitment and other issues, such as getting to the trial facility.

Many other barriers have been reported in the literature. These include: a dislike of randomisation<sup>13</sup> and the potential to be in a placebo group; lack of knowledge of both the processes involved in clinical research<sup>19</sup> and the trials that are available<sup>18</sup>, and a lack of trust in medical research<sup>19</sup>.

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<sup>8</sup> NIHR Clinical Research Network Annual Report 2013/14

[http://www.crn.nihr.ac.uk/wp-content/uploads/About%20the%20CRN/13\\_14%20Annual%20Performance%20Report\\_PUBLIC\\_FV.pdf](http://www.crn.nihr.ac.uk/wp-content/uploads/About%20the%20CRN/13_14%20Annual%20Performance%20Report_PUBLIC_FV.pdf)

<sup>9</sup> CRN Wessex Performance Report May2014, [www.odp.nihr.ac.uk/default.htm](http://www.odp.nihr.ac.uk/default.htm)

<sup>10</sup> Mattson, M.E., Curb, J.D., and McArdle, R. (1985). Participation in a clinical trial: The patients' point of view. *Controlled Clinical Trials*. 6: 156-167

<sup>11</sup> Rosenbaum, J.R., Wells, C.K., Viscoli, C.M., Brass, L.M., Kernan, W.N., and Horwitz, R.I. (2005). Altruism as a reason for participation in clinical trials was independently associated with adherence. *Journal of Clinical Epidemiology*. 58: 1109-1114.

<sup>12</sup> National Institutes of Health, National Cancer Institute, Working Group on Enhancing Recruitment to Early Phase Cancer Clinical Trials. (2004). *Enhancing Recruitment to Early Phase Cancer Clinical Trials: Literature Review*. Bethesda: National Cancer Institute.

<sup>13</sup> Jenkins, V. and Fallowfield, L. (2000). Reasons for accepting or declining to participate in randomised clinical trials for cancer therapy. *British Journal of Cancer*. 82(11): 1783-1788.

<sup>14</sup> Chu, S.H., Jeong, S.H., Kim, E.J., Park, M.S., Park, K., Nam, M., Shim, J.Y., and Yoon, Y. (2012). The views of patients and healthy volunteers on participation in clinical trials: An exploratory survey study. *Contemporary Clinical Trial*. 33: 611-619

<sup>15</sup> Solomon, M.J., Pager, C.K., Young, J.M., Roberts, R., and Butow, P. (2003). Patient entry into randomized controlled trials of colorectal cancer treatment: Factors influencing participation. *Surgery*. 133(6): 608-613.

<sup>16</sup> Basche, M., Baron, A.E., Eckhardt, S.G., Balducci, L., Persky, M., Levin, A., Jackson, N., Zeng, C., Brna, P., and Steiner, J.F. (2008). Barriers to enrolment of elderly adults in early-phase cancer clinical trials. *American Society of Clinical Oncology*. 4(4): 162-168

Although little literature looks into healthcare professionals' motivations regarding clinical research, several have looked at the barriers to getting involved. The research suggests that concerns for patients represent significant barriers to participation. In in-depth interviews with clinicians in South-west England, clinicians suggested that concerns for individual patients and respect for patients' preferences for different treatments prevented them from approaching patients and getting involved<sup>20</sup>. Further, concern for patients and a worry about the impact on the doctor-patient relationship was shown to be a significant barrier in Ross et al's meta-analysis<sup>21</sup>.

### 3.4 Why do people take part, or not take part, in related activities?

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Many reasons, both similar and dissimilar to those expressed above, are noted in the literature that motivate blood and organ donation. Coad et al<sup>22</sup> found that those who knew someone who had donated or received an organ were more likely to agree with donating an organ to a family member or friend. Further, Wildman and Hollingsworth<sup>23</sup> note that those who have donated blood before are more likely to donate again.

Further, Cohen and Hoffner<sup>24</sup> note that self-interest explains motivations to become an organ donor. 40% said they would be willing to sign a blood donor card. Self-interest motivations were the most important predictor of willingness to sign the card, including pride and satisfaction with the decision, otherwise known as the 'warm glow' feeling.

A questionnaire of university students in Japan showed that being in good health, having time to donate, being given opportunity to donate and helping others were the most important motivations for those who both had given blood before and those who had not<sup>25</sup>.

The same study also looked at barriers to taking part. These were very much the opposite of the motivators, and included having time to donate, not knowing when and where to donate and not being given the opportunity to donate were considered barriers to taking part<sup>25</sup>. Lack of knowing where to go and it not being in a convenient place was corroborated by a further study of American adults, as well as a fear of needles and pain<sup>26</sup>.

### 3.5 Summary

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In summary, although many people believe that clinical research is important and are willing to take part, this is not reflected in rates of participation. Reasons why people take part in clinical research include altruism, the influence of a healthcare professional and a benefit to themselves. Major barriers to participation include the risk to themselves and time commitments. Clinician barriers generally revolve around a concern for their patients. Significantly different motivators and barriers to taking part in related activities include knowing someone who has taken part, taking part before and knowing what opportunities were available. >>>

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<sup>17</sup> Bevan, E.G., Chee, L.C., McGhee, S.M. and McInnes, G.T. (1993). Patients' attitudes to participation in clinical trials. *British Journal of Clinical Pharmacology*. 35(2): 204-207

<sup>18</sup> Mills, E.J., Seely, D., Rachlis, B., Griffith, L., Wu, P., Wilson, K., Ellis, P., and Wright, J.R. (2006). Barriers to participation in clinical trials of cancer: a meta-analysis and systematic review of patient-reported factors. *Lancet Oncol*. 7: 141-148

<sup>19</sup> Lovato, L.C. and Kristin, H. (1997). Recruitment for controlled clinical trials: Literature summary and annotated bibliography. *Controlled Clinical Trials*. 18: 328-357

<sup>20</sup> Langley, C., Gray, S., Selley, S., Bowie, C., and Price, C. (2000). Clinicians' attitudes to recruitment to randomised trials in cancer care: A qualitative study. *Journal of Health Services Research and Policy*. 5(3): 164-169

<sup>21</sup> Ross, S., Grant, A., Counsell, C., Gillespie, W., Russell, I., and Prescott, R. (1999). Barriers to participation in randomised controlled trials: A systematic review. *J Clin Epidemiol*. 52(12): 1143-1156

<sup>22</sup> Coad, L., Carter, N., and Ling, J. (2013). Attitudes of young adults from the UK towards organ donation and transplantation. *Transplantation Research*. 2: 9-14

<sup>23</sup> Wildman, J., and Hollingsworth, B. (2009). Blood donation and the nature of altruism. *Journal of Health Economics*. 28: 492-503

<sup>24</sup> Cohen, E.L. and Hoffner, C. (2012). Gifts of giving: The role of empathy and perceived benefits to others and self in young adults' decisions to become organ donors. *Journal of Health Psychology*. 18(1): 128-138

<sup>25</sup> Ngoma, A.M., Goto, A., Yamazaki, S., Machida, M., Kanno, T., Nollet, K.E., Ohto, H. and Yasumura, S. (2013) Barriers and motivators to blood donation among university students in Japan: Development of a measurement tool. *Vox Sanguinis* 105(3): 219-224

<sup>26</sup> Adelbert, J.B., Schreiber, G.B., Hillyer, C.D., and Shaz, B.H. (2013). Blood donations motivators and barriers: A descriptive study of African American and white voters. *Transfusion and Apheresis Science*. 48(1): 87-93

## 4. Likelihood to participate in clinical research

### 4.1 The public view clinical research as important

To provide a background to people's perceptions of clinical research, we asked respondents to tell us how important they thought it was for the NHS to support research into new treatments. As figure 1 below shows, the overwhelming majority of people (90%) think that it is either important or very important.

However, of those who responded to the survey, only 10% have actually taken part in clinical research. There is a clear gap between how important the area is seen to be, and how many people are taking part.

Figure 1

How important do you think it is, if at all, for the NHS to support research into new treatments for patients?

Base: 1101



#### 4.1.1 Demographic Differences

**Age** Belief that supporting research is important is lowest in 18-24 year olds (73%). As people get older, they are more likely to believe that it is important, peaking at 96% for 75-84 year olds.

**Gender** Females (95%) are more likely to say supporting research is important than males (85%).

**Educational attainment** Those who have qualifications other than a degree are the most likely to view research as important (97%). Those who have no educational qualifications are least likely (80%).

**Employment status** Students (90%), retired people (83%) and those who are employed (76%) are more likely to see clinical research as important, compared to those who are self-employed (69%), home-makers (67%), or out of work and not looking for work (55%).

**Dependents** Those with dependents (96%) are more likely to view clinical research as important than those without dependents (90%).

**Health** Those with good (80%) or very good health (80%) are more likely than those with fair (70%) or very bad (54%) to view research as very important.

**Previous participation** Those who have participated in clinical research (99%) are more likely to say supporting research is important than those who have not (89%).

**Knowing someone who has taken part** Those who know someone who has taken part in clinical research (97%) are more likely to see supporting research as important, compared to those who don't (89%).

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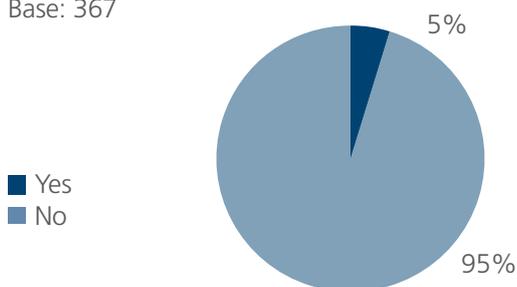
## 4.2 Few people have been asked to take part in clinical research

Importantly, of those surveyed, only 15% recalled a time when a healthcare professional had discussed involvement in clinical research with them. Further, of the 43% who had seen a healthcare professional in the last month, only 5% had clinical research discussed with them (Figure 2, below).

**Figure 2**

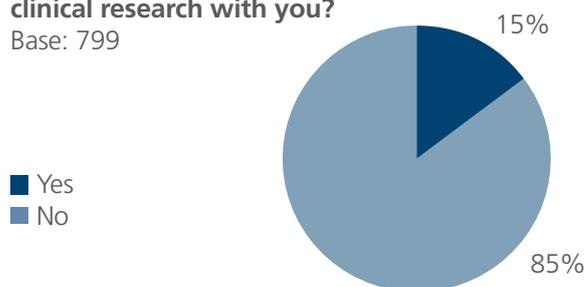
**Did the healthcare professional you saw discuss involvement in clinical research with you?**

Base: 367



**Do you recall a time at any point in your life when a healthcare professional has discussed clinical research with you?**

Base: 799



Increasing the number of conversations taking place between clinicians and their patients about clinical research is likely to increase the number of people who take part. In the in-depth interviews, people often said they reason they had not taken part before was because no-one had ever asked.

*"I just haven't been asked."*

*"No-one's ever asked me."*

Further, previous research has shown that trust in healthcare professionals is high, with 72% of adults saying that they trust a medical professional to provide them with information about clinical research<sup>27</sup>. This was also seen in the in-depth interviews, where many respondents expressed a great deal of trust for their doctor.

*"So if they said 'blardy blardy blah', would you take part? Then I probably would have done, because we gained that much trust."*

*"Yes I would trust them if they talked about clinical research because the consultant I've been under for four years now, my GP I've known for over 20 years now so they're people that I've known long enough to trust."*

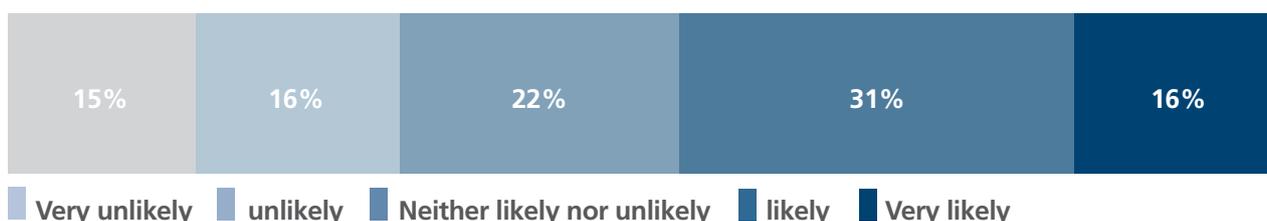
## 4.3 Likelihood to participate

Although only 10% of people have taken part in clinical research, the results would show appetite for participation is higher than this. When respondents were asked if they would consider taking part in clinical research, just under half (47%) agreed that they would be likely or very likely to (Figure 3, below).

**Figure 3**

**How likely is it that you would be willing to participate in clinical research in the future?**

Base: 1101



<sup>27</sup>Butt, S., Clery, E., Abeywardana, V., Phillips, M. (National Centre for Social Research). Wellcome Trust Monitor 1. London: Wellcome Trust; 2010

### 4.3.1 Demographic differences

The demographic differences below explore whether some people are more likely than others to participate. Characteristics of people who are more likely to participate include:

- Having previously participated (64%) or knowing someone who has (63%)
- Having a good understanding of clinical research (63%)
- Students (58%) and those unable to work (63%)
- Having a degree or equivalent level of education (58%)
- Registered organ donors (58%)
- People in very good health (57%)
- People who do regular volunteer work (55%)
- People who have given blood (54%)
- People aged 35-64 (52%).

**Age** People aged 35-64 (52%) are most likely to agree that they would be willing to take part in clinical research, this decreases amongst 25-34s (48%), 16-24s (46%), 65-74s (49%) and in particular 75-84s (32%) and 85+ (12%).

**Understanding of clinical research** Those who have a very good understanding of clinical research (63%) are the most likely to say they would take part in clinical research, followed by those that have some (54%), little (40%) or none (39%).

**Previous participation** Those who have participated before (68%) are more likely to say they would be willing to take part than those who have not (45%).

**Knowing someone who has taken part** People who know someone who has participated in clinical research (63%) are more likely to say that they are willing to take part than those who don't (44%).

**Educational attainment** Those with a degree or a degree equivalent (58%) and those who have other qualifications (52%) are more likely than those with no qualifications (35%) to say they would take part.

**Employment status** Students (66%), those who are unable to work (62%), and those who are employed for wages (52%) are more likely to say they are willing to take part than those who are those who are retired (37%) and out of work and looking (26%).

**Volunteers** Those who give help as a volunteer to clubs or organisations weekly (55%), monthly (53%) or occasionally (54%) are more likely to say they are willing take part than those have volunteered in the last year (46%) and those who give unpaid help on an individual basis (36%).

**Giving blood** People who have previously given blood (54%) are more likely to say they would participate than those who have not given blood (45%).

**Organ donors** Those who are registered as organ donors (58%) are more likely to say they would participate than those who are not (42%).

**Health** Those who have very good (57%), good (49%) and bad health (47%) are more likely to say they are would take part than those who have very fair (35%) or bad health (32%).

>>>

#### 4.4 Likelihood to participate in various types of research

To expand on people’s likelihood to take part, we asked people about different scenarios they would be willing to take part in.

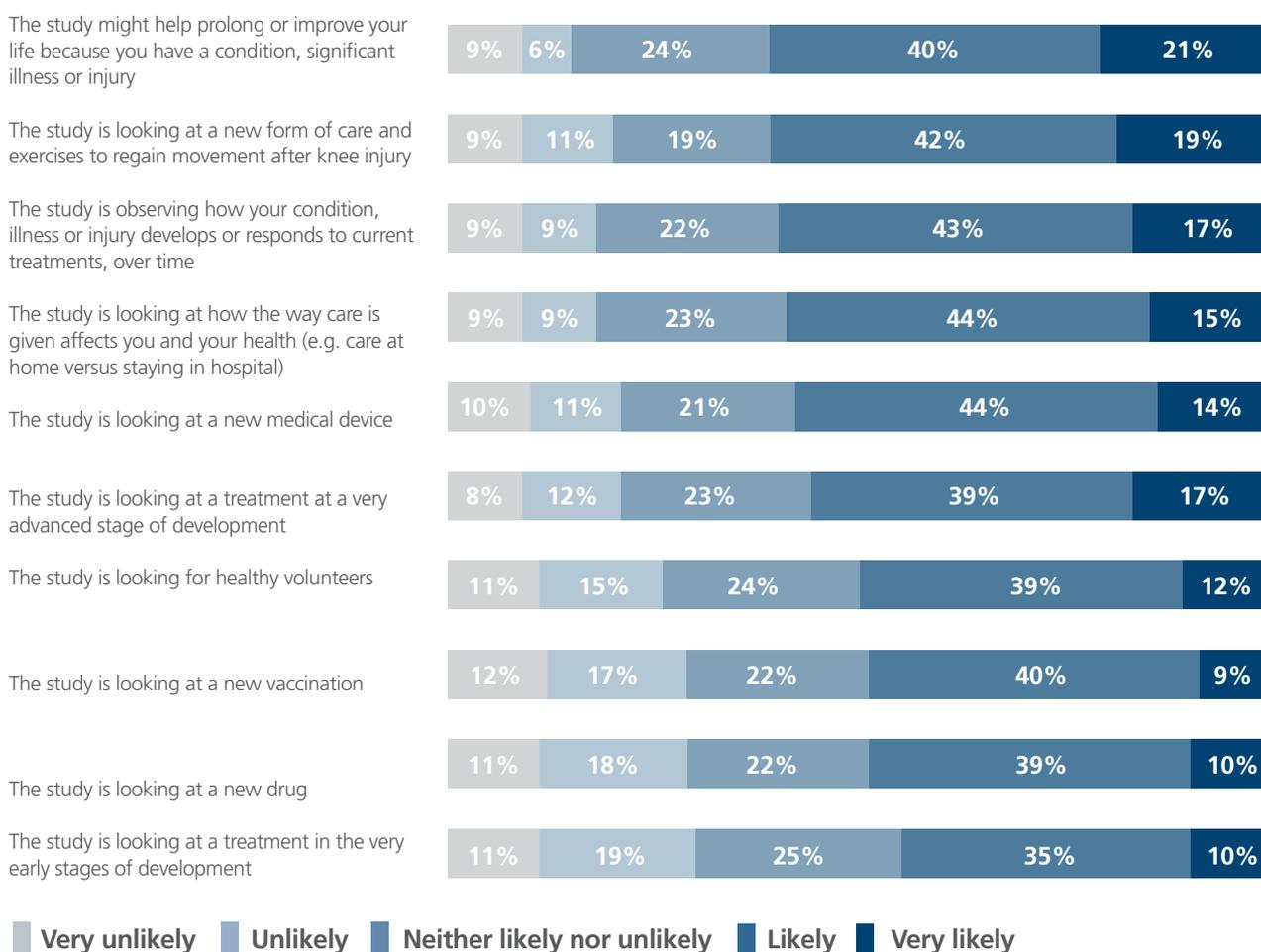
As shown in Figure 4 (below), the scenarios that might improve their own health or care are those in which people were most willing to participate . Likelihood to participate extends to 61% in the scenario where it may help prolong a respondents’ own life, or where it is looking at new forms of care and exercise to regain movement after a knee injury.

In contrast, the scenarios which people were least willing to take part reflected those which were at earlier stages of the research process. This may be because research into new medications or treatments is seen as riskier.

**Figure 4**

#### How likely is it you would be willing to take part in clinical research if...?

Base: 1101



## 5. Motivations for taking part

### 5.1 Why do other people take part in clinical research?

In order to understand what motivates people to take part in clinical research, we asked respondents to tell us what they thought motivated other people to take part. The most commonly cited reasons were:

- Helping others/altruism
- A positive impact on their own health
- A personal interest in a particular disease/condition.

### 5.2 What would motivate you to take part?

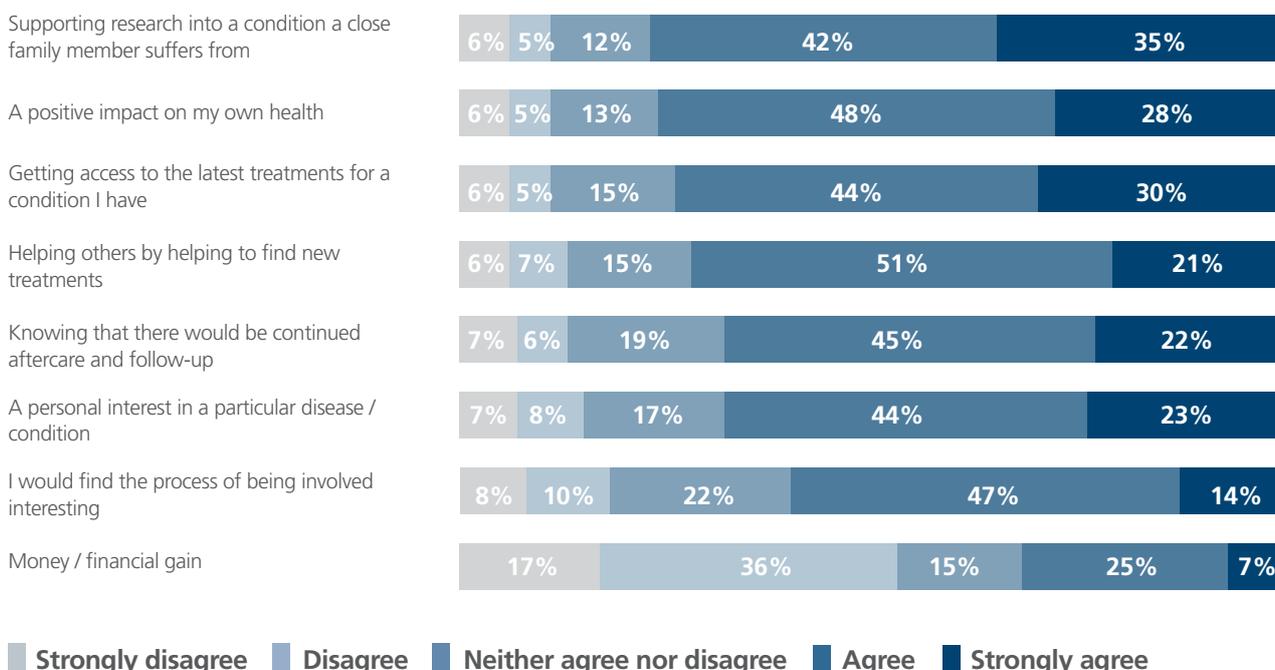
To look into motivations further, we asked people what would motivate them (*rather than others*) to take part in clinical research. When people are speaking about their own motivations, they tend to agree more with statements which are related to personal motivations, i.e. helping to improve their own, or a close relative's, health. However, altruistic motivations are still important, with 72% agreeing that they would be motivated by helping others.

Respondents also indicated that other things would motivate them, beyond those factors seen earlier. Knowing that aftercare would be available (67%) and an interest in a particular disease (67%) are both seen as important to respondents. Just 32% of respondents said that money would motivate them to take part.

Figure 5

#### To what extent do you agree or disagree that the following would motivate you to take part in a clinical trial?

Base: 1101



>>>

### 5.2.1 Demographic differences

**Understanding of clinical research** Those who have no understanding of clinical research (58%) are the least likely to agree that they would be motivated by getting the latest access to treatment for a condition they have.

**Age** 35-44 year olds (76%) are more likely to agree that they would be motivated by helping others by finding new treatments than 16-24 (70%) and 25-34 (64%) year olds.

34-44 (86%), 44-54 (85%) and 55-64 (84%) years olds are more likely to agree that they would be motivated by a positive impact on their own health than 16-24 (64%), 25-34 (70%) and 75-84 (64%) year olds.

35-44 (77%), 45-54 (80%) and 55-64 (78%) year olds are more likely to agree that they would be motivated by getting access to the latest treatment for a condition they have than 16-24 (64%), 25-34 (67%), 75-84 (70%) and 85+ (53%) year olds.

**Gender** Women (80%) are more likely than men (75%) to agree that supporting research into a condition a close family member suffers from would motivate them to take part.

**Educational attainment** Those with a degree of degree equivalent and those with other qualifications are more likely than those who have no qualifications to say they are motivated by helping others by helping to find new treatments, a positive impact on their own health, getting access to the latest treatment for a condition they have and supporting research into a condition a close family member suffers from.

**Employment status** Students (90%) are more likely to agree that they are motivated by helping others by helping to find new treatments than those who are employed (76%), self-employed (70%), retired (66%) and out of work and looking (50%). Employed persons (77%) are more likely to be motivated by getting access to the latest treatment for a condition they have than those who are retired (71%). Students (96%) are more likely than any other group to strongly agree that they are motivated by supporting research into a condition a close family member suffers from.

## 5.3 Exploring motivations in more depth

---

When exploring what would motivate people to take part some clear themes emerged from both the open survey questions and the in-depth interviews,. The key motivations are summarised below.

### It would have a positive impact on my own health

Many felt that they would be motivated to participate because it may have a positive impact on their own health.

*"I've got a few health problems so I would like to take part to see if there any treatments or information in regards to arthritis that would help me"*

*"I have arthritis - anything new to improve life or find a cure."*

*"Finding a drug that helps me."*

*"If anybody could help me with my lifestyle and my health, I'm in a lot of pain, I'm overweight, so that would help."*

Although some people who responded did not currently suffer from a condition, they suggested they would be motivated to take part if they did and it would help that condition.

*"I still think the key motivation for me to do it would be if there was something detrimental to my health or something for my health and well-being to improve my lifestyle."*

*"Of course I would, if I had a condition that required treatment and was offered something that would alleviate that."*

>>>

Further, some suggested that they would take part as a last resort if nothing else would help their condition.

*"If I had something that was as of yet untreatable I'd give it a go, but otherwise no."*

*"If I was in an unfortunate situation of having a life threatening illness then I tend to think you grasp at anything."*

### **Altruistic motivations and helping the people around me**

A willingness to help with clinical research relating to a condition that those close to them suffer from was evident in people's responses.

*"Because my mother has dementia."*

*"In recent years a lot of people I know have suffered from cancer and arthritis."*

*"I suppose its family history, we have had a run in with cancer so I suppose we would be interested in getting involved."*

*"My son's diabetic, anything that would help."*

Respondents also suggested that they were motivated by a more general altruistic sense of helping others.

*"Because I want to help people."*

*"If it helps give people a better life."*

*"It's being out there trying to help somebody that is unable to help themselves."*

### **It will help advance medical science**

Some respondents expressed that they would be likely to take part because it may help improve medicine and medical science.

*"Because it is interesting and it helps the process of medical science."*

*"I feel if people don't participate then science will not advance, for everyone's benefit."*

*"It is important to help the development of medicine and if people aren't helping then there would be no progress and it wouldn't get anywhere."*

### **I would find it interesting**

Respondents said that they would be motivated to take part in various types of trials because they found it interesting.

*"I find that really quite interesting, I quite like a bit of psychology myself, I'd like to see what goes on in their heads to make it go one way or the other."*

*"Yeah that's a fascinating thing, it's just so clever!"*

*"I'm quite interested in exercise and diet."*

*"Because it would be interesting to see how your health can be affected by those types of things."*

>>>

### **Because I've taken part before**

Those who had already taken part in clinical research suggested they would again because of their previous experience.

*"Previous experience in a clinical trial."*

*"Already have been part of a clinical trial for cancer. So far it is a beneficial experience."*

*"I have already taken part and thought it helped."*

*"I have previously been part of a clinical trial and had a good experience."*

### **Money**

Earning money through participating was a clear motivation for a minority of people.

*"Depending on what the cash incentive was. I wouldn't participate in it if there was no financial gain because of the dangers behind it."*

*"It would depend what it was in aid of and if it was for money."*

*"If there was a large pay out I would take part."*

## 6. Barriers to taking part

### 6.1 Why don't other people take part?

We also looked into the barriers to taking part in clinical research. When asked what may stop other people from taking part, respondents mentioned:

- Being worried about the risks
- Lack of knowledge/information
- Lack of time to be involved.

### 6.2 What stops you from taking part?

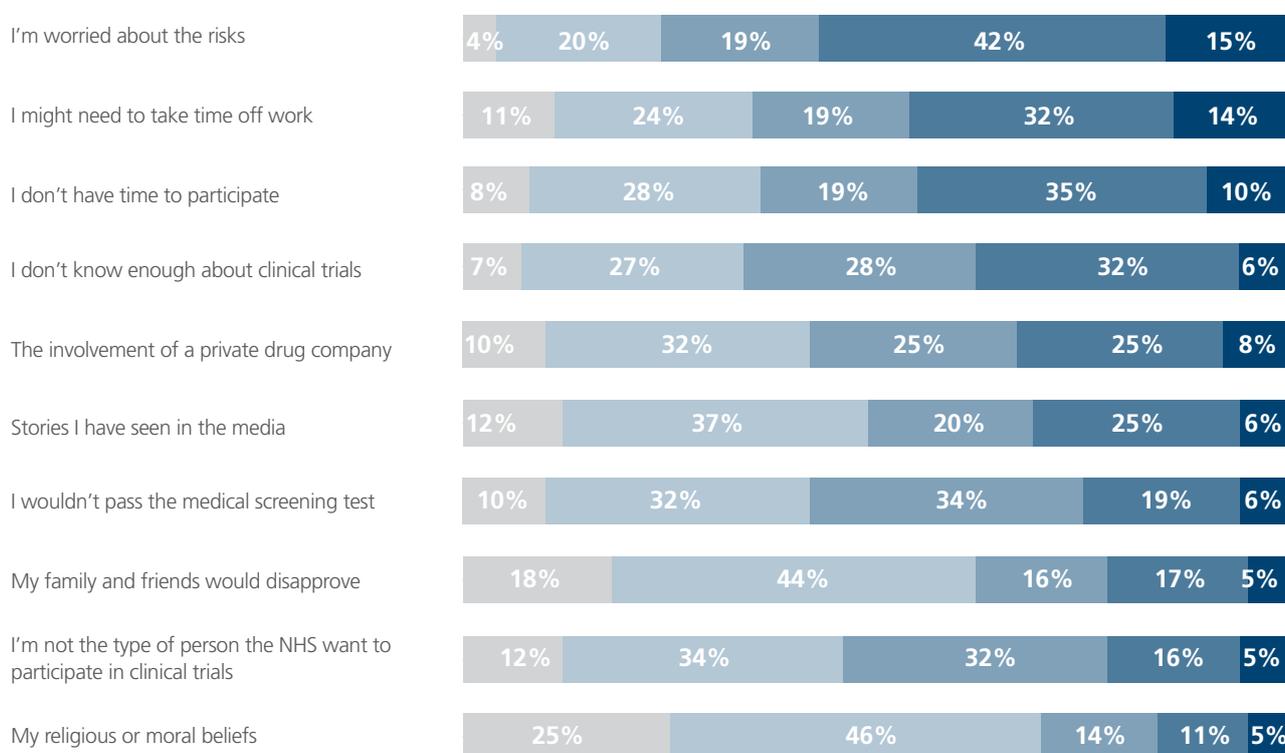
In order to explore this further, respondents were asked what would stop them personally (rather than others) from taking part. Respondents' answers reflected concerns about the risks involved in clinical research, a lack of knowledge and information, and practical issues with time and having to take time off work.

When prompted, it was clear that there were other issues which concerned respondents. For some, the involvement of private drug companies (33%) and stories they have seen in the media (31%) would stop them from taking part in clinical research.

Figure 6

#### To what extent do you agree or disagree that the following would stop you from taking part in a clinical trial?

Base: 1101



Strongly disagree
  Disagree
  Neither agree nor disagree
  Agree
  Strongly agree

>>>

### 6.2.1 Demographic differences

**Understanding of clinical research** Those who have a very good understanding (41%) are the least likely to agree they are worried about the risks, rising with some understanding (55%), little understanding (60%) and no understanding (62%). Those who have no (50%) or little understanding (48%) are more likely to agree that they don't have the time to take part than those with some (40%) or very good understanding (37%).

**Age** Those aged 85+ (70%) are the most likely to say that not knowing enough about clinical research stops them from taking part. Those ages 75-84 (43%) and 85+ (59%) are the most likely to think that they are not the type of people the NHS want to take part.

**Gender** Women (62%) are more likely to say that a worry about the risks would stop them from participating than men (52%). Women (48%) are also more likely to worry about needing time of work than men (43%).

**Educational attainment** Those with no qualifications are least likely to agree that they are worried about the risks of participating (50%), that they don't have the time to participate (39%), and that they may need to take time off work (33%). However, this group are the most likely to agree (27%) that they are not the type of person the NHS wants to participate.

**Employment status** Those who are unable to work are least likely to agree (38%) that they are worried about the risks than those who are employed (58%), self-employed (66%) and homemakers (63%).

**Dependents** Those with dependents (66%) are more likely to be concerned about the risks than those without (54%). Those without dependents (23%) are more likely to think that they are not the type of person the NHS wants than those who do (15%). Those with dependents (54%) are more likely to say they do not have the time than those who do not (41%).

**Health** Those with very bad health are most likely to agree that they are worried about the risks (62%) and that they are not the type of person the NHS wants (57%).

## 6.3 Exploring barriers in more depth

---

From the open-ended survey questions and the in-depth interviews, we were able to explore these barriers further. The key barriers are summarised below.

### Risk

Some expressed a fear of the risks involved, and that a worry of side effects would stop them from participating.

*"I wouldn't want to risk my own health in any way."*

*"I'm worried about risks – 'elephant man' comes to mind."*

*"I wouldn't want to take part because of the unknown side effects."*

*"Something could go wrong and leave you worse off than you were before you started."*

*"I would be scared. It's something new and I would feel like I was the person finding the side effects to a drug."*

People also expressed that the risks gave them concerns about the people around them they have responsibility for.

*"I've got two kids and wouldn't want to risk it."*

*"Because I've got a family, I'm more likely not to because if anything happens to me it will leave my kids without their mother."*

*"I would feel what would happen to me and the rest of the family if something did go wrong, what would happen to the rest of the family, how would they be able to cope?" >>>*

### **I don't know enough**

Many also expressed a lack of knowledge would prevent them from taking part.

*"Not sure whether it would be for me. I don't know enough about it."*

*"Because I don't know enough about it."*

*"My lack of knowledge about the process is the thing that stops me from taking part."*

### **I don't have time**

Further, many expressed that they just did not have the time, nor would they be able to take the time off work to take part:

*"No time off work."*

*"It would be hard to fit time around my life for it."*

*"I wouldn't have time to take part."*

*"I couldn't afford to take time off work."*

### **I am not the right sort of person**

A reason for which some people said they wouldn't be likely to take part in clinical research was that they felt they were not the right sort of person.

*"Don't know whether I would fit the criteria."*

*"They are not looking for people like me."*

*"Not suited for it."*

Many respondents went into detail about the specific reasons they felt they were inappropriate. Some thought their age meant they may not be suitable.

*"I'm too old."*

*"I'd think you want younger people for trials."*

*"I'm 63 now and I'm not at all sure if I would be suitable."*

Other people suggested that they may not be useful, or be good at it.

*"I'm not sure I'd be qualified but possibly."*

*"I don't think I would have enough know-how on the way the two different things operate."*

*"I can't see how I would be useful."*

*"I'm not very good at following cameras and things, I wouldn't be very good at that."*

>>>

Many held perceptions that they would be inappropriate because they are fit and well.

*"They can't cure something if you haven't got it."*

*"You can't perform an operation on someone that doesn't need it."*

*"Drugs are given to someone in order to cure something, so presumably they would have something."*

*"If there's nothing wrong with me, why am I taking part?"*

### **I don't like drugs or needles**

A number of respondents also mentioned a fear of what would be involved, particularly relating to needles and drugs.

*"If it involves taking tablets or having injections I don't like either."*

*"I don't like needles and I'm just not interested."*

*"I wouldn't take part as I am scared of needles and I don't like taking drugs."*

### **I'm healthy/I'm unhealthy**

Those who were healthy saw this as a reason for being unwilling to take part:

*"I don't want to tempt fate, but I am in normal health at the moment."*

*"I am a healthy person and would like to keep it that way"*

However, those who were unhealthy also saw this as a reason to not take part:

*"I have medical problems of my own, that I wouldn't wish to agitate further."*

*"I have health problems and it would be foolish, there would be risks, I think my risks would be heightened."*

### **I don't trust them**

For some people, a lack of trust of those who run clinical studies was apparent.

*"I wouldn't trust the people conducting the studies."*

*"Don't trust the people that are running it, they are not open, they are not as open as I'd like them to be what's going on. If you're putting yourself at risk."*

*"I never trust those people."*

## **6.4 What do people mean by the 'risks' involved?**

---

As risk is such an important barrier, we explored the concept of risk in more detail as part of the in-depth interviews. When we asked people about the risks involved in clinical research, key themes to emerge were:

### **The unknown**

Many respondents saw the risks as being linked to something unknown.

*"I guess the unknown, that's the biggest thing. You don't know the outcome, you don't know how you're going to react towards something, because we're all very different."*

*"You're going into an unknown, you don't really know till you do it."*

>>>

### **A bad reaction**

Many saw the risks as a bad reaction to what was being researched.

*"Having an adverse reaction to whatever it is you're trialling."*

*"Something could go drastically wrong and the person on the trial could have some dreadful reaction to whatever it was he or she was given."*

### **A condition I already have getting worse**

Many people saw the risk as them feeling worse off because of the trial, particularly where they already experience ill-health.

*"I would have to make sure there was no chance it would make my health conditions worse than they already are."*

*"Medical experiments are a bit more awkward, you're testing on people who are ill already; the downside risk is that either it doesn't work or it makes you worse."*

### **Risks are inevitable**

However, many respondents saw the risk was an inevitable part of clinical research.

*"Obviously there is going to be side effects, that's the whole point."*

*"Well, that's what it is really isn't it, there's going to be risks in doing what you're doing."*

*"I understand there is a risk, there's a risk on anything you do really."*

*"Obviously I don't want to die, but there's always risk involved."*

## **6.5 How are people forming opinions about risk?**

---

We also explored how people felt that they had formed their views on clinical research.

### **Lack of knowledge about the risks**

A common theme suggested that many people felt that they didn't know enough about the risks of clinical research, and that their opinions were based on this lack of knowledge.

*"Well I just think it's a lack of knowledge."*

*"Probably lack of knowledge about the individual thing. I think it's probably not knowing too much about things..."*

*"It's not something I know a lot about, it's uneducated."*

### **Personal experience**

Others suggested that their own personal experience had helped them to form opinions on the risks.

*"I've seen what other SATIN's can do, because I've seen it with my own eyes so as you say personal experience."*

*"It's personal experience and having to do risk assessments in my job."*

*"Through my work as a nurse and the things I've done, seen and heard, it all makes people more aware of what's happening."*

>>>

## **The media**

The media was commonly cited, both in a positive and negative sense.

*“On the television, you hear about things that have gone wrong. Sometimes even after a drug has been approved and subsequently side effects, might only be a small number of people that it impacts to that extent, but you hear about it in the press.”*

*“Just by generally reading newspapers and watching television over a large number of decades.”*

*“Basically just looking at media, reading the paper, frequent death by clinical research would be an issue but it’s not there.”*

## **I’ve looked into it myself**

Some respondents had proactively researched into the issues themselves.

*“I suppose I’ve been interested and I’ve done a little bit of background reading.”*

*“Through my own personal research.”*

*“I read a bit online, that is just basically what I’m going off.”*

## **General awareness of it**

Some could not say exactly where or how they had formulated their opinions, and put it down to a general awareness of the subject.

*“A little awareness.”*

*“I suppose it’s just what you hear, the things I pick up.”*

*“I find it hard to pinpoint a time where I had formulated an opinion, because it’s to do with everything I have ever learned, read, thought.”*

## **6.6 What might reassure people?**

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We also looked into what would help reassure people about the risks.

### **I’d feel better if I had the information**

Many respondents felt that if they had more information about the risks, they would feel better about what was involved.

*“Providing I knew, someone really talked about it face to face, rather than on the phone perhaps. I’d probably feel more secure.”*

*“I would want to know a lot more information; I wouldn’t do something without knowing the risks.”*

*“It doesn’t scare me off, it makes me a little bit, you know, I want to know exactly what I’m going into and what the outcomes might be.”*

>>>

### **I'd feel better depending on who was doing it**

Others suggested that the company who does the research would be a factor.

*"The thing that would make me more confident is the people who are in charge, it's all about people, if I'm being asked to do anything and I felt the people who were running it were idiots I wouldn't do it, I'd want to evaluate the people."*

*"A recognised company that's doing it."*

### **You just need to weigh it up**

Some also felt that they just needed to weigh up the risks themselves and make an informed judgement.

*"If the risks are explained clearly you need to make a judgement on it."*

*"You as a person have to be make a judgment call as to understand all the risks and the adverse effects that could happen to you because everybody is different."*

*"I would investigate and look at what the risks are at the different levels; at the start of the trial, midpoint and at the end."*

*"I would investigate, i am quite good at research, I would probably look at what people are doing now, what I was taking, if I was taking something for you I would have already done my own research into it."*

## 7. The experience of taking part in clinical research

### 7.1 What motivated people to take part?

---

Of the 10% of respondents who have taken part in clinical research, it was important to find out why they chose to participate. Generally, their motivations echo those given earlier. The main reasons for taking part in research were:

- A positive impact on their own health
- Helping others/altruism
- A particular interest in a disease/condition
- Being asked to take part by a clinician.

Those who we spoke to in the in-depth interviews who had taken part in clinical research before echoed similar motivations:

*"I thought there was something positive that could have come out of it for me."*

*"I was motivated more because of my dad dying of cancer."*

*"[My doctor] asked me and I couldn't think of a reason not to."*

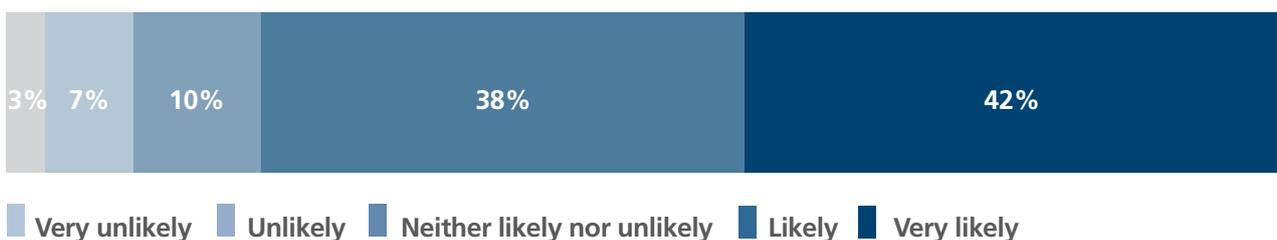
### 7.2 Would people recommend the experience?

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It is of particular interest that 80% of those who took part in clinical research would recommend the experience to a family member or friend. We can gauge from this that when people do take part in clinical trials, their experiences are positive.

**Figure 7**

**Based on your experience, how likely would you be to recommend taking part in clinical research to a friend or family member?**  
Base: 98 (Respondents who have taken part in a clinical trial)



### 7.3 Why would people recommend the experience?

---

To explore further why people were likely to recommend the experience, we asked them to explain why. Some clear themes emerged.

#### **It was a good experience**

Many said they would recommend taking part because the experience they had was positive.

*"It was very easy!"*

*"It was beneficial for me, I was given a new drug that helped me."*

*"Because I have taken part and the whole experience was very good I got a lot of help and support, having cancer made me do it."*

*"I had a positive experience but I feel that it is something everyone should take part in."*

#### **If it would help that person**

Some also suggested they would recommend it particularly if it would help the individual considering participating.

*"Depending on whether it would be helpful to the individual."*

*"If it helps your condition because I am disabled I would really recommend it to anyone."*

*"My son is allergic to peanuts and I know there has been lots of research done into it, if the opportunity should arise that he could test something to help him I would recommend it."*

*"Because it can provide you with opportunities that are not available through normal healthcare channels."*

#### **To advance medicine**

As seen earlier, many suggested they would recommend taking part because it would help to advance medicine.

*"It is important not just for me and my family, it is important to know everything that we need to know."*

*"If people didn't take part in trials, then we wouldn't get any nearer to cures."*

*"It is helpful and you can't prove cures if you don't help out."*

*"If you don't take part, you won't see how they will benefit others and yourself."*

#### **Because it's not harmful**

Many suggested they would recommend the experience because there was no particular harm in taking part.

*"There was no hassle it didn't cost me anything and it helped so why not."*

*"It doesn't affect you, doing it helps out in the long run."*

*"If there's no risk, and there's no harm, then absolutely, if you can benefit the research aims then yeah. As long as there's no significant health risks or any other major risks."*

*"Because there is no harm in it, it's all good."*

>>>

### It's still their choice

However, although they would recommend the experience, many were cautious and said they would respect their personal choice:

*"It's up to them, but I wouldn't dissuade them."*

*"I wouldn't push anyone it's their choice."*

*"If they had the time I would recommend it but not everyone has the time."*

*"I wouldn't pressure anyone. My experience was fine."*

### 7.4 Why would people not recommend the experience?

Those who were unlikely to recommend the experience also expressed some key concerns.

#### It's their choice

Those who were unlikely to recommend their experience suggested that was because they did not want to influence other people's decision and would allow them to make their own choice:

*"It's up to people to make up their own mind."*

*"It is up to the individual to decide whether they want to do it or not."*

*"It is a personal choice."*

*"I wouldn't want to lead them to do something that they didn't know anything about on my recommendation."*

### 7.5 Knowing someone who has taken part

Of those surveyed, 16% said that they know someone who has taken part in clinical research. 44% of these people said that they would be more likely to participate in clinical research in the future based on the experience of the person they know, compared to just 7% who said they would be less likely. As with personal experiences, it would appear that knowing someone who has taken part has a positive impact on perceptions of clinical research.

**Figure 8**

**From what you know about their experience, would you say it has made you...?**

Base: 173



- More likely to participate in clinical research in the future
- Neither more or less likely to participate in clinical research in the future
- Less likely to participate in clinical research in the future
- Not sure

>>>

## 7.6 Why would people be more likely to take part, knowing someone who has?

---

In order to explore why people felt they may or may not be motivated to take part through knowing someone who has, we asked them to elaborate. For those who were more likely to participate, the key themes are explored below..

### **It improved their condition**

Those who said they were more likely to participate spoke very much around the motivations that mentioned earlier, e.g. the improvement that they saw in a condition.

*"It was very good, it had no side effects and it helped out the problem."*

*"My partner's Granddad took part in clinical trials a few year back for Parkinson's disease and it prolonged his life by many years and the whole family was very supportive of the trails."*

*"I have seen the improvements the trials have given."*

*"My mum has recently gone through treatment for an illness, she tried a new drug in a trial and it was very successful."*

### **A sense of helping people**

Linking back again to people being motivated by altruism, those who said that they were more likely to participate said that they would because it helped others.

*"My brother found it interesting, and if it was going to help others I would"*

*"It's beneficial to both me and humanity!"*

*"Just because it's a positive. He knows he's terminal so either way, he likes to think some good is being done on his way out."*

### **They had a good experience**

They also mentioned that it was generally a good experience:

*"My friend tried it and had a very positive experience."*

*"The people I know have had good experiences."*

*"My husband took part and had a good experience"*

## 7.7 Why would people be less likely to take part, having known someone who has?

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### **They had a bad experience**

Those who said that they were less likely to participate on the basis of knowing someone who had participated in clinical research were concerned because of bad experiences and negative side effects which they experienced.

*"Because she got a lot of side effects from the treatment."*

*"Some serious repercussions of being involved."*

*"It was dangerous."*

*"I do not feel it was ethical."*

*"Because you don't get enough information or feedback."*

### **It was a disappointment**

Many also were disappointed with the outcome, as they did not see any positive effects. This again reflects people's desire to help themselves through the clinical trial:

*"Because the outcome has not been good."*

*"We were both disappointed."*

*"Total waste of time."*

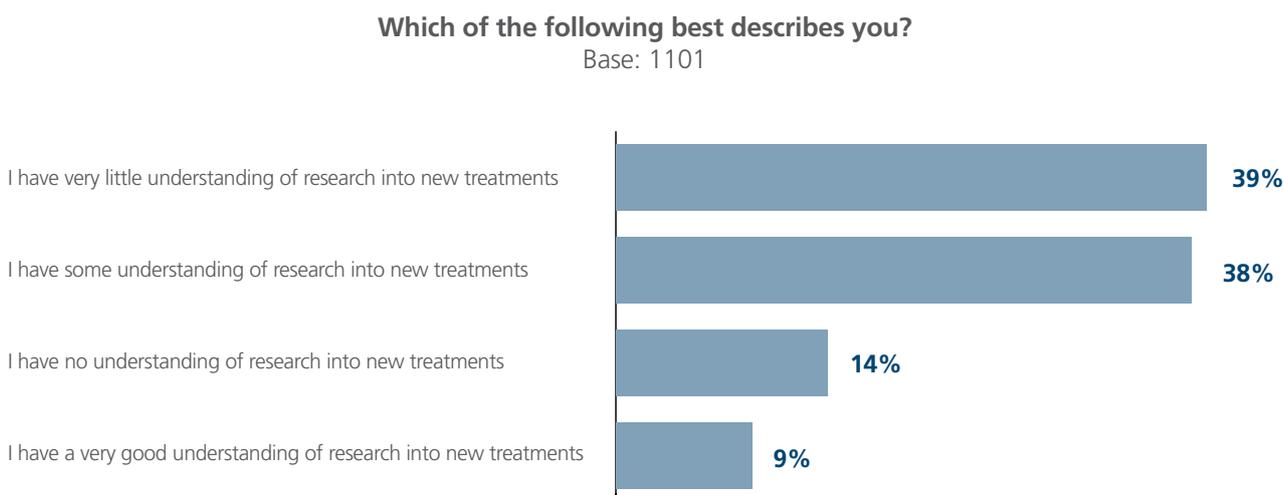
*"No effect at all."*

## 8. Knowledge and information

### 8.1 Level of understanding of clinical research

Knowledge and information surrounding clinical research was explored. As seen in section 3.3, those who had greater understanding of clinical research were more likely to participate. From Figure 9 we can see that respondents see themselves generally as having a low understanding of clinical research.

**Figure 9**



#### 8.1.1 Demographic differences

**Participation** Those who have participated in clinical research (24%) are more likely to say they have a very good understanding than those who have not (8%).

**Knowing someone who has taken part** Those who know someone who has taken part in clinical research (19%) are more likely to say they have a good understanding of clinical research than those who do not know someone who has taken part (8%).

**Media** Those who recall seeing media coverage about clinical research (58%) are more likely to say they have a good or some understanding than those who have not (41%).

**Age** Those aged 16-24 (37%) are more likely to describe themselves as having a very good understanding than those aged 25-34 (13%), 55-64 (10%), 65-74 (13%), and 75-84 (11%).

**Educational attainment** Those with degree or degree equivalent qualifications were most likely to describe themselves as having a very good understanding of clinical research (17%). Those with no qualifications were most likely to describe themselves as having no understanding (20%).

As Figure 10 (overleaf) shows, respondents tend to associate testing medicine and drugs with clinical research more often than they would identify tests on educational programmes or looking at how care is given. Many people view taking untested drugs as a major risk associated with clinical research, and this may be linked to the perception that clinical research is mainly about testing medication and drugs.

>>>

**Figure 10**

**Which of the following do you think might be the subject of a clinical study?**

Base: 1101



From the in-depth interviews, it is also clear that when many people are talking about clinical research, they mainly mean research into drugs or medication. As well as in other areas, this is quite apparent when people describe what clinical research is.

*"The first thing that comes to mind is some sort of drugs."*

*"It's where you basically, you trial drugs on someone."*

*"New drugs, reactions to similar drugs that don't cost as much, comparisons of drugs. Maybe people's responses to whether they're on drugs or whether they're not, so whether they think they're having something."*

*"Clinical research is researching cures or drugs that assist people to lead better and healthier lives."*

## 8.2 Seeking information

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Only 13% of people have sought information about clinical research. When seeking information, people tend to look to:

- General internet search/Google
- Talking to a healthcare professional
- Specific websites, particularly relating to specific conditions.

Of those who have not sought information before, when was asked where they would look if they did, they would also turn to a general internet search or speaking to a healthcare professional.

## 8.3 What information would you need?

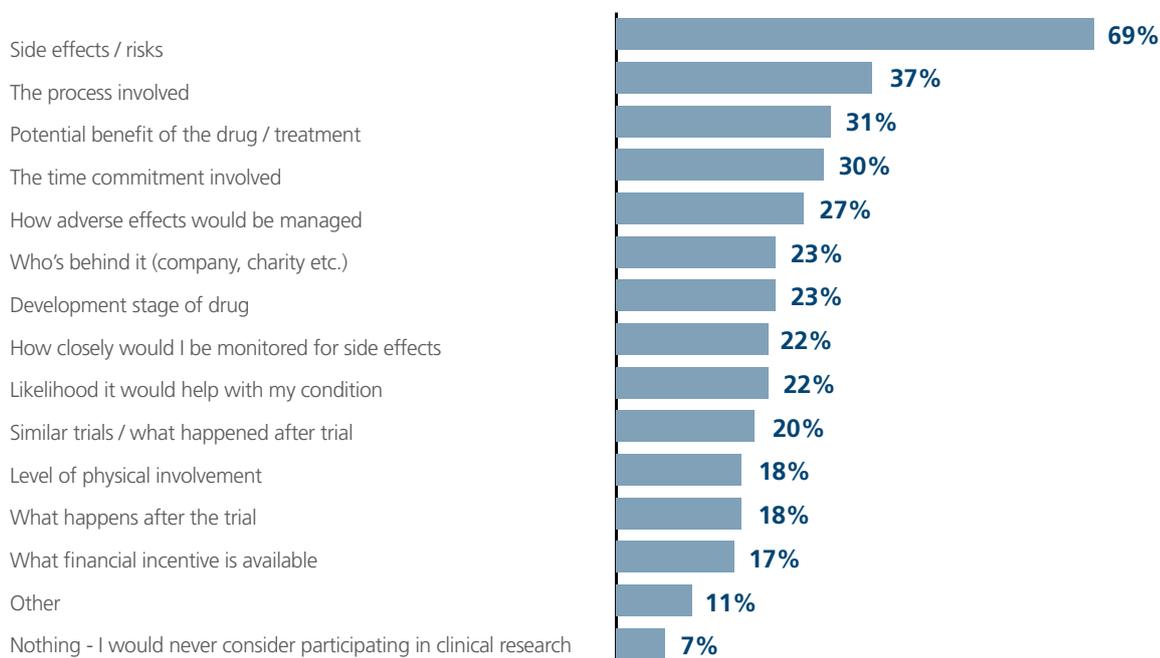
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It is important to understand what information people would need in order to take part, as we have seen previously that levels of understanding are low, and respondents have expressed that lack of knowledge and information is something which would stop them from taking part. Overwhelmingly, the vast majority of people would want more information about risk and side effects.

**Figure 11**

**Before taking part in clinical research, what types of information would you want to know?**

Base: 1101



During the in-depth interviews, many respondents indicated that they felt they needed a lot more information about clinical research before taking part:

*"I would want information on the type of research it is, if I have the information I'd feel fine then."*

*"I'd need more information, I'd need to know what the gain would be."*

*"Some good hard information, I dunno, just information I think."*

*"Just information. Either electronically or in the mail so I could read it in my own time. Things like what the trial was, what the research trial is on, and things like that."*

*"I wouldn't take part unless I was given adequate information to make a reasoned decision, otherwise I wouldn't go ahead with it."*

## 8.4 Media coverage

When asked if they recalled any media coverage of clinical research, only 35% stated they remembered seeing something. Both positive and negative stories were recalled equally. In relation to side effects, only 12% recall seeing a story about a bad reaction to drugs.

Although many people recall negative stories, media coverage may not be the source of people's concerns about clinical research. It was clear in the in-depth interviews that many did not trust the media on the topic:

*"One of the things I think I have learnt about stories coming from the media, is if you sit tight and wait a year or two, something else comes along that negates the last one."*

*"Whatever comes on the TV/radio/newspapers I always take with a pinch of salt, because they are not informed people who are saying it."*

*"No, I don't read the newspaper and don't take a lot of notice of the news because I think it's hyped up."*

## 9. Healthcare professionals' perceptions of clinical research

This section focuses on interviews conducted with healthcare professionals.

### 9.1 What do healthcare professionals think of clinical research?

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Perceptions of clinical research were generally positive. The key findings are summarised below. All healthcare professionals expressed the belief that clinical research was both necessary and important to do.

*"I think research has to be done."*

*"I really feel should be looked into"*

*"It's necessary for medical progress."*

*"I think it's absolutely imperative."*

*"I think clinical research is really important."*

*"I think it's incredibly important."*

Many thought clinical research is essential to progress medicine and medical science. Particularly people spoke about improving treatments.

*"It's to see if there can be an improvement in the process that we use or in the treatment that they have."*

*"I mean if we're to move forward and develop better treatment and better management of health conditions then it's an essential component."*

*"It's one method that can be used to try to improve the practice."*

*"It may help us give better treatment basically."*

Nurses and those whose specialist areas are rapidly changing see it as a part of their day to day working life.

*"It's just seen as an automatic part of something we do, to involve the research team."*

*"We've been doing it for such a long time, it's a part of day-to-day business really."*

*"It's engrained in our culture on the unit."*

*"It's bread and butter to us anyway because treatments are changing so quickly and always have to be tested."*

>>>

Although most perceptions of clinical research were positive, some said that not all clinical research was of the same standard. This view was held by GPs and clinicians, rather than by nurses. Generally scepticism was held because some clinical research was seen as an effort to publish, and therefore, the quality was less of a concern than the quantity of it.

*“Quite a lot of it is a complete waste of time. People just do it to rack up publications.”*

*“I think clinical research is really important but it’s done by the wrong people. It’s done by people who just need to publish papers and they don’t really care what they’re churning out as long as it gets in their publication in the paper, so I think there’s a lot of kind of cooking stuff that goes on really.”*

*“The quantity of research way outstrips the quality of it, and that’s the problem I think.”*

## 9.2 Who do they think are getting involved in research?

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Alongside perceptions of clinical research itself, we also looked into who healthcare professionals thought were more likely to get involved in research.

Many interviewees mentioned that there are some people who take the path of research and some who take the path of practice, expressing a distinct separation in activity and motivations.

*“I think the kind of person who becomes a GP is less of the research person.”*

*“If you’re in a hospital, particularly academic departments, then that’s their job.”*

*“It is pretty separate and those who are clinical researchers who do a bit of on the ward stuff and then there are a bunch of clinical people who are only ever going to be clinicians.”*

GPs and clinicians expressed the view that certain personality types were more likely to get involved in research. Generally, these were more academic people, who pay more attention to detail and are more analytical.

*“More attention to detail, completer/finisher type people.”*

*“They’ve got to enjoy doing things all the way through, they’ve got to have a particular, I won’t say obsessional but perfectionist qualities. They’re people who are involved and enjoy detail and enjoy getting stuck into things in a big way.”*

*“I mean there are different personality types but definitely those who are more interested in academia.”*

Many associated different job roles with a greater likelihood of being involved in clinical research. These roles included those with more of a medical emphasis, those who have certain specialisms and trainees.

Those who said that people who had a more medical emphasis would be more involved thought so because of the need to research into medication and treatments for those conditions.

*“To a certain extent that’s more likely for the medics than the non-medics.”*

*“I suppose medicine is probably more keen on keeping up to date with research and probably more involved. Well, medications, they always have to be researched. And conditions. Current conditions people are suffering and what’s sort of prevalent at the time.”*

>>>

Those who specialised in certain areas were generally seen to want to be involved because they dealt with people who were rarer cases, who maybe had tried everything and got involved to help their patients.

*“Well the sort of specialities where all the treatments that they do are part of a clinical trial. Oncologists and haematologists, they kind of have to be involved, whereas people in more general sorts of things, have less opportunities perhaps.”*

*“I think probably the specialist nurses. And those consultants with special interest... you see the worst types of cases and you just want something new and innovative, be it a trial or whatever, if it'll help, it's worth going for.”*

Trainees were seen to be more involved because of a need to publish.

*“Trainees are very keen to do some clinical research and get some papers published, so it aids them in that respect.”*

*“I think there's a certain element of the junior people who want to get more papers so they can be appointed to get on.”*

Others also thought that those who had training in conducting research were more likely to be involved in it.

*“Some clinicians have done clinical research in a very supported role as part of their registrar training and those consultants are often the ones who then go on and continue to do research.”*

*“I think it's in their training, because it's part of their training to conduct trials and do research when they're medical students.”*

## 10. Motivations for getting involved in clinical research

### 10.1 What motivates healthcare professionals to get involved?

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As an important aim for hospital Trusts is to get more healthcare professionals involved in clinical research, we were particularly interested in what motivates, or what healthcare professionals thought motivated others', involvement. The key themes are summarised below.

Nurses and GPs said that they thought a key motivator was to advance the field of medicine they were in and their practice.

*"The main thing is the interest of finding out and creating new directions."*

*"I think they need to see a direct correlation towards it improving their own practise. So the trials that we run here would change our practise here in the emergency department."*

*"I think the main thing is the interest of finding out and creating new directions in a particular subject."*

*"The benefit to knowledge within the practice."*

*"The need for new advances, new drugs, new treatments."*

All healthcare professionals agreed that patient benefit was critical. Some spoke generally about the benefit to the wider patient group that research was taking place.

*"We have to progress, we have to look at improving patient outcomes and that might involve research. It is about improving patient outcomes."*

*"It's all about getting it right for the patient, but it actually has to be something that you're going to change to make it better for your patient group and then you become very motivated."*

*"Trying to find out what is the best treatment for my patients. Furthering our understanding so we can pass better care on."*

*"Trying to find out what is the best treatment for my patients."*

Others suggested that they would be motivated to get involved because their patients themselves would also benefit from getting involved.

*"Potential benefit to the patients as a result of taking part in the research."*

*"If you think if it's going to be an advantage to the patient, if they're going to benefit from being on the trial, if there's something extra that can be added to their normal protocol."*

>>>

Nurses and GPs also felt that personal financial remuneration, either directly or through other benefits, was also a key motivator for getting involved in clinical research.

*"We took part in that, and the true reason why we take part is often there's some money that goes along with it, and if we enter patients into trials then we get some money back."*

*"There were a lot of doctors involved and they liked the freebies."*

*"If you tell someone you'll get £5 for every form you fill in, or maybe £10, they're more likely to do it aren't they, to be honest."*

*"I think if you agree to do some research with your patient group then there are, certainly from drug companies and things, there is a financial payback, if you like."*

However a financial motivation was shared by all healthcare professional groups in terms of bringing income into their organisation.

*"Also the income to the Trust in terms of research, the income generated."*

*"The financial benefit to the practice."*

*"Obviously a hospital is a business looking to make some revenue on the back of that, so commercial projects are of relevance and of interest."*

GPs and clinicians expressed that an interest in research and learning about how things work was also a key motivator for getting involved.

*"I suppose if you like. I imagine there are some people out there that do actually like doing that type of research, keeps the brain healthy and active doesn't it."*

*"Some people have an academic interest more than a clinical interest."*

*"Interested in purely finding out how things work and then trying to establish medical facts."*

Clinicians and nurses also said that they felt that career development was a reason why they, or others, may get involved in clinical research.

*"Career progression."*

*"There are those people who feel that they will personally gain as a consequence of doing clinical research because it aids their CV so will be more likely to get involved in it."*

*"Yes, you do the research because it ticks a box to review in your career."*

*"I suppose professional advancement, taking part for the papers, to get their names in lights, as it were. There's certainly a professional advantage having that on your CV."*

GPs also expressed career motivations for taking part, however, they felt that people did clinical research as a means of publishing papers. This was generally seen in a more negative light, though it was seen as a motivation for others to take part.

*"It's done by people who just need to publish papers and they don't really care what they're churning out as long as it gets in their publication in the paper."*

*"I think it's just about people being interested in research, but the actual goal behind that is just to have loads of papers behind your name to show that you're a successful academic."*

*"You kind of have to publish, there's a feeling it should be published."*

## 11. Barriers to getting involved in clinical research

### 11.1 What stops healthcare professionals from getting involved?

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To understand increasing participation in clinical research, we looked into why people weren't taking part in clinical research, or what they thought the barriers to getting involved were. We also asked why they thought they themselves, and other healthcare professionals, did not take part.

Time was seen as a significant factor as to why people did not want to take part in clinical research. GPs and clinicians felt that their working days were already pressured.

*"There's not enough hours in the day to do the job anyway."*

*"Well personally, I mean we can all make ourselves busy enough seeing patients and find something else to do with our time so it's very easy not to do research."*

*"Yeah, you couldn't physically fit it in to everything that goes on at the day at the moment."*

*"I think at the moment it's time, the fact that they are under a lot of pressure because of targets and the fact that governments change and then general practice has to change so they're all chasing their tails in terms of just running a practice is involved."*

On a related note, GPs and clinicians felt that a key barrier was that they had to use their own time to do it rather than having time within the working day to get involved.

*"From my own experience, the only time you would be able to do it would be on your own time because there's just not that time allowed during the working day."*

*"You don't get any time set aside to do it so you do it all in your own time."*

*"At the end of the day I certainly have no voice left, and it's probably eight o'clock at night when I get home sometimes, and I'm like, 'okay I'm just going to sit down and have a glass of wine, watch some telly, get on with something else,' you know rather than sitting there and burning the midnight oil gathering data about something or other."*

All healthcare professionals commented on the amount of time that doing clinical research takes itself. Generally, however, when people were referring to the research being time consuming, they were referring to the whole process of initiating the research themselves, rather than becoming involved in an already existing project.

*"The trouble with research is you have Nobel Prize winning idea in the bath, it takes you three years to get anything done and then to publish and peer review it. So you need to be quite patient, don't you?"*

*"I did a project in 2004 and it takes so long to start to get it off the ground that's what makes me not want to do that again in a hurry."*

*"And timing, it takes so long to get these things up and going."*

*"It's a large piece of work to put a grant application together I believe and to get funding and go to all the R&D approval and the ethics approval – all the things that are completely necessary to make sure it's robust and safe research but it's time-consuming."*

>>>

Many also feel that the processes associated with initiating research projects are complicated and bureaucratic and therefore off-putting .

*"I think there is a lot of bureaucracy there and I do think it could be slimmed down a bit... it is still quite complicated."*

*"There's a lot of form filling to get anything done."*

*"The admin hassle of it, there is so much paperwork involved; the European Union has so much to do with it they don't help at all the red tape and paperwork around getting research done is such a nightmare, and the funding."*

*"Well I think it is discouraging that you've come up with these fantastic thoughts and ideas, and then your enthusiasm wanes, I think. There's lots of barriers put ahead of you because you've got to tick this box and tick that box. Obviously the boxes have to be ticked, it's all got to be safely done, but it can be a bit dispiriting."*

Specifically, clinicians mentioned how going through the ethics committee can be difficult, and therefore acted as a barrier to taking part.

*"Medical ethics are notoriously hard to get any sort of research through, any sort of ideas through."*

*"Going to the ethics committee takes months."*

*"It can come down to even small things like in our ethics committee, R&D committees there's data confidentiality, it is a bit of a minefield out there and the detail that's gone into it is very fine."*

Further, the process for gaining funding, and the likelihood of receiving it, for a project was said to act as a deterrent to taking part.

*"The funding is a bit difficult."*

*"If you wanted to take on a research project in your department then that would need to come with funding and at the moment that's pretty difficult to obtain."*

*"You've got to back it up with very good credentials as to why you're the most deserving of this particular amount of money which aren't small sums so you have to make your case, be interviewed and, you know, come under scrutiny and defend your reasoning for why it should be yours. It's quite a tough business."*

Clinicians also mentioned that the lack of support they receive for clinical research projects was low. This support ranged from data collection to statistical advice.

*"Looking at all these patients and collating all the data is almost a job for full-time or part-time research assistant. We don't as a general rule have very much in the way of access to those."*

*"It's not the easiest of things to get some statistical advice sorting out the data that one has collected."*

*"The big problem, as with any trust, is having enough research nurses who actually do the donkey work. It usually falls back to clinicians and/or trainees to do it, who are woefully inexperienced, have no time for it."*

>>>

Some expressed that they were not aware of what was going on and this lack of awareness acted as a key reason for why they were not taking part.

*"I'm sure there were projects that I could've got excited about, I just didn't know where they were or whose they were."*

*"I mean I haven't gone out and sought that information, but it's certainly not publicly available anyway. I haven't come across it, and I'm someone that is quite aware and familiar with the system and looking in places for things, but nothing has been highlighted."*

*"And yet, perhaps, they're not being made aware of clinical research into what they're doing because perhaps they think, 'well it doesn't affect me,' whereas it does really."*

Further, a lack of being asked or given the opportunity to consider involvement, was also expressed.

*"I've never heard anybody do a sales, hearts and mind marketing exercise that would make you think "oh that could be a definite maybe". Rather than "that's too difficult" or "I know nothing about it"."*

*"We're required to just do bloods whenever and do the trial. I don't think we were actually given the opportunity to get involved independently."*

Some nurses took the view that they were just not interested in taking part. Generally, this was because they found the idea boring and more of an administrative, data collection task.

*"It seemed at the time to be more of an administration, sort of less interesting."*

*"But certainly on a professional level, I found research boring."*

*"There must be people who want to be involved in that, collection and punching numbers into computers, that wasn't something enticing to ask. I'd think, data collection and punching numbers into computers, I won't do that."*

Other nurses said that their lack of desire to be involved was because they were more interested in providing care than doing the research.

*"I didn't want to get involved in it because I didn't see it as a caring profession. I didn't see it as a role where I'd be involved with the families very heavily."*

*"That wasn't what I wanted to do. I wanted to be hands on."*

*"It's not a direction that I really wanted to go down. I have a more clinical background to delivering patient care."*

## 12. Research opportunities

### 12.1 Approaching healthcare professionals

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Those who do recall someone approaching them about a clinical research project reported a variety of different organisations and people who had approached them. Generally, different healthcare professionals said that they were being approached by different people.

Nurses tended to say that they were being approached by their internal team or that information about what they would be taking part in simply filtered down to them.

Clinicians said that they were often approached by their own team and also often from clinical leads within their department or people from the clinical research department at their organisation.

GPs were mostly being approached by external organisations. This included private companies, including pharma, NIHR CRN:Wessex, and the NIHR Primary Care Research Network (PCRN).

Generally, most people are being approached by email. However, when the person approaching was within the person's team, it was sometimes done face-to-face.

There were, however, some that stated that they just weren't being asked.

*"I don't think I've been approached by a private company for ages and ages."*

*"I can't think of anything in the last twelve months from that respect."*

*"I think there's less approaching these days than there was."*

### 12.2 Why are healthcare professionals approaching patients?

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On the whole, the healthcare professionals interviewed are not proactively approaching patients about clinical research. Of those who had conversations with patients about clinical research, there were generally two explanations for the conversation.

Firstly, this was often because of a personal involvement in a research project and these conversations would be clinician-led.

*"I've had at least three or four probably because one of the trials we're doing at the moment."*

*"It was part of what we needed to do for the project – we had to tell them what we were doing and what data we were collecting, giving information."*

*"Because it was my job to recruit them into the trials."*

Secondly, some healthcare professionals said that they were having conversations because their patients had approached them about clinical research, often based on something they had seen in the media.

*"Yes, occasionally patients will read something in the daily papers that a revolutionary new treatment has been written about. So 'can you make a 3D hip replacement for me?' And the answer is no, not at the moment."*

*"Some chap was currently taking part in a research programme: it's a trial of the benefits of aspirin, or otherwise, in a study. He wanted to talk about the recent press that has been on the front page of all the newspapers and whether it was safe for him to carry on."*

### 12.3 Why are healthcare professionals not approaching patients?

---

Because healthcare professionals appear to have few motivations for speaking to patients about clinical research, it is important to understand what is stopping them from having these conversations.

Time was a major factor for not approaching patients.

*"Yes, occasionally I did but I think it's very difficult to do it routinely because you need to spend a lot of time looking into it and if you see 40 patients a day then that's quite difficult."*

*"But in the ten minutes per patient it can be low on their list of priorities I suspect."*

*"I think it's probably the time factor in the clinic as well. They've come in for a purpose, they've only got a 10 minute slots so we're just dealing with whatever they've come in for or whatever they've wanted to discuss."*

As we saw above, being involved in a project meant that professionals were approaching their patients. Conversely, many felt that they were not approaching patients because they were not actively involved in clinical research themselves.

*"I haven't had any particular sort of projects lined up that have needed that sort of input."*

*"I don't because I'm not involved directly."*

As such, many also felt that they were not approaching patients because they lacked knowledge about what was going on.

*"I don't think I had the background knowledge. I didn't know what was out there. I wouldn't have recommended people if I didn't have any knowledge about it."*

*"I haven't been fully aware of what's going on and it definitely hasn't been something I've brought into conversation."*

It was mentioned by some that they don't tend to approach patients because they're not the right person to speak to them about it.

*"No, the research team would come down and do that."*

*"I think probably we'd leave it to the medical staff."*

*"I felt really that for most things, referring to a local consultant was my role."*

Nurses and GPs said that they felt it wasn't really on the patient's agenda to hear about clinical research – patients were more interested in receiving care.

*"I don't think generally patients are really that switched on when they're quite poorly that they worry about clinical research."*

*"And as long as they were happy with their care and we knew it was effective I don't think people are generally – they're in control of their care, but it's not something they stop and think about, I think."*

*"Well it's not the patient's agenda and it's not on my agenda."*

>>>

Others feel the reason they don't speak to patients about clinical research is because their patients aren't asking them.

*"It hasn't come up to be honest."*

*"The public don't ask and I think that's what motivates the professionals, members of the public coming in,*

*"what is this, I've heard about so and so" and then you are honour bound to actually find out about it, find out for them. I think there needs to be more awareness, both professionals and public."*

*"Nobody has ever approached me."*

## 13. Availability of information

### 13.1 Awareness of clinical research

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When asked, the vast majority of those interviewed said that they would feel confident speaking to patients about clinical research. Those who were confident tended to express a general awareness of clinical research and what was going on.

Though no one professed a lot of knowledge, many felt that they knew enough about clinical research generally to have a conversation with patients. They would not, however, be able to speak to patients about specific trials.

*"Vaguely, but not specifically. It all depends on the trial, doesn't it?"*

*"I would probably be about the principles about it and what it means, but not in depth because I wouldn't be involved in that research itself."*

*"General questions about being involved in research projects, yes that's fine, but specifics about the individual trial, that's a bit harder unless you were being given all the background for it."*

*"As long as they didn't ask me the specifics of the trial, for example, but if it was a general question then yes."*

Clinicians and nurses also felt that they knew what was going on around their areas or departments. Conversely, they were not as read up on anything outside their field.

*"Yes, it's going on everywhere. I'm not going to know what's going, you know, in terms of clinical research – with clinical research, medicine, gynae, dermatology, psychiatry – all these different things. Psychiatry represents 5% and if I know 20% of that 5% then that's 1% and that's most probably where I'm at."*

*"Only what's going on in my own department. I wouldn't really know what else is going on, there's loads going on in the trust."*

*"It seems to happen from its own little department and you get to hear about results sometimes but you don't necessarily hear about everything that's going on."*

However, some people feel that they don't know a lot about research and that they are not really kept up to date with what is happening.

*"I don't know anything at all really. I know there are some continual trials, there are some chemo regimes that people are on but I don't really know any more than that."*

*"I haven't been fully aware of what's going on"*

*"You don't really know what's going on and when you hear about it you think 'oh yes, that's quite a good idea, I'm glad they're looking at that' but you don't get to hear about most things that are going on."*

*"I just don't think there was any information electronically, nothing was ever advertised saying this is taking, you know, this trial, taking part, this that and the other. There was never that put over to us."*

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## 13.2 Finding information about clinical research

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To find out information about clinical research, people stated a variety of sources, including:

- General internet search
- The research team
- A colleague
- A research nurse.

Where people didn't feel as confident about their knowledge of clinical research, people often said they would refer a patient to a more appropriate person to get further information.

*"I felt really that for most things, referring to a local consultant was my role and then if the local consultant decided to refer on then that would be fine."*

*"I can always refer them to the right people."*

*"If they're still asking questions then I will get the right people to talk to them."*

## 14. The future

### 14.1 What would make you more likely to get involved in research in the future?

---

As well as understanding the barriers and motivations to taking part, it is important to understand what may help overcome these barriers. This section will focus on what healthcare professionals said would make them more likely to get involved in the future.

Time was seen as a significant barrier. Not surprisingly being given time during work time was said to increase the chances of taking part.

*“If someone would give them time to set aside and do that during work hours, I think it’s a good reason for it to get done.”*

*“Having a bit more time, having it scheduled in for us.”*

*“But I think it’s something you need to be given extra time to do, to do it properly. You can’t do it as an extra and do it when you feel you’ve got the time, it has to be dedicated.”*

*“Make sure that hospitals and trusts put it as part of doctor’s job plans.”*

Nurses and clinicians feel that making the process of involvement simpler and involving less paperwork would be beneficial.

*“I think keep the process of starting the research as simple as possible. Everybody is short of time these days, so simplify that process down. I’d like to think that people are keen to do research, but not if it’s a hassle.”*

*“So the clinicians, all they have to do is get on with the research and not all the paperwork. And make the admin and paperwork a damn sight less.”*

*“More straightforward processes, things like ethics.”*

Clinicians and GPs said that having support available from initiation of the project to managing the project would help them to become involved in the future.

*“If you had a line manager in R&D just to look after you, and say look this is where were up to I need you to do this but I’ve done all this other butts and this is the stage were at now, to project manage, because you don’t have the time, or skills to project manage.”*

*“You know, and the support that’s available throughout really, so you’re not left thinking ‘oh my god I’ve got to do all this’, which I’m sure you wouldn’t do but you know some people may not necessarily know. I think that would be good.”*

*“If there was a facility and they’d set it up for you, I reckon about 30% of GPs would probably be quite interested in research.”*

*“It would be quite a big thing to have to go through the analysis of the data and give the outcomes in statistical terms. Some sort of facility whereby they could present their findings and have them analysed.”*

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Raising awareness was also seen as key. This was suggested in a variety of ways, including through workshops, events, training courses, or newsletters.

*"If they set up professions, short courses maybe, where GPs could come and learn about these things and earn CPD points towards the appraisal that would be an incentive."*

*"Educational events, sponsored evenings or whatever, with something that will appeal to the clinicians to make them want to attend to understand it."*

*"If they gave us a monthly newsletter or some sort of update, just so we could look at it as part of our team brief, then we'd all be more aware."*

*"Perhaps some mini workshops or about what sort of things you're involved in, what sort of research is available, how you can get involved, what sort of roles there are."*

## **14.2 What would make you more likely to get speak to patients the future?**

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Many people felt that the things that would help them get more involved with clinical research would, in themselves, make it easier or more likely to speak to patients. Two clear themes did emerge separately.

Though many feel comfortable speaking to patients about clinical research, some felt that they would be more likely to speak to patients if they had more information.

*"If you have a web-based directory and you go on the directory and search 'depression ketamine' and it would tell you there's a trial in Cambridge and Edinburgh and Belfast and then you could say to the patient 'would you be prepared to travel to Belfast?'"*

*"The clinician needs to know what specific research is available, what is currently happening and then you might mention it in passing."*

*"If they gave us a monthly newsletter or some sort of update, just so we could look at it as part of our team brief, then we'd all be more aware. We do leave it up to the research team really. The emphasis is on them rather than us to recruit."*

Further, some expressed that if they were specifically told to look out for people who may be appropriate for research which is happening, then they would find it easier to remember to speak to patients.

*"And if we were told and asked to look out for patients who might be suitable or suggest ideas for things then yes definitely."*

*"Yes, if you have a list of what trials were going on and what they were looking for then alarm bells would ring when somebody turns up fitting those criteria."*

## 15. Conclusions and recommendations

### 15.1 People are positive about research and participation

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The Wessex population views research in the NHS positively and a large proportion are open to participating: 90% of respondents think that it is important for the NHS to support research into new treatments, whilst 47% think it likely they would be willing to participate in clinical trials in the future.

Those that have participated have positive perceptions, and they will likely have a significant influence on others' future participation: 80% of people who have taken part in clinical research would recommend taking part to a friend or family member, whilst around half (44%) of people who know someone who has taken part in clinical research said that they are more likely to participate now because of their experience.

### 15.2 The critical conversations are not happening

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The key finding that 95% of clinical interactions do not feature discussion of trial treatment options with a clearly willing public is critical to increasing research participation. Our study has confirmed the inherent trust placed in NHS clinicians to deliver clinical trial information and suggests that interventions focussed on clinical consultations could dramatically increase trial recruitment.

#### 15.2.1 Recommendation 1

**Communications supporting participation in interventional trials should be focussed on enabling effective clinical conversations, with a reduced emphasis on broad public awareness approaches.**

### 15.3 Healthcare professionals perceive major barriers to involvement

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The healthcare professionals interviewed were broadly positive about research; however they cite workload, time and lack of local trial information as constraints on discussion of research with patients. Better trial information was also identified as something that would increase the likelihood of discussing trial options with patients.

Clinicians self-segregate themselves into 'researchers' (an academically orientated minority) and 'practitioners', with the latter positive about the benefits of clinical research and open to research referrals/facilitation but unlikely to have direct involvement in, or lead their own, research.

Direct involvement in research by clinicians is limited by lack of programmed/sanctioned time within work plans, perceptions of excessive bureaucracy and perceived lack of support.

#### 15.3.1 Recommendation 2

**Local Clinical Research Networks, local research infrastructure and Trusts' senior leadership should support NHS clinicians' engagement with local clinical trials, and to explore management and education interventions to make communication with patients about trials a routine part of all NHS consultations. Specifically:**

- Investment in integration of valid trial information online and/or in clinical software, for reference and referral during consultations.
- Active engagement of healthcare professionals inclined to perform research to develop their capacity and opportunity to do so, alongside engagement with those not inclined towards research themselves to support them in referring patients onto trials.
- Prospective development of healthcare professionals' attitude, capacity and responsibility re. research through appointment processes and contracts, work planning and CPD.
- Raising visibility and accessibility of R&D support infrastructure, and refocusing R&D support on end-to-end project management of research governance and administration for research active and research-inclined individuals.

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## 15.4 The public need information, of immediate relevance to their health

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Communications that have immediate health relevance and address concerns over risk and time commitments are likely to be most effective. Public participation motivations centred on potential benefits to one's own health or that of close friends and family, whilst perceived risk of harm and receiving the 'unknown' alongside concerns over time commitments and time off work were the biggest barriers to participation.

Better understanding of clinical research modifies perceptions of risk but only a minority have this understanding. Only 9% of respondents reported that they felt they understood clinical research very well, with this group the least likely to agree that risk was a significant barrier to participation. Generic online searches, condition-specific online sources of information and healthcare professionals were the primary sources of information, with a high degree of trust in the information provided by professionals.

### 15.4.1 Recommendation 3

**Public communications and engagement should have a greater emphasis on informing and empowering people at the point of care or enquiry, to enable discussion of trials with clinicians. Specifically:**

- Integration of trial information, participation information and concrete means of enquiry into online service information, consultant profiles and into appropriate printed material, e.g. patient information, newsletters etc.
- In addition to active engagement and materials for patients, resources for their family and friends should be implemented to enable discussion and wider participation in relevant research.
- Clear information on risk and the nature of trial treatment options, including clear statements on the degree of uncertainty of potential benefits and treatment allocation, should be prominent in all communications, engagement and conversations.

## 15.5 Time and fitting participation into life is a concern

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Enabling participants to fit research participation around work and home commitments is likely to support greater participation. Concerns over time commitments needed to participate in studies, including taking time out of work and fitting such activity into daily/family life were significant barriers to participation.

### 15.5.1 Recommendation 4

**Changes to clinical research delivery to improve convenience and flexibility for participants, alongside interventions that lower the practical threshold to participation should be investigated and evaluated. Specifically:**

- Expansion of out-of-hours/evening, community and offsite research clinics.
- Engagement with major local employers re. schemes to enable onsite participation, or release for attendance at hospital/community clinic should be explored. This includes NHS organisations themselves.

## Appendix 1 – Public survey demographics

<b>Roughly how often over the last 12 months have you given unpaid help to any groups, clubs or organisations?</b>	<b>%</b>	<b>Count</b>
At least once a week	11%	123
Less than once a week but at least once a month	7%	82
Less often	8%	83
I give unpaid help as an individual only and not through groups(s), club(s) or organisation(s)	6%	69
I have not given any unpaid help at all over the last 12 months	61%	673
Don't know	6%	70
<b>Total</b>	<b>100%</b>	<b>1101</b>

<b>How is your health in general?</b>	<b>%</b>	<b>Count</b>
Very bad	2%	25
Bad	5%	59
Fair	25%	275
Good	36%	393
Very good	32%	348
<b>Total</b>	<b>100%</b>	<b>1101</b>

<b>Do you have any long-standing physical or mental impairment, illness or disability?</b>	<b>%</b>	<b>Count</b>
Yes	27%	300
Bad	61%	669
Prefer not to say	12%	132
<b>Total</b>	<b>100%</b>	<b>1101</b>

Age	%	Count
16-24	10%	115
25-34	14%	154
35-44	17%	187
45-54	18%	199
55-64	16%	178
65-74	13%	138
75-84	8%	91
85+	4%	39
<b>Total</b>	100%	1101

Gender	%	Count
Male	48%	532
Female	52%	569
<b>Total</b>	100%	1101

Do you have any educational qualifications for which you received a certificate?	%	Count
Yes	60%	659
No	40%	442
<b>Total</b>	100%	1101

Do you have any professional, vocational or other work-related qualifications for which you received a certificate?	%	Count
Yes	9%	41
No	91%	401
<b>Total</b>	100%	442

Was your highest qualification...?	%	Count
At degree level or above	39%	271
Another level of qualification	61%	429
<b>Total</b>	100%	700

<b>Do you (or your household) own or rent your current accommodation?</b>	<b>%</b>	<b>Count</b>
Own it outright	66%	721
Buying it with the help of a mortgage/loan	6%	69
Part own and part rent (shared ownership)	4%	39
Rent it (includes all who are on Housing Benefit or Local Housing Allowance)	19%	212
Live here rent-free (including rent-free in relative's/friend's property but excluding squatters)	5%	58
Squatters	0%	2
<b>Total</b>	<b>100%</b>	<b>1101</b>

<b>Ethnicity</b>	<b>%</b>	<b>Count</b>
White British	91%	1003
BME	8%	85
Prefer not to say	1%	12
<b>Total</b>	<b>100%</b>	<b>1101</b>

<b>Employment status</b>	<b>%</b>	<b>Count</b>
Employed for wages	54%	592
Self-employed	6%	65
Out of work and looking for work	3%	32
Out of work but not currently looking for work	2%	17
A homemaker	3%	32
A student	2%	25
Retired	27%	299
Unable to work	4%	41
<b>Total</b>	<b>100%</b>	<b>1101</b>

Household income	%	Count
£0 - £9999	25%	273
£10,000 - £19,999	18%	200
£20,000 - £29,999	15%	170
£30,000 - £39,999	13%	149
£40,000 - £49,999	10%	113
£50,000 - £59,999	9%	101
£60,000 - £69,999	3%	38
£70,000 - £79,999	2%	27
£80,000 - £89,999	1%	9
£90,000 - £99,999	1%	8
More than £100,000	1%	13
<b>Total</b>	100%	1101

Dependents	%	Count
Yes	23%	258
No	72%	797
Prefer not to say	4%	45
<b>Total</b>	100%	1101

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## Further information



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