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*National Institute for
Health Research*

Survey of Lay Members of Research Ethics Committees (RECs)

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Report of a survey of lay members of Research Ethics Committees (REC)

1. Summary

This report documents the findings of a survey of lay members of Research Ethics Committees (REC). The survey was carried out by INVOLVE on behalf of the National Research Ethics Service (NRES) NHS Service Users and Ethical Review Advisory Group between September and November 2008.

Contact was made with REC lay members via a letter distributed through REC administrators. The letter encouraged individuals to either complete an online questionnaire or to complete and return a hard copy of the questionnaire. Two hundred and twenty five lay members responded to the survey.

Describing REC lay members

- Over half (51%) of the respondents were aged 61 or over, with just under half (49%) aged 60 or under.
- There were slightly more female than male respondents in the survey: 108 respondents (51%) were female and 102 (49%) were male.
- A high proportion (84%) of lay members were educated to degree level or above.
- 192 respondents (92%) described their ethnic origin as white (British, Irish or other), 5 respondents (2%) described their ethnic origin as asian and 4 respondents (2%) described their ethnic origin as black.
- 27 respondents (13%) reported they had a disability.
- 163 respondents (83%) described their sexual orientation as heterosexual or straight, 25 respondents (13%) chose not to answer this question.
- 77 respondents (36%) described their current or most recent occupation as in the public sector. 67 respondents (32%) described their current occupational status as retired.

Lay member perspectives

- Respondents were asked to select from a series of pre-defined categories the type experience they brought to the REC. Respondents were able to give more than one answer. One third of respondents reported having experience as a health professional (33%) and over one third (38%) had experience in the research field. Overall, 87 (38%) respondents indicated they had experience of either long term use of health or social care

services or caring for someone who uses services, with a further 23 (10%) of these respondents falling into both of these categories.

- Respondents were asked whether they saw their primary role on the RECs as providing an NHS or social care service user or carer perspective. Approaching half (44%) of the respondents who answered this question indicated that they had experience of being a service user or carer and considered this to be the main or primary perspective that they brought to the REC.
- Respondents were also asked whether they saw themselves as bringing a specific perspective to their REC. Many REC members highlighted how they provided a range of different perspectives. One hundred and seven (52%) respondents described their professional background, 73 respondents (39%) identified bringing a patient, carer or service user perspective and 25 respondents (13%) specifically identified that they did not have a medical, clinical or NHS background.

Lay member participation on RECs

- The survey included a range of questions relating to lay member participation in the REC including whether they thought lay members should be paid for their work on the REC.
 - Most respondents (66%) had three or more years experience as a member of a REC.
 - The main ways that REC lay members reported hearing about membership were either through an advertisement or from a friend or colleague. Seventy (38%) respondents had heard through an advertisement and 63 (34%) through a friend or colleague. A further 44 (24%) said that they heard through other means.
 - The vast majority of lay members reported that they felt that their views as a lay member were fully taken into account in the deliberations of their REC. Ninety two per cent felt that their views were either always or often taken into account. Respondents were most positive about the quality of chairing and the group dynamics. However, a large proportion also rated the training that they had received as helpful.
 - Respondents were fairly evenly spread in their preference for whether lay members should be paid an allowance for their work for the REC. The most common reason that respondents gave for supporting the idea of payment, was that payment would recognise the time commitment and expertise required to contribute to a REC. For those respondents who did not support the idea of payment, the primary reasons related to the wish to retain the voluntary and independent principles of REC work.
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2. Introduction

This report documents the findings of a survey of lay members of Research Ethics Committees carried out by INVOLVE on behalf of the National Research Ethics Service (NRES) NHS Service Users and Ethical Review Advisory Group. INVOLVE is funded by the National Institute for Health Research, to promote active public involvement in NHS, public health and social care research (www.invo.org.uk).

The Governance arrangements for NHS Research Ethics Committees – GAfREC (Department of Health, 2001) specifies that in each committee which has a maximum of 18 people, at least one third (i.e. six members) of the membership should be 'lay' members. These are people who are:

'...independent of the NHS, either as employees or in a non-executive role and whose primary personal or professional interest is not a research area. The 'lay' membership can include non-medical clinical staff who have not practised their profession for a period of at least five years. At least half of the 'lay' members must be persons who are not, and never have been either health or social care professionals, and who have never been involved in carrying out research involving human participants, their tissue or data' (Department of Health, 2001)

INVOLVE is aware that although the role of lay members of Research Ethics Committees (RECs) is described in GAfREC, there are a range of views about current practices in respect of lay membership. Dyer (2004) linked the public participation in health services agenda with the role and function of RECs, and the role lay members play is an important aspect of this. The issue of public representation on research ethics committees was raised in recommendation 7 of the Report of the Ad Hoc Advisory Group on the Operation of NHS Research Ethics Committees (Department of Health, 2005), which recommended that membership should be drawn from a wider mix of society.

In 2002 and 2003, INVOLVE facilitated workshops with service users and carers on behalf of the Department of Health about their views of research ethics review (Boaz, 2002 and 2003). Whereas there was support for research ethics review in general, there were sometimes important differences between what users and carers considered to be ethical research and traditional considerations in RECs. There was also a strong view that there should be assured service user and carer input into the work of RECs in order to ensure there was a better understanding of the context of user and carer experience in deliberations on the ethical merit of research proposals.

The NRES carries out regular equal opportunities monitoring of the membership of RECs but little is known about the current background of NHS REC lay members across the UK, and what kind of input into RECs they actually have. In order to remedy this situation INVOLVE undertook this survey of lay REC members to begin to build a clearer picture, particularly with regard to the input of health and social care service users and carers into ethical review of health research.

3. Aims

The aim of the survey was to find out about the range of contributions that lay members are able to provide on RECs. The word 'lay' is a very broad term, so the contributions and perspectives offered by lay members may be quite broad and varied. The survey sought to find out more about the current range of backgrounds, contributions and perspectives of lay members across RECs nationally.

4. Approach

It is estimated that there are about 5-600 lay members of RECs across the UK and all of these were given the opportunity to respond to the survey. The survey was entirely anonymous with responses neither linked to an individual or REC.

The survey asked questions about:

- The background and demographic characteristics of lay members
 - What attracted lay members to contribute to a REC
 - What sort of knowledge, experience and perspective they saw themselves as contributing to their REC
 - Whether lay members should be paid for their contribution to RECs
 - Their ability to contribute to the REC and the factors which help or hinder this
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5. Methods

The survey was designed by INVOLVE in discussion with members of the NRES NHS Service Users and Ethical Review Advisory Group. Following piloting of the survey with four ethics committees, and further feedback from the Department of Health and NRES, the survey was conducted over a two month period between September and November 2008. See Appendix 2 for a copy of the questionnaire.

Initial contact was made via a letter distributed by NRES and REC administrators to all lay members. The letter encouraged the option of completing the survey online using Survey Monkey software. However, a paper copy of the survey with a free post address was also provided. Halfway through the survey period, the administrators sent reminder emails to REC members. Both online and postal returns were returned directly to INVOLVE and were completely anonymous.

All the returned paper surveys were entered into the Survey Monkey software. The complete dataset was transferred into an Access database for analysis. The survey contained a combination of closed and open questions. With the closed questions, respondents were asked to choose from a number of pre-defined answers and for some questions they could indicate more than one answer. In the analysis the frequency of responses for each question were counted and the percentage calculated. For a small number of questions responses were compared to the responses of other questions to explore whether there were any patterns across the respondents. For the open-ended questions respondents were asked to explain the answer to a previous question or invited to describe their experiences in more detail. For these questions the analysis focused on reading through all of the answers and identifying the main issues that were raised by the majority of the respondents. These responses were then counted and percentages calculated.

6. Results

Two hundred and twenty five lay members responded to the survey. Assuming 600 lay members across all RECs, this gives an estimated response rate of 37.5%.

Respondents were not required to complete all the questions in the survey and many left questions blank, therefore in the presentation of the results the total count for responses do not always equal 225. Where percentages are given, these are based on the number of respondents to the question, rather than the total responses to the survey (due to rounding percentages may not always add up to 100). For most of the questions and categories devised for the open-ended questions, respondents could fall into more than one category, therefore the total responses are often greater than the number of respondents.

The results are presented in three sections:

1. Describing REC lay members
2. Lay member perspectives
3. Lay member participation in RECs.

6.1 Describing REC lay members

Figures A1-A7 in the appendix, provide the detail of the demographic characteristics of the respondents to the survey. These are summarised as follows:

Age

Over half (51%) of the respondents were aged 61 or over, with 102 respondents (49%) aged 60 or under. In the NRES Equal Opportunities Monitoring Survey of REC members carried out by NRES in 2007, the figures

are similar with 46% of lay members being aged 61 or over. This contrasts with the age of professional members in the NRES survey, where members were much younger with only 9% aged 61 or over. It also contrasts with the national picture with around 21% of people in England and Wales being aged 60 years and over.

Gender

There were slightly more female than male respondents in the survey. One hundred and eight respondents (51%) were female and 102 (49%) were male. This finding is similar to the monitoring survey carried out by NRES, which found slightly more female than male lay members as well as Census data for 2001, where 51% of the general population were recorded as female. However, the NRES Monitoring survey found that amongst professional members there were slightly more male than female members.

Education

A high proportion (84%) of lay members was educated to degree level or above. One hundred and four respondents (50%) were educated to postgraduate level, 72 respondents (34%) were educated to degree level and 34 respondents (16%) were educated up to diploma level. A slightly smaller percentage of those who defined themselves as service users and carers (Question 3) reported being educated to degree level or above (77% versus 88%) but the percentages were still high for both groups. This proportion contrasts with the general population. The Census data for 2001 indicates around 20% of the population aged 16-74 in England and Wales were educated to degree level or above.

Ethnic origin

One hundred and ninety two respondents (92%) described their ethnic origin as white (British, Irish or other), 5 respondents (2%) described their ethnic origin as Asian and 4 respondents (2%) described their ethnic origin as black. The proportion of lay members describing their ethnic origin as white is the same as for the overall population, reported in the 2001 National Census, i.e. 92%. These figures are similar to the NRES monitoring survey where 89% of lay members and 91% of professional members described their ethnic origin as white.

Disability

Twenty seven respondents (13%) considered they had a disability. The proportion was similar amongst the lay members in the NRES Monitoring Survey, where 12% reported they had a disability. Amongst the professional members in the NRES survey the proportion was 3%.

Sexual orientation

One hundred and sixty three respondents (83%) described their sexual orientation as heterosexual/straight, 4 respondents (2%) described their sexual orientation as homosexual, 4 respondents (2%) described their sexual orientation as bisexual and 25 respondents (13%) chose not to answer this question.

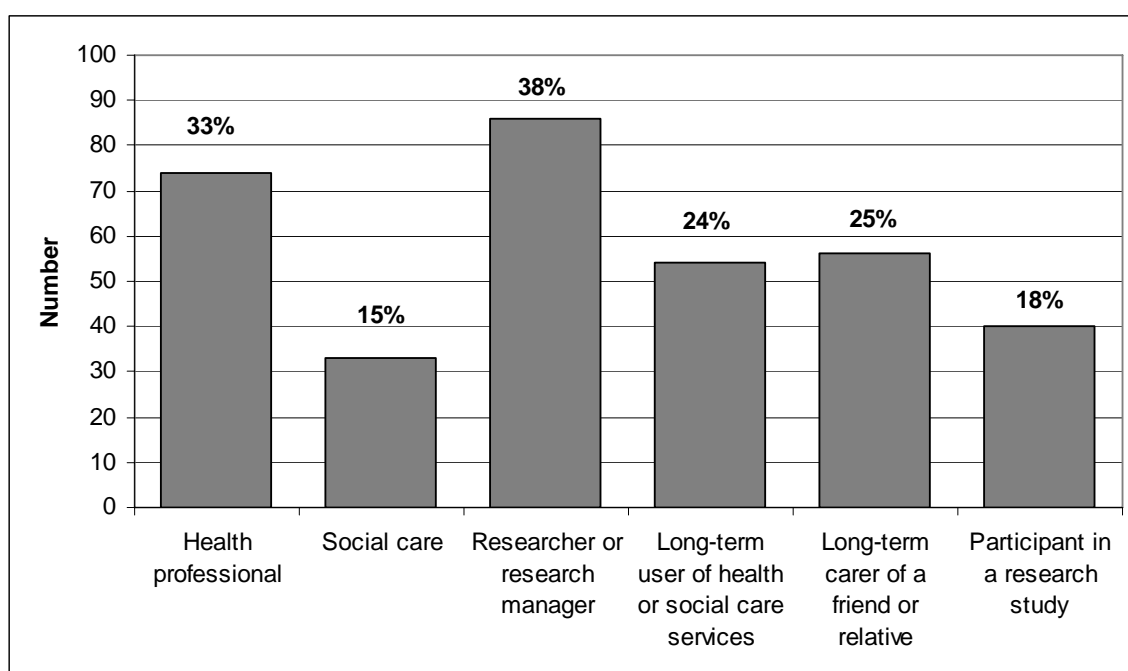
Occupation

Seventy seven respondents (36%) described their current or most recent occupation as in the public sector. Sixty seven respondents (32%) described their current occupational status as retired.

6.2 Lay member perspectives

This section of the results presents the data on the perspectives that lay members brought the REC. This was explored with them in a number of questions throughout the survey.

Figure 1: Which if any of the following experience do you bring to your REC? (Question 1)



Initially, respondents were asked to select from a series of pre-defined categories the type of experience they brought to the REC and they were asked to tick all that applied. The results of this question are presented in Figure 1. One third of respondents had experience as a health professional and over one third had experience in the research field.

Overall, 87 (38%) respondents indicated they had experience of either long term use of health or social care services or caring for someone who uses services, with a further 23 (10%) of these respondents falling into both of these categories.

As well as the categories identified above, respondents were asked to describe any other experiences they felt they brought to the REC. These responses fell into four categories:

- A. descriptions of professional experience (mainly in the statutory or private sector)
- B. descriptions of experience working in the voluntary sector

- C. descriptions of personal or life experiences, including use of health and social care services and/or caring for someone who uses health and social care services
- D. descriptions of other public involvement work.

One hundred and ninety eight respondents offered further description of their experiences and these are detailed in table 1. The most common response to this question was to describe in further detail the professional experience lay members believed they brought the REC.

Table 1: What other experience do you feel you bring to the REC? (Question 2)

| Description of other experience | Number (%) (n=198) |
|---|-----------------------|
| A. Professional perspective from the statutory/private sector (for a breakdown of professional areas see table 2) | 154 (78%) |
| B. Experiences from the voluntary sector | 79 (40%) |
| C. Personal or life experience, including service user/carer perspectives | 36 (18%) |
| D. Other public involvement | 19 (10%) |

For the 154 respondents who highlighted their professional experiences, where possible, responses were categorised according to professional group and are presented in table 2.

Table 2: Professional categories of other experience respondents brought to the REC (Question 2)

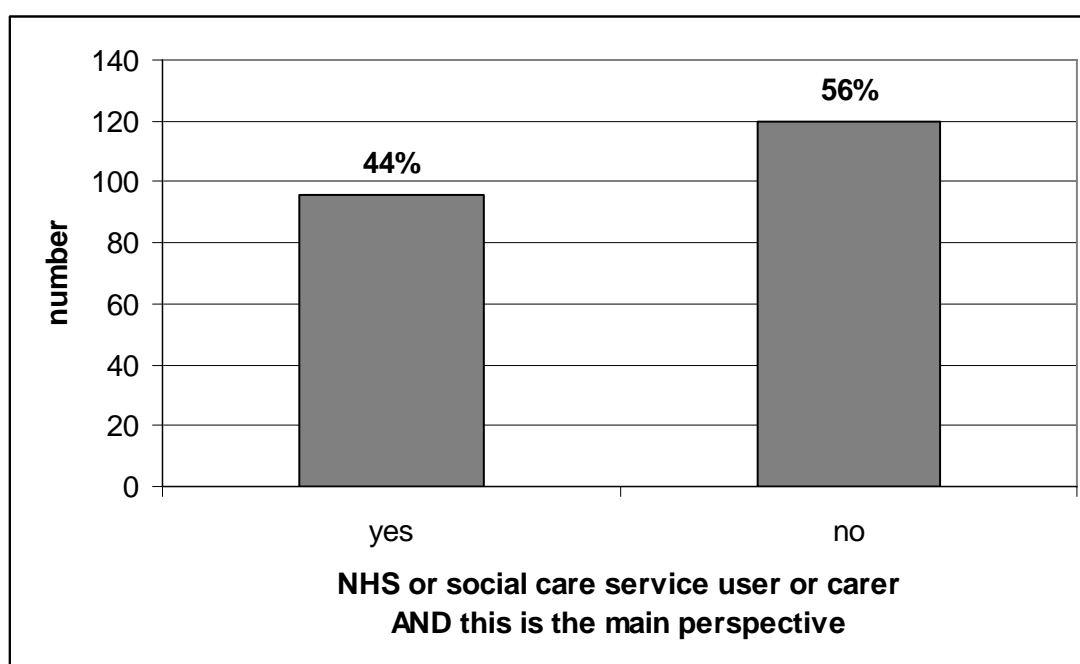
| Professional category | Number (%) (n=154) |
|--|-----------------------|
| Education sector – school and university teaching and non-health university research | 66 (42%) |
| Health and social care sector – including counselling/pastoral support, health research, pharmaceutical industry | 47 (31%) |
| Law and ethics – including experience as Justice of the Peace or magistrate | 27 (18%) |
| Local authority role including local councillors | 13 (8%) |
| Other: prison/police service (4) business (2), engineering (3), management (3), armed forces (1), financial services (1), veterinary science (1), trade union (1), not specified (4) | 20 (13%) |

Amongst those that reported bringing professional experience to the REC, 66 (42%) brought experience from the education sector (for example working in schools or Universities), and 47 (31%) reported experience from working in the health or social care sector. Twenty seven (18%) brought experience in law or ethics.

NHS or social care service user or carer

The NRES Advisory Group wished to gain a clearer picture of the proportion of lay members who saw their primary role on the RECs as providing an NHS or social care service user or carer perspective. Respondents were therefore asked whether they would both describe themselves as either having experience of being a user of health or social care services or of caring for someone who uses health or social care services **and** whether they would describe this as being the main or primary perspective that they brought to the REC. Figure 2 details the responses to this question.

Figure 2: Would you describe yourself as an NHS or social care service user or carer? (Question 3)



As shown in Figure 2, approaching half of the respondents (96) who answered this question indicated that they had experience of being a service user or carer and they considered this was their main or primary perspective.

Respondents were asked to make additional comments about their experiences of being a user of health or social care services or of caring for someone who uses health or social care services and how this relates to their own situation and perspective (Question 4). Ninety-three people made additional comments including those who identified as a user or carer and those who did not. Of these, 10 confirmed that they did not see themselves as a service user or carer and 43 offered only a description of their experiences.

However, twenty-eight respondents (12%) described how their experiences of being a service user or carer related to their REC work. In the main, these respondents thought that their experiences as a user or carer enabled them to bring the patient or research participant perspective. Many were concerned about communicating information about research to research participants and consent procedures. This is illustrated by the following comment:

'Issues relating to clear communication of risk; the quality, understanding and communication of information provided to participants; the capacity to consent and the vulnerability of participants remains a personal priority while serving on a REC. These issues are of course balanced for me by a sincere desire to see ethically driven research that will benefit people served by the NHS.' (382)

Some, for example, highlighted a situation where they had been vulnerable and would pay attention to how researchers proposed to communicate about research in these situations:

'A few acute incidents have given me some insight into consent & communication issues when e.g. in pain or muddled by anaesthetic.' (873)

As indicated above, a number of respondents thought that while they may have personal experience as a service user or carer this did not mean they saw this as their primary perspective. Others commented on how they felt they brought several perspectives. For example:

'I do have this experience and use it to inform my decisions but not my main / primary perspective' (016)

'... feel I have a broad experience of life having worked in social work, health services and education. Am very involved with all my own large family and feel that through them, I am able to reflect the thoughts of generations below my own and feedback to the REC' (507)

Fifteen respondents found this question difficult to answer or commented that they did not agree with the wording of the question. For some, this was because they considered that most people were service users and so did not agree with the distinction being made, for example:

'There cannot be many people who are not users of health care services, so I find question 3 slightly weird' (634, responded yes to question 3)

'I have only answered yes to question 3 because I have had experience through most of my life using NHS services - as have most people in the UK' (970, responded yes to question 3)

For others, the difficulty was that either they felt they brought numerous perspectives and not just one, or they felt that their experience as a service user or carer was either not directly relevant to their work on the REC, or were concerned that there was the potential narrowing of their expertise to one type of experience and that if they viewed applications as a user or carer this would be a biased perspective:

'It is difficult to separate out skills and experience' (945, responded yes)

'Can't answer question 3 in yes/no fashion - my experience as a patient and carer contributes as one of several perspectives - no more or less. For some research it is relevant for some it is not' (352, responded no to question 3)

'Not my primary or main perspective. I really do not like this question. I bring who I am to the ethics committee, which is the sum of my experiences, knowledge and personal makeup. An important part of that is being a parent of a child with extensive special and medical needs. However, if I brought that as my main perspective, or indeed if I thought of myself as bringing that, then it would be a very bad thing and my contribution to the ethics debate would be limited, biased and inappropriate. I think this is reducing the role of the lay person as to someone with just a personal perspective which is way too narrow.' (039, responded no)

'Is this relevant to ones ability to ethical review' (474, responded yes)

Specific perspectives

The issue of the perspectives REC lay members bring to their work was explored further when respondents were asked whether they thought they brought a specific perspective to the REC (see Table 3).

Table 3: Do you see yourself as bringing a specific 'perspective' to your REC? (Question 11)

| | Number (%) (n= 210) |
|-------|--------------------------------|
| Yes | 159 (76%) |
| Maybe | 32 (15%) |
| No | 19 (9%) |

For those who answered yes or maybe, respondents were invited to describe the perspective they believed they brought. One hundred and eighty seven respondents offered further comments:

- 107 respondents (52%) described their professional background as their specific perspective
- 73 respondents (39%) identified bringing a patient, carer or service user perspective
- 37 respondents (20%) described their perspective as being a potential research participant
- 25 respondents (13%) specifically identified that they did not have a medical, clinical or NHS background.

Potential participant perspective

For those who described their specific perspective as a potential research participant, they felt it was important to 'view studies from the participant's eyes' (151). In the main, this served two purposes; to monitor and improve the way information about the research was communicated to research participants and also to protect the interests of research participants:

'I look at the projects from the point of view of the patient. Sometimes the professionals get too involved in the science and forget what it is proposed to "do" to the individuals taking part in the study. Professionals take a different view on medical procedures to the lay member.' (122)

'As a reasonably articulate member, I believe that I bring a usefully critical eye in particular to the quality of Patient Information Leaflets and other documents that are meant to inform lay participants in research projects. As originally drafted, some are at best ambiguous and others are simply misleading.' (257)

'I may sometimes take the role of "Guardian" on behalf of others and feel an element of protection as I would be loath to agree to clinical research which had major negative effects which I had had a part in signing off.' (312)

Non-health related perspectives

Having a perspective that was not associated with medicine or health care was thought important by some respondents because they did not have 'allegiance' (843) with medical colleagues who were proposing research projects, could counter the dominance of the medical/NHS perspective on the RECs and identify issues that may not have been considered by those with medical/health experience:

'I see myself as a truly "lay" member of my REC. Most of the other members of my REC (including lay), have or are, working in an NHS/research/medical area. As a non-expert and having been on the receiving end of the medical profession in many areas... I see things in a different way from the highly trained medics, scientists and NHS management. This, in my view, keeps a healthy balance in my committee as I certainly come with a different perspective. It took courage in the beginning to voice my views. However, I have always been heard as the chair is excellent.' (519)

'... I don't have medical knowledge, but sometimes that can be useful as it forces researchers to have to explain to me, coherently, what they are doing; and if they can't do that, it often reveals underlying flaws in their research....' (889)

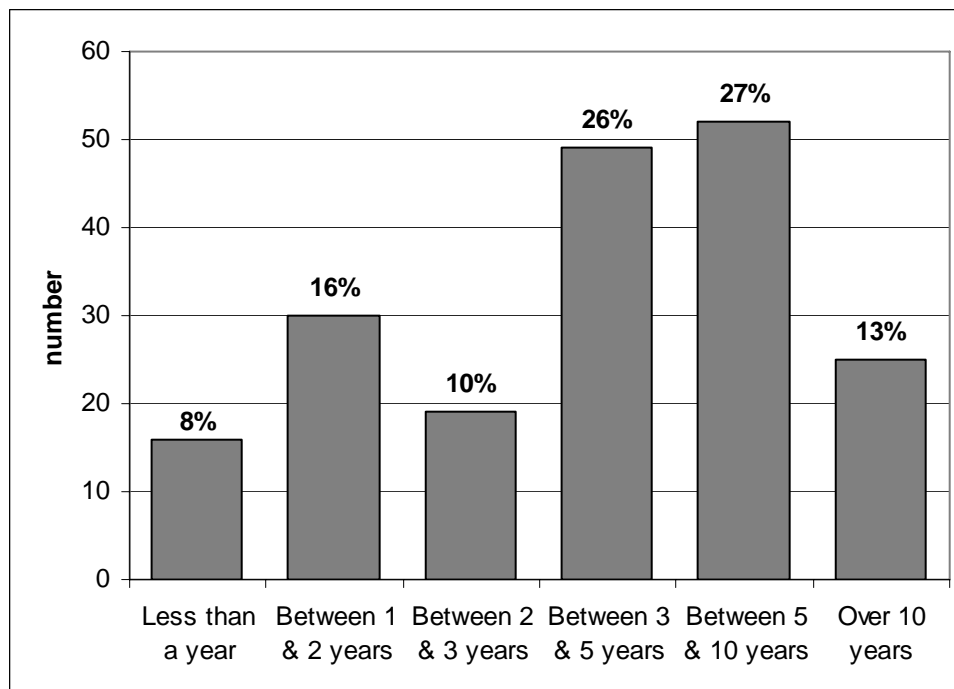
6.3 Lay member participation in the REC

The survey included a range of questions relating to lay member participation in the REC including whether they thought lay members should be paid for their work on a REC. These data are presented in this section.

Experience

Firstly, respondents were asked about the length of experience they had on RECs. This may be related to membership of more than one REC. As Figure 3 shows most respondents had three or more years experience on RECs.

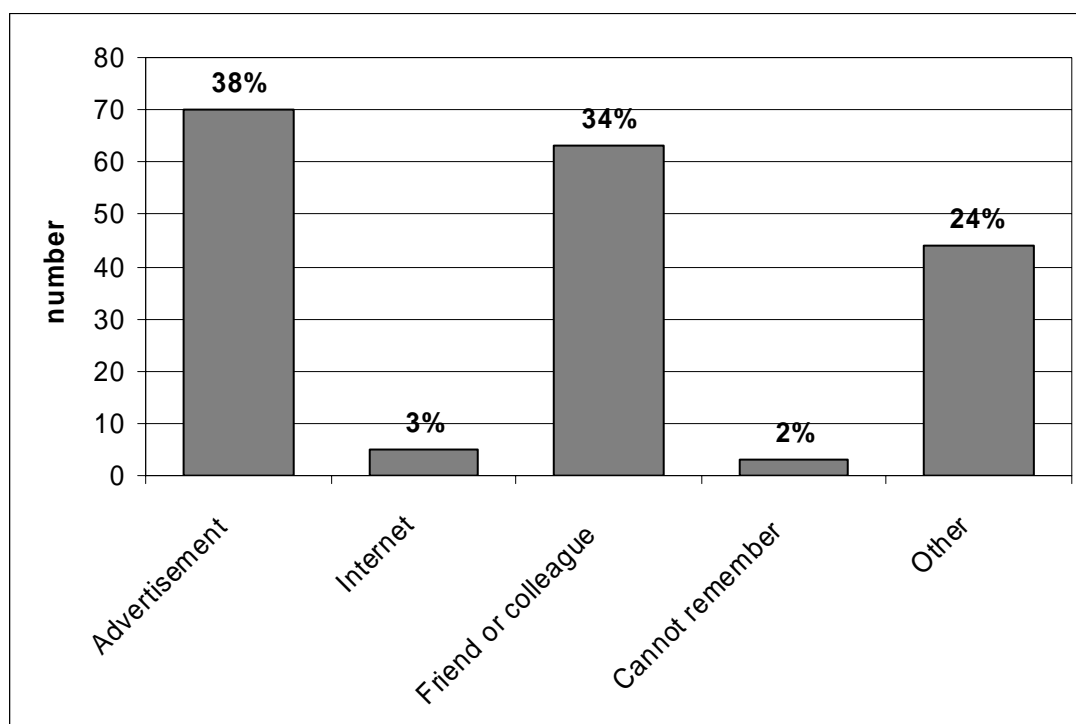
Figure 3: How much experience have you had as a lay member on RECs? (Question 12)



Recruitment to RECs

Respondents were asked how they first heard about the opportunity to become a lay member. As figure 4 shows, most either heard about membership through an advertisement or from a friend or colleague. Seventy (38%) heard through an advertisement and 63 (34%) through a friend or colleague. A further 44 (24%) said that they heard through other means.

Figure 4: How first heard about the opportunity to become a lay member (Question 13)



Those who had become a REC member more recently (i.e. within the last 5 years) were more likely to have heard about the opportunity to become a lay member via an advertisement (44%), compared with those who had been members for over 5 years (28%). Amongst those who had been members for 5 years or over, the most common given response was that they found out through ‘other’ sources. The main reasons given under the ‘other’ category, were that they heard about membership through other organisations that they were linked to, for example Community Health Councils, NHS Trusts and Health Authorities, or that they had been invited to join.

Views taken into account

Respondents were asked if they felt their views as a lay member were fully taken into account in the deliberations of the REC. The responses are detailed in table 4.

Table 4: Do you feel that your views as a lay member are taken fully into account in the deliberations of your REC? (Question 5)

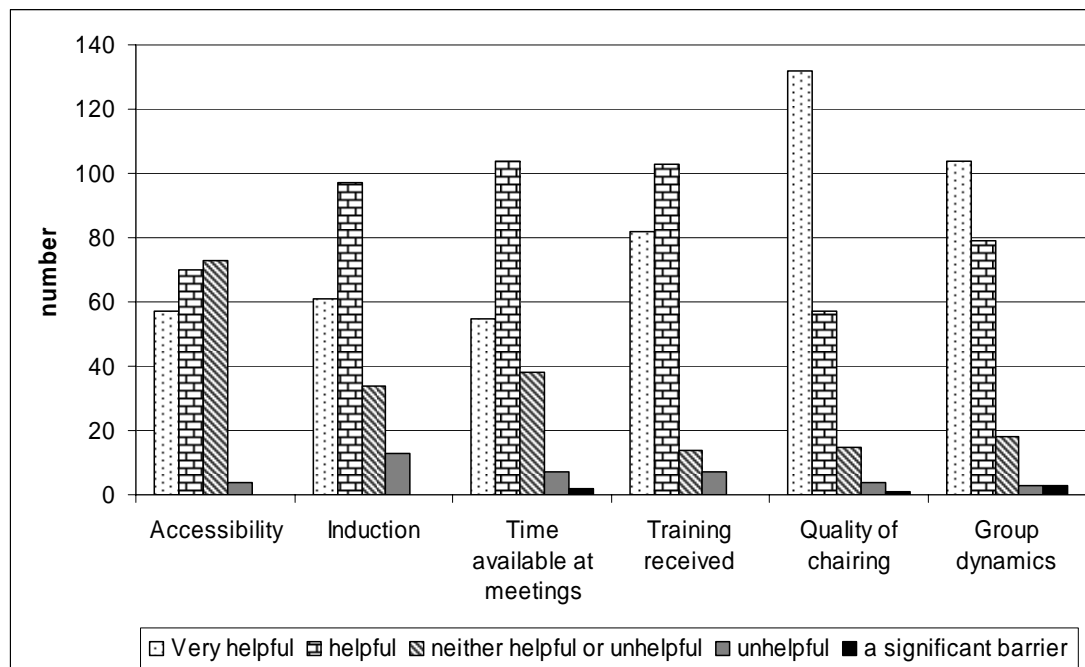
| | Number (%) (n= 210) |
|---|--------------------------------|
| Always taken into account | 135 (65%) |
| Often taken into account | 57 (27%) |
| Sometimes taken into account | 15 (7%) |
| Not sure whether views taken into account | 2 (1%) |

Of the 210 people who answered this question the majority felt their views were taken into account. The responses were broadly similar between those lay members who described themselves as bringing a service user or carer perspective to the REC and those who did not (Question 3). Those who brought a service user or carer perspective were slightly more likely to respond that they felt their views were often taken into account (30% versus 25%) and slightly less likely to respond that they were always taken into account (62% versus 67%).

Enabling contributions to RECs

Respondents were asked to indicate how helpful or unhelpful they found different aspects of their REC. They were asked about accessibility (e.g. physical access, level of language etc), induction (when they joined the REC), time available at meeting, training received, the quality of chairing, and group dynamics. See figure 5, for a summary of responses. For each topic, they were asked to score on a scale - very helpful, helpful, neither helpful or unhelpful, unhelpful or a significant barrier. Few rated any of the aspects of their REC unhelpful or a significant barrier. Respondents were most positive about the quality of chairing and the group dynamics. The ratings were similar amongst those who saw their primary role on the REC as a service user or carer and other lay members (Question 3).

Figure 5: What have you found helpful or unhelpful in enabling you to contribute to your REC? (Question 6)



Note: The column on the left of each topic is the most positive (i.e. very helpful and on the right, the least helpful (i.e. a significant barrier).

Respondents were also asked in open questions about any support that they found helpful as well as anything that hindered them being able to contribute to their REC (Questions 7,8 and 9). The main barrier identified by respondents

to full participation in RECs was the language used by applicants in their lay summaries as well as their full applications. The following quotes illustrate some of the issues raised:

'Language of researchers is still often not comprehensible to lay people despite instructions on the form' (025)

'Abbreviations of medical terms, drugs and procedures are a nightmare for lay members unfamiliar with new or recent clinical studies' (233)

'The research applicants insist in copying and pasting from their research protocol and ignore the repeated requests to explain their proposal in lay man's terms. Our committee is now starting to take a stand on this' (653)

Other factors mentioned by small numbers of respondents as hindering their involvement were:

- the amount of paperwork involved
- the amount that needed to be covered in meetings
- accessibility and timing of meetings and training
- lack of induction training
- lack of clarity on legal issues
- lack of understanding of technical issues (e.g. statistics)
- poor chairing and
- lack of support from other members.

Reflecting the responses to question 6 above, the main support cited by respondents as helping them to contribute to their RECs included:

- training
- support from the chair and the co-ordinator
- administrative support
- support from other members of REC

'All the training of course, but notably the ready availability of and advice from the chair and the co-ordinator' (956)

'Most of my experience was on one REC and overwhelmingly, it is the quality of chairing and the chair's acknowledgement of the contribution of all members that is the greatest support. In addition, regular training and initially a sound induction made a difference' (306)

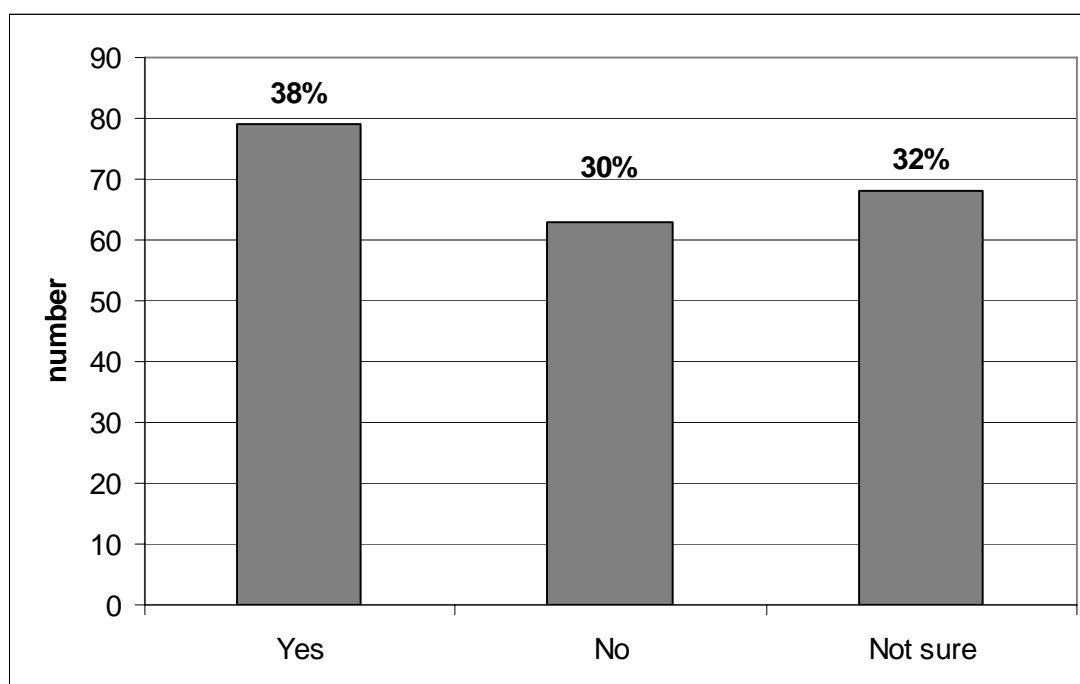
Payment to lay members for REC work

As figure 6 shows, the 210 respondents who answered the question, were fairly evenly spread in their views on whether lay members should be paid an allowance for their work for the REC. Slightly over one third of respondents thought that REC lay members should be paid, with just under one third

disagreeing with this and the remaining being unsure about this issue. Whether the respondent supported the idea of an allowance for REC work was compared with a number of demographic characteristics. There were no discernable patterns, therefore no suggestion that people with a particular background were more likely to support the idea of payment than others.

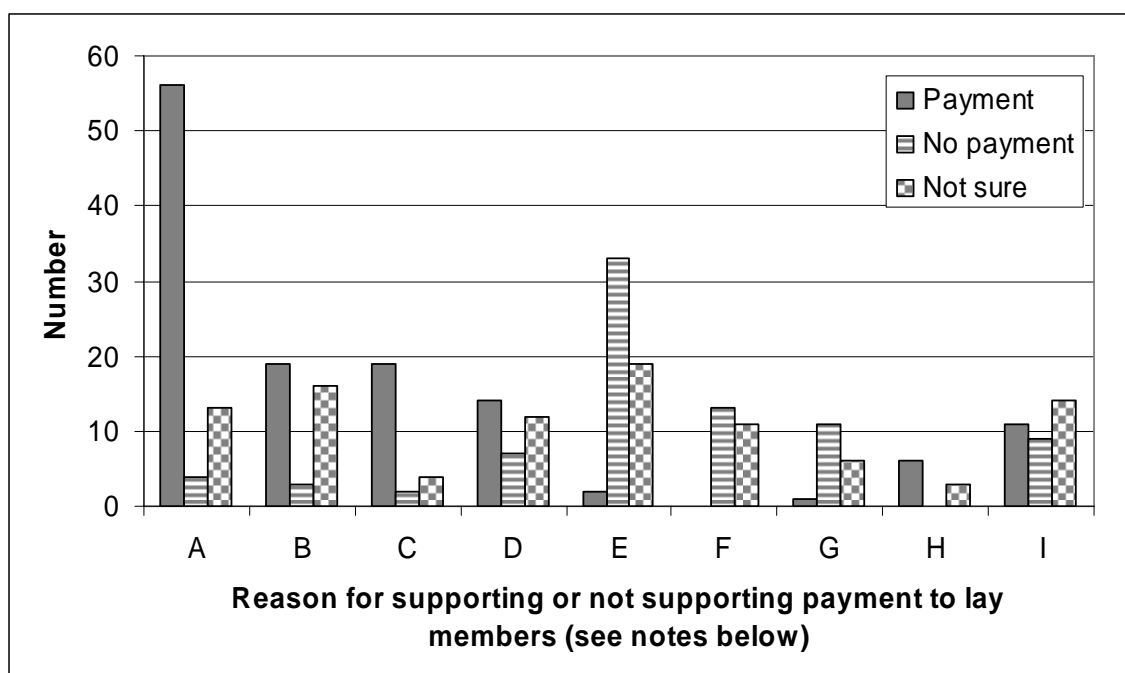
Interestingly, there was a small difference between lay members who described themselves as being an NHS or social care service user or carer and other lay members (Question 3). The former were slightly less likely to feel that they should be paid than other lay members (34% versus 40%).

Figure 6: Do you think lay members should be paid an allowance for their work for the REC (Question 10)?



Respondents were invited to give the reasons for their preference in relation to payments for lay members. A number of reasons were given, which have been grouped according to whether the reason was in support of payment to lay members or against the principle of payment. Figure 7 presents this data followed by a commentary on the responses.

Figure 7: Categories of answer shown by view on payments



- A. The substantial time commitment required and the expertise lay members contribute to the REC should be acknowledged with monetary reward.
- B. Payment may encourage participation by wider sections of the community
- C. Payment should be in the form of an allowance (e.g. to cover any loss of earnings) rather than salary.
- D. Lay members should be paid because most other members of the committee are participating as part of their main employment.
- E. Payment may strength commitment and aid retention of lay members
- F. The importance of retaining the voluntary principle.
- G. Payment may attract people to the REC for the 'wrong' reasons.
- H. The importance of retaining lay members' independence and payment may compromise this.
- I. Other reasons

Preference for payment of an allowance to lay members

The reasons that respondents gave for supporting the idea of payment for REC work are detailed below, with the most common reason being payment would recognise the time commitment and expertise required to contribute to a REC. Following the list some illustrative quotes are given:

- 56 respondents thought payment to lay members would acknowledge the time commitment and expertise required to contribute to a REC (reason A)
- 19 respondents thought that payment may encourage wider participation (reason B)

- 19 respondents thought that payment would promote parity with other members of committees who would be undertaking REC work as part of their main employment role (reason D)
- 14 respondents in support of payment thought this should be in the form of an allowance to cover loss of earnings, rather than a salaried position (reason C)
- 6 respondents thought that payments to lay members would strengthen people's commitment to the REC and may aid retention (reason E).

The following quotations illustrate some of these points:

'It is sensitive, confidential, valuable and interesting work, needing considerable thought, expertise, and time. I think this deserves to be acknowledged.' (519)

'...Not paying lay members automatically excludes many people who can ill-afford to attend. This cuts down on the pool of appropriate people and tends to make committees elitist and only for those who have an adequate income.' (962)

'... Many expert members of the committee undertake the role as part of their paid employment or from a situation of being in full-time employment usually within the NHS. Paying an allowance to lay members would recognize the time and commitment involved.' (345)

Preference for not paying an allowance to lay members

For those respondents who did not support the idea of payment for REC work the primary reasons related to the wish to retain the voluntary and independent principles of REC work. In general, these respondents saw their work on the REC as a way to contribute to the community or a public service. Their motivation was in the intrinsic reward of the REC work, for example, the satisfaction gained from interesting work or increased learning and understanding about research and the NHS. The detailed findings are listed below followed by some illustrative quotes:

- 33 respondents thought it was important to retain the voluntary principle in relation to REC work (reason F).
- 13 respondents thought that payment would change the reason why people joined RECs, in that they would be motivated by the financial reward rather than altruistic reasons, which may attract the 'wrong' (997; 340) type of people (reason G).
- 11 respondents thought that principle of payment could undermine their current independence of the NHS (reason H).

The following quotations illustrate some of these points:

'I don't do this for the money. I do it because I am a public-spirited citizen. I don't think any of my fellow lay members would be interested in the money. And to be honest, by the time one has paid NI and higher rate tax on it, it has to be very well paid to make it worthwhile being paid at all.' (889)

'The only way lay (and professional) members can retain their independence is by not being paid.' (548)

Uncertainty about the payment of an allowance to lay members

Respondents who were unsure whether lay members should be paid an allowance spanned the whole range of issues in their given reasons. As figure 5 shows there was no particular reason that was strongly associated with those people who were unsure about the issue of payment:

'I am undecided about this as I have to balance two issues, one I am a volunteer and two I have to give up time from business.' (734)

'On the whole I support the volunteer, provision of service, but recognize that this does involve costs to the individual. If Professional reps are to be paid however, the same should apply to lay member. Possibly this would encourage lay membership.' (903)

7. Conclusions

This survey was carried out to provide a snapshot of the range of backgrounds, contributions and perspectives of lay members. The survey included a mixture of closed and open ended questions. Two hundred and twenty five lay members responded to the survey, an estimated response rate of 37.5%. Whilst the response rate was not high, the characteristics of those that replied were similar to the results from the NRES Monitoring survey of lay members (2007).

Diversity of lay members

One of the reasons for the INVOLVE survey was to find out about the diversity of lay REC membership. Diversity of REC membership is important both to ensure public confidence in the decisions of ethics committees but also to help bring a range of skills, knowledge and perspectives to bear on the REC process and the substance of REC work. In the review of the operation of NHS Research Ethics Committees (2005), the Department of Health Report of the Ad Hoc Advisory Group, recommended that:

'membership needs to be drawn from a wider mix of society and that all members need to be supported by appropriate training.' (Department of Health, 2005)

The Ad Hoc Advisory Group reported that membership of RECs:

'... is drawn in general from a relatively narrow spectrum of society, members tending to be professional in background and from an older age group. We do not have evidence of ethnic mix but doubt that RECs overall reflect the mix of the communities that make up our society.'
(Department of Health, 2005)

Changes in appointment procedures for members appear to have resulted in a higher proportion of lay members being recruited to ethics committees via advertisement (rather than through friends or colleagues), with 44% of those who had become a member in the last 5 years hearing about joining via an advertisement compared with 28% of those who had been a member for over 5 years. However, this more open method of recruitment does not appear to have significantly increased the diversity of membership.

This survey found that in relation to several characteristics, the limited diversity amongst lay members reported by the Ad Hoc Advisory Group, was still present in 2008. Compared to the population in general (Census 2001 data) significantly more lay members were aged 61 or over (51% compared to 21%) and educated to degree level or above (84% compared to 20%). However, the proportion of respondents describing their ethnic origin as white was similar to the overall population reported in the 2001 national census (92%). As the survey did not link responses to individual RECs we cannot comment on whether committees reflect regional variations in ethnicity.

Lay member perspectives

As part of the survey we wished to gain a clearer picture of the perspectives that lay members brought to their REC. The criteria for lay members, requires that they should be independent of the NHS, but can include non-medical clinical staff and social care professionals. However, the experience that many lay members brought to their REC were as health professionals (33%), and working in the research field (38%). In addition, nearly half (48%) said that they had experience of either long term use of health or social care services or caring for someone who uses services (respondents were able to give more than one answer).

INVOLVE believes that active service user and carer involvement can help to improve the quality of research. This includes helping to ensure that ethical issues are addressed from a service user and carer perspective. We therefore asked respondents whether they saw their primary role on the RECs as providing an NHS or social care service user or carer perspective. Nearly half (44%) of the respondents who answered this question indicated that they had experience of being a service user or carer and considered this to be the primary perspective that they brought to the REC.

Thus it would appear that a high proportion of lay members bring both health care professional and service user and carer perspectives to their RECs. However, respondents had very mixed views about bringing a service user or carer perspective, ranging from those who felt that their experiences enabled them to better understand the patient or research participant perspective, to those who either felt that their experience as a service user was not directly relevant or were concerned that their was a potential narrowing of their expertise to one type of experience, risking them bringing a biased perspective. Others felt that most if not all people were service users and so did not agree with the distinction we were trying to make.

Participation on RECs

The Ad Hoc Advisory Group commented on the issue of payment to REC members and concluded that:

'the totally voluntary system of RECs may not be sustainable and, indeed may no longer be appropriate. It is likely that it inhibits application for membership by sections of society that should be better represented.' (Department of Health 2005).

As part of this survey we asked the REC lay members for their views on payment. Respondents were fairly evenly spread as to whether they thought lay members should be paid an allowance for their work for the REC, with just over a third (38%) believing that lay members should be paid. However, this finding should be considered within the context that all current lay REC members applied to become a member knowing that the work was voluntary. Thus it is difficult to tell from this survey of current voluntary lay members whether or not payment might attract membership from wider sections of society.

Overall, the lay members who responded to the survey appeared to feel that they were adequately supported in the work that they did for their REC, and the vast majority reported that they felt that their views were fully taken into account in the deliberations of their REC. Respondents were most positive about the quality of chairing and group dynamics. A large proportion also rated the training that they had received as helpful. However, one area where many respondents reported difficulties was in the language used by research applicants in their lay summaries, as well as their full applications.

8. References

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Boaz, A. (2003) **'Department of Health consultation on research ethics in social care: A summary of the follow up consultation event with social care service users and their representatives'** INVOLVE.

Department of Health (2001) **Governance Arrangements for NHS Research Ethics Committees** (GAfREC) Department of Health. (www.dh.gov.uk)

Department of Health (2005) **Report of the Ad Hoc Advisory Group on the Operation of NHS Research Ethics Committees** Department of Health. (www.dh.gov.uk)

Dyer, S. (2004) **'Rationalising public participation in health services: the case of research ethics committees'** Health and Place 10 (2004) 339 - 348

National Research Ethics Service (2007) **Equal Opportunities Monitoring Survey of REC members** NRES

National Statistics (2001) **Census 2001: the most comprehensive survey of the UK population** (www.statistics.gov.uk/census2001/census2001.asp). Accessed 09 February 2009.

Appendix 1

Detailed demographic information on survey respondents

Figure A1: How old are you? (question 17)

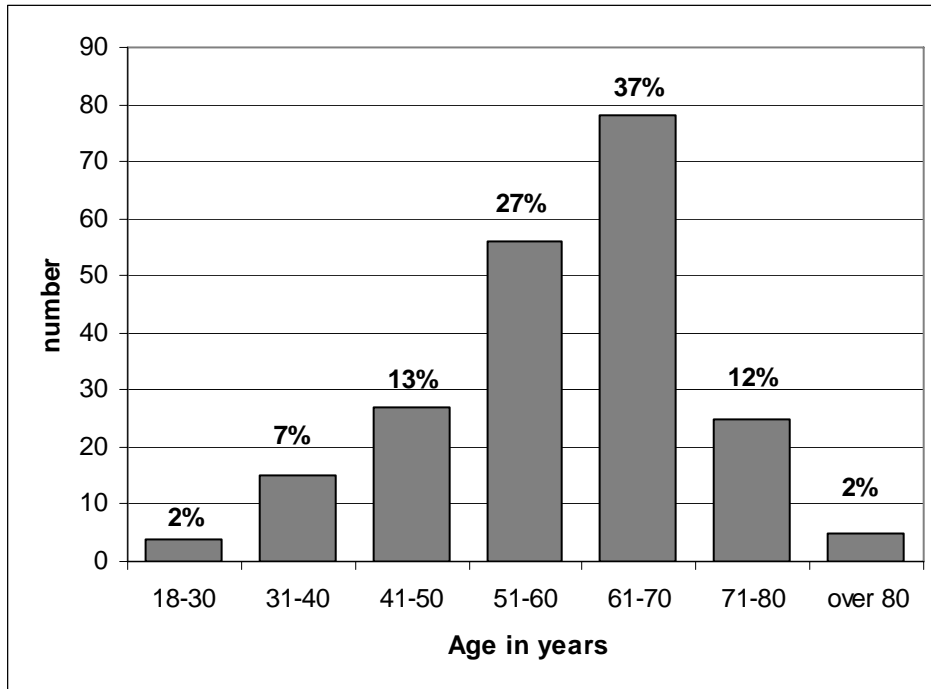


Figure A2: Gender (Question 19)

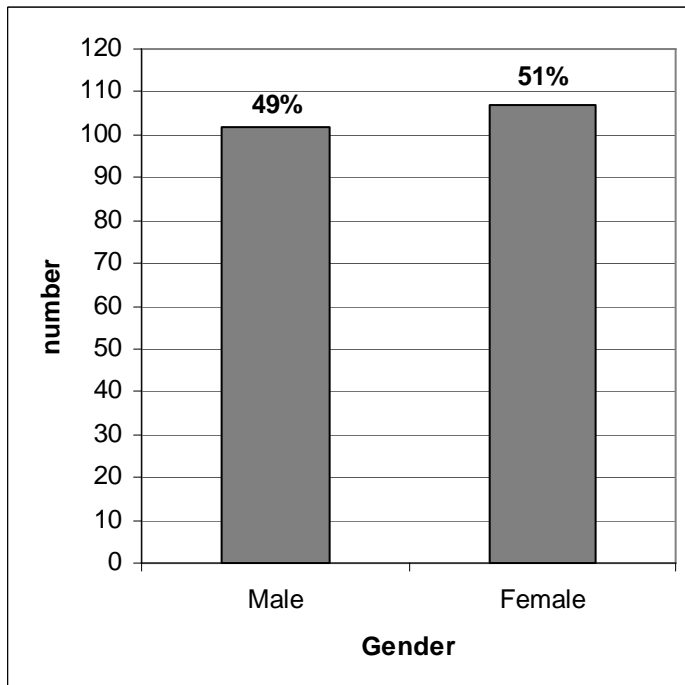


Figure A3: Which (if any) of the following qualifications do you have? (Highest qualification reported) (Question 18)

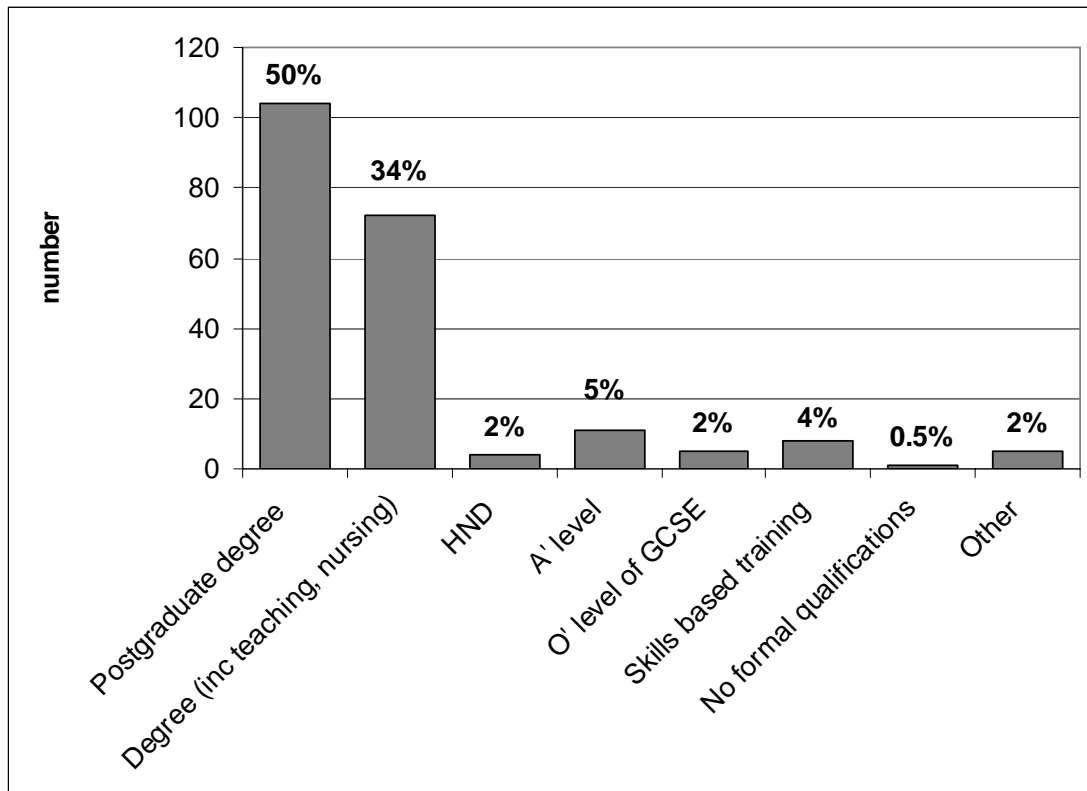


Figure A4: How do you describe your ethnic origin? (Question 21)

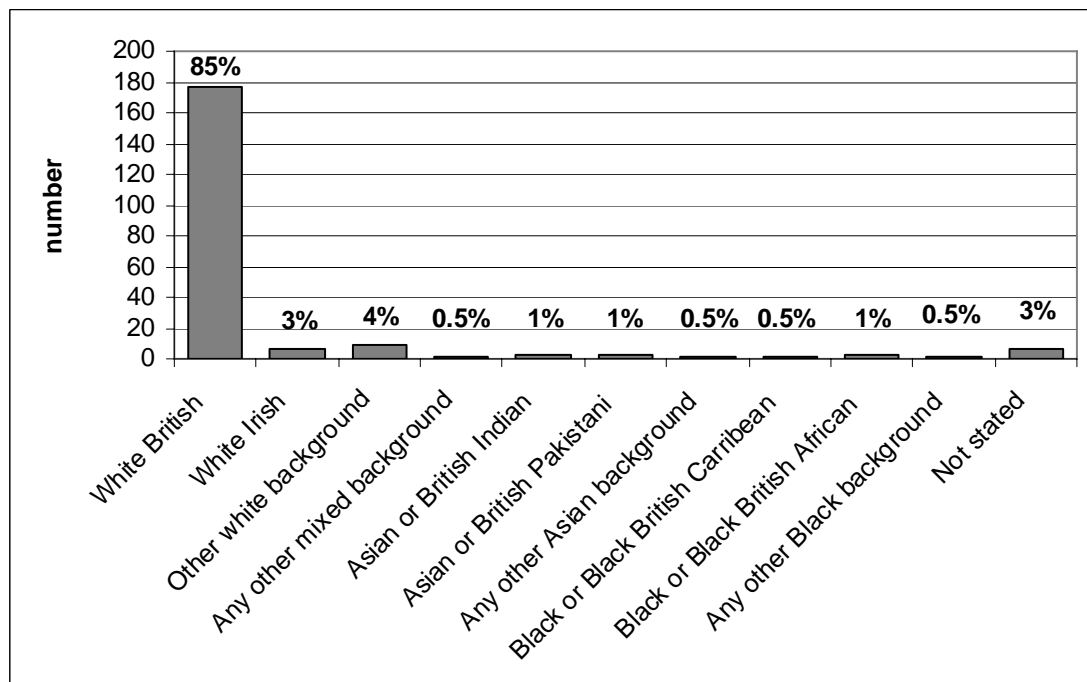


Figure A5: Do you consider yourself to have a disability? (Question 22)

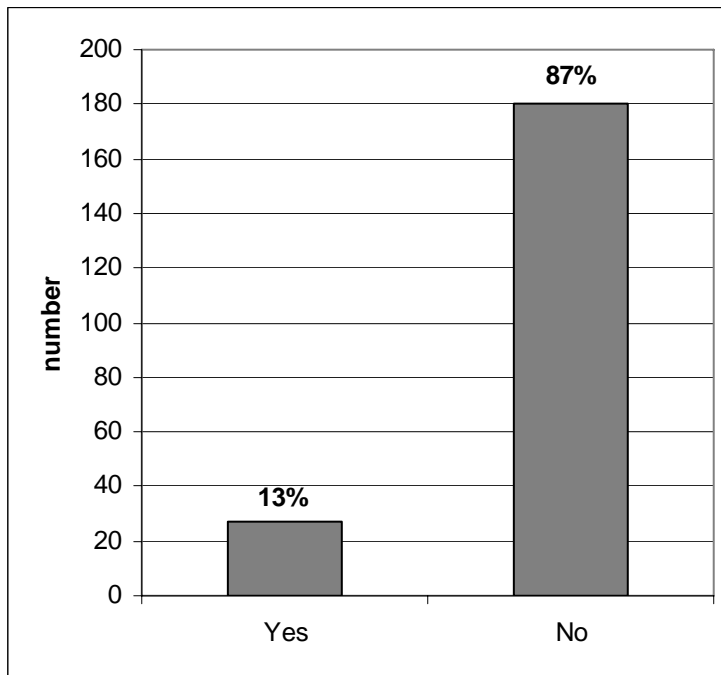


Figure A6: How would you describe your sexual orientation? (Question 20)

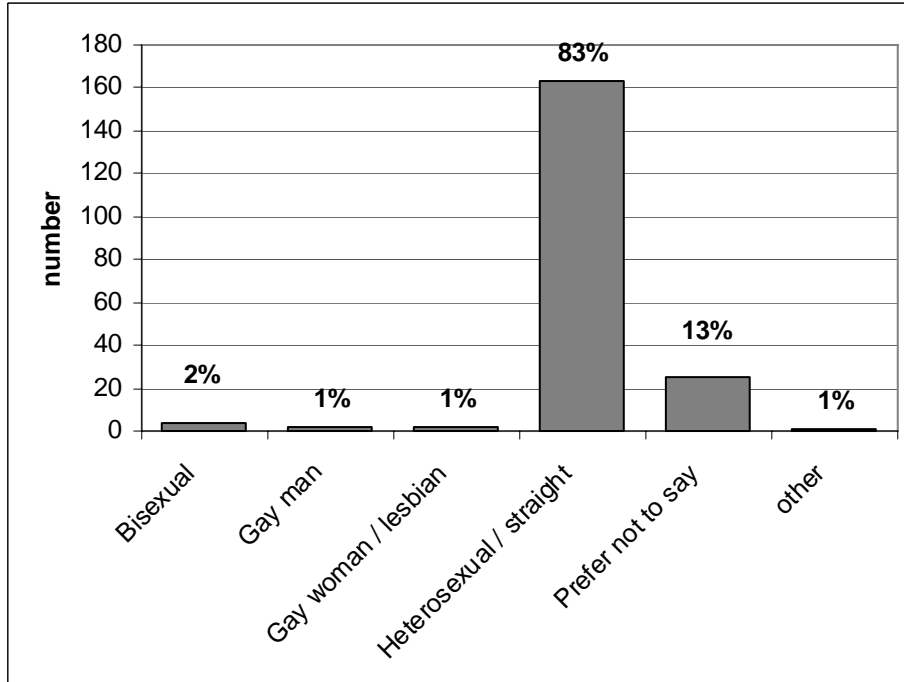
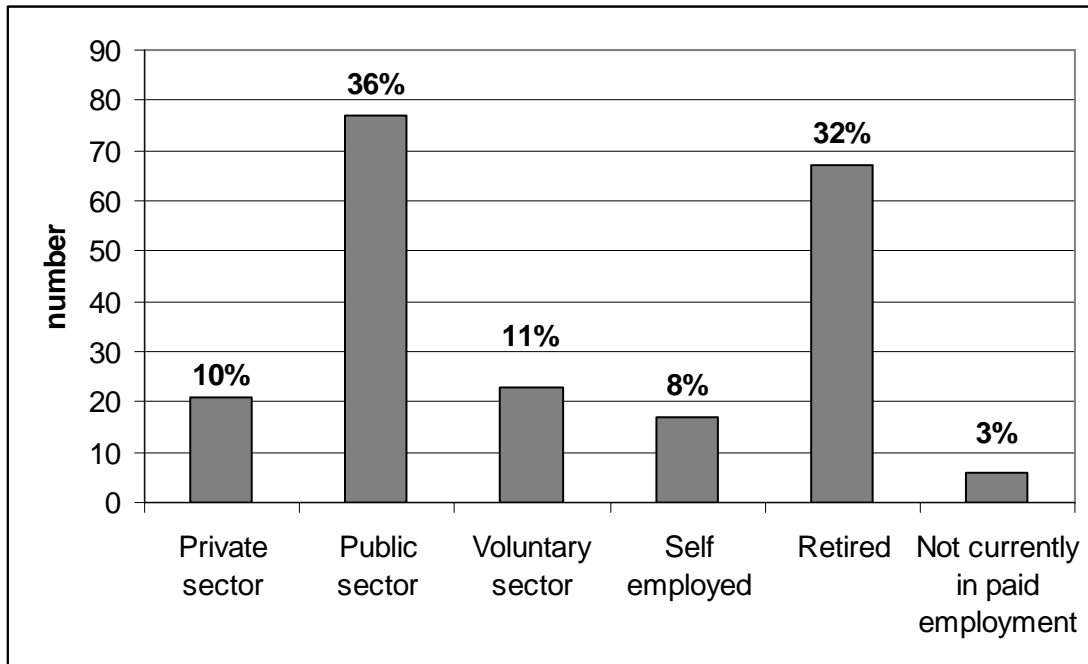


Figure A7: Which of the following best describes your current or more recent occupation? (Question 15)



Appendix 2

Copy of questionnaire for REC lay members.

Survey of REC lay members

(i) Aims and background

INVOLVE is conducting a survey of REC lay members on behalf of the work of the National Research Ethics Service (NRES) Advisory Group on NHS Service Users and Ethical Review. The survey aims to gain a better understanding of the perspectives, experience and knowledge that lay members bring to the work of RECs and the diversity of perspectives amongst the membership.

We would like to know more about the role you have as a lay member on your REC.

- we would like to know about the range of backgrounds of lay members,
- the range of inputs lay members offer, and
- what helps or hinders these inputs being taken into account.

The survey is supported by the NRES Advisory Group and will be important to its work. It is anonymous and the responses will not be linked to any individual or REC. You do not have to answer all the questions.

The report of the survey will be fed back to all RECs. We would be grateful if you could complete the survey by 3rd November 2008.

Please complete the questionnaire online using the link: <http://tinyurl.com/5vbIn3>. Alternatively you can complete this hard copy and return to the freepost address below:

REC Survey, INVOLVE
FREEPOST SCE 15836
Eastleigh, SO50 9ZW

About INVOLVE:

INVOLVE is funded through the National Institute for Health Research to promote and support active involvement in NHS, public health and social care research. To find out more about INVOLVE, see our website www.invo.org.uk

If you have any questions about the survey please contact Sarah Buckland at INVOLVE - telephone 02380 651088, Email: admin@invo.org.uk



Survey of REC lay members

(ii) Experience you contribute

The first questions relate to the experience you contribute as a lay member of your REC.

Please tick one or more categories as appropriate to you.

1. Which if any of the following experience do you bring to your REC?

- Experience from working as a health professional
- Experience from working in social care
- Experience as a researcher or research manager
- Experience as a long-term user of health or social care services
- Experience as a long-term carer of a friend or relative
- Experience of being a participant in a research study e.g. as a patient, or as a healthy volunteer.

2. What other experience do you feel you bring to the REC?

(for example experience representing your local community, working as a volunteer, or relevant experience from previous or current employment)

Survey of REC lay members

3. Would you describe yourself as an NHS or social care service user or carer?

By this we mean, do you have experience of being a user of health or social care services or experience as a carer of someone who uses health or social care services AND also bring to the REC a service user or carer perspective as your MAIN or PRIMARY perspective

Yes

No

4. If you have any comments about question 3 and how it relates to your own situation and perspective – please write in the box below

Survey of REC lay members

(iii) Contributing to the deliberations of your REC

5. Do you feel that your views as a lay member are taken fully into account in the deliberations of your REC?

- Always
- Often
- Sometimes
- Never
- Not sure

6. We would like to find out what you have found helpful or unhelpful in enabling you to contribute to your REC. Please tick one circle for each of the statements below:

| | Very helpful | Helpful | Neither helpful or unhelpful | Unhelpful | A significant barrier |
|---|-----------------------|-----------------------|------------------------------|-----------------------|-----------------------|
| Accessibility (e.g. physical access, level of language, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Induction (when you joined the REC) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Time available at meetings | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Training received | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Quality of chairing | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Group dynamics | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Survey of REC lay members

7. Please tell us about any support that you have found helpful as a lay member of an REC, and who gave/gives that support.

8. Please tell us about anything else that you have found helpful in enabling you to contribute to your REC:

Survey of REC lay members

9. Please tell us about anything that has hindered you being able to contribute to your REC:

10. Do you think lay members should be paid an allowance for their work for the REC?

Yes

No

Not sure

Please give the reasons for your answer

Survey of REC lay members

(iv) Perspective you bring to your REC

11. Do you see yourself as bringing a specific 'perspective' to your REC?

Yes

No

Maybe

If 'yes' or 'maybe', what perspective(s) do you see yourself as bringing?

Survey of REC lay members

(v) Membership of REC

12. How much experience have you had as a lay member on RECs?

- Over 10 years
- Between 5 & 10 years
- Between 3 & 5 years
- Between 2 & 3 years
- Between 1 & 2 years
- Less than a year

13. How did you first hear about the opportunity to become a lay member?

- Advertisement
- Internet
- friend or colleague
- cannot remember
- Other (please specify)

Other (please specify)

14. What was the main reason you decided to become a member of a REC?

Survey of REC lay members

(vi) Background information

We would appreciate it if you could give us some background information about yourself. The Governance Arrangements for RECs says that they should have a balanced distribution of members. The following questions are to help us gain a better understanding of the diversity of lay members of ethics committees. Some of this information was requested in previous surveys from NRES, but it would be helpful here to be able to link it with other information you have given us in this questionnaire. The survey is anonymous, but if you do not wish to complete certain questions then please leave them blank.

15. Which of the following best describes your current or most recent occupation

- Private sector
- Public sector
- Voluntary sector
- Self employed
- Retired
- Not currently in paid employment

16. If you are retired or not currently in paid employment, please provide details of your most recent occupation

17. Age

- 18 - 30
- 31 - 40
- 41 - 50
- 51 - 60
- 61 - 70
- 71 - 80
- Over 80

Survey of REC lay members

18. Which (if any) of the following qualifications do you have?
(Please tick all that are relevant)

- Postgraduate degree
- Degree (including teaching, nursing)
- HND
- 'A' Level
- 'O' Level or GCSE
- Skills based training
- No formal qualifications
- Other*

*Please specify

19. Gender

- Male
- Female

20. How would you describe your sexual orientation?

- Bisexual
- Gay man
- Gay woman / Lesbian
- Heterosexual / Straight
- Prefer not to say
- Other (please specify below if you wish)

Other (please specify)

Survey of REC lay members

21. How would you describe your ethnic origin?

- White British
- White Irish
- Other white background
- Mixed White and Black Caribbean
- Mixed White and Black African
- Mixed White and Asian
- Any other mixed background
- Asian or British Indian
- Asian or British Pakistani
- Asian or British Bangladeshi
- Any other Asian background
- Black or Black British Caribbean
- Black or Black British African
- Any other Black background
- Chinese or Chinese British
- Any other Chinese background
- Not stated

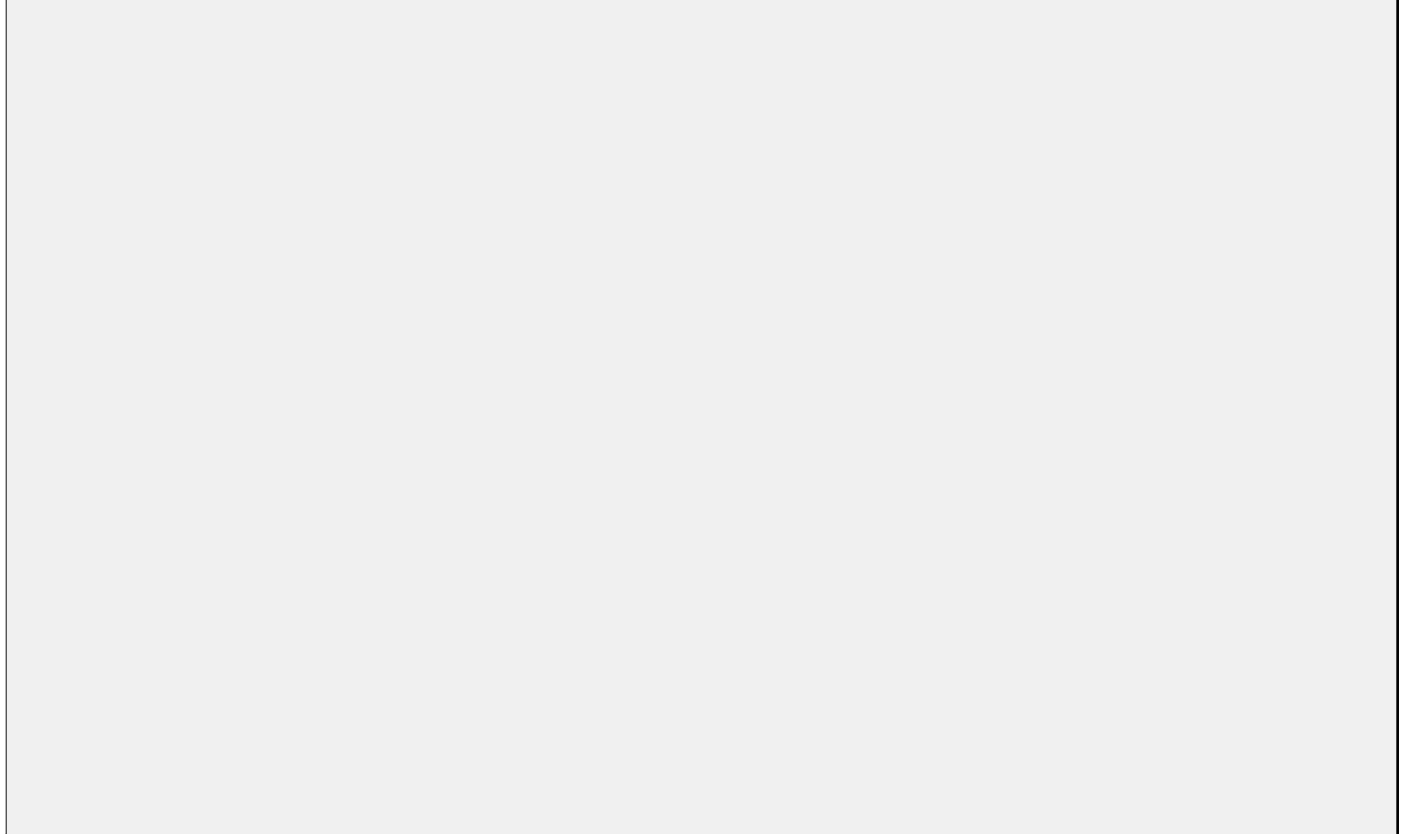
22. Do you consider yourself to have a disability? (A disability is a physical or mental impairment that has a substantial and long term adverse effect on a person's ability to carry out normal, day to day activities. Disability Discrimination Act, 1996)

- Yes
- No

(vii) Thank you!

Thank you for filling in this questionnaire.

23. Do you have any other comments?



Survey of REC lay members

What will happen next?

Thank you for being so helpful with this survey. The results will be collated and a report presented to the NRES Advisory Group by INVOLVE. Copies of the report will also be fed back to all RECs.

None of the information you have given can be linked to an individual or a particular REC.

Please check that you are happy with what you have written before clicking the 'DONE' button below.



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INVOLVE

Promoting public involvement
in NHS, public health and
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