

INCREASING RESPONSE RATES AMONGST BLACK AND MINORITY ETHNIC AND SELDOM HEARD GROUPS

A REVIEW OF LITERATURE RELEVANT TO THE NATIONAL
ACUTE PATIENTS' SURVEY

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Executive summary

Introduction

This report presents the findings of a literature review on increasing survey response rates amongst Black and minority ethnic and seldom heard groups. It has been prepared by the Picker Institute Acute Co-ordination Centre on behalf of the Healthcare Commission as part of the development work for the NHS acute patient survey programme.

The response rates for the NHS inpatient surveys are reasonably high for a postal survey (63% in 2004 and 59% in 2005). Variations in response rates between different sub-groups have however been identified. For example, response rates amongst young people and amongst Black and minority ethnic groups are particularly low. These findings have generated concerns about the extent to which the survey results are representative of the views of certain groups. In the context of evidence that it is these same groups that experience most difficulties in terms of accessing health services, these low response rates demand attention.

This review identifies a range of difficulties in including certain groups in health postal surveys. There remain, however clear reasons for continuing to use standardised instruments for measuring patient experience.

Why do variations in response rates matter? – Response Bias

Low response rates raise concerns about the reliability of the findings because responders may differ from non-responders. There is considerable evidence to suggest that response rates are lower amongst certain groups. Reasons for non-participation in a postal survey amongst some of these groups are self-explanatory – communication barriers that impede self-completion of a questionnaire and a lack of contact information. There is however limited published evidence examining non-response and the characteristics of non-responders. This is largely because information on non-responders is naturally hard to obtain.

US studies have shown repeatedly that people from black and minority ethnic groups are less likely to respond to postal surveys than people from some other groups. Response rates are also generally lower amongst people living in areas with more residents who were non-white. Other groups less likely to respond to postal surveys include:

- the very old
- younger adults
- men
- those in poorer health
- the disabled
- people on low income
- those who live alone
- people with a lower level of education

Both methodological and statistical techniques have been used to reduce the risk of non-response bias in postal surveys. The methodological approaches to reducing non-response bias are explored in this review and include both approaches to increase response rates amongst groups that are typically less likely to respond and intensive follow up contacts of non-respondents. Statistical approaches to reducing response bias include the imputation of, and adjustment for, missing values. One of the difficulties in imputing for non-respondents in the national patient survey is the lack of complete data on ethnic group for the sample.

Why are response rates lower amongst certain groups?

Three main reasons for low response rates have been identified: disengagement, poor literacy and poor contact information. Research has shown rates of civic participation to be similar amongst all those born in the UK, regardless of ethnicity. It has therefore been suggested that theories of acculturation and literacy and language may be better explanations of low response rates in the national patient surveys.

Strategies for increasing response rates amongst Black and minority ethnic and seldom heard groups

Various strategies have been proposed to counter low response rates resulting from disengagement:

Targeted information introducing the research

The use of specialist media, community organisations and networks to communicate with Black and minority ethnic and other seldom heard groups

Emphasis on confidentiality

Strategies to address communication barriers largely centre on the production of questionnaires in formats that are appropriate for different visual and literacy impairments, including the use of simple, straightforward language and the production of culturally appropriate translations.

Measuring the impact of strategies for increasing response rates amongst Black and minority ethnic and seldom heard groups

There is limited evidence about the impact of strategies for increasing response rates amongst Black and minority ethnic and seldom heard groups. Evidence shows that unconditional monetary incentives and to some extent conditional monetary incentives, are associated with increased response rates to mailed surveys.

Evidence from studies manipulating questionnaire characteristics to determine effects on response rates shows that keeping a questionnaire short has a positive effect on response rates and that varying the colour or the quality of the paper on which the questionnaire is printed is largely ineffectual. The interest or relevance of the questionnaire to a participant also has a positive impact on response rates.

The reviewed studies suggest that both introductory contacts and reminders are likely to have a significant effect upon increasing response rates in both non-patient and patient populations.

There is also evidence that the use of recorded delivery and stamped reply envelopes is likely to enhance response rates.

The implications of this review for the acute patients survey

1. Advance publicity and covering letters need to include messages targeted at specific seldom heard populations. It may be appropriate to translate some of this material. Attempts should also be made to communicate survey findings to seldom heard populations.
2. All material should have a statement in 16 point font about the availability of material in alternative formats (if these are to be supplied).
3. Further research is needed to investigate the readability levels of the inpatient survey and the literacy levels in the patient population.
4. The inclusion of patients with poor literacy needs further investigation e.g. providing the questionnaire in alternative formats, for example audiotape or CD with the questions clearly spoken aloud.
5. Further research is needed on the inclusion of people with learning disabilities.
6. Further evidence is needed to explain the variations in response rates amongst different groups. Targeted non-response studies are therefore recommended, if ethical approval can be obtained.
7. Approaches to improving the completeness of ethnic group classification in the sample data need to be explored e.g. improved collection at point of admission / compulsory field in electronic patient record.
8. Further work is needed to develop strategies for the inclusion of patient groups for whom accurate contact data may be unavailable.
9. Empirical studies have shown unconditional monetary incentives, shorter questionnaires and introductory letters and reminders to be effective in increasing response rates amongst all groups. There is a lack of empirical evidence about the effectiveness of other strategies that might have potential for increasing response rates amongst Black and minority ethnic and seldom heard groups, and further research is needed.
10. The use of mixed mode methodologies to collect data has been identified as a potential approach to both including seldom heard groups in health surveys and to capturing their views using other methods. This forms the subject of a separate review.

1 Introduction

This report presents the findings of a review of the literature on survey response amongst Black and minority ethnic and seldom heard groups². It has been prepared by the Picker Institute Acute Co-ordination Centre on behalf of the Healthcare Commission as part of the development work for the NHS acute patient survey programme.

1.1 Background

The impetus for this review is two-fold. Firstly, concern over poor response rates from members of Black and minority ethnic and seldom heard groups, when compared with some other groups, to patient experience surveys in the Healthcare Commission (CHAI) patient survey programme. Secondly, a desire within CHAI to address this, given recent changes in the Race Relations (Amendment) Act (2000) that requires all public bodies to demonstrate that they are promoting race equality.

Increasing the rate of participation from members of Black and minority ethnic and seldom heard groups in the patient survey programme is not only important in terms of ensuring representation and inclusiveness, but also because high response rates would ensure greater confidence in the results. If survey processes under-represent ethnic minorities or any other groups, then this may introduce bias in any findings about them and in the results as a whole.

Current equalities legislation requires that procedures are in place to ensure that the research process takes into account views of other groups who in the past may have been excluded from the research process, e.g. the mentally and physically disabled, homeless people, travellers and asylum seekers. Taking into account the views of members from these groups is not only important in terms of inclusiveness and representation but could also help to reduce the potential for bias in the results due to the under-representation of these groups.

The reasons why some members of Black and minority ethnic and seldom heard groups are less inclined to participate in postal surveys are clear. For example individuals with a visual or learning impairment or those who do not speak or read English would find postal questionnaires difficult to complete or comprehend. By recognising some of the specific problems and addressing them in the design stages of the research, non-response from these groups may be reduced in postal surveys.

² Seldom heard groups have been defined as those who are denied an effective voice by public and voluntary service providers and who are the most vulnerable to ill-health because of social and economic disadvantage. This includes minority ethnic groups, people with disabilities or mental health problems, refugees, travellers, homeless people, ex-offenders, migrants who don't speak English and others who are socially excluded.

Source: Anna Coote (2006) 'Structures in Healthcare. Chapter 5. The role of citizens and service users in regulating healthcare'. In Andersson E, Tritter J and Wilson R (Editors) (2006) Healthy Democracy. The future of involvement in health and social care. London: Involve and NHS National Centre for Involvement http://83.223.102.125/involvenew/mt/archives/blog_37/Healthy_Democracy/Healthy_Democracy.pdf
Last accessed 23/01/07

1.2 Aims and objectives

The aim of this review is to identify studies which have examined issues relevant to survey response rates amongst Black and minority ethnic and seldom heard groups. A key objective is to identify strategies that have been adopted to increase response rates amongst these groups and to evaluate the impact of these measures in practice. A further objective is to identify measures that the evidence suggests might be put in place on the NHS acute patient surveys for England to increase response rates amongst Black and minority ethnic and seldom heard groups. The findings will have implications for the national NHS patient survey programme in general.

1.3 Methods

Searches of published literature were made using the Dialog Datastar database via the Athens portal. Searches were also conducted of unpublished literature using the Google search engine on the Internet. A detailed account of the search strategy is contained in Appendix One.

A preliminary analysis and coding of the material identified through the literature search resulted in the generation of five key themes which structured the review. These themes broadly relate to context, response bias, barriers to participation, strategies for increasing participation and measuring the impact of these strategies in practical studies.

1.4 Structure of Review

Following this introductory section, the findings of the review are set out in six further sections as follows.

Section two sets the context for the review including national government, Department of Health and Healthcare Commission policies. It also outlines current evidence about variations in access to health services between different demographic groups.

Section three includes a discussion of why variations in response rates are a concern, covering the characteristics of non responders, non-response bias and strategies to overcome this. The subject of non-response to specific questions within a questionnaire (item non-response) is also briefly discussed in this section.

Section four outlines three main reasons for non response to postal surveys – disengagement, communication barriers and poor contact information.

Section five sets out various strategies for increasing response rates focusing on non response caused by disengagement and communication barriers. It also includes a detailed section on preparing cultural adaptations of questionnaires.

Section six sets out the available empirical evidence that measures the impact of strategies to increase response rates amongst Black and minority ethnic and seldom heard groups.

Section seven sets out ten implications of the review for the acute patients' survey programme.

2 Context of the Review

The acute patient survey is part of the national patient survey programme administered by the Healthcare Commission on behalf of the Department of Health. Since 1998, NHS facilities have been required to carry out regular surveys of a sample of their patients using standardised, validated postal questionnaires. The programme was designed to provide “systematic evidence to enable the health service to measure itself against the aspirations and experience of its users, to compare performance across the country, and to look at trends over time”.³

Within the programme coordinated by the Acute Advice Centre at Picker Institute Europe since 2002, patients have been surveyed about their experiences of hospital inpatient services, services for children and young people, maternity services and emergency and ambulance services and outpatient services. This review is concerned primarily with the adult inpatient survey but its findings will inform other acute patient surveys and other surveys within the national patient survey programme.

Individual NHS acute trusts are responsible for conducting the inpatient surveys under the guidance of the Acute Advice Centre which aims to ensure that these organisations carry out the surveys in a consistent and systematic way.

This review identifies a range of difficulties in including certain groups in postal health surveys. Nevertheless, there remain clear reasons for continuing to use standardised instruments for measuring patient experience. In particular, their standardization in content, sampling, and administration which facilitates valid comparisons across population groups,⁴ between different organisations and over time.

2.1 Variations in response rates

The average national response rates for the NHS adult acute inpatient surveys are reasonably high for a postal survey (63% in 2004⁵ and 59% in 2005⁶). There are however, significant variations between the response rates achieved by different NHS trusts. Variations in response rates between different sub-groups have also been identified.^{7 8} Analysis shows response rates to be comparatively lower amongst the following groups.⁹

³ Department of Health. The new NHS – modern, dependable. Cm. 3807. London: 1997

⁴ California Pan-Ethnic Health Network (2001) ‘Diverse Patients, Disparate Experience: The use of standardized patient satisfaction surveys in assessing the cultural competence of health care organizations’. California: CPEHN, p. 23. Available at: <http://www.cpehn.org/pdfs/CPEHN%20Final%2001.pdf> Last accessed 12/06/06

⁵ Healthcare Commission (2005) Variations in the experiences of patients in England: Analysis of the Healthcare Commission’s 2003/2004 national survey of patients. Commission for Healthcare Audit and Inspection. Available at: http://www.healthcarecommission.org.uk/_db/_documents/04021208.pdf Last accessed 26/06/06

⁶ Picker Institute Europe Coordination Centre analysis 12/09/06

⁷ Commission for Health Improvement (2004) Unpacking the patients’ perspective: Variations in the NHS patient experience in England. Available at: http://www.chai.org.uk/_db/_documents/04003496.pdf Last accessed 26/06/06

- Young people
- Men
- Black and minority ethnic groups
- Patients treated by trusts located in London
- Patients treated by trusts located in deprived areas

As would be expected, organisations with patient populations made up of greater numbers of these groups are likely to have lower response rates.

Response rates amongst young people and amongst Black and minority ethnic groups are of particular concern. For example, in the 2005 adult inpatient survey, the adjusted response rate for people aged 16-35 was 37% compared with 69% and 71% for those aged 51-65 and 66-80 respectively.¹⁰ The response rate for white patients was 61%, compared with 41% for Asian or Asian British and 42% for Black or Black British patients.¹¹ Within these groups there are even starker variations as shown in the tables overleaf. For example the response rate for white men aged 16-35 was 30% and amongst Black or Black British men in this age group the response rate was just 25%. The response rate for Asian and Asian British women overall was low (39%) but particularly low amongst those in the youngest and oldest age groups – 33% in each case.

These findings have generated concerns about the extent to which the survey results are representative of the views of certain groups. These concerns need to be seen within the context of the current race, disability, equalities and human rights legislation. They are particularly worrying in the context of the current evidence about the disadvantages experienced by these and other minority groups in terms of accessing health services and the relationship this has with their health outcomes.

⁸ Healthcare Commission (2005) op cit

⁹ Commission for Health Improvement (2004) op cit p. 19

¹⁰ Response rates have been adjusted to exclude questionnaires returned as undelivered for any reason including address unknown or the death of the patients

¹¹ Graham C (2006) Inpatient Survey 2005 Additional Analysis. Picker Institute Europe Acute Coordination Centre Unpublished Report 12/09/06

Table 2.1: 2005 Inpatients Survey: Response rate by ethnic group

Ethnic group	Adjusted Response Rate %
White	61
Asian or Asian British	41
Black or Black British	42
Chinese, Mixed or other ethnic group	49
Total	59

Table 2.2: 2005 Inpatients Survey: Response rate by age, sex and ethnic group

Adjusted Response Rate % Ethnic group	Male					All men	Female					All women
	16-35	36-50	51-65	66-80	>80		16-35	36-50	51-65	66-80	>80	
White	30	48	68	74	61	61	45	59	73	72	50	62
Asian or Asian British	29	42	52	55	49	44	33	41	41	46	33	39
Black or Black British	25	35	48	55	45	40	36	47	50	50	48	44
Chinese, Mixed or other ethnic group	33	41	57	60	57	48	36	51	65	61	47	50
Total	30	47	67	72	61	59	43	57	71	70	50	60

2.2 The Department of Health's standards for better health

Released in July 2004, the Department of Health core and developmental standards make explicit reference to equality and human rights:

“The standards-based approach in both health and social care means that organisations... need to make sure that they are reaching **all** parts of their population and working to reduce inequalities in health and in access to all services. Particular attention will be paid to black and minority ethnic communities where they are disadvantaged in this way.”¹²

‘National Standards, Local Action’ states that NHS organisations need to address the different needs within their local population in respect of:

“area, socio-economic group, ethnicity, gender, disability, age, faith and sexual orientation, on the basis of a systematic programme of health equity audit and equality impact assessment.”¹³

As was mentioned above, analysis of NHS acute patient survey results show variations in response rates between groups based on gender, area, ethnicity and age. The ability to conduct further analysis of response rates based on other demographic factors is limited by the information about patients available in the sampling frame. For example, the sampling frame does not contain the information to allow us to work out response rates by other factors such as socio-economic group, disability, faith and sexual orientation. It is therefore not possible to analyse variations in response rates by these characteristics.

The questionnaire, on the other hand, does ask for information about some of these factors. For example, core questions are asked about age of leaving full-time education as a proxy for socio-economic group and about disability and health status. Variations in patient experience can therefore be analysed based on these factors. There is however, a limit to the demographic information that can be gathered using a postal self-completion questionnaire without negatively impacting on response rates. So for example, direct questions are not asked about socio-economic group, nor about faith and sexual orientation. It is therefore not possible to assess whether there are variations in patients' experiences of health care on the basis of these factors.

There is however, evidence that people from certain groups do have more difficulties accessing health care and there is a clear link between deprivation and health outcomes. Some of this evidence will be explored in Section 2.3 below.

¹² Department of Health (2004) National Standards, Local Action: Health and Social Care Standards and Planning Framework, 2005/06-2007/08. Available at:

<http://www.dh.gov.uk/assetRoot/04/08/60/58/04086058.pdf> Last accessed 21/06/06

¹³ Department of Health (2004) op cit, p.12

2.3 Healthcare Commission (2006) Race Equality Scheme

The Race Relations (Amendment) Act 2000 placed a statutory duty on all public bodies to demonstrate that they are promoting race equality from May 2002.¹⁴ In February 2005, the Healthcare Commission presented a plan for consultation as part of the requirement set out in the Act. In 2006 this was consolidated in the publication of a Race Equality Scheme setting out the framework for action to promote race equality in the work of the Healthcare Commission.¹⁵ The forward to the Scheme contains the statement in the box below.¹⁶

Box 3.1: Statement from the Healthcare Commission Race Equality Scheme (2006)

The fact that there is a difference in patients' experience, which is linked to ethnicity, matters to us at the Healthcare Commission. It is not justifiable, and we are determined to play our part as regulator in highlighting such inequalities and assessing and encouraging healthcare organisations in challenging them

The Healthcare Commission race equality strategy to 2008 includes the following strategic goal:

“Promote action to reduce inequalities in people’s health and increase respect for human rights and diversity”

With the initial priority to:

“Ensure an explicit focus on inequalities, human rights and diversity in assessments.”¹⁷

In its Race Equality Scheme, the Healthcare Commission sets out how it can make an impact on race equality in each of its three broad functions: inspecting, informing and improving. Its statements in relation to its ‘informing’ role are of particular interest to the aims of this literature review. It states that it will

“maximise our contribution to improving the effectiveness of ethnic monitoring in healthcare (as) the foundation on which NHS bodies... can assess and address health inequalities, difficulties in access and discrimination experienced by some black and minority ethnic individuals and communities”.

¹⁴ Healthcare Commission (2005) ‘Healthcare Commission: Statement of Intent: Promoting human rights and reductions in inequalities in health and healthcare’ Paper presented to Meeting of the Healthcare Commission, 24 February 2005. Available at:

http://www.healthcarecommission.org.uk/_db/_documents/04015089.doc Last accessed 14/06/06

¹⁵ Healthcare Commission (2006) ‘Race Equality Scheme’. London: Commission for Healthcare Audit and Inspection. Available at: http://www.healthcarecommission.org.uk/_db/_documents/04022843.pdf Last accessed 14/06/06 font size

¹⁶ Healthcare Commission (2006) op cit, p.4

¹⁷ Healthcare Commission (2006) op cit, p.8

It states that it will do this in a number of ways, two of which are of significance for this review:

- Modelling best practice in all our studies, surveys and audits
- Highlighting, in our reports, instances where lack of data on ethnicity or low representation of people from black and minority ethnic groups in sample populations means that ethnic variation analysis is not possible.¹⁸

Appendix B of the Scheme sets out the plan of action. Actions that are of relevance to this review are set out in the box below.

Box 3.2 : Healthcare Commission Race Equality Scheme: Plan of Action – actions of specific relevance to the national patient survey programme¹⁹

2.9	There is a requirement under the Department of Health's new national targets on patient experience to specifically monitor the experience of black and minority ethnic groups. We will undertake analyses to investigate the black and minority dimension of patient experience
5.3	Insert multi language note in all published key findings reports to provide details on how readers can obtain copies of the report in other languages and formats
5.4	Carry out and publish, in collaboration with the analysis team, analysis that examines national variations in the experience of patients by ethnicity
5.5	Deposit published data on surveys of patients with the UK data archive to enable researchers to carry out analysis of diversity and race equality
5.6	Ensure that the design of surveys and cognitive testing takes account of the views and experiences of black and minority ethnic groups
5.7	Strengthen the survey guidance issued to the approved contractors and trusts. Centrally fund the use of language line
5.8	Insert 20-language leaflets in survey packs explaining how respondents can access the use of language line
5.9	Explore, with communications and the newly appointed survey coordination centres, the costs and benefits of targeted pre-survey publicity
5.10	Commission independent expert review of the issue with recommendations on further action
5.11	Investigate feasibility of including response by ethnicity in the trust level benchmark reports and spreadsheets
5.12	Investigate the sample size required to enable variations analysis at trust level and the cost implications
5.13	Review benefits of replacing descriptive 'key findings' overview reports with targeted press releases and strengthened variations reporting

2.4 Access to services – variations by ethnic and minority groups

The link between social deprivation and health outcomes has been widely reported²⁰. Increasingly the relationship between poor outcomes and difficulties in terms of accessing health services is being acknowledged:

¹⁸ Healthcare Commission (2006) op cit, p.10-11

¹⁹ Healthcare Commission (2006) op cit, Appendix B: Plan of Action. Wording as in the original.

“Access to, and ease of use of health services has been identified as an important potential source of inequality in the health experiences of different ethnic groups in Britain, which may influence both the quality of care and the outcomes of that care. Accordingly, inequalities in access to, and use of, health services may play a contributory role to inequalities in health status.”²¹

A 2004 paper by the Healthcare Commission describes trends in health inequalities. It suggests that some of the links between deprivation and poor health outcomes are unavoidable, at least in the short term, but that other aspects are avoidable, particularly those resulting from poorer access to services:

“Those in greatest need of public services often have the lowest usage levels and poorest access to services, including healthcare. Patient experience also varies by age, gender, social class, ethnicity and geography.”²²

In 2004 CHI published an analysis of variations between different groups in the results of the national patient surveys conducted in 2002 and 2003²³. Subsequent reports presented analysis of variations in the 2003/2004 and the 2004/2005 national patient survey programmes^{24 25}. These reports provide some information about the experiences of patient groups by a range of different characteristics including:

- Age
- Gender
- Ethnic origin
- Education (as a proxy for social group)
- Self reported health status
- Type of trust and method of admission
- Deprivation

The 2004 analysis showed that the following groups tended to report less favourable experiences²⁶:

²⁰ King’s Fund (2006) Access to health care for minority ethnic groups. Kings Fund Briefing. London: King’s Fund. Available at: http://www.kingsfund.org.uk/resources/briefings/access_to_health.html Last accessed 26/06/06

²¹ Netto G, Arshad R, de Lima P, Diniz FA, MacEwen M, Patel V and Syed R (2001) ‘Audit of Research on Minority Ethnic Issues in Scotland from a ‘race’ perspective’. Scottish Executive Central Research Unit (para 5.59). Available at: <http://www.scotland.gov.uk/cru/kd01/red/auditethnic-00.asp> Last accessed 14/06/06

²² Raleigh VS and Polato GM (2004) Evidence of health inequalities. London: Healthcare Commission

²³ Commission for Health Improvement (2004) Unpacking the patients’ perspective: Variations in the NHS patient experience in England. Available at: http://www.chai.org.uk/_db/_documents/04003496.pdf Last accessed 26/06/06

²⁴ Healthcare Commission (2005) Variations in the experiences of patients in England: Analysis of the Healthcare Commission’s 2003/2004 national survey of patients. Commission for Healthcare Audit and Inspection. Available at: http://www.healthcarecommission.org.uk/_db/_documents/04021208.pdf Last accessed 26/06/06

²⁵ Healthcare Commission (2006) Variations in the experiences of patients using the NHS services in England: Analysis of the Healthcare Commission’s 2004/2005 national survey of patients. London: Commission for Healthcare Audit and Inspection. Available at: http://www.healthcarecommission.org.uk/_db/_documents/Surveys_Variations_Report_200612211042.pdf Last accessed 23/01/07

²⁶ Commission for Health Improvement (2004) op cit, p. 23ff

- Women
- Younger people
- Respondents leaving school at an older age
- People from minority ethnic groups
- Patients with a poorer self reported health status
- Those living in deprived PCTs
- People living in London

The 2005 and 2006 analyses revealed similar patterns in the experience of different patient groups. The 2005 report concludes however that,

“Although there are strong and consistent variations between patient groups, a relatively small proportion of variation – around 10% for most surveys – is explained by the factors considered in the analysis (and there) are a number of other factors that could contribute to the variations.”²⁷

Most of the groups shown to have had less favourable experiences are amongst those typically regarded as seldom heard or less likely to respond to health surveys. For example, the 2004 response rates to the patient surveys were lower for young people and non-white groups, in London and in deprived areas. The most significant variation in experience was related to self reported health status but determining the relationship between this factor and response rates is not straightforward. There is however, a growing body of evidence linking characteristics that determine poor response rates to quality of care and outcomes:

“According to research, [in the US] non-English-speaking patients and patients with low literacy skills face the greatest threat of receiving poor quality of care. Paradoxically, patients with low literacy skills also face the greatest barriers to responding to self-administered quality assessment tools such as the CAHPS® surveys.”^{28 29}

The available evidence clearly suggests that response rates are likely to be lower amongst the groups who are more likely to report unfavourable experiences. This suggests that the results from the patient surveys may overestimate positive experience and provides a strong argument for further investigation of the characteristics of non-responders and strategies for increasing response rates.

²⁷ Healthcare Commission (2005) op cit, p.5

²⁸ Morales LS, Weidmer BO and Hays RD 'Readability of CAHPS® 2.0 Child and Adult Core Surveys'. In Cynamon and Kulka (eds) (2001) pp83 – 90

²⁹ The Consumer Assessment of Healthcare Providers and Systems (CAHPS) programme is a US public-private initiative to develop standardised surveys of patients' experiences. It is similar to the Picker Surveys in that it emphasizes patient experience and is therefore highly relevant to the development of the NHS inpatient survey programme. For further information see: <https://www.caahps.ahrq.gov/default.asp> Last accessed 25/08/06

3 Why do variations in response rates matter? – Response Bias

In an examination of data quality in questionnaire surveys, Bowling describes why low response rates are a concern:

“The lower the response rate to a study, the greater the danger that the responders may differ from non-respondents in their characteristics, which affects the precision (reliability) of the survey’s population estimates, resulting in study bias, and weakening the external validity (generalizability) of the survey results”.³⁰

She goes on to state that the evidence about the differences between responders and non-responders in health related research is inconclusive:

“While there is much literature reporting on differences between respondents and non-respondents in relation to individual studies, overall reviews and systematic reviews of health-related literature on the differences between responders and non-responders are inconsistent or inconclusive.”³¹

It is widely accepted that certain groups are less likely to return completed questionnaires in a postal survey. These groups have become known as the seldom heard:

- The mentally ill and physically disabled
- Individuals with language barriers
- Individuals with limited literacy skills
- The less well educated and,
- The elderly

To this list can also be added the homeless, asylum seekers, travellers and other highly mobile populations for whom a lack of contact information makes inclusion in postal surveys problematic.

Reasons for non-participation in a postal survey amongst some of these groups are self-explanatory – communication barriers that impede self-completion of a questionnaire and a lack of contact information. There is however limited published evidence examining non-response and the characteristics of non-responders more generally. This is largely because information on non-responders is naturally hard to obtain.

3.1 The characteristics of non-responders

In conducting this review we examined the published evidence available about variations between responders and non-responders in health related studies. We found a limited amount of published

³⁰ Bowling A ‘Mode of questionnaire administration can have serious effects on data quality’. Journal of Public Health (2005) 3 May, Vol. 27, No.3:281-291

³¹ Ibid

empirical evidence regarding variations by gender, age, ethnic group, social group, occupational group and health status in responses to postal surveys. Most material was based on studies conducted in the US. The review identified just three UK empirical studies of postal survey non-response. The evidence was particularly limited in terms of published empirical studies of variations in response rates by factors such as mental health, disability or by social characteristics such as homelessness. Just one US paper was found that examined participation in interview surveys by groups defined as vulnerable by their economic, social, psychological, physical health and child maltreatment status.³²

Several US studies have compared the characteristics of respondents and non-respondents in postal surveys and found differences with respect to sex, age, race, social class, occupational group, home circumstances, education, and healthy lifestyle behaviours.^{33 34 35 36 37 38 39 40}

Repeatedly, US studies have shown that people from black and minority ethnic groups are less likely to respond to postal surveys.^{41 42 43 44 45 46 47 48} Response rates are also generally lower amongst people living in areas with a higher proportion of nonwhite residents.⁴⁹

³² Widom CS and Czaja SJ. 'Reactions to research participation in vulnerable subgroups'. *Accountability in Research* (2005) Apr-Jun, vol. 12, no.2: 115-38

³³ Mangione T (1995) *Mail surveys. Improving the quality*. Boston: JSI Research and Training Institute

³⁴ Harrison RA and Cock D. 'Increasing response to a postal survey of sedentary patients – a randomised controlled trial' *BMC Health Services Research* (2004) 10 November, 4:31

<http://www.biomedcentral.com/1472-6963-4-31>. In a review of the literature on increasing response rates Harrison and Cock cite the following five articles:

Bostrum G, Hallquist J, Haglund BJ, Romelsjo A, Svanstrom L and Diderichsen F. 'Socioeconomic differences in smoking in an urban Swedish population. The bias introduced by non-participation in a mailed questionnaire'. *Scand J Social Med* (1993) 21:77-82

Hill A, Roberts J, Ewings P and Gunnell D. 'Non-response bias in a life-style survey'. *J Public Health Med* (1997) 19:203-207

Jackson R, Chambless LE, Yang K, Byrne T, Watson R, Folsom A, Shahar E and Kalsbeek W. 'Differences between respondents and nonrespondents in a multicenter community-based study vary by gender and ethnicity'. *Journal of Clinical Epidemiology* (1996) Dec, Vol. 49, No. 12: 1441-46

Lahaut VMHCJ, Jansen HAM, Mheen DVD and Garretsen HFL. 'Non-response bias in a sample survey on alcohol consumption'. *Alcohol Alcoholism* (2002) 37:256-260

Launer LJ, Wind AW and Deeg DJH. 'Nonresponse patterns and bias in a community-based cross-sectional study of cognitive functioning among the elderly'. *Am J Epidemiol* (1994) 139:803-812

³⁵ Fowler FJ, Gallagher PM, Stringfellow VL, Zaslavsky AM, Thompson JW and Cleary PD. 'Using telephone interviews to reduce nonresponse bias to mail surveys of health plan members'. *Medical Care* (2002) Vol. 40, No. 3: 190-200

³⁶ Fowles JB, Weiner JP, Knutson et al. (1994) 'A Comparison of Alternative Approaches to Risk Measurement' Park Nicollet Medical Foundation. Final Report. Physician Payment Review Commission Grant Number 93-G07. Minneapolis, MN. cited in McCall N, Khatutsky G, Smith K and Pope GC. 'Estimation of non-response bias in the Medicare FFS HOS'. *Health Care Financing Review* (2004) Vol. 25, No. 4, Summer

³⁷ Rogers WH, Ware JE, Gandek B et al. (2000) *Examining Longitudinal Outcomes in the Medicare Health Outcomes Survey: preliminary recommendations*. Boston MA cited in McCall et al (2004) op cit

³⁸ Khatutsky G and Pope GC (2002) 'Analysis of Non-Response Bias in the Medicare Health Outcomes Survey.' Health Economics Research Inc. Waltham MA cited in McCall et al (2004).

³⁹ Locker D, Slade GD and Leake JL. 'The response rate problem in oral health surveys of older adults in Ontario'. *Canadian journal of public health* (1990) May-Jun, vol. 81, no. 3:210-4

⁴⁰ Heberlein TA and Baumgartner R. 'Factors affecting response rates to mailed questionnaires: a quantitative analysis of the published literature'. *American Sociological Review* (1978) Vol. 43 (August): 447-462

⁴¹ Elliott MN, Edwards C, Angeles J, Hambarsoomians K and Hays RD. 'Patterns of Unit and Item Nonresponse in the CAHPS® Hospital Survey.' *Health Services Research* (2005) Dec, Vol 40: 2096

Generally, the very old are less likely to respond^{50 51 52 53} as are younger adults^{54 55} Studies have also shown that younger non-respondents are healthier than respondents of the same age, whereas elderly non-respondents are less well than elderly respondents^{56 57 58}

Other factors associated with nonresponse are being disabled,⁵⁹ institutionalised,⁶⁰ male⁶¹ and on a low income^{62 63 64} Living with other people⁶⁵ and a higher level of education^{66 67 68 69 70 71} were associated with a greater likelihood of response.

⁴² Khatutsky and Pope (2002) cited in McCall et al (2004).Op cit

⁴³ Rogers et al (2000) cited in McCall et al (2004) op cit

⁴⁴ Renfroe EG, Heywood G, Foreman L, Schron E, Powell J, Baessler C, Warwick D, Morris M and Hallstrom A. 'The end-of-study patient survey: methods influencing response rate in the AVID Trial'. *Controlled Clinical Trials* 23 (2002) 521-533

⁴⁵ Pirzada A, Yan LL, Garside DB, Schiffer L, Dyer AR and Daviglius ML. 'Response rates to a questionnaire 26 years after baseline examination with minimal interim participant contact and baseline differences between respondents and nonrespondents'. *American Journal of Epidemiology*, 2004 Jan 1, vol. 159, no. 1, p. 94-101

⁴⁶ Zaslavsky AM, Zaborski LB and Cleary PD. 'Factors affecting response rates to the Consumer Assessment of Health Plans Study survey'. *Medical care* (2002) June, vol. 40, no. 6:485-99

⁴⁷ Collins RL, Ellickson PL, Hays RD and McCaffrey DF. 'Effects of incentive size and timing on response rates to a follow-up wave of a longitudinal mailed survey'. *Evaluation review* (2000) August, vol. 24, no. 4:347-63

⁴⁸ Evans BR, Peterson BL and Demark WW. 'No Difference in Response Rate to a Mailed Survey among Prostate Cancer Survivors Using Conditional versus Unconditional Incentives'. *Cancer Epidemiology Biomarkers and Prevention* (2004) Vol. 13/2:277-278

⁴⁹ Zaslavsky AM, Zaborski LB and Cleary PD. 'Factors affecting response rates to the Consumer Assessment of Health Plans Study survey'. *Medical care* (2002) June, vol. 40, no. 6:485-99

⁵⁰ Khatutsky and Pope (2002) cited in McCall et al (2004) op cit

⁵¹ Rogers et al (2000) cited in McCall et al (2004) op cit

⁵² Pirzada et al (2004) op cit

⁵³ Ito H, Shingai N, Yamazumi S, Sawa Y and Iwasaki S. 'Characteristics of nonresponders to a patient satisfaction survey at discharge from psychiatric hospitals'. *Psychiatric Services* (1999) Vol. 50/3: 410-412

⁵⁴ Elliott et al (2005) op cit

⁵⁵ Renfroe EG, Heywood G, Foreman L, Schron E, Powell J, Baessler C, Warwick D, Morris M and Hallstrom A. 'The end-of-study patient survey: methods influencing response rate in the AVID Trial'. *Controlled Clinical Trials* 23 (2002) 521-533

⁵⁶ Fowles et al (1994) op cit

⁵⁷ Paganini HA, Hsu G, Chao A and Ross RK. 'Comparison of early and late respondents to a postal health survey questionnaire'. *Epidemiology* (1993) Vol. 4/4:375-379

⁵⁸ Strayer M, Kuthy R and Sutton S. 'Elderly nonrespondents to a mail survey: a telephone follow-up'. *Special care in dentistry : official publication of the American Association of Hospital Dentists the Academy of Dentistry for the Handicapped and the American Society for Geriatric Dentistry* (1993) Nov-Dec, vol. 13, no. 6:245-8

⁵⁹ Zaslavsky AM, Zaborski LB and Cleary PD. 'Factors affecting response rates to the Consumer Assessment of Health Plans Study survey'. *Medical care* (2002) June, vol. 40, no. 6:485-99

⁶⁰ Fowles et al (1994) Op cit

⁶¹ Pirzada et al (2004) op cit

⁶² Fowles et al (2004) op cit

⁶³ Renfroe et al (2002) 521-533

⁶⁴ Zaslavsky et al (2002) op cit

⁶⁵ Renfroe EG, Heywood G, Foreman L, Schron E, Powell J, Baessler C, Warwick D, Morris M and Hallstrom A. 'The end-of-study patient survey: methods influencing response rate in the AVID Trial'. *Controlled Clinical Trials* 23 (2002) 521-533

⁶⁶ Ibid

⁶⁷ Pirzada et al (2004) op cit

Teitler and colleagues also found that the characteristics of responders were different to those of non-responders and conclude that more knowledge is needed of people's reasons for not participating.⁷²

Similarly, another US study compared the characteristics of responders and non-responders to a postal survey of women with abnormal cervical smears. Initial non-responders were contacted by telephone and completed the same survey over the telephone. Mailed questionnaires and follow-up interviews were provided in both Spanish and English. The overall response rate was 70% (n=733 completed questionnaires) with just over half returned by mail and just under half completed by telephone. Thirty-four percent of the telephone surveys were completed in Spanish, compared with 13% of the mailed surveys (P<.001).⁷³ This suggests that Spanish speakers were more likely to complete the questionnaire over the telephone.

The above studies of non-response were all carried out in the US and it could be argued that characteristics of non-response may be country specific. Just six UK studies were found that examined response rates for different socio-demographic groups in healthcare related postal surveys.

One examined response rates in a postal survey in the Grampian region of Scotland with a random sample of 10,000 adults registered with a general practitioner.⁷⁴ Patients were initially contacted by letter to obtain consent to be sent a postal or electronic questionnaire. Respondents at the consent stage were more likely to be female, less likely to live in deprived postal areas and more likely to be older.⁷⁵ These findings were replicated in a postal health survey of 8,645 patients in Birmingham.⁷⁶ Response rates to both questionnaires were higher among older age groups a finding replicated in a study of age-related non-response bias.⁷⁷ Another UK study also found that older people were more likely to respond, though it only reported for people under 45 compared to

⁶⁸ Zaslavsky et al (2002) op cit

⁶⁹ Larroque B, Kaminski M, Bouvier-Colle MH and Hollebecque V. 'Participation in a mail survey: Role of repeated mailings and characteristics of nonrespondents among recent mothers. Paediatric and Perinatal Epidemiology (1999) Vol. 13/2: 218-233

⁷⁰ Shahar E, Folsom AR and Jackson R. 'The effect of nonresponse on prevalence estimates for a referent population: Insights from a population-based cohort study'. Annals of Epidemiology (1996) Vol. 6/6:498-506

⁷¹ Collins RL, Ellickson PL, Hays RD and McCaffrey DF. 'Effects of incentive size and timing on response rates to a follow-up wave of a longitudinal mailed survey'. Evaluation review (2000) August, vol. 24, no. 4:347-63

⁷² Teitler JO, Reichman NE and Sprachman S 'Costs and benefits of improving response rates for a hard-to-reach population'. Public Opinion Quarterly; Spring 2003; Vol.67:126-138.

⁷³ Nelson KM, Geiger AM and Mangione CM. 'Racial and ethnic variation in response to mailed and telephone surveys among women in a managed care population'. Ethnicity and Disease (2004) Vol 14/4:580-583

⁷⁴ Angus VC et-al. 'The requirement for prior consent to participate on survey response rates : a population-based survey in Grampian'. BMC Health Services Research, 18 November 2003, vol. 3, no. 21, URL: <http://www.biomedcentral.com/content/pdf/1472-6963-3-21.pdf>

⁷⁵ The odds ratios for response at the 95% confidence interval were 1.5 (female vs male); 0.59 (less deprived areas vs more deprived areas); 2.82 (people born in 1930-39 compared to people born in 1970-79).

⁷⁶ Roberts LM, Wilson S, Roalfe A and Bridge P. 'A randomised controlled trial to determine the effect on response of including a lottery incentive in health surveys'. BMC Health Services Research (2004) 8 Nov, Vol. 4

⁷⁷ Tennant A and Badley EM. 'Investigating non-response bias in a survey of disablement in the community: implications for survey methodology'. Journal of Epidemiology and Community Health (1991) Sep, vol. 45, no. 3: 247-250

those over 45.⁷⁸ Two other studies found that non-responders were more likely to be very much older,⁷⁹ and in the case of one study, more likely to be in poorer physical health than responders.⁸⁰ The Grampian and Birmingham findings of lower response rates from patients in more deprived areas were also seen in a postal survey of oral health status in England (59.6% compared to 77.7% in more affluent areas surveyed).⁸¹

A recent UK study examined both household and interviewer factors associated with refusal and non-contact in three UK government household surveys (the General Household Survey, the Family Expenditure Survey and the Labour Force Survey).^{82 83} These UK government surveys are, however, interview based rather than postal surveys, and non-response patterns are likely to vary across survey modes. Nevertheless, in a multi-level analysis, Durrant showed that interview **refusal** was more likely to occur if the householder had no formal qualifications, was unemployed or self-employed, was in poor health, and lived in a multiple adult household. **Non-contact** was more likely if the householder lived in a flat, as opposed to a house, if it was a single person household, and if the household had no person in employment. Overall, these results indicate that socio-economic status is associated with both refusal and non-contact but poor health is associated with refusal only.

Durrant did not report on response rates by ethnic group and neither do recent Health Survey for England (HSE) reports.^{84 85} The 1998 HSE, however, found that in the interview stage of the survey, participants of black ethnic origin were less likely than others to participate in the second stage of the survey involving tests with a nurse.⁸⁶ A similar study in New Zealand reported the same results with the response rates amongst black participants being considerably lower than

⁷⁸ Meadows KA, Gardiner E, Greene T, Rogers D, Russell D and Smoljanovic L. 'Factors affecting general practice response rates to a postal survey of health status in England: a comparative analysis of three disease groups'. *Journal of Evaluation in Clinical Practice* (1998) 4, 3, 243-247

⁷⁹ Victor CR. 'Some methodological aspects of using postal questionnaires with the elderly'. *Archives of Gerontology and Geriatrics* (1988) 7;2: 163-172

⁸⁰ Emberton M and Black N. 'Impact of non-response and of late-response by patients in a multi-centre surgical outcome audit'. *International Journal for Quality in Health Care* (1995) 7:47-55

⁸¹ Tickle M, Craven R and Blinkhorn AS. 'Use of self-report postal questionnaires for district-based adult oral health needs assessment'. *Community Dental Health* (1996) Dec vol. 13;4:193-8

⁸² Durrant GB (2006) 'An investigation of household unit-nonresponse in UK Government household surveys'. *Proceedings of Q2006 European Conference on Quality in Survey Statistics*

⁸³ Durrant's work was influenced by a number of earlier studies into non response in household interview surveys including:

1. Campanelli P, Sturgis P and Purdon S (1997) *Can you hear me knocking? An investigation into the impact of interviewers on survey response rates*. London: NatCen
2. Foster K (1998) *Evaluating Non-response on Household Surveys*, GSS Methodology Series No. 8. London: Government Statistical Service
3. Groves RM and Couper MP (1998) *Nonresponse in household interview surveys*. New York: Wiley

⁸⁴ For more information about the Health Survey for England see <http://www.dh.gov.uk/en/Publicationsandstatistics/Surveys/HealthSurveyForEngland/Healthsurveyresults/index.htm> Last accessed 19/03/07

⁸⁵ The 2004 survey included a boost sample of the major minority ethnic groups in England and response rates for each of these groups are reported at: <http://www.ic.nhs.uk/pubs/healthsurvey2004ethnicfull> Last accessed 19/03/07

⁸⁶ Boreham R, Brookes M, Erens B, Laiho J, Primatesta P and Prior G. 'Survey methodology and response' Chapter 8 in Erens B and Primatesta P (eds) (1999) *The 1998 Health Survey for England. Cardiovascular Disease. Volume 2: Methodology & Documentation*. The Stationery Office. Available at: <http://www.archive.official-documents.co.uk/document/doh/survey98/hse-08.htm> Last accessed 31/08/06

that for white participants, particularly in men.⁸⁷ The results for white participants in this study also mirrored those found by Durrant with white male respondents reporting a higher socioeconomic status, better general health and a lower prevalence of cardiovascular disease and associated risk factors than white male non-respondents.

The non-response characteristics from these interview based surveys are similar to the findings from the US studies of non-response in postal surveys in that they suggest refusal is closely associated with socio-economic factors and health status. In contrast to these findings Groves and Couper reported higher participation rates amongst Black and minority ethnic groups and people from lower socioeconomic status, once contact was established, in their analysis of non response to household interview surveys.⁸⁸ Their findings support theories that ethnic participation may vary between different countries.

As Bowling has suggested, the evidence about differences in the characteristics of responders as opposed to non-responders in postal self-completion questionnaire surveys is inconsistent and inconclusive.⁸⁹ While the above studies find differences in socio-demographic characteristics between respondents and non-respondents, other US studies find few or no differences between responder and non-responder characteristics.^{90 91 92 93}

UK studies have also reported no evidence of responder bias. One study with a response rate of just 37% to a postal survey of 2,389 patients suggested there was no evidence of non-response bias.⁹⁴ Another reported no response bias in a postal survey of 60,000 women with a response rate of 49%.⁹⁵ Similarly a postal questionnaire of 137 women in Ireland with response rates of 38% reported little evidence of response bias.⁹⁶ In all three studies however, these claims appear to be based on limited analysis of socio-demographic factors.

⁸⁷ Jackson R, Chambless LE, Yang K, Byrne T, Watson R, Folsom A, Shahar E and Kalsbeek W. 'Differences between respondents and nonrespondents in a multicenter community-based study vary by gender and ethnicity'. *Journal of Clinical Epidemiology* (1996) Dec, Vol. 49, No. 12: 1441-46

⁸⁸ Groves and Couper (1998); op cit

⁸⁹ Bowling A 'Mode of questionnaire administration can have serious effects on data quality'. *Journal of Public Health* Vol. 27, No.3, pp. 281-291. 3 May 2005

⁹⁰ Mond JM, Rodgers B, Hay PJ, Owen C and Beumont PJV. 'Nonresponse bias in a general population survey of eating-disordered behaviour'. *International Journal of Eating Disorders* (2004) Vol. 36, No. 1: 89-98

⁹¹ Ito H, Shingai N, Yamazumi S, Sawa Y and Iwasaki S. 'Characteristics of nonresponders to a patient satisfaction survey at discharge from psychiatric hospitals'. *Psychiatric Services* (1999) Vol 50, No. 3: 410-412

⁹² Strayer M, Kuthy R and Sutton S. 'Elderly nonrespondents to a mail survey: a telephone follow-up'. *Special care in dentistry* (1993) Nov-Dec, Vol. 13, No. 6: 245-8

⁹³ Woodruff SI, Conway TL and Edwards CC. 'Increasing response rates to a smoking survey for U.S. Navy enlisted women'. *Evaluation and the Health Professions* (2000) Vol. 23/2:172-181

⁹⁴ Mallen C, Peat G, Thomas E and Croft P. 'Severely disabling chronic pain in young adults: prevalence from a population-based postal survey in North Staffordshire.' *BMC Musculoskeletal Disorders* (2005) 21 Jul, Vol 6: 1471-2474

⁹⁵ Maconochie N, Doyle P and Prior S. 'The National Women's Health Study: Assembly and description of a population-based reproductive cohort'. *BMC Public Health* (2004) 7 Aug, Vol. 4: 1-8

⁹⁶ Sharp L, Cotton SC, Alexander L, Williams E, Gray NM and Reid JM. 'Reasons for participation and non-participation in a randomized controlled trial: postal questionnaire surveys of women eligible for TOMBOLA (Trial Of Management of Borderline and Other Low-grade Abnormal smears)'. *Clinical trials* (2006) vol. 3, no. 5:431-42

A US general population survey of eating disorder behaviour found that respondents and non-respondents did not differ on socio-demographic, physical or mental health characteristics.⁹⁷ Similarly, a patient satisfaction survey found that though non-responders were older, there were no significant differences between responders and non-responders on other demographic or clinical diagnostic factors.⁹⁸ In a postal survey of elderly people, Strayer and colleagues compared demographic and health differences of respondents and non-respondents subsequently followed up by telephone.⁹⁹ No significant differences in demographic, health or quality of life characteristics were found between respondents and non-respondents.

3.2 Non-response bias

The evidence from studies that find differences between respondents and non-respondents on socio-demographic and other characteristics underscores the need to evaluate any non-response bias.

Non-response bias is the systematic difference between the outcome scores for survey respondents and the (unknown) scores that would have been obtained if all subjects had completed the survey. The degree of bias is determined by two factors:

- the difference in scores between respondents and non-respondents and
- the overall response rate.

Teitler and colleagues¹⁰⁰ examined the effects of differing response rates on estimates of characteristics of a sample, and the cost and benefits of increased response rates on respondent characteristic estimates. They showed that estimates of age and level of education at different levels of response rates were similar to those from the total eligible sample. However, estimates of the proportion of Black and White respondents at different levels of response rates varied. With a low response rate the proportion of Black fathers was underestimated and White fathers overestimated. Estimates of the proportion of Black and White respondents corresponded more closely to the proportions in the total eligible sample as the response rate increased. Similarly, other factors such as whether the father was romantically involved with the mother or whether the father would provide support corresponded more closely to the proportions in the total eligible sample as the response rate increased.

While the above study suggests that increasing response rates results in more precise estimates of sample characteristics, other evidence suggests that the relationship between response rates and non-response bias is mixed.¹⁰¹ In a review of 63,473 cases from 50 different US surveys of paediatricians, correlational analyses were conducted to examine whether surveys with lower response rates had increasing levels of response bias. The study found that the average response bias was fairly small for all factors studied (age, gender and membership type) and even for the surveys with the lowest response rates, the amount of response bias never exceeded 5 percentage points for gender, 3 years for age, or 3 percent for membership type. They conclude

⁹⁷ Mond et al (2004) op cit

⁹⁸ Ito et al (1999) op cit

⁹⁹ Strayer et al (1993) op cit

¹⁰⁰ Teitler JO, Reichman NE and Sprachman S. 'Costs and benefits of improving response rates for a hard-to-reach population'. Public Opinion Quarterly (2003) Spring; Vol. 67: 126-138

¹⁰¹ Smith P (2006) Review of BME coverage in the Healthcare Commission's patient survey programme (unpublished report) p. 18

that more attention should be devoted by investigators to assessments of response bias rather than relying on response rates as a proxy of response bias.¹⁰²

Another US study reached similar conclusions following an examination of how survey estimates and data quality changed as additional respondents completed the survey. Improvements in response rates over the range examined (up to 65%) did not change estimates appreciably nor affect data quality. The authors emphasise however, that these results should not be overstated to imply that extremely low response rates are credible.¹⁰³

3.3 Strategies to reduce non-response bias

Both methodological and statistical techniques have been used to reduce the risk of non-response bias in postal surveys. The methodological approaches to reducing non-response bias are explored in the later sections of the report (Sections 5 and 6). They include both approaches to increase response rates amongst groups that are typically less likely to respond and intensive follow up contacts of non-respondents. For example, one US study found that though older and disabled respondents, ethnic minorities, less educated respondents and respondents living in high non-white ethnic density areas all had lower response rates, intensive telephone follow up of these groups improved the representativeness of the sample.¹⁰⁴

Statistical approaches to reducing response bias include the imputation of, and adjustment for, missing values.^{105 106} McCall and colleagues compared two statistical approaches to adjustment for non-response bias - response propensity weighting, based on an adjustment for the likelihood of responding, and imputation of missing values for non-respondents based on regression. They found that both of these methods produced nearly identical estimates of non-response bias in scores of physical and mental health.

One of the difficulties in imputing for non-respondents in the national patient survey is the lack of complete data on ethnic group for the sample. This problem is not unique to the UK. A recent US study identifies inadequate coding of ethnicity and language as one of the difficulties with using large scale standardised surveys to gather the views of Black and minority ethnic groups. It recommends improved coding at the point of collection and outlines guidelines for achieving this.¹⁰⁷ Smith undertook an analysis of Black and minority ethnic coverage for the national patients survey programme and reached a similar conclusion. He reported a need to improve ethnic coding to

¹⁰² Cull WL, O'Connor KG, Sharp S and Tang SS. 'Response rates and response bias for 50 surveys of pediatricians'. Health Services Research, 2005 Feb, vol. 40, no. 1:213-26

¹⁰³ Schoenman JA, Berk ML, Feldman JJ and Singer A. 'Impact of differential response rates on the quality of data collected in the CTS physician survey'. Evaluation & the health professions (2003) March, vol. 26, no. 1:23-42

¹⁰⁴ Zasalavsky AM, Zaborski LB and Cleary PD. 'Factors affecting response rates to the consumer assessment of health plans study survey'. Medical Care (2002) Vol. 40, No. 6: 485-499

¹⁰⁵ McCall et al (2004) op cit

¹⁰⁶ Locker D. 'Response and nonresponse bias in oral health surveys'. Journal of public health dentistry (2000) Spring, vol. 60, no. 2:72-81

¹⁰⁷ California Pan-Ethnic Health Network (2001) 'Diverse Patients, Disparate Experience: The use of standardized patient satisfaction surveys in assessing the cultural competence of health care organizations'. California: CPEHN

<http://www.cpehn.org/pdfs/CPEHN%20Final%2001.pdf>

Last accessed 12/06/06

enable an accurate assessment of the response bias caused by variations in response rates amongst different ethnic groups.¹⁰⁸

We have so far concentrated on response bias caused by non-completion or non-return of questionnaires. We will turn now to look briefly at a second form of non-response; that of item non-response, where questions are not completed on returned questionnaires.

3.4 Item non-response

There is evidence that in self-administered health surveys in general, item non-response is greatest amongst the elderly¹⁰⁹, Black and minority ethnic groups and the less well educated.¹¹⁰ Bowling reports that “higher item non-response is generally reported in postal surveys compared with face-to-face ... and telephone interviews and electronic methods had more complete item response rates than the various paper and pencil methods.”¹¹¹ This is confirmed in a London randomised controlled trial comparing response of postal versus face to face administration of a survey of care for the dying.¹¹²

Owen and colleagues have conducted a systematic analysis of patterns of item non-response across seven cultural groups in the United States¹¹³. They found that of the eleven studies that have examined racial and ethnic variations in item non-response, seven reported finding differences and four others did not. They argue that:

“This small body of research suggests that minority group respondents and members of less acculturated immigrant groups may have greater difficulties comprehending survey items that in most cases are developed by middle-class representatives of a nation’s dominant cultural group. In addition, they may be less willing to reveal sensitive information during survey interviews. Based upon this research, we hypothesize more broadly that minority cultural groups in general will have higher non response to individual survey items than non-Hispanic white respondents”.

They went on to examine item non response rates in a US health survey and found higher item non response rates among one or more of the minority groups examined, when contrasted with non-Hispanic white respondents. African American respondents most commonly had higher item non response rates to health questions. They also found that education was consistently associated with item non response. In general, health question item non response was greater among less educated respondents.

¹⁰⁸ Smith P (2006) op cit

¹⁰⁹ Elliott MN, Edwards C, Angeles J, Hambarsoomians K and Hays RD. ‘Patterns of Unit and Item Nonresponse in the CAHPS Hospital Survey’. Health Services Research (2005) Vol. 40: 2096, December

¹¹⁰ Owens L, Johnson TP and O’Rourke D ‘Culture and Item Nonresponse in Health Surveys’ in Cynamon ML and Kulka RA (eds) (2001) ‘Seventh Conference on Health Survey Research Methods’. Maryland: Department of Health and Human Services. Available at: <http://www.cdc.gov/nchs/data/conf/conf07.pdf> Last accessed 13/06/06

¹¹¹ Bowling A ‘Mode of questionnaire administration can have serious effects on data quality’. Journal of Public Health Vol. 27, No.3, pp. 281-291. 3 May 2005

¹¹² Addington HJ, Walker L, Jones C, Karlsen S and McCarthy M. ‘A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death’. Journal of Epidemiology and Community Health (1998) 52;12: 802-807

¹¹³ Owens et al (2001) op cit

Separate examination of trends in refusals and ‘don’t know’ answers further suggests that both information processing and social desirability considerations may contribute to these differentials:

“Given that survey questionnaires are most commonly constructed by white middle-class researchers, it should not be surprising that non-white respondents might be somewhat more likely to experience difficulties interpreting survey questions, even after careful pre-testing. Likewise, members of minority groups may understandably be more reluctant to report about sensitive, particularly illegal, health related behaviours.”

To date, little research has focused on patterns of item non-response amongst different demographic groups in the national patient survey programme. Following the 2006 national survey of adult inpatients, however, the Acute Co-ordination Centre has begun to investigate trends in this area. Whilst this work is at an early stage, preliminary results show some variations do appear to exist between different ethnic groups in levels of item non-response to the survey as a whole. For example, significantly higher rates of item non-response – represented as the proportion of all responses per patient coded as ‘missing’ in the data – were observed for patients from black and black British groups compared with patients from white or from Asian or Asian British backgrounds¹¹⁴. Further research is however needed to determine any possible influence of confounding factors such as differences in other group-level demographic variables such as age, sex, geographic location, and patient journeys, as well as to look in detail at the patterns of item non-response to specific questions on the survey.

This part of the report has explored what is known about variations in the characteristics of non-responders compared with responders in terms of item and unit response. It found that whilst the evidence is not wholly consistent, the published empirical evidence does consistently identify variations based on ethnic group and health status. The next section of the report will examine the published evidence that explains these variations. It will examine why response rates are lower amongst certain groups. This will be followed by a section describing strategies suggested to increase response rates amongst these groups. Finally Section six examines the empirical evidence available to measure the impact of these strategies.

¹¹⁴ Graham, C. (2007) Unpublished research based on the 2006 national inpatient survey.

4 Why are response rates lower amongst certain groups?

This section of the report will examine the theories that have been put forward to account for lower response rates amongst certain groups. It will be seen that much of the limited evidence relates specifically to lower response rates amongst Black and minority ethnic groups.

In a review of literature on modes of data collection and their impact on data quality, Bowling suggests three main reasons for non-response in postal questionnaire surveys:

“respondents’ unwillingness to participate in the study,
the investigator’s inability to contact respondents
and communication barriers (eg literacy barriers, sensory impairment)”¹¹⁵.

Heberlein and Baumgartner relate high postal survey response rates to lowering the costs involved in completing and returning a questionnaire. They suggest that these costs may be lower for some groups resulting in higher response rates amongst those groups. They give examples of higher response rates amongst students and military personnel and argue that these groups ‘may find a request to complete a form more familiar and easy to comply with than other groups.’¹¹⁶ They also suggest that students are more likely to find it easy to read the questionnaires and be more familiar with the cognitive tasks involved in their completion. The other cost to respondents considered by Heberlein and Baumgartner relates to ‘the possibility that the information provided will invade privacy and implicate the individual’. They did not however report any evidence that this cost may impact differentially on different groups. The implication that could be drawn from their work would be that some groups may perceive these costs as greater than others, thus making them less likely to return a completed questionnaire.

Groves and colleagues have conducted what is probably the most exhaustive exploration of factors affecting survey response.¹¹⁷ Most of this work has been devoted to exploring participation in household interviews surveys. Some of it is therefore of little direct relevance to postal survey response rates, such as their work on the impact of interviewer behaviour and characteristics. Other aspects of their work provide some very useful insights into variations in participation rates. For example, their work around the more conceptual aspects such as ‘theories of attitudes and behaviours that might inform an understanding of survey participation.’¹¹⁸ They have also argued that these factors may change over time as, for example, ‘the degree of social responsibility felt by a sample person may be affected by such factors as the legitimacy of societal institutions, the degree of social cohesion, and so on’.¹¹⁹ The implication of their work is that these factors may impact differentially on different socio demographic groups. For example, they have considered

¹¹⁵ Bowling (2005) op cit

¹¹⁶ Heberlein and Baumgartner (1978) op cit

4. ¹¹⁷ Groves RM and Couper MP (1998) Nonresponse in household interview surveys. New York: Wiley

¹¹⁸ Groves RM, Cialdini RB and Couper MP (1992) ‘Understanding the decision to participate in a survey’. Public Opinion Quarterly, Volume 56: 475-495

¹¹⁹ Ibid

the impact of housing costs and education as indicators of social-exchange influences and the impact of alienation on survey participation.¹²⁰

In his review of Black and minority ethnic response rates to the NHS patient surveys, Patten Smith suggests two theories for lower response rates amongst these groups – disengagement and lower literacy rates.¹²¹ Similarly, Market Research Society guidelines for conducting research with Black and minority ethnic groups, state the following in accounting for lower response rates to self-completion questionnaires amongst certain ethnic groups:

“The reasons.... range from lack of understanding of research, suspicion of the purpose, language and poor literacy etc.”¹²²

The following sections will examine the evidence around the reasons cited for low response under two main headings. The first relates to theories of disengagement and the second to communication barriers including poor literacy and language skills. It will also examine a third factor – poor contact information - which specifically affects certain groups recognised to be disadvantaged in terms of accessing health services – the homeless and highly mobile populations such as travellers, refugees and asylum seekers.

4.1 Disengagement

Disengagement from government and ‘official’ institutions has been put forward as a reason to explain low response rates amongst Black and minority ethnic groups^{123 124} and disengagement from the survey process has been put forward as a reason for non response in general.¹²⁵

A literature search was conducted to identify literature which considered concepts related to the notion of disengagement as a factor in relation to response rates in social surveys. To identify studies that empirically addressed the notion of civic engagement we used the following search terms: ‘disengagement’, ‘alienation’, ‘citizenship’, ‘community’, ‘responsibility’ and ‘participation’ in conjunction with ‘survey response’.

A number of studies were identified that empirically explored the influence of concepts relating to disengagement as factors influencing postal survey response behaviour. A Hong Kong study found a significant association between these survey response theories and survey participation.¹²⁶ Both this study and a US study found the most significant determinants of response to relate to factors associated with social exchange theory whereby ‘survey respondents participate in a mail

¹²⁰ Groves and Couper (1998) op cit

¹²¹ Smith P (2006) ‘Review of BME coverage in the Healthcare Commission’s patient survey programme’

¹²² Market Research Society (MRS) Guidelines for conducting research amongst different ethnic groups. Available at: http://www.mrs.org.uk/networking/ern/downloads/guidance_ethnic_research.pdf Last accessed 14/06/06

¹²³ Groves and Couper (1998) op cit

¹²⁴ Smith P (2006) ‘Review of BME coverage in the Healthcare Commission’s patient survey programme’

¹²⁵ Bowling (2005) op cit

¹²⁶ Poon PS, Albaum G and Evangelista FU. ‘Why people respond to surveys: a theory based study of Hong Kong respondents’. *Journal of International Consumer Marketing* (2003) Vol 16, no. 2: 75-90

survey if they expect an equitable exchange'.¹²⁷ Another US study of non response found that students who decided not to participate in university longitudinal surveys perceived their organization more negatively and were more likely to feel exploited in social relationships.¹²⁸ Neither study, however, reported on the socio-demographic characteristics of participants as opposed to non participants, so it is not possible to draw conclusions about the implications for response rates amongst specific groups.

Groves and Couper examine the evidence around the influence of 'social isolation theory' or disengagement on household interview survey response rates for different socio-demographic groups.¹²⁹ They find no evidence to support their hypothesise about a relationship between response rates and ethnic groups or age which is determined by factors associated with disengagement.

No papers were found that empirically examined notions of disengagement relating to non response to postal surveys in the UK, however two papers were identified that were of relevance.^{130 131}

Elam and colleagues looked specifically at factors that could affect the participation of Black Africans in the 2003 Health Survey for England (HSE). As was discussed above (in Section 3.1) the HSE is a householder interview survey. They do however identify a number of barriers to participation of these groups which are relevant to the notion of disengagement under discussion here (see box overleaf).

¹²⁷ Childers TL and Skinner SJ. 'Towards a conceptualization of mail survey response behaviour'. *Psychology and Marketing* (Special Issue: Psychology, Marketing and Direct Mail) (1996) vol. 13, no. 2: 185-209

¹²⁸ Spitzmüller C, Glenn DM, Barr CD, Rogelberg SG and Daniel P "If you treat me right, I reciprocate": Examining the role of exchange in organizational survey response. *Journal of Organizational Behavior*, Feb 2006, vol. 27, no. 1, p. 19-35

¹²⁹ Groves and Couper (1998) op cit; pp 131-154

¹³⁰ Elam G, McMunn A and Nazroo J. (2001) 'Feasibility study for health surveys among black African people living in England. Final report – implications for the Health Survey for England 2003'. Joint Health Surveys Unit of University College London and the National Centre for Social Research. p23. Available at: <http://www.publications.doh.gov.uk/pdfs/healthrptfeasibafricansurvey.pdf> Last accessed 25/08/06

¹³¹ Home Office Research, Development and Statistics Directorate (2004) '2003 Home Office Citizenship Survey: People, Families and Communities. Home Office Research Study 289'.

Box 4.1: Barriers to participation of Black Africans in the Health Survey for England¹³²

Section 3.2 Participation

Key findings

- ◆ Although responses to personal participation to a survey such as the HSE were generally enthusiastic among individuals interviewed for this study, both individuals and community representatives identified the following potential barriers to participation:
 - ◆ a lack of trust between the black African population and the wider British population along with a fear that any information provided in a research setting may put social security benefits in jeopardy or may be subject to the scrutiny of social services officials.
 - ◆ The experiences of hostile situations in home countries would have left some people wary of government agents.
 - ◆ a cultural preferences for information not to be written down as this meant running the risk of the information being misused. It was not clear whether this would apply to information being recorded directly into a computer.
 - ◆ a reluctance to discuss health issues because people with poor health did not want to be perceived to be a burden on the state, and so jeopardise their asylum applications. Also people did not want news of their poor health to travel home to friends and family in Africa.
 - ◆ A feeling that the research was unimportant or that their contribution to the research was unimportant.
 - ◆ Both community representatives and individuals in communities felt that black African groups had been over-researched.
- ◆ In addition to barriers to participation in the black African population generally, certain specific groups were identified as potentially being less likely to take part in the HSE:
 - ◆ Those who work many jobs or long hours.
 - ◆ Older people.
 - ◆ Those who have recently arrived in the UK.
 - ◆ Those who do not speak English.
 - ◆ People with stigmatised illnesses.

¹³² Elam et al (2001)op cit

In 2003 the Home Office conducted a survey of people's participation in a range of activities associated with the notion of citizenship.¹³³ Some of these activities can be taken as a proxy for indicators of civic engagement and can therefore be used to test the theory of disengagement as a cause of low response rates amongst Black and minority ethnic groups. Whilst some of the evidence supports this hypothesis, some of it does not.

For example, the extent to which people perceive they can influence their local area might be seen as a proxy for engagement. The Home Office study found that Asian and Black people were more likely to feel they could influence decisions regarding their local area than white people (43% and 47% compared with 37% respectively).¹³⁴ Black Africans were particularly more likely to feel they could influence their local area (50%).¹³⁵

Interestingly, people of Chinese ethnic origin were the least likely to feel able to influence decisions affecting their local area. Yet response rates amongst this group in the 2005 inpatients survey were higher than those for other ethnic groups (46%, compared with 41% and 42% for Asian or Black groups respectively). There appears therefore to be an inverse relationship between response rates and the extent to which people feel able to influence their local area, which does not intuitively support theories of disengagement to explain low response rates.

There is also an inverse relationship in terms of age and participation in the NHS patient surveys. Younger people are less likely to respond to the NHS surveys but were found in the Home Office survey to be more likely than older people to feel they were able to influence decisions in their local area.¹³⁶

Evidence on formal political activity represented by voting is mixed when taken as an explanatory factor for response rates. The Home Office survey found that whilst similar for White and Asian ethnic groups, voting is significantly lower amongst all other ethnic groups (24% of Whites did not vote in either the last general or local election compared with 23% of Asians, 39% of Blacks, 42% of mixed race, 58% of Chinese and 48% from Other ethnic groups).¹³⁷

Although the Home Office survey did not ask specifically about willingness to complete a survey about hospital services, it did ask about other aspects of civic participation and rates of civic participation could be taken as an indicator of people's likelihood to complete a survey. Anecdotally, one reason given for completing questionnaires about the NHS is a sense of duty or of giving something back to the NHS.

The findings with regard to civic participation support, to a certain extent, theories of disengagement as an explanation for low response rates. For example, the civic participation rate was particularly low (32%) among those living in areas with the highest concentration (10% or more) of minority ethnic households.¹³⁸ Civic participation rates were also significantly lower in areas of high deprivation.¹³⁹ On the other hand, there were high rates of civic participation amongst people of mixed race and those of Bangladeshi origin (42% and 39% respectively compared to 39% for White people). People of Chinese origin had the lowest rate of civic

133 Ibid

134 Op cit, p. 29

135 Op cit, Table 2.18; p. 31

136 Op cit, p. 29

137 Op cit, Table 2.23; p. 39

138 Op cit, p. 188 and Table 6.8, p. 203

139 Op cit, Table 6.9, p. 203

participation (24%) and the rates for other Asian and Black groups was lower than for that of White groups (29% to 34%).¹⁴⁰

Rates of civic participation were in fact similar amongst all those born in the UK and the ethnic variation in civic participation appears to be explained by country of birth.¹⁴¹ This would suggest that theories of acculturation and literacy and language may be better explanations of low response rates in the national patient surveys. These themes are explored in the next section of the report (Section 4.2).

Amongst White groups civic participation was lowest in younger people, while in contrast young Asian people were more likely to engage in civic activities.¹⁴² Older Asian women had very low rates of involvement (26% compared with 37% among Asian men).

This evidence about participation in a range of civic activities is inconsistent in supporting theories of disengagement as an explanation for low response rates amongst Black and minority ethnic groups. The Home Office study did however provide other evidence that provides support to the notion that low response rates amongst Black and minority ethnic groups is a result of their alienation from public services in general and from NHS services in particular.

People were asked about the extent to which they expected to be treated better or worse than others by their local GP practice. Overall, just 2% of participants expected to be treated worse than others. Asian people, particularly those of Pakistani origin were slightly more likely than White people to expect to be treated worse (3% and 5% compared to 2%). Black people, particularly those of African origin were significantly more likely to expect to be treated worse, as were those of Chinese origin (6%, 8% and 7% respectively compared to 2% of White people). A similar pattern is borne out by the statistics regarding beliefs about other public services.

The survey found that people who held favourable views about their neighbourhood were more likely than those with negative views to have engaged in civic participation.¹⁴³ Black and minority ethnic groups were less likely to hold favourable views of their neighbourhood. The case in London is somewhat different. Londoners tend to score lowest on measures related to community spirit and they had the most unfavourable views about their neighbourhood. However they scored some of the highest rates of civic participation and informal and formal volunteering.¹⁴⁴

To conclude, evidence supporting theories of disengagement as an explanation for low response rates amongst Black and minority ethnic groups and disadvantaged populations is weak. However, although there is limited hard evidence to support these theories, strategies for involving seldom heard groups in research frequently include to methods for increasing trust amongst these groups. These strategies will be explored in more detail in Section 5.1 below.

¹⁴⁰ Op cit, p. 189 and Table 6.13, p. 205

¹⁴¹ Op cit, p. 190 and Table 6.16, p. 207

¹⁴² Op cit, p. 189

¹⁴³ Op cit, p. 191

¹⁴⁴ Op cit, p. 201

4.2 Communication barriers

In 2002 Clark estimated that there were a significant number of people in Great Britain with a disability that may affect their ability to communicate:

- 7.3 million people with literacy difficulties
- 8.7 million people who are deaf or hard of hearing
- 1.7 million people with a visual impairment, unable to read standard print with ease
- 1 million people with a learning difficulty
- 6 million people with mental health issues¹⁴⁵

In addition, there are significant numbers in England who do not speak English as a first language. There is no accurate figure for the proportion of English residents who do not speak English. However, it is possible to estimate a figure by drawing on data from a number of different sources. According to the 2001 Census, slightly less than 13% of the population of England and Wales are from minority ethnic groups. Of course, many of these people will have been born in the UK, or have lived here for some years, and will speak English fluently. However, reported fluency in English is low amongst some ethnic groups who are concentrated in particular geographical areas. For example, in 1997 it was estimated that 42.5% of those of Bangladeshi origin, 34% of those of Pakistani origin, 24.5% of those of Indian origin and 24% of those of Chinese origin did not speak English fluently.¹⁴⁶ Extrapolating from these figures in 1998 it was estimated that more than 40,000 people from these ethnic groups living in the east London boroughs of Newham and Tower Hamlets did not speak English fluently.¹⁴⁷

Szczepura and colleagues estimated that 0.8% of England's population (376,052 people) have language difficulties.¹⁴⁸ Another study estimated that the across England and Wales something in the region of 671,000 people of Bangladeshi, Pakistani, Indian and Chinese origin do not speak English fluently. Rates of non-English fluency are higher amongst women than men and increase with age as shown in the table below.

¹⁴⁵ Clark L (2002) Liverpool Central Primary Care Trust Accessible Information: Project Report (August). Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Clark,%20Laurence/liverpool%20NHS.pdf> Last accessed 29/06/06

¹⁴⁶ Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S and Beishon S (1997) Ethnic Minorities in Britain Diversity and Disadvantage - Fourth National Survey of Ethnic Minorities. London: PSI

¹⁴⁷ Sheldon H (1998) Counting the Cost of Cultural Diversity. Report of Phase One of The Bilingual Advocacy and Interpretation Research Project. In Cox CL, Leahy G and Malik F (2002). Counting the Cost of Cultural Diversity. Final report of The Bilingual and Interpretation Research Project. A Review of the Evidence on Consultation Times and Ethnic Minority Needs in Ambulatory Services. London: Health Care Research Unit, City University. (July) Appendix 1. Available at: http://www.city.ac.uk/barts/research/reports/pdf/cox_c/bilingual.pdf Last accessed 7 July 2004

¹⁴⁸ Szczepura A, Johnson M, Gumber A, Jones K, Clay D and Shaw A (2005) An overview of the research evidence on ethnicity and communication in healthcare. Warwick: Warwick Medical School

Table 1: Literacy in English and in any language¹⁴⁹

	Women 30-49	Men 30-49	Women 50-74	Men 50-74
Able to read English(1991)	%	%	%	%
Indian	67	83	34	71
Pakistani	31	77	7	54
Bangladeshi	15	60	4	38
Unable to read any language(1991)	%	%	%	%
Indian	4	2	25	6
Pakistani	31	7	68	16
Bangladeshi	24	3	52	19
Able to read English(1994)	%	%	%	%
Indian	78	98	42	79
Pakistani	55	82	31	55
Bangladeshi	37	87	13	62

In addition, there are many recent arrivals from European, African, South American and other Asian countries who are likely to have difficulties communicating in English.

Local variations in the characteristics of the population, such as the size of the ethnic group within a locality and the typical length of residence in the UK will determine the exact proportion who have not yet learned English. For example, a 1996 study found that in areas with high proportions of Black and minority ethnic populations nearly two thirds of those of Pakistani ethnic origin and more than half of those of Bangladeshi origin were unable to speak English sufficiently to participate in an interview.¹⁵⁰

In terms of ability to read English, the same study found that amongst Pakistanis, 29% were unable to read a newspaper in English at all and a further 13% would not be confident doing so. Amongst Bangladeshis the proportions rose to 35% unable to read a newspaper at all and a further 19% who would not be confident doing so.¹⁵¹

Literacy amongst Asian groups has been most widely studied. There has been little attention paid to the needs of other groups. A study by the Central Office of Communications examined language and literacy amongst Black Africans living in the UK. They report the following findings:

- people from Uganda and Nigeria tend to speak English, however comprehension of English may be a barrier to participation for some, particularly among Ugandans
- there are black African people who do not feel entirely comfortable with English and this may impede their participation

¹⁴⁹ Smith P (2006) based on Rudat (1994) and Johnson, Owen, Blackburn, Rehman and Nazroo (2000)

¹⁵⁰ Emery B and Stubbington C. 'Communicating with the Asian population' Market Research Society (1996) Conference Papers

¹⁵¹ Ibid

- unlike many other black African groups in the UK, the Somali population includes a large proportion of people for whom Somali is their only language, particularly among women and older people
- significant numbers of Somali women may be illiterate either in English or in Somali or in both¹⁵².

In the US, Morales and colleagues have investigated the implications of poor literacy for self-completion postal questionnaires.¹⁵³ They argue that immigrants from developing countries may have a lower educational attainment than the general population and therefore poorer literacy and that:

“The mismatch between an intended respondent’s reading ability and the survey instrument may have important implications for the validity of patient satisfaction research, particularly for self-administered surveys. Some of the consequences of this mismatch may include low response rates, especially in vulnerable populations, and unreliable responses because of poor item comprehension.”

They describe the application of different types of readability techniques to the English and Spanish versions of the CAHPS® surveys. They found that both versions had readability levels of 7th grade (approximately age 11). Quoting surveys that show that 50% of welfare recipients read at or below the 5th grade level (approximately age 9), they argue that the surveys may be written at a readability level that is too high for Medicaid populations. They argue that furthermore the readers’ ability to understand the cognitive task asked by a survey is influenced by factors besides literacy, such as their interest, experience, knowledge, or motivation. It was argued in Section 4.1 that all these factors may be lower in BME populations who were not acculturated.¹⁵⁴

Elsewhere it is reported that the CAHPS survey instruments worked better with the respondents who seemed to be more educated or acculturated. The latter was usually lower for non-English-speaking respondents and was seen to impact on the extent to which respondents were familiar with the terminology and landscape of the health care system in the United States.¹⁵⁵

Li and colleagues suggest that because of language barriers to participation, postal surveys will often overlook those likely to be the most vulnerable:

“Since lack of language ability is often a barrier to accessing health care and other social services, the inability to speak English may well contribute to disparities in health.”¹⁵⁶

¹⁵² Elam et al (2001) op cit

¹⁵³ Morales LS, Weidmer BO and Hays RD ‘Readability of CAHPS® 2.0 Child and Adult Core Surveys’. In Cynamon and Kulka (eds) (2001) pp83 – 90

¹⁵⁴ For ease of discussion, the concept of acculturation is presented in a straightforward way here. It is however recognised that the concept is in fact highly complex cf Berry J "Conceptual Approaches to Acculturation", in Kevin Chun, Pamela Balls-Organista and Gerardo Marin (2003), *Acculturation: Advances in Theory, Measurement, and Applied Research*, APA Books.

¹⁵⁵ Weech-Maldonado R, Weidmer BO, Morales LS and Hays RD ‘Cross-Cultural Adaptation of Survey Instruments: The CAHPS® Experience’. In Cynamon and Kulka (eds) (2001) ‘Seventh Conference on Health Survey Research Methods’. Maryland: Department of Health and Human Services. p.80. Available at: <http://www.cdc.gov/nchs/data/conf/conf07.pdf> Last accessed 13/06/06

¹⁵⁶ Li RM, McCardle P, Clark RL, Kinsella K and Berch D (2001) *Diverse Voices. The inclusion of language-minority populations in national studies: challenges and opportunities*. Bethesda, MD: National Institute on Aging and National Institute of Child Health and Human Development

They go on to argue that:

“In view of strong national commitments to... developing cultural competence in health service delivery, researchers and policy makers should give added attention to language as a potential barrier excluding people from national surveys, as well as from access to health care and social services.”¹⁵⁷

They are writing here of the US, but the implications are equally as applicable to the UK political and legal context. Their argument certainly seems persuasive in the light of evidence from the national inpatients’ survey.

Analysis of the 2005 Inpatients’ survey shows considerable variation in response rates within ethnic minorities by age and sex. Thus, South Asian males and females aged under 35 are just as likely to respond as their white counterparts. However, South Asian females aged over 65 are less likely to respond. This variation in likelihood of responding to surveys by younger and older Asian groups may be due partly to acculturation, with the younger South Asians being more integrated and fluent in English than older female South Asians. Lack of fluency in English in elderly South Asians seems a credible hypothesis. Firstly, because response rates generally increase with age and secondly, because other elderly English speaking ethnic minorities e.g. Black-British females are just as likely to respond as their white counterparts. This requires further investigation and perhaps in-depth interviews may reveal reasons for non-participation in surveys.

Implications for the national acute patients’ survey

Further evidence is needed to explain the variations in response rates between and within different ethnic groups. Targeted non-response studies are therefore suggested.

4.3 Barriers to participation: poor contact information

We found no published evidence about the implications of poor contact information, that is name and address, for non-response bias in postal surveys.

This section of the report has examined two main barriers to the inclusion of certain groups in postal surveys. The next section will examine the strategies that have been suggested in order to overcome these barriers. It is followed by a section examining the impact of these strategies where they have been adopted in practice (Section 6).

¹⁵⁷ Ibid, p.1

5 Strategies for increasing response rates amongst Black and minority ethnic and seldom heard groups

The previous section examined two main theories of why response rates in postal surveys are lower amongst particular groups in the population – disengagement and communication barriers. This section will examine the strategies that have been proposed in response to each of these. Section six which follows will examine the published evidence available about their impact on response rates in practice.

5.1 Tackling barriers caused by disengagement

The Market Research Society (MRS) Guidelines for conducting research amongst different ethnic groups emphasise that researchers need to address potentially low levels of awareness of market research amongst some ethnic groups. They recommend that researchers “prepare detailed information detailing the purpose (and any consequences) of a research project to assuage respondent concerns.”¹⁵⁸ They suggest that a range of issues need to be addressed and included in such information. These are set out in the box below.

Box 5.1: MRS Guidelines on content of information to increase awareness of market research amongst Black and minority ethnic groups¹⁵⁹

- Purpose of the research
- Confidentiality of responses
- Name of the client
- Any potential re-contact including quality control checks
- The value of taking part in the research i.e. any specific benefits or outcomes for the individual or their community.

Sills and Desai also emphasise the importance of communication to involve BME groups in research. For example, stage 2 of their Seven Stage Process for Effective Communication reads:

“the message needs to be of interest to the audience.... (and) relevant to the needs of the intended recipients and to the circumstances under which the message will be received.”¹⁶⁰

¹⁵⁸ Market Research Society (MRS) Guidelines for conducting research amongst different ethnic groups http://www.mrs.org.uk/networking/ern/downloads/guidance_ethnic_research.pdf

Last accessed 14/06/06

¹⁵⁹ Ibid

¹⁶⁰ Sills A and Desai P. ‘Qualitative research amongst ethnic minority communities in Britain’. Journal of the Market Research Society. Vol 38, No. 3. July 1996

A Government Communications study makes the following recommendations in respect of communicating with Black and minority ethnic communities:

- Specialist media are essential to access key sub-groups in ethnic minority communities eg women, older people and those who speak little or no English
- Government communicators could also develop relationships with local organisations and individuals to enhance the effectiveness of distribution and generate word of mouth publicity through existing community networks¹⁶¹

To increase response rates to the Health Survey for England amongst Black Africans, Elam and colleagues emphasise the need for confidentiality to be stressed to participants and for any approach material to “sell the importance of this research for individuals in the black African community.”¹⁶² To achieve this they suggest publicising the survey through community organisations and other venues and feeding results back through these channels. They found that Black Africans were sceptical about the purpose of the research and suggested that¹⁶³,

Consequently, the need to emphasise, not only the value of the research, but also of the value of potential respondents’ input to the topic, was repeatedly underscored. This should begin with the introductory letter that is sent to each household selected to take part in the HSE, in advance of an interviewer visit. It will be important that this letter clearly tells people what the research is about, why it is being done, why it is important to them and their communities, and why their input is valuable, in an honest and convincing manner so as to express the HSE’s legitimacy and trustworthiness. It may, therefore, be particularly important for these groups to see the fruits of their labours, perhaps in the form summary booklets to community organisations (being careful to manage expectations about how long it will take for results to be published). More emphasis could be placed on other benefits of participating in the HSE, such as the communication of health results to respondents following interviewer and nurse visits.

Implications for the national acute patients’ survey

In terms of the national inpatients survey, these studies support the need for targeted messages in materials such as advance letters and publicity and in covering letters, for example emphasising confidentiality. The findings also support the need for summaries of survey results to be made available to patients.

¹⁶¹ Turnstone Research and Connect Research & Consultancy (2003) COI Communications Common Good Research: Ethnic Minority Communities. London: COI Communications. Available at: http://www.cre.gov.uk/downloads/coi_cg_research_emcomms.pdf Last accessed 25/08/06

¹⁶² Elam et al (2001) op cit, p.iii, cf p.22

¹⁶³ Elam et al (2001) op cit, p.22

5.2 Addressing communication barriers to participation

The previous section of the report outlined how various studies have emphasised the importance of effective communication as a means for engaging groups that may otherwise be unlikely to participate in social surveys. This section will examine two specific communication barriers to participation in postal surveys – visual impairments, cognitive impairment and poor literacy.

Visual impairment

The Royal National Institute for the Blind (RNIB) estimates that two million people in the UK have a sight problem. Contrary to expectation, UK postal questionnaire surveys have been shown to be an effective method for gathering feedback from patients with visual impairment^{164 165}, including those with a greater degree of impairment.¹⁶⁶ In order to communicate with these groups the RNIB recommend that written material is printed using 14 point text ideally and 12 point as a minimum.¹⁶⁷ However, they emphasise that this will not suit everyone and material should be produced in a range of formats including larger print, audio recordings, Braille and electronic documents on disk or over the internet. They point out that people with a visual impairment,

“have low expectations of getting information in a way they can read, so they don’t ask for it. This is often misinterpreted by organisations as a lack of demand.”

They recommend that all material should have a statement in 16 point font about the availability of material in alternative formats.

The size of the font is the key factor regarding legibility and most people prefer their large print in the range of 16 to 22 point. However other factors are also important, including those set out in the box below. The RNIB guidance also provides advice about presenting information on websites, video, Braille, spoken word audio and e-text.

¹⁶⁴ Webb AC and Markus AF. ‘The diagnosis and consequences of Stickler syndrome’. *British Journal of Oral and Maxillofacial Surgery* (2002) 40;1:49-51

¹⁶⁵ Ford HL, Gerry E, Johnson MH and Tennant A. ‘Health status and quality of life of people with multiple sclerosis’ *Disability and Rehabilitation* (2001) 15 AUG; 23;12:516-521

¹⁶⁶ Wolffsohn JS, Cochrane AL and Watt NA. ‘Implementation methods for vision related quality of life questionnaires’. *British Journal of Ophthalmology* (2000) 84;9:1035-1040

¹⁶⁷ RNIB (2003) ‘See it Right Summary Booklet’. London: RNIB. Available at: http://www.rnib.org.uk/xpedio/groups/public/documents/publicwebsite/public_printdesign.hcsp Last accessed 20/06/06

Box 5.2: RNIB guidelines for materials for people with a visual impairment¹⁶⁸

- black text on a white background provides the best contrast
- clear typeface, lower case and non-italicised type styles are easiest to read
- space between lines should be 1.5 to 2 times the space between words on a line
- use bold type weights
- use a font with clear numbers
- keep lines between 60-70 letters
- present information in medium length paragraphs
- align text to left hand margin and avoid justified text
- leave clear margins or lines between columns
- horizontal text is easiest to read
- avoid text over images
- leave extra space on forms as handwriting tends to be bigger
- place headings, page numbers etc in the same place on each page
- leave clear spaces and or breaks between paragraphs and sections
- avoid glossy paper
- when folding paper avoid creases that obscure the text
- avoid binding methods that make it difficult to flatten the document

Cognitive impairment

The most common cause of cognitive impairment is dementia,¹⁶⁹ estimated to effect just over 1% of the UK population and nearly 600,000 people living in England.¹⁷⁰ According to research by the Alzheimer's Society, one in five people aged over 80 and one in twenty over the age of 65 have a form of dementia.¹⁷¹ Their research does not provide details of incidence by degree of symptom and many of those with dementia will have mild cognitive impairment. However, because dementia is a progressive disease older people are more likely to experience more severe symptoms. Most people with dementia are aged over 65, however Black and minority people are more likely to be affected at an earlier age – 6.1% of all those with young onset dementia are from these groups, compared to 2.2% of the total UK population with dementia who are younger than 65.¹⁷²

People with a learning disability are the other major group likely to be effected by cognitive impairment. As was seen above, Clarke has suggested that there are in the region of one million

¹⁶⁸ Ibid

¹⁶⁹ <http://www.alzheimers-research.org.uk/info/statistics/>

Last accessed 27/03/07

¹⁷⁰ Knapp M and Prince M (2007) Dementia UK - A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society. London: Alzheimer's Society http://www.alzheimers.org.uk/News_and_Campaigns/Campaigning/PDF/Dementia_UK_Full_Report.pdf

Last accessed 27/03/07

¹⁷¹ Ibid

¹⁷² Ibid

people in the UK with a learning disability that may impair their ability to communicate or approximately 2% of the population.

Postal self completion questionnaires have been used to gather evidence from people with cognitive impairment in the UK,¹⁷³ the Netherlands,¹⁷⁴ Sweden¹⁷⁵ and Canada¹⁷⁷. It is unlikely however that those with more severe symptoms will be able to complete a questionnaire without help.¹⁷⁸ The inclusion of those with milder impairments are considered in the following section on literacy.

Literacy

In 2002, Clark suggested that there are 7.3 million people in Great Britain with literacy difficulties.¹⁷⁹ This forms a significant proportion of the population who are likely to have difficulties completing a postal questionnaire such as the national inpatient survey. People with literacy difficulties are likely to fall into three main categories: those who have never learnt to read or write beyond a limited level, those who have a physical or mental disability which affects their ability to read or write and those who speak another language and have not learnt to communicate in English. There is also some degree of overlap between these three groups as the following section on language and literacy will explore.

In the US, Morales and colleagues have investigated issues regarding the implications of poor literacy for self-completion postal questionnaires.¹⁸⁰ They conclude that although the US CAHPS® surveys were written at a level that might make them inaccessible to people with poor literacy it may be difficult to lower their readability level. They argue that if the surveys are to provide useful information then they:

“need to collect information on a range of complex topics that require respondents to be familiar with concepts and vocabulary unique to health care. Shortening the survey and

¹⁷³ Geddes JM, Fear J, Tennant A, Pickering A, Hillman M and Chamberlain MA. ‘Prevalence of self reported stroke in a population in northern England’. *Journal of epidemiology and community health* (1996) Apr; 50:2: 140-3

¹⁷⁴ van Uffelen JGZ, Chin A, Paw MJM, Klein M, van Mechelen W and Hopman RM. ‘Detection of memory impairment in the general population: screening by questionnaire and telephone compared to subsequent face-to-face assessment’. *International journal of geriatric psychiatry* (2007) Mar; 22; 3:203-10

¹⁷⁵ Vestling M, Tufvesson B and Iwarsson S. ‘Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction’. *Journal of Rehabilitation Medicine* (2003) May, 35:3: 127-31

¹⁷⁶ Ekman M, Berg J, Wimo A, Jönsson L and McBurney C. ‘Health utilities in mild cognitive impairment and dementia: a population study in Sweden’. *International journal of geriatric psychiatry* (2006) 29 Nov

¹⁷⁷ Alessi CA, Josephson KR, Harker JO, Pietruszka FM, Hoyl MT and Rubenstein LZ. ‘The yield, reliability, and validity of a postal survey for screening community-dwelling older people’. *Journal of the American Geriatrics Society* (2003) Feb; 51:2: 194-202

¹⁷⁸ Hebert R, Bravo G, Korner BN and Voyer L. ‘Refusal and information bias associated with postal questionnaires and face-to-face interviews in very elderly subjects’. *Journal of Clinical Epidemiology* (1996) 49:3: 373-381

¹⁷⁹ Clark L (2002) Liverpool Central Primary Care Trust Accessible Information: Project Report (August) <http://www.leeds.ac.uk/disability-studies/archiveuk/Clark,%20Laurence/liverpool%20NHS.pdf>
Last accessed 29/06/06

¹⁸⁰ Morales LS, Weidmer BO and Hays RD ‘Readability of CAHPS® 2.0 Child and Adult Core Surveys’. In Cynamon and Kulka (eds) (2001) pp83 – 90

simplifying the vocabulary too much may cause the level of information gleaned from the CAHPS® surveys to fall, defeating the original purpose of CAHPS®.”¹⁸¹

They conclude that the answer for including people with low literacy in self-completion questionnaires lies in finding a balance between obtaining information at a level for the findings to be useful and presenting the questions at a readability level that can be understood by a high proportion of the target audience.

People with learning disabilities are one group who are likely to have poorer literacy than the general population. It has been suggested that the prevalence of people with learning disabilities in England is around 2%, equating to around 1 million people (Emerson and Hatton 2004). The British Institute for Learning Disabilities state that there are 3-4 people with a severe learning disability and 6 with a mild learning difficulty for every 1000 people in the population, suggesting a total figure of about 1.2 million.¹⁸²

We found one study relating specifically to the inclusion of people with learning disabilities in postal surveys. This study used an illustrated questionnaire and letter of invitation to secure a response rate of 54% in a postal survey of self advocacy groups for people with learning disabilities in the English midlands.¹⁸³ The general recommendations on ensuring appropriate readability levels would also be relevant for the inclusion of these groups.

Morales and colleagues point out that immigrants and asylum seekers from developing countries are likely to have lower educational levels than the general population and therefore poorer literacy.¹⁸⁴ This explains why much of the guidance on including Black and minority ethnic groups in postal surveys emphasises issues of literacy as much as those of translation. For example, the MRS guidance for increasing participation amongst Black and minority ethnic groups in self-completion surveys focuses on issues of language and literacy (see box below).

¹⁸¹ *Ibid*

¹⁸² National Patient Safety Agency (2004) Listening to people with learning difficulties and family carers talk about patient safety. National Patient Safety Agency. Available at:

[http://www.npsa.nhs.uk/site/media/documents/296_speaking_up_report\(1\).pdf](http://www.npsa.nhs.uk/site/media/documents/296_speaking_up_report(1).pdf) Last accessed 08/08/06

¹⁸³ McNally S. 'A survey of self-advocacy groups for people with learning disabilities in an English region'. *Journal of Learning Disabilities London* (2002) Jun, vol. 6, no. 2: 185-99

Part II (2003) Sep, vol. 7, no. 3: 231-50,

¹⁸⁴ Morales (2001) *op cit*, pp83 – 90

Box 5.3: MRS guidelines for increasing Black and minority ethnic response rates to self-completion questionnaires¹⁸⁵

- Enclose a translated sheet that allows the respondent to request the information in another language.
- Researchers should be aware that when respondents who have literacy or language barriers complete self-completion questionnaires, it is possible that the respondents may have enlisted the assistance of family and friends. Therefore the responses may not necessarily reflect the views of the targeted respondents.
- If materials are translated please make sure the translations are checked properly for sense and if possible, piloted. Too often, translations have been literal or just plain wrong.

Similarly, the COI Communications report on good communications with ethnic minority communities also focuses on issues of language and literacy (see box below)

Box 5.4 : COI Communications recommendations for communicating with Black and minority ethnic communities¹⁸⁶

- Summary versions of longer leaflets in straightforward language;
- Bilingual leaflets rather than translations;
- Leaflets with a strong visual and pictorial element;
- Audio and video material, in English and Mother Tongue

Sills and Desai describe the strategies employed by the London Borough of Newham for researching the views of its non-English speaking populations¹⁸⁷. Newham conducts an annual

¹⁸⁵ Market Research Society (MRS) Guidelines for conducting research amongst different ethnic groups. P 4-5

http://www.mrs.org.uk/networking/ern/downloads/guidance_ethnic_research.pdf

Last accessed 14/06/06

¹⁸⁶ Turnstone Research and Connect Research & Consultancy (2003) COI Communications Common Good Research: Ethnic Minority Communities. London: COI Communications

http://www.cre.gov.uk/downloads/coi_cg_research_emcomms.pdf

Last accessed 14/06/06

¹⁸⁷ Sills A and Desai P. 'Qualitative research amongst ethnic minority communities in Britain'. Journal of the Market Research Society. Vol 38, No. 3. July 1996

residents' questionnaire survey backed up by focus groups with minority groups to explore their needs in greater detail than can be revealed in a quantitative survey. They describe how, in a study examining the communication needs of non-English speaking residents, they held focus groups with people with limited formal education and fluency in English. Same sex, single language groups were held with men and women aged 25-50, speaking Punjabi, Urdu and Bengali/Sylheti. Participants were recruited by Council interpreters through local community organisations. The study resulted in a seven stage process for effective communication (see box below).

Box 5.4 : Effective communications: 'The seven stage process'¹⁸⁸

1. The level of awareness
2. The message
3. The level of literacy
4. The language
5. The medium
6. The delivery
7. Regular monitoring

Some of these stages are relevant to increasing engagement as discussed in the previous section. Others are relevant to overcoming communication barriers, for example, Stage 3, 'the level of literacy':

"Low levels of literacy... means that text... is often written at too advanced a level for the audience.... Indeed, the need for plain, straightforward English text was at least as important as the need for translations."¹⁸⁹

Also, Stage 5, 'the medium':

"The translation of written materials is the principle way... (to) disseminate information to non-English speaking residents. However, the research found that oral communication was the preferred medium for many residents, including English speakers."¹⁹⁰

Emery and Stubbington similarly suggest that personal contact will be an important element of any campaign aimed at groups who are likely not to speak English fluently. They also advocate "more appropriate targeting of communications and more innovative approaches, maybe involving new, and as yet untested, methods."¹⁹¹

Sills and Desai suggest that the translation of questionnaires is complex and resource intensive. Li and colleagues make a number of recommendations in terms of practices of translating questionnaires, which include vetting by experts and testing with monolingual speakers to test

¹⁸⁸ Op cit, p.262

¹⁸⁹ Ibid

¹⁹⁰ Op cit, p.264

¹⁹¹ Emery B and Stubbington C. 'Communicating with the Asian population' Market Research Society (1996) Conference Papers

cultural and linguistic appropriateness.¹⁹² The need for the careful development of culturally appropriate translations of research instruments has been widely recommended. These issues are explored in a subsequent section of the report (Section 5.4).

Implications for the national acute patients survey

Further research is needed to investigate the readability of the inpatient survey and the literacy levels in the patient population. Research into alternative approaches to communicating with patients with communication impairments is also warranted.

5.3 Addressing barriers caused by a lack of contact information

We found no published studies describing strategies for tackling barriers caused by inaccurate or missing contact information which would affect the inclusion of the homeless and highly mobile populations such as refugees and asylum seekers and young people.

Implications for the national acute patients survey

Further work is needed to develop strategies for the inclusion of patient groups for whom accurate contact data may be unavailable.

5.4 Addressing cultural barriers: developing culturally competent adaptations of health surveys

In 1991 Ecob and William described a translation procedure that involves having questionnaires translated into the required language by one person and then back translated by someone else.¹⁹³ This process is now quite widely accepted as necessary when making translations of questionnaires for “checking the translation process and exploring how well concepts that may be well understood in English translate into other languages with the same meaning”.¹⁹⁴

However, other studies have suggested that accurate translations alone are insufficient and that adaptations need to take into account a range of cultural variations.^{195 196 197} For example, one

¹⁹² Li et al, (2001) op cit

¹⁹³ Ecob R and William R (1991) Sampling Asian minorities to assess health and welfare *Journal of Epidemiology and Community Health* 45:93-101

¹⁹⁴ Scottish executive central research unit (2001) Scoping study for a national survey of Scotland's minority ethnic populations. Edinburgh: The Stationery Office. p40. Available at: <http://www.scotland.gov.uk/cru/kd01/red/minethnic-01.pdf> Last accessed 20/06/06

¹⁹⁵ California Pan-Ethnic Health Network (2001) 'Diverse Patients, Disparate Experience: The use of standardized patient satisfaction surveys in assessing the cultural competence of health care organizations'. California: CPEHN

<http://www.cpehn.org/pdfs/CPEHN%20Final%2001.pdf>
Last accessed 12/06/06

¹⁹⁶ Morales, LS (2000) 'Assessing Patient Experiences with Healthcare in Multi-Cultural Settings.' Dissertation for Doctor of Philosophy in Policy Analysis. RAND Graduate School. Chapter 2: Cross-cultural

study found that the validity of a closed response survey question was greater for white than for South Asian interviewees¹⁹⁸ and cognitive interviews to assess translations of the US CAHPS questionnaire found more problems with adjectival scales compared with numeric scales.¹⁹⁹ In addition, Watson has suggested that:

“Normal semantic agree-disagree scales do not on the whole work with older Asian respondents. Scales of five, seven, nine or whatever inevitably attract the central, neutral response due to a desire not to cause any offence, so four point scales are more preferable.”²⁰⁰

In 2001 a US study argued that culturally competent health surveys needed to explicitly identify which items may be of particular relevance to Black and minority ethnic groups.²⁰¹ They reviewed three consumer health surveys including the Picker Institute US hospital survey and the CAHPS health care plan survey, and identified a number of items from each instrument that might have special significance for consumers from diverse racial, ethnic or cultural background. They identify three broad categories of items set out in the box below.

adaptation of survey instruments: the CAHPS experience. Available at:

http://rand.org/pubs/rgs_dissertations/RGSD157/RGSD157.ch2.pdf Last accessed 12/06/06

¹⁹⁷ Stewart AL and Napoles-Springer A. ‘Health-Related Quality of Life Assessments in Diverse Population Groups in the United States’. *Medical Care*. 38(9) Supplement II:II-102-II-124, September 2000

¹⁹⁸ Boniface DR and Burchell H. ‘Investigation of validity of closed questions in a survey of British South Asian and white populations’. *Ethnic Health* (2000) Feb; 5(1):59-65

¹⁹⁹ Weech-Maldonado R, Weidmer BO, Morales LS and Hays RD ‘Cross-Cultural Adaptation of Survey Instruments: The CAPHS® Experience’. In Cynamon and Kulka (eds) (2001) ‘Seventh Conference on Health Survey Research Methods’. Maryland: Department of Health and Human Services. Available at: <http://www.cdc.gov/nchs/data/conf/conf07.pdf> Last accessed 13/06/06

²⁰⁰ Watson MA ‘Researching minorities’ *Journal of the Market Research Society* (1992) Vol. 34, no. 4, October, pp 337-344

²⁰¹ California Pan-Ethnic Health Network (2001) op cit

Box 5.6 : Items of particular relevance for Black and minority ethnic patient groups²⁰²

1. Items that elicit reports about the attitude of staff and practitioners toward the patient and the adequacy of communications between practitioner and consumer
2. Items that elicit patient ratings of various aspects of care
3. Items related to health status and health behaviours

Morales suggests that:

“Cultural competence refers to the requirement that the translated instrument adequately reflect the cultural assumptions, norms, values, and expectations of the target population”.²⁰³

He argues that a cultural adaptation is not just about accurate translation of the original research instrument because that instrument may contain ideas or concepts that do not hold meaning for the target culture. The California Pan-Ethnic Health Network (CPEHN) study identifies four main difficulties with producing culturally appropriate translations of research instruments, set out in the box below.

Box 5.7 : Difficulties with maintaining equivalence in translated surveys²⁰⁴

1. *Words and phrases may not translate directly or have cultural parallels from one language to another*
2. There may be a cultural component to the way survey respondents interact with scoring scales
3. Certain questions, topics or phrases may be offensive when translated across languages and cultures
4. Item prompts may not be meaningful for respondents from diverse cultures

The box below sets out the terms in the CAHPS health surveys that presented particular difficulties in translation.²⁰⁵ It has been suggested that a survey conducted with a poorly adapted instrument may lead to conclusions that are mistakenly attributed to differences between the source and target populations.²⁰⁶

²⁰² California Pan-Ethnic Health Network (2001) op cit, p. 18-19

²⁰³ Morales, LS (2000) op cit

²⁰⁴ California Pan-Ethnic Health Network (2001) op cit, p. 27

²⁰⁵ Weech- et al (2001) op cit

²⁰⁶ Weech- et al (2001) op cit

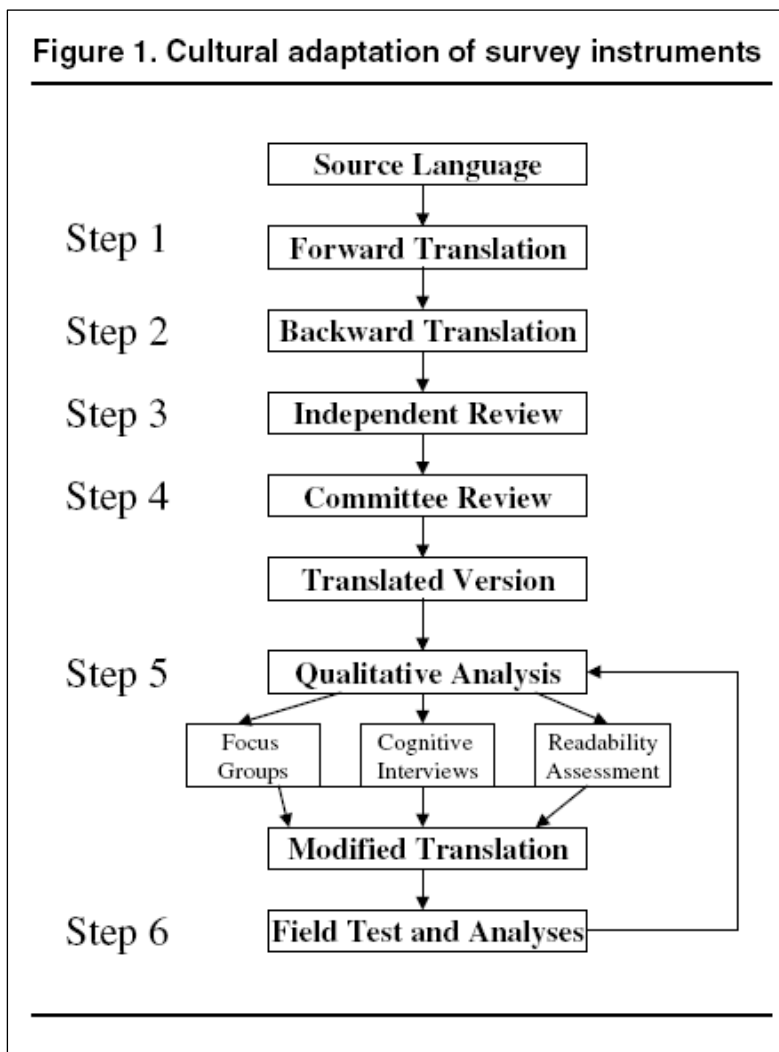
Table 1. Terms that presented difficulty in translation

Original English	Alternative Wording Used in the Final Spanish Version	Back-translation
health insurance plan	plan de seguro médico	medical insurance plan
health provider	profesional de salud	health professional
rating/rate	calificación/califica	grade/grade
usually	normalmente	normally
preventive health steps	medidas de salud preventiva	preventive health measures
listen carefully	escucharon atentamente	listen attentively
health care	atención médica	medical attention
prescription medicine	medicamentos recetados	prescribed medications
male or female	niño o niña/hombre o mujer	boy or girl/man or woman
background	ascendencia	ascendancy
grade	año	year
school	estudios	studies
highest	avanzado	advanced

In response to these difficulties Morales has proposed a framework for cross-cultural adaptation that includes:

- Translation (forward, back, independent and expert review)
- Qualitative analysis (focus groups, cognitive tests and readability assessments) and
- Field testing and analysis (psychometric testing) .207

This framework has been developed into a set of guidelines for translating CAHPS survey materials²⁰⁸ and is set out in the diagram below.²⁰⁹ Similar guidelines have been suggested for the translation of European health survey instruments.²¹⁰



²⁰⁷ Morales, LS (2000) op cit

²⁰⁸ Guidelines for Translating CAHPS Survey Materials. Available at:http://www.cahps.ahrq.gov/content/resources/CrossCultural/RES_CC_GuidelinesForTranslating.asp?p=103&s=34 Last accessed 12/06/06

²⁰⁹ Weech- et al (2001) op cit

²¹⁰ Tafforeau J, Cobo ML, Tolonen H, Scheidt-Nave C and Tinto A (2005) 'Guidelines for the development and criteria for the adoption of health survey instruments'. Luxembourg: Office for Official Publications of the European Communities.

6 Measuring the impact of strategies for increasing response rates amongst Black and minority ethnic and seldom heard groups

The aim of this section of the literature review is to set out the evidence that measures the impact of strategies for increasing response rates amongst Black and minority ethnic and seldom heard groups. There is limited evidence about the impact of strategies in general and virtually no published evidence about the impact of some strategies for increasing response rates amongst seldom heard groups. For example, we found no studies measuring the impact of increasing font size to accommodate people with a visual impairment or of increasing the readability of a questionnaire (including visual prompts, signposting and making translations available).

6.1 The impact of strategies to increase response rates amongst Black and minority ethnic groups

The literature review identified three papers that examined various strategies used to increase response rates in postal surveys from ethnic minority groups. Such strategies included monetary incentives²¹¹, a phone card on completion and return of questionnaire²¹² and a comparison of mail versus telephone mode of data collection.²¹³ These studies were all conducted in the US.

All three study designs were postal surveys of randomly selected individuals from different ethnic groups. The studies assessed response rate enhancement strategy in Asian-Americans with limited English²¹⁴, White and non-White prostate cancer survivors²¹⁵ and respondents from African-American, American Indian, American Latino, Somali and Hmong ethnic groups, enrolled on a public health care program.²¹⁶

Providing incentives to ethnic groups was associated with an increase in response rates. Beebe et al (2005) showed that providing a pre-paid \$2 incentive increased response rates across all ethnic groups except among the American Latino group. In this study the \$2 was given unconditionally.

²¹¹ Beebe TJ, Davern ME, McAlpine DD, Thiede Call K and Rockwood TH. 'Increasing Response Rates in a Survey of Medicaid Enrollees: The Effect of a Prepaid Monetary Incentive and Mixed Modes (Mail and Telephone)' *Medical Care* (2005) Vol 43, No. 4

²¹² Evans BR, Peterson BL and Demark-Whnefried W. 'No Difference in Response Rate to a Mailed Survey among Prostate Cancer Survivors Using Conditional versus Unconditional Incentives'. *Cancer Epidemiology, Biomarkers and Prevention* (2004) Vol 13, 277-278, February

²¹³ Ngo MQ, Kaplan SH, Sorkin DH, Clarridge BR and Phillips RS. 'Surveying Minorities with Limited English Proficiency: Does Data Collection Mode Affect Data Quality Among Asian Americans?' *Medical Care* (2004) Vol 42, No. 9, 893-900

²¹⁴ Ngo et al (2004) op cit

²¹⁵ Evans et al (2004) op cit

²¹⁶ Beebe et al (2005) op cit

However, conditional incentives have been shown not to increase response rates in ethnic minority groups but do increase response rates in non-ethnic groups.²¹⁷ Evans et al (2004) showed that the response rates for white and non-white groups of prostate cancer survivors were similar regardless of whether they were offered a conditional or unconditional incentive (a telephone card).²¹⁸

The evidence pointing to increased response rates when unconditional incentives are given to ethnic minority groups is consistent with the evidence from studies of non-ethnic groups. Edwards and colleagues (2002) in a meta-analysis of factors associated with increasing response rates showed that respondents were more than twice as likely to return a questionnaire when offered an immediate monetary incentive.²¹⁹

The mode of data collection in surveys has been shown to have an effect on response rates from ethnic minority groups. A US study compared response rates to a mail versus telephone survey in a sample of Vietnamese, Mandarin, and Cantonese Chinese speaking patients with limited English proficiency. A higher response rate was achieved by phone interviews (75%) as compared with mail surveys with telephone reminder calls (59%).²²⁰

Another US study found that Spanish speaking women were more likely to participate in a telephone survey that offered an incentive than in a postal survey.²²¹ Similarly, Teitler and colleagues used a mixed mode strategy to increase response rates amongst a hard-to-reach population. They found that more resource intensive modes of recruiting participants – by telephone and field work – increased response rates amongst black people and those with lower educational attainment.²²²

The results of the studies reviewed here of strategies to increase response rates from ethnic minority groups cannot be considered to be unreliable using as they do large, randomly selected, representative samples of ethnic groups from the community²²³ or patients from a cancer registry.²²⁴ However, the main difficulty with the review of these studies is that the studies are not of United Kingdom samples. All are of US samples.

Implications for the national acute patients survey

Taking all of the above, the question is whether the results of the above studies would generalise to UK samples if an incentive strategy in a mail out survey were implemented. Given that immediate incentives have been shown to increase response rates in ethnic and non-ethnic groups it is not unreasonable to assume that they would do so in patient surveys. However, such considerations need to be weighed against increasing survey costs in the patient survey programme.

²¹⁷ Dommeyer CJ. 'How form of the monetary incentive affects mail survey response'. *J Market Res Soc* 1988;30:379-85

²¹⁸ Evans et al (2004) op cit

²¹⁹ Edwards P, Roberts I, Clarke M, DiGuseppi C, Pratap S, Wentz R and Kwan I. 'Increasing response rates to postal questionnaires: systematic review'. *BMJ* 2002; 324:1183-91

²²⁰ Ngo et al (2004) op cit

²²¹ Nelson KM, Geiger AM and Mangione CM. 'Racial and ethnic variation in response to mailed and telephone surveys among women in a managed care population'. *Ethnicity and Disease* (2004) Vol 14/4:580-583

²²² Teitler JO, Reichman NE and Sprachman S 'Costs and benefits of improving response rates for a hard-to-reach population'. *Public Opinion Quarterly*; Spring 2003; Vol.67:126-138.

²²³ Beebe et al (2005) and Ngo (2004)

²²⁴ Evans et al (2004) op cit

6.2 The impact of strategies to increase response rates generally

The literature review identified twenty-five papers that examined various strategies to increase response rates in general, including a review²²⁵ and five meta analyses.^{226 227 228 229 230} Such strategies included incentives (e.g. monetary and sweets), questionnaire characteristics (e.g. saliency of content, length, colour and quality of paper), covering letter characteristics (e.g. hand signed or printed signatures, signed by doctor versus administrator), characteristics of mailing (e.g. overnight or regular, standard or recorded, postage, use of postage stamps or prepaid envelopes, envelope size, and introductory and reminder postcards).

Incentives

Of all the strategies used to increase response rates, providing an inducement to complete the questionnaire has been shown to be most effective in increasing response rates. Edwards and colleagues (2002) in a meta-analysis of forty-nine trials of the use of incentives showed that although incentives increased the likelihood of responding to the survey, unconditional monetary incentives had a much greater effect than both non-monetary incentives and incentives conditional upon return of questionnaire.²³¹

There is considerable evidence about the positive impact of incentives in surveys of health professionals. A Randomised Control Trial (RCT) in the US compared survey response rates amongst doctors where an incentive was given upfront as opposed to on completion of the survey. The promised-incentive group achieved a significantly lower response rate (56%) compared with the up-front- incentive group (71.5%).²³² In a survey of US pharmacists, a gift voucher increased the response rate from 53.5% to 65.9%.²³³ Similar findings were seen in a Hong Kong RCT of the impact of incentives on response rates in a survey of 3,335 Chinese medicine practitioners. Response rates were higher among those offered incentives than those without.²³⁴ In addition, a US randomised trial of doctors found that the response rate amongst those offered a \$5 bill (61%)

²²⁵ King KA, Pealer LN and Bernard AL. 'Increasing response rates to mail questionnaires: a review of inducement strategies'. *American Journal of Health Education*, 2001 Jan-Feb, vol. 32, no. 1, p. 4-15, 24-5

²²⁶ Edwards et al (2002) op cit

²²⁷ Fox RJ, Crask MR and Kim J (1988) Mail survey response rate: A meta-analysis of selected techniques for inducing response. *Public Opinion Quarterly*, 52, 467-491. Note that this study reports effect sizes as an averaged absolute difference between response rates in experimental and control conditions from each of the included experiments rather than as an odds ratio, which is more common in contemporary reporting.

²²⁸ Heberlein and Baumgartner (1978) op cit

²²⁹ Nakash RA, Hutton JL, Jorstad-Stein EC, Gates S and Lamb SE. 'Maximising response to postal questionnaires – a systematic review of randomised trials in health research'. *BMC Medical Research Methodology* (2006) 6:5

²³⁰ Yammarino FJ, Skinner SJ and Childers TL (1991) Understanding mail survey response behavior: a meta-analysis. *Public Opinion Quarterly* 55, 4:613–39.

²³¹ Edwards et al (2002) op cit

²³² Delnevo CD, Abatemarco DJ and Steinberg MB. 'Physician response rates to a mail survey by specialty and timing of incentive'. *American journal of preventive medicine* 2004 Apr, vol. 26, no. 3:234-6

²³³ Paul CL, Walsh RA and Tzelepis F. 'A monetary incentive increases postal survey response rates for pharmacists'. *Journal of Epidemiology and Community Health*, 2005 Dec, vol. 59, no. 12

²³⁴ 34.7% vs. 28.5%, chi square=14.34, p<0.001

was 32% higher than the response rate among those receiving a \$2 bill.²³⁵ Another US randomised trial of radiologists found little difference in response rates between a \$5 and \$2 bill (27.5% and 29% respectively), but both resulted in significantly higher response rates than resulted from no incentive at all (15.5%).²³⁶

In contrast with these studies that show a clear increase in response rates linked to incentives, a Norwegian study of GPs found that although there was a higher response rate among respondents who received non-conditional incentives, this difference was not significant at the 5 percent level.²³⁷ The findings of an Australian survey of doctors was similarly inconclusive, though the incentive in this case was small and non-monetary.²³⁸

There is however, limited evidence about the impact of incentives in surveys of patients. The Beebe study mentioned above showed an increase in response rates in a survey of patients. In a recent US postal survey of childhood cancer survivors and their parents, significant differences in response rates were observed between groups offered different types of incentive, with unconditional incentives yielding significantly higher response rates than conditional incentives for older children (64.4% versus 49.0%), younger children (62.5% versus 43.6%) and their parents (64.8% versus 41.5%).²³⁹

Some studies suggest that an increase in the monetary value of the incentive is associated with a corresponding increase in response rates,^{240 241} though other studies find inconclusive results.^{242 243 244} or no significant difference.²⁴⁵ However, other token incentives, such as including a mint

²³⁵ Asch DA, Christakis NA and Ubel P. 'Conducting physician mail surveys on a limited budget: a randomized trial comparing \$2 bill versus \$5 bill incentives.' *Medical Care* (1998) January, 36 (1): 95-99

²³⁶ Doody MM, Sigurdson AS, Kampa D, Alexander BH, Ron E, Tarone RE and Linet MS. 'Randomized trial of financial incentives and delivery methods for improving response to a mailed questionnaire'. *American Journal of Epidemiology* (2003) Vol. 157(7): 643-651

²³⁷ Tjerbo T, Kvaerner KJ, Botten G and Aasland OG. '(Use of incentives to enhance response rates in questionnaire surveys)'. *Tidsskrift for den Norske laegeforening* (2005) 22 Sep, vol. 125, no. 18: 2496-7

²³⁸ Robertson J, Walkom EJ and McGettigan P. 'Response rates and representativeness: a lottery incentive improves physician survey return rates'. *Pharmacoepidemiology and drug safety* (2005) Aug, vol. 14, no. 8:571-7

²³⁹ Rosoff PM, Werner C, Clipp EC, Guill AB, Bonner M and Demark WW. 'Response rates to a mailed survey targeting childhood cancer survivors: a comparison of conditional versus unconditional incentives'. *Cancer epidemiology biomarkers & prevention : a publication of the American Association for Cancer Research cosponsored by the American Society of Preventive Oncology* (2005) May, vol. 14, no. 5:1330-2

²⁴⁰ Patten SB, Li FX, Cook T, Hilsden RJ and Sutherland LR. 'Irritable bowel syndrome: are incentives useful for improving survey response rates?' *Journal of Clinical Epidemiology* (2003) 56: 256-261

²⁴¹ Collins RL, Ellickson PL, Hays RD and McCaffrey DF. 'Effects of incentive size and timing on response rates to a follow-up wave of a longitudinal mailed survey'. *Evaluation review* (2000) August, vol. 24, no. 4:347-63

²⁴² Field TS, Cadoret CA, Brown ML, Ford M, Greene SM, Hill D, Hornbrook MC, Meenan RT, White MJ and Zapka JM. 'Surveying physicians: do components of the 'Total Design Approach' to optimizing survey response rates apply to physicians?' *Medical Care* (2002) Vol 40, No.7:596-606

²⁴³ VanGeest JB, Wynia MK, Cummins DS and Wilson IB. 'Effects of different monetary incentives on the return rate of a national mail survey of physicians'. *Medical care* (2001) Feb, vol. 39, no. 2:197-201

²⁴⁴ Fiset L, Milgrom P and Tarnai J. 'Dentists' response to financial incentives in a mail survey of malpractice liability experience'. *Journal of public health dentistry* (1994) Spring, vol. 54, no. 2:68-72

²⁴⁵ Chan TMF, Tse SHM, Day MC, Tong ETF and Suen LKP. 'Randomized trial of use of incentive to increase the response rate to a mailed survey'. *Asian Journal of Nursing Studies*, 2003 Aug, vol. 6, no. 3:36-43

sweet, a free pass to a park or entry into a prize draw, with the questionnaire are associated only insignificantly with an increase in response rates.^{246 247 248 249}

Questionnaire characteristics

In postal surveys, the exact form and content of the communication with sample members – the initial questionnaire and subsequent ‘reminder’ mailings – may have an influence on overall response rates. A number of studies have investigated the effects of specific physical attributes of the questionnaires and mailings used in postal surveys on response rates, and have looked at how apparently subtle changes to such characteristics may yield increased response rates. Strategies tested have included a range of factors to do with the colour, length, and even the quality of paper used for questionnaires and envelopes.

The effects on response rates of questionnaire length have been frequently tested. Intuitively, it would seem reasonable to suggest that longer questionnaires may result in lower response rates, as people might be deterred from completing an instrument that appears likely to be highly time-consuming. Unsurprisingly there is evidence to support this, and in particular two recent systematic reviews have given weight to this supposition. In a review of 40 trials featuring over 40,000 participants, Edwards et al (2002) report a mean odds ratio²⁵⁰ of 1.86 for response rates to shorter versus longer questionnaires, although the inclusive selection of 40 different trials means by definition that ‘longer’ and ‘shorter’ are defined extremely loosely here – it is not clear what the average difference, or the distribution of differences in length represented here are²⁵¹. A second systematic review by Nakash, Hutton, Jørstad-Stein, Gates, & Lamb (2006), including only trials recruiting from patient populations and rejecting poor quality studies, reported an average 1.35 odds ratio for the use of a short versus a long questionnaire based on four different trials, three of which showed significantly better response rates for shorter questionnaires²⁵².

Research on when a longer questionnaire will impair response rates is, however, not entirely in agreement. It should be noted that of the four studies reported in Nakash et al (2006) one showed no significant differences between a longer and a shorter version of the questionnaire, and this

²⁴⁶ Field et al (2002) op cit

²⁴⁷ Halpern SD, Ubel PA, Berlin JA and Asch DA. ‘Randomized trial of \$5 versus \$10 monetary incentives, envelope size, and candy to increase physician response rates to mailed questionnaires’. *Medical Care* (2002) Vol 40, No. 9: 834-839

²⁴⁸ Ryu E, Couper MP and Marans RW. ‘Survey incentives: Cash vs. in-kind; Face-to-face vs. mail; Response rate vs. nonresponse error’. *International Journal of Public Opinion Research* (2006) Spring, vol. 18, no. 1:89-106

²⁴⁹ Moses SH and Clark TJ. ‘Effect of prize draw incentive on the response rate to a postal survey of obstetricians and gynaecologists: A randomised controlled trial’. *BMC Health Services Research* (2004) 28 June, Vol. 4:1-3

²⁵⁰ Odds ratios (OR) are a measure of effect size useful for comparing differences in dichotomous proportions from multiple separate conditions, and as such are commonly used to report effects on response rates of experimental manipulations in the systematic reviews and meta-analyses. For example, an odds ratio of 2.00 would represent a doubling of the likelihood of a sample member responding, whereas an odds ratio of 1.00 would show no change whatsoever.

²⁵¹ Edwards, P., Roberts, I., Clarke, M., DiGuseppi, C., Prata, S., Wentz, R. & Kwan, I. (2002) Increasing response rates to postal questionnaires: systematic review. *British Medical Journal*, 324, 1183-91.

²⁵² Nakash, R.A., Hutton, J.L, Jørstad-Stein, E.C., Gates, S., Lamb, S.E. (2006) Maximising response to postal questionnaires – A systematic review of randomised trials in health research. *BMC Medical Research Methodology*, 6:5

study was conducted by the Picker Institute and used a very similar questionnaire to that presently used for the national inpatients survey²⁵³. In this survey, a four page and 12 page survey were compared and no differences in response rates, item completion rates, or responses to the shared survey items were found, suggesting that questionnaires of the kind currently used in the patient survey programme should not suffer from reduced completion rates with lengths of up to 12 pages. Other research and reviews have reported no significant effect²⁵⁴ or even a negative effect²⁵⁵ of questionnaire length on response rates, even when including extremely long instruments.

Little research has been reported focusing on the effects of the quality of paper used for questionnaires. One physician survey, focusing on gynaecologists in the UK, randomised recipients to receive either a high quality or lower quality paper version of the questionnaire and found no significant differences in response rates between these groups²⁵⁶. Whilst this survey actually showed a non-significantly lower response rate in the 'high-quality paper' group, however, the overall response rate to the survey is extremely low and this hampers the extent to which findings can be generalised. Furthermore, 'paper quality' is narrowly defined in the trial as a factor of weight, and the difference between the paper stock used for the two groups is so marginal – 80gsm for the 'low quality' group, and 100gsm for the 'high quality' group – that it would be difficult to fairly argue that differences in weight within such a range would represent a particularly salient manipulation. In fact the authors themselves concede the possibility that "recipients of 'high' quality paper did not readily distinguish it from there (*sic*) general day to day paperwork" (p3) and acknowledge that it may be necessary to consider the possible impacts of other features of paper and stationary quality, such as watermarking, colour intensity, and the use of laid paper. As such, and given that the sample included physicians rather than patients, we consider the effects of paper *quality* – as opposed to weight – on response rates from patient groups to be inadequately tested as yet.

Varying the colour of both the paper and ink of questionnaires have also been investigated as possible means of improving response rates. In their systematic review Edwards et al (2002) report a significant increase in response rates when using coloured as opposed to blue or black ink for questionnaires (OR = 1.39) – although this is based on only one trial – but analysis of eight trials fails to show an increased response rate when using coloured as opposed to white paper²⁵⁷. By contrast to this latter finding, an earlier meta-analysis based on three studies conducted between 1963 and 1977 found a small but significant effect of using a green versus a white questionnaire (mean effect size 2.0%; $p \sim 0.034$)²⁵⁸. More recently the effect of using a green

²⁵³ Jenkinson, C., Coulter, A., Reeves, R., Bruster, S., Richards, N. (2003) Properties of the Picker Patient Experience questionnaire in a randomised controlled trial of long versus short form survey instruments. *Journal of Public Health Medicine*, 25(3):197-201.

²⁵⁴ Yu, J., & Cooper, H. (1983) A quantitative review of research design effects on response rates to questionnaires. *Journal of Marketing Research*, 20 (1), 36-44.

²⁵⁵ Heberlein, T.A., & Baumgartner, R. (1978) Factors affecting response rates to mailed questionnaires: a quantitative analysis of the published literature. *American Sociological Review*, 43 (4), 447-461, pp452.

²⁵⁶ Clark, J.T., Khan, K.S., & Gupta, J.K. (2001) Effect of paper quality on the response rate to a postal survey: A randomised controlled trial. ISRCTN32032031. *BMC Medical Research Methodology*, 1:12.

²⁵⁷ Edwards et al (2002). Note that the latter analysis – for colour of questionnaire paper – is approaching significance for a slight increase in response when using coloured paper, with a relatively small mean odds ratio of 1.06 (95% CI 0.99 to 1.14).

²⁵⁸ Fox, R.J., Crask, M.R., & Kim, J. (1988) Mail survey response rate: A meta-analysis of selected techniques for inducing response. *Public Opinion Quarterly*, 52, 467-491. Note that this study reports effect sizes as an averaged absolute difference between response rates in experimental and control conditions from each of the included experiments rather than as an odds ratio, which is more common in contemporary reporting.

questionnaire has been tested in a randomised trial by Etter et al (2002), who found no significant differences in response rates in conditions using green versus white paper²⁵⁹. This paper also reported a meta-analysis based on 10 experimental studies, which, pooling results from trials using different colours, found no significant difference in weighted risks of responding for trials using coloured rather than white questionnaires (RR=1.02, p=0.17). This analysis did show, however, a slight increase in response rates when using pink paper (RR=1.12, p=0.04), but not when using any other tested colour. Based on this the authors conclude that “printing questionnaires on colored (*sic*) paper does not substantially increase response rates in surveys, except for pink paper” (p185), but there are at least two reasons to be concerned about the accuracy of this. Firstly, none of the included experiments individually show a significant improvement in response rates in experimental conditions. Secondly, the control response rates are extremely low (ranging from 14.0% to 25.6%) for the three included experiments looking at pink questionnaires, whereas they are considerably higher for other colours – because of the use of relative risk as a measure of effect size, this raises the distinct possibility that the significant difference associated with using pink paper may represent a type 1 error (a false positive). Based on the extremely mixed findings from a range of different studies, then, we would cautiously conclude that there is no firm evidence for a beneficial effect on response rates of using a coloured questionnaire.

Characteristics of the covering letters used in postal surveys, as well as those of the questionnaires, may be important in influencing response rates. An important example here is personalisation of the approach: most commonly embodied by including the intended recipient’s name as part of the salutation on the covering letter rather than a generic term (eg, “Dear Patient”). A number of early studies have reported benefits associated with this approach: for example, Simon (1967) reported that the use of a personally typed rather than a form letter yielded 7% and 8% increases in responses rates in two surveys of the general public²⁶⁰, and similar results were reported in Yu & Cooper’s (1983) review²⁶¹. Current research, too, supports the positive effect of personalisation on response rates in postal surveys²⁶²: Overall, then, we find compelling support for the positive effect of personalisation of cover letters.

Content

Certain specific features of the content of a questionnaire and its supporting information may have an effect on response rates, and a number of researchers have looked at the possibility of experimentally manipulating such features to induce improved response rates. Since the majority of these factors are inexorably linked to the nature and design of the questionnaire and its aims, however, we avoid a detailed discussion of these here: the questionnaires used in the acute survey programme exist as part of a continued time-line, and significant changes to their content or design would not be considered advisable. Nonetheless, it is important to briefly note the overall importance of such features.

A grouping principal for considering the effects of many content related factors is that they may relate to respondents’ perceptions of the *importance* of the study, and this has long been

²⁵⁹ Etter, J.F., Cucheraut, M., & Perneger, T.V. (2002) Questionnaire color and response rates to mailed surveys. *Evaluation and the Health Professions*, 25(2), 185-199.

²⁶⁰ Simon, R. (1967) Response to personal and form letters in mail surveys. *Journal of Advertising Research*, 7, (1), 28-30.

²⁶¹ Yu, J., & Cooper, H. (1983) *op cit*.

²⁶² Edwards, P., et al. (2002) *op cit*.

acknowledged as being strongly linked to likelihood of response²⁶³. Saliency, in particular, has an obvious and direct relationship with perceived importance, and is considered as one of the most important determinants of response rates²⁶⁴. Manipulating this experimentally in order to bring about improvements in response rates is not, however, a trivial task: saliency is highly subjective and hard to measure. As such, strategies to make questions 'more salient' may often prove elusive and vague.

For the national patient survey programme, the overall saliency of the questionnaire and the extent to which recipients perceive it to be important have always been fundamental considerations of the design process. The questionnaire has been developed and tested to ensure that it is as interesting and as broadly acceptable as possible to people from a range of backgrounds, but until recently little evidence has existed regarding the differences between ethnic groups in terms of the areas of healthcare that carry with them the greatest perceived value and importance. We have recently undertaken a survey to investigate this, and although analysis is presently at a relatively early stage, there is some indication that systematic differences exist between different ethnic groups in the aspects of care that are most important to them. For future surveys, we will continue to explore this field of research and seek to ensure that questionnaires retain as great as possible a perceived importance level to patients from black and minority ethnic groups.

Pre-approach letters

A UK randomised controlled trial examined the impact of a pre-warning letter sent seven days in advance of the main questionnaire to 627 adults referred to a community exercise scheme. The overall response rate was low – 30% in the group sent an advance letter and 21% in the control group. However, this represents a relative 43% increase in the response rate as a result of sending the advance letter.²⁶⁵

An Australian study showed that a personal contact prior to a postal survey of GPs resulted in a higher response rate than from GP's who had not had been contacted beforehand (75% versus 63%).²⁶⁶ In a telephone survey of 348 elderly people aged over 60, Iredell and colleagues showed that response rates were higher from respondents who had received a pre survey mailed postcard than from those who had not (74% versus 59%).²⁶⁷

The results from these studies are consistent with results from Edwards (2002) meta-analysis of 28 studies of pre-survey contacts. This showed that pre-contact compared to no pre-contact increased response by a mean average odds ratio of 1.54 and in some studies increased the likelihood of

²⁶³ Eg Heberlein, T.A., & Baumgartner, R. (1978) *op cit*.

²⁶⁴ eg Groves, R.M., Singer, E., & Corning, A. (2000) Leverage-Saliency Theory of Survey Participation: Description and an Illustration. *Public Opinion Quarterly*, 64: 299-308.

²⁶⁵ Harrison RH and Cock D. 'Increasing response to a postal survey of sedentary patients – a randomised controlled trial'. *BMC Health Services Research* (2004) 4:31

²⁶⁶ Harris C, Day N, Young D, Potiriadis M, Southern D and Dunt D. 'Improving general practice survey response rates: Bells (primers), whistles (reminders) and carrots (incentives)'. *Australian Journal of Primary Health* (2005) Vol. 11, No. 2

²⁶⁷ Iredell H, Shaw T, Howat P, James R and Granich J. 'Introductory postcards: do they increase response rates in a telephone survey of older persons?' *Health Education Research* (2004) Vol. 19, No. 2: 159-164

responding by as much as 50%.²⁶⁸ In contrast another review of studies of pre-notification letters found that they did not increase response rates in surveys of doctors.²⁶⁹

Reminder letters

A survey of Australian GP's showed that though reminders in general improved response rates overall, some forms of reminder were better than others. For example, a letter followed by a phone call was more effective than a letter alone (79% versus 65%), which in turn was better than no reminder at all (65% versus 45%).²⁷⁰

Similarly, a meta-analysis of 12 studies found that the odds of response were increased by a third when participants who did not respond to the initial mailing were contacted by mail or telephone. The odds of response were increased by almost a half when questionnaires were included during postal follow up.²⁷¹

The effect of reminders on increasing response rates has also been examined with patient groups. A meta-analysis of RCT's of strategies used to improve response rates in surveys of patient populations showed that respondents were nearly four times more likely to respond to a more intensive follow up effort in terms of reminders, either by phone or mail, compared to usual follow up reminders.²⁷² In a postal survey of 9,100 patients in Denmark, Norway, and the Netherlands the response rate amongst those receiving a reminder letter was significantly higher compared with the group that did not (79% vs. 62%).²⁷³

A US study compared differences in response rates to a reminder postcard couched in amiable language as opposed to one which used insistent wording. There was no significant difference overall, however insistently worded postcards sent to nurses did result in a significant increase in response rate.²⁷⁴

Covering letter

Sending a covering letter with the questionnaire explaining the purpose of the survey is standard practice in postal surveys. A number of studies have examined varying features of the covering

²⁶⁸ Edwards et al In The Cochrane Library, Issue 1, 2004

²⁶⁹ Kellerman SE, Herold J. 'Physician response to surveys: A review of the literature'. American Journal of Preventive Medicine {AM-J-PREV-MED}, 2001, Vol/Iss /Pg. 20/1 (61-67)

²⁷⁰ Harris et al (2005) op cit

²⁷¹ Edwards et al In The Cochrane Library (2004) op cit

²⁷² Nakash et al (2006) op cit; the authors do not however define what is meant by 'intensive' as opposed to 'usual' follow up methods.

²⁷³ Vedsted P, Mainz J and Olesen F. '(The significance of a reminder and physician's motivation for the response rate of a questionnaire survey in general practice)'. Ugeskrift for laeger (2001) 1 Oct, vol. 163, no. 40:5529-32

²⁷⁴ Price JH, Yingling F, Walsh E, Murnan J and Dake JA. 'Tone of postcards in increasing survey response rates'. Psychological reports (2004) April, vol. 94, no. 2:444-8

letter, for example hand or printed signatures²⁷⁵, signature by a doctor or a coordinator of the study²⁷⁶, and endorsement of the survey by an opinion leader.²⁷⁷

A RCT of coronary heart disease (CHD) patients comparing response rates where the letter was signed by a doctor as opposed to the study co-ordinator found that response rates did not differ significantly between the two groups of respondents.²⁷⁸ Similarly, response rates did not differ in a survey of gynaecologists where signatures were hand-written versus printed.²⁷⁹ However, personalisation of a letter, for example by including hand written notes has been shown to increase response rates.²⁸⁰ Conversely, a covering letter with an opinion leader's endorsement led to lower response rates.²⁸¹ All of these studies were, however, of non-patient samples.

The evidence from the Bhandari study is consistent with a meta-analysis of four studies comparing response rates in surveys that included a letter from a well known source. This showed that questionnaires were no more likely to be returned when the covering letter was sent by a senior or well known source compared with a less senior, less well known source.²⁸²

A US randomised trial compared response rates to an electronic survey when covering letters of different intensity were sent to participants. They found that the response rate where the survey was introduced with what they describe as 'high intensity' language was significantly higher than for what they describe as 'low intensity language' (48% compared to 35%).²⁸³ They do not however, explain how they define difference in intensity of language.

Mode of Mailings, envelope size and response rates

Other strategies to increase response rates have included varying the methods of mailing, for example recorded versus standard delivery and varying envelope size.

Yi (2005) showed that response rates for recorded delivery were significantly higher than when using standard delivery (88% versus 82%).²⁸⁴ Another US randomized trial found a significant increase in the response rate when a third reminder in a postal survey was sent recorded delivery

²⁷⁵ McKenzie-McHurg K, Tully L, Gates S, Ayers S and Brocklehurst P. 'Effect on survey response rate of hand written versus printed signature on a covering letter: randomised controlled trial'. *BMC Health Services Research* (2005) 5:52

²⁷⁶ Renfro EG, Heywood G, Foreman L, Schron E, Powell J, Baessler C, Warwick D, Morris M and Hallstrom A. 'The end-of-study patient survey: methods influencing response rate in the AVID Trial'. *Controlled Clinical Trials* 23 (2002) 521-533

²⁷⁷ Bhandari M, Devereaux PJ, Swiontkowski MF, Schemitsch EH, Shankardass K, Sprague S and Guyatt GH. 'A randomized trial of opinion leader endorsement in a survey of orthopaedic surgeons: effect on primary response rates'. *International Journal of Epidemiology* (2003) 32:634-636

²⁷⁸ Renfro et al (2003) op cit

²⁷⁹ McKenzie-McHurg et al (2005) op cit

²⁸⁰ Field et al (2002) op cit

²⁸¹ Bhandari et al (2005) op cit

²⁸² Edwards et al (2002) op cit

²⁸³ Anderson PA and Blackburn TR. 'An experimental study of language intensity and response rate in e mail surveys.' *Communication Reports* (2004) Summer, 17; 2: 73-84

²⁸⁴ Yi SW, H JS, Ohrr H and Yi JJ. 'A comparison of response rate and time according to the survey methods used: a randomized controlled trial'. *European Journal of Epidemiology* (2005) 20: 131-135

compared to first class mail (41% vs 25%).²⁸⁵ Further, Renfroe et al (2005) showed that response rates were significantly higher for questionnaires delivered overnight compared with regular mail (75% versus 68%). However, using postage stamps rather than pre-paid business franked reply envelopes has been shown not to be associated with an increase in response rates in a UK survey - Harrison et al (2005) showed that there was only a miniscule non-significant difference (58.7% versus 57.2%) in response rates to respondents receiving postage stamped or business franked reply envelope.²⁸⁶ In contrast, a meta-analysis of fourteen studies found that questionnaires were 26% more likely to be returned if they had a stamped return envelope rather than a pre-printed business reply envelope.²⁸⁷ Another review also found that the use of stamps on both delivery and return envelopes was effective in increasing response rates in surveys of doctors.²⁸⁸ These findings were mirrored in an RCT of Korean-Vietnam veterans.²⁸⁹ The evidence from these studies is otherwise largely consistent with the Edwards' meta-analysis of studies. In meta-analysis of 6 studies comparing response rates for recorded versus standard delivery, Edwards et al (2003) showed that respondents were over twice as likely to return the questionnaire when recorded delivery rather than standard delivery was used. However, stamped outward envelopes were no more likely to be returned than franked envelopes.

The use of large standard sized envelopes had little impact on response rates (56.6% versus 55.5%).²⁹⁰

Summary

Clearly, unconditional monetary incentives and to some extent conditional incentives (though not token incentives) are associated with increased response rates to mailed surveys.

The evidence from studies manipulating questionnaire characteristics to determine effects on response rates really only shows that keeping a questionnaire short has an effect on increasing response rates and, that varying the colour or the quality of the paper on which the questionnaire is printed on is largely ineffectual in increasing response rates. The interest or relevance of the questionnaire to a participant also has a positive impact response rates.

The reviewed studies suggest that both introductory contacts and reminders are likely to have a significant effect upon increasing response rates in both non-patient and patient populations.

There is also evidence that the use of recorded delivery and stamped reply envelopes is likely to enhance response rates.

²⁸⁵ Del Valle ML, Morgenstern H, Rogstad TL, Albright C and Vickrey BG. 'A randomized trial of the impact of certified mail on response rates to a physician survey and a cost-effectiveness analysis'. *Evaluation and the Health Professions* (1997) Vol. 20(4): 389-406

²⁸⁶ Harrison RA, Holt D and Elton PJ. 'Do postage-stamps increase response rates to postal surveys? A randomized controlled trial'. *International Journal of Epidemiology* (2002) 31: 872-874

²⁸⁷ Edwards et al In *The Cochrane Library* (2004) op cit

²⁸⁸ Kellerman SE, Herold J. 'Physician response to surveys: A review of the literature'. *American Journal of Preventive Medicine {AM-J-PREV-MED}*, 2001, Vol/Iss /Pg. 20/1 (61-67)

²⁸⁹ Yi SW, Hong JS, Ohrr H and Yi JJ. 'A comparison of response rate and time according to the survey methods used: A randomized controlled trial'. *European Journal of Epidemiology* (2005) Vol. 20/2:131-135

²⁹⁰ Halpern et al (2002) op cit

Implications for the national acute patients' survey

The literature review examining strategies to improve response rates suggests that some strategies are more likely to increase response rates than others. Thus, unconditional monetary incentives, shorter questionnaires and introductory letters and reminders have all been shown to be effective in increasing response rates in the general population, as does the relevance of the survey to the participant. There is also limited evidence that incentives increase response rates in Black and minority ethnic groups.

7 The implications of this review for the acute patients survey

This review identifies a range of difficulties in including certain groups in postal health surveys. It will be shown that people who have difficulty reading and writing are less likely to respond to a postal survey. Nevertheless, there remain clear reasons for continuing to use standardised instruments for measuring patient experience because their standardization in content, sampling, and administration facilitates valid comparisons across population groups,²⁹¹ and across different organisations and across time.

The review identifies some practical changes that could improve response rates amongst groups less likely to respond and these are set out in ten points below. There is however, limited evidence about the likely impact of these initiatives and any change needs to be carefully monitored. In the meantime additional work is needed to ensure to explore the health experiences of seldom heard patients in more depth. The use of focus groups, one-on-one interviews, organisation and population-specific surveys have been suggested for capturing this in-depth information.²⁹² Continued work is needed to identify appropriate approaches to combining data gathered using these alternative methods with data gathered from the standardised surveys.

1. Advance publicity and covering letters need to include messages targeted at specific seldom heard populations. It may be appropriate to translate some of this material. Attempts should also be made to communicate survey findings to seldom heard populations.
2. All material should have a statement in 16 point font about the availability of material in alternative formats (if these are to be supplied).
3. There is a need to explore the feasibility of further research to investigate the readability levels of the inpatient survey in addition to literacy levels in the patient population.
4. The inclusion of patients with poor literacy needs further investigation eg providing the questionnaire in alternative formats, for example audiotape or CD with the questions clearly spoken aloud and the translation of the questionnaire into community languages.
5. Further research is needed on the inclusion of people with learning disabilities.
6. Further evidence is needed to explain the variations in response rates amongst different groups. Targeted non-response studies are therefore recommended.
7. Approaches to improving the completeness of ethnic group data need to be explored eg improved collection at point of admission / compulsory field in electronic patient record.
8. Further work is needed to develop strategies for the inclusion of patient groups for whom accurate contact data may be unavailable.
9. Empirical studies have shown unconditional monetary incentives, shorter questionnaires and introductory letters and reminders to be effective in increasing response rates amongst all groups. There is a lack of empirical evidence about the effectiveness of other strategies

²⁹¹ California Pan-Ethnic Health Network (2001) 'Diverse Patients, Disparate Experience: The use of standardized patient satisfaction surveys in assessing the cultural competence of health care organizations'. California: CPEHN, p. 23. Available at: <http://www.cpehn.org/pdfs/CPEHN%20Final%2001.pdf> Last accessed 12/06/06

²⁹² California Pan-Ethnic Health Network (2001) p. 19

- that might have potential for increasing response rates amongst Black and minority ethnic and seldom heard groups and further research is needed.
10. The use of mixed modes has been identified as a potential approach to both including seldom heard groups in health surveys and to capturing their views using other methods. This forms the subject of a separate review.²⁹³

²⁹³ Graham, C. (2007) Mixed mode survey methodologies: a report with respect to the NHS acute patient survey programme. Oxford: Picker Institute Europe.

Appendix One: Search strategy

The following databases were searched using Dialog DataStar via the Athens portal:

- Allied & Complementary Medicine – 1985 to date
- British Nursing Index – 1994 to date
- DH-DATA – 1983 to date
- EMBASE – 1996 to date
- EMBASE – 1974 to date
- King's Fund – 1979 to date
- MEDLINE – 1996 to date
- MEDLINE – 1950 to date
- CINAHL (R) – 1982 to date
- PsycINFO – 1806 to date

The terms used in the searches and articles retrieved and reviewed are shown in the table below. Abstracts of all articles generated by the search were reviewed to determine if they were relevant to the subject of the literature review, in particular whether they added knowledge to issues relevant to increasing response rates to postal surveys amongst Black and minority and seldom heard groups. Full versions of any relevant articles were obtained and reviewed by the main author. The articles were annotated to indicate which themes they covered and key findings were included in separate sections to make up this report of the literature.

Searches conducted on 20 January 2006:

Search term	Articles retrieved	Unique articles retrieved	Relevant articles retrieved	Articles reviewed
Postal + response bias (in title or abstract only) + ethnic\$	0	0	0	
Mail\$ + response bias (in title or abstract only) + ethnic\$	4	4	0	
Respon\$ + ethnic\$ (in title only)	548	250	3	Allison et al (2003) Jackson et al (1996) Nelson et al (2004)
Nonrespon\$ + character\$ + survey (in title and/or abstract)	372	156	20	Collins et al (2000) Fiset et al (1994) Fowler et al (2002) Ito et al (1999) Kellerman and Herold (2001)

				<p>King et al (2001)</p> <p>Larroque et al (1999)</p> <p>Locker (2000)</p> <p>Locker et al (1990)</p> <p>Mond et al (2004)</p> <p>Ngo et al (2004)</p> <p>Paganini et al (1993)</p> <p>Pirzada et al (2004)</p> <p>Renfroe et al (2002)</p> <p>Shahar et al (1996)</p> <p>Strayer et al (1993)</p> <p>Tambor et al (1993)</p> <p>VanGeest et al (2001)</p> <p>Woodruff et al (2000)</p> <p>Zaslavsky et al (2002)</p>
<p>Response rate\$ + survey\$ (in title) (limited to references added in last 48 months)</p>	193	66	22	<p>Angus et-al (2003)</p> <p>Beebe et al (2005)</p> <p>Bhandari et al (2003)</p> <p>Chan et al (2003)</p> <p>Clark et al (2001)</p> <p>Cull et al (2005)</p> <p>Delnevo et al (2004)</p> <p>Evans et al (2004)</p> <p>Jepson et al (2005)</p> <p>McKenzie-McHarg et al (2005)</p>

				Moses and Clark (2004) Patten et al (2003) Paul et al (2005) Price et al (2004) Robertson et al (2005) Rosoff et al (2005) Ryu et al (2006) Schoenman et al (2003) Spooner (2003) Tjerbo et al (2005) Vedsted et al (2001) Yi et al (2005)
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Searches conducted on 4/07/06:

Search term	Articles retrieved	Unique articles retrieved	Relevant articles retrieved	Articles reviewed
Homeless\$ + question\$ + respon\$ (in title and abstract only)	143	105	1	Widom and Czaja (2005)
Traveller\$ + gyps\$ + question\$ (in title and abstract only)	7	5	0	
Postal + question\$ (in title and abstract only) + visual impair\$ (in whole document)	45	18	3	Ford et al (2001) Webb and Markus (2002) Wolffshohn et al
Postal + response bias (in title and abstract only) +	0	0	0	

vis\$ impair\$ (in whole document)				
Postal survey + disab\$ (in title and abstract only)	503	152	2	McNally (2002); (2003)
Postal AND response bias + disab\$ (in title and abstract only)	20	6	2	Mallen et al (2005) Tennant and Badley (1991)
Postal AND response bias (in title and abstract only) + demog\$	25	10	6	Addington et al (1998) Angus et al (2003) Maconochie et al (2004) Roberts et al (2004) Sharp et al (2006) Tennant and Badley (1991)
Postal AND response bias (in title and abstract only) + soci\$	82	34	2	Tickle et al (1996) Victor (1988)
Postal + question\$ (in title and abstract only) + cognitive impair\$ (in whole document)	52	23	6	Alessi et al (2003) Ekman et al (2006) Geddes et al (1996) Hebert et al (1996) van Uffelen et al (2007) Vestling et al (2003)

Searches using the terms identified in the tables were also conducted on the internet using the Google search engine between January and July 2006. These searches generated most of the material reviewed in the sections of the report other than section 6.

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