

# Do income questions and seeking consent to link medical records reduce survey response rates? A randomised controlled trial among older people

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## SUMMARY

*Traditional measures of socioeconomic status may not be reliable for older people and income may be a useful measure for research into inequalities in health. At the same time, researchers increasingly wish to link survey findings to individual data taken from medical records. For this, consent must be sought. To examine whether questions on household income and seeking consent for medical record linkage affected response rates, a postal health survey of patients aged 65 to 74 was undertaken in an inner London practice. The overall response rate was 62.8%. In this study, the inclusion of an income question or seeking consent to access medical records did not reduce response rates to a health survey among older people.*

**Keywords:** patient consent; older people, questionnaire survey; socioeconomic status.

## Introduction

CONCERN over the public reaction to questions on income has resulted in their omission from the 2001 Census in the United Kingdom.<sup>1</sup> However, traditional measures of socioeconomic status, such as social class, may not be reliable for older people and income may be a useful measure for research into inequalities in health.<sup>2</sup> At the same time, new provisions of the Data Protection Act and recommendations of the Caldicott Report on patient confidentiality make it essential that researchers seek consent to link survey findings to named information on diagnosis, referral, and treatment.<sup>3</sup> In this study, we examine whether questions on household income and seeking consent for medical record linkage affected response rates in a postal health survey of older people.

## Method

The study population was of patients aged 65 to 74 years in an inner London practice who had consulted within the past two years (414 patients in 367 households). A randomised factorial design was used such that individuals in each participant household had an equal chance of receiving questionnaires with or without an income question and a consent form for access to their medical record. Randomisation at household level was used to reduce contamination between the groups. The study had 80% power at  $P = 0.05$  to detect a difference in response rate of 15 percentage points between those receiving the income or consent questions and the appropriate control group. The income question asked for a banded estimate of household income, similar to the question asked in the Census rehearsal.<sup>4</sup> Questionnaires without the income question included questions on benefits and pensions received. The rest of the questionnaire asked a range of questions on physical and mental health, social circumstances, social support, and living arrangements. The invitation letters for the study were sent jointly from the practice and the academic department and co-signed by a general practitioner (GP) from the practice who is one of the authors. However, the information sheet made it clear that this was an academic study and that individual results would not be shared with the practice. Participants were not aware that we were investigating differences in response rates to different questions. Non-responders were followed up with a second and third posting at one and two months after the initial posting. Non-responders were also telephoned at the time of the third posting where a phone number was available.

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Submitted: 15 May 2000; Editor's response: 22 October 2000; final acceptance: 31 October 2000.

©British Journal of General Practice, 2001, 51, 223-225.

Table 1. Response rate by randomisation group.

Questions received	Posted	Returned after first posting	Returned after final posting	Excluded	Corrected response rate after first posting <sup>a</sup>	Corrected response rate (%) at end of study <sup>b</sup>
Consent and income	104	41	70	7	42.3	72.2
Consent only	104	39	60	3	38.6	59.4
Income only	105	36	58	3	35.3	56.9
Neither income nor consent	101	34	57	11	37.8	63.3
All groups	404	150	245	24	38.5	61.2

<sup>a</sup>Difference between groups  $P = 0.79$ . <sup>b</sup>Difference between group  $P = 0.13$

Table 2. Response rate in each intervention group.

	Posted	Returned	Excluded	Corrected response rate
Income question				
Yes	209	128	10	64.3%
No	205	117	14	61.3%
Difference (95% CI)				3.1% (-6.5–12.7) $P = 0.53$
Yes	208	130	10	65.7%
No	206	115	14	59.9%
Consent sought				
Difference (95% CI)				5.8% (-3.8–15.3) $P = 0.24$

## HOW THIS FITS IN

### What do we know?

Questions on income have been removed from the 2001 Census because of concern over public reaction. Concern over patient confidentiality means that consent is required to link medical records to other patient data, such as those collected by a questionnaire. Little information is available on the effect this will have on response rates.

### What does this paper add?

Asking for consent to linked medical records to questionnaire data and inclusion of questions on income did not reduce response rates to a postal questionnaire among older people. Fears that increasing safeguards on the use of individual data could limit research may be unfounded.



## Results

Two hundred and forty-five completed questionnaires were returned and a further 24 patients (18 households) were identified as having changed address or died. Thus, the overall response rate was 62.8% (245/390) or 63% (220/349) at household level, counting any response from a household as a responding household. Response rates did not differ between the four randomised groups, either after the first posting or at the end of the study (Table 1). Response rates were slightly higher in the group whose questionnaire included the income question and in the group who received a form requesting access to their medical records, but not significantly so (Table 2). There was also evidence of an interaction such that those who received both the income question and the consent form had the highest response rate ( $P = 0.05$  for interaction). Ninety-seven (75.8%) of those who returned an income question completed it and 113

(86.9%) of those who returned a form asking for consent gave consent to access their records. Of those who answered the income question, 35 (36.0%) reported an income of £120 per week or less. There was no difference in income distribution between those who did and did not receive the consent form ( $P = 0.49$ ). Analysis by household response did not change our findings.

## Discussion

In this study, the inclusion of an income question or seeking consent to access medical records did not reduce response rates to a health survey among older people. The relatively low overall response rate probably reflects the nature of our study population but does not invalidate our findings, which are based on randomised allocation to questionnaire type. Our findings contrast with the Census test which showed a marginally lower response rate among those who received an income question, especially inner-city residents.<sup>4</sup> This may be owing to the context of our question, within a detailed health questionnaire or that the control group received questions on benefits and pensions. Alternatively, there may be age-related variations in attitudes to income questions such that older people object less to such a question. Also, in our survey, individuals who objected to the income question may have felt able to omit the question. Although the overall response rate was not affected a minority (24%) of our responders chose not to answer the income question, which may reduce the value of income as a measure of social status. The generalisability of these findings needs to be confirmed in affluent populations and in the context of other types of questionnaires.

It is reassuring for primary care researchers concerned over changes in data protection legislation and the implications of the Caldicott Report that seeking consent to access records did not reduce response rates. Our finding that of

those returning a questionnaire seeking consent to access records only 13% refused is comparable to a recent report of 10% refusal among asthma and angina patients from 81 practices.<sup>5</sup> Fears that increasing safeguards on the use of individual data will restrict epidemiological research may be unfounded.

## References

1. *Hansard* 10 January 2000. London: The Stationery Office.
2. Smith J, Harding S. Mortality of women and men using alternate social classifications. In: Drever F, Whitehead M (eds). *Health Inequalities*. Decennial supplement. London: The Stationery Office, 1997: 168-195.
3. Vandenbroucke JP. Maintaining privacy and the health of the public. *BMJ* 1998; **316**: 1331-1332.
4. Office for National Statistics. *Income data for small areas*. London: Office for National Statistics, September 1999.
5. Baker R, Shiels C, Stevenson K, *et al*. What proportion of patients refuse consent to data collection from their records for research purposes? *Br J Gen Pract* 2000; **50**: 655-656.

## Acknowledgements

We would like to thank the staff and patients of the participating practice for their involvement in and support for this study.