Surveys using general practice registers: who are the non-responders?

Daniel Pope and Peter Croft

Abstract

Background General practice population registers are important sampling frames for surveys of disease prevalence, lifestyles and health needs. In any survey there is a problem of non-response in the target population which can reduce precision and may bias any estimates derived from the study. Bias related to those who choose not to respond has been studied, but the problems posed by those who no longer live at the address on the register have received less attention. The specific objectives of this study were to estimate the number of non-responders in a registered general practice population who had not received a questionnaire (‘ghosts’) as distinct from those who chose not to respond to it (‘refusers’) and to determine whether ghosts and refusers were different from non-responders in ways which might affect the purpose of the survey.

Methods A total of 500 people aged 18–75 years were selected from a general practice register in Stockport for a postal survey of shoulder pain in the adult population. Forty-one were identified as ‘ghosts’ during the survey. After three mailings of a baseline screening questionnaire for shoulder pain and a further mailing of a final reminder, there were 120 further non-responders. They were classified as ghosts or refusers on the basis of a comparison of their current address on the practice register with that on the electoral roll. A matched sample of 120 survey responders was identified and was used to check the accuracy of the electoral roll in classifying non-responders. Ghosts and refusers were compared with the sample of responders using consultation information obtained from medical records at the practice, if the latter were available.

Results In total, 108 of the 500 people in the sample (22 per cent) were classified as ‘ghosts’ – 41 on the basis of information obtained during the survey and 67 on the basis of a comparison with electoral roll details. In addition, 48 were classified as refusers on the basis of the electoral roll comparison. This compared with 8 (7 per cent) of the matched sample of responders who would have been classified as ‘ghosts’ using the electoral roll. People who had addresses outside the electoral district were excluded from classification. Medical records were available for 105 (90 per cent) of the responders, 31 (46 per cent) of the ghosts and 40 (83 per cent) of the refusers. Of those who had consulted at least once for any reason in the previous two years, a similar proportion of responders and refusers (48 per cent and 46 per cent) had attended because of musculoskeletal problems, but responders were more likely to have consulted specifically about shoulder pain (10 per cent compared with 3 per cent, but based on small numbers). Ghosts by contrast had a lower proportion of consultations for both all musculoskeletal (33 per cent) and shoulder-specific problems (none), but were more likely to have consulted with a psychological problem than responders.

Conclusions We have estimated the number of non-responders to a survey of shoulder pain who were likely not to have received the baseline questionnaire (ghosts) to have been 22 per cent of a sample drawn from a practice-based Family Health Services Authority register. The error of using the electoral roll to make such a classification was found to be small, with only 8 (7 per cent) of the sample of responders being misclassified as ghosts. Those ghosts who still had records at the practice appeared to differ from refusers with respect to musculoskeletal and psychological morbidity. It may be inappropriate to exclude ghosts from the denominator in population surveys.

Keywords: surveys, primary care, non-response, bias

Introduction

Health surveys based on postal questionnaires are attractive because of low cost, practicality and geographical reach. However, in any mailed survey there is a problem of non-response which can reduce precision and may bias results derived from the study. There are two broad groups of people who do not respond in a postal survey: (1) those who do not receive the questionnaire, because of incorrect addresses, moves or migration, institutionalization or death...

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(these we will refer to as ‘ghosts’); (2) those who receive the questionnaire but choose not to respond (here referred to as ‘refusers’).

It is important to estimate the extent of non-response bias, i.e. any potential distortion of a study result which arises because of non-response. This will involve two steps: first to determine the number of ghosts – and hence the number of refusers – among non-responders, and second to investigate the extent to which both ghosts and refusers may differ from responders with respect to the characteristics being studied. Demographic characteristics can provide some information about potential non-response bias, but do not necessarily identify the relevant differences between responders and non-responders.

The ways in which refusers might differ from responders have been studied – painful symptoms may be more likely to elicit a response, unhealthy lifestyles to inhibit a reply. A frequent approach to ‘ghosts’ is simply to exclude them from the denominator. The extent to which this might bias a population survey is not known.

We have conducted a cross-sectional postal survey, the overall aim of which was to estimate the prevalence of shoulder pain in the community. The specific objectives of the study presented here were (1) to estimate the number of non-responders to the postal survey who were ghosts and (2) to determine whether ghosts differed from refusers and responders with respect to their previous consultation patterns for musculoskeletal problems.

Methods

The postal survey

The cross-sectional postal survey involved a self-completion questionnaire mailed to an age-stratified random sample of 500 people, aged 18–75 years, selected from a general practice register in Stockport, England. The short screening questionnaire asked about any musculoskeletal pain experienced during the month before the survey, with additional specific enquiry about shoulder pain.

The questionnaires were mailed with reply-paid envelopes. People who had not responded were sent up to two repeat mailings at one-month intervals. Three months later, a final mailing was sent to those who had not replied to the second reminder. It consisted of a single sheet containing three key questions about current shoulder pain and its duration, together with an explanatory letter and reply-paid envelope.

After all the mailings were completed, a total of 339 replies had been received, an overall response of 73.9

per cent. The study population consisted of the 161 people from whom no questionnaire was obtained.

The non-responder study

Estimating the number of ghosts and refusers

The details of all subjects who had not responded to the survey after the final single-sheet questionnaire were checked against the electoral roll as an estimate of how many were not living at the address to which the survey had been mailed. The electoral roll itself may not be accurate, and this was investigated by selecting a control group of responders to compare with electoral roll information. The controls were sampled to ensure a distribution of age and gender similar to that of the non-responders. Our basic necessary assumption was that, if electoral roll and age–sex register coincided, that person was considered a current resident at that address.

Electoral rolls are available to the public in local libraries and are indexed alphabetically according to street name within each polling district. Addresses only appear on the record if residents are registered to vote. Against each address is a list of all people living there who have registered. Checking was carried out by a research assistant (with the permission of the general practice involved) who was unaware of the response status of individual patients in the study groups. Strict confidentiality was maintained.

Non-responders could be placed in one of five categories according to the entries on the electoral roll and the general practice register: (1) the person’s full name and address was the same on the electoral roll and the practice register; (2) the electoral roll recorded the same surname and address as the practice register but different initials; (3) the electoral roll recorded a different surname at the same address as the practice register; (4) there was no entry on the electoral roll for the name and address recorded on the practice register; (5) the address recorded on the practice register could not be checked on the electoral roll as it was outside the electoral district.

On the basis of this information, study definitions of two types of non-responder were constructed as follows:

Refusers: person’s surname appeared on the electoral roll at the appropriate address (1) and (2).

Ghosts: different surname on electoral roll (3) or no-one from the mailing address appeared on the roll (4). A similar categorization of electoral roll status was carried out for the matched sample of responders and for the ghosts identified during the course of the survey. This was to determine the validity of using electoral roll entries to categorize non-responders.
Subjects in each of the two matched study groups could also be separated into those with and without medical records in the practice.

**Estimating non-response bias: demographic information**
The age and gender distributions of ghosts and refusers were compared. This information was available from the general practice register.

**Estimating non-response bias: survey characteristics**
The frequency and content of consultations in the two years before the survey was assessed for non-responders and the control group of age- and gender-matched responders. The information was obtained from the medical records by a research worker unaware of the response status of the subjects.

As the absolute number of consultations recorded would be affected if, unknown to the practice, the subject had moved away, we analysed the proportion of an individual's total number of recorded consultations which were related to musculoskeletal pain in general and to shoulder pain in particular. For the same reason, the analysis was restricted to those who had consulted at least once in the two-year review period. Consultations for psychological problems were reviewed as a general measure of consultation behaviour.

**Results**
The age and gender distributions of the two matched study groups (responders and non-responders) were similar: mean ages 33 and 37 years, respectively; proportion of men 60 per cent and 59 per cent.

**Estimating the number of ghosts and refusers**
Table 1 summarizes the results of comparing the mailing list of names and addresses obtained from the practice register with entries on the electoral roll. The two study groups are shown, together with a similar comparison carried out for the 41 'ghosts' identified in the course of the survey. Eight people in the two study groups (five non-responders, three responders) had addresses outside the electoral district, and these individuals have been excluded from the comparison, leaving 115 non-responders and 117 responders.

Overall, 48 (41.8 per cent) of the non-responders were recorded on the electoral roll as living at the same address (or having someone of the same surname at the address) as that recorded on the practice register, compared with 109 (93.2 per cent) of the responders. The next two categories in Table 1 (different surname on the electoral roll or the address on the mailing list did not appear on the electoral roll) define ghosts, and can be used as the basis for classifying individuals as 'unlikely to have received a questionnaire'. Most of the non-responders (n = 67, 58.2 per cent) fell into these categories.

<table>
<thead>
<tr>
<th>Electoral roll status*</th>
<th>Survey ghosts† (n = 41)</th>
<th>Non-responders (n = 115)</th>
<th>Responders‡ (n = 117)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
</tr>
<tr>
<td><strong>Match</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full name on electoral roll at mailing address</td>
<td>9</td>
<td>22.0</td>
<td>37</td>
</tr>
<tr>
<td>Same surname, different initial on electoral roll</td>
<td>4</td>
<td>9.8</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>31.8</td>
<td>48</td>
</tr>
<tr>
<td><strong>Non-match</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Different surname on electoral roll at mailing address</td>
<td>22</td>
<td>53.7</td>
<td>55</td>
</tr>
<tr>
<td>House not on electoral roll</td>
<td>6</td>
<td>14.6</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>68.3</td>
<td>67</td>
</tr>
</tbody>
</table>

*χ² test for difference = 74.1, df = 5, p < 0.005.
†Ghosts identified during the survey (i.e. notified to us by current residents and Post Office).
‡Age and sex matched to non-responders.
## Table 2: Characteristics of responders and non-responders

<table>
<thead>
<tr>
<th>Age</th>
<th>All responders (n = 339)</th>
<th>Non-responders (n = 156*)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>18–39 years</td>
<td>145</td>
<td>43</td>
</tr>
<tr>
<td>40–59 years</td>
<td>119</td>
<td>35</td>
</tr>
<tr>
<td>60+ years</td>
<td>75</td>
<td>22</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>All responders (n = 339)</th>
<th>Non-responders (n = 156*)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Males</td>
<td>152</td>
<td>45</td>
</tr>
<tr>
<td>Females</td>
<td>187</td>
<td>55</td>
</tr>
</tbody>
</table>

*Five subjects were excluded who lived outside the district.

### Validity of using electoral roll to estimate 'ghosts' and 'refusers'

A small number of responders (n = 8, 6.9 per cent) did not appear on the electoral roll, and yet we must assume that they are not 'ghosts' because they must have received a questionnaire in order to return it. This figure (i.e. the proportion of apparent ghosts among responders) gives an estimate of the error when the electoral roll is used to detect inaccuracies in the practice register. In our study, the estimate would be that four of the 115 non-responders would have been incorrectly classified as ghosts rather than refusers.

By contrast, there are the 41 ghosts identified during the course of the survey. Their entries on the electoral roll would have classified 13 (31.8 per cent) as refusers rather than ghosts, had the additional information obtained in the course of the survey not been available. This gives an estimate of the potential misclassification of non-responders as refusers rather than ghosts. In our study, the estimate would be that up to 15 of the non-responders might have been incorrectly classed as refusers rather than ghosts.

### Demographic comparison of responders and non-responders

In Table 2, the age and gender of ghosts and refusers are compared with those of all 339 study responders. A higher proportion of ghosts and refusers were in the youngest age group when compared with responders, with the highest figure among ghosts who had been identified during the survey. Refusers were more likely to be male than other groups.

### Summary

Figure 1 illustrates the status of non-responders after the survey and the checking of the electoral roll. The original target population sample of the survey was 500. A total of 161 did not return a questionnaire. Of those, 108 were ultimately classified as ghosts who were unlikely to have received a questionnaire (41 identified on the basis of information obtained during the survey, 67 on the basis of the electoral roll entries); 48 were classified as refusers; five lived outside the electoral district studied. However, there may be errors in the electoral roll, and our estimates suggest that the true ghost figure is between 65 and 76 per cent of non-responders.
TABLE 3 Content of consultations: comparison of responders and non-responders (95% CIs given in parentheses)

<table>
<thead>
<tr>
<th></th>
<th>Responders (n = 117)*</th>
<th>Ghosts (n = 67)</th>
<th>Refusers (n = 48)</th>
<th>Total (n = 115)*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No. %</strong></td>
<td>No. %</td>
<td>No. %</td>
<td>No. %</td>
<td>No. %</td>
</tr>
<tr>
<td>Medical records available</td>
<td>105 90 (83-95)</td>
<td>31 46 (34-59)</td>
<td>40 83 (70-93)</td>
<td>71 62 (52-71)</td>
</tr>
<tr>
<td>Any consultations in the past 2 years†</td>
<td>93 89 (81-94)</td>
<td>21 68 (49-83)</td>
<td>33 83 (67-93)</td>
<td>54 76 (65-85)</td>
</tr>
<tr>
<td>No. of consultations (median and IQR†)</td>
<td>5 2-10</td>
<td>1 0-3</td>
<td>4 2-9</td>
<td>3 1-6</td>
</tr>
<tr>
<td>Details of consultations§</td>
<td>Any musculoskeletal pain in past 2 years</td>
<td>45 48 (38-59)</td>
<td>7 33 (15-57)</td>
<td>15 46 (28-64)</td>
</tr>
<tr>
<td>Any shoulder pain in past 2 years</td>
<td>9 10 (5-18)</td>
<td>0 0 (-)</td>
<td>1 3 (0-1-16)</td>
<td>1 2 (0-01-10)</td>
</tr>
<tr>
<td>Any psychological problems in past 2 years</td>
<td>10 11 (5-19)</td>
<td>4 19 (5-42)</td>
<td>2 6 (1-20)</td>
<td>6 11 (4-23)</td>
</tr>
</tbody>
</table>

*People whose addresses were outside the electoral district were excluded.
†Shown as a percentage of those in each group who had medical records available.
‡Interquartile range.
§Details of consultations are shown as a percentage of those in each group who had any consultations in the past two years.

responders and the true refuser figure is between 20 and 32 per cent.

Comparison of consultations

Medical records could be traced for 105 of the sample of responders (89.7 per cent), and for 71 (61.7 per cent) of the non-responders. The non-responders with records in the practice included ghosts, as defined by the electoral roll comparison (31 records available out of 67, or 46.3 per cent), and refusers (40 records available out of 48, or 83.3 per cent).

In the two years before the survey, responders had consulted on average more often than non-responders [median consultation number in responders was 5, interquartile range (IQR) 2-10, compared with 3 in non-responders, IQR 1-6] (Table 3). When looking at the categories of non-responders, refusers had a higher median consultation number (4, IQR 2-9) than ghosts (1, IQR 0-3), the former being closer to the responders' figure.

The analysis of consultation content was restricted to those individuals with at least one entry in the records for the two-year review period. Table 3 illustrates that a higher proportion of responders with medical records had consulted at least once in the two-year period (88.6 per cent) than non-responders overall (76.2 per cent) and ghosts in particular (67.7 per cent); refusers were again closer to responders (82.5 per cent). Among responders, a similar proportion of people (48.4 per cent) had consulted with any musculoskeletal pain during the two-year period compared with non-responders (42.6 per cent). The proportion of refusers who had consulted (45.5 per cent) was again close to the figure for responders and was higher than the corresponding figure for ghosts (33.3 per cent). However, for shoulder pain, more responders had consulted than either non-responders overall, or ghosts and refusers separately (9.7 per cent versus 1.9 per cent, 0 per cent, and 3 per cent, respectively). By contrast, there was a similar consultation prevalence for psychological problems among responders (10.8 per cent) and non-responders (11.1 per cent). When looking at the categories of non-responders separately, a higher consultation prevalence for psychological problems was found among ghosts (19 per cent) than in either refusers (6.1 per cent) or responders.

Discussion

In a community-based survey of shoulder pain, it has been estimated that 22 per cent of the sample drawn from a practice-based age-sex register were unlikely to have actually received the mailed questionnaires because of inaccuracies in the general practice register.
('ghosts'). The other non-responders (9.6 per cent of the sample) were considered to represent non-participants who had received a questionnaire ('refusers').

Such figures must remain estimates because 67 of the 108 ghosts were not identified by direct information obtained during the survey, but from incompatibilities between the practice register and the local electoral roll. The electoral roll itself will be subject to inaccuracies\(^8\) – new arrivals or people who choose not to register to vote, for example. We have attempted to estimate the extent of electoral roll inaccuracy from the number of questionnaire responders who were classified as ghosts by this method. Their number was small (\(n = 8, 66\) per cent of responders), and we conclude that a comparison of practice register and electoral roll does indeed account for most of the ghosts among non-responders. This is supported by the fact that this figure is almost identical to the estimate of Bickler and Sutton, who investigated the residential status of a sample of women on a Family Health Services Authority (FHSA) list after checking their names against the electoral register.\(^9\) They classified the subjects as 'matches' and 'non-matches' depending on the electoral roll status, and reported that 92 per cent of the women whose names appeared on both registers (matches) were found to be living at the listed address, whereas 8 per cent were not. This may not be true for all groups. A study by Bowling et al. of an elderly population, for example, found that the electoral roll itself did not necessarily reflect true 'current address'.\(^8\) These researchers found that a combination of electoral register and general practice register was a more reliable method for identifying elderly people in a practice population than either on its own.

Once ghosts have been identified, how should they be treated in the presentation of the survey results? One common approach is to exclude them from the target population number, and recalculate the response rate. This assumes that people who 'probably did not receive a questionnaire' should not have been on that target list in the first place.

There is a problem with this approach. The survey procedure began with a random sample derived from the practice register. This sample thus represented all those on the register on that day. However, the register at any point in time cannot be expected to reflect with total accuracy 'all those alive and living at the address shown, who would use this practice if they were ill and who will receive a questionnaire if it is mailed to the address on the register'. People are regularly emigrating and moving in or out of households in a practice area, and it is highly unlikely that a register could exist which reflected current vital status and residence without any error. It can therefore be argued that the 500 names sampled in our survey represent a 'true' sample of registered patients, even though on the day of sampling and mailing, some will have moved, migrated or died.

Is this important? There is evidence to suppose that moving general practice is linked to health status. In older men, mobility between practices is associated with a higher cardiovascular morbidity;\(^10\) in young women, by contrast, the fitter group tend to be more likely to move.\(^11\) Therefore ghosts as a group might represent a sector of the population who have certain distinctive health characteristics. Our study has provided some evidence that this is so. Among ghosts with medical records available and who had consulted the practice at least once during the two years before the survey, consultation rates had been lower than among responders, both in total and separately for musculoskeletal symptoms. It could be argued that this is inevitable because many would have left the practice at some point in that two-year period. This is partly reflected in the lower proportion of records which were traced for the ghosts compared with non-responders. However, consultation rates for psychological problems were higher in this group than in the responders. These analyses were all based on small numbers, and the hypothesis that ghosts have a different illness experience from responders and refusers would need further investigation using sources other than medical records. However, our finding does provide some basis for the conclusion that excluding ghosts from the denominator in a population survey may leave an unrepresentative sample of the general population with respect to their health status. Such ghosts should be included, and their potential contribution to non-response bias assessed.

However, this is all relative to the purpose of the survey, and depends on the question being asked. For example, a study of the effects of an increased toxic discharge from an incinerator on the local population would demand an accurate geographical sampling frame. By contrast, a prevalence survey of respiratory symptoms might assume a practice register to be representative of all subjects registered with a general practice and so might usefully include 'ghosts'. For refusers the issues are clearer. There is no dispute that they remain part of the 'target population' sample. The important question is about bias: was their non-response related to differences from responders which are relevant to the survey findings? Our analysis of consultation data suggests that their morbidity (judged by care-seeking) was in general similar to that of responders, and different from that of ghosts. The assumption is that their self-reported morbidity would not differ greatly either. However, there was a
difference in their propensity to consult with shoulder problems — the main object of the survey. Numbers were small, but the conclusion is that prevalence estimates of shoulder problems based on the responders may be an overestimate of the prevalence in the total population.

It is perhaps surprising that morbidity was similar between responders and non-responders, as previous surveys in the general population have suggested the opposite. Most studies of symptoms, however, have suggested that those with the symptom under investigation are more likely to respond, and this is compatible with our result. What our figures suggest is that there may not be a difference between responders and non-responders with respect to their general care-seeking behaviour.

A general practice register should clearly be reasonably up to date before constructing a sampling frame for a survey. There are important ethical and practical reasons for this, as well as the need to keep the number of non-responders to a minimum. The better the response, the less will be the effect of any non-response bias. However, whatever the actual response rate, the important issue to investigate is whether non-response bias is present, and if so, what effect it might have. Our study has indicated for the first time that it is important to consider the role of bias in ghosts as well as refusers. How important this is will depend on the question being asked and the choice of sampling frame to answer it. If that section of the community who regularly move home or who for any reason have not registered to vote are different from the rest of the population with respect to illness or lifestyles, then their automatic exclusion from the survey denominators may not be justified.

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References


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