SHORT REPORT

Linking questionnaires to primary care records: factors affecting consent in older people

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Primary care databases provide rich consultation and prescribing information,[1] but lack individual background detail. Linking to information from questionnaires can overcome this, but requires individual informed consent.[2] [3] The generalisability of linked data will be constrained by low consent rates and any differences between those giving and those withholding consent, in addition to any non-response bias. Most studies examining the consent issue, have either focused on patients with specific illnesses,[3] or have had limited comparison measures.[4] A recent large study found that men, younger people, and subjects with the symptom under investigation, were more likely to give consent, but lacked information on service use, or other measures of physical and psychological health.[5] We conducted a wide ranging health and social survey and compared older people who gave and withheld consent to link questionnaire data to their primary care records.

PARTICIPANTS, METHODS, AND RESULTS

A detailed account of the survey methods has already been published.[6] A postal survey was conducted, with an offer of assistance in completion, with patients aged ≥65 years from two London practices. The questionnaire is available on request from the authors and is also on the journal web site (http://www.jech.com/supplemental) and included details on: demographic factors; physical health; psychological measures (including depression, anxiety, and health beliefs); social support; socioeconomic measures; and a request for consent to link questionnaire data with subjects' computerised primary care records. Logistic regression was used to examine associations between other factors and consent to link, with results expressed as odds ratios (OR) and 95% confidence intervals (CI). Three groups (questionnaire non-responders; responders withholding consent to link; and responders giving their consent to link) were created on the practice computer system. The number of primary care consultations for the 12 month period after the questionnaire, was downloaded for each group, with no identifying individual data. Crude mean consultation rates for each group were estimated from total number of consultations and number of subjects per group. The 95% confidence limits were based on assuming these were generated by a Poisson process with over-dispersion parameter 2.1 (estimated from earlier data on individual level consultation rates from responders who gave consent to linkage).

The survey response rate was 75% (1704 of 2276) of whom 92% (1565 of 1704) gave their consent to link questionnaire and primary care data. Older subjects had higher response rates (65–74 year olds 785 of 1090 (72.0%) ≥75 years 919 of1186 (77.5%) $\chi^2 = 8.7$, p = 0.00) but there was no sex difference in response (men 629 of 842 (74.7%) women 1075 of 1434 (75.0%) $\chi^2 = 0.01$, p = 0.93). Subjects with poorer health were more likely to give their consent, both for physical health factors and for anxiety and depression (table 1). Demographic factors (age, sex, practice, ethnic group) health locus of control, smoking, alcohol use, and social support measures were not associated with consent. For several socioeconomic measures, there was a trend for the more affluent to be more likely to give consent (income, occupational pension, and private health insurance) but this was only statistically significant for owning a car OR 1.8 (1.2 to 2.6). These findings were similar when analysed for each practice separately.

Overall mean consultation rates (number of consultations/ number of subjects) (95% CI) for the 12 months after the questionnaire were as follows: non-responders 7.8 (4436/ 572) (7.3 to 8.2); responders withholding consent 8.3 (1160/ 139) (7.8 to 8.8); responders giving consent 9.6 (14946/1565) (9.2 to 9.9).

COMMENT

A high percentage of older people gave consent for their primary care records and questionnaire results to be linked, consistent with other studies.[3] [5] No significant age or gender differences in consent were seen in our study, although the trend was for men and younger subjects to be more likely to consent, as reported by Dunn in their larger study with greater power.[5] We found that those giving consent were more likely to have poorer physical and psychological health, and to use primary care services more. These findings were consistent across both practices and with findings among adults that those with the symptom under investigation were more likely to give consent.[5] These differences between those giving and withholding consent (consent bias) add to reported differences in service use between survey responders and non-responders[7] (response bias).

Our study findings therefore have important implications for researchers collecting non-anonymised data from primary care. Firstly, although 92% of responders gave consent to linkage, this provides further data attrition on top of that attributable to non-response, and needs consideration in sample size calculations. Secondly, the finding that, in older subjects at least, those giving consent are likely to have poorer physical and psychological health and to use primary care services more, implies that studies based on such subjects could overestimate disease prevalence rates. This provides more ammunition for those arguing against the necessity of informed consent for all studies using identifiable data, on the basis that the incomplete data obtained may be unrepresentative.[2] [8] Maximising consent rates will reduce, but not eliminate this consent bias.

Table 1 Factors associated with giving consent to link questionnaire with primary care records

Variables*	Consent given N = 1565 n (%)	Consent not given N = 139 n (%)	Odds ratio for consent given (95% CI)
A: Demographic factors:			
Age (n = 1704)			
65–69	356 (92.7)	28 (7.3)	1.0
70–79	711 (92.1)	61 (7.9)	0.9 (0.6 to 1.5)
80 or more	498 (90.9)	50 (9.1)	0.8 (0.5 to 1.3)
Sex (n = 1704)			
Male	585 (93.0)	44 (7.0)	1.0
Female	980 (91.2)	95 (8.8)	0.8 (0.5 to 1.1)
Ethnic group† (n = 1677)			
White	1492 (92.2)	126 (7.8)	1.0
Non-white	54 (91.5)	5 (8.5)	0.9 (0.4 to 2.3)
Practice (n = 1704)			
Practice 1 (inner city)	644 (93.1)	48 (6.9)	1.0
Practice 2 (suburban)	921 (91.0)	91 (9.0)	0.8 (0.5 to 1.1)
B: Physical health			
Limiting longstanding illness (n = 1704)			
No	860 (89.6)	100 (10.4)	1
Yes	705 (94.8)	39 (5.2)	2.1 (1.4 to 3.1)
Pain interferes with activities (n = 1610)			
Not at all	665 (90.4)	71 (9.7)	1.0
A little bit	358 (93.0)	27 (7.0)	1.4 (0.9 to 2.3)
Moderately/extremely	460 (94.1)	29 (5.9)	1.7 (1.1 to 2.7)
Disability score (n = 1624)			
0–5 none or mild disability	1016 (91.0)	100 (9.0)	1.0
6–18 moderate or severe disability	481 (94.7)	27 (5.3)	1.8 (1.1 to 2.7)
Number of doctor diagnosed conditions (n = 1704)			
0	314 (88.5)	41 (11.6)	1.0
1–2	933 (91.6)	86 (8.4)	1.4 (1.0 to 2.1)
3 or more	318 (96.4)	12 (3.6)	3.5 (1.8 to 6.7)
C: Psychological factors/health behaviours			
Geriatric depression scale (GDS15) (n = 1602)			
0–5 low	1120 (91.7)	101 (8.3)	1.0
6–15 high	362 (95.0)	19 (5.0)	1.7 (1.0 to 2.8)
FEAR anxiety scale (n = 1613)			
Low 0–1	1132 (91.5)	105 (8.5)	1.0
High 2–4	357 (95.0)	19 (5.1)	1.7 (1.1 to 2.9)
Health locus of control			
Internality (n = 1613)			
Low	454 (92.7)	36 (7.4)	1.0
High	1035 (92.2)	88 (7.8)	0.9 (0.6 to 1.4)
Powerful others (n = 1594)			
Low	1101 (91.8)	98 (8.2)	1.0
High	371 (93.9)	24 (6.1)	1.4 (0.9 to 2.2)
Chance (n = 1603)			
Low	460 (91.1)	45 (8.9)	1.0
High	1018 (92.7)	80 (7.3)	1.2 (0.9 to 1.8)
Current smoking status (n = 1658)			
Non-smoker	1296 (92.1)	112 (8.0)	1.0
Smoker	234 (93.6)	16 (6.4)	1.3 (0.7 to 2.2)
Frequency of alcohol intake‡ (n = 1628)			
Frequent	457 (93.8)	30 (6.2)	1.0
Occasional	696 (91.3)	66 (8.7)	0.7 (0.4 to 1.1)
Never	349 (92.1)	30 (7.9)	0.8 (0.5 to 1.3)
D: Social networks and support			
Marital status (n = 1589)			
Married/cohabiting	603 (92.1)	52 (7.9)	1.0
Widowed	549 (91.5)	51 (8.5)	0.9 (0.6 to 1.4)
Divorced/separated	143 (94.1)	9 (5.9)	1.4 (0.7 to 2.8)
Single	168 (92.3)	14 (7.7)	1.0 (0.6 to 1.9)
See relatives as much as would like (n = 1597)			
Yes	967 (93.0)	73 (7.0)	1.0
No	514 (92.3)	43 (7.7)	0.9 (0.6 to 1.4)
See friends as much as would like (n = 1590)			
Yes	1119 (92.2)	95 (7.8)	1.0
No	355 (94.4)	21 (5.6)	1.4 (0.9 to 2.3)
Have a confidante (n = 1650)			
Yes	1315 (92.6)	105 (7.4)	1.0
No	209 (90.9)	21 (9.1)	0.8 (0.5 to 1.3)
Loneliness (n = 1658)			
Never	808 (92.6)	65 (7.5)	1.0
Sometimes	597 (92.7)	47 (7.3)	1.0 (0.7 to 1.5)
All the time/often	131 (92.9)	10 (7.1)	1.1 (0.5 to 2.1)
E: Socioeconomic factors:			
Own home (n = 1460)			
No	469 (91.4)	44 (8.6)	1.0
Yes	874 (92.3)	73 (7.7)	1.1 (0.8 to 1.7)
Car availability (n = 1520)			
No	677 (89.7)	78 (10.3)	1.0
Yes	719 (94.0)	46 (6.0)	1.8 (1.2 to 2.6)

Table 1 Continued

Variables*	Consent given N = 1565 n (%)	Consent not given N = 139 n (%)	Odds ratio for consent given (95% CI)
Social class (n = 1456)			
Manual	523 (93.1)	39 (6.9)	1.0
Non-manual	835 (93.4)	59 (6.6)	1.1 (0.7 to 1.6)
Occupational pension (n = 1536)			
No	538 (91.5)	50 (8.5)	1.0
Yes	890 (93.9)	58 (6.1)	1.4 (1.0 to 2.1)
Private health insurance (n = 1647)			
No	1343 (91.9)	119 (8.1)	1.0
Yes	176 (95.1)	9 (4.9)	1.7 (0.9 to 3.5)
Household income§ (n = 479)			
<£120 pw	179 (95.7)	8 (4.3)	1.0
£120pw	288 (98.6)	4 (1.4)	3.2 (1.0 to 10.8)

*All questionnaire measures are fully referenced in our previous paper.[6] †There were a small number of people from ethnic groups other than white, so these have been grouped together. ‡Alcohol use: frequent = daily use; occasional = weekly or monthly use; never = not at all. §Household income used for practice 1 only, question removed because of negative comments and missing values.[6]

CONTRIBUTORS

TH, DC, and CV were all involved in designing the study and with data analysis (TH and DC) and interpretation (TH, DC, CV). CB was involved in the collection, processing, and analysis of data. SDW advised and supervised downloading of data from the practice computer systems and was involved in interpretation of data. IC was involved in processing data from the computer system and with data analysis and interpretation. All authors were involved in drafting the paper and in approving the final version of the paper. TH will act as guarantor for the paper.

The questionnaire used in the study is available on the journal web site (http://www.jech.com/supplemental).

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