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Large panel-survey data demonstrated country-level and ethnic minority variation in consent for health record linkage

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Abstract

Objectives: To investigate individual, household, and country variation in consent to health record linkage.

Study Design and Setting: Data from 50,994 individuals aged 16−74 years recruited to wave 1 of a large UK general purpose household survey (January 2009−December 2010) were analyzed using multilevel logistic regression models.

Results: Overall, 70.7% of respondents consented to record linkage. Younger age, marriage, tenure, car ownership, and education were all significantly associated with consent, although there was little deviation from 70% in subgroups defined by these variables. There were small increases in consent rates in individuals with poor health when defined by self-reported long-term limiting illness [adjusted odds ratio (OR) = 1.11; 95% confidence intervals (CIs): 1.06, 1.16], less so when defined by General Health Questionnaire score (adjusted OR = 1.05; 95% CIs: 1.00, 1.10), but the range in absolute consent rates between categories was generally less than 10%. Larger differences were observed for those of nonwhite ethnicity who were 38% less likely to consent (adjusted OR = 0.62; 95% CIs: 0.59, 0.66). Consent was higher in Scotland than England (adjusted OR = 1.17; 95% CIs: 1.06, 1.29) but lower in Northern Ireland (adjusted OR = 0.56; 95% CIs: 0.50, 0.63).

Conclusion: The modest overall level of systematic bias in consent to record linkage provides reassurance for record linkage potential in general purpose household surveys. However, the low consent rates among nonwhite ethnic minority survey respondents will further compound their low survey participation rates. The reason for the country-level variation requires further study.

Keywords: Informed consent; Health record linkage; Selection bias; Survey; Country-level variation; Ethnic minority variation

1. Introduction

Cross-sectional studies provide a snapshot of the characteristics of society at a point in time and are an efficient way to determine the prevalence, changing prevalence and social patterning of disease and associated risk factors in the population [1−3]. Repeated cross-sectional demographic and health surveys, using standardized data collection procedures across populations and consistent content over time, have been used to support evidence-based policy development and in the planning and monitoring of health and development programs in low- and middle-income countries [4]. A combination of interviews and health examinations can also be used to investigate the prevalence of diagnosed and undiagnosed disease in the population [5,6].

Survey data can be further enhanced by linking to routine administrative data to create a longitudinal cohort, and as these routine administrative data are collected for other purposes, this is an extremely efficient process with no additional burden to cohort members. Within the United Kingdom, both the Health Survey for England [7] and the Scottish Health Survey [8] provide good examples of what can be achieved. For example, data from the Health Survey for England have been used to determine the role of elevated inflammatory markers in the higher rates of cardiovascular mortality among passive smokers [9] and the influence of low levels of physical activity on coronary heart disease risk among UK-born South Asians [10]. More recently, analysis of pooled data from 11 independent Health Surveys for England (from 1994 to 2004) has demonstrated that even modest elevations in psychological distress were associated with subsequent all-cause mortality and mortality from cardiovascular disease and external causes [11]. In Scotland, health survey data linked with

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What is new?

Key findings

- This large general purpose household survey showed little evidence of systematic variation in consent to link health records across most demographic and socioeconomic factors.
- Consent to linkage was lower in nonwhite ethnic groups which will further compound the generally lower participation rates in these groups.
- Marked variation between countries was evident despite the standardized survey methodology.

What is the implication and what should change now?

- The need to maximize survey response rates is emphasized, and there may be a need to further enhance the already boosted ethnic minority sample.
- Further research is needed to understand and learn from the variations in levels of consent between nations.

hospital data have been used to determine the social and lifestyle factors related to risk of psychiatric admission [12] and the transgenerational relationship between birthweight and maternal cardiovascular risk [13].

However, in the United Kingdom, informed consent from the survey respondent is a prerequisite for subsequent record linkage; therefore, any ensuing variation in consent rates may introduce a selection bias that could affect the external validity of the study findings and accentuate or confound any participation bias in the original survey. Participation bias has been reasonably well characterized, and studies have demonstrated that respondents participating in surveys are more likely to be female [14]; be of higher socioeconomic status and employed [15–17]; and to be educated [18] and married [15,18]. Some authors have found higher participation in older age groups, whereas others did not (see Galea and Tracy [19] for review). The findings for ethnicity are also unclear, with some reporting higher response rates in whites and others reporting similar response rates across all ethnic groups [18,20]. Furthermore, studies have shown that responders in general are also likely to have better health [21–24] and to have more healthy lifestyles [25,26]. However, the salience of the survey is also important as people are more likely to respond when the focus of the survey has particular relevance to them, except where the condition is perceived as being stigmatizing [27].

Although some studies have examined predictors of consent to record linkage, they are far fewer than those focused on survey response, and with a few exceptions [14,28], they are either among smaller, nonrepresentative samples or among samples that are larger but survey specific (e.g., a female only sample). Factors associated with consent appear to be similar to those associated with survey response, but there are inconsistencies. For example, some studies show a gradient of increased likelihood of consent with increasing age [29,30], whereas others found that older respondents are less likely to consent [14,31]. Higher socioeconomic position (i.e., socioeconomic status, educational level, car ownership, having private health insurance) is generally associated with higher rates of consent to record linkage [32,33]. However, in a large, nationally representative general survey, Knies et al. [28] found no effects for income. There is also evidence that those with health problems and higher levels of primary health care utilization have higher rates of consent [14,28,30,33]. Given the paucity of studies using large population-based samples, the limited numbers of factors considered within studies, and evidence of inconsistencies in the findings, there is a rationale for further research in this area.

Therefore, the aim of the present study was to examine sociodemographic and health factors associated with not consenting to record linkage among respondents to a representative general population survey and to compare these to the factors known to be related to survey response. Of particular interest is additional variation in consent rates between countries in the United Kingdom. Published and unpublished data from health surveys have demonstrated that although the consent rates for record linkage have remained high at approximately 90% in Scotland [8], the rates in England have declined from 96% in 1994 to 78% in 2009 (for linkage to cancer and death data) [7], and only 64% of respondents to the equivalent survey in Northern Ireland in 2005–06 consented to record linkage. However, such differences may have arisen due to variation in survey design, the wording or the location of the consent question within the questionnaire, or the general context of the survey. The present study uses one of the world's largest longitudinal household surveys, the Understanding Society survey, for which data are collected during an annual interview. Respondents are asked for their consent to linkage of their survey responses to administrative data related to health, education, economic circumstances, and transport. The advantage of Understanding Society, in addition to its large size, is the use of a standardized methodology across the four countries of the United Kingdom.

2. Method

2.1. Data source

The data for this analysis were collected during wave 1 of the main-stage Understanding Society survey, which was carried out over 24 months between January 2009 and December 2010 [34]. This comprised a general population