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J Med Ethics 2011 37: 50-55 originally published online November 11, 2010
doi: 10.1136/jme.2010.037903

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Public attitudes to the use in research of personal health information from general practitioners' records: a survey of the Irish general public

Brian S Buckley,^{1,2} Andrew W Murphy,¹ Anne E MacFarlane¹

¹Department of General Practice, National University of Ireland, Galway, Ireland

²School of Medicine and Dentistry at the University of Aberdeen, Aberdeen, UK

Correspondence to

B S Buckley, Department of General Practice, Clinical Sciences Institute, National University of Ireland, Galway, Ireland; bsbuckley@iol.ie

Received 18 May 2010

Revised 14 August 2010

Accepted 2 September 2010

Published Online First

11 November 2010

ABSTRACT

Introduction Understanding the views of the public is essential if generally acceptable policies are to be devised that balance research access to general practice patient records with protection of patients' privacy. However, few large studies have been conducted about public attitudes to research access to personal health information.

Methods A mixed methods study was performed. Informed by focus groups and literature review, a questionnaire was designed which assessed attitudes to research access to personal health information and factors that influence these. A postal survey was conducted of an electoral roll-based sample of the adult population of Ireland.

Results Completed questionnaires were returned by 1575 (40.6%). Among the respondents, 67.5% were unwilling to allow GPs to decide when researchers could access identifiable personal health information. However, 89.5% said they would agree to ongoing consent arrangements, allowing the sharing by GPs of anonymous personal health information with researchers without the need for consent on a study-by-study basis. Increasing age (by each 10-year increment), being retired and primary level education only were significantly associated with an increased likelihood of agreeing that any personal health information could be shared on an ongoing basis: OR 1.39 (95% CI 1.18 to 1.63), 2.00 (95% CI 1.22 to 3.29) and 3.91 (95% CI 1.95 to 7.85), respectively.

Conclusions Although survey data can be prone to response biases, this study suggests that prior consent agreements allowing the supply by GPs of anonymous personal health information to researchers may be widely supported, and that populations willing to opt in to such arrangements may be sufficiently representative to facilitate valid and robust consent-dependent observational research.

BACKGROUND

The value to research of personal information in medical records has long been accepted. The records maintained in general practice are of particular value, containing data spanning lifetimes relating to morbidity and process of care. However, while the research benefits offered by patients' data are clear, in recent decades there has been a growing recognition of patients' rights to privacy and confidentiality. Concerns over inappropriate use of personal data of all kinds have led to new laws nationally and internationally, so that the rights of the public to privacy and confidentiality are more clearly defined and robustly protected than ever. These legal developments, combined with growing

ethical constraints within healthcare, increasingly restrict access to patients' personal information for research. Generally, data can be accessed only if prior informed patient consent is secured or if data are anonymised so that there is no reasonable way of identifying the patients involved.^{1 2}

Concerns have been expressed that, while respect for patient privacy and confidentiality must be maintained, there is a danger that constraints may become too strict; that, in order to prevent limited and possibly theoretical harm to individuals, work may be prevented which offers very large benefits to society.^{3–5} Research has identified significant differences in outcomes between consenters and non-consenters to data collection from medical records. The implication of this 'consent bias' is that, if entirely reliant on consent, observational epidemiology and health services research may become so seriously affected by selection bias that it is no longer valid.^{3 6 7}

If policies are to be devised that strike a balance between facilitating important research while protecting peoples' right to privacy, the views of the public on such matters must be understood. Yet few large studies among representative samples of national populations have been conducted, so it is difficult to draw robust conclusions about approaches to confidentiality and consent that may be generally acceptable. Research suggests considerable support for publicly funded healthcare research,^{1 8–10} but also a generally poor level of understanding of what information is recorded in medical records, how it is used in research processes and the difference between 'confidential' and 'anonymous' data.^{1 9–16} Attitudes to the use of personal information in research are affected by the nature of the information itself, what it will be used for and who might see it. Some feel more protective towards information of a 'sensitive' nature, relating to topics such as mental or sexual health, alcohol or substance use, abuse, adoption and abortion.^{1 10 11 15 17–19} University researchers are reportedly regarded more positively than pharmaceutical industry researchers.^{9 10 16 19} Concerns exist about employers, schools or insurance companies seeking access to personal health information.^{11 15 16 20 21}

This study explores attitudes among a large sample of the Irish public towards the use of general practice medical record data for research.

METHODS

This was a mixed methods study consisting of qualitative and quantitative work. In the qualitative

phase, focus groups were conducted using age (18–35, 36–55 and 56–70 years) and gender as sampling parameters. Participants were recruited through general practices, a method which had been used successfully in previous research in this area, and procedures designed for selecting and approaching patients which ensured practices were unaware of which patients participated.¹⁰ A topic guide was used to explore public *knowledge* of the content of general practice medical records; public *attitudes* relating to the use of general practice medical records in research and service delivery; and *contexts, factors* and *strategies* which affect these attitudes. This work will be reported separately. The key themes that emerged and informed the development of the questionnaire are summarised in box 1.

In the quantitative phase a survey was conducted of a large national sample of the Irish public. Informed by the themes emerging from the focus groups and by a review of the literature, a questionnaire was designed which sought data relating to awareness of the content of medical records, attitudes to access to personal information by researchers and factors that influence both of these. Evidence suggested that levels of understanding of many of the issues and terms associated with the research were poor, so the questionnaire was developed carefully to ensure that it was clear, concise and accessible. The questionnaire employed vignettes to clearly explain different types of data and consent procedures. It was piloted among the patients of a practice that was not involved in the research.

The names and addresses of a nationally representative sample of 4000 members of the Irish public (in terms of gender, age and region) were requested through a subsidiary of the Irish post office that designs and supplies such databases. The questionnaires were posted along with an explanatory leaflet and a prepaid envelope for anonymous return. In addition to data about knowledge of records content and attitudes to data use, the questionnaires collected information on age, gender, employment status, socioeconomic status, rural or urban habitation and 'healthcare contact' (ie, previous or current employment in healthcare or recent household experience of ill health or disability). Socioeconomic status was determined according to eligibility for free General Medical Services (GMS) within the Irish health system; at the time of the study approximately

one-third of the Irish population was GMS-eligible, representing the least affluent members of society.

Statistical analysis

χ^2 tests were used to analyse the distribution of preferences relating to the use of personal information in subgroups defined by demographic variables. For further consideration of factors associated with preferences, responses to some questions were converted to dichotomous data and logistic regression was used to examine associations between preferences and demographic, socioeconomic or healthcare contact variables. A significance threshold of $p=0.01$ was adopted in all analyses to compensate for unrecorded confounders that are more likely to exist in observational research.²¹ The analysis was conducted using SPSS Version 16.0.

Sample size calculation

In Baker's study, 61% gave consent for the collection of anonymous data from their general practice records.²² Hoeyer reported 62% general consent by Scandinavian patients to access to personal health records.²³ Accepting that 60% of our sample may have similar consent preferences suggests that, for a total of 1000 responses, the 95% confidence limits will be 56.9% and 63.1% (StataCorp Release 9, 2005); these appear acceptable. With a lowest estimated response rate of 30% cited as typical for a non-targeted general public postal survey by the dataset provider, a total sampling frame of 3333 was determined.

RESULTS

The questionnaire was sent to 4000 adult recipients (1388 men, 2612 women), nationally representative in terms of age bands, socioeconomic status and region. The imbalance in the numbers of men and women in the recipient list resulted from an error by the national semi-state organisation that supplied the dataset but, as no association was found between sex and consent preferences, the error is believed not to have undermined the research significantly. Questionnaires were returned undelivered by the national postal system in 117 cases. The total delivered was therefore 3883. Completed questionnaires were returned by 1575 (40.6%); 434 of 1388 men (31.3%), 1127 of 2612 women (43.1%) and 14 were returned with gender not indicated. The demographic data for responders are reported in table 1. Compared with the national adult population, respondents were more likely to be female, retired and have received third level education.

Attitudes to sharing personal data for research

The questionnaire described scenarios that illustrated different approaches to the sharing of personal information for health research purposes. Table 2 shows the answers received from the total responding sample. Only one significant association between sex and responses to the questionnaire items was found using χ^2 tests: 86.6% of men compared with 92.2% of women said they trusted their GP to store their personal information confidentially and securely ($p<0.01$).

Prior consent for ongoing sharing of data for research

The questionnaire described a scenario in which the respondent's GP is asked to provide patients' personal information to researchers at a university on an ongoing basis. Rather than having to ask patients every time, it is proposed that patients should indicate in advance what their consent preference would be. The patients are given three levels of prior consent to choose from, adapted from the Medical Research Council's General Public Consultation Final Report.¹² These three 'consent levels'

Box 1 Key themes from focus groups

- ▶ Participants were positive about the use of names and addresses in GP records to make contact with patients in order to invite them to participate in research.
- ▶ In general, participants were positive about the idea of anonymised data from GP records being used for research purposes, with a strong feeling that the outcomes of such research can be for the 'greater good'. These altruistic tendencies were more evident in the female groups.
- ▶ Concerns around data security, mentioned in all groups, were stronger in the male groups. The female groups expressed more concern about information becoming known at a local level while men were more concerned with the potential impact on employment and insurance.
- ▶ When the use of identifiable data was discussed, all groups were again positive in general about research being carried out but felt strongly that individuals whose information is being used should be asked for permission or at the very least told that this is happening. Sensitive and personal issues were raised to a greater extent within this scenario.

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Table 1 Demographic data for survey responders

	n	% Of total responders	% Of national population aged >18 years*
Total	1575	100	
Gender			
Male	434	27.6	49.4
Female	1127	71.6	50.6
Not reported	14	0.9	
Age			
18–25	12	0.8	17.5
26–35	100	6.3	23.4
36–45	285	18.1	20.2
46–55	415	26.3	16.9
56–65	311	19.7	13.2
66–75	315	20.0	8.5
75–85	131	8.3	5.1
85+	0	0.0	0.2
Not reported	6	0.4	
Employment status			
Employed	804	51.0	62.6
Homemaker	202	12.8	15.8
Unemployed	54	3.4	4.6
Retired	391	24.8	8.5
Unable to work (sickness/disability)	106	6.7	Unknown
Current GMS eligible	563	35.7	32.7
Ever GMS eligible	375	23.8	
Ever worked in healthcare	348	22.1	
Education completed			
No formal education	3	2	16.7
Primary education only	58	3.7	
Secondary education	801	50.9	44.6
Third level education	699	44.4	26.9
Not reported	14	0.9	
Habitation			
City	493	31.3	
Town	495	31.4	
Rural	574	36.4	
Illness or disability in household in last 3 years			
Physical	724	46.0	
Mental/emotional	396	25.1	

*2006 census, Central Statistics Office (accessed 11 December 2009).²⁴

are presented in table 3. Significant associations between demographic variables and prior consent preference levels were examined with χ^2 tests; the results are shown in table 4.

With responses converted to dichotomous data, logistic regression was used to consider the association of demographic variables with prior consent preferences for ongoing provision of data to researchers while controlling for age, sex, employment, education and GMS status, experience of work in healthcare, rural or urban location and whether the household had recently been affected by physical or emotional ill health or disability. Increase in age by each 10-year increment was significantly associated with an increased likelihood of responding that 'any information can be provided' rather than any other answer (OR 1.39, 95% CI 1.18 to 1.63; $p<0.01$). Compared with completion of third level education, completion of only primary education was significantly associated with an increased likelihood of responding that 'any information can be provided' rather than any other answer (OR 3.91, 95% CI 1.95 to 7.85; $p<0.01$). Compared with being employed, being retired was significantly associated with an increased likelihood of responding 'any information can be provided without asking me' (OR 2.00, 95% CI 1.22 to 3.29; $p<0.01$).

Table 2 Responses to vignette-based questions relating to access to personal information

	Yes % (n)	Not sure % (n)	No % (n)
Use of GP database to contact patients about research			
Would it be OK for your GP to provide researchers with a disease-specific list of patients that includes your name and address?	68.7 (1082)	9.3 (146)	20.7 (326)
Anonymous data			
Would you be willing to let your GP decide when to provide <i>anonymous</i> information to researchers without informing you?	83.7 (1318)	3.7 (59)	12.1 (190)
Would you prefer to be asked, even if the time and expense needed to ask all patients meant that less health research could be done?	20.1 (317)	6.3 (99)	71.5 (1126)
Identifiable data			
Would you be willing to let your GP decide when to provide <i>identifiable</i> information from your records to researchers without informing you?	38.7 (609)	14.0 (221)	45.5 (716)
Would you like to be asked before <i>identifiable</i> information is provided to anyone else outside the practice?	71.9 (1133)	4.4 (69)	22.3 (351)
Allowing researchers to see records			
Would you be willing to let your GP decide whether researchers can see your records without informing you?	36.1 (568)	12.8 (201)	50.3 (792)
Would you be happier if the researchers are themselves trained doctors and nurses?	60.3 (950)	11.6 (183)	26.9 (423)
Data security in GP practices			
Do you trust your GP to store your personal information confidentially and securely?	90.5 (1425)	7.4 (117)	2.0 (32)
In your experience, are practice staff always careful to prevent information about patients from being seen or heard by other patients?	62.6 (986)	19.9 (314)	17.2 (271)

Knowledge of content of medical records

Respondents were asked what information they believed would be regularly included in records kept by GPs and were provided with a list of items that they could tick. There are no detailed and mandatory guidelines on precisely what information is recorded, but general guidance indicates the sort of information that should be recorded.^{20–25} The list on which respondents could indicate the information that they believed is regularly recorded included items recommended in such guidance, some which may be recorded because they have a bearing on certain conditions and items that are unlikely to be recorded. Responses indicated that levels of understanding of the information recorded by GPs were high and levels of misguided beliefs about recording were low.

DISCUSSION

Summary of key findings

A large majority of this national sample was willing to opt in to an ongoing consent arrangement that would allow their GP to

Table 3 'Consent levels' for prior consent for ongoing provision of personal medical data by GPs to researchers

Red*	No information at all can be provided to researchers without asking me
Amber*	Anonymous information can be provided but GP must ask me before identifiable information can be provided
Green*	Any information can be provided without asking me

*Colour codes adapted from MRC General Public Consultation Final Report.¹²

Table 4 Preferences relating to prior consent requirements for GPs to provide data to researchers on an ongoing basis by demographic variables: % of variable (n)

	Red	Amber	Green	χ^2 ; df; p value
Total sample	10.2 (161)	67.5 (1063)	22.0 (347)	—
Males	8.5	67.9	23.6	2.2; 2; 0.33
Females	10.9	67.6	21.5	
18–25	8.3	83.3	8.3	1.9; 12; <0.01
26–35	13.3	77.6	9.2	
36–45	19.1	70.0	11.0	
46–55	12.8	76.1	11.1	
56–65	5.8	69.1	25.1	
66–75	4.8	56.2	39.0	
76–85	3.1	51.9	45.0	
Employed	10.5	76.2	13.4	1.42; 8; <0.01
Homemaker	13.4	72.6	13.9	
Unemployed	18.5	61.1	20.4	
Retired	5.6	52.9	41.4	
Unable to work (illness or disability)	15.1	59.4	25.5	
GMS currently or ever (<65 years old)	15.1	67.2	17.7	8.6; 2; 0.013
No HMS currently or ever (<65 yrs old)	11.1	76.4	12.5	
Primary education only	15.5	34.5	50.0	4.5; 6; <0.01
Secondary education	8.6	67.8	23.5	
Third level education	11.6	70.4	17.9	
City	12.2	67.1	20.7	5.6; 4; 0.23
Town	10.7	66.4	22.9	
Rural	8.1	69.2	22.8	
Physical illness or disability in household in previous 3 years				
Yes	10.8	67.3	22.0	4.1; 2; 0.81
No	9.8	68.0	22.2	
Mental or emotional illness or disability				
Yes	11.1	63.8	25.1	3.8; 2; 0.15
No	9.9	69.0	21.1	

df, degrees of freedom; HMS, General Medical Services.

share anonymous data with researchers without the need to ask for consent on a study-by-study basis. On the other hand, a large majority said they would prefer to be asked before identifiable information was passed on at any time. Only one-third was willing to let GPs decide when to allow researchers to see their medical records.

Study strengths and limitations

This study has benefited from the use of mixed methods. A difficulty that has hampered much research in this field has been how best to clarify and define, for the general public, some of the complex concepts and terms involved such as ‘identifiable data’ and ‘anonymisation’.¹² Focus group work in this study has helped in the development of methods for describing these issues in an accessible way in the survey questionnaire. The study has limitations that must be acknowledged. Despite efforts to explain complex and unfamiliar concepts as described, it is impossible to be sure to what extent respondents in a paper-based survey such as this fully understand the issues. In-depth interviewing with explanations may yield different responses. It was clearly regrettable that the state agency that supplied the sample failed to stratify for sex correctly, which resulted in men being under-represented. However, no association was found between sex and preferences relating to prior consent requirements for GPs to provide data to researchers so the failure is believed not to have undermined the research significantly. The response rate is low compared with many postal surveys published in the medical

literature: however, many such studies are targeted at specific groups with known prior interest in or association with the survey topic, whereas this was a mail survey of the general public. In addition, the topic is one that is recognised in the literature as being hard to grasp and about which much of the public does not feel knowledgeable.^{1 12 19 26 27} In other quantitative studies that have considered this area, the response rate has been varied with the true response rate in a survey of clinic attendees ‘unknown’;¹⁹ the rate of attendance at discussion groups 5.3%,⁹ response to an online/telephone survey comparing people with stigmatised conditions with the general public 22.6%²⁸ and in a Canadian telephone survey 58%.²⁷ The youngest age groups were under-represented in both the qualitative and quantitative phases of the study. The study is limited to the Irish general public only, and findings may not be generalisable easily to other countries, regions or health systems. The respondents appear to be reasonably representative in terms of the factors measured and efforts were made to record and control for previous exposure to ill health and healthcare, a known influence on attitudes to data use. However, it is possible that residual confounding by unmeasured factors has influenced the results. Also, as with all observational research, it is possible that some of the findings have occurred by chance, although a robust significance level has been adopted to compensate for this effect.

Attitudes to allowing researchers access to personal medical information

There have been ongoing debates about how best to ensure that observational and epidemiological research retains its potential to support effective and equitable healthcare and improve public health, while respecting individuals’ rights to privacy. Discussions have included models in which patients could agree a level of ongoing consent for the use of their personal information by researchers as a way of affording individual self-determination without the onerous requirement for prior written consent on an individual study-by-study basis that threatens to undermine such research.^{27 29} The ‘traffic light’ system of three ‘consent levels’ that were presented as options to the respondents in this study were adapted from the MRC’s public consultation where they were discussed as a way of allowing patients the opportunity to have their consent preferences recorded periodically and included as part of their medical records.¹²

Two-thirds of respondents (67.5%) said they would agree with the ‘amber’ option that would allow GPs to pass on anonymous information but require them to ask for consent to pass on identifiable data. A further 22.0% said they would agree to the ‘green’ option that any data could be passed on without GPs having to ask for consent each time. Thus, 89.5% of a large and comparatively representative national sample would agree to an ongoing consent arrangement that would allow for the sharing of anonymous data with researchers without the need to be asked for consent on a study-by-study basis. This is generally in line with the 83.7% positive response to the similar separate question, “Would you be willing to let your GP decide when to provide *anonymous information* to researchers without informing you?” and suggests some face validity. Logistic regression identified an association between increasing age and a greater willingness to allow any data to be passed on by GPs on an ongoing basis, and older age groups were over-represented among respondents in the survey. However, even among the most reluctant age group (those aged 36–45 years), more than 80% were willing to allow ongoing sharing of at least anonymous data with researchers.

Respondents were asked about the ‘traffic light’ system only after they had answered a series of preliminary scenario-led

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questions that introduced issues relating to different types of data and approaches to data sharing. A sizeable majority of respondents (68.7%) felt that they would be happy for GPs to supply their name and address to researchers so that they could be sent a research study questionnaire based on the fact that they had a specific condition. This is in line with other research that suggests that the use of disease registers to enable researchers to identify and contact potential participants is acceptable. That the proportion of respondents who find this use of records to be acceptable is smaller than the 87% who considered that the National Cancer Registry could use its records for this purpose may reflect differences in the perceived relative importance of research into cancer and research into asthma, which was the condition used in the scenario in the current study.⁸ The findings in this survey are in line with other research that has found that very few were concerned about allowing the use of anonymised data or felt that consent should be sought for the use of such data.^{10 12 15} A minority (38.7%) said that they would be happy for GPs to decide when to pass on personal health information from which they could be identified, while 45.5% said that they would not be willing for this to happen. A considerable majority of 71.9% said they would prefer to be asked before such information was passed on, while 22.3% said they would not prefer to be asked. Again, this is in line with previous research that has stressed the importance to the public of the two key pillars of maintenance of confidentiality and consent for access to personal information.^{12 15 19} The high degree of trust in GPs to store personal information confidentially and securely and the greater willingness to allow trained clinicians to see their medical records as part of a research process also echoes previous research findings about who the public trusts most.¹² Nevertheless, only 36.1% of respondents said they would be happy for GPs to decide whether researchers can see their records without being informed.

High levels of support were reported for the sharing by GPs of anonymous data and of trust in GPs keeping personal health information confidentially and securely. Combined with low levels of support for allowing researchers access to records without consent, this may suggest that extraction and sharing of anonymous datasets from electronic patient records would be widely acceptable.

The lack of engagement with the study by people in the youngest age groups is striking. Those who did respond displayed more caution about the use of their medical data than the older respondents, but the lack of response makes it difficult to assess whether only those concerned about data use responded or whether these responses are representative of the views of younger people. Previous research has suggested that young adults are more worried than others about allowing others to see their personal information.³⁰

Several demographic factors appear to influence the degree of control people want to be able to exercise over whether or not their personal medical data are used in research. Univariate analysis revealed significant associations between age, employment status and education and consent preferences. The age-related trend was particularly marked. Compared with other age groups, only small numbers of those aged 18–25 years and 26–35 years responded to the survey, but a large majority of these groups opted for the middle level of consent while few said any data could be shared. This can be compared with only just more than half of those aged 66–75 years and 76–85 years opting for the middle level, with 39.0% and 45.0% respectively allowing any data to be shared. This age-related trend was confirmed by multivariate analysis that controlled for other factors. That this trend has been detected so clearly is of interest

and may relate to generational differences in general. It seems likely that the trend also relates to a perception, highlighted in the focus groups, that employment security is an important area of potential risk presented by the sharing of personal health information. This is supported by the significant association of retirement with an increased likelihood of selecting the consent option that would allow any information to be shared without the GP asking the patient.

Conclusions

Despite trends that might be detected in public opinion, it must be acknowledged that opinions vary widely and are influenced by various factors so that it may be difficult to identify consent protocols that will be acceptable to all. It seems that the healthcare and research communities must remain cautious when designing protocols for accessing patient records.

However, in this study, large majorities supported the use of anonymous data without the need for consent and indicated that they would be willing to opt in to ongoing consent arrangement that would allow GPs to pass anonymous data to researchers without the need to seek consent every time. Over 90% trust their GPs to keep their personal health information confidentially and securely. It therefore seems likely that secure extraction of anonymous patient data for research use may be widely supported by the public.

Regression analysis controlling for other factors identified age and retirement as being associated with particular consent preferences. However, no complex pattern of multiple associations between consent preferences and other demographic factors was detected, and this may suggest that populations willing to give consent for ongoing sharing of personal health information by GPs with university researchers will be sufficiently representative to facilitate valid and robust consent-dependent observational research.

What is already known on this subject

Concerns have been expressed that constraints on research access to patient data may become too strict, affecting the feasibility and validity of observational research. Studies have suggested that, while many people are supportive of the use of their records in research, many are also concerned about inappropriate data use or leaks. Studies have also suggested there is a generally poor level of understanding of what information is recorded in medical records and how it is used in research processes.

What does this study add

Patient views are diverse and researchers must remain cautious in developing protocols for accessing patient data. However, a large majority in this study supported the use of anonymous data without the need for consent and were willing to opt in to ongoing consent arrangement that would allow GPs to pass anonymous data to researchers without the need to seek consent every time. Populations willing to give consent for ongoing sharing of personal health information by GPs with university researchers may be sufficiently representative to facilitate valid and robust consent-dependent observational research.

Acknowledgements Thanks are due to Pauline Clerkin, qualitative researcher; to Dr Mike Robling and Dr Kerry Hood of Cardiff University; and to the staff and patients of the health centres that took part in the research.

Funding The study was funded by the Health Research Board of Ireland (Project Grant RP/2006/42).

Competing interests None.

Ethics approval This study was conducted with the approval of the research ethics committee of the Irish College of General Practitioners.

Contributors BSB, AWM and AMaC contributed to the design of the study and to the writing of the paper. BSB conducted the analysis, led the writing of the paper and was Principal Investigator on the study.

Provenance and peer review Not commissioned; externally peer reviewed.

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