Public Opinions about Participating in Health Research

Kay Teschke, PhD,[1] Suhail Marino, BA,[1] Rong Chu, MSc,[2] Joseph K.C. Tsui, MD,[3] M. Anne Harris, MSc,[1] Stephen A. Marion, MD, MS, MHSc[1]

ABSTRACT

Objectives: Privacy legislation has limited options for recruiting subjects to health studies. Policy changes are motivated by assumptions about public attitudes towards participation, yet surveys of attitudes have rarely been done. We investigated public willingness to participate in health research and how willingness was affected by various factors.

Methods: A survey of adults randomly selected from the telephone directory was conducted in British Columbia, Canada. Mailed self-administered questionnaires asked about willingness to participate in health research and the influence on willingness of the method of subject selection, the organization making the contact, and other factors.

Results: There were 1,477 respondents (58% of eligible); 85% were willing to participate in health research at least sometimes. The organization making the contact influenced comfort about participation: 10% of respondents felt uncomfortable if contacted by a university, 12% if by a hospital, 26% if by government, and 55% if by private research firms. Factors most positively influencing choice to participate were future health benefits to society (87%) and oneself (87%), and receiving a copy of the study results (81%).

Conclusions: Participation in health research appears to be viewed favourably by members of the public, and participation may be highest when university or hospital-based researchers are able to contact subjects directly using information from government databases.

Key words: Epidemiology; ethics; participation

La traduction du résumé se trouve à la fin de l'article.

Can J Public Health 2010;101(2):159-64.

Over the last 20 years in Canada and elsewhere, the climate for research examining disease etiology has changed. Administrative databases have made it easier to identify individuals with diseases beyond those with research registries (typically cancer), opening the possibility of population-based study designs. However, this opportunity has raised concerns about releasing records to researchers for whom the data were not originally collected. In the late 1990s, some jurisdictions enacted legislation and ethics review boards implemented policies that restricted release of personal identifying information to enable subject contact. However, much etiological research requires subject contact to elicit details about lifestyle, occupations, residences, and other information not routinely recorded in administrative databases.

Academic and legal interest in the impact of research on subject privacy and, more recently, of privacy legislation on research, has resulted in ethics policies and policy commentaries by researchers, lawyers, and government agents.[1-11] A surprising aspect of the work to date is that little attention has been given to the opinions of those whose privacy is being protected, i.e., what do members of the public think? Some opinion research has examined the issue of consent prior to analyses of administrative data stripped of identifiers.[12-18] Surveys examining the public's desire to actively participate in research and the method of selection and contact are rare.[19-21]

To better understand public opinions, we conducted a survey of the willingness of British Columbia adults to participate in health research and how willingness was affected by the methods of selection, contact, and other factors.

METHODS

Households in the Vancouver region as far as Hope and Squamish, and on Vancouver Island except Victoria (identified using postal codes and representing about half the provincial population, including a wide range of community and socio-economic circumstances) were selected via simple random sampling from the residential listings of the Canpages directory. This method was chosen because it is population-based (though it misses approximately 10% whose numbers are unlisted, who have no telephone, or who have only mobile service; personal communication, Telus, August 2006) and because listed telephone numbers are in the public domain and therefore constitute the only sampling frame from which researchers currently can directly contact a sample. Because residences, not individuals, were the sampling frame (one reason that administrative databases are preferred for population sam-

Author Affiliations

1. School of Population and Public Health, University of British Columbia, Vancouver, BC
2. Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, ON
3. Department of Neurology, University of British Columbia, Vancouver, BC

Correspondence: Kay Teschke, School of Population and Public Health, University of British Columbia, Vancouver, BC V6T 1Z3, Tel: 604-822-2041, Fax: 604-822-4994, E-mail: kay.teschke@ubc.ca

Acknowledgements: We appreciate the kind participation of all the study respondents. Hasina Jamal and Saleema Dhalla were the research assistants who conducted the mailings and telephone follow-up. Malcolm Maclure, British Columbia Ministry of Health, had the initial idea to question the subjects of our Parkinson's disease study about their willingness to participate in health research and the method of identification. This study was funded by the British Columbia Medical Services Foundation.

Conflict of Interest: None to declare.

© Canadian Public Health Association, 2010. All rights reserved.

Table 1. Participation in the Survey

	n	(%)
Households mailed surveys	3000	
Ineligible, name not at this address (% of mailed)	309	(10.3%)
Ineligible, unable to complete survey in English (% of mailed)	110	(3.7%)
Ineligible, deceased or too ill (% of mailed)	47	(1.6%)
Eligible (% of mailed)*	2534	(84.5%)
Refused† (% of eligible)	183	(7.2%)
No contact, eligibility & refusal status unknown (% of eligible)	874	(34.5%)
Surveys completed (% of eligible)	1477	(58.3%)

* This is a maximum estimate of the number eligible. It does not take into account those who may be ineligible but who were not contacted and whose eligibility status could not be identified.

† This is a minimum estimate of the number of refusals. It does not take into account those who were not contacted and whose non-response may have indicated refusal to participate.

pling), the covering letter asked that the adult with the next upcoming birthday respond. Respondents were restricted to those well enough to participate and able to read English.

The study was conducted from fall 2006 to spring 2007. The self-administered questionnaire was mailed, followed as necessary by two mailed and two telephone reminders. It was pretested on a convenience sample of 25 adults from a range of educational backgrounds. It included four questions, listed in full in the tables and figures that follow.

Data analyses included summary statistics and confidence limits (95%) for the proportions (p) willing to participate, calculated as $p \pm 1.96 * (p * (1 - p) / n)^{1/2}$, where n is the sample size. Logistic regression was done to examine the joint impact on willingness to participate (dichotomized as yes or sometimes vs. never or almost never) of the age and sex of the respondents, and mailing. Multiple linear regressions examined the influence of the same independent variables on the answers to each of the 23 factors queried in the other questions.

The study methods were reviewed and approved by the University of British Columbia Behavioural Research Ethics Board.

RESULTS

The 1,477 participants were 54% female and the average age was 54.0 years (SD=15.7, range: 19 to 97). The participation rate of 58.3% (Table 1) is a conservative estimate, since the number of eligible participants listed includes those who were not contacted. Their eligibility and refusal status is unknown.

Willingness to participate in health research

Most respondents (85.3%) were willing to participate in health research at least some of the time (Table 2). Figure 1 illustrates the proportions willing to participate, stratified by the mailing to which they responded. Willingness declined with the number of mailings; however, even among those who needed several reminders, over 70% were willing.

Women were somewhat more reluctant to participate than men (never or almost never willing: 15.4% vs. 12.3%, respectively). Those who responded "sometimes willing" were younger than those who gave more definite responses in either direction (mean age 51.0 years vs. always or most of the time willing, 54.9 years, and never or almost never willing, 58.9). In logistic regression, sex was not significant ($p>0.2$), but both mailout and age were ($p<0.0001$) (odds ratios for willingness to participate: first mailout = 3.6, second mailout = 2.0, compared to third mailout; ages 19-29 = 0.77, 30-39 = 7.4, 40-49 = 4.3, 50-59 = 4.4, 60-69 = 4.0, 70-79 = 4.9, 80-89 = 2.3, compared to 90-97).

Table 2. Answers to the Question, "Are You Willing to Participate in Health Research?"

	Percent Giving Each Response N=1435*	
	%	(95% CI)
Yes, always or most of the time	41.7%	(39.2-44.3)
Sometimes	43.6%	(41.0-46.2)
No, never or almost never	14.8%	(13.0-16.6)

* N is smaller than reported in Table 1, because some respondents did not answer this question.

Factors influencing willingness to participate

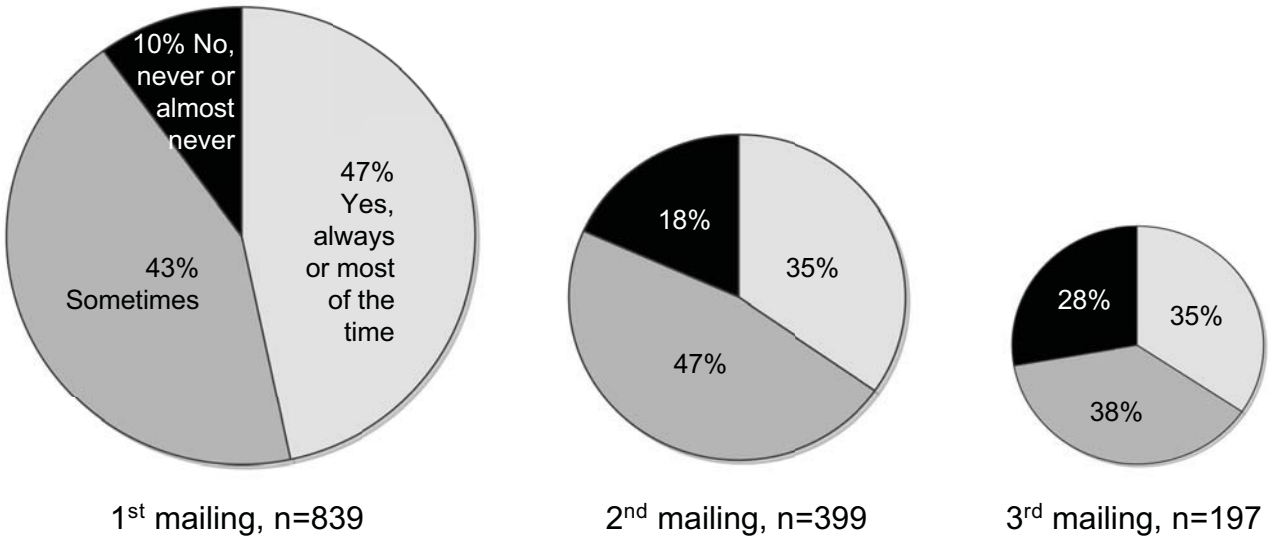
Figure 2 lists the five methods of selection queried. Respondents felt most comfortable being selected from a government list of the population, but the level of comfort for each of these methods was not high, and there was relatively little differentiation between methods. A method designed by the Ministry of Health to help maintain confidentiality of a patient's medical status (i.e., including in the sample both those selected as patients and those selected from the population as a whole so that no one knows which until they are contacted and agree to participate) did not help respondents feel more comfortable.

Figure 3 shows the question about organizations contacting subjects. Respondents felt most comfortable participating in research when contacted by universities or hospitals (68% and 65% comfortable, 10% and 12% uncomfortable, respectively). A higher proportion (26%) felt uncomfortable participating in research when contacted by governments alone, though this was tempered somewhat if universities or hospitals were their research partners. Most respondents (55%) felt uncomfortable participating in research when contacted by private research firms.

Figure 4 lists a series of other factors that might influence whether respondents felt better or worse about participating in health research. Respondents were most positively influenced by the potential to provide future health benefits to society or to themselves (87%). The next strongest positive influence was receiving a copy of study results (81%). Knowing how much time the study would take was a more positive influence than compensation for that time (77% vs. 55%, respectively). Information about the study was a positive influence for most respondents, though information about study funding and design were more important than information about method of selection (71% and 72% respectively, vs. 63%). Most respondents felt positively about their doctor deciding whether they should be contacted (60%), but this was not the case for the pharmacist making that decision (35%). Having intermediaries make the decision about contact was one of the most negative factors, with 15% and 29% feeling negative about their doctor or their pharmacist deciding, respectively. Ethics review by a university was a positive influence for most (65%), but privacy impact assessment by the government was not (46% positive influence, 13% negative). Ethics review and privacy impact assessment may not have been understood by respondents, since these questions had the largest proportions of missing responses (7.9% and 12.5%, respectively, vs. 4.2 to 6.9% for all other questions). Some respondents asked the meaning of a privacy impact assessment.

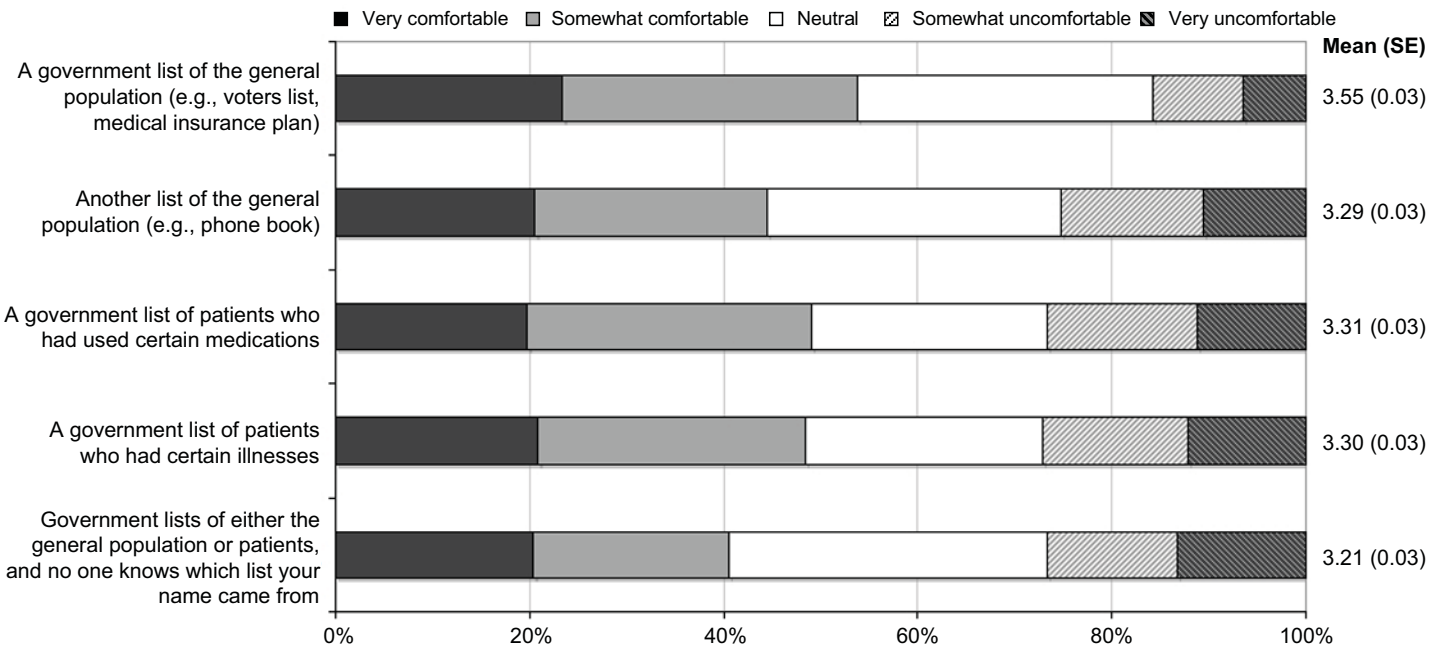
In multiple linear regressions to examine the influence of mailing, age and sex on the answers to each factor, the only variable that had a consistent association with mean scores was mailing, with those answering on the second or third mailing giving lower scores to all

Figure 1. Answers to the question, "Are you willing to participate in health research?", stratified by mailing to which participant responded



Note: Areas of circles proportional to numbers answering that mailing.

Figure 2. Answers to the question, "How would the method of selecting you affect whether you felt comfortable and willing to participate in health research?"



Note: All answers above were preceded by the phrase "You were selected at random from . . ." Means and standard errors (SE) for each method are to the right of the chart, and are based on Likert scale responses assigned as 1=very uncomfortable to 5=very comfortable.

methods of selection and all contact organizations. None of the variables was associated with responses to the fourth question.

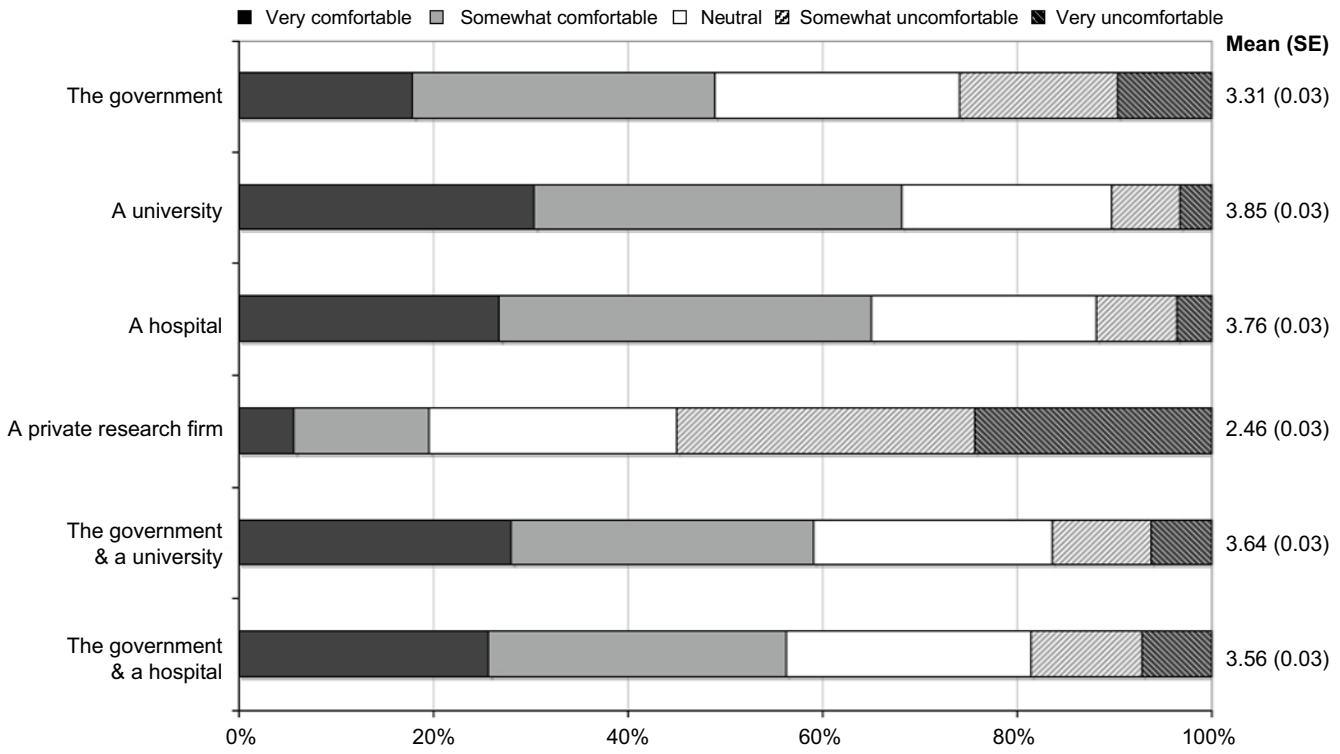
DISCUSSION

Most respondents (85%) were willing to participate in health research in at least some circumstances. The decreasing proportions willing to participate among those answering after the second and third mailings suggest that the non-respondents would have a lower willingness to participate. However, even among those who replied to the later mailings, the majority were willing to participate in health research, suggesting that non-response was not solely indicative of lack of interest.

Respondents felt most comfortable being selected from a government list of the population, though there were few differences by mode of selection. One contradictory result suggests that this may be an area of inquiry that needs discussion with participants: the selection method meant to maintain confidentiality of medical status received less support than direct selection from medical records.

The organization contacting participants was important to comfort about participating in health research. Most respondents felt uncomfortable being contacted by a private research firm. In Canada, such research has the least stringent oversight: it does not require peer review, nor review by a human subjects ethics board.

Figure 3. Answers to the question, "How would the organization contacting you affect whether you felt comfortable and willing to participate in health research?"



Note: All answers above were preceded by the phrase "You were contacted by a letter from . . ." Means and standard errors (SE) for each organization are to the right of the chart, and are based on Likert scale responses assigned as 1=very uncomfortable to 5=very comfortable.

Respondents felt most comfortable being contacted by university or hospital researchers and less comfortable about government contact. This suggests that requiring government data holders to contact study subjects prior to contact by university or hospital researchers may reduce response rates and therefore study quality.[13,22,23] Because our study was conducted by a university, potential participants favouring university-based contact may have been more willing to complete our survey. This might explain some of the comfort gap between university vs. hospital contact, but seems unlikely to explain the much greater difference in comfort with contact by government or private research firms.

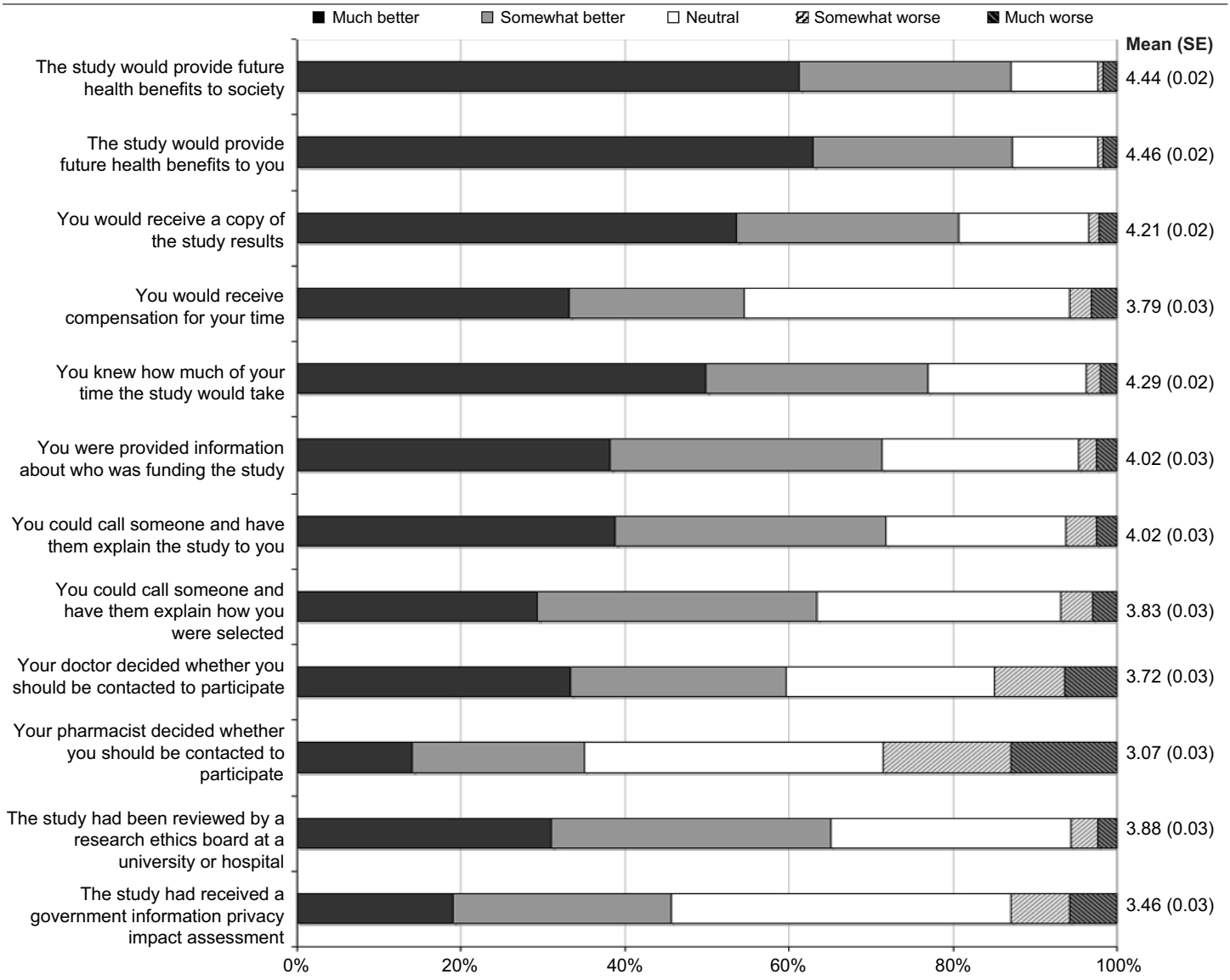
Among other factors postulated to motivate or detract from participation in health research, the strongest motivators were future health benefits to the individual or to society. Many respondents wrote comments about their illnesses or those of family members and the importance of health research to society. Information about the study was also a strong motivator, and the most important information was study results. This has influenced us to send brochures summarizing study results to every participant of our research. Having a doctor as a gatekeeper for participant contact was positive for more than half the participants, but negative for 15%. Comments on the surveys suggested this may have been due to negative feelings about the medical system and the influence of pharmaceutical companies. Pharmacists as gatekeepers elicited more negative responses than all other factors.

Our study measured self-reported preferences, not behaviour. Potential gaps between stated preferences in a hypothetical context and behaviour[24] limit our ability to estimate the true proportion who would participate in research, however, opinion surveys remain important in a policy-making context. Without population-based survey data, ethics boards and government policy-makers are left to be influenced by negative feelings of small numbers of complainants.

Our study and the few others that have addressed the use of administrative databases for identifying subjects for contact-based research are beginning to elucidate public attitudes. In a US study of 735 patients using antihypertensive medication, almost none objected to the use of medication records to identify them.[19] Two studies asked directly about the potential chain of events from a medical record to study contact: an Australian study with 301 respondents;[20] and a British study with 2,872 respondents.[21] The majorities were willing to have records released to researchers for subject contact. Surveys to date suggest that people recognize the value of research to public health, and point to features that positively influence participation. Remaining complexities related to sample selection and the path to subject contact likely require research methods other than a self-administered survey. Willison suggested a deliberative forum such as a citizen's jury as a means to present and consider competing interests related to personal privacy and health research.[25]

Balancing privacy and research in the public interest is not easy, even for experts. Recent studies in Europe and Canada have shown that those responsible for ethics reviews and for policies related to individual consent have defined many different standards of practice.[26,27] Given the difficulty of these decisions, we hope that others will continue to investigate public opinions. They are vital to researchers who need to approach study respondents appropriately, to policy-makers who must set rules that protect privacy while allowing legitimate access to data for the public good, and to the public whose privacy and health must be the joint foundations for the path followed.

Figure 4. Answers to the question, "Would any of the following make you feel better or worse about participating in health research?"



Note: Means and standard errors (SE) for each factor are to the right of the chart, and are based on Likert scale responses assigned as 1=much worse to 5=much better.

REFERENCES

1. Canadian Institutes of Health Research, Natural Sciences and Engineering Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Ottawa: The Councils, 1998 (with 2000, 2002, 2005 amendments).
2. European Union. Directive 95/46/EC of the European parliament and of the council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and the free movement of such data. 1995.
3. *Data Protection Act 1998*. London: Stationery Office, 1998.
4. Plater S, Seeley E, Dixon LA. Two routes to privacy protection: A comparison of health information legislation in Canada and the United States. *J Womens Health* 1998;7:665-72.
5. Appelbaum PS. Protecting privacy while facilitating research. *Am J Psychiatry* 2000;157:1725-26.
6. Verity C, Nicoll A. Consent, confidentiality and the threat to public health surveillance. *BMJ* 2002;324:1210-13.
7. Coleman MP, Evans BG, Barrett G. Confidentiality and the public interest in medical research – will we ever get it right? *Clin Med* 2003;3(3):219-28.
8. Peto J, Fletcher O, Gilham C. Data protection, informed consent and research. *BMJ* 2004;328:1029-30.
9. Beskow LM, Botkin JR, Daly M, Juengst ET, Lehmann LS, Merz JF, et al. Ethical issues in identifying and recruiting participants for familial genetic research. *Am J Med Genet* 2004;130(4):424-31.
10. Iversen A, Liddell K, Fear N, Hotopf M, Wessely S. Consent, confidentiality, and the Data Protection Act. *BMJ* 2006;332:165-69.
11. Hewison J, Haines A. Overcoming barriers to recruitment in health research. *BMJ* 2006;333:300-2.
12. Baker R, Sheils C, Stevenson K, Fraser R, Stone M. What proportion of patients refuse consent to data collection from their records for research purposes? *Br J Gen Pract* 2000;50:655-56.
13. Woolf SH, Rothemich SF, Johnson RE, Marsland DW. Selection bias from requiring patients to give consent to examine data for health services research. *Arch Fam Med* 2000;9:111-18.
14. Asai A, Ohnishi M, Nishigaki E, Sekimoto M, Fukuhara S, Fukui T. Attitudes of the Japanese public and doctors towards use of archived information and samples without informed consent: Preliminary findings based on focus group interviews. *BMC Med Ethics* 2002;3:E1.
15. Nelson K, Garcia RE, Brown J, Mangione CM, Louis TA, Keeler E, Cretin S. Do patient consent procedures affect participation rates in health services research? *Med Care* 2002;40:283-88.
16. Willison DJ, Keshavjee K, Nair K, Goldsmith C, Holbrook AM. Patient consent preferences for research uses of information in electronic medical records: Interview and survey data. *BMJ* 2003;326:373-77.
17. Robling MR, Hood K, Houston H, Pill R, Fay J, Evans HM. Public attitudes towards the use of primary care patient record data in medical research without consent: A qualitative study. *J Med Ethics* 2004;30:104-9.
18. Zurita L, Nohr C. Patient opinion – EHR assessment from the users perspective. *Medinfo* 2004;11(Pt 2):1333-36.
19. Beto JA, Geraci MC, Marshall PA, Bansal VK. Pharmacy computer prescription databases: Methodologic issues of access and confidentiality. *Ann Pharmacother* 1992;26:686-91.

20. Campbell Research and Consulting. *The Impact of Privacy Legislation on NHMRC Stakeholders – Comparative Stakeholder Analysis*. Report to National Health and Medical Research Council, Department of Health and Ageing, Canberra, 2004. Available at: http://www.nhmrc.gov.au/about/_files/st8.pdf (Accessed March 23, 2009).
21. Barrett G, Cassell JA, Peacock JL, Coleman MP. National survey of British public's views on use of identifiable medical data by the National Cancer Registry. *BMJ* 2006;332:1068-72.
22. Kho ME, Duffett M, Willison DJ, Cook DJ, Brouwers MC. Written informed consent and selection bias in observational studies using medical records: Systematic review. *BMJ* 2009;338:b866.
23. Harris MA, Levy AR, Teschke K. Personal privacy and public health: Potential impacts of privacy legislation on health research in Canada. *Can J Public Health* 2008;99:293-96.
24. Little J, Berrens R. Explaining disparities between actual and hypothetical stated values: Further investigation using meta-analysis. *Economics Bulletin* 2004;3:1-13.
25. Willison D. Privacy and the secondary use of data for health research: Experience in Canada and suggested directions forward. *J Health Serv Res Policy* 2003;8(Suppl 1):17-23.
26. Willison DJ, Emerson C, Szala-Meneok KV, Gibson E, Schwartz L, Weisbaum KM, et al. Access to medical records for research purposes: Varying perceptions across research ethics boards. *J Med Ethics* 2008;34:308-14.
27. De Wet HCW, Dekker JM, Van Veen EB, Olsen J. Access to data from European registries for epidemiological research: Results from a survey by the International Epidemiological Association European Federation. *Int J Epidemiol* 2003;32:1114-15.

Received: June 18, 2009
Accepted: November 19, 2009

RÉSUMÉ

Objectif : Les lois sur la protection des renseignements personnels limitent les options lorsqu'on veut recruter des sujets pour des études sur la santé. Ce mouvement de fond repose sur certaines hypothèses quant aux attitudes du public à l'égard de la participation. Pourtant, les sondages sur les attitudes sont rares. Nous avons donc examiné la volonté du public de collaborer à la recherche en santé et l'influence de divers facteurs sur cette volonté de collaboration.

Méthode : Nous avons mené un sondage en Colombie-Britannique, au Canada, auprès d'adultes sélectionnés au hasard dans le bottin téléphonique. Nous leur avons posté des questionnaires à remplir soi-même. Les questions portaient sur la volonté de collaborer à la recherche en santé et l'influence de divers facteurs (dont la méthode de sélection des sujets et l'organisme établissant le contact) sur leur volonté de collaboration.

Résultats : Sur les 1 477 répondants (58 % des sujets admissibles), 85 % étaient disposés à participer à la recherche en santé au moins de temps à autre. L'organisme établissant le contact influençait le degré d'aisance à l'idée de participer : 10 % des répondants se sentaient mal à l'aise s'ils étaient contactés par une université, 12 % s'ils l'étaient par un hôpital, 26 % s'ils l'étaient par le gouvernement, et 55 % s'ils l'étaient par une firme de sondage privée. Les facteurs les plus propices à la collaboration étaient l'intérêt futur de l'étude en question pour la santé collective (87 %) et pour la santé personnelle (87 %) et le fait de recevoir un exemplaire des résultats de l'étude (81 %).

Conclusion : La participation à la recherche en santé semble être vue sous un jour favorable par les personnes du public, et cette participation est sans doute la plus élevée lorsque des chercheurs rattachés à une université ou à un hôpital peuvent directement contacter les sujets en trouvant leurs coordonnées dans des bases de données gouvernementales.

Mots clés : épidémiologie; éthique; participation

CPHA•ACSP
CANADA'S PUBLIC HEALTH LEADER
LE LEADER CANADIEN EN SANTÉ PUBLIQUE

Since 1910, the Canadian Public Health Association has been Canada's Public Health Leader. CPHA:

- ☑ encourages citizen involvement in Public Health policy and programming;
- ☑ brings together diverse individuals and organizations, creating a united voice on Public Health issues in Canada and around the world; and
- ☑ champions universal and equitable access to the basic conditions necessary to achieve health for all.

CPHA's strength is its members who give us credibility, direction and authority. To continue to be the voice of Public Health, CPHA needs your expertise and support.

Join your voice to ours.

Join CPHA today.

Call us at 613-725-3769 ext. 118,
e-mail us at « membership@cpha.ca »
or visit us on-line at www.cpha.ca