Public Opinions about Participating in Health Research

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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

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 influence on willingness of 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.
Factors influencing willingness to participate

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 3 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 1. Participation in the Survey

<table>
<thead>
<tr>
<th>Households mailed surveys</th>
<th>3000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible, name not at this address (%) of mailed</td>
<td>309 (10.3%)</td>
</tr>
<tr>
<td>Eligible, unable to complete survey in English (%) of mailed</td>
<td>110 (3.7%)</td>
</tr>
<tr>
<td>Eligible, deceased or too ill (%) of mailed</td>
<td>47 (1.6%)</td>
</tr>
<tr>
<td>Eligible (%) of mailed</td>
<td>2534 (84.5%)</td>
</tr>
<tr>
<td>Refused (%) of eligible</td>
<td>183 (7.2%)</td>
</tr>
<tr>
<td>No contact, eligibility &amp; refusal status unknown (%) of eligible</td>
<td>874 (34.5%)</td>
</tr>
<tr>
<td>Surveys completed (%) of eligible</td>
<td>1477 (58.3%)</td>
</tr>
</tbody>
</table>

* 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.

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

<table>
<thead>
<tr>
<th>Percent Giving Each Response</th>
<th>N=1435*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, always or most of the time</td>
<td>41.7% (39.2-44.3)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>43.6% (41.0-46.2)</td>
</tr>
<tr>
<td>No, never or almost never</td>
<td>14.8% (13.0-16.6)</td>
</tr>
</tbody>
</table>

* N is smaller than reported in Table 1, because some respondents did not answer this question.
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.
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.\textsuperscript{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\textsuperscript{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.\textsuperscript{19} Two studies asked directly about the potential chain of events from a medical record to study contact: an Australian study with 301 respondents;\textsuperscript{20} and a British study with 2,872 respondents.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.
REFERENCES


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.


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