

Attitudes of research ethics board chairs towards disclosure of research results to participants: results of a national survey

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Background: The offer of aggregate study results to research participants following study completion is increasingly accepted as a means of demonstrating greater respect for participants. The attitudes of research ethics board (REB) chairs towards this practice, although integral to policy development, are unknown.

Objectives: To determine the attitudes of REB chairs and the practices of REBs with respect to disclosure of results to research participants.

Design: A postal questionnaire was distributed to the chairs of English-language university-based REBs in Canada. In total, 88 REB chairs were eligible. The questionnaire examined respondents' attitudes towards offering participants completed study results, methods for delivering this information, and barriers to disclosing results.

Findings: The response rate was 89.8%. Chairs were highly supportive (94.8%) of offering results to research participants. Only 19.5% of chairs responded that a policy or guideline that governed the return of research results to participants existed at their institution. Most chairs (72.0%) supported the idea of their REB instituting a set of guidelines recommending that researchers offer results to participants in a lay format. Chairs identified the major impediments to the implementation of programmes offering to return results to participants as being financial cost (57.5%) and retaining contact with research participants (78.1%).

Conclusions: University-based REB chairs overwhelmingly support the offer of research results to participants. This is incongruent with the frequent lack of existing REB guidelines recommending this practice. REBs should support guidelines that diminish identified barriers and promote consistency in offering to return results.

The practice of offering to return a summary of research results to research participants upon study completion has received increasing support in recent years.^{1,2} Offering to share completed study results with all participants of research studies acknowledges the ethical principle of respect for people. This practice avoids treating research participants as a means to an end, and may have direct positive consequences for the participant and indirect benefits for research as a whole.^{1,2} Some of the benefits of returning results include:

- (1) the results may act as a sign of acknowledgement, appreciation or reward;
- (2) offering results may minimise the feeling of being exploited on the part of the participants;
- (3) the results might improve the long-term health of the participant;
- (4) offering results might improve the perception of research in the public, thereby increasing the number of people that participate in research projects.

Some of the potential risks include:

- (1) the dissemination of unreliable results;
- (2) psychological stress at having to relive a difficult time;
- (3) "survivor guilt" for those participants who may have received a superior treatment;
- (4) employment or insurance discrimination for those participants who are identified as being at greater risk for future long-term health problems or illnesses;
- (5) the significant investment for researchers, in terms of both time and money, in disseminating the results.

Although some believe that research participants should be informed of all results that may have a perceived therapeutic benefit for them, we support informing participants of the risks and benefits of receiving results and ultimately leaving the decision about whether to receive results up to them.^{3,4} This latter strategy is an inherently different practice from providing

results to those participants who request them. The onus should be on the researcher, not the participant, to offer results and provide a means of contact, so that the potential benefit of offering results as a sign of acknowledgement or thanks may be fully appreciated. Although there are potential risks to receiving research results, studies have repeatedly found that participants would elect to be offered results despite these risks.^{5–9} Evidence shows that participants are not often offered research results despite a moral obligation on the researcher to do so.^{10–12} Ascertainment of support for the practice of offering results to participants by research ethics board (REB) chairs is an essential component of ensuring that researchers adhere to this responsibility.

International research ethics regulatory statements are inconsistent regarding the issue of returning results following completion of a study. North American regulations provide little guidance to researchers about the practice of offering completed study results to participants; it is vague in Canadian policy,¹³ and not addressed in US regulations.¹⁴ Specifically, the Tri-Council Policy in Canada considers a description of "how the subjects will be informed of the results of the research" as additional information that may be required to be provided to research participants. However, there is no specification as to which projects this may apply.¹³ The US Common Rule makes no mention under the heading of "additional elements of informed consent" or elsewhere that research participants should be informed of the results of the research project.¹⁴ In contrast, the *International ethical guidelines for biomedical research involving human subjects* considers disclosure of the findings of research in general and results that relate to the health status of individual subjects to be essential information for prospective

Abbreviations: IRB, institutional research board; REB, research ethics board

research subjects.¹⁵ Item 5.4.8 of the UK Medical Research Council's *Guidelines for good clinical practice in clinical trials* (1998) states an apparently non-binding: "Where feasible, trial participants should also be notified of progress with the trial and eventual outcome of the trial".¹⁶ Despite these internationally recognised guidelines, researchers representing North America, Europe and Asia report with similar frequency that they are seldom obliged by their institutional research board (IRB)/REB to offer results to participants.¹⁰

The potential of nationally promulgated human research ethics policy to positively influence researchers is clear, as most funding agencies in Canada require REB approval as a stipulation to release federal funding. Parallel practice is found in the USA. We have found, using a survey of a subset of REBs in Canada, that institutional policies guiding return of results generally do not exist.¹⁷ Attitudes of chairs of REBs favouring or disapproving of this practice are unknown. The adoption in the future of such policies will require the support of local REBs, particularly the chairs, and the exploration of this theme was a driver for the current study.

We thus examined, for the first time to our knowledge, the attitudes of the chairs of university-based REBs towards the practice of returning research results to research participants, and whether Canadian university-based REBs currently require researchers to offer results. Furthermore, we draw on the expertise of the REB chairs in this study to determine how results should best be returned and what were the perceived barriers to the implementation of this practice. These findings are expected to be of use to international REBs/IRBs in reflecting on their current practice and in providing evidence for the appropriateness of implementing local REB policy regarding the return of research results to participants.

METHODS

The IWK Health Centre REB (Halifax, Nova Scotia, Canada) approved the study. A list of all universities in Canada was obtained from the website of the Association of Universities and Colleges of Canada.¹⁸ Chairs of university-based REBs and of REBs that had reciprocal agreements with university REBs were included in the study. Primarily French-language universities were excluded from the study.

Contact information for chairs was obtained by two methods: (1) a concurrent study¹⁷ conducted by us, which asked members of the Canadian Association of Research Ethics Boards¹⁹ to provide contact information for REB chairs; and (2) an internet search.

The survey was designed using the tailored design method as described by Dillman,²⁰ which encourages respondent trust and seeks to create a perception of increased rewards and reduced costs to increase survey response rates. This method of survey design is generally regarded as the gold standard for survey development in the social sciences.²⁰ The questionnaire examined the demographics of the REB chairs and of the institutions, attitudes regarding notification of results, timing of disclosure in relation to study closure, need for peer review before disclosure, methods of disclosure, and support for REB policy requiring disclosure of results. The questionnaire was reviewed prior to distribution with a past REB chair and a bioethicist for clarity and face validity. Reliability of the questionnaire was determined by examining the internal consistency of responses to the same question phrased differently. The questionnaire was determined to be reliable after the same number of chairs opposed the return of results in three different questions.

An email contact to REB chairs preceded the questionnaire by 1 week. This was followed by an information letter, serving as the consent document and promising confidentiality, and an attached questionnaire sent by mail. Reminders were sent to

non-respondents at 1, 3 and 6 weeks. The chairs were given an opportunity to receive a summary of the results of the completed study.

Statistical analysis

Data from the completed questionnaires were collected in Microsoft Excel (Microsoft Corp., Seattle, Washington, USA) and entered into EpiInfo V3.3.2 (Centers for Disease Control, Atlanta, GA, USA). The data were analysed using descriptive techniques. Fisher's exact test was used to determine statistical significance, which was set at $p < 0.05$. Confidence intervals were set at 95%.

RESULTS

There were 91 Canadian universities at the time of this study. Nineteen primarily French-language universities were excluded, leaving 72 universities. Some universities had >1 REB chair. Contact information was available for 89 eligible REB chairs, representing 72.2% (52/72) of the English-language universities in Canada. Universities lacking contact information either did not have a university website (1), an identifiable REB (17), or contact information for the REB (2) listed on the website. REB chairs from universities in all 10 Canadian provinces were represented in the study. One REB chair was found to be redundant—that is, contact information was duplicated for the same REB chair. Thus, 88 REB chairs were eligible. The response rate was 89.8% (79/88) with 87.5% (77/88) completed surveys analysed. Some answers added up to >100%, as chairs could select more than one choice. There was a mean (SD) of 2.0 (2.6%) (range 0–7) respondents per question for missing data. Table 1 compares the institution size of the REB chair respondents with non-respondents.

Demographics of research ethics boards and chairs

Respondent characteristics are shown in table 2. Table 3 outlines the fields of research evaluated by committees chaired by respondents to the study, which were broad.

REB practices and policies

REB chairs were asked how often research protocols that come before their REB indicate a plan to offer to return results to research participants; 32.9% (24/73) indicated rarely (1–25% of the time), 30.1% (22/73) indicated occasionally (26–75% of the time) and 32.9% (24/73) indicated regularly (76–99% of the time).

Chairs were asked if their REB has a written policy or guidelines that govern the return of research results to research participants following the completion of research projects. Only 19.5% (15/77, 95% 95% CI 11.3 to 30.1) of chairs indicated that a policy or guidelines existed at their institution. However, 26/74 (35.1%) chairs responded that their REB routinely required, as part of the review process, that informed consent forms contain a statement that research participants have a right to

Table 1 Comparison of institution size for REB chair respondents versus non-respondents

Size of institution*	Respondents, n (%), (n = 79)	Non-respondents, n (%), (n = 10)
<10000	21 (26.6)	5 (50.0)
10000–19999	17 (21.5)	1 (10.0)
20000–29999	15 (19.0)	2 (20.0)
30000–39999	17 (21.5)	1 (10.0)
>40000	9 (11.4)	1 (10.0)

*Size of institution was based on total number of students in 2004 as described by the Association of Universities and Colleges of Canada.¹⁸

Table 2 Demographic characteristics of REB chair respondents (n=77)

Characteristics	Respondents
Age (n=70)	
Mean, years	53.2
Median (range), years	53.5 (32-73)
Gender (n=73)	
Male	47 (64.4)
Female	26 (35.6)
Experience as REB member (n=76)	
Mean, years	6.1
Median (range), years	5.0 (0.17-23.0)
Experience as REB chair (n=76)	
Mean, years	3.3
Median (range), years	2.0 (0.0-15.0)
Any experience personally conducting research with human participants (n=76)	68 (89.5)
Any experience personally conducting human-based research and returning results to participants (n=63)	33 (52.4)
Currently conducting research on human participants (n=76)	47 (61.8)
Currently involved in human-based research and returning results to participants (n=46)	38 (82.6)

*Data are n (%) unless otherwise indicated.

receive research results. No significant association was detected between the field of research that the REB was mandated to oversee and the existence of a written policy guiding the return of results. Similarly, there was no significant association between the field of research and whether the REB required the informed consent forms to state that participants have a right to research results.

Attitudes of REB chairs

The majority of chairs either strongly (55/77, 71.4%, 95% CI 60.0 to 81.2) or somewhat supported (18/77, 23.4%, 95% CI 14.5 to 34.4) offering results to research participants at study completion. None opposed the practice, and 4/77 (5.2%, 95% CI 1.4 to 12.8) were neutral. Table 4 describes REB chair support for offering results to research participants based on demographics and experience as an REB member and chair.

In total, 81.8% (63/77) of REB chairs felt it was appropriate to offer to return results during the original consent process, and just 23.4% (18/77) felt it was appropriate to offer them at the conclusion of the study. Over half (56.6%, 43/76) of chairs felt that the completed study results should be returned to research participants after the data are complete and analysed; 10.5% (8/76) after acceptance for peer-reviewed publication; and 10.5% after publication of the results in a peer-reviewed format (8/76).

Nearly three-quarters (73%) of chairs either strongly (35/74, 47.3%) or somewhat supported (19/74, 25.7%) researchers establishing a mechanism to maintain contact with research participants for the purposes of returning research results. Most chairs either strongly (41/71, 57.5%) or somewhat supported (17/71, 23.9%) researchers informing participants of the possible harms and benefits of receiving results and most (82.9%) strongly (36/76, 47.4%) or somewhat supported (27/76, 35.5%) researchers budgeting for the cost of returning research results in their research proposals. The majority of chairs (72%) also strongly (32/75, 42.7%) or somewhat supported (22/75, 29.3%) the idea of their REB instituting a set of guidelines suggesting that researchers offer research results to participants in a lay format; 9.3% were opposed to the concept. Fewer REB chairs supported the mandatory offer of a return of results through a policy: 24.0% (18/75) strongly supported, 16.0% (12/75) somewhat supported, 24.0% (18/75) neither supported nor

Table 3 Field of research reviewed by research ethics boards (self-reported by REB chairs) (n=77)

Research field*	Respondents, n (%)
Social sciences	59 (76.6)
Humanities	49 (63.6)
Medicine	28 (36.4)
Non-medicine health sciences	43 (55.8)
Law	11 (14.3)
Other†	10 (13.0)

*Respondents could indicate more than one field of research.

†Includes environmental sciences, education, linguistics, biological sciences, business, natural sciences and engineering.

opposed, 17.3% (13/75) somewhat opposed and 18.7% (14/75) strongly opposed.

Table 5 shows the perceived major impediments to implementation of a successful programme of returning results to research participants. Respondents offered their own perceived impediments to returning results to participants. Some of the "other" responses included: remembering to return results; lack of relevance for the participant; laziness of the researcher; time commitment and labour involved for researcher; writing in lay language; communicating the meaning of the results to participants when it is not always known; and "there are no impediments". Table 6 describes the recommendations of the REB chairs recommended should be done to facilitate the return of results at their institutions. "Other" responses were significant (23.6%) and included responses such as: researchers should be educated about returning results; no recommendations; results should be made available on website; if the research is not funded, the cost should be borne by the researcher; and research participants should be encouraged to ask for results "none of the above".

DISCUSSION

Our study showed a very high degree of support among REB chairs for offering research results to participants at study completion. Although only 19.5% of chairs belonged to REBs with policies or guidelines to return results to research participants at study completion, chairs were very supportive

Table 4 Support for offering results by characteristics of REB chairs

Characteristics	Strongly support offering results	Somewhat support offering results	Neither support nor oppose offering results	p Value
Age (n=70)				
30-45 (n=15)	8	5	2	0.001
46-60 (n=40)	33	6	1	
61-75 (n=15)	11	4	0	
Gender (n=73)				
Male (n=47)	33	11	3	0.066
Female (n=26)	21	4	1	
Years as member of REB (n=76)				
<6 (n=50)	38	9	3	0.008
6-10 (n=15)	9	5	1	
11-30 (n=11)	8	3	0	
Years as chair of REB (n=76)				
≤2 (n=45)	33	9	3	0.010
3-4 (n=17)	11	5	1	
5-15 (n=14)	11	3	0	

Table 5 Impediments to successful programmes to offer to return research results to participants. (n = 73)

Impediment	Responses*, n (%)
Contacting research participants	57 (78.1)
Financial cost	42 (57.5)
Preparation of research results	19 (26.0)
Psychological consequences of information to recipient	17 (23.3)
Stress for researcher of providing information	10 (13.7)
Stress for research participant of receiving information	10 (13.7)
Other	17 (23.3)

*Chairs could select more than one item.

of the implementation of guidelines that suggest that researchers offer results at the REB level. Interestingly, chairs were significantly less supportive of guidelines mandating that researchers offer results to participants. This may be explained by the potential barriers identified by chairs (i.e. contacting research participants, financial cost, preparation of results) that must be overcome to achieve the aim of routinely offering research results to participants. Although significant, some of these barriers can be ameliorated with appropriate financial and study planning and design. Notably, REB chairs indicated that allocating financial support from funding agencies and amending the Tri-Council policy to support the return of research results would facilitate the return of results to participants.

Most REB chairs felt that results should be offered during the initial consent process and returned after the data collection is complete and analysed. Our results show that more chairs felt that results should be returned after data collection is complete and analysed than after acceptance following peer review. This may reflect the desire for chairs to ensure that research results are returned to participants in a timely manner, given that the time from data analysis to peer review or publication can often be considerable. It must be acknowledged however, that peer review of results increases the likelihood that results disclosed to participants are valid and reliable, and helps to ensure that results that are later found not to be statistically significant are not communicated to participants. On the other hand, ensuring that results are disclosed to participants prior to publication avoids the potential perception on the part of the participants as being “the last to know”. Although most research results are not publicised in the mass media, for those results that are, participants are at least deserving of having the option of being informed of the results prior to disclosure to the general public.

Chairs also supported researchers establishing a mechanism to maintain contact with participants for disclosing results, informing participants of the risks and benefits of receiving results and budgeting for the costs of disclosing results.

Our findings lend confirmation to previous research with principal investigators and clinical consent practice in the Children’s Oncology Group.^{10–11} These studies found that return of research results is seldom practised. REB chairs in the current study indicated that researchers generally disclosed research results to participants more often than has been found in previous research.^{10–11} This may be explained by the high proportion of REBs in the current study that review research in the social sciences and humanities, where disclosure of results may be more common, particularly in collaborative, indigenous and participatory action research. Research in the humanities and social sciences, in contrast to the majority of biomedical research, is more commonly minimal risk; there may be more opportunity for informal contact with participants; obtaining responses from participants may be integral to the research project itself; and returning results may be seen as a form of

Table 6 Actions to facilitate the return of research results to research participants (n = 72)

Action recommended	Responses*, n (%)
Allocate financial support from funding agencies	44 (61.1)
Amend Canadian Tri-Council research ethics policy to support the return of research results	35 (48.6)
Mandate return of results through local REB guidelines	20 (27.8)
Other	17 (23.6)
Allocate financial support from researcher’s own institution	13 (18.1)

REB, research ethics board.

*Chairs could select more than one item.

public education. There was, however, no association between the field of research that REBs were mandated to oversee and the existence of an REB policy guiding the return of research results to participants. Thus, although researchers in the social sciences and humanities may be more likely to offer results to research participants, this does not seem to influence the presence of a policy guiding this practice.

Our study has found a significant gap between the support of REB chairs for offering a summary of research results and REB policy. This raises the question of what prevents REBs from instituting policy on REB practices that they clearly support, and whether there are other areas of REB policy and practice that are deficient. A previous study by our group on REB policy to disclose research results to participants found that for the few REBs that had policies to return results to participants, the policies are vague about how this should occur.¹⁷ There is obviously a need to study REB policy on a national level so that REBs can benefit from the experience of other REBs. Perhaps a “blue ribbon” panel to create a model policy that could be later adopted by the Tri-Council Policy Statement would facilitate the practice of offering results to participants. REBs could then create more detailed policies (if necessary) that would apply to the research methodologies and participant populations that exist at their institution. The specific details and requirements for the level of researcher–participant interaction and the associated costs to researchers will naturally vary depending upon the risk and consequences of the research findings and the desires of participants.^{8–21} The fundamental tenets of offering to return research results should include ensuring that the return of results is a voluntary decision, made by participants who are informed of the harms and benefits of receiving the results. REBs must provide guidance on acceptable practice for returning results to participants, given the nature of the research project, the type of project and the potential harm to the participant.

It is recognised that research participants are unduly burdened by participation in research projects that do not contribute to the furthering of widely applicable knowledge.²⁷ This situation is illustrated by the finding that as many as half of all published abstracts never come to full manuscript publication.^{22–26} Support by REBs of a mandate to offer a return of peer-reviewed research results may thus have the positive consequence, although not directly intended, of improving the submission of peer-reviewed work for publication.

A response rate of 89.8% is considered extremely high for a postal survey, and strengthens the applicability of our results. REBs from all major universities and all regions of the country were well represented, and there were no differences between institution size for respondents and non-respondents. One limitation is that we did not survey REB chairs of Canadian universities using French as the main language. It is unlikely, however, that there would be an inherent difference in the research that is conducted or the issues that arise with respect

to return of results. Another limitation of the study is that we did not have a pilot study. However, we did have the study reviewed by a bioethicist and a former REB chair for clarity and face validity. Furthermore, fewer than two-thirds of respondents responded to certain questions. The validity of our questionnaire has not been established over time or for different populations of respondents, as it is a new instrument. However, the content validity can be demonstrated by comparison of a study conducted by our group of REB coordinators,¹⁷ in which there was a similar frequency of REBs that had a policy governing the return of research results.

CONCLUSIONS

We have found that university-based REB chairs are overwhelmingly in support of the practice of offering to return research results to participants. This should provide momentum to the development of local REB guidelines and/or revision of national policies. Further research is now required to determine the practical application of these policies recommending the offer to disclose research results, including the optimum timing and means of indicating a commitment to disclosure. It will be important to determine the desires of participants, details of the financial ramifications of this process, and the application of our findings to non-university and industry settings.

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