
A H F M R



ALBERTA HERITAGE FOUNDATION
FOR MEDICAL RESEARCH

*Protecting People While Generating Knowledge:
Ethics in Health Research, Evaluation and Quality Improvement
May 4-6, 2008*

– Executive Summary Evaluation Report –

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INTRODUCTION

This report summarizes responses to the survey form used to evaluate the inaugural *Protecting People While Increasing Knowledge: Ethics in Health Research, Evaluation and Quality Improvement* conference held in Calgary Alberta, May 4th – 6th, 2008. The purpose of the evaluation was to assess delegates' experiences at the conference. The evaluation form was also used to gather feedback on what had worked well for the attendees and provide suggestions for how the event could be improved in the future.

THE DELEGATES

In total, 163 delegates from across Canada representing health service managers and professionals, ethics board members, researchers, evaluators, senior research policy makers, and government and non-government funding agencies attended the conference. Of those, 77 completed the evaluation form for an overall response rate of ~47%.

A notable number of the delegates (44%) reported that their primary responsibilities at work involved a *combined* focus including research, program evaluation (PE) and quality improvement/ assurance (QI/A) tasks. Fewer than 20% of those surveyed reported having a work focus that was limited to one of the three areas of interest: research, PE and QI or QA, while 13% of the respondents reported having a primary work focus in areas other than those assessed in the evaluation.

Approximately two-fifths (40%) of the individuals surveyed reported that in their current role health research, evaluation and/or quality assurance/improvement tasks take up 76-100% of their time. 21% reported that health-related knowledge generating activities typically occupied 51-75% of their time and for the remaining 38%, less than 50% of their workloads involved time spent in health-related knowledge generating activities.

KEYNOTE SPEAKERS/PRESENTERS

Overall, the opening and closing keynotes were very well received by the delegates and praised for the practical applicability and usefulness of the information relayed. The various other speakers and presenters featured at the *Protecting People* conference were also generally well received and rated quite positively by the majority of the surveyed delegates.

BREAKOUT SESSIONS/PANEL PRESENTATIONS

Responses to the breakout sessions were extremely positive. 90% of the delegates agreed that the small group breakout sessions on day one were effective in identifying the ethical gaps and issues experienced by and/or known to the session attendees. The three panel presentations fared much the same. Again, responses were positive, with a majority of the delegates agreeing that the panels succeeded in providing an overview of the initiatives being undertaken across Canada to address ethical oversight issues in knowledge generating projects. Of the delegates surveyed who attended the *Ideas to Action* workshop on day two, the majority (71%) tended to agree that the goals for the session had been realized in identifying actions to address the issues.

CONFERENCE GOALS & OBJECTIVES/LOGISTICS

The majority of the delegates believed the conference's overall goals and objectives had been "very much" achieved. The vast majority of the surveyed delegates rated the various aspects of the conference logistics *excellent* in terms of quality, and many of those surveyed agreed that the conference was worth the time and money, was appropriate for their professional development needs and was practical and relevant in terms of providing attendees with resources to inform their practices.

DELEGATES' EXPERIENCE OF THE CONFERENCE

Overall, 91% of the delegates surveyed reported enjoying their experience at the conference; many respondents look forward to the opportunity to attend similar conferences in the future, and to pursue the action items necessary to address the outstanding ethical issues and challenges discussed at the conference. In addition, the majority of the conference attendees surveyed, including those with advanced knowledge and experience with ethical issues in health-related knowledge generating projects, were very satisfied with the inaugural *Protecting People* conference. More than 90% of the delegates reported that their expectations for the event had been met, and 86% reported that they would recommend the conference to others.

What delegates liked most about the event:

- The conference's overall organization and format.
- The quality of the information presented.
- The interactive nature of the conference.
- The opportunities to network
- The diversity of the delegates.

What delegates liked least about the event:

- Insufficient break time.
- Information overload.
- Lack of time to thoroughly explore 'next steps' and solutions.

Delegate's personal learnings/insights gained:

- Improved understanding of new developments in ethics processes/options for research *and* non-research projects.
- Increased awareness of others who face similar issues and their different approaches/solutions.
- Realization that there appears to be growing interest in issues related to ethics at a national level.
- Increased awareness of the need to standardize/ streamline ethics review processes.
- Clarification of processes for PE/QI /QA ethical review.

What delegates report they are taking home to put into practice:

- Promote the use of available tools/ protocols and resources (i.e., ARECCI / other online tools).
- Promote thinking of ethics in a broader sense (i.e., to include non-research projects).
- Improve organizational ethics review practices and culture.
- Consider proposing/ implementing new organizational processes/practices for ethics review (e.g., development of a policy/procedure manual for PE/QI/QA ethic review; begin informal discussions of possible PE/QI/QA processes on the job; put together an internal review committee).
- Present a conference summary to colleagues.