

Protecting People While Increasing Knowledge: Ethics in Health Research Evaluation and Quality Improvement

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OBJECTIVE ONE: Does one size fit all?

Identifying issues/gaps in the ethical management of knowledge-generating projects

Breakout Session #2

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Evaluating the Program Evaluation Proposal: Who, where, why, and how?

Key Points of Presentation

1. Program evaluation proposals should be evaluated.
2. Who has the knowledge to undertake this task?
3. How and where should program evaluations proposals be evaluated?

Abstract

It is with great interest that our multi-disciplinary team learned of the upcoming, ground-breaking conference, Protecting People While Increasing Knowledge in Canada's Health Care and Research System. With the first author as discussant, we wish to be involved in this forum. It is in our patients' best interests that clinical practice is informed by their input and subsequently adapted through on-going evaluation. During the past fifteen years, members of our team, which includes health care professionals from the disciplines of social work, spiritual care, and psychology, have evaluated our clinical programs in a comprehensive cancer care facility. When the evaluation was extensive and the burden on the participants was large, we sought research ethics approval. When the evaluations were brief, we consulted the patient representative to ensure that the evaluation was not unduly burdensome to patients and was conducted ethically. Although we can articulate why our program evaluation proposals should be evaluated, we continue to struggle with questions of who should evaluate proposals and of where and how they should be evaluated. Clearly, program evaluation research proposals need to go to research ethics committees for approval. Clinical ethics committees may be able to assist with some aspects of evaluating burdens to be placed on patients. Possibly, there is a need for a third, streamlined process where the mandate is built sensibly and economically on the expertise of the membership of the other committees.

Background Information

In a cancer care setting, we have been undertaking internal evaluation of our psychosocial and spiritual programs for well over a decade (eg. Hundleby et al., 1996, 1997, 2002; Nekolaichuk, et al. 2007; Turner et al. 2007). It has been our practice to adhere to recognized program evaluation standards such

as those set out by The Joint Committee on Program Evaluation Standards (1994).

Why Undertake Evaluation of Program Evaluation Proposals?

In our case, evaluation of program evaluation proposals has been important because most of our evaluations have been internal. In these circumstances, it is important to have an unbiased, knowledgeable individual or committee offer an opinion on the feasibility, ethical soundness, and potential usefulness of the project.

Who Should Undertake Evaluation of the Proposals?

In the past, when a program evaluation proposal was extensive and the burden on the participants was large, we obtained institutional research ethics approval. When the evaluations were brief, we consulted the patient representative to ensure that the evaluation was not unduly burdensome to patients and was conducted ethically.

In her role of supporter of patient rights, the patient representative in our setting continues to offer advice with regard to our clinical program evaluations. A description of her role in our institution is included in the Appendix.

At present, we have just completed an extensive evaluation of the individual, psychological counselling offered in our setting (Nekolaichuk, et al. 2007; Turner et al. 2007). With regard to this project, our purpose was consistent with a research focus and the questions of who, where, why, and how were easily answered. The evaluation project was submitted for research ethics review and also received research funding.

How and where should program evaluations proposals be evaluated?

Nerenz and colleagues (2003) set out guidelines for quality improvement projects in general and address the need for research ethics review in specifically defined circumstances. Clearly, program evaluation research proposals need to go to appropriate research ethics committees for approval. Clinical practice ethics advisory committees may be able to assist with some aspects of evaluating burdens to be placed on patients.

Conclusions and Implications

There are gaps in the ethical management of knowledge-generating projects and one size does not fit all. Possibly, there is a need for a third, streamlined process where the mandate is built sensibly and economically on the expertise of the membership of the other committees

References

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Appendix

Patient Representative

The Patient Representative is a non-medical, neutral person who will help patients/families understand their rights and provide them with a process to seek information and solutions to problems concerning their care at the Cross Cancer Institute.

The Patient Representative addresses questions such as “what questions to ask staff and caregivers, or who will make my healthcare decisions for me when I am no longer able to do so.”

The Patient Representative encourages and welcomes comments and suggestions in order that we continually improve “Customer Service” at the Cross Cancer Institute.

