Exploring Ethicists’ Perspectives of Healthcare Ethics Program Effectiveness

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science Institute of Health Policy, Management & Evaluation and Collaborative Program in Bioethics, Joint Centre for Bioethics University of Toronto

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Abstract
Proliferation of ethics programs in healthcare organizations has occurred without rigorous evaluation. This qualitative study explored what makes an ethics program effective from the perspective of 15 practising ethicists across Canada. Objectives were to: describe how practising ethicists define ethics program effectiveness, identify evaluation strategies, and identify critical success factors.

Ethicists defined effectiveness as: 1) meeting standards; 2) making a difference; and 3) delivering value for investment. To evaluate, ethicists assessed: ethics program activity data, qualitative feedback, relevant accreditation results, peer review, and pre- and post- results. Ethicist competencies and attributes, organizational understanding of, and support for, the ethics program, and a community of practice were critical success factors.

Effectiveness emerged as a multi-dimensional concept. Findings provide a preliminary outline of what an ethics program evaluation framework might include and inform practice standard development, ethicist training programs, and organizational oversight for ethics programs.
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Introduction

The purpose of this study was to describe and operationalize the concept of *healthcare ethics program effectiveness* in order to inform ethicist practice, improve ethics program evaluation, and contribute to the literature on ethics program effectiveness. Using qualitative methods, I sought to explore ethicists’ perspectives on what makes an ethics program effective. In this chapter, I provide background information on the development of ethics programs in healthcare settings and on the importance of exploring the concept of effectiveness as it applies to healthcare ethics programs. I identify the purpose and objectives of this study, outline the primary research question that guided the study, and provide an overview of the contents of this thesis.

1.1 Background

In Canada and elsewhere, healthcare organizations are increasingly creating a formal infrastructure to support patients, staff, physicians, and other stakeholders in addressing ethical issues emerging in clinical care, organizational decision-making, and research (Davis, 2006; Foglia, Fox, Chanko, & Bottrell, 2012; Førde, Pedersen, & Akre, 2008; Fox, Myers, & Pearlman, 2007; Gaudine, Thorne, LeFort, & Lamb, 2010; Gauthier, Lantos, & Payot, 2013; Godkin et al., 2005; MacRae et al., 2005; Reiter-Theil, 2001; Slowther, McClimans, & Price, 2012; Zhou et al., 2009). Over the past two decades, there has been a marked rise in the number of ethicists, ethics committees, and ethics consultation services in Canadian healthcare organizations (Frolic, 2012; Gaudine et al., 2010; Godkin et al., 2005). For example, a 2008 survey found that 85% of Canadian hospitals with over 100 beds had clinical ethics committees compared to 58% in 1989 and 18% in 1984 (Gaudine et al., 2010). In 2005, Godkin and colleagues reported that three of nine Toronto hospitals increased investments in ethics program human resources (i.e., ethicist positions and administrative supports) between the time of data collection (June 2003) and publication. Although Frolic (2012) estimated the number of practising ethicists across Canada to be under 100, she noted that this number has “grown exponentially over the past 20 years” (p. 154).
A number of factors have been driving this growth, including increasing emphasis on values in health policy and organizational decision-making (Frolic, 2012; Johnson et al., 2009; McGee, Spanogle, Caplan, Penny, & Asch, 2002), development of accreditation standards requiring healthcare organizations to implement mechanisms to address the ethical issues arising in patient care, organizational practices, and research (Accreditation Canada, n.d.), and heightened focus on patient values as a component of high quality care (Nelson, Garden, Shulman, & Splaine, 2010a). Moreover, there is emerging evidence linking ethics programs and services to: a) shortened length of hospital stay (Schneiderman, Gilmer, Teetzel, Dugan, Goodman-Crews, & Cohn, 2006); b) enhanced moral climate (Filipova, 2011); c) improved patient satisfaction (Department of Veterans Affairs, National Center for Ethics in Health Care (NCEHC), 2007); d) improved staff satisfaction and retention of healthcare human resources (Tulsky & Fox, 1996; Ulrich et al., 2010; Wojtak, 2002); e) reduced risk of litigation (NCEHC, 2007), and f) reduced healthcare costs (NCEHC, 2007; Tulsky & Fox, 1996).

Ethics infrastructure can range from small ethics consultation teams or ethics committees comprised of institutional staff and physicians with basic ethics training, who volunteer their time to offer consultation support on ethics cases, organize ethics education events for staff and physicians, or provide input on organizational policy, to a “lone ethicist” on staff or on retainer who has the sole responsibility and accountability for delivering one or more ethics-related services to a single site or multiple sites (MacRae et al., 2005), or to a comprehensive ethics program led by one or more ethicists with advanced ethics training working in concert with designated staff and physicians to provide a full range of ethics services, including: a) ethics education, consultation and case review; b) policy review and/or development; and c) support for ethics committees and research ethics boards (Davis, 2006; MacRae et al., 2005; Godkin et al., 2005). In the Greater Toronto Area, a Hub and Spokes model has been piloted, which consists of an ethicist or ethicists at the “hub” and ethics facilitators embedded in clinical programs radiating from the hub like the “spokes” of a wheel who integrate ethics support locally and aid in the local delivery of ethics program services (MacRae et al., 2005).

Although it is increasingly common to find ethics programs in healthcare organizations, this growth has occurred without rigorous evaluation. As early as 1992, Griener and Storch wrote
that there was a lack of data to demonstrate the impact of ethics programs on clinical practice. Two decades later, there has still been little documented progress in evaluating the effectiveness, assessing the quality, or determining the impact of ethics programs. A recent study by Gaudine, Thorne, LeFort, and Lamb (2010) found that 35-43% of 126 hospital ethics committees surveyed in Canada were not evaluating their effectiveness or monitoring the quality of their services. Similarly, a study by Fox, Myers, and Pearlman (2007) found that only 28% of 600 ethics consultation services surveyed in the United States reported having a formal evaluation process.

With the rise of evidence-based healthcare and the health quality agenda in an era of financial constraint, ethics programs, along with other healthcare services, are coming under greater scrutiny to evaluate their contribution to quality and impact on patient care and organizational practices (Aulisio, 1999). Healthcare funders and decision-makers are demanding increased accountability and emphasizing empirical research to support resource allocation decisions (Fox, 1996; Gibson, Mitton, & DuBois-Wing, 2011; Singer & Mapa, 1998; Swetz, Hook, Henriksen Hellyer & Mueller, 2013). Increasing attention is being paid to program evaluation – that is, the systematic data collection on a program’s outputs, characteristics, and outcomes to determine whether programs are effective, how to improve the program, and/or in what future directions the program should move (Patton, 2002). Fox (1996) defines evaluation as a determination of “the merit, worth, or value of something, or the product of that process” (p. 116).

In healthcare, program evaluations are used to determine whether and to what extent a program is: a) being implemented as planned (implementation evaluation); b) functioning as planned (process evaluation); and c) achieving its intended objectives and is “worth” the resource investment (outcome evaluation) (Capwell, Butterfoss, & Francisco, 2000; Hollander, Miller, & Kadlec, 2010, p. 41). Given that resources in healthcare are finite, if there is evidence that a healthcare program or service is: 1) not efficacious – that is, the program cannot work under ideal circumstances such as those in prospective randomized controlled trials (RCTs) (Drummond, Sculpfer, Torrance, & O’Brien, 2005, p. 7; Institute of Medicine (IOM), 1990); 2) not effective – that is, the program does not work in everyday practice (Drummond et al., 2005; IOM, 1990); or 3) not available to anyone who could benefit from it (Drummond et al., 2005; Fox, 1996), then it is not “worth doing”. Similarly, a healthcare program or service may work in
practice and be available to those who need it, but the program may be *inefficient* – that is, the program is too costly or there are more benefits gained from investing the resources elsewhere (Drummond et al., 2005). Whereas most healthcare programs have undergone evaluations to determine whether they “work” and are “worth doing”, there have been relatively few documented evaluations of healthcare ethics programs despite their proliferation over the past 20 years. Like other healthcare programs, ethics programs must be able to demonstrate their effectiveness, and whether they are worth the resources invested in them. Without knowledge of whether ethics programs “work” in healthcare organizations, decision-makers such as healthcare administrators cannot determine whether ethics programs are “worth doing”.

Ethics programs report increasing pressure to demonstrate their effectiveness and to justify their call on resources (Crigger & Wynia, 2013; Fox, 1996; Sullivan, Ashbury, Pun, Pitt, Stipich & Neeson, 2011; Swetz et al., 2013). Resource investments into ethics programs may include ethicist and administrative staff salaries and benefits, office space and equipment, staff time to participate in ethics program structures (e.g., ethics committees) and activities (e.g., ethics education sessions), and costs associated with ongoing professional development of the ethicist and other ethics program personnel. As total healthcare expenditures continue to rise and ethics continues to gain importance in healthcare, it is becoming even more important for ethics programs to evaluate their effectiveness, availability, and efficiency (Fox, 1996). The importance of ethics program evaluation has been linked to: a) demonstrating contribution to ethics quality in health organizations, b) ensuring programs are meeting their goals, c) identifying inefficiencies and areas for targeted improvement, and d) justifying resource investment and expenditures (Fox, 2013; Gibson, Godkin, Tracy, & MacRae, 2008; Tulsky & Fox, 1996; Wynia, 2006). However, minimal empirical work has been done in evaluating ethics programs and determining how ethics programs contribute to, or impact healthcare organizations, healthcare professionals, and patients and families. A critical step before being able to evaluate ethics programs is being clear on how effectiveness is defined and what implications this has for its evaluation.

In order to evaluate the *effectiveness* of healthcare ethics programs – that is, whether healthcare ethics programs “work” – evaluators need an operational definition of *healthcare ethics program*
effectiveness. An operational definition is an “objective and measurable variable” that stakeholders agree is a “valid representation of the concept” (Hollander et al., 2010, p. 41). To date, however, there is a lack of consensus about how to operationalize the concept of healthcare ethics program effectiveness. Moreover, evaluations of ethics programs have followed a current trend in evaluation of simplifying evidence of effectiveness into a list of quantitative indicators devoid of context. According to Hollander and colleagues (2010), this evaluation approach tends to produce lower quality results because indicators need context to have meaning in evaluation. For example, are low costs an indicator of program efficiency, or do they indicate that costs have shifted to other parts of the organization? Often, as Hollander and colleagues (2010) argue, these kinds of evaluations result from an emphasis on accountability without reflection on the content, meaning, or relevance of indicators. Although many articles have identified indicators and success factors for ethics programs, ethics services, and ethics service providers, none has addressed whether these indicators and success factors are valid representations of the concept of healthcare ethics program effectiveness. This study intends to fill this gap in the literature by aiming to describe and operationalize the concept of effectiveness as it applies to healthcare ethics programs.

Although several authors have called for increased research into ethics effectiveness (Fox, 1996; Godkin et al., 2005; Griener & Storch, 1992; MacRae et al., 2005; Slowther & Hope, 2004; Williamson, McLean, & Connell, 2007), empirical research has been limited. There is a shortage of evidence as to: (a) how ethics programs are evaluated in practice; (b) what contributions, if any, they make to healthcare institutions; (c) whether ethics programs offer measurable benefits worthy of resource investment; (d) against what criteria or standards ethics programs ought to be evaluated; (e) how ethicists know whether their ethics programs are effective; and (f) under what conditions are ethics programs more or less effective. Most studies of ethics program effectiveness have used survey methods and have focused on a single component of ethics programs such as ethics case consultation, or a single ethics program model: the hospital ethics committee.¹ No sources reviewed for this study have explored the concept of

¹ The current state of empirical literature on ethics program evaluation is discussed in more depth, in chapter 2 of this thesis.
effectiveness as it applies to healthcare ethics programs as a whole or from the perspective of the ethicists leading these programs. Ethicists and other program stakeholders (e.g., funders, administrators, ethics service providers, etc.) have little evidence-based guidance about how to evaluate ethics program performance, establish a baseline for evaluation, improve the quality of ethics activities, or demonstrate ethics program value.

Despite the potential benefits of evaluating the effectiveness of healthcare ethics programs, no systematic evaluative framework including performance measures, benchmarks, or success factors, has been developed. One possible reason for this is that traditional methods for defining and evaluating the effectiveness of healthcare interventions – i.e., randomized controlled trials – may not be suitable for evaluating ethics services. Chen and Chen (2008) have argued that the randomized controlled trial (RCT) cannot be used to establish the effectiveness of ethics consultation given a lack of standardized practices for ethics consultation and lack of reasonable placebo. Similarly, Tulsky and Fox (1996) have argued that outcomes typically used in health services research to measure the effectiveness of healthcare interventions – i.e., mortality, morbidity, and functional status – “are wholly inappropriate for evaluating ethics consultation, and new measures must be created” (p.111). A comprehensive evaluation of healthcare ethics program effectiveness will require looking beyond a single ethics service to the multiple components of an ethics program. However, the same arguments against using the RCT or mortality rates to evaluate the effectiveness of ethics consultation can be made for ethics education, policy review and development, and other ethics program components. As such, defining and evaluating the effectiveness of ethics programs as a whole remains a complex challenge.

1.2 Key Definitions

For the purpose of this study, the term “ethicist” or “practising healthcare ethicist” refers to a person with advanced theoretical and practical training in ethics whose primary institutional role and accountability is to provide expert leadership in: ethics program management (including ethics committee management); clinical, organizational, and research ethics consultation; ethics education of staff, physicians, and other formally-affiliated actors (e.g., researchers, board members); policy development and review; and mentorship of staff and students in a healthcare
organization (Practicing Healthcare Ethicists Exploring Professionalization (PHEEP), 2011). The term “ethicist” excludes those whose primary professional role involves academic scholarship, undergraduate, graduate or post-graduate education, or Research Ethics Board management (PHEEP, 2011). *Ethicist* should be distinguished from ethics committee chairs or other formally designated individuals who play a supporting role in the planning and delivery of ethics program services, but whose primary institutional role and accountability is not to the ethics program (e.g., a clinical professional who sits on the ethics committee or serves on an ethics consultation team), who has basic but not advanced ethics training (e.g., ethics facilitator, post-graduate fellow, intern), or who participates in the ethics program primarily in a training capacity (e.g., student, post-graduate fellow) (Chidwick et al., 2010).

A “healthcare ethics program” or “ethics program” refers to a formal identifiable structure in a healthcare organization – and for the purpose of this study, led by an ethicist – that offers a variety of services to patients, families, healthcare providers, and administrators to identify and address ethical issues they encounter in the healthcare environment (Gibson et al., 2008). A *comprehensive* ethics program refers to an ethics program that delivers ethics consultation services in clinical and organizational ethics (and as appropriate, research ethics), provides ethics education opportunities for staff, physicians, and other institutional stakeholders, and plays a significant role in policy development and/or review. Comprehensive ethics programs should be distinguished from stand-alone ethics committees, ethics consultation teams, or other formal structures that are not led by an ethicist and offer only ethics consultation or policy review as services.

### 1.3 Study Goal and Objectives

The goal of this study was to describe and operationalize the concept of healthcare ethics program effectiveness. By operationalizing the concept of effectiveness, research findings will inform ethicist practice, facilitate efforts to evaluate healthcare ethics programs, and contribute to the research on effective ethics programs. Using qualitative methods, I explored the research question: *What makes an ethics program “effective” from the perspective of practicing healthcare ethicists in Canada?* Following from this research question, I identified five study objectives:
1. To describe how practicing healthcare ethicists define ethics program effectiveness.
2. To identify strategies that ethicists are using to evaluate the effectiveness of their ethics programs.
3. To identify factors that ethicists perceive as key enablers to achieving ethics program effectiveness.
4. To identify factors that ethicists perceive as barriers to achieving ethics program effectiveness.
5. To determine how evaluation of healthcare ethics program effectiveness might be improved.

I examined ethicists leading ethics programs in Canadian healthcare institutions that offer services in ethics consultation, ethics education, and policy development and/or review to patients, families, healthcare professionals, and administrative staff to address the numerous ethical issues that arise in healthcare settings. As program leaders, ethicists are uniquely positioned in healthcare organizations to comment on the concept of effectiveness as it applies to ethics programs as a whole. Ethicists have specific knowledge about the structure, activities, goals, resources, and factors that enable and impede the effectiveness of ethics programs. They are accountable for the delivery of ethics program services and for “developing quality improvement processes to measure and enhance effectiveness of the ethics program” (Chidwick et al., 2008, p.35).

1.4 Chapter Outline

In the next chapter, I review the existing literature on effectiveness as it relates to healthcare ethics programs. I begin by summarizing the theoretical literature related to ethics program effectiveness. I then identify the empirical work that has been done on this topic. By highlighting gaps and inadequacies in the existing literature, I provide the rationale for this study.

In Chapter 3, I describe the methods I used in this study. Specifically, I describe the use of qualitative methods to explore ethicists’ perspectives of ethics program effectiveness. I explain the process I used for data collection and analysis, and identify and respond to some of the limitations of the study design.
In Chapter 4, I present the study findings. This chapter begins with a description of how participating ethicists define effectiveness, including indications that ethicists use as supporting evidence of *effectiveness*. Next, I present the strategies that ethicists are using to evaluate ethics program effectiveness. I also describe the factors that participating ethicists perceive as key enablers of and barriers to achieving ethics program effectiveness.

In Chapter 5, I reflect on the study findings in light of the existing literature related to ethics program effectiveness. I discuss study implications on practice and the field of healthcare ethics. Finally, I identify some of the limitations of the study findings and future directions and research questions generated from the study findings.
Literature Review

In this chapter, I review the published literature on effectiveness as it relates to ethics programs in healthcare organizations. The chapter is divided into three sections. In the first section, I explore how ethics effectiveness has been defined and conceptualized in the theoretical and empirical literature. In the second section, I review articles focused on evaluation of healthcare ethics programs including: 1) ethics program models purported to improve effectiveness; 2) effectiveness of ethics program services; 3) characteristics of, and factors contributing to, effective ethics programs and services; 4) effectiveness of ethicists and those delivering ethics services, and 5) proposed evaluation strategies. Finally, I explore professional perspectives on ethics program effectiveness through a review of the emerging grey literature, including relevant policies and reports. By highlighting gaps and inadequacies in the existing literature, I provide the rationale for this study exploring what makes a healthcare ethics program effective.

2.1 Defining Ethics Effectiveness

In 1996, *The Journal of Clinical Ethics* published a series of articles devoted to framing conceptual issues and methodological questions around what (i.e., quality in terms of structure, process, and outcomes; access and availability, and/or efficiency) and how to evaluate ethics consultation. In their editorial, Tulsky and Fox (1996) identified two “unanswered” questions about ethics consultation: 1) Is it worthwhile? And 2) If ethics consultation is effective, “which models are the most effective and under what conditions are different models more or less effective?” (Tulsky & Fox, 1996, p. 111). They argued that the greatest barrier to evaluation was “the absence of a coherent conceptual framework and a deliberative, systematic, integrated, farsighted approach” (p. 111). Fox proposed that *effectiveness* could be defined as “the degree to which an intervention achieves it intended goals” (Fox, 1996, p. 118) and argued that in order to evaluate ethics consultation effectiveness, the goals of ethics consultation must be clearly specified. Fletcher and Siegler (1996) outlined a “consensus statement” on the goals of clinical
ethics consultation. A multidisciplinary group of 28 individuals used a “consensus-building” approach where they debated proposed goals of ethics consultation articulated in pre-completed questionnaires through group discussions, and revised, refined, and approved a final consensus statement that “could service as a guide to potential evaluators” (Fletcher & Siegler, 1996, p. 124). However, although these goals were clear, they were not sufficiently specified to provide a robust basis for evaluation (Fletcher & Siegler, 1996). Despite this early call for greater conceptual clarity on definitions of effectiveness, most of the research reported in the literature has been empirical in nature, using the term effectiveness without explicitly defining it. Gibson and colleagues (2008) recognized this gap in the literature, stating that although there is general clarity on the goals of clinical ethics, “it remains unclear how clinical ethics effectiveness should be defined and evaluated” (p. 322).

Where effectiveness is defined, the empirical literature highlights a wide variance in definition. For example, Dörries and colleagues (2011) discussed effective ethics committees as ones that integrate ethics throughout a healthcare organization. For Nelson and colleagues (2010a), an effective ethics committee enhances quality of care by proactively addressing ethical issues at a systems-level through the collaboration of ethics committees, clinicians, and quality improvement professionals; they distinguished this from less effective approaches which focus more narrowly on addressing discrete ethical issues on a case-by-case basis. For Davis (2006), an effective ethics program is one that has influence across the organization. He linked ethics program “success” to its ability to respond to the fluctuating needs of the healthcare organization and states that maintaining an ethics program, and ensuring the program is effective depends on the ethics program standardizing practice, and being flexible and adaptable to change.

### 2.2 Evaluation of Healthcare Ethics Programs

The literature on evaluation of healthcare ethics programs has tended to focus on evaluating effectiveness in ethics programs – that is, the effectiveness of discrete ethics program services

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2 Participants all had experience with ethics consultation, worked in a variety of settings, and represented “the fields of bioethics, clinical ethics, healthcare professionals, healthcare administration, social science, and health services research” (Tulsky & Fox, 1996, p. 112).
(e.g., ethics consultation), structures (e.g., hospital ethics committees), or ethics service providers (e.g., ethicists, ethics consultants, and ethics committee members). Few articles have discussed effectiveness of ethics programs, where the ethics program is the object of study. In the following sections, I outline the current literature on evaluating effectiveness in and of ethics programs.

2.2.1 Effectiveness of Ethics Program Models

A few articles explore the effectiveness of various ethics program models or structures (Altisent, Martin-Espildora, & Delgado-Marroquin, 2013; Bayley, 2006; Davis, 2006; Fox, Bottrell, Berkowitz, Chanko, Foglia, & Pearlman, 2010; MacRae et al., 2005; Mills, Rorty, & Spencer, 2006; Winkler, 2009). Many of these articles discuss a new ethics program model, compare it to traditional models, and argue that the new model is more effective than other models. These articles tend to identify the challenges facing other models and demonstrate how the new model addresses these challenges. For example, MacRae and colleagues (2005) describe the Hub and Spokes ethics program model as emphasizing “a commitment to improvement and effectiveness” (p.258). They claim that the Hub and Spokes model addresses the challenges faced by the lone ethicist model and other ethics programs that may not be integrated throughout an organization, sustainable from a resource investment perspective, or accountable for their performance. The goal of the Hub and Spokes model, which has been implemented in seven university-affiliated hospitals, is to “create a platform towards better evaluation and effectiveness” (p.256).

Similarly, Davis (2006) argues that the lone ethicist and ethics committees are “failing to thrive” because they have not yet evolved into programs integrated into the healthcare organization delivering ethics consultation, education, and research. Such programs are more likely to be successful in healthcare organizations compared to lone ethicists or ethics committees (Davis, 2006; Mills et al., 2006). Conversely, Altisent and colleagues (2013) argue that individual ethicists are more accessible, flexible, and timely in their response to ethical issues in the organization. Davis (2006), MacRae and colleagues (2005), and others who propose more “effective” ethics program models do not describe what definition or criteria they are using to judge effectiveness or success of the ethics program.
Others have used case study methodology to describe differences between ethics programs (Gaudine et al., 2011; Godkin et al., 2005; Neff-Smith, Giles, Spencer, & Fletcher, 1997). The Project Examining Effectiveness in Clinical Ethics (PEECE) study, for instance, used a retrospective case study approach to compare and contrast existing clinical ethics services in nine hospitals in the Toronto area (Godkin et al., 2005). PEECE describes the differences and similarities between their ethics programs in terms of: a) structure, b) activities, c) resources, d) accountability structures, e) program components, f) services offered, and g) evaluation strategies. They also found that six of the nine hospitals in this study had formal evaluation processes in place. These evaluation processes included annual reviews, goal setting, ethicist performance reviews, and evaluation feedback after educational activities.

A number of empirical articles explore the prevalence, function, and perceived impact of hospital ethics committees (Akabayashi, Slingsby, Nagao, Kai, & Sato, 2007; Becherlmann & Blechner, 2002; Coughlin & Watts, 1993; Fox et al., 2007; Gaudine et al., 2010; Gonsoulin, 2009; Johnston, 2010; La Puma et al., 1988; McGee, Spanogle, Caplan, & Asch, 2001; McGee et al., 2002; McNeill, 2001; Nelson, Rosenberg, Mackenzie, & Weeks, 2010; Slowther, Bunch, Woolnough, & Hope, 2001; Slowther et al., 2012; Storch, Griener, Marshall, & Olineck, 1990; Zhou et al., 2009). Many of these articles feature the results of surveys and questionnaires with ethics committee members and chairpersons, and ethics service end-users that included questions related to the perceived effectiveness, success, and impact of hospital ethics committees (Chwang, Landy & Sharp, 2007; Fretwell Wilson, Neff-Smith, Phillips, & Fletcher, 1993; Gaudine et al., 2010; Grady, Danis, Soeken, et al., 2008; Perkins & Saathoff, 1988; Schierton, 1992; Smith, Day, Collins, & Erenberg, 1992; Whitehead, Sokol, Bowman, & Sedgwick, 2009). For example, Schierton (1992) measured ethics committee success by examining the number of ethics committee outputs over a given amount of time: numbers of education sessions delivered, guidelines developed, and case consultations provided. Similarly, Gaudine and colleagues (2010) reported on findings of a 2008 survey that identified the “perceived effectiveness and impact” of hospital ethics committees (p.132). They asked survey respondents (mainly clinical ethics committee chairpersons) to rate the “overall effectiveness” of various committee functions and the impact of the ethics committee on the organization. Their results suggest that clinical ethics committees are “perceived as most effective” in providing ethics education, consultation
and support, and policy and procedure development, but not “as effective” in monitoring or evaluating the effectiveness of the ethics committee’s functions (p.136). Apart from listing a number of ethics committee functions and goals that survey respondents were asked to rate as effective or having a beneficial impact, Gaudine and colleagues (2010) do not discuss what constitutes effectiveness or beneficial impact. Moreover, they do not identify what evidence committees ought to use to rate themselves as “very effective” or “not effective” for each function, or as having a “beneficial” impact for each goal. The other surveys also lack definitions of effectiveness, success, and impact.

2.2.2 Effectiveness of Ethics Program Services

Although relatively few studies have explored ethics program effectiveness, there have been a number of articles on evaluating discrete ethics program services. Many articles related to healthcare ethics program evaluation break down ethics programs into discrete ethics services to be separately evaluated. A few articles address ethics education, or ethics policy development and/or review delivered by hospital ethics committees by identifying possible measures of effectiveness (Griener & Storch, 1992; Scheirton, 1992). Griener and Storch (1992), for example, propose evaluating the actual impact of a policy on practice as an outcome measure of effectiveness in policy development and review. The number of new policies developed by the ethics committee develops and adopted by the hospital may be a measure of the committee’s effectiveness, but this measure does account for the possibility that these new policies have negative effects on practice (Griener & Storch, 1992).

Most articles focus exclusively on clinical ethics consultation as a single ethics program service. For example, in 1996, The Journal of Clinical Ethics devoted a special section of the journal to the “Evaluation of Case Consultation in Clinical Ethics”. Over 10 years later, in 2009, the Cambridge Quarterly of Healthcare Ethics published a special section entitled the “Coming of Age in Clinical Ethics Consultation: Time for Assessment and Evaluation”. Articles in these journals have attempted to articulate goals, objectives, possible outcome measures, and proposed evaluation strategies for ethics consultation at the individual level (e.g., the specific patient, family, or healthcare professionals involved in a consultation) or at the organizational level (e.g., the long term effect on healthcare provider practice or the organizational climate). As noted
previously, Fletcher and Siegler (1996) proposed ethics consultation goals that could be used to evaluate the effectiveness of an ethics consultation service including: a) maximizing benefit and minimizing harm “to patients, families, healthcare professionals, and institutions”; b) facilitating conflict resolution; c) informing policy development, quality improvement, and resource allocation; and d) building ethics capacity in organizations (p. 125). Similarly, Fox and Arnold (1996) proposed evaluating the extent to which: a) clinical practice meets ethical standards; b) end-users are satisfied with the process and outcomes of ethics consultations; c) conflicts are resolved; and d) healthcare professionals and administrators are better able to address the ethical issues they encounter, as measures of the effectiveness of an ethics consultation service. In the 2009 issue, Aulisio and colleagues (2009) compare the numbers and types of ethics consultations before and after changing to a more integrated ethics consultation service and suggest that in their experience the change increased utilization of the ethics consultation service where it previously was “failing to thrive”. Pläfflin, Kobert, and Reiter-Theil (2009) propose four criteria for evaluating clinical ethics consultation: 1) content criteria (e.g., ethical content of consultations is clearly identified); 2) structural criteria (e.g., necessary people are involved in consultations); 3) process-oriented criteria (e.g., those involved in consultations are able to actively participate); and 4) outcome-oriented criteria (e.g., consultations have “fair and satisfying” results) (p. 412).

One gap in these articles about the goals and outcomes proposed to evaluate effectiveness is that they do not lead directly to developing evaluation strategies for ethics programs or to a better understanding of what constitutes effectiveness in the context of healthcare ethics programs. Whether these are the goals that ethics programs actually aim to achieve in practice and do achieve in practice is unknown. Tulsky and Fox (1996), for instance, argued that ethics consultation has the potential to be a “worthwhile service” and yet “rigorous studies demonstrating that consultation yields beneficial outcomes for patients remain to be conducted” (p. 110). They state that the only way to assess the actual impact of ethics services is to determine whether ethics services are achieving their intended goals and what the unintended consequences are for patients, healthcare professionals, and organizations. However, what constitutes evidence of meeting goals in practice has not yet been determined. For example, what is evidence that healthcare professionals are better able to address the ethical issues they
encounter in practice? As Fox and Arnold (1996) have noted, valid measurement tools to evaluate the outcomes of ethics consultation, or other ethics services have yet to be developed.

Although the theoretical literature emphasizes uncertainty about measures of effectiveness, a number of process and outcome measures have been used in studies attempting to evaluate ethics services and ethics service providers. These measures include: a) end-user satisfaction and perceived level of helpfulness of ethics consultations (Chwang et al., 2007; DuVal, Clarridge, Gensler, & Danis, 2004; Ehleben, Childs, & Saltzman, 1998; La Puma & Darling, 1992; McClung, Kamer, DeLuca, & Barber, 1996; Schneiderman et al., 2006; Yen & Schneiderman, 1999); b) staff awareness of ethics resources; c) increased ethics program outputs such as the number of ethics consultations or education sessions delivered (Romano, Wahlander, Lang, Li, & Prager, 2009; Swetz, Crowley, Hook, & Mueller, 2007; Whitehead et al., 2009); d) ethics program service utilization (Smith et al., 1992); e) accessibility and availability of ethics services (Hurst, Reiter-Theil, Perrier, et al., 2007); and f) mortality, length of stay, and number of days receiving artificial nutrition, hydration, and ventilation for patients in the intensive care unit following an ethics consultation (Schneiderman, Gilmer, & Teetzel, 2000; Schniederman, Gilmer, & Teetzel, 2003). A handful of qualitative studies also contain references to ethics program stakeholder perceptions of what constitutes evidence of effective ethics practice of: a) ethics committees (Racine, 2007; Rawlins & Bradley, 1990); b) clinical ethics consultations (Førde et al., 2008; Orr, Morton, deLeon, & Fals, 1996); c) ethics rounds (Svantesson, Löfmark, Thorsén, Kallenberg, & Ahlström, 2008); and d) ethicists’ roles in managing ethical issues (Frolic & Chidwick, 2010). This evidence is summarized in the table below.

Table 1: EVIDENCE OF EFFECTIVE OR SUCCESSFUL ETHICS SERVICES AND/OR PROVIDERS

<table>
<thead>
<tr>
<th>Evidence of effective or successful ethics services and/or ethics service providers</th>
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<tbody>
<tr>
<td>End-users are satisfied with process and outcome of the ethics service.</td>
</tr>
<tr>
<td>End-users find the ethics services helpful.</td>
</tr>
<tr>
<td>The ethics service is responsive to the needs of the organization.</td>
</tr>
<tr>
<td>Qualified individuals deliver ethics services.</td>
</tr>
<tr>
<td>There is ethical reflection integrated throughout the organization.</td>
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</tbody>
</table>
Patient outcomes are improved.
Decision-making in the organization is transparent and considers values.
Ethics services proactively address ethical issues.
Staff satisfaction is improved.
The ethicist collaborates with other areas of the organization, like quality improvement.
There are mechanisms for sharing best practices.

There is currently no consensus in the literature, however, about whether the indicators, measures, or evidence identified in the literature are valid representations of effectiveness. For instance, Williamson, McLean, and Connell (2007) argue that using end-user satisfaction as a primary measure of the “value of ethics services can be problematic” given that satisfaction is subjective and not necessarily related to the quality of service (p.3). Moreover, indicators, measures, or evidence of ethics service effectiveness may not represent ethics program effectiveness, as the effectiveness of ethics programs may not be reducable to the effectiveness of discrete ethics program services (Tulksy & Fox, 1996).

2.2.3 Factors Contributing to Effective Ethics Programs

A number of other articles that discuss the effectiveness of ethics programs identify factors that may contribute to ethics program effectiveness. The vast majority of the literature is focused on ethics program models built around ethics committees or ethics consultation services (Dörries, Boitte, Borovecki, Cobbaut, Reiter-Theil, & Slowther, 2011; Dubler, Webber, Swiderski, & the National Working Group for the Clinical Ethics Credentialing Project Faculty, 2009; Fukuyama, Asai, Itai, & Bito, 2008; Hoffman, 1993; Mills et al., 2006; Nilson, Acres, Tamerin, & Fins, 2008; Opel, Wilfond, Brownstein, Diekema, & Pearlman, 2009). Only a few articles identify factors contributing to the effectiveness of comprehensive ethics programs led by an ethicist (Chidwick et al., 2010; MacRae et al., 2005). The literature is comprised primarily of expert reflections on ethics programs by practising healthcare ethicists or by ethics scholars linked to healthcare ethics programs through academically affiliated healthcare organizations rather than empirical studies per se.
Dörries, Boitte, Borovecki and colleagues (2011) identify factors that may prevent clinical ethics committees from, or enable them to, integrate ethics in a healthcare organization. According to Dörries and colleagues (2011), misperceptions of the ethics programs as the “ethics police” and a lack of knowledge around how to demonstrate their value present challenges for ethics committees. Being strategically positioned in a healthcare organization, responsive to the organization’s needs, and “proactive” can act as enablers to integration (Dörries et al., 2011). Similarly, Chidwick and colleagues (2010) identify organizational culture, context, and needs; the resource investment (e.g., support staff) into an ethics program; and an ethicists’ skills, background, and interests as factors that affect whether an ethicist will be able to be effective in a healthcare organization.

Common characteristics of or factors contributing to effective ethics services in the literature include: a) being proactive, b) being responsive to organizational needs, c) having standards of practice, d) using qualified ethics service providers, e) being integrated throughout the organization, f) having adequate and ongoing resource support, and g) being accountable to senior leadership for ethics program performance. A few authors also compare ethics programs where these factors or characteristics are present to those where they are lacking and propose that the former are more effective than the latter (Davis, 2006; Dubler et al., 2009; Fox et al., 2010; Mills et al., 2006). These comparisons are summarized in the table below.

Table 2: PROPOSED CHARACTERISTICS AFFECTING ETHICS PROGRAM EFFECTIVENESS

<table>
<thead>
<tr>
<th>Characteristics of more effective ethics programs</th>
<th>Characteristics of less effective ethics programs</th>
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<tbody>
<tr>
<td>Integrated through the healthcare organization</td>
<td>Isolated in one area of the organization</td>
</tr>
<tr>
<td>Offers a range of services</td>
<td>Focused on one service (e.g., consultation)</td>
</tr>
<tr>
<td>Comprehensive program model led by an ethicist</td>
<td>Lone committee or ethicist</td>
</tr>
<tr>
<td>Qualified ethics service providers</td>
<td>Ethics service providers lacking requisite skills</td>
</tr>
<tr>
<td>Proactive</td>
<td>Reactive</td>
</tr>
<tr>
<td>Accountable to senior leadership</td>
<td>Unclear reporting relationship</td>
</tr>
<tr>
<td>Has clear practice standards</td>
<td>Use <em>ad hoc</em> approaches to practice</td>
</tr>
</tbody>
</table>
A number of articles feature ethics service providers describing the “evolution” of their ethics programs and identify the factors that contributed to “successful” ethics programs, and “lessons learned” to inform the development of other ethics programs and future research on effectiveness (Aulisio, Moore, Blanchard, Bailey, & Smith, 2009; Boyle, 2008; Chidwick, Faith, Godkin, & Hardingham, 2004; Doyal & Colvin, 2002; Fox et al., 2010; Guo & Schick, 2003; Hardingham, Faith, Godkin, & Chidwick, 2011; Murphy, 2006; Pläfflin et al., 2009; Slowther, 2008; Turner, 2003; White II, 2006). For example, Boyle (2008) describes developing ethics services that “add demonstrable value” to healthcare organizations and delineates five “guiding principles” that would be indications of an ethics service that adds value: 1) “ethical reflection” is built into all processes across the organization; 2) “ethics mechanisms” help transform the organization by identifying and addressing ethical issues; 3) organizational decision-making is transparent; 4) actual and potential ethical issues are addressed proactively; and 5) ethics mechanisms are evaluated based on whether they: lead to better quality care, increase staff satisfaction, and advance organizational values (p. 5-6). Similarly, Chidwick and colleagues (2004) describe what they, as practising clinical ethicists, perceived as key elements that “appeared to contribute to an effective clinical ethics program” and to their success as clinical ethicists: integration; organizational support and resource investment; a community of practice “within and outside of the field of ethics”; and the ethicists’ skill set.

### 2.2.4 Effectiveness of Ethicists and Other Ethics Services Providers

Another factor associated with ethics program effectiveness in the literature is the effectiveness of those delivering ethics services. Many authors have discussed the necessary skills, competencies, and education background of ethicists, ethics consultants, and clinical ethics committee members (Chidwick et al., 2010; Childs, 2009; Davis, 2006; Dubler et al., 2009; Hamel, Slosar, & Repenshek, 2013; Hoffmann, Tarzian, & O’Neil, 2000; Kesselheim, Johnson,
& Joffe, 2010; Larcher, Slowther, Watson & the UK Clinical Ethics Network, 2010; Russell & Pape, 2007; Silva, Gibson, Sibbald, Connolly, & Singer, 2008; Tarzian, 2009). In a qualitative study involving interviews with practising healthcare ethicists about organizational ethics, Silva, Gibson, Sibbald, and colleagues (2008) reported that ethicists perceived a lack of “institutional savvy” and “knowledge and understanding of organisational decision-making” (p. 322) as a limitation to their effectiveness in addressing organizational ethics issues. To be effective in addressing such issues, Silva and colleagues (2008) suggest that clinical ethicists need skills “to navigate and sustain complex institutional relationships” and “a practical understanding of: how organisational decisions are made, the functional roles and responsibilities of different institutional actors, and the healthcare environment within which the organisation functions” (p. 323). Similarly, Foglia, Pearlman, Bottrell, and colleagues (2009) suggest that in order for ethics committees to meet “key institutional stakeholders needs” and help address organizational ethics issues, ethics committees will need to include individuals with knowledge of health systems, finance, and human resources (p. 34).

A few articles are written as critical reflections by practising ethicists on how ethicist knowledge, skills, and/or practice relate to effectiveness. For example, Russell and Pape (2007) described four kinds of knowledge necessary for ethicists to perform successful ethics consultations: 1) knowing the facts and ethics content of presenting ethical issues; 2) knowing the process of how to perform ethics consultations; 3) knowing why ethical issues arise; and 4) knowing how and when to apply their skills in each ethics consultation. Similarly, Hardingham, Faith, Godkin, and Chidwick (2011), reflecting on their transition from ethics trainees to practising full-time ethicists, identified four key lessons they learned in their first year of practice about how to be successful in their new professional role: 1) “attending to the process” of ethics services, and not only focusing on outcomes; 2) “building relationships” and developing “ethics champions” in the organization; 3) “facing resistance” and gaining ethics program end-user trust, and 4) “keeping the vision” by managing misperceptions of the ethics program role.

There is some disagreement in the literature, however, as to which skills and competencies contribute to or impede effectiveness. For example, Chwang, Landy and Sharp (2007) found that individuals who perform ethics consultations require ethics expertise and knowledge of
clinical practice in order to “contribute effectively” to patient care in the intensive care unit (p. 320). Whereas Schierton (1992) found that having a physician chair the ethics committee was one of the factors that impeded the committee’s success and decreased effectiveness. A physician chair, according to Schierton (1992), was more likely to have trouble gaining the trust of non-physicians on the ethics committee who perceived physicians as biased and loyal towards other physicians and of non-committee member physicians who perceived ethics committees with distrust, regardless of the physician chair’s level of ethics expertise.

In many articles, authors emphasize the need to account for the performance of ethicists and other individuals who deliver ethics services, particularly to justify the existence of ethics programs in healthcare organizations (Agitch, 2009; Dubler et al., 2009; Guerrier, 2006; Fox, 1996; Slowther & Hope, 2000; Slowther et al., 2012). Dubler and colleagues (2009) argue that ethics committees and ethics consultants should be just as transparent and accountable as other clinical services in healthcare organizations. Ethics services should be regularly evaluated through peer review and a quality improvement process to determine whether they “meet established and evolving standards” (Dubler et al., 2009, p. 33). These discussions around qualifications, skills, and standards are reflected in a current movement in the field towards credentialing, standardization, and the professionalization of healthcare ethics, which defines practice standards and competencies for individuals who deliver ethics services3 (Acres, Prager, Hardart, & Fins, 2012).

2.2.5 Proposed Evaluation Strategies

In writing about ethics committees, Bernard Lo (1987) was one of the first authors to articulate evaluation criteria against which such committees should be judged. These included: patient and family access to the ethics committee; transparency of decision-making; satisfaction with the ethics committee review process and recommendations; consistency of committee

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3 The move towards professionalization in the field of healthcare ethics is described in more detail in Section 2.3.
recommendations and actions taken with legal and ethical principles; and existence of an internal review mechanism to ensure these criteria are met. Since then, others have proposed evaluation criteria and strategies for ethics committees (Hoffman, 1993; Wilson et al., 1993), ethics consultation (Pläfflin et al., 2009; White, Dunn, & Homer, 1997) and ethics service providers (Chwang et al., 2007; Tarzian & the ASBH Core Competencies Update Task Force, 2013). Few, however, have proposed how to evaluate the effectiveness of comprehensive ethics programs, even though there is recognition that any robust evaluation should include an evaluation of more than just ethics consultation (Gordon, 2007; Griener & Storch, 1992; Hoffman, 1993; Tulsky & Fox, 1996). For example, Davis (2006) proposed that an “effective” strategy to evaluate the impact on moving to an ethics program from an ethics committee is to assess organizational climate and the ethical issues that arise in an organization by reviewing ethics consultations performed over time to identify trends. Hoffman (1993) proposes a criteria-based evaluation framework for ethics committee functions (i.e., consultation, education, policy development) based on an assessment of access, quality, and cost-effectiveness. Tulsky and Fox (1996) proposed a pre-post evaluation strategy to document the effect of an ethics intervention on clinical practice. In addition, they recommended that ethics consultation activity should be tracked in a database to aid in identifying patterns or trends in consultations such as the number of consultation requests, types of ethical issues consulted on, and the areas of the hospital that are requesting ethics consultations.

Tulsky and Stocking (1996) described potential research designs for evaluating the effectiveness of ethics consultation, including: a) randomised controlled trials; b) a “pre/post/pre study” where data would be collected before providing ethics consultation, during a period of time when ethics consultation was provided, and a period of time after returning to the pre-intervention state in order to evaluate whether ethics consultation made a difference, or if the differences were due to temporal trends; and c) pre/post intervention assessments without a return to the pre-intervention state.

According to Lo (1987), the “gold standard” of consistency with legal and ethics principles is that recommendations and actions taken are consistent with issues that have “widespread consensus”, found in Jonsen (1983) as statements on ethical issues set out by the President’s Commission for the Study of the Ethical Problems in Medicine and Biomedical and Behavioral Research. These statements are “as close as could be, consensus opinions” on how certain ethical issues should be approached in healthcare (Jonsen, 1983, p.262).
state. Schneiderman, Gilmer, and Teetzel (2000; 2003) employed a randomised controlled trial design to examine the effect of ethics consultation on patients in the intensive care unit of a hospital. Svantesson, Anderzén-Carlsson, Thorsén, Kallenberg, & Ahlström, (2008) proposed using a pre/post intervention design based on quantitative and qualitative data analysis to understand whether applying an ethics intervention (e.g., ethics consultation, ethics rounds, etc.) or introducing an ethics program in an organization has any effect on clinical practice or organizational climate.

Although most authors recognize that prospective randomised controlled studies would provide the strongest evidence of the effectiveness (Black, 1996; Fox & Tulsky, 1996; Sibbald & Roland, 1998; Tulsky & Stocking, 1996), a few argue that these types of studies are not the “right tool” for evaluating the effectiveness of ethics services (Chen & Chen, 2008; Fox & Tulsky, 1996). The empirical literature has demonstrated the variability of ethics services across ethics service providers, programs, and organizations; as such, using randomised controlled trials to evaluate ethics services such as ethics consultation is, as Chen & Chen (2008) state, “methodologically problematic” (p. 595). These and other challenges to evaluating ethics programs in healthcare organizations have prevented empirical research from being conducted on evaluation and effectiveness in the context of healthcare ethics programs. Fox and Tulsky (1996), for example, claim that pre and post evaluations are time-consuming and demanding. Others have pointed to the lack of “valid and reliable measures” of quality and effectiveness (Dubler et al., 2009; Hoffman, 1993). Whatever the reason, there remains a lack of rigorous empirical research or evaluations of healthcare ethics program effectiveness in the literature, to date.

2.3 Policy Documents and Professional Group Perspectives

Current policy documents and professional group perspectives have addressed issues related to ethics program effectiveness, mainly through delineation of standards for healthcare organizations and ethics service providers. Healthcare accrediting bodies such as Accreditation Canada and the Joint Commission have articulated standards related to ethics that healthcare organizations are required to meet in order to receive accreditation (Accreditation Canada, 2008; Joint Commission Resources, 2011). Similarly, national bioethics societies such as the Canadian Bioethics Society (CBS) and the American Society for Bioethics and Humanities (ASBH), and
other professional groups have begun exploring and articulating practice standards and core competencies for ethics programs and providers, namely ethicists and ethics consultants.

Accreditation Canada requires organizations to: a) develop and implement ethics frameworks that define a formal process for addressing ethical issues, and ensure that staff know how to use the framework; b) build capacity in the organization to address ethical issues; c) work to improve worklife culture and reduce staff stress and fatigue; and d) incorporate ethical considerations into resource allocation decisions (Accreditation Canada, 2008). The Accreditation Canada standards, as they are applied nationally across most healthcare organizations, are increasingly being used by healthcare organizations as a way of demonstrating that ethics programs are meeting relevant ethics-related standards. However, the standards articulated in these policy documents were not developed as a means of assessing ethics program effectiveness, but rather for assessing quality and safety of healthcare organizations. Moreover, standards were not developed using scientific methods, nor is there wide consensus on whether these standards are valid representations of healthcare ethics program effectiveness.

In the United States, the Department of Veterans Affairs (VA) National Center for Ethics in Health Care’s Integrated Ethics model is “a comprehensive approach to managing ethics in healthcare organizations” with the goal of improving “ethics quality” in healthcare organizations (NCEHC, 2013a). This model integrates ethics consultation for clinical ethics issues, “preventive ethics – addressing ethical issues on a systems level”, and “ethical leadership – creating a positive health care ethics environment” in order to achieve high quality ethical healthcare practices (Fox, 2005). As Foglia, Cohen, Pearlman, and colleagues (2013) explain, to sustain ethics quality improvement, ethics programs need to focus on ethical practices in: “decisions and actions, systems and processes, and environment and culture” (p. 44). “Striving for Excellence in Ethics” by The Catholic Health Association of the United States (CHAUSA) and Ascension Health (2011) outlines the essential components of a “robust” ethics program, standards for these components, and an assessment tool for measuring the extent to which standards are met (Hamel et al., 2013). In “Striving for Excellence in Ethics”, the essential components are: 1) ethics expertise; 2) ethics committees; 3) ethics consultation; 4) ethics education; 5) policy review and development; 6) community outreach; 7) institutional
integration; and 8) leadership support (The Catholic Health Association of the United States (CHAUSA) & Ascension Health, 2011). Finally, the University of Toronto Joint Centre for Bioethics has proposed an “Ethics Roadmap” that outlines four stages in an ethics program’s development over time – from “emerging” to “achieving [standards]” to “excelling” to “leading” – and specifies key characteristics and guiding principles at each developmental stage (Gibson, Faith, Kaufman, & Winsor, 2011). The roadmap has been piloted in two healthcare organizations in conjunction with strategic and operational planning for the ethics program (unpublished findings).

The ASBH and the CBS have been actively involved in efforts to professionalize and standardize ethics practice, largely in response to concerns that those who provide ethics consultations are not sufficiently qualified to do so (Aulisio, Arnold, Younger, and the Society for Health and Human Values and Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, 2000; Childs, 2009; Clinical Ethics Consultation Affairs (CECA) Committee, 2010; Coughlin et al., 2008; Dubler et al., 2009; Frolic, 2012). Many practising ethicists have argued that credentialing ethics service providers will help ensure that they have the skills necessary to “effectively” practice ethics (Ipatkchian, 2011, p. 14). The ASBH’s “core competencies” for ethics consultants, for example, define the requisite skills, knowledge, “attributes”, attitudes, and behaviours for effective ethics consultation (American Society for Bioethics and Humanities (ASBH) Core Competencies Update Task Force, 2011; Tarzian et al., 2013). Tarzian and the ASBH Core Competencies Update Task Force (2013), for example, argue that meeting standards helps ensure high quality healthcare ethics consultation. Moreover, ethics consultation that adheres to best practice standards facilitates research and evaluation of ethics consultation. Similarly, the United Kingdom UK Clinical Ethics Network (UKCEN) issued a “consensus statement on core competencies for clinical ethics committees” in response to the Royal College of Physicians’ 2005 report on Ethics in Practice that recommended that

5 ASBH core competencies for ethics consultants include: a) skills in ethical assessment, process, and evaluation and quality improvement; b) the ability to run an “effective” service; c) knowledge of moral reasoning, ethical theory, and common bioethical issues and concepts; and d) “attributes”, attitudes, and behaviours in leadership, courage, and integrity.
effective clinical ethics committees require stated core competencies and training for members to acquire these competencies (Larcher et al., 2007). These professional group perspectives, however, presume that ethics services are “effective” and “worthwhile” activities if delivered by qualified individuals (Bishop, Fanning, & Blinton, 2009; Tulsky & Fox, 1996). Moreover, the professional discourse on credentialing and standardization does not define what constitutes an effective ethics service or program.

In Canada, there has been an increasing focus on the practice of ethicists in healthcare ethics programs. The Canadian Bioethics Society created a “Taskforce on Working Conditions for Bioethics” in 1999 to develop a common role description and code of ethics for healthcare ethicists, and identify mechanisms for resolving issues concerning an ethicist’s “moral integrity” (MacDonald et al., 2000; Chidwick et al., 2010). Almost 10 years later, the Taskforce drafted a set of ideal role and responsibilities for ethicists, recognizing that each ethicist’s priorities will differ based on: (1) organizational context, culture, and needs; 2) ethicist skills, background, and interests; and (3) the ethics program’s human resources. The Taskforce’s work in describing what ethicists do was meant to help communicate the value of ethicists to healthcare organizations, and was a prerequisite to being able to evaluate ethicist performance (Chidwick et al., 2010). Building on the work of the Taskforce, a group of practising healthcare ethicists formed Practicing Healthcare Ethicists Exploring Professionalization (PHEEP) in 2009, in response to growing concerns about the lack of practice standards for ethicists (Frolic, 2012). In contrast to the ASBH Core Competencies Update Task Force’s focus on competencies for ethics consultants, PHEEP focuses on standards of practice for ethicists across the entire range of ethics services that they provide (Frolic, 2012). According to Reel (2012), such standards set out the minimum expectations for ethicists’ practice and performance, and guide evaluation of ethicists’ practice. In 2012, the HEC Forum featured PHEEP’s work in a special issue of the journal, with articles addressing: the nature, history, and arguments for and against professionalization; conceptual and practical issues related to developing and implementing a model of professionalization; possible practice standards for ethicists; and linkages between practice standards and ethicist training programs (Simpson, 2012). PHEEP’s next steps include pursuing an empirical study to examine ethicists’ “lived experiences” and the differences in ethicist practice across Canada (Frolic, 2012). PHEEP’s hope is that their work will lead to more
sustainable, effective, and accountable ethicists and ethics programs; improve the quality of ethics services delivered in healthcare organizations; and optimize resource investments into ethics programs (Frolic, 2012). PHEEP’s work is an important step towards defining and evaluating ethicists’ practice in healthcare ethics programs; however, their work to date has not explored the concept of **effectiveness** as it applies to ethics programs.

### 2.4 Key Knowledge Gaps

Almost all of the literature related to ethics program effectiveness suggests an increasing focus on the quality and evaluation of ethicists, ethics services, and ethics programs in healthcare organizations, and highlights the need for more research in this area (Agich, 2009; Frolic, 2012; Griener & Storch, 1992; Hoffman, 1993; Williamson, 2007; Williamson et al., 2007). Whether theoretical, empirical, or policy or professional group perspectives, the literature emphasizes the paucity of empirical research studies on the effectiveness of ethics programs and the need to address this gap.

Even though most authors discuss effectiveness in the context of healthcare ethics programs, much of the literature presupposes a shared meaning of the concept of effectiveness. The literature lacks a robust definition of effectiveness as it applies to ethics programs. The literature has left many unanswered questions about the concept of **healthcare ethics program effectiveness**. Specifically, how is the concept of **healthcare ethics program effectiveness** defined in practice? How it is measured? How is it evaluated? What counts as evidence of ethics program effectiveness and from whose perspective?

The literature contains several empirical articles on effectiveness in ethics programs, notably the effectiveness of ethics program services such as ethics consultation, the effectiveness of ethics program structures such as the hospital ethics committee, and the effectiveness of ethics program personnel such as ethicists and ethics consultants; however, few studies have examined the effectiveness of healthcare ethics programs as a whole. There is a gap in knowledge of how ethics program effectiveness is understood and whether effectiveness of ethics programs is distinct from effectiveness in ethics programs – that is, the effectiveness of discrete ethics program components. Moreover, there is a gap in knowledge of how to evaluate effectiveness of
ethics programs, and what ethics program services, components, or factors contribute to, or are barriers to effectiveness.

Only a few studies have examined effectiveness from the perspective of ethicists and this work has mainly consisted of reflections on personal experience beginning with the presumption that ethics programs are worthwhile endeavours. None of the literature reviewed for this study has used qualitative methods to explore the concept of effectiveness as it applies to healthcare ethics programs as a whole, in Canada or abroad, or from the perspectives of the ethicists leading these programs. Exploring effectiveness from ethicists’ perspectives is important because of their unique position as ethics program leaders with specific knowledge of the structure and function of ethics programs. The lack of articles from the perspective of practising ethicists, as individuals with the primary responsibility and accountability for delivering ethics program services, constitutes a critical gap in the literature.

This research study is a first step in addressing gaps in the literature about how to conceptualize, measure, and evaluate healthcare ethics program effectiveness in practice. This study addresses ethics programs as a whole, and includes different ethics program models. By addressing comprehensive ethics programs a whole, this study avoids what Tulsky and Fox (1996) have called the “strong temptation” to separate ethics program evaluation into evaluations of ethics program components and not whole programs. This temptation, according to the authors, ought to be overcome given that the different roles of ethics programs are “not as easily separated in practice as they are in theory” (p. 7).

Given the paucity of applied research on ethics program effectiveness, particularly on how to conceptualize healthcare ethics program effectiveness and what factors contribute to effective ethics programs, I sought out to explore: What makes an ethics program effective from the perspective of ethicists? The purpose of this study was to operationalize the concept of healthcare ethics program effectiveness in order to inform the current practice of ethicists, improve ethics program evaluation, and contribute to the literature on ethics program effectiveness.
Methods

Qualitative methods are the method of choice when there is little known about a research topic or about a concept (Morse & Field, 1995). According to Morse and Field (1995), if a topic has not been thoroughly investigated or there is little information about a phenomenon in the literature, “an exploratory descriptive study using qualitative methods should be conducted” (p. 13) rather than a study using quantitative methods. Qualitative methods are also best when investigating complex phenomena in natural settings (Patton, 2002). Given the lack of literature on the concept of effectiveness as it applies to healthcare ethics programs and the complexity of healthcare ethics programs, qualitative methods were particularly suited to explore how ethicists define effectiveness of healthcare ethics programs. Qualitative methods were used in this study to gain in-depth information and develop a rich description of ethicists’ perspectives of ethics program effectiveness.

In this chapter, I describe the qualitative tradition and theoretical orientation for my research. Next, I identify the approaches I used for sampling and participant recruitment. Following a brief discussion of ethical considerations to protect study participants, I detail the process that I used for data collection and data analysis. Finally, I discuss issues of credibility, rigor, and methodological limitations of the study.

3.1 Qualitative Tradition and Theoretical Orientation

For this research, I adopted the tradition of qualitative description as described by Sandelowski (2000) to produce a “comprehensive summary of events in the everyday terms of those events” (p. 334). I chose this approach because it is particularly useful when a simple description in participants’ own language is desired and research questions are policy and practice-relevant. I used qualitative description to obtain practicing ethicists’ definitions of “effectiveness of ethics programs”, the strategies they are using to evaluate their ethics programs, and the factors they believe contribute to, or impede, healthcare ethics program effectiveness. Given that one purpose of the study is to inform the current practice of ethicists, a rich description summarizing how ethicists defined and evaluated effectiveness and what ethicists thought were enablers and
barriers of effectiveness using language that ethicists themselves used will facilitate sharing study results with practicing ethicists and addressing study implications in practice.

Qualitative description is also particularly suited to gathering minimally theorized “answers to questions of special relevance to practitioners and policy makers” (Sandelowski, 2000, p. 337). The questions “how do ethicists define effectiveness”, “what factors contribute to an effective program”, and “how do ethicists evaluate their ethics programs” are not only relevant to practicing ethicists, but also to healthcare administrators deciding whether to invest or continue to invest resources into ethics programs, to accreditation and professional bodies developing standards for ethics programs and ethicists, and to researchers interested in ethics program evaluation research.

As is common in qualitative descriptive studies, naturalistic inquiry was the theoretical orientation that guided this research (Sandelowski, 2000; Sandelowski, 2010). This orientation involves studying phenomena in as natural a state as much as a research study allows rather than trying to control or create conditions, like in a laboratory setting (Lincoln & Guba, 1985). Naturalistic inquiry aims to understand how people experience, interpret, and construct events in the real world (Kuzel, 1998). Accordingly, I did not commit, a priori, to a theoretical view of healthcare ethics program effectiveness (Sandelowski, 2000). Moreover, effectiveness has not yet been theorized in research on healthcare ethics program evaluation. Instead, I used an inductive approach, deriving themes from the study data. I recognized these data as resulting from my interviews with participants as opposed to resulting from nature (Lincoln & Guba, 1985).

3.2 Sampling

I used “purposeful sampling” – a strategy where the researcher strategically seeks out participants to fit with the research goals and objectives (Patton, 1990). In this study, I used this sampling approach to identify and select key informants from a list of practising healthcare ethicists in Canada who would be able to provide rich information and useful insight about the effectiveness of healthcare ethics programs (Patton, 1990). Within this sampling approach, I used “maximum variation sampling” – selecting a diverse range of individuals to capture
common themes within the variation and “snowball sampling” – selecting individuals relevant to the study and asking them to recommend other relevant individuals (Patton, 1990).

To select participants for study inclusion, I used maximum variation sampling. I sought variation in the disciplinary background of participating ethicists, years of experience as an ethicist, and the type, size and geographic location of the healthcare organizations where ethicists work. By selecting a diverse sample, I was able to explore shared and unique ways in which different ethicists define effectiveness and evaluate their programs. In addition, according to Patton (1990), data collection and analysis of a small, but diverse sample yields rich descriptions and shared patterns from across a wide variety of sources. After each key informant interview, I asked the study participant, “What other ethicists do you think I should talk to that are thinking about ethics program effectiveness and how to evaluate ethics programs?” This “snowball sampling” technique generated a list of potential information-rich key informants (Patton, 1990). Using “snowball sampling” enabled me to identify key individuals who were recognized by their peers as able to contribute meaningful and relevant information to the study.

My sample included 15 practicing healthcare ethicists from across Canada: eight from Central provinces, four from Western Canada, and three from Atlantic Canada. Half of the sample had humanities backgrounds (e.g., philosophy, law, theology, etc.) and the remaining half had clinical backgrounds (e.g., medicine, nursing, social work, etc.).6 Their experience working as ethicists ranged from one year to more than 10 years. About half of the sample had been practicing as an ethicist for more than five years. I selected participants from organizations ranging from single-site to multi-site, from academic health centres, hospitals, long-term care centres, and regional health authorities, and located in urban, suburban and rural areas. Most participants were in solo ethicist practices, where they were the only ethicist in their institution. A few participants worked on a team with other ethicists. A notable portion of participants had access to formal and/or informal networks of other practising ethicists in their region. All

6 Given the relatively small bioethics community in Canada, to safeguard anonymity of the study participants, I have not identified the number of ethicists per specific disciplinary backgrounds or the specific provinces in which they work.
participants worked in ethics programs offering ethics consultation, education and training, and policy development and/or review as ethics program services. I stopped sampling after 15 ethicists when the final few interviews generated very little new information. One criterion for informing a decision to stop sampling is when saturation is reached – that is, when collecting more data does not produce enough new information to justify data collection efforts (Lincoln and Guba, 1985). Fifteen sampling units is also consistent with Kuzel (1999) who writes that sample size in qualitative research is not fixed, but when aiming for maximum variation, between 12 to 20 sampling units are generally required. Moreover, the goal of this qualitative study was not to generalize findings to all ethicists in all healthcare ethics programs, which might be the goal of a quantitative study, but rather to describe emerging themes within a variation of ethicists and ethics programs across Canada.

3.3 Participant Recruitment

Participants were recruited from across Canada via email through the Canadian Bioethics Society, a national professional bioethics network. The Canadian Bioethics Society Executive Committee approved sending a recruitment letter to the Society’s listserv (Appendix A). The listserv includes the emails of healthcare ethicists across Canada. The recruitment email included a summary description of the study, inclusion and exclusion criteria, and contact information for the researchers. Potential participants were asked to contact me directly if they met the criteria and were interested in more information about participating in the study.

Within two weeks of the recruitment letter having been sent to the listserv, 11 ethicists contacted me with an interest in participating in the study. Of these, I invited seven to participate in the study. Four were not invited to participate in the study because they practiced in the same healthcare organization, setting, and/or geographic location as other ethicists who had already been selected to participate. Approximately six weeks after the initial recruitment email, the Canadian Bioethics Society sent out a follow up reminder email through the listserv on my behalf. This reminder email emphasized the need for participants from Atlantic Canada and Western Canada. Following this email, one additional ethicist contacted me and was invited to participate in the study. Through snowball sampling, I invited nine additional ethicists to
participate in the study. Seven of these ethicists agreed to participate in the research. Time constraints were cited by the other two ethicists as the main reason for declining to participate.

3.4 Ethical Considerations

To protect study participants, I obtained their written consent for participation using a signed informed consent form and information letter detailing the study purpose, potential risks and benefits, and privacy and confidentiality provisions. When scheduling the informant interviews, I sent participants the letter of information and informed consent form for their review. I also described information about the study purpose, potential risks and benefits, privacy and confidentiality provisions, and their rights as a research participant to study participants verbally before the key informant interviews. I allowed participants the opportunity to ask further questions about the study before beginning the key informant interviews. Participants were assured that their participation was voluntary, and that they could withdraw from the study at any time, for any reason, without penalty.

I used numeric codes in lieu of participant names and the healthcare organizations where they work on interview transcripts to protect confidentiality and anonymity of study participants. Participant names and the names of the organizations where they work linking them to the numeric codes were stored separately from the transcript data. I digitally recorded each of the interviews with permission from participants and personally transcribed the audio files. Electronic and hard files were treated as personal information and securely stored. In addition, data were de-identified prior to data analysis. When data were reported, quotes that could reveal the identity of a participant or his/her organization were not used.

The University of Toronto Health Sciences Research Ethics Board granted ethics approval to this study on December 21, 2010.

3.5 Data Collection

I collected data for this study through key informant interviews. Between January and May 2011, I conducted semi-structured, in-depth interviews with participating ethicists. Each interview lasted between 45 minutes and one hour. Following standard data collection principles
for qualitative interview research, study participants selected the date, time, and (for face-to-face interviews) location of the interview (Morse & Field, 1995). Five interviews were conducted face-to-face in a private room. The remaining interviews were conducted by telephone for feasibility because of distance.

The purpose of interviews is to allow the researcher to understand another person’s perspective (Patton, 1987). The interviewer must provide a framework that allows people to respond to open-ended questions in an accurate and honest way (Patton, 1987). To accomplish this task, I used an interview guide with open-ended questions related to ethics program effectiveness (Appendix D). The interview guide contained a list of questions to be explored to ensure that the same material was covered in each interview, but allowed for probing to elucidate more information about effectiveness and evaluation of healthcare ethics programs (Patton, 1987). I pilot-tested the interview guide with three individuals before beginning the data collection interviews to ensure that the questions I was asking were clear to participants, and to obtain feedback on my interviewing technique. I refined the interview guide based on pilot test feedback and kept it open to modification during data collection as themes were identified in the analysis. I also sent the revised interview guide to key informants in advance of the interviews as I received feedback in the pilot test that having the questions in advance allowed respondents to prepare for the interview by reflecting on the topic and making preparatory notes.

In each key informant interview, I tried to establish a rapport with the study participant to gain their trust and elicit more in-depth information (Fontana & Frey, 2000; Morse & Field, 1995). I conducted the interviews primarily in English. For the interviews with participants for whom

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7 Of the five in-person interviews: one was conducted at the study participant’s office; one was conducted in the researcher’s office; and the remaining three were conducted in a meeting room at the University of Toronto Joint Centre for Bioethics.

8 Because I decided to sample ethicists from across Canada, it was not possible to hold all of the interviews face-to-face due to a limited research budget. Conducting most of the interviews by telephone was identified as a potential limitation of the study design and is addressed in more detail in section 3.7.

9 One of these individuals was a former practicing healthcare ethicist and two are currently practicing healthcare ethicists affiliated with the Clinical, Organizational and Research Ethics Network at the University of Toronto Joint Centre for Bioethics.
French was a first language, I allowed them to answer questions in French if they were more comfortable doing so. Participants were able to provide detailed responses in English, saying only a few words in French throughout the interviews, which I translated to English, and asked them to confirm that this was the word they were looking for. For the telephone interviews, I began the call by checking whether the study participant was feeling settled and comfortable and was able to speak without interruption for approximately 45 minutes to one hour. Following Patton’s (1987) suggestions for sequencing interviews, I began the interviews with “easy to answer” questions that ask for simple factual information followed by more challenging questions to answer that ask about the participant’s opinion on or interpretation about what they had just described.

First, I asked ethicists to describe their ethics program and the organization(s) in which they work, including information about: their ethics program structure, mandate, goals, and objectives; ethics services offered; to whom the ethicist and ethics program reports within the organizational reporting structure; and available resources (e.g., number of ethics program staff). Once participants had described their program in detail, I then asked them about how they define effectiveness. To help me understand participants’ definition of the concept of effectiveness as applied to ethics programs, I asked them probing questions about how they would know that an ethics program was effective, what signs they would look for, how they could demonstrate this, and what they would measure to demonstrate this.

I used probing questions throughout the interviews to go more in-depth into participants’ responses, to have them provide more detail or elaborate on a response, or to clarify what they had said to ensure I was understanding their perspective and the language they were using (Patton, 1987; Fontana & Frey, 2000; Britten, 1995). As much as possible, I tried to use the participant’s wording when asking follow-up or probing questions in the interviews to improve the quality of the participant’s responses (Britten, 1995; Patton, 2002). For instance, if a participant referred to his/her ethics program as an “ethics department” when asked to describe their ethics program, I adopted this vocabulary and asked how he/she defined effectiveness of the ethics department. Once participants described how they would know that an ethics program was effective, I proceeded to ask them what they perceived as enablers of and barriers to
achieving effectiveness in their ethics program. I probed why they thought these were enablers or barriers, how they ensure that enablers are in place, and how they address barriers. These questions helped elicit rich descriptions of the factors that contribute to an effective ethics program. I chose to sequence these questions later in the interviews because they asked about more sensitive topics.

I ended the interviews by asking “Is there anything else you would like to share about how you define or evaluate ethics program effectiveness that we haven’t talked about?” to allow participants to discuss anything else related to the research question that the interview, up to that point, had not covered (Morse & Field, 1995). Afterwards, I allowed the participants to ask me any additional questions and I encouraged them to contact me via telephone or email should they wish to share any additional information. One participant sent me a follow-up email to provide more information about how she defines effectiveness. I also reminded participants that I might contact them by email for clarification as needed and would send them a summary of the results for a validation step.10

After each interview I made notes on observations I made about the participant during the interview and on my reflections on the interview itself. For example, I noted things like whether the participant seemed rushed, relaxed or preoccupied as well as my impressions of how the interview went and what I might do differently next time. When I transcribed the audio files, I noted these observations and any non-verbal communication in the transcriptions such as long silences or pauses in the conversations; body language or gesturing (for face-to-face interviews only); laughs and coughs; and changes in the volume, pitch and speed of the participant’s responses (Fontana & Frey, 2000).

3.6 Data Analysis

In qualitative research, Sandelowski (1995) writes that collecting, analyzing, and interpreting data happen at the same time. After the first two data collection interviews were complete, I started to analyze the data. Data collection and data analysis continued simultaneously with each

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10 This validation step is known as a “member check” and is described in more detail in section 3.7.
informing the other (Sandelowski, 1995). Patton (2002) argues that the data being collected and
the analysis of such data are improved by collecting and analyzing data simultaneously and being
open to new ideas in analysis. Areas of potential interest that I identified in data analysis
informed additional probing questions that I asked in data collection interviews and information
reported by key informants in interviews informed areas of potential interest that I began to look
for when analyzing the data. However I was careful not to limit questions I asked in data
collection to those that were informed by this analysis, and I accommodated new insights and
challenged preliminary insights in the analysis.

As is typical in qualitative descriptive studies, thematic analysis was the analytic method I used
in this research (Sandelowski, 2010). I used thematic analysis as described by Braun and Clarke
(2006) to look for, identify, analyze, interpret, and report prevalent patterns and themes across
my data set. A theme, according to Braun and Clarke (2006), represents a critical idea that
appears throughout the data and relates back to the overarching research question. I determined
prevalence of patterns related to the concept of effectiveness in healthcare ethics programs by
searching across all of the interviews.11 To identify themes in the data I used an inductive
approach whereby the identified codes and themes were derived from the interview data and not
from a pre-existing coding or theoretical framework as would be the case in a deductive
approach to thematic analysis (Braun & Clarke, 2006). I applied codes to the data looking for
patterns related to effectiveness of healthcare ethics programs without referring to the literature
on the concept of effectiveness or on ethics program evaluation to inform the coding. This
approach is consistent with the theoretical orientation of naturalistic inquiry that I used to guide
the study, as previously described.12

Data analysis moved back and forth through the six phases of thematic analysis as described by
Braun and Clarke (2006). Although I describe my analysis here in a linear fashion moving from
one phase to the next, the actual analysis was non-linear, moving throughout the phases of

11 Braun and Clarke (2006) argue that “there is no right or wrong method for determining prevalence”, what matters
is consistency in the approach (p. 83).

12 See section 3.1.
thematic analysis as necessary. According to Braun and Clarke (2006), analysis moves between all of the data collected, the smaller sections of coded data being analysed, and the written analysis being developed. The first phase of analysis – called *immersion* – involved becoming familiar with the data (Braun & Clarke, 2006). I immersed myself in the data by transcribing the audio files verbatim, proofing the transcripts against the audio files for accuracy, and repeatedly reading the data. Checking transcripts for accuracy allows the researcher to process the interview as a whole and identify critical pieces of data (Braun & Clarke, 2006). After proofing, I read the transcripts again without coding to familiarize myself with the interview as a whole and begin to think about possible patterns. I read and re-read each transcript searching for areas of interest: patterns, issues, words, phrases, and examples. I manually underlined these areas in the transcripts in black ink and noted reflections and ideas about the data and possible codes in the margins of the transcripts. In this phase, I also created descriptive summaries and written reflections of the transcripts which were attempts to briefly paraphrase the interview data (Sandelowski, 1995).

In the second phase I generated “initial codes” by systematically assigning labels to segments of data in each interview and then across all of the interviews. Codes labelled any interesting features (e.g., words, phrases, sentences, paragraphs, ideas, concepts, etc.,) in the data (Miles & Huberman, 1994) that were potential patterns and themes related to the research question. I coded the data manually by writing notes in different coloured pens in the margins of the interview transcripts and then typed the code and copied-and-pasted its accompanying data extract (with surrounding data for context) to an electronic spreadsheet (Braun & Clarke, 2006). In this early phase of analysis, I often coded the same data extract for multiple potential themes and patterns. Through this phase of analysis, I developed a long list of initial codes that were identified from across the data set.

Phase 3 involved identifying themes in the data by sorting the codes and their accompanying data extracts (Braun & Clarke, 2006). In this phase, I started to think about how the codes could be sorted, how they were related, which codes could be combined, and what possible themes tied the codes together. I also continued to developed codes in this phase of analysis and revisit the list of initial codes. I started to reflect on different possible themes based on the codes and data
extracts, and the relationships of codes to one another. This was accomplished using three different types of visual representation.

Sandelowski (1995) writes that visually representing data allows researchers “to look at their data and, therefore, to see suggestive patterns or relationships both within and across cases, which, in turn, can put them onto distinctive analytic paths direction them to what to look for” in their data (p. 374). I produced an electronic spreadsheet table where I organized and re-organized codes into possible themes. Based on this spreadsheet, I created a “thematic map” to visualize patterns in the data, and their connections (Braun & Clarke, 2006). When creating the thematic map, I also used separate pieces of paper to organize my thoughts and ideas of connections and themes. Throughout the analysis, I continued to write “memos” to myself about ideas and relationships between codes, themes and their potential meanings (Glaser, 1978).

The next phase of analysis began with reviewing the candidate themes identified in the previous phase and making revisions to them (Braun & Clarke, 2006). In phase 4, I based decisions on whether to keep themes or to revise them using Patton’s (2002) criteria for judging categories: internal homogeneity and external heterogeneity. I first looked at the themes I had identified and the data extracts belonging to each of the themes to judge whether the data in the themes were related in a coherent and meaningful way (internal homogeneity). If the data extracts within each theme met this criterion, I moved on to consider whether the themes were distinct from one another (external heterogeneity).

If there were many overlapping data extracts across themes or the themes seemed too similar, I took this as a sign that I needed to revise my themes and revisit where the coded data extracts belonged within the themes (Patton, 1987). Some themes contained many of the same data extracts and were combined to create a new theme. Others were reworked into separate themes based on the data extracts not cohering or discarded as I realized that they did not work with the data. In this phase, I re-worked my thematic map based on the revised themes and considered

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13 Glaser (1978) defines a memo as “the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding” (p. 83).
whether the map represented the entire data set in an accurate and meaningful way (Braun & Clarke, 2006). This involved re-reading the transcripts with the thematic map in mind, and in some cases, re-coding the data or refining my list of codes. Once I was satisfied with my thematic map I began the fifth phase of analysis.

Phase 5 involved what Braun and Clarke (2006) refer to as defining and refining themes – that is, identifying what the core meaning is of each theme and how this relates back to the data. I also identified which themes were over-arching and which were sub-themes, or “themes-within-a-theme” (Braun & Clarke, 2006, p. 92). In this defining and refining phase, I re-read the data extracts for each theme and identified what was important about the data extract in relation to the research question and study objectives. I thought about what each theme meant, what assumptions I made around the themes, and how each theme was related to how ethicists define healthcare ethics program effectiveness and what ethicists think makes a healthcare ethics program effective. Throughout this phase, I approached the themes by questioning what they were telling me about healthcare ethics program effectiveness and evaluation.

The final phase of analysis involved reporting the data in a way that demonstrates that the analysis had merit and was valid (Braun & Clarke, 2006). In this last phase, I wrote up the results of my analysis to tell the “story” of the data and how it relates to my overarching research question: “what makes an ethics program effective from the perspective of practising healthcare ethicists?” I tried to be faithful to the interview data (Sandelowski, 1995), using data extracts to exemplify the themes and sub-themes I identified and named, and to illustrate my analysis of the data set. The data extracts I selected also helped demonstrate that the themes were, in fact, prevalent across the data set (Braun & Clarke, 2006).

### 3.7 Credibility, Rigor, and Limitations

In qualitative research, Patton (2002) writes “the researcher is the instrument” (p. 566). As such, it is important for the qualitative researcher to be reflexive – to be self-aware, self-reflecting and considering how who the researcher is influences data collection, analysis and interpretation – to enhance the credibility of the research (Borkan, 1999; Patton, 2002). Throughout the study, I reflected on potential sources of bias, on my assumptions, and on my academic and professional
experiences that may have affected the probing questions I asked participants and my analysis of the data. In particular, I examined how working in healthcare ethics and sharing a similar disciplinary background to some participants helped reduce language barriers, but also had the potential to prevent me from seeing the data as an outsider would. To address this potential problem, I tried not to assume shared meaning of terms used by participants in the interviews. I also used peer-review with my thesis committee members to ensure the codes I used in analysis were data-derived, and invited their alternative analysis of themes and interpretations.

To further enhance credibility of the findings, I conducted “member checking” with key informants. Descriptive summaries of the data and themes were distributed to participants for their comments. Although there is some disagreement around member checking as a validation strategy in qualitative research,\(^\text{14}\) member checking was an appropriate strategy for this study as qualitative descriptive studies seek descriptive and interpretive validity (Sandelowski, 2000). In qualitative descriptive studies, the researcher seeks to report what study participants described (descriptive validity) and what they meant by these descriptions (interpretive validity) in a way that participants themselves would find accurate (Maxwell, 1992). Eleven participants responded by email to the member check document. Of these, two noted that they would review the document and send comments, but were unable to do so due to time constraints. Four responded that the member check document accurately reflected their perspectives and they had nothing further to add. One participant noted that the member check document reflected what she had said in the interview, but that her perspective had evolved since she participated in the study to connect effectiveness more strongly to quality improvement. The remaining five respondents provided detailed comments confirming that the key findings reflected their perspectives and expanding on selected quotes and sections in the document. Based on these responses, I went back to the larger summary of the results to determine whether their expanded comments were captured in the results section. In most cases, participants’ expanded comments

\(^{14}\) Lincoln and Guba (1985) argue that member checking “is the most crucial technique for establishing credibility” (p. 314). Sandelowski (1993) on the other hand claims that “its potential to enhance qualitative work belies the deeply theoretical and ethical difficulties in this technique that may serve paradoxically to undermine the trustworthiness of a project” (p. 4).
validated the key findings. In a few cases, I made slight refinements such as re-wording sections and better introducing quotes to clarify what participants meant by their descriptions of effective ethics programs. Member checking validated the original findings and enhanced the quality of the results.

A potential limitation of the study that I identified was using telephone interviews for the majority of the data collection interviews. Telephone interviews allowed me to obtain relevant data from ethicists across Canada who would otherwise not have been able to participate in the study (Miller, 1995). However, Sturges and Hanrahan (2004) argue that the cost-savings achieved by using telephone interviews should not come at the expense of data quality. In comparing the transcripts of interviews conducted in-person with those conducted by telephone, I could find no striking differences in the quality of the telephone interview data. Telephone interview participants were just as verbose, detailed and forthcoming with their responses to the interview questions as participants in face-to-face interviews (Miller, 1995).

Unlike the face-to-face interviews, however, I was unable to see the participant’s non-verbal communication such as gestures, eye contact, or facial expressions communicating, for example, that a participant might not have understood a question or was reluctant to provide an honest or accurate answer to a question (Shuy, 2003; Miller, 1995). Likewise, participants were unable to see my gestures, head nods, or facial expressions communicating my attention and interest in their responses. Occasionally, participants in telephone interviews asked whether they were responding to the question in a way that was clear to me. To account for the lack of non-verbal communication, I used vocal responses such as “that’s interesting, can you tell me more…” or “hmm” throughout the phone interviews to provide participants with verbal feedback that they were providing helpful responses (Patton, 1987) and to solicit additional information.

Another possible limitation of the study is that I chose to focus on the perspectives of ethicists to the exclusion of other ethics program stakeholders such as patients, families, healthcare professionals, and management that use the ethics program; ethics program staff such as ethics consultants, post-graduate ethics fellows, or ethics facilitators; or those with organizational oversight for ethics programs. While the perspectives of these other stakeholders are important and merit investigation, this study aimed to describe ethicists’ perspectives in-depth rather to
explore a breadth of perspectives. Borkan (1999) argues that “depth of description is critical both in avoiding superficiality and in ensuring that the issues, concepts, and contextual realities have been suitably explored” (p. 193).
Study Findings

In this chapter, I present findings of the study exploring ethicists’ perspectives on what makes an ethics program effective. Study findings are organized according to my research objectives. In section 4.1, I begin by providing a description of how participating ethicists define effectiveness of healthcare ethics programs and the indications they use as evidence of an effective ethics program. Next, in section 4.2, I identify the strategies ethicists are using and/or thinking of using to evaluate effectiveness. In section 4.3, I describe the factors that ethicists perceive as enablers of and barriers to achieving ethics program effectiveness.

4.1 Definitions of Ethics Program Effectiveness

Ethicists in the study defined healthcare ethics program effectiveness in three different, but not mutually exclusive ways. The majority of ethicists spoke about ethics program effectiveness in all three of these ways, but tended to focus their descriptions of how they define effectiveness on one of the three. The first way ethicists defined ethics program effectiveness was operationally in terms of achieving the organizational mandate for the ethics program, achieving ethics program goals and objectives, or meeting standards relevant to ethics programs. This definition was operational as it was specified through what the ethics program does and the ethics program’s measurable outputs. It was seen as an “objective” way of assessing whether, given the ethics program’s operations, the ethics program achieves what it sets out to do. The second way that participating ethicists defined effectiveness was aspirationally in terms of making a difference and being helpful. The aspirational definition of effectiveness moved beyond the day-to-day operational objectives of an ethics program toward the ethics program’s vision of what it sought to accomplish in the longer term, especially through the eyes of those who were using the ethics program. Although the aspirational definition was conceptually distinct from the operational definition, some ethicists described setting making a difference and being helpful as an ethics program goal. The third way that ethicists defined effectiveness was in terms of delivering value for investment or bang for the buck. This definition of
effectiveness was conceptually linked to efficiency as it focused on how ethics program inputs (e.g., time, personnel) were used to generate desirable ethics program outputs and outcomes.

When asked how they would know that an ethics program was effective, the ethicists suggested three general types of indicators or evidence of effectiveness: i) “measurable” evidence, often referred to as “metrics”, “measures” and “proxy measures”, which could be systematically collected and tracked using a formal evaluation method; ii) “anecdotal” evidence, such as informal yet explicit feedback from ethics program funders or end-users, that was unsolicited, episodic, and not readily collected in a systematic way; and iii) “visceral” evidence, described as “more of a feeling”, which conveyed tacit information, often at an interpersonal level, about the impact of the ethics program or an encounter between the ethicist and an ethics program user. Some indicators and evidence were more closely associated with some definitions of effectiveness than others. In the following sections, each definition of ethics program effectiveness and its corresponding indicators or evidence are described in detail,

4.1.1 Operational Definition of Effectiveness

There were two formulations of effectiveness under the operational definition: 1) Achieving the organizational mandate for the ethics program, and ethics program goals and objectives; and 2) Meeting ethics standards. In what follows, I will describe each formulation in turn, including what ethicists look for as evidence of achieving mandate, goals, and objectives and meeting ethics standards.

Formulation #1: Achieving Mandate, Goals, and Objectives

An effective ethics program, according to participants, is one that achieves what it is mandated to do. Ethicists discussed the ethics program mandate at two levels: 1) achieving organizational mandate and expectations for the ethics program, and 2) achieving the goals and objectives set within the ethics program.

i) Achieving organizational mandate and expectations for the ethics program

Many ethicists related effectiveness back to the broader mandate of the ethics program as set by the organization’s senior leadership or ethics program funders. Participants defined effectiveness
as achieving what the organization has mandated the ethics program to do, for example successfully meeting the mandate “to provide high quality, accessible ethics consultation, education and policy input” within the institution (Ethicist 06F). Another ethicist explained that ethics program effectiveness is more than the effectiveness of discrete clinical ethics services, but rather it is about the how the ethics program meets the mandate that is set in the larger organizational context.

*I think we locate our ethics service and program, which I anticipate is a trend more generally now, but uh, within the broader perspective of where does ethics fit within the organization, how is it as a resource to our colleagues within the organization and ultimately to our family members and patients, and so, I see its effectiveness as: ‘are we meeting the mandates that we have set out for ourselves in the bigger picture?’* (Ethicist 12L)

Most study participants conceived of their organizational mandate as delivering ethics consultation, education, and policy development to address ethical issues that arise in the healthcare environment. A few participants also specified alignment with the organization’s mission, goals, and/or values. For example, one ethicist reported that the organizational mandate for her ethics program is “improve patient and family experience and care, and contribute to improve staff work life” (Ethicist 07G).

Another way that participating ethicists described effectiveness was as meeting organizational expectations of the ethics program, including how the purpose of the ethics program is defined at an organizational level. As one ethicist put it:

*If it's from the organization saying, look, what we really just need is a reactive service that deals with ethical issues that come up, we're not interested in the proactive piece or we don't want to invest in that, well, if that's sort of the mission of your program and you're doing well in that, then that's effective.* (Ethicist 14N)

**ii) Achieving ethics program goals and objectives**

A similar way of defining ethics program effectiveness was in terms of achieving the goals and objectives specified within the ethics program. Effectiveness, as one ethicist stated, “depends on what... what your purpose is and, you know, effectiveness is then... uh... it depends on what is
your objective or purpose” (Ethicist 09I). An ethics program is effective to the extent it is able to meet the goals it sets for itself. Another participant commented:

Well increasingly, it relates to the goals you set out, and if you’re trying to reach a goal, and you know what your indicators are, and you know what it’s going to look like when you’ve reached there, and it’s successful. You successfully reach those goals and it’s done something effective. I mean, it depends on what your goal is, so if your goal is to decrease moral distress or increase patient satisfaction or to decrease length of stay or whatever it is… (Ethicist 02B)

For other participants, an ethics program can be more effective if it achieves more of its goals and objectives. For instance, if a program’s goals are to raise awareness of the program and help people address ethical issues independently, then a program that gets many repeat calls for help addressing ethical issues has been “somewhat effective” because staff are aware of the program. However, the ethics program has not been “very effective” because staff are not learning to address ethical issues on their own.

Although effectiveness was defined in terms of achieving ethics program goals, participants did not prescribe what the goals and objectives of an effective ethics program ought to be. Rather, they provided a variety of examples of possible goals and objectives such as: completing a specific ethics project (e.g., creating a new ethics-related policy), being recognized as a resource, being available on site, providing “accessible” ethics services, decreasing “moral distress”, alleviating “moral uncertainty”, increasing patient satisfaction, or helping the organization meet Accreditation Canada standards related to ethics. Ethicists cited many of these possible goals and objectives of an ethics program as indications of ethics program effectiveness.

Evidence of Achieving Mandate, Goals and Objectives

Ethicists cited two types of evidence of achieving the organizational mandate for the ethics program and achieving ethics program goals and objectives: 1) explicit recognition of the ethics program in the organization, and 2) utilization of ethics program services. However, evidence identified in support of achieving organizational mandate for the ethics program and achieving ethics program goals and objectives focused almost exclusively on the latter formulation – that is, participating ethicists did not distinguish a unique organizational mandate component in specifying evidence of this formulation of effectiveness. Rather, their descriptions of supporting
evidence of effectiveness tended to collapse into a single focus on evidence of achieving ethics program goals and objectives.

Evidence of *achieving ethics program goals* was specified in terms of use of ethics program services, e.g., increasing ethics awareness in the organization, improving uptake of ethics consultation services. For example, one ethicist, whose ethics program goal was to increase ethics awareness in the organization, felt that an increased number of ethics consultations from a broad range of programs in the hospital and an increased number of requests for input on policies signaled that the ethics program was having a desired effect within the organization. This ethicist stated:

> When I first started doing the program, I got consultations from, probably from about four departments. So maybe from like Critical Care, Emerg, um... Mental Health, something else; last year when I did my audit - I'll send these to you – I had consultations from eight departments, including Outpatients. Outpatient clinics, doctors from the community calling me, so I think, to me, that was a successful plan because when I originally started, Critical Care was the only place that called me, really, and then you went to more areas, so a larger awareness of what ethics is and what ethics consultation, more awareness, and more policy, So I'll get called more about policies and that sort, to me that means the success is by measurement of who's calling me and where departments are calling me. And so what it is, if someone's not calling, maybe I should be going to that area and talking to them because maybe there's no ethics awareness there. (Ethicist 10J)

Although many ethicists looked to numbers of discrete program activities such as the number of ethics consultations performed or education sessions delivered, most cautioned that the number of program outputs is not a sufficient measure of effectiveness. One participant stated: “*Yeah, an effective program would be a program that people actually knew about and made use of at appropriate times, so I would include that as a type of measure too, but I worry a little bit about looking to just raw numbers, um... It wouldn’t be enough*” (Ethicist 07G). Similarly, increasing or decreasing program outputs may be difficult to interpret and may indicate different things. Ethicists questioned whether a decreasing number of ethics program outputs (e.g., consultation requests) was “*because of lack of awareness or because things are looking better?*” (Ethicist 10J). Another ethicist commented:
There's that classic problem in clinical ethics consultation, of when you hear about things less, is that indicative of capacity's been built and people can handle it themselves so they’re not calling you? Or, is it an issue of they’re not calling you and there's a problem you're not hearing about, and you don't know? So it's a very hard thing to measure. (Ethicist 14N)

Instead, in evaluating his/her ethics program, this ethicist emphasized documenting which program areas of the hospital are contacting the ethics program for support and the complexity of the ethical issues that people are identifying. For example, an effective ethics program would be frequently accessed for support with “specialist issues” requiring ethics expertise as opposed to basic ethical issues or questions that physicians and staff ought to be able to handle independently. This ethicist stated: “if you're a really well integrated effective service, you'll get a lot of calls about specialist issues because people will be looking for that expertise” (Ethicist 14N).

Formulation #2: Meeting Ethics Standards

The second formulation of the operational definition of ethics program effectiveness emphasized i) meeting industry standards, specifically those ethics standards set by Accreditation Canada, and ii) professional standards set by ethicists themselves.

i) Meeting Accreditation Canada ethics standards

According to a few participants, Accreditation Canada standards are widely accepted standards used to assess the quality of healthcare services across the country. Although the Accreditation Canada standards are not specifically designed to evaluate ethics programs, ethicists have been using the standards to define ethics program effectiveness. For example, one participated stated that an effective ethics program is one that helps the organization achieve “100% compliance with all of the Accreditation Canada requirements” (Ethicist 04D). Conversely, an ineffective ethics program is one that does not meet the Accreditation Canada standards related to ethics such that the organization does not pass the ethics component of the Accreditation process.

Well, we need to, I think, ultimately demonstrate effectiveness in ensuring that people pass the ethics piece of Accreditation. Um... I think if we weren't able to do that, then we would definitely be seen as ineffective. So that's sort of a negative standard in terms of some positive criteria that are set out for us. (Ethicist 11K)
Although the majority of participants thought that helping the organization meet Accreditation Canada standards was important for an ethics program to be considered effective, many questioned defining effectiveness based on meeting the standards, or defining ineffectiveness based on not meeting the standards. According to one ethicist, the standards are “sort of the minimum criteria and hopefully, my hope is that we, sort of, go beyond what we're expected to do as far as meeting Accreditation criteria” (Ethicist 12L).

Many ethicists did not think that ethics program effectiveness could be reduced to a measure of organizational compliance with Accreditation Canada ethics standards. For instance, one participant explained that the Accreditation Canada ethics standards are not sensitive enough to pick up on whether an ethics program is having an effect in the organization or is just “window dressing” in an organization. A few other ethicists shared this view, noting that the standards are inconsistently applied to ethics programs in different organizations. Some organizations with well developed ethics programs do not necessarily receive high ratings from Accreditation Canada whereas other organizations with “struggling” ethics programs do. A healthcare organization, for example, could demonstrate that it is meeting the Accreditation Canada standard that requires a framework for addressing ethical issues by showing the Accreditation surveyors “a very beautiful document”, but not support the ethics program to do day-to-day work such as ethics education and training. One ethicist, however, commented that the problem may not be with the standards themselves, but rather, with their application by the Accreditation Canada surveyors.

ii) Meeting professional standards for ethicists

The other set of standards that ethicists used to define ethics program effectiveness were those set by ethicists themselves either by professional peers working in the wider bioethics community or within the ethics program. Standards set by those in the wider bioethics community were not clearly specified during the interviews, however a few participants, mentioned the American Society for Bioethics and Humanities (ASBH) core competencies for ethics consultation. Many participants noted that there are currently no professional standards for practicing healthcare ethicists in Canada. Nevertheless, some participating ethicists, particularly those who worked in the lone ethicist model, used other ethicists in their
communities of practice to determine their effectiveness – that is, whether they met “the relevant standard” from a peer reviewer perspective. Ethicists also looked at “emerging good practices” from their communities of practice and from the literature.

Standards set by those working within the ethics program tended to relate to how the ethics program functions, including how well ethics services “fit” with the organization’s culture. As a result, how ethics program effectiveness is defined is “very organization specific” so what might work in one organization might not work in another organization. For some ethicists, this meant that an assessment of an ethics program’s effectiveness is conceptually and pragmatically linked on a local level to how the ethicist leading the program believes that the program ought to operate, how the ethicist and ethics program personnel approach the practice of ethics, and how the ethicist understands what it means to be a “good ethicist”.

The same ethicists acknowledged that different people will have different understandings of what it means to be a “good ethicist”. For example, some might think “what it means to be a good ethicist is to give good recommendations, substantive recommendations about what someone should do in a decision, whether it’s at a policy level or a clinical practice level” (Ethicist 15O). This is different from others who think that ethicists should not be prescriptive in their recommendations, but rather should facilitate open dialogue among affected parties toward reaching a decision. Moreover, some ethicists argued that “meeting standards” is not the same as “meeting expectations”. One ethicist explained:

The perceived added value is they said, ‘it's good, thank you for contributing to that conversation because I think that you made a difference to us’. But that's their perception of it. You could actually have just – you could have done something completely different, and said something that didn't meet your standard. So I could have stood up and said, ‘you're wrong! We should have done this!’ And if they thought, ‘oh, that's great, thank you for telling us,’ they may still have perceived that I added value in that conversation, but I didn't actually do – I didn’t make a contribution to the standard of conversation that I want to hold myself accountable to, that I want to hold our service accountable to. So that's, I think, an example of the distinction between the adding value and meeting the standards, or effectiveness of the service. (Ethicist 15O)
Evidence of Meeting Standards

Two types of evidence of meeting standards were most commonly cited by participants: 1) organizational success in meeting ethics and ethics-related standards in an accreditation survey with no “red flags”; and 2) positive peer review.

1. The organization is rated as meeting accreditation requirements with no “red flags”

For most ethicists, evidence of meeting the Accreditation Canada standards related to ethics was that the organization was rated as having met requirements related to ethics in the accreditation process. In addition, a sign of an effective ethics program was that the organization did not receive any “red flags” in the Accreditation Canada survey process. Red flags would signify that the organization has failed to meet a minimum standard in areas related to the work of the ethics program. In particular, ethicists commented that evidence of effectiveness would be that the accreditation survey results show that staff in the organization are aware of the ethics program resources, they know how to access these resources, and they use them to aid in identifying and addressing ethical issues in their work. According to one participant, by asking whether staff are aware of the ethics program and are able to make decisions using an ethical framework, “you can get a sort of proxy bit of information regarding whether or not we’re meeting goals or we’re effective” (Ethicist 06F). Similarly, another ethicist stated:

Accreditation standards are such that staff are supposed to be aware of the resources that are available for ethics services. So according to the Accreditation standards, you know, they go out and they interview staff and if someone says they don’t know that those services are available or they don’t know how to access them, then obviously the [healthcare organization] is given some kind of advice about the fact that they need to make improvements. So I think that’s one way, that staff need to be knowledgeable and you should be able to go out and speak to staff and find out that yes, they know exactly what to do if they have an ethical concern or an issue, that they know what the process is for accessing the resources that they need. (Ethicist 13M)

2. Positive peer review from other ethicists

For standards set by those working in the field, ethicists looked to the perspectives of other ethicists within their ethics program and external to their ethics program to determine whether they met the relevant standard. Many ethicists commented that they ask other ethicists to review
their work and to provide an assessment of whether they “got it right”. One participant stated: “usually people are looking at the process of the ethics consultation and the outcome of it, and they'll comment on both and say, 'you know, I think the process of analysis here is fair enough, I think you probably got the right answer’” (Ethicist 04D). Similarly, another ethicist talked about applying peer review to evaluate policy development processes and whether policies and processes are consistent with what other ethicists are doing in their practice. Another example given was response time for requests for ethics consultations relative to their colleagues within the ethics program. A few ethicists cited a timely response to consultation requests as a standard that their program tries to meet. As such, they track how long it takes the ethics program staff to respond to requests for ethics support and compare response times internally. According to one ethicist, “our standard is [to respond to a consultation request] within the day, so we do evaluate it informally together to make sure we're on track. So I think that's, to us, that's a measure of success: we can respond quickly” (Ethicist 01A).

4.1.2 Aspirational Definition of Effectiveness

In this section, I describe two formulations of the aspirational definition of effectiveness – 1) Making a difference; and 2) Being helpful – and detail what ethicists look for as evidence of each formulation. Unlike achieving mandates, goals and objectives, or meeting standards, neither “making a difference” nor “being helpful” are necessarily measurable. Effectiveness, as making a difference and being helpful, is conceived in particular to be concerned with ethics program outcomes rather than ethics program output (e.g., number of ethics consultation requests) per se. If the outputs do not make a difference or are not perceived to have been helpful by the end-user, then the ethics program cannot confidently claim to be effective.

Formulation #1. Making a Difference

An effective ethics program, according to some, is one that makes a difference to staff experience and/or to the organization’s moral climate and ethical culture – that is, how the organization defines what constitutes ethical behaviour and the process for addressing ethical issues in the organization (Rodney, Doane, Storch, & Varcoe, 2006). The question of effectiveness is a question of “What actual difference are we making on the ground?” The “on
the ground” difference was explained as seeing changes in those who use the ethics program services, such as: reduced “moral uncertainty” and “moral distress” of staff, increased staff comfort in addressing the ethical issues encountered in the healthcare setting, or increased attention paid to ethical considerations in practice.

*I would define effectiveness within our services as seeing a change in those who regularly call us – to see a comfort evolve within them, or as far as their reasons why they’re calling us and having a degree, seeing or perceiving a degree of independence within themselves and saying, ‘I’m more comfortable to handle these kinds of issues that come up, either on a regular basis or even sporadically’ – that kind of thing.* (Ethicist 12L)

Another way of defining effectiveness as making a difference was at the broader organization level. Effectiveness was defined as having a positive effect on the healthcare organization. One participant noted, "I guess, effectiveness, to me, is that we are making a difference in enhancing the ethics culture of the organization" (Ethicist 03C). This perspective emphasized the longitudinal impacts of an ethics program over time. According to one participant:

[Y]ou do an education session and people were like, ‘Oh, that was great, fantastic, just what I needed!’ But, what I'm always left with at the end of that is like, 'Great, today was good, but what difference does that make long term in practice?' And so I think that, in looking at effectiveness, it will show up sort of long term, in terms of things like the ability of people to recognize ethics issues as they arise and then to have the capacity to address the sort of, not just the everyday ethics issues – I think there's already a fair amount of capacity [for this] – but there's the capacity, as well, to address some of the more challenging ethics issues. And then I think the other thing that you see long term is organizational change, around ethics issues as well as around incorporating ethics perspectives into decision-making, into policy review. And so it just becomes part of the fabric or part of the way that the organization works. (Ethicist 11K)

To these participants, the long term or “big picture” is where effectiveness matters most. If, in the long term, the ethics program does not have a positive effect on the healthcare organization, on staff quality of life, on clinical practice, or on patient care, then it is not an effective ethics program.

**Evidence of Making a Difference**

There were four most commonly cited types of evidence of making a difference related to: 1) staff capacity to identify and address ethical issues; 2) ethics program resources being accessed
and used by staff; 3) changes in organizational climate; and 4) uptake of ethics program practices by other health organizations.

1. Increased ability to identify and address ethical issues

If an organization has an effective ethics program, staff in the organization will be better able to identify and address ethical issues that arise and build ethical decision-making into their everyday practice whether at the clinical level or organizational level. When, over time, more and more staff and physicians in an organization could be shown to be aware of ethical issues, identify these in their work, and are able to appropriately address them, ethicists felt like the ethics program was making a difference. Ethicists described tracking data on what ethics program services (i.e., ethics consultations, policies reviewed and/or developed, and ethics education sessions) are being used, at what frequency, and by whom, including the incidence of repeat end-users. The more that staff from different areas of the hospital are represented ethics program end-users, the more that ethicists felt that the program was perceived to be making a difference.

2. Ethics program resources being accessed and used by staff

One ethicist called it a “little victory” for the ethics program when someone who previously would have never used the ethics program seeks it out as a resource. When people start to “rely on the ethics service as a resource in the work they’re doing” (Ethicist 03C), seek out the ethicist to contribute to an organizational or clinical decision, or invite the ethicist to help develop or review a policy, this was perceived as “a sign of success”, particularly if the ethicist is invited back after his or her initial involvement.

_The organizational piece, I think it's about comfort amongst senior management. Will they call you? Do you sit at all those tables, and do they keep using you? And do they endorse your service? Do they speak to it and say, 'You know, this is a program that provides us with useful advice and we're glad it's here.' They don't always say that explicitly, but, sometimes they do, actually. We had that happen at a Board meeting; someone, the Chair of one of our major committees stood up and said, 'You know, this service is really, really useful to us'. So I think for me, that's effectiveness. When they all think that we belong and we provide something useful for them. So that's not a fine metric, but I think for that sort of an audience, that's when you know._ (Ethicist 14N)
Similarly, many participants commented that when they are asked to be involved in rounds or to sit on a committee, particularly if they weren’t asked to be involved in previous years, it gives them a sense that they are perceived as useful and effective.

_When people call you, when people recognize you, when you walk in the corridors and uh... doctors ask you to maybe do a presentation with them, or nurses, to just, you know, ‘can you come and have a talk with us, we have this, you know, not a consultation per se, but just for the sake of, let’s do something different than we’re used to and think ethics is, it’s a nice way to grasp that thing’. For me, it shows something. And we have more and more of that in the last two years compared to the last 12 years that I've been here._ (Ethicist 09I)

_So it would have never, never happened two years, before the last two years. Never! They would have never thought that I could be useful on that. And now there were actually a few people saying, ‘No, no, we need ethics on that, on that committee.’ So for me, it's like, I know it's not a quantitatively or, you know, criteria-based um... um... satisfaction or effectiveness, but I know it means something._ (Ethicist 09I)

Others questioned whether they were making a difference if the same people were repeatedly asking for the help on the same kinds of issues without learning from the past consultations or education sessions. One ethicist explained that, on one hand:

_Sometimes it's as simple as getting a sort of an increased number of consults for the really complicated things. When a team stops consulting you because they don't need to anymore – that they've learned a lot about, from the process itself; it's not that you've gone in and solved stuff, that they've actually, you've been collegial enough and helpful enough, that they've actually learned something from the consult. So, you know, there are units here that used to be very high referrers and aren't so much anymore, but when we get a referral, it's a really difficult case or somebody who's really concerned..._

On the other hand:

_[For] some units, it could be an increase in referrals, so a unit that rarely refers and we then make a particular type of effort, either trying to connect with particular types of staff or offer an in-service and do that and you know the referrals start to go up, that's success, but on a sophisticated unit, that wouldn't be success to me. Well great, they're calling, so at least they recognize an ethical issue when they see one, but they're not learning from the situations, so the consults are the same. So I would think, I would feel like we've been somewhat effective – they know who we are, they know how to call us, all those basic things._ (Ethicist 01A)
3. Positive organizational climate

In an organization with an effective ethics program, where ethics “matters”, people would not be afraid to talk about ethics or approach the ethics program for help addressing the ethical issues in their work. Moreover, an organizational culture that encouraged using the ethics program as a resource was an indication of an effective ethics program. One participant commented:

*I think it would look more like, effectiveness would be increased in the culture of our organization that would encourage participation in these ethics conversations, and I don't get a mixed message either within the ethics service itself um, because they weren't clear or they need clarity around what we provide, or around those managers who, you know, say that they're supporting and encouraging ethics services, whereas, maybe unconsciously, their behaviours create this weird dynamic where, I'm not sure that I can actually ask someone outside of my immediate interdisciplinary team to have a conversation about what's going on or how I might be supported. I'm not sure if that's clear or not, but, uh... I don't know if you're familiar with, or you yourself can resonate with that idea. There's the spoken word and then there's the implied what behaviours seem to indicate, which is the unspoken expectation. Um... and so I would hope that, one of our measures for effectiveness is to see a continued growth in organizational culture and units specific and discipline specific cultures whereby they have a greater comfort with contacting our services.* (Ethicist 12L)

One ethicist noted that when senior leadership starts talking about ethics, particularly “*about the ways in which ethics was making an impact on whatever, the culture, whatever it was, that would be really huge and a sign that you have an effective, you know*” (Ethicist 07G). Furthermore, ethics discussions would continue in the organization without the ethicist or ethics program staff facilitating the discussion.

Hearing about positive changes in practice in the organization sustained over the long term also signaled to the ethicist that the ethics program was making a difference. For example, one ethicist described hearing from a healthcare administrator that the administrator had made a change to a particular program to ensure more equitable access to services after attending a presentation by the ethicist on access to care. This kind of change in practice gave ethicists a “concrete” sense of effectiveness. According to one participant, “*That, for me, is the concrete; there was a change in practice that was directly related to the work that we are doing. So that's sort of my sense*” (Ethicist 11K). Similarly, when people incorporate ethical considerations into
clinical and organizational decision-making after an ethics consultation or an ethics education session, ethicists thought that this was indicative that the ethics program was making a difference, particularly when these changes are sustained months after an interaction with the ethics program. One ethicist commented: “I think we look to how people are actually practicing, and what actually happens versus asking people immediately after, ‘Well, will this make things better?’ You know, the proof will be months down the road, or a year down the road. How are things then?” (Ethicist 14N).

4. Local and regional uptake of ethics program practices

Finally, some ethicists thought that an “indirect or soft measure of effectiveness [is] that you're actually making a difference to not only the people that brought up the problem to you..., but in a broader sphere” (Ethicist 06F). For these ethicists, transferring knowledge outside of the organization was a sign that the ethics program was making a difference to the practice of ethics in healthcare. One ethicist explained:

Well I think if you have people who are working together and understand what others have used as possible resolutions or solutions to problems and see how those have been effective elsewhere you can put those in place in your own institution. You can also, there's always some synergy that occurs when like-minded people are together, coming up with, coming up with different recommendations and different ideas of how to resolve issues. So there's a benefit there, and all of those things will naturally improve effectiveness because it seems, in my mind, quite counterproductive to have all kinds of individual groups going along developing individual solutions when you know, there's many common issues that we all share that we could probably learn a lot about how others have done things and take those solutions into our own settings. (Ethicist 13M)

Another ethicist gave the example of a policy and tools for addressing ethical issues during care transitions that one of the ethics committees in his ethics program had developed. The policy and tools were not only adopted in other healthcare organizations and in other provinces, but added to the policy and “actually moved it a little bit further forward, um, so that's I think, a very nice measure of effectiveness” (Ethicist 06F).
Formulation #2. Being Helpful

Some ethicists defined effectiveness as “being helpful” to staff, patients, and families in the healthcare organization. This type of effectiveness arose if, for example, an ethics program intervention was perceived by ethics program end-users to have been helpful in addressing an ethical issue or challenge in their daily work. For example:

So we, we’ll often get comments back from people either early on, or months later, saying how much difference it made for them to actually have the chance to sit down with somebody. They appreciated the interest, the time, the focused sort of dedicated resource of an ethicist or a whole group of ethics committee members that were interested enough in their problem to give them that time, and that it helped them work through the problem, maybe come to a good resolution, but mostly helped them feel comfortable, ok. So we get a lot of that and I suspect that’s the same everywhere in the country when ethics groups help people out. That, that’s a pretty strong sense, it’s informal, but it helps us know that we’re heading on the right track. (Ethicist 06F)

Ethicists that used this definition described effectiveness as something that was “more visceral”.

One ethicist explained:

Most of it for me is very visceral, and I know some people keep metrics and all and we’ve talked about that, but, you know, if when I get a call and somebody said ‘when I thought about this problem and I thought I need to call ethics’ or ‘I knew this was an ethical issue’ or ‘my supervisor said I should give you a call’ or ‘can you come and help, we’d really appreciate it’. Those things to me are, tell me, I’ve been, we’ve been effective as a program, we’ve told enough people, many people know how to contact us and when to use us, more or less, those things really point to, and it feels more anecdotal, rather than just sheer numbers, so it’s not always numbers going up or down or, that can just be interpreted differently depending on what’s going on, but there’s that sense of recognition of an ethical issue and there’s a sense a recognition that there’s a program and that we can be helpful, that there’s a trust in the program that if we’re not, even if we don’t come up with what people want, that we’ve been helpful, we’ve been respected and we’ve respected the people involved in the consultation, whatever level it’s at, and that people feel that and are glad to see us and invite us back if necessary. To me, that feels effective. (Ethicist 01A)

Evidence of Being Helpful

Participants emphasized: 1) repeat ethics program end-users, and 2) positive feedback from end-users as evidence of ‘being helpful’. Participants received unsolicited feedback from end-users; they also sought out formal feedback on the ethics program and its services.
1. Repeat end-users

A few ethicists cited “repeat users” of ethics services, and getting called back or invited to participate in another event as a sign of effectiveness. For example, one participant described a five month process of working with a small group of nurses that started with one ethics consultation to debrief a set of challenging cases, which led to “several other informal meetings” and then, subsequently, to an ethics education for all nursing staff in the program. Another ethicist gave the example of having been invited by senior management to participate on different organizational committees, citing these invitations as evidence of a positive level of comfort among senior managers to have a formal ethics presence. The ethicist stated: “I think it's about comfort amongst senior management. Will they call you, do you sit at all those tables and do they keep using you?” (Ethicist 14N). One ethicist, who used the term “success” interchangeably with effectiveness, summarized the significance of this type of evidence: “So that's how I'm measuring success within departments, how they perceive me, because if they're not calling me back, maybe they don't think it was beneficial to them” (Ethicist 10J).

2. Positive feedback from end-users

Another sign that an ethics program is being helpful is that the ethicist receives positive feedback from ethics program end-users and from senior leadership about how the ethics program has helped them. According to some ethicists, receiving feedback that the ethics program “was really helpful” (Ethicist 01A) or that people appreciated the time and effort ethics program staff took to help with an ethical dilemma gives the ethicist an “informal” sense that the ethics program is being helpful. This feedback may be non-verbal or verbal. One ethicist described a feeling of trust and respect between the ethicist and the end-users: “that kind of feeling, it's like, there's the welcome..., they respect me, they know I respect them, and that there's a sense of trust. To me, that feels effective without being able to really measure it” (Ethicist 01A).

Evidence of word-of-mouth marketing of the ethics program by end-users also signaled to the ethicist that the ethics program was helpful. One ethicist described home care nurses expressing their appreciation for ethics education sessions saying that the nurses “tell all their colleagues” about the education sessions and encourage them to attend future sessions (Ethicist 06F). At the
senior management level, this word-of-mouth marketing was evidence that the ethics program is helpful. One participant explained:

Do they speak to it and say, ‘you know, this is a program that provides us with useful advice and we’re glad it's here’. They don’t always say that explicitly, but, sometimes they do actually. We had that happen at a Board meeting, someone, the Chair of one of our major committees stood up and said, you know, this service is really really useful to us, so I think for me, that’s effectiveness. When they all think that we belong and we provide something useful for them. So that’s not a fine metric, but I think for that sort of an audience, that’s when you know. (Ethicist 14N)

Ethicists described following up with end-users after ethics consultations to determine end-user satisfaction; “What happened, or was the advice followed, or not? Were people content with what happened or not?” (Ethicist 05E). According to one participant:

So to me, that feels like success when there’s an end point where at least somebody is satisfied with what has happened, it may not be an end point or you know, the violin music at the end, but that there's a sense of satisfaction on that referrer's part and on my part too, that I can walk away saying, "I think I caught most of the important points." That feels like I did a good job or a good enough job. (Ethicist 01A)

Some ethicists described end-user satisfaction as an “indirect measure” of ethics program effectiveness. Others argued that, while satisfaction may be an indicator of “being helpful”, other indicators were perceived to be more reliable such as repeat ethics program end-users, being invited to participate in another event, or word-of-mouth evidence.

4.1.3 Effectiveness as Delivering Value for Investment (Efficiency)

The third conception of ethics program effectiveness emphasized the extent to which the ethics program made optimal use of its people, time, money, and other resources to generate value. This concept described, what some ethicists referred to as, the “value for investment” of the ethics program: an effective program would deliver good value for investment i.e., it would optimize the use of its resources in achieving the organizational mandate for the ethics program, achieving ethics program goals and objectives, meeting standards, making a difference, and/or being helpful.
Delivering Value for Investment or “Bang for the Buck”

Participating ethicists described an effective ethics program as one that provides “value” for the resources invested in the program, or as some participants put it, one that delivers “bang for the buck”. This definition tended to be used to describe the inputs and the outputs of an ethics program – that is, how ethics program staff spends their time and energy and what outputs are generated from these efforts. For instance, an ethics program initiative, such as a new ethics-related policy, which took hours to create, but that wasn’t used by the organization because it was not perceived to be helpful notwithstanding the hours invested would be considered an inefficient use of ethics program resources. Such a program initiative was described as not providing value to the organization. One participant illustrated this with the example of an end-of-life policy created by the ethics program:

For policy development, you develop an end-of-life policy and have an order form for DNRs and nobody uses it. And you could find that out from an audit. So it's qualitative data. Nobody uses the form you created, spent hundreds of hours doing it, nobody uses it. So how is that helpful? So we get asked those questions. There's no value out there for the time that we put into it. Collectively, we spend hundreds of thousands of hours on end-of-life, ethicists collectively in [the province] and, you know, I really question whether we're getting the value out of that, with the things that we've created to address that. And we have to look critically at you know, what we think we're doing when we're doing what we're doing. What is the value added to the patient experience when nothing that we've developed for this end-of-life policy is ever being used by a nurse? (Ethicist 02B)

In addition, ethicists described effectiveness as being able to target their interventions to achieve the desired outcome without wasting resources or using more time or effort than was necessary. A key component of this definition of effectiveness was how different ethics program services might contribute additively to positive outcomes – e.g., if an ethics education session led to improved ability of staff to address ethical issues on their own without relying exclusively on the ethicist’s direct support, or if monitoring of ethics case consultations flagged a systemic problem that could be addressed through more explicit policy guidance to staff. Such interventions would ideally equip end-users with the knowledge and skills to proactively or preventively address ethical issues that they may encounter in the future. For example, one ethicist observed that if people are properly trained to identify ethical issues, ethics program end-users would: “have identified their difficulties before the ethics consultation and would come to the ethics
consultation with the intention of gathering information, gathering more information on the problem and come out of the consultation with capacity to make a choice. That would be effective” (Ethicist 08H). Hence, an efficient use of ethics program resources would contribute to behavioural changes and sustained ethics capacity over time. Absence of such changes might indicate that the ethics program’s efforts had been “wasted” or were not being optimized to achieve the desired outcomes. As such, number of ethics program outputs given time or resources invested would not by itself be a sufficient measure of an ethics program’s “value for investment”. If an ethics program is not building ethics capacity, even if it is producing a high volume of outputs (e.g., ethics consultation requests), it is not providing value to staff or to the organization in the most efficient way possible.

Finally, ethicists described how demonstrating an ethics program’s value for investment was an important factor in building a business case for sustained or increased ethics program resources. As one ethicist explained:

So we’re starting to look at renewing the contract and in that process we need to say, ‘Well look, we've been – you’ve got bang for your buck so far, so please give us another five years’ worth of funding.’ So it's something we're certainly concerned about and trying to, in some ways, trying to capture some of the anecdotal pieces and sort of put them into a compelling format, but also trying to think about how else might we demonstrate that we've been effective. (Ethicist 11K)

As a result of healthcare organizations valuing the efficient use of resources, ethicists are using efficiency and value for investment to support the business case for maintaining and/or increasing the resource investments into the ethics program. Determining effectiveness is “the super critical question, particularly in a healthcare environment where we’re all evidence based and if you can’t find the evidence for you being worthwhile, your funding disappears” (Ethicist 11K).

Evidence of Delivering Value for Investment

Participating ethicists cited two types of evidence of delivering value for investment: 1) A high volume of ethics program outputs using ethics program inputs; and 2) Increased or maintained resource investment into the ethics program.
1. **Maximizing use of ethics program resources**

A minimum requirement of an effective ethics program is that the resources invested into the ethics program are actually used in such a way that there is demonstrable value to the organization in terms of ethics program outputs (e.g., education sessions delivered, ethics consultations performed, ethics policies developed or implemented) or outcomes (e.g., perceived as helpful by end-users). A high volume of ethics program outputs relative to the ethics program inputs was evidence of generating value for investment. One ethicist stated: “so I think those measures of how many sessions we’ve given internally and what topics are we covering, how many policies have we been involved with reviewing or developing or rolling out, is seen as a measure of success, I think, by the organization” (Ethicist 01A). Similarly, another ethicist said:

> So it would be things like, we had X number of requests that we were able to respond to. So people came to us for information and we were able to provide that... all of the various activities so we're able to say, for your contribution to the [ethics program], people from the district are able to access these various educational opportunities... (Ethicist 11K)

A few ethicists discussed comparing their ethics program’s outputs and resources to ethics programs in other healthcare organizations. These comparisons helped ethicists assess how well they were using their ethics program’s available resources to achieve similar outputs or outcomes. For example, one ethicist noted:

> The small little pockets of evaluation we have done, show that we're not doing a very good job and the reason we're not is because we don't have the appropriate resources to be able to do what's needed...You know, when you compare that to, you know, the resources that are available in Toronto... in an analogous size health authority, so there’s that piece. (Ethicist 13M)

One ethicist argued that an ethics program that was doing more work in more areas would be more effective than an ethics program that was only working in some areas with the same investment of resources. In comparing across healthcare organizations, however, the ethicist acknowledged that organizational context was a relevant factor in assessing the value for investment of an ethics program, stating:

> I think if you were getting into the business of comparing programs, the program that's a superstar in research and does more consultations than anyone, and is well integrated with your senior management and you compare that to a busy
ethics consultation service, which one is more effective, well I think people who are doing more in more domains, I'd say that's a more effective program. So we can make some comparative things, but it's tricky. Again, these programs are individual organizations, so ultimately how useful they are to that organization is the main, the main concern. So I think you have to be careful when you start doing comparisons across. (Ethicist 14N)

2. Increased or maintained resource investment into the ethics program

Further evidence of that the ethics program was delivering “bang for the buck” was in organizational decisions to increase or at least to maintain resource investment. If ethics program resources are decreased, it might signal that the ethics program is not providing good value for investment or that other programs in the organization are perceived to have greater value for investment and hence, a more compelling case for these resources. Alternatively, some ethicists argued that resource investment may not be a sign of an ethics program’s value for investment _per se_, but could indicate instead that the organization “likes” the ethics program staff without reference to any specific outputs or outcomes. One ethicist commented:

_Not so long ago, the organization was facing a huge budget deficit. So they had to cut many, many, like hundreds of millions of dollars. And we didn't get cut! [Both laugh] So it's actually an indicator of success... effectiveness, I think. But actually, that's not true! It's an indicator that they like us. Whether it's an indicator of effectiveness, I'm not sure. So, I'm not sure._ (Ethicist 15O)

A small number of ethicists remarked that resource investment into the ethics program could merely be “window dressing” and not at all indicative of ethics program effectiveness. One ethicist explained that she has seen organizations where money is invested to create one “big document” or to have one big event, but “when you want to train people, meet the teams and help them on the field, ‘Oh well, we don't have money for that, we don't have time for that’. Um, or they don't hire the person that can support that in the institution” (Ethicist 09I). Alternatively, the organizational perspective and ethics program perspective of what constitutes value for investment may be different. The organization may have higher or lower expectations than the ethicist of the value the ethics program should deliver based on its resource investment. As such, for many ethicists, resource investment, by itself, was not an indication that an ethics program provides value.
4.2 Strategies to Evaluate Effectiveness

Ethicists described a number of strategies they are using and thinking about using to measure and evaluate ethics program effectiveness. Many ethicists are collecting data about their ethics program activities. However, most participants expressed uncertainty around whether the data they collect is “the right data” to tell them about whether their ethics program is effective. Moreover, ethicists were unsure how to interpret this data to evaluate effectiveness. This uncertainty around evaluation was one reason that ethicists cited for not engaging in formal evaluation activities even though they recognized the importance of evaluation. Participants also described a number of other reasons why they might not be evaluating ethics program effectiveness. This section presents the evaluation strategies ethicists are using or thinking about using to evaluate their programs, and ethicists’ reasons for not formally evaluating their programs.

4.2.1 Ethics Program Evaluation Strategies

Most participating ethicists are engaged in some kind of evaluation activity and are thinking about additional strategies they might use to evaluate ethics program effectiveness. Strategies that ethicists are currently using to evaluate their ethics programs include: 1) comparing data within and across ethics program activities, 2) assessing qualitative feedback, 3) using Accreditation Canada survey results, 4) engaging in internal and external peer review, and 5) comparing pre- and post- results. Ethicists described “formal” and “informal” evaluation strategies. Formal strategies tended to involve systematic or deliberate data collection such as analyzing end-user questionnaires. Informal strategies tended to be unstructured and based on ad hoc data collection such as gathering anecdotal feedback about the ethics program.

1. Comparing Ethics Program Activity Data

Most participants are engaged in collecting and comparing data within and across ethics program activities. Some used low tech methods for data collection and analysis such as paper files and excel spreadsheets. Others used more high tech data collection and analysis methods such as electronic databases. Ethicists viewed measurement of ethics program activities as a necessary precursor to ethics program evaluation. As one ethicist stated: “you can't know you're effective
until you actually measure what you're doing” (Ethicist 14N). Ethicists described collecting “quantitative metrics” on the number of: a) ethics consultations; b) policies developed, reviewed, and implemented; c) education sessions; d) attendees of ethics events; e) invited presentations; and f) publications in academic journals. Some ethicists quantified “qualitative” data including: types of ethical issues prompting requests for ethics services, distribution of ethics service requests across programs in the organization, and competencies of the ethicist. For example, one ethicist suggested surveying ethics consultation end-users to have them “rate the effectiveness of the person doing the consult” (Ethicist 09I) to determine how ethicists and ethics consultants “can be more, you know, effective as consultants” – that is, “what other knowledge or competencies should we [ethicists] get?” (Ethicist 09I).

Ethicists collected this data on an ongoing basis and reviewed it monthly, quarterly, and annually to allow for comparison over time. For example, one participant described “monitoring attendance and number of ethics consultations, number of policies that we've been involved with, those kinds of things, monitoring our activities, counting them numerically and comparing them to past events” (Ethicist 03C). By documenting what services are being used, where and by whom they are being used, and how utilization is changing over time, ethicists were able to identify opportunities for capacity improvements and to target their efforts toward underserved areas. In explaining her approach to evaluation, one ethicist commented:

Sometimes you can impute some proxy measures from that, saying, you know, we're getting a lot of consults from this one area we need to do some work there, you know, to help educate, especially if they're repeat consults, but you could also say, we're not getting any consults from that area. We're either not valued or they don't even know about us or they're not aware, morally, of problems that they're facing in the moral realm and we need to help them learn how to identify those and get some help. So, you know, that would be one interesting thing that we could do. (Ethicist 06F)

A few participants described using ethics program activity data to identify “trends” across the ethics program. These ethicists compared metrics within and across ethics program activities to learn about how the different activities are affecting each other. For example, following an ethics education session on a particular ethical issue, ethicists assessed whether the number of ethics consultations requested about that ethical issue increased or decreased. One ethicist
stated: “[A] neat way of putting the point is: if you’re truly effective, all of these things sort of reinforce each other. So your policies should help with the consults and it should influence what you have to provide consults for and vice versa” (Ethicist 14N). This ethicist, however, noted the difficulty measuring whether and how the ethics program activities influence each other, saying: “But actually capturing how those things are occurring is a tough issue. So I think the work is figuring that out more” (Ethicist 14N). To facilitate data collection, comparisons, and trending, some ethicists are beginning to develop electronic databases or recording systems. One ethicist outlined the “large number of metrics” on ethics education, consultation, policy, and academic involvement that his program collects and compares. According to this participant:

Well, when I started, measurement was sort of job one. We had a paper system of measurement which recorded key things, but there wasn't a way to efficiently summarize that data, compare it, and analyse it. So we put a database in place that looked at a huge number of metrics... So across all the domains we’ve got metrics and that's in place, and that's very solid. Going forward, I think the challenge is evaluation, in terms of what this means. And so I think we need to get a clearer picture of sort of referre patterns and how that relates to the education that we’re doing. So rather than looking at metrics within a silo, how are these all affecting one another? So if we put this policy in place and we do all this education, are we seeing a change in consult patterns? But you need a lot of data to do that and we're building up a lot, but it's a difficult thing to figure out what's changing what. (Ethicist 14N)

Even with an electronic recording system to facilitate data collection and analysis, evaluating effectiveness was still perceived as a challenge, especially with de-identified data. Recent changes in privacy legislation prevented ethicists from saving detailed information about the ethics consultations they are performing, which makes it difficult for ethicists to evaluate long-term outcomes for the cases they are consulted on. One participant stated:

It's hard to conclude effectiveness from that. You know, we can look back at it; there are no identifiers, so it's not so easy to figure out ‘what did I do with that case?’ You're not supposed to identify things too much, so if you can recognize it, you can go back and wonder whether you, whether what you did led to success or effectiveness or not. (Ethicist 01A)

Moreover, ethicists recognized that a database is “only as good as what we put into it, obviously” (Ethicist 01A). A few noted that much of the data they are capturing may not be useful for evaluation purposes. One ethicist who was collecting multiple “indicators” using an “Excel
“Um, some of the indicators may not be, may be good. I don't know. I don't really know yet. I think it's nice to collect them, but maybe they're indicators that aren't good” (Ethicist 10J). Similarly, another ethicist pared down the data he was collecting after realizing it was not being used. He explained:

*I used to collect a lot more and then I realized that it didn't have any added value. It was just data. We didn't do anything with it. So I stopped collecting it... I just look at the themes and the areas of... here, I can tell you what I do now: the ethical issues, the themes, major areas, the consults, who called me” (Ethicist 02B).

2. Assessing Qualitative Feedback

Ethicists used qualitative feedback such as open-ended responses on questionnaires or informal conversations with end-users about what end-users thought worked well, what was valuable, what did not work well, and what could be improved to supplement quantitative data about the ethics program. Quantitative methods of evaluation (e.g., surveys) were perceived to be useful in some situations, but provided “too limited of a picture” (Ethicist 14N). Some dimensions of ethics program activity (and hence effectiveness) were thought to be “very difficult to quantify” or could only be understood in context. For example, quantitative measures can capture whether more people are using ethics program services, but not what measurable effect the ethics program is having on the ethical culture of the organization.

*Um... but it's also something that came up in our own strategic planning of you know, people wanting dashboards, our quality department wanting dashboards, to measure or demonstrate growth over time within our programming. But the items that we identified as areas needing growth were very difficult to quantify, to actually measure, here's a demonstrating of growth in our ethics services or in our programs. And the things the quality shop was looking for really weren't, I mean, we could capture increase in ethics consultation, we could capture the kinds of ethics consults that we were um, we were experiencing, whether organizational, clinical, so we could have numeric things that we could capture, but they weren't really speaking to the overall enhancing the culture of our organization. They were maybe reflective of trends going on at the time, but not necessarily are we genuinely meeting needs? And so there was more of a qualitative piece that we're trying to capture. And I think it's still in the process of developing relationships to have those qualitative kinds of pieces to, um, effectiveness. (Ethicist 12L)
Using qualitative feedback to complement quantitative data gives ethicists a more robust picture of ethics program effectiveness. As one ethicist explained:

*Having less consults in an area doesn’t mean that there are less issues in an area. It may mean that people may not be bothered to call anymore. Now, when you build capacity in your staff, then they don't need to call you because they now know what to do and they're doing it, they don't need to call you all the time to do it. So less consults may mean they aren't even getting to the ethical issues because they're already circumventing them from occurring. But we don't have any data or research to help us know that. When it’s one and when it’s the other, or where maybe it’s due to another reason or five more reasons that we don’t know about yet. So, you can’t link it back or draw conclusions. I think it can help you probably going forward, but I don’t think you can look back and say well we fixed it. And that's the struggle with ethics.* (Ethicist 02B)

Fewer ethics consultations might be a measure of effectiveness, but only if the decreasing number of ethics consultations were due to increased ethics capacity. The further step of determining effectiveness needs to happen through other evaluation methods.

*You would have to set up some sort of, of a way to evaluate that so that you were sure that the reasons the number of consults was decreasing was because people were able to resolve issues more effectively on their own. And I think that could be done using particular research methods.*

(Ethicist 13M)

Some ethicists systematically sought out this qualitative feedback about how the ethics program has made a difference to staff, whereas others collect it on an ad hoc basis. Those who did not systematically seek out feedback on the ethics program, but take note of unsolicited feedback when they receive it, tended to think that the qualitative feedback is “*on the verge of anecdotal, more than anything else*” (Ethicist 12L). Ethicists who actively seek out qualitative feedback followed up with ethics program end-users, most often with those who requested an ethics consultation or attended an education session. One participant stated:

*So I think what we’re doing right now is measuring really well within each of the domains and it's more qualitative in terms of feedback about “you know what, we encountered this issue, but thanks to your education session a couple of weeks ago, we actually knew how to deal with this substitute decision-maker and we*

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15 These specific “*particular research methods*” are “participant observation” and “ethnographies” as discussed on pages 72-73.
Some ethicists described using “a standard evaluation form” to collect this feedback about “relevance to practice, and, you know, was it presented well, but also asking about what more do you want to learn about on this particular topic as well as what other topics do you want to learn about” (Ethicist 11K). Other ethicists sometimes informally meet with people after the ethics consultation to determine what happened as a result of the consultation from the end-user perspective and whether the end-user thought that the ethics consultation was helpful. Ethicists use this information to plan future ethics program activities and identify opportunities for improvement.

The ethicists outlined different ways of using qualitative feedback to evaluate effectiveness. One ethicist proposed conducting an “audit on satisfaction” by asking people after an ethics consultation whether they were satisfied with the outcome and whether they would be a “repeat customer”. Others, however, argued that end-user satisfaction was not a reliable measure of ethics program effectiveness. According to one participant, “there isn’t a necessary link between someone saying, ‘you’re fantastic, great’ or ‘no, you’re terrible’, and that actually being the case or not” (Ethicist 14N). Similarly, another noted:

So, you know, imagine you send out a form in that case, and they say, yeah, this is fantastic, best thing ever. And then another person, you tell them what they don’t want to hear, and they say the consult was terrible, absolutely. What have you learned from that sort of evaluation? I don’t think you’ve learned very much, right, about how effective the service was, because it’s a satisfaction measure. And we love... I don’t want to say "we", but healthcare people love patient satisfaction and the Picker scores, but they don’t tell you very much. Because you can provide excellent healthcare and people can be incredibly dissatisfied because people don’t like being in hospitals. No one likes taking all this time and sitting in a room and having all these things done. People don’t like that. So, you can identify areas where you can improve patient satisfaction. I don’t have a problem with patients being satisfied, but I think you have to be careful with putting too much stock in what those mean in terms of, you know, the success in achieving a program’s objectives. (Ethicist 14N)

Instead, one ethicist proposed obtaining qualitative feedback from ethics consultation end-users “about their experience with ethics services – not whether they like us or not, but whether we
actually achieved the objectives that we're seeking to meet” (Ethicist 15O). Finally, another ethicist was thinking about triangulating qualitative feedback from different stakeholders, including the end-user, ethics program staff, and patients and families, to provide a more robust assessment of the ethics program intervention. This ethicist stated:

So probably trying to get uh, feedback from people to whom the service was provided, so some kind of an assessment. Um, particularly from people who are actually supposed to be benefitting the most from it – so, not just the team, for instance, but actually the patient or family who was involved. Um, so this is for ethics consultation that we’re talking about right now. Um, my, my, and my own colleagues, if I had some, our assessment of how well it went. So, kind of a triangulation thing, right. Uh, you’d want to hear from the team too, about what their experience was. So, all the interested parties get some kind of formal feedback. (Ethicist 07G)

Some ethicists expressed a strong preference for applying more “rigorous” and “objective” methods to evaluation. For example, one participant argued that simply asking ethics program service end-users for their feedback was “not a very useful way of evaluating your service” (Ethicist 04D) and may not generate “credible” or “reliable” evaluation results. This individual stated:

It would be very easy to go to the people I work with and say, ‘Hey, what do you think of this job I'm doing?’ Or get them to fill out a survey or something. But, like I said, those results, I don't think would be reliable because, first of all, the way I select my sample, unless it's a random sample of people in the organization, it's going to be inherently biased. And the people that choose to respond to it would be biased as well. (Ethicist 04D)

This ethicist reported using Accreditation Canada results and peer review as evaluation strategies because they are “objective sources” rather than using qualitative feedback. Another ethicist proposed applying qualitative research methods such as “participant observation” and “ethnographies” to evaluate whether an ethics program is effective. This ethicist emphasized that observing “what’s happening in practice” in the organization is “the only real way that you’re ever going to know whether or not, on the unit, that uh, there are people who are able to deal effectively with their own issues, you know” (Ethicist 13M). An ethicist could perform an “ethnographic study” on a unit where the ethicist knew there to be a number of ethical issues “to see, actually, how people are identify issues, what happens when they do identify an issue, how
they’re resolved” (Ethicist 13M). However, this strategy is resource intensive and requires methodological expertise, which may be barriers to its regular use:

I think there needs to be resources available for people to be able to develop, to use research methods that are out there, right now, but to modify them to be able to collect the information that we need to know, because it isn’t all just about numbers, and you know, there are participatory methods and other ways that we could structure ethics research projects that would give us the kind of data that we need. Using focus groups and using participatory methods, ethnographies, etc. And that’s not always been popular in evaluation, you know, people are focused on the numbers, and so I think that that’s a bit of a barrier, both in terms of being able to implement those kinds of studies, but also to get resources to do them in the first place. You know, what would really exciting, for example, would be to set up an ethnographic study on a particular unit where you know that there are a number of ethical concerns or issues, and to be able to, you know, do participant observation over a period of time to see actually how people are identifying issues, what happens when they do identify an issue, how they’re resolved. You know, that’s the kind of data that we need, and um, the resources are very scant to be able to do that. (Ethicist 13M)

3. Using Accreditation Canada Results

Many participants cited using results from the Accreditation Canada surveys and the “Tracer Methodology”\(^\text{16}\) to get “proxy information” about how well the ethics program was serving the organization’s ethics needs. Accreditation Canada survey results give “snapshot views” about organizational awareness of ethical issues, availability of ethics services and supports, and staff and physician ability to identify and address ethical issues in practice. One ethicist explained:

You can measure it a little bit through Accreditation Canada standards – and we’ve recently been accredited – but again, it’s a, you know, you can get snapshot views. We have done, through Accreditation Canada and otherwise, those kind of surveying instruments to say: How aware are you of the ethics program? Do you know how to make decisions based on ethical frameworks? And by that you can get a sort of proxy bit of information regarding whether or not we’re meeting goals or we’re effective. (Ethicist 06F)

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\(^{16}\) Tracer methodology is used by Accreditation Canada surveyors during the accreditation process to determine whether an organization is compliant with standards and the extent to which critical processes are implemented. It involves tracing the path of a patient or “an administrative process” through activities such as document review, observation, touring the organization, and speaking with staff, patients, families, and other relevant parties to learn about the quality of service delivery and organizational management (Accreditation Canada, 2009).
The Accreditation Canada surveys ask all of the staff in the organization “broad questions” about how the organization handles ethical issues. According to one participant, if an ethics program receives negative survey results, it gives the ethicist an idea of where there might be a problem, but the ethicist still needs to do further work determining why the result was negative. For instance, is the ethics program actually ineffective or was there “one case that everyone has on their mind and it was handled poorly and that is what they're talking about, not a general issue? So it takes hard work to follow up” (Ethicist 14N).

Some ethicists emphasized the “Tracer Methodology” that Accreditation Canada uses as a “rigorous” and “objective” process to assess effectiveness, although others disagreed, arguing that “many surveyors don’t know much or nothing about ethics and ethics programs” which limits the rigor of the evaluation (Ethicist 01A). Nevertheless, one ethicist stated that an Accreditation Canada assessment is “completely out of my hands, like, I'm just the first starting point, but then they go throughout the organization and ask people, and find out what work I've actually done, not just what I say I've done” (Ethicist 04D). In this evaluation strategy, the Accreditation Canada surveyors interview the ethicist and staff to determine whether the organization meets standards around awareness and accessibility of the ethics program. One ethicist described the process:

Well I think that one of the things that could happen, and I think in some ways it does happen in part, you know, when accreditation occurs, because Accreditation standards are such that staff are supposed to be aware of the resources that are available for ethics services, so according to the Accreditation standards, you know, they go out and they interview staff and if someone says they don’t know that those services are available or they don’t know how to access them, then obviously the agency is given some kind of advice about the fact that they need to make improvements. So I think that's one way, that staff need to be knowledgeable and you should be able to go out and speak to staff and find out that yes, they know exactly what to do if they have an ethical concern or an issue, that they know what the process is for accessing the resources that they need. (Ethicist 13M)

A few other ethicists thought that this process could be used outside of an Accreditation Canada assessment to evaluate whether people were aware of the ethics program and knew how to make appropriate use of the services. It would be a “useful test” of effectiveness to take a “random sampling” of staff throughout the organization. If the ethics program were effective, staff
“would know about the service, they would be able to tell you when they would use it” (Ethicist 07G).

Although ethicists were using Accreditation Canada processes and results as a component of their approach to their ethics program evaluation, most did not think that it was a necessary or defining strategy to evaluate ethics program effectiveness. Instead, its value was primarily in being “one of the huge levers” for organizational change and for ethics program advocacy. One ethicist explained that “a good Accreditation” is used to create a platform for requesting additional resources for the ethics program; however, it is not used to determine whether the ethics program makes a difference to the organizational culture.

So that, yeah, accreditation most certainly does have a role in establishing a sense in evaluations, but I have to confess, it isn't necessarily the barometer according to which we measure you know, effectiveness. I think, again, effectiveness goes more around, to the organizational culture, which yeah, accreditation and developing our own culture has that relationship, but um, I think it's more, are we owning our own sense to be better and to do more, or is it being driven externally by a need to be evaluated by somebody else. (Ethicist 12L)

4. Engaging in Internal and External Peer Review

Some ethicists cited peer review internally at the ethics program level with other ethicists on staff and/or with clinical ethics committee members, and externally with the broader bioethics community as evaluation strategies. At the ethics program level, ethicists who worked in a comprehensive ethics program model with other ethicists used peer review as a way of evaluating and improving the effectiveness of their own practice. Ethicists reviewed the variance in the number and type of ethics program activities from month to month and identified recurring trends and opportunities for improvement. During this process, ethicists discussed individual approaches to practice across ethics program activities and evaluated whether they are providing quality ethics program services as individuals and as a group. They asked their ethicist colleagues within the ethics program to comment on their work and make suggestions as to how they might be more effective. For example, one ethicist reported:

We do discuss our cases, whatever we're doing, with each other. So I think, more informally, we sort of process either, we process together how effective we thought we were, we talk about a case and say, 'It probably would have been
In healthcare organizations with ethics committees or similar structures, the ethics committee provided a forum for quality case review. The ethics committee case review process provides ethicists with multiple perspectives on whether ethics consultations that were performed met standards and/or made a difference to staff. According to one participant: “this case review that happens at the level of the committees, where we're reviewing you know, individual cases periodically, that, that's another form of evaluating how effective the ethics services are, in responding to and meeting needs” (Ethicist 13M). Another ethicist stated:

> When I do present consults back to the committee, that's an opportunity to review again the work and I get lots of additional discussion from people from quite a variety of backgrounds. Um, that helps sort of retrospectively to assess the effectiveness of sort of specific things going on in the service. (Ethicist 05E)

Some ethicists, however, found it hard to use the results to improve ethics program effectiveness when there is no formal mechanism for acting on identified areas for improvement. One participant explained that because peer review with the ethics committee is so informal, there is “no structure or effort in place to say, well, if we really wanted to make a difference, we've got this recurring problem here around restraint policy or something like that, let's, you know, let's create an initiative” (Ethicist 07G).

External peer review at the broader bioethics community level consisted of asking practising ethicists in other healthcare organizations to review ethics program activities and evaluate whether ethics program practices meet the standards of other ethicists. Although used in particular by ethicists in lone ethicist programs, many participants emphasized the value of checking the quality of their work with professional peers in other institutions and jurisdictions. For example, one ethicist has a biweekly teleconference with other ethicists in her province to discuss challenging cases, improve consistency, increase education, and enhance the quality of
ethics work. Another ethicist sent out the policies she reviews and the results of her ethics consultation process to other ethicists working in the field, and asks for their expert opinions. This ethicist stated: “the only way I can determine if I get it right is to be judged by my peers” (Ethicist 04D).

5. “Pre and Post” Comparisons

A few ethicists described using pre- and post- comparisons as an evaluation strategy – comparing results from a survey before an ethics program intervention (pre-) to results from the same survey after the ethics program intervention (post-). For the ethics program as a whole, a few ethicists described performing an annual ethics needs assessment to determine staff and organizational needs in terms of ethics supports and comparing the survey results with previous years to identify how things are changing from year to year. One ethicist noted:

We're going to do a needs assessment to see where the needs are in the community. Where they are? Because we won't know, because this is going to get bigger. The needs could be in gerontology. They could be in acute care, cardiac; so we're going to create a survey, and that's going to be hopefully in June. So that will help give us some numbers, and then you repeat it, right, so then we have another year and see where it's going. (Ethicist 10J)

Similarly, another ethicist thought that it would be useful to have “some validated tools” to do a “needs assessment” in the organization and determine awareness of the ethics program.

For ethics program interventions, ethicists would survey end-users before and after the ethics program performs an ethics consultation, delivers an ethics education session, or implements an ethics related policy. One ethicist, who defined ethics program effectiveness in terms of making a difference by alleviating moral distress and uncertainty, described creating an instrument using a Likert scale to determine a staff person’s self-identified level of moral distress and moral uncertainty before and after the ethics consultation. This ethicist explained:

We're working on a different instrument now, um, that's going to be focused a little more on asking people to identify the level on a Likert scale of moral distress and moral uncertainty, which I think are two very different things potentially, and then before and after the consultation to get some sort of a sense of whether or not we actually made a difference, because very often why we're asked for consults is because people have a sense of either moral uncertainty: What do I do? I don't know the right thing moving forward or I'm distressed at this, please help walk me
through ways to feel like I'm doing the morally right thing, or guide me. And we want to see are we actually making a difference for people. (Ethicist 06F)

To evaluate whether ethics education is effective, ethicists ask staff to do a self-assessment before and after the education session rating their ability to address ethical issues. According to one ethicist:

*We also do sort of these rigorous pre and post assessments. So basically before they start the course they do a self-assessment that's a half hour study asking them questions about how they would evaluate their own ability to think about certain kinds of things and then we do that afterwards as well. So we're asking about the self-assessed change they've experienced that's as a result of participating in the course. And that's true for several of the events, the pre and post self-assessment. (Ethicist 15O)*

Some ethicists described assessing clinical practice pre- and post- implementation of a new ethics related policy to evaluate whether the policy was having the desired impact. Before the policy is implemented, ethicists measured the baseline of current practice. After developing and implementing the policy, ethicists surveyed staff and audited charts to determine whether staff know about the policy and are using it. Using this strategy, ethicists are able to “demonstrate by, either by evidence or change in practice, that things are being done differently” (Ethicist 02B). One ethicist described using this strategy to determine whether staff changed how they report adverse events after the ethics program developed and implemented a new disclosure of adverse events policy:

*I surveyed every single person before and after, and the data showed that everybody understood what the disclosure policy was. The data showed that they knew what to do if there was an adverse event, and nothing happened. Nobody reported adverse events. We went back in six months and we said, ‘So how are you doing with your adverse events?’ ‘What are you talking about’ was their response. ‘We don't know what you're talking about’. So whatever I did, and the data showed, had no impact whatsoever, and they forgot it 15 minutes after they left. (Ethicist 02B)*

Some ethicists noted limitations to a pre- and post- comparison approach in evaluating ethics program effectiveness. One participant noted that most ethicists are not “skilled in developing valid surveys, me included. So I’m not convinced that the data we collect [pre and post] is all that useful, especially when we don’t know what we need to measure in the first place” (Ethicist 01A). According to another participant, pre- and post- types of evaluations only give a narrow
measurement of whether a policy is making a difference. She illustrated this point by describing a no cardiopulmonary resuscitation (CPR) policy that the ethics program recently re-wrote. The ethicist was able to compare “pre and post in terms of are people at least writing these orders in great details, you know, how does that look alongside the documentation in the chart, you know, we'll have some data there. But does that say that the policy's effective or not?” (Ethicist 12L). The pre- and post- comparison gives an idea of effectiveness, but “it doesn't say what's the quality of discussions with substitute decision-makers and patients in informing them of the risks and benefits of CPR, and that's a hard thing to get at, and that's probably the more important piece” (Ethicist 12L).

4.2.2 Reasons for Not Formally Evaluating Effectiveness

Ethicists believed that evaluating ethics program effectiveness is important. Ethicists who were actively engaged in evaluation tended to be those who: a) had five or more years of work experience as an ethicist, b) were leading more established ethics programs, c) were on-site at their healthcare organization five days per week, or d) worked with other ethics program staff (e.g., multiple ethicists, ethics fellows, or an ethics program coordinator). However, many reports that they were not currently engaged in formal program evaluation activities. Most of these ethicists tended to be: a) fairly new in their roles, b) leading recently established ethics programs, c) paid to be on-site at their healthcare organization fewer than three days per week, or d) already felt very valued by the healthcare organization. Nevertheless, these ethicists were engaged in some kind of data collection or measurement of ethics program activity and were also thinking about what evaluation strategies might be used to evaluate ethics program effectiveness. Many of their suggested strategies were currently being used by other ethicists who were more actively engaged in evaluation.

Ethicists cited four reasons for not formally evaluating ethics program effectiveness:

i. The ethicist is unsure of how to evaluate ethics program effectiveness,
ii. The ethics program does not have the resources or capacity for evaluation,
iii. The ethics program is still in its early development, or
iv. The ethicist feels the ethics program already has sufficient “buy-in”.
i. **The ethicist is unsure of how to evaluate ethics program effectiveness**

Many ethicists expressed uncertainty about how to evaluate ethics program. In particular, ethicists did not know what measures of effectiveness or measurement tools they should be using. One ethicist commented that, “I think we don’t have good measures, uh, regarding effectiveness. I don’t know how people can really assess the quality of what I’m doing, which worries me. We don’t have good benchmarks” (Ethicist 05E). Most participants emphasized that there is currently little guidance in the field of ethics around how to measure ethics program effectiveness. One participant stated: “you need to collect the right data, and do we know what that data is? I don’t know, and we certainly don’t know in ethics, yet. I mean, what counts as evidence? I don’t know. It’s pretty complicated” (Ethicist 02B). Similarly, another reported: I actually think for some of these things it’s not clear how to tell and even if you want to, around say policy for instance, how would you know whether that was an effective policy development process? So having some criteria to turn to” (Ethicist 07G). As a result of not having “good measures” or criteria for evaluation, some ethicists do not have formal evaluation mechanisms in place to evaluate the effectiveness of their programs.

ii. **The ethics program does not have the resources or capacity for evaluation**

A few ethicists were not formally evaluating effectiveness because their ethics programs do not have the resources or capacity to develop or implement evaluation methods. Most of these ethicists operate in a lone ethicist program model and/or are only on-site at their healthcare organizations a few days a week. Although these ethicists recognized the importance of evaluation, they report being purely “reactive” to the ethical issues that arise in the organization requiring their assistance. They do not have the time or resources to be “proactive” or to engage in formal program evaluation activities. According to one participant:

*And I think there’s a... there’s work to be done in identifying and, uh, developing and then using benchmarks. But I, myself, personally, have not been able to get it going, and I think it’s because I’m not here enough, and there isn’t enough resources at the institution to kind of champion and take it on. Uh, you know, no one is taking that initiative in a way that makes it happen. The previous quality officer that we had here, I did, we, our offices are in the same area of the hospital and in fact, next door. And I did try several times to see if we could get quality benchmarks pre and post, you know, for the new end-of-life decision-making*
policy coming out and some things like that, but she was just never interested. She said, ‘Yeah, but you know, our priorities are elsewhere.’ (Ethicist 05E)

Similarly, another ethicist reported that even though data about her ethics program might be helpful information to have, she lacks the time and resources to develop data collection methods for evaluation. She stated:

So we don’t have any forms or statistics that we’re collecting at this point. It might be helpful, but uh, at the same time it’s a matter of – and this may get to one of your later questions – Do we have the time and the resources to actually collect that information? Um, I know, personally, I just simply don’t, I have the interest to do so, but I just don’t have the time or the resources. (Ethicist 12L)

For a few participants, being able to evaluate and demonstrate effectiveness would help them make the “business case” for increased resources to the ethics program. However, with a lack of measures of effectiveness and a lack of resources and capacity to identify measures, these ethicists reported being unable to evaluate effectiveness. One participant stated:

The nurses and leadership are all about if you have benchmarks and measures it makes a difference. And I’ve been trying, over a few years, to try to get them to increase the work that, you know, the resources. And I think having someone point to it is ridiculous. The hospital’s been growing like crazy and um, we’re way behind what we should have. But, you know, I don’t feel like I can make the business case or the ethics case to show that what we do makes a difference. Or that what we do is so far behind, without any measures to do that. (Ethicist 05E)

iii. The ethics program is still in its early development

Other ethicists commented that their ethics program was recently established and they felt that it may be too early to evaluate effectiveness. As one stated: “But we’re very young and that’s, you know, part of the challenge. It's maybe not even time to be evaluating yet, regarding effectiveness” (Ethicist 06F). These ethicists felt that their ethics program is still a new development within their organization. Given that they are still building the ethics program infrastructure, current organizational expectations to demonstrate effectiveness are not yet “well laid out”. Moreover, they are unsure whether they will be able to assess effectiveness given the how new the ethics program is. Nevertheless, these ethicists reported that eventually they would need to evaluate the ethics program and demonstrate effectiveness, particularly in order to justify the resources the program receives. For example, one ethicist who is currently developing an
ethics program using the Hub and Spokes model explained that in the following year, the ethics program will need to demonstrate the value for resource investment especially given the investment of time and effort by ethics facilitators across program areas in this ethics program model. She stated:

_I think there will be a need to prove um... because this is a new; this is really new, like this is a new program, a new development, so I think this Hub and Spoke thing will have to show up. Because there will be some resource issues with that. So we're going to have to show that this is a good thing because they'll have to put some money into it. And right now, there's been no resources. They are far and few between. So we're going to have to prove that this model is actually going to work. So that's going to be our next year's goal, is to actually set our goals and make sure there are effective goals._ (Ethicist 10J)

iv. The ethicist feels the ethics program already has sufficient “buy-in”

A few other ethicists who were not currently engaged in formal evaluation reported not feeling the impetus to evaluate effectiveness. These ethicists felt that their ethics program was already valued by their organization. They did not feel a sense of urgency to demonstrate ethics program effectiveness. One participant explained:

_Actually, you know, my, the person I report to is interested in what we're doing, but purely from the perspective of wanting to toot the horn of ethics services and really just promote the service, not necessarily to meet, to make sure that we're meeting some standard. But I think that's also a function of the fact that we are a very high performing service in the region. We're a very small resource and we do a heck of a lot of things that are very well received, so I think there's no concern that we're not meeting a minimum standard. I think that if that wasn't the reputation that the service had, then I think there may be more concerns about well, what are you doing, sort of thing._ (Ethicist 15O)

Similarly, another participant, for whom demonstrating ethics program effectiveness was not a priority, reported that the senior leadership team already understands the value of the ethics program without the ethicist having to provide evaluation results. This ethicist felt that the ethics program had sufficient “buy-in” from senior leadership such that she did not need to justify the existence of the ethics program or the financial resources it receives. According to this individual:

_Some of the reasons why it's not the highest priority for me is I already feel like we have buy-in in the organization from administration for our existence within
ethics and there’s a shared appreciation amongst the senior leadership to, and a shared understanding of the value of the ethics, both clinically and organizationally, um, to be in existence... And so I already feel like we have buy-in and don't have to justify the existence of an ethics program within our organization, which is often, at least, the voice that I hear within my own colleagues – that they want to collect information, they want to collect data about effectiveness so that [participant puts emphasis on this point] they can either get more resources for their programming or legitimize their existence within their own organization and therefore give themselves a little bit more of, um, I guess, a platform, which I think is needed in healthcare generally... Now, that doesn't mean to say that showing or demonstrating effectiveness is going to hurt us, I mean most certainly it would be great to demonstrate greater effectiveness. (Ethicist 12L)

4.3 Critical Success Factors for Ethics Programs

Ethicists identified a number of critical success factors for ethics programs effectiveness. Critical success factors are organizational elements that are necessary for an ethics program to be effective. Ethicists considered the presence of these factors to enable ethics program effectiveness. Conversely, when the same factors were absent, ethicists considered their absence to present a barrier or an obstacle to achieving effectiveness. Without the factors, it was difficult, but not impossible, to achieve effectiveness. Barriers were not insurmountable, but required time and ethicist “creativity” to overcome. For some, barriers were a matter of degree and might relate to the developmental stage of the ethicist, ethics program, and/or healthcare organization. Ethicists cited four critical success factors for ethics programs: 1) competencies and attributes of ethicists and ethics program staff, 2) organizational understanding of the ethics program, 3) organizational support, and 4) community of practice.

1. Ethicist and Ethics Program Staff Competencies and Attributes

Ethicists’ skills, “competencies”, and “attributes”, and those of other ethics program staff (e.g., ethics committee members, ethics fellows, etc.), can enable or hinder ethics program effectiveness. Ethicists and ethics program staff “have to be competent”: clinical staff are “more likely to access them because they will be able to have their questions addressed by people that are knowledgeable and have the expertise to respond appropriately” (Ethicist 13M). Moreover, being able to speak the “medical language” and “understand health professionals” helps establish credibility and enhances the likelihood of influencing clinical practice, particularly if
ethicists do not have a clinical background. If the ethicist and ethics program staff are perceived as lacking the requisite knowledge and skills to practice, the ethics program will not be thought of as being credible.

A few ethicists described professional skills as facilitating positive interactions between themselves and ethics program end-users as well as other colleagues within the health organization. For example, one ethicist thought that her ability to problem solve, manage conflict and group dynamics, understanding “human relationships, and the skills of communicating, and negotiating, or managing sensitive discussions... helps a lot” (Ethicist 05E). Another ethicist emphasized the importance of how the ethicist works with staff in the organization, stating: “If you're not liked, and it’s not just being liked or disliked, but you know, if people don't like you, don’t like your approach, don't like the way you work, they will not take you in” (Ethicist 09I).

Many ethicists commented that personal “attributes” and “personality” matters just as much as credentials. Personal “attributes” and personality could affect whether an ethicist “fits” in an organization. One ethicist might not be effective at one organization, but might be “highly effective” at another “because it just isn’t a personal fit or a style fit or what their interests are” (Ethicist 01A). Likewise, what works in one organization might not work in another because the ethicist’s approach to leading the ethics program is not a “good fit” in the organization. Moreover, a few participants emphasized that it is not just about “being a scholar”. As one ethicist stated, “Even though you could have like 17 PhDs, uh, you know, you have to work the work, and talk the talk, walk the walk, and talk the talk” (Ethicist 09I). Similarly, another noted: “It’s not really your knowledge, but how you’re perceived. So if you go in there, and, um, try to tell people what to do, or do something, you’re not going to make any in-roads, especially with physicians, because you’re viewed as judging their behaviour” (Ethicist 10J).

Nevertheless, knowledge and training in program management were perceived as critical factors in achieving effectiveness. Some ethicists highlighted their own lack of training, specifically training in how to manage an “effective” ethics program, as a barrier to leading an “effective ethics service”. One ethicist explained:
Some [barriers] come from my lack of training and, you know, in management, or, you know, I don’t have any training in management. I don’t have any training in ... project management. Because, you know, it’s a very specific training to learn and to be, have a good leadership in dealing with different projects at the same time. And I think have an ethics program, it’s like a big project management thing because you have to, you know, you have to do the training, you have to think about the education program you want to, for the different teams and so on. And I don’t have any formal training in that, and that’s why I learn ... as I do it. So this is a problem because it’s harder and it doesn’t give results as easily or as fast as I could get if I were more trained in the real tools to do it. So I think I’m one of the factors. (Ethicist 09I)

Similarly, another ethicist stated that, “If I knew more about how to run a more effective ethics service, or if I had more opportunity to spend more time in an additional internship with somebody very experienced; so, definitely my own level of education and training” (Ethicist 07G).

2. Organizational Understanding of Ethics

**Trust in the ethicist and ethics program**

Study participants reported that when staff and senior leadership in the organization trusted them and trusted the ethics program, it was easier to be effective. Trust in the ethicist created the conditions for people to seek out the ethics program and its services, and for the ethics program to demonstrate its value to the organization. Without trust, staff and senior leadership would not seek ethicists out or use the ethics program services. As a result, it would be hard for the ethics program to achieve its mandate, meet Accreditation Canada standards, or deliver value to the organization through use of the ethics programs resources. To build trust, ethicists need to be responsive to the “actual needs” of those that the ethics program is meant to serve. According to one participant, “the biggest reason I think people wouldn’t call an ethics department is because they don't trust us. So once they see that we have the same goals as them, that we have the same commitment with, as them, that we’re part of the team, they seem to come around” (Ethicist 04D).

Being responsive to needs also involves addressing “new and emerging clinical issues” by working on ethics initiatives related to these issues. One ethicist explained:
My sense is that if you're responsive, you're more likely to make the sort of difference in terms of organizational or individual practice, than you are if you're just pursuing sort of what the hot topic in bioethics is at the moment. Um, because I think that the risk, to a certain degree, is being seen by healthcare providers and administrators as being out of touch, or that what you're doing is nice in theory, but not grounded or linked to practice, and so, that sort of is irrelevant in a certain way, and so being responsive is sort of ensuring that what we're doing is indeed relevant to the people whose needs we're supposed to serve in our activities. (Ethicist 11K)

Conversely, it would be “much less effective” if the ethics program were driven by the personal or academic interests of the ethicist as opposed to organizational needs. For instance, if an ethicist delivered an education session that he or she alone was interested in, like cloning, healthcare providers would “tune out” and not be receptive of the education. By being responsive to needs, people are more likely to listen to “messages around ethics. That is, they are more likely to see ethics discussion as relevant and applicable when they have identified the need for that discussion” (Ethicist 11K). For example, according to one ethicist, it “makes for pretty effective education” when the ethicist tailors his or her teaching approach to the needs of end-users.

Being on-site, available, accessible, and approachable were considered to be necessary for establishing an “ethics presence” in the organization.

I have a presence, which probably speaks to my success vis-a-vis or you know, in comparison to, to at least some colleagues in the past who worked at some of the other institutions or who worked here. I have an office here, I'm here, I come regular hours. People at least see me regularly, um, but – that helps. (Ethicist 05E)

Another ethicist underscored that presence is “everything [to ensuring ethics program effectiveness]. Ok, money’s everything, that’s [laughing, then pauses]; it’s the other really big everything” (Ethicist 07G). This ethicist went on to explain that presence is not just “having an office door with your name on it”. Rather, presence is about “getting to know people and developing relationships that might not be about ethics, you know, just literally the getting to know stuff” (Ethicist 07G). Given that staff tends to deal with issues at a local, “peer-to-peer”, or team level, having a presence “on the ground” was perceived to be essential if the ethics program were to be known and used as a resource to address the complex ethical issues that arise in
practice. Without an organizational presence, staff will not know who the ethicist is, approach the ethicist, or trust the ethics program. For example, one ethicist explained that her ethics program does not receive many ethics consultations requests from one of the hospital sites where there is no ethicist presence. She described a similar situation at another hospital site that changed once another ethicist was assigned to work there full time. The new ethicist became familiar to staff and developed a presence there. She stated:

> [T]his is another aspect of effectiveness: presence. It's really hard to be present when you don't have an office. And when you don't have the time, they haven't resourced the position so you can't even be there. If people don't know who you are because you're not there, where to find you, it's really hard to be effective. (Ethicist 01A)

A sustained presence enables the ethics program to achieve “more long term changes” throughout the organization. Some ethicists commented that a permanent presence helps the ethicist get to know the organization, understand what and where the needs are, embed changes, and provide ongoing support. One ethicist, however, commented that it is sometimes “a good feature” if the ethicist is not physically embedded at the organization as it allows the ethicist to speak his or her mind. She explained:

> It feels sometimes like I go in, say a bunch of stuff that, you know, may or may not be contextually appropriate, and then leave. And sometimes, anecdotally, people have said that, you know, that's effective because I can come in and say things that I wouldn't be able to say otherwise if I was there all the time. I don't know the politics, the history and things like that, but sometimes it's a good feature. (Ethicist 11K)

Nonetheless, most ethicists thought that “at least one” dedicated full time person was required to increase the likelihood of the ethics program being effective. One ethicist stated that, “I don't think you can do this with halves and bits. I think you need someone that is working at this full time, um, at least one. So, any kind of dual role, I think the chances of being very effective are probably lower (Ethicist 07G).

Ethicists found it difficult to be effective when they were not seen as someone that “can help” and are misperceived by staff in the organization. This often occurs because people “have had a bad experience with ethics” (Ethicist 04D) or have “misperceptions” of the role of the ethicist
and ethics program. One ethicist referred to these misperceptions as “attitudinal” barriers to achieving effectiveness. She stated:

And one of the other things too is that there’s still a lot of, um... sort of misconceptions around the role of ethics committees and of ethics support in different organizations, so there are some barriers there just in terms of the attitude, that if you call in the ethics committee it’s a sign that, you know, you did something wrong or you failed somehow or that the ethics committee is going to come in and make a decision for you. These are things that ethics committees have worked really hard against, but they still come out in terms of some of the comments that they’ve gotten after a team has had a consult sort of thing. And as well as, sometimes the ethics committee is still being seen as who you call in to make people do what you want as a team, sort of thing. So I think those sorts of attitudinal pieces are hard to address, but are also a challenge in terms of achieving effectiveness. And again, achieving those sorts of embedded long term changes, both practice and sort of awareness in the organizational fabric. (Ethicist 11K)

A few participants highlighted the difficulties overcoming the “misconceptions, bias, [and] prejudices about what ethics is” (Ethicist 06F). One recurring misperception is that ethics is about “compliance”. One of the challenges to achieving effectiveness is that sometimes “the ethics service is regarded as like a regulatory body, and not a consultative body” (Ethicist 08H) – that the ethics program is the “ethics police”. As a result, people become “defensive” or fearful of the ethics program’s involvement. When people are afraid to use the ethics program services, either because they do not trust the ethicist or they work in a “blame kind of organization”, “the amount of work that it takes to be seen, to be seen as somebody that is helpful, it gets harder and harder” (Ethicist 01A).

3. Organizational Support

The third critical success factor for ethics programs is organizational support for ethics. Organizational support was comprised of: i) public displays of support from senior leadership, ii) investment of resources into the ethics program; and iii) “ethics champions” throughout the organization able to get the word out about the ethics program.
i. Public displays of senior leadership support

Senior leadership support, such as publicly acknowledging the ethics program and the work of the ethicist and strategically positioning the ethicist to have an organization presence, was perceived as critical for an ethics program to be effective. Senior leadership that speaks positively of the ethics program and invites the ethicist to participate on various committees facilitates awareness and acceptance of the ethics program throughout the organization. One ethicist explained:

Support of leadership: I think if you have a program that doesn't have, like, meaningful support, you're pretty dead in the water. I think it's going to be very hard to function effectively because you need, um, their support in being visible, but also they have, you know, the purse strings. So I think leadership's a big key. (Ethicist 07G)

Another noted that his program was able to meet all of the Accreditation Canada standards related to ethics because the program had the support from the senior team and Board of Directors. He stated:

So the CEO and Board of Directors really empowered the Ethics Department to do what it needs to. So we developed our department around the Accreditation standards and then said, 'If you're going to re-design the way health services are delivered in this province, this is how we suggest that you establish an ethics department'. So it's because really structuring it, it's because of the support from the executives, and Board of Directors. Yeah, so they've given us the resources, the staffing and all of those things that are required. (Ethicist 04D)

ii. Resource investment into the ethics program

For participants, financial resources invested into the ethics program were perceived as critical to achieving ethics program effectiveness; whereas a lack of resource investment was a barrier to effectiveness. Key to this was a positive relationship with senior management, which holds “the purse strings”. According to one participant: “Effectiveness is really strained when your resources are really low, so there's not enough of you, or you're really isolated in the work that you do, um, or that you fight for every little improvement that you can justify that the organization is just not there with you” (Ethicist 01A). Another ethicist stated that the reason why her program is not “doing a very good job” is because it is not resourced appropriately. She said:
Number one, the biggest barrier that I see in my own jurisdiction is that, you know, any evaluation right now of what's happening, and the small little pockets of evaluation we have done, show that we're not doing a very good job and the reason we're not is because we don't have the appropriate resources to be able to do what's needed and we don't have the, well maybe with the new structure it will help somewhat, but you know, to have 0.7 of an ethicist for a health authority of this size is, is really just ludicrous. You know, when you compare that to, you know, the resources that are available in Toronto, you know, in an analogous size health authority, so there's that piece. That's a big barrier. You know, when you already know that you don't have enough resources to do what it is that needs to be done, it's highly unlikely that you're going to get very positive outcomes when you start to collect information. So there's that piece. (Ethicist 13M)

Many ethicists commented that they are unable to provide as much value to their organization as they would like because there are not enough resources to support the ethics program and their time is “spread thin”. For example, although ethicists wanted staff to use the ethics program services, they also felt that they could not increase their workload by advertising the ethics program because they don’t have “enough people”. They also wanted to be able to fund ethics committee members or ethics program staff to enhance their ethics skills to increase needed capacities, but lacked the resources to do this. With more resources, ethicists would have more time, more presence, and could “do more” in the healthcare organization.

Participating ethicists also thought that more resources would enable them to be “proactive” and make more a difference. Specifically, they would be able identify and address recurring issues proactively to prevent them from recurring as frequently. According to many participants, this approach would lead to a more effective ethics program. For example, one ethicist described a proactive ethics consultation service as being of more help than a “purely reactive” service. He explained:

*This goes back to the proactivity stuff. So if we're talking about consultations, um, you know, you can count on seeing recurring issues because they are products of more complex hospital policy, for instance. So you might have consultations that relate to the policy on wait times for certain procedures. Um, if, yes, a more effective program would not only provide consultation service, but it's that VA preventative ethics stuff, they would actually have – Veteran's Affairs, do you know what I'm referring to? I thought you would, but just in case – Um, so their whole approach about sort of taking a look to see what's going on and seeing if we can address it further upstream so that in future we've been proactive and these issues won't come up as often. So I think that's a really important part of,
otherwise you've got a consultation service that's purely reactive. And you're just, it's a waste of resources, it's a waste of time, and it's a lost opportunity to help future people where addressing it where it needs to be addressed. (Ethicist 07G)

Some ethicists thought that if the senior leadership team supported the ethics program, the program would be treated as a priority and would receive more resources. These ethicists tended to be those who were not paid to be at the healthcare organization five days out of the week. Others noted that healthcare resources are limited and ethics is not the only program in a healthcare organization in need of resources. Moreover, whether an ethics program receives the resources the ethicist asks for is not the same as being supported in the organization. Having organizational support means “the reasons are there if you can't have that, what you feel like you need from the organization” (Ethicist 01A). For these ethicists, a lack of resources is a challenge, but not one that is insurmountable:

\[ I \text{ suppose resources. I could say that not having as much resources as you'd like to have or knowing that you could do more if you had more people, but at the same time, I think that the old saying 'necessity is the mother of all invention and innovation' is so true because we haven't had the funds to hire a batch of ethics consultants and so we have gone about engaging with the people who work throughout the system to be the ethics facilitators has actually been very good because now they're dispersed throughout the whole place and they're the kind of eyes and ears and nose and mouth of ethics in the system and so they're able to spot and identify things, and a lot of things that could become big ethical issues or problems they kind of get identified earlier on in a big number of instances and get adjusted so they don't become a problem simply because someone identifies the fact that the way we're saying something or the way we're approaching something or the way that we're failing to consult on something is going to cause us a bigger problem further down the road, so you know, it kind of works out. (Ethicist 03C) \]

iii. Active “ethics champions”

Ethics champions were defined as key people in the organization who, through their role or position in the organization, help to get the word out about the ethics program, promote the use of its services, and support the ethics program in other ways. They can be administrative staff, clinical staff, chaplains, physicians, or any other staff in the organization. As one participant noted:

\[ You \text{ can have a great champion who is just a... someone who can actually get it [ethics] out there. If you can get more champions in different areas, that's better. } \]
And they don’t always have to be the leader, um, because you know, change can come from below. So that's important. If you can find some champions, wherever it is, it’s nice to be at the top because that empowers the staff below. (Ethicist 10J)

Ethics champions use ethics language and speak positively about the ethics program in different areas of the organization. According to participant, “word of mouth” is a powerful strategy for gaining support for the ethics program, integrating ethics throughout the organization, and helping the ethics program make a difference. Study participants emphasized the importance of having ethics champions strategically positioned in the organization to influence ethics change. In particular, it was thought that an ethics program is more likely to be successful in achieving its organizational mandate, if there are other institutional actors who can bring their influence and expertise to bear in advancing the ethics program. One ethicist stated:

[Y]ou have to have believers, you have to have allies, you have to – for me, one of the things that was more important, and not important for me as the most important, but I saw it was important for the way our hospital works – I had to have the support of some doctors who were important in the hospital or whose um, you know, who were respected. Otherwise, I knew as a strategic point that it would not work whatever I would try, you know. So I had to find some people like that, doctors, head nurses, so it’s really strategic at the same time. (Ethicist 09I)

4. “Community of Practice”

The fourth critical success factor for ethics programs is participation in and access to a “community of practice” – that is, “a network that would be a resource and a support for ethicists” (Ethicist 02B). A community of practice includes colleagues within and outside the organization with whom ethicists can collaborate, in person or electronically.

I think, having colleagues, whether they're bioethicist colleagues on site or other colleagues that you can join with whether it's formally as a forum for education or an ethics committee to drive, I'm not wedded to an ethics committee structure or an ethics forum structure, but that you know that there are people in the organization that have an interest in ethics and they're doing the work out there as well, in their own way, and that you can either formally or informally connect with those people. (Ethicist 01A)

Colleagues in the community of practice do not necessarily have to be bioethics colleagues because, as one participant put it, “Ethics in an organization isn’t the sole responsibility of those who work in the area of ethics. It’s everyone’s business” (Ethicist 03C). In addition, a few ethicists commented that it was important to include those who have other skill sets that the
ethicist might be lacking, for example, quality experts with experience in measurement and evaluation. Having a community of practice was reported to be especially critical for ethicists operating as the only individual in their organization with dedicated responsibilities for ethics. These ethicists identified working in isolation as a barrier to achieving ethics program effectiveness. One such ethicist commented that it is hard to be effective when an ethicist has no one with whom to discuss or debrief difficult cases or from whom to obtain feedback on professional practices in ethics. A community of practice enables an ethics program to deliver value to the organization, and meet its mandate more effectively than an ethicist working alone. One participant explained:

We would be constantly reflecting on what's being done and improving and building, whereas now it's like treading water. It's just, that would be the big difference for me, by far. Um, I'd have a chance to say, 'Ok, you know, this is what I've done here. What are you doing? Did that work well? Is there some resource you know about? Can we document better?' There would be somebody to help share the workload, but just the community, the community part of it. It's not even the extra help. It's just, you know, the need to do things with others. I just think, yeah, that we would, we would more routinely grow the program and improve it, and I think that's hard to do when you're one person, at least with the amount of time I have. (Ethicist 07G)

Having discussions with others working in the field also helps ethicists meet standards for their ethics program and work towards a common set of ethics program standards and competencies. For instance, one ethicist explained that in her training program, she did not learn about competencies, but learned about this through an external network of ethicist colleagues. She stated:

[Y]ou're talking about programs, but the fact is what's taught right now in the university program that I was trained in, in the [university name], we don't learn that. We don't learn how to do the things on site. And we don't talk about competencies, and we don't talk about the core competencies, we don't talk about um, what it takes to be an ethicist and what it takes to do the job. So for me, having that outside network, uh, for a while was a salvation. And what I did was try to do my own network here with my colleagues with some of my colleagues to keep on, you know, so that was really, really helpful. (Ethicist 09I)

Similarly, other ethicists thought that working in a community of practice allowed for sharing of resources, tools, and effective strategies. According to one ethicist:
Well I think if you have people who are working together and understand what others have used as possible resolutions or solutions to problems, and see how those have been effective elsewhere you can put those in place in your own institution. You can also, there’s always some synergy that occurs when like-minded people are together, coming up with, coming up with different recommendations and different ideas of how to resolve issues. So there’s a benefit there, and all of those things will naturally improve effectiveness because it seems, in my mind, quite counterproductive to have all kinds of individual groups going along developing individual solutions when you know, there’s many common issues that we all share that we could probably learn a lot about how others have done things and take those solutions into our own settings. (Ethicist 13M)

A few ethicists emphasized the lack of standardization in their own ethics program and across ethics programs as a barrier to achieving effectiveness. They felt that the ethics community as a field needs to “come together” to talk about standards of practice and how to evaluate effectiveness.

4.4 Summary of Key Findings

Participants defined healthcare ethics program effectiveness in three different ways: 1) operationally in terms of achieving the organizational mandate for the ethics program, achieving ethics program goals and objectives, and meeting standards; 2) aspirationally in terms of making a difference and being helpful; and 3) delivering value for investment. These three definitions and corresponding evidence of effectiveness are summarized in Table 3 below.

The participating ethicists described a number of strategies that they use or have been thinking about using to evaluate effectiveness. In formal evaluations, a variety of survey, qualitative interview, ethnographic, and mixed methods were used to collect and analyze data. Informal evaluative data was generated in an ad hoc way through documentation of anecdotal and/or unsolicited feedback of ethics program impact from an end-user perspective. The most commonly used evaluation strategies were: a) comparing data within and across discrete ethics program activities; b) assessing qualitative feedback; c) using Accreditation Canada survey results; d) engaging in internal and external peer review; and e) comparing pre- and post-results.

Although ethicists thought that ethics program evaluation was an important activity, many were not currently engaged in formal program evaluation activities for four reasons:
i. The ethicist was unsure of how to evaluate ethics program effectiveness,

ii. The ethics program did not have the resources or capacity for evaluation,

iii. The ethics program was still in its early development, or

iv. The ethicist felt that the ethics program already has sufficient “buy-in”.

Those ethicists who were not formally evaluating their programs tended to be new in their roles as ethicists and/or leading a newly established ethics program, have part-time employment at their organization (i.e., less than 3 days per week), or express a lack of urgency from the organization’s senior leadership to defend or justify the ethics program’s value in the organization.

Ethicists identified four critical success factors for effectiveness: 1) ethicist and ethics program staff competencies and attributes, 2) organizational understanding of the ethics program, 3) organizational support, and 4) community of practice. When these factors were present, an ethics program was more likely to be effective – that is, they provided enabling conditions for ethics program effectiveness. When these factors were absent, their absence was perceived as a barrier to achieving effectiveness.
Table 3: ETHICISTS’ DEFINITIONS AND SUPPORTING EVIDENCE OF ETHICS PROGRAM EFFECTIVENESS

<table>
<thead>
<tr>
<th>Definition Type</th>
<th>Formulations</th>
<th>Supporting Evidence of Effectiveness</th>
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<tbody>
<tr>
<td>OPERATIONAL</td>
<td>1. <strong>Achieving Ethics Program Mandates, Goals, and Objectives</strong></td>
<td>• Increasing or decreasing outputs of discrete ethics program activities, specifically: ethics consultation; policy review and development; and education, based on ethics program goals. E.g., if goal is to increase ethics awareness, evidence of meeting goal is an increase in the number of ethics consultations requested</td>
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<tr>
<td></td>
<td>i) Achieving organizational mandate and expectations for the ethics program</td>
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<td></td>
<td>ii) Achieving goals and objectives set within the ethics program</td>
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<tr>
<td></td>
<td>2. <strong>Meeting Ethics Standards</strong></td>
<td>• Organization rated as meeting accreditation requirements with no “red flags”</td>
</tr>
<tr>
<td></td>
<td>i) Meeting Accreditation Canada standards related to ethics</td>
<td>• Positive peer review from other ethicists within and external to the ethics program to determine whether relevant professional standards were met. E.g., responding to ethics consultation requests in a timely manner</td>
</tr>
<tr>
<td></td>
<td>ii) Meeting professional standards for ethicists</td>
<td></td>
</tr>
<tr>
<td>ASPIRATIONAL</td>
<td>1. <strong>Making a Difference</strong> to the organization’s moral climate, ethical culture, patients, families, and staff</td>
<td>• Increased ability to identify and address ethical issues, and build ethical decision-making into practice</td>
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<td></td>
<td>2. <strong>Being Helpful</strong> and perceived as helpful by ethics program end-users</td>
<td>• Short term increase in the number of ethics program activities, repeat end-users from broad areas of the organization, and decrease over time in number and type of similar activities</td>
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<td></td>
<td></td>
<td>• Increased recognition of ethics program as a valuable resource</td>
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<td></td>
<td></td>
<td>• Positive organizational climate where people are not afraid to seek out the ethics program as a resource</td>
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<td></td>
<td></td>
<td>• Local and regional uptake of ethics program practices</td>
</tr>
<tr>
<td>DELIVERING VALUE FOR INVESTMENT</td>
<td>1. <strong>Delivering Value for Investment or “Bang for Buck”</strong></td>
<td>• Number of ethics program outputs relative to inputs.</td>
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<tr>
<td></td>
<td></td>
<td>• Increased or maintained resource investments.</td>
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Discussion

This chapter provides a discussion of the study findings related to the key knowledge gaps identified in the literature (see section 2.4). First, I reflect on how the study findings provide insight into and further our understanding of the concept of healthcare ethics program effectiveness\(^\text{17}\). Second, I discuss emerging tensions in conceptualizing the effectiveness of ethics programs versus effectiveness in ethics programs. Third, I explore the ethicist role in relation to ethics program effectiveness. Fourth, I outline some strategies for improving ethics program evaluation. Fifth, I outline the implications of the study findings for development of ethics practice standards, professional education and training of ethicists, and organizational oversight for ethics programs. Finally, I identify limitations of the study findings and outline future research questions and directions arising from this study.

5.1 The Concept of Healthcare Ethics Program Effectiveness

The study findings shed light on the concept of effectiveness as defined by practicing healthcare ethicists. A review of the literature underscored the need for greater clarity on how effectiveness is defined in order to establish a coherent conceptual basis for evaluating the contribution and impact of ethics programs in health organizations. Much of the current literature on ethics program evaluation has assumed a definition of effectiveness without rendering it explicitly. Although there was some early work to theorize effectiveness in relation to ethics consultation (Tulsky & Fox, 1996; Fox, 1996; Fletcher & Siegler, 1996; Tulsky & Stocking, 1996), the definition of effectiveness in relation to ethics programs had not been explored in depth until this study. In this study, effectiveness emerged as multi-dimensional concept, which may be best understood as a continuum (i.e., relative not absolute) and to comprise a temporal component.

\(^{17}\) In this chapter, I use the terms effectiveness, ethics program effectiveness, and healthcare ethics program effectiveness interchangeably to refer to healthcare ethics program effectiveness. When referring to other types of effectiveness, such as the effectiveness of the ethicist or of discrete ethics program services, these are specified.
Effectiveness as a multi-dimensional concept

In this study, there was no single definition of effectiveness, but there was convergence around three different but not mutually exclusive definitions. Although one definition might be emphasized over others in interviews, the ethicists tended to invoke elements of the other definitions, at least to some extent (see section 4.1). This suggests that ethics program effectiveness may be “a family of properties” (p. 219) – a concept made of multiple features, rather than a single feature (Ashcroft, 2002). For example, making a difference (e.g., having a positive impact on organizational moral climate) could be specified as an operational goal of the ethics program. Similarly, evidence of meeting standards might be explicitly linked to delivering value for investment, particularly when compared to previous ethics program performance and/or compared to other similar ethics programs. Differences between ethicists in how they defined effectiveness seem more likely to reflect differences in emphasis on or understanding of the ethics program’s role rather than fundamental disagreements about what constitutes ethics program effectiveness. An ethicist, for example, who understands the ethics program’s role as contributing to an organizational system (i.e., policy or programmatic orientation) might reasonably emphasize achieving the organizational mandate for the ethics program, contributing to meeting ethics-related accreditation standards, and/or making a difference to the organizational climate; whereas an ethicist who understands the ethics program role as meeting needs (i.e., process or service orientation) might emphasize achieving ethics program goals and objectives, meeting professional standards for ethicists, and making a difference to staff.

Each of the three definitions is also present in the literature; however, this is the first time they have emerged together as conceptually linked to the ethics program effectiveness. The operational definition is evident in how ethics quality in healthcare organizations is described in the literature. For example, Wolf (1994) argued that the first step in assessing ethics quality is to agree on basic organizational and individual “standards of ethics knowledge and behavior” (p. 125). Similarly, the United States Department of Veterans Affairs National Center for Ethics in Health Care defines ethics quality as organizational practices meeting ethical standards and its IntegratedEthics program is intended to advance these standards (NCEHC, 2013b). The aspirational definition is implicit in discussions of determining whether an ethics consultation
service is “worthwhile” by assessing whether the service maximizes benefit and minimizes harm to staff and organizations, has a long term effect on organizational climate, builds ethics capacity; results in satisfied end-users, and helps resolve conflicts (Fletcher & Siegler, 1996; Fox & Arnold, 1996; Tulsky & Fox, 1996). Finally, the third definition – delivering value for investment – is evident in how the literature specifies the strategic importance of ethics program evaluation as a critical element in establishing a business case for ethics program resources (Crigger & Wynia, 2013; Dörries et al., 2011; Fox, 1996; Sullivan et al., 2011; Swetz et al., 2013; Williamson et al., 2007).

**Effectiveness as relative along a continuum**

Consistent with the literature (Chidwick et al., 2010; Davis, 2006; Dubler et al., 2009; Dörries et al., 2001; Fox et al., 2010; Mills et al., 2006), financial resources, human resources (e.g., ethics program personnel, ethics champions), and organizational environment emerged as relevant factors contributing to the overall effectiveness of an ethics program. Ethics programs might be more effective or less effective depending on these factors. If there is an ethics program that is doing all the right things, but is in an organization devoid of the critical success factors identified in section 4.3., the ethics program would not be as effective as it could be if all of the critical success factors were in place. This raises the idea that effectiveness may be a continuum concept rather than an all or nothing concept. The notion of a continuum has been used by others to describe a range of ethics-related behaviors resulting from ethics program activities (Bottrell, Pearlman, Foglia, & Fox, 2013); however, it has not been explicitly applied to ethics program effectiveness. Rather than being merely ineffective or effective, an ethics program may be more or less effective along a continuum with varying degrees of effectiveness. An ethics program could be deemed *ineffective* if it failed to achieve its mandate, goals or objectives, to meet standards, or to generate any valuable outputs notwithstanding the input of resources or the presence of relevant success factors. However, in most cases, an ethics program will exceed this minimum threshold – for example, an ethics program might meet some but not all standards and still ‘make a difference’, or meet all standards but at a minimal level, or to exceed all standards, but fail to ‘be helpful’ in the eyes of ethics program users, or to ‘be helpful’ but not efficient in its use of program resources. The degree of effectiveness may be contingent on a number of factors, including presence or absence of critical success factors (described in section 4.3).
may also be assessed relative to where the ethics program is along the continuum at a previous point in time (i.e., its relative effectiveness may have improved or declined over time) or to similarly situated ethics programs (e.g., in terms of resource investment, type of health organization, presence/absence of critical success factors) in other health organizations.

Ethicists in this study and authors in the literature identified resources and protected time as a requirement for effective or high quality ethics programs (Hamel et al., 2013; Swetz et al., 2013), but study findings raise questions about whether resource constraints necessarily translate into an ineffective ethics program. Study findings were imprecise about the threshold of resource investment required to enable ethics program effectiveness. For example, how many resources and of what kind are necessary for ethics program effectiveness? Is investment in a full time ethicist position required to achieve ethics program effectiveness? An ethics program may have one ethicist on staff three days a week compared to a program with multiple ethicists on staff five days a week, but be located in an organization with a good understanding of the role of the ethicist and ethics program, making it easier for the ethics program to achieve its goals, meet relevant standards, and make a difference. Similarly, study findings raise questions about whether additional resources generate increased effectiveness. If resources are not being used strategically or optimally, investing more resources into an ethics program may not generate increased effectiveness. This suggests that the interplay of critical success factors not just resource investment alone may determine relative effectiveness. As such, ethicists may need to look critically at their programs to understand what they need to increase effectiveness rather than looking for increased financial investments as necessarily contributing to increased effectiveness. For example, what is happening with current resources? Are they currently being optimized or are they underutilized? Before the organization invests additional resources into an ethics program, the ethics program needs to demonstrate that it has a good understanding of how current resources are being optimized and what value additional resources would deliver.

**Effectiveness as a temporal concept**

Ethics programs evolve and change over time. This study identified an additional factor – maturity of the ethics program – that may be associated with ethics program effectiveness. An ethics program’s effectiveness ‘profile’ may be different at different times in the trajectory of an
ethics program’s development. This is because an ethics program’s capacity to ‘meet objectives’, ‘meet standards’, ‘make a difference’, and so on may change over time as the program matures or as the organization grows accustomed to or embraces the ethics program’s contribution. A newly established ethics program may have more modest goals and objectives than a mature ethics program and yet be successful in meeting its goals and objectives, i.e., to be effective. Similarly, a newly hired ethicist may be helpful to some people in the organization, but not as helpful as later on when the ethicist becomes established in the organization and more well known by staff.

The temporal nature of ethics program development was previously raised in section 2.3. in relation to the University of Toronto Joint Centre for Bioethics “Ethics Roadmap”, which outlined four stages in an ethics program’s development from “emerging”, to “achieving”, the “excelling”, and finally “leading” (Gibson et al., 2011). The “Ethics Roadmap” describes what an ethics program ought to look like in various stages of development, recognizing that moving between stages takes time. Moving across the continuum of effectiveness may also take time. Study findings provide insight into how effectiveness might be thought of in various stages of ethics program development, but does not provide a similar “roadmap” for what is needed to move from less effective to more effective. For example, there may be no fixed combination or balance of what critical success factors, specific kinds of resources, or ethics program components that ethics programs need in order to be more effective at different times in their trajectories, though different things might be more important at different times. Moreover, it is unclear what factors, resources, or components are absolutely necessary or simply “nice to have”.

In an emerging stage of an ethics program, where it has been newly established in an organization, the ethicist needs to build the foundation for an effective ethics program, including ensuring the appropriate ethics program structures and critical success factors are in place. Ethicists who are building ethics programs in an organization where one previously did not exist or newly hired ethicists (either early career or more experienced ethicists) need to: identify and understand organizational needs; develop or revise ethics program materials and resources; raise awareness of the ethics program; and build relationships with front-line staff and senior leaders.
to receive organizational support, identify ethics champions, and form a community of practice. These are in addition to ethics program management responsibilities, day-to-day work activities, and developing their knowledge and skills. This work continues as the program develops and matures, and the ethicist becomes established in the organization. Expectations for how much time this takes for an early career ethicist might be lower compared to expectations of a more experienced ethicist in the same situation.

Over time, ethics program effectiveness may increase or decrease. For example, a new ethics program may be able to perform a certain number of consultations, provide a certain number of education sessions, and be successful in achieving certain goals and objectives or making a difference in a subset of clinical programs or staff. After a while, as the ethics program becomes more visible in the organization and as the ethicist develops a wider network of organizational relationships, the ethics programs may begin to achieve a broader set of goals and objectives and extend the reach of its impact on clinical programs or staff. There may then come a point when the ethics program has maximized the use of its resources, beyond which investment of new resources may be required for expanding the ethics program’s impact. To overreach this threshold in the absence of new resources would undercut its current effectiveness and the ethics program would be at risk of decline. At such times, an ethicist might reasonably ask: does the ethics program need new resources or are there more efficient ways to use available resources to achieve the desired effects? Similarly, an ethics program may experience a change in other critical success factors, which may affect its capacity to mobilize its resources to sustain or expand its effectiveness. For example, an ethics program may thrive given a change in senior leadership in a way it was unable to do in the previous leadership regime. Finally, as an ethicist’s skills and experience evolve over time, an ethics program may achieve a greater degree of overall effectiveness.

5.2 Effectiveness of Ethics Programs and in Ethics Programs

Although the study set out to investigate effectiveness of ethics programs, the ethicists tended overall to focus their responses on effectiveness in ethics programs – that is, the effectiveness of ethics program services, structures, and providers (i.e., ethicists, ethics consultants, and ethics committee members). In this section, I discuss possible tensions in conceptualizing the
effectiveness of ethics programs versus effectiveness in ethics programs and possible reasons why ethicists may be focusing evaluation on the latter.

In this study, ethicists saw ethics program services as inter-related – that is, effective ethics policy development leading to ethics education sessions; effective education sessions leading to ethics consultation requests; and so on. Evaluating ethics program services informed evaluation of the ethics program. Hence, effectiveness in ethics programs may be inseparable from ethics program effectiveness. It is unclear, however, whether conceptions of effectiveness in and of ethics programs are equivalent. Effectiveness of ethics consultation, for example, may not have operational, aspirational, and value for investment dimensions. Likewise, supporting evidence of ethics program effectiveness may not indicate effectiveness of specific ethics program services, structures, or providers. Moreover, ethics program effectiveness may not be reducible to the effectiveness of ethics program services. Effective ethics program services do not necessarily amount to an effective ethics program.

Ethicists were using a scattershot of methods to evaluate ethics program effectiveness rather than aligning methods with their definitions of effectiveness. Similarly, ethicists seemed to focus on their effectiveness as individual service delivers, rather than focusing on the effectiveness of the ethics program in relation to the broader organizational mandate and goals. The study findings suggest that the participating ethicists were not, in general, thinking programmatically about how to evaluate their ethics program as a whole nor as the ethics programs contributed to the overall function of the healthcare organization. Appreciation of the inter-relationships between ethics program services and the link to ethics program effectiveness indicates that ethicists are applying some “systems thinking” (MacRae, Fox, & Slowther, 2008), within the ethics program, but they were not necessarily thinking about the relationship between the ethics program as a whole and the organization as a whole. Ethicists, however, might not have the time, experience, training, socialization, or instinct to think programmatically about where the ethics program fits in the broader organizational context. The average ethicist may not have had the training to prepare one to think in this way, in addition to thinking about how to deliver ethics program services. This experience might be different for ethicists who are not new in their roles and/or have had access to other “leaders” who can help them develop these skills.
Ethicists may be focusing on effectiveness in ethics programs because ethics program activities can be measured, improved, and provide examples of tangible value to senior administrators and other stakeholders who may be more likely to support an ethics program if improvements are demonstrated quantitatively (Crigger & Wynia, 2013). However, if ethicists are evaluating their programs for accountability purposes, study findings shed light on a possible disconnection between what ethicists are measuring and what senior leaders, to whom ethicists are accountable, find important. If senior leaders are applying “systems thinking” to healthcare as has been suggested in the literature (MacRae et al., 2008), they may value the broader organizational impact of the ethics program (i.e., effectiveness of ethics programs) over the particulars of ethics program services (i.e., effectiveness in ethics programs). The possible disconnection between what ethicists are measuring to demonstrate effectiveness and what senior leaders value might mean that ethicists are wasting resources to evaluate things in ethics programs that are not necessarily relevant to those to whom they are accountable for use of resources.

5.3 Ethicist Role in Effective Ethics Programs

Ethicists in this study linked the effectiveness of the ethics program to their own effectiveness as ethics professionals. According to participating ethicists, if they were not themselves effective – if they did not feel that they, as ethicists, were meeting professional standards, achieving their professional objectives, making a difference through their professional activity, or delivering value as an ethics service provider – then the ethics program could not make a strong claim to being effective. This may explain why study participants tended to specify critical success factors for ethics programs in terms of what they themselves needed to fulfil their professional role as ethicist (i.e., competencies, attributes, organizational support, organizational understanding of their role, and a community of practice) rather than what the overall ethics program needed. Ability to evaluate ethics program effectiveness emerged as an important competency of practicing ethicists, which suggests that ethicist knowledge and skill may be a relevant factor in assessing and demonstrating ethics program effectiveness. This has been recognized in the ASBH Core Competencies for ethics consultation, among which it is specified that at least one member of the ethics program staff needs basic skills in evaluation and quality
improvement, and needs to be able to access someone with advanced skills in this area (ASBH, 2011).

There were also surprising silences in the data around competencies that would seem to be relevant, particularly given ethicists’ definitions of effectiveness. For example, few ethicists emphasized program leadership or management competencies as critical for ethics program effectiveness despite defining effectiveness as ‘achieving the organizational mandate’ for the ethics program or ‘making a difference’ to organizational culture. Similarly, although one dimension of effectiveness was ‘achieving ethics program goals and objectives’ and ‘meeting standards’, study participants did not identify program planning, goal setting, or monitoring compliance with standards as important competencies. Even though ethicists were, for the most part, leading ethics programs, the majority of ethicists made no mention of specific leadership skills and competencies required to be an effective health services leader, such as: change management; planning; visioning; establishing partnerships; political know-how; systems thinking; financial skills; and managing human resources (Canadian College of Health Leaders, 2009; National Center for Healthcare Leadership, 2006). Indeed, these findings suggest that although ethicists may have primary responsibility for developing, implementing, and evaluating ethics programs, they do not see themselves as leaders or as managers within their health organizations.

Ethicist perceptions of their leadership role and required competencies were not a primary focus of this study. However, this incidental finding may provide evidence of a lost opportunity in the formal professional training, education, and socialization of ethicists with significant implications for the effectiveness of ethics programs in health organizations. An ethicist can be highly experienced and skilled at delivering ethics program services, but if he/she does not understand the organizational context, it may be a challenge to achieve ethics program effectiveness as he/she may not know how to ensure that critical success factors are in place and then take advantage of these factors. Leadership skills may help ethicists take advantage of critical success factors, strategically position themselves in an organization to optimize their effectiveness as ethics service deliverers, and think programmatically about effectiveness – that is helping them to think about the ethics program in the broader context of the organization.
Different Ethicists have Different Priority Levels for Evaluating Ethics Programs

Ethics program context, ethicist skills, and ethicists’ motivations for evaluation may affect the different levels of priority that ethicists assign to evaluation as an ethics program activity. The literature emphasized the importance of evaluation for improving the quality of ethics program services, and strengthening accountability for use of resources (Fox, 1996; Gibson et al., 2008; Tulsky & Fox, 1996; Wynia, 2006), but identified a lack of evaluation capacity (i.e., knowledge and appropriate tools) as a potential reason why there has not been much work completed on evaluating ethics programs. Study findings confirmed this, and also shed light on other reasons behind evaluating or not evaluating ethics programs (section 4.2.2).

Ethicists’ attitudes toward evaluation may affect the degree of engagement in evaluative activities. In this study, there were some ethicists who saw ethics program evaluation as a constitutive component of their professional role as ethics program leaders (e.g., to ensure the ethics program was delivering high quality services; to demonstrate accountability for the use of organizational resources), whereas others saw ethics program evaluation instrumentally as a tactic invoked to ensure the survival of their programs and their positions in the organization, hence if their ethics program was not at risk, they did not feel compelled to evaluate it. Organizational factors may heighten a sense of urgency to evaluate ethics programs. It is notable that, among those ethicists who set a high priority on ethics program evaluation, there were some who reported not having a strong sense that the ethics program was valued in the organization or feeling that their position within the organization was vulnerable. By contrast, the ethicists who expressed less of an imperative to evaluate were more likely to express a sense of being valued by their organizations. Hence, without organizational buy-in or a secure position, ethics program evaluation may take on a primarily instrumental importance among ethicists who feel a need to demonstrate their worth and the worth of their ethics program. Finally, professional skill and experience may be relevant factors in explaining engagement in ethics program evaluation. Those study participants who were less likely to evaluate their ethics programs were leading fairly new ethics programs or were new in their role.

Without a pressing need to demonstrate effectiveness, other tasks take priority in ethics programs with finite resources. But evaluation need not be an activity to maintain or secure more
resources. Demonstrating effectiveness can be strategically important for ethicists. For instance, it can help gather information for ethics program planning, raise the profile of the ethics program and create awareness, and communicate the role of the ethics program and the role of the ethics program, leading to organizational support and understanding of ethics. Consistent with what has been identified in the literature, ethicists can use evaluation to generate data to identify performance measures and compare performance within their own programs over time, and across ethics programs (Fox, 1996; Godkin et al., 2005; Mills, Tereskerz, & Davis, 2005; Smith, 2007).

5.4 Improving Ethics Program Evaluation

To date, a number of evaluation tools and strategies for ethics services have been described in the literature (Bottrell et al., 2013; Crigger & Wynia, 2013; Foglia et al., 2013; Hamel et al., 2013; Pearlman et al., 2013; Schildmann et al., 2013; Smith et al., 1992; White et al., 1997). Most recently, Pearlman and colleagues (2013) described the Integrated Ethics Staff Survey (IESS) – a tool used to measure ethics quality, assessing staff perceptions of ethical practices and ethics culture in a healthcare organization – stating that IESS could be used to “evaluate the effectiveness of ethics programs” (p. 13). Similarly, Foglia and colleagues (2013) outlined their process for surveying staff using IESS questions mapped onto the Ethical Leadership Compass Points (ELC) – a tool that helps foster an environment for ethical practice – to understand ethical leadership and culture of Veterans Affairs healthcare organizations. Nevertheless, the study findings underscored continued uncertainty about how best to evaluate ethics programs.

Although there appears to be no single evaluation method that sets the “gold standard” for evaluating ethics program effectiveness, there is emerging consensus that a mixed methods approach – using a combination quantitative and qualitative methods – may provide “the richest and most informative” findings (Tulsky & Stocking, 1996, p. 141) about how an ethics program is performing.

Although the study findings are not sufficient in themselves to establish an evaluation framework for ethics programs, they do provide insight into and a preliminary outline of what such a framework might include. Given the multi-dimensional definition of effectiveness, the evaluation framework would address operational, aspirational and value for investment dimensions of
effectiveness. Each definition might provide a domain of evaluation, which could be supported by relevant metrics and indicators, some of which might be locally defined whereas others would defined in relation to professional standards or benchmarks. The evaluation framework would take into account contextual factors (e.g., ethicist experience, ethics program resources, presence of other critical success factors) as well as the developmental stage of the ethics program. Further research will help to flesh out and validate the operational parameters of this evaluative framework.

5.5 Study Implications

In this section, I describe the implications of the study findings for the development of ethics practice standards; training and professional development of ethicists; and organizational oversight of healthcare ethics programs.

Development of Ethics Practice Standards

The study findings may usefully inform current efforts in the ethics field towards professionalization and standardization of ethics practice, including the work of PHEEP in Canada and the ASBH in the United States. Among the critical gaps in such efforts is the specification of core competencies and professional practice standards for evaluating ethics programs as whole. This would complement current evaluation work in relation to discrete ethics program activities, notably ethics consultation. On the one hand, this would involve clarifying the practicing healthcare ethicist’s professional role in ethics program evaluation, notably as a constitutive element of professional accountability. On the other hand, the scope of professional accountability for ethics program effectiveness could be distinguished from the professional scope of other relevant actors, such as senior leaders, who share accountability for ethics programs within healthcare organizations. The multi-dimensional definition of effectiveness, which emerged from this study, may also shed light on the types of core competencies – knowledge, skills, and attributes – that may be necessary to achieve the operational, aspirational, and value for investment dimensions of ethics program effectiveness. For example, the operational definition underscores the importance of skills in program planning and priority setting; the aspirational definition underlines the value of results-oriented leadership; and the delivering value for investment definition highlights the benefits of strategic thinking abilities.
and operational management (e.g., budgeting, business case development) skills. In addition, the findings suggest that “systems thinking” (MacRae et al., 2008) may also be a desirable competency enabling ethicists to think more programmatically about ethics program management and evaluation, rather than focusing on service delivery alone.

**Professional Training and Education of Ethicists**

The study findings identified gaps in the training and education of practicing healthcare ethicists, particularly related to ethics program management overall and to ethics program evaluation specifically. Ethicist training programs, such as the University of Toronto Joint Centre for Bioethics Ethics Fellowship Program, University of Chicago MacLean Center Ethics Fellowship, and the Cleveland Fellowship in Advanced Bioethics, need to ensure that the curriculum and learning opportunities for trainees align with the necessary skills and competencies to lead effective ethics programs. Ethicist training programs could borrow from established leadership competencies through the Canadian College of Health Leaders and National Centre for Health Leadership, and include training on project management, program planning, and evaluation techniques so that ethicists can learn how to develop and maintain an ethics program, create a business case for ethics, and evaluate and improve their programs. Many ethicists in this study expressed a lack of confidence in their knowledge and skills in program management, evaluation, and quality improvement. Practising healthcare ethicists may need to seek out evaluation workshops and other professional development opportunities to acquire evaluation and leadership skills to facilitate: evaluating effectiveness, identifying opportunities for improvement, implementing best practices, and developing a business case for the ethics program. New ethicists may benefit from learning from a more experienced ethicist about what competencies are most important in early career, and emerging standards and best practices. Building this into professional development plans may help ethicists achieve these goals with the support of the organization (i.e., with protected time and resources). This might also be achieved through formation of a broad community of practice including those with specific non-ethics expertise.
Organizational Oversight of Healthcare Ethics Programs

The study findings underscore the need for health administrators with organizational oversight of ethics programs to work with ethicists in clarifying the organizational mandate of the ethics program, ensuring strategic alignment of the ethics program with organizational goals and objectives, and facilitating operational alignment of the ethics program within the organizational structure (including relevant program areas and organizational committees) and processes. This would include setting expectations for ethics program performance, which take into account the developmental phase of the ethics program, the extent or limits of ethics program effectiveness proscribed by resources invested, and other contextual factors affecting the ethics program’s ability to be effective, including the critical role of senior leaders in advancing the ethics program’s mandate. Clarifying organizational priorities and how the ethics program can help the organization meet these priorities would help ethicists focus ethics program efforts on high priority areas for the organization, and target ethics program evaluation on these areas. The priority of evaluation as part of organizational oversight also needs to be communicated to ethicists and appropriately managed, recognizing ethicists’ reasons for not formally evaluating ethics programs. To facilitate efforts to evaluate ethics programs, resources might need to be invested in professional development for ethicists to build evaluation capacity in their programs, or to hire people with evaluation expertise where ethicist capacity to evaluate might be lacking. For ethicists who feel they have sufficient program buy-in, emphasizing the importance of quality improvement may help re-frame evaluation activities as contributing to a quality healthcare organization, rather than as a mechanism for justifying the ethics program’s existence.

5.6 Limitations of the Study Findings

In this study, using the term effectiveness could have had a framing effect on participants. Using other terms, like success, excellence, quality, value, or performance might have yielded other findings. Participating ethicists started to introduce some of these other terms and to use these interchangeably within a single line of discussion. Hence, the relationship of these terms to effectiveness was largely implied and warrants further investigation.

Another possible limitation of the study findings is that only the views of those ethicists leading ethics programs and interested in participating in this research are represented. It is possible that
participating ethicists’ perspectives may differ from those who did not participate in the study. Moreover, this study focused exclusively on ethicists’ views rather than a broad range of ethics program stakeholders. As such, the findings are not representative of the perspectives of practising healthcare ethicists across Canada or ethics program stakeholders in general. Additionally, study findings represent the views of participants at a given point in time and as ethicists and programs develop and mature, their views may also change. Given that this was a qualitative study, the findings cannot be generalized and were not intended to be generalized. However, the findings give a richer and more in-depth account of ethicists’ perspectives on healthcare ethics program effectiveness than surveys or more generalizable methods would have yielded.

Similarly, generalizability may also be limited by the organizational settings within which the study participants worked. All study participants were employees are large health organizations and worked primarily in acute care. In Canada, the acute care sector has made the most investments in ethics programs, but ethicists working in different sectors, like home and community care or long-term care, may have different perspectives of how ethics program effectiveness is defined. Moreover, there might be different critical success factors for ethics programs in other types of healthcare organizations. In addition, only ethics programs that used an ethicist-led model were explored. Findings may be different in organizations where the ethics program is led by an ethics committee, which is more common in smaller health organizations. Finally, this qualitative study aimed to describe ethicists’ perspectives of what makes ethics programs effective. As it was an exploratory study, causal relationships between ethics program attributes and effectiveness cannot be concluded from the findings.

5.7 Future Directions

This exploratory study described how a group of practising ethicists defined ethics program effectiveness. This research takes steps to fill a gap in the literature on ethics program effectiveness and evaluation, but further research is needed.

First, more conceptual and empirical work is needed to better understand the multiple dimensions of ethics program effectiveness and how they are related, and to address
methodological questions around how to evaluate effectiveness of ethics programs. Conceptual work exploring the notion of a continuum of effectiveness relative to ethics program maturity could lead to a conceptual framework that could be applied to empirical research studies evaluating a sample of ethics programs over time.

Second, as noted above, this study focused on ethicists’ perspectives to the exclusion of other ethics program stakeholders. Empirical research including a breadth of stakeholder perspectives would help to inform understanding of effectiveness and ethics program evaluation. Ethics program end-users, ethics program staff, senior leadership, reporting managers, and funders, particularly given the emphasis in this study and the literature on demonstrating value for investment, may have different perspectives on how to define and measure ethics program effectiveness. Determining how different ethics program stakeholders define effectiveness can help ethicists target their evaluations and reporting on ethics programs’ worth. For example, reporting managers and funders may not be as concerned with how many activities are provided per year, and instead may care more about whether patient care is improved through having an ethics program in the organization. A time series design looking at a group of ethics program end-users over time and measuring their confidence in making ethical decisions and addressing various ethical issues before and after different ethics interventions, like ethics consultations or ethics education could reveal how and when ethics programs make a difference in healthcare organizations.

Third, further studies of ethics program effectiveness could also investigate the relationship between critical success factors and ethics programs. A more focused study selecting for variation in ethicist experience levels (e.g., early-career, mid-career, late-career), the financial and human resource investment into the ethics program, and the age and maturity of the ethics program might reveal how each critical success factor influences effectiveness. Study findings raised unanswered questions such as: What is the optimal level of inputs and outputs for an ethics program at different points in its development? How does effectiveness change as ethics programs develop and mature over time?

Fourth, although this study was not designed to determine how ethicists’ performance is being assessed, ethicists in this research linked their individual effectiveness with the effectiveness of
their ethics program. Further research could explore potential causal relationships between ethicists’ effectiveness and ethics program effectiveness. Studying variations in ethicists’ background, training, experience levels, time spent on different ethics program activities, and skills and core competencies could determine how ethics program effectiveness differs between healthcare organizations according to different ethicist characteristics. Such work might also inform current work on credentialing and professionalization in Canada by the Practising Healthcare Ethicists Exploring Professionalization groups and in the United States by the American Society for Bioethics and Humanities.

Finally, the study revealed an appetite for greater collaboration among ethicists across Canada to develop and test ethics program evaluation frameworks and methods. Further work could be done to identify performance measures and indicators for ethicists and ethics programs, or to develop tools for assessing ethics program effectiveness. Delphi methods could be used to build expert consensus on key indicators and metrics of ethics program effectiveness. The resulting evaluation framework could then be piloted in various ethics programs and subsequently refined for broader use.

5.8 Conclusion

In this study, I set out to explore what makes an ethics program effective from the perspective of practicing ethicists from across Canada. This study addresses a gap in the literature on how to conceptualize, measure, and evaluate ethics program effectiveness. The literature on ethics program effectiveness emphasized the need for more research in this area as there has been a paucity of empirical research studies on the effectiveness of ethics programs as a whole. In order to assess effectiveness, effectiveness needs to be defined, measures of effectiveness need to be identified and then applied to determine whether effectiveness has been achieved.

Through this research, I learned that effectiveness can be formulated in different, but not mutually exclusive ways. In practice, however, effectiveness may not capture what ethicists think about when they reflect on the importance of ethics programs in healthcare organizations. For practising ethicists working in different ethics program models across different healthcare organizations, effectiveness was not the only thing that they were concerned about when thinking
about evaluating their programs. Effectiveness may be a catchword for other things like *return on investment, value, making a difference, being helpful, success, excellence,* or *quality:* different concepts that ethicists think about when thinking about ethics program evaluation.

The study findings provide a starting point for further research studies and the creation of a framework for evaluating ethics programs. This study contributes to a better understanding of what makes ethics programs effective and how to evaluate ethics programs. Even though there is no single formula for achieving or evaluating effectiveness, study results highlight critical factors that contribute to effective ethics programs and provide ethicists with some guidance on how they might go about evaluating their programs. More work is needed to develop a robust evaluation framework for comprehensive ethics programs so that ethics programs can be evaluated and improved. There is challenging work ahead, but there is appetite among ethicists to meet the challenges together.
References


Appendices

Appendix A: Recruitment Letter from Canadian Bioethics Society Executive Committee

Dear Colleagues,

RE: Research Study – “Exploring Ethicists’ Perspectives of Health Care Ethics Program Effectiveness”

We are writing to inform you about a graduate thesis research study being conducted at the University of Toronto by Kimberley Ibarra (M.Sc. Candidate, Department of Health Policy, Management & Evaluation and Collaborate Program in Bioethics) under the supervision of Dr. Jennifer Gibson (Department of Health Policy, Management & Evaluation, and Joint Centre for Bioethics, University of Toronto) and in collaboration with Dr. Elizabeth Peter (Lawrence S. Bloomberg School of Nursing, University of Toronto). The purpose of the study is to describe ethicists’ perspectives of ethics program effectiveness across Canada. The study aims to contribute to the sparse literature on ethics program effectiveness and evaluation, and inform current practice in health care ethics by interviewing ethicists about their perspectives of ethics program effectiveness.

The researchers are seeking to interview practicing health care ethicists from across Canada who meet the following criteria:

- Currently in the formal role of “ethicist” in a health care organization in Canada (e.g., hospital, long-term care facility, regional health authority, etc.);

- Leading an established (i.e., at least one year old) clinical and organizational ethics program – that is, an ethics program offering ethics services to patients or clients, families, physicians, clinical staff and/or administrative staff including case consultation, education, and policy development/review;

- Not primarily a research ethicist or not primarily involved in research ethics review.

The researchers are looking to recruit 15 – 20 ethicists from across Canada by February 2011, and hope to conduct interviews between January 2011 and April 2011. If you meet all of the above criteria and are interested in participating in the study, or would like more information, please contact Kimberley Ibarra (Principal Investigator) at (416) 876-0075 or kim.ibarra@utoronto.ca. Your participation in this research study is entirely voluntary.

Thank you for consideration.

Executive Committee, Canadian Bioethics Society
Appendix B: Letter of Invitation to Participate in Research Study

Dear Colleague,

RE: Research Study – “Exploring Ethicists’ Perspectives of Health Care Ethics Program Effectiveness”

We are writing to invite your participation in a graduate thesis research study exploring ethicists’ perspectives of the concept of “effectiveness” as it applies to health care ethics programs in Canada. The purpose of the study is to describe ethicists’ perspectives of ethics program effectiveness across Canada. The overarching research question is: what makes an ethics program effective from the perspective of ethicists? The study objectives are to: (1) describe how practicing ethicists define ethics program effectiveness in health care organizations; (2) identify strategies ethicists are using to evaluate the effectiveness of their ethics programs; (3) identify organizational and other factors that ethicists see as key enablers or barriers to ethics program effectiveness; and (4) determine how evaluation of ethics program effectiveness might be improved in health care organizations.

As you know, ethics has received increased attention in health care, particularly as an important component of high quality care. With the rise of evidence-based health care and the quality agenda, there has also been a growing interest in ethics program evaluation. Ethics programs are being called to demonstrate return on investment and accountability for resources. However, there has been little documented progress in evaluating ethics program effectiveness. As a result, there is a lack of consistent guidance around how to assess and improve ethics program performance and quality, and how to demonstrate program value. This study aims to contribute to the sparse literature on ethics program effectiveness and inform current practice by interviewing ethicists on their perspectives of ethics program effectiveness.

You have been identified as a practicing health care ethicist who can shed light on ethics program effectiveness and provide valuable insight into health care ethics program effectiveness and evaluation based on your experience leading an established clinical and organizational ethics program in a health care organization in Canada. Your participation in this research study is entirely voluntary. For your information and review, we have attached the interview questions and a consent form to this letter. If you are interested in participating or have any questions, please contact Kimberley Ibarra (Principal Investigator) at (416) 876-0075 or kim.ibarra@utoronto.ca. If you agree to participate, Kimberley will conduct the interview at a time of your choosing by telephone or, where possible, in person. The interview will take approximately 45 minutes. If you prefer that we do not contact you further regarding participation in the study, please let us know.

Thank you for considering our invitation.

Kimberley Ibarra, M.Sc. candidate, Health Services Research student, University of Toronto, Department of Health Policy, Management & Evaluation, and Joint Centre for Bioethics

Jennifer Gibson, PhD, Assistant Professor, University of Toronto, Department of Health Policy, Management & Evaluation, and Director, Partnerships & Strategy, University of Toronto Joint Centre for Bioethics
Study Title: Exploring Ethicists’ Perspectives of Health Care Ethics Program Effectiveness

Principal Investigator: Kimberley Ibarra, M.Sc. Candidate, University of Toronto Department of Health Policy, Management & Evaluation and University of Toronto Joint Centre for Bioethics, 416-876-0075, kim.ibarra@utoronto.ca

Faculty Supervisor/Sponsor: Jennifer Gibson, PhD, Assistant Professor, University of Toronto Department of Health Policy, Management & Evaluation and Director of Partnerships & Strategy, University of Toronto Joint Centre for Bioethics, 416-978-1395, jennifer.gibson@utoronto.ca

INFORMED CONSENT

You are being asked to consider participating in a research study. Participating in this study is entirely voluntary. This form explains the purpose of the study, and provides information about the study procedures, possible risks and benefits, and the rights of participants. Please read this form carefully and ask any questions you may have.

INTRODUCTION

Over the past two decades, ethics has received increased attention in health care, particularly as an important component of high quality care. Health care organizations have been investing resources into developing and maintaining ethics programs, and there has been a marked rise in the number of ethicists, ethics committees, and ethics programs in Canada and abroad. With the rise of evidence-based health care and the quality agenda, there has also been a growing interest in ethics program evaluation. Ethics programs are being called to demonstrate return on investment and accountability for resources. However, there has been little documented progress in evaluating ethics program effectiveness. As a result, there is a lack of consistent guidance around how to assess and improve ethics program performance and quality, and how to demonstrate program value.

You are being approached for this study because you have been identified as an individual who can provide valuable input on evaluating the effectiveness of ethics programs and you meet the following criteria for inclusion in the study:

- Your formal institutional role is “ethicist”;

...
- You are leading an established (i.e., at least one year old) clinical and organizational ethics program – that is, an ethics program offering ethics services such as case consultation, education, and policy development/review to patients/clients, families, physicians, and clinical and administrative staff;

- You are working in a Canadian health care organization; and

- You are not primarily a research ethicist or involved in research ethics review.

WHY IS THIS STUDY BEING DONE?

The purpose of the study is to describe ethicists’ perspectives of ethics program effectiveness across Canada. The overarching research question is: what makes an ethics program effective from the perspective of ethicists? The study objectives are to: (1) describe how practicing ethicists define ethics program effectiveness in health care organizations; (2) identify strategies ethicists are using to evaluate the effectiveness of their ethics programs; (3) identify organizational and other factors that ethicists see as key enablers or barriers to ethics program effectiveness; and (4) determine how evaluation of ethics program effectiveness might be improved in health care organizations.

WHAT WILL HAPPEN DURING THIS STUDY?

You are being asked to participate in an interview. The interview will be organized and facilitated by Kimberley Ibarra (Principal Investigator) under the supervision of Dr. Jennifer Gibson. The interview will be approximately 45 minutes in length and will take place in a private meeting room in a location of your choosing. If an in-person interview is not possible, the interview will be conducted by telephone or videoconference. The interview questions have been shared with you in advance for your information. You will also be asked if you can share any relevant documents (e.g., ethics program evaluation framework) that may be relevant to ethics program effectiveness or evaluation. If necessary for clarification, you may be contacted after the interview by the Principal Investigator for follow-up. Follow-up questions will be limited to approximately 15 minutes.

The interview will be digitally recorded. Audio files will be transcribed by the Principal Investigator and analyzed by the study investigators. A written summary of the aggregated and anonymized findings will be sent via email to all participants for their comments and feedback, for a member check. The purpose of a member check is to validate the findings. Participants will not be identified in the member check email or the member check document. Once the member check is complete, the findings will be used to complete a Master of Science thesis, and related academic publications and presentations. After the project is complete, participants will be given a copy of the full study report.

The only people who will have access to the data are the study investigators. Study data will be kept for seven years after study completion. At this time, all electronic data will be deleted from all computer hard drives used in the study and all hard copy data will be shredded and destroyed by the secure waste disposal service contracted by the University of Toronto.

Participating in this study is voluntary. Participants will not be paid to take part in this study, nor is it expected that your participation will result in any additional expenses to you. Your decision to participate (or not to participate) will be kept confidential. You may refuse to participate, may
decline to answer any question or participate in any parts of the study, or withdraw from the study at any time – all without negative consequences. Should you choose to withdraw from the study, we will seek your direction on use of the data. If you do not give permission to use the data in the study or in the absence of explicit instructions, the data will be destroyed and any record of your participation will be deleted from our files.

**HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?**

It is anticipated that 15 – 20 ethicists from across Canada will participate in the study.

**WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?**

There are four foreseeable risks in participating in the study:

1. You may become uncomfortable discussing some topics during the interview, but you may also refuse to answer some questions or stop the interview at any time if you experience discomfort.

2. The interview may involve disclosure of information that identifies particular people or situations at your organization. To minimize such risk, the interview facilitator will encourage study participants to refrain from using names or other personal identifiers. All names and identifiers will be deleted during the transcription process and replaced by codes. To maintain confidentiality, study transcripts will be encrypted and stored in a secure location. The key for participant codes and interview schedules will be stored separately from the data in a password-protected folder on a secure server with access to only the Principal Investigator.

3. You will be asked to share documents that are publicly available and/or those you feel comfortable sharing externally. There is a possibility that some of these documents entail social risks to persons named in them or to institutions, such as loss of status or privacy. You have the option not to provide the researchers with documents and/or to withdraw from the study completely. Documents will be de-identified (e.g., names of institutions or persons removed) prior to data analysis or any reporting of findings.

4. Given the relatively small bioethics community in Canada, we cannot exclude the possibility that someone might be able to identify you as a participant based on knowledge of contextual factors. The study team will make every effort to preserve confidentiality of study participants and will anonymize the data, particularly in the use of direct quotes in reporting study findings. If it is apparent that a particular participant would be easily identified in reports or publications and is quoted or discussed in a manner that may place him or her at social risk, the researchers will contact the participant before publication for direction on whether to redact the information.

**WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING IN THIS STUDY?**

While there are no direct benefits to participants, there are indirect benefits from a better understanding of the concept of effectiveness as it applies to health care ethics programs which could lead to improvements in participants’ local ethics program activities and services, and in the field of health care ethics.
DO THE INVESTIGATORS HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

1. You have the right to have this form and all information concerning this study explained to you.

2. Participating in this study is voluntary. You may refuse to participate, may decline to answer any question or participate in any parts of the study, or withdraw from the study at any time – all without negative consequences. Should you choose to withdraw from the study, you are encouraged to contact Kimberley Ibarra (Principal Investigator) at kim.ibarra@utoronto.ca or 416-876-0075. If this should happen, we will seek your direction on use of the data. If you do not give permission to use the data in the study, the data will be destroyed and any record of your participation will be deleted from our files. In the absence of explicit instructions, we will default to destroying the data and removing record of your participation from our files.

3. If you have any questions about this study, you may contact Kimberley Ibarra or the faculty supervisor of this study (Jennifer Gibson, jennifer.gibson@utoronto.ca, 416-978-1395). If you have any questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may contact the Office of Research Ethics at the University of Toronto at ethics.review@utoronto.ca or 416-946-3273.

4. You have a right to receive a copy of this signed and dated informed consent form before participating in the study.

5. You have the right to be informed of the results of the study once the study is complete.
DOCUMENTATION OF INFORMED CONSENT

Full Study Title: Exploring Ethicists’ Perspectives of Health Care Ethics Program Effectiveness

Name of Participant: ____________________________________________________

Participant

By signing this form, I confirm that:

- This research study has been fully explained to me and all of my questions answered to my satisfaction.
- I understand the requirements of participating in this research study.
- I have been informed of the risks and benefits, if any, of participating in this research study.
- I have been informed of the rights of research participants.
- I have read each page of this form.
- I authorize access to my personal information and research study data as explained in this form.
- I agree to participate in this study.

_______________________  __________________________  _________________
Name of participant (print)  Signature  Date

Person obtaining consent

By signing this form, I confirm that:

- This research study and its purpose have been explained to the participant named above.
- All questions asked by the participant have been answered.
- I will give a copy of this signed and dated document to the participant.

_______________________  __________________________  _________________
Name of person obtaining consent (print)  Signature  Date

Statement of Investigator

I acknowledge my responsibility for the care and well-being of the above participant, to respect the rights and wishes of the participant as described in this informed consent document, and to conduct this study according to all applicable laws, regulations and guidelines related to the ethical and legal conduct of research.

_______________________  __________________________  _________________
Name of investigator (print)  Signature  Date
Appendix D: Interview Guide

Interview Questions for Study Participants

1. Please describe the ethics program at your institution (e.g., program structure, ethics personnel, reporting relationships, ethics program mandate, available resources, etc).

2. How do you define effectiveness of your ethics program or of an ethics program in general?

3. What steps are you or your institution taking to address/measure/evaluate effectiveness of your ethics program?

4. What are the expectations on you or your ethics program related to effectiveness?

5. What has enabled you to succeed in these areas? What are the key success factors or enablers of your ethics program? How do you know you are successful?

6. What are the barriers to your program achieving “effectiveness” and how have these been addressed?

7. Are there any documents related to ethics program evaluation that you are able to share with me for the purposes of this study? (e.g., ethics program plans, annual reports, evaluation frameworks, accreditation standards for ethics, or ethics service evaluation results)

8. Is there anything else you would like to tell us about how you define or evaluate ethics program effectiveness?

Prompts:

What do you mean by ____________…?

Can you explain what ______ means?

Can you tell me a little bit more about that…?

You mentioned ____________... can you give me an example of what that looks like?