HOW LEGAL THEORY COULD SAVE THE LIFE OF HEALTH CARE ETHICS

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements for the Degree of Doctor of Philosophy

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Lay Abstract

Ethics consultation has had a place in healthcare for decades, however the nature of the work is not well understood by many critics and defenders. Practicing healthcare ethicists (PHEs) have been described as compromised and ineffectual; politicised and undemocratic; and their promise to offer sound advice has been deemed irredeemably incoherent in the context of value pluralism. I tease out what is instructive in these critiques and argue that they may be answered by reviewing the conflict of interest literature and by exploring what is distinctive about the PHE role.

I introduce a typology of hard cases with an emphasis on penumbral ethical cases, and contend that legal theory, especially that part which deals with H. L. A. Hart’s penumbral cases, can help PHEs to describe theoretical disagreement in hard cases. I also argue that jurisprudence can be useful in the exploration of topics related to the professionalization of PHEs.

Abstract

Healthcare ethics consultation has had a place in healthcare for many decades yet the nature of the work is not well understood by many of its critics as well as its defenders. Practicing healthcare ethicists (or PHEs) have been described as compromised and ineffectual; politicised and undemocratic; and their promise to offer sound advice has been deemed irredeemably incoherent in the context of value pluralism. I tease out what is instructive in these critiques and argue that they may be answered by reviewing the conflict of interest literature and by exploring what is distinctive about the PHE role.

The most challenging aspect of any PHE’s role is to provide support for the management of so-called hard cases, therefore I introduce a typology of hard cases. Emphasis is placed on what I call (borrowing from the legal theoretical literature) penumbral ethical cases. Legal theory, especially that part of legal theory that deals with what H. L. A. Hart called penumbral cases, can help PHEs (and others) to appreciate the fact that theoretical disagreement need not signal that the field has little to offer, nor need it imply that all answers are equally defensible in the hardest of cases.

Finally, I argue that legal theory can provide a jumping-off point for the study of insufficiently explored topics related to PHE professionalization. Legal theorists have long attended to the relationship between law and morality, the problem of obedience in wicked legal systems, and the supposed tension between democracy and the role of an expert judiciary. An appreciation that these debates are not unique to the practice of healthcare ethics may help PHEs to engage critics with a renewed confidence and some fresh approaches to perennial, and hitherto unproductive, arguments.

Preface

No part of this document has previously been published.

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Acknowledgements

Morality as a Problem, from *The Gay Science*, Book V

*It makes the most material difference whether a thinker stands personally related to his problems, having his fate, his need, and even his highest happiness therein; or merely impersonally, that is to say, if he can only feel and grasp them with the tentacles of cold, prying thought. In the latter case I warrant that nothing comes of it…How is it that I have not yet met with any one, not even in books, who seems to have stood to morality in this position, as one who knew morality as a problem, and this problem as his own personal need, affliction, pleasure and passion?*

Nietzsche, despite his great accomplishments and influence, seems to have moved in the unluckiest of circles. In the five hospital systems where I have served as a practising healthcare ethicist, I have had the pleasure of knowing many high-spirited (to use his felicitous phrase) women and men (patients, families, and professionals) for whom grappling with the problems of morality is a passion. I am deeply grateful for their companionship, past and present, and for the countless lessons that they have imparted.

For my dissertation project I am especially indebted to those who have contributed to my academic development. Elisabeth Gedge, my PhD supervisor, encouraged me to explore a path (bioethics) that I’d never imagined would be mine, and she graciously welcomed me back to the academic fold when I feared that was no longer possible. My committee members, Wilfrid Waluchow and Lisa Schwartz, showed great enthusiasm for a project that I feared would interest only me. Christy Simpson proved to be a superb external reader and provided the bridge between town and gown that the work has always needed.

Finally, I offer thanks to those with whom I currently work most closely; that is, my wonderfully wise and supportive bioethics team members (Andria, Bob, Daniel, Donna, Jen, Jed, Kevin, and Ruby), and my ever-optimistic vice-president, Joy. Healthcare needs more like them.

*For Cornelius*

*Twenty years of talking past one another have made us kinder, clearer, and infinitely more patient with one another. Always becoming, yours…*

Introduction

Philosophers, theologians, and social scientists have been working alongside physicians, nurses, and other members of the traditional health care professions in hospitals, clinics, and long-term care facilities for at least fifty years. Their roles have not been strictly academic, although some of their responsibilities (teaching, researching, and publishing) would be entirely familiar to their university-based colleagues. What sets them apart is the applied, indeed strikingly practical, nature of their work. Even when their projects touch on large theoretical problems, such as the nature of personhood, or the limits of individual liberty, they generally are motivated by pressing considerations such as an attempt to fill a gap in the policies of their home institutions or a desire to answer questions raised by specific patients or health care providers.

This group, variously called bioethicists, clinical ethics consultants, practicing health care ethicists, or simply ethicists, is routinely involved in deliberations concerning some of the most controversial aspects of healthcare delivery. The topics they engage are wide-ranging and encompass questions such as when to withdraw life-sustaining treatment, whether consent to treatment or research participation must always be informed, and how to establish criteria for access to expensive but unfunded therapies. Given the high level of value disagreement that attends issues like these it is not surprising that those that I will call Practising Healthcare Ethicists (PHEs), following the convention of the Canadian Association of Practising Healthcare Ethicists (CAPHE), have been subject to sharp criticism. The colourful labels that have been assigned to practitioners allude to the character of the concerns that have been raised by their critics. Names like "Secular Priests," "Philosopher Kings," "Wizards of Oughts" and "Ethical Experts" all invite scepticism and anxiety about the workings of a largely unknown and unregulated category of consultants whose very existence appears, paradoxically and simultaneously, to threaten the independence both of health care providers and of their patients.[[1]](#footnote-2)

An effort to disentangle the various threads that make up the fabric of the charges against the field can be informative. Like garments designed to flatter the human form they are artful with respect to what they reveal and conceal. Although they can sound superficially the same, closer examination reveals at least three distinct types of objection to the presence of ethics consultants in health care. Their work is reputed to be *compromised* and ineffectual because it is situated in and dependent upon the very institutions it ought to critique (Carl Elliot); *politicised* in a way that is elitist and anti-democratic (Carl Elliot, Tom Koch); and finally, irredeemably *incoherent* in the context of value pluralism (Tristram Engelhardt Jr., Giles Scofield). Not surprisingly, each of these charges points to features of the practice that warrant greater attention than they are generally afforded. In the pages that follow I aim to address each of these in turn.

My hope is that in so doing I can tease out some of the subtleties that have been ignored in the rush to knit together an account of what can, at least from the outside, seem a more mysterious and exclusionary field than I believe it to be. I will argue that each of the charges that have been levelled against the practice of ethics consultation provides a thread that can be unravelled and re-knit into a more serious critique of the field, a critique that provides both a threat and an opportunity for its practitioners. Most importantly, I want to suggest that to date there has been no systematic attempt to supply an account of what I want to describe as theoretical disagreement in bioethics. Disagreement too often has been blithely glossed over as insignificant, or trivialized as partisan and irresolvable. This, however, is only part of the reason that health care ethics consultants are vulnerable to the charges that I describe above. In the pages to come I hope to demonstrate that the practice of ethics consultation can benefit greatly from a more critical reflection on the relationship between the theoretical and the practical dimensions of that work. Just as legal theorists can offer ways to understand and interpret the disparate elements that constitute judicial practice and decision-making, I want to argue that the work of academic bioethicists can contribute in more meaningful ways to the reasoning processes that are integral to the practice of ethicists working in healthcare settings. By this I do not mean to imply that the bedside or the boardroom ought to be, or even can be, transformed into something akin to a graduate seminar, and I certainly don't wish to suggest that consultants invoke abstruse concepts or adopt a more esoteric vocabulary when interacting with clinical colleagues, health care managers, or the patients and families that they serve. On the contrary, I believe that much of the applied ethicist's work, like that of the practicing lawyer, police officer, or ordinary citizen, does not require an explicit effort to parse the meanings of the words and concepts that they use, or a conscious attempt to delineate the limits to their application. When clinicians indicate that a patient's consent has been obtained it will not always, or often, be an occasion to ponder freedom of the will or the continuity of the self over time. When life-saving interventions are performed in our emergency rooms and operating theatres it is rare, at least in the Canadian context, to raise questions about the obligations of a community to its members or, more complex yet, questions about the nature of community and the conditions for membership.[[2]](#footnote-3)

Of course, hard cases do arise in health care and they demand extra effort of those involved in decision-making processes. It's not self-evident that consent is valid when a patient is overwhelmed with anxiety, in pain, or under any other form of duress, and it is not obvious that exorbitantly priced but efficacious treatments should be supplied, or even offered, to all who might derive some benefit from them. Health care ethics consultants are often called upon to provide advice in cases like these because the stakes are high, the way forward is unclear, and stakeholders are at a loss or in a state of disagreement. It should not be surprising, therefore, that their involvement attracts controversy. Easy cases are decided without them, contentious cases are their proverbial bread and butter, and some of the most challenging cases attract considerable media attention, and give courts and lobbyists ample work to do too.[[3]](#footnote-4)

In North America all, or nearly all academically-affiliated hospitals employ a practicing healthcare ethicist (or ethicists),[[4]](#footnote-5) yet the role remains poorly understood by many of its champions as well as its critics. Whilst there is a strong, and growing, momentum to professionalize the field (core competencies, practice standards, qualification tests, and codes of ethics are being developed and refined as I write), it is still reasonable to say that those who use the services of practicing healthcare ethicists often remain unclear about what they can expect from practitioners (conceptual clarification, mediation, advice, direction, or some combination thereof) and what warrant they have for the work that they do.

In the chapters that follow I will attempt to reconstruct the critiques of some of the field’s most vocal critics and try to highlight the main strengths and limitations of their objections. In an effort to show what is at stake in these arguments I will describe the current state of health care ethics consultation and will pay particular attention to the renewed and growing enthusiasm for transforming the work of its practitioners into a regulated health profession. Ultimately, however, I hope to persuade the reader that a vigorous and defensible account of the field is yet to come. My penultimate chapter will call for an account of clinical ethics consultation that draws upon a conviction that the practice must be understood as interpretive, political - albeit in a non-partisan way - and, when done well, scrupulously fair. These chapters will be necessary preparatory work for what I take to be the point of this project; that is, to offer an explanation of why competent, careful, practising healthcare ethicists sometimes disagree in difficult cases. This is what I described as "theoretical disagreement" earlier on, and it borrows from the insight of the late legal theorist Ronald Dworkin who famously observed that there are two main ways that lawyers and judges, as well as ordinary citizens, can disagree about "propositions of law."[[5]](#footnote-6) On his account, which I will draw upon quite heavily, disagreements may be empirical or theoretical in nature. Empirical disagreement, simply put, refers to those disagreements concerning factual matters such as whether there is a statute or prior legal judgment that is applicable to a case under consideration. These sorts of disagreements generally can be settled swiftly through reference to authoritative texts. In Ontario, for example, those wanting to resolve an argument about who is the legally authorised decision-maker for an incapacitated patient need only look to the hierarchy of decision makers listed in the province's *Health Care Consent Act*.[[6]](#footnote-7) Theoretical disagreement, on the other hand, can persist even after the statute books have been competently and thoroughly reviewed and understood. This is because theoretical disagreement finds its roots in value-laden questions related to both the grounds and the force of law. To return to our earlier example, there is no canonical text and no applicable statute, which can tell our disputants why or whether the sorts of decision makers identified by the *Act* ought to be given the power to decide for others. The answers to these sorts of questions may be inferred from a reading of the *Health Care Consent* *Act*, or by parsing arguments made in other legal sources such as the rulings of Ontario’s Consent and Capacity Board hearings, but they are different in kind and answering them requires interpretive effort. That effort, moreover, will frequently entail reflection on the relative weight of various legal and ethical principles - weight that will vary depending on the particulars of individual cases and the values of their interpreters. This story, however, is a complex one which will unfold over the course of the pages that follow. At this point, suffice it to say that I believe that health care ethics consultation, although in some ways very different from jurisprudence, demands of its practitioners an ability to gather together the relevant clinical and contextual features of a patient's case (including relevant laws, policies, and local conventions including the so-called standard of care) as well as the multiple preferences, values, principles, and theoretical approaches that are relevant to a resolution of the question, or questions, it has prompted. Although I have never heard it described in this way, these cases can give rise to either empirical or theoretical disagreement (or both simultaneously) and an awareness of the distinction between the two has the potential to clarify what is at issue when parties disagree.

Given my indebtedness to the work of Ronald Dworkin (and to its subsequent critics and defenders) it may come as no surprise that I will conclude my project with a modest attempt to defend an egalitarian liberal account of the aims of clinical ethics consultation[[7]](#footnote-8). Many readers would not endorse that particular interpretation of the practice, but I shall be content if they can concede the point that this is a viable alternative to the way the practice is described (or mis-described) by many of its most vocal critics and supporters. Given that the field is at least a half-century into its development, it seems reasonable to suppose that health care ethics consultants will have competing accounts or conceptions of the practice. Indeed, because practitioners come to their work from diverse home disciplines, possess a wide range of value-orientations and life experiences, and are routinely expected to weigh-in on questions that are the most contested in our, or any, society, it may seem surprising to suppose that they share a practice at all. My first chapter, therefore, will serve as a brief overview of the current state of the field. (My emphasis is on the North American context because health care ethics consultation is well established here and is amply described in a burgeoning academic and professional literature.) It will offer a preliminary answer to the provocative question raised by one of the Canadian pioneers of the field, Professor William (Bill) Harvey: What are we doing when we are doing what we are doing? My hope is to push further yet, and by the conclusion of this project, propose an answer to a question that I think he believes is implicit in, or at least follows from, his own: What *should* we be doing when we are doing what we are doing?

Chapter One: A Compromised and Ineffectual Field?

*Professing to be professionals (What is the nature of the work?)*

Those seeking to understand what practicing healthcare ethicists do, or may reasonably be expected to do, might fruitfully begin their enquiries by reviewing employment advertisements posted by those who seek to employ them, or by reviewing the role descriptions that have been developed by practitioners in order to clarify the character and scope of their work.[[8]](#footnote-9) The nature of the practice will vary somewhat depending on institutional context: an ethics consultant working in a mental health facility may find herself employing slightly different skills, knowledge, or expertise than her colleague across town at a children's hospital but, for the most part, their daily tasks will be much the same. As the literature on professionalization reveals, the work of the PHE generally falls within four broad categories: clinical ethics consultation (which responds to requests for assistance in resolving value conflicts arising in the care of specific patients), organizational ethics support (which includes policy development and review as well as assistance with one-off decisions which do not pertain specifically to the care of individual patients), supplying education to staff and others on ethical topics, and conducting and evaluating research.[[9]](#footnote-10) It is the first of these that has attracted the most attention and controversy, although it can convincingly be argued that these are not entirely separable domains.[[10]](#footnote-11) Health care ethicists generally find fodder for their educational efforts, and inspiration for their research, in the cases that come before them. Similarly, policy development is almost always motivated by a desire to address clinical or organizational gaps, and rarely can be useful if it is uninformed by research and unaccompanied by an appropriate educational plan. The policies of health care institutions cover incredibly wide-ranging topics such as organ donation after cardio-circulatory death, disclosure of medical error, and the appropriate management of relationships with pharmaceutical industry representatives. They are rarely authored by ethicists alone (indeed, it is routine for representatives of a dozen or more professional practice areas to have a hand in their writing), and they nearly always undergo multiple layers of committee review, but an ethics consultant often can exert a tremendous influence with respect to the content and disposition of the final product. Even the most independent chief executive officer, or confident medical advisory committee, may be reluctant to grant approval to a policy or guidance document that has been described as ethically deficient by the institution's own ethicist or ethics consultation service.

Perhaps it is the perception that clinical ethics consultation is performed without the kind of oversight and stakeholder involvement that is typical of policy work (and of research review) that generates concern among its critics. In most institutions an ethicist will, after all, provide support to physicians, staff, senior leaders, and patients or families whenever any of these parties have standing, or a legitimate legal or ethical stake in a particular case. It is for the most part true that the content of a meeting with a health care ethicist will be protected by privacy legislation (and the parties need never disclose the nature or substance of their discussions if disputed issues can be resolved behind closed doors) but such legislation pertains to all encounters between health care providers and their clients.[[11]](#footnote-12) Practicing ethicists, physicians, pharmacists and physiotherapists (to name but a few) do not differ in this regard. There must, therefore, be something distinctive about the practice of ethics consultation that generates a level of concern or suspicion that other clinical work (such as performing patient examinations, prescribing prescription medications, and designing rehabilitation routines) simply does not engender.

Some of the earliest literature that argued against the professionalization of the field (dating from the late 1990s through to the last decade or so) offers insights into possible reasons for anxiety about the increasing influence of institutional ethicists. These objections gradually have receded as the focus of the professionalization debate has shifted from *whether* the field should professionalize to very pragmatic questions concerning *how* professionalization should occur. Although some who perform ethics consultation (especially in remote, rural, or under-serviced areas) do so as dedicated volunteers, or as secondments from their primary responsibilities, there is a large and growing constituency which holds the view that the approach to the work cannot depend upon the fortuitous interests and assorted aptitudes of those without systematic training in the field. The professionalization movement, therefore, currently is occupied with the development of fair and meaningful processes for assessing the quality and competence of individual ethicists, or ethics services, and the programs that train them.[[12]](#footnote-13) It may be argued, however, that the push toward certification, qualification, and accreditation has left more fundamental questions unanswered.[[13]](#footnote-14) These questions, which I have registered very briefly already, reflect underlying concerns about the authority, neutrality, and value of the work that clinical ethicists do. Before turning to these searching questions, however, it may be most useful to begin with a brief description of the practice of health care ethics consultation.

*Consultation content and method*

The most recent edition of a tremendously influential report called *Core Competencies for Health Care Ethics Consultation*, is the product of four years of work by a task force of the American Society of Bioethics and Humanities (ASBH) which described itself in 2006 as a multidisciplinary organization with a membership of “more than 1600 health care professionals, teachers, consultants, and others who have an interest in the field of clinical and academic bioethics and the health-related humanities.”[[14]](#footnote-15) The ASBH, and specifically its Core Competencies Taskforce, did not purport to speak for all health care ethicists in North America, or even in the United States, but in the course of developing this now foundational document it took care to solicit the opinions of many practitioners, and interested parties (whether they were members of the Society or not) were welcome to comment on drafts of the report before it was finalized. (Draft versions were posted on-line at the Society’s website and on a variety of relevant listservs, and opportunities for additions and corrections were made available electronically as well as at ASBH annual meetings.) The report offers, therefore, a definition of health care ethics consultation that is as close to a consensus statement as the field currently allows: “Healthcare ethics consultation (HCEC or ‘ethics consultation’) is a set of services provided by an individual or group in response to questions from patients, families, surrogates, healthcare professionals, or other involved parties who seek to resolve uncertainty or conflict regarding the value-laden concerns that emerge in healthcare.”[[15]](#footnote-16)

As one might infer from the austerity of the definition, the report allows for a range of approaches to the resolution of value conflict. The authors are agnostic as to whether services should be provided by individuals or by teams, or whether consultants should be drawn from medicine, the regulated health care professions, or from the social sciences and the humanities. They are even circumspect about what counts as an ethical issue. They are, however, more prescriptive with respect to what they call the matter of method when they caution against two ill-advised approaches to conflict resolution. The first, which is called the ‘pure consensus approach,’ sees the ethicist as a mediator focussed solely on the outcomes of the consultation: if agreements are forged between opposing parties (for example, between a patient’s family and his treating team), then the consultation can be deemed successful. The substance of the agreement, in other words, is inconsequential. The second, which is labelled simply the ‘authoritarian approach,’ makes the ethicist the ultimate arbiter of disputes: that is, she will judge whose values ought to prevail. On this latter approach, to return to our earlier example, the ethicist is charged with the task of deciding whether the family or the team has the better case, and she is empowered to override them both and may propose, or indeed impose, an alternative of her own.

The authors of the *Core Competencies* make the reassuring claim that “[t]he field has rejected both of these extremes.”[[16]](#footnote-17) These are merely provided as foils for the approach that they recommend and, presumably, most practising health care ethicists endorse. This middle way is dubbed the ‘ethics facilitation approach’ and it combines the knowledge, skills and attributes[[17]](#footnote-18) that are important to fostering the sort of respectful and effective communication required to reason through the complexity generated by competing value commitments. If the health care ethicist is committed to this method, her aim will not be to impose her own conception of the good on her clients. (Indeed, it would be rare for her values to be in the foreground at all.) According to the *Core Competencies* report, “The consultant helps relevant decision makers fashion a plan that respects the needs and values of those involved and that is within the bounds of ethical and legal standards.”[[18]](#footnote-19)

Those who are concerned about the potential for health care ethics consultation to provide cover for an elitist and unstated agenda (that of the ethicist herself, or of her employers) may take some comfort in the care that the authors have taken to construct this deceptively simple statement. It should be noted that it is the “relevant decision makers” who are to arrive at a plan that “respects the needs and values” of the involved parties.[[19]](#footnote-20) The ethicist has a role, and it is by no means an insignificant one, but that role is to ensure that the consultation is focussed on its ultimate aim, which is “to improve the quality of health care through the identification, analysis, and resolution of ethical questions or concerns.”[[20]](#footnote-21) To make this end more likely the Core Competencies Task Force urged consultants to embrace a facilitator role that is distinguished by two “core features.” These are “(1) identifying and analysing the nature of the value uncertainty, and (2) facilitating the building of a principled ethical resolution.”[[21]](#footnote-22)

The second of these core features, facilitating the building of a principled ethical resolution, is arguably less controversial than the first and its character will be familiar to those non-ethicists (such as genetic counsellors, spiritual care providers, or social workers) who engage in the various non-directive facilitation activities that routinely occur in health care settings. It largely consists in ensuring that the various parties have reliable and reasonably complete information, occasions to participate in the discussions that concern them, and opportunities to be listened to with respect. A skilful facilitator will also be attentive to moments when parties need assistance to identify and clarify the values that they hold and will help them to recognize points of agreement and disagreement. When needed, she will help to resolve uncertainty about factual matters (such as the meaning of medical terminology, or the content of institutional policy, or how to identify a patient’s legally-authorized decision-makers under the *Health Care Consent Act*). Finally, if conflict persists, she will often employ mediation techniques in an effort to resolve or to manage conflicts.[[22]](#footnote-23)

The goal of “identifying and analysing the nature of value uncertainty” is the part of health care ethics consultation that may attract the greater degree of controversy. A consultation typically begins with a request for support in answering an ethically challenging question, such as, Is it ethically defensible to ‘starve’ Mr Beaton who is a frail patient in the final stage of dementia and subject to frequent bouts of feeding-related aspiration pneumonia? This sort of query will trigger fact-finding activities by the ethicist such as reviewing any relevant literature (including institutional policies, professional codes of ethics, relevant bioethics texts, and legal materials); examining the patient’s medical records; and engaging key stakeholders. Who these stakeholders might be is not always self-evident, but if a patient is capable of making his own health-related decisions it will almost always be indefensible to exclude him from this process. Other parties with moral standing typically will be the most responsible practitioner (MRP)[[23]](#footnote-24), any legally authorised surrogates or family members (especially those who represent incapable patients or provide support to those who are capable), and any other members of the health care team who are intimately involved with the patient’s care. (For the purposes of this example, these might be the registered nurses providing direct patient care, a speech-language pathologist, a dietician, a social worker, a palliative care representative, and a spiritual care provider.) If the case is perceived to be legally contentious other parties may be consulted as well, such as hospital counsel, a risk manager or patients’ ombudsman, the unit manager, or representatives of the senior leadership team.

Following the information-gathering stage the PHE may decide that the central ethical question needs to be re-framed or refined. More appropriate questions in the instant case may be the following: Which plan of treatment best respects the known values, or prior capable wishes, expressed by Mr Beaton? Does the proposed plan violate any of the community’s prevailing ethical or legal norms? What benefits and burdens (to Mr Beaton or to others) are likely to be associated with the options under consideration?

The effort to find answers to these questions will be shared by the parties involved in the case and the health care ethicist can assist by helping to unpack the meaning of relevant concepts that commonly arise in the bioethics literature; those pertaining to Mr Beaton’s case might be decision-making capacity, power of attorney for medical care, best interests, the duty of care, the doctrine of double effect, or the right to refuse medical treatment. Explication of these concepts often will be needed as the PHE helps parties to identify the course, or courses, of action that generally are thought to be ethically defensible in cases of this kind. The consultant will not, in other words, act as an ethical arbiter. As the brochures of many ethics services promise, ultimate authority for decision-making rests in the hands of patients (or their legally authorized decision-makers) and their health care providers.[[24]](#footnote-25)

Despite the fact that health care ethicists are rarely called upon to mediate disputes that do not elicit differing perspectives or evoke strong feelings, the process only rarely culminates in legal contests. High profile cases like those of Teresa Schiavo or Hassan Rasouli may attract considerable media attention, or prompt interventions by politicians and special interest groups, but it is only their visibility that is exceptional. Nearly all experienced ethics consultants have been involved in cases with similar elements, and many health care institutions have been inclined to establish ethics services largely in order to promote non-litigious approaches to dispute resolution.[[25]](#footnote-26) Grief, miscommunication, unrealistic expectations, and value-conflicts can generate frustrations that are addressed more efficiently and effectively at well-mediated team and family meetings than in a court of law. An ethics consultation can be called to help parties to uncover the bases of their disagreements and to arrive at strategies that can resolve conflicts altogether or that will allow disputants to narrow the field sufficiently so that a few mutually acceptable solutions can be found.

Legal remedies remain open to those who are not satisfied by the processes or outcomes of ethics consultations, but only a small percentage of those involved in consultations report dissatisfaction or, as was noted earlier, take their concerns into courts of law. What this means admits of no clear answer, although there is a growing interest in developing better ways to understand and measure what may be described as quality in clinical ethics consultation. It should be acknowledged that reports of satisfaction from consultation requestors and participants can be deeply misleading as a quality measure. After all, the most vocal parties may be content with outcomes that violate the rights, or disregard the values, of patients or their caregivers. Participants may be frustrated, moreover, when processes are acknowledged to be fair but the outcomes are inconsistent with their interests or preferences. While neither of these concerns constitutes a reasonable basis for abandoning the practice altogether they do help us to better understand why its critics can be difficult to satisfy.

*Sophistry and the status quo*

It is perhaps not surprising, therefore, that despite the assurances offered by the ASBH Core Consultation Taskforce, those who are most critical of health care ethics consultation have not seen the process as a benign one. Unlike those who seek to make consultation methods more consistent, transparent, and accountable - some of the aims of those who seek professionalization - many of these critics have focussed attention on what they believe to be the limitations of the ethics consultants themselves. As we have already observed, PHEs have been described as compromised, politicised, or in pursuit of incoherent ends. It is the first of these charges to which I shall turn first.

Carl Elliott, who worked for four years at McGill University (where he was on the faculty of the Biomedical Ethics Unit and a staff member at the Montreal Children’s Hospital), and is now a professor in the Center for Bioethics at the University of Minnesota, has been among the most vocal of the critics who see the field as compromised and ineffectual. In a memorable essay, entitled “Pharma Buys a Conscience,” he described his colleagues as “show dogs” who are unwilling to bite the hands that feed them.[[26]](#footnote-27) Elliott does not generally make a distinction between academic bioethicists and those working in clinical settings, and that may not matter overmuch, as he maintains that both those working at universities and those in the direct employ of medical centres have reason to be attentive to financial imperatives. Elliott’s chief concern appears to be that those doing ethics work will be unable to resist, or perhaps even recognize, the biases introduced into their analyses by those who pay their stipends or salaries. His most critical remarks are reserved for those who offer advice to pharmaceutical companies or to for-profit institutional review boards or IRBs (the latter is the American term for what Canadians call research ethics boards), but his view of other ethics consultants appears to be equally jaundiced. In response to Thomas Donaldson, the Mark O. Winkelman Professor of Law and Ethics at the Wharton School of the University of Pennsylvania, who compares ethicists to accountants who must depend upon a reputation for integrity in order to credibly perform their duties, Elliott issues the following challenge,

...ethical analysis does not really resemble a financial audit. If a company is cooking its books and the accountant closes his eyes to this fact in his audit, the accountant’s wrongdoing can be reliably detected and verified by outside monitors. It is not so easy with an ethics consultant. Ethicists have widely divergent views. They come from different religious standpoints, use different theoretical frameworks and profess different political philosophies. They are also free to change their minds at any point. How do you tell the difference between an ethics consultant who has changed her mind for legitimate reasons and one who has changed her mind for money? What distinguishes the consultant who has been hired for her integrity from the one who has been hired because her moral viewpoint lines up nicely with that of company executives?[[27]](#footnote-28)

The connection between Elliott’s critique of ethicists who offer consulting services to the pharmaceutical or device industries (those we might for the sake of brevity call ethical entrepreneurs) and those who earn their livelihood advising hospital staff, physicians, and patients may appear to be a tenuous one, but even in a publically-funded health care system, such as the one we have in Canada, it is important to acknowledge that pressures to contain costs are never entirely absent from deliberations concerning the alternatives that are deemed possible, realistic, or ethically defensible. The case of a patient who is persistently unconscious and occupying a critical care bed may provoke as much consternation as the implementation of a randomised clinical trial designed to test the effects of a novel chemotherapeutic agent that may benefit the few at a significant cost to the many. It may be obvious that questions pertaining to fairness in the distribution of health care goods and services arise in so-called organizational ethics consultations (whose purpose is often to order institutional priorities), but they can also generate lively discussions in clinical ethics consultations called to address quotidian concerns such as the content of an individual patient’s discharge plan. A safe transition from hospital, and indeed a patient’s ultimate discharge destination (his own home, a long term care facility, or a homeless shelter), may depend almost entirely upon decisions about who ought to bear the costs of the human and financial resources that he requires.[[28]](#footnote-29) Furthermore, if the judgement of health care ethics consultants is vulnerable to distortion owing to pressures exerted by payors, then it is not obvious whether casual employment (in the form of time-limited contracts) or permanent full-time work will present the greater threat to ethical independence. The freelance consultant jeopardises future offers of employment, whereas the permanent employee risks demotion or dismissal. Ethicists typically have no trade unions or professional associations to which they can appeal should an organization decide that their services are no longer required, and in the clinical context there is no guarantee that the principle of academic freedom will be recognised.[[29]](#footnote-30) So, in either case, if Elliott’s reasoning is sound, it would seem that PHEs routinely will be obliged to exchange integrity for financial security.

*The art (or artifice) of compromise*

This is a serious charge but it is by no means a new one as a well-known Canadian example demonstrates. In the late 1990s Elliott was one of a sizeable group of mainly academically-affiliated bioethicists who drew attention to what they perceived to be the inaction of the national health care ethics community in the face of a research scandal at Toronto’s Hospital for Sick Children (SickKids). The case concerned an important multi-site clinical trial of deferiprone (L1), an investigational agent designed to protect sufferers of an inherited disease called thalassaemia major (also known as Mediterranean anaemia) from the effects of iron overload which is caused by the frequent blood transfusions they require. Dr Nancy Olivieri, a prominent paediatric haematologist, was the principal investigator for the SickKids trial site, and over time she became convinced that L1 was losing its efficacy in her young participants. More concerning, however, was additional evidence suggesting that L1 was responsible for serious liver toxicities as well as an acceleration of liver fibrosis. Olivieri reported these concerns to the study’s sponsor and to the hospital’s research ethics board. The latter directed her to revise her informed consent form without delay and to inform study subjects of this increased risk of trial participation. Apotex, the industry sponsor, retaliated swiftly. It terminated the trial at the SickKids site and threatened legal action should Olivieri, or any other member of the research team, disclose these local findings without the company’s prior approval. The rest of the details of the story are complex and contested, and include many players including Olivieri’s local co-investigator, senior administrators at the Hospital for Sick Children and the University of Toronto, the Ontario College of Physicians and Surgeons, the Canadian Association of University Teachers, the leadership of the University of Toronto’s Joint Centre for Bioethics and, significantly, Mary Rowell, who was one of SickKids’ two full-time health care ethicists, and the Bioethics Program’s representative on the hospital’s research ethics board.

The Hospital for Sick Children is a teaching hospital that is fully affiliated with the University of Toronto and Olivieri turned to these, her home institutions, for support when confronted with the sponsor’s threats. Apotex challenged her interpretation of the data and attempted to halt the disclosure of her findings to study participants, conference audiences, and eventually the readers of leading medical journals including the *New England Journal of Medicine*. University officials made unsuccessful efforts to mediate the dispute, and Olivieri resigned or was relieved of her position (interpretations vary) as the director of the Hemoglobinopathy Research Program at the Hospital for Sick Children.

A number of scientific and other colleagues came to Olivieri’s defence but, in a much-cited article entitled “The Olivieri Debacle: where were the heroes of bioethics?” Françoise Baylis of Dalhousie University focussed on what she called the “deafening silence from the Canadian bioethics community;” a community which has, as she wryly observed, a significant membership who regard themselves as duty-bound to “speak truth to power.” Baylis painted an unflattering picture of a field that appeared to have become as ineffectual as it was institutionalized. She argued that the Olivieri case marked a significant moment in the development of the field. It forced the uncomfortable realization that health care ethicists are either incapable of, or unwilling to do, the kind of work that should be at the very heart of the practice:

The time has come to critically examine the failure of Canadian bioethicists to play a role in this precedent setting research ethics controversy. It is important to question the meaning and value of bioethics work in clinical and academic settings, if bioethicists say and do nothing (or very little) in difficult and complicated cases that directly challenge fundamental ethical standards and principles.[[30]](#footnote-31)

It is certainly true that the ethicists most intimately acquainted with this clinical trial (both those at The Hospital for Sick Children and those at the University of Toronto’s Joint Centre for Bioethics) did not have a significant public presence at the height of the Olivieri controversy. It is important to distinguish, however, between the public and private activities of those directly involved in the case. There is also benefit to be derived from considering the differences between the roles and obligations of the academic and the applied members of the discipline. It may be true, as Baylis claims, that “the role of bioethics in helping to resolve the controversy was, at best, very limited,”[[31]](#footnote-32) but it is not obvious what sort of actions the “heroic” health care ethicist ought to have performed. A more useful exercise might have been to ask instead what sort of actions a competent or conscientious PHE might be expected to perform in circumstances like these. If those actions are inevitably inadequate or suspect, owing to factors such as insurmountable institutional pressures or unmanageable conflicts of interest, then Baylis may have been correct to call the “meaning and value” of the entire field into question. The call for heroism, on the other hand, is by definition a call for extraordinary conduct. What this might consist in, and whether it can in some circumstances be obligatory, is a matter better deferred until after we pause to examine some of the practice norms that are applicable to situations of this kind.

*Research ethics: rules, regulations, and review*

In Canada, as in most developed countries, the review of human subjects’ research is more closely regulated than nearly any other activity occurring in a health care context. If “all [or most] of medical ethics is but a footnote to informed consent,” to use Mark Kuczewski’s striking phrase, then the ethical review of research proposals must be its highest embodiment.[[32]](#footnote-33) It has been many decades since researchers have been free to follow their hunches and pursue promising lines of enquiry without external oversight. Indeed, clinical investigators operate in an environment where every blood draw, every chart review, and every interaction with study participants is scrutinized to ensure that consent is obtained and risks and benefits are appropriately described and distributed. The *Tri-Council Policy Statement* (now in its second edition) has guided Canadian researchers and research reviewers for almost twenty years, but even before its development and promulgation, the World Medical Association’s *Declaration of Helsinki,* and the *Belmont Report* (among other well-known guidance documents), supplied ethical standards by which research could be evaluated. The principles contained in these foundational documents reveal common themes although they are elaborated in a variety of ways. As the *Belmont Report* (released by the American National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in April of 1979) succinctly states: “Three basic principles, among those generally accepted in our cultural tradition, are particularly relevant to the ethics of research involving human subjects: the principles of respect for persons, beneficence and justice.”[[33]](#footnote-34)

Like all broad principles, these statements require interpretive effort in order to be action guiding, but research ethics is an area that is sufficiently well developed to admit of an extensive body of what might be regarded as precedent-setting cases. The Willowbrook State School study, for example, highlights the coerciveness of making access to care (in that case in the form of an institutional placement for children with disabilities) conditional on study enrolment; the Tuskegee Syphilis Study illustrates the injustice of keeping participants uninformed – and without an offer of treatment – when a safe and reliable cure has become readily available; and the Stanford Prison experiment, to offer yet another infamous example, supplies a caution to anyone who might believe that randomised clinical trials are always to be taken more seriously than socio-behavioural investigations. As the last of these examples illustrates, studies can be laden with risk even in what seem to be innocuous circumstances; that is, when they are conducted on able-bodied participants who appear to be free to resist obvious sources of coercion.

These case studies are well known to students of bioethics but, even if they were not, members of Canadian research review boards have a number of other resources on which they can, and generally do, rely. Both publically-funded REBs (such as those serving hospitals, public health agencies, and universities) and private, for-profit, research ethics boards currently have well-developed organisational structures which include standard operating procedures based on the content of regulatory documents such as the *Tri-Council Policy Statement*, the *Canadian General Standards Board Guide*, the so-called *Common Rule* (formally known as the United States’ *Code of Federal Regulations, Section 45, Part 46*), as well as other pertinent Health Canada and the United States’ Department of Health and Human Services polices. In addition, board co-ordinators and managers are employed to ensure the completeness and consistency of investigators’ submissions, internal and external monitors verify compliance with approved protocols, and, in recent years, most Canadian hospitals and universities have established institutional offices whose mandate is to uphold research integrity.[[34]](#footnote-35)

Despite the great range of research settings, and the variety of study types and topics that investigators explore, the process that leads from research submission to approval is remarkably invariant. Research coordinators screen submissions in an effort to ascertain the risks they present and to ensure the completeness of the files. (A board coordinator will determine, for example, whether important elements have been overlooked such as a clinical impact assessment from a manager or division head, a conflict of interest declaration, or an agreement to supply services such as those provided by a medical laboratory or imaging department.) Specialised content reviewers offer more detailed evaluations of proposals in light of their specific expertise. Studies which are deemed greater than minimal risk (defined by the *Tri-Council Policy* *Statement* as “research in which the probability and magnitude of possible harms implied by participation in the research is no greater than those encountered by participants in those aspects of their everyday life that relate to the research”[[35]](#footnote-36)) receive full-board reviews in face-to-face meetings which must conform to a number of procedural requirements pertaining to board composition, quorum, and the criteria for approving or rejecting proposals. Conditions for the renewal, amendment, and termination of board-approved studies are also set out in standard operating procedures and federal regulations. Some slight variations exist between institutions, but owing to the development of formal training programmes for board administrators and members, the availability of venues for electronic exchange around common concerns (such as the Canadian Association of Research Ethics Boards and the American Institutional Review Board Forum), as well as opportunities for in-person networking at national and regional conferences, research review processes across Canada and the United States operate in much the same way.

This lack of variability is relevant to understanding the sorts of preparations and deliberations that occur before approval is granted to any investigator proposing to initiate a clinical trial. Although Dr Olivieri’s controversial thalessemia study came to the public’s attention in the summer of 1998, the very year that the first iteration of the *Tri-Council Policy Statement* was released, it is not the case that research review was conducted in a casual or idiosyncratic manner at that time. Because the trial involved the use of an investigational agent in a paediatric population it would have received a full-board review by a variety of SickKids’ experts and lay members. The REB’s scientific reviewers would have weighed the evidence pertaining to the agent’s efficacy and safety, a methodologist would have scrutinised the study’s design for validity and generalizability, and the board’s lawyers and community members would have had the responsibility of considering the comprehensibility and reasonableness of the informed consent document. In addition, the board member “knowledgeable in ethics” (as the *TCPS* now describes the role) would have been accountable for attending to any ethically salient aspects of the proposal. In an effort to fulfil that obligation, a board’s designated ethicist typically leads or engages in discussions concerning the study’s likely impact on participants, non-participants, family members or caregivers (as appropriate), and on institutional resources. Specifically, she would be expected to raise questions related to the coerciveness of the recruitment strategy; the merits or drawbacks associated with including or excluding specific populations; any special vulnerabilities of participants; as well as the nature and likelihood of potential harms (understood to include physical, emotional, or social/reputational harms) and benefits associated with participation, or alternatives to study participation. A research ethics board’s designated ethicist also typically identifies privacy risks associated with the use of study specimens or data (including their collection, transfer, retention and destruction) although this responsibility, in more recent years, has often been shared with institutional privacy officers possessing a specialised knowledge of relevant legislation and information technologies. It is also important to note that an approval granted by a research ethics board is never a sufficient basis for a study to proceed. Initiation must await a more comprehensive institutional authorization which will depend upon other aspects of the project including the following: evidence pertaining to the experience, training, and certifications of the investigator(s) and the rest of the research team; resource implications that could affect the clinical care of participants or patients; and the details of any contractual agreements struck between the institution, the principal investigator, and the study sponsor. Large teaching hospitals like SickKids now have entire departments dedicated to scrutinizing research-related grants and contracts to ensure that the roles and responsibilities of each of the contracting parties are clear. They negotiate with trial sponsors over matters such as patent rights and exemptions, the amount of liability insurance to be carried by contracting parties, the procedures to be performed to ensure that the privacy and confidentiality of research participants is respected, and any restrictions on the publication or other dissemination of research findings.[[36]](#footnote-37) One of the legacies of the so-called Olivieri affair is that most Canadian health care institutions now have a keener appreciation of the risks associated with weak or ambiguous contract arrangements. Although investigators frequently complain about the time it takes to finalise legal agreements between their home institutions and study sponsors, her story is a compelling reminder of the importance of attending closely to this step during the clinical trial review process.

All of this detail is not offered to downplay the responsibilities of the ethicist most closely associated with this well-known trial, but it does help us to identify which aspects of the project might reasonably be thought to have fallen within her purview and which might not. Presumably, at the time of its initial approval, the principal investigator, her funders, and her research ethics board, all had sound reasons for believing that the study presented an opportunity to improve the wellbeing of the young research participants who would test L1’s efficacy and tolerability. Moreover, such studies do not (and, even then, did not) escape scrutiny after they receive approval from an institutional REB. High risk and multi-site drug trials normally have independent Data Safety Monitoring Boards (DSMBs) in place to watch for emerging trends that might reveal troubling patterns of adverse events. National healthcare regulators (such as Health Canada or the United States’ Food and Drug Administration), and REBs require that serious adverse events be reported to them promptly, and annual renewals of on-going projects are contingent upon receipt of information such as the rate at which participants are recruited, and the number who have been hospitalised, harmed, or withdrawn from participation. Any proposed amendments to study procedures must also be sanctioned by the REB of record. If a study has received initial approval at a full-board meeting, then its eligibility for continuing approval (which is typically re-assessed on an annual basis) must be reviewed at a full-board meeting as well.

These mechanisms for ensuring the safety of human participants are far from fail-safe but they do provide predictable and systematic opportunities for identifying and managing emerging risks. An unexpected exacerbation of disease is always grounds for notifying a study’s research ethics board; therefore Dr Olivieri was correct to report her concerns, and to seek the advice of her board’s chairperson, when she came to believe that the balance of burdens and benefits had shifted for participants enrolled in the deferiprone trial.

Although some commentators, both at the time of the controversy and after, have portrayed the conflict between Olivieri and Apotex merely as a scientific disagreement over the interpretation of study-generated data, it is widely accepted that their dispute implicated two principles that are considered fundamental to the ethical conduct of human subjects’ research. As a clinician-researcher, Olivieri had an obligation to protect participants by informing them of any newly identified risks associated with their continued enrolment. This duty entailed providing them with an opportunity to withdraw from further participation in the trial at any time. In addition, the sponsor’s insistence that all of Olivieri’s communications be vetted through its representatives was a flagrant violation of its duty to respect her right to exercise academic freedom. Current practice allows sponsors to postpone publication for reasonable time periods (normally a matter of a few months after data collection has been completed) in order to provide them with opportunities to seek additional reviews of the data, or to make comparisons between sites in multi-centred trials; however, a complete prohibition on information-sharing, or a significant delay in dissemination, would always be judged an unacceptable violation of ethical norms. One of the contracts between Apotex and Olivieri stipulated a three-year wait before her findings could be shared.[[37]](#footnote-38) A provision like this not only has the potential to jeopardize the safety of current and future participants, but also threatens to undermine the public’s confidence in the research enterprise itself. As Manitoba ethicist Art Schaefer posited “it was, from the outset, inconceivable that any court in Canada would have upheld such a contract.” In addition, he offered a particularly bald assessment of the case; it was a contest between “corporate values vs. civic values, it’s about human well-being vs. profit, it’s about institutional corruption."[[38]](#footnote-39)

The spectre of capital was certainly never far from discussions over the rift between Olivieri and Apotex. The company, which now boasts annual revenues of approximately two billion dollars was, and remains, Canada’s largest manufacturer of generic drugs.[[39]](#footnote-40) Both the chief executive officer and the president of Apotex were known to have close ties to the hospital and the University of Toronto, and the company was in a position to offer generous incentives to those willing to cultivate relationships with them. In the late 1990s, the SickKids Hospital Foundation was negotiating with investors over opportunities to attach their names to professorships, endowed chairs, and even its entire research institute, and in 1998 it verified that Apotex was inviting proposals from the city’s academically-affiliated hospitals to compete for a ten million dollar donation. The university itself was purported to be discussing a fifty-five million dollar endowment with the company.[[40]](#footnote-41)

It was against this background that the chair of the SickKids REB issued an unequivocal directive in response to Olivieri’s disclosure. The Board would not be drawn into disputes over the interpretation of the trial data. As the local principal investigator, and physician most responsible for the wellbeing of participants, Olivieri was to revise the study’s informed consent documents and to inform participants of her concerns without delay. The ethical responsibility to disclose the possible risks associated with this study was not unclear or contested; at least as far as the hospital’s body responsible for research oversight was concerned.[[41]](#footnote-42)

Informing study subjects of a fresh assessment of risk is a different matter, however, from a decision to terminate a study entirely. In many clinical trials, including this one, an investigational agent that isn’t well tolerated by some participants, or is indeed toxic to them, can be a boon to others. A move to halt a trial prematurely - which was Apotex’s response to the updated informed consent process - is ethically problematic not only because it abruptly halts access to study drugs (a distressing development for those who may be benefitting from them), but also because it undermines the contributions of all who have agreed to assume the risks of participation. A study that ends before clear inferences about safety and efficacy can be drawn is one that generates risks without commensurate rewards. Early termination can be warranted but, as Miriam Shuchman observes in her account of the Olivieri affair, worries over a sponsor’s commercial interests never constitute an ethically defensible justification for doing so: “Ethicists advise that the way to stop a trial is to follow ‘stopping rules’ established ahead of time by the sponsor and the scientists.”[[42]](#footnote-43) These stopping rules help outside experts, such as independent data safety monitoring boards that include statisticians and clinical investigators, to interpret data that suggest that a trial has become too risky to continue. Their determinations can be prompted by evidence suggesting that a drug is (or threatens to become) toxic or ineffective, or is clearly superior or inferior to alternative treatment modalities, but ultimately they will be based on a judgement that the benefits associated with gathering additional data are out-weighed by the overall burdens endured by current study participants.[[43]](#footnote-44)

*Institutional interests and the obligations of ethicists*

The literature is replete with accounts of the tremendous financial stakes associated with the development of novel therapeutics, especially so-called blockbuster drugs, and the distorting influence of money upon relationships (between sponsors, researchers, research institutes, study participants, and all of the various combinations thereof) so it is perhaps not surprising that this case aroused suspicions about the motives of the principal actors.[[44]](#footnote-45) Apotex had a clear financial interest in seeing this drug come to market. Its investment was substantial and the medication that was the chief competitor to L1 brought its manufacturer a return of $400 million (US) per year.[[45]](#footnote-46) Similarly, the research arm of SickKids Hospital, like that of all academic medical centres, was dependant on the good will of drug manufacturers like Apotex not only for the support of individual clinical trials but ultimately for funds to sustain the employment of scientists, managers, lab assistants, coordinators and the large research infrastructure that facilitates the approval, administration, and supervision of such studies. In addition, drug company executives and shareholders, like other successful businesspeople, are avidly pursued as benefactors who can provide hefty contributions to hospital foundations. Although these foundations are corporate entities that are meant to operate at arm’s length from the medical centres or hospitals with which they are affiliated, the success of their fundraising efforts can have important implications for a hospital’s financial plans. They cannot contribute to operating budgets (they are not permitted by law to provide salary support for clinicians or for costs directly related to the provision of patient care) but they do solicit donations that allow institutions like SickKids to undertake ambitious projects that their more limited government funding cannot cover.[[46]](#footnote-47)

Of course, financial conflict of interest (F-COI) is far from the only trust-related issue that is of concern in the research environment, and research-intensive hospitals are obliged to alert their investigators and research ethics board members to the potential for these challenges to arise in a variety of guises. Columbia University has a comprehensive account of conflict of interest (one which some might regard as too inclusive)[[47]](#footnote-48) embedded in a web tutorial devoted to the responsible conduct of research. Its content is typical of those proffered by institutional research review offices.

A conflict of interest involves the abuse -- actual, apparent, or potential -- of the trust that people have in professionals. The simplest working definition states: A conflict of interest is a situation in which financial or other personal considerations have the potential to compromise or bias professional judgment and objectivity. An apparent conflict of interest is one in which a reasonable person would think that the professional’s judgment is likely to be compromised. A potential conflict of interest involves a situation that may develop into an actual conflict of interest. It is important to note that a conflict of interest exists whether or not decisions are affected by a personal interest; a conflict of interest implies only the potential for bias, not likelihood.[[48]](#footnote-49)

Although the language of conflict of interest may not have been explicitly invoked in association with the name of Mary Rowell, the context seems to demand that the question of her interests be addressed directly. Rowell was the practicing healthcare ethicist most closely identified with the case, and although Baylis subsequently clarified that her charge of ethical cowardice was not solely, or even primarily, directed at the SickKids ethicist, it might prove instructive to explore whether her action, or inaction, was blameworthy in some way. The public record is not very rich in this regard (despite two official hearings and a four hundred-plus page book on the subject), but in a brief letter contained in a special issue of the *Journal of Medical Ethics* Rowell described some of her responses to the so-called Olivieri debacle:

I requested that the Hospital initiate a truly independent review, a suggestion that was not accepted. On several occasions I spoke with news reporters who sought my opinion. In those interviews I consistently and without reservation, supported Dr Olivieri's position and I was critical of the hospital for its lack of support for Olivieri and her colleagues, and for what I saw as the hospital's misreading of the issues at hand in the case. I have always publicly supported the view that "given her interpretation of the data at the time Olivieri had no choice but to do what she did" (for the wellbeing and safety of children in research) (personal transcript of Dr M Shuchman in an interview on "Quirks and Quarks", CBC). I contributed in this vein to both the Naimark report and the report completed by the Canadian Association of University Teachers; the latter being a review that I believe to provide a public report of integrity. In numerous cases I was not quoted despite my willingness to be so; a point of concern and disappointment to me.

In addition to the wider public support offered I spoke for Olivieri, and in a manner critical of the handling of the case by the hospital, at two meetings of the Canadian Bioethics Society, in numerous public presentations, and at hospital and university rounds and lectures. Perhaps Baylis is correct that I should have done more. What more I might have done, at that time, is unclear to me. Importantly too, my affection and respect for the Hospital for Sick Children remains strong. Every institution has its failings and its internal problems. My view is that in the Olivieri case and its sequelae the hospital publicly demonstrated such failings. What can be hoped for is that situations such as this teach us well how to proceed in the future.[[49]](#footnote-50)

One might conclude that Rowell was unable to mount an effective defense against the influence of this wealthy sponsor, but it is by no means obvious that her financial reliance on her employer rendered her unwilling, or too conflicted, or too ethically compromised, to do so. Her letter catalogues the internal efforts and public declarations that she made in support of Olivieri and her research team, even in the face of some compelling reasons to remain more circumspect. As a hospital employee and REB member, she might plausibly have sought refuge in an obligation to keep the deliberations of the Board, and any advice that she may have offered to her leadership team, confidential. There may be no uncontroversial way to describe what a particular ethics consultant’s accountabilities might have entailed in such a case, especially when the public record permits only partial insights into the opportunities that her role might have afforded, but advising those who were responsible for decision-making, and taking steps to educate the institution and, ultimately the external community, on the ethical dimensions of the case, are certainly actions that are consistent with the core responsibilities articulated in the American Society of Bioethics and Humanities’ *Code of Ethics and Professional Responsibilities*.[[50]](#footnote-51) The seven code elements which, at least in that document, enumerate the practicing ethicist’s responsibilities are: Be competent; Preserve integrity; Manage conflicts of interest and obligation; Respect privacy and maintain confidentiality; Contribute to the Field; Communicate responsibly; and Promote just healthcare within HCEC. The authors of the code have acknowledged that these duties are expressed in a manner that is particularly relevant for clinical ethics consultants but they also maintain that clinical consultation is not their exclusive domain. I endorse this view, and would further assert that hybrid cases (of the sort mentioned earlier in the context of Bean’s taxonomy) are far more prevalent than one might recognize based on common case descriptions. Furthermore, it is almost certain that Rowell considered clinical and organizational issues as she navigated the ethically turbulent waters of the Olivieri affair.

Not all Code elements were directly applicable to this case (such as those that encourage making original contributions to scholarship or providing mentorship to junior colleagues) and it may reasonably argued that invoking it is anachronistic, as the document was not yet written in 1998, but the Code (like most professional codes of ethics) was never meant to introduce new duties to the field. Instead, it was written to clearly articulate, and to publically affirm, the duties that most practicing North American ethicists have long believed they already possess. It should be noted, furthermore, that Rowell’s efforts to influence her institution’s decision-makers went well beyond the ordinary activities of a research ethics board member (even one designated as the member knowledgeable in ethics). She didn’t merely assess the ethical merits of a freestanding research protocol, participate in deliberations within the confines of a REB meeting, or limit her dissent to a vote to revoke an on-going trial’s approval. It appears that her efforts to persuade her employer, and to alert the wider community, were persistent and waged on multiple fronts. Because a practicing healthcare ethicist has legal as well as ethical obligations to keep confidential much of the information to which she is privy, it may be inferred that Rowell believed that she had to balance those obligations against other more compelling duties that she had to fulfil. In her efforts to protect the welfare of study participants, and the reputation of the principal investigator, Rowell appears to have resolved any conflicts of interest, or conflicts of obligation (for the moment I will set aside the question of which descriptor is more apt), in a manner that gave priority to the safety and informational needs of participants. In doing so, and by speaking publically and responsibly, she made a clear effort to preserve her personal and professional integrity. Whether her actions are better described as heroic, or simply as competent, in light of her professional role as a hospital ethicist, is an interesting question, but it is one whose answer may not settle the concern that motivated this digression into the Olivieri affair in the first place. The case ought to attract our attention because it illustrates the pressures that large material interests can exert even in a publically funded healthcare system, and because it exposes something significant about the ambivalence, or lack of clarity, that continues to plague our community’s conceptions of the practicing healthcare ethicist’s role.

*Conflict of Interest (COI) for ethics consultants: a primer*

Greater insights might be gleaned if we retrace our steps just a little and make a more systematic effort unpack the concept of conflict of interest. The definition used by Columbia University to educate its researchers contains elements that will be familiar to any who have surveyed the considerable literature on the ethics of the professions, but its effort to encompass latent, potential, actual, and apparent COI may be too broad and distracting for present purposes. Instead it may be more illuminating to look to the literature on the ethics of the professions that is associated with Michael Davis and his critics. They have devoted great attention to efforts to define COI with precision. The concept admits of a number of variations, and debate continues to refine what remains a contested concept, but commentators in this field tend to speak of a particular type of relationship; that is, one in which one party is reliant upon another to act or to exercise judgement on her behalf. A conflict of interest, according to Davis, author of the much-cited text *Conflict of Interest in the Professions*, “is a situation in which some person P (whether an individual or corporate body) stands in a certain relation to one or more decisions. On the standard view, P has a conflict of interest if, and only if, 1) P is in a relationship with another requiring P to exercise judgment in the other's behalf, and 2) P has a (special) interest tending to interfere with the proper exercise of judgment in that relationship.” Davis further notes that “[t]he kind of exercise of judgment required for a conflict of interest must involve P's having considerable latitude and discretion in acting on behalf of the other party.” Finally, he maintains, “[t]he kind of "interest" that satisfies condition 2) is any influence, loyalty, concern, emotion, or other feature of a situation tending to make P's judgment (in that situation) less reliable than it would normally be, short of P becoming incompetent.”[[51]](#footnote-52)

If this “standard view” of COI is applied to the Olivieri affair we can see that Rowell might convincingly be described as someone embroiled in just that sort of situation. As the institution’s ethicist her duty was to exercise judgement with respect to the responsible conduct of research, and more specifically to assess the merits of disclosing the unfavourable side effects associated with the on-going use of an experimental agent. There were no uncontroversial thresholds for reporting adverse events to which she could appeal, or pre-determined stopping rules that rendered discretion moot. Rowell’s responsibility was to exercise her judgement in an unanticipated circumstance on behalf of those to whom she owed that duty. It seems uncontroversial to say that the parties to whom she owed that duty were the research participants (that is, the adolescent thalassemia sufferers, who were reliant upon her and other actors in the research enterprise), as well as the primary investigator, institutional officials, and even future patients. The duty itself consisted in a responsibility to ensure that the study-related risks to which participants were exposed were not undue or undeclared. It also should be noted that the fact that the responsibility was shared did not dilute or diminish the ethicist’s accountability. Responsibility understood in this sense is not the zero sum game that might be implied if one were seeking to assess damages in a tortious legal action. Of greater relevance is the conventional usage that makes reference to the professional moral duties that one party has with respect to another. Indeed, it is worth noting that other parties almost certainly had additional obligations that were in tension with the responsibility to act on the participants’ behalf (for example, the principal investigator was responsible for preserving the integrity of the scientific process, whereas the hospital’s legal counsel was responsible for steering the institution clear of any breach of contract). Each of these parties faced the difficult task of clarifying and prioritising each of their own role-related responsibilities.[[52]](#footnote-53)

Without more detailed information on the nature and intensity of the pressures that Rowell faced it is impossible to fully catalogue all of the “(special) interest[s]” which had the potential to inhibit “the proper exercise of [her] judgment in that relationship.” She may have feared material losses if she felt that a recommendation that disadvantaged her employer might result in her dismissal or the elimination of any performance-related salary increases which she otherwise might have expected, and it’s evident from her response to Baylis’s charges that she felt the emotional tug of loyalty to The Hospital for Sick Children. If Davis’s definition of conflict of interest is a reasonable one, it is appropriate to acknowledge that ethicists in the employ of healthcare institutions are always, or often, embroiled in conflict-ridden situations of this sort. The stakes may not always seem quite as high because few cases attract external attention and, more importantly, because the likelihood and degree of harm associated with impaired judgement will vary greatly from one case to another. However, if we understand conflict of interest, pace Davis, as a *tendency* for special interests to threaten the independence of judgement then we must concede the point that practicing healthcare ethicists are as likely to be subject to these temptations as others who exercise significant discretion as part of their work. The conditions of their employment, an embeddedness that makes relationships with colleagues and superiors as indispensable as it is complex, as well as their financial dependency on their employers, means that an awareness of COI is a precondition for competent judgement. The entanglements of practicing healthcare ethicists will make some conflict mitigation strategies difficult or unavailable, but it is not obvious that the role is therefore always hopelessly compromised or that it should be abandoned altogether. The alternatives, I’d wager, would be equally bad or far worse.[[53]](#footnote-54)

Chapter 2: Conflicted consultants: Surveying the Canadian context

Given the high profile of the Olivieri affair, one may be surprised to learn that the mainstream bioethics literature has not been greatly occupied with the topic of conflict of interest - except as it is applied to non-ethicists. This is as true in United States as it is in Canada, although that country has faced its own controversial cases. As Giles Scofield, a persistent critic of the professionalization movement within bioethics, has stated: “[t]urn to the field of medical ethics consultation, and what one discovers is not that discussions about boundary issues are absent, but that medical ethicists publicly discuss the problems that boundary issues pose to *other* professionals, and try as best they can to bury those issues insofar as they concern them, what they do, or how they do it” (emphasis in original).[[54]](#footnote-55) One need not embrace Scofield’s scepticism to conclude that this is an area that merits further exploration. A few years ago, however, practicing healthcare ethicists Andrea Frolic and Paula Chidwick made a useful contribution to the field by soliciting stories from their Canadian colleagues about their direct experiences with COI. Although their sample size was modest - despite assurances of confidentiality, only thirteen ethicists ultimately agreed to have their stories shared - their efforts yielded two papers containing detailed narratives that illustrated the variety of respondents’ experiences with direct and indirect pressures that they believed had threatened the independence of their judgements.[[55]](#footnote-56) In an effort to leave the meaning of conflict of interest open to interpretation, Frolic and Chidwick declined to provide their respondents with a definition of the concept. As a result, the ethicists relayed a variety of incidents that reflected their disparate understandings and experiences. COI was identified in all of the diverse domains within which they practiced, including clinical consultation, organizational ethics consultation, and research ethics consultation and review. To preserve the anonymity of their participants the responses were rolled up into five composite cases that represented recurrent themes which the authors described as: “research funding conflicting with research ethics; disclosing ethical issues when ‘due process’ is absent; conflicts between organizational values and the personal values of the clinical bioethicist; promoting justice within organizations; and balancing competing loyalties and obligations within an organization.”[[56]](#footnote-57)

Two findings stand out when one reviews their findings. First, the way that conflict of interest was understood by participating ethicists sometimes departed significantly from mainstream conceptions of the concept, including the one offered by Davis above. Second, the distress the ethicists experienced was often great enough to prompt lasting changes in their attitudes towards their work. Indeed, over half of the respondents indicated that they had changed employers or left the field entirely owing to their experiences of COI. Both of these discoveries may be unsurprising given the variety and complexity of cases routinely faced by healthcare ethicists and the relatively isolated nature of the work. While an individual PHE may interact with many colleagues across multiple programs and at all levels of an organisation, the fact remains that in any healthcare setting she is nearly always the only person, or is one of a very few people, doing the sort of work that she does.[[57]](#footnote-58) There is no critical mass of practicing healthcare ethicists (as there is, for example, of registered nurses, social workers, or physicians) that a practitioner can depend upon for validation and advice; and no professional college exists to hear disputes or to establish practice standards. A significant occupational hazard, therefore, appears to be a natural inclination toward what some REB critics have called ‘mission creep.’ The ethicist, and others, may come to view her role as unlimited in scope; whenever a concern arises that can be described as having a values-based dimension, the ethicist - spurred on by her own sense of rightness or by the distress of others - may be drawn into the melee. This may account for the fact that despite long-standing efforts to disavow monikers like the ‘ethics police’ or the ‘conscience of the corporation’ these usages persist and boundary dilemmas flourish.

Frolic and Chidwick readily allow that many of the experiences that their respondents relayed fell outside of any of the conventional definitions of conflict of interest. Moreover, the cases that did appear to fit within the standard usage were deemed unrelated to the financial incentives that critics have identified as a significant risk to the independent exercise of judgement. By their own admission, the ethicists’ powers of discernment were jeopardised primarily by tendencies that fall into what some have described as subjective categories. The quotation below encapsulates the respondents’ struggles succinctly:

None of the situations participants described in our pilot study fit typical examples of conflicts of interest involving pecuniary interests or nepotism; however… participants’ experiences did involve a personal interest (such as job security, reputation, relationships, personal values or academic freedom)[[58]](#footnote-59) that (appeared to) conflict with a perceived professional duty (as identified by the bioethicist, her colleague, employer or peer); most cases also involved ‘‘in-role’’ conflicts between different duties or different clients the bioethicist serves.[[59]](#footnote-60)

The distinction between “in-role” and “out of role” conflicts of interest, borrowed from political scientist and management professor Andrew Stark, is a key component of Frolic and Chidwick’s efforts to categorise and unpack the sorts of challenges faced by their respondents. Briefly stated, an out-of-role COI is said to arise whenever a professional gives priority to interests originating outside of her primary or work-related responsibilities. Citing Stark, Frolic and Chidwick note that the usage encompasses a multitude of possibilities including: ‘‘influences, loyalties, concerns, emotions, predispositions, prejudgments, animuses, biases, affiliations, experiences, relationships, attachments, moral constraints, [and] ideological agendas.’’[[60]](#footnote-61) In-role conflicts of interest, on the other hand, are those fostered by the way that an actor’s professional responsibilities are structured. They arise because the professional has “more than one role with respect to any given principal” (a circumstance which incidentally may be familiar to healthcare workers from references to Stark Law[[61]](#footnote-62) governing physician self-referral), or because “the professional occupies the same role with respect to many principals.’’[[62]](#footnote-63)

It is important to note that this in-role and outside-of-role conceptualisation of COI, is not uncontroversial. Although in-role or structural challenges to the effective performance of the role are important ones, it is not self-evident that it is always helpful to categorise them as a species of conflict of interest at all. Furthermore, what Stark describes as outside-of-role conflicts of interest might be described instead as a list of interests – some of which threaten independent judgement (standard conflicts of interest) and some of which do not (which we might call simple interests). His two types of inside-of-role conflicts of interest, moreover, appear to point to different problem; that is, is a pervasive and troubling uncertainty about the nature and boundaries of the role itself. Each of these issues is worthy of considerable and separate attention. Although Frolic and Chidwick’s investigation endeavoured to uncover something important about practicing ethicists’ experiences of COI in Canada, their definitional ecumenicalism appears to have yielded different yet equally consequential discoveries. A direct engagement with their incidental findings will need to be deferred, however, to permit a brief digression into some problems associated with the study participants’ naturalistic conceptions of conflict of interest.[[63]](#footnote-64)

*Outside interference: Laundry lists and the efficacy of efforts to come clean*

One of the contributions that the social scientific literature, and especially the feminist branch of that literature, has made to our understanding of the scientific enterprise is the insight that, despite many scientists’ claims to the contrary, there is no value-neutral way of understanding or describing the world. As Lisa Bero and Quinn Grundy have observed in a recent article titled “Why having a (nonfinancial) interest is not a conflict of interest,” some uneasiness about ‘nonfinancial interests’ can be attributed to a “growing recognition that the social context in which research is conducted will impact the research questions that are asked, the studies that are funded, the research outcomes, their dissemination, and their interpretation.” Against the naïve belief that scientists approach all aspects of their inquiries with a neutral detachment they endorse the more complex view that “social values, interpretation, and theoretical commitments are essential parts of research at every phase.”[[64]](#footnote-65)

Journal editors and funding agencies have also embraced this insight over the past few years and the effort to control for the influence of so-called nonfinancial conflicts of interest has led many of them to mandate disclosure of an increasingly long inventory, what some observers have derisively dubbed a ‘laundry list,’ of the many sorts of interests that researchers may possess. Bero and Grundy note that a study published in 2016 by Khaled Shawwa *et al*, revealed “that 57% of the National Library of Medicine’s core clinical journals required disclosure of at least one form of non-financial conflict of interest.”[[65]](#footnote-66) This is a significant development because the National Library of Medicine, which is maintained by the (U.S.) National Institute of Health, is the world’s largest repository of biomedical information. Another study, published by Xavier Bosch *et al*, in *The European Journal of Investigation* reported that their review of 399 high impact biomedical journals revealed that 70.2% of the journals’ editors required nonfinancial conflict of interest disclosures. These authors noted that “[n]onfinancial COI, sometimes called ‘private interests’, may be of a political, academic, personal, ideological or even religious nature, and are therefore notoriously difficult to define.”[[66]](#footnote-67) Helpfully, the Shawwa study enumerated the kinds of wide-ranging non-financial interests that editors took to be worth declaring. Bero and Grundy have captured them in a convenient table that has been reproduced below:

**Box 1. Examples of Interests in Biomedical Research**

Personal, religious, or political beliefs

Personal experiences

Advocacy or policy positions of the researcher or organization with which they are affiliated

Intellectual, theoretical, or school of thought commitments

Type of training; professional or academic education

Profession or discipline

Academic competition or rivalry

Career advancement or promotion

Glory seeking or desire for fame

Dominant researcher in an area of research

Personal experience with subject of research

Personal relationship with someone who has the disease or condition under study

Role as investigator on study included in a systematic review

Published opinion essay or commentary on topic of research

Institutional affiliation or academic associations[[67]](#footnote-68)

Although the metaphor of a laundry list generally is invoked to reference any exhaustive list of items like the one above, what is often forgotten is its now bygone meaning – a meaning that is surprisingly germane to the present discussion. A few years ago, in a charming piece for the *Denver Post*, popular columnist Ed Quillen recalled his youthful employment in his grandfather’s commercial laundry facility. As a teenager lacking any experience or enthusiasm for the work he was expected to do, he was assigned the painstaking task of sorting and recording, on a pre-printed form of archaic origin, each article of clothing to insure against loss and to identify processes for proper care. The interesting aspect of the exercise, now largely forgotten in an era of home washing machines and colourfast dyes, was determining which item fell under each heading. A laundry list, it seems, was not the unending and indiscriminate behemoth that the term connotes now. It was a comprehensive and useful tool for classification. With its assistance even a fourteen-year old boy became adept at distinguishing a chemise from a counterpane; a laundry list was an aid to the effective exercise of discretion rather than an invitation to despair.[[68]](#footnote-69)

Bero and Grundy appear to have a similar end in mind. They aim to sort *conflicts of interest*, which have a tendency to introduce certain troubling kinds of bias into expert judgements, from *interests* (what we might call for the sake of clarity, simple interests) that are inevitable and inseparable from the identity, role, and responsibility of the person who possesses them. Despite the provocative title of their paper, they do not maintain that all conflicts of interest stem from pecuniary interests; indeed, they explicitly acknowledge the distorting effects that interpersonal relationships can have on judgement (friends, relations, colleagues, and competitors are explicitly mentioned and power imbalances are especially noted). Their original contribution to the discussion, however, is the introduction of three “rules of thumb” which they believe can sort the interests we ought to be most worried about from other, less troubling, types of interests. Their rules, stated in the barest form, follow.

First, it is theoretically possible, though not always necessary, to eliminate a conflict of interest….Second, the direction of the bias produced by a conflict of interest is consistent within a set of circumstances….Third, conflicts of interest can be widespread, and their scope of influence may extend far beyond an individual.[[69]](#footnote-70)

A tool to identify the interests that present the greatest threat to the responsible exercise of judgement would, if dependable, be a welcome addition to the current discourse pertaining to conflicts of interest. These rules of thumb (hereafter, the Bero-Grundy rules) may not provide the detailed direction of an old-fashioned laundry list but they do prompt the user to reflect upon and, indeed, sort out the applicability and potential efficacy of various relationship management strategies (including, but not limited to, avoidance and disclosure), as well as the likelihood and potential magnitude, of any harm or harms associated with reliance upon judgement that is impaired. It is important to recognise that the Bero-Grundy rules will apply only to what Stark described as external or out-of-role threats to judgement. Although Frolic and Chidwick’s respondents appeared to be less concerned about these than with structural or internal conflicts of interest it is appropriate that each of these challenges is addressed in turn. I will begin with out-of-role conflicts because I believe that these are the conflicts that trouble the field’s critics most of all. Analysis of in-role or structural conflicts of interest will be deferred momentarily, but we will revisit them via a treatment of the larger problem of role confusion and its effect on some of the ethical dilemmas arising in the provision of health care ethics consultation.

*The case of the committed graduate student: interests worth worrying about?*

This sketch of the Bero-Grundy argument has been fairly abstract so far and may benefit from an example that fills in some of its contours. Not all cases need be located in the area of research (any activity requiring judgement in the service of another will do) but it may be illuminating to sort out some of that department’s linens before moving on to other applicable areas. The following hypothetical example may be of help:

Ambi, an ethicist at a large inner-city teaching hospital, has developed an interest in the ethics of population health as well as a passion for devising practical strategies for addressing the complex needs of patients suffering from opioid dependency. Her prior experience includes the loss of a close friend to opioid overdose, and she worked briefly as a public health nurse with a needle exchange program before pursing her doctoral studies and enrolling in a bioethics fellowship program. She recently has secured a grant from the Canadian Institute of Health Research to support research on the efficacy and ethical dimensions of an approach that endeavours to foster trust between people who use opioids and her local oncology program. She hypothesizes that harm-reduction strategies, which promise people with substance use disorders non-judgemental access to cancer care, will result in increased treatment adherence and better scores on outcome measures related to quality of life (including reports of patient satisfaction), as well as overall morbidity and mortality. [[70]](#footnote-71)

If we accept the claim that all interests should be categorised as conflicts of interest, any of Ambi’s study-related findings will need to be accompanied by disclosures describing her personal history, disciplinary training, theoretical orientation, and associated political commitments. But, one must wonder, what is one to do with this additional information? Ought reviewers to scrutinise her writings and presentations for biases that may have escaped her notice, and, if so, how ought this to be done? Should her work be viewed with greater suspicion than that of Jeremy, a fellow student exploring the same topic who lacks ‘lived experience’ of this kind? Should she be nudged into an area of inquiry for which she has less enthusiasm to ensure that she adopts an attitude of scientific detachment? Finally, compare any concerns that one might have about bias in Ambi’s case to those that might arise if one learned that Jeremy, the ‘disinterested’ student, is to have his studies supported by a generous scholarship from ‘Parent Power,’ a charitable trust with an international reach whose stated mission is to ‘counteract influences that make illicit drug use socially acceptable and attractive to the young.’ Let us imagine that our fictional foundation’s annual report contains stories of adversity and triumph, which emphasize character-development and celebrate abstinence-based approaches to addiction. Let us further suppose that Jeremy’s funding comes in the form of an ‘unrestricted educational grant’ that is renewable on an annual basis. He needs only to file an annual report demonstrating that he is making reasonable progress on his studies and affirming that his research falls within the mandate of the granting agency.

If we apply the Bero-Grundy rules to the example above, we can sort our cases quite readily. First, it is helpful to note that however hard she might try, Ambi is incapable of eradicating her supposed conflicts of interest because they are inseparable from her identity. She cannot shed her past, her values, her passions, or her education simply by willing them away; the suggestion is as incoherent as it is impossible. Second, the “direction of the bias” that may be introduced by Ambi’s interests is not necessarily predictable. While her desire to understand and to come to terms with her personal experiences may have led her in the direction of empirical bioethics, and the theoretical and methodological approaches of its feminist theorists may have helped her to organise her thinking, none of these influences is predictive of particular findings in the way that pharmaceutical sponsorship is known to shape outcomes in clinical trials.[[71]](#footnote-72) If her primary hypotheses are not confirmed it is not obvious that her work will be seen as uninteresting or without value. Indeed, she may be spurred on to seek alternate explanations or to look for intervening variables that have been overlooked in her preliminary investigations. Third, even in the unlikely event that Ambi’s dissertation sparks a swell of interest in her findings, the contributions of a single scholar are unlikely, without significant external support, to have an impact that extends beyond her local circumstances. It is the rare academic who can change the direction of an entire field, and even a significant impression in an established discipline pales in comparison to the effect that industry influence can exert on political and economic systems.[[72]](#footnote-73)

On the other hand, the application of the Bero-Grundy test to Jeremy’s case yields a far different result. Although it may be difficult for him to access alternate funding that will meet his needs, especially when competition for support from the national granting agencies is stiff, it is a relatively straightforward matter to distinguish each of his interests from his identity. Jeremy’s interest in financial support quite clearly can be separated conceptually (if not practically) from his interest in pursuing this particular research project, and a comparable grant from the Social Sciences and Humanities Research Council would presumably suit his purposes equally well. Recalling the second part of the test we must ask whether the “direction of any bias produced by a conflict of interest [is expected to be] consistent within a set of circumstances.” If Jeremy is anxious that his financial support will be jeopardised by findings that undermine a commitment to an abstinence-based approach to addiction, his inquires may be limited in scope even if he fails explicitly to recognize any constraints he has placed on his hypotheses and methodology.[[73]](#footnote-74) Finally, depending on the reach of the sponsoring agency, Jeremy’s work has the potential to have an influence that goes well beyond that which is ordinarily anticipated with grant-funded work. If Parent Power has its own far-reaching media outlets, and a well-connected and receptive community, his work may be promoted in venues other than academic conferences and specialty journals. Indeed, findings that are consistent with the funder’s aims may gain traction in the popular and trade presses irrespective of the rigour of the methodology or the strength of the evidence.

A brief clarification may be in order. Bero and Grundy do not claim that their rules of thumb have the power to identify all problematic cases of conflict of interest, nor do they suggest that a researcher’s personal or professional identity is irrelevant to efforts to uncover bias in the exercise of their primary duty or duties. Instead, they make the more modest claim that “[c]ommercial sponsorship of research and investigator financial conflict of interest are two forms of conflict of interest which have the strongest evidence base….,” moreover they suggest, they ought to attract close scrutiny because “even when the methods meet high standards for internal validity, financial conflicts of interest may influence research results though other mechanisms, such as the framing of the question, how the study is actually conducted, and whether it is fully and accurately reported.”[[74]](#footnote-75)

For clear cases of conflict of interest there are familiar, if often inconsistently applied, management strategies that may diminish their impact. A researcher may recuse herself from participation in a project, or she may agree to follow a conflict of interest management plan. Conflict management plans are variable, and ideally are tailored to address the specifics of a particular research project, but they typically include safeguards like the following: the creation of an independent data safety monitoring board that performs an analysis of study data at specified times during the conduct of the research (and has the power to recommend alterations, or to suspend the study altogether, if risks become too great to permit continuation); a requirement that the conflicted investigator be barred from accessing raw data; the employment of a neutral party to engage in participant recruitment, or to conduct informed consent conversations; [[75]](#footnote-76) and/or an agreement to disclose to potential participants the nature (and less often, the extent) of the investigator’s conflict, or conflicts, of interest.[[76]](#footnote-77)

For those influences that Bero and Grundy have described as personal and professional interests there are, however, no such widely accepted management strategies and, despite the journal editors’ laundry list referenced above, it is not self-evident that they would serve any useful purpose. This is not because the interests and identities of researchers have no effect on research agendas or on the kinds of findings that their work is likely to uncover. Indeed, as Bero and Grundy have noted, “an interested view – grounded in personal experiences and beliefs, education and disciplinary training, and intellectual commitments – is crucial to rigorous research and scientific debate.” This is because an interested view can spark curiosity and sustain commitments especially when projects are of long duration, and any rewards modest or in the distant future. Moreover, when such interests are regarded with suspicion, or conflated with conflicts of interest, the results can be deeply concerning. The recusal of all who have simple interests can have the paradoxical effect of threatening to advance the agendas of the most powerful and ethically compromised parties. Unlike, academically affiliated scholarship, which generally is self-funded, or grant-funded research (research which often operates within such slim margins that completion, much less the dissemination of findings, is often in jeopardy), industry sponsored research is nearly always sufficiently well-resourced to promote the financial and political ends of the funder. Bero and Grundy continue: “Recusal of scientists based on their personal beliefs and experiences can serve exclusionary purposes and falsely identify certain individuals, who also possess personal beliefs and experiences, as ‘objective,’ narrowing the diversity of perspectives involved in decision making.”[[77]](#footnote-78) On their view, an alternative and more defensible way to deal with investigators’ interests is not to encourage them to recuse themselves from all areas in which they have interests, but instead to promote the practice of reflexivity; that is, to make conscious efforts to uncover and explore the values, beliefs, and experiences of the individuals and groups engaged in a particular enterprise. They do not claim to provide an in-depth analysis of the literature on reflexivity, nor does this brief treatment constitute an attempt to do so, but the questions they have crafted are a helpful guide to those seeking an alternative to the language of COI when discussing the effects that the identities of individuals might have on their contributions to the research enterprise. Because these may provide useful framing for the upcoming discussion of ethicists’ so-called conflicts of interest, they are worth reproducing in full:

**Key Questions for Reflexivity**

Who is the researcher?

* What are their *professional* identities? What is their discipline, educational background, or training? Where are they employed? What is their career stage, and are they in a position of influence? What is their area of research or theoretical perspective? What are their advocacy positions?
* What are their relevant personal identities, including age, race/ethnicity, gender, religious or political affiliations, and life experience?

How could who they are affect the design, conduct, or reporting of research?

Who or what is the focus of the research? For whom does this have consequences? What are those consequences?

Who or what is placed at risk by this research? How?

Who or what is advantaged by this research? How?

What are the ethical, social, political, or economic implications of this research?[[78]](#footnote-79)

*COI, Reflexivity, and the Nature of Ethicists’ Interests*

Having had an opportunity to unpack the Bero-Grundy distinction between conflict of interest and simple interests, it may be timely to revisit the five themes that the practicing ethicists in the Frolic-Chidwick study characterised as instances of conflict of interest. Succinctly stated, these were: “research funding conflicting with research ethics; disclosing ethical issues when ‘due process’ is absent; conflicts between organizational values and the personal values of the clinical bioethicist; promoting justice within organizations; and balancing competing loyalties and obligations within an organization.”[[79]](#footnote-80)

Because the examples included in this qualitative study were presented as composite cases (and necessarily lacked the rich detail that would have rendered their respondents identifiable) some nuance is lost. It is interesting to note, however, that very few of these cases, even on Frolic and Chidwick’s inclusive understanding, are helpfully described as straightforward instances of conflict of interest; that is, unless one is to take the absolutist position that ethicists cannot exercise unbiased judgement so long as they draw salaries for their work. It may be considered a commonplace that anyone charged with exercising discretion on behalf of another is conflicted when her analysis might attract the disapprobation of those who pay her wages, but this critique goes by a little too quickly. It is worthwhile to pause for a moment, therefore, to look at some of Frolic and Chidwick’s case examples, to see what they can illuminate about the pressures faced by the practicing healthcare ethicists they surveyed. Following this it may be possible to ascertain whether their so-called conflicts were ameliorable with appropriate management strategies.

Frolic and Chidwick’s first example, which references a tension between the interests of a research funder (and by extension those of the healthcare institution which employed her), and generally accepted standards of ethics in human subjects research, appears to be a straightforward case of financial conflict of interest (F-COI). The PHE was asked by a research ethics board chair to provide an independent ethical analysis of a controversial research protocol. She did so, and the Board, equipped with her report, voted to reject the submission. After the REB made this determination, however, a hospital administrator informed the ethicist of the institution’s financial stake in the study, and insisted that she had exceeded her authority by rendering an opinion on the disposition of the trial. An ethicist’s responsibility, on this leader’s view, is merely to enumerate the arguments for and against a project. It is not to recommend, or critique, a particular course of action.

It is not clear from the narrative whether the respondent’s immediate supervisor, or other internal or external stakeholders (aside from the administrator in question), exerted pressure on the bioethicist to approve or to make the case for the approval of a project that she deemed ethically problematic. The REB, after all, took her recommendations seriously and subsequently voted to reject the protocol. If this case is to qualify as an instance of F-COI, it seems that a number of distinct and rebuttable assumptions need to be defended. These are that the ethicist had good reason to believe that the interests of the research funders were aligned with those of the healthcare institution; that institutional officials were largely united in their desire to see the study approved; that these officials were prepared to advance an agenda that could leave them open to reproach from the public, and vulnerable to sanction by regulatory agencies; that the ethicist was unconfident that her independence would be respected by her supervisor or supervisors; and, finally, that her failure to endorse the project would be sufficiently objectionable to provoke sanctions against her. It should be acknowledged that a PHE advancing what may be a poorly received position may well find the independence of her judgement threatened by any of these or similar variables. (Indeed, it seems reasonable to acknowledge the fact that these sorts of considerations lurk in the background of many cases on which ethicists are invited to comment.) Some practising healthcare ethicists will encounter such pressures more directly and often than others, because they have regular access to leadership tables. Those who are only occasional contributors to boardroom discussions may find themselves in especially vulnerable positions if they find themselves without allies on senior management teams and unfamiliar with the expressive conventions and group norms (ethical and otherwise) of high-level institutional committees.[[80]](#footnote-81)

It may be prudent for practicing healthcare ethicists to be attentive to the financial realities faced by publically funded systems, and the increasing pressures for hospitals to embrace so-called private-public partnerships may make financial conflicts of interests an even greater threat to institutional integrity than they were in the past. What is not clear, however, is that ethicists generally are expected to favour positions that maximise revenue generation opportunities for their employers. When invited to provide advice on a specific case, a practicing healthcare ethicist typically supplies an analysis that details the opportunities and risks associated with the various courses of action being proposed. She may regard some possibilities as so ethically deficient as to be indefensible and, if that is the case, she ought to provide compelling reasons for making such claims as well. A failure to provide a thorough and forthright analysis has the potential to leave the institution vulnerable to more rigorous and potentially damaging external criticism, and the ethicist’s supervisors would be wise to welcome rather than to reject positions that challenge their perspectives, or conflict with their immediate interests. In short, if the institution and the PHE are clear about how she can best perform her role (which typically will mean that she has considered the interests of all parties including the institution and its financial interests[[81]](#footnote-82)), the impact of the conflict will be substantially diminished. The ethicist would not be harming her employers by mounting a vigorous dissent to a preferred course of action. On the contrary, she would be supplying them with the resources needed to come to an informed decision, even if that decision were one that she personally would be inclined to disavow. The bioethicist who was the study respondent at the centre of the research ethics case came close to appreciating this insight when she noted that, “[t]his was a conflict between my professional obligations as a bioethicist to render honest ethical analysis, versus saying what my institution wanted to hear.”[[82]](#footnote-83)

The other cases that fell within the ambit of Frolic and Chidwick’s naturalised conception of COI are even less clear-cut than the first. These cases concerned ethicists who seemed to be genuinely perplexed about key aspects of their roles. They were uncertain about who their client or clients might be, and were equally conflicted about the nature of the service they were to provide (ally, advocate, whistle-blower, or window-dressing?). Without clarity on such fundamental issues the opportunities for boundary crossings and burnout are plentiful. It is hardly surprising, therefore, that many invoked the language of moral distress and that half of the respondents indicated that they had changed employers or had left the field entirely owing to the challenges they faced.

The particulars of the cases differ significantly, but anchoring the analysis in the ethicists’ own words may be helpful in illustrating what Frolic and Chidwick, adopting the usage of Andrew Stark, described as “in-role” conflicts of interest; that is, those related not to external interests that conflict with the ethicists’ professional duties, but conflicts that were described as competing obligations that were “intrinsic to the professional’s role.”[[83]](#footnote-84) One PHE, frustrated by her administration’s failure to discipline a group of surgeons for poor performance and for failing subsequently to disclose the full extent of their risky practice stated, “[a]ll of my attempts at internal advocacy have been blocked or silenced. Some people think that as the ethicist I should be whistle-blowing and going to the media.”[[84]](#footnote-85) Another ethicist, frustrated by a hierarchical climate, opaque priority-setting standards, and a callous approach to human resource management, found herself confronted by an angry chief executive officer when she attempted to communicate her concerns directly to the hospital’s board of governors: “It was made clear to me that I was not going to be fired this time, but I should never go to the Board directly with anything negative in the future.”[[85]](#footnote-86) Yet another ethicist found herself torn between an obligation to protect confidentiality and a desire to shield a colleague from embarrassment; and in the final case, a PHE found herself torn between an impulse toward cost containment and the competing intuition that her job involved “advocating for patient needs first” by alerting her employer “that the hospital had to get its act together to create an appropriate process for dealing with uninsured patients.”[[86]](#footnote-87) The outcome of her decision to prioritise the needs of patients was a gradual but, on her view, purposeful, reorganization of her responsibilities, so that she was assigned greater responsibility for research ethics work and was consequently less available for clinical ethics consultation. In other words, the institution did not discipline her directly, but her leadership team found a way to keep her clear of the areas where her contributions were likely to be perceived as problematic.[[87]](#footnote-88)

*Stark’s contrasts: Intrinsic COI and the character of professional identity*

The idea that a professional might face multiple and competing demands on her time and expertise makes intuitive sense, but not all instances of conflicting responsibilities - what Frolic and Chidwick sometimes describe as competing interests - present the sort of challenge to independent judgement that signals a straightforward conflict of interest or even an intrinsic conflict of responsibilities in Stark’s sense. An intrinsic conflict, on his understanding, is generally precipitated by one of two distinct types of circumstances:

Some [Type 1] arise because the professional occupies more than one role with respect to the same principal, such that the existence of the second role impairs her capacity to exercise the first. Others [Type 2] occur because the professional must exercise the same role with respect to more than one principal, such that the presence of a second principal impairs her capacity to exercise her role on behalf of the first.[[88]](#footnote-89)

Although the terminology which identifies it varies, references to intrinsic conflicts of responsibilities are familiar features of the ethics codes or value statements of many professional colleges, and examples of what I have labelled Type 1 and Type 2 are easily generated. An oncologist who is responsible for directing a particular patient’s cancer treatment may also be the principal investigator on a randomised controlled trial for which that patient is eligible. In a case like this the physician typically will be obliged to manage her Type 1 conflict by recusing herself from some study-related activities such as obtaining consent for subject enrolment, or for determining whether participants’ adverse events are related to study participation. This is not only because the dual-role may generate confusion for the patient-participant who is apt to conflate the goals of clinical care and research, but because it is difficult for the oncologist to prioritize and manage these, often conflicting, aims as well. As a treating clinician it may be unpalatable for the professional to accept that her patient could be made worse off by enrolling in the trial (perhaps by being randomised to a control arm which offers no access to a promising novel agent, or by exposing him to as yet unknown drug-related toxicities), but as a researcher the oncologist’s primary obligation will be to preserve the scientific integrity of the trial, even if that means that some participants will be subjected to study-related procedures without any prospect of benefit.[[89]](#footnote-90)

A non-medical, but immediately recognizable, example of a Type 2 conflict (where the professional occupies the same role with respect to two or more parties) is the case of a lawyer approached to represent parties on opposite sides of a legal transaction such as a divorce settlement or a real estate conveyance. Providing representation for both principals may be unproblematic, so long as the conflict is disclosed and the parties agree to the dual-representation but, as many lawyers and clients have learned, these arrangements swiftly can become untenable if the parties’ interests cease to align and an amicable arrangement devolves into a legal contest. Should this occur at least one party will need to seek alternate representation, and a lawyer who is inattentive to this possibility may find herself subject to disciplinary action.[[90]](#footnote-91)

One of the practicing healthcare ethicists in the Frolic-Chidwick study offered an especially poignant glimpse into her struggles related to intrinsic conflicts of interest. Although this ethicist did not describe a specific conflict in the context of a challenging case, it was evident that her professional interactions were frequently strained by the effort to manage the competing interests and obligations that were intrinsic to her role:

I do not feel like these relationships or loyalties have ever been adequately sorted out in my hospital, so there is a danger of being co-opted by one party or another. I am often asked to affirm decisions health care providers have made. They will say, “This is what I think I should do in this case, do you see anything that I have missed?’’ It is a good question, an important question and one people should be asking. But it can be tempting to just affirm their decisions, rather than ask the deeper questions like, “What does the patient want?’’ This is not always the question people want to hear, they often just want you to say they are right. And the truth is, given the complexity of these cases, you can often find good reasons for doing one thing or another, but it is dangerous for the ethicist to serve the function of justifying people’s actions.[[91]](#footnote-92)

This PHE didn’t supply sufficient detail to allow the reader to characterise her conflicts with precision, but her recognition of a need to sort out “relationships or loyalties” is an invitation to look for Type 1 and 2 conflicts that may make an ethicist’s employment challenging. Type 2 conflicts (where the bioethicist performs the same function with respect to two or more parties) may present the most obvious risks to integrity, and the worry about a conflict between the health care provider’s (or providers’) point(s) of view and that of a particular patient (or patient proxy) is one to which anyone offering clinical ethics consultation should be attuned. Because PHEs typically offer their services to healthcare practitioners, patients, families, leadership teams, and even researchers, there is ample opportunity for them to find themselves “occupying the same role with respect to more than one principal.” If we revisit the case of Mr Beaton, we can easily imagine a healthcare team and family divided about the benefits and burdens of ongoing nutritional support in the context of his advancing dementia and attendant frailties.[[92]](#footnote-93) The number of parties claiming to have standing in the case may be great and, while the PHE’s involvement will likely have been precipitated by a request from one (or more) of them, she will not owe a special duty to a particular requestor despite the fact that this party’s perspective has provided her first glimpse into the narrative that will become part of her case analysis. This is a feature of clinical ethics consultation that can be easily be overlooked by participants, and inexperienced or inadequately prepared consultants. It may be tempting simply to address the enquiry that is posed by the party who initiates the ethicist’s involvement when that question itself ought to prompt further exploration. As was intimated earlier, the appropriateness of feeding Mr Beaton may be the presenting problem, but it will need to be located in a larger conversation that attempts to unpack the patient’s and providers’ values. If these conflict, or are unclear, then the PHE will be obliged to seek opportunities to reconcile these competing interests and points of view. Goals of care conversations that begin in a request for an ethicist’s involvement are almost never resolved by reference to uncontroversial rules (to anticipate language that will be explored more fully in subsequent chapters, the key questions often involve theoretical rather than empirical disagreement), and the way that the ethicist contributes to case deliberations may well be scrutinized for evidence of bias or conflicting commitments.

Mr Beaton’s case may also generate a Type 1 conflict for the PHE, although this possibility may be less straightforward for her and for others to discern. As a reminder, Stark suggests that a Type 1 conflict is generated when “the professional occupies more than one role with respect to the same principal, such that the existence of the second role impairs her capacity to exercise the first.” The practicing ethicist, for example, may be engaged in the development of institutional policy and procedures that are directly applicable to this patient’s case. These policies may, for example, offer direction with respect to the allocation of institutional resources, or establish criteria that influence discharge decisions. Unfortunately, a policy which is designed to address the needs of patients throughout the institution, or across the healthcare system, may not lead to a desirable outcome in a particular patient’s case. As one of the participants in the Frolic-Chidwick study discovered, advocating for compassionate approach in a specific patient’s circumstance may entail a conflict with the interests of other patients.

Another possible source of Type 1 conflict is a variation on the one faced by the physician-investigator. Bioethicists are encouraged by their peers, and often by their employers, to make scholarly contributions to their field but these contributions may take the form of case studies which use their professional experiences, including patient narratives, as the subject of their analyses. Although many published accounts consist of composite cases, and it is not yet routine for PHEs to seek consent from individual participants when they wish to use their stories, it is worth reflecting on the way that a practicing healthcare ethicist’s interest in her academic status might influence her conduct in particular cases and her clients’ perceptions of her role.

That these are not chronic or disabling sources of unease is a subject worthy of further investigation. It may be hypothesized that time spent in health care environments results in a gradual process of enculturation that makes PHEs largely oblivious to their biases and blind spots, or it may be the case that many have found strategies or systems that generally allow them to prioritise competing claims without difficulty. The next chapter will permit a fuller elaboration of these challenges to integrity (and potential management strategies), but before tackling what we might provisionally call the politics of bioethics, it may be helpful to revisit Stark’s analysis of COI one more time. His discussion of fiduciary obligation and agency relationships may offer insights that can advance the effort to disentangle some of these difficulties.

*Agency relationships and ethical obligations*

A quick review of the preceding sections may be in order. According to the standard view, at the heart of a conflict of interest is a tension between a professional’s duties to her client, or clients, and secondary or “meddlesome interests,”[[93]](#footnote-94) that interfere with that professional’s exercise of judgement. While PHEs may not be immune to these difficulties, Frolic and Chidwick’s investigation suggests that intrinsic conflicts, those related to ethicists’ multiple, and sometimes conflicting, roles constitute a far greater source of concern than extrinsic conflicts of interest such as a desire for financial gain or for career advancement.

It may be an error to suppose that the potential for external conflicts of interest is a less significant threat to the independent judgement of PHEs than intrinsic conflicts, but this is not a matter that needs to be settled in order to make progress on efforts to understand the nature and extent of the field’s COI-related shortcomings. Stark offers an intriguing observation when he suggests that “[i]n Tolstoyan fashion, conflicts of interest arising from out-of-role sources are all alike, but every profession experiences in-role conflicts in its own way.”[[94]](#footnote-95) One of the sources of this variability appears to lie in the relationship of particular professions to their principal(s) or to the party (or parties) that they serve. Lawyers, as we have seen, need to be clear with respect to the duties that they owe to their individual clients. A failure to understand and meet these obligations can have grave consequences for all who are implicated, and recusal may be the only ethically defensible management strategy for the lawyer who finds herself representing clients who have developed irreconcilable and competing interests. This response to COI makes sense in such cases because lawyers have fiduciary obligations specifically to these clients. They are in a so-called agency relationship and, therefore, are obliged to protect their principals’ interests against the competing claims of other parties.

Not all professionals, however, stand in a special or fiduciary relation to their principals. In fact, Stark suggests that some professionals – specifically, journalists, critics, judges, and public officials – “owe their professional responsibilities to the public.”[[95]](#footnote-96) To elaborate further, he asserts that “judges bear a primary obligation to the public for whom they work to do justice; to faithfully interpret, clarify, improve, and rationalize the law.”[[96]](#footnote-97) He concedes the point that they may owe additional duties to particular litigants (two of the examples he offers are the duties to settle cases expeditiously, and to preserve confidentiality), but it is important to notice that under this conception any intrinsic conflicts that arise as the judge performs her duties must be resolved in a manner which gives priority to the public’s interest.

How one is to know what the public’s interest consists in with respect to a particular case is, of course, an intriguing question, and it too is likely to attract considerable controversy. Stark signals that prospect when he offers the bracing suggestion that there may be no “empirical reality for journalists and judges… [that] "is always knowable, accessible, or beyond contestation” against which one can test the independence of their judgements.[[97]](#footnote-98) Moreover, if an external observer is to accuse these types of professionals of impaired judgement owing to an intrinsic conflict of interest, the solution cannot simply be to eliminate the conflict by recusal or to manage it via disclosure. The conflict, if that is the descriptor that best captures the dilemma, is an inescapable aspect of the role. The judge will need to be attentive to all of the interests that are implicated in the cases that come before her and none should be permitted to undermine her duties to the community as a whole.

PHEs, for better or worse, appear to be candidates for inclusion in Stark’s small set of peculiarly, and perhaps precariously, situated professionals. Like journalists, literary critics, and judges, they do not act as agents of the individuals who seek their services. The most important duty that they owe, that is, the duty to exercise their judgement in a manner that is unbiased, well-informed, and fair-minded, is a duty owed to the community they serve (however that community may be defined). And, as is the case with journalists, critics, and judges, the diagnosis and cure for what ails individual practitioners, or the whole of the practice, will not easily be settled via appeal to uncontroversial, extrinsic standards. PHEs will need to offer an account of what they do that makes sense of a range of acceptable bioethical world views while permitting the outside scrutiny that is necessary to tackle the charges of partiality, politicization, and incoherence with which this project began.

Chapter 3: Scrutinizing the Standing of Principles: On the Politics of Bioethics

The preceding chapter concluded with the suggestion that the greatest threats to the integrity of practicing healthcare ethicists may not be the temptations associated with extrinsic conflicts of interest (such as the inducements that come in the form of contracts with pharmaceutical companies or even the promises of secure salaries), but instead come in the form of intractable, perhaps inescapable, challenges associated with the nature of the role (at least as it is often structured). Although some ethicists may see themselves as champions of underdogs in the healthcare encounter (such as patients who are vulnerably situated owing to a tragic combinations of variables such as illness, socio-economic status, or addiction), it must be acknowledged that even a PHE who holds that view will have difficulty defending a conception of the role that limits her sphere of responsibility to the interests of a single patient or patient population. If ethicists are, however, not agents of particular parties but are accountable to a wider community (like Stark’s judges, critics, and journalists) they will need to find, or produce for themselves, a conception of the role that informs their deliberations and allows them to contribute productively to the challenges presented by complex cases. PHEs, unlike judges, may not (and generally ought not) have the authority to render binding decisions, but framing questions, participating in (or leading) mediation sessions, and offering advice are also tasks that should not be taken lightly. Some of the threats to judgement that may be associated with the practice of ethics consultation and support are, therefore, the subject of this chapter.[[98]](#footnote-99) Whether they can be appropriately managed, and what an apt management strategy might consist in, are important topics to which I will return after a much needed exploration of the imprecise but, increasingly widespread, charge that bioethics is a partisan endeavour.[[99]](#footnote-100)

*Conflict of interest or political interference? Bioethicists eating their own*

Since the early 2000s, Carl Elliott has opined, bioethicists have become so entrenched in health care institutions that the suggestion that they can serve as the critics of biomedicine is no longer plausible.

The bioethicist was invested with a kind of social authority, partly because of his or her specialised education, but also because of the individual’s distinct place in an institution’s bureaucracy. The clinical ethicist, for instance, was given authority simply by virtue of the fact that he or she occupied the position of “clinical ethicist,” which came with certain trappings (a white coat, an office, a hospital ID, responsibility for certain committees) and a certain amount of deference within the organisation.[[100]](#footnote-101) Today many doctors and nurses working within hospitals feel they cannot just ignore the moral advice of the clinical ethicist even if they believe it is wrong.[[101]](#footnote-102)

Elliott’s indictment of the field can be broken into two distinct claims, and both are relevant to my project. The first of these is the contention that the judgement of PHEs has been corrupted or impaired, whether they are aware of it or not, by the sources of their incomes (be these government grants, pharmaceutical company or device manufacturer sponsorships, or hospital corporations), and the second is the assertion that the influence that they exert diminishes the ability of other health care professionals to express dissenting moral views. More recently, Tom Koch, has offered a version of this second charge by alleging that the disciplinary progress of bioethics has undermined the commitments of physicians to their patients, and has replaced the noble sentiments of the Hippocratic tradition with a neoliberal world view – a world view that allows the rationality of the marketplace to determine the priorities of health care systems and the fates of individual patients. Although these indictments are often run together it is worthwhile to examine them separately, because each contains a number of assumptions that, although contestable, can help shed light on some of the dark suspicions that critics nurture about the field. The first challenge was the subject of my last chapter, and may be recognised as a variation on the conflict of interest charge, but the second is a newer one. It is this second charge - the claim that ethicists have unduly influenced the moral climate of health care institutions and limited the range of contributions that others can make to the ethical environment – to which I shall now turn.[[102]](#footnote-103)

Repurposing a quotation from Confucius, Koch accuses those he calls “medical ethicists”[[103]](#footnote-104) of being “thieves of virtue” who reserve for themselves the right to entertain questions pertaining to matters of value:

Confucius wanted everyone to think about what is right and wrong, to think about what is correct and appropriate in a manner that was broadly conceived and popularly understood rather than narrowly constructed. Defining a virtue or social good for their own benefit, Confucius’s thieves were those who hid behind professional positions and specialist language to make intelligent, practical virtue seem like a special virtue rather than a general good.[[104]](#footnote-105)

This is a striking passage, but it should be noted that it is not merely the purported extent of the ethicist’s influence that is troubling to Koch. On his view, PHEs, as members of the healthcare establishment, have a troubling tendency to act as apologists for the shortcomings of western medical bureaucracies. Koch rejects the claim that the field makes room for a wide range of political, philosophical, and disciplinary perspectives. He states that “[b]ioethicists like to think of themselves as a diverse group of opinionated individuals with a wide range of political views who cannot easily be characterized without caricature,” but he insists that they are mistaken in this belief.[[105]](#footnote-106) Unlike academic philosophers, who have no need for, or interest in, a homogenous approach to their discipline, those who regard ethics as a profession, or nascent profession, are generally not engaged in the difficult work of understanding and explicating the value-related dimensions of challenges arising in clinical care and research; instead, suggests Koch, they are occupied with efforts to ensure that cases are resolved in manner that reinforces bureaucratic inclinations toward cost containment and the advance of a technical rationality. To put it bluntly, PHEs provide the justificatory arguments that allow patient needs to be evaluated in the context of fundable hours and available beds, and permit research participants’ interests to be reduced to data points and bio-specimens (both of which have become valuable market commodities).[[106]](#footnote-107) The preoccupation with informed consent, on this view, is not so much a worry about honouring patient preferences and respecting diverse world views, but a risk management strategy that seeks to keep institutions and their representatives clear of legal difficulties.

In sum, Elliott and Koch are not sceptical about the suggestion that healthcare can benefit from ethical analysis, indeed both have accepted the bioethicist mantle (although Elliott has distanced himself from that identity of late.)[[107]](#footnote-108) They are instead united in their critique of what they see as the influence of the self-interested or unthinking PHE who almost always is tethered by a very short leash and can best be described as her master’s faithful guardian.[[108]](#footnote-109) This critique of healthcare ethicists may be a bit of a straw man but it may yet serve a useful purpose. If we cast it aside prematurely we lose an opportunity to identify some of the opportunities and threats associated with the various conceptions of the practice.

*PHEs and public (health) ethics: building a better bioethics*

What Elliott and Koch get right is the suggestion that PHEs cannot escape the controversial, often political, questions that routinely arise in their practice. Conceding this point might, however, allow an acknowledgement that the term political can be employed in an ecumenical way. To suggest that bioethics is a political practice might, for example, reference the kinds of partisan debates that bioethicists waded into during the years that Leon Kass led George W. Bush’s newly created President’s Council on Bioethics. As is well known, that council was noteworthy for its ability to move a conservative political agenda forward, and had a particular interest in inhibiting embryonic stem cell research and therapeutic cloning.[[109]](#footnote-110) Bioethics need not, however, be this sort of explicitly partisan endeavour to qualify as political in nature. As Mark Brown has argued in “Three Ways to Politicize Bioethics,” terms like “political” and politicization are contested concepts and “[w]hat counts as political often becomes a political question itself.”[[110]](#footnote-111) The following passage, which draws upon the insights of political theorist M.E. Warren, seems apt for our purposes because it encourages reflection on the way that politics intersects with bioethics:

. . . politics is a subset of social relations in which people face pressure to undertake collective action in the context of conflict over the means, goals, or domain of their activity, where at least one party seeks to resolve the conflict through the exercise of power. Power may be physical, economic, or cultural. It may be exercised directly through command or indirectly through structuring people’s choices, interests, or identities . . . the common feature of different forms of power is that they elicit compliance of some with the aims of others. Because bioethical dilemmas are often intertwined with power, and because they often involve conflicts of value, interest, opinion, or worldview, bioethics today is easily politicized.[[111]](#footnote-112)

Brown’s view might also accommodate a further bit of equivocation on the meaning of the term “politics.” That is, it might reference the way that the personal circumstances of patients necessitate, or ought to invite, consideration of wider societal concerns (what was meant by the old rallying cry, “the personal is the political”), but it might also refer to the insight that every point of view reflects a constellation of, often unexamined, values, and entail the further implication that there is no way for an ethicist to avoid importing her values, or those for whom she is a representative, or mere megaphone, as she attempts to assist with the process of ethical deliberation. The two fictional examples below, which are loosely based on situations which will be familiar to those consulting in clinical settings, can easily illustrate the point:

Marcus faces discharge against medical advice. He has been deemed “non-compliant” with treatment because his mental illness, alcoholism, and unstable housing situation have often led to missed appointments for chemotherapy infusions. His cancer is deemed treatable, but his most responsible practitioner suggests that he has a poor prognosis because his social situation makes it unlikely that he will ever be found eligible for a stem cell transplant. Wait lists for the procedure are long and some patients have been asked to travel out of the region to access the intervention. A frustrated treatment team suggests that scarce resources should not be allocated to a patient who is unlikely or unwilling to benefit from transplantation.

Malek is a twenty year old man with a spinal cord injury who often resists routine nursing care. He has, therefore, contracted a number of bladder infections and is at risk of prolonged hospitalisation owing to a stage III pressure injury. He can be loud, disruptive, and sometimes verbally abusive with staff and they have expressed a fear of him owing to his gang affiliation. In turn, Malek has complained that staff are racist and unresponsive to his needs. A month ago he suffered a gunshot wound that simultaneously robbed him of his mobility and community. He has been sent to a physical rehabilitation facility and staff are divided over the nature and extent of their obligations to continue to provide him with care. There is pressure to transfer him out of the program because he appears not to be “rehab ready.”

In either of these cases, a PHE called to assist with ethical decision making could endeavour to focus the assembled stakeholders on the four principles famously articulated by Tom Beauchamp and James Childress, but it must be acknowledged that even the most formalistic application of the so-called Georgetown Mantra would be unable to escape a whiff of politics broadly understood.[[112]](#footnote-113) These patients, and their providers, might prefer to attend to the medical aspects of the cases, and the capable person’s right to refuse unwanted treatment (be it chemotherapy, urinary catheterisation, or wound care), but Marcus’s and Malek’s situations implicate far more than the autonomy principle. As Koch suggests, as soon as any of us strives to unpack and apply notions of “‘good’ and ‘bad,’ ‘right’ and ‘wrong,’” we have entered political territory because we invariably end up justifying some options and critiquing or discounting others.

In this context, politics might be described fairly broadly as an effort to define the obligations that we owe one to another, but Koch invokes the adage that “politics is applied ethics” and opines that it is “the dress that Philosophy wears when it seeks to be seen as useful, its subject something that is practical and real, and thus important.”[[113]](#footnote-114) His framing may feel a little uncomfortable when he states that we would have to be duplicitous or naïve to embrace the notion that either philosophy or politics can be entirely without bias, but surely he is right to note the impossibility of accessing “a morality that is real, distinct, and value-free . . . that could be discovered and pronounced rather than self-consciously constructed.” [[114]](#footnote-115) Any effort to make sense of what is ethically at stake in clinical cases like these obliges the PHE (and indeed, all engaged in the process of moral deliberation), to reflect on more than the immediate medical needs of patients or the internal and external standards (such as policies and legal requirements) that constrain or compel certain actions by practitioners and health care institutions.[[115]](#footnote-116) Larger questions of justice will also be lurking in the background, and these may be deliberately placed on, or be taken off, the proverbial table in the course of an ethics consultation. The following might be contributions to such a conversation: How can the needs of these patients be met in the context of competing commitments to other (current and future) patients and staff members? To what extent are these patients responsible for, or victims of, their circumstances? What structural vulnerabilities render them unable, or less able, to access the benefits that are routinely afforded to others? What should health care professionals, or members of the larger community, do to address the social determinants of health that render these patients, and others like them, more susceptible to disease, disability, or death than others of similar ages and abilities? It should also be noted that a failure to surface, or to explicitly engage, these questions does not mean that those assembled have no position on their weight or significance. A willingness to overcome barriers that threaten a particular patient’s access to ongoing care may be profoundly influenced by the health care professionals’ assumptions about the answers to these and other political questions.

As we are about to see, a feminist approach to healthcare ethics, including that which is advocated by Margaret Urban Walker, can accommodate these insights without purging ethical deliberation of the common vocabulary that principlism and other theoretical tools provide. On the contrary, Walker maintains that “[m]oral concepts, principles, values, and argument forms may be starting points for moral deliberation” that need to be supplemented with an understanding that “‘moral problems’ are points in continuing histories of attempted mutual adjustments and understandings among people.”[[116]](#footnote-117) Moral deliberation may not be able to escape the particular histories and value-orientations of those who participate in that effort but (contra Koch), that may be viewed as an asset rather than a liability.

*Who abides and who decides? Joan Tronto on authority in ethics*

Joan Tronto has convincingly argued that hard cases in applied ethics can profit from greater efforts to understand the nature and grounds of the ethicist’s authority. While she does not reject the idea that PHEs can contribute to ethical deliberation in useful ways, she uses the lens of feminist political theory to take a closer look at relationships of power and vulnerability, and the use and abuse of ethical theory, in the clinical setting and beyond. With Art Caplan she derides efforts to engage in the crude exercise of “ethical engineering” or the unreflective effort to apply principles to cases. In its place she advocates for an approach to ethics that draws upon Margaret Urban Walker’s insight that responsibility is relational. A framework that attends to “relational responsibility” is described as one which extends beyond a “dyadic understanding of negotiation, in which the individual reacts to an ‘other,’ understood, usually…in abstract terms.”[[117]](#footnote-118) In Tronto’s words, “a relational approach presumes greater social complexity” and appreciates the insight that “negotiations happen at once along many different dimensions, with others and social context both playing a role. The result is that judgments concerning authority turn out to be not only ‘social’ or anthropological,’ but also political.”[[118]](#footnote-119)

A PHE who takes Tronto’s insights seriously ought to take pains to alert her clinical teams to the features of Malek and Marcus’s situations that render questions of professional and personal responsibility more nuanced than might be apparent at first blush. While all might agree, for example, that point of care providers ought to respect competent and informed refusals of treatment, a relational conception of responsibility could encourage creative problem-solving about how best to enhance the ability of these patients to accept treatments that could benefit them while at the same time preserving their dignity and honouring their desire for independence. When the therapeutic relationship is already fragile owing to mutual suspicion or a clash of world views, a focus on informed consent and treatment adherence is unlikely to yield effective or patient-centred plans of care. On the other hand, an awareness of, and a willingness to question, the power structures that create ethical conflicts or impede their resolution, allows the parties to a consultation to explore alternatives to conventional practices that may make treatment options more palatable. In this spirit, the reasons for Marcus’s missed appointments might be explored in a collaborative manner, and the sources of Malik’s anger probed by staff members who have experience or expertise in dealing with the feelings of loss and disempowerment that frequently attend patients in such straitened circumstances.

In this vein, Tronto approvingly cites Arthur Caplan’s hierarchy-challenging examples of so-called ethics interventions. The first that she imparts occurred on bedside teaching “rounds” and simply consisted of a well-placed question concerning the priority of a group of residents’ interest in efficiency versus a patient’s desire for privacy while toileting. The second was a proposal, pitched to emergency department staff (and presumably to insurance executives), to make an appeal to Medicare for funding to provide air conditioning units for those who were frequent hospital visitors owing to their vulnerability to heat exhaustion. Tronto notes that although Caplan relayed these stories of his “moral efficacy in a hospital setting” in a self-deprecating manner, his homely narratives ought not to obscure the fact that an ethicist can exercise her authority to good or bad effect. On Tronto’s view, debates about the role of principles and theory in bioethics provide only a partial glimpse into what is at stake in the clinical encounter:

…the answer to the question ”who” is authorized to do ethics depends not upon “what” justification practitioners of applied ethics offer, but rather on their social and political location, that is, an answer to the question “where” applied ethics occurs. In this regard, there is a deep level on which the authority of applied ethics rests upon the *political* realities of public and private institutions…these locations, when they put people with different levels of social responsibility, respectability, and power in relationship with one another, force a genuine ethical encounter.[[119]](#footnote-120)

For Tronto then, the justification for a PHE’s role will be found not via an appeal to theory as it conventionally is understood; instead, instances of engagement, or “genuine ethical encounters,” provide the appropriate grounds for the PHE’s authority. Interestingly, however, these ethical encounters offer far more than a source of hope for greater compassion in the delivery of patient care, or even for healthcare systems that enhance equity. Toronto suggests that “[a] more democratic and just society will try to make such locations more widespread and institutions more open. In this way, applied ethics in a democratic society points the way toward making society more democratic.”[[120]](#footnote-121)

This optimistic view of the work of applied ethicists – at least when that work is politically informed and attentive to power differentials – is a refreshing tonic after the harsh appraisals of the field’s critics. Working from the assumption that PHEs inhabit a politically fraught and hierarchical environment, Tronto draws a very different conclusion than Elliott, Koch, and many others. She suggests that applied ethicists need not be hopelessly compromised nor must they enrich themselves via a supposed theft of others’ virtue. Tronto, like Margaret Urban Walker, may reject a view of ethics which assigns primacy to the special argumentative skills of moral philosophy as it is traditionally understood; that is, as a method which abstracts from the messy vicissitudes of the lives of ordinary people, but she does not judge the ethics enterprise worthless. Instead, following Walker, she maintains that its value lies in its insistence that we engage with one another in an ongoing process of negotiation, a negotiation that presumes that we have relationships with one another, and challenges us to reflect on the nature and extent of the responsibilities that those relationships require.[[121]](#footnote-122) Tronto’s analysis may persuade PHEs to abide fewer injustices than they otherwise might and, most importantly, it does not entail the conclusion that an ethicist’s influence on decision making is always compromised when it is situated in the clinic or at the bedside.[[122]](#footnote-123)

*Public (Health) Ethics: Fostering reflection and playing the long game*

The philosopher Susan Sherwin has explored the problems associated with the embeddedness of bioethicists in a slightly different but compatible way. She suggests that those engaged in ethical analysis typically allow others to frame their debates and to decide what might count as appropriate, or useful, answers to the questions that they surface. Invoking the analogy of a huckster’s shell game, one that relies on misdirection and sleight of hand to engage the unwitting rube, Sherwin notices a troubling propensity for bioethicists (both applied and academic) to allow others to set their clinical and research agendas: in short, she observes, if ethicists are not answering questions posed by hospital administrators or concerned or cynical clinicians, they are shaping their agendas in accordance with various funders’ priorities. On her view, the persistence of the debate concerning the moral status of the foetus provides a paradigmatic example of this problem. So long as ethicists are occupied with questions related to foetal personhood they are diverted from other important questions that can be profitably addressed: Does our community treat women, especially single mothers, fairly? What opportunities for flourishing are available to those born with disabilities? Which societal attitudes make control over reproduction inaccessible to some women? Importantly, however, Sherwin appears not to imply that PHEs are like confederates with confidence tricksters running a shell game on an unwitting public. Instead, her analogy suggests that although some ethicists may appreciate or endorse the way that the game is played, it is far more often the case that they are unwitting or reluctant participants who get drawn into a game that is at best a diversion from more important pursuits, and at worst a source of harm to those who are unable to escape its allure.

The shell game analogy is more compelling than a straightforward conflict of interest charge because it prompts the realisation that ethicists, like others in healthcare systems, can be prone to distraction and misdirection despite their best efforts to keep their eyes focussed on worthwhile ends. If they are permitted to step away from diversions, and are able to take adequate time for reflection, ethicists almost certainly will agree that the interaction between performer and participant, like that between healthcare providers and patients, or between PHEs and their various clients, is better understood as a small part of an incredibly complex environment. A carnival game is not merely a test of a barker’s sleight of hand or of a participant’s visual acuity. Both of these things keep the game interesting, but its power lies in its ability to engage bystanders and participants alike despite their awareness that more is going on than meets the eye.

Although the analogy is a useful one, Sherwin is forthright about acknowledging its limitations. A shell game is a carefully orchestrated performance, and winners and losers are clearly and immediately identifiable. The various complex and interrelated variables that are predictive of any patient’s health outcomes, however, are not always easy to identify and they are certainly not directed by a single actor with selfish or malign intentions. An ethics consultation, such as the one which contemplates the prospect of transferring Malek out of a rehabilitation bed, is likely to follow a difficult and frustrating clinical interaction or series of interactions, and can offer few or no easy wins. Even if his care providers are to find him a more appropriate care setting (one that is resourced with good psychological supports, skilled wound care nurses, and social workers with superb connections to community resources), Malek’s post-discharge prospects are likely to be bleak, and the conditions which led to his disaffection and injury will almost certainly remain unresolved for him and for those who remain within his circle of intimates.[[123]](#footnote-124)

For all of these reasons it may be correct to suggest that PHEs should engage in discussions with a far larger group of stakeholders than they ordinarily do. Lasting and just solutions to health-related challenges require conversations that must take place beyond the bedside or the boardroom. Unfortunately, as Sherwin has observed, bioethicists, generally have not played the long game when it comes to ethical concerns:

Repeatedly, bioethicists either: (1) focus on questions of individual responsibility and individual rights and ignore discussion about the moral dimensions of public policy, or (2) they take existing public policy as the norm and ask about how to modify it for improvement. They (we) are sidetracked, again and again, from examination of important larger ethical issues by the need to answer narrower issues that get put in our paths through the terms of a debate that others have initiated. These distractions make it difficult to find and hold fast to a vision of ethical priorities while trying to address the moral framework introduced by others, that is, we are caught up in the temptations of ethics as a shell game.[[124]](#footnote-125)

Sherwin surely is correct to urge those working in applied ethics to expand their sphere of concern to include factors which lie beyond the traditional scope of clinical ethics, or even of public health ethics. She has coined the phrase ‘public ethics’ to describe her vision for a new kind of ethics which appreciates that “[t]here are moral responsibilities at every level regarding how we are to behave, individually and collectively, if we are to avoid the worst effects of global warming, ethnic hatred, water shortages, extreme poverty, and so on.”[[125]](#footnote-126) Sherwin’s proposed public ethics not only contemplates collaboration with non-traditional partners in the effort to answer large bioethical questions and to promote more equitable outcomes for individual patients. It also incorporates a feminist relational perspective which “looks not only at the behaviour of individual patients, providers, and administrators, but also at society and asks how dominant values and institutional options tend to direct individuals in particular directions despite obvious problems with these options.”[[126]](#footnote-127) Sherwin is clear that this work is not solely the responsibility of those who call themselves bioethicists, but she does seem to believe that they have skills well suited to joining this important effort.

To return to the metaphor which drew us to Sherwin’s insights in the first instance, this conception of public ethics challenges PHEs to step away from the hurly-burly, at least on occasion, in order to examine the deeper questions that reflection on their practices might uncover. They are encouraged to join, or to initiate, a long game that employs the insights of relational theory to motivate “changes at all levels of human organization, both formal and informal, in pursuit of moral values.”[[127]](#footnote-128) The scope of the project, however, like the difficulties it seeks to address, is not modest. In Sherwin’s words, “[w]e must think not only about how to change the individual patient or her provider (as is the pattern in non-relational bioethics) but also how to change society.”[[128]](#footnote-129)

*“Wicked problems” and virtuous solutions: Beyond bioethics’ boundaries?*

Although her article was written more than a decade ago, Sherwin’s analysis was prescient as there has been a growing interest of-late in health care’s so-called wicked problems. Despite the suggestive name, these are not problems that are generated by particularly malicious actors, nor need they be problems that strike one as especially evil. The phrase is borrowed from a landmark paper on social planning by Horst Rittel and Melvin Webber who sought a memorable term to describe challenges which are unique, difficult to define, lacking uncontroversial descriptions or definitions, and impossible to address adequately without engagement from multiple and diverse kinds of stakeholders. According to their theory, those who identify such problems will not be able to articulate what success might consist in without appeal to the values that prompted the inquiry in the first instance (nor, to use Rittel and Webber’s phrase, do these problems allow “stopping rules” that allow the social planner to know that the project is complete). Because of interdependencies between systems, every problem can be understood as a symptom of yet another problem, and an effort to address one may have serious and unintended consequences for another. Finally, despite the fact that she has no ability to undo what she has done, the planner has “no right to be wrong” because the effects of her interventions are likely to be significant and far reaching. Wicked problems stand in sharp contrast with the “tame or benign” challenges faced by natural scientists and engineers for whom “the mission is clear . . . whether or not the problems have been solved.”[[129]](#footnote-130)

The wicked problems literature, once largely of interest to social planners and management executives, is now being mined by health care professionals who have come to understand, just as Sherwin did, that the problems that ail individual patients often can usefully be construed as symptoms of much larger societal or systemic issues.[[130]](#footnote-131) Success in tackling these challenges requires, at minimum, an appreciation of the importance of the social determinants of health (typically the province of public health ethics) and, indeed, may require an understanding of the broader issues (such as political instability, environmental degradation, or even, for example, the consequences of armed conflict) that can be gathered under the heading of public ethics. In brief, what Rittel and Webber take to be true of the work of the social planner might be applicable to the expanded mandate that Sherwin and Tronto envision for bioethics. Both occupations are called to engage problems that, to use Adrienne M. Young’s apt description, typically “are ill-defined: and . . . depend on elusive political judgement for resolution. (Not “solution.” Social problems are never solved. At best they are re-solved – over and over again.).”[[131]](#footnote-132)

Interestingly, Rittel and Webber had an early appreciation of the fact that efforts to professionalise the work of social planners were impeded by their inability to adopt the problem-solving style of more traditional professions – an inability that they believed was owing to their subject matter rather than a deficiency in the planners themselves. They may have been speaking with their tongues planted firmly in their cheeks when they observed that the public might be judged perverse for “having condoned professionalism when it was really only dressed-up amateurism and condemning professionalism when we finally seem to be getting good at our jobs,”[[132]](#footnote-133) but Rittel and Webber understood that the supposed contrariness of an uncertain public presaged an important, if more academic, debate about the need for a new conception of the professions.[[133]](#footnote-134) Many professionals, even those in well-established fields, can no longer assume that the problems they face always will be straightforward ones which are amenable to technical solutions. Social planners and practicing healthcare ethicists, as newcomers to the professionalization debate, might feel the sting of scepticism rather more than some others, but the following passage may provide context if not comfort:

now that . . . relatively easy problems have been dealt with, we have been turning our minds to others that are much more stubborn. The tests for efficiency, that were once so useful as measures of accomplishment, are being challenged by a renewed preoccupation with consequences for equity. The seeming consensus, that might once have allowed distributional problems to be dealt with, is being eroded by the growing awareness of the nation’s pluralism and of the differentiation of values that accompanies differentiation of politics. . . . There seems to be a growing realization that a weak strut in the professional’s support system lies at the juncture where goal-formation, problem-definition and equity issues meet.[[134]](#footnote-135)

In light of Rittel and Webber’s sensitivity to the fact that engineering models and metaphors constitute a deflated currency in the age of the modern professional, it is interesting to note the ease with which they reach for them (even in the context of a critical appraisal). The usage makes for a pleasing literary device, and may have been particularly appealing to the audience at the American Academy of Sciences which was the first to hear their wicked problems analysis. Their choice of analogy, however, ought not to slip by without remark because bioethics has long employed an engineering language of its own – a language which invites some misleading inferences. Ethicists may not discuss struts (weak or otherwise) but, as Sherwin has astutely noted, the language of foundations and frameworks may be all too familiar, and structural metaphors can play epistemological and ethical roles that have undesirable effects for which their aesthetic value cannot compensate.[[135]](#footnote-136)

*Progressive lenses: illuminating ethical issues or distorting experience?*

In a paper called “Foundations, Frameworks, Lenses: The Role of Theories in Bioethics,” Sherwin notes that the language of foundations can provide both a sense of security and a methodology in a landscape that can sometimes feel perilous and unknowable. As the wicked problems analysis illustrates, ethical problems can seem insoluble but, as Sherwin observes, “[f]oundationalism is a highly attractive way of understanding the nature of abstract thought in ethics. It encourages us to believe that all true claims can (at least in principle) be ‘grounded in’ solid, undeniable truths and it directs us to evaluate controversial claims by considering whether or not they are supported by plausible theoretical assumptions.”[[136]](#footnote-137) Unpacking those assumptions and attending to their significance is, however, important work – work that she and H. Tristram Engelhardt Jr. have undertaken with vigour. Their analyses and conclusions couldn’t differ more, but the way that they differ can shed needed light on the persistent worry that applied ethics cannot produce answers that are free of partiality and politics.

Engelhardt shares Tom Koch’s keen awareness of, and disappointment in, the fact that the ethical standards which guided the medical practices of earlier generations are, to a large extent, no longer compelling. The reasons for this, he suggests, are two-fold. First, physicians now stand in a very different relation to their patients than they once did. For a variety of reasons physicians have, suggests Engelhardt, become members of an economic interest group rather than a “self-confident guild.”[[137]](#footnote-138) Although they still are, for the most part, fee-for-service (or independent, rather than salaried) practitioners, they are also members of interdisciplinary health care teams and their practice is subject to scrutiny by insurers, quality committees, and other internal and external parties.[[138]](#footnote-139) Second, in the late twentieth century, most Western societies experienced a gradual, but significant, cultural shift that weakened the influence of religion (particularly that of the Protestant Christian denominations) on public life. For medicine, Engelhardt suggests, the implications of this shift have been profound:

The metaphysical foundations that supported the traditional views that guided healthcare in the West were politically delegitimated as a basis for healthcare policy. As a result, traditional moral commitments regarding reproduction, dying, and death were brought into question, as for instance with respect to abortion, artificial insemination by donors, and the use of physician-assisted suicide. . . . The traditional moral culture for medicine had lost its foundations, and a new one required articulation.[[139]](#footnote-140)

Although one might celebrate, mourn, or be apathetic about the changes described in Engelhardt’s potted history, it is impossible to deny his claim that modern medicine is practised in a societal context which is characterised by a diversity of moral views – views which pertain both to the conduct and standing of its individual members, and to the broader aims and responsibilities of the profession itself. Medicine is not, and cannot, be an endeavour which is insulated entirely from the complex problems (some of them wicked, in the sense described earlier) arising in our increasingly heterogeneous and too-often divided political communities. A health care provider (who need not be a physician, although physicians are Engelhardt’s particular focus) has no warrant to resolve difficult cases arising in care provision solely via reference to her personal views about the good, or even the good of her patient. To offer what is now a relatively uncontroversial example, a Jehovah’s Witness who is in need of a heart transplant is not obliged to accept surgery only on the terms his surgeon deems optimal. A bloodless surgery may offer survival statistics that are bleaker than those associated with conventional alternatives, but it is far from obvious that the better procedure will be one that involves the use of blood products. Although surgical teams may insist that physiological outcomes are better when transfusion can be supplied as needed, even those who are most focussed on the technical aspects of the procedure are unlikely to deny that the patient’s values are central to any effort to evaluate the success of the intervention. Even the most secular surgeon now accepts that, for many of her patients, a life purchased at the cost of a soul is one which comes at a price that is too dear.

Cases involving religious objections to the use of blood products may seem relatively straightforward, but it is important to note that if this is so it is only true because adherents of the affected faith have been assiduous about educating the medical community about their beliefs, and because there have been numerous legal decisions that have affirmed the right to refuse unwanted interventions.[[140]](#footnote-141) Other faith traditions and value-orientations are less well understood, however, and the work of a PHE is often precisely to help mediate discussions between patients and health care providers in order to assist each of these parties as they take on the hard work of devising a plan of care when their world views collide. It is not the case that bioethicists have special access to a privileged store of moral knowledge that is unavailable to others, but PHEs do have a specific responsibility, by virtue of their roles, expertise, and education to attend to the ethical dimensions of the cases (clinical, organisational and research-related), that arise in the institutions in which they work. To use Margaret Urban Walker’s phrase, an ethics consultation may be one way of keeping moral space open in an environment that is prone to thinking in terms of technical rationality.

In the next chapter we will turn to what I’ll describe as hard cases. Hard cases prompt reflection on what is distinctive, and perhaps most controversial, about the PHE’s work. My aim is to demonstrate that while hard cases may be challenging or complex – or even in wicked in the sense that I’ve just described – they need not be mysterious, opaque, or even insoluble.

Chapter 4: Ethics as Interpretation: Lessons from Legal Theory

At the outset of this project I claimed that the charges levelled by some of the critics of health care ethics consultants, and consultation, deserve greater attention because our efforts to address them might illuminate aspects of the work that have been neglected in the (I believe, worthwhile) effort to professionalise the field. As a reminder, these charges consist in the various, and somewhat contradictory, claims that the work of ethicists is: *compromised* and ineffectual (often framed as a conflict of interest charge); elitist and *politicised* (which may be implicit in the assertion that the health care ethicist imposes her world view on unsuspecting stakeholders); and, finally, *incoherent* in the context of value pluralism (sometimes expressed as a yearning for frameworks or foundations). The previous chapters have consisted of efforts to reconstruct some forms of each of these challenges with a view toward showing why they need not be decisive arguments against the practice (despite the fact that each contains important lessons with respect to the ways that the practice might lose its bearings or find them). While these indictments were never intended to be comprehensive, they are familiar and serious charges, and they were selected specifically because they encourage an examination of the nature of the work and thereby bring us closer to answering the overarching question with which we began, What *should* practicing healthcare ethicists be doing when they are doing what they are doing?

The short and easy answers to that question have, to some extent, already been proffered. PHEs should endeavour to assist parties tackling hard cases arising in healthcare as they attempt to come to decisions, or try to craft positions, in order to render them ethically better than they otherwise might be.[[141]](#footnote-142) The nature of the PHE’s involvement in a specific case will vary depending on the context in which it arises and the needs of the parties seeking her support. She may serve as a resource to identify pertinent (non-medical) information for parties seeking to know the content of precedents, policies, procedures, laws, and other applicable standards; she may mediate disputes between stakeholders that have come into conflict; and, finally, she may be asked to interpret and apply contested concepts (such as fairness, best interests, coercion, or duty) in order to identify a path forward in light of a particular case or institutional stance.[[142]](#footnote-143)

Information-gathering, mediation, and interpretation may (depending on how they are understood) sound like fairly straightforward and uncontroversial activities. The critics of practicing healthcare ethicists, however, challenge the members of the field to think more deeply about the ways that these activities may provide occasion for an ethicist to introduce bias or exert undue influence over the important value-laden decisions that are made regularly in the healthcare context. Because it would be unlikely for deviation from settled practice to go unnoticed, and uncontested, in routine consultations what we might call hard cases will provide our point of departure. Although I don’t use the terminology in precisely the way that our colleagues in jurisprudence do, it should gradually become evident that their insights have inspired my analysis and recommendations.

*What makes a hard case hard?*

Bioethicists are typically consulted when those involved in health-related decision-making are faced with circumstances or questions that they find problematic or perplexing in some way. A novice health care practitioner, or a new hospital employee, might ask for direction with respect to a question that can be answered empirically, or via reference to well-established rules or norms (for example, a nursing student or surgical resident might ask the bioethicist: Who should make treatment decisions for an incapable patient without any known family or community? Is informed consent necessary for even a very low risk medical intervention?), but the more interesting and controversial part of the PHE’s work will consist of what might be dubbed “hard cases.” The nature of hard cases varies however, and it may be useful to distinguish the chief ways that hard cases are hard. The categories may overlap, and while cases may be challenging in more than one way, the effort to parse their content provides an occasion to think about the work in a fresh way; that is, it can invite bioethicists specifically to draw upon some of the lessons of legal theory.

As may be expected in a stressful health care environment, some cases may be described as hard primarily because they are emotionally taxing. For example, a case involving a patient with an injury, disease, or disability that causes great suffering, especially if that suffering cannot be ameliorated, may be described as hard in this sense. In addition, if a health care provider identifies closely with a particular patient, he may want to consult with a PHE to reassure himself that he has not overlooked important details, or lost critical perspective, owing to the psychological demands of the case. Ethicists too may experience this type of angst when a case strikes an emotional chord, although they may lack access to advisors or communities of practice with whom the case may be reviewed. We may call this kind of case an *evocative case*, recognising that some consultations have the potential to elicit strong feelings toward, or against, particular patients or patients in particular circumstances.[[143]](#footnote-144)

Another type of hard case (also emotionally challenging, but for a

different reason than the first) is one which generates what is often described as moral distress. *Morally distressing cases* were first described in the academic nursing literature and, although the phrase is often used without great precision, the concept can be traced back to an enormously influential text by Andrew Jameton that was published in 1984. Jameton’s focus was on threats to the morale and professionalism of nurses, and he described moral distress as the feeling evoked by situations in which the provider “knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.”[[144]](#footnote-145)

Much has been written on the topic since this early effort to name a common source of staff burnout and disaffection, but the concept remains a useful one, especially when it is expanded to cover distress prompted by a tension between a professional’s sense of ethical integrity and a myriad of external forces (such as institutional, legal, or interpersonal factors) that prevent her from acting in accordance with those values. An example might be the case of an intensivist faced with a substitute decision-maker who insists on maintaining full code status for a patient with a profound and diffuse brain injury. Even if the physician does not share the values of the patient’s legally-authorised representative, she may be obliged to act in accordance with those values so long as the situation is not physiologically futile.[[145]](#footnote-146) Similarly, a healthcare ethicist may experience moral distress because she believes that a Ministry of Health funding formula which fails to cover routine dialysis for impoverished and uninsured patients (especially when those patients seem to meet what she sees as the criteria for community membership) fails any reasonable test of justice.[[146]](#footnote-147) It is important to notice that these cases can be distinguished from evocative cases because they point to a very specific source of tension. Despite the name, which I employ because of an established literature, not all evocative cases are morally distressing, although many morally distressing cases are likely to be evocative too.

A third kind of hard case arising in health care is that which lacks clear answers because there appear to be few applicable standards, precedents, settled practises, or other clear guides to aid judgement and action. Existing standards, or well-established principles, may pull the clinician (or, indeed, the practicing ethicist) in opposing directions or they may seem not to be entirely on-point, yet decisions will need to be made and a way forward must be found. Such a case might involve, for example, a request to supply an evaluation of the ethical merits and shortcomings associated with the use of a novel technology (an example might be non-hypothesis driven research on machine learning algorithms), or to provide an appraisal of a treatment option which seems to fall outside of the standards ordinarily governing current practice (such as a proposed case of surgical innovation).[[147]](#footnote-148) In addition, a clinical case may feel hard because it requires that decisions be made with only the scantiest evidence about a patient’s relevant values or interests; perhaps because he never possessed decisional-capacity or because, although previously capacitated, he was silent on matters relevant to current decision-making imperatives. We might call these kinds of hard cases, following the terminology coined by the legal theorist H. L. A. Hart, *penumbral cases* because they take their stakeholders into a zone of indeterminacy where it can seem that no answer can be deemed right even if some appear to be clearly wrong.

As was mentioned earlier, the varieties of hard cases described above (those to which I have given the labels ‘evocative,’ ‘morally distressing,’ and ‘penumbral’) are not meant to be mutually exclusive: an evocative case may lack clear precedents, and a morally distressing case may be evocative. It is also true that they need not comprise a bioethicist’s entire consultation caseload; other types of hard cases may well exist. My ambition, however, is not to offer a comprehensive account of the practicing healthcare ethicist’s labours, or even of her full range of consultation cases.[[148]](#footnote-149) My immediate task is the more modest one of naming and distinguishing some familiar categories of health care ethics consultation in order to determine whether we can think more productively about how to engage some of the most challenging and contentious aspects of that work.

*Practising in the penumbra: variation and values*

Although those cases that I have labelled ‘evocative’ and ‘morally distressing’ do not constitute a small or inconsequential part of a clinical ethicist’s work, it seems reasonable to suggest that these are not the kinds of cases which present unique or especially problematic challenges for the field. Indeed, the literature of most, if not all, of the health-related professions makes mention of the various boundary dilemmas that I reference within the broader category which encapsulates evocative cases; and morally distressing cases are, by definition, troubling precisely because they leave little doubt about the kinds of actions that are expected of the health care professional (despite her desire to avoid or resist them). Penumbral cases, on the other hand, would seem to present the greatest opportunities for bioethicists to render opinions, or to offer analyses, that are compromised, politicised, or incoherent in the ways that these terms are intended to capture. Before we can assess the gravity of these charges, however, it will be helpful to have at least a modest acquaintance with what H.L.A. Hart described as the “problems of the penumbra.”

In an elegant and much-cited paper called “Positivism and the Separation of Law and Morals,” Hart offered an analysis of the way that judges reason through the cases that come before them. Noting that a particular school of legal thought, that associated with the so-called American Realists, were onto something important when they suggested that what judges do differs from how they describe what they do, Hart observed that - despite the fact that our language often suggests otherwise - rules, including legal rules, such as a very simple one that forbids the use of vehicles in a public park, may accommodate a range of understandings. Although the rule might clearly prohibit the operation of automobiles in a specific public space, it is far from self-evident, for example, that children’s toys or all manner of human-powered conveyances are also to be subject to the ordinance:

Are these, as we say, to be called “vehicles” for the purpose of the rule or not? If we are to communicate with each other at all, and if, in the most elementary form of law, we are to express our intentions that a certain type of behaviour be regulated by rules, the general word we use – like “vehicle” in the case I consider – must have, some standard instance in which no doubts are felt about its application. There must be a core of settled meaning, but there will be, as well, a penumbra of debatable cases in which words are neither obviously applicable nor obviously ruled out...[[149]](#footnote-150)

Hart’s essay, and indeed the body of his work on the nature of law, has made an important contribution to an enduring and nuanced literature that concerns the way that legal standards can be identified, how judges judge, and the nature of the relationship between legal and moral standards. Legal positivists, including Hart, are often associated with the position most clearly expressed in John Austin’s famous dictum, “the existence of law is one thing; its merit or demerit is another,” whereas so-called natural lawyers, or interpretivists, like Ronald M. Dworkin, have insisted (to varying degrees) that law and morality are never entirely separable.[[150]](#footnote-151) The way that legal theorists approach hard cases is especially interesting to the receptive ethicist for a number of reasons that will gradually become evident. First, those mired in sorting out the ethical challenges that arise in the daily work of healthcare may be surprised to discover that even legal standards - standards that are often taken to be clear, dispositive, and largely unchallengeable - are not self-announcing. As Hart observed:

Fact situations do not await us neatly labelled, creased, and folded, nor is their legal classification written on them ready to be simply read off by the judge. Instead, in applying legal rules, someone must take the responsibility of deciding that words do or do not cover some case in hand with all of the practical consequences that cover this decision.[[151]](#footnote-152)

Second, how judges understand, and resolve, the uncertainty inherent in penumbral cases is a source of considerable debate. Some legal theorists maintain that penumbral cases are those in which the law has essentially run out and it is the judge’s responsibility to legislate in the gap that remains. Others have insisted that the law can never run out because adjudicators are charged with the work of interpreting existing legal materials - including moral principles - which they believe to be implicit in prior decisions and legal statutes in order to offer interpretations of what the law requires in the cases that have come before them. Whichever approach one finds more convincing (and, I admit that both are far more complex than this gloss suggests) it may be comforting to know that there is a deep and sophisticated literature that has engaged the challenges presented by hard cases – particularly hard cases of the penumbral kind - and has offered some promising strategies to aid in their resolution.

It may seem perplexing to respond to one the most controversial aspects of the PHE’s work by referencing an area of scholarship which is fraught with debates that are as contentious as any arising in the practice or literature related to clinical ethics consultation. If I may paraphrase Hart, however, the sovereign virtue in jurisprudence is clarity, and we may learn much even from positions in these debates that we think wrong, especially when those positions are clear and cogent.[[152]](#footnote-153) The various debates in legal theory that, for example, have engaged the relationship between law and morality, and the nature of judicial discretion, may not have been settled once and forever, but they have produced some ways of thinking about the law that may shed needed light on how we might understand, and resolve, the penumbral cases arising in clinical ethics consultation. Both law and medicine, after all, are complex social practices which engage controversial and high stakes questions which defy easy answers. In addition, as I suggested earlier, some of the hard cases arising in healthcare may be challenging in precisely the way that they are hard in legal decision-making. Even when the relevant medical facts are uncontested, there may be no ethical (or indeed, legal) standards that are clearly applicable to a specific case. Alternatively, there may be a number of competing standards, principles, or values that may influence ethical decision-making. Although it is generally accepted that there are cases which may be resolved by reasonable people in different ways, ethicists can productively assist stakeholders by examining the underlying justifications for proposed solutions to ensure that they take account of relevant facts, and are not political or partial in ways that violate stakeholder’s rights, undermine the credibility of the consultation process, or threaten the very integrity of the practice of medicine. In this respect, there are aspects of clinical ethics consultation which can benefit from long-standing debates within jurisprudence, including those which endeavour to understand the nature of what is sometimes described as judicial discretion.

*The core and the penumbra: Settled questions and unsettling ones*

As Hart’s example illustrates, even standards that seem to be straightforward are not always uncontroversial with respect to their meaning or application. A simple rule, like the “no vehicles” injunction, may support a variety of interpretations including ones that prohibit, or permit, the use of bicycles, roller skates, or toy automobiles in a common space. Someone (in a legal context it will be a judge) therefore, must decide what that rule means for the cases that fall, in Hart’s words, in the penumbra or outside the “core of settled meaning.”[[153]](#footnote-154) Legal theorists have spilled a great deal of ink on analyses of how judges make, or ought to make, decisions in such cases, and Hart himself noted that one plausible approach might be simply to admit that “laws are incurably incomplete and we must decide these penumbral cases rationally by reference to social aims.”[[154]](#footnote-155) These aims, however, are also subject to interpretation, and may be judged morally desirable, neutral, or pernicious, and Hart understood this to be case. His essay did not commit him to a particular strategy for adjudication, nor did it say anything about how one might choose between competing social aims. Instead, Hart endeavoured to show that it is possible both to distinguish the law as it is from the law as one might wish it to be, and to refute the notion that judges must make decisions in automatic or mechanical ways if they are to avoid succumbing to the inference that the law is merely arbitrary in the sense that it is reducible to a particular judge’s pet policies or personal preferences. With respect to the interpretation of legal standards, Hart concluded that, “we live among uncertainties between which we have to choose, and … the existing law imposes only limits on our choice and not the choice itself.”[[155]](#footnote-156)

The lessons for bioethicists, even in this very austere account of a much more nuanced debate, are manifold. To begin with, PHEs who have been asked to aid stakeholders in the resolution of hard cases may find it tremendously helpful to begin their efforts by attempting to distinguish the aspects of the cases that are in need of interpretation, or subject to discretion, from those which are settled or relatively uncontroversial. In other words, an important aspect of any clinical consultation will be to identify, in no particular order, pertinent “facts” such as a patient’s diagnosis and prognosis (recognising that the latter may vary in light of any proposed treatment options); his relevant goals, values, and wishes; other stakeholders’ pertinent goals, values, and wishes; contextual features that render various options more or less desirable or attainable (such as the financial or other costs associated with embracing or forgoing each of these alternatives); any policies, laws, institutional goals, or professional obligations that limit certain options or make them more readily attainable; and, finally, who has the authority and responsibility to make which decisions. All of these variables, to echo Hart, place limits on choice even if they do not dictate the choice itself, and once that is well understood the practising healthcare ethicist, and those who rely on her services, can identify precisely what falls within the sphere of discretion. To return to an earlier, and relatively simple, case before moving to a harder one, the PHE advising the intensivist on her obligations with respect to a request for “futile” cardiopulmonary resuscitation (CPR) will need to clarify the aspects of the case which are settled or are largely non-negotiable. In many jurisdictions this will mean that she cannot write a do not attempt resuscitation (DNAR) order without the approval of the patient’s legally-authorised representative (LAR) or representatives, and the decision-maker or decision-makers should be advised as to the obligations associated with the LAR’s role (that is, to give direction that is in accordance with any known relevant wishes that the patient expressed while capable or, if no known wishes are applicable, to act in the patient’s best interests).[[156]](#footnote-157) If the medical, legal, and policy-related facts of the case have been articulated clearly, but disagreement persists, the ethicist’s role may simply be to make the parties aware of how they may initiate their local dispute-resolution process.[[157]](#footnote-158) In Ontario, such cases can be referred to a quasi-judicial body known as the Consent and Capacity Board (CCB) which will rule on who has decision-making authority in each of the cases which come before it. While the CCB’s decisions clarify who has the legal right to make decisions for particular incapacitated patients, they do not engage substantive issues such as whether resuscitation is the right option for a particular patient given his current status, known values, and best interests. Moreover, the Board is not empowered to entertain broader and more philosophical questions such as, Can it ever be ethically desirable or defensible to attempt resuscitation on patients who are not expected to survive the intervention or are almost certain to have poor physiological outcomes?

These last questions are ones that the ethicist is obliged to engage far less often than the public might expect, at least in her capacity as a practicing healthcare ethicist. The consultant’s role generally is focused on questions that relate to the rights, duties, values, and interests of particular individuals or institutions and, as the case related to resuscitation status suggests, there may be little room for discretion once the settled aspects of a case have been identified. Just as an automobile fits within the so-called core, or settled meaning, of the term vehicle, it is generally uncontroversial that legally authorised representatives – meaning those appointed by patients or identified via statutory law – are the parties who possess the right to direct care for decisionally-incapacitated patients.

Some consultation cases, however, require more than information-sharing, or the identification of appropriate decision-makers, and the path forward may be far less illuminated. Parties seeking guidance in resolving these penumbral cases may ask specifically for the ethicist to offer her view on deeply contested matters such as whether a “futile” resuscitation can be defended on moral grounds, or whether a patient’s critical care physicians should be able to refuse to honour requests for CPR that they deem non-beneficial or harmful. Alternatively, a patient’s family members may wish to know if it can be defensible to decline or discontinue treatment options that members of the clinical team regard as routine or medically appropriate. Such cases can take the ethicist into more challenging and contested territory; zones of engagement where her clinical and bioethical colleagues may hold a range of perspectives about how best to proceed. These are the kinds of cases that the critics of clinical ethics consultation may find most disturbing because they allow no prospect of resolution which can be described as entirely value-neutral, and there is a potential for the ethicist’s world-view to have a disproportionate influence on decision-making. Next, I will turn to a topic which is generating precisely these sorts of worries both in the popular imagination and in the emerging professional literature.

*MAID in Canada: Making Sense of our Legal and Ethical Obligations*

Following a landmark Supreme Court decision known as *Carter vs Canada* many Canadian PHEs have found themselves reflecting on, and responding to, hard questions related to medical assistance in dying (MAID).[[158]](#footnote-159) The fact that the county’s highest court has recognised a limited right to medical aid in dying, and the subsequent passage of a statute setting out criteria for eligibility, has not meant that all related ethical questions have been settled for patients, health care institutions, or for those who find their employment within those institutions. On the contrary, in the post-*Carter* era, a great many PHEs have seen a significant increase in requests for consultation support and policy advice as a variety of hard questions have arisen concerning, for example, the MAID-related duties of health care providers; the nature and limits of conscientious objection and conscientious commitment; and the balance to be struck between a respect for patient self-determination and the duty to protect those who are vulnerably-situated.[[159]](#footnote-160) Attempts to respond to these requests will be most successful if there is clarity about the kinds of questions that they are (legal, ethical, or purely procedural, for example) and, as we will see next, if there is greater transparency about what ethicists are doing when they are engaging these new, and frequently divisive, concerns.[[160]](#footnote-161)

In the three years that have passed since the *Carter* decision, there have been a number of developments that have added clarity, and some complexity, to efforts to understand the implications of that ruling for patients and health care providers. Most noteworthy was the passage of Bill C-14 in the Canadian Parliament on June 17, 2016. This resulted in a statute that amended the *Criminal Code*, established the conditions that must be met for a person to be found eligible for medical assistance in dying, and outlined the administrative procedures that must be followed by health care practitioners who are authorized to provide MAID interventions and related supports.[[161]](#footnote-162) Some aspects of the legislation are relatively straightforward, and require little interpretive effort, such as the legal safeguards which stipulate that the requestor be at least 18 years of age; that the request be made in writing and witnessed by two independent parties; that the eligibility assessors be nurse practitioners or physicians who are independent of one another; that a minimum reflection period of ten clear days elapse between the request and the provision of the intervention; and that the requestor be capable of giving consent immediately before MAID is provided. Other aspects of the legislation, including some of the criteria that must be met for a patient to be considered eligible, have been far more difficult to unpack and have generated controversy even within the ranks of MAID assessors and providers.[[162]](#footnote-163) Chief among these is the requirement that the patient have a “grievous and irremediable condition” which is defined as follows in Section 241.2 (2) of the Act:

A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

(a) they have a serious and incurable illness, disease or disability;

(b) they are in an advanced state of irreversible decline in capability;

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and

(d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.[[163]](#footnote-164)

Although the phrase “grievous and irremediable” is now a legal term of art, and efforts to parse its meaning have been helpful in some respects, many aspects of the statute continue to generate legal as well as ethical uncertainty. Section 241.2(2) (c), for example, makes the test of suffering a subjective one, one of which the patient is the ultimate arbiter; however, a health care practitioner, even one who is a reasonably experienced MAID assessor or provider, may find herself unsettled by a particular patient’s report of intolerable suffering and may conclude that amelioration would be possible if only his social or financial circumstances were more favourable. She may, for example, find it difficult to reconcile herself to the fact that a relatively isolated long term care resident in an advanced stage of amyotrophic lateral sclerosis (ALS) will almost certainly experience far greater suffering than a celebrated cosmologist who shares his medical status, but continues to be animated by conceptual conundrums and to be buoyed by abundant human and technological resources. The uncomfortable and unavoidable reality is that while health care providers understand that the practice of medicine consists in far more than ordering, and responding to, the results of nerve conduction tests or measures of lung capacity, a significant number of them had not dwelt – prior to the *Carter* decision - on how such results might translate into questions regarding the quality of their patients’ lives (or the nature and extent of their suffering). Although some patients’ requests for aid in dying may be understandable (given their current health status as well as their settled values, wishes, and beliefs), their most responsible providers must now confront the normative dimensions of their work with a greater urgency than before.

In a similar vein, although the section 241.2(2)(d) requirement that the patient’s natural death be “reasonably foreseeable” may help to rule out suicidal ideation as a basis for eligibility, it too has fostered ambiguity and generated a measure of anxiety within the medical community. While some physicians or nurse practitioners may be relatively comfortable providing MAID to a requester with a fairly certain and short prognosis, such as a patient with metastatic cancer who is expected to survive only six months to a year, these are not the only patients who have the right to have those requests fulfilled.[[164]](#footnote-165) Indeed, in June of 2017, the Ontario Superior Court of Justice clarified that the legislation does not, and cannot, offer the sort of specificity that would make interpretation of the reasonable foreseeability criterion entirely straightforward. In denying a patient’s (A.B.’s) request that the court issue a declaration finding her eligible for MAID, Justice Perell offered the following statutory interpretation:

… natural death need not be imminent and that what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan… [I]n formulating an opinion, the physician need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime…These are matters at the core if not the whole corpus of medical knowledge and better known to doctors than to judges. The language reveals that the natural death need not be connected to a particular disease or condition and rather is connected to all of a particular person’s medical circumstances.[[165]](#footnote-166)

In short, while the justice acknowledged the messiness that can be an unavoidable aspect of medical assessment, he was unequivocal in his judgment that resolving this untidiness was not the province of the law. In support of his view, Justice Perell cited the words of Jody Wilson-Raybould, then Canada’s Minister of Justice and Attorney General, who stated at the time of Bill C-14’s introduction that its “flexible” language was “deliberately chosen to ensure that people who are on a trajectory toward death in a wide range of circumstances can choose a peaceful death instead of having to endure a long or painful one.” Wilson-Raybould continued with the observation that, “[i]t makes sense to limit medical assistance in dying to situations where death is reasonably foreseeable, where our physicians, nurse practitioners, and others, can draw on existing *ethical* and practical knowledge, training and expertise in addressing these challenging circumstances” [emphasis mine].[[166]](#footnote-167)

Health care professionals generally accept the reality that their patients experience suffering in a variety of ways and they are familiar with prognostic uncertainty, especially when dealing with illness, disease, or disability that is chronic and tough to manage. MAID cases, however, can seem especially fraught because they represent the end of a relationship between patient and provider (a trial of therapy is an alternative to assistance in dying, not what MAID itself offers), and because they force reflection on the purpose, or purposes, of the practice of medicine itself.[[167]](#footnote-168) This may explain, at least in part, why palliative care physicians, the group that some members of the public believed would be the best equipped to respond to requests to hasten death, has been one of the most reluctant to embrace this new role.[[168]](#footnote-169) Palliative care specialists have worked hard to promote the view that their focus is on pain and symptom relief, and the suggestion that some suffering cannot adequately be addressed by means other than the provision of death can be difficult to accept. Some palliative care providers have made their processes of discernment public, and a significant shift in thinking has occurred in the past few years, but it must be noted that this movement has not solely, or primarily, been the result of increased clarity about the legal consequences, or lack thereof, which might issue from a misconstrual of statutory law.[[169]](#footnote-170) The Canadian Medical Protective Association (CMPA), which makes medico-legal services available to all physicians licenced in Canada, does offer advice about practitioners’ legal exposure with respect to particular circumstances, and that advice can be a comfort in borderline cases, but, as many PHEs will attest, MAID providers frequently desire counsel of a different kind. Dr Sandy Buchman, a palliative care physician and the current president of the Canadian Medical Association, has been remarkably forthright about his struggle to re-examine his professional duties in light of the legalization of medical assistance in dying. His remarks on the progression of his thoughts on the topic are worth reproducing at length:

MAID’s complexities pose ethical challenges for the profession and for individual physicians. I began deep personal reflection. What are the goals and values of medicine? Can hastening death be an ethical and legitimate goal? What is the nature of suffering? What is the role of the physician in relieving suffering? What does it mean to respect patient autonomy?

I continue to reflect on these questions. I make the choice to provide assisted death to my patients because I believe that it is a compassionate response that fully respects patient autonomy.

It was not an easy decision. I had been a family physician for more than 35 years, and a palliative care physician for the past 11 years, before MAID became legal. My education and beliefs had led me to seek to extend life whenever possible and appropriate, and certainly not to hasten a patient’s death.

This was anathema to me. It took me the better part of two years to sort through my deepest emotions, my values, and the tenets of my faith to decide that I would help my patients die. Ultimately, helping eligible patients who wanted choice over the manner and timing of their deaths is consistent with what I have always done: relieve suffering.[[170]](#footnote-171)

Although Buchman’s openness may be unusual, his preoccupations are not, and while many members of the Canadian public may approve of his perspective, a significant percentage of physicians are opposed to his point of view. Indeed, the reactions to his commentary, which appeared in a recent issue of the *British Medical Journal*, were swift and polarised. A letter authored by seven of his Canadian colleagues enumerates concerns that will sound familiar to those who have been following the MAID debate:

Dr. Buchman romanticizes euthanasia. He calls it “the most patient-centered service I could offer,” leading to “the most peaceful death I had ever witnessed.” Peer reviewed, published evidence demonstrates that most requests for euthanasia are motivated by a desire for control, or a fear of dying, not by uncontrolled symptoms such as pain or shortness of breath….These existential issues include fear of loss of control, questioning the meaning, purpose and value of life, fear of what comes after death, demoralization, and fear of being a burden to others…. [H]astening the death of a patient removes any further therapeutic opportunities. Simply bowing to “patient autonomy” and ending a life without working hard to alleviate the deeper total pain is hardly “patient centered” in the most robust sense of that term.

….[I]gnored in Buchman’s account are those whose lives are made even more vulnerable by the very existence of euthanasia, including those with disabilities, mental illness, dementia, children, seniors, and those who lack resources including financial, social supports, or access to palliative care.[[171]](#footnote-172)

It is clear that reflection on the moral standing of MAID is required of all physicians who live in jurisdictions where it currently is, or soon is likely to be, a legal option. Moreover, even healthcare practitioners who work in hospitals, hospices, and palliative care facilities that do not offer access to the intervention can find themselves confronted by the ethical questions that occupy the members of their wider communities. Their patients may seek referrals to willing providers, and their professional colleges, and employers, will have expectations about the responses that they are permitted or obliged to give. However, even in this sometimes charged environment, the role of the healthcare ethicist does not, and should not, differ from what it typically is: she may offer education that can prepare staff, physicians, and patients for respectful engagement in the face of conflicting or uncertain values; she may help to answer, or to clarify, the nature of the questions they may be posing; she may offer mediation, or debriefing sessions, that can help to identify and manage some of the distress that hard cases elicit; and, most controversially, when her advice is sought, she may offer her interpretation of the right way (or ways) to deal with the difficult normative questions that must be confronted by patients, health care providers, and institutions in light of this new medical, legal, and social development.

The final clause of the preceding statement may seem to be in tension with my earlier claim that PHE’s disavow any ambition to be seen as the consciences of their colleagues or of the corporations that employ them. After all, presuming to offer right, or at least better, answers to hard questions may sound perilously close to the kind of ethical imperialism that the critics of the field have decried. Further detail is in order, therefore, before we can distinguish appropriate guidance from unacceptable interference with respect to the matter of MAID.

As was noted early on, Canadian ethicists typically are active in multiple and often inter-related healthcare activities. For many this has meant that the *Carter* case has served as a call to action, and whatever their views on the arguments unfolding in the courts or in the newspapers, they have felt duty-bound to enhance their understandings of the philosophical as well as the practical implications that the Court’s judgement might have for their communities and institutions. Some ethicists have offered expert testimony to legal or governmental bodies, many have participated in public debates and deliberations, and a great number have helped to write the policies or frameworks that define their institution’s MAID-related expectations of (participating and non-participating) physicians, employees, learners, and volunteers.[[172]](#footnote-173) It is noteworthy that a number of hospital-based ethicists also have assumed the responsibilities of running their home institution’s MAID programs. This may be owing to a willingness to fill a much needed gap in service (hospitals have not yet received additional Ministry of Health funding to support this emotionally demanding and time-intensive work), or it may be motivated by a sense that MAID is more intimately connected with ethical concerns than other operational initiatives.[[173]](#footnote-174)

*Inside traders or honest brokers? Examining the terms of the PHE’s relationship(s)*

Clinical ethics consultation, as it relates to MAID, can engage some of the most sensitive personal and professional concerns that a PHE is likely to encounter. Because a healthcare provider’s participation in MAID is always voluntary, a MAID assessor or interventionist likely will have reflected on her own position with respect to such topics as patient self-determination, or the value of alleviating suffering, long before she has agreed to accept her initial case.[[174]](#footnote-175) It is a truism, however, that all of us are unique in our particularity, and the healthcare ethics consultant may be engaged by a provider to help probe the reason (or reasons) why specific cases are experienced as unusually challenging. The hard cases typology that I introduced earlier may be helpful in distinguishing the various roles that ethicists may play in response to the assorted MAID-related cases that may have need of her attention.

First, if the case is an *evocative* one, the patient’s story may be especially poignant and, with sensitive questioning, a MAID assessor may discover that perplexity dissolves when sorrow, rather than ethical complexity, is identified as its source. The progression of metastatic disease may have turned hope for remission into a desire for a peaceful death, and an exploration of the emotions that attend a shift with respect to the goals of care may transform a hard case into a straightforward, if melancholic, one.

Second, a *morally distressing* case may become more manageable once a MAID provider has an opportunity to explore precisely what makes her case hard. She may find herself unable to fulfil a patient’s request because his capacity to consent has become questionable or has been lost altogether. In such a case, the legal prohibition on advance requests may oblige her to withhold the intervention, but opting for the prudent course may not strike her as the morally right thing to do. In such a case the PHE may not need to point out the arguments that favour action or inaction. Instead, she may be engaged to offer a sympathetic ear, or to provide a reiteration of the features of the case that render MAID provision a professional and legal hazard.

A *penumbral case*, however, may require greater conceptual effort to disentangle than the previous two, precisely because (as with legal penumbral cases) it cannot easily be resolved by consulting relevant rules, precedents, or analogous cases. The case of a frail elderly couple seeking to die together, via MAID, after many decades of happy marriage may strike some as hard, because the source of the healthier spouse’s suffering is not purely physical in nature, but is rooted in the fear of a future without his beloved.[[175]](#footnote-176) Their assessor may find herself torn with respect to the question of eligibility because although she believes their distress to be genuine and compelling, she may worry that it does not meet the requisite legal and ethical thresholds (because the loss of a loved one is a pain that is a universal and surmountable part of the human condition). Consultation with a slight and contradictory literature may yield little guidance as well. While some have argued that the relief of existential suffering is therapeutic, and a good that can be pursued via MAID, others are concerned about interpretations of eligibility that treat old age and frailty as grievous and irremediable conditions.[[176]](#footnote-177) In a case of this kind, the PHE must not succumb to the temptation to substitute her moral beliefs for those of the assessor. On the other hand, it is unlikely that presenting a catalogue of current perspectives will offer either comfort or a strategy for resolving the conflict.

As has already been acknowledged, an ethicist’s approach to consultation generally ought to be non-directive, and decision-making authority should remain with the primary stakeholders: the patients, the providers, and any others, who will bear the brunt of the burdens, or responsibilities, associated with those decisions. The ASBH *Core Competencies* Guide has described the skills, knowledge, and attributes essential to the proper conduct of clinical ethics consultation as it is so conceived. A question that has largely been neglected, however, on both sides of the Canadian-American border, is how practicing healthcare ethicists ought to respond when those stakeholders seek something other than mediation, clarification, or education about available options. On occasion, PHEs may specifically be asked to evaluate the evidence before them and to deliver an ethical assessment of their own. This is especially true with respect to organisational ethics consultations, but it can occur in clinical cases too, especially when they are of a penumbral kind. How ethicists respond to such requests is a delicate matter and may shape perceptions of the field’s interests and influence. This takes us back to our earlier worries about undue influence or conflict of interest – worries that may be assuaged if we pause to consider what we’ll call, with credit due to Francis Kamm, the insider-outsider problem for practicing healthcare ethicists.

*Taking sides or occupying the middle ground? An insider/outsider approach to the practice of ethics consultation*

In a brief, but densely argued paper, “The Philosopher as Insider and Outsider: How to Advise, Compromise, and Criticize,” Kamm considered the now well-known dilemma faced by Dan Brock during the year he served as staff philosopher for the President’s Commission on Ethical Issues in Medicine. Despite the fact that Brock believed that the distinction between killing and letting-die was ethically immaterial in a number of medical contexts, he did not share that conviction with the commissioners out of an overriding concern that forthrightness would forfeit any prospect of securing consensus on important policy matters. Brock regretted the need to be “manipulative” but, suggests Kamm, he held the view that unlike academic philosophers, who are bound to “follow the truth wherever it leads regardless of consequences and to leave no assumptions unchallenged…philosophers in the public realm should not do likewise” because their duties are owed to the public.[[177]](#footnote-178) Discharging those duties appropriately, Brock maintained, consists in supporting whichever policy or policies are most likely to advance the public good.

Even if we presume that Brock was prescient enough to anticipate all of the effects of his omission or manipulation, it is not at all obvious that he did what was right by endeavouring to do good. Kamm identifies three normative duties (which she admits may not be entirely equivalent to contractual duties or employment terms) that provide insight into the nature of a philosopher’s role on a government-sponsored commission:

I suggest that the philosopher's primary duties should include helping point out problems with and implications of the commissioners [sic] own views, giving the commission his considered judgment on what a bottom line should be and his reasons for it, and informing the commissioners of philosophical views held by others when these differ from his own. The first and third duties derive from a normative theory of why we have a commission, i.e., selecting certain individuals to become better informed about issues. The philosopher's second duty – to actually philosophize - is consistent with another aspect of the normative conception of a commission. For the sake of public credibility one may form a commission which includes representatives of various views present in the community, but these individuals should engage in reflection and reason giving, not merely voting and compromising. A philosopher should be able to guide them in certain respects in trying to reach a conclusion by himself reflecting and reason-giving.[[178]](#footnote-179)

The first of these, which we might abbreviate as the duty “to point out problems with and implications of [others] views” seems consistent with the role of an applied ethicist who has been invited to lend her perspective to efforts to resolve a challenging case. Attention to the inter-personal dimensions of the consultation may be needed, especially if the case is an emotive or distressing one (and it may be especially delicate if the stakeholders are directly and personally engaged), but if PHEs are, as the ASBH has asserted, tasked with “identifying and analysing the nature of the value uncertainty” this would seem to be one of her chief responsibilities.[[179]](#footnote-180) A consultation that failed to identify the reasons for doubt or disagreement could scarcely prompt a resolution. Moreover, if the case is organisational in nature, and the question that must be answered is related to the organization’s policy or priorities (such as whether a hospital-based MAID program ought to restrict its service provision to patients with terminal illnesses and short prognoses), the PHE will be charged with the very same task, albeit with far more stakeholders. As part of this effort she will unearth, and help to examine, the various arguments and assumptions that support and oppose the approaches under consideration.

The third duty of the philosopher-insider, according to Kamm, is to inform requestors of “philosophical views held by others when these differ from his own.” This duty serves an educational function to be sure, but its value, like the HCEC’s code obligation to “speak responsibly,” does more than provide context and confidence. In presenting contrary views (preferably in a manner that reflects a commitment to conversational charity) the consultant commits herself to transparency and provides an opportunity for others to accept or reject her own.

The second duty of the philosopher-insider, which Kamm pithily describes as the duty “to actually philosophize,” may be the most controversial of the three. In “giving the commission his considered judgment on what a bottom line should be and his reasons for it” the philosopher has the potential to affect others’ thinking and behaviour in a direct and significant way. For an ethicist practicing in a healthcare setting this sort of influence may seem inapposite, although it should be noted that her stakeholders need not heed her advice (just as Kamm’s hypothetical commissioners were free to disregard their philosopher’s recommendations).

Brock’s case is an instructive one because he conceived of his duty in a way that may appeal to many PHEs. He was willing to supress his own reservations, and to conceal his philosophical processes, in order to secure a policy outcome that might otherwise have been scuttled. This exercise in diplomacy however came at a cost higher than the price of a clear conscience.[[180]](#footnote-181) By failing to speak forthrightly Brock failed to fulfil the duties that Kamm detailed. The commissioners lost the opportunity to hear, learn from, and to judge his arguments for themselves; and in his failure to philosophize he made an assumption about what the “bottom line” should be. To use Kamm’s words, that bottom line was not determined via “reflection and reason giving” but by “merely voting and compromising.”[[181]](#footnote-182)

Philosophizing at the bedside, boardroom, or benchside[[182]](#footnote-183) – even, or perhaps especially when, it is skilled or persuasive – may appear inconsistent with a respect for stakeholder self-determination but, as Kamm’s analysis shows, a failure to do so may be more problematic yet.[[183]](#footnote-184) What might be condemned as insider influence (or the imposition of the ethicist’s values) may in fact be quite the opposite, an effort to act as an honest broker. If my application of Kamm’s analysis is at all convincing, it can be said without contradiction, that the task of the PHE must be modest and ambitious; and, at the same time, collaborative as well as solitary.

In the next section we will return to legal theory, a department of philosophy where penumbral questions, and the matter of their resolution, have been a subject of long and nuanced debate. For if Kamm is right, and applied ethicists must sometimes engage in “reflection and reason-giving,” then it is important for PHEs to be thoughtful and transparent about the sorts of reasons that these might be.

*Integrity in interpretation: the right answer (or answers) for applied ethicists?*

Although it was H. L. A. Hart who first identified the problems of the penumbra, one of his successors is best known for persistent efforts to dispel its darkness. Through a series of books and articles, Ronald Dworkin advanced a theory of interpretation that endeavoured to show how judges should adjudicate in hard cases, particularly hard cases of a penumbral kind.

While Hart suggested that the penumbra was an area where adjudicators were obliged to exercise their discretion, Dworkin perceived constraints even in those putative gaps. As he stated in a paper that introduced an early iteration of his approach: “In very hard cases, as in very easy ones, ‘judicial discretion’ mis-describes judicial obligation.”[[184]](#footnote-185) Although judges must make decisions when no precedent or rule is on point, he maintained that their choices are constrained by principles – principles that are not external to the law but implicit in it, not the product of the judge’s private preoccupations but derived from publically available materials, and (as he stated in later work) determined by what his conception of what justice or fairness demands:

From time to time a particular case may force a judge to engage in such a debate, to decide, as it were, a jurisprudential issue. But a judge who believes himself faced with such an issue is no more entitled to choose an answer on private grounds here than at any earlier or later point in his reasoning; he is expected here as there to justify his decision in terms of what he takes to be the most fundamental community conceptions of social or political justice. Even here, in other words, he is expected to argue to public, rather than to rest on private, standards.[[185]](#footnote-186)

On Dworkin’s view, in those hard cases, where no statutes or precedents dictate a particular outcome, principles and purposes remain, and the judge’s duty is to render decisions which manifest a commitment to integrity; that is, those which treat the body and practice of law as though it exhibits principled consistency. In other words, when more than one decision might fit with the settled law, the one he ought to endorse is that whichmakes the best *moral* sense of the practice itself.

Dworkin invokes language that is inspirational and aspirational, and it might be regarded as an ideal to be sought rather than one which can be achieved. Indeed, his interpretive strategy, dubbed law as integrity, was illustrated through the device of an ideal judge. Hercules, as he styled him, was described as “a lawyer of superhuman skill, learning, patience, and acumen.”[[186]](#footnote-187) His task was to take each case as an occasion for the exercise of an ambitious interpretive strategy, one that treated his community as if it were a community of principle; that is, one which has a claim to legitimacy because it endeavours to treat all who are subject to the law’s commands as though they are worthy of equal concern and respect.

Dworkin’s theory of adjudication is far from uncontroversial, and as I acknowledged at the outset, it may seem odd to invoke one sort of controversy in the effort to resolve yet another. Integrity as an interpretive strategy may have value, however, for jurisdictions that belong to ethics rather than law. It may help PHEs to consider and make explicit, the reasons for their recommendations; or, to use Kamm’s words, to feel free to philosophize when that is precisely what is required. Applied ethicists may not render binding decisions, and in that respect the analogy may not be apt, but their efforts to exercise judgement and the methods that underlie their recommendations ought to be open to review, revision, and critique.[[187]](#footnote-188)

A common criticism of “law as integrity” is that it represents arguments and decisions that are the products of Dworkin’s personal, liberal egalitarian, world-view as if they were the objective and rational outcomes that would be generated by any honest interpreter of the law. I acknowledge the fact that penumbral cases may invite a variety of interpretations that both fit and justify the settled law, and that reasonable adjudicators may arrive at different decisions when faced with the very same data. My object, however, is not to take a position on Dworkin’s so-called “right answer thesis” which argues that there are uniquely right answers to hard cases at law. Instead, I want to make the much more modest suggestion that the fact of theoretical disagreement in such cases need not imply that those who adjudicate them must be rendering arbitrary decisions, or that the entire process of judging is irredeemably conflicted, undemocratic, or incoherent.[[188]](#footnote-189)

An easy objection to this line of argument might be to suggest that healthcare ethics differs significantly from the law in one very significant respect. Legal cases, including the most challenging ones which come before a nation’s highest court, can be situated within a well-established tradition that includes a large body of statutory and common law. Moreover, in legal decision-making, while parties may argue about the significance of prior decisions, and the interpretation of legal language, they possess a reasonably high degree of agreement about what count as legal standards and where to look to find them. When Gloria Taylor, and the family of Lee Carter, decided to challenge the prohibition on physician aid-in-dying, their lawyers, and those opposing them, could readily identify and cite the legal provisions about which they were in disagreement; and while ordinary Canadians, and legal scholars, may not have achieved unanimity with respect to the moral standing of MAID (or on what grounds it might be defended or opposed), it is uncontroversial to suggest that the Supreme Court made a cogent argument when it struck down the broad statute that criminalised all assistance in dying.

While I take these objections to be legitimate ones, I would argue that they are far from fatal. While PHEs may not have precedents that are as clear as legislators’ statutes or judges’ rulings, the practice of healthcare ethics faces important constraints of its own. A PHE practicing in the penumbra may wish to ignore her current context, and the body of canonical cases or the extensive literature that supplies the values, concepts, and standards applicable to her jurisdiction, but if she were to offer an interpretation that is idiosyncratic, ideological, or opaque, it likely would not, and should not, find support within the community she serves. Differences are to be expected with respect to the weight that practicing ethicists ascribe to established principles, values, and contested concepts, and their interpretations of what these entail will diverge, but a range of interpretations does not imply that anything goes, or that all interpretations can be justified equally well. A PHE who would suggest for example, that patient self-determination had no significance in her evaluation of the moral standing of MAID, would not merely be advancing a controversial interpretation of an important issue. She would be striking out in a direction that failed to take account of, or fit with, prior practise at all.

*Philosophizing in the Penumbra: Advising on Access to MAID*

While I have argued that PHEs are less often asked to philosophize (in Kamm’s sense) than the field’s critics might lead one to believe, I also acknowledge that reflection and reason giving can be an important and influential aspect of the role. Although I have touched on this briefly already, the topic can benefit from a more detailed exploration, particularly since I have claimed that analysing and advising on penumbral cases is akin to the exercise of judicial discretion (along with the risks and opportunities that such activities entail). Below, I introduce a hypothetical organisational ethics consultation to illustrate how a PHE might provide support to a divided leadership team. Earlier I provided a glimpse into the nature of a penumbral clinical case, but for this purpose I have selected an organizational example instead. These are instances where the PHE’s advice is likely to be sought (rather than information-giving, clarification, or mediation) and they may be the most controversial of all, because they have the potential to affect far more stakeholders than a consultation that focuses on the concerns of a particular patient, family member, or healthcare provider.

Let us imagine that a PHE has been asked to assess the merits of a plan to limit her institution’s MAID services to the sub-set of requesting patients who have clear diagnoses and relatively short prognoses.[[189]](#footnote-190) The clinicians who have advanced this proposal (let’s call them Short Prognosis Providers or SPPs) have argued that providing MAID to those with chronic diseases and uncertain prognoses, typically those who are also frail and elderly, is problematic both on practical and ethical grounds. In support of their position the SPPs make three distinct claims: first, hospitals need not, and do not, provide all services that patients legally may request; second, a failure to define the limits of a “reasonably foreseeable natural death” may thwart efforts to recruit and retain potential providers (owing to the anxiety that might be generated among those who find themselves challenged to interpret what that criterion allows); and, third, a willingness to accede to such requests undermines the respect for life, especially the lives of vulnerable persons, that Bill C-14 was designed to protect.

The practicing healthcare ethicist reasoning through this case – whatever her particular worldview or political inclinations – would almost certainly have to invoke familiar ethical concepts and precedent cases in order to evaluate the ethical merits and demerits of a proposal to limit access in this way. Whether she regards MAID as a valid and defensible treatment option, or sees herself as a conscientious objector, she must look beyond her personal intuitions in order to offer an analysis that can be understood and evaluated by those who must bear the weight of this decision.

The first claim, that hospitals are not obliged to provide all services that are legally permissible, is clearly true but requires further exploration. Healthcare institutions tend to specialise and, even when services are recognised as vital or important, patients can be referred to other facilities that have greater capacity or better expertise to meet their needs. Efforts to coordinate rather than duplicate services can enhance rather than diminish access to care, but what is crucial in all cases is that operational decisions not be justified on grounds that discriminate against particular patients, or categories of patients, on grounds that cannot be defended in a principled way.

In light of these considerations the PHE might conclude that, unless a timely and effective referral can be made to an alternate service, preventing frail elderly patients with chronic diseases or disabilities (such as spinal stenosis, or degenerative arthritis, ALS, or chronic obstructive pulmonary disease) from accessing her institution’s MAID services would be as problematic as the practices of therapeutic abortion committees that restricted access to that option to women who were survivors of rape or incest. She might argue that in both kinds of cases health care services are being structured in a way that prioritizes the concerns and values of influential members of institutions over those of identified patient populations and the professionals who were willing to meet their needs.[[190]](#footnote-191)

As we have already seen, the “reasonable foreseeability” criterion has presented some interpretive challenges, so the SPPs’ second claim is not entirely implausible. The likelihood of a staffing shortage, however, is a practical matter that can be distinguished from related questions of an ethical kind. Even if recruitment and retention are affected by worries about the open-textured nature of the standard it is far from self-evident that the appropriate response would be to constrain judgement in a place that the legislature (and subsequent court rulings) have left open to the providers’ discretion. Efforts to ensure adequate education and support for assessors, and to recruit expertise from diverse specialties (geriatric psychiatry, neurology, respirology, and palliative care come to mind), are possible responses to the prospect of clinical uncertainty that have the potential to enhance the competence and confidence of willing practitioners without jeopardising access to patient care.

The third proposition (that the provision of MAID to patients with longer prognoses undermines respect for the lives of vulnerable persons) is a more complex charge than it might seem. The PHE might be inclined to look to empirical data available from other jurisdictions to see if there is evidence to support the assertion that the provision of medically-assisted deaths to patients with longer prognoses (LPPs) results in a diminished respect for their lives, or contributes to a shift in societal attitudes that makes the frail elderly feel coerced into requesting aid in dying, but such evidence (even if it were more reliable and valid than it tends to be) would be difficult to translate to a fresh context and, more importantly, would not render the rights, values, and preferences of local patients and providers moot. Fortunately, the PHE’s obligation to her institution, and to the stakeholders that rely on her judgement, does not require that she re-adjudicate the matters already decided by the courts, nor is it within her scope to evaluate the eligibility of particular patients (a matter that falls squarely within the jurisdiction of MAID assessors and providers). In this instance, the PHE’s responsibility is to offer guidance on a fairly narrow question with the potential for significant impact; that is, she is to advise on the ethical significance of the proposal to restrict access to MAID to a sub-group of legally eligible patients. To clarify, her task is not, at least in the context of this consultation, to weigh in on debates with respect to the public’s or the Court’s positions with respect to MAID. It is to provide an evaluation of the ethical merits of a particular program design within a specific clinical context.

Once the ethical question (or questions) have been distinguished from other sorts of considerations it is easier, if not easy, to see how the case might be resolved. The central questions in the instant case might be: Does the SPP proposal fit with current practice as well as a service that would be available to all potentially eligible patients? and, Which program structure can best be justified on ethical grounds?

Although the SPP proposal might be defended via appeal to non-maleficience (or a desire to shield a vulnerable population from the harm of coercion), the PHE’s recommendation ultimately must turn on the way that she reconciles that value with other competing concerns. The justice–related implications of a plan to limit access based upon institutional value judgements about the relative burden of suffering borne by whole classes of patients might be made plainer by efforts to find relevant analogies. The parallel with abortion has already been noted, but an even more stark contrast might be drawn by noting the difficulty the community might have with attempts to defend denying other potentially eligible patient populations access to assessment. It might be argued, for example, that patients who hail from communities that are generally considered structurally vulnerable, such as the insecurely housed or those who have physical disabilities, should be excluded on the basis that they are subject to undue pressures more often than patients who lack these disadvantages. After all, threats to patient autonomy need not be overt to be powerful and they may consist in a lack of attractive available options rather than through direct efforts to manipulate or to force patients to choose interventions that are not consistent with their values and preferences.[[191]](#footnote-192) An acknowledgement of that reality, however, need not yield the conclusion that such patients ought to be denied access to MAID interventions, or even to assessment opportunities. After all, vulnerably-situated patients are not routinely excluded from participating in other high-stakes healthcare decisions, and it is a commonplace that patients’ risks and potential benefits ought to be assessed in light of their particular circumstances rather than via comparison to some ideal conception of the group or groups with which they may be identified.[[192]](#footnote-193)

Finally, although autonomy is not the value that ought always to claim priority (despite some caricatures of the so-called Georgetown mantra)[[193]](#footnote-194) it does seem reasonable to endorse the view that (given appropriate safeguards against coercion) patients, not providers (or institutional officials) ought to be the ones whose values will direct their plans of care.[[194]](#footnote-195)

Although PHEs might assign very different weights to ethical principles like autonomy, non-maleficience, beneficence, and justice in this, or other cases, it is unlikely that they would regard none of these concerns as insignificant at all. For example, it is likely that a feminist bioethicist like Sherwin, and an Orthodox Christian bioethicist like Engelhardt, would both find it important to engage the question of whether the attitudes of medical professionals, and the social circumstances of these very vulnerable patients, might make MAID seem like a reasonable choice largely because it is, to invoke a common trope of the discipline, the “least worst” option in a society that distributes wealth unequally and tolerates sub-optimal access to specialised services like palliative care.

*Illuminating the Ethical Penumbra: How Jurisprudence Can Help*

I have argued that “reason-giving and philosophizing” in penumbral cases is the most controversial ethical aspect of the PHE’s role. Like adjudicators in hard legal cases PHEs are not elected by those they serve, and the persistence of theoretical disagreement (or the impossibility of eliminating all differences with respect to the relative importance of particular values in the context of specific cases) may lead to scepticism about the very possibility of deliberation that is coherent, transparent, and fair. Greater transparency about the nature of the process, and an exploration of the kinds of reasons that ought, and ought not, to factor in ethical deliberation is one way to respond to these concerns. This will not dispel disagreement about what right, or better answers, consist in, but if it is understood that answers must be given, and that all answers will reflect a conception of how best to extend, or interpret, the social practice within which they arise, it may easier to defend this aspect of the PHE’s role.

It is interesting to note that legal philosopher Wilfrid Waluchow appears to have more confidence in bioethical reasoning than many of its own practitioners. In *A Common Law Theory of Judicial Review* he dismisses the notion that judges might be in need of extraordinary ethical acumen by noting that though they “might be well schooled in the law, [they] are in no sense of the term moral authorities who would ace their final exams in moral philosophy were they enrolled in Plato’s Academy. Indeed, [he adds] the notion of a moral expert or “moral authority comes very close to contradiction.”[[195]](#footnote-196) By way of contrast, he maintains,

… health care ethicists…might be said to be moral authorities within their particular domains of special competence. This is because they have specialist knowledge of particular moral norms like those governing informed consent, or the conducting of research on human subjects. But their authority does not stem from special powers of moral insight; its [sic] stems from specialist knowledge of relevant nonmoral facts and from their having thought long and hard about the moral issues that arise from their special areas of activity.[[196]](#footnote-197)

Waluchow may grant practicing ethicists too much credit in the preceding passage and, given his positivist pedigree, he might wish to qualify his remarks in the context of ethical penumbral cases. After all, his aim in the very text I have just cited, is to unpack and assess a variety of arguments against the legitimacy of what he calls common law constitutionalism, or of legal systems that rely upon judges’ abilities to interpret the broad moral terms that are contained in charters and bills of rights. (Societies that rely on such approaches, according to their critics, undermine the democratic commitment to self-governance by granting all-too-human judges the awesome powers of Platonic guardians or of philosopher kings and queens.) However, even if he might temper his remarks upon greater reflection, it is worth taking a slight detour into the territory that he calls common law constitutionalism. His defence of those jurisdictions contains important insights applicable to the adjudicative aspect of the practice of healthcare ethics consultation.

*Fruits of the living tree: what a common law conception offers healthcare ethics consultation*

Waluchow is one of the best known proponents of a branch of the philosophy of law known as inclusive legal positivism, and, as such, he is careful to distinguish the grounds for establishing the validity of a legal standard from concerns about its substantive moral content. Like other positivists he takes seriously the claim that a law, or indeed an entire legal system, may be designed to advance wicked ends, and accepts that those who are charged with the responsibility of interpreting and enforcing the law may find themselves in a position where Dworkin’s approach (to see law as a social practice which exhibits integrity, or expresses equality of concern and respect for all of its citizens), bumps up against the reality that no interpretation can adequately fit the settled law and simultaneously provide a moral justification for its content.[[197]](#footnote-198) As an *inclusive* positive, however, he accepts the view that other standards, such the abstract rights of political morality enshrined in a nation’s constitutional charter or bill of rights, require efforts to determine the precise nature of those rights in the context of particular legal cases. The controversial Canadian *Charter of Rights and Freedoms*, in Waluchow’s succinct summation, secured for its citizens “the right to equality before and under the law; the right to life, liberty, and security of the person, coupled with the right not to be deprived of the former except in accordance with the principles of fundamental justice; and the right to freedom of thought, belief, opinion, expression, and association.”[[198]](#footnote-199)

Because a charter-based society obliges those entrusted with the task of adjudication to decide cases in a way that makes sense of abstract and controversial language they can face considerable criticism if their decisions are perceived as idiosyncratic, or unduly political, or contrary to the values held by a majority of the voting public. Indeed, much of Waluchow’s effort in *A Common Law Theory of Judicial Review* is devoted to unpacking and weighing the arguments of the so-called Critics and Advocates of judicial review in societies like our own. The conclusions he draws are the outcome of a painstaking effort to recreate and evaluate arguments that are too complex to reproduce here, but it is heartening to discover that ultimately he concludes that moral principles, when embedded in legal sources, and as interpreted by an unelected and imperfect (because entirely mortal, situated, and perhaps entirely too homogenous) judiciary, need not undermine the democratic process:

… in the end, we are very well served by a Charter understood as the common law supposes – as one developed and applied by judges in partnership with other government bodies such as legislatures, and with the people themselves as they grapple with the complex, ever-changing nature of their constitutional commitments. This idea of partnership is, once again, well worth bearing in mind. As repeatedly stressed above, nothing in the nature of judicial review yields a doctrine of judicial supremacy. Far too often, judges who strike down or otherwise alter legislation on Charter grounds are criticized for claiming superior authority over legislatures, and for engaging in a naked power grab. Yet as we have seen, this need not be so. The role of legislating general rules (whose moral consequences are sometimes unforeseeable) is fully compatible with the role (reserved for another body) of deciding - or advising – on what must be done in the foreseeable cases of potential conflict with the developing norms of constitutional morality. Seen in this light, judges and legislatures need not be seen to be in competition with each other over who has more courage or the better moral vision. On the contrary, they can each be seen to contribute, in their own unique ways, from their own unique perspectives, and within their unique contexts of decision, to the achievement of a morally sensitive and enlightened rule of law.[[199]](#footnote-200)

*Imagining McLachlin: a Hercules for healthcare ethics?*

With Waluchow’s assessment to buoy us, it may be wise to revisit our reflections on the characteristics that one might recommend in a desirable, if not ideal, moral deliberator. As was noted earlier, Judge Hercules, Dworkin’s model adjudicator, had an inspiring but awesome remit. His task was to resolve the hardest of hard cases by drawing on an encyclopaedic knowledge of the law and social practises, and superhuman powers of reasoning, in order to render judgments that best fit and justified prior legal decisions. An attractive aspect of Dworkin’s right answer thesis, the suggestion that the judge always must strive to find the morally best answer to hard cases at law, is the implication that there is an objectivity to this process, and that there is no warrant to conclude that there are no right answers to hard cases simply because the answers on offer may be controversial, political, or difficult to derive and defend.[[200]](#footnote-201)

Critics of Dworkin’s theory of adjudication have been quick to notice, however, that Hercules’ perfection offers an unrealistic and misleading standard for guiding or evaluating the decision-making abilities of human judges operating in specific legal systems. Even if his skills, knowledge, and attributes were mortal, rather than divine, there are other aspects of this ideal-typification that ought to give one pause. Hercules carries out his labours in solitude, he faces no financial or temporal pressures, and his judgements unrealistically appear to belong to him alone. Judges who serve on most countries’ supreme courts would, however, find this model unrecognisable and, almost certainly, undesirable. After all, even the chief justices of the highest courts find themselves thinking in community with others and, although it may take some time for the results of their deliberations to become known to the parties to a dispute (or to the broader public to whom they must make their reasons known), it would be surprising to learn that they feel no obligations to hand down decisions that are both timely and attentive to the social contexts in which they are rendered.

If a super-human judge is an imperfect source of inspiration for practicing healthcare ethicists it may yet be possible to conjure up an ideal to which they might aspire. We might call her PHE McLachlin, and assume from the outset that although she aims to offer advice that both fits and justifies the healthcare practice in which she participates, she is limited and imperfect, as all mortals are. Her interpersonal skills are reasonably well-developed, she possesses an incomplete grasp of medical terminology and common illnesses, has a partial but ever-growing, knowledge of health law, policy, and social norms and values. Although her subject matter is vast and mutable, she must nearly always attend to cost and time constraints. She may not be a philosopher but she has an ability to partake of the methods of that discipline, and she is always obliged to think with others – others who may include patients, healthcare professionals, administrators, and policy makers (and any combination thereof) - whose values often will be in conflict, and may differ from her own.

It is important to acknowledge that McLachlin’s involvement in hard cases will generally be triggered by a request by one, or more, of the stakeholders who are desirous of her support. Although her services may be available to all, she is a consultant who becomes privy to the confidential details of a case only when her counsel is invited and, should she find herself in a situation where her advice or recommendations are sought, the final decisions which flow from that advice, are never hers to make.

Despite these limits on her authority, the critics of healthcare ethics are not wrong to be concerned about her influence. The hard cases that trigger her engagement are by their very definition fraught with peril, and the independence of her role can be a source of its weakness as well as a strength. Whenever it is appropriate, McLachlin may make her contributions to a case transparent to the patient and his circle of care via an entry in a healthcare record, but this is a purpose-built tool that is designed for other forms of inter-professional communication.[[201]](#footnote-202) Entries made in progress notes, or in other portions of patients’ charts suffer from a number of significant limitations. They tend to be difficult to locate, Spartan in their description, and narrowly focussed on outcomes or other clinically-relevant variables.[[202]](#footnote-203) Organisational and research ethics consultations, moreover, tend not to lend themselves to standard documentation processes, although records of their proceedings may be contained (or referenced) in briefing notes, meeting minutes, or white papers, or in the guidelines and policies which they ultimately inform.

In short, unlike Hercules (or, indeed, his real-life counterparts), PHE McLachlin finds herself largely unconstrained by the opinions of any legislature, electorate, or inquisitive fourth estate. This seems appropriate, given the advisory nature of her role, and the importance of her clients’ right to confidentiality, but its appropriateness is not a guarantee of quality - and the question of quality in clinical ethics consultation is an important one, one that the professionalization movement has hoped to answer. In my final chapter I will attempt to deliver on my early promise; that is, to show how legal theory might save the life of health care ethics (or at least reinvigorate the discipline by disposing of some well-worn debates). I believe I have assembled the pieces that are needed for a more substantial discussion about the practice of healthcare ethics, and suggest that we need only stitch them together in order to answer the charges of its critics. As my final chapter will show, what is most needed now is a commitment to quality – rather than a counsel of perfection. Legal theoretical debates may not provide a template for assessing success in that endeavour, but they can shed light on some of the tools that are required, and others that can safely be set aside.

Chapter 5: Professionalizing PHEs: The Promise of a Practice Worth Wanting

*Scofield’s latest critique: gathering wool or communicating concerns?*

In his most recent publication Giles Scofield has asked, once again, why “the field continues to be plagued by the problem of describing, explaining, and justifying how and why it is that others should seek … [its] expert advice.”[[203]](#footnote-204) Ethics consultation, he asserts, is a field “which, for some mysterious reason, seems to be in perpetual need of having its life saved.”[[204]](#footnote-205)

My aim throughout this project, begun long before his latest salvo, has been to dispel some of the mystery that has cloaked the field, and to show that there can be a response to its critics which is an alternative to defensiveness or despair. Scofield’s latest critique, a variation on an earlier theme, consists mainly in the claim that “the status of clinical ethics consultation is both a practical and a political problem.”[[205]](#footnote-206) Its “power and authority” demands “domestication” because, he proclaims, there is an undeniable tension between its “epistocratic ambitions” and “the foundational values of a democratic society.”[[206]](#footnote-207)

Scofield’s paper is a reminder that the old anxieties about the field have not been put to rest. By tackling the topics of conflict of interest, conflict of commitment, the nature of adjudication, and the place of politics in ethics, I do not believe that I have attempted to resuscitate a field in need of life support. I do, however, hope that I have contributed to its well-being because, although I reject his dismal diagnosis, I believe that some of the discipline’s theoretical and practical deficits constitute a risk to its current and future practitioners, and to the parties that they aim to serve.

I have argued that the work of practicing healthcare ethicists need not be construed as compromised and ineffectual; politicised and undemocratic; or irredeemably incoherent in the context of value pluralism. Although I believe each of these critiques to be misguided, I have acknowledged the worries that may motivate them, and have attempted to render them in more plausible and specific forms in order to better understand their significance and to estimate their force.

*Hard cases, philosophizing, and the practice of PHEs*

Healthcare ethics consultation can be demanding work, and I have introduced a typology of hard cases to illustrate some of the reasons why this can be so. Although the way that I use the language of emotive and morally distressing cases is new, my hope is that the content to which they refer will have an intuitive appeal, and that PHEs will recognise that there is an established literature that (although not written with them in mind) is apt and useful in sustaining resiliency and protecting independence when either, or both, are threatened by a PHE’s history or disposition, or the structures within which she works. In addition, I have repurposed Hart’s analysis of hard cases to elucidate the features of a specific type of hard case, that is, the penumbral case, which can benefit from systematic efforts to distinguish that which is settled (and largely not open to debate) from the questions which remain unresolved, indeterminate, and often controversial and in need of the ethical guidance that Kamm might describe as philosophical in kind.

*Professionalization and professionalization: scepticism or systemic thinking?*

I have not denied the role that a PHE’s values – including her political ideals – can, and indeed must, play in the performance of her duties. On the contrary, I have flagged the critical perspective that a feminist bioethics can readily supply. Sherwin, Tronto, Walker, and others, have provided a much needed caution against complacency. They urge us to question settled narratives, and to resist easy answers, about crucial concerns such as the scope of the PHE’s subject matter, the tools available for her analysis, and the nature and extent of her responsibilities. Wicked problems, or the work of public ethics, is a significant challenge for twenty-first century PHEs, and the efforts needed to tackle them can never be purged of politics broadly-understood. By this I mean simply to suggest that institutions, and the individuals they employ, are obliged to re-examine perennial value-laden concerns that are assuming ever greater urgency. These may be expressed via questions such as, Who are our clients? What are our obligations? and, How should our healthcare systems allocate their resources in light of their needs and preferences? Although each of these questions is controversial, and the answers they are likely to elicit complex, I have argued that the work that is required to address them need not attract a sceptical response.

Progress of the professionalization of ethics has been slow, uneven, and subject to heated debate. Although the reasons for this may be best understood by anthropologists, sociologists or historians, some barriers are obvious and surmountable, if not easily overcome. Although I have paid particular attention to the need for what Kamm calls “philosophizing” I have not claimed that the work is best done by those with an entirely academic bent. Indeed, I have argued that this specific feature of the work is not the largest part of the PHE’s mandate and while it is important, and draws on philosophical skills (namely reason giving and reflection) these are not so esoteric that others cannot exercise them appropriately and with competence just as other adjudicators do.[[207]](#footnote-208)

*Certification, accreditation, and public protection: McLachlin meets MAID*

Critics like Scofield and Koch have regarded professionalization as the self-interested pursuit of an élite. In the words of the former, the defences of clinical ethics are not about a practice that needs saving so much as they are attempts to “support the way of life …[their practitioners] have grown accustomed to enjoying and the revenue-generating academic programs that produce such persons.”[[208]](#footnote-209) Saving the livelihood of ethicists is hardly a defensible, much less noble aim, if all (or most) of their efforts contribute little that can benefit the clients they serve. Fortunately, the motives of those calling for the professionalization of ethics consultation need not be noble in order to achieve entirely worthy ends. Transparency, consistency, and evaluation of quality are all likely to be products of professionalization and, while this may mean that the field becomes less open to the idiosyncratic interpretations of independent practitioners, the benefit to the public can more than compensate for this loss.

The sceptical response to consultation is, as I hope that I have shown, sustained by a belief in the imperfections of ethicists and some curious conceptions of influence and of expertise. As an alternative, I have proposed that legal theory, especially in its efforts to understand the nature and limits of interpretation in adjudication; the relationship between law and politics; and the possibility of reconciling value pluralism with democracy, provides us with a fresh way to conceive of these concerns. Although its controversies are lively, and many of its questions remain unresolved, its scholars seem to acknowledge that these questions are worth engaging (and western legal systems worth defending) even in the face of ongoing academic and political debates.

PHE McLachlin, has been introduced as a model of a realistic rather than idealistic kind. Her skills, knowledge, and perhaps even what the Core Competencies document refers to as attributes, are assumed to be teachable and amenable to evaluation through well-designed training programs that supplement the would-be consultant’s academic background with clinical experiences tailored specifically to the PHE’s responsibilities. An appropriately tailored training and mentorship program, or the establishment of a regulatory college, may not provide the guarantee of quality or transparency that can be provided by an open court, or of a Supreme Court record, but it is also important to accept when the legal analogy runs out. PHE McLachlin is not always, or primarily, an adjudicator and her recommendations (on the occasions when they are offered) are not equivalent in impact to a binding judgement even though they may on occasion have significant local influence or exert force that is akin to local precedent.

Left unanswered by this dissertation are a number of pressing issues that are ripe for sustained attention: the lack of socio-economic and cultural diversity in the discipline, the place of advocacy in response to perceived injustices (which may be a part of the project of public ethics as Sherwin describes it), and the protections (which may include academic freedom) that would render the topics that I have raised, as well as other controversial issues, safer to surface and to address.

As McLachlin meets MAID, and the other pressing ethical issues of our time, I believe that she needs all of the support and guidance that professionalization can provide. This project has not been presented as a roadmap to professionalization, but it is hoped that it offers fresh reasons for thinking that the journey is well worth taking and that some of its barriers are (relatively) easy to overcome.

### Bibliography

### *A.B. vs Canada* (Attorney General) 2017 ONSC 3759. Accessed: 8 February

### 2019. <http://eol.law.dal.ca/wp-> content/uploads/2017/06/20170619152447518.pdf.

Abdool, Rosalind, Michael Szego, Daniel Buchman, Leah Justason, Sally Bean,

Ann Heesters, Hannah Kaufman, Bob Parke, Frank Wagner and Jennifer Gibson. “Difficult Healthcare Transitions: Ethical Analysis and Policy Recommendations for Unrepresented Patients.” *Nursing Ethics* 23, no.7 (November 2016): 770-783.

Ackerman, Terrence F. "Medical Ethics and the Two Dogmas of Liberalism."

*Theoretical Medicine* 5, no.1 (1984): 69-81.

Adams, DM. “Ethics Expertise and Moral Authority: Is There a Difference*?”* *American Journal of Bioethics.* 13.2 (2013): 27-8.

Agich, George J. "Expertise in Clinical Ethics Consultation." *HEC Forum* 6.6 (1994): 379-383.

Andereck, William S. "The Clinical Ethics Consultant: Verifying the Qualifications of a New Type of Practitioner in a Community Hospital." *Journal of Healthcare Management* 57.4 (2012): 264-273.

Andre, Judith. *Bioethics as Practice*. Chapel Hill: University of North Carolina Press, 2002.

Angrist, Misha. “A Conversation with writer and troublemaker Carl Elliott,”

Part I, *PLOS Medicine/GenomeBoy* (12.02.2011). Online [https://www.geneticsandsociety.org/article/conversation-writer-and- troublemaker-carl-elliott-parts-i-ii](https://www.geneticsandsociety.org/article/conversation-writer-and-%09troublemaker-carl-elliott-parts-i-ii). Accessed: 27 April 2018.

Ankeny, Rachel A. "How History and Philosophy of Science and Medicine Could Save the Life of Bioethics." *The Journal of Medicine and Philosophy* 28.1 (2003): 115-125.

Appelbaum, P.S, L. H. Roth, C.W. Lidz, P. Benson, and W. Winslade. "False hopes and Best Data: Consent to Research and the Therapeutic Misconception.” The Hastings Center Report 17.2 (1987): 20–24.

Arras, J D, and T H Murray. "In Defence of Clinical Bioethics." *Journal of Medical Ethics* 8.3 (1982): 122-127.

Arras, John D. "The Hedgehog and the Borg: Common Morality in Bioethics." *Theoretical Medicine and Bioethics* 30.1 (2009): 11-30.

American Society for Bioethics & Humanities' Core Competencies Update Task Force. *Core Competencies for Health Care Ethics Consultation: The Report of the American Society for Bioethics and Humanities* (2nd Ed.). Glenview, IL: American Society for Bioethics & Humanities, 2011.

American Society for Bioethics & Humanities. *Improving Competence in Clinical Ethics Consultation: An Education Guide.* Glenview, IL: American Society for Bioethics & Humanities, 2009.

Aulisio, Mark P. "Meeting the Need: Ethics Consultation in Healthcare Today." In *Ethics Consultation from Theory to Practice,* Eds. Mark P. Aulisio, Robert M. Arnold, and Stuart J. Younger. Baltimore: Johns Hopkins University Press, 2003. 3-22.

Aulisio, Mark P., Robert M. Arnold, and Stuart J. Younger. *Ethics consultation: from Theory to Practice*. Baltimore: Johns Hopkins University Press, 2003.

Baker, Robert, Ken Kipnis, Stuart J. Youngner, and Nancy Dubler. "Fine-Tuning the Future*." Hastings Center Report* 40.3 (2010): 6-8.

Baker, Robert. "In Defense of Bioethics." *The Journal of Law, Medicine & Ethics* 37.1 (2009): 83-92.

Baker, Robert, and Laurence B. McCullough. "Medical Ethics' Appropriation of Moral Philosophy: The Case of the Sympathetic and the Unsympathetic Physician." *Kennedy Institute of Ethics Journal* 17.1 (2007): 3-22.

Baker, Robert. Response to Commentators on “A Draft Model Aggregated Code of Ethics for Bioethicists." *The American Journal of Bioethics* 5.5 (2005): W12-W13.

Baker, Robert. "A Draft Model Aggregated Code of Ethics for Bioethicists." *The American Journal of Bioethics* 5.5 (2005): 33-41.

Battin, M. P. et al., “Legal Physician Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in ‘Vulnerable’ Groups,” *Journal of* *Medical Ethics* 33.10 (2007): 591-97.

Baylis, Françoise. "The Olivieri Debacle: Where Were the Heroes of Bioethics?" *Journal of Medical Ethics* 30.1 (2004): 44-49.

Baylis, Françoise, Jeanne Des Brisay, Benjamin Freedman, Larry Lowenstein, and Susan Sherwin. "A Reply to Giles R. Scofield, J.D." *HEC Forum* 6.6 (1994): 371-376.

Baylis, Françoise. *The Health Care Ethics Consultant*. Totowa, N.J.: Humana Press, 1994.

Bean, Sally. "Navigating the Murky Intersection between Clinical and Organizational Ethics: A Hybrid Case Taxonomy." *Bioethics* 25.6 (2011): 320-325.

Beauchamp, Tom L. *Standing on Principles: Collected Essays*. New

York: Oxford University Press, 2010.

Beauchamp, Tom L., and LeRoy Walters. *Contemporary Issues in Bioethics*. 2nd ed. Belmont, Calif.: Wadsworth Pub. Co., 1982.

Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. 5th edition. New York: Oxford University Press, 2001.

Beauchamp, Tom L. "History and Theory in ‘Applied Ethics.’” *Kennedy Institute of Ethics Journal* 17.1 (2007): 55-64.

Bero, L.A. and Quinn Grundy. “Why Having a Nonfinancial Interest is Not a Conflict of Interest.” *PLOS Biology* (2016) December 21: 1-8. Online: Accessed: 8 February 2019.

Bishop, Jeffrey P. Joseph B. Fanning, and Mark J. Bliton. "Of Goals and Goods and Floundering About: A Dissensus Report on Clinical Ethics Consultation." *HEC Forum* 21.3 (2009): 275-291.

Boatright, John R. “Conflict of Interest: A Response to Michael Davis.” *Business and Professional Ethics Journal* 12.4 (1993): 43-46.

Boetzkes, Elisabeth A. *Readings in Health Care Ethics*. 2nd ed. Peterborough, Ont.: Broadview Press, 2012.

Bosch, X, et al. “Financial, Nonfinancial and Editors' Conflicts of Interest in High-Impact Biomedical Journals.” *European Journal of Clinical Investigation* 43.7 9 (2013): 660–667.

Bosk, CL. "Professional Ethicist Available: Logical, Secular, Friendly." *Daedalus* 128.4 (1999): 47-68.

Bowman, Kerry. "What are the Limits of Bioethics in a Culturally Pluralistic Society?" *The Journal of Law, Medicine & Ethics* 32.4 (2004): 664-669.

Brody, Howard. “Clarifying Conflict of Interest.” *The American Journal of* *Bioethics* 11.1 (2011): 23-28.

Buchman, Sandy. “Why I Decided to Provide Assisted Dying: It is Truly Patient Centred Care.” *British Medical Journal* 364 (2019): 1412.

Bruce, Courtenay R., Trevor M. Bibler, Adam M. Pena, and Betsy Kusin. “A Qualitative Exploration of a Clinical Ethicist’s Role and Contributions during Family Meetings.” *HEC Forum* 28.4 (2016) 283-299.

Cannistra, Stephen A. “The Ethics of Early Stopping Rules: Who is Protecting Whom?” *Journal of Clinical Oncology* 22.9 (2002) 1542-1545.

Carrese, J. A., P. Goodman-Crews, A. Heesters, M. Jurchak , C. Mitchell , N. Mokwyune , K. Parsi , T. Powell , K. E. Powderly , T. Rosell , W. Shelton, A. H. Antommaria , M. L. Smith , J. Spike, A.Tarzian, L.Wocial, K. A. Berkowitz, J. Berger, J. Carrese, B. H. Childs , A. R. Derse, C. Gallagher, and J. A. Gallagher. "HCEC Pearls and Pitfalls: Suggested Do's and Don'ts for Healthcare Ethics Consultants." *Journal of Clinical Ethics* 23.3 (2012): 234-40.

*Carter V. Canada* (Attorney General) - SCC Cases (Lexum). Scc-Csc.Lexum.Com, Last modified 2015. <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>. Accessed: 1 February 2019.

Chambers, Tod. "The Art of Bioethics." *Hastings Center Report* 35.2 (2005): 3-3.

Charo, R. Alta. "Passing on the Right: Conservative Bioethics is Closer than it Appears." *The Journal of Law, Medicine & Ethics* 32.2 (2004): 307-314.

Chidwick, Paula, Jennifer Bell, Eoin Connolly, Michael D. Coughlin, Andrea Frolic, Laurie Hardingham, and Randi Zlotnik Shaul. "Exploring a Model Role Description for Ethicists." *HEC Forum* 22.1 (2010): 31-40.

Childs, Brian H. "Credentialing Clinical Ethics Consultants: Lessons To Be Learned." *HEC Forum* 21.3 (2009): 231-240.

Cho, Mildred K., Sara L. Tobin, Henry T. Greely, Jennifer McCormick, Angie Boyce, and David Magnus. “Strangers at the Benchside: Research Ethics Consultation.” *American Journal of Bioethics* 8.3 (2008): 4–13.

Cline, Cheryl, Ann Heesters, Barbara Secker, and Frolic Andrea. "Education for Ethics Practice: Tailoring Curricula to Local Needs and Objectives." *HEC Forum* 24.3 (2012): 227-43.

Cohen, G.A. “Facts and Principles.” *Philosophy & Public Affairs* 31.3 (Summer 2003): pp. 211-245.

Cohen, I. Glenn, Holly Fernandez Lynch, Effy Vayena, and Urs Gasser (Eds.). *Big Data, Health Law, and Bioethics.* New York: Cambridge University Press, 2018.

Council of Canadian Academies. The Expert Panel Working Group on Advance Requests for MAID. *The State of Knowledge on Advance Requests*

*for Medical Assistance in Dying.* Ottawa, ON: Council of Canadian Academies, 2018.

Crosthwaite, Jan. "Moral expertise: A Problem in the Professional Ethics of Professional Ethicists." *Bioethics* 9.4 (1995): 361-379.

Cummins, Deborah. “The Professional Status of Bioethics Consultation.” *Theoretical Medicine* 23.1 (2002): 19-43.

*Cuthbertson vs Rasouli* 2013 SCC 53, [2013] 3 S.C.R. 341. <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/13290/index.do>. Accessed: 12 February 2019.

d'Agincourt - Canning, Lori. "Not in Isolation: How History can Inform the Debate on Professionalization." *HEC Forum* 24.3 (2012): 165-70.

Dana, Jason and George Loewenstein “A Social Science Perspective on Gifts to Physicians from Industry.” *Journal of the American Medical Association* 290.2 (2003): 252-255. Online: https://pdfs.semanticscholar.org/8b05/8d01e582e4bb06ac333b4bc740d6f29a104d.pdf. Accessed: April 20, 2018.

Davis, Michael. "Comments on Baker's Draft Model Aggregated Code of Ethics for Bioethicists." *The American Journal of Bioethics* 5.5 (2005): 57-59.

Dawson, A. "IAB Presidential address: Contextual, Social, Critical: How We Ought to Think About the Future of Bioethics." *Bioethics* 27.6 (2013): 291-296.

Dawson, A. “The Future of Bioethics: Three Dogmas and a Cup of Hemlock.” *Bioethics* 24.5 (2010): 218-225.

Devolder, Katrien and Thomas Douglas. “The Epistemic Costs of Compromise in Bioethics.” *Bioethics* 32.2 (2018): 111-118. <https://onlinelibrary.wiley.com/doi/abs/10.1111/bioe.12418>. Accessed: 30 January 2019.

de Vries, Raymond G., and Charles L. Bosk. "The Bioethics of Business: Rethinking the Relationship between Bioethics Consultants and Corporate Clients." *The Hastings Center Report* 34.5 (2004): 28-32.

Dickens, Bernard and Rebecca Cooke. “Conscientious Commitment to Women's Health.” *Obstetrics and Gynaecology* 113.2 (2011): 163-166. <https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1016/j.ijgo.2011.02.002>. Accessed: 12 February 2019.

Dolgin, Elie. “Human-Subjects Research: The Ethics Squad.” *Nature* 514.7523

(2015)*.* Online: <http://www.nature.com/news/human-subjects-research-the-ethics-squad-1.16186>. Accessed: 5 November 2014.

Downar, James, Russell Goldman, Ruxandra Pinto, Marina Englesakis, and Neill

K.J. Adhikari. “The ‘Surprise Question’ for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-Analysis.” *The Canadian Medical Association Journal* 189.13 (2017): E484–E493. Accessed: 8 February 2019.

Downie, Jocelyn and Kate Scallion. “Forseeably Unclear: The Meaning of the

‘Reasonably Foreseeable’ Criterion for Access to Medical Assistance in Dying in Canada.” Forthcoming: *Dalhousie Law Review*. <http://eol.law.dal.ca/wp-content/uploads/2018/07/Foreseeably-Unclear_SSRN.pdf>. Accessed: 24 March 2019.

Downie, Jocelyn. “In a Nutshell II: Ontario Court Decision and MAID.” *Impact*

*Ethics* 28 July 2017. <https://impactethics.ca/2017/07/28/in-a-nutshell-ii-ontario-court-decision-MAID/>. Accessed: 7 February 2019.

Downie, Jocelyn. “The Supreme Court Decision in Rasouli.” *Impact Ethics*

21 October 2013. <https://impactethics.ca/2013/10/21/the-supreme-court-decision-in-rasouli/>. Accessed 12 February 2019.

Downie, Jocelyn. "Glass Houses: The Power of Money in Bioethics Research." *International Journal of Feminist Approaches to Bioethics* 2.2 (2009): 97-115.

Drane, James F. "Founders of Bioethics: Concepts in Tension, dialogue and

Development." *Theoretical Medicine and Bioethics* 33. 1 (2012): 1-9.

Dubler, Nancy N., and Carol B. Liebman. *Bioethics Mediation: a Guide to Shaping Shared Solutions*. New York: United Hospital Fund of New York, 2004.

Dubler, Nancy Neveloff, and Jeffrey Blustein. "Credentialing Ethics Consultants: An Invitation to Collaboration." *The American Journal of Bioethics* 7.2 (2007): 35-37.

Dubler, Nancy Neveloff, Mayris P. Webber, Deborah M. Swiderski, and the Faculty and the National Working Group for the Ethics Credentialing Project. "Charting The Future: Credentialing, Privileging, Quality, and Evaluation in Clinical Ethics Consultation." *Hastings Center Report* 39.6 (2009): 23-33.

Dworkin, Ronald. *Justice in Robes*. Cambridge, Mass.: Belknap Press, 2006.

Dworkin, Ronald. Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom. New York: Knopf, 1993.

Dworkin, Ronald. “Objectivity and Truth: You’d Better Believe It.” *Philosophy & Public Affairs* 25.2 (1996): 87-139.

Dworkin, Ronald. *Freedom’s Law: The Moral Reading of the American Constitution*. Cambridge: Harvard University Press, 1996.

Dworkin, Ronald. *Law's Empire*. Cambridge, Mass.: Belknap Press, 1986.

Dworkin, Ronald. *Taking Rights Seriously.* Cambridge, Mass.:Harvard University Press, 1977.

Dworkin, Dworkin. “Judicial Discretion.” *The Journal of Philosophy* 60.21 (1963): 624-638.

Eckenwiler, Lisa A., and Felicia Cohn. *The Ethics of Bioethics: Mapping the Moral Landscape*. Baltimore: Johns Hopkins University Press, 2007.

Eggertson, Laura. “Most Palliative Physicians Want No Role in Assisted Death.” *Canadian Medical Association Journal* 187.6 (2015): E177. <http://www.cmaj.ca/content/cmaj/187/6/E177.full.pdf>

Ehleben, C.M., B.H. Childs, and S.L. Saltzman. “What is it Exactly that You Do? A ‘Snapshot’ of an Ethicist at Work.” *HEC Forum* 10.1 (1998): 71-71.

Elliott, Carl. *White Coat, Black Hat: Adventures on the Dark Side of Medicine*. Boston: Beacon Press, 2010.

Elliott, Carl. “Throwing a Bone to the Watchdog.” *Hastings Center Report* 31.2 (2001): 9-12.

Elliott, Carl. “Pharma Buys a Conscience.” *The American Prospect* 12.17 (2001): 16-20.

Emmerich, Nathan. "What Would You Do? Juggling Bioethics and Ethnography." *Sociology of Health & Illness* 31.7 (2009): 1112-1113.

Engelhardt, H. Tristram. "Core Competencies for Health Care Ethics Consultants:

In Search of Professional Status in a Post-Modern World." *HEC Forum* 23.3 (2011): 129-145.

Engelhardt, H. Tristram. "Credentialing Strategically Ambiguous and Heterogeneous Social Skills: The Emperor Without Clothes." *HEC Forum* 21.3 (2009): 293-306.

Engelhardt, H. Tristram. "Bioethics Critically Reconsidered: Living After Foundations." *Theoretical Medicine and Bioethics* 33.1 (2012): 97-105.

Engelhardt, H. Tristram. "Consensus Formation: The Creation of an Ideology." *Cambridge Quarterly of Healthcare Ethics* 11.1 (2002): 7-16.

Engelhardt, H. Tristram. "Confronting Moral pluralism in Posttraditional Western Societies: Bioethics Critically Reassessed." *Journal of Medicine Philosophy* 36.3 (2011): 243-60.

Ford, Paul J. and Denise M. Dudzinski. “Specters, Traces, and Regret in Ethics Consultation.” The Journal of Clinical Ethics 16.3 (2005): 193-195.

Fins, Joseph J., Eric Kodish, Felicia Cohn, Marion Danis, Arthur Derse, Nancy Neveloff Dubler, Barbara Goulden, Mark Kuczewski, Mary Beth Mercer, Robert A. Perlman, Martin L. Smith, Anita Tarzian and Stuart J. Younger. “A Pilot Evaluation of Portfolios for Quality Attestation of Clinical Ethics Consultants.” *The American Journal of Bioethics* 16.3 (2016): 15-24.

Fins, Joseph J. and F. Miller. "Clinical Pragmatism, Ethics Consultation, and the Elderly Patient." *Clinics in Geriatric Medicine* 16.1 (2000): 71-81.

Fins, Joseph J. "Praxis Makes Perfect?" *The Hastings Center Report* 23.5 (1993): 16-19.

Fins, Joseph J. "Encountering Diversity: Medical Ethics and Pluralism." *Journal of Religion and Health* 33.1 (1994): 23-27.

Fins, Joseph J. "A Secular Chaplaincy." *Journal of Religion and Health* 33.4 (1994): 373-375.

Frolic, Andrea and Paula Chidwick. Political and Interpersonal Aspects of Bioethics Consultation. *Theoretical Medicine* 13 (1992): 31-44.

Frolic, Andrea. “Who are We When We are Doing What We are Doing?” *Bioethics* 25.7 (2011): 370-382.

Frolic, Andrea and Chidwick, Paula. “A Pilot Qualitative Study of ‘Conflicts of Interests and/or Conflicting Interests’ Among Canadian Bioethicists. Part 1: Five Cases, Experiences and Lessons Learned.” *HEC Forum* 22.1 (2010a): 5-17.

Frolic, Andrea and Chidwick, Paula. “A Pilot Qualitative Study of ‘Conflicts of Interests and/or Conflicting Interests’ Among Canadian Bioethicists. Part 2: Defining and Managing Conflicts.” *HEC Forum* 22.1 (2010b):19-29.

Fox, Ellen, Sarah Myers, and Robert Pearlman. "Ethics Consultation in United States Hospitals: A National Survey." *The American Journal of Bioethics* 7.2 (2007): 13-25.

Fox, Renee C., and Judith P. Swayze. *Observing Bioethics: A Sociological History*. Oxford: Oxford Univ. Press, 2008.

Freeman, Lindsey M., Susannah L. Rose, and Stuart J. Youngner, “Poverty:

Not a Justification for Banning Physician-Assisted Death,” *Hastings Center Report* 48.6 (2018): 38-46.

Gallie, W.B. “Essentially Contested Concepts,” *Proceedings of the Aristotelian Society* 56.1 (1955): 167 - 198.

Gaudine, A., L. Thorne, S. M LeFort and M. Lamb. "Evolution of Hospital Clinical Ethics Committees in Canada." *Journal of Medical Ethics* 36.3 (2010): 132-137.

Geppert, Cynthia, and Wayne Shelton. "A Comparison of General Medical and Clinical Ethics Consultations: What Can We Learn from Each Other?" *Mayo Clinic Proceedings* 87.4 (2012): 381-389.

Godkin, M. Dianne. "Project Examining Effectiveness in Clinical Ethics (PEECE): Phase 1--Descriptive Analysis of Nine Clinical Ethics Services." *Journal of Medical Ethics* 31.9 (2005): 505-512.

Grady, Christine. "Reflections on Two Decades of Bioethics: Where We Have Been and Where We are Going." *The American Journal of Bioethics* 13.1 (2013): 8-10.

Grant, Kelly. “Medically Assisted Death Allows Couple Married Almost 73 Years to Die Together.” *The Globe and Mail*, 1 April 2018. https://www.theglobeandmail.com/canada/article-medically-assisted-death-allows-couple-married-almost-73-years-to-die/. Accessed: 11 February 2019.

Green, Ronald M. "The President's Council on Bioethics-Requiescat in Pace." *Journal of Religious Ethics* 38.2 (2010): 197-218.

Greenberg, Rebecca, Kyle Anstey, Rosanna Macri, Ann Heesters, Sally Bean, and

Randi Zlotnik-Shaul. "Bioethics Consultation Practices and Procedures: A Survey of a Large Canadian Community of Practice," *HEC Forum* 26.2 (2013): 135-146.

Grundy, Quinn*. Infiltrating Healthcare: How Marketing Works Underground*

*to Influence Nurses*. Baltimore: Johns Hopkins University Press, 2018.

Guest, Stephen. *Ronald Dworkin*, 3rd ed. Stanford California: Stanford Law

Books, 2013.

Guillemin, Marilyn and Lynn Gillam. “Ethics, Reflexivity, and ‘Ethically

Important’ Moments in Research,” *Qualitative Inquiry* 10.2 (2004) 261-280.

Harding, Sandra. “Rethinking Standpoint Epistemology: What is ‘Strong

Objectivity?’” in Linda Alcoff and Elizabeth Potter, eds., *Feminist Epistemologies*. Routledge, 49-82, 1993

Hart, H.L.A. *The Concept of Law*. 2nd ed. Oxford: Oxford University Press, 1994.

Hart, H.L.A. “Positivism and the Separation of Law and Morals,” *Harvard Law*

*Review* 71.4 (1958): 593-629.

Hedgecoe, A. "Bioethics and the Reinforcement of Socio-Technical Expectations." *Social Studies of Science* 40.2 (2010): 163-186.

Hedgecoe, Adam M. "Critical Bioethics: Beyond the Social Science Critique of Applied Ethics." *Bioethics* 18.2 (2004): 120-143.

Heesters, Ann and D. Talbot. “FaCE-ing and Managing Boundary Dilemmas in

Volunteer Management.” *e-Volunteerism* Volume XVIII, Issue 1 (2018). Online: https://www.e-volunteerism.com/FaCE-ing\_Boundary\_Dilemmas.

Heesters, Ann, Daniel Z Buchman, Kyle W. Anstey, Jennifer A. H. Bell, Barbara J. Russell, Linda Wright. “Power of Attorney for Research: The Need for a Clear Legal Mechanism.” *Public Health Ethics* 10.1. (2016): 101-104.

Heesters, A. "500 hats: Exploring the Challenges of Boundary and Community -Reflections on Professionalization." *HEC Forum* 24.3 (2012): 171-8.

Heesters, Ann M. "Real Help for Those Who Have Been Morally Wounded." *Canadian Nurse* 105.3 (2009): 40. <https://www.cna-aiic.ca/en/canadian-nurse-home/articles/issues/2009/march-2009/real-help-for-those-who-have-been-morally-wounded>. Accessed: 15 January 2019.

Henriksen, Joan M., Megan S. Remtema, Kevin Whitford. “Law Is Not Enough: The Importance of Ethics Consultation in Complex Cases.” *American Journal of Bioethics* 17.7 (2017):79-80.

Heimer, Carol A. “‘Wicked’ Ethics: Compliance Work and the Practice of Ethics in HIV Research,” Social Science & Medicine 98 (2013), 371-378.

Herx, Leonie. Srini Chary, Ed Dubland, David Henderson, Bernard Lapointe, Robin Fainsinger, and Valerie Schulz. “Take Off the Rose-Coloured Glasses. A Response to Drs Buchman and Blackmer,” *British Medical Journal* 364 (2019). 8 February 2019. https://www.bmj.com/content/364/bmj.l412/rr-18. Accessed: 10 February 2019.

Holm, Soren. “Not Just Autonomy - The Principles of American Biomedical Ethics.” *Journal of Medical Ethics* (1995) 21: 332-338.

Hoffmaster, Barry and Cliff Hooker. *Re-reasoning Ethics: The rationality of deliberation and Judgment in Ethics.* Cambridge: MIT Press, 2018.

Hoffmaster, Barry. “From Applied Ethics to Empirical Ethics to

Contextual Ethics. *Bioethics*. 32.2 (2018): 119-125.

Hoffmaster, C. Barry. *Bioethics in Social Context*. Philadelphia: Temple

University Press, 2001.

Hoffmaster, Barry. “Anatomy of a Clinical Ethics Consultation.” *Human*

*Studies*. 22.1 (1999):53-68.

Hoffmaster, Barry. "Can Ethnography Save the Life of Medical Ethics?" *Social Science & Medicine* 35.12 (1992): 1421-1431.

IOM (Institute of Medicine). 2009. *Conflict of Interest in Medical Research, Education, and Practice.* Washington, DC: The National Academies Press.

Ives, Jonathan; Dunn, Michael. “Who's Arguing? A Call for Reflexivity in

Bioethics.” *Bioethics* 24.5 (2010): 256-65.

Jameton, Andrew. *Nursing Practice: The Ethical Issues.* Englewood Cliffs, NJ: Prentice Hall, 1984.

Jansky, M, G. Marx, F. Nauck, and B. Alt-Epping. "Physicians' and Nurses' Expectations and Objections Toward a Clinical Ethics Committee." *Nursing Ethics* 20.7 (2013):771-83. *http://nej.sagepub.com/content/early/2013/05/23/0969733013478308.full.pdf*. Accessed: 28 June 2013.

Johnson, Michael P. and Kathleen J. Ferraro. “Research on Domestic Violence in the 1990s: Making Distinctions.” *Journal of Marriage and Family* 62.4 (2000): 948-963.

Jonsen, Albert R. *The Birth of Bioethics.* New York: Oxford University Press, 1998.

Jonsen, Albert. "Life is Short, Medicine is Long: Reflections on a Bioethical

Insight." *The Journal of Medicine and Philosophy* 31.6 (2006): 667-673.

Jonsen, Albert R. "Casuistry as Methodology in Clinical Ethics." *Theoretical Medicine* 12.4 (1991): 295-307.

Kamm, Frances. “A Right to Choose Death? A Moral Argument for the Permissibility of Euthanasia and Physician-Assisted Suicide.” *Boston Review*, (Summer, 1997) 20-23. Online: <http://bostonreview.net/archives/BR22.3/Kamm.html>. Accessed: 10 February 2019.

Kamm, Frances Myrna. “The Philosopher as Insider and Outsider: How to Advise, Compromise, and Criticize.” *Business & Professional Ethics Journal* 9.1/2 (1990): 7-20. Online: http://www.jstor.org.myaccess.library.utoronto.ca/stable/27800028. Accessed: 10 February 2019.

Kaposey, Chris, Fern Brunger, Victor Maddalena, and Richard Singleton. “Models of Ethics Consultation used by Canadian Ethics Consultants: A Qualitative Study.” *HEC Forum* 28.4 (2016):273-282.

Kaveny, M. Cathleen. "Diversity and Deliberation." *Journal of Religious Ethics* 34.2 (2006): 311-337.

Kearns CE, Schmidt LA, Glantz SA. (2016) “Sugar Industry and Coronary Heart Disease Research: A Historical Analysis of Internal Industry Documents.” JAMA Internal Medicine. 1; 176 (11):1680-1685. doi: 10.1001/jamainternmed.2016.5394.

Kelly, Susan E. "Public Bioethics and Publics: Consensus, Boundaries, and Participation in Biomedical Science Policy." *Science, Technology, & Human Values* 28.3 (2003): 339-364.

Khoja, L, L Horsley, A Heesters, J D Machin, C Mitchell, AR Clamp, GC Jayson, J Hasan “Does Clinical Trial Participation Improve Outcomes in Patients with Ovarian Cancer?” *European Society for Medical Oncology Open*. April 2016. Online: http://esmoopen.bmj.com/content/esmoopen/1/4/e000057.full.pdf.

Kipnis, K. The Certified Clinical Ethics Consultant. *HEC Forum*, 21.3 (2009): 249-261.

Kirby, J. and C. Simpson. A Deliberative Engagement Methodology for Exploring Professionalization. *HEC Forum* 24.3 (2012): 18-201.

Koch, Tom. *Thieves of Virtue: When Bioethics Stole Medicine*. Cambridge, Mass.: MIT Press, 2012.

Koch, T., and S. Jones. "The Ethical Professional as Endangered Person: Blog Notes on Doctor-Patient Relationships." *Journal of Medical Ethics* 36.6 (2010): 371-374.

Kottow, M. "Ethical Quandaries Posing As Conflicts Of Interest." *Journal of Medical Ethics* 36.6 (2010): 328-332.

Korenman, Stanley G. “Teaching the Responsible Conduct of Research in

Humans, Chapter 4. Conflicts of Interest (COI) – Definitions.” Online: http://ori.hhs.gov/education/products/ucla/chapter4/default.htm. Accessed: July 10, 2015.

Kuczewski, M. Two Models of Ethical Consensus, or What Good is a Bunch of Bioethicists? *Cambridge Quarterly of Healthcare Ethics*, 11 (2002): 27-36.

Kuczewski, Mark G. Reconceiving the Family: The Process of Consent in

Medical Decisionmaking. *The Hastings Center Report* 26.2 (1996): 30-37.

LaPuma J., Schiedermayer D. (1994). *Ethics Consultation: A Practical Guide*. Boston, MA: Jones and Bartlett Publishers.

Latham, Stephen R. "The (Low) Life of Ethics Codes." *The American Journal of Bioethics* 5.5 (2005): 46-48.

Lemmens, T. and Benjamin Freedman. “Ethics Review for Sale? Conflict of Interest and Commercial Research Review Boards.” *Milbank Quarterly* 78. 4 (2000): 547-584.

Lenzer, J. When is a Point of View a Conflict of Interest? *British Medical Journal* 2016; 355:i6194.

Li, Madeline, Sarah Watt, Marnie Escaf, Michael Gardam, Ann Heesters, Gerald O’Leary, Gary Rodin. "Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada.” *New England Journal of Medicine* 376. 21 (2017): 2082-2088.

Lilje, C. "Ethics Consultation: A Dangerous, Antidemocratic Charlatanry?" *Cambridge Quarterly of Healthcare Ethics* 2.4 (1993): 438-42.

Lindemann, Hilde, Marian Verkerk, and Margaret Urban Walker. *Naturalized Bioethics: Toward Responsible Knowing and Practice*. Cambridge: Cambridge University Press, 2009.

Lo, Bernard, Marilyn J. Field, Eds. *Conflict of Interest in Medical Research, Education, and Practice.* IOM, 2009, Online: <https://www.ncbi.nlm.nih.gov/books/NBK22942/pdf/Bookshelf_NBK22942.pdf>. Accessed: July 8, 2017.

London, Alex John. “Artificial Intelligence and Black-Box Medical Decisions: Accuracy Versus Explainability.” *Hastings Center Report* 49.1 (2019): 15-21.

Mackie, J.L. “The Third Theory of Law,” *Philosophy and Public Affairs.* 7.1 (1977): 3-16.

Macrae, S., Chidwick, P., Berry, S., Hebert, P., Zlotnik Shaul, R., Faith, K. and Singer, P. Clinical Bioethics Integration, Sustainability, and Accountability: the Hub and Spoke Strategy. *Journal of Medical Ethics* (2005). 256-261.

McCoy, Matthew S and Ezekiel J. Emanuel. “Why There Are No ‘Potential’ Conflicts of Interest.” *Journal of the American Medical Association* 317.17 (2017): 1721-1722.

McCullough, Laurence. "Towards a Professional Ethics Model of Clinical Ethics." *Journal of Medicine and Philosophy* 32.1 (2007): 1-6.

McGee, S. (2011). Ideology and Politicization in Public Bioethics. *Cambridge Quarterly of Healthcare Ethics*, 20.1 (2011): 73-84.

Melley, Christopher D. "The Philosopher in the Health Care Setting: Objections and Replies." *HEC Forum* 4.4 (1992): 237-254.

Merrill, Thomas W. "Distracted by Religion: On Doing Bioethics in Public." *Perspectives on Political Science* 38.2 (2009): 107-112.

Merry, Michael S. "Libertarian Bioethics and Religion: The case of H. Tristram Engelhardt, Jr." *Bioethics* 18.5 (2004): 387-407.

Michels, Kevin H. “What Conflicts Can be Waived? A Unified Understanding of

Competence and Consent,” *Rutgers Law Review* 65.12 (2012): 109-172.

Miller, Franklin G. "The Case for a Code of Ethics for Bioethicists:

Some Reasons for skepticism." *The American Journal of Bioethics* 5.5 (2005): 50-52.

Miller, Jessica. "A Code of Ethics for Bioethicists: Prospects and Problems." *The American Journal of Bioethics* 5.5 (2005): 66-68.

Mokwunye, Nneka O., Virginia A. Brown, John J. Lynch, and Evan G. DeRenzo. "Hiring a Hospital Staff Clinical Ethicist: Creating a Formalized Behavioral Interview Model." *HEC Forum* 22.1 (2010): 51-63.

Moreno, Jonathan D. "Ethics Consultation as Moral Engagement." *Bioethics* 5.1 (1991): 44-56.

Moreno, Jonathan D. "The End of the Great Bioethics Compromise." *Hastings Center Report* 35.1 (2005): 14-15.

Morin, Karine. "Code of Ethics for Bioethicists: Medicine's Lessons Worth Heeding." *The American Journal of Bioethics* 5.5 (2005): 60-62.

Muller, Jessica H. "Anthropology, Bioethics, and Medicine: A Provocative Trilogy." *Medical Anthropology Quarterly* 8.4 (1994): 448-467.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (1979). Online: <https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf>. Accessed 2 June 2019.

Ontario Ministry of Health and Long Term Care. “Patient Based Funding Overview.” Online: <http://www.health.gov.on.ca/en/pro/programs/ecfa/docs/ecfa_funding_pres.pdf>.

[Osagie K. Obasogie](https://www.amazon.com/s/ref=dp_byline_sr_book_1?ie=UTF8&text=Osagie+K.+Obasogie&search-alias=books&field-author=Osagie+K.+Obasogie&sort=relevancerank), [Marcy Darnovsky](https://www.amazon.com/s/ref=dp_byline_sr_book_2?ie=UTF8&text=Marcy+Darnovsky&search-alias=books&field-author=Marcy+Darnovsky&sort=relevancerank) (Eds.). *Beyond Bioethics: Toward a New Biopolitics.* Oakland: University of California Press (2018).

Quillen, Ed. “Origin of the Laundry List.” *The Denver* *Post* (June 5, 2008). Online: <http://www.denverpost.com/2008/06/05/origin-of-the-laundry-list/> Accessed: 7 July 2017.

Quist, N. Inside Baseball and Ethics Consultation: A Comment on “Ethics

Been Very Good to Us.” *The Journal of Clinical Ethics*, 23.2 (2012), 169-71.

*R v. Morgentaler* 1988. 1 S.C.R. 30.

<http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/288/index.do>. Accessed July 22, 2019.

Rasmussen, L. "The Chiaroscuro of Accountability in the Second Edition of the Core Competencies for Healthcare Ethics Consultation." *Journal of Clinical Ethics* 24.1 (2013): 32-40.

Rasmussen, Lisa M. "An Ethics Expertise for Clinical Ethics Consultation." *The Journal of Law, Medicine and Ethics* 39.4 (2011): 649-661.

Raymond, Nathaniel. “Reboot Ethical Review for the Era of Big Data.” *Nature*

568 (2019): 277.

Online: <https://www.nature.com/articles/d41586-019-01164-z?utm_source=Nature+Briefing&utm_campaign=7a83897cb0-briefing-dy-20190416&utm_medium=email&utm_term=0_c9dfd39373-7a83897cb0-43265497> Accessed: April 18, 2019.

Reagan, Leslie J. "Reviews of Books: Bioethics in America: Origins and Cultural Politics M. L. Tina Stevens." *The American Historical Review* 107.5 (2002): 1599-1600.

Réaume, Denise. “Is Integrity a Virtue? Dworkin's Theory of Legal Obligation.” *The University of Toronto Law Journal* 39.4 (1989): 380-409.

Reel, K. “Denying Assisted Dying Where Death is *Not* ‘Reasonably Foreseeable’:

Intolerable Overgeneralization in Canadian End-of-Life Law*.” Canadian Journal of Bioethics* 1.3 (2018): 71-81.

Reel, K. "The Benefits of Practice Standards and Other Practice-Defining Texts: and Why Healthcare Ethicists Ought to Explore Them." *HEC Forum* 24.3 (2012): 203-17.

Reel, K., Ann M. Heesters and the Members of PHEEP (Practicing Health Care Ethicists Exploring Professionalization). Commentary on D. K. Sokol, D.K. (2012). “Is Bioethics a Bully?” *British Medical Journal*, 345. <http://www.bmj.com/content/345/bmj.e5802/rr/603802>.11

Regenberg, Alan C. and Debra J. H. Mathews. "Resisting the Tide of Professionalization: Valuing Diversity in Bioethics." *The American Journal of Bioethics* 5.5 (2005): 44-45.

Richards, Naomi. “Old Age Rational Suicide.” *Sociology Compass* 11:e12456 (207). <https://onlinelibrary.wiley.com/doi/epdf/10.1111/soc4.12456>. Accessed: 10 February 2019.

Rittel, Horst W.J. and Melvin M. Webber. “Dilemmas in a General Theory of Planning.” *Policy Sciences* 4.2 (1973): 155-169.

Roberts, Marc J. and Michael R. Reich. “Ethical Analysis in Public Health.” *The Lancet* 359.9311 (2002): 1055-1059.

Rothman, David J. *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making.* New York: Basic Books, 1991.

Rowell, Mary. "The Olivieri Debacle: Where Were the Heroes of Bioethics? A Reply." *J Med Ethics* 30.1 (2004): 50.

Rubin, Susan, and Laurie Zoloth. "Clinical Ethics and the Road Less Taken: Mapping the Future by Tracking the Past." *Journal of Law, Medicine and Ethics* 32.2 (2004): 218-225.

Satel, S. (2010). The Limits of Bioethics: Where the Profession Ends and Politics Begins. *Policy Review*, 159.

Satel, S. (2010). The Right (and Wrong) Answers. Review of Fox and Swazey’s *Observing Bioethics*. *New Republic*. Online: <https://sallysatelmd.com/articles/2001/who-needs-medical-ethics/>. Accessed: 30 March 2018.

Satel, S. and Stolba, C. (2001). Who Needs Medical Ethics? *Commentary.* <https://sallysatelmd.com/articles/2001/who-needs-medical-ethics/>.

Accessed: 30 March 2018.

Savulescu, J. "Editor’s Note: How Can We Make a Difference? The Perils of Heroism." *Journal of Medical Ethics* 30.1 (2004): 52.

Schuklenk, Udo, and Jim Gallagher. "Status, Careers and Influence in Bioethics." *The American Journal of Bioethics* 5.5 (2005): 64-66.

Schuklenk, Udo. "National Bioethics Commissions and Partisan Politics." *Bioethics* 22.6 (2008): ii-iii.

Scofield, Giles. "What – if Anything – Sets Limits to the Clinical Ethics

Consultant’s ‘Expertise’”? *Perspectives in Biology and Medicine* 61.4 (2018): 594-608.

Scofield, Giles. “I Should Have Known (Better?).” *Narrative Inquiry in Bioethics*

6.1 (2016): 34-36.

Scofield, Giles. "Response: Narcissus Meets Pandora." *The Journal of Law, Medicine & Ethics* 28.3 (2000): 243-244.

Scofield, Giles. "Commentary: The Wizard of Oughts." *The Journal of Law, Medicine & Ethics* 28.3 (2000): 232-235.

Scofield, Giles. "Motion(less) In Limine." *The Journal of Law, Medicine & Ethics* 33.4 (2005): 821-833.

Scofield, Giles R. "The Health Care Ethics Consultant." *HEC Forum* 6.6 (1994): 363-370.

Scofield, Giles R. "What Is Medical Ethics Consultation?" *The Journal of Law, Medicine & Ethics* 36.1 (2008): 95-118.

Scofield, Giles R. “Ethics Consultation: The Least Dangerous Profession?” *Cambridge Quarterly of Healthcare Ethics* 2 (1993), 417-448.

Secker, Barbara, Cecile Bensimon, Cheryl Cline, Dianne Godkin, Ann Heesters and Kevin Reel. "Examining Methods to Assess Core Knowledge Competencies: A Canadian Perspective." *The American Journal of Bioethics* 14.1 (2014): 30-3.

Self, D. J. "Is Ethics Consultation Dangerous?" *Cambridge Quarterly of Health care Ethics* 2.4 (1993): 442-5.

Sherwin, S. "Whither Bioethics? How Feminism Can Help Reorient Bioethics." *International Journal of Feminist Approaches to Bioethics* 1.1 (2008): 7-27.

Shields, Jon A. "Bioethical Politics." *Society* 43.3 (2006): 19-24.

Shuchman, Miriam. (2005). *The Drug Trial: Nancy Olivieri and the case that rocked the Hospital for Sick Children*, First ed. Toronto: Random House.

Sibbald, Barbara. “Doctors Left to Define Foreseeable Death in New Law.” *Canadian Medical Association Journal* 188.11 (2016): E243–E244.

Siegler, Mark, and Peter A. Singer. "Clinical Ethics Consultation: Godsend or God Squad?" *The American Journal of Medicine* 85.6 (1988): 759-760.

Simpson, C. (2012). “Getting Engaged: Exploring Professionalization in Canada.” *HEC Forum* 24(3): 149-151.

Simpson, C. "Mapping our Practice? Some Conceptual "Bumps" for us to Consider." *HEC Forum* 24.3 (2012): 219-26.

Smith Iltis, Ana. "Bioethics As Methodological Case Resolution: Specification, Specified Principlism and Casuistry." *The Journal of Medicine and Philosophy* 25.3 (2000): 271-284.

Smith, M.L., K. Weise, and E. Kodish. "Toward a Competency-Based Certification of Clinical Ethics Consultants: A Four Step Process." *Journal of Clinical Ethics* 21.1 (2010): 14-22.

Smith, W.J. "The Question of Method in Ethics Consultation: Transforming a Career into a Profession?" *American Journal of Bioethics* 1.4 (2001): 42-3.

Society for Health and Human Values–Society for Bioethics Consultation. *Core Competencies for Health Care Ethics Consultation: The Report of the American Society for Bioethics and Humanities*. Glenview, IL: American Society for Bioethics Consultation; 1998.

Sokol, Daniel. "Is Bioethics a Bully?" *British Medical Journal* 345: e5802 (2012). <https://www.bmj.com/content/345/bmj.e5802>. Accessed: 4 September 2012.

Sokol, D. K. "Sweetening the Scent: Commentary on “What Principlism Misses." *Journal of Medical Ethics* 35.4 (2009): 232-233.

Spike, Jeffrey P. "Resolving the Vexing Question of Credentialing: Finding the Aristotelian Mean." *HEC Forum* 21.3 (2009): 263-273.

Steinkamp, Norbert L, Bert Gordijn, and Henk ten Have. "Ethical Expertise Revisited: Reply To Giles Scofield." *Kennedy Institute of Ethics Journal* 18.4 (2008): 385-392.

Steinkamp, Norbert, Bert Gordijn, and Henk ten Have. "Debating ethical expertise." *Kennedy Institute Ethics Journal* 18.2 (2008): 173-92.

Strong, Carson. "Lost In Translation: Religious Arguments Made Secular." *American Journal of Bioethics* 5.3 (2005): 29-31.

Strong, Carson. "Theoretical and Practical Problems with Wide Reflective Equilibrium in Bioethics." *Theoretical Medicine and Bioethics* 31.2 (2010): 123-140.

Swiderski, Deborah M., Katharine M. Ettinger, Mayris Webber, and Nancy N. Dubler. "The Clinical Ethics Credentialing Project: Preliminary Notes from a Pilot Project to Establish Quality Measures for Ethics Consultation." *HEC Forum* 22.1 (2010): 65-72.

Tarzian, A. J., Wocial, L. D., and the ASBH Clinical Ethics Consultation Affairs Committee. “A Code of Ethics for Health Care Ethics Consultants: Journey to the Present and Implications for the Field.” *American Journal of Bioethics*. 15.5 (2015): 38-51.

Tarzian, A. "Health Care Ethics Consultation: An Update on Core Competencies and Emerging Standards from the American Society for Bioethics and Humanities' Core Competencies Update Task Force." *American Journal of Bioethics* 13.2 (2013): 3-13.

Tarzian, Anita J. "Credentials for Clinical Ethics Consultation: Are We There Yet?" *HEC Forum* 21.3 (2009): 241-248.

Thomas, John E., and Wilfrid J. Waluchow. *Well and good: Case studies in Biomedical Ethics*. Rev. Ed. Peterborough: Broadview Press, 1990.

Thompson, Jon, Patricia Baird, and Jocelyn Downie. *The Olivieri Report: The Complete Text of the Report of the Independent Inquiry Commissioned by the Canadian Association of University Teachers*. Toronto: J Lorimer, 2011.

Toulmin, S. "How Medicine Saved the Life of Ethics." *Perspectives in Biology and Medicine* 25.4 (1982): 736-750.

Tronto, Joan. “Who is Authorized to Do Applied Ethics? Inherently Political Dimensions of Applied Ethics.” *Ethical Theory and Moral Practice* 14.4 (2018): 407-417.

Turner, Leigh. "Politics, Bioethics, and Science Policy." *HEC Forum* 20.1 (2008): 29-47.

Turner, Leigh. "Bioethics in Pluralistic Societies." *Medicine, Health Care and Philosophy* 7.2 (2004): 201-208.

United States Department of Veteran Affairs National Center for Ethics in Health Care, Integrated Ethics Program at <http://www.ethics.va.gov/integratedethics/>

Veatch, RM. "Ethics Consultation: Permission from Patients and Other Problems of Method." *American Journal of Bioethics* 1.4 (2001): 43-5.

Verkerk, M. and Lindemann, H. (2012) Toward a Naturalized Clinical Ethics. *Kennedy Institute of Ethics Journal*. 22(4), 289-306.

Volpe, RL. "Training Currently Practicing Members of the Ethics Consultation Service: One Institution’s Experience." *Journal of Clinical Ethics* 22.3 (2011): 217-22.

Vulnerable Persons Secretariat. *Vulnerable Persons Standard.* <http://www.vps-npv.ca/read-the-standard-20>. Accessed: 11 February 11, 2019.

Walker, Margaret Urban. “Keeping Moral Space Open: New Images of Ethics Consulting” *Hastings Center Report* 23.2 (1993): 33-40.

Walker, Margaret Urban. "Feminism, Ethics, and the Question of Theory." *Hypatia* 7.3 (1992): 23-38.

Walker, Margaret Urban. "Moral Understandings: Alternative Epistemology for a Feminist Ethics." *Hypatia* 4.2 (1989): 15-28.

Walker, T. "What Principlism Misses." *Journal of Medical Ethics* 35.4 (2009): 229-231.

Waluchow, Wilfrid J. *A Common Law Theory of Judicial Review: The Living Tree.* New York: Cambridge University Press, 2007.

Waluchow, Wilfrid J. *The Dimensions of Ethics: An Introduction to Ethical Theory*. Peterborough, Ont.: Broadview Press, 2003.

Watkins, Liza T., Galit Sacajiu, and Alison Karasz. "The Role of the Bioethicist in Family Meetings about End of Life Care." *Social Science & Medicine* 65.11 (2007): 2328-2341.

Wear, Delese, and Mark G. Kuczewski. "The Professionalism Movement: Can We Pause?" *The American Journal of Bioethics* 4.2 (2004): 1-10.

Williams-Jones, Bryn. "Book Review: Who Owns Life?" *Theoretical Medicine and Bioethics* 25.2 (2004): 165-169.

Wolf, Susan M., and Jeffrey P. Kahn. "Bioethics Matures: The Field Faces The Future." *Hastings Center Report* 35.4 (2005): 22-24.

Young, Adrienne M. “Solving the Wicked Problem of Hospital Malnutrition.” *Nutrition and Dietetics* 72 (2015): 200-2004.

Zoloth-Dorfman, L, and SB Rubin. "Navigators and captains: expertise in clinical ethics consultation." *Theoretical Medicine* 18.4 (1997): 421-32.

1. In using the term unregulated I do not mean to suggest that PHEs face no constraints on their practice. Their work is circumscribed in a variety of important ways. Like others employed in health care they are subject to institutional policies, legal standards, and a wide range of organizational conventions. Most also have role descriptions that describe their institutional responsibilities (although these may be written in fairly general terms and may include phrases like ‘other duties as required.’) What ethicists do not have, and this can elicit incredulous responses in health care settings, is a professional college or other regulatory body that establishes the obligations that practitioners owe to their colleagues and to the public, and that describes the penalties associated with breaches of duty. [↑](#footnote-ref-2)
2. A qualification is in order here. A few years ago, the Canadian government faced sharp criticisms from health economists, bioethicists, and some professional associations over the limitations it placed on the range of services that would be funded for the treatment of uninsured patients. The debates over the content of the Interim Federal Health Plan evoked (at least implicitly) questions concerning the nature and obligations of community. Some uninsured patients, typically undocumented labourers, have lived and worked in Canada for decades and many have Canadian-born spouses and children. It can be a great challenge for healthcare workers to deny them services, such as kidney dialysis or organ transplantation, when their need is great and the prospect of a return to their country of origin entails great hardship or certain death. These are not, however, debates that are typically held in the emergency rooms and operating theatres of the country. There the questions raised are very focused and pragmatic and seek solutions to the immediate problems of identifiable patients. Clinicians may chafe against the cost constraints that limit the treatment options that they can offer to those on their caseload but it is relatively rare for them to expand their field of enquiry to include reflections on conceptions of justice and community. [↑](#footnote-ref-3)
3. Typically the public becomes aware of ethical issues arising in health care when cases like those of Teresa Schiavo or Hassan Rasouli become front-page news, news that can be quite sensational. The Schiavo case featured a family fractured by disputes over decision-making authority for an incapable patient. (In re Guardianship of Schiavo, 851 So. 2d 182 (Fla. 2d Dist. Ct. App. 2003). The Rasouli case, recently before the Canadian Supreme Court, foregrounded questions concerning the authority of surrogate decision-makers and the importance of procedural justice in so-called futility cases. While no clinical ethicist would describe these as easy cases, I’d wager that few would describe them as novel.

   [↑](#footnote-ref-4)
4. According to research conducted by Ellen Fox, formerly of the United States’ Department of Veterans Affairs, and reported by Mark P. Aulisio in *Ethics Consultation from Theory to Practice*, “100% of US hospitals with 400 beds or more, federal hospitals, or hospitals that are members of the Council of Teaching Hospitals and over 81% of all US hospitals have an ethics consultation service of some kind” p. 20. My own informal inquiries confirm that the Canadian context is much the same and I am unaware of any academically-affiliated Canadian hospital that does not have a health care ethicist in its employ. [↑](#footnote-ref-5)
5. Dworkin coined the phrase, propositions of law, to encompass "all the various statements and claims people make about what the law allows or prohibits or entitles them to have." *Law's Empire*, 4. [↑](#footnote-ref-6)
6. I do not mean to suggest that such cases never present health care providers with challenges in acceding to the requests of legally authorized decision-makers. An unmarried, incapable patient may have two adult children with equal standing under the Act who hold utterly divergent views concerning their parent’s preferences or best interests. The province’s Consent and Capacity Board deals with these cases often, but their task is rarely the straightforward, empirical one of identifying who has the legal right to act on a parent’s behalf. [↑](#footnote-ref-7)
7. My position should in no way be confused with an economic liberal or classical liberal point of view. Others may well endorse such an orientation to the practice but I do not. [↑](#footnote-ref-8)
8. Some work of this sort has already been done. A relatively early and influential document was presented at the Canadian Bioethics Society’s 2008 spring meeting and is described in an article by Paula Chidwick et al. “Exploring a Model Role Description for Ethicists.” *HEC Forum* 22 (2010): 31- 40. [↑](#footnote-ref-9)
9. For this purpose the label "research" refers to investigations into topics that have ethical dimensions, such as whether it is ever permissible for minor children to donate solid organs to family members. Clinical ethics consultants may engage in research that is empirical or conceptual in nature in their efforts to contribute to their field, and their approaches to these questions will depend to a large extent on the disciplinary training they received prior to entering the field or the colleagues with whom they collaborate. Both types of research are familiar and legitimate for health care ethicists to pursue. I want to distinguish these activities, however, from another common responsibility of the practicing ethicist; that is, the research review and evaluation that she may perform as a member of a Research Ethics Board (REB) or an Institutional Review Board (IRB). I would concede the point that research review can raise complex questions but when it does so I would argue that the activity that ensues might better be categorized as research ethics consultation rather than research ethics review. For a description of research ethics consultation see: Elie Dolgin’s piece “Human-subjects research: The Ethics Squad” in *Nature.* Online: <http://www.nature.com/news/human-subjects-research-the-ethics-squad-1.16186>. Accessed: January 26, 2018. [↑](#footnote-ref-10)
10. Sally Bean, who is a practicing health care ethics consultant in Toronto, has made a compelling argument for the existence of composite consultation cases which straddle the distinctions that are typically drawn between clinical, organizational, and research ethics. As many practicing healthcare ethicists can attest, a case concerning the appropriate limits of patient care may prompt reflections on the adequacy or defensibility of organizational policy, or may raise concerns about the permeable membrane that separates innovative therapy from research. The implications of Bean’s “hybrid taxonomy” go beyond the challenge to adequately log and report what ethicists do. Indeed, this way of thinking may provoke skepticism about the very nature of consultation work. This is a point to which I will return in due course. [↑](#footnote-ref-11)
11. Most Canadian and American PHEs agree that it is important to preface ethics consultations with a limited assurance of confidentiality. It is typical for clinical ethicists to remind requestors and participants that, although confidentiality is important and respected whenever possible, they will observe legal reporting requirements such as the obligation to report suspected child abuse or a credible threat of suicide or homicide. [↑](#footnote-ref-12)
12. The recent spate of articles on credentialing clinical ethics consultants is an important development for the field and it is in many cases motivated by the concerns that drove the earlier debate; that is, worries that the recommendations of an inadequately trained healthcare ethics consultant could have grave consequences for those who are her clients. Attention directed toward finding ways to measure the skills, knowledge, and attributes of competent consultants (the term ‘attributes’ replaces the older, perhaps more familiar, language of character traits) is very different from earlier discussions which challenged the very presence of these “strangers at the bedside” to invoke David Rothman’s memorable phrase. My point is not that the credentialing debate is wrong-headed. (Indeed, I have contributed to it myself.) It is simply that these important earlier questions remain largely unanswered. [↑](#footnote-ref-13)
13. These terms have acquired a specificity that will be lost on those who have not been attending closely to the professionalization debate. In ASBH parlance, individual ethicists may apply to be certified to lead ethics consultations (through a so-called quality attestation process) whereas institutions (such as hospitals or other health care institutions) may have ethics services that may be accredited to perform ethics consultations. Graduate directors of existing educational programs are currently exploring the standards that they believe to be essential in a fully accredited ethics education-training program.

    [↑](#footnote-ref-14)
14. *Core Competencies for Healthcare Ethics Consultation*, 2nd edition, page 57.

    [↑](#footnote-ref-15)
15. Ibid., 2. [↑](#footnote-ref-16)
16. Ibid., 6. [↑](#footnote-ref-17)
17. The term “attribute” may generate some puzzlement here. It, along with “attitude” and “behavior,” appears in the second edition of the *Core Competencies* as a replacement or placeholder for “character.” The substitution reflects the authors’ desire to avoid the implication that these traits cannot be taught or evaluated. Indeed, the acquisition and cultivation of the attributes they describe as connected to the skillful performance of the ethicist’s role are described as the work of a lifetime. These attributes, attitudes, and behaviours are as follows: tolerance, patience, and compassion; honesty, forthrightness and self-knowledge; courage; prudence and humility; leadership and integrity. Ibid., 32-33.

    [↑](#footnote-ref-18)
18. Ibid., 7. [↑](#footnote-ref-19)
19. In some cases the identification of relevant decision-makers may generate uncertainty or constitute an ethical challenge of its own. If, for example, if it is anticipated that a patient’s treatment preferences might be overridden owing to a family member’s disapproval it may be problematic to include that relative at specific points in the decision-making process even though he has a strong interest in the patient’s decisions. These cases arise with some regularity in clinical settings even though it is generally advisable to engage family members at some stages in the decision-making process. A clinical ethicist may recommend a step-wise process for engaging those with moral standing. A patient may need to be engaged in a private and supportive setting to devise a strategy to bolster his ability to choose on his own behalf when those closest to him have strong preferences that differ from his own. [↑](#footnote-ref-20)
20. Ibid., 3. [↑](#footnote-ref-21)
21. *Core Competencies*, p7. [↑](#footnote-ref-22)
22. The Core Competencies Task Force explicitly references Dubler and Lieberman’s approach to bioethics mediation (although the authors accept that the ethics community employs other types of ethics facilitation as well). This differs from other forms of mediation that are designed to limit the range of options in order to expedite consensus. Mediation, in the context of ethics consultation, has as its aim “principled consensus” which is agreement that results in a plan of action that, according to Dubler and Lieberman, does not violate the community’s legal and ethical standards. I leave aside for the moment the interesting question of whether a principled consensus should ever violate legal standards in order to satisfy ethical ones. Ibid, p.6, n. 12.

    It is interesting to note that the question of obedience to wicked law and wicked legal systems is an important one that has long been a part of legal theoretical debate, and that discussion may be an instructive one for those interested in theoretical disagreement in healthcare ethics. [↑](#footnote-ref-23)
23. I use the MRP designation quite purposefully because, increasingly, the professional who has the ultimate professional responsibility for a case may be either a nurse practitioner or a physician. This description is appropriate to either case. [↑](#footnote-ref-24)
24. The steps involved in ethics facilitation are succinctly set out in the Core Competencies report, pp. 7-9. [↑](#footnote-ref-25)
25. The features they share, and which arise almost routinely in consultation cases originating in settings as different as critical care units and geriatric psychiatry units, are conflicting perspectives concerning quality of life and disputes about who has (or ought to have) the authority to decide when that quality is so poor as to allow or require withdrawal of life-sustaining treatment. To complicate the matter further, life-sustaining treatment may involve the prolonged use of scarce resources like beds in intensive care units or entail the placement of ubiquitous and inexpensive equipment like percutaneous endogastric feeding tubes. [↑](#footnote-ref-26)
26. Carl Elliott. “Pharma Buys a Conscience, “*The American Prospect*. 12.17 (2001): 16-20. [↑](#footnote-ref-27)
27. Carl Elliott, *White Coat, Black Hats: Adventures on the Dark Side of Medicine*, (Boston, MA: Beacon Press, 2010),144. [↑](#footnote-ref-28)
28. Mobility devices (such as walkers or wheelchairs), physical rehabilitation sessions, home modifications, or personal care services, may not be funded adequately, or at all, by provincial insurance plans. This means that the least well-off can find themselves obliged to accept institutionalization in cases where others with similar injuries or disabilities can expect to return to their own homes with adequate supports in place. [↑](#footnote-ref-29)
29. In Quebec hospitals some ethics consultants belong to labour unions but my understanding is that they owe any related protections to their membership in the provincial civil service rather than to their roles as healthcare ethics consultants. Moreover, even in that context, ethicists who accept management-level roles cannot belong to trade unions. [↑](#footnote-ref-30)
30. François Baylis, “The Olivieri Debacle: Where Were the Heroes of Bioethics?” *J Med Ethics* 2004; 30:44-9. [↑](#footnote-ref-31)
31. Ibid., 45. [↑](#footnote-ref-32)
32. Kuczewski, Mark G. “Reconceiving the Family: The Process of Consent in Medical Decisionmaking.” *The Hastings Center Report*, March-April 1996. [↑](#footnote-ref-33)
33. Online: <https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf> Accessed: 2 June 2019. [↑](#footnote-ref-34)
34. In 2011 the major Canadian federal funding agencies, (the Canadian Institute of Health Research, CIHR; the National Science and Engineering and Research Council, NSERC; and the Social Sciences and Humanities Research Council, SSHRC) released a framework articulating their expectations of researchers and institutions that are in receipt of federal funds. In their words, this product, called the Responsible Conduct of Research (RCR) Framework, “sets out the responsibilities and corresponding policies for researchers, Institutions, and the Agencies, that together help support and promote a positive research environment. It specifies the responsibilities of researchers with respect to research integrity, applying for funding, financial management, as well as requirements for conducting certain types of research, and defines what constitutes a breach of Agency policies. For institutions, it details the minimum requirements for institutional policies addressing allegations of policy breaches, and articulates their responsibilities for promoting responsible conduct of research and reporting to the Agencies.” Online: http://www.rcr.ethics.gc.ca/eng/policy-politique/framework-cadre/#11. Research Integrity Officers are charged with ensuring that their institutions comply with these standards. The Tri-Agency Framework is not backed with the threat of legal sanctions, nor is it supported with funding for investigators who can ascertain whether parties are compliant with this guidance, but researchers and institutions that breach Agency policy do risk the prospect of losing their current funds as well as eligibility to apply for any future funding.

    It is interesting to note that there is no authoritative definition of research misconduct in Canada, nor have the Tri-Agencies attempted to establish one, but there is fairly broad agreement that, at minimum, activities such as those proscribed by the U.S. National Institute of Health (NIH) fall within this category: “Research misconduct is defined as fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or in reporting research results, according to 42 CFR Part 93.” The NIH Office of Extramural Research cautions that, “Research misconduct does NOT include honest error or differences of opinion.” [Emphasis in original]. Online: http://grants.nih.gov/grants/research\_integrity/research\_misconduct.htm.

    [↑](#footnote-ref-35)
35. *TCPS2*, Chapter 2, Part B. Available online: <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter2-chapitre2/eng/policy-politique/initiatives/tcps2-eptc2/chapter6-chapitre6/#ch6_en_a6.12>. Accessed 5 June 2019. [↑](#footnote-ref-36)
36. The main point here is that institutional approval differs from research ethics board approval. In the Canadian regulatory environment an institution cannot give its blessing to a study that has been rejected as unethical by its own duly-constituted REB. The converse, however, does not obtain. This is part of a commitment to ensuring that the ethical review of research takes place at arm’s length from administrative pressures to promote research within a health care organization. According to the Tri-Agencies, research ethics boards must report to the highest body in an organization. This is typically the institution’s Board of Trustees which in Ontario is regulated by the *Public Hospitals Act* which grants it responsibilities for “decision-making and oversight,” including, as one Board’s own interpretation states, the obligation to “ensure there are systems in place that ensure management is operating in an ethical way that complies with all relevant statutes, regulations and hospital by-laws” (this is from the University Health Network Board’s Terms of Reference, Online: <https://www.uhn.ca/corporate/AboutUHN/Governance_Leadership/Board_Trustees/Documents/Board_of_Directors_Board_Terms_of_Reference.pdf>. Accessed: 5 June 2019. A Board of Trustees is composed of a group of voluntary, elected community members and appointed senior institutional representatives. It typically includes an organization’s President or Chief Executive, the Chief of Staff and others such as the Chief Nursing Executive. Only independent trustees are voting members of these boards. [↑](#footnote-ref-37)
37. Miriam Shuchman. *The Drug Trial* (Toronto: Random House Canada, 2005), 274. See also page 25 of the Olivieri report commissioned by the Canadian Association of University Teachers p. 25 which distinguishes between two inappropriate confidentiality clauses contained in contracts by Olivieri and Apotex. One was for consulting and the other pertained to the reporting of trial results. Jon Thompson, Patricia Baird, and Jocelyn Downie. *The Olivieri Report: The Complete Text of the Report of the Independent Inquiry Commissioned by the Canadian Association of University Teachers*. Toronto: J Lorimer, 2011. [↑](#footnote-ref-38)
38. Ibid. [↑](#footnote-ref-39)
39. This figure was obtained from Apotex’s own website: <http://www.apotex.com/ca/en/about/default.asp>. Accessed 8 January 2018. [↑](#footnote-ref-40)
40. Ibid., 259. [↑](#footnote-ref-41)
41. There were relevant precedents and standards to be consulted in the research ethics literature in the late nineties, but since that time any residual questions related to consent and disclosure have been regarded as settled. *TCPS2*, released by the Canadian Tri-Council Agencies in 2010, speaks directly to researchers’ obligations to ensure that the consent of participants continues to be valid throughout the lifespan of a project. This means that changes in a trial protocol, or information that may reasonably be thought to affect a participant’s willingness to consent, must be disclosed to those participants promptly. Article 3.3 of *TCPS2* unambiguously states that, “researchers shall disclose changes to the risks or potential benefits of the research. This gives participants the opportunity to reconsider the basis for their consent in light of the new information.” Some members of the ethics community who have a keen memory of this infamous deferiprone trial still refer to this passage as the Olivieri clause.

    Earlier versions of the *TCPS* were less explicit than this current formulation, but even then these principles were not unknown to those immersed in the worlds of research and research ethics. The *Declaration of Helsinki* recognized the right of participants to withdraw from research without penalty as early as 1964, and the Tuskegee syphilis study (conducted by the United States’ Public Health Service between 1932 and 1972) was universally condemned for withholding vital information from the servicemen (and the sexual partners of those men) enrolled in that long-running clinical trial. [↑](#footnote-ref-42)
42. Miriam Shuchman, *The Drug Trial* (Toronto: Random House Canada, 2005), 158. [↑](#footnote-ref-43)
43. A lack of efficacy is concerning because it may leave participants who are suffering from serious diseases reliant for too long on unproven agents when established therapies remain available to them. In this case, for example, there was an effective treatment for iron overload but many patients found the frequent injections it entailed to be so distasteful that they often failed to follow their treatment regimens. Because the ultimate cost of frequent treatment non-adherence was death, the prospect of losing access to L1 was catastrophic for those who were responding well to the study agent. Establishing rules about when a trial should be halted early is a complex matter and can be ethically controversial. It is important to note, however, that these rules should be agreed upon *before* a trial begins and communicated in lay language to potential participants. In addition, the body that conducts interim analyses of study data (the Data Safety Monitoring Board or DSMB), and decides which events are to trigger trial cessation, should not have any direct involvement with the study. For a brief overview of the topic see Stephen A. Cannistra, “The Ethics of Early Stopping Rules: Who is Protecting Whom?” *Journal of Clinical Oncology*, May 1, 2002, vol. 22, no. 9, 1542-1545. [↑](#footnote-ref-44)
44. Interactions between journal publishers, prescribers, and patients are also discussed in an extensive and growing literature, but that it not my present concern. [↑](#footnote-ref-45)
45. Shuchman, ibid., 30. [↑](#footnote-ref-46)
46. In September of 2013 SickKids announced the opening of its new $400 million research institute. The provincial and federal governments supplied $150 million for the project, but the remainder was obtained through donations from individual and corporate sponsors. The hospital website acknowledges the significance of donor funds on its website: “Philanthropy is a critical source of funding for SickKids -- one of the world’s foremost paediatric health-care institutions. For the fiscal year ending March 31, 2013, SickKids Foundation made an unprecedented investment of $92.6 million in children’s health, a direct result of generous community and corporate support.” [http://www.sickkids.ca/AboutSickKids/Newsroom/SickKids-towers-over-bay/index.html](http://www.sickkids.ca/aboutsickkids/newsroom/sickkids-towers-over-bay/index.html) [↑](#footnote-ref-47)
47. Matthew S. McCoy and Ezekiel J. Emanuel recently contributed a paper to the *Journal of the American Medical Association (JAMA)* with the provocative title “Why there are no ‘potential’ conflicts of interest.” Their chief concern, which I take to be a valid one, is that the language of potential COI adds no additional safeguards for those dependent upon the judgement of others and, in fact, may trivialize genuine threats. If one has a secondary interest that has the potential to distort judgement, or to interfere with one’s ability to perform one’s duties in an impartial manner - that is, one’s primary interest - then a COI already exists and ought to be avoided or managed. The potential that we find worrying is the potential for a harm to occur as a result of biased judgement. It is not the potential for the existence of a COI. The authors go further and suggest that conflicts of interest are ubiquitous and not in themselves ethically blameworthy and they argue that a failure to appreciate this distinction is as dangerous as it is confused. [↑](#footnote-ref-48)
48. Stanley G. Korenman. *Teaching the Responsible Conduct of Research in Humans,* Chapter 4. Conflicts of Interest (COI) – Definitions. Online: <http://ori.hhs.gov/education/products/ucla/chapter4/default.htm>. Accessed: July 10, 2015. [↑](#footnote-ref-49)
49. Mary Rowell, "The Olivieri debacle: where were the heroes of bioethics? A Reply." *J Med Ethics* 30.1 (2004): 50. [↑](#footnote-ref-50)
50. ASBH, Code of Ethics and Professional Responsibilities for Healthcare Ethics Consultants (2014), http://asbh.org/uploads/publications/ASBH%20Code%20of%20Ethics.pdf. [↑](#footnote-ref-51)
51. Michael Davis and Andrew Stark, *Conflict of Interest in the Professions*, Oxford University Press, 2001 at p. 8. [↑](#footnote-ref-52)
52. The portrayal of this case is often simplified to such an extent that ethically salient features of the situation are omitted. For example, Olivieri was in possession of local data concerning the effects of the study agent on the participants she enrolled, but it is less than certain that she had reliable information about overall trends with respect to L1. In large multi-center trials it is sometimes the case that pooled data, or longer-term data, will not support local findings. I do not mean to suggest that disclosure of preliminary findings is never warranted, or that it was unwarranted in this case. My observation instead is designed to highlight the need for discretion by multiple parties in cases where the significance of interim results is uncertain. *The Drug Trial* by Miriam Shuchman is one source that retains the complexity that makes this case ethically compelling. [↑](#footnote-ref-53)
53. Healthcare institutions might dispense with ethicists altogether and leave all complex ethical judgements to the consciences of the administrators or the various professionals involved in specific cases. Alternatively, they might engage external ethics consultants to perform this work instead. Unfortunately, other ethicists, including self-employed ethicists, those who work in university departments, and those affiliated with free standing bioethics institutes, may face challenges to independence as great, or even greater, than those who are located within a health system hierarchy. This topic is deserving of a lengthier treatment than is possible here but it is important to recognize that concern about ‘ethics for hire’ has generated significant debate and many commentators quite rightly have worried about the ways that compensation can influence outcomes. To take but one example, private research ethics boards have been regarded with suspicion largely because of fears that drug and device companies will ‘shop around’ for lenient boards willing to approve risky protocols that academically affiliated review boards would likely reject. Although commercial REBs insist that they are being paid for exercising their expertise – rather than for specific outcomes – it is easy to infer that a commercial board runs the risk of losing business if it is regarded as more ethically rigorous or demanding than its competitors. See, for example, Lemmens and Freedman, “Ethics Review for Sale? Conflict of Interest and Commercial Research Review Boards.”

    Investigators who hold appointments in academic institutions, including academically-affiliated hospitals, on the other hand, are obliged to secure the approvals from the REBs of their home institutions. They are typically prohibited from conducting research involving their institutions’ patients, staff, or resources without REB approval. The conflicts that might arise owing to institutional financial entanglements, or relationships with specific board members who are their colleagues, are acknowledged and managed (with, one supposes, varying degrees of efficacy) by ensuring that there is board member diversity (including the participation of lay or unaffiliated members) and by requiring appropriate declarations of conflict and recusals of conflicted members at the outset of all deliberations.

    [↑](#footnote-ref-54)
54. Giles R. Scofield."What Is Medical Ethics Consultation?" *The Journal of Law, Medicine & Ethics* 36.1 (2008): 105. [↑](#footnote-ref-55)
55. This type of research, especially when the response rate is low, nearly always prompts questions about the representativeness of results. It's entirely possible that those who were willing to share their experiences of conflict of interest, however they defined it, self-selected so as to bias the findings in the direction of those who were the most or the least conflicted. However, absent resources that offer a broader scan of ethicists’ experiences regarding the topic we have only this study and a smattering of public reports to rely upon.

    [↑](#footnote-ref-56)
56. Andrea Frolic and Paula Chidwick. “A Pilot Qualitative Study of ‘Conflicts of Interests and/or Conflicting Interests’ Among Canadian Bioethicists. Part 1: Five Cases, Experiences and Lessons Learned.” *HEC Forum* (2010) 22, 15. [↑](#footnote-ref-57)
57. In addition, even in Canada’s busiest hospitals, with programs that employ a half-dozen ethicists or more, each practitioner typically bears sole or primary responsibility for the delivery of services at a particular institutional site or for a number of specialized programs. A director of ethics may lead such a program, and assist her team in establishing a reasonably unified direction, but practicing healthcare ethicists are still, for the most part, lone wolves who can expect to practice with a significant degree of independence. [↑](#footnote-ref-58)
58. It is interesting to note that practicing healthcare ethicists often invoke academic freedom as a basis for asserting a right to take unpopular positions. Even in university-affiliated teaching hospitals, however, it is not clear whether employees have a right to invoke academic freedom, and how far that supposed right might protect them against institutional sanctions. This is further complicated by the fact that a great many practicing healthcare ethicists hold appointments as sessional lecturers or as adjunct faculty in university departments and therefore may be able to publish or make public statements as members of the academy. Distinguishing their academic personae from their institutional identities may not be a straightforward matter, especially in an era where hospitals routinely encourage their staff members to publish in academic journals and maintain a lively presence on social media platforms. The purported academic freedom of hospital-based ethicists is a topic that could benefit from a rigorous analysis but it is not the focus of this project. [↑](#footnote-ref-59)
59. Frolic and Chidwick, *HEC Forum* (2010) 22, 10. [↑](#footnote-ref-60)
60. Andrew Stark, *Conflict of Interest in the Professions*, 2001, p. 336. [↑](#footnote-ref-61)
61. Coincidentally, Stark Law (more properly known as the Physician Self-Referral Act) is set of American federal laws that prohibit a specific type of conflict of interest by physicians. The titular Stark is not Andrew Stark but Pete Stark, a long-serving Democratic Party congressman from California. [↑](#footnote-ref-62)
62. Stark. 2001, p. 336. [↑](#footnote-ref-63)
63. With respect to their methodology, Frolic and Chidwick stated that they “chose not to prescribe a definition at the outset of our interviews; by leaving the term open to their interpretation, we hoped to generate a more naturalistic view of how bioethicists experience conflicts of interest and conflicting interests (COI) in their roles.” Ibid. 20. [↑](#footnote-ref-64)
64. Lisa A. Bero and Quinn Grundy. “Why having a (nonfinancial) conflict of interest is not a conflict of interest.” December 21, 2016, *PLOS Biology*, 2. [↑](#footnote-ref-65)
65. Bero and Grundy referencing K. Shawwa et al. “Requirements of clinical journals for authors? Disclosure of financial and non-financial conflicts of interest: A cross-sectional study,” 1. [↑](#footnote-ref-66)
66. Xavier Bosch *et al*, in *The European Journal of Investigation,* 663. The authors describe the move toward expanded disclosure as a positive trend and opine that the disclosures “have received comparatively little attention even though they may, at times, have a negative effect on the transparency of publication, the fairness of reviews and the honesty of reporting.” [↑](#footnote-ref-67)
67. Bero, ibid., 2. [↑](#footnote-ref-68)
68. Ed Quillen. “Origin of the Laundry List.” *The Denver Post.* (June 5, 2008) <http://www.denverpost.com/2008/06/05/origin-of-the-laundry-list/>. Accessed online: 7 July 2017. [↑](#footnote-ref-69)
69. Bero, ibid.,3. [↑](#footnote-ref-70)
70. PHEs, and especially ethics fellows, would rarely be the sole investigators on such a research project but for the sake of clarity I have created an example which limits the number of relevant actors with complicating interests. [↑](#footnote-ref-71)
71. For a very brief description of various theoretical approaches to public health ethics see “Ethical analysis in public health” by Marc J Roberts and Michael R Reich in *The Lancet*, Vol. 359, March 23, 2002: Online: <https://pdfs.semanticscholar.org/3cad/c70f93ea0f6e9f46bd2fc79c13e88cca45ad.pd>. Accessed: February 19, 2018. [↑](#footnote-ref-72)
72. Bero and Grundy reference the tobacco industry’s ability to undermine evidence concerning the effects of second-hand smoke and Coca-Cola’s distorting effect on nutrition research, but one can easily generate other equally compelling examples. In recent months the news media have been exposing evidence on the way that the sugar industry has systematically diverted the public’s attention away from their product by funding studies that focus on the risks of dietary fat. For a slightly older but more scholarly treatment of these latest revelations see Kearns *et al*, “Sugar Industry and Coronary Heart Disease Research: A Historical Analysis of Internal Industry Documents” in *JAMA Intern Med*., Nov. 2016.

    [↑](#footnote-ref-73)
73. For a concise introduction to the social science literature on the relationship between sponsorship and unconscious bias see Dana and Loewenstein, “A Social Science Perspective on Gifts to Physicians from Industry.” Online: <https://pdfs.semanticscholar.org/8b05/8d01e582e4bb06ac333b4bc740d6f29a104d.pdf>. Accessed: April 20, 2018. [↑](#footnote-ref-74)
74. Bero, ibid., 4. [↑](#footnote-ref-75)
75. Research ethics boards are often adamant that those who obtain consent from research participants not be in a position to compel or coerce enrollment. Research coordinators, or other non-clinical hospital staff members, often in the employ of the primary investigator, generally will obtain participants’ signatures on informed consent forms. The rationale is that patients that may be concerned about disappointing their treating clinicians will feel free to reject such overtures from an intermediary. Whether this is supported by good quality evidence is not entirely clear.

    [↑](#footnote-ref-76)
76. It is becoming common for research ethics boards or hospital compliance officers to insist that principal investigators include disclaimers in informed consent documents that state that the investigator (and sometimes the sponsoring institution) has an interest in the research that potential participants are encouraged to disregard as they weigh the benefits and burdens of participation. Unfortunately, these statements are often vague enough to capture academic interests as well as financial entanglements and the potential research participant (who frequently is also the investigator’s patient) has no way to distinguish between a researcher who is a shareholder in a corporation (which may be publically-held or for profit) and the researcher who is motivated by academic interests or a desire to find new treatment options for a patient population that has few or no alternatives to an inadequate standard of care. In addition, there is a literature that suggests that potential research participants are inclined to place greater trust in investigators who disclose their conflicts (whether or not that trust is warranted or misplaced). Conflict of interest declarations may, therefore, exacerbate rather than diminish the problem that they are meant to address. [↑](#footnote-ref-77)
77. Ibid., 5. Indeed, Bero and Grundy began their paper with a reference to a court case in which a judge expressed suspicion over the commitments of expert witnesses who had built their academic careers on establishing a relationship between smoking and cancer. According to the authors, the judge in *McTear v. Imperial Tobacco* “believed that the experts’ ‘nonfinancial’ interests constituted the greater risk to expert opinion.” For a discussion of this case see: “Why Having a (Nonfinancial) Interest is Not a Conflict of Interest,” 1. [↑](#footnote-ref-78)
78. Ibid., 6. [↑](#footnote-ref-79)
79. Frolic and Chidwick, 2010, 15. [↑](#footnote-ref-80)
80. Directors of hospital-based bioethics programs may be regular members of decision-making bodies such as institutional Quality of Care Committees (which regularly review medical errors, near misses, and safety trends); Research Integrity Committees which review the results of investigations into allegations of research misconduct; Medical Advisory Committees (which approve corporate policy and program minutes, set standards for physician credentialing, and receive regular reports from officials such as the chief executive, chief financial officer and chief operating officer); and, in more recent years, Relationship Management Committees (which create, or review, conflict of interest management plans for staff, physicians, scientists, and officials). Because members of these committees are largely senior officials such as chiefs of programs, ombudspersons, senior legal counsel, and vice-presidents, an ethicist’s regular attendance can provide her with access to potential allies, as well as an enhanced appreciation of the preoccupations of these parties, and a sense of which proposals have a reasonable prospect of success. This may be a mixed blessing, as it may generate further opportunities for what some have labelled structural conflicts of interest, but this is a topic to which I will return presently. [↑](#footnote-ref-81)
81. By referencing the financial interests of the institution I do not mean to suggest that they function as a trump card or that they be assigned disproportionate weight. I merely acknowledge the fact that health care institutions must make decisions that take into account the resources that they have at their disposal. In Canada, hospitals are publically-funded institutions and if their boards and chief executive officers fail to deliver balanced budgets they may be subject to significant sanctions including, in the worst case scenario, being placed under the control of an external supervisor. [↑](#footnote-ref-82)
82. Frolic and Chidwick, *HEC Forum* (2010) 22:5-17, 8. [↑](#footnote-ref-83)
83. Frolic and Chidwick, *HEC Forum* (2010) 22:19-29, 23. [↑](#footnote-ref-84)
84. Ibid., 9. [↑](#footnote-ref-85)
85. Ibid., 10. [↑](#footnote-ref-86)
86. Ibid., 11. [↑](#footnote-ref-87)
87. The PHE’s suspicions may have been well founded but it should be noted that research ethics consultation is not without its own high stakes cases, and it too requires the exercise of judgement. If the ethicist, however, was largely assigned administrative tasks related to research review (such as ensuring that protocols are consistent with well-established standards pertaining to informed consent or privacy protections) then it may be reasonable to infer that these new duties were designed to reduce her range of discretion and influence. [↑](#footnote-ref-88)
88. Andrew Stark, “Comparing conflict of interest across the professions,” in *Conflict of Interest in the Professions*, 336. [↑](#footnote-ref-89)
89. The tendency to believe that participation in research will be of benefit to patient-participants is a phenomenon that was helpfully captured by Paul Appelbaum and colleagues who coined the phrase “therapeutic misconception.” In recent decades an extensive and nuanced literature on this topic has been generated which is not necessarily relevant to this project, but it is important to recognize Appelbaum’s core insight which is that researchers and participants alike are inclined to minimize or deny the disadvantages associated with study participation. [↑](#footnote-ref-90)
90. The legal profession has an interesting way of conceptualizing these kinds of conflicts. If challenged, a lawyer must be able to demonstrate that the dual-representation is what is described as a consentable conflict. For a lawyer’s conflict of interest to be consentable she must be able to establish both that the clients were fully informed of the nature of the conflict, and that she was able to fulfil her duties to each of them in a competent manner. In addition, a lawyer engaged in case involving dual representation must be vigilant to the possibility that a consentable conflict may devolve into an unconsentable one. If, for example, one of her clients decides to sue the other she will need to alert these parties that she can no longer function as lawyer to them both. A lawyer who fails to do so may find herself disbarred. The gravity with which such conflicts are addressed reflects the conviction that a lawyer’s inadequately managed conflict of interest presents a problem not only for the lawyer and her clients but for the integrity of the justice system itself. For a helpful introduction to this topic see: Kevin H. Michels, “What Conflicts Can be Waived? A Unified Understanding of Competence and Consent,” *Rutgers Law Review* 65, no. 12 (2012): 109-172. [↑](#footnote-ref-91)
91. Frolic and Chidwick, *HEC Forum* (2010) 22:5-17, 11. [↑](#footnote-ref-92)
92. In cases of this kind it is common for opinions to be divided within teams and within families so the example need not imply a straightforward conflict between the interests of a family, or a patient’s decision maker, and the interests of a unified team. [↑](#footnote-ref-93)
93. I have not invoked this usage employed by John R. Boatright before but meddlesome is a convenient shorthand for the various external interests (such as money, status, or professional advancement) that may distort a professional’s judgement in a case that involves a conflict of interest. [↑](#footnote-ref-94)
94. Andrew Stark, “Comparing conflict of interest across the professions,” in *Conflict of Interest in the Professions*, ibid. [↑](#footnote-ref-95)
95. Ibid., 343. [↑](#footnote-ref-96)
96. Ibid., 342. [↑](#footnote-ref-97)
97. Ibid., 345. [↑](#footnote-ref-98)
98. By using the phrase ‘ethics consultation and support’ I mean to reference the full range of activities that are typically part of a healthcare ethicist’s work. The fact that some of my case examples focus on clinical consultation (particularly in the form of a single patient’s care-related concerns) does not imply that I believe this to be the most important or canonical part of the PHE’s work. My cases were chosen to illustrate specific aspects of the work or to make arguments clearer, but I fully endorse Bean’s view that a great many, if not most, cases are hybrid in nature and implicate clinical, organizational and, often, research-related concerns. [↑](#footnote-ref-99)
99. # A collection of essays called *Beyond Bioethics: Toward a New Biopolitics* has recently been released and it joins other volumes whose titles may not expressly reference the political character of the field but that are nonetheless occupied with similar or related concerns. A few such offerings are: Tom Koch’s *Thieves of Virtue*, Lisa Eckenweiler and Felicia Cohn’s, *The Ethics of Bioethics,* and Barry Hoffmaster’s *Bioethics in Social Context.*

    [↑](#footnote-ref-100)
100. Some health care ethics consultants do wear white coats but most do not, and their symbolic significance is not lost on members of the field. Those who wear them, such as the ethicists who work at the physician-owned Cleveland Clinic, report that they do so in order to be taken seriously in an environment where their standing might readily be undermined without them. [Private communication with member of that program.] Other ethicists regard the white coat as misleading; even if they are also physicians, they are not practicing medicine when they are performing ethics consultations. In addition, some see the white coat as symbolic of a hierarchical posture that they do not wish to endorse or represent.

     [↑](#footnote-ref-101)
101. Carl Elliott. *White Coat, Black Hats: Adventures on the Dark Side of Medicine, 150-151.* [↑](#footnote-ref-102)
102. I recognize that these charges have both descriptive and normative dimensions. My interest is not in uncovering strategies for measuring the degree of influence that ethicists exert in healthcare settings or even in surveying their ideological orientations. It is, rather, in answering a more philosophical question, that is; is the PHE’s work necessarily political and, if so, should that be a cause for concern?

     [↑](#footnote-ref-103)
103. Although Tom Koch and Giles Scofield, among others, use the phrase “medical ethicist” to describe those I am calling practicing healthcare ethicists, the usage is not a widespread or unproblematic one. Many in the field view the modifier “medical’ as unnecessarily limiting (as it seems to exclude issues that arise in public health and global health ethics, for example) and is reflective of a tendency to place priority on the practice of medicine or the work of physicians. In contrast, the PHE designation can make space for conversations about the social determinants of health and recognize the diverse stakeholders who engage in ethical deliberation. [↑](#footnote-ref-104)
104. *Thieves of Virtue: When Bioethics Stole Medicine*, 18. [↑](#footnote-ref-105)
105. Ibid., 5. [↑](#footnote-ref-106)
106. There is truth to the claim that health systems attend closely to the costs associated with care provision. Provincial Ministries of Health impose funding formulas that specify the rates that can be charged for procedures such as hip and knee replacements and dictate the number of days that hospitals will paid to keep patients in their beds. For an Ontario example see the Ministry of Health and Long Term Care’s “Patient Based Funding Overview.” Online: <http://www.health.gov.on.ca/en/pro/programs/ecfa/docs/ecfa_funding_pres.pdf>. Accessed: 10 July 2010. Similarly, institutional offices of Research Operations struggle with challenge of generating high quality research with insufficient public and private funds. Biorepositories offer opportunities to generate revenues to support costly knowledge-generating activities. What is not self-evident, however, is the contention that PHEs generally will regard these financial considerations as more important than the competing interests of patients and research participants. [↑](#footnote-ref-107)
107. Elliott’s academic appointment is with the Center for Bioethics at the University of Minnesota, however, many of his recent publications are aimed at a popular audience and appear in mass market periodicals like the *New Yorker* and *The Atlantic*. Some of his most noteworthy articles have exposed abuses in human subjects’ research, and in recent years, Elliott has suggested that he has greater confidence in the ability of investigative journalists to promote the good of research participants than the efforts of practicing healthcare ethicists or of institutional review boards: “A Conversation with writer and troublemaker Carl Elliott,” Part I, PLOS, <https://www.geneticsandsociety.org/article/conversation-writer-and-troublemaker-carl-elliott-parts-i-ii>. Accessed: 27 April 2018.

     [↑](#footnote-ref-108)
108. See especially Carl Elliott’s “Throwing a bone to the watchdog.” *Hastings Center Report* (2001), 9-12. [↑](#footnote-ref-109)
109. During the Council’s tenure a flood of articles were published by prominent bioethicists critiquing its composition as well as its specific recommendations. See, for example, “The Endarkenment” by R. Alta Charo in Eckenwiler & Felicia Cohn (eds.), *The Ethics of Bioethics: Mapping the Moral* *Landscape.* Johns Hopkins University Press (2007). Contrary to Koch’s contention, most members of the field were far from supportive of what might have been described as the Council’s neo-conservative agenda.

     [↑](#footnote-ref-110)
110. Mark B. Brown, Three Ways to Politicize Bioethics, *The American Journal of Bioethics* 9 no. 2, (2009): 44. [↑](#footnote-ref-111)
111. Ibid. [↑](#footnote-ref-112)
112. Principlism, most often identified with the work of Tom L. Beauchamp and James F. Childress, is one of most recognizable frameworks for ethical decision-making. The principles in which it is grounded are autonomy, beneficence, non-maleficence, and justice. Beauchamp and Childress have clarified that they see do not see these principles as occupying all of the space that is available for moral reasoning. Instead they suggest that they should “function as an analytic framework that expresses the general values underlying rules in the common morality” or serve as “guidelines for professional ethics.” See: Beauchamp, Tom L. and James F. Childress, *Principles of Biomedical Ethics*, Fifth ed.,12. Unfortunately, the language of rules and the crude application of principles to cases can support precisely the sort of engineering approach to ethics that many of its critics deride. My view is that while it can support such an approach, it is not inevitable that it do so. [↑](#footnote-ref-113)
113. Koch, 111. Earlier, I made reference to the very interesting question of whether PHEs should take legal standards to be binding in all cases. Whether laws constitute porous or impermeable boundaries in a case may depend on a number of variables (such as whether the law is habitually disobeyed and what the penalties for disobedience are likely to be) which will not be addressed here. These are questions which could very fruitfully be addressed via the establishment of practice standards should PHEs succeed in becoming a regulated healthcare profession.

     [↑](#footnote-ref-114)
114. Ibid. [↑](#footnote-ref-115)
115. I leave aside the question of whether an ethicist should ever recommend a course of action which conflicts with the law or with policies set by the colleges of the regulated health professions, or of the institution that employs the PHE and those seeking her counsel. This question is an important one which has interesting parallels in jurisprudential debate. As PHEs explore professionalization, they may benefit from engagement with a broader literature which is careful to distinguish law from morality and which looks at the question of obedience to so-called wicked law. [↑](#footnote-ref-116)
116. See especially: Margaret Urban Walker’s “Keeping Moral Space Open: New Images of Ethics Consulting” in the *Hastings Center Report* 23.2 (1993), 35. [↑](#footnote-ref-117)
117. Joan Tronto, “Who is authorized to do ethics? Inherently political dimensions of applied ethics,” *Ethical Theory and Moral Practice*, 14.4 (2011), 414. [↑](#footnote-ref-118)
118. Ibid., 414. [↑](#footnote-ref-119)
119. Tronto, 416. [↑](#footnote-ref-120)
120. Ibid. [↑](#footnote-ref-121)
121. Tronto, 413. [↑](#footnote-ref-122)
122. Indeed, Tronto cited Caplan’s experiences in order to provide clear illustrations of some ways that ethicists can, and ought to, use their role-based authority to reduce power differentials in very hierarchical settings such as bedside teaching rounds. She is not so naïve as to imagine that the PHE will always prevail, but she appears to be optimistic enough to countenance an institutional ethics practice which permits the consultant to engage strategically in the art of compromise without becoming hopelessly compromised.

     I would not suggest that this aspect of the work is easy or uncontroversial. As a member of the ASBH task force that drafted the code of ethics for practicing healthcare ethicists, I can attest that the code element that spoke to the obligation to “Promote Just Health Care” was the one which generated the most vigorous discussions within the group. For further discussion see: A. J. Tarzian, L.D. Wocial, and the ASBH Clinical Ethics Consultation Affairs Committee. “A Code of Ethics for Health Care Ethics Consultants: Journey to the Present and Implications for the Field.” *American Journal of Bioethics* 15.5 (2015): 38-51.

     [↑](#footnote-ref-123)
123. Even an ethics consultation which explicitly acknowledges the influences of racism and poverty in shaping Malek’s past, and his prospects for the future, will have only a limited prospect of addressing these variables in ways that can meet his needs. A skilled PHE should be capable of mediating discussions between members of a clinical team that has become divided over his expressions of anger, but she will not be able to guarantee that he has access to discharge destinations that are barrier-free in all of the ways that he requires. This is not to suggest, however, that the healthcare ethicist has no role in addressing these issues in other ways (policy, advocacy, and education come to mind) and in other venues. How much professional responsibility a PHE should take for advocacy work is a complex matter which is acknowledged, but cannot fully be addressed, by this project. [↑](#footnote-ref-124)
124. Susan Sherwin. Whither Bioethics? How Feminism Can Help Reorient Bioethics, *International Journal of Feminist Approaches to Bioethics* 1.1 (2008), 23-24.

     [↑](#footnote-ref-125)
125. Ibid., 12. [↑](#footnote-ref-126)
126. Ibid., 14. [↑](#footnote-ref-127)
127. Ibid., 15. [↑](#footnote-ref-128)
128. Ibid., 13. [↑](#footnote-ref-129)
129. Horst W. J. Rittel and Melvin M. Webber. “Dilemmas in a General Theory of Planning,” *Policy Sciences* 4.2 (1973), 160. [↑](#footnote-ref-130)
130. See, for example, Adrienne M. Young. “Solving the wicked problem of hospital malnutrition,” in *Nutrition and Dietetics* 72 (2015), 200-204, or Carol A Heimer. “‘Wicked’ ethics: Compliance work and the practice of ethics in HIV research,” *Social Science & Medicine* 98 (2013), 371-378. [↑](#footnote-ref-131)
131. Ibid. [↑](#footnote-ref-132)
132. Ibid., 156. [↑](#footnote-ref-133)
133. For a superb treatment of the evolution of the professions in the United States, as well as an analysis of the debate surrounding the professional status of clinical ethics consultants see Deborah S. Cummins, “Professional Status of Bioethics Consultation.” *Theoretical Medicine* 23 (2002), 19-43. [↑](#footnote-ref-134)
134. Ibid. [↑](#footnote-ref-135)
135. Susan Sherwin. “Foundations, Frameworks, Lenses: The Role of Theory in Bioethics,” *Bioethics* 13.3-4 (1999) 198-205.

     [↑](#footnote-ref-136)
136. Ibid, 200. [↑](#footnote-ref-137)
137. H. Tristram Engelhardt, Jr. “Consensus Formation: The Creation of an Ideology.” *Cambridge Quarterly of Healthcare Ethics* (2002) 11, 8. [↑](#footnote-ref-138)
138. Physicians are still high status members of healthcare teams but other professionals are becoming more insistent about the value of the contributions that they bring to the table. At least in academic teaching hospitals it is common for other team members to hold advanced degrees and many are quick to reference the fact that hierarchical communication structures have negative effects on safety, quality, efficiency, morale, and the patient experience. [↑](#footnote-ref-139)
139. Ibid. [↑](#footnote-ref-140)
140. These kinds of cases can generate uncertainty, on occasion, but hard cases are generally ones involving minors, decisionally-incapacitated persons, or individuals thought to be particularly vulnerable to coercion. [↑](#footnote-ref-141)
141. My focus here remains on consultation, broadly understood. It is acknowledged that ethicists also devote a great deal of their professional time to teaching, research, and policy development, but these activities are not generally understood to be controversial in the ways that have been described thus far. Admittedly, this may be a mistake because an ethicist can exert great influence through her efforts in each of these areas of practice. I, however, will not dwell on these other possible sources of concern because they are not unique to the PHE’s work, and because these types of work are sufficiently public to allow them to be observed and critiqued by other members of the health care and lay communities. The content and outcomes of ethics consultations, on the other hand, are generally known only to participants or to those privy to the content of the confidential patient records that contain the consultants’ recommendations. [↑](#footnote-ref-142)
142. In describing the nature of their work, PHEs sometimes distinguish case-based consultations from other types of consultations, or requests for clarification or advice. A case-based consultation need not pertain to the care of specific patient, however. As was noted earlier, it may involve questions arising in the conduct of human subjects’ research, or in the effort to set organizational priorities. It may also involve a combination of any of these three possibilities. [↑](#footnote-ref-143)
143. There is a considerable literature on patients in challenging circumstances that latterly referenced the so-called hateful or impossible patient. In addition, ethicists do consult on cases with a view toward helping providers to identify and reinforce boundaries in circumstances where boundary-crossings are likely to occur. Typologies of boundary crossings have been offered in the psychological, professional, and ethical literature. One type involves straightforward conflict of interest scenarios, but others describe relationships that threaten to erode professional boundaries because the patients are seen as, in some way, unlike other patients because of the associations, positive or negative, that providers make with them. (A patient may, for example, remind a professional of a beloved or despised relative, or remind her of a prior case that was especially rewarding or upsetting.) It is reasonable to suppose that bioethicists are not immune to these all-too-human challenges.

     [↑](#footnote-ref-144)
144. Andrew Jameton. *Nursing Practice: The Ethical Issues.* Englewood Cliffs, NJ: Prentice Hall (1984), 6. [↑](#footnote-ref-145)
145. It should be acknowledged that futility is a controversial concept especially in the critical care context. My aim is not to engage that extensive literature, but to offer an example of a specific type of hard case, and a common and easily recognizable source of moral distress. [↑](#footnote-ref-146)
146. Uninsured patients are typically eligible only for emergency services (that is, those time-sensitive interventions necessary to preserve life and limb). This means that regularly scheduled dialysis treatments generally cannot be billed to provincial insurance plans and hospital administrators need to decide whether to absorb these costs or to instruct patients to seek emergent care when their condition becomes critical. Because hospital global budgets are under significant pressures the latter option often is pursued. A healthcare ethicist may advocate for compassionate access to this or other uninsured services but there is no guarantee that her organization will accept her recommendation. Moreover, when faced with a specific case she cannot decide by fiat that the service will be provided on a regular schedule and without cost to affected patients. [↑](#footnote-ref-147)
147. I offer these examples because it is becoming clear that research involving artificial intelligence and very large data sets is not easily evaluated by applying the standards that currently govern access to patient information or research on human subjects. Similarly, the ambiguous category called ‘surgical innovation’ covers a large range of novel or experimental procedures attempted in the context of clinical care, many of which present a significant challenge to valid consent. Innovative surgical practices typically are not seen to be subject to the principles that comprise the *Tri-Council Policy Statement* because these interventions are generally deemed not to be human subjects’ research as it is defined in that document.

     [↑](#footnote-ref-148)
148. A social scientist might find it interesting to capture and categorize the various themes that surface in the consultation work of North American PHEs. I have not attempted such an empirical exercise and readily admit that my typology may need to be adjusted should such research yield information that indicates that these categories require augmentation. I am not, concerned, however, that a challenge to my rough and ready typology would do much damage to the general thrust of my argument. [↑](#footnote-ref-149)
149. H.L.A. Hart. “Positivism and the Separation of Law and Morals” *Harvard Law Review* 71.4 (1958): 607. [↑](#footnote-ref-150)
150. John Austin, *The Province of Jurisprudence* *Determined* (Library of Ideas ed., 1954) 184-185 quoted in Hart, ibid., 596.

     [↑](#footnote-ref-151)
151. Ibid. [↑](#footnote-ref-152)
152. Ibid., 593. [↑](#footnote-ref-153)
153. Ibid., 614. [↑](#footnote-ref-154)
154. Ibid. [↑](#footnote-ref-155)
155. Ibid., 629. [↑](#footnote-ref-156)
156. For the sake of simplicity I leave aside the complexities that are sometimes associated with determining what a given patient’s best interests consist in. [↑](#footnote-ref-157)
157. For present purposes I leave aside the very interesting question of whether law or institutional policies constitute firm, or relatively porous, boundaries for ethical deliberation. I accept that it is a relevant and fruitful area for exploration, but I am focusing here on ordinary rather than extraordinary consultation cases. Suffice it to say that practicing healthcare ethicists occasionally do find it appropriate to point out that some options (for example, the sterilization of a mentally incapable, but sexually active person, upon the request of that person’s LAR) could be legally and professionally perilous whatever the ethical or pragmatic arguments marshalled in support of a particular intervention. The PHE would be remiss in her duties if she were to omit this important context in her efforts to identify the ethical options available to various stakeholders. An effort to provide context need not include an opinion on the ethical merits or demerits of that context, however. [↑](#footnote-ref-158)
158. *Carter v. Canada* (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331. Date: 2015 02 06. Online: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>. Accessed: February 7, 2019. [↑](#footnote-ref-159)
159. The phrase “conscientious commitment” was coined by Bernard Dickens and Rebecca Cooke to describe a healthcare provider’s desire to overcome barriers to care provision on what they regard as ethical grounds. The subject of their discussion was women’s reproductive health but the term is equally applicable to the MAID context. [↑](#footnote-ref-160)
160. As one might anticipate by now, I do not believe that MAID obliges healthcare ethicists to approach their work in a new way. The legal permissibility of MAID, however, has brought ethical questions into greater prominence than they have typically enjoyed in some quarters, and it provides PHEs with an exceptional opportunity to illustrate how they may be helpful in addressing some of the difficult issues that arise both in the delivery of clinical care and in corporate decision-making with respect to institutional priorities and obligations.

     [↑](#footnote-ref-161)
161. In Canada only nurse practitioners and physicians are legally eligible to act as MAID assessors and interventionists, however, other health care providers including pharmacists, registered nurses, spiritual care providers, and numerous others, have ethical and sometimes new legal or professional responsibilities related to the care of patients who request, or make inquiries with respect to, medical assistance in dying. [↑](#footnote-ref-162)
162. I use the terms assessors and providers to distinguish two groups of practitioners that are intimately involved with MAID provision in Canada. MAID assessors are responsible for determining (via reference to the criteria set out in the statute) whether specific patients can be deemed eligible for the intervention. MAID providers, also known as interventionists, are those who administer the medications that result in the deaths of consenting, eligible patients. Not all assessors perform MAID interventions, but all who provide the interventions must satisfy themselves, just before the procedure is initiated, that the patient remains willing and eligible to proceed. [↑](#footnote-ref-163)
163. Bill C-14. *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (2016). Assented to June 17, 2016, First Session, Forty-second Parliament, 64-65 Elizabeth II, 2015-2016. Accessed: February 6, 2019. https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent. [↑](#footnote-ref-164)
164. Some early efforts to operationalize the reasonable foreseeability condition drew on the so-called surprise question sometimes used by palliative care specialists to identify those who are at the end of life and likely in need of their expertise. The question is, in essence, Would I be surprised if this patient died within the next twelve months? I leave aside the debate over the prognostic accuracy of this tool for cancer or other patient populations. My point is that since a recent Ontario Superior Court decision it has become evident that this approach is more restrictive than the courts intended.

     [↑](#footnote-ref-165)
165. *A.B. v. Canada* (Attorney General), 2017, ONSC 3759, page 12. Online: <http://eol.law.dal.ca/wp-content/uploads/2017/06/20170619152447518.pdf>. Accessed: February 8, 2019. [↑](#footnote-ref-166)
166. Jody Wilson-Raybould quoted in *A.B. v Canada*, ibid., p.6. [↑](#footnote-ref-167)
167. The “grievous and irremediable” criterion which must be met for a patient to be deemed eligible for MAID does not oblige him to accept any or all treatments that may ameliorate his suffering or even cure his medical condition. The patient’s suffering must only be irremediable in the sense that any treatments that may be proposed are unacceptable to him. A patient’s refusal of a therapy, or even a trial of therapy, that the physician believes to be reasonable can sometimes be very difficult for a healthcare provider to accept.

     [↑](#footnote-ref-168)
168. Commenting on the fact that a 2015 poll showed that 75% of palliative care physicians expressed the view that members of their specialty should not be engaged in aid in dying, even if were to become a legal option, Dr Susan MacDonald, a past president of the Canadian Society of Palliative Care Physicians stated that, “There’s a huge misconception out there that that’s what palliative care is — it’s all about death… No. The great majority of it is about life and living life as best as you possibly can, not just from a physical perspective, but from an emotional and spiritual and psychological perspective...” Source: “Most palliative physicians want no role in assisted death.” Laura Eggertson. *Canadian Medical Association Journal* 187.6 (2015): 187.6, E177. http://www.cmaj.ca/content/cmaj/187/6/E177.full.pdf. Accessed: February 10, 2019. [↑](#footnote-ref-169)
169. Admittedly, the physician who initially judged A.B. eligible for MAID expressed a fear that he would be charged with murder but, perhaps surprisingly, this is rarely the reason that practitioners offer (to their colleagues or to ethicists) for harbouring doubts about whether they should participate in MAID assessments or interventions. [↑](#footnote-ref-170)
170. Sandy Buchman. “Why I decided to provide assisted dying: it is truly patient centred care.” *British Medical Journal* 364 (2019): 1412. Https://www.bmj.com/content/364/bmj.l412 Accessed: 31 January 2019. [↑](#footnote-ref-171)
171. Leonie Herx, Srini Chary, Ed Dubland, David Henderson, Bernard Lapointe, Robin Fainsinger, and Valerie Schulz. “Take off the rose-coloured glasses. A response to Drs Buchman and Blackmer,” *British Medical Journal* 364 (2019). 8 February 2019. <https://www.bmj.com/content/364/bmj.l412/rr-18>. Accessed: 10 February 2019. [↑](#footnote-ref-172)
172. For a description of one hospital’s approach to some of the challenges presented by the

     legalization of MAID see Madeline Li, Sarah Watt, Marnie Escaf, Michael Gardam, Ann Heesters, Gerald O’Leary, and Gary Rodin. "Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada.” *New England Journal of Medicine*. 376.21, May 25, 2017. [↑](#footnote-ref-173)
173. This latter justification, however, is one that likely would not survive careful scrutiny. Although MAID cases present ethical challenges that may be top of consciousness at present, it is not obvious that they are greater than the difficulties faced, for example, in the context of organ donation (where resources are absolutely scarce and patient eligibility requires judgement about a complex inter-relationship between social and medical variables). Despite this fact, I know of no PHEs who are leading, or being considered as operational leads, of multi-organ transplant programs. [↑](#footnote-ref-174)
174. The *Carter* decision and the policies of various regulatory colleges have affirmed that conscientious objections to MAID participation must be respected, therefore direct participation in MAID is limited to willing volunteers. Some controversies persist with respect to the meaning of the term “participation,” but this example is not designed to delve into that debate. Rather it is to explore the nature of some of the concerns that have been raised by MAID assessors and providers in the hard cases they have faced. [↑](#footnote-ref-175)
175. For a real-life example see: Kelly Grant. “Medically assisted death allows couple married almost 73 years to die together.” The *Globe and Mail*, 1 April 2018. <https://www.theglobeandmail.com/canada/article-medically-assisted-death-allows-couple-married-almost-73-years-to-die/>. Accessed: February 11, 2019. In this specific case, one partner was initially assessed as meeting the criteria for MAID but she elected to hang on, despite her suffering, until her husband’s physical decline was sufficient to render him more clearly eligible for the intervention. [↑](#footnote-ref-176)
176. The “Vulnerable Persons Standard” was developed by a group of individuals with expertise in ethics, law, medicine, public policy, and disability advocacy who regard age and frailty, among other conditions, as especially concerning grounds for MAID eligibility. Their view is that “stigma, abuse, coercion, isolation and depression” may drive such requests and every effort should be made to overcome these potentially coercive factors. The standard may be accessed online at: <http://www.vps-npv.ca/readthestandard>.

     On the other hand, the anthropologist Naomi Richards has written about the ageist biases that may motivate refusals to acknowledge the ethical defensibility of rational suicides or requests for aid in dying in the context of what some have called a completed life. [↑](#footnote-ref-177)
177. Francis Kamm, “The Philosopher as Insider and Outsider: How to Advise, Compromise, and Criticize,” *Business & Professional Ethics Journal* 9.1/2 (1990): 7. Online: http://www.jstor.org.myaccess.library.utoronto.ca/stable/27800028. Accessed: February 10, 2019. [↑](#footnote-ref-178)
178. Ibid., 8-9. [↑](#footnote-ref-179)
179. *Core Competencies*, p.7. [↑](#footnote-ref-180)
180. “The Epistemic Costs of Compromise” by Katrien Devolder and Thomas Douglas *Bioethics* 32.2 (2018) is a recent article which probes some additional problems with Brock’s defense. The authors note that a failure to articulate the genuine reason, or reasons, for a compromise position may have two serious unintended consequences. The first is that subsequent arguments which draw on the deceptive one may start from premises which are insufficiently justified because of the authority that has been granted to those with acknowledged expertise with the result that each iteration will result in worse compromises or policy positions. The second is that the overall quality of debates in bioethics may become (or be) poorer owing to an unwillingness to engage in the sort of uncensored philosophical debate that gives academic philosophy its rigor. Their proposed solution, to encourage distinct venues for each type of debate however, seems to miss the mark for all of the reasons described in my discussion of Kamm’s duties. A better solution, on my view, would be to promote increased interaction between academic and clinically-based ethicists, and to carefully consider the role-related obligations of each. [↑](#footnote-ref-181)
181. Kamm, 9. [↑](#footnote-ref-182)
182. The reference to benchside consultation is a reminder of the fact that PHEs advise researchers on ethical issues related to their various knowledge-generation activities. It is not meant to invoke the activities of the courts despite the fact that I am drawing some insights from the literature that speaks to that domain. I borrow this usage from Cho et al.’s description of their research ethics consultation service.

     [↑](#footnote-ref-183)
183. It is not at all obvious that it would be respectful to stakeholders in clinical, organizational, or research ethics consultations for the PHE to withhold (or worse yet, mislead them about) the grounds for her judgements. This would seem to leave her vulnerable to the charge of ethical imperialism that Koch and others levy. Offering reasons which can be openly discussed and accepted, or rejected, on their merits seems appropriately inclusive and it should be acknowledged that the PHE is almost never entrusted with the full weight of decision-making. This generally falls to the parties (be they patients, clinicians, institutional authorities, or scientific investigators) who are the primary stakeholders in the consultation. [↑](#footnote-ref-184)
184. Ronald Dworkin, “Judicial Discretion.” *The Journal of Philosophy* 60.21 (1963): 637. [↑](#footnote-ref-185)
185. Ibid., 638. [↑](#footnote-ref-186)
186. Ronald Dworkin, *Taking Rights Seriously*, 105. [↑](#footnote-ref-187)
187. In contrast a Brockian approach, or one which secures consensus by suppressing or denying the PHE’s own position, would appear to substitute strategy for principled argument. If ethicists are to act as honest brokers, or as sounding boards for those who seek their advice, a strategic approach would seem to be more misleading (or manipulative) than morally neutral. [↑](#footnote-ref-188)
188. It is important to recognize that one need not be a Dworkinian to accept the claim that the inclusion of principles in judicial reasoning need not imply that those legal arguments are arbitrary or incoherent. For a nuanced argument that comes from the inclusive legal positivist tradition see Wilfrid Waluchow’s book *A Common Law Theory of Judicial Review*. There Waluchow argues that judges may be constrained by moral principles provided those principles become part of the law via appropriate mechanisms. An appropriately constituted charter of freedoms or bill of rights may, for example, render certain principles legally binding, and the fact that they need to be interpreted, or weighed, in particular cases in no way undermines their status as legal standards. [↑](#footnote-ref-189)
189. In all jurisdictions, oncology patients constitute the largest percentage of MAID requestors and, although prediction is always an inexact science owing to individual variables, this population generally allows providers to have greater confidence in prognostication than most others do. [↑](#footnote-ref-190)
190. Prior to the Supreme Court of Canada’s *Morgentaler* decision, abortion services legally could be provided only in accredited institutions which had therapeutic abortion committees or TACs (which had a minimum of three members and could not include the physician providing the service) that would decide whether the continuation of the pregnancy might constitute a harm to the requesting woman. The requirement for a TAC to decide on eligibility subordinated women’s preferences for their own care to the opaque and idiosyncratic values of committee members who were not members of their circles of care. This led some members of the Court to determine that the status quo violated women’s rights to liberty, equality, and security of the person. [↑](#footnote-ref-191)
191. The Vulnerable Persons’ Standard might be seen as an effort to raise awareness of just such concerns, but our PHE would be remiss if she did not note that The Standard was controversial even among those it sought to protect.

     [↑](#footnote-ref-192)
192. Even if one were to accept the proposition that it is appropriate to generalize from the characteristics of entire groups in order to make assessments of individuals, the SPP proposal would need to confront the charge that denying access to longer prognosis patients fails the test of non-maleficence because these patients have the potential to suffer much longer than those with short and more predictable prognoses.

     [↑](#footnote-ref-193)
193. For a discussion of the influence of the four principles, and especially the principle of autonomy on healthcare ethics see, for example, Soren Holm, “Not just autonomy - the principles of American biomedical ethics.” *Journal of Medical Ethics* (1995) 21: 332-338. [↑](#footnote-ref-194)
194. Legal theorists have had much to say about the relationship between liberty and equality that may be relevant to debates in healthcare ethics. Especially interesting is Ronald Dworkin’s claim that if liberty and equality were to come into conflict equality would have to prevail. See especially “The Place of Liberty,” in *Sovereign Virtue* (Cambridge: Harvard University Press, 2000), pp. 120–183. [↑](#footnote-ref-195)
195. Wilfrid Waluchow, *A Common Law Theory of Judicial Review*, page 162. [↑](#footnote-ref-196)
196. Ibid., note 55, p 162*.* [↑](#footnote-ref-197)
197. For example, a valid statute – valid because it was enacted in the way that a particular legal system requires – may have content that strikes much of the citizenry as clearly discriminatory (such as a law which explicitly denies same-sex couples the rights and protections enjoyed by those in heterosexual unions), yet it may be impossible for legal officials to deny its existence. [↑](#footnote-ref-198)
198. Waluchow, ibid., p1. [↑](#footnote-ref-199)
199. Ibid., 269-270. [↑](#footnote-ref-200)
200. Although he does not endorse Dworkin’s right answer thesis, Waluchow makes the important observation that the very fact of disagreement and uncertainly about right answers (in law, morality, or in other controversial domains) does not warrant the conclusion that there are no right answers to hard questions. He notes that while there may be no extant evidence that can eliminate all doubt about a specific historical claim, this absence of evidence does not entail the absurd conclusion that there is no truth of the matter at all. (Consider, for example, the speculation as to whether Queen Victoria had an intimate relationship with her groomsman John Brown).

     The analogy for practicing healthcare ethicists may not be immediately obvious, but it does not seem unreasonable to suggest that they should endeavor to seek the right answers to the hard cases that come before them. The fact that those right answers may be controversial, or that PHEs may engage in theoretical disagreements about how relevant values and precedents are to weighed in light of the facts of a particular case, does not mean that skepticism is the default position one ought to take in response to these challenges. [↑](#footnote-ref-201)
201. I qualify this claim because some clinical consultations will not be suitable for inclusion in a patient chart. A consultation which consists of a request for help in understanding a professional’s ethical obligations with respect to a particular patient’s requests or demands (such as an insistence on having a provider of a particular race or sexual orientation) may not find its way into the chart especially if there is no need for what is often called a behavioural safety alert. (The stigmatizing effect of such an entry may be outweighed by any marginal safety gain.)

     As another example, a patient may refuse entirely to have an ethicist involved in her case. If this occurs, the PHE may still assist the clinical team but her involvement will have to be more carefully circumscribed. She can offer non-nominal support by way of a discussion of general principles but she should not view the patient’s chart or become privy to specifics (such as the patient’s name, age, or other identifiers) that violate the patient’s expectation of privacy. Should professionalization of the work of PHEs occur, it will be important to establish practice standards that can render the approach to such cases more consistent and transparent than is currently the norm. [↑](#footnote-ref-202)
202. Although there is a scant literature that speaks to the elements that should be contained in a ‘chart note’ which serves as a record of a clinical ethics consultation, the documentation practices of practicing ethicists are highly variable. PHEs may record the highlights of team and/or family meetings and summarize the concerns that prompted their involvement, as well as the nature of any consensus that may have been achieved, but health records are only appropriate sites for documentation when the consultants’ recommendations are germane to the care of particular patients. Many common issues, such as conflicts within teams, confidential requests for values clarification, or requests for aid in responding to the problematic behaviours of individuals (or the shortcomings of institutional directives) may never find their way into any record that is subject to scrutiny or to quality assurance activity. These limitations are especially salient now that most PHEs no longer keep detailed ethics consultation records. Owing to the legal cautions which advise against retaining so-called shadow charts, ethics services tend to maintain, at most, only non-nominal records, such as databases containing elements such as consultation themes, volumes of requests, and the programs in which they originate. Data of this kind may help a PHE to justify the allocation of her time, or to argue for greater resources, or to target her education efforts, but they are poor surrogates for substantive measures of the quality of the consultations themselves. [↑](#footnote-ref-203)
203. Giles Scofield. “What—If Anything—Sets Limits to the Clinical Ethics Consultant’s ‘Expertise’?” *Perspectives in Biology and Medicine*, Volume 61. 4 (2018): 595. [↑](#footnote-ref-204)
204. Ibid., 596. [↑](#footnote-ref-205)
205. Ibid. [↑](#footnote-ref-206)
206. Ibid. [↑](#footnote-ref-207)
207. Although Margaret Urban Walker might be disinclined to accept my emphasis on adjudication (which I stress only because it is often regarded as the most contentious part of the work), I believe that we have a shared understanding of how best to prepare PHEs for their roles. In response to the professionalization movement she has noted that the academic preparation typically provided to those who study ethics at the graduate level is inadequate to the task of performing ethics consultation in the hierarchical, and very complex, clinical environment.

     In her words “The old staples of conceptual and analytical skills, honed specifically for medical and clinical contexts, remain important tools. They are necessary to keep track of where the discussion has (and has not) been going. But knowing where the discussion might or could go, and how the process is shaped not only by ideas but concretely by actors and environments, requires other sorts of preparation as well.” Among the other kinds of preparation she recommends, are “wide (and critical) conversance with the actual terms …of moral assessment in the society the institution takes as its community.” In addition, she notes that the PHE must have a “sensitivity to configurations of authority and dynamics of relationship that can either help structure that space or deform it” Walker, 1993, 39.

     We would do well to construct PHE apprenticeship programs that draw on these insights, and I agree heartily with her recommendations that the field provide apprenticeship opportunities that are interdisciplinary, clinically-situated, and that they explore what she calls “[f]lexible networks of inside and outside ethicists, linking the moral space of particular institutions to other sites of ‘the reflexive social dialogue.’” Ibid. [↑](#footnote-ref-208)
208. Ibid., 595. [↑](#footnote-ref-209)