

# Guidance for Healthcare Ethics Committees

Second edition



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In memory of J. David Hester:
"We can be Heroes, just for one day"
- David Bowie/Brian Eno



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## **Preface**

In 1992 The Joint Commission on Hospital Accreditation (The Joint Commission) began requiring every accredited hospital to have a mechanism to handle ethical concerns within its institution. In response to this (and other cultural forces in medicine), hospitals across America have come to satisfy the requirement by constituting an institutional healthcare ethics committee (HEC). Physicians, nurses, administrators, social workers, chaplains, community volunteers, and, others populate these committees. Yet by their own admission, many of these individuals, while well intentioned and personally invested, have neither training in ethics nor the tools at their disposal to aid in their ethical considerations. Even more basically, not many members of an HEC, not to mention a healthcare institution writ large, are comfortable explaining what constitutes an ethical consideration. So, while these individuals are the people both medical professionals and patients turn to for ethical insight into the complexities of medical decision-making, they themselves recognize that they are often underprepared to handle the depth and complexity of many moral problems raised by health care.

It is within this context that we offer this book. The purpose of this text is to serve as a primer for members of HECs regarding the three main roles that comprise the function of an HEC: consultation, policy, and education. The book provides material to aid in elucidating and educating about these functions for the many different persons who find themselves confronted with ethically challenging medical situations by virtue of being members of some HECs.

While we, the editors, have worked for decades in this field, we know our limitations, and thus, to facilitate attaining this goal, we have invited leaders in the field of ethics to author chapters in their areas of expertise. Chapters are directed at educated individuals who are members of HECs, whether they are new to the committee or they simply seek to solidify their knowledge on particular topics. The chapters herein try to cover each topic in such a way as to inform and support the work of HECs specifically. For example, the chapter on Advance Care Planning does not go into detail about forms, conversation partners, and other features of Advance Directives (these can vary by state and there are many other sources to find and describe those specifically). Instead, the authors describe the ways in which HEC members may encounter ethical concerns about Advance Directives and end-of-life planning, as well as how HEC members can engage productively with the issues presented.

Further, in order to make the material as accessible as possible, we have oriented each chapter around a consistent format. Every chapter opens with a set of objectives, then proceeds to a case or series of cases, followed by key content, and concludes with questions for discussion. We would like to take a moment to explain each of these features:

<sup>&</sup>lt;sup>1</sup> Some writings call these "hospital ethics committees," some call them "institutional ethics committees", or "clinical ethics committees." We have chosen the term "healthcare ethics committee," and will use that term throughout this volume.

In this text, we use the terms "ethics" and "morals"/"morality" as well as "ethical" and "moral" interchangeably.



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- (1) **Objectives:** Objectives for each chapter were negotiated between the editors and the chapter authors. When possible, we used objectives suggested in the *Education Guide for Improving Competencies in Clinical Ethics Consultation* (2009) published by the Clinical Ethics Education Task Force of the American Society for Bioethics and Humanities (ASBH). However, since this guide is directed exclusively at ethics *consultation*, many objectives were altered or authored with a broader committee charge in mind. Nevertheless, the connection to the ASBH Task Force helps to standardize, where possible, the topics and approaches contained herein.
- (2) Cases: All chapters begin with at least one case. Many chapters include multiple cases, or iterations of the same case, throughout the work. The purpose of such cases in this work is twofold. For one, cases give a concrete demonstration of the way the individual chapter topics may present themselves to members of HECs. Note that such demonstrations are not meant to be representative or categorical; rather, they are meant to be illustrations of the kinds of things to which an HEC must attend. Second, when taken as a whole, the cases in the text demonstrate how individual personal, professional, institutional, social, cultural, or religious values can affect the emergence of and response to ethical issues in a clinical setting. These conflicts of value are important motivators of ethics cases, and it behooves members of HECs to consider the ways in which these conflicts broadly construed may affect both the form and function of their committee.
- (3) Content: We felt it was important to have scholars recognized in specific fields to write the chapters for which they have particular expertise. This experience not only lends expert, knowledgeable insight to the text but also enables HEC members to be introduced to the individuals who help shape scholarship in this arena. However, because the chapters are all independently authored, they may vary a bit in terms of tone and style. We have ensured consistency of format whenever we could, but as editors we felt it was important for each chapter author to present material in their own voice.
- (4) Questions for Discussion: Each chapter ends with three kinds of questions to prompt thought and discussion within the HEC: Conceptual questions focused on broad considerations of values and norms; Pragmatic questions designed to look at practical considerations; and Strategic questions that look to issues of implementation and action. However, partly because of the diversity of authorship described above, the orientation of the questions at the end of the chapters will vary as well. Some authors chose to ask summary or reading comprehension sorts of questions to ensure that readers understood the main points of the chapter. Others use the questions to further the conversation on the topic and to challenge the reader to think beyond the text contained in the chapter. Regardless, we think that the questions at the end of each chapter may be useful tools for beginning a dialogue within the HEC about each topic at hand.

This volume is organized into three main sections: introduction/preliminaries, consultation, and a final section capturing policy development, organizational issues, and education. Among these sections, the bulk of the chapters focus on consultation, as this often presents the most significant challenges to committee members and clinical topics are wide and varied. While conceived of as a comprehensive volume, each chapter of this



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text is capable of standing alone as a teaching module through which an ethics committee can work together or members can work individually.

\* \* \*

This text is now in its second edition, and we have been motivated by the feedback from previous readers and reviewers while updating this volume. We began by rethinking the chapters included in the volume, and then eliminated some chapters from the previous edition (typically by marrying with another chapter) and added chapters on topics that were not in the previous volume. We also decided to loosen the word count restriction for a few chapters where the topics were such that they needed a little more space in the volume than others (though, to be sure, we believe in tight, digestible chapters; thus, no chapter is more than 5 000 words). Also, every chapter that was kept from the previous edition has been updated/rewritten by its author.

The other major shift that occurred well into the writing of this edition is the SARS-CoV-2 pandemic. To say that this has transformed the way we think about health care is by no means an understatement. Global health really has become local health as the mobile nature of contemporary society ensured that few areas were spared the need to consider carefully how to both care for those infected and protect those who were not. Indeed, this is one of the times in health care when the work that we do in ethics – namely, identify core values and help to adjudicate values conflicts – took center stage. Healthcare leaders at all levels collaborated with their ethics staff to ensure they were able to allocate scarce resources in a way that was fair, consistent, transparent, and inclusive.

Yet despite ethicists' considerable expertise in these areas, it was by no means an easy activity in which we engaged. There was much debate in the professional ethics community about the best way to allocate scarce resources; to identify, prioritize, and communicate public health ethics principles as compared with more traditional individually focused healthcare ethics principles; and how to address the clear inequities in care that the pandemic illuminated. Early data demonstrated that there were clear differences in approach by different ethicists at different institutions, and only time will tell if greater unanimity emerged with the broad sharing of information that characterized the response to pandemic planning.

We can only imagine how those engaged in ethics at smaller institutions, without the benefit of a professionally trained ethicist, fared during these difficult times. To the extent that state health departments collaborated with professional ethicists and the resulting material was widely available, ethics committees ought to have been able to avail themselves of both the ethical justifications and practice standards enumerated therein. But for those states that were slower to publish such documents, or those institutions without good access to ethical resources, we suspect that ethics committees may have been relied upon to an extent not previously witnessed in their organization. And it is those individuals, and those committees, to whom this volume is directed. We can only hope that the background and thought processes demonstrated in these chapters will help to form the foundation for those called upon to respond to both local and global challenges in healthcare ethics.

\* \* \*



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Large projects like this are never done by one or two persons, and we want to express our gratitude to many others (and our apologies for anyone we might miss). First, we appreciate the work of the chapter authors; both previous and new authors put in a great deal of time with already busy schedules. Further, we thank those who, over the past decade, used the previous editions and then gave us their insights and support for a new edition. This leads us to Cambridge University Press for readily supporting the publication of this book. To Nick Dunton, who was of invaluable help in making this second edition happen, we wish fair winds and following seas on your retirement. We also appreciate the work of Jessica Papworth and Olivia Boult who stepped in and continued the effortless partnership with the Press.

As we noted in the first edition, the idea for this book was generated from the time we have both spent serving on HECs at a variety of institutions. We are grateful for the insights that have been gleaned from these experiences, especially in recognizing the challenges of educating a group of diverse, time-constrained, dedicated healthcare professionals. We continue to have these HECs in mind as we assembled this text and hope that our efforts have proved fruitful.

Finally, we are grateful to our institutions and our families for their support of this work. Toby has had important support from the Center for Ethics at Emory University during the first edition and Prime Review Board and the National Center for Ethics in Health Care at the US Department of Veterans Affairs during the development of the second. For Micah, the Department of Medical Humanities & Bioethics, and its parent unit, the College of Medicine at University of Arkansas for Medical Sciences has allowed the time and provided the resources necessary to produce this work. We are, however, most indebted to our families: James (for Toby) and Kelly, Emily, Joshua, and Matthew (for Micah), without whom nothing good in our lives is possible.