

The Empire State Bioethics Consortium: A Collaborative Response to Health Care Ethics Challenges of the Pandemic and More

By Robert N. Swidler, Timothy Kirk, Amy Scharf and Louis Voigt

Introduction

The Empire State Bioethics Consortium (ESBC) is a new not-for-profit organization for health care ethics professionals across New York State. Initially formed in response to the COVID-19 pandemic, its mission extends beyond pandemic-related ethical issues:

to identify and respond to health-related ethical issues faced by individuals, families, populations, and communities throughout New York State, and by those entrusted with their care, with an emphasis on remediating structural inequities in health care and public health.¹

ESBC is still in its formative stage. But since the first impromptu videoconference call on March 23, 2020 it has grown exponentially. It has been attracting members from across the state, from founders of the field with decades of experience to graduate students still completing their training.

As discussed below, the pandemic revealed that health care ethics professionals in New York had been working without strong connections with their colleagues in other institutions. As a consequence, they were hampered in their institutions by a need for information, for peer group thinking and advice, for model policies, and for moral support. ESBC emerged organically in response to that need and is providing that interinstitutional forum. As importantly, it is starting to meet its promise as a resource for the public and a source of support and training for new medical ethics professionals.

Background²

In March 2020, the COVID-19 pandemic swept across New York City and beyond with devastating effect. Health care professionals lacked information about pretty much everything important: the nature of the disease; how it was transmitted; how to test for it; how to guard against contracting it; how to treat it; and who was most at risk for infection, serious disease and death.³ Hospitals and nursing homes were overwhelmed with desperately sick patients. This extraordinary surge caused critical shortages and a need for unprecedented rationing of resources—notably personal protective equipment (PPE) for staff (e.g., masks, gloves, gowns);⁴ ventilators and critical care beds for patients;⁵ and testing supplies for the public.⁶

COVID-19 brought reality to issues that health care ethicists had been contemplating in theory for years—the allocation of scarce resources, ensuring access to care for minority and disadvantaged patients, the right to demand seemingly futile care, crisis standards of care, the right to experimental medications, etc. Just as clinicians confronted a deluge of COVID-19 patients, NYS ethicists faced a deluge of ethical issues with an intensity and urgency not seen at least since the AIDS crisis in the 1980s.

In March 2020, some ethics professionals in New York City began videoconferencing to share information and ideas. (“Ethics professionals” as used here means not just clinical ethicists, but physicians, nurses, academics, lawyers, social workers, administrators, association staff and others with a particular background, experience or role in addressing health care ethics matters). Initial conversations included participants from, among other institutions (in alphabetical order), Greater New York Hospital Association; the Hastings Center; Memorial Sloan Kettering Cancer Center; Montefiore Medical Center; Mount Sinai Hospital; New York Presbyterian Columbia University & Weill Cornell Medical Centers; NYC Health & Hospitals; Northwell Lenox Hill, Maimonides and Long Island Jewish Medical Centers; NYU Langone Medical Center, Roswell Park Comprehensive Cancer Center; and the University of Rochester Medical Center.

The group’s initial project was a collective letter to Governor Andrew Cuomo, which it sent under the new name Empire State Bioethics Consortium. The letter asked to approve a statewide policy on patient triage and allocation of scarce resources to replace the patchwork of inconsistent or nonexistent hospital policies.⁷ It also called for a range of preventive measures to protect New Yorkers, including helping nursing homes maintain sufficient supplies of PPE; increasing the availability of COVID-19 testing to locations with vulnerable populations; instituting guidelines to protect New Yorkers with disabilities against discrimination in the allocation of scarce health care resources; augmenting palliative care resources and personnel at health care facilities; and addressing socioeconomic disparities in the accessibility of health care.

It is unclear what influence, if any, that initial letter had on public policy. Nonetheless the effort was remarkable and unprecedented: diverse New York institutions came together with one voice to request ethically sound health pol-

icy measures. Moreover, the exchange of views and ideas among ESBC participants likely influenced practices at their respective health care institutions.

The first few video calls led to a consensus that weekly calls were needed. In turn, the weekly call participants identified and invited additional individuals involved in ethics at other institutions to participate. A professionally diverse group emerged, with participants from other New York City institutions and well as from Rochester, Albany, Syracuse and elsewhere.

As the pandemic forced more and more people to work remotely, a large segment of the public became adept at Zoom and other videoconferencing applications.⁸ Without this growing facility with Zoom, it is doubtful that ESBC would have taken root as it did.

By the summer of 2020, as the pandemic (deceptively) appeared to be subsiding, the group began to recognize its value and potential beyond responding to COVID-19. Discussions began to turn to creating an organization. There were several discussions about the pros and cons of incorporating. The name “Empire State Bioethics Consortium” was agreed upon.

The group has already engaged in several valuable projects. ESBC organized and presented four 90-minute webinars that explored questions germane to the pandemic, including states’ obligations to their citizens, ethics consultations, provision of palliative care, and the concepts of inequities, vulnerability, and justice.⁹ These webinars, which were free and open to the general public, featured panel discussions between ESBC members and bioethics experts from across the U.S. ESBC has posted the webinars on YouTube and they have had several thousand views.

A long-term care workgroup formed to highlight disparities for nursing home residents issued a statement criticizing severe visitor restrictions on ethical grounds. The statement attracted considerable news media attention.^{10,11,12}

In June 2021 ESBC members presented to the New York City Council on ethical issues relating to ethical issues raised by the COVID-19 pandemic, including the law and ethics, mandatory vaccination, and the need to address racial disparities in pandemic policies.

Empire State Bioethics Consortium Today

Corporate Status. By Spring 2021, ESBC decided that the group had an enduring value and purpose, and that it should incorporate as a New York State not-for-profit corporation. Incorporation would demonstrate its seriousness and commitment, would force it to sharpen its governance and purpose, and enable it to engage in activities toward that purpose. It incorporated on April 22, 2021—about a year after the informal phone calls started. The organization adopted bylaws in June 2021, and elected as its first chair Louis Voigt, M.D, intensivist and chair of the ethics

committee at Memorial Sloan Kettering Cancer Center. ESBC received tax-exempt status on December 21, 2021 (relating back to the date of incorporation). It also launched a website—<https://www.empirestatebioethics.org/>.

Membership. Currently the organization has dues paying members from across the state. Per the bylaws, an applicant for membership must: (a) have significant knowledge, experience or involvement in bioethics or bioethical issues; and (b) reside or work/practice in New York State or have other strong present or past connection with New York State. A membership committee reviews application and credentials. The ESBC website provides information about applying for membership.

Governance. ESBC has a 12-member board of directors. The current directors are diverse professionally, racially and geographically. A nominating committee, independent of the board, proposes director candidates to the members.

Diversity. Diversity is a core value of ESBC. This is reflected in Article IV of the bylaws, “ESBC fosters a culture of inclusion and a holistic approach to diversity in its Membership and leadership seeking representation and recruitment that is inclusive of individuals who have been marginalized or disenfranchised.”

Meetings. In recent months, ESBC members have been meeting monthly. Meetings usually include some organizational business, and then discussion of a substantive bioethics topic. In recent meetings members have discussed:

- whether DNR orders require consent if resuscitation would offer no benefit and ventilators are unavailable;
- whether to recognize religious exemptions from vaccination requirements;
- whether to limit liability for health care professionals for decisions made under public health emergency circumstances;
- vaccine mandates;
- ethical implications of the shortage of health care workers;
- the scope of professional obligations to unvaccinated patients.

Advocacy. As a 501(c)(3) organization, ESBC cannot engage in substantial lobbying, i.e., attempting to influence legislation, and cannot support or oppose political candidates. It can, however, express its views on health care ethics issues of the day. Under ESBC’s bylaws the members need to approve any such position by consensus. In practice, ESBC members express a wide range of views on most issues and engage in some lively debates. As a result, it is not likely to engage in substantial advocacy, even without regard to IRS limitations. But for the limited issues where ethics professionals across the state achieve, ESBC can be

a powerful voice, as it was in advocating for relaxation of visitation rules in nursing homes.

Planned Events/Activities. ESBC held a conference on March 16, 2022, *Responding to Contemporary Ethical Issues in Our Communities: A Call to Action*. Dr. Joseph Ravenell of NYU Langone Health/NYU Grossman School of Medicine was keynote speaker. The organization is now planning other webinars, activities and projects that will further its mission.

Conclusion

ESBC is an organic response to a pressing unmet need. Under the extreme pressure of the pandemic, professionals involved in health care ethics in New York needed to reach out to colleagues for information, advice, and moral support—and to share their information with the public. ESBC is becoming that forum.

There are other high-regarded organizations that contribute greatly to the field of ethics. Some address bioethics issues nationally or internationally;¹³ others focus on New York but address a broader range of health policy or health law issues.¹⁴ There is a government task force on bioethics.¹⁵ But ESBC is unique and alone in being a nongovernmental organization focused exclusively on health care ethics in New York. With each meeting it is clearer that this organization will endure and will become an important voice, resource and asset for health care ethics in the state.

More information about the Empire State Bioethics Consortium is available online: <https://www.empirestate-bioethics.org/>.

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All the authors are board members of the Empire State Bioethics Consortium.

Endnotes

1. <https://www.empirestatebioethics.org/about-us>.
2. Joseph J. Fins, M.D. offers an excellent and uplifting description of the background of ESBC in his article, *Is Deliberative Democracy Possible During a Pandemic? Reflections of a Bioethicist*, 41 J. Theoretical and Philosophical Psychology 216, at 222-223 (2021).
3. See, e.g., Marc Lipsitch, David L. Swerdlow, Lyn Finelli, *Defining the Epidemiology of COVID-19—Studies Needed*, 382 N Engl J Med 13 (2020), published online Feb. 19, 2020, and calling for urgent study of these phenomena.
4. Douglas Kamerow, *COVID-19: The Crisis of Personal Protective Equipment in the US*, 369 BMJ (2020).
5. See, e.g., Jeremy R. Beitler et al., *Ventilator Sharing During an Acute Shortage Caused by the COVID-19 Pandemic*, 202 Am J Respir Crit Care Med 4 (2020), describing a protocol for ventilator sharing between patients emergently developed and approved by hospital leadership, ethics committee, and New York State Department of Health.
6. Will Lieberman-Cribbin et al., *Disparities in COVID-19 Testing and Positivity in New York City*, 59 Am J Prev Med 3 (2020).
7. Letter from the Empire State Bioethics Consortium to Governor Andrew Cuomo 5 (May 20, 2020) (on file with the Empire State Bioethics Consortium).
8. Janine Hacker et al., *Virtually In This Together—How Web-Conferencing Systems Enabled a New Virtual Togetherness during the COVID-19 Crisis*, 29 Eur J Inf Syst 5 (2020).
9. The topics of the four webinars were 1) What are the Obligations of the State during a Pandemic?, 2) Ethics Consultations During Covid; 3) Inequality, Vulnerability, and Health Justice: Learning from the Pandemic; 4) The Importance of Palliative Care During the COVID-19 Pandemic. Links to full-content webinar recordings are available at <https://www.empirestatebioethics.org/events>.
10. Elizabeth Weingast and Karen Lipson, *Ease Restrictions for Vaccinated Nursing Home Residents*, Albany Times Union, June 8, 2021, <https://www.timesunion.com/opinion/article/Commentary-Ease-restrictions-for-vaccinated-16231388.php>.
11. ESBC Long-Term Care Workgroup, *Vaccinated and Still Isolated: The Ethics of Overprotecting Nursing Home Residents*, Hastings Center Bioethics Forum, April 19, 2021, <https://www.thehastingscenter.org/vaccinated-and-still-isolated-the-ethics-of-overprotecting-nursing-home-residents/>.
12. Michael Rubinkon, *Protect Them to Death: Elder-Care COVID Rules Under Fire*, Associated Press, June 19, 2021, <https://apnews.com/article/coronavirus-pandemic-nursing-homes-restrictions-elderly-2c6b98804219c731a5e8a9b843594381>.
13. E.g., American Society for Bioethics and Humanities and the Hastings Center.
14. E.g., Greater NY Hospital Association (GNYHA) the Association of NYS (HANYs), the New York Academy of Medicine, and the NYS Bar Association Health Law Section.
15. The New York State Task Force on Life and the Law, which is operated by the New York State Department of Health, has had enormous influence on health care ethics-related policies in New York State and far beyond. It developed New York laws and regulations and influenced policies on brain death, DNR orders, health care proxies, surrogate decisionmaking, assisted reproductive technologies, organ transplantation, genetic testing, surrogate parenting, allocation of ventilators and more. But while it still exists, it has been inactive since before the COVID-19 pandemic. Moreover, unlike ESBC it is a governmental organization, and not a broad forum for professionals involved with health care ethics. Several Task Force members and staff members are also ESBC members. See also Joseph Fins, M.D., *supra*, note 2.