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Brainstorm Newsletter

An Interdisciplinary Newsletter about Advances in Health Ethics Theory and Practice

- May 2019

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**PRAGMATIC
HEALTH ETHICS
RESEARCH UNIT**



Profile of the Month

Maya Goldenberg, PhD



Maya Goldenberg is an Associate Professor in the Department of Philosophy at the University of Guelph. Her research focuses on medical epistemology, and specifically addresses how knowledge claims come to be justified in health care. She has explored this question in the pressing context of evidence-based medicine, and has now broadened the question to examine vaccine hesitancy and refusal of childhood vaccines as a conflict over knowledge claims that pits scientific institutions against the public. She aims for

practical relevance and socially-engaged philosophy. Maya is a member of the Canadian Immunization Research Network and the Social Science and Humanities Research Network. She has presented her research to Public Health Ontario, and published an editorial (with podcast interview) in the Canadian Medical Association. She is currently very near completion of a book manuscript (to be published by University of Pittsburgh Press) on vaccine hesitancy from a social epistemology and philosophy of science perspective.

Short statement on pursuing practically relevant philosophy, and the link between epistemology and ethics.

Working on practically relevant or applied philosophy required reflexivity between the theoretical and the practical. Philosophers are trained in theory, and philosophy has historically relied on simple “thought experiments” to test out theories and intuitions. Practical or real-world problems are far more complex, and so they test the theoretical assumptions more rigorously, even necessitating theoretical modifications at times. In my current project, I developed a good understanding of vaccine hesitancy by reading widely in sociology, science communications, behavioural psychology, public health, medical rhetoric, science journalism, and popular science writing. Twitter has been really useful for meeting and engaging with scholars in these field. We don’t go to the same conferences so likely would not have never met otherwise.

I am trained in philosophy of medicine and feminist philosophy, two branches of philosophy that happen to attend to the relationship between knowledge and norms. Philosophy of medicine recognizes that epistemic claims impact patient care and well-being, while feminist philosophy considers whose knowledge counts (the power/knowledge interface). So epistemology and ethics are always closely aligned. I carry that thinking in my own research, which tends to look at the ethical implications of epistemic issues, and the ways that epistemic issues influence ethical discussions.

Selected Publications:

1. Maya J. Goldenberg. Vaccines, values and science CMAJ April 08, 2019 191 (14) E397-

E398; DOI: <https://doi.org/10.1503/cmaj.181635>

2. Maya J. Goldenberg, "Public Misunderstanding of Science?" Reframing the Problem of Vaccine Hesitancy." *Perspectives on Science* 24:5 (2016): 552-581.
3. Maya J. Goldenberg, "[Whose social values? Evaluating Canada's 'Death of Evidence' Controversy](#)" *Canadian Journal of Philosophy* 45:3 (2015): 404-424.

Social Media:

Twitter: @maya_goldenberg

Events and Announcements

[Montreal Health Ethics Seminar Series](#)

The seminar series is a bilingual monthly seminar/webinar series aimed at bringing people together to think about and discuss issues in health ethics. Our aim is to promote health ethics through seminars that foster dialogue between groups of participants with different perspectives (e.g., academics, clinicians, patients, community members). These seminars will appeal to audiences both within and outside of academia and healthcare settings with the goal of increasing mutual awareness about health ethics and promote interdisciplinary and community reflections on various cross-cutting health ethics topics.

Join us for our next seminar/webinar in March:

When: May 9th, 2019, 12-1PM

Where: Institut de recherches cliniques de Montréal (110 avenue des Pins Ouest, Auditorium Jacques Genest) OR livestreamed through our [YouTube page: Pragmatic Health Ethics](#)

What: Annie Pullen-Sansfacon (Université de Montréal) "What is our responsibility with regard to the care of transgender youth?"

All conferences are free and require no registration!

Visit our website or email us for more information about where seminars will be archived for future viewing or educational use (e.g., journal clubs, classroom, continued education):

<http://www.pragmatichealthethics.ca/outreach/montreal-health-ethics-seminar-series/>

[Philosophical Issues in Research Ethics Workshop - Rotman Institute of Philosophy - Call for Papers](#)

November 7, 2019 - November 8, 2019

The Philosophical Issues in Research Ethics Workshop will bring together leading scholars in

the field. Building on the success of the two-day workshop held at Carnegie Mellon University in November 2018, this workshop seeks to:

1. Create a high-level forum for exchange of ideas among philosophers working on problems in research ethics;
2. Foster a community of like-minded scholars; and,
3. Provide opportunities for senior trainees and junior faculty to be mentored by senior faculty.

Paper submissions from faculty within five years of first appointment, postdoctoral fellows and job-market-ready doctoral students are invited. Papers must address a philosophical issue in the ethics of research involving human participants and must be no more than 5,000 words in length.

All submissions must be received on or before the deadline of July 15, 2019.

[Science and Democracy Network 18th Annual Meeting - Call for Abstracts](#)

The Conference Planning Committee invites abstracts (up to 300 words) on a theme appropriate for discussion at the workshop. The closing date for abstract submissions is **May 6, 2019 (extended)**. Decision will be made in about a month from that date. You should submit your abstracts via [the online form](#). Please direct any questions to Shana Ashar at shana_ashar@hks.harvard.edu.

If your abstract is accepted by the Conference Planning Committee, you will be expected to provide a final paper for circulation to other workshop participants no later than **August 5, 2019**. Please keep this date in mind as you respond to the call for abstracts.

The conference will be organized around the following major themes:

- **Institutions:** Role of governmental and non-governmental institutions in producing, using, disseminating or contesting authoritative knowledge; institutions with claims to epistemic authority include NGOs, corporations, international governmental organizations, scientific institutions, the state and its agencies.
- **Citizenship and Participation:** Forms and modes of citizen mobilization and expression around scientific or technological issues, including (new) social movements, new forms of participation, consumer activism, patient groups, indigenous peoples, and “liminal citizens” (endangered species, animals, embryos, and stem cells, for example).
- **Communication and Representation:** Intersection between political and expert or professional discourses; role of mass media in presenting science, with particular interest in visual representation; political implications of information and communication technologies, databases, identification technologies, etc.

Under each theme, priority will be given to work that effectively integrates issues of political

and epistemic authority. Approximately 28-30 abstracts will be accepted. Preference will be given to abstracts from people who did not present last year (though this is not an absolute rule).

As in prior years, proposals for individual papers and panels of 3-4 papers on topics of broad interest for science and democracy will be accepted. Such proposals must meet high standards of theoretical significance and/or political or policy salience. Please note that, to ensure widest participation, only one panel proposal can be accommodated in the final program. If you submit a panel proposal, but would also be willing to have the entries considered individually, please so indicate.

We would also like to solicit proposals for roundtables on current issues of relevance to SDN members, for example, reflecting on recent political developments challenging knowledge and expertise. The program may be able to accommodate one such panel (60-90 minutes) provided it is sufficiently interesting and inclusive. Panelists need not present formal papers but should represent a breadth of research experiences and institutional affiliations.

Special Session for Graduate Students

This year's annual meeting will feature two bracketed, half-day sessions for graduate students on Wednesday, August 28th and Saturday, August 31st. This session will offer graduate students an opportunity to submit and present papers for feedback from senior SDN members, in addition to joining the entire SDN conference as participants. To submit an abstract for a graduate student paper, please follow the link to the online form, upload your abstract, and check the box for a graduate student submission. Limited travel funds maybe available for graduate students who demonstrate need. If you are a graduate student looking for a travel stipend, please check the appropriate box on your abstract submission form.

[**This is your Brain on Poverty: Neuroscience, Ethics and Early-Childhood Deprivation - Conference**](#)

**Medical College of Wisconsin
Center for Bioethics and Medical Humanities
Milwaukee, WI
June 13, 2019**

The Center for Bioethics and Medical Humanities at the Medical College of Wisconsin is sponsoring a day-long conference exploring the link between neuroscience and early childhood deprivation, and the associated ethical issues. Poverty is one of the major factors contributing to disparities in early child development, and in the US, poverty affects one in five children. This conference is intended to facilitate a dialogue on the issue of the

neuroscience of poverty and explore the clinical, ethical, social, and policy implications related to the effects of adversity on the brains of children. The conference features keynote presentations by Martha Farah, PhD, Director of the Center for Neurosciences and Society at the University of Pennsylvania, and Fatimah Loren Muhammad, Executive Director of the National Network of Hospital Based Violence Intervention Programs. Speakers from the Medical College of Wisconsin include Fabrice Jotterand, PhD, MA (Center for Bioethics and Medical Humanities); David Nelson, PhD, MS (Family Medicine); and, Jennifer Koop, PhD, ABPP (Neurology and Neurosurgery). Additional support for this conference comes from the Institute for Health & Equity and the Clinical & Translational Science Institute at the Medical College of Wisconsin.

[International Neuroethics Society - Call for Abstracts](#)

The International Neuroethics Society (INS) invites researchers from around the world to submit abstracts for presentation at our 2019 annual meeting in Chicago, IL, USA. The meeting will feature a wide range of exciting talks, discussions, and networking opportunities with experts, researchers, and up-and-coming leaders in the field of neuroethics.

This is an opportunity to share your neuroethics research with international colleagues who are actively aligning ethics, law, society, and policy with advances in neuroscience. We welcome abstracts related to the field of neuroethics from any disciplinary background, whether the work is empirical or theoretical in nature. Investigators at all career stages are encouraged to submit one or more abstracts.

Abstracts will be peer reviewed. Acceptance will be based on content, available space, and overall program balance. Poster presentations will take place on Thursday and Friday, October 17 and 18, 2019; opportunities for oral presentations will also be available, with details to follow.

The submission deadline is June 24, 2019, at 11:30pm EDT. Incomplete or late submissions will not be accepted. All submissions must be made through the abstract submission form.

[Postdoctoral Fellow - The Pragmatic Health Ethics Research Unit - Call for Applications](#)

The Pragmatic Health Ethics Research Unit is seeking TWO (2) postdoctoral fellows or graduate students to work on two main projects. The first project examines the ethical and social implications of health care transitions for youth with chronic conditions, including rare diseases. The second project examines the ethics of registry-based-type-1 diabetes research.

Applications will be reviewed on an ongoing basis until the position is filled.

[Hamilton Health Sciences Clinical and Organizational Fellowship](#)

The Office of Clinical & Organizational Ethics at Hamilton Health Sciences invites

applications for a one-year (full-time) fellowship in clinical and organizational ethics, beginning September 2019.

Hamilton Health Sciences (HHS) is located in Hamilton, Ontario, Canada. Home to more than half a million residents, Hamilton is situated at the western tip of Lake Ontario midway between Niagara Falls and Toronto. It is the site of McMaster University, known internationally for its innovative medical school and research programs and the home of evidenced-based practice. Hamilton has a rich cultural community with its own professional theatre company, art galleries and professional sports team. The Royal Botanical Gardens and the Bruce Trail are within minutes of the hospital sites.

Hamilton Health Sciences is comprised of 6 hospitals and a cancer centre, serving more than 2.2 million residents in Central South West Ontario. Each of the facilities offers specialized services that together make HHS one of the most comprehensive health care systems in Canada. Hamilton Health Sciences is an academic health centre with several sites affiliated with the Faculty of Health Sciences at McMaster University. This allows patients to benefit from innovative treatments/research, and staff and students to actively participate in research and teaching endeavours.

HHS has a long tradition of innovations in health care ethics, and has the longest standing clinical ethics committee in Canada. The Office of Clinical & Organizational Ethics won a Leading Practice award from Accreditation Canada in 2011 for developing high quality clinical and organizational ethics services from bedside to boardroom, and won another Leading Practice in 2015 for its innovative programs in promoting resilience amongst health professionals. Since 2014, HHS has also partnered with the Regional Ethics Network (REN), is comprised of 6 partner organizations from across south-western Ontario. The REN is unique in Ontario, offering access a the full range of ethics services (consultation, education, policy work and capacity-building) for small organizations, including a variety of community hospitals, home care agencies and community service partners. Thus, the REN supports continuity of care across the healthcare continuum, from hospital to home.

Fellowship Offers:

- Comprehensive training in clinical ethics consultation, including the opportunity to conduct ethics consultations for a high volume service at Hamilton Health Sciences, and with the partners of the Regional Ethics Network (REN)
- Participation in organizational ethics projects and issues
- Exposure to a variety of ethical issues in diverse hospital settings and community health services
- Participation on a variety of committees
- Continuous and supportive mentorship from staff ethicists and programme director
- Participation in creating and delivering educational resources and events to health professionals
- Participation in policy review, development and evaluation

- Preparation for an active career as an ethicist in a variety of health care settings
- Participation in research and scholarly activities within the office of ethics
- Full-time fellowship to maximize opportunities for learning and growth

Required Qualifications:

- Minimum masters or terminal professional degree (MA, JD, PhD, MD or equivalent)
- Some graduate training in bioethics or applied ethics
- Canadian citizen or permanent resident
- Strong presentation and teaching skills
- Ability to be self-directed and meet own learning goals
- Strong organizational skills, working both independently and collaboratively to achieve strategic goals and deadlines
- Excellent oral and written communication skills in English
- Ability to be reflective, self-aware, compassionate, mature, collaborative and committed to quality and innovation

Required application materials:

- Current curriculum vitae
- A letter describing the reasons for your interest in applying for the fellowship, including any particular topics or questions you are most interested in exploring. This letter is an important opportunity for you to tell us about yourself, your interests, your preparation, what you can contribute to the work of the Office of Ethics at HHS, your motivations in pursuing training in health care ethics and why you feel that you are the ideal candidate.
- Two letters of reference- 1 academic, 1 professional/work related

The deadline for receipt of completed applications is **Friday, May 10th 2019**. Only completed applications will be reviewed and considered for interviews.

Literature

Interdisciplinary Foundations of Health Ethics

[Restoration of brain circulation and cellular functions hours post-mortem](#)

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[Patient and public involvement: Two sides of the same coin or different coins](#)

[altogether?](#)

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DeMartino ES, Sperry BP, Doyle CK, Chor J, Kramer DB, Dudzinski DM, Mueller PS. JAMA. 2019 Apr 23; 321(16): 1629-31.

[Mobile health ethics and the expanding role of autonomy.](#)

Schmietow B, Marckmann G. Med Health Care Philos. 2019 Apr 22.

[Taking patient virtue seriously.](#)

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Methodologies and Practices in Health Ethics

[Understanding Patients' Preferences: A Systematic Review of Psychological Instruments Used in Patients' Preference and Decision Studies.](#)

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[Public attitudes towards novel reproductive technologies: a citizens' jury on mitochondrial donation.](#)

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[Relationships and burden: An empirical-ethical investigation of lived experience in home nursing arrangements.](#)

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[Research participants' preferences for receiving genetic risk information: a discrete choice experiment.](#)

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[Use of a Decision Aid for Patients Considering Peritoneal Dialysis and In-Center Hemodialysis: A Randomized Controlled Trial.](#)

Subramanian L, Zhao J, Zee J, Knaus M, Fagerlin A, Perry E, Swartz J, McCall M, Bryant N, Tentori F. Am J Kidney Dis. 2019 Apr 3.

News and Social Media

[Lawsuits Lay Bare Sackler Family's Role in Opioid Crisis](#)

Hakim D, Rabin RC, Rashbaum WK. The New York Times. April 01, 2019.

[Most of us support mandatory vaccines for schoolkids, but is it good policy?](#)

Braley-Rattai A. The Conversation. April 04, 2019.

[Scientists Partly Restore Activity in Dead-Pig Brains](#)

Yong E. The Atlantic. April 17, 2019.

['Exhilarating' implant turns thoughts to speech](#)

Gallagher J. BBC News. April 24, 2019.

[Why the most common developmental disability in Canada is misdiagnosed or missed – and the devastating results](#)

Hrvatin V. The National Post. April 25, 2019.



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