

McGILL UNIVERSITY

SOCI 515/HSSM 610

MEDICINE AND SOCIETY/THE SOCIOLOGY OF MEDICINE

Fall 2021

Professor: Alberto CAMBROSIO

Office: 3647 Peel St.

Tel.: 514 398-4981 (direct) or 514 398-6033 (secretary)

E-mail: alberto.cambrosio@mcgill.ca

About the course

The course is a *seminar* designed primarily for graduate students. The seminar will focus on the sociology of biomedical activities, including clinical and laboratory practices, translational research, and recent developments at the interface of medicine and genomics. Its main objective is to examine how biomedicine shapes and is shaped by societal developments. Biomedicine is a very diverse field and sociologists of biomedicine have investigated a motley of different topics, ranging from the production of visual inscriptions, to the dynamics of medical discourse, the structure of medical texts, the development of diagnosis and classification, the role of biomedical instruments and devices, the evolution of different styles of research, the rise of patient activism, the emergence of biosocial identities, the commercialization of medical research, and so on. Because the field is so large, no single course could possibly cover its entire breadth. I have selected a number of topics corresponding to several key activities of contemporary biomedicine, such as diagnosis, screening, etc., with a focus on recent developments, such as evidence-based medicine and genomics. In addition to introducing students to these selected topics, readings are meant to familiarize them with different sociological approaches and methods that have been used to analyze biomedical activities.

Course requirements

The course will follow a seminar format. Students are expected to contribute to each session in the form of preparation, participation, and focused questions for discussion. I have selected three *required readings* for each session. All readings are articles from E-journals or E-book chapters that can be accessed via the McGill library website (I included the link in the list of references). I will be happy to provide a list of additional readings to students who would like to explore a given topic more extensively.

Students must fulfill the following three requirements:

- First, each student will be expected to write a brief (1-2 pages) *comparative* summary of each week's required readings. The adjective "comparative" refers to the assessment of how readings relate (or not) to each other: What do they have in common? What differentiates them? How do their approaches and arguments differ? Are they compatible or incompatible with one another in terms of their assumptions?

What are the comparative strengths and weaknesses of each article? The summaries should be e-mailed to all course participants (myself included) *no later than the Saturday preceding the Monday class during which we will discuss the readings*, in order to allow discussion leaders (see next point) to prepare their comments. Students are expected to read each other's comments prior to class.

- Second, each student will participate in leading the discussion of required readings during one class period, either individually or as part of a team of two or three students. At the beginning of the semester, each student should sign up for one or more sessions for which s/he agrees to act as the seminar facilitator, with the responsibility for introducing the discussion, keeping it moving, and making sure pertinent points are covered. Discussion leaders should act as a team and present an *integrated* overview of each week's readings and of the issues and questions they raise (as contrasted with discussing each reading in turn). Their overview should be based on their own critical analysis of the readings and include a summary of the comments emailed by the other students. An outline of the overview should be circulated before the beginning of each class.
- Finally, students will submit a seminar paper at the end of the course (4000-6000 words). The paper will analyze a topic of their choice in the sociology of medicine. Any topic will do as long as it deals with biomedicine (broadly defined), and as long as it implements the methodological and theoretical tools discussed in the course. The paper is *not* to be conceived of as an essay review of secondary sources. Rather, it should be based on the analysis of primary sources (medical literature, interviews, etc.). The paper must include a section in which the topic is discussed theoretically or conceptually, with reference to the literature from class readings and/or other relevant analytical material that you have found. Students are therefore strongly advised to choose a topic as soon as possible. In particular, they are required to submit a short (3-4 pages) *term paper proposal* by mid-October. The proposal should include a short description of the topic to be discussed in the term paper, clearly lay out the research question, describe its importance, consider potential answers to the question, and describe what types of material you will gather to answer the question, including a short bibliography. This assignment is worth 10 percent of the final grade. This assignment is necessary: you will not receive a grade on the final paper if you do not complete it.
 - *Term paper proposals are due on October 25.*
 - *Papers are due on the last day of classes (December 6).*

The grade will be determined by:

- a) Written summaries of readings: 30% of final grade
- b) Class participation: 10% of final grade
- c) Oral Presentation: 10% of final grade
- d) Term paper proposal: 10% of final grade
- e) Seminar paper: 40% of final grade

In accord with McGill University's Charter of Students' Rights, students in this course have the right to submit in English or in French any written work that is to be graded." (approved by Senate on 21 January 2009 - see also the section in this document on Assignments and evaluation.)

Conformément à la Charte des droits de l'étudiant de l'Université McGill, chaque étudiant a le droit de soumettre en français ou en anglais tout travail écrit devant être noté (sauf dans le cas des cours dont l'un des objets est la maîtrise d'une langue).

© Instructor generated course materials (e.g., handouts, notes, summaries, exam questions, etc.) are protected by law and may not be copied or distributed in any form or in any medium without explicit permission of the instructor. Note that infringements of copyright can be subject to follow up by the University under the Code of Student Conduct and Disciplinary Procedures.

STATEMENT ON ACADEMIC INTEGRITY

McGill University values academic integrity. Therefore, all students must understand the meaning and consequences of cheating, plagiarism and other academic offences under the Code of Student Conduct and Disciplinary Procedures (see www.mcgill.ca/students/srr/honest/ for more information). (approved by Senate on 29 January 2003)

L'université McGill attache une haute importance à l'honnêteté académique. Il incombe par conséquent à tous les étudiants de comprendre ce que l'on entend par tricherie, plagiat et autres infractions académiques, ainsi que les conséquences que peuvent avoir de telles actions, selon le Code de conduite de l'étudiant et des procédures disciplinaires (pour de plus amples renseignements, veuillez consulter le site www.mcgill.ca/students/srr/honest/).

COURSE SCHEDULE AND REQUIRED READINGS

NOTE: While the seminar focuses on readings that are directly related to biomedicine, most of the readings explicitly refer to the field of *Science & Technology Studies* (S&TS). Ideally, students should have already taken an introductory course to S&TS, although this is not a requirement. For students with no prior exposure to S&TS, the following textbook provides a useful introduction:

- S. Sismondo. 2010. *An Introduction to Science and Technology Studies, Second Edition*. Malden, MA: Wiley-Blackwell.

Additional recommended readings:

- B. Latour. 1987. *Science in Action: How to follow scientists and engineers through society*. Cambridge, MA: Harvard University Press.
- B. Latour. 2005. *Reassembling the Social. An Introduction to Actor-Network Theory*. Oxford: Oxford University Press.

- M. Callon. 1995. Four models for the dynamics of science. In S. Jasanoff, G. E. Markle, J. C. Petersen & T. Pinch (Eds). *Handbook of Science and Technology Studies*. Thousand Oaks, CA: Sage Publications, pp. 29-63.

The following handbook provides overviews of several subdomains of S&TS:

- U. Felt, R. Fouché, C.A. Miller and L. Smith-Doerr (Eds). 2016. *The Handbook of Science and Technology Studies, Fourth Edition*. Cambridge, Mass: MIT Press.

Students with a special interest in genomics may want to consult the following handbook:

- S. Gibbon, B. Prainsack, S. Hilgartner, and J. Lamoreaux (Eds). 2018. *Routledge Handbook of Genomics, Health & Society, Second Edition*. London: Routledge.

DETAILED SCHEDULE

1/ September 13 GENERAL INTRODUCTION

2/ September 20: The sociology of disease

- (a) S. Timmermans & S. Haas. 2008. Towards a sociology of disease. *Sociology of Health & Illness* 30: 659–676.
<https://mcgill.on.worldcat.org/oclc/5156508764>
- (b) A. Kerr et al. 2018. The sociology of cancer: a decade of research. *Sociology of Health and Illness* 40: 552-576.
<https://mcgill.on.worldcat.org/oclc/7317312349>
- (c) S. Timmermans. 2013. Seven warrants for qualitative health sociology. *Social Science & Medicine* 77: 1-8.
<https://mcgill.on.worldcat.org/oclc/823611098>

3/ September 27: 20th century (bio)medicine

- (a) M. Berg. 1995. Turning a practice into a science. Reconceptualizing postwar medical practice. *Social Studies of Science* 25: 437-476.
<https://mcgill.on.worldcat.org/oclc/5548945853>
- (b) N. Rose. 2001. The politics of life itself. *Theory Culture and Society* 18(6): 1-30.
<https://mcgill.on.worldcat.org/oclc/440867041>
- (c) S. Jasanoff. 2011. Introduction: Rewriting life, reframing rights. In: S. Jasanoff (Ed.), *Reframing rights: bioconstitutionalism in the genetic age*. MIT Press, 1-27.
<https://mcgill.on.worldcat.org/oclc/753680776>

4/ October 4: Analyzing clinical work

- (a) M. Berg. 1992. The construction of medical disposals: medical sociology and medical problem solving in clinical practice, *Sociology of Health & Illness* 14: 151-180.
<https://mcgill.on.worldcat.org/oclc/5156485860>
- (b) M. Berg. 1996. Practices of reading and writing: the constitutive role of the patient record in medical work. *Sociology of Health & Illness* 18: 499-524.
<https://mcgill.on.worldcat.org/oclc/5156492058>
- (c) N. Mackintosh & N. Armstrong. 2020. Understanding and managing uncertainty in health care: revisiting and advancing sociological contributions. *Sociology of Health &*

Illness 42(S1): 1–20.

<https://mcgill.on.worldcat.org/oclc/8641405842>

NO CLASS on October 11: Happy Thanksgiving!

5/ October 18: Clinical research and medical technologies

- (a) S. Timmermans & M. Berg. 2003. The practice of medical technology. *Sociology of Health & Illness* 25: 97–114.

<https://mcgill.on.worldcat.org/oclc/356336440>

- (b) P. Keating and A. Cambrosio. 2007. Cancer clinical trials: the emergence and development of a new style of practice. *Bulletin of the History of Medicine* 81: 197–223.

<https://mcgill.on.worldcat.org/oclc/123810057>

- (c) J. Petty & C.A. Heimer. 2011. Extending the rails: how research reshapes clinics. *Social Studies of Science* 41: 337–360.

<https://mcgill.on.worldcat.org/oclc/5792314773>

6/ October 25: Diagnosis

- (a) P. Atkinson. 1995. *Medical talk and medical work*. Sage, chapter 4 (Reading the body), 60–89.

<https://mcgill.on.worldcat.org/oclc/32764947>

- (b) A. Mol. 1998. Missing links, making links. On the performance of some atheroscleroses. In M. Berg & A. Mol (Eds), *Differences in medicine: unraveling practices, techniques and bodies*. Duke University Press, 145–165.

<https://mcgill.on.worldcat.org/oclc/37615960>

- (c) A. Jutel & S. Nettleton. 2011. Towards a sociology of diagnosis: reflections and opportunities. *Social Science & Medicine* 73: 793–800.

<https://mcgill.on.worldcat.org/oclc/748971097>

7/ November 1: Diagnosis meets genetics/genomics

- (a) A. Hedgecoe. 2003. Expansion and uncertainty: cystic fibrosis, classification and genetics. *Sociology of Health & Illness* 25: 50–70.

<https://mcgill.on.worldcat.org/oclc/5156500455>

- (b) P. Bourret. 2005. BRCA patients and clinical collectives: new configurations of action in cancer genetics practices. *Social Studies of Science* 35: 41–68.

<https://mcgill.on.worldcat.org/oclc/5548921078>

- (c) D. Navon. 2011. Genomic designation: how genetics can delineate new, phenotypically diffuse medical categories. *Social Studies of Science* 41: 203–226.

<https://mcgill.on.worldcat.org/oclc/5792315272>

8/ November 8: Screening

- (a) S. Timmermans & M. Buchbinder. 2011. Expanded newborn screening: articulating the ontology of diseases with bridging work in the clinic. *Sociology of Health & Illness* 34: 208–220.

<https://mcgill.on.worldcat.org/oclc/778713883>

- (b) N. Armstrong & H. Eborall. 2012. The sociology of medical screening: past, present and future. *Sociology of Health & Illness* 34: 161–176.
<https://mcgill.on.worldcat.org/oclc/6894902680>
- (c) D. Armstrong. 2012. Screening: mapping medicine's temporal spaces. *Sociology of Health & Illness* 34: 177–193.
<https://mcgill.on.worldcat.org/oclc/778713892>

9/ November 15: Making up people

- (a) I. Hacking. 2006. Genetics, biosocial groups & the future of identity. *Daedalus* 135(4): 81-95.
<https://mcgill.on.worldcat.org/oclc/103392627>
- (b) D. Navon & G. Eyal. 2016. Looping genomes: diagnostic change and the genetic makeup of the autism population. *American Journal of Sociology* 12: 1416–1471.
<https://mcgill.on.worldcat.org/oclc/6026307354>
- (c) A. Petersen, A.C. Schermuly, & A. Anderson. (2019). The shifting politics of patient activism: from bio-sociality to bio-digital citizenship. *Health* 23: 478-494.
<https://mcgill.on.worldcat.org/oclc/7988390077>

10/ November 22: Beyond medicalization

- (a) P. Conrad. 2005. The shifting engines of medicalization. *Journal of Health & Social Behavior* 46: 3–14.
<https://mcgill.on.worldcat.org/oclc/5546056501>
- (b) N. Rose. 2007. Beyond medicalisation. *Lancet* 369: 700–702.
<https://mcgill.on.worldcat.org/oclc/110499689>
- (c) K. Weiner et al. 2017. Have we seen the geneticisation of society? Expectations and evidence. *Sociology of Health & Illness* 39: 989–1004.
<https://mcgill.on.worldcat.org/oclc/6964140672>

11/November 29: Patient activism, lay expertise

- (a) S. Epstein. 1997. Activism, drug regulation, and the politics of therapeutic evaluation in the AIDS era: a case study of ddC and the 'surrogate markers' debate. *Social Studies of Science* 27: 691-726.
<https://mcgill.on.worldcat.org/oclc/5549030578>
- b) V. Rabeharisoa. 2003. The struggle against neuromuscular diseases in France and the emergence of the 'partnership model' of patient organisation. *Social Science & Medicine* 57: 2127–2136.
<https://mcgill.on.worldcat.org/oclc/112378874>
- (c) A. Panofsky. 2011. Generating sociability to drive science: patient advocacy organizations and genetics research. *Social Studies of Science* 41: 31-57.
<https://mcgill.on.worldcat.org/oclc/5792313874>

12/December 3 (Friday) Evidence-based medicine and its tools

- (a) D. Armstrong. 2007. Professionalism, indeterminacy and the EBM project. *BioSocieties* 2: 73-84.
<https://mcgill.on.worldcat.org/oclc/361403785>

- (b) T. Moreira. 2007. Entangled evidence: Knowledge making in systematic reviews in healthcare. *Sociology of Health & Illness* 29: 180-197.
<https://mcgill.on.worldcat.org/oclc/440352841>
- (c) L. Knaapen. 2013. Being evidence-based in the absence of evidence: the management of non-evidence in guideline development. *Social Studies of Science* 43: 681–706.
<https://mcgill.on.worldcat.org/oclc/7021647068>

13/ December 6: Summing up and student presentations

APPENDIX: TERM PAPER SPECIFICATIONS

Students may choose to write their final paper on a *biomedical controversy*. This is probably the easiest option for students with no previous experience in the sociology of biomedicine. The term “biomedical” is to be broadly understood, so as to include topics related to laboratory research, clinical science, as well as clinical (diagnostic and therapeutic) practices in the various disciplines and specialties related to health. However, two elements must be present:

- There must be evidence of a controversy, i.e., of two or more groups of practitioners disagreeing over the meaning, use, value, etc. of a given biomedical fact, technique or practice.
- You must be able to *document* the existence of such a controversy by citing and referring to *primary* sources (scientific and medical journals).

Your work will be assessed not only on the basis of the analytical content of the paper, but also on the basis of your ability to find a suitable case-study by perusing the scientific and medical literature.

1) What do we mean by “biomedical controversy”?

The term “controversy,” as used in this Appendix, refers to any discussion or debate involving differences of opinions on any given biomedical topic. For example, a debate concerning whether substance X (say: salt) does or does not play a role in producing effect Y (say: increasing blood pressure) qualifies, for our present purposes, as a biomedical controversy. Biomedical controversies can, in some cases, escalate to major confrontations, but this is not necessarily the case. Depending on the actual controversy, the number and spectrum of actors involved will vary: some controversies will be confined to debates among health-care professionals, while others will involve representatives of patient groups, social activists, journalists or even politicians. Moreover, controversies do not necessarily involve only two camps, pitted against each other: there can, in fact, be several different positions concerning any given issue, and disagreements can focus not only on the interpretation of a given issue but also on the approach and methodology that is likely to lead to the “right” conclusion. To qualify as a *biomedical controversy*,

irrespective of its size and extent, the debate must center on a medical issue in its “technical” sense: for instance, a purely ethical debate about whether a given medical technique (say: xenografts, i.e. organ transplantation using animal organs) ought to be performed or not for moral or religious reasons will not qualify as a biomedical controversy; by contrast, a debate about whether xenografts can transmit animal viruses to humans (and are thus an acceptable medical technique) will qualify.

2) *Why analyze controversies?*

University students are typically taught established facts corresponding to the state of the art at any given time. Often, no mention is made of the uncertainties surrounding the establishment of a given fact or its application to real world situations. This is why students often experience a reality shock when classroom teachings have to be applied in real-world situations. Two distinct sources of uncertainty can be distinguished: a) uncertainties related to the “messy” nature of laboratory and clinical work; b) uncertainties related to the social implications of biomedical activities. These two sources of uncertainty interact in often-unpredictable ways. There are thus two main reasons why one may want to analyze biomedical controversies: from a general point of view, because this will give us a better understanding of the production of medical knowledge in real world situations, and from a practical point of view, because this will help students to develop a critical assessment of the gap between textbook and real-world biomedical activities.

3) *How to analyze controversies?*

The purpose of this exercise is to reconstitute some of the uncertainties that characterize clinical and laboratory practices by focusing directly on those uncertainties: *our purpose is thus NOT to analyze controversies in order to find out who is right and who is wrong, but in order to understand how each of the parties in the controversy have come to espouse and defend a given position.* Participants in controversies tend to dismiss their opponents’ points of view by arguing that they are “irrational,” “inconsistent,” “illogical,” “methodologically flawed,” and so on. Once the controversy has been settled, these assessments are often used retrospectively to a-symmetrically “explain” why losers were doomed from the very outset and winners won because their position was the right one. If we want to understand the dynamics of a controversy, it is thus better (although not necessary) to examine an ongoing dispute, that is, a controversy that has not yet met closure: since we do not know yet which position will “win”, we cannot use the outcome to account for the controversy. Moreover, we should refrain from using terms such as the above-mentioned ones (rational, irrational, etc.), since they are not analytical terms but, rather, rhetorical tools used by actors in a controversy.

A *symmetrical* analysis of a controversy will include the following five steps:

a. The controversy: a short, initial description

Begin the analysis of the controversy by *briefly* describing the situation at hand: What is the field in which the controversy takes place? What is at stake in the controversy

(as defined by the participants)? What are the competing positions in relation to the controversial issue? These elements will be analyzed in more detail in subsequent sections of the paper, but it is important to give, at the very outset, a brief overview of the empirical issues under examination.

b. The relevant actors

Introduce and characterize the various actors involved in the controversy (remember: there can be more than two sides). The term “actors” applies both to human actors (individual or collective, such as associations, institutions, etc.) and to non-human actors (such as microorganisms, diseases, equipment, etc.): what are, in other words, the various entities (human and non-human) that play a role in the controversy?

c. How is the controversial knowledge produced?

It is important to avoid restricting the controversy to purely logical or textual arguments. One has to look at the different methodologies, tools and instruments used to produce the controversial claims. In short: what is the “material culture” of the groups involved in the controversy? The different research sponsorship networks to which participants are linked are another important element contributing to the production of knowledge: can you describe them? Which role do they play in the controversy?

d. A history of the controversy

The fourth step amounts to providing an analytical summary of the development of the controversy. For instance, a controversy can begin in a given setting and then branch out to multiple settings (it can leave the secluded world of the laboratory and become public), additional kinds of actors can get involved, and so on. How did the controversy unfold? How have the positions evolved? Were there any major turning points?

e. Analytical account

The final step should include the following element: by referring to the secondary literature, explain how the particular controversy you analyzed can teach us something about the dynamics of biomedical practices.

4) How to select a controversy: empirical guidelines

As previously mentioned, the first major requirement is to select a controversy, ideally one that has not yet been settled, although “historical” controversies can also be selected. It is easy to do: for instance, editorials in clinical journals (*Lancet*, *NEJM*, *BJM*, *JAMA*, etc.) often focus on controversial issues. Electronic databases such as *PubMed* and *ISI Web of Science* are quite helpful in locating additional references.

Once you have found a set of possible controversies, your final choice should be based on the following practical (and admittedly “fuzzy”) criteria:

- The controversy should not be too narrow, i.e., it should involve a certain number of people, not be confined to a single setting, be discussed in different kinds of publications; in short: focus on a topic that is more than a mere “technicality.”
- The controversy should not be too broad: a topic such as “new reproductive technologies” involves too many issues and too many actors. Pick a controversy that is “doable” given the time allotted to this assignment. Remember that it is better to submit a comprehensive analysis of a smaller controversy than a partial analysis of a broader one.
- Make sure that you have access to the relevant information: summaries of the controversy provided by secondary sources are not enough. You should use original documents (publications, reports, etc.).

FOR ADDITIONAL INFORMATION ON THE ANALYSIS OF CONTROVERSIES SEE:

- S. Sismondo. 2010. *An Introduction to Science and Technology Studies, Second Edition*. Malden, MA: Wiley-Black; chapter 11 (Controversies), pp. 120- 135.
- T. Venturini. 2010. Diving in magma: how to explore controversies with actor-network theory. *Public Understanding of Science* 19: 258–273.