

HPSC0012 Policy Issues in the Life Sciences

Course Syllabus

2021-22 session | Convenor: Professor Brian Balmer | b.balmer@ucl.ac.uk
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Course Information

The purpose of this course is to provide students with a critical overview of policy issues arising from developments in the biological sciences. The course will cover a variety of issues which will include: biomedical research policy, the BSE crisis, debates about the social acceptability of recombinant DNA research (GM crops, genetic testing, DNA profiling), controlling biological weapons research, biodiversity, human and animal experimentation. The course will also introduce students to some of the theories dealing with the complex relationship between science and society.

By the end of this course you should:

- Be able to analyse the social and political dimensions of debates in the life sciences
- Be able to evaluate the consequences of developments in life sciences
- Have detailed knowledge of a number of case studies of policy issues in the life sciences
- Be able to criticize simplistic and popular notions of the relationship between science, technology and society.

Basic course information

Course website:	On Moodle
Moodle Web site:	Search 'HPSC0012'
Assessment:	This term's course will be assessed on the basis of two written assignments: review (40%) and an essay (60%).
Timetable:	www.ucl.ac.uk/timetable
Prerequisites:	no pre-requisites, course designed for year 2 and above undergraduate students
Required texts:	See reading list
Course tutor:	Professor Brian Balmer
Contact:	b.balmer@ucl.ac.uk
Web:	https://www.ucl.ac.uk/sts/people/professor-brian-balmer
Office location:	22 Gordon Square, Room 2.3
Office hours:	See Moodle or Staff Website (above)

Schedule

UCL Week	Topic	Date	Essential Reading
6	Introduction: Science & Social Change	28 Sept- 4 Oct	King, A (2017), Stilgoe, J et al (2006)
7	"A conflict of interest?": Biomedical Research Policy and University-Industry Links	5-11 Oct	Parry and Greenhough (2018)
8	Genetic Screening and Testing	12-18 Oct	Press, N (2008) and POST (2012)
9	DNA Profiling and Crime	19-25 Oct	Nuffield Council on Bioethics (2007),
10	GM Crops and Science Policy	26 Oct-1 Nov	See Moodle
11	Reading Week	8 Nov	
12	"Mad Cow Disease": BSE, CJD and Science Advice	2-7 Nov 15 Nov	Millstone, E and van Zwanenberg, P (2003), Forbes, I (2004),
13	Biodiversity	16-22 Nov	See relevant section of reading list
14	Controlling Biological Weapons	23 -29 Nov	Lentzos, F. (2013), 1972 Biological Weapons Convention
15	Human Experimentation	30-5 Dec	Multiple options see Moodle.
16	Animal Experimentation	6-13 Dec	Sanders, S and Jasper, JM (1994),

Assessments

Summary

	Description	Deadline	Word limit	Feedback by
1	Review article (40%)	8 Nov 2021	1,000 Level 6/iBSc students: 1,500 words	https://www.ucl.ac.uk/academic-manual/chapters/chapter-4-assessment-framework-taught-programmes/section-8-assessment-feedback
2	Long Essay (60%)	21 Dec 2021	2,000 Level 6/iBSc students: 2,500 words	

Full details and instructions are at the end of this document.

Assignments

This term's course will be assessed on the basis of *two* written assignments (see above and end of this document). A list of suggested essay questions is included with this reading list. If you wish to write an essay connected with the course but not on the list you should see me to discuss a title. Students may discuss any aspects of their essays with me during my office hours. There is no exam for this course but you are expected to show evidence of wide reading and critical thought in your essays.

Full details and instructions are at the end of this document

Essays must be submitted via Moodle. In order to be deemed 'complete' on this module students must attempt both assignments and attend at least 7 out of 10 seminar sessions.

See the www.ucl.ac.uk/sts/handbook for late penalties and over-length penalties.

Criteria for assessment

The departmental marking guidelines for individual items of assessment can be found in the STS Student Handbook. Also you should carefully read the guidance on each assignment.

Aims & objectives

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By the end of this course you should:

- Be able to analyse the social and political dimensions of debates in the life sciences
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Important: Course expectations and online learning

This is a provisional plan that might change depending on enrolment numbers and COVID-19. Each week there will be:

1. One seminar (either online or face-to-face depending on COVID-19 situation) each week (see UCL timetable for times and Moodle). You will be allocated to a seminar group. The seminars are **not** optional.
3. The Monday seminar will have preparatory work (see Moodle) – so regard each week's work as starting Tuesday (for the preparatory work) and culminating in the lecture and

seminar the *following* Monday.

There will be a reading week, with no lectures or seminars, see course schedule.

A poor seminar attendance record, usually more than 3 undocumented absences, may result in an 'incomplete' mark which is equivalent to a fail.

If any student is concerned about discussing any of the political issues covered in this module online then please notify Brian asap. One option is to give you 'observer' status for those sessions where you can still attend if you want, but will not be expected to actively participate.

Please note that electronic recording of lectures is not permitted without permission from the course tutor.

Reading for this course: The notes that you take in lectures will not be detailed enough to understand a topic or to write an assignment on that topic. It is therefore essential that you make use of the reading list. You are *not* expected to read all of the material. You will be expected to read at least one piece each week in preparation for seminars and you will certainly need to read widely for your essays and may include material from beyond the reading list. However, read critically: you don't have to read everything, you can agree or disagree with everything you read – but you should be able to say why you hold your views and where possible use other things you have read to support your reasons.

Where to find the reading material: There is no one text which covers this course. Most of the reading material is available online – much of it through online electronic on-line electronic journals accessible through the UCL library web-site.

A small number of key or more difficult to find readings marked have been digitized by the Library and can be obtained by clicking on the link to the Online Reading List on the Moodle page (right hand side).

You are also encouraged to use the internet for research. However, make sure you reference the full web address, the site title and date visited. Be critical of what you read and be careful of purely descriptive sites such as Wikipedia – I will be looking for evidence of some hard thinking and argument in your essays, not simple regurgitation of basic information. Also note that plagiarism, particularly involving internet sources, will be treated as a severe exam irregularity.

Accessibility: I am working towards making the module as accessible as reasonably possible. I have tried to provide transcripts of all my videos, I can provide Powerpoint slides with alternative titles for images and can provide files such as .pdfs in other formats. Please contact me if you have any accessibility requests.

Important policy information

Details of college and departmental policies relating to modules and assessments can be found in the STS Student Handbook www.ucl.ac.uk/sts/handbook

All students taking modules in the STS department are expected to be familiar with these policies.

Topic 1: Science and Social Change

In order to engage seriously with debates concerning science, technology and society it is important to think beyond oversimplified models of the science-society relationship. This session will introduce you to some of the critical thinking that has taken place on this subject.

Essential Reading:

Stilgoe, J et al (2006), *The Received Wisdom: Opening Up Expert Advice* (London: Demos).
Chapter 1 'Speaking truth to power'... but if you are enjoying it keep reading... Demos is a think-tank, so think rather than take copious notes... which bits do you agree/disagree with?
[Available at <https://www.demos.co.uk/files/receivedwisdom.pdf>]

Optional COVID-19 Connection:

Geddes, M et al (2020), 'Seven Questions for Studying Science, Knowledge and Policy in a Covid-19 World' <https://blogs.sps.ed.ac.uk/skape/2020/05/26/seven-questions-for-studying-science-knowledge-and-policy-in-a-covid-19-world/>

Additional Readings:

Guthman, Julie, and Sandy Brown. "Whose Life Counts: Biopolitics And The "Bright Line" Of Chloropicrin Mitigation In California's Strawberry Industry." *Science, Technology, & Human Values* 41.3 (2015): 461-482

Topic 2: Research Policy and the Life Sciences

This topic explores how the landscape of academic research has changed over the past thirty years or so. Given that we cannot spend an infinite amount of money on biomedical research, we have to decide what to fund and what not to fund. 'We' in this context used to mean only scientists – after all, they do the science – but has increasingly included Government, industry and 'consumers'.

Essential Reading:

Parry, B and Greenhough, B (2018), *Bioinformation* (Cambridge: Polity) [e-book, UCL Library]
Chapter 1 and 3

Optional Covid-19 Connection

Zhou, Yanqiu Rachel (2021) Vaccine nationalism: contested relationships between COVID-19 and globalization, *Globalizations*
<https://www.tandfonline.com/doi/full/10.1080/14747731.2021.1963202>

Additional Reading:

Theories:

Hessels, LK and van Lente, H (2008), 'Re-thinking new knowledge production: A literature review and a research agenda', *Research Policy* 37(4):740-760
[Summarises some of the key criticisms of the Mode 1/2 thesis]

Lakoff, A (2010), 'Two Regimes of Global Health', *Humanity Journal* 1(1) on-line at
<http://humanityjournal.org/issue-1/two-regimes-of-global-health/>

[Thoughtful discussion of a case study about avian flu research and how global issues shape what research gets done]

Industry-Academia:

Josephine Johnston, "Conflict of Interest in Biomedical Research," in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley (Garrison, NY: The Hastings Center, 2008), 31-34.
<http://www.thehastingscenter.org/briefingbook/conflict-of-interest-in-biomedical-research/>

Parry, B and Greenhough, B (2018), *Bioinformation* (Cambridge: Polity) [e-book, UCL Library]
Chapter 2 [e-book, UCL Library]

Lock, M (2001), 'The Alienation of Body Tissues and the Biopolitics of Immortalised Cell Lines' in Scheper-Hughes, *Body & Society* Vol.7 No.2-3 pp. 111-120.

Fabbri, A *et al* (2018), "The Influence of Industry Sponsorship on the Research Agenda: A Scoping Review", *American Journal of Public Health* November 2018, Vol 108, No. 11 pp.e.9-16.

Vedel, Jane Bjørn, and Alan Irwin. "'This Is What We Got, What Would You Like?': Aligning And Unaligning Academic-Industry Relations." *Social Studies of Science* 47.3 (2017): 417-438.
(Argues against a firm division between academia and industry)

Rosenbaum, L (2015), 'Reconnecting the Dots — Reinterpreting Industry–Physician Relations' *N Engl J Med* 372:1860-1864 (<http://www.nejm.org/doi/10.1056/NEJMms1502493>)

AND

Steinbrook, R, Kassirer, J Angell, M (2015), 'Justifying conflicts of interest in medical journals: a very bad idea', *BMJ* 2015;350:h2942
(<http://www.bmj.com/content/350/bmj.h2942.full.pdf+html>)

Sarah Wadmann (2014) 'Physician–industry collaboration: Conflicts of interest and the imputation of motive', *Social Studies of Science* August 2014 44: 531-554 (argues that 'conflicts of interest' is unhelpful in analyzing industry-academia relations)

Sismondo, S. (2008). 'How pharmaceutical industry funding affects trial outcomes: Causal structures and responses'. *Social Science & Medicine*, 66(9), 1909-1914.

Nelkin, D and Andrews, L (1998), 'Homo economicus: commercialisation of body tissue in the age of biotechnology', *Hastings Center Report* Vol.28 pp.30-39.
[Digital reading list][More on the John Moores case]

Topic 3. Genetic Testing and Screening

The Human Genome Project was a global attempt to locate all of the genes in the human genetic complement. Commentators are now talking about a postgenomic age, particularly as we head towards ideas such as 'personalised medicine' and whole genome testing. The social and ethical implications for health care, insurance and employment have been widely discussed with benefits for health but also possible discrimination in a 'genetic supermarket'.

Essential Reading:

Nancy Press, "Genetic Testing and Screening," in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley (Garrison, NY: The Hastings Center, 2008), 73-78.

<http://www.thehastingscenter.org/briefingbook/genetic-testing-and-screening/>

AND

Horton, R *et al* (2019), 'Direct to Consumer Genetic Testing', *British Medical Journal*, (BMJ), 367 (Oct). <https://www.bmj.com/content/367/bmj.l5688>

Optional COVID-19 Connection:

(Not genetic testing but raises similar issues)

Jecker NS (2021), Vaccine passports and health disparities: a perilous journey, *Journal of Medical Ethics* Published Online First: 09 July 2021

Additional Reading

Parry, B and Greenhough, B (2018), *Bioinformation* (Cambridge: Polity) [e-book, UCL Library] Chapter 4.

Phillips, K *et al* (2018) 'Genetic Test Availability And Spending: Where Are We Now? Where Are We Going?', *Health Affairs*, May; 37(5): 710-16.

Hogarth, Stuart, and Paula Saukko (2017), 'A Market In The Making: The Past, Present And Future Of Direct-To-Consumer Genomics.' *New Genetics and Society* 36.3 (2017): 197-208.
(Good review of the literature on direct to consumer genetic tests, also links this to the topic)

of bioinformation. Use the bibliography and other articles in this special edition to follow up aspects that interest you)

Sharon, T (2015), 'Healthy Citizenship beyond autonomy and discipline: tactical engagements with genetic testing, *BioSocieties* 10(3):295-316

(argues that when people reject genetic tests or results it is more than simply a case of willful ignorance)

Nelson, Alondra (2018), "The social life of DNA: racial reconciliation and institutional morality after the genome", *British Journal of Sociology*, 69:3 pp.523-537.

Thomas H. Murray (2019) "Is Genetic Exceptionalism Past Its Sell-By Date? On Genomic Diaries, Context, and Content", *The American Journal of Bioethics*, 19:1, 13-15.

Webborn, N *et al* (2015), "Direct-to-consumer genetic testing for predicting sports performance and talent identification: Consensus statement", *British Journal of Sports Medicine* Vol. 49 pp. 1481-1482

Kalokairinou, L *et al* (2018), "Legislation of direct-to-consumer genetic testing in Europe: a fragmented regulatory landscape", *J Community Genet.* Volume 9, [Issue 2](#), pp 117–132.

Swallow, J (2020) 'Markers of biology and "being": imaginaries of deterioration and the biological redefinition of Alzheimer's disease', *New Genetics and Society*, 39:1, 13-30

Saukko, P. *et al* (2006) 'Are genetic tests exceptional? Lessons from a qualitative study on thrombophilia'. *Social Science and Medicine* 63 (7): 1947-1959.

Mendes, Á., Paneque, M., Clarke, A. *et al.* (2019) 'Choosing not to know: accounts of non-engagement with pre-symptomatic testing for Machado-Joseph disease'. *Eur J Hum Genet* **27**, 353–359.

Topic 4 DNA Profiling (Fingerprinting)

DNA fingerprinting can be regarded as a powerful tool for forensic science. Alternatively, with the possibility of a national DNA fingerprint database, the technology could be regarded as an infringement of civil liberties. This session will cover the debate over the virtues and dangers of the technique.

Essential Reading:

Archard, D (2019), *Forensic Futures*, Nuffield Council on Bioethics, Forensic Uses of Bioinformatics Blog: <https://www.nuffieldbioethics.org/blog/forensic-futures>

Nuffield Council on Bioethics (2007), *The Forensic Use of Bioinformation: Ethical Issues* (Comprehensive so read selectively, especially look at Ch 3 which deals briefly with the ‘if you’ve nothing to hide, you’ve nothing to fear’ arguments or the Executive Summary for a quick overview of the issues) <https://www.nuffieldbioethics.org/publications/forensic-use-of-bioinformation>

Optional COVID-19 Connection:

Fahey, R and Hino, A (2020), ‘COVID-19, digital privacy, and the social limits on data-focused public health responses’, *International Journal of Information Management* in press: <https://bit.ly/2EHTYSG>

Additional Reading:

Simon A. Cole, Michael Lynch (2006) ‘The Social and Legal Construction of Suspects’ *Annual Review of Law and Social Science*, Vol. 2: 39-60 (Thought-provoking discussion of DNA databases)

Jasanoff, S. (2006). Just evidence: the limits of science in the legal process. *The Journal of Law, Medicine & Ethics*, 34(2): 328–341.

Amelung, N and Machado, H (2019), “Affected for good or for evil: The formation of issue-publics that relate to the UK National DNA Database”, *Public Understanding of Science*, Volume: 28 issue: 5, pp: 590-605

Kruse, C (2012), ‘Legal storytelling in pre-trial investigations: arguing for a wider perspective on forensic evidence’, *New Genetics and Society* 31(3): 299-309

Skinner, D and Wienroth, M (2019), ‘Was this an ending? The destruction of samples and deletion of records from the UK Police National DNA Database’, *BJHS Themes* pp.99 - 121 <https://www.cambridge.org/core/journals/bjhs-themes/article/was-this-an-ending-the-destruction-of-samples-and-deletion-of-records-from-the-uk-police-national-dna-database/B9454A08928AAE907FB0C8FF7103CFA3>

Norris, Robert J.(2016), "Framing DNA: Social Movement Theory and the Foundations of the Innocence Movement." *Journal of Contemporary Criminal Justice* 33.1: 26-42.

Karen J. Maschke, “DNA and Law Enforcement,” in *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, ed. Mary Crowley (Garrison, NY: The Hastings Center, 2008), 45-50. <http://www.thehastingscenter.org/briefingbook/dna-and-law-enforcement/>

Dahl, J. Y. and Sætnan, A. (2009). 'It all happened so slowly'—on controlling function creep in forensic DNA databases'. *International Journal of Law, Crime and Justice*, 3(37): 83–103

Wallace, H (2006), 'The UK National Database: Balancing Crime Detection, Human Rights and Privacy', *EMBO Reports*, Vol 7 (Special Issue) pp26-30

Lynch, M and McNally, R (2003), ' "Science", "common sense", and DNA evidence: a legal controversy about the public understanding of science', *Public Understanding of Science*, 12(1): 83-104. (Detailed case study that challenges the distinction between 'common sense' and 'scientific' evidence)

Topic 5. Release of GMOs into the Environment

Biotechnology presents modern societies with immense opportunities - but also immense challenges. A key problem is whether or not the deliberate release of genetically modified organisms (GMOs) into the environment is safe – both for human health and the environment. In an area of contested claims and where the evidence is not clear-cut, this topic raises more fundamental issues about the role of science and expertise in the regulation of technology.

Essential Reading

Kuzma, Jennifer (2018), 'Regulating Gene Edited Crops', *Issues in Science and Technology*, Vol. 35, Iss. 1, (Fall 2018): 80-85.

Optional COVID-19 Connection

(Acceptance and Resistance to New Technologies)

Harrison, E. A., & Wu, J. W. (2020). Vaccine confidence in the time of COVID-19. *European Journal of Epidemiology*, 35(4), 325–330.

Additional Reading:

Two sharply contrasting views of the GM Debate read **both**:

1. Leyser, O (2018), "GM crop ruling shows why the EU's laws are wholly inadequate", *The Conversation*

<https://theconversation.com/gm-crop-ruling-shows-why-the-eus-laws-are-wholly-inadequate-100675>

2. Stirling, A (2018), "Is The New European Ruling On GM Techniques 'Anti-Science'?", STEPS Centre (Aug. 6, 2018).

<https://steps-centre.org/blog/european-court-of-justice-ecj-gene-editing-anti-science/>

Compare:

Juma, C (2015), *The New Harvest: Agricultural Innovation in Africa* (Oxford: OUP) Chapter 3 (Leapfrogging in Genetic Technologies) (UCL Library e-book)

With:

Matthew A. Schnurr, Brian Dowd-Urbe (2021), 'Anticipating farmer outcomes of three genetically modified staple crops in sub-Saharan Africa: Insights from farming systems research', *Journal of Rural Studies* (in press) (UCL e-journals)

Bonneuil, C *et al* (2008), 'Disentrenching Experiment: The Construction of GM Crop Field Trials as a Social Problem', *Science, Technology & Human Values* 33:201-229 (Uses quite a bit of STS theory, non-STs students persist though, shows how the debate was not just about one thing, but was 'framed' differently over time)

Turnbull, C *et al* (2021), 'Global Regulation of Genetically Modified Crops Amid the Gene Edited Crop Boom – A Review', *Front. Plant Sci.*, 24 February 2021

| <https://doi.org/10.3389/fpls.2021.630396>

Jasanoff, S (1995), "Product, Process, or Programme: Three Cultures and the Regulation of Biotechnology", in M. Bauer (ed) *Resistance to New Technology: Nuclear Power, Information Technology and Biotechnology* (Cambridge: Cambridge University Press) pp311-331 (An older article but shows how different regulatory frameworks can treat the same technology differently, particularly depending on how they think about the role of science in informing the debate). [Digital reading list - Moodle]

Beumer, K., Swart, J.A.A. (2021), 'Who is the African Farmer? The Importance of Actor Representations in the Debate About Biotechnology Crops in Africa'. *J Agric Environ Ethics* 34, 1 (2021) [Online, open access]

Hicks, (2017), "Genetically Modified Crops, Inclusion and Democracy", *Perspectives on Science* Vol 25(4): 488-520.

Mayer, S and Stirling, A (2004), 'GM crops, for good or bad? Those who choose the questions, determine the answers', *European Molecular Biology Organisation Reports*, 5 (11): 1021-24 (On-line under *EMBO Reports*).

Hunter, P (2014), 'Genetically Modified Lite' Placates Public But Not Activists', *EMBO Reports*, Vol15 No.2 138- (think about how this proposal to defuse the debate is 'framing' the issue)

Leguizamón, A (2014), 'Modifying Argentina: GM soy and socio-environmental change', *Geoforum* Vol 53: 149-160 [Links to biodiversity topic]

Helliwell, R *et al* (2019). 'NGO perspectives on the social and ethical dimensions of plant genome-editing'. *Agriculture and Human Values* 36, 779–791.

Bonneuil, C, Foyer, J and Wynne, B (2014), 'Genetic Fallout in biocultural landscapes: Molecular imperialism and the cultural politics of (not) seeing transgenes in Mexico, *Social Studies of Science* 44(6): 901-29 (more on how the debate is 'framed')

Topic 6: BSE, CJD and Science Advice

The BSE saga that took place in the UK from 1986 onwards is one of the most dramatic public health crises of the 20th century. Over three million cattle were slaughtered and the overall cost of the crisis exceeded four billion pounds. For years, the Government and its scientific advisers kept repeating that "British Beef is safe". Yet, in March 1996 they announced that BSE had spread to humans. How can we explain this spectacular shift.

Essential Reading

Two very different views of the BSE affair, read both:

Millstone, E and van Zwanenberg, P (2003) 'BSE: A Paradigm of Policy Failure' in *The Political Quarterly* Vol.74 No1. pp27-37

Forbes, I (2004), 'Making a Crisis out of a Drama: The Political Analysis of BSE Policy-Making in the UK', *Political Studies* 52: 342-357

Optional COVID-19 Connection

(Read both)

Ramakrishnan, V (2020), 'Following the Science', *The Royal Society Blog*
<https://royalsociety.org/blog/2020/05/following-the-science/>

Tim Rhodes & Kari Lancaster (2020) Mathematical models as public troubles in COVID-19 infection control: following the numbers, *Health Sociology Review*, 29:2, 177-194

Additional Reading

Key reading for essay

Millstone, E and van Zwanenberg, P (2001), 'Politics of Expert Advice: Lessons from the Early History of the BSE Saga', *Science and Public Policy*, Vol 28 (April) No.2 (More detailed empirical analysis which shows how 'scientific' decisions were framed by wider social, economic and political considerations)

BBC News (2019), 'Cases of vCJD still to emerge after mad cow disease scandal'
<https://www.bbc.co.uk/news/uk-scotland-48947232>

Zafar, S *et al* (2018), "Animal TSEs and public health: What remains of past lessons?", *PLoS Pathog* 14(2): e1006759.
<https://journals.plos.org/plospathogens/article?id=10.1371/journal.ppat.1006759>

Opinion Piece (2015), 'When the Cows Went Mad', *New Scientist*, Feb 28 2015.

Ferrari, M (2017), 'A Comparative Study of Communication about Food Safety Before, During and After the "Mad Cow" Crisis', in Kathleen Hall Jamieson *et al* (eds), *The Oxford Handbook of the Science of Science Communication*, Oxford: Oxford University Press (E-book UCL Library)

Stilgoe, J *et al* (2006), *The Received Wisdom: Opening Up Expert Advice* (London: Demos). Chapter 2 'The new shape of expert advice'.
[Available at <http://www.demos.co.uk/publications/receivedwisdom>]

Beck, M *et al* (2005), 'Public Administration, Science, and Risk Assessment: A Case Study of the U.K. Bovine Spongiform Encephalopathy Crisis' *Public Administration Review* Volume 65 Issue 4, Pages 396 – 408. [Besides analysis, this has a useful chronology and overview of key committees]

Millstone, E and van Zwanenberg, P (2005), *BSE: Risk, Science and Governance* (Oxford: OUP) (E-book UCL Library).

Frewer, L and Salter, B (2002), 'Public attitudes, scientific advice and the politics of regulatory policy: the case of BSE', *Science and Public Policy*, 29(2), p137- 45.

Jasanoff, S (1997), 'Civilization and Madness: The Great BSE Scare of 1996', *Public Understanding of Science* Vo.6 pp.221-232

Miller, D (1999) 'Risk, science and policy: definitional struggles, information management, the media and BSE', *Social Science and Medicine* 49(9), pp.1239-1255

Winter, M (1996), 'Intersecting Departmental Responsibilities, Administrative Confusion and the role of science in Government: The Case of BSE', *Parliamentary Affairs* Vol.49 No.4 pp.550-565.

Topic 7. Biodiversity, Bioprospecting and Biopiracy

This topic introduces the political and ethical implications of conceptualising biodiversity as a valuable resource to be conserved *and* used. We will think about the effects of regulating international access to biodiversity through the 1993 UN Convention on Biological Diversity (1993) and explore the concepts of *bioprospecting* and *biopiracy* to discuss what value means in this context (and to whom), what ideas of ownership of nature and knowledge are at play, and how the uneven global distribution of biodiversity, knowledge and technology is relevant to these discussions.

Essential Reading:

Hallam, S (2016), *Biotechnology and Society* (Chicago: Chicago University Press). Chapter 22: Bioprospecting and Biocolonialism. [Moodle – course electronic reading list].

Optional COVID-19 Connection:

Rondeau, D., Perry, B. & Grimard, F. 'The Consequences of COVID-19 and Other Disasters for Wildlife and Biodiversity'. *Environ Resource Econ* (2020).
<https://link.springer.com/article/10.1007/s10640-020-00480-7>

Additional Reading

Garrison, N.A. (2012). "Genomic Justice for Native Americans: Impact of the Havasupai Case on Genetic Research". *Science Technology and Human Values*, 38(2) pp.201-223.

Reardon, J and Tallbear, (2012), " 'Your DNA Is Our History': Genomics, Anthropology, and the Construction of Whiteness as Property ", *Current Anthropology*, Vol. 53, No. S5 pp. pp. S233-S245

Kowal, E (2013), 'Orphan DNA: Indigenous Samples, Ethical Biovalue and Postcolonial Science', *Social Studies of Science* 43(4): 577-597.

McAfee, K (1999) Selling Nature to Save It? Biodiversity and Green Developmentalism. *Environment and Planning D: Society and Space* 17: 133-154.

(Critical paper from a geographical perspective that argues that the Convention for Biological Diversity is a consequence of a 'green developmentalism' paradigm that constructs genetic diversity as valuable raw material that can be traded internationally).

Berlin, B and Berlin, AE (2004) Community Autonomy and the Maya ICBG Project in Chiapas, Mexico: How a Bioprospecting Project that Should Have Succeeded Failed. *Human Organisation*, 63(4): 472-486.

AND

RAFI (1999) Biopiracy Project in Chiapas, Mexico Denounced by Mayan Indigenous Groups. News Release. 01.12.99. Available online at

http://www.etcgroup.org/sites/www.etcgroup.org/files/publication/348/01/news_biopiracy_chiapas.pdf

Brush SB (1999) 'Bioprospecting the Public Domain'. *Cultural Anthropologist*, 14(4): 535-555.
(Anthropological perspective on the 'fit' between the kind of relationships and knowledge engendered by bioprospecting and those of Peruvian farmers who conserve potato diversity in their fields).

Delgado, GC (2002), 'Biopi[®]acy and Intellectual Property as the Basis for Biotechnological Development: the Case of Mexico'. *International Journal of Politics, Culture, and Society* 16(2): 297-318.

Merson, J (2000) 'Bio-Prospecting or Bio-Piracy: Intellectual Property Rights and Biodiversity in a Colonial and Postcolonial Context'. *Osiris* 15: 282-296.

Hayden, C (2003) *When Nature Goes Public: the Making and Unmaking of Bioprospecting in Mexico*. (Princeton: Princeton University Press).

(Chapter 3 is particularly relevant for her analysis of the demise of the ICBG Maya project. Pp 85-89, 100-1050.

Macilwain, C (1998), 'When Rhetoric Hits Reality in Debate About Bioprospecting'. *Nature*, 392(6676): 535-540.

Hayden, C (2007) 'Taking as Giving: Bioscience, Exchange, and the Politics of Benefit-sharing'. *Social Studies of Science*, 37(5): 729-758.

(Considers biomedical and clinical research as well as bioprospecting to comment on the asymmetries caused by the commercialisation of the results of research and attempts to solve it by instituting benefit sharing).

Banerjee, M. (2019) "Biopiracy in India: Seed Diversity and the Scramble for Knowledge." *Phytomedicine (Stuttgart)*: 296-301.

Topic 8. Biological Weapons Control

In 1991 it was *estimated* that a 20kt nuclear warhead could kill 40,000 people and injure another 40,000; a chemical warhead of 300kg Sarin (nerve gas) could under the same conditions kill 200-3,000 people; a 30kg anthrax bomb would probably kill between 20,000 - 80,000 people. Biological weapons are relatively easy and cheap to make and it is believed that several countries currently have undeclared biological weapons programmes. This session looks at the nature of biological warfare and possible methods for controlling biological weapons.

Essential Reading:

Use the internet to look up the difference between chemical and biological weapons.

Links to both readings are on the Moodle site:

Lentzos, F. (2013). *Hard to Prove: Compliance with the Biological Weapons Convention*. (King's College London). <http://www.filippalentzos.com/wp-content/uploads/2014/10/Hard-to-Prove-Compliance-with-the-Biological-Weapons-Convention.pdf>

Also read the text of the 1972 Biological Weapons Convention (it is a short treaty):
<https://www.un.org/disarmament/wmd/bio/>

Optional COVID-19 Connection:

Goodman, M and Lentzos, F (2020), 'Battles of Influence: Deliberate Disinformation and Global Health Security', *Centre for International Governance and Innovation*:
<https://www.cigionline.org/articles/battles-influence-deliberate-disinformation-and-global-health-security>

Additional Reading:

Glenn Cross & Lynn Klotz (2020) Twenty-first century perspectives on the Biological Weapon Convention: Continued relevance or toothless paper tiger, *Bulletin of the Atomic Scientists*, 76:4,185-191.

Lentzos, F (ed) (2016), *Biological Threats in the 21st Century: The Politics, People, Science and Historical Roots* (London: World Scientific) (E-book UCL Library) [Read selectively from Section 2 on Bioweapons in Today's Context, depending on the emphasis of your essay.]

Moodie, Amanda (2015), 'In Good Health? The Biological Weapons Convention and the "Medicalization" of Security', *The Nonproliferation Review*, Vol. 22, No.1, pp.71-82.

Kemp L, Aldridge DC, Booy O, Bower H, Browne D, Burgmann M, *et al.* (2021), '80 questions for UK biological security'. *PLoS ONE* 16(1) (online – UCL e-journals or open access)

Edwards, Brett (2017), 'We've got to talk: The militarization of biotechnology'. *Bulletin of the Atomic Scientists*, August 4, 2017. <https://thebulletin.org/2017/08/weve-got-to-talk-the-militarization-of-biotechnology/>

Lentzos, F (2014), 'The risk of bioweapons use: Considering the evidence base' *BioSocieties* 9, 84–93. [Roundtable discussion with experts about the risk of from BW].

Vogel, K (2008). "Framing Biosecurity: An Alternative To The Biotech Revolution Model?" *Science and Public Policy* 35(1): 45-54.

Balmer, B (2015), 'The Social Dimension of Technology: The Control of Chemical and Biological Weapons' in Gonzalez, W.J. (ed) *New Perspectives on Technology, Values and Ethics: Theoretical and Practical Discussions*. (Dordrecht: Springer) pp.167-182. [Moodle E-reading list]

Carus, S (2017) A century of biological-weapons programs (1915–2015): reviewing the evidence, *The Nonproliferation Review*, 24:1-2, 129-153

Buchanan, A and Kelley, M (2013), 'Biodefence and the Production of Knowledge: Rethinking the Problem', *Journal of Medical Ethics* 39: 195-204.

James Revill and Catherine Jefferson (2014), 'Tacit knowledge and the biological weapons regime', *Science and Public Policy* 41 (5): 597-610

Chemical and Biological Non-Proliferation Regime after Covid-19 Webinar (2020)
Speakers: Lijun Shang, Tatyana Novosiolova, Michael Crowley, Brett Edwards, Simon Whitby and Malcolm Dando (1.5 hours video) (<https://www.londonmet.ac.uk/research/research-initiatives/policy-engagement/biological-and-chemical-security-project/>)

Topic 9 Human Experimentation

This topic covers human experimentation from a sociological and policy perspective. Although we will touch on the ethics of human experimentation, we will be more concerned with what motivates people to take part in biomedical research, what (if any) contribution they can make if they are given a 'voice' rather than being treated as passive research material, and how we theorise the researcher-subject relationship.

Essential Reading:

EITHER

Steven Epstein (1995) 'The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials' *Science, Technology & Human Values*, Vol. 20, No. 4, 408-437

OR

Goodare, H., & Lockwood, S. (1999). 'Involving patients in clinical research'. *British Medical Journal* 319 724-725.

OR

Williamson, C. (2001). 'What does involving consumers in research mean?' *Quarterly Journal of Medicine* 94(12), 661-664. [for a consumer perspective]

Optional Covid-19 Connection:

Richards AD (2020), 'Ethical guidelines for deliberately infecting volunteers with COVID-19' *Journal of Medical Ethics* 46:502-504. <https://jme.bmj.com/content/46/8/502.abstract>

Additional Reading

Franklin, S (2019), 'Ethical Research: The long and bumpy road from shirked to shared', *Nature* 574, 627-630 <https://www.nature.com/articles/d41586-019-03270-4>

Fisher, J A (2007) 'Governing human subjects research in the USA: individualized ethics and structural inequalities', *Science and Public Policy*, 3 (2) pp 117-126.

Lanzarotta, T (2020), 'Ethics in retrospect: Biomedical research, colonial violence, and Iñupiat sovereignty in the Alaskan Arctic', *Social Studies of Science*, Volume: 50 issue: 5, page(s): 778-801.

Riggare, S (2020). Patient researchers — the missing link? *Nature Medicine* 26: 1507.

Johnson, CY (2020), 'A trial for coronavirus vaccine researchers: Making sure black and Hispanic communities are included in studies' *Washington Post* 20 July.
<https://www.washingtonpost.com/health/2020/07/26/trial-coronavirus-vaccine-researchers-making-sure-black-hispanic-communities-are-included-studies/>

Anne-Floor M Schölvinck *et al* (2020), Patient involvement in agenda-setting processes in health research policy: A boundary work perspective, *Science and Public Policy*, Volume 47, Issue 2, Pages 246–255.

Milken Institute (2019), *Advancing Models of Patient Engagement: Patient Organizations as Research and Data Partners* <https://bit.ly/34HvF2n>

Active patients, research subjects and the geography of human experimentation

Cooper, M (2012), 'The Pharmacology of Distributed Experiment – User-generated Drug Innovation', *Body & Society* Volume: 18 issue: 3-4, page(s): 18-43.

Weinstein, M. (2001). 'A public culture for guinea pigs: US human research subjects after the Tuskegee study'. *Science as Culture* 10(2), 195-223. [fascinating insight into 'professional guinea pigs']

Epstein, S (2008), 'Patient Groups and Health Movements' in Hackett, EJ *et al* (eds) *The Handbook of Science and Technology Studies*, Third Edition (Cambridge: MIT Press).(UCL Library E-book)

Lindén L (2020). 'Moving Evidence: Patients' Groups, Biomedical Research, and Affects'. *Science, Technology, & Human Values*. August 2020.

On globalisation and biomedical research in developing countries:

Merz S. Global Trials (2020), 'Local Bodies: Negotiating Difference and Sameness in Indian For-profit Clinical Trials'. *Science, Technology, & Human Values*. October 2020.

Rajan, K.S. (2005). Subjects of Speculation: Emergent Life Sciences and Market Logics in the United States and India. *American Anthropologist*, 107(1), 19-30.

Rajan, K S (2002), 'Banking (on) biologicals: commodifying the global circulations of human genetic material' Available at <http://www.sarai.net/publications/readers/02-the-cities-of-everyday-life/02biologicals.pdf> [Analysis of the John Moores case]

Memon, R., Asif, M., Khoso, A.B. *et al.* (2021), 'Recognising values and engaging communities across cultures: towards developing a cultural protocol for researchers'. *BMC Medical Ethics* 22, 47 (2021) [online, open access] <https://bmcmethics.biomedcentral.com/articles/10.1186/s12910-021-00608-4>

Cooper, M (2008), 'Experimental Labour—offshoring Clinical Trials to China'. *East Asian Science, Technology and Society* 1 March 2008; 2 (1): 73–92.

Volunteers' understandings

Corrigan, O. (2003). 'Empty ethics: the problem with informed consent'. *Sociology of Health and Illness* 25(3), 768-792.

Featherstone, K., & Donovan, J. (2002). "Why don't they just tell me straight, why allocate it?" The struggle to make sense of participating in a randomised controlled trial'. *Social Science and Medicine* 55 709-719.

Morris, N. and Balmer, B. (2006). Volunteer human subjects' understandings of their participation in a biomedical research experiment. *Social Science & Medicine*, 62(4), 998-1008.

Nupur Jain, Marci D. Cottingham & Jill A. Fisher (2018) 'Disadvantaged, outnumbered, and discouraged: women's experiences as healthy volunteers in U.S. Phase I trials', *Critical Public Health* (Published online: 10 Oct 2018)

Corrigan, O and Tutton, R (2006). 'What's in a name? Subjects, volunteers, participants and activists in clinical research'. *Clinical Ethics*, 1, 101-104.

Topic 10. Animal Experimentation

Most of the literature on animal experimentation focuses on ethics – is it right or wrong. While not wholly ignoring this debate, a more policy-orientated social science literature tries to understand the social dynamics of the debate. From this perspective analysis tries to understand how the debate gets fought; what sort of rhetoric, strategies or tactics are employed on both sides; why people become involved in the issue etc.

The Wellcome Information Service (see front of reading list) has a large collection of material on issues in animal experimentation and you are encouraged to explore their resources.

The social dynamics of the debate:

These are not arguments for or against, but analyses of the history of the issue and of the types and styles of arguments used:

Essential Reading

Sanders, S and Jasper, JM (1994), 'Civil Politics in the Animal Rights Conflict: God Terms versus Casuistry in Cambridge, Massachusetts', *Science, Technology and Human Values* Vol.19 No.2 pp169-188

Optional COVID-19 Connection:

Wellcome Animal Research Nexus, *AnNex Newsletter* (2020), COVID-19 Special Edition, Issue 4
<https://bit.ly/3jtNmql>

Several short articles – read 2-3 that interest you.

Additional Reading:

Nelkin D and Jasper JM (1992), 'The Animal Rights Controversy', in Nelkin D (1992), *Controversy: The Politics of Technical Decisions* (3rd Edition) (Newbury Park: Sage) pp26-44.
[Moodle - Digital Reading List]

Greenhough, Beth, and Emma Roe (2018), "Exploring The Role Of Animal Technologists In Implementing The 3Rs." *Science, Technology, & Human Values*, July 43(4): 694–722.

McLeod, Carmen, and Sarah Hartley (2018). "Responsibility And Laboratory Animal Research Governance." *Science, Technology, & Human Values*, July 43(4):723-741

Davies, G (2021), 'Locating the 'culture wars' in laboratory animal research: national constitutions and global competition', *Studies in History and Philosophy of Science Part A*, Volume 89, Pages 177-187,

D. Lyons, 'Protecting Animals versus the Pursuit of Knowledge: The Evolution of the British Animal Research Policy Process', *Society & Animals* 19 (2011) 356-367

Hobson-West, P. "Ethical Boundary-Work In The Animal Research Laboratory". *Sociology* 46.4 (2012): 649-663.

Hobson-West, P. (2010) The role of 'public opinion' in the UK animal research debate. *Journal of Medical Ethics* 36(1): 46–49.

Michael M and Birke L (1994), 'Accounting for Animal Experiments: Identity and Disreputable "Others"', *Science, Technology and Human Values* Vol.19 No.2 pp189-204

Frickel, S et al (2010), 'Undone Science: Charting Social Movement and Civil Society Challenges to Research Agenda Setting', *Science, Technology and Human Values* 35(4):444-473. [See CASE STUDY No.4.]

Holmberg, T and Ideland, M (2012), 'Secrets and lies: "selective openness" in the apparatus of animal experimentation', *Public Understanding of Science* vol. 21 no. 3: 354-368

Munro, L (2005), 'Strategies, Action Repertoires and DIY Activism in the Animal Rights Movement', *Social Movement Studies* Vol 4 (1): 75 – 94. (Argues, based on empirical study, that the majority of animal activists employ non-violent means).

ESSAY TOPICS FOR POLICY ISSUES
IN THE LIFE SCIENCES
Autumn 2020-21

Assignment 1: Review
READ THIS CAREFULLY

If you have not already taken the UCL academic integrity online course (20 mins approx.) then take the time to complete it: <https://moodle.ucl.ac.uk/enrol/index.php?id=17435>

Note: This assignment asks you make links between a topic from the module and policy issues arising from the COVID-19 pandemic. The pandemic has affected us all in different ways and if you have been directly affected in such a way that you would prefer not to do an assignment involving COVID-19 then let Brian know and he will provide an alternative.

Each main topic on the reading list has one or two readings labelled 'Covid-19 Connection'. This assignment should be a brief (1000 word +/-10%, exclude references) review of **one** week's COVID-19 Connection item(s) from the reading list. It should be taken from a topic on the course for which you do not write an essay (assignment 2).

Your review should draw links between the issues raised by the COVID-19 Connection and the main topic. *What insights from the main topic can be applied to the COVID-19 Connection issue?*

Your review should concentrate on the COVID-19 Connection piece(s), but also read 3-4 other pieces from the main topic to place the review in context.

Your review should make links between the COVID-19 Connection piece and the topic covered for that week (eg what lessons can be learnt, what are the similarities and differences in terms of challenges posed etc). The review should not be a 'stand-alone' discussion of the COVID-19 Connection piece without reference to the topic covered that week (or other topics covered on the module).

NB: If you choose a topic we have not yet covered in class, the markers will *NOT* assume you have watched the lecture videos or done any of the other exercises/tasks.

You should use the following as a check list. Not all of the points will be relevant or necessary for every review.

- Clearly set out the title(s) of the piece(s) you are reviewing. You should also give your review its own title which captures the main message you want to get across.
- Note that after the first reference to the COVID-19 Connection article e.g. (Richards 2020) it is okay in this review to simply refer to page numbers (eg. pp20-21) for the main piece you are reviewing.

- Avoid “In this article...” or suchlike as an opening sentence. Introduce the topic before the article/chapter.
- Provide the reader with an outline of the contents of the COVID-19 Connection pieces(s).

However - do not spend too much of your word quota on this descriptive material.

- Your review should also be analytical:

What are the key links that you want to draw out between the COVID-19 Connection articles(s) and the main topic?

What insights (eg theoretical, practical, parallels, potential pitfalls, lessons learnt, assumptions to be challenged etc) from the main topic can be applied to the COVID-19 Connection issue?

What are the strengths and weaknesses of the various argument(s)?

What are the strengths and weaknesses of the authors’ use of evidence?

- **It is better to focus well on discussing one or a few key links (they do not have to be the obvious links) – the aim is *not* to produce a ‘laundry list’ of links without much discussion.**
- ***Note: It is essential that you don’t just provide a judgement but also the reasons for your judgement e.g. don’t just say that ‘the argument is strong’, ‘the section on X is good’ say why it is strong or what is good about it***
- While the clarity or style of the writing is important and can be commented on, this is not the main point of your review which should focus on the substantive content of the piece reviewed.
- Your style of writing for this review should be academic (i.e. this is not a blog post or suchlike).
- You can read and cite material beyond the reading list but this review is meant to be short so prioritise material in the reading list.
- Remember that qualitative studies – and there are plenty on the reading list - don’t aim to be statistically representative – they go for depth rather than breadth.¹ (Think of the difference between a study designed to count the number of weddings taking place in the UK vs a study designed to find out what it feels like to be getting married).
- Finish with an *overall* judgement about the strength/quality/relevance (depending on the content of your review) of the links you have drawn.
- See the www.ucl.ac.uk/sts/handbook for late penalties and over-length penalties.

Further advice on writing is available in: **A. Northedge (2005), *The Good Study Guide***. There are e-versions available from UCL library (Chapters 10-11 are most relevant).

¹ If you want to quickly read a bit more about this see: <https://www.simplypsychology.org/qualitative-quantitative.html>

Assignment 2: Essay
READ THIS CAREFULLY

Assignment 2: Essay

This essay should be 2000 words (+/- 10%) long (excluding the bibliography) and you are expected to read widely around the topic. You do not need to use all your sources to the same extent in order to answer the question set (i.e. don't write a general essay on the subject), but you do need to demonstrate that you have consulted a range of relevant sources by explaining the reasons/evidence for your answer.

You are welcome to read and cite relevant material beyond the reading list – but ensure you have read the essential reading and some of the material from the reading list for your chosen topic. Whether or not you choose your own title (see below), your essay should demonstrate engagement with material covered on the module.

There are no set number of sources that make a good essay and it is not necessary to read everything on the reading list or in the same amount of depth or detail. Keep focused on the question 'is this helping me answer the essay question?' as a rough guide. Also, you should have a sentence in the introduction that either says "This essay will argue that... [answer to the question]" or which articulates your argument clearly using similar wording.

Format

Essays should be spell-checked, 1.5 line spaced, minimum 12 point type with citations to references both in the essay and with a list of these references at the end. You must include **page numbers** and a **word count** (that excludes bibliography). I prefer Harvard referencing style (Google it) but you can use any citation convention as long as you are consistent, consult some of the journals on the reading list for styles.

Please read the guidelines on how to write an essay (Moodle) or consult: **A. Northedge (2005), *The Good Study Guide***. There are e-versions available from UCL library (Chapters 10-11 are most relevant). Students who wish to write an essay connected with the course but not on the list should see me to discuss a title. See the front of your reading list for due dates.

See the www.ucl.ac.uk/sts/handbook for late penalties and over-length penalties.

Essay Questions (by topic):

NB: For all questions you should start your background research with the essential reading on this reading list for your chosen topic.

Topic 2. Industry-Academia Links

EITHER

Is there really a "great divide" between academic research and industry R&D?

[Note the phrase comes from the Vedel and Irwin reference p. 420]

OR

Does it matter who owns your bioinformation?

(See topic 7, note slightly different wording – you can confine this to human or all bioinformation, but be clear which)

Topic 3. Genetic Testing

“The growing market for direct-to-consumer genetic testing may promote awareness of genetic diseases, allow consumers to take a more proactive role in their health care, and offer a means for people to learn about their ancestral origins.”

[\[https://ghr.nlm.nih.gov/primer/testing/directtoconsumer\]](https://ghr.nlm.nih.gov/primer/testing/directtoconsumer)

Critically discuss whether greater regulation of direct-to-consumer genetic testing would stifle these advantages.

Topic 4. DNA Profiling.

“Just as science can free the innocent, it can also identify the guilty” (Romney cited in Jasanoff 2006). To what extent can DNA profiling live up to this expectation?

Topic 5. GM Crops.

Is the ‘GM crop debate’ only about GM crops?

Topic 6. BSE

Was there a BSE ‘crisis’?

Topic 7. Biodiversity

EITHER

Can ‘bioprospecting’ ever be carried out responsibly?

OR

Does it matter who owns bioinformation?

(See topic 2, note slightly different wording – you can confine this to human or all bioinformation, but be clear which)

Topic 8. Biological Weapons Control

EITHER

What, if anything, can be done to prevent the use of biological weapons?

OR

Is the Biological Weapons Convention a ‘toothless’ relic of the Cold War? Can it be strengthened?

Topic 9. Human Experimentation

A typical biomedical research web-site for recruiting volunteers claims that: “Aside from the satisfaction of helping medical science, you’ll be paid for the time you spend here”

[\[https://www.londontrials.com/who-are-we\]](https://www.londontrials.com/who-are-we). Based on academic research about the role of volunteers in biomedical research, what more can be said about what happens

when people volunteer for biomedical experiments?

Topic 10. Animal Experimentation

Have the public debates over animal experiments become irredeemably characterized by “mutual suspicion and name calling that preclude communication or compromise” (Sanders and Jasper, 1994)?

N.B I am happy for you to develop your own question or modify one the suggested questions. **BUT** you must first discuss this with Brian or your seminar tutor.