London Interdisciplinary Social Science Doctoral Training Partnership

Advanced Research Methods in Social Sciences

Course Code & Title	**LISS309 Researching Vulnerable Populations**
Convenor(s)	Dr Ludovico Carrino, https://kclpure.kcl.ac.uk/portal/ludovico.carrino.html

Institution	King's College London	**Department**	LISS DTP, Global Health & Social Medicine
Academic Year	2019 - 20	**Term**	Summer
Number of Sessions	5	**Length of Session(s)**	~5 hours each

Day, Date	Start : End	Room Location
Monday 11 May 2020	1000 : 1610	
Tuesday 12 May 2020	1000 : 1610	
Wednesday 13 May 2020	1000 : 1610	Online – URL given after enrolment
Thursday 14 May 2020	1000 : 1610	
Friday 15 May 2020	1000 : 1610	

Enrolment Link:	https://bit.ly/LISS309 You may be prompted to log into SkillsForge

Course Description:

This module will be problem-focused and examine a series of common debates surrounding researching vulnerable populations in a contemporary and forward-looking context. The module will explore contrasting responses from different interest groups (e.g. patients, healthy participants, researchers and professional bodies) and theoretical standpoints, including the social and behavioural sciences, and public and social policy, where appropriate.

The contexts and questions that are the subject of social science and health research have increased phenomenally, against a background of new legislation (e.g. Mental Capacity Act 2005), research governance (e.g. Ethics Committee approval) and clinical imperatives (e.g. understanding how best to provide health and social care for increasing numbers of older people with dementia). This raises many complex issues for research staff in health and social sciences, particularly when working with people or in situations where vulnerability is a key issue.

This module has been designed to focus on understanding and responding to these complexities. Students will focus on relevant guidelines and policies, the implications that exist for individuals, families, public and private sectors, and how they might ensure the safety and protection of participants and the researcher. Real research situations will be used to convey and debate ethical imperatives throughout the research process.

Course Outline:

Monday 11 May 2020
1. Introduction to 'vulnerable populations' and overview of the course
This session will provide an outline of the course and the assignment, explaining how the sessions interlink, aims of the course, and expectations of students and lecturers. It will also consider in what contexts and situations individuals and populations may be considered to be vulnerable:

2. What is a vulnerable population?

Essential Reading:

Berry, S.R. (2004) For purposes of research, palliative care patients should not be considered a vulnerable population. *Clinical Oncology*, 16, 223-224

Hawryluck, L. (2004) People at the end of life are a vulnerable research population. *Clinical Oncology*, 16, 225-226

Recommended Reading:

Park, S.S., & Grayson, M.H. (2008) Clinical research: protection of the 'vulnerable'? *Journal of Allergy and Clinical Immunology*, 121, 1103-1107

Peternelj-Taylor, C.A. (2004) Conceptualizing nursing research with offenders: another look at vulnerability. *International Journal of Law and Psychiatry*, 28, 348-59

Schüklenk, U. (2000) Protecting the vulnerable: testing times for clinical research ethics. *Social Science & Medicine*, 51, 969-977

Seidenfeld, J., Horstmann, E., Emanuel, E.J., Grady, C. (2008) Participants in Phase 1 Oncology Research Trials: Are They Vulnerable? *Archives of Internal Medicine,* 168 (1), 16-20.

3+4. Epistemology and Critical Approaches to Research: Lecture and workshop

This lecture outlines the challenge to traditional research methods and its assumptions from the Critical approaches. These include questioning the epistemology and nature of research methods used.

Essential Reading:

Gray, D.E. (2009) Chapter 2: Theoretical perspectives and research methodologies. *Doing Research in the Real World.* Sage: London

AND/OR

Bryman, A. (1984) The debate about quantitative and qualitative research: a question of method or epistemology? The British Journal of Sociology, 35(1), 75-92

Recommended Reading:

Bengtson, V.L; Burgess, E.O., Parrott, T.M (1997) Theory, explanation, and a third generation of theoretical development in social gerontology, *Journal of Gerontology: Social Sciences*, 52B, 2, S72-S88

Gibson B.E., & Teachman, G. (2012) Critical approaches in physical therapy research: investigating the symbolic value of walking. Physiotherapy Theory and Practice, 28(6), 474-484

Tuesday 12 May 2020

1. Ethics throughout the research process

This session will consider how ethical issues run throughout the research process, from deciding what topic to research, through gaining research funding, to ownership and dissemination of findings.

Essential Readings

Behrens, T, & Gray, D. (2001). Unintended consequences of cooperative research: Impact of industry sponsorship on climate for academic freedom and other graduate student outcome. *Research Policy*, 30, 179-199.

Ellsberg, M, & Heise, L. (2002). Bearing witness: Ethics in domestic violence research. Lancet, 359, 1599-1604.

Recommended Reading

Academy of Social Sciences, (2014) *Towards Common Principles for Social Science Research Ethics? A Discussion Document,* AcSS Working Group (copy will be given out at the lecture).
Connolly, P., (2003) *Ethical Principles for Researching Vulnerable Groups,* Office of the First Minister and Deputy Prime Minister, Belfast.
Wager, E. (2011) Coping with scientific misconduct. *British Medical Journal* 343, 992- 993

2. Sampling and recruiting vulnerable and hard to reach groups: options and responsibilities
This session considers the benefits, pitfalls and ethical issues inherent in accessing and recruiting vulnerable people to a social science or health research study.
Essential Reading:

Miller, T., & Bell, L. (2002) Consenting to what? Issues of access, gate-keeping and 'informed consent', in M Mauthner, M Birch, J Jessop, Miller T (eds) *Ethics in Qualitative Research*. Sage, London.

Recommended Reading:
Abrams, L.S. (2010) Sampling 'hard to reach' populations in qualitative research. *Qualitative Social Work*, 9 (4), 536-550.
Anderson, D.G. & Hatton, D.C. (2000) Accessing vulnerable populations for research. *Western Journal of Nursing Research*, 22 (2), 244-251.
Browne, K. (2005) Snowball sampling: using social networks to research non-heterosexual women. *International Journal of Social Research Methodology*, 8 (1), 47-60.
Chiang, V.C., Keatinge, D., Williams, S.K. (2001) Challenges of recruiting a vulnerable population in a grounded theory study. *Nursing and Health Sciences*, **3**, 205–211
Faugier, J., & Sargeant, M. (1997) Sampling hard to reach populations. *Journal of Advanced Nursing*, 26, 790–797.
Gabb J. (2004) Critical differentials: querying the incongruities within research on lesbian parent families. *Sexualities*, 7 (2), 167-182
Moore, L.W., & Miller, M. (1999) Initiating research with doubly vulnerable populations. *Journal of Advanced Nursing*, 30 (5), 1034-1040.
Smith, L.J. (2008) How ethical is ethical research? Recruiting marginalized, vulnerable groups into health services research. *Journal of Advanced Nursing,* 62 (2), 248–257.

3. Encouraging participation and conducting research in one's workplace.
What is informed consent? Can consent be truly informed? How can investigators be assured that they do not recruit participants through coercion? This session will also consider the relationship, responsibilities and conflicts of interest present when the two roles of worker and researcher may occur in a research situation.
Essential Reading:

Birch, M., & Miller, T. (2002) Encouraging participation: Ethics and responsibilities, in M Mauthner, M Birch, J Jessop, Miller T (eds) *Ethics in Qualitative Research*. Sage, London
Bell, L., Nutt, L. (2002) Divided loyalties, divided expectations: research ethics, professional and occupational responsibilities, in M Mauthner, M Birch, J Jessop, Miller T (eds) *Ethics in Qualitative Research*. Sage, London.

Recommended Reading:

Dickert, N., & Grady, C. (1999)What's the price of a research subject? Approaches to payment for research participation. *New England Journal of Medicine*, 341 (3), 198-203.

Hawkins, J.S., Emanuel, E.J. (2005) Clarifying Confusions about Coercion. *Hastings Center Report*, 35 (5), 16-19.

Permuth-Wey, J., Borenstein, A.R. (2009) Financial remuneration for clinical and behavioural research participation: ethical and practical considerations. *Annals of Epidemiology*, 19, 280-285.

Singer, E., Bossarte, R.M. (2006) Incentives for survey participation: when are they 'coercive'? *American Journal of Preventive Medicine*, 31 (5), 411-418.

Burgess, M.M. (2007) Proposing modesty for informed consent. *Social Science & Medicine*, 65, 2284-95.

Miller, T., & Boulton, M. (2007) Changing constructions of informed consent: qualitative research and complex social worlds. *Social Science & Medicine*, 65, 2199-2211.

Murphy, E., & Dingwall, R. (2007) Informed consent, anticipatory regulation and ethnographic practice. *Social Science & Medicine*, 65, 2223-34.

Robinson, L.C. (2010) Informed consent among analog people in a digital world. *Language & Communication*, 30, 186–191.

Grinyer, A. (2001) Ethical dilemmas in nonclinical health research from a UK perspective. *Nursing Ethics*, 8 (2), 123-132.

Ritchie, L. (2009) Wearing two hats: interviewing older people as a nurse researcher. *Medical Sociology Online*, 4 (1), 14-24

Nestle, M. (2001) Food company sponsorship of nutrition research and professional activities: a conflict of interest? *Public Health Nutrition*, 4(5), 1015-1022

4. Conducting research in conflict and post-conflict contexts: lecture
This is the last of three sessions that focus on a particular vulnerable population. What are the ethical issues surrounding research with participants in conflict and post-conflict contexts?
Essential Reading:

Ellis B.H., Kia-Keating, M., Yusuf, S.A., Lincoln A., and Nur, A. (2007) Ethical Research in Refugee Communities and the Use of Community Participatory Methods. *Transcultural Psychiatry,* 44: 459-481

Zwi, A.B., Grove, N.J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D., & Tarantola, D. Placing ethics in the centre: Negotiating new spaces for ethical research in conflict situations. *Global Public Health*, October 2006; 1(3): 264-277

Recommended Reading:

Black, R. (2003) Ethical Codes in Humanitarian Emergencies: From Practice to Research? *Disasters*, 27(2), 95–108

Ford, N. Mills, E.J., Zachariah, R., & Ross Upshur, R. (2009) Ethics of conducting research in conflict settings. *Conflict and Health*, 3(7) doi:10.1186/1752-1505-3-7

Schopper, D., Upshur, R., Matthys, F., Amir Singh, J., Bandewar S.S., Ahmad, A., & van Dongen, E. (2009) Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Medecins Sans Frontieres. *PLOS Medicine*, 6(7) e1000115

Zwi, A.B. & Banatvala, N. (2000) Public health and humanitarian interventions: developing the evidence base. British Medical Journal, 321, 101–5

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Wednesday 13 May 2020
1. Ethical guidelines, policies, positions, and duties
Guidelines and policies from social research organisations (including SRA, BPS, BSA and ESRC) will be covered in this session, along with professional positions and duties. We will ask: Should there be common standards?

Recommended Reading

The British Psychological Society, (2009), *Code of Ethics* and (2009) *Code of Human Research Ethics*. BPS.

Economic and Social Science Research Council (ESRC), 2012, *ESRC Framework for Research Ethics (FRE) 2010 Updated September 2012* ESRC

RESPECT (2004) *RESPECT Code of Practice for Socio-Economic Research*, The Institute for Employment Studies, Brighton.

Tollman, S.M, Bastain, H, Doll, R, Hirsch, L. J., Guess, H.A (2001) What are the effects of the fifth revision of the Declaration of Helsinki? *British Medical Journal,* 323, 1417-1423

Zion, D., Gillam, L., Loff, B. (2000), The Declaration of Helsinki, CIOMS and the ethics of research on vulnerable populations. *Nature Medicine*, 6 (6), 615 – 617.

2. Mental Capacity Act 2005: What every researcher should know
This lecture will cover the legal and ethical basis of consent, capacity, and competence.

Essential Reading:

NHS Research & Development Forum. (2008) *A simple guide to the Mental Capacity Act 2005 in relation to research*. www.rdforum.nhs.uk/docs/mca_guidance.doc

Recommended Reading:

Parker J, Penhale B, Stanley D. (2010) Problem or safeguard? Research ethics review in social care research and the Mental Capacity Act 2005. *Social Care and Neurodisability*, 1 (2), 22-32.

http://eprints.bournemouth.ac.uk/13405/2/Problemorsafeguardfinaldraft211209.pdf

Warner J, McCarney R, Griffin M, Fisher P. (2008) Participation in dementia research: rates and correlates of capacity to give informed consent. *Journal of Medical Ethics*, 34,167–170.

3+4. Practical and ethical challenges in conducting research with people with dementia: lecture and workshop
This is the second of three lectures that focus on a particular vulnerable population. What are the specific ethical issues surrounding social research with people with a learning disability or cognitive impairment? A question surrounding social research with learning disability or cognitive impairment is set for class discussion and debate.

Essential Reading
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The Department of Health's website contains several important documents and guidelines on research with vulnerable populations:

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityAct2005/DH_078789

Recommended Reading:

Fisk, J.D., Beattie, B.L., Donnelly, M. (2007) Ethical considerations for decision making for treatment and research participation. *Alzheimer's & Dementia*, 3, 411-417.

Holt, R., Siddiqi, N., Young, J. (2008) The ethics of consent in delirium studies. *Journal of Psychosomatic Research*, 65, 283-87.

Patel, MX., Doku, V., Tennakoon, L. (2003) Challenges in recruitment of research participants. *Advances in Psychiatric Treatment*, 9, 229-238.

Kim, S.Y.H., Cox, C., Caine, E.D. (2002) Impaired decision-making ability in subjects with Alzheimer's disease and willingness to participate in research. *American Journal of Psychiatry*, 159, 797–802.

Thursday 14 May 2020
1. Research governance
This lecture will consider the place and importance of research governance in the health service; differences between the roles and approaches of NHS, University and Social Care Ethics Committees.

Essential Reading:
Haggerty, KD. (2004) Ethics Creep: Governing Social Science Research in the Name of Ethics. *Qualitative Sociology*, 27 (4), 391-414.

Recommended Reading:

Armstrong, N., Dixon-Woods, M., Thomas, A., Rusk, G., Tarrant, C. (2012) Do informed consent documents for cancer trials do what they should? A study of manifest and latent functions. *Sociology of Health and Illness*, DOI: 10.1111/j.1467-9566.2012.01469.x

Shaw, S.E., Petchey, R.P., Chapman, J., Abbott, S. (2009) A double-edged sword? Health research and research governance in UK primary care. *Social Science & Medicine*, 68, 912-18.

Gittner, L.S., Roach, M.J., Kikano, G., Grey, S., Dawson, N.V. (2011) Health service research: the square peg in human subjects protection regulations. *Journal of Medical Ethics,* 37,118-122.

Murray, L., Pushor, D., Renihan, P. (2012) Reflections on the Ethics-Approval Process. *Qualitative Inquiry* 2012 18: 43-54.

2. Privacy, anonymity and confidentiality throughout the research process
This session will ask how far claims to uphold confidentiality can be met in the 21st century.

Essential Reading:

Tilley, L., Woodthorpe, K. (2011) Is it the end for anonymity as we know it? A critical examination of the ethical principle of anonymity in the context of 21st century demands on the qualitative researcher. *Qualitative Research*, 11 (2), 197-212

Recommended Reading:

Berry, D.M. (2004) Internet research: privacy, ethics and alienation: an open source approach. *Internet Research,* 14 (4), 323-332.

Damianakis, T., & Woodford, M.R. (2012) Qualitative research with small connected communities: generating new knowledge while upholding research ethics. *Qualitative Health Research*, 22 (5), 708-718.

Grinyer, A. (2002) The anonymity of research participants: assumptions, ethics and practicalities. *Social Research Update*, Issue 36, University of Surrey.

Kaiser, K. (2009) Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, 19 (11), 1632-1641.

3+4. Ethical issues in research with children and young people: a children's rights perspective. Lecture and workshop

This is the first of three lectures that focus on a particular vulnerable population. What are the specific ethical issues surrounding research with children and young people? A question surrounding social research with children is set for class discussion and debate.

Essential Reading:

Bell, N. (2008). 'Ethics in child research: rights, reason and responsibilities' *Children's Geographies*, 6(1): 7-20.

Recommended Reading:

Cocks A. (2006). The Ethical Maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood*, 13(2): 247-266.

Danby S, Ewing L, Thorpe K. (2011) The novice researcher: interviewing young children. *Qualitative Inquiry*, 17 (1), 74-84.

Driscoll, J. (2012) 'Children's rights and participation in social research: Balancing young people's autonomy rights and their protection'. *Child and Family Law Quarterly* 24(4): 452-474.

Swartz S. (2011) 'Going deep' and 'giving back': strategies for exceeding ethical expectations when researching amongst vulnerable youth. *Qualitative Research*, 11 (1), 47-68.

Friday 15 May 2020
1. Identifying and managing risk and harm: Conducting research in the Court of Protection
This session will consider what constitutes 'risk' and 'harm' in social science and health research and the various ways that researchers and review boards seek to minimise these.

Essential Reading:
Weijer C. (2000) The ethical analysis of risk. *Journal of Law, Medicine & Ethics*. 28, 344-361.

Recommended Reading:

Corbin, J. & Morse JM. (2003) The unstructured interview: issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry*, 9 (3), 335-354.

Lowton, K. (2005) Trials and tribulations: understanding motivations for clinical research participation amongst adults with cystic fibrosis. *Social Science and Medicine*, 61, 1854-1865.

Mills, EJ., Singh, S., Singh, JA., Orbinski, JJ., Warren, M., Upshur, RE. (2005) Designing research in vulnerable populations: lessons from HIV prevention trials that stopped early. *British Medical Journal*, 331, 1403-1406.

Thompson, RA. (1990) Vulnerability in research: A developmental perspective on research risk. *Child Development*, 61 (1), 1-16.

Paterson, BL., Gregory, D., Thorne, S. (1999) A protocol for researcher safety. *Qualitative Health Research,* 9, 259-269.

Sullivan, CM., Cain, D. (2004) Ethical and safety considerations when obtaining information from or about battered women for research purposes. *Journal of Interpersonal Violence*, 19 (5), 603-618.

3+4. Conducting research in conflict and post-conflict contexts: lecture and workshop
This is the last of three sessions that focus on a particular vulnerable population. What are the ethical issues surrounding research with participants in conflict and post-conflict contexts?

Essential Reading:
Ellis B.H., Kia-Keating, M., Yusuf, S.A., Lincoln A., and Nur, A. (2007) Ethical Research in Refugee Communities and the Use of Community Participatory Methods. *Transcultural Psychiatry,* 44: 459-481

Zwi, A.B., Grove, N.J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D., & Tarantola, D. Placing ethics in the centre: Negotiating new spaces for ethical research in conflict situations. *Global Public Health*, October 2006; 1(3): 264-277

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Recommended Reading:
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Lowton, K. (2005) Trials and tribulations: understanding motivations for clinical research participation amongst adults with cystic fibrosis. *Social Science and Medicine*, 61, 1854-1865.

Mills, EJ., Singh, S., Singh, JA., Orbinski, JJ., Warren, M., Upshur, RE. (2005) Designing research in vulnerable populations: lessons from HIV prevention trials that stopped early. *British Medical Journal*, 331, 1403-1406.

Thompson, RA. (1990) Vulnerability in research: A developmental perspective on research risk. *Child Development*, 61 (1), 1-16.

Paterson, BL., Gregory, D., Thorne, S. (1999) A protocol for researcher safety. *Qualitative Health Research,* 9, 259-269.

Sullivan, CM., Cain, D. (2004) Ethical and safety considerations when obtaining information from or about battered women for research purposes. *Journal of Interpersonal Violence*, 19 (5), 603-618.

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Essential Reading:

Ellis B.H., Kia-Keating, M., Yusuf, S.A., Lincoln A., and Nur, A. (2007) Ethical Research in Refugee Communities and the Use of Community Participatory Methods. *Transcultural Psychiatry,* 44: 459-481

Zwi, A.B., Grove, N.J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D., & Tarantola, D. Placing ethics in the centre: Negotiating new spaces for ethical research in conflict situations. *Global Public Health*, October 2006; 1(3): 264-277

3. The reflexive researcher

It is important for the researcher to be aware of themselves within the research situation. This is done through being reflexive. This lecture looks at the different types of reflexivity along with some practical hints.

Essential Reading:

Finlay, L. (1998) Reflexivity: an essential component for all research? *British Journal of Occupational Therapy*, 61, 10, 453-456

AND/OR

Finlay, L., (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209-230

4. Concluding discussion and questions

Number of students: 5