**Title:** KISS309 RESEARCHING VULNERABLE POPULATIONS

<table>
<thead>
<tr>
<th>LEADER</th>
<th>Dr Hanna Kienzler (<a href="mailto:hanna.kienzler@kcl.ac.uk">hanna.kienzler@kcl.ac.uk</a>)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEPARTMENT</td>
<td>Global Health &amp; Social Medicine</td>
</tr>
<tr>
<td>ACADEMIC YEAR</td>
<td>2016-17</td>
</tr>
<tr>
<td>TERM</td>
<td>Summer</td>
</tr>
<tr>
<td>TYPE OF EVENT</td>
<td>Short Course</td>
</tr>
<tr>
<td>LOCATION</td>
<td>S0.13 Strand Building, Strand campus</td>
</tr>
<tr>
<td>NUMBER OF SESSIONS</td>
<td>5</td>
</tr>
<tr>
<td>LENGTH OF SESSION</td>
<td>5 hours (10am-4pm with lunch break)</td>
</tr>
<tr>
<td>TIME AND DATE</td>
<td>15 May 2017</td>
</tr>
<tr>
<td></td>
<td>16 May 2017</td>
</tr>
<tr>
<td></td>
<td>17 May 2017</td>
</tr>
<tr>
<td></td>
<td>18 May 2017</td>
</tr>
<tr>
<td></td>
<td>19 May 2017</td>
</tr>
<tr>
<td>DESCRIPTION</td>
<td>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</td>
</tr>
</tbody>
</table>
situations will be used to convey and debate ethical imperatives throughout the research process.

<table>
<thead>
<tr>
<th>COURSE OUTLINE</th>
<th>Monday 15th May 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Introduction to 'vulnerable populations' and overview of the course</strong></td>
<td></td>
</tr>
</tbody>
</table>
| *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

| *Recommended Reading:*

| **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:*
|

AND/OR


*Recommended Reading:*


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 16th May 2017**

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**


   **Recommended Reading**


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:

Recommended Reading:

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:

Recommended Reading:


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


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:


Recommended Reading:


Wednesday 17th May 2017

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


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


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:

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


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
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/Deliveringadultssocialcare/MentalCapacity/MentalCapacityAct2005/DH_078789

Recommended Reading:


**Thursday 18th May 2017**

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:**


**Recommended Reading:**


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:**

Recommended Reading:


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:

Recommended Reading:


Friday 19th May 2017

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:**

**Recommended Reading:**


**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:**

**Recommended Reading:**


**2. User involvement in research: personal, ethical, methodological and practical issues**

This session will consider the increasing practice of involving members of vulnerable populations in the research proves. We consider how far this is feasible, and the benefits and drawbacks of involving users in this way.

**Essential Reading:**


**Recommended Reading:**


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:*


AND/OR


4. Concluding discussion and questions

**READING LIST**

**Recommended Readings**

The following references are not essential to read but may be of interest to you as you attend the course.


<table>
<thead>
<tr>
<th>Source</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leaning, J. (2001)</td>
<td>Ethics of research in refugee populations. The Lancet, 357, 1432-1433</td>
</tr>
<tr>
<td>Oakley, A. (1998)</td>
<td>Gender, methodology and people’s ways of knowing: some problems with feminism and the paradigm debate in social science, Sociology, 32, 4, 707-732</td>
</tr>
</tbody>
</table>

**PREPARATION**

You will be enrolled to view relevant online material via the KEATS page for this particular course (rather than on the KISS DTC KEATS pages). Please consult the convenor if you are not auto-enrolled by the first day.

**ELIGIBILITY**

The only prerequisites are that this module does assume knowledge of basic research design and research methods. It does not focus on clinical research (RCTs etc) although many of the practical and ethical issues raised may be applicable in clinical research settings.

**NUMBER OF STUDENTS**

15