Semester 2, Block 3 & 4
2017-18
Health and Human Rights: Principles, Practice and Dilemmas
SCPL11015

Course Convener:
Dr. Anuj Kapilashrami

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Health and Human Rights: Principles, Practice and Dilemmas

Credits: 20 credits, Semester 2, Block 3 & 4
Assessment: 1000 word blog; 3000 word essay

Times and locations:

Class: Monday 15:10 – 18:00 [LG11, David Hume Tower]

Contact details:

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Course Programme

- The course will be structured around 10 teaching units taught as single 3 hour class. The course will be taught via an interactive combined lecture and seminar format and include group work and discussions on issues, case studies, audio/visuals and presentation to peers. You will be expected to read in advance and take active part in class, as this is central to the learning process. The timetable for each course unit is provided below.

- The description of each course unit is given further in this handbook and contains the lecture outline and key indicative readings. Instructions for the class and any group work requiring preparation will be disseminated to students a week before (either via email or LEARN).

Please check your university email account regularly!

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<td>Introduction to course and human rights principles</td>
<td>Dr Anuj Kapilashrami</td>
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| 2 Jan 22 | Global mental health and Human rights | Dr Sumeet Jain  
Social Work, University of Edinburgh |
| 3 Jan 29 | Human Rights and Health Systems: The right to health care | Dr Anuj Kapilashrami |
| 4 Feb 5 | Migration, health and human rights | Dr Anuj Kapilashrami  
& Thea Gruchy  
African Centre for Migration & Society, University of Witwatersrand |
| 5 Feb 12 | Pandemics, Human rights and access to treatment | Oonagh O’Brien  
Queen Margaret University |
| 6 Feb 26 | Women’s reproductive rights & freedom from violence | Dr Anuj Kapilashrami  
& Fatou Baldeh (on FGM) |
| 7 Mar 5 | Rights and bio-ethics in clinical and public health research | Prof Roger Jeffery  
& Anuj Kapilashrami |
| 8 Mar 12 | Health Impact Assessment and relevance for Human Rights | Dr Margaret Douglas  
Consultant in Public Health  
NHS Lothian |
| 9 Mar 19 | Tobacco control from a human rights frame | John Watson  
Deputy CEO at ASH Scotland |
| 10 Mar 26 | Global instruments, participative governance & the role of social movements | Dr Anuj Kapilashrami |
| 11 April 2 | Group presentations; Feedback & Essay Guidance session (TBC) | Dr Anuj Kapilashrami |
Introduction

Aim: To provide students with an understanding of human rights and rights-based approaches and to enable them to apply these to contemporary challenges in global public health policy and practice.

Human rights and rights-based approaches have found a new resonance in contemporary global health and sustainable development debates. Yet there continues to be a disconnect between policy commitments, policies and practice of rights in health. Furthermore, despite growing acknowledgement and references to human rights among non-governmental organisations, advocacy groups, political parties, governments and individuals, several questions arise in relation to its theory and practice. For example, how are abstract yet universal human rights principles understood and put into practice in diverse contexts? What does claiming a human right entail? What are barriers to claim-making? These questions are pertinent especially in view of the criticism that ‘rights have arrived but justice has not followed’ (Unnittthan & Pigg, 2014).

This course will examine key concepts, principles and instruments of human rights and bioethics and discuss its application to the right to health and contemporary challenges in global public health policy and practice. These challenges will be explored through specific case studies which address wide ranging ethical questions: from system level (financing and delivery of health care), individual litigation, community level organising to addressing ethical questions in biomedical/life sciences and public health research.

We will examine ethical issues in public health in a global context and examine ways in which rights-based approaches to health have been used to empower communities to seek entitlements, shape and reform policy at international and national level. Human rights (and Bioethics) will be the foundational tools for critically evaluating global health policies and their impact.

The course will enable students to:

- Examine the theory of health and human rights and introduce international legal instruments and covenants and their relevance to health.
- Critically assess ways in which the right to health and rights-based approaches have been used to empower communities, reform policy at international /national level, and by individuals, in litigation to gain access to entitlements.
- Apply human rights principles to contemporary challenges in global public health via case studies.
- Critically analyse the challenges involved in operationalising a rights based approach to health and in monitoring its progress.

Background reading

Gruskin, S., D. Bogeche, et al. (2010). "'Rights-based approaches' to health policies and

BOOKS:

Readings on Topics in health and human rights

Health systems and human rights

Globalisation, governance and human rights implications
HIV, Sex work, marginalisation and Human rights

Rights based approaches and techniques
**Assessment**

This course will be assessed via

i) **Blog post** of under 1000 words, on a Human Rights issue that has struck you while attending an event, in conversations or reading. (30% of overall grade); due on 12pm Thursday, 8 March, week 7 of the Course

ii) **Written Essay** between 3000 words (70% of overall grade). Essay titles and guidance will be distributed in the fourth week. The essay must be submitted by 12pm on Thursday 12 April 2018.

Feedback will be returned by 29th March for the Blog post, and by for the Written Essay.

**Directions for Writing and commenting on Blog posts**

There are a number of ways to approach writing a blog post: consider a reading in relation to its historical or theoretical context; write about an issue discussed at an event/meeting held on a rights/advocacy issue relevant to Scotland, the UK or an international context; formulate an insightful question or two about the reading and then attempt to answer your own questions. Students will also be encouraged to respond to others posts, building upon it, disagreeing with it, or re-thinking it. This response will not be assessed.

Writing an effective academic blog requires many of the same skills as any piece of academic writing – solid elaboration, thoughtfulness, clear argument, careful proofreading and accurate punctuation.

**Assessment Criteria (Guidance given to students):**

Exceptional (++): The blog post is on a relevant human rights issue, focused and puts forward a coherent argument integrating examples with explanations or analysis. The post demonstrates awareness of its own limitations or implications, and it considers multiple perspectives when appropriate. The post reflects in-depth engagement with the topic.

Good (+): The blog post is reasonably focused, and explanations or analysis are mostly based on examples or other evidence. Fewer connections are made between ideas, and though new insights are offered, they are not fully developed. The post reflects moderate engagement with the topic.

Satisfactory (Av): blog post is mostly description or summary, without consideration of alternative perspectives, and few connections are made between ideas. The post reflects passing engagement with the topic.

Underdeveloped (-): blog post is unfocused, or simply rehashes others’ opinions/previous comments, and displays no evidence of student engagement with the topic.

Very Limited (--) : The blog post departs from the topic, is poorly developed and/or consists of few disconnected sentences.

**Word limits**

Students are expected to exercise judgement in planning and drafting their coursework, revising their text and deciding which material is most relevant. All coursework submitted by
students must state the word count on the front. Word length includes footnotes and endnotes, appendices, tables and diagrams, but not bibliographies. Blogs and Essays that exceed the word limit will attract a penalty of 5 marks.

**Submission and return of coursework**
Coursework is submitted online using our electronic submission system, ELMA. You will not be required to submit a paper copy of your work. Marked coursework, grades and feedback will also be returned to you via ELMA. You will not receive a paper copy of your marked coursework or feedback.

For Assessment requirements you should consult the [Taught MSc Student Handbook 2017-18](#). This is available on Learn.

Requirements included are:
- Coursework submissions
- Extension request
- Penalties
- Plagiarism
Unit 1  Introduction to course and human rights principles
Presenter: Dr Anuj Kapilashrami

Summary:
The first lecture will introduce the course structure and format, give an overview of the key principles of human rights, its links to global health, and introduce current themes and topics in health and human rights. We will examine the history of the human rights movement, and its current salience by examining the opportunities and threats posed by the social, economic and political processes of globalisation, for the growth of the human rights movement.

NOTE: It is recommended to students that in addition to at least TWO of the key readings listed below, they choose one additional reading covering a topic from other units, such as criminalisation of HIV transmission and human rights or mental health or reproductive and sexual rights.

Key readings:


Recommended:


Unit 2: Global mental health & Human Rights
Presenter: Dr. Sumeet Jain

Mental health disorders are major contributors to the global burden of disease. Concerns about the human rights of people with mental health problems and a ‘treatment gap’ have led to development of the movement for global mental health (mGMH).
Driven by a coalition of academics, mental health professionals and service users, mGMH has sought to improve access to mental health care in low and middle income countries to reduce inequalities in provision of care and improve human rights for people with mental health problems. The mGMH has played an increasingly significant role in North-South knowledge transfer in mental health, through efforts to re-shape mental health policy and service delivery through ‘evidence-based’ interventions (Lancet Global Mental Health Group, 2007; Patel et al., 2011). However, critics question the cross-cultural applicability of the GMH ‘evidence’ base, much of which is based on research conducted in Euro-American contexts. They argue that such interventions promote medicalization of distress, edit local particularities and supplant pre-existing means of social and moral support, including forms of traditional healing (Das and Rao, 2012; Summerfield, 2012). Psychiatric survivors/service user groups from the global south and north question whether service delivery strategies proposed by GMH advocates and global efforts towards national mental health policies and laws are in line with the spirit of the UN Convention on the Rights of Persons with Disabilities (https://www.un.org/development/desa/disabilities/).

This session will:

- Consider the importance of language and terminology in debates about mental health and human rights
- Critically analyse key debates around global mental health and human rights including the role of the UNCRPD.
- Case studies will allow us to explore how local ways of conceptualizing ‘mental health’ and ‘human rights’ shapes the responses of institutions, communities, individuals and families.

**Key readings**

Davar, B. V. (2012). Legal frameworks for and against people with psychosocial disabilities. Economic & Political Weekly, 47(52), 123. Optionally READ ALONG WITH short responses by:


Useful websites:
- Mental Health Worldwide [www.mentalhealthworldwide.com](http://www.mentalhealthworldwide.com)
- PANUSP - a user/survivor group in South Africa [www.panusp.org](http://www.panusp.org)

**Recommended Reading**


**Unit 3 Human rights and health systems**

**Presenter:** Dr Anuj Kapilashrami

**Summary:**
This lecture will introduce students to the argument that human rights should be an integral component of efforts to strengthen and reform health systems. The starting point of this class will be examining what the right to health entails, and discussing the content and principles of health rights. We will then define a health system and contextualise human rights in a health systems setting; explicating the tension between ‘access’ and ‘provision’ (and the underlying philosophical tension between positive and negative rights). We then review the extent to which human rights are already incorporated into health systems, before describing the range of models that have been applied to better incorporate a human rights-based approach. Viewing health systems through a rights-based 'lens' reveals synergies that could benefit a
range of health issues. These are introduced in the lecture, with particular attention given to maternal health. There will also be an opportunity for further discussion and application of concepts via group work.

**Key readings:**


**Unit 4: Migration, health and human rights**
Presenter: Anuj Kapilashrami & Thea de Gruchy

**Summary**
Migration is increasingly recognised as a central determinant of health but responses to health fail to adequately consider diverse population movements. Globally, people migrate for a range of reasons with the majority moving within their country of birth. Approximately 3-4% of the world’s population is estimated to be a cross-border migrant. Whilst most move (in diverse ways) in search of improved livelihood strategies, the global cross-border population also includes a significant number of refugees and asylum seekers. In this session, we will unpack the diverse category of “migrant” and explore why the relationship between migration and (the right to) health is contested at the local, national, regional and international levels. Using specific examples from research in Scotland, Balkans, and South Africa we will examine migrants’ access to public services and justice systems.
Drawing on the case of South Africa – located within a region of diverse population movements and a high communicable disease burden – we will explore the plural health systems and diverse help-seeking strategies present and how understanding this is central to developing improved “migration-aware” responses to health. We will consider the responsibilities of the state to provide (free) public healthcare – in a resource-limited context - to different cross-border migrant groups, including refugees, asylum seekers and undocumented migrants.

**Key readings:**


**Recommended readings:**


Unit 5: Pandemics, Human rights and access to treatment
Presenter: Oonagh O’Brien

Summary:
Despite great advances in treatment for HIV and a huge expansion in the delivery of treatment the virus still contributes significantly to the burden of disease faced by people across the world especially in countries with low and middle incomes. Many people with HIV remain unable to access the treatment they need as a result of poor quality health-care services, drug unavailability and inaccessibility and fear of stigmatisation within their communities. Treatment is necessary to reduce transmission of HIV and associated infections such as TB, Cervical Cancer and Malaria, yet is not always available to those who need it most. Looking at the historical background of treatment provision as well as focusing on current debates and campaigns, this unit will explore the relationship between human rights, HIV and associated infections.

This lecture will:

- Discuss the history and challenges of Human Rights and HIV
- Consider history of AIDS activism, and examine key points around which people organised such as HIV treatment, human rights, sexuality, criminal justice, transparency and better access to clinical trials and social justice
- Explore the relationship between human rights and access to essential medicines
- Draw on practical global case-studies to highlight the everyday challenges in accessing treatment

Key readings:


Unit 6: Women’s reproductive rights and freedom from violence: Individual vs cultural rights
Presenter: Anuj Kapilashrami & Fatou Baldeh

The lecture will look at how women’s rights have been framed and at the historic and contemporary struggle of the women’s movement in establishing and claiming these rights. We then focus on how application of international human rights law to sexual and reproductive health issues supports, guides and undermines efforts to improve policy and seek justice. Here we examine the genesis of women’s sexual and reproductive rights, appraise progress, threats and contestations in applying a universalist human rights paradigm to issues that are culturally rooted. Drawing on examples of specific SRHR for example right to abortion and freedom from violence (specific practices of Female Genital Mutilation and domestic violence) we will examine how legal arguments have been applied in theory and in practice, explore linkages between public health and human rights approaches and discuss some of the challenges in advocating for a human rights-based approach to sexual and reproductive health.

This session will:
- introduce key historic milestones in the acknowledgment (and achievement) of women’s rights
- examine the conceptual framing of women’s sexual reproductive rights and identify key women’s rights issues, threats, challenges and key contestations in applying a human rights approach to gender
**Key readings:**


**Recommended Readings**


Unit 7: Human rights and bioethics in clinical and public health research
Presenter: Dr Anuj Kapilashrami

Summary:
This lecture will cover critical ethical issues arising in transnational clinical and public health research. Using case studies of research undertaken in South Asia, we first examine contemporary developments and complex actor networks in transnational research and key violations of human rights (and other bioethical issues) emergent in both clinical as well as public health research. We then review emerging frameworks for addressing ethics in experimental research. We will also consider an example of research around an HIV prevention trial to develop a health and human rights approach, and explore practical ways in which human rights can strengthen disease interventions and how to design research in this area.

Key readings:


Recommended readings


**Unit 8: Health inequalities, health impact assessment and human rights**
Presenter: Margaret Douglas

**Summary:**

‘*Health is a fundamental human right indispensable for the exercise of other human rights.*’ (Office of the High Commissioner for Human Rights (2000) CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12))

This session will briefly consider the extent to which the right to the highest attainable standard of health is achieved within the UK and focus on the reasons for the marked inequalities in health between different groups of people in the population. It will then consider impact assessment as a way to enable impacts on health and human rights to be taken into account in policy and decision making.

The lecture will discuss some conceptual background to the use of Health Impact Assessment, and consider some projects that have integrated consideration of health, and other aspects of human rights, into equality impact assessment. In the seminar, students will use an impact assessment approach and apply this to a case study. Following the lecture and seminar students should gain an understanding of impact assessment as an approach to the integration of human rights and health in shaping policy making.

**Key readings:**


Recommended readings:


Unit 9: Tobacco control and human rights
Presenter: John Watson

Summary:
This session will use the field of tobacco control as a case study to consider how human rights frameworks can be a powerful tool in articulating public health goals. At the same time, it demands greater accountability and even restraint from those who would exert authority in order to discourage harmful behaviours.

Public health advocates working in tobacco control have long faced opposition, often encouraged by vested interests, centred on the concept of “smokers’ rights”. We will consider how such claims fare when placed against the acknowledged right to health, and what appeal can be made to freedom and choice when dealing with the commercially driven promotion of a product as addictive as heroin. Discussion will include using a human rights perspective to review a range of potential anti-smoking interventions.

Key readings:


Unit 10: Global instruments, participatory governance & the role of social movements
Presenter: Anuj Kapilashrami

Summary
The human right to health guarantees a system of health protection for all and is enshrined in several international covenants. However, as other economic, social and cultural rights, health rights is a vast and contested domain facing both systemic and operational challenges. Although in its infancy, the contemporary health and human rights movement has become nuanced in its approaches and strategies to invoke rights and guarantee health entitlements by utilising a number of instruments including law and other informal ways of enforcements.

This concluding class has twin objective. First, we focus on the various instruments (and role of hard & soft law) and provide examples of how international law has been used in the past to protect health. Here we will focus on monitoring of human rights abuses in relation to health, as conducted by large human rights organisations, such as Human Rights Watch and Amnesty International. We will also discuss a proposal for a Framework Convention on Global Health which is being advanced by the Joint Action and Learning Initiative (JALI) for global health. Second, we focus on bottom up, participatory action and the role of social movements in realising the right to health and holding states to account. Through the case study of the People’s Health Movement – both global and the UK- we will examine how social movements negotiate health rights and entitlements from the States, especially in contexts that are embedded in structural violence. Specifically, we will examine key human rights principles that guide strategies, actions and policy positions of the People’s Health Movement.

In this session we will
• examine key instruments and approaches used by advocates of human rights
• consider global challenges and threats in negotiating the right to health
• look at a specific example of negotiating health rights in practice, and critically examine how bottom-up movements of solidarity and action offer countervailing power to resist threats in realising the right to health.

Key reading:


Recommended reading:


Some useful networks to link with:

✓ People’s Health Movement (PHM) UK & Scotland: http://www.phm-uk.org.uk/. To be part of the ‘Students in the PHM’ society, write to Mark Gotink at s1672786@sms.ed.ac.uk OR Eva Gallova at eva.gallova@gmail.com
More information on PHM global: http://www.phmovement.org/
✓ Medact: http://www.medact.org/
✓ Politics of Health Group: http://www.pohg.org.uk/
✓ Gender, Rights and Development Network:
Speakers’ biographies

Dr Anuj Kapilashrami is a lecturer and Programme Director for the MSc in Global Health and Public Policy. She has an interdisciplinary background in sociology and public health with a specialisation in policy and systems research, and sexual and reproductive health. Her work is at the intersections of health politics and development praxis, with particular focus on their interface with gender, human rights and social justice. Over last fifteen years she has worked with various development actors and social movements in India, the UK and Europe in varying capacity. Her research examines global and local interface in health policy and systems, with particular focus on translation of global policy ideas and discourse and its implications for governance and commercialisation of health systems. She also works on gender and health inequalities and issues related to gender based women. She currently chairs Gender Rights and Development (GRAND), an international network of academics and practitioners working on Gender, Rights and Development issues, which has membership in Africa, Europe and India. She is also a member of Steering group of the UK People’s Health Movement (and convenes the PHM Scotland), Development Studies Association (Scotland) and Associate Director for the Centre for South Asian Studies at Edinburgh University.

Jo Vearey is an Associate Professor at the African Centre for Migration & Society, University of the Witwatersrand, where she is involved in designing and coordinating research programmes, teaching, and supervising graduate students. Jo is a South African National Research Foundation rated researcher and has established the migration and health project Southern Africa (maHp) through a Wellcome Trust Investigator Award. With a commitment to social justice, Jo’s research explores ways to generate and communicate knowledge to improve responses to migration, health and wellbeing in the southern African region.

John Watson is Deputy Chief Executive at Action on Smoking and Health (ASH) Scotland, the independent Scottish charity working to reduce the health and inequality caused by smoking. He oversees the organisation’s work engaging and supporting front line service organisations and community groups to speak to the people they work with about smoking and providing guidance and training on how those who wish to stop smoking can be helped to do so. His background centres on campaigning and communicating with a number of charities, having previously led Amnesty International’s office in Scotland over five and a half years, engaged Scottish politicians on behalf of children’s charity Barnardo’s and worked as a campaigner for international development and environmental NGOs. John has a particular interest in the delicate balance between proactively helping people and interfering in their lives, and in how human rights provides both opportunities for public health professionals to articulate their aims along with restrictions on the mechanisms that can justifiably be used to achieve them.

Margaret Douglas has been a Consultant in Public Health in NHS Lothian, Scotland since 2000. Currently she leads the Board’s health inequalities strategy and provides public health support for partnership work in West Lothian, in which role she chairs West Lothian Health Improvement and Health Inequalities Alliance. Her main areas of interest are the physical and
socio-environmental determinants of health, and ways to influence these through partnership work with local authorities and other agencies.

Dr Douglas has a longstanding interest in Health Impact Assessment and during her public health training she worked for a short time in the WHO European Centre for Health Policy on HIA. More recently she was seconded to Scottish Government to work on the development of Health Inequalities Impact Assessment. She has been chair of the Scottish Health and Inequalities Impact Assessment Network (SHIIAN) since it was established in 2001. SHIIAN aims to promote and support HIA in Scotland and produces evidence based guides that outline the links between health and other policy areas including transport, housing, greenspace and community venues.

Oonagh O’Brien (Lecturer) is an anthropologist with over twenty year experience of working in gender, HIV and sexual health. She has previously worked with on clinical networks and HIV care, HIV in European Prisons and on community based action research with Irish migrants in London. She has worked extensively with participatory methods and has carried out extensive research and monitoring and evaluation projects, particularly in the fields of Gender and Sexual Health in a number of settings including Europe, Colombia, Uganda, Nepal and South Africa and Scotland. She is an active participant on the Lothian African Sexual Health and HIV Strategy Group. Her current research interests centre on the prevention of female genital mutilation (FGM) and she is lead researcher for MY Voice a Scottish government funded strategic intervention to increase understanding and experiences of FGM by giving a voice to women, men and young people from FGM affected communities in Scotland as well as developing toolkits with the NGO Tearfund to work on social connections, peacebuilding and gender based violence with displaced people and refugees in Kurdistan.

Roger Jeffery has been Professor of Sociology of South Asia at the University of Edinburgh since 1997. His recent research projects have investigated secondary education, the outcomes of schooling, access to pharmaceuticals, and issues of governance, collaboration and knowledge generation in bio-medical and public health trials in South Asia. From 2011-15 he was Dean International (India) and Director of the Edinburgh India Institute, both at the University of Edinburgh. He was a founder member of the University’s Centre for South Asian Studies, and served as its Director from January-July 2015. He has acted as a consultant for DfID, the World Bank, and the Swiss National Science Foundation. In addition to many articles and book chapters, he has published (with Craig Jeffery and Patricia Jeffery), 2010, *Education, Unemployment and Masculinities in India* (Social Science Press); co-edited (with Craig Jeffrey and Jens Lerche), 2014, *Development Failure and Identity Politics in Uttar Pradesh*, (Sage); and co-edited (with Anthony Heath) 2010, *Change and Diversity: Economics, Politics and Society in Contemporary India* (Oxford University Press).

From 2009-14 he was President of the European Association for South Asian Studies. For more details see his web-site: [http://www.sps.ed.ac.uk/staff/sociology/jeffery_roger](http://www.sps.ed.ac.uk/staff/sociology/jeffery_roger)

Sumeet Jain is Lecturer in Social Work at The University of Edinburgh. He has conducted field work on community mental health in Uttar Pradesh State, India. He currently teaches mental health social work, qualitative research methods, culture and mental health as it applies to the ‘global south’. Current research interests include: critical perspectives of ‘global mental health’,

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community mental health policies and services in the ‘global south’, and the relationship between poverty, mental health and development. Sumeet Jain is Associate Editor, *Anthropology and Medicine* journal. Webpage: [http://www.sps.ed.ac.uk/staff/social_work/jain_sumee](http://www.sps.ed.ac.uk/staff/social_work/jain_sumee)