

Ciara Staunton

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Current Employment

Senior Lecturer in Law (Grade 8)	Department of Law and Politics, School of Law, Middlesex University, 2018–present
Senior Researcher	Centre for Biomedicine, EURAC, Italy, 2019–present
Consultant	National Health Laboratory Service, Johannesburg, South Africa
Honorary Research Associate	Department of Medicine, University of Cape Town

Professional Experience

Lecturer in Law (Grade 7)	Department of Law and Politics, School of Law, Middlesex University, 2016–2018
Post-doctoral researcher	Centre for Medical Ethics and Law, Stellenbosch University, South Africa, September 2013 – July 2016
ARESA Co-ordinator	Centre for Medical Ethics and Law, Stellenbosch University, South Africa, September 2013 – July 2016
Intern	World Health Organisation, Geneva, Switzerland, September–December 2012
Part-time lecturer	School of Law, National University of Ireland, Galway, January 2011 – September 2013
Legal Researcher	Law Reform Commission of Ireland, Ireland, July 2008 – September 2010
Legal Researcher	Rape Attrition Project, National University of Ireland, Galway, Ireland, April–November 2008

Membership of Professional Bodies

Fellow of the Higher Education Authority

African Society for Bioinformatics and Computational Biology

European Society of Human Genetics

International Society for Computational Biology

Qualifications

Postgraduate Certification in Higher Education

Middlesex University 2019

PhD in Law

The Regulation of Stem Cell Research in Ireland, National University of Ireland, Galway

Awarded November 2013

Masters (LL.M) in Public Law, 1st Class Honours

National University of Ireland, Galway

Awarded November 2007

Bachelor of Civil Law, 2.1 Honours

National University of Ireland, Galway

Awarded October 2006

Administration

LLB Programme Leader

School of Law, Middlesex University

January 2019 – January 2020

ARESA Co-ordinator

Department of Medicine, Stellenbosch University

2013 - 2015

Teaching and Learning

Courses taught

Middlesex University

Medical Law (Module Leader), Tort (Module Leader),
Intellectual Property Law LLM (Module leader)

Stellenbosch University

Advancing Research Ethics in Southern Africa (ARESA)

NUI, Galway

The Regulation and Patenting of Biotechnology LLM
(Module Leader)

Postgraduate Supervision

Current PhD students

Claudia Carr	'Healthcare professionals and informed consent: the implications of Montgomery for patients, including those with learning disability' Commencement: January 2018
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Postgraduate Diploma in Research Ethics

2016	Regulatory oversight of human genetic research and protection of vulnerable population participating in genomic research in Africa
2015	Building community partnerships: understanding community engagement as a pillar for ethical conduct of HIV vaccine research in Africa

Masters in Law (dissertation)

2019	A Critical Analysis of Patent Protection and its effects on access to medicines in India
2018	Implications of Bilateral Agreements in Medicine under the Patent Act 2005
2013	Surrogacy in Ireland: The Legal Implications of Surrogacy Arrangements entered into outside the State
2012	Sperm Donor Children in Ireland: Accessing Parental Identity

External Examiner

2020	MSc Bioinformatics: Mr Peter Abiodun, University of the Western Cape "Exploring the influence of Organizational, Environmental and Technological factors on information securities policies and compliance on biomedical data at South African higher institutions"
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2021

PhD in Law: Ms A A Jogi

“Artificial intelligence and healthcare in South Africa: Ethical and legal challenges

Research Funding

Research Council Funding

Wellcome Trust, “The governance of data sharing for genomic and other health-related data in Africa” (£25,323.00) – Principal Investigator (2018-2019)

NIH National Human Genome Research Institute, *Community Engagement for H3Africa Biobanking Research: The Tygerberg Model* (\$240,000 over 3 years) – Co-investigator (2011–2014)

Irish Research Council Postgraduate Scholarship, 2010–2013 (€16,000 per annum, plus fees) (2010–2013)

International Travel Awards

Global Forum on Bioethics, Travel Grant, Mexico City, 24 June 2014

International Society for Stem Cell Research (ISSCR) Travel Award, 2012 (\$900)

Law and Society Association Travel Award, 2012 (\$500)

Phyllis and Albert Sussman Subsidy to attend the Hastings Centre as a visiting scholar, 2011

University Funding

Middlesex University, HEIF dissemination grant (2018) £3810

Middlesex University, HEIF small research grant *The regulation of stem cell research in Ireland: proposals for regulatory reform* 2017 (£2,000)

University of Stellenbosch Scientific Travel Grant, 2016 (R15,000/\$1,500)

University of Stellenbosch Scientific Travel Grant, 2015 (R15,000/\$1,500)

University of Stellenbosch Scientific Travel Grant, 2014 (R15,000/\$1,500)

NUI, Galway School of Law Travel Award to present at the SLSA Annual Conference, 2012

NUI, Galway School of Law Travel Award to present at the Scottish Young Legal Researchers Colloquium in Dundee, 2011

NUI, Galway School of Law Travel Award to present at the Genomics Conference *Ten Years After: Mapping the Societal Genomics Landscape* in Amsterdam, 2010

International Academic Excellence and Standing

Consultant to the South African National Department of Health June 2021 - present

Consultant to the South African National Institute for Communicable Diseases June 2019–present

Invited participant at the Africa Union Consultation on Biosecurity and Biosafety Legal Framework 19-21 January 2021

Invited participant at the Africa Union Validation Meeting for Infection Prevention and Control, 19-20 May

Invited participant at African Union/African Centre for Disease Control workshop on Implementing Pathogen Genomics in Public Health Institutions 15–16 January 2020

Fellow Brocher Foundation Visiting Residency Program 2020

Invited participant at OECD workshop on ‘Collaborative platforms for personalized health: realizing the potential of genomics and biobanks’, 17–18 September 2019, Stockholm, Sweden

Advisory Group Member – Examining stakeholders’ engagement and acceptability of biobanking in Sub-Saharan Africa: The KEMRI-CGMRC as a case study (2019–present)

Visiting Researcher, Centre for Biomedicine, EURAC, Italy, July 2018

Visiting Researcher, KEMRI-Wellcome Trust, June 2018

Visiting Researcher, Centre for Applied Ethics, Stellenbosch University, June 2018

Visiting Fellow, Department of Genetics, University of Cape Town, April–May 2018

Co-opted member of Wellcome Trust Society and Ethics Interview Committee, January 2017

Visiting Scholar, Hastings Centre, New York, August–September 2011

Knowledge Transfer

Developed Access to COVID-19 Tools Accelerator *Data Governance Framework* (2021)

Developed a legal opinion for the South African NHLS on the dissemination of HIV test results for at-risk babies, 2019

Involved in the development of regulations for stem cell research with the Stem Cell Regulations Committee of the Kingdom of Bahrain, 2018

Requested by the Uganda National Council for Science and Technology to provide guidance on the protocol and SOPs to develop a national biorepository in Uganda, July 2018

Key stakeholder in the drafting of *Ethics and Governance Framework for Best Practice in Genomic Research and Biobanking in Africa* (published January 2017 – now adopted by research ethics committees across Africa)

Invited to give evidence to the Joint Oireachtas Health Committee on the Protection of Life During Pregnancy Act, 2013

Peer Reviewer

Previously peer reviewer for the following journals:

BMC Medical Ethics
CRISPR Journal
Developing World Bioethics
International Data Privacy Law Journal
Journal of Medical Ethics
Medical Law International
South African Journal of HIV Medicine

Publications

Book Chapters

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| 2022 | C Staunton “Open science, data sharing and pandemic preparedness” in J Grogan & A Donald (eds) <i>The Routledge Handbook on Law and the COVID-19 Pandemic</i> (Routledge, 2022) |
| 2022 | C Staunton , M Labuschaigne “The rationality of South Africa’s State of Disaster during COVID-19 in J Grogan & A Donald (eds) <i>The Routledge Handbook on Law and the COVID-19 Pandemic</i> (Routledge, 2022) |
| 2021 | C Staunton , R Adams, L Horn, M Labuschaigne “A framework to govern the use of health data for research in Africa: a South African perspective” in D Weisstub (ed) <i>Medical Research Ethics: Challenges in the 21st Century</i> (Springer, 2021) |
| 2021 | M Labuschaigne, C Staunton “Article 18 of the Convention of Human Rights and Biomedicine: some reflections and observations” in A den Exter (eds) |

- 2021 **C Staunton** “Individual rights in biobank research under GDPR”, S Slokenberga, O Tzortzatou, J Reichel *GDPR and biobanking. Individual rights, public interest and research regulation across Europe* (Springer, 2021)
- 2016 **C Staunton** “Protecting the patient and embryos *in vitro*: the need for embryonic stem cell research regulations in Ireland”, M Donnelly & C Murray *Ethical and legal debates in Irish healthcare: confronting complexities* (Manchester University Press, 2016)

Peer-reviewed articles (currently under review)

- C Staunton**, K Tschigg, G Sherman “Data protection, data management, and data sharing: stakeholder perspectives on the protection of personal health information in South Africa” *PLOS One*
- C Staunton**, S Slokenberga, A Parziale, D Mascalzoni “Appropriate safeguards & Article 89 of the GDPR: considerations for biobank, databank and genetic research” *Frontiers in Genetics*

Peer review articles (accepted and in press)

Peer-reviewed articles (published)

- 2021 Biolaw journal
- 2021 **C Staunton**, E Hannay, J Oomen, M Johnson, R Kadam, R Sampath “The governance of personal data for COVID-19 response: perspective from the Access to COVID-19 Tools Accelerator” (2021) *BMJ Global Health* **6**:e006095
- 2021 **C Staunton**, M Kusters, P Pramstaller, D Mascalzoni “Return of Research Results (RoRR) to the healthy CHRIS cohort: designing a policy with the participants” *J Community Genet* (2021). <https://doi.org/10.1007/s12687-021-00536-1>
- 2021 **C Staunton**, R Adams, M Botes, J de Vries, M Labuschaigne, G Loots, S Mahomed, N Ni Loideain, A Olckers, MS Pepper, A Pope, M Ramsay “Enabling the use of health data for research: developing a POPIA Code of Conduct for research in South Africa” (2021) *South African Journal of Bioethics and Law* 14(1) 33
- 2021 **C Staunton** “ACT-Accelerator Data Governance Framework: balancing individual rights with the public interest in responding to COVID-19 (2021) *South African Journal of Bioethics and Law* (14)1: 4

- 2021 D Mascalzoni, R Biasiotto, M Borsche, N Brüggemann, A Di Grandi, M Gögele, S Frygner-Holm, C Klein, M Kösters, **C Staunton**, P Pramstaller, M Krawczak, A Hicks “Balancing scientific interests and participant rights in developing a recall by genotype (RbG) policy” *European Journal of Human Genetics*
- 2021 NS Munung, PC Chi, A Abayomi, M Afolabi, J Ambe, K Bonarwolo, F Kombe Kajoleh, **C Staunton**, S Ujewe, K Yusuf, G Tangwa “Perspectives of different stakeholders on data use and management in public health emergencies in sub-Saharan Africa: a meeting report” *Wellcome Open Res* 2021, 6:11
- 2020 **C Staunton**, C Swanepoel, M Labuschaigne “Between a rock and a hard place: COVID-19 and South Africa’s response” (2020) 7(1) *Journal of Law and Biosciences*
- 2020 **C Staunton**, R Adams, M Botes, ES Dove, L Horn, M Labuschaigne, G Loots, S Mahomed, A Olckers, MS Pepper, A Pope, M Ramsay, N Ni Loideain, J de Vries “Genomic research and privacy: a response to Thaldar & Townsend” (2020) 110(3) *South African Medical Journal* 175
- 2020 **C Staunton**, R Adams, D Anderson, T Croxton, D Kamuya, M Munene, C Swanepoel “Protection of Personal Information Act 2013 and data protection for health research in South Africa” (2020) *International Data Privacy Law Journal* 160-179
- 2020 **C Staunton**, J de Vries “The governance of genomic biobank research in Africa: reframing the regulatory tilt” (2020) *Journal of Law and Bioscience* doi.org/10.1093/jlb/lso18
- 2019 P Tindana, A Yakubu, **C Staunton**, J de Vries, “Engaging Research Ethics Committees and Regulatory Authorities in the development of an Ethics and governance Framework for Genomic research in Africa: The H3Africa Model” (2019) 20(69) *BMC Medical Ethics*
- 2019 **C Staunton**, R Adams, M Botes, ES Dove, L Horn, M Labuschaigne, G Loots, S Mahomed, J Makuba, A Olckers, MS Pepper, A Pope, M Ramsay, N Ni Loideain, J de Vries “Safeguarding the future of genomic research in South Africa: broad consent and the Protection of Personal Information Act 2013” (2019) 109(7) *South African Medical Journal* 468
- 2019 **C Staunton**, A Abayomi, F Bassa, K Moodley, “Negotiating requests for reimbursement for community engagement: challenges in developing an educational video for genomic biobanking research in South Africa” (2019) 14(5) *Journal of Empirical Human Research Ethics* 501-503
- 2019 **C Staunton**, R Adams, A Abayomi, ES Dove, N Harriman, L Horn, M Labuschaigne, N Mulder, A Olckers, A Pope, C Swanopoel, N Ni Loideain, J de Vries “Ethical and practical issues to consider in the governance of Data Sharing for Genomic and Human Research Data in South Africa: a meeting report” *AAS Open Res* 2019, 2:15
- 2019 **C Staunton**, S Slokenberga, D Mascalzoni “The GDPR and the research exemption: considerations on the necessary safeguards for research biobanks” *European Journal of Human Genetics* (2019) 27(8) *European Journal of Human Genetics* 1159

- 2019 **C Staunton**, E de Stadler “The Protection of Personal Information Act, 2013: Implications for Biobanks” (2019) 109(4) *South African Medical Journal* 232
- 2019 K Moodley, **C Staunton**, T Rossouw, M de Roubaix, Z Dube, D Skinner “The psychology of “cure” – unique challenges to consent processes in HIV cure research in South Africa *BMC Medical Ethics* (2019) 20(9) *BMC Medical Ethics*
- 2018 **C Staunton** “It's about actually having a proactive regulatory framework versus a reactive one': Stakeholder perspectives on the governance of embryonic stem cell research in Ireland” (2018) 24(2) *Medico-Legal Journal of Ireland* 97
- 2018 A Yakubu, P Tindana, A Matimba, S Munung, K Littler, **C Staunton**, J de Vries, “Model framework for governance of genomic research and biobanking in Africa – a content description” *AAS Open Res* 2018, 1:13
- 2018 M Hendricks, G Nair, N Garrett, **Ciara Staunton**, M Pather, D Baatjies, M Kidd, K Moodley “Evaluation of the impact of an educational video as a consent tool on knowledge about cure research among patients and caregivers at HIV clinics in South Africa” (2018) 4(2) *Journal of Virus Eradication* 103-107
- 2018 **C Staunton**, M deRoubaix, T Rossouw, J Black, D Baatjies, M Hendricks, K Moodley “Ethical challenges in developing an educational video to empower potential participants during consent processes in future HIV cure research in South Africa” (2018) *Journal of Virus Eradication* 99-102
- 2018 **C Staunton** “The Regulation of embryonic stem cell research in Ireland: Developments since the Commission on Assisted Human Reproduction” (2018) 18(1) *Medical Law International* 35-58
- 2018 **C Staunton**, P Tindana, M Hendricks, K Moodley “Rules of engagement: stakeholder perspectives on community engagement for genomic and biobanking research in South Africa” (2018) 19(13) *BMC Medical Ethics*
- 2017 J de Vries, N Munung, A Matimba, S McCrudy, O Ouwe Missi Oukem, **C Staunton**, P Tindana, A Yakubu “Regulation of genomic and biobanking research in Africa: a content analysis of ethics guidelines, policies and procedures from 22 African countries” (2017) 18(8) *BMC Medical Ethics*
- 2016 K Moodley, T Rossouw, **C Staunton**, CJ Colvin, “Perspectives on the ethical and social implications of proposed HIV cure research: exploratory conversations from South Africa” (2016) 17(26) *BMC Medical Ethics*
- 2016 **C Staunton** “Harmonisation of biobank regulations in Africa: Lessons to be learned from Europe” (2016) 13(4) *Contemporary Issues in Law* 267–286
- 2016 **C Staunton**, K Moodley, “Community engagement for biobanking research: perspectives from Africa” (2016) 20(2) *Asia Pacific Biotech News* 14-26
- 2016 **C Staunton**, K Moodley, “Data mining and biological sample exportation from South Africa – a new wave of bio-exploitation under the guise of clinical care?” (2016) 106(2) *South Africa Medical Journal* 136–138

- 2016 K Moodley, **C Staunton**, M de Roubaix, M Cotton “HIV Cure Research in South Africa: A preliminary exploration of stakeholder perspectives” (2016) 28(4) *AIDS Care* 524–527
- 2016 J Nie, A Gilbertson, M de Roubaix, **C Staunton**, A van Niekerk, J Tucker, S Rennie, “Healing without Waging War: Beyond Military Metaphors in Medicine and HIV Cure Research” (2016) 16(10) *American Journal of Bioethics* 3–11
- 2016 **C Staunton** “Informed Consent for HIV cure research in South Africa: Issues to Consider” (2015) 16(3) *BMC Medical Ethics*
- 2015 J de Vries, A Abayomi, K Littler, E Madden, S McCurdy, O Ouwe Missi Oukem-Boyer, J Seeley, **C Staunton**, G Tangwa, P Tindana, J Troyer and The H3Africa Consortium “Addressing ethical issues in H3Africa research – the views of ethics committee members. Report of the H3Africa Ethics Consultation Meeting, 2nd of June 2014” (2015) 9(1) *HUGO*
- 2014 C Beyer, **C Staunton**, K Moodley “The implications of Methylphenidate use by healthy medical students and doctors in South Africa” (2014) 15(20) *BMC Medical Ethics*
- 2013 A Abayomi, A Christoffels, R Grewal, L Karam, C Rossouw, **C Staunton**, C Swanepoel, B van Rooyen “Challenges of Biobanking in South Africa to facilitate indigenous research in an environment burdened with HIV, TB and emerging non-communicable diseases” (2013) 11 (6) *Biopreservation and Biobanking* 347–354
- 2013 **C Staunton**, K Moodley “Challenges in biobank governance in Sub-Saharan Africa” (2013) 14(35) *BMC Medical Ethics*
- 2013 **C Staunton** “*Brustle v Greenpeace*, Embryonic Stem Cell Research and the European Court of Justice’s New Found Morality” [2013] *Medical Law Review* 21 (2), 310–319
- 2012 **C Staunton** “Issues Concerning Embryonic Stem Cell Research in Ireland” (2012) 18(1) *Medico Legal Journal of Ireland* 38
- 2011 **C Staunton** “As Easy as A, B and C: Will *A, B and C v. Ireland* Be Ireland’s Wake-up Call for Abortion Rights?” (2011) 18 *European Journal of Health Law* 205–219
- 2009 **C Staunton** “The Development of Health Care Planning in Ireland” (2009) 15(2) *Medico Legal Journal of Ireland* 74

Annotated Statutes

- 2019 **C Staunton** “Health (Regulation of Termination of Pregnancy) Act 2018” in Clark (ed.) *Irish Current Law Statutes Annotated 2018* (Thomson Roundhall, 2019)
- 2014 **C Staunton** “Protection of Life in Pregnancy Act, 2013” in Clark (ed.) *Irish Current Law Statutes Annotated 2013* (Thomson Round Hall, 2014)

Reports

Law Reform Commission *Report Legal Aspects of Professional Home Care* LRC 105-2011

Law Reform Commission *Report Advance Care Directives* LRC 94-2009

Law Reform Commission *Consultation Paper Advance Care Directives* LRC CP 51-2008

Invited Papers

- 2021 C Staunton, A Parziale, S Slokenberga, D Mascalzoni “Safeguards and responsibilities in biobank, databank and genetic research” 8th International Workshop on Genome Privacy and Security 22 September 2021
- 2021 “Open science, data sharing and data protection in biobank research” European, Middle Eastern & African Society for Biopreservation and Biobanking, 12 September 2021
- 2021 “Protection of Personal Information Act (POPIA) and NHLS Data” PathReD Conference, 12 August 2021
- 2021 “Protection of Personal Information Act (POPIA) and the processing of personal information of children: implications for clinical care & research” South African National Institute of Communicable Diseases 24 March 2021
- 2021 “Research and the General Data Protection Regulation” South African Academy of Sciences, 10 March 2021
- 2021 “Research and the Protection of Personal Information Act 2013” University of Cape Town, South Africa, 23 February 2021
- 2021 “Data Protection & the use of Health Data in South Africa” Department of Psychiatry, Stellenbosch University, South Africa, 23 February 2021
- 2021 “Schrems II: International data sharing & equity in health research” Computers, Privacy and Data Protection Conference, 27 January 2021
- 2020 “Research and the Protection of Personal Data Under the GDPR” Brussels Privacy Symposium, 2 December 2020
- 2020 “Protection of Personal Information Act 2013: implications for clinical practice” Wits Donald Gordon Medical Centre, Johannesburg, 25 November 2020
- 2020 “Towards a Code of Conduct for the National Health Laboratory Service” National Institute for Communicable Diseases, Johannesburg, South Africa, 19 November 2020

- 2020 “A proposal to reframe the regulatory tilt in genomic biobanking research in Africa” Mason Institute, University of Edinburgh, 21 January 2020
- 2019 “Benefits and Challenges of Health Data Sharing” Information Law and Policy Centre, University of London, 5 December 2019
- 2019 “Barriers to Assisted Reproduction” Feminism, Fertility and the Future Workshop, National University of Ireland, Galway, 4 December 2019
- 2019 Keynote: “Developing data governance frameworks for health research in Africa” International Society for Computational Biology & African Society for Bioinformatics and Computational Biology Conference, Kumasi, Ghana 12 November 2019
- 2019 Data governance and the use of health data for research” Lagos Ministry for Health, Nigeria, 6 November 2019
- 2019 Data governance and the use of health data for research” University of Ibadan, Nigeria, 4 November 2019
- 2019 “The Governance of Data Sharing for Health Research in South Africa” National Health Laboratory Service, Johannesburg, 30 July 2019
- 2018 “To use or not to use...The re-use of health research data according to international norms” EURAC, Italy, 5 July 2018
- 2018 “Genomic and biobanking research in Africa: procedural norms and benchmarks for good governance” KEMRI-Wellcome Trust, Kenya, 14 June 2018
- 2018 “Data sharing, biobanks and privacy” South African National Bioinformatics Institute, Cape Town, 21 May 2018
- 2018 “Good governance for genomic and biobanking research in Africa” Centre for Applied Ethics, Stellenbosch University, South Africa, 17 May 2018
- 2018 Keynote: “Good governance for stem cell research”, Bahrain, 6 May 2018
- 2018 “Emerging principles of good governance for genomic and biobanking research in Africa” UNISA, Pretoria, 3 May 2018
- 2018 “Engaging stakeholders to develop governance frameworks for genomic and biobanking research in sub-Saharan Africa” National Academy of Sciences, Hungary, 10 April 2018
- 2018 “Good governance for genomic and biobanking research in Africa” Central European University, Hungary, 12 February 2018
- 2017 “Consistently inconsistent: the regulation of stem cell research in Ireland” The Regenerative Medicine Institute, Ireland, 29 November 2017

- 2017 "Governance of genomic and biobanking research in Africa: legal challenges and ethical complexities" Centre for Research Ethics and Bioethics, Uppsala University, 13 February 2017
- 2016 "Data and sample sharing across borders" 4th Annual Bioethics Seminar, Cape Town, South Africa, 20 May 2016
- 2016 "Biobanking and public engagement" Workshop on human genetic research for Africa: improving outreach and public understanding, ICGEB, Cape Town, 25-26 February 2016
- 2015 "Effective Strategies for Engaging with Communities Around Biomedical Research" National Institutes of Health (NIH), Bethesda, Maryland, 14 October 2015
- 2014 "Empirical Research on HIV Cure Research" 2nd Annual Bioethics Seminar, Cape Town, South Africa, 25 October 2014
- 2014 "Informed Consent for HIV Cure Research in South Africa" at Unintended and Intended Implications of HIV Cure: A Social and Ethical Analysis, Brocher Foundation, Geneva, 7-9 May 2014
- 2014 "A failure to regulate, a failure to protect: embryonic stem cell research and the unprotected embryo" at Emerging Issues in Irish Health Care, University College Cork, Ireland, 4-5 April 2014
- 2013 "Challenges in Biobanking in Sub-Saharan Africa" 2nd Annual ARESA Seminar, Cape Town, South Africa, 19-20th September 2013
- 2012 "Achieving Consensus when Ethics is in Conflict" University of Manchester, December 2012
- 2012 "The Evolution of Reproductive Rights in Ireland: A Discussion" World Health Organisation, Geneva, November 2012