SOCiETY AND ETHICS RESEARCH GROUP

Overview of Outputs:
2016–2020
"We are social scientist and genetic counselling academics who believe in a partnership between science and society - we are all in this together to understand, communicate and improve human health."
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“Between 2016 and 2020 the Society and Ethics Research Group grew from just one person to a core team of 10 (including a PhD student and 2 affiliated staff members). Over that time we have built and consolidated a strong sense of identity, all working together to understand and explore the impact of genomics and biodata on people. We are very practically focussed, aiming to deliver social sciences work that genuinely makes a difference to shifting policy, practice and teaching, specifically within the field of genomic medicine.

We believe strongly that as academics, our work has to break out of academic circles, so that it can serve society in some way and so we pay particular attention to film making and translation of our work for media and public audiences. I am so proud to lead the team; we value a core set of personal skills, including humility, curiosity and fortitude and hope these will stand us in good stead as we move forward into the new Wellcome funding cycle. This report highlights some of our achievements over the last 4 years in terms of policy, journal citations, media presence and teaching.”

Prof Anna Middleton
Founder and Lead of the Society and Ethics Research Group
SER TEAM'S OBJECTIVES

Core Ambition:

To foster conversations, build trust and enable transparency, by engaging public audiences with the breadth of genomic science and its impact on society.

SER and PE joint objectives:

1. Enhance public awareness of genomics globally, focussing on diverse communities and crossing disciplines and barriers, to create shared understanding

2. Empower all stakeholders to engage with genomics, so that their voices are heard in research and policy, by enabling people-centred conversations

3. Improve and influence learning experiences and career journeys
TEAM PROFILES

Lauren Robarts - Senior Manager
Lauren supports all activities of the Society and Ethics Research group by project managing the logistical side of research projects and managing the team. Given her creative flare she also leads on everything relating to design, film production and multimedia. Lauren has a master’s degree in filmmaking from Goldsmiths, University of London and a bachelor’s degree in history and environmental science from Georgetown University in Washington DC.

Richard Milne - Senior Social Scientist
Richard is a sociologist of science, technology and medicine. He has particular expertise in qualitative research methods, including focus groups, interviews and ethnographic approaches. He received his PhD from University College London in 2010 and also currently holds a research post in the Institute of Public Health at the University of Cambridge. He has previously held posts at UCL, the University of Sheffield, Birkbeck University of London and on secondment at the PHG Foundation health policy think tank.

Alessia Costa - PDF Social Scientist
Alessia is a social anthropologist with an interest in multi-disciplinary research and expertise in qualitative methods, including ethnographic and socio-material approaches, interviews and participatory research. She has a strong interest in medical science and technologies, especially regarding patient experience, clinical practice and the social construction of scientific knowledge. Alessia received her PhD in 2015 from the School of Oriental and African Studies (SOAS) and has previously worked at the University of Reading and King’s College London.

Anna Middleton - Head of Group
Anna is a creative researcher with expertise in designing innovative surveys and conducting focus groups to explore and understand what people think about the application of genomics. She is passionate about delivering research that has real practical value. Her PhD is in Psychology and Genetics and she is also a registered genetic counsellor. She is Professor/Affiliate Lecturer, Faculty of Education, University of Cambridge.
Christine Patch – Principal Staff Scientist in Genomic Counselling
Having started her professional career as a nurse Christine has worked in genetics since the late 1980’s latterly as consultant genetic counsellor in an NHS regional genetics centre. She has been involved in direct patient care in addition to leading, developing and managing clinical genetic services during that time. Her PhD and post-doctoral work focused on evaluating genetic testing strategies. She maintained her nursing registration until January 2020, having recognised the major contribution that nurses and allied health professionals will make to genomic health care in the future.

Jerome Atutornu – Doctoral Candidate
Jerome is the inaugural PhD student for this collaboration between the Faculty of Education (University of Cambridge) and Wellcome Genome Campus Society and Ethics research group. His hope is that this study will unearth barriers to engagement so that culturally competent educational strategies can be employed to ameliorate these. Jerome is a lecturer in diagnostic radiography at the University of Suffolk in Ipswich and still practices radiography at Bury St. Edmunds.

Emma Garlick – Team Administrator
Emma assists with the day to day scheduling of the Society and Ethics Research group. She has an extensive background in administration having worked at the National Maritime Museum for the past 9 years in the Picture Library. Working closely with the museum’s Photography Department she has an eye for aesthetics and enjoys using pictures to explain complicated topics.

Katherine Morley – Affiliate Consultant Epidemiologist
Kate works for RAND Europe in Cambridge, she is subcontracted to lead on the statistical analysis of quantitative data collected by the group. She received her PhD from the University of Queensland, Australia, in 2007. She then took post-doctoral positions at the Centre for Molecular, Environmental, Genetic and Analytic Epidemiology at the University of Melbourne, the Department of Human Genetics at the Wellcome Trust Sanger.

Jonathan Roberts – Social Scientist
Jon works at the Society and Ethics Research group one day a week and the rest of the time he works clinically as an NHS Genetic Counsellor at Addenbrooke’s Hospital, Cambridge. Much of his research focuses on how developments in genetics and genomics are impacting society. He is particularly interested in genetics in popular culture and genetics and identity. Jonathan also has an ongoing research interest in patient empowerment and evidenced based genetic counselling.

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Felicity Boardman – Affiliate Social Scientist with a Specialism in Bioethics and Disability
Felicity is an associate professor in medicine ethics and society from Warwick Medical School. Her research career has focused on the social and ethical implications of genetic technologies, and in particular, their relationship to disabled people and their families. She is currently in receipt of a Wellcome Trust Investigator Award exploring attitudes towards pre-conception carrier screening in the “Imagining Futures” project.
**IMPACT ON POLICY:**
Policy where we have offered some consultation


IMPACT ON POLICY:
Policy we have written or directly contributed to


IMPACT ON POLICY:
Committee work with policy outcomes


- Middleton A (2019) Invited Ethics and Genomics lead for the Topol Review commissioned by the Secretary of State for Health


- Middleton A (2019) Roundtable on Governance of Human Genome Sequencing for the Centre for the Fourth Industrial Revolution UAE. Dubai 5th Nov, UAE

- Milne R (2020) Member of the Ethics and Feedback Advisory Group for the Accelerating Detection of Disease programme


Accelerating Detection of Disease

The Accelerating Detection of Disease challenge represents a pioneering programme to recruit 5 million volunteers into a research study that aims to invent new ways to detect and prevent the development of diseases.


Welcome

This is a survey about your online health data and how it might be used by others.

It's really simple – watch the films and answer a few questions. The films tell you all you need to know. Hover your mouse over underlined words and you’ll see a glossary.

The survey can be filled in by anyone and everyone, so please forward on. Your involvement is completely anonymous and we’ll store all your answers securely at the Wellcome Genome Campus, Cambridge, UK.

Consent is implied if you start answering the questions; Click here if you are in Australia, then come back to this page. Anonymous data from the study may be shared with other social science researchers for future studies.

At any point, you can bookmark this page and come back later.
- Milne R (2020) Societal considerations in host genome testing for COVID-19. Genetics in Medicine. Published online ahead of print, 8th June


- Voigt TH, Holtz V, Niemiec E, Howard HC, Middleton A, Prainsack B (2020) Willingness to donate genomic and other medical data: results from Germany. European Journal of Human Genetics. Published online ahead of print, 1st April


- Ormond KE, Laurino MY, Barlow-Stewart K... Middleton A (2018) Genetic counselling globally: Where are we now? American Journal of Medical Genetics (Special Issue: Genetic Counselling in the Era of Precision Medicine), vol. 178, issue 1, pp 98-107


- Thorogood A, Bobe J, Prainsack B... Middleton A et al on behalf of the Participant Values Task Team of the Global Alliance for Genomics and Health (2018) APPLaUD: access for patients and participants to individual level uninterpreted genomic data. Human Genomics, vol.12, article 7


PRESENTATIONS, CONFERENCES AND PUBLIC ENGAGEMENT

- Milne R (2020) Living in risk: bodies and space in ‘early’ disease detection. London School of Hygiene and Tropical Medicine medical anthropology seminar, December (up coming)


- Roberts J (2020) Problematic concepts in science communication: deficits, dialogues and expertise. Invited speaker as a part of the Society and Ethics Research Seminar Webinar Series. 28 July. Online

- Patch C (2020) How do we ‘do’ consent? Clinical & research models in genomic medicine 100,000 Genomes Project and beyond. Invited speaker as a part of the Society and Ethics Research Seminar Webinar Series. 12 August. Online


- Patch C, Roberts L (2020) A conversation between Christine Patch of Genomics England and Lauren Roberts of SWAN. Session 0103: Diagnosing Undiagnosed Rare Disease Patients: Tools and Resources to strengthen the voice of the undiagnosed Rare Disease Community at the 10th European Conference on Rare Diseases & Orphan Products. Online, 15th May

- Patch C (2020) Implementing a hybrid clinical/research model in genomic medicine: post 100,000 Genomes Project. Spoken presentation. European Society of Human Genetics 2020 Virtual Conference. 8 June. Online

- Implications
  - Personal utility: how to think and talk about ‘diagnosis’?
  - Implications for services: follow up care and family-centred communication
Global public survey

To understand attitudes and concerns related to the sharing of DNA and health information

37,000 completed samples, ‘representative’ public recruited via Dynata (global market research company)

22 countries
15 languages
Jerome Atutornu’s translation of the Your DNA Your Say survey into Twi (above, left) and him recording the Twi audios in the Radical Lounge Studios, Ipswich (above, right)


Milne R (2019) From Genomes to GPS: socially responsible research and the future of data-driven medicine. Invited speaker as a part of the Society and Ethics Research Seminar Series. 9 December. Wellcome Genome Campus, Cambridge, UK

Milne R (2019) Ethics and AI in medicine. Invited speaker as a part of the Sanger/EMBL-EBI Seminar Series. 3 December. Wellcome Genome Campus, Cambridge, UK


From Genomes to GPS: socially responsible research and the future of data-driven medicine

Dr Richard Milne | Wellcome Genome Campus Society and Ethics Research

Monday 9 December 12:30-13:30
Kendrew lecture theatre, Wellcome Genome Campus, CB10 1SA

The future of medicine is increasingly described in terms of ability of big data analytics to inform disease detection, diagnosis and treatment. Dr Milne will discuss the social and ethical questions associated with the collection, sharing and use of biomedical data at scale. He will report findings from the global Your DNA, Your Say study of public attitudes to genomic data sharing and ongoing work on challenges associated with data-driven medicine.

Guests external to Campus please register at bit.ly/SERseminarDDM

- Milne R (2019) Learning from experiments in public and participant involvement. Invited presentation at the 6th International Workshop on Genome Privacy and Security (GenoPri’19) Boston, USA, 21st October


- Middleton A (2017) Involving the public in conversations about genomics: making personalised medicine resonate. 1st European Alliance for Personalised Medicine Congress. 27-30 November, Belfast

- Middleton A (2017) Gnomes and Genomes. Public Engagement event: Genes at Queen’s; Queen’s University, Belfast 25th November


- Middleton A (2017) World Congress on Genetic Counselling. 4 – 6 October. Wellcome Genome Campus, Cambridge, UK

- Middleton A (2017) Socialising the Genome - making genomics resonate. World Congress on Genetic Counselling, 4th October, Cambridge UK. Spoken presentation


Patch C (2019) Genomics, patients and families; the practice of genetic counselling. Invited speaker, Swiss Society of Medical Genetics Annual Meeting 2019. 4 April. Lausanne, Switzerland


- Roberts, J (2018) Science on Screen. Panel discussion at the Francis Crick Institute, 7 November
- Roberts, J (2018) Introduction to early years researching. Presentation: British Society Genetic Medicine annual meeting, 2 October
- Middleton A (2016) DNA and Big Data. Invited panel member and presenter on Personalised Medicine: The Promise, the Hype and the Pitfalls. University of Oxford. 9 September, Oxford

- Roberts J (2016) Future of personalised medicine. Pint of Science, 30 May

- Middleton A (2016) Gathering attitudes from the public towards data sharing: survey and films. CHIPME meeting, 21st May, Barcelona, Spain


- Middleton A (2016) Overview of Genetic Counselling. 1 day workshop delivered with Dr Christine Patch from Guys and St Thomas’ Hospital. Invited by the Centre for Arab Genomic Studies as part of the Pan Arab Human Genetics Conference, Dubai 21-23 January
TEACHING


- Roberts J and Middleton A (2019, 2020) Designed and wrote What is Genetic Counselling for FutureLearn, a 6 week course, 2 hours per week, collaborating with Wellcome Genome Campus Advanced Courses and Scientific Conferences. Online, June

Dr Anna Middleton
Head of Wellcome Genome Campus Society and Ethics Research, Chair of Association of Genetic Nurses and Counsellors 2018/2019

Dr Jonathan Roberts
Genetic Counsellor Researcher, Wellcome Genome Campus Society and Ethics Research Group

- Milne R (2018) Teaching: Responsible Research and Innovation in Big Data Research, Computer Science doctoral training centre, University of Cambridge, December


- Middleton A (2017) Designed and co-delivered the yearly Genomic Practice for Genetic Counsellors course, 3 day course. Advanced Courses and Scientific Conferences, Connecting Science, Wellcome Genome Campus. Cambridge UK, 7 February
- Roberts J (2018) MSt Genomic Medicine (Module 1) Cambridge University, October


- Roberts J (2018) MSt Genomic Medicine (Counselling Module) Cambridge University, April

- Middleton A (2016) Socialising the Genome: Policy implications of genomics. Teaching on the Master programme at POLIS University of Cambridge, 17th Nov, 1st Dec, two hour sessions

- Middleton A (2016) Ethics and Genomics. Teaching on the Wellcome Trust Advanced Course for professionals: Molecular Pathology and Diagnosis of Cancer, Genome Campus, Hinxton, Cambridge, 14th October

Anna Middleton: The Genioz Study (2019) Australian Research Council Discovery grant “Understanding the Australian public’s expectations of personalised genomics” awarded to The University of Melbourne in November 2014, DP150100597, Co-Investigators: Prof Sylvia Metcalfe (Australia), Dr Ainsley Newson (Australia), Dr Kathleen Gray (Australia); Ms Bronwyn Terrill (Australia), A/Prof Clara Gaff, (Australia), Dr Anna Middleton (UK), Prof Brenda Wilson (Canada) ($582,200)

Richard Milne: Alzheimer’s Association Research Grant (AARG) (2019) “Co-creating an ethical framework for social media use in prevention trials” Co-applicants: Julie Robillard (Canada), Serge Gauthier, McGill University (Canada) Matthew Larriviere (UK) ($147,000)

Richard Milne: Wellcome Trust Seed Award in Humanities and Social Science (2018) For “An empirical ethics study of the development of data driven techniques for the assessment of cognition” (£90,000)

Anna Middleton: Translation Fund grant, Biodata Innovation Centre (2017) For “Music of Life” (£50,000)

Anna Middleton: Personal fellowship Wellcome Public Engagement (2016) ‘Socialising the Genome’ (£40,000)

Anna Middleton: Genomics England (2016) ‘Socialising the Genome’ (£40,000)

Anna Middleton: Academic Courses and Scientific Conferences Retreat grant, “A global genomics nursing alliance to accelerate integration of genomics into everyday professional practice”, Wellcome Trust. Co-applicants: Prof Maggie Kirk (UK), Prof Laurie Badzek (USA), Dr Caroline Benjamin (UK), Dr Kathleen Calzone (USA), Dr Jean Jenkins (USA), Dr Anna Middleton (UK), Dr Emma Ionkin (UK) (£30,000)

Anna Middleton: Medical Humanities Small Grant “Prioritising Participation”, 203161/Z/16/Z, Wellcome Trust. Co-applicants (all UK): Dr Pauline McCormack, Prof Simon Woods, Dr Anna Middleton, Dr Julia Willingale-Theune, Dr Steve Scott, Dr Saskia Sanderson, Prof Chris McKeivitt (£4,955)
The Genioz study aimed to investigate the Australian public's expectations of personal genomics.
Alessia Costa conducting an interview with a member of the public via Zoom for the SPACE project, 2020
TRADITIONAL PRESS/MEDIA


- Murphy M (2019) Quotes from Anna Middleton. ‘How popular at-home DNA tests are putting a strain on the NHS’ The Telegraph. 24th December

- Eugenics: Science’s Greatest Scandal (2019) Interview with Anna Middleton. BBC 4

- Graham, K (2019) Quotes from Jonathan Roberts. ‘Would you ask DNA detectives to predict if your child might get cancer? Thousands of families now use gene tests to see what the future holds.’ The Daily Mail. 3rd June

Graham K (2019) Interview with Jonathan Roberts. Would you ask DNA detectives to predict if your child might get cancer? Thousands of families now use gene tests to see what the future holds. Daily Mail. 3 June


Scialom M (2019) Interview with Anna Middeton. ‘DNA genie left bottle with ancestry testing’, says Wellcome ethics researcher. Cambridge Independent. Published online 22 May

Cocker R (2019) Quotes from Anna Middleton. ‘This Harvard scientist wants your DNA to wipe out inherited diseases – should you hand it over?’ The Telegraph. 16 March

McKie R (2019) Interview with Anna Middleton. ‘At last, hope for families living in the shadow of Huntington’s disease: An innovative drug may soon offer new ways to fight this cruel inherited condition.’ The Guardian. 3 March

Varghese S (2019) Quotes from Richard Milne. ‘How early is too early to find out you’ve got an incurable disease?’ WIRED. 5 February


- Cocker, R (2019) Quotes from Anna Middleton. ‘A mail-order DNA test revealed I had a half-brother I knew nothing about.’ The Telegraph. 26th January


- Scialom, M, (2018) Interview with Anna Middleton. ‘Cambridge life scientists comment on first-ever gene-editing of two girls in China.’ Cambridge Independent. Published online 5 December


- McKie, R (2018) Interview with Anna Middleton. ‘Woman who inherited fatal illness to sue doctors in groundbreaking case.’ The Guardian. 25th November


- Patel D, (2018) Interview with Anna Middleton. DNA+ Money, Radio 1 Stories. BBC iPlayer Radio 1


- Mann, C, (2017) [radio]. Interview with Anna Middleton. The Dotty McLeod Breakfast Show. BBC Radio Cambridgeshire. 21 June. 8:00


- Mills, G, (2017) [radio]. Interview with Anna Middleton. Do your genes reveal your disease destiny? Part of the show Should I sequence my genes? University of Cambridge Radio. 13 April


- Arney, K (2016) [radio]. Interview with Anna Middleton. Talking about genes, interview with Anna Middleton. University of Cambridge Radio. 5 April


- McKie, R (2016) Quotes and research featured from Anna Middleton. ‘Can’t figure out genetics? Here’s a handy guide: Advertising expert joins project to explain science in plain English.’ The Guardian. 13th March

- Robarts L (2019) Society and Ethics Research Wellcome Genome Campus. Delegates from the 2019 World Congress on Genetic Counselling

- Robarts L (2019) Society and Ethics Research: Behind the Scenes. Wellcome Genome Campus

- Robarts L (2018) Future of Genetic Counselling

- Robarts L (2018) Your DNA Your Say—the survey and translations


- Robarts L (2019) Society and Ethics Research Wellcome Genome Campus. Voices of Genetic Counsellors (playlist)

- Public Engagement exhibition, the content for the exhibition, films and genetic counsellors were all provided by Society and Ethics Research: “Empowering People: Genetic Counselling in Focus”. 2 October 2019–June 2020, Wellcome Genome Campus Conference Centre, Cambridge, UK
Christine Patch in the exhibition Empowering People: Genetic Counselling in Focus at the Wellcome Conference Centre
- Robarts L (2018) World Congress of Genetic Counselling 2017 Highlights
- Robarts L (2017) World Congress on Genetic Counselling 2017 Inspirations
- Robarts L, Middleton A (2017) Socialising the Genome - making genomics resonate. World Congress on Genetic Counselling, 4th October, Cambridge UK. Spoken presentation
- Robarts L (2017) Direct to Consumer Genetic Testing and Genetic Counselling

- Robarts L (2016) Genetic Counselling in Action role play videos


- Arney, Kat (2020) Can you have a ‘perfect genome’? Myths and misconceptions in genomics [Genetics Unzipped: The Genetics Society podcast, S3.06] 12th March

- Genetics Literacy Project (2020) Podcast: The phrase ‘Who’s Your (Grand) Daddy’ has shocking relevance to Jack Nunn, as the Australian geneticist learns of his surprising link to Britain’s most notorious ‘sperrinator’. Genetic Literacy Project: Science Not Ideology [Online]


- Graham, K (2019) ‘Would you ask DNA detectives to predict if your child might get cancer? Thousands of families now use gene tests to see what the future holds.’ The Daily Mail. 3rd June


- Cocker, R (2019) ‘This Harvard scientist wants your DNA to wipe out inherited diseases – should you hand it over?’ Yahoo News. 16th March


- I’m a Scientist Get Me Out of Here. (2019) Richard Milne was invited as an expert scientists on: Discussions on genetics with school children based around 2018 Royal Institution Christmas lectures. [online] January


- News-Medical.net (2018) Researchers outline the need to maintain public trust in use of health data for research


- Ria Novosti (2017) Your DNA Your Say project reviewed in a Russian newspaper: Thieves genes: why British scientists study the views of Russians about DNA. Ria Novosti [Online]


- Chico, V; Middleton, A (2017) Legal duty to share genetic information goes to trial. [Blog] GenomEthics


- Cancer Core Europe (2016) Your DNA Your Say survey; What if our DNA and medical information were part of our online footprint? [Blog] Cancer Core Europe
Imagine Science Film Festival (2020) Voices of Genetic Counsellors - So Much More Than Just a Test. New York, USA (Online). October 16-23

Raw Science Film Festival (2020) Music of Life: What is a Gene. The Shrine Auditorium, Los Angeles, USA. 16 April

The Tulane Public Health & Social Justice Film Festival (2020) Voices of Genetic Counsellors: So Much More Than Just a Test. The Tidewater Building, Tulane University, New Orleans, USA. 3 April


International Freethought Film Festival (2017) Socialising the Genome. Gallery at Avalon Island, Orlando, Florida, USA. 5-7 May
- New Medial Film Festival (2017) Socialising the Genome. The Landmark, Los Angeles, USA. 6 June
- International Freethought Film Festival (2017) Your DNA Your Say. Gallery at Avalon Island, Orlando, Florida, USA. 5–7 May
- International Filmmakers Festival (2017) Socialising the Genome. London, UK. 17 February
- New Filmmakers New York Winter Showcase (2017) Your DNA, Your Say. Anthology Film Archive, New York City, USA. 8 January
- Raw Science Film Festival (2016) Your DNA, Your Say. Zanuk Theatre at Fox Studios, Los Angeles, USA. 10 December
- Viten Film Festival (2016) Your DNA, Your Say. Museum of Natural History, Bergen, Norway. 12 November
- Awareness Film Festival (2016) Socialising the Genome. Heal One World, 1 Los Angeles, USA. 10 October