SOCIETY AND ETHICS RESEARCH GROUP

Overview of Outputs: 2016-2020

WELLCOME GENOME CAMPUS
CONNECTING
SCIENCE

"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."


BIG PHARMA RESEARCHER

CONTENTS

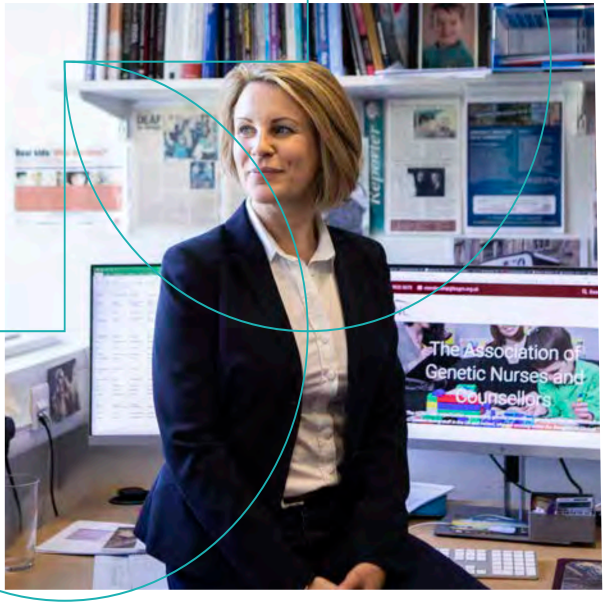
IMPACT ON POLICY

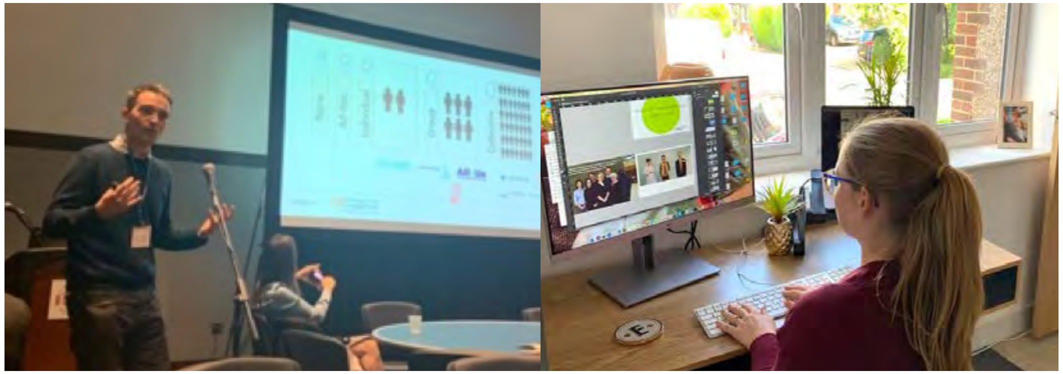
INTRODUCTION

"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

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.

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.

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.

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.

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.

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

- Cantú C, Cheng G, Doerr S, Frost J and Gambacorta L for the Bank for International Settlement (2020) On health and privacy: technology to combat the pandemic. BIS bulletin no. 17. 19th May

- Biotechnology Council (2020) White paper from the Global Future Council on Biotechnology. World Economic Forum (in press)

- Parliament. House of Commons Science and Technology Committee. 20 April 2018. Genomics and genome editing in the NHS Third report of session 2017-19 . HC 349. London: The Stationary Office. Reference 208, pg 31-32

Genomics and Genome Editing in the NHS

Read our report online now

House of Commons Science & Technology Committee

- Parliament. House of Commons Science and Technology Committee. 20 April 2018. Genomics and genome editing in the NHS Third report of session 2017-19 HC 349. London: The Stationary Office. Reference 144-146, 60, pg 26, 28

GENERATION GENOME

Annual Report of the Chief Medical Officer 2016

Generation Genome

- Milne R (2019) Ethics Lead for the Alzheimer's Research UK Early Detection of Neurodegeneration (EDoN) study'

- Davies, S.C. Annual Report of the Chief Medical Officer 2016. Generation Genome London: Department of Health (2017)

– Science and Technology Committee. Inquiry into Commercial Genetics. Anna Middleton called as a witness. Parliament Live TV. 15 October 2019. Online. Available at: https://parliamentlive.tv/

IMPACT ON POLICY:

Policy we have written or directly contributed to

- GA4GH Policy Framework: Participant, patient and public engagement in genomics research and health implementation (2020)

- Regulatory and Ethics Work Stream of the Global Alliance for Genomics and Health (2020) Responsible Data Sharing to Respond to the COVID-19 Pandemic: Ethical and Legal Considerations. 15th May

- Middleton A, Patch C (2020) Health Education England's Genomic Education Programme Nursing and Midwifery Round Table. London 27th January, UK

- Fellmann F, van El CG, Charron P... Patch C, et al (2019) European recommendations integrating genetic testing into multidisciplinary management of 2019.02.14 - Letter from Eric Topol to Anna sudden cardiac death. European 2019.02.14 - Letter from Eric Topol to Anna Journal of Human Genetics, vol. 27, pp 1763-1773

NHS
Health Education England

14th February 2019

Dear Anna,

It has been an extraordinary experience to have worked with you over the past year, culminating in the publication of our report and the launch program on Monday. Not knowing the way it would be received, it is gratifying to see the very supportive press coverage and positive feedback among peers on social media.

I thank you personally for so freely sharing your expertise, insights and time to help make the review something we can all be proud of, that it can surely help the NHS, and potentially more broadly around the world, towards restoring the care in healthcare.

After such a long period of working together there is a sadness (and relief, of course) in seeing the work draw to a close. I consider it a privilege to have had this unique opportunity to collaborate with you and such an exceptional group of people. Once again, I am appreciative of your contribution to the Review and look forward to staying in touch. Together we will track this post-review phase to be sure our recommendations are actualized, and that NHS healthcare transformation lives up to its potential.

Yours sincerely,

Dr Eric Topol

NHS

The Topol Review

Preparing the healthcare workforce to deliver the digital future

An independent report on behalf of the
Secretary of State for Health and Social Care
February 2019

THE NHS
CONSTITUTION
the NHS belongs to us all

- Topol Review (2019) Preparing the healthcare workforce to deliver the digital future. Final Report February 2019 – A Call For Evidence. Health Education England

IMPACT ON POLICY:

Committee work with policy outcomes

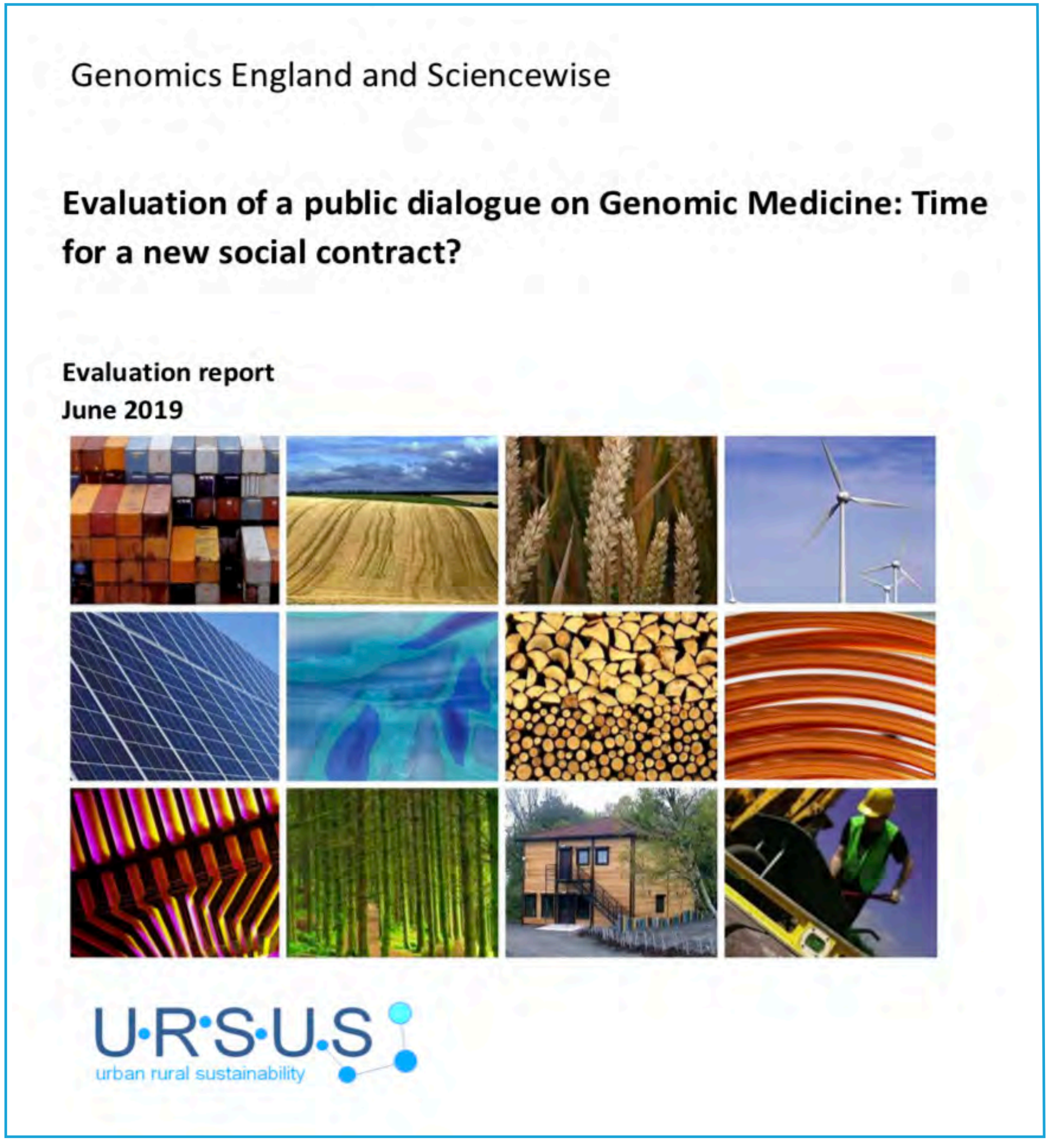
- Milne R (2020) European Health Data and Evidence Network (EHDEN) (2018). Available at: https://www.ehden.eu [Accessed 9 January 2020

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

- Middleton A chair (2019) Chair of Research Oversight Committee meeting. GenCOUNSEL: Optimization of Genetic Counselling for Clinical Implementation of Genome-Wide Sequencing. GenomeCanada: GenomeBC office,Vancouver, 5th December

- Middleton A (2019) Invited council member of the Global Future Council on Biotechnology. World Economic Forum 2-4th November, Dubai, UAE

- Middleton A (2019) Chair of the oversight committee for The Social Contract project: "Evaluation of a public dialogue on Genomic Medicine: Time for a new social contract?" Genomics England and Sciencewise Evaluation Report. June



Genomics England and Sciencewise

Evaluation of a public dialogue on Genomic Medicine: Time for a new social contract?

Evaluation report
June 2019

U·R·S·U·S
urban rural sustainability

- 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

- Lord Willis of Knaresborough’s Round table discussion (2019) Health Education England’s Genomics Education Programme - Nursing and Midwifery. Health Education England: Radisson Blu Edwardian, London, 1st May

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.

PUBLICATIONS

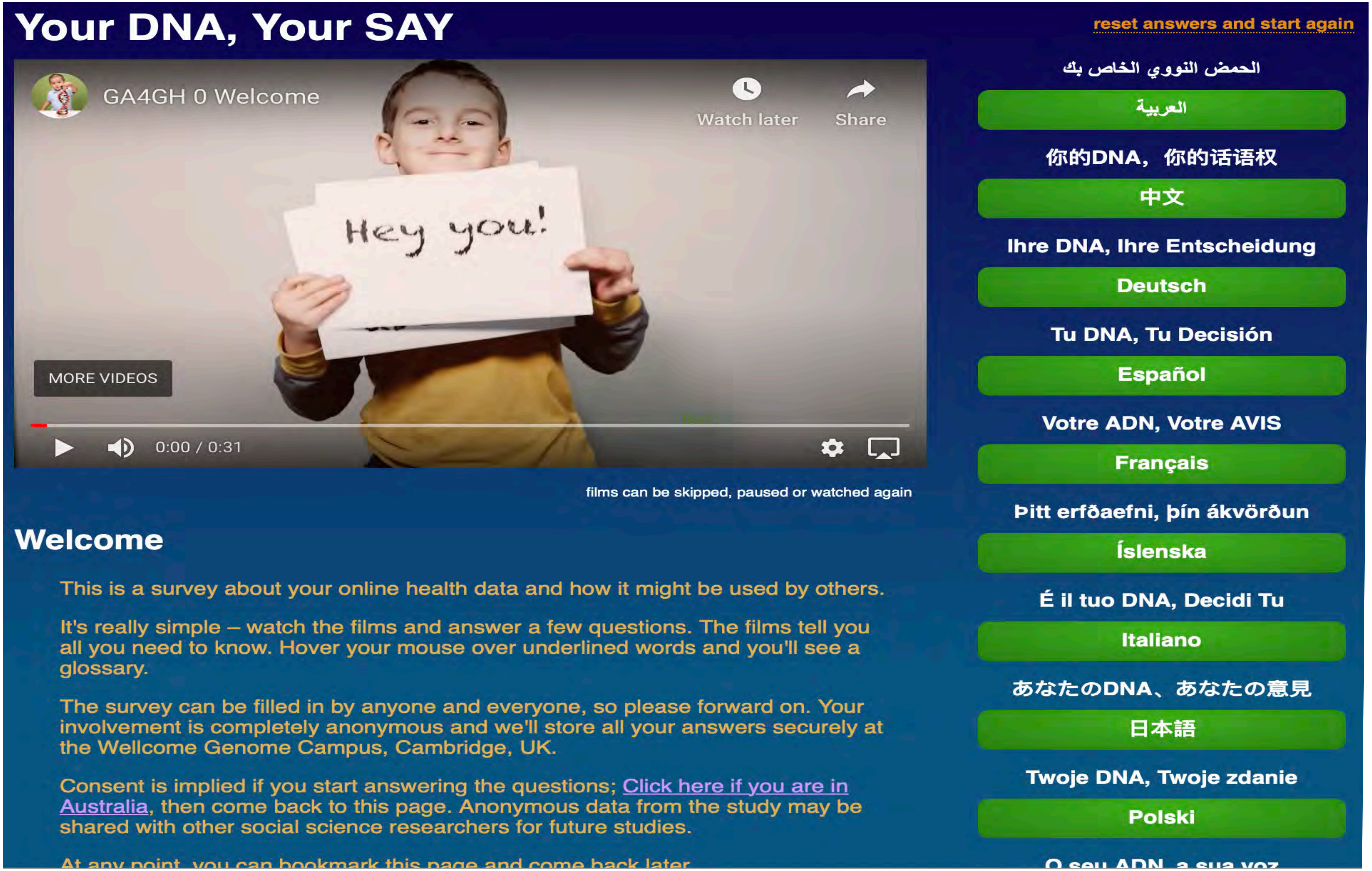
- Middleton A, Milne R, Atutornu, J… Patch, C, Robarts L, Roberts J, Morley, K et al (2020) Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data? American Journal Human Genetics (online publication 17th September 2020)

- Parkhill J, Lindsay SJ, Jones P… Roberts J, et al (2020) Oxford Biology Primers: Genomics. Oxford: Oxford University Press, pp 47-64

- Tonkin E, Calzone K, Badzek L… Middleton, A, Patch C, et al (2020) A Maturity Matrix for Nurse Leaders to Facilitate and Benchmark Progress in Genomic Healthcare Policy, Infrastructure, Education, and Delivery. Journal of Nursing Scholarship. Published online ahead of print, 27 June

AJHG
The American Journal of Human Genetics

- Middleton A, Patch C, Roberts J, Milne R, Costa A, Robarts L, Atutornu J (2020) Professional duties are now considered legal duties of care within genomic medicine. European Journal of Human Genetics. Published online ahead of print, 8th June



Your DNA, Your SAY

reset answers and start again

films can be skipped, paused or watched again

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.

الحمض النووي الخاص بك

العربية

你的DNA，你的话语权

中文

Ihre DNA, Ihre Entscheidung

Deutsch

Tu DNA, Tu Decisión

Español

Votre ADN, Votre AVIS

Français

Þitt erfðaefni, þín ákvörðun

Íslenska

É il tuo DNA, Decidi Tu

Italiano

あなたのDNA、あなたの意見

日本語

Twoje DNA, Twoje zdanie

Polski

O seu ADN, a sua voz

Your DNA Your Say survey page, Global public perceptions of genomic data sharing, American Journal of Human Genetics, 2020

- Milne R (2020) Societal considerations in host genome testing for COVID-19. Genetics in Medicine. Published online ahead of print, 8th June

- Milne, R., and Costa, A, (2020) Disruption and Dislocation in Post-COVID Futures for Digital Health. Big Data & Society, vol. 7, issue 2

JOURNAL OF NURSING SCHOLARSHIP

- Tonkin E, Calzone KA, Badzek L... Middleton A, Patch C, et al (2020) A Roadmap for Global Acceleration of Genomics Integration Across Nursing. Journal of Nursing Scholarship, vol. 52, issue 3, pp 329-338

- 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

- Middleton A, Milne R, et al (2020) Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data. European Journal of Human Genetics, vol. 28, issue 4, pp 424-434

- Milne R (2020) The rare and the common: scale and the genetic imaginary in Alzheimer’s disease drug development. New Genetics and Society, vol. 39, issue 1, pp 101-126

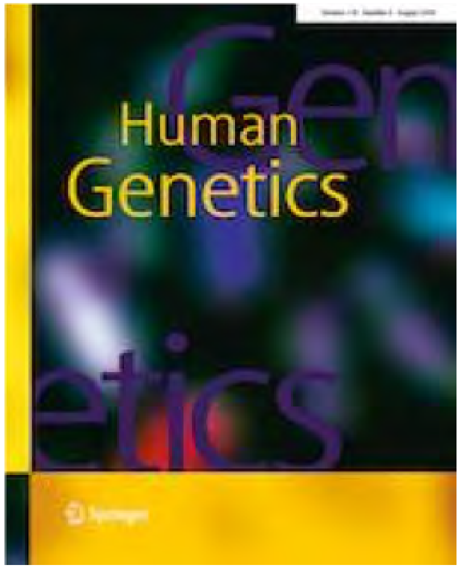
- Savard J, Hickerton C, Metcalfe SA... Middleton A, et al (2020) From Expectations to Experiences: Consumer Autonomy and Choice in Personal Genomic Testing. AJOB Empirical Bioethics, vol. 11, issue 1, pp. 63-76

- Fellmann F, Rial-Sebbag E, Patch C, et al (2020) ESHG PPPC Comments on postmortem use of genetic data for research purposes. European Journal of Human Genetics, vol. 28, pp 144-146, February

- Wright CF, Ware JS, Lucassen AM... Middleton A, et al (2019) Genomic variant sharing: a position statement [version 2; peer review: 2 approved]. Wellcome Open Research, vol. 4, no. 22

- Fellmann F, van El CG, Charron P... Patch C, et al (2019) European recommendations integrating genetic testing into multidisciplinary management of sudden cardiac death. European Journal of Human Genetics, vol. 27, pp 1763-1773

- Milne R, Morley KI, Howard H... Atutornu J, Farley L, Middleton A, et al (2019) Trust in genomic data sharing among members of the general public in the UK, USA, Canada and Australia. Human Genetics, vol. 138, issue 11-12, pp 1237-1246



- Sanderson SC, Hill M, Patch C, Searle B, Lewis C, et al (2019) Delivering genome sequencing in clinical practice: an interview study with healthcare professionals involved in the 100 000 Genomes Project. BMJ Open, vol. 9, issue 11

- Lewis C, Loe BS, Sidey-Gibbons C... Patch C, et al (2019) Development of a measure of genome sequencing knowledge for young people: The kids-KOGS. Clinical Genetics, vol. 96, issue 5, pp 411-417

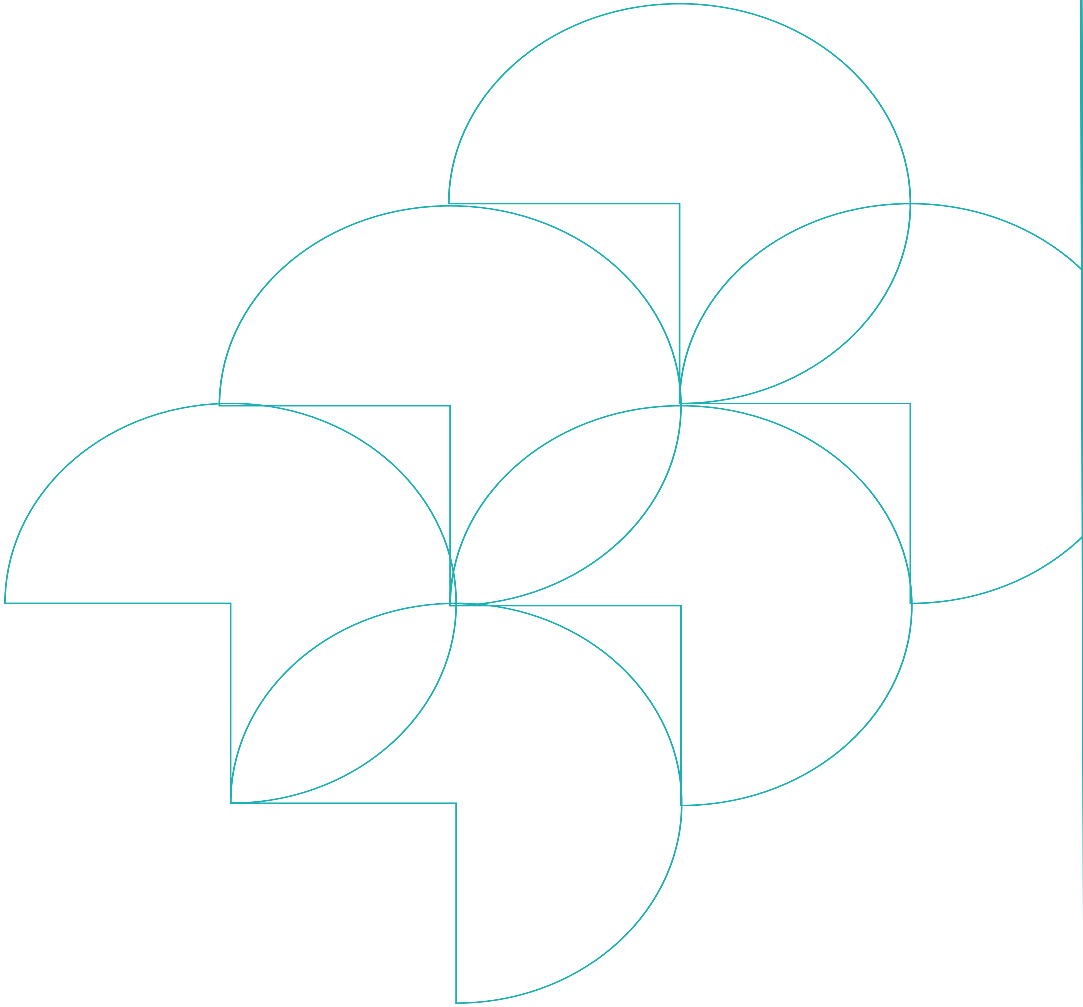
- Savard J, Hickerton C, Tytherleigh R... Middleton A, et al (2019) Australians' views and experience of personal genomic testing: survey findings from the Genioz study. European Journal of Human Genetics, vol. 27, issue 5, pp. 711-720

- Savard J, Hickerton C, Tytherleigh R... Middleton A, et al (2019) Australians' views and experience of personal genomic testing: survey findings from the Genioz study. European Journal of Human Genetics, vol. 27, issue 5, pp. 711-720

- Middleton A, Milne R, et al (2019) Attitudes of publics who are unwilling to donate DNA data for research. European Journal of Medical Genetics, vol. 62, issue 5, pp 316–323

- Metcalfe SA, Hickerton C, Savard J... Middleton A, et al (2019) Australians' perspectives on support around use of personal genomic testing: Findings from the Genioz study. European Journal of Medical Genetics, vol. 62, issue 5, pp 290–299

- Middleton A, Milne R, Robarts L, Roberts J, Patch C (2019) Should doctors have a legal duty to warn relatives of their genetic risks? The Lancet, vol. 394, issue 10215, pp 2133-2135



THE LANCET

Volume 394 · Number 10215 · Pages 2125–2200 · December 14–20, 2019 www.thelancet.com

"Our empirical work suggests that there is public support for a legal duty to inform relatives of their genetic risk of disease. However, turning a professional duty, as currently exists, into a legal duty would change the face of medicine."

See Comment page 2133

Editorial
The elusive end to HIV in the USA
See page 2125

Perspectives
Tore Godal: quiet colossus of global health
See page 2142

Articles
APBI after breast-conserving surgery for early-stage breast cancer
See page 2155

Articles
Obeticholic acid for the treatment of non-alcoholic steatohepatitis
See page 2184

Viewpoint
Air pollution and chronic airway disease
See page 2198

£5.00 Registered as a newspaper ISSN 0140-6736
Founded 1823 · Published weekly

- Machirori M, Patch C, Metcalfe A (2019) Black and Minority Ethnic women's decision-making for risk reduction strategies after BRCA testing: Use of context and knowledge. European Journal of Medical Genetics, vol. 62, issue 5, pp 376–384

- Patch C, Middleton A (2019) An evolution from genetic counselling to genomic counselling. European Journal of Medical Genetics, vol. 62, issue 5, pp 288-289

- Roberts J, Archer L, DeWitt J, Middleton A (2019) Popular culture and genetics; friend, foe or something more complex? European Journal of Medical Genetics, vol. 62, issue 5, pp 368–375

- Chico V (2019) Reasonable expectations of privacy in non-disclosure of familial genetic risk: What is it reasonable to expect? European Journal of Medical Genetics, vol. 62, issue 5, pp 308-301

- Abacan M, Alsubaie L, Barlow-Stewart K... Middleton A, et al (2019) The Global State of the Genetic Counseling Profession. European Journal of Human Genetics, vol. 27, issue 2, pp 183-197

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ELSEVIER

EUROPEAN JOURNAL OF
MEDICAL
GENETICS

Editor-in-Chief:
ALAIN VERLOES

- Sundby A, Watt Boolsen M, Sølvsten Burgdorf K... Middleton A et al (2019) The preferences of potential stakeholders in psychiatric genomic research regarding consent procedures and information delivery. European Psychiatry, vol. 55, pp 29-35

- Calzone K, Kirk M, Tonkin E... Middleton A (2018) Increasing nursing capacity in genomics: Overview of existing global genomics resources. Nurse Education Today, vol. 69, pp 53-59

- Lawler M, Morris A, Sullivan R... Middleton A, et al (2018) A roadmap for restoring trust in Big Data. The Lancet Oncology, vol. 19, issue 8, pp 1014-1015


Contents lists available at ScienceDirect

European Journal of Medical Genetics

journal homepage: www.elsevier.com/locate/ejmg

Editorial

World congress on genetic counselling

- Middleton A, Patch C, Biesecker B (2019) Editorial: World congress on genetic counselling. European Journal of Medical Genetics, vol. 62, issue 5, pp 287

- Middleton A, Patch C, Biesecker B (Eds) (2019) Evidenced-Based Genetic Counselling [Special issue]. European Journal of Medical Genetics, vol. 62, issue 5


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CONNECTING SCIENCE
SOCIETY+
ETHICS
RESEARCH

WELLCOME GENOME CAMPUS
CONNECTING SCIENCE
ADVANCED
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CONFERENCES

WORLD CONGRESS ON
GENETIC COUNSELLING

2-4 October 2019
Wellcome Genome Campus, UK

#WCG2019

Researching the impact
of genomics on people,
viewing this through the
lens of Genetic Counselling.

- Metcalfe SA, Hickerton C, Savard J… Middleton A (2018) Australians' views on personal genomic testing: focus group findings from the Genioz study. European Journal of Human Genetics, vol. 26, pp 1101-1112

- Middleton A, Niemiec E, Prainsack B… Farley L, Morley KI, et al (2018) 'Your DNA, Your Say': global survey gathering attitudes toward genomics: design, delivery and methods. Personalized Medicine, vol. 15, issue 4, pp 311-318

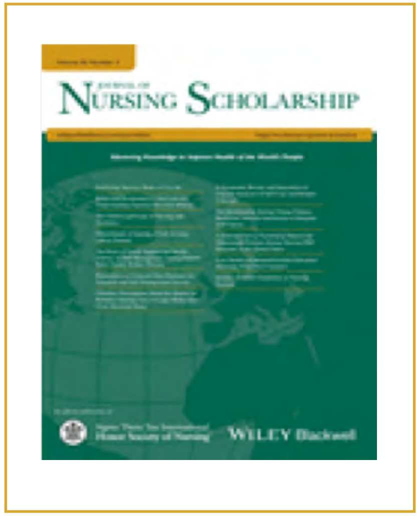
- Patch C, Middleton A (2018) Genetic counselling in the era of genomic medicine. British Medical Bulletin, vol. 126, issue 1, pp 27–36

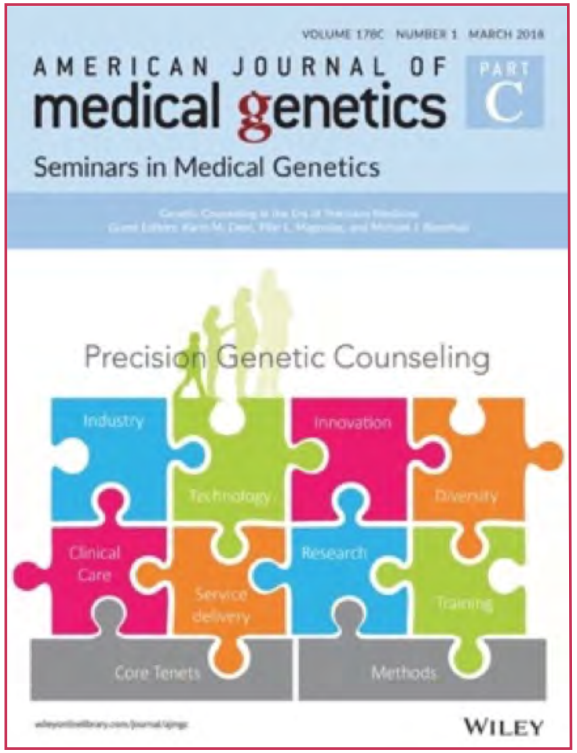
- Calzone KA, Kirk M, Tonkin E… Middleton A (2018) The Global Landscape of Nursing and Genomics. Journal of Nursing Scholarship, vol. 50, issue 3, pp 249–256

- 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

- Middleton A (2018) Society and personal genome data. Human Molecular Genetics, vol. 27, issue R1, pp R8–R13.

- 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





- Roberts J, Middleton A (2018) Genetics in the 21st Century: Implications for patients, consumers and citizens [version 2; peer review: 4 approved]. F1000Research, vol. 6, issue 2020

- Sundby A, Boolsen MW, Burgdorf KS... Middleton A (2017) Stakeholders in psychiatry and their attitudes toward receiving pertinent and incident findings in genomic research. American Journal of Medical Genetics Part A, vol. 173, issue 10, pp 2649-2658

- Ormond KE, Mortlock DP, Scholes DT... Middleton A et al (2017) Human Germline Genome Editing. American Journal Human Genetics, vol. 101, issue 2, pp 167-176

- Gray K, Stephen R, Terrill B... Middleton A et al (2017) Consumer Health Informatics Aspects of Direct-to-Consumer Personal Genomic Testing. Studies in Health Technology and Informatics, vol. 245, pp 89-93

- Middleton A (2017) Data Sharing and Participation: Your DNA, Your Say. The New Bioethics, vol. 23, issue 1, pp 74-80

- Middleton A, Mendes Á, Benjamin CM, Howard HC (2017) Direct to consumer genetic testing – where and how does genetic counselling fit? Personalized Medicine, vol. 14, issue 3, pp 249-257

- Parry V, Middleton A (2017) Socialising the Genome. The Lancet, vol. 389, issue 10079, pp 1603–1604

THE LANCET

- Middleton A, Marks P, Bruce A... Patch C, et al (2017) The Role of Genetic Counsellors in Genomic Healthcare in the United Kingdom: A Statement by the Association of Genetic Nurses and Counsellors. European Journal Human Genetics, vol. 25, pp 659–661

- Wright C, Middleton A, Barrett JC, Firth HV, FitzPatrick DR (2017) Returning genome sequences to research participants: Policy and practice [version 1; peer review: 2 approved]. Wellcome Open Research, vol. 2, issue 15

PRESENTATIONS, CONFERENCES AND PUBLIC ENGAGEMENT

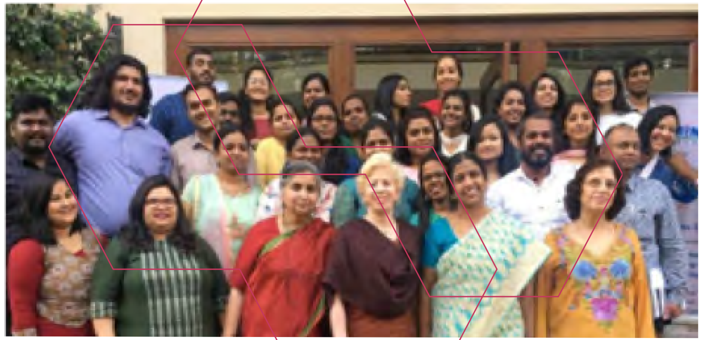
- Milne R (2020) Living in risk: bodies and space in `early’ disease detection. London School of Hygiene and Tropical Medicine medical anthropology seminar, December (up coming)

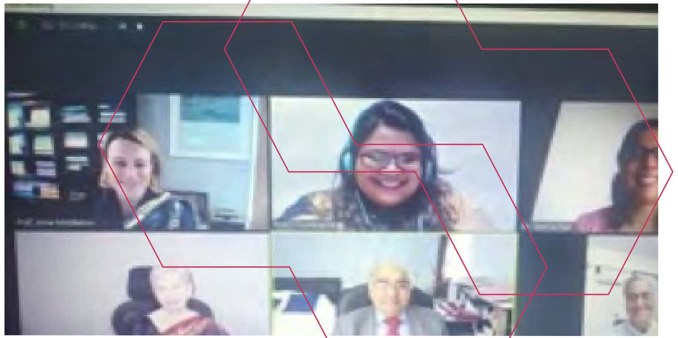
- Milne R (2020) Ethical challenges in the data-driven detection of dementia. In: 2020 Alzheimer Europe conference symposium on Dementia research and AI: ethical, legal and social implications, October (up coming)

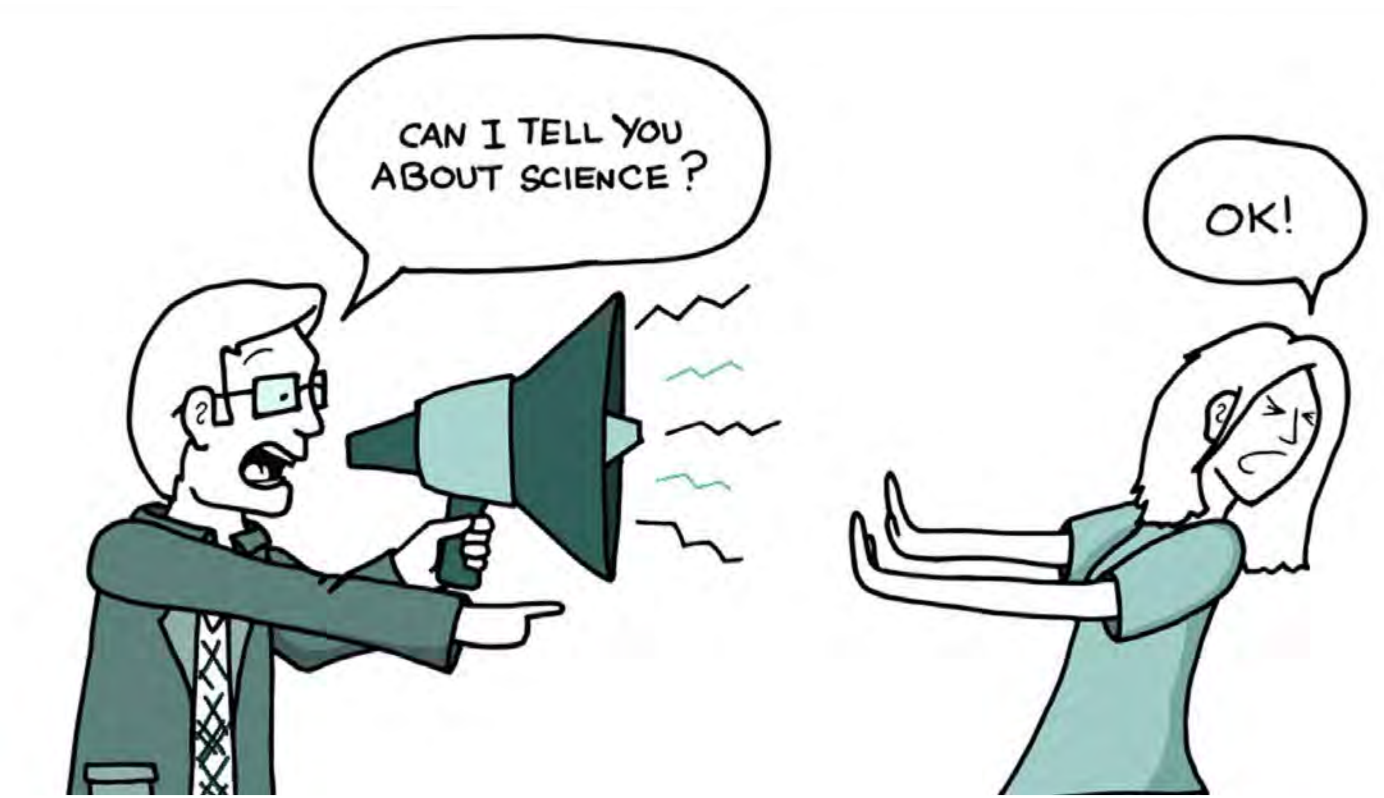
- Costa A, Milne R (2020) Detecting value(s): moral economies of digital innovation in early disease detection. Society for the Social Studies of Science: 4S/European Association for Studies of Science and Technology conference, August

- **Milne R, Costa A, Brenman N (2020) Casting long shadows: phenotyping dementia and the making of the digital ageing subject.** Society for the Social Studies of Science: 4S/European Association for Studies of Science and Technology conference, August

- Middleton A (2020) Ethics and genomic data sharing: global public attitudes. In: Board of Genetic Counselling India 5th Annual e-Conference 2020. 02 June. Online







- 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

- Milne R (2020) Covid and Society: The implications of immunity passports. Invited speaker as a part of the Society and Ethics Research Seminar Webinar Series. 9 July. 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

- Middleton A (2020) How to help society interact with genomic technology. Invited plenary speaker. European Society of Human Genetics 2020 Virtual Conference. 8 June. Online

- 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

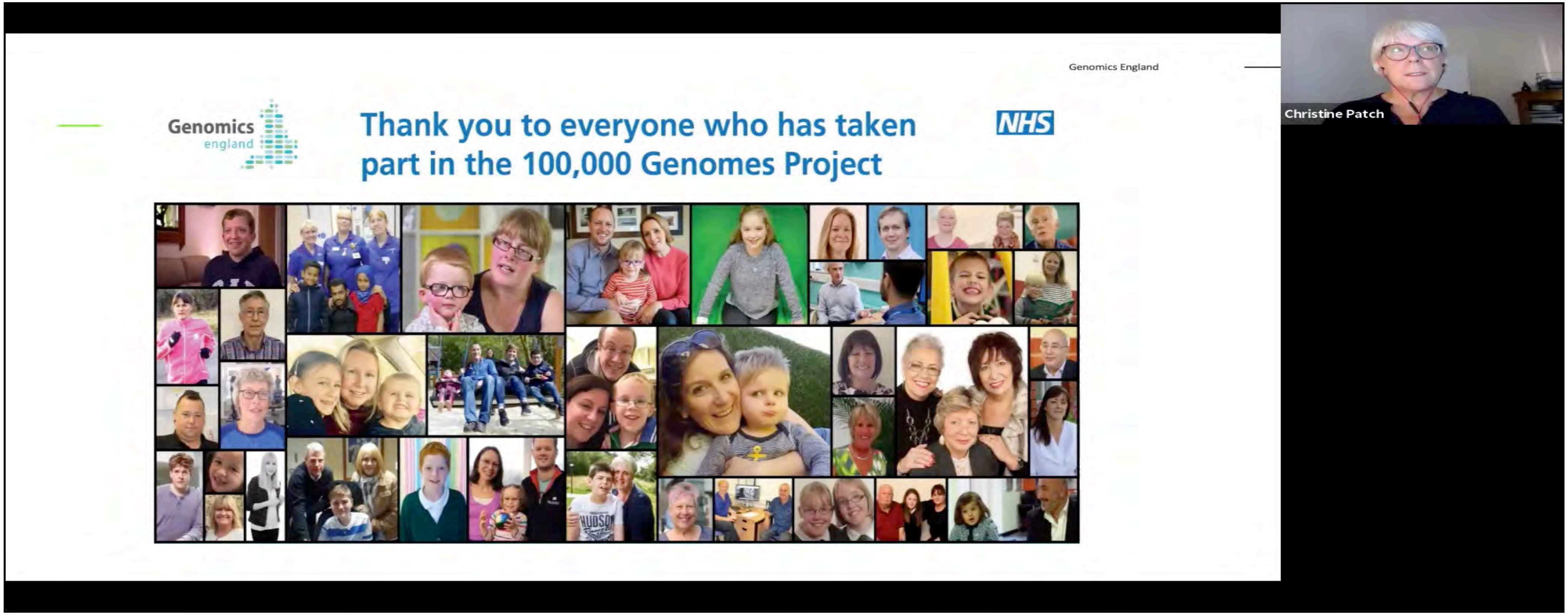
ESHG

Welcome to the European Human Genetics Virtual Conference

ESHG 2020.2 - Live in Your Living Room

JUNE 6–9, 2020

We are proud to present the ESHG 2020.2 speakers



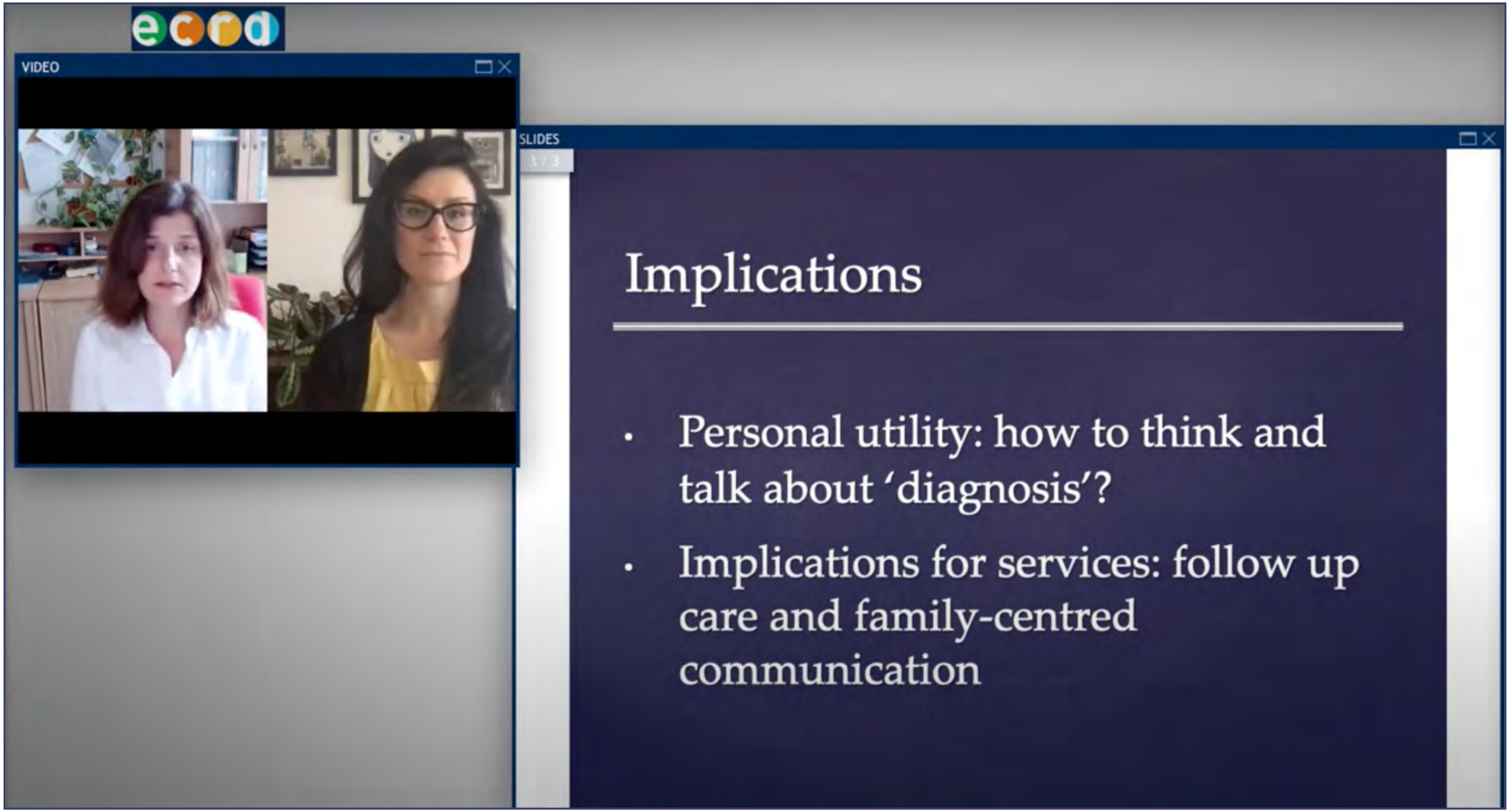
Genomics England

Genomics england

Thank you to everyone who has taken part in the 100,000 Genomes Project

NHS

- Costa A, Frankova V (2020) What next after the search for a diagnosis? Hearing families' experiences. Spoken presentation. Session 0104: What's Next After the Search for a Diagnosis? The Future of Specialised Health Services at the 10th European Conference on Rare Diseases & Orphan Products. Online, 15th May

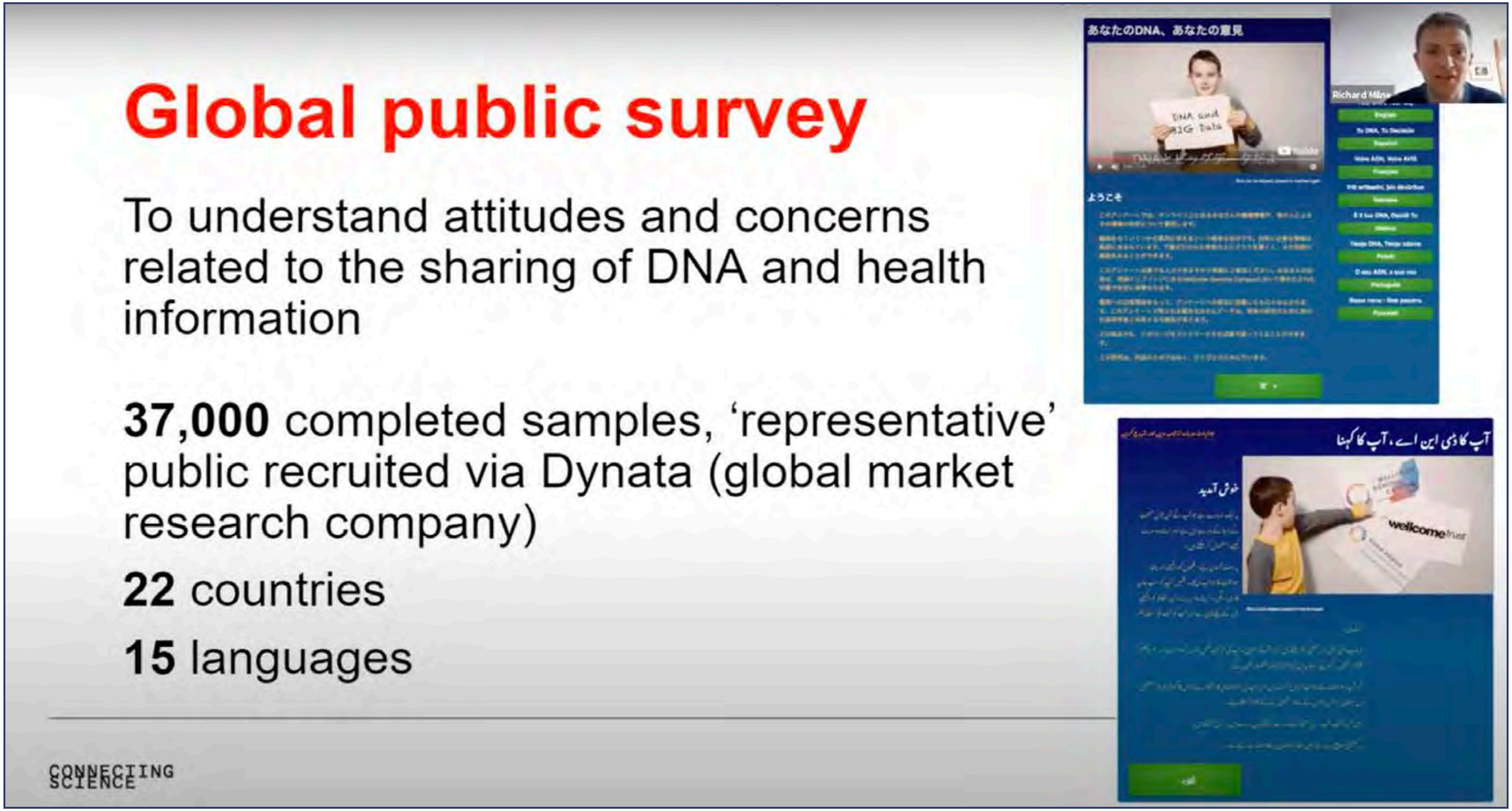


Implications

- Personal utility: how to think and talk about 'diagnosis'?
- Implications for services: follow up care and family-centred communication

- Milne R, Middleton A (2020) Your DNA, Your Say: Global public views on sharing genomic data. Invited presentation at Genomics in Health Implementation Forum. Online. 23rd March

- Patch C: Programme Committee Theme Leader (2020) The 10th European Conference on Rare Diseases & Orphan Products, 14-15th May Online



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

W'awoboasu ho asɛm yɛ w'asɛm

✔ Akwaaba

- Abɛɛfo ntentanfidie so ase ahyɛnsodeɛ
  - ○ Nipa/afoforo a wɔ bɛtumi ahwɛ/anya saa nsɛmmoano bi/yi
  - ○ Sɛ Adɔkotafoɔ bɛ̃tumi ahu/ahwɛ nsɛmmoano no
  - ○ Sɛ Ampɛ–mfaso nhwehwɛmufoɔ bɛtumi ahwɛ/anya nsɛmmoano no
  - ○ Sɛ Apɛ–mfaso nhwehwɛmufoɔ bɛtumi ahwɛ/anya nsɛmmoano no
  - ○ Ɔhaw a ebetumi asi
  - ○ Nsɛm a yɛ hwɛ anim
  - ○ Gyidie
  - ○ Nsɛmmisa a etwa to kakra bi a ɛfa wo ho
  - ○ Fa wo mmuae bra

undefined

Abɛɛfo ntentanfidie so ase ahyɛnsodeɛ

Wode woho nsɛm ato abɛɛfo ntentanfidie so pɛn (sɛ ebi a wo anaa obi na ɔde too hɔ)?

○ Mewɔ meho nsɛm wɔ abɛɛɛfo ntentanfidie so
○ Me ngye ndi sɛ meho nsɛm wɔ abɛɛfo ntentanfidie so
○ Me ntumi nka nsi so pi

Me pa wo kyɛw, yiyi nea ɛfa woho nyinaa wɔ mmuayɛ a ɛtoato so yi mu

Edin
nhwɛsoɔ; Blɔg, nkitahodi kuw, abɛɛfo ayɔnkofa ahodoɔ, nsɛmmoano bea ɛfa odo nketaho die,

Wo tenabea? (Akyikwan anaa Eɔmail)
nhwɛsoɔ: Abɛɛfo ntentanfidie so adwadie

Wo awo da
nhwɛsoɔ, abɛɛfo ayɔnkofa ahodoɔ, awontoatoaso, abusuantuatuasoɔ a ewɔ Abɛɛfo ntentanfidie so

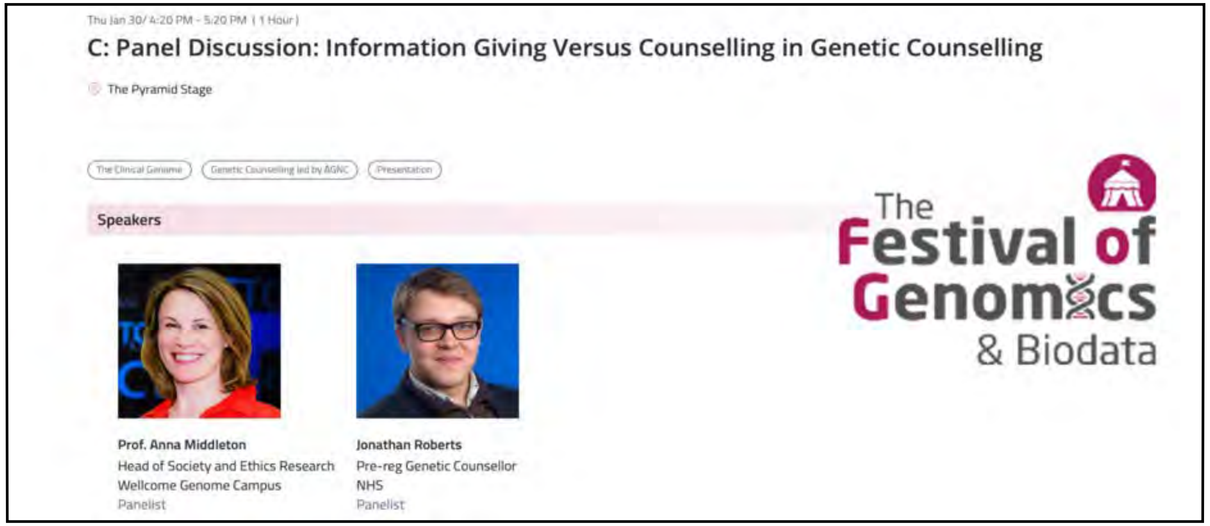
Sika korabea ho nsɛm
nhwɛsoɔ Abɛɛfo ntentanfidie so sikakorabea, toɔgye ho nsɛm

Ayaresa ho nsɛm
nhwɛsoɔ:, aduro nhyɛgye, apomuden ahyɛnsodeɛ, mfikyikɔ susudua, yadeɛ ho nsɛnkyerɛnne

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)

- Middleton A, Roberts J (2020) Panel Discussion: Information Giving Versus Counselling in Genetic Counselling. Festival of Genomics. London, UK, 30th January

- Roberts J (2020) Genetics in Pop Culture: Friend or Foe. Festival of Genomics. London, UK


Thu Jan 30/ 4:20 PM - 5:20 PM (1 Hour)

C: Panel Discussion: Information Giving Versus Counselling in Genetic Counselling

The Pyramid Stage

The Clinical Genome | Genetic Counselling led by AGNC | Presentation

Speakers

Prof. Anna Middleton
Head of Society and Ethics Research
Wellcome Genome Campus
Panelist

Jonathan Roberts
Pre-reg Genetic Counsellor
NHS
Panelist

The Festival of Genomics & Biodata

- 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

- Milne (2019) Ethical challenges associated with the prediction and prevention of Alzheimer's disease. Invited presentation at the PQMUL MOHR Intergrated Academic Training Symposium: Prediction and Prevention in Neurodegenerative Disease. London, UK, 29th November

- Middleton A (2019) The genetic testing maze: who is there to support you? Wellcome Genome Campus Connecting Science and the Association of Genetic Nurses and Counsellors. Cambridge, UK, 2nd October. panel chair/public engagement

- Middleton A (2019) The genetic testing maze: who is there to support you? Wellcome Genome Campus Connecting Science and the Association of Genetic Nurses and Counsellors. Cambridge, UK, 2nd October. panel chair/public engagement

SOCIETY AND ETHICS RESEARCH
SEMINAR SERIES

SOCIETY+
ETHICS
RESEARCH

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

WELLCOME GENOME CAMPUS

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

CONNECTING
SCIENCE

- Middleton A, Milne R (2019) Your DNA Your Say. Invited plenary presentation at the Global Alliance for Genomics and Health 7th Plenary Boston, USA, 22nd October

- 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

- Patch C (2019) Genetic Counselling in the Era of Genomics Medicine. Invited speaker as a part of the 6th Congress of the Serbian Genetic Society. 13 October. Hotel Fontanta, Vrnjačka Banja, Serbia

- Milne R (2019) Your DNA, Your Say: Public perceptions of genomic data sharing. Symposium on Personal Control of Genomic Data for Research. Bethesda, Maryland, USA via web, 26th September. Spoken presentation

- Atutornu J (2019) Ethnicity and ancestry in genomics. Invited speaker, EDIS Symposium, Wellcome Genome Campus, 9th September. Hinxton, Cambridge

- Atutornu J (2019) Scientific and ethical imperatives for opening up genomic research. "Let's get genomical" Pint of Science. Cambridge, UK, 22nd May. Spoken presentation/public engagement

- Middleton A (2019) Your DNA Your Say! "The genomic revolution: searching for a cure for the 1 in 17" Pint of Science. Cambridge, UK, 22nd May. Spoken presentation/ public engagement

- North K, Hill S, Goodhand P, Middleton A, Gaff C, Rehm H, Stark Z (2019) Panel: Sharing Resources - moving from research into clinical care at the 2019 National Initiatives Meeting. London, UK, 3rd May

- Patch C, Gaff C (2019) 'Research use of clinical (genomic) data: Experience of Genomics England/NHS and Australian Genomics.' 2019 National Initiatives Meeting. London, UK, 3rd May

WGC Advanced Courses and Scientific Conferences · 9 Sep 2019

Jerome Atutornu from our Connecting Science @ConnectingSci: Society and #Ethics team, discussing sample disparity in #genomics research at #EDIS2019 @Genomethics @TADG_Creavin

- Milne R (2019) Learning from Patients, Learning from Animals: translation in dementia research. 'Patient and Public Involvement and Engagement (PPIE) with Animal Research-Scientist and Stakeholder Workshop'. 11th April, London

- Patch C (2019) Delivery of ethical and effective genomics health care. Invited speaker, Winds of Change, 43rd Human Genetics Society of Australasia (HGSA) Annual Scientific Meeting. 4 August. Wellington, New Zealand

- Patch C (2019) Genetic Nurse to Genetic Counsellor to Genomics: Reflection on 30 years. European Society for Human Genetics Annual Conference, ELPAG Awards Lecture. Gothenburg, Sweden, 17th June. Spoken presentation


Ramona Moldovan
@ramonazmoldovan

Such a treat! Aad Tibben & Christine Patch, the genetic counselling stars we celebrated #eshg2018 and #eshg2019. Congratulations Chris for well deserved ELPAG award ✨


Sian Ellard
@EllardSian

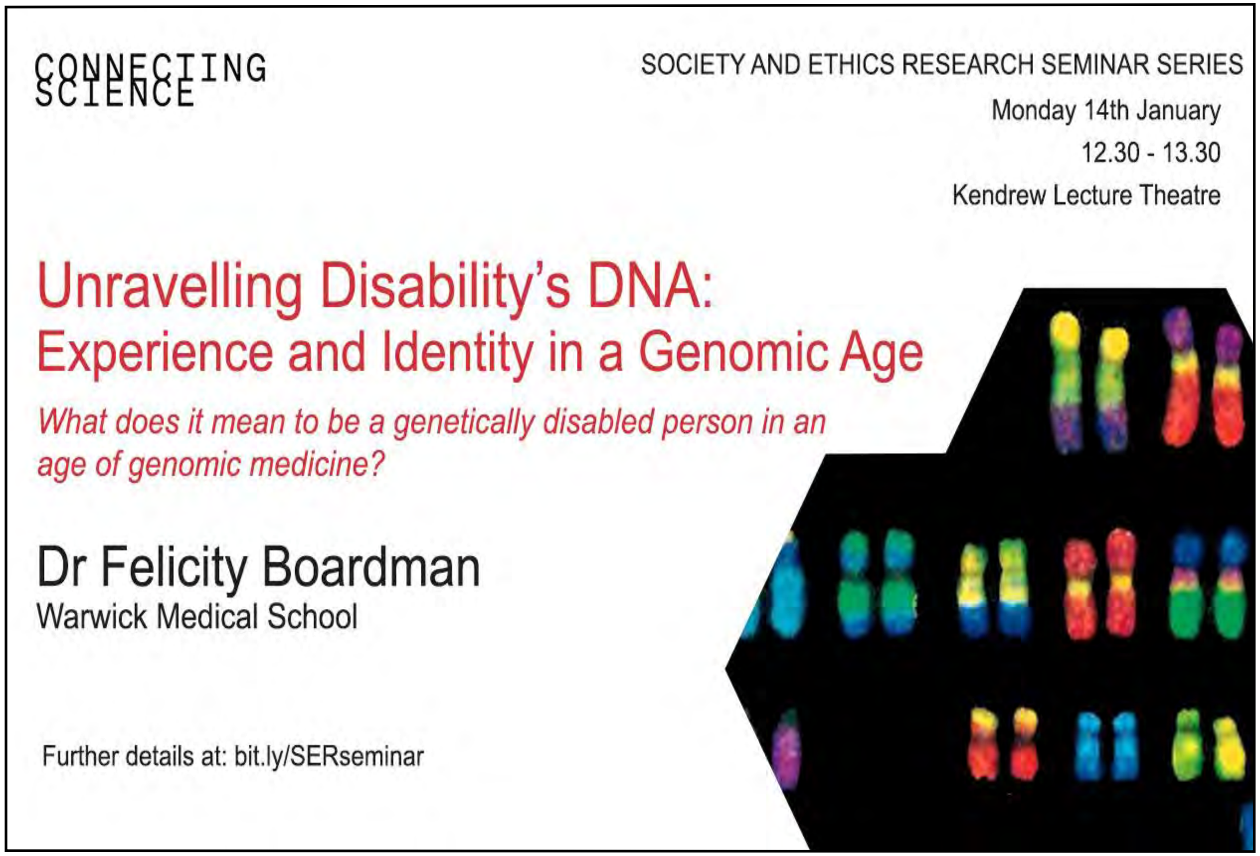
Many congratulations to Chris Patch giving the ELPAG award lecture #ESHG2019 @BritSocGenMed @Genomethics @theAGNC

- Middleton A (2018) Public attitudes towards genomics and genomic data sharing. Responsible Genomic Data Sharing Panel: Right to Benefit at the Global Alliance for Genomics and Health (GA4GH) 6th Plenary. Basel, Switzerland, 4th October

- Middleton A (2018) How is society responding to genomics? Invited speaker at New Scientist Instant Expert Masterclass, 'You and Your Genome.' 2 June, London

- Middleton A (2018) Society and Ethics Research 2017/2018 Review. Presentation at the Connecting Science Annual Review, 22nd May, Wellcome Genome Campus Conference Centre, Cambridge

- Middleton A (2018) How is society responding to genomics? Invited speaker at New Scientist Instant Expert Masterclass, 'You and Your Genome.' 2 June, London



CONNECTING SCIENCE

SOCIETY AND ETHICS RESEARCH SEMINAR SERIES
Monday 14th January
12.30 - 13.30
Kendrew Lecture Theatre

Unravelling Disability's DNA:
Experience and Identity in a Genomic Age

What does it mean to be a genetically disabled person in an age of genomic medicine?

Dr Felicity Boardman
Warwick Medical School

Further details at: bit.ly/SERseminar

- Boardman F (2019) Unravelling Disability's DNA: Experience and Identity in a Genomic Age. Invited speaker as a part of the Society and Ethics Research Seminar Series. 14 January. Wellcome Genome Campus, Cambridge, UK

- Middleton A (2018) Society and Ethics Research 2017/2018 Review. Presentation at the Connecting Science Annual Review, 22nd May, Wellcome Genome Campus Conference Centre, Cambridge

- Middleton A (2018) Cambridge Science Festival 2018, Genomics in a Jiffy, 22 March. Michaelhouse Cafe, Cambridge, UK

- Middleton A (2018) Your DNA, Your Say – public attitudes towards genomic data sharing. Festival of Genomics. London, UK, 30th January

- Middleton A (2018) Public Engagement Efforts: Your DNA, Your Say. Second International Summit on Human Genome Editing, Hong Kong, 29th November. Spoken presentation and panel discussion

- 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 (2018) 'Music of Life' a new metaphor for genomics, delivered as film within genetic counselling. EMPAG conference within European Society of Human Genetics Conference. Milan, 16th June

- Middleton A (2017) Your DNA, Your Say. Genetics Society/British Society for Genetic Medicine Meeting. Royal Society, London 23-24 November

- Middleton A (2017) Your DNA, Your Say. GA4GH 5th Plenary. Hilton Orlando, USA 17th October. Spoken presentation

- Chico V (2017) ABC v St Georges Healthcare NHS Trust: Sharing genetic information in families. World Congress on Genetic Counselling. 4th-6th Oct. Wellcome Genome Campus, Cambridge, UK

- Roberts J (2017) Genetics and Popular Culture. World Congress on Genetic Counselling. 4th-6th Oct. Wellcome Genome Campus, Cambridge, UK

- 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

- Middleton A (2017) Making genomics more 'sociable': talking to patients about the science. Improving Patient Care and Outcomes: Genomics Transforming Healthcare. Yorkshire and Humber NHS Genomics Medicine Centre. 27th September. Studio Venues, Leeds

- Middleton A (2017) Engaging with our Research: Your DNA, Your Say. Wellcome Trust Back to Bases series, London 25th September

- Wayne MacGregor, contemporary dance choreographer. The Society and Ethics Research group were consulted as experts on genomics and ethics for the 2017 dance performance and tour called (chor.) 2017," Autobiography" premiered 5 October- 6 October 2017, Sadler's Wells Theatre, London, UK, viewed 4 October 2017

- Middleton A (2017) Who decides what's right in genomics - why the public matters. Kaleidoscope Melting Pot event. London 20 Sept

- Middleton A (2017) Socialising the Genome - making genomics resonate. World Congress on Genetic Counselling. 4th-6th Oct. Wellcome Genome Campus, Cambridge, UK

- Middleton A (2017) Socialising the Genome via Your DNA, Your Say. 17th Biennial Congress of the Southern African Society for Human Genetics. 14th August. Durban, S.Africa

- Middleton A (2017) Socialising the Genome (how we did it). GC-SA Genetic Counsellors Workshop. SASHG Bienneial Congress. 12th August. University of Kwazulu-natal, S.Africa

- Middleton A (2017) Genomic Counselling. Genetic Counsellors Workshop at the SASHG Biennial Congress 2017. 12th August. University of Kwazulu-Natal, S.Africa

- Middleton A (2017) Socialising the Genome. Genetic Counsellors Workshop at the SASHG Biennial Congress 2017. 12th August. University of Kwazulu-Natal, S.Africa

- Middleton A (2017) Socialising the Genome. Invited keynote at the Congresso Interdisciplinar en Genetica Humana 25-28 April, Madrid

- Middleton A (2017) Public Perceptions of Genomics. Invited keynote at the Association of Genetic Nurses and Counsellors annual conference. Leeds, 24th April

- Middleton A (2017) Ethics and Genetics. Invited presentation to the Forward Institute Leaders residential course, 22nd March, Wellcome Genome Campus Conference Centre, Cambridge

SCIENTIA ET LABORE

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Public Lecture

THE DIVISION OF HUMAN GENETICS

GC NETWORK, (Pty) Ltd

Dr Anna Middleton

Cambridge, UK

"Socialising the Genome"

Thursday 10 August 2017
16:00 – 17:00

- Middleton A (2017) Your DNA, Your Say. Cambridge Festival of Science evening event with the public. 13th March, Michael-House cafe, Cambridge

- 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

- Alexander A, Bodra A, Milne R, Whitaker K, (2019) Automating the crowd: Who is the real Mechanical Turk? 22nd January. The Alan Turing Institute, London, UK

- Milne, R (2019) I'm a Scientist Get Me Out of Here. Discussions on genetics with school children based around 2018 Royal Institution Christmas lectures. [online] January

- Middleton A (2018) How is society responding to genomics? Second Annual Genomic Medicine Conference. Cambridge, UK, 5th December. Spoken presentation

- Middleton A (2018) Your DNA, Your Say – public opinion on data sharing. RAREfest 2018. Cambridge, UK, 1st December. Spoken presentation

- Middleton A (2018) 'Public responses to genomics - global views'. 2nd EAPM Congress. Milan, Italy. 26th November. Spoken presentation

- Middleton A (2016) Socialising the Genome. Invited Ann McPherson Memorial Lecture. Green Templeton College, 10th October, Oxford

- Middleton A (2016) Prioritising Participation: Your Genome, Your Research Agenda. Introduction to Participant GeCIP for Social Science and Ethics. Wellcome Trust, 29th September, London

- 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

- Chico, V (2016) Sharing genetic information in families. Kendrew Auditorium, EBI, Wellcome Genome Campus, Cambridge, England 26th September. Spoken presentation

- Middleton A (2016) Genome Data Privacy. Invited panel member for public event by the British Science Association, supported by Genomics England. Wellcome Collection, 20 September, London

- Middleton A (2016) DNA and Big Data. Invited panel memberand presenter on Personalised Medicine: The Promise, the Hype and the Pitfalls. University of Oxford. 9 September, Oxford

- Middleton A (2016) Invited Closing Keynote Speaker: Socialsing the Genome. International Society of Nurses in Genetics (ISONG) World Congress, 6th August, Dublin, Ireland. Spoken presentation

- Middleton A (2016) Attitudes towards genomic data sharing. Curating the Clinical Genome conference, 23rd June, Cambridge UK. Spoken presentation

- Middleton A (2016) Socialising the Genome. Social and Behavioural Research in Genomic Medicine Symposium. UCL Institute of Child Health, London, 17 June

- Metcalfe SA, Terrill B. Hickerton C, Savard J, Turbitt E, Newson A, Gaff C, Gray K, Middleton A, Wilson B (2016) Exploring Australian public knowledge and understanding of genetic concepts and terminology in the era of personal genomics. European Society of Human Genetics, 23rd May, Barcelona, Spain. Spoken presentation

- Middleton A, Borra J, Parry V, Nevin-Ridley K, Sanders A, Rayner J (2016) Socialsing the Genome. European Society of Human Genetics, 23rd May, Barcelona, Spain. Spoken presentation

- Roberts J (2016) Futue 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) Teaching technology and genomics in a rapidly changing environment in the UK. Global trends in genetic counsellor education. Transnational Aliance of Genetic Counseling (TAGC) Fourth International Meeting. The Global State of Genetic Counseling, 20th May, Barcelona, Spain

- Middleton A (2016) Invited chair and organiser of the credentialing session for Transnational Aliance of Genetic Counseling (TAGC) Fourth International Meeting. The Global State of Genetic Counseling, 19th May, Barcelona, Spain

- Middleton A, Borra J, Parry V, Nevin-Ridley K, Sanders A, Rayner J (2016) Socialising the Genome. International Congress of Human Genetics. 036-6. Kyoto, Japan 7th April. Spoken presentation

- Middleton A on behalf of the DDD project (2016) Engaging 7,000 people about the return of results from sequencing research. International Congress of Human Genetics. CIS18-4. Kyoto, Japan 5th April. Invited Plenary Spoken presentation

- Middleton A (2016) Gathering attitudes from the public towards data sharing: survey and films. GA4GH Global Engagement Workshop. Kyoto International Convention Centre, Japan 3rd April. Spoken presentation

- 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

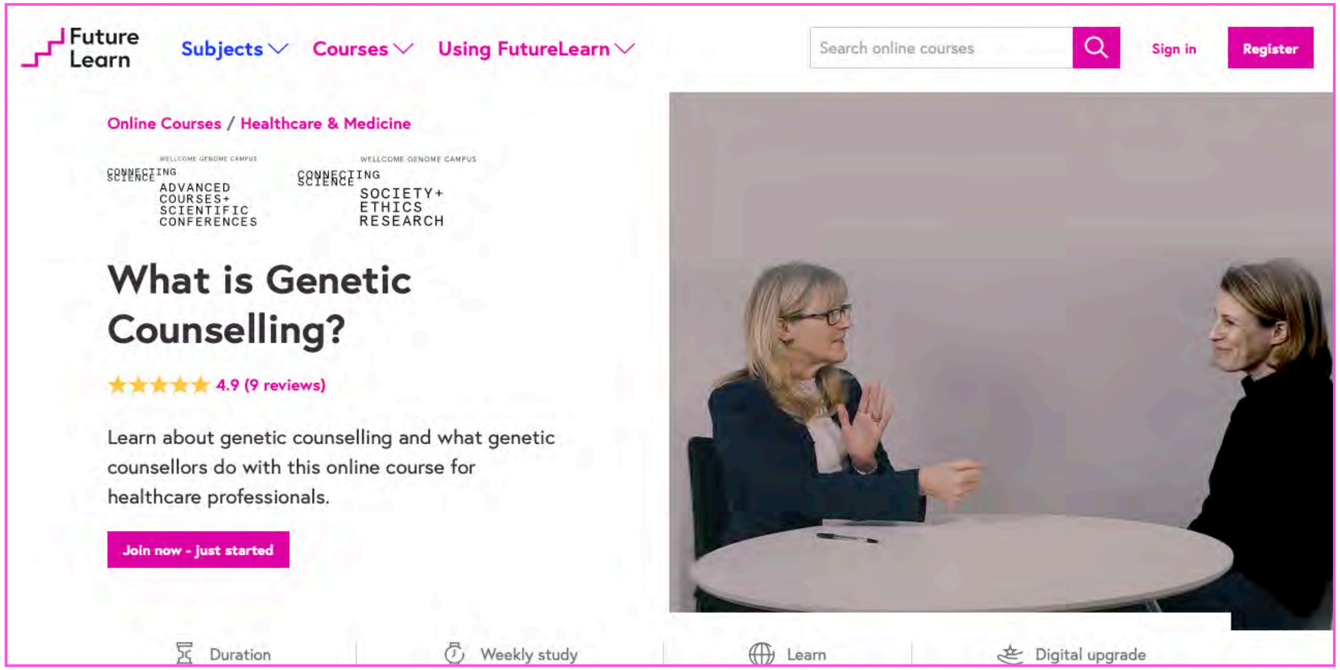
- Milne R (2020) Ethics, Genomics and Society. Stem Cell Research doctoral training centre, King’s College London, 17th January

- Middleton A (2019) Delivered lecture on the Molecular Pathology and Diagnosis of Cancer course. Advanced Courses and Scientific Conferences, Connecting Science, Wellcome Genome Campus. Cambridge UK, 21 November

- Milne R (2019) Ethics and Genomics. Current ethical issues in genomics (Workshop). 4-Year PhD Programme, Wellcome Trust Sanger Institute & University of Cambridge, 19th June

- 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

- Middleton A (2019) Delivered course introduction on the Genomic Practice for Genetic Counsellors course. Advanced Courses and Scientific Conferences, Connecting Science, Wellcome Genome Campus. Cambridge UK, 28 January



What is Genetic Counselling?

Learn about genetic counselling and what genetic counsellors do with this online course for healthcare professionals.

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

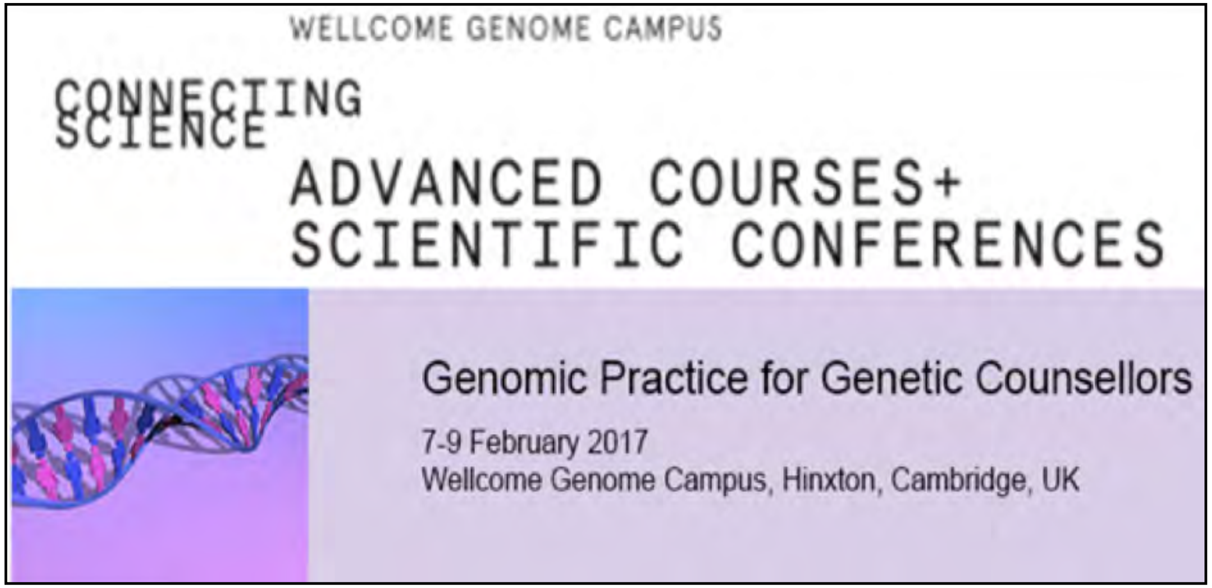
- Milne R (2019) Genomics and Ethics. Stem Cell Research doctoral training centre, King's College London, 11th January

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

Milne R (2018) Ethics and Genomics. Teaching on Responsible Research and Innovation in Big Data. The Centre for Scientific Computing, University of Cambridge, December

- Middleton A and Kenwrick Sue (co-module leads) (2017 and 2018) Designed, delivered and co-ordinated the Counselling Skills for Genomics module (150 hours) on the Mst Genomic Medicine for health professionals, supported by Health Education England. University of Cambridge, 3-7 April

- 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



WELLCOME GENOME CAMPUS

CONNECTING SCIENCE

ADVANCED COURSES+ SCIENTIFIC CONFERENCES

Genomic Practice for Genetic Counsellors

7-9 February 2017
Wellcome Genome Campus, Hinxton, Cambridge, UK

Gateway to Genetic Counselling

for Nurses & Midwives

UNIVERSITY OF CAMBRIDGE

Image: Darryl Leja, NHGRI

Assessed courses in Human Genomics & Genomic Counselling to prepare Nurses and Midwives for the increased role of genetics in healthcare.

- Funding available for NHS staff from Health Education England
- For information or to apply contact: Kath.Dogan@ice.cam.ac.uk

NHS
East of England
NHS Genomic Medicine Centre

- Roberts J (2018) MSt Genomic Medicine (Module 1) Cambridge University, October

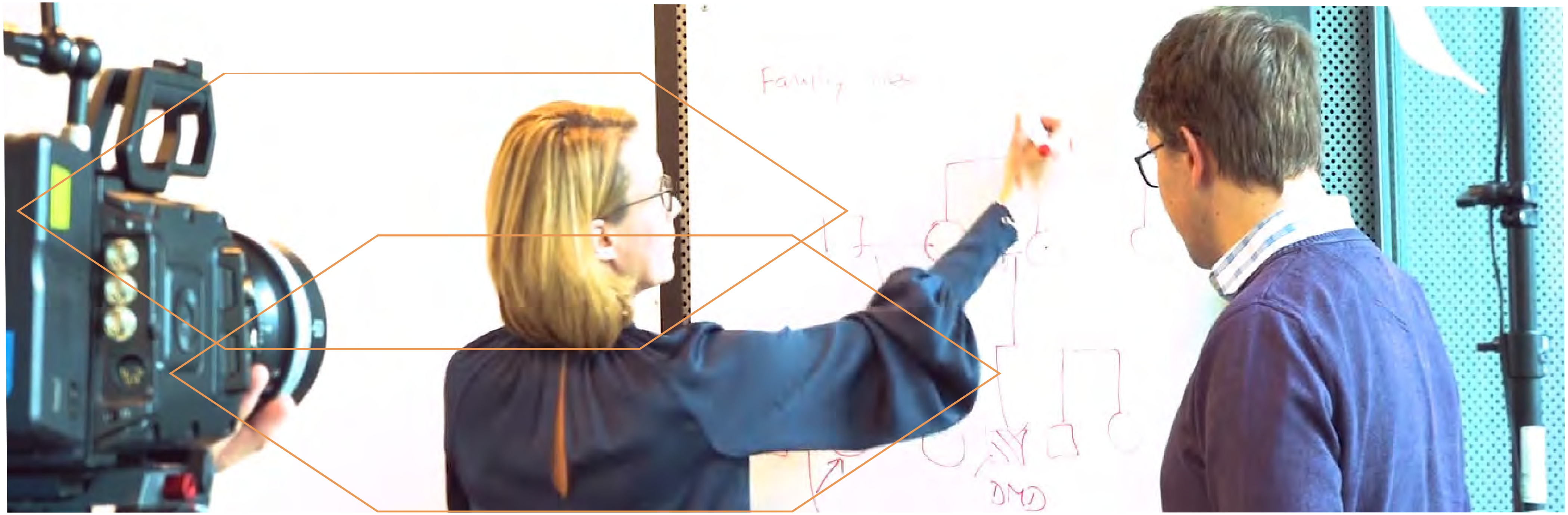
- Middleton A (2018) Delivered course introduction on the Genomic Practice for Genetic Counsellors course. Advanced Courses and Scientific Conferences, Connecting Science, Wellcome Genome Campus. Cambridge UK, 6 February

- 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

- Middleton A (2016) Tutor on Public Engagement Masterclass,Conference Centre, Wellcome Genome Campus, Cambridge, 20-22 July



EXTERNAL GRANTS

- 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 Tonkin (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 McKevitt (£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

- Arney K (2020) Interview with Richard Milne and Anna Middleton. The Alzheimer's Gene [Ingenious, BBC Radio 4] 9th April

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

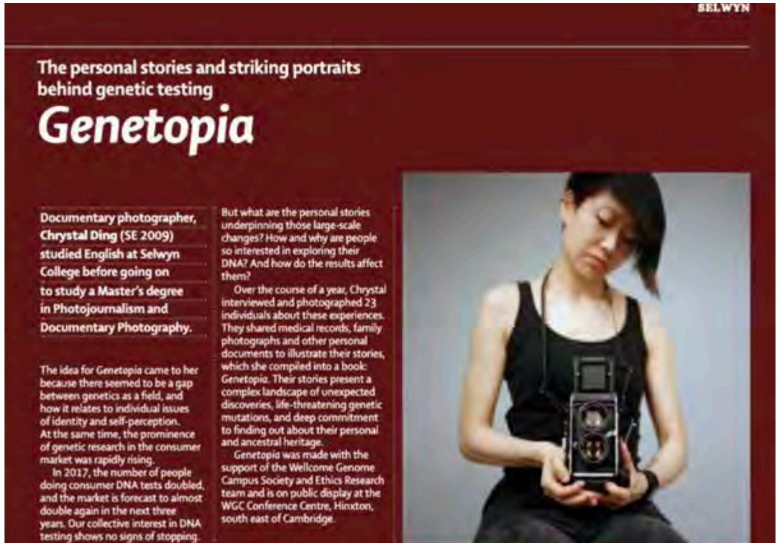
- Eugenic's: Science's Greatest Scandal (2019) Interview with Anna Middleton. BBC 4

- 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) Quotes from Anna Middleton. `The DNA Dilemna', Marie Claire UK, June 2019 pp.144-145

- 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

- Selwyn Magazine (2019) Interview with Chrystal Ding. Genetopia: The personal stories and striking portraits behind genetic testing. Made in association with the Society and Ethics Research team. Summer 2019, Issue 26, pp 19



SELWYN

The personal stories and striking portraits behind genetic testing

Genetopia

Documentary photographer, Chrystal Ding (SE 2009) studied English at Selwyn College before going on to study a Master's degree in Photojournalism and Documentary Photography.

The idea for Genetopia came to her because there seemed to be a gap between genetics as a field, and how it relates to individual issues of identity and self-perception. At the same time, the prominence of genetic research in the consumer market was rapidly rising.

In 2017, the number of people doing consumer DNA tests doubled, and the market is forecast to almost double again in the next three years. Our collective interest in DNA testing shows no signs of stopping. But what are the personal stories underpinning those large-scale changes? How and why are people so interested in exploring their DNA? And how do the results affect them?

Over the course of a year, Chrystal interviewed and photographed 23 individuals about these experiences. They shared medical records, family photographs and other personal documents to illustrate their stories, which she compiled into a book: Genetopia. Their stories present a complex landscape of unexpected discoveries, life-threatening genetic mutations, and deep commitment to finding out about their personal and ancestral heritage.

Genetopia was made with the support of the Wellcome Genome Campus Society and Ethics Research team and is on public display at the WGC Conference Centre, Hinxton, south east of Cambridge.

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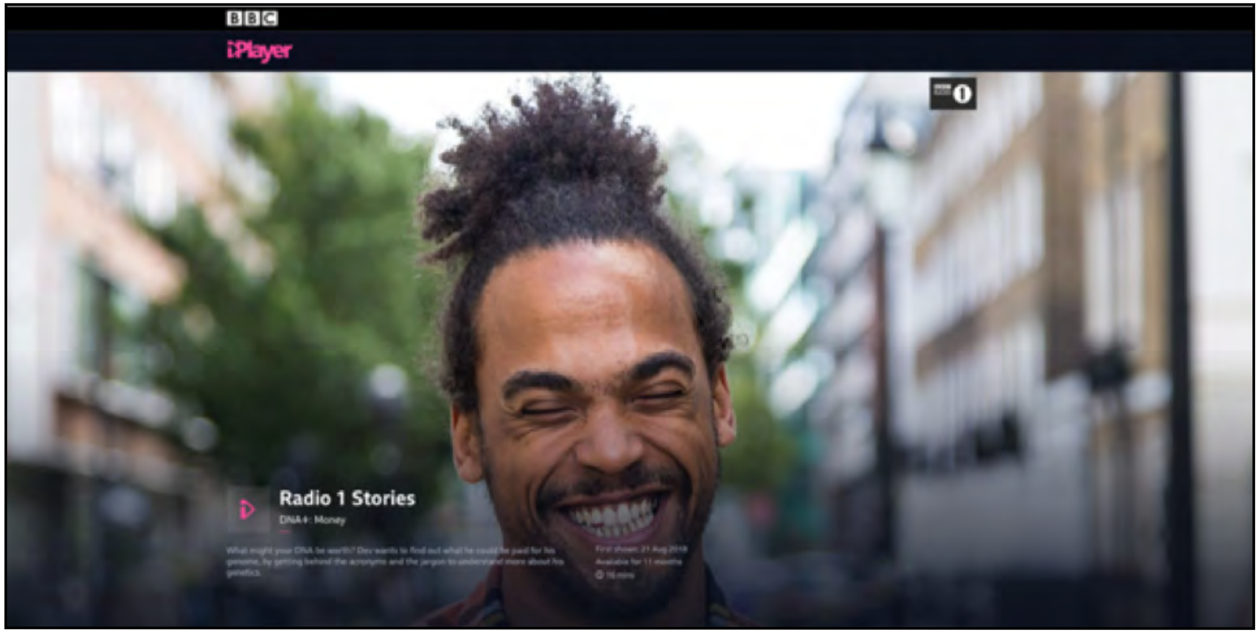

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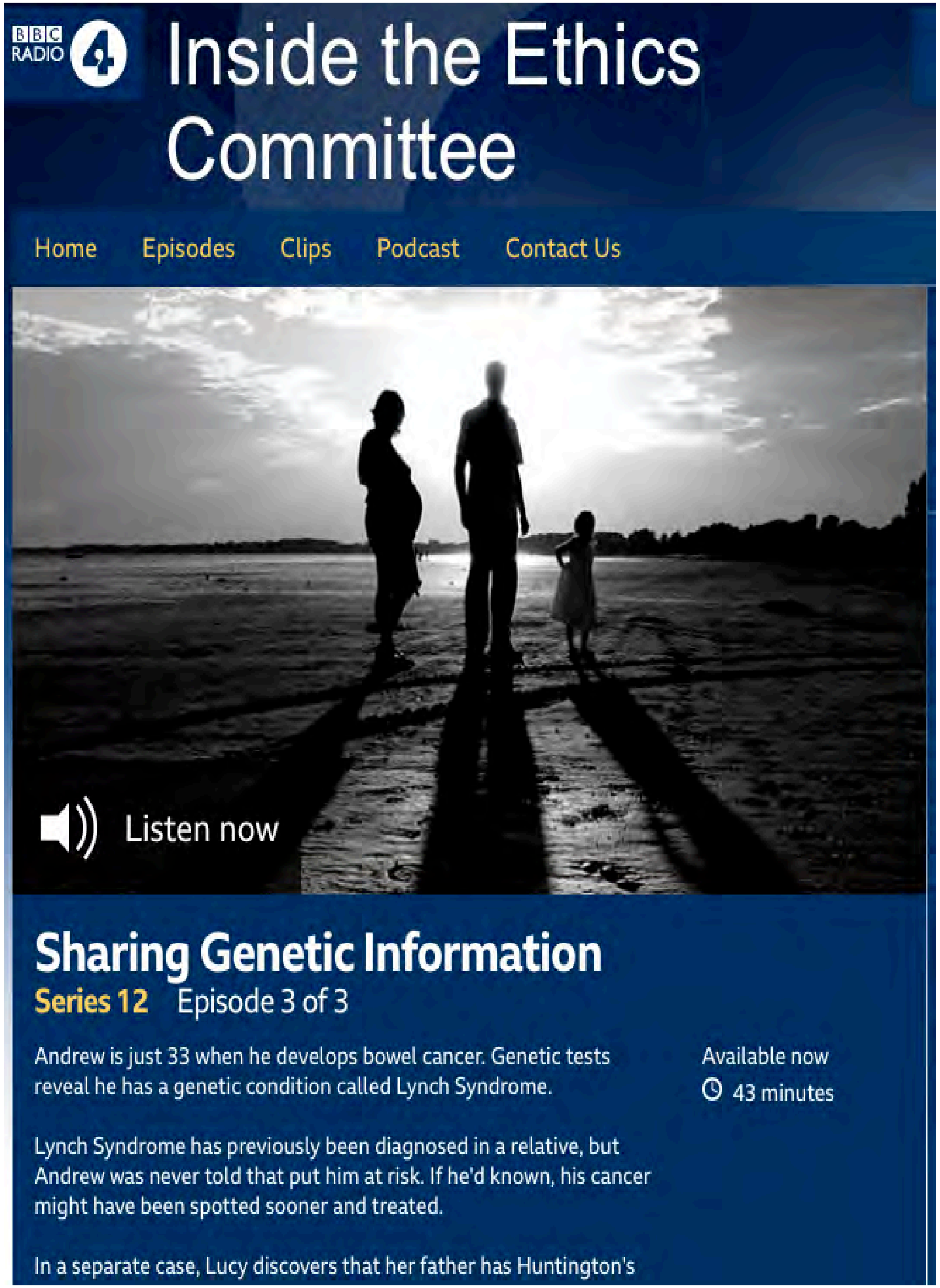

Inside the Ethics Committee

Sharing Genetic Information

Series 12 Episode 3 of 3

Andrew is just 33 when he develops bowel cancer. Genetic tests reveal he has a genetic condition called Lynch Syndrome.

Available now

43 minutes

Lynch Syndrome has previously been diagnosed in a relative, but Andrew was never told that put him at risk. If he'd known, his cancer might have been spotted sooner and treated.

In a separate case, Lucy discovers that her father has Huntington's

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theguardian

Genetics

The Observer

Robin McKie

Sunday 13 March 2016 00.04 GMT

Can't figure out genetics? Here's a handy guide ...

Advertising expert joins project to explain science in plain English

Many of those surveyed associated genomes with gnomes.

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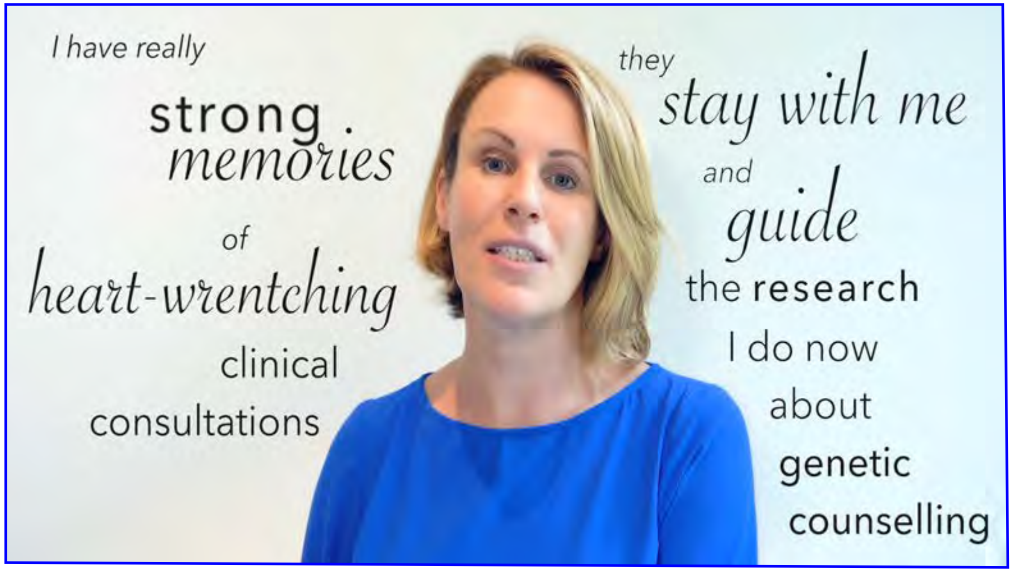

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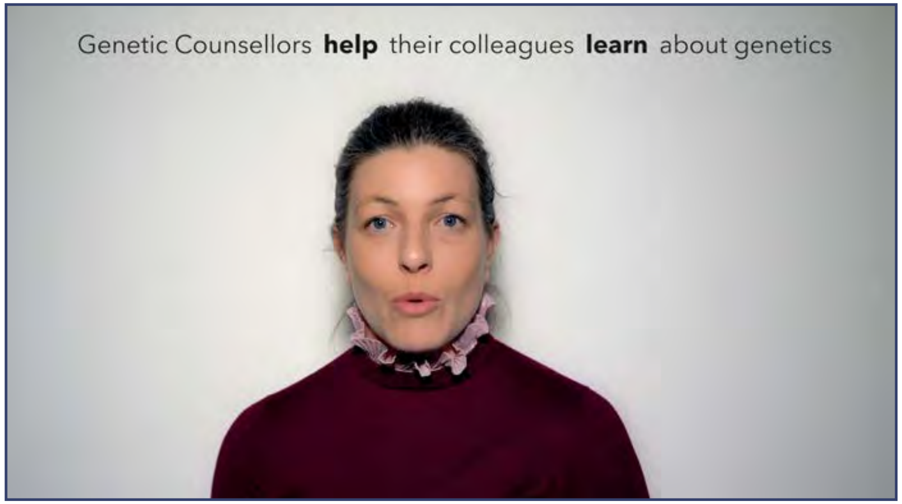

Christine Patch in the exhibition Empowering People: Genetic Counselling in Focus at the Wellcome Conference Centre

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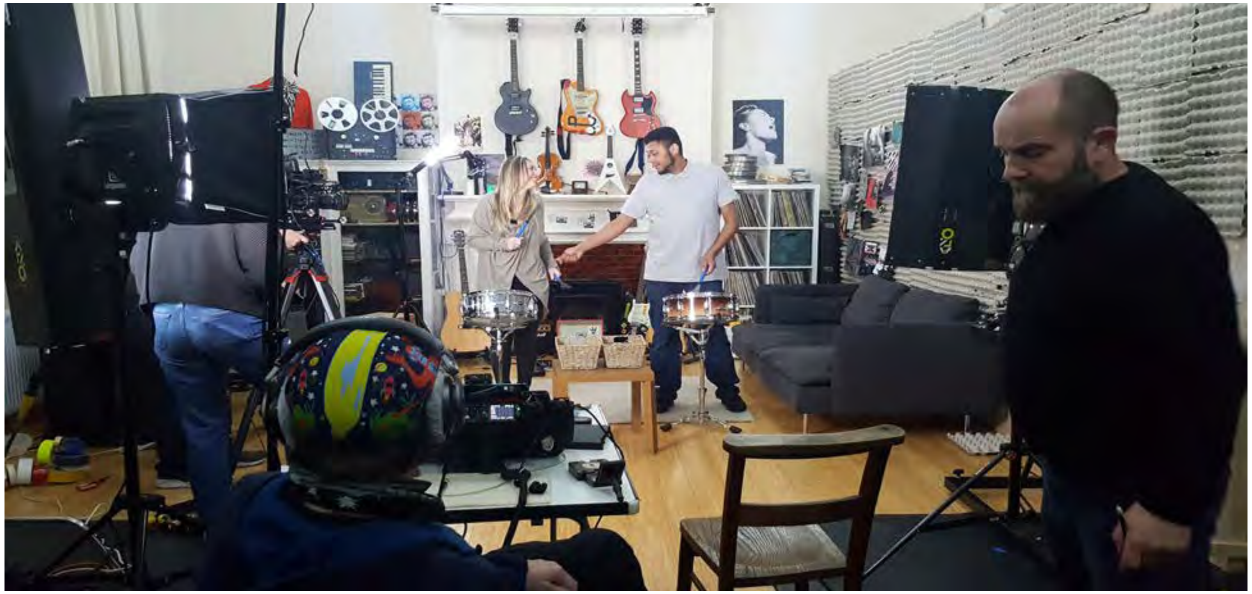

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SCIENCE NOT IDEOLOGY

genetics unzipped

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Anna Middleton, Kat Arney, Laura Boyes, Michelle Bishop | March 16, 2020

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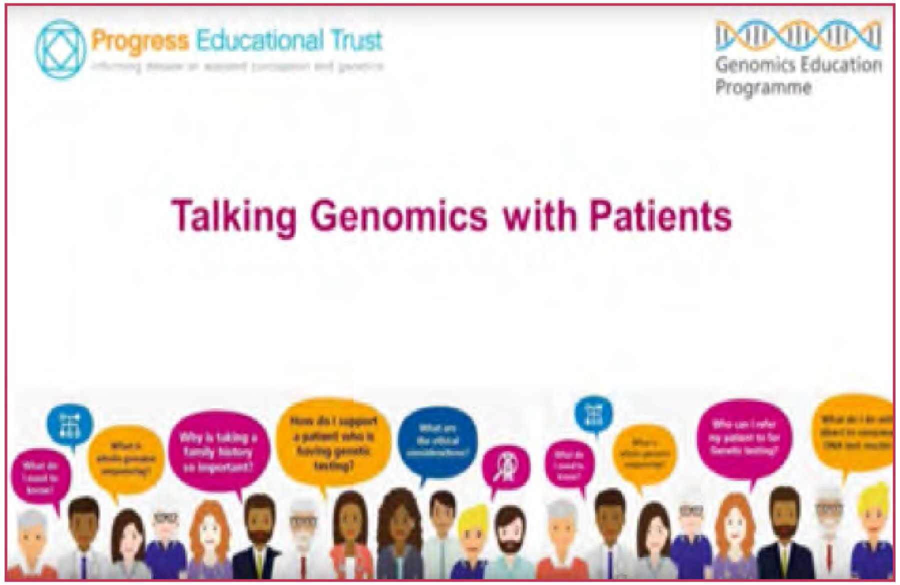

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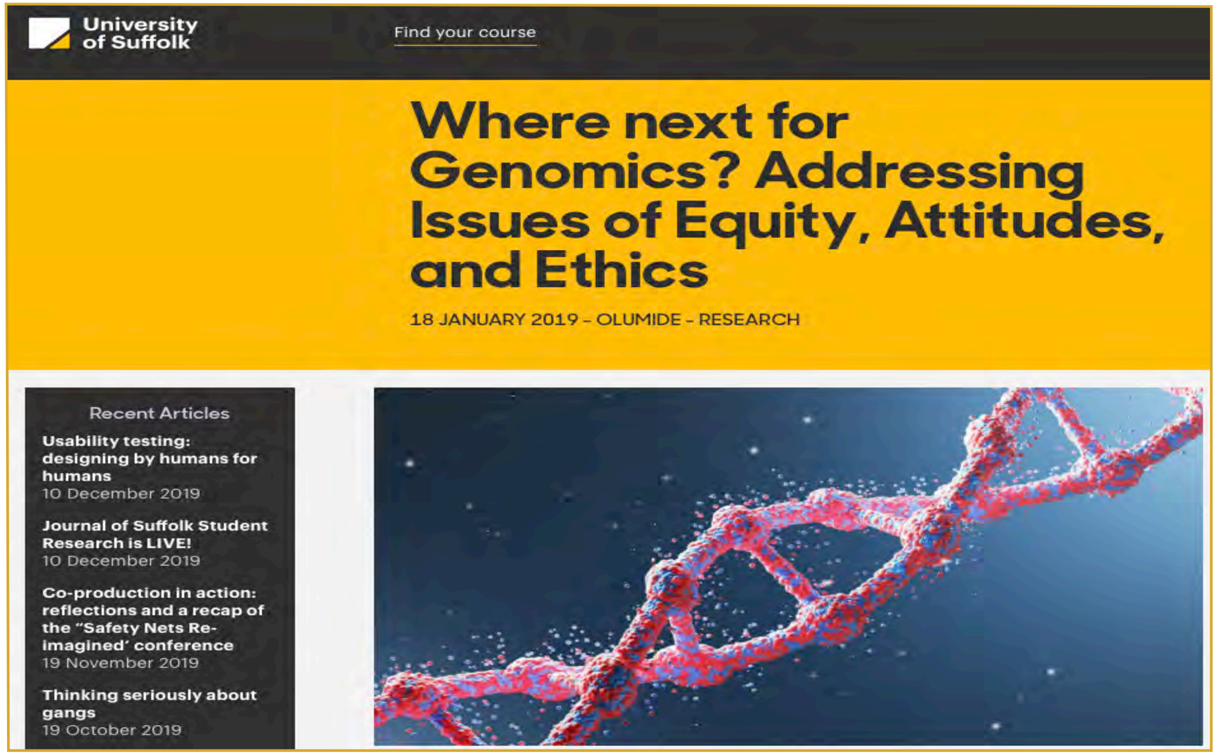

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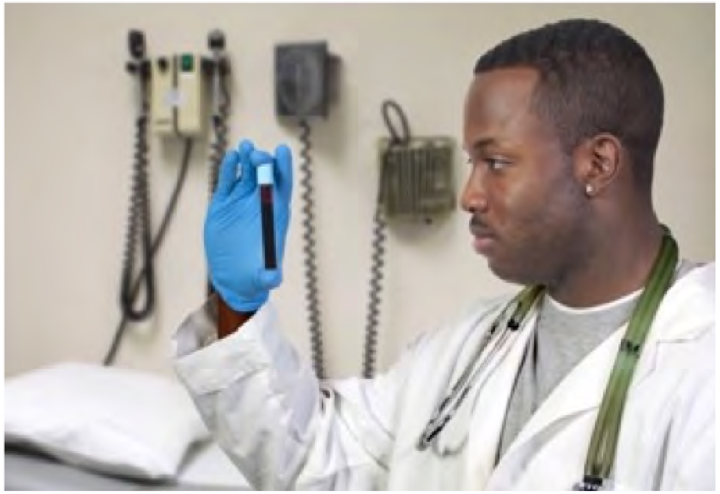

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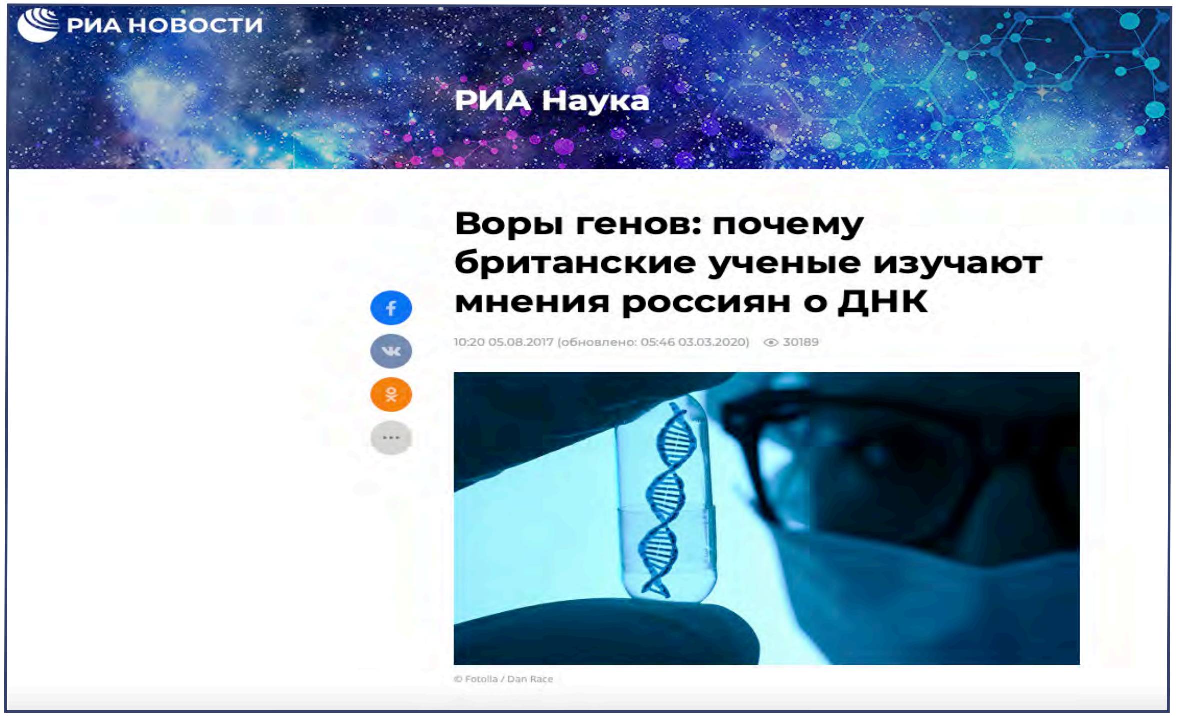

РИА НОВОСТИ

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- 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

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- 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
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