

WELLCOME GENOME CAMPUS

CONNECTING SCIENCE

Ideas
Experiences
Conversations
Learning
Health
Questions
Society
Research

ANNUAL REVIEW 2018/19

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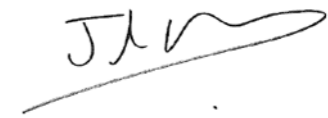
At Connecting Science our mission is to enable everyone to explore genomic science and its impact on research, health and society. As this past year has shown, genomics is influencing the world around us rapidly and in unpredictable ways, making our work more relevant than ever.

In a year when the first genome-edited babies may have been born, investigating the societal implications of genomic technologies and listening to public opinion on what scientists and clinicians should do, rather than what they could do, has become even more important. And with genome sequencing potentially becoming available commercially through the NHS, where are the public voices in this discussion? How are their hopes and concerns about genomic data sharing being considered? And do we have a workforce with appropriate skills and resources to deliver this sort of service?

We tackle these challenges head on, and strive to ensure that the work we deliver has real impact across our public and professional audiences. We empower individuals and communities to share skills and learning, undertake effective engagement, and contribute to debate and dialogue around the many issues raised by genomics and biodata. At the heart of everything that Connecting Science does is the people that we work with, and we are continually looking to diversify these audiences and extend our reach into new communities.

This year's annual review picks up many of these themes and provides a range of stories about our work, its impact, and our people; from building a community of engaged researchers on the Wellcome Genome Campus, to trialling innovative new delivery methods to improve training and research outcomes. As ever, we are very grateful for the support of our collaborators, and are genuinely inspired by your commitment and enthusiasm. Thank you for another diverse, stimulating and fulfilling year.

Best wishes,

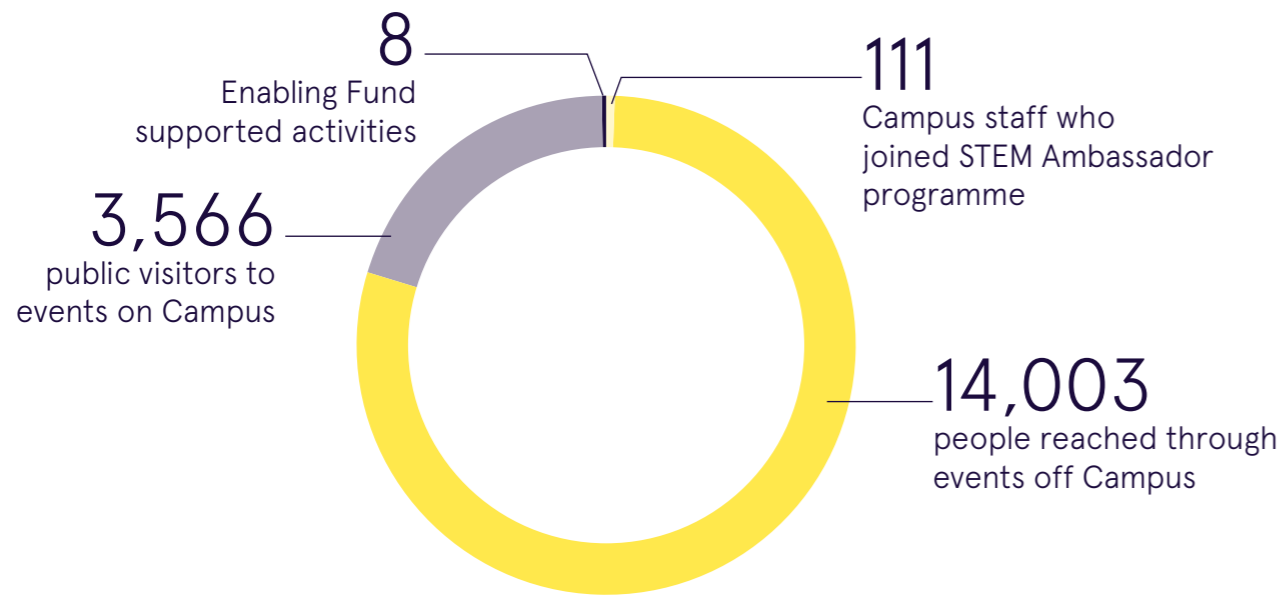


Prof Julian Rayner

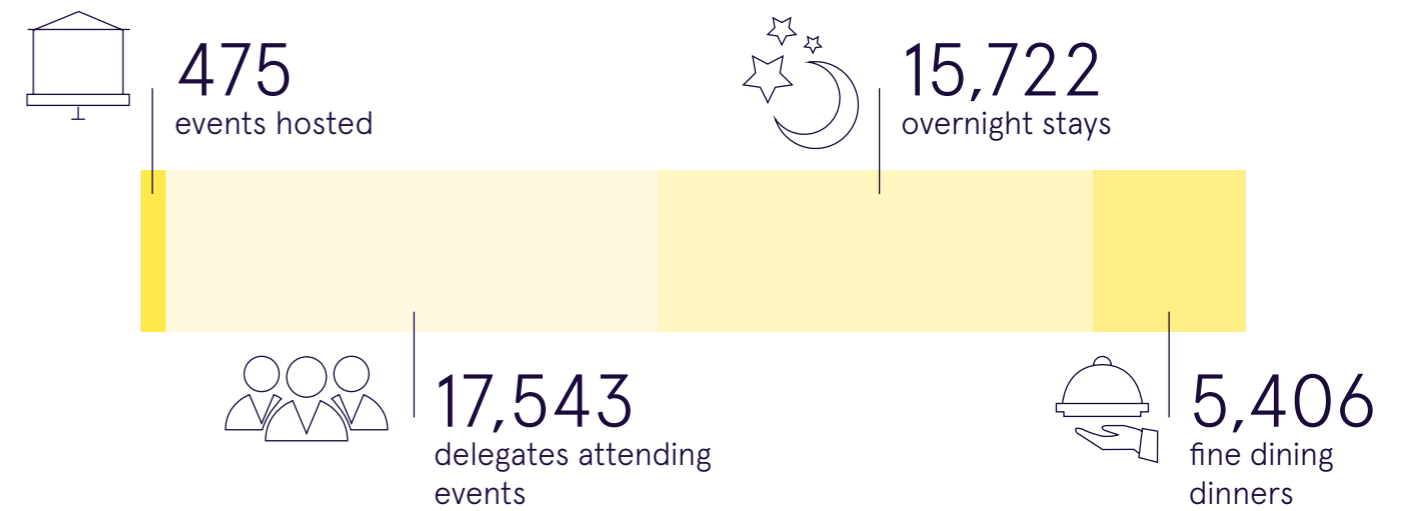


DIRECTOR'S INTRODUCTION

Public Engagement



Conference Centre

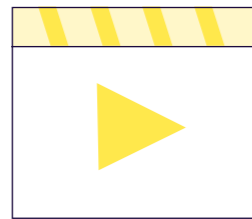


CONNECTING SCIENCE IN

TWELVE MONTHS (OCT 17 – SEP 18)



more than
35,000
participants from
16 countries
completed Your DNA Your Say surveys



8
resources created
(learning tools and films)

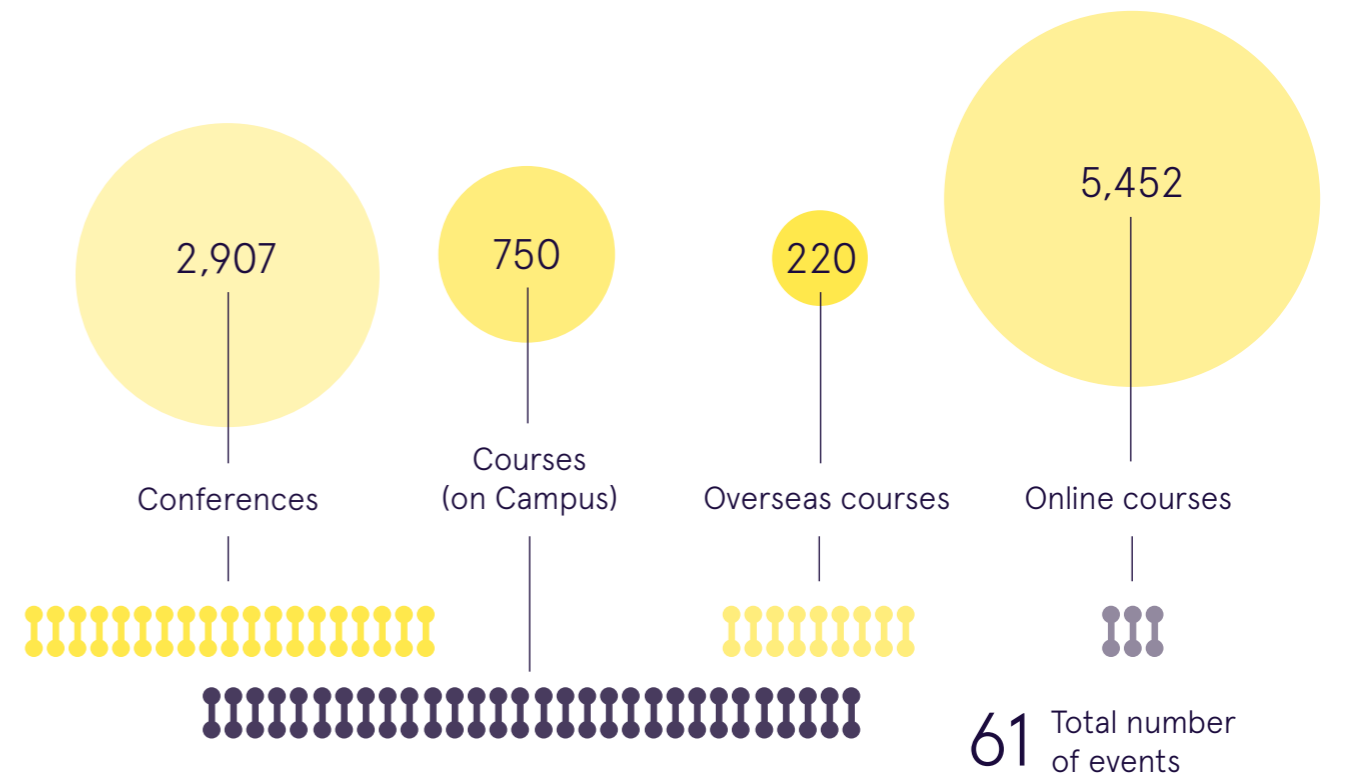


12
academic peer-reviewed
publications

Society and Ethics Research

3,877 Total number of delegates

5,452 Total online active learners



Advanced Courses and Scientific Conferences

CATALYSING CHANGE





Congratulations to Wellcome Genome Campus for achieving a Silver #EngageWatermark Award! This award recognises their strategic support for #publicengagement and commitment to improve the support offered. @wellcomegenome @WGCengage #Engage2018

@NCCPE

2019... First @Scicling Year! Feeling VERY GRATEFUL to the whole amazing @WGCengage team & @rayner_julian at the @wellcomegenome Campus & @STEAMCEU from the @EducacionCan for their excellent support! It's being & gonna be AWESOME! Check <http://www.scicling.org> out!

@Scicling

Save the date for our #RAREsummit19 23 Sept @WGCCConfCentre. What a fabulous venue! Accessible accommodation on site is excellent, conference facilities light and airy and we can pack 300 delegates in. Thanks for the site visit yesterday! #RareDisease #PatientsAsPartners

@camraredisease



We work with a wide range of partners to make a difference



WATERMARK OF ENGAGEMENT – A CAMPUS-WIDE STORY OF CHANGE

Changing the way public engagement is thought of, and valued, across our Campus community has been at the core of our work in Wellcome Genome Campus Public Engagement over the past year. Here, Dr Steve Scott, Senior Public Engagement Coordinator, and Dr Kenneth Skeldon, Head of Wellcome Genome Campus Public Engagement, reflect on this ambition, with the goal to make everyone who works on Campus feel they can play a part in our public engagement journey.

A remarkable asset of the Wellcome Genome Campus is the community of people who work here, spanning a huge range of roles. Researchers, scientists, technicians, software developers, bioinformaticians, professional services and support staff all contribute, in one way or another, to advancing the frontiers of research.

We believe this sense of ownership should also extend to the engagement work we create with our wider communities. Enabling a culture of support and opportunity that speaks to this diverse community, has been a key focus for our public engagement effort over the past year.

To help us assess our way of working and to plan tangible change, we decided to open up our engagement strategy to external scrutiny. Therefore, in late 2017, we commenced a benchmarking and evaluation exercise led by the UK's National Coordinating Centre for Public Engagement called the Engage Watermark. Although universities across the UK have already submitted their engagement work to the Watermark assessment process, we are the first multi-institute research campus to do so.

The Watermark process combines self-assessment, external interviews, and expert review to assess attitudes, motivators and values associated

with public engagement. This is designed to help assess the culture of engagement, how it is valued and recognised, and to identify core strengths and areas for development. For the Wellcome Genome Campus, we had the particular challenge of comparing the two main institutes on Campus – the Wellcome Sanger Institute and the EMBL-European Bioinformatics Institute – which have distinct governance, sectoral and cultural attributes, each affecting how public engagement is embraced.

After a thorough journey, we arrived at a milestone in November 2018, when we were recommended for a Silver Engage Watermark. Our Watermark was earned as much for



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The Campus' Watermark Action Plan is among the most reflective and thorough I've seen since we launched the Watermark in 2015. It's a robust response to a complex engagement challenge, involving multiple institutes, diverse roles and a range of individual motivations to engage

Paul Manners, Director of the National Coordinating Centre for Public Engagement

”

our plan of action moving forward, as for the evidence created over the 14-month review process. Our action plan highlights important criteria – around reward and recognition, institutional governance and the involvement of publics in our approaches – that we are now concentrating on.

Above all, the Watermark is a symbol of achievement for our whole Campus community. We are proud

of the work everyone at the Campus has done to help secure our silver recognition, and we are confident that by working progressively with our staff, students, and external communities on the road ahead, we will collectively convert silver into gold.

Silver
Engage
Watermark

National
Co-ordinating
Centre for
Public Engagement

SUPPORTING RESEARCHERS WORLDWIDE TO BUILD CAPACITY FOR NEXT GENERATION SEQUENCING BIOINFORMATICS

The Advanced Courses and Scientific Conferences programme of Overseas Courses are in high demand, with many more applicants than available places. Developing the programme in low- and middle-income countries and regions will only become sustainable by supporting regional instructors to deliver training.



In 2019, for the first time, we have developed an independent instructor team for the Next Generation Sequencing (NGS) Bioinformatics course in the Latin America and the Caribbean region.

Dr Marcela Sjöberg Herrera from the Facultad de Ciencias Biológicas de la Pontificia Universidad Católica de Chile, lead instructor on this new regionally-led course, had noted the increasing demand for high-quality training in NGS bioinformatics and was keen to co-organise and host a spin-off course. She did this with the support and guidance of UK-based experts Dr Thomas Keane (EMBL-EBI) and Dr Jacqui Keane (Wellcome Sanger Institute), the course's lead developers. Having been an instructor on the course at the Institut Pasteur in Uruguay in 2018, Dr Sjöberg Herrera took the lead in organising the course in January 2019 at her university in Santiago, Chile. To help deliver the course she brought together a team of skilled and incredibly motivated instructors and assistants originating from, or based in, Latin America.

“ Latin American countries need formal high-quality training for next generation sequencing bioinformatics, and the high number of applicants demonstrates this need. The course will contribute to building capacity in genomic sciences for future generations in Latin America. ”

Dr Marcela Sjöberg Herrera, Instructor

The 26 participants, from 10 Latin American countries, were postgraduates or postdoctoral fellows working in a wide range of bioscience fields including genetic diseases, cancer, environmental biology and biodiversity. This variety was relevant because the techniques and tools covered in the course are applicable to any organism from bacteria and parasites, to snakes, plants, and humans.

First on the course schedule was an Advanced Learning and Training (ALT) session, a two-part training unit developed by the Advanced Courses and Scientific Conferences team and designed to support personal learning and teaching others. This prepared participants for getting the most from the course during the week and equipped them with tools for disseminating what they learnt back at their own institutions. This was followed by a speed networking exercise, a good way for participants to start interacting and telling each other about their work.

The course then consisted of lectures and hands-on practical exercises for analysing NGS sequence data using various tools, sequence alignment and quality control, variant calling, RNA-seq and ChIP-seq analysis, sequence data visualisation and accessing public data repositories.

“ I want to highlight the importance to perform a theory and practice course. I think it is very important to learn by doing, and is the best way to learn bioinformatics. ”

Course participant

Seminar talks by invited speakers and instructors on their own cutting-edge work emphasised the power of next generation sequencing technologies in addressing a wide range of biological questions, such as applications in vascular disease research, melanoma, and single cell transcriptomics in mouse embryonic development.

“ The seminars made me understand better the applications of the techniques. All the seminars were useful because they showed different ways to use NGS. ”

Course participant

The course feedback highlighted that the experience was very rewarding for both instructors and participants, with all participants stating that they were able to apply the tools and analyse NGS data and would be able to continue practising the various exercises on their own. Importantly, feedback revealed that having an all-Latin American team - leading by example through excellent teaching and inspiring talks - was highly motivational by providing relatable mentorship and role models.

“ Having trained at the Wellcome Sanger Institute, coming back to Latin America and now training others shows how this expertise is being seeded and is making a difference in the quality of the collaborations and the science we are doing. ”

Daniela Robles, Instructor

Demand for NGS bioinformatics training continues to grow in these regions as evidenced by the high number of applications for the course. A similar regional instructor team model is being piloted in Africa in collaboration with H3Africa Bioinformatics Network.

Developing collaborations with regional experts will increase capacity for bioinformatics training in low- and middle-income regions in Africa, Asia and Latin America, and regional instructor teams will make it possible to run the course multiple times each year. The Advanced Courses team are also currently exploring additional delivery methods to increase the accessibility of their courses by using online-based platforms and distance learning.

HOW SMALL CHANGES LEAD TO GREAT IMPROVEMENTS

Since Connecting Science was created, the Conference Centre has committed to seeking new business primarily from organisations involved in scientific and medical progress. This narrowing in the potential client base served to focus our business minds, and over the last three years, the Conference Centre has been implementing a steady review process: analysing every step of a client’s interactions with us, as well as the myriad of operational processes that exist in a venue such as ours.

As part of the commitment to the community that we are part of on the Wellcome Genome Campus, we offer preferential rates to all biomedical sciences organisations, both from within Campus and the wider sector. The aim of this is to build solid relationships with clients working in the same field as us, making the Conference Centre an accessible venue in a location of significance, where customers can fulfil the potential of their event, and want to return.

The quality of the relationships developed with clients certainly affect the success of the events held here. Getting to know our clients and their audiences allows us to cater

specifically to their needs. Working with customers repeatedly allows us to gain a deeper understanding of their expectations, and for clients to experience our capabilities. Ultimately, these both lead to an improved experience for the end customer: the delegate.

Central to winning a client’s confidence is the delivery of consistent quality across the full spectrum of services offered. To do this we operate with highly experienced and dedicated staff under a strong management structure, constantly reviewing and improving our operational and administrative processes. Staff undergo regular training across a

broad range of subjects, and we’re not afraid to trial new approaches (and sometimes reject them!).

A few years ago we brought our customer feedback system in-house. This allows us to manage customer satisfaction surveys ourselves and process feedback more efficiently. All feedback, both positive and negative, is shared widely within the relevant teams, and we meet regularly to identify improvements based on feedback, decide what action to take, and discuss the timeframe, budget and practicalities. If these improvements relate to our facilities rather than processes, they are considered alongside our long-term rolling maintenance planning.

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CLIENT: HEALTH ENTERPRISE EAST INNOVATION SHOWCASE

We chose the conference facility for some very clear reasons: The beautiful surrounds and proximity of the venue to good transport links, the professionalism of staff, the high quality of the venue itself and the amazing wow factor, which is key when holding any type of corporate event. And finally numbers. The venue has the capacity to hold large-scale events whilst giving delegates, sponsors and stallholders plenty of space to breathe and take in the amazing surroundings!

Feedback from delegates concerning the venue was over 90% approval rate, which I feel is a great testament to the Conference Team and the venue! Just keep doing what you’re doing.

”

as good as new; and to exercise greater flexibility with customers and their requirements.

We are able to improve thanks to feedback from our guests and clients, and the good relationships we work hard to nurture. These improvements benefit both our external customers and helps us to better support the activities of Connecting Science and the wider Wellcome Genome Campus.

What is it they say - test, review, refine, repeat? You could say that is our motto!

This year has seen our highest customer satisfaction ratings in recent times. We are pleased to feel in control of these results and confident that our systematic refinement of processes, and dedication to a stringent renovation and maintenance programme has delivered the results we intended. The consequence of increased satisfaction amongst delegates and

event organisers is how clients are encouraged to return and strengthen our relationship. The positive impact of increased business can be felt at numerous levels: increased volume allows us to be more confident when seeking the best value from our external contracts; to commit to maintenance plans that keep us equipped with the latest AV equipment and our facilities looking



EMPOWERING RESEARCHERS TO EXPERIMENT WITH ENGAGEMENT

The Wellcome Genome Campus Public Engagement Enabling Fund was launched at the end of 2017 to support great ideas for public engagement from staff and students across the Campus. Awards of up to £1,500 are available on a competitive basis for activities that engage public audiences with the science and innovation that takes place on the Wellcome Genome Campus. Here, Dr Susan Vickers, Researcher Engagement Coordinator in the Public Engagement team, reflects on the initiative so far.



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Our event took place at the Saturday Market [Saffron Walden] to encourage STEM interactions between people from the Wellcome Genome Campus, Cambridge University, and local families. We engaged with over 150 in four hours and got good recognition for supporting the local community in a different way.

Dr Sirarat Sarntivijai, ELIXIR Interoperability Platform Coordinator and Enabling Fund recipient for 'Science and Sushi'.

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“
The Enabling Fund has benefited me to a great extent. First, to make me realise that we have an excellent Public Engagement team supporting our ideas to make them real. All in all, I have improved my communication (even in social media!) and organisational skills.

Dr Alejandro Marin-Menendez, Postdoctoral Fellow, Wellcome Sanger Institute, and Enabling Fund recipient for 'Scicling'.

”

Swapping thoughts, opinions and knowledge between the public and our Campus community is motivational and can inspire new ideas and approaches. We want everyone at the Wellcome Genome Campus to feel empowered to engage the public, and the Enabling Fund is just one of the ways we support staff and students to do this.

While designing their engagement project, we ask applicants to reflect on a few overarching qualities. Applications for activities that encourage dialogue and discussion, leading to more people-centred research at the Wellcome Genome Campus, are particularly welcomed. We also ask applicants to reach and empower people otherwise unlikely to interact with the Campus and promote equality and diversity in the course of planning and delivery.

These considerations are designed to encourage quality applications, while still enabling a wide variety of engagement activities. It is hoped

that by welcoming a broad range of ideas, we can support staff and students to use their work skills, in tandem with their personal motivations and passions, to connect with audiences in meaningful ways. This has been embraced by our Campus community, who have been successful in receiving funding for projects that bridge genomics with a wide range of areas such as sushi making, art, history, cycling, and music.

Since launching, we have funded 13 exciting and varied projects. Applying for and receiving money from the Enabling Fund is only the first step in a public engagement activity, and we have seen staff and students at the Wellcome Genome Campus working hard, with our support, to make their creative engagement ideas a reality. Through these projects we have enabled relationships to be developed with a wide variety of audiences, including school children, local communities, science festival visitors, church congregations, and prisoners and their families.

In the year ahead, we will support a further 3 rounds of the scheme and look forward to stimulating more creative and exciting projects with strong and varied purposes for engagement. As we go, our Enabling Fund will support our Campus community to develop a powerful collection of new engagement stories and approaches, highlighting why these projects matter to everyone involved.

“
The enabling fund allowed me the opportunity to design a public engagement activity, through which I and several colleagues at the Wellcome Genome Campus have developed a number of new skills. The event increased our enthusiasm for research and public engagement, and our confidence in talking about our research.”

Dr Lowri Williams, Visiting Researcher, EMBL-EBI, and Enabling Fund recipient for 'Battles of the Cells'.



We are exploring the challenges and opportunities this emerging field presents for us all



A New Deal on Data: we need a people-powered conversation about data <https://www.genomicsengland.co.uk/a-new-deal-on-data/> ...
@Genomethics @wellcomegenome @sangerinstitute

@GenomicsEngland

Woo hooo!!! My wording 'socialising the genome' has made it to the final cut at the launch of the #TopolReview - genomics needs to be made a sociable concept for people. @WGCethics

@Genomethics

'We need to help patients understand they have the option to agree to use of data to help themselves and others'. #datasharing #WCGC17

@GeneticAll_UK



THE MEANING OF 'MY' DATA IN THE GENOMICS AGE



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What about perhaps the most personal data about us that can ever exist? Our genome, the unique sequence of DNA, that makes us, us.

”

Everyone living in today's world is surrounded by increasing amounts of data about themselves. Whether that's the information and data we provide knowingly when we enter our personal and financial details to make purchases via the web, or the sort of data that we generate when we go out walking with a fitness tracker.

Lots of this data is quite personal to us, and some of it we might not think is going to be of much interest to anyone else. But it is all being recorded, stored, and potentially accessed by someone, for research, profit, or both. And as large scale data breaches at a variety of multinational companies and service providers show, personal data is, quite rightly, a sensitive topic.

So what about perhaps the most personal data about us that can ever exist? Our genome, the unique sequence of DNA, that makes us, us. We might not immediately connect a visit to the doctor with discussions around data ownership, access, and privacy, but this is all changing. The Society and Ethics Research team (SER) have been following a case, known as 'ABC v St George's Healthcare NHS Trust', on how we practice medicine in the genomics age. This landmark legal case was brought by the daughter of a man with Huntington's Disease who is suing the hospital caring for her father, claiming that the hospital had a duty of care to share her father's diagnosis with her, against her father's wishes. His genetic information was not shared, and the confidentiality of its 'owner' was maintained, a decision that affected the complainant's reproductive choices and as, a consequence, the health of her child. Was this the right decision? Or should the rights of family members who are affected

by some of this genetic data also be considered? The case is still ongoing and, whatever its outcomes, it has already sparked some very pertinent questions.

Even if you're not having a genetic test as part of treatment, you might still be sharing your genetic data with other people. As 'direct to consumer' testing companies such as 23&me and AncestryDNA increase their reach, more of us are contributing our data to their genetic databases. Who is this data being shared with? What is it being used for? And what do we as citizens think about this? These are the sorts of questions that the SER team are actively investigating. Their Your DNA, Your Say project is a global survey gathering attitudes to genomic data sharing across the world. As results from English-speaking regions of the globe are analysed, it is clear that these populations perceive DNA data as something exceptional and different from other medical data. It has also emerged that trust and risk associated with DNA data sharing can vary significantly by gender, with women generally more conservative in this area.

In this age of big data how do we establish a shared position between scientists who would like to access our genetic information to improve understanding of human health and disease, and us as individuals, populations and communities whose

data this is? Anna Middleton, Head of SER, Vivienne Parry, Head of Public Engagement at Genomics England, and Julian Borra, citizen and Founder of Thin Air Factory, believe we need a New Deal on data. They have issued a call for a people-powered conversation, which will create a deal with two clear parties, two clear beneficiaries, and equally mutual rewards. This deal is based on institutions, and policy-makers clearly articulating the assumptions behind the benefits of data-driven research and making these available for debate; and society accepting the small but inherent risk in sharing our data with individuals and organisations.

Whilst there are no easy answers to what this New Deal looks like exactly, it is clear that people and scientists need to reach an understanding for the journey into human discovery to be a fair, joint venture. And it is through the collection of opinions on a big-data scale that will inform us where the starting point of these conversations should be.

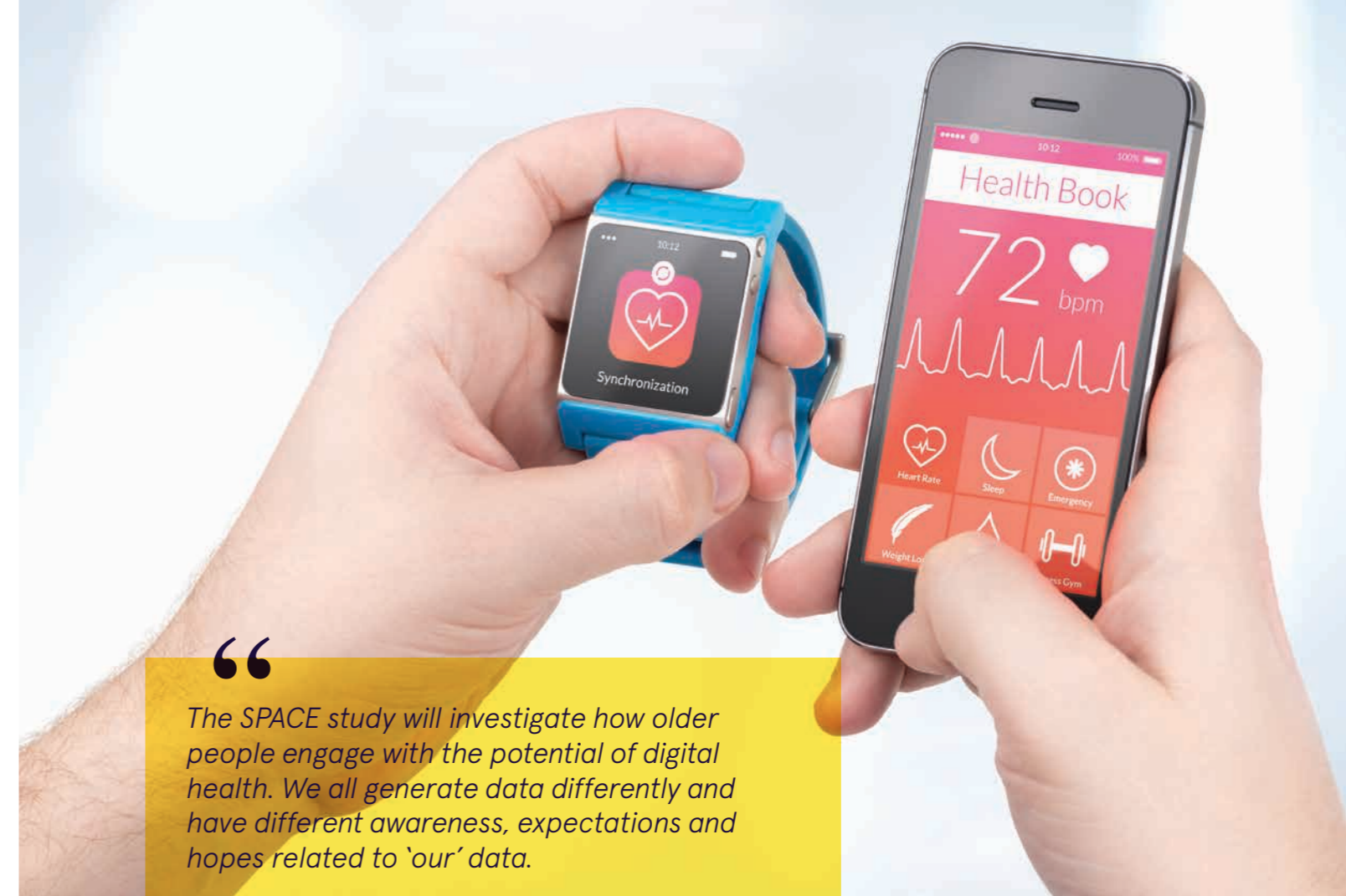
EXPLORING THE ETHICAL CHALLENGES OF DATA-DRIVEN MEDICINE

Senior Social Scientist Dr Richard Milne describes a new project starting in the Society and Ethics Research group.

We live amid a stream of data about us generated by devices from sequencing machines to smartphones. Data are collected, sorted and used by individuals, companies, public services and governments. This data-saturated environment provides the basis for the development of what the Nuffield Trust describes as 'ADA' technologies – those involving Algorithms, Data or Artificial intelligence.

The convergence of different data sources and technologies has been described as forming a 'digital phenotype', and as potentially transformative for healthcare. The 2019 Topol Review, commissioned by the Secretary of State for Health and Social Care, highlights its potential for the future of the NHS. Alongside the potential of these innovations come questions about how they should be used, by whom, how they should be governed and, perhaps most importantly, how we ensure a fair distribution of any benefits. These are questions that we have previously encountered in relation to genomic data, and are accentuated by the expanding scope of data and of those who control them – including companies that have not traditionally been involved in healthcare, such as Apple, Facebook or Google.

The SPACE (Stakeholder Perspectives on ethical challenges in the use of Artificial Intelligence for Cognitive Evaluation) study focusses on social and ethical questions associated with the use of ADA technologies in healthcare and biomedical research. It focusses on the assessment of cognitive change and dementia. This is an area of pressing clinical need, where data about behaviour and cognition



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The SPACE study will investigate how older people engage with the potential of digital health. We all generate data differently and have different awareness, expectations and hopes related to 'our' data.

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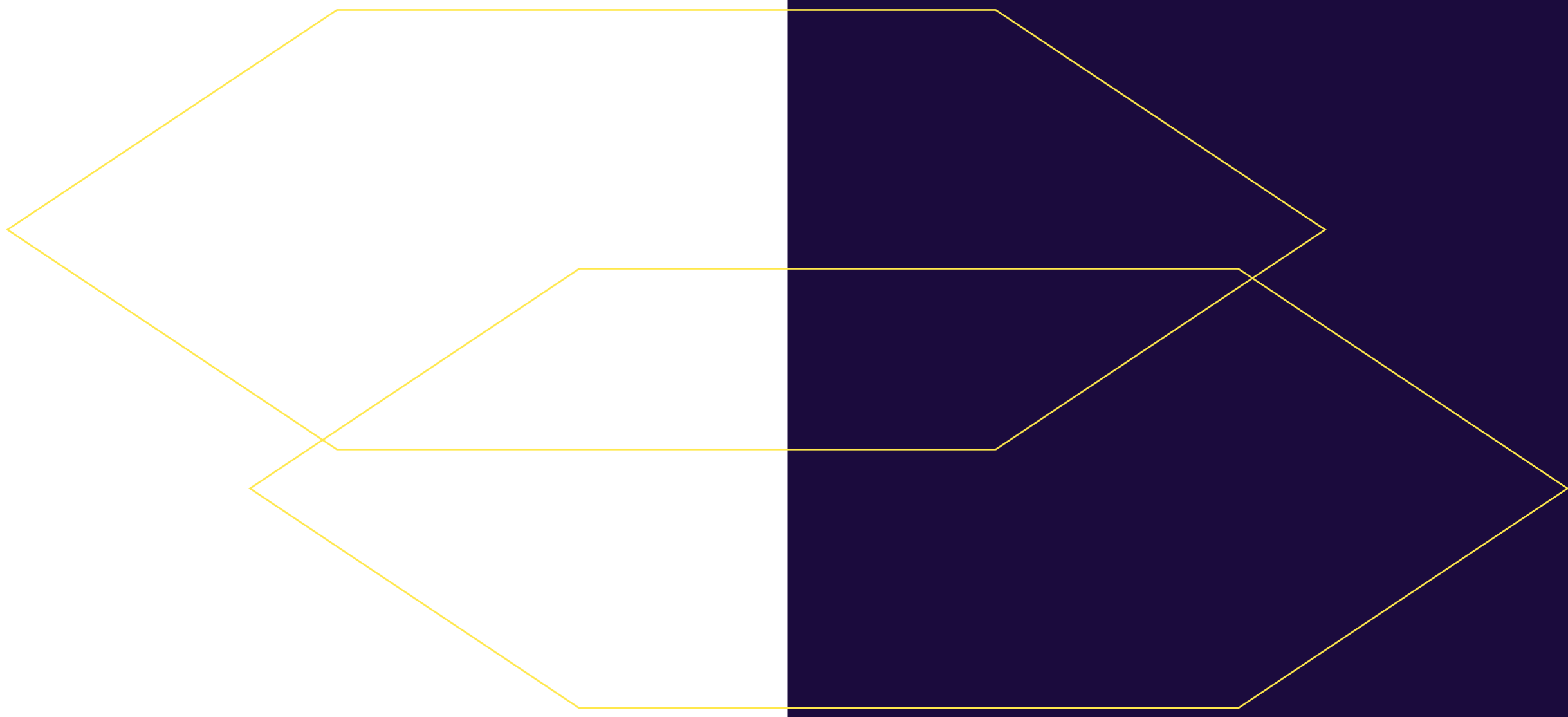
from different sources might make a valuable contribution to understanding and treating illness, but which presents challenges associated with an older and potentially vulnerable population.

SPACE is an 'empirical ethics' study which uses a social scientific approach to identify the actual ethical issues which emerge in the process of developing new technologies, and make sense of the experiences and judgements of the individuals and groups involved. In the first stage, we will be working with researchers and technology developers to see what ethical challenges come up in the course of gathering data and developing AI approaches. The use of different types of data, including those that aren't obviously health data, raises concerns in several areas. These include the challenges of ensuring valid informed consent in cases where people might have cognitive impairment, but also in terms of justice and working towards the fair distribution of benefits across society.

Alongside this work with scientists, the SPACE study will investigate how older people engage with the potential of digital health. We all generate data differently and have different awareness, expectations and hopes related to 'our' data. For some, such as 'quantified selfers', using data from a range of sensors and devices has become a way of knowing themselves better. For many people however, data are invisible and incidental – the digital exhaust from everyday life. In this stage of the project, we will examine whether and how people can engage with the

data produced by and about them, explore expectations and concerns about data use in health surveillance, monitoring and screening, and consider the potential of different ways of governing data use.

The project will finish by drawing this empirical work together to produce recommendations related to ethical challenges in digital health, and consider how new frameworks and forms of governance might contribute to understanding and realising the potential of new technologies for those people most at need.



DIVERSIFYING AUDIENCES



We develop innovative ways to stay connected to existing audiences, and to reach new ones



So proud to get my certificate for Bacterial Genomes: Disease Outbreaks and Antimicrobial Resistance on @FutureLearn #FLbacterialgenomes

@alnoamany2007

I loved being part of #lifelab. What a great team to work with and a fantastic opportunity to inspire the next generation of scientists. It is such a pleasure to share with the public and particularly with children how scientists are using DNA to answer questions about our lives.

@LittlestoryCo

Grateful to have been included in the first ever plant genomics meeting at the Wellcome Genome Centre, Cambridge, featuring recent breakthroughs in Arabidopsis & crop research. I hope the next gen of conifer scientists will be able to apply these approaches #plantgenomes2018

@SallyNAitken



ONLINE COURSES: REACHING MORE PEOPLE, INCREASING IMPACT, AND IMPROVING CAREERS

The popularity of the lab, computational, and lecture and discussion courses run by Advanced Courses and Scientific Conferences at the Wellcome Genome Campus and various overseas locations is evident: they are heavily oversubscribed and we are having to turn away many applicants very eager for training.

In addition to these, we know there are many others who are unable to attend our events due to timing, other commitments, or financial constraints. In response to this, in 2017 we began developing a series of 10 free, online courses, open to all. The aim of this was two-fold: to broaden global reach, and expand the diversity of our biomedical genomics training programme.

“11,000 learners from over 140 countries have benefitted from this programme since its launch in April 2018, showing the increased reach of this type of training delivery, important for capacity building in genomics.”

Rebecca Twells, Head of Wellcome Genome Campus Advanced Courses and Scientific Conferences

This innovative series of courses, created in collaboration with scientists from the Wellcome Sanger Institute, and delivered in partnership with the digital social learning experts, FutureLearn, covers

a range of topics, such as bacterial genomics, antimicrobial resistance, and computational tools for analysing genomic data.

The bacterial genomes series of online courses is based around the highly popular face-to-face course, Working with Pathogen Genomes, which is held regularly in Asia, Africa and Latin America, as well as in Hinxton. We designed these courses with Professor Nicholas Thomson (Wellcome Sanger Institute) to form a suite of training materials ranging from introductory concepts to advanced tools, so that learners can choose some or all of the courses to meet their needs at their particular career or project stage.

The introductory course, Bacterial Genomes: Disease Outbreaks and Antimicrobial Resistance, is accessible to a wide range of people, including undergraduates and non-scientists, as well as researchers and clinical staff keen to learn more about this topic. The more advanced courses, developed with Dr

Anna Protasio (Research Associate, University of Cambridge) and colleagues, are aimed at scientists and healthcare professionals needing to analyse bacterial genome data for research projects and diagnostic use.

“I have learnt much more about bacterial genomes in only one week than in my whole medical studies. It was amazing and inspiring.”

Learner on Bacterial Genomes: Disease Outbreaks and Antimicrobial Resistance

Advanced Courses and Scientific Conferences sponsors these courses so they are free to everyone, with ongoing access to all the material as well as a certificate on satisfactory completion. Each course is repeated twice a year, providing multiple opportunities for professional learners to start, or return and complete their training. Content is delivered via a mix of videos, featuring scientists from leading international research institutes, articles, and tests and quizzes to



validate learning. Some courses also include peer review activities and practical exercises.

As well as catering for those who work full-time, these courses are also valuable tools for Continuing Professional Development learning, since professional accreditations have been obtained from relevant bodies including The Royal College of Pathologists and The Royal College of Nursing.

One course, launching this summer, What is Genetic Counselling?, is a Connecting Science collaboration, developed by Dr Jonathan Roberts from Society and Ethics Research. We are currently developing new online courses with partners such as Health Education England and the University of Cambridge to contribute further to the transformation of more scientific careers, increase provision in low- and middle- income countries, and help train the NHS healthcare workforce in genomics.

Visit wgc.org.uk/acsc/online to see our upcoming and currently running online courses.

“

I like sharing information and MOOC like this one because I am working full time as an assistant professor and I have no time during the day. These online courses perfectly fit with my needs for flexibility in attending, listening and discussing with other professionals.

Learner on Bacterial Genomes: Disease Outbreaks and Antimicrobial Resistance

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STARTING NEW GENOMICS JOURNEYS WITH SCHOOLS ACROSS OUR REGION



Last Spring, our Public Engagement team launched a number of schools outreach initiatives aimed at developing relationships with pupils and teachers in some of the most underserved areas for science enrichment across the region. Dr Mike Norman, Science Engagement and Outreach Officer, assesses how the outreach programme is impacting both Campus scientists and the schools involved.

Over the last year, we have expanded our outreach programme considerably to enable a much wider and more diverse audience to engage with the themes and topics that span different areas of Campus research. A large aspect of this work has been to establish relationships with schools to support them with class sessions, and giving different people across the Campus multiple opportunities to get involved, including our growing cohort of STEM Ambassadors – now almost 150 strong.

As part of this, our School Roadshow initiative was launched in the spring of 2018, with the specific aim to reach new audiences in secondary schools who had never engaged with the Campus. Following an analysis of our region, we identified localities within the top 30% of deprivation ranked by the Government's child education and skills metric, as well as the bottom 30% for social mobility assessed by the 2017 State of the Nation report.

There are numerous schools within these criteria located in the local region, across Cambridgeshire, Norfolk, Suffolk and Northamptonshire. Crucially, we have found that many schools within these measures also have little or no access to any science enrichment offer, something that doesn't always follow from deprivation or mobility metrics. In the first few months of the roadshow, we have interacted with 25 schools within these areas; engaging over 2,400 young people.

Our aim is for our outreach to form the first stage of a relationship we develop with schools. To help achieve this, we have launched a bursary scheme, encouraging schools to visit Campus after we have been to their school, which 25% of our roadshow partner schools have already taken advantage of. We are also heartened by the number of teachers and pupils seeking further classroom-based enrichment opportunities as a consequence of our interactions. Feedback from pupils and teachers has been hugely positive with differences being reported in pupils' awareness and knowledge of genomics, and more generally, in their enthusiasm towards STEM topics and careers.

Looking to the year ahead, our outreach work and new relationships with schools are becoming firmly established. The appetite for engagement opportunities across the Campus is growing, illustrated by the fact that, in the last year, over 35 school visits were planned and delivered solely by researchers, many during British Science Week. Our STEM Ambassador cohort also continues to grow with the number of Campus ambassadors likely to reach 200 by the end of the year.

The connections we are making through our schools outreach work also have potential to be amplified through other aspects of our education programme, such as our strategic partnership with the Primary Science Quality Mark (a CPD programme that helps schools to achieve a quality mark in science teaching and learning). For this, the Campus acts as a hub providing support and helping the schools meet the award standard through innovative training and facilitating access to resources and researchers.

An ultimate goal and clear indicator of positive impact of our work would be if the relationships we develop through our outreach efforts encourage schools to embark on a longer-term plan for sustainable change. This is a long journey involving continued and proactive engagement, stimulated through our outreach efforts: one which we're at the start of and feel passionate about!

LIFELAB – REACHING OUT TO NEW COMMUNITIES

European Researchers' Night is an annual event held in 360 European cities on the last weekend of September. Funded by the European Commission's Marie Skłodowska-Curie Actions, it's one of the world's largest public interactions with research initiatives. Becky Gilmore, Exhibitions and Interpretation Coordinator in the Public Engagement team, explains more about the first-ever Cambridgeshire event, LifeLab, and why it's adding value to our outreach work.

LifeLab's mission is to highlight the diversity and value of research through quality interactions between researchers and the public. Its focus is on life science and biotechnology, given our region's strength in these areas, and on engaging with communities less connected with the opportunities these sectors present.

From Friday night pizza with a slice of science, to a pop-up lab enabling Saturday shoppers to get hands-on with experiments, LifeLab's programme brought researchers, discovery – and fun! – to Cambridge and Peterborough. In the lead-up to the Night, a schools programme shared the wealth of life science career opportunities in the region. Marking the European Year of Cultural Heritage, LifeLab revealed lesser-known stories from Cambridge's long history of research and the social impact it has made.

“ So inviting, we stayed longer than expected. Really good to see this in our town! ”

LifeLab visitor, Peterborough

Over 36 hours, 140 researchers interacted with 3,100 people, with a further 500 pupils participating in the schools programme. Of our visitors, 45% had not attended another science-related event in the previous two years. This reflects our aim to take public engagement beyond the usual boundaries, recognising the diversity of Cambridgeshire as a county and bringing research to where people are already – shopping centres, streets, and libraries – connecting with those who might not seek out these experiences. For example, we focused on Peterborough, a vibrant city with a growing technology hub. Evaluation has shown that people were excited to discover science

on their doorstep and that LifeLab also had positive outcomes for participating researchers.

“ Since our stand was related to people's health, [visitors] were sharing their personal stories, some of which were really moving, [and] still stay in my mind. It makes the research meaningful. ”

Researcher, Cambridge

“ I had a really interesting conversation with someone around what the job of an animal [technician] involves and how it is never too late to enter into the industry. ”

Researcher, Peterborough

LifeLab returns this year, building on its successes and strengthening its European connections. We will be coming to a third Cambridgeshire location, with a host of activities in



the cathedral city of Ely. Our schools programme will connect researchers to schools across the region, and inspire deeper community interactions. We will be sharing researcher stories; celebrating the impact of people from wide-ranging backgrounds who contribute to life science discoveries. With plans already in progress, LifeLab 2019 is set to be even bigger and better!

“ Brilliant to have science in these spaces. It's very important as a way to encourage science careers and we would like more for children in Peterborough! ”

LifeLab visitor, Peterborough

LifeLab is coordinated by Wellcome Genome Campus Public Engagement partnering with five Cambridgeshire-based research institutions: The

Wellcome Sanger Institute, the Babraham Institute, EMBL European Bioinformatics Institute, the University of Cambridge, and the MRC Laboratory of Molecular Biology.



30 YEAR ANNIVERSARY AWARDS: IMPACT AND FEEDBACK

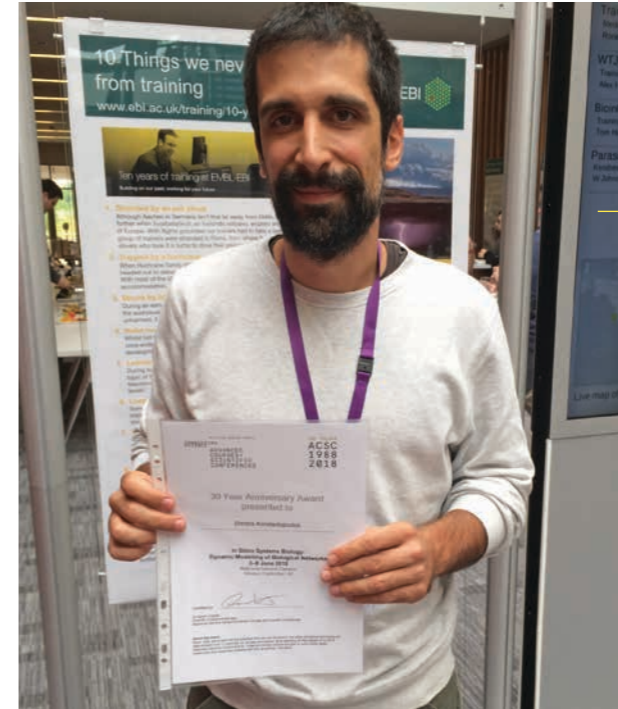
To celebrate their 30th anniversary, in 2018 Advanced Courses and Scientific Conferences awarded 30 free places to attend their events at the Wellcome Genome Campus. Applications were received from 47 countries, and a diverse selection of applicants travelled to Hinxton throughout the year. Here is some of the feedback given to us by the award winners on their experience of the event and their time on Campus.



Nidaa Ababneh (University of Jordan)

Attended: RNA Transcriptomics course

My research project involves the use of iPSCs and CRISPR technologies to generate isogenic lines from patients with genetic hereditary disorders. The course has really broadened my horizons into understanding the RNAseq technology. The fact that it involved both lab work and data analysis was a great combination to clearly understand the technique. The course was very useful and very well organised.



Dimitris Konstantopoulos (Institute of Molecular Biology and Genetics, Greece)

Attended: In Silico Systems Biology course

My project focuses on the development of bioinformatics tools to investigate the dynamics of transcription during DNA repair. I was really impressed by the structure of the course. It was a fantastic experience for me, and I'm very grateful for the opportunity I have been given to participate in such an event, to discuss with some of the experts of the field, and to visit and stay in one of the most famous institutes in the world.

Isabella Ferreira (University of KwaZulu-Natal, South Africa)

Attended: Bioinformatics Resources for Immunologists course

My PhD project focuses on understanding the lymph node HIV reservoir in the face of suppressive antiretroviral therapy. The single cell RNA sequencing tutorials were extremely useful as they gave a great outline of the analysis pipeline and I have already found this as a great guide to my own analysis. I had the most wonderful experience. I met such interesting people from all over the world and have made great connections with them. I would strongly recommend this course to anyone doing any immunological work.

Juli Petereit (University of Nevada, Reno, US)

Attended: Proteomics Bioinformatics course

My main research focus has been in data analytical approaches for genomic and transcriptomic data. I plan on using the learned material to educate our graduate students and PIs by offering a lecture on the possibilities of proteomic studies. This course was exceptional and invaluable. The amount I learned within the week would have taken me months to gather and explain to myself. I now feel comfortable to take on our proteomics data processing and analysis.

Diana Vieira (Instituto Gulbenkian de Ciéncia, Portugal)

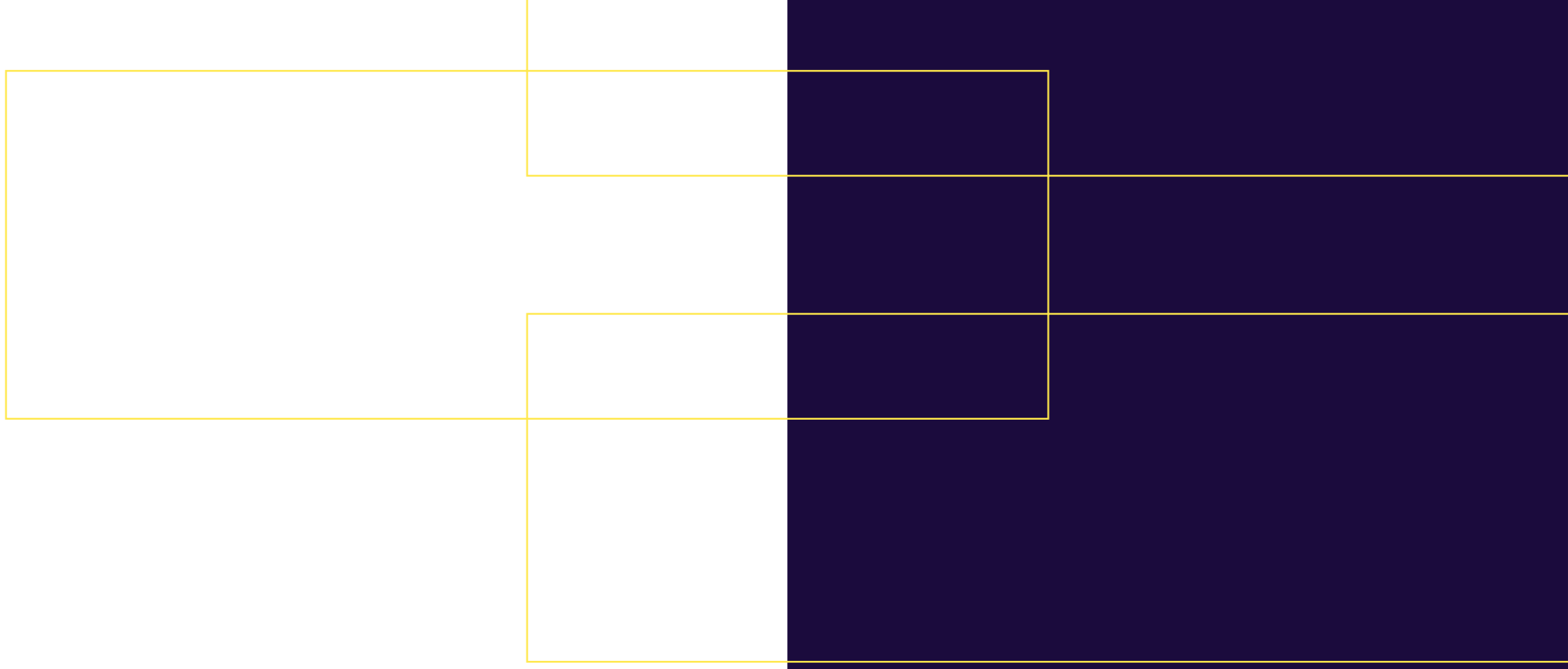
Attended: Drosophila Genetics and Genomics course

The course was of great importance to deepen my knowledge in Drosophila genetics. I was able to learn genome editing techniques, such as CRISPR/Cas9, and from all the lectures I also learned the techniques involved in genome sequencing and editing. All the knowledge acquired will allow me to evaluate and choose the most appropriate approach to analyse my own data. I'll be applying what I learned on the course as I have recently obtained funding for my own research project. The experience at the Wellcome Genome Campus was wonderful.

Eyituoyo Okoturo (University Of Liverpool, UK)

Attended: Next Generation Sequencing Bioinformatics course

My research is on the molecular biology of the malignant transformation of the pre-malignant lesion – Proliferative Verrucous Leukoplakia (PVL). The course helped in my interaction with my bioinformaticians in showing correlation between callings thresholds and tumour composition through the use of histology photomicrographs. My experience will remain memorable. A big thank you to all of the instructors. This course has inspired my 500 cancer genome project in Nigeria.



SPOTLIGHT ON GENETIC COUNSELLING



Genetic counselling has been listed as one of the best job growth markets for the future @theAGNC @acgs_news <http://www.nanalyze.com/2016/12/best-jobs-for-future/> amp/ ...

@Genomethics

With #GeneticTesting becoming a routine part of medical care which diseases do we want to eradicate from our society? & how are these conditions actually experienced? Great blog post on the social & subjective sides to disease severity #ethics #GenomEthics

@YaldaJamshidi

"We already provide support and counselling to people, but we must ensure that provision keeps pace with the expansion of predictive testing." [Secretary of State Matt Hancock, speaking at the Royal Society] There are less than 300 genetic counsellors in the UK, we urgently need support to help sustain the profession.

@Genomethics



As this profession has developed, we are supporting genetic counsellors' move into the age of genomic medicine



THE FUTURE OF GENETIC COUNSELLING

Dr Jonathan Roberts discusses how genetic counselling may develop in the new age of genomic medicine.



A still from the *Music of Life* project. This video explains autosomal dominant inheritance, with the one wooden drumstick representing the dominant version of a specific gene, which may be inherited from a parent.

When I tell people I am a genetic counsellor I get three responses. First, someone might make the following joke; "What? Does that mean you counsel genes?". Second, someone may choose to share their family history with me. Third, and most commonly, somebody asks; "Err, what is a genetic counsellor?"

It's a good question, and one we will be addressing fully in a new online course – What is Genetic Counselling? – currently being developed by the Society and Ethics Research and Advanced Courses and Scientific Conferences teams. But as this course isn't live yet I'll provide the short version: Genetic counsellors are healthcare professionals, who are trained in medical genetics. They also have advanced training in counselling

Enter genetic counsellors, a profession that sought to be an antidote to eugenics. It did this by adopting some important ethical principles, which included patient-centred care, informed consent, and non-directives (the patient supported to use their own judgment, rather than rely on that of others). In short, genetic counselling sought to empower patients.

As we move into the 'genomic era', genetic counsellors are still empowering patients. But the ecology of healthcare is changing, whole genome sequencing is coming fast, and it is likely that it will soon be a routine part of healthcare. As healthcare changes, our profession also needs to evolve, and as such there is a pressing need for research to provide an evidence base for genetic

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”

and communication skills. Genetic counselling can be described as the support people receive when they have, or are at risk of having, a hereditary condition. We have three genetic counsellors in Connecting Science: myself, Dr Christine Patch, and Prof Anna Middleton.

Before we go into what the future might hold for genetic counsellors, I want to go back and explain a little about how this profession came about. The 19th and first half of the 20th century saw the modern day revival of the eugenics movement. Eugenics is the belief that some groups of people are superior to others, based on their genetics, and eugenic policies aim to eliminate people viewed as inferior from the population (the most horrific example of this being the Holocaust). Many countries, including the UK and the USA, had eugenic policies that continued well into the 20th century.

The post-war period saw a number of developments in science and attitudes as understanding of genes and human health advanced – for example, in 1959 the cause of Down's syndrome was found to be due to the presence of three copies of chromosome 21. At the same time, pre-natal testing became more available, and in 1967 abortion was legalised in the UK. This meant that genetics became part of reproductive care in the NHS and, given the history, you can see why people may have been a little nervous.

counselling. Society and Ethics Research will be at the forefront of this research. We have a strong connection to the Clinical Genetics team at Cambridge University Hospital NHS Foundation Trust, and we are researching innovative ways of improving patient care with them. Our latest project is 'Music of Life', for which we developed six short films that explore the metaphor of genes as music. We are investigating if these are useful for patients and counsellors as a way of understanding and starting discussions about genetic terminology.

Connecting Science is at the forefront of the genomic training of genetic counsellors in the UK, delivering events, networks, and resources to support us to stay at the cutting edge of our profession.

So, what is the future of genetic counselling? All we really know is that it is exciting and that it is being shaped by work from Connecting Science. My advice: watch this space!

WHO WE ARE

Wellcome Genome Campus Advanced Courses and Scientific Conferences

fund, develop and deliver training and conferences that span basic research, cutting-edge biomedicine, and the application of genomics in healthcare.

Team led by Dr Rebecca Twells

Martin Aslett, Jemma Beard, Dr Pamela Black, Karon Chappell, Adam Crewdson, Dr Treasa Creavin, Lucy Criddle, Dr Darren Hughes, Dr Alice Matimba, Dusanka Nikolic, Sarah Offord, Julie Ormond, Dr Nicole Schatlowksi, Nicola Stevens, Yvonne Thornton, Kate Waite, Zoey Willard, Laura Wyatt

Wellcome Genome Campus Conference Centre

boasts world-class event and meeting spaces designed for knowledge sharing in the scientific research community.

Team led by Linda Prior

Kelly Butler, Tanya Hudgell, Martyn Kelsey, Rebecca Loffman, Kat Mace, Bart Siwek, John Suckling, Amy Sullivan, Sophia Tirelli-Hurst

Wellcome Genome Campus Public Engagement

supports sharing and discussion of the pioneering science that takes place on the Wellcome Genome Campus.

Team led by Dr Kenneth Skeldon

Mark Danson, Francesca Gale, Natalia Gorohova, Becky Gilmore, Dr Mike Norman, Laura Olivares Boldú, Dr Steve Scott, Emily Sullivan, Dr Susan Vickers, Dr Louise Walker

Wellcome Genome Campus Society and Ethics Research

uses quantitative and qualitative research methods to investigate the psychological, social and ethical impact of genomics.

Team led by Prof Anna Middleton

Jerome Atutornu, Lauren Farley, Dr Richard Milne, Dr Kate Morley, Dr Christine Patch, Dr Jonathan Roberts

Wellcome Genome Campus Connecting Science Programme Office

coordinates strategic projects, manages funding and governance, and provides marketing and communications support across the programme.

Team lead by Prof Julian Rayner

Emily Boldy, Dr Ireena Dutta, Catherine Holmes, Katrina Robinson

OUR PARTNERS AND NETWORKS

Accademia Europea di Bolzano, Italy
 African Society for Human Genetics
 Asia Pacific Society of Human Genetics
 Association for Science Education
 Association of Genetic Nurses and Counsellors
 Association of Science and Discovery Centres
 Babraham Institute
 Beijing Institute for Wetlands Research
 British Science Association CREST Awards
 Cambridge Junction
 Cambridge LaunchPad
 Cambridge Stem Cell Institute
 Black Label Productions Ltd
 British Science Association
 Café Scientifique
 Cambridge Science Centre
 Cambridge Science Festival
 Cancer Research UK
 Centre for Law and Genetics, University of Tasmania, Australia
 Cold Spring Harbor Laboratory, USA
 College of Medicine, University of Malawi
 Connect EB
 Dublin City University
 Ely Cathedral Science Festival
 European Commission (Horizon 2020)
 European Molecular Biology Laboratory
 European Science Engagement Association
 European Network of Science Centres and Museums
 European Researchers' Night
 Duke University, USA
 FutureLearn
 Genetic Counsellor Registration Board
 Genomics England
 Glassworks Barcelona SL
 Global Alliance for Genomics and Health
 Global Genomic Nursing Alliance
 H3Africa
 H3ABioNet
 Health Education England
 Human Cell Atlas
 International Society for Neglected Tropical Diseases
 Institute for Research in Schools
 Institute of Hygiene and Tropical Medicine, Uruguay
 Instituto de Biologia Molecular e Celular, Portugal
 International Congress of Human Genetics
 Kamineni Hospitals, India
 Kenya Medical Research Institute
 King's College London
 Kyoto University, Japan
 Royal College of Pathologists
 Mahidol University, Thailand
 Meet Cambridge
 Meetings Industry Association
 Monash University Malaysia
 MRC Laboratory of Molecular Biology

MRC Unit The Gambia
 Museums Association
 National Coordinating Centre for Public Engagement
 National STEM Learning Network
 National University Hospital of Iceland
 Norwich Science Festival
 Nuffield Foundation
 OCR
 One Nucleus
 Osaka University, Japan
 Oxford University Clinical Research Unit, Vietnam
 Oxford University Press
 Pan American Health Organisation
 Primary Science Quality Mark
 Princes Teaching Institute
 Public Communication of Science and Technology Network
 PulseNet América Latina y el Caribe
 Research Centre of Medical Genetics, Russia
 Rhein-Waal University of Applied Sciences, Germany
 Royal College of Pathologists
 Royal College of Physicians
 Royal College of General Practitioners
 Royal Society
 Ruhr University Bochum, Germany
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 Sigma IT Consulting AB
 Social Mobility Foundation
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 Thin Air Factory Ltd
 Transnational Alliance of Genetic Counsellors
 UK Research and Innovation
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 University of Cambridge
 University of Cape Town, South Africa
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 University of Malta
 University of Uppsala, Sweden
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 Wellcome Genome Campus
 Wellcome Sanger Institute
 West African Centre for Cell Biology of Infectious Pathogens, Ghana
 Wissenschaft im Dialog, Germany



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PUBLICATIONS

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GET IN TOUCH

Connecting Science

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[@ConnectingSci](https://twitter.com/ConnectingSci)

Advanced Courses and Scientific Conferences

More about our events: wellcomegenomecampus.org/coursesandconferences

Email coursesandconfs@wellcomegenomecampus.org

[@ACSCevents](https://twitter.com/ACSCevents)

Conference Centre

More about our spaces and facilities: wellcomegenomecampus.org/conferencecentre

Email: conference.centre@wellcomegenomecampus.org

[@WGCCConfCentre](https://twitter.com/WGCCConfCentre)

Public Engagement

More about our activities: wellcomegenomecampus.org/engage

Email: engage@wellcomegenomecampus.org

[@WGCengage](https://twitter.com/WGCengage)

More about our resources: yourgenome.org

[@yourgenome](https://twitter.com/yourgenome)

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