

**wellcome  
connecting  
science**

# Annual review 2023



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## Directors' introductions

Genome sequences hold information about our past, present and future, both as individuals, and as a species that has been shaped by evolution and the world around us. Genomes therefore belong to us all, and genomic science is at its best when all involved are empowered to contribute, and to benefit.

Inclusion is at the very heart of our mission – we aim to enable everyone to explore genomic science and its impact on research, health and society – and this ‘everyone’ is hugely important to us. We think carefully about the audiences we are seeking to engage, evaluate whether our programmes are having the

desired impact, and continually challenge ourselves to do better. It is that focus on ‘everyone’ that we showcase in this annual review. In the following pages you will read about how we make sure that patient and public voices are heard in genomic research and policy, how we tackle the lack of diversity within the genomic

researcher workforce, and our research that explores different perspectives on DNA, data, and identity.

Our work with professional audiences spans the globe and often targets very specific underserved audiences in Africa, Asia and Latin America. We have recently concluded a new study into the experiences of researchers from minoritised backgrounds at our events, in order to help us deliver these more equitably in the future. Finally, we have been researching the history of Hinxton Hall, to better understand the context within which outstanding genomics research and training takes place on the Wellcome Genome Campus.

As ever, I’m completely in awe of the incredible Wellcome Connecting Science team that

delivers this work, and our collaborators and partners, many of whom work at the Wellcome Sanger Institute. It takes energy, planning and passion to deliver our programme, and to reach tens of thousands of current and aspiring genome scientists every year. Thank you for everything you do – it’s an honour to work with you!

Prof Julian Rayner,  
Director, Connecting Science





## Directors' introductions

As an organisation we aspire to be a trusted global leader in deciphering life and empowering society.

Connecting Science plays a key role in delivering our vision through creating learning, training and engagement opportunities with Sanger science, delivered across

the globe, and accessed in an equitable way. Having taken up the leadership of the Wellcome Sanger Institute earlier this year, I am hugely excited to explore

opportunities to build upon our existing impact in this area.

Prof Matthew Hurles,  
Director, Wellcome Sanger Institute



## Genomic Futures: creating inclusive careers programmes for the next generation of scientists

“

*For many young people, a career in science (and genomics in particular) just isn't seen as an option. They may not see themselves as a 'scientist' or are not aware of the diverse range of careers that are out there waiting for them. It is so important to facilitate access to programmes such as Genomics Futures so that we can break down these barriers and smash those scientist stereotypes. We showcase relatable role models, and enable young people to experience first-hand what it's like to work in different areas of genomics.”*

Francesca Gale,  
Head of Science Engagement and Enrichment



Our Engagement and Society team member, Cindy Smidt, hosts a visit in our Open Lab space

Wellcome Connecting Science acknowledges that access to science education and engagement is not equal, and we are committed to raising the aspirations of all young people, encouraging them to explore careers in science through our schools engagement programme.

Over the past year, we have focussed on providing a wide range of free opportunities for school students and young

people to interact with industry professionals and learn about careers in genomics.

### **A unique insight into different career pathways**

We created a series of short films providing a unique insight into some of the different career pathways and job roles available in genomics, from conservation genetics, to bioinformatics and

genetic counselling. In the films, colleagues from across the Wellcome Genome Campus discussed their career paths, and what makes them so passionate about working in the field of genomics.

We launched the videos in March during National Careers Week, and they have since been screened on school visits, at careers fairs, and featured on [Your Genome](#). They have reached over 60,000 people on social media!

Alongside these films, we also created a collection of career profile handouts, which are a useful starting point for students considering a career in science, and support teachers exploring different job types with their students.



## Genomic Futures outreach programme

Through our in-person outreach programme, we visit schools and colleges in the East of England, with our Genomic Futures careers stand and staff from across the Wellcome Genome Campus. Students have the opportunity to talk to genomics professionals, find out about more routes into different careers, and get hands on trying out genomics-related skills.

We also offer year-round visits to Campus for UK state schools, sixth forms and collages. These include activities, presentations from experts, and a chance to visit the Open Lab, and see one of the world's largest DNA sequencing facilities. Over the past twelve months, these visits have inspired 6,019 young people, and received excellent feedback. We are now taking bookings well into 2024.

For all our outreach work, we prioritise supporting schools in areas of high deprivation, with

a high proportion of students in receipt of pupil premium, and in areas of low social mobility.

“

*I have been teaching for 37 years and this has been the most inspirational day I have ever had. I have learnt so much as a teacher and the pupils have all had an amazing experience.*

*None of us will forget this day. Thank you.”*

Teacher at St Clement Danes School, Hertfordshire

## Expanding our reach with virtual work experience

This summer, we held our first virtual work experience course for 14-18 year olds based in the UK, hosted on a careers platform, Springpod. The interactive free course, entitled ‘Genomics, Science and Data Careers’, enabled young people to experience the diverse range of career options in these fields, and learn about employability skills such as teamwork, communication and interview preparation. The course included videos, interactive

quizzes, activities and webinars. Participants also had the opportunity to address questions

to staff from the Wellcome Sanger Institute, and across the Wellcome Genome Campus.

The response we received was remarkable. Over 1,450 signed up for the programme, and 607 young people took the time over their summer holidays to achieve at least a Bronze level of course completion.

This year was the first time that we were able to provide this type of experience for young people nationally, removing financial and

geographical barriers that many face when seeking in-person work experience opportunities. Reaching those who do not have connections to the industry, or whose parents have not previously studied science, 31% of participants indicated they are the first member of their family considering University.

Our virtual work experience course received excellent feedback, with an average rating of 8.4 out of 10. We also saw some impressive increases in student awareness of careers in the industry; how confident they feel about finding a job in the future; and how confident they would feel about speaking to an industry professional.

Starting as a trial, its success means we plan to continue to offer this experience to young people over the coming years.

“

*We worked with staff from across the Wellcome Genome Campus, from lab-based roles, data roles and non-scientific roles to highlight the massive diversity of jobs on Campus.*

*We put on two live webinars, which were really popular with the students, and allowed them to ask questions to our hosts and speakers. It's been amazing to see the student feedback from this course, and we're excited for this to become a staple part of our careers offering.”*

Em Haydon,  
Science Engagement Manager

“

#### Participant feedback

*This programme has been amazing, it has been really informative and useful. It really opened my eyes to the field of genomics and its many uses in the modern world.”*

As well as our virtual work experience course, we also delivered an in-person work experience opportunity. The “Genome Academy, held over the summer, was a three-day immersive workshop with 18 places available for Year 12 students. Genome Academy included lab tours, the opportunity to learn about the latest cutting-edge science taking place at the Sanger Institute, and hands-on experience with lab techniques

such as DNA extraction, amplification, and sequencing, as well as training with bioinformatics tools.

Our schools engagement programme is continually growing and evolving, and our aim is to ensure that it is as inclusive as possible to support the broadest participation.

“

#### Participant feedback

*Thank you so much for this opportunity to learn so many new things about an area of science that I have never learnt about. You have given me a strong insight into what I want to do in the future and it has been incredible.”*



## Addressing inequality: supporting people for better science



Members of our Engagement and Society team, including PhD candidates Jerome Atutoru and Sasha Henriques.

One of our key programme objectives is to positively impact policy, practice and careers. As part of this goal, we aim to ensure that our professional-facing activities acknowledge structural inequality in the UK, and actively include and promote the participation of both current, and the next generation, of Black and other under-represented healthcare and research professionals.

Workforce development is part of this endeavour, and we believe that supporting a diverse and inclusive cohort of research professionals is one way to ensure that the benefits of genomics-based knowledge can be experienced by everyone in our society.

We work collaboratively to make our activities with global communities inclusive; increase awareness and understanding of research inequality between the Global North and South; and address specific barriers to both

participating in, and benefiting from, research. We support a number of short and longer-term initiatives to translate our aims into actions; here is snapshot of some of them.

This year, we participated as a host organisation as part of the [Health Data Science Black Internship Programme](#). As an expanding field with the potential to transform the future of health and care for all, the UK has an urgent need for new health data scientists. This internship programme is for early

career Black data scientists – a heavily under-represented group in the sector, and is run by Health Data Research UK and the UK Health Data Research Alliance in partnership with 10,000 Black Interns initiative. It aims to tackle the underrepresentation of Black people within the health data science sector, and to provide talented candidates with the experience they need to kick-start their science careers.

team, supporting the development of new approaches to accessing our bioinformatics training resources for researchers across the world.

Together with the Wellcome Sanger Institute we currently fund and support PhD research students in the social sciences at the University of Cambridge who are exploring the intersection of genomics, diversity, and inclusion,

Lydia Okoibhole was previously a research assistant and has interests in the sociocultural and economic determinants of effective

ancestry are encountered. Human population categories are regularly used in genomics research, and how these terms are defined and

“  
*Working with expert genome sequencing instructors on these courses has been a truly enriching experience. It allowed me to dive deep into the administrative aspects while benefiting from a supportive environment and invaluable feedback, which I intend to carry forward throughout my professional journey.”*  
 Elvis Anunwa, medical student and HDRUK intern

We were delighted to host medical student Elvis Anunwa during the summer in 2023. Elvis worked as part of our Learning and Training

building on their lived experience as people of Black heritage in the UK.

“  
*There are many things a PhD will give me the opportunity to do and achieve but I am most looking forward to contributing knowledge to a field that is incredibly important and one that I am very passionate about. Sickle cell disease is a condition that doesn't get the spotlight I feel it deserves and social science research on this topic is limited so I am genuinely excited to become an expert in a field that impacts my community.”*  
 Lydia Okoibhole, first year PhD student

health engagement. She joined us as a PhD student in October 2023.

Sasha Henriques was a genetic counsellor in the NHS, and is currently investigating what constitutes ‘socially just’ genomics research practice around data categorisations when issues around race, ethnicity and

implemented in the categorisation of genomic data impacts our understanding of genes and their function. The language used to describe population groups may have contributed to the unequal outcomes of genomics research for individuals from different ethnic or geographical backgrounds. Sasha’s project explores how and

why researchers, and the public, use these population descriptors, and seeks to understand the systems that underpin ethical choices for genomic researchers using human data. Ultimately

a PhD project based around attitudes and perspectives to genomics within Ghanaian communities. Jerome's project has asked speakers of Twi and Ewe, in Ghana and in the UK,

benefits more equitable between communities in the Global North and Global South.

healthcare practice in the UK and globally.

“



*Thanks to the enhanced studentship stipend, I am excited that I can focus solely on this project, without the need to juggle other professional responsibilities. This generous opportunity has enabled me to stretch my own potential, whilst embracing being part of a community that I can also view through a researcher lens.”*

Sasha Henriques, second year PhD student

her work will inform policy and guidance recommendations for scientists working in this field. Jerome Atutornu is a senior lecturer in radiography at the University of Suffolk and former healthcare professional, but more recently has been focussing on

for their views on DNA data and privacy, whom they trust with this data, and if they would be willing to share it. By capturing and understanding global perspectives on attitudes to genomics we can move towards making both research practices and research

“



*I am interested in ensuring that genomics does not exacerbate existing health disparities by facilitating discoveries that will disproportionately benefit only the well-represented communities. There were times when I felt quite anxious about certain aspects of my PhD research. However, I have been amazed by the depth and breadth of the support available within the Engagement and Society team in Connecting Science, and more widely too. Looking back, I realise that there was no need to be anxious.”*

Jerome Atutornu, final year PhD student

We are delighted to support this talented group of research professionals as they establish and develop their careers, and look forward to seeing the impact their work has on research and



## Changing conference culture

Research conferences, symposia, and meetings, form a key part of academic life across all subject areas from the sciences, to the arts. Conferences provide a platform for sharing new knowledge, meeting collaborators, and building key connections which enable career development.

As a [leading developer and provider of research conferences](#) which are focussed on genomics, health and disease, Wellcome Connecting Science has always been interested in the experiences of delegates at our meetings. We know, both from individual feedback, and longer-term analysis, that our conferences provide excellent opportunities for knowledge exchange and networking; and have contributed to the development of new projects, collaborations, and research approaches. This is reassuring if you are ‘in the room’ and actively participating in these meetings; but what about those

who aren’t in the room, and why might they be absent?

In 2022, we commissioned SEA-Change Consultancy, a behavioural science-led consultancy with a focus on diversity and inclusion, to report on the views of researchers from different backgrounds, on their conference experiences. We were particularly interested in the experiences of researchers from racially minoritised backgrounds, as although our conference delegate base achieves broad parity in relation to gender, it is not particularly diverse in relation to race and ethnicity.



A conference delegate participating in a Q&A session

“

*It is only by stepping back and asking members of the research community about their experiences, that we are able to build our understanding of how we can improve our own offer, and influence others. ”*

Dr Michelle Bishop,  
Associate Director Learning and Training



## What we found

Using both quantitative and qualitative approaches SEA-Change identified a number of themes relating to the experience of those from minoritised and non-minoritised groups at UK research meetings. Although based on a small sample, an anonymous survey revealed that those from minoritised backgrounds faced more financial challenges in attending research conferences (including our own), and were less likely to feel welcome at these events. When asked what conference organisers can do to make everyone feel more included, most ethnically minoritised

interviewees highlighted the need for changes in policies and behaviours. In-depth interviews also revealed the intersections between race, gender and career-stage; with barriers to conference attendance relating to time, funding, and caring responsibilities cited broadly, but with minoritised groups being impacted more by some of these elements.

## How we're responding

This report has produced a number of important insights and recommendations, both for our programme and the conferencing sector in general. We have used the results of this research to

reflect on our strategic goals and operational processes, and how they influence the inclusiveness (or not) of our conferences.

We have committed to:

- Creating a new and intersectional inclusion policy to diversify conference participation
- Enhancing our Code of Conduct with clear expectations around behaviour and how to access help and support
- Improving how we promote our financial support options, including bursaries and carers grants, to specific target groups
- Ensuring our marketing and communication uses inclusive

approaches, particularly around language

- Monitoring and responding to the impact of these actions on our conference participant base through 2024.

We will provide updates on our progress, as we move from reflection to action, so sign up to our newsletter or follow us on social media, to keep in touch with our programme and our Learning and Training team. We are also interested in sharing our experiences with stakeholders in this sector, and if you would like to receive a copy of the full report please contact us.

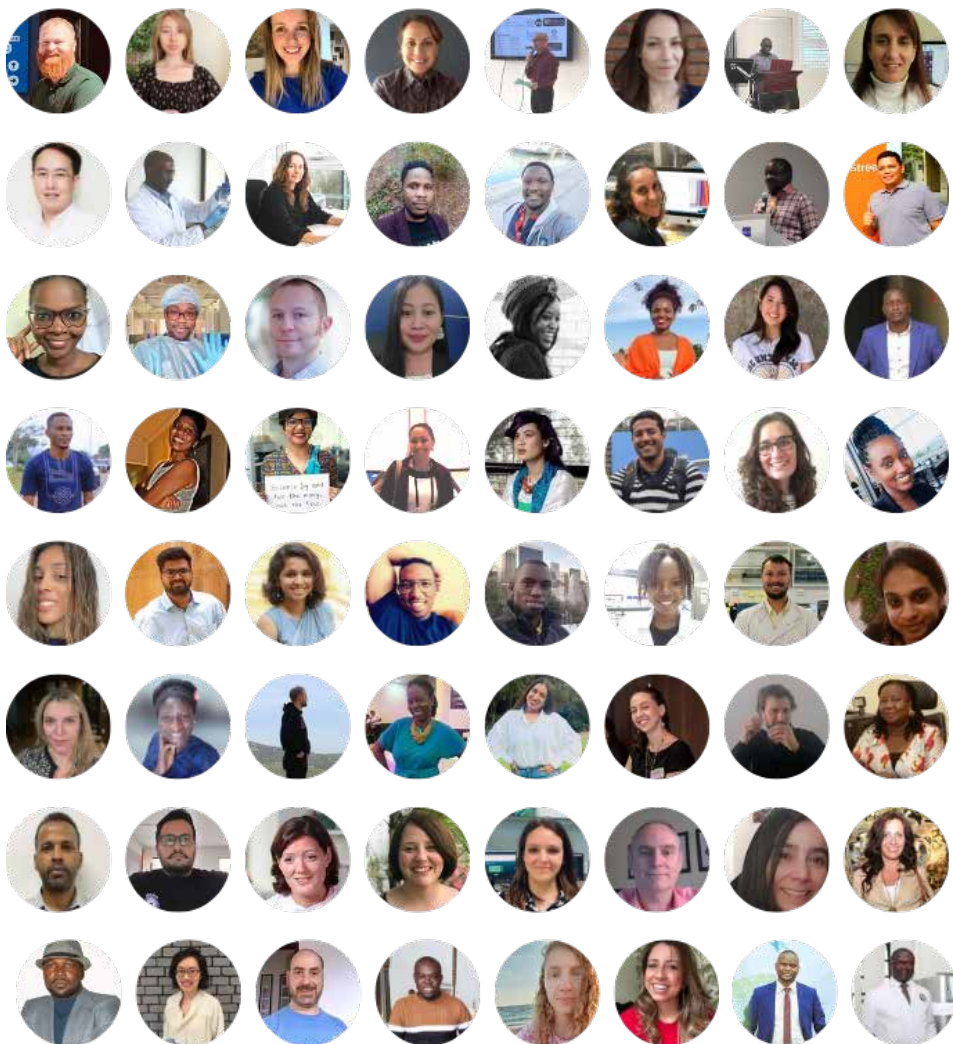


An informal break at a Wellcome Connecting Science conference held in Hinxtion Hall Conference Centre



A poster session with conference delegates

## Lessons from the pandemic: developing a model for global capacity building



A snapshot of the global community who contributed to the development of the COG-Train project

The pandemic shone a spotlight on the value of genomics in infectious disease surveillance to inform public-health decisions.

For Wellcome Connecting Science it was the springboard for the COG-Train project, a pioneering initiative for building global capacity in genomics, in partnership with the COVID-19 Genomics UK Consortium (COG-UK). Working with researchers in pathogen genomics and public health from across the world, this project enabled the sharing of knowledge and skills developed in genomics during the SARS-CoV-2 pandemic.

### A transformative journey in online learning

Over 15,000 learners from across the globe joined our series of massive open online courses (MOOCs) to better understand how to address the most challenging global infectious diseases. The

topics covered in the five courses spanned an introduction to viral genomics, to the challenges in genomics surveillance and global health, including important concepts such as metadata and biobanking.

*“Our initial aim was to facilitate an increase in global genome sequencing and analysis capacity, reduce sequencing inequality, and enhance pathogen surveillance. We wanted to engage a global scientific audience, to develop capacity and improve preparedness for future infectious disease outbreaks.”*

Dr Treasa Creavin, Head of Scientific Meetings and Digital Learning

Although originally focused on SARS-CoV-2, each course built on principles and processes applicable to others global health threats. The final course emphasised recent public health emergencies - Legionellosis in Argentina, and cholera in Yemen - explaining how genomics helps inform public health decisions by containing infectious diseases, preventing future global health threats, and better protecting human populations.

### Increasing the impact of bioinformatics training

To increase the impact of the MOOCs, we developed a series of virtual bioinformatics courses aimed at different audiences.

We used a blended, distributed classroom model to deliver training in 28 classrooms. Working with a team of 12 viral genomics experts, we developed ‘SARS-CoV-2 Bioinformatics for Beginners’, which introduced

the core concepts and skills in bioinformatics, the identification of viral variants, and how to share data with the world. We delivered the course using multiple platforms, including Zoom for interactive sessions, a Learning Management System, GitHub repository, and YouTube. The support of 95 staff members across 28 classrooms enabled 350 researchers based in 22 countries across Asia, Latin America, and Africa to benefit from the training.

“

*It was exciting to pilot an adaptation to our existing distributed model, to see how this remote classroom training approach would work across all the time zones within the different classrooms at the same time.”*

Dr Jorge Batista da Rocha, Education Developer, Lead for COG-Train Virtual and Distributed Classroom Courses

In addition, more advanced hands-on training targeted scientists, who were already working in viral genomics, with 59 researchers from 20 countries based in Asia, Latin America and the Caribbean, participating in virtual courses.

### Breaking barriers: global collaboration and sharing resources

We started with a team of 19 collaborators (based in nine countries) for the first MOOC,

and grew to 44 collaborators, based in 21 countries, by the final one. This created a democratic model for delivering education and training; considering all the knowledge and expertise of scientists based in institutions worldwide, and not only led by those based in the Global North.

Working with this diverse, global community also fostered a 1:1 gender balance across the project – out of 121 collaborators, 53% were women. Indeed, our course on web-based bioinformatics, which is historically a male-dominated topic, was led by one man and four women!

To enhance learning, increase accessibility and help develop Communities of Practice, which support collaboration beyond the initial training offer, course materials are now available on our [GitHub page](#).



“When developing and delivering these course materials, we were committed to the FAIR principles: Findability, Accessibility, Interoperability, and Reuse of digital assets. The material is licenced under an attribution CC-BY-4.0, which means you can share and adapt the material for any purpose upon acknowledgement”.

Dr Liã Bárbara Arruda, Education Developer,  
Lead for COG-Train MOOCs

### Establishing capacity in pathogen genomics – beyond skills training

As we adjusted to a post-pandemic world, we saw an opportunity to build on the success achieved through COG-Train, and worked with healthcare, research and training experts to establish an effective and sustainable approach towards capacity building for pathogen genomics. Partnering with the Ethiopian Public Health Institute (EHPI) in Addis Ababa, and collaborating with 17 public health scientists and genomics

training experts from across Africa, we delivered a workshop on bioinformatics tools and analysis. Moving beyond developing skills in viral sequencing and bioinformatics, the goal was to empower scientists to build capacity for pathogen genomics in research and service delivery in public health.

Attended by over 30 public health and research professionals who are implementing genomics for pathogen surveillance, we focused on how to establish infrastructure and genomics workforce capacity; how to design sequencing and data workflows; and interpretation and public health decision-making. Provided with educational tools

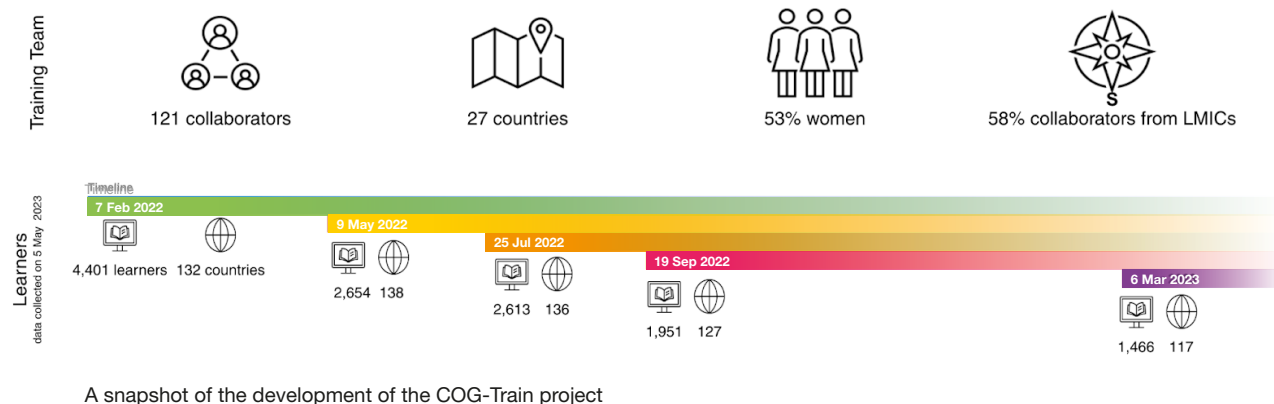
and resources, attendees explored local and regional needs for genomics workforce development, as well how to cascade skills and knowledge to their colleagues and wider communities through training.

“Genomics capacity building needs to move beyond training with a focus on broader issues, such as leadership strengthening and training approaches which include infrastructure and workflow development, access to funding and workforce development for it to be sustainable.”

Dr Alice Matimba,  
Head of Training and Capacity Building

Understanding regional priorities for pathogen genomics in Africa, and developing strategies for deploying genomics in an African context, is just one way in which COG-Train has developed and utilised a sustainable model for capacity building. More broadly the COG-Train initiative has supported its participants in navigating the global policy landscape and emphasised opportunities for collaboration, an ethos that has contributed to all our global training and capacity development activities.

[Access free resources developed through the COG-Train project.](#)





# Sustainability, science and success

As a global learning, training and engagement programme, we are conscious of our responsibility to operate as sustainably as possible, across all our activities. For us, sustainability includes reducing our environmental impact, and boosting access and inclusion.

## A greener venue

Our beautiful venue, Hinxtion Hall Conference Centre, hosts over 500 events and around 20,000 delegates each year, including those coming to our own Campus-based learning and training activities. This summer, Hinxtion Hall received a silver Green Meetings award from Green Tourism, the largest and most established sustainable certification programme in the world. The result of a rigorous assessment, a Green Meetings Award means that a business works responsibly, ethically and sustainably, contributes to their

community, is reducing their impact on the environment, and aims to be accessible and inclusive to all visitors and staff.

Thanks to our Wellcome Genome Campus Estates and Facilities team, we have a waste management system through which we monitor and measure our non-organic and organic waste, as well as water and energy consumption. We use cleaning and washing products and systems that are not damaging to the environment, and we encourage wildlife and biodiversity on site. Campus wide, we assess our

The Hinxtion Hall estate and wider Wellcome Genome Campus have a number of different environments which support biodiversity



Our partners Restaurant Associates have the highest Food Made Good accreditation by the Sustainable Restaurant Association



suppliers for their commitment to sustainability, ethical trade practices, and equality.

Our Campus Gardening team collects and uses the coffee grounds from the Hinxtton Hall kitchen, as well as frying oil, which they convert into biodiesel onsite and use to power vehicles on Campus. This year we have also set up Conference Centre-specific compost bays to reduce the amount our green waste travels.

At our meetings and events, our food and drink is ethically and responsibly sourced or produced; with many elements locally-grown or produced, which reduces food miles. Our partners, Restaurant Associates, have the highest Food Made Good accreditation by the Sustainable Restaurant Association, which covers sourcing, society and environment. They are also committed to Net Zero by 2030. [Find out more.](#)

We also regularly review, monitor, and measure, our consumption of

single use items, setting targets for reduction. We do not have plastic cutlery or disposable salt and pepper sachets, and we have replaced all plastic water bottles in our accommodation and bar, with water machines and canned water.

### **Promoting inclusivity and accessibility across Wellcome Connecting Science**

To support people with different physical accessibility requirements we have made a number of adaptations to our venue, the latest improvement being the installation of a gated lift allowing step-free access to the auditorium's stage area.

Over the last few years, we have also invested in virtual and hybrid conferencing equipment for most of our meeting rooms. This gives our event organisers the ability to hold meetings that are accessible to those who would otherwise not be able to attend due to geography or cost, or those individuals and organisations who are reducing the amount they

travel internationally for work. Our scientific conferences programme now runs on a hybrid model, with hundreds of delegates attending each event virtually.

The Learning and Training team also used technology to reach scientists across Africa, Asia and Latin America, reducing both travel and cost implications. For example, over 350 researchers based in 22 countries participated in 'distributed' classrooms, using multiple platforms to access our SARS-CoV-2 Bioinformatics for Beginners course. Read more on page 13: Lessons from the pandemic: developing a model for global capacity building.

Tackling other barriers to attending to our Campus events, we support a carer grant to help delegates with the costs of caring for children or dependent family members. We have also been exploring potential barriers relating to race and ethnicity at research conferences, and how these intersect with other identities. Read about the

outcomes on page 11: Changing Conference Culture.

By considering sustainability both as a strategic priority, and in terms of operational actions, we aim to ensure that we reduce our impact on the environment, whilst still making a positive impact on people. We are aware that sustainability is an ongoing process, so if there is anything you'd like to see from our venue or from our wider programme, please [get in touch!](#)





## Global training: getting hands-on with helminths and community engagement

The Wellcome Connecting Science training offer includes wider professional skills that will enhance research practice and career development. One recent example is the integration of community engagement into training to support helminth research and disease control.

### Helminths

Parasitic worms, known as helminths, are responsible for a range of infectious diseases globally. The World Health Organization estimates that helminth infections, transmitted through contaminated soil, affect around 1.5 billion people, around 24% of the world's population. These infections cause chronic and recurrent disease, resulting in poor cognitive development, poor school and work performance, and poor socioeconomic development. Helminth diseases effectively keep communities who are already experiencing poverty, in poverty.

Using new sequencing technologies to generate helminth genomes offers the potential to improve our understanding of parasite biology; support the discovery of new drugs; and enhance public health surveillance and the identification of drug resistance. Often, scientists who focus on helminth research, diagnostics, and surveillance, work alongside community and public health initiatives. Although engagement with affected communities is vital for their work, a training gap in this area has resulted in limited opportunities and resources for effective public



Course participants delivering their engagement activities with school students in Khon Kaen, Thailand

and community engagement in these regions.

### The course

Our Helminth Bioinformatics training course held in Thailand in May 2023 was developed with genomics experts based in Asia, led by Dr Arporn (Koi) Wangwiwatsin, Khon Kaen University, and Dr Stephen Doyle from the Wellcome Sanger

and Engagement and Society teams, we were able to develop a public engagement training module that was delivered as part of course.

The starting point for developing the engagement training component was to ensure it would integrate well with the core bioinformatics content, and feel relevant for the participants. We

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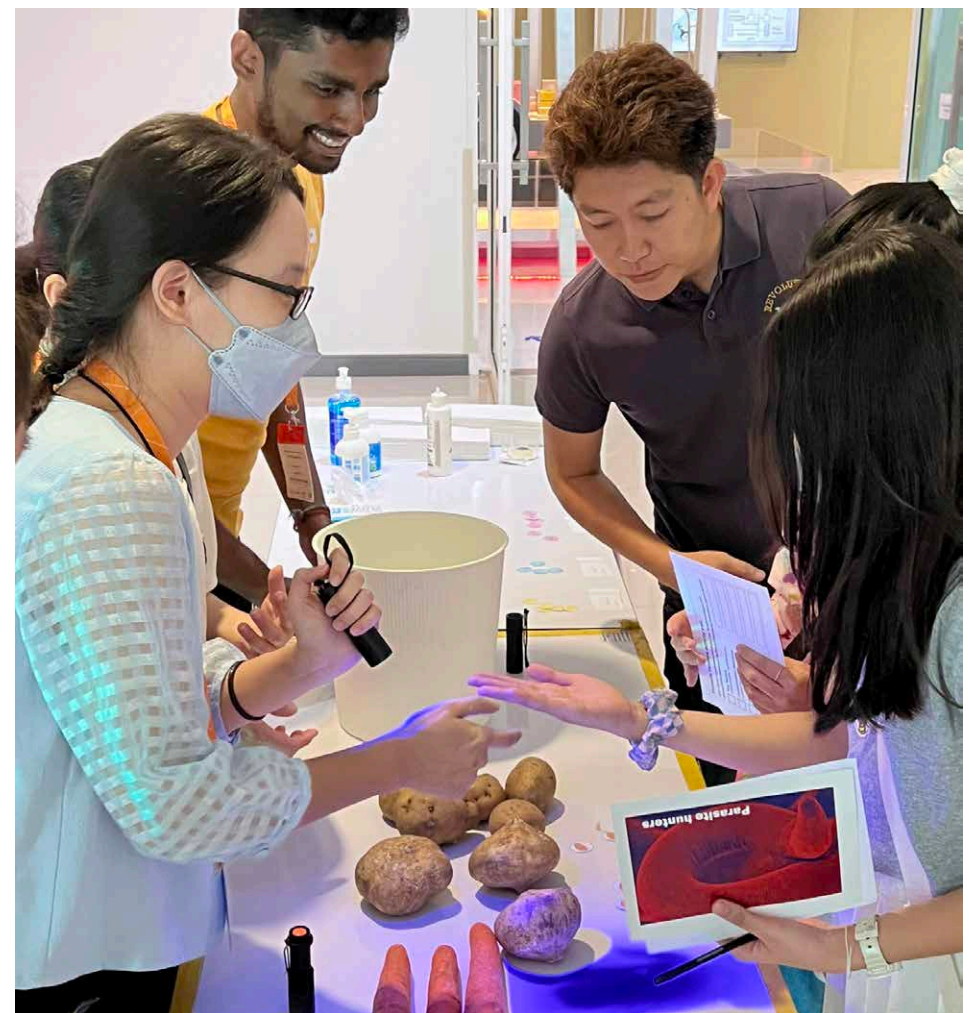
*We have previously implemented professional development skills such as grant writing, as part of many of our courses.*

*When our Global Pathogen Training Needs survey identified a gap in public engagement skills, we were able to respond by working with colleagues across Connecting Science to create relevant training for our course participants.”*

Dr Alice Matimba,  
Head of Training and Capacity Building

Institute. Building on Koi’s personal experience and enthusiasm for science engagement, and working across our Learning and Training,

were also aware that engagement might be quite frightening for some of those new to it – of the 21 participants who gave information



Course participants discussing transmission of pathogens with young people

ahead of the course, 19 gave ‘lack of understanding about science engagement’ as an obstacle to doing more – and we designed everything with this in mind: a balance of inspire, challenge, and support.

### Engagement event

Three sessions were spread over the week long course – the first

focussing on theory and building a shared understanding of what ‘engagement’ means; the second moving to practical application and developing potential activities; and finally, delivering these activities during a one-day-long event at a local museum in Khon Kaen, for 150 students from nearby schools. Young people and school students can be particularly influential in



the context of helminth and other infectious disease research, and are often key to disseminating knowledge in their communities.

So they were an important audience for the engagement skills we wanted to develop. Course participants were tasked with running one of five stalls, with a core, and an extension, engagement activity. Their aim was to discuss specific agreed talking points with the students, while also having conversations about genomics skills and careers.

### What did course participants think about this experience?

*“Upon completing the engagement training, I have realised the importance of treating engagement activities with the same level of significance as my research. As a result, I am committed to incorporating them into my work routine accordingly.”*

Helminth Bioinformatics Asia 2023,  
Course participant

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*Developing and delivering engagement training sessions embedded within a broader science skills course was new to me, and frankly a little scary. I shouldn't have worried. The scientists responded really well to our engagement training; and the activities not only developed engagement practice but also seemed to enhance their scientific skills by giving them a place to strengthen bonds with other participants, and crystallise learning by discussing techniques with school students.”*

Jack Monaghan,  
Science Engagement Manager

The response was overwhelmingly positive! Our evaluation methodology used a ‘blob tree’ to capture thoughts and feelings, at the start and end of their training. The majority of the cohort started the week being nervous, unsure or anxious; but by the end of the museum activity, they reported feeling confident, excited and inspired.

These engagement sessions also strengthened skills beyond the area of working with the

community, such as supporting communication, teamwork, collaboration, and translating ideas into goals. Connecting Science is uniquely placed to draw on the breadth of our expertise to develop this type of enhanced training. Having demonstrated the relevance in one setting, we are now seeking to continue accelerating helminth research by replicating this mode of training through partnerships in other regions.

## What if...? Influencing research policy and practice through lived experience

We all experience life differently, due to our individual circumstances, identities, and interests. And sometimes the views and perspectives that we derive from our lived experiences means that we can make a unique contribution in all sorts of diverse areas.

Lived experience of disability, health and illness, is particularly pertinent when considering genomic research and its applications in diagnosing and treating specific diseases.

For example, it is estimated that more than 2.4million people in the UK are currently living with a genetic condition. This includes disorders, such as cystic fibrosis or sickle cell anaemia, which are caused by variation in a single gene and can be inherited in families. In the future it may be possible to use human genome editing to treat or prevent serious genetic conditions. We believe that those with lived

experience of these conditions can, and should, provide a valuable perspective to the discussion and decision-making around this topic.

In September 2022 we hosted a Citizens' Jury in partnership with [Genetic Alliance UK](#) and [Involve](#). The jury consisted of 21 individuals whose lives have been affected by hereditary disease. The Citizens' Jury considered the question: Are there any circumstances under which a UK Government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions? The four-day event was the first time that patients, rather



Capturing the discussions at the Citizens' Jury

“

*What kind of future do we want, in our lifetime, and who gets to decide? I don't have the answers, or a preconceived idea of what the 'right' direction of travel should be, but I do know that as a society we've got to start talking, collectively.”*

Professor Anna Middleton,  
Associate Director Engagement and Society

than policymakers or professionals, have been asked about their views on this complex topic. Each of the jurors had personal experience of a genetic condition and were chosen to provide a diversity of age, ethnicity, socio-economic, and educational backgrounds. Ultimately, the jury voted in favour of asking the UK government to

consider changing the law to allow genome editing of human embryos to treat serious genetic conditions. One year on from their verdict, the jury members have remained in touch as a close network, and we continue to identify opportunities with policy-makers, healthcare professionals and scientists, to amplify their voices.

“

*There are not many positives about living with a rare disease, but the experience of the Citizens' Jury has certainly been one of them. I am grateful to have had this unique opportunity to have my say on one of society's most complex and significant issues.”*

A member of the Citizens' Jury





Patient advocates visiting a sample collection site in Kenya, along with global cancer research colleagues.

“

*Understanding more about our patient advocates experiences as part of this research has provided insights that we, and others, can use in future projects; working with the Connecting Science team enabled us to access different expertise, that supported our advocates to both contribute to the project, and reflect on the impact of these contributions.”*

Dr Laura Humphreys, Project Manager, Mutographs

Cancer is a health condition that is likely to impact us all, either through a personal diagnosis, or through a friend or family member. The Cancer Research UK-funded Mutographs of Cancer project, is led by Professor Mike Stratton at the Wellcome Sanger Institute, and aims to identify specific ‘DNA signatures’ in the human genome that are linked to cancer development. The

Mutographs project team includes two patient advocates, Mimi McCord and Maggie Blanks, with lived experience of cancer, who have actively offered insight and challenge in support of the project and its researchers.

Over the summer of 2022, Damian Hebron and Dr Alessia Costa, from our Engagement and Society team, conducted a series of interviews with Mimi, Maggie, and several of the staff working on the project to understand how the process of patient advocacy had worked, what had gone well, and what might be improved in future projects. Their work is summarised in a report that we hope can influence the landscape for patient involvement and advocacy, as part of a shared research endeavour.

[Patient advocacy - Learnings from Mutographs report](#)

## The history of Hinxtton Hall: understanding our work in a historical context



A portrait of Edward Greene by Johan Zoffany, probably painted in the late 1700s or the early 1800s

Our venue, Hinxtton Hall Conference Centre, hosts a range of learning, training, and engagement events for our programme; as well as being available for other Campus-based, and external organisations.

The Hall and the wider estate form the oldest part of the Wellcome Genome Campus. The origins of the Hall, its foundation and ownership, have been mostly unknown to us, until this year, when we commissioned Historian, Melanie Backe-Hansen, to fill in the numerous gaps.

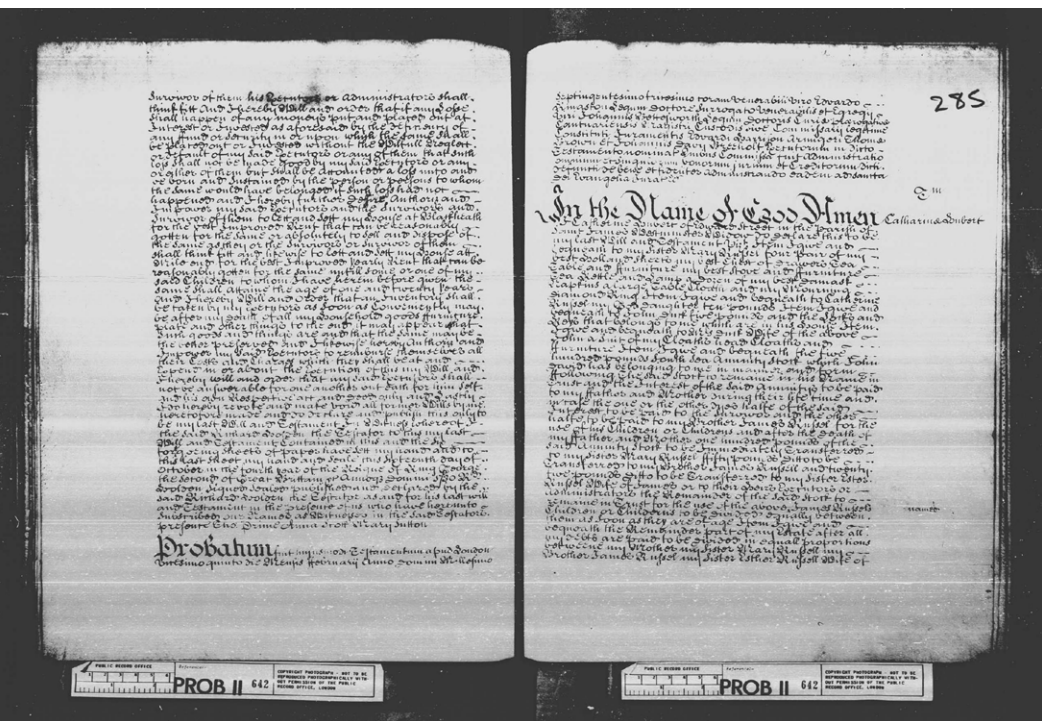
### Hinxtton Hall and the East India Company

The Hinxtton estate consisted of various farm dwellings in the early 1700s, before becoming the site of a gentleman's hunting and fishing retreat in the 1730s. Around a decade later, the estate moved into the ownership of the Holden family. The Holden family were

deeply involved in the East India Company.

The East India Company was founded in 1600 to undertake trade in the Indian subcontinent and East Asia. Its business was mainly focused on cotton, indigo, porcelain, tea, and silks, with these products then appearing in affluent households across Britain. The Company was also involved in the trade of enslaved people across the Atlantic and Indian oceans.

Captain Richard Holden was a ship owner and a captain for the East India Company for 20 years, between 1711 and 1730. He captained two East Indiamen



An extract from the will of Captain Richard Holden

**The same Day died at his House at Black-Heath, after a long Indisposition, Capt. Richard Holden, formerly Commander of the Ship Mary, in the East-India Company's Service, where he acquir'd upwards of 20,000 l. the Bulk whereof he has left to his two Sons.**

An extract from the newspaper, The Daily Courant, reporting the death of Captain Richard Holden in 1731

sailing ships, which were designed to carry both passengers and goods. Sailing this route in the early 1700s was perilous, with significant threats from pirates and illnesses, as well as no accurate tools or instruments for navigation. But for those who did survive these trading journeys, the rewards were huge. By the time Captain Richard Holden died, he was able leave a fortune to his family. His daughter Mary Holden inherited £12,000 in 1731, equivalent to almost £30million today.

Mary Holden married at the age of 16, a few years after the death of her father. And although it is her husband John Bromwell Jones, who is often named as the builder of Hinxton Hall, its construction was undoubtedly at least partly, if not wholly, funded from Mary's fortune from her father's East India Company activities.

The political, cultural, and financial impact of the East India Company on British society was huge during this era, and continued through its role in the development of the

British Empire. It is clear that it also had a role, if an indirect one, in the development of the Wellcome Genome Campus today.

**Hinxton Hall, the Duke of Cleveland, and the British Empire**

Almost a hundred years after the Holden family financed the building of Hinxton Hall, the Greene de Freville family set about expanding the Hall in line with the fashions of the early of Victorian era. Edward Humphrys Greene de Freville added a range features, including

the highly-decorative Pompeiian Room. Upon his marriage to Julia Flower in 1846, she brought with her substantial wealth from her own family connections. Julia was the granddaughter of the 1st Duke of Cleveland, who is recorded as receiving compensation for the ownership of enslaved people in Barbados. The University College London Centre for the Study of Legacies of British Slavery database shows that he owned 233 enslaved people on the Lowther plantation, and received the modern equivalent of around



£6million, after slavery was abolished within the British Empire.

The generational wealth held within these families enabled the de Freville's to live a very comfortable lifestyle in the countryside in Hinxton, with several servants; as well as a home in Mayfair in London. Their wealth trickled down, supporting many community activities in Hinxton, including performances by the village Amateur Dramatic Society, repairs to the village church, and Christmas events with gifts for local children.

### **Hinxton Hall and the Wellcome Genome Campus today**

By delving deeper into this aspect of Hinxton Hall and its history, we can see how this rural part of South Cambridge has a range of global connections, and reflects some of the major social and political movements that were taking place across the UK through the 1700 and 1800s. This history has influenced the Britain that we live in, in the 21st century,

and its legacy forms the basis of many of the relationships between the Global North and the Global South today.

Wellcome, the Sanger Institute, and Connecting Science have not been funded directly by wealth from the East India Company or from profits from the trans-Atlantic trade in enslaved people.

But without these activities and the creation of the Hinxton Hall estate, would Sir John Sulston have selected this location for the Wellcome Genome Campus? Would the science that took place during the Human Genome Project have happened in the same way, with the same people, somewhere else? We don't know!

But as a programme, and an organisation, that is interested in our place in society, understanding who benefits from our work, and equitable access to research; reflecting on the history of our buildings is just one way in which we consider how the legacy

of events and activities from hundreds of years ago, impact on different communities today.

“

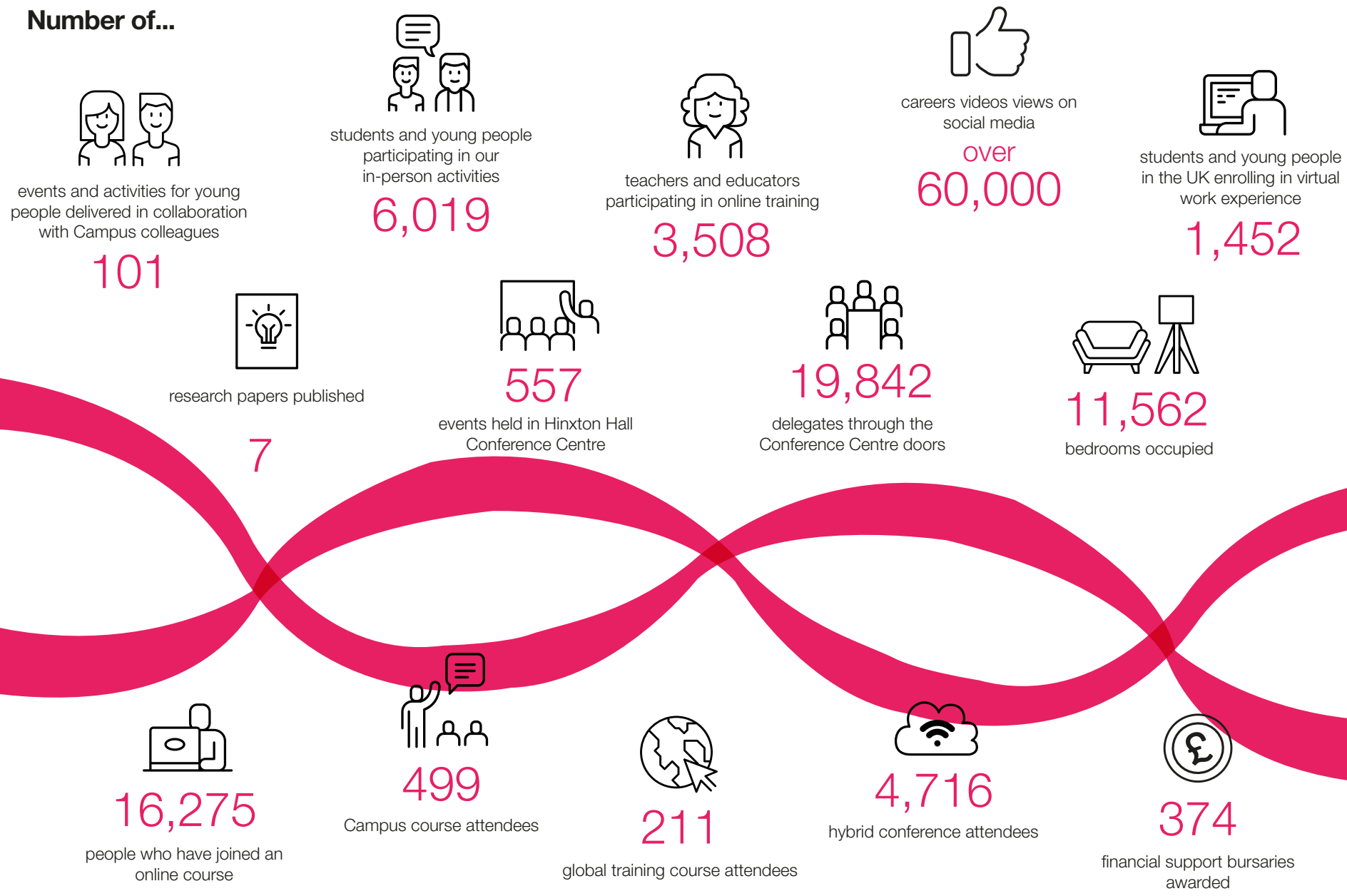
*But without these activities and the creation of the Hinxton Hall estate, would Sir John Sulston have selected this location for the Wellcome Genome Campus?”*



The East Indiaman Repulse (1820) in the East India Dock Basin

# Our year in numbers

## Number of...



## Our influence

We aim to share our learnings and expertise across the wider training, engagement and policy sectors, to support and influence change. Below is a selection of some of our recent publications, citations, and presentations; and significant committee positions held by our team members.

### Highlight publications 2022-23:

Abrudan M, Matimba A, Nikolic D, Hughes D, Argimón S, Kekre M, Underwood A, Aanensen DM; NIHR Global Health Research Unit on Genomic Surveillance of Antimicrobial Resistance. **Train-the-Trainer as an Effective Approach to Building Global Networks of Experts in Genomic Surveillance of Antimicrobial Resistance (AMR).** [Clin Infect Dis. 2021 Dec 1;73\(Suppl 4\):S283-S289.](#)

Alimohamed MZ, Mnika K, Adadey SM, Barbosa-Matos R, Avram E, Nevondwe P, Akurugu WA, Mupfukurirwa W, de Miranda Cerqueira JX, Dore R, Săbău ID, Kalantari S, da Silva ARGF, Anzaku AA, Matimba A, Chauke PA, Johari M, Nembaware V, Mroczek M. **Advancing intercontinental collaboration in human genetics: success story of the African and European Young Investigator Forum.** [Eur J Hum Genet. 2023 Oct 26.](#)

Atutornu J, Milne R, Costa A, Patch C, Middleton A. **Towards equitable and trustworthy genomics research.** [EBioMedicine. 2022 Feb;76:103879.](#)

Bishop, M. **Genetics and Genomics Education and Training in Developing Countries** (Chapter 3) in [Genomic Medicine Skills and Competencies, 1st Edition: June 10, 2022. Editor: Dhavendra Kumar. Paperback ISBN: 9780323983839](#)

Matimba A, Ali S, Littler K on behalf of the H3Africa Ethics and Community

Engagement Working Group, et al. **Guideline for feedback of individual genetic research findings for genomics research in Africa.** [BMJ Global Health 2022;7:e007184.](#)

Middleton A, Costa A, Milne R, Patch C, Robarts, Tomlin B, Danson M, Henriques S, Atutornu J, Aidid U, Boraschi D, Galloway C, Yazmir K, Pettit S, Harcourt T, Connolly A, Li A, Cala J, Lake S, Borra J, Parry V. **The Legacy of Language: What we say, and what people hear, when we talk about genomics.** [HGG Adv. 2023 Aug 31;4\(4\):100231.](#)

Milne R, Morley KI, Almarri MA, Atutornu J, Baranova EE, Bevan P, Cerezo M, Cong Y, Costa A, Feijao C, de Freitas C, Fernow J, Goodhand P, Hasan Q, Hibino A, Houeland G, Howard HC, Hussain Sheikh Z, Malmgren CI, Izhevskaya VL, Jędrzejak A, Jinhong C, Kimura M, Kleiderman E, Liu K, Mascalzoni D, Mendes Á, Minari J, Nicol D, Niemiec E, Patch C, Prainsack B, Rivière M, Robarts L, Roberts J, Romano V, Sheerah HA, Smith J, Soulier A, Steed C, Stefánsdóttir V, Tandre C, Thorogood A, Voigt TH, Wang N, Yoshizawa G, Middleton A. **Return of genomic results does not motivate intent to participate in research for all: Perspectives across 22 countries.** [Genet Med. 2022 May;24\(5\):1120-1129.](#)

Milne R, Aidid U, Atutornu J, Bircan T, Boraschi D, Costa A, Henriques S, Patch C, Middleton A. **What Difference Can Public Engagement in Genome Editing Make,**



and for Whom? [Am J Bioeth. 2023 Jul;23\(7\):58-60.](#)

Pichini A, Bishop M. A nationally agreed cross-professional competency framework to facilitate genomic testing. [Genet Med. 2022 Aug;24\(8\):1743-1752. doi: 10.1016/j.gim.2022.04.023.](#)

Pichini A, Tatton-Brown K, Thomas E, Bishop, M. (2023). A cross-professional competency framework for communicating genomic results. [Journal of Genetic Counseling, 00, 1–10.](#)

Roberts, J, Milne, R, Middleton, A, Patch, C and Morley, K. (2022). Opportunities for poaching: using the public's enjoyment of popular culture to foster dialogues around genetics. [JCOM 21\(06\), Y01.](#)

Wright CF, Campbell P, Eberhardt RY, Aitken S, Perrett D, Brent S, Daneczek P, Gardner EJ, Chundru VK, Lindsay SJ, Andrews K, Hampstead J, Kaplanis J, Samocha KE, Middleton A, Foreman J, Hobson RJ, Parker MJ, Martin HC, FitzPatrick DR, Hurles ME, Firth HV; DDD Study. Genomic Diagnosis of Rare Pediatric Disease in the United Kingdom and Ireland. [N Engl J Med. 2023 Apr 27;388\(17\):1559-1571.](#)

#### **Selected citations:**

Your DNA Your Say was cited in Genomics Beyond Health: What could genomics mean for wider government? Government Office for Science (2022). [Project Report January 2022. Foresight, pp. 171.](#)

#### **Selected invited presentations:**

Bishop M, International Congress of Human Genetics, Cape Town, South Africa (2023)

Bishop M, G2MC Annual Meeting, Geneva, Switzerland (2023)

Matimba A, PHA4GE Annual Meeting, Cape Town, South Africa (2023)

#### **Selected committee memberships:**

Michelle Bishop is the Co-Lead of the G2MC Resource Center Working Group and a member of the G2MC Steering Committee; and a member of the International Pathogen Surveillance Network (IPSN) Country Scale-up Accelerator.

Sasha Henriques is a member of the Diversity and Inclusion Advisory Board for Our Future Health.

Richard Milne is a member of the Ethics Advisory Board for Our Future Health, and a member of the Genomics England Newborn Genomes Programme Working Group.

Christine Patch is the Chair of the Data Access Committee for Genomics England.

# Our people

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Jerome Atutornu / PhD Student

Lauren Baird / Conference and Events Organiser

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Dr Jorge Batista da Rocha / Education Developer

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### **Hinxton Hall Conference Centre**

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