

Enabling global
conversations
on the ethical
issues raised by
discovery science

Annual Report

YEAR 3

1st Jan – 31st
Dec 2024
Cambridge

Kavli Centre for Ethics, Science, and the Public
Faculty of Education, School of Humanities and Social Sciences
University of Cambridge
Cambridge, UK

Annual Report Year 3
1st January – 31st December 2024

Our brand identity uses curved shapes to represent
the concepts of 'connecting' and 'bridging' with an abstract
representation of joined human figures.



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Overview from the Director



Director, Professor Anna Middleton

The Kavli Centre for Ethics, Science, and the Public in Cambridge has made significant strides in 2024 toward fulfilling our mission of empowering discovery scientists to consider and navigate the ethical and societal concerns associated with their work.

By engaging diverse publics and fostering interdisciplinary collaboration, we are shaping a future where science and society work hand in hand to understand and solve identified challenges.

Governance for the Kavli Centre

In 2024 a new Steering Group for the Centre was set up, Chaired by Prof Hilary Cremin, Head of the Faculty of Education at the University of Cambridge. The focus of this group will be to offer governance as well as support for meeting our matched funding requirements, should we pass the Foundation's evaluation. The group consists of Emma Griffiths (Development and Alumni Office), Ros Griffin (Head of Development, School of the Humanities and Social Sciences), Daniel Wunderlich (Assistant Director, Research Office, School of the Humanities and Social Sciences), Jo-Anne Dillabough (Co-Head of Research, Faculty of Education), Thury Agustsdottir (Business and Operations Manager, Faculty of Education). The group reports to the Faculty of Education Research Committee and also the School of Humanities and Social Sciences. As the Kavli Centre Director I will now report into this group as well as attending the Research Group and Centres leaders meetings every term and submit an annual report to the Research Committee.

The Kavli Centre is now officially and firmly embedded in the infrastructure of the University, which in turn offers us institutional security and support for our continuation, long term.

New Faculty of Education Requirements for all Research Centres

Research Centres within the Faculty of Education, including the Kavli Centre, are now required by the faculty to provide evidence that they advance high impact research, foster a dynamic research environment, and drive the creation of new knowledge. From 2025 onwards, all Centres must demonstrate how they act as international hubs for collaborative research, engage extensively with global networks of social science researchers, and prioritise collaborative efforts by developing clear and substantial research agendas aligned with their missions.

A key focus is on securing funding to support impactful research and drive innovation. In addition to global networks and contributions to international research agendas, Centres should work to attract top-tier researchers, mentor early career researchers, and integrate doctoral students into research teams. They also need to emphasise skills development and uphold principles of Equality, Diversity, and Inclusion (EDI). The new requirements fit beautifully with what the Foundation has already asked of us.

Matched Funding for 2027

We are grateful for the Foundation's additional \$250k to support the running of the Centre for 2027 and are delighted to announce that we have secured (and exceeded) the required \$250k in matched funding.

In 2025, the Centre will receive a £100k grant from ARIA (Advanced Research and Invention Agency), led by Dr. Richard Milne. ARIA, is a public body under the UK government's Department for Science, Innovation and Technology. This grant will fund a portion of Dr Milne's core salary starting Spring 2025, enabling him to focus on exploring ethics for public good. With this grant added to the previous excess in matched funding we have already secured, we have now completed (and exceeded) our matched funding requirements.

First Kavli PhD Student to Finish

All of our PhD students receive their formal academic supervision from both myself and Dr Richard Milne; they also receive all of their social sciences training in research methods via the Faculty of Education. It is of great personal satisfaction to me that our first PhD student, Jerome Atutornu, successfully defended his PhD viva in September 2024 and has now officially passed his PhD. We celebrated with champagne in the Kavli Centre!



First PhD Thesis supervised by the Kavli Centre



Celebrating Jerome's successful PhD viva in the KESP office: Dr Catherine Galloway, Dr Mariam Rashid, Claudette Burch, Dr Jerome Atutornu, Prof Anna Middleton, Dr Richard Milne, Lydia Okoibhole

In 2024 our Innovation and Translation lead Catherine Galloway produced a film, made by Cambridge TV, on my own personal journey to leading the Kavli Centre. The motivation for the film's creation was to provide a human and personal testimony of my commitment to the Kavli Centre that could be shared with potential future donors to the Centre.

Uncoupling of Wellcome Connecting Science

2024 has been a year of change for the Kavli Centre – the team have continued to deliver the outputs we promised, and this has been achieved whilst also managing a cloud of uncertainty and volatility stemming from the cultural changes that have occurred at Wellcome Connecting Science throughout the year.

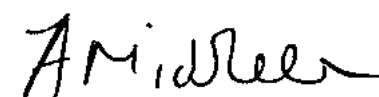
Our two original sponsors of the partnership between the University and Wellcome Connecting Science have left (Prof Julian Rayner and Prof Sir Mike Stratton) and a new strategy has been announced for the Sanger Institute. It is testimony to the Kavli team's resilience and fortitude that they have remained steadfast while Richard and I have coped with institutional unrest that often accompanies leadership and strategic change.

I have personally been on the receipt of behaviours that do not align with my values for equity, diversity and inclusion and have been left with no choice but to uncouple Wellcome Connecting Science from the partnership with the Kavli Centre which means that sadly they are no longer our official collaborators. I thank Wellcome Connecting

Science for its historical contribution and support and wish the organisation well moving forward with its new leadership and strategy.

Everything we promised in our Kavli strategy for 2024 has been delivered and we are excited to build and extend on this as we move into Year 4 of our Cambridge Kavli Centre for Ethics, Science, and the Public.

The Director,
Professor Anna Middleton



The Kavli team: **Dr Catherine Galloway** (Innovation and Translation Lead), **Dr Richard Milne** (Deputy Director), **Dr Daniela Boraschi** (Issac Newton Trust Postdoctoral Fellow), **Sasha Henriques** (PhD Candidate), **Lydia Okoibhole** (PhD Candidate), **Dr Jerome Atutornu** (PhD Candidate), **Dr Mariam Rashid** (Issac Newton Trust Postdoctoral Fellow), **Claudette Burch** (Lead Administrator and Office Manager), **Prof Anna Middleton** (Director)



Documentary film **Inheritance and Heritage** on a personal journey setting up the Kavli Centre

Multidisciplinary collaboration among scientists, ethicists, and public engagement experts

In 2024 we have deepened our connections with specific groups of experts. The following offers an overview of partners who are available for involvement in the ripple effects mapping.

Deaf, sign-language experts we collaborated with from the **British Deaf Association**



Discovery Scientists

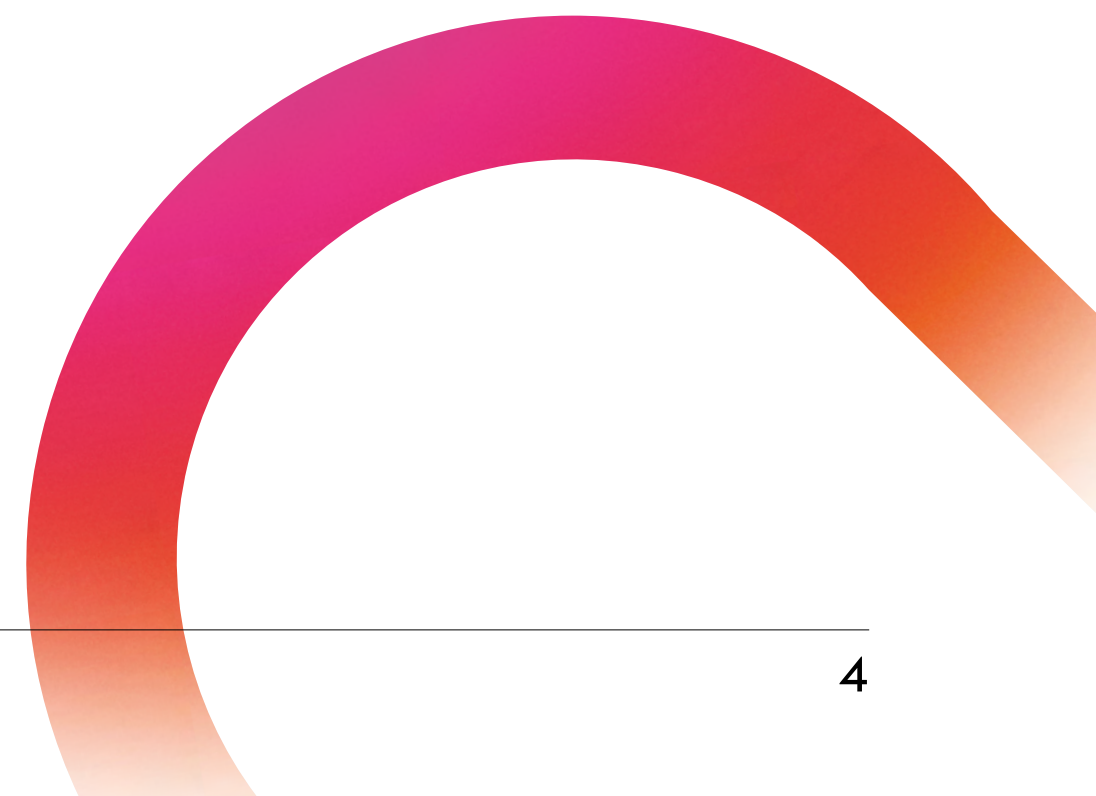
In the Creativity for Scientific Change project, we are collaborating with numerous AI scientists from the Cambridge Centre for AI in Medicine (CCAIM), including Prof Mihaela van der Schaar and Dr Fergus Imrie. We have also interviewed multiple scientists from both the University of Cambridge's Stem Cell Institute and the Sanger Institute, including Prof Sarah Teichmann, Dr Carl Anderson, Dr Muzz Haniffa, Prof Nick Thompson. We have supported Prof John Suckling, Co-Director of the Centre for Human-Inspired Artificial Intelligence and Director of Research in Psychiatric Neuroimaging in the delivery of panel discussion moderation and chairing on societal issues of AI.

We partnered with Prof Neil Lawrence, Chair of AI@Cam and Dr Katie Light from Accelerate Programme for Scientific Discovery to deliver public dialogue on AI. For our Hopes and Fears events we have partnered with the following scientists across multiple disciplines across the University: Dr Nazneen Khan; (researching climate change and its impact on women's reproductive health); Dr Shabnum Maqbool (researching materials that can be useful for solar cells and renewable energy generation); Dr Sheheryar Banuri (behavioural economist and expert on motivation and public policy); Dr Nadia Radzman (plant peptide regulation and legume biology expert, with a focus on future food security and climate); Dr Yaning Wu (public health scientist researching how to mitigate potential side effects of blood donation); Dr Florian Jaeckle (pathologist researching coeliac disease diagnosis using new machine learning software).

Public and Community Engagement Experts

We have been working with community engagement experts from Centric, based in South London, on the Only Human project: Dr Shaun Danquah (Founder and Director of Innovation), Dr Anthony Baker (Strategic Director, lead for our social sciences research) and Muhammed Rauf (Director of Business Development).

For the British Deaf Association policy project, we worked with Deaf experts in policy and Deaf community engagement: Ashley Kendell (Deaf British Sign Language Broadcaster); Rebecca Mansell (Deaf, CEO of the British Deaf Association), Dr Robert Adam (Deaf, Chair of the BDA); Yolande Dennis (Deaf, deaf awareness trainer); Dr Graham Turner (hearing) and Tom Lichy (Deaf) (both Policy leads for the BDA).



We have also continued to deepen our connections with the University of Cambridge Public Engagement team, including Dr Lucinda Spokes (Head of PE), Beth Elliot (Community Engagement Manager) and David Cain (PE and Festival Manager).

We also collaborate with Jana Wendler and Victoria Shennan from the Berlin School of Public Engagement as well as with Marina Joubert from Public Engagement with Science at Stellenbosch University, South Africa. Our work with Abbey People has involved regular connections with Nicky Shepard (CEO Abbey People).



Hilary Cox Condron, Community Artist, and Dr Nadia Radzman Discovery Scientist

Creatives

For our public engagement work with Abbey People we worked with community artist Hilary Cox Condron and for Hopes and Fears events we worked with Tom McLean who designed our imagery. For the Only Human projects we have worked with advertising executives and communications experts including Indy Selvarajah, Wojciech Glomski and Bayley Kite.

We continue to partner with film makers from Cambridge TV, Carl Homer and Joe Donaghy on the documentaries we make about our work.

For the British Deaf Association event we also partnered with Deaf film maker Angela Ansell. We have also learnt from artists Kofi (Larry) Achiampong and David Blandy as well as Lisa Anderson, Manager Director of Black Cultural Archives for Sasha Henriques' PhD project.



Sasha Henriques' collaboration with Black Cultural Archives, London

Broad participation that promotes diverse, equitable and inclusive approaches

The Kavli Circle

To ensure that we build a diverse network of partners and participants, we have intentionally focussed on creating interesting networking and social opportunities to build a circle of friends, we have called this our 'Kavli Circle'. This is our growing network of supporters dedicated to amplifying the impact of our work as we prepare for the Foundation's 2025 evaluation. This vibrant community brings together discovery scientists, creative professionals, and engagement experts to spark innovation and collaboration. In 2024, we hosted three events to draw our network together.

Our spring CHATTACA event at the Arts Picturehouse Cinema in Cambridge featured private screenings of GATTACA and Human Nature, sparking in-depth discussions on CRISPR technologies and their ethical implications. Over 50 discovery scientists from various disciplines across Cambridge University attended, marking the start of a rich network to drive future engagement.

In the summer, as a group, we attended TEDxCambridge, themed "Transformation" and brought together scientists specialising in gene editing, artificial intelligence, as well as creative experts to exchange perspectives on how we might work together.

To close the year, our Winter Kavli Circle event included a lively dinner at Giovanni's pizzeria, centred on the Netflix film Joy, which celebrates the birth of IVF in Cambridge.

The event united communications experts, scientists, and Kavli team members for meaningful dialogue.

We are starting to build a web presence for each member of the Kavli Circle, and have obtained consent for members to be available for the Foundation's ripple effects mapping, as needed.



Building our Kavli Circle Web Presence

Equity, Diversity and Inclusion Audit

We are deeply committed to inclusivity, but growth in operationalising this requires an understanding of the skills and knowledge we lack. To assess our current position, we have engaged EDI expert Dr Saher Ahmed to conduct an audit of our work. This audit process begins with individual interviews with each team member during Spring 2025. Based on these insights, Saher will develop a roadmap to help us expand our skills and experience, strengthening our collective commitment to equity, diversity, and inclusion. She will also help us to write our EDI policy.

Increasing Diversity and Inclusion

2024 has been a year where we have intentionally sought out specific groups of people to work with. Building on our Postdoctoral Associate, Dr Mariam Rashid's lived experience as a Muslim woman who observes Ramadan, she chose to create a Hopes and Fears event specifically focussed on Iftar, which is the meal when the fast is broken. She led on the creation of food-based evening discussion between scientists and members of the public to enjoy together, on the theme of ethical issues raised by science (see later for more details).

We also delivered an event for the British Deaf Association (BDA), which is a group that represents the 200,000 sign-language-using people in the UK. The British Sign Language (BSL) Act was passed in the UK on 28 April 2022. This historic legislation officially recognised British Sign Language as a language of England, Wales, and Scotland. Its passage marked a significant step in promoting the rights of Deaf individuals and improving access to services. When designing our event for Deaf members of the public, we paid specific attention to scaffolding the event so that it could be led by Deaf leaders rather than us.

We worked with Ashley Kendall, a prominent TV presenter who is well known amongst the Deaf community.

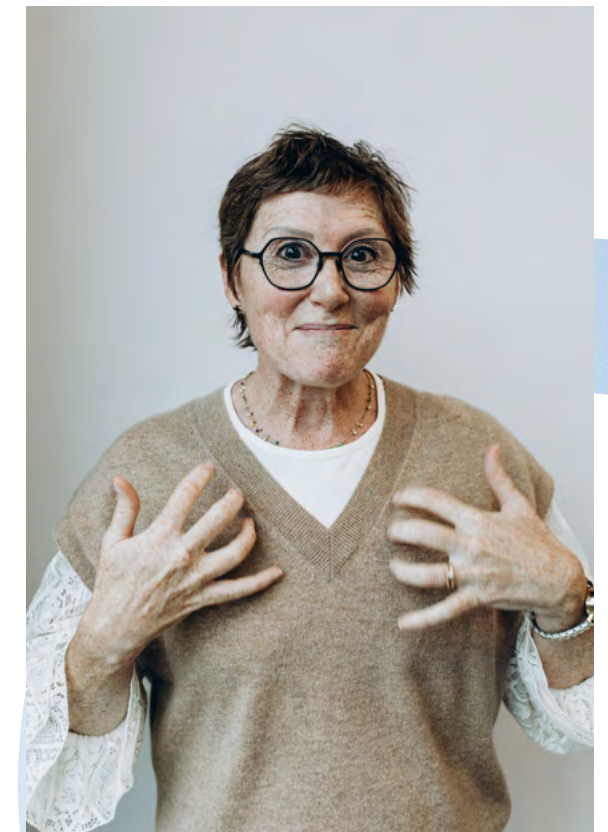
We also chose Deaf film-maker, Angela Ansell to direct the film we made of the event. She worked directly with the hearing camera operators, using an interpreter to provide instructions on shots and angles. To prepare our Kavli staff and hearing film crew, we arranged Deaf awareness training with a local Deaf colleague, Yolande Dennis, who came to the Kavli Centre to share insights about Deaf culture and etiquette and teach us some BSL.



Deaf film maker **Angela Ansell** (left) talking with hearing film maker **Carl Homer** via the interpreter



Deaf facilitator for our event on genetics, **Ashley Kendall**



Deaf awareness trainer for our Kavli team, **Yolande Dennis**

Evidence-based and cutting edge methodologies: Public engagement at early stages of scientific discovery

The Hopes and Fears Iftar

Led by Dr Mariam Rashid and Dr Catherine Galloway, The Hopes and Fears Iftar event delivered public engagement at the early stages of scientific discovery by facilitating encounters between members of the public and scientists to discuss the societal and ethical questions associated with science. The intended outputs lead to an increase in public trust that engagement with scientific institutions can lead to meaningful collaboration and change.

There's something special and calming about good conversation over a good meal. This is even truer for the Islamic community during the holy month of Ramadan. Mealtimes truly become community affairs at Iftar (the meal at the end of the day, when Muslims break their fast), with mosques often opening their doors to dozens of families.

As we entered Ramadan in 2024, we hosted an Iftar meal for 40 people. People from all walks of life came through the doors, Muslims as well as non-Muslims. As the children settled in at our 'curiosity stations' (i.e. arts and crafts activities to keep them occupied) the adults sat down with

one of our five volunteer scientists – and, of course, a heaped plate of delicious food!

Our scientists were themselves majorly Muslim; this may have played a part in breaking down the perceived hierarchy between our 'publics' here and our 'scientists'. Our publics were local people who saw our posters advertising our event. Ramadam is one of those experiences in that, whether you are a scientist or not, you will have spent the day hungry! The atmosphere of the event certainly reflected this – it felt like we simply had a room full of people talking about their feelings and our shared scientific future over a meal.



Dr Mariam Rashid from KCESP (left) welcoming members of the public to the Iftar event on ethical issues raised by discovery science



Discussing ethical issues raised by discovery science

"So, I think one of the impactful conversations that I had was from The Hopes and Fears Lab and that actually [...] whenever like I felt kind of like demotivated about the work that I'm doing, I would remind myself of the conversation that I had from the public and why it is important."

DISCOVERY SCIENTIST

"Science is just a tool. It can be used as a benefit for mankind, if the scientist behind it holds on to the good morality and positive values."

MEMBER OF THE PUBLIC

Abbey Lab

Led by Dr Catherine Galloway and Dr Mariam Rashid, the 2024 Abbey Lab delivered public engagement at the early stages of scientific discovery by facilitating encounters between members of the public and scientists to discuss the societal and ethical questions associated with science. This leads to an increase in public trust that engagement with scientific institutions can lead to meaningful collaboration and change.

As part of our long-term mission to connect with the Abbey community — a district in Cambridge facing significant deprivation—we were honoured to be invited to join a local science festival. This event, organised by community leaders, featured other organisations such as AstraZeneca, Cambridge University Botanic Gardens, Ninja Theory, and the Centre for Computing History.

Our goal was to create an inspiring, family-friendly engagement event that showcased our work and also empowered the local community. Reflecting on the 2023 Abbey Lab event, where residents emphasised the importance of mental health, we crafted our 2024 contribution around this theme. Central to this effort was Dr Nadia Mohd-Radzman, a postdoctoral botanist at the University of Cambridge.

Nadia’s pioneering research uses CRISPR technology to enhance plant nutrition for better mental health outcomes. Attendees engaged with her on ethical issues surrounding gene editing and its relevance to community concerns. Her feature in The Guardian newspaper added depth to these conversations, fostering pride in meeting a scientist addressing local priorities.

We aimed to make science accessible and exciting. At the heart of our event was the “Wonder Wall,” an interactive art installation inspired by the Hopes and Fears project. Children and adults shared their scientific questions and ideas directly on the wall. Designed with community artist Hilary Cox Condon, this vibrant centrepiece celebrated curiosity and creativity, making science feel approachable.

We encouraged attendees to see themselves as “wonder-full” contributors to scientific dialogue, measuring their “wonder levels” and affirming their value with badges reading “Wonder-FULL Abbey!”

With over 100 families participating, the event strengthened community confidence in engaging with science. It demonstrated the power of collaboration—bringing together residents, artists, and scientists to spark meaningful conversations. By breaking barriers, we fostered a sense of belonging and rooted science in the community’s aspirations.

Our efforts earned the trust and appreciation of local leaders, who have already invited us to participate in their 2025 science festival. They value our ability to design original, dialogue-focused experiences tailored to their community’s needs.

“We have a major problem with growing numbers of young people experiencing mental health problems in the UK today, and helping them eat a proper, healthy diet is going to be crucial in tackling this.”

DISCOVERY SCIENTIST, DR NADIA MOHD-RADZMAN, INTERVIEW IN THE GUARDIAN NEWSPAPER



Only Human

Prof Anna Middleton’s project, **Only Human**, researches how to deliver public engagement at the early stages of scientific discovery by exploring new approaches for engagement about ethical questions associated with genetics. The intended output includes new public engagement strategies that discovery scientists can use.

In partnership with Ketchum PR agency, a bespoke PR campaign in September and October 2024 sought to drive traffic to the OnlyHuman website, where the public can view project films and participate in our research. Key strategies included a social media campaign led by Liv Little—writer, broadcaster, and advocate for women of colour. Liv shared project related content via her platforms, amplifying its reach. Posters were displayed in shopping centres and at bus stops across London, and a film premiere was held at the Genesis Cinema in Brixton. Domino sets from the *Liming with Gran* film were distributed to barbershops and community centres. The PR campaign resulted in over 3,000 online views of the Only Human films within two months.

We will shortly be releasing the three films produced by Ridley Scott Film Productions, promoted through press releases, film festivals, and director Yasmin Godo’s channels.

In February 2025, Centric, the project’s community engagement partner, will conduct focus groups with 40 participants from London’s Black and Asian communities. These groups will evaluate the Ridley Scott and Ketchum films, examining how framings and



Social media influencer **Liv Little** who promoted **Only Human** via her social media platforms

metaphors facilitate public connection to genomics and its ethical implications. Filmed focus groups (with consent) will be uploaded to the project’s website, contributing to a publicly accessible dataset for secondary research and engagement activities.

Centric, a community-led research hub in Lambeth and Southwark, addresses racial inequities and empowers communities of colour. Their role includes leading the design, recruitment, consent, filming, and analysis of data, ensuring a culturally sensitive and inclusive approach grounded in direct community input.

In 2025, the project will establish an Advisory Board to oversee public engagement activities and expand the consortium of partners using the project’s films. This will strengthen the evidence base on effective communication strategies and ethical engagement in genomics research.



Promoting **Only Human** in shopping centres across London



Promoting **Only Human** via public posters at bus stops across London

Measure of Dialogic Public Engagement with Genetics

Led by Dr Richard Milne, a thorough literature review has now been conducted, and the first constructs of a measure of dialogic public engagement have been created and published.

The survey includes items from the British Science Association’s measures of engagement, measures of Science Capital, cognitive attitudes, emotional/ affective attitudes, communicative self-efficacy, dialogic open-mindedness, empathetic responsiveness and ability to trust.

Due to the uncoupling of the Kavli Centre from Wellcome Connecting Science, we no longer have the collaboration with Dr Tuba Bircan to draw upon, so this means that we have not been able to progress with the psychometric testing of the survey before recruitment.

In 2025, we will pick up the planned translation and recruitment of the survey with the hope that this is completed before the 2025 evaluation.

Pre-print of the constructs within the **measure of engagement**



Community Engagement in Sickle Cell Research

PhD candidate Lydia Okoibhole's project facilitates discussion with community members on the societal and ethical questions associated with cutting-edge sickle cell research. This will be used to create policy for scientists on how to navigate the ethical issues raised by their research, as well as offering recommendations for how to conduct community engagement at early stages of scientific discovery. The intended output includes new community engagement strategies that discovery scientists can use.

Lydia began the second year of her PhD in October 2024, focusing on the intersections of genomic research, healthcare systems, and community engagement in the context of Sickle Cell Disease (SCD) research. Her project seeks to understand the experiences, needs, and perspectives of SCD-affected communities in the UK, examining barriers and enablers to engaging individuals with lived experience in genomics research. With a mixed-methods approach grounded in Community-Based Participatory Research (CBPR) principles, the study combines quantitative surveys on public attitudes to genomics, qualitative focus groups with the SCD community, interviews with healthcare professionals, and a co-produced workshop on integrating findings and developing a community-informed framework of public engagement.

Community engagement is central to the project, acknowledging the historic marginalisation and systemic racism experienced by Black African and Caribbean communities disproportionately affected by SCD. Guided by critical race theory, the research prioritises collaborative and inclusive methods, including an advisory group of individuals with lived experience of SCD and partnerships with London based SCD community groups for recruitment and feedback. A planned co-produced workshop will ensure that community voices actively shape the research and its outcomes.

This study aims to provide insights into the needs and experiences of the SCD community, ensuring that advancements in discovery science are guided by those most affected. Additionally, it contributes to theoretical advancements in CBPR, offering a transferable framework for engaging other marginalised communities in genomic research.



Lydia Okoibhole with a group of Sickle cell researchers and academics at ASCAT conference in London



Lydia Okoibhole at the Postgraduate Bioethics conference in Cambridge

Evidence-based and cutting edge methodologies: Empowering scientists to consider & navigate ethical & societal concerns

Ethical and Societal Concerns of the Deaf Community

Led by Prof Anna Middleton with the support of Dr Catherine Galloway, Dr Mariam Rashid, and Claudette Burch, The British Deaf Association policy event facilitated the connection of Deaf sign language using adults with the ethical issues raised by the latest developments in genetics research. This facilitation supported the creation of a Deaf-led policy for the Deaf community on cutting-edge genetics – which will be used to empower scientists with new perspectives from the Deaf community. This project also contributes to an increase in public trust that engagement with scientific institutions can lead to meaningful collaboration and change.

The British Deaf Association (BDA) approached the Kavli Centre asking if we would bring them up to speed with the latest developments in genetics so that they could write their policy on genetics for Deaf, sign language-using people in the UK.

We scoped out a full day's discussion on gene therapy for deafness and the ethical issues raised by newborn sequencing for all babies in the UK, recently launched by Genomics England across the National Health Service. Two clinical scientists who have worked in the genomic medicine service in East Anglia (Anna Middleton and Jon Roberts) initiated deliberations about the science with the 15 members of the Deaf community attending.

The deliberations were then delivered in British Sign Language, led by a Deaf broadcaster, with interpreters present for the hearing members of the Kavli Centre.

The day was structured so that it was led by the Deaf community in culturally appropriate ways rather than by the hearing members of the Kavli Centre. Gene therapy and genetic testing for deafness, whether delivered via newborn sequencing or pre-natally, has been offered to patients across the UK with no consultation whatsoever with the Deaf community.



KCESP organisers of the event: Dr Catherine Galloway, Prof Anna Middleton, Dr Mariam Rashid, Claudette Burch

Our event underscored the necessity for including representation from the Deaf community in discussions about policy and the legal frameworks, particularly around the genetic testing of embryos – which is due for discussion by Parliament in the near future.

We arranged for Deaf and hearing film-makers to capture the day so that the BDA could distribute the information and discussion across the Deaf community around the world. The documentary film we have made about the deliberative event, as well as the BDA policy and campaign, will launch in 2025.



Discussing the policy implications of genetic research for the **British Deaf Association**



Discussing the ethical implications of Otoferlin gene therapy research

“As person born with a genetic hearing loss, raised by Deaf parents, growing up within the deaf community, I was enthralled by the work of the Kavli Centre for Ethics, Science, and the Public. The Kavli Centre created a beautiful partnership with the British Deaf Association, which brought the latest information on genetics to Deaf people so that we could write our own policy on genetics”.

DEAF, BRITISH SIGN LANGUAGE USER,
MEMBER OF THE PUBLIC



Discussing the societal consequences of genetic research for the **Deaf community**

Ghanaian Publics’ Societal and Ethical Concerns about Genetics

PhD candidate Jerome Atutornu’s research empowers discovery scientists working in genetics to consider and navigate the ethical and societal concerns of the Ghanaian publics by understanding what shapes attitudes towards genomics and data sharing. Through the delivery of evidence-based policy on public engagement, scientists are provided with a toolkit for how to conduct public engagement at the early stages of scientific discovery so that they can partner with Ghanaian publics to co-design research and recruitment.

The success of genomic research depends on the availability of large amounts of data that can be shared across scientific, geographical and legal jurisdictions. These data are derived from the willingness of the public to donate their data. The success of the genomics industry (nonprofit, for-profit, research and clinical) depends on public acceptance of the use and sharing of their data, which depends on public awareness of and familiarity with genomics across various populations, including those from across the African continent.

The thesis explored the attitudes of the Ghanaian public towards genomics and genomic data sharing. Using a mixed-methods study design, this work interpreted findings from eight focus groups (n = 40) and a structured survey delivered in the Ewe and Twi languages to 987 people living in Ghana and the UK.

The data suggests that the group studied have moved to a post-trust era where legal assurances are sought as a condition for donating data to the scientific community rather than mere trust.

These data inform a set of policy recommendations for genomic scientists on how to conduct ethical community engagement when aiming to increase the representation of Ghanaian publics in genetic research.

This study has also resulted in the creation of new translated words for “DNA information” in the languages of Ewe and Twi. These are

Dzɔdzɔmekadonu and *Awobɔasu*

(DzorDzormekadonu and Awoborasu, respectively). These words are periphrastic (derived from the combination of several component words), such as ‘that within our blood which shows how we are linked’. Further, in seeking to find common ground during communications, the word ‘blood’ would serve as a key metaphor in orienting people to the subject of genetics.



Dr Jerome Atutornu and Phd supervisor Prof Anna Middleton

Translation:

“As far as trust is concerned, it does not matter who the person is. It would be difficult to just trust somebody. We would have to sign legal agreements for such DNA data to be released. I think that would be better. Then, there would have to be an agreement that it would be held confidentially. But saying you would trust someone without signing an agreement? No, you cannot trust someone like that.”

MEMBER OF THE PUBLIC FROM GHANA

Creativity for Scientific Change: empowering AI scientists through ethics and art

Postdoctoral Associate Dr Daniela Boraschi’s Creativity for Scientific Change project empowers AI scientists to consider and navigate ethical and societal concerns by understanding what shapes their awareness of, and the ability to act on, the ethical issues associated with discovery science. It also implements creative engagement approaches to connect discovery AI scientists with the public via art, and to measure whether this supports scientists in evolving how they do their science. This leads to an increase in scientists’ ability to anticipate and reflect on the social and ethical implications of science as a normal part of everyday scientific practice.

The project has focused on the ethics of Generative AI in medicine in collaboration with the van der Schaar Lab (vdSL) and the Cambridge Centre for AI in Medicine (CCAIM). This is an emerging field of computer science at the intersection of medical research, drug discovery, clinical science and public health, set to transform medical knowledge production and healthcare practices, with still limited empirical social science literature.

The project has encouraged discovery scientists to expand their understanding of ethics beyond simply adhering to existing ethical standards and regulations. It has explored new socio-ethical considerations that are emerging from unsupervised generative processes through interdisciplinary collaboration and creativity, involving both research and engagement strategies.

Ethical considerations on synthetic data in everyday machine learning research for healthcare

INTERVIEW WITH:

INTERVIEW BY



DR FERGUS IMRIE
Florence Nightingale
Bicentery Fellow,
University of Oxford,
Department of Statostic



DR DANIELA BORASCHI
Research Associate,
University of Cambridge,
Kavli Centrefor Ethics,
Science, and the Public



Dr Boraschi has also begun exploring the views of discovery scientists towards using a photo-elicitation creative method to discuss engagement with the ethics of AI in medicine. This has led to the drafting of a co-authored commentary with Prof Mihaela van der Schaar, Dr Richard Milne and Dr Alessia Costa titled “Governing Synthetic Data in Medical Research – The Time is Now”. Accepted to The Lancet Digital Health, advocating for a standardised research agenda and governance frameworks to ensure ethical, safe, and high-quality development and use of synthetic data in medical research.

At the end of 2024, Daniela launched a creative brief asking for designers to collaborate on a creative engagement project titled “Framing Ethical Futures: Using Posters to Connect Scientists and the Public on Medical Synthetic Data”. The aim is to connect AI scientists with members of the public and inspire participation in discussions on the socio-ethical implications of synthetic data in medical AI.

“Ethics needs to be a two-way discussion, doesn’t it? When I first answered, I was imagining much more ‘this is what we do, and how we do it in an ethical way’, and there wasn’t any component of ‘ethics also needs to be what you want us to do, or at least, there needs to be some component of that’...But at least there must be much more involvement [of the public] and discussion because ethics evolves.”

DISCOVERY SCIENTIST

“There was something that has triggered a few thoughts that I hadn’t had before, and there certainly could be a lot of opportunity to move beyond the sorts of logical, evidence-based arguments that someone like me would come up with as to why X is a good thing to do. It’s not going to work for anybody, but there’s undoubtedly a need to find different, I won’t say better, just different ways of communicating because there will be better for some people and worse for others, but at least it gets you to a broader audience and raises the general level of understanding and that in the end has to be a good thing.”

DISCOVERY SCIENTIST



Empowering Scientists to Consider Social Justice in Their Research

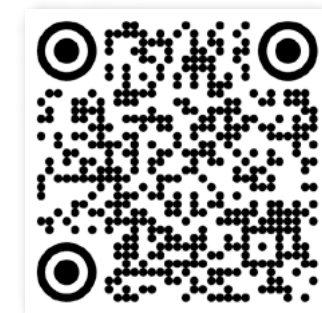
PhD candidate Sasha Henriques’s research empowers discovery scientists working in genetics and biodata to navigate and consider ethical and societal concerns raised by their research by understanding what shapes their awareness of, and the ability to act on, the ethical issues associated with lack of diversity in genomics. It also explores the publics’ perspectives on the ethical issues associated with genetics.

Sasha has completed the longitudinal interviews with senior scientists from the Sanger Institute to explore how and why genomic researchers conceptualise race, ethnicity and ancestry information. She has also completed the ethnographic observations of scientists at work in their professional environment to explore the genomic research ecosystem and the embodiment of social justice within genomic research. She has also collected archived material from the Human Genome Project and also interviewed scientists who were directly involved in this to explore how ethnicity was considered historically within the creation of the HGP.

In addition to interviewing discovery scientists, Sasha has also conducted ethnographic research and interviews at public exhibitions on race and racism in genetics at the Black Cultural Archives and the Wellcome Collection in London. She has also contributed directly to these exhibitions, working directly with artists Kofi (Larry) Achiampong and David Blandy who created a film on eugenics which involved the classification of humans in genetics. Sasha is currently analysing the autoethnographic part of her project and writing up her thesis ready for submission in 2025.



Podcast interview of **Sasha Henriques’** work



Video interview of **Sasha Henriques’** work



The Collaborative Futures Academy 2024

The Collaborative Futures Academy 2024, led by Dr Richard Milne and Dr Catherine Galloway teaches discovery scientists how to conduct public engagement at early stages of scientific discovery through the facilitation of ethics discussion. This leads to an increase in scientists' trust in publics and other experts and measures change in how empowered scientists feel.

The Collaborative Futures Academy is a free online programme that provides space for those involved in public engagement with research to explore questions that arise in their work in more depth and detail. It brings together a diverse international cohort of passionate engagers to reflect on their practice, gain new perspectives and build their skills. CFA24 was the fourth iteration of the Academy and focussed specifically on the role of emotions in engagement. It took place over three days and included a mix of presentations, discussion workshops and creative pieces.

The programme was delivered uniquely online and centred on the UTC time zone, reflecting the European and South African location of the organising team. It was attended by 45 participants from 16 countries across Asia, Europe, Africa and North and South America.

Overall, the evaluation of CFA24 was exceptionally positive, particularly in relation to the quality of facilitation, the opportunity for meaningful reflection, and the possibility for emotional exploration that it enabled. Key findings related to participants' experiences, the value of focusing on emotions in engagement, and the effectiveness of an online setting for such a programme.

The focus on emotions was highly valued, with participants recognising that emotions are often an underexplored but crucial element of public engagement. The Academy helped participants to practice and develop skills such as empathic communication, active listening, and storytelling. Many found the emphasis on emotions transformative in their understanding of engagement practices and in how they planned to incorporate emotional awareness into their future work.

The online nature of CFA24 worked effectively for most participants, especially in terms of accessibility. The virtual environment allowed the Academy to convene a geographically and professionally diverse group, which would have been difficult to achieve with an in-person event.

"I really liked the dynamic that you organised in the small groups, the chance we had to talk to interchange ideas and experiences, and the reflection in collective about emotions and the importance of emotions ... and also listening, not more talking, but more listening to other people, taking into account the local context, the cultures, the diversity of points of views...it was a very respectful space."

PUBLIC ENGAGEMENT PRACTITIONER

"Since I come from a very scientific background. I always thought, you know ... OK, just put the science out there and that's how it'll work. People will understand, because the truth overcomes everything. And that was my very naive view. And now just bringing in emotions and the humane aspect and using, for example, art as an equaliser, or really talking about emotions as an equaliser in a space where you have this societal hierarchy between science and the ivory tower. I think it's really pushing my engagement practice for sure"

DISCOVERY SCIENTIST

Potential for broad reaching impact that radiates throughout science

2024 Publications

Milne, R., Bircan, T., & Middleton, A. (2024, September 24). *A model of dialogic public engagement with genetics and genomics research*. Pre-print <https://doi.org/10.31235/osf.io/uhsxr>

Milne, R., Galloway, C., Rashid, M., Boraschi, D., Burch, C., & Middleton, A. (2024). *The Hopes and Fears Lab: Enabling dialogue on discovery science*. Journal of Science Communication, 23(7), Article N05. <https://doi.org/10.22323/2.23070805>

Costa, A., Atutornu, J., Bircan, T., Boraschi, D., Henriques, S., Milne, R., Okoibhole, L., Patch, C., & Middleton, A. (2024). *From “Inclusion in What” to “Equity in What”: (Re)Thinking the question of in/equity in precision medicine and health*. The American Journal of Bioethics, 24(3), 89–91. <https://doi.org/10.1080/15265161.2024.2303147>

Goodman, J. R., & Milne, R. (2024). *Signalling and rich trustworthiness in data-driven healthcare: An interdisciplinary approach*. Data & Policy, 6, Article e62. <https://doi.org/10.1017/dap.2024.62>

Costa, A., & Milne, R. (2024). *Detecting value(s): Digital biomarkers for Alzheimer’s disease and the valuation of new diagnostic technologies*. Sociology of Health & Illness, 46(S1), 261–278. <https://doi.org/10.1111/1467-9566.13678>

Pannunzio, V., Komashie, A., Walsh, S., Milne, R., Kipouros, T., & Lamé, G. (2024). *Exploring indicators of system-of-systems resilience: Outcomes of a health systems design workshop at an international conference*. Proceedings of the Design Society, 4, 2675–2684. <https://doi.org/10.1017/pds.2024.267>

Key Panel Discussion Moderation

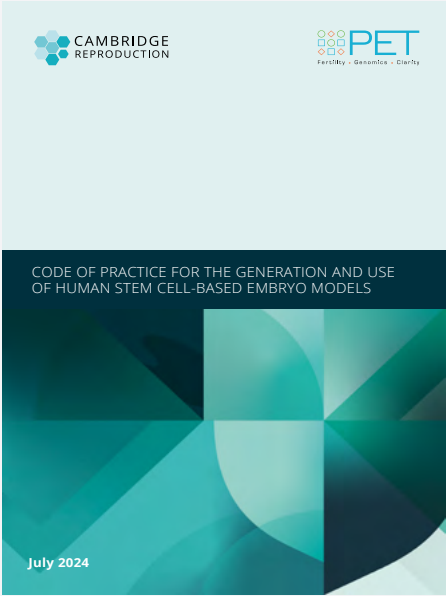
Dr. Catherine Galloway was the Chair and Moderator for the key panel discussion at a conference organised by the Centre for Human-Inspired Artificial Intelligence, University of Cambridge on 29th October 2024. Title: Ethical and societal implications of AI for patients and mental health care. Audience: 200+ discovery AI scientists at the University of Cambridge.

Influencing the governance of science

Prof Anna Middleton sat as a member of the Oversight Group as the public engagement with ethics expert on the Public Dialogue on the governance of research involving stem cell-based embryo research, funded by UK Research and Innovation, Sciencewise and the University of Cambridge. This contributed to the creation of a Stem Cell-Based Embryo Models Code of Practice for scientists to support scientists in working ethically with embryo models that currently fall outside of existing regulatory frameworks.

“At Kavli we think the broader and deeper the conversation, the better the science will be in the end. Because what is science for, what’s all this discovery about, if it isn’t making the largest difference to the greatest number of people?...We are all – collectively – at a “fork in the road...We are poised to “make a choice”, collectively, about how far, how deeply, we are going to let machines intervene in the lives of our children and subsequent generations.”

DR CATHERINE GALLOWAY



Code of practice for scientists to use in research

Recommendations on AI, for Government based on public dialogue

We collaborated with ai@cam and Hopkins Van Mil to convene public dialogue workshops to better understand public perspectives on the role of AI. In September 2024, 40 members of the public took part in two workshops, in Liverpool and Cambridge, together with AI specialists from the University of Cambridge, University of Liverpool, King’s College London, and University of Manchester. We can now share those findings in a new ai@cam report: AI and the Missions for Government: insights from a public dialogue, that offer the first analysis of how the public think that AI could help deliver the Missions for Government.



Public dialogue for use in government policy

Radiating the Hopes and Fears Concept

The Hopes and Fears Lab continues to evolve, and this year marks an exciting milestone with the release of our ‘Mini Manifesto’. Designed by Dr Catherine Galloway, Dr Mariam Rashid and our H&F artist Tom McLean, this 15-page guide responds to a question we’ve often heard: “How can we bring The Hopes and Fears Lab to scientists around the world?”

The Mini Manifesto is a manual with step-by- step instructions for hosting your own Lab, tips for briefing scientists, and even a detailed shopping list accessible via a QR code. Thoughtful touches, like Tom’s reimagined H&F characters as downloadable stickers, ensure the Lab’s visual identity remains cohesive worldwide.

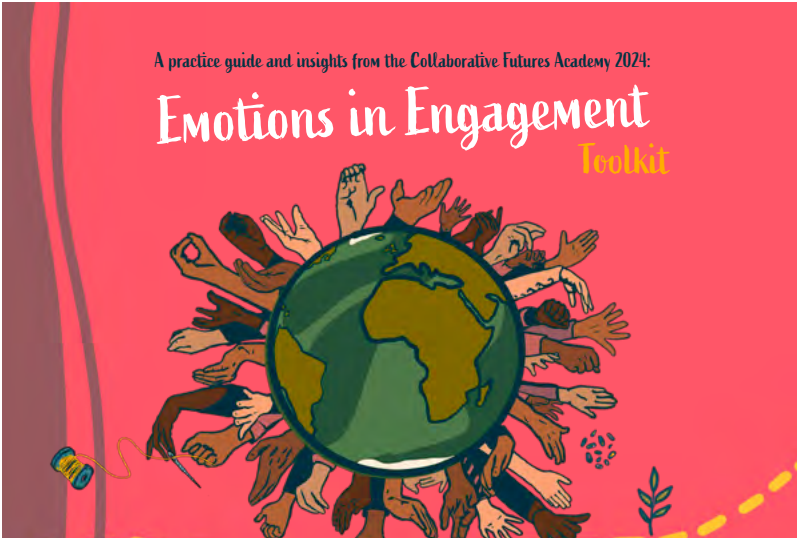
With inquiries from across the UK and as far as the United States, the Manifesto empowers individuals and institutions to spark transformative conversations in their own contexts. Available online and in a charming letterbox-sized package, it reflects our commitment to making science accessible, creative, and impactful.

“AI needs to be managed, not just by the private companies, the Government need to manage what’s going on, not just give AI a free reign.”

PUBLIC PARTICIPANT, CAMBRIDGE

Toolkit for the Emotions on Engagement

For the Collaborative Futures Academy 2024, we cocreated an artist-designed toolkit, available for wide distribution, which explains the process and methods for using emotion in engagement.



Toolkit for the Emotions in Engagement outputs from the Collaborative Futures Academy 2024



Looking to 2025

The Hopes and Fears Lab will be strengthening interdisciplinary collaborations, such as those with the Cambridge Centre for AI in Medicine and the Engineering Biology Interdisciplinary Research Centre. Notable projects include staging the Hopes and Fears Lab: AI Edition at The Copper Kettle café in Cambridge (an iconic and famous café, opposite Kings College Chapel used by local people) and the Future of Life Edition, aligning with the 50th anniversary of the Asilomar Conference.

Spearheaded by our two Postdoctoral researchers, Dr. Daniela Boraschi and Dr. Mariam Rashid we will be exploring the development of a Creative Ethics Chatbot, to facilitate ethical reflection among computer scientists through text-based dialogue and creative imagery, effectively integrating ethics into research processes.

As part of the Cambridge Alumni Festival, we will be hosting another Hopes and Fears Lab for visiting alumni to Cambridge, showcasing the Kavli Centre's interdisciplinary impact.

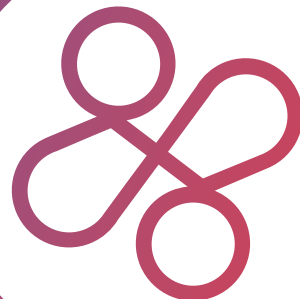
In terms of the ethics and science film festival we promised, we held our first foray into film festival delivery via the CHATTACA event we developed with the Artshouse cinema in Cambridge, showing two films on genetics together with a hosted discussion about the ethical implications of the science.

We are partnering with the Cambridge Festival organisers, who have significant experience of reaching large international audiences with both in person and online events, to support us to deliver our 'Just.Good.Science' film festival in Spring 2025. Here we will show the films we have already created for the Only Human project as well as documentary films we have made on Kavli Centre activities as well as opening up the ability for film makers around the world to submit films for showing at the Festival.

And finally Dr. Daniela Boraschi is exploring a new research partnership with Cambridge AI and machine learning scientists on digital twins and will also be setting up a new collaboration on ethics with discovery scientists from the Cambridge Stem Cell Institute (CSCI).

Changes and Adjustments

Due to the uncoupling of Wellcome Connecting Science we have experienced delays to progressing the survey outputs we had planned for 2024. The International public survey is paused while we assess what we can feasibly deliver without the statistics expertise that would have been provided by Wellcome Connecting Science. The scientist survey recruitment is underway and has been promoted extensively across Cambridge University. Recruitment has finished in S.Africa and we will navigate the analysis process throughout 2025.



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and the Public