Inclusive Research and Experimental Design
9th September
Welcome to the EDIS Symposium 2019: Inclusive Research and Experimental Design.

Research to improve human health should aim to create equal and better health outcomes, from biomedical research through to clinical trials. This symposium will take the concepts of Equality, Diversity and Inclusion and look at how these are applicable to research and experimental design.

About EDIS

EDIS is a coalition of organisations in the science and health sector working together to improve equality, diversity and inclusion. Originally founded by Wellcome, GSK and The Francis Crick institute in 2017, EDIS can draw on expertise from across the science and health field to develop a coalition with power to influence and drive evidence-based change. The current members of EDIS are shown below:

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Our vision

Our vision is that everyone should have equal opportunities and access to a successful career within Science or Health, its research and its outcomes.

Our mission

Our mission is to build a powerful, connected and coordinated movement to advance Equality, Diversity and Inclusion in Science and Health research.

Our impact

Our impact statement is ‘Equal and better health outcomes’.
Facilities

- Accessible toilets are located both in the gallery space next to the auditorium, and in the seminar suite space past seminar room 6.
- Gender neutral toilets are located in the seminar suite space past seminar room 6. These are clearly labelled with the available facilities inside.
- Seminar room 5 is the designated quiet room.
- A seating area is available at the back of the gallery space. There will also be seating in some of the seminar rooms.
- Baby feeding facilities are available in the seminar suite space past seminar room 6. Baby changing facilities are in the gallery space bathrooms by the auditorium.
- The Crick’s prayer room and washing facilities are located within the staff section of the building. If you need access to these facilities during the day, please let staff know at registration and they will organise for a building pass and escort to be made available.
- Induction loops are available in the following areas: reception, auditorium and seminar rooms (infrared loop system). You will need to switch your hearing aid to the ‘T’ position. In addition, we ask all speakers and any questions from the audience to use the microphones.
- All assistance dogs are allowed in the ground-floor communal areas and in the collaboration areas on each floor. Please remember to not distract or pet an assistance dog as they are there to assist a disabled person. Handlers of an Assistance Dog: An open green space (Purchase Street Open Space) to the left (North) of the building can be used to exercise and toilet a dog. There are dog waste bins available in the dog exercise area here.
- Building evacuation will be signalled by a continuous alarm. If this is heard, staff will help to escort all attendees out of the building via emergency exits and North to Purchase Street Open Space, the designated assembly point.

If you think you require a personal emergency evacuation plan (PEEP), please contact us ASAP

How the symposium will run

- Live captioning is being provided by mycleartext throughout the day. There will therefore be regular short breaks to allow the writers to rest.
- If you need a seat reserved for you in the front row, back row or an aisle seat please let us know on registration (including wheelchair and mobility aid users due to steps inside the auditorium).
- There will be breaks during the symposium and regular changes of topic. If you need to leave the room for a break at any other time, please do so. Please be considerate of other attendees.
- If you think you require a personal emergency evacuation plan (PEEP), please contact us ASAP

Wi-Fi

Free Wi-Fi is available for visitors. There are two networks you can use:
- The Cloud Wi-Fi is available to all visitors to the Crick Lab. To use the Wi-Fi, select the ‘Wi-Fi Guest’ option and then sign in using the same email and password as you would in a coffee shop.
- The Crick is a registered eduroam institution. eduroam (which stands for education roaming) is the secure, world-wide roaming access service developed for the international research and education community. It is available for visitors from other academic sites.

To use this if you wish to ask a question without using the microphones.
- If you do not want your voice to be recorded when asking a question, please alert the staff member with the roaming microphone. They will be able to ask your question for you.

Volunteers will be on hand to hold and pass a roaming microphone around members of the audience during question and answer sessions.
- We will draw questions from twitter using the hashtag #EDIS2019 for relevant sessions. Please use this if you wish to ask a question without using the microphones.
- If you do not want your voice to be recorded when asking a question, please alert the staff member with the roaming microphone. They will be able to ask your question for you.
Breaks and refreshments

- A full allergens list for food is available and clearly marked vegetarian, vegan and special dietary request options will be available.
- Straws will be made available for refreshments for those who need them.

Inclusivity

- Pronoun stickers are available for all attendees, we strongly encourage the use of these by everyone.
- If you need any additional help during the event, please ask one of the hosts or volunteers who will do their best to help you. Volunteers will be wearing coloured badges, so you can easily identify them.
- We will try our best to reduce background noise. We ask attendees to try to reduce distracting noises.
- Mechanisms to reduce sensory issues are totally acceptable. Attendees are requested not to remark on tinted glasses, earplugs/defenders, headphones, or any other aids.
- Silent Clapping: The sound of many people clapping together can be uncomfortable or painful to some autistic people and clapping maybe difficult for some disabled people. For this reason, you are welcome to replace the traditional clap with a wave of the hands. Don’t worry if you forget (it takes a bit of practice!), even if a few people clap, the overall noise level will have been reduced.
- Autistic behaviours: Repetitive movements or behaviours, echolalia, distractibility, fidgeting or moving about, different or impaired conversation skills, avoidance of eye contact, perseveration (obsessiveness), are expected and accepted. Please try to bear in mind the need for speakers / attendees to be heard.

Communication and networking

- Be social media savvy – please check with your colleagues and presenter before posting any images online. Please do not quote any other attendees or share discussions under ‘Chatham house’ rules.
- If posting pictures of any of our materials, please ensure you tag these with: #EDIS2019 and @edisgroup.
- Want to connect with others? Please bring business cards with you or exchange contact details during the breaks/networking event as unfortunately we’re unable to share the attendee list.
- We warmly invite you all to stay for the networking event following the talks. Volunteers will show you where to go.
- We’d like to thank and credit the following sources and groups for guidance in creating this accessibility guide and helping us to create an inclusive symposium: NADSN, LGBT+NoN, AdvanceHE and Auto Trader Group plc.

EDIS Symposium 2019: Code of Conduct & Inclusion Statement

All delegates, speakers, sponsors, volunteers and staff at any EDIS event are required to read and follow the Code of Conduct. Organisers will implement this code throughout the event.

Ethos

This Code of Conduct aims to enable all delegates, speakers, sponsors, volunteers and staff to enjoy, participate in and contribute to the EDIS symposium 2019 and to ensure that individuals or groups do not feel harassed or uncomfortable in participating in the event or EDIS associated activities. EDIS welcomes you to take part in the symposium and hope that this code helps you to participate fully.

The EDIS symposium 2019 will be exploring concepts relating to equality, diversity and inclusion of individuals and underrepresented groups. This may include age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex or sexual orientation or any other aspect of diversity not included as cont....
a protected characteristic by the Equality Act 2010. Addressing and promoting equality, diversity and inclusion in research provides the opportunity to make research better and more relevant to all members of society. This approach to seek diversity is not to use differences to further marginalise groups without power or those who experience systemic exclusion.

**Expectations**

The EDIS Symposium is dedicated to providing a harassment-free experience for everyone, regardless of protected characteristics protected by the Equality Act or aspects of diversity not currently covered by the Act (e.g. socio-economic status). We do not accept harassment or intimidation of symposium delegates, speakers or staff in any form whether verbal, physical, or written (including on Social Media or by email). Symposium participants who do not adhere to these rules may be removed from the symposium at the discretion of the organisers.

Harassment includes, but is not limited to:

a) Offensive or unwanted conduct on the basis of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex or sexual orientation which has the purpose or effect of violating dignity or creating an intimidating, hostile or degrading environment.

b) Use of sexualised or other inappropriate images or unwelcome sexualised content, inappropriate physical contact, unwelcome sexual attention or stalking.

c) Sustained interruption of speakers or those asking questions.

d) Unwanted photography or filming.

Intimidation includes, but is not limited to:

a) Making threats

b) Bullying

c) Personal attacks

If you are being harassed, notice that someone else is being harassed, or have any other concerns, please contact a member of symposium staff immediately. Symposium staff can be identified through their coloured badges. Symposium staff will be happy to help participants contact venue security or local law enforcement, provide escorts, or otherwise assist those experiencing harassment or intimidation to feel safe at the event. The symposium organisers reserve the right to remove any individual from the event if they break the Code of Conduct. No reimbursement of event or associated costs will be made. We expect participants to follow these rules at all EDIS events and associated activities.

**Event-specific inclusion statement for EDIS 2019**

EDIS is an inclusive collaboration that seeks to place equality, diversity and inclusion at the heart of science and health research. The 2019 EDIS symposium focuses on several dimensions of diversity and seeks to enable respectful, evidence-based discussion about all of these dimensions. In addition, we wish to promote inclusion in research and in the EDIS symposium itself. For instance, we wish to foster evidence-based consideration of concepts relating to genetic variation and we suggest avoiding use of labels of race and ethnicity as a proxy for genomic variation. Similarly, we wish to highlight that the EDIS symposium is trans- and non-binary inclusive and EDIS will not accept the exclusion of trans and non-binary experiences at the symposium or associated activities.

The purpose of our focus in the EDIS symposium is to consider and address inequalities in funding, research content and health outcomes experienced by systematically marginalised and excluded groups. EDIS has organised the practical arrangements for the symposium in a way that EDIS hopes fosters inclusion and respect. The symposium organisers welcome any feedback from symposium attendees on how we might achieve any further improvements for future events.
References:
1. The Equality Act 2010 guidance
2. Stonewall glossary of terms
3. ‘Examining how race, ethnicity and ancestry data are used in biomedical research’. VL Bonham et al., Jama, 2018
4. ‘Gender equality in science, medicine, and global health: where are we at and why does it matter?’. Shannon G et al, The Lancet. 2019
5. LGBT+ Health inequalities Parliamentary Office of Science and Technology
6. ‘Local action on health inequalities: understanding and reducing ethnic inequalities in health’ Public Health England. 2018
8. The Missing Diversity in Human Genetic Studies G. Sirugo et al. Cell, 2019

Programme

**9.30-10.00**
Registration and refreshments

**Session 1 (Whole Auditorium)**

**10.00-10.15**
Welcome (Crick)

**10.05-10.15**
Introduction (EDIS)

**10.15-10.50**
Diversity, decision-making and biomedical bubbles – Professor James Wilsdon

**10.55-11.15**
Inclusive research priority setting - Katherine Cowan

**11.15-11.40**
Break (refreshments served)

**Session 2 (Split Auditorium)**

**11.40-12.40**
Auditorium 1: The sex and gender dimensions in research – Professor Robin Lovell-Badge, Dr Natasha Karp, Dr Inés Pineda-Torra
Auditorium 2: Diversity in clinical trials and AI - Dr Anya Harry, Peju Oshisanya, Dr Mohammed Kamran

**12.45-13.45**
Auditorium 1: Ethnicity and ancestry in genomics - Professor Ewan Birney, Dr Emma Baple, Jerome Atutornu
Auditorium 2: BAME participation in health research - Naina Patel, Toni Brasting, Farrah Nazir

**13.45-14.45**
Lunch and stalls from EDIS members
Crick, GSK, Wellcome, The Academy of Medical Sciences, Association of Medical Research Charities, AstraZeneca, Babraham Institute, Benevolent AI, Biochemical Society, British Pharmacological Society, Daphne Jackson Trust, Elizabeth Blackwell Institute for Health Research, EMBL-EBI, Wellcome Sanger Institute and Connecting Science

**Session 3 (Split Auditorium)**

**14.45-15.15**
Involved research communications – Dr Bella Starling, Cassie Wilson, Grace McCorkle

**15.20-16.10**
Gendered Innovations – Professor Londa Schiebinger

**16.10-16.15**
Closing remarks (EDIS)

**16.15-17.00**
Drinks and networking
Jerome Atutornu

Jerome is the inaugural PhD student for this collaboration between the Faculty of Education (University of Cambridge) and Wellcome Genome Campus Society and Ethics research group. His hope is that this study will unearth barriers to engagement so that culturally competent educational strategies can be employed to ameliorate these. Jerome is a lecturer in diagnostic radiography at the University of Suffolk in Ipswich and still practices radiography at Bury St. Edmunds. Jerome has also worked in the private sector providing Lithotripsy services to most of the NHS Trust in the East of England after a period of service in the military. Jerome became interested in genomics and personalised healthcare during his MSc and has been hooked since. He has subsequently undertaken master’s modules in genomic medicine at the University of Cambridge.

Ewan Birney

Ewan Birney is Director of EMBL-EBI with Dr Rolf Apweiler and runs a small research group. He is also EMBL-EBI’s Joint Head of Research, alongside Dr Nick Goldman. Ewan completed his PhD at the Wellcome Sanger Institute with Richard Durbin. In 2000, he became Head of Nucleotide data at EMBL-EBI and in 2012 he took on the role of Associate Director at the institute. He became Director of EMBL-EBI in 2015. Ewan led the analysis of the Human Genome gene set, mouse and chicken genomes and the ENCODE project, focusing on non-coding elements of the human genome. Ewan’s main areas of research include functional genomics, DNA algorithms, statistical methods to analyse genomic information (in particular information associated with individual differences in humans and Medaka fish) and use of images for chromatin structure. Ewan was elected an EMBO member in 2012, a Fellow of the Royal Society in 2014 and a Fellow of the Academy of Medical Sciences in 2015. He was made a Commander of the British Empire (CBE) in 2018. Ewan is a non-executive Director of Genomics England, and a consultant and advisor to a number of companies, including Oxford Nanopore Technologies, Dovetail Genomics and GSK.

Emma Baple

Dr Emma Baple is a Senior Lecturer in Genomic Medicine at the University of Exeter and a Consultant Clinical Geneticist at the Royal Devon and Exeter Hospital. Emma works closely with Professor Andrew Crosby, Professor of Medical Genetics at Exeter and together they lead the community genomics research group. Their principle interest is in the use of new genetic technologies to identify the cause of rare genetic disorders and the translation of that knowledge into improved clinical diagnostic testing and treatment strategies. Their research involves the investigation of the molecular causes of inherited disorders within a community setting, stemming from the identification of the causal disease gene through to more detailed studies of the biological pathway and disease mechanism responsible. Recent important examples include: the delineation of a new autosomal recessive tubulinopathy associated with PRUNE mutation and the identification of a hypomorphic mutation of PCNA that underlies a novel autosomal recessive DNA repair disorder.

Toni Brasting

Toni Brasting is a Strategic Design & Innovation Manager in the Public Engagement team at Wellcome, where Toni helps Wellcome teams put people at the centre of research in particular Wellcome Priority Areas such as Snakebites, Data, Our Planet Our Health and Mental Health. She works with these teams to design new ways of engaging the public in order to create real change. Toni has worked in a range of industries, mainly in the area of human centred design and programme development, including the Australian Public Service, Publishing, Oil and Gas and Video Games, among others. She has a knack for identifying the key problems affecting an area on inquiry and has a love of putting pen to paper to draw the problem and the system surrounding it. Toni, originally from country Australia, loves dinosaurs and making video games in her spare time. Please email t.brasting@wellcome.ac.uk to contact Toni.
Katherine Cowan

Katherine Cowan is an independent facilitator and Senior Adviser to the James Lind Alliance (JLA) (www.jla.nihr.ac.uk). Since joining the JLA in 2008, she has been a key contributor to the development of its method of bringing patients, carers and health and social care practitioners together to set priorities for research. Katherine co-wrote and edited the original JLA Guidebook. She has chaired over 30 research Priority Setting Partnerships and facilitated at more than 50 priority setting workshops internationally, including for autism, schizophrenia, childhood disability, palliative care, dementia, Parkinson’s, depression, spinal cord injury, frailty and sight loss. Katherine’s professional background is in social research and her work includes facilitation, training, qualitative research and coaching. She has a particular interest in public participation in decision-making processes. She has a Masters in Coaching and Mentoring Practice and has worked as an independent consultant for 12 years. Katherine lives in St Leonards-on-Sea and recently started playing the violin again (after a 34-year pause). For more details, including publications, please visit www.katherinecowan.net. @Katherine_JLA

Lilian Hunt

Dr Lilian Hunt is the Programme Lead for EDIS. Lilian received her PhD in Genetics from UCL whilst at The Francis Crick Institute investigating non-coding genetic variation in human developmental disorders. It was here that she helped bring together Wellcome, The Francis Crick Institute and GSK as founders of EDIS and has developed and led the coalition to its recent expansion. Lilian runs the EDIS programme of work bringing expertise from her research experience together with lived experience as a queer woman in science and EDI knowledge to drive a research and evidence-based approach to inclusion. Lilian also represents EDIS on the National Institute for Health Research’s INVOLVE Diversity and Inclusion working group, with a focus on inclusive patient and public involvement in health research. Lilian has spoken extensively on the topics of diversity and inclusion in science and health research to a variety of audiences, notably for the Science Museum, Wellcome Trust, the Social Innovation Exchange and as part of the UN’s He for She Arts Week.

Anya Harry

Dr Anya Harry is the Global Lead for Clinical Trial Diversity at GlaxoSmithKline. Her passion for this area evolved from her experiences in clinical care, public health and drug development and research. Previously, she was a Director in Clinical Development providing leadership and medical support for early as well as late stage programs and device initiatives in the Respiratory Therapeutic Area. After several years as a pulmonary-critical care physician in private practice, Dr Harry became a medical officer and subsequently a branch chief at the US Food and Drug Administration. Prior to joining GlaxoSmithKline, she directed a multidisciplinary team for a global consulting firm with a large focus on rare diseases. Dr Harry received her MD, PhD from Mount Sinai School of Medicine and completed residency at Yale New Haven Hospital. She completed a combined pulmonary and critical care medicine training at the University of Pennsylvania and the National Institutes of Health. Dr Harry has authored many peer reviewed articles and book chapters.

Mohammed Kamran

There is significant Health Inequality and Genetic Disparity in the UK. Future Genetics is focused on the discovery and development of disease biomarkers in areas of unmet clinical need. We as a society need a healthcare system that is able to provide the best and most appropriate treatments to different patients, and where individuals and families are sufficiently empowered to make life-style decisions that are based on their personal genetic-makeup. Future Genetics is committed to developing the means to help society live better and healthier lives.

Dr Kamran is the CEO for Future Genetics. He brings strategic vision and significant experience to the organisation. He is a member of the Royal College of Science association. He has 20+ years of Academic, Clinical Trials, R&D, and Pharmaceutical Medical Affairs experience. Dr Kamran holds a PhD in Molecular Medicine from Imperial College London School of Medicine and was a Postdoctoral Research Fellow at the University of Oxford (Institute of Molecular Medicine). He has managed successful clinical trials incorporating genetics and R&D genomics studies across the UK and USA. Most importantly, his focus is to help make a difference by reducing inequality.
Natasha Karp
Dr Natasha Karp is a Principal Data Scientist (Biostatistician) with AstraZeneca, Cambridge, UK. Dr Karp has fifteen years’ experience spanning biosensors, proteomics, drug-discovery and genotype-phenotype mapping and has worked in both commercial and academia settings, including the Wellcome Trust Sanger Institute and the University of Cambridge. Dr Karp has been published widely; with 24 first or senior author and 42 co-author international peer reviewed journal articles. Dr Karp is driven to finding practical solutions to the challenges of in-vivo research with a particular interest in improving replicability, reproducibility and generalizability of the studies. Recently, Dr Karp has focused on the potential of change management theories to help the scientific community make the changes needed to improve the quality of our science.

Robin Lovell-Badge
Robin Lovell-Badge is a senior group leader and head of the Laboratory of Stem Cell Biology and Developmental Genetics at the Francis Crick Institute. He established his independent laboratory in 1982 at the Medical Research Council (MRC) Mammalian Development Unit, University College, London. In 1988 he moved to the MRC National Institute for Medical Research (now part of the Francis Crick Institute), becoming Head of Division in 1993. His lab relocated to the new Francis Crick Institute in October 2016. He was elected a member of EMBO in 1993, a Fellow of the Academy of Medical Sciences in 1999, and a fellow of the Royal Society in 2001. He is a Fellow of the Royal Society of Arts, and a Fellow of the Royal Society of Biology. He has received the Louis Jeantet Prize for Medicine, the Amory Prize, the Feldberg Foundation Prize, and the Waddington Medal of the British Society for Developmental Biology. He was awarded a CBE in the 2018 New Year’s Honours List. He is also very active in both public engagement and policy work, notably around stem cells, genetics, human embryo and animal research, and in the ways science is regulated and disseminated.

Grace McCorkle
As an independent public contributor with Manchester Clinical Research Facility (MCRF), Grace is a staunch advocate for the progression of greater equality, diversity and inclusion in public health research and the delivery of healthcare services, believing one is intrinsically linked to the other. First and foremost, her focus is to improve the health outcomes for communities living on low incomes, however, her passion and drive is to address health inequalities against women across the globe. Grace has influenced change, more openness and wider discussions on local and national platforms to improve policy, research practice and patient experience. As a public contributor member of MCRF Executive Committee, Chair of MCRF Involvement & Engagement Group and member of BRAG (BAMER Research Advisory Group), Grace contributes to the strategic and operational frameworks aiming to eradicate health inequalities across Greater Manchester through research. Before MCRF, she was the Chair of Manchester University H@PPI Group which was established to bridge the gaps between the public’s understanding of health data and the advancement of medicine within health informatics. Beyond public health research, Grace is an executive within the social housing sector working to eradicate homelessness and create opportunities for individuals and communities to thrive.
Farrah Nazir
As Strategic Design & Innovation manager, Farrah Nazir oversees several programmes and initiatives that help the public play their own role in Wellcome’s mission to improve health. Farrah focuses on opportunities to redefine the relationship organisations have with both their people and with research and evidence. Farrah is currently involved in several internal projects that explore this relationship, including:

- Wellcome’s staff forum transformation programme: Leading a team of 18 representatives at the Wellcome Trust to reimagine their role in helping staff identify, raise and develop ideas to make Wellcome an event better place to work.
- Systems thinking at Wellcome: Working in collaboration with the science research culture team to discover Wellcome’s appetite for taking a systems design approach to its work.
- Implementing Diversity & Inclusion at Wellcome Collection: Working in collaboration with the Collection’s Inclusive Practice Lead to understand the needs of staff when it comes to exploring equity, diversity & inclusion.

Farrah also leads several projects designing change at a sector wide level, including:

- Employee Wellbeing Sector: Investigating how to improve employee health through empowering commercial organisations to access the latest health research and apply this into the workplace.
- Mass media: Experimenting with new models to embed research and evidence within the commissioning and editing of media content that reach mass audiences.
- Charities as a platform: Discovering opportunities to strengthen the social sector as a way to improve public engagement.

Peju Oshisanya
An advocate for diversity and inclusion in data generation in clinical research, Peju is passionate about raising awareness about the importance of including a more diverse population in research and the potential benefits of Artificial Intelligence in enabling this. Peju is an innovative operational strategy expert with over 15 years wide-ranging experience relating to strategic programme leadership, planning and management of clinical trials with responsibility for global clinical programmes. She started her career working in early drug discovery and exploratory phase focused on the transition of early stage assets to clinical development. Following this, she moved into programme management responsible for key clinical programmes and assets within Eli Lilly, Sanofi Aventis, Pfizer and Takeda. After gaining extensive experience with major pharmaceutical organisations, Peju has moved her career to working with start-up organisations and SMEs. In her current role as director of programme management, she is responsible for driving the asset strategy to maximise the value of both early and late phase drug development programmes in a pioneering start-up that harnesses artificial intelligence to accelerate and enhance scientific discovery. Achievements include: Keynote Speaker and panellist at various International Symposiums; European Chapter Lead for Women of Colour in Pharma (WOCIP); Award winner on leadership and team management.
Naina Patel

Naina Patel is currently studying for a PhD at De Montfort University on a scholarship from East Midlands CLAHRC which commenced in October 2015. This has offered an opportunity to apply her qualitative research experience and prior community development expertise to the exploration of lay multi-generational conceptualisations of dementia in multi-ethnic communities. The research involves lay participants from white British, Indian Hindu Gujarati and Caribbean communities in Leicester. Prior to the PhD, Naina was employed as a qualitative researcher in applied health research at the University of Leicester from 2005. In this post, she contributed to the cultural adaptation of DESMOND structured education for people with type 2 diabetes. She subsequently led the qualitative evaluation of LET’s Prevent (Type 2 diabetes) for South Asians and more recently for the STOP Diabetes structured education programme for people with intellectual disabilities. Naina has also conducted a programme of translational research projects and seminars to address psychological insulin resistance in patients and healthcare professionals. A major highlight of her work has been to successfully adapt a translation methodology for the translation of the Leicester Risk Assessment Score for type 2 diabetes, into four South Asian languages. It is currently being rolled out nationally.

Londa Schiebinger

Londa Schiebinger is the John L. Hinds Professor of History of Science at Stanford University, and Director of the EU/US Gendered Innovations in Science, Health & Medicine, Engineering, and Environment project. She is a leading international expert on gender in science and technology, an elected member of the American Academy of Arts and Sciences, and the recipient of numerous prizes and awards, including the prestigious Alexander von Humboldt Research Prize and Guggenheim Fellowship. Schiebinger presented the keynote address and wrote the conceptual background paper for the United Nations’ Expert Group Meeting on Gender, Science, and Technology in 2010 with an update in 2014. She will speak on Gendered Innovations, which harnesses the creative power of sex and gender analysis to enhance excellence and reproducibility in science and technology. Over the past decades, governments and research organizations have taken three strategic approaches to gender equality: 1) “Fix the Numbers of Women” focuses on increasing women’s participation; 2) “Fix the Institutions” promotes gender equality in careers through structural change in research organizations; and 3) “Fix the Knowledge” or “Gendered Innovations” stimulates excellence and innovation by integrating sex and gender analysis into the design of research.

Bella Starling

Bella Starling is a Wellcome Trust Engagement Fellow and Director of Public Programmes at Manchester University NHS Foundation Trust. Her career has spanned basic research, science writing, biomedical ethics, public engagement, patient involvement and science policy, as a practitioner, action researcher, strategic adviser and funder. She is passionate about inclusion in, and democratisation of, research; her Fellowship explores how public engagement with research acts as a catalyst for social change. Sometimes, she is called a change-maker.
James Wilsdon

Professor James Wilsdon is an interdisciplinary social scientist who researches research and tries to make sense of the politics and governance of science. James has had a longstanding commitment to the linked imperatives of equality, diversity and inclusion in research, and has worked at various points over the past 20 years on public engagement, research funding, career pathways and research evaluation. James currently chairs the UK’s Campaign for Social Science, and from 2014-15 led a UK government review of the role of metrics in the research system, published as ‘The Metric Tide’. Prior to that, James was director of science policy at the Royal Society. James is particularly interested in how we can better align support for EDI at an individual and career level, with support for diversity in terms of research priorities, modes and funding structures - an issue which he and colleague Richard Jones explored in a recent report for Nesta on ‘The Biomedical Bubble’. https://wakelet.com/wake/4cf86c10-9667-4dea-918f-b99805ecbb3b

Cassie Wilson

Cassie joined Public Programmes at Manchester University NHS Foundation Trust as Project Manager (Communications and Engagement) at the end of 2017. Initially managing ‘Breathtaking Lungs’, the team’s large-scale public engagement project which aimed to raise awareness of respiratory health and research, Cassie is currently leading a complete rebrand of the team’s communications, actively involving patient and public stakeholders along the way. Prior to this, Cassie spent many years working in youth and community development with a public health focus before training as a journalist and working in public relations and communications for a housing provider. Fundamental to her work has always been the philosophy that all voices should be heard, not just the loudest or most confident and articulate.

Join EDIS

Membership of EDIS is restricted to organisations. Individuals are strongly encouraged to participate in EDIS by registering to the EDIS mailing list and agreeing to support its core principles.

If your organisation is interested in becoming a member of EDIS, please email Lilian Hunt, Programme Manager at l.hunt@edisgroup.org.

Member commitments are as follows:

- To nominate a named sponsor with sufficient seniority for EDIS within their organisation, with the clear ability to advocate for change at a decision-making level within their organisation. This individual will be identified on the EDIS website and is expected to make reasonable efforts to attend members’ meetings.
- To pay membership (and any other) fees due to EDIS in a timely manner. Membership fees are set according to the number of employees an organisation has.
- To make an explicit and visible commitment to change where necessary, both internally and as part of the broader science and health research field, to help achieve the aims and objectives of EDIS.
- To report annually to EDIS on progress made against delivering on its commitments in a manner agreed upon by the members and Development Board in advance.
- To participate fully in EDIS, including to share knowledge, lessons learned and best practices with EDIS and with other member organisations.
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