### SHORTLIST 2020

# 2020 Medical Humanities Awards



Arts and Humanities Research Council



The Arts and Humanities Research Council (AHRC) – in association with the Wellcome Trust – has announced the 2020 shortlist for the Medical Humanities Awards.

The list showcases the best research taking place at the interface of the arts and humanities and medicine and celebrates its positive impact on medical outcomes.

## Hearing the Voice

#### University of Durham

Hearing voices that others don't is an experience people typically associate with distress – with the suffering of psychosis, with the fear of the unusual or unshared, with the shame arising from social stigma. Over the last eight years, we have pursued three closely related goals: to help those who are distressed by their voices, to find out what voices are like and why they happen, and to explore how hearing voices is an important and meaningful part of human experience.

Putting lived experience front and centre of our research, our interdisciplinary approach has brought the knowledge, critical instincts and creative processes of the arts and humanities together with clinical, scientific and experiential perspectives to transform the way people think about voices. We have published major studies of people's experience of hearing voices in contexts ranging from contemporary mental health services to medieval mysticism, from spiritual worship to the practices of writing and reading. We have transformed scientific approaches by shedding light on the connection between voices and ordinary self-talk, sensory perception and memory. Working in partnership with voice-hearers and clinicians, we produced the world's most comprehensive website about hearing voices (understandingvoices.com) and a new clinical tool for the management of unusual sensory experiences (MUSE) now used in Early Intervention in Psychosis services across the North of England. We have also brought our research to thousands across the world in exciting and innovative ways: a major touring exhibition on hearing voices, documentary film and theatre, and Ninja Theory's award-winning video game Hellblade: Senua's Sacrifice.





### **Music and Motherhood**

#### Rosie Perkins (Royal College of Music)

This research was the first large-scale study to investigate systematically how singing can support women with postnatal depression (PND). This is important because PND affects around one in eight mothers in the UK. Adherence to antidepressants can be low and access to psychological therapies slow, so there was a need for a new psychosocial intervention that is effective and accessible.

The research, funded by Arts Council England, involved researchers from the Centre for Performance Science at the Royal College of Music, Imperial College London, and UCL. We used a variety of research approaches, including a Randomised Controlled Trial (RCT), interviews, surveys, and experiments. Our main finding was that group singing classes for mothers and their babies can speed up recovery from PND among women with moderate-severe symptoms. After six classes, these mothers had a decrease in symptoms of nearly 35%. Women reported that singing provides an authentic and multicultural creative experience, calms babies, provides 'me-time', supports achievement and identity, and can enhance mother-infant closeness. It can also decrease psychological and biological markers of anxiety.

As a result of the research, a new intervention based on group singing has been developed, trialled, and positive outcome demonstrated. The programme has been implemented as an ongoing service – Melodies for Mums – by Breathe Arts Health Research. The research has been the basis for professional development of musicians and health practitioners, fed into key policy documents, and raised public awareness via extensive media coverage including a feature on BBC2 Trust Me I'm a Doctor.



### **Casebooks Project**

https://casebooks.lib.cam.ac.uk/

Lauren Kassell, Michael Hawkins, Robert Ralley, John Young, Joanne Edge, Yvonne Martin-Portugues, Natalie Kaoukji (Department of History and Philosophy of Science, University of Cambridge)

Medical encounters are fundamental to healthcare, health and wellbeing now and in the past. So too are medical records.

The Casebooks Project has transformed one of the largest surviving sets of private medical records in history from dozens of impenetrable manuscript volumes into an accessible digital archive.

Simon Forman, a renowned astrologer-physician in Elizabethan London, and his protégé, Richard Napier, recorded their arcane practices day by day for four decades. They documented the everyday sicknesses, worries, hopes and dreams of thousands of people, from beggars to bishops, most of whom are otherwise lost to history.

This work took a decade, and was supported by grants of almost £2 million from the Wellcome Trust. The result is a digital edition mounted on an open access website.

Readers can navigate the astrologers' messy manuscripts and make sense of their contents, from the perspectives of the doctors and their patients. They can browse images of the original volumes, and study explanations of everything from how to read old handwriting to the range of remedies that the astrologers prescribed.

The work of the Casebooks Project provides a model for combining medical history and digital humanities. It is changing how research is conducted and how medicine 400 years ago is understood.

The research has inspired a prize-winning video game, Astrologaster, as well as international headlines, several short films, and an exhibition of work by acclaimed artists.



# Evaluating evidence in medicine

#### John Williamson (University of Kent)

Evidence-based medicine (EBM) assesses the quality of scientific studies and uses those studies deemed to be of sufficient quality to judge whether a treatment is effective. Previously, philosophers have questioned whether EBM is right to view certain clinical studies as high quality, with low risk of bias. This project focused instead on mechanistic studies, which aim to shed light on the mechanisms by which the treatment operates, and which EBM takes to be of inherently low quality. We argued that EBM undervalues mechanistic studies: they need to be assessed alongside the clinical studies, and these assessments need to be integrated, in order to yield reliable judgements of effectiveness. This yields an improvement to EBM, which we call EBM+ (ebmplus.org).

The project involved a collaboration between Philosophy at Kent; Science and Technology Studies at UCL; Philosophy at Amsterdam; the National Institute of Health and Care Excellence (NICE) and the International Agency for Research on Cancer (IARC).

The team produced general guidance on how to evaluate mechanistic studies in practice and how to integrate this evidence with that from clinical studies. This guidance was made available in an open access handbook, <u>Evaluating evidence of mechanisms in medicine</u> (Springer 2018).

The project results fed into improvements to the methods manual of IARC, which now systematically reviews mechanistic studies and treats them on a par with other studies, and to that of NICE, which now also treats mechanisms more systematically, thereby enhancing the assessment of evidence in medicine by these key public health bodies.



# An Ounce of Prevention: A History of Social Psychiatry in the USA, 1939–Present

#### Matthew Smith (Strathclyde University)

'An Ounce of Prevention: A History of Social Psychiatry in the USA, 1939–Present' explores the last time when the prevention of mental illness was central to mental health policy, specifically, in the United States shortly after the Second World War. These years were dominated by *social psychiatry*, a preventive approach to mental health that emphasised how poverty, inequality, social isolation and community disintegration caused and exacerbated mental illness. Based on pioneering, interdisciplinary research, social psychiatric ideas influenced to the end of the asylum era and the emergence of community mental health. By 1970, however, the political will needed to enact the socioeconomic changes required to prevent mental illness was lacking. Social psychiatry and its preventive approach was forgotten.

I used extensive archival research, psychiatric literature and oral history interviews to retrace the spectacular rise and fall of social psychiatry. My ultimate aim was to use this history to advocate for more preventive approaches to mental health today. I have used blogging, public lectures, podcasts, media interviews and worked with schools to inform mental health professionals, mental health charities, social reformers, educators and the general public how the history of social psychiatry can point the way to more preventive mental health policies. One example is Universal Basic Income (UBI), which was recommended by some social psychiatrists, but to no avail. UBI provides a guaranteed income to every citizen with no means testing or qualifications. It would also help to alleviate the very factors - poverty, inequality, social isolation and community disintegration - that social psychiatrists associated with mental illness.





# Visual Representations of the Third Plague Pandemic

#### Christos Lynteris (St Andrews University)

A medical anthropologist, Dr Christos Lynteris is a Senior Lecturer at the Department of Social Anthropology of the University of St Andrews. His research focuses on the anthropological and historical examination of zoonotic diseases, epidemic control, and medical visual culture.

Dr Lynteris was Principal Investigator of the European Research Council funded project *Visual Representations of the Third Plague Pandemic* (2013–2018) at the University of Cambridge (CRASSH) and the University of St Andrews (Social Anthropology).

The project studied how epidemic photography emerged for the first time in the course of the third plague pandemic, which caused over twelve million deaths across the globe between 1894 and 1959. Examining over 10,000 plague images and their contextual archives, the project has shown how photography contributed to the formation of modern epidemiology and epidemic control, as well as to the notion, experience and imagination of "the pandemic".

The project also worked closely with archives across the globe, funding the digitisation of plague photographs, which are now made available online on Open Access bases.

On being shortlisted Christos said: "The nomination reflects the outstanding research conducted by the project's research team, which has transformed the way we see photographs of epidemics: no longer as mere illustrations of outbreaks, but primarily as ways of reasoning about, imagining and negotiating the multiple causes, meanings and outcomes of such events"



# Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE)

#### Joanne McPeake (University of Glasgow)

Survivors of critical care often experience, physical, emotional and cognitive problems following discharge. Previous research has focused on physical recovery rather than how patients recover in their own environment. By using humanities research in innovative ways, I have changed the landscape of care internationally for this patient group.

After developing the first Intensive Care Unit (ICU) Patient and Family Council in the UK, I was able to understand the cultural and social world in which patients recovered. Co-produced with patients and family members, I led the development of a health and social care recovery service- Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE). This service blends clinical visits with peer and social welfare support, working across acute and community sectors. As well as improving patient health and wellbeing, this work has been awarded national prizes including the BMJ innovation Award (2016) and has been spread to nine hospitals in the UK. I have also led an international research collaborative. This work, involving almost 50 centres, has focused on improving the patient and caregiver journey through humanities research.

Across all work, I am driven by the patient voice, as well interdisciplinary collaboration. I have worked in partnership with academics from div erse backgrounds to ensure that my research results tangible improvements. Partnerships also span clinical specialties, as well charitable sectors.

My current work, which has been awarded a healthcare improvement fellowship from THIS.Institute, explores the impact of social support during recovery and utilises humanities-based research to understand areas for improvement.



# Improving evidence evaluation in medicine

#### Michael Wilde (University of Kent)

I completed a PhD in Philosophy in 2015. I was then a postdoctoral researcher on an AHRC-funded project: "Evaluating Evidence in Medicine" (June 2015—May 2018).

On this project, I argued that a failure to consider the reliability of *combinations* of different types of evidence has led medical researchers to wrongly dismiss particular types of evidence, including expert judgement and bench research into the mechanisms of disease. Alongside my colleagues, I also provided a number of case studies to show how medical decisions can be improved by relying upon combinations of different types of evidence, rather than simply the evidence from comparative clinical studies.

Unfortunately, there is currently little guidance on how exactly to evaluate such combinations of different types of evidence. I therefore co-authored the first handbook to help healthcare professionals make improved medical decisions by evaluating evidence of mechanisms alongside evidence from comparative clinical studies: *Evaluating Evidence of Mechanisms in Medicine: Principles and Procedures* (Springer, 2018).

In doing all this, I benefited from regular visits to medical organizations, including the National Institute for Health and Care Excellence (NICE) and the World Health Organization's International Agency for Research on Cancer (IARC). I even managed to successfully recommend improvements to the evidence evaluation methods employed at these organizations by drawing upon the research of the project team. After this, I was invited to be a formal discussant in a workshop looking to improve the evidence evaluation methods employed by the National Toxicology Program of the US Departments of Health.



# Pyrrhic Progress: The Global History of Antibiotics and AMR

#### Claas Kirchelle (University of Oxford)

Understanding the long-term biological and social factors impacting infectious disease control is crucial to improving health systems. My research fuses approaches from history and biomedicine to analyse how societies have managed microbial environments since 1945. I am particularly interested in how laboratory networks and new technologies like genomic sequencing and antibiotics transformed disease control. I am passionate about using historical research to help decision-makers and engage publics beyond academia.

During my doctoral and postdoctoral research at Oxford (2012–2019), I analysed the historical factors shaping antibiotic use and antimicrobial resistance. My research produced an award-winning doctoral thesis and two monographs (*Pyrrhic Progress*, 2020; Turriano Prize) on antibiotics in food production and animal welfare science and politics (*Bearing Witness*, 2021). My books highlight that understanding how different communities produce expertise can decode long-standing conflicts about drug and welfare regulation.

Beyond history, I have co-authored high-profile interdisciplinary publications on antibiotic stewardship, typhoid control, and public pharmaceutical development. My research has informed official antibiotic reviews. I have also used history to engage wider audiences about protecting our antibiotic commons and improving access to vaccines and sanitation by curating two award-winning exhibitions, advising on radio and theatre dramas, and authoring media commentaries. In 2016/17, I co-curated the 'Back from the 'Dead' exhibition on antibiotics. In 2020, I co-launched the international exhibition *Typhoidland* (www.typhoidland.org) on the history and future of typhoid control. Supported by a Wellcome Trust University Award, I am currently analysing the laboratory networks underpinning global disease surveillance at University College Dublin.



# Performing Periods: Challenging Menstrual Normativity through Art Practice

#### Bee Hughes (Liverpool John Moores University)

My project Performing Periods: Challenging Menstrual Normativity through Art Practice combines sociological, art historical, and artistic methods to investigate how our cultural attitudes towards menstruation have formed, and crucially how they can be challenged. The research analysed historic advertising and current online medical advice to demonstrate the links between consumer and clinical knowledges in shaping ideas about menstruation rooted in traditional gender roles. It examined art from 1970–present to develop a deeper understanding of images of menstruation, and how art can both uphold restrictive norms and erode them. Finally, the project reflected on my own experiences of menstruation. Here, I aim to produce artworks that represent a menstruating body that disrupts common cultural narratives of periods as shameful, hidden, and only happen to women.

This PhD research has multiple outcomes, including: a written thesis and other publications, over sixty original artworks, four curated exhibitions, one solo exhibition of my work (2019), and participation in six group exhibitions in the UK and internationally. I have presented and exhibited at conferences and public events, including Being Human festival (2018), Women's Environmental Network's Environmenstrual Festival (2019) hosted by Amnesty UK. My project has enabled me to discuss menstrual stigma with people of all genders and ages from primary school to retirement. I am proud that my project gave me the tools to lobby my students' union to campaign for the university to provide free menstrual products on campus. The campaign was taken up and led to the introduction of free products in 2018.





# The Weight of Expectation: how stigma gets under the skin and is bad for our health

#### Oli Williams (Kings College London)

The Weight of Expectation: how stigma gets under the skin and is bad for our health.

Oli Williams' doctoral research joins the dots between inequality, health, and everyday life. It demonstrates how the 'war on obesity' promotes stigma. Oli's aim was to understand how this stigma impacted people living in one of the most deprived areas in England. This involved observing local weight-loss groups, and combining local people's day-to-day experiences of weight-management with biomedical and social research.

The findings highlight how ineffective weight-based stigma is at preventing weightgain or promoting weight-loss. Instead this stigma detrimentally impacts people's health and discriminates against poorer sections of society. Oli collaborated with illustrator Jade Sarson to turn these findings into an evidence-based comic: *The Weight of Expectation*. Artwork from the comic was exhibited nationally, including a joint exhibition with photographer Abbie Trayler-Smith.

The comic is having international impact. It is used in health services and medical education around the world to support current healthcare professionals improve standards of care and to teach the next generation about the detrimental impacts of weight-based stigma. Because of this the British Science Association selected Oli to deliver the Margaret Mead Award Lecture for Social Sciences at the British Science Festival.

This work also supported a petition calling on Cancer Research UK (CRUK) to stop running stigmatising obesity campaigns. The petition received public support, extensive media coverage and led to constructive dialogue with CRUK. Oli was subsequently selected to contribute to the All-Party Parliamentary Group on Obesity, and was the only early-career researcher invited to speak at the parliamentary conference 'How to Beat Obesity Stigma?'



# Fragile Faces: Disfigurement in Britain and its Colonies (1600–1850)

#### Emily Cock (Cardiff University)

My research employs an interdisciplinary medical humanities approach to uncover the experiences and representations of individuals living with facial difference in Britain, America and Australia, c.1600–1800. Oliver Cromwell might have wanted to be painted 'warts and all', but how did facial appearance really affect how people were treated? My work engages with the UK charity Changing Faces' call for 'face equality'—the recognition of disfigurement as merely one manifestation of human difference. My research on the ethical dimensions of the histories of medicine and disability also informs my teaching—challenging students to think empathetically about others, regardless of time, identity or word-view—which empowers these students as future researchers, community leaders and activists, and practitioners across diverse fields.

With Patricia Skinner I edited Approaching Facial Difference: Past and Present (Bloomsbury, 2018): the first book to bring together scholars and practitioners of facial difference from a range of disciplines. The book has been well received by historians and medical practitioners, indicating potential impact on understandings of facial difference, discrimination, and medical practice. My monograph, *Rhinoplasty and the Nose in Early Modern British Medicine and Culture* (Manchester University Press, 2019) not only enriches understanding of early modern surgical practice and representation, but also historicises contemporary critiques of embodiment, plastic surgery, medicine and publishing, and related fields. The book clearly demonstrates the necessity of an interdisciplinary methodology for historical medicine, as paying attention to poetry alongside the medical treatises allowed me to illuminate underappreciated cultural and social influences on medical practice.



# Worli Koliwada: My Neighbourhood, my responsibility (WK:MNMR)

#### Selina Busby (Central School of Speech and Drama)

The Women of Worli Koliwada: My Neighbourhood, My Responsibility is an international interdisciplinary project bringing together a research team and participants from the UK and India. Beginning in 2005 in Dharavi, the largest slum in India and now in its 15<sup>th</sup> year, the project demonstrates the value of arts and humanities research in providing new evidence on the health and wellbeing of Dalit women in Worli Koliwada, in Mumbai. The Dalit is the lowest caste in India; women are the lowest members of that caste. Applied theatre is used in the research to examine community needs and health issues created by lack of space, sanitation, and waste disposal and to propose sustainable solutions. Our participants include researchers from the community, arts practitioners, social workers, and NGOs.

With local grassroots NGOs, the women explore and address their specific needs and work with the research team to develop possible solutions relating to their health and wellbeing. The research findings are recreated as pieces of theatre performed publicly by the women, enabling them to advocate for better living conditions. The project has highlighted the value of transferable arts methodologies to Indian NGOs, community stakeholders, and policy makers.

Involving the women directly in artistic collaboration combats the isolation they experience and develops their concentration skills, communication, and teamwork, thus enhancing their quality of life. The work has significant impact on the mental and physical health, and wellbeing of the women, who consistently report positive changes in these respects.



> Cinema, Memory and Wellbeing: promoting the wellbeing benefits of film-related reminiscence for marginalised over-65s and those living with dementia in Brazil and the UK

#### Professor Lisa Shaw (Liverpool University)

The aim of this research (Cinema, Memory and Wellbeing: promoting the wellbeing benefits of film-related reminiscence for marginalised over-65s and those living with dementia in Brazil and the UK) was to evaluate the effectiveness of short clips of feature films from the 1950–60s in improving the emotional wellbeing of the growing population of older adults and those living with dementia in Brazil by prompting shared reminiscences. A further aim was to study how the resilience, effectiveness and skills set of carers could be improved by strengthening their relationships with those they care for via these film-centred reminiscence activities.

The main outcomes were the creation of a Portuguese-language 'Cinema, Memory and Wellbeing' Toolkit and training sessions for carers, based on the research conclusions, and the book Music, Movies and Memory: Tools for Wellbeing in Later Life, co-edited by Professor Shaw (Emerald, 2020), aimed at academics and carers. The research and its practical application have led to significant changes in working practices, with the methodology being promoted by Petrópolis city council (Rio de Janeiro state) and adopted in the city by the Fazenda Inglesa GP practice and the São João de Deus residential home – a centre of excellence for dementia care. Via a partnership with the Museum of Image and Sound (MIS), Campinas, the research methodology has been adopted by professional and unpaid carers in the state of São Paulo. In response to the additional urgent wellbeing challenges posed by the Covid-19 lockdown in Brazil, extensive online resources have been created, featuring weekly posts of short clips of varied films and opportunities to share the memories they trigger virtually and participate in Zoom group reminiscence sessions.



> What's at stake in the fake? Indian pharmaceuticals, African markets and global health' and 'Biotrash: The economic afterlives of medical garbage'

#### Sarah Hodges (Warwick University)

Sarah Hodges' research investigates how health policy impacts individual well-being across the global south – in particular, how policies designed to protect the health of the public often fail. Through her decades-long on-the-ground research, Hodges connects with people at the margins of health policy design and shines a light into the liminal spaces they inhabit. She shows how health policy, despite best intentions, often falls short of reaching its public.

With her work on Biotrash – the economic afterlives of medical waste – Hodges literally walked from hospital compounds to scrap yards and back again. This research exposed the practical effects of twenty-first century laws designed to protect communities from the potential infective risks of used, discarded medical waste. She found that current regulations fail to take into account the lived reality of waste on the ground. Namely, the role of urban scavengers who recover and reprocess much of global south cities' medical waste.

Today, Hodges studies the risks that the pharmaceutical global supply chain poses to far-flung communities. Along with her research team based in India and Africa, she examines how international drug safety mechanisms ignore the complex journeys that medicines undertake between leaving factory floors and finding ordinary consumers. Her team's on-going research also points to how drug safety consumer education campaigns themselves may have left some of the most vulnerable even more at risk.

By using the tools of the medical humanities to highlight hidden challenges that policymakers often face, Hodges joins them in the quest to improve global health.



## Performing Arab Cancer

#### Abir Hamdar (University of Durham)

In Arab culture, cancer is quite literally a disease without a name. It is commonly and euphemistically referred to as "that disease". Accordingly, the history of Arab cancer is often the history of a silence - of shame, taboo, and prohibition - and this silence particularly affects women. This project gives voice to Arab women's experiences of the disease through arts-based research. Based on extensive qualitative fieldwork (in the form of personal interviews) conducted with female cancer patients from the Arab world, the project deploys creative, performative, visual and critical practice to generate a 'living archive' of Arab female cancer stories and testimonies. In the period from 2017 to the present, I wrote, produced and curated a series of arts outputs - including two ethnodramas, a short film and a video installation - in collaboration with international artists, healthcare practitioners and cancer NGOs to highlight women's subjective experience with the disease. This ongoing arts-based research has begun the task of breaking the social taboo around cancer, creating new insights for understanding Arab patients' experience of cancer and influencing how doctors evaluate patient narratives of this disease.



### Polio across the Iron Curtain

#### Dora Vargha (Exeter University)

My research on the Cold War politics of polio epidemics in the 1950s has explored a crucial moment in global health history from an Eastern European perspective, entwining an analysis of international organizations, state socialist governments, the medical profession, and parents and children in an epidemic that did not respect geopolitical divisions. My book, Polio Across the Iron Curtain (Cambridge University Press, 2018, winner of the 2019 EAHMH Book Prize) has allowed me to investigate the manifold politics of vaccine development, use and failure; treatment regimens and postwar disability; and scientific collaboration and mistrust. This research led me to think more about what the history of epidemics can contribute to understanding and informing current policies in epidemic management. I particularly got interested in epidemic temporalities and started developing a conceptual framework on After the End of Disease. This work, in turn, led to several publications, among them cowritten articles in The Lancet and the Boston Review, and a policy workshop at the Wellcome Trust in 2019 co-organized with colleagues from Oxford and the University of Edinburgh, where we began developing guideline suggestions for international organisations in epidemic management, based on expertise in medical humanities and social sciences. In 2020, I contributed with my research on the history of polio and global health to the work of the World Health Organization's Western Pacific Office, as a member of the Foresight Thinktank on the History of Pandemics. Our report, titled History as a Partner in Public Health will be published this Autumn.



### Lauren Kassell

#### University of Cambridge

Lauren Kassell's research combines careful attention to archival evidence, while asking broad historical questions about medicine, magic, sex and generation.

Over the past decade, she directed the Casebooks Project, which produced a pioneering digital edition of thousands of medical records from the years around 1600, together with ancillary materials, including work with artists and a video game. She also took a leading role in a collaborative project on the history of reproduction that culminated in the field-defining volume, Reproduction: Antiquity to the Present Day (2018), edited with Nick Hopwood and Rebecca Flemming.

She has helped to establish Cambridge as an international centre for teaching and research in the history of medicine. She has mentored, with a style that is inspirational and inclusive, dozens of early career scholars. She has led crossdisciplinary innovations in teaching, including, with colleagues from Sociology and Social Anthropology, the establishment of a new MPhil in Health, Medicine and Society that attracts students from across the globe. Her work has been supported by numerous grants, totalling more than £4 million, from the Wellcome Trust.

She is developing a multi-volume history of medicine that will take stock of what the field has achieved over the past century, and establish new agendas for future generations.

Throughout her career, she has brought people together to question what health and medicine mean, to interrogate evidence about difficult topics with rigour and imagination, and to demonstrate that critical, historical analysis is as much about the present as it is about the past.



### **James Mills**

#### Strathclyde University

In 2011 Professor Yong-an Zhang of Shanghai University and I sat next to one another at a conference dinner. Having never met before, we found that we had plenty in common; research into global drugs histories; expertise in Asian contexts; growing Masters programmes; spicy chicken from the menu. As our conversation flowed, we arrived at the same question: why had we not met before?

The answer was that there were few points of contact between those working in the Medical Humanities in China and those in the UK. Since 2011 I have lead the response to this as Principal Investigator on multiple projects and programmes that have grown collaborative research, training and teaching environments in the Medical Humanities between the UK and China. Key highlights include:

### Shared Futures: Co-developing Medical Humanities in China and the UK (MHCUK), 2019–2022

Partners are Fudan University, Shanghai University, the Shanghai Academy of Social Sciences (SASS) and Manchester University. The Wellcome Trust and the partners invested £1.3 million to enable Chinese postgraduates to study in the UK and postdoctoral Fellows to work in China.

### The Asian Cocaine Crisis: Pharmaceuticals, consumers and control in Asia, c. 1900–1945, 2016–2022

A Wellcome Trust funded (£1.1 million) research project that examines the origins and outcomes of the cocaine market in Asia early in the twentieth-century. Team members have researched in China, Germany, India, Korea, Myanmar, the Netherlands, the UK, and the USA.

#### AHRC Research Networking Scheme - International Award, 2012–2015

Title, International Health Organizations (IHOs): The history for the future network



## Nicola Shaughnessy

#### University of Kent

My leadership of an interdisciplinary programme of research projects, associated public engagement activities and postgraduate training, aims to demonstrate the value of arts and science collaboration, developing new approaches that enrich understanding of neuro-differences and mental health. Complementing this is a commitment to participatory community research and leadership.

I've led three AHRC-funded projects to enhance understanding of autism through creative research methods and psychological sciences. Imagining Autism developed novel methods for working with autistic children in special schools and new approaches to evaluation. Follow-on funding supported training and resources for teachers, health professionals, families and carers. These have been developed into online resources and are being used in special schools by teachers trained in Imagining Autism. Playing A/Part contributes new knowledge about autism and gender through creative clubs and practice research in schools. The project has a steering group of autistic women, autistic researchers and practitioners. As well as producing books, edited collections and journal articles on applied theatre and health, outputs include a film documentary and a range of media features.

Dissemination of this work has also involved leadership of a research centre and three international conferences in three years. I am co-founder and editor of Methuen's international Performance and Science series. This has produced pioneering volumes on Performance, Psychology and Medicine.

Having supervised PhD students drawing on personal experience in projects on autism, dyslexia, and psychic distress, I developed new approaches to training for neurodivergent postgraduate researchers. This is offered as evidence of participatory leadership making a difference.



### Victoria Bates

#### University of Bristol

Dr Victoria Bates is Senior Lecturer in Modern History at the University of Bristol. Her expansive research expertise ranges from nineteenth-century forensic medicine to current-day sensory studies. Victoria has recently focused on developing new types of impactful interdisciplinarity, through partnerships between medical humanities researchers and professionals in creative and design industries. Her Future Leaders Fellowship, 'Sensing Spaces of Healthcare' (UKRI, 2020–24/27), brings together history, medical humanities, spatial/sensory studies and design for the first time. A key part of this project is a collaboration with Fresh Arts (Southmead Hospital) and GOSH Arts (Great Ormond Street Hospital) to develop and install a sensory prototype that will improve the hospital environment for all those who use it. This Fellowship builds on Victoria's previous work as lead of a multidisciplinary project on nature, wellbeing and the non-visual senses (2018, AHRC). The project involved developing novel research methods through an '<u>immersive experience</u>' using olfactory and acoustic technologies. Victoria is also dedicated to building inclusive research communities. She is the co-founder/lead of two networks: 'Senses in Modern Health/care Environments', and 'MedEnv: Intersections in Medical and Environmental Humanities' (Wellcome Trust, 2019–22). These international and interdisciplinary networks bring together creative partners, professional stakeholders and early career researchers. Victoria also leads a number of medical humanities initiatives at a more local level. For example, as part of her commitment to supporting postgraduate and early career scholars in the field, she runs a 'Regional Medical Humanities' network and training programme across the South West and Wales.



## **Prof David Turner**

#### Swansea University

Professor David Turner is an internationally renowned historian of disability whose research has played a leading role in the development of this subfield of Medical Humanities.

In Disability and Industrial Society: a Comparative Cultural History of British Coalfields 1780–1948 (Wellcome Trust, 2011–16), Turner's team of researchers have changed our understanding of the Industrial Revolution by putting the marginalised voices of disabled people at the centre of the story. The research reveals the hidden histories of men, women and children disabled and working in, or servicing, the coal industry. It examines medical, welfare and community responses to disability in the coalfields and has challenged the notion that disability inevitably led to the end of a person's working life by showing that the occupationally-diverse nature of the coal industry allowed employment opportunities for those left impaired by accidents.

The research has enhanced public understanding through the exhibition, *From Pithead to Sickbed and Beyond: the Buried History of Disability in the Coal Industry before the NHS*, in collaboration with Swansea's National Waterfront Museum. In highlighting an aspect of the Welsh industrial past previously ignored in museum interpretations, the exhibition extended the range and improved the quality of evidence for an important aspect of the region's history and identity, and enhanced the inclusivity of the Museum's presentation of industrial history.

The research has raised awareness of resources for disability history in archives and has also empowered disabled people and organisations to undertake their own research projects drawing on the expertise of Swansea's research team.



### ECZEMA!

#### Maria Fusco (Dundee University)

*ECZEMA!*, written and directed by Maria Fusco, explores the life of eczema, a chronic skin condition affecting an estimated 15 million people in the UK, including the writer herself.

There is limited public awareness of the existence of eczema in adults or its often drastic effects on the individual: this work makes a distinctive cultural space for the condition creating new insights into what it is like to live in someone else's skin.

Fusco collaborated with Professor Sinead Langan, London School of Hygiene & Tropical Medicine; Centre of Evidence Based Dermatology at University of Nottingham; The Eczema Society and NHS Wales to reach out to adult sufferers, facilitating creative writing workshops, directly giving voice to sufferers for the first time. Each iteration of the performance is enhanced by words from these workshops their testimony is woven into the performance text.

Fusco's 30-minute black comedy powerfully embodies what it is to live in cooccupation and incessant dialogue with the disease. One voice, representing eczema sufferers, is in desperate dialogue with the might of huge pipe organ, representing the eczema itself, for skin is the largest organ in the body. *ECZEMA!* is set to a specially composed score made from Fusco's motion-captured scratching.

The work was commissioned by National Theatre Wales to celebrate 70 years of the NHS. It premiered at BBC Symphony Hall, Cardiff (July 2018) touring to South London Gallery (June 2019) and is available as a vinyl record produced by internationally renowned Accidental Records.



### **Maternal Journal**

www.maternaljournal.org @maternaljrnl

#### Laura Godfrey-Isaacs & Samantha McGowan

Maternal Journal is a growing community movement that uses creative journaling to explore thoughts, feelings, and experiences through pregnancy, birth, and beyond. Journaling is known for its positive effect on mental health and helps to process and better understand the emotions and expectations around birth and parenting.

Set up in 2017 by two mothers, with experience in midwifery, the arts, and communication, Maternal Journal supports people to establish their own creative journaling practice that fits in with their everyday life, using simple tools and techniques in collaboration with visual artists, poets, writers, and performers.

Maternal Journal works for people journaling by themselves or in a group. The website provides free journaling resources as well as advice and guidance and there are regular posts on social media to inspire creativity and connection.

The project is inspired by the feminist tradition of journaling and its powerful potential to address the changes, challenges, and joys of birth, mothering, and being a parent, and encourages stories of motherhood and birth in all its forms.

From the first workshops and small beginnings, there are now more than 50 journaling groups around the world and a lively online community, with around 20,000 visits to the website every year. During the pandemic, the movement has exploded with groups setting up on Zoom and sharing ideas and images through social media, which has helped to bridge the gap in missing maternal community groups and services.



### **Ergo Sum**

#### Dr Ellie Chadwick

Ergo Sum is a cutting-edge community-led project which uses technologies and performance to explore issues surrounding mental and neurological health. Created/ led by Dr Ellie Chadwick, this innovative interdisciplinary work facilitates exciting collaboration between artists, academics (across multiple disciplines), medics, support groups and patients. The project has had multiple activities in London, Coventry and the South West, with ongoing wider engagement planned for 2020–21.

Through working closely with charities and community groups, theatre company Sleight of Hand have created a unique multi-sensory experience that puts audience members "inside the heads" of characters experiencing conditions such as schizophrenia, anxiety, depersonalisation, post-traumatic stress disorder, and autistic sensory overload. The work combines live theatre performance with projection mapping, binaural ("3D") sound and haptic technology in order to fully immerse audiences in these experiences and engage them with the topic of mental and neurological health.

This unique work thus generates new embodied understanding and, through community-led approaches, most importantly puts patients' experiences at the centre of the work. At a time when mental health is the second largest source of burden of disease in England, with numbers of people accessing treatment steadily increasing, and further strain put upon mental healthcare due to the pandemic, this is a timely and important project aimed at reducing stigma, aiding understanding, and encouraging empathy. Find out more about the project here -

<u>https://www.sleightofhandtheatre.co.uk/ergo-sum</u> - and view our image gallery here -<u>https://www.sleightofhandtheatre.co.uk/gallery-ergo-sum.</u>



# Change Minds, archives for mental health

#### Laura Drysdale (Restoration Trust)

Since 2015 The Restoration Trust has partnered Norfolk Record Office and local mental health providers to run Change Minds, an archives and mental health programme. A new Change Minds project, Dr Hills' Casebook, is now underway.

Change Minds engages people with mental health challenges in a transformative co-created archival adventure. Over 15 three-hour sessions, a facilitated group of around 10 people investigate case records of patients in local 19th C. asylums. Everyone choses a patient and learns research skills as they investigate their life story. They use this research as the basis for creative writing, art and theatre, leading to a shared public event.

Communications, exhibitions, performances and publications extend Change Minds' reach and normalise conversations about mental illness then and now.

Credible research into outcomes for people is integral to Change Minds. Our question is: Does a creative exploration of history and identity through archives achieve sustained, measurable health and wellbeing outcomes for people with mental health conditions?' Mixed methods research led by Dr Scaife, a social psychologist at UEA found that people's wellbeing improved, including longer term.

No comparable research has taken place in the archives sector so Change Minds generated great interest. Norfolk Record Office now host a national Archives and Wellbeing Network that is seeking funding for programmes in England, Scotland and Ireland using a hybrid remote/outdoor model evolved in response to Covid-19. UEA is trialling a version of Change Minds for student wellbeing and Bethlem Museum of the Mind piloted Change Minds Online during lockdown.



### SHORTLIST 2020

# 2020 Medical Humanities Awards



Arts and Humanities Research Council

