ART/DATA/HEALTH

data as creative material for health and wellbeing

Arts & Humanities Research Council | UK Research and Innovation

Monday 16 December 2019

University of Brighton, Grand Parade, M2

info@artdatahealth.org.uk

University of Brighton

Welcome

We hope that today's event will be the start of productive conversations and future research encounters. The **ART/DATA/HEALTH symposium** is an opportunity for the project advisory board and other expert thinkers to get together and explore some key themes around art, data and health. The day is split into five sections: presentations about the project; talks about datafication, design and social justice; talks about digital technologies and tackling health inequalities; a panel on the ethical issues and the implications of data in the mediation of science and health; and talks about arts and health.

To accommodate discussion, instead of following the usual academic conference and workshop room layout we will adopt the **fishbowl conversation** format during the day, and the meeting room will be laid out accordingly. This means that there will be opportunities for those in our network of experts who are not in the speaker programme to join the discussion if they wish to.
We look forward to hearing your thoughts!
During the event we would like to hear from you about what you think are the most important research questions to investigate relating to health data, community engagement and creativity. It would be great to hear **your views on:**

- the role of arts in understanding data for health and wellbeing
- creating positive impact for communities with data.

What are some key questions that the project, or follow up projects, should explore from your perspective?
What might be the most important outcomes?

We would like to have your input around these issues at the Symposium, either during your talk (if you are a speaker/chair) and/or during the discussion, and lunchtime networking.

If you don't find an opportunity during the day, there is also the option of sharing your views by email, either by writing a brief paragraph or by adding your views and comments to the table of initial starting-point questions at the end of this email. It would also be helpful to hear from you if you think there is new research that already tackles some of the same issues in an innovative way. Please return your email to info@artdatahealth.org

What is the project about

The academic research project **ART/DATA/HEALTH** creates an innovative and interdisciplinary process that offers new tools, at the intersections of data science with art practice, to approach two key issues in healthy aging and prevention: digital skills and health literacy.

The project uses health data as the source of experiential stories and as the source material for creative expression. Data-based art can help raise awareness about the ethical, social and cultural issues of personalised medicine, but is however still missing from public health, community-based initiatives. Data representations can help stakeholders comprehend large amounts of data and identify patterns. In a series of exploratory workshops, a community of artists, academics and people living in Brighton and Hove will use a combination of creative media, storytelling and data analytics to explore evidence around health. They will co-produce creative work that takes various forms using both anonymised personal and open statistical health data.

The project is supported by a UK Research Innovation/Arts and Humanities Research Council Leadership Fellowship Grant (2019-2021).
Principal Investigator: Dr Aristea Fotopoulou
Key partners: Brighton Fringe Festival, Brighton Digital Festival, Brighton and Hove Council Public Health, NHS Clinical Commissioning group, OASIS, RISE, Wellsbourne Centre.

Programme

9.30 – 10.00 **Arrival and coffee**

10.00 – 10.15 **Why art, health and data? Project overview**
Aristea Fotopoulou

10-15 – 10.30 **The story so far: project background and approach**
Elodie Marandet and Harriet Barratt

10.30 – 11.45 **Panel 1: Health, design and data justice**
Chair: Alice Fox (School of Art, University of Brighton)

- Catherine D'Ignazio (Urban Science and Planning, MIT)
  Lessons from the *Make the Breast Pump Not Suck Hackathon*
- Lina Dencik (Data Justice Lab, Cardiff)
  Civic participation in a datafied society

- Emmanuel Tsekleves (Imagination, University of Lancaster)
  Health, data and speculative design

11.45 – 12.00 **Coffee**

12.00 – 13.15 **Panel 2: Data technologies, ethics and communication around health and wellbeing: new responsibilities to publics?**
Chair: Bobbie Farsides, Brighton and Sussex Medical School

- Natalie Banner (Understanding patient data project, Wellcome Trust)
  We need to talk about data.
- Sally Wyatt (Digital Cultures, Maastricht University)
  Digital technologies: shifting responsibilities for health communication
- Kate O'Riordan (School of Media, Film and Music, University of Sussex)
  At the intersection of genomic data, genetic technologies and human embryos

13.15 – 14.00 **Lunch**

14.00 – 14.45 **Roundtable: Implications of new and emerging digital and data technologies for health inequalities**
Chair: Gabrielle Samuel (Department of Global Health and Social Medicine, King's College London)

- Neil Singh (Brighton and Sussex Medical School, GP)
  Teleconsultation: the iDoc will see you now
- Flis Henwood (Social Informatics, University of Brighton)
  Digital health inequalities in HIV care: reflections on a participative project
- Polly Irvin (RISE)
  Working with RISE

14.45 – 16.30 **Panel 4: Arts and Health**
Chair: Harriet Barratt, ART/DATA/HEALTH

- Alistair Hill (Public Health, Brighton and Hove Council)
  The art of good health
- Anna Dumitriu (Commissioned artist, ART/DATA/HEALTH)
  Making meaning: exploring bacterial genomics through art to communicate antimicrobial resistance
- Catherine Baxendale (Invisible Flock Collective)
  Hold: an ongoing exploration of how digital art practices can explore issues of physical and emotional isolation through creative uses of technology
- Susie Freeman (Pharmacopeia)
  Turning medical data into visual spectacle

16.30 – 16.45 **Event reflections**
Chair: Aristea Fotopoulou

17.00 **Event ends**

Project team

Aristea Fotopoulou (Principal Investigator) is Principal Lecturer in Media and Communications, University of Brighton. Her academic research focuses on social, cultural and political aspects of digital media and data-driven technologies (e.g. self-tracking, wearables, big data, AI). She has published around information politics, activism and digital culture, intersectionality and queer studies, and more recently on the cultures, practices and politics of data. Her first book "Feminist activism and Digital Networks: Between Empowerment and Vulnerability" (Palgrave/MacMIllan 2017) was welcomed as "required reading in social justice classrooms", and she is currently completing her monograph "Feminist Data Studies: big data, critique and social justice" (SAGE Publications, forthcoming, under contract). She leads ART/DATA/HEALTH, after completing the project "Critical data literacy and creativity for advocacy", a pilot study funded by Rising Stars, University of Brighton.

Harriet Barratt (Researcher) is completing a PhD at the University of Sussex on the role and representation of medical objects in literature, psychoanalysis and material culture, funded by the CHASE/AHRC Doctoral Training Partnership. Harriet has worked in academic publishing for Oxford University Press, communications for the European Commission, public sector bid-writing at the Sector Skills Council for the creative and cultural industries, and arts partnership development for the University of Brighton's College of Arts and Humanities. She is also a regular oral history volunteer and a member of the BSUH NHS Trust's Onward Arts Group.

Elodie Marandet (Researcher) is a qualitative researcher with interests in neoliberalism, subjectivities, governance and social policies. Her work has focused on the restructuring of the welfare state in the UK, including family and welfare-to-work policies, gender and post-compulsory education as well as aid relations and global governance. She has a PhD from Brunel University. Her work has been published in the British Educational Research Journal and Space and Polity, and she recently contributed to a volume of a Springer Major reference Work on the Geographies of Children and Young People. Elodie is a member of the consultancy network Keep Your Shoes Dirty and has worked as a tutor at the Institute of Development Studies.

Bobbie Farsides (Fellowship mentor) is Professor of Clinical and Biomedical Ethics, Brighton and Sussex Medical School; NICE Special Advisory Panel Member; and Board member Human Fertilisation and Embryology Authority Deputy Chair Statutory Licensing Committee (HFEA). She has led public participation projects with funding from the Arts Council England for SICK! Festival 2014 and the Wellcome Trust People's Award for SICK! Festival 2015 (Brighton & Manchester). She has been awarded a University of Brighton Community University Partnership Project (CUPP) in conjunction with the Basement Theatre Brighton to build cross county networks in arts, humanities and medicine.

Speakers

Natalie Banner is the Lead for *Understanding Patient Data (UPD)*, an initiative hosted at Wellcome to make uses of health data more visible, understandable and trustworthy. UPD works with patients, charities and health professionals to champion responsible uses of data, feeding into policy development, creating accessible resources and identifying emerging issues that may affect public confidence in the use of health data. This includes exploring emerging data-driven technologies and how to create the right ethical and governance frameworks for these in healthcare and research. Prior to joining Wellcome, Natalie was a postdoctoral research fellow in philosophy at King's College London.

Catherine Baxendale is a member of *Invisible Flock Collective*. Invisible Flock are an award winning interactive arts studio operating at the intersection of art and technology. We create highly sensory installations and environments that ask audiences to renegotiate their emotional relationship to the natural world. We believe that art today must have a positive impact on society and the world we live in and as artists we have a responsibility to open up collective thinking and to build space for critical enquiry. The medium of technology has always been the best way for us to articulate new questions and generate alternative understandings of complex systems. Drawing directly from the world around us we aim to create art and foster relevant art practices that have a long lasting transformative effect and that sit across multiple contexts and adjacent sectors, allowing us to bring technology and creative thinking to bear in contexts such as education, design, the developing world, urban planning and healthcare. For over ten years we have explored the edges of technology, immersion and storytelling; creating GPS powered AR art games, transforming discarded beach plastic into 3D printed artworks, co-designed work with individuals living with dementia, created large ambisonic public sound installations as well as pioneering digital/physical installations that exist out at sea. In the past 2 years we have developed and showcased work in Finland, Brazil Kazakhstan, Kenya, Nigeria, Indonesia, Qatar, India and in galleries, museums and public spaces all over the UK proof of a global ambition to create art that matters. We are one Arts Council England's National Portfolio Organisations and also regularly work with organisations such as the British Council, the FinnishInstitute, Stockholm Environment Agency, the Wellcome Trust, Jerwood Charitable Foundation as well as multiple academic institutions.

Lina Dencik is a Reader at Cardiff University's School of Journalism, Media and Culture (JOMEC). Her research concerns the interplay between media developments and social and political change, with a particular focus on resistance. In recent years, she has moved into the areas of digital surveillance and the politics of data and she is Co-Founder of the Data Justice Lab. Lina has written several articles and books, most recently, Digital Citizenship in a Datafied Society (with Arne Hintz and Karin Wahl-Jorgensen, Polity Press 2018). Her current project, funded by an ERC Starting Grant, is 'Data Justice: Understanding datafication in relation to social justice' (DATAJUSTICE).

Catherine D'Ignazio is a scholar, artist/designer and hacker mama who focuses on feminist technology, data literacy and civic engagement. She has run women's health hackathons, designed global news recommendation systems, created talking and tweeting water quality sculptures, and led walking data visualizations to envision the future of sea level rise. With Rahul Bhargava, she built the platform Databasic.io, a suite of tools and activities to introduce newcomers to data science. Her forthcoming book from MIT Press, *Data Feminism*, co-authored with Lauren Klein, charts a course for more ethical and empowering data science practices. Her research at the intersection of technology, design & social change has been published in the *Journal of Peer Production*, *the Journal of Community Informatics*, and the proceedings of *Human Factors in Computing Systems (ACM SIGCHI)*. Previously, D'Ignazio was an assistant professor at Emerson College in the Journalism Department. In Jan 2020, D'Ignazio will be an assistant professor of Urban Science and Planning in the Department of Urban Studies and Planning at MIT where where she is starting the Data + Feminism Lab.

Anna Dumitriu is a British artist who works with BioArt, sculpture, installation, and digital media to explore our relationship to infectious diseases, synthetic biology, healthcare and robotics. She has an extensive international exhibition profile including ZKM, Ars Electronica Festival, BOZAR, The 6th Guangzhou Triennial, The Picasso Museum, Philadelphia Science Center, The Museum of Contemporary Art Taipei, LABoral, Art Laboratory Berlin, The History of Science Museum Oxford, Furtherfield London and HeK Basel. She was the 2018 President of the Science and the Arts Section of the British Science Association. Her work is held in public collections including the Science Museum London and Eden Project. She is Artist in Residence on the Modernising Medical Microbiology Project at The University of Oxford and with the National Collection of Type Cultures at Public Health England.

Alice Fox is Deputy Head of The School of Art at the University of Brighton where she founded the pioneering MA Inclusive Arts Practice. In 2003 Alice founded the Rocket Artists' Studios for artists with learning disabilities and their non-disabled collaborators. She has worked for many years with participatory performance and visual arts alongside some of the world's most socially excluded groups, in particular people with learning disabilities. Alice often applies her research whilst training NGOs, museum, health & education workers. Alice is currently delivering inclusive arts projects for Tate Exchange, The National Gallery and The British Council in Taiwan, Singapore, Vietnam, South Korea and Nepal. In recognition of her ground breaking Inclusive Arts work Alice won the Times Higher Education Award 2017 for Excellence and Innovation in the Arts. Alice is also a Trustee for Epic Arts in Cambodia and an advisor for SuperheroMe, Singapore.

Susie Freeman studied textiles Manchester School of Art and the RCA in London where she developed a signature technique of pocket knitting. Trapping tiny objects in a delicate web of filament her fabrics can present hundreds of objects in a single piece or focus on a small selection, making it possible to show similarities, contrasts, histories and developments. She often works with family doctor Liz Lee in the SciArt collaborative Pharmacopoeia, best known for *Cradle to Grave,* commissioned by The British Museum where it remains on display. Recent exhibitions include '*WOWI - What Once Was Imagined*' at the Royal College of GPs in London and a *'Braids' & Ribbons'* jacket selected by Yinka Shonibare for *Criminal Ornamentation* Arts Council Collection touring exhibition: RAMM Exeter, Yorkshire Sculpture Park, Southampton Art Gallery.

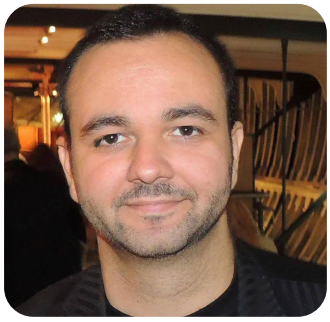
Flis Henwood is Professor of Social Informatics at the University of Brighton. As a social scientist with a background in science and technology studies and medical sociology, her research focuses on understanding the design, development and use of information and communications technologies (ICTs) in everyday work and life settings, with particular emphasis on how such technologies mediate and shape health and social care practices. Examples of past projects include: the development and use of electronic patient records (EPR) in the maternity services; the use of the internet by lay people seeking information about health risks; the use of ICTs to support self-care in the context of 'obesity'; mid-life and older adults' engagements with the discourses of self-care, personal responsibility and choice in the context of the new 'healthy living' imperative; the creation of electronic patient records in primary care and renal care; the information and support needs of people with dementia and their carers; and a longitudinal evaluation of the Alzheimer's Society's 'self-management' programme for people with early stage dementia (2014-2017). Flis's current and recent projects include a 5-year EU-funded EmERGE project on the development and evaluation of a mobile 'phone app for stable HIV patients (2015-2020) and a 3-year Leverhulme-funded project exploring the everyday practices of self-monitoring (2016-2019).

Alistair Hill is the Director of Public Health for Brighton and Hove. He heads up the public health team at Brighton & Hove City Council and leads action to improve the health of residents, working with local communities and partners organisations across the city. His most recent public health annual report, The Art of Good Health, explored the positive impact being involved in the arts and creativity can have on health and wellbeing at all stages of life and is available at http://www.bhconnected.org.uk/content/reports

Kate O'Riordan came to Digital Media through work on the ethical and social aspects of computing in the 1990s. Her work on gender, sexuality and digital culture extended to social issues in web design and development, personal media production, digital imaging in medicine, computer gaming, community, social and activist media. Her more recent work has engaged with issues about other emerging technologies including biotechnology, cloning, genomics and public engagement with science and technology. After working as a visiting lecturer at Brighton and the University of Middlesex in the 1990s she came to the University of Sussex in 2001. At Sussex she worked in both Continuing Education and Media, Film and Music. During this time she also worked at the University of Lancaster through a secondment and held a part post at the University of California, Santa Cruz. She sometimes blogs at Biodigital Lives https://biodigitallives.wordpress.com/.

Gabrielle Samuel is a social scientist whose main interests relate to the ethical and social issues associated with innovative 'big data' biotechnologies in the health and forensics arenas. Her research spans a range of innovative biotechnologies, especially in genomics, including the UK's 100,000 genomes project, direct-to-consumer-genetic testing, and forensic genetic technologies (forensic DNA phenotyping; law enforcement searching of recreational DNA genealogy databases). She has also published in the fields of neurotechnologies (in particular fMRI and deep brain stimulation), umbilical cord blood banking, and synthetic biology. Gabrielle also explores the ethical issues raised by innovative health research methodologies (e.g. social media, big data, AI research). Gabrielle currently has two posts. First, as part of the VISAGE project, and working with Professor Barbara Prainsack, she is exploring the regulatory, ethical and social issues of forensic DNA phenotyping. Second, she holds a Wellcome Trust seed grant, which is exploring the appropriateness of Higher Education Institution ethics frameworks for health research which uses AI.

Neil Singh studied medicine at the University of Cambridge, where he won the Cuthbert Prize in medical humanities. After initially working in hospital medicine as an Academic Trainee, then a Clinical Research Fellow at the University of Cambridge (working on stem cell biology), he realised his interests lay not at the level of molecules, but rather in the study of the health determinants of entire populations. He completed a Masters in Public Health at the American University of Beirut, as an NIH-funded SHARP Scholar. He is now proud to be a primary care physician working locally, with a particular clinical interest in caring for vulnerable groups. Neil is also a writer and his work on health has featured in The Independent, The New Statesman, and Open Democracy.



Dr Emmanuel Tsekleves is a senior Lecturer in design for health at ImaginationLancaster; a design-led research lab that reaches into the impossible and making it possible. Driven by the UN's Sustainable Development Goals, Emmanuel's research focuses on tackling community health challenges across the world. He is currently working on understanding cleaning practices and driving infections from homes in Ghana; developing health and care policies for senior citizens in Malaysia using creative methods; and in promoting seafood across Europe through co-designing new ready-to-eat seafood products and their corresponding packaging with groups of older people. Emmanuel is the convenor of the international Global Health special interest group, which brings together researchers across disciplines in promoting healthier living, focusing on developing countries. He has made more than 80 academic publications, including the Routledge Design for Health book (2017) and the forthcoming Routledge books in Design for People Living with Dementia (2020) and Global Challenge Design (2020). His research has received extensive public attention in print press and online media outlets, reaching more than 15 million readers in the UK and overseas.

Sally Wyatt is Professor of Digital Cultures at Maastricht University in the Netherlands. She originally studied economics (at McGill University in Canada and the University of Sussex in England). She has worked and/or held fellowships in Canada, England, Switzerland and elsewhere in Europe. Her main intellectual affinity is with Science and Technology Studies (STS). For many years, her research has focused on digital technologies, both how they are used by people wishing to inform themselves about health-related issues, and how scholars themselves use digital technologies in the creation of knowledge. Her most recent book, co-authored with Anna Harris and Susan Kelly, is called *CyberGenetics. Health Genetics and New Media* (Routledge, 2016). The book includes poems by Caoilinn Hughes, and speculative fiction by the authors. It was awarded the Foundation for the Sociology of Health and Illness Book Prize in 2017.

Abstracts

Catherine D'Ignazio (Urban Science and Planning, MIT)
Lessons from the *Make the Breast Pump Not Suck Hackathon*

In this talk I will discuss the evolution of the Make the Breast Pump Not Suck Hackathons. Hosted at the MIT Media Lab in 2014 and 2018, these two hackathons shared a name but had an entirely different approach and set of participants. For the 2018 version, we centered equity and community innovation and learned many lessons in the process.

Lina Dencik (Data Justice Lab, Cardiff)
Civic participation in a datafied society

Citizens are increasingly assessed, profiled, categorized and 'scored' according to data assemblages, their future behavior is predicted through data processing, and services are allocated accordingly. In a datafied society, state-citizen relations become quasi-automated and dependent on algorithmic decision-making. This raises significant challenges for democratic processes, active citizenship and public engagement. At the same time, we have seen a (re)emergence of citizen-centered democratic practices, from citizen assemblies to crowdsourced policies, that suggest a recognised need to enhance citizen voice in decision-making. Drawing on the on-going collaborative project 'Towards Democratic Auditing' carried out by the Data Justice Lab, in this talk I will engage with the question of advancing civic participation in a context of rapid technological and social transformation, considering also experiments in new democratic practices to ensure legitimacy, transparency, accountability and intervention in relation to data-driven governance. In so doing, I will outline emerging terrains for developing citizen agency in a datafied society.

Emmanuel Tsekleves (Imagination, University of Lancaster)
Health, Data and Speculative Design

The new era of Internet of Things has the potential to impact health services and be a game-changer for the healthcare industry. In the context of the Internet of Health Things (IoHT), an individual often can be identified by data resulting from such connected devices. Especially when one considers the acceptance of IoHT within the context of the home environment and continuous activity monitoring several more legal, ethical issues arise. This includes the balance between the patient as the owner of data, the documentation and use of the data (Appelboom et al, 2014), patient identification and confidentiality (Mukhopadhyay, 2015), data sharing and management (Pasluosta et al, 2015; Majumder, Mondal & Deen, 2017). Given the fact that data privacy within IoHT is a matter of ongoing vivid legal, social, and ethical debates (Appelboom et al, 2014; Pasluosta et al, 2015) design research and especially speculative design can actively contribute in this area.

Speculative design is an approach that enable us to think about the future prospectively and critically (Sterling, 2009; Dunne and Raby, 2014). The prime objective of speculative design is to force an aspect of the future into the present so that it demands a response. Speculative design creates narratives for these futures in a variety of formats – provocations, prototypes, products, images, films and so on – to express the urgency of change which is required and focus a debate around the action that could be taken (Kirby, 2010). As the adoption of these technologies, within this context, depends on its acceptance in society (Pasluosta et al, 2015), speculative design can be employed as a tool to facilitate and encourage the

drawing out of concerns. It can help raise questions regarding the societal, economical, legal and ethical issues of current and future IoHT. As the ethical discussion cannot not be addressed with a one-fit-all approach, speculative design can in turn assist in fostering debate that leads to the design of IoHT products and services; that are not simply desirable by different stakeholder groups (service users, clinicians, etc.) but are also socio-ethically explored. In the presentation several two studies of speculative designs in the area of health and data (one from the author's research) will be showcased opening a debate in this field.

Natalie Banner (Understanding Patient Data project, Wellcome Trust)
"We need to talk about data"

Data about us is increasingly being collected by all sorts of organisations, for purposes that might not always be clear. Health data is particularly important: collecting and using it can yield insights that could have a profoundly beneficial impact on our health and health services, but at the same time it is uniquely sensitive. This raises pressing social and ethical questions about who gets to use health data, for what purposes, and how people can exert any choice or control over what happens to it. But "data" as a term is pretty dull and the language of data is full of dry, technical and confusing terms, which creates an immediate challenge for anyone wanting to bring these important societal issues to life and explore people's views. In this talk I highlight some of the key reflections from Understanding Patient Data, an initiative set up to support conversations about health data, and consider their implications for the ART/DATA/HEALTH project.

Sally Wyatt (Digital Cultures, Maastricht University)
Digital technologies: shifting responsibilities for health communication

Digital technologies are at the very least contradictory regarding health communication. On the one hand, they offer almost infinite possibilities for people as patients and carers to inform themselves about their health, possible diagnoses and treatments. They can also share their health experiences with others very easily. 'Big data' promises more precise and personalised diagnosis and treatment. On the other hand, digital technologies and the major platform companies (e.g. Facebook, Amazon, Google) threaten the privacy and well-being of people through their massive data collection activities. In addition, for people to make effective use of the opportunities provided, they need a myriad of skills, including 'digital literacy' but also 'health literacy'.

Drawing on examples from research about direct-to-consumer genetic testing and online discussions about mental health, in this presentation I will discuss the changing configuration of skills and literacies needed by individuals, health care professionals, platform companies and governments. How are responsibilities for health-related information and communication between these different actors shifting?

Kate O'Riordan (School of Media, Film and Music, University of Sussex)
At the intersection of genomic data, genetic technologies and human embryos

Genomics generates and is constituted as big data and this is produced, managed and mediated through a range of digital technologies. These range from genome sequencing technologies which drive whole economies, to public health programmes like Genomics England, to direct to consumer kits such as 23andMe or ancestry testing. A new intersection between IVF and genomic data has emerged through the catalyst of genetic editing technologies (CRISPR-Cas9), and their application in embryo work. The presentation engages with questions about responsibility in relation to media publics in this area, and extends this discussion to think about the limits of art – especially bioart – when it comes to genomics, human embryology and IVF.

Neil Singh (Brighton and Sussex Medical School, GP)
Teleconsultation: the iDoc will see you now

How do you want to see me? I'm a GP, and you'll soon have new ways of accessing my care, beyond the traditional face-to-face and telephone consultations. New consultation options, primarily video and text-based, are rapidly becoming commonplace alternatives and are proving to be "disruptive technologies" to our existing healthcare system. They promise a future where seeing your GP is quicker, more convenient, and less costly for the NHS. But is that true? In this talk, I will be assessing the potential for smartphone-based consultations to make NHS care more efficient and to allow doctors to reach underserved populations - including in under-resourced settings, even in times of conflict. But I will also be critically appraising: (a) how such innovations could change the doctor-patient relationship, and (b) the potential repercussions to the healthcare economy. I will focus in particular on the potential impact of such technology on vulnerable populations, and on health inequities.

Flis Henwood (Social Informatics, University of Brighton)
Digital health inequalities in HIV care: Reflections on a participative project

In this presentation, I will explore the theme of 'digital health inequalities' through a focus on a large, multidisciplinary 'research and innovation action' project that has been developing, implementing and evaluating an mHealth platform for HIV care in participation with clinicians and patients/people living with HIV across 5 EU clinical sites between 2015 and 2020 -the EmERGE project.

I will start with some conceptual work- exploring what we might understand by 'digital health inequalities', challenging some assumptions in policy agendas as well as in some sociological thinking. Working at the boundary of sociology of health and illness and science and technology studies, I will argue that whilst we cannot specify digital health inequalities in advance of examining how difference *and disadvantage* are produced in specific sociotechnical configurations of digital health, we can still work with an inequalities 'imagination'. I then illustrate these points with reference to the work of the 'sociotechnical evaluation and co-design' workpackage of the EmERGE project where I will discuss how an inequalities imagination informed our approach to 'participation', a process often thought to help combat inequalities.

I will explore how we approached 'participation' at two levels- i) participation in care (enabled via digitally-supported increased 'self-management') and ii) participation in technology development (facilitated via our co-designed approach). I will reflect on what inequalities were surfaced in and between these levels of participation and how they were addressed.

Alistair Hill (Public Health, Brighton and Hove Council)
The Art of Good Health

Evidence demonstrates the positive impact being involved in the arts and being creative can have on health and wellbeing at all stages of life. The arts can build better emotional health and wellbeing, promote healthy lifestyles, help people manage long term conditions, reduce social isolation, improve communication, have a good death and support the bereaved.

Headline figures show that in Brighton & Hove people are more likely to engage with the arts than elsewhere in the country – but also suggest that there is unequal access and participation affecting neighbourhoods and groups including people with disabilities and carers. If we don't reverse this there is a risk that unequal access to arts and creativity will increase health inequalities.

As part of the Brighton & Hove Cultural Framework, practitioners and professionals from the arts and health & wellbeing sectors are collaborating to achieve our ambition to be a nationally recognised centre of excellence for the arts and culture in improving wellbeing and tackling health inequalities.

Anna Dumitriu (Commissioned artist, ART/DATA/HEALTH)
Making Meaning: Exploring Bacterial Genomics Through Art to Communicate Antimicrobial Resistance

Abstract: Anna Dumitriu will discuss her artworks that explore infectious diseases, antimicrobial resistance and whole genome sequencing technologies through BioArt, digital technologies and sculpture. She will discuss how art can help make meaning for audiences and communicate complex issues in science and healthcare, bringing a personal dimension to abstract ideas. Dumitriu has an extensive track record of working with whole genome sequencing and synthetic biology in collaboration with laboratories around the world including University of California Irvine, Technion in Haifa, the Modernising Medical Microbiology Project at the University of Oxford and the National Collection of Type Cultures at Public Health England (the oldest collection of pathogenic bacteria in the world). She recently presented some of her projects at the Centers for Disease Control's Global AMR Challenge Event during the UN General Assembly in New York and at the Médecins Sans Frontières Conference on Tuberculosis in Eastern Europe and Central Asia in Tashkent (Uzbekistan) where she gained a deeper understanding of the effects of stigma on healthcare practices, a subject she is continuing to explore through ART/DATA/HEALTH.

Catherine Baxendale (Invisible Flock Collective)
Hold: An ongoing exploration of how digital art practices can explore issues of physical and emotional isolation through creative uses of technology.

I would like to use our project Hold as an example of how as artists we are in a unique position to borrow tools from multiple disciplines, to create meaningful collaboration and to explore the frictions and meeting places between the tech and the 'art' of a creative work.

Can we use artistic provocation to build complex and sometimes non-verbal conversations, does technology and the use of data as an artistic medium allow us to find new ways of articulating, communicating and understanding changes to our lived environments, our mental health and our relationships?

Susie Freeman (Pharmacopeia)
Medical Data Into Visual Spectacle

In the 20 years family doctor Liz Lee and I have worked together medical records have moved from the brown envelope to the digital age. However, our working method has remained essentially the same. When a subject has been chosen Liz gathers data and talks to patients, collects health related materials, pills and packets… then our iterative process begins. Our aim is to present a reconfiguration of health data within artworks which enable a viewer to grasp what is often complex information. Success or failure of each piece, whilst there has to be a voracity in relationship to the data, is that the artwork has to seize and hold an audience visually for understanding to occur.

Directions

The symposium takes place in M2 (mezzanine), Grand Parade main building, 58–67 Grand Parade, BN2 0JY.

Travelling to Brighton:

Brighton is just under an hour from London and is on a direct train line from London Gatwick Airport. The city is served by a direct rail link from the Eurostar Service at St Pancras, as well as easily accessible from the major ports of Dover, Portsmouth, Southampton and the local port of Newhaven. National Express coaches also regularly service the city.

Directions:

By foot/train - From Brighton railway station: the entrance to Trafalgar Street is on the right-hand side of the station as you leave and it runs under the station entrance area and down the hill. Follow it to the bottom of the hill and then turn right onto Grand Parade. Cross to the other side of Grand Parade and keep walking towards the sea. The university's Grand Parade building is on the left, opposite Victoria Gardens before you get to the Royal Pavilion.

By bus - The central location of our City campus places it at the heart of the Brighton and Hove bus network and makes it easy to reach the site from any area of the city.

Visit the Brighton and Hove Company website for timetables and more on special ticket deals for students.

By car - City campus is home to the university's arts and humanities. Other facilities on this site include the St Peter's House Library, the Sallis Benney theatre, university gallery and the university's Phoenix nursery. CENTRIM (Centre for Research in Innovation Management) is located in Dorset Place.

Our City campus is in the centre of Brighton. The campus is easily accessible on foot, bike and public transport. Car parking in the area is limited.

From the A23 or A27: Follow signs for the city centre and seafront. As you enter the city, a one-way system will lead you towards the sea via Grand Parade. The university's Grand Parade building is on the left, almost opposite the Royal Pavilion. Due to the site's central location, car parking is extremely limited. There are a number of signposted NCP car parks located nearby.

Stay in touch:
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