

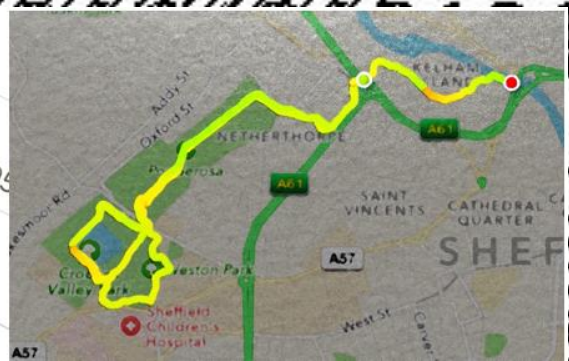
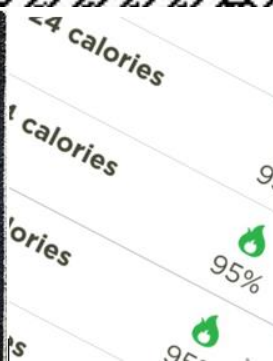
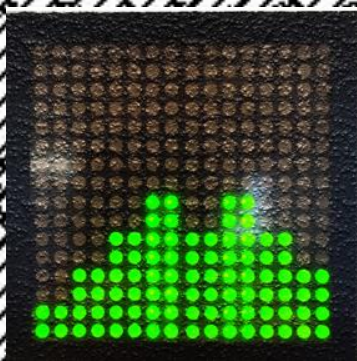


Digital Health/Digital Capitalism

Leeds Beckett University

4th July 2016

Rose Bowl RB 231



Schedule

09:15-09:45 Registration

09:45-10:00 Intro - Chris Till

10:00 - 11:00 PLENARY Nick Fox 'The micropolitical economy of posthuman health'

11:00-11:15 Coffee and snacks

11:15-12:50 4 paper sessions

1. Tamar Sharon - Disruptive innovation in digitally-enabled medical research. Research ethics, privacy and power.
2. David Hill - Autonomy, Automation and Care for the Self: Temporalities of Health in Digital Capitalism.
3. Joseph Savirimuthu - Do Algorithms Dream of "Data" Without Bodies?
4. Christel De Maeyer - Sleeping with Cognitive Capitalism.

12:50-13:50 lunch

13:50-15:05 3 paper sessions

1. Lynne Pettinger, Ewen Speed, Andrew Goffey - Integrated Care and Collaborative Competition: exploring the limits of digital healthcare.
2. Caroline Molloy - In what ways does the drive towards digital health increase the potential for a shift from public to private provision?
3. Federica Lucivero - From knowledge to power? Articulating expectations of patients' empowerment through access to health records.

15:05-15:20 coffee

15:20 – 16:20 PLENARY Graham Scambler 'Digital sociology or sociology of the digital? A case study on health.'

16:20-16:30 Close

16:30-17:30 Drinks

'Sleeping with Cognitive Capitalism'

Christel De Maeyer, Department Graphical Digital Media, Artevelde University College Ghent and Eindhoven University of Technology

Today data is surrounding us almost everywhere. We as users of different applications and devices feed the data machine. We track ourselves with devices and mobile apps, we produce news feeds about ourselves on numerous platforms, we are data, we are content.

As we create detailed digital profiles of ourselves we should think about what is happening with all this data. Is this data exploited, sold to data brokers, advertisers or is it used as research material? Or is it just passive around us?

A whole new economy is rising out of our detailed digital profiles. Not only in the advertisement space, where this data is used to target us even more within our supposed field of interest, but also in our health space and workspace this data can be used for the better or worse. Ethics and privacy are elements that we need to consider more clearly. By considering aspects of ethics and privacy, can we lay a responsibility with the companies who produce and develop these devices and apps? Do we need to think about a new label especially for devices and apps targeted at the domains of health and workplaces that regulates and stipulates the conditions for development and design. A set of criteria to what these devices and apps have to comply? If we want to create trust within this environment for a wider adoption, it might be time to create more transparency in data ownership and the design and development of a new generation of products and services.

The micropolitical economy of posthuman health

Nick J Fox, University of Sheffield

The emergence of digital health and illness technologies (Lupton, 2014), and the digitisation of capitalist economic production (Roche, 2012) reflect the increasing cyborgisation of organic matter within current economic and social relations. However, sociology has tended to displace from attention the non-human materialities that contribute to social production, privileging the human body and its agency over the agentic capacities of both physical things (including technologies) and 'information'. The latter comprises not only 'data', but also ideas, memories, conceptual frameworks, systems of thought and social codes, all of which can have material effects and contribute to production. Such a post-anthropocentric sociology of production and the digital may be helpfully informed theoretically by the 'turn to matter' in new materialist theories and methodologies (Coole and Frost, 2010; Fox and Alldred, 2016).

In this paper I will explore such a new materialist and posthuman approach to 'digital health' and digital capitalism', by micropolitical investigation of what digital technologies actually *do*, within the contexts of contemporary social relations. This enables new insights into the impacts of the digital upon social production. However, it also opens up ways for digital technologies to be used to promote radical and transgressive possibilities, by re-engineering the interactions between technologies and other materialities. I conclude by discussing how the digital might thus be co-opted to establish 'citizen health' – a collective, bottom-up model of health and care that rejects both the marketisation of health and the paternalism of the welfare state.

Autonomy, Automation and Care for the Self: Temporalities of Health in Digital Capitalism

David Hill, Lecturer in Digital Communication and Culture, University of Liverpool

Concepts of dwelling and recollection are central to the moral philosophy of Emmanuel Levinas, for whom sites of self-care are vital for the sort of infinitely demanding responsibility towards others that is central to his account of existence. In this paper I will assess two examples of what might be understood as a kind of outsourced care for the self. First, the development of caring robots in Singapore, designed to keep aging Singaporeans in good health by motivating them to participate in “desirable” forms of exercise and diet. Then, the use of personal fitness and health monitors such as Fitbit, which measure steps walked, calories burned, quality of sleep, and so on. The argument here is that these technologies subjectify the individual further within the temporalities of digital capitalism, incorporating ultimately unhealthy rhythms that turn over sites of dwelling to colonisation by capital. This temporality of digitalisation realises – albeit in revised fashion – Jean-François Lyotard’s warning about the threat of Mr Nice Guy Totalitarianism: be fit or be obsolete. In order to challenge this logic of control, I will argue that we ought to situate a Lyotardian understanding of this process within recent calls for *autonomy over automation* (from eg Franco “Bifo” Berardi, Christian Marazzi, Paul Virilio) so that care for the self is re-established as a mode of sociality rather than as neoliberal entrepreneurship.

From knowledge to power? Articulating expectations of patients' empowerment through access to health records

Federica Lucivero, Marie Curie Fellow, Social Science Health and Medicine Department, King's College London

In his last book, *The patient will see you now*, Eric Topol argues that digital platforms, by enabling citizens and patients to access health-related information, have the potential to invert the power relationship between patients and doctors. Less radically, proponents of patients online access to medical records in NHS England expect that access to tests, GP notes, hospital consultations will bring patients in control of their health and care and produce knowledge and awareness for healthy living choices and prevent disease. In this context, GP surgeries in England are required to enable patients to digitally access a summary of their medical records and full access is expected by 2018. According to the UK Secretary of State for Health, Mr Jeremy Hunt, patients will soon be able to contribute to such records through self-reported information and data collected through apps and wearable sensors.

The democratizing and empowering potential of digital technologies is a core argument for their proponents, but what does “empowerment” exactly mean in these discursive and material practices? What is the relationship between access to information and knowledge and between knowledge and power?

This paper reflects on the meaning of “empowerment” discourses surrounding digital health through the case of digital access to personal health record through. It builds on preliminary findings of an exploratory study conducted in a GP surgery in Northern England, pioneering in enabling patients to access their medical records. The analysis of the interviews shows that practices of access to records go beyond the patient/doctor centric dichotomy. This analysis of lived practices aims to shed light on broader discourses of empowerment through digital health.

In what ways does the drive towards digital health increase the potential for a shift from public to private provision?

Caroline Molloy

The drive towards digital health provision has strong potential to serve a shift away from public provision, in several ways:

1. We are seeing increased collection of data through digital monitoring and self-monitoring of positive and negative health behaviours, and also of health service usage. Both the content of the data, and the act of its collection, have the potential be used to establish a political narrative of 'personalisation', the 'quantified self' and 'co-production' that departs from the traditional 'universal' and 'shared risk' model of health care provision that has been at the root of the NHS (but is compatible with non-universal, co-pay models such as the old – and new – US systems). It potentially also allows the gathering of data for new 'outcomes based' models and investment models.
2. Under the commercial legal framework now governing health administration, state provision of healthcare cannot be automatically maintained if the provision is 'innovative'. Digital health is the prime example of 'innovative' provision being pushed from the top of the NHS – via a wide array of policy, cultural and financial methods.
3. The free market has long found professional ethics to be a block. The provision of healthcare through digital means has considerable potential to cut out the traditional gatekeeper – the GP – and link patients directly to drugs and treatment providers.

Integrated Care and Collaborative Competition: exploring the limits of digital healthcare

Lynne Pettinger, Dept. of Sociology, University of Warwick

Ewen Speed, School of Health & Human Sciences, University of Essex,

Andrew Goffey, School of Cultures, Languages and Area Studies, University of Nottingham

This paper considers the way digital health data is produced and used in the context of massive organisational change and, a political belief in the effectiveness of digital health. Increasing private provision of care services under the umbrella of the NHS raises all kinds of questions about the production and movement of patient health and administrative data: can the data be trusted? What incentive do organisations have to share data effectively when they are both collaborators and competitors? This paper uses a case study of how a ‘frailty service’ for elderly patients was established to explore healthcare in an era of digital technologies.

Whilst the frailty service appeared to be a logical, reasonable and important contribution to improving patient care, actually setting it up involved all kinds of tensions. The promises of software to produce and exchange information about patients were hard to meet in practice. Of particular importance were the tensions around competition versus collaboration, around the (in)ability of software to deliver promises, around ignorance about software (especially of those who have commissioned it), and around the dearth of skilled medical and IT workers to make systems work. Whilst software promises all kinds of solutions, its implementation can be seen as rendering incapable skilled and caring workers, both by making care harder, and by shifting skilled care work from medic to machine. ‘Digital health’ in the context of an under-funded healthcare service is a challenge that changes the nature of care work in digital capitalism.

Do Algorithms Dream of “Data” Without Bodies?

Joseph Savirimuthu, School of Law and Social Justice, University of Liverpool

Personal data is now regarded as a critical component in driving innovation and opportunity in the mobile and customised health economy. The emergence of self-tracking and personalisation of health, well-being and experience is reigniting debates about the new phase of digital enlightenment. Following very much in the steps of Francis Fukuyama, some are predicting that smart technological infrastructures foreshadow the end of law and the emergence of justice in “algorithmic” robes. How do we begin to engage questions regarding the ethical implications of individuals being reimagined through bodies of data within the formal ontology of information systems? Formulating a response to the status quo has meant that lawyers and policymakers will now have to confront an empirical reality: technological innovations promise personalisation and convenience against the background of individuals (seemingly) assenting to the normalisation of the role of sensors and algorithms as conduits for agency. It is these preoccupations that define the principal argument presented in this paper. I draw principally from Phil Agre’s vernacular of “ontology of capture” and “grammar of action” to articulate the significance of algorithmic structures of thought for rules on the protection of personal data. An understanding of the governmentality of the “algorithmic turn” it is argued requires a renewed focus not solely on the health information of bodies but bodies of health information. No account of agency will be complete without consideration of the significance of algorithmic structures of thought for law’s ability to preserve the cluster of values set out in Articles 7 & 8 of the Charter of Fundamental Rights.

Digital sociology or sociology of the digital? A case study on health

Graham Scambler

The advance of what some call the digital age has been recent and rapid. I begin by charting its emergence and defining a family of terms in current but confusing usage. The main theme of the talk is the tension between: (1) the sociology of the digital, and (2) digital sociology. My predilection is for (1). In light of this I position 'digitalisation' within the compass of post-1970s financial capitalism and go on to suggest a series of outstanding quandaries for sociologists. In conclusion I advance and defend a number of hypotheses linking social change, digitalisation and health.

Disruptive innovation in digitally-enabled medical research. Research ethics, privacy and power

Tamar Sharon, Philosophy Department, Maastricht University

Digital technologies like wearables and mobile apps are increasingly seen as powerful new tools in the move towards more personalized and data-driven health and medicine. Not just as the producers of “small data” that individuals can use to manage and optimize their health, but, more recently, as enabling new methods for acquiring and managing data required for biomedical research. This has opened the way for major consumer tech companies, such as Apple, Google and IBM, which have had little interest in health care in the past, to enter the space of medical research. In the terms we have become accustomed to hearing from Silicon Valley, medical research seems “ripe for disruption”. But in fields outside medicine and health, disruptive innovation has often been synonymous, in practice, with bypassing institutional norms and governmental oversight. In light of this it is paramount to think through the ethical issues that this disruption can lead to in the area of medical research. Not just in terms of research ethics and privacy, but also in terms of new power asymmetries that may emerge. This talk draws on literature in critical data studies to analyze the political economy of the new research models and partnerships that are being developed in the context of digitally enabled medical research.

Directions to venue

Car

Leeds has good motorway links to the M1, M62 and M621.

Approaches to Leeds City Centre:

North: A1-58; East: M62 to J29 then M61 to J3; South/South East: M1 to J43 then M621 to J3; West: A65 Kirkstall; North-west: A60 via Headingley

If you are using a Sat Nav please use the postcode [LS1 3HB](#) for directions to the Rose Bowl car park

Rail

Our main City Campus buildings are a 15 minute walk from Leeds City Rail Station or you can get the Bus from outside the station to the Rose Bowl.

Bus

The Leeds City Bus links the bus and rail stations with our City Campus (Portland Way). It runs every few minutes from 06:30 to 19:30 and costs 50p per journey.

Cycling & Walking

Our campuses are connected by advisory, sign posted cycle routes. We have plenty of cycle parking on campus and some buildings have showers and lockers.

Air

Leeds Bradford International Airport is a 20 minute taxi drive from City Campus or the 757 airport bus direct takes 25 minutes and stops on the Headrow and at Leeds Bus Station.

Scan here for Google Maps directions from Leeds train station to Leeds Beckett Rose Bowl:





