Computers, Cyborgs, Webs and… medical sociology?

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These are the notes that I wrote for the plenary. Unusually for me, as I often work from PowerPoint or bullet point notes, I wrote a script. So here it is, a version of my ideas for my talk. What I actually said on the day strayed from this text at points.

I want to begin by thanking the MedSoc committee for inviting me to give this plenary. It is an honour. Truly. It feels like coming home.

I confess that initially I wasn’t sure what to talk about. Empirical research? Methodology? Last year Kathy Charmaz talked about grounded theory and David Armstrong ‘did’ Durkheim and Darwin. And later at this conference Sarah Cunningham-Burley’s plenary is on biomedicine, bodies, identity and diseases.

I settled on this title “Computers, Cyborgs, Webs and… medical sociology?” because in my recent research I have been increasingly pre-occupied with these things. No-one else seems to have nabbed this topic so it seemed a safe place to start. And hey, you all came. So, thank you.

I am based in the Faculty of Health Sciences at Southampton and have the label ‘Professor of Medical Sociology’, but I have spent time over the past five years hanging out with computer scientists at Southampton. They have a cool building and, until Carl May arrived in Southampton, a better coffee machine. Thanks to them, a lot of my reading and thinking has been around ideas and debates that are on the periphery of medical sociology or sometimes not really connected to health and illness at all.

So this is what I plan to discuss. Computers, cyborgs and the Web. The ellipses and the question mark in the title are deliberate. I want to reflect on the possible connections between these things and things in between that might not be listed, and also to take a pause... so that we can try to understand the possible linkages. I want to (re)connect these technologies to medical sociology.

Here goes...

Within our lifetimes we have experienced the technological revolution centred on information and communication technologies.

Digital technologies include computer hardware and software, micro-electronics and global digital communication and data systems. In my working lifetime these technologies have been transformed (does anyone else want to admit that they were proud to have twin floppy drives?)
The words we attach to these things signal their reach and significance:

*Mobile.*
*Ubiquitous.*
*Pervasive.*

Digital technologies have transformed society in much the same way that the steam engine revolutionised the industrial era. Castells has characterised this process as a paradigm shift. In *The Rise of the Network Society* (2010) he argues that a new economy has emerged - which is informational, global and networked. Digital information and communication technologies have been at the heart of this transformation.

*New information technologies, by transforming the processes of information processing, act upon all domains of human activity, and make it possible to establish endless connections between different domains (Castells 2010: 78 emphasis added).*

In this important book, Castells elaborates this claim and explores the impact of this shift on work and organisation. I want to pick up on his theme of work and organisation here. But before I do that I want to remind us that medicine has not escaped this transformational process. (Notwithstanding that it is a field relatively unexplored by Castells himself). Digital information and communication technologies are embedded in the delivery and organisation of medical knowledge and health care. Sometimes we forget they are there.

In the UK, informational transformations mean that your GP records are most likely electronic (even if there is a Lloyd envelope somewhere in the archive), as are most of the records about your formal health care; data from x-rays and diagnostic results are routinely digitally transferred between service providers and professionals, booking systems for secondary care are computerised and online, telemedicine or ‘care at a distance’ and remote telemonitoring of symptoms and behaviours is becoming more commonplace, computer algorithms support clinical and sometimes patient decision making, and there are even a range of NHS ‘endorsed’ health behaviour apps.

Sociology and the parallel disciplinary field of Science and Technology Studies have examined many of these phenomena, including e-Health records (e.g. Haland 2011 Halford et al 2010) and a range of telemedicine and telehealthcare interventions (May et al 2001a MacFarlane et al 2006; Dyb and Halford 2009, Oudshoorn 2011; Roberts et al 2012; Mort et al 2009 Milligan et al 2011) May et al 2001b 2003; Timmons 2003; Heeks 2006; Nicolini 2006).

In one of the most important papers in medical sociology of the past decade Sarah Nettleton (2004) argued that informationalisation had fundamentally altered medicine. She described how evidence based medicine was only really possible with digital archiving and retrieval and the rise of informational bodies and e-Health. Medical knowledge had she argued, escaped: the Dr-Patient relationship was becoming a meeting between experts because of shared access and co-production of information. Moreover, flows of information within networks meant that medicine was also ‘scaped’ - information was diffuse, distributed, and digitally mediated, unrestrained by time or space. This new cosmology of e-scaped medicine, engendered by changes in technologies - the changes Castells also describes - had fundamentally changed medical knowledge and practice.

I want to suggest that we - medical sociologists - must get to grips with the challenges and opportunities of informationalism. I will begin by briefly transporting you back to the 1980s (...I know some of you were there, I have the MedSoc disco photos).
My first empirical study looked at the problem of waiting lists for a district hospital (Pope 1991). Queues of people waiting months and sometimes years for planned surgery. One of the first things I learned was that the digital revolution had happened in the NHS because the waiting list was on a computer. Except that it was also on paper. The list was housed on cards in a wooden cabinet system not unlike the one pictured here.

Digital data processing was the solution to managing waiting. Except that it didn’t work. The medical secretaries and surgeons and others who used the list everyday needed a particular kind of store - one that was accessible, immediate, tactile, visually meaningful. The list was not a neat linear data queue but a living storehouse of goods serving myriad different needs. For me one of the most enduring memories was that the computer printout was stored by the bins - signalling for anyone who came into the office the worth of this digitised data.

This taught me an important lesson - technologies don’t automatically work. They have to be brought into use by people. Computer technology can fail to deliver the intentions of developers and innovators. It can trigger resistance (e.g. the secretaries and carpenters colluded in keeping the cabinet functioning). This means that if we are to understand technologies in healthcare we need to understand socio-technical relations (the relationships between computers and people who use them and the context in which this interaction occurs).

Since I carried out that study computers have become ubiquitous and more powerful. I began work at a time when our SPSS analyses were processed overnight on the mainframe at the Manchester processing centre. Computer technologies got smaller. Processing got faster. Today I have more computing power in this iPhone than they needed to send men to the moon. Computing has become pervasive and mobile.

Alongside these hardware developments a digitised network has evolved. The internet (the network of networks that uses a standard protocol – TCP/IP - to connect computers) began in 1960s. It was commercialised in 1990s, moving out of military, into academe and commerce and into the home, and now, here, to the palm of your hand.

The paradigm shift that Castells describes has computer technology is at its heart. This new informational paradigm is transforming work and the organisation of work - and this is profoundly shaping society. Castells talks about at least two types of worker that emerge from the engagement with information technology. Confusingly he has different ways of describing workers - as core and disposable - and as networkers and flex-timers (and those who are excluded - the jobless, the switched-off, the digitally excluded).

Networkers are the privileged few. They are what Andrew Ross (2003) refers to as ‘no collar’ workers : digitally savvy, highly connected and highly mobile, adaptable, possessing multiple and transferable skills. These are a largely metropolitan elite who live in ‘the space of flows’. Castells has a particularly biting description which may make aspirational types wince:

*There is an increasingly homogenous lifestyle among the information elite that transcends the cultural borders of all societies: the regular use of SPA installations (even when travelling), and the practice of jogging; the mandatory diet of grilled salmon and green salad, with udon and sashimi providing a Japanese functional equivalent; the pale ‘chamois’ wall colour intended to create the cozy atmosphere of inner space; the ubiquitous laptop computer, and Internet access; the combination business suits and sportswear; the unisex dressing style and so on.* (Castells 2010:447)

Below the informational divide are flex-timers. They do flexible work unconstrained by traditional 40 hour week. Nor is it tied to a particular workspace - work can be undertaken on
the move and at home. Contractual rights are forfeited (social benefits, career pathways) and with them notions of employee loyalty to their employer. Work tasks are heavily surveilled and workers are disposable and casualised.

This new division of labour cannot be apprehended by debates about 'the end of work' or deskillng'. It is profound. "This transformation has shaken our institutions, inducing a crisis in the relationship between work and society" (Castells 2010:296)

Call centre work epitomises new ways of working in the informational economy. Castells himself spends some time explaining how finance has become an automated globalised industry built on digital information and communication technologies. But these new forms of work can also be found in healthcare. Computer decision support systems allow the incorporation of clinical expertise (research evidence) in computerised algorithms which can be used to organise and deliver health services from call centres.

Computer based algorithms were initially used to support doctors and nurses – for example the prescribing support tool previously called Prodigy now part of NICE Clinical Knowledge Summaries. Computer decision support systems or CDSS now underpin a new experiment – the use of non-clinical (clerical) workers to manage and prioritise patients seeking urgent an emergency care.

Working with a team of researchers at Southampton we have completed two ethnographic studies of telephone services for prioritising and managing calls (Pope et al 2003, Turnbull et al 2012) . The services we studied use a computerised algorithm - CDSS - in 999 making decisions about whether you really need an emergency ambulance on a blue light or whether you should take a painkiller and wait and see your GP in the morning. And in out of hours and NHS 111, they identify emergency calls and reroute these and direct patients to services, booking out of hours appointments and providing information as required.

These healthcare call handling staff are a relatively cheap labour force. Many of the workers are part time. Many, but not all, are female. In this computerised healthcare work expertise (clinical evidence) is conceived as firmly located in the machine. Human beings are needed simply to press keys and click a mouse - and talk to the caller to get information to populate the algorithm.

Except that - just like the computer waiting list - this technology does not quite work as anticipated. Call handling work entails multitasking: talking through the headset, clicking a mouse, typing text, trying to establish rapport and control the pace of the call to ensure that the right information is obtained. It can be quite intense. We noticed that as the call handlers gained experience and became familiar with the system they were able to anticipate answers. They began to, as they described it, ‘drive the system’, directing probes and translating responses:

*I observed [call-handler] trying to control the call pace. She was reading different options and clicking on them once the questions had been asked. Sometimes she did not read and was anticipating the answer. It was evident that she could not wait to finish she seemed quite impatient. Every time the call-handler was asking a question the patient talked about a new symptom. It was very difficult to triage. Study 1: Call handler observation, Urgent care Site 3*
[the CDSS] also teaches you, because every time you use it, you learn. When you read the information, the next time you come to do that call again you know what to say. You [learn] to say things in different ways ... like, the dreaded, 'have you got a ripping or tearing pain question?' Everyone says, 'yes', to that, so you learn how to say it in different ways. [the CDSS] helps you do that with the supporting information. Study 2: Call handler, Focus group, 111 Site 5

These workers exercise what STS scholars refer to as interpretive flexibility – they deploy discretion and experiential expertise to perform the task at hand in ways that adapt the technology. Over time this lends a clinical aspect to their work - they share team knowledge of symptoms and diseases, drawn on personal experience and learn from the algorithms to deliver the service.

Another striking feature of this work - which you have to remember is located in industrial call centre units, far removed from the patients and callers they work with, is the emotional labour it entails. Nicky James’s insightful observation made in 1992 of the emotional component of nursing work applies here in these personal exchanges mediated by telephone, spatially separated. And echoing James’s work this emotional labour is organisationally invisible and ambivalent: these staff appear to receive less support than their clinical colleagues yet on the face of it they are perhaps less equipped to deal with these situations.

Once I had the case of a 3 year old child who was unresponsive, lying in the arms of his mum. I had to leave the control room and went to cry into the toilet. It was so difficult. I could not deal with it. How could I help in such a difficult situation? … Nothing prepares you for this. Study 1: 999 call handler interview

We have been analysing these data and have begun to argue that call handling in health care is a new form of healthcare work. Call handling in health services is distinct from call handling in banking and insurance. It clearly has many features that resonate with labour process theory, and with Castells’ ideas about flex-workers. This new workforce are low paid, part time and casualised, and their work is indeed subject to surveillance. It also has features which medical sociologists recognise - it is a patient -provider interaction albeit one in which the provider is not a clinician. It displays communication modes we understand from doctor and nurse -patient interactions. And it has this undercurrent of emotional labour. It also has some other interesting, perhaps more novel, features.

This work provides a place for older health workers to ‘end up’ while continuing to use skills acquired in clinical roles - we came across several staff who were former nurses and paramedics looking for fixed shift work , and a less demanding working environment. As well as this age variation, some of the sites we looked at also had an incredibly diverse workforce on other characteristics such as class, employment background, race, education and to an extent gender.

This is a growing workforce: in every site we studied there were plans for expansion. And with this there are tentative steps towards professionalization - we joked at the outset that we might be able to design a diploma course on the back of our ethnographic work and by the end of our study some stakeholders had begun to identify a need for NVQ level qualifications for these call handler staff.

Healthcare call handling clearly disrupts traditional divisions of labour and hierarchies, but it is not solely deskilling and substitution. Yes this work is creating new strata of workers but it also generating new roles for existing staff. In each of the sites, despite the initial techno-
optimism surrounding the computer system, a cadre clinical workers has been employed to augment and support call handling - to provide supervision, training and support for tricky, difficult cases.

These workers are flex-workers in Castells’ terms. They can be understood using his ideas and some concepts from labour process theory and sociology of work. But we also need a medical sociological perspective to fully understand the health aspects of this work.

Thinking about these data some more I have begun playing with the idea of cyborgs. Drawing on Actor Network Theory and Haraway (1991) I started to see the call handlers and the CDSS technology as human-machine configurations - to understand the necessary mutual shaping of the technology and the user. The CDSS and the call handlers appeared to be tightly bound together in a symbiotic relationship.

Jennifer Lapum and colleagues in Ontario have recently written (2012) about cyborgs in nursing, as a way of thinking about how to overcome the traditional opposition between technology and practice. They say: “it is time to take pleasure in the social reality of cyborgs and messy borders” and they call for nurses to acknowledge their cyborg ontology. In essence they seek to reconcile the human-machine.

While Lapum et al’s paper made an interesting point it clearly focused on clinical workers (nurses) not clerical staff. Moreover describing health care call handlers (or nurses) as cyborgs does not quite capture the performativity of this work.

Drawing on other thinking about work as practice (notably Bourdieu and Stephen Turner) I have begun to ask : Is this work in fact a cyborg practice? The machine (the computer decision support system) and the worker/call handler remain distinct and separate entities but in the moment of practice - in the minutes of each call - they combine and take on the cyborg. The call handler cannot function without the CDSS, but neither can the CDSS work without her. This is neither machines taking control or the humans. They are both necessary to the accomplishment of the task of call handling. But once this is done they separate and become discrete actors.

I offer this emergent concept to you to play with (as I will continue to do) and ask could we begin to explore the deployment of information technologies in healthcare using ‘cyborg practice’ to push our empirical and theoretical work further?

Having looked at computers and cyborgs I turn now to the Web.

Just 20 years old, the WWW is a system of interlinked hypertext documents that is enabled by a modest piece of computer code programmed by Tim Berners Lee and Robert Cailliau. HTTP (the Hypertext transfer protocol) - a vague but exciting idea - was initially developed to share data among physicists at CERN and now has an estimated 3.68 billion indexed pages, 600 million websites and some 2 billion users.

To understand the Web it is helpful to borrow from Actor Network Theory. The Web is a temporarily stabilised network (or network or networks). The Web we use today has altered over the past 20 years and is morphing as I speak.

The earliest http allowed us to link and explore a web of documents. These were static web pages. These were flat and fixed. The emergence of the so called Web 2.0 brought dynamic content allowing users to interrogate, adapt and interact with websites notably interactive social media platforms - Facebook, Twitter - that allow users to communicate and collaborate, to create and engage with Web content. The semantic web or Web 3.0 promises to convert this Web from a Web of interactive documents to a Web of Data.
To simplify hugely this requires identifying data entities using uniform resource identifiers (URIs) - these can be used to point to and ultimately connect entities. URIs comprise locators (URLs) and names (URNs) which together define what an item is and where you can find it. The URL for BSA medical Sociology Group can be specified as the path http://www.britsoc.co.uk/medical-sociology.aspx where resource called medical-sociology can be found in a network host whose domain name is britsoc.co.uk. URLs provide a unique string that identifies web resource in ways that potentially allow machine linking of data.

Why does this matter for medical sociology?

The Web is pivotal to e-scape medicine. The linking of documents was essential to the release of medical knowledge from the confines of medical institutions and professions. Imagine the fate of EBM, or systematic reviewing and Cochrane without the searching, retrieval and archiving affordances of the Web. Moreover the features hardwired into the Web - openness and democracy - mean that the digitally literate and enabled patient can create and consume information about health, illness, and care. The loss of medical control so eloquently talked about by Sarah Nettleton, that has empowered expert patients (in positive and negative ways) was powered by the first and second iterations of the Web. The emergence of the interactive Web has enabled new opportunities for patients and carers to connect across place and time. A proliferation of online support groups allow patients link to each other - one to many, and many to many.

This is an area where there is some work in medical sociology but not enough. Clive Seale, Sue Ziebland and Jonathan Charteris-Black (2006) did a comparative keyword analysis of interview data and two support group sites and showed that online conversations play out established gendered linguistic patterns and made some interesting observations about subjective perceptions of the privacy of web forums. Earlier work by Ziebland (2004) used interviews collected for DIPEX (now healthtalkonline) to explore the consequences of easier access to health information and argued that this appeared to engender a “felt imperative to be (or present oneself as) an expert and critical patient, able to question advice and locate effective treatments for oneself.” Anne-Grete Sandaunet (2008) from Tromso suggested similarly that online support groups might not be as empowering and participatory as they appear - certainly not for all patients.

Questions remain that medical sociology could and should explore so that we understand how the Web is changing interactions and health behaviours (and how we in turn are changing the Web).

Take ‘The Body’ a topic that medical sociologists have been interested in (colonising) for some time. The Web provides a space for what Castells calls ‘networked individualism’ in essence platforms for individuals to rework the self and identify. Martyn Hammersley and colleagues have done some early interesting work studying ProAna forums on the Web where people with anorexia discuss strategies for reshaping their physical bodies. I have recently begun supervising a doctoral student - Becki Nash - who is looking at the making and remaking of material and virtual bodies on the Web. She is interested in the ways that Botox and dermal fillers are advertised and purchased online, their use enabled by DIY video guides posted on YouTube, and how these bodily practices are valorised and alternately vilified in Web imagery and atrocity stories of necrotic flesh and augmentation gone wrong. This is scratching the surface.

I am interested in some other properties of the Web. The first is big data: digital data sets so large they require non-standard processing facilities and software, which offer potential for real time analyses and if the semantic Web arrives, machine linked data. Mike Savage and
Roger Burrows (2007; 2009) have alerted us to the vast amount of data generated outside the academy by routine use of digital technologies - ranging from Tesco loyalty cards to utility and government records to scraping of activity data from the Web itself. These data might change what we know about health.

For example open data on prescriptions has been used to generate new analyses of prescription data - here is a recent example of the analysis of generic versus branded statin use. The open data people are excited about this. And I can see why they NHS policy makers might be - it might give them targets for intervention or cuts. But as a sociologist I am interested in what is behind these data - what does this mean and what makes patterns these patterns. Why would some of the poorest areas of the country have prescribing practices that cost more than some of the least deprived? What are the connections between patient help seeking behaviour, professional practices and the pharmaceutical industry and different models of healthcare organisation.

We have recently been doing some work about Twitter. This micro-blogging site which has an estimated 300 million users creating over 200 million Tweets a day is another lovely exemplar of Castells’ network society. Twitter is all about information flows across time and space between distributed and loosely connected individuals. And it’s another source of big data that we might want to harness for medical sociology. To date much research about Twitter can be characterised as ‘Twitterology’ - studies using naive content analysis and natural language programming which have delivered a hundred and one varieties of sentiment analysis. These studies typically collate large numbers of tweets and count keywords - like ‘happy’ - and this ‘analysis’ is used to compare the emotional states of nations and peoples across the globe.

Surely we are more methodologically adept than this?

In collaboration with Ramine Tinati and Les Carr (both of whom have backgrounds in computer science) and Susan Halford (a fellow sociologist) we have been exploring the potential of mixed methods for analysing Twitter data - and moving it from big to wide data (Tinati et al 2014). Ramine has developed software to dynamically model Tweets which can be used to explore the network properties of this part of the Web - looking at initiators and amplifiers , tweets and retweets and at flows of data over time. We are also looking at what happens if you combine this type of technical analysis with interview and documentary analysis. As a small demonstration Ramine ran the software looking at 677 tweets that used the hashtag #saveournhs (see http://www.cost-of-living.net/twitter-analytics-sociology-and-saveournhs/). This shows some interesting phenomena. Some key tweets propagate the network extremely rapidly. A few are part of long retweet chains. Several tweets specifically reference a hyperlink. Significant nodes do not necessarily have large numbers of followers. Some are positioned in the network in ways that suggest they offer what Putnam refers to as bridging capital or “a sociological WD-40” (Putnam 2000:22-3).

Maybe this kind of analysis can inspire some of you to engage with ‘the largest human information construct in history’ and to begin looking at how the Web shapes and is shaped by us and how we might explore the Web in the context of a sociology of health and illness.

When I wrote the abstract for this paper I said I wanted to talk about cybernetics. I think this is worth squeezing in if I can.

Castells is a post-Marxist scholar. Marx remains a key influence running through his work, much of which has latterly focussed on resistance. The other key theorist I mentioned was Haraway who is linked to another locus of resistance - Feminism. Into this mix, I want to add someone that you might not have heard of, Stafford Beer.
Stafford Beer died on August 23rd 2002. He was an operational researcher, regarded as the founder of management cybernetics. He was interested in complex social systems and had the notable distinction of working for 2 years Allende’s ill-fated Chilean government. Beer described cybernetics as an interdisciplinary subject focused (following Norman Weiner) on communication and control that explicitly recognises the connections between humans and machines. Cybernetics is concerned with having a goal and taking action to achieve it or as Beer put it “the science of effective organisation”. I wonder if we can borrow his ideas to inform the way medical sociology thinks about information and action?

Stafford Beer was clear that massive data are useless in themselves. He believed that technologies like computers could be harnessed to help people deliver change, but were not an end in themselves. He looked for models and ways of understanding complexity to intervene to make things better. A lot of his writing resonates with Castell’s more recent work which has focused on networked social movements - Occupy, uprisings in Egypt, Arab Spring as levers for social change.

I have talked about Computers, Cyborgs and the Web. I have suggested that we might want to draw in theorists like Castells and Haraway to help us get to grips with the challenges of informationalism. Castells might be a useful starting point for thinking about the technical transformation of health care work and Haraway - despite her opacity - might make us reconsider cyborgs in this context. I firmly believe that we have to notice the Web. We need to explore the co-construction of health and illness and web technologies and we must harness the potential of the Web for analysis - I demonstrated one possibility that might be used to explore social movements and networks of resistance centred on our own NHS.

But in closing I want to return to Stafford Beer. Presciently, in the context of what I have said about the information economy, network society, flex-workers, cyborgs and the Web he wrote that

\[\text{Science has been sold as the servant of man in the wrong way, and for the wrong reasons. Let us start with the source of wealth: production. Here science is put forward as the promoter of efficiency...But it is necessary to become conscientiously aware of the alienation that all this has induced in the industrial worker so that social scientists are now engaged in frantic attempts to restore some sense of humanity to the working situation in which so many find themselves. \ldots Something has gone wrong. (Stafford Beer 1974:23)}\]

I feel that this is the most important connection in my talk - the connection between medical sociology and political activism. Perhaps the final challenge I can offer - to you, to medical sociology, is to connect the things I have spoken of so that we can act, and fight for the things that we know matter to patients and their families.

Thank you.
REFERENCES


