The Digital Humanity in Health and Care seminar series launched with its first of three events on Tuesday 27th June. The collaboration between mHabitat (Dr Victoria Betton) and the School of Media and Communication (Dr Helen Thornham) explores contemporary dilemmas around ethics, morals and humanity in a digital age. The workshops bring together people across the spectrum of those accessing health and care services, practitioners, policy makers, digital designers, tech organisations and regular people.
The overarching questions threading through the series are these:

- What does digital humanity look like? And what does it look like in relation to health and care and in relation to the axes below of policy, leadership and citizenship?
- Where is digital humanity in health and care? Is it, and could it be in systems? If it is in the human, then is this enough in a changing landscape?
- How can we be digitally humane? What everyday, digital, connective or community actions or reflections can we make or do?

SPEAKERS:

Mark Brown
Mark Brown is development director of Social Spider CIC. He writes and speaks regularly on digital, mental health and other issues. He was one of Nursing Times and Health Service Journal’s social media pioneers 2014. Mark has worked on a number of digital projects, both with mHabitat and with other partners. He has been a contributing author on a number of articles on digital and mental health and regularly speaks on co-production of digital in public sector environments. @Markoneinfour

Dr Christopher Till
Chris Till is a sociologist who researches technologies and health. He is interested in how technologies help to shape our understandings and practices of health and bodies. In particular, he is concerned with the role of corporate and commercial interventions. He is a Senior Lecturer in Sociology at Leeds Beckett University. thisisnotasociology.blog @chrishtill

Dylan Roberts
With more than 28 years’ experience, 16 in CIO and equivalent roles, Dylan Roberts currently holds the position of Chief Digital and Information Officer for the Leeds City Council and the three Leeds CCGs with an external focus on delivering better outcomes for people and the economy of Leeds.

Roberts oversees a range of collaborative change programs at a national, regional and city level. These include the Leeds place based Digital Health and Wellbeing Programme spanning deliverables across the seven Health and Care organisations, the award winning Data Mill North open data platform and Observer Top 50 radicals Urban Sustainable Development Lab.

Dylan sits on the National Information Board and as chair of the Local CIO Council leads local public CIO’s contributions and influence into government policy and strategy. He is placed at No 4 of the 2017 CIO 100 that recognises the most transformative and disruptive CIOs in the UK. Chief Digital and Information Officer, Leeds City Council @DylanRRoberts
At our first workshop, we looked specifically at issues relating to POLICY not only because, as Mark Brown argued, ‘delivering public services is a political act’, but also because policy issues often belatedly and inadequately ask questions about humanity, morality and ethics. Policy, as Paul Maltby (former Director of Data at the Government Digital Service) tells us, is a word that describes the government’s position or approach to a particular issue. It is an orientation as well as a practice; a method as well as a process, and this means – for Maltby anyway – that it is fluid, changeable and potentially really dynamic. In a context of budget and people cuts, and where one of the overarching feelings that has emerged from past workshops is of being done to – not only by systems, and processes, but also technologies and people; what might a policy designed with humanity, morality and ethics look like?

In attempting to explore this though, we were reminded that policy and the digital are not so easy bedfellows as Maltby also reminds us, and in a shifting landscape, when we talk about policy and digital together, we are talking about something that is fluid rather than static. Our questions come from within a changing and complex digital culture – a point made by Dylan Roberts in his talk, when he drew his map of the contemporary frameworks in which local policy decisions were made. For Roberts, thinking about the role of digital technologies and systems within the public sector, contemporary policy focuses on ‘better outcomes’ for citizens: a pragmatic goal within existing systems overlaid with the effects of austerity, competition and outsourcing. Roberts’ map, in which the council sits within a triangle of information, human endeavour and technology, is not so far removed from the image above, detailing the professional policy standards framework that is meant to visualise the far wider and relational context in which any policy decision should be made. What was notable for both visualisations is the way that decisions are set within a complex mesh of systems and processes. Both are riddled with the politics of the market, that are woven into each hexagon in the diagram above, and that are infiltrated with and through digital and human systems. These are the frameworks for health interventions whether we like it or not, and a central issue that emerged from our workshop related to the way the market had a very different understanding of issues of morality, ethics and humanity: one that was far from, if not completely oppositional to, the understandings that were actually needed in (digital) health policy.

At the same time, and as our discussion also clearly evidenced, we live in a world of rapid change – not only (and as is so often claimed) of digital technologies, but also of politics, of social imaginaries, and of policy. This is a world of snap elections and back door bungs, but it is also a world where change happens everyday and policy can be redirected towards a more humane and humanitarian focus at the tip of a hat. It is a world in which policy, as we know it, is being redesigned and rethought everyday and in keeping with the spirit of positive disruption and inclusive of a much wider set of people than ever before. Central policy decisions now include digital as well as policy officials across the UK and we can trace such changes to local communities and organisations as well. We only have to look at our own doorstep and the work that mHabitat does in terms of pulling together a cross sector of practitioners and stakeholders in spaces where positive disruption can be possible. Our workshop for example, included patients and carers, health and care practitioners, academics, digital and tech organisations, SMEs and social enterprises. All of us have an invested and a professional interest in digital humanity: all of us are working to effect change.

If these are the frameworks, then: what are the issues? Below are three main issues that emerged from our workshop discussion. In his talk, Mark Brown detailed how futurists deal in three kinds of futures: probable (continuing the status quo), possible (creative, explorative
and imaginative), and preferable (ideological).

The three points below probably engage in possible futures, but we are working towards making them probable by thinking at a range of scales and approaching the issues in a variety of ways. The first point for example, is about policy and politics. The second is about design. The third is about changing our social imaginary to not be about ‘them’, but about ‘us’. Indeed, some issues we were all in agreement on, were that policy, design and imagining need to go hand in hand, and scalability should not be about small getting big, but about appropriateness and context. The points below are noted with these issues in mind.

1. WE NEED TO CONSIDER WHO DESIGN AND CHANGE IS FOR, AND WHO IT ACTUALLY SERVES.

Many of the services and products we discussed around healthcare interventions are built on a model of efficiency. Efficiency – as both Mark Brown and Dylan Roberts discussed – is in turn understood in relation to speed and cost effectiveness. This premise is built into the design of digital solutions and apps, which are generally organised in relation to the generation of economically valuable data. While there is a clear synergy between the data captured by health apps for example, and the data the health services are interested in for clinical reasons, this synergy creates a financial motivation in terms of the economic and constitutive value of personal data within a wider medical (and metric) system. We might see this as a necessary compromise within increasingly privatised systems, but nevertheless, it creates ‘solutions’ that are designed within financial and data imperatives, rather than those fit to potentially very contextual and local issues.

Consider, for example, the Raspberry Pi hack that was designed in conjunction with Leeds Council and which Dylan Roberts discussed as part of his talk. This is a local and small-scale solution to the isolation older people living on their own can feel. It was designed as a local telecom system for use within a block of apartments: people could opt in or out of a conversation populated by the inhabitants of the apartments. As Roberts detailed, this was a solution built with end users in mind, entirely fit for purpose, cost effective for them and solves a major but highly localised issue. It is also a solution that offers very little financial benefit for the designers: it is minimally scalable, offers little profit and is a solution that the council has not been able to properly prototype because of lack of interest from tech companies.

Roberts discussed this as an example of the perpetual loop the public sector finds itself in, trying to engage in ‘better outcomes’ but within a highly competitive – if not saturated – market, within which the council is supposed to operate on a level playing field seemingly in direct competition with corporations. But this is also a very good example of two things. First what we need to work towards – design for people.

Secondly that the parameters of the market are not those we should be situating decision making within. We need a different economics and we need different parameters of success that are not financial. We already have some good suggestions and models out there, not only in terms of organisations, but also principles.
2. THE TRANSLATION OF RELATIONS TO TRANSACTIONS WITHIN EXISTING SYSTEMS IS A PROBLEM

The framework Roberts described also underpins the wider shift towards digital solutions as potentially cost and time efficient. As Brown argued however, this often stripped away relational engagements, replacing them with a transactional and systems model in which agency and autonomy were taken away from people and located instead in constitutive metrics within systems. This means that the experience and understanding of an exchange between, for example, a health practitioner and a patient had changed. We have replaced human and relational exchanges with a transactional model that is stripping out connection, empathy, communication, agency – and we wonder why stress levels and workplace dissatisfaction have increased.

More than the negative effects of this on morale and wellbeing – a fact that we see in the low numbers of recruitment across the health (and public) sector – is that the aim of a digital solution very often takes the notion of transaction as a default starting point. You want an app that helps with diabetes? Then let’s design one: you input data, we will visualise it for you while we share that data to a corporate organisation to make money from it. Some of these apps are better than others of course, and many try to start from a recognition that diabetes is individual as well as a complex health condition: Long-term illnesses are complex, relational and lived. They are woven with issues around shame, frustration, denial and attempts at agency. None of these related issues can be solved through a transactional approach, yet they are inherent to long term condition. At the same time let’s not forget that the wider narrative around diabetes and other long-term illnesses is framed almost exclusively in financial terms and the cost to the NHS and the taxpayer. These feed one another not least because the market logic that sees diabetes in financial terms is the same market logic underpinning metrics of success in app or tech design. But what if we designed with a relational model in mind?

The first step in doing this is rethinking data: as public, as open and not as proprietary. Ownership and profit go hand in hand. But there are other models out there. Ceri Batchelder who co-runs Connect & Create for example, drew our attention to the ehealth system in Estonia, where health records are open and the system was built from scratch in keeping - not with probable futures in mind, but with preferable ones. In the UK, while we may boast a move towards paperless health records by 2020, this is a small push that does little to upset the fundamental overhaul that is needed in our thinking about data.
3. THE NEED TO LOCATE OURSELVES WITHIN THE SYSTEMS WE DESIGN

These issues bring us onto the third point from the workshop: that very often when we think about systems, we think of them as somehow over there. That the systems we are thinking about are somehow outside us, and that while we may be politically invested in changing them, they do not somehow impact us on a daily basis. Nowhere was this clearer than with Chris Till’s talk, where he drew on the work of Nicholas Christakis to discuss the spread of behaviours, values and ideas. Christakis is a highly influential thinker and Yale Professor who understands social networks as contagious diseases in terms of mapping how ideas spread. As Till discussed the work of Christakis, he offered us two network visualisations of powerful nodes within networks around which were clusters. We are meant to understand such a visualisation as representing the organisational structure of ideas, but what became really clear from not only the talk but also the wider discussion of healthcare, was that such diagrams underpin our conceptualisations that we are not somehow inherently entwined within the systems we discuss. Mark Brown summed this up in the discussion when he reflected that he adopts a position of critical observer – but that this does not always translate into action. It is a familiar refrain and one that is encouraged through organisational mappings, systems thinking and network visualisations. If we stopped thinking about the systems as over there, but instead thought of them as lived everyday – might we be more motivated to change?

Policy also starts from a presumption that the policy makers are not within the systems they are seeking to change. Instead – as the diagram above indicates – their expertise comes from a position of outsider: a policy maker is outside the system and thus able (so the logic goes) to recognise the different frameworks, issues and contexts in which a decision should be made. This is a pseudo-positivist stance, that feeds the idea that policy impacts us, and works against the idea that we actually live and change policy (and idea that both Mark Brown and Paul Maltby are working towards). One of the best ways to tackle this is to extend Mark’s question of what we might actually want to happen, to our own personal experiences: understanding these not as private, but as shared and everyday - and designing on that basis. These issues emerged through our discussion of the ways long term health issues were accompanied not only by feelings of shame, but also of overt hostility.

The experiences recounted during the workshop were about how patients are simultaneously encouraged to see themselves as in control of their own care, whilst they are also expected to be compliant. This happens within wider policy and media discourses that frame long-term health in primarily economic terms as the recent discussions around the proposed ‘dementia tax’ articulate. Framing long-term health conditions in economic terms is a familiar refrain that seems to feed a perpetual cycle of shame and guilt.
These are big and complex issues – and words. But the first step – as Mark Brown was suggesting, and as we began to do, is to ask better questions. The second step is to imagine better experiences. The third is to seek to live better systems.

The wider government approach to policy making is changing. The One team Government Manifesto, drawn up last month talks about the need to have ‘deep regard for citizen experience of a policy or service’, as well as the importance of designing policy that answers ‘citizen or user needs’. There is much hope here then, but this also suggests that perhaps our focus is too narrow: it is not the policies themselves that are problematic: it is our inability to imagine a different future, a different metric of success, and a different framework outside the overwhelming logic of the market.

The policy seminar is one in a series of three in the Digital Humanity in Health and Care series. A collaboration between mHabitat and the School of Media and Communications at the University of Leeds. You can view papers from each of the three seminars as they are published here: http://wearemhabitat.com/open-library/