

DIGITAL HUMANITY IN HEALTH AND CARE

#03 CITIZENS

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The Digital Humanity in Health and Care seminar series held its second event on Tuesday 25th July. 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:



Sue Sibbald

Sue is a Peer Specialist working at Sheffield Health and Social Care NHS Foundation Trust (SHSCFT) with people who have Borderline Personality Disorder or identify with that diagnosis. She also trains staff at the Trust and has spoken on issues such as whether there should be a revolution in Mental Health, digital peer support and patients as partners. [@BPDFFS](#)



Olivia Butterworth

Olivia is Head of Public Participation NHS England. She leads the Patient and Public voice team, which work to promote citizen participation and engagement. [@LiviBF](#)



Chris Birchall

Chris is a Lecturer in Digital Media at the University of Leeds with a background in web, software, database and GIS development. He researches issues around citizenship and systems, using digital methods and exploring the relationship between digital technologies and social change. C.T.Birchall@leeds.ac.uk

At our final workshop, we looked specifically at issues relating to CITIZENSHIP, and we started with the reminder from Sue Sibbald that people use technologies and apps unevenly. Often we use them for a short period of time before moving on to a different app, and we engage with a wide range of platforms, apps and services for a wide range of needs and support. Olivia Butterworth reminded us in her presentation that this approach does not align to many institutionally led approaches to the digital, whereby the digital is approached as an all-encompassing 'one stop' place for patients, citizens or users. In fact, as all our presenters argued, this is not how people use digital resources, and unless we start with this in mind, whatever we design and build will always be inadequate. Sue asked us to also consider whether the digital helps homeless people, or those who use foodbanks – and her provocation was a reminder not only to think about who is left behind in the so-called digital revolution, but also about the way that the design of digital resources can increase inequalities. This has been a common refrain across all the workshops in the series.

At the same time, and as Sue Sibbald discussed, the pressure to move resources online – particularly in the area of mental health – is increasing, as we feel the impacts of huge government cuts in funding. The double edged sword of austerity and the digital go together, but the digital can also hold a great amount of resources for managing (particularly) mental health conditions. Finding one's own systems of support (whether that is mobile games for emotional management, social media for peer support, wearables for health and mood tracking), is often disconnected from NHS services which are seeking to develop holistic support systems, even when such a resource may well be untenable.

Olivia Butterworth argues that digital platforms that endeavour to be all-encompassing are problematic, for the reasons outlined by Sue in terms of how people use digital resources already; they are also problematic because of in house management and governance. This additional layer, which also implicates interaction online is hugely important: institutional attempts to 'open dialogue' with patients are often seen for what it is: lip service to a democratic principle which might actually mask or prevent interaction, or a PR exercise that is fearful of actual feedback. The discussion in relation to this point for example, listed patient participation groups in GP surgeries that had little or no attendance from GPs, online forums for discussion that had no contribution from NHS staff members, and fear of online platforms because of the potential for reputational damage. None of these examples appeared to consider how citizens engage with each other already, or how institutions should or could work with citizens and for what purpose.

If governance and management add an extra layer to Sue's points, so does the build and design of the system – which is where Chris Birchall concentrated in his talk. He argued that systems create exclusions and inequalities by the very nature of being designed for a specific purpose. The human within a system may be a metric, a particular algorithm or data set – but where that human appears and how s/he appears within a system is important. Chris argued that we need alternative systems, not just alternative choices within systems. Existing systems are built on a transactional model, the end user is a service user and the system delivers data or services that are chosen by the user. This model is one increasingly coming under critique when applied to the public sector. Think of, for example, the way that Internet Service Providers (ISP) subcontract out constituent elements of an overall service provision to create mini markets that are supposed to promote efficiency through competition. What this means is that the logics of competition, which may run counter to end-user interests, are inscribed into the systems themselves, creating huge inequalities within the systems themselves as well as for the end users who are positioned by them. And in relation to the end user, the assumption that the end user is somehow empowered because of these systems has been widely critiqued by [researchers](#) and [policy](#) makers. These are complex arguments, but the overall premise was that our existing digital systems within healthcare and beyond, are built to prioritise efficiency, cost and time but what might well be more appropriate are systems built to prioritise reflectivity, dialogue and choice.

Within these contexts of people, institutions and systems, our workshop discussed the future for digital health – which is not, of course, the same as what the NHS is doing in relation to the digital, but encompasses far wider practices.

1. CITIZENS HAVE A ROLE IN THE FUTURE OF DIGITAL HEALTH

To a large extent of course, citizens are already shaping digital healthcare through their existing practices. What was really clear from the many roles Sue Sibbald described – from setting up online chat groups on Twitter, to gaming, to promoting groups and organisations, to supporting peers – was that citizens are already an established online presence. We are already changing and engaging in digital health. This means not only that we need to widen our understanding of what digital health is to include these activities and resources; it also means that we need to validate and support these resources through recognition of them. If new, institutionally driven digital services compete with these resources, not only will they be less successful, they are also seeking to drive digital health through competition, rather than through support.

Often, citizens who create online resources also experience the conditions they are supporting: they have invested time and energy – at personal cost - to creating excellent support online. Validation does not necessarily mean financial support (given the funding cuts across the sector) but does mean that we need to take these voices seriously as expert contributors to policy, system design or services.

2. THE DIGITAL NEEDS TO BE UNDERSTOOD AS AN ALREADY ESTABLISHED PRACTICE AND BEHAVIOUR OF PEOPLE

The digital is an already established presence in people's lives: any new resource has to fit into what people are already doing. If people are using a patchwork approach to digital resources – differentiating between what services offer them at different times, for different needs, then new digital resources need to be built with this in mind. We need a deeper reflection of where a particular NHS service may fit as a digital service into already-existent offerings (not as a catch-all provision), but as filling an identified gap. This would mean that design would have to be in keeping with citizen practices and that products would have to be created with users.

Social media in particular need to be understood as normative spaces – it is part and parcel of our behaviour, identity and practice. In the context of our workshop, we talked about this in a number of ways. Firstly in terms of acknowledging that anger, hostility, complaints or likes were rational and normal responses organisations should expect online. People may use one forum to express anger and another to express support and this means that the content of any one forum should not be taken as representative. If we accept that social media are part and parcel of our everyday lives, then this means that we should not be trying to contain or control conversations on social media in a top down or PR way. Instead, we should engage discursively with social media – just as we might do as practitioners in other settings. Secondly, it means that mobile free zones within health organisations are increasingly problematic, particularly if patients are using a range of digital resources as support. We need to rethink policies around mobile phone use and WiFi provision within organisations. Third, practitioners need to be able to engage in these spaces as expert professionals, who are supported as such by the organisations who they represent. The concerns around reputational damage or limitations around what practitioners are allowed to say online are preventing health organisations to actually engage with patients in ways that are meaningful for patients.

3. WE LIVE IN A NEW WORLD, BUT WE BEHAVE AS IF IT ISN'T NEW

The two points above both point to the fact that we live in a new and different world, but that we are not acknowledging this. The use of digital resources is only going to increase – partly because of legislation within the sector and funding cuts, partly because of increasing digital penetration across the UK, and partly because of behaviour and existing practices. If we don't recognise that the terrain has shifted, we can't adequately plan for the future. More than this though, our decisions around healthcare provision are likely to be reactive rather than forward looking. Acknowledging this is a new world impacts on system build and design, leadership and management, policy and economics and this is a continuing theme across all the workshops within this series. When we think about digital health, we need to think about organisations, systems and people together, just as we need to design services and systems that also prioritise connectivity, dialogue and relationships.

These are big and complex issues – and part of the challenge of the workshop series has been to think about the big and the small together: in order to think of citizenship differently, we need to think about what citizenship is in organisations, systems and for people and practices. Often when we think about this, we discover great examples of citizenship that are occurring despite the constraints of funding cuts, restructuring and changes to policy. If we find good examples within this environment, imagine what could be possible in a different environment – one where the digital was embraced, where systems were built along different models, and where practitioners were recognised as experts and supported to make decisions.