

Patient-held records: putting patients in control through technological change

“ The stages of technologically driven change have been well described: in stage 1, technology empowers the current human players within the current system; in stage 2, it replaces many of the human players within the current system; and in stage 3, it overturns much of the current system and replaces it with something else.¹

One example is that of banking. Historically, when you needed to withdraw money from your bank account, you went to your bank; you got into a queue; you spoke to a clerk who checked that you had sufficient funds and authorised the withdrawal; and you were handed your cash. You could only do this in your country of residence, Monday to Friday between 9 am and 5 pm. The money was yours, yet the bank had the power to determine not only whether you were allowed to withdraw it, but also when and where.

Then came the ATM, or automated teller machine (from bank teller, the US term for a bank clerk). In stage 1, the ATM has empowered customers. In stage 2, the ATM has partly replaced bank tellers. And in stage 3, the ATM has replaced old-style banking, any basic transactions such as withdrawing cash now being possible 24/7 almost anywhere the world. Today, when you need money, you insert your banking card into one of these machines, identify yourself through your PIN, check how much money you have, and decide whether or not to withdraw cash. You are in control from start to finish. If there was historical evidence of the opinions of bank tellers, it wouldn't be surprising to find that they had been opposed to ATMs.

Patient-held records (PHRs) are not dissimilar: they empower patients. In a literature review on pages 118–123 of this issue of the *European Journal of Palliative Care*, Tania Blackmore highlights positive and negative views held by acute clinicians on the use of PHRs for palliative patients. Despite strong evidence that PHRs improve patient outcomes, clinicians express certain concerns. And we're not even at stage 2 or 3 of this technologically driven change, which many, in healthcare, find too threatening to even contemplate – wouldn't it be like turkeys voting for Christmas?

But the number of health- and social care professionals looking after one single patient is growing while budgets are under increasing pressure: the only way forward is to embrace technology and establish 'virtual' multidisciplinary teams supporting patients in real time thanks to an individual digital care plan accessible to all. That care plan could, for example, be created by the GP practice, reviewed by the hospital, updated by the hospice, and used by the ambulance service when called to the patient out-of-hours.

In my opinion there are two ways of driving healthcare change through technology. The first is training professionals; this is a slow and arduous process that resembles snakes and ladders: you spend years climbing up the ladder step by step, and then political change happens and you suddenly slide all the way back down. The second is to go directly to the patients.

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Give them PHRs. Give them direct control and reduce the power of the professionals who currently act as the 'middle men'. Over one and a half billion people manage their own Facebook accounts. Why wouldn't patients be able to manage a 'healthcare account' documenting their stated wishes and preferences?

I believe that the greatest revolution in healthcare will take place if we give all patients digital PHRs. Obstacles such as negative attitudes of professionals will have to be overcome. The question of trust will be key: clinicians will have to be convinced that they can act based on a patient's PHR, without worrying that their decisions could later be challenged. But at the end of the day, PHRs may be the only way to bring about high-quality, multidisciplinary and patient-centred healthcare that is affordable and available 24/7. ”

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Reference

1. Goodenough OR. Getting to computational jurisprudence 3.0*. In: Santosuosso A, Goodenough OR, Tomasi M (eds). *The Challenge of Innovation in Law – The Impact of Technology and Science on Legal Studies and Practice*. Pavia: Pavia University Press, 2015.