

# When will a digital NHS recognise the patient?

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ABSTRACT

Very few commentators writing about how to make the NHS sustainable ever mention harnessing the power of IT-enabled patients. Still fewer take the home seriously as a place where care (perhaps the lion's share of it) occurs. If one thinks of the care continuum, it should normally start and end with the home. A sustainable health delivery model has people caring for themselves expertly at home, knowing when to call on others for help and knowing what to do once they are back home again.

**KEYWORDS:** NHS, patient and public involvement

## Introduction

A month ago, I wanted to start accessing my GP record to manage my health. The surgery's online information was sketchy so I rang to ask what I needed to do. The receptionist had no idea. After a long wait on hold, I was told to come to the surgery to complete a form. When I arrived, the receptionist had never heard of the form. After a search, she located one. Having completed the form, I was told it would take a couple of weeks for someone to check that my record was okay to share with me. They would not contact me; I would need to ring to find out if access was granted. A less determined patient might have fallen by the wayside – if they had known about record access at all. Despite the best efforts of the NHS's Patient Online<sup>1</sup> resource, there is precious little in my surgery to alert anyone to the opportunity. And even less encouragement for patients to use their records as a tool to manage their health.

That is why I am not surprised that in the latest report on digital health – *Making IT work: harnessing the power of health information technology to improve care in England*<sup>2</sup> – the vision of the patient as a future active user of digital health tools is pretty absent. According to the consultee list, patients hardly contributed to the thinking behind the report.

The report's main author, Professor Robert Wachter, acknowledges that patients and clinicians have to make the technology work (citing the recent care.data fiasco as justification), extols the virtues of user-centred design and mentions in passing patient portals and self-care devices. Yet his recommendation for 'a robust independent evaluation of

the programme' doesn't give much thought to the impact on patients.<sup>4</sup>

Reading the Wachter report reminded me of the *Yes Minister* television sketch about the perfectly running hospital, whose success was dependent on having no patients to gum up the works! Nowhere did I get the sense that the patient was seriously considered to be someone who could benefit directly from digital health technology.

## Is the Wachter vision really the future?

From where I stand as a patient, the Wachter report is still promoting a vision where the patient is a pretty passive recipient of (we hope) improved care based on more of our data being shared by those who treat us. As someone who needs to treat myself during the 99.9% of the time when I am alone with my comorbidities, why is my access to this data not a higher priority? In this digital utopia, where are my digital health tools?

Integrated care, based on interoperable IT systems, looms large in the report. But why is the interoperability with my systems on the back burner? How else can I do my bit and check that everyone else is doing theirs? Where are the whizzo apps that are going to keep me active and my long-term conditions at bay? If this is the digital health future, it is a dangerously short-sighted one. As long ago as 2010, in its forward-looking report, *Future Physician*,<sup>5</sup> the Royal College of Physicians called on the government to recognise that:

- > a modern healthcare system must allow patients to access and contribute to their health records; and
- > partnership and self-management will depend on patient access to information (p 19).

## What should digital health be doing for me now?

Very few commentators writing about how to make the NHS sustainable ever mention harnessing the power of IT-enabled patients. Still fewer take the home seriously as a place where care (perhaps the lion's share of it) occurs. If one thinks of the care continuum, it should normally start and end with the home. A sustainable health delivery model has people caring for themselves expertly at home, knowing when to call on others for help, and knowing what to do once they are back home again. Apart from obvious funding issues, to keep this continuum functioning effectively:

### > We all need to work from the same information.

As the Wachter report suggests, all parties must be able to share basic clinical and social care information. This will

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not happen without common standards for all records used in direct care so that information is exchangeable, accurate when exchanged and always in the right place in the record. For these reasons, the Professional Record Standards Body is funded to bring together health and social care professionals, patients and IT systems suppliers in the four nations to develop agreed standards for care records and promote their adoption.

➤ **I must travel with clear instructions.**

Referrals, discharges and other transfers must be accompanied by information that enables all parties to be effective. Patients (and carers) must know what is expected of them at each care point, especially during transfers of care. They also need the means to know what they can expect from others – whom and by when. Patients will know what commonly goes wrong at transfer points. They should be involved when digital transfer systems are being designed or updated.

➤ **My information must not go missing.**

NHS administration, long a Cinderella component of the NHS, needs to be given a serious upgrade, both in technology and staffing. Technology has the power to improve administration, but poorly paid and poorly trained administrators can undo the good very quickly. Almost every patient has stories about tests repeated or appointments rescheduled because key information was lost. I can only imagine the cost of administrative failures to the NHS every year and yet they are hardly ever talked about in public.

➤ **I must be tooled up to do my bit.**

Patients need good digital tools, such as the many apps available to people with diabetes – eg mydiabetesmyway (an interactive website in Scotland with leaflets, videos, educational tools and games containing information about diabetes and the ability to view up-to-date diabetes clinic results<sup>6</sup>) – and the well-used Renal Patient View, which offers similar support.<sup>7</sup> If prevention is better than cure, fitness trackers and other digital wellness tools need to be developed according to agreed quality standards so that they can interact with health records to establish robust baselines and chart progress. Most important of all, clinicians must encourage and support patients to use all of these tools in the context of their care: staff at the Haughton Thornley Medical Centres actively encourage patients to access their GP record and to take advantage of support, guidance and a wealth of tools and information for effective self-management of their health and care and managing consent for information sharing.<sup>8</sup>

➤ **Partnership is more efficient than paternalism.**

Professor Wachter mentions the profound cultural changes that must go hand in hand with technology to achieve maximum impact. A key component of any culture change is professional training. Working in partnership with patients, using digital health tools and shared care records, is a skill that all clinicians need to learn, but don't at present. Dr Richard Fitton, a retired

GP and international commentator on patient record access, is currently leading a movement to introduce these skills into medical schools' curricula.

## Conclusion

The Wachter report sets out principles and recommendations for the basic underpinnings of an IT-enabled NHS. But until the patient is seen as a potential active user of digital health tools alongside care professionals, then progress will be slower than it should be. This cannot continue to be a worthy aspiration, hedged about with caveats. Of course there are serious challenges to address, such as getting the consent process right and rethinking how care is delivered at a time when care professionals are stretched to breaking point. A few care providers, like Haughton Thornley Medical Centres, are managing to tackle both to good effect. Others need to follow. Technology is being developed and improved all the time, but its benefits will not be realised without a sea change in the NHS that commentators like Professor Wachter need to lead.

The NHS has reached the point where its sustainability is in question without major changes to the role of the patient. Not every patient will want or need to use digital tools to manage their health, but increasing numbers will, as people born into a digital world reach middle age and experience their first long-term health problems. They should be trusted, encouraged, digitally enabled and supported as part of mainstream care delivery starting now. They could be the saving of the NHS!

As Dr Fitton observes:

*Patients and information are the two most underused resources in the NHS. ■*

## Conflicts of interest

The author has no conflicts of interest to declare.

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