

# Giving patients online access to their records:

opportunities, challenges, and scope for service transformation

Many people use online applications to communicate with friends, book travel and hotels, order goods, organise diaries and conduct their affairs. It is therefore reasonable that patients may expect to interact with their general practice online. Internationally online access is provided by some general medical services providers<sup>1</sup> and in certain specialist areas.<sup>2</sup> While many UK practices already have websites for their patients that point them towards online repeat prescription ordering, appointment booking, and other services,<sup>3</sup> few offer online access to records, the NHS Operating Framework states less than 1%. This is despite many primary care computerised medical record systems having the required functionality.

### **PATIENT ONLINE: NHS POLICY FOR GENERAL PRACTICE FROM 2015**

The NHS Commissioning Board (NHS CB) expects all general practices in England to offer *Patient Online* services by 2015.<sup>4</sup> In this context *Patient Online* describes patients accessing services online; booking and cancelling appointments, ordering repeat prescriptions, communicating online with the practice, and accessing their electronic health record [EHR].

In 2012 The Royal College of General Practitioners (RCGP) was commissioned by the Department of Health to produce guidance for patients and practices about what *Patient Online* may mean for English primary care. The RCGP response, in 2013, has been published as *Patient Online: The Road Map*.<sup>5</sup> The RCGP worked closely with patient groups and professional organisations to examine the pros and cons of offering online services. The Road Map describes the workload implications of implementing these innovations, the potential benefits to patient care and how to mitigate risk and minimise harm and the need for practice support, training and education. It addresses patient safety and legal concerns and includes a shared risk register developed with the Caldicott information governance review.<sup>6</sup> A linked systematic review assessed the factors which may affect the provision of online access to EHRs and services, and the impact of such access on the quality and safety of health care is in progress.<sup>7</sup>

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### **ACCESS TO RECORDS IS NOT NEW**

In the UK patients have had the right of access to their health records since the 1990s. This right is currently included within the Data Protection Act and also in the NHS constitution.<sup>8</sup> The Data Protection Act makes GPs responsible, as Data Controllers, for the accuracy, security and confidentiality of the records they keep. Generally GPs discharge their obligation to provide a copy of data held by printing that patient's EHR and passing it to them.

### **OPPORTUNITIES AND CHALLENGES FROM ONLINE ACCESS**

Electronic access provides scope to use services without waiting for the practice to answer the phone; thus allowing appointment booking to be done at patient convenient times, and potentially freeing-up reception time. Paper is not a suitable medium for many people with visual impairments, whereas electronic records are accessible by using computers with assistive-technology reading aids. Online access to test results may reduce demand on healthcare organisation time but patients may need help to understand results as the meaning and significance of 'normal' and 'abnormal' ranges may depend on the context. Supporting health literacy will be important.

There are also benefits to patients of sharing the record with someone else; for example, family or carer, in terms of offering support, as well as risks such as

inappropriate or coercive access to the records. People with parental responsibility for younger children normally have an automatic right to access their children's records, and this is likely to be beneficial.<sup>9</sup> Once children have the mental capacity, parental access is only acceptable with the child's permission.

Many health professionals and patient groups have concerns about online access to records. These concerns include the potential for litigation-defensive practice, the making of more extensive notes that could be shared with the patient at the time of crisis, the impact on the length of consultations from the need to answer email queries, the need to change the way in which records are written, and the risk of inappropriate access to third-party information with risks around coercion in the setting of domestic abuse.

### **OPPORTUNITY FOR MUTUAL TRANSFORMATION**

New technologies create challenges; they force the 'actors' in a workplace to rethink what they do.<sup>10</sup> Managing this uncertainty takes organisational improvisation, and commitment. From a socio-technical perspective we would expect mutual transformation of the organisation, clinical workflow and the technology from the introduction of *Patient Online*.<sup>11</sup> The medical record changes from the role of *aide memoire* of the clinician to a record shared with their patient. The adoption of

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*Patient Online* may change the nature of how the records are used, relationships with patients and carers, and the recording of interactions. Previous attempts to provide online services, including patients' access to summary records<sup>12</sup> and of an outpatient booking system intended to be used at the point of care have not always been positive, perhaps because their transformational impact was not considered sufficiently.<sup>13</sup>

*Patient Online* potentially offers benefits, but practices will need help and training in order to encourage wider uptake. Success with *Patient Online* will come with organisational flexibility, a commitment to undertake any necessary transformation of our working practices, and further development of the technologies if found lacking or to have unintended consequences. Failure to recognise this need for mutual transformation may result in slow progress and have practitioners retreat into defensive practice. One possible strategy for practices is to implement one or more elements described in the *Road Map*.<sup>5</sup>

Health services need to adapt in order to take advantage of what IT can offer; the implementation of *Patient Online* will be no exception.

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**REFERENCES**

1. Palen TE, Ross C, Powers JD, Xu S. Association of online patient access to clinicians and medical records with use of clinical services. *JAMA* 2012; **308(19)**: 2012–2019.
2. Basch E, Artz D, Dulko D, *et al*. Patient online self-reporting of toxicity symptoms during chemotherapy. *J Clin Oncol* 2005; **23(15)**: 3552–3561.
3. Howitt A, Clement S, de Lusignan S, *et al*. An evaluation of general practice websites in the UK. *Fam Pract* 2002; **19(5)**: 547–556.
4. Department of Health. *The power of information: putting all of us in control of the health and care information we need*. London: DH, 2012. <http://www.informationstrategy.dh.gov.uk> (accessed 1 May 2013).
5. Rafi I, Morris L, Short P, *et al*; on behalf of the Patient Online Working Groups. *Patient online: The Road Map*. London: RCGP, 2013. <http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/-/media/Files/CIRC/POA/RCGP-Road-Map.ashx> (accessed 8 May 2013).
6. Department of Health. *Information: to share or not to share? Information governance review*. London: DoH. <http://caldicott2.dh.gov.uk> (accessed 1 May 2013).
7. Mold F, Ellis B, de Lusignan S, *et al*. The provision and impact of online patient access to their electronic health records (EHR) and transactional services on the quality and safety of health care: systematic review protocol. Accepted for publication *Inform Prim Care* 2013: in press.
8. Dixon J. A constitution for the NHS. *BMJ* 2009; **338**: b330.
9. British Medical Association. *Parental responsibility. Guidance from the British Medical Association*. London: BMA, 2008. <http://bma.org.uk/practical-support-at-work/ethics/ethics-a-to-z> (accessed 1 May 2013).
10. Berg M. Implementing information systems in health care organizations: myths and challenges. *Int J Med Inform* 2001; **64(2–3)**: 143–156.
11. Berg M, Toussaint P. The mantra of modeling and the forgotten powers of paper: a sociotechnical view on the development of process-oriented ICT in health care. *Int J Med Inform* 2003; **69(2–3)**: 223–234.
12. de Lusignan S, Seroussi B. A comparison of English and French approaches to providing patients access to summary care records: scope, consent, cost. *Stud Health Technol Inform* 2013; **186**: 61–65.
13. Rashid M, Abeyesundara L, Mohd-Isa A, *et al*. Two years and 196 million pounds later: where is Choose and Book? *Inform Prim Care* 2007; **15(2)**: 111–119.