Debate & Analysis

Patients’ access to their electronic record: offer patients access as soon as you can

INTRODUCTION
The UK Treasury fired the starting gun for records access [RA] when it set a target: anyone who wants to should be able to have access to their electronic GP record by April 2015.1 It suppliers now have this in their sights, and the Royal College of General Practitioners (RCGP) has been steering the multiple stakeholders down the road to implementation.2

A number of factors have led to this stage. RA is no longer a technological problem: the technology has been available for some years. Thousands of patients in the UK and millions elsewhere have been using RA in various forms and the roof has not fallen in. Patient benefits, such as saving time, improved communication, and a sense of control over their health conditions, are becoming increasingly apparent. The government has become committed to open data as a means to growth. In addition the RCGP has issued guidance for clinicians.3

Despite the evidence and the optimism at the centre, GPs remain very reluctant to offer the service which is free to practices and patients in the UK. This article makes the case for GPs to offer RA as soon as their systems make it possible.

SAFETY
The Francis report makes specific reference to RA,4 suggesting that poor care would have been more difficult to continue if patients and families had had real time access to their records. Accounts by patients using RA describe sharing their GP records with clinicians in secondary care in the UK and abroad.5 This must make care safer.

‘Access to my personal records is an excellent benefit both to myself and other medical specialists — in fact, information/test results I have obtained from my records have actually helped other consultants with their diagnosis and subsequent treatment.’ (Patient)2

‘I have a chronic disease and feel a real partner in the management of my health. Whether I am at home or abroad I can monitor information and share it with any other health professional involved in my care. I would be lost without it now!’ (Patient)2

Sometimes it is only the individual patient who can identify an error in the record: improving the accuracy of the record may be one of the key benefits of RA.

PATIENT INVOLVEMENT
We can now see, as experience and research continues, that RA affects not only the patient’s ability to look after themselves, but also their relationships with clinicians and with their own illnesses and comorbidities.

Changed relationship with illness
Evaluation using a modified version of the Patient Enablement Instrument6 by the MyRecord project (www.myrecord.org.uk) explored patients’ experience and suggests that RA helps patients feel more in control of their illness and more confident (Table 1). Numbers are small but data continues to accumulate.

Change relationship with the clinician
There is ample evidence that patients with RA feel more trusting of, and trusted by, their GP.7 Data from the MyRecord project also suggest that conversations between clinician and patient are changed by RA (Table 2). Patients experience increased support and more engagement with their clinicians as a result of RA.

Table 1. Adapted Patient Enablement Instrumenta

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am more able to cope with life</td>
<td>2 (4.76)</td>
<td>9 (21.43)</td>
<td>27 (64.29)</td>
<td>2 (4.76)</td>
<td>2 (4.76)</td>
<td>42</td>
</tr>
<tr>
<td>I am more able to understand my illness</td>
<td>2 (4.76)</td>
<td>13 (30.95)</td>
<td>21 (50.00)</td>
<td>4 (9.52)</td>
<td>2 (4.76)</td>
<td>42</td>
</tr>
<tr>
<td>I am more able to cope with my illness</td>
<td>1 (2.38)</td>
<td>11 (26.19)</td>
<td>23 (54.76)</td>
<td>5 (11.90)</td>
<td>2 (4.76)</td>
<td>42</td>
</tr>
<tr>
<td>I am more able to keep myself healthy</td>
<td>2 (4.76)</td>
<td>12 (28.57)</td>
<td>21 (50.00)</td>
<td>5 (11.90)</td>
<td>2 (4.76)</td>
<td>42</td>
</tr>
<tr>
<td>I am more confident about my health</td>
<td>1 (2.38)</td>
<td>17 (40.48)</td>
<td>19 (45.24)</td>
<td>3 (7.14)</td>
<td>2 (4.76)</td>
<td>42</td>
</tr>
<tr>
<td>I am more able to help myself</td>
<td>5 (11.90)</td>
<td>18 (42.86)</td>
<td>13 (30.95)</td>
<td>4 (9.52)</td>
<td>2 (4.76)</td>
<td>42</td>
</tr>
</tbody>
</table>

aData from myrecord.org.uk.

Table 2.

Self-care and shared decision making
Patients say that RA helps them look after themselves because they can understand better what they need to do and why.8 They describe that they adhere to medication more than before RA and that they are more likely to stick with healthy behaviours. This is partly because they can read the instructions again when they need them, in the notes. They also describe feeling more in control of their care and being more able and informed to take decisions about their management. These are self-reported data but there is some objective evidence for compliance9 and self-care.10

CONVENIENCE
Although there are natural concerns that RA will result in more work for primary care, current evidence suggests that RA makes life easier in many respects for practices and patients. As yet unpublished evidence (C Fitton, R Fitton, A Hannan, et al, unpublished data, 2013) suggests that if 30% of patients used RA at least twice a year, a 10,000-patient practice would save 2520 doctor appointments, 1110 nurse appointments, 420 healthcare assistant appointments and 7950 telephone calls. Assuming a consultation rate of 5.3% annually11 that equates to a release of 11.3%
of appointments per year, with significant resource savings for patients and the environment:

‘I … recently sustained an injury which required several hospital appointments under two consultants at two hospitals. Being able to access my medical records and letters of referral was an enormous help, allowing me to track my progress through the health system without troubling the surgery.’ [Patient]²

These self-reported data are very similar to US data.² New, more objective US data, however, suggest RA takes up more time.¹³

This study compares patients who used RA combined with e-messaging services with those who did not use either. It showed that rates of office visits, telephone encounters, after-hours clinic visits, emergency department encounters, and hospitalisations increased in those with RA and e-messaging.

It is not clear whether it was the RA or the e-messaging component which made the difference.

RESPONDING TO OBJECTIONS
The General Practitioners Committee has concerns about RA. Some have already been mentioned.

Coercion
One important issue is that a family member with RA could be coerced into releasing personal data. We know that coercion is common, is frequently hidden, and is rarely reported.¹³ There are no simple technical fixes, although it may be possible in the future for patients to hide data in an electronic ‘walled garden’. Probably the immediate most effective counter is to warn patients of the possibility on sign-up and ensure that all parties allow that the patient’s RA can be switched off at any time. In addition, there is worry that the insurance industry, for instance, could approach patients directly, bypassing their GP, and ask for personal data, saving themselves time and money. There is no evidence of this happening either in the UK or in the US (where it is illegal) but it certainly should be guarded against.

Third-party data
The Data Protection Act is clear which aspects of third party data have to be excluded from patients’ view.

The Road Map¹⁴ recommends that risks will be dramatically reduced if systems ensure that retrospective access is minimised. It is suggested that patients would by default be able to see free text and consultation notes only after a certain date agreed either nationally or by each practice.

Patient anxiety and misunderstanding
There is understandable concern that patients will be made anxious by what they read, fuelled partly by misunderstanding. Studies suggest that patients understand 75% of what they read.¹⁵

Inappropriate anxiety does occur, but it appears to be unusual. Mostly patients even with serious illness, appear reassured. The group most prone to concern at RA is those with mental health problems.¹⁶

<table>
<thead>
<tr>
<th>Table 2. Changing conversations²</th>
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<tbody>
<tr>
<td></td>
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<td></td>
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<tr>
<td>I am more confident to ask my GP questions</td>
</tr>
<tr>
<td>My GP listens to me more</td>
</tr>
<tr>
<td>My GP and I make decisions together</td>
</tr>
<tr>
<td>Access to my patient record is important to me</td>
</tr>
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</table>

²Data from myrecord.org.uk.

©British Journal of General Practice
This is the full-length article (published online 28 May 2013) of an abridged version published in print. Cite this article as: Br J Gen Pract 2013; DOI: 10.3399/bjgp13X668384
REFERENCES


