

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

Table 1. Adapted Patient Enablement Instrument^a

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

^aData from myrecord.org.uk.

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.

Changed 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.

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%

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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.¹² 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

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ETHICAL ARGUMENTS

Apart from all these practicalities we need to consider that we have a right to our own data. We should not have to ask for it from the NHS, seeking permission to see our own information. We should have access to it and use it as we see fit. It is an issue of human rights. The NHS has a moral duty to share it with the patient as and when we want it.

The small issue of power is also relevant. Shifting paternalism/maternalism includes sharing the information that helps maintain the unequal power balance between patient and clinician and patient and the system. Evidence shows that record access does go a small way to shifting that.

And finally, the concept of ‘power balance’ suggests that this is a zero-sum game: there is a limited amount of power and if one person has more the other must, as a consequence, have less. Experience suggests that this is not the case. Power can expand to include patient and clinician: both can be empowered and gain through sharing information.

CONCLUSION

Record access with simple precautions is safe and convenient for patients. Most of the significant risks can be mitigated, but we shall need to find technical and organisational responses to minimise the dangers of coercion. When used wisely it is likely to increase capacity in primary care.

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Competing interests

Brian Fisher is codirector of PAERS Ltd www.paers.net which enables all EMIS practices to offer patients free secure online access to their GP records.

Provenance

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Table 2. Changing conversations^a

	n (%)					Total
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
I am more confident to ask my GP questions	4 (9.52)	18 (42.86)	14 (33.33)	5 (11.90)	1 (2.38)	42
My GP listens to me more	4 (9.52)	4 (9.52)	26 (61.90)	4 (9.52)	4 (9.52)	42
My GP and I make decisions together	5 (11.90)	13 (30.95)	18 (42.86)	2 (4.76)	4 (9.52)	42
Access to my patient record is important to me	28 (66.67)	11 (26.19)	2 (4.76)	0 (0)	1 (2.38)	42

^aData from myrecord.org.uk.

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