

VIEWS & REVIEWS

PERSONAL VIEW

Paperless records are not in the best interest of every patient

Rupert Fawdry says that a unified paper record of health and social care would improve communication among professionals and institutions

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Pregnant women throughout Britain have a paper care record that is openly readable, easily updatable, and immediately correctable. I assumed that housebound patients would have something similar. With so many comorbidities, when else would a single paper record make such sense? My 99 year old mother's recent experience highlighted my naivety.

She still lives in her own home. Besides friends and family, those involved in her care include her family doctor, district nurses, several social care departments, Age UK, and a private home care company. These provide food, company, and help with complex medication. But each party insists on a separate set of records, making it necessary at my every visit to check four binders without bookmarks, two separate drug charts, and several huge ambulance forms of mind boggling complexity.

My suggestion that a unified system of care records might be better has been met with such comments as, "We don't have permission to write in each other's notes," and, "We're not sure if we're even allowed to look at documentation created by others."

Recently, after one of her recurrent falls, my mother was with difficulty persuaded by familiar paramedics to let them take her to the emergency department. Within hours, she was insisting on going home. I soon received a phone call from the private home care company: "What had been happening? Where was her new medication?" Her tablets were eventually discovered in her pocket. A letter had been emailed to her general practitioner on a Sunday and was inaccessible to her carers. How much better if she had had her own paper record used by everyone, including hospital staff. This would have low cost; it would reduce errors at handovers; and individuals, rather than organisations, would become the hub of their own medical and social care.¹

I have had to complete many forms on my mother's behalf, each asking similar questions. I reduced my irritation by creating sticky labels that detail legal next of kin, language and other handicaps, allergies, current drugs, and so on, but this did

nothing to reduce the hours healthcare staff spent re-entering data digitally at the expense of providing direct patient care. Why not print QR codes on sticky labels for the repetitive data that are needed in several places? Incompatible computer systems could use smartphone technology to read them.

How many times have we heard that the NHS will soon be totally paperless? One recent official statement is that this will happen by the end of 2015.² In its recent strategy document the Department of Health called for information to be "recorded once, at our first contact with professional staff, and shared securely between those providing our care."³

But this presupposes universal, secure access to integrated multidisciplinary electronic records. True interoperability and openness of care records cannot be achieved unless ways are found to include those patients and carers who do not have immediate access to the internet. Technologies now allow data entered on preprinted proformas to be automatically digitalised, stored using battery power, and later transmitted to centralised databases, but such solutions still feed into incompatible electronic silos.

Despite the enthusiasm of many, it will never be cost effective to try to make complex databases "talk" to each other.

Integrating any two complex digital records cannot be done without expensive and time consuming rewriting of thousands of lines of software code. In banking, the failure of Santander's proposed takeover of RBS branches was attributed to massive problems of cost and speed in migrating and integrating data,⁴ and the recent Bank of Scotland £4.2m fine came after its failure to reconcile just two incompatible mortgage systems.⁵

Data collection must never be prioritised above improving individual patient care,⁶ and record systems that put individual care first will always be unavoidably complex, partly because different disciplines have different needs. Improving paper systems is cheap compared with upgrading software. We first need to facilitate high quality paperwork. Only afterwards should we concrete our knowledge into digital formats.

Experience creating Britain's most popular maternity record system has convinced me that the best way forward is to consider all the current paperwork used, posting it on an openly accessible website for all to analyse.⁷ The Electronic Encyclopaedia of Perinatal Data, which I created and maintain, is one such example (<http://eepd.org.uk>). A similar approach is being used in the development of a national paper drug chart,⁸ and will eventually be essential in every subspecialty.

For this approach to work we must, as in the United States, have a legal declaration that blank forms cannot be copyrighted.⁹ And every publicly funded computer system must openly document the exact wording of every question and every answer option.

Paper records have many other advantages over digital ones,¹⁰ and it is time for politicians, clinicians, and healthcare managers to reject the idea of a paperless NHS. Instead, clinical commissioning groups should insist that all housebound patients and those with long term conditions have a single personal paper drug chart and a unified paper daily care record to accompany them wherever they go.

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