Use the cloud for what it's good at

Matt Hancock's <u>latest 'vision' for a post-covid NHS</u> is for him to keep your medical records in the cloud, rather than each NHS care-providing organisation having the patient records needed for their care. <u>Shared care records</u> *are* important, but context is also vitally important – and 'context collapse' in patients' detailed records is a real problem, both for care and for patient safety.

Compared with the strong professional and legal obligations on clinicians and hospitals to keep accurate records of their decision-making – especially around complex, life-critical treatments – Matt Hancock's DHSC clearly has <u>a great deal to learn</u> about keeping accurate records, and making them available when needed. It is all too easy for DHSC to typify the NHS as a 'monolith' and to see patients as an annoyance, frustrating the best laid plans of Ministers, but such characterisations do not reflect the real world.

A stroke every Tuesday morning?

Consider this: when treating a seemingly recovering patient, a GP is confused – the person in their consulting room does not seem to have suffered a stroke every Tuesday morning for the last few months, but that is what their medical record shows.

It transpires that the practice had been following national guidance and had shared the patient's health record with the associated physic clinic to provide updates. And while from the GP's perspective the stroke was why the patient had originally needed physic, from the physic's perspective the stroke was the reason why that patient was there every Tuesday – so that is what got recorded.

Furthermore, when a patient is removed from a practice list without moving to a new practice, one continuing process legacy from the old spine infrastructure is that the PDS record for that patient has the ODScode overwritten with a reason for delisting,¹ so that the practice that still holds the legacy records can no longer be discovered. The patients' records effectively disappear from everywhere.

A record *written to* **by everyone is owned by no one.** As usual, this is not to say that the Secretary of State has not identified a problem but, from his perspective, he cannot tell whether a solution is good or otherwise. Such an institutional process failure may provide a prime case for individual led approaches like 'personal data stores' such as Solid or the Turing's HAT,² etc. but the direction suggested is not native to the culture and patient safety-led practices of the NHS.

¹ In the previous spine infrastructure, adding new fields was harder than now, so the field got reused. Patients continue to have their records lost as a result of that shortcut.

² <u>https://www.hat-lab.org</u>

A patient-focussed messaging system, not an admin-focussed records system

Some years back, in pursuit of a previous policy from DHSC, NHS England held a '<u>bonfire of</u> <u>the faxes</u>'. What both ignored in their zeal to go paperless is that fax machines served an important *clinical* purpose – namely receipts, and a physical token that you could see had landed on someone's desk.

Just as you may have a pigeon hole for post and internal messages in an office environment, so should there be a 'virtual pigeon hole' for every patient, based on their NHS number. Thus when a patient moves a step along a care pathway, their pigeon hole on the Spine will contain any records relevant to their care that have been left there by their previous clinician, with all Notes from (say) the last 72 hours being visible too.

Such Notes – in the form of <u>FHIR messages / data</u> – could be left 'attached to' the patient's NHS Number, and their Shared Care Record, so the next doctor to see the patient would be able to electronically pick them up. This would be especially useful in cases where a patient ends up in a different care location to where a clinician expects – removing issues that arise from depending on a sense of location, and replacing them with a patient focus that allows greater continuity of care along disjointed care pathways.

A virtual pigeon hole and messaging approach helps maintain continuity and handoff of care as it is focussed across *time*, not across care providers.

Since we wrote our <u>original post on fax machines</u> (and associated thinking) in 2015, FHIR has standardised and rolled out widely. This means that there could be machine-readable FHIR data alongside any doctor-readable text, which could be handed off and picked up – even if the two services don't interoperate.

At a minimal initial stage, all this would require is some relatively small tweaks to the Spine and to SCR for a trial, and some willing parties to lead. If the trial works, it can be extended.

Such an approach would allow GPs to be able to read the messages passed between secondary care providers and others in the NHS, allowing a much more complete GP view of their patients' care. Access controls would mean this can only work where there is a direct care relationship with the provider, so to avoid some of the 'creepy single doctors' problem – full mitigation of this will require the patient to be able see how that part of their SCR has been accessed, as with the rest of their SCR.

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