More detail than you (probably) ever wanted to know about Local Health and Care Record systems.

The Exemplars

Five LHCR Exemplars have been chosen, covering 40% of the population of England.

While some areas will be attempting to make two or more existing (or developing) systems 'interoperate', in order that patients' and service users' data flows correctly along care pathways, it appears others may instead scrap what's already in place / under development and commission a new system instead. While this latter approach may address (some) data flows within that area, it does not tackle what purports to be the purpose of the exemplars, which is to demonstrate functional interoperability across / between disparate systems – most acutely, across the interface with social care (an aspect which, as ever, seems very poorly represented).

Will the LHCRs be yet another round of spending on established, well-trodden shared *health* record technologies – in preparation for making patients' data more readily available for a range of secondary uses – or will they instead tackle the strategic and systemic failings of (consensual, safe and transparent) information flows within and across the health *and care* system?

System C & Graphnet Care Alliance

Of the five Local Health and Care Record Exemplar areas, three contain at least one shared record system based on Graphnet's CareCentric software – meaning the lowest common denominator of mass copying may predominate.

Whether it is wise to award an effective monopoly to a single supplier remains to be seen; the NHS has taken pains to avoid this is in other areas. That Graphnet's software – and just as crucially, its architectural approach – seems to be the platform underpinning the majority of the LHCREs suggests similar pains would be sensible, if only to ensure legitimate alternatives to mass data copying are properly explored.

Of course, if the political goal is to proceed at pace via 'data ponds' to NHS England's Data Lake, and/or to convert these 'Hubs' into Data Trusts for further exploitation, then it might be sensible to come clean as soon as possible. Hiding such plans from the public is unlikely even to go as well as the care.data programme in 2013-16 (RIP).

1) Wessex LHCRE proposes to 'merge' the Hampshire Health Record (HHR), that has been using Graphnet's CareCentric software for well over a decade – and that was recently renamed the 'Care and Health Information Exchange' (CHIE) – and the Dorset Care Record.

The long-standing problems with HHR are well-documented, and continue despite the re-branding to CHIE. From Southern Health NHS Foundation Trust's Board Papers, 27/3/18: *"We recognise that CHIE* ***does not yet offer clinicians an optimal view of care records nor work seamlessly with all existing clinical systems*** *and so we will be upgrading the functionality of the system in May 2018."*

We note the CareCentric-based CHIE/HHR was adopted by the Isle of Wight in May 2018, and shall watch with close interest to see whether the mess that is HHR means it will be retendered. For now, as this PowerPoint presentation strongly suggests – cf. both "5 purposes of information sharing" slides, and the Architecture diagram on slide 13 – any new or developed system will be steeped in NHS England's Data Lake thinking.

The Dorset Care Record signed a £7.8 million 5-year framework contract with New Zealand firm Orion Health in April 2017, part funding of which came from NHS England's Integrated Digital Care Fund. Orion's Rhapsody Integration Engine takes a fundamentally different approach to that of CareCentric – based on use of APIs, including FIHR, and message exchange – that could achieve interoperability without mass data copying. Media coverage relating to Rhapsody-based shared records programmes elsewhere in the country suggests close attention will be necessary (Orion's Rhapsody platform was recently sold to private equity firm Hg Capital.)

Wessex LHCRE (as does TVS) falls under South, Central & West CSU, which – along with a number of its local CCGs – has suffered persistent Information Governance problems, documented in an extensive list of related NHS Digital Data Sharing Audits, that have included multiple breaches of agreement with NHS Digital, and not being able to determine who is a data processor and who the data controller in joint projects!

Until such basic principles have been properly established, it would seem extremely unwise to begin using (pre-GDPR definition "anonymised") patients' data for, say, Commissioning purposes – as per the second bullet point in the Editor's Notes of NHS England's announcement of the Wessex LHCRE. Mixing secondary uses with direct care was the root cause of Manchester's DataWell's collapse; there is no reason to expect the same will not occur elsewhere if other secondary uses are introduced by fiat.

2) Thames Valley and Surrey LHCRE combines a number of systems or programmes at varying stages of development, including Milton Keynes University Hospital's Health Information Exchange, Oxfordshire's Cerner Toolkit-based Digital Population Health Plan, and Buckinghamshire's My Care Record - which, though incredibly poorly communicated (e.g. the patient FAQ is buried on the CCG's website), is at this stage using Graphnet's CareFlow Connect service for viewing patients' GP records, as well as CareCentric for other purposes.

Berkshire's 'Share Your Care' programme, that went live in January 2018, is delivered using a computer system called 'Connected Care', also built on Graphnet's CareCentric software. The development of Connected Care was led by South, Central & West CSU, which has been shown to have serious Information Governance problems over a number of years.

For example, as detailed in data sharing audits by NHS Digital in November 2016, then August 2017 and a follow-up in November 2017, investigations of SCWCSU and related CCGs uncovered that not only did it process individual-level patient data outside the EEA for nearly two years – a "major breach" (para 2, p2) of its Data Sharing Contract with NHS Digital – but that it *continued* to do so for almost a year *after* it had been informed this was happening.

In addition to the breach itself, the CSU had performed no risk assessment of this (item 1, p4); data provided by NHS Digital did not even appear in its information asset register (final para, p6); it did not formally record the intended purpose of data use, or the structure, definition and

means of data collection (item 4, p4); and agreements between the CSU and CCGs were not even clear who was the data controller and who was the data processor (item 3, p7)!

The Surrey Care Record, scheduled to be launched on 29 August 2018, is based on Patients Know Best's software. According to South, Central and West CSU's Surrey Heartlands plan, both the "Roadmap" (see slide 6) and "Architectural approach" (slide 5) for Surrey show an intended "Enterprise Data Warehouse" design, with access for purposes beyond direct care by "Decision Support" as well as "Data Analysts/Scientists" clearly indicated. It is unclear how these secondary uses will satisfy PKB's public promises about control and transparency for patients on how their records are accessed. This may not follow the best practices we have laid out, and which some suppliers have emphasised elsewhere.

With some of these systems so recently launched, or yet to be launched, it is difficult to tell how well they will all interoperate in practice. The overall intended LHCR approach, however, is quite clearly to copy all data to a CareCentric-provided "Analytics Repository" (see 'Connected Care Vision', slide 7) from where it may be made available for purposes beyond direct care. It remains to be seen how claims on this slide – that such detail-rich, individual-level linked data can be "anonymised", and that "explicit consent" will be sought for all uses "outside direct care" – will be delivered in practice.

(This LHCRE may also be of particular political interest, as it is the one that covers Theresa May's as well as other senior Ministers' constituencies...)

3) Greater Manchester LHCRE would appear to be based on some sort of combination of CareCentric and DataWell – though the Information Governance review of the latter in 2017 appears to have been so bad, the programme and public links to it have almost entirely disappeared. (DataWell previously existed in the 'Connected Health Cities' workstream of the Health e-Research Centre at the University of Manchester, which is also the parent entity of the relevant AHSN.)

Somewhat oddly, given this 2017 statement, that also identifies DataWell's original technology partners: *"The exchange has been built by AHSN on a* software platform from US company LumiraDx and working with IBM and EY *(formerly Ernst & Young). "There is no central data warehouse," Thew said. "**DataWell is an information exchange and data moves at the point of need**."* - UKA Health and Care, 12/7/17

DataWell was however, just 10 months later, being referred to as some sort of 'data cleansing tool': *"Parts of Greater Manchester already use a system called CareCentric by Graphnet, which the remaining areas will also be adopting. CareCentric works by connecting different systems and sharing information between them. **An existing tool called DataWell will also be used to cleanse the data**, removing duplication and errors."* - University of Manchester, 24/5/18

DataWell was predicated on the mixing of direct care delivery with secondary use (research), an approach that was/is unsupportable in what must first and foremost be a shared care record. From a technical perspective – given mixing was a choice, not a necessity – this may prove to have been unfortunate; according to public statements such as the UKA Health & Care one above, DataWell used APIs and 'just in time' information, as opposed to CareCentric's mass data copying approach.

‘Roll your own’ / other suppliers

4) The **One London LHCRE** has merged (as of 5/3/18) the Local Care Record in Bromley, Lambeth and Southwark with a system called Connect Care in Bexley, Greenwich and Lewisham. We are aware there are a number of LHCR “demonstrators” across London, but confine our comments to information that is actually public at this point.

While almost no information appears to be publicly available on the technical side of Connect Care, or its governance, the ‘Skunkworks’ of the Academic Health Sciences Centre, King’s Health Partners, that is behind the Local Care Record – an organisation now known as KHP Online – has given an outline of the LCR’s development path from the initial linking of three hospital Trusts (from CSC’s old iSoft software to Advanced Health and Care’s CareNotes) through to integration with GP systems (primarily EMIS Web, but also other providers through Healthcare Gateway’s MIG).

KHP Online appear to be taking an API-based, not data copying, approach – incrementally adding in systems and services, while maintaining its primary focus on the information necessary for the provision of care.

Lacking any further detail on Connect Care, it is not possible to determine the approach it takes – nor which approach to shared care records will be adopted across South London. It is to be hoped the transparency of what One London is doing will significantly improve as the Exemplar proceeds. It may be that a fresh digital approach, fully focussed on user needs, can deliver a modern consensual, safe, and transparent model that others, most notably Graphnet, have entirely failed to deliver. It could also go very badly wrong.

5) Yorkshire and Humber LHCRE already includes the Leeds Care Record and Rotherham Health Record. The Yorkshire & Humber Academic Health Science Network (AHSN) took the opportunity of the awarding of LHCRE status in June 2018 to announce a new collaborative, the ‘Yorkshire & Humber Digital Care Board’, that “will result in the creation of a new Yorkshire & Humber Care Record”.

This may or may not conflict with ongoing plans for the Leeds Care Record – based on Leeds Teaching Hospitals NHS Trust’s in-house electronic health record, called PPM+ – which was approved for a further 3 years development in January 2018. The Leeds Care Record has previously worked with suppliers including Healthcare Gateway (for MIG), InterSystems HealthShare (for its Master Patient Index) and PI CareTrak (for social care).

Meanwhile, Rotherham’s Electronic Patient Record (EPR) infrastructure was, once again, “overhauled” in April 2018. Rotherham NHS Foundation Trust has stuck with Meditech EPR / Healthcare Information System (HCIS) for many years – backed up by BridgeHead Software, partnering with Dell, for “data and storage management” – despite serious issues that required the intervention of Monitor in 2013, and several subsequent updates.

A December 2017 paper detailing Rotherham Health Record’s Privacy Impact Assessment and Information Sharing Agreement suggests (p8 of 43-page PDF): *“The RHR portal receives data only from existing Systems and does not retain any clinical patient information locally within the*

portal", which, while appearing consistent with the data flows indicated on p11, does not address exactly what the RHR portal is and how it operates – or whether data is being copied elsewhere.

We note the ISA does makes it clear (section 4.3, p27) that, for the RHR, *"'Direct care' does not include research, teaching, financial audit, service management activities or risk stratification."* Will secondary users instead simply 'route around' the portal and access the BridgeHead/Dell data store directly? Much more clarity is required.

Summary

For each of these systems, the devil is in the detail. We have previously outline the principles behind such systems.

As with all care systems, it is not just what they do today, but what NHS England wishes them to do tomorrow. Once GP data has been copied into these systems, it is under the control of NHS England and available for purposes beyond direct care. This loophole needs to be closed by a clear guarantee to each patient when introducing such systems, and as part of any future NHS legislation for ACOs (ICPs) that loophole removed.

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