

Data

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The Primary Care Record is a rich source of data (the 'detailed care record' (DCR) that is routinely used to support patient care; it provides the basis for safer care and links to computerised clinical decision support.

Generally, patients expect their clinical information available whenever and wherever they receive care, understanding the efficiency and safety that this brings, and in most cases thinking this already happens.

The GP, as data controller, currently feels exposed, as there is a worry that information governance standards are not universally applied across the wider NHS, nor potentially fit for purpose (National Data Guardian review).

Naturally, GPs have a desire to protect themselves from legal challenges.

The ICO inevitably becomes concerned and cites schedule 7 of the DPA as their grounds for concern.

In reality, every NHS organisation must be deemed fit to hold and use patient data otherwise they would be shut down.

There is now a school of thought that supports sharing of the GP held detailed care record within localities (some very large) with an automatic share out (to a specified list of other organisations) and a patient consent to view at each of the point of care within that locality.

This is backed by a 'local sharing agreement'.

The ICO has supported this approach (although it usually states that it cannot endorse a particular approach, only offer advice).

The consequence of going down this route is that sharing of the DCR will be restricted to localities.

The sick on holiday, the injured in an accident away from home; the patient recuperating with relatives, patients cared for at regional or supra-regional centres, those living on the borders of localities – all will be deprived of the benefit that access to their records will afford them.

Full access in real time to the DCR, together with sharing back of information created at the point of care, is the goal of interoperability.

Of special note is the handling of safeguarding information – where children may be deliberately taken out of area to avoid detection of harm.

This approach is wrong

Paying the GP system suppliers to restrict sharing to cover over a more systemic concern - spend money to deliver a sticking plaster when the right solution (bearing in mind the progress with inter-systems interoperability that is being made in the supplier community that will enable linkage between all NHS providers) is to beef up IG, develop a national sharing model, put patients more in control, and support data controllers in the release of the record for direct clinical care.

The National Data Guardian has charged NHS Digital with dealing with the IG issues (recommendation 8)

The idea that the NHS in a locality is more trustworthy than more distant neighbours – but the locality size is such that no single member can have knowledge of the security standards and training of all organisations – so in effect this is the same as the broader NHS with the same ‘spread’ of organisations

Wider availability of the shareable record exposes the data controller to greater risk as the pool of potential rogue staff is increased – this must be acknowledged as the necessary risk to enable the broader access to the DCR, but comes with the benefit of access controls and audit, unlike the paper record.

As Fiona C said at EXPO – much tougher sanctions are needed.