The Next Steps on the Five Year Forward View reiterated the need for integrated care. The NHS and the healthcare IT industry know that integrated care demands integrated data, if safe consistent patient care is to be provided.

Andrew Meiner, managing director of integrated care records provider Stalis, says that's not happening. To change things, we need national and industry action on open standards; and NHS service providers need to make sure they are used, Meiner writes.

Just before the general election was called, NHS England set out the progress that it wants to see taken on the Five Year Forward View. The Next Steps on the Five Year Forward View report reiterated the message that the key to closing the growing gap between funding, demand and cost is for health and social care organisations to do things differently.

It requires the integration of processes and services, and to integrate services you need to integrate their data. This seems obvious; and is generally accepted by those close to the task. Yet, in practice, it is not happening.
The GP vendors are contractually committed to releasing their data under GPSoC, but progress is extremely slow. And in the acute sector, the EPR vendors are still storing data in their own way, using proprietary standards.
It is extremely frustrating, because if you want data-driven change in healthcare, then you have to have open standards for how data is structured. So, the question is how we can make this happen.

Well-known standards
We're certainly not short of standards organisations or open standards. There is Integrating the Healthcare Enterprise or IHE, which has led on Cross-Enterprise Document Sharing, better known as XDS.
There is Health Level 7 (HL7), which provides a framework and standards for the integration and exchange of healthcare information, and which is behind Fast Healthcare Interoperability Resources, or FHIR.

And there is the openEHR Foundation, which is co-ordinating the work on openEHR. But openEHR is more of an approach than a standard, because it separates information from its use, so it can be templated into useful tools.
These standards are different and not mutually exclusive. XDS is a proven way of distributing clinical documents using a pull mechanism and sharing those documents across large geographic regions.

FHIR is the logical evolution of HL7v2 and HL7v3, and allows complex point to point integrations to be built quickly and cheaply. So, both XDS and FHIR can use the CDA, or Clinical Document Architecture, that defines the structure of some medical records, but their use cases would be different.
XDS is the better choice if you want to search for clinical documents for a patient, while FHIR makes more sense if you want to transfer care responsibility from one provider to another. FHIR also allows data from mobile devices and wearables to be integrated.

OpenEHR, meanwhile, is the most aspirational to deliver, but it promises to promote collaboration between clinicians and data analysts by providing a common language and tools for them to use.

Setting things on FHIR is not enough

Until recently, though, these three main groups did not really talk to one another with any sense of a common aim to support integration. So, you could have two integration projects, doing great work in different parts of the country, that still couldn't talk to each other.

A good example is London, where there are something like 60 data exchanges. Some are built around proprietary standards and some around different open standards. London is trying to join them up, but only to share documents.

To really gain the benefits of integrated data and understand the health needs of a population through analytics you need to add a source of good quality standardised data based on something akin to openEHR.

National action needed

The industry has taken some steps to bring these standards together, with the INTEROPen initiative. This is a forum for companies to collaborate on the design and application of technical interoperability standards; and almost 100 are now signed up.

NHS Digital is also focused in this area and has started to interact with INTEROPen. It has published an interoperability handbook and is working on further 'offers' for local bodies, including open interfaces, a business justification for integrated records, and help with the information governance issues they tend to throw up.

So, there are some good steps being taken at a national level, and there is industry buy-in. However, because there are different initiatives underway, there are different architectures being proposed to pull things together.

But, what we really need is for someone at a national level to say: 'this architecture, using these standards' – and also 'these companies can provide you with these components'.

Benefits of an open ecosystem

If that happened, and everybody followed the architecture, then it would be possible to share information around and analyse it. It would be possible to retain existing suppliers. It would create new space for innovation.

If there was a truly open ecosystem for healthcare, in which data was separate from the systems that create and store it, then developers could come in and use it to develop new products using modern, mobile technologies.

Unfortunately, while the Next Steps document had some good things to say about approved systems and approved configurations for electronic patient records, it had much less to say about standards. From that perspective, it was a bit of a missed opportunity.

Customers: demand your data…

The other missing piece is customer input and demand. NHS organisations, after consultation with the public and taking into account Caldicott principles, really need to say: "This is our data, and we choose how to store it, who to share it with, and what to do with it."

When I travel around the country I see organisations at very different stages of their digital journey. Some providers are just trying to get off a burning platform and install a new patient administration system.

Some are focusing on functionality, but not thinking about the way in which the systems that could deliver that could also lock-in their data. Some are thinking about the integration piece, but not always looking at the bigger picture.

The challenge for the growing number of integrated care projects out there is the short term demand to deliver on a particular initiative or to generate cash savings.

That can make it tempting to go for an apparently cheaper, proprietary solution to 'fix' a problem or get a tick in the efficiency box.
It can make it harder to go for a more strategic option that will require more capital up front, but put the whole healthcare economy in a better place in the longer term.

Having that national steer on architecture and standards would help customers make better choices in the face of those pressures; but I think we will also need a few visionaries with exceptional leadership skills to show the way.
What we all need to remember is that this is the NHS' data. It is not the vendors' data. It should be structured so the NHS can do what it needs to do with it; because, in the end, we will all benefit from that.