

The negotiable standard

An opinion by David Stables

I have been asked to provide a 1000 word opinion on the best approach to establishing standards for interoperability.

As I have never been short of an opinion here it is, before it changes that is. 1,300 words actually.

Before launching into the solution, it is worth taking a quick look at what the problem of health interoperability standards is and why it hasn't yet been solved. After all, standards for data exchange such as XML/JSON and standards for the transport of data such as HTTP are global standards that have been in place for some time. Why not then standards for healthcare data exchange?

The underlying reason is simple. There is as yet no agreed and fully specified Information model for electronic health records.

It seems that scientists are now able to describe everything we can see or measure via the theories of general relativity or quantum field theory yet we cannot apparently write down the model for health records. We can spend billions on finding a particle that scientists already knew existed but appear unable to agree on what an allergy is! We all have the underlying Information model in our heads of course but when we articulate it, we find everyone else disagrees with us!

Nevertheless we are definitely getting closer and closer to this ultimate target. We are beginning to zone in on it via a series of elliptical orbits of ideas. These different ideas often appear at first sight to be at odds with each other, but they are in fact getting closer to the underlying model. Archetypes (openEHR), resources (FHIR), expressions (Snomed-CT) are all partial solutions to parts of the underlying IM and have considerable overlap. Each one is adding to the sum of knowledge and they are all evolving and will be soon replaced with ideas even closer to the target.

This failure to achieve a common model has profound negative consequences when trying to establish standards for interoperability.

Firstly, if we don't know what the model is, how can we teach it to students and professionals? The answer is we cannot. Without an information model it is hard to articulate a health process that uses it! Trying to explain data exchange and record content at the moment is like trying to describe how to do open heart surgery without knowing where the coronary arteries are.

Secondly, it allows gaming. Protectionist suppliers game via a combination of helpful suggestions (which they know will be rejected) and requests for certainty (which is never provided). Protectionist professionals simply sit back and allow the informaticians to tie themselves in knots. On the other side of the game net in the past has been the centre with statements mandating a particular approach, which is by far the best ploy from a supplier's perspective as they know the mandated approach to be unworkable.

So can we make progress despite this? Yes of course we can. There have been many times over the last 30 years where benefit has accrued through the implementation of standards. There is a

common pattern to these successes. I see the following as the pattern that works and in my opinion we should follow it.

Let us first assume that there is a desire to deliver real benefit to real patients via the real live exchange of information for a particular group of health related processes, and that we want this to happen NOW. It is likely to be something that nearly everyone would want and the benefit is likely to be clear. It does not need to be too ambitious though. Seemingly simple things like sending a lab result (done: EDIFACT) or transferring a GP record to another GP (done: HL7 V3) , or transferring a list of medications from a GP to a hospital when the patient is admitted (not done, hey that's one to do!) are all good solid processes that if addressed will save lives and save time.

Then having "first got your project(s)", then the steps are as follows:

1. Get a group of provider and commissioner organisations together who have purchasing power, by which I mean sufficient power to substantially increase the business of suppliers who can provide solutions and decrease the business of those who resist. This is hard but avoiding this step by going for standards first is a cart before the horse. There is often a misunderstanding of cause and effect with regard to standards. Standards are an effect of the desire to interoperate at scale and not a cause.
2. Create a community of interested clinicians, informaticians, technologists, suppliers, people with influence, and digital leaders and set out to rapidly create a variety of straw man standards proposals that are "just about right" for the tasks in hand. Call it INTEROPen.
3. At a project level get a group of healthcare professionals and technologists together, a mixture of those responsible for delivering services to real patients and those commissioning those services. Only include those people who understand how computers work, have an interest both in delivery and the information model, can communicate well with each other, are collaborative in nature, and prepared to give their time. Include supplier technologists and clinicians who have already been incentivised and are chomping at the bit to get going. Exclude the mealy mouthed and those that provide lip service.

This step is even harder than step 1 as very few people have both time and genuine mouths.

4. As a group select your preferred "starting point" for the standard you are planning to use. Select a standard that is likely to be closer to the ultimate information model target than the currently deployed standard. Do not stay still and do not go backwards, choose something that is nearer to the model target and solves the immediate problem and makes the next project easier also. Funnily enough the one from the community in step 2, can't think why.
5. Then get to it, using the expertise available. If the standard does not quite cope with what you need for your project, then do something that's quite like the standard, but don't worry if it is not actually totally the standard. Remember that in any event the standard will have been replaced by the time you have implemented it, probably by something even closer to the target. **The standard is negotiable**, right up to the point at which the beta phase is signed off. After that **freeze it** until the next upgrade.
6. Don't get hung up on the standard and remember that the real issue is making sure that the stuff produced is clinically safe rather than 100% accurate. Nothing is any good until a

clinician sees data passing from one system into another and achieving the objective. This is the start and the end. The bit in the middle is the easy bit.

7. Remember that the implementation schema need not be the same as the information model. Accept pragmatic suggestions from suppliers. Make sure you and they have the implementation tools available so that developers can develop, testers can test, and clinicians can understand. If you need to hire an expert to interpret a message, then you have got the wrong solution. Give it to an ordinary doctor or nurse. If he or she can read it and understand it, it can work.

Finally, throughout all meetings, workshops, conferences, commercial negotiations and internet correspondence, have in mind the patients who are dying on trolleys in hospital wards for want of a bed. Remember why you are doing this and the cost of failure and the benefit of success.

Yours in hope and expectation!

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