

BCS Health Open Debate on Hospital Data and Data Sets Collection

9 September 2013

What data exists now and what are our priorities for data collection?

Current hospital systems retrospectively record activity data for inpatient, outpatient and all attendances, with only limited clinical information, just diagnosis and procedures. This information collection is driven by income generation for fee for service payments and is submitted to SUS form which HES is derived. This data is not typically collected by clinicians at point of care for clinical purposes. There are other central returns for discrete datasets.

A starting point would be to understand what data is currently available outside of HES. Laboratory and pathology results are mainly digitised and accessible. As a priority additional diagnosis information such as dates of diagnosis would help to understand the patient journey and build better patient pathways. Whilst we are not yet in a position where such additional data would aid clinical decisions, accurate and timely updated data will improve the quality of care given to patients and provide a richer view of patient care across the care continuum.

The group agreed that the potential scope of acute data extracts that is being consulted on was hugely ambitious and many thought could take 15-20 years as it has done in general practice.

It is widely accepted that electronic patient records are a cornerstone. But the current reality is that most hospitals are only just now starting to put in order communications, clinical documentation and electronic prescribing that will derive the richer clinical data that is being sought. This capability requires local investment but importantly requires extensive transformation programmes to successfully drive clinician adoption and usage. The group recognised that hospitals have a maturity roadmap to digitisation of the clinical information and that care.data's ambition will need to align to this natural process but that this could be accelerated through initiatives such as the current Technology Fund for safer hospitals.

What about the priorities for other types of data such as PROMs and PREMs and having them linked, after all we need to know the outcome of interventions.

What needs to be done to achieve our priorities and improve data collection?

It was agreed that the data extracted needs to be derived from data generated by clinicians that has been collected for direct care purposes. Whereas at the moment the data collection drive has been business and administrative. These have to come together with business purposes being driven from clinical purposes.

The collection of data should be prioritised by demand. Who needs this data and for what purposes? What are the use cases for which we need the data? Should NHS England set the clinical challenges that need resolving to generate the requirements for what data needs to be centralised? Without such an approach guiding the prioritisation of what needs to be extracted, there is danger that much time effort and money is spent without the expected return on investment.

A call was made for an incremental approach, where effort is constrained to realistic data extractions to gain the learning of how the information can be utilised with demonstration of results and benefits, before the next incremental is invested in.

Achieving a dataset requires published formats, extensible definitions and a starter data set agreed.

Change through increasing awareness and sharing knowledge is required at clinical team level, all stakeholders need to understand the processes followed to collect data and to also understand the value data collection can provide.

Need to do this and maintain the 'context of care'. Providing data liquidity and access through portals in the local market are not sufficient if we cannot help patients and carers understand the context of care and where patients are on their care pathways.

What are the challenges?

Data is a currency, to maximise the potential that the data can have for health economies, quality of data is needed to raise its value to data consumers. Improving the quality of data is a huge challenge that needs addressing just as has been the case in general practice. A multi-pronged approach will be required including standards for clinical content, professionalism standards for clinicians, contractual obligations through commissioners, and so on. Do we need funding for data to be checked at source at the clinical team level? The patient has an important role in improving data quality especially as they will increasingly access and control their medical records.

Although much progress has been made on clinical noting standards that need to be adopted, there is no agreed standard for clinical content at the data level. This has resulted in a marketplace of systems that have proprietary information models, and even if content was standardised there will be other reasons for variations like laboratory reference ranges will vary with different equipment manufacturers. This must be understood as linking data in care data through NHS number and demographics is not sufficient for interoperability of data from different systems for onward analysis. This could impact and limit the possible uses of the data. Record standards provide a long term solution, in the short term greater awareness of the different methods and purposes of data collection will help remove silos and maximise the use of existing data. Will HSCIC help to manage this data linkage or leave to others? What happened to the NHS logical data model?

It is widely acknowledged that coded data makes for cleaner analysis, however we must not discount the masses of free text data available and the potential value that it holds, to a certain extent you could argue that the over structuring of data could have an adverse effect through interference thus reducing

the quality of data for research purposes. For example the system may record an antibiotic prescription in one place and a diagnosis of chest infection in another place, but it could be the unstructured text that records that the antibiotic was prescribed for the patient due to their chest infection.

Google did not specify how data should be submitted to it, but it dealt with the complexity of data that was out there and made sense of it. Google Flu Trends does just this to predict outbreaks of flu just as well as any structured programme. We will never harmonise data standards across all health, social care and wellbeing settings – there will always be heterogeneity. So how much effort do we need to put in to standardising data at the front end compared to the effort to put in to managing complexity in the backend making sense of it. The answer is that we need to do both – and we do need effort to standardise where it makes sense as that supports delivery of safe patient care.

Information Governance needs to be proportionate and will continue to create challenges for the process of collecting and using data, transparency of how data will be used is necessary to continue the trust that a patient has with their clinician. Control of risk is essential, and we need to acknowledge that as touch points, such as when someone visited a hospital, go up so the anonymity of data reduces.

To maintain the value of data to the consumer, data needs be current and easily accessible. At present data consumers are able to collate rich data directly from hospital providers. Using a central hub could extend the process of acquiring data and devalue the data available, it is essential from the consumer's perspective that HSCIC and data controllers have efficient processes in place to release data.

Moving from recording patient consultations and interactions on paper to recording in IT systems is likely to strain resources, it assumes a degree of computer literacy across the health sector to be truly achievable. It's to be expected that resources will face initial strain until the level of computer literacy is increased across the NHS, therefore change needs to take place at a pace which is appropriate to the resources available and their perceived value for collecting the data.

To resolve some of the difficulties associated with collecting data, the health sector needs to learn from companies such as google. Whilst ambitious programmes of collecting data can provide motivation, progress requires continuous incremental review and planning to ensure the best possible outcomes are achieved.

Thinking further ahead, how do we build on NHS data collection and link into other Public Sector data collection such as the police and social care?

The centre needs to provide clarity on what is there to do and what it is not going to do. It is clear that some areas where industry provided services will now disappear. But without this clarity industry will be uncertain and may hesitate in its innovation and development of services if it thinks the centre may end up doing and effectively removing the market.

How can NHS England better support data collection?

- Engage and work with stakeholders
- Invest in the basics such as data quality and data validation
- Give incentives for providers to collect high quality data
- Provide data standards so that implementation can be guided to enable consistent analysis
- Fund initiatives to stimulate adoption of EPR programmes
- Penalties for providers who do not meet quality standards enforced through commissioners contracts and the quality regulator, CQC

How can hospitals make use of this initiative to improve care and what are the benefits for engaging?

If hospitals and their staff are not clear on what value it derives for them and why they are doing it, this initiative is unlikely to be a success. This is compounded by the fact that the data capture does not come for free and that it is entangled with the investment required for electronic patient records systems and the associated transformation and culture change.

If the initiative encourages and supports the planned roll out of electronic patient records systems, then hospital providers will benefit from the local capture of clinical information. If electronic patient records are implemented to the extent that clinical decision support can be used there will be benefits to individual care, improved safety and standardisation of care and increased efficiency.

Hospitals will need access to national data for research and to direct patient care decisions. By way of example - with the advent of personalised medicine through the adjoining of genomics data to patient medical records comes new challenges. If we discover 200 genetic variants of a cancer rather than the 5 histopathological types we are used to, then it will soon be clear that a hospital provider no matter how large they are will not have sufficient patient numbers for each unique type to learn how to treat each unique type.

How do hospitals need to change and how will this initiative enable hospitals to focus on the patient care pathway?

All clinicians should be made to use a 'system,' they should not rely on information to be inputted by others, the positives of this would create 'real time' point of care data that can be used immediately.

Accurate data will assist re-admissions and ensure a course of action is taken with a holistic view of the care recently given to a patient.

The change in practice requires education and knowledge sharing. Progress requires increased computer literacy and a promotional piece around the added benefits. Increased confidence in using technology will help assist clinicians to focus on the patient care pathway using real time information.

Hospitals need to be more agile for change. We should focus on younger generation coming in to the work place with different attitudes to technology and data to disrupt and champion.

Conversely, there is a risk that this initiative could drive focused data collection rather than making the flow of clinical information as part of the patient pathway more complete.

What does it achieve at a national level and what are the limits of its use?

At a national level, the use of hospital data can be used to standardise levels of care and deficiencies in care for common conditions will become more apparent.

The use of data will enable better analysis of patient journeys across the country, providing more information on the effectiveness and outcomes of care pathways. However, limits of use may be that at a national level the context of the data is lost.

There is a really important community angle. This data has the potential to assist with assisting equality of care services across the nation. It can also support services being tailored for the specific needs of a region and identify wider social issues affecting each community. The potential benefits could go beyond health, for instance a regional boom in child birth could forecast an increased need for schooling or other infrastructure.

National data collections have the potential to allow analyses of the effectiveness of new practices and select regional areas which have the correct conditions to test new practice. Is the cancer data we already have an early opportunity to show benefits.

We shouldn't see this central mechanism as the only mechanism as it will become the lowest common denominator. We also need local projects with local richness of data and knowledge.