

**BCS, The Chartered Institute for IT
Consultation Response to NHS England HSCIC's 'Hospital Data and
Data Sets Collection':**

**NHS England and HSCIC's 'Hospital Data and Data Sets Collection':
Dated: 16 September**

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NHS England and HSCIC's 'Hospital Data and Data Sets Collection': Dated: 16 September

Closing date: 16 September

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

Currently 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.

Early priorities

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.

BCS Recommendation: Extract data that is already widely available where it enriches current data such as HES, as this could provide some early wins.

EPR implications

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 successful 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.

BCS Recommendation: Align hospital data extraction plans to EPR maturity adoption models, ensuring extracts are optional for higher levels of functionality that have not yet been obtained by the majority of hospital providers.

BCS Recommendation: Accelerate the roll out and adoption of EPRs through incentive programmes such as 'Safer Wards, Safer Hospitals' Technology Fund. In 2010 [ref 1] we recommended that all organisations providing care to the NHS should be given notice that they will be expected to use EPRs in a meaningful way within five years.

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

Driven through clinical care provision

Like others, BCS believes that 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.

Change through increasing awareness and sharing knowledge is required at clinical team level.

BCS Recommendation: Data should be derived as a by-product of direct care provision for patients wherever possible.

BCS Recommendation: Stakeholders need to understand the processes followed to collect data and to also understand the value data collection can provide

There is a need for this initiative to maintain the 'context of care'. Providing data liquidity and access is not sufficient if we cannot help patients and carers understand the context of care and where patients are on their care pathways.

BCS Recommendation: This initiative needs to maintain the 'context of care' to best support patients and their carers.

Value based prioritisation

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.

BCS Recommendation: The data to be extracted from hospitals should be prioritised based on demand and clinical value, and evaluated against the cost and return on investment.

An incremental approach is required 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 data extraction is invested in.

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.

BCS Recommendation: Plan for incremental increases in data extraction with each increment needing to demonstrate value to patients and care professionals.

What are the challenges?

Data Quality

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. The patient has an important role in improving data quality especially as they will increasingly access and control their medical records.

BCS Recommendation [ref 1]: Weaknesses in data quality need to be addressed at the point of collection through data standards, validation and enforcement. BCS recommend a multipronged approach through:

- **determining a minimum set of information agreed with the health and care professions that has value to the care process**
- **clarifying the professional obligations and professional monitoring for data quality and completion of minimum data requirements;**
- **clarifying the legal obligations of organisations around data quality and completion of minimum data requirements;**
- **greater external scrutiny and audit of data and information quality;**
- **creation and enforcement of clinical standards/guidelines for record-keeping, data recording and sharing, with intercollegiate standardisation across Royal Colleges and professional societies to ensure that information is comparable and terminology consistent;**
- **imposing national data standards inside contracts with health and care providers, with penalties for non-conformance.**

BCS Recommendation [ref 1]: Reinforce data quality through both professional and public data and information audit. We recommend a multipronged approach through:

- **transparency of provider and commissioner information to enable the public to hold their local health system to account;**
- **encouraging patients to access their medical records and feedback on data inconsistencies;**
- **encouraging a market for data quality facilitation tools, such as medical record audit tools, training services and peer comparison;**
- **inspection enforced through commissioners contracts with health care providers.**

BCS Recommendation [ref 1]: We recommend that the annual financial audit of health care providers should include a check that the data held on their core data systems matches the data submitted to the Care Quality Commission (CQC), Monitor, the commissioners and other statutory returns.

Clinical informatics

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?

BCS Recommendation: Hospital data extracts will require published formats and extensible definitions along with a logical record architecture to support data interoperability.

BCS Recommendation [ref 1]: We recommend the creation and enforcement of clinical standards/ guidelines for record keeping, data recording and sharing, with intercollegiate standardisation across Royal Colleges and professional societies to ensure that information is comparable and terminology consistent . [Appropriate leverage of the Professional Records Standards Body will be vital].

BCS Recommendation [ref 1]: We recommend that data standards/ guidelines for sharing structured medical record data with patients should be put in place and that these should strongly encourage the move to use of plain English in medical notation.

BCS Recommendation [ref 1]: Alongside clarity on the data standards that must be followed and a regime of penalties and sanctions on organisations that fail to comply, BCS recommend that an obligation be placed on any organisation that has the power to set a mandatory standard – such as commissioners, Monitor, CQC – to behave professionally.

Analytics

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.

Recommendation: Standardise data at the front end of care delivery where this makes sense, but also expect to leverage new technologies to manage the data heterogeneity that will inevitably exist across the health and wellbeing sector.

Information market

To maintain the value of data to the consumer, data needs to 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.

Recommendation: HSCIC and other safe havens must have efficient and inexpensive processes in place for releasing data, whilst maintaining proportionate information governance.

The HSCIC needs to provide clarity on what it 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.

Recommendation [ref 1]: Clarity of roles is required for the Health and Social Care

Information Centre and the marketplace in terms of information management. This must offer

an integrated view of the health market and the supply chain that will come together to deliver information services. This is critically important to help shape a vibrant market through leadership and signalling of how everyone can appropriately engage. Core functions of the centre would include setting data and indicator standards, deciding and controlling national

data requirements, ensuring data quality and publishing official statistics and data.

Recommendation [ref 1]: The Health and Social Care Information Centre needs to ensure better informatics impact assessment at the earliest stages of Department of Health policy development. Data quality, data standards, public trust.

Recommendation [ref 1]: It is important that providers of care to the NHS and their informatics suppliers are given appropriate notice and reasonable time to prepare for the data standards that are to be imposed.

Staff training and education

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.

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.

BCS Recommendation [ref 1]: Education curricula for doctors, nurses and other care professionals be adapted to educate on the use and value of data and information and the use of information and tools with patients. For those that are already practising, education should be provided as part of the continuing professional education.

BCS Recommendation [ref 1]: We recommend that a sustainable health informatics workforce capacity and capability infrastructure is put in place, spanning health, public health and adult social care, and the public, private and third sectors. Such an approach should be encouraged by commissioners and regulators as a means of improving the quality and professionalism of the health informatics workforce and thereby the quality of data and the management of patient- and organisation-critical IT and information systems.

BCS Recommendation [ref 1]: We recommend that the development of a range of clinical coder training is continued and that coder and information analyst development centres are established across the country to provide training and wider professional skills; quality-controlled by the Department of Health, but provided by NHS, academic or commercial bodies.

Information governance

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.

BCS Recommendation [ref 1]: Guidelines must be clear when care professionals should share identifiable patient data in order to create anonymous merged data sets for secondary purposes. They must also be clear when it is legitimate to re-identify the patient without consent when new concerns are coincidentally discovered in pseudonymised data sets, as a care professional would normally do under their duty of care.

How can NHS England better support data collection?

Recommendations are covered in other sections. In summary we feel NHS England can better support data collection through:

- 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.

Recommendation: Align the clinical data extraction requirements to progress in implementing richer clinical EPR functionality releasing benefits locally. If clinicians understand the value of the data locally they will understand the need to make this data available more broadly.

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.

Recommendation: Working through Academic Health Science Networks and Local Clinical Research Networks we recommend clinical research is integrated with clinical care provision to create a virtuous value cycle where evidence based research findings are more rapidly adopted in clinical care and data from clinical care more rapidly supports research.

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

All clinicians must use health IT solutions for capturing clinical information and they should not rely on information to be inputted by others. This data needs to be input in a timely manner at the point of care. By way of example nurses failing to enter patient observation data until the end of their shift will prevent the identification of patients at risk of sepsis. 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 capture and real-time of clinical data will drive up data quality.

Recommendation: Clinicians must be responsible for entering clinical data, and capture needs to occur as close to the point of care as possible to maximise patient safety and increase its utility and quality.

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.

Online Consultation <https://consultations.infostandards.org/nhs-england/hes/>

References

Ref 1: Recommendations made in the BCS Health report 'Preparing the NHS for an information revolution' <http://www.bcs.org/upload/pdf/liberating-the-nhs.pdf>

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