

Cerner Ltd. Response to the Consultation ‘Making Open Data Real’

Introduction

Cerner warmly welcomes the Coalition Government’s consultation paper: ‘Making Open Data Real’ and its vision to ensure ‘Open Data’ becomes the operating principle of public services. We agree that more accessible, higher quality data can support better quality public services that are more responsive to individual and community needs, giving freedom and professional discretion to those who deliver them, while providing better value for taxpayers’ money.

Cerner recognises that Open Data empowers individuals and enables them to choose what sort of public service they want and find the best provider to meet their need. We agree that more needs to be done to ensure citizens can access meaningful data about their public services and believe that individuals should have a right to access and control their own service use record, such as their personal health record (PHR).

Given Cerner’s expertise in working with the NHS for more than two decades, and that our electronic medical record system is in place in 25 countries on six continents, we have chosen to demonstrate in our response how the six opportunities of Open Data, identified in the consultation paper, can be realised through the implementation of electronic medical records. In addition, we have set out how integration and operability standards could be developed to increase the diversity of provision without hindering the integration and coordination of care.

Cerner hopes to work as a constructive partner with the Government and the Cabinet Office in realising the vision set out in ‘Making Open Data Real’. We would welcome the opportunity to discuss with officials how we could use our international experience, reach and existing relationships with providers of NHS services to support implementation of Open Data.

Realising the potential of Open Data: electronic medical records

1. Accountability

In order to demonstrate accountability, Cerner believes that every NHS organisation (hospital trust, community service or general practice) collecting coded clinical data at individual level, whether this be an electronic patient record or retrospectively coded data, should allow patients free remote access to the data about themselves from a home computer, with appropriate individual security¹.

Furthermore, a standard anonymised data set of clinical, quality and access measurements could be required in a timely manner from all providers of healthcare to the NHS and this data set could be placed into the public domain to enable effective scrutiny of health services. A range of clinically evidence based outcome indicators could be developed by NICE and the Care Quality Commission (CQC) and placed into the public domain to give healthcare professionals comparative data that identifies and encourages excellence, and drives up quality and outcomes. These indicators could be applied to NHS data and the

¹ This would provide access to the data but would not allow patients to change it without specific controls in order to avoid system abuse for purposes such as insurance or employment. Nevertheless, there would be legitimate reasons to change data, e.g. a new address.

results made available through NHS Choices on a monthly basis to support the provision of real and effective patient choice.

2. Choice

As the policy of allowing patients free remote access to their health records is being implemented, organisations could indicate whether this service is available (i.e. that patients have the ability to choose providers that can offer this service). This service could be made available by having a single public portal to all NHS data that can influence choice. Part of the problem facing 'would-be consumers of choice' is where to find meaningful data: it is across multiple websites, a number of which are not available to anyone but NHS employees. There needs to be a single simple source of 'choice' this could be under the management of the NHS Information Centre (NHS IC).

Centrally gathered statistical data could be anonymised and put into the public domain free of charge to enable detailed analysis. The NHS IC could be responsible for clustering and linking this data and providing sufficient information on data set sources and data item meanings to allow appropriate interrogation by those seeking to analyse the data. The data could be sufficiently granular to allow comparisons to be made at a level that aligns with the level of choice that patients are being offered. Performance data gathered by commissioners, the Department of Health or other tiers of health service administration could be routinely placed in the public domain in a timely manner, approximately 28 days from measurement, to allow further analysis and publication.

Data already collected by Choose and Book could be used to improve utilisation through more informed choice; options include:

- Publishing data on the number of bookings that fail due to slots not being available in the provider system for electronic bookings or the provider system not being available. Currently, the failure rate is approximately 15%; this is an indication as to which providers are failing to open their systems to Choose and Book and enable individuals to make more informed decisions on where they would prefer to be referred to by awareness of providers mainly offering paper based referral.
- Publishing the number of electronic bookings made and the providers referred to (broken down by GP practice); this could be compared with traditional paper referrals and expressed as a percentage of 'patient choice' available. This could be used as a proxy measure for the extent to which primary care providers are offering genuine choice to patients.
- Publishing the percentage of outpatient appointment slots that are made available for Choose and Book electronic referrals, broken down by providers. Again, this could be used as a proxy measure for the extent to which providers are offering genuine choice.
- Providing greater public access to a catalogue of services available from providers so patients can make their own independent search in order to inform any discussion they make in consultation with their GP.

Cerner believes Choose and Book could evolve from an application that allows patients and GPs only to book an initial out-patient appointment at any willing provider to one that operates as a 'choice facilitation engine' which could enable increased scope into follow-up appointments, tertiary referrals and walk-in clinics. Any new version of Choose and Book could provide a standard interface search function by providing an integration layer that allows patients to use any tool or application that conforms to the integration standards to query, make or change bookings. This service could be made available by:

- Developing the choose and book application so that there is screen integration into GP systems thereby facilitating use with patient data across both systems;
- Making Choose and Book available for interrogation by patients – there is potential for having two levels of access to Choose and Book in order to enable GPs and the general public secure access; bookings made by patient/general public would still need the secure access number to complete a GP referral booking;
- The existing Choose and Book application could retain its overall intelligent architecture but become cloud based with a published layer conforming to defined integration standards²; and
- Extending Choose and Book into enabling choice of GP or primary care provider by enabling the booking of appointments at GPs and other primary care providers. GP performance data could be publicly available enabling valid choices for patients when they are looking for GPs that provide specialist services e.g. specialist female care.

3. Productivity

Cerner agrees that public reporting of costs and comparative outcomes can be an effective driver of efficiency. Without greater use of high-quality and accurate data, the NHS cannot create the required productivity savings i.e. the need to reduce the NHS's projected costs by £20bn over the next five years whilst maintaining or improving patient outcomes.

Providing online access to medical records can enable the delivery of healthcare services to be changed radically while reducing costs and improving quality of services. For example, electronic medical records can drastically cut the time healthcare professionals spend manually charting patient data, improving management of clinical resources, and enabling clinicians to treat patients in a more timely fashion which will help with their recovery³.

4. Quality and outcomes

High-quality and easily accessible data is a pre-requisite for driving up quality of care and patient outcomes. Electronic medical records can be integrated across devices enabling clinicians to access real-time data such as lab results across hospital departments, to make more informed decisions leading to improvements in patient outcomes and the delivery of more co-ordinated care.

Electronic medical records can improve diagnostic accuracy as they enable clinicians to see immediately what has been advised by their colleagues and access the patient's test results. Furthermore, electronic medical records can improve the safety of healthcare delivery. Evidence shows that computerised physician order entry (CPOE) has been proven to reduce medication errors by up to 84%⁴ while electronic medical records have been successfully used in the US to quickly inform healthcare professionals about drug recalls⁵.

² As the designers of the Choose and Book system, Cerner would be happy to share with the Government on a confidential basis our analysis of how the core Choose and Book system could be developed to become a hub supporting multiple clients making enquiries and bookings and many vendors receiving those queries and instructions.

³ Penn State Hershey Medical Centre, the US.

⁴ Source: AHRQ hospital, the US

⁵ http://www.cerner.com/blog/how_EHRs_can_improve_safety_of_healthcare_delivery/?langType=1033

In addition, evidence based guidance can be integrated into electronic medical records to support clinicians in delivering high-quality care. For example, the BMJ Evidence Centre has developed 'Action Sets' which pre-define the appropriate diagnostic and treatment orders for a range of common conditions covering up to 90% acute admissions. The use of Action Sets has been shown to improve consistency and quality of patient care, reduce handwriting and transcription errors as well as helping to ensure local and regional guidelines are observed. Properly implemented Action Sets improve patient safety as they enable clinicians to easily access most up-to-date evidence, guidelines and research.

Following appropriate security checks and taking into account the needs of vulnerable groups, patients could be able to download their PHR which would be separate to their electronic medical record. The PHR could be available in a standardised format and patients would be empowered to both hold and update the record. We believe that patient outcomes are significantly enhanced when patients play a greater role in the management of their care – this has been the case within maternity for a significant period of time already with widely acknowledged improvements in overall outcomes.

Cerner agrees that publication of meaningful data can improve patient engagement and participation in their care. We believe that three things need to be in place for patients to be able to fully participate in their care:

- The patient requiring access to a personal health record which is owned by them and containing both information gathered by the NHS and notes taken by the patient – they would also have control over whom has access to their data;
- The patient needs to know what to expect from the NHS together with their care timetable (including information such as expected length of stay) so that they know if what they are receiving is standard practise – hospitals could be required to send out an expected pathway with every appointment letter; and
- Patients need to have the opportunity to be brought together with other people with the same condition or circumstance – this could be done through a variety of social and other networking practises. For example, sophisticated search technology could link patients anonymously, where a patient has said they are prepared to be found. A tool running across the spine could allow a patient to hit the 'find someone like me' function by matching a range of variables provided by the patient; it could search across all the patients who have said they are prepared to have their data searched and provide potential compatible matches⁶.

At least as important as making it possible for patients to be empowered consumers of healthcare is the need to enable and incentivise patients to be full participants in the management of their health. Thus, it could be argued that the NHS needs a fundamental shift to:

- Patients managing their own health with technology designed to prompt them over such issues as diet and exercise;
- Patients managing their own long term condition with technology enabling the patient to monitor and adjust their lifestyle, adjust their medication or determine when they need treatment; and

⁶ Cerner has developed unique natural language searching of health information. We would be willing to show this to the Government, on a confidential basis, and explain how it could support social networking, as described in the paper, and transform the potential of the NHS to offer a world leading environment for quality management, research and scientific development.

- Patients using the internet to manage their interactions with the NHS including:
 - Booking, cancelling and rearranging their appointments, reducing the need for appointment clerks;
 - Checking themselves into appointments and correcting their personal details at booths in the GP surgery or hospital clinic;
 - Interacting with a clinician by phone (landline, mobile and VOIP), text, webcam, or email, rather than requiring a face to face appointment; and
 - Carers getting advice and support from the NHS through the internet, expert applications and on-line support groups.

Examples of technology being used in this way include patients attending anti-coagulation clinics to have their dosages adjusted. There are 900,000 patients being managed either by regular appointments with their GP or, quite frequently, attending packed hospital outpatient clinics. A Lancet meta-study⁷ indicated that if patients are capable of self-monitoring and self-adjustment, outcomes are often better. In the trials, 38% of patients were happy to self-manage their medication and it has been estimated that up to 90% of patients would be capable to do this with proper guidance. Technology and trust can create better outcomes at lower cost. We believe that many of these examples already happen across the NHS but that this needs to be replicated on a national basis whilst respecting localism.

5. Social growth

Cerner agrees that the provision of wider online access to medical records will enable the delivery of health services to be changed radically, reducing cost and improving quality of care. Electronic records will provide commissioners of care with the right information at the right time, helping them make informed decisions about future commissioning of services.

6. Economic growth

Cerner recognises that Open Data can be a driver of economic growth and that a new market in healthcare information can thrive if data is freely available in a standardised format for use and re-use. However, there are significant differences across the NHS between the measurement, collection, reporting, analysis and publication of data. Some metrics are measured individually by clinicians but not collected at an organisational level; others are collected but not reported; others still may be reported but not published or used. High quality IT can enable reporting to easily be translated to collection, reporting, analysis and publication of data, maximising the impact and cost effectiveness of data collection.

We believe that access to and the transfer of high quality information in a confidential environment is a key imperative for driving choice and integrating care, translating the concept of any qualified provider into reality. However, without the ability to measure outcomes and indicators, they become meaningless. We believe that the National Institute for Health and Clinical Excellence (NICE) and other Government agencies with responsibility for designing health outcomes and quality measures could gain significant value by engaging with the healthcare information technology community in order to ascertain:

- What is already or can be measured using existing technology;

⁷ Lancet 2006:367:404-11

- What is not currently measurable within existing technology but with minimal adjustment could be measured because of a need for the data from clinicians and/or management;
- What metrics would require significant change in order to measure because of a need for the data from clinicians and/or management; and
- What is not measurable regardless of the need for the data from clinicians and/or management.

We believe that data supplied by any qualified providers to the NHS could be collected centrally by the NHS IC. This could be enforced through commissioning contracts and NICE Quality Standards. Within a month of receipt, the NHS IC could publish all the data it receives whilst maintaining the appropriate level of confidentiality for patients. This could provide a market opportunity for both the presentation and comparison of any willing provider data.

An Enhanced Right to Data

- Is providing an independent body, such as the Information Commissioner, with enhanced powers and scope the most effective option for safeguarding a right to access and a right to data?

We believe it is important that an independent body, such as the Information Commissioner can safeguard a patient's right to access data. The Information Commissioner's Office (ICO) is committed to upholding the data privacy of individuals and their right of access to official information held by public authorities. The ICO already carries out data protection audits with NHS trusts so it would be sensible to enhance the Information Commissioner's role as part of the implementation of the Open Data agenda.

- Are existing safeguards to protect personal data and privacy measures adequate to regulate the Open Data agenda?

Cerner believes that the Data Protection Act and the Privacy and Electronic Communications Regulations provide a robust regulatory framework to support the regulation of the Open Data agenda. However, as the Government's proposals are further developed, existing legislation will need to be reviewed to ensure it is fit for purpose. In addition, existing guidelines used by NHS organisations, such as the Information Governance Toolkit should be reviewed and updated to assist trusts in implementing the Open Data agenda.

- What might the resource implications of an enhanced right to data be for those bodies within its scope? How do we ensure that any additional burden is proportionate to this aim?

It is important to conduct a thorough impact assessment of the new requirements of the Open Data agenda to ensure the regulatory burden on the bodies within its scope is proportionate.

- How will we ensure that Open Data standards are embedded in new ICT contracts?

Setting Open Data standards

- What is the best way to achieve compliance on high and common standards to allow usability and interoperability?

Increasing the diversity of provision (and therefore choice) need not be at the cost of hindering the integration and coordination of care. Developing and enforcing integration and operability standards in the software supply market will be critical to ensuring this premise. The Department of Health could (either itself or through an arms-length body or through a subcontracted organisation with no links to a supplier) develop the Interoperability Tool Kit (ITK) to provide 'plug and play' standards and an environment for testing kite-marking compliant software. The NHS could seek to adopt internationally recognised industry standards wherever possible in order to reduce the cost of developing and implementing solutions in the NHS; the major vendors in each health and social care sector could form a panel to give advice on these standards. The kite marking services could be funded by charging the industry for testing services, in return for which, testing will be undertaken expeditiously. Standards and kite marking could be extended to patients' own devices; this way, a network of home devices, purchased by a patient on the high street, can be created that can be connected to the internet and used to upload data into the patients' PHRs.

We believe that in a devolved NHS, with reduced top-down control, it is vital that the National Commissioning Board, the regulators and other powerful forces – the CQC, NICE and the NHS IC – be accountable for minimising the burden on healthcare providers and maximising the information available to the public. These organisations could align their information requirements in a coherent manner, ensuring that the data is captured once for commissioning, quality inspections and public review, and is published to a common set of standards. In order to do this they could form an Information Policy Board, chaired by the Chief Executive of the Commissioning Board, to agree data requirements and publication standards. Additional data requirements set nationally could be notified to the Secretary of State in writing by the Chair of the Board; the minutes of these meetings could be published and they could take advice from a panel of major suppliers, major NHS and independent sector suppliers and academic institutions, whose advice could also be published.

- Should we consider a scheme for accreditation of information intermediaries, and if so how might that best work?

We would encourage the Government to develop kite marking for providers wanting to store PHRs on behalf of patients. Requirements for obtaining the kite mark could include the ability to delete all trace of the PHR on request of the patient. We would be happy to work with the Government and other stakeholders to develop the kite marking scheme for providers.

Corporate and personal responsibility

- What could personal responsibility at Board-level do to ensure the right to data is being met include? Should the same person be responsible for ensuring that personal data is properly protected and that privacy issues are met?

Cerner would like to see every NHS provider to appoint a chief clinical information officer (CCIO) who would have Board-level responsibility for information quality and transparency. Cerner believes effective information project design and delivery requires board-level championing and CCIOs can provide long-

term commitment, expertise and leadership on IT projects as well as to ensure that information is used to improve services.

In many NHS trusts the Chief Executive has the overall responsibility for data protection within the Trust. In addition, trusts have a dedicated board member responsible for ensuring the Trust complies with the Data Protection Act as well as information risk officers and dedicated information governance managers to ensure the Trust's compliance with existing legislation.

As the Government's proposals for Open Data are further developed, it will be important to consider whether responsibility for ensuring a patient's right to data should fall under the remit of the existing data protection arrangements or whether, for example, a CCIO would be the most appropriate person at Board-level to have responsibility for this issue.

- Would we need to have a sanctions framework to enforce a right to data?

The Information Commissioner has a number of options available for taking action to change the behaviour of organisations and individuals that collect, use and keep personal information. They include criminal prosecution, non-criminal enforcement and audit. As the Government develops its proposals for Open Data, Cerner believes they should investigate whether a similar framework of sanctions could be developed to enforce a patient's right to data.