A Vision and 12 Point Plan for Chief Clinical Information Officers, to ensure the quality of NHS clinical information

January 2014

Introduction

The NHS is in a unique position to collect share and apply clinical information to improve health. The information on one of us can help the health of all of us. We can rightly be proud of how information and the knowledge it has generated has saved or transformed lives, but recognising this also means accepting that the stakes are high. Failure to deliver on the promise of information will be a failure to improve services and health outcomes. We cannot afford to miss this opportunity if we are to deliver sustainable, high quality health services which are equipped to meet the challenges of an ageing population.

Yet too often potential has not been realised. The CCIO movement in the UK has been born out of the frustration experienced by clinicians scarred by the National Programme for IT. Three tribes struggle for the soul of every electronic patient record project, the clinicians who need a way of recording things as convenient as pen and paper, the managers who need to count activity and the IT crowd who need to deliver the technology.

We need to remember that the ultimate goal of health informatics is to improve patient care. Within the NHS, it is the clinicians who are the principal users of information systems. It is also clinicians who are closest to the needs of their patients. If systems don't work for the clinicians, then they don't work for anyone.

The National Programme for IT forgot that clinicians are the prime collectors and users of information and, when the error of this was realized, clinical involvement was tokenistic, too little and too late. The success of electronic patient records in general practice shows what can be achieved when the clinician is in the driving seat. Our task is to replicate this in other care settings, albeit at a larger and more complex scale.

Hard lessons have been learnt and we are determined that in future the clinical voice should guide IT development, informed by the interests and preferences of patients. The formation of the CCIO leaders network is part of our contribution to achieving this. It is easy for us to blame others for past failures, but we must also accept responsibility for delivering future successes. We will get the clinical information systems we advocate for. Fully functioning electronic patient records, used to their full potential, have the potential to deliver more health gains than any other intervention. We need to act like it.

This is why the development of a cadre of professional CCIOs is so important. We must make it our task to ensure that the NHS gets the systems it needs to deliver the information required to drive quality of care. In doing so, there are certain truths we hold to be self evident:

- If a clinical information system is to serve patients well it must first serve clinicians well.
- Clinical information systems must involve users in their design and continuous improvement.
- The NHS needs a vibrant, open market in EPR systems which is transparent from the point of view of usability, functionality and crucially, cost.
- The use of standards to promote open and interoperable systems, enabling the sharing of patient data is essential. This commitment to openness must extend to collaboration and exchange of best practice. For many CCIOs the collaborative nature of open source software development is particularly attractive, being analagous to medical practice.
- Implementation of clinical information systems will not be successful if they make clinicians' lives harder

This document sets out our vision for clinical information, as well as a practical 12 point plan to begin to translate this vision into reality. It has been developed following discussions within the CCIO Leaders Network and is intended to stimulate thinking, debate and action to improve the quality of clinical information in the NHS.

Dr Joe McDonald

Deputy Medical Director NTW NHS Trust

Chairman Chief Clinical Clinical Information Officers Leaders Network

Chairman British Computer Society Mental Health Group

Information can save lives

Some of the biggest health breakthroughs have only come because of the collection and analysis of information. Without the appropriate data, the link between smoking and cancer would not have been discovered, nor would many of the new targeted medicines transforming cancer care. The very process of collecting and publishing clinically relevant data is credited with reducing mortality rates following cardiac surgery by approximately one third.

As well as identifying patterns which can transform the way in which we approach the prevention and treatment of illness, high quality information can improve the quality, consistency, safety and efficiency of care.

Information should be an essential prerequisite of modern healthcare. On a population level, the absence of high quality information is the equivalent of asking a surgeon to operate in the dark or a haematologist to treat leukaemia without knowing a blood count.

Information is a powerful clinical tool

Information is a clinical tool and should be treated as such. We need to ensure that people with the right skills are in a position to lead on clinical information and to maximise the benefit for patients. This means ensuring that senior clinicians have oversight of information policy and implementation, as well as oversight of the systems used to collect the information which will be the cornerstone of modern care.

You wouldn't want someone with the wrong skills and experience in charge of radiotherapy or trauma surgery, so why would you for clinical information?

The cost of failure of information can be every bit as significant as the cost of any other failure in clinical care. For example, a failure to provide information on drug intolerance can lead to a fatal adverse event. Yet the impact of failure can also be more widespread. Although the impacts of most examples of poor clinical practice are isolated to the patient in question, the failure of information can affect many thousands of people; missed opportunities to improve care and money wasted rather than focused on what matters.

Delivering high quality information at scale

As with many areas of healthcare, technology offers the possibility of transforming the way in which clinical information is collected, processed, analysed and used. The opportunity is there to do more, faster and better.

Yet, as with other areas of clinical practice, translating this promise into reality requires careful planning, investment and leadership.

A key benefit of high quality information is that it enables you to learn from previous examples and avoid repeating mistakes. Yet there is a danger that, in information policy, we will repeat the failures of the past.

Few people will defend the NHS IT Programme and it is widely recognised that a major cause of its failure was that it failed to place clinicians in the driving seat. Clinicians were expected to adapt to the technology and not technology to clinical practice. The needs of system engineers were placed above the needs of clinicians or the patients they care for.

Chief Clinical Information Officers

Chief Clinical Information Officers (CCIOs) have been established to address this. CCIOs should provide clinical leadership on all information projects, ensuring that the system is the servant of high quality clinical care and not the opposite.

A step change in clinical leadership on IT is required and the purpose of CCIOs is to deliver it. The CCIO Leaders Network has been established to support this process:

Giving CCIOs a voice

- Creating opportunities from CCIOs to learn from each other

- Persuading the wider health community of the importance of high quality clinical information and the critical role CCIOs can play in delivering it

- Persuading the NHS at every level to introduce policies and practices that deliver high quality information

- Holding the profession to account for its performance

For many clinical information leaders poor experience of clinical information systems provided under the NHS IT Programme and by the subsequent market has proved a formative experience. They, more than anyone, feel the frustration of what has been a missed opportunity to deliver more effective, safer and efficient services for patients.

Yet for others, working on more focused clinically-led programmes, the power of information and the ability to translate potential into practice is evident. CCIOs want to seize the opportunity created by the new momentum in NHS IT policy to improve the quality of information systems, encouraging transparency about performance, openness of systems and a spirit of collective endeavour to deliver the quality of information required for a health system which is ready to face the future.

As a starting point, CCIOs have told us that clinicians, patients and carers should be involved more directly in the design, development and delivery of clinical information systems. Poor clinical information systems should not be tolerated any more than another aspect of health services that potentially damages patient outcomes. There should be transparency over the costs and performance of systems and development should encourage collaboration and contribution from all providers who can make a difference.

Our vision

We believe the NHS should be a system that recognises clinical information as a key part of clinical practice, where the availability of the right information at the right time is as important as the availability of the correct medicines. Where organisations pride themselves on the quality of their information, much as they should do any other aspect of the care they provide.

Most importantly, the NHS should be a system where the information is routinely used to improve the quality of care to patients both today and in the future. Where patients are empowered to use their own clinical information to inform self care, but where the NHS will also use it to ensure that not only are the right services there when the patient needs them, but that the experience of the patient is used to inform the care given to others.

For our vision to be realised, investment in clinical information must match the value it can deliver. Yet, in the medium term, good quality information should enable easier and better clinical practice than what went before. It should ensure that important information is only collected once at the point of care and that patient records become a shared resource for clinicians and patients.

Realising our vision will be a collaborative endeavour. It will involve partnerships between clinicians and patients, between different parts of the NHS system and between suppliers.

Delivering the vision: our 12 point plan for clinical information

The renewed commitment from the Department of Health and NHS England to improving information systems in the NHS is welcome. However, the importance of rapid delivery should not override the need for clinical leadership. Indeed, without high quality clinical leadership, ambitions for an information-led NHS will fail. It is therefore vital that the quality – as well as delivery – of information is included in every aspect of the NHS.

Regulation

Following the Francis Report, there has been a renewed and welcome emphasis on the role of quality regulation, including the appointment of chief inspectors for hospitals, primary care and social care. However, inspection can only be effective if it is based on the right information. In order to support this:

1. The Care Quality Commission should include information quality measures in its inspection criteria for all providers of health and social care

2. The appointment of a senior responsible clinician for information should be seen as one way of an organisation demonstrating its commitment to information quality

Commissioning

Commissioning should be a key driver in NHS quality improvement. However, effective commissioning on the basis of quality is only possible if the right information is available. Commissioning also has a role to play in ensuring that the correct information is collected and used on the first place. In order to support this:

3. NICE should produce a cross-cutting quality standard on clinical information, establishing core standards and metrics for the collection and use of information

4. NHS England should integrate these standards into the Standard Contract for NHS services. The Standard Contract should make clear that all clinical information supplied by providers should be overseen by a lead clinician with responsibility for information quality

5. NHS England's work on the future of primary care and urgent care services should make clear the importance of clinical leadership on information, establishing core common standards across both sectors

6. The Secretary of State for Health should make clear that ensuring the collection of high quality data is an essential prerequisite for commissioners in fulfilling their statutory duty to promote research

Incentives

Financial incentives are an important driver of health service behaviour. However, intelligent incentives which reward improvements in quality can only be designed and implemented with timely access to the right clinical information. In order to support this:

7. NHS England should make clear in its fundamental review of incentives that high quality information is an essential prerequisite for incentives but that incentives can also play a role in encouraging the development of high quality information

8. Quality assurance of information should be made a pre-qualifier for incentives such as CQUIN payments. This could be achieved by a clinician with lead responsibility for information within a commissioner agreeing that information is of a suitable quality

9. CQUINs (or their equivalent) should be used to incentivise the collection of new or developmental data sets as part of integrated information systems. Once an information source is established, it should be viewed as a core requirement of any contract

Quality reporting

High quality care for all made clear that the way in which providers of NHS services account for the quality of their care can be an important driver of quality improvement itself. However, reporting will only be effective if it is based on information which is relevant to patients, the public or commissioners. In order to support this:

10. The Department of Health should update guidance on quality accounts, in line with the findings of the 'Keogh 14' review. It should be mandatory for providers to report on the quality of their data and all accounts should be signed-off by a senior clinician with responsibility for clinical information

11. The Department of Health should involve clinicians and patients in identifying the mandatory quality measures which will be of most use to them

Education and training

Our vision is based on clinicians providing leadership for information policy and delivery. However, at present, little emphasis is placed on the importance of high quality clinical information within medical training. In order to address this:

12. Health Education England should establish clinical information as part of the curricula for all clinicians