

LIBERATING THE NHS – AN INFORMATION REVOLUTION

ACADEMY OF MEDICAL ROYAL COLLEGES RESPONSE

The Academy of Medical Royal Colleges welcomes the opportunity to comment on the consultation paper “*An Information Revolution*”.

The Academy’s membership comprises Medical Royal Colleges and Faculties across the UK. Individual Colleges and Faculties have submitted their own responses to the White Paper and the accompanying consultation documents. This response does not seek to summarise or encompass all those submissions but rather concentrates on some key generic issues which are of interest or concern to members as a whole. As such this response does not directly address the specific questions in the consultation.

General

The Academy recognises the central importance of information both for patients to understand and make decisions about their care and for clinicians to assess and improve the quality of care they provide. The Academy therefore welcomes the proposals in “*An Information Revolution*” and the Government’s commitment to developing and implementing an information strategy that meets the needs of a 21st century health service in supporting patients, clinicians and healthcare organisations deliver and access the best healthcare possible.

The Academy endorses the statement that without fundamental changes to data collection improvements in NHS and social care will be held back. The Academy recognises that key aspects of the Government’s policy such as the Outcomes Framework and increased Patient Choice depend on high quality information. Indeed without high quality information and information systems these initiatives will fail. In an area where expectation has consistently exceeded delivery it is, therefore, crucial that there is real commitment to effective implementation of the ambitions of “*An Information Revolution*”.

As the consultation acknowledges the Academy has adopted a vision for patient focussed records originally developed by the Royal College of Physicians of London www.aomrc.org.uk/publications/statements. It is the Academy’s opinion that this vision should be taken up with a view to having outcome data (and data for many other purposes) derived directly from the electronic patient records that comprise data recorded as part of the process of routine clinical care by 2020. However, adoption of this vision is not merely a specific approach to a technical issue but implies a whole new philosophy towards what information is collected and how it is used. In essence, this entails ensuring that clinicians are engaged with and feel they own the process of data collection and usage in a way that does not currently exist.

Standardisation of data and inter-operability of systems are essential in an NHS with an increasing number of providers. It must be a requirement on new providers entering any part of the market that information that they provide and the systems that they operate must be compatible with the rest of the NHS.

Engagement of clinicians

The Academy believes that one of the fundamental problems with information systems in the NHS at present is the lack of engagement and ownership by clinicians. Many clinicians, and indeed managers, do not feel that the information systems into which they must input data are providing them with relevant, timely and useful information. When users feel that they are merely “feeding the beast” of information collection, it is unsurprising that the quality of data is poor. The Academy endorses the view that accuracy of data is the bedrock for meaningful information.

The Academy fully recognises that much of the responsibility for the quality of data must lie with clinicians themselves. Clinicians need to take that responsibility and ownership of the data, but that will not happen until they believe the systems provide them with useful outputs. The current vicious cycle of poor outputs feeding continued scepticism needs to be broken.

The purposes of information

The consultation sets out headings for different uses of information – patient choices, outcome improvement and accountability. The Academy endorses the principle of recording data once and using it in a number of ways, but it is crucial that there is clarity over the purpose for which information is required. Different purposes will require differing approaches to using the information. What an individual clinician or team of clinicians require to analyse and improve the quality of the services that they provide will not be the same as that which an individual patient requires to enable him or her to make an informed choice about providers, or what a board requires to monitor the performance of their organisation. Information that is not gathered and presented in a manner appropriate to its purpose will hinder informed decision making.

Information for improved outcomes

The Academy has welcomed the proposed Outcomes Framework. Moving to an outcomes based approach for measuring success depends on having the accurate data to inform indicators. The Academy’s response to the Outcomes Framework, acknowledges that the production of accurate data is more developed in some specialties than others. Whilst recognising the difficulties involved it is important that there is progress in developing data and indicators in clinical areas where they are currently less advanced. But is important that, in the meantime, the service does not concentrate only on those things it can readily measure.

Patient records

The Academy is pleased to see that its view on patient records (set out in its statement “*Case and Vision for Patient Records*”) was referred to in the consultation, and consider that the statement is in line with views expressed in the consultation. The Academy statement says that “*electronic records that are focused on the patient, rather than the disease, intervention or location will be essential. Such records must cross organisational boundaries, so that appropriate information can be recorded by both practitioners and patients, and accessed by them, in a wide variety of clinical and care contexts. The record of the dialogue between the clinician and the patient, the decisions made and the actions taken are the cornerstone of the patient record.*”

It continues, “*To achieve clinical interoperability, and to ensure the validity of aggregate information when data from many records are integrated and analysed, the structure and content of the record must be standardised*”. This is crucial to the success of effective patient records. As the consultation acknowledges the work undertaken for the Academy

by the Royal College of Physicians (London) on developing standards in profession record keeping is an important step on that path.

The Academy supports the principle of patients having access and control over their records (recognising the caveat set out in paragraph 2.5 that this does not mean that they will be able to remove the original record from the care provider or alter or delete what a clinician or care professional has entered into their record unless it is incorrect). The Academy considers that if patients have control over their own records it will enable them to have more responsibility for their own care.

Information for patient choice

The Academy recognises the need for relevant and accurate information to be available to patients to assist them in making choices about their care. Whilst patients are obviously able to make decisions based on available information, it is important that the NHS itself seeks to ensure that the information that it provides to patients is clear, relevant and comprehensible. Misinformation and misinterpretation of information is a real danger for patients.

The Kings Fund report "*Choosing a high-quality hospital*" published in November 2010 recognises the value of information for patients but makes important conclusions which the Academy would endorse:

"This research reinforces the importance of paying attention to what information is presented and how, and cautions against a mantra that 'more information is always better'.

People find it difficult to make trade-offs between quality, safety, patient experience and location. Our findings suggest that the government should be cautious about the ability of patients (apart from those who are highly numerate) to make these complex decisions without some decision support."

The report concludes that "*there needs to be an evidence-based approach to the public reporting of comparative performance information in future. Simply allowing all the information currently held about the quality of care to be put in the public domain will not result in people making informed choices.*"

The "presumption of openness"

The Academy supports the "presumption of openness" set out in the consultation. The Government is committed to providing transparency about public service data and believes "*freeing up public data and putting it in people's hands can help them have more of a say in the reform of public services*" (Cabinet Office website). Whilst not opposed to this approach the Academy is unconvinced that all the benefits ascribed to this policy will automatically occur. Simply giving people a plethora of information will not in itself lead to effective engagement about the shape and performance of services. Having an "army of armchair auditors" cannot be a replacement for proper monitoring and auditing of standards.

Academy of Medical Royal Colleges
January 2011