Submission to the Francis enquiry

October 2011

How can information be better used within the NHS?

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Our role

HQIP promotes quality improvement programmes in healthcare based on clinical data and proven clinical best practice. These include clinical audits, registers, databases, confidential enquiries, significant event audit and accreditation. These sources provide a wealth of valuable information to improve quality. HQIP promotes best practice, but also commissions over 60 national or regional data driven quality improvement programmes, including very large studies such as the national diabetes and joint registry audits, which between then have over 4 million records; as well as longitudinal studies which have been operating for nearly sixty years in one case.

This paper covers the use of clinical data and information for secondary purposes, such as planning and monitoring clinical services nationally and locally, and in outcomes measurement and large scale change programmes. It does not specifically cover information in use at an immediate level for clinical decision making.

This paper summarises from a range of HQIP's work on improving data flow for quality and the drivers for the culture and environment of data collection for quality improvement that form HQIP's core work and future interests. Separate pieces on data quality in data systems, on education, on the role of professional bodies and much more, including numerous resources to improve the use of data within quality improvement are found on our website at www.hqip.org.uk. However the views expressed in this paper are the views of Robin Burgess and not HQIP, as requested by the enquiry.

The responses in this paper follow the requirements and headings set by the enquiry. Therefore, there is limited discussion of some issues related to information that was not requested, notably a detailed discussion of data quality issues. For these issues, refer to other documents, including a larger version of this paper, on HQIP's website.

How data should drive change

HQIP believes that clinicians in all disciplines, working with patients, should take the lead in collecting data that is relevant to the care they provide, and acting on the findings to improve their practice so as to achieve better patient outcomes. This is a professional responsibility which also serves the need to supply data for management and policy purposes.

The process cycle of clinical audit involves the comparison of clinical practice against proven guidelines or best practice, and the cycle is not complete until a change programme has been put in place and over time has shown continuing improvement. Where this happens there is a clear momentum towards active use of information within a change cycle. Data is thus not just collected to be looked at and put aside: it's a dynamic process of change within practice, led by those who provide and receive it. There is a large body of evidence to show, that where done according to best

practice, clinical audit is very effective in not just providing data, but driving change. In national audit, practice on stroke and MI have been radically transformed by audit data, to name only two examples. This has not just been with regard to compliance with best practice, but can be shown in terms of better patient outcomes.

All healthcare information needs to be collected for a purpose; on its own, without incorporation in systems which ensure it is used actively to drive practice, or in the wrong hands, it is often meaningless. HQIP's purpose is to promote improvement processes within which reliable data and information are used to drive change and improve outcomes. The purposes for which data and information are required, and the needs of its stakeholders, should determine and refine the data that is collected and the way it is analysed and reported. Overall in the NHS too much data is collected which is simply process data which neither drives change nor improves outcomes. It is not embedded in change programmes or systems which enable it to be used meaningfully to drive change activity; it's just data. This includes HES and a lot of QOF data, which simply records processes that have taken place. Whilst the theory is that data, on its own will magically transform practice, this is not what happens in practice; data needs a change context. Clinical audit – and some other processes – provides this.

Whilst the focus of collection of data should be in the hands of clinicians, this is not to say it is theirs and no-one else's. This data has great richness for multiple purposes and there should be no sense of this not being openly available, whether to managers, patients or media. I cover this below under transparency in relation to external stakeholders, but internally within the healthcare provider setting such data should be available and reviewed by many more than just clinical groups.

It is also important that data is benchmarked and 'benchmarkable'. There is a risk that if each provider collects its own data and promotes it in individual ways, the patient will not be able to see through a mass of data which is not the same. They will not be able to compare, and nor will the commissioner. We believe data should be specified for benchmarking purposes. National audit data is one of the most reliable sources of data for benchmarking between services because it is the same data set in all places. Anyone can make reliable comparison.

It is also important that the mix of data collected needs to fit the purpose intended. To simplify, much routine data does not adequately measure outcomes because it involves collection of simpler and easier to collect process measures. Outcomes can be derived from such data but they are less reliable. All too often, routine data is just data; to be effective in driving change it needs to be applied within a system of active use and re-analysis. This often does not happen so its value is limited. Clinical audit data is of a higher level of quality and so it is capable of measuring outcomes but also of achieving change in outcome as it is, by definition and process a dynamic change/measurement cycle.

Yet audit data still also records much process data which points to adherence to best practice which is likely to lead to better outcomes and more importantly, also meets patient experience criteria of quality. There is still a need for process adherence data alongside outcome monitoring data. We cannot move, within national data collections like clinical audit, solely to outcome data recording because of the richness and value of process measures within these systems.

Patients

The choice of data to be collected, in whatever method of data collection for whatever purpose, needs to be based on the needs and wishes of the patient, alongside the clinician or the manager. Audits and all other data or information gathering exercises should be designed with patients involved in their governance, and ideally collecting some of the data themselves. This will mean that the data is relevant to their interests and measures their concerns. They should be asked their experience and their perceptions of their outcome, and have a hand in deciding which outcomes are monitored.

Programmes of measurement and change should ideally be structured on the care pathway or journey of the patient rather than on specific items or segments of their care, such a specific clinical procedure. However, historically this is what has tended to happen and it needs to change.

Providing valuable data to others and helping them to use it

Information needs to be valuable to clinicians, patients, managers, regulators and commissioners. Audit data, because it actually measures quality of service and outcomes, is of value to regulators. They can reliably use such data to give an accurate picture of the performance of provider organisations. Regulators lack good data – I will talk about routine data later – and as such audit data is of immense value in preparing risk profiles, for examples, and in offering assurance of the culture and ethos of an organisation. National audit data has value, and can help determine failing is in achievement of outcomes in clinical care, and can identify outliers; but the long lead time and analytical timeframes sometimes mean it is less immediately available for inspection data requirements. Local audit data, and an active culture of audit in an organisation, is also essential as a marker of a healthy organisation focused on quality. At one level, for the level of review regulators do, the actual information is less important than the fact that active programmes of high quality review of practice take place, and there is evidence of acting on findings. This was not present in Mid Staffs. Regulators should actively use both local and national audit data for the light it sheds on the culture of quality in an organisation and the achievement of outcomes alongside adherence to clinical best practice. Regulators need to be reassured that boards use audit and other high quality data as a strategic tool in management of quality.

The actual data and results of audit are of even greater value to local commissioners – and we must ensure that new clinical commissioning groups understand the value of audit and what it tells them. HQIP is preparing educational and guidance materials to this end, but the job of ensuring they do is clearly much wider than HQIP's responsibility. PCTs were generally good users of audit data. Transition poses risk that this culture may be lost.

Managers – notably NHS Trust boards, still need to move further along the path of looking at quality alongside other management information, and whilst the leadership of clinical information should come from clinicians, boards have to have ownership and use this information as part of strategic management. We have issued a publication about this (available on our website at http://www.hqip.org.uk/assets/Guidance/HQIP-Clinical-Audit-Simple-Guide-online1.pdf) and whilst there is some evidence of greater board awareness there are also still signs that too many boards and senior executives do not look enough at information about quality. HQIP will produce further material and training resources before the end of 2011. There is a trend in management practice to see audit data and registers as being a clinical domain which boards do not review and yet they invest in small parallel 'quality improvement' teams who carry out parallel review processes, often

based on far less well worked methodologies, which are fed directly into management. Boards have to start to review good quality clinical data and not try to work separately from the established methods of review of clinical practice that exist; they should use them actively.

Engaging clinicians

As we have said, auditing your practice ought to be seen as something a professional clinician does because they are a clinician rather than because it is imposed on them or mandated. Thus programmes that clinicians have devised and support are the best way of ensuring their compliance and their belief in the data. Unless there is clinical buy-in data collection is likely to fail. Results that are open to challenge by clinicians lose their credibility.

Hence professional bodies and the educational systems that produce clinicians need to promote and educate about review methods, and on this they sadly fall down. Education on quality improvement, including the collection of data for this purpose, is extremely limited in all disciplines, and often only occurs as part of CPD, not as part of pre-qualification training. Much specific training in audit, conducted at FY1 and 2 levels, is badly carried out – an argument that it needs to be improved, rather than replaced by methods which do not use good research data and methods. We need to make more effort to ensure that young clinical professionals understand the value of data driven scientific methods of quality improvement through their training. HQIP has been consulting on curricula content and standards for training at all levels in clinical audit, but no similar piece of work has been carried out for any other area of quality improvement. There are no agreed or defined competences to work in quality improvement or teaching structures for quality improvement other than what HQIP is doing for audit.

Colleges and professional bodies work hard to promote use of good quality data as part of audit and related processes. It is fair to say however that medicine leads the way, and within that certain centres, such as surgery, psychiatry and the physicians. Not all clinical professions and certainly not all sub-specialties within disciplines are at the same level in promoting a culture of quality improvement based on data. HQIP is working to improve how smaller groups, and some larger ones, can promote these methods and the culture of good use of data to their members. This said, we do not believe there is a widespread problem of attitude amongst clinicians to collecting and using data for quality improvement; just concern that the right data is collected, and that it is used sensibly and meaningfully.

Revalidation and appraisal play a useful role in encouraging use of this skill set and the value of scientifically acquired information.

Information gathering systems

However the collection of data for review purposes is time consuming, especially for more detailed review processes like audits and databases. As budgets are cut the role of specialist clinical audit staff or their equivalents, or even administrative staff in collecting and entering data, is being reduced. This means that increasingly clinicians are asked to collect large volumes of data. In clinical audit for example, junior doctors and nurses are responsible for the bulk of data collected in national audits for cancer, cardiac care, hip fracture, joint replacement and much more. In secondary or tertiary care these typically involve bespoke data collection tools which are not integrated into

routine data collection. In Primary care there is much better data collection through routine electronic methods, and data can be extricated electronically for the purposes of audit or research easily without any need for bespoke data entry and the time this involves. This raises the whole question of the state of routine secondary care data, such as HES, and the well known and discussed limitations of the current codes and coding practice. Put in one sentence, HES is not fit for quality improvement processes. It is largely process data of extremely limited value and very poor accuracy and detail. We are aware that HES codes are being reviewed via the NHS Information centre, but really there needs to be a more fundamental review of the nature of data collection in secondary care.

We advocate greater use of integrated data collection, all electronic, that meets the needs of routine management and process data and serves the need of audit and research. In the absence of any centralised approach for all NHS data there are interesting models of attempting to do this in specific sectors – in Arthritis through the Inbank project for example; in neonatal care the SEND neonatal database fuels multiple uses. Given the problems of single data portals we support grouped data portals for specific conditions – a cancer data portal, or cardiac, for example.

Transparency

HQIP fully supports the main thrust of the drive to greater transparency in reporting of data to an appropriate level of granularity and with greater diversity of format to various audiences, especially patients. Clinicians have to be prepared to share clinical data with patients and not make any assumptions about their interest, rights of access or understanding of data related to them. We are working to ensure that all the programmes we fund achieve targets for better, more detailed reporting. There are challenges in this, because unless data is credible, then clinicians fear that it will mislead and confuse, and lead to poor choices, confusion and poor commissioning. We understand these issues and are working hard to ensure data quality is good enough in all audits for such reports at this granular level are meaningful, although as an aside it is worth noting that the number of experts available to assist in ensuring high quality data is currently limited and needs to be grown. These functional issues should not get in the way of the desire to issue better data, in granular form, in a variety of media.

This issue of data quality affects all data sources. Debates over hospital standardised mortality illustrate the meaninglessness of poor data. Any data in the public domain needs to be analysed appropriately and definitive assessment made by independent groups who are not marked by technical incompetence, external bias, or limitations in the science. In our clinical audits we manage this through active commissioning of appropriate qualified groups, representing all interests including patients, and free from editorial bias or persuasion, to produce scientifically, independent and credible reports. This has not been true of a lot of data analysis in the public domain, notably that produced on HSMR.

This brings up a very real risk of the transparency agenda, notably in the idea that raw data should be available for anyone to conduct their own analyses. We believe this could have unfortunate consequences and needs to be carefully progressed. The issue is that any person or body could conduct analyses that are based on poor science or misguided or inadequate methodology, or distorted by sectional or commercial interests. It opens the door to publicity for bad science, where inadequate teams conduct methodologically flawed analyses. At the very least it can create

misleading reporting, that people believe tells them something but is poorly analysed or constructed. There is risk of re-analysis from partisan viewpoints – such as industry or specific service providers looking to increase market share, and the result is confusing for all. Do patients need a mass of conflicting reports on service quality, when they may not be versed in the subtleties of research practice, or do they need reports and data they can trust? Such a free for all will also reduce clinician willingness to comply and it's a potential waste of money. It will confuse commissioners and lead to bad commissioning decisions. Appropriate transparency is a good thing; bad transparency is disastrous. We will need to find ways to ensure that analyses are somehow distinguished by some process. This may need to be some sort of kite marking of reports through some independent process; solely kite marking centres which produce reports (such as happens via NICE) will not be enough because casual web searching will break the link between report and centre, making all reports seem of similar veracity to those who do not know how to judge them and cannot always see that the centre that produced the report has been validated. Too much data that cannot be adequately seen to be independent and reliable would not aid, but instead blur transparency.

Integrated care

Turning to integrated care there are two obvious boundaries; primary to secondary healthcare and healthcare to social care. On social care HQIP is working to promote an adapted form of clinical audit to the social care field. This is challenging, as social care does not have the same traditions or structures in place – such as guidelines and data collection systems. This is a long term developmental issue, and the nature of the social care world is that there is less top-down and more middle or bottom up in the way practice changes. This would be fine if it had the same network of professional bodies and regulatory requirements in place that support audit in medicine and other healthcare settings. HQIP is working to ensure that the new college of social work, the competencies expected in the regulated social work professional, and for those who work in care homes, all include a requirement to focus on review of professional practice. This is a long road ahead, and we are only at the beginning. Simply assuming the integrated pathway of care that goes out of healthcare into social care will all measure the same things and collect the same information and then use it to drive change, is naive. Instructing this to happen is naive. It is a long term development process.

Transfer of information between healthcare settings and meaningful data about pathways is a separate issue of huge size and cannot be given justice here. We promote and commission audit methods which straddle secondary and primary care wherever possible. Promoting more general sharing of clinical information across this divide is an area of considerable need, although not an area we focus on. However we are partners to work on such areas as improving record keeping and handover practice which address elements of this, and support dissemination of best practice from such centres as the RCP, but also from Australia – the Ossie system - and from an EU funded programme, Handover.

International learning

The latter point illustrates that we are keenly international in outlook. We are active members of the international and European quality societies, ISQUA and ESQH (the current author is on the executive of the latter) and of course there is much to learn from practice worldwide. That said,

Britain is one of the absolute leaders in collection and use of meaningful data for clinical practice. We have for example nearly as many registers, audits and databases as the USA, and far more than Sweden for example, which is often cited as a model of good use. In practice our data quality and reporting of data is at least as good as in Sweden. Most of Europe lags far behind and whilst there is very good Australian and Canadian practice, neither has, for example, anything like the same volume of national clinical audit activity and data. Nonetheless, we believe there is much to learn from international practice, in such areas as patient control and carrying of records across care boundaries (Poland); patient engagement (Italy); handover practice (Australia) and overall system organisation of data (Singapore). There are so many others.