Consultation response

The King's Fund's response to the Department of Health's public consultation on *an Information Revolution*

14th January 2011

The King's Fund seeks to understand how the health system in England can be improved. Using that insight, we help to shape policy, transform services and bring about behaviour change. Our work includes research, analysis, leadership development and service improvement. We also offer a wide range of resources to help everyone working in health to share knowledge, learning and ideas.

This response is one of two submitted by The King's Fund to the government's consultations: on an information revolution and on greater choice and control. These responses are also available on our website, together with our previous consultation responses on regulation, outcomes, democratic legitimacy and commissioning, and the original response to the White Paper, *Equity and Excellence: Liberating the NHS*.

We have recently published two reports that have significant implications for the government's approach to information and choice, *Choosing a high-quality hospital: the role of nudges, scorecard design and information*, and *Patient choice: how patients choose and how providers respond*. We draw on these in our responses but suggest that those developing policy in these areas may wish to refer to the reports directly.

Overview

We welcome the broad direction of travel proposed in *An Information Revolution;* specifically, the move towards greater availability of timely and reliable information for patients, the public and the NHS, and the enhanced use of technology and informatics to achieve these aims.

Provided data can be quality-assured, the methods for data collection are standardised, the correct metrics are used, and the presentation of data is carefully considered, there is real potential for progress in the development of a market for the publishing of information in the NHS. Publishing performance data can lead to improvements in the provision of high-quality care (see Raleigh and Foot 2010) and has also supported patients to make informed choices (Dixon *et al* 2010).

However, the scale of the ambitions outlined in the consultation is considerable, particularly in the current financial climate of the NHS and the extent of forthcoming structural change. The ambitions of the information revolution will require considerable technical, managerial and cultural change to be realised in full. Further, an information vacuum may develop as primary care trusts (PCTs) are abolished and while alternative information systems and outputs tailored to GP consortia are being developed. This poses a real risk to the day-to-day operations of the NHS. We believe plans to revolutionise the use of information should move forward with caution to ensure that the most effective information system can be guaranteed in the longer term.

Key Issues

Transparency

We welcome the proposals to give people control of their patient records and agree that greater transparency of this information should support patient empowerment, shared decision-making and self-management. The proposals to develop/reinforce data sets to help clinicians make quality improvements are also encouraging. As we outline in our report, *Getting the measure of quality: opportunities and challenges (*Raleigh and Foot 2010)*,* developing such data sets will be a complex task, and we would encourage the Department to read the recommendations from this report before taking these plans forward.

The government's aim to publish much more information about the performance of health care providers is a positive one, which has the potential to drive quality improvements in the provision of health and social care. Publishing information on performance has been shown to prompt providers whose performance is poor to improve as a result of concerns about their reputation, but patients do not make much use of this information to inform their choice of provider (Shekelle *et al* 2008). Our research found that selecting a high-quality provider based on clinical quality measures is a difficult task and requires a high level of numeracy; patients may need support with these complex decisions. Published information about the quality of services needs to be clear, easily understood, consistent and comparable if it is to help patients to make more informed choices (Boyce *et al* 2010).

As mentioned above, careful consideration will need to be given to the collection and presentation of data before it is published, and evidence on the publishing of performance data via quality accounts has demonstrated how difficult it is to achieve the right conditions for capturing and publishing information to drive quality improvements.

Our recent publication, *How do quality accounts measure up? Findings from the first year* (Foot *et al* 2011)*,* suggests that quality accounts are a good first step in the government's planned 'information revolution', but to fully deliver a meaningful and transparent picture of quality for patients and the public, providers will need to give a clearer account of the quality of care in future. The report describes the variation in quality accounts as an 'inevitable' outcome of the way they have been designed, in particular the conflicting aims of publishing them as a tool for local quality improvement and as a form of public accountability. While we support the retention of locally defined measures, the report concludes that the public would be better served by including some nationally comparative, quality-assured key measures of quality. This information could then be replicated consistently in all quality accounts, with providers adding other measures relating to local priorities.

Data

Data protection

The proposals aim to make more information publicly available, while simultaneously safeguarding patient confidentiality and data protection issues. Unless carefully managed, these two aims could conflict with each other. Current data protection legislation restricts a great deal of NHS information from being widely available to the public. The department should prioritise straightening out the practical implications of data protection associated with publishing more information on performance, public health, etc.

GP consortia boundaries

The proposals for flexibility with GP consortia boundaries also raise a number of challenges for the effective use of data and information.

- Most NHS data flows are mapped to statutory boundaries (eg, ward, local authority, PCT) that may not align with the future boundaries of GP consortia; it is unclear whether or not it will be possible to reconfigure all NHS data sets to these new boundaries, but the Department should seek to clarify this through the development, and evaluation of, the GP pathfinder pilots.
- The potential lack of co-terminosity between GP consortia and local authority boundaries could mean they are each responsible for different geographies and therefore populations. There needs to be more detail on how and to whom information will be made available across these different boundaries. This will require particular consideration of the use of public health data by GPs.
- In future, GP consortia will have responsibility for unregistered populations, but it is unclear how information will be tracked for these groups (especially transient populations).
- Extending the choice of GP to beyond patients' area of residence will create challenges for information flows based on practice lists or geographically defined practice populations.
- ONS population denominators are used in the construction of many indicators (eg, public health indicators), and it may not be possible to reconfigure them to GP consortia boundaries.

The Information Centre (IC) should prioritise supporting GP commissioners to get the data flows and analysis right.

There is also a role for the IC (potentially in conjunction with Public Health Observatories/ Quality Observatories) to support the commissioning process by developing and providing tools, resources, and software for commissioners. These should deploy evidence-based approaches to data analysis to support joint strategic needs assessment (JSNA), commissioning and decommissioning decisions, contract management, tracking of outcomes and performance management.

Public health and health improvement data

The consultation makes very little reference to the use of information to support public health or health improvement services. Public health, health improvement and reducing health inequalities are essential functions of the NHS, not least with the potential for general practice to play a key role both as commissioners and providers. Due priority should be given to supporting the development, publication and use of public health data as part of the 'information revolution'.

Market in information providers

We support the development of markets for innovative analytical tools and information technology applications to enhance access to and use of information, and for published information. There is potential for greater innovation in the presentation of information, provided by a wide range of organisations. These markets will not only support patients to make informed choices, but will also help clinicians and providers to deliver high-quality care. However, there needs to be a system of accreditation for information providers, and information needs to be quality assured, particularly given the complexities in developing and analysing robust clinical indicators. There is a strong case (as practised in most developed countries) for having centralised, quality-assured information (that, for instance, meets the Code of Practice for Official Statistics) about the performance of NHS providers, commissioners and services. The Information Centre (IC) is the logical body to manage and publish this information.

Costs

The current financial climate will make it difficult to implement the ambitious proposals set out in the consultation, and there may be limited appetite for investment in IT at a very financially challenging time for NHS. Investment that does take place will need to be offset by efficiency gains.

We recommend that investment is channelled into the IC to support it to develop standardised data sets and data collection methods that can be then be used by information providers to publish information for patients, the public, providers and commissioners.

There are also costs involved in the reporting and collection of data in terms of the burden they place on organisations, both at the level of the IC, and individual providers and commissioners. Despite developments in IT, the collection of accurate information will still require significant input from clinicians as well as IT staff.

Where possible, the IC should seek to consolidate and integrate existing NHS information architecture – eg, through driving data quality improvements, data integration, data linkage and inter-operability (including the development and implementation of standardised, structured electronic patient records), and greater use of data from the national clinical audits.

Consultation questions – Chapter 1

Q1: What currently works well in terms of information for health and adult social care and what needs to change?

The UK health system is fortunate in having national information flows that do not exist in many other developed countries. For example, there is excellent data on public health (the Compendium indicators etc), hospital care (Hospital Episode Statistics), and on hospital infections from one of the most internationally effective surveillance systems run by the Health Protection Agency. There is also data on the experience of patients using the NHS, and on patient-reported outcome measures (PROMs), from some of the largest and most comprehensive survey programmes internationally. The NHS is therefore data rich in very many ways.

The consultation document acknowledges many of the improvements to information flows that are currently needed.

- timeliness of, access to, and completeness of data
- data standards and quality
- data linkage – ie, linkage of patient records across data flows, such as primary and secondary care
- a consistent policy on data protection applying across the entire spectrum of information flows (currently, different criteria apply to different data sets)
- improvements to the recording of ethnicity and availability of information by equality strands.

Standardising care records**,** promoting inter-operability and enhancing the use of information technology and digital services will definitely set out to address these issues. Whether these ambitions will be achieved will depend on the detail of the approaches and systems that are put in place to achieve them. It is also important that sufficient time and investment are committed to achieve these ambitions.

Q2: What do you think are the most important uses of information, and who are the most important users of it?

There are many uses and users of information. Our recent publication, *Getting the measure of quality: opportunities and challenges,* outlines the following important uses and users of information.

- Clinical teams wanting to improve their performance will want disaggregated and complex information on the processes and outcomes of care at team or individual consultant level.
- Patients or a public audience – for example, for quality accounts or NHS Choices – will require simpler information at a less granular level, presented without the complex statistical formats that professionals use to aid their interpretation of the data.
- Commissioners are interested in outcomes and increasingly require information linking quality to productivity and cost-effectiveness.

Electronic patient records will facilitate greater engagement from patients, accuracy in patient-level data, and promote self-management.

Q3: Does the description of the information revolution capture all the important elements of the information system?

The model described in paragraphs 1.10-1.13 and on page 13 does broadly capture the important elements; however, the following should also be considered.

- The aim of driving improvements in data quality is arguably best met by publishing indicators on data quality for individual organisations, including for NHS-funded independent sector providers – and not by publishing information relating to performance based on data known to have data quality problems. We therefore support the requirement to publish indicators about the quality of organisations' data in quality accounts, although we recommend that publishing information on data quality could be most usefully co-ordinated and published centrally, to enable comparison, rather than in individual quality accounts.
- If the intention is that patient record data will be compiled into aggregated data sets, and then used for measuring quality of care and informing research, there are a number of issues that arise. Robust quality indicators, for example, require sophisticated statistical analysis for risk-adjustment to enable fair comparisons across organisations, and such analysis can be fully undertaken only on patient-level data, not aggregated data. Likewise, aggregated data is of little use for research purposes. For the same reason, publishing aggregated data or even data 'in a relatively basic form, as close to the time of recording as possible' risks being misleading for the public and patients and will not be enough to enable informed choice.

Q4: Given the current financial climate, how can the ambitions set out in this consultation – to make better use of information and technology to help drive better care and better outcomes – be delivered in the most effective and efficient way?

The assumption is that increased availability of information will encourage self-care and drive quality improvement and innovation, thereby reducing health care costs and offsetting the investment costs in IT. Yet there may be limited appetite for investment in IT at a very financially challenging time for NHS. Investment that does take place will need to be offset by efficiency gains.

A pragmatic and cost-effective way of using information to deliver better care is through consolidation and integration within the existing NHS information architecture – eg, through driving data quality improvements, data integration, data linkage and inter-operability (including the development and implementation of standardised, structured electronic patient records).

Data from the national clinical audits should be brought into use for commissioning and assessment of quality as a matter of priority. Participation in audit is no longer an acceptable criterion of performance, given that many national audits were implemented several years ago.

Further recommendations are outlined in our response to Q5.

Q5: Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?

We believe the centre has three particularly important priorities, which will support the development of meaningful data and avoid data overload and confusion, especially for patients. These priorities are: carefully managing the introduction of new information systems; providing data and tools to support commissioning and quality improvements; and co-ordinating the analysis and publication of performance information for public accountability.

As we said in our response to the *NHS Outcomes Framework* (The King's Fund 2010), choices about introducing new information flows need to be taken carefully and should be informed by a comprehensive review of current and proposed information flows in the NHS. The benefits (cost savings and otherwise) of extracting information from existing sources should be weighed against those of new data collections. Such a review can build on the information scoping exercise undertaken for the National Quality Board report, *Information on the Quality of Services*.

The IC (in conjunction with Public Health Observatories/ Quality Observatories) can support the commissioning process by developing and providing tools, resources, and software for commissioners. These should deploy evidence-based approaches to data analysis to support JSNA, commissioning and decommissioning decisions, contract management, tracking of outcomes and performance management.

The IC or other central bodies also have a crucial role to play in analysing and disseminating – both to the NHS and to the public – reliable, quality-assured information about health and social care services in consistent, statistically robust and user-friendly formats for different audiences. Our recent report, *How do quality accounts measure up? Findings from the first year* (Foot *et al* 2011), suggests that the future for public accountability needs to focus more on the centralised provision of standard, consistent and comparable quality measures, published in forms that enable interpretation and comparison. Our report, *Choosing a high-quality hospital* (Boyce *et al* 2010), provides guidance on how information about the quality of services can be provided to patients in a way that helps patients to make choices.

Consultation questions – Chapter 2

Q6: As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?

No response written

Q7: As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?

No response written

Q8: Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.

No response written

Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?

Research by The King's Fund's Point of Care programme has found that there are certain points in the care pathway for cancer patients when they are particularly stressed or anxious, and require specific forms of information to support them (see www.thekingsfund.org.uk/thepointofcare for details of this programme). For example, at the point of diagnosis, patients have expressed a need for information about the disease itself and about the options for treatment and the side-effects of treatments. Macmillan research shows that patients need information about non-health issues, for example, when anxious about the financial implications of their illness (Stewart 1995).

There are also, of course, basic principles in providing adequate information to patients to help mitigate stress and anxiety. For example, the way in which information is communicated at all points of the care pathway is important; it is widely acknowledged that good communication between doctors and patients has a positive impact on health outcomes. Professional training must adequately cover the delivery of timely and relevant information to patients, and approaches to shared decision-making.

Q10: As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?

Please see our response to the *Greater Choice and Control* consultation

Q11: What additional information would be helpful for specific groups - eg.

- **users of maternity and children's health services;**
- **disabled people;**
- **people using mental health or learning disabilities services;**
- **the elderly;**
- **others?**

No response written

Q12: What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?

No response written

Q13: What are the information needs of people seeking to self-care or live successfully with long-term physical and mental health conditions and what support do they need to use that information?

Research by Rijken *et al* (2008) found that for people to manage their long-term condition, or to self-care, they need to have adequate access to both resources and support programmes. There are information requirements associated with both. Patients need to know about the programmes available to them, understand and be able to speak the language of the programme leader and other group members, and be sufficiently literate to be able to read and understand accompanying written materials. Basic patient education and individual support must not be replaced solely by published information, as not all groups will be able to use this to effectively self-manage.

Co-ordination of care is especially important to support people with chronic diseases, and shared care records can be particularly effective in this area, though need to be developed carefully (as discussed above). Information about agreed care pathways and protocols, along with the relative roles and responsibilities of those involved in a patient's care, also need to be clearly communicated to patients to support their involvement in their own care.

Further development of information prescriptions, avoiding hospital admissions via the use of computer software tools, and research into the cost-effectiveness of telecare and telehealth, to support self-management for people with long-term conditions is needed. However, there will also need to be sufficient investment and commitment to build on and learn from these initiatives.

Consultation questions – Chapter 3

Q14: What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?

No response written

Q15: What additional information about outcomes would be helpful for you?

No response written

Q16: How can the benefits of seamless and joined up information be realised across the many different organisations (NHS and non-NHS) a service user may encounter?

The benefits of integrated care in the United States have been realised in integrated systems where the level of investment in IT has been high (Curry and Ham 2010). All the case studies examined in our research have implemented electronic health records and many use IT systems to spread good practice and ensure consistent standards. Kaiser's HealthConnect allows care teams to access patient information and the latest best-practice guidance in one place and facilitates collaboration between generalists and specialists in different settings. As well as communicating with professionals, patients are able to access their own records and arrange 'e visits' as well as face-to-face appointments. Patients can also access laboratory results, order repeat prescriptions and read summaries of their health conditions.

Q17: For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?

Information-sharing will be particularly important for individuals who are frequent users of services, whose needs straddle the responsibilities of several organisations and cannot be met in isolation or those in complex or vulnerable situations. This will include people with long-term health conditions (see response to Q13) and those with mental health and learning disabilities.

IT systems that facilitate the timely and efficient flow of information are often cited as an essential enabler of integrated care (eg, Feachem *et al* 2002 and Fulop *et al* 2005 cited in Curry and Ham 2010). The strengthening of the co-ordination of care plans, which act as the central point of reference for everyone involved in the care of an individual with long-term conditions, should be prioritised (see recommendations in our report *Clinical and service integration),* while the success of virtual wards will be largely determined by the successful sharing of information across organisations. Formal evaluations of the success of virtual wards to support complex patients with multiple needs for whom a single multidisciplinary team is unlikely to have all the necessary expertise are only just under way, but lessons about the effectiveness of information-sharing should inform further development of this approach.

Several predictive models, such as the Patients at Risk of Re-Hospitalisation (PARR), the Predicting Emergency Admissions Over the Next Year (PEONY) model, and the Reduce Emergency Admissions Risk model (Prism), have varying degrees of accuracy in predicting future admission (Purdy 2010). Those models that include data from primary care records perform around 10 per cent better than those that rely on secondary care data alone. In order to improve the performance of predictive models, detailed data on individual patients need to be available. The same developments should be made across health and social care boundaries (abiding by data protection legislation), and the use of predictive modelling, threshold modelling and clinical knowledge should also be further explored across these organisational boundaries.

There still remains a lack of robust evidence about the cost-effectiveness of telehealth and telecare. Part of the challenge is turning findings from multiple small-scale pilots into a business case on a larger scale (Goodwin 2010). There are a number of barriers to adoption and implementation of such technologies, the key one being the high initial investments (Liddell *et al* 2008, cited in Curry and Ham 2010). The process of scaling telehealth services is also a barrier to the adoption of such technologies (Goodwin 2010). The Department of Health's evaluation of its Whole System Demonstrator programme should go some way to filling the evidence gap, and inform further development.

Q18: What are your views on the approach being taken and the criteria being used to review central data collections?

The criteria listed for the review of central data collections are largely sound, as long as their application ensures that meeting even one criterion is adequate justification for retaining a data flow. We make the following suggestions.

- Another criterion should be included, namely, that the data return relates to aspects of care that are known to matter to patients – for example, waiting times. Evidence of timely and equitable access to services is required to demonstrate compliance with equality legislation and the essentials of good-quality care. Another example is PEAT scores, which capture vital information about the care environment, but do not fit neatly with any of the criteria listed.

- The focus should not be restricted to outcomes. As the NICE Quality Standards, and many evidence-based measures of quality used internationally show, many dimensions of high quality relate fundamentally to processes of care. Please refer to our consultation response to the *NHS Outcomes Framework* for more detail on this (The King's Fund 2010).

- Data collections take years to implement and embed into central and local information and management systems. Any data returns that do not meet the specified criteria should still be examined carefully to explore their origins and whether they are still relevant. Data returns identified for termination should be publicly consulted on, and responses taken into account before final decisions are taken.

Q19: How could feedback from you be used to improve services?

Hearing how patients experience services is essential for quality improvement. The Point of Care programme has used an 'experience based co-design' approach to improve services, based on research by Bate and Robert (2006). We have evidence of cancer patients and staff listening to each other's experiences of using the services, identifying areas for improvement, and then working together to make improvements to the breast cancer and lung cancer services in two London teaching hospitals (The King's Fund, The Point of Care 2010). We would recommend that the Department review this research.

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?

The King's Fund has been working with King's College London on a project *'What matters to patients?'*, commissioned by the Department of Health and the NHS Institute. This research directly addresses this question; we will be producing recommendations shortly.

Q21: What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?

Our research (*Choosing a high-quality hospital)* suggests that previous patient experience can either attract or deter a person from choosing a certain hospital. Providers should thus focus on delivering a high-quality experience for patients, which will require organisations to ensure that providing patient-centred care is embedded in their mission. The underlying circumstances at Mid Staffs were not dissimilar to those faced by many trusts today: the drive to become a foundation trust, the need for savings, but, critically, savings made without considering the potential impact on the care of patients. Prioritising patient surveys and regularly monitoring patient experience, supported by staff who are fully engaged and trained to deliver high-quality care, should improve providers' responsiveness to feedback.

It is also hard to overstate how profound the impact of PROMs could be for the NHS, patients and the public. As outlined in our report (Devlin and Appleby 2010), the possible uses for this information are extensive, including supporting patients to make informed choices, helping commissioners to place contracts with the best performing providers, and exerting evidence-based pressure on those who are under performing. PROMs could also provide basic evidence to inform the revalidation of clinicians and the performance management of hospitals. Linking information on PROMs to patients' medical records and other data sets would, for the first time, allow proper evaluation of broader government health policies as they affect equity: not just how much benefit, but who benefits and by how much.

The crucial first step is for trusts and PCTs/ GP consortia to ensure they have plans in place for the collection of PROMs. Aside from the technical requirements for this to happen, both patients and staff will need to be persuaded of the benefits of this information. In particular, it is important that those who provide the data are able to see the results; trusts should plan ways of feeding back PROMs results to individual patients. Clinicians also need to be involved in deciding how they will use the data to improve the quality of care they provide.

Q22: Which questions, if asked consistently, would provide useful information to help you compare and choose services?

Choosing a high-quality hospital explores how information can help patients to make informed choices. It is based on a research study, which began with a series of focus group discussions, the results of which informed the design of an online experiment. People were presented with information using a number of different 'scorecards' comparing the performance of hospital, and different 'nudges' were used to influence their choices.

The online experiment showed that making informed choices using comparative information on the quality of hospitals is difficult, even for people who are used to using the internet. The way in which information was presented on screen made a difference to people's decisions – but the impact was not always as expected. Patients can be prompted to pay more attention to clinical quality, but the impact of specific prompts depend on a number of factors – for example, patients' age, their level of education, etc.

This report includes useful information for policy-makers and information providers, including practical suggestions as to how information can be presented and ordered to maximise the chances of decisions being made on the basis of quality.

Q23: What will help ensure that information systems – and the data they collect – are appropriate to support good commissioning at different levels, including decisions by individual patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?

Commissioners will require information on the needs of their population, disaggregated and complex information on the processes and outcomes of care at team or individual consultant level (used to improve performance), and outcome data linking quality to productivity and cost-effectiveness.

The proposals for flexibility with GP consortia boundaries raise a number of challenges for the effective use of data and information. The Department needs to clarify the following to support good commissioning at this level.

- How and to whom information will be made available across GP and local authority boundaries (that may or may not be coterminous).
- How information flows relating to unregistered populations (particularly transient populations) will be tracked
- How information flows based on practice lists or geographically defined practice populations will 'follow the patient' in cases where they choose to register with a GP outside their area of residence
- Whether or not it will be possible to reconfigure all NHS data sets to the new GP consortia boundaries
- Whether or not it will be possible to reconfigure ONS population denominators (used in the construction of many indicators) to GP consortia boundaries

The IC should prioritise supporting GP commissioners with getting the data flows and analysis right.

The IC (potentially in conjunction with Public Health Observatories/ Quality Observatories) can also support the commissioning process by developing and providing tools, resources, and software for commissioners. These should deploy evidence-based approaches to data analysis to support JSNA, commissioning and decommissioning decisions, contract management, tracking of outcomes and performance management.

The King's Fund Inquiry into the quality of general practice due to be published in March 2011 comments further on these issues, and we will share these findings with the Department to further inform thinking around the most effective uses of information at GP level.

Consultation questions – Chapter 4

Q24: How can health and care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?

To facilitate improvements in data quality and greater engagement of clinicians in data recording reality, we suggest the following are needed.

- The information system needs to be tailored to clinicians as the primary users/target audience for the data – as with the MINAP and CCAD data, which is largely owned and used by clinicians for internal quality improvement purposes, with publication emanating as a by-product of that process.

- Information systems must record the data that clinicians consider useful. For example, clinically useful data is often related to care processes rather than outcomes.

- The production of quality-assured, standardised, appropriately risk-adjusted and benchmarked data can drive the use of information and its application for improvement. On the other hand, inappropriate use of information for performance management, target-setting or publication to 'name and shame' will induce perverse behaviours and disengagement with the information agenda, which could come to be perceived as a threat rather than a tool.

- Leadership engagement with and commitment to the use of information for driving improvement in the quality and efficiency of services, and in public health. Use of information by boards and senior management should become standard practice. (See response to Q27.)

- Showcasing examples of good practice in using information effectively.

The reports, *Getting the measure of quality* (Raleigh and Foot 2010), and *The Intelligent Board 2010: Patient Experience* (Cornwell 2010) provide further information on how to develop an information culture and secure staff engagement.

Q25: As a clinician or care professional, how easy is it for you to find the evidence you need to offer the best possible care and advice? What could be done better?

NHS Evidence has bought about signficant improvements in finding evidence for clinicians and care professionals.

The Map of Medicine should be promoted and used more widely by commissioners and providers to plan and deliver high-quality services.

There are also a number of ways that health librarians and their resources could be mobilised to enable easier retrieval of evidence/information, including training clinical and non-clinical staff to access evidence and information at the local level.

Q26: Clinicians, practitioners, care professionals, managers and other service provider staff will be expected to record more data and evidence electronically. How can this be facilitated and encouraged? What will be the benefits for staff and what would encourage staff to reap these benefits?

No response written

Q27: What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?

Using leadership approaches to overcome organisational barriers to managing and using information and technologies is an important first step for the development of professional information management capacity and capability. Approaches should be refreshed at the local level, and commitment at board level to employ these approaches throughout organisations should be secured. Delivering frequent and innovative training programmes would support the development of clinical and non-clinical staff capacity and capability to effectively use IT.

Consultation questions – Chapter 5

Q28: The 'presumption of openness' in support of shared decision-making will bring opportunities - but may also generate challenges. What are the greatest opportunities and issues for you a) as a care professional? or b) as a services user?

Increasing the transparency and accessibility of information will support shared decision-making, and there is greater scope for innovation and use of technology in communicating information to different audiences and in developing tools and applications for processing and disseminating information.

Recent research by Dixon *et al* (2010), and Boyce *et al* (2010) showed that patients need information to be clear, reliable and relevant to them, and that the focus for professionals in supporting a culture of shared decision-making rests on them being able to also access information developed along these same lines.

Information providers should be encouraged to compete to publish information in innovative ways. This will support the development of high-quality information that is more accessible and helpful than current provision.

Provider accreditation and defined information standards should be developed and set at a national level before information on health promotion, healthy lifestyles, risk reduction, and symptoms is disseminated, so that patients, the public and the NHS receive accurate, evidence-based information that supports them to make healthy choices.

This also applies to publishing information on the quality and outcomes of treatments and disease management. Data quality is taken seriously only when it matters: to make it matter, providers (both clinical and non-clinical) must be given opportunities to correct and comment on the data; this requires professionals to understand what constitutes good-quality data.

The development of robust and credible clinical indicators requires access to patient-level records. Giving a 'market' of information providers the freedom to independently analyse aggregated data sets could result in poor-quality outputs, and regulation by the IC must be focused enough to manage this risk. Methods of data analysis and adjustment should also be set by the IC, in conjunction with the National Quality Board (NQB) (see below).

Q29: What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?

Please see answer to Q28

Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and 'intermediaries'? Would factors such as cost and bureaucracy outweigh any benefits?

Patients will need support from 'navigators' who are able to point them in the right direction and to help them understand data and make the right choices, especially with the extension of personal budgets (please see also response to Q28, and our overview. Our forthcoming inquiry into general practice will also provide further evidence on this theme). Central accreditation and assurance systems would also support the development of a high-quality market for published information that can be used to inform patients, the public, providers and commissioners.

There is already a system of accreditation in place for providers of information about health and treatments in development; consideration could be given to whether this should be extended to providers of information about the quality of services.

High reliability will depend on having detailed knowledge of the data and analytical requirements, the requisite analytical skills, and getting the details of individual indicator constructions and interpretation of the results right. While it would not be feasible to quality assure all individual outputs from multiple providers, even with considerable resource and administrative infrastructure, at least the broad credentials of an organisation can be established. NHS organisations would benefit from having standard methods and data sources for indicators to inform quality accounts, balance scorecards, NHS comparators etc.

It will be important to get the methods for developing quality indicators right. This should build on the work to develop quality indicators by the NQB (www.dh.gov.uk/en/Healthcare/Qualityandproductivity/NationalQualityBoard/DH_120140). The NQB could oversee the work and approve the standards, and commission the IC to develop certain indicators. The practical work would be managed and supported by IC, rather than within the Department.

Q31: How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.

Our reports, *Choosing a high-quality hospital*, and *Patient choice: how patients choose and providers respond,* demonstrate the importance of providing information that is accessible, in sensitive formats (including Braille, translated languages, and sign language), and ordered in ways that 'nudge' patients to make choices on the basis of quality. Such information will also support providers to talk through and advise patients in the absence of direct access to information technology.

Q32: Are there other datasets that you think could be released as an early priority, without compromising individuals' confidentiality? Would there be any risks associated with their release - if so, how could these be managed?

No response written

Consultation questions – Chapter 6

Q33: The information revolution can deliver many improvements. What are particular benefits or other challenges – including sustainability, business, rural or equality issues – that need to be considered in developing the associated impact assessment?

No response written

Q34: Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?

Information needs to support joint strategic needs assessment (JSNA), commissioning, and measurement of access to services and outcomes for population sub-groups, especially for those at risk of poor health and access to health and social care. It is important that this information is readily available at the level of GP consortia, to enable them to undertake JSNAs and health equity audits jointly with local authorities, as currently done by PCTs.

In this context, we also recommend the mandatory recording of ethnicity for every user of health and social care services.

Assurances also need to be made as to the transfer of data, intelligence and systems from quangos, such as the Health Protection Agency, that will shortly cease to exist.

Bibliography

Bate P, Robert G (2006). 'Experience-based design: From redesigning the system around the patient to co-designing services with the patient'. *Quality & Safety in Health Care*, vol 15, pp 307–10.

Boyce T, Dixon A, Fasolo B, Reutskaja E (2010). *Choosing a high- quality hospital: the role of nudges, scorecard design, and information*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/choosing_a.html (accessed on 13 January 2011).

Cornwell J (Chair) (2010).*The Intelligent Board 2010: Patient Experience* [online]. Dr Foster Intelligence website. Available at: www.drfosterintelligence.co.uk/patientexperience/Intelligent%20Board%202010.pdf (accessed on 13 January 2011).

Curry N, Ham C (2010). *Clinical and service integration, the route to improved outcomes*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/clinical_and_service.html (accessed on 13 January 2011).

Department of Health (2010).National Quality Board report, *Information on the quality of services:final report* [online].Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117314 (accessed on 13 January 2011).

Devlin N, Appleby J (2010). *Getting the most out of PROMS: putting health outcomes at the heart of NHS decision- making*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/proms.html (accessed on 13 January 2011).

Dixon A, Robertson R, Appleby J, Burge P, Devlin N, Magee H (2010). *Patient choice: how patients choose and how providers respond*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/patient_choice.html (accessed on 13 January 2011).

Foot C, Raleigh V, Ross S, Lyscom T (2011). *How do quality accounts measure up? Findings from the first year*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/quality_accounts_1.html (accessed on 13 January 2011).

Goodwin N (2010). 'The state of telehealth and telecare in the UK: prospects for integrated care'. *Journal of Integrated Care*, vol 18, issue 6.

Purdy S (2010). *Avoiding hospital admissions, what does the research evidence say?*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/avoiding_hospital.html (accessed on 13 January 2011).

Raleigh V, Foot C (2010). *Getting the measure of quality: opportunities and challenges*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/quality_measures.html (accessed on 13 January 2011).

Rijken M, Jones M, Heijmans M, Dixon A (2008). 'Supporting self-management', in Nolte E, McKee M, *Caring for people with chronic conditions, a health system perspective*. Maidenhead: Open University Press, 2008.

Shekelle PG, Lim Y-W, Mattke S, Damberg C (2008). *Does public release of performance results improve quality of care?* London: The Health Foundation. Available at: www.health.org.uk/publications/does-public-release-of-performance-results-improve-quality-of-care/ (accessed on 13 January 2011).

Stewart MA (1995). 'Effective physician-patient communication and health outcomes'. *Canadian Medical Association Journal*, vol. 152, no 9, pp. 1423–33.

The King's Fund (2010). 'Response from The King's Fund to the consultation *Transparency in outcomes: a framework for the NHS*'. Available at: www.kingsfund.org.uk/document.rm?id=8785 (accessed on 13 January 2011).

The King's Fund, The Point of Care (2010). 'Experience-based co-design'. The King's Fund website. Available at: www.kingsfund.org.uk/current_projects/the_point_of_care/codesign.html (accessed on 13 January 2011).