National Quality Board

Information on the Quality of Services – Final Report

Document	Final Report
Developed by	The National Quality Board Quality Information Strategy Sub-Group, chaired by Professor David Haslam.

Supporting annexes

Also see the Interim Report and supporting annexes (March 2010), available at http://tinyurl.com/qis-interimreport

Introduction

Data are numbers, words, or images that have yet to be organised or analysed to answer a specific question

Information is produced through processing, manipulating and organising data to answer questions, adding to the knowledge of the receiver[1]

1. In December 2009, the National Quality Board agreed to develop a strategy for information on the quality of health services. An Interim Report was presented to the Board in March 2010; this is the Final Report. Both reports have been developed by a sub-group to the Board.
2. The National Quality Board asked the strategy to focus on four issues:
   a. What is the purpose and vision for quality information?
   b. What quality information is available?
   c. How should information be communicated?
   d. Who should do what?
3. The Interim Report articulated a vision, and examined current performance against it, including a review of quality information availability. The Interim Report highlighted a number of issues which needed to be resolved to meet this vision.
4. This Final Report provides recommendations for how the overall system can improve how information is created, used and communicated, and how the system itself should be structured.
5. The Report is underpinned by six detailed annexes, which examine: Data Quality (A1), Thinking Differently (A2), Filling data gaps (A3), Infrastructure (B1), Presenting Quality Information (C1), and Making Data Publicly Available (C2).

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[1] Source: Audit Commission (2007); See also Annex 1.2 (Glossary) to the Interim Report

Challenges

6. The Interim Report's vision for quality information set out a need for information on the quality of services which was:
    a. **Available**. Covering the right areas and being accessible to all.
    b. **Trusted**. Inspiring confidence and drawn from high quality data.
    c. **Insightful**. Answering the questions users want to ask.
7. The Report showed that we face significant challenges in reaching this vision; a summary is shown in Box 1.

Box 1 – Key findings from Interim Report (March 2010)

- **Availability**. 40% of health programme budgeting areas, representing £20bn of annual expenditure, are without any nationally collected quality information.
- **Data quality.** Significant issues across all care settings, particularly mental health and community care **-** posing challenges to QIPP ambitions to shift care out of hospitals.
- **Organisations**. Responsibility for collecting data currently spread across different organisations, resulting in duplicate responsibilities, and clear scope for rationalisation.
- **Communication**. Significant issues of trust, understanding of complexity, and a focus on official failure.

Recommendations

8. Given the magnitude of the challenges exposed by the Interim Report, full system-wide changes are required. As such, whilst the annexes to this report focus on specific topics, our recommendations are structured around themes.
9. **This report recommends that the public need to be placed at the centre of a simpler, more open, and more trustworthy system of quality information.**

‘The public at the centre’ [2]

10. Quality information should only exist to improve the health and care of the public. At present, the benefits of quality information are not being fully exploited. For example, we know that making information publicly available can better support patients, clinicians, and service managers in improving health and care. However, almost all information is in some way restricted.
11. Our recommendations are founded in what will, either directly or indirectly, improve the health or care for the public. We recommend that all future policy starts with this principle **[R01]**.

‘Simpler’

12. Our system is currently complex, with a web of different national organisations processing data on behalf of local providers. Ownership of data is diffuse and unclear.
13. We recommend that the systems set up to collect data and turn it into useful information are radically simplified. Over time, the system should move to a layout founded on local responsibility **[R02]**, as set out in Box 2.

Box 2 – The ‘local responsibility’ model

- ***The state***[3] sets (based on clinical input) the requirements for the data that providers need to collect and the data quality standards this data needs to meet. To minimise duplication, the state may also fund a central aggregation of data;
- ***Providers*** collect, cleanse and release data (in an appropriate anonymised form) on the internet for all to see and re-use. Providers also support clinicians in collecting data that is needed to improve local services, where this is not mandated centrally;
- ***A plurality of auditors*** audit the data quality of providers, with the state acting where standards have not been met.
- ***A plurality of analysts*** (for example: patient groups, the media, private sector, the state) to analyse and present the data in different ways to different audiences.

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[2] In this report, ‘the public’ refers collectively to the public, patients and service users.

14. Moving to this system will take time, and whilst we recommend it is accepted as our long-term vision, in the short-term the state should start to rethink its role in three ways:
    a. **Collections**. Before making it the responsibility of local organisations, all data collections should be brought together in a single body whose role should be to publish this data online as efficiently and quickly as possible **[R03]**.
    b. **Analysis and presentation**. The state must proactively help create a market for the analysis and presentation of information. Whilst the state should ensure a market is working, it must recognise it is not a monopoly provider, and should not crowd out what the market could provide. The roles of statutory (or publicly funded) organisations should be reviewed to determine whether the state is best placed to be providing their analytical functions, and whether their analysis is stifling the creation of a market **[R04]**.
    c. **Local responsibility**. The state should make a clear statement that data quality is the responsibility of local providers. This should include reflecting data quality in local contracts and Registration Requirements. In addition, all providers should be required to meet the same data quality specifications **[R05]**.
15. To take forward (a) and (b), we recommend that further consideration is given to how the roles of current statutory organisations need to change, particularly taking into account the significant potential to make efficiency gains.

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[3] In this report, ‘the state’ includes all statutory organisations. For example, the Department of Health, Care Quality Commission, NHS Information Centre, amongst others.

16. The Quality Information Strategy sub-group would be prepared to take forward this work, in partnership with the Department of Health's review of arms length bodies. **[R06]**

'More open'

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17. Too much data relating to the quality of services is currently unavailable, reducing its potential benefits.
18. Barring significant other reasons, all data that may be used to address questions relating to quality should be made freely available in an appropriate anonymised form. This is essential to create both a market of analysts outlined above, but also to show transparency and accountability.
19. This should happen through all data being accessible through www.data.gov.uk. There are a large number of actions which need to happen across national datasets for this to happen; these are detailed in Annex C2. We recommend these are progressively implemented **[R07]**, in particular, speeding up existing processes around extracting data from primary care.
20. To achieve this, a number of supporting functions are required **[R08]**.
    a. **Co-ordinating function**. Role to coordinate delivery to data.gov.uk to ensure that data is prepared in the right format, at the right time, to the right standards and governance controls.
    b. **Design governance.** Responsibility for 'secondary use' design governance to act as a guardian of standards across all nationally collected health data. This would increase the ability to link data sets and provide greater flexibility.
    c. **Data linkage.** Service to create new national linked datasets from large, detailed level resources, including the creation of tables which map how different datasets relate to each other.

21. A decision as to which organisation takes these functions forward should be made in the context of the additional piece of work on infrastructure outlined above in paragraph 17.
22. To make data free to reuse, issues around data ownership and governance need to be addressed. To do so, we recommend the consideration of a number of actions outlined in Table 4 of Annex C2 **[R09]**.
23. We currently have much data, but little information. In terms of creating new information, an early area of focus should be increasing information along clinical pathways including social care **[R10]**.
24. Where there are areas which have a complete lack of data, the National Quality Board should play a more active role. To ensure gaps in priority areas are addressed first, all methods to increase nationally collected data should link to the Board's work on prioritising clinical areas **[R11]**.
25. This should include central returns through a formal link with the Review of Central Returns, but also other methods such as the development of Clinical Data Standards, and the topic selection for clinical audits.
26. In addition, the National Quality Indicator Development Group (a sub-group to the Board) should report through the Board's annual report on how gaps in both data and information are being addressed **[R12]**.
27. The Group should also seek to work more systematically with other parties, in particular the representative groups for clinicians, to develop new quality information for the benefit of patients. These parties should include the Academy of Medical Royal Colleges, specialist societies, and commercial ventures **[R13]**.
28. To promote greater openness between different public services, the National Quality Board should actively promote more engaged local data-sharing between public services **[R14]**. The Board will need to be mindful of privacy concerns in doing so, and explore ways of meeting these.

29. Having more data available will increase the importance of making the best possible use of it. To do so, local capacity to be creative needs to increase in order to drive service improvement, particularly across pathways. There should be a form of analytic community with the capacity and space to do this; to deliver this we recommend **[R15]**:
    a. **Developing skills**. Professionalisation of analytic and informatics staff;
    b. **Sharing expertise**. Creation of a critical mass, through networks or other means, of groups of analytic and informatics staff to share expertise; and
    c. **Freeing up time**. Creation of sufficient time for this group of people to actually use information in this sort of way.
30. In doing this, analysts will need to work closely with clinical colleagues. We recommend the Department of Health examines ways to reinforce clinical leadership in developing data and using information, including in the short-term, amending the criteria for Academic Clinical Excellence Awards to include leadership in developing new quality indicators **[R16]**.

‘More trustworthy’

31. At present, there are concerns both at a technical level about the quality of data, and by the public about what information on the quality of services means. These issues are failures of trust. Users of information, be they clinicians or patients, need to be able to have confidence in what the information is telling them, and be able to trust that it is reliable.
32. As such, changes are required to improve trust in the quality of data produced by providers, and trust in how information is presented.
33. With regards to the quality of data collected, we recommend the use of a number of mechanisms to deliver improvements:

    a. **Contracts**. All NHS-funded organisations and providers should be contractually obliged to provide data to a standard quality and in an interoperable format that will allow data-matching with records in other care contexts **[R17]**.
    b. **Regulation**. Monitor and CQC should be more active in using the powers they possess to take action on poor data quality, and set out more clearly how these powers should be used. If these powers are deemed to be insufficient, the National Quality Board should consider how these powers could be increased **[R18]**.
    c. **Audits**. The Board should consider the introduction of full annual audits of data quality for providers, with results made public like financial accounts **[R19]**. This could go forward through strengthening of current plans for third party assurance of Quality Accounts.
    d. **Quality Accounts** should contain a section that requires providers with poor data quality scores to make this an improvement priority, and report their progress against its achievement **[R20]**.
    e. **CQUIN.** It should be considered whether the CQUIN framework could include a requirement for a data quality assessment **[R21]**.

34. To drive data quality nationally, the Data Quality Board should redefine its role to focus on improving awareness of best practice in data quality in health and social care, and highlighting evidence that data quality generates improvements in care quality for patients **[R22]**.
35. To improve trust in how information is presented, we recommend a set of measures should be accepted by those presenting quality information.
36. Whilst a range of options should be explored about how to take forward these measures, our preferred option is for this to form the basis of a Code of Practice for those presenting quality information **[R23]**. A draft code is shown in Box 3.

Box 3 – Code of Practice for presenters of quality information

Information presenters should:

i. Avoid overselling their wares. As no one agency has a complete picture, presentations should encourage audiences to gain additional insights by accessing other sources.
ii. Avoid encouraging an undue focus on a single indicator. In particular presentations of new indicators should be made in the context of what is already known. Relevant context may include other measures of the same aspect of quality, or related concepts, such as data quality.
iii. Adopt user-led design techniques to develop presentations that integrate multiple indicators so that they may be viewed and understood as a set.
iv. Ensure that their presentations are supported by meaningful and accessible materials designed to help the intended audience make use the quality information that is being published
v. Ensure that supporting materials include full disclosure of methods, definitions, and data sources.

37. With regards to (v) above, we recognise that there will be concerns from commercial organisations regarding intellectual property. Given the transparency benefits, the National Quality Board should push very hard against this resistance in order for more open disclosure on methodology.
38. The state should strongly support this; firstly, by ensuring full disclosure is included within any new contracts **[R24]**, but also by reviewing its own involvement in the analysis and presentation of information, as outlined in paragraph 14.
39. Events at Basildon and Thurrock NHS Foundation Trust in late 2009 highlighted public confusion as to the role and actions of the statutory organisations involved. To reduce future confusion, where it is the responsibility of statutory organisations to publish or respond to the publication of quality information, communications need to be clear, joined up, and prompt **[R25]**.

40. To achieve this, statutory organisations should establish clear points of contact and protocols for sharing information. They should also consider developing either their own or common 'validations of concern' for quality information to ensure they have a rapid understanding of both the meaning of information and how they should respond **[R26]**.

41. To further improve presentation, the Department of Health should consider further how independent advice on the interpretation and use of health care quality information may be made available to public audiences **[R27]**.

42. To improve trust in what particular datasets (rather than information) mean, we recommend a requirement that data providers publish declarations alongside each dataset to help with understanding the data **[R28]**. These declarations should highlight advice on interpreting the data, any data quality issues, and any restrictions upon use of the data.

Conclusion

43. In our Interim Report we highlighted that, despite the challenges, we saw our vision as achievable. **This firmly remains our view**.

44. This report has outlined that significant actions are required across a wide range of areas. Even if all of our recommendations are accepted, we recognise that it will take several years for them to be fully implemented

45. However, if the National Quality Board are keen to make progress, we recommend that the single most important action is to make a clear, unified commitment to making information on the quality of services a priority area, and to signal this widely across the NHS.

46. New Health Ministers have indicated that they want to act on quality information. We recommend that the Board uses this strategy as a basis for advice to Ministers to inform policy development.

Recommendations – Complete list

No.	Recommendation	Annex
R01	Future quality information policy should start from the principle of what will, either directly or indirectly, improve the health or care for the public.	
R02	The local responsibility model should be accepted as the long-term direction for information infrastructure, and work should start on the detailed thinking required to transition to this model.	B1
R03	All data collections should be brought together in a single body whose role should be to publish this data online as efficiently and quickly as possible.	B1
R04	The state must proactively help create a market for the analysis and presentation of information. Whilst the state should ensure a market is working, it must recognise it is not a monopoly provider, and should not crowd out what the market could provide. The roles of statutory (or publicly funded) organisations should be reviewed to determine whether the state is best placed to be providing their analytical functions, and whether their analysis is stifling the creation of a market.	B1
R05	The state should make a clear statement that data quality is the responsibility of local providers. This should include reflecting data quality in local contracts and Registration Requirements. In addition, all providers should be required to meet the same data quality specifications.	B1
R06	The Quality Information Strategy sub-group should take forward a further piece of work reviewing organisational roles as set out in R04 and R05, and also to consider who should take forward the functions recommended in R08.	B1
R07	All data should be accessible through www.data.gov.uk. Actions set out in Annex C2 should be progressively implemented in particular, speeding up existing processes around extracting data from primary care.	C2
R08	A number of supporting functions are required**:** a. Co-ordinating function. Role to coordinate delivery to data.gov.uk to ensure that data is prepared in the right format, at the right time, to the right standards and governance controls. b. Design governance. Responsibility for 'secondary use' design governance to act as a guardian of standards across all nationally collected health data. This would increase the ability to link data sets and provide greater flexibility. c. Data linkage. Service to create new national linked datasets from large, detailed level resources, including the creation of tables which map how different datasets relate to each other.	C2
R09	The data ownership issues set out in Table 4 in Annex C2 should be considered.	C2

No.	Recommendation	Annex
R10	The creation of information along clinical pathways, including social care, should be prioritised.	A3
R11	All methods to increase nationally collected data should link to the Board's work on prioritising clinical areas. This should include central returns through a formal link with the Review of Central Returns, the development of Clinical Data Standards, and the development of clinical audits.	A3
R12	The National Quality Indicator Development Group should report through the Board's annual report on how gaps in both data and information are being addressed	A3
R13	The National Quality Indicator Development Group should seek to work more systematically with other parties, in particular the representative groups for clinicians, to develop new quality information for the benefit of patients. These parties should include the Academy of Medical Royal Colleges, specialist societies, and commercial ventures	A3
R14	The National Quality Board should actively promote more engaged local data-sharing between public services	A1
R15	There should be a form of analytic community with the capacity and space to do this. The following actions should be taken: a. Developing skills. Professionalisation of analytic and informatics staff; b. Sharing expertise. Creation of a critical mass, through networks or other means, of groups of analytic and informatics staff to share expertise; and c. Freeing up time. Creation of sufficient time for this group of people to actually use information in this sort of way.	A2
R16	The Department of Health should examine ways to reinforce clinical leadership in developing data and using information, including in the short-term, amending the criteria for Academic Clinical Excellence Awards to include leadership in developing new quality indicators	A3
R17	All NHS-funded organisations and providers should be contractually obliged to provide data to a standard quality and in an interoperable format that will allow data-matching with records in other care contexts.	A1
R18	Monitor and CQC should be more active in using the powers they possess to take action on poor data quality, and set out more clearly how these powers should be used. If these powers are deemed to be insufficient, the National Quality Board should consider how these powers could be increased	A1
R19	The National Quality Board should consider the introduction of full annual audits with results made public, similar to financial audits	A1
R20	Quality Accounts should contain a section that requires providers with poor data quality scores to make this an improvement priority, and report their progress against its achievement	A1
R21	Consider whether the CQUIN framework should include a clear requirement for a data quality assessment	A1

No.	Recommendation	Annex
R22	The Data Quality Board should redefine its role to focus on improving awareness of best practice in data quality in health and social care, and highlighting evidence that data quality generates improvements in care quality for patients	A1
R23	There should be a Code of Practice for those presenting quality information, which includes: i. Avoid overselling their wares. As no one agency has a complete picture, presentations should encourage audiences to gain additional insights by accessing other sources. ii. Avoid encouraging an undue focus on a single indicator. In particular presentations of new indicators should be made in the context of what is already known. Relevant context may include other measures of the same aspect of quality, or related concepts, such as data quality. iii. Adopt user-led design techniques to develop presentations that integrate multiple indicators so that they may be viewed and understood as a set. iv. Ensure that their presentations are supported by meaningful and accessible materials designed to help the intended audience make use the quality information that is being published v. Ensure that supporting materials include full disclosure of methods, definitions, and data sources.	C1
R24	The state should ensure full disclosure of information methodology is included within any new contracts	C1
R25	Where it is the responsibility of statutory organisations to publish or respond to the publication of quality information, communications need to be clear, joined up, and prompt	
R26	Statutory organisations should establish clear points of contact and protocols for sharing information. They should also consider developing either their own or common 'validations of concern' for quality information to ensure they have a rapid understanding of both the meaning of information and how they should respond.	
R27	The Department of Health should consider further how independent advice on the interpretation and use of health care quality information may be made available to public audiences	C1
R28	There should be a requirement that data providers publish declarations alongside each dataset to help with understanding the data. These declarations should highlight advice on interpreting the data, any data quality issues, and any restrictions upon use of the data.	C2

National Quality Board

Information on the Quality of Services - Final Report - Supporting Annex A1

Workstream	A1 – Data Quality
Annex purpose	To set out for recommendations for how to improve data quality of health care information on the quality of services
Who has it been developed by?	Led by Tim Kelsey, with contributions from the Information Centre, and comments from across the sub-group.

Workstream A1 – Data quality

The interim NQB Quality Information Strategy contained an annex on Data Quality which reviewed a number of key health and social care datasets in terms of their accessibility, quality and usefulness. It concluded that data quality is a major challenge for the NHS and an obstacle to quality improvement. In many cases, data is collected but difficult to access and of variable quality. The focus of this review was the short term improvement of comparative administrative data which is essential to the achievement of QIPP objectives, but the same principles will help promote quality in other emerging genres of data relevant to quality, such as patient experience and PROMs.

The general principle which should be applied is that robust data is the only means by which the NHS and its professionals who deliver care will be able to measure quality. Reliable data will also allow market stimulation, plurality of care and ultimately lower cost and more productive services. Reliable records will also directly improve patient care and reduce the incidence of adverse and never events. This document outlines recommendations that the NQB could consider to improve the quality of data in health and social care.

These include:

1. Mandating collection
2. Audit and inspection (external assurance)
3. National infrastructure
4. Increase dissemination, access and use

The rest of this paper explores these issues in detail.

Summary – List of recommendations

	Recommendation
R17	All NHS-funded organisations and providers should be contractually obliged to provide data to a standard quality and in an interoperable format that will allow data-matching with records in other care contexts.
R21	Consider whether the CQUIN framework should include a clear requirement for a data quality assessment.
R18	Monitor and CQC should be more active in using the powers they possess to take action on poor data quality, and set out more clearly how these powers should be used. If these powers are deemed to be insufficient, the National Quality Board should consider how these powers could be increased
R22	The Data Quality Board should redefine its role to focus on improving awareness of best practice in data quality in health and social care, and highlighting evidence that data quality generates improvements in care quality for patients
R19	The National Quality Board should consider the introduction of full annual audits with results made public, similar to financial audits.
R20	Quality Accounts should contain a section that requires providers with poor data quality scores to make this an improvement priority, and report their progress against its achievement
R02	The local responsibility model should be accepted as the long-term direction for information infrastructure, and work should start on the detailed thinking required to transition to this model.
R14	The National Quality Board should actively promote more engaged local data-sharing between public services

1. Mandating collection by NHS-funded organisations

In general, NHS-funded organisations – both providers and commissioners – do not invest adequately in data quality. Contractual obligations, where they exist, are weak and rarely enforced. It is, however, essential to data quality that those closest to the data own lead responsible for its accuracy – it enables them to improve the quality of their service, design reliable metrics and report their performance to their peers and patients. The previous report identified some serious concerns about variable data quality and access in primary care, in particular. These concerns were highlighted in a recent report by the Health Select Committee.[4] Poor data quality means that routine primary care administrative data is rarely shared with secondary providers to enable the construction of metrics across care pathways, or with commissioners to enable assessment of productivity and performance.

Recommendation [R17]

All NHS-funded organisations and providers should be contractually obliged to provide data to a standard quality and in an interoperable format that will allow data-matching with records in other care contexts.

Recommendation [R21]

Consider whether the CQUIN framework should include a clear requirement for a data quality assessment.

In addition to both of these recommendations, there is a clear requirement that contracts between providers and commissioners should also formally include an enforceable obligation to produce high quality data.

Whilst there is particular urgency in the context of QIPP in providing the administrative data assets that will enable quality analysis across the care pathway, there is a general principle that all NHS-funded organisations should

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[4] http://www.ehiprimarycare.com/news/5788/improve_pct_data_skills_say_mps

be under contractual obligations to meet minimum data quality and data matching requirements which will extend beyond simply administrative data into other data areas – such as patient experience or PROMs – in due course. There are three distinctive types of obligation – to comply with national data standards; to comply with approved coding practice; and to relevant standards of access and timeliness. In addition to contractual obligations, regulatory action is required.

Recommendation [R18]

Monitor and CQC should be more active in using the powers they possess to take action on poor data quality, and set out more clearly how these powers should be used. If these powers are deemed to be insufficient, the National Quality Board should consider how these powers could be increased

Besides making the cultural commitment to better data, NHS-funded organisations will need to improve their professional capacity in many areas to meet meaningful contractual obligations. This will involve the recruitment of larger numbers of audit clerks and coders, increased training to ensure higher skilled audit clerks, better management and support around technical management of data sets i.e. definitions of data, data dictionaries, coding systems, and improved IT systems to make recording and checking of data easier. The following recommendation is made in this context.

Recommendation [R22]

The Data Quality Board should redefine its role to focus on improving awareness of best practice in data quality in health and social care, and highlighting evidence that data quality generates improvements in care quality for patients

It is noted, for example, that there are instances of world-class innovation in the NHS in this context. In south east London, GPs have provided patients with direct access to their medical records and the impact on the accuracy of those records and on improvements in the patient experience have been highly significant[5].

2. External Assurance

In addition to NHS-funded organisations being obliged to meet data quality and matching standards, it will be necessary for them to undergo detailed external assurance. The Audit Commission noted in its last data quality report: “Recent work has shown that the quality of data in the NHS is often not what it needs to be to meet the demands now being placed upon it.[6]

Administrative data in all care contexts must be regularly scrutinised to ensure coding is of the best possible quality. There are examples in secondary care, where there has been a significant focus on data quality over the last decade, of manipulation in coding to improve clinical or financial outcomes.

Recommendation [R19]

The National Quality Board should consider the introduction of full annual audits with results made public, similar to financial audits.

There have been concerns that such a requirement could impose undue financial and administrative burdens on NHS funded organisations. Private and public sector professionals, such as the Audit Commission, should be invited to propose audit models which would minimise such costs but would still meet the standard required to maintain public confidence. Monitor is already working on defining such standards with professionals. Organisations publishing Quality Accounts are already required to demonstrate significant commitment to self-reported data quality assessments, building on Monitor’s guidance for NHS foundation trusts.

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[5] See http://www.paers.co.uk/index.shtml

[6] http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/31032009figuresyoucantrustREP.pdf

Recommendation [R20]

Quality Accounts should contain a section that requires providers with poor data quality scores to make this an improvement priority, and report their progress against its achievement

3. Infrastructure change

Recommendation [R02]

The local responsibility model should be accepted as the long-term direction for information infrastructure, and work should start on the detailed thinking required to transition to this model.

The role of central government should be that of data quality 'requirement setter' - including the setting of compliance thresholds - for all bodies and professionals who are funded by the NHS. There is an urgent need for a set of clear national standard definitions for all key data sets, with the greatest current urgency in connection with primary care data. This would ensure that consistent data was collected across the plurality of providers or commissioners in a certain sector or pathway. Collection and analysis could then be carried out by the market against this common specification.

The centre should also be responsible for holding to account any NHS organisation which is not supplying data to these standards. It should publish an annual data quality report on all NHS – organisations either in partnership with the Care Quality Commission and other relevant regulators, or independently. The Data Quality Board, set up by the NHS Information Centre in 2008 in response to the Informatics Review, brings together representatives from DH, Audit Commission, National Institute, the CQC, NHS IC, Primary Care, Connecting for Health and front-line NHS and Social Care organisations – the objectives for which are to systematically improve the quality of data across NHS & Social Care - this could be charged with oversight of the compliance thresholds and also with responsibility for promoting awareness to the local NHS.

Currently, there is confusion over national responsibilities for NHS data - regulators, the Department of Health, professional associations, more than 18 arms-length bodies and the NHS Information centre itself seem to have a role. It is not the purpose of this paper to propose the shape of a future national infrastructure that will ensure improved leadership in data quality but it is essential that the Department of Health designates one single authority as the lead agency in the development and promotion of NHS data standards. This authority should also have a legal requirement to demonstrate that the NHS is making data available as fast as possible, with the minimum level of ‘red-tape’ required from those seeking to use it. It is vitally important that national or local organisations who can demonstrate a public interest benefit are not, for example, deterred from using the data because of any undue bureaucratic burden.

While central government has a clear role in data requirement setting for organisations in receipt of NHS funding, it does not necessarily follow that it should play such a role in data collection, aggregation or dissemination. Improved data quality may be better served by obliging local organisations to have the responsibility for collecting and publishing data to interoperable national standards which will allow any third party to produce comparative analysis of quality outcomes.

4. Increase dissemination – share as much as possible

Local public services providers are increasingly engaged in joint strategic commissioning of key health-related services – practical success hinges on local data-sharing.

Recommendation [R14]

The National Quality Board should actively promote more engaged local data-sharing between public services

This recommendation will be key not just to improved data quality but also to more effective and high quality local services. The government enquiry (Laming enquiry) following the death of ‘baby Peter’ highlighted the lack of data sharing in terms of both communication and information technology[7] and the urgency by which this should be improved. The ‘Cardiff model’ has shown that integrating data and information across police, healthcare and local authorities has enhanced the prevention of violent crime[8] and reduced cost in all services.

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[7] http://publications.everychildmatters.gov.uk/eOrderingDownload/HC-330.pdf

[8] See www.vrg.cf.ac.uk for more information

National Quality Board

Information on the Quality of Services - Final Report - Supporting Annex A2

Workstream	A2 – Thinking differently
Annex purpose	How to create the conditions where measurement fit for the challenges of the new decade can thrive
Who has it been developed by?	Led by Richard Hamblin, with comments from across the sub-group.

Workstream A2 – Thinking differently:

Contents

Summary – List of recommendations

	Recommendation
R15	There should be a form of analytic community with the capacity and space to better use data creatively. The following actions should be taken: d. Developing skills. Professionalisation of analytic and informatics staff; e. Sharing expertise. Creation of a critical mass, through networks or other means, of groups of analytic and informatics staff to share expertise; and f. Freeing up time. Creation of sufficient time for this group of people to actually use information in this sort of way.

Section A: Case for change - Why we need to think differently

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1. The last ten years has seen an explosion in the use of performance measures around healthcare in England, and there is little doubt that this has been part of a broader international trend in stimulating improvement through the measurement (and in some cases publication) of performance. Critics have attacked this as centralising, top down and clinically irrelevant, but it is hard to argue that this has driven step changes in performance, particularly at first around access, but more latterly, at least apparently, in areas such as infection control.
2. We downplay these achievements at our peril. The NHS, having failed to deal with the issue of long waits for elective care for more than half a century, completely neutralised this as an issue in a little over 3 years, and rigorous measurement played its part.
3. However, successes of this sort are probably self limiting. Commentators on the broader public sector have identified this heavily managerial approach as being appropriate for moving public sector performance from substandard to acceptable, but insufficient to move from good to great, which requires local innovation (and by implication innovation in measurement and use of information as well). Such a view was a clear implication of the Darzi review.
4. In addition we have seen four negative consequences of how information has been used in the last ten years:
   - Clinician disengagement – information being seen as part of “management” and having no link with quality of care; and yet as, for example, the Bristol enquiry showed, intelligence use of information would have identified weaknesses in care quickly, and clinical commitment to responding to it would have driven improvement
   - Gaming, manipulation and misreporting of data around threshold points in targets is well established as a response of at least a minority of healthcare providers

  - De-professionalisation of analysts; ten years ago there were pockets of innovation in use of information that really addressed and changed healthcare practice, today we are still left with pockets of good practice. We have a lot of analysts doing nothing more than feeding central returns, and the consequence of this is that those with the imagination and energy to make a difference leave.
  - The consequence of a managerial paradigm for measurement is a fixation with analysis at the organisational level, when the issues for health care are increasingly across boundaries

5. So in the broadest sense, we will need to think differently about information.
6. We will need to see it not as an instrument of managerial control, but a key to creatively questioning the quality and efficiency of services in order to improve both.
7. We will need to see it not as a centrally imposed menu, but to allow creativity in identifying and addressing local issues.
8. We will need to see it not primarily through an organisational and managerial paradigm, but to bring different data together to describe the experiences of individuals.
9. But how do we get there?

Section B: What don't we have already that we might want?

10. We have identified that we don't have all that we might want – recognising that there is a lack of information about out of hospital care in particular, but we need to be careful before deciding that collecting more and more data is the solution.
11. Collecting data is expensive, and new data sets in particular take time to be useful – anything we mandate in 2010 will not drive improvements before 2015 at the earliest.
12. Internationally the UK and England specifically is actually at the cutting edge of collecting information about , at least in terms of information across a national system, and taken as a whole (there are individual examples of more clinically relevant data in small pockets internationally – for example audit registries in the Nordic countries, the VA's Vista system and so forth). This has been to such an extent that at a recent international conference on issues of performance measurement and incentives the UK was cited as entering a "measurement frenzy" in the 2000s.
13. It is certainly true that in terms of available data the rest of the world is behind us, as shown in Table 1.

Table 1 – International comparisons of data availability

Country	**Data availability**
United States	Isolated pockets (VA, Group Health, Geisinger, some of the big hospitals) but nothing system wide, and certainly nothing comparable – Joint Commission have to collect information bespokely, everything is aggregated returns (e.g. HEDIS) not comparably data sets with the capacity to reanalyse inventively
Canada	Substantially behind, just starting on the journey we are making – e.g. they are currently piloting 10 QOF type indicators cf our 146 five years ago.
Netherlands	About a fifth of the available indicators we have – towards the front end of where the rest of Europe is
France	A few process indicators and nothing publicly available in disaggregated form – national publication is via a Paris magazine and recognised to be statistically rudimentary.

Table 1 – International comparisons of data availability	
Country	**Data availability**
Nordic countries	Have made good progress on clinical registries and the Danes are probably the furthest ahead on these, but they have nothing in the way of patient feedback that we have.

14. Through our collaborations with the European Partnership of Scrutinising Organisations it is clear that the availability of data in the UK is substantially ahead of Europe as a whole and this is related to the NHS's near- monopoly of provision.
15. It is worth thinking about what we already have in terms of information – and it is substantial – even for non-hospital settings. The following method of classifying data was proposed by Gwyn Bevan, reflecting the thinking of Donabedian.

Table 2 – Method of classifying data (Bevan)	
Structure	
Process (clinical) – clinical process adherence	**Process (patient)** – experience
Outcome (clinical) – mortality, morbidity	**Outcome (patient)** – PROMS

16. This classification can be used to identify where we have data sources which can provide useful intelligence. What this shows is that there aren't major gaps where there is not some data available which could be used constructively. What is there (across a system as a whole) that we do not currently have? The answer is not a lot, or not a lot that we could get without major investment in collection.

Table 3 – Coverage across different data classifications	
Structure: ESR, Staff survey, AHC data, QOF etc	
Process (clinical) - HES (analysable of activities, referral patterns etc) - National Clinical audits - QOF - GP Prescribing data	**Process (patient)** - Patient Surveys across all sectors
Outcome (clinical) - HES (analysable for outcomes)	**Outcome (patient)** - PROMS (programme being

Table 3 – Coverage across different data classifications	
Structure: ESR, Staff survey, AHC data, QOF etc	
- Some National Clinical Audits - Some QOF	established)

17. There remains a gap within social care, but even here there is a process in place for this (the NASCIS programme), and as we demonstrated below there are things that can be done with available data (including, actually, healthcare data) that start to ask the right sorts of questions about healthcare to allow improve

Section C: Using it more intelligently?

18. An alternative view is that the issue is less one of trying to collect the perfect information (time consuming, costly and most of which we have programmes in place for) as much as how intelligently we use what we are collecting.
19. As we alluded to in the introduction to this section, there are two fundamentally different uses for information to either report on performance, or to raise questions about quality. The last ten years have been dominated by a need to report centrally around a number of targets. This, however, is a different set of skills to the imagination, invention and understanding required to use information intelligently to ask serious questions about quality, understand the answers and monitor improvement within and organisation.
20. In short the analytic community around the NHS is now too diffuse and de-professionalised.
    - The organisational decentralisation in the 1990s destroyed the old RHA information departments which had critical mass and capacity to think creatively to extract intelligence – Quality Observatories are a step in the right direction but remain too small.
    - The information agenda of the 2000s has concentrated on information systems rather than using what we have intelligently – for example we have even lost useful conferences such as the annual IA Casemix conference, which had a clear analytic focus. Such conferences as now exist tend to be very IT focused.
    - The managerial agenda of targets has undoubtedly achieved much, but has several deleterious side effects one of which is to limit invention among local analytic departments – there are a few centres of excellence (often in university teaching hospitals) but not enough
    - Another is to drive a wedge between managers and clinicians, such that there is suspicion about the value and veracity of information and a lack of a common shared language.

- At the same time the ability to use information by commissioning agencies remains underdeveloped, as noted with some force by the recent Health Select Committee report into commissioning.

21. This state of affairs was recognised in the Informatics strategy which had a stream on developing an informatics/analytic community, but, in the light of the travails and large expenditure associated with Connecting for Health, this has not developed as we would have hoped.
22. An interesting point is whether we can simply leave this to the market to fill the gap. Private sector provision is certainly an option for how the necessary analytic resource becomes available (although we need to recognise that whoever provides, if the NHS and or local authorities are funding this we are talking about tax payer funding). However, simply expecting a market for intelligent analysts to appear strikes me as naïve, if no-one wishes to buy the service. At the moment, and despite having impressive private sector providers with individually excellent products, it is not clear that many NHS trusts would see either the creation of their own intelligent analytical department nor purchase of a comprehensive service of this type from a private sector provider as a priority.
23. Failure to exploit the information as we might means that the collection of information is seen as unimportant (hence quality is bad), a burden (thus resented) and clinically irrelevant (although HSMR and mortality outliers are starting to challenge this perception)
24. If we are serious about a quality information strategy we should make its use, rather than the collection of information, where as a system we are bleeding edge already, our priority.

Section D: A live example – how we could start measuring care across systems for older people using existing data.

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25. We know from recent work undertaken inside CQC that there is a massive variation in the quality, outcomes, patterns and costs of care for older people, which cannot be explained by demography, deprivation or supply side effects. This has profound implications for the experience of individuals and the cost implications are potentially huge.
26. Understanding this variation and what is causing it is the essential first step to addressing issues of poor experience and wasteful provision. Yet older people are more likely to have complex and multifarious needs, receive care (which overlaps) in many different setting, and suffer from long-standing fractures between health and social care (and between different healthcare organisations).
27. Considerable effort has been put in by academic units in modelling likely needs, using existing data (some of it only available locally). Yet even with nationally existing data alone much can be done, provided we accept the mindset that we are using the information to ask questions and improve, rather than to provide judgements.
    - The MAISOP project in Scotland has left some useful indicators that we can use, and we can gather others from the data sets available to us.
    - Patterns of management of chronic conditions across geographical areas can be derived from QOF
    - Availability of home care and other out of hospital care can be derived from the NASCIS system
    - Patterns of emergency hospital admission and related OBDs, discharge patterns, and referrals from care homes can be derived from HES.
    - These data together, intelligently analysed can produce in the region of 15-20 useful indicators which can describe variations sufficiently well to form hypotheses and ask questions about how best to improve care. But this requires a change in mindset. What we cannot do from this is

form a very clear judgement that we can publish out to the world at large

Section E: Conclusion

28. Collecting more data is costly – both directly and indirectly. More fundamentally, unless there is clear evidence of it being used imaginatively we will meet objections about cost and burden of collection.
29. Existing available information can be used creatively to provide the necessary information for driving service improvement across pathways, but local capacity to be creative is essential for this to happen.
30. In order for this to happen there needs to be some form of analytic community with the capacity and space to do this.

	Recommendation
R15	There should be a form of analytic community with the capacity and space to better use data creatively. The following actions should be taken: g. Developing skills. Professionalisation of analytic and informatics staff; h. Sharing expertise. Creation of a critical mass, through networks or other means, of groups of analytic and informatics staff to share expertise; and i. Freeing up time. Creation of sufficient time for this group of people to actually use information in this sort of way.

31. There are a wide range of ways of doing this involving the NHS itself, other agencies, third/private sector partners but however done the minimum that we need to deliver this is:
    - Professionalisation (possibly formal) of analytic staff
    - Creation of a critical mass, through networks, agencies or other mechanisms of large enough groups of analytic staff to share expertise,
    - Creation of sufficient time for this group of people to actually use information in this sort of way

32. This analytic community does not need to be provided by the NHS itself (although they are likely to pay for its services) but it will need an impetus from the NHS to deliver it, if not central direction, then a “burning platform”, and the need to make major savings without harming patient care may prove just such an opportunity.

National Quality Board

Information on the Quality of Services - Final Report - Supporting Annex A3

Workstream	A3 – Filling data and information gaps
Annex purpose	To set out a five-year roadmap for filling the gaps
Who has it been developed by?	Led by the secretariat, with comments from across the sub-group.

Workstream A3 – Filling data and information gaps

Introduction

1. The NHS collects a wealth of data in different care settings – data that underpins ‘information’ describing the process and outcomes of care.
2. However, as both the Interim Report and the development of *Indicators for Quality Improvement* showed, data and information coverage right across all NHS services is variable, covering isolated parts of care pathways and sometimes missing different aspects of quality altogether. Sometimes, there is no systematic information available at all. This annex describes how filling data and information gaps can be addressed.

The vision for 2015

3. By 2015, the vision is to ensure that patients and professionals have ready access to meaningful information about the full range of services that the NHS provides, supported by high quality underpinning data.
4. For professionals, this means having clinically relevant robust quality indicators, that support the respective roles of every person working within a clinical team.
5. For the public and patients, this means having robust information, tailored to their needs, about the delivery of *all* NHS care, in all settings and across care pathways, which enables them to understand and make informed decisions about their care.

Contents

  - **F** Action
  - **G** Five year road map
- Conclusion

Summary – List of recommendations

	Recommendation
R11	All methods to increase nationally collected data should link to the Board's work on prioritising clinical areas. This should include central returns through a formal link with the Review of Central Returns, the development of Clinical Data Standards, and the development of clinical audits.
R12	The National Quality Indicator Development Group should report through the Board's annual report on how gaps in both data and information are being addressed
R13	The National Quality Indicator Development Group should seek to work more systematically with other parties, in particular the representative groups for clinicians, to develop new quality information for the benefit of patients. These parties should include the Academy of Medical Royal Colleges, specialist societies, and commercial ventures
R16	The Department of Health should examine ways to reinforce clinical leadership in developing data and using information, including in the short-term, amending the criteria for Academic Clinical Excellence Awards to include leadership in developing new quality indicators

Realising the vision

6. Filling the gaps to meet the 2015 vision will require a co-ordinated approach, taking into account the factors shown in Table 1.

Table 1 – Requirements to fill data gaps

	Requirement	Detail
A	**Leadership**	Setting direction on information requirements, against the backdrop of why information is important
B	**Principles**	Being clear about good practice in developing quality information
C	**Governance**	Which ensures good practice is followed and provides an overview of what action is required and by whom
D	**Frameworks**	Building on existing mechanisms which support the development of good quality information in efficient ways
E	**Multi-discipline approach**	Making sure that NHS professionals, the informatics community and information analysts are involved in developing the right information to meet the needs of professionals, patients and the public.
F	**Action**	Identifying the actions that will lead to results, building on activities already underway.

A: Leadership

7. The National Quality Board was established to provide a focal point for driving quality improvement in the NHS. The Board has already signalled the importance of developing good quality information to underpin all the elements required to deliver those improvements, and has taken specific action to tackle this.
8. For example, through its subgroup, the National Quality Indicator Development Group (NQIDG), it has commissioned work to develop broader and better patient safety indicators.
9. The Board also has responsibility for advising on priorities for quality improvement in the NHS, supported by an objective evidence-base. Work on this to date has highlighted the need to develop more information on a range of clinical topics to ensure that the evidence base is as robust and comprehensive as possible.
10. Although there are gaps, the volume of data currently collected demonstrates that the burden of data collection on the NHS needs to be

kept to a minimum, to protect the time that front-line staff need to deliver high quality care. Where new data collections are necessary, it is important that they are prioritised.

Recommendation [R11]

All methods to increase nationally collected data should link to the Board's work on prioritising clinical areas. This should include central returns through a formal link with the Review of Central Returns, the development of Clinical Data Standards, and the development of clinical audits.

B: Governance for developing quality information

11. A 'governance' model for developing quality indicators was also introduced in January 2010, managed via a new National Quality Board sub-group – the National Quality Indicator Development Group (NQIDG). This group is tasked with taking a strategic view of the drivers of quality information needs and how those needs can be met, promoting the re-use of data, as well as ensuring that quality information is robust and developed in partnership with NHS professionals (ie robust and credible for its purpose).
12. The need for this group is demonstrated by the growing interest in and appetite for measuring (and reporting) the quality of NHS services and this comes to light in many ways.
13. For instance, through themed statistical bulletins published by the NHS Information Centre and information for the public through NHS Choices, to independent guides, such as those produced by Dr Foster, and forthcoming Quality Accounts, which all NHS providers will have to publish from 2010 onwards.

Recommendation [R12]

The National Quality Indicator Development Group should report through the Board's annual report on how gaps in both data and information are being addressed

C: Principles

14. Quality information development needs to be based on robust standards and be ‘user-led’ – whether the user is a member of the public, a patient or a professional delivering NHS services. The key principles are shown in Box 1.

Box 1 – Key principles to underpin developments

- Quality information developments should be led by professionals and patients, as part of a multidisciplinary approach involving information specialists
- Robust methodologies for good quality information need to be applied
- Use and re-use of data should be encouraged to minimise data collection burdens
- Clear roles and responsibilities of key organisations need to be spelled out.

15. These principles have been agreed by the National Quality Board as the basis for quality indicator development and will support better information about quality.

D: Frameworks

16. There are two frameworks that can underpin this, one of which is already well established, relating to statistical good practice, the other on quality indicator development, which builds on existing mechanisms for developing robust information.

Table 2: Frameworks to underpin data development

National Statistics Code of Practice	The Code of Practice provides an important set of principles and protocols which apply specifically to developing and publishing official statistics, but which are also generally useful in the context of developing robust information that will end up in the public domain.
Governance for quality indicator development	The National Quality Indicator Development Group (a sub-group of the National Quality Board) is responsible for putting the Board’s strategic vision for quality information into practice, by having oversight of the drivers for quality indicator development and developments that are already underway.

17. Using these frameworks will ensure that the right information is developed and published to support quality improvement, and to provide more openness and transparency about how the NHS operates.

E: Multidisciplinary approach

18. A multidisciplinary approach is required to ensure that all the relevant audiences have the best information on quality to meet their needs. The three disciplines are shown in Table 3.

Table 3: The three disciplines

Clinical, medical and professional groups	• Organisations such as medical Royal Colleges, Specialist Associations, and other representative groups eg Allied Health Professionals, should lead the way, using their expertise in setting out ‘what’ should be measured, and leading the way in developing information, from a professional standpoint. • While many such organisations are involved in developing quality information, it is recommended that NQB explore how this can be done in a more focused way, for instance through the Academy of Medical Royal Colleges, Specialist Associations, Allied Health Professionals and other staff and patient groups.
Informatics	• The Informatics community is vital for taking ‘what’ should be measured, and providing the expertise on ‘how’ to implement those measurements, to ensure that data are fit for purpose and can be used to derive robust, meaningful information about the quality of services that the NHS provides.
Analysts	• The analytical community at national and regional/local level should provide the expertise on how to take data and analyse it in ways that provide meaningful information to the various users of information, supporting quality reporting and quality improvement.

Recommendation [R13]

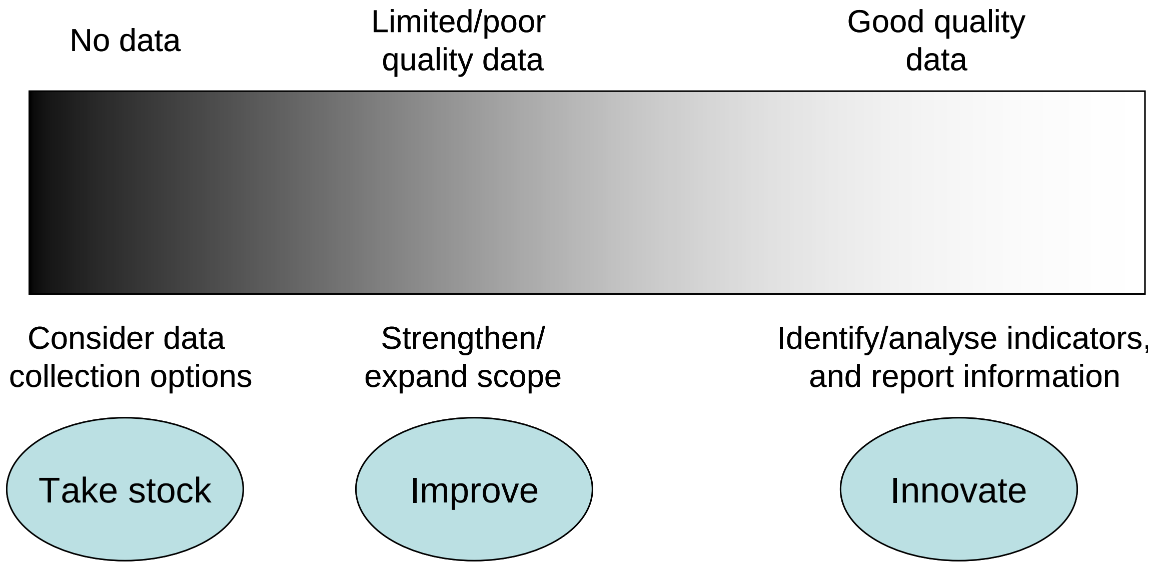
The National Quality Indicator Development Group should seek to work more systematically with other parties, in particular the representative groups for clinicians, to develop new quality information for the benefit of patients. These parties should include the Academy of Medical Royal Colleges, specialist societies, and commercial ventures.

Recommendation [R16]

The Department of Health should examine ways to reinforce clinical leadership in developing data and using information, including in the short-term, amending the criteria for Academic Clinical Excellence Awards to include leadership in developing new quality indicators.

F: Action, roles and responsibilities

19. **Strategic leadership** – the National Quality Board provides the strategic leadership for quality improvement, including the development of quality information, through its sub-group the National Quality Indicator Development Group (NQIDG). This group takes into account the broad range of drivers for quality information and target activity accordingly – whether through specific pieces of work, or prioritising development for *Indicators for Quality Improvement*.
20. **Identifying data and information needs** – in putting NQB's vision into practice, NQIDG maintains an overview of gaps in quality indicator coverage and developments in train, so that it can promote activity that fills those gaps and commission work, through professionals, informatics experts and information analysts, to ensure that robust quality information can be developed.
21. However, the diagram below illustrates that NQIDG will need to be mindful of the potential links between efficient data collection as well as the information that can be developed from this data, for instance, recognising that thought needs to be given to data collection options as well as how to derive better information from existing data.



22. **Underpinning governance** – this was outlined under "Principles" and is managed by the National Quality Indicator Development Group.
23. **Utilising existing structures and processes** – much of what is required to improve quality information is already in place, but will become increasing co-ordinated in a strategic way through the National Quality Indicator Development Group. The structures already in place include:
    - NHS Information Centre for Health and Social Care – which provides the authoritative focal point for health and social care data.
    - Professional groups – including Royal Colleges, Specialist Associations and other professional bodies, which should be the focal point for developing clinically robust information
    - Regional analytical functions/organisations – such as the Quality Observatories and Public Health Observatories, who are key generators, users and publishers of quality information
    - Review of Central Returns (ROCR) – which manages and reviews the data collection burden on the NHS and has introduced time limitations to ensure that collections are periodically reviewed to establish if they remain necessary
    - Information Standards Board (ISB) – which articulates the standards for data collection and implementation in the NHS

24. **Working with the NHS** – this is essential for ensuring that credible information is developed to describe the quality of health care across the NHS, working with the organisations and individuals who deliver care.
25. **Working with patients/public** – seeking out the views of patients and the public will foster a greater *understanding* of what these audience are interested in, and the information they need to be active participants in care. Scrutiny of published information, such as Quality Accounts, and engaging with groups such as National Voices provides a platform for strengthening quality information.

G: The five-year roadmap

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26. Achieving the 2015 vision will require bringing together a range of activities, with some key milestones as follows:

- Year 1 – 2010-11
    i. Mapping current activity/developments underway relating to quality data and information (NQB/NQIDG)
    ii. Identifying key strategic gaps to be filled (NQB/NQIDG)
    iii. Scope where new data is required and begin development work on priority areas (Multidisciplinary, including informatics community)
    iv. Expand scope of available quality information analysis based on existing data, particularly relating to pathways of care (NHS IC, QOs and wider analytical community)
    v. Alignment of Clinical Data Standards Assurance delivery with prioritisation principles; demonstration of improvement in data quality and clinical outcomes by involvement of clinical groups in the development of clinical data standards

- Year 2 – 2011-12
    i. Development and testing of new indicators (Royal Colleges, Specialist Associations, Allied Health Professionals, other

    staff and patient groups supported by informatics and analytical community)
    ii. Begin implementing tested indicators (Health professionals supported by informatics community)
    iii. Begin development work on lower priority areas (eg where good information is already available)
    iv. Delivery of core Clinical Data Standards to meet priority clinical information requirement gaps
- Year 3-5 – 2012-13 to 2014-15
    i. Expand scope of available quality information across all care pathways
    ii. Review existing data and information to ensure quality information remains necessary and relevant
    iii. Ongoing delivery and benefits realisation of core Clinical Data Standards meeting priority clinical information requirement gaps.

Conclusion

27. Filling the gaps will require leadership from the National Quality Board to identify and drive through improvements to the available quality information, building on the considerable efforts that the NHS already puts in to support this.
28. However, the Board will also need to further strengthen the alignment between existing structures and processes that can support the efficient development of robust and meaningful data and quality information in partnership with key producers and audiences for that information.

National Quality Board

Information on the Quality of Services - Final Report - Supporting Annex B1

Workstream	B1 – Infrastructure
Annex purpose	To set out recommendations for how to improve the infrastructure required for quality information.
Who has it been developed by?	Led by the secretariat, with contributions from across the sub-group.

Workstream B1 – Infrastructure

Introduction

1. The Interim Report of the Quality Information Strategy examined the roles of the national statutory organisations with regards to quality information. It was clear from this work that “the current situation results in overlapping and duplicate responsibilities, and clear scope for rationalisation.”[9]
2. This paper sets out proposals for how the infrastructure supporting quality information could be improved.
3. As well as exploring how best to address the issue of overlapping responsibilities, the paper considers how infrastructure can best help achieve the vision of quality information.
4. This paper has drawn on discussions across the sub-group, including a short workshop chaired by David Haslam. It is underpinned by functional analysis (Section A), with the proposals covering both the long-term vision for infrastructure (Section B), and the actions which need to be taken in the short and medium term to move towards this vision (Section C).
5. This paper incorporates the proposed annex on regional infrastructure. The current focus of information regional infrastructure are Quality Observatories; a background paper is available as Annex 3 to this paper.

Contents

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[9] Interim Report, paragraph 20

Summary – List of recommendations

	Recommendation
R02	The local responsibility model should be accepted as the long-term direction for information infrastructure, and work should start on the detailed thinking required to transition to this model.
R05	The state should make a clear statement that data quality is the responsibility of local providers. This should include reflecting data quality in local contracts and Registration Requirements. In addition, all providers should be required to meet the same data quality specifications.
R03	All data collections should be brought together in a single body whose role should be to publish this data online as efficiently and quickly as possible.
R04	The state must proactively help create a market for the analysis and presentation of information. Whilst the state should ensure a market is working, it must recognise it is not a monopoly provider, and should not crowd out what the market could provide. The roles of statutory (or publicly funded) organisations should be reviewed to determine whether the state is best placed to be providing their analytical functions, and whether their analysis is stifling the creation of a market.
R06	The Quality Information Strategy sub-group should take forward a further piece of work reviewing organisational roles as set out in R04 and R05, and also to consider who should take forward the functions recommended in R08.
R16	The Department of Health should examine ways to reinforce clinical leadership in developing data and using information, including in the short-term, amending the criteria for Academic Clinical Excellence Awards to include leadership in developing new quality indicators

Section A: Functional analysis

6. The Interim Report analysed the roles of the statutory organisations represented on the Quality Information Strategy sub-group. This showed that information functions were spread across different organisations without a clear rationale as why this was necessary. For example, many organisations were involved both in the collection and analysis of data[10].
7. At the National Quality Board meeting in March 2010, the Board were highly supportive of the work and conclusions made in the Interim Report. The Board were keen that the second phase of the strategy explicitly considers the national infrastructure issue in depth.
8. For the final report, the analysis has been developed in two ways:
    a. The organisational mapping has been expanded to include all arms-length bodies, as shown in Annex A. This confirms the findings of the Interim Report that functions are currently widely spread, with opportunity for rationalisation; and
    b. The broad functions used in the Interim Report[11] have been refined, particularly with regard to the functions required to get data freely available.[12]
9. Table 1 details these refined functions.

Table 1 – Functions

	Function	**Description**
1	**Specifying *what* data should be collected and to what standards**	Set requirements of what data organisations need to collect, and the accompanying data standards
2	**Collecting data**	Recording of data within organisations
3	**Manufacturing data**	Transferring raw material into usable data
4	**Cleansing data**	Detecting and correcting corrupt or inaccurate data
5	**Releasing data**	Making data freely available in a raw form
6	**Assuring data quality**	Auditing healthcare providers' collection of data

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[10] See Annex 2.3 to the Interim Report on organisational roles

[11] Collection/Publication of data/Analysis/Presentation of information

[12] As the vision set out in the Interim Report includes a proposal that "barring significant other reasons, all quality information should be made freely available" it makes sense to talk about the infrastructure required to reach this point.

Table 1 – Functions

	Function	Description
7	**Taking action on sub-standard data quality**	Acting on healthcare providers if they do not meet agreed data standards
8	**Analysing data**	Interrogating data to make conclusions. Includes aggregating data
9	**Presenting information**	Presentation of information to a specific audience group accompanied by explanatory analysis and interpretation.

Section B: Long-term vision

10. This section details a long-term vision for information infrastructure. It sets out principles for how a model could be structured. In moving towards the model, there would need to be careful thinking on how to overcome a number of obstacles.

What does the long-term infrastructure need to achieve?

11. Whilst overlapping responsibilities require clarification in the short and medium term, by looking at the long-term we have a chance to recommend how the national infrastructure can help meet the vision set out in the Interim Report. Central to the vision is that information is:
    a. **Available** (currently much more data could be publicly available)
    b. **Trusted** (currently significant issues with poor data quality)
    c. **Insightful** (currently data doesn’t cover all required topics)
12. The infrastructure must play a positive role in achieving this vision.

The ‘local responsibility’ model

13. To contribute to meeting this vision, we recommend that the infrastructure for quality information needs to change, with three principle themes:
    - Greater responsibility for providers in collecting and releasing data
    - The state focusing on the functions it is uniquely placed to provide
    - An innovative free market of organisations involved in analysis and publication

14. At present, the responsibility for data quality lies more with national statutory organisations than the providers actually collecting the data. This lack of responsibility has subsequent impacts on data quality.
15. To increase local responsibility for data, a future model of information infrastructure is to place local organisations firmly at the centre of data production. We term this the ‘local responsibility’ model.
16. In this model, there are a radical change of responsibilities - outlined below and mapped against the functional analysis in Annex 2.
    a. The ***state*** sets the data requirements that providers need to collect, and the data quality standards this data needs to meet.
    b. Healthcare ***providers*** collect data and take on all responsibilities up to and including releasing the data (in an appropriate anonymised form) on the internet for all to see and re-use. These responsibilities include manufacturing and cleansing the data.
    c. Providers adherence to the state’s standards are audited by a ***market of auditors***. The auditors’ role is to ensure correct processes are being followed.
    d. If providers have not been following standards, sanctions can be taken either by the ***state*** or by the ***regulator***.
    e. Once data has been released, there is a ***free market of analysts*** to put the data into different forms and present in different ways. The state would be able to have its own analytical function doing this as much as any other organisation.
    f. The ***state*** may consider funding a central aggregation of data to minimise duplication in creating national data sets from the locally published data. However, the state would not have a role in presenting information to the public, beyond the objectives of the state’s organisations.

Recommendation [R02]

The local responsibility model should be accepted as the long-term direction for information infrastructure, and work should start on the detailed thinking required to transition to this model.

What needs to happen at a regional level?

17. In this model, the role of the state focuses on what it is in a unique position to provide. In terms of analysis, statutory bodies should be only involved in doing what is necessary for them to fulfil their core objectives.
18. There will need to be a regional element to fulfil health economy objectives. This regional role will include providing some in-house analytical function in order to help them meet their objectives, and an ability to facilitate comparisons and learning across healthcare providers within their region.

Section C: Short and medium term actions

19. The 'local responsibility' model is a fundamental change, and requires a long-term transition. In the short and medium term, we recommend the following actions in order to improve the current infrastructure and move towards the long-term ambition:

Recommendation [R05]

The state should make a clear statement that data quality is the responsibility of local providers. This should include reflecting data quality in local contracts and Registration Requirements. In addition, all should be required providers to meet the same data quality specifications.

Recommendation [R03]

All data collections should be brought together in a single body whose role should be to publish this data online as efficiently and quickly as possible.

Recommendation [R04]

The state must proactively help create a market for the analysis and presentation of information. Whilst the state should ensure a market is working, it must recognise it is not a monopoly provider, and should not crowd out what the market could provide. The roles of statutory (or publicly funded) organisations should be reviewed to determine whether the state is best placed to be providing their analytical functions, and whether their analysis is stifling the creation of a market.

Recommendation [R06]

The Quality Information Strategy sub-group should take forward a further piece of work reviewing organisational roles as set out in R04 and R05, and also to consider who should take forward the functions recommended in R08.

Annex 1 - Arms length bodies functions regarding information

Collection of Data

- Care Quality Commission (CQC)
- Health Tissue Authority (HTA)
- Monitor
- NHS Blood and Transplant (NHSBT)
- NHS Information Centre (NHSIC)
- National Patient Safety Association (NPSA)
- Human Fertilisation and Embryology Authority (HFEA)
- Medicines and Healthcare products Regulatory Authority (MHRA)
- NHS Business Services Authority (NHSBSA)
- NHS Institute (NHSi)
- NHS Litigation Authority (NHSLA)
- National Treatment Agency (NTA)

Publication of data

- Human Fertilisation and Embryology Authority (HFEA)
- NHS Information Centre (NHSIC)
- Medicines and Healthcare products Regulatory Authority (MHRA)

Interpretation and analysis of data

- Care Quality Commission (CQC)
- Health Tissue Authority (HTA)
- Monitor
- NHS Blood and Transplant (NHSBT)
- NHS Information Centre (NHSIC)
- National Institute for health & Clinical Excellence (NICE)
- National Treatment Agency (NTA)
- Human Fertilisation & Embryology Authority (HFEA)
- Medicines and Healthcare products Regulatory Authority (MHRA)
- NHS Business Services Authority (NHSBSA)
- NHS Institute (NHSi)
- NHS Litigation Authority (NHSLA)
- National Patient Safety Association (NPSA)

- **Presentation of Information**

- Alcohol Education and Research Council (AERC)
- Human Fertilisation & Embryology Authority (HFEA)
- Medicines and Healthcare products Regulatory Authority (MHRA)
- NHS Business Services Authority (NHSBSA)
- NHS Information Centre (NHSIC)
- National Institute for health and Clinical Excellence (NICE)
- National Treatment Agency (NTA)
- Care Quality Commission (CQC)
- Health Protection Agency (HPA)
- Monitor
- NHS Institute (NHSi)
- NHS Litigation Authority (NHSLA)
- National Patient Safety Association (NPSA)

Annex 2 - Information production functions

	Function	Description	State function?	Who's role?
i.	**Specifying *what* data should be collected and to what quality**	Set requirements of what data organisations need to collect, and the accompanying data standards	Yes. State sets requirements which providers and auditors must follow.	The state
ii.	**Collecting data**	Recording of data within organisations	No	Individual healthcare providers
iii.	**Manufacturing data**	Transferring raw material into usable data	No	Individual healthcare providers, being able to contract out
iv.	**Cleansing data**	Detecting and correcting corrupt or inaccurate data	No	Individual healthcare providers, being able to contract out
v.	**Releasing data**	Making data freely available in a raw form	No	Individual healthcare providers
vi.	**Assuring data quality**	Auditing healthcare providers' collection of data	No (other than setting requirements for auditors)	Market of auditors, adhering to standards set by state.
vii.	**Taking action on sub-standard data quality**	Punishing healthcare providers if they do not meet agreed data standards	Yes	Regulatory licensing function. Also levers held by NHS Chief Executive.
viii.	**Analysing data**	Interrogating data to make conclusions. Includes aggregating data	Yes, where required to fulfil purposes of state organisations. No state monopoly.	Free market
ix.	**Presenting information**	Presentation of information to a specific audience group accompanied by explanatory analysis and interpretation.	Yes, where required to fulfil purposes of state organisations. No state monopoly.	Free market

Annex 3 – Update on Quality Observatories – *Robert Winter*

Background

Quality Observatories came out of the NHS Next Stage Review (NSR), which identified the need for the NHS to measure quality, the underlying principle of the NHS. Each SHA was asked to establish a formal Quality Observatory (QO), building on existing analytical arrangements in the region. The role of these observatories is to:

- enable local benchmarking
- support the development of metrics, and;
- By doing so help front line staff innovate and improve the services they offer

How are they achieving this?

Quality Observatories are very much regional organisations and are developing with a focus on regional priorities working closely with their clinicians and organisations. Collectively, QOs have identified a number of ways through which they can support the drive for quality improvement, these include:

- providing benchmarked intelligence on quality performance
- providing ‘bespoke’ services to clinical leaders
- promoting and developing quality indicators which span patient safety, effectiveness and patient experience
- continuing to support the wider performance agenda by providing an early warning system for potential quality concerns
- providing and supporting the development of analytical capacity
- supporting innovation and the adoption of best practice through the proactive sharing of knowledge

Quality Observatories cover the entire healthcare landscape including acute, primary care, community and, in the future, social care too. Currently the target audience is predominantly NHS professionals, though plans are progressing for information to be made more widely available to the general public.

The ambition for Quality Observatories is that they support clinicians and managers in their efforts to improve quality by providing accurate information on quality measures. They will service that is based at the local level, highlighting local variations and challenges and working with clinical teams to drive improvements in quality.

Quality Observatories are in the early and varying stages of establishment. The table below provides a summary of how QOs are developing across the regions.

Though most are still in the early stages of development, QOs have already started to produce products and services that clinicians and organisations are finding useful in identifying areas of where improvements need to be made.

Table 1 – Update on Quality Observatories			
Organisation	**Funding source**	**Website**	**Services provided**
London QO	Joint funded by Commissioning Support for London and NHS London	http://lqo.csl.nhs.uk/	• focussing on quality and efficiency • evidence and innovation translated into information that can be applied in practice
Northwest Observatory	Funded by member subscription	www.advancingqualityalliance.nhs.uk	• Offers programmes delivering intelligence, improvement and knowledge
Quality Intelligence East (QIE)	Multiuser service funded by all 14 PCTs	www.qie.eoe.nhs.uk in the process of development a public facing website accessible to the general public	• Benchmarking • Reporting on hospital mortality trends • Quality profiles • Development of Metrics to support commissioners • Development of metrics for the region's clinical programme boards
Yorkshire and Humber QO	SHA funding but moving to subscription funding	www.yhqo.org.uk	• QIPP resource packs
North East Quality Observatory	Subscription based funding	www.neqos.nhs.uk	• Surveillance measures • Advisory service
South East Coast	SHA funded	www.qualityobservatory.nhs.uk	• Dashboard design and metrics development • Tool development • Benchmarking • 1-2-1 coaching sessions • Web based analytics development
East Midlands Quality Observatory		www.emqo.eastmidlands.nhs.uk	• Clinical programme metric development and measurement • CQUINN metric development • QIPP resource packs • Benchmarking and advisory support
West Midlands	SHA funded	www.wmqi.westmidlands.nhs.uk	• Development of metrics for regional clinical programme boards
South Central QO	Currently business case and options appraisal for next phase of development	Under development	• Knowledge management function
South West		Under development	

National Quality Board

Information on the Quality of Services - Final Report - Supporting Annex C1

Workstream	C1 – Presentation of information about quality
Annex purpose	To set out for recommendations for how to improve the presentation and communication of quality information
Who has it been developed by?	Led by Robert Cleary, with support from Sally Brearley and John Carvel, and comments from across the sub-group.

Workstream C1 – Presentation of information about quality

Contents

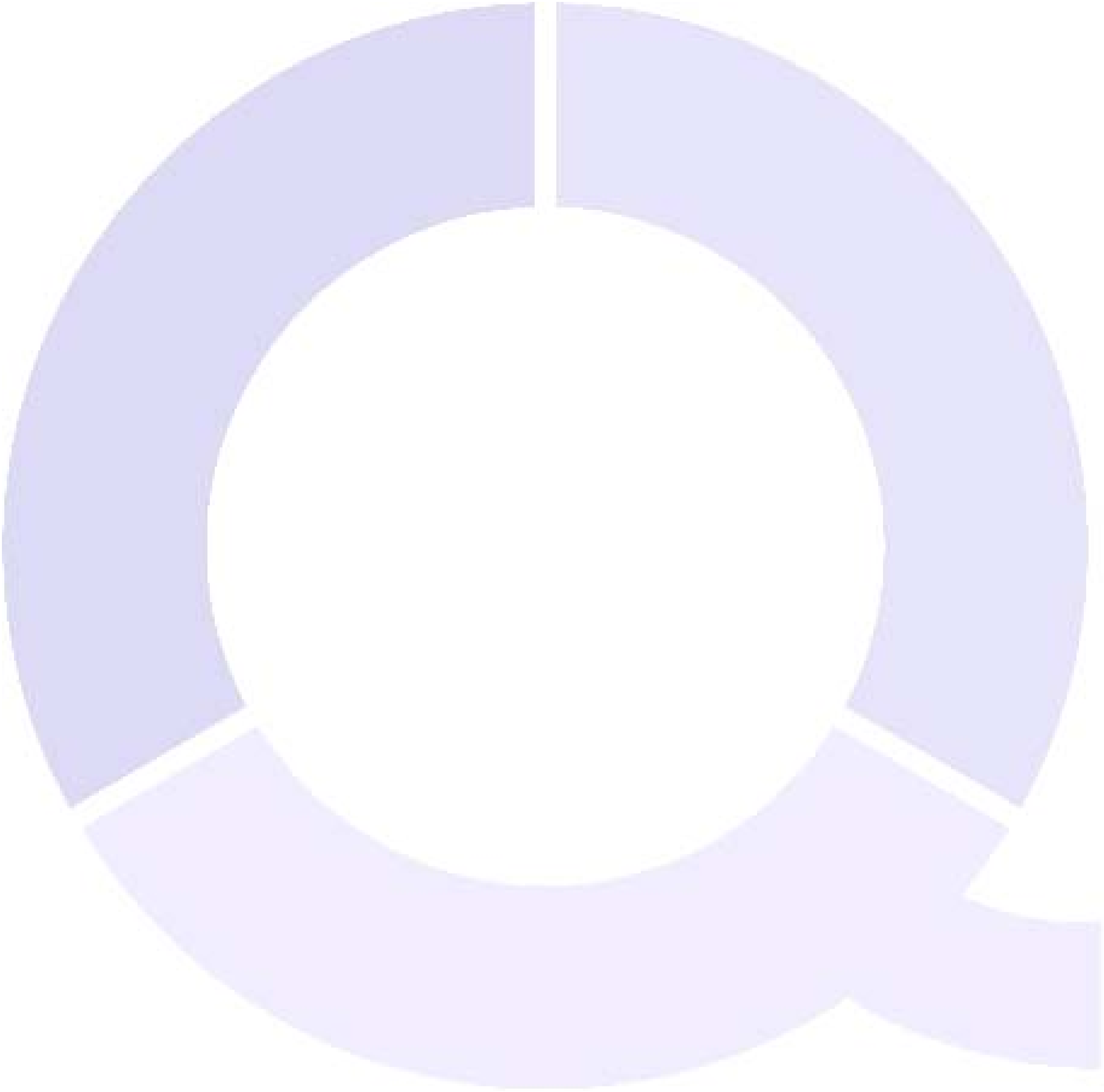
Summary – List of recommendations

	Recommendation
R23	There should be a Code of Practice for those presenting quality information, which includes: vi. Avoid overselling their wares. As no one agency has a complete picture, presentations should encourage audiences to gain additional insights by accessing other sources. vii. Avoid encouraging an undue focus on a single indicator. In particular presentations of new indicators should be made in the context of what is already known. Relevant context may include other measures of the same aspect of quality, or related concepts, such as data quality. viii. Adopt user-led design techniques to develop presentations that integrate multiple indicators so that they may be viewed and understood as a set. ix. Ensure that their presentations are supported by meaningful and accessible materials designed to help the intended audience make use the quality information that is being published x. Ensure that supporting materials include full disclosure of methods, definitions, and data sources.
R24	The state should ensure full disclosure of information methodology is included within any new contracts
R27	The Department of Health should consider further how independent advice on the interpretation and use of health care quality information may be made available to public audiences

Section A: Case for change

1. As our conception of quality in healthcare has become more sophisticated, the task of presenting clear information about that quality has become more difficult. Ten years ago, discussions of quality were often dominated by considerations of access. Today the same debates are more likely to encompass a multi-dimensional concept of quality that includes accessibility, safety, effectiveness and the patient experience.
2. This complexity is compounded by developments in the technology of assessment. For example, in recent years we have seen the concept of assurance maturing to the point that is has become an integral part of the regulatory assessment of the NHS. Over the same period there have been advances in the assessment of outcomes, increased attention given to formal measures of patients' own experiences and a better developed understanding of how to assess system, as opposed to individual, failings.
3. An increasingly complex concept of quality, and the widening range of options by which to assess it, has been accompanied by a rise in the number of agencies reporting on quality. Some of the reporting of recent high profile failures in quality suggests that the system's ability to present a clear message to the public has not kept pace with the overall quality agenda.
4. This annex examines:
    a. the recent reporting of information about the quality of care at Basildon and Thurrock University Hospitals NHS Foundation Trust;
    b. the research literature on communicating information about the quality of health care to a public audience; and
    c. the conclusions, re. presentation, arising from a small consultation exercise with a group of patient representatives.
5. This examination is in order to make recommendations on presentational matters, in the light of this report's overall goal of achieving public information that is available, trusted and insightful. The recommendations

focus on the needs of patients and the public. However in making them we have borne in mind their impact on providers of health care.



Section B: How do you improve?

6. In considering how to improve the public presentation of information about quality, we need to consider the purposes of that presentation. Elsewhere in this report[13] we have identified the uses which patients and the public have for information about quality:
    - Assessment (including for the purpose of public accountability)
    - Choice (using information to make a choice between services, professionals or treatment types)
    - Engagement (engaging more effectively with services through an understanding of their strengths and weaknesses)
7. Given this range of purposes, the set of ideal presentations will have many elements: some service-specific, some organisation wide; some cross sectional; some longitudinal; some at a high level of abstraction (to address e.g. 'value for money'); some concrete and particular (so that they may be related to individuals' own personal values). Consequently, it is important that those constructing presentations for a public audience are clear about the purpose(s) they wish to serve. Without this clarity, presentations that are ‘fit for purpose’ cannot be achieved reliably.
8. It is also important to bear in mind the wide variation within public audiences, in the willingness/ability to process statistical information about quality. Under some circumstances it may be possible to tune presentations to individuals’ capabilities, or to their preferences as to how quality information is communicated. However, a more general principle also applies: if we are to avoid presentations that increase health inequality, we have to pay particular attention to communicating effectively with low literacy and low numeracy audiences.

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[13] See Annex 1.2 to the Interim Report

9. Recent reporting of quality concerns at Basildon and Thurrock University Hospitals NHS Foundation Trust and at Mid Staffordshire NHS Foundation Trust has tended to focus attention on single ‘hospital wide’ indicators of performance – Hospital Standardised Mortality Ratios (HSMRs), Dr Foster’s Patient Safety Score, the Care Quality Commission’s Quality of Services rating.
10. However, it is apparent from both the particulars of high profile hospital failings[14] and from the analysis of the figures underlying global measures[15], there tends to be limited correlation between how a hospital performs against different quality standards; differences in the quality of care within hospitals can be larger than the differences between hospitals. While it is possible to ‘drill down’ to a more specific level of analysis we know that even at the level of single hospital departments some things may be done well and others badly[16].
11. As a consequence of this variation effective presentations will generally encompass sets of measures that may be viewed in conjunction – i.e. the 'report card' concept. This approach also allows for the integration of information derived from different forms of assessment – combining objective measures of process and outcome with more subjective measures of experience, for example. In a review of more than 40 websites dedicated to the reporting of health care quality, Damman et al[17] conclude that a degree of such integration is necessary to avoid users overlooking important information, or becoming bogged down in a lengthy sequential process.

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[14] Using hospital mortality rates to judge hospital performance: a bad idea that just won’t go away. Richard Lilford, Peter Pronovost, BMJ 2010;340:c2016

[15] A 37-Year-Old Man Trying to Choose a High-Quality Hospital: Review of Hospital Quality Indicators. Michael D. Howell. JAMA. 2009;302(21):2353-2360. Published online November 3, 2009

[16] Wilson IB et al, Correlations among measures of quality in HIV care in the United States: cross sectional study. BMJ 2007

[17] Damman OC, van den Hengel YKA, van Loon AJM, Rademakers J
An International Comparison of Web-based Reporting About Health Care Quality: Content Analysis. J Med Internet Res 2010;12(2):e8

12. Report cards seek to convey a more complex message that carried by single indicators and this complexity increases the presentational challenge. We have known for some time that consumer use of report cards to be limited by: difficulty in understanding the information; available information not reflecting interests; lack of trust in the data; and problems with timely access[18]. While the development of web-based presentations of quality information goes some way to addressing the last of these issues, websites presenting healthcare quality information to the public still suffer from problems of intelligibility, inadequate transparency and indicator sets that are not well tuned to their subject matter and audience[19].
13. While not all these problems can be resolved by presentational techniques alone, those devising presentations for the public can increase transparency (and perhaps as a consequence, trust) by ensuring that the source of the information presented is well specified and that methods by which information has been derived from the underlying data are explained in terms suitable for the audience. Similarly, web based presentations in particular can allow users to tailor presentations to their needs by techniques such as sorting, filtering, selection, highlighting etc..
14. On the central question of intelligibility, the message from the research literature is, perhaps unsurprisingly, keep it simple. Simple presentation and explanation improves users' knowledge of and attitude towards quality information[20]. More importantly, users of health care quality information have been shown to have better comprehension and make better choices when presentation formats are designed to reduce the 'cognitive burden' placed on the viewer[21]. Crucially, these effects are seen in particular among those with relatively poor numeracy.
15. In the context of report cards that present multiple indicators that cognitive burden can be reduced by making it easier for individuals to weigh up the relative importance of the component indicators. Two techniques are

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[18] Marshall M et al, JAMA, 2000; 283(14):1866-1874

[19] Leonardi MJ et al. Publicly Available Hospital Comparison Web Sites. Arch. Surg. 142(9). 2007.

[20] Faber et al. Public Reporting in Health Care Med Care 2009

[21] Peters E et al, 'Less is more in presenting quality information to consumers.' Medical Care Research and Review, Vol. 64, No. 2, 169-190 (2007)

particularly helpful here: (1) providing uniformity in the scales used across indicators (so that high is always good, for example, or where all indicators use, say, a five point scale)[22]; and (2) highlighting the *meaning* of information presented via numerical indicators[21].

16. On the latter point, the evidence shows the clear advantage of presenting evaluative categories alongside numbers (so that numbers in the range x to y are labelled as e.g. ‘good’) as a means of helping users integrate numerical information within their overall assessment[23]. Reducing the burden of interpretation that falls on users has of course a corresponding impact on those devising presentation formats. In order to make the users’ task more manageable, information providers will need to evaluate categorically the underlying numbers, and present that evaluation. A strategy of reporting ‘just the facts’ may end up communicating little, particularly to those most in need of the information.
17. A third means of reducing the cognitive burden of complex report cards is to present groups indicators as summary composites. Taken too far and we end up with the single index of ‘quality’ that masks important variation. However, a recent review[24] provides a basis for the judicious use of composites. In particular, the authors highlight the need to avoid combining variables with ad hoc or arbitrary weights. Instead they stress the need to consider the weights/values of those who will be using the score. The logic is that if we wish to help people who may have difficulty in constructing a trade off that reflects their values, then we should aim to identify a set of weights that approximates that audience’s values, so that we can apply them on their behalf.
18. Such an approach may be useful where the interpretation of the component indicators is particularly challenging. Consider measures of safety that include the technical (e.g. bacteraemia per 10,000 elective bed days) with the possibly counterintuitive (e.g. a high rate of reported

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[22] Boyce T, Dixon A, Fasolo B, Reutskaja E. Informed Choice on NHS Choices. Interim Report. The King’s Fund. April 2009.

[23] Peters E, Dieckmann NF, Västfjäll D, Mertz CK, Slovic P, Hibbard JH. Bringing meaning to numbers: the impact of evaluative categories on decisions. J Exp Psychol Appl 2009 Sep;15(3):213-227.

[24] Jacobs et al 'Composite Performance Measures in the Public Sector' Centre for Health Economics 2007

adverse events being a good thing). Under these circumstances the use of a composite measure, summarising these indicators, may well increase accessibility. However, to do so in a way that is helpful to the intended audience, we would need to understand how representatives of that audience, given the time and guidance to understand the component indicators, would weight the individual indicators' contribution to an overall assessment.

Experience beyond health care

19. Many of the issues relating to the public presentation of information about health care quality are echoed in other sectors of the public services, such as education[25]. They are also seen in more general terms in the development of web-based assessment / decision tools, most notably the comparison sites focusing on insurance, travel and the utilities[26,27].
20. While such sites may use specific presentational techniques that can be adapted to information about health care quality, there is probably more benefit to be obtained by adopting some of the research and development techniques that are already commonplace in the development of e-commerce applications.
21. For example, important principles on how to present complex information to a lay audience are to be found in the 'usability' literature, including popular texts such as Steve Krug's 'Don't Make Me Think!'[28]. Much of the emphasis of this literature is on a design process that is user-led. It is often tempting to leave the design of indicator presentations to 'experts' – the people who really know about the information being presented. Those experts are however unlikely to be representative of the intended public audience.

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[25] Department for Children, Schools and Families. A School Report Card: consultation document. December 2008. Retrieved from www.dcsf.gov.uk .

[26] Webcredible. Future comparisons: What's next for price comparison websites? August 2009. Retrieved from www.webcredible.co.uk .

[27] Which? Comparing the comparison sites. Retrieved from www.which.co.uk .

[28] Steve Krug. Don't Make Me Think! New Riders 2005.

22. The user-led alternative is to ask what assessment or task the user trying to complete (see for example[29]). Consider a situation in which the task is to choose a clinic that is within 10 miles from home, is judged by the regulator to be among the best in the avoidance of health care associated infection and has relatively high levels of satisfaction among its users. With this definition, one can determine empirically which of a set of alternative presentations is most effective. This investigation might employ metrics such as: the proportion of users that complete the task successfully, the time they took, and the 'disaster rate', i.e. proportion of users who believed they had completed the task but had done so by arriving at an answer that did not meet the task's criteria.
23. Damman et al's recent review of web based health care quality reports[17] concluded that current presentations of this kind information do not appear to be generally selected in this systematic fashion. In the case of NHS Choices, it is certainly true that some early design decisions were expert led. By investigating what actually works for our users, we are now well-placed to improve the effectiveness of our presentations.

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[29] Customer Care Words – Top Task Management for Websites. www.customercarewords.com .

Section D: Review of the current approach

24. Public information on health care quality is currently disseminated via a range of channels serving a variety of purposes. Presentationally, these channels can generally be categorised as falling in to one of two broad groups:
    - Publicly available information – information that is placed in the public domain but has not been tailored for a patient or public audience. Such publications may be aimed at another specific audience, or may relate to formal requirements in respect of public accountability, without reference to a specific audience.
    - Information for the public – information that has been published with the primary purpose that it is accessed and used by the patients or the public.
25. Under the first of these headings are official statistics generally emanating from the Government Statistical Service and the NHS Information Centre (NHSIC). Typically published as topic-based reports using simple tabular presentations, they feature only limited interpretation of the figures and may be best thought of as source material for the creation of information for the public. Also under this heading are many of the outputs from national clinical audits. These are generally in the form of comprehensive annual reports and tend to use simple tabular and graphical presentations, often at relatively high levels of aggregation (national or regional), with lower levels often anonymised[30].
26. Key examples of presentations under the heading of ‘information for the public’ include:
    - NHS Choices: This service has an explicit focus on a public audience, using a report card format to support both choice (in the case of elective care topics) and engagement (generally in the context of long term conditions).

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[30] There are of course exceptions to these broad generalisations. For example, the NHSIC has for example made Primary Care QOF information available via an interactive website that aims to help a public audience understand and use the information. Similarly, the Society for Cardiothoracic Surgery in Great Britain and Northern Ireland has for some time published survival rates at low levels of aggregation and in a form explicitly designed for use by patients and the public.

- Regulatory outputs, especially those from the Care Quality Commission (CQC). While clearly serving multiple audiences, considerable care has been taken to provide information that is accessible and useful to a public audience. Routine outputs tend to be presented as report cards that support the purposes of assessment, choice and engagement. More discursive condition or service-specific based outputs, sometimes based on samples of providers, are also provided and are probably less relevant to provider choice.
- Independent information providers. In the report card vein, Dr Foster provides a range of patient-focused outputs that support choice and engagement. Within the third sector, patient groups are another key contributor. Presentations from patient groups tend to focus on a single campaign issue and, while typically presented in accessible terms, often appear to be designed to capture media interest rather than acting as a primary source for patients and the public.
- Health care providers. For example many trusts and independent sector providers now provide report card like presentations for their services, which are aimed at patients and the public. Supporting engagement and accountability, the variable format of such outputs tends to undermine their use in the context of provider choice. Furthermore, while negative or disappointing results are not entirely absent, providers' presentations tend to be stronger on positive messages of promotion and reassurance.

27. Across these various sources of information for the public, two common factors seem particularly pertinent to providing presentations that are available, trusted and insightful.
28. Firstly, while the report card format is frequently the primary means of presentation, the various information providers also rely on the news media to draw attention to their outputs. There is an inherent tension between the report card's ability to integrate a wide range of information, both new and old, and potentially contradictory, and the news media's requirements for material that is focused, novel, and supportive of a clear

conclusion/headline. Most providers of health care quality information for the public have made statements of the form “these results should not be viewed in isolation”. However, these statements can be sometimes found in press releases that actively encourage the focusing of attention on whatever the latest result happens to be.

29. Secondly, while many information providers have made considerable effort to provide presentational formats that are accessible, there is often little or no collateral material designed to help a public audiences understand what they are being presented with. Where there is such supporting material, it can lack the sophistication and user focus that is found in the main presentation. For example, we learn in supporting material from the CQC that to have achieved a score of ‘fully met’ in respect of ‘existing commitments’ means that an organisation has “...performed consistently well for the existing commitments assessment.”[31]. Similarly, while NHS Choices provides somewhat wordy explanations of individual indicators[32] (which capture little attention from its audience), when it comes to explaining the report card concept, or how an individual might engage with it, none of the eye-catching multi-media content used elsewhere on the site is to be found.

30. Getting the balance right between the information to be communicated and the material to support that communication is not easy. Raleigh and Foot note that presentations need to be adequately 'qualified' (in the sense that limitations and caveats should be made clear) to avoid alarm among patients and demoralisation among providers[33]. However, presentation for public audience needs take into account the audience’s capacity to engage with such qualification. Initial presentation on NHS Choices emphasised upfront explanation of strengths and weaknesses of the information being presented. When the presentation was revamped, overall understanding of the report card increased as the presentation was

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[31] Care Quality Commission. What do these scores mean? Retrieved from http://healthdirectory.cqc.org.uk/_db/_system/What_do_these_scores_mean.pdf .

[32] NHS Choices. Mortality Ratios. Retrieved from http://www.nhs.uk/Scorecard/Pages/IndicatorFacts.aspx?MetricId=95&OrgType=5

[33] Raleigh VS and Foot C. Getting the Measure of Quality. King's Fund 2010

simplified and results were made more prominent relative to the explanation. By saying less NHSC communicated more.

31. It may be that information providers are not best place to provide supporting explanatory material, and, where some evaluation of the quality and utility of the information itself is required, they will lack an independence that may be important. It is not clear however who is well placed to provide this third-party view. Academic analysis of reporting mechanisms and content will arrive eventually but it is not generally available in near enough to real-time. It may also emphasise a longer term methodological debate, as opposed to optimising short term understanding of currently available information. For example academic input to the debate about the meaning of high HSMRs has been criticised as potentially distracting from the key quality concerns, as opposed to illuminating them[34].

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[34] Shahian and Norman 2010. Annex to Mid Staffs report.

Section E: Analysis of the opportunities for change

32. While we need to recognise the strengths of current approaches, the Basildon and Thurrock case study reveals there are issues which require attention.
    - Most outputs tend to overstate the extent to which they are definitive - this perception is increased when single items are presented in isolation, either at source or in their transmission via the news media.
    - When information from different sources points in different directions - this is seen as evidence that one or other source is flawed. Indeed the source agencies can contribute to this impression. It would be more constructive for all parties to present their information as contributions to a picture that is inherently complex.
    - The 'official' status of some information is a double edged sword - it can tend to increase trust, but when the information is contradicted this may be taken as an indication that officialdom has missed or is concealing something.
    - Presentations of regulatory judgements, based on a wide range of performance information, have been undermined by the publication of one component of that information. Individual facts presented in isolation appear to trump evidence based judgement, even when those facts are far from constituting a comprehensive evidence base.
    - There is a lack of public understanding about the complexities of data on quality - but resources (particularly ones that are independent of information providers) to help are currently very limited.
    - Paradoxically, however, sources of public facing information on quality can fail to communicate effectively when they embed information within detailed and nuanced explanations.

33. There are now particular opportunities for developing the presentation of information on quality:

    - Making Public Data Public is an initiative that aims the increase the use of, and trust in, official information by making the raw data underlying that information accessible. It is to be hoped that this will encourage innovation in the presentation and communication of information on health care quality.
    - New agencies (e.g. patientopinion.org.uk) are entering the field, collecting their own data and reporting on quality of care.
    - Quality Accounts are due this year for an initial set of health care providers. In addition to the mandatory inclusion of a limited set quality indicators, providers are being encouraged to use Quality Accounts as an opportunity to be open and creative in the presentation of information about the quality of their services.
    - As part of the developing regulatory system, CQC has indicated an intention to moving to the publication of richer and more real-time information about the risks to quality it perceives within providers.

34. The problems illustrated by the Basildon and Thurrock case study, can be addressed in part by a shift to a different style of presentation.
35. Such a shift moves us on from a system in which, for example, the Healthcare Commission summarised a range of quality assessments within a monolithic annual composite indicator entitled 'Quality of Care'. The impression given is one of comprehensive certainty. In the emerging system, an increasing range of agencies will present a multi-dimensional picture of quality and the CQC will report a dynamic and disaggregated assessment of risks to quality of care.
36. The challenge of communicating this more complex picture to a public audience can be met if information providers adopt user-led design techniques to manage the cognitive burden placed on the users of the information they are presenting. The benefit of meeting this presentational challenge lies in a public audience that is more realistically engaged with the difficult business of assessing quality in healthcare.
37. The cost of this realism is that the agencies involved, and their audiences, will have to operate in a less certain world. Results will be inconsistent (because health care providers are); reports will be challenged by new information (because there is no single authoritative view).
38. Audiences will have to work harder, to come to their own judgements on the basis of the evidence available, and providers will be faced with a wider range of indicators that apparently demand a response from them.
39. The latter consequence of this presentational shift is of particular concern. If we give providers more numbers to optimise, do we risk overload and consequently damage, rather than improvement, to the quality of care? The answer may lie in another shift: As it becomes impractical to manage directly all the numbers that are used by external audiences to judge quality, organisations may have to fall back on managing via a view of quality that is only available internally - trusting that the cruder indicators available to the public will follow.

Section G: Recommendations

40. Meeting the challenges associated with a more sophisticated concept of health care quality lies primarily in the hands of information providers.
41. To improve trust in how information is presented, we recommend a set of measures should be accepted by those presenting quality information.

Recommendation [R23]

There should be a Code of Practice for those presenting quality information, which includes:

i. Avoid overselling their wares. As no one agency has a complete picture, presentations should encourage audiences to gain additional insights by accessing other sources.
ii. Avoid encouraging an undue focus on a single indicator. In particular presentations of new indicators should be made in the context of what is already known. Relevant context may include other measures of the same aspect of quality, or related concepts, such as data quality.
iii. Adopt user-led design techniques to develop presentations that integrate multiple indicators so that they may be viewed and understood as a set.
iv. Ensure that their presentations are supported by meaningful and accessible materials designed to help the intended audience make use the quality information that is being published
v. Ensure that supporting materials include full disclosure of methods, definitions, and data sources.

Recommendation [R24]

The state should ensure full disclosure of information methodology is included within any new contracts

Recommendation [R27]

The Department of Health should consider further how independent advice on the interpretation and use of health care quality information may be made available to public audience

National Quality Board

Information on the Quality of Services - Final Report - Supporting Annex C2

Workstream	C2 – Making more data publicly available
Annex purpose	To set out for recommendations for how to improve the public availability of data
Who has it been developed by?	Led by Tim Straughan and Andrew Frith, with comments from across the sub-group.

Workstream C2 – Making more data publicly available

Introduction

42. The Interim Report concluded that there was much more data that could be made routinely available. To make more data available requires overcoming a number of barriers.
43. This document sets out the approach to that problem, specifically it seeks to answer the following three questions:
    - What prevents nationally collected information being made routinely available?
    - How can barriers be overcome?
    - How can health lead the way in openness and accessibility across government?

Contents

Summary – List of recommendations

	Recommendation
R07	All data should be accessible through www.data.gov.uk. Actions set out in Annex C2 should be progressively implemented in particular, speeding up existing processes around extracting data from primary care.
R08	A number of supporting functions are required**:** d. Co-ordinating function. Role to coordinate delivery to data.gov.uk to ensure that data is prepared in the right format, at the right time, to the right standards and governance controls. e. Design governance. Responsibility for 'secondary use' design governance to act as a guardian of standards across all nationally collected health data. This would increase the ability to link data sets and provide greater flexibility. f. Data linkage. Service to create new national linked datasets from large, detailed level resources, including the creation of tables which map how different datasets relate to each other.
R09	The data ownership issues set out in Table 4 in Annex C2 should be considered.
R28	There should be a requirement that data providers publish declarations alongside each dataset to help with understanding the data. These declarations should highlight advice on interpreting the data, any data quality issues, and any restrictions upon use of the data.

Section A: Case for change – Why make more data available?

44. The vision set out in the Interim Report includes a proposal that *“barring significant other reasons, all quality information should be made freely available.*” This is due to the range of benefits of making data publicly available, as outlined in Table 1.

Table 1 – Benefits of data availability	
Improve clinical outcomes	Organisations which systematically use data to generate clinical quality information such as mortality, incident and intervention measures as part of local quality improvement regimes, routinely demonstrate better clinical performance than those that do not. Nationally collated data is an important part of the picture, but that national data is not consistently made available in the most accessible forms to support improvement activities.
Public expectations	The continued drive towards increasingly open, transparent and accountable government is predicated upon the availability of suitable information to enable public scrutiny and challenge. Public expectation is high; we have an increasingly rich and pervasive internet, yet data about our public services is seemingly rooted in old fashioned ‘government controlled’ models.
Enable innovative re-use	There are many different organisations with the intellectual capability to generate new quality information for example academic, professional, not-for-profit, and commercial bodies. They can play an important role in helping to fill information gaps, and to create new insight for quality improvement at a greater rate than if reliant upon a small number of national bodies. However we do not yet have an effective means of engaging them and exploiting their capabilities to generate useful quality information which can be shared across the NHS.

45. Evidence from other sectors reinforces the use of information as a key aspect of quality improvement. For example, major improvements in airline safety in the ‘70s and ‘80s were a direct consequence of better use of information (coupled with a more open and accountable culture).

Section B: Data which could be made more available

46. We know that across almost all data sets, there is more data that could be made available in more flexible and useable forms[35].
47. The means of making data more available differs across different data-sets. Annex 1 outlines the different mechanisms which can be used. A summary is available below in Table 2.

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[35] See Interim Report

Section C: How and when to make more data available

48. The creation of the data.gov.uk website as part of the Cabinet Office “Making Public Data Public” initiative presents an opportunity to exploit health data in an effective way.
49. data.gov.uk offers two main opportunities for quality information:
    - As a signposting service to health data, making it easier for users to find data and to work with that data effectively; and
    - As a means to generate new uses and analyses of health data more rapidly than might otherwise be created through traditional means.

Recommendation [R07]

All data should be accessible through www.data.gov.uk. Actions set out in Annex C2 should be progressively implemented in particular, speeding up existing processes around extracting data from primary care.

50. These resources should be complemented with supporting information such as the interpretation, quality and constraints declarations detailed later in this paper.
51. Exploiting data.gov.uk requires us to think differently about how we handle data in order to make it useful and useable.
52. It requires us to expose more details about the quality data in a standard form, and to prepare underlying data such that it can be machine read. Not much of the existing health data is in such appropriate forms, although as we know there is a huge amount of material that could be made available.
53. There are four main choices on how we could tackle this issue:
    - Physically move all of the quality data into one logical place, and therefore service data.gov.uk from that resource in true open data service fashion. It would ensure absolute compliance with standard data models, definitions and data processing, however

it is likely to be expensive, time consuming and difficult to achieve for all health data.

- Allow all data source owners to serve their data directly to data.gov.uk, with guidance about what materials need to be supplied and in what form, although this approach would not facilitate any proper conformance to standards / models and affords less control over publication
- Drive all access to quality data through ‘toolkits’ instead, for example by navigating a user from the data.gov.uk website to say, the IQI web tool. Once there, users would interact with the IQI tool to get the data they require
- Further extend the toolkit approach by enabling the toolkits to work interactively with data.gov.uk by providing application interfaces, for example opening up the NHS Comparators toolkit as a web service such that a data.gov.uk user could directly query the content of NHS Comparators and use the data directly in their own solutions.

54. We need to use a pragmatic blend of these approaches to effectively enable the data from each of the different sources. For example:
    a. where there is an established toolkit such as NHS Comparators, we will ‘open’ that tool using an application interface to get at the contents;
    b. where there is an established patient level data source, such as HES, then we will enable an increased level of access to that information with a more open and flexible interface; and
    c. where the data source is say, currently hidden in a formal publication, then we will take the data used to create it and hold it in pragmatic repository and serve it to the data.gov.uk in the requisite form.

Recommendation [R08a]

a. Co-ordinating function. Role to coordinate delivery to data.gov.uk to ensure that data is prepared in the right format, at the right time, to the right standards and governance controls.

Section D: Barriers to data availability

55. The UK compares internationally well in terms of sources of information on the quality of services. However, there are some significant barriers which prevent us doing that which we need to understand and resolve, specifically:
    - Barrier 1 - Complex landscape
    - Barrier 2 - Data ownership and governance
    - Barrier 4 - Content and interpretation
56. The rest of this section explores these issues in detail.

Section D: Barrier 1 – Complex landscape

57. The NHS is a complex set of organisations and processes. Data is captured across that complex landscape in different ways and for different purposes.
58. Whilst the goal is to capture data once and reuse it many times, the reality is some way from that ideal. This is because of different data collections, processing, ownership and governance arrangements result in data ‘buckets’ that do not always lend themselves to easily reuse.
59. The main problem is that data is collected in different ways, from different systems, at different levels of granularity, conforming to different data and information design standards. Examples of this are shown in Table 3.
60. Because of this:

Recommendation [R08b]

b. Design governance. Responsibility for ‘secondary use’ design governance to act as a guardian of standards across all nationally collected health data. This would increase the ability to link data sets and provide greater flexibility.

61. The aim would be to ensure that ‘data buckets’ are more closely aligned, thereby increasing their ability to be interlinked, but also to provide greater flexibility.

Table 3 – Difficulties of different systems and data standards	
Hospital Episode Statistics	Hospital Episode Statistics (HES) detailed patient level activity data collected from front-line patient administrative systems via monthly data extracts to the central Secondary Uses Service (SUS) data repository.
Central returns	Aggregate information in the form of central returns, often manually collated by NHS provider units and sent to the Department of Health’s UNIFY system
Prescribing information	Detailed item level prescribing information collected from all community pharmacies both manually and electronically and gathered into the Business Services Authorities ePACT system
Survey data	Population sample survey data collected via Health Survey for England house-to-house survey by the NHS Information Centre’s survey contractor.

Patient experience	Patient experience data collected by Care Quality Commission from sample patient questionnaires.
Quality and Outcomes framework	Primary Care Quality and Outcomes (QOF) data collected by electronic data extract from GP systems and collated via Connecting for Health's (CfH) QMAS system

62. Advantages of having data collected in one system includes the ability to be a feeder for other data processes and thereby creating secondary data 'buckets'. This is the case with the SUS system where the base data in SUS is used to generate the HES data 'bucket', and also the Payment By Results (PbR) data 'bucket'.
63. The lack of standards and information model conformance means that it is much harder to take data from one source and match it with data from another to derive some other useful combination.
64. If we are to extract maximum value from the data we collect we need to:
    a. Govern the standards and models more closely for new collections; and
    b. seek ways to cross-match data from different sources to increase the chance of developing new combined-information.
65. The general approach to (b) is to provide some intermediary 'mapping' from one code set to another to facilitate data linkage. Those mappings should be made routinely available on data.gov.uk alongside the datasets to which they relate so that other users can exploit them.
66. Some data linkages are complex. One option is for an authorised agent to process that data in a safe haven environment – this capability has been referred to in other reports as an "Honest Broker" service.

Recommendation [R08c]

c. Data linkage. Service to create new national linked datasets from large, detailed level resources, including the creation of tables which map how different datasets relate to each other.

Section D: Barrier 2 – Data ownership and governance issues

67. Data which is collected for one purpose but reused for other purposes can be subject to a number of particular governance problems, for example contravening the Data Protection Act or being subject to national statistical governance protocols.
68. In particular, there are four specific issues outlined in Table 4.

Recommendation [R09]

The actions outlined in Table 4 in Annex C2 should be considered.

Table 4 – Specific data ownership and governance issues

Open Data Sharing Agreements

- We need to foster the principle that data is a public good and can be routinely shared.
- If we are to make more data routinely available, **we recommend any new data collection has an open sharing agreement established from its inception, and that this agreement is consistent with the data.gov.uk and Creative Commons Licence (CCL) principles.**

Statistical Governance and Release of Useful Data

- Where organisations are subject to specific statistical governance protocols, there are generally two issues to be dealt with: data content, and timing of data release.
- Data content protocols typically related to matters such as ‘small numbers’ whereby small datasets can result in the identification of an individual and which would therefore contravene data protection principles. It is relevant to recognise the terms of the protocol in any data release such that it is absolutely clear to any data re-user.
- **We recommend that all data releases have a clear statement about the applicable protocol and any consequent limitations on the data as a result.**
- The more important factor is that data *supporting* statistical publications are not always released alongside their respective publications. There is too much material in the form of Adobe, Word or other such ‘closed’ document format, which means that it is much harder for people to extract the relevant data to a useable format.
- **We recommend a protocol is created that requires the publication of useable data tables to be published alongside any statistical publication and implement this for all key national statistics**

Handling NIGB Issues and Supporting More Open Access

- The NIGB Ethics and Confidential Committee (ECC) ensures that personal health and

Table 4 – Specific data ownership and governance issues
care information is not misused, and that the commitments set out in the Care Record Guarantee (CRG) are properly policed. • There are sometimes data requests which need to be considered by NIGB-ECC to ensure that the commitments made in the CRG are upheld. There are also special exemptions for legal reasons or matters of greater ‘public good’. • Each request is considered on its own merits by the NIGB-ECC, with permission granted (or rejected) for the particular purpose in each case. Requests of this nature can take some time to consider which can be frustrating for the data requestor, and can limit the pace of any research work as a result. • Researchers would like more ready access to such detailed record level data, however current arrangements do not allow. One way which is currently being progressed is via dedicated research databases with specific license to operate granted by the NIGB-ECC; the CfH Research Capability Programme (RCP) is leading the work to establish such databases. We are generally supportive of this initiative. • In the meantime, the QIS must consider that access to such data will continue to be problematic and therefore practical means must be sought to make more data available. One practical step would be to open a little more of the existing national resources, but in doing so create some control limits on the data which prevent small numbers and personal identifiable data being made available. • **We recommend that the feasibility of providing more flexible data extraction from existing resources for minimal investment is investigated.**
Practical Data Processing / Funding Issues • Providing information for reuse purposes is not usually core business, and the steps necessary to make it suitable for reuse may require reprocessing of the data, or the addition of supplementary information. • There are a number of potential options: - require organisations to absorb any costs under either the general principles of RUPSI, which allows a reasonable charge to be made, or freely as part of the MPDP open data initiative, for any reprocessing or formatting that is required - provide a small pot of ‘extraction’ funding which can be used on a priority basis to fund any necessary reprocessing or formatting, and pay data providers for the work - provide a 3rd party data management service which takes raw data and carries out any data formatting or processing or coding adjustments on behalf of providers - simply require the data is provided in its raw form, and let users do their own reprocessing or formatting and bearing the costs themselves • The latter of these is likely to be the quickest and cheapest way of making data available, but the consequence is possibly less utility of the data as a result. • **As such, in addition to promoting the supply of raw materials to data.gov.uk, is**

Table 4 – Specific data ownership and governance issues
promoted, we recommend a small data management service in created to facilitate easier manipulation of raw data. This would involve making simple data tools available to data providers to ease the process of providing data. • **We recommend the NHS Information Centre takes on this role.**

Section D: Barrier 3 – Content and interpretation issues

69. There is concern from data owners that when the data is made available to others that “don’t understand that topic” the data could easily be misinterpreted. Similarly there are aspects of the data such as quality which might also lead to incorrect suppositions.
70. To counter this,

Recommendation [R28]

There should be a requirement that data providers publish declarations alongside each dataset to help with understanding the data. These declarations should highlight advice on interpreting the data, any data quality issues, and any restrictions upon the use of the data.

71. The declaration, to go alongside the publication of any data would include:
    - an “interpretation” declaration; setting out basic facts to help with interpreting the data, or which will guide the user towards a correct interpretation, or other such useful context
    - a “data quality declaration”; setting the basic quality characteristics of the data, and highlighting any particular quality aspects which need to be considered when using the data
    - a “constraints declaration” ; setting out any restrictions in the data which might prevent use in certain circumstances, or for particular purposes
72. These statements are consistent with the sorts of meta-data statements that are already in place on the data.gov.uk website for each dataset, such as “Licence”, “Temporal Granularity”, “Precision”, “Version” etc. Providers of data should be required to include these statements whenever data is made available.

Annex 1 – Making More Data Available – Specific Ways & Means

Analysis by care setting				
Care Setting / Themes	**Primary Source of Data?**	**Data Available to Support Quality Information?**	**Available in the Public Domain, and in what form?**	**How Could More Information be Made Routinely Available? & Implications?**
Primary Care				
GP Patient Record (information about patient conditions, treatments and interventions	Data held in General practice systems; data not routinely provided except for specific purposes such as QOF. Practice systems subject to GPSoC contractual terms held by CfH Some information collated by 3rd party research data agencies eg GPRD.	No, but can be made available to support specific purposes such as QOF, and directly and locally enhanced service provision (DES and LES) incentives. Local access to information through general MIQUEST tool, where agreement has been reached by PCTs and practices. Local analysis by GP practices and/or PCTs for planning purposes, generally using their own systems (EMIS Data quality is improving – the PRIMIS service demonstrates improvements in coding and recording over recent years, but there are significant accessibility , governance and data consistency issues which prevent more widespread use.	No, some information in the public domain from PCTs, but generally limited to QOF specific outputs, or those in support of DES and LES incentive schemes. Information not routinely provided in the main.	More detailed level information should be provided via the GP Extraction Service when that comes online in 2011, with standard data extraction queries run on a periodic basis (See also QOF note below)
Dental (information about treatments and interventions)	Detailed information for payment purpose – manual and electronic provided to Business Services Authority	Is made available for basic analytical purposes in simple data tables, but also a warehouse of the dental information is used by BSA to do various analyses in support of dental contract etc	Limited to publications and basic data tables	Options include either a.) create a standard extract file that could be made available, or b.) open the BSA data warehouse directly Contextual material should be provided alongside to cover issues such as data quality, definitions and standards

Analysis by care setting

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
Pharmacy (Information about primary prescribing and dispensing)	Detailed information provided to NHS Business Services Authority	Is made available for basic analytical purposes in simple data tables, and through tools such as ePACT available to PCT for the purposes of contract management and analysis	Limited to publications and basic data tables	Simple PCT level summary information now provided via NHS IC iView tool. Links to iView tool from the data.gov.uk website in the first instance should be provided. Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Eye Care (Information about primary eye care and dispensing)	Largely survey based information, collated by various industry organisations, but mostly collated by NHS IC	Is made available for basic analytical purposes in simple data tables	Limited to publications and basic data tables	Basic eye-care data tables to be made available in machine readable form via data.gov.uk in first instance, then longer term provision via NHS IC iView tool Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Quality and Outcomes Framework (QOF) Incentives and payments scheme	As indicated above Information extracted from GP clinical records to support the QOF payment scheme	Data is provided annually to support the QOF assessment and payment scheme. Data is generally available	Yes, data on QOF achievement is made available in publicly accessible form on NHS IC website	Existing QOF data could be separated from the QOF website and made available in more flexible machine readable form via data.gov.uk, or via NHS IC web service, linked from data.gov.uk site Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Community				
Activity	Negligible information	No	No	Nothing possible at this time. Longer

Analysis by care setting

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
(Information about community care contacts and interventions)	available. Contact and activity data is however present in localities where local community service information systems are in place, however coverage is patchy			term collection of a limited Community Dataset will provide essential information which can then be shared more openly
Mental Health				
Activity (Information about mental health care contacts and interventions)	Mental Health Minimum Dataset from mental health trusts, collated through SUS channels Some limited and one-off national returns also.	Available, but data quality has been an issue. Dataset also in need of rework to better match care deli methods. Only recently reworked the national data flow mechanisms to make information more generally available. Coverage is also an issue, as not all providers submit, and no requirement for 3rd sector information collection	Available in a summary, limited fashion via NHS IC website, via new online MHMDS tool.	Data underpinning the NHSIC MHMDS tool could be separated and provided directly to data.gov.uk, or via NHS IC as a web service, linked from data.gov.uk Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Secondary Care				
Inpatient Activity (Information about secondary care inpatient events / episodes)	Detailed record level data flows through SUS, and in more refined form in HES	Data is routinely available to support a variety of secondary uses, but is generally supplied in summarised form, or under formal data sharing agreements to NHS and 3rd parties Information based upon this data is routinely available through standard national tools such as NHS Comparators	Available as standard summary data tables on HESOnline Various statistics and indicators based on this data published through other channels such as NHS Choices, etc	Already available in summary data tables on HES Online. Next step is to enable the underlying database for SPARQL, or aggregates via NHS IC webservices Impact: major shift in enablement, likely to be expensive, and therefore might be best to consider this as part of HES reprocurement which is under way now
Outpatient Activity	Detailed record level data flows through SUS, and in	Data is routinely available to support a variety of secondary uses, but is generally	Available as standard summary data tables on HESOnline	Already available in summary data tables on HES Online. Next step is to

Analysis by care setting

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
(Information about secondary care outpatient events / episodes)	more refined form in HES	supplied in summarised form, or under formal data sharing agreements to NHS and 3rd parties Information based upon this data is routinely available through standard national tools such as NHS Comparators. Quality of data is improving over time	Various statistics and indicators based on this data published through other channels such as NHS Choices, etc	enable the underlying database for SPARQL, or aggregates via NHS IC webservices Impact: major shift in enablement, likely to be expensive, and therefore might be best to consider this as part of HES reprocurement which is under way now
A&E Activity (Information about secondary care A&E events / episodes)	Detailed record level data flows through SUS, and in more refined form in HES	Data is routinely available to support a variety of secondary uses, but is generally supplied in summarised form, or under formal data sharing agreements to NHS and 3rd parties Information based upon this data is routinely available through standard national tools such as NHS Comparators. Quality of A&E data is improving, but lags other datasets	Available as standard summary data tables on HESOnline Various statistics and indicators based on this data published through other channels such as NHS Choices, etc	Already available in summary data tables on HES Online. Next step is to enable the underlying database for SPARQL, or aggregates via NHS IC webservices Impact: major shift in enablement, likely to be expensive, and therefore might be best to consider this as part of HES reprocurement which is under way now
Waiting Times (Information about secondary care waiting times including specific clinical themes such as cancer waiting times)	Detailed record level data flows through SUS (and others systems in the case of Cancer ie EXETER system)	Data is routinely available in standard analyses / statistics published through DH for example. Detailed data can be accessed for analysis as required, but usually some form of data sharing agreement required to do so	Available as statistics on DH website and others such as NHS Choices	Take data from existing publications and separate from presentation on DH website, post data in first instance to data.gov.uk. Consider putting data into NHS IC warehouse and enable via NHSIC webservices, or direct SPARQL Contextual material should be provided alongside to cover issues such as data quality, definitions and standards

Analysis by care setting

Care Setting / Themes	**Primary Source of Data?**	**Data Available to Support Quality Information?**	**Available in the Public Domain, and in what form?**	**How Could More Information be Made Routinely Available? & Implications?**
				Impact: need to check scalability
Hospital Prescribing	limited information, only available through 3rd party commercial agents (IMS Health), however obviously this information is available from local hospital pharmacy systems	Is used by NHS IC and others on a paid for service basis to conduct various drug useage analyses	Limited, typically publications and standard reports	Would have to buy data from IMS, and likely to be significant costs / licensing implications as data not owned by NHS; could make available limited report extracts via data.gov.uk, or via iView tool
Pathology and other related diagnostic Services	limited information available nationally, not routinely collected in any national returns or data collections except for some isolated referral information	Not routinely available. Some limited benchmarking has been developed with Keele University around pathology services	Nothing typically published, but some benchmakring available to subscribers for pathology	Possibly capture this data via benchmarking service which is being developed now by combination of Keele / Leeds Uni and NHS IC under the QIPP programme. Make available from that repository via NHS IC iView, linked to data.gov.uk
Imaging and other related diagnostic Services	National data provided through central returns and detailed data submissions for a variety of imaging and diagnostics. Typically through the UNIFY system	Data is available and is routinely analysed for achievement of imaging and diagnostic targets (key policy)	Yes, but typically summary performance statistics via DH website and others	Take data from existing publications and separate from presentation on DH website, post data in first instance to data.gov.uk. Consider putting data into NHS IC warehouse and enable via NHSIC webservices, or direct SPARQL Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
General Statistics	Range of national statutory	Data available in aggregate form only, but	Yes, available as statistics on DH	Take data from existing publications and

Analysis by care setting

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
(various national activity orientated collections and returns)	data returns provided by secondary care in addition to above detailed data returns, covering a range of topics such as occupied beds, waiting times, activity, A&E etc. Collected via UNIFY system	is generally used to support things such as Vital Signs monitoring, statistical publications, performance management etc. Information is also routinely provided to other parties such as CQC, NHS IC and others.	website (and others), often with summary tables	separate from presentation on DH website, post data in first instance to data.gov.uk. Consider putting data into NHS IC warehouse and enable via NHSIC webservices, direct SPARQL Impact: need to check scalability Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Population Health				
Population Health Surveys	Generally sample survey based information collections, ranging from the large scale Health Survey for England, through to of locality information collected by Public Health Observatories, SHAs and others. Lifestyle information also gathered nationally by NHS IC through things like smoking, obesity, alcohol etc surveys.	Data generally available to Public Health Observatories, NHS IC and others working in the 'health needs' field, some under more formal data sharing agreements.	Outputs from the surveys are generally made available formal publications, with data sometimes available alongside these. Often provided as official national statistics	Take data from existing publications and separate from presentation on NHS IC website, post data in first instance to data.gov.uk. Consider putting data into NHS IC warehouse and enable via NHSIC webservices, direct SPARQL Impact: need to check scalability Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Obesity	National Child Height and Weight Measurement scheme collects data from	Yes, data is available to Public Health Observatories, SHAs, PCTs and others to support their health needs assessment	Available as on-line tool via NHS IC website.	Directly enable the NCMP database for webservice or SPARQL.

Analysis by care setting				
Care Setting / Themes	**Primary Source of Data?**	**Data Available to Support Quality Information?**	**Available in the Public Domain, and in what form?**	**How Could More Information be Made Routinely Available? & Implications?**
	schools on an annual basis.	activities.	Outputs available as standard publications	Impact: need to check scalability Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Child Health	Data to support child and maternal health is collated by Yorkshire and Humber Public Health Observatory and draws data from many different sources including SUS, HES, surveys, audits, research etc	Yes, data is available, typically through various tools	Information made available through ChiMat website provided by the Public Health Observatory	Directly enable the ChiMat database for webservice or SPARQL methods Impact: need to check scalability Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Health risk and protection information	Mandatory reporting to HPA for health incidents,	Data is available, but is generally only provided on a needs basis to organisations such as CQC for regulatory purposes, DH for monitoring purposes etc	Information routinely published such as MRSA rates in formal reports / summary data tables	Start with openly available MRSA and CDiff data. Publish table directly on data.gov.uk in first instance. Establish data sharing agreement, and plan to take regular data feed into NHS IC warehouse Impact: likely to need some standards alignment with other datasets eg reference codes etc Contextual material should be provided alongside to cover issues such as data quality, definitions and standards

Analysis by clinical theme

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
National Programme Budgeting Categories				
Infectious diseases Cancers & tumours Disorders of the blood Endocrine MH Disorders Learning Disability Neurological Problems of Vision Problems of Hearing Problems of Circulation Respiratory System Dental Problems Problems of GI System Problems of the Skin Problems of MSK Trauma and Injuries Genito Urinary System Maternity Conditions of Neonates Adverse effects & poisoning Healthy individuals Social care needs	Generally possible to identify activity in relation to the majority of these categories using data collected via SUS and HES, and the various clinical diagnoses and treatment codes in the clinical record, although as set out earlier there are some areas where. More difficult in terms of making assessment of the effectiveness or outcome against these various conditions, for example: • Blood disorders • Learning disability • Problems of Hearing • Problems of GI System • Problems of the Skin • Problems of MSK • Adverse effects & poisoning • Healthy individuals • Social care needs	Variously available, generally from sources already described above eg SUS / HES. Limited information about outcomes though.	Some programme budget online tools are available eg NCHOD (PBC), Public Health Observatories (SPOT), but usually only available to the NHS	Where already provided in a toolkit, separate the data content (summary) and make that available via data.gov.uk in first instance. Consider deriving this data from underlying HES/SUS information instead, and make available via NHS IC webservice, or direct SPARQL Impact: major impact if switch to deriving this information from source instead of reuse of summaries
Domains of quality				
Safety	Incident and near miss data routinely provided to National Patient Safety Agency Other information which fits this category includes infection rates	Data available from NPSA and HPA as needed.	NPSA now providing online access to ‘profiles’ MRSA and CDiff information routinely published by HPA	Acquire NPSA data feed and provide as NHS IC iView service, or via SPARQL? May be best to let new NPSA Direct portal service information directly to the data.gov.uk website?

Analysis by clinical theme

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
	(such as MRSA and CDiff) Other measures and metrics derived from various existing sources such as SUS, HES data, locally collected information			Need to establish sharing agreements with NPSA, plus will also need contextual information about data quality, standards and definitions
Effectiveness	Information to support effectiveness is variously captured in data flows described above such as SUS, QOF etc	Many different measure and metrics built upon the national flows	Various outputs such as formal statistics, webtools such as IQI, NHS Comparators etc	Consider opening up tools via API's as a first step, via NHS IC webservice. Where that is not possible, then warehouse the data and provide upwards to data.gov.uk via NHS IC webservice, longer term enable SPARQL Impact: need to check scalability. Need to think about issues associated with APIs and/or deriving data from source, and potential problems with aligning with other toolkits. High costs? Contextual material should be provided alongside to cover issues such as data quality, definitions and standards
Experience	Patient experience information now being tracked at point of care, but locally so. Various national data and survey information supports this theme, eg the Patient Experience and Action Team (PEAT) annual, annual national patient surveys	Data available from the different national surveys and collections, locally gathered information less available for comparison / national purposes obviously	Survey outputs generally published online	Survey data provide directly to data.gov.uk. Longer term warehouse this and provide via NHS IC webservice or SPARQL

Analysis by clinical theme

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
	(CQC) and others			
Clinical Outcomes				
Health Outcomes (including prevalence information)	Data to support general outcomes is variously available for different clinical headings. Information to support this topic is generally derived from one of the other sources identified above eg population health surveys, national data collections, research studies etc. However not all clinical areas are covered effectively	Majority of outcome information is collated by National Compendium of Health Outcomes (NCHOD) which makes data and analyses routinely available to the likes of Public Health Observatories, Commissioners, DH et al	Yes, information is generally available to NHS but also some of material is publicly accessible	New NCHOD contract provides enablement means so that we can open this up directly to data.gov.uk for SPARQL. Will be providing a webservice layer too via NHS IC MyIC portal
Patient Reported Outcomes	Data now being routinely collated for a range of inpatient procedures through questionnaires	Data starting to be collated now	Intention is to publish analytical outputs routinely	Put data in NHS IC warehouse and enable via webservice and SPARQL Impact: new BAU service being configured to support PROMS data analysis and deli.
Clinical Audit				
A number of national clinical audits covering specific clinical themes, for example: • Cancer (eg Bowel, Head and Neck, Oesophgeal etc) • Cardiac (eg Heart Failure, congenital defects, MINAP etc)	Clinical audit data is collected in response to national clinical audits, collected by a variety of bodies including Royal Colleges, Associations, NHS IC and others. Information is collected by different means into different data repositories, depending upon the audit provider.	Data is available in a variety of systems, however it is not commonly located within the same audit data repositories, and therefore data linkage between audits is an issue. Likewise linkage with other key information sources such as HES data can be problematic.	Generally simple online presentation of data made available and formal reports produced from the audits.	Major issues with ownership of data, and information governance. Need negotiations resolved with HQIP and NCAAG before progressing. Longer term, explore possibilities with data extractions from audits, and re-provision via NHS IC audit support unit (warehoused data, opened via NHS IC webservice?)

Analysis by clinical theme

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
• Long-term conditions (eg Diabetes) • Mental health • Older people • Women and children	Audits are 'commissioned' by association of Royal Colleges under guidance from national Clinical Audit Advisory Group	Can be difficult to get data sharing agreements established to reuse audit data Quality of data can be good, but coverage is generally the issue (ie % of eligible patients versus those recruited to the audit)		

Management information

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
Financial Information				
Financial activity / expenditure and cost information	Routine provision of financial information from all NHS bodies in form of various data returns to DH (including reference costs, expenditure detail, capital provision etc), not detailed transaction level, but summarised financial positions (information also includes primary care, but because of nature of 'contracted' status of	Yes, data is available for analysis, but generally confined to finance functions / departments of NHS and DH bodies	Information formally published	Data provision directly from DH to data.gov.uk in suitable formats. Derive from FIMS system?

Management information

Care Setting / Themes	Primary Source of Data?	Data Available to Support Quality Information?	Available in the Public Domain, and in what form?	How Could More Information be Made Routinely Available? & Implications?
	primary care practitioners, the information is more limited in scope)			
Workforce				
NHS Staffing, Workforce and Vacancy Information	Majority of organisations part of Electronic Staff Record (ESR) scheme, so detailed information available about staffing, grades etc is collected	Yes, data is available. Generally information is provided to NHS IC and DH for national workforce analysis. Quality is known to be problematic in certain areas / staff groups, but quality is improving.	Yes, data is increasingly made available through online tools such as NHS IC iView workforce tool, but like other key national statistics workforce can be subject to formal publication controls.	Data available via NHS IC iView tool, link from data.gov.uk in first instance, then longer term look to provide warehouse link via NHS IC webservice or direct SPARQL enablement
Primary Care Workforce	Information collected by NHS IC on primary care workforce including Doctors, Dentists and Optometrists by various annual surveys	Data is generally only available for the production of national analyses / publications, but is sometimes made available in simple data tables alongside the publication	Generally via formal publications	Separate data from formal publication and make available directly to data.gov.uk
Social Care Workforce	Some limited aggregate information gathered through annual national returns.	Data available in summary tables only	Data is generally published as formal national publications by NHS IC	New dataset based return currently being considered. In short-term take existing data collection and provide via NHS IC NASCIS service