First National Data Quality Review: Executive Summary
Quality Information Committee

Executive Summary

Introduction to the report

This report has been produced by the Quality Information Committee (QIC) for the National Quality Board and represents the first attempt to produce a national picture of data quality in the health and social care system including all registered providers.

The Quality Information Committee is a committee of the National Quality Board. The prime drivers for QIC are to improve alignment within the system and focus on the improvement of care for people through the better use of information.

The Quality Information Committee recognises that decisions made in the health and social care system in England, whether clinical, managerial or financial, need to be based on information which is of the highest quality. All of this information is derived from individual data items which are collected from a number of sources either on paper, or more increasingly from electronic systems.

Information is derived from data and hence data quality is crucially important in supporting patient care, clinical governance, management including finance, service planning, policy and public scrutiny to assure us all that we are improving effectiveness, efficiency, safety and economy of health and social care.

This piece of work is taking place in a changing organisational and cultural context, but takes as given all existing governmental policy and strategy. It recognises the excellence of the recently published 'Health and Social Care Information Centre publication: 'The quality of nationally submitted health and social care data, England – 2012'[1] and seeks to supplement that publication with a wider and deeper scope of national data quality activity.

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[1] The Quality of Nationally Submitted Health and Social Care Data, England, First Annual Report, 2012 - available on the HSCIC website - http://www.ic.nhs.uk/article/2187/National-Data-Quality-Assurance-Report-2012

This report aims to:

1. Produce the first comprehensive collection and review of the work that is current and at national level which deals with data quality in the health and social care system in England;

2. Produce a list of recommended actions to strengthen the ability of the system to improve data quality;

3. Identify and share examples of best practice in improving data quality

This piece of work has been undertaken using a qualitative mixed methods approach. The first method used to gain materials for the report was to undertake a thorough search of research literature and grey literature to identify recent national work undertaken relating to data quality. The second method involved writing to a wide range of organisations asking them to:

- share their perceptions with regards to data quality in the NHS and social care system;
- describe any work that their organisation had undertaken to measure data quality;
- describe actions that their organisation had undertaken to improve data quality.

Individual submissions are referred to as appropriate throughout this report with a summary of all submissions referenced at the rear of this document.

The Quality Information Committee worked hard to engage with and encourage participation from a wide range of national bodies that should be active in the field of data quality within the health and social care system and would like to thank everybody that helped with and contributed to this report for their efforts.

The Quality Information Committee will be undertaking a review of the methodology used to produce this first national report on data quality to ensure that improvements are made to future reports. The QIC welcomes feedback from contributors and readers of the report to inform this review.

Key findings

There was strong evidence that the health and social care system does not reflect its focus on the patient and client in the way it approaches and manages data quality. QIC concluded that it needed to make recommendations both on the place of the patient/client in data quality and the general place of data quality in a health and social care system. This report therefore seeks to differentiate between perceptions and activities relevant to direct patient care (i.e. the data

required for the direct care of a patient) and indirect care (data which may be used for a range of managerial purposes).

The perceptions of data quality demonstrated the cultural and operational differences between different parts of the health and social care system. Summarising the perceptions of data quality for direct patient care it was felt that there was:

- Insufficient presence of uni- or multi-professional record keeping standards and conformance to the ones that are present;

- A lack of consistent definitions to enable NHS personnel and patients to unambiguously recognise clinical situations and conditions. This is combined with a lack of relationship to the equivalent data definitions in the reference terminology that computers use in the electronic record;

- Many of the IT systems have unique designs to meet a particular purpose. These are generally in secondary and community care focused on secondary use not the direct client and patient care;

- The separation between secondary and primary use creates challenges rather than resolves them;

- Lack of ownership and leadership in this domain leads to greater diversity than is necessary.

The summary position concerning the perceptions of data quality for indirect care was:

- Patient, client or service user perspective is lacking;

- Perceptions of data quality for basic statistics in NHS Hospital Care and Payment by Results is acceptable, but has room for improvement;

- Systemically data quality is poor with significant internal inconsistency made worse by gaps and overlaps;

- Data linkage capacity to fully exploit data appears limited;

- Serious concern about the systemic desirability and practical feasibility on the utility of specific secondary use collections for other purposes for which they were not designed;

- A statistical perspective offers tools and expertise regarding the improvement in data quality.

The top six high level themes which emerged from the question; 'What are the top specific data quality issues that affect what you do?' appear below.

- The lack of a consistent positive culture toward information and data;

- The lack of detailed professional standards of record keeping especially those which can be built into the computer environment and be audited;

- The lack of professionalism in data recording for non-profession-based data collections including the lack of implementation guidance;

- Lack of interoperable IT systems across health and care;

- Lack of business knowledge and expertise to effectively implement that knowledge at scale within the health and social care system;

- A lack of definitions that ensure that there is consistency between how the data is defined in the computer and how staff recognise the same thing is present in a given real life situation.

In addition, two cross cutting themes emerged which relate to the lack of patient or client centredness in what the system has done with its data. The system is currently poor at providing data to patients and clients to make informed choices about their care. The second cross cutting theme relates to the critical importance of all providers being treated in the same way. Both of these issues are addressed by recommendations in this report.

A variety of data quality improvement activities are being undertaken by a range of national bodies. These vary considerably in their approach and scope. They are detailed later in this report.

Parallel to this report a Review of Information Governance was taking place. The findings of that review are yet to be published, but this report was used to furnish the review team with an up to date picture of data quality in the health and social care system. They also heard evidence that because of poor data quality commissioners and others who wished to link data had to rely on personal confidential data rather than de-identified data for local access or using other methods as described by the Administrative Data Taskforce set up by the Cabinet Office. In short poor data quality creates an undue reliance on personal confidential data which gives the impression that information governance hampers data linkage whereas the real culprit is poor data quality and to a much lesser degree the ability to use privacy enhancing technology to link data. Improvements in data quality therefore have a major benefit of improving patient privacy and increasing patient trust in the health and social care system.

Recommendations

As a result of this work, the QIC recommends the following: -

1. **There should be a minimum definition of data quality in the health and social care system in England and this definition should be reviewed on a 5 yearly basis and be:**
   'Data quality is the state of accuracy, completeness, reliability, validity, timeliness and systemic consistency that makes data fit for purpose'

   Implementation
   This definition should be agreed by the members of NQB and formally implemented in their relevant documentation, contracts and other products and processes from 1st April 2013 which should include and not be limited to Planning Guidance, national or standard contracts, data quality improvement plans. These activities are especially relevant to NHS Commissioning Board, Clinical Commissioning Groups, Department of Health, Public Health England and Local Authorities and enable the Health and Social Care Information Centre to have a consistent and systemic understanding of data quality on which it can base its annual report.

2. **There ought to be a hierarchy of uses or purposes of data with the top priority being that: Data from the Patient/Client that is recorded for their direct care has primacy of purpose over other uses unless explicitly specified**

   Implementation
   NHS CB and Secretary of State approved collections and data standards should follow this recommendation via their direction to the HSCIC.

   The HSCIC should ensure that new data collections should always specify which reference terminology eg Read Codes or SNOMED CT codes [see recommendation 5] should be present and if the collection creates a new classification the mapping from these record terms should be specified and be available to the health and social care system to minimise transaction costs, random error, unforeseen events and wasteful duplication.

   The NHS CB and SoS should insist this happens universally by 2016 utilising their approval and publication responsibilities for information standards and direction power for collections.

   Principal Bodies [NICE, Monitor and CQC] should also align their collections with the published data standards, where possible.

The HSCIC and any directly or indirectly commissioned central data repositories should be configured to accept codes from clinical coding systems deployed in the health and social care system where they are agreed data standards for direct patient care from 2016.

3. **There should be a serious strategic effort to improve the structure and content of patient and client records for direct care by multi-professional teams including the patient and where appropriate their carer. This work must include its implementation in the computer environment in timescales practically feasible for IT system suppliers**

   Implementation
   The Professional Standards Authority with the HSCIC should be commissioned to describe a 5 year programme of work to derive the structure and content of electronic patient records which can be implemented in a timely manner by industry, shared between professions and with patients such that professionals and patients trust the content of such records as the structure is understood, the terms defined, and the record keeping behaviours known for important sections of the patient record.

   Once agreed through the Informatics Services Commissioning Group the programme should be initiated formally through a summit planned for September 2013 between the leaders of the professions, patients, the people who use the services, politicians, industry and the health and social care system organisations at which a strategy for taking this agenda forward is agreed for the next five years.

4. **Poor data quality should be managed in exactly the same way as poor care and poor financial management as these aspects of health and social care will increasingly be reliant on data to make decisions therefore the fidelity of the data is at the heart of the future assessment of the system**

   Implementation
   In the context of a:
   - o Common definition of data quality as in recommendation 1 AND
   - o Priority that secondary use information derives from data to support direct care unless otherwise specified in recommendation 2 AND
   - o Improved structure and content data in direct care records as in recommendation 3

   Then:
   The implementation of poorly designed electronic record systems that prevent best professional practice is a provider Board responsibility and

the Board members should be held to account by commissioners and regulators.

Providing poor quality contracting information is a provider failing and should incur sub-optimal remuneration for activity, this should be enacted by DH & Local authorities and NHS CB & CCGs, unless it can be shown that the capture of contracting data is detrimental to patient care in which case this issue should be escalated to NHS CB and HSCIC for resolution. This should occur from 01.04.2014.

Poor record keeping should be viewed seriously and impact on professional status. Currently it does not rate as high as essential training for organisational requirements in the culture of providers, deaneries and professional bodies. As a minimum record keeping should be part of the revalidation process and be part of the yearly assessment through 360⁰ feedback from colleagues and patients who increasingly will have access to records from 1ˢᵗ April 2014. {See recommendation 5}

Internal or external complaints about the standard of records and communications from them should be formally part of the quality reporting in every provider from 1ˢᵗ April 2014 and specifically identified. This should include failures to share as well as excessive sharing and be instituted through the national contract.

The Data Quality Improvement Plan document to be issued by the NHS CB on 31ˢᵗ March 2013 should explicitly include the key aspects of the report.

5. **There should be a common reference terminology for the care content of all health and social care system person based records where the content is structured and coded in IT systems. This data standard should ideally either itself be the content of indirect care data sets or map to such classification data items so that resource is not wasted undertaking separate collections or undertaking inappropriate manual transcriptions**

Implementation
The NHS CB and the Secretary of State should approve one or more reference terminologies to be used in direct care for the health and social care system through their information standards approval mechanisms.

The NHS CB and Secretary of State should ensure the graduated implementation of these data standards through a 5 year strategy which is supported by industry and includes but is not limited to utilising the following drivers:
   o HSCIC delivered information standards with their implementation guidance

- New collections being specified using these data standards
- Existing collections migrating to these data standards to be completed in 10 years
- National Standard Contracts requiring them
- NICE outputs utilising these data standards
- Payment systems like QOF using these data standards along with classifications where necessary
- National audits using these data standards along with classifications where necessary.

6. **Clinical and social care guidelines and indicators produced by NICE should contain definitions to enable staff and patients to unambiguously recognise the subject of the guideline and ideally reference the acceptable values from the data standard or reference terminology which the computers will use**

   <u>Implementation</u>
   NICE has already begun to take ownership and deliver on this recommendation.

7. **The Health and Social Care Information Centre should be asked to extend its existing (legal) remit for reporting of data quality of the data that is submitted to it to include all data quality so that the data quality for direct care is given at least the same health and social care profile as that currently given indirect care data**

   <u>Implementation</u>
   The NHS CB and the SoS should commission HSCIC with the support of other NQB members to extend the basis of its annual data quality report from secondary uses or indirect care to include direct care.

8. **Data quality within the health and social care system should be part of any national alignment, co-ordination or commissioning system**

   <u>Implementation</u>
   The Department of Health is developing an Informatics Services Commissioning Group with substructures in the areas of information governance, collections, information standards and Care Data. Data Quality is not included. QIC believes NQB should ask that data quality is included so that there is pooled sovereignty. This would include maintenance of the data quality definition, producing an annual data quality report or statement, enabling awareness of best practice and co-ordinating national initiatives along with any commissioned activity related to data quality including but not limited to the reporting of national data quality via the HSCIC.