

RCN Response to Making Open Data Real Consultation

With a membership of over 400,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

The RCN welcomes the opportunity to respond to the Cabinet Office's *Making Open Data Real Public Consultation* and is supportive of the Government's stated aim to promote greater transparency of information for patients and carers.

Summary

The RCN welcomes the simplification of the current processes for accessing data, for example, by reducing the number of Freedom of Information requests, and the promotion of a vision for the proactive publication of information. The RCN has welcomed the increase in available information about health care and services that has happened over the past few years, however we are aware that it is both limited in content, and by virtue of being uncoordinated, does not, and cannot, provide all of the necessary answers needed for a new patient-centred health care system.

However, we recognise that securing greater access to and utilisation of data will be dependent upon the trust that providers are able to offer the public in respect of their handling of personal, and often sensitive, information. This is especially true in respect of healthcare, and is an issue that healthcare staff must be on supported on if they are to maintain patient and public trust and confidence. The RCN believes most strongly that it is of the utmost importance that all staff involved in the gathering and handling of sensitive information are suitably trained, and that they are supported by clear and unambiguous processes, procedures, and publicly available policies

Of specific concern to the RCN is the lack of standardisation of data collection across organisations and sectors. We believe most strongly that unless this is addressed, it will be impossible to achieve the level of data comparability necessary to deliver patient choice, or to deliver quality and safety improvements.

We are also concerned that, irrespective of the Government's claim that increased provision of 'open data' will empower individuals, and concomitantly deliver 'Open Public Services', the document gives too little consideration to the needs of specific marginalised groups, and especially vulnerable patients, those without internet access, or with poor literacy levels.

In respect of the actual consultation, we are mindful that as framed by the proposals, small service providers entering the healthcare market as any qualified providers may initially struggle to meet the demands for open data publication. We would recommend that support and guidance be made available to ensure that the market does not lose out on their valuable input.

Further to this point we would also recommend that contractual requirements to comply with open data publishing be backed up by support, advice, and where appropriate other forms of motivation. Public bodies may additionally require support to balance the right to information with the right to privacy which might incur added cost.

In relation to the proposal for the accreditation of open data quality, which we believe is essential for gaining trust, we are concerned that the Public Data principle which rates speed of data release over data quality may lead to patients basing healthcare decisions on inaccurate data.

The RCN believes most strongly that patient groups and third sector organisations must be involved in driving the demand for open data, and must therefore be able to obtain assurance that provider organisation board level governance is suitably mandated to provide the correct balance between privacy and transparency.

For patient use, to support the choice agenda there needs to be a user friendly approach to publication as described in the RCN Response to the Open Public Services White Paper¹

Finally the RCN would draw the Government's attention to the need to ensure that all possible measures are taken to mitigate any unnecessary increase in the burden of administration required to increase the quantity and quality of available data. We would recommend the use of real time feedback mechanisms, such as with clinical dash boards, as a simple to use means by which to increase clinicians' interest in the quantity and quality of data obtained at the point of collection.

¹ Royal College of Nursing (2011), RCN Response to the Open Public Services White Paper, London (RCN).

Glossary of key terms

1. Do the definitions of the key terms go far enough or too far?

The RCN feels that the glossary does not give enough detail about what datasets contain or how each dataset is developed. We would recommend further work be undertaken into identifying and defining each dataset element, so that they can give maximum value for the effort and cost of collection. This should involve input from those involved in data collection, as well as user stakeholders. The definition used by the Information Centre² gives an excellent description of the purpose and development process of dataset development and provides reassurance of rigour and thoroughness.

We believe that the increased range of data from different care providers envisaged in the *Open Public Services White Paper* will provide a richer picture of healthcare across the spectrum and has the potential to link data from different sectors. However, this will create challenges in terms of standardising information which is not addressed adequately in the consultation document. Information shared, across health, social care and the justice system often uses different entity names or values. The work of the Connecting for Health Data Standards Service³ ensures consistency and correct coding and could be built on to include more shared datasets from other sectors.

2. Where a decision is being taken about whether to make a dataset open, what tests should be applied?

The RCN would recommend the following issues be considered when making a decision to open any dataset:

- **Value to users-** consideration should be given to involving users from different domains, e.g. the public, academic researchers, commercial enterprises, to determine what data is likely to be valuable. The involvement of users in the development process of the NHS Quality Accounts⁴ provides a good example of this in practice.
- **Cost of collection and publication-** data which is very costly or difficult to collect and/ or process may make it less viable. The burden of data collection on front line services should also be considered
- **Risks to information governance** – assurance that individual patient identity can be protected, especially when a number of data sources are linked which could increase the likelihood of identifying individuals.
- **Quality assurance-** source data must be complete and accurate, and if not, any release must be accompanied by a notice informing recipients that steps

² NHS Information Centre, Dataset Development and Approach. Available at www.ic.nhs.uk/services/datasets/approach

³ Connecting for Health, Data Standards Service. Available at www.connectingforhealth.nhs.uk/systemsandservices/data

⁴ Department of Health, Quality Accounts. Available at www.dh.gov.uk/en/Healthcare/Qualityandproductivity/Makingqualityhappen/index.htm

are being taken to improve the quality of future releases, and give the timescale for achieving this.

3. If the costs to publish or release data are not judged to represent value for money, to what extent should the requestor be required to pay for public services data, and under what circumstances?

The RCN supports the principle of open data being the default position (with any necessary exemptions as required by confidentiality and privacy regulations), and that requestors should therefore only be required to pay if cost is the only factor preventing publication. We would also argue strongly that any charge made to users should be transparent and be only as much as is necessary to cover the cost of providing the data.

4. How do we get the right balance in relation to the range of organisations (providers of public services) our policy proposals apply to? What threshold would be appropriate to determine the range of public services in scope and what key criteria should inform this?

The RCN believes that all organisations currently subject to Freedom of Information (FOI) requests should be in scope. We would also recommend that all service providers providing any public service, or funded wholly or partially from public or charitable funding be included in the requirement to provide data.

5. What would be appropriate mechanisms to encourage or ensure publication of data by public service providers?

The RCN recommends the following mechanisms:

- Assistance and guidance concerning where to publish, data format and standards to aim for; many public sector providers already collect data for internal use but do not have the mechanism for sharing this externally in a meaningful and re-usable format
- Guidance and support to perform data collection and analysis; providers who are new to public service provision may not initially have the capacity or ability to provide data for publication and for some this burden could be detrimental to their ability to compete. Easy access to simple to use guidance would facilitate this process for them
- Specific guidance and guidelines should be produced for public sector providers, with illustrative examples of how they can benefit from using the data they collect, including using it to drive service improvements.

An Enhanced Right to Data

6. How would we establish a stronger presumption in favour of publication than that which currently exists?

The RCN supports the premise of a status quo that favours open data, and would recommend the following mechanisms to support this change:

- The use of other public policy agendas, such as open choice of services, to push the need to provide information for comparison with competitors
- The use and promotion of benefits for providers, such as financial savings gained through reduction in the cost of processing FOI requests

- The promotion of examples and case studies of good practice which can help similar organisations to realise the benefits and determine the best approach, for example, how to streamline processes to improve data collection and information management
- A contractual requirement for all public bodies to publish data proactively. This will need to be suitably monitored and enforceable, in health and social care by using the new arrangements envisaged in the Health and Social Care Bill.

7. Is providing an independent body, such as the Information Commissioner, with enhanced powers and scope the most effective option for safeguarding a right to access and a right to data?

The RCN supports the proposal for an independent body to safeguard the rights to access and to data, and feel that an Information Commissioner (IC) would be a good way to achieve this. However, we believe that this role will require sensitive management to ensure that the IC powers do not push providers into breaching data protection in an effort to comply with open data policies.

We also believe that it will be important that the IC's punitive powers are not overused, and that supportive measures are employed to enable and guide organisations. There will need to be a lead time during which companies new to public service provision are allowed to make their systems ready and fit for purpose. An IC would be also well placed to be a source of advice and guidance on how to comply with the new data provision requirements, while also balancing the right to information and the right to privacy.

8. Are existing safeguards to protect personal data and privacy measures adequate to regulate the Open Data agenda?

The RCN notes that there is still a degree of nervousness amongst health and social care providers around the usage of personal data. The concerns which underlie this nervousness must be addressed if the public are to be adequately reassured about the safety and security of information held about them, and resulting unnecessary barriers removed.

The presence of sensitive information within a dataset can mean that providers are reluctant to share any of the data and they may need guidance about how to detach and block sensitive data items so that the non-sensitive data can be published⁵

9. What might the resource implications of an enhanced right to data be for those bodies within its scope? How do we ensure that any additional burden is proportionate to this aim?

The RCN believes that the cost of procuring solutions for data collection and management will be an additional burden for small organisations new to public service provision. Across the board, the new requirements will most likely

⁵ Access Info Europe (2011). Beyond Access: Open Government Data and the Right to (Re)Use Public Information. Available at www.access-info.org/documents/Access_Docs/Advancing/Beyond_Access_7_January_2011_web.pdf

necessitate increased investment in staff training, so that good data collection practices are created and supported at the front end.

10. How will we ensure that Open Data standards are embedded in new ICT contracts?

The RCN recommends that this be achieved by including them in providers' contracts.

Setting Open Data standards

11. What is the best way to achieve compliance on high and common standards to allow usability and interoperability?

The RCN believes that public usage of open data will depend on how well they trust the data. It will therefore be vital that some form of official approval mechanism is created to build a reputation for quality. We would recommend the use of an accreditation system to mitigate risk, measure performance, and drive up the quality of data, however, any accreditation must be achieved fairly i.e. not purely self-assessment. The information standard, in use for the accreditation of healthcare information providers, may provide a good template for such a system.

The RCN has reservations regarding the publication of inaccurate data which could be misleading to the health service users, as described by the Public Data Principle, which states that "Speed may mean that the first release may have inaccuracies; more accurate versions will be released when available" (*Making Open Data Real*, page 56). The RCN recommends the development of a publicly available methodology for identifying quality of published data. Released data should be authentic, and representative of data used as part of a public body's activities or reporting duties rather than data that is produced purely for release on an open data site.

Participation in public sector accreditation and the Public Data Principles should be a requirement for commissioning so that competition can help to drive up the standards of information available.

12. Is there a role for government to establish consistent standards for collecting user experience across public services?

The RCN recommends the creation of a standard methodology to support comparisons. The development of such standards must include input from service users and providers with central support and backing.

13. Should we consider a scheme for accreditation of information intermediaries, and if so how might that best work?

The RCN believes that the accreditation of information intermediaries, who provide a service to display and present data in a usable format, may help to drive up standards of data quality. We feel that the requirement for employees of

such companies to be members of existing industry associations such as UKCHIP⁶ or the British Computer Society⁷ would help to achieve accountability.

Corporate and Personal Responsibility

14. How would we ensure that public service providers in their day to day decision-making honour a commitment to Open Data, while respecting privacy and security considerations.

The RCN notes that the utmost requirement within healthcare is for the protection of patient information. This is often in conflict with the use of aggregate information based on patient data for service delivery, clinical improvement or research, although these are slowly gaining acceptance, and most NHS organisations now publish waiting times and certain outcome information.

However, the RCN believes that a further culture change may be needed in order to make the leap to routine proactive publication of a wider set of data. Patient groups and third sector organisations can play a large part in this process by creating a demand and signify to health organisations that the data is valued. Organisations such as the World Bank have recognised the value in providing data proactively in supporting policymakers to make better-informed decisions and measure improvements more accurately, to support research and broadening understanding of issues⁸.

15. What could personal responsibility at Board-level do to ensure the right to data is being met include? Should the same person be responsible for ensuring that personal data is properly protected and that privacy issues are met?

The RCN believes that data protection and privacy should be an organisation wide concern and Boards may require support from a number of departments to ensure clear lines of accountability. We would recommend that in order to avoid conflicts of interest, the person with responsibility for information publication should not also be responsible for privacy.

16. Would we need to have a sanctions framework to enforce a right to data?

The RCN supports the creation of a sanctions framework. We believe that it would clarify what data will and will not be available and could help to ensure consistency across public service providers. We would recommend that all stakeholders likely to be affected by such a framework are included in its development.

17. What other sectors would benefit from having a dedicated Sector Transparency Board?

⁶ UK Council for Health Informatics Professions. Available at <http://www.ukchip.org/>

⁷ British Computer Society, the Chartered Institute for IT. Available at <http://www.bcs.org/>

⁸ The World Bank, Open Data. Available at <http://data.worldbank.org/>

There is not enough information to answer this question.

Meaningful Open Data

18. How should public services make use of data inventories? What is the optimal way to develop and operate this?

The RCN believes that data inventories, searchable by topic and organisation type, would be very useful for categorising and finding data. The use of a single inventory would simplify the process of discovering what data is published and, if it is not published, the reason why. We would further recommend that the data inventory be available for download online and via mobile application software. It is also important that those who do not have internet access are not disadvantaged by lack of information, and would recommend that the data should also be available in hard copy on demand.

19. How should data be prioritised for inclusion in an inventory? How is value to be established?

The RCN recommends the following considerations be taken into account:

- examination of download rates for existing data releases; this will give an idea of usefulness and value
- examination of FOI requests and prioritisation of the most frequently requested topics
- we would further recommend that consultation be undertaken with providers and users of existing published data and with the public about what would be most useful.

20. In what areas would you expect government to collect and publish data routinely?

The RCN would recommend that all governmental bodies, including arms length bodies produce performance data, and that detailed data be provided in areas of major public expenditure.

21. What data is collected, unnecessarily? How should these datasets be identified? Should collection be stopped?

The RCN recommends that all datasets should be examined at regular intervals to ensure value to users, currency and cost effectiveness.

22. Should the data that government releases always be of high quality? How do we define quality? To what extent should public service providers „polish“ the data they publish, if at all?

The RCN believes that as far as is reasonably practicable all government releases should be high quality; that is robust, accurate, complete, based on easy to follow collection principles, and able to be interrogated. Where data cleansing is required for consistency it should not change the intent or meaning of the data and supporting information should clearly identify that data cleansing has been performed.

Government sets the example

23. How should government approach the release of existing data for policy and research purposes: should this be held in a central portal or held on departmental portals?

The RCN would recommend the creation of a central portal for accessing data. This would be useful for allowing easy access to data, and for making comparisons across different providers and sectors.

24. What factors should inform prioritisation of datasets for publication, at national, local or sector level?

The RCN believes that the publication of datasets should be prioritised by level of existing demand regardless of sector level.

25. Which is more important: for government to prioritise publishing a broader set of data, or existing data at a more detailed level?

The RCN believes that in seeking to improve the overall provision of data, government should work to the principle that data should be published at whatever level and detail will be most useful its end users.

In support of this point, we note that broad data consists of aggregated detailed data, and that within healthcare the use of detailed data in real time can drive improved patient outcomes, for example, with clinical dashboards at ward and hospital level.⁹

Innovation with Open Data

26. Is there a role for government to stimulate innovation in the use of Open Data? If so, what is the best way to achieve this?

The RCN believes that there is a role for government to stimulate the provision of free access to public data for research, social enterprise and commercial research purposes. We believe that such provision can stimulate innovation and development, and that this should be publicised in areas such as business enterprises and showcased in industry and public sector journals.

However, we are aware that the investment required by individual organisations to manage and publish data may be more than the benefits gained, and for the public sector this could be a distraction at a time when focus needs to be on efficiency. This must be considered in the development and promulgation of any programme for innovation.

Royal College of Nursing, November 2011

⁹ Connecting for Health, Clinical Dashboard Toolkit. Available at <http://www.connectingforhealth.nhs.uk/systemsandservices/clindash/toolkit>