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LIBERATING THE NHS: AN INFORMATION REVOLUTION

Key Points

The Royal College of Obstetricians and Gynaecologists:

- ***Supports the principle of collecting data once only as part of care in a uniform manner to be used in all health and social care settings***
- ***Supports the concept of using the same data for patients, professionals and administrators***
- ***Believes that the data must be uniform, accessible, meaningful and understandable***
- ***Supports the role of the NHS Commissioning Board in the management of the whole portfolio of standards - from terminologies through to datasets and patient record standards***
- ***Believes that the aspirations set out in this document can only be realised with appropriate investment and improvement in IT systems.***
- ***Believes that clear and accurate outcome data will facilitate patient choice***
- ***Supports the need for NHS, independent (private) and voluntary providers of NHS care to submit data to the Information Centre according to nationally defined standards.***
- ***Believes that the information revolution will facilitate a culture change to ensure healthcare is a partnership between the professional and the patient resulting in the opportunity to enhance the education and training curricula for future professionals.***

The Royal College of Obstetricians and Gynaecologists (RCOG), an international organisation, which includes all UK-based specialists in the discipline, welcomes *Liberating the NHS: An information revolution*. This response represents the views of the leadership of the RCOG and its UK-based membership, whose views were sought as part of this consultation process.

Consultation questions – Chapter 1

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

The current good examples include patient-held maternity record, GP patient records, some clinical service outcomes (cardiac surgery), and national reports from CQC, NHS LA and HES derived annual reports, e.g. maternity statistics. There has been a big improvement in capturing patient experience, e.g. maternity user surveys by the Healthcare Commission and its successor CQC, Picker Institute surveys. These examples of good practice should be extended throughout health and social care.

There are huge banks of data that needs to be converted to useful information. The lack of national datasets should be remedied, e.g. national maternity dataset should be implemented immediately. There is an urgent need for nationally agreed outcome measures that are clinically meaningful.

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

The RCOG believes that the most important uses of information are patient choice, facilitating integrated care provided by different professional teams/organisations, supporting high quality care, ability to improve health and social care and benchmark on a national and international basis. In addition, there are important ramifications for research, audit, education and training. It is also essential for commissioning services and policy development.

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

Yes, it does.

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

Better use of information and technology can help drive better care and better outcomes by supporting interconnectivity and not by duplicating existing data collection. There is a need for uniformity of specifications for IT providers to encourage competition and value for money. Minimum datasets must be uniform and accessible to all, e.g. patients and professionals.

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

The Centre can achieve the greatest positive effect by focussing on clinically meaningful nationally agreed minimum datasets in the key areas of healthcare, e.g. maternity dataset.

Consultation questions – Chapter 2

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

The user groups are better placed than the RCOG to answer this question.

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

The users need levels of access, of which telephone and online communication would be very helpful.

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

The RCOG supports the concept of sharing medical records and embraces the Department of Health's Information Governance Toolkit. We also support the proposal to centrally develop and to maintain standards by the NHS Commissioning Board.

In relation to risk, the biggest concern is breach of security. In addition, due recognition must be taken of sensitive aspects within the patient record, for example, disclosures involving third parties, sensitive past medical and surgical history, such as termination of pregnancy, or sexually transmitted disease.

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

No comment.

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

The RCOG believes that user groups are better placed to respond to this question.

Q11: What additional information would be helpful for specific groups – e.g.:

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

The RCOG believes that user groups are better placed to respond to this question. We would however wish the available information to be risk adjusted within a local context.

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

No comment.

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

No comment.

Consultation questions – Chapter 3

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

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

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

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

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

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

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

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

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

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

The RCOG believes that the following information can facilitate clinically appropriate patient choice about a safe and high quality service:

- the service available.
- professional teams involved.
- need nationally agreed generic and specialty specific outcomes - hospital mortality, infection rates, ovarian cancer survival rates, IVF success.

We agree that improvements can be made by collecting meaningful data differently and its inter-linkage. This does not necessarily mean collecting more data but rather collecting different data.

Consultation questions – Chapter 4

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

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

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

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

The RCOG believes attitude to data input and quality assurance of that data at resource level is essential. This can be achieved by the active involvement of clinicians and other care professionals, and seeing that data turned into meaningful local clinical information.

The principles of data protection and information governance remain essential. This in turn will facilitate the collection of nationally agreed minimum datasets. Accessibility remains the key against a

background of protecting patient anonymity. The information must be useful and meaningful. It must be accurate. Portals such as NHS Evidence, data within HES should be developed and promoted ideally in conjunction with professional bodies and agencies, e.g. RCOG.

Accurate data is essential, e.g. coding and outcomes, for patient choice and for hospital comparison. It enables improvement measures to be realised and benchmarking undertaken. Relevant meaningful denominators must be used and case mix included.

The collection of national data and its analysis needs to be timely and available in a time frame which is then useful for patients and professionals alike. All data for example should be available within 12 months.

Consultation questions – Chapter 5

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

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

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

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

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

Accurate meaningful data is powerful. Informed patients and professionals should be the norm and not the exception. Minimum levels of information should be accessible in a uniform manner for relevant and timely comparison. The danger is that excessive bureaucracy will slow down the process. Evolving measures of clinical outcomes for example should be championed and explored rather than relying upon standard measures such as HAI or HSMR which have proved controversial. They must be appropriate and meaningful for patients.

In terms of accessibility, thought must be given as to how this information reaches the most vulnerable who do not have access to the internet or those unable to utilise the electronic media, e.g. availability of information in local libraries, local community centres. It would also be important to have information in different media accessible to the disadvantaged, e.g. to cater for non internet users, visually impaired and deaf sign language.

Consultation questions – Chapter 6

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

No comment.

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

No comment.



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