Westminster Hall debate on the use of digital records in the NHS

Royal College of Physicians' briefing

Introduction

This briefing has been produced by the Royal College of Physicians (RCP) ahead of the Westminster Hall debate on the use of digital records in the NHS on Thursday 28th April 2016. The RCP believes that fully digital patient records will bring benefits to the NHS, including direct benefits to patient care. However, unless the recording of information is of sufficient quality it will not benefit patient care.

Summary

- Fully digital patient records have the potential to improve the quality of patient care, improve NHS quality improvement and research activities and lead to potential cost savings
- The public must be provided with more information to ensure that the benefits of patient data can be balanced with individual confidentiality
- The recording of patient information must be of sufficient quality

The benefits of making patient records fully digital

Fully digital patient records will bring benefits to the NHS, but to do so they need to be based on standards for the structure and content. Common standards are essential to enable interoperability between digital records in different care settings. Standards-based digital records will provide the following benefits:

Improved quality of patient care:

- Easier for care professionals to bring together a **person-centred view of the patient** from all the disparate records held in different settings and over time
- **Improved communication** between professionals in different care settings
- Easier to drive timely, relevant automatic clinical alerts (e.g. for prescribing errors and duplicate test orders)
- **Improved safety** through reduced transcription errors (e.g. re-entering information in general practice from paper discharge summaries)
- Easier for patients to access their records for self-care purposes

Improved NHS quality improvement and research activities:

- Much improved ability to carry out records-based audit and quality improvement activities
- Much improved ability to carry out records-based research (with appropriate protection of confidential data and respect for those who wish to opt out)

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- Support for the development of stratified medicine which enables doctors to provide patients with specific treatments according to individual needs. It requires the collection of genotype (information on individual's genetics) and phenotype (lifestyle and environmental information from patients).

Potential cost savings:

- Reduced duplication of test orders and unsuccessful treatments
- Reduced errors: Mistakes in prescribing harmful drug interactions or drugs to which a patient is allergic could be prevented as key data relevant to patient management is easier to locate
- Reduced time spent searching for missing paper records

Privacy and protection of patient data

The RCP recommends the following steps are taken to ensure privacy and protection of patient data:

Promote the importance of information sharing to the public

- Support clearer public understanding of the purposes that patient data is used for
- Distinguish clearly between three activities using data:
    1. Short term data-driven quality improvement and research carried out within the NHS
    2. Longer term research carried out externally by academic/third sector organisations, which will result in a public report
    3. Use by commercial organisations for their own purposes.
- Consider offering members of the public a differential opt-out for the latter two activities, but not for the first, which is an inevitable consequence of using NHS services (unless that person has a legitimate reason to opt-out).
- Develop a list of acceptable reasons for people to opt-out of NHS data processing (e.g. people on a crown witness protection scheme)
- Ensure that those with a legitimate requirement for privacy receive appropriate advice about safeguarding their data, even when data are anonymised
- Carry out privacy impact assessments and arrange that all NHS data systems default to the highest level of privacy, as required by the EU General Data Protection Regulation[1]

Monitor the work of external organisations using NHS data:

- Recognise that any individual person-based record can be re-identified, no matter how many identifiers have been removed. Simply anonymising datasets, then banning re-identification activity is not enough. We have to ensure that such activity is immediately detected.

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[1] Reform of EU data protection rules. http://ec.europa.eu/justice/data-protection/reform/index_en.htm [Accessed 26 April 2016]

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- One way to do this is to restrict distribution of NHS datasets to external organisations wishing to make use of NHS data. Instead, enable these external organisations to analyse data only while it is held for them on NHS Digital servers, which allows the NHS to monitor attempts to re-identify patients.

Make NHS datasets fit for purpose:

Currently the collection of data can often be: **Costly, inefficient and inaccurate.**
- **There are inconsistencies in data collection**. ICD10 codes[2] (used in secondary care) and Read codes[3] are different. For example, there are 47 read codes for asthma. As a result, epidemiologists and researchers spend a lot of their time trying to make sense of and clean up clinical data which is costly and inefficient.
- **The collection of data is often not standardised or collected at the point of use.** There are huge variations in record structures and clinical language, and major problems with the coding of clinical concepts. Patient information should be recorded at the point of care.
- **The quality of data is key to the entire process.** The RCP has been leading, through the Professional Records Standards Body (PRSB), to develop standard recording procedures. These are supported by professionals from a range of medical specialties. The Government must set out the requirement for national records standard for health providers for the structure and content of patient records.

About the RCP

The RCP is patient centred and clinically led, with 32,000 members working worldwide in hospitals and communities across 30 different medical specialties to improve patient care and reduce illness.

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[2] ICD is used by physicians, nurses, other providers, researchers, health information managers and coders, health information technology workers, policy-makers, insurers and patient organizations to classify diseases and other health problems recorded on many types of health and vital records.

[3] Read Codes are a coded thesaurus of clinical terms. They provide the standard vocabulary by which clinicians can record patient findings and procedures in health and social care IT systems across primary and secondary care e.g. General Practice surgeries and pathology reporting of results.

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