

## **'Safeguarding of NHS Patient Data'**

### **Westminster Hall Debate Tuesday 25 March 2014**

**The British Medical Association (BMA) is an independent trade union and voluntary professional association which represents doctors and medical students from all branches of medicine all over the UK. With a membership of over 153,000 worldwide, we promote the medical and allied sciences, seek to maintain the honour and interests of the medical profession and promote the achievement of high quality healthcare.**

#### **Background**

The Health and Social Care Act 2012 (HSCA) gave powers to the Health and Social Care Information Centre (HSCIC) to collect and share confidential information from medical records. One of the first uses of these powers will be the care.data scheme, commissioned by NHS England. The stated aim of this service is to make better use of the valuable information in medical records to improve the quality of patient care.

The HSCIC will link data extracted from GP systems with data from other health and social care settings. The data to be extracted from GP systems includes coded personal confidential data such as referrals, all NHS prescriptions and other clinical data. Identifiers (date of birth, postcode, NHS number and gender) are required so that data can be linked with the data from other care settings e.g. hospitals, in order to analyse patient care across pathways. Once a patient's record has been linked, the information that could identify a patient is removed and a reference number for the record is allocated instead.

As data controllers, it is the obligation of all GP practices under the Data Protection Act (DPA) to take action to raise patient awareness about care.data before data extraction begins. NHS England also committed to raising awareness among patients nationally through a range of activities, which included a leaflet delivered to all households in England.

#### **Concerns with the safeguarding of patient data**

The BMA, along with other health organisations including the Royal College of General Practitioners<sup>1</sup>, is concerned that the public awareness campaign leading up to the scheduled launch of the care.data scheme did not yet reach a significant number of patients, resulting in a lack of awareness about the changes and patients' right to object. Furthermore, concerns have been raised by patients and health professionals around the safeguards in place to protect patient data. Misinformation reported in the media has contributed to these concerns in recent months.

NHS England subsequently announced a delay to the roll-out of the extracts until autumn 2014.<sup>2</sup> The BMA welcomes this delay.

The BMA notes Government amendments to the Care Bill, which will introduce increased protections for the handling of patient data. This is part of a range of measures to reassure both doctors and the public that appropriate safeguards are in place.

The primary aims of the BMA's discussions with NHS England on care.data have been to maintain the highest standards of confidentiality within the existing legal framework, make patients aware of the changes and to maximise patients' control over their medical records. Our support for care.data has been predicated on achieving these aims.

### **Amendments to the Care Bill**

The BMA views the Government's use of the Care Bill to amend the HSCA as a positive step in helping to strengthen the safeguards around the dissemination of patient information from the HSCIC. These measures will help reassure both doctors and the public that additional protections are in place.

The changes made to the Bill at Report stage in the House of Commons<sup>3</sup> include that:

- **Amendments to the HSCA so that the HSCIC will only be permitted to disseminate data 'for the purposes of the provision of improving health care or adult social care or for the promotion of health'.** The BMA understands that this would enable data to be made available for a range of health and care related purposes, including commissioning, public health and research, but not for commercial purposes such as insurance. Furthermore, the HSCIC must satisfy itself that the 'recipient is competent to handle the data in compliance with all statutory duties and to respect and promote the privacy of recipients of health services and adult social care';
- **In carrying out its functions, the HSCIC must have regard to the need to respect and promote the privacy of those receiving health services and adult social care services in England;**
- **The HSCIC must have regard to advice given to it by the committee appointed by the Health Research Authority, the Confidentiality Advisory Group (CAG), when publishing or otherwise disseminating information.** Additionally, the Secretary of State will be given powers to set out specific criteria which must be considered by the CAG in providing their advice e.g. that an applicant for access to data has not breached confidentiality in the past.

*The BMA welcomes these additional restrictions on the dissemination of information.*

In relation to the role of the CAG, whose responsibility it is to provide independent scrutiny for access to confidential identifiable data, the BMA understands that under regulation 5 of the Health Service (Control of Patient Information) Regulations 2002, CAG does not have powers to consider the processing of pseudonymised data or 'potentially identifiable' data. Therefore this new clause would not provide for independent scrutiny for these releases of data. We believe it must be made clear through secondary legislation that the CAG's role will now encompass scrutiny of pseudonymous outputs, as well as identifiable outputs, from the HSCIC.

There are also further amendments to the Care Bill relating to the misuse of data provided by the HSCIC that predicate that:

- **It will be an offence to misuse information requested and received from the HSCIC.** This will apply where information is used in a way that violates the agreement with the HSCIC, uses the data outside the agreed limits, or uses information in such a way that enables individual patients to be identified by a third party;
- **Any such offence will be liable to sanctions, including imprisonment or an unlimited fine.** Furthermore, the conviction must be disclosed on all future applications to access data from the HSCIC.

*The BMA welcomes these increased sanctions against the misuse of patient data.*

In addition to these amendments, we understand that the Government has given a commitment that a patient's right to object to data flowing to the HSCIC will be respected (save in exceptional public

interest circumstances), and we seek further assurances from the Government on this through subsequent guidance.

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**For further information, please contact:**

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## References

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<sup>1</sup> [RCGP voices concerns about care data](#) (12 February 2014)

<sup>2</sup> NHS England, 19 February 2014: <http://www.england.nhs.uk/2014/02/19/response-info-share/>

<sup>3</sup> Commons Hansard, 11 March 2014: <http://www.publications.parliament.uk/pa/cm201314/cmhansrd/cm140311/debtext/140311-0001.htm#14031152000001>