



Prof Sir Brian Jarman

Summary of my views about Care.Data

(23 Feb 2014)

- 1. I approve of the use of accurate, anonymised, clinical information for research and improvement of care.** I don't approve of very sensitive confidential clinical information being accessed by several organisations without patients being properly informed of what will happen to their data and only being able to opt out of its use. There's a possibility of identifying individuals and of data breaches. Mishandling of the care.data scheme could lead to patients losing confidence in their GPs and the NHS. Care.data is a potentially useful data but if we get it wrong it may prevent its use for years.
- 2. Tim Kelsey, NHS England's national director for patients and information, stated in a 2009 article for Prospect Magazine:** "But no one who uses a public service should be allowed to opt out of sharing their records. Nor can people rely on their record being anonymised"
<http://www.prospectmagazine.co.uk/magazine/longlivethedatabestate/#.UwnzY2ePPGg>
Caldicott2 supports sharing of identifiable data for direct care but not for other purposes. It rejected the concept that "consent deal" between the NHS and patients that use of their personal confidential data (PCD) would be legitimate.
<http://webarchive.nationalarchives.gov.uk/20130805112409/http://caldicott2.dh.gov.uk/>
- 3. Care.data is opt-out rather than opt-in.** The Data Protection Act (DPA) usually requires organisations by default to offer opt-in. Yet for the confidential care.data opt-out is the only option. This suggests a lack of informed consent. The leaflet sent to people in their junk mail gives little information about the drawbacks. To have informed consent patients need to be told of the risks as well as the benefits.

The leaflet "Better information means better care" that is being sent to most* households states on the last page: 'And you can change your mind at any time' implying that a person who has not opted out can change their mind and have their data removed or deleted. However, it seems that the intention is that once data has been uploaded it cannot be removed or deleted, and that will also apply to third parties who have accessed the data and the data will not be retrospectively anonymised. <http://www.leighday.co.uk/News/2014/February-2014/Legal-action-taken-day-before-NHS-patient-data-sha>

Patients themselves will not have online access to their care.data record, i.e. their personal confidential data (PCD) that is being shared with third parties. They are not able to see what information is being shared or correct any inaccuracies and so will not be able to make an informed choice regarding the use of their data. Healthcare providers will also not have access but companies that could use it for profit-making may be given access to pseudonymised data.

*An FOI request to the Royal Mail indicates that "...the leaflet has not been delivered to households that have registered with the Royal Mail's 'door to door opt-out'." This may equate to at least 198,000 households http://www.twosides.info/Content/NewsPDF_33.pdf and https://www.whatdotheyknow.com/request/royal_mail_contract_for_caredata#incoming-484935

4. **The caredata update submitted to the HSCIC board** for its meeting on 05/02/2014 identified that “the programme team is working at risk in some areas without an approved business case and funding stream. The funding source(s) for the programme going forward is not yet confirmed.” See page 6 of: [http://medconfidential.org/wp-content/uploads/hscic/HSCIC Board Papers - 05 February 2014/3c.%20%20care.data.pdf](http://medconfidential.org/wp-content/uploads/hscic/HSCIC_Board_Papers_-_05_February_2014/3c.%20%20care.data.pdf)
5. **The NHS England Privacy Impact Assessment** (dated 15/1/13, page 6) states: "The Extraction of Personal Confidential Data from providers without consent carries the risk that patients may lose trust in the confidential nature of the health service."
<http://www.england.nhs.uk/wp-content/uploads/2014/01/pia-care-data.pdf>
6. **The 'amber' level pseudonymised data is 'potentially identifiable' data** and some patients can be identified. It is illegal to make unauthorised links and anyone reporting that they have made a link without permission will be admitting to a crime. It is necessary to make clear whether the aggregated anonymised 'amber' data that will be made available will record the LSOA (lower layer super output area, roughly equivalent to the first half of post-code, an average of 672 households in the 2011 census), Year of Birth and gender identified and whether it will include the General Practice code.
7. **Patients are used to the use of their hospital data** in Hospital Episode Statistics (HES) from 1988 but the GP data has more than 10 times as much data as hospital admissions and contains details e.g. of prescriptions, mental health plans, tests, alcohol use that have traditionally been confidential between a patient and their GP. Trust has usually accrued over long periods and patients often share personal information with their GP that they have not shared anyone before. Many GPs will have given guarantees regarding confidentiality in according with the NHS Code for Confidentiality, which states that patients should be allowed to "decide whether their information can be disclosed or used in particular ways."
<https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice>.

The Police, and other organisations are, under the terms of the Health and Social Care Act 2012, entitled to apply for access to the GP care.data dataset. The organisations would pay the cost-recovery charge to access the data (but would be entitled to profit from use of the data).

[http://www.hscic.gov.uk/media/12866/caredata-addendum---Information-Governance-Assessment/pdf/care.data_addendum_-_IG_assessment_-_September_2013_\(NIC-178106-MLSWX.A0913\).pdf](http://www.hscic.gov.uk/media/12866/caredata-addendum---Information-Governance-Assessment/pdf/care.data_addendum_-_IG_assessment_-_September_2013_(NIC-178106-MLSWX.A0913).pdf)

If the data is linked with identifiers and confidential clinical information from GPs, it would lead to a very detailed database of nearly person in the country. Some organisations already have very large databases at identifiable person level but those databases do not normally include medical data given in confidence by patients to their GPs.

The Department for Work & Pensions (DWP) and HM Revenue & Customs (HMRC) have applied to the National Information Governance Board (NIGB) for access to personal health data - see minute 5c of the NIGB meeting on 5 December 2012.

<http://www.hra.nhs.uk/documents/2013/09/ecc-meeting-5-december-2012.pdf> Some data be shared with US companies in June?

The HSCIC holds the patient demographic service which has NHS number, date of birth, full names and every address which a person has ever had. By receiving the NHS number with the GP data means it can easily be linked to this patient demographic data and thus disclose full details of everyone. It is misleading to say there will only be an extract of a coded number and the information is anonymous because the extract can easily be linked to the patient demographic data. If the data is anonymised there would be no need for a Read Code to prevent release of identifiable data from the HSCIC data.

The argument that the GP care.data would give GPs information from earlier GP records carries less weight when it is realised that GPs already receive the medical NHS records that are automatically transferred from earlier GPs as part of the UK NHS general practice system.

8. ***There have been data breaches data and data errors.*** We don't know if any audits have been carried out or what they show so we can't provide public assurance on this point.
9. **GPs will not be in breach of GMC guidance for disclosing personal confidential data** as part of the care.data programme. They will, however, be in breach of the statutory requirement if they do not disclose the data. GPs are thus being placed in difficult situation in which they either risk being in breach of the HSCA statutory responsibility to disclose data to the HSCIC or are in breach of the Data Protection Act (DPA) if not all patients are fully informed and understand. This is potentially damaging for the doctor patient relationship as well as the relationship and trust between the profession and NHS England.
10. **The recently (18/02/2014) announced six month pause** before the start of the upload of GP records for care.data is welcome as it gives a chance for genuine engagement with patients and doctors about their concerns and to ensure these are addressed. NHS England needs to engage with other patient and professional groups beyond the RCGP and BMA such as the EMIS NUG (national user group of doctors) and general practice experts who understand the data and how it is recorded, to avoid it being misunderstood and/or misused. There needs to be clarity regarding purposes – what are the limits to the proposed care.data extract? Will it include direct care and if so what are the implications for patients who opt out? There needs to be a plain statement about when opt-in/opt-out is appropriate and what it means legally and practically. Patients need to be able to express their choices in a simple way and be confident that their wishes will be respected. Requiring patients to opt-in to the care.data after being informed of the advantages and disadvantages of doing so would ensure that they would be giving informed consent for the scheme to go ahead, as is happening in Scotland where "Unlike in England, general practices will be able to opt out—entirely, from specific uses, or case by case. Practices can review each request before data are released to SPIRE [The Scottish Primary Care Information Resource], with no response taken to mean no."
<http://www.bmj.com/content/348/bmj.g1702?ijkey=z3JOAYNT2Wi42B9&keytype=ref>

Sir Brian Jarman can be found on Twitter at [@Jarman](https://twitter.com/Jarman)