

# UK government to sell personal data

Mary Smith  
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Last week's announcement that Revenue and Customs (HMRC) is considering making taxpayers' personal data commercially available to private companies has further demonstrated the UK government's determination to turn a profit from private information.

The announcement comes two months after the temporary suspension of a similar scheme involving medical data, confirming that the suspension of the Care.data programme was purely a tactical exercise. *The Guardian* reported that HMRC is considering legislation allowing the release of anonymised tax data to companies, researchers and public bodies. Officials are discussing "charging options."

The government insists personal data will be protected, but HMRC has already been responsible for major breaches of personal data. These included the 2007 loss of discs relating to child benefit claimants, containing personal information about 25 million people.

The similar situation in the National Health Service (NHS) is more advanced. In February the government suspended the Care.data scheme just weeks before its implementation. The decision followed criticism of the lack of clear information, but it only delayed the scheme until September. It is now reported that Care.data will be launched with autumn trials at between 100 and 500 General Practitioner practices.

Doctors were concerned about Care.data, which will make private medical records accessible to researchers, for-profit organisations and businesses.

The government denies data will be sold, but shortly after the suspension it emerged that some patient records had already been sold to private companies.

Health Secretary Jeremy Hunt has since announced legislation to prevent information being shared where there is no clear benefit to the health service. Given his determination to break up and privatize the NHS, this commits to nothing. A Department of Health statement reaffirmed support for the project, and a source admitted that the real concern was "to explain the programme to the public."

The central database will be the Health and Social Care Information Centre (HSCIC) in Leeds. HSCIC claims all

records are kept confidentially, but where the leaflet mentioned only postcode and NHS number for linking records, HSCIC also identifies date of birth and gender.

The data will include medical diagnoses and complications, specialist referrals, prescriptions, family history, screening results, blood tests, BMI, smoking habits and alcohol consumption. It is a massive collection of personal information.

Circulating this information among medical professionals seems laudable, but even its advocates noted problems. Dr Ben Goldacre, a passionate supporter of integrating medical data for research purposes, wrote of the "clear mistake" in promoting Care.data as simultaneously a research tool and a venture for commercial exploitation.

Goldacre offered advice on how to rescue the project as a scientifically useful exchange of data after its "bungled implementation." A week later he wrote that he was "embarrassed" to find the situation worse than he had thought.

Dr Neil Bhatia, a Hampshire GP, set up a non-commercial website, [www.care-data.info](http://www.care-data.info), to provide information not on the leaflet. Bhatia insisted that the scheme "is *not* about sharing your medical information with doctors, nurses or other health professionals ... [or] providing essential medical care."

The leaflet, he said, was solely about Care.data, which is not the same as the Summary Care Record already used to ensure medical access to records necessary for effective treatment.

Bhatia argued that Care.data is not anonymous. Sensitive information will be extracted from your GP records for HSCIC databases. Former President of the British Medical Association Professor Sir Brian Jarman warned that it could take profit-making companies just two hours to identify patients from date of birth and hospital number.

HSCIC plans to charge for releasing information, including identifiable information. It sells data, which will not be used to provide direct medical care. Hunt's legislation will not change that.

Patients are automatically enrolled in Care.data unless they opt out. The leaflet did not explain that opting out of

Care.data does not mean opting out of the Summary Care Record.

Under the 2012 Health and Social Care Act GPs must allow HSCIC to extract information unless individuals opt out. NHS England threatened some GPs, like Dr Gordon Gancz in Oxford, for opting out all patients except those who agreed to participate. Bhatia criticized their “threatening” tactics against doctors opposed to the scheme. NHS England said they would review cases where “abnormal numbers” of patients had opted out, but only once data collection had begun.

HSCIC replaced the NHS Information Centre (NHSIC) as an Executive Non-Departmental Public Body in April 2013. Its board includes advisers to health authorities and private healthcare companies, a former Ministry of Defence civil servant, an accountant who advised on NHS services, a DH economist on private finance, capital investment privatization and payment by results, and a former executive director of an investment bank.

HSCIC will administer Care.data with software and services from ATOS, which has been awarded a five-year contract worth £8 million pounds.

Interested organisations can obtain small amounts of data free, but a table of charges will be applied to the type of material requested: “Green,” £800-£1,200; “Amber,” pseudonymised data, £900-£1,800; “Red,” personal confidential, £1,700-£2,000.

HSCIC said they would not make a profit selling the data, although some buyers might be profit-making companies. Days after Care.data’s suspension it emerged that 13 years of hospital data, covering 47 million patients, had already been sold to the Society of Actuaries for information used in aiding insurance companies on setting prices for critical illness.

This took place under NHSIC. HSCIC says it broke rules and admits there may have been other such releases of data, but will not say more until “later this year.”

HSCIC told a parliamentary select committee hearing it could not share documentation on these releases because they were committed by NHSIC. As Goldacre noted, HSCIC “is in the same building, doing the same job, with almost identical personnel and all the old records” as NHSIC. The actuaries’ report carries the HSCIC logo and consent.

Public health minister Jane Ellison then told parliament the data released by HSCIC was “publicly available, non-identifiable and in aggregate form.” This, said Goldacre, was “utterly untrue.” The “line-by-line data” contained “every individual hospital episode, for every individual patient, with unique pseudonymous identifiers—which was then aggregated into summary tables by the actuaries.”

That week Tim Kelsey, NHS England director of patient

information, revealed that the technology to pseudonymise data at source for the Care.data programme was not yet ready for use.

The major software companies for GP systems, TPP and Emis, welcomed the delay to Care.data, arguing that pseudonymisation would allay most anxieties.

TPP’s Dr John Parry said the delay gave the NHS “a golden opportunity...to set data export standards...whilst protecting patient confidentiality.” Dr Hasib ur-Rub, of the Emis National User Group, met Kelsey in December to argue for pseudonymisation at source. Most patients, he said, “are fine with anonymised data sitting on a government database, [but] they remain very anxious about identifiable data sitting there when it is not for direct patient care.”

That is not HSCIC’s priority. An NHS England privacy impact assessment in January concluded pseudonymisation at source was impractical. Kelsey insisted bluntly that extraction of GP data would continue in September regardless.

This is in hand, confirming that the delay was not aimed at concerns about anonymity and commercial availability of data. The NHS has been handling hospital episode statistics data safely for 25 years, said Kelsey: if people are unhappy they can opt out.

There is widespread mistrust of Care.data, because circulation of medical and scientific data is tied to a commercial programme. HMRC now want to extend that to financial data.

Workers cannot trust such an organisation to keep medical records confidential. Individuals have the right to opt out of Care.data, but this is no solution. The devastating crisis of the capitalist system means that gains won in decades of struggle, like health care, are being smashed for profiteers. A defence of health care and scientific knowledge can only be conducted on the basis of uniting the working class internationally on a socialist programme.



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