

Comment

‘Care.data’: Bungled opportunity or unjustified intrusion?

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There are many reasons why it would be valuable to link data about care given in general practice with hospital data and analyse them for information and research purposes as in NHS England’s plans for care.data. It would enable tracking of people registered with an NHS GP in England who receive specific types of hospital care to assess the problems for which they subsequently consult GPs, including the monitoring of the side effects of new drugs. Similar systems have been implemented successfully and proved useful elsewhere, including Scotland, Wales, the Nordic countries, Western Australia, and British Columbia. The people concerned in developing systems in these countries have developed statistical techniques for linkage and data security procedures and engaged with the public to explain what they are doing

Why are things so different in England? In other countries systems, like these are usually run as collaborations between universities and health services and other public sector organisations. Care.data is being managed differently in that it is led by NHS England, which has commissioned the work from the Health and Social Care Information Centre, an executive non-departmental public body of the Department of Health. Its failure to establish public confidence and widespread popular fears that the data will be used for commercial purposes may be a consequence of the number of people from the private sector in key roles in these two organisations.

Leading care.data for NHS England is Tim Kelsey, NHS National Director for Patients and Information, a former journalist and co-founder of Dr Foster, a company whose ‘joint venture’ with the former NHS Information Centre has been the subject of a critical enquiry by the parliamentary Public Accounts Committee.¹ Kingsley Manning, founder and managing director of health and information consultancy firm Newchurch, has been appointed Chair of the Health and Social Care Information Centre, and its new Chief Executive, Andy Williams, also came from the private sector.²

What data will be extracted from GPs' records?

To communicate with the public, NHS England published a vague and uninformative leaflet which was disseminated to households via junk mail deliveries, with the inevitable consequence that many were immediately binned along with the pizza advertisements they accompanied. The leaflet proclaimed that 'Better information means better care'³ but very little information was given about what information was going to be uploaded by the Health and Social Care Information Centre from GPs' IT systems or about how it would be used. This led to considerable confusion over what will and will not be seen.

It was not explained that the data to be uploaded and linked is completely different to the clinical information in Summary Care Records, which are shared between individual patients and their doctors. Since then, fuller but still not very detailed information about the data that will be uploaded has been placed on the Health and Social Care Information Centre web site.⁴ Little explanation has been given about how the data will be analysed and used or what information derived from the analyses will be made available publicly. It is also unclear to what extent analyses will be done in the Health and Social Care Information Centre and published in line with the National Statistics Code of Practice and to what extent they will be outsourced to private companies such as Dr Foster and Newchurch, whose clients have to pay for their services.

In fact the aim is to link together records with coded information about health problems diagnosed, prescriptions issued and other categories of care provided by GPs with data about care provided in other places, notably hospitals. None of the free text, which often contains confidential details that people share with GPs, will be uploaded. No names and addresses will be included, but to do the linkage with other data, records will include people's dates of birth, post code and unique NHS number. Once data linkage has been done, identifying information will be removed from records released for analysis.⁵ There is considerable debate about the effectiveness of this process and whether the data from which identifiers have been removed can be linked with data from publicly available sources to identify individuals

Opting out

In response to public concerns about care.data, NHS England's leaflet offered individuals the option of opting out of having their coded general practice data uploaded to care.data and also to opt out of having other records relating to them used for purposes other than clinical care. In doing so, however, it bracketed together research and commercial uses. This means that it is impossible to opt out of commercial use but not to research use. As a consequence if high numbers of people opt out, any data available for research in future will have non-random chunks missing. Given the considerable public support for medical research, this is a lost opportunity.

The NHS England leaflet, described above, fuelled campaigns to promote opt out spearheaded by Medconfidential. Medconfidential is part of the organisation

BigBrotherwatch, founded by Matthew Elliot, founder of the Taxpayers Alliance and named by the Daily Telegraph as one of the Top 50 right wing campaigners.⁶ BigBrotherwatch had successfully campaigned against the introduction of identity cards and to encourage people to opt out of using Summary Care Records. Interestingly, however, from a different political perspective, Keep our NHS Public, an organisation with a generally left of centre agenda claimed that the main purpose of care.data was to calculate premiums for an insurance-based NHS and told its supporters and pensioners groups that opting out would protect them from this. There were a number of press reports which created concern about the ways in which exiting data are released and used.

The ‘pause’

In response to this, NHS England announced a pause in February, delaying the start of uploading of GP records from April to September. It is, however, unclear what it is happening during this pause.

Meanwhile, the opt out campaign continues. A number of articles in the press have fuelled concerns further, with reports that data with personal identifiers have been released to private companies. Some of these reports may be less reliable than others. For example, an article in the Daily Telegraph reporting that ‘The medical records of every NHS hospital patient in the country have been sold for insurance purposes’⁷ turned out to relate to a statistical analysis by a working party of the Institute of Actuaries. There has been similar confusion between the use of data by pharmaceutical companies for research purposes and use by their marketing departments.

Use of data by commercial organisations

The worries may have less to do with privacy per se and more to do with a climate of distrust. In particular, there are concerns that names and addresses will be released to commercial organisations. The government has yet to respond to very real fears about privatisation by answering the key questions about care.data mentioned above.

Particular issues also arise with respect to Commissioning Support Units, organisations which do analyses for Care Commissioning Groups. These organisations have no basis in law and are temporarily hosted by NHS England. Originally it was planned to float these organisations on the stock market. While these plans have been suspended in favour of turning them into social enterprises, staff mutuals, customer controlled social enterprises or joint ventures, It is still intended that they will be in the private sector, although there is a more recent option for Clinical Commissioning Groups to take them back in house.

Other questions about patient records arise irrespective of whether patients opt out of care.data. What is the position of patients registered with practices owned by companies such as Virgin, Serco or The Practice plc? Do these companies use their patients’ records for their commercial purposes even if they opt out of the national system?

Knock on effects – blocking access to existing data

In March, the Health and Social Care Information Centre initially responded to the growing furore by stopping new applications for existing data for analysis. Then, after Kingsley Manning, Chair of the Health and Social Care Information Centre and Max Jones, its Director of Information Services, appeared before the House of Commons Health Committee on April 8 to answer mainly critical questions as part of an inquiry into the handling of NHS patient data, all releases of data were stopped.

These moves were not publicly announced and all enquiries about how long this moratorium would last were ignored. It applied both to private companies and other organisations accessing data. There are two routes to accessing data. Private companies and other organisations can apply for a Commercial data Re-use License to access data for analysis. Public sector organisations can apply to the Confidentiality Advisory Group of the Health Research Authority to analyse confidential data without individual consent under Section 251 of the National Health Service Act 2006.⁹ Applicants have to demonstrate that their purpose is for the public good, that it is impractical to contact the usually large numbers of people concerned, that they have NHS ethics approval and that they have the facilities to hold and process the data securely.

The moratorium has created an impossible situation for anyone applying for data for research, especially where research has been funded on time-limited contracts and applicants have already obtained Section 251 and other approvals. Then on May 9, an emailed letter disclosed, again without a public announcement, that existing data access agreements would be reviewed over the summer, after which new applications would be considered, meaning a wait of many months. This letter was subsequently placed on the HSCIC web site on May 13, removed on May 14 and reinstated on May 15.¹⁰ On the whole, press reports alleging malpractice relate to data released with commercial re-use licenses. While it is important to ensure that these are investigated to ascertain whether or not the allegations of malpractice are true, the approach taken means that analyses which have Health Research Authority approval have to wait until this has been done.

This still leaves many questions unanswered. Will private companies wanting to access the data now have to go through the same extremely rigorous procedures as academic researchers who apply to access data for research purposes? If so, will there be prohibitions on commercial uses and will this be policed and by whom?

Unless the government addresses public concerns by providing satisfactory answers to these questions, England will lose the opportunity to establish care.data as the valuable resource which it could potentially have been. Meanwhile, it has had a damaging impact on our ability to use the data already collected about health care and the blocking of bona fide analysis has wasted an unknown amount of the funding which the research councils and other funders have invested in research using administrative health data. Once again the government's privatisation agenda has wasted public funds.

References

Warning: *The content of some of the web sites referenced here, especially that of the Health and Social Care Information Centre, are subject to frequent changes, so that their content may well have changed since they were accessed to write this article*

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