(Open) Health Care Data

Submitted on 16 May 2014 by Martin Alvarez-Espinar

Health care is a basic service for citizens. Data related to this sector, although very sensitive, can represent many potential opportunities to improve disease prevention and treatment.

The EC's DG Health and Consumers tries to align all national laws on health. One of the objectives of the current EU Health Strategy is "supporting dynamic health system and new technologies", sometimes called electronic health (or eHealth). eHealth strategies should include additional features based on Open Data and PSI reuse.

Heath care data exists in various forms, each of which can provide different reuses and opportunities for society:

- Public spending and public policy on health care
- Performance indicators of individual health care providers
- General, anonymised information on population health statistics (e.g. data on occurrence of certain health conditions differentiated by age, income or location)
- Specific information about individuals (e.g. patient records)

Further economic benefits could come from innovative services, particularly by companies who offer services to health care providers and the public sector. For example, to increase efficiency and effectiveness through process redesign, information management and equipment sales and maintenance.

Open data on **public spending and public policy on health care** will contribute to greater transparency in the same way that other open government data does.

Open data on the **performance of health care providers** will allow funders (either government or private insurance companies) and, ultimately, citizens, to compare the price-performance of the health care providers and encourage providers with lower performance to improve. In areas where patients are given a choice of providers, price and performance data for health care providers would allow patients to take an informed decision on which health care provider to select.

Open data on **health-related statistics** will allow public policy to be tested and improved. For example, cross-referencing health data (e.g. occurrence of certain diseases) with environmental data (e.g. measurement of air quality) and location data (e.g. vicinity of polluting factories) can support land-use and city planning to reduce public health risk. Such cross-referencing could also help to develop specialised health services close to where the highest concentration of patients needing those services are located, and allow pharmaceutical companies and other providers to target health care workers in those areas.

While it may not be a good idea for **information about individuals** to be fully open, it would certainly help efficiency and effectiveness of health care if such data could be shared among health professionals. This would result in health professionals having a better view of the individual history of patients and, for example, could help to avoid the risk of prescribing drugs for which a patient has an allergy.

Patient Records

One of the basic aspects, and perhaps the most sensitive of the health care systems, is patient records. These records are collections of medical information about individual patients or population managed by health institutions, hospitals and other healthcare providers. In general, the transition from traditional paper-based record to electronic health record (EHR) enables efficiency in the management of this information and offers efficient new uses to improve health care systems.

Through the use of such technology, and by using common formats and terminology to define these EHRs, we can achieve **real cross-border safe and secure healthcare services**.

Some initiatives are working on the definition of standard formats. For instance, the epSOS (European Patient Summary Open Services) project has defined a standardised set of protocols and basic medical data that includes the most important clinical facts - the epSOS Patient Summary. This Summary has been already implemented in over 200 medical practice centres and pharmacies across Europe (see the active sites). Although the main goal of this common representation and exchange of information is the interoperability among health institutions and clinicians, **patients should be able to access (and store) their own health records**. This individual access could be useful for citizens when traveling to countries that are not connected to those EHR systems, and also to complement their personal health records (PHR), maintained by patients themselves. Some of the national health systems in Europe already offer their **citizens to download their own medical records**.

The case of Care.Data

For more than 60 years, Britain's health care has been provided by its National Health Service, a tax payer-funded, centralised system that delivers care that is free at the point of delivery. The fact that it is a nationwide, centralised system has an important side effect: the nation's health records are all in the hands of one single organisation. The NHS in England recognises that this data holds enormous potential and so in April 2013 launched a new service, the Health & Social Care Information Centre - a revamp of the previous NHS Information Centre. This new body's flagship programme, Care.Data, was launched in early 2014. The NHS England website describes how:

‘It is important that the NHS can use this information to get a complete picture of what is happening across health and social care, and to plan services according to what works best. The new **system will provide joined-up information about the care received from all of the different parts of the health service**, including hospitals and GP practices’.

This is a laudable aim. Analysing a wealth of data to see what health care services are most effective and what can be done better. It's the kind of thing that excites the open data movement … although the outcome was not so exiting!

The problem came in the execution. Health records in Care.Data are pseudonymised, (not disclosing full names), although they do include your date of birth, full postcode, NHS Number and gender. **This level of detail worries some people for understandable reasons, but another worry is what the data will be used for**. It turns out that the Health & Social Care Information Centre has already ‘shared’ the pseudonymised data with the **insurance industry** –for 'shared', read 'sold.'

Finally, a leaflet that was meant to go to every household in the country providing information about the programme (including details on how to opt out of it) was badly written and was actually only delivered to about half the population (buried no doubt under a pile of fast food flyers). Further problems exist, as highlighted by prominent health care activist Ben Goldacre, all of which amount to a complete loss of trust in the system. What could have been a good news story for the use of a mass data to make a real improvement in a nation's healthcare **became a public relations fiasco**, complete with one tabloid newspaper trumpeting: *NHS delays plan to harvest your details: Victory for the Mail as database is shelved for six months*. Care.Data was never meant to be open data, and won't be when it is re-launched later this year, but when handling data as sensitive as personal health records, **it's particularly important to take people's privacy seriously**–or stand back and see the whole thing backfire.

This blog post has been written by the ePSI Platform Advisory Board members: Makx Dekkers, Phil Archer and Martin Alvarez-Espinar.