As a result of the care.data fiasco in 2014, HSCIC has been through a period of institutional reform, including and especially around its policy of data releases. This process of reform appears to have particularly aggrieved some in the Public Health community who argue that, since the Health and Social Care Act 2012 came into force, they have been unable to receive the same data they may have previously received. The time frames suggest these issues may be interacting.

Writing in the British Medical Journal recently, one Public Health researcher lamented that his institution had been unable to sign the paperwork to allow HSCIC to release data for a project. HSCIC is the custodian of the nation’s medical histories; in making data available for legitimate research, it simply requires you fill in a form honestly. That shouldn’t be too high a bar.

The power to “Require” data

The catastrophe of care.data was in large part precipitated by HSCA 2012 powers that allow NHS England to Direct HSCIC in such a way that it can “require” confidential patient data be provided by a body. While HSCIC has gone through significant reform during this period, Public Health England (PHE) – which has an identical power under HSCA 2012 – has not done so. Were PHE to use its power in the same manner as NHS England attempted, a similar result would occur. Every criticism of NHS England’s approach to the legal basis for care.data could be repeated with PHE.

PHE’s ‘Office of Data Release’

Public Health England’s ‘equivalent’ to HSCIC’s Data Access Request Service and approval body DAAG (now IGARD) appears to be a body at PHE called the “Office for Data Release” (ODR), established by Professor John Newton, PHE’s Chief Knowledge Officer, some time between 2013 and 2014.

While it is published that Chris Carrigan, who founded the National Cancer Intelligence Network (NCIN) which transferred into PHE in April 2013, is responsible for Office for Data Release, ODR’s actual membership is unpublished, and it appears to have no public web presence other than an e-mail address, a form and a guidance document on a page buried within the NCIN website. (ODR is mentioned on the CPRD website, with reference to accessing data from the National Cancer Data Repository, but no further details are given.)

PHE’s failure to achieve accreditation aside, the Information Fair Trader Scheme assessment report on Public Health England from July 2015 paints a somewhat disturbing picture of the current

---

1 BMJ 2015;351:h5087 [http://www.bmj.com/content/351/bmj.h5087](http://www.bmj.com/content/351/bmj.h5087)
3 [https://publichealthmatters.blog.gov.uk/author/chris-carrigan/](https://publichealthmatters.blog.gov.uk/author/chris-carrigan/)
state and status of ODR within PHE, for example:

“Whilst the development and introduction of PHE’s Office for Data Release (ODR) is a positive development and has the potential to be a model of best practice in terms of simplicity in the future, to be worthwhile it needs to be properly resourced and developed as the route for all re-use requests where data is not made available under the OGL. Further work is required to make this transition.” - para 11, p7

“The intention is that ODR will be the route for all PHE data releases in the future, but when interviewing other PHE staff we found some confusion concerning whether the ODR is already operational and some key interviewees were not aware of its function. In fact, ODR has been operating with a limited remit for over 12 months, specifically to clear in the first instance a backlog of requests to access cancer registrations data.” - para 13, pp7-8

Responsibility for licensing re-use, including commercial re-use, is distributed across multiple teams and PHE “Opportunity Assessment Groups”, which neither record nor publish their decisions in a transparent fashion, nor join up properly with ODR (paras 14-16, p8). And ODR decisions appear limited exclusively to cancer data, not other types of data re-use (para 18, p9).

PHE continues to collect data from partner organisations, directly from organisations such as NHS laboratories, NHS acute trusts and primary care, and it commissions other data collections, including surveys. Especially given the fact it is acknowledged that “some re-users request information for non-research purposes, or require information where there is potential that patients could be identified by amalgamating datasets”, PHE must commit to the adequate resourcing and implementation of proper procedures – including transparency and governance – around all data releases.

It is simply unacceptable, both in terms of risk and of public confidence, that PHE’s Office of Data Release at the end of 2015 is in a far worse state than equivalent arrangements at HSCIC at the end of 2013, before the care.data fiasco publicly blew up.

Research use

That some in the Public Health arena feel particularly affected by HSCA 2012, and ‘side effects’ of the care.data fiasco – itself facilitated by HSCA 2012 – is a separate matter from whether HSCIC is now verifying the information provided for all data requests.

medConfidential sees no reason under the current rules that legitimate Public Health researchers should be restricted, should they provide all of the information requested on the HSCIC form.

The public are generally content to allow bona fide researchers to access data for “research” – especially research in the public interest, and Public Health is clearly within that remit. However, the public do expect that researchers follow the rules and procedures, which include filling in HSCIC’s form correctly and completely, and meeting the agreed conditions.

17 December 2015

8 BMJ 2015;351:h5087 http://www.bmj.com/content/351/bmj.h5087/rr-2