

MedConfidential first follow-up submission to the DH Caldicott Consultation:
Data Handling at Public Health England - a cargo cult approach to data release

When HSCIC¹ was discovered to have sold data to insurers, it went through a process of reform.² At the same time, Public Health England was discovered to have sold data to marketers to create a health index for marketing,³ and amongst the distractions of the collapse of care.data, PHE chose to do nothing.

PHE makes claims to transparency - they publish a data release register⁴ as if publication is the only critical step. That data release register would not have included the data that was sold to the marketers. Is that data still being sold? We don't know as PHE's data release register includes only some releases, often those with the most scrutiny, letting problematic projects with reduced scrutiny slip through the cracks.⁵

PHE approaches consent and transparency as a cargo cult activity - going through the motions without an understanding of the processes they aren't following, and possibly have no notion that there is a problem. It falls short of the standards of HSCIC in 2013, let alone 2016.

As the National Archives found:⁶

"we were told that PHE has no Open Data policy and that whilst there is a knowledge strategy, there is no policy to support this and it has not been implemented. We were told that the strategy has not been owned by PHE and is not appropriately resourced and supported and this is a barrier to getting information to potential re-users."

The mission of PHE is improve health and wellbeing, and reduce inequalities. That is impossible to do if PHE silos continue to only care about their own narrow interest. PHE was created to resolve the problems of many public health organisations, now there is one organisation with the yearnings of past silos and continuance of past failure that prevents effectiveness.

The problems are not new, and solutions are available, and those solutions already being applied elsewhere.⁷ A Caldicott Compliant data model has the opportunity to use data to protect and improve the nation's health and wellbeing, and reduce health inequalities.

As we move to a post-care.data Caldicott compliant world, there is the opportunity to resolve multiple issues. What is the ideal data regime for public health?

¹ For simplicity, we use current legal names of entities throughout this document.

² While the status quo is not perfect, there is a recognition on all sides both that progress has been made, and that there is more to do.

³ <http://www.independent.co.uk/life-style/health-and-families/health-news/hospital-records-used-to-target-ads-on-twitter-and-facebook-say-privacy-campaigners-in-latest-nhs-9166633.html>

⁴ <https://www.gov.uk/government/publications/phe-data-release-register-2016-to-2017>

⁵ https://www.whatdotheyknow.com/request/office_of_data_release_omissions

⁶ <http://www.nationalarchives.gov.uk/documents/information-management/phe-ifts-report.pdf>

⁷ Such as in the Accredited Safe Havens work, details of which are published: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2016-03-17/HL7133/>

The problem is Public Health England and a unchanged legacy of failure

“PHE recognises that it needs to do more to improve access to the datasets it collects and manages. Employees at PHE explained that the organisation has been focussed on collecting data and using it internally but capacity for data release to others has been limited and at times unable to meet the growing demand for these improving data collections.”⁸

Public Health England is demonstrably incapable of ensuring the people it is supposed to serve get the data they need, and the public are told they have.

According to the Health Select Committee,⁹ reasons for public health failures to receive data are not down to legal reasons, but the lack of provision for the right environment to handle it:

- *“IGLevel 2 toolkit not in place in our LA”*
- *“PHE have sourced Hospital Episode Statistics (HES) on behalf of Local Authorities from the HSCIC. However, this was done with little consultation with local teams who generally do not have the resources to warehouse and manage the dataset”, “PHE will not provide access to anonymised data at record level,”*
- *“The CSU have advised that only commissioners with Accredited Safe Haven status (ASH stage 1) are able to receive data”¹⁰*
- *“PHE have concerns over the provision of individual level data because of confidentiality. The only personal information that was ever previously provided was age, gender, ethnic group and partial postcode”*
- *Accessing data on suicide “Means completing data sharing framework through HSCIC and a further (different) data sharing agreement which identifies need for N3 or IG Level 2 toolkit”*

The HSCIC is the statutory national safe haven for data, and now has well developed policies for review, release, and audit of data releases. PHE does not have any of those processes. Responsibility for all data release, dissemination, and access control should move to HSCIC as part of a Caldicott Compliant data regime...

Public health analysts accessing suicide data for legitimate purposes is not in of itself problematic. But why is it too much to ask that they follow the data management rules? By the public health teams own admission, they are demonstrably incapable of doing so. This does not have to remain the case. However, it is unlikely that PHE is in a position to change this, and HSCIC should be tasked with providing a consensual, safe, and transparent access regime for data for public health, including the disease registries.

⁸ <http://www.nationalarchives.gov.uk/documents/information-management/phe-ifts-report.pdf>

⁹ Pages 71-75 of Public health post-2013 Second Report of Session 2016-17. House of Commons Health Committee. <http://www.publications.parliament.uk/pa/cm201617/cmselect/cmhealth/140/140.pdf>

¹⁰ ASH stage 1 is a low bar for the safe handling of data.

Consensual

The Caldicott model will apply perfectly well to all the disease registries, sharing data in a way which does not impact direct care,¹¹ for later secondary analysis of sub-populations.

Where Public Health requires non-consented data, those cases can be made, and should be made to Parliament and the public - after all, the examples of the override of dissent are generally those of public health. This principle was in our primary submission, and should not change. The information needed for necessary population denominators, published as Official Statistics, should also have a statutory mandate.

Safe

The reason for data access, for care or for public health, is to use data to keep people safe, as well as using data safely. Against either criteria, PHE have failed dangerously.

Equivalent tools and facilities to those being made available for researchers and commissioners should be available to public health analysts (both at PHE and beyond). In many cases, the divide is a false one, as both groups asking the same questions with only differing intent. Custom statistics should be available at national scale to to both solve local problems, prioritised by the public health communities, and to foster comparisons.

The financial benefits of disease prevention may be even greater than savings possible post-diagnosis, but inter-ALB squabbling and routine assumptions of public health exceptionalism are unhelpful. PHE replicating linkages also done by HSCIC¹² results in duplicated effort and a perpetuation of a flawed and idiosyncratic process. Linkage being done in HSCIC, to the highest of standards needed by public health, would prevent the data needed for identification leaving the safe haven, resulting in safer handling all round.

Transparent

The continual special pleading of Public Health England and related entities should not be dismissed out of hand. They should be able to access the data they need - but they should follow the rules, and be seen to follow the rules, just like everyone else.¹³

PHE should publicly commit to being within the broad Caldicott Consent opt out, with all exceptions being on a clear statutory basis, and avoid actions in private that undermine their public words.

PHE should not be able to have secret committees and processes - they should meet the same standards for transparency and independent governance as HSCIC. In practice, this means using the processes already in place at the statutory safe haven and abolishing the PHE data release function, replaced by one which is consensual, safe and transparent.

¹¹ See submission 2.

¹² NHS numbers are now mandated by the Lefroy Act.

¹³ As one former PHE senior staffer replied, when told the PHE data release register for last year contained 75 entries, "but we release hundreds of datasets"...

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