

# Delivering the promise to patients: opting out of secondary uses doesn't affect your care

This paper is the overview of a set covering how various functions of the NHS can use properly structured aggregated, accurate statistics, replacing the (s251) use of detailed individual level medical records, that are subject to dissent.

In various papers, we cover Risk Stratification<sup>1</sup>, Invoice Reconciliation generally<sup>2</sup>, and A&E Invoice Reconciliation<sup>3</sup> in particular.

## Introduction

Patients who are given the choice of secondary use of their data, primarily under the banner of research, are routinely told that their care will not be affected if they opt out.

While this may be substantively true, research based tools are beginning to use individual level data to offer capabilities to commissioners and GPs that mean that the promise can be broken. The promise to patients that their care will not be affected must be met.

Similarly, as a result of adequate tools and data products for other secondary uses, there has been a tendency to reuse detailed individual level records where a properly designed aggregated dataset would be

MedConfidential has previously introduced papers<sup>4</sup> on the concept and implementation of a safe setting<sup>5</sup>, to meet the needs of bona fide research to access individual level patient records in a safe, consensual and transparent manner. We now update the risk stratification and invoice reconciliation sub-annexes in light of many informative conversations about details.

Those conversations have shown that such an approach is feasible, with no lack of will or imagination on the part of those who would be required to implement parts. However, we have seen no significant leadership from the institutional drivers, beyond the repeated concerns highlighted by IIGOP<sup>6</sup>.

There is an absolute need for GP system suppliers to be involved, facilitating the interface between the models created by research and the application of a particular model to the entire

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<sup>1</sup> this paper was first circulated in January 2015

<sup>2</sup> this paper has been slightly updated since the first version in January 2015

<sup>3</sup> this paper will be published in early September 2015.

<sup>4</sup> <https://medconfidential.org/2014/the-department-of-health-protecting-personal-health-and-care-data/>

<sup>5</sup> formerly described as the Health Research Remote Data Laboratory (HRRDL) now the HSCIC Secure Data Facility.

<sup>6</sup> <https://www.gov.uk/government/publications/iigop-annual-report-2014>

registration list of a particular practice (or, in the case of commissioners, the aggregated counts of people in an area).

We do note that there are existing solutions which avoid need disclosure of identifiable data (e.g. [www.qrisk.org](http://www.qrisk.org)) which are as implemented a software library which can be integrated into clinical systems. However, there is a significant integration and support cost in order to develop those capabilities, and support them on an ongoing basis. This proposal is a lightweight model that supplements, but does not replace, those existing integrations. Heavily used tools, with ongoing support, will benefit greatly from that full integration model; this proposal is to get between a proof of concept, and wider deployment, prior to full integration with multiple providers etc.

We see no reason that data used for commissioning purposes, for invoice reconciliation, or for risk stratification, is exempt from consideration under the principles of safe, consensual and transparent.

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