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Christopher Graham, Information Commissioner  
Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire SK9 5AF

11<sup>th</sup> June 2015

**Re: Patient objections to their data leaving their GP practice for secondary uses**

Dear Information Commissioner,

In our recent complaint regarding patient objections and data leaving HSCIC, we noted that HSCIC does not currently extract data under the care.data programme or receive 9Nu4 objection codes from GP practices, but that there is a patient objection code (9Nu0) listed in NHS England's code definitions, which is given to GP practices<sup>1</sup> as:

*Prevent PCD leaving the GP practice – where a patient objects to PCD leaving the GP practice use the '**Dissent from secondary use of GP patient identifiable data**' code (Read v2: 9Nu0 or CTV3: XaZ89 or SNOMED CT 827241000000103).*

This 9Nu0 opt out - as expressed, and as promoted throughout the care.data fiasco - covers all patient data leaving the practice for secondary uses, irrespective of destination.

It is not an HSCIC-specific objection; for the patient, it is (as many patients have told us they understand it to be) an objection to their information leaving their GP practice for any purpose other than their direct medical care. However, while under the care.data programme no patient data has yet flowed to HSCIC, **there are currently other flows of individual-level data leaving GP practices which should respect 9Nu0.**

If the operation of the codes relating to flows of data from GP systems to HSCIC are to be investigated, we believe these other flows - both to other arm's-length bodies of the Department of Health and to other organisations - from GP practices should be given an equivalent priority.

We are not at this point making a formal complaint on behalf of patients, but can your Office please investigate and confirm that - where it has been added to the patient's record by the data controller - the 9Nu0 objection code for secondary use of GP patient information is being appropriately respected for all existing flows of data out of GP practices, and that the implications of this are properly understood?

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<sup>1</sup> <http://www.england.nhs.uk/wp-content/uploads/2013/08/cd-guide.pdf>

One key area of focus for investigating such flows of individual-level data should probably be the Clinical Practice Research Datalink (CPRD)<sup>2</sup>, QResearch<sup>3</sup>, THIN<sup>4</sup> and TPP ResearchOne<sup>5</sup> - each of which uses systems that are run by the relevant GP providers. While your Office is no doubt already aware of these, and they should all have appropriate DPA compliant measures in place, e.g. fair processing for patients, it is our current understanding that while at least one of those organisations' systems *does* honour patients' recorded 9Nu0 objections, and another claims to do so, at least one other may still be disregarding them.

While these four organisations by no means represent the only other flows of data from GP practices, they are the largest long-standing flows of individual-level data (in some, rare, instances including "free text") and they provide services that are in many respects almost identical in intent to aspects of care.data. If public confidence is to be regained, there can be no "surprises" for patients who believe they have opted out.

We have begun to see the emergence of a number of "care.data-like" projects<sup>6</sup> - most worryingly, ones which conflate direct care with secondary uses - which seek to have other bodies replicate the processes of care.data for their own purposes. In the case of "CareTrak", this is based on an extension of existing work "tackling 'high cost' patients". Can your Office confirm that the data processing of this and any other programmes which 'merge' direct care and secondary uses will honour existing and ongoing patient consent choices - specifically, the 9Nu0 code for GP data?

And for data that such programmes may wish to acquire from hospitals, will they be collecting it from HSCIC - where 9Nu4 can and should be honoured - or will it bypass all of the national consent processes patients are currently being asked to rely on for secondary uses of their data?

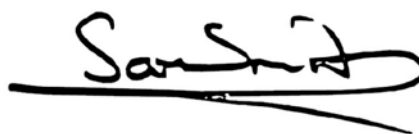
We should emphasise that medConfidential fully supports and believes that better "integrated care" is essential; however, mixing in secondary uses is a recipe for infecting direct care with the same sort of public concerns as we've seen for care.data.

We look forward to hearing the results of your enquiries.

Yours sincerely,



Phil Booth  
medConfidential



Sam Smith  
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<sup>2</sup> <http://cprd.com> - run by the Medicines and Healthcare products Regulatory Authority (MHRA)

<sup>3</sup> <http://www.qresearch.org> - run privately by EMIS and the University of Nottingham

<sup>4</sup> <http://www.thin-uk.net> - run privately by INPS and IMS Health

<sup>5</sup> <http://www.researchone.org> - run privately by TPP in association with Leeds University and Innovate UK, the UK Government's Technology Strategy Board

<sup>6</sup> <http://www.pulsetoday.co.uk/your-practice/practice-topics/it/gp-records-to-be-shared-without-patient-permission-to-tackle-high-cost-patients/20010180.article> - this relates to just one of more than a dozen "pioneer" locations across the country, not all of which propose to operate in the same way, but several of which already propose to mix direct care with secondary use.