

## medConfidential response to NHS England ICP consultation

The goal of the ICP/ACO model is to address longer term questions. Many of the problems that the NHS and DH struggle to address on a two year timescale can much more easily be solved within ten years, especially beyond the core ICP remit.

### Legislation

In the legislation which is already necessary for ICPs to operate, **the National Data Opt-Out should be placed on a statutory footing**. The non-statutory implementation should be complete by March 2020, and a statutory basis should raise the confidence of patients. While this may not be an urgent issue, it should be an explicit commitment, both as to how data will be used within an ICP, and beyond.

### Data flows

Every data flow in and around the NHS should be consensual, safe, and transparent. Patients should be able to see how their data is used. Many of the innovations envisaged in and for the NHS will require patients' data. If the NHS wishes to use data in 'innovative' or potentially risky or controversial ways, the trust that is built from transparency of projects and governance will assist in the successful delivery of such projects. Lack of it will not.

Currently, the most straightforward way for a patient to see how their data has been used is at [TheySoldItAnyway.com](http://TheySoldItAnyway.com). The NHS Login service, due to launch shortly after this consultation closes, should make showing patients how their data is used entirely feasible.

There are many reasons for the NHS to use patients' data and, in the longer term, it should not be afraid of making the case for each of these uses to patients (in the shorter term, it needs to simply create a list of them). In the timescale that the ICPs are considering, it must do both. The question remains whether it does so strategically and with confidence and clarity, or only in response to cockup or catastrophe. Traditionally, it has been the latter.

### ICPs and data (also applies to CCG/STPs etc)

Direct care, and management of the NHS, both require a reliable data infrastructure that satisfies necessary data protection law, the common law duty of confidence, and other obligations on which the NHS must deliver, both as a whole and in each part.

*For direct care*, creating data silos by regions/CCGs/STPs, etc. will eternally lead to problems where those 'inconvenient' patients cross an arbitrary administrative boundary, created by the NHS. For the ICP, that may be at the boundary between it and whatever is the other side of that boundary on a map. Data silos should be avoided, and interoperable systems used to ensure that a clinician with a direct care need can access relevant, timely information.<sup>1</sup> To deliver on such a requirement, patients must have confidence that they can

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<sup>1</sup> <https://medconfidential.org/2018/local-health-and-care-records-exemplary-or-just-more-of-the-same-old/>

see who has accessed what information when, to know that their data has not been accessed inappropriately.

Where a record such as the SCR should have been accessed for direct care purposes, but was not, showing a patient where their record was *not* accessed could offer powerful evidence to increase the take-up and usage of such systems to aid patient care across the NHS, and detect unwarranted variations of care.

*For secondary uses*, over the course of the time periods being considered, NHS England, CSUs, whatever CCGs turn into, and other levels of the NHS will have to resolve the many data issues ignored since NHS England was founded.

Many of the complex questions facing data-using services will be significantly simpler if, over the long time periods being discussed, NHS bodies have a mechanism to routinely and centrally provide information so that patients can reasonably expect that, should they wish to look, they know how their data is used.

A top-down commitment to full transparency and a coherent data infrastructure will allow an informed discussion about how data is used, and how data should be used.

The National Data Opt-out must clearly apply across the entire system, and all secondary uses of NHS data should also be in a register – in addition to being able to be seen by the patients whose data was used.

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Annex: An alternative billing methods for the ICP model which do not rely on a broad s251 approval.