



Our Ref : NIC-33991-N9M6G

12 May 2016

Phil Booth
Sam Smith
medConfidential

by email : coordinator@medconfidential.org

Dear Phil and Sam

Thank you for your letter dated 29th April and, in particular, for your recognition of the hard work that has gone into developing the system for implementing the type 2 objections. As I'm sure you are aware this is, and remains, a high priority for the HSCIC and as an organisation we are continuing to devote considerable resources to ensure that the ICO Undertaking and Direction are implemented in full by mid-October.

You raised a number of specific issues in your letter related to the Direction and Undertaking and these are answered in turn below:

1. Clarifying the position in relation to objections being honoured for any "pseudonymised" or "de-identified" data flow not covered by a stated exception (c, d, or f)?

- Type 2 objections will not be applied to data which is made available in an anonymised form such that individuals are not identified. This includes where the data are aggregate eg counts of information or where it complies with the ICO's Code of Practice (CoP) on Anonymisation as stated in section 1(b)ii of the Direction.
- The CoP recognises a distinction between providing anonymised data to the public at large and providing anonymised data for limited access and chapter 7 describes a set of 12 key safeguards to be considered when releasing data for limited access. Replacing direct identifiers with pseudonyms and/or de-identification are not in themselves sufficient to meet the ICO's CoP.
- HSCIC policy position is that type 2 objections do not apply where direct identifiers in the data sets have been removed or replaced with pseudonyms; and the data dissemination application has been taken through the end to end Data Access Request Service (DARS), which includes the request being considered by the Data Access Advisory Group (DAAG), or in the future the Independent Group Advising on the Release of Data (IGARD). In such cases the Data Sharing Framework Contract (DSFC) in combination with the Data Sharing Agreement (DSA) set out terms and conditions which go above and beyond the 12 safeguards set out in the ICO code of practice.

2. What steps is HSCIC taking to implement point 2 of the Direction on further analysis of the impact of type 2 objections, and whether the members of the former care.data advisory group have all been asked to participate in that work?

- HSCIC has published CCG level data on the rates of type 2 objections and intends to publish rates of type 2 objections at GP practice level from 17 May 2016.
- We will also be producing analyses of the impact of objections on individual datasets to assist customers of our data access services, subject to their priorities and HSCIC resource availability. The first one has been [published](#) on the DARS webpages and covers Hospital Episode Statistics (HES). It looks at the impact on aggregate totals of HES key fields before and after type 2 objections have been applied, including age bands, gender, broad ethnicity groups, procedure and diagnosis groups. We will continue to work with our data customers to identify what further analyses may be useful.
- The Direction is aimed at HSCIC, so the team responsible for the implementation of type 2 objections will liaise with any and all programmes prior to them going live with any data disseminations. This, of course, will include care.data.

3. National Cancer Registration Service is using a PIAG approval from 2001. What steps are all bodies involved taking to upgrade the Information Governance standards to those which will be in place after the Caldicott Review?

- HSCIC will fully conform to the agreed policy position following the publication of the Caldicott Review and the government response to it. HSCIC is not in a position to speak for other bodies.
- HSCIC regularly reviews the standards applicants are expected to meet, in line with developments in mandated standards and best practice such as the Information Governance Toolkit.
- The Confidentiality Advisory Group (CAG) provides independent advice on the uses of confidential patient information for purposes beyond direct patient care including maintaining a public register of all approved applications and undertaking annual reviews of these applications. The National Cancer Registration Service approval made under the predecessor body PIAG remains extant and continues to be reviewed by CAG as appropriate.

4. Regarding the decommissioning of the old "accredited safe havens" in DSCROs, what is the timescale for migrating those to the central IT system? Will that be complete by 14 October 2016? It would appear that the only policy statement made following the 2014 consultation is an answer to a Parliamentary Question.

- DSCROs are not operating as accredited safe havens but rather are operating as a part of HSCIC. As such disseminations from DSCROs must comply with the requirement to respect type 2 objections by 14 October 2016. This will be done either by upholding type 2 objections or by disseminating data which is deemed to be "out of scope" eg anonymised in line with the ICO Code of Practice.

- Compliance with the ICO's Anonymisation Code of Practice will be an important step towards reducing the levels of identifiable data in use by commissioners and is the cornerstone of the proposed future state. During 2017 the proposed Data Services Platform is planned to progressively replace the data processing work that is currently undertaken in DSCROs.

5. ICO undertaking subclause (5) on the follow up work planned with data customers inc how many such contracts currently exist, whether those organisations have been contacted yet? Will confirmation that they no longer disseminate data further be included in the next Data Release Register?

- Following the recent communication announcing type 2 implementation to data customers we are planning a range of more targeted and detailed communications including those to meet the specific requirements of the ICO undertaking subclauses 4, 5 and 6. We are currently developing communications material that will provide customers with the specific information and instructions they need as well as confirming the data recipients covering the period in question to establish who we will be writing out to. These steps will be completed within the 3 month period agreed with the ICO.

6. Given various parts of this Direction require ongoing implementation, what plans to HSCIC have for keeping the public and stakeholders informed on progress?

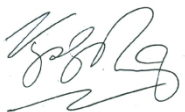
- We are continuing to work with our stakeholders, the public and customers as part of our on-going implementation work including continuing dialogue with the ICO.
- We have provided a range of information on our webpages for the public and our data customers but recognise that this is a first step and will continue to develop this material as well as providing information, as appropriate, through other routes eg via NHS Choices and webinars/face to face meetings with research and business intelligence customers.
- We will also be consulting with the Joint GP IT committee about the best ways to support and work with GPs to publicise type 2 implementation as we see this as an important way to route communications to patients.
- We would like to work with medConfidential to help us to get some of these messages out to members of the public who have been affected and would welcome a further dialogue with you about this.

Thank you also for highlighting your wider concerns in relation to public trust and, in particular, around a safe and secure login system for the public to access digital health services. HSCIC fully recognises the importance of delivering a safe, secure system and we fully concur with the view that in developing any secure login service for the NHS we need to build on existing clinical practices around identity verification and safeguarding of access to patient information. The 'citizen identity project' is currently at an early, concept stage but we fully recognise the importance of ensuring any secure login solution is developed 'hand-in-hand' with the clinical community. To strengthen clinical involvement for this project

HSCIC is actively recruiting a suitably experienced clinical lead. In parallel HSCIC is reviewing the governance arrangements to ensure there is appropriate clinical representation whilst strengthening the links with the Patient Online programme. I understand our clinical lead has set up a meeting with the medConfidential team to explore how we can work together on this project and share our plans for engaging the clinical and health and care community.

In terms of public trust as set out in our strategy the public need to have confidence that their personal data is being handled safely and securely, and we recognise there is public concern about this. We are working with government and other stakeholders to prepare for a national opt-out in line with the recommendations from the NDG review which are due to be published shortly. Public trust and security is also a shared priority across the wider health and care system as set out in the National Information Board work programme going forwards. We will continue to work closely with our partners to play our part in this important agenda.

Yours sincerely



Kingsley Manning
Chair