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Dear Kingsley and Noel,

Firstly, congratulations to everyone at HSCIC for all the work necessary to be able to implement the Direction to process type 2 objections. That the clarification questions below are so specific and short shows the breadth of effort in the run up to January to get a comprehensive patient dissent system in place, since work began at HSCIC very late in 2014.

We also welcome the appointment of Noel Gordon as the new chair of HSCIC, alongside his existing position on the board of NHS England. We hope that this appointment will represent a continuance of the progress at HSCIC since the Partridge Review in mid-2014. We also hope that this will encourage similar progress to begin at NHS England, so that there are coherent incentives to give Information Governance due regard, in a manner which NHS England arguably entirely failed to do for care.data.

On that point, with the implementation of the type-2s seemingly substantially complete, our highest national concern is now the "citizen identity" project at NHS England and HSCIC. It risks a style and scale of awareness and perception as care.data, should there continue to be no integrated and specific clinical leadership grounded in the highest standards of Information Governance.

For delivering "NHS Digital", a safe, secure login system is absolutely necessary, and any national scale failures of the type currently likely, will have a significant negative impact on the uptake of digital services, likely for years. If digital services are to become a tentpole of future NHS care, the primary login infrastructure should be build around existing clinically based practices, not as a "tech project" which treats patients and clinicians as a risk to whose behaviour must be managed.

HSCIC has been forced down that path once by NHS England. Hopefully the lessons will be learnt by both organisations.

The Undertaking and the Direction

We have specific questions on particular parts of the Direction:

1. Reflecting previous statements about individual level data, and recognising that the Direction uses specific legal terms, can you please confirm that the type 2 objection, as implemented, covers all individual level data flows leaving the HSCIC for purposes beyond direct care (except in the cases listed in paragraphs c, d, or f)?
 - a. To be specific, is that objection honoured for any “pseudonymised” or “de-identified” data flow not covered by a stated exception (c, d, or f)?
2. What steps is HSCIC taking to implement point 2 of the Direction, and whether the members of the former care.data advisory group have all been asked to participate in that work?
3. We note that the 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?
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.¹
5. Regarding subclause (5) of the undertaking:

“HSCIC should contact recipients of data sets it provided in the period January 2014 – April 2016 (which included patient data where Type 2 objections can be processed and upheld in accordance with the Direction) and where the agreement allowed the recipient to onwardly disseminate the data, to make them aware that this data should no longer be disseminated further. HSCIC should do this within three months.”

Can you confirm how many such contracts currently exist, whether those organizations have been sent that instruction? Will confirmation that they no longer disseminate data further be included in the next Data Release Register?

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

The current position is a dramatic improvement over the situation prior to the Direction - promises to patients are now being kept. However, it remains the case that promises are not being seen to be kept.

¹ <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2016-03-17/HL7133/>

Over time, as with the “citizen identity” project and care.data, lessons are easily forgotten by those with ideas and a narrow incentive to push a flawed objective or design.

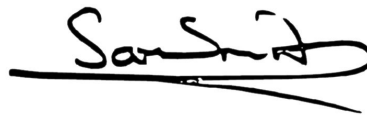
Rebuilding trust, in an environment where it is easily damaged, requires patient knowledge of how data about them has been used, and in a “single NHS login” world, how that login has been used and where.

The appointment of an overlap between HSCIC and NHS England boards is very welcome. While the necessary culture change at NHS England is beyond the ability of a single individual to deliver, it is, nevertheless, a step forwards, that can have real benefits in practice.

Yours sincerely,

A handwritten signature in black ink that reads "Phil Booth". The letters are cursive and somewhat stylized.

Phil Booth

A handwritten signature in black ink that reads "Sam Smith". The signature is written in a cursive style with a long horizontal line underneath.

Sam Smith

Cc Andy Williams, Martin Severs, James Hawkins.