

medConfidential initial response to the UKSA consultation on the Code of Practice on Statistics

Transparency to and for data subjects is missing from this Code, just as it is missing from Part 5 of the Digital Economy Act.

In the long term, confidence in statistics is impossible in a hostile environment if there is not transparency to citizens on how data is copied and why. UKSA has deep public trust - it should build on that, rather than assuming it will always remain. Should there be a “care.data for Government” or a “[data controller in Chief](#)”, it will be too late to fix it.

The first thing that a school child today likely hears about a “census” are the issues around with the school census - which may affect them or their classmates in highly adverse ways. Any explanation that “The Census” is “different” will fall on deaf ears - trust will have been lost, and no one will be listening.

As such, we offer some comments around transparency and trust:

1. Principle T4: The phrase “, and seen to be met” should be added

While, for UKSA/ONS, it is a tautology that you will demonstrate the confidence in statistics, it is necessary at the very highest levels for other organisations to make the same commitment, even when they lack the institutional culture of ONS/UKSA.

As a result, Figure 1 should also include an overarching bar of “transparency”, that all of the process integrity measures covered there should be seen to work, rather than being trusted to work with little evidence provided.

2. Page 6, Part 1: while the pillars are aspirational, for public confidence, it is necessary to demonstrate how those aspirations are being met or otherwise.
3. Page 11: defining T4, “organisations” and “businesses” are used inconsistently.
4. Page 11, Add as T4 (7):

(7) It is to be expected that the individuals, organisations, and businesses who provide data (digitally) to any part of Government, where it is reused for research and statistics, should be able to see the benefits and outputs of their contributions, in the same context as they provide the original data.¹

This also allows V1-3 & 5 to be delivered, and be seen to be delivered, by those whose data is used to guarantee them.

¹ <http://www.infiniteideasmachine.com/2017/04/what-does-a-citizens-view-of-government-look-like/>

5. Given the focus in the Code on process integrity around pre-release access, it should be an expectation that in the the next revision of the Code (after 2.0) will add additional process integrity via accountability to all those who can access population scale datasets, and that safe settings will be widespread or mandatory.

It is unlikely that this will appear in the code, but in the discussions around it.

We are happy to discuss details on this further as convenient, and as issues evolve over the period of the consultation - and as such, we may submit supplementary responses to this consultation.

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July 2017

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About medConfidential

medConfidential is an independent non-partisan organisation campaigning for confidentiality and consent in health and social care, which seeks to ensure that every flow of data into, across and out of the NHS and care system is *consensual, safe, and transparent*.

Founded in January 2013, medConfidential works with patients and medics, service users and care professionals; draws advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy; and believes there need be no conflict between good research, good ethics and good medical care.