

medConfidential note to the UKSA statistics assembly

Question 2: Areas of interest:

Code of Practice; communications and engagement; linkage/integration

Q3+6¹: Statistical Priorities, User Needs and Trustworthiness

Sir Ian Diamond, National Statistician in 2021 said:²

“There’s no god given right for us to have data. There needs to be a really sound public good reason for collecting data, and using data, and people need to feel absolutely comfortable that their data are being used properly and kept securely and in a way that satisfies all forms of privacy”

Does the Assembly agree with the National Statistician’s statement? Does ONS deliver to the standards the Assembly expects?

Assuming the National Statistician does not disavow his own words, *where can an interested citizen go to know “that their data are being used properly and kept securely”*? Does that source cover all ONS TREs? Or is an unevidenced and uninformed “feel” the only criteria for data uses?

The framing of “User needs”³ will always demand more data, faster, more linkages, more details, less public choice, and more risk from the public whose views are not taken into account by those who want ever more. Who provides the balance long after the assembly ends?

One can read a variety of promises about the operation of the Integrated Data Service on the [ONS website](#),⁴ but very little information about what is done with the data. The most complete information is provided for academic projects in the [former-Secure Research Service](#), and nothing is published about what Government staff do with IDS held data. Every project in the IDS should be in a public list, just as every [academic project](#) is required to be.

¹ Question 3: Why do you think these are important topics to discuss? &

Question 6: Statistical priorities and public and user needs, including data gaps

² Sir Ian Diamond speaking at the Institute for Government <https://www.youtube.com/watch?v=tz9NihCTzqA&t=2373s> .

³ Especially without the removed asterisk.

⁴ This problem covers the entire statistical system, not just ONS/UKSA. Academic projects under the Digital Economy Act are covered, NHS England’s Advisory Group on Data publishes minutes and has a data uses register, some ONS owned projects re published as a result, but the pinpricks of transparency are amongst chasms of darkness and opacity – we don’t know what we don’t know.

Does the Assembly agree with this Recommendation from Parliament:

The Public Administration & Constitutional Affairs Committee's [report on Transforming the UK's Evidence Base](#) says, on page 35:

101. Although statisticians and researchers publish a wealth of information on which data sources they hold, and how they are used, very little information is made available about how personal data are being used for the purposes of government analysis.

102. We recommend that the analysis function explore options for improving transparency around the use of personal data in official analyses, and that this work be made publicly available.

In short, does the Assembly think views of data should be what people “feel” or what they can “know”?

“Know” vs “feel”

Abdicating governance and giving out data purely because someone is seen as “trustworthy” today is a rapid route to them becoming the scandal of tomorrow.

Simply saying “public good” over and over is insufficient – it is the actions of [HDRUK \(and their sockpuppets⁵\)](#) and the [disgraced biobank](#) with whom they share a culture. Does the Assembly have any view on whether this software should be allowed into the “national data library”?

Ian Diamond’s “good chaps” theory of data access

If someone says they’re doing good, perhaps it should be checked, even if they work for a government department. There must be a balance of proportionality and privacy, expressed as “trustworthiness” and “value” in the OSR framework. Of course, something could claim to be “trustworthy”, “quality”, “value” and utterly toxic. A 2018 project wanted some cancer patient data to look at “causes of cancer”, which seemed fine until it became public that it was being [done by a tobacco company](#). The claim that something “[didn’t breach the rules](#)” may simply suggest the rules were insufficient.

⁵ The sockpuppet organisations of HDRUK are designed to offer a pretence of public support via logos from other brands with staffers paid to attend meetings who all have line management reporting up to the HDR CEO, with minimal or no disclosure. The data research world has imitated the model of 55 Tufton Street.

Public acceptability: Surveys and Admin Data are not similar

The public can choose to reply to a survey, they can choose to refuse to answer particular questions, or in an expression of British politeness, simply lie in answers to questions they do not wish to answer honestly. The 2001 census reported many “jedi” and no statisticians were harmed by the answers, at most a few may have been temporarily inconvenienced by the press coverage.

In a census of admin data, if you give incorrect answers to DWP or the Home Office, they remove your ability to buy food, or deport you from the country. ONS treating admin data as akin to a survey is untenable over time, even without the text of the [HDR Review](#) being public.

Policy based evidence making

Officials like to see a fictional distinction between the policy functions of a department and the delivery functions. This is entirely a convenient fiction for civil service hierarchies to believe that their decisions do not change people’s lives for the worse. It is not seen by anyone outside Government. It is unsustainable to tell the public that ONS powers and data are not used to make decisions about your individual service/ benefits because it is only used to inform decisions about what your individual service/benefits are.

One government of the day can not constrain the next, so it is impossible for certain promises or restrictions to be kept over the long term. The previous government made promises to the public and NHS about how data collected during the pandemic would be used; [the new government tore the promises up and kept the data](#).

A Data Preference Service, because [data mining is the new junk calls](#)⁶

Should ONS force a citizen to have their data included for purposes that they find objectionable? If a person would refuse to answer the question in person, should ONS be able to collect the data anyway by ignoring their wishes? Should those who wish to share data with Government be required to disclose and offer opt outs? Will the burden be entirely placed upon the citizen to notify every service they engage with?

The desire to move to an administrative census will be dependent upon public support and compliance with the parts that can never be administrative.

In the [context of government services evolving](#), ONS may need more and more bullying and force to get ever less data.⁷

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⁶ <https://medconfidential.org/wp-content/uploads/2024/08/Data-preference-service.pdf>

⁷ Similarly, HDRUK relying on sock puppets and focus groups as the evidence base is no better than relying on twitter polls. The focus groups upon which NHS England cite when advocating for Palantir was merely [10 people](#).

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.