

## medConfidential note to the Inclusive Data Taskforce

Work elsewhere on this topic shows it is possible to collect data on inclusivity and/or equalities safely, without raising privacy or abuse concerns. That having been said, it is also entirely possible to undermine the *entire* equalities agenda if such collection is done badly.

We hope the Taskforce chooses wisely, and medConfidential is happy to offer any contributions that may assist in that success. We recently published a worked example as part of other work on the topic of COVID-19 and Universal Credit,<sup>1</sup> but two main points arise.<sup>2</sup>

### 1. Confidence in the system today

When data on inclusion is collected, there must be absolute confidence on the part of those volunteering their data to the system. As with other data collection exercises, collection should be voluntary. As it is voluntary, if the collection does not have public confidence, then people will simply skip the question – or give the ‘safe’ answer, rather than the true one. If there is not widespread public confidence, the taskforce will have failed both in and of itself, and also in undermining other systems which do command public confidence and respect.

A necessary condition to ensure confidence is that the questions asked on inclusivity are well defined – Equality Act protected characteristics being the most obvious ones, but possibly also including socio-economic equality as part of ‘levelling up’.

Standard, explicit (and brief!) assurances must be given prior to collection as to how all inclusivity data will be collected and used, any breach of which would constitute a breach of the Data Protection Act for what is special category personal data. Such breaches are something the ICO takes seriously.

### 2. Confidence in the system tomorrow – Transparency

Whenever data is collected, there must be absolute transparency about all of the projects using it and the outputs of those projects – this inclusion data is collected to be used, and everyone should be able to see how it is used. Transparency will also aid in highlighting analyses that may have been more akin to ‘policy-based evidence-making’.

For public bodies, and largely for private bodies operating digital services, the simplest way to ensure that data is used in line with expectations is that *it should not be collected by the primary data controller for the service*, but rather by a separate service which is integrated into the user’s journey throughout the service. That integrated but separate service should be attached via exceptionally clear and strong legal contracts and stated behaviours.<sup>3</sup>

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<sup>1</sup> <https://medconfidential.org/2020/universal-credit/>, specifically Annex 4H.

<sup>2</sup> <https://medconfidential.org/wp-content/uploads/2021/03/4H-UC-and-effects.pdf>

<sup>3</sup> We rehearse this approach here: [https://docs.google.com/document/d/1iVo1xdZ\\_HiFxbFPjekJe\\_TrbCRjqxVVkrawO9tQUWyM/view](https://docs.google.com/document/d/1iVo1xdZ_HiFxbFPjekJe_TrbCRjqxVVkrawO9tQUWyM/view)