Data Dissemination and Anonymisation in 2016

While there are many "definitions" of anonymisation that have been used for many years, 2016 has seen two points of legal clarity against which they should be compared. Both of these fundamentally undermine the assertion that pseudonymised HES is anonymised.

1. GDPR

The forthcoming General Data Protection Regulation states:1

"The principles of data protection should apply to any information concerning an identified or identifiable natural person. Personal data which have undergone pseudonymisation, which could be attributed to a natural person by the use of additional information should be considered to be information on an identifiable natural person.

2. Clarity on the Anonymisation Code of Practice

The new book from the UK Anonymisation Network, The Anonymisation Decision making Framework says quite clearly on page 16² (emphasis added):

"Anonymisation – refers to a process of ensuring that the risk of somebody being identified in the data is negligible. This invariably involves doing more than simply de-identifying the data, and often requires that data be further altered or masked in some way in order to prevent statistical linkage.

We can highlight further **the difference between anonymisation and de-identification (including pseudonymisation)** by considering how re-identification might occur:

- 1. Directly from those data.
- Indirectly from those data and other information which is in the possession, or is likely to come into the possession, of someone who has access to the data.28

The process of de-identification addresses no more than the first, i.e. the risk of identification arising directly from data. The process of anonymisation, on the other hand, should address both 1 and 2. Thus the purpose of anonymisation is to make re-identification difficult both directly and indirectly. In de-identification — because one is only removing direct identifiers — the process is unlikely to affect the risk of indirect re-identification from data in combination with other data."

It is for both these reasons, amongst others, that the new opt out must cover all patient level datasets.

¹ Para 26 http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016R0679&from=EN

² http://ukanon.net/wp-content/uploads/2015/05/The-Anonymisation-Decision-making-Framework.pdf