GDPR consultation submission from medConfidential

medConfidential supports the submissions from Privacy International, Open Rights Group, and Genewatch. We add additional comments here around administrative data, exemplified by medical records.

As regards health data and medical records, and sensitive personal data more generally, there need be no conflict between good research, good ethics and good medical care, all facilitated by a strong data protection regime that protects.

Existing GDPR language, without excessive derogations, already allows for *bona fide* research using health data. The language was written such that legitimate and public interest research can be conducted. Organisations that cannot meet the current ethical standards may seek extra derogations, beyond those advocated by organisations such as the Wellcome Trust. Excessive derogations that will cause a loss of public confidence in the regime will cost the overall UK economy more than any loophole could create.

care.data was legal - and still collapsed in public acrimony. The more the loopholes, the more likely that fraudsters and charlatans[1] will again try and acquire their short-term gain at the wider expense of trust in the regulations.

From conversations with others in the medical world, medConfidential does not expect any roll back under GDPR of existing DPA rules or a plain reading of GDPR.

Transparency

Around Article 9, transparency, and the commentary that accompanies HMG's future discussions of GDPR in HMG and NHS environments, should make plain that it is an expectation that individuals understand how their records have been used.

GDPR will cover all aspects of UK information processing - we cannot know what industry you are in, the details of your local hospital, how it performs, or how it uses medical records today, let alone in a decade's time. However, what we do know is that how it uses medical records in 100 months' time will be very similar to how it uses medical records in 98 months' time. Things will evolve; change is compounded upon change – and if citizens receive information on how data about them was used yesterday, they will be in a good position to make informed decisions about tomorrow.[2]

GDPR is vital to that process, which is the digital transformation of any and every service for as long as GDPR remains the law.

medConfidential
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[1] https://medconfidential.org/2015/pharmacy2u-did-not-keep-a-record-of-whose-data-they-sold/
[2] NHS GPs already do https://medconfidential.org/for-patients/your-records/

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.