

Proposed amendment to prohibit marketing to patients using individual-level data from HSCIC¹

Marketing to patients using data collected by or in any part of the NHS is highly controversial. Patients and the public do not expect this to happen, and can be extremely distressed when it does so unexpectedly – especially where a diagnosis has been given, but the patient has not yet shared it with all in their household.

While it can be difficult to track down the precise source of such ‘data leakage’, the recent case of Pharmacy2U – which exploited its association with NHS prescription fulfilment to ‘opt patients into’ marketing based on obscure and misleading terms and conditions – has prompted wider investigation of the e-prescriptions system by the Information Commissioner’s Office. That investigation is ongoing; action on the Pharmacy2U incident itself is expected shortly.

Unscrupulous data brokers acquire data from wherever they can, including the purchase of charity donor lists, and use them for their own gain. The charitable sector must get its own house in order, but the Government can take a lead with an explicit, statutory ban on any individual-level data that leaves the HSCIC being used for any marketing purpose.

The principle: No individual-level patient data released by HSCIC should be used for marketing purposes.

Legitimate marketing simply doesn’t need this data. If an individual patient wishes to be marketed to, then that is between the patient and the relevant company or organisation with which they already have a relationship; this does not, and should not, involve or relate to HSCIC.

Proposed Language:

2 (4) (c) A condition under paragraph (b) must prohibit the use of marketing to patients.

or

2 (3) (c) shall prohibit the purpose of marketing to patients.

N.B. The above clauses relate to the 18 September draft of the Bill sent by email. In the earlier published 9 September draft, subsection (4) above is numbered (5).

The prohibition applies only to data that is disseminated by HSCIC under contract. Data published by HSCIC for all to use (“open data”) is not subject to a data sharing contract, so the provision would not apply.

¹ The limitation to data from HSCIC is due to the scope of the Bill. We are aware this would not be a comprehensive ‘ban’ but it would represent a significant, coherent and necessary step towards improvement.

The alternative for legitimate marketers

Data published openly by HSCIC as statistics is aggregated into tabulations, i.e. standard analyses which can be reused by anyone, for any purpose, and are generally produced for small geographies where there is identified demand.

Experian and similar companies routinely use such data from the Census in such a manner, where 'raw' or individual-level population data is simply not available. ONS runs a process to identify the tables for which there is demand, and proactively publishes those tables. ONS can be commissioned to publish tables that haven't previously been produced, and the production of new, non-disclosive tables mean they will be assessed for automatic inclusion in future publications.

Figures on propensity to particular conditions, comorbidities or outcomes should be published for standardised geographies, subject to disclosure control on small numbers. Properly constructed, those figures would represent the entire population, and not just the population who have not opted-out.

In short, there is no need for individual-level data to be used for marketing purposes and, given significant concern and the ongoing corrosive effects on public trust and confidence of various types of commercial re-use, HSCIC should be legally prohibited from releasing patient-level data for marketing purposes.

medConfidential
2 October 2015