Royal College of General Practitioners

RCGP Parliamentary Briefing – Care.data

March 2014

Overview

The RCGP believes that, if implemented correctly, care.data has the potential to deliver enormous benefits to patients by helping the NHS to improve the quality of care it delivers and to better prepare for outbreaks of infectious disease. However, we are concerned that many people remain uncertain about the safeguards that will apply. The public's trust in the way in which the NHS treats their personal data cannot be overvalued and it is paramount that we do everything possible to protect and uphold it.

We welcomed NHS England's recent decision to delay the implementation of the scheme by six months. However, it is vital that NHS England uses this time effectively. The RCGP has recently written to NHS England setting out six key demands which we believe must be addressed before care.data can go ahead.

We are urging MPs to constructively challenge the Government to ensure that NHS England implements the RCGP's six demands and does more to inform and reassure the public about how their data will be used.

RCGP is calling for:

1. **Clarification of the purposes for which "amber" (pseudonymised but potentially identifiable data) can be disclosed**, with particular assurance that organisations outside the NHS will not be permitted to use such data for commercial purposes. *The Government has been quoted by the media (The Times) as stating that new legislation to be included in the Care Bill will "put beyond any doubt that the HSCIC (Health and Social Care Information Centre) cannot release identifiable or potentially identifiable patient data for commercial, insurance or other **purely** commercial purposes". Instead, we understand that data will only be released where there is a clear health benefit and peoples' privacy is assured. We welcome this but would urge MPs to press the Government to clarify what is intended by "**purely**" commercial purposes, and whether this will mean that data could be released if it has both potential health benefits and commercial application.*

2. **Confirmation that any information disclosed by the Health and Social Care Information Centre (HSCIC) to third parties will not be sold for profit**, but instead be charged for on a cost-recovery basis only.

3. **Confirmation of who will take decisions on the disclosure of identifiable and potentially identifiable data**, and the robust controls that will be put in place to manage its use. *The Government has assured RCGP that new legislation included in the Care Bill will place on a statutory footing an expert advisory committee with strict new criteria on releasing identifiable or potentially identifiable patient data. We understand* an *independent assessment of the ethical basis for any request will be required before any application can be considered. Again, we welcome this and would urge MPs to ensure this takes place.*

Moreover, **it is vital that the NHS England significantly boosts its efforts to communicate the scheme to the public** by taking measures such as:

4. **National TV, radio and online adverts** highlighting the need for people to decide whether they wish to opt out.

5. **A personalised letter to everyone whose records could potentially be uploaded onto the care.data system**, to supplement the leaflet which is already being distributed to each household.

6. **Further work to ensure that information is accessible to those with physical and or learning disabilities**, and that appropriate support is available to enable them to make an informed choice.

Detailed plans have yet to be spelt out (as of 1 March 2014) regarding the measures to be taken to boost the public communication of the scheme and the safeguards in place for patients. RCGP would urge MPs to press the Government to ensure NHS England acts on the demands above to ensure effective measures are in place.

The RCGP supports the principle that care.data should work on the basis that patients are able to 'opt out' of the scheme – providing the concerns outlined above are addressed so that patients can make an informed decision. The alternative – that patients have to 'opt in' for their data to be included – would be unworkable, because it would be highly unlikely to cover enough data from which to draw reliable conclusions about the health needs of our patient populations.

We are therefore urging MPs to support the principle behind the care.data scheme and its potential to deliver benefits for patients, on the condition that patients are given absolute assurance about how and by whom their data will be used and that they are made aware of their right to opt out.

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