

4W25 Quarry House
Quarry Hill
Leeds
LS7 2UE
tim.kelsey@nhs.net
0113 825 0674

14th April 2014

Area Team Reference number 01515
ROCR approval applied for

Dear colleague,

Better information means better care – Care.Data

Care.data is an initiative to ensure more joined-up data is made available to clinicians, commissioners, researchers, charities and patients to improve the quality, safety and effectiveness of local care services.

In February, it was announced there would be a six month extension to the start of collections which, in the first place, will link data from hospitals with general practice. We are using this period to listen and act on the views of patients, the public, GPs and stakeholders, and to explain the benefits and risks involved.

One of our first steps has been to establish an independent care.data advisory group. This group is chaired by Ciaran Devane, who is Chief Executive of Macmillan Cancer Support and is one of NHS England's non-executive directors. You can find out more about this group on the NHS England website [here](#).

We have heard common themes emerging over the last number of weeks and as a result, we have been discussing with the BMA, Healthwatch, Royal College of General Practitioners and the independent advisory group, a proposal for a phased roll out of the GP data extraction process to begin in the autumn. This will involve a cohort of between 100 and 500 GP practices to trial, test, evaluate and refine the collection process ahead of a national roll out.

In addition, steps have already been taken in making changes to the law. This will increase the protection of confidentiality and ensure there is greater transparency around the release of data by the Health and Social Care Information Centre (HSCIC). This work is continuing and we will update you on these changes separately. Over the coming months, the HSCIC will work to provide assurances over the safety of data collected, stored and shared, including the option of accessing data from a controlled environment, sometimes referred to as a 'data-lab' or 'fume-cupboard', for use by organisations requesting data.

We need to do more to ensure that patients and the public have a clear understanding of the care.data programme and will continue this over the coming weeks and months. In particular, we have been asked to provide greater assurance on issues such as: patients' right to object to their identifiable data being shared; protecting privacy; the

burden on GPs; and the controls around data. We will work with stakeholders to produce support materials, such as an optional template letter for patients and ways of making opting-out more straightforward.

We want to hear your views and suggestions so we can take action to improve and build confidence in the care.data programme. We will also be engaging with patient groups, GPs and other stakeholders through local and regional engagement events.

This letter is the first of what will be regular updates so please do let us know if there are any topics you would like us to cover. In addition, we would welcome your individual comments or representations about issues related to the care.data programme. Please email us at england.cdo@nhs.net. We will ensure that all comments and feedback are noted and considered as part of this process of listening.

Kind Regards

A handwritten signature in black ink, appearing to read 'TK', with a long horizontal stroke extending to the right.

Tim Kelsey
National Director for Patients and Information
NHS England

On twitter: @tkelsey1

Executive Assistant: Louise Wain | l.wain@nhs.net | T: 0113 82 50674