

CARE.DATA PROGRAMME

The government will spend £1m sending a patient information leaflet about the controversial care.data programme to every household in England.

As part of a joint £2m public awareness campaign being run by NHS England and the Health and Social Care Information Centre, 22m homes will receive the leaflet in January and extractions will begin in spring next year.

The total cost includes around £800,000 in funding for a helpline to answer people's questions about the scheme, to help take the pressure off GP practices.

The A5 leaflet will not be addressed to anybody in the household, but will clearly indicate that it is from the NHS and explain how people can opt-out of their data being extracted.

Patients will have a minimum of four weeks from the time of the leaflet drop to be able to object before extracts begin, but can also opt-out after they have commenced.

The care.data programme involves taking a large monthly dataset from all GP practices covering patient demographics, events, referrals and prescriptions.

This will be linked with Hospital Episode Statistics and other data-sets to create new Care Episode Statistics, giving a more holistic view of patient journeys in the NHS.

Datasets from care.data will be available publicly in aggregate form and in pseudonymised form to commissioners and health researchers.

GPs received a letter in late August explaining care.data and telling them that they have eight weeks to inform their patients about the scheme before extractions begin. Patients can opt out of the extracts by telling their GP, who can insert a Read code in their record.

However many GPs had expressed concern that this would not be sufficient to meet their obligation to inform patients under the Data Protection Act. Some had advocated a mass opt-out of the scheme until they felt patients were properly informed.

In a press conference held yesterday, NHS England's director of patients and information Tim Kelsey, chief data officer Geraint Lewis, and clinical and public assurance director of the HSCIC Dr Mark Davies, emphasised that the eight-week period was always a minimum and not intended to indicate that extractions would begin directly after that time.

They focused on highlighting the benefits of care.data in helping to manage the NHS by planning health services more efficiently and tracking patient outcomes. Dr Lewis also said that individual patients would be able to download their personal confidential dataset or theograph. When asked why, he said they might choose to share this with a health professional or charity.

The speakers claimed that there has not been any 'delay' to the roll-out of care.data. However, NHS England's business plan, released in April, set the target for 75% of GP practices to be providing a full extract to care.data by September 2013.

In a statement, HSCIC chair Kingsley Manning acknowledged that the benefits of care.data can "only be delivered in the context of public understanding and trust" and that feedback from doctors and the public had led the organisation to "take this more slowly".

GPs have already been sent posters and leaflets about the programme to use in their practices and information about the scheme has been sent to 350,000 charities to share with their members. There will also be a "social media campaign", although what this will involve was not made clear.

NHS England said the Information Commissioner's Office has endorsed the approach being taken to inform patients.

Hampshire GP Dr Neil Bhatia said the news of a leaflet drop only heightened his fears about properly informing patients about the care.data programme.

This is because his local commissioning support unit has recently started sending out patient information about the Summary Care Record. This is a completely different programme, which involves a limited patient dataset being uploaded to the NHS Spine where it can be viewed by emergency physicians involved in that patient's care.

"Naturally patients are absolutely confused about the two, don't know what to opt-in or out of, don't understand the difference and don't know if one opt out applies to the other."

Dr Bhatia said he has been spending a lot of time explaining the difference between the two to patients and he believed that even in areas where the SCR is already rolled out, patients will still be confused.