

# Patients asked to opt out or be included in database

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**NHS England has begun sending leaflets out to every household in England to inform residents that information from their patient records will be used in a national database unless they actively opt out.**

The ambitious care.data programme aims to join up anonymised patient data from a number of care settings into one data collection kept by the Health and Social Care Information Centre. This will be available to clinicians and researchers.

The leaflet, entitled “**Better information means better care**”, is part of a £2m publicity campaign launched in the wake of concern being raised by GPs and privacy campaigners that patients were not being well enough informed about the new database.

The leaflets will not be addressed to a specific householder or be sent in an envelope. Television and radio advertising [were ruled out on “cost effectiveness” grounds](#).

The British Medical Association, which was consulted on the wording by NHS England, welcomed the information campaign.

Tony Calland, chair of its medical ethics committee, said: “The BMA is extremely pleased that NHS England is raising awareness about changes to the way patient data is handled in the NHS.

“Following the efforts of the BMA, commissioners will only

have access to anonymised or pseudonymised data and if patients decide not to give permission for their data to be shared they can inform their GP.

One senior information governance expert said that while the publicity was a welcome move, “major challenges remain”.

Julia Hippisley-Cox, a professor at the University of Nottingham and a GP who specialises in information governance, said: “Whilst the public information campaign is a significant step forward, we still need to ensure better transparency for patients - I couldn’t find in the patient information sheets how patients can discover who has their confidential data or for what purpose.

“We also need to be sure public benefits can actually accrue from this - that means robust and reliable analyses of data.

“My understanding is that no data from before 1 April 2013 is to be collected, which means NHS England can’t undertake even the most basic analyses of incidence or prevalence rates.”

Those who wish to restrict their data being extracted and collated in this way are invited to speak to their GP.

Mark Davies, medical director at the information centre, said the body was “set up as the legal ‘safe haven’ for protecting and managing patient information”.

“We want everyone to feel confident that their information is kept private and used in non-identifiable form to improve the quality of health and social care for everyone,” he added.

Care.data has faced criticism in the past, particularly from GPs, who have a legal responsibility to inform patients of how their data is to be used.

They previously complained that they had not been given enough time to inform patients and offer them the opportunity to

opt out if they wish. As a result, NHS England pushed back its timetable to begin extracting patient data from last autumn to this coming March.

The information commissioner's office said it would continue to advise NHS England, GPs and the other relevant bodies about the importance of ensuring patients fully understand the options available to them.

An ICO statement said: "It is a fundamental principle of the Data Protection Act that people are aware of how organisations may use or disclose their personal information.

"We expect all of the organisations involved to make sure patients are aware of these changes, how their information will be used and how they can object to this if they wish to do so."