

7 in 10 patients surveyed hadn't heard of the Summary Care Record

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Despite an extensive public information campaign only three in ten people living in the areas piloting the NHS Summary Care Record (SCR) have heard about the programme, according to a study published on bmj.com today.

Several areas in England (of which three were studied) have been piloting the SCR, an electronic summary of a patient's medical record accessible to NHS staff via the internet, and HealthSpace, an internet based personal health organiser from which patients can view their own SCR.

The English government is about to roll out the programme nationwide. Patients who do not want an SCR have to actively opt out. The programme has proved controversial with a range of alleged benefits and drawbacks, from better clinical care and fewer medical errors to high costs and threats to confidentiality.

Researchers from University College London set out to document the views of patients and the public towards the SCR in three pilot areas. Focusing particularly on people with low health literacy, potentially stigmatising conditions, or those with difficulty accessing healthcare, they carried out 103 interviews with people who had recently used the health service in their area, and held seven focus groups with people recruited from voluntary sector organisations.

They found that even though nearly all of the local population had

received a letter informing them about the SCR being introduced in their area, most were not actually aware of either the SCR or HealthSpace. Many wrongly believed that electronic records were already shared between health professionals.

Two thirds of people were positive about the SCR and happy not to opt out. But very few were totally in favour of the idea. For most people, say the researchers, the decision about whether to have an SCR was dependent on their own personal experience and involved a process of weighing the positive against the negative.

The most common perceived benefits of the SCR included having medical details safely and consistently in one place and not having to fill out forms or remember what medication they were taking. The latter was particularly important for people with a low health literacy. The most common perceived drawbacks were inappropriate people having access to their records or security breaches.

People with complex health problems or who'd had adverse drug reactions tended to view the SCR positively. People who had been victims of mistaken identity or identity fraud tended to be the most opposed to the SCR.

Most people were not interested in a HealthSpace account with some describing it as 'pointless' and 'irrelevant'. The overwhelming reason for people not wanting a HealthSpace account was a lack of interest in their own health record.

Although most patients wanted to have an SCR, they also wanted to control who had access to it at the point of care. This led the researchers to conclude that it would be more pragmatic and ethical if the mode of consent were to change from 'opt out' where anyone with a 'legitimate relationship' can view the record, to a 'consent to view' model.

Source: British Medical Journal

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