

Patients' views on electronic patient records

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The digitisation of patient records needs much wider consultation if the NHS is to retain public confidence in patient confidentiality, says a new survey published today by the *New Economics Foundation* and the Centre for Science Education at Sheffield Hallam University.

The nationwide survey of 6000 people, supported by the Wellcome Trust, used new in-depth consultation tools to explore attitudes to the digitisation of records amongst both adult and younger people.

Of those surveyed, 57 per cent of adults and 67 per cent of young people were enthusiastic about the potential benefits to treatment and healthcare from switching to digital patient records. However, the overwhelming majority of both groups believe that patients should be able to choose whether or not to be included in any digital database containing personal health data.

Almost all of those surveyed felt that patients should have access to their

own records, but only 35 per cent of adults and 36 per cent of young people were in support of online home access. Only 11 per cent and 13 per cent backed allowing patients to add additional information to their records.

Stephen Whitehead, coauthor of the report, commented on the findings: "The NHS holds incredibly private, sensitive information about almost every person in the UK, but there is little public understanding of what happens to that information. Unless the NHS takes decisive action to narrow the divide between [public perception](#) of how information is used and the reality, the use of [electronic patient records](#) risks seriously undermining public trust in its ability to protect confidentiality."

The survey also found "very significant opposition" to sharing identifiable data for research without patient consent.

"The service must take steps", Stephen Whitehead continued, "to curb the most potentially controversial uses of public [health records](#) and open up debate on how it is legitimate to use our most personal details."

The report gives seven recommendations:

1. The right of patients to opt out of a database system at any time should be recognised.
2. Where patients might benefit from sharing records outside of the primary care environment, this should be only on the basis of explicit consent.
3. Non-medical staff and medical staff not directly participating in a patient's treatment should not have access to identifiable patient information in any form.
4. All patients should be given the right to review copies of their electronic patient records in in-surgery booths or similar arrangements.
5. Patients should be able to view an audit trail of who has been

accessing their records and when.

6. Section 251 of the Health and Social Care Act should be reviewed as the practice of grant exemptions to the common law of confidentiality and has the potential to significantly undermine [public trust](#) in confidentiality.

7. Organisations responsible for the roll-out of electronic patient records must engage with the public more effectively to identify what forms of data sharing are accepted as legitimate.

More information: *Who Sees What: Exploring public views on personal electronic health records* is published by the [New Economics Foundation](#).

Provided by Wellcome Trust

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