

Care.data aims to make better use of patient information to improve care in the future. However, consumers reported to us that they felt unable to make an informed decision about whether to opt out of the programme.

After consulting with stakeholders, the programme is now [planning 'pathfinder' projects](#) in four areas of England. The projects will test the clarity of the patient communications materials and the effectiveness of the data extraction process.

Our research indicates that many adults would be happy to donate their personal health data to help research if it was anonymous. We believe guaranteeing anonymity and control are key to giving consumers confidence.

To help we have developed ten principles to collecting and sharing personal health and care data.

## **10 principles on information sharing**

- 1 People can access their own health and social care data and records to see what the system has collected and who they are sharing it with.
- 2 Data is collected and shared in a manner that does not unjustifiably compromise people's anonymity, safety or treatment.
- 3 Collecting and sharing data cannot be used to justify treating people on an unequal basis with others.
- 4 Data collection and sharing will not have impact on a person's wellbeing by, for example, causing them additional anxiety or distress.
- 5 People are provided with all the information they require about Care.data or any other data sharing initiative, to make an informed choice about whether they want to opt in or out.

6 Frontline professionals are upfront and honest about the benefits and dis-benefits of opting in or out of Care.data or any other similar programme.

7 If an opt out is offered, it must be a genuine option (i.e. not overly burdensome) and people must be informed about the restrictions and limitations of this option.

8 If someone raises a concern or makes a complaint about the collection or sharing of their records, this must be taken seriously and staff must take immediate action to address the concern and, if it relates to a breach of confidentiality, put safeguards in place to restore the person's anonymity.

9 People should be able to opt out of Care.data later if they change their mind about the programme in future.

10 People should be offered an opportunity to get involved in local decisions at their GP surgeries about whether or not records are shared with the Care.data programme.

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Local Healthwatch in the pathfinder areas will be working to ensure that members of the public can make an informed decision on whether to opt-out of sharing their data.

Last November, the Government appointed Dame Fiona Caldicott as National Data Guardian. The Government made clear that [no data will be extracted from GP practices](#) as part of the care.data programme until Dame Fiona has advised the Secretary of State for Health that she is satisfied with the proposals and safeguards.