

Citizens Jury

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Information Commissioner's Office

Can a public body legally create records about you?

- Yes
- Any organisation can potentially create a record which contains information about you
- There are legal requirements to abide by and rules which must be met

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What must organisations do when they create a record?

Follow the Law

To do that they must;

- Maintain a duty of confidence
- Meet the principles of the Data Protection Act
- Follow the spirit and the articles of the Human Rights Act
- The key point is that organisations have to handle your information in line with the law and there are some restrictions on what they can do and how they must do it.

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Confidential Information

- When you provide a professional or an organisation with information about your health you usually have an expectation it will remain private.
- You may recognise that others providing treatment to you will see the information but would expect it to otherwise be kept private.
- Organisations have a duty to ensure that happens.

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What protection does the DPA offer?

- Protects information about you (that identifies you) if you are still alive!
- It doesn't apply to anonymised data – This is data which has been de identified
- What about the grey area in the middle?!
- Linked data, the risks/likelihood of re identification, the content and context - jigsaw effect
- Safeguards – protection if re identified

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Protecting the information

- Organisations can only collect and use data when it is legitimate, fair and secure to do so.
- They must have systems in place to make sure the information is up to date and relevant to the purpose they are using it for.
- They must protect the information from unauthorised use and hacking.

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Can an organisation create a record without asking me or telling me?

- Yes, in many circumstances they can create one without asking you.
- They don't always have to ask but almost always they do have to tell if they are using information about you (that which relates to you and if you are still alive!).
- Organisations are bound by law to tell you what they are doing with information about you, why and how they are doing it whom they are sharing it with.
- How should they/do they tell you?

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How do organisations protect the information?

Some of the things the practical things they have to do are;

- make sure the information they have is correct
- put technology in place which allows the data to be protected properly
- train the staff to be able to handle personal data properly
- Be able to provide the information they have which is about you to you on request

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Who can have access to the record?

- Several organisations could be allowed access to the record commercial NHS etc.
- In deciding to share the information the organisations must follow a Data Sharing Code which sets out how the information should be handled.
- It is the responsibility for the originating organisation to make sure that the receiving organisation/s can legitimately, fairly and securely gain access and use the information.
- If anonymised it is done so to a specific standard.
- Once the receiving organisation has been given access they must also ensure the data is handled in an appropriate way i.e not re identified or protected.

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Who owns the information in the record?

Patient Records

- Not all of the information contained within the record may be information about you.
- Some information may relate to another person.
- Some information may be medical opinion.

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Who owns the information in the record?

- The law doesn't state that anyone is the owner of the personal information held by an organisation.
- You may 'own' the information before you provide it to an organisation.
- Once they have it you have some protection in regard to how it is used, but you don't 'own' the actual information or the patient record.
- The organisation doesn't 'own' the information either, but they do have responsibility for it.

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What rights do you have?

Some of your rights are;

- To have a copy of the information which relates to you (such as a copy of your patient record) provided to you on request;
- in certain circumstances have inaccurate personal data rectified, blocked, erased or destroyed (not always opinions); and
- complain to the Information Commissioners Office if you feel the data has been handled incorrectly.

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Who holds the organisations to account?

- The Information Commissioners Office
- Department of Health/NHSE/HSCIC
- The role of the National Data Guardian
- Professional standards bodies and regulators – GMC, CQC etc

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In summary

- All organisations can potentially create, hold, use and share information about you
- Neither you nor the organisation 'owns' the information in the record
- The Data Protection Act provides protection for any information which identifies you (if you are alive!)
- An organisation doesn't always have to ask your permission but they almost always have to tell you what they are doing
- You have certain rights
- Several organisations have responsibilities to ensure the organisations using information about you are acting in a legitimate, fair and appropriate way

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