Throughout your life, information is recorded about you by different organisations. Within the NHS, doctors need to keep information about your illnesses and treatment so that if another doctor sees you they know what care you have received so far. This information is kept securely and access to it is carefully controlled.

1. This factsheet provides information on the following:
2. Why is confidentiality important?
3. What are the rules on confidentiality?
4. Confidentiality and professionals outside the NHS
5. Confidentiality and carers
6. Confidentiality and complaints

1. Why is confidentiality important?
Confidentiality is a basic principle in the relationship between professionals and patients. Confidentiality is based on:

Privacy, which is in turn related to the notion of respect for the person - people have a right to decide how information about themselves should be shared with others, and public interest. Good medical care requires patients to be frank to enable the doctor to make an accurate diagnosis and plan treatment; if patients could not trust clinicians to keep 'secrets', honesty would become less likely and this would undermine medical care.

2. What are the rules on confidentiality?
There is no act of parliament that covers confidentiality between health professionals and patients. Each professional organisation has a separate policy on confidentiality that must be kept to. Often confidentiality is covered in the organisations code of practice. All staff working for the NHS have a legal duty to follow the NHS Code of Practice on Confidentiality. Further guidance is given to individual professionals by their regulatory bodies. For instance, principles governing confidentiality for doctors can be found in guidelines produced by the UK General Medical Council, "Confidentiality: Protecting and Providing Information".

In addition to telling professionals how to maintain confidentiality, these documents instruct them who can read information about you, what information they have access to, and under what circumstances information about you can be given to other people.

The basics of confidentiality
Confidentiality policies are in use in most health, social, government and voluntary organisations servicing people with mental health problems. A copy of the confidentiality policy should be available for any services you or someone you care for is receiving.
What information is confidential?

Confidential information is any information that may be disclosed in a form that may identify you without your consent.

Can I choose who I want told about my health?

Before disclosing any information about yourself, the doctor or another professional, must ask for your consent. You may want a member of your family or a friend to know some information that the doctor has told you. Mental illness may affect your judgement at times and so it can be a good idea to tell the doctor in advance who you would like to be told if you become ill, and what information you would like them to be told.

What if I do not agree to information being disclosed?

If you have ‘mental capacity’ (i.e. your judgement is intact) then you have the right to refuse disclosure of information about yourself. Even if you are unwell, and a doctor wishes to disclose information s/he must still ask your permission and talk through with you the consequences of not disclosing the information. However, if it is decided that you cannot make this decision because of poor mental capacity, and the doctor is convinced that it is essential and in your best interests, then the doctor can disclose the information to an appropriate person or authority.

There are some exceptional circumstances when a doctor can disclose information without your consent, even if you have mental capacity. These circumstances are where the health and safety of yourself or others could be at risk. Within mental health, risk is defined loosely as risk of death or serious physical harm, either to yourself or others. An example of this would be when you tell your doctor that you are going to kill yourself, and they decide that they should disclose this information to another worker who works closely with you but outside the NHS such as your social worker.

3. Confidentiality and professionals outside the NHS

The principles of confidentiality are carried through into almost all services you are likely to use. Each service will have a confidentiality policy which should be made available to you on request. There should be strict rules about disclosure and you should be consulted before any disclosure is made or told if information is going to be disclosed about you without your consent.

As within the NHS, information is shared between staff. However, this should be done on a need to know basis and there should be guidelines as to how this is done. When information is shared outside an organisation, the organisations guidelines should be followed.

4. Confidentiality and carers

While the guidelines for disclosure of confidential information to other professionals is usually clear, how much information can be disclosed to family, friends and carers and under what circumstances is often misunderstood. It is common for family
members who wish to discuss their relative who has a mental illness with a member of the mental health team to be told that this is not possible because of 'patient confidentiality'. For example a GP may refuse to accept information about a patient's deteriorating health even though it is appropriate to use it in order to assess the situation. Rethink research has found that many professionals have insufficient understanding of the law and guidance on confidentiality, and may not have the confidence to share information when it would be sensible to do so.

**What information can be given to me without consent?**

You may ask for information about a condition from any doctor or psychiatrist. The doctor/psychiatrist should be able to provide you with general information, similar to the sort of information that Rethink's National Information and Advice Service provide. This information can help a carer understand someone’s mental illness, how to deal with problem behaviours or who they can turn to for help.

**What if I want information about a particular person?**

Getting an early agreement with your relative and friend and the treatment team can help avoid later dilemmas over confidentiality. This can be done when your friend/relative is reasonably well and able to participate with you and the treatment team in a meeting, spelling out the circumstances under which discussions with you can take place, and what information can be exchanged.

For example, there might be agreement that if the person shows particular early warning signs of becoming ill again, the treatment team can discuss this with the carer so as to reduce the likelihood of further deterioration. It could also be agreed what help the carer might require from the treatment team on an ongoing basis in order to cope better with their relative's illness.

George Schmukler, Dean of the Institute of Psychiatry has provided some useful ways for carers to approach the problem of confidentiality and disclosure with friends and family on the Mental Health Care website at:

http://www.mentalhealthcare.org.uk/schizophrenia/carer/confidentiality

Another way of making an agreement can be through an advance statement / directive. In this way the person with the mental illness decides what, and at which time, information is shared with specified people. It is best if this is done with the agreement of the treatment team and the people specified. Rethink’s National Information and Advice Service can provide you with further information on making an advance statement.

**When can confidential information be disclosed without consent?**

As discussed previously disclosure may be made in the interests of others where a failure to disclose the information may expose the patient, or others, to risk of death or serious harm. However, as yet there are no guidelines as to what constitutes serious harm. A clinician may also have a ‘duty of care’ towards carers, over and above that to the patient. This means that they may have a duty to inform the carer if the person could be a danger to the family.
The National Service Framework for Mental Health (1999) sets out standards the Department of Health expects from its mental health services. It states that 'the service user's consent should always be explicitly sought before information (about medication, other treatment and care) is passed on to their carer' and that 'if the service user is incapacitated, information may be passed to the carer if it is in the service user's best interests'.

5. Confidentiality and complaints

A breach of confidentiality can be very upsetting. It can weaken the trust between a professional and yourself. If you think that there has been a breach of confidentiality it is important to determine if and why a disclosure was made. Firstly you should obtain a copy of the guidelines on confidentiality used by the organisation. You may wish to ask the person who breached your confidentiality under what grounds they did this. An advocate should be able to help you do this.

If you do not get any satisfactory explanation as to why your confidentiality was breached and you feel that relevant guidelines were not followed then you can make a complaint to the organisation in question. A copy of the complaints procedure should be available from the organisation or a member of staff. An advocate or the Rethink National Information and Advice Service can help you make a complaint.

Further information:

The Rethink Information and National Advice Service produces a number of fact sheets on a range of different issues that affect people with mental illness. They are also able to give confidential, impartial, practical advice on all aspects of mental illness. They can be contacted at:

Rethink National Information and Advice Service
15th Floor
89 Albert Embankment
London
SE1 7TP

Tel: 0845 456 0455 or 020 7840 3188 (Monday-Friday 10am – 2pm)
Email: advice@rethink.org www.rethink.org

The National Information & Advice Service welcomes your feedback on whether this information was helpful to you.

You can provide feedback in the following ways:

By email: Please email your feedback to us at feedback@rethink.org.

By post: You can write to us at the following address:

National Information & Advice Service
Rethink
By telephone: You can call us on 0845 456 0455 or 020 7840 3188

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