



Somerset Partnership



NHS and Social Care Trust

CONFIDENTIALITY AND INFORMATION SHARING WITH FAMILIES AND CARERS

BEST PRACTICE GUIDELINES

Aim

The subject of confidentiality and sharing of information is a significant concern for service users, their families or carers and staff. The purpose of this document is to examine the issues in order to set out what users of services, families and carers might reasonably expect and to provide guidance for staff on best practice in this area.

The Trust is committed to working in partnership with people who experience mental health problems, and with their families and carers. It recognises that providing effective treatment relies on a three-way partnership between people who experience mental health problems, their families and carers, and professionals.

Definition

We have used the term 'families and carers' in its broadest sense to denote the most relevant people in the social network. It is important to clarify with the service user who they see in this role, recognising that this may change over time.

Benefits of Information Sharing

Agreement at an early date between service users, their families and carers and staff about information sharing can prevent problems from occurring later on.

Families and carers can provide useful information about progress; for example what might be going well or not well, medication side effects and behaviour which may be causing concern.

Information for families and carers about symptoms, diagnosis and treatment can offer reassurance and enable them to provide effective support.

Paying attention to the needs of all the family may help preserve relationships during periods of difficulty.

It can be helpful to see an individual's problems in the light of their social context. Research has shown that involving families in treatment can often have a beneficial effect on clinical and social care outcome.

Consent to Share

It is necessary for the service user/ patient to give consent for information about his or her treatment to be shared with family, friends or carers.

There are, however, circumstances when confidentiality may be broken, which largely relate to issues of public safety, including child protection. (Department of Health (2003), *Confidentiality: NHS Code of Practice*)

Case example;

David, aged twenty-four, has a diagnosis of schizophrenia and had been detained under the mental health act in a local secure setting for the past nine months. During this time he made repeated threats of physical violence towards members of staff and to his parents, who he blames for his compulsory admission. Prior to his admission he had also assaulted his father. He has said that he does not wish his parents to be involved in any discussions about his treatment.

When the time came for David to move to a less secure, open ward he did not wish his parents to be informed.

Following discussion by the multi disciplinary team involved in his David's care it was decided, in the light of the change in level of security and the potential increased risk to his parents' safety given his repeated threats, to inform David's parents of their son's move to an open ward. This decision was shared with David and a record was made in his case notes.

It is important that issues around “confidentiality” are not used by staff as a reason not to listen to families and carers, or for not discussing fully with service users the need for families/carers to receive information so that they can continue to support them.

It is best practice for staff to ask clients their views on sharing information at the earliest opportunity. This should normally be as part of the initial assessment or admission process. Where possible, families / carers should also be part of this process. (Sharing information on a “need to know” basis with those family

members/carers identified by the service user should be regarded as the norm in providing effective care).

Case example:

George is referred to the Community Mental Health Team by his G.P. having become significantly depressed.

- *George is sent an appointment letter which encourages him to bring family members, carer or friend to the initial assessment meeting.*
- *George is accompanied by his wife, Anne, to this initial meeting, where the staff member discusses the benefits of family/carers being closely involved and having information about diagnosis and treatment.*
- *George and Anne are offered the opportunity to meet with the staff member independently as well as together, to share information and agree confidentiality issues.*
- *The outcome of these discussions is clearly recorded in the patient records.*
- *Anne is offered a carer's assessment.*
- *Information provided by Anne is considered and recorded.*
- *George and Anne are given information on services, mental health issues, who to contact in a crisis.*

- The assessment process and subsequent treatment should also enable the service user, members of their family and, as appropriate, informal carers to be seen separately as standard practice. (Lambeth Primary Care Trust (2004) Report of the Independent Inquiry Team into the Care and treatment of D.)

Interviews together and separately maximise the possibility of a more complete initial assessment and subsequent updating of information.

- Families and carers also have the right to expect that information that they provide will not be shared with the client / outside organisations without their consent. However, staff will need to explain that the same exceptions, when confidentiality may be broken, also apply.

- Where someone has experienced acute illness, the use of advance directives which include information sharing with family and carers may be helpful. Advance directives are written when someone is well to record what they would like to happen should they become unwell again.

Case example:

When Maria is readmitted to hospital in an acute psychotic state she clearly states that she does not wish her husband, Nick, to be involved in any discussions about her care. However, at a prior meeting with a member of the community mental health team when well, Maria had given her permission for information and decisions to be shared with Nick if she became acutely unwell again.

- The emphasis should be on the importance of information sharing to providing effective care, and this should form the background for discussion. When sharing is refused the issue needs to be explored to find out whether, for example, this applies to all information or just some sensitive areas. This issue will need to be revisited at intervals to reflect the user's health status and changing care delivery.

Case example:

Jean was adamant that she did not want her family to be told anything about her involvement with the mental health services. When her Community Psychiatric Nurse took the time to establish the reasons for this attitude, Jean revealed that she was concerned lest something that she had been keeping secret from her family might be revealed to them. The Community Psychiatric Nurse was able to reassure her that this was not the case and to negotiate with her what she felt comfortable in being shared with her family.

- A decision by a service user to prevent information from being shared with their family / carer who provides them with

substantial support should be considered in the light of their mental capacity and their family's/carer's need to know that information in order to provide effective care.

- Details of decisions should be recorded in the individual's electronic record, to enable all staff to relate to family and carers from an informed position.
- Where clients do not wish information to be shared, families/ carers still have the right to be heard by staff and to input their views into the service.

Not all information sharing requires the consent of others.

Staff need to meet with family members in the knowledge that they are generally doing the best they can in difficult circumstances and in the recognition that they may be experiencing considerable stress, be uncertain as to how to respond to their relative and may have little or no prior experience of mental health services. They would be helped by the routine availability of information such as the following:

- Information on the way the service works
- Information on relevant mental health issues
- Information on their rights to a carer's assessment
- Information on support available for carers
- Who to contact to share information
- Who to contact in the event of a crisis

Advice and Guidance

The Caldicott Report, published in 1997, led to the requirement for each Trust to appoint a Caldicott Guardian. Caldicott Guardians are responsible for agreeing and reviewing internal protocols governing the protection and use of patient identifiable information.

The Caldicott Guardian (Trust Medical Director) is a source of reference for issues where staff have concerns about information sharing when explicit consent has not been given.

Summary Checklist

In all cases support for families and carers should include:

- A statement in initial appointment correspondence/communication to the service user that families and carers are welcome to attend for part of the initial assessment interview(s) because involvement of families and carers in the care process is helpful.
- Discussion during the assessment process to understand the role of the service user's family or carer.
- The provision of general information about mental health problems, mental health services, carers support and how they operate.
- The offer of a formal assessment of carers' needs at least annually, including the provision of a carer's care plan.
- Inclusion in the service user's care plan of the role of carers and family members.
- Access to family-based services after assessment, for example Family Therapy, Family Support Services, family consultations with team members.
- The identification of young carers and their subsequent referral to the young carers co-ordinator.
- Where appropriate, the care co-ordinator will be proactive in seeking information concerning the service user – their behaviour and problems – from the carer/family/social network.
- The care co-ordinator receiving and recording in RiO information provided by the carer/family/social network.
- The care co-ordinator, during the review process, confirming/checking the service user view of family and carer involvement and reconsidering this as/when appropriate.

In cases where the service user accepts family and carer involvement, this support should also include:

- Participation in assessments, reviews and care planning meetings and arrangements.
- The provisions of the service user's care plan and where relevant, a relapse management plan.
- Ways of accessing the service user's care co-ordinator routinely and in crisis.

Source Documents

1. Department of Health (2002), *Developing Services for Carers and Families of People with Mental Illness*
2. Royal College of Psychiatrists (2004) *Carers and Confidentiality in Mental Health: Issues involved in information sharing. (Partners in Care, RCP and Princess Royal Trust for Carers)*
3. Department of Health (2003), *Confidentiality: NHS Code of Practice.*
4. South West Child Protection Procedures www.swcpp.org.uk/
*Somerset Partnership NHS and Social Care Trust
Safeguarding Children Policy*

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