

Briefing *Paper*



Sharing mental health information with carers: pointers to good practice for service providers

Key points

- Carers play an important role in many service users' lives. Their knowledge and expertise represent an enormous resource for statutory and voluntary mental health services. These are reasons why it is so important to include them through sharing information.
- Providing carers with information to support them in their role can improve outcomes for both service users and carers.
- Before carers can be meaningfully involved in mental health care teams, there will need to be a 'cultural shift' within the mental health system, to recognise the importance and value of the carer's role.
- Carers fear being denied access to important information to help them in their role. They are also concerned that their own confidences may be broken.
- For professionals, one of the biggest difficulties is how to identify the appropriate carer in order to share or acquire relevant information.
- Highly complex issues dictate how, when and why information can be shared in mental health. There is no single 'blueprint' for good practice on information sharing in mental health.
- Effective information-sharing strategies to improve the quality of care provided can, nevertheless, be developed. Service users, carers and professionals should all be involved in generating such strategies.
- The ideal information-sharing strategy can be tailored to individuals' needs and requires professionals to make carefully weighted judgements.
- Professionals need training to help them to understand the roles of carers and to work with carers effectively. Training should be accredited in order to encourage attendance.
- Fear about breaching patient confidentiality has frequently created a barrier to effective involvement of carers in mental health care.
- The study summarised in this briefing paper managed to identify only a handful of good policies advising on how to share information with carers. Too many policies concentrated on the negative effects of sharing information with carers, rather than on the benefits.

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Key points *continued*

- The study classified 'information' in mental health into three categories: general information; personal information; and personal-sensitive information. Decisions regarding appropriate information sharing with carers should always take into account the type of information being sought or shared, and what the carer already knows.
- While almost 70 per cent of service users in this study agreed that their carers should have access to some personal information to support them in their caring role, others did not support carer involvement.
- It is therefore not helpful to involve carers uncritically. Involvement must be based on a clear understanding of the context of care, the long-term relationship between service user and carer, the service user's wishes, and the needs of the carer.
- One example of positive engagement with carers would be for professionals to incorporate carers' assessments into routine practice. Other helpful initiatives include carer advocates or support workers, carer education, and carer support groups.
- Carers and professionals should always seek the service user's consent to share personal and personal-sensitive information. Professionals should document the service user's response, and regularly update the decision giving or withholding consent. If confidentiality needs to be breached, the professional should normally explain this to the service user and the carer in order to address the needs of both parties.
- The researchers have suggested a framework of strategies that professionals can adopt when a service user withholds consent to share information. Most do not rely on breaking confidentiality.
- Both carers and service users believe that, if standards of mental health care improved, carers would need less information and support as their caring roles would have been made easier by earlier recovery of service users' mental health.



According to the 2001 census, there are about 6.8 million carers in England, of whom about 1.5 million are providing care for a relative or friend with a mental illness or some form of dementia. The carer of someone with a mental illness is often a vital support, allowing him or her to live in the community, whereas, without the carer, this might not be possible. Yet, despite recent Government initiatives that have recognised the importance of the carer's role, many carers still feel that the health and social care professionals who look after their friend or relative marginalise them.

Many carers feel left out of the discussions between the professional and the person who is seeking help. Details of treatments, symptoms, and long-term outlook may not be shared with them. Conversely, the carer may be the first to spot the signs that the person they look after is going to relapse: carers feel that they need to be taken seriously when they convey this type of information to professionals, and want to feel confident that professionals will respond in an appropriate way.

According to one recent survey, carers perceive that mental health professionals use confidentiality as a reason for withholding information from them, even where the mentally ill person had encouraged them to be involved.

Against this background, the NHS Service Delivery and Organisation Programme commissioned a study to identify good practice within mental health services for the sharing of information between mental health professionals and carers. The study was carried out by researchers from the Health Services Research Department at the Institute of Psychiatry in London, led by Vanessa Pinfold, in partnership with the mental health charity, Rethink severe mental illness. Professor Peter Huxley of the Institute of Psychiatry was the Principal Investigator. The study involved extensive consultation with carers, service users and professionals.

This briefing paper summarises the findings of the report, a full version of which can be found at

"I object to information sharing without my being told what information is being shared so that I can correct errors."

Service user

“On my son’s discharge from hospital after an episode of acute psychosis we had no information about his condition, how he would behave, how we should react to him. We had no experience in dealing with him when unwell. We were expected to just cope – a complete nightmare!” **Carer**

www.sdo.lshtm.ac.uk/carers.htm#huxley. In particular, it describes a framework of strategies for professionals to follow in the event that a mentally ill person withholds his or her consent for his or her carer to be given information.

In the report, the researchers define a mental health ‘carer’ as a relative, friend or neighbour who provides practical and emotional support to someone with a mental health problem. They use the term ‘service user’ to describe someone who uses or has used psychiatric services. This briefing paper uses the term ‘professional’ to encompass health and social care professionals working in mental health.

The researchers attempted to address some of the specific problems encountered by young carers, carers of people with dementia, and carers from black and ethnic minority groups, but suggest that more research involving larger numbers of people from these groups will need to be done in order to draw reliable conclusions.

The information-sharing dilemma

Carers need information to enable them to care most effectively for the service user, and to feel supported. They may need to know about changes in medication, or to look out for certain types of behaviour that may indicate that the service user is about to relapse. They may need certain information in order to preserve their own health and wellbeing. They also have a right to have their own needs assessed.

The service user has a right to privacy. Confidentiality is an essential ingredient of the ‘therapeutic alliance’ between the service user and the professional, helping the service user to trust the professional and so aiding his or her recovery.

At the same time, there may be doubts about the service user’s ability to make informed judgements when experiencing an acute episode, concern for the safety of the individual or the public, and a need to comply with the demands of current mental health legislation (the Mental Health Act 1983 will soon be replaced). (For a full list of references to relevant legislation and Government guidance, refer to the full report of this research at www.sdo.lshtm.ac.uk/carers.htm#huxley)

A key problem for the health professional may be in identifying who the main carer is, and what to do if there are concerns that the carer’s relationship with the service user could be abusive.

Professionals in general are often uncertain about what information they may share, and carers are often unaware of their rights.

Some professional bodies, such as the British Medical Association and the General Medical Council, have produced clear guidelines saying that medical professionals may disclose information to carers without the service user’s consent, if this is clearly in the service user’s best interests, and to enable carers to provide care. When doing so, professionals will adhere to the principles and guidance in the Mental Capacity Act 2005.

However, to date, the policies produced by Government, professional bodies or local health and social care services have not addressed *how* professionals should handle patient confidentiality with respect to mental health carers. The operational guidance that exists (guidance that tells people not just what to do, but how to do it) is both inconsistent and scattered throughout many documents – both nationally and in local guidance.

With the aim of developing clear guidance for professionals on what information can be shared with carers, the research team carried out a survey of information-sharing practices in mental health. This work included a review of the literature, including published papers, legislation and national policies; asking service providers for examples of relevant policies; a survey of service users, carers and professionals to identify examples of good practice; and a series of in-depth interviews, discussion groups and workshops. For a full account of the methods, please refer to the full report at www.sdo.lshtm.ac.uk/carers.htm#huxley.

Providers’ policies

Having approached more than 170 NHS Trusts and social services departments, and a range of other organisations, the researchers received 56 relevant documents, but only 11 (20 per cent) of these focussed substantially on carers. The best policies were those where carers themselves had helped to write them.

Peter Huxley said: “It was disappointing how few Trusts had appropriate policies. It seems that many Trusts and providers neglect the relevance and importance of carers to the mental health system.”

Although the research did not point to a single ‘blueprint’ model for information sharing, it was nevertheless possible to identify many ‘good practice points’ for developing appropriate policies.

Vanessa Pinfold emphasises that none of these can be totally prescriptive. “They must allow for professional assessment and discretion not only with regard to the service user’s situation, but also the context of care, the carer’s circumstances, and the consequences of providing or withholding information,” she said.

All kinds of variables can affect the decision about how and when to share information, and what information to share. For example, when an adult service user is living at home with his parents, and he attends an outpatient clinic with his mother, it is clear-cut that his mother is his carer. But if he attends with a neighbour or friend, it can be much more difficult for the professional to assess the status of the neighbour or friend, and how much information should be shared with him or her.

Likewise, there is a much greater onus on the professional to share information with the service user’s parent/carer if he/she lives at their home – even if he/she says he/she does not want information shared. But if the service user has responded to treatment, has moved out from the family home, and is trying to be more independent of his/her parents, it may be time for the professional to try to persuade the parents that they no longer need the same level of involvement that they have been used to.

The nature of the information shared can also vary according to the circumstances. The researchers defined three different types of information:

- **General information.** This includes information already in the public domain on mental health problems, and information about treatments or local services.
- **Personal information.** For example, specific information about the type of medication the service user is on, the diagnosis and what care is planned.
- **Sensitive personal information.** This would include information of a highly personal nature, such as HIV status, details of previous sexual or emotional abuse, and the service user’s views about family members.

Information that may be general in one context, however, could be classified as “sensitive personal information” in another. For example, giving a carer a leaflet about schizophrenia when they know that this is the service user’s diagnosis would count as general information; but if the carer did not know the diagnosis, such an act could be a serious breach of confidentiality.

“I think it should be written down when the client is well, stable, somewhere prominent the things they want done when they’re ill and things they don’t want done. Come the time when they’re ill it’s too late to start collecting consent.” Service user

Information-sharing is something professionals have to get right first time. As one service user told the researchers, “Possibly the most important thing about sharing is, once you have, you can’t change things, you only get one chance, so it has to be right.” The report emphasises that professionals, faced with weighing up the kinds of issues outlined above during the short period of a consultation, need more training to help them make these difficult decisions. Training must involve carers, as well as service users, if professionals are to understand their views.

Select principles of good practice

From the service user’s perspective

- **Consent should be collected before information is shared with carers, including the use of advance agreements.** Such agreements allow individuals to specify what care they would prefer to have in a future situation where they may not be able to recognise that they need help. Fewer than one-third (31%) of service users felt there are no situations where information should be shared without their consent. Only 12% of service users reported that they are routinely asked by professionals for consent to share personal information, 25% are sometimes asked, 24% rarely, and 18% never. 72% said they had never signed a ‘consent to disclose’ form.
- **Involvement of the carer should not undermine the service user.** A minority (9%) of service users thought that boosting the role of carers might undermine the voice of the user, diminish empowerment of the user, or reduce the user’s independence.
- **Service users should be involved in decisions to invite carers to meetings.** A third of service users (32%) did not want carers to be given separate time with professionals to discuss their concerns. This group always wanted to be present if professionals and carers were discussing them.

From the carer’s perspective

- **Carers do not have sufficient general or personal information to support the service user.** Mental health services must provide carers with basic information on mental health problems and ways of coping as a carer. 33% of carers said they did not have enough information to support their caring role. 79% said they needed access to personal information about the person they support.
- **Where professionals are unable to share personal information with carers because the service user**

“We feel that if information had been provided our son’s care would have been better and his recovery quicker.” Carer

has not consented, the professional should give a supportive explanation, to prevent confidentiality being perceived as a ‘block’ to communication between professionals and carers. Only 1 in 3 carers were given a supportive explanation in cases where information was not shared because the service user did not consent to it.

- **A cultural shift within mental health is required: professionals must change their attitudes towards working with families. Carers ask for professionals to respect their expertise and knowledge.**

From the health professional’s perspective

- **Professionals say lack of time is a barrier to sharing information with carers.** 68% of psychiatrists gave this as a reason why they would not share information with carers.
- **Policies are helpful.** For professionals working in the statutory sector, only 48% knew of a policy on sharing confidential information with carers, 41% did not know and 11% were certain that no such policy existed. Where a policy was known to exist, 20% rated it as “very helpful” and 62% as “quite helpful”.

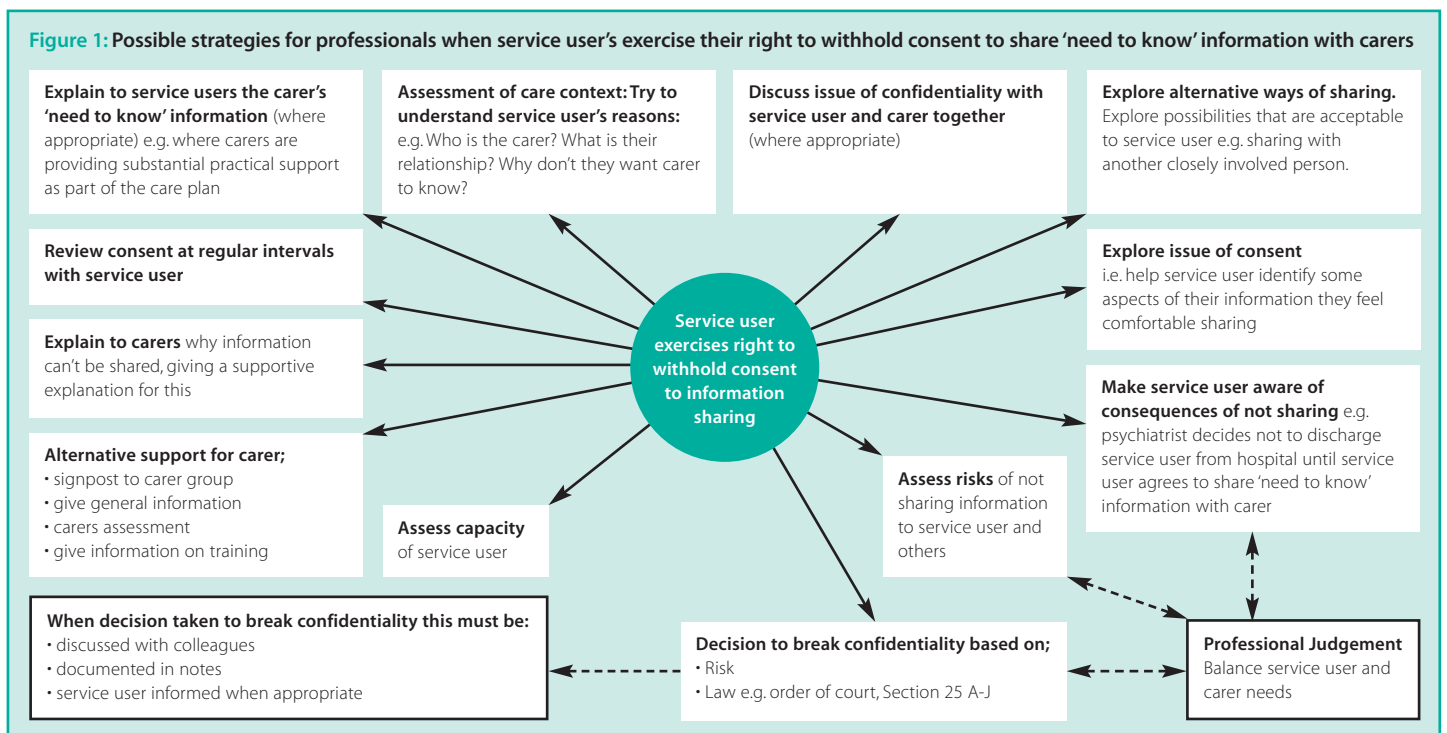
- **Professionals were more likely to be sympathetic to the idea that confidentiality should be broken.** 97% of professionals identified circumstances where confidentiality could be broken – mostly because of concerns about patient safety and/or risk to others.

Collated good-practice points

When the three perspectives were collated, the researchers identified several additional good-practice points, including:

- **Involve service users and carers in developing individual information-sharing strategies.** The research clearly identified the importance of open and honest communication between all parties – service user, carer and professional – to allow them to work together to promote the service user’s recovery. Vital factors in this process included clear boundaries relating to sharing of information, and an understanding of an individual’s need for information or privacy.
- **Improve service users’ and professionals’ understanding of the importance and value of sharing information with carers.** It is important to train staff to work with carers, and to provide policies and guidance, including supervision, to help them to decide appropriate levels of information sharing. Service users may also need support to understand the needs of carers in terms of information sharing; carers may need help in accepting less information than they might like, in order to respect the service user’s wishes.

Figure 1: Possible strategies for professionals when service user’s exercise their right to withhold consent to share ‘need to know’ information with carers



Consent to information sharing

When information needs to be shared with a carer, the service user should be asked for consent. The consent should be informed, written, voluntary, recent and competent. It should be documented in the notes, and the decision to give or withhold consent regularly updated. Good practice in the collection of consent involves the use of routine 'disclosure to consent' forms or advance statements.

When service users withhold their consent to share information

Where consent is not given, the professional needs to assess whether it is appropriate to break confidentiality. If this is deemed to be the case, the decision should normally be discussed with both the service user and the carer unless it may place either party at risk, and the reasons for this decision should be documented in the service user's notes.

The report presents a summary of strategies that professionals can use when a service user withholds consent to share information that a carer 'needs to know' (see Figure 1). Most of these do not rely on breaking confidentiality. When considering these strategies, professionals need to have in mind that:

- The service user has a right to withhold information from their carer.
- Many carers acknowledge that they "do not want to know everything".
- Carers need to have access to general information to help them negotiate a way through the mental health system and their service user's mental health problems.

Conclusion

The overriding goal, Pinfold emphasised, is mutual understanding. "It is all about there being greater awareness of the rights and responsibilities regarding information sharing of all three parties: service user, carer and health professional," she said. "There was evidence that where Trusts had strong policies on information sharing, which had been co-written with carers, these were useful. Professionals had access to good guidance, service users were fully involved and carers felt supported."

"I think sometimes staff are worried about saying the wrong thing. They don't know what language to use, are frightened of upsetting the carer, and aren't sure what they can and cannot share." Community Psychiatric Nurse

Further Information

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rethink

The research summarised in this briefing paper was carried out by the Health Services Research Department, Institute of Psychiatry, Kings College London and Rethink.

The full report, this briefing paper and details of current SDO research in the field can be downloaded at:
www.sdo.lshtm.ac.uk/carers.htm#huxley

Additional copies of this briefing paper can be ordered from Rethink at: www.rethink.org/publications
Call: Rethink Front Door Service on 0845 456 0455
Email: info@rethink.org

Other resources to support both carers and professionals to work together effectively include:

Rethink Carers Educational Training Programme – CETP.
For more information visit: www.rethink.org/cetp
or call 0845 456 0455.

Caring and Coping – guide for mental health carers.
Order copies from: www.rethink.org/publications
or call 0845 456 0455.

Partners in Care training resource (Sept 2005).
Available from: www.rcpsych.ac.uk/publications

Research website for carers from Institute of Psychiatry and South London and Maudsley NHS Trust:
www.mentalhealthcare.org.uk

About the SDO Programme

The SDO R&D Programme is a national research programme managed by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) under contract from the Department of Health's R&D Division.

For further information about the NCCSDO or the SDO Programme visit our website at www.sdo.lshtm.ac.uk or contact:

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