

Carers and Confidentiality Policy

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EXECUTIVE SUMMARY:

- **Guidance for staff on sharing information with carers**

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[**policies@sussexpartnership.nhs.uk**](mailto:policies@sussexpartnership.nhs.uk)

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1.0 Purpose

Carers play an important role in many service users' lives. Their knowledge and expertise represent an enormous resource for statutory sector mental health services. Sussex Partnership NHS Foundation Trust (the Trust) is committed to the key standards in the Carers Trust Triangle of Care model for carer inclusion and support and this involves a specific commitment to developing policy and practice protocols regarding confidentiality and sharing information.

Staff members often struggle to balance the needs of carers with the right to confidentiality of service users. This guidance gives general advice about sharing information – the ideal information sharing strategy however is one that is designed with and tailored to all the individuals involved in a specific situation– the service user, carer and staff.

2.0 Scope of the guidance

This guidance is concerned with the sharing of personal information, that is, information about an individual's personal circumstances and mental health in the past, present and future.

3.0 Legislative and guidance context

This guidance is based on feedback from carers and carer's organisations, existing protocols and practice in the local authority areas where the Trust operates and national best practice such as the Triangle of Care where information sharing and confidentiality is one of its six key elements to increasing carer engagement. The guidance is underpinned by the Trust's information governance framework.

The Trust's overarching aim in relation to data sharing is to ensure that there is an appropriate balance between the protection of the patient's information, and the use and sharing of such information to improve care. The Trust's information governance framework adheres to the Data Protection Act 1998 & GDPR and associated guidance and legislation, guidance from the Information Commissioner's Office, and the recently in force Health and Social care (quality and safety) Act 2015 which strengthens the duty to share information with appropriate agencies in the interests of providing appropriate care to patients. The Trust has a framework of ratifying information sharing agreements to ensure data can be shared appropriately between organisations in order to facilitate care to patients.

4.0 Trust expectations

In relation to carers, as an organisation, we will:

- Listen without bias or prejudice and take what carers say seriously,
- Recognise carers as partners who have relevant and important knowledge about the person for whom they care,
- Ask carer's opinion – which will be respected and valued and where necessary kept confidential,
- Give carers the choice on whether they wish to take on, or continue with, the role of carer,
- Provide staff who understand the distress and anxiety that caring can cause and provide carers with help to cope with this,
- Inform carers about how the information they provide would be used.

These commitments and the individual circumstances of carers' information requirements should be the drivers of a personalised and flexible response to their questions. This response should reflect carers' diverse cultural and ethnic backgrounds.

5.0 The importance of sharing information with carers

Sharing information may be difficult but done well it can improve outcomes for both service users and carers.

- The carer is often the person who knows the service user best. They may have regular contact over many years, often with on-going responsibility for all aspects of the service user's welfare.
- The carer is often the only constant support in a service user's life, as friends lose touch and professionals move away. Many service users experience regular and sudden changes in the professional team caring for them. This can make the building of trusting relationships difficult and important information about the service user may be lost if the carer is not included in regular discussions.
- The changing nature of mental illness can cause sudden crises, often out of hours, to which the carer may have to respond. This can be very stressful as immediate and appropriate professional support is not always available. However, if the carer has knowledge and understanding of the crisis plan, they can often persuade the service user to follow it, for example by agreeing to contact their key worker or by taking the recommended medication.
- The wellbeing of the carer can be greatly improved if they are encouraged to feel part of a supportive team, with ready access to up-to-date information. Without this, the carer may feel unable to continue giving the practical and emotional support that is so important to the service user.
- If carers are excluded from important discussions and decisions involving the service user, this can have serious practical, financial and personal consequences for both the carer and the service user. Not being involved increases feelings of isolation, grief and loss which are common to many carers.

6.0 Issues to consider when sharing information with carers

6.1 Ethical and legal obligations

All professionals working in mental health services are bound by law and professional codes of conduct to a duty of confidentiality to their service users. They also have a duty of confidentiality to carers.

6.2 Consent

For professionals, the most important issue is the informed consent of the service user to the disclosure of information to the carer. Many service users and carers are unaware of this and do not realise that the service user must give consent before any information can be shared.

There are only a few situations where permission is not required to share confidential information: where it is required by law for example a court order, where disclosure is in the public interest for example to protect a member of the public from harm, including a carer or to protect the service user.

Complex issues can arise when the service user is unable to give informed consent, for example at certain times during an acute episode or when the service user has dementia. In such situations decisions about information sharing must be made in the service user's best interests using the framework of the Mental Capacity Act.

Children and young people using our services also need to be as involved as possible in decisions about who knows information about them. Special consideration should be given to young people who may be 'Gillick competent'. (Note: Gillick competency and Fraser guidelines refer to a legal case which looked specifically at whether doctors should be able to give contraceptive advice or treatment to under 16-year-olds without parental consent. But since then, they have been more widely used to help assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions.)

6.3 Carers may also face problems with information-sharing

Carers can be the first to notice changes in the service user's behaviour. The service user may not realise that they are ill and may not want professionals to be contacted. This can cause serious problems for the carer as the service user may interpret any action as a breach of their trust and confidentiality.

Having insufficient information can, in some circumstances, seriously jeopardise the carer's ability to care safely and effectively. This consideration must form part of the care planning and risk assessment processes. Carers will often not realise or feel they can refuse to continue their caring role if they do not have sufficient support (including information) to do so. Therefore a carer's apparent acceptance of a situation should not be assumed to represent a safe or therapeutic scenario.

6.4 Accessibility

Carers have different levels of knowledge about the services that the Trust delivers. Discussions with a carer should make no assumptions about their understanding of the way our services are organised or mental health in general. Consideration should also be given to the need for spoken word and sign language interpreting.

6.5 Protected Characteristics –Equality Act 2010

In order to create productive relationships with carers it is important to recognise that their diversity and their personal experiences may impact on the way they engage with our services as a carer. Staff members should be taking into account the protected characteristics of both the carer and the patient making themselves aware of all of the carers protected characteristics whilst also being conscious of any private disclosure the cared for person might have made which might conflict with the religious or cultural beliefs of the carer. For example, a service user might choose to inform you of their sexual orientation but by doing this they are not giving you permission to discuss this freely in front of their carer – this could be inadvertently 'outing' them, which might negatively affect their mental health. In order to maintain healthy relationships with carers, and between carers and cared for people, it is vital that staff members remember that not everyone feels the same way about any given subject. Any given protected characteristic may be particularly sensitive for any individual carer or patient and this should always be acknowledged and treated

respectfully by our staff members, despite what your own personal values and beliefs might be.

7.0 Practice tips

7.1 Dignity and respect

Carers may well be stressed and concerned when we meet them– they are likely to respond well if we treat them as partners in care and with courtesy and respect. Three key pieces of knowledge should underpin all our work in this area:

1. It does not breach confidentiality to simply talk or listen to a carer.
2. It is important to remember that what a carer tells you is also confidential and should not be shared with the service user without explicit consent.
3. It is not a breach of confidentiality to discuss an issue that the carer already knows about.

7.2 Start as soon as possible

Information sharing should be the subject of discussion before information is shared. Explaining the benefits of information sharing to the service user while they are well can go a long way towards preventing problems which may occur when they become unwell.

7.3 Use the systems that we have

Making and reviewing decisions about information sharing should be an integral part of planning an individual's care - many of the processes we already use in the organisation can assist in this. The Care Programme Approach and risk assessment are standard tools available for mental health management and can, especially alongside more user focused instruments such as WRAP plans, form a framework in which a strategy for information sharing can be made involving all affected – staff, carers and the service user. Advance directives and crisis plans should specifically address how confidentiality is managed when situations become difficult. Carer's assessments can be used to highlight carer's information needs and other support they need to care.

Managing confidentiality this way means that decisions are made involving everyone that they concern, everyone knows what decisions have been made and there is collective responsibility for them. Using existing systems also saves time and makes working with carers mainstream – not a difficult add on.

7.4 Recording

Use the documentation provided to record decisions about information sharing. Records should be clear and specific about what to share, what to withhold and with whom. Some services have specific forms for people to sign in order to give their permission for information about them to be shared. In other areas decisions are recorded in notes only. Whatever method is used it is essential that decisions about information sharing are referred to in case notes, are up to date and easily identifiable to all people working with an individual.

7.5 Be supportive

Acknowledging a situation is difficult and offering a supportive explanation can go a long way to alleviating carers concerns about confidentiality. We should also ensure that carers have the right information, and suggest where they might seek support and further advice – for example from PALS or carer organisations.

7.6 If you face a difficult situation, consider....

- The nature of the information
People vary on what they regard as confidential, or there may only be a small part of their history such as substance misuse or sexual history that they do not want disclosed.
- Situations change
Exceptional circumstances may mean that staff get an unclear picture of the relationship between a service user and a carer– some time spent on understanding it may help. For example, all parties may feel exhausted and estranged in the immediate aftermath of a compulsory hospital admission - this may change as the crisis abates.
- Everyone is different
Carers will differ in the quantity and type of information they want, when they want it and from which member of the mental health team they receive it. Many will get information directly from the patient, most will gain it gradually and some will seek general information from the voluntary sector.
- Find out what they know already
It does not breach confidentiality to discuss issues with the carer that they already know about.
- Risk
Even if consent to share information is withheld by the service user it is essential that we listen to the concerns of carers around clinical risk issues

7.7 Check list for sharing information with Carers

What kinds of information do carers want?	Is the service user's consent required?	What can you do if consent is not given?
<p>Information to help the carer in their caring role.</p> <p>This may include:</p>	--	--
<ul style="list-style-type: none"> Factual information about a health problem, for example general information about symptoms and treatments 	No	--
<ul style="list-style-type: none"> Information about the cared-for person's diagnosis and prognosis 	Sometimes (Remember information which the carer <i>already</i> knows, isn't confidential)	<p>Explain to the service user the value of sharing the information.</p> <p>Explore alternative ways of sharing e.g. sharing information with another closely involved person.</p> <p>Does the service user consent to parts of the information being disclosed?</p> <p>If information can't be shared, give the carer a supportive explanation about this, and, consider when this decision could be reviewed.</p>
<ul style="list-style-type: none"> Information about medication, side effects, how to take it etc 	No	--
<ul style="list-style-type: none"> How to contact the service if things go wrong 	No	--

<p>Information about their rights as a carer and the support available to them:</p>	<p>--</p>	<p>--</p>
<ul style="list-style-type: none"> • Carers Assessments 	<p>No</p>	<p>--</p>
<ul style="list-style-type: none"> • Breaks 	<p>No</p>	<p>--</p>
<ul style="list-style-type: none"> • Carers Centre and other voluntary agencies 	<p>No</p>	<p>--</p>
<p>Consultation and involvement in care planning</p>	<p>Sometimes</p>	<p>Discuss the consequences of not sharing the information.</p> <p>Assess the risks of not sharing the information.</p> <p>Consider the capacity of the service user.</p> <p>Does the service user consent to parts of the information being disclosed to certain people?*</p> <p>If information can't be shared, give the carer a supportive explanation about this, and, consider when this decision could be reviewed.</p>

Prepared by the Carers Centre for Brighton and Hove

*Particular care should be taken about what is and is not included in conversations about care planning with carers -for example a service user may have personal information they do not wish to share with their parents but would be happy for that information to be known to staff.

8.0 Further Sources of information

8.1 Within Sussex Partnership

If issues arise about managing confidentiality and carers you should raise the subject in the first instance with your team and manager.

Additional advice and assistance in resolving concerns for carers is also available from the Patient Advice and Liaison Service (PALS) and the Patient Experience Team.

The Executive Director of Nursing & Quality is the organisation's Caldicott Guardian and is responsible for all issues in relation to information protection. The Information Governance Team will also advise on issues of data protection and information sharing.

Annual Information Governance training is a mandatory requirement for all staff.

8.2 Externally

Local and national Carer's organisations offer a wide range of support and expert advice to carers including around confidentiality. See appendix.

9.0 Development consultation and ratification process

This guidance was initially developed in 2011 with the Trusts Carer Reference Group including staff, carers and carer organisations. It was consulted on with the Information governance Team and individually with carers.

The guidance was subject to further consultation in 2015 through the Trust Triangle of Care Advisory group which includes staff, carers and carer organisations.

10.0 Equality and human rights impact analysis

Initially undertaken 14th November 2011. Updated 19/5/2016

11.0 Monitoring

11.1 Compliance

This guidance will be reviewed annually by the Triangle of Care advisory group chaired by the Deputy Director of Social work who will also monitor compliance via feedback through PALS and complaints data. Any areas of non-compliance will be taken up with the relevant senior manager.

11.2 Training

Information Governance training is mandatory for all staff. Carers' awareness training is undertaken as part of the Triangle of Care commitment in inpatient

units and in community teams, and explicitly addresses the issue of confidentiality and information sharing.

12.0 Dissemination and implementation of guidance

The information will be made available to carers via the Trust website and through local operational services

This guidance will be circulated among wider staff groups through placement on the Trusts intranet in accordance with the organisations policy for procedural documents.

This guidance will be circulated amongst the Complaints and PALS teams and management.

13.0 Document control including archive arrangements

The document is managed in accordance with the policy for procedural documents.

14.0 Reference documents and contacts

Information Governance Policy:

<http://policies.sussexpartnership.nhs.uk/corporate/information-governance-policy>

Confidentiality Policy:

<http://policies.sussexpartnership.nhs.uk/corporate/confidentiality-policy>

Triangle of care: Carers Included – a guide to best practice in acute mental health care

<http://static.carers.org/files/caretriangle-web-5250.pdf>

Carers Trust: <https://www.carers.org/>

Carers Centre (Brighton): <http://www.thecarerscentre.org/>

Care for the Carers (East Sussex): <http://cftc.org.uk/>

Carers Support (West Sussex): <http://www.carerssupport.org.uk/>

Carers First (Kent and Medway): <https://www.carers.org/local-service/tonbridge>

Carers Together (Hampshire): <http://782186386632763965.weebly.com/>

ICE (Improving Carers' Experience): <http://www.iceproject.co.uk/>