

## **Family and Friend Carers Confidentiality Policy**

(Replaces Policy No. 096/Corporate)

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### **EXECUTIVE SUMMARY:**

- **Guidance for staff on sharing information about patient care with family and friend carers**

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## **1.0 Purpose**

Family and friend carers (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 can 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 Definition of a Carer**

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support (Carers Trust).

Using this definition, many people in many different roles to a person who uses services can be seen as a carer. It is therefore important that staff routinely ask people who are in their care who is involved in their support systems and networks in order to identify who may be a carer to them at the earliest opportunity, and who they would like involved in their care (and at what level of involvement and information sharing). This should be regularly reviewed. Staff should also speak to visitors and people that they come into contact with through caring for people using services to raise awareness of who may be seen as a carer and how they can be supported.

## **3.0 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.

General information is information that cannot identify an individual i.e. Information about medication, side effects, how to take it etc. or team/ward information like visiting hours or the services they provide.

## **4.0 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 service user'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 2018, GDPR and associated guidance and legislation, guidance from the Information Commissioner's Office, and the Health and Social care (quality and safety) Act 2015 which introduced a new legal duty requiring health and adult social care bodies to share information where this will facilitate care for an individual

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 service users.

## **5.0 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 requested by the carer, kept confidential, unless carer is happy for their opinion to be shared with the service user and others involved in their care or if there is a risk of harm to self or others.
- Give carers the choice on whether they wish to take on, or continue with, the role of carer,
- Support staff to understand the distress and anxiety that caring can cause and how to provide carers with help to cope with this,
- Inform carers about how the information they provide would be used.
- Inform carer that the person they care for is safe.

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.

## **6.0 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. These three aspects 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. Be aware that in these circumstances information might be shared- when protecting children from significant harm, protecting (vulnerable) adults from serious harm and prevention/detection of serious crime and disorder.
3. It is not a breach of confidentiality to discuss an issue that the carer already knows about.

The carer is often the person who knows the service user best. They may have had 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.

## **7.0 Issues to consider when sharing information with carers**

### **7.1 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.

As a professional and legal standard, when staff do share confidential information they should:

- Only disclose the minimum that is necessary for the purpose
- Share only with those people who need to have it and make sure it's accurate and up-to-date
- Make sure it's shared in a timely fashion
- Make sure it's shared safely and securely.

### **7.2 Consent**

For professionals, a key issue encountered 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.

It is recognised that complex issues can arise when the service user is unable to give informed consent to share information, for example at certain times during an acute episode or when the service user has been diagnosed with 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 2005. These should be read in conjunction with the Safeguarding Adults at Risk and Safeguarding Children policy and the MCA policy

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.)

### **7.3 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 mentally unwell and may not want professionals to be contacted by a carer. 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.

### **7.4 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.

### **7.5 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 service user. 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 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 service user and this should always be acknowledged and treated respectfully by our staff members, despite what your own personal values and beliefs might be.

Whilst implementing the Triangle of Care with carers the Trust recognises the differences within all the protected characteristics in the Equality Act 2010. The Trust recognises that the best person centred care takes account of difference with regards equality, human rights and diversity.

## **8.0 Practice tips**

- It’s up to the service user what information is shared – seek consent where possible
- They can change their mind at any time
- Not all information is confidential information – e.g. general information about services and medication
- Consent to share information in writing is ideal but records should be made of any verbal consent to share.
- When recording consent to share information, be as specific as possible
- If the SU does not have capacity to consent to sharing information with a carer, wait until they regain capacity if possible, or make a decision as an Multi-Disciplinary Team to share in their best interests.

### **8.1 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.

### **8.2 Start at the first contact or as soon as possible**

Information sharing should be the subject of discussions before information is shared. Ask as part of the conversation open questions such as “who would you like involved in your care at the moment”. This should be regularly revisited. Explaining and exploring 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.

### **8.3 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.

Use the Trust’s information sharing agreement in conversations with the service user and also the carer, where appropriate, about what information is known and can be shared. It is important to regularly clarify if the service user has given consent to share all, partial or no confidential information.

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 decisions 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.

If Trust staff make a decision to share information without consent, and they have followed all practicable steps and have a clear and logical documented rationale for their decision, they will be supported by the Trust (please see letter from Sam Allen, Chief Executive dated 20<sup>th</sup> December 2018 – Appendix 1)

When making decisions to share information without consent, this should be discussed as a team rather than an individual making the decision, where possible. The details of and rationale for the decision and who it was shared with needs to be clearly documented. Signpost to appropriate safeguarding team for specialist support and information.

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.

#### **8.4 Recording**

Where the person has the mental capacity to make decisions around information sharing, Information sharing and expectations should be the subject of discussions as soon as possible and before information is shared. 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 (within our service and other partner services). 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.

Review consent to share either at care plan reviews or when there are changes in service users's mental health or circumstances, e.g., inpatient admissions and discharge.

#### **8.5 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.

## 8.6 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

### 8.7 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><b>Information to help the carer in their caring role.</b></p> <p><b>This may include:</b></p>	--	--
<ul style="list-style-type: none"> <li>• Factual information about a health problem, for example general information about symptoms and treatments</li> </ul>	No	--
<ul style="list-style-type: none"> <li>• Information about the cared-for person's diagnosis and prognosis</li> </ul>	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, where practicable negotiate with carer a date when this will be reviewed.</p>
<ul style="list-style-type: none"> <li>• Information about medication, side effects, how to take it etc</li> </ul>	No	--
<ul style="list-style-type: none"> <li>• How to contact the service if things go wrong</li> </ul>	No	--

<b>Information about their rights as a carer and the support available to them:</b>	--	--
• Carers Assessments	No	--
• Breaks	No	--
• Carers Centre and other voluntary agencies	No	--
<b>Consultation and involvement in care planning</b>	Sometimes	<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, where practicable negotiate with carer a date when this will 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.

## **9.0 Further Sources of information**

### **9.1 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 Complaints & Patient Advice and Liaison Service (PALS) Team.

The Chief Medical Officer – Rick Fraser 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. Lynn Richardson is the Freedom to Speak Up Guardian for the Trust.

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

### **9.2 Externally**

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

## **10.0 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.

## **11.0 Equality and human rights impact analysis**

Initially undertaken 14<sup>th</sup> November 2010. Updated 19/5/2016, 23/9/2018 and 26/03/2019.

## **12.0 Monitoring**

### **12.1 Compliance**

This guidance will be reviewed by the Triangle of Care advisory group chaired by the Carer Leader 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.

## 12.2 Training

Information Governance training is mandatory for all staff. Carers' awareness training is undertaken as part of the implementation of the Triangle of Care membership scheme, and explicitly addresses the issue of confidentiality and information sharing.

## 13.0 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 team and management.

## 14.0 Document control including archive arrangements

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

## 15.0 Reference documents and contacts

Good Psychiatric Practice- Confidentiality and Information Sharing (3rd edition) (CR209 Nov 2017) - Royal College of Psychiatrists  
[https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr209.pdf?sfvrsn=23858153\\_2](https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr209.pdf?sfvrsn=23858153_2)

Best practice when service users do not consent to sharing information with carers: National multimethod study Slade and Pinfold 2007  
<https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/best-practice-when-service-users-do-not-consent-to-sharing-information-with-carers/517CA897D35A941ED8AEAD3ECE308CAD>

Information sharing & suicide prevention consensus statement – January 2014  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/271792/Consensus\\_statement\\_on\\_information\\_sharing.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/271792/Consensus_statement_on_information_sharing.pdf)

DH (2003) Confidentiality NHS Code of Practice  
<https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice>

Confidentiality and Information Sharing Factsheet (2016) Rethink  
<https://www.rethink.org/media/1284/confidentiality-and-information-sharing-for-carers-friends-and-family-factsheet.pdf>

Sussex Partnership NHS Foundation Trust- Information Governance Policy:  
<http://policies.sussexpartnership.nhs.uk/corporate/information-governance-policy>

Sussex Partnership NHS Foundation Trust – Working with Families and Carers – Guiding Principles (see attached – Appendix 2)

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  
[https://professionals.carers.org/sites/default/files/thetriangleofcare\\_guidetobes tpracticeinmentalhealthcare\\_england.pdf](https://professionals.carers.org/sites/default/files/thetriangleofcare_guidetobes tpracticeinmentalhealthcare_england.pdf)

Safeguarding Children Policy and Procedures:  
[https://www.sussexpartnership.nhs.uk/sites/default/files/documents/safeguarding\\_children\\_policy\\_final.pdf](https://www.sussexpartnership.nhs.uk/sites/default/files/documents/safeguarding_children_policy_final.pdf)

Safeguarding Adults at Risk Policy:  
<https://policies.sussexpartnership.nhs.uk/download/clinical-1/148-safeguarding-vulnerable-adults>

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

Carers Centre for Brighton & Hove: <https://www.thecarerscentre.org>

Carers Hub (Brighton & Hove): <https://www.carershubs.co.uk>

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://www.carerstogether.org.uk/>

Changes Ahead [www.facebook.com/actionsupportgroups/](http://www.facebook.com/actionsupportgroups/)

Worthing Rethink: [www.facebook.com/groups/worthingmentalhealthcarers/](http://www.facebook.com/groups/worthingmentalhealthcarers/)