

# STANDARD OPERATING PROCEDURE

## Information Sharing with Carers and Significant Others

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<b>Ratified and Quality Checked by: Date Ratified:</b>	Information Governance Group 16 November 2022
<b>Name of Trust Strategy/Policy/Guidelines this SOP refers to:</b>	

**VALIDITY – All local SOPS should be accessed via the Trust intranet**

### CHANGE RECORD

Version	Date	Change details
<i>Principles of confidentiality and information sharing with Carers and significant others</i>		
V1.0	Nov 2008	<i>Principles of confidentiality and information sharing with carers and significant others document agreed for used.</i>
V1.1	July 2010	<i>First review</i>
V1.2	May 2012	<i>Second review</i>
<i>Transferred to SOP16-007 information sharing with carers and significant others-</i>		
V1.0	Sept 2016	<i>Reviewed and updated to a Standard Operating Procedure.</i>
V1.01	September 2018	<i>Update references to Data Protection Act 2018 and General Data Protection Regulation.</i>
V2.0	Sept 2019	<i>Update 3.4 to make it clear that it refers to confidential information.</i>
V3.0	July 2022	<i>Expanded scope to advise that significant others include friends and family members who may not wish to be defined as a carer but nonetheless care for and support the patient. Added a section called Useful links and included the Rethink guidance on confidentiality and information sharing for carers, friends and family.</i>
V3.1	Nov 2022	<i>Section 3.2 and 3.4 updated following an SI investigation. Link to NHS Transformation guidance added. Approved at Information Governance Group (16 November 2022).</i>

## Contents

1. INTRODUCTION .....	3
2. SCOPE .....	3
3. PROCEDURES .....	3
3.1. Obtaining Explicit Consent .....	3
3.2. Refusal/Limitations on Consent .....	4
3.3. Patients who Lack Capacity .....	4
3.4. Advanced Statement/Decision and Reviewing Consent.....	5
3.5. Support/Information for Carers.....	5
3.6. Carers Confidentiality.....	5
4. REFERENCES/DEFINITIONS .....	6
5. USEFUL LINKS .....	6
Appendix 1: Royal College of Psychiatrists – Good Practice Checklist .....	7
Appendix 2 - Equality Impact Assessment (EIA).....	8

## **1. INTRODUCTION**

Within the process of the providing high quality health care packages to people who use services provided by Humber Teaching NHS Foundation Trust there is a recognition that in many cases, carers are providing valued and vitally important care and support, sometimes on a full-time basis.

There is also an understanding that carers often feel “cut-off” from, and “ill-informed” about, the care of people close to them, even though they may be providing a significant level of care.

Humber Teaching NHS Foundation Trust and its partners in providing services see people who are carers as ‘partners in care’, and not just as a resource.

Carers may also have different needs, views and expectations to service users and should therefore be considered separately, in their own right, rather than being an addition to the service user’s assessment and care plan.

Carers who support clients who have their care needs supported by different services within the Trust’s portfolio of services (Mental Health/Learning Disabilities/Acute and Primary Care) will have differing information and support requirements

Community staff and named nurses (within inpatient care) will be expected to listen to and take into account the views of carers in relation to the cared for person, including such issues as the current position of the caring relationship and whether this can be maintained. It is also important to offer carers appropriate means of assessing their own needs within what is often a demanding caring role.

A carer should be able to expect the following principles in their relationship with the care team:

- Full recognition and understanding of their contribution
- Support to meet their needs as a carer
- Information to assist their understanding of the patient’s health presentation
- Involvement as a partner in care.

The Good Practice Checklist (appendix 1) produced by the Royal College of Psychiatrists outlines the information that may be shared with carers, subject to the consent issues outlined below.

## **2. SCOPE**

This procedure applies to all employees of the Trust, including all staff who are seconded to the Trust, contract and agency staff involved in the provision of health and social care.

Significant others includes friends and family members who may not wish to be defined as a carer but nonetheless care for and support the patient.

When applying this procedure, there is a marked distinction between general information and confidential information. General information relates to a patient’s general wellbeing and the routines of the unit or service. Confidential information relates to information about the care and treatment of the patient.

## **3. PROCEDURES**

### **3.1. Obtaining Explicit Consent**

In the majority of situations, patients will agree to involving and informing the carer in all areas of their contact with services.

At the earliest opportunity, health and social care professionals should obtain the patient's decision regarding the disclosure of confidential information to carers and significant others. This should be documented in the [Information Sharing Decision Record](#). The form should be stored prominently in any manual health record and also stored on the patient's electronic record.

Health and social professionals will positively emphasise to the patient the benefits of open communication with carers, outlining the positives that can be added to the care package by everybody involved in their care being fully involved in working together.

Obtaining consent is an on-going process and should be re-visited throughout treatment, particularly where new confidential information arises.

A patient's refusal or limitation on consent does not prevent general information being disclosed to the carer, see 3.5 for further information.

### **3.2. Refusal/Limitations on Consent**

Any specific issues patients do not wish to be discussed or disclosed with their carer must be clearly documented.

Where a patient has expressed a wish for confidential information not to be shared, this, in the majority of cases, will be adhered to.

Where staff wish to share information with carers due to a risk to self or others, but the patient has refused consent to share and has capacity, the issue should be discussed at an MDT with legal advice being sought if necessary, there are circumstances where a capacitous patient's wishes can be overridden.

An advance decision/statement made by someone can be overridden at any time by the author. Staff should confirm with the client that the information still reflects their current wishes for how care should be delivered (this may include parameters around confidentiality).

The carer will be made aware of these systems and the timescales that this decision making process will take.

Where urgency does not allow for the process of an MDT or primary care team to meet, the decision to override a patient's unwillingness to share information will be based on an individual's Professional Code of Conduct, Performance and Ethics regarding confidentiality.

Where a carer's request for confidential information cannot be met, staff must inform the carer of the process, be clear that their requests will be discussed with the MDT and the reasons for withholding information that is deemed to be confidential will be explained in full. Continued support to the carer from the staff involved with the patient's care will be ongoing.

### **3.3. Patients who Lack Capacity**

If the individual is unable to give permission to share information due to an assessed lack of capacity at that point in time, the implications of the Mental Capacity Act will need to be considered. The [Mental Capacity Act and Best Interest Decision Making Policy.pdf \(humber.nhs.uk\)](#) must be followed. The assessment of capacity must be recorded on the Capacity Form and the best interest decision on the Best Interests Decision Form. The documents must be stored in the electronic health record and any manual health record.

An example would be a decision to disclose confidential information that is considered essential for the carer to be aware of, such as risk issues and any ongoing care information. Such decisions should be made by the MDT or the Primary Care Team, taking into consideration the views of the carers/significant others as to the likely wishes of the patient and if it is in the patient's best interests to do so.

Where there is a current advance statement/decision that has been made by the patient this should be used to guide practice if possible.

### **3.4. Advanced Statement/Decision and Reviewing Consent**

The use of advanced statements/decisions is encouraged. These allow patients to plan, when they are well, what they would like to happen in the event of them becoming unwell.

If a patient has refused permission for confidential information to be shared with the carer, this decision in the health record should be regularly updated so that all staff are aware of any changes in the patient's attitude regarding confidentiality.

You should use your professional judgement to decide if you need to check whether the patient's decision has changed or may not extend to all information. For example, if a patient has previously refused consent when unwell or if you are considering sharing more sensitive information than has previously been shared with the carer. Consent changes must be documented in the health record so that all staff are aware of any changes in the patient's decision in the sharing of information.

### **3.5. Support/Information for Carers**

There is a marked distinction to be made between general information, such as requests regarding the patient's general wellbeing, routines of the unit or service where care is being provided from and information that can be seen as "confidential" such as details regarding the patient's current health.

When a member of staff is in discussion with a carer/supporter/significant other they should:

- Establish the past/current caring relationship.
- Clarify what the carer/significant other already knows about the client's situation/health difficulties.
- Actively listen to the carer/significant others requests and respond accordingly.

Even when consent is withheld, carers should be given/offered by the named nurse/care co-ordinator:

- General information concerning: mental and general health problems/challenges, Medication (dosages, side effects, what to be aware of).
- Information regarding care processes, routines.
- Signposting to and/or offered help to access organisations that can provide further information and support (Hull Carers' Information and Support Service (CISS)/East Riding Carers Support Service, RETHINK, other condition specific information services).
- Contact details of the named nurse/care co-ordinator on the unit/community team to enable consistent support and reassurance, not only during periods of crises.
- Time and opportunity to share information regarding their unique knowledge of the patient and that this is recognised as an important and valued part of the assessment process.
- Time and opportunity to discuss any difficulties they are experiencing in their caring role and help to try and resolve these.

To ensure that adequate information is given, this information will be discussed with the carer/significant other and also offered as written/printed information where appropriate.

### **3.6. Carers Confidentiality**

Information shared by carers should also be entered into the patient's health record. This information will be classed as "third party" information and carers can, in fact, ask for this information to remain confidential at the point of entry. Carers should be informed that if a patient requests to see their notes under the Data Protection Act 2018/General Data Protection Regulation, this information will only be revealed if the carer consents or if it is possible to disclose the information without revealing the identity of the third party.

Staff can also restrict access to information if it may cause serious harm to the physical and/or mental wellbeing of the patient or any other person. A clear statement of consent/dissent from the carer should be recorded in the case notes on each occasion the carer provides information.

#### **4. REFERENCES/DEFINITIONS**

[Confidentiality Code of Conduct N-061.pdf \(humber.nhs.uk\)](#)

[Mental Capacity Act and Best Interest Decision Making Policy.pdf \(humber.nhs.uk\)](#)

HSCIC: A guide to confidentiality in health and social care

Royal College of Psychiatrists: Carers and confidentiality in mental health leaflet

[Sharing information with unpaid carers - NHS Transformation Directorate \(england.nhs.uk\)](#)

#### **5. USEFUL LINKS**

[Confidentiality and Information Sharing - For Carers, Friends and Family \(rethink.org\)](#)

## Appendix 1: Royal College of Psychiatrists – Good Practice Checklist

Carers are given general factual information, both verbal and written about:

- The mental health diagnosis
- What behaviour is likely to occur and how to manage it
- Medication – benefits and possible side effects
- Local inpatient and community services
- The Care Programme Approach (CPA)
- Local and national support groups

Carers are helped to understand:

- The present situation
- Any confidentiality restrictions requested by the patient
- The patient's treatment plan and its aims
- Any written care plan, crisis plan or recovery programme
- The role of each professional involved in the patient's care
- How to access help, including out of hours services

Carers are given:

- The opportunity to see a professional on their own
- The right to their own confidentiality when talking to a professional
- Encouragement to feel a valued member of the care team
- Confidence to voice their views and any concerns they may have
- Emotional and practical support
- An assessment of their own needs with their own written care plan (i.e. if the patient has a serious mental illness or learning disability).

## Appendix 2 - Equality Impact Assessment (EIA)

For strategies, policies, procedures, processes, guidelines, protocols, tenders, services

1. Document or Process or Service Name: Information sharing with Carers and Significant Others SOP
2. EIA Reviewer (name, job title, base and contact details): Karen Robinson, Information Governance Officer, Mary Seacole Building, Willerby Hill, Willerby. 01482 477856.
3. Is it a Policy, Strategy, Procedure, Process, Tender, Service or Other?: Standard Operating Procedure

<b>Main Aims of the Document, Process or Service</b>
The procedures sets out how the Trust will share information with carers and significant others.
Please indicate in the table that follows whether the document or process has the potential to impact adversely, intentionally or unwittingly on the equality target groups contained in the pro forma

Equality Target Group	Is the document or process likely to have a potential or actual differential impact with regards to the equality target groups listed?	How have you arrived at the equality impact score?
1. Age	Equality Impact Score Low = Little or No evidence or concern (Green) Medium = some evidence or concern (Amber) High = significant evidence or concern (Red)	a) who have you consulted with
2. Disability		b) what have they said
3. Sex		c) what information or data have you used
4. Marriage/Civil Partnership		d) where are the gaps in your analysis
5. Pregnancy/Maternity		e) how will your document/process or service promote equality and diversity good practice
6. Race		
7. Religion/Belief		
8. Sexual Orientation		
9. Gender re-assignment		

Equality Target Group	Definitions	Equality Impact Score	Evidence to support Equality Impact Score
<b>Age</b>	Including specific ages and age groups:  Older people Young people Children Early years	Low	Issues regarding capacity and best interests have been covered in the procedure.
<b>Disability</b>	Where the impairment has a substantial and long term adverse effect on the ability of the person to carry out their day to day activities:  Sensory Physical Learning Mental Health  (including cancer, HIV, multiple sclerosis)	Low	Issues regarding capacity and best interests have been covered in the procedure.
<b>Sex</b>	Men/Male Women/Female	Low	No issues identified
<b>Marriage/ Civil Partnership</b>		Low	No issues identified
<b>Pregnancy/ Maternity</b>		Low	No issues identified
<b>Race</b>	Colour Nationality Ethnic/national origins	Low	Information sharing decision record will be interpreted where necessary.
<b>Religion or Belief</b>	All religions  Including lack of religion or belief and where belief includes any religious or philosophical belief	Low	No issues identified



<b>Sexual Orientation</b>	Lesbian Gay Men Bisexual	Low	No issues identified
<b>Gender Reassignment</b>	Where people are proposing to undergo, or have undergone a process (or part of a process) for the purpose of reassigning the person's sex by changing physiological or other attribute of sex	Low	No issues identified

### Summary

<p>Please describe the main points/actions arising from your assessment that supports your decision above.</p> <p>Potential negative impact in relation to those who lack capacity to consent understanding due to non-English speaking.</p> <p>There are measures in place to mitigate the potential negative impact.</p>	
EIA Reviewer – Karen Robinson	
Date completed: November 2022	Signature: K Robinson