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<p align="center">Information Sharing and Gathering: Co-produced Guidance for the Mental Health Clinical Board</p>	
<p>Introduction and Aim</p> <p>The aim of the co-produced guidance is to ensure consistent, lawful, and respectful practices in sharing and gathering information within mental health services. This includes engaging service users and their families to support effective treatment, safety, and shared decision-making.</p> <p><i>The best people to shape effective mental health services are those people who are accessing them. At Cardiff and Vale University Health Board, we aim to work co-productively with service users, family members, trusted friends and carers, who have lived experience of navigating the mental health system to involve them in decisions about how these services should be delivered. As a result, the Cardiff and Vale Mental Health Clinical Board (MHCB) has commissioned Caniad, an organisation that supports people who want to have their voices heard, influence decisions, and help to shape mental health and substance misuse services. Clinicians from the MHCB, with individuals with lived experience as a service user or carer, have worked together to produce this guidance document.</i></p>	
<p>Objectives</p> <ul style="list-style-type: none"> • <i>Improve patient experience and safety in the care they receive.</i> • <i>Enhance understanding of consent to share information within the MHCB.</i> • <i>Provide guidance to understand when confidentiality should be breached in-line with the law.</i> • <i>Enhance family and network engagement in gathering relevant information to support the care of a service user supported by the MHCB.</i> • <i>Enhance sharing information with service users and to enable shared decision making.</i> • <i>Development of resources to support the guidance in practice.</i> 	
<p>Scope</p> <p>This procedure applies to all of our staff in all locations including those with honorary contracts within the MHCB.</p>	
Equality and Health Impact Assessment	<i>An Equality and Health Impact Assessment (EHIA) has not been completed as the document is guidance.</i>

Documents to read alongside this Procedure	Cardiff and Vale University Health Board Privacy Policy for Patients and their Families
Approved by	<i>Approved by the MHCB Controlled Document Oversight Group.</i>

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<u>Disclaimer</u>	
If the review date of this document has passed please ensure that the version you are using is the most up to date either by contacting the document author or the Governance Directorate .	

Summary of reviews/amendments			
Version Number	Date of Review Approved	Date Published	Summary of Amendments
1	24/10/2025	08/12/2025	<i>New Guidance Development</i>

1. Introduction

Effective and ethical information sharing and gathering is vital for safe, person-centred mental health care. Involving service users, family members, trusted friends and carers respecting confidentiality, and prioritising shared decision-making supports recovery and strengthens therapeutic relationships.

This document will provide guidance on:

- Consent to share processes within the MHCB
- When to breach confidentiality
- Sharing information with service users
- Good practice on information gathering

This guidance has been co-produced, drawing on insights from both lived experience and clinical practice, with direct quotations included to illustrate key points.

The term "service user", is used throughout the document and refers to a person who accesses or receives services from the MHCB.

In this document a carer refers to a person who is a significant part of their life and provides unpaid support for a loved one. This may be a friend, spouse, young carer, sibling. Individuals may not see themselves as a carer, but may identify as a trusted friend, part of their network or a loved one. These terms have been used interchangeably throughout the document.

The guidance aims to improve patient safety, experience and outcome by detailing practice that should be used and promoted. This should be used alongside clinical judgement and the law, aligning to professional responsibilities.

1. Consent to Share

We will always seek a service users informed consent before sharing information about their care or treatment. Adults are presumed to have capacity unless there is a reason to doubt this, in which case we will follow the Mental Capacity Act (2005). Consent is voluntary, can be withdrawn at any time and will be reviewed regularly. In some cases, information may need to be shared without consent. For example, where required, a patient who is detained under the Mental Health Act (1983) where there is risk indicated which would warrant a breach in confidentiality. To protect the person or other from serious harm, or to meet legal and safeguarding duties. Any decision to share information will be limited to what is necessary and will be clearly documented (It is important to note that this will only apply in line with the law).

Consent to share information in the MHCB means that a service user gives permission for information relating to their care and treatment to be shared with specific people or agencies.

Informed consent will ensure that service users understand:

- What information will be shared
- With whom (e.g., family, GP, other professionals)
- Why it is being shared (e.g., treatment coordination, safety)

- What might happen if they choose not to share

Types of information often shared includes:

- Mental health assessments
- Diagnosis and recovery pathways
- Care and treatment plans (CTP)
- Crisis plans
- Safety plans
- WARRN risk formulations
- Risk and safety concerns
- Discharge plans
- Admission plans
- Key meetings such as ward round and outpatient appointments

Legal Basis of Information Sharing

Processing for Direct Care Purposes

Cardiff and Vale University Health Board (UHB) processes personal data for the purposes of providing direct care to patients in accordance with the UK General Data Protection Regulation (UK GDPR). The lawful basis for this processing is:

- **Article 6(1)(e):** Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller (the UHB's 'public task').
- **Article 9(2)(h):** Processing is necessary for the purposes of preventive or occupational medicine, medical diagnosis, the provision of health or social care, or the management of health or social care systems and services (special category data for health/social care services).

The Information Commissioner's Office (ICO) provides further guidance on the use of the public task lawful basis (Public task | ICO) and on processing special category data (Special category data | ICO).

Consent and Direct Care

Where information is processed for the purposes of a patient's direct care, **consent is not the lawful basis** for processing. Agreement to receive direct care services is not the same as consenting to information sharing. The lawful basis arises from the provision of direct care itself. However, it remains essential to consider the patient's reasonable expectations and to respect any objections they may raise regarding the sharing of their information.

When Consent is Required

If information sharing falls outside the parameters of direct care (for example, sharing information with solicitors or third parties not involved in direct care), it may be necessary to seek explicit consent from the patient. This is to ensure compliance with the common law duty of confidence, which applies to confidential patient information within the patient–clinician relationship. The NHS Code of Practice on Confidentiality, while dated, remains a useful reference for the key principles underpinning confidentiality in healthcare.

Caldicott Principles

This policy is underpinned by the Caldicott Principles, which guide the use and sharing of patient information. In particular, **Principle 7** states:

“The duty to share information for individual care is as important as the duty to protect patient confidentiality.”

This principle reflects the balance between sharing information to support safe and effective care and maintaining the confidentiality and trust of our service users.

Discussing consent to share

Consent must be voluntary, based on clear communication, and ideally given in writing. Staff must facilitate conversations about involving others:

“With your permission, I’d like to share details of your care plan with your mother, who’s been supporting you at home. This will help her understand how to respond if you become unwell. You can choose what information is shared, and you can withdraw consent at any time.” – quotation from a clinician working within MHCB.

If consent is refused but sharing and gathering information is essential for safety, explain:

- Why the decision was made e.g. discussing a Mental Health Act assessment outcome with the Nearest Relative, they are named on a safety plan, imminent risks.
- What will be shared, with whom, and how e.g. sharing information with a GP regarding care and treatment, sharing discharge plans to a person that cares for them.

How to record consent to share

In the MHCB, consent to share is recorded on the electronic note system PARIS on a form called ‘Consent to Share 2a’, which is saved under clinical information.

An example of this is below:

FORM 2A CONSENT TO INFO SHARE Expand all Collapse all Send to folio Print Notify More actions

Consent To Share Information More actions

(CPA) FORM 2A
 Services are delivered by teams of professionals. It will be necessary for other members of the team, who may be involved in your care, to have access to information about you, on a need to know basis. This will include your GP, medical staff, nurses, including midwives and health visitors, occupational therapists, social workers, and psychologists.

In addition to those listed above I am happy for necessary information about me to be shared with the following people (eg specifically named family members, named voluntary bodies / workers)

Share information with:

Prefer not to share information with:

If you change your mind and wish to alter those listed on this form then ask your Care Coordinator

There may need to be some circumstances where agencies duties in the public interest, may require the disclosure of information that would otherwise be kept confidential. Examples of this include where a child is at risk, or where there is evidence of serious criminal activity.

The services Cardiff and Vale UHB provides are funded by the NHS and Local Authority. Information will be stored on computers and / or on paper as part of your care record to enable these organisations to carry out the necessary management, administrative and other work required to deliver your care safely and effectively. If we arrange a service from a third party (eg day care from a voluntary organisation, housing related support from a housing association) we may pass information they require to meet your needs. You have a right to ask to see the records kept about you.

Service User agreed Date agreed

(For printed forms only)
 Service User Signature Date

“You need to know what is important to the person” – quotation from a service user of the MHCb.

On the consent to share form details should be added such as:

- Who the service user wants information to be shared with i.e. trusted friend, loved one, family member and/or wider network.
- Contact details for the person or organisation named in the consent to share.
- Any specific information they would like to add which can support in information sharing such as days or time of the week they can be contacted.
- Who the service user does not want information to be shared with.
- Any specific information a service user does not want to be shared.
- If preferred by the service user, or as a safeguarding measure a password could be created which is known by staff and those who the service user has given consent to share.
- The date and time the consent to share was agreed.

Please note contact details for family members and loved ones should also be included under associated people. The contact information should be checked on a regular basis to ensure the information is up to date. Consent to share must be reviewed regularly, especially if the service users presentation, care team changes, or a new request has been made by the service user.

The expectation is that as a minimum this consent to share is reviewed annually (if the service user has annual reviews), however if new contact is made with a team consent to share must be completed. For example, a service user is

referred from the community mental health team to the crisis team/ hospital admission. This would trigger a new consent to share.

If no consent to share has been provided.

If no consent to share information has been given, it can lead to family members feeling isolated, upset and frustrated:

“It feels like a battle to get info” – quotation from a family member of a service user

“On one of my visits to see my son in the adult mental health ward, I was told I was not able to see him as he did not want to see me. It was devastating to hear that I was not able to see my son” – quotation from a family member of a service user

In these situations, staff should respond in a compassionate and transparent way. An example of this below:

“I can hear how worried you are, and I really appreciate you reaching out and wanting to support them. At the moment, I’m sorry to say they haven’t given us permission to share details about their care or situation. I hear how difficult and frustrating that can feel, especially when you’re concerned about their wellbeing.

While I can’t share personal information right now, I can still listen to any concerns or feedback you have. If there’s something you think we should know that could help us support them, please do share it. Also, I’m happy to talk in general terms about the support we can offer, and ways you might be able to help them, even without the full picture. I will document your concerns, and your views on sharing this information. I will continue to discuss consent to share and let you know if this changes. ” – quotation from a clinician working within MHCB.

The importance of sharing information

Services need to engage and collaboratively work with individuals, their families and networks. This should include sharing information to develop Care and Treatment Plans. Involving the service user in creating their plan gives them a sense of control over their care. It helps build trust and engagement, a shared responsibility, and better outcomes (National Institute for Health and Care Excellence, 2019).

The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH, 2025) reports that collaborating more closely with families can strengthen suicide prevention efforts. Services should actively involve families from the first point of contact, continuing throughout the entire care pathway, including during the development of crisis plans and hospital discharge planning.

“Even though patients are effectively being cared for by families following discharge, family don’t have info to help them do this” – quotation from a family member of a service user

With consent, family members, carers, trusted friend and network must be invited to key collaborative meetings such as ward rounds, discharge planning meetings and Care and Treatment plan reviews. It is the expectation that this is standard practice to support co-production.

Co-producing care and treatment plans with service users and their family transforms care from something done *to* someone into something built *with* them. This can lead to safer, more effective, and more compassionate mental health support.

2. Breaching confidentiality

- Confidentiality is central, but sharing may be appropriate if **failure to share increases risk of death or serious harm**. This approach aligns with UK GDPR and Data Protection Act 2018 legal frameworks. Service users must understand when and how information might need to be shared, including circumstances that override confidentiality (e.g., imminent risk). Breaching confidentiality in these circumstances is supported by the MHCB, professional bodies and law. The Department of Health (2021) produced a consensus statement with:
 - Royal College of Psychiatrists
 - Royal College of General Practitioners
 - Royal College of Nursing
 - The Royal College of Midwives
 - Institute of Health Visiting
 - Directors of Adult Social Services (ADASS)
 - The British Association of Social Workers
 - The British Psychological Society
 - Mental Health Network NHS Confederation

“We strongly support working closely with families. Obtaining information from and listening to the concerns of families are key factors in determining risk. We recognise however that some people do not wish to share information about themselves or their care. Practitioners should therefore discuss with people how they wish information to be shared, and with whom.

Wherever possible, this should include what should happen if there is serious concern over suicide risk.

We want to emphasise to practitioners that, in dealing with a suicidal person, if they are satisfied that the person lacks capacity to make a decision whether to share information about their suicide risk, they should use their professional judgement to determine what is in the person’s best interests in accordance with section 4 of the Mental Capacity Act 2005.

We also wish to remind practitioners that for the purpose of data protection law, if consent cannot be given, or reasonably expected to be obtained, from an individual considered to be at risk of neglect or harm, or obtaining consent would prejudice the provision of protection from neglect or harm, disclosure without consent may also be made where there is a legal power to share and it is necessary for reasons of substantial public interest.

It is important that the practitioner records their decision about sharing information on each occasion they do so and also the justification for this decision.

Even where a person wishes particular information not to be shared, this does not prevent practitioners from listening to the views of family members, or prevent them from providing general information such as how to access services in a crisis.”

Full information on the consensus statement can be found here:

[Information sharing and suicide prevention: consensus statement -](#)

[GOV.UK](#)

If someone lacks capacity and is at imminent risk, practitioners should use judgment in the person’s best interests, following Mental Capacity Act principles (add link).

When an individual lacks the capacity to make a decision for themselves, their right to confidentiality remains protected. However, information about them may be shared when it is necessary to provide appropriate care or treatment, to protect their safety or the safety of others, or when required by law. Any decision to share information must be in the individual's best interest, taking into account their known wishes, feelings, values and any views from those legally authorised to act on their behalf, such as a Lasting Power of Attorney or Court Appointed Deputy. Information should only be shared with those who need to know the minimum necessary should be disclosed. A clear record must be kept of what information was shared, who whom and the reasons for doing so.

A quick reference guide can be found in **Appendix I**.

3. Information Gathering

Even without consent, staff working within the MHCB should listen to family concerns and have an open-door approach to receiving information for this to occur.

“How do I know if this information is being logged or not?” – quotation from a family member of a service user.

Staff should reassure the person who has contacted the team that their input is valued and has been appropriately logged onto PARIS (this can be documented under carer contact). Agreed actions should be shared, such as the information has been escalated to their Responsible Clinician. Staff should clarify any confidentiality limits whilst encouraging ongoing communication. It is important to make sure there is a shared understanding of what information has been provided, therefore active listening and summarising the information back can support this.

Open dialogue is an approach within the MHCB which puts network members alongside the person of concern in hearing what is important to each network member. It is a collaborative approach to decision making which incorporates ‘no decision about me, without me’. In this context a network is defined by their social network. This could be friends, family, involved staff members etc. Voices within the network are given equity, and the network find solutions for what is important to the individual.

Biographical tools can be used in a person-centred way. The biographical tool used in CVUHB is ‘read about me’, and encourages conversations with services users, carers, family members and trusted loved ones. This tool is used within Mental Health Service for Older People as an opportunity to gather patient centred information.

Staff should provide family and loved ones with general (non-confidential) safety information such as:

- Contact details of the service users care team and general information on the service, without confirming if the service user is under the care.
- Within a community facing team, the role of the duty worker and how to contact them (except for the Crisis Home Resolution Treatment Team which runs 24/7, duty workers can be accessed 9am to 5pm Monday to Friday). NHS 111 (Option 2). This is the primary service for urgent mental health needs in Wales. You can call 111 and press option 2 to speak with a mental health professional directly. This service is available 24/7, regardless of your location in Wales. It's free to call, even from a mobile with no credit.
- 999 or attendance at an Emergency Unit for life threatening and emergency concerns.
- General signposting advice relating a specific concern such as housing support, substance misuse support, benefits, debt management can be provided. This list is not exhaustive.

Family, loved ones and carers should also be signposted to carer support and advice such as:

- Cardiff and Vale Recovery College: Experience of Caring (<https://cavuhb.nhs.wales/our-services/welcome-to-the-cardiff-and-vale-recovery-wellbeing-college/>)
- Resources for unpaid carers (<https://cavuhb.nhs.wales/patient-advice/patient-experience/unpaid-carers-information-service/resources-for-unpaid-carers/>)
- Adferiad (<https://adferiad.org/our-services/carers/>)
- Caniad CVUHB (<https://adferiad.org/services/caniad-cvuhb/>)
- Carers Assessment for those living within Cardiff Council (<https://www.cardiff.gov.uk/ENG/resident/Social-Services-and-Wellbeing/Carers/Carers-assessment/Pages/default.aspx>)
- Carers Assessment for those living within the Vale of Glamorgan Council (https://www.valeofglamorgan.gov.uk/en/living/social_care/adult_services/Unpaid-Carers/Carers-Assessment.aspx)
- Solace (carer support for older adults)
- Dewis Cymrun
- Carers Wales
- Concerns/PALS

4. Ensuring inclusivity

Inclusivity ensures that every individual regardless of their background, identity, language, ability, or circumstance can access, understand, and benefit from healthcare services. It is not only a legal and ethical obligation but a cornerstone of compassionate, person-centred care.

NHS Wales has a legal obligation to provide interpretation and translation services, including British Sign Language, to ensure equitable access to healthcare. Options include:

- Telephone interpretation via Language Line
- Face-to-face interpreters through WITS
- Online interpretation with the use of Microsoft Teams and other videoconferencing
- Document translation for written materials.

Under the Equality Act 2010, the MHCBC must make reasonable adjustments to ensure disabled individuals can access and understand shared information. This includes:

- Using accessible formats (e.g. Easy Read, large print)
- Providing communication support (e.g. interpreters, assistive technology)

5. Training and Resources

The consent lead for the UHB can face-to-face training to the UHB on a request basis in a group format.

Consent training on ESR is now mandatory and has a refreshment period of 3 years.

Information sharing and gathering in the context of risk is contained in the Mental Health Clinical Board WARRN and Suicide Awareness and Mitigation Training.

Thank you to Caniad and the clinician representatives who generously contributed their time, insights, and experiences through workshops to support the development of this document.

References

Department of Health and Social Care (2021) Information Sharing and Suicide Prevention: Consensus Statement. Available at: [Information sharing and suicide prevention: consensus statement - GOV.UK](#) (Accessed 11.07.2025)

The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH, 2025) *Resources* [online] Available at: <https://sites.manchester.ac.uk/ncish/resources/> (Accessed 29.06.2025)

National Institute for Health and Care Excellent (2019) *Suicide Prevention Quality Standard* [online] Available at: <https://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-behavioural-and-neurodevelopmental-conditions/suicide-prevention> (Accessed 29.06.2025)

Appendix I: Information sharing quick reference guide

	Consent	Information which can be shared	Legal basis for sharing information
Service user with capacity	Service user gives consent	Any information can be disclosed for which consent is given.	- Service user consent - UK GDPR A 6 1(a) & 9 2(a)
Service user lacks relevant capacity	Service user unable to give informed consent	Can share relevant information in line with Mental Capacity Act– requires capacity assessment and best interest’s decision.	- UK GDPR UK GDPR A 6 1(e) A 9 2 (c) & Schedule 1 Part 2 DPA 2018 - DPA 2018, Schedule 2 Part 1 - Human Rights Act 1998 (HRA) 1998 Art. 2 & 3. 2)

			Mental Capacity Act
Service user with capacity	Consent not obtained but not refused (e.g. physically unable to contact ex-service user or inability to seek consent due to time constraints).	Necessary, proportionate, and relevant information shared, in an emergency situation only where it is not reasonable to obtain consent.	- UK GDPR A 6 1(e) UK GDPR A 9 2 (c) & Schedule 1 Part 2 DPA 2018 - DPA2018 Schedule 2 Part 1 - Perhaps Human Rights Act 1998 Art. 2 & 3.
Service User with capacity	Service user refuses consent. Risk to service user only and harm is not serious.	No information can be shared.	None
Service User with capacity	Service user refuses consent. Risk to service user only and harm is serious (e.g. risk of murder, rape, manslaughter).	Necessary proportionate and relevant information.	-UK GDPR A 6 1(e) & A 9 2 (g) & Schedule 1 Part 2 DPA 2018 -DPA2018 Schedule 2 Part 1 Public interest in safeguarding outweighs duty of confidentiality - Perhaps Human Rights Act 1998 Art. 2 & 3
Service User with capacity	Service User refuses consent. Risk to other adults or significant harm to children.	Necessary proportionate and relevant information.	-UK GDPR A 6 1(e) & A 9 2 (g) & Schedule 1 Part 2 DPA 2018 -DPA2018 Schedule 2 Part 1 -Perhaps Human Rights Act 1998 Art. 2 & 3. -Children's Act 1989.
Service User who is alleged to have committed abuse	Consent not sought (due to risk to others).	Necessary proportionate and relevant information about risk to others.	-UK GDPR A 6 1(e) A 9 2 (g) & Schedule 1 Part 2 DPA 2018 -DPA 2018 Schedule 2 Part 1 -Perhaps Human Rights Act 1998 Art. 2 & 3. Criminal Justice Act 2003 Schedule 2 35.
Service User who is alleged to have committed significant harm against children	Consent either not sought or withheld.	Necessary, proportionate, and relevant information on significant harm to children, unless this would be unreasonable in all the circumstances of the case.	-UK GDPR A 6 1(e) A 9 2 (g) & Schedule 1 Part 2 DPA 2018 -DPA 2018 Schedule 2 Part 1 -Possibly Human Rights Act 1998 Art. 2. -Criminal Justice Act 2003 s.235 - Children's Act 1989.
Former Service User	Unable to obtain consent within timescale.	Limited information – was the person known to Cambridge & Peterborough Foundation Trust	-UK GDPR A 6 1(e) A 9 2 (g) & Schedule 1 Part 2 DPA 2018 - DPA 2018 Schedule 2 Part 1 -Possibly Human Rights Act 1998 Art. 2. -Criminal Justice Act 2003 s.235
Service User at risk of exploitation by terrorists	Consent either not sought or withheld.	Necessary, proportionate, and relevant information on risk of harm to patient and others	-UK GDPR A 6 1(e) A 9 2 (g) & Schedule 1 Part 2 DPA 2018 - Prevention of Terrorism Act 2000 19 - DPA 2018 Schedule 2 Part 1

<p>A dead service user</p>	<p>Consent not possible</p>	<p>when disclosure is required by law</p> <p>when a person has a right of access to records under the Access to Health Records Act 1990 (Executor of the will/Proof of Claim) and the service user had not stated that it should not be shared.</p> <p>All requests for sharing information must be passed to the Trust's Access to Records Department for processing.</p>	<p>DPA 2018 Schedule 2 Part 1 (5)</p> <p>Access to Records Act 1990 section (3)(1)(f)</p>
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