

CARER ENGAGEMENT AND INVOLVEMENT GUIDANCE
















PICU
QUALITY NETWORK
FOR PSYCHIATRIC
INTENSIVE CARE UNITS

Editors: Maisie Webster, Ciara McAree,
Kelly Rodriguez

Date: August 2023



CONTENTS

	BACKGROUND	3
	PURPOSE.....	3
	CONSENT AND CONFIDENTIALITY	4
	BARRIERS.....	5
	WARD-LEVEL EXAMPLES	6
	HOSPITAL-LEVEL EXAMPLES.....	7
	ORGANISATION-LEVEL EXAMPLES.....	8
	QNPICU FAMILY AND FRIENDS STANDARDS: GOOD PRACTICE EXAMPLES	9
	INVOLVEMENT WITH QNPICU	12
	APPENDIX 1: ACKNOWLEDGEMENTS	14
	APPENDIX 2: GOOD PRACTICE EXAMPLE DOCUMENTS.....	15
	APPENDIX 3: REFERENCES	15
	APPENDIX 4: CONTACT DETAILS	16

BACKGROUND

Psychiatric Intensive Care Units (PICUs) face a number of barriers to engaging carers due to the nature of services. Carer engagement is frequently an item for discussion during QNPICU peer-reviews, with services looking for ways in which they could increase their engagement with carers. There have also been barriers to engaging carers in QNPICU processes. As a result of this, the QNPICU Carers Working Group was introduced. The group explored the barriers PICU services face when trying to engage carers and identified good practice examples. Additionally, the group reviewed the Family and Friends section of the QNPICU standards as part of the wider standards revision processes.

PURPOSE

This guidance document aims to provide PICU services with good practice examples to help improve their engagement with carers. Within the document, the Family and Friends standards from the QNPICU 3rd edition (2023) have been included, with examples outlining what services can implement in order to meet these.

JARGON BUSTER

For the purpose of this document, the term **'carer'** will refer to any family, friend, visitor or loved one of a patient.



JARGON BUSTER

'QNPICU' is the **Quality Network for Psychiatric Intensive Care Units**. We measure PICU services against a set of Quality Standards through the process of peer-review.



CONSENT AND CONFIDENTIALITY

During QNPICU peer-reviews, we often hear that staff are unsure of what information they can and cannot share with carers. This uncertainty may mean that carers feel excluded from discussions relating to patient care, leading to valuable information and the opportunity to offer support to carers being missed. To overcome this, staff need to be aware of both the limits of confidentiality and the information that can, and should, be shared with carers.

Mutual expectations around confidentiality should be discussed in conversations between patients, carers and staff as soon as possible following admission. These mutual expectations should also be reviewed at regular intervals.

Where patients give consent to information being shared, this should be done. Although this should be reviewed regularly, consent does not need to be gained before every discussion with a carer. Where patients have given consent for carer involvement, staff should invite and encourage carers to attend any relevant meetings, with services making reasonable adjustments as needed (such as providing carers with the opportunity to attend virtually via an online meeting or via a phone call, as well as considering whether travel support is required for those attending in person).

When a patient withdraws consent, carers can still receive non-confidential information, for example, general information about the service. Furthermore, staff do not require patient consent to speak to carers, receive information from them, or offer support to them. Additionally, carers have the same right to confidentiality for any information disclosed, and staff must respect this (The Triangle of Care, 2013).



BARRIERS

During the carers working group meetings, some key barriers to carer engagement explored included:

LENGTH OF STAY

The majority of patients will be on a PICU ward for a short time. This can make it challenging for staff to build relationships with carers as they have a short timeframe to make contact with, gather information from and offer support to carers. This can be particularly challenging where carers are difficult to identify due to the patient being unwell/unable to provide contact details.



PREVIOUS EXPERIENCES

Carers may have had negative experiences with other services in the past. This could affect how they feel about services. This is something staff should be aware of during their interactions with carers.



DISTANCE FROM SERVICE

Carers may live far away from the service and find it difficult or costly to visit or attend meetings.



STAFFING PRESSURES

Nationally, many PICU services are facing difficulties with short staffing. This can make it challenging for staff to make contact with carers and build relationships.



CARERS TIME

Many carers have jobs and other responsibilities which mean they cannot always communicate with services during core working hours.



GOOD PRACTICE EXAMPLES

The below good practice examples have been shared by the members of the QNPICU Carers Working Group. These examples have been categorised as initiatives to be introduced at ward-level, hospital-level and Organisation-level, as some funding may be required:

WARD-LEVEL EXAMPLES

A checklist for initial phone calls



This should include key questions to ask carers and a list of information which can and cannot be shared with carers, based on whether their loved one has given consent for their involvement in their care. This allows all staff members to confidently communicate with carers, not just those who have taken a lead role in carer engagement.

Ward-specific carers information pack



This should include key information about the ward, such as contact details for key staff, admission criteria, therapies/activities available to patients, visiting processes and pictures of the ward environment. This should also include information around local sources of advice and support for carers, carer support networks and how to access a statutory carers' assessment.

Proactive communication



When a patient is admitted, the ward should allocate one staff member to proactively make attempts to contact their carer as soon as possible. The aim is for this staff member to be the key contact for that carer throughout their loved one's stay.

Weekly contact



An appointed staff member should have allocated time on a weekly basis to contact carers to provide updates, gather feedback and to ask what the service can be doing to support them. This could be done via telephone calls, emails or letters.

WARD-LEVEL EXAMPLES

Carers champion



A carers champion should be identified for the ward. This is a member of staff who supports carers and acts as a key contact for carer information for the ward. They also aim to improve communication and engagement with carers and act as a link to gather information from the carer and cascade it to the team. This is an additional responsibility for a staff member who is passionate or has a key interest in carer engagement.

Carer awareness training



Provide all staff members with carer awareness training. This could be done via e-learning or in person training. Ideally, a carer expert by experience would be involved in the design and delivery of this training.

HOSPITAL-LEVEL EXAMPLES

Carers contact audits



During first contact, carers should be asked how frequently they would like to be contacted by the service. Contact with carers should be audited at ward/hospital level on a monthly basis to identify whether the frequency of contact is in line with the requests of carers.

Weekly carers meetings



A weekly meeting should be held which run for an hour and allow carers to ask questions, raise concerns and have discussions with the team. This could be with specific staff members each week, or with rotating staff members from different disciplines. Options to join virtually/over the phone should be offered.

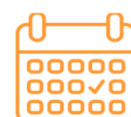
HOSPITAL-LEVEL EXAMPLES

Carers lead



A carers lead should be recruited for the ward/hospital. This would be a standalone role and could involve reviewing and updating carers' information packs, conducting quality improvement projects around carer engagement, delivering carer awareness training to staff (which should be co-designed/co-delivered with carers), being the main point of contact for all carers and organising carer visits to the service.

Carers events



Carers events should be held at the service to allow carers to socialise with other carers and spend time with their loved ones in a social setting. These events could be carer focused educational events, or casual events for patients and carers to enjoy, for example, a summer fair, festive market or afternoon tea. These events could also be facilitated on a larger scale by the Organisation.

ORGANISATION-LEVEL EXAMPLES

Carer involvement and engagement strategy



A carer involvement and engagement strategy should be developed in partnership with appropriately experienced carers. The strategy could include measures to support a carer's own needs around information and support, how they can be involved in the care of their loved one and opportunities to be involved in service developments, training and improvements.

Organisation-wide carer information



An Organisation-wide carers information pack should be created which details the Organisation's carer initiatives, strategies, relevant policies and opportunities for involvement. This should be provided in conjunction with ward-level information.

Electronic carer records

A dedicated carers area should be available on the electronic system used by the organisation. This is to record details of carers, including their contact details and frequency of contact. This should be created in line with GDPR.



QNPICU FAMILY AND FRIENDS STANDARDS: GOOD PRACTICE EXAMPLES



Jargon Buster

The Third Edition of the QNPICU Standards was published in July 2023. Type 1 Standards are 'Essential', Type 2 Standards are 'Expected' and Type 3 Standards are 'Desirable'. The full edition of the standards can be found [here](#).



Standard 69 (Type 2)

The team provides each carer with accessible carer's information.

Service email accounts have been set up for carers to contact, making the team more accessible. Carer champions are in place who attend carers meetings and have developed a new carers information booklet.

Cobden Unit, Pennine Care NHS Foundation Trust

Clinicians have an hour each week protected for carers and try to spend this time answering questions "over a cup of tea". This helps carers to ask questions that they may not be confident asking in front of the entire team, or may not want to ask in front of their loved one.

Nile Ward, Central and North West London Foundation Trust

Standard 70 (Type 1)

Carers are supported to access a statutory carers' assessment, provided by an appropriate agency.

The carer's information pack is comprehensive, and includes key information for carers such as how to access a statutory carers' assessment and how they can be involved in their loved one's care. Carers are proactively supported in accessing this assessment following written information.

Caspian Ward, Central and North West London Foundation Trust

Standard 71 (Type 2)

Carers are offered individual time with staff members, within 72 hours of the patient's admission, to discuss concerns, family history and their own needs.

As a part of the admission process and checklist, time is taken to contact carers to not only gather information about their loved one and their history which supports initial assessments and risk assessments but also to discuss their concerns and how the service can support them. The aim is to do this within 72 hours of admission.

Ward 1, IPCU, NHS Lothian

Standard 72 (Type 2)

Carers feel listened to and supported by the ward staff members.

Carers spoke highly of staff and felt that they were approachable, accessible, and always available to speak to them, even if carers called during the night. A carer provided an example of this stating that when they brought items to their loved one, such as clothing or food, one of the staff members would come out to introduce themselves and provide an update on their loved one.

Sherbourne PICU, Coventry and Warwickshire Partnership Trust

There is a carers centre onsite that is signposted to carers, this is a place where carers can go to talk before or after their visit and is open throughout the whole week 10am-4pm. Carers can also stay overnight in this centre in case they travel long distances to visit their loved one. The accommodation is open seven days a week, 365 days a year.

Heygate Ward, St Andrew's Healthcare

The carers spoken to on the day spoke highly of the service and fed back that there was 'fantastic communication' between them and the team. There was daily contact and they were informed that they could contact the service at any time for information. The social work input at the service is noteworthy, the carers spoke highly of the work that they have done and stated that they have been supportive and informative throughout the whole process. They receive regular progress reports from the social worker.

Bayley Ward, St Andrew's Healthcare

The service goes above and beyond to alleviate my concerns, provide support and give me information over the telephone.

PICU Harlands Hospital, 2020-2021

They answer all my questions and are very helpful!

IPCU Tayside, 2020-2021

They really took the time to explain the medication and take my son's concerns seriously. I am extremely impressed with Nile ward.

Nile Ward, 2020-2021

Standard 73 (Type 1)

Carers are supported to participate actively in decision making and care planning for the person they care for, where the patient consents. This includes attendance at ward reviews.

Carers are regularly invited to be involved in the decisions around the care and treatment of their loved ones. They are also accommodated if they cannot attend face to face meetings and events as they can join ward rounds remotely and are kept updated with the patients' progress overall.

South Hampton Ward, Cygnet Health Care

Standard 74 (Type 1)

The team knows how to respond to carers when the patient does not consent to their involvement.

Carers shared that when their loved one has withdrawn consent, the service continued to share general information and always reassures carers their loved one is 'well and safe'. There are also procedural reminders for all staff, including a family admission checklist for nurses and a specific family support care plan template to support with this.

Nile Ward, Central and North West London Foundation Trust

Standard 75 (Type 2)

Carers have access to a carer support network or group. This could be provided by the service, or the team could signpost carers to an existing network.

A weekly carers clinic to help support carers has been developed. During this clinic carers can talk to the staff team about their loved one and general hospital provision. There is also space to talk about the anxieties they may have as carers with other carers.

ES1, South London and Maudsley NHS Foundation Trust

Standard 76 (Type 1)

Staff agree leave plans with the patient's carer where appropriate, allowing carers sufficient time to prepare.

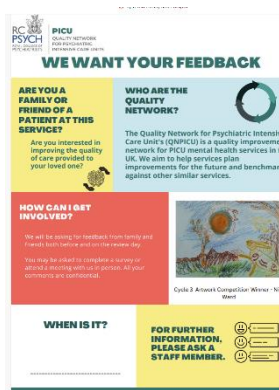
*This is a **new** standard and therefore does not have any good practice examples from services. To meet this standard, we would expect feedback from carers reflecting that they have been involved in developing their loved one's leave plans. For example, the service may reach out to carers before any planned leave to gather their feedback.*

INVOLVEMENT WITH QNPICU

The involvement of carers on our peer-review days is vital. We would like to work collaboratively with our member services to find ways in which we can engage carers and gather their feedback in a meaningful, confidential way. Gaining feedback from carers about their experiences is an important part of the peer-review and there are a number of ways this can be facilitated:

NETWORK POSTERS

Services should inform carers of the upcoming peer-review in advance, signpost carers to the Network's website and explain how carers can be involved before and during the review. This can be explored via email, during calls with staff members, during visits and/or meetings. Services can use the Network's poster for carers (sent via email during the self-review phase) to help advertise the date and encourage carers to attend in person or virtually to speak with the peer-review team. It is important to explain that the review team will want to talk about their experience of the service, and they do not need consent from their loved one to be involved.



SURVEYS

When the Quality Network representative contacts the service regarding survey links and paper copies of surveys, the service should disseminate these (both links and paper copies) and request pre-paid envelopes at the earliest possible convenience. The staff member responsible for carer involvement should support carers in completing these and remind carers regularly during the self-review period to complete these.



REVIEW ATTENDANCE

Services should widely advertise the date of the peer-review and send out formalised invites following the same process as with other carer events. To encourage attendance in person, services should consider offering carers the opportunity to visit their loved one on the day of the peer-review and inviting them to partake in the lunch and networking session of the peer-review.

INVOLVEMENT WITH QNPICU

VIDEO CONFERENCING

Where carers are unable to visit the service face to face, the service should organise an MS Teams meeting (or equivalent) with the peer-review team to be able to feedback on their experiences virtually as a group. Carers can join the meeting at the allocated time via telephone or laptop/computer. Carers do not need to have their cameras on if they do not wish to.



TELEPHONE CALLS

Where carers do not have access to the internet, or would prefer to provide feedback individually, the service should prepare a list of carers the peer-review team can call during the peer-review day. The peer-review team can arrange to speak to a number of carers during the allocated slot. Services should seek consent from carers for the peer-review team to make contact and inform them of the time the peer-review team is likely to call.



INTERVIEW QUESTIONS

Where carers express interest in engaging with the peer-review but cannot attend on the date set, the Quality Network representative can share the interview questions with the service to be shared with the carers. The completed question sheet can then be returned within an agreed timeframe.



Contact us

We would like to hear from you if you have any other ideas on how to involve carers in the peer-review process, so that we can share this with other services. Additionally, feel free to contact us if you have any questions regarding this document.

Please contact us at:

Email: picu@rcpsych.ac.uk



APPENDIX 1:

ACKNOWLEDGEMENTS

The Quality Network for Psychiatric Intensive Care Units is extremely grateful to the members of the Carers Working Group for their time and expertise in the development of this guidance document:

Dino Patel, Carer Representative, The Royal College of Psychiatrists

Laura Sheridan, Group Service Improvement Manager, Cygnet Health Care

Jutta Neumann, Senior Support Worker, Cygnet Health Care

Sarah Stephenson, Social Worker, Cygnet Health Care

Eve Kaklamanos, Clinical Manager, Cygnet Health Care

Fiona Kennedy, Group Social Work Lead, Cygnet Health Care

Sharon Spurling, Head of Network Development, Carers Trust

Ellie Johnstone, Lead Social Worker, St Andrew's Healthcare

Jenna Matthews, Carer Experience and Improvement Manager, Lancashire and South Cumbria NHS Foundation Trust

Mariella Cantoni, Assistant Psychologist, Central and North West London NHS Foundation Trust

Paul Hann, Assistant Psychologist, Central and North West London NHS Foundation Trust

APPENDIX 2: GOOD PRACTICE EXAMPLE DOCUMENTS

[Cygnet Health Care: Carer, Family and Friend Strategy \(2023 – 2025\)](#)

[Cygnet Health Care: Carers Passport](#)

[St Andrew's Healthcare, Northampton: Heygate Ward Introductory Letter](#)

[St Andrew's Healthcare, Northampton: Carers Centre Brochure](#)

[St Andrew's Healthcare, Northampton: Heygate Ward 'A Carers Guide'](#)

[St Andrew's Healthcare, Northampton: 'Sharing Information with Carers: Decision Framework'](#)

[St Andrew's Healthcare, Northampton: Carers 'Confidentiality Prompts'](#)

APPENDIX 3: REFERENCES

Carers Trust. The Triangle of Care Toolkit – A Resource for Mental Health Service Providers; 2013. <https://carers.org/resources/all-resources/53-the-triangle-of-care-carers-included-a-guide-to-best-practice-in-mental-health-care-in-england>

Quality Network for Psychiatric Intensive Care Units- Third Edition; 2023. https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/picu/qnpicu-standards-for-psychiatric-intensive-care-units-2023.pdf?sfvrsn=689cc35c_4

APPENDIX 4: CONTACT DETAILS

Contact Information

Kelly Rodriguez, Programme Manager

✉ kelly.rodriguez@rcpsych.ac.uk

☎ 0208 618 4063

Maisie Webster, Deputy Programme Manager

✉ maisie.webster@rcpsych.ac.uk

☎ 0208 618 4023



Ciara McAree, Project Officer

✉ ciara.mcaree@rcpsych.ac.uk

☎ 0208 618 4021

Address

Quality Network for Psychiatric Intensive Care Units
Royal College of Psychiatrists
21 Prescott Street
London
E1 8BB

Website

[Psychiatric Intensive Care Units | Royal College of Psychiatrists \(rcpsych.ac.uk\)](https://www.rcpsych.ac.uk/quality-network-for-psychiatric-intensive-care-units)

Online discussion platform

picu@rcpsych.ac.uk or www.khub.net



Any enquiries relating to this publication should be sent to us at:

picu@rcpsych.ac.uk

The artwork displayed on the front cover of this document was created by a patient at Leverndale IPCU.

PICU

The Royal College of Psychiatrists
21 Prescott Street
London
E1 8BB

www.rcpsych.ac.uk/picu