Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl

This response was submitted to the Health and Social Care Committee consultation on Improving access to support for unpaid carers.

UC10: Ymateb gan: Coleg Brenhinol y Seiciatryddion | Response from:
Royal College of Psychiatrists

Consultation response by RCPsych Wales – Improving access to support for unpaid carers

About RCPsych Wales

The Royal College of Psychiatrists is the professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and setting and raising standards of psychiatry.

We work to secure the best outcomes for people with mental illness, learning difficulties and developmental disorders by promoting excellent mental health services, training outstanding psychiatrists, promoting quality and research, setting standards and being the voice of psychiatry.

Nationally and internationally, the College has a vital role in representing the expertise of the psychiatric profession to governments and other agencies. RCPsych Wales represents more than 600 consultant and trainee psychiatrists working in Wales.

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Introduction

RCPsych Wales recognises the important role that unpaid carers play in supporting people with mental health conditions, learning disabilities, cognitive decline and other challenges. Often family members or close friends, carers provide practical help, emotional support, and advocacy, often at significant personal cost to their own wellbeing.

We are committed to ensuring that carers are valued as partners, with their knowledge and experience informing treatment planning and service delivery. It is equally important that carers are offered appropriate support, information, and respite. Their contribution is essential to improving outcomes for patients and sustaining compassionate, person-centred health services.

The College is pleased to have a number of paid Carer Representative roles which bring the lived experience of mental health issues to various projects and provide an opportunity to work with mental health professionals to improve the quality of care.[1]

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[1] Royal College of Psychiatrists (n.d.). *Patient and Carer Representative Roles* [online]. Available here.

While the information provided below does not directly relate to the inquiry's terms of reference, we wish to draw the Committee's attention to it for wider context and consideration.

Core Standards for Mental Health Services

The Royal College of Psychiatrists' College Centre for Quality Improvement (CCQI) has developed core standards for both inpatient[2] and community mental health[3] services.

The first edition of the core standards was published in 2014 following work undertaken with the British Standards Institution (BSI). The fourth edition of the standards was published in early 2022 and a further edition is due for publication shortly.

While not mandatory, the standards define best practice by promoting equitable access to services, experience and outcomes for patients and carers and sustainability in mental health care. They are rated as type 1 'essential', type 2 'expected', and type 3 'desirable'.

The standards are used across the College's quality and accreditation networks. Each network uses the set of standards most relevant to them (i.e. inpatient or community) and then adds specialist standards that ae specific to the service type that they work with.

Specifically in relation to carer engagement and support, the standards for inpatient mental health services set an expectation that:

- Carers are supported to participate actively in decision making and care planning for the person they care for. This includes attendance at ward reviews where the patient consents. This is a type 1 'essential' standard.
- Carers are supported to access a statutory carers' assessment, provided by an appropriate agency. This is a type 1 'essential' standard.
- Carers are offered the opportunity to speak with staff members, within 48 hours of the patient's admission, to discuss concerns, their own needs and to share and receive information.[4] This is a type 2 'expected' standard.
- The team provides each carer with accessible carer's information. Information should be provided verbally and in writing (e.g., in a carers' pack). This includes the names and contact details of key staff members on the unit and who to contact in an emergency. It also includes other local sources of advice and support such as local carers' groups, carers' workshops and relevant charities. This is a type 2 'expected' standard.
- Carers feel supported by the ward staff members. This is a type 2 'expected' standard.

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[2] Royal College of Psychiatrists (2022). *CCQI Standards for Inpatient Mental Health Services: Fourth Edition*. London: Royal College of Psychiatrists. Available here.

[3] Royal College of Psychiatrists (2022). *CCQI Standards for Community Mental Health Services: Fourth Edition*. London: Royal College of Psychiatrists. Available here.

[4] This reflects amended wording from the 2022 standards, which will appear in the updated standards to be published shortly.

Specifically in relation to carer engagement and support, the standards for community mental health services set an expectation that:

- Carers (with patient consent) are involved in discussions and decisions about the patient's care, treatment and discharge planning. This includes attendance at review meetings where the patient consents. This is a type 1 'essential' standard.
- Carers are supported to access a statutory carers' assessment, provided by an appropriate agency. This advice should be offered at the time of the patient's initial assessment, or at the first opportunity. This is a type 1 'essential' standard.
- Carers are offered individual time with staff members to discuss concerns and their own needs. This is a type 2 'expected' standard.
- The team provides each carer with accessible carer's information. Information should be provided verbally and in writing (e.g. carer's pack). This includes the names and contact details of key staff members in the team and who to contact in an emergency. It also includes other local sources of advice and support such as local carers' groups, carers' workshops and relevant charities. This is a type 2 'expected' standard.
- The team actively encourages carers to attend carer support networks or groups. There is a designated staff member to promote carer involvement. This is a type 3 'desirable' standard.

Please note that the above points are not exhaustive of the full range of standards which refer to carers.

Dementia Care

The National Audit of Dementia is a clinical audit programme commissioned by the Healthcare Quality Improvement Partnership on behalf of the Welsh Government and NHS England.[5]

It measures the performance of healthcare settings against standards relating to care delivery which are known to impact people with dementia while in hospital.

These standards are from national and professional guidance, including NICE Quality Standards and guidance, the Dementia Friendly Hospitals charter, and reports from the Alzheimer's Society, Age Concern and Royal Colleges. Standards are updated for every round of audit.

A carer questionnaire has been used in this audit since 2017.[6] It provides 2 scores on key areas of overall care quality and the quality of information and communication.

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[5] Royal College of Psychiatrists (n.d.). *National Audit of Dementia* [online]. Available here.

[6] Royal College of Psychiatrists (n.d.). *Carer Questionnaire* [online]. Available here.

In 2023-24 (Round 6), 170 carers of people with dementia responded to the carer questionnaire across Welsh 10 hospitals, with 7 hospitals returning sufficient questionnaires to receive scores.[7]

The results for 2023-24 demonstrate that both scores on overall care quality and the quality of information and communication increased in Wales from 2022-23 (Round 5), having previously decreased between 2019 and 2023.

Carer rating of overall care quality in Wales:
- 2022-23 – 67%
- 2023-24 – 73%
- 2023-24 E&W average – 68%

Carer rating of communication in Wales:
- 2022-23 – 59%
- 2023-24 – 64%
- 2023-24 E&W average – 63%

However, exploring the data in more detail reveals that, at a hospital level, overall care quality scores ranged from 63% (Nevill Hall Hospital) to 80% (Bronglais General Hospital) and communication scores from 31% (Nevill Hall Hospital) to 75% (University of Hospital Wales). This suggests a worrying difference in the quality of carer experiences in different hospitals.

Questions attracting lowest positive responses overall were those on keeping the carer informed and asking about their needs, followed by whether staff were informed about dementia and kept the person with dementia and carer involved in decisions.

The 2023-24 carer questionnaire results for Wales are available here at pages 82-88. Reports for individual hospitals are available here.

Carers' Expectations

The Third Round of CCQI's National Audit of Dementia Care in General Hospitals 2016-17 incorporated work on what carers should expect when a person with dementia is admitted to hospital.[8] The following findings were identified.

When a person with dementia goes into hospital, a person who cares for them can expect:

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[7] Royal College of Psychiatrists (2024). *National Audit of Dementia Care in General Hospitals 2023-24: Round 6 Wales Audit Report*. London: Healthcare Quality Improvement Partnership. Available here.

[8] Royal College of Psychiatrists (2017). *National Audit of Dementia Care in General Hospitals 2016-2017: Third Round of Audit Report*. London: Royal College of Psychiatrists. Available here.

1. To be able to visit at any time to provide care or support whenever this is needed, including overnight.
2. That the nature of their relationship to the person with dementia is respected: the carer's presence is welcome to support good care, but should not be depended on as necessary to provide personal care and support, unless this is their expressed wish.
3. The hospital and staff to recognise the value of carer input to the care of the person with dementia.
4. To receive clear written information from the hospital designed for carers, including:
    - Any times when carers may not be present, e.g. to protect the privacy of the person they are visiting or other patients
    - information about how to communicate with staff in the hospital and who to contact
    - information about any help provided by the hospital e.g. with refreshments, meals or parking

With the consent of the person with dementia, or as part of a best interests decision making process:

5. To be kept clearly informed about the care and progress of the person with dementia during the hospital stay, including being involved in decisions made about care.
6. To be involved in the discussion about place of discharge and support needs of the person with dementia, including adequate notice of discharge.
7. To receive a copy of the discharge plan. This should be a written care plan that sets out the support that will be provided to meet the assessed needs of the carer and/or person with dementia.
8. That the hospital will seek current personal information (as distinct from medical information) to help provide the best possible care for the person with dementia. This will include details such as the persons preferred name, parts of their life story that they like to talk about (family, pets, work, hobbies), personal preferences (food, drink, how they like to communicate), whether they need help or support with personal care, whether there is anything that is likely to cause distress (e.g. sudden noise) and how to help them if this occurs.
9. That healthcare professionals will have awareness and understanding of the standard of care required by people with dementia, delirium and cognitive impairment admitted to hospital and of the local care pathway or other procedures in place.
10. That the person with dementia is not excluded from therapeutic interventions aimed at improving mobility or cognitive stimulation and that healthcare professionals can accommodate their needs to provide adequate support.
11. That the person with dementia receives adequate support with nutrition and hydration.
12. That appropriate food choices are available for the person with dementia, including finger food, snacks and lighter meal options. The menu should include photos to help them choose.

13. To be appropriately directed to services that can provide further advice and support, including a referral to the local authority for a carer's assessment. A carer's assessment from the local council (adult social services department) will determine whether carers are eligible for support. Support could include services provided directly to the carer, or services provided to the person they care for.
14. That carers are represented within the hospital and asked regularly to provide anonymous feedback to help improve the quality of care.

Supporting Co-production and Lived Experience

There is strong evidence to support that taking part in co-production, as well as being part of a community of peers, is a positive experience both for people with experience of mental health problems and those involved in mental health commissioning and provision. Co-production contributes to a sense of shared identity and purpose among all involved.

However, the experience of mental health carers is often institutionally undervalued. Despite carers often having significant expertise and understanding about the person they care for, they may sometimes be ignored or treated as a nuisance by ward staff. Even when carers aren't ignored, there may not be a culture of proactive engagement. For example, some carers may not be contacted promptly with updates about their loved one's care, or not invited to care planning or discharge meetings. The lack of communication with carers can negatively impact the quality of care planning and is often highlighted in serious incident reviews. It also increases the carer burden.

It's important that carers have a central part in co-production, right through from supporting an individual patient's care to being involved in service design and delivery including carer peer support. The carer perspective should be threaded through all initiatives and shouldn't be treated as an afterthought.

The College's Co-production Working Group has developed six key principles of co-produced commissioning.[9] These principles were selected as fundamental to supporting co-production in mental health commissioning, based on people's views and experiences.

- **C – Celebrate Involvement**
  All types of involvement are important and fundamental to the process and should be celebrated at each stage and be received with an open and fair approach. Co-production is a continuous process rather than an aim or event and there should be ownership, understanding and support of the process from everyone involved throughout.

- **A – Adaptable**

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[9] Royal College of Psychiatrists (n.d.). *Working Well Together* [online]. Available here.

Adapting the approach to co-produced commissioning to ensure the community of interests voice is heard at every level, ensuring that inequalities are identified and addressed throughout.

- **R – Resources**
  Organisational and dedicated resources, and integration into processes, should be built in at every level. Co-production should be built into work programmes and business plans and resourced as a fundamental integrated part of the whole commissioning process. There should be a dedicated member of staff to champion co-production in practice.

- **I – Influence of Power**
  A collective understanding that acknowledges the power of individuals and organisations, the influence it can have and the perceptions it can lead to. A culture of honesty, value and respect should be fostered, with each person committed to sharing power and taking responsibility for the decision-making they take part in.

- **N – Needs-led**
  Accessibility is fundamental to co-production, so people's needs should be considered and any barriers minimised. This includes consideration of the location of meetings and events, travel to and from venues, and preferred methods of communication. Terminology should be discussed and agreed at the start, and communication should always be clear and available in agreed formats. The environment and space must also be accessible, inviting and supportive of the overall values of co-production. The environment needs to foster creativity, courage and curiosity, so that everyone present has an equal opportunity to be involved.

- **G – Growth**
  Quality assurance needs to take place to maintain, improve and grow the co-produced commissioning process as well as the quality of services. This should be evidenced through outcome measures.

The College's National Collaborating Centre for Mental Health has also identified some additional considerations to support effective working with carers:[10]

- It's important to: proactively reach out to carers and provide clear and accessible information about participation opportunities.
- When staff do the following, carers will be more likely to engage in co-produced activities on the ward:
  - build relationships based on trust with carers;
  - involve carers in decisions relating to their loved ones; and

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[10] National Collaborating Centre for Mental Health (2025). *Supporting Co-production and Lived Experience Leadership Across the Culture of Care Work*. London: Royal College of Psychiatrists. Available here.

  - invite carers to care planning meetings (with consent).
- Consideration of carers' needs and avoidance of acronyms and inaccessible jargon may increase carer engagement. Carers can be confused and intimidated by the language used of the ward. (For example, they may not know what 'restrictive practices' or 'Section 17 leave' are, and they are often not given a welcome pack or orientation to the ward).
- Carers often have a valuable insider/outsider perspective on wards. Carers are insiders in the sense that they are intimately concerned with the care their loved ones receive, but at the same time they can look at the ward with the fresh eyes of someone who is outside the institutional mental health care system.
- When doing co-production, it's important to create safe spaces where carers feel comfortable sharing their thoughts and feelings.
- The toll of being a carer can impact their ability and inclination to engage. Carers may be physically and mentally exhausted by the difficulties of caring for a loved one who is deteriorating and/or the difficulties associated with them being admitted to an inpatient ward.
- Carers often have high demands on their time. As well as looking after their loved ones they may have jobs or other commitments which can make it difficult to attend meetings on wards.
- Covering the costs of looking after a loved one while a carer is engaged in a co-production activity may increase carer engagement. Combining co-production activities with 'me time' and offering refreshments may also make the offer more attractive and relevant to carers.
- Validating the experience of carers by making sure they feel heard and understood in co-production meetings may encourage them to continue with co-production activities.