

Guidelines for Services participating in patient and carer surveys

PCOC is facilitating a quality activity aimed at improving patient and carer outcomes through the administration of two surveys:

- One designed to capture a **patient's** experiences; and
- One designed to capture the **carers** experiences for those carers currently looking after a patient.

A minimum of 20 surveys of both patient experience and carer experience must be completed and returned.

Ethics approval has been received from the University of Wollongong Human Research Ethics Committee, proposal number HE06/045. As this is a quality improvement activity and meets the NHMRC "When does quality assurance in health care require independent ethical review?" questions for exemption, then individual patient consent is not required, and will be inferred if the questionnaire is completed. However, services agreeing to participate in the surveys will need to determine whether they require separate ethics approval.

Background

The Patient experience survey uses ***The Patient Outcome Scale 2*** [1, 2]

This survey tool was devised following a systematic review of outcome measures in palliative care. It involved a literature review of measures. The POS was piloted in hospice, home, hospital and other community settings. The questions cover physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs. There are two versions of the survey instrument. One is for completion by those patients able to independently participate. The other is a staff-rated version for those patients who are not well enough to complete their own survey and require assistance by staff.

The Carer experience survey uses ***FAMCARE 2 for carers*** [3, 4]

This survey tool was devised to rate carers experience of palliative care from their perspective and the patient's perspective. There are 17 questions about the availability of care, the quality of patient care and psycho-social issues. In addition, four questions have been added to FAMCARE 2 to measure more practical issues relating to being a carer such as awareness of the Carer Payment or help with practical tasks. These questions have been tested and are now routinely collected in the Ongoing Needs Identification (ONI) tool used in community care services in NSW and Queensland [4].

Preparation for participating

1. Obtain executive approval
2. Determine if ethics approval is required in your service.
3. Establish a small working group to develop an action plan that includes:
 - Distribution of the survey to patients and carers
 - Survey collection
 - Assistance with survey completion (where required). The tracking form provided may be used to assist with this process.
4. Set a time period for surveys to be conducted. This will depend on the number of eligible patients and carers.
5. Contact PCOC zone coordinator:
 - If you require any assistance with the above steps
 - To confirm your start and estimated completion date
 - To confirm the number of surveys required (minimum 20 patient and 20 carer).

Eligibility Criteria

Patients and carers must agree to participate in the survey. However, patients may be assisted by a staff member or carer/family if they are unable to independently complete the survey due to language, literacy or physical impairment or cognitive impairment.

Patient Survey

In a ***designated inpatient palliative care unit***, the survey can be administered to patients who agree to participate and whose inpatient episode is 3 days or longer.

In a ***consultation/liason service in an inpatient setting***, the survey can be administered to patients who agree to participate and to those who are being seen for the second or subsequent time and at least 3 days after the first visit.

In a ***consultation/liason service in an outpatient clinic or in the community***, the survey can be administered to all patients who agree to participate and who have had at least one previous visit.

Carer Survey

The survey is to be administered to one carer per patient.

Before you administer either survey

Both surveys have an Office Use Only box. These should be complete before the survey is administered. This is an example of how to complete this box.

Office Use Only
Service: Anywhere palliative care service
URN: 123456
Date: 3/09/07

Administering the Patient Survey

There are two versions of the patient survey. One is designed for patients to complete and the other is designed to be completed by a staff member.

1. The surveys are completed on an either/or basis. The options for administering the survey, in order of preference, are:

Patient-rated version

- The patient rated version is the preferred survey as the most valuable feedback is directly from the patient.
- Some patients will not be able to complete the survey. In this case, suggest that a carer/ family member help the patient complete the survey.

Staff-rated version

- If the patient is unable to complete the patient-rated version, but willing to participate in the survey, then a member of the palliative care team completes the staff rated version in discussion with the patient.

2. Select eligible patients and utilise the tracking document to distribute the surveys
3. On distribution of the survey, record the date, service and MRN details on the survey instrument
4. Ask the patient to read the survey information and/or explain it to the patient. For patients receiving the survey by post it is best to let them know to expect the survey.
5. Distribute the survey:

Inpatient: Give to the patient and ask that it be completed by the end of the day.

Outpatient/community: Post the survey to the patient with a return envelope or deliver the survey on a visit and collect at next visit.

6. If the patient has not been able to complete their survey but wishes to participate, select the staff rated version.
7. On receipt of completed surveys, act on any information relevant to inform the patient's care plan then and report the results of the surveys into quality improvement processes.
8. When the survey period is ended and the surveys have been reviewed, send a copy of the surveys together with a copy of the patient survey tracking form to PCOC University of Wollongong, Centre for Health Service Development. Building 29. 2522

Administering the Carer Survey

There is one version of the carer survey and all carers should be encouraged to complete this (one carer per patient). If a carer requires assistance to complete the survey, a palliative care staff member provides such assistance if no one else (such as a family/carer) is in a position to do so.

This tool is designed to be completed by the main or primary carer while they are caring for the patient. It is designed to be brief and simple in order to minimise respondent burden.

When using this tool it is essential that you advise the carer that their participation is voluntary, their responses are confidential and that their responses will not affect the quality of the service they receive.

1. Select eligible carers and utilise the tracking document to distribute the surveys
2. On distribution of the survey, record the date, service and MRN details on the survey instrument
3. Ask the carer to read the survey information and/or explain it to the carer. For carers receiving the survey by post it is best to let them know to expect the survey.
4. Distribute the survey:
 - Inpatient:** Give to the carer and ask that it be completed by the end of the day.
 - Outpatient/community:** Post the survey to the carer with a return envelope or deliver the survey on a visit and collect at next visit.
5. If the carer has not been able to complete their survey but wishes to participate, assist the carer to complete the survey.
6. On receipt of completed surveys, act on any information relevant to inform the care plan and report the results of the surveys into quality improvement processes.
7. When the survey period is ended and the surveys have been reviewed send a copy of the surveys together with a copy of the carer survey tracking form to PCOC University of Wollongong, Centre for Health Service Development. Building 29. 2522

References

1. Hearn J and Higginson IJ (1999) *Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group.* Qual Health Care. Vol 8, No 4, 219-27
2. Cohen R, Mount BM, Strobel M and Bui F (1995) *The McGill Quality of Life Questionnaire: A Measure of Quality of Life Appropriate for People with Advanced Disease.* Palliative Medicine, Vol 9, 207-219
3. Kristjanson LJ (1993) *Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care.* Soc Sci Med, Vol.36, No.5, 693-701.
4. Owen A, Ramsay L, Holt N and Eagar K (2004) *Ongoing Needs Identification In Queensland Community Care: Why Use the Tier 1 Screening and Referral Tools - Evidence and Explanations.* Centre for Health Service Development, University of Wollongong.