Association for Palliative Medicine

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FAMCARE Overview

Background

- The service evaluation replicates the study by Stein Kaasa's group *[Ringdal et al, 2002].*

- The survey sent to main carers is called the FAMCARE 2 tool. Prof Aoun has given permission for use of the FAMCARE 2 tool for the purposes of the survey; he has also confirmed that the tool can be used in bereaved relatives.

Methodology

- The service evaluation runs from the 1st of August to the 29th of September. It covers deaths between 1st of June to the 30th August.

- The participants are bereaved "main" carers of patients referred to the service for end-of-life care. Surveys received up to the 31 December will be analysed.

- Inclusion criteria – see above.

- Exclusion criteria – cognitive impairment; MDT feel inappropriate to contact main carer

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- Settings
  a) Hospital (hospital support teams) - **HS**
  b) Specialist Palliative Care Inpatient Unit - **IU**
  c) Community (home care teams) - **HC**

- The FAMCARE 2 tool will be completed on a single occasion by the main carer 4-8 weeks after the patient's death. The FAMCARE 2 tool will be sent with a generic covering letter, a GDPR Privacy Notice and a return/freepost envelope addressed to the APM.
  These documents should be sent independent of other correspondence from the service (e.g. routine bereavement correspondence).
- The data will be analysed by Compleat Secretariat, and feedback given to the individual services. Services will receive their own data, and also comparable (anonymous) data from other services.

- The service evaluation is being overseen by Dr Jaya Kane. All queries about the service evaluation should be initially directed to the Compleat Secretariat.

Information for Project Leads about setting up service evaluation

- **The "Project Lead" must be a member of APM**; each service can only have one Project Lead, but the data from a service can be used for appraisal/revalidation by all of the doctors associated with that service.

- The Project Lead must register their interest with Compleat Secretariat, and will be allocated a "Unit/service" ID.

- The Project Lead can register more than one service/type of service, e.g. hospice inpatient unit and home care team. It should be noted that data from each service/type of service will be analysed separately.

- The Project Lead is responsible for the cost of the audit which is £125 per service per year (to be paid within 14 days of receipt of invoice).

- No documents will be issued until payment has been received.

- Please note that no refunds will be processed once documents have been issued.

- The Project Lead needs to inform other members of the unit/service about the project.

- The Project Lead is responsible for obtaining local clinical governance approval. The National Research Ethics Committee has deemed that the project constitutes a service evaluation, and so there is no need to obtain local research ethics committee approval. The Information Commissioner's Office has suggested that it is legitimate to use carers' contact details in this situation.

- The Project Lead is responsible for issuing the pre-populated privacy policy along with the site specific carer letter and FAMCARE 2 tool.

- The Project Lead is responsible for printing the site-specific carer letter, the GDPR Privacy Notice (**after amendment to reflect the site's name, address and contact details**) and the FAMCARE 2 tool (from standard templates available from Compleat secretariat).

- The tool **must** be printed as **double sided and on white A4 paper (no staples please). PLEASE DO NOT AMEND THIS TEMPLATE IN ANYWAY**. If this template is amended in anyway, the Compleat Secretariat will be unable to process any of these responses.

- The Project Lead is responsible for requesting the appropriate number of freepost envelopes from the APM secretariat.

- The Project Lead needs to set up a local mechanism for dealing with any queries, carer distress, and carer complaints that may arise from the project.

- The Project Lead needs to keep a spreadsheet (template available from APM secretariat) to record the number of deaths, the number of questionnaires sent out and the reason for not sending out questionnaires to certain carers during the period of the project.

- The Project Lead also needs to inform the APM Secretariat about any complaints arising from the service evaluation.

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References

1. Kristjanson LJ. Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. Social Science and Medicine 1994; 36: 693-701

2. Aoun S, Bird S, Kristjanson L, Currow D. Reliability testing of the FAMCARE-2 Scale: measuring family carer satisfaction with palliative care. Palliative Medicine 2010; 24: 674-81

3. Ringdal GI, Jordhoy MS, Kaasa S. Measuring quality of palliative care: psychometric properties of the FAMCARE scale. Quality of Life Research 2013; 12: 167-76