



Service Evaluation of Bereaved Relatives' Satisfaction with End-of-Life Care

Background

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

Methodology

- Duration of service evaluation – 1 August to 29 September (covers deaths during the period 1 June to 30 August – see below)
- Subjects – consecutive 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 (information on exclusions to be collected).
- Settings
 - a) Hospital (hospital support teams) - **HS**
 - b) Specialist Palliative Care Inpatient Unit - **IU**
 - c) Community (home care teams) - **HC**
- Method – 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 and a return/Freepost envelope addressed to the APM. The FAMCARE 2 tool/generic covering letter should be sent independent of other correspondence from the service (eg routine bereavement correspondence). *[Prof Aoun has given permission for us to use the FAMCARE 2 tool for the purposes of the survey; he has also confirmed that the tool can be used in bereaved relatives (although the wording has been amended from present tense to past tense).]*
- Data analysis – 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 (Lead) and Dr Annabelle Mondon-Ballantyne (Support) 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 £100 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 printing the site-specific carer letters and the FAMCARE 2 tools (from standard templates available from Compleat secretariat). These must be on printed **double sided on white A4 paper (no staples please)**. **PLEASE DO NOT AMEND THE TEMPLATE IN ANYWAY**. If any templates are amended in anyway, 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 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 APM Secretariat about any complaints arising from the service evaluation.



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

EU General Data Protection Regulations (GDPR)

The EU General Data Protection Regulations (GDPR) came into force on 25 May 2018 and will be directly applicable as law in the UK. It replaced the Directive that is the basis for the UK Data Protection Act (DPA) 1998. The basic premise of the DPA will remain; the GDPR will be an enhancement of the DPA.

The APM processes a lot of sensitive information about both patients and staff. We have a responsibility to ensure that this information is protected at all times and shared in an appropriate manner. This includes the processing of Data for the FAMCARE service evaluation in which organisations contact Next of Kin or Carers.

The legal basis for organisations to contact NOK/carers under GDPR is "direct care", dealt with under: Article 6(1)(e) of GDPR; '...for the performance of a task carried out in the public interest or in the exercise of official authority..', using the Article 9 condition for direct care or administrative purpose 9(2)(h)"...medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems...'

It is a legal requirement to advise the NOK/carers at the time of collection what their contact information will be used for. It would be best practice to inform them in advance that you may contact them. Possible ways to do this under the new GDPR law, is to display or provide "fair processing notices" or via the privacy policy notice that the APM will provide along with your organisations documents.