

FAMCARE Report March 2021

Overview

FAMCARE is an annual audit run by the Association for Palliative Medicine which started in 2013. It consists of a survey sent out to recently bereaved relatives. Participating services are either a hospital based palliative care team, hospice inpatient unit or a home care team specialising in providing end of life care. Once completed, surveys are returned to the APM for analysis. Participating services receive individual feedback (including their own data) and also comparable (anonymous) data from other services. An annual report detailing trends, discussions and suggestions is compiled and is made available on the association's website. Currently, there is an archive consisting of annual reports dating back from 2014 available on the website.

FAMCARE is run under the supervision of an audit lead, audit support and the secretariat. The lead is responsible for overseeing the smooth running of the audit and also to compile the annual report.

Dr Kane took over as audit lead from Dr Cox in 2019 and is currently completing the annual report for FAMCARE 2020; more detailed information will be available on the website. The position of audit support is unfilled after Dr Annabelle Mondon-Ballantyne stepped down from her duties.

FAMCARE 2019

Results from FAMCARE 2019 were overall similar to results from 2018. Similar to 2018, fewer services participated and the likely cause was due to the concerns over new GDPR and sending surveys to bereaved relatives. Additionally, the National Audit of Care at the End of Life (NACEL) was being run for the second time and some teams may have chosen to postpone taking part in FAMCARE as well. In addition, the response rates (percentage of people returning surveys) remains consistently low.

Ensuring We Are Compliant

In 2020, the FAMCARE team worked closely with Crimson Crab to ensure the service is following the rules and regulations to be fully compliant with the updated EU General Data Protection Regulations (GDPR). Relatives now receive a GDPR privacy notice along with other documents. The FAMCARE page (on the APM's website) includes clear information on GDPR and importantly, there is a link to the legitimate interest test conducted for the processing of personal data by end of life care providers to enable their participation in the FAMCARE survey carried out by the APM.

Changes to FAMCARE

Given the current unforeseen climate, the APM felt it was vital to continue with the audit and data collection through the COVID-19 pandemic. Being GDPR compliant has allowed us to continue, whilst following rules and regulations.

A change to the practice has been the manner in which we have handled negative comments from relatives. In this cycle, we have received negative comments from 10 individuals. This data has not been collected before, so we are unable to tell if there have been more this cycle.

Looking Forward

Though this year has seen a reduction in participation from services (55 in 2020 compared to 57 in 2019), this may be a reflection on the limitations placed by the COVID-19 pandemic and the pre-existing reasonings listed above (GDPR concerns and NACEL).

FAMCARE has made changes to the GDPR compliancy we offer and it is likely this amendment has not been noticed by many services yet. This March, we are introducing a new informative A4 advert in the e-bulletin and our aim will be to have this featured in more wide spreading journals to boost enrolment. We will also work to encourage more healthcare professionals in palliative care settings to take up the role of 'project lead' within FAMCARE - something which may be possible with the emergence of the affiliate membership within the APM.

FAMCARE has also changed the method of handling negative feedback. Though we are clear that the APM takes no responsibility in the care offered by the specialist service, we are now active in responding to distressed relatives and provide a bridge of communication between relatives and the services that provided their loved one with care.

FAMCARE continues to be a vital resource to services providing specialist end of life care and we will continue to improve to better serve our participants and uphold the reputable image of the APM.

Dr Jaya Kane
FAMCARE Lead
March 2021