APM Seeking Excellence in End-of-life care – User guide to data collection

Thank you for agreeing to participate in the APM SEECare service evaluation. Please identify 1 day in the collection week (25/04-01/05/22) on which your team will collect data. Please use either the excel spreadsheet or the paper tool, whichever is easiest for you and your team. Please note that for ease of collation, and to make this data more useable for yourselves we ask that data recorded on the paper tool is transcribed to the excel database prior to return.

- For the paper questionnaire – please put a tick in the box next the appropriate answers. Opportunities to write free text are indicated by a dotted line.
- When completing the excel database, please use the tab labelled “Data entry” to input your data. Please select from the dropdown boxes and write free text where appropriate.
- If you cannot find a piece of information requested. Please leave the box blank and write a brief explanation at the end of the questionnaire or excel document.
- Please send the completed data to APM Office office@compleat-online.co.uk
- Prior to returning the database, please ensure there is no patient identifiable information included and that the formatting of the document has not been altered.

Areas Predicted to Cause Consternation:

Identification of patients for inclusion
- On the day of collection, a member(/members) of the hospital palliative care team (doctors, CNSs, ANPs or PAs – please contact APM office if any questions) will attend each inpatient ward (excepting ED, ITU/HDU areas) and identify patients who are recognised as dying but not yet known to the hospital palliative care team.
- Sites will vary in the best method of identification on the ward - we advise speaking to the nurse in Charge of the ward, +/- a member of the responsible medical team & asking them to identify any patients meeting inclusion criteria. If other methods are used then please include this when returning registration form (if predicted) or database (if discovered during collection).

Patient number
- **This should not be the identifiable patient medical record number** but instead a separate number allocated to the patient for this project to keep information recorded pseudonymous. If using the paper collection sheet then these can be pre-allocated when printing. Otherwise, this can be reformatted when 'cleaning' the excel spreadsheet prior to return. Some sites will have multiple people collecting data, in which case you are welcome to use prefixes on your numbering (for example Simon Tavabie’s patients may be ST1-5 and Ollie Minton’s might be OM1-5 for ease of pseudonomysation).

Grading of severity of symptoms
- As specialists in palliative care, we recognise that there may be differences in the professional’s assessment of severity of symptoms and so have left some prompts around how this might best be guided. These are available in both formats of the collection tool.

If, on reviewing the collection tools prior to the snap shot day, there are any other areas of confusion/concern please do not hesitate to get in touch with the SEECEcare team via office@compleat-online.co.uk