E A R L Y

ADDITIONAL INFORMATION

IMPROVE END OF LIFE CARE, SET UP AND MANAGE A SUPPORTIVE AND PALLIATIVE CARE REGISTER IN PRIMARY CARE

E	**Early identification**	EMIS Early Identification Tool, best practice, MDT identification
A	**Advance care planning**	Facilitate discussion and communication with patients and family
R	**Record**	And share information
L	**Look again**	Review and update preferences
Y	**You can continually improve**	Through mortality reviews/reflection/ change in practice

BACKGROUND - WHY HAVE A SUPPORTIVE AND PALLIATIVE CARE REGISTER?

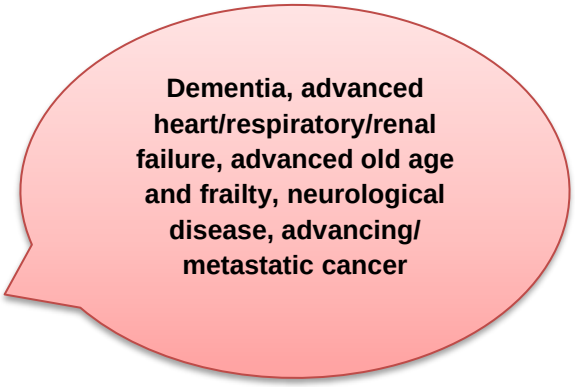
- Keep the patient and their needs at the centre of the discussion.
- Great opportunity for multidisciplinary learning and peer support.
- On average 1% of your practice population (list) will die each year; however, there is much variability between practices and populations.
- Aim to identify the individualised practice target for your supportive and palliative care register.
- Between 75% and 90% of deaths can be predicted/anticipated, offering opportunities to explore preferences with patients and their families.
- Identifying patients thought to be in their last year of life enables earlier discussion of their wishes and improved care at the end of life.
- Although it can appear difficult to identify, it is important to include frail elderly people, people deteriorating with non cancer diagnosis e.g. chronic lung disease, chronic kidney disease, dementia, heart failure, stroke, MS, MND, Parkinson's disease and multiple comorbidities as well as cancer patients.
- Following the top tips guide will help your practice to embed and sustain improvements in the end of life care.

- Using a practice supportive and palliative care register will help you to plan a co-ordinate care for all your patients with less than a year to live.
- It is important to prepare and monitor your supportive and palliative care meetings. This will include:
  - Nominate a lead clinician within your practice.
  - Nominate a lead administrator with IT and organisational skills.
  - Ensure using the appropriate palliative care QOF read codes. There are additional palliative read codes you may find useful.
  - Familiarise yourself with your IT system and palliative care template including EPaCCS Templates.
  - Ensure you have appropriate representation from the multidisciplinary team – GPs, district nurses, community matrons, clinical nurse specialists, practice nurses, community specialist palliative care nurses, GP trainees, etc.
  - Agree to set up a regular team meeting at least quarterly but where possible monthly.
  - Plan meetings in advance, where possible an annualised programme.
  - Establish terms of reference, including attendance and quorum, for meetings.

E - Early identification

EMIS Early Identification Tool, best practice, MDT identification

- Aim to identify patients early – especially important for people with dementia and multiple co-morbidities.
- Utilise the EMIS electronic early identification search tool, which utilises the Gold Standards Framework Proactive Identification Guidance, other disease specific registers, those in receipt of a DS1500, those with a DNACPR in place and those residing in care homes.



- Use existing predictor tools alongside the EMIS search tool to prospectively identify patients e.g. GSF Proactive Identification Guidance (PIG), Supportive & Palliative Care Indicators Tool (SPICT).
- Review those identified through the EMIS search and ask yourself – "*would I be surprised if this patient died in the next 12 months*?" (the surprise question).
- Encourage your team to use the surprise question when seeing patients in day to day practice.
- Use other information – e.g. hospital specialist letters, patient's own concerns, patient's choice e.g. patient with advanced chronic kidney disease who chooses not to have dialysis, carer concerns, other staff concerns (care home/nursing home, district nurses, community matrons etc.), admissions to hospital, use of out of hours service (OOHS).

- You may not need to discuss every patient on the list at every meeting e.g. stable patients coded green or A. Priorities those; Amber/Red, those with changing needs, new additions since the last meeting, anyone a team member has concerns about.

A – Advance Care Planning

Facilitate discussion and communication with patients and family

- Identify a lead clinician who knows the patient the best – this is the person best placed to have conversations with the patient (ACP, PPC, Preferred Place of Death (PPD), DNACPR etc.) and to coordinate care. This person could be from primary, secondary or third sector care. Share outcomes with all settings to avoid duplication of conversations.
- Ensure key clinicians' training is appropriate and current, e.g. ACP, DNACPR.
- Special mention of the importance of early ACP in patients with Dementia whilst the patient still has capacity.
- May take several discussions to allow effective advance care planning.
- Use every opportunity to discuss wishes and preferences for future care and check consent to share information is given.

R - Record

And share information

- Record outcomes from meetings:
    - Clinical – e.g. anticipatory prescribing, care needs assessment, discussions with patient/family
    - Administrative – updating register, alerts, OOHS notifications, maintenance of register
- Although consent to share information with other health care professionals is implied (GMC Guidelines on Confidentiality) it is good practice to gain explicit consent. Electronic patient records shared across organisational boundaries require explicit consent; this can be verbal or written but should be recorded electronically.
- Discuss with patient and gain consent to share information.
- Create EPaCCs record for all patients identified as being appropriate for the palliative and supportive care register.
- With consent, ensure all those involved in the persons care are aware of their preferences; i.e. **secondary care teams, district nurses, community matrons, practice nurses, clinical nurse specialists, out of hours service, ambulance service, care homes, domiciliary care providers**, etc.
- Share the right information with the right people in order to do the right thing at the right time in the right place.

L - Look again

Review and update preferences

- This can be done outside of the regular meeting – establish a smaller key team e.g. administrator, lead GP, practice nurse, district nurse or other key person.
- Add new patients identified as being in last year of life.
- Remove patients (those who have died or moved to another practice) – for audit purpose consider saving this information in a separate database.
- Move patients according to their needs/changing health status e.g. now actively dying (amber to red; C to D), increasing decline (green to amber; A to B). Remember patients could also improve to go from red to amber or green.
- Add new important statements e.g. now has DNACPR order, change in preferred place of death. Update EPaCCs record.
- Use every opportunity to discuss wishes and preferences for future care and check consent to share information is given.

Y - You can continually improve

Mortality reviews / reflection / change in practice

- Review outcomes for patients.
- Discuss all deaths since the last meeting including deaths of patients who were not on the register and sudden or unexpected deaths – consider bereavement care needs.
- Complete after death analysis – spreadsheet tool available. Will help you to highlight:
    - Good practice from “good deaths”;
    - Supports the team; validates and shares good practice;
    - Learn lessons to inform service improvement;
    - Patients who died in hospital – was this the preferred place of death? If not, could the admission have been prevented?
    - Patients not on the register who died – could they have been identified?
- Encourage a culture of trust and learning from each other.
- Identify training needs of team and seek opportunities for education and training, e.g. Advance Care Planning programme, DNACPR training.
- Consider champions within your organisation to support staff development.