

Primary Care Measures: indicator review

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① You are now reviewing the PCM indicator(s) for: **Dying well**

① **Caution:** The information on this page is provided for testing purposes and may be subject to amendment. It may contain errors or not be fully reflective of consensus public health advice or relevant services, therefore should only be used with care.

STEP

A

Strategic context

① Consider the national strategic context for prioritising improvement action in this area (in conjunction with your health board's IMTP and Regional Partnership Board's Area Plan):

- The majority of people would prefer to die at home and the stated intentions of both statutory and voluntary healthcare providers aim to support this. Direct enquiry and identification of preferences for end-of-life care is associated with patients achieving their preference for place of death. Patients whose preferred place of death was unknown were more likely to be admitted to hospital for end-of-life care (BMJ Support Palliat Care 2019 Mar;9(1):[84-91](#).)
- Indicators for this topic are reported via Primary Care Measures (although "place of death" data on PCIP data correspond to neither the measure description [deaths by usual residence] nor the original intent [deaths by place of preference]; no meaningful analysis is possible and this PCM is therefore not reported here).

▼ PCM national variation

① Primary Care Measures (PCM) are a set of care quality indicators for primary care in Wales. The charts below emphasise variation between and within health boards; for further information see [here](#). Beneath the charts are improvement action options that may inform cluster IMTPs. Variation is a natural phenomenon and can be healthy e.g. it can be a deliberate result of innovation in primary care settings that seeks to test improvements in processes or deliver better care outcomes. Variation that is observed in a healthcare context may be referred to as *inequality*; inequality that is judged to be both avoidable and socially unjust is termed *inequity* (sometimes alternatively described as *unwarranted variation*).

Variation in proportion of patients on the palliative care register, by cluster within each health board, 2015/16 (Source: PCIP, Nov 2019):



STEP B Improvement actions for GP practice cluster members

① Consider which of the following actions could be taken forward:

▼ Identify patients for the supportive and palliative care register

- MacMillan Cancer Support produce a *Top tips guide to supportive and palliative care meetings* [[link](#)], "top tip" 3 of which advises:
- Aim for early identification of patients in the last years of life—this is especially important for people with dementia.
- Use existing predictor tools e.g. GSF Proactive Information Guidance (PIG 2017), Supportive and Palliative Care Indicators Tool (SPICT), Primary Care Electronic Frailty Index (eFI).
- Encourage everyone in the team in all settings to ask 'Would I be surprised if this patient died in the next 12 months?' (the surprise question).
- Use other information—e.g. hospital phone calls or specialist letters, patients 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.), frequent unplanned admissions to hospital, use of out of hours services (OOHS).
- Discuss with the patient and gain consent to them being added to the supportive and palliative care register, explain the benefits such as the ability to share electronic information.

▼ Maintain the supportive and palliative care register

- MacMillan Cancer Support produce a *Top tips guide to supportive and palliative care meetings* [[link](#)], "top tip" 9 of which advises:
- 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 years of life.
- Remove patients (those who have died or moved to another practice).
- Move patients according to their needs/ changing health status e.g. now actively dying (amber to red), increasing decline (green to amber).
- Add new important statements e.g. now has DNACPR order, change in preferred place of care.

▼ Facilitate preferred place of death

- MacMillan Cancer Support produce a *Top tips guide to supportive and palliative care meetings* [[link](#)], "top tip" 6 of which advises reviewing outcomes for patients who died in hospital—was this the preferred place of death? If not, could the admission have been prevented?
- "Top tip" 9 refers to maintaining the palliative care register and the importance of adding new statements e.g. change in preferred place of care.

▼ Ensure awareness and implementation of NICE guidelines/ quality standards

- *Improving supportive and palliative care for adults with cancer*. Cancer service guideline [[CSG4](#)] (Published date: March 2004) includes recommendations suitable for adoption by healthcare professionals. This guideline covers best practice in developing and delivering cancer services for adults. It aims to ensure that people with cancer, and their families and carers, are well informed, cared for and supported from before formal diagnosis onward.
- *End of life care for adults* [[QS13](#)] (Published date: November 2011; Last updated: March 2017) sets out 16 quality statements, any of which could form a focus for collective local improvement action. This quality standard covers care for adults (aged 18 and over) who are approaching the end of their life. This includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It also covers support for their families and carers. It includes care provided by health and social care staff in all settings. It describes high-quality care in priority areas for improvement.
- *Care of dying adults in the last days of life*. NICE guideline [[NG31](#)] (Published date: December 2015) includes recommendations suitable for adoption by healthcare professionals. This guideline covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. It aims to improve end of life care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life.

- *Care of dying adults in the last days of life* [QS144] (Published date: March 2017) sets out 4 quality statements, any of which could form a focus for collective local improvement action. This quality standard covers the clinical care of adults (aged 18 and over) who are dying, during the last 2 to 3 days of life. It describes high-quality care in priority areas for improvement.
- *End of life care for adults: service delivery*. NICE guideline [NG142] (Published date: October 2019) includes recommendations suitable for adoption by healthcare professionals. This guideline covers organising and delivering end of life care services, which provide care and support in the final weeks and months of life (or for some conditions, years), and the planning and preparation for this. It aims to ensure that people have access to the care that they want and need in all care settings. It also includes advice on services for carers.



Improvement actions for wider cluster members

① Consider which of the following actions could be taken forward:

▼ Facilitate preferred place of death

- Development of actions required.



What is happening in Wales?

① Consider whether shared learning/ local experience might guide your own implementation of the evidence:

▼ Placeholder project description

- *What problem was being addressed?* Placeholder.
- *What was done to address it?* Placeholder.
- *How does this evidence good practice?* Placeholder.
- *What key learning can be shared?* Placeholder.
- *Who did it or who can be contacted in the event of queries?* Placeholder.

① Have something to share? Please let us know [here](#).

① **Caution:** Any text entered into the following sections will not be saved if you navigate away from this page, or close the browser window before selecting PRINT.

STEP **E**

What do you know about community views on this?

① Consider any relevant citizen/ community voice information (e.g. from surveys, complaints, engagement events, or your health board's well-being or population needs assessments). Summarise this into the following box:

STEP **F**

What assets or partnership opportunities can you identify?

① Consider any relevant local assets or potential partner organisations that might facilitate co-production. Summarise this into the following box:

STEP **G**

Do you need more data before making a decision?

① If relevant, consider any additional data (or information) requirements that might ensure a more informed decision on determining action. Summarise this into the following box:

STEP **H**

What is your provisional decision?

① Having reviewed PCM indicator data and considered evidence-informed quality improvement options, please record initial thoughts on proposed actions. You may also wish to record related thoughts around potential service models, capacity requirements, workforce development or financial considerations. Ideally, discuss these with both the wider cluster and with your local public health team ([LPHT](#)). Summarise your proposals for action into the following box:

① Now this page (e.g. to PDF) so you have a record of your entries (Steps E-H). You may then close the Print view browser window and review another PCM indicator.