

The Daffodil Standards

Self-Assessment Evidence and Guidance

RCGP and Marie Curie UK General Practice Core Standards for
Advanced Serious Illness and End of Life Care

Abbreviations

EOLC- End of Life Care
ASI- Advanced Serious Illness
SMART- Specific, Measurable, Attainable, Relevant, Time-based
MDT- Multidisciplinary Team
GSF- Gold Standards Framework
EC4H- Effective Communication for Healthcare
LGBT- Lesbian Gay Bisexual Transgender
BAME- Black, Asian, and Minority Ethnic
LD- Learning disability
SPICT- Supportive and Palliative Care Indicators Tool
PIG- Proactive Identification Guidance
ADRT- Advance decision to refuse treatment
LPA (H&W)- Lasting power of attorney (for health and welfare)
DNACPR- Do not attempt cardiopulmonary resuscitation
AWI- Adults with Incapacity
MCA- Mental Capacity Act
PPG- Patient Participation Group
EPaCCS- Electronic Palliative Care Co-ordination Systems
KIS- Key Information Summary
OOH- Out of Hours
PCSP- Personalised Care and Support Planning
JNSA- Joint Strategic Needs Assessment
CCG- Clinical Commissioning Groups
NICE- The National Institute for Health and Care Excellence
HSCP- health and social care partnerships
SPC- Specialist Palliative Care
ACP- Advanced Care Planning
SNAP- Support Needs Approach for Patients

Standard 1: Professional and competent clinical and non-clinical staff required to provide high quality, safe & compassionate care in Advanced Serious Illness and EOLC

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
1.1 Ensure that each individual staff member (clinical and non-clinical) understand their role and responsibility for Advanced Serious Illness and EOLC	1.1a Ensure individuals can demonstrate an understanding of which skills relate to their role and consider staff training requirements to support Advanced Serious Illness and EOLC core standards	• Agree as a practice, which clinical and non-clinical staff are involved in caring for people and care-givers. • Training needs assessment for staff. • Relevant Learning action plan for staff with SMART objectives.	• Agree realistic practice SMART objectives (Specific, Measurable, Achievable, Realistic and Timely); for reviewing training needs of staff • Discuss and agree as a practice the key skills anticipated necessary for different staff roles. Example reflection frameworks Skills for Health EOLC Core Skills Education and Training Framework NHS Education for Scotland: PEOLC: Enriching and Improving Experience NHS Wales Collaborative End of Life Care Delivery Group • Reflect on how previous experiences, attitudes, beliefs and personal barriers may affect the way staff work – cover issues affecting each standard e.g. non-identification of patients and carers, shared decision making, communication etc. • Consider staff understanding of how to handle: - o Complaints and complements - o Incidents, errors and near misses - o Ethical, legal and safeguarding issues, such as consent, confidentiality, capacity and duty of candor - o Conflict in difficult situations - o Compassionate Communication and interpersonal skills - o Communication and information needs of people with disabilities, sensory loss, cultural and language variation • Reflect with staff to make sure they have achieved or have a plan in place to achieve training on standards, which relate to their role. This may be done together during a practice meeting with reflection on cases or as part of an appraisal.
	1.1b Individuals have completed training on the standards that relate to their role	• Evidence of training and learning completed and impact.	• Demonstrate practice support to clinical and non-clinical staff to achieve relevant agreed learning needs. • Demonstrate reflection and learning about training, learning events, case studies etc. and show resulting impact or changes made in practice.

	1.1c Demonstrate the application and impact of using the standards	Examples include: • Case history(s) presented at MDT meeting. • Patient/ carers and staff feedback presented at MDT meeting.	Practices should consider what type of reflection works for staff. Emphasis should be on rich discussion, reflection and steps needed to make continuous improvement – not unnecessary paperwork. If changes are being made, then agree how you will know that an improvement is made. Who's involved, SMART goal, what to monitor in real-time practice and regular review process. • Case histories can include learning around each standard when relevant. This can apply to both clinical and non-clinical staff, e.g. staff experience of identifying a patient or carer, learning from a sensitive conversation etc • A mechanism for obtaining feedback from patients/ carers and staff who will not be present at the MDT meeting. The process for this can be decided at the practice.
	1.1d Demonstrate assessment, induction training on standards, appropriate to role, for all <u>new staff</u> .	• Induction procedure • Consider mentoring opportunities	• The induction procedure should be pitched to the appropriate level for different staff. It would discuss the principle commitment to quality improvements as well as the ambition that 'every contact counts', including respect and dignity. • Share practice's supporting documentation and where possible, there should be a face to face discussion which should allow reflection on how previous experiences, attitudes and beliefs and personal barriers may affect the way they work. Examples include, as a regular discussion point discussion about patients who have died during a practice/ palliative care meeting; liaising with local hospice to enable visit to hospice as part of induction. Process may vary to be relevant to the staff member.
1.2 Ensure all staff understand the feelings and communication needs of people approaching the end of life and their families/carers	1.2a Improve the understanding and sensitive communication of individual staff and the team collectively, around dying, death and bereavement.	• The practice has access to a range of methods to increase understanding of experiences of people and carers at the end of life. e.g. articles, books, resources, • The practice demonstrates reflection on sensitive communication, appropriate to people's needs	• Understand the importance of sensitive communication skills and any specific communication needs e.g. for people with disabilities, cognitive impairments, sensory loss or if their first language is not English. • Help staff access training on the requirements of NHS England's Accessible Information Standard e.g. Health Education England's free e-learning module. Scottish resources include EC4H. Health Education in Wales (HEIW) provides CPD modules and training for all staff and the NHS Wales ESR training resources can be used for training and appraisal evidence. • Share list of forums, books and resources. Give staff the opportunity to read and discuss experiences of people and carers at the end of life, living with personal illness, loss and personal care giving. • Consider inequality groups such as LGBT, BAME, LD, dementia and children. • Consider both associated positives and negatives of death and dying, age range, gender, mix of patients and carers.

1.3 Have practice clinical and non-clinical leads for Palliative & EOLC	1.3a Appoint clinical and non-clinical leads with relevant leadership, skills, knowledge and understanding to do this role	• Leads known to whole team. • Where possible, has time allocated. • Coordinate agreed ambition for quality improvement activity via the standards, in the practice	• Regularly review the time allocation and job plan (i.e. what they will do to coordinate quality improvement activity via the standards, in the practice). Create expected Leads 'Planner'. • Consider responsibilities, objectives and outcomes of the role, across each standard. Should include agreeing induction process for staff and monitoring for new evidence related to EOLC. • Consider how to engage with Patient Participation Group, if there is one within your practice. • Consider connecting with other practice EOLC leads, if there are others in your primary care networks/ federation. • Consider how to share learning and delivery at scale with wider colleagues
	1.3b Lead(s) responsible for coordinating implementation of the standards	• An action plan/Gantt chart for implementing quality improvement activity via the standards	• Lead to consider: - o Demonstrate how any quality improvement activities result in continuous improvement in practice. - o Communication of learning within the practice, primary care networks/federations and wider system - o Free Quality Improvement module: e.g. West of England Academic Health Science Network Education Pathway or NHS Scotland. The Life Science Hub Wales provides quality improvement learning and tools, as well as advice via Improvement Cymru. End of life care leads can also consider registering their quality improvement ideas as NHS Wales Bevan Commission Exemplar projects • Demonstrate evaluation and improved outcomes • Information on Gantt charts are included in the RCGP guide Quality improvement for General Practice, found at http://www.rcgp.org.uk/QI

QI1: CONTINUOUS IMPROVEMENT:

Example SMART Goal: Yearly SWOT (Strengths/ Weaknesses/ Opportunities/Threats) analysis of the practice's ability to provide high quality, safe and compassionate care for people affected by Advanced Serious Illness, EOLC and bereavement.

Standard 2: There is early identification and recording that a person, has an Advanced Serious Illness, or EOLC needs

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
2.1 Early identification of patients	2.1a Understand how to identify people who have an Advanced Serious Illness, or EOLC needs	- An agreed protocol for identifying people with an Advanced Serious Illness, or EOLC needs. - Include seamless transition of practice supportive care registers, such as those for: dementia, frailty, disease specific long-term conditions, recurrent admissions, palliative care. - Demonstrate active use and timely, regular reviews of people identified on the register.	- As far as it is possible, aim to collate all those people with the greatest need on your Advanced Serious Illness and EOLC 'supportive care' register or Palliative Care register (Scotland and Wales' Quality Assurance and Improvement Framework) - Agree how all members of the practice team can highlight people who may benefit by being on the supportive care register - Agree flagging mechanism on practice computer and what this means for the patient - Understand different disease trajectories, for example, BMJ: Palliative Care from Diagnosis to Death video and article - Understand your practice population and varying cultural, psychological and access needs taking into account; long term health conditions, disabilities (including learning disabilities), BAME, deprivation, elderly, care home residents, homelessness, prisons etc. - Understand how this fits your local population and who you may expect to be on a supportive care/ EOLC register. - Evidence use of clinical judgement, risk stratification and consider use of prompts such as Supportive and Palliative Indicators Tool (SPICT) or GSF (PIG) to identify people at risk of deteriorating or dying and those who may benefit from a palliative care approach. Examples include: Electronic Proactive Assessment and information Guide for EOLC Electronic Frailty Index (eFI) can be used in Scotland. NHS Wales End of Life Care Delivery Plan, Delivery Aim 2: Detecting and Identifying Patients Early

2.2 Practice Advanced Serious Illness and EOLC register	2.2a Have a robust system in place to record and review patients requiring EOLC	• Easily accessible register. • Staff aware of how to access and code on the register. • System to flag identified patients to all staff to enable quick, effective decision-making and access. • The practice register size represents an expected proportion of people in the practice with Advanced Serious Illness and EOLC needs or reasons recorded why this does not align with the local population.	• Demonstrate continuous improvement each year in identifying people in your practice affected by Advanced Serious Illness and EOLC needs – aiming to identify people with predictable EOLC needs. • Evidence use of active practice ‘Palliative/ Supportive Care’ register for patients (and carers) with Advanced Serious Illness, and EOLC needs.
	2.2b Have a robust system in place to record and review patients requiring EOLC	• Patients have a named GP. • Offer ‘What Matters Most to You and Yours’ conversations. • Patients have capacity assessed and recorded. • Patients have documentation recorded, e.g. ADRT, LPA for health & welfare, DNACPR. • Age of patients recorded. • Diagnosis recorded: highlighting cancer/ non-cancer. • Inequality group recorded. • Communication and information needs, e.g. any sensory loss or disability (including learning disabilities) • Patients’ care and support holistic needs and preferences are recorded.	• Consider <u>inequalities within CQC thematic review</u> (relevant to all countries) • Consider differences between expected and unexpected deaths, this could be done through a focused <u>retrospective death audit</u>. Work with local Medical Examiners Example <u>Definitions</u>: ‘An expected death is the result of acute or gradual deterioration in the patient’s health and often due to advanced disease and terminal illness. An unexpected death is one that is not anticipated or related to a known illness that has been previously identified, or unnatural or unexplained.’ • When patients have a diagnosis that is likely to lead to a loss of capacity in the future, it is important to timely raise this with the patient and to offer appropriate information, support and the opportunity to understand legal documentation available to support their care and wellbeing preferences. • Capacity is decision and time - specific; it should be clear that this recording of overall capacity relates to documenting 1: whether there is an impairment of/disturbance in the functioning of someone's mind/brain; and 2: whether this may affect the person's capacity to make a particular decision. If yes, the documentation can then include details of how/when capacity for specific decisions should be assessed, and who should be involved in this. • These issues are summarised <u>here</u> for England & Wales as well as <u>here</u> for Scotland (Adults with Incapacity (AWI)).

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QI 2: CONTINUOUS IMPROVEMENT:

Monthly recording of percentage of patients on practice list that is on Palliative Care/ Supportive Care Register. Displayed on a line graph, considering a number (or %) that is aligned with their population. Defined practice population (or %) = number of deaths in the last 12 months / total practice population

Example SMART goal: Within 6 months, increase from 20% to 60% of people with palliative care needs, who die to have been on supportive/ palliative care register.

Evidence base: 60-70% of people have an expected death and planning can support their needs with early identification of their needs.

Notes:

Enhancing good practice and reducing variation in care. As your practice works towards consistently identifying your practice-relevant % of people who have an expected death, the next step could be to consider

- ‘Deep dive’ learning from expected deaths: e.g. what care and support does ‘identification’ trigger in your practice? e.g. Carer identification, What Matters Most conversations and care planning. How is this coded consistently? Is there variation in equity between who receives this care, for example by age, diagnosis, disability or ethnicity?
- Learning from unexpected deaths.

Audit template can be used to consider variation in equity of care and different aspects of care and support triggered following identification.

Standard 3: Carer Support – before and after death

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
3.1 Early identification of carers	3.1a Achieve consistent identification of carers	An agreed protocol for identifying carers of people who have advanced serious illness or who may be approaching the end of life.	- Consider how all members of the team can contribute to carer identification. - Record the patient's main carer(s) and their details, for example, name, address, contact number, relationship to patient, for example, spouse, neighbour, son (state if young carer) or paid carer - Record if Next of Kin and if Lasting Power of Attorney. - Add this within the Emergency Care Summary (Scotland). - Evidence use of actively collecting and updating carers of people on practice 'Palliative/ Supportive Care' register. - In agreement with carer, ensure 'Is a Carer' is coded appropriately and highlighted in the record of the carer. - As the patient on the 'Palliative/ Supportive Care' register dies and the person is no longer a carer, the code should be removed from the record. In agreement with the carer, update coding to acknowledge the bereavement if appropriate. This should enable/ trigger practice bereavement support offer (Standard 7)
3.2 Identification of carers' needs	3.2a Enable (conduct/sign-post to) holistic carer assessments	Where possible, record a holistic carer assessment, that is, to identify problems from their perspective: both in terms of their needs as 'clients'(a patient) and their needs as 'co-workers'(caring for a person).	- Consider what is helpful to include in holistic carer assessments. - Consider involving your PPG / PPI groups if developing your own practice holistic assessments. Many HCPs report being fearful of opening up 'a can of worms' by asking carers what support they feel they need, but evidence shows that it is often quite simple things that make a difference and even just being asked is in itself supportive. Consider Carers Support Needs Assessment Tool Carers Support Needs Assessment Tool – Online Training

	3.2b Support carers both as 'clients' and 'co-workers'	- Information provided to carers which can include understanding of the patient's illness, how to manage symptoms and medicines, what signs to look out for, when to make a call for help. - Make contact with the carer after the patient's death to assess what on-going support is required.	- Acknowledge carers are a resource in patient care. - Consider how the practice supports carers to preserve their own psychological and physical health, as 'clients' (directly or signposting). - Consider how the practice provides information, knowledge and skills to carry out their role as 'co-worker' more effectively (directly or signposting) - Consider Social Care signposting for a formal carer's assessment - Consider specific needs and legal issues for young or vulnerable carers - Consider a practice / local resource of useful information for carers - Be aware of the legal requirements around carer involvement in decision making for the patient, e.g. MCA/ Best Interest/ AWI <u>Example of Family Carer's Prescription</u>
	3.1c Develop inter-practice communication	A system for communication between practices to address when the patient's carer does not belong to the same GP practice as the patient.	- Consider having a system in place for raising safeguarding alerts - Consider Consent, Confidentiality and Information Governance when sharing information with other practices and the wider system, such as hospices, community nursing, social care etc.

QI3: CONTINUOUS IMPROVEMENT:

Monthly recording of percentage of carers identified for patients on Palliative Care/ Supportive Care Register. Displayed on a line graph with an increasing objective to reach around 60-90% of Supportive Care Register patients, or a % that is aligned with their population.

Evidence base: 60-90% of people in the last year of life are likely to have an informal carer e.g. spouse/ partner, sibling, son/daughter, neighbour /friend.

Example SMART goals: Within 6 months,

- a) **Increase from 40% to 60% informal care-giver identification for people on on Palliative Care/ Supportive Care Register**

Notes:

Enhancing good practice and reducing variation in care. As your practice works towards consistently identifying your practice-relevant % informal care-givers, you can also consider how the practice enables carers to have their needs assessed and the care and support carers are offered.

- b) **Increase from 0% to 30% assessment of informal care-giver needs e.g. [CSNAT.org](https://www.csnat.org)**
c) **Increase 0% to 15% sign-posting/ referral to support, as per care-givers need(s)**

Standard 4: Seamless, well-planned, coordinated care

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
4.1 Multi-disciplinary team meetings	4.1a Understand the role and optimum outcomes of the MDT meeting in Advanced Serious Illness and EOLC	- Practice agreement for MDT meetings, for example, how often, who attends, goals etc - Objectives of MDT agreed by practice team and recorded. - Assess effectiveness of meetings by obtaining feedback by attendees.	- Consider peer discussion to agree roles and responsibilities for each team member. - Consider peer discussion to agree objectives of MDT. - Consider peer discussion / reflective reading on what makes an effective MDT. - Consider process for: new patients, dying, deteriorating and stable. - Consider who and how to involve for specialist advice, for example, Specialist Palliative Care, Geriatrics, Paediatrics etc. - Consider elements such as frequency of review to cover patients, quality of symptom control, quality of documentation, safeguarding issues, patient and carer involvement etc. - Consider visiting another practice, hospital or hospice MDT or invite external peer review. - Agree practice agreement for MDT meetings, including clinical governance arrangements. - Consider how to work with non-NHS bodies, for example, social services, housing, voluntary sector - Consider how you may involve PPG - Consider asking the practice team what makes a good meeting and how you may record these factors in each meeting, for example, construct a simple template with these factors and fill in after a meeting.

	4.1b Hold regular Advanced Serious Illness, and EOLC MDT meetings	• Evidence of holding regular practice MDT for people with ASI + EOLC needs. • The meetings include an effective mechanism to review patients and carers on palliative/ supportive care register in a timely manner. Record date of review and any change/outcome and include in patients notes.	• Not all patients and carers on the register can be reviewed at each meeting but a mechanism needs to ensure those of highest priority are discussed but that no one is ignored over a significant period.
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	4.1c Have input from interface teams, for example, hospice, community nursing, social prescribing etc.	Minutes/notes of MDT meetings showing: • Community nursing attending MDT regularly. • Evidence liaisons and partnerships built with other services to attend MDTs and/or provide multidisciplinary and cross-sectoral care, for example, specialist palliative care/hospice, geriatricians, mental health, social care, local voluntary sector services, social prescribing, paediatrics • Established route for advice /referrals to senior clinicians in specialist palliative care/hospice, geriatrician, psychiatrists, paediatrics etc.	• Consider the most effective ways to have input and communicate with MDT members in and outside MDTs to achieve well-planned, safe care. • Consider use of technology and virtual MDT working. • Consider if there are benefits from multi-practice MDTs • Consider how to make the most effective use of people's time and maximise different professionals' strengths in order to contribute to meeting the needs of patients and carers.
4.2 Coordination of care across all care settings	4.2a Communicate across care settings	• System in place and recorded to coordinate care across all care settings. For example, EPaCCS, Emergency Care Summary (Scotland) or hand-held notes. • Case examples showing evidence of active use, regular and timely reviews and updating	• Agree the system to be used within the practice. • Consider how the practice primary record communicates with the system. • Consider the risks/benefits of the system. • Consider how the system communicates within your locality/ wider system For example, Out of Hours, Ambulance Services, hospices, community nursing etc • Consider how to make sure records are contemporaneous with the practice primary record and how to enable a relevant copy to the patient. EPaCCS = Electronic Palliative Care Coordination Systems. KIS= Key Information Summary (Scotland) Welsh Clinical Portal (WCP), Patient Administration System and digital interfaces
4.3 Data Collection	4.3a Achieve consistent data collection	• Agree and have recorded standardised coding list for ASI + EOLC within the practice.	• Understand, agree and use best-practice, standardised coding within the practice for Advanced Serious Illness and EOLC, for example, diagnostic information, urgent access flags etc. • Follow best-practice ASI + EOLC coding list. • Ensure quality and safe care is supported through access to reliable, timely clinical information and data.

4.4 Data Sharing	4.4a Have a system for data sharing	• System in place and recorded for sharing clinical information and PCSPs for people on the palliative / supportive care register – available to Out of Hours and Emergency Services. • System in place and recorded for sharing clinical information and PCSPs for people on the palliative / supportive care register – available to cross-sector integrated services, for example, EPACCS/KIS.	• Agree the system to be used within the practice.
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Example SMART goals: Within 3 months, review current and agree future consistent EOLC codes, aligned to MDT template column headings, to be recommended for use by all staff. This forms your monitoring dataset, across key Daffodil Standards. Monitor use and repeat review following 6 months of use.

Standard 5: Care is based on the assessed unique needs of the patient, carer and family

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
5.1 Implement Personalised Care and Support Planning (PCSP)	5.1a Understand the role and optimum outcomes of Personalised Care and Support Planning (PCSP)/Anticipatory Care Planning (ACP)	- Objectives of Personalised Care and Support Planning (PCSP)/Anticipatory Care Planning (ACP) agreed by practice team and recorded - Objectives need to cover: - Medical planning - Demedicalised (non-health) Wellbeing planning, such as mapping care and support networks to enable care preferences	- Consider What Matters Most Conversations to base conversations, planning and recording with patients and families: - Medical plans, such as Emergency Treatment and Care Plans/ Treatment Escalation Plans. Noting, escalation of care may be palliative care or disease modifying care. There may be different models of care required appropriate to the situation and guided by planning. - Demedicalised plans, such as mapping care and support networks to enable care preferences - Consider evidencing peer discussion to agree objectives of PCSP/ACP - Peer discussion / reflective reading on what makes effective PCSP/ ACP. - Consider another practice, hospital or hospice system or invite external peer review - Consider use of patient and carer feedback to improve outcomes - Recognise the relevant legal framework in relation to o Valid consent - Capacity Assessments and Best Interest decisions - Advance Decision Making and Lasting Power of Attorney - Adults With Incapacity (Scotland)
	5.1b Achieve consistent PCSP / ACP process for patients	- Use a holistic PCSP / ACP template to identify and record the key medical and 'demedicalised' information for PCSP - Holistic PCSP/ACP template used relevant to age, diagnosis, cultural and psychosocial needs - Offer sensitive conversations on items in minimum dataset and record on PCSP/ACP template - Use of PCSP/ACP recorded for people on Practice Register	- NHS England Personalised Care & Support Planning Handbook - Core Information - NHS Wales Advance & Future Care Planning resource site www.wales.nhs.uk/AFCP Healthcare Improvement Scotland's ACP Toolkit. - Considering using common assessment tools to identify and assess needs. For example, SNAP tool – Support Needs Approach for Patients National Voices' Guide to Care and Support Planning RCGP's Collaborative Care and Support Planning Toolkit - Sample letters designed by one practice can be used in the process

		• The practice team have constructed a process map of PCSP/ACP • Learning tools and videos available including www.advancecareplan.org.uk • Offer copy and/or access (if available) of PCSP/ACP to patient	• <u>Letter to patient – my life plan (invite)</u> • <u>Letter to patient – my life plan (new)</u> • <u>Letter to patient – my life plan (review invite)</u> • <u>Letter to patient – my life plan (updated)</u> <u>Managed MDT</u> • <u>My life plan – first consultation</u> • <u>Treatment escalation plan</u>
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	5.1c Achieve consistent quality of PCSP/ACP, including DNACPR	The recorded plan, including EOLC dataset, once started is completed and regularly reviewed and updated, in a timely manner and includes: • Medical plans including assessment of pain, other physical symptoms and emergency health and care planning. • Demedicalised plans, such as mapping care and support networks to enable care preferences. • Assessing and reviewing mental capacity. • Benefits guidance, e.g. DS1500. • Sensitive involvement and communication with patients, families and carers. • DNACPR documentation, where appropriate. • Holistic needs, including: practical, communication & disability, psychological, social, spiritual and cultural needs. • Date and place of death recorded within 2 weeks of death.	• Evidence continuous improvement of assessing, documenting and reviewing mental capacity. • Evidence documentation of relevant and sensitive communication with patients, families and carers, embedding 'What Matters Most' conversations • Consider CQC recommendations from Protect Respect Connect for quality assurance practice processes for DNACPR decisions and for discussions and decision making to be individualised and part of the wider PCSP/ACP journey. DNACPR decisions • Consider using common assessment tools to identify and assess needs. e.g. SNAP tool – Support Needs Approach for Patients • Consider how to ensure patients' pain and/or other physical symptoms will be effectively managed. • Consider how to ensure decision-making is shared with the patient and those important to them. • Consider how to meet the communication and information needs of patients' with disabilities and sensory loss, in line with NHS England's Accessible Information Standard.
	5.1d Achieve person-centred care	• 'What Matters Most' and 'Goals of Care' conversations are commenced and recorded early. • How care is aligned to those goals recorded. • Information on self-management and enhanced care models available to patients and their carers.	• Evidence that conversations about 'What Matters Most' and 'Goals of Care' commence early to optimise opportunities to align care to those wishes. • Consider how the practice evaluates sensitive and compassionate communication. • Consider how patients have an opportunity through early identification to benefit from self-management and enhanced care models. • Evidence family and carers are involved in planning patient-centred care • When patients lack capacity, ensure an understanding of how to make best interest decisions and involving LPAs and Court of Protection deputies, as appropriate. AWI for Scotland, as above. • Reflect how the practice minimises non-beneficial or burdensome care in partnership with the patient and those important to them. • A toolkit on PCSP for patients not necessarily at EOLC can be found at https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/person-centred-care-toolkit.aspx

QI5: CONTINUOUS IMPROVEMENT: The practice has identified areas for improvement from their process map (see 5.1b). They then use the 3 questions from the Model for Improvement, which are: 1. What are we trying to accomplish? 2. How will we know if a change has made an improvement? 3. What changes can we make that will result in an improvement? One of these changes at a time are taken into a Plan-Do-Study-Act cycle. Guidance on Model for Improvement and PDSA cycles can be found at <http://www.rcgp.org.uk/QI>

Example SMART goals:

1. **In month 1, identify areas for improvement in PCSP / ACP from practice process map**
2. **Retrospective audit of people who have a CPR/ DNACPR status recorded and quality of decision making. Noting best practice guidance DNACPR status is not recorded in isolation but as part of wider PCSP/ ACP process and** It is unacceptable for advance care plans, with or without DNAR form completion to be applied to groups of people of any description. These decisions must continue to be made on an individual basis according to need. [See RCGP joint statement.](#)
3. **Over 6 months, increase from 20% to 50% (% relevant to the practice) of people on Palliative /Supportive Care register to be offered ‘What Matters Most’ and ‘Goals of Care’ conversations with resulting PCSP/ ACP created and recorded with the patient and family at the centre**

Standard 6: Quality care during the last days of life

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
6.1 Provide care in the Last Days of Life, that aligns with the Five Priorities for Care:	6.1a Understand the importance of the Five Priorities for Care for the Dying Person (Wales: Care Decisions Guidance): https://www.england.nhs.uk/ourwork/qual-clin-lead/lac/ 1. The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly. 2. Sensitive communication takes place between staff and the person who is dying and those important to them. Conversations are appropriately documented. 3. The dying person, and those identified as important to them, are involved in decisions about treatment and care. 4. The people important to the dying person are listened to and their needs are respected. 5. Care is tailored to the individual and delivered with compassion – with an individual care plan in place	A practice policy agreement on caring for patients and those important to them in the last days of life, to recognise the objectives from the Five Priorities of Care above, to include: • Timely recognition of imminently dying person • Care is safe, effective, responsive and appropriate • Care plans are developed, implemented and reviewed regularly to support people who are imminently dying, their families and carers • Timely symptom control assessments using best-practice guidance and tools • Evidence that patients, family and carers are provided with information and support in accessible ways	• Active involvement and discussion of the five priorities of care for the dying person. This includes consideration of how to avoid preventable transfers of patients who are imminently dying. • Consider how to meet the communication and information needs of patients' with disabilities and sensory loss, in line with NHS England's Accessible Information Standard. • Consider NICE (NG31) • Wales: Care Decisions Guidance
	6.1b Implement the five priorities of care (or equivalent in Wales)	• Audit to evidence implementation. • Invite and review feedback from patients and those important to them. • Have an escalation process in place to raise issues and concerns with relevant stakeholder.	• Not all the priorities are easily recorded and hence audited but you need to be practical and audit those that are recorded and encourage consistent coding and future recording. • Consider how to best involve patients, families and carers to learn how the practice delivers EOLC • Consider how the practice evidences use in practice, in MDTs and PCSPs/ACPs • Consider enablers and barriers to providing high- quality, safe care for people affected by ASI + EOL.

6.2 Provide treatment appropriate to the needs of the patient in the last days of life	6.2a Be able to prescribe and have readily available medications to control symptoms and for anticipatory prescribing in the last days of life	- Local guidance within the practice on how to prescribe anticipatory medications. - Shared practice agreement on how to access palliative drugs in and out of hours.	- Understand your local prescribing formulary for opioids and other palliative drugs (Just in Case prescribing). - Understand the process to access palliative drugs in and out of hours. - Consider NICE (NG31) and Scottish Palliative Care guidelines. - The agreement to include palliative drugs covering issues such as: - Symptom control: pain, breathlessness, nausea and vomiting, noisy secretions, terminal agitation and delirium - Clinically assisted hydration and nutrition where required. - Consider reviewing and stopping medications where appropriate- consider creating review templates for Just in Case medication and linking to personalised care plans. - Awareness of the legal framework for providing treatment, e.g. best interest decisions under the Mental Capacity Act/ AWI and the need to refer cases to the Court in certain circumstances
	6.2b Be able to access someone to set up and use a syringe driver.	Local guidance within the practice on the use of syringe drivers.	Understand best practice prescribing for syringe drivers
6.3 Monitor the quality of care per death provided to include the whole EOL period	6.3a In practice mortality review for all patients using Daffodil Standards and QOF Retrospective Death Audit Excel .	- At each MDT, discuss, complete and record mortality reviews on all deaths between MDTs, ideally monthly. Daffodil Standards Retrospective Death Audit Excel. - SEA for deaths covering the last days of life, written up and discussed with the practice team. - Share learning outcomes with team and wider stakeholders, as necessary. e.g. CCG, GP cluster group (Wales), HSCP (Scotland), hospitals, community providers.	- Consider reflection on Expected and Unexpected deaths on any potentially preventable/avoidable harm (for example, poor pain control) and deaths - Mortality Review template for deaths - Reviews with Medical Examiners - For example, evidence of mortality reviews for: - Deaths that were “unexpected” and not on the register but could have been anticipated to see lessons learnt and ensure preventable/avoidable deaths are highlighted - Expected deaths – to ensure high-quality care and support planning took place. - Understand the process to refer to Safeguarding Boards in cases where death is linked to abuse or neglect

QI 6: CONTINUOUS IMPROVEMENT: Audit implementation of 5 priorities of care across all deaths and action taken where outcomes achieved do not meet the practice accepted standards. Continuous monitoring of these criteria e.g. pain and symptoms assessed regularly in last days of life. For example, consider if the practice has a **reliable system** in place to assess with the patient and those important to them the **5 priorities of care** AND document that the **5 priorities of care** have been met, where possible.

[Example SMART goal:](#)

Over 12 months, increase from 10% to 50% of people who died on palliative/ supportive care register, to have had documented the 5 key principles of Priorities for Care of the Dying (England) - 'CRISP' – Communicate, Recognise, Involve, Support, Plan & Do / Care Decisions for the Last Days of Life (Wales)

Standard 7: Care after death & Bereavement Support

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
7.1 Have understanding and be able to manage grief and bereavement.	7.1a Understand the process of anticipatory grief and bereavement	Roles and responsibilities for each team member discussed and recorded	- Consider and discuss peer practice at MDT - Understand the difference between the 'normal grief process' and more complex grief that may require medical intervention. For example, consider bereavement risk assessment - Understand best-practice guidance, to agree objectives of optimum grief and bereavement support.
	7.1b Understand how all staff can support bereaved people	- Practice policy of what patients and carers can expect from the practice to support their individual anticipatory grief and bereavement needs e.g. compassionate bereavement response, condolence letters, information leaflet, death certification, bereavement call/ visit, referral to services - Practice plan on verification of death and certification	- Consider setting up or linking with peer support networks available for the bereaved, run from local practices in cohorts. - Contact with the key family member or carer after death. In agreement with bereaved person, code bereavement if appropriate. - If appropriate and possible, actively contact relatives where death was unexpected and pre-bereavement contact would not have been made - This activity can be generated from having a record of the carer/family involved and from the Supportive Care Register being marked as 'patient died'. Therefore, the practice can develop a clear understanding of when and how to offer support to bereaved relatives. - Consider practice or CCG / cluster (Wales) , HSCP (Scotland), wide leaflets and online information. Care After Death publication updated with new guidance for Registered Nurses on verification of expected deaths
7.2 Knowledge of local systems	7.2a Ensure the bereaved are aware of how the practice can support and also local support available	- Practice support information available - How the practice can support a bereaved person - Local /National offer signposting to available bereavement support in the community and services	- Agree practice protocol when staff member becomes aware a patient is bereaved. For example: compassionate bereavement response, coding, condolence acknowledgement, practice / sign-posting to support, annual flag if appropriate. - Consider practice links and collaboration with local carer support and bereavement support groups - Consider children and adolescent specific support groups – either following loss of a parent/adult or for parents following loss of a child - Consider culturally specific support groups

QI7: CONTINUOUS IMPROVEMENT: Regular audit of support offered to the bereaved, for example, documented contact with the bereaved, support information given.

Example SMART goal:

1. In month 1, agree process for increasing identification and coding of bereaved people known to the practice – to cover all deaths, including expected, unexpected/sudden, all ages, all causes including miscarriage and SIDS.
2. Over 12 months, increase from 10% to 60% of family members / informal care-givers/ next-of-kin identified on the practice 'supportive care register' to be contacted **and** offered condolences/ sign-posted to information on dealing with grief and bereavement within 1 month (practice to decide) of the person on the register dying.
(Note these will only cover expected deaths)

Standard 8: General Practice being hubs within Compassionate Communities

The General Practice commits to:	To meet this standard the practice commits to:	Self-Assessment	Practice Guidance
8.1 Support the development of compassionate communities	8.1a Develop the practice itself as a compassionate community	• Discussion in practice meeting what would be expected within a practice to actively support practice team (clinical and non-clinical) in personal death, crisis, loss. • Practice plan documented for supporting staff in loss. • Plan annually reviewed. • Staff survey.	• Consider current compassionate culture within the practice and how important it is to the practice and how/why this may be improved. • Consider how different experiences of staff in personal death, crisis, loss. • Consider how staff feel valued by the practice. • Consider a clear open mechanism for both staff and patient/ carer feedback, actively and sensitively encouraging participation. • Consider how the practice shows compassion to staff and other colleagues, affected by a bereavement of serious illness. Multi-professional mini-modules • <u>'Practical steps to assessing your baseline and developing a compassionate workplace culture and leadership in general practice (0.5 CPD points)'</u> • PODCAST on https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards/end-of-life-care-quality-improvement-resources.aspx 'Developing a compassionate workplace culture and leadership in general practice – learning from a GP pilot site (0.5 CPD points)' • Awareness of national resources for instance from Compassionate Cymru

	8.1b Learn lessons from patients and their carers	System is in place to actively debrief staff and wider team on deaths, particularly where death is unexpected or goes wrong: • This could be as part of discussion of deaths at practice meeting or MDT. • Survey of patients and/or bereaved relatives and carers. • SEA recorded and shared when one has occurred. • Respond to any compliments or complaints and share lessons learned. • Evidence a system is in place to record and track actions of incidents/ compliments/ complaints/ feedback in order to understand and learn from the care and experience of people who died within the practice over the year, for example, against SWOT analysis. • Patient / carer with lived experience sensitively invited to be on an active PPG.	• Consider how the practice delivers compassionate care to patients, families and carers. • Consider how to involve your PPG / PPI groups, enabling dialogue with hard to reach groups. • Consider the practice system in place to actively debrief staff and wider team where death is unexpected or does not go to plan AND also where things go right/ well. • Recognise patients who died without capacity and without documented wishes for care (ADRT, LPA for H&W) – identify when and where discussions on advanced care planning could have been instigated and share these so that opportunities aren't missed with patients facing similar circumstances.' Alongside, this consideration of whether the person and family's EOL wishes were followed and whether any learning points around working in partnership, or conflict resolution, were identified. • Consider how the practice engages with hospices, hospital specialist care teams, community service development in providing care to people affected by ASI and EOLC. • GP practice networks may consider holding Schwartz-type rounds to support colleagues.
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	8.1c Utilise wider community resources	• Has information on the benefits of primary care practice models for social prescribing. • Has information showing how to access to community support groups to combat issues such as, isolation and loneliness. • Refers to community support groups. • Practice system in place outside consultations, to actively support people affected by life- limiting illness, death and dying, long term caregiving and bereavement by for example, having at least one of the following: - o Patient groups, for example, carers, bereaved, people living with life-threatening illnesses or the very old, to meet each other so that they may seek support from each other. - o Practice volunteers, for example, rotating neighbourhood volunteer groups. - o Practice register of patients with relevant experience who may wish to be involved. - o Support to the wider community, for example, offering support to formal and informal carers. - o Services offered by voluntary sector linked with the practice. - o Services offered by practice (+/- in collaboration) as part of primary care network/ federation, social prescribing or community development services.	• Social prescribing models aim to unlock assets based with the community that support de-medicalised care and combating issues such as, isolation, depression, anxiety and loneliness. • Consider mapping of the local services available to support people in the community with Advanced Serious Illness, and EOLC needs. • Consider how PPG champions could support development • Consider a local end of life care pathway/contact list template. • Consider the local community support groups available. • Consider how to support marketing and advertising, enabling community access. • Consider local voluntary sector and services offered. • Consider how your practice system can actively support people affected by life- limiting illness, death and dying, long term caregiving and bereavement - o This may be done by encouraging a system for patient groups, for example, carers, bereaved, people living with life-threatening illnesses or the very old, to meet each other so that they may seek support from each other. • CCGs/Clusters ideally could support a centralised, regularly updated local directory of services/charities/support networks.
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QI8: CONTINUOUS IMPROVEMENT: In order that lessons can be learned from the experience of advanced serious illness, EOLC, caring responsibilities, death and bereavement. Lessons can be shared with the relevant people.

Example SMART goals:

Over 12 months, assess whether practice staff/ patients/ carers feedback the practice is meeting the end of life care needs, and show how any information provided is used to help improve care and support by achieving a minimum of:

1. 2-5 family/care-giver or patient interviews e.g. semi-structured discussion, using an agreed template or annual carer survey relevant to EOLC needs.
2. Staff feedback to support the QI planning e.g. survey, debriefs, SEAs

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3. MDT feedback to support the QI planning e.g. survey, discussion at MDT
 4. Annual evaluation of compassionate organisational culture