EMIS Web
EPaCCS template guide

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NHS
Cheshire and Merseyside
Strategic Clinical Networks

NHS
Greater Manchester, Lancashire and South Cumbria
Strategic Clinical Networks

The importance of EPaCCS in supporting End of Life Care

by Dr Peter Nightingale (RCGP)

Introduction

Caring for a patient right through to the end of life can be one of the most satisfying aspects of general practice, but it is also one of the most challenging.

Most people prefer to be cared for at the end of their lives at home, with dignity and their symptoms controlled, but many fail to achieve this. The current situation of multiple admissions in the last year of life, many of which are unplanned and potentially avoidable, is unsatisfactory for patients and does not make the best use of resources.

Many of us have been working hard to find the 1% of patients within our practice likely to be in the last year of life, and take a more proactive approach to their care, but this is not always easy.

In order to effectively identify and support patients we need to use both national and locally developed tools to proactively manage care.

Having recognised a patient might be within the last year(s) of life, it is beneficial both to the patient and their families to proactively manage care. This is likely to support patients to be cared for in the place of their choice and to reduce the likelihood of unnecessary investigations, interventions and hospital admissions. The use of an EPaCCS system should help collect key information about the patient and their care, help shape multidisciplinary team meetings and encourage information sharing across the wider system.

Previously known as locality registers, electronic palliative care coordination systems (EPaCCS) enable the recording and sharing of people's care preferences and key details about their care with those delivering care. The systems support co-ordination of care and the delivery of the right care in the right place, by the right person, at the right time.

There is strong evidence that EPaCCS supports patient choice, shared decision making, individual care planning and integration of care across sectors.
Many areas have already implemented or are in the process of implementing EPaCCS across localities. Available data suggests that their use helps people to die in their preferred place of death, decreases the percentage of hospital deaths and increases the percentage of deaths at home and in hospices.
Other key benefits include improvements in communication and information sharing between healthcare professionals and support for making appropriate decisions about patients' care.

The Electronic Palliative Care Co-ordination System (EPaCCS) template
EMIS Web version

This template is for all EMIS Web users to enter information for patients considered to be in their last year of life. It is not an EPaCCS on its own, but is standardised to match all other templates across the North West to ensure easy communication between systems once this becomes possible – for this reason, please use only the terms listed (with their underlying Read codes) to enter End of Life Care information.

The template is named the '**End of Life & Palliative Care Co-ordination**' template and can be found in **Templates & Protocols > EMIS Library > Extended Healthcare** (it replaces all previous palliative or end of life care templates, such as the Macmillan palliative care template). It has been updated to incorporate all the changes made by the Information Standard Board for Health and Social Care, reference ISB 1580 Amd16/2013. For further information about ISB 1580 and the changes that have been made to this template go to http://www.isb.nhs.uk/documents/isb-1580/amd-16-2013/index_html

The template is divided into the following eight pages to correspond to the elements of End of Life Care:

1. Summary of EoLC Status / Plans
2. EoL Diagnosis and Function
3. Demographic and Social
4. Carers
5. Patient Preferences
6. Care and Support in the Last Days of Life
7. Death Details
8. Template Information

This template is intended to facilitate greater continuity of care across all health providers (including NWAS). It includes important patient information that may be required in order to provide optimum care to patients.

The template has been designed to include the Qualifying diagnostic Read codes from the GMS Contract QOF Palliative Care indicator set 2014/15 (Palliative care ruleset_v28.0), highlighted below with a yellow border. It also uses the Read code for 'GSF Prognostic Indicator Stage A (blue) - year plus prognosis' to help GPs identify vulnerable patients and meet the DES requirement for case management registers, protecting patients from unplanned admissions.

Who is responsible for completing this template?

- The GP or a designated person within the practice.

How frequently does the information need to be updated?

- Following any End of Life Care discussions or on completion of any type of Advance Care Plan, or after any significant change occurs.
- Following receipt of any End of Life Care information from other health providers.

Please refer to the **Revised North West End of Life Care Model 2015** for further details on when to update EPaCCS information (see Other Useful Resources).

NB - Following the death of a patient, it is important that you complete the Death Details page, to ensure your locality's EPaCCS is suitably updated.

Patient consent

It is important, as part of an End of Life Care conversation with a patient, to explain that they need to give their consent for their wishes and care preferences to be shared with the other organisations potentially involved in their end of life care (such as the ambulance service, out of hours GPs, hospices, hospitals etc) as without consent this will not happen. In the case of a patient lacking capacity this consent will need to be provided by someone acting in their best interests (see below for definitions).

9Nu6.	Consent given for sharing end of life care coordination record
9Nu7.	Withdrawal of consent for sharing end of life care coordination record
9Nu8.	Best interests decision taken (Mental Capacity Act 2005) for sharing end of life care coordination record
9Nu9.	Consent given by legitimate patient representative for sharing end of life care coordination record
9Nu90	Consent given by appointed person with lasting power of attorney for personal welfare (MCA 2005) for sharing end of life care coordination record

Once consent has been given, subsequent conversations should not need to revisit the consent issue, even if information is being recorded on another system, as the consent given is for the sharing of an "end of life care coordination record" across all of the systems involved in the EPaCCS.

Consent for sharing via the MIG

If information entered on your EMIS Web system is being shared with other organisations through the use of the Medical Inteoperability Gateway (MIG) provided by Healthcare Gateway Ltd, then an additional two codes come into play:

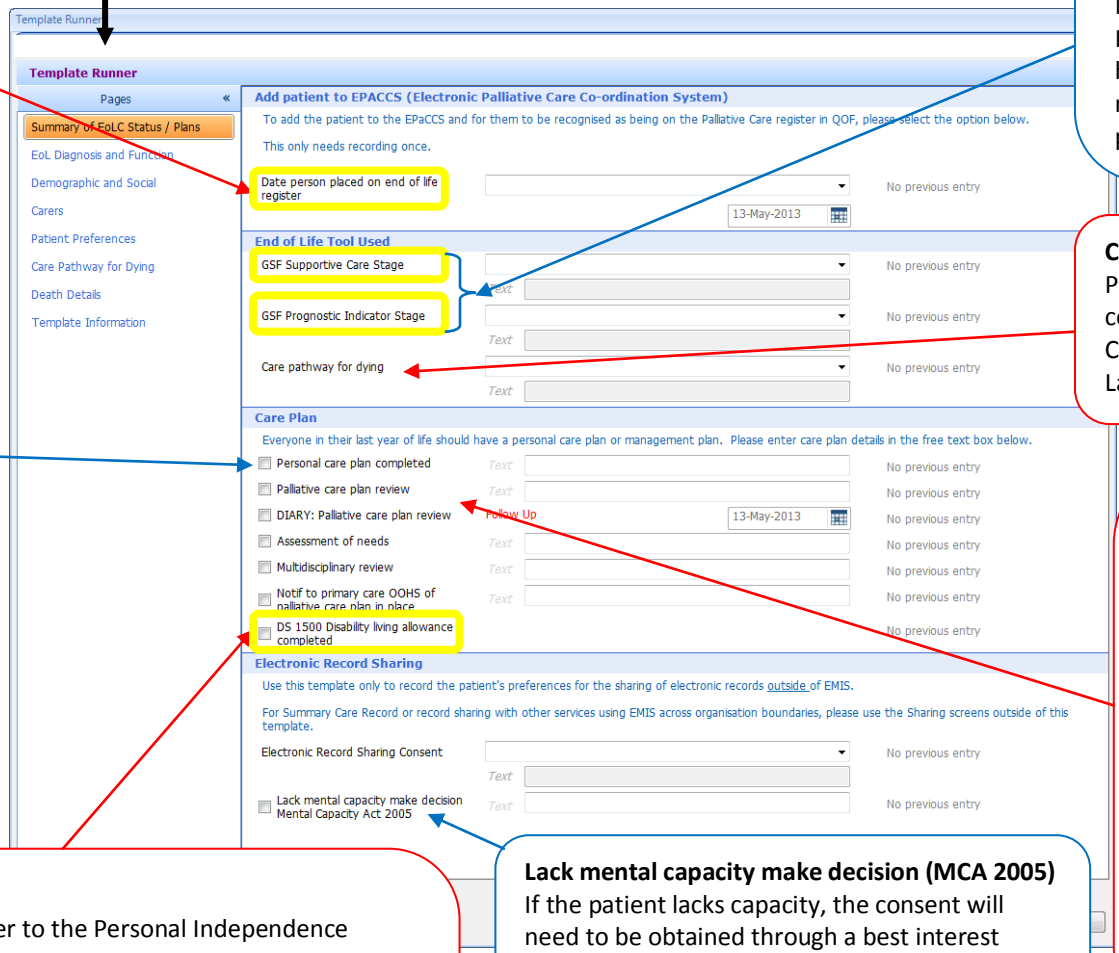
93C0.	Consent given for upload to local shared electronic record
93C1.	Refused consent for upload to local shared electronic record

The 93C1. code **blocks all data** from leaving the GP practice for the patient, regardless of any of the other End of Life Care consent codes above being entered. Therefore, it is crucial that this is properly explained to the patient, so that there is no confusion about what is or isn't being shared. If a patient had previously not wanted to share any information, but then wants to have their wishes and care preferences shared with the other organisations potentially involved in their end of life care, it will be necessary to either remove the 93C1. code or add code 93C0. to counter it.

NB - It is therefore crucial that in the case of a patient lacking capacity where a 93C1. code had previously been applied, that if a best interest decision is taken, or consent is given by a legitimate patient representative or lasting power of attorney, the 93C1. code is also removed (or 93C0. applied), to allow the information to be shared.

These eight pages group together aspects of the patient's End of Life Care.

Summary of EoLC Status / Plans



Add patient to EPaCCS
This is the date that the patient has been identified as potentially being in their last year of life.
DO NOT re-enter this date.
If entering retrospectively for someone previously identified, but not added to the EPaCCS, please ensure you enter the date they were identified and not today's date.

GSF Supportive Care / Prognostic Indicator Stage
Please indicate the stage of the patient's illness, by using either coding to suit the needs of the care setting, in line with local GSF practice.
NB - using the code for GSF Prognostic Indicator Stage A (blue) - year plus prognosis helps GPs meet the DES requirement for case management registers, and can help protect patients from unplanned admissions.

Care pathway for dying
Please note – this field will be updated when codes are available for the Individual Plan of Care and Support for the Dying Patient in the Last Days and Hours of Life.

Personal care plan completed
A personal care plan (sometimes known as a 'support plan') documents the care and treatment actions necessary to meet a person's needs, preferences and goals of care. These must have been agreed with the person receiving care or by those acting in the person's best interests as part of a comprehensive holistic assessment.
This is different from advance care planning which is about preferences and wishes for future care.

Palliative care plan review
This is where you can log the recent GSF/Palliative care/MDT meeting, or individual review, and add a DIARY entry for the next review (e.g. at the next GSF/Pall. care/MDT meeting). These meetings must take place at least once every three months, but the frequency of review will vary depending upon the stage and complexity of the person's illness and their circumstances. This date may therefore need adjustment (e.g. if there is a change or deterioration in a person's condition or in their personal circumstances).

Lack mental capacity make decision (MCA 2005)
If the patient lacks capacity, the consent will need to be obtained through a best interest decision, a legitimate patient representative, or appointed person with lasting power of attorney.

DS 1500 Disability living allowance
Please note - this field will be updated to refer to the Personal Independence Payment (PIP).
If the patient has a terminal illness or progressive disease and are not expected to live for longer than six months, they may be able to apply for benefit under special benefit rules called the Special Rules.
The advantages of making a claim under the Special Rules are:

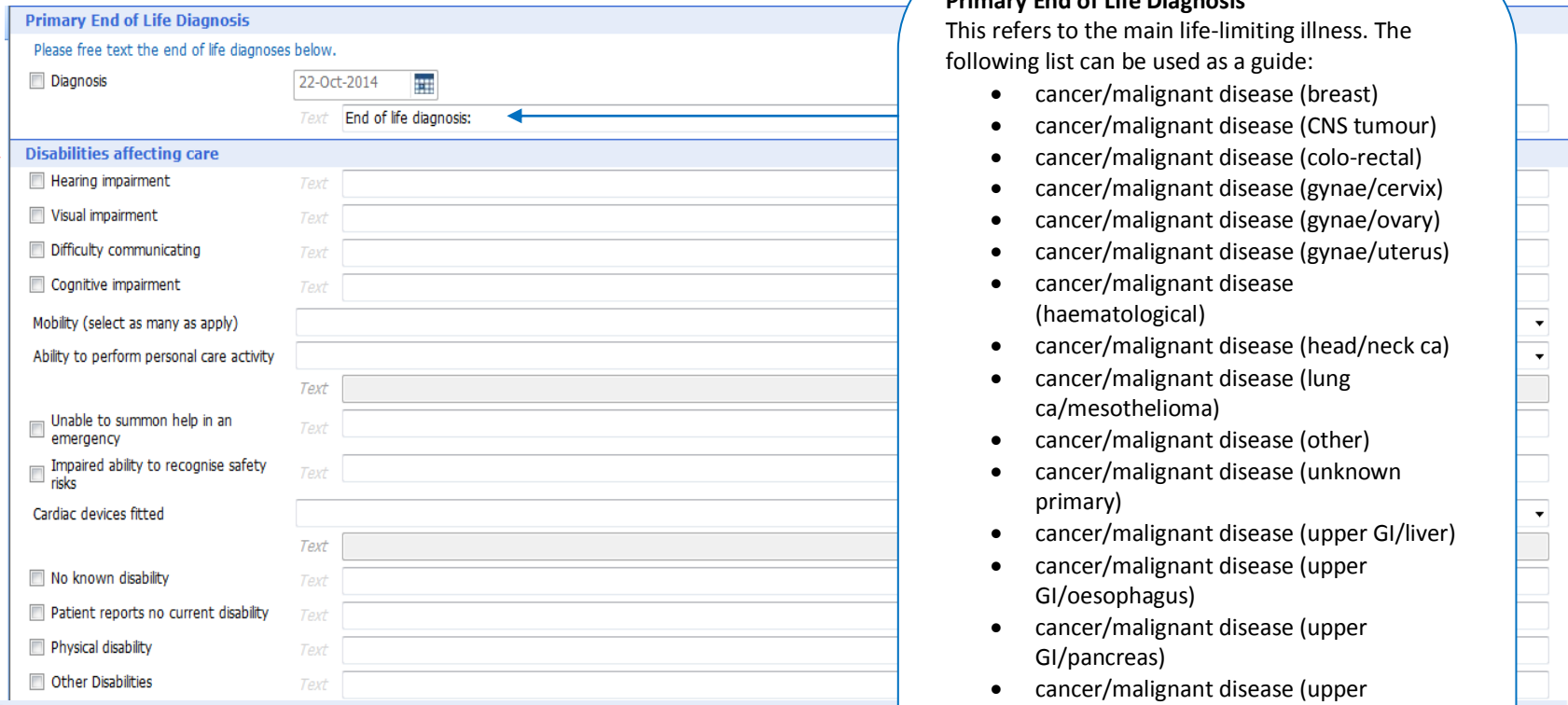
- It is easier
- Claims are dealt with faster
- You automatically get the highest rate of benefit
- Benefit can be paid straight away

Read codes from QOF Palliative Care indicator set 2014/15

9Ng7.	On end of life care register
8CM1.%	On gold standards palliative care framework
9EB5.	DS 1500 Disability living allowance (terminal care) completed

EoL Diagnosis and Function

Disabilities affecting care
These fields flag any additional disabilities that would potentially impact on the patient's care needs.



Primary End of Life Diagnosis
This refers to the main life-limiting illness. The following list can be used as a guide:

- cancer/malignant disease (breast)
- cancer/malignant disease (CNS tumour)
- cancer/malignant disease (colo-rectal)
- cancer/malignant disease (gynae/cervix)
- cancer/malignant disease (gynae/ovary)
- cancer/malignant disease (gynae/uterus)
- cancer/malignant disease (haematological)
- cancer/malignant disease (head/neck ca)
- cancer/malignant disease (lung ca/mesothelioma)
- cancer/malignant disease (other)
- cancer/malignant disease (unknown primary)
- cancer/malignant disease (upper GI/liver)
- cancer/malignant disease (upper GI/oesophagus)
- cancer/malignant disease (upper GI/pancreas)
- cancer/malignant disease (upper GI/stomach)
- cancer/malignant disease (urological/bladder)
- cancer/malignant disease (urological/kidney)
- cancer/malignant disease (urological/prostate)
- cancer - unknown
- chronic renal failure
- chronic respiratory disease
- dementia / Alzheimer's
- frail / elderly
- heart failure
- motor neurone disease
- neurology
- other heart and circulatory conditions
- all other conditions – please specify

Modified Karnofsky Performance Scale (IP35, COM 32)

The Karnofsky performance scale is a measure of the patient's overall performance or ability to perform activities of daily living. It is a single score between 10-100 assigned by a clinician
work and self care.

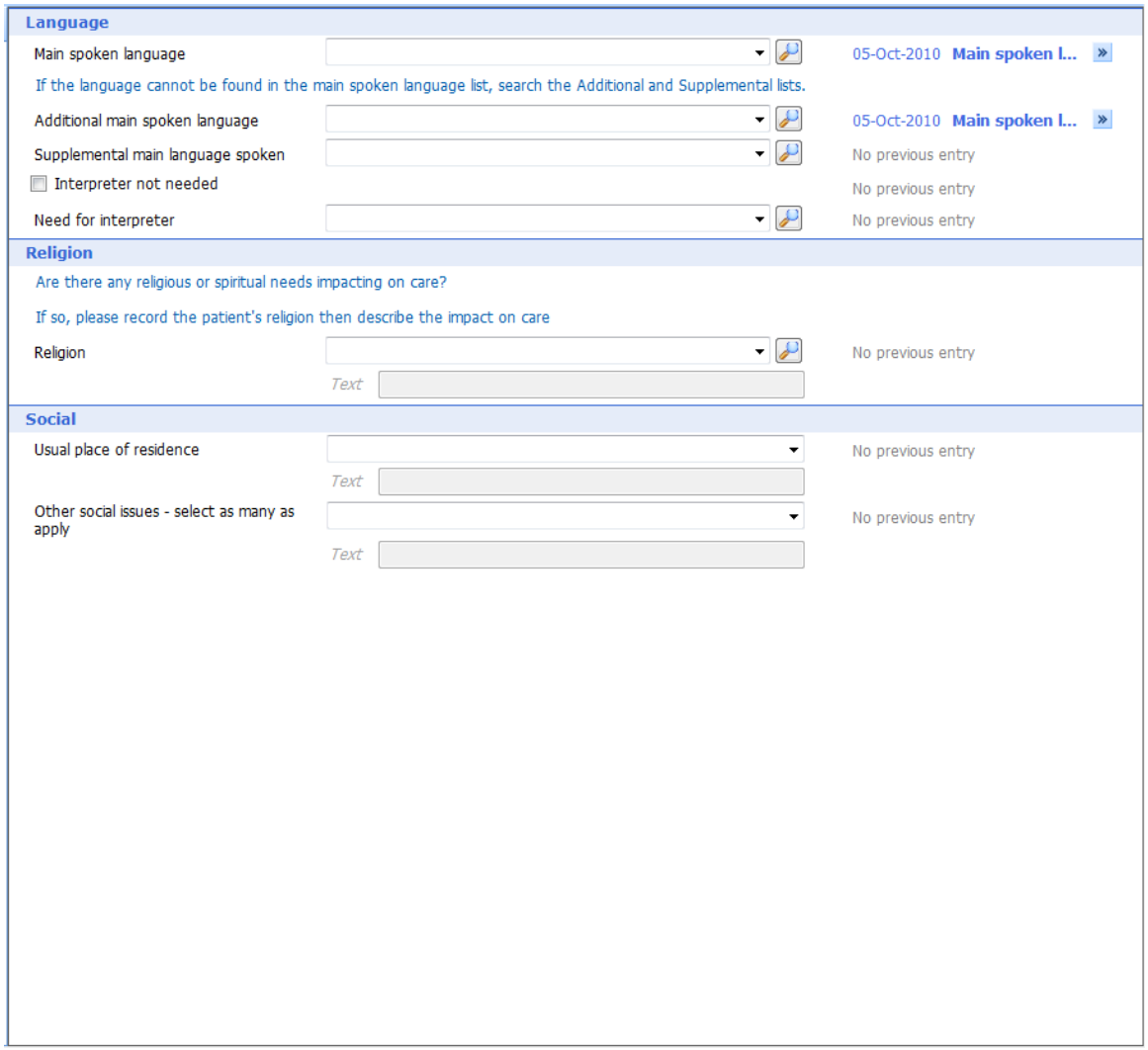
Scoring scales:

100%=Normal, no complaints or evidence of disease
90%=Able to carry on normal activity, minor signs or activity
80%=Normal activity with some effort, some signs of symptoms
70%=Care for self, unable to carry normal activity or do active work
60%=Occasional assistance but is able to care for most needs
50%=Requires considerable assistance and frequent medical care
40%=In bed more than 50% of the time
30%=Almost completely bedfast
20%=Totally bedfast and requiring nursing care and/or family
10%=Comatose or barely arousable
0%=Dead

Modified Karnofsky Performance Scale /100

Text

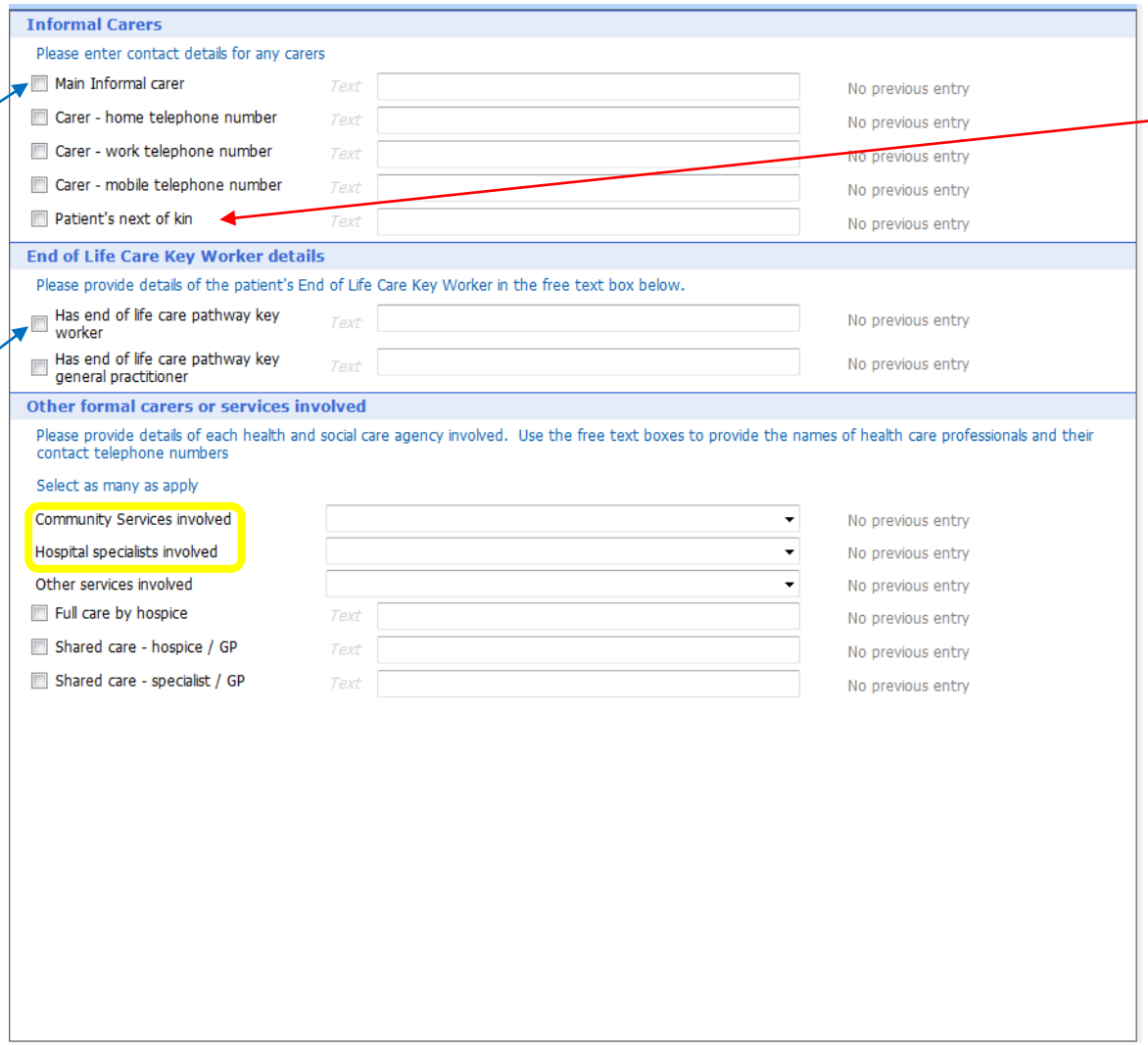
Demographic and Social



Carers

Main Informal carer
This would be the main carer (a family member or friend) who has agreed to take on this role.

Has end of life care pathway key worker
This is the key professional who co-ordinates the End of Life Care of the patient.

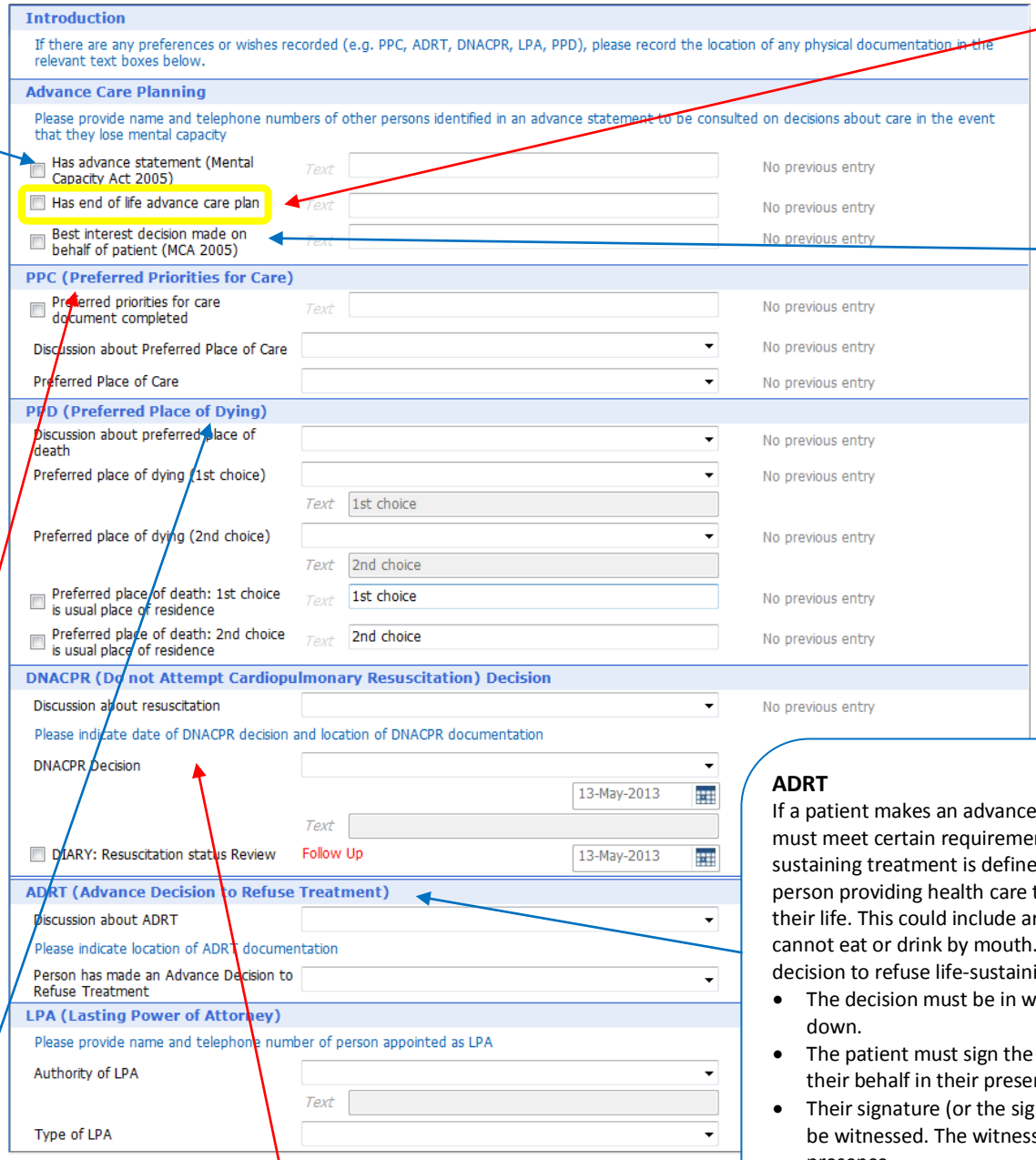


Patient's next of kin
This person may differ from the main informal carer.

Read codes from QOF Palliative Care indicator set 2014/15

9NNd.	Under care of palliative care specialist nurse
9NNf0	Under care of palliative care physician
9NgD.	Under care of palliative care service

Patient preferences



Has advance statement (Mental Capacity Act 2005)
This is a general statement of a patient's wishes and views. It allows a patient to state their preferences and indicate what treatment or care they would like to receive should they, in the future, be unable to decide or communicate their wishes for themselves. It can include non-medical things such as food preferences or whether they would prefer a bath to a shower.
It could reflect their religious or other beliefs and any aspects of life that they particularly value. It can help those involved in their care to know more about what is important to them. It must be considered by the people providing their treatment, when they determine what is in their best interests, but they are not legally bound to follow the patient's wishes.

PPC
Refers to a version of an advance care plan that is available to download. It is likely to contain the patient's advance statement of wishes and preferences including their preferred place of care at the end of life or maybe where they would prefer to die. Further information can be downloaded at http://www.nhsiq.nhs.uk/resource-search/publications/eolc-ppc.aspx

PPD
Some patients will choose to discuss their preferred place of death or this may have been previously written down within an advance care plan.

DNACPR
Please refer to the Unified DNACPR policy.

Has end of life advance care plan
Has the same meaning as an advance statement but it more likely to refer to a patient's preferred place of care at the end of life or maybe where they would prefer to die.

Best interest decision made on behalf of patient
If a person lacks mental capacity to make a particular decision then whoever is making that decision or taking any action on that person's behalf must do this in the person's best interests. They should take into account any evidence they have of the patient's past wishes, their beliefs and values, and they should consult the patient's friends, family and carers where appropriate. The law gives a checklist of key factors which decision makers must consider - further information can be found at http://www.bestinterests.org.uk/best_interests/

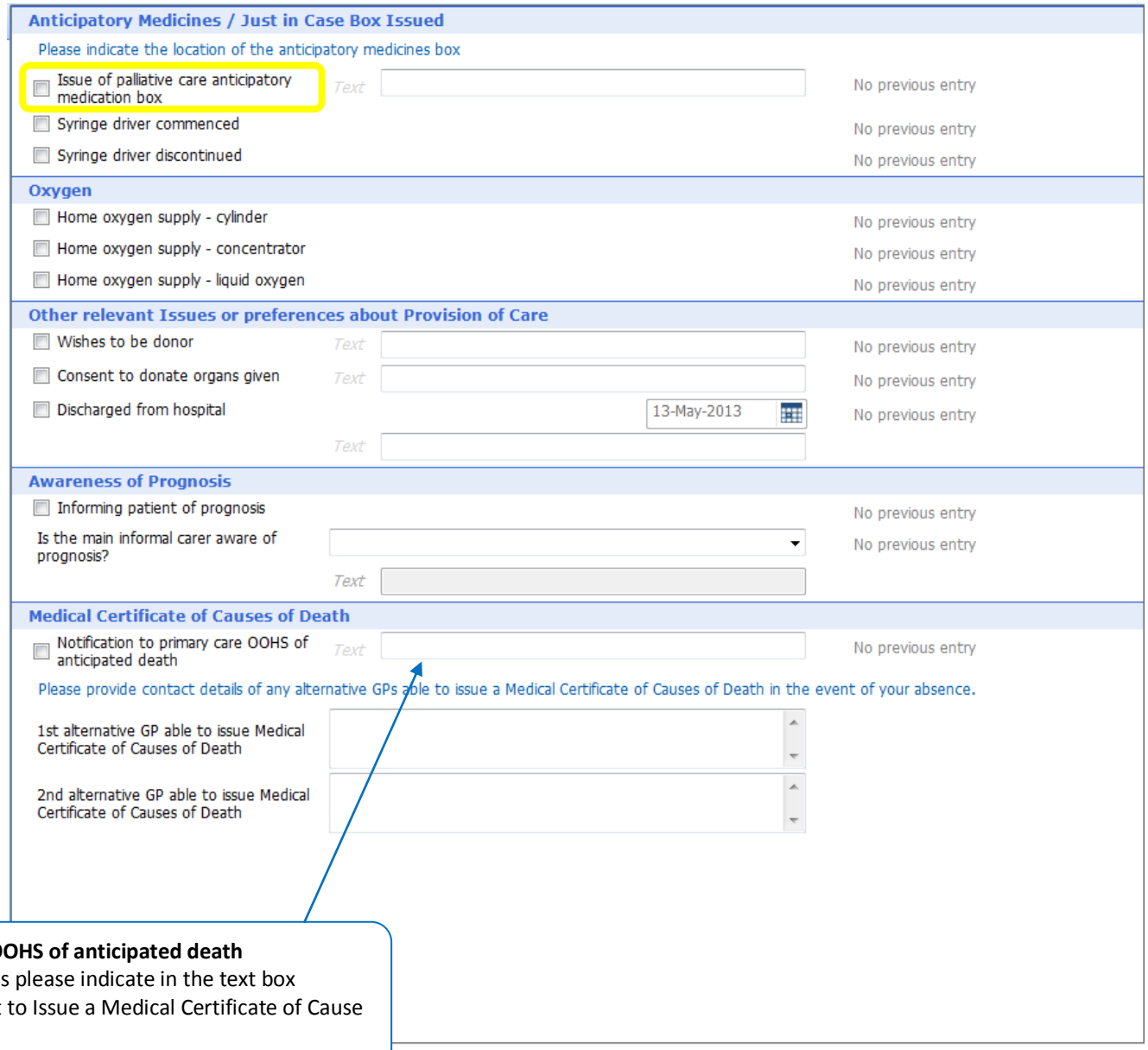
ADRT
If a patient makes an advance decision to refuse life-sustaining treatment, it must meet certain requirements set out in the Mental Capacity Act. Life-sustaining treatment is defined in the Act as treatment that, in the view of the person providing health care to the person concerned, is necessary to sustain their life. This could include artificial nutrition and hydration to someone who cannot eat or drink by mouth. The legal requirements for a valid advance decision to refuse life-sustaining treatment are as follows:

- The decision must be in writing. The patient can ask someone else to write it down.
- The patient must sign the document. They can instruct someone to sign it on their behalf in their presence if they can't sign it themselves.
- Their signature (or the signature of the person signing on your behalf) must be witnessed. The witness must also sign the document in the patient's presence.
- They must include a written statement that the advance decision is to apply to the specific treatment even if their life is at risk

Further information can be downloaded at http://www.adrt.nhs.uk/

Care and Support in the Last Days of Life

*(tab is currently called **Care Pathway for Dying** – will change on next template update)*

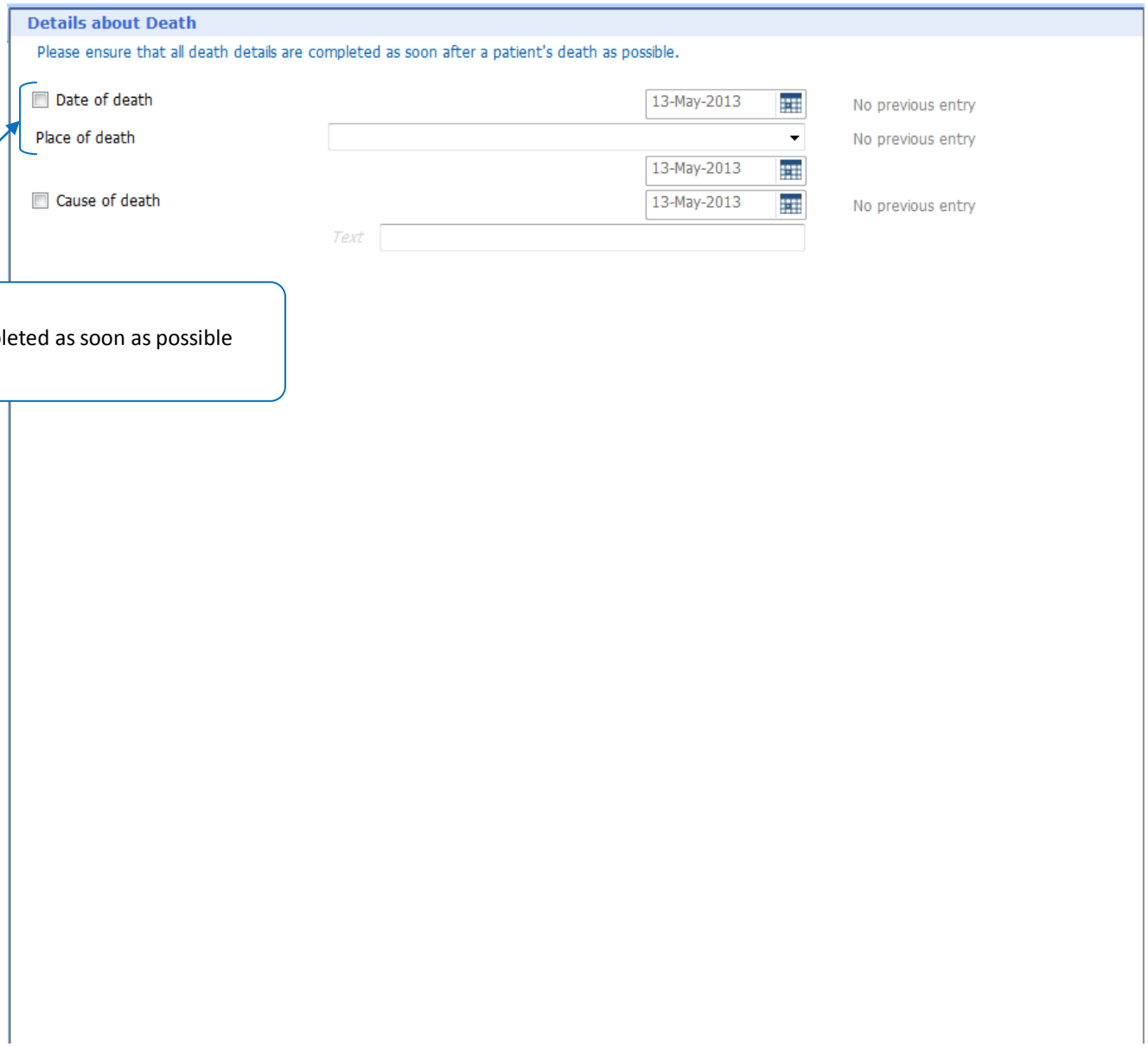


Notification to primary care OOHS of anticipated death
For all Greater Manchester GPs please indicate in the text box whether a Statement of Intent to Issue a Medical Certificate of Cause of Death has been completed.

Read code from QOF Palliative Care indicator set 2014/15

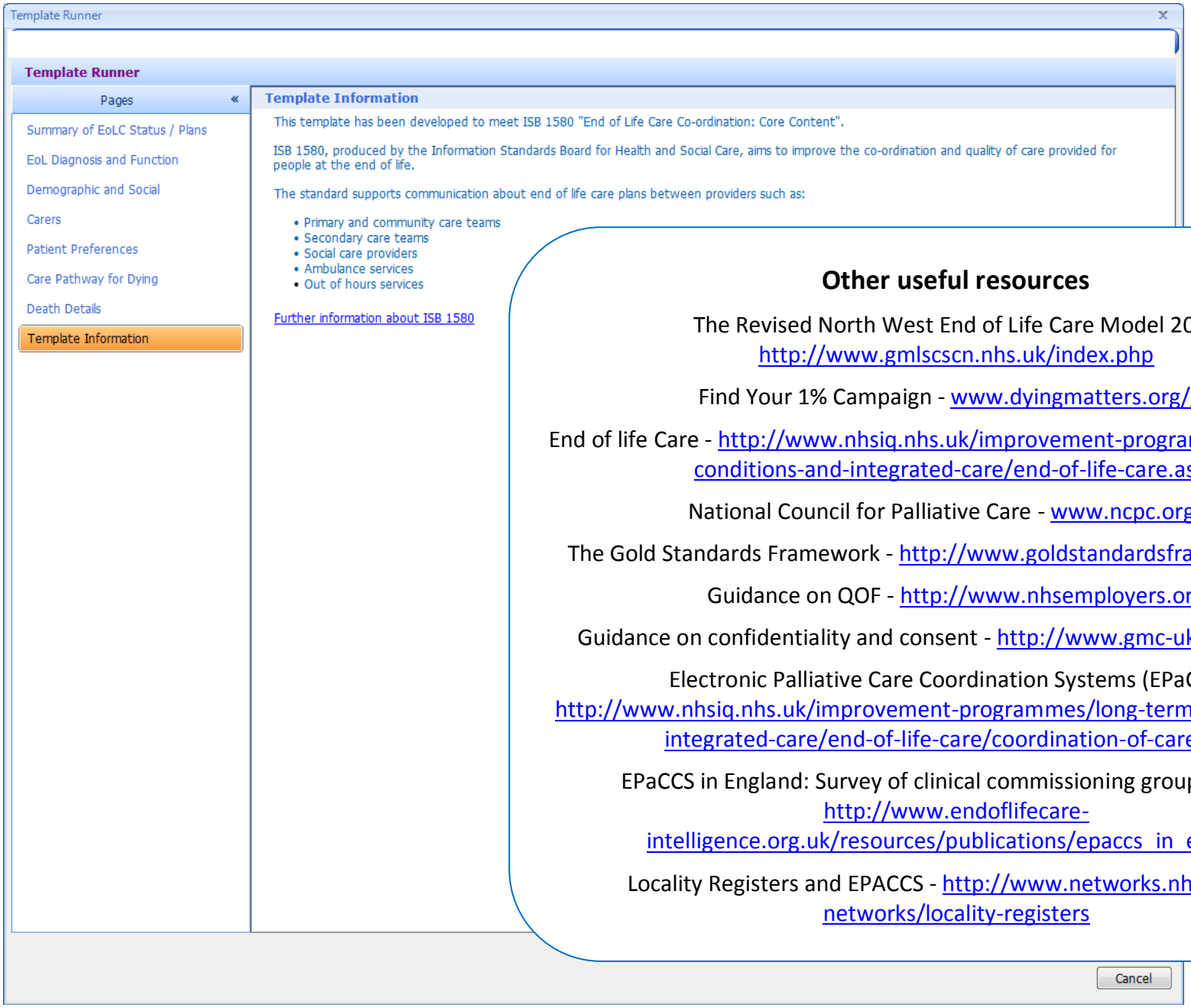
8B2a.	Prescription of palliative care anticipatory medication

Death Details



Date of death / Place of death
These two sections **MUST** be completed as soon as possible after a patient's death.

Template Information



Other useful resources

The Revised North West End of Life Care Model 2015
http://www.gmlscscn.nhs.uk/index.php

Find Your 1% Campaign - www.dyingmatters.org/gp

End of life Care - http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care.aspx

National Council for Palliative Care - www.ncpc.org.uk

The Gold Standards Framework - http://www.goldstandardsframework.org.uk

Guidance on QOF - http://www.nhsemployers.org

Guidance on confidentiality and consent - http://www.gmc-uk.org/guidance

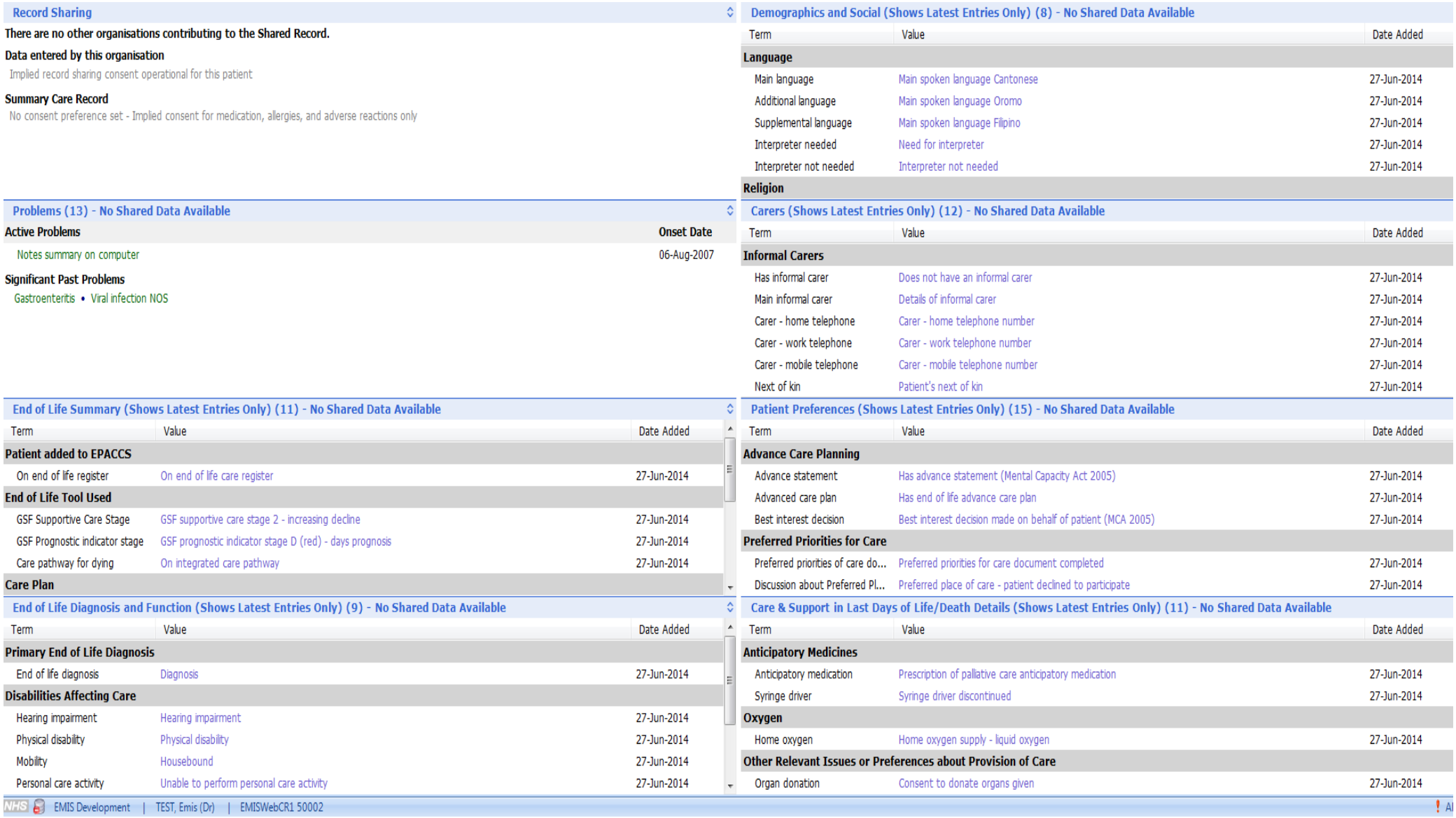
Electronic Palliative Care Coordination Systems (EPaCCS) - http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/coordination-of-care.aspx

EPaCCS in England: Survey of clinical commissioning groups (2013) - http://www.endoflifecare-intelligence.org.uk/resources/publications/epaccs_in_england

Locality Registers and EPACCS - http://www.networks.nhs.uk/nhs-networks/locality-registers

End of Life Care summary view

It is possible within EMIS Web to select a summary view for a number of areas, including one specifically set up for End of Life Care information entered as part of an EPaCCS (see screenshot below). This will bring together in one view all of the information from the EPaCCS dataset collected over time, to support and enhance the work done in GSF / palliative care / MDT meetings.



Record Sharing

There are no other organisations contributing to the Shared Record.

Data entered by this organisation

Implied record sharing consent operational for this patient

Summary Care Record

No consent preference set - Implied consent for medication, allergies, and adverse reactions only

Problems (13) - No Shared Data Available

Active Problems	Onset Date
Notes summary on computer	06-Aug-2007

Significant Past Problems

Gastroenteritis • Viral infection NOS

End of Life Summary (Shows Latest Entries Only) (11) - No Shared Data Available

Term	Value	Date Added
Patient added to EPACCS		
On end of life register	On end of life care register	27-Jun-2014
End of Life Tool Used		
GSF Supportive Care Stage	GSF supportive care stage 2 - increasing decline	27-Jun-2014
GSF Prognostic indicator stage	GSF prognostic indicator stage D (red) - days prognosis	27-Jun-2014
Care pathway for dying	On integrated care pathway	27-Jun-2014
Care Plan		

End of Life Diagnosis and Function (Shows Latest Entries Only) (9) - No Shared Data Available

Term	Value	Date Added
Primary End of Life Diagnosis		
End of life diagnosis	Diagnosis	27-Jun-2014
Disabilities Affecting Care		
Hearing impairment	Hearing impairment	27-Jun-2014
Physical disability	Physical disability	27-Jun-2014
Mobility	Housebound	27-Jun-2014
Personal care activity	Unable to perform personal care activity	27-Jun-2014

Demographics and Social (Shows Latest Entries Only) (8) - No Shared Data Available

Term	Value	Date Added
Language		
Main language	Main spoken language Cantonese	27-Jun-2014
Additional language	Main spoken language Oromo	27-Jun-2014
Supplemental language	Main spoken language Filipino	27-Jun-2014
Interpreter needed	Need for interpreter	27-Jun-2014
Interpreter not needed	Interpreter not needed	27-Jun-2014
Religion		

Carers (Shows Latest Entries Only) (12) - No Shared Data Available

Term	Value	Date Added
Informal Carers		
Has informal carer	Does not have an informal carer	27-Jun-2014
Main informal carer	Details of informal carer	27-Jun-2014
Carer - home telephone	Carer - home telephone number	27-Jun-2014
Carer - work telephone	Carer - work telephone number	27-Jun-2014
Carer - mobile telephone	Carer - mobile telephone number	27-Jun-2014
Next of kin	Patient's next of kin	27-Jun-2014

Patient Preferences (Shows Latest Entries Only) (15) - No Shared Data Available

Term	Value	Date Added
Advance Care Planning		
Advance statement	Has advance statement (Mental Capacity Act 2005)	27-Jun-2014
Advanced care plan	Has end of life advance care plan	27-Jun-2014
Best interest decision	Best interest decision made on behalf of patient (MCA 2005)	27-Jun-2014
Preferred Priorities for Care		
Preferred priorities of care do...	Preferred priorities for care document completed	27-Jun-2014
Discussion about Preferred Pl...	Preferred place of care - patient declined to participate	27-Jun-2014

Care & Support in Last Days of Life/Death Details (Shows Latest Entries Only) (11) - No Shared Data Available

Term	Value	Date Added
Anticipatory Medicines		
Anticipatory medication	Prescription of palliative care anticipatory medication	27-Jun-2014
Syringe driver	Syringe driver discontinued	27-Jun-2014
Oxygen		
Home oxygen	Home oxygen supply - liquid oxygen	27-Jun-2014
Other Relevant Issues or Preferences about Provision of Care		
Organ donation	Consent to donate organs given	27-Jun-2014

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Any comments or suggestions for future updates of this guide? Please send to Stephen Burrows – stephen.burrows@nhs.net