Cheshire EPaCCS

Digital Roadmap



2019 - 2023

**Executive Summary**

This is Cheshire’s digital roadmap for the implementation of an Electronic Palliative Care Coordination System (EPaCCS); a key digital initiative enabling advance care planning and improved communication and coordination of care at end of life.

Covering a four-year period, this roadmap provides an overview of the shared digital vision for EPaCCS across Cheshire and sets out the short, medium and longer-term goals (and required plan) to fully embed the system within the local end of life healthcare system and to ensure greater alignment overtime with the wider digital strategy for Cheshire and Merseyside.

This digital roadmap has been developed in line with the Palliative Care Coordination: Core Content ‘Requirements Specification1’, and the associated ‘Information Governance Guidance2’ and ‘Implementation Guidance3’, as well as the ‘EPaCCS Recommended IT System Requirements4‘ documents.

**Introduction**

People considered to be approaching end of life often require care that is supported by a combination of health and social care services, which are often provided by a wide range of professionals and staff groups, as well as by their families and other carers.

EPaCCS is a nationally recognised system for enabling improved communication and better coordination of care. EPaCCS is underpinned by technology, which facilitates the recording and sharing of accurate, consistent and timely information about patients in their year of life, so that the right information is available in the right place, for the right person, to make the right decisions, at the right time.

The overall aim of EPaCCS is to improve patient experience and care at the end of life, by putting patient’s wishes and preferences at the centre and helping to create an environment where healthcare professionals (regardless of employer) can work easily together.

**A digital vision for EPaCCS**

 ***A fully embedded system that enables the transfer of information electronically, to support advance care planning and improved communication and coordination of care at the end of life***

***We will do this by:***

* Using technology to identify those individuals with progressive life-limiting illness whom would benefit from advance care planning, such as people with a dementia diagnosis, people with long-term conditions and people who are severely frail, as well as those individuals with a cancer diagnosis.
* Empowering individuals (and their families/carers) to have direct access to their EPaCCS record and enabling them to contribute information to it, so that they have greater control over determining what information is recorded and how it is then shared.
* Supporting healthcare professionals to have proactive, person-centred conversations with individuals about their condition and their wishes and preferences for end of life care, and enabling them to then share this information with others professionals involved in delivering care
* Empowering healthcare professionals to have direct access to accurate, consistent and timely information, electronically, at the point of care delivery, to support appropriate treatment decisions and interventions



**Our Approach**

Improving experience and quality of care for patients coming to the end of their lives is everyone’s business – there is no single individual, team, service or organisation that can do this alone.

We are therefore taking a whole-systems approach to delivering EPaCCS across Cheshire i.e. organisations and practitioners are committed to working together to plan and implement coordinated actions, that address several key success factors, required to achieve the shared vision for EPaCCS. These critical success factors include:

**Our Pledges**

***We will:***

* **Make the most of what we already have** by using existing systems and trying best to connect our present digital resources and committing to new ways of working
* **Co-design and co-produce with the person at the centre,** by working with patients and staff; ensuring that what we develop is designed around what works for them
* **Share our learning and also learn from others**, both locally and nationally; creating a learning from best practice approach

**Our Digital Partners**

Implementation of EPaCCS across Cheshire involves the following partner organisations:

|  |  |
| --- | --- |
| * Central Cheshire Integrated Care Partnership
 | * NHS South Cheshire CCG
 |
| * Cheshire & Wirral Partnership NHS Foundation Trust
 | * NHS Vale Royal CCG
 |
| * East Cheshire Hospice
 | * NHS West Cheshire CCG
 |
| * East Cheshire NHS Trust
 | * St Luke’s Hospice
 |
| * EMIS Health
 | * The Countess of Chester Hospital NHS Foundation Trust
 |
| * Graphnet
 | * The End of Life Partnership
 |
| * Mid Cheshire Hospitals NHS Foundation Trust
 | * The South Cheshire and Vale Royal GP Alliance
 |
| * NHS Eastern Cheshire CCG
 |

**Cheshire EPaCCS – Achievements So Far**

Implementation of EPaCCS across Cheshire commenced with an early adopter pilot in East Cheshire during 2013 –14. The learning and outcomes of the pilot evaluation were used to subsequently plan the phased roll-out of EPaCCS across Cheshire (phase 1 during 2014 /15 and phases 2,3 and 4 during 2015/16 onwards***.***

As part of implementation an EPaCCS steering group comprising representation from key partner organisations was established and importantly, continues to meet on a regular basis to oversee EPaCCS implementation and provide the necessary direction and expert advice required to plan and deliver local developments.

To date partners across Cheshire have digitally achieved the following:

* Compliance with the Palliative Care Coordination Information Standard (ISB 1580), which specifies the core content required to support high-quality, coordinated end of life care
* Compliance with SNOMED CT coding , meaning we’re all using the same language which makes it easier for clinicians to view shared information
* Secured EMIS Health for two of the three Hospices (East Cheshire Hospice and St Luke’s) and Hospitals (MCHFT & MDGH) meaning that they are now using EMIS Web software to record EPaCCS information
* Signed EPaCCS information sharing agreements for the secure recording, storing and sharing of end of life information between relevant partner organisations – *see appendix for current information sharing agreement matrix*
* Secured EMIS Web EPR Viewer for GP OOHs in South & Vale Royal giving clinicians 24 hour access to patients’ GP records, including end of life information
* Influenced the prioritisation of EMIS Health access for a number of teams that frequently care for people at the end of life: Specialist Palliative Care, Acute Oncology, Tumour site specific specialist nurses, Integrated Discharge & Heart Failure.
* Development plans for the integration of EPaCCS with the Cheshire Care Record that are built using national Interoperability Toolkit (ITK) specifications.

***The following page provides a visual overview of the current EPaCCS landscape across Cheshire***

**Key:**

 Solid Green Line – Coded EPaCCS data exchanged **** Pink cylinder- Access to EPaCCS data via EPR Viewer

 Dashed Green Line – Data exchange in development  Faded pink cylinder – Access to EPaCCS data required/in development Blue Cylinder – Instance of EMIS with active end of life coding Solid Turquoise Line – Exchange with CCR enabled

  Faded blue cylinder – Instance of EMIS requires/in development Dashed Turquoise Line – Exchange with CCR in development

Read only access to patients’ GP record via EMIS EPR Viewer

Current EPaCCS Landscape

**St Luke’s**



ECT

MCHFT

**EMIS Web users - End of Life Care Summary View**

(Holistic view of all EPaCCS coded information)

CCICP

**Liquidlogic**

Social Care

**ERRIS**

North West Ambulance Service

**ADASTRA**

NHS 111

**CALL 111**

**Care Notes**

Mental Health

**Cheshire Care Record (CCR)**

**Graphnet Care Centric v.3 software**



**GP Out of Hours (OOHs)**

**EMIS Web v. Primary Care**

**EMIS Web v. Hospices**

**EMIS Web v.**

**Community**

**EMIS Web v.**

**Hospitals**

ECT

MDGH

COCH

ECT

 CWP

X 88 GP Practices

CCICP

 CWP

 HOGS

**ECH**

To help contextualisethe current EPaCCS landscape, the following sections provide a detailed summary of the local systems ‘specification’. *In creating this section people should refer to the ‘EPaCCS Recommended IT System Requirements’ document (page 17 Requirements Summary), as a guide.*

**Information Governance**

Where data is transferred between organisations, a secure legal basis for doing so is needed. This should additionally be supported by data sharing agreements to ensure there are appropriate information governance safeguards and adequate data security and data protection measures in place.

Each delivering organisation should ensure a **Privacy Impact Assessment** **(PIA)** has been completed or retrospectively undertaken. Further guidance on performing a PIA can be found on the [Information Commissioners Office website](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/accountability-and-governance/data-protection-impact-assessments/)

**Approach** – In order for a complete EPaCCs record to be available and usable participating organisations must agree to information sharing via the EMIS system whether this is via enabling data sharing from within an organisations own EMIS system or via other connections to other local Patient Information Systems such as the Cheshire Care Record. This data sharing should meet the specifications outlined in the local Minimum Dataset for End of Life.

Organisations are also advised to complete data sharing agreements with all partner organisations based on the templates that can be found in the local EPaCCs Operational Policy.

**EPaCCs Consent** – Consent wording for the EPaCCs template is dictated nationally. At a local level, patients EPaCCs data will still be shared even if this consent box is unticked, this is because consent checkboxes within the EMIS EPaCCS template have no relation to the general sharing consent for the patients’ whole medical record. The Cheshire EPaCCS steering Group have produced [a consent statement](http://epaige.azurewebsites.net/wp-content/uploads/2018/12/Cheshire-EPaCCS-consent-position-2017.pdf) that describes this function and how it should be applied locally.

Further details of recommended implementation standards around Audit and Data Security and Confidentiality can be found on the [NHS Digital Website](https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci1580-palliative-care-co-ordination-core-content#current-release). However all implementations of EPaCCs should also consider other local and national guidance, standards and legislation such as General Data Protection Regulation where applicable.

**Interoperability**

Using EPaCCS dataset in line with the national information standard – with all our different systems meeting the same standard and using the same language, information can be shared and viewed by other healthcare professionals

The core dataset for EPaCCS is held within EPaCCS records, based on the North West EPaCCS Template

*There is a national interoperability specification, which includes specific interoperability messages that have been developed to help information flow between different systems and therefore support care co-ordination such as* ***notifications, document retrieval***

**Functional Overview**

Systems are designed to perform specific tasks to fulfil specific functions. Locally any implemented system where possible should seek to confirm with the [Requirements Specification](https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci1580-palliative-care-co-ordination-core-content#current-release) outlined in national information standard SCCI11580.

It is recommended that each provider record any areas where their implementation is not able to meet the national recommended standards.

Locally it is recommended that any EPaCCs implementations supporting system be capable of the following:

***General***

* Data items conform to the national information standard for palliative care (SCCI 1580)
* Supports the recording of palliative and end of life preferences
* capture a consent decision that relates directly to recording and sharing an EPaCCS record
* Allows for the removal of EPaCCS related information
* Prompts a review date to be set when an EPaCCS record is created
* Provides prompts users about recording cardiopulmonary resuscitation
* All coded information should be capture using SNOMED CT codes

***Patient Access***

* Allows for the printing of EPaCCS records
* Information provided to a patient can be filtered

***Reporting***

* Provides reporting capabilities
* Supports full data extracts
* Provides a summary view of all the EPaCCS coded information in a patients’ record
* Prevents further access to a patients EPaCCS record if the patient withdraws their consent

**Technical (Non-Functional) Overview**

Systems must work in a certain way in order to meet ‘business’ needs. This section helps to describe the technical (or quality) aspects of our current EPaCCS.

***Data***

* Information held within the system is coded using SNOMED CT
* SNOMED CT data is kept up-to-date
* NHS Numbers are used as the primary unique identifier for a person
* Documentation can be attached to EPaCCS records
* Changes to the core data set can be made easily

***Infrastructure***

* Accessible over N3
* Offline access is provided (via EMIS Mobile and via locally redundant infrastructure where appropriate)
* Interoperability between non-EMIS systems is supported by the Graphnet Care Centrix software

***User Interface***

* A person’s preferences appear as a single record
* Cross-organisational tasks, alerts and warnings

**Access to EPaCCS data via EMIS Web**

**Hospitals**

**Mid Cheshire Hospital NHS Foundation Trust (Leighton Hospital)** has an EPaCCS instance of EMIS web, which runs alongside their OOH and A&E instances. There are a number of key clinical teams that have been given appropriate access rights to EMIS to use EPaCCS within their working practice, these include:

|  |  |  |
| --- | --- | --- |
| **Team**  | **No. of Licences**  | **Access rights**  |
| Macmillan Specialist Palliative Care | X2  | Read and Write  |
| Macmillan Lung Cancer  | X4  | Read and Write |
| Acute Oncology  | X5  | Read and Write  |
| Bowel cancer screening | ? | Read only  |
| Heart Failure  | X2  | Read and Write  |
| Upper GI  | X3  | TBC  |
| Head and Neck  | X1 | TBC  |
| Haematology  | X2 | Read and Write  |
| Integrated Discharge  | X9 | TBC  |

**East Cheshire NHS Trust (Macclesfield District General Hospital)** provides physical health services for the population of Eastern Cheshire. All ECNT palliative care teams, community nursing and therapy services, adult and paediatric, use EMIS Web as their full EPR with full read and write access to EPaCCS as well as via their mobile device using the mobile app or Horizon virtual desktop, allowing access anytime, anywhere. Several areas within the Acute setting now have access to EMIS Web and are actively encouraged to access EPaCCS and the shared records and summaries.

With full sharing agreements across all East Cheshire Primary Care organisations as well as East Cheshire Hospice we are able to share appropriate EPaCCS summary screens.

Whilst East Cheshire GP OOH service remains on Adastra they do have full access to EMIS Web, able to view EPaCCS, full patient records and book published appointments directly into GP surgery diaries.

**Community Services**

**Central Cheshire Integrated Care Partnership** provide physical health services for the populations of South Cheshire and Vale Royal. During the summer of 2018, the partnership procured and transitioned staff to a new EMIS.org, following the re-commissioning of the community contract in 2016 (previously staff were using ECT’s version of EMIS Community). All staff have full read and write access to EPaCCS through EMIS Web and have mobile working software (EMIS Mobile) to enable them to access all the core elements of EMIS Web anytime, anywhere.

NB: As part of CCICP’s transition to EMIS Community there were a number of services which were not in scope including the GP Out-of-Hours Service. GP OOH continue to use ADASTRA as their primary clinical system, however staff within the service have been permitted read only access to EMIS Web via EMIS EPR Viewer.

**Hospices**

**St Luke’s Hospice** provide palliative and end of life care to people in the Cheshire Area. During 2017 St Luke’s Hospice implemented a new EMIS Community system to replace their use of Crosscare. All staff both in care and day hospice have access to EMIS and are coding EPaCCS information within their settings

**East Cheshire Hospice** provide palliative and end of life care to people in East Cheshire and Buxton area. The Hospice have been using EMIS Web as their clinical system since April 2015. All clinical staff in all services have access to EMIS Web and are using coded templates to record patient information. The Hospice has an EPaCCS template and summary screen available to all services.

**Primary Care**

There are 88 individual practices across Cheshire, each with their own instance of EMIS.

**Other routes of digital communication**

* Cheshire Care Record allows interoperability with non-EMIS systems and is provided by Graphnet using the Care Centrix software. Participating partners currently include: East Cheshire NHS Trust, Mid Cheshire Hospital Trust, Countess of Chester Hospital, Cheshire Wirral Partnership, and a growing number of GP Practices that represent Primary Care.

* North West Ambulance Service (NWAS) uses a Clinical IT system called ERRIS. This system provides a secure portal for organisations to inform NWAS of care planning arrangements for specific patient groups.

Current concerns with using this communication route include, requires a separate log-in, is an additional task that needs completing alongside many other similarly important tasks, and limitations to the information held within ERISS that subsequently affect the quality of the information relayed to ambulance crews on the ground.

* Special Patient Notes for NHS 111 and GP OOH - Notes that can be attached to a new or existing patient to alert or highlight any specific care requirements, long term care plans or any other item of useful information for the patient. They will show up in the main Adastra v3 system when the patient contacts the service.

**Cheshire EPaCCS - Where we want to be, digitally?**

There are a number of gaps in terms of current access to and subsequent use of electronic end of life information. Partners across Cheshire plan to address these gaps through the EPaCCS steering group including:

* Ambulance service, NHS 111, Social Care and Mental Health to have access to end of life information via the Cheshire Care Record
* EPaCCS module to be part of the Hospitals EPR
* Find solutions so that Care Homes are part of the EPaCCS landscape
* Explore solutions for partners currently not involved in EPaCCS
* Enable patient access to EPaCCS records
* Upload Advance Care Planning documentation within EPaCCS including DNACPR forms

With regards to outstanding functional and non-functional requirements, Partners expect to see progress with:

* Printable version of the End of Life Care Summary View which could then be taken on home visits, or left in the front of care home notes
* Equality reporting to support organisations in ensuring equitable provision of care and support at end of life

**Future Considerations/Dependencies/Assumptions**

**Considerations**

MCHFT and MDGH are to jointly commence procurement of an Electronic Patient Record (EPR) called Cerner. This is a system already used at Wirral University Teaching Hospital, whom are currently developing an end of life module. The local EPR is likely to terminate use of EMIS Web software at the hospitals and efforts will be required to ensure that data feeds from within Cerner can easily integrate and transfer information between itself and existing EMIS systems.

EMIS Cloud development – Current planned developments to move EMIS into a cloud based infrastructure will eliminate current sharing issues between Primary Care and Community Care systems where by entries in EPaCCs records in the community systems are not fed back into the Primary Care systems. However, these developments will most likely not be seen in the Community EMIS environment for 5-10 years.

Care Home technology limitations – Many Care Homes still operate in an environment where computers are situated only in management offices and technology is not widely available to care staff.

NWAS are working across a much wider geography than Cheshire and are currently exploring their involvement in the Care to Share work across Cheshire & Merseyside. Developments in Greater Manchester Health & Care Partnership around EPaCCS also have the potential to impact on the Eastern Cheshire locality due to patient flows.

Requirement to further understand the planned implementations of EPR and EPaCCs within the West Cheshire Area.

**Dependencies**

Delivery of Cheshire Care Record development activity

Delivery of a Hospital EPR with abilities for EPaCCS integration

NWAS solutions for interoperability with the CCR are realised and progressed

IT solutions for Care Home access to EPaCCS are identified

Partners are willing to share data and data sharing agreements remain relevant and up to date

**Assumptions**

Ambulance service have access to electronic devices

Staff working out in the community have access to EMIS Mobile

**Digital Challenges and Barriers**

* Providing patient’s with access to view and contribute to/update their EPaCCS record
* Uploading of ACP documentation
* EPaCCS Reporting – GP system is currently the primary system
* IT Leadership & resources
* Overall engagement – functionality requires commitment from staff to new/different ways of working to realise the potential of EPaCCS
* Up-to-date information – discrepancies between different systems data entries do not become embedded within other clinical systems only the professionals native system
* Care Homes not using electronic IT systems. A lot of their patient records and care plans are paper-based and we have over 120 care homes within our geography
* Number of practices choose not to share their information with other organisations/professionals, including not participating in the Cheshire Care Record
* Misconceptions around EPaCCS, including around the consent position
* Commitment to information sharing amongst partners- including keeping data sharing agreements’ relevant and up to date

**How are we going to get where we aspire to be?**

|  |
| --- |
| **Short-Term Goals (to March 2019)** |
| **Key Area**  | **Deliverables**  | **How**  | **By Who**  |
| **Data Exchange**  | Test EPaCCS data feed from EMIS to the Cheshire Care Record To influence inclusion of EPaCCS within Hospital EPR implementation plans Develop unified approach to data sharing agreements across partners Resolve data sharing issues between MCHT , CCICP & St Luke’s | * Identify test practice
* Identify test patient
* Obtain practice & patient consent to test
* Enable the practice
* Test data feed
* Evaluate

-Secure representation from EPaCCS clinical and IT leads within EPR design plans* Draft Initial Agreement
* Review with local steering groups and partners
* Implment agreement with providers (EMIS etc)
* Publish Templates
* Replace agreement where appropriate

Work with partner organisations to identify the source of the problem and to resolve | EMIS & Graphnet EPaCCS Steering GroupEPaCCS steering groupEMIS/ CCICP/MCHT/SLH |
| **Data Collection**  | EPaCCS reporting across all partner organisations to provide a full –picture of EPaCCS uptake and the quality of its use locally  | * Establish viable reporting mechanisms with partners
* Agree ongoing reporting arrangements and secure commitment/resources
 | EPaCCS Steering Group  |
| **Improve uptake** | Launch of template for Cheshire Wirral Partnership Community TeamsSupport Primary Care Quality Improvement work Define Western Cheshire approaches to EPaCCS  | * Work with CWP to develop template and to launch across District Nursing and Macmillan Teams
* Run a series of Quality Improvement workshops with Primary Care Networks aligned to use of EPaCCS
* Include Western Cheshire plans within digital roadmap
 | CWP/EoLP/West CCGEoLP/CCG’sWest CCG |
| **Medium-Term Goals (April 2019 – March 2020)**  |
| **Direct patient access to EPaCCS Record**  | * Deliverables to be defined by the Patient Knows Best Project in Cheshire East
* Align activity to GP Practice patient access related activity
 | * Link with patient knows best project leads to explore potential solutions
* Link with wider work around patient access
 | EoLP/ Cheshire East CouncilSteering Group |
| **Data exchange** | - To pilot sharing of EPaCCS data with NWAS | - Secure NWAS representative at EPaCCS steering group- link to wider interoperability projects between Cheshire Partners & NWAS  | Steering Group/EoLP |
| **Care Homes**  | - Develop and test models of using EPaCCS in Care Homes  | - link to other care home initiatives to integrate EPaCCS agenda  | Steering Group/EoLP |
| **Longer-Term (April 2020 and beyond)** |
| Digital maturity  | ACP documentation uploaded to EPaCCS record  | TBC | TBC |

**Glossary**

|  |  |
| --- | --- |
| **Adastra**  | A web-based system ….  |
| **CBD Number** | A Customer Database number for EMIS Health clients. Each instance of EMIS is assigned a CBD number.  |
| **EMIS EPR Viewer**  | A version of the EMIS software specifically for read only access to Electronic Patient Records |
| **EMIS Health** | A provider of healthcare technology (systems/software/services) |
| **EMIS Mobile**  | A software application that allows healthcare professionals to securely access all core elements of EMIS Web through their mobile devices, anytime, anywhere  |
| **EMIS Web** | A clinical system that allows healthcare professionals to record, share and use information  |
| **Functionality**  | The tasks that an electronic system is able to do i.e. the system provides reporting capabilities  |
| **Instance of EMIS** | An occurrence of EMIS. Different organisations have set up their own instances of EMIS (often known as EMIS.orgs) – linked to CBD number  |
| **Interoperability** | The ability of one electronic system to exchange and make use of information from another electronic system  |
| **ITK Messages**  | Messages sent via an ITK system |
| **ITK Toolkit**  | Insight Toolkit (ITK). ITK is an open-source, cross-platform system that provides developers with an extensive suite of software tools for image analysis |
| **IT Solution**  | An aggregation of products and services, as opposed to a single, discrete product to help solve a ‘business’ problem. For example, for antivirus software to be a solution to preventing, detecting and removing malicious software it would need to be bundled with related products, such as spam filters or a backup service.  |
| **N3 Connection**  | The private internet/connectivity service provided specifically to NHS providers and partners |
| **HSCN Connection** | Health and Social Care Network. The private internet/connectivity service provided specifically to NHS providers and partners. Will replace N3 |
| **Technical**  | How an electronic system behaves to satisfy a user’s standards and needs i.e. information should be coded using SNOMED CT  |
| **User Interface**  | The means by which the user and a system interact, in particular the use of input devices and software. |

**References**

|  |  |  |
| --- | --- | --- |
| **Ref** | **Title**  | **Source**  |
| 1. | National End of Life Care Intelligence Network. Palliative care coordination: core content. Requirements Specification | <http://www.endoflifecare-intelligence.org.uk/national_information_standard/end_of_life_care_coordination> |
| 2. | Electronic Palliative Care Coordination Systems: Information Governance Guidance  | [https://webarchive.nationalarchives.gov.uk/20160921152006/http://systems.digital.nhs.uk/qipp/library/index\_html#end-of-life-care-1](https://webarchive.nationalarchives.gov.uk/20160921152006/http%3A//systems.digital.nhs.uk/qipp/library/index_html#end-of-life-care-1) |
| 3. | National End of Life Care Intelligence Network. Palliative care coordination: core content.Implementation Guidance  | <http://www.endoflifecare-intelligence.org.uk/resources/publications/implementation_guidance> |
| 4. | EPaCCS Recommended IT System Requirements | <http://www.endoflifecare-intelligence.org.uk/national_information_standard/end_of_life_care_coordination>  |

Appendix 1. North West EPaCCS Dataset

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Possible grouping** | **selection** | **Read V2** | **Read CTV3** | **SNOMED** | **text** | **Read code term** | **Item No** | **SCR** |
| **Demographics** | **s** |  | **Record creation date** | **2** |  |
| **s** |  | **Planned review date** | **3** |
| **s** |  | **Date and time of last amendment** | **4** |
| **s** |  | **Person family name** | **5** |
| **s** |  | **Person forename** | **6** |
| **s** |  | **Person preferred name** | **7** |
| **s** |  | **Person birth date** | **8** |
| **s** |  | **NHS number** | **9** |
| **s** | **01 Number present and verified 02 Number present but not traced 03 Trace required 04 Trace attempted - No match or multiple match found 05 Trace needs to be resolved - (NHS number / Patient detail conflict) 06 Trace in progress** | **NHS number status indicator code** | **10** |
| **s** |  | **Person gender** | **11** |
| **s** |  | **Person address** | **12** |
| **s** |  | **Person telephone numbers** | **13** |
| **s** |  | **Usual GP name** | **19** |
| **s** |  | **Practice details** | **20** |
| **Consent status** | **m** | **9Nu6.** | **XaaYI** | **882921000000109** | √ | **Consent given for sharing end of life care coordination record** | **1** |   |
| **9Nu7.** | **XaaYJ** | **882941000000102** | √ | **Withdrawal of consent for sharing end of life care coordination record** |
| **9Nu8.** | **XaaYK** | **882961000000101** | √ | **Best interests decision taken (Mental Capacity Act 2005) for sharing end of life care coordination record** |
| 9Nu9. | XaaYL | 882981000000105 | √ | Consent given by legitimate patient representative for sharing end of life care coordination record |
| **9Nu90** | **XaaYM** | **883001000000106** | √ | **Consent given by appointed person with lasting power of attorney for personal welfare (MCA 2005) for sharing end of life care coordination record** | √ |
| **On gold standards palliative care framework** | **s** | **8CM1.** | **XaJv2** | **414937009** | **** | **On gold standards palliative care framework** | **33** | √ |
| **GSF Supportive Care Stage** | **s** | 8CM10 | XaR50 | 518901000000101 |  | Gold standards framework supportive care stage 1 - advancing disease |  | √ |
| 8CM11 | XaR53 | 518941000000103 |  | Gold standards framework supportive care stage 2 - increasing decline |  | √ |
| **8CM12** | **XaR5A** | **519041000000106** |  | **Gold standards framework supportive care stage 3 - last days: category C - wks prognosis** |  | √ |
| 8CM13 | XaR5B | 519061000000107 |  | Gold standards framework supportive care stage 3 - last days: category D - days prognosis |  | √ |
| **GSF Prognostic Indicator Stage** | **s** | **8CM15** | **XaZb7** | **845701000000104** |  | **Gold standards framework prognostic indicator stage A (blue) - yr plus prognosis** |  | √ |
| **8CM16** | **XaZbA** | **845721000000108** |  | **Gold standards framework prognostic indicator stage B (green) - months prognosis** |  | √ |
| **8CM17** | **XaZbD** | **845751000000103** |  | **Gold standards framework prognostic indicator stage C (yellow) - weeks prognosis** |  | √ |
| **8CM18** | **XaZbE** | **845771000000107** |  | **Gold standards framework prognostic indicator stage D (red) - days prognosis** |  | √ |
| **Likely prognosis** | **s** | **2Jg..** | **XacdB** | **968211000000101** | **** | **Last months of life**  | **34** | √ |
| **2Jf..**  | **XacFk**  | **955231000000109**  | **** | **Last weeks of life** | √ |
| **2JE..**  | **XaQg1**  | **511401000000102**  | **** | **Last days of life** | √ |
| **Personal care plan / review date** | s | 8CMD. | XaRB2 | 523051000000100 | √ | Personal care plan completed |  | √ |
| s | 9Ne0. | XaKSG | 185551000000106 |   | Single Assessment Process summary care plan completed |  | √ |
| s | 8CM3. | XaLG1 | 196121000000104 | √ | Palliative care plan review  | **2** | √ |
| s | 389.. | Ua1P6 | 225343006 |  | Assessment of needs |  |  |
| s | 9e02. | XaQ8a | 492321000000103 |  | Notification to primary care OOHS of palliative care plan in place  | √ |
| **Allowances / benefits** | s | 9EB5. | 9EB5. | 514591000000108 | **√** | DS 1500 Disability living allowance (terminal care) completed |  |
| s | 9EB8. | XabBG | 910051000000109 | √ | Personal Independence Payment claim form completed |
| s | 9RL5. | XaXUh | 769351000000107 | √ | NHS continuing healthcare funding granted |
| **Ambulance service notified** | s | 9G8.. | XaZmb | 854021000000106 | √ | Ambulance service notified of patient on end of life care register |
| **Patient held palliative care record** | s | 9367. | XaZZe | 845021000000105 | √ | Patient held palliative care record |
| s | 9365. | XaMie | 280151000000107 |   | Carer holds patient care plan | √ |
| **Supportive Care needs** | s | 8BJ2. | XaIlN | 243114000 |  | Supportive Care |  |
| s | 9l4.. | XaQjr | 184087005 |  | Patient removed from supportive care register |
| **Palliative care** | s | ZV57C | ZV57C | 470191000000109 | √ | [V]Palliative care |
| s | 8BJ1. | XaIpI | 363676003 |   | Palliative Treatment |
| s | 8BAP. | XaIpY | 395092004 |   | Specialist palliative care |
| s | 8BAR. | XaIsf | 395670002 |   | Specialist palliative care treatment - inpatient | √ |
| s | 8BAS. | XaIt6 | 395694002 |   | Specialist palliative care treatment - daycare | √ |
| s | 8BAT. | XaIt7 | 395695001 |   | Specialist palliative care treatment - outpatient | √ |
| **End of Life diagnosis** | **s** |  |  |  | √ | **Primary End of Life Care diagnosis** | **26** |   |
| **s** |  |  |  | √ | **Other Relevant End of Life Care Diagnoses and Clinical Issues** | **27** |
| **Disabilities affecting care** | **m** | **F5A..** | **XE0s9** | **15188001** | √ | **Hearing impairment / [ CTV3 / SNOMED: Hearing loss ]** | **28** | √ |
| **F49D.** | **XE16L** | **397540003** | √ | **Visual impairment / [ CTV3: Impaired vision ]** | √ |
| **13oB.** | **Xa4Cq** | **288579009** | √ | **Difficulty communicating** |   |
| **28E3.** | **Ua189** | **386806002** | √ | **Cognitive impairment** | √ |
| 13VM. | Ub0in | 197521000000108 | √ | Physical disability | √ |
| 1P80. | Xa2u6 | 284774007 |   | Able to perform personal care activity | √ |
| 1P81. | Xa2u7 | 284775008 | √ | Unable to perform personal care activity | √ |
| 1461. | 1461. | 161465002 | √ | H/O: dementia |   |
| **1PA0.** | **Xaato** | **325541000000106** | √ | **Unable to summon help in emergency** | √ |
| **13i2.** | **XabGs** | **914271000000103** | √ | **Impaired ability to recognise safety risks** | √ |
| **13VCZ** | **13VCZ** | **21134002** | **√** | **Disability NOS** |   |
| **115M.** | **XaX0D** | **750691000000106** | √ | **No known disability** | √ |
| **11520** | **XaaYD** | **703154009** | √ | **Patient reports no current disability** | √ |
| **Functional status** | **s** | **38QF.** | **Xab0M** | **901361000000101** | **\*** | **Australia-modified Karnofsky Performance Status scale** | **29** | √ |
| **Allergies** | **s** |  |  |  | **√** | **Allergies / adverse drug reactions** | **30** |  |
| **Cardiac device** | s | ZV450 | ZV450 | 427121000000106 | √ | [V]Cardiac pacemaker in situ |   | √ |
| s | 2JS.. | XaNR7 | 429082009 | √ | Patient with internal cardiac defibrillator pacemaker | √ |
| **Occupational exposure** | s | ZV4C. | ZV4C. | 401841000000108 | √ | [V]Occupational exposure to risk-factors |  |
| **Frailty** | m | 13C1. | 13C1. | 160680006 |  | Fully mobile |  | √ |
| 13C2. | 13C2. | 160681005 |  | Mobile outside with aid | √ |
| 13C3. | 13C3. | 160682003 |  | Mobile in home |  |
| 13C4. | 13C4. | 160683008 |  | Needs walking aid in home |
| 13C5. | 13C5. | 160684002 |  | Confined to chair | √ |
| 13C6. | 13C6. | 160685001 |  | Bed-ridden | √ |
| 1611. | 1611. | 161825005 |  | Appetite normal |  |
| 1612. | XE24f | 269813009 |  | Appetite loss - anorexia |
| 1613. | 1613. | 72405004 |  | Appetite increased |
| 1614. | XE0qa | 267023007 |  | Excessive eating - polyphagia |
| 1615. | Ua1iv | 64379006 |  | Reduced appetite |
| 161Z. | 161Z. | 161824009 |  | Appetite symptom NOS |
| 1621. | XE2th | 271398006 |  | Weight steady |
| 1622. | 1622. | 161831008 |  | Weight increasing |
| 1623. | 1623. | 161832001 |  | Weight decreasing |
| 1624. | 1624. | 161833006 |  | Abnormal weight gain |
| 1625. | XE0qb | 267024001 |  | Abnormal weight loss |
| 1626. | XaKaA | 416528001 |  | Intentional weight loss |
| 1627. | XaXTs | 448765001 |  | Unintentional weight loss |
| 1628. | XaXjS | 449361003 |  | Pattern of weight gain |
| 162Z. | 162Z. | 161829004 |  | Weight symptom NOS |
| 2231. | 2231. | 162701007 |  | O/E - Fully conscious |
| 2232. | 2232. | 162702000 |  | O/E - Mentally confused |
| 2233. | 2233. | 162703005 |  | O/E - Delirious |
| 2234. | 2234. | 162704004 |  | O/E - Drowsy |
| 2235. | 2235. | 162705003 |  | O/E - Semiconscious |
| 2236. | XE1h1 | 268913004 |  | O/E - Unconscious/comatose |
| 2237. | 2237. | 162707006 |  | O/E - Conscious level fluctuating |
| 2238. | XaKSA | 416865008 |  | O/E - Clouded consciousness |
| 2239. | XaKSB | 417473004 |  | O/E - Decreased level of consciousness |
| 223Z. | 223Z. | 162700008 |  | O/E - level of consciousness NOS |
| **Language** | **s** | **9NU0.** | **XaI8X** | **315594003** | **√** | **Interpreter needed** | **14** | √ |
| s | **13l../13u../13w..** | **XaPGh/XaPGi** | **370157003** | **** | **Main spoken language** | **15** | √ |
| **Religion** | **s** | **135../13y../13z..** | **135..** |  | **√** | **Religion / [ CTV3: Religious affiliation ]** | **58** |  |
| **Ethnic category** | s | 9i… | XaJQu | 92381000000106 |   | Ethnic category - 2001 census |
| **Sexual orientation** | s | 1b0.. | X766r | 42035005 | √ | Bisexual |
| 1b1.. | X766q | 20430005 | √ | Heterosexual |
| 1b20. | E2201 | 89217008 | √ | Lesbian |
| 1b21. | E2200 | 76102007 | √ | Male homosexual |
| 1b3.. | XaPO2 | 440583007 | √ | Sexual orientation unknown |
| **Social - accommodation** | **s** | **13F2.** | **13F2.** | **160725005** | **√** | **Lives alone - help available** | √ |
| **13F3.** | **13F3.** | **160726006** | **√** | **Lives alone - no help available** | √ |
| **13FH.** | **13FH.** | **160756002** | **√** | **Lives with relatives** | √ |
| **13F61** | **13F61** | **160734000** | **√** | **Lives in a nursing home** | √ |
| **13FK.** | **XaImT** | **394923006** | **√** | **Lives in a residential home** | √ |
| **13HQ.** | **XE0pK** | **105568001** | **√** | **In prison** |  |
| **13D..** | **Xa8O5** | **266935003** | **√** | **Homeless** |
| **13FZ.** | **13FZ.** | **224209007** | **√** | **Housing NOS** |
| **Social - family** | **m** | **13W9.** | **13W9.** | **21959005** | **√** | **Single parent family**  |
| **13WL.** | **Ua0II** | **224120001** | **√** | **Family with young children**  |
| **13WP.** | **Ua0IO** | **224126007** | **√** | **Family with school aged children** |
| **13WQ.** | **Ua0IQ** | **224128008** | **√** | **Family with teenage children** |
| **13WJ.** | **13WJ.** | **161083000** | **√** | **Help by Relatives**  |
| **Other social issues**  | **m** | **13Z1.** | **13Z1.** | **161112004** | **√** | **Illiteracy** | √ |
| **13Z5.** | **13Z5.** | **161138004** | **√** | **Literacy problems** | √ |
| **13Z8.** | **13Z8.** | **161152002** | **√** | **Social problem** |  |
| **13ZN.** | **XaIOM** | **390790000** | **√** | **Asylum seeker** |
| **13ZR.** | **XaKbP** | **416142000** | **√** | **At risk of emotional/psychological abuse** |
| **13ZS.** | **XaKbQ** | **417427001** | **√** | **At risk of discriminatory abuse** |
| **13ZT.** | **XaKbR** | **416936003** | **√** | **At risk of physical abuse** |
| **13ZW.** | **XaKbT** | **417361000** | **√** | **At risk of sexual abuse** |
| **13Z..** | **13Z..** | **160476009** | **√** | **Social/personal history NOS** |
| **Organ donation** | **s** | **139..** | **139..** | **160654005** | **√** | **Wishes to be donor** |
| s | 8922. | 8922. | 182774007 | **√** | **Consent to donate organs given** |
| **Other preferences** | **s** |  | √ | **Other Relevant Issues or Preferences about Provision of Care** |
| **Patient is a carer** | s | 918G. | Ua0VL | 224484003 |   | Is a carer |  | √ |
| m | 918W. | XaKBe | 413761004 | √ | Carer of a person with Learning Disability | √ |
| 918X. | XaKBf | 413763001 | √ | Carer of a person with Physical Disability  | √ |
| 918Y. | XaKBg | 413764007 | √ | Carer of a person with Sensory Impairment  | √ |
| 918y. | XaZ4h | 824401000000105 | √ | Carer of a person with Dementia | √ |
| 918c. | XaKBj | 413760003 | √ | Carer of a person with Chronic Disease  | √ |
| 918d. | XaKBl | 413762006 | √ | Carer of a person with Mental Health Problems | √ |
| 918m. | XaMHZ | 248611000000108 | √ | Carer of a person with Terminal Illness | √ |
| **Main carer and/or next of kin details** | **s** | **918F.**  | **918F.**  | **184156005** |  | **Has a carer**  | **16** | √ |
| **918V.** | **XaJvD**  | **414041006** | **** | **Does not have a carer**  | √ |
| **s** | **91800** | **Ua0VP** | **224487005** | **√** | **Details of carer** | √ |
| **s** | **918J.** | **XaJOJ** | **408400006** | **√** | **Carer - home telephone number** | **17** | √ |
| **s** | **918K.** | **XaJOK** | **408401005** | **√** | **Carer - work telephone number** | √ |
| **s** | **918L.** | **XaJOL** | **408402003** | **√** | **Carer - mobile telephone number** | √ |
| s | 9182. | 9182. | 184142008 | √ | Patient's next of kin |  | √ |
| **Awareness of diagnosis** | s | 1H0.. | 1H0.. | 162565002 | √ | Patient aware of diagnosis |   |
| s | 1H1.. | 1H1.. | 162566001 | √ | Patient not aware of diagnosis |
| s | 1H2.. | 1H2.. | 162567005 | √ | Family aware of diagnosis |
| s | 1H3.. | 1H3.. | 162568000 | √ | Family not aware of diagnosis |
| s | n/a | XaZKn | 473308007 | √ | Carer aware of diagnosis |
| **Awareness of prognosis** | s | 67D1. | XaClt | 310868002 | √ | Informing patient of prognosis | **18** |
| s | 67G1. | XaE7h | 313010003 | √ | Informing next of kin of prognosis |
| **s** | **66W31** | **XaX1e** | **751961000000104** | **√** | **Relative aware of prognosis** | √ |
| **66W41** | **XaXBG** | **760101000000101** | **√** | **Relative unaware of prognosis** | √ |
| **s** | **66W30** | **XaX1d** | **473301001** | **√** | **Carer aware of prognosis** | √ |
| **66W40** | **XaVzE** | **711951000000105** | **√** | **Carer unaware of prognosis** | √ |
| **End of Life Care Key Worker** | **s** | **9NNZ.** | **XaQkE** | **512831000000101** | **√** | **Has end of life care key worker** | **21/22** | √ |
| **s** | **9NNa.** | **XaQkJ** | **512891000000100** | **√** | **Has end of life care key general practitioner** | √ |
| **Careworkers or services involved in care** | **m** | 9NN6. | XaAOt | 305455009 | √ | Under care of GP | **23/24/25** | √ |
| 9NNA. | XaAQs | 305580007 | √ | Under care of Practice Nurse | √ |
| **9NNF.** | **XaARG** | **305602008** | **√** | **Under care of dietician**  | √ |
| 9NNV. | XaLKF | 201481000000104 | √ | Under care of social services | √ |
| **9NNd.** | **XaZhw** | **850951000000107** | **√** | **Under care of palliative care specialist nurse**  | √ |
| **9NNe.** | **XaZi1** | **851011000000103** | **√** | **Under care of oncologist**  | √ |
| **9NNf.** | **XaAP7** | **852031000000100** | **√** | **Under care of physician**  | √ |
| **9NNf0** | **XaAPW** | **305496007** | **√** | **Under care of palliative care physician**  | √ |
| **9NNf1** | **XaAPQ** | **305490001** | **√** | **Under care of care of the elderly physician**  | √ |
| **9NNf2** | **XaAPC** | **305476004** | **√** | **Under care of respiratory physician**  | √ |
| **9NNf3** | **XaAP9** | **305472002** | **√** | **Under care of cardiologist**  | √ |
| **9NNf4** | **XaAPU** | **305494005** | **√** | **Under care of neurologist**  | √ |
| **9NNf5** | **XaAPT** | **305493004** | **√** | **Under care of nephrologist**  | √ |
| **9NNg.** | **XaAQS** | **305554006** | **√** | **Under care of nurse** | √ |
| **9NNg0** | **XaAQU** | **305556008** | **√** | **Under care of clinical nurse specialist** | √ |
| **9NNg1** | **XaAQm** | **305574004** | **√** | **Under care of community based nurse** | √ |
| **9NNg2** | **XaAQq** | **305578001** | **√** | **Under care of district nurse** | √ |
| 9NNR. | XaLJP | 201161000000102 | √ | Under care of community matron | √ |
| **9NNh.** | **XaAP6** | **305469009** | **√** | **Under care of pain management specialist**  | √ |
| **9NNi.** | **XaAPz** | **305525000** | **√** | **Under care of surgeon**  | √ |
| **9NNj0** | **XaARJ** | **305605005** | **√** | **Under care of occupational therapist**  | √ |
| **9NNj1** | **XaARR** | **305613006** | **√** | **Under care of physiotherapist**  | √ |
| **9NNj2** | **XaARU** | **305616003** | **√** | **Under care of speech and language therapist**  | √ |
| **9NNk.** | **XaZri** | **405775000** | **√** | **Under care of social worker**  | √ |
| 9NgD. | XaLKI | 201511000000105 | √ | Under care of palliative care service | √ |
| **9NgZ.** | **XaZj7** | **851821000000100** | **√** | **Has spiritual and cultural support**  | √ |
| **9NgW.** | **XaZhv** | **850931000000100** | **√** | **Has social services care manager**  | √ |
| **9Nga.** | **XaZj9** | **851851000000105** | **√** | **Has social care assessor**  | √ |
| **9Ngb.** | **XaZm0** | **853721000000106** | **√** | **Has direct care worker**  | √ |
| **9Ngc.** | **XaZm1** | **853741000000104** | **√** | **Has healthcare support worker**  | √ |
| 9Nh0. | XaLkE | 246931000000107 | √ | Under the care of community palliative care team | √ |
| 9Nh2. | XaLr5 | 247691000000100 | √ | Under care of community respiratory team | √ |
| 66S3. | 66S3. | 170935008 | √ | Full care by hospice | √ |
| 66S4. | 66S4. | 170936009 | √ | Shared care - hospice and GP | √ |
| **Referrals** | s | 8H7g. | XaAex | 306237005 | √ | Referral to palliative care service |   |   |
| s | 8HH7. | XaIlk | 25411000000109 | √ | Referral to community specialist palliative care team | √ |
| s | 8H72. | XaBSn | 308436005 | √ | Referral to District Nurse |   |
| s | 8HY.. | XaAeN | 306205009 | √ | Referral to Hospice |
| s | 8HHB. | XaAey | 306238000 | √ | Referral to Social Service | √ |
| s | 8H7y. | XaIwd | 38921000000104 | √ | Referral to housing department |   |
| s | 8H7.. | XE0iP | 3457005 | √ | Other referral |
| **Advance care planning** | s | 8CME. | XaRFF | 526611000000100 | √ | Has end of life advance care plan |  | √ |
| **s** |  | √ | **Name and details of additional person to be Involved in Decisions (1)** | **54/55** |   |
| **s** |  | √ | **Name and details of additional person to be Involved in Decisions (2)** | **56/57** |
| **s** | **9NgH.** | **XaYlc** | **816281000000101** | **√** | **Has advance statement (Mental Capacity Act 2005)** | **35** | √ |
| s | 9NgE. | XaYYQ | 765141000000105 | √ | Best interest decision made on behalf of patient (MCA 2005) |  | √ |
| s | 9NgzG | XaZfO | 849101000000103 | √ | Standard authorisation for deprivation of liberty under Mental Capacity Act 2005 given |   |
| s | 2JR.. | XaXvr | 787381000000106 |   | Lack mental capacity make decision (MCA 2005) |
| **Preferred priorities for care - discussion** | m | **9NgJ.** | **XaXrX** | **785091000000102** | **√** | **Preferred priorities for care document completed** | **33** | √ |
| 8Ce8. | XaR4x | 518841000000107 |  | Preferred place of care - discussed with patient |  | √ |
| 8Ce9. | XaR4y | 518861000000108 |  | Preferred place of care - discussed with family | √ |
| 8CeA. | XaR55 | 518981000000106 |  | Preferred place of care - patient unable to express preference | √ |
| 8CeB. | XaR7D | 520541000000100 |  | Preferred place of care - patient declined to participate | √ |
| **Preferred place of care - location** | s | 8Ce0. | XaQTk | 505401000000102 | √ | Preferred place of care - home | √ |
| 8Ce1. | XaQU3 | 505431000000108 | √ | Preferred place of care - hospice | √ |
| 8Ce2. | 8Ce2. | 505461000000103 | √ | Preferred place of care - community hospital | √ |
| 8Ce3. | XaQU5 | 505491000000109 | √ | Preferred place of care - hospital | √ |
| 8Ce4. | XaQU7 | 505551000000102 | √ | Preferred place of care - nursing home | √ |
| 8Ce5. | XaaYt | 883161000000106 | √ | Preferred place of care - residential home | √ |
| 8Ce6. | XaR4m | 518661000000109 | √ | Preferred place of care - learning disability unit | √ |
| 8Ce7. | XaR4n | 518681000000100 | √ | Preferred place of care - mental health unit | √ |
| **Preferred place of death 1 - discussion** | **m** | 8CN1. | XaIsy | 395687000 | √ | Preferred place of death: discussed with patient | **36/37/38** | √ |
| 94ZB. | XaR4u | 518801000000109 | √ | Preferred place of death: discussed with family | √ |
| **94Z6.** | **XaQzq** | **517111000000103** | **** | **Preferred place of death: patient unable to express preference** | √ |
| **94Z7.** | **XaQzr** | **517131000000106** | **** | **Preferred place of death: discussion not appropriate** | √ |
| **94Z8.** | **XaQzt** | **517161000000101** | **** | **Preferred place of death: patient undecided** | √ |
| **94ZD.** | **XaXOt** | **766391000000108** | **** | **Preferred place of death: patient declined discussion** | √ |
| **Preferred place of death 1 - location** | **s** | **94Z1.** | **XaJ3g** | **110481000000108** | **√** | **Preferred place of death: home** | √ |
| **94Z2.** | **XaJ3h** | **108401000000102** | **√** | **Preferred place of death: hospice** | √ |
| **94Z3.** | **XaJ3i** | **89751000000108** | **√** | **Preferred place of death: community hospital** | √ |
| **94Z4.** | **XaJ3j** | **109401000000108** | **√** | **Preferred place of death: hospital** | √ |
| **94Z5.** | **XaJ3k** | **89761000000106** | **√** | **Preferred place of death: nursing home** | √ |
| **94Z9.** | **XaR4q** | **518741000000100** | **√** | **Preferred place of death: learning disability unit** | √ |
| **94ZA.** | **XaR4s** | **518771000000106** | **√** | **Preferred place of death: mental health unit** | √ |
| **94ZE.** | **XaQiX** | **512071000000106** | **√** | **Preferred place of death: residential home** | √ |
| **PPD 1 - usual place of residence** | **s** | **94ZF.** | **XaYsj** | **819211000000102** |  | **Preferred place of death: usual place of residence** | **39** | √ |
| **Preferred place of death 2 - discussion** | **m** | 8CN1. | XaIsy | 395687000 | √ | Preferred place of death: discussed with patient | **40/41/42** | √ |
| 94ZB. | XaR4u | 518801000000109 | √ | Preferred place of death: discussed with family | √ |
| **94Z6.** | **XaQzq** | **517111000000103** | **** | **Preferred place of death: patient unable to express preference** | √ |
| **94Z7.** | **XaQzr** | **517131000000106** | **** | **Preferred place of death: discussion not appropriate** | √ |
| **94Z8.** | **XaQzt** | **517161000000101** | **** | **Preferred place of death: patient undecided** | √ |
| **94ZD.** | **XaXOt** | **766391000000108** | **** | **Preferred place of death: patient declined discussion** | √ |
| **Preferred place of death 2 - location** | **s** | **94Z1.** | **XaJ3g** | **110481000000108** | **√** | **Preferred place of death: home** | √ |
| **94Z2.** | **XaJ3h** | **108401000000102** | **√** | **Preferred place of death: hospice** | √ |
| **94Z3.** | **XaJ3i** | **89751000000108** | **√** | **Preferred place of death: community hospital** | √ |
| **94Z4.** | **XaJ3j** | **109401000000108** | **√** | **Preferred place of death: hospital** | √ |
| **94Z5.** | **XaJ3k** | **89761000000106** | **√** | **Preferred place of death: nursing home** | √ |
| **94Z9.** | **XaR4q** | **518741000000100** | **√** | **Preferred place of death: learning disability unit** | √ |
| **94ZA.** | **XaR4s** | **518771000000106** | **√** | **Preferred place of death: mental health unit** | √ |
| **94ZE.** | **XaQiX** | **512071000000106** | **√** | **Preferred place of death: residential home** | √ |
| **PPD 2 - usual place of residence** | **s** | **94ZF.** | **XaYsj** | **819211000000102** |  | **Preferred place of death: usual place of residence** | **43** | √ |
| **Cardiopulmonary resuscitation decision**  | **s** | **1R00.** | **XaZVX** | **450475007** | **√** | **For attempted cardiopulmonary resuscitation** | **44** | √ |
| **1R10.** | **XaZ9c** | **450476008** | **√** | **Not for attempted cardiopulmonary resuscitation** | √ |
| **s** |  |  | **Date of cardiopulmonary resuscitation decision** | **45** |  |
| **s** | **1R…** | **Xa9tR** | **304251008** | **** | **Date for review of cardiopulmonary resuscitation decision** | **46** |
| **s** |  | **√** | **Location of cardiopulmonary resuscitation documentation** | **47** |
| **s** | **9NgV.** | **XaZZn** | **845151000000104** | **√** | **Not aware of do not attempt cardiopulmonary resuscitation clinical decision** | **48** | √ |
| **s** | **67P0.** | **XaLwc** | **873341000000100** | **√** | **Resuscitation discussed with patient** | √ |
| **s** | **67F2.** | **XacqM** | **975291000000108** | **√** | **Family member informed of cardiopulmonary resuscitation clinical decision**  |  |
| **s** | **671E3** | **XacqN** | **975311000000109** | **√** | **Carer informed of cardiopulmonary resuscitation clinical decision**  |
| **Legal Advance Decision to Refuse Treatment[ ADRT ]** | **s** | **9NgG.** | **XaYld** | **816301000000100** | **√** | **Has ADRT (advance decision to refuse treatment) (MCA 2005)** | **49** | √ |
| **s** | **9NgG0** | **XaYle** | **816321000000109** | **√** | **Has advance decision to refuse life sustaining treatment (MCA 2005)** | √ |
| **s** | **9NgK.** | **XaYv4** | **820621000000107** | **√** | **Has involved healthcare professional in discussion about ADRT (MCA 2005)** | √ |
| **s** |  | **√** | **Location of Advance Decision to Refuse Treatment Documentation** | **50** |  |
| s | 9X0.. | XaCEL | 310302007 |   | Advanced directive discussed with patient |  | √ |
| s | 9X1.. | XaCEM | 310303002 |  | Advanced directive discussed with relative | √ |
| **Lasting Power of Attorney [ LPA ]** | s | 9W4.. | XaOc4 | 341041000000103 | √ | Lasting power of attorney property and affairs | √ |
| **s** | **9W5..** | **XaOc5** | **341051000000100** | **√** | **Lasting power of attorney personal welfare** | **51** | √ |
| **s** | **9W8..** | **XaYlg** | **816361000000101** | **√** | **Has appointed person with personal welfare LPA (MCA 2005)** | **52/53** | √ |
| s | **9W80.** | **XaYlh** | **816381000000105** | **√** | **Has appointed person with personal welfare LPA with authority for life sustaining decisions (MCA 2005)** | √ |
| **Anticipatory Medicines / Just in Case Box issued** | s | 8BAe. | XaQ8S | 443761007 |   | Anticipatory Palliative Care | **31/32** | √ |
| **s** | **8B2a.** | **XaaD3** | **871021000000106** | **√** | **Prescription of palliative care anticipatory medication** | √ |
| **s** | **8BMM.** | **XaPmq** | **376201000000102** | **√** | **Issue of palliative care anticipatory medication box** | √ |
| s | 8BC4. | XaIlh | 394907006 |  | Syringe driver commenced |  | √ |
| 8BC5. | XaIlj | 394909009 |  | Syringe driver discontinued | √ |
| **Care of patient with epidural in situ** | s | 8C1N. | XaIrK | 395185007 |  | Care of patient with epidural in situ |  |
| **Oxygen** | s | 745E2 | XaMGg | 229241000000100 |   | Oxygen Therapy single assessment |
| s | 66Yj. | XaLL9 | 201671000000104 | √ | Home oxygen supply - cylinder | √ |
| s | 66Yk. | XaLLA | 201681000000102 | √ | Home oxygen supply - concentrator | √ |
| s | 66Yl. | XaLLB | 201691000000100 | √ | Home oxygen supply - liquid oxygen | √ |
| s | p42.. | p42.. |   | √ | Nebuliser |   |
| **Discharged from hospital** | s | 8HE.. | 8HE.. | 183665006 | √ | Discharged from hospital |
| **Anticipated death** | s | 9e01. | XaQ8Z | 492291000000108 | √ | Notification to primary care OOHS of anticipated death |  | √ |
| s |  | √ | Additional GP details to issue a Medical Certificate of Cause of Death |   |
| **Unexpected death** | s | 94A.. | XE2IP | 270115005 | √ | Referral to coroner |
| **Date of death** | **s** | **94E..** | **XaJOG** | **399753006** | **** | **Date of death** | **59** |
| **Place of death** | **s** | **9491.** | **9491.** | **184293009** | **√** | **Patient died at home** | **60** |
| **9493.** | **9493.** | **184295002** | **√** | **Patient died in nursing home** |
| **9494.** | **9494.** | **818961000000101** | **√** | **Patient died in residential institution NOS** |
| **9495.** | **9495.** | **184297005** | **√** | **Patient died in hospital** |
| **949A.** | **XaEK5** | **313372007** | **√** | **Patient died in hospice** |
| **949B.** | **XaJ2g** | **89671000000108** | **√** | **Patient died in community hospital** |
| **949H.** | **Xac3V** | **928321000000105** | **√** | **Patient died in learning disability unit** |
| **949J.** | **Xac3W** | **928311000000104** | **√** | **Patient died in mental health unit** |
| **949Z.** | **949Z.** | **366044004** | **√** | **Patient died in place NOS** |
| **s** | **949E.** | **Xaafy** | **887801000000106** |  | **Patient died in usual place of residence** | √ |
| **Cause of death** | s | 94B.. | 94B.. | 184305005 | √ | Cause of death |  |   |
|  |  |   |   |   |   |   |  |   |
|  |  |   |   |   | **\* Modified Karnofsky Performance Scale (IP35, COM 32)**  |   |  |   |
| **White text - red background** | **EoLC flag** |   | 100% | Normal, no complaints or evidence of disease  |  |   |
| **Bold text - pink background** | **ISB - mandatory** |   | 90% | Able to carry on normal activity, minor signs or activity  |  |   |
| **Bold text** | **ISB - optional** |   | 80% | Normal activity with some effort, some signs of symptoms of disease  |  |   |
| Black text | NW EPaCCS items |   | 70% | Care for self, unable to carry on normal activity or to do active work  |  |   |
| Yellow striped background | QOF code |   | 60% | Occasional assistance but is able to care for most of own 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 by professionals and/or family  |  |   |
|   |   |   |   |   | 10% | Comatose or barely arousable |  |   |
|   |   |   |   |   | 0% | Dead  |  |   |