

Wessex Care Records - Taking End of Life information sharing forward within the region



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Version Control

Version	Date	Name
V0.1 – First Draft	27/12/2019	Ian Haywood
V0.2 - Amendments	31/12/2019	Emma Wray
V0.3 – Amendments	02/01/2020	Ian Haywood
V0.4 – Amendments	02/01/2020	Faye Brooks
V0.5 – Amendments	20/01/2020	Craig Wakeham
V0.6 - Amendments	01/05/2020	Ian Haywood

Executive summary

As part of its milestone deliverables, the Wessex Care Records programme made a commitment to support the delivery of end of life information within the shared care records. In July 2019, the programme team hosted an end of life workshop, bringing clinicians from across the region together to highlight the problems currently experienced in end of life care. The workshop led to the development of an [end of life user story](#)¹, highlighting information requirements and current system bottlenecks.

The General Medical Council defines people as ‘approaching the end of life’ as those likely to die within the next 12 months. This includes individuals whose death is imminent (expected within a few hours or days), those with advanced, progressive, incurable conditions, general frailty and co-existing conditions that mean people are expected to die within 12 months, existing conditions if people are at risk of dying from a sudden acute crisis in their condition and life-threatening acute conditions caused by sudden catastrophic events. End of life planning starts, for many, significantly prior to the final declining stages, and as such planning documentation which encompasses end of life management varies considerably.

In Wessex, there is a history of efforts towards improving end of life care, specifically regarding improving patient experience with better information sharing. Based on baseline mapping work undertaken as part of the WCR use case exploration, these efforts remain within isolated pockets of the region. For a long period, strategic end of life networks, with focused oversight from the ICS/STP have been inactive, resulting in smaller groups emerging and subsequently disbanding. Efforts have historically been based around the adoption of common ‘templates’, predominately within primary care, which have failed to fully recognise or address whole system or wider clinical representation.

Nationally the recent drive for interoperability has seen the development of both an end of life dataset and corresponding interoperability standard, this work is still in its infancy and is focused on a very small and focused use case/s. The emergence of these standards does however, offer the opportunity to reignite focus, particularly where a shared platform exists. The national picture, as highlighted in the End of Life Care Interoperability Review², reflects a similar picture as Wessex in terms of failed or limited attempts towards interoperability and information sharing barriers.

The Wessex Care Records activities have identified two views towards end of life within the shared care records;

1. The wider perspective encompassed within the whole longitudinal record. This includes medical and social history, test and results, and diagnosis. This information is more patient contextual and wider than just end of life per se.
2. The end of life specific dataset. This being the specific details associated with preparation for and during the end of life phase. This would include patient’s wishes and decisions regarding care and death, advanced decisions, lasting power of attorney, and DNACPR decisions.

Wessex now find ourselves in a position where national datasets and interoperability mechanisms are maturing, and there is increasing evidence of how end of life data can be shared through common



platforms. As such, the proposed actions for the Wessex Care Records programme team and Clinical Reference Group are as follows;

1. Agreeing the Wessex EOL data set. (The What.)
 - a. Do we agree that the emerging End of Life Dataset encompasses the specific information we wish to consume into the shared care record?
2. Defining the Wessex requirements. (The How.)
 - a. What is the expectation of the shared care record for the consumption and sharing of end of life data? How is it envisaged to operate?
3. Identify our lens/es. (The Who.)
 - a. Considering all the various sources/systems of data, do we want to focus our efforts from one clinical lens i.e. Primary care? Choosing a lens will enable the development of a more focused use case/issue to address. Identification of a lens will also provide specific focus with regards to the systems in use and format of the data.

To achieve the above, a requirement gathering exercise *to be held to*: present the data set, focus on the key aspects within, agree the primary sources of the data, and thus identify the lenses in which we need to focus. These requirements should then translate into a functional specification for the development of the end of life interface.

In addition, we should continue to engage with Yorkshire and Humber LCHRE to better understand their continued efforts with the new dataset, and look further at the solutions that have already been deployed within the Orion platform such as in Kent. This latter point should then extend into a development conversation within Wessex, with the need to determine if this is a local (Dorset / Hampshire), or pan-Wessex pathway solution.



The end of life problem

To understand how a shared care record may assist end of life clinicians, it is important to reflect on the perceived problem/s being faced. The following is an amalgamation of problem statements made by clinicians during the discovery phase;

“The definition of end of life care varies between organisations, with the starting point for this care being fluid on a patient by patient basis. As a result, ‘end of life’ information is spread across numerous templates/documents in multiple organisations and systems, and may not be recognised as ‘end of life’.”

“There is no standardised dataset or format used by organisations making transferability of information difficult from one system to another. Individual organisations have local and statutory requirements for holding and using information collected, making it difficult to move away entirely from local recording into a single centralised platform, there is resistance to then duplicate this data entry to another platform.”

“There has been no collective/common voice articulating the clinical need or expectation of a shared platform.”

Inferred Requirements (For the solution)

Through the various engagements since July 2019, several requirements have been made by clinicians through conversations, meetings, and email exchanges. These present an idea as to the envisaged solution that *could* help progress future development, these need to be ratified as part of any requirements gathering exercise;

- Clinicians want a single, shared source of the truth, “a shared plan”.
- Where a plan is created, they want to clearly know that it exists, irrespective of who or where it was created. They don’t want to have to search for the plan.
- They want to have consistency in the information that is being recorded to support the idea of sharing.
- They want, in more cases than not, to have the information reside/held within their primary IT system, allowing them to work within their primary system but be shared with other parties.
- They want to be able to use their own template of choice and not be forced into the adoption of a generic template that may not meet their local or clinical needs.
- They want the shared care record to clearly flag or mark a patient that is ‘end of life’ or has an ‘end of life plan’, drawing attention to the existence of information.
- They want all ‘end of life’ information collated together, enabling quicker review without having to search around a record.



The national perspective

NHS Digital, led by Project Manager Terrence Daniel, undertook a review of end of life care interoperability. [The report ²](#), published in March 2018, uncovered a cross-section of efforts nationally to better collect, collate and share end of life data, and set out a series of use cases for future consideration.

The report noted that;

“In the current system, there are several reasons why a patient’s preferences may not be acted upon:

Not every patient approaching end of life seems to get the chance to have their wishes discussed and recorded. Historically, cancer patients have had more opportunities than others.

Deciding the correct time for the discussions and decisions to be made is itself a delicate decision. Patients may not wish to discuss care preferences or their situation and similarly, not all care professionals are comfortable discussing end of life preferences with their patients. Family members or other carers, with the patient’s approval, may also be involved.

Preferences, when recorded, are often held (either on paper or electronically) within processes that make it hard for those wishes to be easily shared.

Care professionals, especially those in urgent and emergency care situations, lack the ability to quickly become aware of the status of the patient and any advance wishes that they may have made.”

It is these latter two points that are most applicable to the role of shared care records, exposing the information in a place and way that clinicians can quickly, safely, and confidentially act upon them.

The report defined 4 key components for future delivery;

1. Definition of a Minimum and Standard Dataset for Urgent and Emergency Care
2. Development of FHIR Standard Message
3. Deliver a First of Type (FoT) messaging using FHIR standards and API designs
4. The NHS Online Programme - Patient Access Using FHIR Standards

These four points are picked up in this report.

The report puts emphasis on the increased use of the Summary Care Record (SCR), and states that *“a longitudinal view of the patient’s medical records should be preserved within GP systems (and GP systems all feed SCR)”*. In addition, the following point is also of importance regarding the use of shared care records;

*“A primary benefit of interoperability is eliminating the re-keying of patient data. Where EoL information is being entered into a native system, it **must** be possible to pass that data on to other systems. This is most important where EPaCCS are not hosted on the patient’s GP system. In these cases, any updates to the EPaCCS **must** be transmitted to the GP system and thence on to the SCR.”*

The report also offers some useful use cases, which have clear acceptance criteria that could be used as part of the Wessex work.



National standards

In September 2015, the [Palliative Care Co-ordination: core content standard \(SCCI1580\)](#) ³ was released. This information standard specifies the core content to be held in electronic palliative care co-ordination systems (EPaCCS), formerly known as locality registers. The standard includes 60 data items that are both read and snomed coded.

More recently the Professional Record Standards Body (PRSB) released their [Core Information Standard](#) ⁴, which defines a set of information that can *potentially* “be shared between systems in different sites, settings, professionals and people using services”. The core information standard includes a dedicated subset for End of Life Care plans, incorporating 8 sub categories, that loosely mimic data items defined within the SCCI1580 standard;

- Advance statements
- Cardio-pulmonary resuscitation (CPR) decision
- Anticipatory actions
- Anticipatory medicines/equipment
- Awareness of prognosis
- Estimated prognosis
- Preferred place of care
- Preferred place of death

Alongside the work of the PRSB, NHS Digital have been running a project to develop an End of Life Minimum Dataset (based largely on SCCI1580) and a corresponding set of FHIR resources to support the transportation and ingestion of end of life data from/by various systems/sources. As of July 2019, work was focused on the creation of a first of type (FOT) pilot working with Yorkshire and Humber LCHRE, West Yorkshire and Harrogate EPaCCS, and Yorkshire and Humber Ambulance Service (YAS). A follow-on project was later initiated by NHSX to carry out the technical implementation utilizing the work done by NHSD – that had hit some barriers due to resourcing but is believed to be back underway. The unpublished end of life minimum dataset ⁵ is currently at V2.2, the corresponding FHIR profiles can be viewed [here](#) ⁶.

These national standards provide definitions of what *should* be shared, and in what format this would be expected. Adopting standards across all organisations in which end of life decisions are made is the first step in supporting and enabling better information sharing.



The Summary Care Record (SCR)

For some years the national Summary Care Record has been available to frontline clinicians to provide basic information to help guide clinical decisions. This information can be enhanced to provide additional information (AI) which includes end of life preferences.

At its most basic, the SCR contains information on patients' medications, adverse reactions and allergies. With additional 'express consent' applied within EMIS Web or TPP SystmOne, the basic dataset can be expanded to include;

- significant medical history (past and present)
- reason for medication
- anticipatory care information (such as information about the management of long term conditions)
- end of life care information (from the SCCI1580 national dataset)
- immunisations

The SCR is fed from primary care (GP) systems, and as such presents a limited view of the whole 'end of life' record that is spread across Community, Acute, Mental Health and Social Care. It does however offer a single, national resource, for the hosting of end of life information.

Do not Resuscitate and the Summary Care Record

Whilst the end of life dataset and information standard encompasses many data items, the most commonly expressed need amongst clinicians is regarding patient resuscitation decisions. There are two notable aspects to this;

- **Advance Decision to Refuse Treatment (ADRT)** – A legally binding decision made by a patient to refuse a specific type of treatment at some time in the future. An advance decision is binding, and takes precedence over decisions made in the best interest by other people. This may include a patient's decision regarding;
- **Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)** – A medical decision about resuscitation which is not in itself legally binding and does not override clinical judgment. All DNAR decisions are based on legislation and guidance. A DNACPR decision provides clinical advice as to whether CPR should be attempted should the patient be in cardiac or respiratory arrest.

Do not resuscitate decisions are essentially (and currently) recorded in two ways;

1. The actual decision (paper copy)
2. The electronic marker of the decision

The actual decision, made with or by a clinician will be recorded and shared with the patient and/or family. These decisions are often recorded on specific documentation, attached to any medical notes, and copies provided to all parties involved in care. There is no nationally agreed template for these decisions, although the [Resuscitation Council](#)⁷ provides guidance for local consideration. The patient will retain a copy which will be stored safely in a location that should be accessible to a clinician should the need arise.

The electronic marker of the decision is an electronic record of the decision, held in a clinician's IT system. This would include;

- Cardiopulmonary resuscitation decision
- Date of cardiopulmonary resuscitation decision
- Date for review of cardiopulmonary resuscitation decision
- Location of cardiopulmonary resuscitation documentation (Physical copy)
- Awareness of cardiopulmonary resuscitation decision

A copy of a do not resuscitate decision *should* be provided to a patient's GP, at which point it *should* be recorded on the practice system. If the patient has consented to provide additional information, details of this decision would be provided to the national SCRa. There is therefore already a process and national database, with wider clinical access in place, that enables the sharing of do not resuscitate decisions – it is therefore important to consider this alongside any future Shared Care Record development in this area. It is worth noting that the SCR is only fed from primary care systems, and any shared care record development *should* consider the implications of how it chooses to obtain and display any resuscitation decision from other sources.

In addition to the above, consideration should also be made as to why, if a system is already in place, this is deemed not suitable or sufficient. In the case of Ambulance Trusts, it would appear several reasons are highlighted;

- Front line Clinicians (Ambulance crews) are unable to access the summary care record from their mobile devices. This, in the case of Wessex, is equally true of the shared care records.
- Where they can access the SCR, information is not in an easily consumable format. The end of life information is split into sections, a large portion of the information is towards the bottom of the page, and much of the information is in coded format. This may be equally true of the shared care record.
- Clinicians are unwilling (either through professional judgement or Trust policy) to act upon an electronic marker, instead they will seek the physical signed paper copy. This last point is particularly pertinent given the consequences to clinicians who incorrectly act upon a DNACPR decision. This may be equally true of the shared care record.

The above should act as both a guide for shared care record development, and a challenge to overcome working with Trusts.



End of life care planning documentation

The term, end of life care plan is perhaps the most confusing aspect of the end of life conversation. The term care plan is used to describe a range of things, both electronic and physical, and these often encompass or reference other electronic or physical documents. In primary care systems, the plan is often described as a template, as it is viewed as a mechanism for capturing data items rather than a physical document that is produced. The key idea of the plan, in which ever guise it takes, is to act as a single source of the truth.

The term end of life is also subjective. In Hampshire, particularly the work of Steve Plenderleith, there is a view of referring to these documents as ‘future plans’, recognising that they collate information across a spectrum of time and are not necessarily at the end of life.

Types of plans

Plans are often described in a range of ways, often interchangeably, and increasingly have common data sets. Examples include (but are not limited to);

- Treatment Escalation (TEP)
- Advanced Care Plan (ACP)
- Proactive or personalised care plan (PCP)
- Comprehensive Geriatric Assessment (CGA)

Each of these documents and processes are different, and have specific purposes, with some for clinical ownership/input, some for patient. These are further explained within the End of Life Care Interoperability Review².

Increasingly with the personalisation agenda within Health and Social Care, these planning templates are adapting to be more patient centric, capturing unstructured, non-coded, text responses covering things such as wishes, beliefs etc. These data items are perhaps some of the most difficult ones to review in terms of a common data set, as each template takes a different approach to capturing this type of information.

The interchangeability of the terms and language used by clinicians also leads to the misunderstanding of their purpose and relevance to other clinicians. A TEP within an acute setting may or may not be comparable to one in a community setting, and the relevance might not be linked with an alternative ACP.

Adult Social Care and non-medically focussed plans

Outside of the more medically focused plans, social care is another fundamental partner in end of life support. A major aspect of the social care process is based upon assessment and care planning, which following the introduction of the Care Act 2014 have very clear purposes. Social care services are subject to assessment and the determination of support is based upon eligibility of a patient’s unmet needs. All patients are entitled to an assessment, but may not go on to have further support based on the outcome of the assessment – these patients are considered ‘self-funding’.

Social Care Assessments seek to determine the number of unmet needs a patient has, whilst social care plans seek to address how these needs can be met. Both documents form the core dataset which includes details such as the patient’s history, wishes, preferences, and care needs.



Adult Social Care support is generally split into two; Domiciliary and Residential. Councils are predominantly, and increasingly, commissioning these services from the private sector. At the point of commissioning the assessment and care planning documentation is shared with the provider. The provider will then create further documentation and plans tailored to the delivery of services and local monitoring.

Councils also provide, or commission out, services such as equipment provision, Reablement, and Occupational Therapy. Many of these services also fall into shared or integrated services with Health. Critically though, singular common systems are not shared amongst partners, so additional documentation/plans are created.

Unlike Health, Social Care has far less 'coded' data items, making commonality of data between Health and Social care difficult to identify. Perhaps the most common data set that is easily identifiable is the 'patient view', which encompasses things such as background, religious views, preferences and wishes for care.

Hospices and Care Homes

Perhaps the most significant barrier identified through the July 2019 workshop was data in and out of hospices and care homes. Private and 3rd sector organisations are significant parts of the end of life journey and hold a considerable amount of the day to day data, which includes care planning. At present, much of this data is siloed, non-accessible due to perceived information governance (IG) barriers, and technical limitations/constraints. In some cases, this has been overcome through localised shared care records, for example Hospices such as Countess Mountbatten (Hampshire) utilising TPP SystmOne to have shared access to community and primary care data.

The Care and Health Information Exchange (CHIE) have begun to breakdown some of these barriers in Hampshire, with a limited number of hospices and care homes in the area being enabled access through secure devices. The barriers remain though; Information Governance, and the sharing of patient information outside of NHS trusted systems.

The shared care record solution needs to recognise the role of hospices and care homes, and the delivery of any end of life solution needs consider the technical limitations and capabilities. Increasing access, and ability to contribute, to the shared care record for these organisations needs to remain a priority dependency to be addressed as part of the end of life work.



Wessex Care Record activities

Following the workshops in July 2019, the Wessex Care Records Business Analyst has continued to engage clinicians across the region to further develop the user story and gain further insight into the activities being conducted both locally and nationally. These are described in brief below;

Hampshire & The Isle of Wight position

Wessex Senate previously presented a business case to the Hampshire and Isle of Wight STP, for the creation of a project team to bring together existing end of life care planning activities across Hampshire and the Isle of Wight. These activities were led by Debbie Kennedy, Wessex Senate Manager, with a view to mobilising all End of Life stakeholders and get them working in the same direction on a 'unified approach'. This approach set out to firstly, digitise the RESPECT form and interface this with the Future Planning Template, and secondly, phase out the use of existing universal DNACPR paper form. This work appeared to be gaining traction, having had agreement from the H&IOW Clinical Executive Group in June 2018, but failed to fully establish due to lack of funding towards a programme/project team.

Recently a new group has emerged in Hampshire, led by Jackie Ardley, Chief Nurse for Solent Health Trust with the same vision, to promote consistent end of life planning using a consistent end of life template and shared software platform. This group is in its infancy having met twice, but a paper has been presented to the Hampshire and Isle of Wight STP requesting commitment to the adoption of a single care planning template. As of December 2019, STP commitment to this new programme of work has not been confirmed.

The Hampshire and Isle of Wight Partnership of Clinical Commissioning Groups have also begun a push for primary care to enable enhanced information to be shared with the SCR for more patients. This includes a push for all partners to utilise a common 'plan template', which they are advising should be the 'Future Planning Template'. This work is being done in unison with South Central Ambulance Services (SCAS), with a view to enabling ambulance crews to have more access to end of life care planning information.

The Isle of Wight in isolation presents a different view. Within their Primary and Community estate all Trusts utilise TPP SystmOne, which enables sharing of templates and information. The island uses a local template, similar in design and content to that of the Future Planning Template. The national interoperability review identified this approach as a common theme amongst individual trusts, but highlighted the barrier of information sharing with non TPP SystmOne systems i.e. Acute and Social Care. Indeed, the Isle of Wight have expressed the need for a common platform that would enable these partners to contribute, particularly where Acute care is transferred to the mainland.

In Hampshire two primary care planning templates are prevalent; The future planning template (ACP) produced by Dr Steve Plenderleith, and RESPECT (PCP) from the resuscitation council. Within the Isle Of Wight a local derived template, similar to The Future Planning Template is in operation within primary and community settings.

CHIE is currently consuming some end of life care documentation from Southern Health. These plans are being consumed as documents and presented back as PDFs for clinical viewing. This approach



means that multiple plans can exist for a single patient, each held and viewed separately. Additionally, CHIE utilises the EMIS Health CRV interoperability solution to enable real time access to primary care EoL plans. This solution makes the latest primary care plan available for viewing within CHIE, but the information is not persisted or editable within the shared care record.

Dorset Position

Dorset does not currently appear to have a common vision for end of life care coming from the Integrated Care System (ICS), with the most active CCG workstream currently focused on personalisation and the new Network Contract Direct Enhanced Service specifications for the Primary Care Network (PCN). This newly emerging work appears to be articulating the need for a common platform with centralised care planning ability, but it is still in its infancy and clear digital requirements have not yet emerged.

As with Hampshire, Dorset has a history of care planning templates which includes the Proactive Elderly Advanced Care (PEACE), Lulworth and **Brownsea** forms, and the more recently developed Dorset Care Plan, with some low-level reviews of RESPECT.

The Dorset Care Plan was produced as a frailty project but with funding from the CCG. It is stipulated in the Enhanced Frailty LES as the advanced care plan (ACP) document that should be used across Dorset. Unfortunately, despite being mandated, a variety of advanced care plans are being used in different surgeries across Dorset. It has been specifically designed for the read codes to automatically feed diagnoses and free text into the Summary Care Record so that a live document can be seen by OOH and paramedics. The Dorset Care Plan, as per Future Planning Template, and the Isle of Wight template, are all sharing similar read coded information that can be pushed to the Summary Care record.

The Dorset Care Record (DCR) does not currently consume or present any end of life information. It was at one state suggested that the GP MIG view may enable some end of life information to be visible, but this is incorrect based on the MIG functionality that has been purchased.

Other solutions

When considering centralised care planning activities, it is important to also look to the wider market, and there are several prominent examples;

Kent West

Kent West, comprises of 8 CCGs and the Medway unitary authority covering a population of approximately 480,000 residents, and have been utilising the Orion Amadeus (clinical portal) solution for approximately 5 years. Initially, Kent West set out to procure a solution which could enable them to complete shared care planning activities. They went live on this basis with a solution they refer to as the Care Plan Management System (CPMS). This has since evolved into a more comprehensive shared care record solution incorporating feeds wider than just care planning activities.

Kent's implementation of Orion appears very like that of Dorset and Hampshire. Data is persisted where possible and a range of feed types such as HL7, CSV etc. are utilised to gather datasets from



partners organisations. GP data is provided by a non-persisted MIG view, similar to that used within DCR.

The Kent solution has two approaches to the consumption of care planning information;

- Documents are consumed from partners and presented back as PDF. In this format care and crisis plans are consumed from community and mental health settings. Documents in this format are copies of locally held versions, and sit alongside each other, giving organisational perspectives. A clinician would be required to review each care plan if wanting to understand a holistic picture of care. This is the same approach currently utilised (in a limited fashion) as CHIE in Hampshire.
- Kent have also taken up the use of 'pathways' within Orion, and in doing so, have built care plans into the platform. These plans exist solely in the platform and are populated manually within, the expectation being that clinicians will utilise this single version of the truth and have no local version. Clinicians therefore are required to transcribe information from any local system or template into the master template - there is no pull of information from partner systems, and no push back to partner systems. As the completion of these 'forms' are within a 'pathway', the patient must be enrolled for a plan to exist. They have 3 pathways currently in operation;
 - The Electronic Shared Care Plan
 - Comprehensive Geriatric Assessment
 - MDT management and actions

Kent has made a conscious decision to change clinical practice, moving away from local recording of care planning and to a singular shared plan that only exists in the shared care record (Orion solution). Information created in these plans is stored solely in the shared care record with no data pull or write-back to any partner system. In order to gain clinical adoption of this new method of working, Kent is focusing on Single Sign On (SSO) to enable clinicians direct access, and the introduction of 'flags' within the primary systems to the existence of a plan. An example of this is within their Ambulance Trust, in which a care plan flag will show where the patient has a plan within the shared care record. This prompts the user to navigate to the shared care record to review the plan.

The feedback from Kent was very honest, the 'pathways' approach has enabled a common approach through a single electronic system but has not been fully embraced by all. Information is being rekeyed from primary clinical systems into the shared platform, with complications in being able to design a robust solution and lack of 'standards' being highlighted as a reason for not being able to automatically push and pull information. A step change approach had been adopted, in which first physical documentation was consumed and shared enabling all partners to clearly see what others were recording, which later led to the development of the electronic shared care plan and the change in clinical practice.

Coordinate my Care

[Coordinate My Care \(CMC\)](#) is an NHS initiative, hosted by The Royal Marsden NHS Foundation Trust and in place since August 2010, permitting key information about an individual and their preferences for care (an Urgent Care Plan) to be recorded and accessed by a range of NHS and non-NHS service providers.



The content of CMC's Urgent Care Plan covers the SCCI 1580 End of Life Care data standard, and considerably extends it. The platform offers:

- Centralised Web based platform, accessible via N3 or 2 factor authentications
- Patient or clinician initiated urgent care plan
- Contains information about the patient, their diagnosis and medication, key contact details of regular carers and clinicians, personal preferences across a range of possible care circumstances
- Pre-loaded patient demographic information from PDS (NHS Spine)
- Concise front summary screen, which provides 'headline' care plan information

ReSPECT (Online)

[ReSPECT](#) is both a process and a form (template), which traditionally has been paper based but is increasingly moving towards electronic format. The adoption of an electronic format is for local systems to decide and create, however the Resuscitation Council requires foresight and approval of any adoption of an electronic RESPECT template. As a predominantly paper based solution at present, it requires the patient to be the primary conduit for the transfer of information; it is therefore limited in its ability to easily share with other clinicians.

RESPECT originated from a 2014 systematic review of DNACPR decisions. Following the review, it was agreed on a need to improve patient and family involvement in decision-making, to consider CPR decisions in the context of broader care and treatment, and to record the outcome on a form that would be used and recognised across the UK. Following this, over 30 individuals, representing both the public and professional organisations from across the health sector, formed a Working Group to develop the new approach.

Feedback from the Resuscitation Council (UK) has confirmed that Scotland are piloting a fully digitised version of the ReSPECT form using an archetype model. This is with the view to having a cloud based system which is visible and can be amended by all. Discussions are ongoing with NHSD and NHSX about a system for England. Given the increased adoption of ReSPECT across the country, this move towards a potential cloud based central solution makes it more akin to Coordinate my Care, and therefore needs to be considered alongside the role of the shared care record in the same way.

The major drawbacks to these types of solution are;

- Additional Training and information governance requirements upon Clinicians
- Separate login from their core/primary system
- The need to manually transcribe information between systems



Conclusion

This paper set out to highlight activities both nationally and locally within end of life interoperability, with a view to shaping the next steps that will enable Wessex to realise their objectives as defined in the End of Life Use Case.

The national team (NHSE) have made significant strides following the review of end of life care interoperability report, with many their key components now in delivery. However, the national impetus has not yet translated to local delivery, and this is where Wessex now find ourselves able to build upon the work being achieved in other exemplar areas.

NHSE continue to invest and support the use of the Summary Care Record (SCR) as a platform for centralised data sharing. This platform, by taking information from a single source, puts emphasis on the primary care record. As with other shared solutions, accessibility and interoperability to the platform remain a limitation to be overcome. Equally the emergence of the Local Care and Health Records (LCHR) may disrupt some of the drive towards a centralised platform based on a GP longitudinal record, as information begins to be consumed and shared through the new networks utilising the newly emerging standards.

Historically there have been many local projects undertaken to improve interoperability, many focusing on a shared template to gather a consistent data set. These local projects have however failed to adopt a truly centralised platform, one which would enable all partners to share and contribute, with many therefore failing to fully establish and gain full adoption. These efforts have generally been based around primary care with some extension to community settings using a common system such as TPP SystmOne. There has been no lasting drive at a strategic level on either side of Wessex, with Hampshire perhaps more actively attempting to move forward with a shared vision for end of life care management.

End of life information is predominately centred around and described in the form of Care planning templates. These templates have numerous descriptions, purposes and uses, and are often used interchangeably by Clinicians involved in care. Each organisation involved in care has a need to retain information in local systems (for both local and statutory purposes), which creates a constraint in moving towards a singular central platform without the need for 'double entry' of data.

Many solutions are emerging, many with NHSE backing and funding, that enable the centralised coordination of care through a common platform. However, as recognised in the review of end of life care interoperability, these solutions are additional systems requiring clinicians to adopt new ways of working, in some cases additional logins, and more significantly the re-transcribing of data from primary/source systems. This will improve; however, they will also need careful consideration against the role/functionality of the shared care record (LCHR) and the Summary Care Record in delivery a joined-up solution to end of life care management as there is a danger that new information silos will appear.



Proposed next steps

Wessex need to articulate a vision for end of life care within the shared care record, building upon the existing use case work. To achieve this the following are proposed next actions to be agreed;

1. Initially through the WCR Clinical Reference Group (CRG), Review the emerging end of life data set and confirm this encompasses the information expectation of clinicians within Wessex.
 - a. This to be further broadened to the wider clinical reference groups within HIOW and Dorset, plus potentially through patient engagement groups.
2. Define the priority aspects of the data set, including the identification of partner organisations who currently collect/hold this information.
 - a. Identification of partners will extend to the identification of systems and templates in use
 - b. This work should provide a clearer clinical lens, putting focus on partners and enabling a more defined/narrow use case i.e. "As an ambulance crew..."
 - i. All lenses to be considered and tackled in a prioritised order
3. Continuing efforts to bring alignment of emerging programmes within Dorset and Hampshire, articulating the capabilities of the shared care record platform to support end of life care management.
4. Undertake a requirement gathering exercise to articulate the clinical requirements and expectations from the shared care record, driving forward the design of the future solution. This point is on the assumption that the shared care record will act as, or part of, the solution for centralised information.
5. Further engagement with the national team to understand the continued development and roll out of the emerging standards.
6. Schedule a site visit/presentation from Orion customers such as Kent West, to better understand their approach and developed solution, gathering lessons learned information.

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