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**End of Life Care Interoperability Review**

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Glossary of Terms

| Term / Abbreviation | Description |
| --- | --- |
| ACP | Advance or Anticipatory Care Plan |
| ADRT | Advance Decision to Refuse Treatment |
| API | Application Programme Interface |
| CIDS | Community information dataset. Now being replaced by CSDS. |
| CQC | Care Quality Commission |
| CSDS | Community services dataset |
| CYPACP | Child and Young Person Advance Care Plan |
| DNACPR | Do Not Attempt CPR |
| EFI | Electronic frailty index. |
| EoL | End of life. |
| EPaCCS | Electronic Palliative Care Coordination System. |
| ePCS | Electronic Palliative Care System – previous system employed in Scotland. |
| FHIR | Fast Health Interoperability Resource |
| FoT | First of Type – effectively a pilot of the standard to ensure suitability and deliverability of the standard. |
| GP | General Practice or General Practitioner |
| HHR | Hampshire Health Record. |
| ISB | Information Standards Board for Health and Social Care. Replaced by SCCI. |
| LHCIE | London Health and Care Information Exchange |
| NRLS | National Record Locator Service |
| PCP | Personalised Care Plan |
| PDS | Personal Demographics Service – Spine service that maintains definitive list of all demographics for persons receiving NHS care. |
| PHC2020 | Personal Health Care 2020 – umbrella term for the overall strategy for transformation of NHS interoperability by 2020. |
| PoC | Proof of Concept – early test of a new system or idea. Often a prototype solution that is not re-used. |
| PPC | Preferred Priorities for Care – a form of advance statement |
| PRSB | The Professional Records Standards Body |
| ReSPECT | Recommended Summary Plan for Emergency Care and Treatment |
| SCCI | New national governance arrangements for information standards, data collections and data extractions came into effect on 1 April 2014. On this date the Standardisation Committee for Care Information (SCCI) took over responsibilities from the Information Standards Board for Health and Social Care. |
| SCR | Summary Care Record. |
| SCR AI | Summary Care Record additional information. |
| SCRa | Summary Care Record application. |
| TEP | Treatment Escalation Plan |

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# Introduction

## Background context

There is a long history of the NHS recording the end of life preferences of patients. These preferences have been recorded in many ways (on paper and electronically) in both legally binding formats and other formats designed to be advisory. Patient preferences can be medical, such as advance decisions to refuse treatment, or be social, such as their religious wishes or details of who will look after the dog should they be admitted to hospital.

From September 2015 there has been a national standard (SCCI 1580) that defines the minimum dataset for EoL care including patient care preferences.

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.

During the past 10 years, attempts have been made to resolve this problem by rollout of Electronic Palliative Care Coordination Systems (EPaCCS), designed to both record the patient’s preferences and pieces of key data to support the patient at their end of life. Whilst these systems have had some success, standalone solutions have suffered from their inability to share the information widely and the need to rekey data into them from other capture sources.

GP systems (through agreed entry templates) can now record much of the data defined within SCCI 1580 and several areas have rolled out solutions based upon these local templates.

The national rollout of Summary Care Record (SCR) and the additional information (SCR AI) datasets has meant that a rich dataset of EoL preferences, approaching the SCCI 1580 standard, could be made available from GP systems to all viewers of SCR across the whole NHS in England. This requires the consent of the patient and the correct sharing settings being applied by the GP.

One of the most compelling metrics often discussed is the proportion of patients able to exercise their decision to die in the familiarity of their own home or another place where they are known and feel comfortable, such as their care home or hospice. This metric is often seen as the key success factor (or otherwise) of EPaCCS implementations, the data is published by Public Health England as part of their [End of Life Profiles](http://fingertips.phe.org.uk/profile/end-of-life/data).

2015 End of Life Profiles data for England show location of death percentages:

* 46.7% Hospital
* 22.6% Care home
* 22.8% Home
* 2.16% Other places
* 5.6% Hospice

## Objectives of This Document

To describe:

* the business requirements of users of end of life preferences, as user stories;
* some of the current systems in place for delivery of end of life preference solutions;
* options for future changes (both business and IT) that will deliver improvements in the outcomes for patients and their carer and the NHS and social care.

# Management Summary

## The Key Requirements

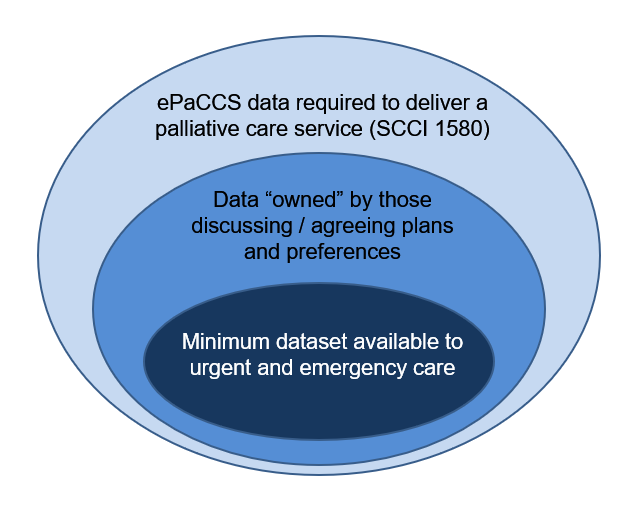
* Any proposed national direction ***must not*** dictate what kind of EPaCCS solution will best serve each community – they have different budgets, commitment, and IT footprints.
* Whether or not the local EPaCCS is delivered via GP systems, a longitudinal view of the patient’s medical records should be preserved within GP systems (and GP systems all feed SCR).
* SCR is the single, national, common system in use across England where it ***should*** be possible to at least view a minimum dataset of EoL information, once the GP has incorporated that information into their system and the patient has given consent.
* SCRa allows a low-barrier entry for all users to get access to the data. SCRa ***should*** be encouraged to improve accessibility to the data (through removal of the need for smartcards and HSCN compatibility) and innovate their solution (through active product management). Suppliers ***should*** be further encouraged to incorporate SCR access within their native systems.
* Regardless of which EPaCCS solution is employed, all the local teams are endeavouring to standardise data collection. Either through the APIs and datasets they are using to upload to their EPaCCS or through development of agreed local templates. SCCI 1580 (the agreed national dataset) ***must*** be taken forward as the basis of a minimum FHIR standard for those parts of SCCI 1580 which are ***specific*** to end of life care, planning and preferences. This ***must*** be accomplished through dialogue with all those that have already solved the problem locally.
* 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 NHS Online programme** is tasked with delivering a ministerial directive, that states that patients will be given the opportunity to *express end of life care preferences online or through an app*. How the NHS Online programme intends to deliver this remains unclear (as, at the time of writing, the team is still undertaking discovery work), but the Integration Programme ***may be needed to help define*** a national minimum dataset for the “view” and thereafter constructively discuss what parts of that dataset ***may*** be edited directly by the patient.

## Potential key components

### Define a Minimum and Standard Dataset for Urgent and Emergency Care

Local EPaCCS solutions generate templates and local standards that suit their complete health and social care community. Nationally, the focus must be to ensure that a minimum dataset can be delivered to urgent and emergency care. This will uncover those important data items that must always be shared with a patient’s GP and hence the SCR, or directly with urgent and emergency care systems.

The approach to defining the dataset will be to reflect upon all the clinically reviewed standards that have been delivered and the national approach to resuscitation, and the work currently under way in England.



There is a host of information that must be accessible to those delivering EoL care, such as the correct demographics and GP registration information and a patient’s current medications and allergies. However, much of this information is subject to other current or proposed transfer standards. This project ***must*** only focus on those data elements that form a patient’s specific plans and preferences for their EoL care.

Transmission of these preferences and plans will be triggered by the generation of, or changes to, those data elements. Other changes such as changes to medications will be the subject of other FHIR standards.

The initial project must focus on the minimum viable product to ensure delivery. Therefore, this work must not be viewed as a one-off. If successful, this work will lead to extensions and improvements to that minimum dataset which will require a strong commitment to maintaining the specification on an ongoing basis, with strong clinically led ownership of that content.

### Develop FHIR Standard Message and API designs

Definition of the national dataset will lead to development of the FHIR standards for that dataset. It is hoped that the national FHIR standards can be produced quickly enough for them to be incorporated into the London programme.

The FHIR standard can be employed by all local implementations of EPaCCS where data exchange is required to avoid double-keying. These use cases may include:

* Transmission of EPaCCS data from a source system into a local integrated care record.
* Transmission of changes within a local EPaCCS solution to the patient’s GP system.
* Transmission of changes within a GP system to a local EPaCCS solution.
* Transmission of changes within a local EPaCCS solution to an urgent care system.
* Real-time access of EoL data from any host system.

### Deliver First of Type (FoT) messaging using FHIR standards

To prove the efficacy of the FHIR standard, the national programme team must support one (or more) local implementations of this standard. It is hoped that the London programme can act as such a FoT implementation. However, several of the other localities discussed in this document have technical footprints that would lend themselves well to being included in the FoT process.

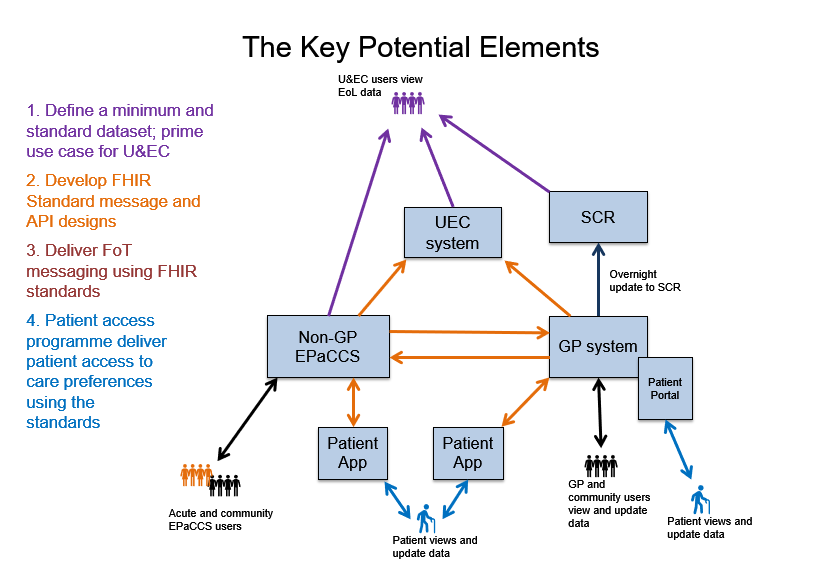
One issue that must be concluded early in the project will be the capacity for change within the GP supplier community, as there are already many PHC2020 projects requiring changes in these systems.

### The NHS Online Programme - Patient Access Using FHIR Standards

The commitment to provide patient access to EoL preferences in 2018 will make the NHS Online programme a specific FoT use case.

The NHS Online programme’s options could be to directly access GP systems or local EPaCCS, either using an interface within the system or via an app using APIs that the systems have offered. It remains to be seen what their final option will be.

Regardless of the option taken, the definition of the standards and delivery of the FHIR resources will be critical to successful delivery.



# Current Solutions/Systems

As part of this elaboration process, some of the current and proposed solutions for recording EoL preferences have been investigated.

## Summary Care Record

SCR is the primary national solution currently in place that can share EoL preference data successfully from GP practice systems to any viewers of SCR.

When a patient signs up for SCR, they can have one of three consent settings:

* Core SCR only.
* SCR with additional information (AI)
* Opt out of sharing.

The default setting is implied consent for core SCR, if the patient doesn’t opt out or choose AI. The Implementation and Business Change (IBC) team are actively involved in extending take-up of SCR AI across England.

### Size of SCR

* Approx. 55m records are now on SCR, with 1,500 areas/sites viewing the data.
* In late 2017, SCR has recorded 130,000 SCR views per week and rising, of which 100,000 views were directly through the SCR browser application (SCRa).
* Other views are either through implementations which open SCRa in a window inside native applications (1-ckick) or through a fully integrated API (e.g. GP systems such as SystmOne, EMIS, and Vision and other systems such as Lorenzo, Rio, Adastra and IC24).

### SCR with Additional Information

The SCR v2.1 AI capability is live in EMIS, SystmOne, and Vision GP systems. However, it is not yet available via Microtest (with dates to be confirmed).

<https://digital.nhs.uk/summary-care-records/additional-information>

The AI is managed by an "inclusion set" which defines information that can be pulled out of the GP system into SCR. This inclusion set aligns with the [SCCI 1580 dataset](#_SCCI_1580_Standard).

SCR AI both adds completely new datasets and extends the core.

Eg.

* Reason for medications – the current medications are already available in SCR, but this adds (as both code and supporting text) the reason those meds were prescribed.
* Significant past medical history.
* Reason for medication.
* Significant previous procedures.
* Anticipatory care information.
* Immunisations & problems - anything coded as a diagnosis, with supporting text
* Anticipatory medications.
* Problems and issues.
* Allergies and adverse reactions.
* Immunisations.
* Accessible information standard (SCCI 1605) communications preferences for the patient.
* Personal Preferences, including EoL preferences – combinations of coded data and free text.

AI standard headers and the datasets are reviewed each year - coded in SNOMED

It is now a priority of NHS Digital to deliver more AI coverage. Currently less than 5% of SCR records in total have AI. The target is to increase this value to 15% by Dec-2018 to provide coverage for the most vulnerable patients.

There is also a target for SCR to be able to report upon utilisation for specific cohorts of patients. Patients receiving palliative care are included on this list. The target is that 80% of patients with specific disease/conditions listed with have AI by Dec-2018.

### GMS Contract - Identification and management of patients with frailty

The GMS contract has been extended so that general practice must now proactively promote the ability to provide AI where the patient is deemed to be frail. Frailty is defined by the electronic frailty index (EFI). The EFI takes various indicators and gives a value for patient's frailty. Patients aged 65 and over must be proactively targeted to have a completed and regularly reviewed EFI.

The GMS PMS Core Contract Data Collection element of the *GP Contract Services 2017-18* publication contains the frailty and SCR counts. This available at the following link:

<http://digital.nhs.uk/catalogue/PUB30147>

### Marks and flags within Spine and/or SCRa

There are plans in place to enhance SCRa or other Spine services (such as PDS) to make it easier for viewers to quickly see where there’s important additional clinical or personalised care information e.g. Has a palliative care plan or care preferences. This would be undertaken alongside the existing work on Flagging, which will help to uncover which information held in the patient record would be worthy of the increased visibility of a flag and how the data will be collected underneath each flag.

### Strategic Authentication and Authorisation

One of the issues of using SCRa in ambulance trusts is that mobile teams have problems logging on with smartcards. There are also large numbers of other potential users, such as social care and care homes, where the huge overhead of getting access to the NHS network is a real barrier to uptake. The outlook is this could be delivered in the next 12 months.

As a follow-on from the delivery of the Strategic Authentication and Authorisation project, SCRa will be rolled out to the 6 ambulance trusts that are not within the first tranche of the NRLS programme (there may be a crossover with the London Ambulance Service). This schedule is designed to protect ambulance trusts from an overload of change.

### Strengths

* SCR AI is national – the service is already delivered with a national footprint, which protects viewers from any artificial borders that could be introduced by local, regional or system-imposed boundaries. Data sharing agreements are all covered off within the SCR framework as SCR has its own IG model based on a national public information programme and national rollout.
* The service is supported by NHS Digital, leaving less local need for implementation effort. Any authorised viewers with browser access and the patient’s permission to view, can access the SCR AI data through the SCRa application.
* Interoperability is built in – data extracts from GP systems have already been delivered and many suppliers are already embedding SCR within the native systems through the APIs.
* There are already supported national targets to drive further uptake of SCR AI and there are already projects running to enable SCRa to be accessed without the need for smartcards or other potential barriers to take-up.
* SCR is a catch-all *safety net* service – where there is nothing else in place locally, SCR ***can*** support the business to extend the footprint of local EPaCCS solutions beyond their standard EPaCCS users.

### Weaknesses / Issues

* **Consent –** Primary care could baulk at having to have another consent discussion.
* **A Local solution is already in place –** Where there is already a local solution in place, primary care feels less need to utilise SCR AI.
* **GP-centric view** – only EoL preferences held on GP systems can be shared to SCR and therefore community and acute EPaCCS data would have to be transmitted or transcribed into GP systems before it appears on the SCR. An exception to this is SystmOne, where information shared back to the GP practice from other elements of the shared patient record can be added to SCR automatically.
* **Data not clearly visible** – as the wealth of data available within SCR increases, the impact of individual data items will reduce. Future developments of SCR must tackle prioritisation of the data that is most important.
* **SCR does not support attachments** – some key elements of information are signed documents such as advance statements. SCR does not support attachments but in the future documents could be accessed via the NRLS in SCRa.
* **Recently no SCRa Business Owner** – SCRa has technical owners, and if SCRa is to be a national solution of ***growing*** importance, then strong business leadership is imperative. David Corbett at NHS Digital is the new product owner for SCR and is responsible for writing the SCR strategy, therefore it is expected that this issue is being addressed.

## National Record Locator Service (NRLS)

### Proof of Concept

The initial NRLS proof of concept (PoC) was using end of life preferences with Leeds Teaching Hospital. EoL data that was generated within Leeds Teaching Hospitals could be viewed (through NRLS pointers) by other external users. The PoC has now come to an end.

### How it works

Data sources attempt to upload a pointer to NRLS that shows they have a crisis care plan for this patient. If there isn't one already for patient, then they can upload a pointer.  If there is one NRLS blocks them uploading a pointer.  This resolves the issue about who "owns" the data - the new organisation trying to upload will have to follow the current NRLS pointer to the previous org and ask them to relinquish the 'plan' for the patient.

Users of NRLS (like ambulance trusts) may have their native systems (or maybe the SCR or SCRa) warning them there's an NRLS pointer.  They follow the pointer to the source system.  NB. The pointer could link to data that can be seen by the system, i.e. user can view the plan, or (where source system has older technology) could just return a message to say "this patient has a MH Crisis Care Plan, please call the team on this number… ".

### NRLS Phase 1

Dataset:  Mental Health Crisis Care.

Sources: 11 mental health trusts.

Viewers: 4 ambulance trusts – London (LAS), Yorkshire (YAS), North West (NWAS), and North East (NEAS).

Plan: 2 ambulance trusts using and viewing in June 2018, and a further 2 in July/August.

Follow-on: Final 6 ambulance trusts from Aug 2018 onwards (tba) - South West, West Midlands, East Midlands, South Central, East of England, South East Coast.

Phase 2 will deliver other plans/datasets, and this will probably include EoL.

### Strengths

* The system utilises the EoL information wherever it has been recorded. If there isn’t already a pointer, then one will be created.
* The system doesn’t specify that the ultimate data source is structured data or not. Could link to a simple message or a scanned document.
* Addresses the “single point of truth” issue neatly by refusing to have more than one pointer live for each parcel of data.

### Weaknesses / Issues

* Doesn’t support users any further, should they be told that pointers already exist for this parcel of data. Whilst the pointer will inform the user of the location of the competing system, NRLS leaves the two data sources to resolve any subsequent conflicts themselves and share information as they see fit (or not).
* The ability of the pointers to link to any kind of data would make it difficult to use the pointers to extract subsets of the data to be rendered within native systems.

## Harrogate – Integration though SystmOne

Dr Kath Lambert has been at Harrogate for the past two years and is leading on the implementation of an EPaCCS through SystmOne. She has already undertaken a similar task in Mid Yorkshire.

<https://www.hdft.nhs.uk/services/palliative-care/epaccs/>

The decision to use SystmOne was taken because it has a very high coverage over the area for GPs, palliative care and community nurses. All areas in West Yorks came to the same conclusion that they would be best adopting a SystmOne template based upon the SCCI 1580 information standard.

Harrogate is the last to come on board, as the challenge was always to get the money to kickstart the process. This came through the *New Care Models* fund. Kath is developing the SystmOne template, which will be very close to what's been done in rest of West Yorks.

### Strengths

* SystmOne provides “out of the box” integration for those organisations sharing the system.
* Consistent templates across all users within this local SystmOne footprint.
* There is a view that GPs are not always the prime sources of palliative care information and that palliative care teams or community nurses may also be capable of recording this data. SystmOne enables this sharing of responsibility.

### Weaknesses / Issues

* **Limited sharing with the hospital** - Read only access is possible via SystmOne EPR Core but few clinicians use this so information recorded in EPaCCS is not readily accessed and any advance care planning undertaken in the hospital cannot be documented on EPaCCS directly.
* **EMIS practices not integrated** - There are a few EMIS practices in Harrogate. They won't be able to access the SystmOne data. Because the number of practice is so low, the community nurses serving these practices will act as the bridge to re-enter EPaCCS data into SystmOne. This increases the potential for introducing errors in the data.
* **Limited information sharing culture** - There is no locally agreed single process for sharing information within SystmOne across the Harrogate district. Individual GP practices have their own policies and practices which means that viewing incomplete records by other SystmOne users is not uncommon.
* **Limited usage of SCR** - Access to SCR for the local GP OOH service (Adastra) is not currently enabled. The hospital can access through SystmOne EPR Core, but few clinicians do. Increasing access to SCR by NHS 111 and the ambulance service is a key step. There is no local coordinated approach to implementing SCR AI. Only GPs can consent/create/update SCR AI, which is a frustration when the EPaCCS project has encouraged all professionals to engage with patients by having ACP discussions and documenting the outcomes.
* **Consent overload** – Users report there are many different consent questions. For example, there is already a consent process to share records in SystmOne, but then the EoL standard also says users must seek/record consent to share. And then there’s another tickbox for SCR sharing. All the steps required increases the reluctance of clinicians.
* **ReSPECT** - there’s been a lot of support for the ReSPECT process and having a nationally agreed form that could be completed alongside patients/carers is very welcome. But as it is a paper-based document it will be difficult to ensure it is aligned to the EPaCCS and, if care is not taken, this will end up just another version of "the truth".

## Hampshire – Integration through SCR AI

Dr Steve Plenderleith (Consultant in Palliative Medicine) is also using the *New Care Models* fund to extend the coverage and usage of EPaCCS data in Hampshire. Their locality has chosen to deliver the integration using SCR AI.

<http://www.futureplanning.org.uk/>

The Hampshire area has a variety of GP systems suppliers and so a solution such as the one in Harrogate driven with SystmOne would not work. Hampshire also has already been part of a failed EPaCCS implementation of a standalone system. The standalone system failed because of the significant rekeying of much of the data that was already available within GP systems. Eventually those providing the data could not maintain it and the system fell into disuse.

The Hampshire programme also plans from June 2018 to show Future Planning information in the Hampshire Health Record V2, which is now called the Care and Health Information Exchange (CHIE). This will enable greater access to the information for a wider range of local services.

Hampshire is now moving forward with their *My Wishes* leaflet, designed to sit alongside the AgeUK *Let’s talk about death and dying* booklet. These publications will encourage people to start a dialogue with those delivering their care, helping them to submit their preferences for care to be added to their GP record using Future Planning templates.

### Advice for a successful EPaCCS

The project has some advice for running a successful EPaCCS.

* **Get the data in first before you sell to data viewers.** If you persuade people to change their habits and use the SCR AI, then you must be fairly sure that the viewers will regularly see useful information. They will not access SCR AI if they never find any added value there.
* **90% of the final year is spent "at home"** and hence a commensurate proportion of future planning takes place in the community. The acute setting is therefore not as important as some people might think. There is significantly less opportunity to discuss and change preferences in acute settings, especially during an emergency. The plans that are drawn up are mostly about what should happen for the patient in the community, so it is most important that the community owns that plan.
* **ReSPECT is potentially a distraction**. Driving paper forms into people’s hands is moving things away from integrated electronic solutions. However, Steve does accept that, treatment escalation planning is something that all clinicians in both acute and community settings should be thinking about.

*“If ReSPECT helps drive TEP training and thinking in acute trusts then that is great. However, forcing a patient and clinician to make one decision about comfort or intensive treatment for all problems doesn’t make sense.”*

A model utilising the established “Comfort / Home / Hospital / Intensive” treatment level idea for each anticipated problem makes much more sense and supports development of a patient’s Treatment Escalation Plan over time, as each problem can be addressed in turn.

* **Early display of flags to highlight presence of more data is key.** The overall design of the SCRa interface/experience (and the supplier software using the API) is critical to pull out the important bits quickly. Treatment escalation and an anticipatory planning tab could be added. ie a section that talks about what is going to happen, not what has happened.
* **Deliver local culture change** to press for and record future care needs and preferences. The important bit is "getting the staff to understand what is important about this".
* **Patients can generate some of their information themselves**. However, entering the data through a website or app would be more useful as bare paper forms with empty boxes can be daunting. Electronic entry solutions can provide prompts and can also deliver legal phrases to ensure certain forms like ADRT have been completed correctly. For example <www.mylivingwill.org.uk>
* **Rollout of templates to GPs was not as difficult as might have been thought**. No major training was needed for GPs, as they are familiar with using templates. Support from CCG end of life and IT GP leads, and the LMC is vital. GPs read e-mails from their LMC!
* **Call it "future planning"** - Hampshire is keen to move away from the "end of life" description. The tools provided in Hampshire work just as well for the wishes, preferences and Treatment Escalation Plans for a 25 year old unstable diabetic or epileptic as they do for an end of life cancer or COPD patient.

### Strengths and Weaknesses

The key strengths and weaknesses of the Hampshire solution reflects the overall entries for SCR above. However, key weaknesses have been mitigated by the project. “Consent overload” concerns were reduced by the support and messages that GP users were initially given. Inability for acute settings and community setting with access to GP systems to make updates was reduced by ensuring clear transfers of care to GPs include information regarding preferences. Hampshire hopes that they could have data merging from acute, community and GP as a later delivery of the CHIE upgrade.

## Humber – Integration through SCR and SystmOne

The Humber CCGs in Hull, East Riding, North and North East Lincolnshire have agreed to use the SCR to share EoL information. Although this isn’t a full EPaCCS system, it is a ‘free’ resource and provides a practical way of sharing information in line with one of the Humber’s Local Digital Roadmap priorities ie increase the use of the Summary Care Record to improve information sharing across the patch. This is beneficial to an area with four CCGs and different palliative care service providers.

As with Hampshire, as the software already exists, the focus of the project is on achieving business change. Initially the SCR project has decided that the most benefit was for people over 65 with medium/severe frailty and everybody within an end of life or palliative care pathway. This approach has been supported by the Local Medical Committee (LMC).

There is currently a North/South split in Humber area where Hull & E Yorks Hospitals have the highest views of SCR in England, whilst North Lincs and Goole Hospitals (NLAG) view in pharmacy and some community services only. Work is underway to increase the use of SCR throughout NLAG including the Emergency Dept.

The Humber project will be undertaking a proof of concept for viewing SCR AI in two care homes, one in North Lincolnshire and one in North East Lincolnshire.

TPP SystmOne and EMIS are the two GP suppliers in East Riding, Hull, North Lincolnshire and North East Lincolnshire. Templates have been developed to capture the Electronic Palliative Care Co-ordination Systems (EPaCCS) data.

### Main Aims in Humber

* Increase the number of patients consenting to share additional information in their SCR. In particular, patients with end of life plans and on the frailty register.
* Educate Humber GP practice staff how to record the patient’s consent to add and share additional information on their SCR.
* Increase the awareness/views of the SCR AI with all Humber care providers.
* Raise awareness of the ability to view the SCR through SystmOne to SystmOne users. Evidence so far shows this is vital for treating patients with an EMIS GP practice or from out of the area.

### Advice from Humber

* **Patient guarantee.**  Recommend that the SCR must be viewable by all urgent care providers, to assure patients that their EoL information is available when travelling outside their local area. Note: Currently urgent care providers can choose to use regional information sharing systems over the SCR. National communications imply SCR can be viewed anywhere in England, however if providers don’t have smart cards/N3 connection or decide not to view SCR, then promoting as available throughout England is misleading.
* **Raise awareness**. Provide case studies that show the benefits of using the SCR as a pragmatic way of sharing/viewing a sub-set of EPaCCS information.

## Coordinate My Care (CMC)

Coordinate My Care (CMC) is an NHS initiative, hosted by The Royal Marsden NHS Foundation Trust and in place since August 2010, permitting the 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. CMC is currently commissioned for use across the 32 London CCG areas.

<http://coordinatemycare.co.uk/>

The CMC service is enabled by a dedicated IT system (provided, hosted and managed since November 2015 by Intersystems), whose user interface is available via a web browser over the N3 network. The interface is rendered intelligently across desktop, tablet and smartphone platforms, with no requirement to install any software or browser plugin on the client PC. Access is also available from non-N3 clients via the Royal Marsden’s two-factor authentication solution, *Authen2cate*.

Clinicians can also provide their patients with online access to CMC through the MyCMC service.

Patients consent explicitly to the sharing of their Urgent Care Plan with care providers. A joint Data Controller Information Sharing Agreement is in place across all CMC user organisations, with over 1,000 signatories. CMC is used across both NHS and non-NHS organisations.

Non-urgent care providers (typically GP practices, hospices, acute Trusts, and community teams) collaborate to establish, maintain, and use the Urgent Care Plans of their patients. Urgent care providers (Ambulance, 111, Out of Hours GPs, A&E, and Urgent Care Centres) are notified automatically by CMC of the existence of Urgent Care Plans for patients in the relevant areas, permitting them to maintain relevant ‘flags’ on their own systems. This allows them to identify the existence of an Urgent Care Plan for the patient at the time of call-out, to access it, and thus to provide appropriate care.

The content of CMC’s Urgent Care Plan has involved extensive discussion between many clinicians. The Urgent Care Plan covers the SCCI 1580 End of Life Care data standard, but considerably extends it. NHS England’s Healthy London Partnership is building new standards for End of Life Care data and for urgent care service interoperability via a generalised ‘Crisis Care Extract’. CMC is closely involved in this work. In addition to End of Life Care patients, the CMC service coordinates care for many patients with a wide range of long term conditions.

To speed up Urgent Care Plan creation and drive accuracy CMC makes extensive use of the NHS Spine Personal Demographics Service (PDS); the NHS number is mandatory on each Urgent Care Plan.

For the convenience of commissioners and other stakeholders, CMC offers a wide range of management information reports. These are available, usually in PDF format, either on an ad hoc basis or as scheduled monthly/quarterly deliveries.

CMC’s 2016-2017 development roadmap will allow patients to give carers access to their CMC Urgent Care Plans, and includes initiation of the urgent care planning process by the patient.

### Strengths

* CMC is well ahead with delivering not only an EPaCCS, but also a service for patients with other long-term conditions that require specific considerations by urgent and emergency care.
* CMC have already done extensive work agreeing an Urgent Care Plan dataset.
* CMC have already considered the urgent care flagging needs.

### Weaknesses / Issues

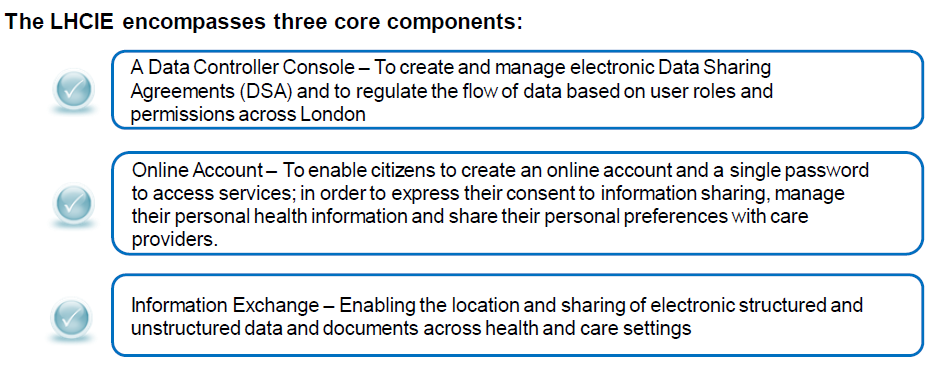
* CMC is a standalone EPaCCS, requiring the data to be entered regardless of the user’s own native IT system solutions.

## London Health and Care Information Exchange (LHCIE)

### Overview of LHCIE

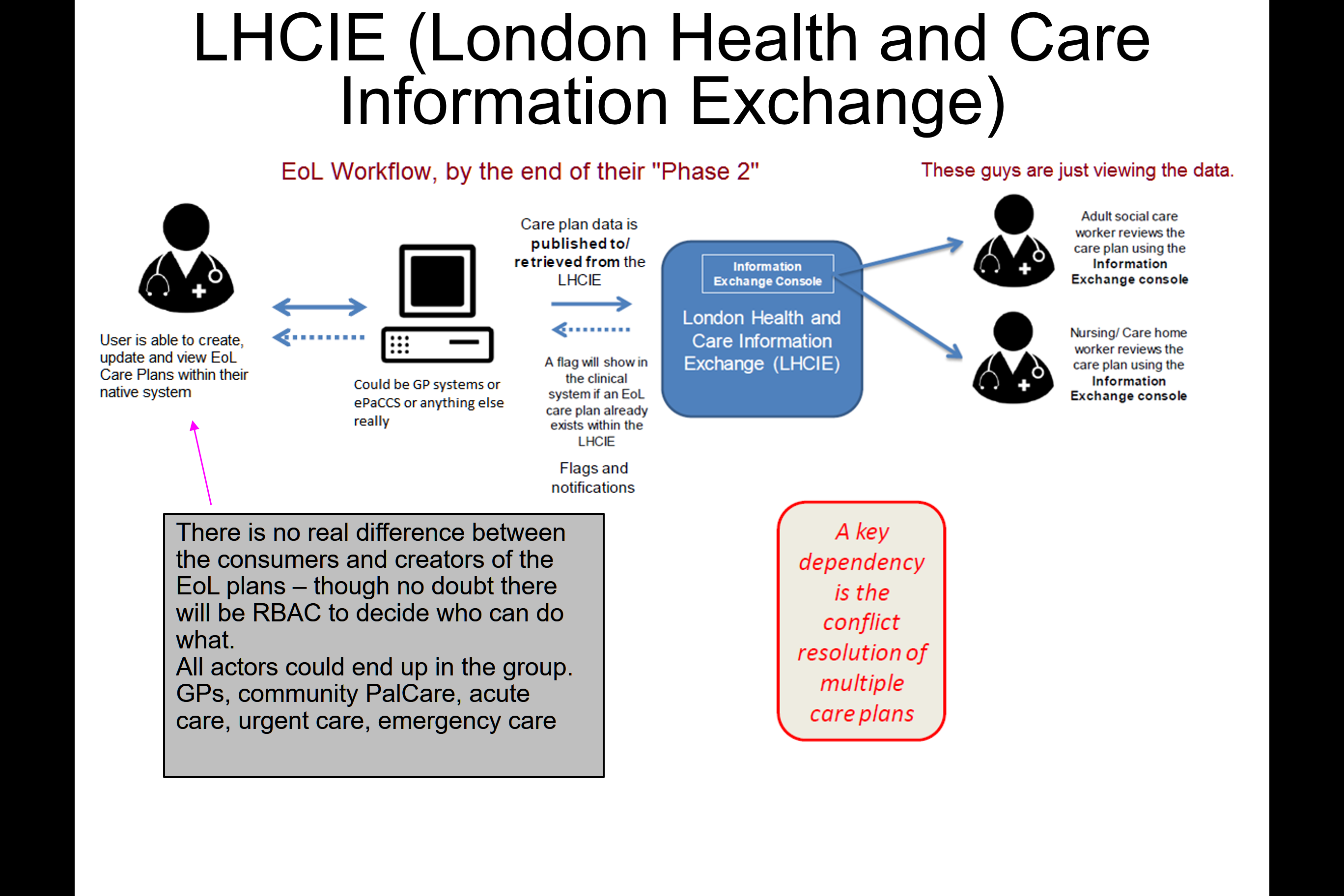
This is an ambitious project to link together IT systems right across London into an interoperating federation of systems. This will be done through defined standards for data exchange coupled with central routing and repositories.

<https://www.healthylondon.org/our-work/digital/end-life-care-coordination/>



The LHCIE has been working extensively with the NHS Digital Programme 14 team to develop the FHIR standard for interoperability of EoL data. There have already been several iterations of the design. LHCIE currently has a consolidated EoL dataset (attached) that is their current template for data to be shared.

The programme are also currently implementing a solution to lift a “crisis care extract” from the Co-ordinate My Care (CMC) London system to make this information more accessible across London.



### Strengths

* Eventually LHCIE will produce a fully integrated system, with shared data embedded within local native systems.
* CMC is already a running system with thousands of personalised care plans already recorded and being accessed by urgent and emergency care. If they can be quickly integrated into LHCIE, then it will get a flying start.

### Weaknesses / Issues

* The complexity of what the LHCIE is undertaking is reflected within the costs (£millions) and the lengthy timescales (the project has been running for around 2 years already).
* There may be concern that a solution produced could be viewed as being *London-centric.*

## NHS Scotland – The Key Information Summary

NHS Scotland implemented *ePCS* back in 2008, which was akin to a standalone EPaCCS. However, ePCS was plagued with the need to rekey data into the system, as it was not fully integrated with other data sources. Hence the system fell into disuse. Early adopters of the KIS were enthusiastic, finding it much easier to use and complete.

<http://www.scimp.scot.nhs.uk/key-information-summary/>

The Key Information Summary (KIS) is a collection of information about a patient extracted from the patient’s GP record. The KIS is an extension of the data shared by the Emergency Care Summary (ECS). The KIS is shared by the GP’s computer system twice a day, making this information available to other people and services looking after the patient. For example, out of hours services, Scottish Ambulance Service or NHS24 may use the KIS to gain more information about people they are in contact with.

Hence the Scottish model is very like SCR AI.

Currently only the GP can change the KIS. Patients can request a printout of their KIS. The patient leaflet says that in the future, it may be possible for the patient or other health service staff to make changes.

Using the KIS formed part of the GP Contract requirements from 2012-2013 and GPs were encouraged to use KIS to create ‘Anticipatory Care Plans’ (ACPs) for vulnerable patients at risk of admission to hospital.

2013-14: 71% of patients with cancer had a KIS, only 32% with other types of life-threatening condition (LTC) had a KIS.

## North East and North Cumbria Connected Health Cities – Palliative Care Plan Project

Like London, the NHS in the North East has embarked upon a far reaching and ambitious plan to create an integrated care record within their region. Initial technical documentation has indicated expected costs to be in the region of £36-£55million. This is being undertaken as part of the Connected Health Cities (CHC) programme.

### Previous History at North Tyneside

North Tyneside has already been integrating their EoL information, through provision of templates and uploads to the SCR. For patients, they have the *Deciding Right* tool (<http://www.necn.nhs.uk/common-themes/deciding-right/>) which has been delivered as part of the Northern England Clinical Network (NECN).

They have been working with 29 practices to introduce standardised care plans. They initially took the minimum SCCI 1580 dataset into an EMIS template and there were 5 sections to complete. When it was shown to the practices they remarked that it was **too long,** and they wanted just 1 page of template. Whilst people are willing to accept larger datasets now, this finding really has made North Tyneside focus on what is really important.

The major common message was that patients have two major pieces of data in common:

* Do you want to be resuscitated?
* Where would you prefer to die?

The project began to capture people who were on EoL registers with the GP and those who had indicated DNACPR.

In North Tyneside there has been no specific patient wishes to access their EoL plan/preferences online. There is a strong requirement from patients to see a copy of their information, to read it through and review it, so it would seem reasonable that an increasing number would be happy to hold that copy electronically and be able to view it in some online way.

North Tyneside believe that the *Deciding Right* forms make an excellent start point for discussion of EoL preferences, but that completion of the forms is a **shared decision** between the patient and the clinical staff.

*Deciding Right* forms are:

* **Ambulance trust special patient notes** – form completed with patient and passed to the ambulance trusts to be keyed onto their own system. The form becomes inactive and must be reviewed annually (or sooner).
* **DNACPR** – form is completed by patients and clinicians where CPR would not be clinically useful or where the patient has decided to refuse CPR.
* **Advance decision to refuse treatment** – gives the patient’s wishes for specific circumstances where they have decided to refuse certain treatments.
* **Emergency health care plan** – extended information about what urgent and emergency care clinicians should expect in certain scenarios. Gives contact details, details of underlying diagnoses, key treatments, and a checklist of anticipated emergencies and advised procedures.

North Tyneside is aware that much of the ReSPECT document covers all three (DNACPR/ADRT/EHCP), but they have completed training and engagement with frontline staff on completion of the three forms and do not wish to cause further confusion by changing to something else.

### Stakeholders

The Palliative Care Plan Project is that part of the overall programme that is investigating delivery of an EPaCCS solution. The core stakeholder group for the project are:

* The Community Health Forum
* Northern England EPaCCS Network
* Northumbria University
* Northumbria Healthcare FT
* North East Ambulance Services
* The Palliative Care Network
* Northern Doctors (OOH)
* North Tyneside Primary Care and Local Authority
* Connected Health Cities

### Project Structure

The project has been broken down into three workstreams, that will work in parallel.

**Data Design and Technology –** Product spec and roll out; Implementation; Information Governance; Data reporting / trends/ collation; Analysis

**Evaluation –** Evaluation strategy; Research; Ethics submission; Engagement; Portfolio of reports and interpretation; Collation of experience and learning

**Communications and Engagement –** Patient / family; CCGs; Specialist and non-specialist care homes; Regional networks; Local authority; Formal requirements

### Geographic Scope

The initial Palliative Care Plans project, for the year up to Dec-2018, will be limited to a smaller geographic footprint.

* North Tyneside CCG, with 10-15 GPs taking part, covering a possible population of 30,000. GPs are split 50/50 between SystmOne and EMIS.
* Northumbria Healthcare FT, which will cover acute and community services. The community uses SystmOne whilst NHFT uses Orion.
* North East Ambulance Services (NEAS), providing 111 and 999 services, using Adastra and Cleric. NEAS is very keen to have something like a DNACPR flag, although they make it clear they will have to be able to trust that it is correct.
* A local authority.
* Possibly care homes and hospices. SystmOne is being introduced to hospices.

A regional EPaCCS network was established a number of years ago, and through this, the project will have access to resources of people. The network is a useful mix of clinicians and systems people.

The project is part of the *Northern England Clinical Network.* All trusts and CCGs are also signed up to this.

CHC have the people that do the theoretical work of designing FHIR messages and discussing the IG implications.

It is possible (but not definite) that Black Pear will lead on delivering the pilot solutions as they have said they can take data from GP systems and pre-populate a cloud record with the information required. This would be a two-way connection, so that changes in the cloud record are reflected directly into the GP system. They also expect the system can provide alerts to others that the care plan exists of has been changed.

In this region, implementation of SCR AI was negatively affected because GPs felt they had to do more (too much) extra work to add the extra information to meaningfully populate it. There has been no big marketing/communications push in this region for SCR AI.

### Strengths

* The project has wide backing and engagement across the region.
* It is looking at data being updated within GP systems by external users via the shared cloud system.
* This project is working together with academic input from the university. Therefore it is focussing right from the start on the analytics that a good system can produce and not just upon the day-to-day direct care aspects of a solution.

### Weaknesses / Issues

* This programme of work is in the very early stages of development. Even by Dec-2018 (if things go to plan) they will have only produced a small-scale pilot.
* It isn’t clear if the large amounts of money discussed in the technical documents are available to take this programme to a conclusion.

## Derbyshire – Integration using SystmOne

Dr Paul Nathan has been CCIO for Derbyshire for the last 6 months of 2017 and has been looking at creating an integrated EPaCCS solution for the last 4 months.

### Background

Every practice already has its own EoL register within their GP system and practices have community care coordinators (CCC). These community care coordinators organise the care packages for patients, working with social care through MDTs. They effectively own the EoL register.

All GPs have a target to look at their disease registers (all diseases not just cancer), especially where patients have multiple conditions. The GPs are asked to consider if patient could be in last year and the region has been keen to establish other triggers for entering the register, apart from cancer.

Initially the user community was interested in procuring an EPaCCS, but Paul had to adjust their expectations, as there was no local funding for such a system. The most cost effective and deliverable solution was to use SystmOne as the EPaCCS. Some EMIS users are concerned that their community care coordinators are rekeying data into SystmOne after it had already been entered into the EMIS. However, there is hope in Derbyshire that by spring 2018 there might be more integration between EMIS and SystmOne

### Local IT Footprint / Solution

* GP practices - 80% of practices use SystmOne.
* All community services and the Macmillan unit and hospice are on SystmOne.
* GP OOH and Ambulance Service – when a plan is created or amended, the plan is emailed, so they have the information should they need it. There will be some rekeying at these organisations.
* Emergency dept – they have cutdown/read only access with SystmOne. The SystmOne link is particularly used by pharmacy to check the patient’s current medications.
* Derbyshire has the MIG. GP OOH will use it, but the ambulance service tends not to.
* GP extended hours hubs – they are all on SystmOne and have access to patient record where the patient has a SystmOne GP.
* SCR AI – Derbyshire is beginning to use SCR AI. This has been driven by the need to provide the frailty index score.
* There is a locally agreed EoL template within SystmOne for all users.
* SystmOne Data Sharing Permissions – because of the necessity for GPs to set their patients to “share out” for the MIG to operate. Anybody “sharing in” asks for patient consent.
* Patient access/view – Approx 20% of local patients have registered for online access to their GP systems. Of those, only a very few have access to their actual medical records. When they do have access, patient sometimes only get to see information recorded since the data of the agreement to share their records ie. no pre-agreement historical records.

### Strengths

* By using SystmOne, Derbyshire have implemented their solution quickly and with the minimum of cost.
* There are effective shared data standards, driven by the shared SystmOne template.
* Driving the solution from GP systems means that uploads to SCR will also be delivered.

### Weaknesses / Issues

* There is significant re-keying at non-SystmOne practices.
* There is currently no digital integration with urgent care services. They only receive emails with care plans/preferences, which they must store locally and link to their own patient recording systems.
* Emergency care does not seem to be fully using their SystmOne integration.

## Sunderland – Approach to DNACPR

City Hospitals Sunderland NHS Foundation Trust is a Global Digital Exemplar (GDE) and is moving to complete paperless delivery of care. This has brought the issue of the DNACPR form into the fore. The form, by its very nature, is on paper. It is brought into the hospital by the patient or it can be created inside the hospital with the patient. In a highly electronic situation, it becomes increasing likely that clinical staff will overlook paper documentation, and Sunderland have become concerned about this increase in risk.

Unlike many other aspects of EoL preferences and plans, the DNACPR is a formal document that must be:

* completed correctly on a locally agreed form
* signed by senior personnel
* regularly reviewed

Patients with cancer tend to have a clearer progression and once decisions are made they change less often. Other people approaching end of life may change their clinical condition more frequently which may impact on the decision to resuscitate. For all patients it becomes critical that clinicians are sure they are seeing what reflects the patient's current accurate wishes and legal status.

### Within the Hospital

At Sunderland, if a patient has a conversation and a DNACPR form is generated, the form is produced immediately and left in the front of the patient’s IP notes. As this is a paper process, there is always the opportunity for the form to be incorrectly completed.

Their Meditech system is quite capable of recording DNACPR preferences and will also flag this up very prominently on the patient banner on the system. But this then gives the issue that there are now two versions of "the truth". Also, the provenance of the electronic data can be a worry if the clinician cannot see the original document to be sure that it is completed correctly, signed and still up to date.

Sunderland can also access GP information via the MIG, however, this is not the signed document and it is difficult to be sure if it refers to the current, signed document.

Kevin Joisce (Sunderland CCIO) has observed that in Liverpool, the solution is that the electronic version is the version that is used within the hospital. Where they create/amend a DNACPR, there is no paper version generated until a time when the patient is discharged. Kevin is concerned that the point of discharge is already a bottleneck and the correct production of the DNACPR form (with the correct additional signatures) will add complexity at this time.

### On Discharge

On discharge, the hospital can be reasonably sure that a paper DNACPR form will travel back with the patient to their home or care home. The physical presence of this form is critical in situations where there is much less access to IT. It is not uncommon for patients to be readmitted within 24 hours of discharge, so the physical presence of the form for urgent/emergency teams attending the patient and for the hospital receiving the patient is very useful.

If the eDischarge to the GP included DNACPR information, this would take a little while to be updated onto the GP system and a further delay before it updates SCR.

### Key messages:

* There will be weaknesses in new electronic systems, just don't make it worse than the current paper system!
* Compared to other preferences, DNACPR is a special case in that it is a legal document.
* The date created and expiry date of a DNACPR form is critical if it is to be displayed on an electronic system.
* Viewers of electronic DNACPR must be convinced of its provenance.
* The time taken to transmit the changes to other systems is critical.
* If a DNACPR form could be created electronically, this would improve the quality as part-completed or incorrectly-completed forms would not be able to be saved.
* Sometimes paper forms get lost or misplaced and there are existing weaknesses in the current paper system that electronic systems could potentially address.

## Devon – Delivering EPaCCS across the STP

### Current Systems

Devon has a mix of GP systems deployed and therefore a solution such as using the SystmOne EPaCCS capability would not work. However, there may well be a move towards more GPs using SystmOne in the future.

Devon uses a standalone Adastra EPaCCS solution which is part of the overall Adastra solution used by Devon Doctors. As with other standalone solutions, GPs must rekey their EoL data into it and evidence suggests that where it's used it works well, but take-up is patchy.

### Preferred Solution

The EPaCCS team works alongside the STP steering group, looking at possibilities for a shared care record in the future. There was an STP-wide EoL meeting in 2017 and there is now an EoL steering group. The feeling in Devon is that people are now involved and that (hopefully) a working plan is coming together. They are currently generating a business case for a replacement EPaCCS solution.

Devon is looking at a number of options, including using SCR, CMC and Black Pear, and hope to make a decision by June 2018.

### SWAS - South West Ambulance Service

SWAS covers a much wider area to Devon and currently show less interest in being part of a Devon-level EPaCCS. It will be most helpful for NHS Digital to consider how a national solution can support SWAS in accessing SCR, to retrieve a minimum EoL dataset, even if the dataset is not as rich as what is held within their EPaCCS.

## Salford – EPaCCS at GPs and within the EPR

### EPaCCS based on GP systems

Practices in Salford either use EMIS or Vision. In 2010 an EPaCCS was set up using these systems. Users of both systems were given an EPaCCS template, based on the same dataset. This standard dataset came from the national pilot dataset and more recently the Greater Manchester dataset, although it was changed locally to make it smaller and therefore more deliverable.

GP staff put updated patient info into their systems using the EPaCCS template and that saves the record into their patient journal.

Once the change is saved:

* an email with auto generated content is sent to NWAS, GP OOH (Salford), and the district nursing evening and overnight service. Those services then use the email to update their records accordingly.
* an update is sent directly into the Salford Royal EPR through SIRC ([Salford Integrated Care Record](http://www.salfordtogether.com/our_plans/sharing-medical-care-records/)). It does this by taking an SQL extract every night from the GP systems and pushing XML into Salford Royal EPR as a clinical note.

### Salford Royal EPaCCS

The Salford Royal EPR has an EPaCCS and staff with access can input directly into this EPaCCS. This includes Trust acute staff, district nurses and the community Macmillan team.

Updates to this EPaCCS generate updates to others:

* an email with auto generated content is sent to NWAS, GP OOH (Salford), and the district nursing evening and overnight service. Those services then use the email to update their records accordingly.
* An update is sent to the patient’s GP system via DocMan. GP staff receive a document and then they must manually update the information into their system.

### Issues

* The GPs updating process not efficient, requiring rekeying of data received the from the Salford Royal EPaCCS.
* When GP EPaCCS data is transmitted to the Salford Royal EPR, the process causes the Read-coded data to be displayed in a “jumbled up” fashion making it harder for users to read and understand. Any pure text entry in the GP data is lost.
* They would like a more automated way of the Salford Royal EPaCCS data being available to NWAS and the GP OOH service and are considering that an upgraded SIRC could be used.
* SCR – The Trust has decided not to roll out smartcards, and this is the sticking point that makes SCR unusable. They would look more seriously at SCR if NHS Digital could change the authentication model away from smartcards.
* Care Homes – GP staff must print out all the EPaCCS data and give it to the local care homes as at a lot of care homes, frontline staff don't have access to computers.

### Future Plans

* Salford are trialling the MIG at their GP OOH service, which uses Adastra. Adastra’s links to the MIG should make it possible for the GP OOH service to see GP EPaCCS data directly. <http://healthcaregateway.co.uk/>
* Future changes to SIRC may allow non-GP users to view the GP-generated EPaCCS data directly from the SIRC, which will remove the need to push the GP data to other systems.

## The NHS Online Programme – Patient access to their plans and preferences

The NHS Online Programme are delivering to the 8 ministerial commitments around patient access to their records. The 8th commitment is access to EoL information.

This *NHS online* service must be nationally available by Dec 2018 and there must be a “clickable” system to be demonstrated at the NHS Expo in Sep 2018.

The programme is currently in the discovery phase, with an expectation that they be surer of their direction of travel by the end of Jan 2018. Until that time they will not have a preferred solution.

Possible solutions could be:

* Patient has direct access via their native GP system patient interface.
* Patient has access to their GP record using an app via APIs provided by GP suppliers (possibly GP Connect APIs)
* Patient has direct or API access to their local EPaCCS or integrated care record.
* Patient has an app that employs the emerging NRLS architecture to link to their record.

Regardless of the technical solutions they propose, they have an urgent requirement for an agreed minimum national dataset of plans and preferences, from which they can decide how or whether that data can be presented to the patient.

### Issues

* This is not an Integration Programme deliverable and should not be seen as such. However, Integration Programme outputs can helpfully inform the NHS Online Programme.
* Once a patient has co-authored their plan with their local clinical support, then a patient-facing IT solution may not be fully trusted unless the complete record can be seen.
* Access to GP systems is likely to be through APIs that are driven by GP Connect and GPSoC (GP Futures). GP Connect have already indicated that such APIs are not on its schedule for 2018. Excluding GP Connect from the process would still limit the project to arguing that their changes are escalated through GPSoC. Senior NHS Digital management will have to resolve this impasse.

# Other Background Information

## CQC - GP practices and the five priorities for care of the dying person

Following the review and phasing out of the Liverpool Care Pathway in July 2014, the Leadership Alliance for the Care of Dying People agreed five priorities for the care of the dying person.

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf>

The Care Quality Commission (CQC) have published their response, detailing how they will be inspecting GP practices based upon those priorities. There is much that can be done integrating EPaCCS with GP systems that will support GPs in responding to inspections. Additionally, the CQC inspections could be supported by national reporting on EoL outcomes.

**1. The possibility that a person may die within the coming days or hours is recognised and communicated clearly** - decisions about care are made in accordance with the person’s needs and wishes, and these are reviewed and revised regularly.

When we inspect we are likely to ask:

* Can we see documentation about a recent death you were involved in, and how you documented communication with the patient and those important to them?
* Is there evidence the persons needs and wishes have been considered?

**2. Sensitive communication** takes place between staff and the person who is dying and those important to them.

Training in communication, person centred approach and symptom control and services available is needed to improve care for all.

When we inspect we will:

* Consider how the practice uses the palliative care register and team meetings to improve coordination and communication with others involved in a person’s care.
* Ask whether practices feel they need more training in communicating with people with a diagnosis other than cancer.

3. The dying person, and those identified as important to them, are **involved in decisions about treatment and care**. GPs should support people to make choices about their preferred place of death.

When we inspect we will

* Want to understand how the practice records discussions about patients’ needs, wishes and preferences (personalised care planning discussions) and how it ensures they are enacted or fulfilled.
* Ask how many of your patients died where they wished (preferred place of care) and in each setting (home, hospital, care home, hospice, other).
* Ask whether an after death analysis is undertaken and any learning can be taken from when people did not achieve their preferred place of care and death.

4. **The people important to the dying person are listened to and their needs are respected.**

When we inspect we will:

* Ask how practices support the family and carers of patients at the end of life and in bereavement.

5. Care is tailored to the individual and delivered with compassion – with **an individual care plan in place**. GPs should coordinate making and following an individualised care plan. Care plans should ideally be owned by the patient but recognised in all settings.

When we inspect we will:

* Look for evidence of supporting patient’s individualised care plans. The patient must be involved in producing these and aware of their existence

## GP Connect

The project has engaged with the GP Connect team, to further understand what their priorities are around EoL care data.

GP Connect are developing a standard method for requesting data from the GP medical record for use in direct care, using FHIR standards and SNOMED CT coding. The work also includes an HTML export of the medical record and the ability for external systems to book appointments directly into a GP practice

However, NHS England has also raised to possibility of GP Connect also writing data into the GP record. Discussions on timescales and priority are ongoing.

GP Connect is working with stakeholders in many different areas of NHS (for example: acute, mental health, child care, community nursing etc) to identify a range of different uses of GP practice data and exactly what data is needed. One of the areas GP Connect is investigating is EoL, and this remains an access point that the NHS Online Programme could use for patient/carer maintained EoL preferences.

The programmes have agreed to work together. Programme 13 can engage with its stakeholders to develop the requirements and data models and GP Connect can then review and incorporate those EoL requirements into the overall requirements for GP practice data.

## ReSPECT - Recommended Summary Plan for Emergency Care and Treatment

ReSPECT is a process that creates personalised recommendations for a person’s clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person’s care and treatment. ReSPECT can be complementary to a wider process of personalised/advance/anticipatory care planning.

A ReSPECT form is a very specific type of personalised care plan (PCP) that summarises the emergency care aspect of a wider advance or anticipatory care planning process. ReSPECT records that information so as to make it accessible rapidly to professionals who need to make immediate decisions about care and treatment in a crisis.

The plan is created through conversations between a person and one or more of the health professionals who are involved with their care. The plan should stay with the person and be available immediately to health and care professionals faced with making immediate decisions in an emergency in which the person themselves has lost capacity to participate in making those decisions.

<http://www.respectprocess.org.uk/>

The plan is created through conversations between a person and their health professionals and is recorded on a paper form which includes their personal priorities for care and agreed clinical recommendations about care and treatment.

The ReSPECT process was created following a systematic review of DNACPR decisions and documents. ReSPECT aims to encourage patient and family involvement in decision-making, to consider recommendations about CPR in the context of broader plans for emergency care and treatment, and to record the resulting recommendations on a form that would be used and recognised by health and care professionals across the UK.

ReSPECT is not a replacement for a DNACPR form; the aim is to promote recording an emergency care plan by many more people, including many whose ReSPECT forms will recommend active treatment, including attempted CPR if it should be needed.

A ReSPECT form can be used to draw attention to the presence of an ADRT and should contain relevant aspects within the summary recommendations for treatment and care.

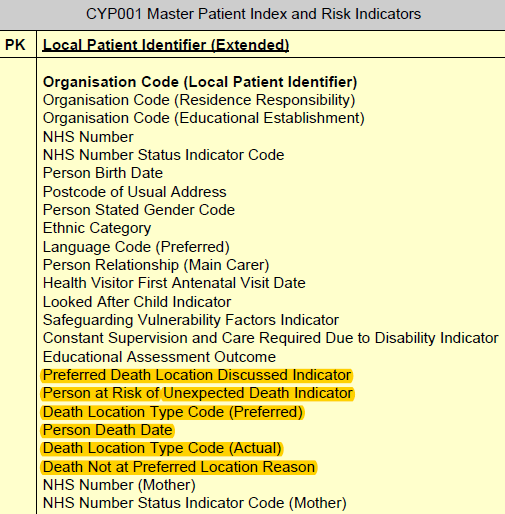
An Advance Decision to Refuse Treatment (ADRT) is a legal document that people in England & Wales can complete to refuse treatment that they don’t want to receive. If it is completed according to the Mental Capacity Act 2005 it is legally binding on anyone who knows about it and who can be confident that it is valid and applicable to the situation that they are dealing with. A ReSPECT form is not legally binding and focuses only on making recommendations about care and treatment that might be considered in an emergency, when a person’s life may be at risk.

## CSDS – Community Services Dataset

NHS digital has already specified and is now collecting the [Community Services Dataset](https://digital.nhs.uk/Community-Services-Data-Set) and the 1st publication of data is due in early 2018.

All providers of publicly-funded community services are legally mandated to collect and submit community health data, as set out by the Health and Social Care Act 2012. The Community Services Dataset (CSDS) has expanded the scope of the previously existing Children and Young People's Health Services (CYPHS) dataset, by removing the 0-18 age restriction, requiring all adult community data to also be submitted.

The structure and content of the CSDS remains the same as the previous CYPHS dataset, which includes provision to return details of patients’ known preference for a location of death and the outcomes compared to that preference.



Extract of CSDS technical output specification.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **C001170** | **PDeathLoc** | **PREFERRED DEATH LOCATION DISCUSSED INDICATOR** | An indication of whether the preferred location of death was discussed with a patient or proxy by a clinician, in the event that there is an expected risk of death before the age of 18 for that person. | an1 | Y | Yes (the preferred location was discussed) |
| N | No (the preferred location was not discussed) |
| **C001180** | **PARDeathInd** | **PERSON AT RISK OF UNEXPECTED DEATH INDICATOR** | An indication of whether a patient is at risk of sudden, unexpected death before the age of 18, as assessed by a clinician. | an1 | Y | Yes (person at risk of unexpected death) |
| N | No (person not at risk of unexpected death) |
| **C001190** | **DeathLocPref** | **DEATH LOCATION TYPE CODE (PREFERRED)** | The preferred location of death as specified by the PATIENT. | an2 | **10** | **Hospital** |
| **20** | **Private Residence** |
| 21 | PATIENT's own home |
| 22 | Other private residence (e.g. relatives home, carers home) |
| **30** | **Hospice** |
| **40** | **Care Home** |
| 41 | Care Home with Nursing |
| 42 | Care Home without Nursing |
| **50** | **Other** |
| 99 | The CARE PROFESSIONAL did not discuss the preferred LOCATION of death prior to the death of the PATIENT |
| **C001200** | **dod** | **PERSON DEATH DATE** | The date on which a person died or is officially deemed to have died, as recorded on the death certificate. | an10 CCYY-MM-DD |  |  |
| **C001210** | **DeathLocAct** | **DEATH LOCATION TYPE CODE (ACTUAL)** | The actual location where the PATIENT died. | an2 | **10** | **Hospital** |
| **20** | **Private Residence** |
| 21 | PATIENT's own home |
| 22 | Other private residence (e.g. relatives home, carers home) |
| **30** | **Hospice** |
| **40** | **Care Home** |
| 41 | Care Home with Nursing |
| 42 | Care Home without Nursing |
| **50** | **Other** |
| **C001220** | **DeathLocReason** | **DEATH NOT AT PREFERRED LOCATION REASON** | This will indicate the reason why the person did not die at their preferred LOCATION of death. | an2 | 01 | Family decided to move patient to hospital |
| 02 | Patient was moved to hospital for clinical reasons |
| 03 | Patient changed their mind |
| 04 | Capacity not available at preferred location |
| 05 | Transfer delays |
| 06 | Social support issues |
| 07 | Need for access to adequate pain relief |
| 98 | Other |
| 99 | Not known |

## Public Health England (PHE) – End of Life Care Profiles

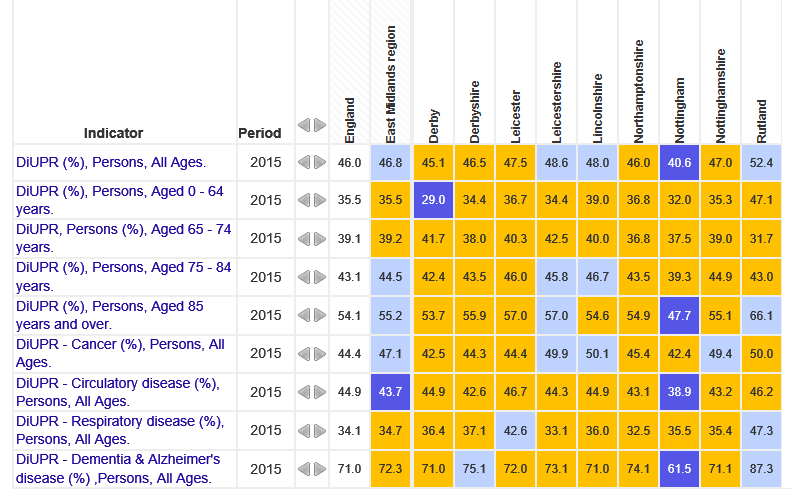
[The end of life care profiles](http://fingertips.phe.org.uk/profile/end-of-life) were developed by Public Health England’s National End of Life Care Intelligence Network to support the NHS, local authorities, health services and other interested stakeholders to monitor comparative information on factors that describe population trends associated with the end of life.

The Profiles are grouped into the following domains:

* Place of Death
* Underlying Cause of Death
* Mortality Rates
* Death in Usual Place of Residence (DiUPR)
* Care home use at end of life
* Dementia (includes Alzheimer’s disease) and other relevant indicators (those extracted from other profiles within PHE).

More domains will be added by PHE as soon as they become available.

Example output is below:



# End of Life Care Interoperability Project Potential Options

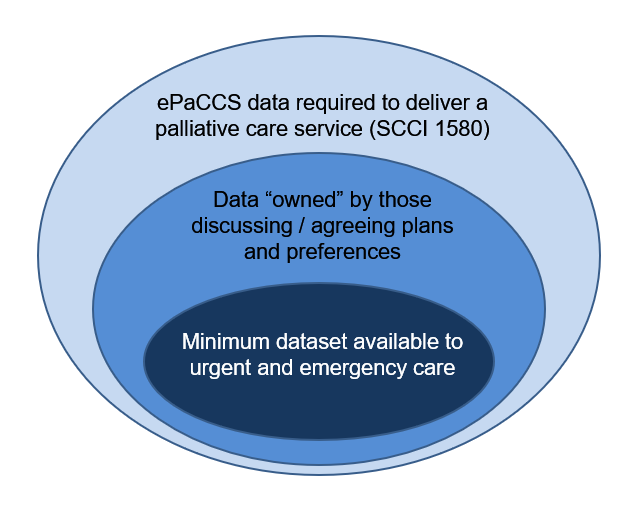
All the options should be considered against the major outcomes that are required for any successful EPaCCS:

1. Every person, who requires one, has a personalised care plan, including their own personal preferences.
2. Clinical staff, working for that person, all have access to the personalised care plan to enable them to make changes to that plan as and when it becomes necessary.
3. The person, or their carers, have access to the plan and can make changes to their preferences when they see fit.
4. Clinical staff in urgent and emergency care (and other settings) are warned of the presence of a plan and preferences, and can quickly view that information, prior to and during any episode of care.

## Produce a National Standard Dataset

Regardless of which EPaCCS solution is employed, all the local teams are endeavouring to standardise data collection. Either through the APIs and datasets they are using to upload to their EPaCCS or through development of agreed local templates, there is a real demand for a clear national minimum dataset (based upon the SCCI 1580 standard) and accompanying FHIR standard. This must be accomplished through dialogue with all those that have already solved the problem locally, by reflecting upon all the clinically reviewed standards that have been delivered, the national approach to resuscitation, and the work currently under way in England.

SCCI 1580 and EPaCCS in general include data that could be viewed as external to the core dataset. This includes information such as demographics and current medications. A key driver for the dataset work will be to identify the ***minimum*** dataset that will deliver key information to urgent and emergency care users (through SCR or other routes) that all localities must comply with.



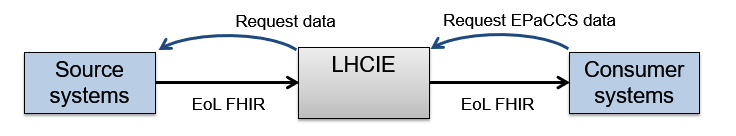
This work is also imperative to support the NHS Online Programme team in their approach to delivery of their EoL ministerial commitment to enable patients access to set and change their EoL preferences.

## Produce a National Standard set of EoL FHIR Resources

The Interoperability Standards Service have already been working with LHCIE for some time on development of the standard. However, there has been a fair rate of change as the overall dataset as London’s requirements have fluctuated. By pinning the minimum national standard dataset with all interested parties, it would be hoped that the work of subsequently generating the FHIR resources could be made into a more stable process. Input from wider stakeholders will be sought during this process.

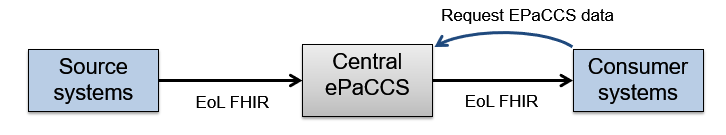
### LHCIE – possible first of type

The national FHIR resources will support LHCIE to extract the plans and preferences data from source systems in a standard format, acting as a first of type (FoT) for these standards.



### Data transfer in/out of EPaCCS

Additionally, other local/regional EPaCCS solutions can employ this standard for transfer of EoL plans and preferences data. Urgent and emergency care systems could act as consumers of EPaCCS systems, making API calls for the EoL data.



### GP system updates

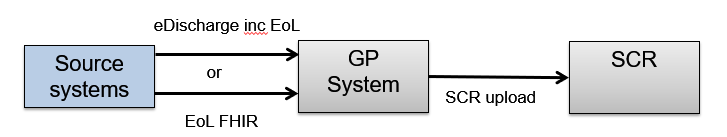
It is also imperative that all GP systems are kept up to date with the latest EoL plans and preferences, both to keep the GP records up to date and to feed the updated information to SCR.

In a situation where the main repository of EoL care plans and preferences is the GP system, there ***must*** be an electronic way of sending changes to that data directly from other services (such as unconnected EPaCCS) into the GP system.

Source systems could trigger updates into the GP systems by using the EoL FHIR standard messaging above. However, it may be more useful for systems to employ the current eMessaging FHIR standards (such as eDischarge) by extending those messages to include EoL FHIR resources.

This would mean that business protocols to accept those messages would already exist within the practice, the coded changes to plans and preferences could be accepted into the GP record alongside the other data.

Discussions with Sunderland about the importance of prompt data for CPR status could also mean that the point of discharge is too late, and that data must be passed earlier to remove clinical risk.



## Work with the Flagging Project to Produce National EoL Flagging from GP System Data

As more and more data is placed into the SCR, there will be a point at which it ceases to be a true *summary* record. The chance for key/important data to become lost in the other data increases. Feedback from urgent care viewers especially, has highlighted the requirement for advance flagging of key information when patients are traced on Spine. The Hampshire project also saw a key improvement would be gained from restructuring the SCR AI offering to enable this key information to come to the fore.

NHS Digital has recently hosted a *flagging workshop*, where the importance of this early view was highlighted.

Possible options to be further investigated could include:

* Agreement of what parts of the minimum dataset constitute information that should form a summary or a flag.
* Messaging direct from GP systems to Spine to maintain flags that can be displayed *on trace.*
* Enhancements to SCRa to further summarise EoL plans and preferences to ensure they are more accessible to time-pressed users in urgent and emergency care.

# Other Current Delivery and Potential Responses for Consideration

The following includes delivery being undertaken by other teams and projects as well as other approaches included for consideration.

## Advance the Rollout of SCR AI

SCR is a national service that has been increasing in usage during recent years. There are also significant targets to increase that take-up, including a target that 80% of patients with specific diseases/conditions listed (including those within end of life) will have AI by Dec-2018. Some regions use SCR extensively whilst others have not used it much at all, indicating there are extensive opportunities for expansion of the service.

The *New Care Models* programme has already funded Hampshire to prove that extending SCR AI usage is not only feasible, but also remarkably cost-effective. Other regions, such as Humber, already have taken the decision that this is the correct short/medium term route to getting personalised care plans and preferences into the hands of those that will act upon them. Where there is a mixed economy of GP systems and community systems it has proved the only option.

NHS Scotland, through their KIS service, have also taken a similar route to delivering within this business area. Further cross-border sharing of knowledge with NHS Scotland should be encouraged, so that both countries work together to resolve their common issues.

NHS England and NHS Digital must take great care, when championing other solutions, not to weaken the message that SCR AI is the ***tactical solution*** that can bring real advantages now. There must also be consideration that funding of other solutions could be diverted to increasing the support for SCR AI.

The fast rollout of tactical appointment booking solutions within urgent care during the past three months, as part of the winter pressures programme, has shown that NHS Digital can mobilise business change quickly if it is well directed and funded.

## Patient Access to EoL Preferences

The NHS Online programme is tasked with delivering a ministerial directive, that states that patients will be given the opportunity to *express end of life care preferences online or through an app*. How the NHS Online programme intends to deliver this remains unclear (as, at the time of writing, the team is still undertaking discovery work), but the Integration Programme *may be needed to help define* a national minimum dataset for the “view” and thereafter constructively discuss what parts of that dataset *may* be edited directly by the patient.

## Produce National Analyses from NHS Digital Data Sources

SCR will produce figures for take-up and utilisation and this can be extended (if not already available) to cover personalised care plans and preferences.

Subject to IG approval, base data, such as date of death, can be extracted from PDS and compared to the personalised care plan information. In this case it would then provide information for people who died with or without a personalised care plan.

PHE already produce EoL Care Profiles. Further analysis is required to understand why this data might not be what the business requires, given that on the surface, it appears to provide national data covering many aspects of interest.

## Develop a National Linking System

A system could be designed, sitting above regional systems such as LHCIE that would link those regional systems together. This would probably sit within the scope of the NRLS. Such a system should be viewed as highly ambitious and outside the scope of this review.

# User Stories

Requirements are described as user stories to enable a better understanding of the issues that require resolution by any integrated system.

## EoL preferences viewable by all care professionals

In order to remove the need to repeat my statement of preferences

As a patient

I want my EoL preferences to be recorded where they can be accessed by all health and care professionals attending to my needs.

**Commentary**

Having to repeat preferences can be both distressing and time-consuming for both patients and carers and the professionals providing care. Having the preferences accessible to all care professionals will lower unwarranted admissions to hospital.

**Acceptance Criteria**

* Care professionals with access ***must*** include: Acute care professionals, community palliative care teams, general practice professionals, care home or hospice carers, 111 call handlers, paramedic control teams, paramedics, UTC clinicians.
* EoL preferences to be viewed ***must*** as a minimum comply with the agreed EoL preferences minimum dataset.

## Preferences completed in a timely manner

In order to ensure that I have a statement of preferences at a time when I am fit enough to complete it

As a patient

I want to be able to have recorded (and review and amend) my preferences for EoL care before those preferences may need to be enacted.

**Commentary**

During the delivery of urgent and emergency care is ***not*** the time or place for patients and their carers to be considering their EoL preferences. Therefore, community professionals must have access to systems that enable them to record the patient’s preferences before there is an emergency.

## All care professionals can update EoL preferences

In order to keep my EoL preferences up to date with my current wishes

As a patient

I want all care professionals in contact with me to be able to alter my shared EoL preferences record in line with my or my carer’s wishes.

**Acceptance Criteria**

* The care professional ***must*** only be able to amend those items of the preferences over which they have jurisdiction.
* The record of the EoL preferences ***must*** contain metadata that records who has changed what parts of the patient’s preferences as a full audit trail.
* The care professional ***may*** be able to view the current EoL preferences via a viewer portal or embedded within their own native IT system.
* Any changes ***must*** be capable of being shared so that other care professionals will have access to the changed record.
* Care professionals ***must*** include: Acute care professionals, community palliative care teams, general practice professionals, care home or hospice carers.

## Up to date preferences are accessible to care professionals

In order to ensure that care professionals always respond to my latest wishes

As a patient

I want to be assured that any updates to my preferences will be promptly shared to systems that will be used by my care professionals.

**Acceptance Criteria**

* Any change to EoL preferences ***must*** be accessible to viewers of systems within 24 hours of the change being made.
* Changes to EoL preferences ***must*** be shared without the need for human re-keying of the data.

## Patient/carers can directly view EoL preferences

In order to ensure that my statement of preferences is completely up to date with my current wishes

As a patient or an authorised proxy of the patient

I want to be able to independently (or with help from my carers) view my statement of preferences whenever I wish to.

**Commentary**

Commitments have been made that patients/carers will have access to their EoL preferences via their own IT applications.

## Patient/carers can directly amend EoL preferences

In order to ensure that my statement of preferences is completely up to date with my current wishes

As a patient or an authorised proxy of the patient

I want to be able to independently (or with help from my carers) update my statement of preferences whenever I wish to.

**Commentary**

Commitments have been made that patients/carers will have access to their EoL preferences and in some circumstances, be able to effect changes to those preferences via their own IT applications. Consideration must be taken to ensure that the patient can only amend those preferences where it is safe for the patient to do so without professional support.

**Acceptance Criteria**

* The patient ***must*** only be able to alter those items of the preferences over which they have jurisdiction.

## Demographics are driven from PDS

In order that the EoL record has most recent contact details

As a patient

I want the latest address contact details for me from PDS to be accessible as part of my EoL preferences.

**Commentary**

Rekeying of demographics details into EPaCCS solutions will add additional work for those recording and maintaining the details and will add the possibility that the details are not up to date.

**Acceptance Criteria**

* Any system displaying EoL preferences ***must*** display the patient's current registered demographics from PDS.
* Users ***must not*** be able to alter the demographics data within the preferences directly

## Medications are up to date

This user story will be delivered by other interoperability projects.

In order that I do not get administered the wrong medications

As a patient

I want anybody offering me care to have a definitive list my current medications.

**Commentary**

Care professionals will require access to a list of the patient’s current medications, however, those maintaining the preferences for the patient are not going to be in a position to, or have the time to, keep this list independently.

**Acceptance Criteria**

* EoL preferences ***must*** include the current medications recorded by my GP practice.
* EoL preferences ***must*** include the current medications prescribed by acute care settings.

## Urgent and emergency care access to preferences

In order that I am not taken to hospital (or another care setting), contrary to my preferences

As a patient

I want urgent and emergency care staff to have access to my EoL preferences ***prior*** to their arrival at my residence.

**Commentary**

Some staff members (such as 111 call handlers) have only restricted access to medical data on IT systems and hence may not be able to get full access to all EoL preference and care plan data. These staff must have access to a flag or indicator within their native systems to indicate that the patient is under palliative care and that they must be quickly routed to a clinical professional where their more complex needs will be better handled.

It is imperative that 999 call handlers are aware in advance, before despatch of an ambulance, that a patient is at their end of life and that they have preferences for how things will be enacted. However, it should also be remembered that a lucid patient retains the right to change their minds at any time.

**Acceptance Criteria**

* Native systems ***must*** display an indicator where the patient has an existing EoL preference or care plan. NB. Further analysis will be required to define those data items that, if set, will cause an overall flag to be set.
* EoL preferences ***must*** be available to 111 and 999 call handlers in line with local data sharing rules.
* EoL preferences ***must*** be available to location-based paramedic support staff (so that the preferences can be transmitted to paramedics).
* EoL preferences ***should*** be available directly to mobile paramedics using their mobile devices.
* EoL preferences ***must*** be available from a national source (such as SCR), either as a standalone system or embedded within the care professional's own local system, where staff do not have access to the preferences within their local systems or directly from local EPaCCS solutions.
* EoL preferences to be viewed ***must*** as a minimum comply with the agreed EoL preferences minimum dataset.

## Access to social care staff

In order that my non-medical wishes are honoured by those providing my personal/social care

As a patient

I want personal/social carers to have access to my EoL preferences prior to undertaking any of my care.

**Acceptance Criteria**

* Carers ***must*** have access to the EoL preferences at my place of residence.
* Carers ***must*** have access to the EoL preferences when undertaking care planning.

## National Reporting – death in preferred place

In order that the benefits of integrated EPaCCS and the quality of EoL care can be better measured

As a nationally-based EoL professional

I want national reporting to show the incidence of people dying in their preferred place of death.

**Acceptance Criteria**

* Data ***must*** be capable of being split across time bands eg. monthly and yearly figures based upon the date of death of the patient.
* Data ***must*** be capable of being split across geographic and organisational boundaries.
* Data ***must*** show totals of preferred place of death vs. actual place of death.
* Data ***should*** be capable of reporting counts by the reason for variance where the actual place of death does not match the preferred place of death.

## National Reporting – treatment in preferred place of care

In order that the benefits of integrated EPaCCS and the quality of EoL care can be better measured

As a nationally-based EoL professional

I want national reporting to show the incidence of people being cared for in their preferred place.

**Commentary**

This is a requirement from Professor Bee Wee. It is unclear how the data can be successfully collected to make the reporting meaningful.

**Acceptance Criteria**

* Data ***must*** be capable of being split across time bands eg. monthly and yearly figures based upon the date of death of the patient.
* Data ***must*** be capable of being split across geographic and organisational boundaries
* Data ***must*** show preferred place of care vs. actual place of care.

## National Reporting – three or more emergency admissions in final 90 days of life

In order that the benefits of integrated EPaCCS and the quality of EoL care can be better measured

As a nationally-based EoL professional

I want national reporting to show the incidence of people with three or more emergency admissions in the last 90 days of life.

**Commentary**

This is a requirement from Professor Bee Wee. This is data that will be collected from other urgent and emergency care data collections. It is probably out of scope for this current piece of work.

## National Reporting – days in hospital in final 90 days of life

In order that the benefits of integrated EPaCCS and the quality of EoL care can be better measured

As a nationally-based EoL professional

I want national reporting to show data for number of days people are spending in hospital during their final 90 days of life.

**Commentary**

This is a requirement from Professor Bee Wee. This is data that will be collected from other urgent and emergency care data collections. It is probably out of scope for this current piece of work.

## National Reporting – when EoL care plan was recorded

In order that the benefits of integrated EPaCCS and the quality of EoL care can be better measured

As a nationally-based EoL professional

I want national reporting to show data for when an EoL care plan was recorded and whether the person consented to sharing of this data.

**Commentary**

This is a requirement from Professor Bee Wee. Further investigation needed to understand how this data can be extracted. However, likely that the minimum dataset will include enough data to make this a deliverable requirement.

**Acceptance Criteria**

* Data ***must*** be capable of being split across time bands eg. monthly and yearly figures based upon the date of death of the patient.
* Data ***must*** be capable of being split across geographic and organisational boundaries.
* Data ***must*** be capable of being split across the patient’s primary diagnosis.

# Appendix A - Types of Personalised Planning Documents

There a several different documents that can be produced for advance care planning. This non-exhaustive list brings together some of the common ones.

## ADRT (Advance Decision to Refuse Treatment, Advance Decision, Living Will)

An ADRT is a **legal document** that people in England & Wales can complete to refuse treatment that they don’t want to receive.

The treatments to be refused **must all be named** in the advance decision. Patients may want to refuse a treatment in some situations, but not in others. If this is the case, they must be clear about all the circumstances in which they want to refuse this treatment.

If it is completed according to the Mental Capacity Act 2005 it is legally binding on anyone who knows about it and who can be confident that it is valid and applicable to the situation that they are dealing with. If you would like to find out more about ADRTs, or make one for free, you can do so at [www.mydecisions.org.uk](https://hscic365-my.sharepoint.com/personal/jowi54_hscic_gov_uk/Documents/End%20of%20Life%20Care/www.mydecisions.org.uk).

## PCP (Personalised, Advance or Anticipatory Care Plan, Advance Statement)

A PCP is made with people who are able and willing to think ahead to a time in their illness when they may be unable to express their preferences. A PCP document is not restricted to planning for an emergency and is likely to contain information about preferences.

The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the capacity to make decisions or to communicate them.

An Advance Statement can cover any aspect of your future health or social care, including:

* how you want any religious or spiritual beliefs you hold to be reflected in your care
* where you would like to be cared for – for example, at home or in a hospital, a nursing home, or a hospice
* how you like to do things – for example, if you prefer a shower instead of a bath, or like to sleep with the light on
* concerns about practical issues – for example, who will look after your dog if you become ill

## CYPACP (Child and Young Person Advance Care Plan)

Special PCP/ACP for child or young person

## PPC (Preferred Priorities for Care, a form of Advance Statement)

Designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life. Elements of a PPC can include:

* People who should be asked about your care if you are not able to make a decision for yourself – those with Lasting Power of Attorney or otherwise: Name, Address, telephone, relationship
* Your preferences and priorities in relation to your health, what has been happening to you?
* What are your preferences and priorities for your future care?
* Where would you like to be cared for in the future?
* Further information - a note of any further information required or questions for professional carers - doctor, nurse or social worker.
* Contact details - contact details for anyone involved in your care: Name, Relationship, Contact number
* Signature, Date – and also sign and date any changes

The PPC is not a legal document but it is covered by the Mental Capacity Act (2005). So if you reach a point where you cannot make a decision about your care, what you have written in the document has to be taken into account by those that care for you.

## EoL Care Plan

End-of-life care plans record a person’s individual care and treatment needs as they approach the end of their life, and are not limited to recommendations for use in an emergency.

## ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)

Paper form - one copy held by the patient

A ReSPECT form is not legally binding and focuses only on making recommendations about care and treatment that might be considered in an emergency, when a person’s life may be at risk. A ReSPECT form can be used to draw attention to the presence of an ADRT and should contain relevant aspects within the summary recommendations for treatment and care.

A ReSPECT form is a very specific type of PCP that summarises the emergency care aspect of a wider Personalised, Advance or Anticipatory Care planning process.

The ReSPECT documentation proposes that the ReSPECT form could replace DNACPR and TEP forms (below).

When healthcare communities implement the ReSPECT process there must be a robust plan to ensure that existing DNACPR forms or TEPs remain valid for a substantial period of overlap. ReSPECT, at the present time, is not a replacement for a DNACPR form; the aim is to promote recording an emergency care plan by many more people, including many whose ReSPECT forms will recommend active treatment, including attempted CPR if it should be needed

## DNACPR (Do Not Attempt CPR)

This is a decision not to attempt CPR, made and recorded in advance, to guide those present if a person subsequently suffers sudden cardiac arrest or dies.

A DNACPR decision may be made and recorded:

* At the request of the person themselves
* As a shared decision (made by the person themselves and their doctor and/or other healthcare team members) that the likelihood of CPR being beneficial in their current situation would not outweigh the potential burdens and risks of receiving attempted CPR
* By the healthcare team, because CPR should not be offered to a person who is dying from an advanced and irreversible condition and therefore CPR will not prevent their death
* By the healthcare team because the person themselves is not able to contribute to a shared decision and a decision has to be made in their best interests.

If a person is unable to contribute to making the decision (for example because they are unconscious, severely demented, or too severely ill to participate in the discussion) the decision will be made by the senior clinician responsible for their care, whenever possible after taking advice from those close to the person, such as family members. However, family members are not expected to or entitled to make the decision unless they have been given legal power (e.g. Power of Attorney) to make such decisions on the person’s behalf.

The decision is usually recorded on a specific CPR decision form, so that it can be recognised quickly, and its content assessed very quickly by those who may need it to guide their decisions and actions in an emergency situation. Increasingly such forms are designed and used to allow recording of a decision that attempted CPR is still appropriate as well as a DNACPR decision, and to allow recording of decisions about other life-sustaining treatments that may or may not be wanted by or effective for the person.

## TEP (Treatment Escalation Plan)

Treatment escalation planning is a mechanism for planning the care of a patient at risk of deteriorating. It is part of overall personalised care planning and the TEP documents the considered ceiling of care which governs the limits of treatment in the event of a patient deteriorating.

# Appendix B - Current Standards and Datasets

## Comparison between datasets

A comparison document has been produced by the SCR team showing the compatibility between the SCCI 1580 standard and what SCR AI can provide. This comparison has been further extended to include the LHCIE consolidated dataset.

## SCCI 1580 Standard

The standard is available [here](http://content.digital.nhs.uk/isce/publication/SCCI1580).

## LHCIE Consolidated Dataset

The consolidated dataset was produced in mid 2017, bringing together what was known at the time as part of the London programme.



## PRSB Crisis Care Headings

These heading were published in January 2017 after extensive consultation during 2016. It forms a basis upon which the LHCIE consolidated dataset was created.

The standard can be found [here](https://theprsb.org/publications/crisis-care-standard).

# Appendix C – Options Appraisal

1) Every person, who requires one, has a personalised care plan, including their own personal preferences.

2) Clinical staff, working for that person, all have access to the personalised care plan to enable them to make changes to that plan as and when it becomes necessary.

3) The person, or their carers, have access to the plan and can make changes to their preferences when they see fit.

4) Clinical staff in urgent and emergency care (and other settings) are warned of the presence of a plan and preferences, and can quickly view that information, prior to and during any episode of care.

|  | **Every person has a personalised care plan/preferences.** | **Clinical staff have access to enter/amend the plan/preferences.** | **Patient/carers have access to the plan/preferences.** | **Urgent and emergency care access to plans and preferences** |
| --- | --- | --- | --- | --- |
| Advance rollout of SCR AI | GPs are being incentivised to have more conversations with patients about EoL preferences. This includes patient with frailty index scores that indicate these conversations should be undertaken. | Only staff with access to the GP record can make direct changes that are uploaded to the SCR AI. Other standalone EPaCCS cannot upload directly to SCR AI and so there must be rekeying. | No impact. | SCR AI is already in place. U&EC users can have access as long as GPs/patients have agreed to share the data. |
| Produce national dataset | Will help to inform nationally what constitutes a minimum dataset for a patient’s plan/preferences. | Acts as an enabler to drive standardised sharing of data between locations that record EPaCCS data. | Acts as an enabler for the NHS Online Programme. Drives out definition of exactly what data must be provided to the patient and what data may be amended by the patient. | Provides a minimum requirement for display of data for U&EC users.  Informs follow-on work to highlight how data will be grouped and managed on display to time-pressed U&EC users. |
| National FHIR standard | More opportunities for patients to discuss and have recorded their preferences. | Clinical staff to record EoL preferences on any host system, safe in the knowledge that it will be transferred to other systems without rekeying. | FHIR standards can be used by the NHS Online Programme as basis for data sharing with patient applications. | U&EC systems can integrate with EPaCCS using the national standards.  SCR AI will be even better completed as all standalone EPaCCS can now automatically update GP systems and hence the SCR. |
| National flagging of GP system data | No impact. | No impact. | No impact. | Much improved safety and efficiency when dealing with patients with EoL preferences. |
| Patient Access to Preferences (NHS Online Programme) | Patients and their carers can commence the process prior to discussions with clinicians. | Prior completion of forms can speed the process with clinicians and help the patient/carer to have already completed much of their decision-making. | Patients and carers can be assured that the NHS holds their correct plans/preferences, by seeing those agreed plans being reflected in their view of the data.  Some changes, that do not require complex clinical conversations can quickly be changed. | No direct impact.  Patients/carers are further informed of what data the NHS holds about their preferences and can better direct U&EC staff in supporting those preferences. |
| National analysis of EoL preferences and performance | National reporting can show take-up by patients and drive resources to those areas where fewer patients appear to be having the opportunity to record their preferences. | National reporting can drive resources to those areas where fewer patients appear to be having the opportunity to record their preferences. | National reporting can drive resources to those areas where fewer patients appear to be having the opportunity to view their preferences. | National reporting can drive resources to those areas where U&EC continue to have poorer access to EoL plans and preferences.  National reporting will also indicate whether the recorded preferences have been acted upon by U&EC clinicians at around the time of death. |