Report to Health and Community Care Scrutiny Committee 21st November 2012

Report of: **Chief Operating Officer, NHS Sheffield**

Subject: Update on progress towards achieving an increase in preferred place of death for Sheffield residents

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Summary:
A vast proportion of the population wishes to die at home or in their care homes, however, we know that both nationally and locally, the majority of people continue to die in hospital. This report sets out the progress made in Sheffield over the last year to improve the quality of End of Life Care and to increase the number of people who are able to die in their preferred place. This report has been requested by the Committee to update it on progress and to enable it to note the ongoing and planned actions to further increase the number of people who achieve their preference.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	
Informing the development of new policy	
Statutory consultation	
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Community Assembly request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	√
Other	

The Scrutiny Committee is being asked to:
Note this report.

Category of Report: OPEN/~~CLOSED~~ (please specify)

Report of the Chief Operating Officer, NHS Sheffield
Update on Progress towards achieving an increase in preferred place of death for Sheffield residents

1. Introduction

1.1 End of Life Care (EOLC) has been defined by the Department of Health as encompassing all with advanced, progressive, incurable illness, in all settings, in the last year of life, and includes patients, carers and family members (including bereavement care)[1]. Research has concluded that 63% of people in Yorkshire want to die at home[2], although in 2008-10 57% of deaths in Sheffield occurred in hospital. This is significantly higher than the England average of 54.5%[3] of deaths occurring in hospital.

1.2 NHS Sheffield and EOLC providers (including Sheffield Teaching Hospitals NHS Foundation Trust and St Luke's Hospice) across the city have been working to increase the number of patients who die at home by addressing issues raised in the National[4] and Sheffield[5] EOLC Strategies. This paper provides an update on actions taken over the last year and those currently being planned. It also outlines the actual and expected impact of these actions on Sheffield's drive to increase achievement of preferred place of death.

2. Background

2.1 In November 2011 a paper entitled 'Achieving an increase in preferred place of death for Sheffield residents' was submitted to the Committee. This outlined the initial phase of a project to increase the support available to enable patients to die at home/care home. At that point, a Clinical Working Group had identified a number of barriers to achieving a good quality death at home/in a care home and was in the process of prioritising these and proposing high level actions to address them.

2.2 This phase of work was completed and approved by the Adult Transforming Community Services Partnership Board in January 2012 and the focus transferred to implementing solutions to remove/reduce the barriers. Non recurrent funding was obtained from both St Luke's Hospice and Macmillan Cancer Support to support implementation of some of the necessary actions.

2.3 The prioritised list of barriers, the actions taken and planned plus the expected/actual impact of these are summarised in Appendix 1. Most of the barriers require an interrelated mix of cultural, behavioural and process changes as well as improvements in knowledge and skills. Addressing any one of these areas won't in itself, reduce or remove the barrier. The actions taken and planned are presented quite simplistically in Appendix 1, but in reality the actions are being managed as part of an overarching system wide improvement plan.

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[1] Department of Health, Working Paper on End of Life Care, 2007

[2] [2] Gomes B et al, Local preferences and place of death in regions within England, Cicely Saunders International, 2011

[3] 2008-10 data, National End of Life Care Intelligence Network atlas available at http://www.endoflifecare-intelligence.org.uk/profiles/Place_of_Death/atlas.html

[4] Department of Health, National End of Life Care Strategy, 2008

[5] NHS Sheffield, Sheffield's End of Life Care Strategy, 2008

2.4 Two of the lynchpins of this plan are a new EOL Home Care model and the recently developed Sheffield Electronic Palliative Care Communicating System (EPCCS). The next section focuses on the progress made with these two specific areas of the project.

3 New EOLC Home Care Model and EPCCS

3.1 The barrier identified as the highest priority for action in order to increase the number of people who die in their preferred place of care was the lack of capacity and inequitable access to home care support. There is currently a range of health and social care providers who deliver similar care, but in different ways with different access criteria at different points, in the patient's last year of life. As a result, a new model for generic EOL domiciliary care has now been developed by health and social care commissioners and provider representatives.

3.2 The aim of this generic model is to meet both the patients' health and social care needs relating to their end of life care and to support their family carers' wellbeing to enable them to continue caring for the patient during their last year of life. The basic principles of the model are outlined in Appendix 2, these have been derived from the feedback obtained through the 2011 EOLC patient and public consultation.

3.3 A business case for the model, which is currently being developed, is predicated on the premise that the model combined with all of the other system wide improvements will reduce avoidable hospital admissions in the last year of life. This will fund the necessary increase in capacity and free social care to support patients who wish to die at home.

3.4 An outline business case will be submitted to NHS Sheffield for approval in December 2012. The case will also be submitted to Sheffield City Council and it is anticipated that this will progress through the system for Cabinet approval in March 2013. A consultation with existing and potential providers is planned for January 2013. Assuming there are no material changes to the business case as a result and approval is granted by both Commissioners, the de- and re-commissioning process for the new model will be able to start in April 2013. It is envisaged that the new model will 'go live' in October 2013.

3.4 As indicated earlier, the introduction of the new home care model by itself will not automatically increase the number of deaths at home. Clinicians also need to identify patients who are in their last year of life, ascertain that the patient wishes to die at home and ensure that their care is tailored to this end. One of the key enablers for all of these actions is the Sheffield EPCCS.

3.5 The Sheffield EPCCS, which was developed as a response to a DH requirement for locality wide End of Life Care registers, aims to facilitate the following objectives:

- identification of patients in their last year of life
- act as a prompt to assess and advanced care plan for this group of patients
- increase communication (both between professionals and patients/carers and between secondary and primary care professionals)
- prompt a change in behaviour and culture amongst secondary care clinicians (recognising when a plan for active treatment may no longer be the most appropriate focus of care).

3.6 A pilot of the EPCCS commenced in November 2011 and enables Secondary Care teams who have identified patients who are in their last year of life to communicate information regarding the patient's understanding of their diagnosis, prognosis and aims of treatment, key workers, Foci of care (summary term for aims of treatment) and management plan recommendations to the patient's GP.

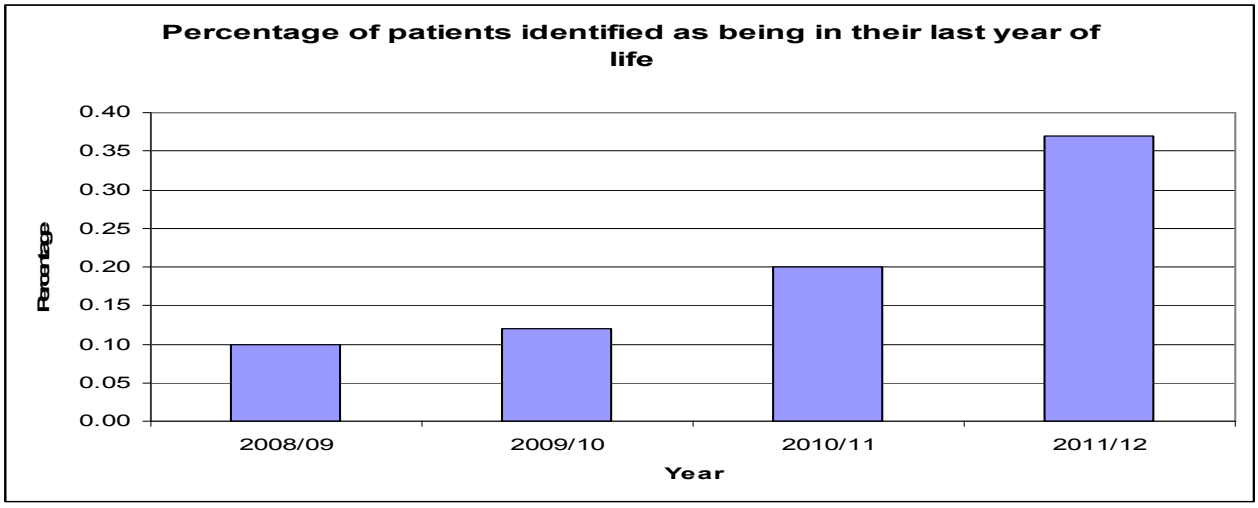
3.7 To date, information on over 1000 patients has been shared through EPCCS and both primary and secondary care clinicians are providing very positive feedback about the usefulness of the information and prompts provided. A formal evaluation of the system is about to commence, and assuming this supports the feedback, it is anticipated that EPCCS will be mainstreamed from April 2013.

4. Assessing the impact on the quality of EOLC

4.1 The Sheffield EOLC Planning and Commissioning Group has agreed four overarching outcome measures to enable the city to chart the impact of its progress with this system wide project. These are

- Percentage of patients identified as being in their last year of life
- Number/proportion of deaths in usual place of residence
- Families/carers feel that everything was done to meet the person's needs and preferences during the last days of life, as far as possible
- Number/proportion of individuals who die in their preferred place

4.2 The graph below indicates the significant increase in patients who are being identified as being in their last year of life from 2010/11 to 2011/12. This is a direct result of actions such as the introduction of the EOLC Facilitation Team and EPCCS.



4.3 The table below describes the percentage of deaths in each place. Usual place of residence is considered to comprise of both deaths at home and in a care home.

	Home	Care Home	**Usual Place**	Hospital	Hospice	Other
2008-10	18.5	17.5	**36**	57	5	2
2011/12	19.2	18.2	**37.4**	57.8	4.1	0.7

Whilst the data for 2011/12 is only a 1 year snapshot, it does indicate a small improvement in achievement of death in usual place. It is anticipated that when the data for 2009-11 is released later this year, it will support this snapshot.

4.4 Information of whether families/carers feel that everything was done to meet the person's needs and preferences during the last days of life has been collected for the first time this year as part of the national VOICES survey. Unfortunately the data was only published at Cluster level, however the survey is currently being repeated and it is anticipated that the results of both surveys will be published at Clinical Commissioning Group level next year. This will enable Sheffield to establish a clear baseline from which to measure itself against.

4.5 The number/proportion of individuals who die in their preferred place is not something that has been historically collected, either in Sheffield or nationally. However, the development and introduction of the GP EOLC clinical templates will now facilitate this and it is expected that baseline data will be available early next financial year for this measure.

5. What does this mean for the people of Sheffield?

5.1 The progress made over the last year and that planned for the rest of this year will make it easier for patients who wish to die at home or in their care home to achieve their wish. Implementation of the actions has started to generate and will continue to build:

- Greater achievement of preferred place of death
- An increase in the number of patients who receive a clear prognosis regarding their condition and make informed choices regarding their priorities for care and death
- An increase in patient's quality of life leading up to death, particularly in relation to service signposting, improved symptom control and dignity
- An increase in family carers' quality of life leading up to death, through increased carer support and service signposting
- An improvement in family carers' experience of their relative's death and subsequent potential reduction in complex bereavement issues

6. Conclusion

6.1 A wide ranging number of actions have been implemented over the last year to improve the quality of care for patients and their carers in the last year of life. Several of the barriers have yet to be addressed, but the project is planning to focus on these over the next six to twelve months. Early quantitative indications and anecdotal feedback indicate that these are beginning to have the desired impact and it is envisaged that these will be supported by evidence of a significant shift in place of death and improved quality of care over the next eighteen months.

7. Recommendation

7.1 The Committee is asked to note this report.

Appendix 1 **Actions Taken to Address Prioritised Problems**

Theme	Issue	Action Taken	Actions Planned	(*Expected*) Impact
Home Care	Capacity and availability issues: • Insufficient capacity within the Intensive Home Nursing Service • Inequitable access to different levels of home care support • Insufficient care home staff with EOLC knowledge • Delays in Continuing Health Care assessments/placements • Input of social care packages within short timescales challenging	• Clinical Working Group reviewed current service models and redesigned one generic model for all domiciliary EOLC • See actions taken to address variation in management of care home patients for issue relating to knowledge of care home staff	• Business Case for new home care model to be submitted for NHS Sheffield and Sheffield City Council approval in Dec 12, with view to new service model in place Oct 13	• *Equitable model of care for all patients with increased capacity and improved responsiveness*
Generalist (Primary) Care	Variation in management of EOLC patients across Primary Care: • Poor multidisciplinary team working in some practices • Not all EOLC patients identified on registers • Not all identified patients are assessed and managed appropriately • Lack of/poor communication with patients and carers regarding prognosis and choices available • Variation in access to case managers and community matrons by residential home patients • Inappropriate referrals for Continuing Health Care Fast Track funding	• Discuss with individual practices as part of facilitation team visits • 2011/12 Clinical Facilitation visits to all GP practices focused on increasing identification of patients in last year of life • 2012/13 Clinical Facilitation visits focusing on appropriate, multidisciplinary assessment and management of patients • EOLC clinical templates for GP practice systems developed and implemented • Communications training for 160 healthcare professionals established to improve quality and quantity of discussion regarding prognosis and choices • Protected Learning Initiative event held on EOLC for 200 GPs Sept 12	• Significant additional training planned for all GP practices on Advanced Care Planning • Fast Track team developing clarified criteria for referral	• Prevalence of patients on GP EOLC registers increased from 0.2% in 2010/11 to 0.37% in 2011/12 • 2/3rds of GPs who attended and evaluated PLI event said they would alter their practice as a result of attending
Specialist Condition Care Teams	• Variation in discharge support for EOLC patients which affects speed with which they are discharged and inappropriate referrals for Continuing Health Care Fast Track funding		• Fast Track team developing clarified criteria for referral • In the longer term, consider need for rapid discharge process	• *Improved speed of discharge and increased likelihood of dying at home/care home*
Specialist Condition Care	Variation in management of EOLC patients across Specialist Condition Teams – Inpatient, Outpatient and Community:	• EPCCS developed and 1000 patients entered onto EPCCS since Nov 11 (provides primary care with info on	• Further development of EPCCS to link to the Summary Care Record,	• Early indications suggest that EPCCS prompts a change in focus of

Teams	• Not all patients are identified when entering EOLC phase of condition • Lack of/poor communication with patients and carers regarding prognosis and choices available • Insufficient clarity over how care shared with Specialist Palliative Care Team and Primary Care • A change in the focus of treatment (from active to palliative) not routinely considered for EOLC patients • Variation in commencement/usage of EOLC advanced care plans • Lack of alternatives to inpatient management for some groups of patients • Variation in Specialist Condition Team management of patients within care homes • Variation in Specialist Condition Care Team input/development of advanced care plans • Use of EOLC pathway – patients put on too early or too late	patients's care plan including focus of treatment) • Evaluation of EPCCS currently being undertaken • Communications training for 160 healthcare professionals established to improve quality and quantity of discussion regarding prognosis and choices • New specifications have included an EOLC focus • Additional investment in EOLC Pathway Facilitator to improve appropriate usage of EOLC pathway • Specialist Palliative Care Team developing a strategy for EOLC within Secondary care	ensure provision of relevant information in A&E/MAU and roll out to more Specialist Condition Teams • Implementation of the AMBER care bundle (identifies patients' whose recovery is uncertain and prompts appropriate care/management) • Significant additional training planned for Secondary and Community Care on Advanced Care Planning	treatment and increased/improved discussion with patients • Improved communication and clarity between secondary and primary care and within secondary care • *Increase in number of EOLC discussions with patients/families and improved quality* • *Improved quality of care in last few days of life through EOLC Pathway* • *Good quality management of patients in their last year of life undertaken routinely by all Specialist Condition Teams*
Equipment	• Access to equipment at short notice to enable the patient to stay at/be discharged home (standard is 2 days from urgent request to delivery and 5 days for routine delivery) • Increased education on how to use the equipment and improved risk assessment and assessments of need for equipment		• Explore routine access to slide sheets, pads and urinals/bed pans/commodes for community nurses, carers and care homes • Consider need to increase number of beds and hoists at Sheffield Community Equipment Library Service • Consider adding to Last Offices Checklist and asking original referrers to contact SCELs • Improve estimated date of inpatient discharge and	• *Improved, timely provision of equipment for patients at home*

			advanced care planning •	

Medication	Access to medication for patients at home
	• Delays in GP Collaborative obtaining emergency supplies of drugs 10pm – 7am
	• Collection of drugs at weekends/bank holidays (knowledge of which pharmacies with stock open/when, distance to an open pharmacy, leaving dying relative alone etc)
	• Administration of drugs (availability, training and confidence of nursing staff)
	• GP awareness of new formulary
	• Difficulties accessing specialist medications
		• Agreed a standard palliative care stock list for pharmacists and 4 Pharmacies with extended opening hours now hold this
		• Details of these pharmacies publicised on EOLC GP templates
		  • Protected Learning Initiative event held focused on prescribing
		  •
		  • 2012/13 Clinical Facilitation visits focusing on appropriate, multidisciplinary assessment and management of patients including pre-emptive prescribing
		• Raised awareness of new formulary within primary care and developed guidelines for particular drugs
			• Details of the pharmacies holding stock to be put onto Sheffield EOLC website	• Improved access to drugs in pharmacies, and at weekends/bank holidays, particularly in the north of the city
				• *Reduction in requests for GP Collaborative to prescribe/provide drugs through increase in pre-emptive prescribing*

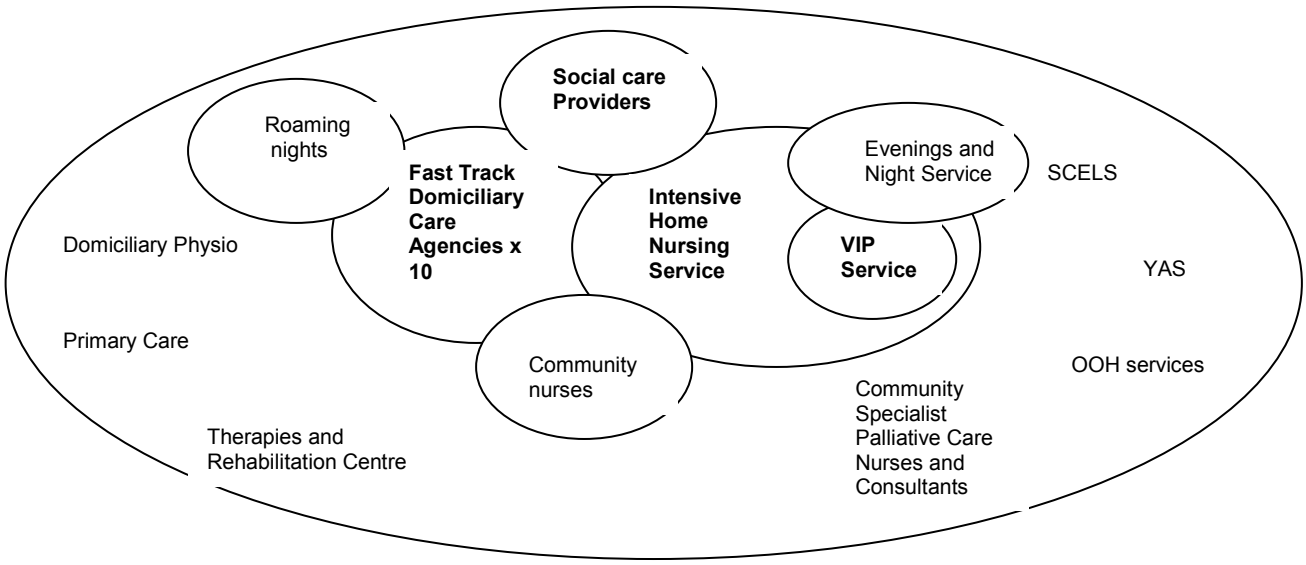
Home Care	Variation in management of EOLC patients in care homes: • Different values, cultures and competencies across different groups of staff • Lack of adequate communication and handovers between staff and with GPs • Communication of prognosis with relatives of care home patients	• EOLC prioritised by Care Home Support Team for 2012/13 • 2 Care Home EOLC Facilitators and an additional Community Specialist Palliative Care Nurse for Care Homes appointed (1 year contracts) • Skills for Care EOLC training for care home managers and staff in place • Network arrangements for care home managers and staff revised and improved • EOLC Care planning information for Care Home GPs revised and improved	•	• *Staff with increased knowledge, understanding and confidence regarding EOLC management* • *Increased communication and discussion of EOLC with patients/families* • 25 Care Homes currently undertaking Skills for Care training
Other needs	Unable to find suitable place of care for 'young' pts whose needs are predominantly nursing rather than Specialist Palliative Care	• MND Stakeholder group considering what the needs of this group of patients are		• *Better understanding of actual needs to inform appropriate commissioning of services*

Appendix 2 Current versus New Model for EOL Home Care

Current Situation
Average number of deaths in Sheffield per year (based on 2008-10 data)

	Hospital	Home	Care Home	Hospice	Other
Percentage	**57**	**18.5**	**17.5**	**5**	**2**
Number	**2832**	**919**	**869**	**248**	**99**

Current Services



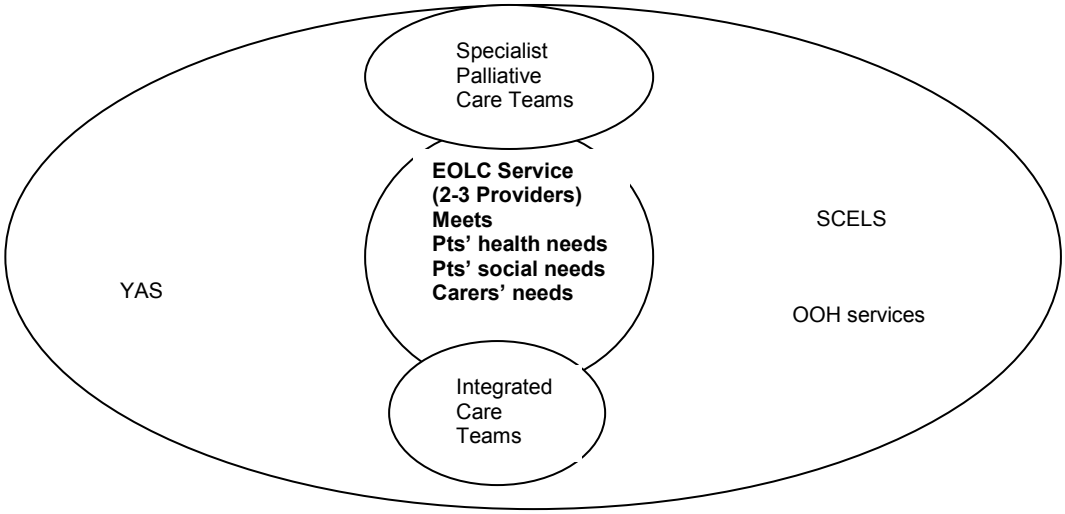
- Only 40% of patients who die each year are identified as being in their last year of life (75% of deaths are predictable). A large proportion of patients may either be accessing support that could be tailored more appropriately to their EOL needs or are not accessing any home care support
- Some patients receive a visiting service, some receive a sitting service and some receive a combination of both. This is based largely on which service the patient is referred to, the capacity of the sitting service and how these services are commissioned rather than on the needs of the patient
- There is minimal provision of EOL home care in the first 9 months of the last year of life, as a result patients are often admitted to hospital because of carer breakdown or crises which could be managed at home if additional support were available
- The needs of family carers in relation to supporting their loved one's wish to be cared for or die at home are not addressed (see above)
- Overlap/potential duplication between health and social care provision – most of the tasks undertaken by health providers support activities of daily living
- People with social care packages are means tested and may have to pay for care. Health care packages are free. Were more people identified as being in the last year of life, their care may transfer from social to health and therefore become free
- Current commissioning arrangements constrain some providers from meeting the patient/family carers needs e.g. health providers cannot meet family carer needs even if this means the patient is kept out of/discharged from hospital
- There is inequity of provision of EOL support to patients in care homes (particularly residential) and their own homes.

New Model

Ambitious average number of deaths in Sheffield per year (2013 onwards)

	Hospital	Home	Care Home	Hospice	Other
Percentage	**30**	**38**	**25**	**5**	**2**
Number	**1490**	**1888**	**1242**	**248**	**99**

New Service



Principles of New Model

- The model will provide practical care, reassurance, support, co-ordination and signposting to service users and their families
- The level and type of care will flex up and down based on their needs, not their length of prognosis
- The service is free to all on the basis that inability/refusal to pay will ultimately incur additional cost to the system (although the implications of this decision will be subject to detailed financial and risk modelling).
- The service will be provided by dedicated support workers who have additional skills and competencies relating to End of Life Care. It will also be expected to utilise (or sub contract) trained volunteers to support some aspects of provision.
- Each family will be allocated a consistent team of staff who will need to work in an integrated and collaborative manner with the Integrated Care Teams and (where necessary) members of the Specialist Palliative Care Teams in the city.
- In some circumstances, the service will act as an 'extra pair of hands with dedicated EOLC expertise' to an existing, long standing package of care and/or in the future to patients residing in residential and nursing homes in order to provide the additional EOL focused care whilst maintaining continuity with existing care providers.

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