



Public Health
England

Protecting and improving the nation's health

National End of Life Care Intelligence Network

Ambulance Data Project for End of Life Care

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Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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Foreword

I am delighted to see this report, the first of its kind to consider the data and information that is available, or could be used by ambulance services to support dying people.

Ambulance services play an important role in transferring people at the end of life to and from hospital, including urgent admissions, rapid discharges to enable people to spend their last days in the place of their choice and planned transfers between settings. Ambulance professionals may verify death and provide immediate support to the bereaved. They frequently are required to make very difficult and time critical decisions.

This publication reports on projects carried out by North West Ambulance Service and South East Coast Ambulance Service. The two projects used different approaches to gain more insight into the role of ambulance services and understanding of data for people who were transferred to or from hospital before death. The projects both found limitation of data that is available to understand patterns of ambulance use in end of life care.

The projects recommend a unified national data set across all ambulance trusts so that people who are approaching the end of life are better identified and their details communicated to the service. This important information will support ambulance professionals to make safe and appropriate care decisions.

Work has also been underway to develop professional guidance for the structure and content of ambulance records. The guidance, due to be published in December 2014, will improve the standard of ambulance records across the country and will provide opportunities to integrate ambulance records with hospital and primary care data.

The work of the two pilots has highlighted the important role that ambulance services play in supporting people and their families and carers at this time and has triggered a decision to add a new end of life care guideline to the next edition of the UK Ambulance Services Clinical Practice Guidelines, which will be produced by the Association of Ambulance Chief Executives (AACE) in 2015.

I hope that other ambulance trusts will read this report with interest and consider whether they wish to replicate elements of this project in their own areas to better understand and develop their role in supporting quality of end of life care.

Dr Fiona Moore, MBE
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The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National Cardiovascular Intelligence Network (NCVIN) analyses information and data and turns it into meaningful, timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

National Mental Health Intelligence Network

The National Mental Health Intelligence Network (NMHIN) is a single shared network in partnership with key stakeholder organisations. The network will seek to put information and intelligence into the hands of decision makers to improve mental health and wellbeing.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

Executive summary

Introduction

The eleven NHS ambulance trusts in England play a crucial part in delivery of high-quality care at the end of life, ensuring that patients receive timely and appropriate emergency care or transport and supporting patient choice regarding end of life care including resuscitation and place of death. The ambulance service is frequently called when there is a sudden deterioration or crisis in a dying person's condition and ambulance clinicians are often the first or only health professionals present at or soon after a death.

The North West Ambulance Service and the South East Coast Ambulance Service participated in a joint project with the National End of Life Care Intelligence Network (NEoLCIN) to explore the collection and use of ambulance data in supporting delivery of end of life care.

North West Ambulance Service Project

This project focused on evaluation of the rapid discharge and transfer of dying patients from a care facility to home or care home.

The project also assessed the impact of their local electronic palliative care co-ordination system (EPaCCS) on calls to the ambulance service.

A clinical audit assistant was employed for three months to support data and collection of rapid discharges and transfers from two hospital trusts in the North West region. Arrangements were made with the hospital trusts to enable sharing of information, which included an information sharing agreement and an honorary contract. The rapid discharges or transfers were identified from the hospital records and an extract of EPaCCS data was provided. The data was then matched with the North West Ambulance Service data for analysis.

South East Coast Ambulance Service Project

This project explored the hospital and ambulance service records of all patients who had been conveyed by ambulance to a local NHS Trust and died in hospital within 14 days of admission between January and September 2012 to determine whether the patients had been identified as being terminally ill or approaching the end of life. It also analysed the profiles of these patients.

North West Ambulance Service Results

A total of 62 patients were identified from the hospital sites during the audit period (1 April 2013 - 31 August 2013). It was difficult to identify rapid discharge patients from both hospital and ambulance records as neither system has a system of categorisation or marking these types of transfer. Therefore, it is expected that the total number of cases is under-represented in this report.

The target response time of two hours (time of booking the transfer to the arrival of the ambulance at the hospital) was achieved for 68.5% of requests. The average time that the ambulance service was at the hospital was 21 minutes.

The number of transfers varied by day of the week with 53% (32) of rapid discharges being carried out on Tuesdays and Wednesdays and only three transfers over the weekend.

Of the 62 cases, 74% had DNACPR documentation or other advance care planning in place at the point of discharge, but only eight had evidence of an agreed care plan in case death occurred during the ambulance transfer.

The majority of patients were discharged to a care home with a smaller number of transfers to a person's own home or a hospice.

The analysis investigated the reason for hospital admission (30% had respiratory problems), diagnosis (majority had cancer) and length of stay (average 18.6 days). The average time from hospital discharge to death was 25 days.

The North West Ambulance Service attended 53 of the 184 patients with an EPaCCS record during the study period (28.8%) of which 88.7% were conveyed to hospital. The most frequent reason for the ambulance call was following a fall or because of respiratory problems.

South East Coast Ambulance Service Results

Of the 414 patients that were conveyed to hospital by ambulance and who died within 14 days of admission:

- 75 (18%) were clearly identified in the medical record as being terminally ill or approaching the end of life
- 34 (8%) medical records indicated that the person may be terminally ill or approaching the end of life
- 260 (63%) medical records did not identify the person as being terminally ill or approaching the end of life

Comparing the profiles of the 75 people admitted to hospital via ambulance that had been identified as terminal or approaching the end of life with people not identified as terminally ill or approaching end of life showed that they were older (average 83 years compared to average 81 years). Out of the group of 75, 68.5% were admitted from home. There was a shorter period of hospital admission to death for this group (3.6 days compared to 4.8 days for those not identified). The most common diagnosis was respiratory conditions (28) and cancer (24). The most frequent cause of death for the 260 people not identified as terminally ill or approaching the end of life was respiratory diseases (78) and stroke (51). Only 10.7% of people identified as terminally ill had Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders recorded on the ambulance system.

Conclusions

Both projects found difficulty in identifying patients that were terminally ill, approaching the end of life or where a rapid discharge was requested. This is because identifiers are often not included in either ambulance or medical records. Not all people on the rapid discharge pathway had DNACPR orders in place nor did they have agreed plans for managing a death during transfer, which causes potential issues for ambulance staff making clinical decisions. The time from discharge to death (average 25 days) was longer than would have been expected, the pathway is intended for people with hours or days to live and suggests that more sensitive criteria may need to be developed.

Respiratory problems were the most common reason for hospital admission in both projects, suggesting that there may be a need for better planning or support systems to manage these patients at home. For those patients with an EPaCCS record, there was more evidence of end of life care planning being in place.

Recommendations

The development of an evidence-based End of Life Care Decision Support Tool is recommended to help ambulance clinicians to identify end of life patients, enable safer and appropriate care decisions and utilisation of clinical advice.

Improved, ongoing monitoring of rapid discharge pathways would be beneficial to ensure that the pathways are accessed for appropriate patients (those expected to die within days) and that they are effective. This will enable ambulance trusts to continue to provide a timely and high-quality service.

While it was recognised that the audit/data collection processes were time consuming, it would be beneficial for the audit (or some aspects of it) to be undertaken at a national level by all ambulance trusts. This could be taken forward through the National Ambulance Clinical Quality Group as part of their annual work programme.

It is recommended that opportunities are identified to present this report to all ambulance services and to link to promotional events for EPaCCS and other information sharing approaches.

Other ambulance services may wish to replicate elements of this project in their own areas to better understand and develop their role in supporting quality of end of life care.

1 Introduction

The National End of Life Care Intelligence Network (NEoLCIN) currently collects and analyses information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. No data is currently collected for the ambulance sector despite them having an integral role in many aspects of end of life care (EoLC). This project is the first attempt to capture data from ambulance services' information systems to explore what information is recorded and how this information can be utilised.

Ambulance services play a crucial part in the delivery of high-quality care at the end of life. Relatives or carers, including care homes, frequently call the ambulance service following a sudden deterioration or crisis in a dying person's condition. Ambulance staff may not have access to key information such as the individual's medical history or advance decisions to refuse cardiopulmonary resuscitation. Ambulance clinicians are often the first or only health professionals present at or soon after a death.

The End of Life Care Strategy (Department of Health 2008) recognised ambulance services' key role in EoLC in three important areas:

- rapid transfer of the dying
- developing appropriate transport for the person/carer
- developing robust information systems to ensure the wishes of the person (for example, DNACPRs) are communicated to ambulance services and staff

This reflected the key aim within the strategy to improve planning for end of life care so that it reflects the individual's needs and wishes, including preferences for where they receive their care and where they would like to die. The strategy also acknowledged that commissioners of ambulance services have a role in supporting improved care; to ensure patients receive timely and appropriate care or transport.

A guide called *The route to success in end of life care - achieving quality in ambulance services* (National End of Life Care Programme, 2012) highlighted how ambulance services could support more people in achieving 'a good death' and reduce unnecessary or unwanted hospital admissions and treatment. The publication aimed to provide guidance and support to ambulance services, commissioners and other providers on how to develop and improve the quality of care using the six steps of end of life care pathway model. It emphasised the need for much greater joint working and integration of services, including further education of ambulance staff.

A study in 2009 highlighted the importance of timely and appropriate ambulance transport in supporting patient choice around place of death (Ingleton et al, 2009). The importance of hospitals and ambulance trusts working together to develop protocols underpinned by responsive commissioning was also highlighted.

Finally, following the independent review of the Liverpool Care Pathway and publication of *More care, less pathway*, the Leadership Alliance for the Care of Dying People (LACDP) proposed a series of outcomes to improve care for this group of people and their families.

The outcomes include ensuring that:

- arrangements are in place to share key information about his/her care, treatment and preferences between professionals and service providers
- people in their last days of life experiencing ambulance transfers that are timely and prioritise their comfort and preferences. Ambulance staff should also know what to do if the situation changes unexpectedly
- professionals are competent in the specific requirements for excellent care in the last days of life

Currently, 11 NHS ambulance trusts in England provide emergency care to people with serious or life-threatening conditions. They also provide a range of other urgent and planned healthcare and transport services, including the provision of 111 services in some areas. Ambulance staff can include a range of clinical staff, such as care assistants, emergency medical technicians and paramedics.

In 2012/13, almost 9.1 million calls to ambulance services were recorded. Of these calls, 6.98 million (76.9%) resulted in the arrival of an emergency response at the scene of the incident.

Following publication of *The route to success* guide, and to explore the potential of ambulance data to support service improvement, the South East Coast Ambulance Service NHS Foundation Trust (SECamb) and North West Ambulance Service NHS Trust (NWAS) agreed to participate in a project to explore the collection and use of ambulance and hospital data to improve end of life care intelligence focusing on the three strategy areas above.

Patients 'approaching the end of life' are defined¹ as people likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

1.1 Project aim

To test the feasibility of identifying end of life care patients within ambulance services and/or other provider services.

To test methods for collecting and analysing ambulance service data in conjunction with other provider services, incorporating as a minimum, the three areas defined within the End of Life Care Strategy.

To assess subsequent intelligence (in terms of quality, volume and cost) created as a result of the data collection and analysis.

To agree data sets and collection/analysis for further consideration/testing on a wider/larger scale.

1.2 Project objectives

From hospital emergency admissions, identify patients who have died within a defined period of admission who were ambulance admissions. Of these patients, identify those whose hospital records indicate that they would be classed as end of life and investigate to see if the ambulance service was notified in advance (for example, address warning/flag request). Possibly, also investigate if any care planning was in place in the community.

Using the outcomes from point 1, try to develop a method for identifying suitable cohorts of comparable patients for any future analysis.

From ambulance data systems, identify addresses/patients who have end of life warning flags against them and investigate any ambulance attendances to analyse

¹ Treatment and care towards the end of life: good practice in decision making. General Medical Council. 2010.

incident type and outcome (for example, conveyed/not conveyed/referral made/diagnosed death etc).

Scope how feasible it would be to map death in usual place of residence to ambulance attendance and intervention.

From the above, analyse different care settings that ambulances attend such as care homes, private dwellings etc.

1.3 Project methodology

From hospital emergency admissions, identify patients, brought to hospital by ambulance, who died within a defined period of admission. Of these patients, identify those whose hospital records indicate that they would be classed as end of life and investigate to see if the ambulance service was notified in advance (for example, address warning/flag request). Possibly, also investigate if any care planning was in place in the community.

Using the outcomes from point 1, try to develop a method for identifying suitable cohorts of comparable patients for any future analysis.

From ambulance data systems, identify addresses/patients who have end of life warning flags against them and investigate any ambulance attendances to analyse incident type and outcome (for example, conveyed/not conveyed/referral made/diagnosed death etc).

Scope how feasible it would be to map death in usual place of residence to ambulance attendance and intervention.

From the above, analyse different care settings that ambulance attend such as care homes, private dwellings etc.

1.4 North West Ambulance Service

The North West Ambulance Service NHS Trust (NWAS) was established on 1 July 2006 following the merger of the Cumbria, Greater Manchester, Lancashire, Cheshire and Merseyside ambulance trusts.

The second largest ambulance trust in England, NWAS provides services to a population of around seven million people across a geographical area of approximately 5,400 square miles. The trust handles over 1.17 million emergency calls per year, with emergency crews attending more than 952,000 incidents each year, with around 800,000 of these requiring emergency transport. This represents approximately 16% of

national activity. The trust also undertakes more than 1.1 million non-emergency patient transport journeys each year.

The trust employs over 4,700 staff who operate from 117 sites across the region and provide services for patients in a combination of rural and urban communities, in coastal resorts, affluent areas and in some of the most deprived inner city areas in the country. Services are also provided to a significant transient population of tourists, students and commuters. The North West region is one of the most culturally diverse areas in England, with over 50 different languages spoken by members of the community. The primary area of focus for NWS was evaluation of the rapid transfer of the dying from hospitals. The study asks:

- is there a locally agreed response time for ambulance bookings
- if so, what is the ambulance service performance in relation to the agreed target
- does the ambulance service have a policy that ensures privacy and dignity, including the ability to enable relative/carers to travel with the patient

In addition, the impact of EPaCCS was also considered due to Salford CCG (formerly NHS Salford) being one of the national pilot sites. The study analysed ambulance calls and outcomes for people registered on the Salford EPaCCS. EPaCCS are electronic systems that provide a shared locality record for health and social care professionals. They allow rapid access, across care boundaries, to key information about an individual approaching the end of life, including their expressed preferences for care.

1.5 NWS policy review and data collection methodology

Being in control and having real choice about where to spend the last days and hours of your life is very important to people approaching the end of life. Getting this right can also have a lasting positive impact on their carers and families. NWS currently operates a rapid discharge and transfer procedure for end of life patients (appendix 1), which aims to provide an ambulance response within two hours for patients who meet the following criteria:

- I. Rapid Discharge Home - rapid discharge of EoLC patients, who are dying, from a care facility to home.
- II. Rapid Transfer to care facility - rapid transfer of EoLC patients, who are dying, to a care facility.
- III. Rapid Transfer Ongoing Care - rapid transfer of EoLC patients, who are symptomatic and require urgent care, and require on-going care and support during transfer.

The procedure is designed to enhance the communication process between NWS and external stakeholders by providing a single point of access for bookings that operates 24 hours a day, seven days a week. A dedicated call handling procedure is also in place to generate a two-hour response for the booked transport, which included the ability for people to receive updates on the progress of the booking or early warnings to be provided of any potential delays (hospital delays with the discharge or delayed ambulance due to increased 999 activity).

The procedure ensures an emergency service vehicle is provided for the transfer, to ensure the patient has privacy and relatives or carers can accompany them. The use of an emergency vehicle also ensures the ambulance staff are appropriately qualified to provide adequate comfort measures, manage complications and make appropriate decisions about resuscitation. Improving the handover process at the hospital (between ambulance and hospital staff) was also addressed in the procedure by specifying that a plan should be developed and agreed for what should happen if the patient began to die during transfer. This included ensuring the relatives and carers were fully aware of any plans.

Following some successful initial pilot work, NWS has continued to work closely with hospitals and hospices across the North West to support the development of rapid discharge pathways. Utilisation of the rapid discharge pathway for dying patients has increased significantly during 2013/14, with 38 hospital trusts and ten hospices now using the booking process. Of the 543 transfer requests that could be identified on the trust call handling system (April 2013 to August 2013), over 90% were responded to within two hours, with 87% transferred home within two hours from the time of booking.

NWS has worked with a large number of acute hospital trusts and hospices across the North West to implement the rapid discharge procedures. Ten of these sites were invited to participate in the project. However, only two hospitals were eventually able to participate. The main reasons for not being able to participate were lack of resource within hospitals to support data collection and concerns about sharing information and the associated information governance risks.

Of the two hospital sites that did agree to participate, one hospital operated a paper-free, electronic clinical record system and the other operated a paper-based patient record system.

NWS employed a clinical audit assistant for three months to support data collection and analysis.

Rapid discharges or transfers were identified from the hospital records. The hospital using the electronic record system provided a spreadsheet containing extracted data. The trust was required to sign an information sharing agreement prior to release of the

data. The clinical audit assistant visited the second hospital to review the identified paper-based patient records. The clinical audit assistant was required to sign an honorary contract (which covered information governance requirements) prior to accessing the clinical records. Both systems highlighted limitations in the retrospective collection of data; the electronic record system did not have all the required data as part of the record system and the paper records were poorly organised with a lack of information recorded.

EPaCCS are being rolled out across many areas in England. The electronic systems enable the recording and sharing of information about an individual at the end of their life, including their wishes and preferences for care. EPaCCS aims to improve the co-ordination of care and supports communication between the range of professional delivering end of life care. This information supports ambulance staff who often have access to minimal information about a person. EPaCCS information will prompt ambulance staff to review advance care planning documents when they are dealing with patients. This will change and improve their decision-making processes and subsequent care for patients. This might include a resuscitation decision, the provision of comfort measures, referral to another primary or community service to prevent an unnecessary hospital admission.

The EPaCCS data extract was provided as a spreadsheet following formal approval from the local EPaCCS project board and signing of an information sharing agreement.

All data was analysed using Microsoft Excel.

1.6 South East Coast Ambulance Service (SECAmb)

A list was obtained of all patients who had been conveyed by ambulance to a local NHS trust and died in hospital within 14 days of admission between January and September 2012. Because patient-identifiable data was required, an encrypted file was sent with assurances from SECAmb that the patient identifiable information would only be seen by two individuals within the trust. This list of 414 patients was then matched against the SECAmb record to identify if the patient had been clearly end of life at the time of the call. The staff who undertook this review had clinical backgrounds and attempted to identify all mentions in the record of any end of life planning or clinical signs that would indicate the patient was end of life at the time of the call. The patients were allocated to one of three groups:

Identified end of life care	<p>Patients whose medical records indicate that the person had been identified as being terminally ill or approaching the end of life.</p> <p>For cancer patients this normally meant a mention that the</p>
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	patient had been told they were terminally ill or a mention of metastatic disease and recent deterioration. For conditions such as chronic obstructive pulmonary disease (COPD) and dementia there was rarely a mention of palliation and the indication was usually based on the presenting signs and symptoms such as long term oxygen therapy and recurrent chest infections or recent reduction in cognitive state.
Queried end of life care	Patients whose medical records, although not explicit, indicated that they may have been identified as terminally ill or approaching the end of life.
Not identified end of life care	Patients whose medical records did not identify the person as terminally ill or approaching the end of life.

At the time of the project there was only one acute trust within SECamb's catchment with an established EPaCCS system. It was not possible to gain access to the required information from this trust.

2 Project results

2.1 NWAS results

To audit the rapid transfer of the dying pathways within the North West, NWAS identified two acute hospital trusts to share information with.

A total of 62 patients were identified from the two hospital sites during the audit period, with hospital records available for 56 of the patients. NWAS record systems were able to provide sufficient detail on the remaining six patients to allow their inclusion in the audit.

It should be noted that there were significant difficulties in identifying rapid discharge patients from within hospital and ambulance systems. Neither system currently has a method of categorising or marking these types of transfers. Therefore, it is expected that there are a greater number of rapid transfers completed than those contained within this report.

Ambulance transfer times

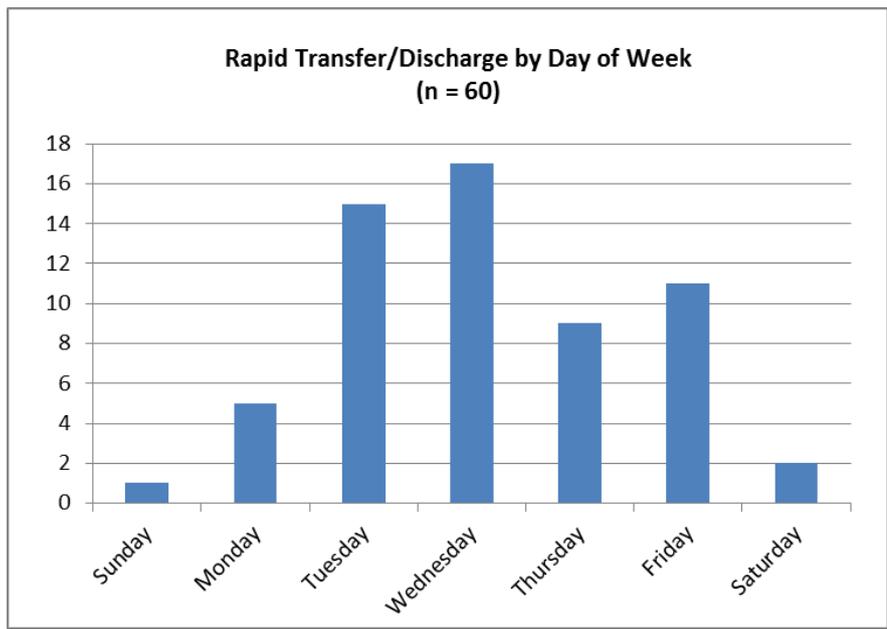
Of the 62 cases, 54 had response times recorded, with 68.5% of those cases (37) receiving a response within the agreed two-hour response time (the time the booking was made to the ambulance arriving at the hospital to start the transfer). The average response time was 1 hour 35 minutes (95% confidence interval \pm 22:32 minutes). The quickest response time was three minutes and the longest response time was 6 hours 53 minutes.

The average on scene time at hospital was 21 minutes (time ambulance arrives at discharging hospital to time ambulance leaves with patient).

The average transfer time from the ambulance being booked to the patient arriving at the agreed destination was 2 hours 17 minutes (95% confidence interval \pm 23:06 minutes). The quickest transfer time was 30 minutes and the longest response time was 7 hours 30 minutes.

The day of the week that rapid transfers were undertaken were also analysed. Data was available for 60 of the 62 records. Chart 1 below provides a summary. Tuesday and Wednesday were the most common days for rapid discharge with 53.3% occurring on these two days. There were only three transfers made over a weekend.

Chart 1: Rapid transfers or discharge by day of the week



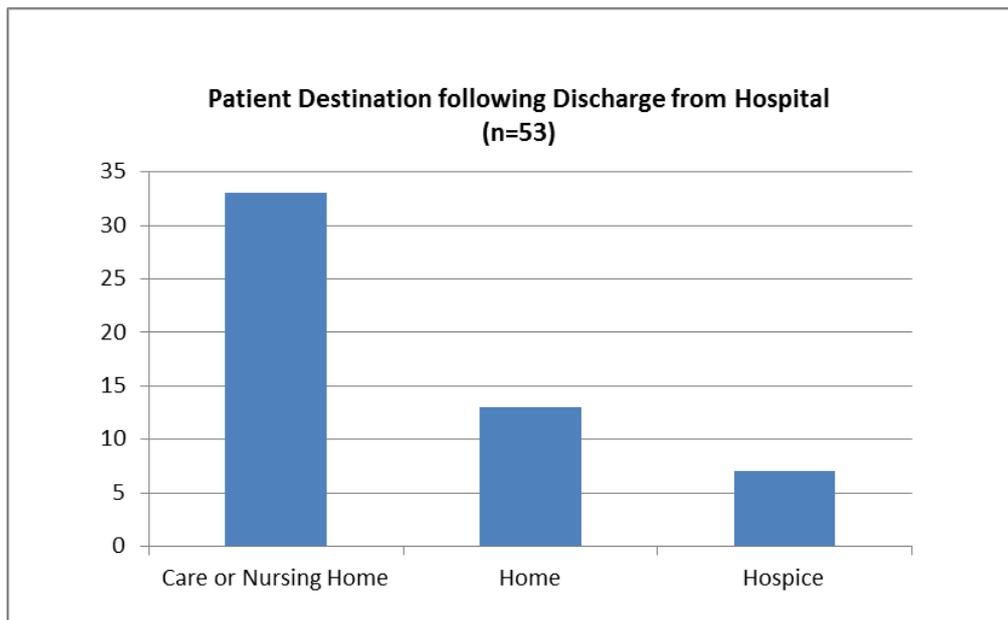
Care planning and documentation

Of the 62 cases, 74.2% had a DNACPR or other form of advance care planning in place at the point of discharge, which was recorded as being provided to ambulance staff at the point of discharge. A copy of the DNACPR form is provided for the transfer after the ambulance crew have viewed the original in the patient’s notes as part of the handover. Only eight cases had evidence of an agreed care plan documented in the discharge summary, in case death occurred during the ambulance transfer.

Transfer/discharge destinations

Chart 2 below provides a summary of the three destinations for patients following a rapid discharge from hospital. Of the 56 patients with hospital records that were available, 53 had the destination recorded.

Chart 2: Patient destination following discharge from hospital

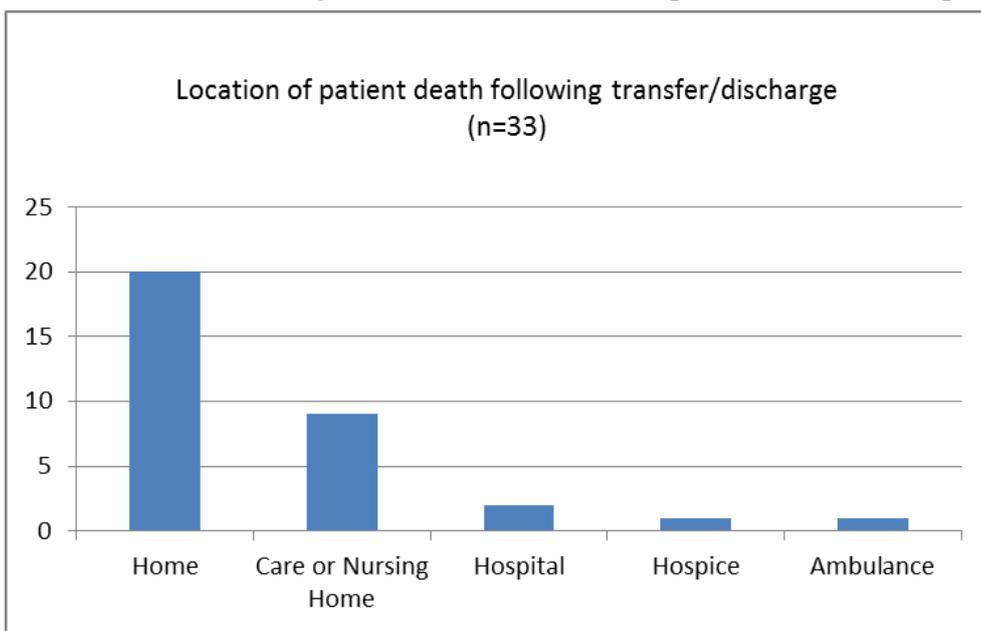


Out of the 53 patients that were transferred, 33 were transferred to a residential or nursing care home, 13 to their own home and seven to a hospice.

Place of death

The place of death was recorded in the hospital notes for 33 of the 62 cases. Chart 3 below provides a summary. Data was not available for the remaining 29 patients. Place of death information is not recorded in ambulance information systems.

Chart 3: Location of patients death following transfer/discharge

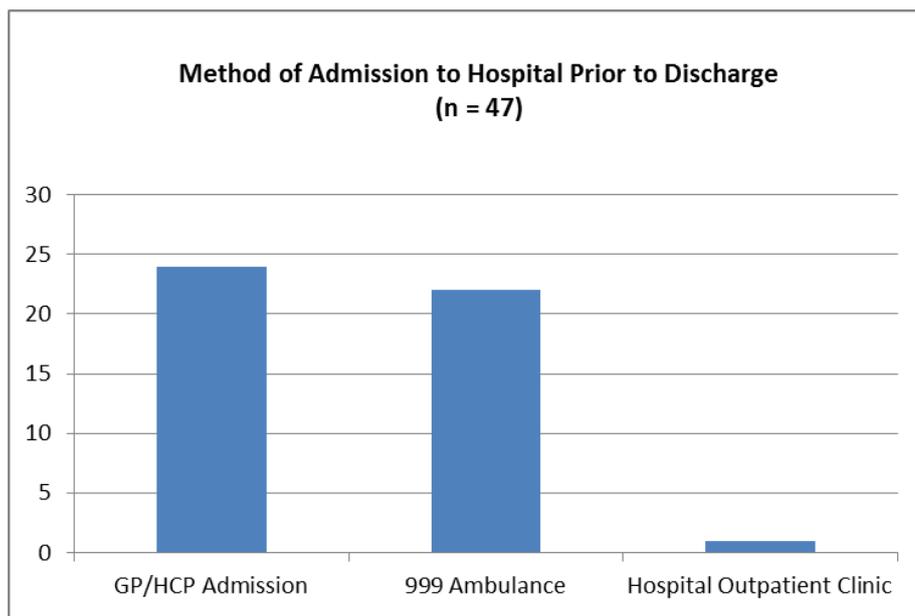


The date of death was also recorded in the hospital notes for 35 of the 56 cases, which enabled further analysis of time of discharge to time of patient death. The average time from date of discharge to date of patient death was 25.1 days (95% confidence interval \pm 15.7 days). The shortest period was less than one day (excluding death in ambulance) and the longest period was 218 days.

Admission to hospital

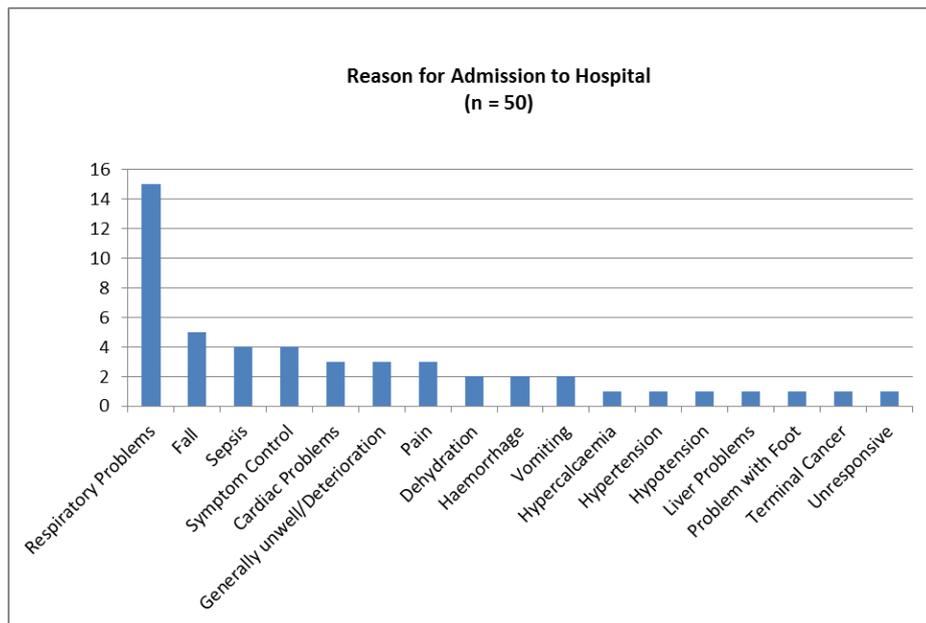
As part of the rapid discharge analysis, it was agreed to look at how long patients had been in hospital for (length of stay), the reason for admission and the method of admission. Chart 4 shows the three types of admission (only 47 of the 62 cases had the information recorded). Of the 47 cases, GPs and other healthcare professionals (HCP Admission) initiated 51% of all admissions. 47% were initiated following a 999 call and 2% were admitted while attending an outpatient clinic.

Chart 4: Method of admission to hospital prior to discharge



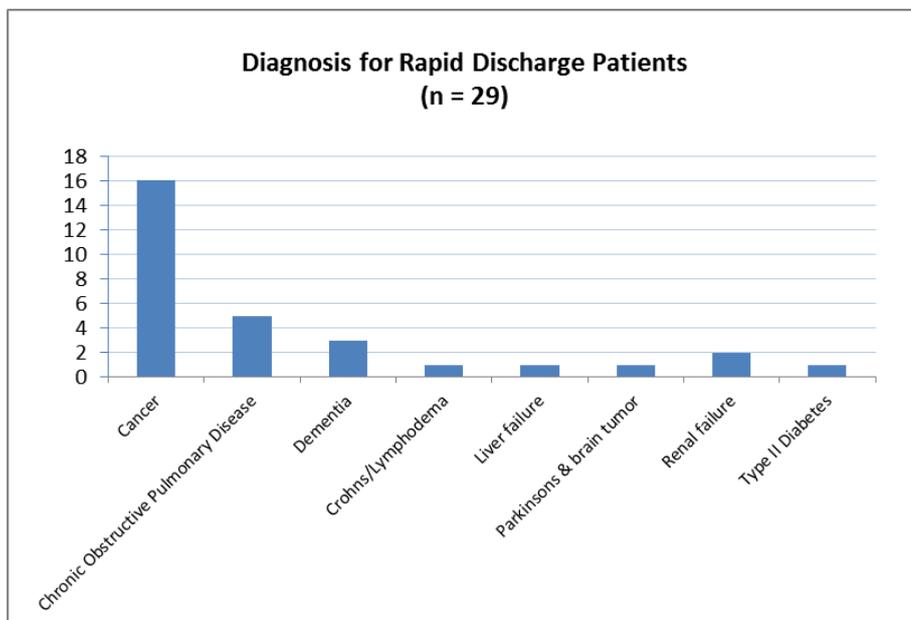
The average length of stay for patients was 18.6 days (95% confidence interval \pm 4.26 days). The shortest period was half a day and the longest length of stay was 72 days. Of the 62 cases, 50 had the reason for admission recorded on either the hospital notes or the ambulance record. In 30% of cases, respiratory problems (pneumonia, shortness of breath etc) were the reason for admission to hospital. Chart 5 provides further analysis of the reasons for hospital admission.

Chart 5: Reason for admission to hospital



The diagnosis of patients who followed the EoLC rapid discharge pathway was available in the hospital notes for 29 of the cases. Cancer accounted for 55% of the cases. Chart 6 provides further analysis of these.

Chart 6: Diagnosis for rapid discharge patients



The service was not utilised for any patients with a diagnosis of cardio vascular disease or stroke.

Electronic Palliative Care Co-ordination Systems (EPaCCS) Data

There were 184 EoLC patients notified to NWAS via EPaCCS between 1 April and 30 September 2012, which resulted in warning flags being placed against patient addresses. The purpose of the flags was to alert ambulance staff to the presence of advanced care planning; to improve clinical decision making. The average age of patients was 80 years old. NWAS attended 53 out of the 184 (28.8%) patients during this time period. The request for an ambulance was made by the following:

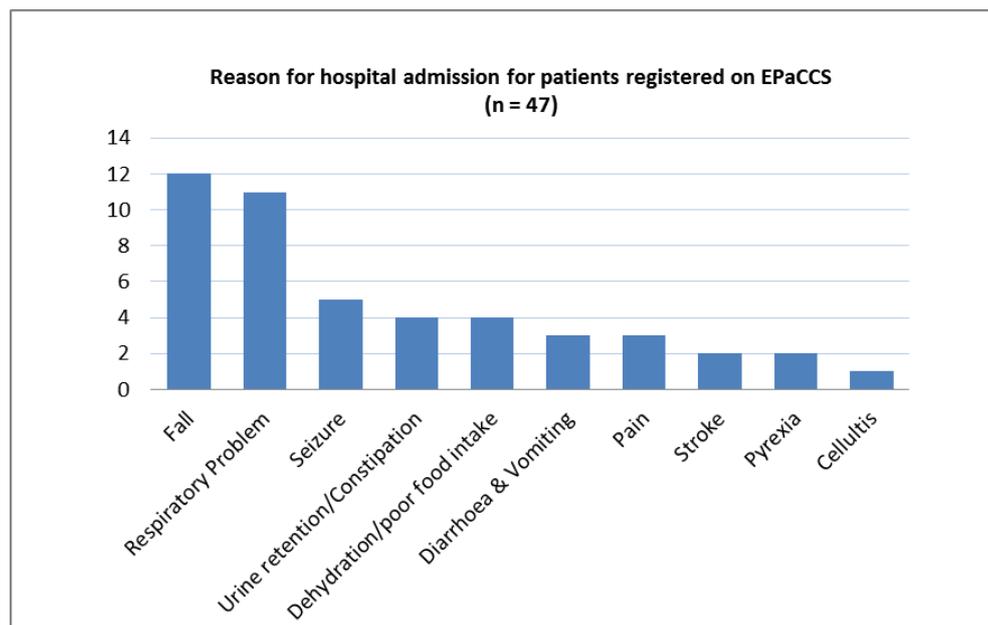
- patients, relatives or carers (including nursing homes) made 999 calls 73.6% of the time (39 calls)
- GP or other healthcare professionals called for a hospital admission 26.4% of the time (14 calls)

The majority of the patients attended by ambulance (39) lived in residential or nursing homes with the remaining 17 living in their own homes. Of the 53 patients attended, 88.7% were conveyed to hospital. However, 14 of the conveyed cases were pre-arranged admissions by a GP or healthcare professional.

Of the six cases that were not conveyed:

- one was a death that was managed at the scene (place where the ambulance was called to) as an expected death, with GP attending and no police involvement
- one was a minor injury in a nursing home that was managed at the scene
- four were patients in their own home who were recorded as having refused transfer to hospital, with a referral made to the patient's GP or district nursing team to follow up
- all 53 patient report forms had recorded that the patient had an end of life care plan. The reasons for admission are highlighted in Chart 7 below

Chart 7: Reason for hospital admission for patients registered as EPaCCS



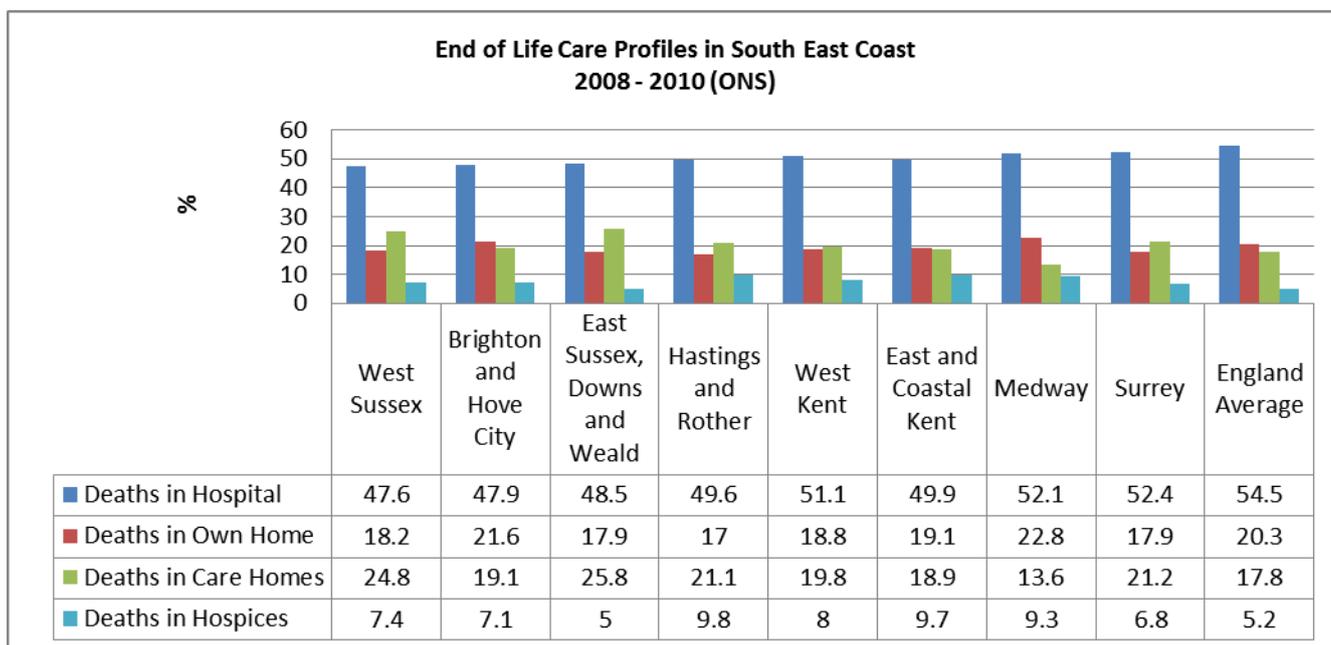
2.1 SECAmb results

All patients

SECAmb covers the counties of Surrey, Sussex and Kent, an area of 3,600 square miles with a population of 4.3 million. In 2012/13, SECAmb received 789,251 emergency calls and mobilised an ambulance 612,364 times from these calls. The area has generally better health than the England average with low levels of deprivation and higher than average life expectancy. There are pockets of relative deprivation in coastal towns and urban areas and parts have significantly higher elderly population than average with large numbers of residential and nursing homes. Premature deaths from cancer and from heart disease and stroke are lower than the England average and death rates from all causes for males and females continue to fall, but deaths and serious injuries from road accidents are worse than average.

End of life care profiles for these counties (Chart 8) indicate a lower than England average number of hospital deaths in all areas. The higher proportion of elderly people in some areas is confirmed by the high number of deaths in care homes compared to the England average.

Chart 8: End of life care profiles for the South East Coast, 2008 – 2010 (ONS)

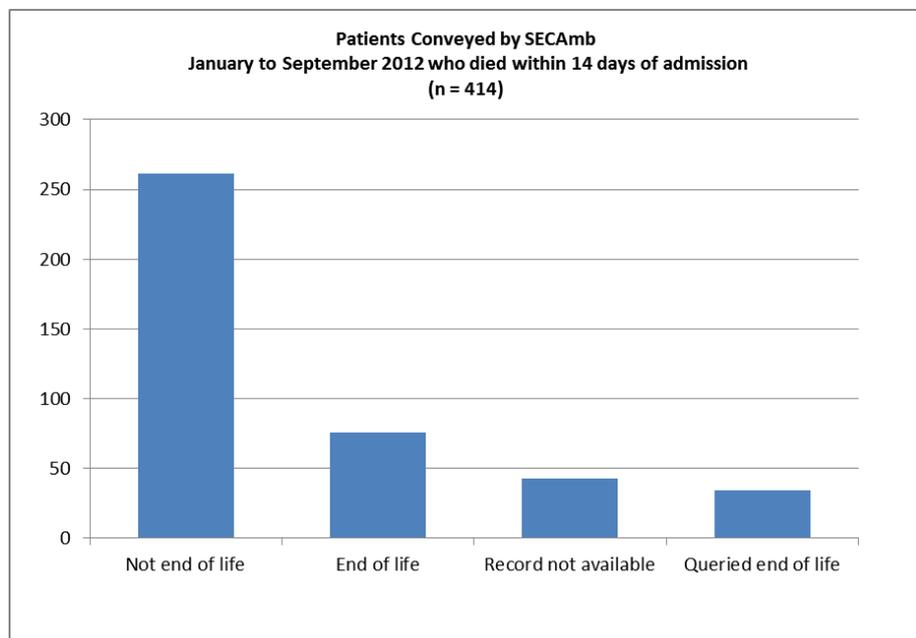


Without an EPaCCS, identification of patients approaching the end of life was labour intensive and extremely time consuming. It also required someone with clinical skills to ‘read between the lines’ of the clinical record to identify these patients. Even with this experience, it was not always clear and 8.2% of patients were identified as end of life. Although the information from this study provides more insight into end of life care provision it is not an easily replicable process.

It would be possible in future for a review to be undertaken of all EPaCCS system patients who had died to identify if any calls to an ambulance trust were made and whether the patient was transported to hospital and compare this to the results from this audit.

Chart 9 outlines the results of this process:

Chart 9: Patients conveyed by SECAmb from January to September 2012 who died within 14 days of admission



Only 18% of patients transferred by ambulance service were clearly identified as at end of life.

Table 1: End of life care profile for the PCT

Deaths in the PCT covered by this trust - 2012	Number
Total number of deaths	3,895
Deaths in hospital	1,891 (49%)
Deaths in hospital following an emergency admission	1,570 (83%)

Due to the number of trusts and configuration of service provision, it was not possible to ascertain the percentage of the total deaths in this PCT represented by this project. The average age at death of the 371 patients whose record could be found was 82.5 years and they had an average length of stay until death of 4.65 days.

Further analysis was undertaken of the three groups to identify the average age at death, average length of hospital stay, reason for the emergency call, underlying diagnosis and place of residence.

Identified end of life care patients

The average age at death for this group of 75 patients was 81.1 years and the average length of stay until death was 3.64 days. Out of the 75 patients, 23 (31.5%) resided in a care or nursing home and 50 (68.5%) lived at home. It was not clear where two patients lived. The acute trust covers an area with a large elderly population and a large number of care and nursing homes. Eight of the 75 patients had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision recorded on the ambulance IT system so crews would have been aware prior to arrival that the patient was likely to be terminally ill or approaching the end of life. It was not clear where two patients lived. The underlying conditions of these patients is indicated in Chart 10.

Chart 10: Underlying conditions of patients identified as end of life

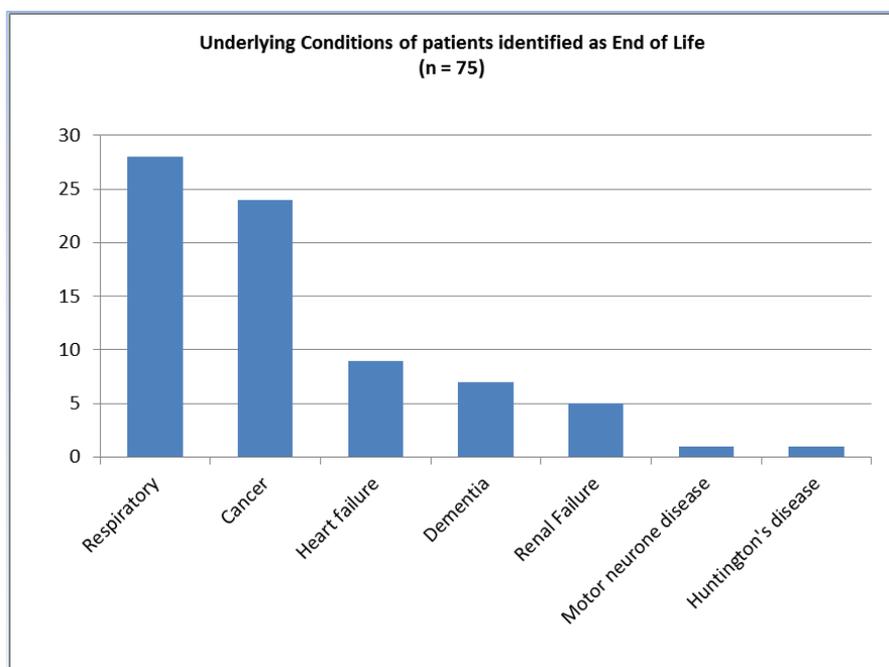
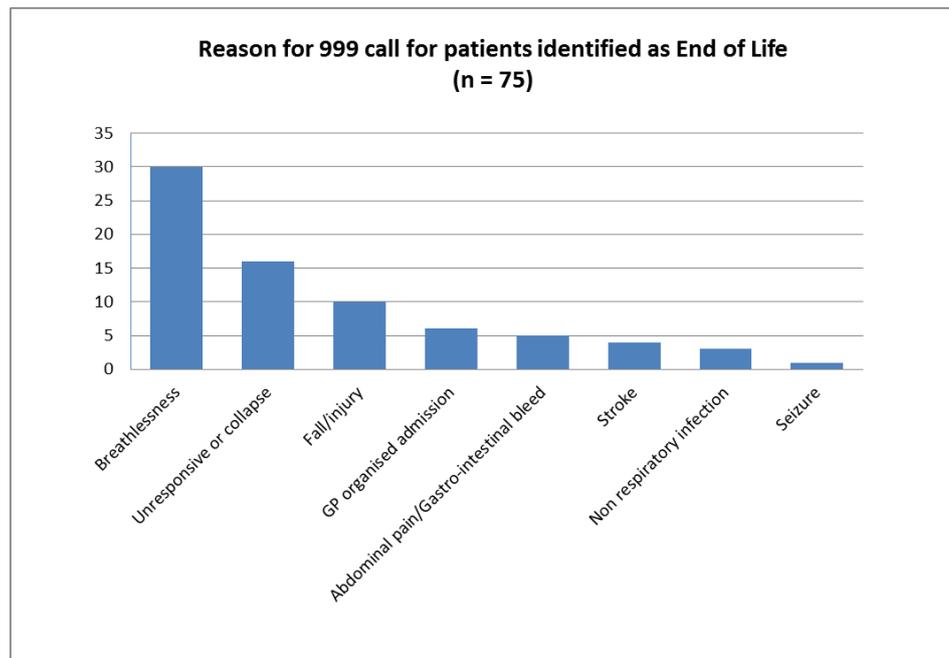


Chart 11: Reason for 999 call for patients identified as end of life



Discussion

The identified end of life care group were slightly younger and had a shorter period from admission to death than the other groups. The most common diagnoses were respiratory conditions including chronic obstructive pulmonary disease (COPD) (28 patients), followed by cancer (24 patients). The common presentation for patients with respiratory disease was a diagnosis of COPD, receiving oxygen therapy and presenting with a new chest infection. Further analysis of the patients with cancer revealed that one-third had common palliative symptoms such as breakthrough pain and breathlessness. With provision of adequate information and support it could be expected that these patients may have been able to be managed and remain at home to die. The other two-thirds had a range of symptoms such as stroke, fall or a new respiratory infection that would have necessitated the ambulance crew taking the patient to hospital unless there was clear end of life documentation and preferred place of death information at the patient’s residence. None of the cancer patients had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order recorded on the ambulance IT system.

Shortness of breath or possible chest infection was the reason for 30 of the calls, followed by 16 patients being unresponsive or having collapsed. The GP had organised the admission for six patients.

Queried end of life care patients

It was uncertain from the medical records whether this cohort of 34 patients had been identified as terminally ill or approaching the end of life. Although all had been diagnosed with a long-term condition, it was not clear on the SECamb clinical record whether this had progressed to an end of life care stage. The average age at death for this group was 83.6 years with an average admission of 5.6 days until death, longer than the other two study groups. Of the 34 patients, 11 (32.3%) were resident in a care or nursing home and 21 (61.7%) lived at home. One patient had a DNACPR decision recorded on SECamb’s IT system, although their cause of death did not reflect the condition mentioned on the DNACPR form. There was a wider range of diagnoses for this group compared to the identified end of life care group as reflected in Chart 12.

Chart 12: Underlying condition of ‘queried end of life’ patients

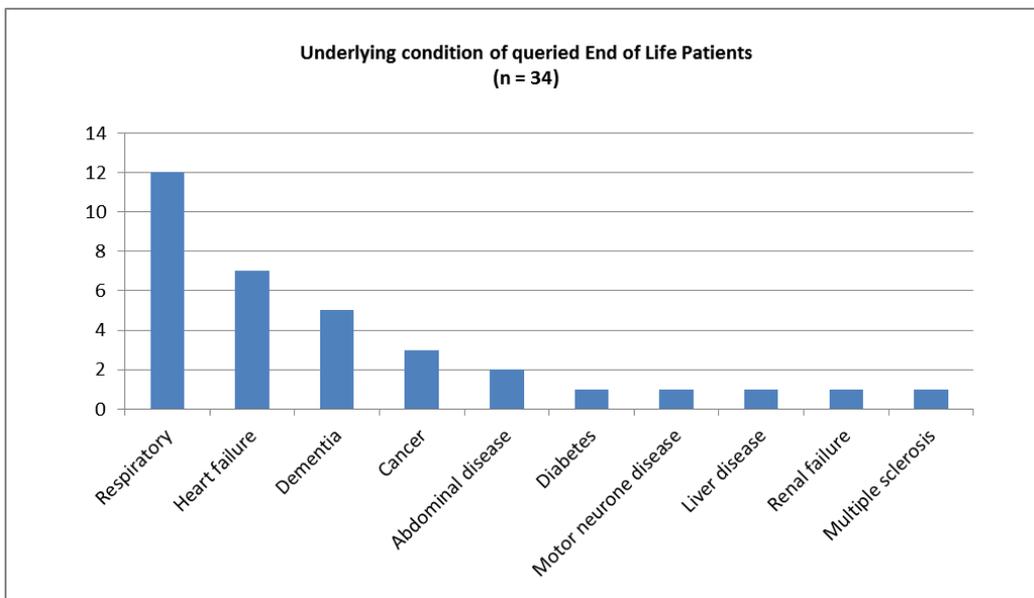
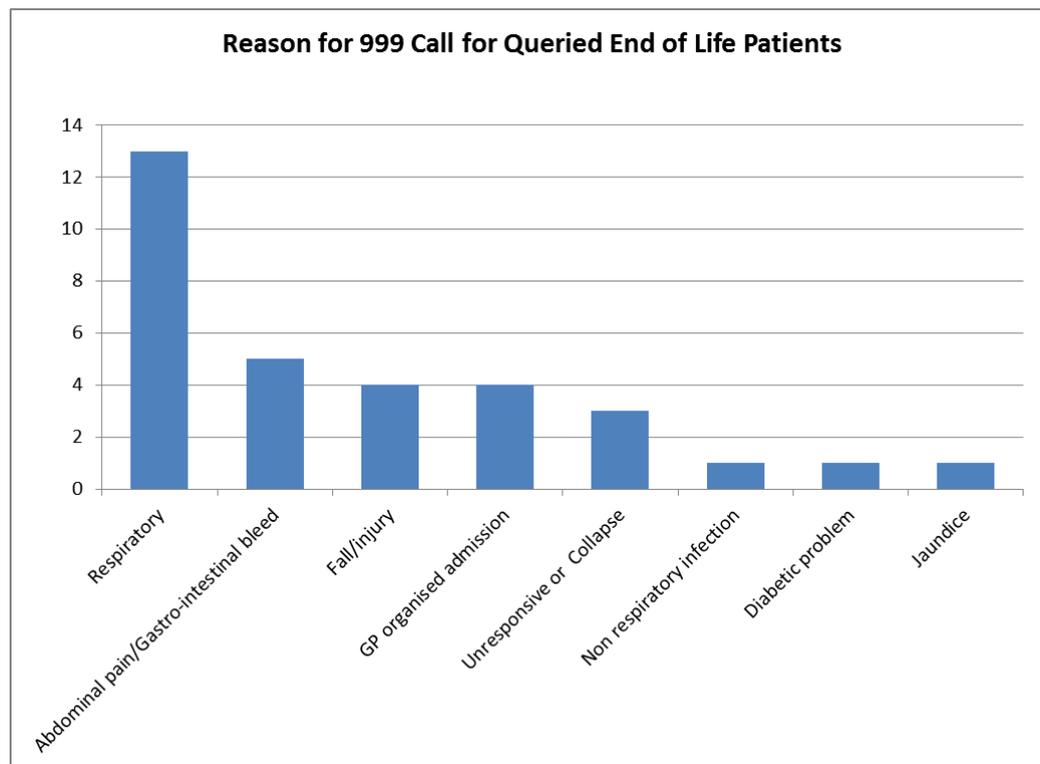


Chart 13: Reason for 999 call for 'queried end of life' patients



Discussion

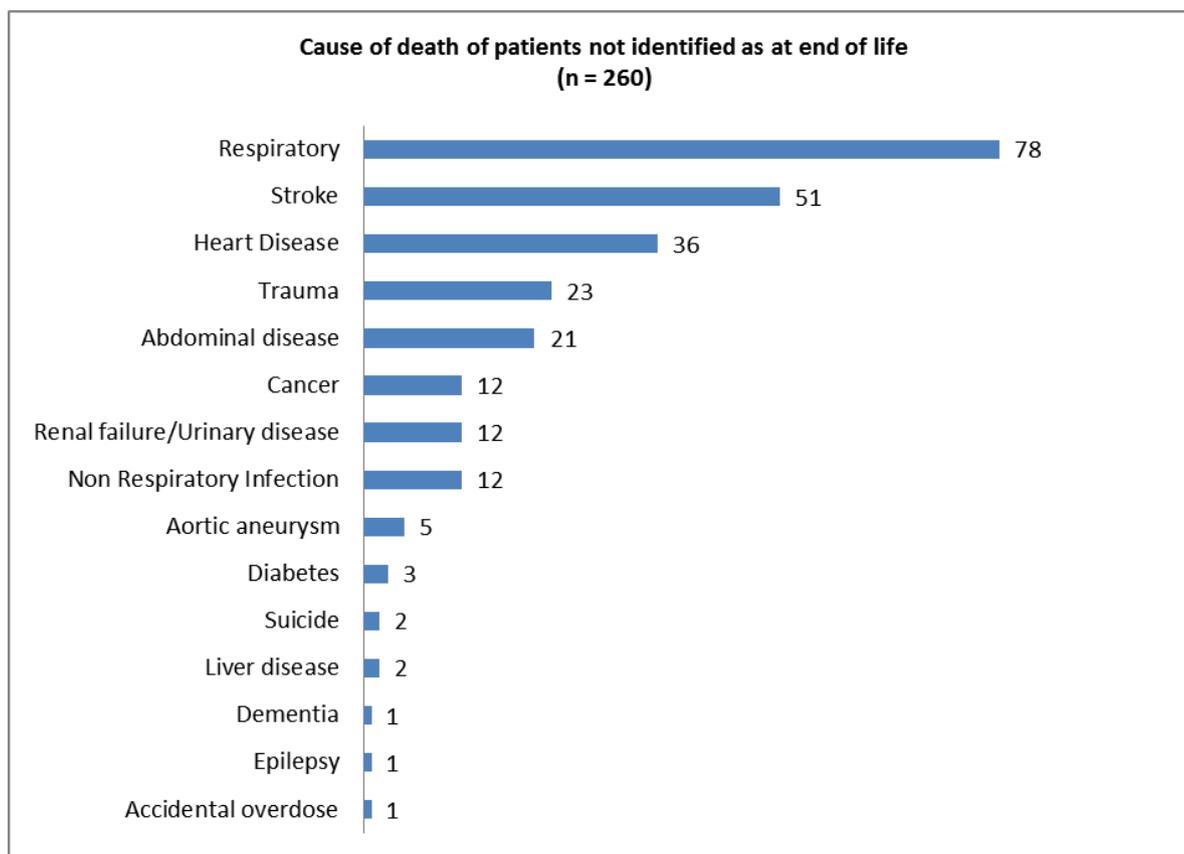
Again the most common underlying condition and reason for admission for these patients was respiratory disease (12 patients). This was followed by heart failure (seven patients) and dementia (five patients). The prevalence of these conditions in this group may reflect the recognised difficulty in identification of the end of life phase. If we consider the 'queried end of life care' patients (34) together with the the 'identified end of life care patients' (75), the respiratory group (12 plus 28) accounted for 37% of the total 109 patients. A typical presentation for this disease was a person with COPD presenting with acute symptoms of shortness of breath from a suspected chest infection. The cause of death was typically pneumonia. It is likely that the patient had a number of previous chest infections requiring hospitalisation and it would be difficult at the time of the ambulance call to determine whether this would prove to be the terminal infection.

Shortness of breath or suspected chest infection accounted for 13 of the calls and the admission was organised by the GP for four of these cases.

Not identified end of life care patients

For completeness an analysis was done of the 260 patients who had not been identified as terminally ill or approaching the end of life. The average age at death of this group was older than the other groups being 83.3 years with an average length of stay until death of 4.8 days. This cohort had the widest range of causes of death than any other group as seen in Chart 14.

Chart 14: Cause of death of patients not identified as at end of life



Discussion

As little clinical detail was available for some of these patients it was necessary to categorise them by cause of death rather than underlying diagnostic group (as the 'identified end of life' and 'queried end of life' patients had been categorised). Respiratory disease/COPD was again the most common cause of death (38%), followed by CVA (20%) and heart disease including myocardial infarction (14%). Stroke, CVD and respiratory conditions accounted for 72% of all deaths in this group. There were a number of younger patients in this group, although the average age at death was similar to the other groups.

3 Conclusions

3.1 NWAS

The inability to easily and robustly identify rapid discharges from either hospital or ambulance electronic administration systems limited the sample size for the audit. From an ambulance perspective, this is mainly due to the national, non-specific coding of healthcare professional bookings. The vast majority of bookings are simply classed as a Healthcare Professional Booking within the Advanced Medical Priority Dispatch System (AMPDS). That said, the sample was sufficient to address the objectives of the study. The target response time within two hours was achieved in the majority of cases (68.5%), with an average response time of 1 hour 35 minutes. There were some cases of a delayed response (in excess of the two-hour target), which were due to periods of high 999 demand. The average time that ambulance crews spent at hospital collecting the person was only 21 minutes, which indicates that hospitals requested transport at an appropriate point in the pathway and that everything was ready for the patient to leave.

Documentation of care planning was not complete with only 74.2% of patients being discharged home to die having a DNACPR decision or other advance care planning recorded. Not only does this cause potential issues for ambulance staff making clinical decisions, it also has a negative impact on the ongoing care for the patient once at their agreed destination. Evidence of agreed plans for managing a death during ambulance transfer was low with only eight cases identified. This again, is a critical element to support ambulance staff to provide appropriate and safe care to patients and to ensure that management of any death is handled compassionately and legally. This is also important for ensuring any relatives or carers are clear about what should happen. The audit identified one death occurring in the ambulance during transfer, which highlights the importance of this planning.

The majority of patients died in their own home or a care/nursing home following rapid discharge. The rapid discharge pathway is intended for patients who have hours or days to live. However, the time from discharge to death was greater than expected with an average of 25.1 days. While prognostication of the dying phase can be difficult, it has to be considered whether such a rapid response by the ambulance service is required on every occasion and whether there needs to be more sensitive criteria developed. Just over half of the patients discharged were originally admitted by their GP, closely followed by emergency 999 ambulance admissions. The majority of these patients were cancer patients (55%) followed by COPD, dementia and a number of other long-term conditions, which are all identified in most end of life care prognostic indicator tools.

The study highlighted the need for paramedic skills in management of respiratory conditions, symptom control, pain, dehydration, vomiting and general deterioration to support people at the end of life.

Analysis of the EPaCCS data highlighted that a large number of patients were being flagged to the ambulance service as having some form of end of life care planning in place. The ambulance contact rate of 28.8% was predominantly as a result of 999 calls made by patients, relatives or carers (including nursing homes), with the remainder being GP or healthcare professional bookings. It is encouraging to note that 100% of ambulance records indicated the patient was on some form of end of life care plan. The majority of calls were made from nursing or care homes for falls and respiratory problems. There was also evidence of calls being made for conditions and symptoms normally associated with end of life. However, the majority of patients (88.7%) were transferred to hospital, which may be attributed to a lack of alternative pathways or referral options.

3.2 SECAmb

The patients identified in this study represent the cohort who were conveyed to an acute hospital and died within a relatively short period. It is unknown how many identified terminally ill or people approaching the end of life that either did not call an ambulance, called and were left in their usual place of residence, or were conveyed to a hospice.

One of the objectives of this project was to identify the information held on ambulance information systems for terminally ill/people approaching the end of life and determine how easy it is to extract this data. The experience from this project found that many people approaching the end of life were not clearly identified in either the ambulance or hospital records. The project was able to identify more people by using the clinical knowledge of those working on the project to 'read between the lines' of the clinical record. This process was difficult and time consuming and could not be carried out routinely.

There were interesting and unexpected results, such as the high incidence of patients with COPD in both the 'identified end of life' and 'queried end of life' care groups. It may be that there is a lack of extensive palliative planning for people with COPD in this particular area or this may represent a wider trend. As discussed previously, in the absence of clear patient pathways that include management of what could be expected to be the terminal respiratory infection, it would be expected that ambulance crews will continue to convey these patients to hospital. Development of rapid discharge processes for this group may be a better mechanism to ensure preferred place of death is achieved.

Around one-third of the identified end of life care and queried end of life care patients lived in care or nursing homes. SECAmb has already provided training and support to some local care and nursing homes about when to call an ambulance (and when not to) including for terminally ill people and those approaching the end of life. This training will continue.

4 General recommendations

Where ambulance trusts use an electronic patient record system, the development of a national Crew Condition Code for end of life care patients would enable ambulance staff to record the patients' diagnostic group. This would significantly improve the ability of ambulance services to interrogate and analyse information systems in relation to the care delivered for end of life care patients. It would also be advantageous for ambulance trusts to develop a unified national data set. The Royal College of Physicians with NHS England and the Health and Social Care Information Centre has published a new **National Ambulance Documentation Standard**. This standard was approved by the Professional Record Standards Body for Health and Social Care and specifies the headings for the ambulance patient record.

Development of an evidence-based End of Life Care Decision Support Tool is recommended that would improve the identification of end of life patients, enable safer and appropriate care decisions and utilisation of clinical advice. North West Ambulance Service is in the process of developing such a tool.

Improved, ongoing monitoring of rapid discharge pathways would be beneficial to ensure that the pathways are accessed for appropriate patients (those expected to die within days) and they are effective. This will enable ambulance trusts to continue to provide a timely and high-quality service.

While it was recognised that the audit/data collection processes were time consuming, it would be beneficial for the audit (or some aspects of it) to be undertaken at a national level by all ambulance trusts. This could be taken forward through the National Ambulance Clinical Quality Group as part of their annual work programme.

It is recommended that opportunities are identified to present this report to all ambulance services and to link to promotional events for EPaCCS and other information sharing approaches.

It is recommended that other ambulance services replicate elements of this project in their own areas to better understand and develop their role in supporting quality of end of life care.

4.1 North West Ambulance Service recommendations

Given that the vast majority of deaths occurred more than ten days following discharge from hospital, the rapid transfer booking criteria should be reviewed to ensure that clinically appropriate patients are accessing this pathway. This may involve a more clinically focussed triage process at the point of making the ambulance booking. The continued rollout of a regional Unified DNACPR Policy that works across all healthcare settings should help to improve awareness and availability of DNACPRs at the point of discharge including; death during transfer planning.

4.2 South East Coast Ambulance Service recommendations

The high number of patients in the 'identified end of life' and 'queried end of life' care groups with advanced respiratory disease or COPD suggests that there would be value in development of a specific COPD pathway/decision support tool.

It is recommended that this audit is repeated after the implementation of a local EPaCCS system to identify the impact on the numbers of patients and their diagnosis and symptoms.

Implementation of the recommendations in the End of Life Care Strategy and Routes to Success for ambulances should continue. This will include ensuring that registered paramedics understand their role and are competent to administer 'as required' drugs for symptom relief at the end of life. This has the potential to greatly reduce conveyance rates to hospital for terminally ill people and will enable more patients who wish to die in their usual place of residence to achieve their preferences. Extension of prescribing rights or creation of Patient Group Directorates is not required for paramedics to administer prescribed 'as required' drugs. However, ambulance services may wish to ensure that adequate training is in place for symptom management.

An end of life care training strategy has been developed including a SECAmb specific E-Learning end of life care module and training programmes provided in conjunction with local hospices. These training sessions are proving to be particularly popular with paramedic practitioners (the senior primary care focused paramedic workforce in SECAmb). Clinical supervisors at the emergency operations centres provide a clinical resource for ambulance staff to support them in managing patients at the scene and avoiding unnecessary hospital transfers.

It is recommended that better understanding of current end of life care practice and sharing of contact details for key staff involved in a person's care, particularly out of hours, and access to support and advice from hospices and palliative care teams also

have the potential to reduce unwanted hospital admissions for people approaching the end of life.

End of life care facilitators and social care champions across the area have been identified who will support dissemination of best practice models and provide a local resource for ambulance staff.

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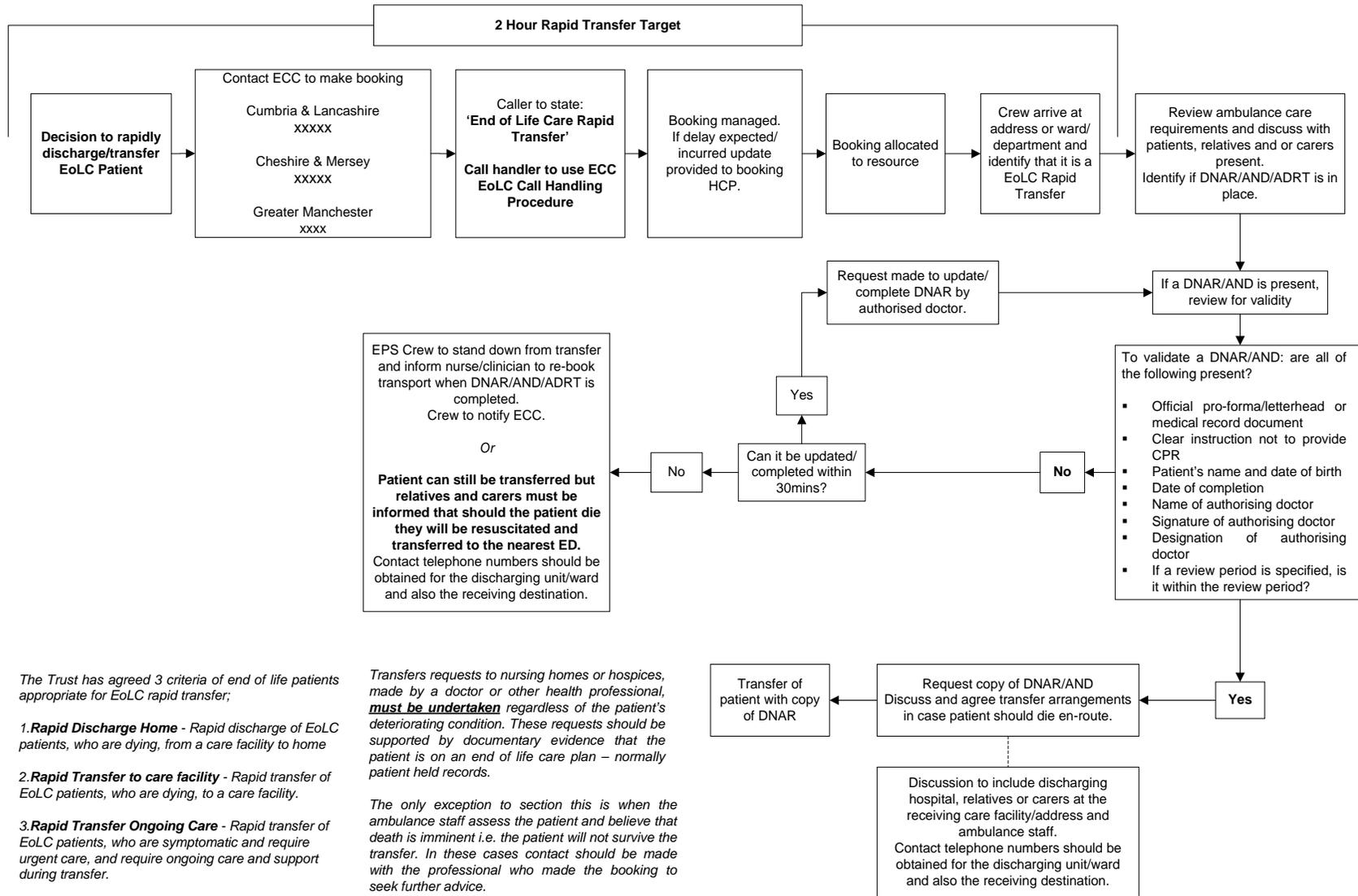
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Appendix 1

RAPID TRANSFER PROCEDURE



The Trust has agreed 3 criteria of end of life patients appropriate for EoLC rapid transfer;

1. **Rapid Discharge Home** - Rapid discharge of EoLC patients, who are dying, from a care facility to home

2. **Rapid Transfer to care facility** - Rapid transfer of EoLC patients, who are dying, to a care facility.

3. **Rapid Transfer Ongoing Care** - Rapid transfer of EoLC patients, who are symptomatic and require urgent care, and require ongoing care and support during transfer.

Transfers requests to nursing homes or hospices, made by a doctor or other health professional, **must be undertaken** regardless of the patient's deteriorating condition. These requests should be supported by documentary evidence that the patient is on an end of life care plan – normally patient held records.

The only exception to section this is when the ambulance staff assess the patient and believe that death is imminent i.e. the patient will not survive the transfer. In these cases contact should be made with the professional who made the booking to seek further advice.