Shropshire Community Health NHS
NHS Trust

Policies, Procedures, Guidelines and Protocols

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Shropshire Community Health
NHS Trust

Palliative and End of life care in the last year(s) of life

A Strategy for adults

2021-2024

Table of Contents

1. Executive summary

Welcome to the second Palliative and End of Life Care in the last year(s) of life. A Strategy for Adults 2021-2024.

The intention of this next strategy for the Community Trust is to build on the new foundation created in the first strategy by addressing areas now more visible that require additions, enlarging and strengthening as laid out in this document.

Importantly while the focus here is further work/activity by the Community Trust, we are now able to say with more clarity, from work we undertook in the first strategy, that to achieve a continuous and consistent quality delivery of End of Life care, concurrent work is required by key sections of our whole health and care system. We identify elements of this work and the blockages and interruptions to our care these issues create. Proposals are outlined for how this work should be taken up by our newly formed Integrated Care System.

In addition there are points at the interface of our Community Trust services with other services that require us to develop criteria for referral into the Trust. We will take responsibility for drawing up such criteria and we expect the system led work to negotiate and agree these with other parties.

This means we are taking exciting steps towards End of Life Care that will provide a quality experience with flow and consistency across our health and care system for our patients, their families and carers and to the satisfaction of our staff and all concerned.

In taking our own Community Trust work forward we have updated our changing data and context, to shape our continuing direction of travel, revised vision and action plan.

Vision

To achieve and deliver excellence in End of Life care for our patients in Shropshire Community Health Trust.
So we will continue to have an upstream approach and to recognise early the number of people/patients who require planning ahead conversations for care/treatment options during their last year(s) of life and to influence the whole system approach to the EOL care we aspire to.

Strategic aims for the SCHT aligned to the vision:

Improving Lives:
Improving early recognition of End of Life, to enable the care and treatment options for patients with progressive illness to receive high quality, upstream End of Life and Palliative care available to everyone who needs it.

Everyone counts:
Equitable, accessible person centred care for all, to meet the wishes and preferences expressed.

Commitment to quality:
Develop and embed success criteria, what does it look like to get it right first time.

Working together for patients:
Empower patients and carers to have greater control over things that are important to them. Patient and public expectations to be partners in care, to be well informed and involved in all choices about care. Development of referral criteria into Community services.

Compassionate care:
To provide high quality communication skills to clinicians to facilitate further wider discussions around choice and the opportunity for opening up conversations to raise and clarify important areas of care affecting life and living while in the last year of life and or when dying.

***Respect and dignity*:**
Develop a dialogue and open culture around death, dying and bereavement. To hand back death, dying and loss to the public to provide more shared partnership dialogue and management in the last years of life. We propose achieving this will be strengthened by the system piece of work engaging with Public Health and Voluntary sector to further widen public engagement. See Appendix 1 for an outline of this.

How we get there-moving forward

In section 5 and 6 we have drawn from a range of data and evidence sources that we have analysed to inform and provide the rationale for the action plan in Section 7. Further detail of the source material can be found in the Appendices.

In this section the content relates to delivery issues, so here we cover:

- The features of Covid 19 that impacted End of Life care
- Storyboard, data collected from Trust Clinicians, Managers and Volunteers
- Learning from Death Reviews
- Frailty
- Interface and subsystem issues

Updated context

In this section the content relates to **context** issues as they affect End of life Care, so here is covered:

- National structural and or directives changes
- Local data sources

What we do know from the analysis of trends and forecasts locally is that there will be an increase in deaths by 22% in the decade 2020-2030 from 4,781 to 6,309 per annum. The greatest number of these deaths will be in those 85 years old and over. This will have the greatest impact on future demand in Shropshire, Telford and Wrekin.

Essentially the data shows we continue to have an aging population and deaths are set to continue to rise during the 3 years of this strategy and beyond. This is an important to factor in our demand and capacity requirements which are addressed in the action plan.

Delivering the agenda
Action plan
The key message to state at the outset of delivering this action plan is that the Community Trust can only achieve some elements of these actions and requires other partners to have the same

upstream approach to end of life care. What we can achieve is to build on the foundation we have set in the first strategy, for clarity the action plan will be in 3 sections, these are:

- Actions specific for SCHT
- SCHT criteria for referral into Community services
- Action taken by SCHT to get the system issues addressed:

Summary

The direction of travel and intention in this strategy continues with an upstream approach to End of Life care.

The beginning of this strategy document sets out what has been achieved from the implementation of our first strategy and what has become visible in relation to other organisations and interfaces between these.

Throughout this document findings are set out from various sources of evidence and information which will define the direction of travel required for End of Life care over the next three years for Shropshire Community Health Trust including the issues to be taken into account and forward by our Integrated Care system.

The impact of COVID 19 rapidly opened up further collaborative working between organisations for End of Life care, it placed death dying and bereavement clearly in the public domain. All of these key findings need to be taken further.

We can see from the predictions in the current demographic information that there continues to be challenges due to the increasing ageing population and longer life expectancy. With increasing age comes the increasing number of older people with Frailty and the likelihood of frequent hospital admissions in the last two years of life. We also know that not as many people die at home who wish to in Shropshire Telford and Wrekin. However trends show that the number of people who die at home and in care homes is on an upward trajectory. Both factors will increase the demand on community services as we aspire to meet the wishes and preferences for those who are in the last years of life. Such actions will reduce the need for unnecessary hospital admissions for End of Life care.

Conclusion

The key action for Shropshire Community Health Trust is to progress upstream working and to require the new Integrated Care Team to lead the work necessary to provide seamless care, flow and connectivity between and within our local health and care system. This in pursuit of excellence in the provision of End of Life care.

We look forward to the time our patients, carers and families can experience that seamless flow and continuity of care during their End of Life care experience. We all expect this.

2. Introduction

Welcome to the second Palliative and End of Life Care in the last year(s) of life. A Strategy for Adults 2021-2024.

The intention of this next strategy for the Community Trust is to build on the new foundation created in the first strategy by addressing areas now more visible that require additions, enlarging and strengthening as laid out in this document.

Importantly while the focus here is further work/activity by the Community Trust, we are now able to say with more clarity, from work we undertook in the first strategy, that to achieve a continuous and consistent quality delivery of End of Life care, concurrent work is required by key sections of our whole health and care system. We identify elements of this work and the blockages and interruptions to our care these issues create. Proposals are outlined for how this work should be taken up by our newly formed Integrated Care System.

In addition there are points at the interface of our Community Trust services with other services that require us to develop criteria for referral into the Trust. We will take responsibility for drawing up such criteria and we expect the system led work to negotiate and agree these with other parties.

This means we are taking exciting steps towards End of Life Care that will provide a quality experience with flow and consistency across our health and care system for our patients, their families and carers and to the satisfaction of our staff and all concerned.

In taking our own Community Trust work forward we have updated our changing data and context, to shape our continuing direction of travel, revised vision and action plan.

3. Background

The intention of the first Palliative and End of Life (EOL) strategy (2017-2021) was to bring Shropshire Community Health Trust (SCHT) in line with national expectations at the time. That was for End of Life care to include not only the last few hours/days of life, the focus of the trust at the time, but also upstream planning for one to two years before expected death.

From the outset the boundary of the 2017-2021 strategy was for End of Life care within SCHT as stated in the CQC requirement at that time. It was not a Shropshire, Telford and Wrekin system wide strategy. It was therefore inevitable that if practice in other parts of the health and care system remained as they were, then ‘blocks’ for delivery of care in the SCHT would be created during the full implementation of the SCHT strategy.

There are ‘blocks’ and these continue to limit the delivery of the full quality and intentions of the Trust to provide an upstream planning ahead approach and delivery to End of Life care. From the outset of the first strategy implementation, Kurt Lewin’s Change Management Model approach was adopted to frame the implementation. His model known as the *Unfreeze- Change- Refreeze* is a three stage process as an approach to change. This enabled us to identify and examine these blocks and issues that have become visible during the last 3 years. These issues/blocks will be identified and outlined further in section 5.

Evidence does show that such an upstream approach to End of Life care has benefits down-stream. Using upstream interventions facilitates the process for ongoing care options for patients to be discussed with them and for intentional choices by patients to be made about ongoing care interventions for their remaining lives. These then inform any 'planning ahead' which includes choices about place of dying and death and what supportive, palliative and or treatment options they would agree to or hope for.

A further CQC inspection took place in January 2019 with a focus on End of Life care. Following this the Trust status transitioned from inadequate/requires improvement to Good for all aspects of End of Life care and recommending the following:

" The service should maintain its momentum with strategy to fulfil its aims and objectives"

This 2nd strategy will enable the momentum to be continued into the next 3 years.

3.1 Key Achievements from 2017-2021 End of Life Strategy

There are many achievements, here a few of the key ones:

- **Working Upstream:** scoping**,** development and implementation of
  - A 'last year of life' identification process, using the clinical indicator tools SPICT (Supportive and Palliative Care Indicators Tool) and Rockwood clinical frailty score.
  - Interventions to put in place over that one year period and during the last days and hours
  - Advanced care planning and recording process supported by the implementation of the ReSPECT process
  - A publication of Patient and carer information leaflets regarding End of Life to ensure consistent information across SCHT
  - Education and training programme to facilitate and enable more complex and emotional conversations with patients, including planning ahead

- **Improved quality of care:** achieved in all dimensions of the CQC criteria
  - Community teams have an increased awareness and experience about care required in the last year of life, and recognise now that they receive referrals for End of Life care patients too late in their disease trajectory, which results in crisis management in the last days and hours of life
  - The number of 'unexpected deaths' in the Community hospitals has decreased to no unexpected deaths since 2018, one of our clear indicators that End of Life is recognised earlier and upstream planning initiated
  - Increase in the use of the Shropshire End of Life plan in the last days of life
  - Anticipatory prescribing- adoption of the West Midlands Palliative Care Physicians-Guidelines for use of drugs in symptom control

- **Changing ways of working and service delivery**
  - The Community Hospital new model of care at Whitchurch- how we got it right for End of Life care in an inpatient setting.
    - In brief, a review of the medical locum supported model highlighted gaps and quality issues, for example frail patients decompensating, inconsistent clinical leadership. The new model with the Advanced Clinical Practitioner in the lead role, with a trainee Advanced Clinical Practitioner and a GP (employed by SCHT) provides daily clinical input and leadership

- Care Home MDT (Multi-Disciplinary team) which was commissioned in Telford and Wrekin to follow the course of the SCHT End of Life strategy implementation
- Dying Well champions (DYC) created and trained so that all Community Hospital wards and teams now have one or more DYC. This has established a link between the End of Life work and the clinical areas.

- **Widened our understanding of the needs and experiences of particular groups of patients within SCHT**
  - Use of Leder (Learning Disabilities Mortality Review), a national programme to learn from deaths of those with a Learning Disability

An End of Life strategy refresh paper was produced and agreed in July 2019. This provides a full report of all our achievements. It outlined further gaps that needed to be addressed in 2020 and beyond as well as identifying the interface issues that had become visible by that time.

These achievements and many more have set the firm foundations for us to be clear about what we need to do next, what needs to be carried forward and progressed further within SCHT and beyond. The next section sets out the vision for the Community Trust and the strategic aims.

4. Vision

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So we will continue to have an upstream approach and to recognise early the number of people/patients who require planning ahead conversations for care/treatment options during their last year(s) of life and to influence the whole system approach to the EOL care we aspire to.

4.1 Strategic aims for the SCHT aligned to the vision:

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5. How we get there-moving forward

In section 5 and 6 we have drawn from a range of data and evidence sources that we have analysed to inform and provide the rationale for the action plan in Section 7. Further detail of the source material can be found in the Appendices.

In this section the content relates to delivery issues, so here we cover:

- The features of Covid 19 that impacted End of Life care
- Storyboard, data collected from Trust Clinicians, Managers and Volunteers
- Learning from Death Reviews
- Frailty
- Interface and subsystem issues

5.1 The features of Covid 19 that impacted End of Life Care

It is necessary that this strategy acknowledges the impact and disruption of the Coronavirus pandemic on End of Life Care in Shropshire, Telford and Wrekin and nationally. It is important that these issues are recognised and used to help inform further actions that emerge for this strategy.

This table sets out a summary of the key points:

Table 1: Covid 19 some issues and what this means for the way forward

Issues	What this means
COVID 19 has forced everyone to reflect on death and dying and bereavement in some shape or form and bringing death into the public domain.	Death, dying and bereavement needs to remain in the public domain, for too many years it has become medicalised. This will be further addressed in the action plan in section 7
It acted as a catalyst for change across all organisations to work together and barriers were removed	That systems worked together to overcome barriers illustrates that our system can work together in this pandemic scenario. This makes possible working towards a system-wide upstream approach to End of Life Care.
Increase in demand/deaths on services locally and nationally. Local data provides local detail on this impact and the significant number of deaths within a week of referral to the community teams.	Locally and in line with this increase during COVID, there is a predicted increase in the number of deaths from 2020-2030 as referenced in section 6. In preparation to meet this demand further work force planning is required to increase capacity and working towards achieving maximum upstream working through-out the system. This is carried through into the action plan in section 7
People connected and mobilised support across neighbourhoods as ‘community volunteers’	This illustrates the importance of the role of communities in End of Life care. To continue this there is a need to harness and increase community involvement. This will be carried through into the action plan in section 7

An online survey commissioned by Marie Curie (October 2020-representative sample size 1,780) found that not everyone was able to get the care and support they needed before the person died at home	Locally there isn't any formal, collated feedback on carers experience of End of Life care support during COVID. The current whole system End of Life review is engaging with the public for their views. This will be taken forward in the action plan in section 7
Digital/virtual ways of working were expedited	Build on recent experiences gained during COVID 19 and enhance the use of technology. This is in the action plan in section 7

(Sources which reflect the national picture during COVID are: Hospice UK Future Vision Programme- Discovery phase- Hospice UK September 2020. You Matter because you are you- An action plan for better Palliative Care- Cicely Saunders International 2021)

5.2 Storyboard, data collected from Trust Clinicians, Managers and Volunteers

The process for developing this strategy has included the collection of data from Community Staff Clinicians, Managers and volunteers. They were asked to state how they currently felt about End of Life care in SCHT, given the implementation of the Strategy 1 and how they would like it to be in the ongoing time period. A Storyboard was created.

A comment included: "*expectation of End of Life care would be a well sign-posted area where I could find all the information I or my family may require- this includes legal, the church, the basics. Plus someone with the knowledge to help at the point of contact"* See Appendix 1 for an example of the system approach to encompass this expectation

Below in Table 2 is a brief summary of a range of the key points from that storyboard, some of these points/themes you will find are recurring throughout the strategy and will be taken through into the action plan (Section 7):

Table 2: Summary of Storyboard findings and feeding of action plan

Storyboard findings	Where and how to be addressed
Community teams have an increased awareness and experience that they receive referrals for End of Life patients too late in their disease trajectory, which results in crisis management in the last days and hours of life.	Provide the SCHT data to inform the system End of Life work. Action plan to Develop criteria for referral into SCHT community services.
What is End of Life care- what are the essential ingredients and where do I go for help	Action plan for system wide agenda to organise for a single portal of access for support/advise/guidance for End of Life care.
There is a predicted increase in demand for community services mainly due to an increasing elderly population, with increasing frailty	Action plan to address increase demand and issues of capacity and workforce This is identified throughout this strategy (section 6).
The impact of COVID on grief and grieving and the importance of bereavement support. Support for carers who are caring for loved ones in the last 12 months of life.	For the system wide agenda to address. The Bereavement support provided during COVID by the local Public Health departments illustrated how essential this is.

The late referrals into community services has an impact on the receiving team and the patient and their loved ones, this calls for the development of a set of criteria for referral into community services for End of Life care.	Action plan: Development of a set of criteria for referral into SCHT community services, to be drawn up and negotiated at system level. System wide upstream working.
Inconsistent practice in recognising when a person is in or approaching or is in the last 12 months of life.	This is an issue for SCHT and a system wide issue. There is a requirement for further development of 'upstream working' in parts of the Trust and this will be taken forward in the action plan
Areas of practice are patchy with regards to dialogue and communication with patients and those important to them	SCHT and wider system actions for upstream working and important conversations
There is a need to increase the number of people who would benefit from an advance care plan/anticipatory care plan/ ReSPECT document.	Good progress has been made since the implementation of the ReSPECT process in 2019, further progress to be carried forward into the action plan
Inconsistent screening and case finding for frailty in all services/community hospital/clinical practice to identify those with moderate to severe frailty to determine the goals of care and treatment.	These are actions for SCHT and the wider system with regards to Frailty and are addressed in the action plan
Citizen engagement/community volunteers for End of Life care	Increase community involvement, connect with the Hospice and Compassionate community programme to make this available across the county. Addressed in action plan

5.3 Learning from Deaths

Learning from death reviews are carried out on every patient death within the Community Hospitals in SCHT and include staff involved in the care and treatment of the patient. Since April 2020 there has been 78 deaths within the Community Hospitals, none were reported as unexpected, this has been a consistent pattern since 2018.

Two recent Learning from Deaths reviews of issues for these deaths that took place in one of our Community Hospitals had resulted in complaints. The key features of the service delivery issues are stated here:

1. Inadequate information gained at the transfer point into the SCHT from the referring external NHS service. This is being addressed as part of the 'interface' issues and revising criteria for the information required by SCHT at such interface points
2. Issues with the level and types of prescribing for pain and symptom management to provide for the ongoing and continuous needs for symptom management and levels of access by Community Hospital staff to GP services input

The interface and systems wide issues these death reviews have raised are also identified in section 5.6

Source: Learning from Deaths report 21/1/21 for Quality and Safety Committee.
Reports/minutes/investigations/reviews can be accessed via the Medical Directorate SCHT Share-point portal for Learning from Deaths and the Network file store via the Learning from Death Facilitator)

5.4 Frailty

People with varying degrees of Frailty access services across the whole health and social care system in Shropshire Telford and Wrekin. While a whole systems approach is required, there are recognised actions that SCHT can address and these will be demonstrated in the action plan section.

Table 3: Summary of Key issues to address in the Frailty agenda

The people with Frailty are a group that would benefit from upstream recognition and planning ahead especially those with moderate to severe frailty
There is a plethora of evidence showing the impact of a prolonged hospital stay can have on those with frailty and hospital acquired functional decline
A recent local report (CSU, October 2020) showed that frailty is the single largest underlying cause of death, accounting for close to half of all deaths in Shropshire, Telford and Wrekin. o This group also uses the largest share of urgent care services in the 85years and over. o Furthermore this group also uses the largest share of bed days
For SCHT it is has been identified that frail patients admitted to SCHT Community hospitals following an admission to the acute trust have not been recognised prior to transfer as potentially being in the last year of life. This group of patients are missing the opportunity to plan ahead and thus prevent some hospital attendances/admissions.
There is some emerging practice evidence that the Clinical Frailty Score (Rockwood) is being used in assessments to determine the degree of frailty and how this can impact on outcomes, treatment and care options. However this isn't a consistent practice across the County. The work streams around frailty have been based in the acute trust front door with little connectivity and flow into the community

5.5 Interface and sub system issues

This section addresses what has become visible during the 2017-2021 strategy implementation in relation to other organisations and the interfaces between the sub systems. The issues set out here will be drawn into the action plan in section 7 for actions that are required to be addressed by the Integrated Care System.

There was always an expectation that if other organisations did not have an upstream approach to End of Life care that this would have an impact on connectivity and flow between our sub systems and impact on care for patients in SCHT. This is evident at the interfaces between:

- Acute hospital to community services in relation to discharges home for End of Life care
- Support from GP practices to Community Staff and access to support and advice for symptom management in a timely way
- Late referrals for End of Life care into community services from partner organisations.

There is now a more visible collection of consequences of current clinical practice and the disconnections in various parts of the system. These are demonstrated in the following:

- Evidence from patient/carer and staff stories depict the impact a late referral has on staff and patient care. There are several clinical situations from our Learning from Deaths review and Datix incident process that illustrate the many areas where lack of flow in and between our subsystems leads to poor care and poor end of life care outcomes. The community teams are often at the interface of such situations, increasing complexity and distress for the patient family and carers.

Access to the Learning from Deaths review reports is via the SCHT's Learning from Deaths Sharepoint portal (Medical Directorate)/Network file store via the Learning from Deaths facilitator.

- Further evidence from the electronic patient records (RIO) evidences the number of patients who die within 28days of referral and a proportion of those who die within a week of referral. The data in the table below demonstrates this:

Table 4: Deaths within 28 days of referral to the community teams April- July 2020

- April 2020- 21 patients died within a week of referral to the IDT's compared to 6 in April 2019
- May 2020- 23 patients died within a week of referral to the IDT's compared to 5 in May 2019
- June 2020 – 13 patients died within a week of referral to the IDT's compared to 17 in 2019
- July 2020- 12 patients died within a week of referral to the IDT's compared to 10 in 2019
- April and May 2020 seeing the biggest increase in deaths within a week of referral.

IDT= Interdisciplinary team.

Source- Electronic patient record- RIO (SCHT data)

Please note – RIO data from January 2018 consistently shows a significant number of deaths within 28 days of a new referral. As expected there was an increase in deaths between April and June 2020 during COVID 19 pandemic episode, however this remains an area for further review as a significant amount of patients die with 28 days of referral, with a peak in most months within a week of referral. See table in Appendix 2.

These late referrals have an impact on the patient and their families, for example crisis management in the last weeks, days of life. Community Staff, in reactive mode are required to arrange so that everything is in place for the patient to stay at home, in scenarios where the patient and or family often are not expecting imminent death, have been unable to plan ahead and have had with no previous opportunity to express wishes and preferences are identified or how these are to be met.

- There is an emotional impact for clinicians in providing care for patients who did not know they were in the dying phase.

- Many are referral requests to start syringe drivers when a person is in the last week(s) of life means that none of the patients have had the opportunity to plan for the last years of life and dying time.

- Discharges/ referrals from other organisations- A Datix report for End of Life care incidents from Patient in the last weeks/days of life and previously unknown to the team 2017-2020 clearly evidences the key concerns and incidents at the interface with other organisations.

Table 5: **Data from SCHT's Datix system**

NHS to NHS concerns (in relation to other organisations) main sub categories are

- Discharge/referral (17)
- Delay in treatment. (11)

These accounted for 51% of all NHS to NHS concerns in relation to End of Life care.

Some examples of the detail of these are:

- Not enough information given to the receiving team following a referral from the acute trust prior to discharge.
- Anticipatory medication/ authorisation sheet not in place on discharge.
- Unaware that an End of Life patient has been discharged until a family member seeks help
- Accessing GP support and advice for symptom management for End of Life care- time spent waiting for call back has resulted in a delay in treatment

Source- SCHT Datix incident reporting system- EOL report 2017-2020

- General Practice/Primary Care End of Life care varies according to the GP practice, there is little evidence of planning ahead taking place and patients are referred to Community services for the last week(s), days of life. However some practices do hold Gold standard framework meetings and have a palliative/frailty register but this isn't consistent practice.

- Consideration also needs to be given to treatment interventions which have massively developed over the last few years where treatments often continue until death.
  Within the Acute Trust, care and treatment is provided via clinical specialities (i.e. Oncology) which is often invasive and costly and provided until death is imminent. (the use of life sustaining treatments)
    - In cases when those interventions have reached their limit these patients are often referred back to Primary and Community Care for End of Life care and are in the last few days of their lives.
    - In most cases there have been no discussions with options laid out with the patient during treatment time about how to manage any clinical situation as the disease or level of health continues to become more chronic or deteriorates.

We are not requesting or expecting such care interventions to stop but as the disease advances at points where clinical indicators shift to illustrate impending last years of life, that upstream planning and options are made available to patients. Referrals could be made at that point to the Community Trust for relationship building and to ensure a range of resources are put in place.

6. Updated context

In this section the content relates to **context** issues as they affect End of life Care, so here is covered:

- National structural and or directives changes
- Local data sources

6.1 National

Since the first strategy there are a range of changes to the NHS structure and ways of working to provide NHS care, as well as recommendations for practice in End of Life care. We have taken account of the following:

NHSEI Integrated Care 2020 *next steps to building strong and effective integrated care systems across England.*
The development of our local Integrated Care System will enable a whole system approach to the issues that have become visible in relation to interfaces, connection with other parts of the system and flow as set out in section 5.5

The NHS Long Term Plan (2019) including:

- the development of Primary Care Networks including a 5 year framework for GP contract reform to implement the NHS Long Term Plan
- the implementation of Integrated Care Systems
- the use of Population heath Management to assess, identify and deliver health and care needs across the local system. Alongside this the development of 'place'

The NHS Long term Plan along with the Place agenda and the GP contract has a thread running through it in regards to End of Life care, specifically for the GP contract to:

- establish and maintain a register of all patients in need of palliative care/support irrespective of age
- hold regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

The overarching aim of the revised quality indicators in the GP contract is to lead to improvements in relation to the following aspects of care:

- Early identification and support for people with advanced progressive illness who might die within the next twelve months.
- Well-planned and coordinated care that is responsive to the patient's changing needs with the aim of improving the experience of care.
- Identification and support for family/informal care-givers, both as part of the core care team around the patient and as individuals facing impending bereavement.

Currently it is unclear locally what progress has been made by the Primary Care Networks re the requirements of the GP contract and End of Life care. This has been identified as an action to address in section 7.

There are opportunities for the 'Place' agenda already in progress within local the health and care system to include End of Life Care, again identified for action in the action plan

Hospice UK Future Vision programme September 2020 Discovery phase (starting the collective sector-wide conversation around re-imagining a more sustainable future for palliative and end of life care). The significance of this document is that it has identified the following:

- Be an integrated partner- the hospice role in the wider integrated care system
- To address the funding arrangements for Hospices in the context of a system wide delivery of Specialist and Generalist Palliative Care and End of Life Care
- Implement digital ways of working-build on recent experiences gained during COVID 19 which has been identified in section on the impact of COVID in EOL care and is also in the action plan in section 7

You Matter Because You are You - An action plan for better palliative care- Cicely Saunders International (January 2021). This document was produced during COVID and addresses the increase in demand that is predicted in the next 20 years and that during COVID people did not access the palliative/End of Life care they needed in 2020. Its significance endorses the key points raised in this strategy with regards to demographics and increased demand, these can be found in 6.2. and the action plan in section 7

Care Quality Commission Report November 2020 Interim **Review of Do not attempt Cardiopulmonary resuscitation** decisions during COVID 19 Pandemic. Prior to COVID the implementation of the Trust first strategy set the foundations around planning ahead and important conversations particularly with the ReSPECT process implementation in 2018 (Section 3.1). This ensured that a person-centred approach had been developed in regards to advance decisions.

6.2 Local

Midlands and Lancashire Commissioning Support unit
A recent report published by the Midlands and Lancashire Commissioning Support Unit (CSU) (October 2020) *Health Service use in the last two years of life*, commissioned by Shropshire and Telford and Wrekin STP, raised some key points which shed light on the challenges that are faced particularly within SCHT and need to be considered and taken forward in this strategy. For example these 4 points have been extracted:

- *Not all treatments add value. Palliative chemotherapy for example, can be associated with worsening quality of life, often without commensurate gains in survival ….*
- *Having declined for decades, the number of deaths has begun to rise and is set to continue*
- *The greatest number of deaths is among those aged 85 and above. This is also the group with the largest expected increase*
- *Fewer die at home that would like to and as person approaches the last year of life (especially older people) their emergency admissions to hospital increases.*

The CSU report above also presented evidence charting how an upstream direction of travel in End of Life care can have significant benefits in the urgent care agenda and for people who are in the last year of life. Some key headlines are:

- *Over 80% attend A/E at least once in the two years prior to their death. Over 80% also have at least one emergency admission. Around 2/3 call 111.*
- *People's use of urgent care starts low and increases slowly for much of the last two years of life. There is a rapid increase a few months prior to death. The same is true for the use of hospital beds.*
- *Use of emergency admissions and A/E attendances increases when death is in close proximity.*

- *In the final year of life, the oldest decedents spent an additional 7 days in hospital compared to the youngest decedents.*

These key issues will be addressed in the action plan in section 7

Health Watch Shropshire **Health Watch Experiences of End of Life and Palliative care services in Shropshire Engagement report** January 2020. The response for this engagement exercise was quite low, some key points were made:

- Some families found lack of recognition by professionals that the person was End of Life did not give them the opportunity to prepare for End of Life
- Only 34% of people who died in 2017/18 had been identified as needing palliative/End of Life care.

These key points have informed the action plan in section 7

Shropshire Telford and Wrekin STP Transformation Plan 2016-2021 It is to be noted that no direct reference to End of Life Care is made and this increases the need for this area of care to be made known to the Integrated care system for their attention

SCHT review of operational delivery
This review is being conducted by the West Midlands Quality Review team. It is also expected to review the End of Life care quality elements of delivery with involvement of the Trust Lead during 2021. Any proposed findings will become part of the Action plan in section 7.

6.2.1 Demographics

The overall population of Shropshire, Telford and Wrekin (STW) is 470,000. Telford and Wrekin has a larger, younger urban population and is ranked as amongst the 30% most deprived populations in England with a population of 180,000.

Sources from Public Health England End Of Life profiles 2018/19 show that key points are:

- In Shropshire Telford and Wrekin 66% of people say they would like to die at home however only 23% do so. However there has been a slow but gradual decline locally in people dying in hospital and this number is below the national average.
- Having declined for decades, the number of deaths has begun to rise and is set to continue both locally and nationally with the greatest number of deaths in those aged 85years and over.
- Frailty has been found to be the single largest underlying cause of death, accounting for close to half of all deaths. Frailty has the largest proportion of deaths in a care home setting.

Whilst waiting for the 2021 census data (expected March 2022) data from 2011 census shows that there is an increase in single person households aged 65years and over. There has been an increase since the 2001 census from 17,566 to 18,077 in 2011.

Taking into account national and local trends of an expansion of this age group, there will be an impact on service provision where this group have no immediate family or spouse to support them in their later years.

6.2.2 Epidemiology

To provide further context and recognition of some of the challenges ahead for Shropshire, Telford and Wrekin the following need to be taken into consideration. These have already been identified in the Shropshire, Telford and Wrekin Sustainability Transformation plan 2016-2021 and SCHT's Palliative and End of Life care strategy for Adults 2017-2021:

- Life expectancy rates have improved steadily over the past decade in Shropshire, Telford and Wrekin however rates in Telford and Wrekin remain significantly worse than the national average.

- 60% of early deaths under the age of 75years are due to preventable cardiovascular diseases, cancers and respiratory disease. Early deaths and survival rates for cancer in Telford and Wrekin are above the national average

- The number of people with a diagnosis of Dementia is increasing and will continue to increase from 6.9% in 2012 to 8.4% by 2030

- Frailty is considered to be a Long term condition, not every older person will be considered frail. However frailty does increase with age, especially for those who are 85years and over. Sources referenced in this strategy showed that frailty is the single largest underlying cause of death, accounting for close to half of all deaths in Shropshire, Telford and Wrekin

In summary for this section, what we do know from the analysis of trends and forecasts locally is that there will be an increase in deaths by 22% in the decade 2020-2030 from 4,781 to 6,309 per annum. The greatest number of these deaths will be in those 85years old and over. This will have the greatest impact on future demand in Shropshire, Telford and Wrekin.

Essentially the data shows we continue to have an aging population and deaths are set to continue to rise during the 3 years of this strategy and beyond. This is an important to factor in our demand and capacity requirements which are addressed in the action plan.

7. Delivering the agenda

7.1 Action plan

The key message to state at the outset of delivering this action plan is that the Community Trust can only achieve some elements of these actions and requires other partners to have the same upstream approach to end of life care. What we can achieve is to build on the foundation we have set in the first strategy, for clarity the action plan will be in 3 sections, these are:

- Actions specific for SCHT
- SCHT criteria for referral into Community services
- Action taken by SCHT to get the system issues addressed:

Actions for SCHT			
Key Action	By whom	Outcome and measurement	Where referred to in the strategy.
Improving lives-to continue with early recognition/upstream planning (advance care planning) Proactive	Development of EOL strategy programme plan. SCHT EOL strategy implementation group.	Evidence of a proactive approach to EOL care: • More people with a Respect	Section 4.1 and 5.2, 5.3, 5.4

approach for when a person is in or approaching the last 12 months of life. Including those people with Frailty	EOL operational group	document. • More people with an advance care plans.	
Commitment to Quality- To meet the wishes and preferences of a person who wishes to die at home.	EOL strategy implementation group EOL Operational group	Reduction in those patients who are recognised as EOL dying in hospital when they wish to die at home.	Section 5 all, 6.1, 6.2
Predicted increase in deaths in those in >85years and the increased demand on workforce for EOL care in the last year of life	Workforce Planning and modelling in SCHT. Also and action for ICS in section 3	Workforce modelling work to report back progress to the EOL implementation group.	Section 6.1 and 6.2.1
Frailty- screening, case finding- goals of care and treatment. Development of a frailty plan for the community trust.	EOL Strategy implementation group Community Hospitals Medical advisors group Care Home MDT Clinical Service managers	Evidence of more screening/case finding of Frail patients. More advance care planning/anticipatory care planning To connect with the proposed system wide approach to frailty (see section 3)	Section 6.2.1 and 5.4
Compassionate care- to further develop skills to have important conversations- enhanced communication skills.	EOL Strategy implementation group. EOL operational group Severn Hospice Health Watch Voluntary sector	All staff who care for people who are End of life to have undertaken communication skills and advanced communication skills. Evidence of increased advance care planning	Section 5.2. 5.5
Respect and dignity. To develop a dialogue and open culture around death, dying and bereavement. Development of a communication plan for engagement of users of community services	EOL strategy implementation group Communications team	A wider understanding of death and dying starting to emerge	Section 5.2. and 5.1
Everyone counts- equitable accessible person centred care for	SCHT – further development of website EOL information for signposting into Community Services and engagement with the public	Consistent and up to date information available to the public on End of Life Care in SCHT.	Section 5.2.

	Integrated care system- following on from this a system wide in access to advice and support, addressed in section 3 of action plan		
Working together for patients-referrals into community services is usually late in a person's disease which can result in crisis management Development of referral criteria into community services	EOL strategy implementation group Team Leaders/wards managers. Clinical service managers	Evidence of upstream working and referrals into the community services in the last months of life rather than in the last weeks and day. Reduction in emergency hospital admissions for those pts who are in the dying phase.	Sections 3.1, 5.2, 5.3, 6.1, 6.2
Further development of the other Community Hospitals, options to consider for current and future medical cover, End of Life care including symptom management	Community Hospital transformation group Medical Director – new GP contract for the Community Hospitals Learning from Deaths group	Evidence of the actions from the Learning from death reviews/complaints embedded into practice	Section 3.1 and 5.2. 5.3, 6.2
Development of quality indicators based on the success criteria for EOL care	Quality Team End of Life operational group	Quality Indicators for EOL care	Section 7
To ensure STW Place agenda includes end of life care	End of Life Lead to ensure input into this piece	The whole system end of life review and its outcomes informs the Integrated care system and further strategy development	Section 6.1
Section 2- the right criteria in place for referral into SCHT community service			
Develop criteria of what we want in place as patients are transferred into community services from other organisations to ensure an upstream approach to EOL care is in place	For development and agreement in SCHT by clinicians then submitted to the system lead for negotiation and agreement with partner organisations	Emerging evidence of whole system approach to upstream working. Referral of patients earlier in their disease trajectory Monitoring the quality of referrals into the	Sections 2,3, 3.1,5.1,5.2., 5.3

		community trust and reporting to Quality and Safety Delivery Group/Committee.	
Section 3- System and interface issues made visible and presented in this strategy and require a whole systems approach			
A system wide agreed direction of travel for end of life care that is working upstream.	A request to the Board to get the system issues addressed	Consistent and best quality patient care ensuring that each part of the system understands its role and input into that direction	Sections 4,5.1,5.5
Variations in End of Life care in General Practice/PCN's Primary Care Networks (PCN's) • To understand the role of the role of PCN's in EOL care and the contractual requirements. • Establish whether all PCN's will be delivering against the service specification. • How will PCN's develop their registers of those who require EOL care within the last year of life and how will this data be shared with other providers? • Inconsistent practice in recognising when a person is in or approaching the last 12 months of life.	A request to the Board to get the system issues addressed.	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	Sections 3.1, all section 5, section 6.1
Patient and public involvement in End of Life care and the role of the Public Health Dept in EOL care.	A request to the Board to get the system issues addressed.	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy	Sections 5.1, 5.2, 6.1

Further engagement and expansion of Compassionate Communities across the county		implementation	
A system wide approach to bereavement support and support for carers	A request to the Board to get the system issues addressed	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	Sections 5.1, 5.2
One point of access/portal for people(patients and carers) to access options for planning care needs, plans for life ahead, death, dying and after	A request to the Board to get the system issues addressed.	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	Sections 5.2, 5.3
To commence End of Life care at upstream points, to be identified against a set of criteria, where preferences, choices and opportunities are discussed with the patient and those important to them. Progressing to a system wide approach to upstream working, advance care planning/planning ahead.	A request to the Board to get the system issues addressed. System wide Advance care plan, task and finish group	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation To reduce the pressures on the Urgent Care system. More people who want to die at home are able to do so.	Sections 2,3,3.1,4,5.2 5.5
Palliative treatment interventions- to bring in upstream planning and options as the disease progressed	A request to the Board to get the system issues addressed	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	Sections 3,3.1 5.2,5.3,5.5
Predicted increase in deaths in those in >85years and the increased demand on workforce for EOL care in the last year of life	ICS- workforce work-stream A request to the Board to get the system issues addressed.	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	Sections 3,5,5.2.5.3, 6.2
A system wide approach to Frailty, a consistent approach to case finding, assessment and goal planning. Connecting the acute trust frailty teams with the wider community.	A request to the Board to get the system issues addressed.	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	Sections 5.2,5.3, 5.4 6.2.1
Citizen	A request to the Board	Progress reported back	Sections

engagement/community volunteers for EOL care	to get the system issues addressed.	to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	5.1,5.2
Further implement and build on digital ways of working. To build on experiences gained during COVID 19	A request to the Board to get the system issues addressed.	Progress reported back to SCHT EOL Strategy Implementation Group to ensure alignment with SCHT strategy implementation	Section 5.1,6.1

Further actions to the plan will be added following any agreed outcomes from the West Midlands Quality Review team piece once completed.

We need to consider revising how we define success and any measurements for patient outcomes. These will need to be aligned to the strategy vision and associated strategic aims. We propose the work for this becomes part of the agenda for the Strategy Implementation group and that we feed into the Integrated Care system processes for system wide agreement. In the meant time we propose the following:

7.2 Measurable patient outcomes/expected outcomes

- Advance care planning/planning ahead/ReSPECT
- Reduction of hospital admissions for those patients who are in the last/weeks days of life.

7.3 Success criteria as defined by some SCHT clinicians to inform the development of the quality indicators for End of Life care as presented in the action plan section 7
Overall these will be directed to elements of providing an upstream panning ahead approach to care delivery

- Dignity- dying with dignity. Free from pain and distress
- Knowing that the patient is End of Life so the patient and family can be prepared and have an understanding of what to expect
- Anticipatory medications written up/symptom management and control
- Avoid crisis situation so that patients death can be planned with support networks in place
- To be able to choose where a patient wants to die
- To address not only physical needs but psychological, spiritual and cultural needs for patient and the family
- Advance care plan in place/ ReSPECT
- Multidisciplinary meetings for End of Life patients
- Shropshire End of Life plan in place in the dying phase

The next 2 sections provide the outline of reviewing and reporting and audit actions as part of the strategy delivery programme

7.4 Reviewing and reporting

- Resume the End of Life Strategy implementation group to oversee the implementation
- Ensure clear connections with SCHT's End of Life Operational Group and its role in delivering the actions.
- Develop a programme plan for the actions- with dates, timeframes and responsibilities.

- Develop a process for reporting that records all those situations where patients are referred into the Trust where no upstream planning has been commenced prior to referral
- Continue Connections with the Learning from Deaths group
- Provide Monthly reporting to Quality and Safety delivery group And Reporting progress to Quality and Safety Committee and Trust Board

7.5 Audit

- National audit for care at the end of life (NACEL) yearly audit
- Annual Shropshire End of Life plan audit
- ReSPECT process and document audit annual
- Ongoing Bereavement survey for Community Hospitals
- Bereavement focus groups
- Datix End of Life incidents
- Complaints and Compliments
- Audit against the referral criteria into community services.
- Learning from death reviews
- Success criteria measures/quality indicators

8. Summary

The direction of travel and intention in this strategy continues with an upstream approach to End of Life care.

The beginning of this strategy document sets out what has been achieved from the implementation of our first strategy and what has become visible in relation to other organisations and interfaces between these.

Throughout this document findings are set out from various sources of evidence and information which will define the direction of travel required for End of Life care over the next three years for Shropshire Community Health Trust including the issues to be taken into account and forward by our Integrated Care system.

The impact of COVID 19 rapidly opened up further collaborative working between organisations for End of Life care, it placed death dying and bereavement clearly in the public domain. All of these key findings need to be taken further.

We can see from the predictions in the current demographic information that there continues to be challenges due to the increasing ageing population and longer life expectancy. With increasing age comes the increasing number of older people with Frailty and the likelihood of frequent hospital admissions in the last two years of life. We also know that not as many people die at home who wish to in Shropshire Telford and Wrekin. However trends show that the number of people who die at home and in care homes is on an upward trajectory. Both factors will increase the demand on community services as we aspire to meet the wishes and preferences for those who are in the last years of life. Such actions will reduce the need for unnecessary hospital admissions for End of Life care.

9. Conclusion

The key action for Shropshire Community Health Trust is to progress upstream working and to require the new Integrated Care Team to lead the work necessary to provide seamless care, flow and connectivity between and within our local health and care system. This in pursuit of excellence in the provision of End of Life care.

We look forward to the time our patients, carers and families can experience that seamless flow and continuity of care during their End of Life care experience. We all expect this.

Consultation
Tina Long- Non Executive Director
Steve Gregory- Director of Operations and Nursing
Dr Jane Povey- Medical Director
Claire Horsfield- Deputy Director for Allied Health Professionals
Angela Cook- Head of Nursing
Dr Karen Stringer- Associate Medical Director (Strategy)
Dying well champion- Deana James
Clinical Services manager (for IDT's)- Donna Jones
Community Hospitals- Jane Hollins
Community Trust volunteer- Elisabeth Morris/Jan Thornhill

Communication of strategy
SCHT Communications team- all staff communication channels
Partner organisations
Health watch
Action for End of Life strategy implementation group- to set up regular updates
Dying Well champions

References

Care Quality Commission 2020 Review of Do not attempt Cardiopulmonary resuscitation decisions during COVID 19 Pandemic. Interim Report November 2020

Cicely Saunders International 2021 You Matter Because You are You- An action plan for better palliative care January 2021

Hospice UK 2020 Future Vision programme – Discovery phase (starting the collective sector-wide conversation around re-imagining a more sustainable future for palliative and end of life care) September 2020.

Midlands and Lancashire Commissioning Support Unit 2020 Health Service use in the last 2 years of life in Shropshire Telford and Wrekin. Report commissioned by STW STP

NHSE 2019 Long Term Plan

NHSE 2019: A 5 year framework for GP contract reform to implement the NHS Long Term Plan

NHSEI: 2020 Integrated Care- next steps to building strong and effective integrated care systems across England

Public Health England 2021 End Of Life profiles 2018/19

Shropshire Community Health Trust: data and reports

- Datix incident reporting system (SCHT) End of life report 2017-2020
- Electronic patient record- RIO (SCHT)
- Quality and Safety Committee SCHT 2021 Learning from Deaths report 21/1/21 for Reports/minutes/investigations/reviews (can be accessed via the Medical Directorate SCHT Sharepoint portal for Learning from Deaths and the Network file store via the Learning from Death Facilitator)
- Shropshire Telford and Wrekin STP 2020 Advance Care plan Framework,

Shropshire Telford and Wrekin STP 2020 Transformation Plan 2016-2021

Glossary

Definitions of Palliative and End of Life care Source General Medical Council 2010 End of Life Care (EOL) is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. Patients are approaching the end of their lives when they are likely to die within the next 12 months. This includes patients whose deaths are imminent (expected within a few hours and 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'
EOL End of Life
ReSPECT Recommended summary plan for emergency care and treatment. This creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices.
SCHT Shropshire Community Health Trust.
SPICT Supportive and Palliative Care Indicators tool. A clinical indicator tool to aid decision making in recognising when a person may be in the last 12 months of life.
Rockwood Clinical frailty score a tool with visual aids and descriptors to guide clinicians in determining the degree of frailty
IDT Interdisciplinary teams (community teams in Shropshire ,Telford and Wrekin)
STW Shropshire Telford and Wrekin

Appendices

Appendix 1
Living well End of Life and care – key elements, journey

No one route or pathway will be appropriate for all the population, patients, family and carers, though it is recommended that all the population have access to the public health agenda and then move in out of health and social care services with the understanding of the advantages of having raised to the surface, discussed dying death and loss as part of the human experience. The journey will not be a linear process in terms of a fixed pathway.

No Public Health led input and no shared foundation of values, what delivery gets rewarded health and care system wide approach re End of Life care happening at the moment in STW

The public Health agenda includes not only that set up and directed by the Public Health but parts of the local authorities but includes, (hopefully in some sort of mapped and recorded way) all those opportunities to address, plan and review this agenda as provided by the local voluntary and charity sector groups and organisations, including Citizens Advice Bureau, Compassionate communities (overseen by Severn Hospice):

- guiding to will writing, how power of attorney works, finance and health and care and access points, how advanced care planning works
- developing and updating online materials to address above in a portfolio approach (Age UK provide such just for will making actions)
- link to housing needs re ageing and becoming less mobile and possible downsizing
- planning ahead and developing care statements

No current ownership mapping or oversight of this level of input, this is where a population health care approach that partners with housing is of great value

Context: Shropshire Telford and Wrekin

- Urban and rural locations
- Ageing population demographic profile with high rates co-morbidities, falls and frailty, epidemiology high for younger age group re cancer, many single households for older people, less family live locally,
- ageing care workforce, many to retire over next 5 years, and lived and worked in this area a substantial time
- High number of deaths in hospital
- A number of voluntary/charity sector older people citizen groups

Population to patient and end of life care journey example from now as system wide approach is put in place

Robert aged 62, has parents ageing and becoming less independent. He wants to know how to get help or advice or materials, raise issues with his parents to discuss dying death and loss in context of their situation. All live in Shropshire Telford and Wrekin location:

- Entry point for him is via Public Health and the conversations start about planning ahead for himself and with his parents
- Entry point for parents into Health and Care systems has already happened via GP and referrals to Acute sector Consultants and to Occupational Therapists for their housing changes, social prescribers via the new GP contract
- Drawing on an IT information and data recording based service leads for the family are identified (in which ever parts of the system the parents are accessing and receiving care) and care coordination between all the many health and care and the sectors commences ensuring seamless care between the boundaries, intersections and interfaces of each subsystem

The health and care system organisations and providers include:

All Public Health as above, GP and GP out of hours, Any of the Acute sector specialities, diagnostic and other services in the Acute sector including A and E, Ambulance service, Community Care Services including Community Hospitals, Hospice, Mental Health Services, Care Homes, social personal care, mortuary, Death certification and registration, bereavement services All the many professional and range of staff groups

The journey requires: A flowing seamless service

- Connections between all the subsystems involved in providing any aspect of health and care
- Sharing of health and care input and plans
- Coordination across boundaries --- boundary/interface points will have entry and exit criteria so SEAMLESS input occurs
- A fit for purpose IT and data recording system
- Training programmes for all levels of staff with agreed directions of travel

Appendix 2

RIO- End of Life data- deaths within a 28days of referral to the Community Nursing Teams

The biggest impact of COVID has been the increase of patients who have died within 28 days of referral to community teams for EOL care. Especially those patients who died within a week of referral.

Table: Patients who died within 28 days of referral to the community teams