

## ADVANCE CARE PLANNING (for adults aged 18 years and above) FRAMEWORK FOR HEALTH AND CARE PROVIDERS



### Revision version control

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***Developed and recommended by the multi-disciplinary Advance Care Plan Task and Finish group.***

The ACP Task and Finish Group reports into the Community and Place Based Programme Board (via the End of Life workstream)

**This framework will be reviewed and updated regularly so please ensure you are accessing the most recent version available here <https://www.severnospice.org.uk/advance-care-planning/>.**

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## Foreword

Advance care planning (ACP), done well and sensitively, is part of normal health and care practice. It is part of good care or “business as usual,” to quote Dr Ian Sturgess, Clinical Lead for Urgent and Emergency Care - Frailty and chair of the Midlands Frailty Collaborative for NHSE/ Midlands Region.

ACP is the opportunity to talk to individuals, their families and those who care for them, including health and care staff working in our hospitals, our communities and care homes, about what matters to them. It is a plan that describes future preferences and health priorities should that person become unwell or no longer have the capacity to tell others what they would like. It may include specific actions that could support the individual closer to home; it may include being cared for in another health care setting, including hospital, for appropriate treatment; it can include an informed decision, discussed with that individual, about resuscitation and other treatment. An initial conversation about ACP can be started by anyone, including the individual or their family or anyone providing their care, but the person completing the forms should have the right training. An ACP can always be reviewed by the individual with their health and care provider at any time.

We know that many local system clinicians already support individuals with these important conversations. In October 2019, health and care organisations in Shropshire, Telford and Wrekin worked together to launch the use of the ReSPECT form. The ReSPECT form records what is important to an individual and the clinical recommendations for their future health and care treatment in the event of a crisis. Before we started using the ReSPECT form locally, we carried out wide-ranging consultation with patient representatives and health and care staff. We see the ReSPECT form as the foundation to ACP. It is a summary that health and care staff can quickly refer to in the event of an emergency when an individual is unable to make or communicate their choices. An ACP records more detail about what matters to the individual as a whole. Every person with an ACP should have a ReSPECT form.

We have written this framework for health and care professionals, with evidence, guidance, training and practical tips, to support the people of Shropshire, Telford and Wrekin and their families, if an ACP is asked for or needed. We have made this framework available online, along with a wealth of supporting information, which can be found on the Severn Hospice website who are kindly hosting the information here <https://www.severnhospice.org.uk/advance-care-planning/>.

Whilst this document is aimed at health and care staff, anyone is welcome to read it but there is an ACP booklet written specifically for members of the public, available in several languages, that can be read on NHS England's website here <https://www.england.nhs.uk/improvement-hub/publication/planning-for-your-future-care/>.

An ACP should ideally be in place ahead of any deterioration in health and it is important that individuals with their families are included in these conversations and understand their own health and care needs. They need information based on evidence about treatments and their success, so that they can understand why certain interventions or decisions might not be effective or in their best interests. When discussing and completing an ACP, it is important to have confidence in the information and evidence you are providing.

*Dr Ian Sturgess says, “For people living with frailty, ACP is part of a ‘quality conversation’. A Clinical Frailty Scale (CFS) of 7-9 (in the validated population) will act as a trigger for clinicians to consider whether such a discussion needs to be considered. The framing of an ACP is to consider from the individual’s perspective ‘what matters to me and not just what is the matter with me’.”*

Evidence shows that increasing frailty (particularly those with a Clinical Frailty Score (also known as CFS or Rockwood score) of 7-9 (see Appendix 2)) and those living with more than one life-limiting illness or disease are linked with poorer outcomes. This is because, for these individuals, their bodies are less able to physically cope and recover from a crisis. The CFS is an approved evidence-based scoring system that can help inform conversations about an individual's treatment options and preferences

Several organisations and healthcare services including the hospice have strongly supported ACP for many years. The Telford and Wrekin care home multidisciplinary team has supported ACP in care homes since 2018 and it was found to be so valuable that in November 2019 they worked with the Frailty Collaborative so that ACP could be extended across the county. Since then the Frailty Collaborative has supported ACP in the Shrewsbury and Telford Hospital NHS Trust and Shropshire nursing and residential care homes. Staff from health, social care and the voluntary sector have worked together to share their learning and experiences.

The new Primary Care Networks link with this activity through the Network Contract Direct Enhanced Service (DES). You can read more about the DES here <https://www.england.nhs.uk/wp-content/uploads/2020/03/network-contract-des-specification-pcn-requirements-entitlements-2020-21.pdf>

The aim of this framework is to bring together our approach to ACP across all organisations in Shropshire and ensure that those who would benefit from ACP are identified and are able to complete an ACP if it's what they want.

Thank you for your continued hard work in caring for the people of Shropshire, Telford and Wrekin.

**The ACP Task and Finish Group.**

## ***A message from Dr Jane Povey, Medical Director, Shropshire Community Health NHS Trust:***

“This has been an extremely challenging year for our community and our health and care services and this revised ACP Framework is a great example of how we are working together to improve health and care provision for everyone, including the most vulnerable across Shropshire, Telford and Wrekin. The framework will enable everyone with deteriorating health to have quality conversations with health and care staff and make a care plan aligned to what matters most to them as individuals.

“Thanks to the enthusiastic involvement of patient representatives, the voluntary sector and both Healthwatches, this framework is being evolved, implemented and steered by our community and enabled by the many experts in the ACP Task and Finish Group.

“I would encourage you to share this widely, and use the supporting information and opportunities for training we will be providing to enable this approach to simply become business as usual for all of us.”

## Glossary of abbreviations

ACP*	Advance Care Planning
ADRT	Advance Decision to Refuse Treatment
BHF	British Heart Foundation
BMA	British Medical Association
BRESUS	British Hospital Resuscitation Study
CCG	Clinical Commissioning Group
CFS	Clinical Frailty Scale (Rockwood)
CNS	Clinical Nurse Specialist
CPR	Cardiopulmonary Resuscitation
CQC	Care Quality Commission
ECIST	Emergency and Urgent Care Intensive Support Team
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
eFI	Electronic Frailty Index
EMIS	Electronic Patient Record System used by Shropshire GPs*
EoL	End of Life
EoLC	End of Life Care
EPR	Electronic Patient Record
ICD/CRT-D	Implantable Cardioverter Defibrillators
ICU/ITU	Intensive Care Unit / Intensive Treatment Unit (Critical Care)
LHRP	Local Health Resilience Partnership
LTC	Long Term Condition
MCA	Mental Capacity Act
MDT	Multidisciplinary Team
mFI	Modified Frailty Index
MPFT	Midlands Partnership NHS Foundation Trust
NICE	National Institute for Health and Care Excellence
PPE	Personal Protective Equipment
PRH	Princess Royal Hospital
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
RJAH	Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust
RSH	Royal Shrewsbury Hospital
SaTH	Shrewsbury and Telford Hospital NHS Trust
SCHT	Shropshire Community Health NHS Trust
SCRai	Summary Care Record additional information
SPIC	Shropshire Partners in Care
SPICT	Supportive and Palliative Care Indicators Tool
STP	Sustainability and Transformation Partnership
WMAS	West Midlands Ambulance Service
* Egton Medical Information Systems	
*ACP can also sometimes refer to Advance Clinical Practitioner	

## Who this framework is for

- All health and social care practitioners
- Patient advocates
- Health and social care leaders and managers
- Anyone filling in a ReSPECT document

NB This document has been written for health and care staff. Although the general public is not the intended audience, this framework is publicly available online. Information about ACP written for the general public can be found by clicking on the following document:



EoLC-Planning-for-  
our-future-care.pdf

## Guidance

ACP is an important and sensitive conversation so we have written this guidance to support the development of new ACPs and the review of those already in place for people living in Shropshire, Telford, and Wrekin. This guidance provides a framework for our local health and care system (STP) approach and is supported by a number of documents and background information, and feedback and experience provided by patient representatives and health and care staff. We thank everyone who has contributed with evidence, experience and concern for patient safety and dignity.

Evidence shows that increasing frailty (particularly those with a Rockwood Clinical Frailty Score of 7-9 (see Appendix 2)) and those living with more than one life-limiting illness or disease are linked with poorer outcomes. This is because, for these individuals, their bodies are less able to physically cope and recover from a crisis. It is important that individuals, their families, and their health and social care providers feel confident that decisions made about care and potential levels of care are based on evidence, not just a reaction to an emergency situation (A review of the evidence for ACP in the community is provided in **Appendix 3**).

This framework is supported by a toolkit, further resources and FAQs based on the questions and feedback we have received. These are all available to read on the Severn Hospice website here <https://www.severnospice.org.uk/advance-care-planning/>

## Key definitions

**Advance Care Planning (ACP)** Advance care planning offers people the opportunity to plan their future care and support, including medical treatment, while they have the capacity to do so.

**Personalised Care and Support Plan** A way of capturing and recording conversations, decisions and agreed outcomes that makes sense to the person. The plan should be proportionate, flexible and coordinated and adaptable to a person's health condition, situation and care and support needs. Should include a description of the person, what matters to them and all the necessary elements that would make the plan achievable and effective.

**Anticipatory Plan** An anticipatory care plan should be considered when a person's health status is expected to change, often called a clinical management plan, it details how an individual's health status may change, what to look for and how to manage the change. This type of plan aims to avoid a crisis.

**End of Life Care Plan** An End of Life Care plan details the treatment, care and support for a person nearing the end of their life. It should include the relevant details of an advance care plan and include anticipatory care needs.

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

Recommended Summary plan for emergency care and treatment, is a summary of all Personalised Care and support plans which has details of what should be considered in an emergency situation. It can include attempt resuscitation (CPR) or do not attempt resuscitation (DNA CPR). A ReSPECT form should be updated if a person's health status or the care setting changes, to check the content, make any necessary additions and to update local records e.g. changes to DNACPR status

**Community Individual Care Plan** is for anyone who needs care or cares for someone else. It includes: the type of support you need; how this support will be given; how much money your council will spend on your care.

**The electronic Frailty Index (eFI)** is a risk stratification tool. It is not intended to be used as a diagnostic tool and should be validated with clinical judgement and other frailty tools. Further information is available on the NHS England website, to read it please click on this link: <https://www.england.nhs.uk/ourwork/clinical-policy/older-people/frailty/frailty-risk-identification/>

**Key message for our health and care staff:** “Think ahead – be proactive: Create, update, and share more advance care plans for our vulnerable patients and their families.”

## **Aims of this framework**

- To enable health and social care staff to support the adult (18 years and above) population of Shropshire, Telford and Wrekin to make informed decisions about their future preferences should their health deteriorate
- To provide a framework that includes the latest evidence and guidance for health and social care staff where these important conversations need to be had and difficult decisions need to be made about the appropriateness of care, care settings and access to emergency or critical care
- To promote a system approach, supported by local clinical expertise and feedback from patient representatives, at a time when the number of very ill people is increasing
- To plan for the discharge of dying patients to their preferred place of care
- To support end of life care of patients in the community
- To support families and communities who may need help to talk about future care with loved ones, and emotional or bereavement support themselves

## **Suggested actions for our local health and social care system**

1. All health and care organisation within our STP area should have an ACP implementation plan and be measuring the impact of ACPs.
2. An initial conversation about ACP can be started by the individual or their family or anyone providing their care, but the person completing the form should have the right training. Two documents that can support early discussions around ACP are the 'Thinking Ahead' Gold



[Standards Framework Advance Care Planning Discussion<sup>1</sup>](#) and the [Planning for your future care booklet<sup>2</sup>](#).

3. For training on ReSPECT please visit <https://learning.respectprocess.org.uk/>. Please visit the ACP pages on the Severn Hospice website for more information about the available resources and training opportunities <https://www.severnospice.org.uk/advance-care-planning/>. Local training and development resources and materials to support the measuring of outcomes are in development – these will be shared when they become available.
4. The ACP must be made on an individual basis, according to need and not applied to groups of individuals or conditions. This is reinforced by the joint statement on advance care planning issued on 1 April by the British Medical Association, Care Provider Alliance, Care Quality Commission and the Royal College of General Practice which can be read here <https://www.rcgp.org.uk/about-us/news/2020/april/joint-statement-on-advance-care-planning.aspx>
5. Ensure the GP practice patient record is as complete as possible using the appropriate codes.
6. Adults (aged 18 and over) most likely to benefit from having an ACP should be given the opportunity to discuss ACP. This might include individuals for whom any of the following apply:
  - is well and chooses to make an ACP
  - is in their last year of life (use the SPiCT tool to help identify people in this stage of their life: [www.spict.org.uk/](http://www.spict.org.uk/))
  - has a Rockwood score of 7-9
  - is a care home resident
  - is an inpatient in hospitals (acute and community)
  - is extremely vulnerable to complications of a pandemic or endemic disease, particularly those who are ‘shielding’
  - is living with advanced or multiple long-term conditions or advanced cancer.
7. Where a person has capacity, as defined by the Mental Capacity Act (2005) (MCA), the ACP should always be discussed with them directly. Where a person lacks the capacity then it is reasonable to complete an ACP by following the MCA best interest guidance with the involvement of their family or other appropriate individuals. To support you with this, the BMA have produced a toolkit available to read on their website here <https://www.bma.org.uk/media/1849/bma-mental-capacity-act-toolkit-2016.pdf>
8. Make sure every individual identified as being end of life has an up to date ReSPECT form (**Appendix 6**) and /or an Anticipatory Plan (**Appendix 7**). The paper copy of the ReSPECT form should be kept with the individual, with a copy emailed to the GP Practice to be added to their GP records. ReSPECT form templates are available on the Severn Hospice website here <https://www.severnospice.org.uk/wp-content/uploads/2019/10/ReSPECT-form-vOct-2019.pdf> or can be found in **Appendix 6**. There is now a new version of the ReSPECT form available - where individuals have a previous version of the ReSPECT

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<sup>1</sup> <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/ACP%20General%20July%202013.v21.pdf>

<sup>2</sup> [https://www.nhs.uk/livewell/endoflifecare/documents/planning\\_your\\_future\\_care%5B1%5D.pdf](https://www.nhs.uk/livewell/endoflifecare/documents/planning_your_future_care%5B1%5D.pdf)

form in place, this will continue to be valid, and there is no need to transfer their information onto the new version.

9. Make sure all care home residents, who have capacity, have the opportunity to talk about ACP, ReSPECT forms and/or Anticipatory Plans and involve their family or advocate where appropriate.
10. Make sure all hospital patients (in our community and acute hospitals) have the opportunity to talk about an ACP. Start and where possible complete (if appropriate) the ReSPECT form and/or Anticipatory Plan, without delaying the patient's treatment or discharge from hospital. Record and share the conversation and patient's wishes with the relevant practitioners using the appropriate documents including the discharge summary. This approach should ideally be part of the discharge process to support a follow-up discussion and appropriate care, particularly if that plan is started but needs sign-off and recording in the community, for example by the individual's GP. Secondary, tertiary and community clinics are also appropriate settings for conversations which should be recorded and shared as above.
11. Use the electronic Frailty Index (eFI) if available to identify individuals in your area of responsibility, who are aged 65 and over and living in their own home, with frailty. A Rockwood score should be completed for everyone with an eFI indicating frailty to validate it. Make sure that those with a Rockwood score = 7 or greater have an up to date review of their ACP (remotely if necessary) and any change to their level of frailty is added to the ReSPECT form. Offer individuals with mild or moderate frailty, Rockwood score = 4 - 6), and who would benefit from an ACP, the opportunity to discuss and complete a ReSPECT form, an ACP and/or Anticipatory Plan. You can read about the Rockwood score on the Guidelines in Practice website for health professionals here: <https://www.guidelinesinpractice.co.uk/care-of-the-elderly/top-tips-frailty-in-older-people/454045.article>. There is also a free mobile app: CFS.
12. The NHS Specialised Clinical Frailty Network states that the "CFS has not been widely validated in younger populations (below 65 years of age), or in those with learning disability. It may not perform as well in people with stable long-term disability such as cerebral palsy, whose outcomes might be very different compared to older people with progressive disability. We would advise that the scale is not used in these groups. However, the guidance on holistic assessment to determine the likely risks and benefits of critical care support, and seeking critical care advice where there is uncertainty, is still relevant." Follow this link to read the statement in full <https://www.scfn.org.uk/clinical-frailty-scale>

This is also reflected in the updated NICE 'COVID-19 rapid guideline: critical care in adults'. It clarifies that the Clinical Frailty Scale should be used as part of a holistic assessment, but should not be used for younger people, people with stable long-term disabilities, learning disabilities or autism. In these circumstances an individualised assessment of frailty should be undertaken. You can read the guidance in full on the NICE website here <https://www.nice.org.uk/guidance/ng159/chapter/2-Admission-to-critical-care>

Where someone has a learning disability or autism, and the timescales allow, please feel free to get in touch with colleagues from our Community Learning Disability teams CLDT (and/or Intensive Health Outreach Team (IHOT)) for advice and support about individualised assessments of frailty. You can call the CLDT on 01743 211 210.

13. If cardiopulmonary resuscitation (CPR), hospital admission and other acute interventions are considered an effective treatment, discussions should be had with the individual and

their family about their preferences. Where appropriate talk to them about the advantages, disadvantages and likely outcomes of hospital admission and treatment e.g. ventilation. Plans should be updated to record the discussions and include contact information of professionals who can be called for advice and support. The Resus Council website provides information and guidance to support these conversations available through this link <https://www.resus.org.uk/respect/>

14. If an individual has an implantable cardioverter defibrillator, (ICDs/CRT-D) or pacemaker, this should be recorded on the ReSPECT form. If somebody is in their last weeks of life, think about discussing deactivation of the shock function of the ICD to avoid painful and distressing shocks that won't improve the clinical picture. There are many GPs who already do this well. The BHF has a good patient leaflet on deactivating the shock function of an ICD which can be read by following this link <https://www.bhf.org.uk/informationsupport/publications/living-with-a-heart-condition/deactivating-the-shock-function-of-an-implantable-cardioverter-defibrillator-towards-the-end-of-life>
15. ACP should be coded, not just scanned, into the individual's GP record.
16. Make sure that any changes in an ACP are shared with the individual's GP so that it can be recorded in their Electronic Patient Record (EPR) and therefore viewable on the individual's Summary Care Record additional information (SCRai) and accessible to other health and care staff.
17. If the individual has opted out of SCR then discuss SCRai consent with them and share the consent decision with the GP practice so that the SCRai status can be updated.
18. Be prepared to support discussions about advance directives, sometimes called a living will, an advance decision to refuse treatment. When having conversations about ACPs, you may have more requests to discuss Advance Decision to Refuse Treatment (ADRT). Individuals can be referred to guidance available on the NHS England website here <https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/>
19. Be aware of and be prepared to support families whose loved ones are very ill in hospital and where clinicians must make very difficult decisions for admissions to critical care (ITU). Please be aware of the NICE guidance relating to admissions to ITU which can be read here <https://www.nice.org.uk/guidance/ng159>
20. Talk to the individual and their family about their emotional well-being and signpost to other services and organisations, including voluntary and community groups, who can provide them with any additional support they may need.
21. You can access training and support to help you develop the skills to have these important conversations by clicking on the following two links:

Covid-19 focused training:

<https://elearning.rcgp.org.uk/mod/page/view.php?id=10389>

Rockwood Frailty training:

<https://rise.articulate.com/share/deb4rT02lvONbq4AfcMNRUudcd6QMts3#/>

## Additional resources

1. Advance care planning guidance in context of COVID-19 for primary care: guidance and a template for advanced care planning
2. <https://www.mdcalc.com/karnofsky-performance-status-scale>
3. Joint statement on advance care planning. Royal College of General Practitioners. 1 Apr 2020: <https://www.rcgp.org.uk/about-us/news/2020/april/joint-statement-on-advance-care-planning.aspx>
4. Royal College of Physicians. Ethical dimensions of COVID-19 for front-line staff. 31 Mar 2020: [www.rcplondon.ac.uk/news/ethical-guidance-published-frontline-staff-dealing-pandemic](http://www.rcplondon.ac.uk/news/ethical-guidance-published-frontline-staff-dealing-pandemic)
5. Supportive and Palliative Care Indicators Tool: [www.spict.org.uk/](http://www.spict.org.uk/)
6. Guidance on social distancing for vulnerable people: <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people>
7. Guidance on shielding and protecting people defined on medical grounds as extremely vulnerable from COVID-19: <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>
8. Responding to Covid-19: The ethical framework for adult social care: <https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care>
9. Information and best practice guidance for COVID-19 care home management: <https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes>
10. ReSPECT resource: <https://www.resus.org.uk/respect/>
11. COVID-19: BGS statement on research for older people during the COVID-19 pandemic: <https://www.bgs.org.uk/resources/covid-19-bgs-statement-on-research-for-older-people-during-the-covid-19-pandemic>
12. Definition of anticipatory care planning: [https://spcare.bmj.com/content/4/Suppl\\_1/A17.2](https://spcare.bmj.com/content/4/Suppl_1/A17.2)
13. Spectator article by Molly Bartlett: [There is nothing brave about signing a do not resuscitate order](#)
14. Easyread information about advanced decisions and staying out of hospital plan



Updated advance  
decision letter.pdf



Easy read  
admission avoidance

## Advance Care Planning – Definitions and Guidance

Please click on the following document to read the draft Shropshire, Telford and Wrekin Sustainability and Transformation Partnership system ACP definitions and guidance



ACP Definitions and  
Guidance V0.4 Novem

## Appendix 1: Qualitative review of Advance Care Planning in care homes in Shropshire, Telford and Wrekin

During 2019/20 the Shropshire, Telford and Wrekin Frailty Collaborative identified an opportunity to work with Care Homes in the region and the Telford and Wrekin Care Home Multi-Disciplinary Team (MDT) to develop a system wide approach to Advance Care Planning (ACP) for Care Home residents.

This project was accelerated as a result of the global pandemic and from the end of March 2020 two SaTH doctors have supported the project for Shropshire Care Homes working alongside the Telford and Wrekin Care Home MDT to develop a model of support for Care Homes. In May 2020, the Community Trust were able to expand the service with nursing staff to enable a multidisciplinary approach that links with Primary Care Community Services and the broader care sector.

We know that the well established Care Home MDT in Telford and Wrekin has evidenced a reduction in the number of avoidable emergency admissions from care homes and early indications are that Shropshire Care Homes are beginning to do the same.

We also know that Advance Care Planning is not just about reducing avoidable urgent care but more about improving the way that we can predict and react to deterioration and how conversations with people can shape these plans to reflect their future wishes and identify what they would want to happen in the event of an emergency.

In August this year, the clinicians that have been working with Care Homes went back to review a number of ACPs that were implemented during the COVID period with the aim to understand if the ACP has had a positive impact on an individual's care. The ACP Review showed:

- In all circumstances the detail of the ACP were implemented
- Nine people reviewed showed a deterioration in their level of frailty (17% of all plans reviewed), 4 care plans needed updating to reflect this and 1 person needed an anticipatory care plan
- 31% of residents reviewed didn't need any health or care support from Community based services
- 63% of the ACP reviewed identified that hospital care was appropriate
- 6 of the 7 people that were admitted to hospital as an emergency were in this 63%
- The resident that was 'not for future admission' sustained a fracture
- We could conclude that all emergency admissions were appropriate

We know that in the first two quarters of this year attendance at A&E and emergency admissions from Care homes decreased, it is likely that this is a direct result of the pandemic.

We used the information that we have to compare this data between similar homes that have had an intervention from the Care Home Enhanced Support Team with those that have not yet had the support.

We found that those homes that have been supported by the team had a greater reduction in emergency activity than those homes that have yet to receive any support. Care Homes that have not had an intervention saw a reduction of -33% in ED activity, for those that had received an intervention this reduction was seen as -48%.

To read the qualitative review and the results of the review looking at the comparative emergency department admissions, please click on the documents below:



Qualitative review  
V1.3 September 2020



Care Home activity  
comparison slides VC



ACP data.pptx



## Appendix 2: Clinical Frailty Scale

### Clinical Frailty Scale\*



**1 Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



**2 Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



**3 Managing Well** – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



**4 Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up”, and/or being tired during the day.



**5 Mildly Frail** – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



**6 Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



**7 Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



**8 Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



**9. Terminally Ill** - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

#### Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia.

Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

\* 1. Canadian Study on Health & Aging, Revised 2008.

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## Appendix 3: Review of the evidence base for advance care planning in the community

### Introduction

It is important to note that this document reviews which treatment options have successful outcomes for patients who are frail and currently living in the community. This is not a rationing document. It includes evidence from before and during the COVID pandemic.

### Cardiopulmonary Resuscitation Outcomes in Hospital

The most recent cardiac arrest audit on hospital inpatients showed a survival rate to discharge of 18.8% overall, but only 11.4% for patients over 80 years. There was no complete follow up in neurological status or quality of life. Patients who survived had a shockable rhythm at the outset of the arrest (Nolan et al 2014). This is an improvement in outcome from the BRESUS study which showed less than 5% survival to discharge in the 1990s. This is likely to be partly due to improvement in resuscitation services in hospitals but also due to wider application of DNACPR to patients who are unlikely to survive the intervention.

### Admission Outcomes in Patients with Advance Frailty (Physical and Mental)

The Clinical Frailty Scale (CFS) was developed and validated in Canada as a tool for improving management of patients with perceived ill health (Rockwood 2005). It has been used to improve and direct services for the older population to improve their experience of the health care system and their outcomes. It has also proved useful as a prognostic indicator as to who will benefit from which interventions.

Currently there are 400,000 care home residents in the UK (Age UK 2019). Individuals with a CFS of 7, 8 and 9 are extremely dependent and will probably be in the last year of their life. They are very unlikely to survive after interventions such as CPR or intensive care support. It is also unlikely that, if they become very unwell with another acute illness such as bronchopneumonia or COVID-19, they will survive the episode and should have supportive treatment, ideally in the community (NICE 2020).

Individuals with a CFS of 5 and 6 are susceptible to any small insult to their health and can decompensate quickly. Critical care data suggests that they will not benefit from artificial ventilation and life support, if they become very unwell from either general illness or COVID-19. However, they may have recovered, with support in a secondary setting if they do not become critically ill and should be offered this option as is normal practice. They also should be reviewed by intensive care if the medical team feel it is appropriate to consider this.

Individuals with a CFS 1 to 4 are generally independent with good physiological reserve. They will benefit from all interventions in secondary care including ITU and CPR unless they decline it. Importantly this is not age-related.

### Specific Studies related to Frailty - pre COVID pandemic

It is important that individuals and their health care providers feel confident that decisions made about levels of care are based on evidence, not just a reaction to acute circumstances. Therefore, detailed below are studies that were conducted before 2019.

#### 1. Emergency Surgical Outcomes in Frail Patients

Frailty is associated with a significantly increased risk of post-operative mortality and morbidity, irrespective of age. Additionally, increasing frailty score is more independently associated with increased level of care on discharge, and more predictive than admission care level. Frailty scoring should therefore be integrated into routine practice to aid decision-making with older surgical patients.

In traumatic spinal injury, increasing frailty using the modified Frailty Index (mFI) in patients under 76 years independently predicted mortality, length of stay and adverse events. Over 76 years the



mFI it was not an independent predictor but needed to be taken in conjunction with age and total motor score on admission.

## 2. Elective Surgery Outcomes in Frail Patients

In the USA, a large-scale study (14,530 patients) showed a high frailty score was associated with significant morbidity, mortality and readmission across elective surgery of many different fields of surgery. An earlier review in the UK found that pre-operative frailty predicts post-operative mortality, complications and length of stay in older patients (mean age 75-87)

## 3. Emergency Medical Admissions in Frail Older Patients in the UK

CFS grade	Length of stay	Readmission rate	In-patient mortality	Care intentions	Service referrals	Post-discharge support
1	4	4%	2%	Detect and manage geriatric syndromes e.g. delirium	General internal medicine	Self-care
2	5	7%	2%			Prevention (e.g. falls, memory clinic)
3	7	11%	2%			
4	8	13%	3%			
5	10	15%	4%			
6	12	15%	6%			
7	13	14%	11%	Think about palliative vs. restorative care	Geriatric medicine	Transitional care
8	12	10%	24%			
9	10	13%	31%			

The table, from the Acute Frailty Network in the UK, shows high mortality and readmission rate for patients with CFS 7, 8 and 9. Importantly if between 10 and 14% are readmitted in 30 days, they will then have the same high mortality rates.

## 4. Critical Care Outcomes pre 2019

The only study which included patients with a CFS of above 5, showed the mortality rate in ICU, and at 30 days, to be excessively higher than those with a CFS of 5 or below. Hence, the NICE guidance for COVID pandemic admission to ICU is a CFS of 5 or below for patients over 65 years. However, this is guidance only and if the medical team feels with a CFS of 6 a patient may benefit from ICU they should be discussed.

Author, year	Setting	Sample size	Age	Frailty	ICU mortality	30-day mortality	Predictors of poor outcomes
Zampieri, 2018	Brazilian ICUs	24,494	Mean 75.7	MFI <sup>1</sup> non-frail (=0), pre-frail (MFI=1-2); frail (MFI ≥ 3)			In-hospital mortality 28.8%; in a multivariate analysis, frailty OR 2.4 for in-hospital mortality
Darvall, 2019 <sup>12</sup>	Australian/ New Zealand ICUs	6203	>80	CFS≥5			In-hospital mortality 17.6% v 8.2%, OR 1.87
Guidet, 2020 <sup>13</sup>	European ICUs	3920	Median 84	CFS median 4 (3-6)	72.5%	61.2%	Age Hazard Ratio 1.02/year; SOFA 1.15/point; CFS 1.1/point
Muessig, 2018	German ICUs	308	Median 84	CFS≥5	22.4%	42.4%	CFS OR 1.4 for 30-day mortality (multivariate analysis)
Langlais, 2018 <sup>14</sup>	French ICU	189	Mean 74	CFS≥5			CFS OR for in-hospital mortality 1.3
Franczek, 2018	Polish ICUs	170	>80	CFS≥5	47.6%	40.4%	SOFA score (OR=1.16), emergency admission (OR=5.1) and frailty (OR=2.3) increased the risk of ICU death
Zeng, 2015 <sup>15</sup>	Chinese specialized geriatric ICU	155	Mean 82.7	Frailty Index			Each 1% increase in FI was associated with an 11% increase in the 30-day mortality risk adjusting for age, sex, and prognostic scores
Shears, 2017 <sup>16</sup>	Canadian ICUs	150	Mean 63.8	CFS			CFS OR 1.2 for ICU, OR 1.19 for hospital mortality
Silva-Obregon, 2020 <sup>17</sup>	Spanish ICU	53	Mean 78		37.7%	52.8%	CFS≥5 Hazard Ratio 4 for one year survival after adjustment for sociodemographics, comorbidities, severity scores, treatment intensity and complications

## 5. Effect of comorbidity on health outcomes

It is difficult to make wide generalisations about the effect of comorbidities on health outcomes. Studies tend to look at specific interventions such as a surgical intervention, cancer treatment or one chronic disease such as diabetes. However, we do know that the number of comorbidities in one patient, the duration and the presence of organ damage do result in a poorer outcome in acute illness. For example in 'out of hospital' cardiac arrest the presence of one or more comorbidity resulted in reduced survival and poorer neurological outcomes. In patients with pneumonia, comorbidities contribute to the risk of dying regardless of their type or origin. Furthermore, after discharge, there is still a high 30-day readmission rate and mortality following pneumonia influenced by patient comorbidities.

## Conclusions

There is a body of evidence that shows increasing frailty and multiple life limiting co-morbidities are associated with poor outcomes, due to lack of physiological reserve in those individuals, particularly patients scoring 7-9 on the CFS, a well validated scoring system.

Advance Care Planning for this part of the population should ideally have been completed previously, but in an overstretched health care system, that has not always been possible. In any conversations taking place now and in the future, it is important that patients and their relatives are included in all conversations. Also, that they receive correct information based on evidence, so they can understand why certain treatments such as CPR, ITU or sometimes secondary care may not be in their best interests.

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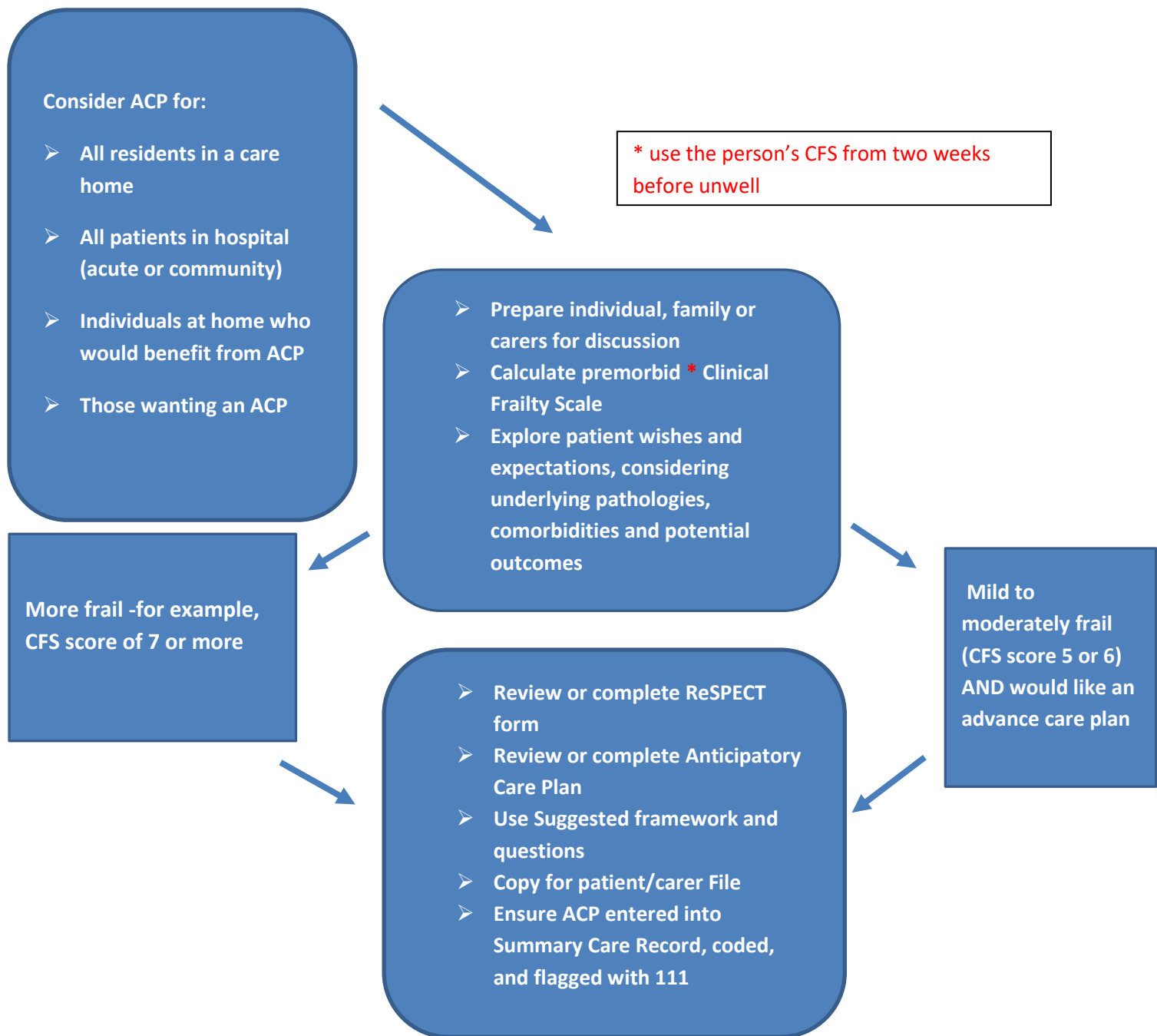
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26. RCP(E) Webinar 19.3/2020

END

## Appendix 4: Advance Care Planning (ACP) Chart




### Additional requirements and information for senior clinicians, leaders and managers

Be up to date with the latest capacity management guidance and supporting documents for anticipatory care planning

Ensure IT access to ACP documentation

Review the overall ACP profile for your area of responsibility to help inform and develop services that meet the local populations need

## Appendix 5: An example of an advance care plan form

Advanced Care Plan		 The Shrewsbury and Telford Hospital NHS Trust	
Name:		NHS number:	DOB:
Address:		Accountable lead GP:	
Home Telephone Number:		Practice Address / contact details:	
Mobile Telephone Number:			
Named next of kin:	Next of kin contact details: Address:		
Relationship:	Telephone Number(s):		
<b>Other Agencies Involved (tick): specify relevant named contacts and contact details if known</b> Community nursing: <input type="checkbox"/> Specialist nursing/ matrons / key workers / hospice: <input type="checkbox"/> Mental health: <input type="checkbox"/> Social care team: <input type="checkbox"/> Specialist acute trust services (eg secondary care, consultant and named hospital): <input type="checkbox"/> Other (eg voluntary sector): <input type="checkbox"/>			
<b>Is there patient consent to share care information with all agencies who are involved in care?</b> If No please specify who can have access to information other than GP: If none specify here: Please tick here if patient themselves lacks capacity to agree &/or understand care plan: <input type="checkbox"/>			
<b>Medical details / care plan:</b> Please list all relevant active problems in the section below (Relevant medical history/long term conditions/active problems list) including any potentially unstable/Brittle conditions listed first if appropriate.			

<b>Thinking ahead:</b>  1. At this time in your life what is it that makes you happy or you feel is important to you?  2. What elements of care are important to you and what would you like to happen in future?  3. What would you NOT want to happen? Is there anything that you worry about or fear happening?  4. Who would you want to speak for you if you were unable to make medical decisions for yourself?																	
<b>If relevant, enter details below:</b> Preferred place of care / death discussed? If yes specify where preferred place of care/death: <b>Resuscitation decision:</b>																	
GP informed:  Agreed by patient:	Involvement/ agreement by any named next of kin/POPP (if relevant): Health Professional completing plan: 2 <sup>nd</sup> health professional: Care worker/manager:																
<b>Anticipatory planning- Intercurrent illness/acute deterioration</b> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th>Problem</th> <th>Desired Outcome</th> <th>Proposed Therapy</th> <th>Monitoring Parameters</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td></tr> </tbody> </table>		Problem	Desired Outcome	Proposed Therapy	Monitoring Parameters												
Problem	Desired Outcome	Proposed Therapy	Monitoring Parameters														

This document can also be viewed by clicking on the document below:



ACP example.docx

## Appendix 6: ReSPECT Form

A new version of the [ReSPECT \(Recommended Summary Plan for Emergency Care and Treatment\) process](#) which supports conversations about care in a future emergency is now available.

[Version 3 of the ReSPECT form](#), is even more patient-centred than previous versions and contains more prompts for explicit clinical reasoning. It addresses areas where misunderstandings have been reported and includes more personable and clearer language. An [FAQ](#) explaining some of the changes has been produced to help embed the new version of the ReSPECT form into practice.

In Shropshire, Telford and Wrekin, we will start using Version 3 over the next few months after we use up existing stocks of Version 2. Where individuals have a previous version of the ReSPECT form in place, this will continue to be valid, and there is no need to transfer their information onto the new version.

Please click on the document below to see a sample of the new ReSPECT form:



ReSPECT  
v3-1-formSPECIMEN

## Appendix 7: Example of an anticipatory plan



First Name-----Last  
Name-----Date of  
Birth-----NHS no-----  
-----

**Problem-**

**Goal /Aim-**

Baseline observations -

Prescribed

Targets

**Plan-**

Day to day management -

Change in symptoms-

Generally unwell -

**Additional Individual Anticipatory Care Plan details:**

Continually review care plan and update as required.

Signature:	Designation:
Print Name:	Date and Time:
Evaluation Outcome of intervention and Rationale for change of care plan:	
Signature:	Designation: RGN Care home MDT
Print Name:	Date and Time:04/03/2020



## Appendix 8: The benefits of forward care planning for palliative care patients

Are there inappropriate palliative patient deaths in emergency departments (ED)? A retrospective study looking at the deaths in a district general hospital ED.



Severn Hospice



University of Chester

Dr Hannah Fox<sup>1</sup>, Dr Matthew Doré<sup>2</sup>, Prof Derek Willis<sup>2</sup>  
Shrewsbury and Telford NHS Trust<sup>1</sup> & Severn Hospice<sup>2</sup>

The Shrewsbury and Telford Hospital NHS Trust



### Introduction

- Palliative patients sometimes present to emergency departments when dying and current policy aims to reduce such unnecessary admissions.
- This study provides a description of palliative care related deaths in an ED and an assessment of how many of these were potentially preventable.

### Methods

- 32 consecutive deaths were reviewed in a district general ED department in Shropshire during September 2016 to August 2017.
- Their presentation, death certification details (1a,b,c and 2), palliative status (Gold standard framework and opinion of GP) and DNACPR status were identified from ED Cas Card Notes, death certificates and from contacting GP practices.
- We retrospectively subjectively assessed whether any patient admission was potentially avoidable.

### Demographics

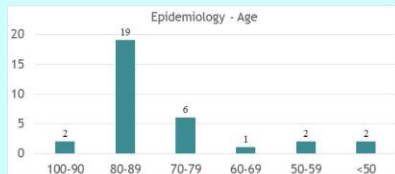


Figure 1: Bar chart to show the distribution of ages of patients. 59% of patients were aged between 80 and 89. The mean age of patients was 78, the median age 83.

Figure 2: Table to show the sex distribution of patients.

	Female	Male	Total
Number of Patients	15 (47%)	17 (53%)	32

### Modality of Death

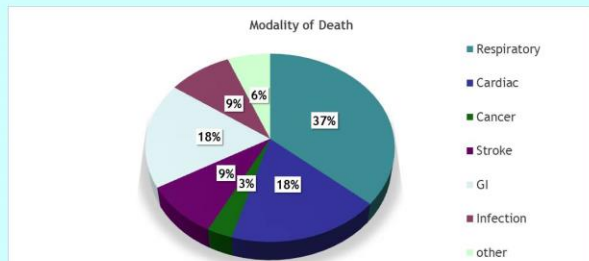


Figure 3: Pie chart demonstrating modality of death. 37% of deaths were attributed to respiratory causes.

### Proportion of patients with an oncological, frailty or dementia diagnosis

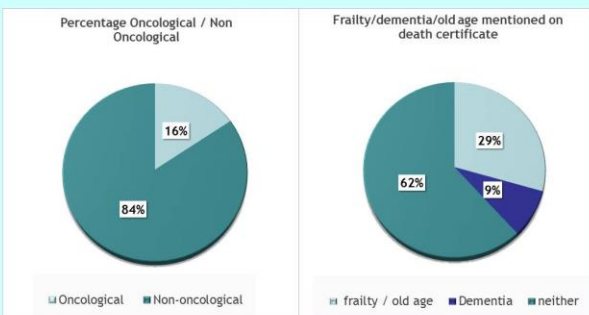


Figure 4: Pie chart to demonstrate 16% of patients that died in ED had an oncological diagnosis (5 out of 32 patients).

Figure 5: Pie chart to demonstrate 29% of patients had frailty or old age and 9% had dementia written on their death certificate.

### Were any of these patients considered palliative?

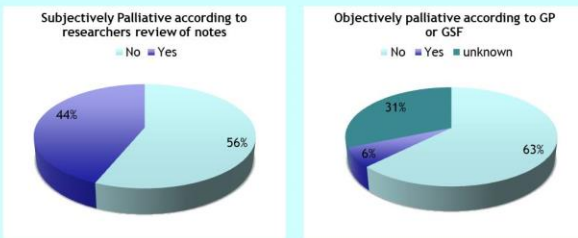


Figure 6: On reviewing the patient notes, 14 out of the 32 patients were identified as potentially palliative by ourselves due to their medical history (44%).

Figure 7: However, when contacting their general practitioner, only 2 patients (6%) had been treated as palliative. The discrepancy between these figures is interesting to discuss, potentially could or should we be identifying more patients as palliative?

### Did these patients have a DNACPR?

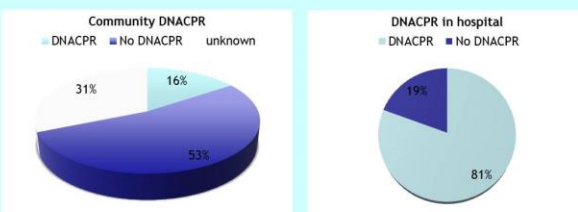


Figure 8: On reviewing patient notes and requesting information from GPs, at least 16% of patients (5) had a community DNACPR. 17 patients did not (53%), and 10 patients (31%) status is unknown.

Figure 9: 26 patients (81%) had a DNACPR either instigated, or continued from the community, in the emergency department.

### Were any of these admissions avoidable?

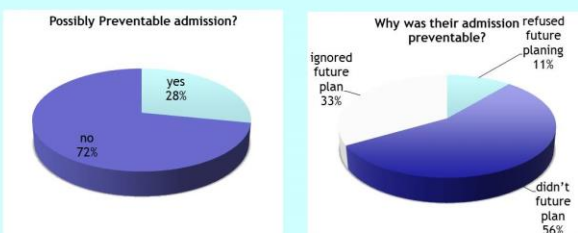


Figure 10: 9 patients admissions (28%), have retrospectively been classed as possibly avoidable. Figure 11: This can be classified further - 5 patients did not have a future plan, 1 patient refused to future plan, and 3 patients had a future plan which was not acted on.

- Of these 9 preventable admissions, 8 were subjectively classed to be palliative by ourselves (89%), but 2 patients (22%) were palliative according to their GP.
- Of the 14 patients deemed subjectively to be palliative, 8 admissions (57%) were potentially avoidable.

### Conclusions

- This study suggests that some palliative patients do present to ED and die, and that some of these admissions were avoidable.
- With ever increasing ED pressures we suggest it's imperative to understand the reasons, assess the scale, and find solutions to inappropriate palliative ED admissions.
- It is important to explore the discrepancy between patients who could be retrospectively judged to be palliative, and those recognised as palliative by their GP.
- By increasing recognition of palliative status of patients and improving forward care planning in the community we may avoid patients being admitted to hospital, when dying in the community may have been preferred by patients and families.

## Appendix 9: A patient's story

### Care Homes in Shropshire, Telford and Wrekin

#### T&W Care Home MDT. Patient Story - Bill

Bill is 69 and living in a nursing home, he has Bronchiectasis and COPD. In the winter of 2019/20 Bill was admitted to hospital 3 times, spending 2 or 3 weeks there as his health deteriorated with frequent exacerbations.

Bill is approaching the end of his life, he is cared for in bed, has lost a significant amount of weight, he is on continuous oxygen and his frailty score was measured as 7/8.

End of Life Care discussions with Bill had taken place in his Care home and this information was recorded in his ReSPECT document



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