

AGENDA ITEM:

**OVERVIEW & SCRUTINY BOARD**

**7 DECEMBER 2010**

**HEALTH SCRUTINY PANEL  
END OF LIFE CARE - FINAL REPORT**

**Introduction**

1. As the Health Scrutiny Panel progressed through its work programme in 2009/10, it held numerous debates around range of topics including emerging national policy, the performance of the local NHS, how high performance could be maintained and propagated and areas for improvement. On numerous occasions, the Panel heard the view expressed by senior officers from the local health and social care economy that End Of Life Care in Middlesbrough, was an area in need of development and improvement. This, allied with the higher national profile afforded to End of Life by the publication of the first national strategy, convinced the Panel that it was a good time to consider End of Life Care in Middlesbrough.
2. End of Life Care is an emotive and sensitive topic to consider, perhaps necessarily so. Death and how society cares for the dying remains, to some extent, a taboo topic that people do not wish to speak about. Indeed, the Panel has come across the view more than once that to speak about it is somewhat morbid and macabre.
3. Still, we live in a time when around 60% of deaths could be considered to be predictable or expected, following illness or frailty. We also live in a time when the proportion of older people in the population is increasing and sadly, death becomes more likely the older one becomes.
4. The changing nature of society and the sorts of death that are prevalent is something that the Panel has heard a great deal about. As Professor Edwin Pugh advised the Panel, the three great causes of death in 1900 were infectious disease, childbirth and accident. These sorts of deaths are relatively quick and do not include a great period of disability, nor require a great deal of support, before death occurs. End of Life Care, therefore, in such an environment is understandably not a major concern.

5. The changing nature of health and healthcare problems, however, now dictates that other causes of death have now become the most prevalent. Such diseases as cancer, dementia and COPD<sup>1</sup> are now significant causes of death, yet are increasingly 'treatable', with some people even being cured of cancer. Nonetheless, the advances of medicine dictate that even those who eventually lose the fight against such illnesses, will have had treatment for their conditions and as such, will live longer with the illness before dying. The fact that people are living with illnesses for longer before dying, raises the very obvious questions of how does, and how should, society support such people at the end of their lives.
6. Demographics indicate that such considerations about End of Life Care should become a bigger and bigger part of health service planning. Gomes & Higginson<sup>2</sup> highlight that the Government's Actuary Department predict that from 2012, there will be a gradual increase in deaths. There are expected to be nearly 590,000 deaths per year in 2030, which is 16.5% more than in 2012. By then, those aged 65 and over will account for 86.7% of all deaths and the very elderly (85 and over) for 43.5%.
7. Aside from *how* we care for people at the end of their life, there is also a debate to be had about *where* we care for them. The Panel has heard a great deal of views expressed about where people die and the choice that people can, or can't exercise, when they are at the end of life. The Panel has heard that around 40% of deaths are those that could not be predicted and it is inevitable that a high proportion of those will take place in hospital.
8. It is the place of death for the 60% of deaths that could be considered to be expected or predictable that the Panel wanted to explore. Gomes & Higginson have highlighted that non-NHS institution deaths have decreased, whilst deaths in NHS hospitals have increased considerably<sup>3</sup>.
9. The key question to explore is whether society, and those at the end of their life, want to receive their end of life care in an acute hospital setting, or whether there are other options for people, such as at home or in a hospice setting. The Panel has heard that it is key to given people choice over this and to respect that choice. Of course, those choices can only be respected and honoured, if the capacity of services allows for the exercising of that choice.
10. Research indicates that a significant number of people would choose to not die in a hospital, although whether services have the capacity to meet those demands is another issue. It would certainly appear to the Panel that there is presently a huge disparity between preferences and reality. Gomes and Higginson highlight this point perfectly when they say

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<sup>1</sup> Chronic Obstructive Pulmonary Disease

<sup>2</sup> Where people die (1974-2030): past trends, future projections and implications for care. Barbara Gomes and Irene J. Higginson, *Palliative Medicine* 2008;22;33

<sup>3</sup> *ibid*

*“In England and Wales the trend up until 2003 has been for decreasing numbers and proportions of deaths at home, especially among older people. A reversal of this trend will be an enormous task.”*

11. As such, the Panel explores in the report how, if those choices are to be respected and acted upon, what is it about services that need to change?
12. Either way, demographics highlight that an expansion of palliative care services is inevitable, such is the likely increase in deaths. The question that remains is where does that expansion take place, in community based services? Hospices? Acute centres? Or should it be a combination of all three? Gomes and Higginson again demonstrate this point clearly when they say

*Either inpatient facilities must increase substantially, or many more people will need community care towards the end of life from 2012 onwards.*

13. The evidence that the Panel has collected is fairly clear: End of Life Care in Middlesbrough needs development and quickly. A question that remains is what do we develop? Do we invest more and more in expensive acute facilities when evidence indicates that most people don't want to die there, or do we reinvest resources in community and hospice services? That is a question for the local health and social care economy to answer and answer it must, fairly swiftly.
14. The Panel is confident that this report adds clarity to the debate and provides assistance to those making such decisions.

### **Terms of Reference**

- To establish the current spend on End of Life Care in Middlesbrough and ascertain where those resources are spent.
- To establish the range, nature and location of services available for End of Life Care in Middlesbrough, the capacity of those services and the level of need placed against them.
- To consider the implications of implementing 'A Good Death', in the light of current service provision in End of Life Care and the developments required to address future need.
- To consider what can be done by the wider community, other than the local NHS, to make a 'good death' the norm in Middlesbrough.
- To consider what could be done to ensure carers received adequate support, when caring for someone at the End of Life Care.
- To seek the views of the local health and social care economy on the current position of End of Life Care in Middlesbrough and the areas of development felt necessary.

## Evidence from Professor Pugh

15. As a first step in considering the topic of EOLC, the Panel held an initial meeting on 3 June 2010, where it heard from Professor Edwin Pugh<sup>4</sup> and Keith Aungiers<sup>5</sup>, about the history of EOLC and the biggest issues facing it today.
16. The panel was initially told about the policy context around EOLC. Reference was made to the importance of the National End of Life Care Strategy from 2008, the Strategic Health Authority's End of Life Strategy from 2008. The Panel was also told of the importance of the NAO report into EOLC that was published in November 2008.
17. The Panel heard that EOLC is not an area of knowledge or practice that remains static and reflects the huge societal changes that continue to this day. The following chart highlights this point perfectly.

### Changing Patterns of Disease

1900	2000
<p><b>Typical Age of Death</b> 46</p>	<p><b>Typical Age of Death</b> 78</p>
<p><b>Top 3 Causes of Death</b> Infectious Diseases Accident Childbirth</p>	<p><b>Top 3 Causes of Death</b> Cancer Organ Failure Frailty/Dementia</p>
<p><b>Disability before Death</b> Not much</p>	<p><b>Disability before death</b> 2-4 years</p>

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18. The Panel was struck with the difference that 100 years can make to the nature of death in the community, the stage it happens, the causes and someone's experience in the years preceding death. It was noted that an average 2-4 years of disability before death creates huge ramifications for Social Care, which presumably will only increase as the proportion of older people in the population increases. In turn, this raises the topic of sustainable funding for Social Care, which is a huge issue in itself.
19. Following the consideration of the 'how' and 'when' which is starkly laid out above, the Panel was also informed that a critical consideration in the delivery

<sup>4</sup> Regional Clinical Lead for End of Life Care, and Consultant in Palliative Medicine, North Tees and Hartlepool NHS Foundation Trust

<sup>5</sup> Head of Projects and Intelligence, Public Health North East (GONE)

and planning of EOLC is also the 'where', i.e. where someone dies. The Panel considered the following chart below

### Place & Preference of the public

Actual	Place	Preferences
61%	Hospital	15%
21%	Home	60%
13%	Care Home	0%
3%	Hospice	15%

20. To build on the data outlined above, the Panel was also appraised of the following

*'Who dies where and with what in Middlesbrough?'*

Category	Hospital %	Hospice %	Home %	Nursing/ Care Home %
Neoplasm	52	12	28	8
Circulatory System	62	0.1	23	13
Respiratory System	70	0.2	16	14
Nervous System	48	0	11	40

Source: Office for National Statistics 2006  
Middlesbrough 1382 deaths in 2006

21. The Panel heard about a perspective from North Tees & Hartlepool regarding EOLC.
22. The Panel heard that there were around 1600 deaths a year in the Trust's area of responsibility. Around 97% of those who died were admitted as an emergency. The Panel was interested to learn that around 25% of hospital deaths are people under 70 years and almost a half are 80 or over.
23. It was confirmed to the Panel that around 25% of hospital deaths occur within the first three days of a stay. Further, admissions where people have died equate to 9.8% of all bed days. To put this into perspective, the Panel was told that nearly 10% of all hospital bed days were being utilised by people who were at the end of life. The Panel was advised that nationally, it is projected that there will be an increase of 20% in deaths.
24. Reflecting on these facts, the Panel agreed that if society continues along such a trajectory, bigger and bigger hospitals will have to be built, with more

and more (expensive) beds dedicated to EOLC. The Panel accepted that a number of deaths (probably around 40%) could be considered to be unexpected, although that still leaves around 60% that could reasonably be expected and planned for.

25. It was considered that this was not the best way for society to deal with the issue, nor could society afford (in pure fiscal terms) to keep building bigger hospitals. It was agreed that society needed a different approach to dealing with EOLC, rather than always relying upon the emergency admission and acute care route.
26. The Panel was also reminded that Care Homes (Residential & Nursing) have a substantial role to play in EOLC. The Panel heard that 1 in 5 people over 65 years will die in a care home and on average 50% of residents die within 2 years of admission<sup>6</sup>. It was noted that one of the implications of the population enjoying longer life expectancy and being able to survive ailments, means that there is an increasing frailty of residents, which brings its own pressures. The panel was also told that according to research<sup>7</sup> 27% of residents in care homes are confused, incontinent and immobile. Whilst improving, there has been a historical isolation of care homes to training and a lack of knowledge of palliative care.
27. The Panel was interested to hear that according to research<sup>8</sup>, around 25% of care home residents die in hospital and there are significant variations between the calibre of support available to support those at the end of life. The Panel heard that according to the NAO research, 59% of care home residents admitted to hospital (who died) could have remained in their care home with extra support.
28. The information above, which was supplied to the Panel, was extremely useful in setting a historical and contemporary context. The Panel then moved onto considering 'where do we go from here?' to enhance people's experience of EOLC.
29. The Panel heard that the North East SHA had recently led a project to identify what the general public would feel is 'a good death' and how that could become the norm for people. The Panel heard that a new vision for a Good Death in the North East had been published which is outlined below:
30. *The North East will have the highest quality services to support individuals (along with their families and carers) in their choices as they approach death. By a good death we mean one which is free of pain, with family and friends nearby, with dignity and in the place of one's choosing*<sup>9</sup>

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<sup>6</sup> Hockley et al (2004)

<sup>7</sup> Bowman et al (2004)

<sup>8</sup> National Audit Office *End of Life Care* November 2008

<sup>9</sup> Please see *Better Health, Fairer Health – A strategy for 21<sup>st</sup> century health and wellbeing in the North East of England*. Can be accessed at [www.northeast.nhs.uk](http://www.northeast.nhs.uk)

31. The Panel was interested to explore why having a good death charter was so important to our health and social care system, as well as our society.
32. The Panel heard that death and dying is a normal, inevitable part of life, which it is more than a 'medical responsibility'. It was said that death and dying is a public health and societal issue, which is the responsibility of the wider community, which should aim to act as a 'compassionate community'. Indeed, it could be argued that an accurate measure of the level of compassion of a local community is how well it deals with the needs of those who are dying and those who are close to those dying.
33. The Panel heard about how, in the view of Professor Pugh, social attitudes towards death and dying had changed over the last few decades, as medicine had become a greater part of our society's life.
34. The Panel heard that in recent decades, a new orthodoxy had developed which seemed to decree that if someone was dying, it duly followed that hospital and a medical environment was an essential prerequisite. It is precisely this view, the panel heard, that needs to be challenged. As the management of death and dying has become more 'medicalised' and hospitalised, the impact has been to erode communities' ability and confidence to deal with death and its implications. As such, people have become 'frightened' of the process of dying and death, so it is now viewed as an issue that only medicine and medical practitioners can preside, even when someone is terminally ill.
35. The Panel heard that it would be much more beneficial for society if death was seen to be more 'normal'. Further the perception that if someone is dying, they need to go to hospital urgently needs challenging. The Panel heard that if someone is expected to die and their conditions can be managed effectively, there is no real worth in them being in hospital, nor is hospital likely to be many people's preferred place to die.
36. Further, the Panel also heard that the concept of someone dying always needing a doctor requires challenge as other healthcare professionals could administer the appropriate support perfectly well, thereby enabling a better use of a doctor's time. Further, death is not a failure of the system, but a normal part of life. Only a bad death is a failure of the system.
37. In addition, the Panel heard that what support exists for EOLC tends to be hugely concentrated in traditional office hours, which only represents around one third of a twenty four hour period. It was emphasised that a lot of people require support out of office hours, when services are seemingly not set up to provide support with sufficient capacity, to deal with the likely demands. This highlighted to the Panel that, despite questionable cultural attitudes determining that those dying should always be admitted to an acute setting, there actually may be very little practical choice for those seeking some sort of medical assistance out of hours, other than admittance to an acute facility. This apparent lack of capacity in 'out of hours' service provision for EOLC,

was something that the Panel expressed a strong interest in exploring further, with appropriate agencies in the health and social care economy.

38. The Panel was interested in exploring the concept of a compassionate community and what that may look like in practice. The Panel heard that the following could be identified as key features of a compassionate community.

- Acknowledges EOLC as the responsibility of the wider community and organisations
- Involves EOLC in local government policy and planning
- Offers people a wide variety of supportive experiences, interactions and communication
- Has a strong commitment to social and cultural difference
- Provides easy access to grief and palliative care services

39. Better health, fairer health 'pledge'

"We will create a charter for end of life care, with a statement of the rights and entitlements that should be honoured both for the individual preparing for death, and for their carers and families. *This should relate not only to medical and nursing care but to the behaviours of all agencies and sectors who deal with these issues.*"<sup>10</sup>

40. By way of confirmation, the Panel heard that death and dying in the north east is:

- Becoming too medicalised
- There is an accepted over use of expensive hospital facilities
- Death remains a social and cultural taboo
- There are wider roles and responsibilities of non NHS organisations and society at large that are currently not addressed

41. The Panel was keen to hear about steps taken so far, across the region, to raise the profile of EOLC. The following points were put forward as examples of progress:

- Draft charter produced by multi-agency regional advisory group
- 2,500 responses to public and organisational consultation exercise
- public awareness and social marketing campaign

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<sup>10</sup> Health Scrutiny Panel's added emphasis



- research into societal attitudes and behaviours
  - joint working with the new national Dying Matters coalition
  - national and regional launches
42. The Panel heard that the movement for a good death would only be successful if it was well supported by the public support by the NHS, local authorities and the VCS. It would also require such organisations to take ownership of the programme and see it as their responsibility to help implement. It was said that there was no reason as to why any of this should not happen, particularly with NHS organisations, as the good death strategy was entirely consistent with the recently published NHS Constitution.
43. The Panel heard that there were a number of practical questions, which the Panel may wish to explore in its consideration of EOLC. These are listed below.
- Is social and health care provision seamless?
  - Do we provide 24/ 7 support?
  - Do we have compassionate human resource policies for people with illness and carers?
  - Are we planning to enable choice of place of living, dying and death?
  - Is EOLC a core skill of staff?
  - Are we creating compassionate communities?
44. It was also emphasised that local authorities have a huge role to play in developing the concept of a good death and compassionate communities.
45. Firstly, there are very practical questions for local authorities to consider such as;
- Are residential homes sufficiently trained, staffed and empowered to avoid unnecessary admissions for people at the end of life, by continuing their care?
  - Are bereavement/grief support services sufficiently configured to assist those close to someone who has died, if they are needed?
  - Secondly, there are conceptual questions to consider such as
  - As community leaders, what are we doing to build compassionate communities?

- Could we support individuals or groups more?
- What work could we do as community leaders to embed the principles of a good death?

## Evidence from NHS Middlesbrough

46. The Panel approached NHS Middlesbrough for their views, as the principal commissioner of health services in Middlesbrough. The Panel met with NHS Middlesbrough representatives on 16 July 2010. In advance of the meeting, the Panel submitted number of questions to NHS Middlesbrough, which were addressed in a paper submitted to the Panel. Those questions and answers formed the basis of the debate.
47. The Panel was interested to hear about the most up to date statistics covering the number of deaths in Middlesbrough. The Panel heard that the most up to date and complete data related to 2007. That information demonstrated that there were 1362 deaths in Middlesbrough in 2007, compared to 1439 in 2005.
48. Related to those numbers of deaths, the Panel heard that circulatory disease was the biggest single cause of death in 2007, causing 31.1% of deaths, with cancer causing 29.1% and respiratory problems causing 15.2% of deaths.
49. The Panel was interested to discuss what level of intelligence NHS Middlesbrough had in relation to the place of death on Middlesbrough. The following data is what was presented to the Panel. It relates to the period from 2004-7.

<b>Place of Death</b>	<b>Male</b>	<b>Female</b>
Hospital	62.1%	57.3%
At Home	22.8%	19.7%
Residential Home	4%	8.7%
Hospice	3.2%	3.8%
Nursing Home	3.7%	8.1%
Elsewhere	2.5%	1.2%
Psychiatric Hospital	1.2%	1.8%

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50. The Panel was also interested to learn the level of explicit budgetary provision for EOLC in Middlesbrough. It was accepted by the Panel that it was very difficult to disaggregate all resources that are currently spent on EOLC, particularly in a hospital setting, although it was noted that NHS Middlesbrough has specific categories of spend could be identified as follows:
- Hospices £410k
  - South Tees Hospitals NHS Foundation Trust £54k

➤ Prescribing £91k

51. The Panel was interested to hear from NHS Middlesbrough about current EOLC service configuration in Middlesbrough. The Panel heard that EOLC is delivered across a variety of areas of service provision. The type of provision available within the community are community hospital beds, the Macmillan nursing team including a Macmillan nurse for care homes, community matrons, district nurses and care home provision. The Panel heard that the continuing care teams ensure there is a robust process in place to facilitate rapid discharge from the acute provider. Teesside Hospice and the Marie Curie Service also deliver services.
52. The Panel was advised that EOLC is also delivered in the Acute Trust and supported by the Macmillan team/ palliative care team, including a palliative care consultant and the clinical matron for end of life and bereavement services. The Panel heard that there is also a pilot project over the next two years, which involves the appointment of a Macmillan nurse post to facilitate palliative discharge<sup>11</sup>. The Panel was interested to hear that there had also been the development of EOLC beds within the Acute Hospital.
53. The Panel was interested to explore which aspect of the Commissioners functions had a principal focus on EOLC. The Panel heard that as a Commissioner NHS Tees has developed a strategic plan, within which are 8 clinical themes, each theme has key initiatives. The key initiatives for EOLC relate to provision of information and advice, training and awareness, and community provision.
54. The strategic delivery group (SDG) is responsible for overseeing the development of the initiatives. There is a Lead Director for the Tees SDG and an Assistant Director is the lead representative South of Tees.
55. The Panel heard that the focus areas for the group were:
  - Single point of contact
  - Increased access to bereavement support
  - Expand sitting service and carers support
  - Expand community nursing (24hr support)

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<sup>11</sup> A new pilot project has been launched which offers dying patients – and their families – the choice to spend the last few days of their lives at home rather than in hospital. The James Cook University Hospital has secured two years funding from Macmillan Cancer Support for an end of life discharge service, which will be evaluated by Teesside University's CHASE – Centre for Health and Social Care Evaluation – team. The service aims to support clinical teams and staff involved in the care and discharge planning of their patients – and families - who ideally want to spend the last days of their life in their preferred place of care. Please see. <http://www.southtees.nhs.uk/UserFiles/pages/5231.pdf> for further details.

- Support for Hospice care
  - Expand community Specialist team
  - Mandatory training (e learning) for care home staff
  - GSF training for Nursing and care homes
  - Implementation of Advanced care Plans
  - Communication skills training
56. The Panel heard that from a provider perspective, the principle focus would be with all services involved in the delivery of palliative/ EOLC for example district nursing, Macmillan nursing service, palliative care services and the Hospice.
57. The Panel highlighted that the research for 'A Good Death' highlights that around 15% of people would wish to die in a hospice and around 60% would like to die at home. The Panel was interested to hear the Commissioner's views as to how Middlesbrough's current capacity for specialised EOLC service provision looks against that demand.
58. The Panel heard that in order to facilitate the 60% wishing to die at home, a significant amount of education and training would be required for generalist services. The training requirements are advanced care planning, gold standards framework, Liverpool care pathway (last days of life), syringe driver training, palliative care guidelines and communication skills. The Panel learned that these areas are all identified in the regional charter, under a time to plan and care and support. The Panel was reassured that all of these areas of competence have been identified as part of the work programme for 2010-2014. Still, the Panel was curious as to how such planning of and investment in workforce development would be maintained and overseen, if PCTs are abolished by March 2013, in line with *Equity & Excellence – Liberating the NHS*.
59. The Panel was advised that there is currently a Macmillan nursing service that covers South of Tees which includes access to occupational therapy, a community consultant and also includes a Macmillan Nurse for care homes. The Panel heard that there is also a Marie Curie service and the rapid response service that is accessible in the community. The Panel was advised that there is also Teesside Hospice, which has a 10 bedded specialist palliative care in patient unit and a 16-place day care service, as well as the availability of community nursing beds at Carter Bequest Hospital.
60. It was reaffirmed that the South Tees Hospitals Foundation Trust there is the acute palliative care consultant and palliative care team which includes Macmillan nurses, Macmillan palliative discharge nurse and a clinical matron for EOLC and bereavement support.

61. The Panel heard that, in the view of the Commissioner, EOLC does not always require specialist provision, but it is crucial to ensure that generalist services and staff are equipped with the knowledge and skill to deliver good quality EOLC.
62. The Panel was interested to hear whether Middlesbrough has a well publicised and accessible information source for those seeking advice or information about EOLC?
63. The Panel heard that information booklets had recently been developed, as information had previously been identified as a gap. The booklets developed include:
  - When someone is dying,
  - What to do when someone is dying,
  - The process of grief and loss,
  - What to tell the children
  - A bereavement information leaflet for children
64. At the time of the Panel meeting, the booklets had gone out to the patient and carer focus group and a range of professionals for proof reading and comment prior to printing.
65. The Panel heard that there is also support and advice available from the district nursing service and the Teesside Hospice. It was said that patients who are known to the district nursing service will be given contact numbers for in and out of hours, as well as a 24 helpline ran by the Teesside Hospice. The Panel was advised that this service is not widely publicised, but is targeted in that it is promoted to patients and carers who are identified as end of life, rather than the general public. The Panel considered more information on the telephone helpline, and its sustainability, later in its evidence gathering, when speaking to THCF. Please see paragraph 264.
66. The Panel was advised that there had been a lot of activity regarding raising public awareness on the subject of death, and dying, through the consultation process, the development of the Regional Charter and the development of the Compassionate Communities Project, led by the University of Teesside. It was said that the University was also part of the national pilot researching communication skills locally for EOLC. The evaluation was scheduled to be presented to the SDG in September 2010, with recommendations.
67. The Panel was also interested to know what NHS Middlesbrough expects commissioned providers to do, to ensure that sufficient time and notice is given to people that they are approaching the End of Life, to ensure that their wishes can be put into practice.

68. The Panel heard that NHS Middlesbrough expects all patients who are on the end of life pathway to have a “preferred priorities of care” document completed. The “preferred priorities of care” document is not a professional document, but the patient’s document and it remains with the patient. The Panel was reassured that training has been provided to professionals across health and social care, including the independent sector, to enable this.
69. The Panel heard that all patients who are at the end of life (6-12 months of life), should be identified on a palliative care register in general practice and their carers should have their needs identified and assessed as required.
70. The Panel was advised that Commissioners expect that all patients, who are at the end of life, be identified on a palliative register in general practice. The practice should have the knowledge and understanding of EOLC and the access to suitable provision. This should include GSF, Preferred Priorities of Care, EOLC pathway (last days of life), prescribing flow charts and syringe drivers access to medication, pharmacy, local support services and out of hours services.
71. The Panel was keen to explore with NHS Middlesbrough, how much progress has been made in Middlesbrough, in its view, regarding the implementation of 'A Good death'?
72. The Panel heard that the North East regional Charter identifies the principles of a good death, some of which are;
- **Respect:** to have clear honest and tailored information and good communication throughout illness or frailty
  - **Time to plan;** if appropriate to be told clearly and compassionately the reality that death is coming
  - **Care:** Access to EOLC in the location we choose, and have clear information on who to contact 24/7, to be given the opportunity to take part in decisions which affect care
  - **Support:** To have support with the practicalities of dying, death and matters after death
73. The Panel heard that NHS Middlesbrough felt that the developments outlined below, supported these statements;
- There has been investment in training and education for the independent providers in the GSF, 8 care homes from Middlesbrough in 2009/10 and a further 8 care homes 2010/11 have joined the programme. It was confirmed that the first wave would be going through the accreditation process in July and November 2010.

- The University of Teesside has also developed a certificate level course for EOLC and care homes [all those who attended the course passed]. The homes that took part included residential care, care homes with nursing, learning disabilities and elderly mentally frail.
  - Tees Valley Alliance is providing EOLC training for domiciliary providers and care homes, at the Further Education colleges across Tees. All courses have been fully booked and there has been strong interest in accessing the NVQ units;
    - HSC 226 to support individuals who are distressed
    - HSC 384 to support individuals through bereavement
    - HSC 385 to support individuals through the process of dying
  - There has been Advance Care planning training for Tees to equip the workforce to deliver good quality EOLC and facilitate preferred priorities of care.
  - The University of Teesside are also undertaking a pilot project funded by the SHA for the development of compassionate communities
  - There has also been the development of information booklets to support the patient, carer and professional this development was supported by the end of life focus group.
  - The University of Teesside has just completed an audit on use of the palliative care register in general practice across Tees. Recommendations supported the development of the information booklets and standardisation and consistency within practices regarding the equity of access and the frequency of the GSF meetings. This work will be further developed over 2010/2011
  - All practices and care homes with nursing received literature and prescribing formularies for palliative care, including the elderly mentally frail liaison team, and the CHC team
  - All developments have progressed due to partnership working across the patch. There is no doubt that there is still further work to be done.
74. The Panel was interested to explore with NHS Middlesbrough the extent to which EOLC service provision is seamless, between organisations, in Middlesbrough.
75. The Panel heard that an end of life questionnaire has recently gone out to all practices across Tees, which would help inform commissioners and providers of the current process and identify areas of good practice and areas where there is need for greater collaborative working. The results were scheduled for collation in September and would hopefully identify where key actions need to be addressed. The Panel did not feel that NHS Middlesbrough on this point

supplied sufficient information, although it has heard from evidence gathered elsewhere that services are not sufficiently joined up.

76. The Panel was interested to discuss whether NHS Middlesbrough was satisfied that EOLC skills are viewed as core Skills for frontline health services workforce.
77. The Panel was advised that EOLC skills are required for all frontline practitioners whether they are in health, social care or the independent sector. It was said that the key to success would be the standardisation of training and education to ensure that a moving workforce has transferable skills, and that the skills acquired are recognised by all organisations involved in the delivery of EOLC. The Panel heard that the SDG are promoting the National EOLC e-learning training programme for all providers, to supplement learning.
78. The Panel was keen to discuss with NHS Middlesbrough where it felt efforts should be focused to develop EOLC in Middlesbrough further.
79. The Panel heard that the focus for 2010/11 would be:
  - The development of a 24 hour advice line
  - Bereavement information packs
  - GSF for care homes
  - GSF in general practice
  - Access to medication
  - Preferred priorities of care
  - EOLC training for care homes and domiciliary providers
  - E learning for EOLC
  - Communication skills
  - Review core services, community nurses, sitting service, hospice, and specialist EOLC.
80. Following consideration of the evidence submitted, the Panel was keen to expand on the topic of the Gold Standard Framework (GSF) and specifically how it was received in residential and nursing homes. It was confirmed to the Panel that if implemented, and applied well, the GSF would prevent people being admitted to acute hospitals at the end of life and would increase the ability of the homes to meet that person's needs, without hospital admittance.
81. The Panel heard that the level of clinical skill and knowledge was typically higher in nursing homes than in residential homes, which resulted in a



scenario where significantly more hospital admissions originated in residential homes. As such, it was accepted that more developmental work would need to be done with the residential sector. It was noted that district nursing and Macmillan services regularly go into residential care, although it was felt that greater knowledge and skill capacity was required in the residential home environment.

82. It was noted that historically, significant proportions of EOLC services had been somewhat 'cancer-centric' and probably still are to a lesser degree. The Panel heard that NHS Middlesbrough would accept this point and would recognise the need to develop EOLC that meet the needs of all people, including those with life limiting illnesses. The Panel was reminded that around 28%-29% of deaths are caused by cancer, yet the history of EOLC is dominated by Cancer Services. The Panel felt it important to highlight that this is not a criticism, nor is it comment that patients with cancer should not have access to such services, merely that those patients at end of life with a non-cancer diagnosis do not seem to be as well provided for.
83. Following consideration of evidence from the principal commissioner of EOLC, NHS Middlesbrough, the Panel was keen to speak to providers of EOLC in Middlesbrough. As such, it held a roundtable discussion with representatives from South Tees Hospitals NHS Foundation Trust (STHFT), Middlesbrough and Redcar & Cleveland Community Services (MRCCS), The Butterwick Hospice (Butterwick) and Teesside Hospice.
84. In advance of the meeting, the Panel supplied the above organisations with some questions, which were responded to in papers submitted to the Panel. Those papers are addressed in turn below.

### **Evidence from South Tees Hospitals NHS Foundation Trust**

85. The Panel heard that in the last six years, EOLC has achieved a higher profile than at any time previously in the 62 years history of the NHS. The Panel learned that the Improving Outcomes Guidance 'Supportive and Palliative Care for Adults with Cancer' (NICE 2004), was created following the NHS Cancer Plan (2000) and highlighted the importance of EOLC, albeit focused on one particular disease group. Since then many National Service Frameworks for specific conditions have included reference to the need for quality EOLC provision.
86. The Panel advised that the National EOLC programme (2004-2007) focused on delivery of three key ambitions:
  - More widespread use of a care pathway for the last days of life (the EOLC pathway or Liverpool Care Pathway)
  - Consideration of 'Preferred Place of Care' to prompt clinical teams to consider where a patient might wish to be cared for at the end of life, (note that the acronym PPC now refers to Preferred Priorities of Care) and

- Adoption of the Gold Standards Framework, a process designed for Primary Care teams to deliver coordinated palliative and EOLC to their patient population.

87. The Panel was advised that the Department of Health's publication of the first End of Life Strategy for the NHS in 2008 was linked closely with Lord Darzi's NHS review (EOLC being one of the eight work streams in his programme). It set out an ambitious, but practical challenge for whole service review of EOLC provision across all healthcare settings.

### **Overview of Trust activity**

88. The Panel was advised that the current focus on EOLC in the STHFT can be considered in relation to five domains and the key points are listed under the following headings: Strategic Issues, Service Development, Education, Governance and Patient/Carer Involvement.

### **Strategy**

89. The Panel learned that STHFT has an End of life strategy written by the Matron for EOLC and Bereavement and the Consultant in Palliative Medicine and approved by Formal Management Group in November 2009. Objectives are defined in line with themes from the national strategy, responsible personnel are specified, there are specific descriptors of methods of measurement and evaluation, and each objective is linked to the relevant measure(s) in the Department of Health Quality Markers for EOLC document (2009).

90. The objectives are grouped into the following themes

- Identifying patients approaching end of life
- Care planning
- Delivery of high quality care in all locations
- Involvement of carers
- Care after death

91. The strategy has a three year time line (2009-2011) and will report its halfway achievements to the Trust Clinical Standards Sub-group in autumn 2010.

92. The Panel was advised that STHFT engages with the locality and the region by having a Consultant serving on the membership of the Tees End of Life Strategic Delivery Group and the NHS North East End of life Clinical Innovation Team.

### **Service Development**

93. The Panel heard that STHFT has achieved the following developments, in developing the way it approaches EOLC.

- Appointment of a Matron for EOLC and Bereavement in April 2008 to support developments and provide clinical expertise, including training, for nursing and medical staff.
- Successful implementation of the EOLC pathway on every adult ward in the Trust; work is ongoing on a pediatric EOLC pathway in line with national developments.
- A rapid discharge of the dying patient process has been developed over the last three years and is now being formally implemented through a two year pilot project, supported by a grant of £120,000 secured by Dr Nicholson from Macmillan Cancer Relief. The process achieves rapid safe well coordinated discharge of the dying patient to their preferred place of care for the last days of life and is being formally evaluated from a professional and carer perspective by the Centre for Health and Social Evaluation at the University of Teesside. The discharge process has been used to support discharge from every department in the Trust including intensive care.
- Developed and implemented an EOLC pathway specifically for use on the Intensive Care Unit.
- Refurbishment of a ward with an architect designed quiet area specifically for the care of patients who are dying, work undertaken by the Trust in conjunction with the Kings Fund's 'Enhancing the Healing Environment' initiative.

## **Education**

94. The Panel learned that EOLC is included in all induction events for new medical staff and in all junior medical training programmes. The Preceptorship programme for new nursing staff also includes EOLC.
95. A module on EOLC has been specifically developed by the University of Teesside for ward nurses at STHFT and is being run for the first time in Autumn 2010. It will be possible to run this module three times per year if staff are enabled to attend.
96. Update sessions on EOLC are provided for the nursing staff on a monthly basis.
97. The Panel heard that an e-learning package for all staff was in the final stages of development and addresses EOLC in general, advance care planning, the care pathway for the last days of life and awareness of the discharge of a dying patient process.
98. It was confirmed that the consultant in palliative medicine conducts joint ward rounds with consultants in the departments of oncology and respiratory medicine, and is a frequent visitor to departmental meetings across the whole organisation.

## **Governance**

99. The Panel heard that the Trust has participated in both cycles of the National Care of the Dying Audit with results reported back to the Nursing and Midwifery Professional Practice Group and the Clinical Standards Group. The implications of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report for the Trust have been summarised and presented to the Clinical Standards Group.
100. It was confirmed that the EOLC Pathway for the last days of life is currently being revised, in line with the latest national recommendations. The current revision has been a collaborative effort between the community palliative care team, community hospitals, Teesside Hospice and acute hospital so that the same care pathway documentation is used in all care settings for consistency. A major benefit of this approach is the ability to transfer patient care directly, which can take place without the replication of paperwork.
101. A quarterly audit on EOLC has been established which particularly examines the use of the EOLC pathway in expected deaths (part of the Commissioning for Quality and Innovation (CQUIN scheme) and the quality of the records kept. The audit samples case notes from all departments and results are shared across the Trust.
102. All complaints about EOLC are reviewed by the consultant in palliative medicine to identify 'lessons learned' and themes, which may guide service and educational developments.

## **Patient/Carer Involvement**

103. The Panel was advised that information leaflets have been produced ('Advance Decisions' and 'When someone is Dying'), which all wards can provide to support patients/carers with information.
104. It was confirmed that examples of best practice have been shared around STHFT via the End of Life Strategy. For example, two departments offer bereavement support consultations following a death, another sends a card of condolence and offers an appointment with the duty consultant at the time of the relative's death and another encouraged a feedback comments process following bereavement.
105. Members heard that the Tees EOLC Group has been consulted or attended by the End of Life Matron to gather views on developments; the patient/carers representative on the Tees Supportive and Palliative Group is also consulted.
106. In addition to general information supplied to the Panel above, there were specific areas of enquiry that the Panel wanted to explore with representatives of the STHFT. An account of that evidence is outlined below.

107. The Panel had heard elsewhere that a significant number of people die in an acute hospital ‘unnecessarily’. The Panel was keen to hear the views of STHFT as to whether this was a scenario it recognises and if so, what should be done about it.
108. The Panel heard that this was a scenario that the STHFT would recognise and accept, although there are several dimensions to the problem, which all require close attention, as the reasons are highly complex and often multiple. A further problem that the STHFT brought to the Panel’s attention is that Acute Trusts do not necessarily know the background of a patient when they are brought in as an admission. As such, if that patient is at the end of life, they are not always able to react accordingly, due to a lack of knowledge.
109. The Panel was advised that an ‘unnecessary’<sup>12</sup> inpatient death might arise because of one or more of the following:
- Lack of clarity about patient choice
  - Failure to recognise patients approaching end of life
  - Failure to engage in future care planning, possibly due to perception of inadequate skills or experience, fear of upsetting the patient/family/carers by exploring sensitive issues
  - Carer fear or fatigue after supporting a patient at home with increasing health and social care needs – frequently compounded by lack of extended family support available
  - Lack of appropriate advice to manage symptoms that change at home or provide reassurance about a given change or development in the patient’s condition
  - Inappropriate admission to hospital of a patient who could have been cared for where they were, perhaps due to being visited by an unfamiliar doctor or one who fears litigation from appearing neglectful by not admitting the patient
  - Inadequate provision of alternatives to admission to acute hospital
110. The Panel asked what could be done to tackle the above themes.
111. It was said that clinicians should be supported to consider the ‘surprise question’ (‘Would I be surprised if this patient died in the next 6-12 months?’). The NHS North East End of life group advocates this process and endorsed in the STHFT end of life strategy, which gives an indication to primary care clinicians, that future care planning needs to begin.

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<sup>12</sup> The Panel heard that a useful barometer of an inappropriate or unnecessary admission would be to consider the question “Is something of clinical worth going to be done for this person, that can only be done in hospital?” Otherwise, the Panel heard that it would be fair to ask, “What is this admission for?”

112. The Panel heard that a problem with this is that it is not easy to be sure of the answer. It can provoke distress if discussed, may appear to the patient (in some cases but not all) to indicate a negative attitude and prospects, rather than being seen as an opportunity for empowerment, to allow discussion of personal preferences in advance of these being difficult to determine. The Panel heard that for this to become 'commonplace' it needs action by clinicians (and training for them to communicate the issues well and empathetically and to be able to negotiate future care plan discussions). It also requires a societal change to consider that this sort of forward thinking is not meant to be morbid, but helpful. The Panel concurred that this is work for all of us and is, in part, underway.
113. The Panel heard that there are further opportunities to develop EOLC, which are outlined below.
- Develop more community care both professional and lay – possibly even volunteers
  - Certainly protect, and probably increase, community hospital bed provision as an alternative to acute hospital when 24hr care is unavoidable
  - Develop 'super' care homes with high calibre staff, rewarded with a higher tariff, to provide an option for admission from home in a crisis rather than acute hospital.
  - Support the Gold Standards Framework for care homes programme and other educational developments for care home staff so they are empowered to keep residents in the care homes and not admit them when they deteriorate but stand to gain nothing from acute admission
  - Support out of hours doctors by greater use of care plans and clear information about escalation of care decisions for frail and 'nearing end of life' patients so they have the confidence to arrange symptom relief but not admission when this is the right thing to do
  - Provide resources for access to 'out of hours' palliative care professionals at the very least with properly funded advice lines and probably with the potential for a visit to advise on care at weekends/bank holidays. The advice support should be robustly configured '24/7'; the visiting service could be day-time hours, seven days per week.
114. The Panel was keen to explore with the STHFT what role an Acute Trust, and particularly a busy Acute Hospital, should play in the provision of EOLC? The panel heard that Acute Trusts have a duty to provide high quality care for those patients who are not expected to die, but who do so nevertheless.
115. In addition, it was necessary to ensure rapid assessment and symptom review of patients admitted, who might have been kept at 'home', including swift reviews of social and health care packages (integrating with community health

and social care professionals) and a repatriation to 'home'. The Panel heard that developments including the Acute Oncology Service and a swifter access to specialist support in Accident & Emergency would be expected to support this process.

116. The Panel also heard that it was crucial to ensure there was expert advice from secondary care clinicians to primary care clinicians, on those patients who may be approaching end of life<sup>13</sup>, in order to facilitate commencement of future care planning.
117. The Panel was keen to hear the views of STHFT relating to how Middlesbrough, as a health and social care system, deals with those at the end of their life and their care. The Panel was advised that there is a lot of good and excellent care in Middlesbrough, with excellent developments and initiatives for the future. Provision, however, is patchy and there is a need for further work to increase the skills of all, to the skills of the best. It was reaffirmed that there remains a pressing need to improve the support services in the community, to prevent unnecessary admissions as discussed above.
118. The Panel enquired as to whether the Trust was confident that frontline staff have sufficient training to deal with people at the end of their life. The Panel was advised that there is plenty of training available. Due to competing demands, however, it can be difficult for managers of clinical teams to release staff for training, whilst prioritising clinical service provision in the face of real financial constraints. The Panel heard that the STHFT's Clinical Matron and Consultant for Palliative Medicine provide both formal and opportunistic training for staff at all levels.
119. A major aspect of EOLC that the Panel had been told is absolutely critical to get right, is out of hours support for patients and their carers. The Panel was interested to hear STHFT's views as to whether EOLC in Middlesbrough is sufficiently '24 hour'
120. The Panel was advised that the crucial word is 'sufficiently'. It was confirmed that there are good services available, including 24-hour district nursing and the palliative care out of hours nursing service. It was noted, however, that the specialist palliative care team provision in the acute (and community) settings is still 'office hours' orientated. It was confirmed to the Panel that in the view of the STHFT, this needs to change, whilst acknowledging the attendant resource implications.
121. There is an informal arrangement for Teesside Hospice to provide an out of hours advice service. Seemingly, this telephone line is provided by THCF 'out of goodwill', but the Panel heard it can distract clinical staff, especially at nights and weekends, from hands-on clinical care. The subject of the telephone line is covered in more detail, later in the report. It was confirmed that a commissioning proposal to secure a more robust service, which was submitted in autumn 2009, through the cancer commissioning round, was

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<sup>13</sup> i.e. last 6-12 months of life.

unsuccessful.

122. It was confirmed that the consultant out of hours rota (Tees-wide), provides for only telephone advice and it is not resourced to support a visiting or face to face consultation service. The Panel heard that no palliative care specialist nurses currently work at weekends, although a key question is whether specialist staff are needed 'out of hours' or whether further investment and support to generalist district nursing teams, would be a more appropriate. The Panel was advised that this is unclear. It was said that it would be helpful for some research to investigate and determine, whether having a specialist nurse or doctor on duty would actually prevent the unnecessary transfer of a patient into acute setting. Or, on the other hand, whether more 'hours' support from health care assistants and district nurses would actually be more productive. The Panel accepted that this remains a point to debate and that work by specialist expertise should be done. It does, however, seem abundantly clear that if reducing the number of EOLC cases being admitted into acute centres is considered to be a strategic goal, current community based out of hours services do not have sufficient capacity.
123. The Panel was interested to hear whether the STHFT satisfied with the role it plays relating to EOLC in Middlesbrough. The Panel was advised that to be satisfied would suggest complacency. It was suggested that there is always more to be done. Providing the core elements consistently well with a fully engaged work force who recognise the importance of this care is the objective of the Trust's End of Life Strategy. The Panel heard that this has not yet been achieved and remains a work in progress.
124. The Panel was also keen to get the views of the STHFT on where future efforts should be concentrated, to develop EOLC in Middlesbrough. The Panel heard that from a STHFT perspective, the main issues are to implement the strategy fully and to be highly collaborative in the provision of EOLC to ensure that patients' priorities are realised, with the support of a skilled and attentive workforce. The Panel was advised that across the health and social economy the greatest opportunity for the future lies in an even greater education and research agenda, building on the existing excellent School of Health and Social Care at University of Teesside.

## **Evidence from MRCCS**

125. The Panel considered a paper supplied by Middlesbrough and Redcar & Cleveland Community Services. The information presented to the Panel is recorded and discussed below.
126. The Panel heard that EOLC is currently high on the national agenda and focuses on:
  - Implementation of Gold Standards Framework



- Advance care planning and discussions about the patients preferred priorities of care / death
- Implementation of the Care pathway for the last days of life (Liverpool Care Pathway) for all expected deaths

127. EOLC is one of the 8 high impact actions for nursing and midwifery (NHS Institute for Innovation and Improvement, 2009), linked to Lord Darzi's NHS review.

### **Current Objectives for MRCCS**

128. The Panel was reminded that The National End of Life Care Strategy (2008) focuses on the identification of quality markers and measures for EOLC.

129. MRCCS is focusing on these with the aim to improve EOLC for the local population by:

- Focusing on the provision of high quality care in the last year of life for all patients, not dependant upon diagnosis
- More widespread implementation of the care pathway for the last days of life
- Implementation of advance care planning using the preferred priorities of care document – choice of care
- To increase the numbers of people who are able to die in the place of their choice and avoid inappropriate admissions to hospital, as identified in the high impact actions (NHS Institute for Innovation and Improvement, 2009)
- Identification of patients in the last year of life for Gold Standards Framework (GSF) (home, primary care hospital and nursing / care home)
- Identification of a key worker (case manager) for patients / carers
- Implementation of holistic assessment and care planning
- Identification of carers needs- referral for carers assessment
- Delivery of care in all locations (home, primary care hospital or nursing/care home)
- Referral to the fast track team in the last days of life
- Working collaboratively with other care providers
- 24/7 face to face care (1 hours response time)
- Provision of bereavement support to carers

- Link with patient and carer involvement via the Tees End of Life (EOL) focus group
- Increase the number of staff undertaking education in EOLC

130. It was confirmed that MRCCS engages with the Teeswide Strategic Development Group and the North East End of Life Clinical Innovation Team.

### **Service Developments**

131. The following were presented to the Panel as Service Developments with MRCCS.

- Development of an End of Life Policy
- Development of an End of Life Strategy linked to the national End of Life Strategy for the NHS (DH, 2008)
- Successful implementation of the care pathway for the last days of life for patients at home, primary care hospitals and care homes
- Progressing with the implementation of the care pathway for the last days of life in nursing homes
- Facilitating the implementation of Gold Standards Framework (GSF) in General Practice (new practices in the development phase)
- Community Nurses, Community Matrons and Macmillan CNS attend GSF with aligned GP practice to support the planning of patient care in the last year of life and support for their carer into bereavement – this improves communication and ensures that services are planned for the individual needs
- Development of a Macmillan CNS (Care Homes) role to support our colleagues provision of EOLC in the independent sector through implementation of GSF and education
- Lead on the implementation of GSF in 14 nursing / care homes 2009-10
- Commencing the GSF programme in 16 nursing homes 2010-11
- Currently working on the development of the care pathway for the last days of life, which will follow the patient (acute, community and hospice)
- Community Matrons liaise with the discharge planning team to support and facilitate speedy but appropriate discharge from secondary care for patients on caseload
- Community Matrons develop crisis management plans with patients that can be shared with other professionals which outline considerations and

options as an alternative to a secondary care admission. This can include rapid response service, emergency respite, Primary Care Hospital beds etc.

- Macmillan CNS liaise with other providers (Teesside Hospice and JCUH MDT) in the provision of seamless care for the most highly complex patients
- Development of a series of local bereavement booklets which have been adopted Teeswide
- Development of community nursing core care plans for palliative care
- Successful implementation of new syringe pumps for symptom control and the deliver of education to support this
- Community Matrons and Specialist Palliative Care Team offer an advance care plan to all patients on caseload and document service users preferences for the last year of life

## **Education**

- Specialist Palliative Care Team worked in partnership with the University of Teesside in the development of a new module aimed at care home staff
- Specialist Palliative Care Team delivery of the new module to nursing / care home staff
- Specialist Palliative Care Team delivery of education at the care home focus group
- Specialist Palliative Care Team delivery of education requested by individual teams within MRCCS and care homes
- Specialist Palliative Care Team work in partnership with the University of Teesside in the planning and delivery of two palliative care modules aimed at certificate, diploma and degree level
- Development and delivery of an induction programme which focuses on EOLC for qualified nurses
- Planning and implementation of educational updates for all MRCCS nursing staff focusing on EOLC (Commencing October 2010)
- Hold an open forum education session 6 times/year for all health and social care professionals within MRCCS
- Delivery of education to General Practitioners during protected time and at request

- Specialist Palliative Care Team attending GSF to deliver 'bite size educational sessions' to the multidisciplinary team
  - Specialist Palliative Care Team involved in informal education on a daily basis with 'generalist professionals' (General Practitioners, MRCCS staff and Nursing / Care home staff)
  - MRCCS staff involved in receiving advance care planning training currently (Teeswide project)
132. Following consideration of the above general information presented, the Panel began to explore MRCCS' views on the substantive questions that the Panel had submitted to MRCCS.
133. The Panel enquired as to the view of MRCCS, on the extent to which local services are integrated when people are facing the end of life? The Panel heard that Four integrated teams (health and social care) within MRCCS provide generalist palliative care to patients in the last year of life. There are two locality teams in Middlesbrough and two in Redcar and Cleveland.
134. It was confirmed that Community Nurses and Community Matrons work within the locality team and specialist palliative care services work into the team, as required for those patients with the most highly complex needs. Community Nurses, Community Matrons and Macmillan Clinical Nurse Specialists (CNS) attend Gold Standard Framework meetings in general practice along with General Practitioners (GP's). The Panel heard that the aim is to discuss all patients in the last year of life. Each patient is allocated a case manager (key worker) this is usually the community nurse who will provide supportive care to patients on a regular basis.
135. The Panel was advised that the provision of palliative care by Community Nurses tends to fall into three distinct areas:
- Psychological support visits where holistic assessments & care plans are formulated and implemented. These support visits enable the community nursing staff to build and develop relationships with patients and families, this rapport and engagement supports Community Nurses in the management of people and their carers at home in the last year of life.
  - The hands on clinical interventions required in palliative care e.g. care in the last few weeks / days of life, syringe pump management, wound care & catheter care.
  - Community nurses visit the carer in bereavement to provide support. However support for carers could be developed further through the provision of sign-posting to other bereavement services
136. The Panel heard that the Community Matrons provide care management for patients with complex non-cancer diagnoses. This includes preparation and

planning for EOLC on an individualised basis. The Community Matrons work closely with all services to co-ordinate appropriate care delivery whilst providing direct clinical care for patients within the last year of life. This care extends into bereavement support for the carer.

137. The Panel was advised that the Multidisciplinary Specialist Palliative Care Team provides holistic assessment, advice and care to patients and carers with the most highly complex needs. The team offers support to carers into bereavement and referral onto specialist bereavement services as required. The team also provides advice and support to generalist providers to enable them to manage the patients' care, including the provision of education.
138. Locality teams can access the Marie Curie Service which provides sitting / support to patients to enable the carer to have some rest from caring. This service is provided across MRCCS, however in Redcar and Cleveland there is also the Palliative Care at Home Service. It was said that both services are vital to ensuring patients are cared for in their preferred place of care and in supporting their carers. They provide different levels of service and have different grades of staff available for sitting / support visits. The Community Nursing Service provides all of the nursing interventions for patients receiving the service. The proposed vision for the support sitting service is to have one service across Middlesbrough, Redcar and Cleveland and an options-appraisal is currently being undertaken. The aim is to offer the same standard of care to patients but with clear and strong links to the Community Nursing Service, for example referral pathways, training and development, line management and clinical leadership.
139. The Panel enquired as to whether there is an EOLC Pathway, as far as MRCCS is concerned.
140. The Panel was advised that it is important that a distinction is made between 'the end of life pathway' (people in the last year of life) and 'the care pathway for the last days of life'. Locally, the end of life pathway has been the provision of care in the last days of life, however nationally the end of life pathway more recently refers to the last year of life. For this reason the current EOLC pathway will be referred to as the 'care pathway for the last days of life'.
141. As such, the Panel heard that this is currently being implemented across all care settings within MRCCS. An ongoing audit which examines the use of the pathway for all expected deaths is being implemented; this has identified that although it is being successfully implemented, education needs to focus on promoting a greater uptake of its use in non-cancer patients. The pathway for the last days of life has been identified as a commissioning for quality and innovation (CQUIN scheme 2010-11) for MRCCS.
142. The Panel was interested to hear that MRCCS is currently working with other care provider services at Teesside Hospice, James Cook University Hospital (JCUH) and Nursing Homes to adapt the current care pathway for the last days of life, so that the pathway follows the patient. JCUH use this pathway

for the rapid discharge of patients from the acute to their preferred place of care.

143. The Panel was advised that MRCCS are currently developing a pathway for the last year of life, which will highlight what can be expected at every stage in the patient / carer journey. It was said that professionals would easily be able to identify what services they should be providing. The pathway for the last year of life will be clearly disseminated and roles defined so that MRCCS staff are aware of the care provision they need to provide. It was noted that although many patients receive the care they require in the last year of life, there are currently inequalities in the provision of care and support, especially for non-cancer patients. The Specialist Palliative Care Team work closely with the Community Matrons to address this issue by examples of good practice and the delivery of education to their 'generalist colleagues' in all care settings throughout Middlesbrough and Redcar & Cleveland.
144. The Panel had previously heard that a significant number of 'unnecessary' admissions into acute centres originate from nursing homes. The Panel was keen to hear MRCCS' views on the role played by Nursing Homes in people's experience of EOLC. The Panel was advised that there has for sometime been an inequality of care provision for patients / residents of Nursing Homes, as the skills of staff have been different than those in other care settings.
145. The Panel was pleased to hear that in order to address this issue a Macmillan Clinical Nurse Specialist role for care homes has been developed; the post holder has clinical responsibility for patients with highly complex needs within nursing homes. The post holder also has responsibility for facilitating the implementation of the GSF in nursing / care homes in Middlesbrough and Redcar & Cleveland. The aim is that every nursing home throughout Middlesbrough and Redcar & Cleveland will be part of the programme. The Panel heard that this aims to improve care to patients / residents in this setting, by empowering staff and encouraging the development of closer and more effective working relationships between private and public providers of care. Staff will plan their patients' care along the pathway and anticipate their patients' needs in advance, rather than waiting for a crisis to occur and the patient being admitted inappropriately at the end of life.
146. It was reaffirmed to the Panel that in primary care, everything pertaining to EOLC revolves around the GSF. The Panel heard that whilst it was accepted that nursing homes had historically left something to be desired with their approach to EOLC, those in the Middlesbrough area were making considerable strides, with significant take up of the GSF. It was also noted that a formal EOLC qualification is now available to nursing home staff via the University of Teesside, which raises the profile of the skills and the staff who obtain such a qualification. To support this point, it was said that 14 care homes are currently on the GSF scheme and 16 already have adopted the GSF framework, in the MRCCS area. The Panel was advised by MRCCS that there is some concern over the numbers of GP Practices that had not, as yet, signed up to the GSF. It was noted that it is impossible to enforce GPs take

up the GSF, although nonetheless it remains a source of disappointment that more practices have not 'signed up' to the GSF.

147. MRCCS representatives emphasised to the Panel that there is a strong desire within Community Services to keep people in their homes wherever possible at the end of life, whether that be in a private residence or a care home of some sort. MRCCS expressed the view that so doing will begin to tackle an undoubtedly heavy rate of admissions to JCUH, which are too high. The Panel expressed an interest in exploring further what exactly an inappropriate admission was. The Panel heard that it centres around whether it is worth admitting someone to hospital for a particular need, or could it be done elsewhere? Or 'what is the admission for?' 'Whats it going to achieve?'
148. On the topic of 'inappropriate admissions', the Panel heard that a major challenge to their prevention is what happens when dealing with EOLC patients 'out of hours'. The Panel heard that out of hours GPs can sometimes admit people, even against the wishes expressed in care plans, as they can be risk averse and without knowing the patient's case, it seems that the physical symptoms require admission. Out of Hours GPs do not necessarily know if someone is on the palliative care register. This was acknowledged as a major weakness of the out of hours service model, that requires careful attention.
149. The Panel was told about a new education programme that had also been developed between MRCCS Specialist Palliative Care Team and University of Teesside, to improve the standard of care provided to patients / residents. The Panel heard that successful implementation of advance care planning (ACP) and the care pathway for the last days of life will prevent inappropriate admissions to hospital and facilitate the patient being cared for in their preferred place of care. The first cohort of students achieved a 100% pass rate with the support of the post holder and the Specialist Palliative Care Team.
150. It was confirmed that a nursing / care home focus group has been set up by the Specialist Palliative Care Team to support staff in their provision of EOLC. The Specialist Palliative Care Team have set up a website working in partnership with North Tees and Hartlepool teams to support the educational needs of staff, with links to all appropriate end of life information and support required for the delivery of care.
151. Community Nursing has been supporting patients in nursing/care homes who require a syringe pump over the past two years. NHS Middlesbrough has funded syringe pumps and training for nursing home staff to enable them to manage their own patients care. Community Nursing will continue to support nursing staff over the coming year until nursing home staff feel competent in the delivery of care. Community Nursing will continue to manage syringe pumps in EMI and Learning Disability Nursing Homes.
152. In other evidence, the Panel had heard the view expressed that too many people die in hospital unnecessarily, which is expensive and usually not

people's preferred place to die. The Panel was keen to hear MRCCS' views on what it could and should be doing about this.

153. The Panel heard that there is currently a lack of clarity about a patient's choice of preferred place of death. It was said that MRCCS staff are currently undertaking advance care planning training, using the preferred priorities of care tool<sup>14</sup>. Currently, patients are not consistently asked if they wish to record their wishes. The Panel heard that MRCCS is involved in the implementation of Advance Care Planning training and in a quarterly audit, which examines the offering of a plan to patients in the last year of life (CQUIN scheme 2010-11). Advance Care Planning is currently in the early stages of implementation within MRCCS, with Specialist Palliative Care Team and Community Matrons leading the way and supporting generalist services.
154. The Panel heard the aim is that within the GSF meeting, the multidisciplinary team discuss the patient's preferred option for EOLC, which means all professionals involved in the patient's care are then made aware of their choices. Discussions at GSF meetings help to support the patient within their own home and aim to facilitate the patient's preferred place of care within either, the patient's home, a hospice, nursing home or primary care hospital.
155. It was confirmed that the aim is to prevent inappropriate admission to the acute sector, by redirecting those who choose to die in hospital to a primary care hospital bed. GSF focuses on future planning for both the patient and carer, good symptom control, communication with the out of hour's medical and nursing services, so that prognosis and place of care is adequately communicated. Input from the key worker / care manager is essential for the success of GSF. The Panel heard that not all staff currently have the knowledge or skills to provide appropriate EOLC, with a good example centering around staff fears of addressing sensitive issues/conversations and their ability, or lack of, to recognise the dying patient.
156. It was said that improvement in this area of practice could be addressed by making EOLC training mandatory. MRCCS have a measure<sup>15</sup> for a community nursing key worker to hold the same patients on their caseload, as the GP has on their GSF register.
157. Allied health and social care professionals are also important as they provide support and equipment/adaptations, which help to maintain the patient at home through the provision of holistic care and support to daily living. MRCCS are currently reviewing the support services available in order to sustain the patient and carer at home.
158. The Panel was advised that patients are often admitted to hospital in the last week/days of life, due to patient/carer fear or fatigue, as a result of increasing health and social care problems. It is, therefore, vital that the patient and carer

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<sup>14</sup> [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk) accessed August 2010

<sup>15</sup> (CQUIN, 2010-11)



have developed a good relationship with their key worker/case manager over the past year.

159. The Panel heard that this ensures that they know the patient and carer well, and they are then able to provide the increasing support and care that is needed, tailored to the individual's preferences. It was noted that this requires anticipatory planning from the key worker/case manager and any other professionals involved in the patient's care. It was said that there are examples of excellent care being delivered, although those examples are somewhat patchy. It was accepted that further work is required to develop the competencies and skills of staff in palliative care, to ensure such competencies were more common place.
160. The Panel was advised that Macmillan Clinical Nurse Specialist, is supporting care homes in addressing advance care plans to prevent inappropriate admission to the acute sector. The post holder is working with the discharge teams at North Tees and Hartlepool Foundation Trust and JCUH in the development of an information pack. The Panel was advised that it is planned that when a patient is admitted to JCUH for active treatment, the pack will inform staff of the patients' individual needs, with the tool being standardised and easily recognisable for acute hospital staff. The tool will also act as a communication tool with Nursing Homes upon discharge. It was confirmed that Nursing Homes who have completed the GSF process are ideally placed to provide an alternative to hospital admission, for those who require further support.
161. The Panel highlighted that according to research done for 'A Good Death'; around 60% of people want to die at home, whereas around 21 % actually do. The Panel was keen to hear whether MRCCS felt there was sufficient capacity in Community Services, to allow more people their wish to die at home.
162. The Panel was advised that locality teams may find it a challenge to cope with increasing numbers of patients being cared for in their own home or a primary care hospital setting. This is because this group of patients requires ongoing support, symptom management, advance care planning, anticipation of future needs and provision of care throughout their last year of life. It was said that whilst MRCCS is currently working hard to provide care in the last year of life for patients and their carers, the implementation of GSF, advance care planning and the EOLC pathway provides a challenge to staffing resources. The Panel heard that as/if more people choose to die in their own home/ community hospital, there would need to be significant re-direction of funding following the patient, from the acute setting to the community. It was acknowledged that such a redirection of funding is easier to speak about, than to achieve. The withdrawal of funding from the acute to the community is not without risk. It is involves delicate balance and timing, which the Panel felt was important to highlight.
163. The Panel also heard that the general public are not always aware of the services that are available to them as they approach the end of life, and such

services need to be communicated much more clearly than they are presently. The point was made, and accepted, that without patients and health staff having a very clear idea of what is available and being empowered to implement that knowledge, the default option tends to be admittance into a hospital. In accord with a point made by the STHFT in evidence, the Panel was told that there needs to be much more open discussions with patients and carers about EOLC, so that patients can make plans for the future and informed decisions about their care. It was also felt that carers require more support networks, to support them in caring for those dying at home.

164. The Panel heard that if we are going to encourage and accommodate more people to choose to die at home if that is their wish, improvements are required in relation to pharmacy dispensing support and specifically the availability of prescribed drugs, when needed on a 24-hour basis. In addition, access to equipment needs to be timely to enable patients to be kept at home if that is their wish. Additionally, the Panel was advised that there would need to be more capacity within carers support and sitting services, in particular overnight care, which would ideally would be provided by social care providers, in the view of MRCCS. The Panel also learned that improved access to continuing healthcare funding via the fast track route would be necessary. This would potentially minimise the risk of a crisis occurring and avoidable admissions to the acute sector.
165. The Panel has heard consistently that a hallmark of a well developed and high performing EOLC system, would be the provision of effective '24 hour' service. The Panel was interested to hear MRCCS' views as to whether the current service provision in Middlesbrough was sufficiently '24 hour'.
166. The Panel was advised that patients/carers be given contact details so that they can contact the community nursing service, as required, on a 24 hour basis. It was confirmed that community nursing are currently able to respond to patients well within the agreed referral criteria of 4 hours and in most cases this can be within 1-2 hours.
167. It was stated, however, that there are challenges in responding to patients across Middlesbrough and Redcar & Cleveland, especially for the out of hours CNS service, due to the geography of the area. The travel to the furthest areas of East Cleveland can take up to 1 hour from the Middlesbrough base and this does not take into account adverse weather conditions, which again delay response times. MRCCS confirmed that a CQUIN measure exists to have 'face to face' contact with patients in the last year of life, within 1 hour at request.
168. The Panel learned that the out of hours nursing service/Marie Curie provision was currently under review within MRCCS. It was stated that MRCCS is committed to the provision of 24-hour care to patients at the end of life, but feels that the provision could be better co-ordinated and more standardised than it currently is. It was said that Out of hours medical providers need to work more closely with the out of hours community nursing services and

primary care hospitals, in order to facilitate the patients preferred place of care/death.

169. The Panel heard that Out of Hours Specialist Palliative Care provision is currently provided by Teesside Hospice on a 'good will' basis. In MRCCS' view, however, Commissioners should adequately fund this, especially if the number of patients being dealt with outside the acute sector is to increase. It was confirmed that Out of Hours Palliative Medicine Consultant cover is provided (Teesside) on a telephone advice basis. There is, however, no face to face provision for Specialist Palliative Care seven days a week. The provision of community nursing, however, is a priority in order to provide continuity and support for patients.
170. The Panel has heard on numerous occasions that EOLC does not necessarily need a huge number of specialist palliative care staff, although what it does need are adequate numbers of generalist staff who are sufficiently trained in EOLC to be able to deal with patients effectively. The Panel was keen to establish whether MRCCS was satisfied that frontline staff were sufficiently trained to deal with the issues connected to EOLC. In addition, the Panel posed the question as to whether MRCCS felt appropriately commissioned to provide effective community services to deliver high quality EOLC, reflective of local need.
171. The Panel was advised that educational provision in EOLC is available and has been accessed by some staff within MRCCS. In addition, Training is provided in house by the Specialist Palliative Care Team within MRCCS and in partnership with University of Teesside and can be accessed locally within the community. MRCCS expects to have the appropriate IT software to provide access to national on line end of life training by the end of 2010. Members heard that the Specialist Palliative Care Team has an educational plan with locally available education and is targeting key staff (new staff at induction and key workers / care managers). Education is also provided by the team at an open forum session and can also be tailored to individual teams at request.
172. The Panel was advised that although there are examples of excellent care, gaps have also been identified. It was confirmed that more work needs to be done to assist staff in understanding their role in the provision of appropriate care and to at least have a general understanding of palliative care and bereavement support. The Panel learned that in order to implement advance care planning, there are training needs for staff in communication skills, so that they can manage difficult conversations appropriately.
173. It was confirmed to the Panel that as the numbers of patients being cared for at home there is need for further investment in the provision of community nursing services to cope with the increasing numbers of patients being cared for at home.
174. The Panel was interested to hear the views of MRCCS regarding areas of EOLC in Middlesbrough that are good and those that require development.

175. In addition, the Panel had heard that, historically, EOLC had been somewhat 'cancer-centric' and patients with other conditions did not receive the same level of support. The Panel was interested to discuss whether MRCCS felt that EOLC is of an equal standard, irrespective of what terminal condition someone has, or whether there are differences in the patient experience, depending upon the condition the patient has?
176. The Panel heard that the local NHS accepted the general suggestion, that traditionally, EOLC had been somewhat 'cancer-centric', although that had changed in recent times. MRCCS expressed the view that it needs to have sufficient numbers of sufficiently skilled and competent staff to provide good EOLC, which is not dependent upon diagnosis. The view was expressed to the Panel that training in EOLC should be considered as mandatory.
177. The Panel heard that Community Matrons and the Specialist Palliative Care Team provide care to patients/carers at the end of life irrespective of diagnosis. Nonetheless, the Panel was advised that some inequalities in the provision of care remain in areas such as patients with Dementia, COPD<sup>16</sup>, Heart Failure, elderly frail and especially the support provided via GSF and the Community Nursing Service. It was confirmed that historically palliative care services have focused on cancer patients, although in recent years the experience that the local NHS has gained has been transferred, to focus on all patients in the last year of life, irrespective of diagnosis. MRCCS are working towards the inclusion of all patients at the end of life receiving equity of care provision. This would mean inclusion in the GSF, providing regular support, appointment of a key worker/case manager, advance care planning, EOLC pathway and preventing avoidable admissions at the end of life.
178. In conclusion to MRCCS' evidence, the Panel heard that MRCCS is currently working to develop an end of life/bereavement policy and MRCCS is also developing a strategy for EOLC. It was also said that EOLC training is to become mandatory for all health and social care professionals, so that staff are sufficiently skilled and equipped, to provide excellent tailored care at home, or as close to home as possible.

## **EVIDENCE FROM BUTTERWICK HOSPICE**

179. A major feature of EOLC, and its provision in England, is the extent to which the Community & Voluntary Sector plays a crucial role in its provision. This is particularly the case when one thinks of the historical and current role played by hospices, in supporting people and their families at the end of life.
180. Given this context, the Panel felt it was crucial to hear the views of local hospices, which provide a significant and important service to local people, to hear their views on how Middlesbrough currently deals with EOLC. Whilst the

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<sup>16</sup> Chronic Obstructive Pulmonary Disease

Butterwick hospice is based in the Stockton Borough and conducts its activity north of the Tees, the Panel was keen to speak to them, particularly about its Out of Hours service. The Panel had heard previously that effective Out of Hours provision for EOLC was a particularly important element of how an area approaches EOLC. Given that Butterwick provides an Out of Hours service, the Panel felt it important to hear about it and establish whether any lessons could be learned for EOLC in south of Tees.

181. Again, in advance of the meeting, a list of initial questions was submitted to the Butterwick Hospice representatives, which were addressed in a paper submitted to the Panel. The Panel discussed that paper and asked supplementary questions as appropriate.
182. By way of introduction, the Panel was advised that Butterwick Hospice Care, a registered Charity, has freely provided a wide range of end of life care to the population of Teesside for over 26 years.
183. Its Mission is as follows
  - *To freely deliver end of life and palliative care, of the highest standard, to patients and their families, regardless of diagnosis, in whatever setting is appropriate and desired by the patient.*
184. The Panel heard that in the last fifteen years the Charity has substantially expanded and now comprises:

### **The Butterwick Adult Hospice and Butterwick House Children's Hospice**

- Both situated adjacent to North Tees Hospital in purpose built accommodation.
- The adult Hospice primarily serves the population of Stockton-on-Tees and provides a ten bed In-Patient unit, a twenty place Day Hospice and an Out of Hours Service (see below).
- The Children's Hospice serves the sub-region from North Yorkshire, in the South, all of Teesside, County Durham through to Sunderland in the North. The Hospice has four beds and has a caseload of some seventy five children – from newborn babies to nineteen year old teenagers.

### **The Butterwick Hospice at Bishop Auckland**

- This serves the rural adult population of County Durham: from Sedgfield in the East to Barnard Castle in the West. Services are provided from the main Hospice building in Bishop Auckland and from outreach sites in the Sedgfield, Stanhope and Barnard Castle Community Hospitals.

- At all locations the Charity provides a comprehensive range of holistic support services for patients and their families including physiotherapy, complementary therapies and family support: counselling, psycho-social support, bereavement and other counselling.
- Last year the Charity delivered care to over 2,300 patients across all sites.

## FINANCE

185. The Panel was advised that Butterwick makes no charge whatsoever for any of its services. Those services are financed by a combination of charitable income (fundraising etc), trading ('charity' shops and two weekly lotteries) and grant and commissioned income from the local NHS (PCTs) and directly from the Department of Health.
186. The Panel learned that Butterwick spends some £3.8 million a year, of which £1.3 million is funded from statutory sources (NHS). It was noted, therefore, that the Charity therefore contributes £2.5 million a year to the local health economy from its charitable resources.
187. The Panel was advised that last year (2009/10), the NHS funded the following percentage of patient care costs (27% is proximately the average national level of NHS support for adult hospice services) :

Adult – Stockton (Stockton PCT) – overall	27%
(Out of Hours Service 75%)	
Adult - Bishop Auckland (NHS County Durham)	50%
Children's – overall	15%

188. The Panel was advised that a negligible amount is received from the local Tees PCTs for children's care, that equates to approximately 25% of all activity (costing some £200,000 a year). NHS County Durham contributes about 25% of patient care costs for children from its locality).

## NHS FUNDING ARRANGEMENTS

189. It was confirmed that for the Adult services provided in Stockton-on-Tees, the PCT fund the Butterwick on an annual grant basis, with the exception of the Out of Hours Service which is funded on a full (but annual) NHS Community Contract. The Panel noted that this essentially means that all statutory funding is short-term, although in practice it has been renewed on an annual basis (often however only well into each financial year) for a number of years.

190. The Panel was advised that as some 90% of all patient care costs are clinical salaries, which are by nature ongoing contractual commitments to the Charity, this short-term funding essentially inhibit service development. The Panel heard that this position is by no means unique to the Butterwick Hospice and is probably replicated in most hospices.
191. The Panel was advised that such arrangements are also not in compliance with the Compact with the Voluntary Sector, to which the NHS is a signatory.
192. The Panel was advised that in each of the last five years, the annual uplift to Butterwick has been less than the inflation rate and is applied to only a percentage of the actual cost of the service. It was said that this has resulted in the NHS funding a reducing percentage of care costs, over a protracted period, increasing the Charity's dependence on its charitable income.
193. By contrast, the Panel heard that the adult services provided to residents of, and commissioned by, NHS County Durham are now funded on a three year Service Level Agreement.
194. The Panel heard that all of Butterwick's funding streams from the NHS have now been frozen at their 2009-2010 levels, as a consequence of the public sector budget constraints. It was said that to put this into some context, this has resulted in the Charity needing to finance £60,000 of inflation costs this year, from increased charitable income.

## **NON STATUTORY FUNDING**

195. The Panel heard from Butterwick that it maintains a high profile and is well respected and valued by the local community. It has a database of over 35,000 mainly local donors who support the charity (many on a regular basis).
196. The Panel was advised that in the current year (2010/11), Butterwick is dependent upon charitable support – including fundraising and trading activities for 65% of its income requirement (which is around £2.5 million). It was confirmed that of this, £700,000 would be generated from charity shops and lotteries and £1.8 million from fundraising activities.
197. The Panel was advised that the Voluntary Sector is by no means insulated from the effects of the recession and Butterwick is finding it increasingly difficult to generate such considerable sums of money on an ongoing basis. In 2009/2010 Butterwick incurred a deficit of £250,000. The Panel heard that this year (2010/11) the Butterwick continues to operate at a revenue deficit, which can only be withstood for so long. The Panel heard that Butterwick is already a very lean organisation with very little 'fat to trim', although typically only has around 30 days running costs at the bank. The Panel heard that whilst the Butterwick is hugely dedicated to the provision of high quality end of life support, ultimately goodwill can only deliver so much. The reality is that such services, delivered to a high quality, do cost significant sums of money.

198. It was confirmed to the Panel that the financial reality is that the Butterwick cannot realistically anticipate increasing its charitable income to fund the development of new services. The Panel felt this posed a number of important questions, regarding EOLC and specifically its funding. A stated ambition of the system is to reduce the numbers of acute admissions at the end of life and facilitate more choice for people in securing their preferred place of care. The Panel would highlight the Good Death research which indicates around 20% of people would select a hospice, which leaves the question of how that sector is developed to deliver that wish, whilst the sector relies increasingly on charitable income.

## **CANCER/NON CANCER**

199. The Panel was interested to explore the idea that EOLC has, traditionally, been somewhat cancer-centric. The Panel heard that may have been a historical view, but Butterwick provides its services on the criteria of need not diagnosis.
200. The Panel was advised that in Stockton, over 95% of all adult patients have a cancer diagnosis. It was said that this percentage, however, is slowly decreasing with particular progress being made with patients referred to the Out of Hours Service.
201. The Panel, conscious that Butterwick operates across two Commissioning areas, was interested as to whether Butterwick has a different experience in any way with County Durham, as opposed to Tees. The Panel was advised that in County Durham, increased NHS funding has enabled Butterwick to increase its capacity and 31% of patients last year had a non-cancer diagnosis. The Panel was particularly interested to hear about specialist dedicated services, provided for County Durham patients suffering neurological conditions and advanced heart disease. It was also confirmed that virtually none of the children has a cancer diagnosis.

## **OUT OF HOURS SERVICE**

202. The Panel was particularly interested to hear about Butterwick's experiences of providing an Out of Hours service, given that the Panel had heard previously how important an effective Out of Hours was for EOLC.
203. The Panel learned that for the last five years Butterwick has provided a highly successful Out of Hours Service, for adults, in Stockton.
204. The service operates between 8 p.m. and 8 a.m. 365 days a year and is staffed by a small experienced team of Registered Nurses, supported by equally experienced Health Care Assistants.
205. The Panel was advised that the service is an integral component of the wider Hospice service. A dedicated clinical administrator who is supported by a Nursing Sister deals with referrals, which are normally received during office



hours. This allows complex cases to be discussed on a clinician to clinician basis.

206. The Panel heard that the key objective of the service is to allow patients to be well managed symptomatically, overnight in their own homes, as their illness progresses. The service also facilitates patients remaining in their preferred place of care and in doing so to reduce avoidable hospital admissions. Importantly, the Service also supports carers who particularly at night can feel vulnerable and uncertain.
207. The Panel was very interested to learn that typically, the Service has a caseload of over 150 patients at any one time. Last year, Butterwick advised, over 80% of patients were supported in achieving their preferred place of care – be that home, residential care home, nursing home or hospice.
208. It was confirmed that four years ago, the University of Teesside's School of Health comprehensively and positively evaluated the Service, at the expense of the PCT.
209. The Panel heard that in the view of the Butterwick, the current PCT review of Community Services and the Transforming Community Services initiative, may result in this service ceasing to receive NHS funding in the foreseeable future. In these circumstances its future will be unlikely.

## **DEVELOPMENT/IMPROVEMENT IN END OF LIFE CARE**

210. The Panel was interested to hear that as Butterwick delivers care of a sub-regional basis, it works with a number of PCTs and can compare and contrast how service development and planning has evolved in recent years – particularly in the Tees Area and across County Durham.
211. The Panel heard that in recent years there has undoubtedly been a greater focus on improving End of Life Care, which is a development that the Butterwick, and the wider hospice movement, very much supports.
212. The Panel was advised that the experience has been that in County Durham there has been a productive and transparent partnership between the NHS, the Local Authorities and the Voluntary Sector in developing and strengthening services.
213. In particular, it was said that the PCT has been able to strengthen the sustainability of all the Hospices in its area by increasing the commissioning rate, for agreed services, to 50% of agreed patient care costs. It has additionally been able to commission new services such as a bereavement service delivered by the four local Hospices forming a consortium to deliver consistent, equitable services on a countywide basis. The Panel was advised

that the benefit of receiving uplift from NHS County Durham is that Hospices such as Butterwick are able to release resources, for the development of new services. In addition, by such organisations as Butterwick becoming involved in the provision of bereavement services, it probably creates a saving for General Practice and reduces the numbers of people seeking assistance for bereavement and depression. In short, the Panel heard that by investing in such support services in the hospice environment, a direct saving on general Practice budgets could be realised.

214. The Panel was advised that in the view of Butterwick, it is apparent how NHS County Durham has improved EOLC and invested the additional End of Life Funding, which all PCTs have received.
215. The Panel was interested to hear that in the view of Butterwick, progress in Teesside in developing a robust end of life strategy has been minimal and there has been little meaningful consultation with the local Hospices. It was confirmed that Butterwick is unaware of any additional investment by the PCT and Butterwick Hospice has received no additional funding.

## **KEY CHALLENGES**

216. The Panel was interested to hear Butterwick's views on the nature of present and future challenges facing End of Life Care.
217. The Panel heard that it is a major advantage that there is now a clear, comprehensive national End of Life Strategy and developing local strategies.
218. The Panel heard the Hospice Movement has historically acted as a pioneer and exemplar in improving EOLC. The Panel was advised that the local population has for many years been well served by Butterwick in Stockton, by Teesside Hospice in Middlesbrough and by Hartlepool Hospice, amongst others.
219. It was confirmed to the Panel that the Butterwick continues to experience a steady demand for all of its services, with consistent optimal levels of patient activity. The Panel heard that Butterwick would suggest this continuing demand for services was not unique to Butterwick and was replicated in other hospices.
220. The point was made to the Panel that demographic changes and an increase in patient expectations, are two key indicators, which lead one to conclude that the demand for hospice services will continue to increase. The point was also made that an ageing population, coupled with ongoing healthcare improvements will increase the complexity of the care which patients referred will need.
221. In conclusion, the Panel heard that It was confirmed to the Panel that local and national hospice funding is somewhat stretched, with approximately one third of all UK Hospices operating at a deficit in 2009/10.

222. It was said that hospices are already fairly lean organisations, with not a lot of efficiencies to be made, whilst the recession has undoubtedly impacted on the population's ability to financially support its local Charities, which includes hospices.
223. The Panel heard that the Government are currently investigating the topic of EOLC and the results of that piece of work will be eagerly awaited. Nonetheless, it seems unlikely, given the national economic picture that the tariffs associated with EOLC will increase, so a number of questions about the funding of EOLC in hospices remains unclear.

## **Evidence from Teesside Hospice Care Foundation**

224. The final evidence source on 16 September was the Teesside Hospice. By way of introduction, the Panel learned that Teesside Hospice was formed in 1982 as a response to the shortfall in specialised care for those suffering from a life limiting illness in the Tees Valley and North Yorkshire region.

### **Teesside Hospice Care Foundation (THCF) - Mission Statement**

*"Teesside Hospice Care Foundation exists to enhance the quality of life for those suffering from a life-limiting illness. It offers specialist palliative care and support to patients and carers, in the belief that each person is entitled to dignity and choice within the best provision of care".*

### **Vision**

225. To provide a Consultant led Specialist Palliative Care service free of charge at the point of delivery for the population of Teesside.

### **Principles**

226. Service provision and development must continue to be needs led. It is recognised that, in practice specialist palliative and end of life care needs may be difficult to identify, assess, quantify and prioritise.
227. The Panel was advised that sources used to identify needs include:
- National policy
  - Local policy
  - The views of patients and carers
  - Help the Hospice's minimum data set questionnaire – which enables the performance of Teesside Hospice to be compared with national data
  - Teesside Hospice audit programme

228. The Panel learned that THCF works with local Acute Hospital Trusts, Primary Care Trusts, Macmillan Nurses, Community Nursing Teams and General Practitioners to deliver specialist palliative care services and expertise to patients, families and carers.
229. Further, the Panel heard that there is a skilled multidisciplinary team, which offers patients holistic care, ensuring that their physical, emotional, social and spiritual needs are cared for. The team includes: Consultants in Palliative Medicine, Hospice Medical Team, Specialist Nurses, Occupational Therapists, Dietician, Social Worker, Physiotherapist, Complementary Therapist, Chaplaincy and Counselling Services.
230. It was said that the terms *palliative*, *end of life*, *supportive care* and *a good death* are used interchangeably by professionals, the media and others and cause confusion to many people. Teesside Hospice supplied a number of definitions to assist the Panel in considering the topic.

## **Palliative Care**

231. The World Health Organisation defined palliative care in 2002 as:

*“An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment”.*

232. They go on to state that: “Palliative care

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- Enhances quality of life, and may also positively influence the course of illness;
  - Applies early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”
233. In addition, the National Council for Hospice and Specialist Palliative Care Services in 1999 defined specialist palliative care as:
- “The total active care of patients with progressive, far advanced disease and limited prognosis, and their families, by a multi-professional team who have undergone recognised specialist palliative care training. It provides physical, psychological, social and spiritual support, and will be given by practitioners with a broad mix of skills, including medical, nursing, social work, pastoral/spiritual, physiotherapy, occupational therapy, pharmacy and related specialities”.*
234. It was confirmed that patients referred to these services would have complex needs, for which the generalist teams require specialist advice and support.
235. The Panel was advised that Teesside Hospice’s primary aim is to act as a resource to the local community to provide *holistic specialist palliative care* at any point during a life-limiting illness.

**The Panel was presented with a list of the services provided by THCF:**

236. Teesside Hospice’s 10 bedded Inpatient Unit provides specialist palliative care to patients for four main reasons:
- To **Control Symptoms** relating to a patients illness such as pain and nausea
  - For **Respite Care** to give families and carers the opportunity to have a break from nursing
  - For **End Stage Care**: Some patients choose to spend their last days in the unit, being admitted during the very late stages of their illness
  - To **Rehabilitate** patients who may have had a long stay in hospital to allow them to return home to their families if that is possible or another care provision when home is not an option

**The Edward & Glenis Guy Day Centre**

237. This Centre offers professional advice and rehabilitation from our multidisciplinary team. Sixteen guests a day enjoy day care from Monday to Thursday at Teesside Hospice and on Friday’s at our satellite day care centre at East Cleveland Hospital in Brotton.

238. The Panel heard that patients visit the day care centre for one day per week for a period of 3-4 months, enabling them to use our services in a welcoming and homely environment. It is often referred to as the "getting on with living department" where a sense of normality is promoted at all times.

### **The Bereavement Counselling Services**

239. A service that provides support to both adults and children (via 'Forget-Me-Not' children's and young adults' bereavement counselling service) and enables people to work through their grief and accept what has happened helping them move forward in their lives.

### **Outpatient Clinics**

240. Teesside Hospice offers a number of outpatient clinics especially designed to manage symptom control. The Consultant-led team sees new patients, reviews the management of existing patients and assesses the needs of Day Care guests. As well as running outpatient clinics, the consultant also offers a domiciliary service, visiting patients too ill to travel to the Hospice, either in their own homes or local hospitals to help increase their comfort and quality of life.

### **Lymphoedema Service**

241. Teesside Hospice offers specialist care and symptom management to patients with lymphoedema - a condition where swollen limbs result from illness or treatment. The clinic at Teesside Hospice sees people with both primary and secondary lymphoedema. The clinic is run to instruct people how to manage their lymphoedema effectively, as there is no cure for the condition, although the earlier it is diagnosed, the more effectively the condition can be managed.

### **End of Life Care**

242. The Panel was advised that it is crucial to develop an understanding about the term 'end of life care', and to relate that meaning to the established definitions of supportive and palliative care. It was said that without such an understanding it may not be possible to define either the client group, or their 'end of life care' needs in a way which is complementary to existing well-established definitions. In addition, it might also result in some confusion on the part of commissioners as to whether a strategy for end of life care constituted a shift of focus to the exclusion of supportive and palliative care that may be needed earlier in the patient journey.
243. It is clear that the beginning of the phase is variable according to the following factors:

- Variation according to condition e.g. cancer, organ failure, frail elderly/dementia
  - Variation according to the perspective of individual patients
  - Variation according to the clinical/prognostic judgement of individual professionals
244. The Panel heard that it might be that the key factor is professional judgement. There may, nevertheless, be criteria that are commonly used by professionals in exercising their judgement. In response to that, the Gold Standard Framework (GSF) Team has recently produced a set of prognostic indicators, that may help in making decisions about when 'end of life' begins. In summary they are:
- **The Surprise Question** – Would you be surprised if this patient were to die in the next 6-12 months?
  - **Patient Choice/Need** – The patient with advanced disease makes a choice for comfort care only (not curative treatment) or is in special need of supportive or palliative care.
  - **Clinical Indicators** – General predictors of end stage illness (multiple co-morbidities, weight loss, general physical decline, serum albumin level, reduced performance status, dependence in most activities of daily living) and condition specific indicators.
245. It was confirmed to the Panel that the focus on end of life has the aim of ensuring that at the point of entering the last phase of life, a comprehensive assessment is undertaken of the individual's supportive and palliative care needs. The search is therefore for a recognisable trigger point for that assessment. Given the variations due to condition, patient perspective and professional judgement, it is clear that there is no common trigger point. In consequence, the trigger is likely to be determined, as discussed above, mainly by professional judgement.
246. Given that the period called end of life has so many variations, it may be that the term can have no formal definition. Nevertheless it would still be important to attribute a general meaning to it that is embedded in and reflective of currently accepted definitions of supportive and palliative care. That would suggest that the following might be acceptable:
- “End of life care is simply acknowledged to be the provision of supportive and palliative care in response to the assessed needs of patient and family during the last phase of life”.
247. The Panel was interested to establish what proportion of funding for THCF comes from the statutory sector. The Panel heard that work was undertaken in 2006 by the Department of Health, regarding the current costs of specialist palliative care services and their sources of funding.

248. The work showed that the estimated total costs of services for adults were between £418 and £440 million, of which £326 million was expended by the voluntary hospices and the remainder by NHS managed services. It was also estimated that the NHS contributed £119 million to the costs of voluntary hospices. The remaining £208 million was funded from charitable sources (NCPC, 2006).
249. The Panel heard that THCF helps over 3,000 people every year, from Tees Valley and North Yorkshire. Bearing in mind that number, The Panel was keen to establish how THCF received its income.
250. It was confirmed that THCF's running costs are in the excess of £2.1 million per year (2009) and the local Primary Care Trusts contribute to around a third of these costs which equates to £635,592. THCF must, therefore, raise £4,100 per day, every day of the year through its own resources. To raise those funds, Teesside Hospice Trading Company (which is the fundraising arm of THCF), currently has 14 charity shops, a weekly subscription lottery with 12,500 players and a fundraising department. The total profit from the Trading Company is transferred to the Hospice's income.
251. The Panel made enquiries as to the nature of that funding and how it was structured. It was confirmed that in previous years THCF has benefited from a 3-year contract. In 2010/11, however, the PCT commitment is for 1 year only, which includes a review of Hospice services.
252. As a direct provider of EOLC services, the Panel was interested to hear THCF's views as to how well the Tees health and social care system, presently deals with EOLC. The Panel heard that, in THCF's view, the provision of EOLC across the Tees area is variable in terms of resource and quality. It was said that there appears to be confusion regarding the clarity of role and function in terms of the District/Community Nurse role, Clinical Matrons and Specialist Palliative Care Nurses (Macmillan Nurses), in terms of delivering palliative and end of life care.
253. In addition, THCF expressed the view that various models of health and social care delivery appear to be in operation, with some localities having integrated health and social care and others having a more fragmented service. Community Hospital's provide a significant amount of general palliative and end of life care and are less accessible in Middlesbrough compared to Redcar & Cleveland.
254. Further, it was pointed out that there are 10 Specialist Palliative Care beds for adults in the Middlesbrough, Redcar & Cleveland population (278,100) compared to 20 beds for the population of Hartlepool and Stockton (281,600).
255. Reference was made to data usually quoted about people's preferences for place of death, which is derived from a telephone survey of a random selection of the general public, undertaken by the National Council for Palliative Care (NCPC) in 2006. THCF expressed the view that the findings do



need to be treated with some caution, since it cannot be assumed that the preferences of those who are in the last phase of life, would match those of the survey sample.

256. Still, having accepted those points the Panel noted the following figures on preferred place of death:

<b>Preferred Place of Death</b>	<b>%</b>
Home	56%
Hospital	11%
Hospice	24%
Care Home	4%
Elsewhere	5%

257. It is clear from the above that substantially more people would prefer to die at home or in a hospice than actually do, and consequently many fewer people would prefer not to die in a hospital or care home. This is entirely consistent with other information that the Panel has considered. The Panel noted that the survey suggests that 24% of people would prefer to die in a hospice, whilst only 4% do so at present. The Panel noted that to meet such a preference level, would require a six-fold increase in hospice beds.
258. The Panel heard that, in the view of THCF, this one simple example demonstrates that patient choice is a challenge and in palliative care this choice is not clear for patients, carers and professionals. It raises a number of difficult questions, such as does choice in palliative care include choice of provider and, if so, between what options – hospice, hospital, community hospital, care home? How will informed choice be ensured?
259. The Panel was advised that historically, palliative care was used as the only option for a patient when active treatment had failed, i.e. 'terminal care'. It is now appreciated that some aspects are applicable from much earlier in the patient's illness and can be used in combination with stabilising or curative treatments. It was said that it is often difficult to predict a point in time in the course of a disease, which marks the move from curative to palliative care. The Panel heard that it is often a gradual process when the aim alters from prolonging life at all costs, to preserving the quality of life and balancing the benefits of treatment with its burden or side effects.
260. The Panel was advised that Teesside Hospice believes that maximising the quality of life for patients and their families through the use of symptom control and good supportive care is relevant at any or all points along the disease pathway – from diagnosis and treatment, to recovery or death.
261. The Panel was interested to hear THCF's views as to whether the Middlesbrough health & social care system has sufficient capacity to deal with the demand, which will grow, around End of Life Care.

262. It was said that it should be acknowledged that families and lay carers deliver a great deal of EOLC. The Panel heard that the necessary resources are not currently available to provide 24 hour care at home, even with the most comprehensive care packages providing a maximum of 4 visits per day (30minutes – 1 hour each), supplemented by Community Nursing support.
263. Furthermore, the Panel was advised that the Out of Hours Palliative Care Service is provided for patients in Redcar & Cleveland PCT areas and is not available to patients in the Middlesbrough PCT area.
264. The Panel heard that access to specialist palliative care telephone advice out of hours for patients, carers and professionals is provided by Teesside Hospice nurses and doctors and through them, occasionally to the Consultant in Palliative Medicine on call for the Tees locality. It was confirmed that this service is not funded by NHS Commissioners, despite requests by NHS Commissioners for business cases to be prepared, to support further development and raising awareness of this advice for the benefit of the population. The fact that this service is relied upon by the local NHS and actually championed by the local NHS as a tool in providing better EOLC, leaves the Panel at a loss as to why it is not contributed to by the local NHS. Indeed, the Panel has heard on numerous occasions that such an advice service has a crucial role to play, if the local health and social care economy is going to tackle the high numbers of unnecessary end of life admissions into acute hospitals.
265. The Panel was advised that THCF provides the specialist palliative care service for the locality, with patients being transferred from the acute hospital palliative care service, for complex symptom management and EOLC. It was confirmed that because of this rising trend over the last 5 years or so, an increasing proportion of patients cared for at THCF have complex needs. This in turn has reduced the capacity for 'straight forward' EOLC and respite care to be delivered, given that there are a maximum of 10 Inpatient beds available.
266. The Panel learned that the knock on effect of this is that more patients will be dying in hospital (acute or community), if support in the home/care home is not an option. The Panel was advised that the capacity for generalist staff<sup>17</sup> to care for these patients is a concern with a substantial need for training and education regarding symptom management and end of life care.
267. The panel was interested to discuss with THCF whether cancer patients use the majority of Teesside Hospice places (In-patient and Day Care). This is something that the Panel had heard is a historical trend and Members were keen to establish whether this was consistent with THCF's experience.
268. The Panel was advised that THCF cares for any patient requiring specialist palliative care, at any stage of a life-limiting illness. The referral criterion does not discriminate against any condition.

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<sup>17</sup> Such as Ward and Community Nurses, GP's and Nursing/Care Home staff

269. The table below is the most recent data comparing Teesside Hospice non-cancer patient activity with the national median.

<b>% new patients with non cancer diagnosis (National Council for Palliative Care, Minimum Data Set, 2008-09)</b>					
In Patient Unit		Day Care		Out Patients (including Lymphoedema)	
Teesside Hospice	National Median	Teesside Hospice	National Median	Teesside Hospice	National Median
9.2%	6.8%	12.8%	11.2%	57.6%	7.9%

270. The Panel was advised that whilst the patients that are referred to THCF are predominantly cancer patients, it does also care for non-cancer patients. It was said that historically, hospice care and expertise regarding symptom management has evolved from a cancer background. It was suggested that this is changing, with the recognition amongst clinicians and in national policy, that palliative care is appropriate for patients with other progressive life limiting illnesses, although the progression of the disease may be more difficult to predict e.g. Motor Neurone disease, Heart & Lung disease.

280. The Panel heard that in THCF's experience, patients who access its services early obtain the greatest benefit, as experienced staff monitor them, with problems being anticipated and managed.

281. The Panel heard that THCF is also committed to providing a complete range of Bereavement Services to adults and children<sup>18</sup>. It was confirmed that this service is open to the public and not exclusively for people who have had care at Teesside Hospice. The counselling team is led by a small team of paid staff, which is supported by a large number of specially trained volunteer counsellors, who are professionally supervised.

282. The Panel learned that 'Forget Me Not' Children's Bereavement Service was launched in 1998, to bridge the gap in support to youngsters under the age of sixteen who have lost a parent or loved one. The Bereavement Service enables people to work through their grief and accept what has happened, helping them move forward in their lives. The panel was advised that this is achieved by positive counselling work consisting of a variety of unique methods, including one to one sessions and group work. It was said that recent research it has been indicated that the emotional health, social and educational needs of children and young people are adversely affected by unresolved grief. In a relationship of trust, the counsellor works creatively with the young person using appropriate aids such as play, art, writing and drama. The Panel heard that the methods employed enable the young person to explore and understand their uncomfortable feelings and take out anger, aggression, hate or resentment in a safe, controlled fashion.

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<sup>18</sup> via 'Forget-Me-Not' children's and young adults' bereavement counselling service

283. It was confirmed that THCF offers a range of education courses in Bereavement, Counselling Skills and Communication Skills, which are held regularly at the Teesside Hospice with some accredited by Teesside University.
284. As a provider of EOLC services in Middlesbrough, the Panel was keen to seek the views of THCF as to where EOLC should develop in the future.
285. The Panel was advised that positive communication about the value and role of hospice care is hugely important. It was reported that some patients and their families can associate hospice and palliative care with 'imminent death' and 'hopelessness', so it was said that its role should be explained carefully. Further, hospices may be seen as places for people to die and patients may turn down referral for intensive symptom control or respite. The Panel heard that whilst some patients have expressed these concerns at the time of referral to THCF, they often report that they wish they had accessed services sooner and have gained a great deal by attending. In addition to supporting conversations about 'a good death' and EOLC, the panel was advised by THCF that some of the myths about hospices and palliative care should be challenged.
286. It was emphasised to the Panel that if palliative care is going to be developed, with more people having more choice over where they receive care, it is essential that local expertise and resource is utilised, to produce local network and national solutions. The Specialist Palliative Care (SPC) workforce can form this resource as they work across local health communities, and by so doing sit outside the traditional organisational boundaries.
287. In addition, the Panel heard that an out of hours palliative care service for Middlesbrough need to be commissioned in the form of a dedicated home care service. The Panel also heard that an adequately funded telephone advice service, with sufficient capacity, should be commissioned swiftly.
288. In conclusion to the evidence from THCF, the Panel heard that if the local health and social care economy approach to EOLC is to develop as required, in line with national and local strategies, it faces major challenges, particularly at a time of economic constraint. It was noted that the impending NHS structural changes<sup>19</sup> also bring about additional complexity and uncertainty.
289. Nonetheless, it was said that there are potentially exciting opportunities, which can only come about with an increased national momentum for improvement, which seems to be the case presently. The Panel heard that the necessary progress can only be achieved by the development of transparent partnerships and real consultation and co-operation between the statutory, voluntary and possibly the private sector.

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<sup>19</sup> Please see *Equity & Excellence – Liberating the NHS*

290. In the current economic climate, the necessary service improvements and developments will only be financially viable, if decisions are made to redirect funding streams. The redirection of funding seems to be an absolutely critical point.

## Evidence from Dept of Social Care

291. The Panel was interested to establish the level of involvement that the Department of Social Care, or its Commissioned providers, have in the provision of End of Life Care.
292. The Panel heard that at a strategic level, there is an End of Life Care Strategy Delivery Group, which exists across Tees, which is one of eight theme groups across Tees. It was reported that when these groups were established, reflecting the themes in “Our Vision, Our Future, Our NHS”<sup>20</sup>, social care departments were offered only one place on each. The representative on the EOLC group is from Stockton Borough Council. The Panel heard that the original intention was that local authority representatives would liaise with their counterparts in the other Local Authorities. It was said, however, that this does not happen in practice, as there is no forum for the sharing of information.
293. It was confirmed that prior to the establishment of the Strategy Delivery Group there was a South Tees group, chaired by a representative from Middlesbrough PCT, which involved more operational staff, but this no longer meets. The Panel heard that in the view of the Department of Social Care, this is a weakness as there is no forum for Middlesbrough’s Dept of Social Care to discuss service improvements / developments relating to EOLC.
294. The Panel was reminded that The Department of Health’s End of Life Care Strategy was launched in July 2008, setting out a vision and broad parameters to promote high quality care for all adults at the end of life.
295. The Panel was interested to learn that a Regional Strategy Development Group <sup>21</sup>took on a commission from Durham PCT in 2009, to take the National End of Life Care Strategy further and produce an End of Life Care Learning Pathway. The group had already produced learning strategies on medication and infection control. It was said that the group broadened the scope of the national strategy, to cover those working within a care associated role or working as volunteers. It also covered those ancillary workers whose main role or function is not providing direct care, but do frequently come into contact with those nearing the end of their life.
296. The Panel heard that the group carried out a mapping exercise linking competencies from the national strategy, with national Occupational Standards and appropriate qualifications. The competencies included:

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<sup>20</sup> The North East Strategic document – please see [www.northeast.nhs.uk](http://www.northeast.nhs.uk)

<sup>21</sup> Consisting of training managers, Sector Skills Councils in Health and Social Care, Colleges, Independent Care Homes and Care Alliances

- Communication
- Assessment and Care Planning
- Symptom management, maintaining comfort and well-being
- Advanced Care Planning
- Overarching values and knowledge

297. It was confirmed that the Department does not commission any specialist services for EOLC. The panel was advised that it relies upon non-specialist providers of domiciliary care and residential/nursing care, to provide services for a whole range of needs, which includes people with terminal illness.
298. The Panel heard that there is a big challenge with regard to the personalisation agenda. Many people are choosing to use personal assistants as opposed to services commissioned by Social Care. The training needs of personal assistants are the responsibility of the person who employs them, but clearly it is in the interests of the Social Care Department that workers have the required skills and abilities to undertake the work associated with End of Life Care.
299. The Panel enquired as to the extent to which local services are integrated when people are facing end of their life and whether there is an End of Life Pathway.
300. It was confirmed that there is an End of Life Pathway for NHS Tees and appropriate people should be identified in General Practice. Gold Standards Framework (GSF) meetings are held frequently in General Practice, some involving multi disciplinary meetings that can include Community Matrons, District Nurses, GP's, Practice Staff and Macmillan Nurses. The Panel heard that the Community Matrons and District Nurses in Middlesbrough are co-located in the same buildings as the Social Workers. Where a need is identified for social care involvement then Community Matrons and District Nurses particularly will refer the person quickly for assessment, care planning and provision of any services.
301. The Panel enquired as to the Department's views on the role played by Nursing Homes, in people's experience of EOLC. The Panel was advised that nursing home staff in Middlesbrough have all received training in the 'last days of life' component of the pathway, with syringe drivers having been purchased for each home and all staff have been, or will be, trained in the use of such. The Panel was advised that this will enable more people to be cared for during the last days of life, in a setting that is familiar to them, as opposed to an acute hospital for example. It was said that in residential care homes, District Nurses provide any nursing input that is required. It was agreed that by their very nature, nursing homes are dealing with a lot of people who require EOLC, so they have a significant role to play. In turn, if nursing home personnel are confident to manage EOLC for people requiring it, this will impact upon hospital admissions and hopefully reduce them.

302. The Panel raised with the Dept of Social the view that it had heard previously, that too many people die in hospital unnecessarily, which is expensive and usually not people's preferred place to die. The Panel was keen to hear the view of the Department of Social Care, as to what could be done about this.
303. The Panel heard that this is a scenario that the Dept of Social Care would recognise as reality and would accept that there is an issue about capacity within services. It was said that whilst some specialist NHS services, especially for people with cancer, exist i.e. Macmillan Nurses, Marie Curie Nurses, they are limited in the number of services they can provide to any one individual. The Panel was interested to learn that the District Nursing out of hour's service is also limited, having only one nurse and one health care assistant on duty for the whole of South Tees overnight.
304. The Panel was advised that the Dept of Social Care does not commission overnight care specifically, but does purchase care from domiciliary care agencies, on a 'spot' contract basis. Additionally, the growth of personal budgets gives people an opportunity to employ their own carer(s). The Panel heard that inevitably, there are discussions between Social Care and the NHS on a regular basis, about who should fund such services. Whilst a person may be terminally ill, they may not have significant health needs in the early stages of the end of life pathway, so the responsibility for funding care lies with Social Care. Towards the last few weeks/days of life, however, funding responsibility may lie with the NHS. The Panel was advised that this does present difficulties if a person is using a Direct Payment to pay for care, as the NHS cannot legally purchase care through such an arrangement.
305. The panel heard that there are certainly difficult times ahead. PCTs are required to make significant savings this financial year, which will inevitably mean staff reductions and working relationships will be affected by such changes. In addition, the Panel acknowledged that the NHS White Paper will lead to commissioning activity being the responsibility of GP Consortia, whilst the precise role of local authorities in that environment remains somewhat uncertain. The Panel heard that the Dept of Social Care would be very keen to work with the Middlesbrough Consortium/Consortia to develop and improve services, for people on the EOLC Pathway.
306. The Panel enquired as to whether the Department of Social Care felt that services for EOLC are sufficiently 24 hours to meet local need. The Panel heard that there are a few services that operate 24 hours, but they are limited. Care Link can provide planned care during the night but for short spells, as it is mainly an emergency response service. Domiciliary Care agencies can provide overnight care on request, either on a 'waking' or 'sleep-in' basis. Nonetheless, the Panel was advised that if the number of people to be supported at home at any one time were significant, then services would probably struggle to meet demand.
307. The Panel was interested to hear whether the Department was satisfied that frontline staff, including those working for commissioned organisations, are sufficiently trained to deal with issues connected to EOLC.

308. It was reported that following the regional launch of the Learning Pathway, the SHA allocated £700,000 for End of Life Care Training, to be co-ordinated by the 4 Care Alliances in the North East. In other areas, the Tees Valley Alliance was given £147,000 to run training linked to the detail covered in the EOLC Learning Pathway. It was confirmed that a collaborative venture between Tees Valley Alliance, Local Authorities, the SHA and the 5 local FE colleges is currently providing free training for workers in the adult care sector in Tees Valley (Hartlepool, Middlesbrough, Stockton, Redcar & Cleveland, Darlington). The Panel heard that the training will address the need to ensure that frontline care staff, including those working for commissioned organisations, are sufficiently trained to deal with the issues connected to EOLC.

### **Evidence from Cleveland LMC**

309. The Panel was mindful of the role that General Practice plays in the provision of EOLC and was keen to speak to representatives of General Practitioners in Middlesbrough. In addition, given the contents of the White Paper and the seeming advent of GP Commissioning Consortia, the Panel felt that a discussion with General Practice on the future of EOLC was crucial.
310. The Panel was pleased to be able to engage with the Chair of the Cleveland Local Medical Committee.
311. The Panel heard that General Practice sees its responsibility to its patients as being from the 'cradle to grave', in line with the founding principle of the NHS. As such, the Panel heard that there is no reason why high quality EOLC should not be seen as a fundamental part of service provision by the NHS, although it would be accepted that there is work to do in relation to EOLC. Reference was made to a Kings Fund survey of GPs relating to EOLC, saying that most GPs feel that more training for GPs is required, particularly so around the use of the GSF to ensure that its application becomes the norm.
312. The Panel heard that General Practice sees itself as intrinsically involved with EOLC and feels that the personal relationship developed with a patient (and their family) is key to delivering high quality EOLC. Nonetheless, the Panel heard that there is a clear view across General Practice that EOLC in Middlesbrough is fragmented.
313. Consistent with other views considered by the Panel, Members heard that General Practice in Middlesbrough also feels that there are a significant number of patients at the end of life who die unnecessarily in an acute centre, such as James Cook University Hospital. The Panel was advised that a common occurrence would be a patient deteriorating out of hours, an Out of Hours GP attending without knowledge of the patient's condition and admitting the patient through a 'safety first' approach, with the person then dying in an acute ward. The Panel heard that no one would accept that this is the optimum care model for a patient at the EOLC. It was also accepted by



the LMC representative that the level of support available to patients and carers Out of Hours, is very much the weakest link in EOLC in Middlesbrough.

314. The Panel heard that there is an enormous amount of goodwill, towards what services do exist for EOLC, although those services would be hugely improved by having their capacity enhanced.
315. The Panel heard that a priority for EOLC in Middlesbrough, should be the improvement of access to hospice beds. It was said that should a patient reach a stage when carers cannot cope, there are only ten inpatient beds at THCF, which can fill up very quickly given the area it serves. As such, if there are no beds available, admittance into JCUH is the only option.
316. The Panel was interested to learn that whilst EOLC is widely recognised as a key component of the NHS' operations, it remains a source of surprise to the public that a significant amount of services are still provided by the voluntary sector, on a goodwill basis. The Panel was advised that even when services are commissioned by the statutory sector, they can often be on a yearly basis, or even on a spot purchase basis, which makes the planning of service development for such organisations very difficult. It was also said that EOLC in Middlesbrough would be much the poorer without the role played by the voluntary sector and should be recognised as such.
317. The Panel was keen to discuss how the proposed GP Commissioning Consortia could develop EOLC. The Panel heard that General Practice in Middlesbrough would be keen to get involved with the planning of EOLC and feels that the proposed Consortia would be a good vehicle for so doing. The Panel enquired as to why, if General Practice was particularly keen to develop EOLC, it had not tried to make such improvements under the previous Practice Based Commissioning Initiative.
318. The Panel heard that GPS felt that PBC was a fairly limited tool to develop services with and that they couldn't achieve all they would have wanted to, within the parameters of PBC. The LMC would accept that PBC was perhaps something of a missed opportunity with regard to developing EOLC, but would feel that a Commissioning Consortia would be an ideal vehicle to improve EOLC in Middlesbrough.
319. The Panel heard that it would be envisaged that the future development of EOLC (or any other service for that matter) would be delivered through a partnership model. Essentially, the Consortia would work with a partner (perhaps a preferred provider) to design and develop a service, meeting certain specifications, with the Commissioning Consortia funding the service. Whilst a lot of the detail would be required to be worked upon, it was clear to the Panel that General Practice in Middlesbrough would be very keen to use the proposed new structures to advance or redesign services, with EOLC clearly viewed as something to tackle early on.
320. In a general discussion about the issues raised, the Panel heard that Dept of Social Care also felt that the proposed GP Commissioning Consortia provided

better opportunities for service development than had been previously. Specifically, the Panel heard that there is presently no formalised vehicle or structure in which partners can collaborate, understand needs and jointly commission for EOLC. Certainly, the Panel heard the clear view from the representatives providing evidence that the proposed new structures would provide a greater opportunity to develop and commission EOLC.

321. The heard views which were positive about the proposed changes for commissioning as far as EOLC is concerned, although they do not come without their challenges. The Panel was also advised that the local health and social care economy faces the possibility of losing expertise from NHS, as it strives to achieve significant management cost reduction targets. As such, there is a danger that organisational memory is lost, just at a time when it is needed to navigate the local health economy through the transition period, before GP led Commissioning Consortia take on their proposed responsibilities.
322. The Panel suggested, and those present agreed, that as EOLC had been identified as an area of service that could be improved by a GP Commissioning Consortia, steps should be taken to begin its development now. It was suggested that an appropriately working group, sitting under the shadow GP Commissioning Consortia could be developed to make progress around EOLC now. This way, the GP Commissioning Consortia could truly begin to operate as Commissioners, albeit in the relative safety of shadow form, and develop skills, networks and aptitudes it will undoubtedly need when it becomes the principal commissioner of local health services.
323. The Panel was interested to discuss with contributors where the priority areas for the development of EOLC were. It was said that community based services, and particularly ones operating on an Out of Hours basis would need to be strengthened significantly. This was said to be particularly so, if the local system was going to make good on the ambition to allow more people to die in their preferred place of care. Linked to this, the Panel heard that those commissioning EOLC should establish need and capacity much more carefully than has been done previously.
324. The Panel noted that there was a lot of responsibility placed on care homes, and the staff working within them, to deliver services and develop expertise in such a way that enhanced people's EOLC. One possible concern linked to that is that the system would be expecting a lot of staff who are not paid particularly well, with the Panel suggesting that a contractual measure could be delivered where more could be paid to homes with better levels of staff expertise connected to EOLC.
325. In conclusion, the Panel heard that EOLC in Middlesbrough is a priority area for development now and should be treated as such. It was said to be unacceptable to wait for the new commissioning developments to be established before improvements to EOLC were sought.

326. In addition, it was emphasised that local authorities should be engaging with General Practice now, to develop relationships with likely consortia members. The idea of establishing comprehensive and effective shadow Consortia arrangements was emphasised as essential.

## Conclusions

1. EOLC is not commissioned or provided in a vacuum and people in the local health and social care system appreciate perfectly well the challenges that national budgetary retrenchment will bring. Given this reality, it seems all the more surprising that the local health system does not seem to be sufficiently addressing the numbers of unnecessary admissions into JCUH at the end of life, which are an expensive and (often) undesirable way of managing someone's care at the end of life. Having made that point, the evidence is fairly clear that there has not been sufficient historical investment in community based services to be able to accommodate the desired shift on End of Life Care provision and this remains a pressing concern. That is, if people were to begin to exercise more choice over their preferred place of care (and death) and it was away from hospital, community services would struggle to cope with the demand.
2. The Panel has heard the unanimous view that lowering the numbers of unnecessary admissions into JCUH for people at the end of life, would typically be a better experience for patients and create significant savings, which could to be invested elsewhere, over time. With that in mind, the Panel finds it very surprising, and rather alarming, that the Teesside Hospice Care Foundation is expected to run a 24 hours advice telephone line 'out of goodwill'. NHS Middlesbrough has, however, previously decided against commissioning the service, whilst advising the Panel that the development of a telephone line is required. The Panel has heard that the prime reason for the admission of people at the end of life is that there are very little other forms of support for people and their carers, and admittance to JCUH often represents the last resort. It strikes the Panel that an adequately resourced telephone advice line could be a very useful tool in keeping as many people as possible in their preferred place to receive their EOLC. The fact that NHS Middlesbrough has not invested in the (apparently much needed) advice line, despite two formal bids supported by South Tees Hospitals Foundation Trust, leaves the Panel uncomfortable.
3. Presently, the Middlesbrough health and social care system does not offer a viable alternative, on a sufficient scale, to dying in hospital, for those who may require some clinical assistance in the last days of life. The Panel has heard that hospices would have to increase capacity by six fold to accommodate those who say they would prefer to use a hospice, according to the 'Good Death' research. Further, community services are not provided on a sufficient scale to keep people out of hospital when their health deteriorates. This is especially true when one considers the apparent paucity of appropriate service provision in the 'Out of Hours' period, as most services dedicated to

EOLC seem to be concentrated on a 8am-6pm, Monday to Friday basis. The Panel has learned that a 'typical scenario' exists where:

*A Patient's health worsens 'out of hours', relatives/carers understandably worry and call for assistance and those attending (usually an Out of Hours GP or ambulance) do not understand the patient's situation. They adopt a safety first approach and typically admit into the patient into hospital and the person often dies shortly after admittance and often after unnecessary tests have been performed by JCUH, who also do not know the patient's situation.*

Until there is adequate 24-hour service provision, the aim to have more people receiving EOLC outside of hospital will never become a reality, as 24 hour service provision is the biggest single issue. The Panel would point to the experience in North Tees and the Butterwick Hospice regarding the reduction of hospital admissions, that an adequately commissioned and provided out of hours service can have. The absence of such a service in Middlesbrough is very significant.

4. The Panel has heard a great deal about the fairly recent orthodoxy, which states that if someone is dying, it indisputably follows that they need to be in a hospital environment with doctors on hand. The logical conclusion of this approach is that everyone, irrespective of medical complaint, dies in hospital. We already know that this is not necessary, or in line with what people in that position tend to want. As such, this orthodoxy requires strong challenge. As society, and specifically society's ability to treat illness has advanced, the Panel has heard that a culture has developed that views death as a failure and a failure for health services. It is the Panels view, that death should not be seen as a failure of health services, but a normal part of the life cycle. Death, per se, should not be seen as a failure of the health and social care system, but a death where the patient does not have their wishes applied, or is not able to exercise choice over their death, should certainly be seen as a failure of the system. In short, death is not a failure of the system, but a bad death is.
5. The Panel has discussed the concept of compassionate communities and specifically, empowering communities to support their members through their end of life and those bereaved. The Panel has heard that as death has become 'medicalised', communities have almost learned to fear death and not to consider it a matter for them. Communities behaving compassionately towards those facing the end of life and their carers, is something tangible that can be done and recognises that death is a natural event. The Panel is pleased to note that Middlesbrough Council already has in place a carers leave policy, where members of staff would be able to assist loved ones at the end of life, whilst still receiving full pay (for a maximum of 5 days). This is a very good example of a compassionate community approach.
6. The Panel has been impressed with the role of JCUH to date in the consideration of EOLC in Middlesbrough and how it can be developed. The Panel would point to the project aimed at rapid discharge as an example of

the Trust's commitment to improving the End of Life Care experience in Middlesbrough.

7. The panel would express a concern over the progress that can be made over the development to EOLC services when one considers the limited future of Primary Care Trusts. The Panel has considered a great deal of evidence pertaining to End of life Care, which indicates that the areas for improvement centre on the capacity of existing services and gaps that exist in service provision. The development of new services and improving the capacity of existing services is essentially a commissioning function. The Panel is concerned whether those commissioning needs can be met, given the limited lifespan on PCTs and the uncertainty surrounding the mechanisms to replace them.
8. The Panel has heard from the Cleveland Local Medical Committee that EOLC is an area that General Practice considers of crucial importance and values its contribution to and involvement in, very much. Given this and the clear need for developments in EOLC, the Panel considers that there is an opportunity for the local health and social care economy to develop and test service models under the arrangements described in the *Liberating the NHS – Equity & Excellence* White Paper. The consensus around EOLC's importance and the need for improvement makes it an obvious priority, which could also assist in developing and testing the new commissioning arrangements.
9. The economic turbulence of recent years and the climate that still prevails has had a noticeable and detrimental impact on the financial viability of hospices. Public donations are predictably under pressure and NHS commissioners appear to favour contracting with such organisations on a yearly basis, which creates its own pressures and uncertainty. The Panel fully understands and accepts the financial picture facing commissioners of health and social care. Still, the Panel feels that there should be an explicit recognition of the important role that hospices play in the provision of EOLC and Commissioners plans should reflect that. It is in the local health and social care economy's own interest to have strong and financially viable hospices to commission and call upon. Delivering high quality EOLC in any locality would become significantly more difficult without an active and viable hospice sector and this needs to be recognised.
10. The Panel has considered demographic projections relating to End of Life Care and those projections have stayed with the Panel. The United Kingdom has an ageing population and from 2012 will experience a gradual, but significant, upturn in the numbers of deaths. The numbers of deaths is, however, only half the story. As people live longer and healthier lives, with better and better access to medical technology, they will have longer periods of ill health or disability before they die, creating a greater demand for end of life care. Our health and social care system stands at this juncture with the option of continuing to do the same thing and essentially build bigger and bigger acute hospitals, with greater and greater sections of those facilities dedicated to end of life care. Alternatively, it can look to develop a network of sustainable local services, aimed at keeping people in their preferred place of

care, which will probably be a more positive experience and represent greater value for the taxpayer. It is, however, absolutely clear that service development needs to begin soon, to better meet the expectations and wishes of those at the end of life now and future generations. Current practice is not sustainable either financially or if we are to better meet people's wishes.

11. The Panel has heard of the progress made in increasing the uptake and application of the Gold Standards Framework, particularly within a nursing home environment. It is of crucial importance that staff in homes are empowered to provide care for residents and therefore keep people there for longer and avoid unnecessary admissions. It is, however, worth noting that staff in such facilities are not, typically, highly paid and it places a great deal of responsibility on them. The Panel also noted evidence that perhaps unsurprisingly, nursing homes tend to have a better record at keeping people at the end of life for longer, whereas residential homes are typically quicker to suggest or arrange an admission. It may be that further work is required with the residential sector, to empower staff to keep residents at home for longer, when they are at the end of life. The Panel was interested in the idea put forward by the Consultant from JCUH, of Middlesbrough having a few 'superhomes' with particularly high levels of skill relating to EOLC. Those homes could be rewarded with a higher tariff, which could encompass better pay for staff with certain expertise. It would be interested to see if this idea could be progressed.

## **Recommendations**

The Panel has gathered a great deal of evidence, from a range of different sources on the topic of End of Life Care in Middlesbrough. The Panel has come across some areas of disagreement, particularly around how services could be configured to deliver end of life care. The Panel has, however, found that one view is held unanimously and that is that End of Life Care in Middlesbrough is not working well and needs significant consideration and development, as a matter of urgency. The following is recommended:

1. That the emerging GP Commissioning Consortia, Department of Social Care and NHS Middlesbrough engage to conduct a root and branch review of End of Life Care in Middlesbrough. That review should identify a new 'whole system' strategic vision for End of Life Care, which should be articulated in new strategy for the development of End of Life Care Services (and their capacity) in Middlesbrough. This is all the more essential given that NHS Middlesbrough's Strategy Delivery Groups, including the one focused on End of Life Care, have been discontinued. The new strategy should include the following:
  - How patient choice will become a more important factor in the location of someone's end of life care and death
  - How the system can better share care plans so patients wishes and status as an end of life care patient can be more widely known, particularly by paramedics and out of hours GPs

- How commissioners will continue to support the rapid discharge programme from JCUH, when its current grant funding expires
- Explicit articulation as to how community services for end of life care and hospice services will be improved and developed in both range and capacity to meet anticipated demand. The Panel feels that community services for End of Life Care should be led by a community based physician, of consultant rank, and supported by specialist GPs.
- How an adequately resourced telephone advice line for those at the end of life and their carers will be provided and made sustainable through mainstream funding. Further, how that phonenumber will connect to community teams providing end of life care
- How services will become significantly more 24/7 in focus
- How residential and nursing homes will become an integral aspect of the delivery of high quality end of life care in Middlesbrough, whilst receiving adequate medical support
- The timescales this will be achieved by
- Measures by which the End of Life Care Strategy's implementation can be judged
- An explicit reference to the level of financial resource dedicated to the improvement of End of Life Care
- A commissioning plan as to how the above will be achieved.

The Health Scrutiny Panel would like to be involved with the development of that strategy.

2. NHS Middlesbrough and the Department of Social Care satisfy themselves that commissioned nursing and residential homes have sufficient capacity, support and skill to facilitate effective End of Life Care on their premises. The Panel would like to hear the outcome of this.

## **BACKGROUND PAPERS**

*Where people die (1974-2030): past trends, future projections and implications for care.*

Barbara Gomes and Irene J. Higginson, *Palliative Medicine* 2008;22;33

*Equity & Excellence – Liberating the NHS* © Department of Health, July 2010.

End of Life Care Strategy - Promoting high quality care for all adults at the end of life  
© Department of Health, July 2010.

Our Vision, Our Future © NHS North East, July 2008.

**Contact Officer:**

Jon Ord - Scrutiny Support Officer  
Telephone: 01642 729706 (direct line)  
Email: [jon\\_ord@middlesbrough.gov.uk](mailto:jon_ord@middlesbrough.gov.uk)