

**Sheffield's End of Life Care Strategy  
 Draft Refresh 2015 - 2018**

**Governing Body meeting**

**D**

**4 June 2015**

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<b>Is your report for Approval / Consideration / Noting</b>	
Consideration and approval	
<b>Are there any Resource Implications (including Financial, Staffing etc)?</b>	
The End of Life Care Strategy is a refresh to reaffirm the vision and direction of travel for end of life care in Sheffield. The work has and will continue to be taken forward by making the best use of existing resources within the system. Delivering the strategy, building on the work to date will need the development of a multiagency plan and will require resources in terms of staff, technology etc within and across organisations to work differently.	
<b>Audit Requirement</b>	
<b><u>CCG Objectives</u></b>	
The End of Life Care Strategy supports all four priority aims of the CCG:	
<ol style="list-style-type: none"> <li>1. To improve patient experience and access to care</li> <li>2. To improve the quality and equality of healthcare in Sheffield</li> <li>3. To work with Sheffield City Council to continue to reduce health inequalities in Sheffield (with respect to inequalities in care in the last year, days and hours of life)</li> <li>4. To ensure there is a sustainable, affordable healthcare system in Sheffield (with respect to where practically possible/clinically appropriate reducing the number of deaths in hospital, through enabling more people to express their wishes and preferences for end of life care outside hospital, and commissioning and providing care to enable this)</li> </ol>	
<b><u>Equality Impact Assessment (EIA)</u></b>	
<b><i>Have you carried out an Equality Impact Assessment and is it attached?</i></b> YES screen enclosed	

## **PPE Activity**

### ***How does your paper support involving patients, carers and the public?***

The refresh of the strategy has been informed by patients, carers and the public through engagement work with the CCG involve me network and Healthwatch. The vision set out in the Strategy has been co-produced with a carer and this, alongside the key priority areas of focus, have been sense checked through the engagement work.

## **Recommendations**

The Governing Body is asked to consider and approve:

- The vision and the direction of travel set out in the strategy.
- The development of a multiagency plan to enable continued delivery of the strategy (informed by the EIA).
- The plan to include where appropriate aspects to be taken forward through integrated commissioning mechanisms.

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## 1. SUMMARY

Sheffield's End of Life Care Strategy sets out the local vision for end of life care which is personalised, well co-ordinated and enables real choice for patients. Our vision is that all patients at end of life, together with those closest to them, are able to express their needs and wishes, and that as far as clinically appropriate and practically possible, these needs and wishes are met. The Strategy builds on its predecessor, it utilises the Sheffield Baseline Review<sup>1, 2</sup>, local research including views of local patients and carers,<sup>3</sup> NICE Quality Standards for End of Life Care, One Chance to get it Right<sup>4</sup> and themes from the National End of Life Care Strategy and its Annual Reports.<sup>5</sup> It details the current understanding of need, service provision and the future plans to commission integrated end of life care for all patients with active, progressive and advanced disease, irrespective of their diagnosis. It acknowledges the key role played by family members, friends and carers in supporting those approaching their end of life and thus the need to ensure that they are supported to undertake their chosen role.

In Sheffield there is a range of high quality specialist and generalist end of life care services. However the uses of the end of life care best practice tools is variable and around 54% of deaths currently occur in hospital and 19.5% in care homes. This is in contrast to national research that has shown that between 50 and 70% of people would prefer to die at home.

Acknowledging this, Sheffield's End of Life Care Strategy outlines a plan to realise the local vision for end of life care through commissioning integrated health and social end of life care services which embed best practice, and working closely with all providers contributing to care in Sheffield. This includes seeking the best experience possible for both patient and carers in the palliative period and in the last few days and hours of life, regardless of where the death occurs. As far as the patient's clinical condition allows, the aim is to deliver real choice for patients.

## 2. INTRODUCTION

Sheffield's End of Life Care Strategy is guided by the themes in the National End of Life Care Strategy and the subsequent annual reports to the strategy<sup>6</sup> It has been developed in partnership with providers, service users and carers, and it updates the End of Life Care Strategy 2008 taken forward by the End of Life Care Commissioning Group.

End of Life Care was initially prioritised in the 2007/08 NHS Operating Framework<sup>7</sup>, which identified the need to undertake baseline reviews. This was reinforced by the National End of Life Care Programme Commissioning Tool kit. This Strategy utilises Sheffield's comprehensive baseline review and findings from a number of research projects to outline the current understanding of need, service provision and Sheffield's current position. The Strategy articulates the vision to commission integrated end of life care for all patients with advanced disease, irrespective of their diagnosis. It acknowledges that in many cases those approaching their end of life are living with multiple long term conditions, including chronic diseases such as diabetes, cardiac and respiratory conditions, alongside dementia and mental health conditions.

The strategy is principally about care for adults, although it is recognised that work needs to be carried out on transition issues, where young people cared for by the Bluebell Wood hospice reach adulthood, and may need further support.

The strategy sits alongside the plans for Long Term Conditions, for Older People, for Dementia and for Care Homes and supports the Sheffield CCG Integrated Commissioning Plan/Better Care Fund, the Sheffield CCG Commissioning Intentions, the Sheffield Health and Wellbeing Strategy and the public health strategy Achieving Balanced Health.

## 2.1 Defining End of Life

End of Life can be difficult to define. Either :

### The WHO Definition of Palliative Care (2002) states

Palliative Care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor to unduly postpone death
- Integrates the social, psychological and spiritual aspects of care as needed and desired by patients and families
- Offers a support system to;
  - Enable patients to access and adhere to optimal clinical care;
  - Address social and legal problems and, in particular, to reduce the impact of poverty on patients and their family members, including children;
  - Help patients to live as actively as possible until death;
  - Help the family to cope during the patient's illnesses and in their bereavement;
- Uses a team approach to comprehensively address the needs of patients and their families, including bereavement counselling, where indicated
- Will enhance the quality of life of patients and their families; and will also positively influence the course of illness
- Is applicable early in the course of illness in conjunction with disease modifying therapies implemented to prolong life, such as chemotherapy and radiation therapy for cancer patients and antiretroviral therapy for HIV/AIDS patients; and includes those investigations needed to better understand and treat distressing clinical complications.

**Or**

The working definition based on the Department of Health Working Paper on End of Life Care [2007]<sup>8</sup>. This states that end of life care should encompass:

- Adults with advanced, progressive, incurable illness (e.g. advanced cancer, heart failure, Chronic Obstructive Pulmonary Disease (COPD), Stroke, chronic neurological conditions and dementia)
- Care given in all settings (e.g. home, acute hospital, ambulance, residential/care home, nursing home, hospice, community hospital, prison or other institution)
- Care given in the last year(s) of life
- Patients, carers and family members (including bereavement care)

Exactly when end of life care begins will vary for each individual, but typically people become frailer, less mobile, and their symptoms and treatment needs may increase. Whilst each patient and family are individuals and it is therefore difficult to put timescales on this, for the purpose of this strategy, end of life care is considered to begin 6-12 months

before death and ending for family and carers 6-12 months after death during the bereavement period.

### **3. POLICY CONTEXT**

Involving people and their carers in decisions about their end of life care and improving access to high quality care closer to home at end of life are both key issues for policy. The White Paper: 'Our health, Our care, Our say' (2006)<sup>9</sup> and 'Delivering Care Closer to Home: Meeting the Challenge' (2008)<sup>10</sup> both set the direction to make care more personalised, responsive and closer to patients' homes. This has been reinforced in subsequent policy documents, together with the need for choice. The White Paper Liberating the NHS (2010)<sup>11</sup> stated "In end-of-life care, we will move towards a national choice offer to support people's preferences about how to have a good death, and we will work with providers, including hospices, to ensure that people have the support they need."

The Government's mandate to the NHS Commissioning Board in 2013 it stated that one of the objectives is to 'pursue the long-term aim of the NHS being recognised globally as having the highest standards of caring, particularly for older people and at the end of people's lives'.

Most recently the Leadership Alliance for the Care of Dying People published 'One Chance to get it Right'; focussing on care during the final days and hours of life

#### **3.1 National End of Life Strategy**

The NHS End of Life Care Strategy (July 2008) identified the following as key:

- Taking a whole system approach
  - The need for strategic commissioning, bringing senior representatives from commissioning and service provision together to plan services
  - Workforce development to support identification of people approaching their end of life and facilitate care planning
  - Coordination of care and the need for a central co-ordinating function to ensure people get the services they require from all the different providers
  - The need for rapid response services on a 24/7 basis in the community to avoid unnecessary hospital admission.

In reviewing local areas, the National End of Life Care Strategy requests commissioners to consider coordination for individuals, transport, provision of home care services (24/7), specialist palliative care and advice for non cancer patients in the community, including care homes and improved education and training.

Since publication of the strategy annual reports have been produced, and the latest, in October 2012 highlights the work which has taken place regarding Death in usual place of residence (Disrupt) as a performance indicator in the Quality, Innovation, Productivity and Prevention programme. It reinforces the need for improved public awareness and supports the Dying Matters campaign, and continues to encourage GPs to identify the patients on their lists who are in their last year of life.

#### **3.2 One Chance to Get it Right**

In Sheffield a local pathway was developed based on the national Liverpool Care Pathway but following growing concern Dame Julia Neuberger was commissioned to review national policy and in July 2013 the report More Care, Less Pathway was

published. It recognised the value of the Liverpool Care Pathway, but recommended that it should be phased out in 6 to 12 months, and replaced with an end of life care plan.

In June 2014 the Leadership Alliance for the Care of Dying People published the response to these recommendations – One Chance to get it Right.

The new document sets out the approach which should be used in future in caring for dying people by health and care organisations and staff caring for dying people in England. The approach should be applied irrespective of the place in which someone is dying and focuses on achieving five Priorities for care when it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

The document also states that care should be

- Compassionate;
- Based on and tailored to the needs, wishes and preferences of the dying person,

And as appropriate, their family and those identified as important to them;

- Includes regular and effective communication between the dying person and their family and health and care staff and between health and care staff themselves;
- Involves assessment of the person's condition whenever that condition changes and timely and appropriate responses to those changes;
- Is led by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services when needed; and
- Is delivered by doctors, nurses, carers and others who have high professional standards and the skills, knowledge and experience needed to care for dying people and their families properly.

There is potential for the National End of Life Care Strategy to be refreshed in light of One Chance to get it Right. Ahead of this NHS England published Actions for End of Life Care: 2014-16. This sets out NHS England's commitments to end of life care for both adults and children. It is within this document that NHS England use the House of Care Model

(developed for long term conditions) as a framework with the following four interdependent components to organise their commitments going forward:

- Engaged, informed individuals and carers
- Health and care professionals committed to partnership working
- Organisational and supporting processes
- Commissioning

### **3.3 Reducing Inequalities**

The recent report *Deprivation and death: Variation in place and cause of death*<sup>12</sup> demonstrates that socioeconomic deprivation is a factor not only in age and cause of death, but also place of death. Nationally, 61% of people living in the most deprived quintile die in hospital, compared to rates between 54-58% for people living in other quintiles, and this is true for each underlying cause of death. Conversely, people in the lowest quintile were least likely to die in a care or nursing home at 11% compared to other quintiles that vary from 16-20%. The proportion of deaths in hospices is also greatest for the least deprived.

People in the most deprived quintile die younger, with twice as many deaths of people under 65 in the most deprived compared to the least deprived.

The cause of death also varies with deprivation, with more people dying both from smoking related cancers of the lung, oesophagus, head and neck, bladder cervix and liver and chronic respiratory disease in people living in the most deprived quintile. There are fewer deaths from malignant melanoma, breast and prostate cancer

This data is significant in that Sheffield has higher rates of deprivation than the England average, with 34% of its population in the most deprived quintile, and 15.5% of its population in the least deprived quintile.

There is also growing national evidence that people from Black, Asian and minority ethnic groups have lower access to palliative and end of life care services<sup>13</sup>. This is very relevant to Sheffield since according to the 2011 census the proportion of people from black and minority groups here is around 14.1%

The Care Quality Commission is currently undertaking a thematic project to understand the barriers which prevent people with the poorest experience of care from receiving good quality, joined up care at the end of life, whilst also identifying good practice.

### **3.4 Palliative Care Funding Review**

The White Paper *Liberating the NHS* included the following text -

“The previous administration made progress in developing payment by results in Acute trusts. The mandatory scope has changed little since 2005/06, and has not incentivised results throughout the system. The Department will review payment systems to support end-of-life care, including exploring options for per-patient funding.”

This work is now in progress and Sheffield is one of the pilot sites, where data is collected to inform a national understanding of palliative care use and associated costs. The national aim is to develop a classification system categorising palliative care patients according to need, and then to attach resource use and costs to each level of need, so supporting tariff development. Sheffield has also extended its remit to cover the range of social care contributing to palliative care provision.



The data collection period has now concluded and Sheffield will continue to participate in the analysis and consideration of the results. Sheffield will also consider further participation in future pilots.

### **3.5 Choice in End of Life Care**

Most recently (February 2015) the Choice in End of Life Care Board published a Review of Choice in End of Life<sup>14</sup> outlining clear recommendations for a national choice offer to be in place by 2020, alongside increasing the coverage of coordinating systems to 100% by 2018 and ensuring that 24/7 out of hospital care is in place by 2019. It also sets out the need for work to continue on outcome and experience measures and suggests that social care at the end of life should be free. It recommends that additional spending is identified to enable this in the next spending review. In addition the House of Commons Health Committee published their final report with respect to end of life care in March 2015<sup>15</sup>, in which they focus on the need for providers to ensure they have a model in place to deliver the approach set out in one chance to get it right. They also make a call to government to set out plans to enable sustainable hospice care, suggest that social care at the end of life should be free and that there needs to be focus going forward on outcome measures.

## **4. LOCAL VISION FOR END OF LIFE CARE**

Our vision is that all patients at end of life, together with those closest to them, are able to express their needs and wishes, and that as far as clinically appropriate and practically possible, these needs and wishes are met.

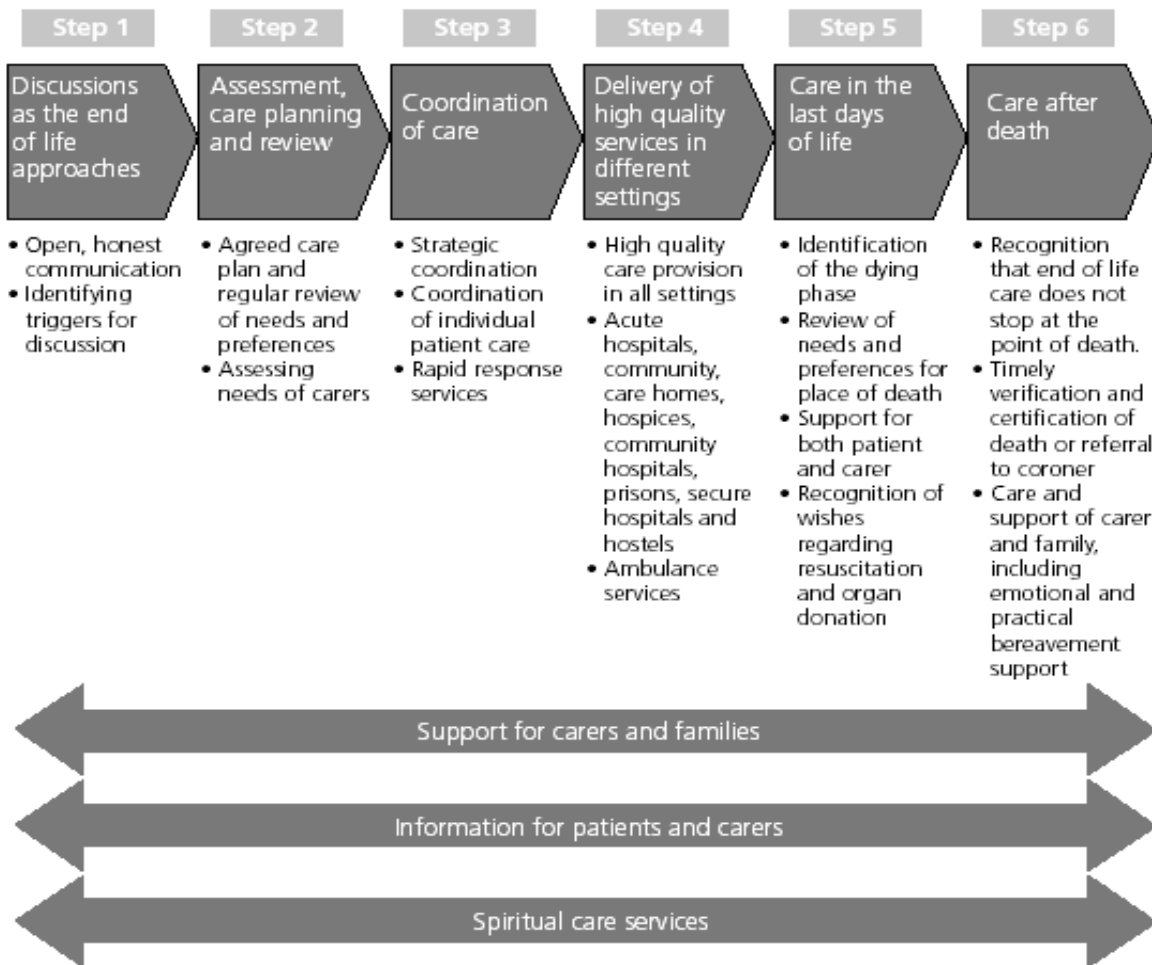
We will commission integrated end of life care for all patients with advanced disease, irrespective of their diagnosis, who are thought to be approaching the end of their life. We have made considerable progress in broadening the traditional focus on cancer to include non-cancer diagnosis, and this will continue, particularly in areas such as Heart failure, renal impairment, dementia, COPD and long term neurological conditions. .

We aim to commission end of life care consisting of high quality, integrated services, embedding best practice and supporting patients and carers in ways which meet their individual needs, including physical, psychological, spiritual, cultural and social needs during end of life care and in bereavement. This will enable a higher proportion of people to receive care and die in the place of their choice. We recognize that a preference for place of death may change as the patient's condition changes, and that flexibility and the capacity to adapt to changing views is an important part of the service.

We aim to commission end of life care to reduce health inequalities and enable equitable access for people from black and minority ethnic (BME) communities, hard to reach groups e.g. the homeless, as well as those living with a learning disability, neurological condition or severe mental health problem.

The diagram below from the Department of Health further identifies the key steps of an end of life care pathway that we aspire to commission. The best practice tools and resources were developed to facilitate a number of the steps identified below.

**Figure 1 End of Life Care Pathway: EOLC Strategy DH 2008'**



Achievement of this vision is dependent on a number of factors, not all of which are within our control. For step 1 we need a society that has increased awareness and a more open attitude to discuss individual preferences for end of life care, together with empowered generalist staff facilitating open and honest communication with patients, recognising and acting when a patient is deteriorating and identifying those approaching the end of their life. The next step is appropriately timed conversations about end of life care, progressing smoothly to step 2 and recording individual patients' preferences through care planning. The way we commission our services will be shaped by our values, which are:-

**Putting the patient, and those close to them, at the centre of what we do.** This means listening to patients about what they want and what is important to them, designing our services around their needs rather than the needs of the services, and responding to their views

**Equity** - We want the highest standard of care for everyone in our population, and we will ask the views of people who may be more vulnerable, or find it more difficult to access services, in order to shape our commissioning and our services so they reach everyone in need.

**Partnership** - We will develop a culture of partnership, with patients and carers, and also with and between our providers, because we believe that patients will have a better experience in a co-ordinated system.

**Continued learning** - We will continuously seek to improve, and we will learn from our local experiences, listening to both patients and staff, and we will also seek to learn from good practice around the country.

## 5. CURRENT STATUS

A key quality marker for end of life care is the place of death, with a major drive to increase the number of people dying at home, or in a care home, as their usual place of residence. For cancer patients, the research from professionals, carers and patients show a preference of 50-70% for a home death. However, for people with non-malignant conditions, just under half have so far reported a preference for home death, and preferences may change over time.<sup>16</sup>

The factors influencing whether someone dies at home or not vary from demographic - higher socio economic status, not being in older age groups, ethnic background, gender, not being married or living alone, - the condition of the patient – cancer diagnosis, absence of complex conditions, symptoms that can be managed in a home setting, to service provision, the presence of a carer and availability of local services.<sup>17</sup>

Sheffield has a registered population of around 580,000 and it is estimated that approximately 1% die annually. This equates to approximately 5800 deaths each year with the commonest causes of death categorised as cardiovascular disease (including strokes), cancers and respiratory disease.

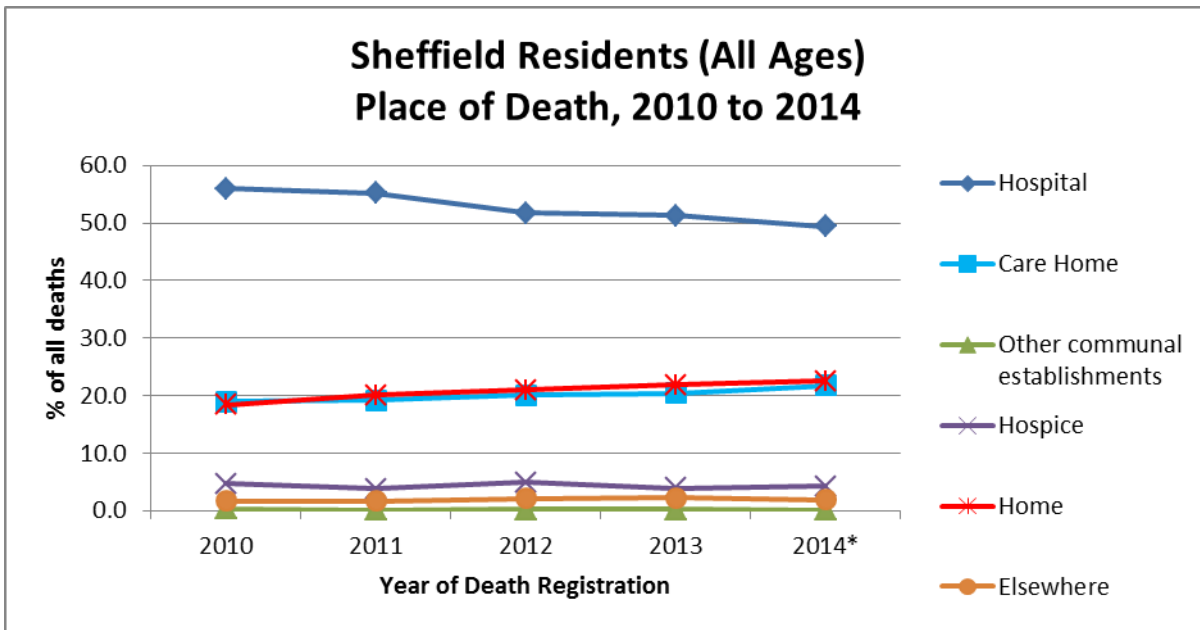
In 2010 primary care palliative care (end of life care) registers had a citywide prevalence of 0.12%, this has now risen to 0.47% in 2013/14. This is most likely due to a combination of the improvement work undertaken since the initial Sheffield EOLC Strategy most notably the primary care facilitation team visits.

Data from the National End of Life Care profile for Sheffield, based on ONS data, showed the following breakdown for place of death in Sheffield and England averages for the years 2010 - 2012

Place of death	Sheffield	England average
Percentage of deaths in hospital	53.84 %	50.71%
Percentage of deaths in own home	19.76%	21.54%
Percentage of deaths in hospice	4.45%	5.59%
Percentage of deaths in care home	19.45%	19.59%
Percentage of deaths other places	2.04%	2.12%

It should be noted that the figure for deaths in hospital includes those in the Macmillan unit on the Northern General site, which is a specialist palliative care unit.

Most recent data on place of death (2014) set out in the chart below shows a small reduction in the number of hospital deaths, with an increase in the number of deaths at home and in care homes (hospice deaths remaining constant).



Overall, according to a national research over 65% of the population wanted to die at home<sup>18</sup>, we are still some distance away from that across England and in Sheffield, although the Sheffield figures have improved. We know that those who currently die at home are more likely to have a cancer diagnosis. This is reflected in national data, according to which only 12% of deaths from neurological causes occur at home, and almost all deaths from dementia happen in either a care home (55%) or hospital (39%)<sup>19</sup>

Sheffield has contributed to a number of local research studies, full details of which can be found in the appendix. One study found that there is variable recognition in identifying people who may be approaching their end of life and initial discussions about people's preferences for end of life care<sup>16</sup>. A number of other local studies highlighted the lack of education, training and support for health and social care staff to manage end of life care issues<sup>11</sup>.

One key study undertaken by The Balance of Care Group focused on auditing the notes of a number of individuals that died in hospital in October 2007 and where possible identifying alternatives. The study used the Gold Standards Framework categories and identified that frailty [42%] was more common as an underlying reason for dying than cancer [30%] or chronic disease [20%] with 8% assessed as dying unexpectedly. It also identified that up to 25% of those dying during this period might have had dementia.

In the Study it was identified that 40% of the patients who died in hospital during the audited period did not have medical need that required them to be cared for in an acute setting. The key categories where alternatives were identified were the frail elderly and those with a cancer diagnosis, where palliative care had not been effectively mobilised in time. For those frail elderly patients it was suggested that suitable alternative could be nurse led non-acute beds or support at home.

## 6. CURRENT SERVICES

NHS Sheffield currently commissions a range of end of life care services from generalist palliative care to specialist palliative care.

## 6.1 Specialist Palliative Care Services

The following table summarises the Specialist Palliative Care Services currently commissioned. It must be noted that St Luke's Hospice and the Cavendish Centre are registered charities and not fully funded by NHS Sheffield.

Provider	Current Service Commissioned
St Luke's Hospice	<ul style="list-style-type: none"> <li>• Inpatient unit – 20 beds for cancer and non-cancer patients</li> <li>• Therapies and Rehabilitation Centre 20 places per day four days a week</li> <li>• Community Specialist Palliative Care Nursing Team</li> <li>• Rapid Response Service 7 days a week</li> <li>• Bereavement Service</li> <li>• Nurse support for nursing and residential homes</li> <li>• Volunteer service both in hospice and in the community</li> </ul>
STHFT-Sheffield Teaching Hospital Foundation Trust Palliative Care Service  STHFT Weston Park	<ul style="list-style-type: none"> <li>• Palliative care team –2 Hospital Support Teams covering the sites of Northern General Hospital, Royal Hallamshire Hospital, Weston Park Hospital</li> <li>• Inpatient unit-18 beds for cancer and non-cancer patients</li> <li>• Outpatients</li> <li>• 24/7 on call advice by consultants and specialist registrar</li> <li>• 7 day a week palliative care CNS               <ul style="list-style-type: none"> <li>• Specialist cancer hospital</li> <li>• Outpatients</li> </ul> </li> </ul>
STHFT Community Service Marie Curie	Intensive Home Nursing Service and Variable Intensity Palliative Care Scheme Complex case managers funded through Macmillan
Continuing Health Care from range of providers	Available via fast Track for Palliative Care Patients – support in the home available for eligible patients. The CCG commissions care for people in their own residence or a nursing home, in line with its Policy on Commissioning Care
Cavendish Centre	Multi-disciplinary service offering supportive care, assessment and counselling and a range of complementary therapies to people with cancer.
Sheffield Macmillan Lymphoedema Service	Management of Oedema including in advancing malignancy

There is an externally funded trial of the implementation of the Amber bundle on particular wards in Sheffield Teaching Hospitals.

In addition, a number of local and national charities provide support for patients and families including Cruse bereavement support.

One example of high quality services is the Variable Intensity Palliative Care Scheme, which is part of the Intensive Home Nursing Service provided by the Sheffield Teaching Hospitals Foundation Trust and Marie Curie. This scheme was recognised by the National Audit Office due to its flexible provision of nursing care and support to enable

individuals to receive palliative care at home. It provides an individualised one to one service with a number of care options to meet individual's needs.

In addition, St Luke's Community Specialist Palliative Care Service delivers specialist care in the community, and provides advice and support to health care professionals across primary care.

## **6.2 Generalist Palliative Care Services**

For many people, the majority of their care during the last year of life comes from generalist services such as GP practices, care homes, district nurses, hospital wards and outpatient departments and domiciliary carers.

It is therefore important to work with the commissioners and providers of these services to ensure that end of life care is understood, and that staff have the appropriate skills and knowledge.

### General Practice

A GP facilitation team consisting of two consultants and two GPs were recruited to work with GP practices to improve their End of life Care. The CCG continues to update general practice on new developments, and to provide update training.

### Sheffield Teaching Hospitals NHS Foundation Trust

The majority of the people who die in Sheffield Teaching Hospitals do so on general wards rather than in the Macmillan unit. The trust has a specialist nurse working across the hospital on EOLC education, and also working with staff on targeted wards to implement the Amber bundle.

### Care Homes

Since 19.5% of the population die in Care Homes, and there are 5173 care home beds in Sheffield, it is important to focus on this area to ensure that high standards are maintained. There is a GP Locally Commissioned Service in place, covering nearly all the care homes, whereby a GP practice takes on the responsibility for providing general medical services for all the patients of the home. A key element is end of life care, and this is included within the quality standards and accompanying training.

St Luke's community team of specialist nurses also work with care homes to provide advice and guidance on palliative care for care home staff, and there is also a nurse focused on providing training.

Skills for Care facilitates an End of Life Care network for care home staff.

## **6.3 Service and Quality Gaps**

There are a number of service gaps identified across the end of life care including key services that do not currently provide 24-hour access and the availability of equipment, alongside social and health care support. In addition there is a lack of bereavement and carer support services, outside of those available at the specialist palliative care services, and respite services are limited. The specialist services commissioned are very committed and strive to improve quality, although there is greater variation in skills and confidence identified in generalist services.

There are also inequalities in access to end of life care, information and support for non cancer patients, people with neurological conditions, dementia, severe mental health problems, a learning disabilities, BME groups and hard to reach groups e.g. the homeless<sup>2/11</sup>.

## 7. REALISING OUR VISION

To deliver our local vision for end of life care, Sheffield CCG will work in partnership with Sheffield City Council as a commissioner, and with our local providers to reach agreed priority standards.

### 7.1 Seeking views of user/carers

The views of users and carers gathered through stakeholder engagement in the baseline review contributed significantly to the understanding of need and the development of this strategy. The refresh has been informed by the CCG 'Involve Me' group and supported by Healthwatch. Through the national Voices work, the national strategy set out national plans to seek the views of carers, including surveying bereaved relatives, which is now ongoing. Locally, there is a need for further development of mechanisms to enable the views of patients and carers to continue to influence commissioning for end of life care.

### 7.2 Assessing Needs

Whilst the previous baseline review helped to understand some of the local need, further work is required to understand the impact of Sheffield's changing population on further need. The baseline review enabled Sheffield to understand the local need at that time and the likely future impact. There is also scope in the future to build on the developing Joint Strategic Needs Assessment.

### 7.3 Strategic Priorities

The baseline review put forward a number of recommendations and assimilating these with the key findings from local research studies, the themes in the National End of Life Care Strategy and recent policy and research documents, has enabled Sheffield to identify local priority areas.

End of Life Care	Local Priority Areas
<p><b>Identification and care planning</b></p>	<p><b>Palliative Care Registers</b>            In order for clinicians across providers, especially generalists, to develop the necessary skills to identify those individuals that are progressing towards their end of life and initiate early discussions there is a need for increased knowledge and skills in end of life care and communication skills. A range of training has been provided, including support teams going into general practice, and overall, Sheffield has a higher proportion of people on palliative care registers than the national average. The range does, however, vary across the city, and training will be maintained.</p> <p><b>Communication System</b>            Sheffield has a communication system whereby clinicians at STH, when a person is identified as at end of life, are enabled to communicate this, together with suggested focus of care, to general practice. This is being expanded across different directorates within STH, with a view to gaining whole hospital coverage.</p> <p><b>Dying Matters</b>            At the same time as training professionals, there is a need to encourage the general population to plan for their own deaths, and the CCG supports the national Dying Matters Campaign every year, as well as using available opportunities to promote the message</p>

	<p>through representation at public meetings, website information, partnership work with other agencies.</p> <p><b>Care Plans</b>  Most general practices are using the Sheffield end of life template for clinical records, but there is a need for continual improvement to systematise their use and improve the quality of the end of life plans with full patient and carer engagement. The CCG is committed to supporting greater use of care planning, and including those people on the palliative care register within its target group, irrespective of their diagnosis (this will include those with dementia with whom care planning for end of life may need to take place earlier).</p> <p><b>DNACPR</b>  The development of an agreed DNACPR form across Yorkshire and Humber has been a major step forward, but there is a need continually to update training for all relevant staff on use of the form, and to keep up to date with best practice.</p>
<p><b>Models of Care</b></p>	<p>Across the country there have been developments of differing models of care, such as hospice at home, and community based teams. It will be important to learn the lessons from this work, and their impact on the quality of care and support for people dying in their preferred place. Locally, St Luke's hospice is piloting a rapid response service, and we hope to learn from this experience and its implications for future commissioning. There are already well trained volunteers in specific roles such as those within the hospice. However we will look to identify the potential opportunities to take this further. We will also learn from the experiences of the Complex case Managers funded through Macmillan.</p>
<p><b>Communication and co-ordination</b></p>	<p><b>Electronic Palliative Care Co-ordination System</b>  There is national requirement for CCG's to work on developing an EPaCCS and whilst we have made progress in our communication system, this is an area with the potential to make considerable improvements in care by ensuring greater communication and co-ordination across agencies and professions. We are currently working on a practical way forward, ideally with colleagues across South Yorkshire.</p> <p><b>Co-ordination of care at home</b>  A key identified need is for greater co-working between the City Council commissioned domiciliary care services and the other services supporting people, at home. We will continue to work with the existing home care providers and where there are opportunities pilot new ways of working.</p> <p><b>Integrated Commissioning</b>  Sheffield's work on the Better Care Fund and integrated commissioning provides potential opportunities for improved quality in EOLC through more integrated working between health and social care agencies.</p>



<p><b>Quality of care in the last days and hours of life</b></p>	<p>One Chance to get it Right gives guidance on the quality standards with a clear focus on the discussions to be held with the patient and family. It is important that we have high quality consistent guidance and systems in place to enable clear documentation. All staff engaged in end of life care, both specialist and generalist must have an understanding of what is needed.</p>
<p><b>Education and training</b></p>	<p>The key to good quality end of life care is staff who are trained, supported and committed. This applies not only to specialist staff, but to all staff who work with patients in a palliative phase. We are committed to continuing and expanding this training to include both NHS staff in primary care, community services, mental health care and generalist medical care, together with domiciliary care staff, care home staff, and staff providing Continuing Health Care. We acknowledge the need for a tailored approach as needs differ across the workforce.</p> <p>This will build on the good work already taking place such as the use of Sage and Thyme and the senior clinical development programme at STH, advanced communications skills courses and the new one day courses for frontline staff developed by Sheffield City Council.</p>
<p><b>Equality of access</b></p>	<p>Since there is evidence that people from BME communities, people with mental health problems, people with learning difficulties and from more deprived communities have lower access to EOLC services: we will seek to learn from the CQC review and good practice elsewhere, how we can ensure that Sheffield provides fair and equitable access.</p>
<p><b>Service User and Carer engagement</b></p>	<p>Palliative care is not the easiest field in which to gain effective service user and carer engagement, since patients may not wish, or may not be well enough to participate, and carers may be very involved in care or grieving. However, there are areas where this has been done well, and we will work with our provider organisations to develop ways of gaining patient and carer views as an integral part of the way we work.</p>

## 8. DELIVERY

In order to deliver this strategy and realise the benefits for users and carers a more detailed implementation plan will be developed by the End of Life Care Planning and Commissioning Group. The plan will work to ensure best use of the existing resources, building on what has been done to date and where necessary develop specific project mandate(s) to take collaborative improvement work forward.

In 2015-16, in addition to maintaining the current level of services for end of life care, the plan is to:-

- Explore the potential for inclusion of End of life Care within the Better Care Fund and Integrated Commissioning
- Work to improve end of life care in the community and plan and specify a pilot for a new model of home care
- Plan for further development of the EPaCCS from a communication system to a co-ordination system, within the overall context of the CCG's information sharing work
- Support work to improve End of Life Care in care homes
- Support development of EOLC in primary care including the Care Homes Locally Commissioned Service and the Care Planning local scheme
- Respond in a timely and co-ordinated way to One Chance to get it Right, including training for primary care
- Support improvements in hospital EOLC including implementation of Amber
- Deliver a Sheffield contribution to Dying Matters week
- Support the training of Continuing Health Care services, and work with the new providers to ensure they are integrated into the End of Life care service across Sheffield
- Revise and update the service specifications for Specialist Palliative Care/End of life Care with our main providers
- Undertake work to identify inequalities in access to specialist end of life care, and take action to address this.

## 9. REVIEW AND ACCOUNTABILITY

Progress against the implementation plan will continue to be monitored by the End of Life Care Planning and Commissioning Group; which is chaired by the CCG Clinical Lead for End of Life Care who is a GP and includes representation from:

- Clinical Commissioning Group
- Sheffield Teaching Hospitals
- Sheffield Teaching Hospitals Macmillan Unit
- Sheffield Teaching Hospitals Community Services
- St Luke's Hospice clinical and managerial representation
- Sheffield City Council
- Continuing Health Care
- Macmillan Cancer Support
- Marie Curie

The GP Out of Hours Service and ambulance service also attend for relevant agenda issues.

The Planning and Commissioning Group is part of the Long Term Conditions, Cancer, Older People and End of Life Portfolio within the CCG .

There are strong links with Sheffield City Council, particularly around work with Care Homes and domiciliary care.

## **10. RECOMMENDATIONS**

The Governing Body is asked to consider and approve:

- The vision and the direction of travel set out in the strategy.
- The development of a multiagency plan to enable continued delivery of the Strategy (informed by the EIA).
- The plan to include where appropriate aspects to be taken forward through integrated commissioning mechanisms.

Paper prepared by: Dr Anthony Gore, CCG Commissioning Lead for Cancer Care  
Jackie Gladden, Senior Commissioning Manager  
Marianna Hargreaves, Senior Commissioning Manager  
Dr Andrew McGinty, Clinical Director – Long Term Conditions Portfolio

On behalf of Tim Furness, Director of Business Planning and Partnerships

May 2015

## APPENDIX

### Further Detail of Local Research Studies

- **A Review of the Provision of End of Life Care services in Sheffield: National Audit Office Whole System Review [draft] July 2008**

This forms part of a National Audit Office (NAO) End of Life Care National Review which sought to understand the strengths and challenges of end of life care in Sheffield. The NAO Review Team interviewed over 40 members of staff involved in the commissioning and delivery of services as well as current patients and carers.

- **Identifying Alternatives to Hospital for People at the End of Life – Draft Report of Findings. The Balance of Care Group in association with the NAO. July 2008**

This retrospective study reviewed all people who died in Sheffield in October 2007. The main focus of this study was on people dying in hospital and looking at the potential for more appropriate alternatives to be in place. This study therefore examined how many hospital deaths might have been avoidable had alternatives been available and given due consideration. Key findings include:

- **Improving Supportive and Palliative Care for Adults with Cancer in Primary Care: a National Survey of General Practices. University of Sheffield. May 2008**

This study set out to establish the extent to which UK Primary Care had adopted recommended practices in relation to supportive and palliative care of adults with cancer and to relate this to participation in previous initiatives. All Sheffield GP Practices were included in this study and results showed: General Practice in Sheffield engages significantly less with end of life care policy initiatives, such as the Gold Standards Framework [19%], than is the case elsewhere in England [61.1%]

- **The Standards We Expect – Choices for End of Life care. Joseph Rowntree Foundation. February 2008**

This study aimed to collect the views of people living in nursing and residential homes, relatives and carers of people living in homes (or those whose loved ones had recently died) and practitioners and managers working in homes. The study explored the choices in end of life care in a care home. It also wanted to find out what participants thought were the barriers to support being person centred at the end of life and how these might be overcome.

## References

- 1 Baseline Review of Services in Sheffield for End of Life Care March 2008
- 3 Healthy Ambitions – NHS Yorkshire & Humber <http://www.healthyambitions.co.uk/index.html>
- 4 Once Chance to get it Right Leadership Alliance for the care of Dying People 2014
- 5 National End of Life Care Strategy Department of Health July 2008
- 6 End of life care strategy Fourth Annual Report Department of Health October 2012
- 7 The NHS in England: Operating Framework for 2007/2008
- 8 Department of Health Working Paper on End of Life Care 2007
- 9 The White Paper 'Our Health, Our Care, Our Say' Department of Health (2006)
- 10 Delivering Care Closer to Home: Meeting the Challenge, Department of Health (2008)
- 11 The White Paper Liberating the NHS Department of Health (2010)
- 12 Deprivation and death: Variation in place and cause of death, National End of Life Care intelligence network (2012)
- 13 Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. Natalia Calanzani, Dr Jonathon Koffman, Irene J Higginson Kings College London, Cicely Saunders International (June 2013)
- 14 What's Important to me. A Review of Choice in End of Life Care, published by the Choice in End of Life Care Programme Board, February 2015
- 15 House of Commons, Health Committee Final Report End of Life Care, March 2015
16. Murtagh, F.E.M., Bausewein, C., Petkova, H., Sleeman, K.E., Dodd, R.H., Gysels, M., Johnston, B., Murray, S., Banerjee, S., Shipman, C., Hansford, P., Wakefield, D., Gomes, B. and Higginson, I.J. (2012) „Understanding place of death for patients with non-malignant conditions: A systematic literature review“, London: National Institute for Health Research, Service Delivery & Organisation
- 17 Dying well at home: the case for integrated working Social Care Institute for excellence (May 2013)
- 18 Home or Hospital? Choices at the end of life (Sept 04) Barbara Gomes, *Research Associate* and Irene J Higginson, *Scientific Director*
- 19 Murtagh, F.E.M., Bausewein, C., Petkova, H., Sleeman, K.E., Dodd, R.H., Gysels, M., Johnston, B., Murray, S., Banerjee, S., Shipman, C., Hansford, P., Wakefield, D., Gomes, B. and Higginson, I.J. (2012) „Understanding place of death for patients with non-malignant conditions: A systematic literature review“, London: National Institute for Health Research, Service Delivery & Organisation

## Equality Impact Assessment

<b>Title of policy or service:</b>	Sheffield's End of Life Care Strategy	
<b>Name and role of officer/s completing the assessment:</b>	Marianna Hargreaves – Senior Commissioning Manager for End of Life Care and Cancer	
<b>Date of assessment:</b>	17 <sup>th</sup> February 2015	
<b>Type of EIA completed:</b>	Initial EIA 'Screening' <input checked="" type="checkbox"/> or 'Full' EIA process <input type="checkbox"/>	<i>(select one option - see page 4 for guidance)</i>

### 1. Outline

**Give a brief summary of your policy or service**

- Aims
- Objectives
- Links to other policies, including partners, national or regional

Sheffield's End of Life Care Strategy sets out the local vision for end of life care which is personalised, well co-ordinated and enables real choice for patients.

Our vision is that all patients at end of life, together with those closest to them, are able to express their needs and wishes, and that as far as practically and clinically possible, these needs and wishes are met. It outlines our plan to realise the local vision for end of life care through commissioning integrated health and social end of life care services which embed best practice, and working closely with all providers contributing to end of life care in Sheffield.

Sheffield's End of Life Care Strategy is guided by the themes in the National End of Life Care Strategy and the subsequent annual reports to the strategy<sup>1</sup> It has been developed in partnership with providers, service users and carers, and it updates the End of Life Care Strategy 2008

**Identifying impact:**

- **Positive Impact:** will actively promote or improve equality of opportunity;
- **Neutral Impact:** where there are no notable consequences for any group;

<sup>1</sup> <sup>6</sup> [End of life care strategy Fourth Annual Report Department of Health October 2012](#)

- **Negative Impact:** negative or adverse impact causes disadvantage or exclusion. If such an impact is identified, the EIA should ensure, that as far as possible, it is either justified, eliminated, minimised or counter balanced by other measures. This may result in a 'full' EIA process.

**2. Gathering of Information**  
 This is the core of the analysis; what information do you have that might *impact on protected groups, with consideration of the General Equality Duty.*

(Please complete each area)	What key impact have you identified?			For impact identified (either positive and or negative) give details below:	
	Positive Impact	Neutral impact	Negative impact	How does this impact and what action, if any, do you need to take to address these issues?	What difference will this make?
Human rights	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>		
Age	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<p>People in the most deprived quintile die younger, with twice as many deaths of people under 65 in the most deprived compared to the least deprived. They are also more likely to die in hospital, which is not necessarily their place of choice. The action plan to underpin the Strategy will need to take this into account so that as far as possible, where clinically appropriate individuals and their families are enabled choices irrespective of their age. A health equity audit has been requested and this is one of the areas it looks to further understand if possible.</p>	<p>Understanding this will enable the action plan to be developed in a way that where necessary specific work can be taken forward so that as far as possible, where clinically appropriate individuals and their families are enabled choices irrespective of their age.</p>

<b>Carers</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	The Strategy acknowledges the key role played by family members, friends and carers in supporting those approaching their end of life and thus the need to ensure that they are supported to undertake their chosen role. This needs to be translated into the action plan.	Increased potential to enable the needs of carers to be identified and assessed, and to ensure support is in place for them to undertake their chosen role.
<b>Disability</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Individuals with disabilities, both physical and learning disabilities are likely to currently experience inequalities in both access to information and end of life care support. A health equity audit has been requested and this is one of the areas it looks to further understand.	Understanding this will enable the action plan to be developed in a way that where necessary specific work can be taken forward to improve equitable access to information and end of life care for those living with a disability. This is being considered in the health equity audit. Although conscious that where information is not available we will look to build in systems to capture this going forward.
<b>Sex</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	There is potential that as men are less likely to seek health advice they may not access information around end of life care and end of life care support as readily as women. There is also potentially a differential in the role that men and woman take in relation to caring responsibilities.	Understanding this will enable it to be considered as part of the action plan going forward as necessary. As such it is being considered in the health equity audit. Although conscious that where information is not available we will look to build in systems to capture this going forward. So that ultimately all those approaching their end of life have equitable access to information and care irrespective of their sex.



<b>Race</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	There is growing national evidence that people from Black, Asian and minority ethnic groups have lower access to palliative and end of life care services <sup>2</sup> This is very relevant to Sheffield since according to the 2011 census the proportion of people from black and minority groups here is around 14.1%. A health equity audit has been requested and this is one of the areas it looks to further understand.	Understanding this will enable the action plan to be developed in a way that where necessary specific work can be taken forward to improve equitable access to information and end of life care for those from Black, Asian and minority ethnic groups.
<b>Religion or belief</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	As a consequence of the historical association between hospice care and Christianity there is potential that individuals from other religions or with other beliefs are not currently accessing hospice care. A health equity audit has been requested and this is one of the areas it looks to further understand if possible.	Understanding this will enable the action plan to be developed in ways that where necessary specific work can be taken forward to improve access to information and end of life care for all irrespective of religion or belief.

<sup>2</sup> <sup>13</sup> Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. Natalia Calanzani, Dr Jonathon Koffman, Irene J Higginson Kings College London, , Cicely Saunders International (June 2013)

<b>Sexual orientation</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	There is potential that lesbian, gay, and bisexual individuals may not access and/or experience care towards the end of their life that is sensitive to their needs.	Understanding this will enable it to be considered as part of the action plan going forward as necessary. As such it is being considered in the health equity audit. Although conscious that where information is not available we will look to build in systems to capture this going forward. So that ultimately all those approaching their end of life have equitable access to information and care irrespective of their sexual orientation.
<b>Gender reassignment</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	There is potential that those currently having had their gender reassigned may not access and/or experience care towards the end of their life that is sensitive to their needs.	Understanding this would enable it to be considered as part of the action plan going forward as necessary. As such it is being considered in the health equity audit. Although conscious that where information is not available we will look to build in systems to capture this going forward. So that ultimately those having had gender reassignment have equitable access to information and end of life care that meets their needs.
<b>Pregnancy and maternity</b>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>		
<b>Marriage and civil partnership</b> (only eliminating discrimination)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>		

<b>Other relevant groups</b>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>		
<b>HR Policies only: Part or Fixed term staff</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

**IMPORTANT NOTE:** If any of the above results in ‘**negative**’ impact, a ‘full’ EIA which covers a more in depth analysis on areas/groups impacted must be considered and may need to be carried out.

Having detailed the actions you need to take please transfer them to onto the action plan below.

<b>3. Action plan</b>				
<b>Issues/impact identified</b>	<b>Actions required</b>	<b>How will you measure impact/progress</b>	<b>Timescale</b>	<b>Officer responsible</b>
Although in some cases such as race there is national evidence that indicates potential inequity in access to information and end of life care. There is a need to understand the potential inequalities locally. In order to enable us to address these going forward.	A health equity audit has already been initiated and key actions will then be identified to both take forward and inform the action plan to underpin the refreshed EOLC Strategy. As will other key intelligence, such as findings from the CQC work,	By embedding the actions from the HEA in the refreshed action plan to underpin the Strategy.	As outlined in the action plan	Marianna Hargreaves

<b>4. Monitoring, Review and Publication</b>				
<b>When will the proposal be reviewed and by whom?</b>	<b>Lead / Reviewing Officer:</b>	Marianna Hargreaves Dr Anthony Gore	<b>Date of next Review:</b>	12mths?

Once completed, this form **must** be emailed to Elaine Barnes, Equality Manager for sign off: [elaine.barnes3@nhs.net](mailto:elaine.barnes3@nhs.net).

<b>Elaine Barnes signature:</b>	
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