Gloucestershire End of Life Care

Gloucestershire End of Life Care Strategy
2016-2019
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Acknowledgement

Gloucestershire Clinical Commissioning Group would like to acknowledge that the development of this strategy has only been made possible by the significant commitment and energy of all the partners listed below. In addition, the views, opinions and experiences of many Gloucestershire residents have been invaluable and have helped shape those writing the strategy identify the 12 strategic aims and priority work areas, enabling the highest quality end of life care services are available to all who live in Gloucestershire, irrespective of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation, and social economic status.

For further information on End of Life Care please visit:
www.gloucesteshireccg.nhs.uk/your-services/eolc/
(to be updated 2016)
http://www.healthwatchgloucestershire.co.uk/
1. **Introduction**

NHS Gloucestershire Clinical Commissioning Group (CCG) and partner organisations are working together to improve services for people who require palliative and end of life care. As a health and social care community, we recognise that sustainable change and improvements can only be realised if we all work in partnership and have a shared vision.

This strategy is an important step in making improvements happen. It has been drawn up with input from a wide range of people, across health and social care providers, the voluntary sector, families and carers. The strategy outlines how we would like to take forward the development of palliative and end of life care services in Gloucestershire over the period 2016-2019.

Each year in Gloucestershire approximately 5,900 people die from a wide range of causes. In common with the rest of England, the largest single underlying causes of death are Cardiovascular disease, Respiratory disease and Cancer. Across Gloucestershire, people die in a range of places, 44.6% occur in a hospital setting; 25.2% of people die at home; 24.2% in a care home; and 3.1% in a hospice.

Care for patients with life-limiting conditions, and for those who are dying, is therefore delivered by a wide range of health and social care professionals, across many settings in Gloucestershire. For this reason our strategy aims to make it easier for people to access the help and services they need, earlier in their illness than they do currently. We also want to respond better to the wishes and needs of patients and their families in relation to where they would like to be cared for and where they would like to die.

As the population ages and more people live with long-term conditions, many of them having more than one long-term condition, it is important that Gloucestershire has a clear strategic direction to meet the population changes ahead.

Therefore, to meet the increasing demand and complexity of care in the future, we have to take steps to improve palliative and end of life care now.

End of life care is everyone’s business, our overall aim in Gloucestershire is to enable an individual and their family to receive high quality of care irrespective of where they die. This includes supporting people to die in the place of their choice, be cared for by the most appropriately qualified person from any provider who follows an individualised plan of care and communicates effectively with all agencies.

The Gloucestershire End of Life Care Strategy is guided by the themes in the ‘National End of Life Care Strategy 2008’, the subsequent annual reports and more recently the ‘Ambitions for Palliative and End of Life Care 2015’.

The strategy and associated implementation plans will be overseen by the Gloucestershire End of Life Care Board which has representation from all providers within Gloucestershire, service users, carers and the Voluntary and Community Sector. It builds upon the good work previously undertaken by all parties across Gloucestershire.

The strategy is principally about care for adults, although it is recognised that work needs to be carried out in relation to those transitioning from child to adult services.

This strategy will underpin the commissioning and delivery of End of Life Care within Gloucestershire. In order to meet individual choice, services will need to be commissioned and provided across a number of different settings, these include: the individuals own home, care homes, sheltered/extra care housing, hospices and hospitals.

In addition it is recognised services will also be required in other locations such as hostels for the homeless and independent living homes for people with learning disabilities and mental health problems.
2. Our commitment

We want to make sure that the highest quality end of life care services are available to all who need it, irrespective of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation, and social economic status. Effective and compassionate care and support will be in place for people who are approaching end of life so that they can have a dignified, peaceful and supported death. Families and carers needs both during and after a person’s death will be recognised and addressed.

We want to ensure that people are given the opportunity to express their preferences about where and how they are cared for, supported and die, and to make it possible for health and social care services to enable their wishes to be met. Irrespective of whether people have expressed their preferences, our aim is that everyone should experience a ‘good end to their life’.

We will design, commission and deliver services in order to provide:

- equitable access to services for all people needing end of life care;
- end of life services based on best practice models; ensuring the best possible care for all people needing end of life support;
- patient-led care which is responsive to the dying person’s needs and wishes;
- a choice of place of care and death, where possible; acknowledging that the physical environment has a direct impact on peoples experiences at the end of their lives and on the memories of those closest to them.
- a pleasant and supportive environment of care where dignity and respect are facilitated
- appropriate support services for both the dying person and those closest to them; in particular pre and post bereavement support.
- good communication between all professionals and with the patient and those closest to them;
- access to timely information and advice for patients, families, carers and staff
- improved co-ordination of care across all service providers;
- increased education and training for staff;

**We will:**

- involve local people, patients and carers in the development and improvement of end of life care services;
- work in the spirit of partnership with health and social care organisations, both statutory and voluntary; and
- review the services we commission and deliver regularly to ensure that they reflect best practice and are responsive to the needs of service users
3. **Defining End of Life**

The “Ambitions for End of Life and Palliative Care Framework” (Sept 2015) uses the same definitions for ‘End of Life’ and ‘Palliative Care’ as they are defined in the ‘One Chance to get it Right’ report, produced in June 2014 by the Leadership Alliance for the Care of Dying People. The Gloucestershire strategy will adopt these same definitions and are described as follows:

**End of life**

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

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

**Palliative care**

As defined by the World Health Organisation, Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of 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; it:

- 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 patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families;

By enhancing the quality of life it is possible to positively influence the course of illness and in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff across all sectors and may be done alongside treatment intended to reverse particular conditions.

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3 Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right: Improving People’s Experience of Care in the Last Few Days and Hours of Life
4. National Policy Context

The Gloucestershire End of Life Board endeavours to be responsive to, national strategy, policy and relevant guidelines whilst understanding local needs in order to ensure that appropriate End of Life services are commissioned and delivered to the population of Gloucestershire.

One of the most prominent issues in recent years relates to the Liverpool Care Pathway (LCP). The goal of the LCP was to ensure that individuals die in a way that was as dignified and as peaceful as possible. However, significant concerns arose regarding how the Pathway was used. An independent review was therefore commissioned, which was led by Baroness Julia Neuberger; the final report, ‘More Care, Less Pathway’, was published in July 2013 and contained a number of recommendations.

Following the publication, the government identified a number of actions, one of which was that “the LCP was phased out and replaced with an individual approach to end of life care for each patient, which would include a personalised end of life care plan supported by condition-specific good practice guidance, agreed with a named senior clinician” (DH 2013).

Accordingly, the LCP is no longer being used in hospital, hospice, care home or community settings in Gloucestershire and providing person-led and person-centred care planning is a key priority for the end of life board.

Included below are brief commentaries in relation to some of important areas of guidance which have had an influence on this strategy’s development.

End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life(DoH,2008)

The aim of this strategy was to “make a step change in access to high quality care for all people approaching the end of life” The strategy identified 12 key areas, listed below, together with associated actions and recommendations.

1. Raising the profile
2. Strategic commissioning
3. Identifying people approaching the end of life
4. Care planning
5. Coordination of care
6. Rapid access to care
7. Delivery of high quality services in all locations
8. Last days of life and care after death
9. Involving and supporting carers
10. Education and training and continuing professional development
11. Measurement and research
12. Funding

National Institute for Health and Care Excellence (NICE) (2011):-Quality Standard for End of Life Care for Adults.

This NICE quality standard defines clinical best practice within this topic area and covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. It does not cover condition-specific management and care or the clinical management of specific physical symptoms.

The standard includes specific, concise quality statements, of which there are 16 relating to the areas listed below. The 16 standards are listed in full and are contained as appendix C within this strategy but cover the following areas:
Leadership Alliance for the Care of Dying People (2014): ‘One Chance to Get it Right’

In response to the Neuberger review, the Leadership Alliance for the Care of Dying People (LACDP) developed a new approach for the care of those in the last few days and hours of life, which is explored in the ‘One Chance to Get it Right’ report. It sets out five Priorities for Care in a person’s last few days/hours:

- 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.
- Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- 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.
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- 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 report highlights that these priorities are transferable across settings and should be adopted and delivered regardless of where someone dies. The primary focus is on the needs and wishes of the dying person and those closest to them, who should be at the centre of decision-making regarding treatment and care.


In September 2015 the National Palliative and End of Life care Partnership published ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020’. Recognising that there is an increasing emphasis on local decision making and delivery, it provides a platform for locally driven change. It enables those who lead local organisations to create new ways to build more effective systems of care, putting existing resources to more creative and effective use, aligning with wider changes flowing from the NHS Five Year Forward View.

The formation of the new Gloucestershire End of Life Board and its associated workstreams is Gloucestershire’s first step to adopting and addressing the implementation of the Ambitions Framework which contains 6 ambitions.
There are a number of foundations that sit underneath the 6 ambitions. These are:

- Personalised care Planning
- Shared Records
- Education and Training
- Involving, supporting and caring for those important to the dying person
- 24/7 access
- Evidence and Information
- Co-design

National Institute for Clinical Excellence: Care of the dying adult (2015)

This guideline covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. It aims to improve end of life care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life. The guidance includes recommendations on:

- recognising when people are entering the last few days of life
- communicating and shared decision-making
- clinically assisted hydration
- medicines for managing pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions
- anticipatory prescribing


This review focuses mainly on the quality and organisation of end of life care. The review aims to help those delivering, planning or using end of life services to ensure that the right care is delivered in the right place at the right time.

The review recognises that helping people to die with dignity, compassion and comfort is an important goal of any health service. It is particularly timely as one of the 6 ‘ambitions’ is to have improved evidence and quality of care.
5. **The picture in Gloucestershire**

Across Gloucestershire there are a number of providers who are involved in the delivery of end of life care. All have a key role to play in a person’s death and are represented on the Gloucestershire End of Life board. They can be summarised as follows:

- Primary care – GP’s and Practice Nurses
- Specialist palliative consultants and nurses (Gloucestershire Hospitals NHS Foundation Trust)
- District Nurses and the wider Integrated Care Teams (Gloucestershire Care Services NHS Trust)
- Specialist nurses/therapists (GHNHSFT and GCSNHST)
- In patient hospice care (Sue Ryder)
- Day Hospice care (Sue Ryder, Great Oaks and Longfield)
- Hospice at Home (Sue Ryder, Longfield, Great Oaks, Kates Home Nursing, Marie Curie, Campden Carers, Fairford supporters)
- Residential and Nursing homes
- Social Care staff (Gloucestershire County Council)
- Community pharmacies
- Ambulance service (South West Ambulance Trust)
- Out of hours (SWAST)
- Community Hospitals (GCSNHST)
- CRUSE Bereavement
- Voluntary and community organisations

Whilst Gloucestershire is one of the healthiest counties in England, the proportion of older people is above the national average and increasing and this trend is expected to continue. According to the Office for National Statistics (ONS) 2012-based projections\(^5\), Gloucestershire will have 85,000 more residents aged 65 years and over in 2037 than in 2012, an increase of just over 70%.

In terms of planning for End of Life provision the higher proportion of older people than the national average is a significant factor that requires careful consideration.

Numbers are projected to increase steadily throughout this period. Over 65s will account for over a quarter of the County’s population at 2037, compared to less than a fifth at 2012\(^6\). The rates of projected growth varies over the six districts and by 2020 Stroud district is projected to have the highest number of people over 65, 75 and 85 in the county.

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Although Gloucestershire benefits from a high standard of living, this wealth is not evenly distributed and pockets of deprivation do exist. Gloucestershire had eight local areas amongst the most deprived 10% in England in 2010. They were all located in Cheltenham and Gloucester districts and accounted for 12,700 residents amounting to 2% of the total population of the county.

Females in Gloucestershire can generally expect to live between 3 and 4 years longer than their male counterparts. Life expectancy for both genders has been steadily increasing in the county over the past decade. Males in the least deprived Gloucestershire decile (10th of population) can expect to live 7.8 years longer than those in the most deprived decile. For females, this gap is 6.3 years. For both genders, this deprivation gap has slightly widened, suggesting that health inequalities are increasing.

The three leading causes of death in Gloucestershire are cardiovascular disease (27.8%) cancer (27.3%), and respiratory disease (14.5%)\(^9\), in line with the national pattern. Premature death rates for all three conditions can be reduced with improved prevention and treatment. Our needs assessment tells us that there are significant improvements to be made for those dying from a respiratory and cardiovascular condition, both in terms of being able to access specialist palliative care, advance care planning and preferred place of death.

**Analysis of Deaths in Gloucestershire.**

The national End of Life Care Strategy 2008 sets out an ambition to provide all adults nearing the end of life, regardless of diagnosis, access to high quality care and to support more people to realise their choices and preferences for care. Survey data suggests that many people would, given the choice, prefer to die at home and few wish to die in hospital.

Over half of people dying in Gloucestershire now do so in their usual place of residence – an improvement of two percentage points in the three years to September 2014, this is slightly below the regional average but significantly above the national figure\(^{10}\).

<table>
<thead>
<tr>
<th>Place of Death 2013 (%)</th>
<th>Gloucestershire</th>
<th>South West</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>25.2%</td>
<td>23.2%</td>
<td>22.4%</td>
</tr>
<tr>
<td>Care Home (LA and non LA)</td>
<td>24.2%</td>
<td>26.6%</td>
<td>21.6%</td>
</tr>
<tr>
<td>Acute/Community Hospital</td>
<td>44.6%</td>
<td>43.1%</td>
<td>48.3%</td>
</tr>
<tr>
<td>Hospice</td>
<td>3.1%</td>
<td>4.9%</td>
<td>5.5%</td>
</tr>
<tr>
<td>Elsewhere</td>
<td>2.9%</td>
<td>2.2%</td>
<td>2.2%</td>
</tr>
<tr>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

- Gloucestershire is better than England in terms of death in preferred place of care (home and care home) but worse than the South West region
- Just under half of people die in a hospital, with the Gloucestershire proportion a little below the national proportion.
- Around a quarter of people die in each of their own home or a care home, with the Gloucestershire proportion a little higher than the national proportion.
- The proportion of patients dying in a hospice in Gloucestershire is lower than the national average.

These statistics, alongside the Gloucestershire EoL needs assessment findings has helped shape our commitments and aims; we know that we must do more to support all individuals to engage with advance care planning, enabling them to have choice in relation to where they would like to die.

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9 Public Health England, 2013, End of Life Care Profiles: Place and cause of death
The number of people dying in an area is the single most important factor of end of life care need. Registered deaths for Gloucestershire by district for 2012-14 is summarised in the following table:

<table>
<thead>
<tr>
<th>Registered Deaths</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Cheltenham</td>
<td>480</td>
<td>556</td>
<td>483</td>
</tr>
<tr>
<td>Cotswold</td>
<td>422</td>
<td>408</td>
<td>411</td>
</tr>
<tr>
<td>Forest of Dean</td>
<td>440</td>
<td>416</td>
<td>441</td>
</tr>
<tr>
<td>Gloucester</td>
<td>511</td>
<td>477</td>
<td>499</td>
</tr>
<tr>
<td>Stroud</td>
<td>546</td>
<td>630</td>
<td>608</td>
</tr>
<tr>
<td>Tewkesbury</td>
<td>394</td>
<td>425</td>
<td>424</td>
</tr>
<tr>
<td>Gloucestershire</td>
<td>2,793</td>
<td>2,912</td>
<td>2,866</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5,705</td>
<td>6,066</td>
<td>5,885</td>
</tr>
</tbody>
</table>

- Stroud district had the highest number of deaths in 2012, 2013 and 2014
- 52% of deaths were females, 48% male

### 5.1 Deprivation and Death

We know 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. This is also 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.

Whilst Gloucestershire is a relatively affluent county, there are pockets of deprivation - further work is needed in order to understand how the national figures translate at a local level. It is anticipated that this work will form part of the planned needs analysis.

### 5.2 Black, Asian and Minority Ethnic Groups

There is also growing national evidence that people from Black, Asian and Minority Ethnic groups have reduced access to palliative and end of life care services. 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.

The findings of this review, together with the results of the Gloucestershire end of life needs assessment will inform the work required to ensure that irrespective of ethnicity, those who need palliative and end of life care will receive it in a timely way.
5.3 Dementia and End of Life Care

One in three people over the age of 65 will die with some form of dementia (Brayne et al, 2006). As the population ages and more people develop dementia, end of life issues will become increasingly important, not only in dementia care, but for society as a whole. Dementia is the third most common underlying cause of death for women in England and Wales, behind heart disease and stroke. It is the seventh most common cause of death in men13.

In 2012, the Prime Minister’s Challenge on Dementia was published. The report built on the National Dementia Strategy published in 2009 and set out a three year programme of improvements in dementia care and also acknowledged the importance of improving end of life care for people with dementia.

The Living Well with Dementia: a National Dementia Strategy (DoH 2009) was a wide ranging national programme to improve standards of dementia care for people, including carers and family, living with dementia. The 17 recommendations covered the span of the disease from memory loss through to end of life. The Prime Minister’s Challenge on Dementia: delivering major improvements in dementia care and research by 2015 (DoH,2012) further built on the progress and developments made, establishing key priorities.

In Gloucestershire, the National Dementia Strategy Local Action Plan worked closely with the End of Life Strategy development to ensure consistent approach to supporting people living with dementia at the end of life. The Local Dementia Action Plan has been revised and developed as a Gloucestershire Dementia Strategy 2015-2018; quality care at the end of life remains a priority and reflects an awareness that transition into the end of life phase for dementia is longer and less distinct than for other life limiting or long term conditions. We know that for those individuals with a dementia diagnosis, access to specialist palliative care and wider generalist end of life care is not always consistently accessed in Gloucestershire. Informed by our end of life needs assessment, the workstreams associated with this strategy will identify priority disease areas for improved end of life care.

5.4 People with additional needs

It is recognised that those individuals who are approaching end of life but have an existing Mental Health condition or a Learning Disability may require specialist and additional support. This is sometimes because of an inequality in accessing health services, but may also be because of increased complexities in co-morbidities and communication difficulties.

The Gloucestershire End of Life Board will adopt best practice from other areas who have implemented systems that support those with a learning disability or mental health condition to ensure that they are identified in a timely way and are given the time to talk about death and dying and the opportunity to express their wants and choices in the care they receive at the end of their life.

There are other communities within Gloucestershire who are often ‘hidden’ and experience difficulties when accessing end of life care, for example those who are homeless or seeking refuge in the county. The end of life board intends to undertake an equality impact assessment of this strategy and the associated work plans to ensure that no groups of individuals are excluded when planning or delivering services.

5.5 Additional areas of consideration

In addition to national and local evidence there are a number of other areas that Gloucestershire is required to address if we are to improve end of life care for the population of Gloucestershire. Three areas in particular will act as enablers for the ‘Ambitions’ within the Ambitions framework for palliative and end of life care to be realised within Gloucestershire.

Electronic Palliative Care Co-ordination Systems (EPACCs)

EPACCs is an electronic system that provides a palliative and end of life specific record sharing for clinicians. This system allows all clinicians involved in a patient’s end of life care to view and edit a master copy of the patient records, enabling all of those involved in a person’s care to understand what a person’s choices and wishes are in relation to their end of life care. Alongside the ‘Joining up your information’ project in Gloucestershire this will provide a joined up health economy wide approach to record sharing and improve quality of care for patients approaching end of life.

13 ONS, 2014, Leading Causes of Death in England and Wales
Advance Care Planning (ACP)

Advance Care Planning is a voluntary process of discussion and review with the aim of helping someone who has the capacity to indicate what their preferences and wishes are for future end of life care. It enables an individual to choose and communicate where and how they are cared for and contributes to person led and person centred future care planning.

If the individual wishes, they can record preference about their care and treatment and an Advance Decision to Refuse Treatment (ADRT) in specific circumstances. These preferences can then be referred to by those responsible for care and treatment if, as the illness progresses, the individual loses capacity to make decisions for themselves.

Support for Families/Carers and Bereavement Services

Families and carers are an integral part of end of life care and are fundamental to the successful delivery of care. Support for family and carers throughout a person’s illness and into bereavement at times inadequate. Gloucestershire has identified carers as a priority area within their Better Care Fund delivery and together with the implementation of the Carers Act; we have an opportunity to improve the availability and quality of support for carers.

In relation to bereavement services we know that this is an integral part of an end of life care model, both for the dying individual and those who are closest to them. All too often this is not the case and results in avoidable distress.
Our strategic aims and priority work-streams

Our strategic aims for End of Life Care in Gloucestershire have been identified following:

- A comprehensive review of the national and local policy context
- Initial findings from the Gloucestershire End of Life needs assessment
- A review of patient, family and carer experience and an understanding of what lessons can be learnt from these experiences, both positive and negative

In addition we have endeavoured to align our strategic aims to the ambitions outlined within the ‘Ambitions for Palliative and End of Life Care’ and the recommendations identified within the National End of Life Care Strategy’.

Our strategic aims identified below build reflect and build upon our commitment to improving end of life care for all and reveal where we think we need to be focussing the commissioning and delivery of end of life services in the next three years.

**Aim 1:** Ensure that each person is seen and treated as an individual; ensuring that appropriate support services are available to meet individual need and that they are treated with dignity and respect as they approach the end of their lives enabling timely access to physical, psychological, social and spiritual care.

**Aim 2:** Ensure identification of a person being at end of life is undertaken in an appropriate and timely way and is communicated sensitively.

**Aim 3:** Ensure information on all options of end of life care is available for individuals, their families and carers.

**Aim 4:** Ensure individuals are given the opportunity to undertake advanced care planning at an appropriate time and make an informed choice of where they would like to die, acknowledging that an individual has the right to change their mind during their care.

**Aim 5:** Ensure that the many services people need are well coordinated, so that patients receive seamless care that meets their needs, priorities and preferences for end of life care.

**Aim 6:** Co-produce with individuals, families, carers, and service providers an integrated model of End of Life care that can be delivered across all providers and locations.

**Aim 7:** Ensure that those closest to the individual are appropriately supported during and after the individual’s death; including the way in which activities immediately after death are undertaken and the availability bereavement support.

**Aim 8:** Ensure equity of provision for all individuals across all settings in Gloucestershire.

**Aim 9:** Ensure staff deliver the best possible evidence based care for individuals at the end of their lives, ensuring that symptoms amongst people approaching the end of life are managed in an effective and timely way.
Aim 10: Ensure resources are distributed effectively in order to provide care of excellent quality and which support patients in their preferred place of death.

Aim 11: Enhance existing End of Life care education programmes for Health and Social Care staff across all providers in order to develop a generalist workforce that have excellent End of Life skills and behaviours.

Aim 12: Support the increase of the community's awareness and discussion of death and dying, supporting the development of compassionate and resilient communities.

6.1 Workstreams

In order to deliver against our 12 strategic aims, it has been agreed that there are a number of priority work-streams that need to be established. Each work stream has its own scope of work, will develop a measurable action plan and will be supported by a multi-stakeholder implementation group that will drive this work forward.

The Gloucestershire End of Life Board will be responsible for providing the governance framework for workstream delivery, monitoring progress and unblocking any barriers to delivery. It should be noted that activity undertaken within the workstreams may be supporting delivery against more than one strategic aim.

As the end of life work progresses in Gloucestershire it may be necessary to develop further time limited work streams to progress particular areas of commissioning or service delivery.

Our current work streams are:

Quality and evidence: To develop a quality dashboard that commissioners will use to measure the quality of care and patient outcome across all providers with respect to end of life care.

The dashboard will use the NICE quality standards (appendix C), metrics contained within the National strategy for end of life that remain current together with some locally agreed measures. This will support the end of life board to measure activity both quality and performance related against all of our strategic aims.

Co-produced model – end of life care: To co-produce with patients, service users and carers a model for end of life care that can be delivered across all providers; ensuring a person led approach is taken to delivering care and acknowledging that any model needs to include how those closest to an individual are supported during end of life and post death. This will support the delivery of strategic aims 1,2,3,5,6,7 and 12.
Education and learning: To develop an evidence based end of life education framework for staff across all providers, including the voluntary sector in order to enhance the skills and competencies of staff in Gloucestershire who provide care to those at end of life. **This will support delivery of strategic aims 1,2,3,7,9,11 and 12.**

End of Life needs assessment: The Needs Assessment will help inform the commissioning and delivery of end of life services within Gloucestershire, identifying any gaps in service provision and identifying areas that may need a particular focus. **This will support delivery of strategic aims 8 and 10.**

EPaCCs: This workstream will explore what further action is needed within the existing ‘Joining up your information’ project to ensure that we have a fully functioning and accessible EPaCC system that will support the implementation of co-ordinated and person led end of life care for an individual. **This will support delivery of strategic aims 1,2 and 5.**

Advance Care Planning (ACP): This workstream will explore and develop opportunities for increasing awareness and uptake of ACP within the community, supporting the development of a network of ACP champions with the aim or ‘normalising’ ACP and adopting strength based community development approaches to achieve this. In addition, the current ACP documentation will be reviewed and refreshed to facilitate a more holistic approach to ACP. **This will support delivery of strategic aims 1,4,6 and 12.**

24/7 to specialist palliative care: To explore and produce an options appraisal in relation to what an enhanced 24/7 specialist palliative care provision would look like. This would include a single point of contact for patients, families, and carers as well as the health and social care staff involved in a person’s end of life care. Options will be presented that cover both a single point of contact service and ones which may assume a more ‘coordination’ role. **This will support delivery of strategic aims 1,2,8,9 and 10.**

Workforce – in partnership with wider workforce development within Gloucestershire we will ensure we have a capable and competent workforce to deliver End of Life Care services.

6.2 How will we know that things are improving?

Knowing when changes to both commissioning and service delivery have made a positive improvement to individuals and those closest to them is a key element of our future work. As we move forward, we must get better at measuring and monitoring end of life care for individuals, ensuring we are measuring the aspects of care that are meaningful to people, demonstrate improved outcomes for those who die in Gloucestershire, the experiences of those closest to them and those that are acting as ‘system enablers’. The end of life board will seek to gather evidence from a number of sources to demonstrate an improvement in end of life care and how as a county we are performing against our strategic aims.

The development of a cross provider quality dashboard will provide us with a significant amount of information that will enable us to understand if we are meeting the 12 strategic aims for improving end of life care. However, it is important that we don’t isolate our measurement to this dashboard alone and continue to monitor our patient/family complaints, concerns and complaints, in order to learn from positive and negative experiences. In addition, we need to explore how we can listen and learn from our frontline staff feedback, frequently they have valuable intelligence in relation to ‘system barriers’ that may be inhibiting an improvement in end of life care and wouldn’t necessarily be captured via a more formal route.

Appendix D presents our strategic aims and what methods of measurement we will use to demonstrate that we are meeting our strategic aims. This appendix does not contain the level of detail that the quality dashboard will produce but does give indicative areas for measurement.
7. **Conclusion**

Both nationally and locally progress in broadening the traditional focus of end of life care for those with a cancer diagnosis to include non-cancer diagnosis has been made.

The Gloucestershire vision is to ensure that effective, personalised and integrated End of Life care is available for all patients with advanced disease, irrespective of their diagnosis, of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation, and social economic status. Effective and compassionate care and support will be in place for people who are approaching the end of life so that they can have a dignified, peaceful and supported end of their life. Families and carers will be supported both during and after a person’s death. The Gloucestshire health and social care community have committed to working in true partnership with each other and with individuals, families and carers to achieve this vision.

End of Life Care in Gloucestershire will be commissioned and delivered in a way that enables the highest standard of care being delivered at all times with robust mechanisms of monitoring and evaluation, drawing upon the experiences of individuals and their families wherever possible.

A new model of care will provide the foundations for person led, integrated care that is communicated and delivered effectively across all providers in order to ensure a person has the end of life experience of their choice that is dignified and compassionate.

All services will embed best practice and support individuals/families/carers in ways that are timely and meet their individual needs, including physical, psychological, spiritual, cultural and social during end of life care and in bereavement.

Delivering this strategy via current and future identified workstreams will mean that we can shape services that can achieve the end of life care that the adult population in Gloucestershire would expect and deserve.
Appendix A – References


Marie Curie Palliative Care Institute Liverpool (2009) Liverpool Care Pathway for the Dying Patient (LCP) Supporting Care in the Last Hours or Days of Life


Appendix B – GLOSSARY of Terms

The terms ‘end of life’, ‘generalist palliative care’ and ‘specialist palliative care’ are often used interchangeably. In practice, the meaning of these terms is different. The section below sets out the definition of these common terms used in this strategy:

End of Life
People are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

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

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

By enhancing the quality of life it is possible to positively influence the course of illness and in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff across all sectors and may be done alongside treatment intended to reverse particular conditions.

Specialist Palliative Care
Specialist palliative care is the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support.

Generalist Palliative Care
Services in all sectors providing day-to-day care to patients with advanced disease and their carers, designed to alleviate symptoms and concerns, but not expected to cure the disease.

Hospice care
A hospice is not just a building; it is a way of caring for people. Hospice care aims to improve the lives of people who have a life-limiting or terminal illness, helping them to live well before they die. Hospice care not only takes care of people’s physical needs, but looks after their emotional, spiritual and social needs as well. It also supports carers, family members and close friends, both during a person’s illness and during bereavement.

Supportive care
This is care which helps people with cancer and other life-threatening illnesses and their families to cope with the disease and its treatment throughout the patient pathway. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

Advance Care Planning (ACP)
The difference between advance care planning and care planning is that the process of ACP can only involve someone with capacity to decide and usually takes place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or the ability to communicate wishes to others. There are three elements to the Advance Care Plan. The advance care plan is offered to all patients who may or may not choose to create this plan as it is a voluntary process. The plan itself is a process – which is subject to review. Under the terms of the Mental
Capacity Act 2005 formalised outcomes of advance care planning might include one or more of the following:

a) A statement of wishes and preferences (Advance statements). This is not legally a legally element of the plan. It captures the wishes of the patient and may include ‘preferred place of care or death’. The patient may change their mind regarding these preferences. There is no set review date but these plans should be reviewed regularly.

b) Advance decision to refuse treatment (ADRT). This is legally binding and patients have to be over 18 to make an ADRT. It is also prescriptive how it is written.

c) Gloucestershire has its own Advanced care Planning Booklet.

d) Lasting power of attorney (LPA). To complete this part of the plan a patient must go through the ‘office of public guardianship’. A certificate is required before lasting power of attorney is granted. Power of attorney may include a third party making decisions over health and wellbeing or finance or both.
### Appendix C: Quality Statements in the 2011 NICE Quality Standard for End of Life Care for Adults

<table>
<thead>
<tr>
<th>Area</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>QS 1: Identification</td>
<td>People approaching the end of life are identified in a timely way.</td>
</tr>
<tr>
<td>QS 2: Communication and Information</td>
<td>People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.</td>
</tr>
<tr>
<td>QS 3: Assessment, Care Planning and Review</td>
<td>People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.</td>
</tr>
<tr>
<td>QS 4: Holistic Support – Physical and Psychological</td>
<td>People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.</td>
</tr>
<tr>
<td>QS 5: Holistic Support – Social, Practical and Emotional</td>
<td>People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.</td>
</tr>
<tr>
<td>QS 6: Holistic Support – Spiritual and Religious</td>
<td>People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.</td>
</tr>
<tr>
<td>QS 7: Holistic Support – Families and Carers</td>
<td>Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.</td>
</tr>
<tr>
<td>QS 8: Coordinated Care</td>
<td>People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person’s current medical condition, care plan and preferences.</td>
</tr>
<tr>
<td>QS 9: Urgent Care</td>
<td>People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.</td>
</tr>
<tr>
<td>QS 10: Specialist Palliative Care</td>
<td>People approaching the end of life who may benefit from specialist palliative care are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.</td>
</tr>
<tr>
<td>QS 11: Care in the Last Days of Life</td>
<td>People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.</td>
</tr>
<tr>
<td>QS 12: Care After Death – Care of the Body</td>
<td>The body of a person who has died is cared for in a culturally sensitive and dignified manner.</td>
</tr>
<tr>
<td>QS 13: Care After Death – Verification and Certification</td>
<td>Families and carers of people who have died receive timely verification and certification of the death.</td>
</tr>
<tr>
<td>QS 14: Care After Death – Bereavement Support</td>
<td>People closely affected by a death are communicated with in a sensitive way and are offered immediate and on-going bereavement, emotional and spiritual support appropriate to their needs and preferences.</td>
</tr>
<tr>
<td>QS 15: Workforce – Training</td>
<td>Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.</td>
</tr>
<tr>
<td>QS 16: Workforce Planning</td>
<td>Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.</td>
</tr>
</tbody>
</table>
## Appendix D – Measuring our strategic aims

<table>
<thead>
<tr>
<th>Strategic Aim</th>
<th>How will this be achieved</th>
<th>How will we measure success</th>
</tr>
</thead>
</table>
| **Aim 1**: Ensure that each person is seen and treated as an individual; ensuring that appropriate support services are available to meet individual need and that they are treated with dignity and respect as they approach the end of their lives enabling timely access to physical, psychological, social and spiritual care. | ● Person led care planning  
● Enhanced skills of staff  
● Equity of access to services | ● Review of complaints/concerns and compliments  
● Number of staff in each provider attending eol training, particularly communication skills, identification and care planning  
● Assessment of service provision across the county  
● Case reviews across providers |
| **Aim 2**: Ensure identification of a person being at end of life is undertaken in an appropriate and timely way and is communicated sensitively. | ● Enhanced skills and training of staff  
● Appropriate and timely documentation on the county’s electronic eol register | ● Number of staff in each provider attending eol training, particularly communication skills and identification in non cancer patients  
● Number of people identified as eol on the counties eol register  
● Non cancer clinical pathways will include eol, eg respiratory |
| **Aim 3**: Ensure information on all options of end of life care is available for individuals, their families and carers. | ● Enhanced knowledge amongst staff  
● Review of county’s eol resources and their accessibility | ● Number of staff in each provider demonstrating an understanding of what resources are available and when they should be used  
● Robust monitoring of eol resource ordering across provider  
● Review of complaints/concerns/compliments |
| **Aim 4**: Ensure individuals are given the opportunity to undertake advanced care planning at an appropriate time and make an informed choice of where they would like to die, acknowledging that an individual has the right to change their mind during their care. | ● Enhanced skills and training of staff  
● ACP embedded within everyday practice across all providers | ● Number of staff in each provider trained in ACP  
● Number of voluntary ACP champions in the community  
● Number of people with an ACP placed on the eol electronic register  
● Number of people on the eol electronic register with an identified preferred place of death  
● Evidence of ACP in use across all services |
| **Aim 5**: Ensure that the many services people need are well coordinated, so that patients receive seamless care that meets their needs, priorities and preferences for end of life care. | ● Development of a co-produced cross provider model of eol.  
● Services are commissioned in an integrated way across health and social care  
● EPaCC system embedded within ‘Joining up your information’ | ● Cross provider eol model developed and in use across all providers  
● Evidence of integrated commissioning in relation to eol  
● Number of patients with an EPaCC in place |
| **Aim 6**: Co-produce an integrated model of End of Life care that can be delivered across all providers and locations. | ● Development of a co-produced model that engages patient, families and carers as partners in its design | ● Number of patients, families and carers involved in the model design  
● Eol Model implemented across all providers |
| **Aim 7**: Ensure that those closest to the individual are appropriately supported during and after the individual’s death; including the way in which activities immediately after death are undertaken and the availability bereavement support. | ● Embed support for individuals and families within eol model.  
● Ensure bereavement support is a key element of eol model  
● Review commissioned specialist and generalist bereavement interventions | ● Eol model embedded across all providers  
● Number of people accessing specialist bereavement interventions  
● Number of people receiving bereavement support from generalist services, eg primary care, community nursing  
● Review of complaints/concerns/compliments |
| --- | --- | --- |
| **Aim 8**: Ensure equity of provision for all individuals across all settings in Gloucestershire. | ● Eol Needs assessment  
● Review of commissioned specialist palliative care services across Gloucestershire | ● Evidence that commissioners have recognised and responded to any inequity of provision identified within the needs assessment  
● Resources are deployed in response to clinical or geographic need  
● Number of non cancer patients accessing specialist palliative care  
● 24/7 specialist palliative care support available |
| **Aim 9**: Ensure staff deliver the best possible evidence based care for individuals at the end of their lives, ensuring that symptoms amongst people approaching the end of life are managed in an effective and timely way. | ● Enhanced staff skills and training | ● Number of generalist staff attending training, particularly symptom management and identification |
| **Aim 10**: Ensure resources are distributed effectively in order to provide care of excellent quality and which support patients in their preferred place of death | ● Review of generalist eol services  
● Review of specialist palliative care services | ● Evidence that commissioners and providers have recognised and responded to any inequity of provision identified within the review of services  
● Number of people who have preferred place of death recorded  
● Number of unplanned admissions for those at eol  
● Case reviews of unplanned admissions for those at eol |
| **Aim 11**: Enhance existing End of Life care education programmes for Health and Social Care staff across all providers in order to develop a generalist workforce that have excellent End of Life skills and behaviours. | ● Evidence based eol education program available for all generalist staff in Gloucestershire | ● Number of generalist staff across providers accessing eol education program  
● Number of staff who report an increase in knowledge, skills and confidence post training |
| **Aim 12**: Support the increase of the communities awareness and discussion of death and dying, supporting the development of compassionate and resilient communities | ● Support the development of community ACP champions  
● Increase public and community awareness and understanding of dying  
● Actively engage with the development of community hubs | ● Number of community ACP champions  
● Number of awareness raising events  
● Number of community offering eol information/support/signposting  
● Number of individuals from the VCS accessing eol education program |
Appendix D – Gloucestershire End of Life Care Resources

Below is a list of resources that have been developed by multi-agencies within Gloucestershire. They are useful tools for staff who are involved in caring for those planning and entering the end stage of life. The majority of these free resources are linked to either face to face training sessions, workbooks or e learning sessions.

<table>
<thead>
<tr>
<th>Resource</th>
<th>What is it used for?</th>
<th>Related training available for ALL health and social care staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning for your Future Care Introductory Leaflet (Trifold leaflet)</td>
<td>This is a gentle introductory leaflet to the main Advance Care Planning (ACP) booklet below. Useful for information racks including GP surgeries. It outlines the main parts of ACP which are applicable to all.</td>
<td><a href="http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/">http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/</a> see calendar of events Face to face training: 1 day workshop on Advance Care Planning Workbook <a href="http://www.e-lfh.org.uk/programmes/end-of-life-care/">http://www.e-lfh.org.uk/programmes/end-of-life-care/</a> Free E learning sessions</td>
</tr>
<tr>
<td>“Planning for your Future Care “ an Advance Care Planning (A4 20 page booklet)</td>
<td>This is the Gloucestershire Advance Care Planning tool. This can help people consider or document: Future wishes regarding where they would like to be cared Treatments they wish to refuse – known as advance decisions. Putting affairs in order Making a Will Funeral Planning</td>
<td></td>
</tr>
<tr>
<td>Shared Care Record for Expected last days of life (A4 booklet/Care Plan)</td>
<td>This is a Gloucestershire wide document providing a structured approach to documentation and care in the last days of a person’s life. It was developed across care settings and is transferable, there are prompts for the key areas to discuss and additional sections for individualisation of care. It can be used by all grades of staff to record the care of the patient and includes an in depth Observation Chart</td>
<td><a href="http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/">http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/</a> see calendar of events Face to face training ½ day Training workshop: “Shared Care Record”</td>
</tr>
<tr>
<td>Symptom Observation Chart (A4 one sheet)</td>
<td>This is a continuation sheet for the Shared Care Record. Please use these rather than photocopying the booklet. For patients who are approaching end of life but not felt to be in last days – i.e. last weeks, this can be considered as an alternative to standard observations and used alone, without the shared care record.</td>
<td><a href="http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/">http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/</a> see calendar of events Face to face training 1 day Training workshop: Symptom Control for registered staff including Drs</td>
</tr>
<tr>
<td>Coping with Dying Code: BLDPO65 (Blue trifold leaflet)</td>
<td>Written and produced by Marie Curie. Helpful and aimed at relatives/Carers who ask questions around what happens to the patient towards the end of life. E.g. food, fluids, breathing etc.</td>
<td>Booklet can be ordered directly from the Marie Curie Institute</td>
</tr>
<tr>
<td>Support for Carers leaflet A5/Code 66895</td>
<td>This short leaflet is currently being updated</td>
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<tr>
<td><strong>Best Interests Decisions for End of Life Care Code GDH 3050</strong></td>
<td>This Advance Care Planning tool can support the process of decision making in best interests <strong>where patients lack capacity</strong>. It can be used to record collective decisions made using appropriate representatives for those with conditions such as Advanced Dementia if decisions were not discussed before the person became unable to document their own wishes</td>
<td><a href="http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/">http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/</a> see calendar of events</td>
</tr>
<tr>
<td>(A4 booklet 16 pages)</td>
<td></td>
<td>Face to face training 1 day Training workshop: Best Interests study half day.</td>
</tr>
<tr>
<td><strong>Preparing for End Stage Dementia (A5 booklet)</strong></td>
<td>Information for people with dementia, their family and carers.</td>
<td></td>
</tr>
<tr>
<td><strong>Your guide to support the use of the Best Interests booklet Toolkit</strong></td>
<td>This is a Staff guide to complete the Best Interest booklet.</td>
<td></td>
</tr>
<tr>
<td><strong>After a Death – Grieving the Loss (A5 leaflet)</strong></td>
<td>This A5 leaflet is useful to give to relatives and carers after a person has died. It gives useful information on what to expect.</td>
<td><a href="http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/">http://www.gloucestershireccg.nhs.uk/your-services/eolc/eolc-training/</a> see calendar of events</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A one day <strong>Supporting Bereaved adults</strong> training day.</td>
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<tr>
<td></td>
<td></td>
<td>Free E learning sessions on Bereavement</td>
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</tbody>
</table>