



Frimley ICS End of Life Care Strategy



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Review Mid-Point		
Version 01:	24/08/2021	Revised Draft to include changes to CCG and update on completed works
Version 02	24/08/2021	Task & Finish group update
Version 03	06/09/2021	Change to Frimley CCG & ambitions update
Version 04	08/09/2022	Revised Draft to include change to ICB and statutory guidance



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Mid-Point Review

1. Foreword

We all find it difficult to talk about and plan for the final months and weeks of life for someone near and dear to us. This strategy will help us to better support individuals, their families and carers, health and social care professionals, and voluntary services to ensure a person's end of life needs are met. We will do this by working collaboratively and through co-design to shape services for the future.

We will aim to ensure easy access to services and information so that people who are dying, their carers and families know what to expect and can make informed decisions about their wishes and what they want to happen at any stage in their journey.

This strategy will support health, social care and voluntary organisations to work together and collaborate on improving services across the system.

We stress the importance of seeking out and listening to the views of our population, to enable us to understand what is important in someone's last year of life so we can inform our future vision for end of life care for our population.

As joint chairs of the Frimley Health and Care ICS End of Life Care Steering Group, we encourage both professionals and patients to seek continual improvement in end of life care services across the ICS.

During the life of this strategy the priorities have changed due to COVID-19 Pandemic. The NHS Frimley Integrated Care Boards (ICBs) End of Life Care Team, comprising the clinical and managerial leads worked closely with the Medicines Management Team to ensure our EoLC Covid Response anticipated the needs of front line staff and our population. During a very short space of time the team implemented guidance, protocols and pathways to support changes across the system. The team has continued to meet regularly and will continue to do so during the pandemic emergency. The advent of NHS Frimley ICB in July 2022 and the Palliative and End of Life Care Statutory Guidance for ICBs provided additional focus for this strategy.

Jo Greengrass, Managerial Chair



Dr Emma Whitehouse, Clinical Chair



2. Introduction and Background



This document has been produced in order to give key stakeholders in End of Life (EoL) Care across the Frimley Health and Care Integrated Care System (FH&C ICS), an overview of the strategic direction in which FH&C ICS aims to take End of Life Care for people of all ages in the foreseeable future; and to inspire action from partners which will lead to improved End of Life Care for adults and children, families and carers.

To gain a full insight into the principles of End of Life Care endorsed by FH&C ICS, and to assist in the reading of this document, this paper should be read in conjunction with the references listed on page 13.

This document built upon the work undertaken by firstly the three Clinical Commissioning Groups (CCGs) and their stakeholders, combined with the FH&C ICS Operating Plan for End of Life Care into a single strategy across FH&C ICS. Since the inception of this strategy, the three CCGs have combined, firstly into the Frimley Collaborative and then from 1st April 2021 into a single entity as Frimley CCG. This has now been replaced by NHS Frimley Integrated Care Board which came into being on 1st July 2022.

The NHS long term plan runs from 2019 – 24 and sets out its priorities for healthcare over the next ten years, including End of Life Care. The FH&C ICS End of Life Care strategy is a five-year strategy and will sit within the overall Frimley Health and Care ICS Strategy. End of Life Care was also referenced within the FH&C ICS 2019-20 System Operating Plan, and sat within the Integrated Care Decision Making work stream. This strategy update will be reviewed by the FH&C ICS End of Life Care Steering Group, and ratified by the FH&C ICS Programme Delivery Board.

The End of Life Care Steering Group has membership from different providers, organisations and sectors to support the delivery of excellent end of life care and also responding to National and local agendas, adaptation and implementation e.g. Ageing Well, Personalisation and Urgent Care Response etc.

The aim of the strategy is to provide direction to deliver all age person centred, high quality, responsive and coordinated End of Life Care. It aims to reduce variation in the care of the dying person and their families and carers across our System, and increase overall satisfaction.

3. Defining End of Life and Palliative Care

End of Life Care

The GMC (2019) defines End of Life Care as *‘Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes:*

- *Those patients whose death is expected within hours or days*
- *Those who have advanced, progressive incurable conditions*
- *Those with general frailty and co-existing conditions that mean they are expected to die within 12 months*
- *Those at risk of dying from a sudden acute crisis in an existing condition*
- *Those with life-threatening acute conditions caused by sudden*



Palliative Care

The GMC (2019) defines Palliative care as ‘the holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient’s pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient’s illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity’. ¹

4. Vision Statement

A community that is able to freely and openly discuss their thoughts and wishes around the end of their lives so they can make dignified and achievable choices which are respected by health and care professionals. All people approaching the end of their lives across the Frimley Heath & Care ICS will receive well-coordinated, compassionate, person centred care, and carers and family members are supported throughout and after the person has died.

5. Desired outcomes at End of Life

- People are proactively identified by all health & social care professionals when the end of their lives are nearing, enabling timely conversations on future care planning
- People’s wishes around death and dying, including preferred place of care are listened to, respected and recorded appropriately
- People receive high quality palliative care and supportive care, twenty-four hours per day, seven days per week
- End of Life Care providers offer a seamless, streamlined, high quality and holistic service, resulting in people being treated with dignity, compassion and respect at the end of their lives and creating a positive experience of the care they receive
- Carers, friends and family members are supported with preparing for loss and bereavement, continuing after the person they care for has died
- Staff are confident, compassionate and competent to deliver person-centred care and advice which enables a good death
- Care is well coordinated and integrated across multi-disciplinary teams working with and around the person, their carers and families

6. National Context and Strategy drivers

In 2015 the National Palliative and End of Life Care Partnership published the ‘Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015 – 2020’. This was refreshed in May 2021¹ The Ambitions framework was developed by a partnership of national organisations across the statutory and voluntary sectors.

It sets out the vision to improve end of life care through partnership and collaborative action between organisations at a local level throughout England. The National Framework sets out six ambitions which are listed below.

¹ <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>



Figure 1 – The Six National Ambitions for Palliative and End of Life Care

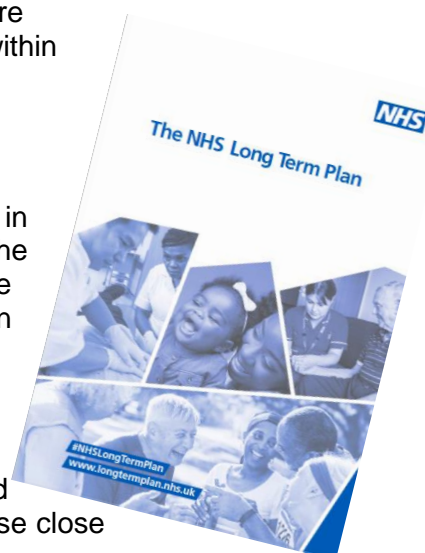


The FH&C ICS End of Life Care Steering group has undertaken the self- assessment toolkit with partners to benchmark where each organisation is starting from and as a result of this activity has identified areas for improvement. The self-assessment will be done on a regular basis over the duration of this strategy.

The NHS Long Term Plan emphasises the need to deliver more personalised care to improve experiences for those who are within their last year of life.

Nationally, we know that:

- Every year approximately half a million people die in England. This is expected to rise by 17% by 2030. The percentage of deaths occurring in the group of people aged 85 years or more is expected to rise from 32% in 2003 to 44% in 2030.
- Approximately three quarters of deaths are expected, not sudden. Therefore, there is potential to improve the experience of care in the last year, months and weeks of life for at least 335,000 new people, and those close to them, each year.
- Currently there are 15 million people in England with a long term condition (LTC). By 2025, the number of people with at least one LTC will rise to 18 million. The number with two or more LTC is projected to increase from 5 million to about 6.5 million. Most





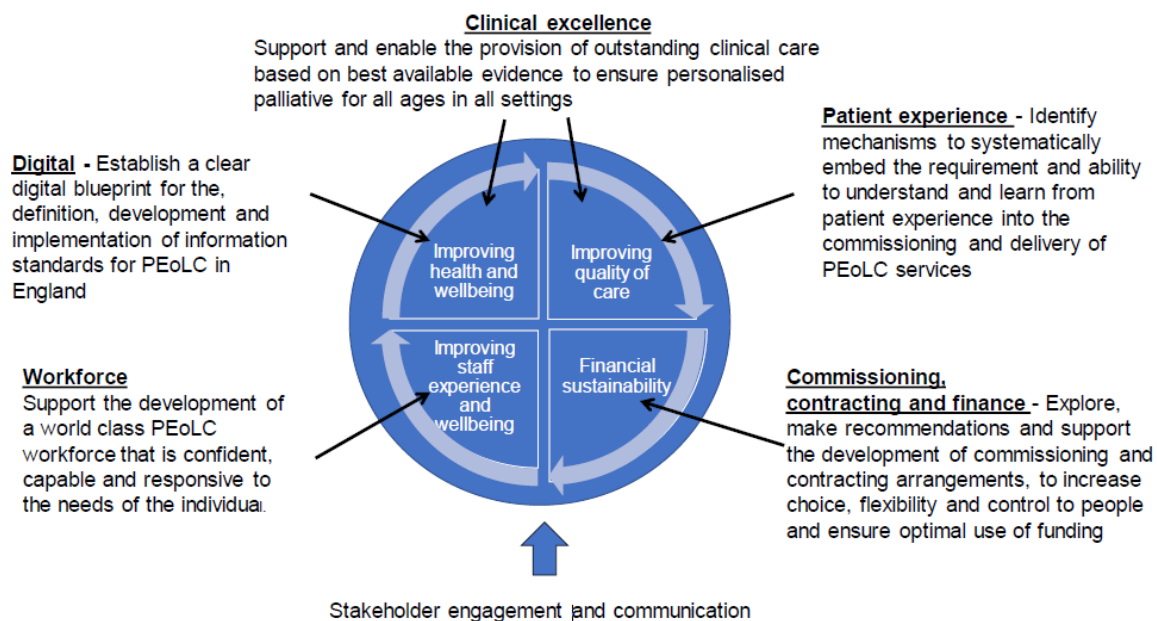
of these people will need end of life care as they approach their last years, months and weeks of life.

- Around half a million carers provide support to people dying at home of a terminal illness. The cost to family carers may include lost earnings, 24-hour care and physical and mental health consequences, some of which may be permanent.
- Between 2001 and 2011, the number of unpaid carers has grown by 600,000, with 1.4 million people providing fifty or more hours of unpaid care per week².
- In 2016, there were over 1.6 million emergency admissions for people in the last year of their life, amounting to around 11 million days in hospital, costing the NHS £2.5 billion.³ It is recognised that improved identification of palliative care needs and services outside of hospital could improve care and reduce hospital costs by £180 million per year.

NHSE Palliative and End of Life care
Looking forward: Our Five Year Delivery Plan

NHSE have a delivery plan to improve Palliative and EOLC, below are the aims for this plan and locally we will be looking at ways to support the delivery of these.

Addressing quadruple aims



² <https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

³ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/emergency-admissions-briefing-paper-2018.pdf>



7. About the Frimley Health & Care Integrated Care System (FH&C ICS)

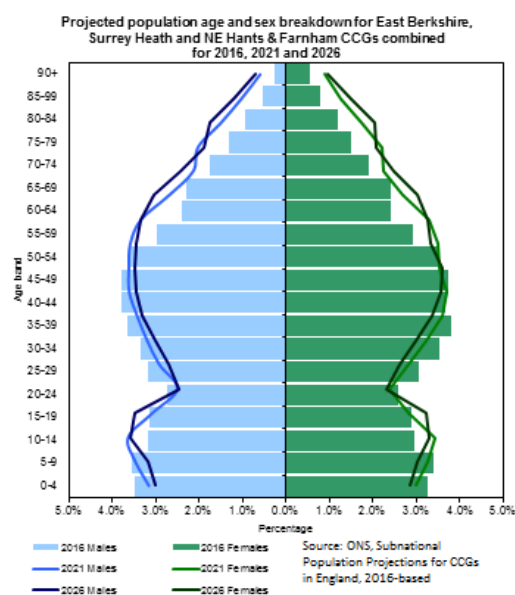
The FH&C ICS has a population of 800,000 people in Bracknell, Royal Borough of Windsor & Maidenhead, Slough, North East Hampshire and Farnham and Surrey Heath Places within Frimley CCG. The ICS involves 30 statutory bodies, including Local Authorities, CCGs, provider Foundation Trusts and others.

Figure 2 – Map of the Frimley Health & Care Integrated Care System.



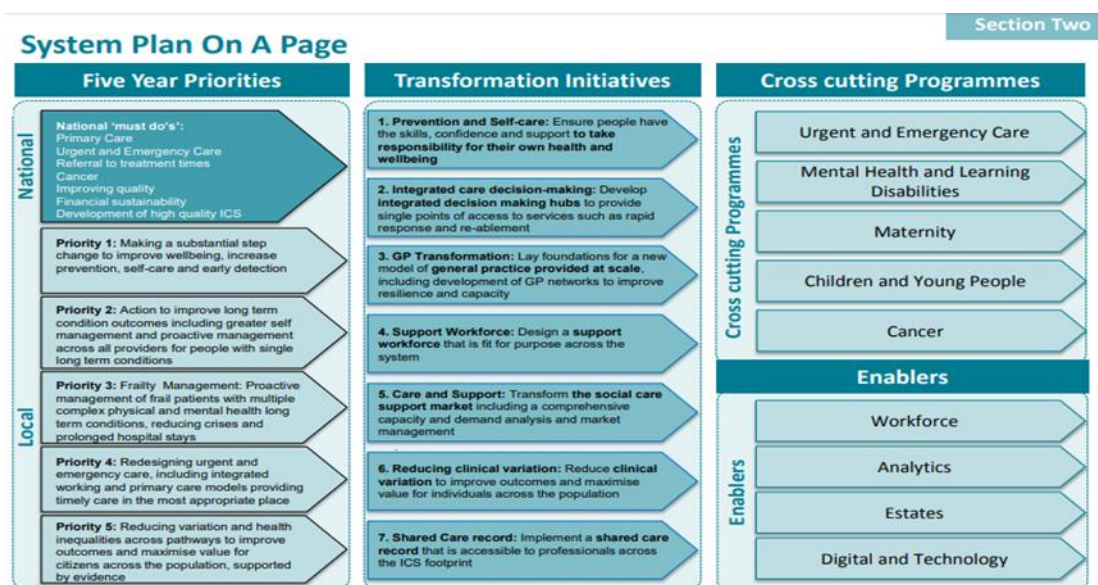
The pyramid below shows the projected population growth for the FH&C ICS. Patients are now living longer with multi-morbidities and complex needs, and services need to ensure that they are able to support the increasing numbers of those aged 85 and older, along with those living with Frailty.

Figure 3 – Projected population growth for the Frimley ICS for 2016, 2021 and 2026





The diagram below shows the FH&C ICS System Plan on a Page. End of Life Care sits within Transformation Initiative number 2 – ‘Integrated Care Decision Making’.



8. Local Context and Strategic Priorities

End of Life Care is a commissioning priority for Frimley CCG within the FH&C ICS. End of Life Care services are currently funded and delivered by a number of organisations from the NHS, local authorities, voluntary sector, independent agencies and via individual means (e.g. informal or family carers).

Despite examples of excellent care offered to patients by our current providers, there remain a number of challenges which affect the quality of care patients may receive. It has been recognised that a large number of patients are not being identified early enough as needing End of Life Care, which can hinder the ability to determine and co-ordinate the appropriate care needed. End of Life Care needs to be co-ordinated between different health and care professionals, which can be extremely challenging and when not delivered appropriately can lead to poor patient care and inappropriate emergency admissions to hospital.

The single FH&C ICS End of Life Care Steering Group incorporating NHS primary, community and secondary care, social care and the voluntary sector works well together with all stakeholders participating in the task and finish groups and the use of steering group meetings to focus on specific aspects/priorities of EoLC to ensure better understanding across the system.

Partners have undertaken a bench marking exercise using the National Ambitions for Palliative and End of Life Care Self-Assessment Tool, to identify the key priorities for FH&C ICS End of Life Care Steering Group. The Heat Map below indicates our combined strengths across the System and the areas for improvement. Working with partners we have achieved a consensus on the priorities for the ICS and partners are now collaborating to improve services and reduce variation in services across the ICS.



Figure 4 – Level descriptors for the Ambitions for Palliative and End of Life Care Self-Assessment

Level	Locality Level Descriptor
Level 0	Not at all ready to achieve/ anticipate barriers to achievement
Level 1	Desire to achieve this ambition but there are currently no plans in place
Level 2	Plans are in place towards achieving this ambition
Level 3	Limited achievement across one or two organisations only
Level 4	Partially achieving e.g. across most, but not all care settings
Level 5	Fully achieving e.g. across all care settings, with supporting evidence available

Figure 5 – Heat map overview of the Frimley ICS performance against the Ambitions for Palliative and End of Life Care Self-Assessment for 2019 and 2021

There has been a positive shift to achieving the ambitions. Areas for improvement are identified within our priorities.

	Level 0	Level 1	Level 2	Level 3	Level 4	Level 5
Ambition 1: Each Person Seen as an Individual	0.0%	9.1%	27.3%	36.4%	27.3%	0.0%
Ambition 2: Each person gets fair access to care	0.0%	10.0%	40.0%	40.0%	10.0%	0.0%
Ambition 3: Maximising comfort and wellbeing	0.0%	0.0%	12.5%	25.0%	56.3%	6.3%
Ambition 4: Care is coordinated	50.0%	8.3%	8.3%	12.5%	20.8%	0.0%
Ambition 5: All staff are prepared to care	0.0%	0.0%	14.3%	42.9%	42.9%	0.0%
Ambition 6: Each community is prepared to help	0.0%	0.0%	75.0%	25.0%	0.0%	0.0%
Key						
	0%		37.5%			75%

	Level 0	Level 1	Level 2	Level 3	Level 4	Level 5
Ambition 1:	0.0%	0.0%	0.0%	31.6%	63.2%	5.3%
Ambition 2	0.0%	0.0%	0.0%	50.0%	50.0%	0.0%
Ambition 3	0.0%	0.0%	0.0%	6.3%	68.8%	25.0%
Ambition 4	0.0%	0.0%	13.0%	47.8%	39.1%	0.0%
Ambition 5	0.0%	0.0%	0.0%	0.0%	57.1%	42.9%
Ambition 6	0.0%	0.0%	25.0%	50.0%	25.0%	0.0%

National data on the Public Health England End of Life Care Profiles indicates the number of deaths occurring in hospital (all ages) has gradually reduced from 2004 – 2018 across the ICS, and the percentage of deaths occurring in Care Homes (all ages) has increased over the same period, both of which are similar to the National benchmark. The percentage of deaths which have occurred at home (all ages) has overall seen an increasing trend from 2004 – 2018, however the Frimley System is below the National benchmark.



Figure 6 – Percentage of deaths that occur in hospital (all ages) for Frimley Health

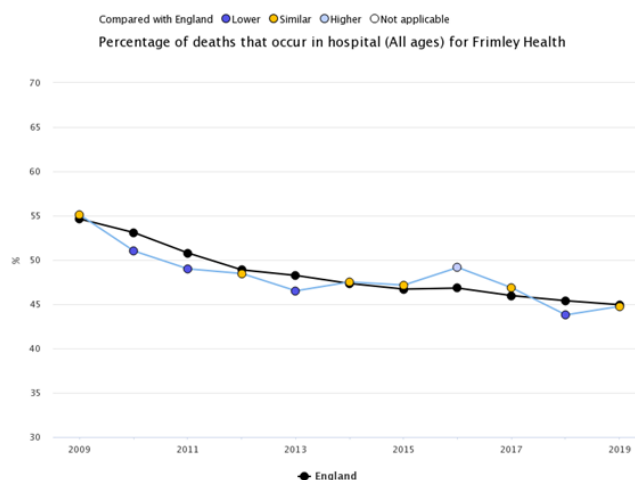


Figure 7 – Percentage of deaths that occur in care homes (all ages) for Frimley Health

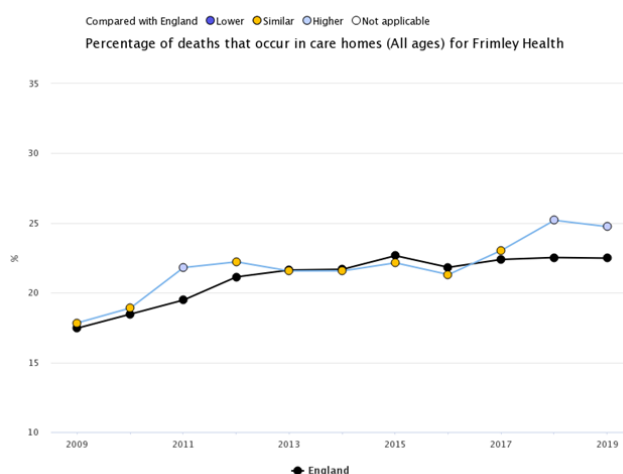
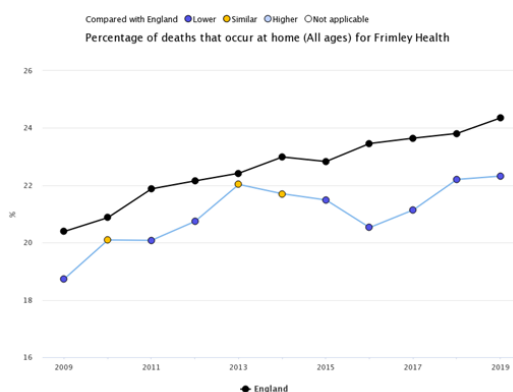


Figure 8 – Percentage of deaths that occur at home (all ages) for Frimley Health



The FH&C ICS End of Life Care Steering Group are working with Business Intelligence Leads to develop an End of Life Care Dashboard which can monitor performance and quality of care against agreed metrics on a local level.

The key priorities for End of Life Care across the FH&C ICS over the next 5 years, outlined below, have been determined by the FH&C ICS End of Life Care Steering Group as areas which need further development, and also align with the national priorities. These priorities will be reviewed on an annual basis and the work plan will be updated accordingly.

Since the start of the strategy the following priorities have been completed:

- The set-up of the End of Life Steering Group, since the COVID-19 Pandemic, this group has continued to meet virtually and work has continued on the task & finish groups
- Completion of the National Framework Ambitions Self-Assessment Tool, this has now been completed three times with more stakeholders completing the self-assessment which is leading to an upward trend in outcomes against the ambitions
- The Production and implementation of a patient diary was superseded by the implementation of ReSPECT across the Frimley system
- Review of the Frimley North Model of 24/7 access to Specialist Symptom Control and Advice, this again was overtaken by COVID-19 Pandemic and formed part of the EoLC COVID-19 Response Team work
- Directory of Services was completed and is reviewed on a regular basis to ensure it remains current
- Training & Education Strategy produced and implemented, with ongoing workforce development
- Integrating Children & Young People's End of Life Care, with an EoLC Children's Group set up that feeds into the EoLC Steering Group

During this period the EOLC Leadership Team was asked to set up the EOLC COVID-19 Response Team to ensure all aspects of EOLC were delivered safely and well during the pandemic. The team instituted a number of improvements, guidance and advice and new EOLC materials to support the public and clinicians across the system during the pandemic see references below for the Response Team timeline.

Priorities	Work Streams
Education & Workforce	ReSPECT Project Implementation
Health Inequalities	Patient & Carer co-design and engagement with different faith & Cultural Groups e.g. People who are Homeless, Gypsy Roma Traveller (GRT), Learning Disability (LD) and Dementia



	Improving conversations around dying well and a good death across the Frimley system
Data & Monitoring	Digital Solutions for Advance Care Plans, aligning with connected Care Reviewing performance and variation
Clinical Effectiveness	Ongoing Best Practice for End of Life Care with supporting business cases for NHSE Funding

9. How will we know if the strategy has made a difference?

The delivery of the strategy and its outcomes will be monitored through implementation plans that measure progress in a range of different ways. Each project will have key performance indicators to achieve the stated outcomes.

A cross section of quantitative or hard metrics and qualitative or soft measures will be used to monitor progress in short, medium and longer term timelines. Some improvement measures will be used to assess variation, some may compare local performance against national standards and patient and carer experience will be regularly gleaned in order to guarantee their voice is at the centre of continuing change and performance review – ensuring the pursuit of targets or efficiency is not undertaken at the cost of personalised and holistic care which is central to the strategy.

References

Frimley Health & Care ICS Strategy [Report template \(moderngov.co.uk\)](#)

Frimley CCG EoLC COVID-19 Response Team Time Line



Frimley
Collaborative EoLC

NHSE Statutory Guidance for ICBs <https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>

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