A Vision for Enhanced Palliative and End of Life Care across the BaNES, Swindon and Wiltshire (BSW) Integrated Care System (ICS)

Prepared for the
BSW Palliative and End of Life Care Oversight Group
with recommendations for 2021 and beyond

March 2021

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Executive Summary

Context

Integrated Care Systems (ICSs) are central to the delivery of the Long Term Plan and brings together local organisations to redesign care and improve population health, creating shared leadership and action. BaNES, Swindon and Wiltshire (BSW) are already working towards operating in this way. In an ICS, NHS organisations, local authority and other partners including the third sector such as hospices "take collective responsibility for the management of resources to improve the health of the population they serve" including:

- Stronger **partnerships in local places** between the NHS, local government and others

- **Provider organisations** being asked to step forward in formal collaborative arrangements that allow them to operate at scale

- Developing strategic **commissioning** through systems with a focus on population health outcomes

- The use of **digital and data** to drive system working, connect health and care providers, improve outcomes and put the citizen at the heart of their own care

To deliver the core aims and purposes of an integrated care system, it is recommended that NHSE and local authorities will need to devolve more functions and resources from national and regional levels to local systems, to develop effective models for joined-up working at "place", ensure they are taking advantage of the transformative potential of digital and data, and to embed a central role for providers collaborating across bigger footprints for better and more efficient outcomes.

Integrating Care, NHSE (2021)

The recent (February) paper from the government sets out their ambition for a more joined up approach built on collaborative relationships, so that more strategic decisions can be taken to shape health and care for the decades to come. Furthermore, they stipulate that it's about population health: using the collective

resources of the local system, NHS, local authorities, the voluntary sector and others to improve the health of local areas.

Integration and innovation, GOV.UK (2021)

It was with these strategic opportunities on the horizon that the BSW Palliative and End of Life Care Oversight Group (a combined provider and commissioner collaborative) was formed in September 2020.

This report outlines the early high level recommendations of this Oversight Group. It is the intent that these recommendations will enhance and build on the good work already in place across the system to achieve equitable, sustainable, cost efficient and outcome driven palliative and end of life care services fit for the current and future needs of the population of BaNES, Swindon and Wiltshire.

Recommendations

The recommendations that follow (with more detail from page 11), which the Oversight Group seek the support of the Population Health Board on, will provide improved health outcomes for all people and their families requiring palliative and end of life care across both place and the system and are based on:

1. National and local policy and strategies in particular the existing CCG strategies/contracts for end of life and the Ambitions for Palliative and End of Life Care document (see references).

2. Quantitative analysis of local demographic and outcome data supplied by the CCG.

3. Qualitative feedback received from an ongoing survey of patients and families experiences of end of life care across BSW.

4. Mapping of local services against items 1, 2 and 3 above.

5. An ambition to deliver services that are both value for money and delivering demonstrable positive outcomes for the local populace.

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The Population Health Board are being asked to endorse the recommendations and empower the Palliative and End of Life Care Alliance to deliver the vision in

the new financial year.

Introduction

The BSW Palliative and End of Life Care Oversight group has had some early successes in agreeing a "population health" approach, mapping the services across the system and setting up a working group to review the use of ReSPECT, however it should be acknowledged this collaboration is still gathering momentum. Membership is getting stronger (see Appendix 3) with representatives from most health and social care commissioners as well as primary and secondary care, community and the third sector providers.

There is strength in the collaboration and in particular the "one voice" approach from the three hospices and the first recommendation builds on this collaboration in describing how (if approved) the evolution of this group into an "Alliance" of the key stakeholders of health and social care providers and commissioners will lead to the development of a BSW wide strategy for end of life care and collective responsibility and accountability for the management of resources (people and finances) to improve the outcomes for people at the end of their life.

Population definition

For the purposes of this work the population described are adults aged 18 years and over and "likely to die within the next 12 months" but includes their needs in the last 1000 days of life (see Appendix 1 for a list of definitions). This includes conditions such as frailty, severe dementia, cancer, heart failure (congestive and ischaemic), respiratory conditions, neurological conditions, stroke, renal failure and liver failure.

The oversight group will ensure strong links with the commissioners and providers of services on offer for people aged under 18 years of age who have a life limiting condition thereby ensuring a seamless transition from child to adult services.

End of life profile

National context

People are living longer; over the next 20 years the population in England is expected to grow by almost 10%, with the number of people aged 75+ expected to grow by almost 60% and the proportion of people aged 65+ with four or more diseases set to double by 2035. One in 3 people admitted to hospital in England as an emergency has 5 or more health conditions and so it is clear that we have a growing elderly population with complex health and social care needs requiring early and equitable access to palliative and end of life care services.

Integration and innovation, GOV.UK (2021)

People are not only living longer, but they are living longer with frailty, long term conditions and / or with complex, multi-morbidities. About 26 million people in England have at least one long term condition (LTC) including an estimated 0.5m at the end of life (NHSE, 2018).

Local context

The current population of the BSW catchment area is approximately 940,000 people registered at 94 GP practices and with access to specialist end of life care provided by three hospices and in three acute hospitals. Place is important because for most people their day to day care and support needs will be expressed and met locally in the place where they live. Palliative and end of life care remains a core part of Primary and community care services and the emphasis must be on close multi-professional working between all professionals across the system. There is already good evidence that our combined care across the BSW CCG geography provides better outcomes in relation to place of death. It is important to stress that not all deaths in hospital should be viewed as a failure of care in the community or a negative experience for the patient and/or family. Of the 8657 deaths in BSW in 2019/20 the breakdown by place of death was as follows:

BSW Place of Death	BSW	National Average
Care home	29%	24%
Own home	29%	23%
Hospital	35%	45%
Hospice Inpatient Unit	4%	5%
Other	3%	3%

Local evidence supplied by BSW CCG suggests that the number of over 65s (already representing 26% of the overall BSW population) are predicted to increase in number from 241,765 in 2020 to 267,710 in 2025 (an increase of 10%) and concurrently the demand on palliative and end of life care services locally is increasing and so too is the number of deaths.

Gaps and variation

Although, as noted above, there are good indications that across BSW CCG commissioners and providers are delivering some good outcomes in palliative and end of life care, the oversight group, having mapped the services on offer across the whole geography and analysed the early (qualitative) survey responses from both patients and families, recognise that there remain gaps and variation in provision across the BSW region i.e.

• Commissioning of palliative and end of life care services, currently organised across three localities and local authorities, means that there are some disparities in what care a person will receive based on where they live e.g. Hospice@Home type services, self-referral.

• There is an inconsistency in how people are identified as being at the "end of life" which can lead to delayed referrals to specialist providers.

• The referral pathway to specialist palliative and end of life care, if not used often by a professional, can appear complicated to understand and time consuming to do.

• We need to move from asking "what is the matter" with people to "what matters to them".

• There are too many ways to source End of life care and equipment.

• There is inconsistent use of the Systm1 patient database across the system and the use of patient and family facing innovative digital technology is limited.

• There is differing use of "advance care planning" and "treatment escalation planning" documentation which can lead to uninformed/poor decision making.

• Specialist palliative and end of life care services in some areas remain at arm's length to Primary Care Networks and require better integration.

• Not all of the population have access to 24-hour community nursing services.

• There is a need for an end of life rapid response service and unified access to/ and provision of Fast Track Continuing Health Care.

• There remains evidence of some organisational/workforce risk aversion to meeting patient specific wishes e.g. to die at home in a homely environment i.e. on the settee.

• The Salisbury Hospice financial model is different leading to inequitable investment in infrastructure such as Systm1 and services i.e. Hospice@Home. Differing models of hospice care also bring strength i.e. Salisbury is a NHS hospice with affiliations to the Acute Trust unlike the other two.

• Prospect Hospice does not currently adhere to Agenda for Change unlike the other two hospices and NHS providers across BSW. Recruitment, particular to the Swindon population, is challenging due to competition with local providers i.e. GWH, SELeCT End of Life team.

- Where some hospice services are different and aligned to meet specific local need this should be viewed as positive, fitting with the concept of "Place" based services.

- There are inconsistencies and gaps in end of life/Hospice@Home type home care.

- People living in the Chew Valley area are referred to specialist services out of BSW.

- Although beginning to be addressed there is no single unified approach to palliative and end of life education and research for professionals and/or the public.

- With multiple providers and competing pressures the system lacks a "one workforce" approach to end of life care service provision.

- As evidenced through the collaborative work of providers and commissioners during Covid 19 there is an opportunity to create a BSW wide "compassionate community" that embraces the role of the community and volunteers in supporting the co-creation and co-delivery of palliative and end of life care.

Recommendations

Recommendations in detail

Introduction

Adopting an evidence based and population health approach, the BaNES, Swindon and Wiltshire (BSW) Palliative and End of Life Care Oversight Group (which has over 20 providers, local authority and CCG members) was formed in September 2020. The objective was to provide a strategic forum where the palliative and end of life care needs of the 940,000 people living in the BSW CCG/ICS area could be mapped against the services being provided (commissioned and charitable) to meet these needs and national and local best practice, research, guidance and policy.

The intent being that this would give an understanding of the extent to which people's palliative and end of life care needs were being met and positive outcomes delivered and any gaps in service provision identified and recommendations made to address these. These recommendations are for BSW CCG/ICS wide changes to provide an equitable, evidence based and whole system approach to the care a person and their family require at the end of life (see Appendix 3 for the Terms of Reference).

This document outlines the high level recommendations and suggested governance framework that, if implemented with the required resourcing, the group believes will add value and provide the best end of life care outcomes for the population of the BSW CCG/ICS regardless of demographic profile, diagnosis or place of care.

The context: The oversight group have adopted the six ambitions identified by the National Palliative and End of Life Care Partnership as the cornerstones of any future developments (see next page).

It is the consensus of the group that, building on current good practice, the six ambitions can be further taken forward by the implementation of the recommendations set out below and a positive first step made in reducing inequity and aligning end of life care provision.

Six ambitions to bring that vision about

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

National Palliative and
End of Life Care Partnership
www.endoflifecareambitions.org.uk

1: Each person is seen as an individual
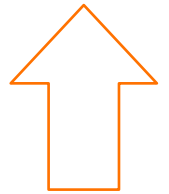
2: Each person gets fair access to care

3: Maximising comfort and wellbeing

4: Care is coordinated

5: All staff are prepared to care

6: Each community is prepared to help

Recommendation 1:
Creation of a "Palliative and End of Life Care Alliance"

1

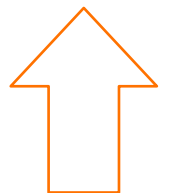It is the recommendation of the group that, following the meeting of the Population Health Board, the current Oversight Group establishes itself as the BSW Palliative and End of Life Care Alliance with accountability for ensuring equitable, outcomes driven and cost efficient palliative and end of life care with delegated budgetary authority.

It is important to stress that the strategic work and recommendations of this group would cut across all of the new NHSE boundaries from PCN to neighbourhood to place to system.

The context: Systems should ensure that each place has appropriate resources, autonomy and decision-making capabilities to discharge these roles effectively, within a clear but flexible accountability framework that enables collaboration around funding and financial accountability, commissioning and risk management. This could include places taking on delegated budgets.

ICSs also need to be able to ensure collectively that they are addressing the right priorities for their residents and using their collective resources wisely (Integrating care, NHSE (2021). They will need to work together with partners to determine:

• distribution of financial resources to places and sectors that is targeted at areas of greatest need and tackling inequalities;

• improvement and transformation resource that can be used flexibly to address system priorities;

• operational delivery arrangements that are based on collective accountability between partners;

• workforce planning, commissioning and development to ensure that our people and teams are supported and able to lead fulfilling and balanced lives;

• emergency planning and response to join up action at times of greatest need; and

• the use of digital and data to drive system working and improved outcomes.

The benefit: This "Alliance" of commissioners and providers, with delegated authority from the ICS, will be a delivery vehicle and accountable for ensuring the provision of evidence based, high quality and cost effective palliative and end of life care across the BSW ICS. By reviewing local place based trends and data, listening to the needs of the populace and aligning with National guidance and best practice it will be accountable for the allocation, disinvestment and reinvestment of resources to ensure positive outcomes for people requiring palliative and end of life care across the whole of BSW.

Led by the three hospices and using the expertise of both specialist providers and commissioners (health and social care) to the fullest potential in one collaborative format, this group will identify and remove areas of duplication with associated identification of areas of financial inefficiency and address any inequities in palliative and end of life care provision across the system.

Targets: Based on local population health data and national drivers the "Alliance" will set and monitor targets/KOOs for the improvement of care. Suggested targets may include:

• Earlier recognition of patients in the last 1000 days, using phase of illness to support better understanding what service might be needed when.

• A reduction in avoidable hospital admissions for patients with palliative and end of life needs.

• Adoption of a shared care record i.e. ReSPECT.

• Adopting or creating a tool to measure an increase in person centred care no matter what the setting.

• Increased co-production of "place based" services with the local community.

• Standardised specialist palliative and end of life care services e.g. inpatient bed capacity commissioned based on population needs data.

• System wide measurement of qualitative data i.e. patient and family feedback through use of a single agreed survey applied across all providers in the system.

• We will develop a tool that allows us to measure the increase in shared decision making i.e. evidencing how patients feel more involved in decisions around their care.

There are several examples where an Alliance as detailed above could achieve these targets by reviewing, enhancing or introducing both general and specialist services to ensure equitable and cost efficient palliative and end of life care across the ICS that adds value e.g.

• A unified model of 7-day specialist Hospice@Home care that includes seamless Continuing Health Care funded care for the hospice providers.

• An evidence based, validated tool for collating patient and family feedback on the care provided.

- A BSW wide review of the palliative and end of life care inpatient bed provision for symptom control, specialist palliative and end of life care and an alternative preferred place of death where home or hospital is not suitable.

- An end of life rapid response service aligned with the current providers of out of hours care.

- A centralised coordination centre (see recommendation 6).

- Renewed focus on palliative and end of life care on the "virtual ward" work stream.

Recommendation 2:
Adopting "What matters to you?"

BSW CCG/ICS should endorse and resource a system wide campaign to encourage all health and social care staff to move away from asking "What is the matter with you?" to a mind-set of "What matters to you?" when working with both patients and their families and carers in the last 1000 days. This change is being endorsed by both NHSE and national bodies such as Macmillan, HospiceUK and the Cicely Saunders Institute in London.

The benefit: Aligned to the NHS Long Term Plan (2019) it drives personalised care to ensure we get a better understanding of what matters to patients and thus develop services with them at the centre. This approach changes a professional's behaviour when working with patients and their families in the last 1000 days. It will support the continued development of high quality compassionate support, care or treatment focused around what people really need and want and support the Advance Care Plan (ACP) discussions.

2

Recommendation 3:

Consistent identification of "end of life" care need.

3

The Oversight group recommends that the new "Alliance" investigates the opportunities and benefits of reinvigorating use of GSF in primary care and adopting the principles of GSF improving coordination of care and outcomes for patients and reviewing the applicability of the NHSE EARLY tool and the RUH "CHAT bundle" (see Appendix 4) to support both early identification of people in the last year of life, improve shared decision making and link to personalised care planning (see Recommendation 4).

The benefit: The Gold Standards Framework (GSF) is an evidence based systematic approach to formalising best practice through improving the organisation and coordination of care for all people with any condition in any setting in the final year of life.

The aims of GSF are to improve the quality of care for all people nearing the end of life – in line with their preferences:

1. Improve the coordination and collaboration of teams supporting them

2. Improve outcomes for people enabling more to live and die where they choose, reduced hospitalisation and improved cost effectiveness

Improving patient outcomes through recommending changes to/or the addition of new services will be targeted at improvements in the care delivered in four key stages in a person's illness trajectory over the last 1000 days of their life (see Appendix 1) i.e. stable, unstable, deteriorating and dying (see table on following page) and across the three main disease trajectories (Appendix 2). It will be important to the work going forward that specialist and generalist end of life care provision is defined, mapped and aligned to each phase as described in the Outcomes Assessment and Complexity Collaborative suite of measures below (see table on following page).

Phase	This is the current phase if...	This phase ends when...
Stable	Patient's problems and symptoms are adequately controlled by established plan of care* and further interventions to maintain symptom control and quality of live have been planned and family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.
Unstable	An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care and/or the patient experiences a rapid increase in the severity of a current problem and/or family/ carers circumstances change suddenly impacting on patient care.	The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crises has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or death is likely within days (i.e. patient is now dying).
Deteriorating	The care plan is addressing anticipated needs, but requires periodic review, because the patient's overall functional status is declining and the patient experiences a gradual worsening of existing problem(s) and/or the patient experiences a new, but anticipated, problem and/ or the family/carer experience gradual worsening distress that impacts on the patient care.	Patient condition plateaus (i.e. patient is now stable) or and urgent change in the care plan or emergency treatment and/or family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) or death is likely within days (i.e. patient is now dying).
Dying	Dying: death is likely within days.	Patient dies or patient condition changes and death is no longer likely within days (i.e. patient is now stable and/or deteriorating).
Deceased	The patient has died; bereavement support provided to family/carers is documented in the deceased patient's clinical record.	Case is closed.

Recommendation 4:

Personalised care planning and the use of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT V3) Template

Although the work has begun, it is the recommendation of the group that BSW CCG/ICS adopt the Resuscitation Council UK validated ReSPECT V3 documentation across all care settings and localities.

The benefit: ReSPECT can be for anyone, of any age, who wants to record their care and treatment preferences. ReSPECT has the potential of enabling a larger cohort of patients to be engaged in 'planning ahead' discussions at an earlier stage, including those who are living with long term conditions. This is a more positive message for patients, staff and families and may enhance support.

A standardised approach to emergency / ACP to support an integrated and holistic way of planning of care. This will facilitate the movement of patients across county boundaries, the country and between Providers.

This single action could support person centred care and ensure the appropriated clinical interventions when they are needed regardless of the setting and that avoidable hospital admissions were reduced.

Resource required: This will require a funded programme of education and training.

4

Recommendation 5:

Improved use of data and digital technology including improved access to and use of Systm1

5

With the launch of the National dashboard for end of life scheduled for release in April 2021 it is important that the new "Alliance" group ensures that the BSW ICS palliative and end of life care work streams and activities are aligned to this work as well as the regional work led by NHSE leads (Kath Rooksby and Saskia Dorman).

The Alliance will ensure that there is systematic measurement of agreed local data and patient outcomes and the creation of a BSW wide KPI dashboard allowing for benchmarking and the development of action plans to address unmet demand, emerging need, inequities or poor impact on both people and the system.

Recognising the impact of Graphnet in supporting interoperability between IT systems, the use of Systm1 should be strengthened so that all relevant providers

and partners (including in the community) have access to and training in the use of the Systm1 patient database. This would support the development of a common End of Life template across the 3 hospices and community and enable faster referral processes and better sharing of key palliative and end of life information about patients across many BSW wide healthcare settings. As required above, reporting would be aligned and consistent.

Linking with the existing BSW IT group, a subgroup of the Oversight Group/Alliance should be set up to review the opportunities to use digital technology to enhance the care of both patients and their families at the end of life i.e. use of an Integrated Care Record (e.g. Graphnet), Virtual Reality, podcasts, Apps, websites, patient owned notes, "coordinate my care" etc.

The benefits: Friction free referrals, access to "live" information on patients across all parts of the system and consistent reporting of outcomes across the ICS to measure the impact of care and support.

Resource required: When the key deliverables are articulated and agreed this will require a funded programme of ICT support, education and training.

A key priority is that all three hospices, as a minimum, should have access to Systm1.

A second priority should be that we create a minimum data set across the three acute providers.

Recommendation 6:
A Single Point of Contact and Coordination

There will be a single point of contact and coordination for palliative and end of life care across the BSW CCG/ICS aligned to 111 and linked to local hospice clinical coordination centres who understand their locality.

The benefits: Members of the public and professionals will no longer have to contact different centres, organisations or coordination hubs for advice, equipment or access to services primarily out of hours. It is mainly for use:

• When the GP surgery is closed.

• As an alternative to ringing 111.

• If someone is finding it difficult to get help during the day and needs some advice.

The new single point of coordination will be a dedicated 24/7 telephone service for people who may be in their last year of life and for their families. The advice provided by the team running the helpline and the services they coordinate will mean that a significantly higher proportion of people will be able to die in the place of their choosing and that every patient should receive the right care, in the right place, at the right time.

Care will be joined up, seamless and by removing duplicative services it will be more cost effective. The aspiration is to replicate the work of the "Gold Line" developed in Airedale (see references) and investigate the impact of "Coordinate my Care" in London.

Resource required: To establish this is going to require a dedicated project team and associated funding to investigate the best model (e.g. Gold Line) and systems required to deliver this across the region with the links to 111 and local hospice specialist services and coordination centres. Recommendations 1-5 need to be in place to support this ambition.

6

Recommendation 7:
A "Compassionate Community" Approach

7

Using the resources and national tools available and the work completed to date by the commissioners, providers and third sector across BSW including 3SG, Virgin Care, the local authorities and the three hospices, the Oversight Group/Alliance will investigate and make recommendations on how BSW ICS can become a "compassionate community".

The benefits: In a "Compassionate Community", the needs of all the inhabitants of that community are recognized and met, the well-being of the entire community is a priority, and all people and living things are treated with respect.

More simply, in a Compassionate Community, people are motivated by compassion to take responsibility for and care for each other. A community where compassion is fully alive is a thriving, resilient community whose members are moved by empathy to take compassionate action, are able to confront crises with innovative solutions, are confident in

navigating changes in the economy and the environment, and are resilient enough to bounce back readily from natural and man-made disasters (What is a Compassionate Community? (charterforcompassion.org)

Communities will be inspired and motivated to support one another working hand in glove with local providers, co-creating services and co-delivering aspects of care and the use of volunteers across the system will be widespread.

Recommendation 8:

Adopting a BSW System-Wide Approach to Workforce Planning and End of Life Care Education and Research

8

The benefits: System workforce planning for palliative and end of life care (including education, training and research) would be an innovative approach that enabled the planning of appropriate skill mix combinations to deliver a coherent, personalised service for the local population requiring both palliative and end of life care. The aim is to develop a workforce that can provide health and care on a whole system basis rather than in silos.

System workforce planning enables workforce risks, challenges and priorities in delivering effective integrated care to be addressed at an early stage. Developing a robust system workforce plan can also help to identify priorities for investment in workforce development, which supports the implementation of the vision for services.

Resource required: This work would be led by the current BSW CCG education governance structures but influenced by the work and recommendations of the Oversight Group/Alliance who can help identify the need for both specialist and generalist resource, education and training.

Next steps

The creation of the BSW ICS creates an exciting opportunity to collaboratively build on the existing models of palliative and end of life care in place across the system and deliver an equitable and financially sustainable model of care that truly makes a difference in the lives of people living in the area.

We have the right partners wanting to work together who want to be bold, make the changes that will deliver the right outcomes for the populace and meet the needs of an integrated care system whilst delivering care at a place level.

If we can go live on the 1st April a mobilisation/work plan detailing the key recommendations, targets, timelines, objectives, outcomes and resource implications for each will be drawn up and articulated with regular feedback provided to the Board on progress.

With the endorsement of the Population Health Board, the Palliative and End of Life Care Oversight Group will continue to meet as an "Alliance" and extend both its membership, accountability and links into the other areas described i.e. education, workforce planning, digital transformation etc.

With the endorsement of the Board and given the authority, continued support and with the right leadership we will deliver health and social care services that meet both the current and future palliative and end of life needs of the population.

Appendices and references

Appendix 1
Definitions

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. *National Palliative and End of Life Care Partnership (2018)* Ambitions for palliative and end of life

The last 1000 days: Leading up to and during end of life, a person will require coordinated palliative and end of life care which in the BSW CCG area will be provided by a range of specialist and generalist services/professionals working in partnership aiming to provide personalised support to both the person who is ill and those close to them. This is particularly important during the last 1000 days of someone's life https://www.last1000days.com/

Palliative care: The World Health Organisation defines palliative care as 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 and end of life care need in BSW: The group has agreed that approximately 0.68% of the BSW population require palliative and end of life care (Marie Curie, 2015 – End of Life Care across the UK | Marie Curie Atlas). This equates to 6351 people in the BSW area and assumes that there must be the care to support a person's family and their carers.

The "surprise question": "Would you be surprised if this person were to die in the next 12 months?" If the answer is "no" what support do they need not to provide positive outcomes for their continued care?
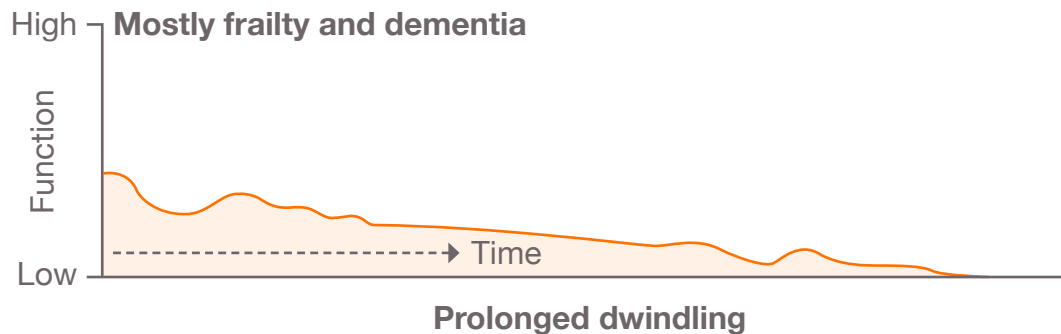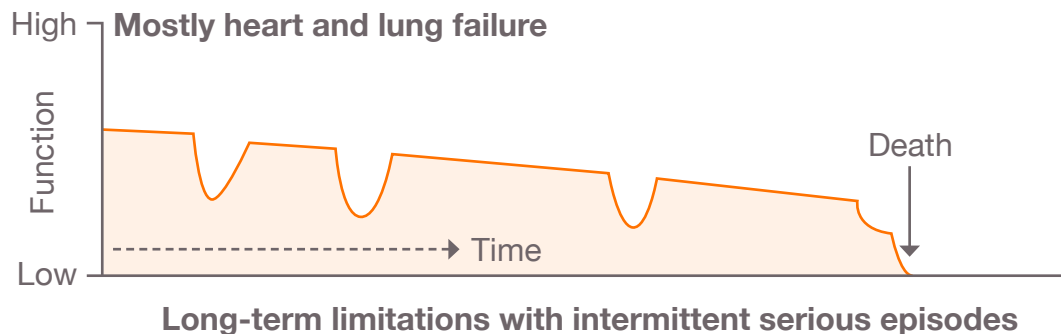
"What matters to you?": An approach that encourages professionals to move their conversation focus from "what's the matter with you?" to "what matters to you?"

General and Specialist end of life care: Many healthcare professionals provide palliative care as part of their jobs. An example is the care you get from your GP or community nurses. Some people need additional specialist palliative care. This may be provided by consultants trained in palliative medicine, specialist palliative care nurses or care assistants, or specialist occupational therapists or physiotherapists.

Appendix 2

The disease trajectories of people supported in palliative and end of life care services

Mostly cancer

High

Function

Low — — — — — — — — — — — → Time

Death

Short Period of evident decline

Mostly heart and lung failure

High

Function

Low — — — — — — — — — — → Time

Death

Long-term limitations with intermittent serious episodes

Mostly frailty and dementia

High

Function

Low — — — — — — — — — — → Time

Prolonged dwindling
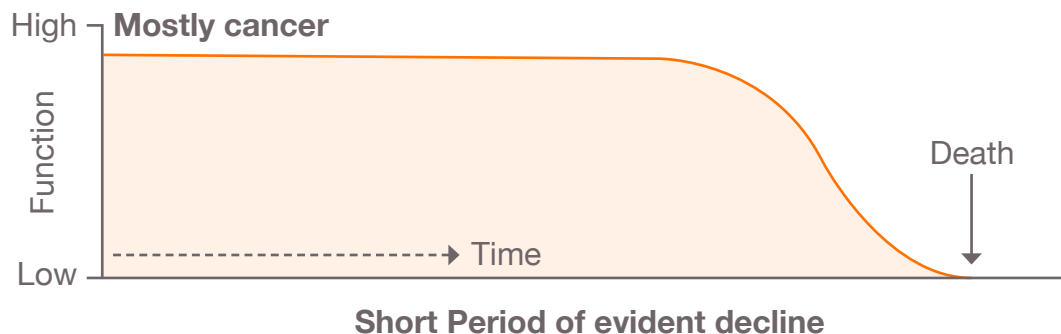
Appendix 3
BSW Palliative and End of Life Oversight Group
Terms of Reference (DRAFT)

Definitions:

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.

National Palliative and End of Life Care Partnership (2018)

Leading up to and during end of life, a person will require coordinated palliative and end of life care which in the BSW CCG area will be provided by a range of specialist and generalist services/professionals working in partnership aiming to provide personalised support to both the person who is ill and those close to them. This is particularly important during the last 1000 days of someone's life
https://www.last1000days.com/

Palliative care: The World Health Organisation defines palliative care as 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.

1. Purpose

The BSW End of Life Oversight Group will support our ability to meet the needs of the local population by providing strategic oversight. Integral to this will be to ensure our population receive safe high-quality care that is evidence based and considers relevant national guidance. The Group will operate as a collective senior leadership forum for BSW, involving all statutory, voluntary and charitable partners.

In this context the Group will:

- Set the BSW system ambitions for palliative and end of life care with associated SMART objectives and outcomes

- Review current commissioned arrangements across BSW with the aim to collectively understand the level of variation of care offer

- Review a range of health population data to collectively understand future demands and capacity requirements and make recommendations

- Influence equal access to care at the end of life

- Link in with the System Capacity work stream to support future capacity needs including training provision

- Share learning and good practice across BSW to deliver transformation

- Scope the opportunities for system working and in doing so provide clarity regarding specialist palliative care and where greater integration is possible

- Agree Digital technology and care record sharing platforms

2. Behaviours and principles

It is recognised that working in a true partnership and collaborative way across all partner organisations and services will present challenges both practically in breaking down barriers to change (i.e. existing models and system constraints) and in how we work together – building parity of esteem across all partner organisations.

The group will be expected to apply and model collaborative and problem-solving behaviours and work in ways that enable us to deliver maximum benefits to our populations and our patients. This means adhering to our agreed principles and ways of working which have been updated considering the recent Covid19 work:

Design Principle	Notes
We work as one system	• We operate as one system with parity of esteem for all partners to plan and deliver high quality, value for money and health & care for our population in BSW • Operating as one system, we approach social care & wellbeing, mental and physical health with equal importance, recognising the interdependency between them • Subsidiarity, transparency and distributed leadership are embedded in how we work
Prevention first, and recognition of the wider determinants of health	• Our professionals focus on health & wellbeing; this starts with prevention • We focus on the wider determinants of health in the way that we design and deliver services with partners • Our approach is asset and strength-based with the capacity and capabilities of individuals, neighbourhoods and communities at the centre of what we do
Care designed around individuals	• Health & Care services are designed with and around individuals and their needs: right service, right place, right time • Teams strive for continual improvement in model of care • Only essential staff are based in healthcare facilities

Design Principle	Notes
Home is best	• Assessments at home • Virtual wards
Digital by default	• Health & Wellbeing apps • First step to access health services: NHS 111; • Assisted technology [x-ref 4]; • Referral opportunity discussions on consultant connect / Video • Virtual emergency care, inpatient and outpatient care
Flexible workforce	• Workforce operates in multidisciplinary teams beyond organisational boundaries • Co-located teams & community hubs • Community and voluntary sectors workforce as a vital part of BSW team
7-day provision	• Hours to be optimised to enable timely decision-making and support

3. Membership

Name	Job Title	Organisation
Amanda du Cros	Deputy Director, Community & Transformation (Acting)	BSW ICS
Bianca McClounan	Quality Support Manager	BSW ICS
Carol Gibson	Quality Lead - EOLC	BSW ICS
Caroline Davies	Associate Director of Nursing	SCHS and GWH PCN
Carolyn Bell	Director of Services	Prospect Hospice
Charlotte Forsyth	Medical Director	GWH
Clare Blakeley	Community Service Manager, West	WH&C
David Jobbins	Interim Deputy Director for Planning	CSU
Ed Presswood	Palliative Care Consultant	RUH Palliative Consultant
Emma Frampton	Medical Director	Dorothy House
Emma Legg	Director, Adult Care Operations	Wiltshire Council
Fiona Castle	Chief Officer Community Pharmacy Swindon and Wiltshire	CPSW

3. Membership
Continued

Name	Job Title	Organisation
Gill May	Director of Nursing & Quality	BSW ICS
Hannah Massey	Service Redesign Lead	BSW ICS
Hazel Dunnett	Leadership Board	Healthwatch Wiltshire
Heather Kahler	Head of Operations – Community Teams and CTPLD	WH&C
Helen Brown	End of Life Clinical Nurse Specialist	GWH
Helen Meehan	Lead Nurse, Palliative and EoLC	RUH
Irene Watkins	Chief Executive	Prospect Hospice
Jacky Cadden	PA to Gill May	BSW ICS
Janet Cottrell	CICT Matron Swindon Community Health Services	GWH
Janet Dabbs	CEO	Age UK BaNES
Janette Bourne	Director	CRUSE Bereavement
Jason Darby	Deputy Nurse Practitioner Lead	Medvivo

3. Membership
Continued

Name	Job Title	Organisation
Jody Smalley	Quality Lead	BSW ICS
Judy Dyos	Director of Nursing	SFT
Judy Walker	Chief Executive	Carer Support Wiltshire
Julie Marshman	Chief Nurse	GWH
Karen Brown	Lead for Palliative and End of Life Care	GWH
Karen Drake	Matron for Specialist Palliative Care	SFT
Kath Rooksby	System Support Lead, Strategy & Transformation, South West	NHSE/I
Lisa Cheek	Director of Nursing & Midwifery	RUH
Lisa Cronan	Head of Quality and Nursing	Virgin Care
Lisa Hodgson	Chief Operating Officer	WH&C
Lynn Cook	Clinical Lead Access to Care & Response	Medvivo
Lynn Organ	Clinical Lead	Medvivo

3. Membership
Continued

Name	Job Title	Organisation
Mark Luciani	GP & Clinical Lead for Ageing Well, Frailty, Dementia & End-of-Life	BSW ICS
Nelly Targett	Clinical Lead for Bath District Nursing Service	Virgin Care
Nicola Hazel	Clinical Director	AWP
Nikki Barnett	Swindon Community Health Service Matron Community Nursing	GWH
Pippa Baker	Clinical Lead	Salisbury Hospice
Richard Bowyer	Nurse Practitioner	Medvivo
Sandra Elmer	Area Chair for Wiltshire and Bath	CRUSE Bereavement
Sara Quarrie	Director of Quality, Professions and Workforce	WHC
Sarah Chapman	Fundraiser	CRUSE Bereavement
Sheila Popert	Medical Director	Prospect Hospice
Tania Elias	Consultant Geriatrician, TEP Lead	GWH
Wayne de Leeuw	Chief Executive	Dorothy House

Chairing of Group

CEOs of hospices and Lead Palliative Consultant (SFT) (rotate/lead/share).

Quorum

The meeting will be quorate if eight of the above organisations are present. The nominated leads from all of the partners are expected to attend the Group meetings or to be represented by a deputy with authority to commit to decisions.

Accountability & Reporting Arrangements

This Group does not constitute a statutory Board in its own right but reports to the BSW Population Health Group and through its members to all relevant organisations through their own internal governance structures.

Frequency

Meetings will routinely be held monthly initially. The meeting schedule will be amended as and when needed to provide the required pace.

Administrative Arrangements

The Oversight Group will be supported by the Director of Nursing and Quality. The Group will be supported administratively by the BSW CCG.

The agenda will be set by the Chair in conjunction with group members. Papers will be collated and distributed at least 5 working days before the meeting.

Monitoring Effectiveness & Review

This is a new forum; therefore, the TOR will be initially reviewed after three meetings.
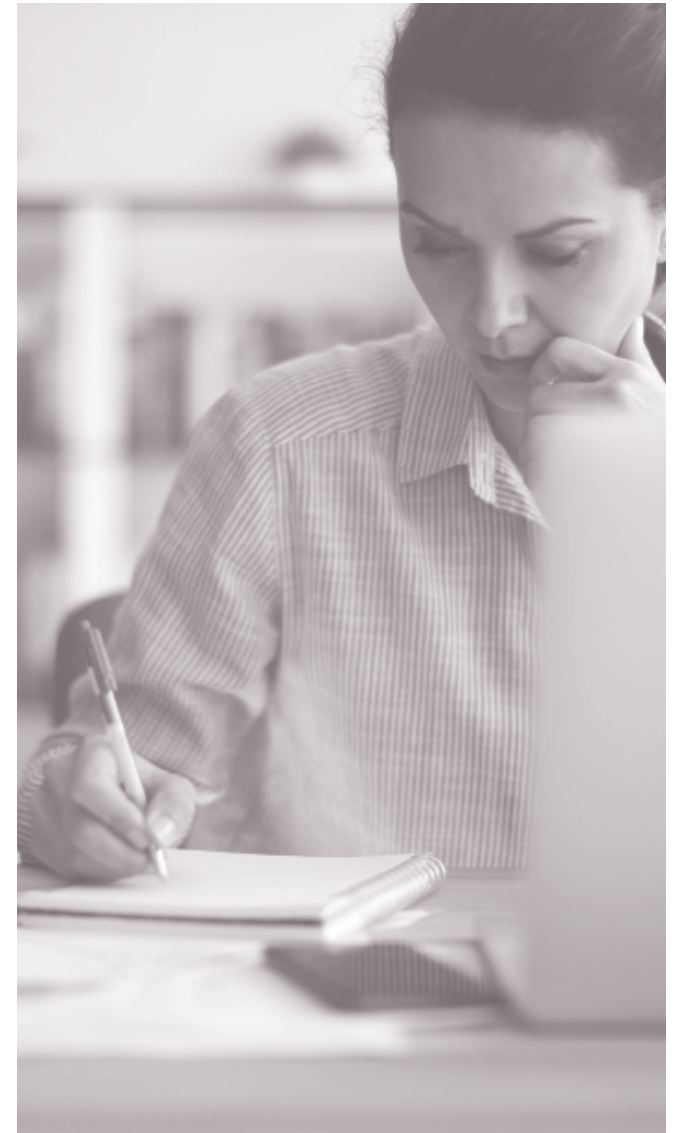
Appendix 4
RUH Community CHAT Bundle

For information on the Conversation Project:

- See the RUH website
  www.ruh.nhs.uk/For_Clinicians
- The Conversation Project CHAT Bundle and resources have been developed by the RUH Palliative Care Team

Conversation Project Community Bundle v1, February 2019
Rachel Davis and Helen Meehan

Consider	Have	Advise	Transfer
Consider whether the patient has an uncertain prognosis or is nearing end of life? Consider: • Rockwood Frailty Assessment • SPICT - Supportive and Palliative Care Indicator Tool • The GSF - Gold Standard Framework Prognostic Indicator Guidance • The 'surprise question' • The patient's narrative • Information from family or carer • Discuss at MDT and GSF meetings	Have conversations with the patient & their family to support Advance Care Planning (ACP): • Think about the environment and your approach • Check their understanding • Acknowledge uncertainty of recovery • Have honest conversations • Listen compassionately to concerns, wishes and preferences • Include discussion of TEP • Offer 'Planning ahead' leaflet and/or 'My wishes'	Advise the MDT following ACP conversations: • Share information on the patient's wishes & preferences • Complete TEP / ReSPECT • Include information from ACP discussions in the plan of care • Document ACP conversations in the MDT records - System 1 and Summary Care Record with additional information • Keep information with the patient, ensure family or carer is aware	Advise the MDT following ACP conversations: • Share information on the patient's wishes & preferences • Complete TEP / ReSPECT • Include information from ACP discussions in the plan of care • Document ACP conversations in the MDT records - System 1 and Summary Care Record with additional information • Keep information with the patient, ensure family or carer is aware

References and further reading

Ambitions for Palliative and End of Life Care (2015-2020) Ambitions for Palliative and End of Life Care (endoflifecareambitions.org.uk)

Atlas of variation for palliative and end of life care in England (2017): Atlas of variation for palliative and end of life care in England

Gold Standards Framework Welcome to Gold Standards Framework

Gold Line: The Gold Line | Airedale NHS Foundation Trust (airedale-trust.nhs.uk)

Gov.UK: Integration and innovation: working together to improve health and social care for all (HTML version) - GOV.UK (www.gov.uk)

NHS England (2018): Enhancing the Quality of life for people living with long term conditions PowerPoint Presentation (psnc.org.uk)

NHS England (2021): Integrating care: NHS England » Integrating care: Next steps to building strong and effective integrated care systems across England

NHS England: NHS England » Personalised end of life care

NHS England. Transforming end of life care in hospitals: transforming-end-of-life-care-acute-hospitals.pdf (england.nhs.uk)

NHS Long Term Plan (2019) NHS Long Term Plan

OACC https://www.kcl.ac.uk/cicelysaunders/attachments/studies-oacc-brief-introduction-booklet.pdf

https://www.england.nhs.uk/wp-content/uploads/2014/10/pall-care-fund-new-appr-fin.pdf

Office for National Statistics Deaths registered weekly in England and Wales, provisional - Office for National Statistics (ons.gov.uk)

Office for National Statistics (2019): Population projections - Office for National Statistics

Public Health England. Older people's hospital admissions in the last year of life (2020): Older people's hospital admissions in the last year of life - GOV.UK (www.gov.uk)

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT): ReSPECT | Resuscitation Council UK

What matters to you: NHS England » What matters to a person is key to their care

What Matters to You Conversations: Home | What matters to me (whatmattersconversations.org)

Prepared for the
BSW Palliative and End of Life Care Oversight Group
with recommendations for 2021 and beyond

March 2021