

A Proposed New System for Health and Social Services

End of Life Care

Scheme-level Outline Business Case (OBC)

Version 2.0

13 June 2012

This document

Purpose of the Outline Business Case

The Green Paper, 'Caring for each other, caring for ourselves', was produced in May 2011. Following public consultation, eight service areas were selected for early service development in 2012 – 2015. Sustaining Acute Services was identified as being 'Business As Usual', and was removed from the OBC list, therefore, seven OBCs have been produced.

Each proposed service change has been developed robustly, with full involvement from stakeholders. Working groups have used an Outline Business Case (OBC) template when discussing and developing the service changes, in order to ensure that all relevant aspects have been considered. The template incorporates guidelines from the UK Government's website on Business Cases as well as the template on the Treasury & Resources website.

Once approved, each OBC will be progressed to Full Business Case (FBC) – this is anticipated to be by Autumn 2012. The FBC will provide detail on the service change, including detailed timescales and action plans for implementation. Service implementation commences once the FBC has been approved and fund secured from the Medium Term Financial Plan, which is due to be agreed in late Autumn 2012.

Structure of this document

This Outline Business Case presents the elements of service change that must be considered in order for plans to be robust, stakeholders to be fully engaged, and risks to be managed effectively.

The case for change for End of Life services is presented, building from the case for change in the Green Paper. The linkage with the HSSD strategic principles and with the relevant services' strategies is clearly identified. The outcome of the Green Paper consultation, and in particular the views of stakeholders received during the consultation period have been presented where applicable, in recognition of the importance of these views.

The OBC then outlines the proposed service change, and the elements thereof, for example, the impact on workforce, on costs and on service delivery / quality. Indicative costs and benefits are outlined. Some rounding adjustments have been made. All costs are presented at prices relevant to the each year, to ensure that the full cost of the proposals is understood. Costs and benefits which are quantitative and qualitative, short and long term and relevant to patients / service users / carers / families, clinicians and the public have been considered.

Implementation considerations are then presented, including stakeholder engagement and communication, key risks and issues for both the implementation period and for the full service delivery.

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Revision history

Version	Date	Author	Description
0.00	01.11.11	KPMG	Template
0.10	30.11.11	KPMG	Generic updates
0.20	19.03.12	Honor Blain	Update
1.0	20.05.12	Rachel Williams	Final review and revision
1.1	12.06.12	Honor Blain / Rose Naylor	SRO review and sign off
2.0	13.06.12	Rachel Williams	Finalisation

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Abbreviations and Definitions

Abbreviation	Definition
COPD	Chronic Obstructive Pulmonary Disease
DNAR/CPR	Do not attempt resuscitation/Cardio Pulmonary Resuscitation
END OF LIFE	End of Life
ELCP	End of Life Care Pathway
FBC	Full Business Case
FNHC	Family Nursing & Home Care (Jersey) Inc
FTE	Full time equivalent employee
GSF	Gold Standards Framework
HSSD	Health And Social Services Department
JGH	Jersey General Hospital
LCP	Liverpool Care Pathway
MDT	Multi Disciplinary Team
MTFP	Medium Term Financial Plan
OBC	Outline Business Case
QOF	Quality Outcomes Framework
RN	Registered Nurse

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1 Executive Summary

In common with jurisdictions and countries across the world, Jersey faces substantial current challenges in ensuring the availability of high quality health and social care for its citizens within a financially affordable sum. The KPMG technical document and the Green Paper, both published in May 2011, demonstrated that health and social care services in Jersey are at a crossroads. Existing capacity is due to be exceeded in some services in the near future, the elderly population is rising disproportionately and almost 60% of the medical workforce is due to retire in the next 10 years.

In early 2011 the vision for health and social care in Jersey was agreed. This clearly stated that services must be safe, sustainable and affordable.

The public consultation on the future of health and social services in Jersey concluded on 22 August 2011. Since that time, a Working Group has been considering the service changes that are required urgently; this Outline Business Case is a result of that process.

1.1 Strategic Context

Available UK statistics indicate that 50% of patients with cancer and 75% of patients with other life limiting illnesses die in hospital. But 65% of the UK population have indicated their preference would be to die at home.

The Department of Health UK End of Life Strategy has significantly improved the delivery of End of Life care across England, Scotland, Wales and Northern Ireland. ¹

The strategy developed following similar initiatives across Scotland, Wales, Ireland highlighted that a community-based model for End of Life care has can be more cost effective and appropriate than hospital care. Work in England is supporting the move to strengthening the community model of service provision with an emphasis on living until the End of Life.²

Subsequent service development requirements have been reported by the Royal College of Physicians, General Practitioners and Registered Nurses with all groups reinforcing the need for all patients experiencing symptoms in connection with End of Life to have a good death with palliative care management of symptoms, physiological, social and spiritual support.³

1.2 The Case for Change

Jersey has an average total of 765 adult deaths per annum. 675 deaths are associated with cancer and/or other life limiting illnesses. This is predicted to rise by 26% by 2029 taking the total number of deaths per annum to circa 845.

There are approximately 2-3 child deaths per annum with 20 children at any one time having life limiting conditions.

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¹ UK Department of Health, End of Life Care Strategy: Quality markers and measures for End of Life care (DH 2009) 2 UK Department of Health, End of Life Care Strategy: Quality markers and measures for End of Life care (DH 2009)

³Royal College of Physicians, End of Life Strategy, Scotland (2009)

50% of current services for End of Life are delivered from hospital, within a medical model of care. This is not the most appropriate setting to manage this group of patients, and is also not sustainable as the ageing population increases; by 2029 the number of deaths is projected to increase by 26%. In the current service model, this would increase the demand for acute beds from 14,145 in 2010 to 17,823 by 2029.

Only 10% of patients at end of life are able to die within the independently funded Hospice. Access to these services is limited to cancer and motor neurone patients only.

The remaining 40% of patients experience end of life within their own homes, or within residential or nursing home settings. The majority of care is delivered by non-registered staff supported by a grant-aided Third Sector community provider, a GP or the Hospice Community teams.

Marie Curie estimate that 62% of people prefer to die in a place of their choice and not a hospital environment. 4

Conversations with families after death and from formal complaints demonstrate the need to change. The issues raised often relate to relatives left shocked at what they see as a sudden loss of a loved one, when there was actually a clear decline but the difficult conversation had not taken place, issues relating to symptom control and the poor environment in which their loved one died, often in a ward bay surrounded by other patients.

In 2011, services were assessed using the standards of the Liverpool Care Pathway (not yet in use in JGH). The audit results mirrored the experience of families and carers in relation to a lack of communication with patients and families about the fact they are dying, inconsistent management of symptoms such as pain, nausea, agitation and breathlessness. The audit also identified that the number of acute beds days being utilised for End of Life Care patients is even higher than the figure published in the Technical Document which underpinned the Green Paper.

There is insufficient capacity and capability within the existing workforce to deliver End of Life care in community settings. Training in communication and how to have difficult conversation with patients and families is required, along with generalist skills in relation to End of Life care.

The lack of a clear agreed pathway means that the management of this group of patients can be inconsistent. In addition, outcomes are not consistently measured, which impedes commissioning and service development.

1.3 Service Objectives for End of Life Care

The End of Life service aims are to:

- Provide patient choice and equity
- Deliver quality services that are outcome focussed and measurable
- Improve the patient and family experience in relation to End of Life care
- Ensure long term sustainability within a model of community based care provision
- Reduce the number of episodes associated with End of Life within the hospital
- Reduce hospital length of stay associated with End of Life care

1.4 End of Life Services by 2015

4 Marie Curie Cancer Care, We know about end of life care, (2011)

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The new service model will provide appropriate choice for people in Jersey in relation to End of Life care. It will be based on principles of privacy, dignity and choice. It comprises:

- The Gold Standards Framework (GSF)
- The Liverpool Care Pathway (LCP)
- End of Life Register
- Specialist Palliative Care Team, providing training and support
- Multidisciplinary Team working
- Rapid Response, 24/7 Home Care team and Night Sitting
- Bereavement Support

A standardised and consistent approach will be implemented, following the **Gold Standards Framework (GSF)** and the **Liverpool Care Pathway (LCP)**. This will be supported by island-wide policies, guidelines and standards, to support strong governance. It will also enable Jersey to measure outcomes and compare with other centres. The LCP is used in more than 1,800 centres across the UK, and the Gold Standard framework is also in use across many PCTs across the UK.

An island-wide **register** will be developed, with the knowledge and consent of the patient. This will record the patient's preferred priorities of care and will provide information to any professional. The register will also provide linkage to appropriate support for patients and their families and will be support regular multidisciplinary team meetings.

The patient will remain under the care of their GP, with support from the **Specialist Palliative Care Team**. Generalist support when required will be provided by the **Multidisciplinary Community teams**.

The LCP will be adapted for Jersey. Care will be provided in a wider range of settings, including in the individual's home. This will be supported by a range of health and social care professionals, including a **Rapid Response**, **24/7 Home Care team and Night Sitting** service, which are outlined in the Intermediate Care OBC.

The Specialist Palliative Care Team will provide training and ongoing support to enhance the knowledge and skills base across professionals and training will be. The development of skills across a broad range of different professionals will lead to a change in behaviour and practice in relation to the "difficult conversation" and advanced treatment planning, using the Gold Standards Framework clinical prognostic indicator as a guide.

Bereavement support is an essential aspect of End of Life Care. Although not all people will want or need the support, clear signposting and equitable access to be eavement services will be required.

The new model of care is in the process of being developed, led by a Palliative Care Nurse Specialist and a Liverpool Care Pathway Nurse. These are both acute-based posts funded through a charity.

Benefits include:

Care available in a wide range of settings, including the individual's home

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- Supporting choice and control, through Advanced Care Planning, with discussion around the preferred priorities of care and advanced directives
- Holistic assessment of patients nearing End of Life to ascertain their needs and preferences
- More open discussion and advanced communication skills to support clinicians with the difficult conversations with patients and families - a recent audit of patients in JGH identified that 50% of patients were unaware they were dying, that 60% of patients were not given the opportunity to discuss their wishes in relation to their care, and that in the case of relatives and carers this was 75%
- Improved care planning, which supports integration and co-ordination and improves
 quality and experience. A recent audit identified that 50% of the patients had not
 had their treatment plans reviewed by a Multidisciplinary Team, and that in 90% of
 cases the GP was not informed that the patient was dying
- Reduced risk of crisis management
- Reduced prescribing
- Improved assessment of spiritual care needs
- · Reduction in acute admissions

1.4.1 The Financial Case

The recurrent additional revenue cost for this OBC by 2015 (at 2015 prices) is £826,000. Additional revenue costs are £399,000 in 2013, £806,000 in 2014 and £826,000 2015

Implementation costs total £133,000 over the period 2013-2015.

The service will require an additional 8.5 FTE.

The cost of overall investment is offset by an estimated annual cost containment of £3.1m (by 2015), which comprises (by Q2, 2015) acute bed day reductions, from caring for 50% of End of Life patients (173) in non-hospital settings. This is projected to save an average of 41 days per patient, with the released capacity being utilised for other acute patients.

Current acute costs of End of Life care are estimated to be c£6 million per annum. The new End of Life Care services aims to reduce the demand for acute bed days by 50% once all End of Life Care staffing, training and services are in place and supplemented by active Primary Care and community services, following the development of Intermediate Care and 24/7 services in community settings.

This will result in a cost containment of £3.1 million per annum from 2014 onwards.

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1.4.2 Implementation Actions and Timescales

ELCP PROJECT IMPLEMENTATION PLAN	2012	2013	2014	2015
Further audit, data collection and analysis of JGH length of stay				
Explore options for GP Macmillan funding				
Test the market for service providers				
External and internal stakeholder consultation				
Review timeline and scope for implementation				
Pharmacy scoping				
Training needs analysis				
Uniformed DNAR/CPR paper developed				
Advanced Care Planning Conference to raise awareness				
IT scoping				
QIF to include End of Life care				
Development of joint standards/policies and guidelines				
Scoping of children's respite and hospice provision				
Development of patient information and website				
Recruitment of Associate Specialist Palliative Care				
Recruitment of GP with Palliative Care Interest				
Work with Third Sector stakeholders to roll out GSFs				
Palliative Care Team and additional workforce in post				
Co-location of teams				
Advanced Communication training roll out - cross sector				
Liverpool Care Pathway implementation				
Specialist training commences				
Commission services to commence in 2014				<u>-</u>
Community End of Life Care services commence				

1.5 Stakeholders, risks, issues, dependencies and enablers

1.5.1 Stakeholders

This OBC has been developed by a working group consisting of Rose Naylor, HSSD's Chief Nurse (Senior Responsible Officer) and Honor Blain (OBC Lead) in collaboration with lead Clinicians, HSSD Nursing, management and Finance, HSSD's Education Department, HSSD Human Resources, Third Sector (clinician and nursing representatives from Jersey Hospice and Family Nursing and Home Care) and members of the GP Community supported by KPMG.

Stakeholders to be engaged as the OBC develops into an FBC include Health and Social Services, Employment and Social Security plus Housing Ministers, Private sector providers, Parishes and Acute services.

1.5.2 Risks and Issues

- Little or no change in cultural approach to End of Life (currently medicalised)
- Lack of capacity and capability in existing workforce
- Lack of standardisation, policies and procedures
- Lack of agreement or shared vision between organisations and professions
- Incompatibility of IT infrastructure
- Limitations in Ambulance IT system
- Requirement to maintain clinical competency for generalists working within End of Life care
- · Lack of equipment and choice of equipment
- Reticence to adapt and adopt the LCP and GSF
- Lack of funding or not securing funding for this OBC

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1.5.3 Dependencies

The End of Life service is dependent upon:

- · Agreeing changes in the End of Life pathway and
- · Non-medical prescribing
- Communication and coordination, particularly with Ambulance Command and JGH
- Adequate services and capacity out of hours
- Commissioning of a hospice model of care for all groups of patients

1.5.4 Enablers

The development of the End of Life service will also require workforce development, as new ways of working will be required, both in terms of skills, locations and care delivery. IT and informatics will be critical to the service's success, as these will support multidisciplinary community working, support individuals in their own homes and provide visibility of outcomes, activity and benefits.

1.6 Next steps

- · Continue to engage with stakeholders, and widen the stakeholder group
- Collect data
- Monitor and analyse JGH deaths following recent audit
- Explore commissioning opportunities through market testing for provision of hospice for all groups of patients
- Regular contact and planned updates with other OBC Leads on a monthly basis, in particular Intermediate Care, COPD and dementia
- Monthly meetings with OBC Working Group to maintain momentum and inform of updates/development or additional analysis being undertaken
- SRO/OBC Lead to meet regularly to facilitate development of the FBC

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2 Introduction and background

2.1 A Global challenge

Every health and social care system is experiencing similar challenges:

- Demographic change is dramatically increasing demand on all health and social care systems.
- Technological advances are allowing efficiency and quality improvements but also creating major new costs.
- Societal change is altering the relationship between services and service users, professionals and the public and between the state and individuals.
- Increasing regulation in health and social care is increasing quality but also reducing freedom to act atypically.
- Service ethos is shifting from treatment to prevention and promoting independence.

Health, social care and Third Sector partners and multi-agency teams need to work closely with one another and with patients, service users and carers to provide tools and evidence-based services aimed at managing demand, promoting health and wellbeing, ensuring equality of access and protecting / safeguarding vulnerable people. Our aspiration is to enable people to be cared for in the most appropriate place, living as productive and independent lives as possible.

2.2 The Challenge for Health and Social Care in Jersey

Jersey is experiencing many of the same challenges as all other health and social care systems internationally, but it also has some unique challenges.

A small island

In normal circumstances our population of just under 100,000 would be considered too small to support comprehensive acute hospital services and very specialist social care services – this would normally be provided for a population of over 250,000. However, geographical isolation and infrequent but material travel difficulties mean that providing a significant level of acute and emergency services locally is essential, and that it is desirable to provide local care packages for people with complex needs.

Accordingly, the unit cost of delivering hospital and social services in Jersey is higher compared with systems serving larger populations. This is because the fixed costs of key services such as Accident and Emergency, intensive care, and secure residential accommodation, which are still necessary to support relatively low levels of activity. This, along with the cost of living (including the cost of land and buildings) in Jersey leads to an additional funding "premium", which increases unit costs. Secondly, it can produce vulnerable services due to workforce models, particularly in the medical workforce, which are relatively light, highly reliant on very small numbers of individuals and where the achievement and maintenance of specialist skills is difficult given relatively low patient numbers.

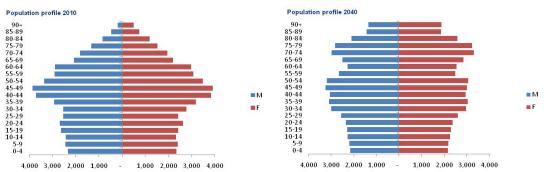
2.2.1 Demography

Given immigration controls the population of Jersey is rising only slowly. But it is ageing rapidly. Over the 30 years from 2010 to 2040 the numbers of residents over 65 is projected to rise by 95%; in the period to 2020 the increase is projected to be 35%.

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This demographic change will create a huge surge in demand for health and social care services which will overwhelm the current capacity of the existing services.

Fig 1. Demographic change in Jersey



Within 5 years, the current numbers of hospital beds, operating theatres, residential and nursing care beds and other key community services will be inadequate to meet demand. These services therefore need to be expanded, supplemented and/or changed urgently to ensure that services can be safely and sustainably provided for the growing elderly population.

2.3 Strategic Principles

The vision of services which are safe, sustainable and affordable was distilled into a set of strategic design principles in late 2010. These were developed by stakeholders across health and social care, and ratified by Ministers:

- Create a sustainable service model efficient, effective, engaging the public in selfmanagement and with consistent access and thresholds
- Ensure clinical/service viability overcome the challenges of low patient volumes, delivering high quality care and minimising risk
- Ensure financial viability reduce the impact of diseconomies of scale, with value for money, an understanding of the costs of care in Jersey and robust procurement
- How should we fund health and social care? establishing a charging model that incentivises care and cooperation
- Optimising estate utilisation ensuring the estate is fit for purpose and utilised to maximum efficiency
- Workforce utilisation and development supporting and utilising the workforce to the best of their abilities
- Clinical governance sustaining a culture of safety, learning and transparency
- Use of business intelligence with robust data to support decision making based on fact, and including patients and the public in service design and decision making

Service principles and assertions:

Social care and health should be integrated as seamlessly as possible on a service user's/patient's life journey, with teams of social care, home care, medical, nursing, occupational therapy, psychology and other staff working together, working with the third sector and private sector providers

Integration will be supported by an organisational and professional mindset that puts people first and at the centre of decision making about their care package, and ensures that needs drive services and not the reverse, to improve emotional, social and health wellbeing.

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Single, integrated care pathways, single assessment and a move towards personalisation and needs driven care will provide choice and empowerment. At present, complex services are provided by a multiplicity of providers, teams and professionals with different referral and access points, assessment frameworks, eligibility criteria and pathways. Simplifying and standardising the current range of approaches would improve co-ordination, providing a holistic, streamlined service which provides support, enablement and choice of care setting for older people and support for their carers.

Services should be planned and delivered within partnerships brining together all sectors of our Islands community and economy.

Where appropriate, service provision should move away from residential care and institutionalisation within social care towards an increase in community provision to allow service users to integrate and lead independent and productive lives as much as possible.

2.4 Stakeholders and public opinion

Between November 2010 and April 2011 a number of stakeholders were interviewed to ascertain their views on the future for health and social care. The key themes were:

- The development of an overall strategic plan as an overarching context for the development of the above is essential. This should address any changes required in the structure of services and relationships between them, as well as future funding mechanism to ensure the changes in service provision required will be delivered
- There is a groundswell of appetite for change
- Considerable scope exists for improvement in the coordination, collaboration and communication between different services and service providers
- Some gaps in service provision exist
- Elements of the operational infrastructure would benefit from strengthening. This
 includes improved mechanisms for data collection and distribution, recruitment and
 retention of key staff, and improvement and better use of estate

2.5 Results of the Green Paper consultation

Between May and August 2010 HSSD consulted on the Green Paper 'Caring for each other, Caring for ourselves'. More than 1,300 Islanders responded to the consultation. The response was overwhelmingly in favour of redesigning health and social services so that they continue to be safe and affordable for the future (86%), and many respondents included detailed comments and viewpoints.

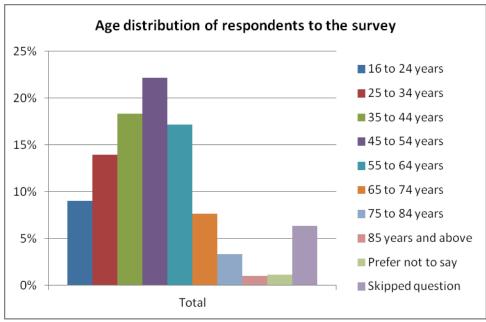
The Green Paper sought views on three scenarios for the future of health and social care:

- Scenario One: "Business as usual" services continue to be provided in the same way and through the same structures as in 2010; spending increases to meet growing demand.
- Scenario Two: "A small increase in funding" the funding allocation does not increase. Services have to be prioritised within this budget and many services will be subject to 'means testing' or will be stopped.

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• Scenario Three: "A new model for health and social care" – prioritised changes to service delivery, to ensure health and social services are safe, sustainable and affordable and are able to meet projected increases in demand.

Responses were received from across all age groups. 69% of responses were received from individuals; 17% from organisations, such as Family Nursing and Home Care, dDeaf Awareness Group and Mind Jersey. More women than men responded.



Responses

The overwhelming message from the consultation was the positive views of Islanders about their health and social services. The majority of the respondents believe it is very (81%) or fairly important (16%) to continue providing a wide range of health and social care services on island. The remaining questions elicited the following responses:

- The majority find it very important (82%) or fairly important (16%) that in future these services are free, or affordable, and available to all.
- The vast majority of people (90%) agreed that "The States should ensure that preventing ill health is as important as curing ill health". Some people felt that a large benefit could be gained from this area in the long term, whilst others were not sure whether this would be possible.
- Mixed views were received regarding having "responsibility for your own health" –
 whether this was for longer waiting times or increased charges for people who
 choose not to look after their own health. In particular, there were concerns about
 "self-inflicted" injuries or illnesses. Some respondents argued that it was not always
 possible for everyone to look after themselves and that vulnerable, ill or disabled
 individuals should not be disadvantaged.
- Most respondents agreed that "People should be able to live in their own home for as long as possible, providing they have the right health and social care support from the States of Jersey, the Third Sector and parishes.
- The vast majority of people (90%) agreed that "Instead of going to a hospital doctor or GP, I would be happy to be seen by a nurse, a pharmacist or other care professional, for appropriate minor procedures such as measuring blood pressure or monitoring my diabetes."

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- Most respondents said they would welcome qualified nurses working with GPs to free up their time, but others were not in favour of nurses doing what they considered to be the work of a GP. Some respondents commented that the GP system in Jersey was already very efficient and they were concerned about damaging patient-GP relations, and others were concerned about the cost of Primary Care to individual patients.
- Respondents also indicated that off-island travel was acceptable for some treatments. Some respondents would rather not have off island treatment, whilst others felt that going away for care to be inevitable on a small island like Jersey. Respondents also expressed views on whether patients should travel off island to see a doctor, or whether doctors should visit Jersey to treat patients.
- Professionals working together to deliver better integrated care was important, but some respondents noted that Jersey's charities should receive more funding and support.
- The vast majority of respondents thought that health and social care should be accessible and affordable, if not free, to all. However, there was a range of views about who should fund this care, and how.
- The need for affordable care was often stressed, and many respondents felt payment and funding needed to be explored in more depth.
- Most respondents said that those who cannot pay should still enjoy high quality health and social care. Opinion was then split about whether the amount of free care available for each person should be capped, with respondents expressing concern about the costs of care for people with long term illnesses and whether they would be able to pay.
- Some respondents commented that if health and social care was capped, for some conditions or for all, this should be means tested. However, others disagreed with means testing and felt that if someone had worked all their lives, they should have as much right to free care as others.
- Some respondents felt it would be fair that those who had lived in Jersey all their lives received free access to treatment but that people who have not paid into the system should not enjoy the same benefits.
- According to many respondents, significant numbers of people visit the Emergency
 Department rather than seeing a GP because there is a charge associated with the
 GP, while a visit to the Emergency Department is free. The majority agreed that if a
 charge applied to visit the Emergency Department for treatment of a minor
 condition, they would be more likely to go to see their GP. Many also suggested that
 GP consultation costs should be reviewed at the same time as Emergency
 Department costs.
- Many respondents felt that there are opportunities to improve current system.
 Suggested ways to improve efficiency included reducing bureaucracy in health and social services, improving communication between organisations and bringing in more third party and profit making organisations to provide care.

2.6 Development of the Outline Business Case

This Outline Business Case (OBC) presents the case for change for End of Life Care. It explains, within the context of current and future safety, sustainability and affordability and against the strategic principles agreed by Ministers in late 2010, the reasons why 'do nothing' is not an option.

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The OBC was developed by a Working Group between August and November 2011. Between November 2011 and March 2012, significant work was undertaken with Treasury to ensure that financial projections are within an indicative cost envelope and sufficiently detailed and accurate for the Medium term Financial Plan submissions in Summer 2012.

The OBC outlines in brief the range of services that have been considered in connection with the proposed new service being introduced, referring to the three Scenarios outlined in the technical document and Green Paper. It presents an outline cost/benefit analysis of the options.

The OBC then outlines the features and timescales of the proposed service changes and assesses the potential impact against a range of factors, including workforce, cost and quality.

This OBC has been prepared by Honor Blain, Senior Manager, Workforce Planning and supported by Rose Naylor, Chief Nurse as the Senior Responsible Officer after consultation with service providers, Third Sector organisations, service users and carers.

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3 The Preferred Option

3.1 The Service Case

International evidence

The UK Palliative Care Review suggests that 32.6% of acute hospital bed days could be released following implementation and delivery of a community focussed End of Life care pathway.⁵

The Department of Health UK End of Life Strategy has significantly improved the delivery of End of Life care across England, Scotland, Wales and Northern Ireland. ⁶

The strategy developed following similar initiatives across Scotland, Wales, Ireland highlighted that a community-based model for End of Life care has can be more cost effective and appropriate than hospital care. Work in England is supporting the move to strengthening the community model of service provision with an emphasis on living until the End of Life.⁷

Subsequent service development requirements have been reported by the Royal College of Physicians, General Practitioners and Registered Nurses with all groups reinforcing the need for all patients experiencing symptoms in connection with End of Life to have a good death with palliative care management of symptoms, physiological, social and spiritual support.⁸

3.2 Current Services in Jersey

On average, 772 adults die in Jersey each year. Of these, an average of 393 adults die in hospital. Data from the States of Jersey Public Health Intelligence and Dr G. Purcell Jones (Table 1), suggests 12% of all deaths are sudden. Based on this assumption, the average number of End of Life patients cared for within JGH per annum is 345. ⁹

In addition, there are approximately 2-3 child deaths per annum with 20 children at any one time having life limiting conditions.

The Medical Director of JGH has estimated that 70% of End of Life patients could be cared for outside of hospital if appropriate community based services were available. It should be noted that further work is being undertaken to quantify and validate this figure.

An audit was conducted during November/December 2011 to analyse the number of JGH deaths in 2010. The results indicated that a total of 14,145 adult bed days per annum were utilised for 345 patients in their last 12 months of life. This equates to an average of 41 acute bed days for each End of Life patient, and a total of 39 acute hospital beds.

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⁵ UK Secretary of State for Health; Hughes-Hallett.T; Craft .A; and Davies.C., Palliative Care Funding Review; Funding the Right Care and Support for Everyone. (July 2011)

⁶ UK Department of Health, End of Life Care Strategy: Quality markers and measures for End of Life care (DH 2009) 7 UK Department of Health, End of Life Care Strategy: Quality markers and measures for End of Life care (DH 2009)

⁸Royal College of Physicians, End of Life Strategy, Scotland (2009)

⁹ States of Jersey Public Health Intelligence and Jersey Hospice Care in "The Need for en End of Life Strategy", Dr G. Purcell - Jones (Aug 2010).

Table 1. Average Annual Jersey Deaths by age and location

1	ge Annual Jer			ocation 200	07- 2010		
Age Group	Hospice	Hospital	Nursing Home	Other	Private Home	Residential Home	Total
Under 10	0	4	0	0	0	0	4
10-19	0	1	0	0	1	0	2
20-29	0	3	0	2	4	0	9
30-39	1	3	0	2	4	0	10
40-49	5	11	1	3	9	0	29
50-59	13	30	1	2	11	1	58
60-69	19	54	5	2	20	1	101
70-79	22	92	15	2	28	3	162
80-89	17	135	50	2	35	19	258
90+	1	60	48	0	13	17	139
	78	393	120	15	125	41	772

Source: Jersey Public Health

At an average bed day cost of £400 per day, (£1,350 for intensive care beds) the total cost of acute stays for End of Life patients is estimated to be c£6 million per annum.

There are a number of challenges with the current service model:

Service design principle	Challenges of the current services				
Create a sustainable service model	 50% of patients with cancer and 75% of patients with other life limiting illnesses die in hospital Acute bed usage for End of Life patients is high. Demand is projected to increase by 26% by 2029 – and increase in annual bed days from 14,145 to 17,823 Dignity and privacy is a significant problem, and the service model is not consistent with best practice. The limitations of the environment often mean that patients and their families are cared for in 6 bedded open bays due to a lack of available side rooms 				
Ensure Clinical/service viability	 Inpatient End of Life care is delivered only by Jersey Hospice Care, but only for patients with cancer and MND. This accounts for 10% of patients Best practice and principles in End of Life Care are not standardised across health and social care There is limited capacity within the existing workforce, and limited specialist expertise regarding End of Life care Community services are not available 24 hours, and generalist staff have limited training and support regarding 'the difficult conversation' 				
Ensure financial viability	 End of Life care accounts for an estimated 39 acute beds days. This is estimated to cost c£6m p.a As demand increases, this cost will increase further 				

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Service design principle	Challenges of the current services
	 In addition, costs are double counted in economic terms, as individuals admitted from care homes will still have a bed within that home which is being paid for (by HSSD or by the individual) Marie Curie estimate that 62% of people prefer to die in a non-hospital environment Community-based End of Life care has been proven to be more cost effective¹⁰
Optimising estate utilisation	 Reducing acute bed demand for End of Life patients by 50% would enable more effective use of hospital estate
Workforce utilisation and development	 There is a lack of a specialist nursing workforce to deliver End of Life care services The generalist nursing workforce is also underresourced, and may have a lack of specialist knowledge and skills to deliver End of Life care There is a lack of a non-registered workforce to deliver care in community settings 24/7 The workforce requires significant investment in education, training and support regarding End of Life care Engagement with teams and with both Primary Care and the Third Sector will be required as the service model for End of Life care develops
Clinical governance and benchmarking	 There is no clear agreed pathway. As a result End of Life management can be inconsistent Island wide policies, guidelines and standards are required
Use of business intelligence	 Data is not consistently collected This hampers population needs assessment and commissioning Metrics and outcomes measures are not consistently collected, which hinders the assessment of quality and value for money

Enhancing End of Life services will enable 50% of End of Life care patients to be cared for within the community. This will release the equivalent of 20 acute hospital beds, resulting in cost containment of c£3.1 million per annum. ¹¹

It will also significantly improve choice and quality of life, as the acute hospital environment is not the most appropriate setting to manage End of Life care. Evidence

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¹⁰ Marie Curie Cancer Care, We know about end of life care, (2011)

¹¹ UK Department of Health, Lord Darzi, Our Health, Our Care, Our Say (2008), Ayrshire & Arran Primary Care Strategy, Your health- we're in it together (2008); States of Jersey HSSD, Caring for Each Other, Caring for Ourselves Green Paper (2011)

from conversations with families after death and from formal complaints demonstrates the need to change. The issues raised often relate to relatives left shocked at the sudden loss of a loved one, when there was a clear decline in their health but no one had had the "difficult conversation". Issues relating to symptom control and the poor environment in which their loved one died, often in a ward bay surrounded by other patients, are often raised. This was supported by an audit was undertaken in 2011.

3.3 Description of Service

The new service model will provide appropriate choice in relation to End of Life care. It will be based on principles of privacy and dignity. The patient will remain under the care of their GP, and a wider range of services will be provided in individual's homes, through a Specialist Palliative Care Team, supporting Primary Care, and enhanced Intermediate Care.

The End of Life Pathway will be applicable to all ages. Entry onto the pathway will be triggered by a consented entry on to the Register. The pathway will be initiated by designated clinicians such as GPs, hospital consultants and nurse specialists/ nurse consultants using the Gold Standards Framework (GSF). This is a UK developed tool to support professionals to identify and facilitate the navigation of patients approaching their End of Life via a standardised set of prognostic indicators. ¹²

The knowledge and skills base across health and social care (including Third Sector and primary Care) will be enhanced, in order to deliver a change in behaviour and practice in relation to the "difficult conversation" and advanced treatment planning. The End of Life service will comprise:

- The Gold Standards Framework (GSF)
- The Liverpool Care Pathway (LCP)
- End of Life Register
- Specialist Palliative Care Team, providing training and support
- Multidisciplinary Team working
- Rapid Response, 24/7 Home Care team and Night Sitting
- Bereavement Support

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¹² www.goldstandardsframework.nhs.uk (Sept 2008)

CROSS SECTOR EDUCATION & TRAINING PROGRAMME EoL •LCP Clinical Gold S •Funding •Night Sitter Spiritual Support ADULT/CHILD Standards l Prognostic indicator Standards framework REGISTER COPD Renal Motor Neuron Parkinson's indicator REGISTER TRIGGERS REFERRAL ROUTE TO ELCP REGISTER •MDT Review •Social Sectary Financial assessment & planning •Ambulance services •District Nurses •Specialist Nurses •Consultants Acute Ward staff Information Social Worker Equipment Social Services Occupational Therapist Specialist care Physiotherapist

End of Life Care Pathway

The Gold Standards Framework (GSF)

Spiritual support

The GSF is a systematic common-sense approach to formalising best practice so that the quality End of Life care becomes standard for every patient. It identifies patients in the last stages of life, ascertains their wishes and, with the individual, designs and delivers End of Life care against a personalised plan.

The framework provides detailed clinical prognostic indicator guidance to enable better identification of patients who made need supportive/End of Life care. This aims to improve the prediction of possible need and provision of care. Using the clinical prognostic indicator, the process will commence with the 'surprise question'. This seeks to establish whether professionals would be surprised if the patient were alive in 12 months. If professional would be surprised, then the individual (with their consent) will be added to the End of Life Register.

The individual's specific needs, symptoms, preferences and priorities regarding their wishes for place of death and resuscitation orders are sought, and a care plan is formulated to enable patients to live and die where they choose. The framework is characterised by a series of colour coded steps within the trajectory of life limiting illness, the stages of which correlate with those evidenced by the Palliative Care Funding Review evidence of *stable*, *unstable*, *deteriorating and dying*.¹³

The Liverpool Care Pathway for the Dying Patient (LCP)

As the patient nears the final stage of their life they will be cared for using the Liverpool Care Pathway, (LCP) irrespective of their care setting. The LCP is in use in over 1800 centres across the UK and is the recognised model for End of Life care, and was promoted by NICE in 2004.

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¹³ UK Secretary of State for Health; Hughes-Hallett.T; Craft .A; and Davies.C., Palliative Care Funding Review; Funding the Right Care and Support for Everyone. (July 2011)

The LCP was originally introduced as a means of translating specialist best practice from the hospice model to the generalist community setting. It is a multidisciplinary tool which supports consistent client-centred symptom management and facilitates the consistent delivery evidence based care. It forms the basis of a quality programme to translate the excellent model of hospice care for the dying into other health and social care settings using an integrated care pathway for the last hours or days of life.

In addition to improving experience, and supporting the delivery of a consistent standardised approach to care delivery, it will enable Jersey to measure outcomes and benchmark across other practice settings.

The LCP focuses on key areas such as communication, nutrition and hydration for care of the dying patients. It does not replace clinical judgment, but aims to guide health and social care staff in managing symptoms in a wide range of settings for people at End of Life and their families/carers. The Pathway and its associated documentation are underpinned by a robust, ongoing education and training programme. This will form a critical component of a Specialist Nurse role.

The LCP documentation guides and enables health and social care professionals to focus on care in the last hours or days of life (approximately 72 hours), to provide high quality, personalised care when their death is expected. The LCP encourages joint medical and nursing assessment, review and reflection with formal and regular Multidisciplinary Team review.

The LCP also acts as an audit tool, and will allow Jersey to benchmark practice against other jurisdictions.

End of Life Register

The 'Electronic Palliative Care coordination system' will be the key tool for managing caseload and monitoring care delivery. Entry onto the register will require consent of the patient, this would reinforce the need for professionals to have the critical conversation regarding ongoing plans and preferences.

The Register will be managed by a Palliative Care Coordinator – a non-registered healthcare worker with clinical experience, IT skills and advanced communication skills. The Coordinator will facilitate and coordinate the regular Multidisciplinary Team meetings to ensure both Gold Standard Frameworks and the Liverpool Care Pathway are effective.

The Coordinator will also develop and coordinate a website that can be easily accessed by patients, relatives and carers. Information will include what to expect at End of Life and signposting to appropriate agencies. In time, this will be included within the citizen's portal.

Specialist Palliative Care Team

An Associate Specialist in Palliative Care will provide clinical leadership to the Specialist Palliative Care Team, and will lead the development of the Register. (S)he will also ensure quality standards are developed and agreed, and pathways are implemented across providers, including HSSD, Jersey Hospice Care, Family Nursing & Home Care and Primary Care.

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The Specialist Palliative Care Team will provide specialist support for patients, relatives and carers in the community.

Involvement will be triggered by the Multidisciplinary Team meeting after and individual has been included on the Register.

Largely community based, the Team will co-ordinate care, enabled and supported by a citizen's portal. It will comprise Community Specialist Palliative Care Nurses, including the Palliative Care Nurse Specialist and the Liverpool Care Pathway Nurse. Medical staff, including GPs and Consultants, will outreach within the community and will also support nursing homes as appropriate.

The team will provide an out of hours on call service, and will refer where necessary to the Rapid Response Team.

Patients may also choose not to receive their End of Life care at home. Jersey Hospice Care will open an additional 6 beds in 2012, increasing their overall in patient bed capacity to 12. From 2013 hospice provision for conditions other than cancer and Motor Neurone Disease patients will need to be developed; this service will be tendered. The required future volume and/or capacity required as a result of the increased patient choice for End of Life care is not yet known. Any potential move to widen hospice access for a range of End of Life conditions would further increase demand on the service.

Training and development will be provided by the Specialist Palliative Care Team. This will incorporate both initial training as services are developed, and ongoing support. An End of Life education strategy has been developed. This reflects three distinct levels of staff training required

- specialist teams
- staff working regularly with End of Life patients
- · staff working occasionally with End of Life patients

Within Primary Care, a post with a palliative care interest will be fundamental to supporting the training of GPs and maximising their understanding and support. This could be provided by a Nurse Consultant or a GPwSI.

Multidisciplinary Team working

Generalist support will be provided by the Community Multidisciplinary Teams.

Multidisciplinary Team working will be developed, incorporating the Community MDTs, Specialist Palliative Care Team, GPs and others involved in a patient's care. This will provide a unified approach to assessment and care delivery. It helps to put the patient in control whilst prompting other agencies to take action when required. It will also ensure that patients and families are signposted to the most appropriate areas for support, this could be financial, practical or therapeutic

Through effective record sharing, multidisciplinary team working minimizes duplication and helps to avoid unnecessary repeated assessments, contributing to effective advanced care planning.

Above all, it aims to deliver a better experience of End of Life care for the individual and their families, promoting dignity and choice in the final phase of life.

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Intermediate Care – 24 Hour Home Care and Rapid Response

The Palliative Care team will refer into the Single Point of Access for Intermediate Care. The appropriate response and service will be provided by that team, with regular communication with the Palliative Care team and the patient's GP.

The Intermediate Care teams (Rapid Response and 24/7 community services) are not expected to be functional until 2014, and FNHC do not have scope to provide End of Life care for the additional patients until the Intermediate care services are available. This will impact the level of choice and quality that can be provided to End of Life patients.

Bereavement Support

The end phase of the GSF directs professionals to provision of bereavement support to carers and families following the death of a loved one in order to support their emotional health and well-being. In addition to existing therapists, key workers and specialist staff will have advanced communication skills to enable effective support to take place between relatives/carers and key worker with whom rapport has been developed.

Children's services

Children's respite and hospice care will be developed in from 2016 onwards. This is included within the Service Workstream and Transition Plan, and is outwith the timeline of this OBC.

A specialist Palliative Care Nurse will be recruited to work with children and their families, including children with a life limiting illness. The post is included within this OBC to facilitate an early response to a more community based model of End of Life care.

3.4 Activity Impacts

On average, 772 adults die in Jersey each year. Of these, an average of 393 adults die in hospital.

Data from the States of Jersey Public Health Intelligence and Dr G. Purcell Jones (Table 1), suggests 12% of all deaths are sudden.

Therefore, in 2010:

48 of deaths in hospital were sudden

345 of deaths in hospital were expected

Nursing and Residential homes:

Accurate data is not known, however, sudden deaths are much less likely than expected deaths. There were 161 deaths in Nursing and Residential homes.

Jersey Hospice Care:

All deaths (78) were expected

Individual's own home:

It is more likely that approximately 15 deaths were sudden, and 110 deaths were expected

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Other locations:

15 deaths were sudden or expected

In addition, there are approximately 2-3 child deaths per annum with 20 children at any one time having life limiting conditions.

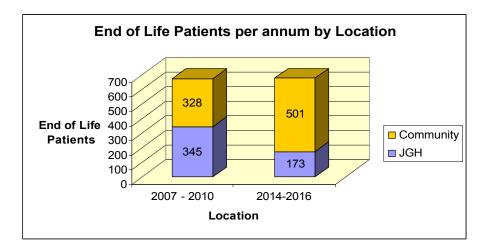
Deaths are projected to increase by 26% by 2029 with an expected increase to 973 deaths per annum.

It is anticipated that, by 2015, 712 individuals will be on the End of Life Register, with the Gold Standards Framework applied all following the Liverpool Care Pathway.

Changing the model of End of Life care will lead to an increase in home care activity. There will be high peaks and troughs of activity throughout the year.

The End of Life service will lead to reductions in activity in a number of areas:

- **Ambulance Services** 68 End of Life care patients per annum avoiding ambulance admission to JGH by 2015
- Acute activity reduction from 345 End of Life patients in 2010 to 173 p.a from 2015. This is based on an assumption that 50% of End of Life patients will be cared for within the community supported by additional staffing investment associated with development of Intermediate Care services. A slight reduction should be experienced from 2013 onwards, following recruitment of specialist staffing to support existing staff with End of Life care.



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3.5 Workforce Impacts

Much of the workforce impacts are dependent on the commissioning workstream which will determine the provider model for the End of Life pathway. Workforce numbers have been based on the establishment of a Specialist Palliative Care Team. Therefore the FTE requirement may reduce dependent on the provider.

			Timing	
Staff	Timing	2013 FTE	2014 FTE	2015 FTE
Palliative Care Nurse Specialist	HSSD 2011-2013 OBC 2014 onwards	-	-	-
Liverpool Pathway Nurse (appointed for 2012 funding required for Jan 2013 and Oct 2013)	McMillan 2011-2012 OBC 2013 onwards	1.50	-	-
Community Hospice Palliative Care Nurses	Hospice	-	-	-
FNHC Palliative Care Nurse	FNHC	-	-	-
Palliative Care Associate Specialist (0.50 of 1.00 funding in 2014)	Hospice 2011-2013 Hospice/OBC 2014	-	0.50	-
GP with Pall Care Interest / McMillan for GP training (Oct 2013 start)	OBC	1.00	-	-
Palliative Care Associate Specialist Admin (for Jan 2014 start)	OBC	-	0.50	-
Consultant Nurse Palliative Care	OBC	1.00	-	-
Children's Palliative Care Specialist Nurse (for Jul 2013 start)	OBC	1.00	-	-
Palliative Care Co-ordinator (July 2013 start)	OBC	1.00	-	-
Palliative Care Team Admin Support	OBC	1.00	-	-
Non Medical Prescribing		1.00	-	-
TOTAL		7.50	1.00	-

Ambulance Workforce

Ambulance staff will be trained in the End of Life pathway and will have specialist End of Life on call services to refer to as an alternative to hospital admission. Information relating to the patients' preferred priorities of care relating to End of Life and DNAR/CPR orders will be available on the Register. This should reduce the length of time spent at each call out. The number of emergency call-outs for End of Life care patients, and the number of transfers from home to admit to hospital would reduce by 68 patients per year.

Specialist Consultant Palliative Care Advice and Support

An off-Island Consultant Palliative Care link is required, to provide specialist End of Life care advice and/or specialist professional support. The service could also be used out of hours; this is similar to the model adopted in Guernsey.

3.6 Infrastructure Impacts

<u>Estates.</u> The End of Life teams will be established and located within a central base. Centralisation of Palliative Care services will support communication and administration and cross sector boundary working. The location of the team will be considered and agreed; the team could potentially be co-located with an existing Third Sector provider.

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<u>IT.</u>. The End of Life team will also require handheld mobile devices, in order to support community working.

The Register

IT infrastructure to support the Register and multidisciplinary assessment, care planning and monitoring will need to link the entire team, including Primary Care and Third Sector providers such as Hospice and Family Nursing & Home Care. A short term solution would be to use the GP out of hours system, as this can link to HSSD TrakCare.

An entry will be placed against the patients name in TrakCare when they are entered onto the End of Life Care Register. This will alert each time a referral or ambulance attendance is requested. This is critical, in order to facilitate the End of Life pathway, and will allow for adequate and appropriate sharing of patient information between organisations.

Long terms plans for HSSD adaptation to a States-wide IT system will enable all IT systems to interface effectively with each other in the future.

Citizen's Portal

From 2014, health and social care professionals, children, parents and families will access information via a citizen's portal. The citizens' portal will enable care to be designed by the individual and care professional, based on the individual's needs and, where appropriate, they choices. It will also enable care packages to be delivered and monitored in a coherent and co-ordinated manner.

The citizen's portal will provide real time information regarding service availability, self care, family support groups etc, to assist the child and family with feeling more in control of their situation.

In the interim period, a Palliative Care Coordinator role will develop an End of Life website containing relevant information, including with contact details and an option for self referral for an End of Life care review. The Coordinator will also assist with signposting for those who choose not to, or are unable to access information via the website. This post is being piloted in the UK and is considered by the NHS End of Life lead to be the most appropriate Single Point of Access for End of Life care.

3.7 Service Delivery Benefits

The new model for End of Life care services will deliver a wider range of services in a wider range of settings. This will be underpinned by a consistent, evidence-based pathway which supports professionals in having the 'difficult conversation', and ensures individuals' views and preferences regarding their care are sought.

Benefits to patients, service users, carers and families include:

- Choice, with the individual's preferences being sought and incorporated into personalised care plans
- Clarity once the 'difficult conversation' has been held, the individual and their carer/family's expectations can be managed, and they can have greater understanding of what might happen and the type and location of care that they will receive. More information will be available, in more accessible locations
- Privacy and dignity, from care being provided in non-acute settings
- Reduction in wait for residential care, as more care is delivered in community settings, thereby reducing the demand for residential care at the end of an

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individual's life. Currently, up to 19 individuals are awaiting admission to a nursing or residential home for End of Life care. As the number of people choosing to be cared for at home increases, this releases capacity for those individuals who chose residential care as opposed to those for whom there are no other options currently

- Reduction in acute admissions and length of stay, as more care is delivered in community settings. This leads to a release of acute capacity
- Reduction in ambulance journeys
- Increase in confidence and reduction in burden on informal carers from the knowledge that 24 hour services are available from the Specialist Palliative Care Team, Ambulance, Rapid Response team and Night Sitting services
- More streamlined access, regardless of age or disease/condition, supported by Single Point of Access and Palliative Care Coordinator linking to the End of Life care teams to co-ordinate an individual's care
- Improved co-ordination, which reduces duplication and improves quality of care
- Improved efficiency in the future, through the use of modern technologies such as telecare

Benefits for teams and professionals include:

- A more interesting and broader role, with enhanced roles and the introduction of specialist nurse roles
- More attractive career paths
- Improved specialist nurse succession planning
- Up-skilling of staff to support their further development
- · Improved team working
- Increased job satisfactions, as staff are able to support more service users and carers in their own homes
- Increased staffing in the community, which should reduce pressure and sickness absence

3.8 Service Delivery: Anticipated Risks

- Undermining the sustainability of Third Sector providers, for example if an additional Hospice provider was successful in winning some contracts for End of Life care
- Undermining competitive tension if all specialist End of Life care was provided by one organisation
- Funding mechanism to support non medical prescribing across community nursing may not be in place in time (HIF)
- Inability to recruit to new roles
- Inability to train and support existing staff in new roles
- Reticence to change the model of care
- Lack of agreement regarding the vision and new model of care
- Reticence from patients / service users and carers to exercise choice
- Reticence from professionals to hold the 'difficult conversation'
- Non-achievement of bed day savings
- Inconsistency of learning outcomes
- Increased costs for home adaptation and equipment
- Increased costs required to incentivise Primary Care activity
- Model of MDTs may struggle in single handed practices
- Lack of coordination between professionals
- IT infrastructure does not link acute, community, Third Sector and Primary Care
- Retention challenges from existing HSSD HCA workforce moving to community roles

3.9 Dependencies and enablers

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- Other service developments and OBCs, in particular Intermediate Care, COPD and Dementia
- Third Sector providers, including Family Nursing & Home Care and Jersey Hospice Care
- Ambulance Service
- JGH, in particular for discharge planning, to ensure that patients are transferred from hospitals to a setting of their choice when appropriate. JGH will need easy and fast access to the Specialist Palliative Care team, a timely response and information regarding the patient's preferred priorities of care.
- Existing Community teams
- Other States Departments, particularly Housing and Social Security
- Older Adults Policy Group
- HSSD Business Plan 2012
- · States Strategic Plan
- Medium Term Financial Plan
- · Health and Social Services White Paper

Workforce:

Detailed scoping and the development of service specifications is required in 2013 in order to clearly define the workforce model.

The workforce model will, to some extent, be dependent on the service provider(s).

All service providers (including HSSD, Third Sector and Primary Care) will need to agree to work closely together, in planning, delivery and training plus ongoing support.

The development of enhanced roles e.g. non-medial prescribing, will support End of Life services. Recruitment, retention and training will need to be carefully managed, and both individuals and teams engaged in order to maximise the chances of the new model being agreed and implemented.

The HSSD E-Learning Strategy also needs to be developed and agreed, in order to support training and development for the existing workforce.

Estates:

As previously noted, the End of Life team will require a base.

As more care is delivered in community settings, there will be an impact in the hospital, through a reduction in demand and a release in capacity.

Commissioning:

Detailed service specifications, along with outcome measures and metrics, will be developed as part of the FBC.

Provider market development is also required, in order to stimulate the market and support plurality and therefore choice.

Market testing and robust processes for selecting the preferred provider(s) will be undertaken, with clear requirements and relationships built.

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Primary Care:

As End of Life care moves increasingly to community settings, the role of the Primary Care team will be increasingly important.

Effective communication and training is required to support Primary Care in End of Life care; in particular, to ensure the patient's GP is aware of their care pathway and their preferences, and to keep them informed of any changes in an individual's health.

IT.

Procurement will be needed for Information Systems and Technology, data systems and security. Systems will need to integrate across the multiple providers of End of Life care, including Ambulance Command and Control IT system, the States of Jersey IT system and GP Central Server. IT integration with Third Sector systems, and cloud computing technology are also required.

The Register, assessments and care plans will be IT based, and these will need to be shared between the various organisations, teams and individuals involved in care.

Awareness and information will require a range of media, including the citizen's portal.

Informatics:

Key outcomes measures for End of Life care will be based on the Gold Standard Framework and Liverpool Care Pathway. Both quantitative and qualitative measures will be agreed, including patient and carer-reported outcomes.

Finance:

Investment is required in End of Life services, in order to release capacity in acute services.

Legislation:

Non-Medical Prescribing

The change in the law relating to non-medical prescribing will impact on the success and value for money of End of Life services. A reduction in GP call outs and visits is anticipated at the point that specialist nurses are legally entitled to prescribe form an agreed End of Life care formulary.

The local law around prescribing has been drafted and is on target for completion in late 2013. This also requires the Social Security Department to revise procedure and policy in relation to defining the groups are professions who are able to prescribe.

The NMC will provide regulation of non-medical prescribers within the Specialist Palliative Care Team. The NMC are the professional regulatory body responsible for setting standards for regulation and continuing professional development (CPD) of non-medical prescribers. Responsibility for updates will rest with the individual practitioners, and a central database will be maintained locally by the Education Team as evidence of CPD.

Social Security

The newly developed law relating to Long Term Care Benefit and rapid assessment for income support will need to be considered in the context of patients requiring significantly increased levels of care in a short timeframe.

The Register will alert the Social Security Department, the patient their relatives and/or carers to any associated cost increases at End of Life. Rapid financial assessment may be required to access informal care support.

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3.10 The Financial Case

3.10.1 Revenue costs

Indicative costs and benefits are identified below. Some rounding adjustments have been made. All costs are presented at prices relevant to that year. Costs and benefits which are quantitative and qualitative, and relevant to patients / service users / carers / families, clinicians and the public have been considered.

The total additional recurrent cost for End of Life care increases to £826k by 2015.

Capacity releasing savings of £1.5m in 2013 and £3.1m recurrently from 2014 are projected. This will be achieved as 50% End of Life patients will be cared for in community settings rather than in hospital.

The revenue cost is estimated to be:

2013 - £399k

2014 - £806k

2015 - £826k

Implementation costs total £133k in 2013.

Capital costs of £108k will be incurred in 2014.

Summary costs 2013 -2015	2013 £000's	2014 £000's	2015 £000's
Implementation Costs	133	ı	ı
Recurrent revenue costs	399	806	826
Capital costs	-	108	-
TOTAL	532	914	826

These costs comprise:

ELCP Costs 2013 - 2015	2013 £000's	2014 £000's	2015 £000's
Staffing	330	534	548
Training & CPD	36	51	52
Consumables	21	196	201
GP Visits	12	25	25
Total recurrent costs	399	806	826

A total of 8.50 FTE will be required to implement the changes proposed.

Telehealth may be appropriate to support individuals at their end of life at home. This technology supports remote monitoring of vital signs, and enables community teams to prioritise visits and care. Costs for telehealth are currently included in the Intermediate Care OBC, and will be further developed in the FBC.

Additional costs would also be incurred to develop enhanced community team. This is included within the Intermediate Care OBC.

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3.10.2 Revenue savings

As noted above, capacity releasing / cost containment of £1.5m in 2013 and £3.1m recurrently from 2014 are projected.

The UK Department of Health estimates that 32.6% of hospital admissions for patients with a palliative care need occur in the last 30 days of life.

In 2010, 345 adults died in JGH. Their average length of stay was 41 days. This equates to 14,145 beds days in total, which is the equivalent to 39 acute beds.

For each patient with a life limiting condition, the cost of their End of Life care associated with dying in hospital has been calculated as circa £17,750 per person. This is based on the average length of stay of 41 days, and an average cost per day of £400 (Intensive Care bed days cost £1,350.14). The HSSD cost End of Life for 345 patients has been calculated at c£6.1 million per annum.

It has been estimated that 50% of End of Life patients will be cared for in non-hospital settings. This will therefore release acute capacity equivalent to £3.1m from 2014. In 2013, as the service develops, the capacity releasing amount is estimated to be £1.5m.

Note: costs are shown at uninflated rates in order to allow comparisons between the years

	2013 £000's	2014 £000's	2015 £000's
JGH End of Life Bed Day Costs	4,600	3,050	3,050
ELCP Revenue Costs	399	806	826
Capital costs	-	108	-
Implementation costs	133	-	-
TOTAL	5,132	3,964	3,876

In addition, it is anticipated that drug costs will reduce due to standardisation and an agreed formulary.

3.10.3 Capital costs

Capital costs of £108k will be incurred in 2014. These include purchase and implementation of an IT system (IEMIS) to enable compatibility; sharing of core End of Life data and access for Palliative Care Staff, GPs, FNHC, Hospice and Ambulance Services.

The capital costs also include an Ambulance Command and Control system to ensure contemporary allocation and decision making for emergency services.

It is anticipated that the Specialist Palliative Care Team could be co-located with one of the Third Sector providers, working across boundaries with a case management approach. The team would be expected to be mobile and develop close links with Intermediate and Rapid Response teams to facilitate referrals and to provide specialist advice to JGH staff, community patients in their own homes and the nursing/residential sector.

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¹⁴ Secretary of State for Health, Palliative Care Funding Review: Funding the Right Care and Support for Everyone: Creating a Fair and Transparent Funding System; the Final Report of the Palliative care Funding Review (July 2011)

3.10.4 Funding

End of Life care should continue to be free at point of delivery for patients

An adequate infrastructure is already in place to enable delivery of service from within the Third Sector, but there is need for a funding stream that enables the development of posts and staff to work across sector boundaries to deliver new services.

It is highly likely that End of Life care will be provided in partnership between HSSD, the Third Sector and Primary Care. HSSD will commission End of Life care in a range of community-based settings, based on evidence and best practice in order to meet national standards.

Discussions need to be held with the Social Security Department regarding the Health Insurance Fund, prescription charges and the Long Term Care Benefit.

The funding of Information Technology also needs to be clarified, in particular for a States-wide system and the GP Central Server.

New payment systems for Primary Care are also being developed, and it is anticipated that the Quality Improvement Framework (QIF) will have agreed by 2013.

Funding for the enhanced End of Life care service will be sought through the Medium Term Financial Plan.

It is assumed that Jersey Hospice Care will continue to fund 0.50 FTE of the Associate Specialist in Palliative Care.

The Macmillan service can be approached to provide temporary charitable funding for posts associated with End of Life and Palliative Care. There is potential to apply for a source of some fixed term funding from the organisation, for up to two years, to cover part of the recurrent funding required from 2013 for the 1.00 full time equivalent GP with Palliative Care Interest post.

Twelve months' funding has been provided by the Macmillan organisation to HSSD for 2012 to enable the recruitment of a Liverpool Care Pathway (LCP) nurse. This nurse is currently in post and recurrent costs are included within the investment required from 2013 onwards.

3.10.5 Managing risk

In order to minimise the financial risk, the following actions must be taken:

- Identify intended benefits carefully
- Monitor the delivery of End of Life services and work collaboratively to ensure that maximum efficiency is achieved delivering a value for money service
- Monitor the success of the service closely
- Make staged investments once the expected benefits are realised

3.10.6 Sensitivity analysis – scenarios

This OBC recognises that delivery of End of Life care outside of JGH is likely to be higher than 32.6%.

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Financial benefits have been calculated on an assumption that 50% of patients would receive End of Life care outside of hospital settings. However, this could be as high as 70%.

Further analysis is required relating to JGH admissions in the 12 months prior to death is required. This analysis will be used at FBC stage to sensitise projections regarding the annual reduction in acute bed days.

3.10.7 Assessment of affordability and value for money

Based on the total anticipated activity, the additional revenue cost for End of Life care in 2013 estimated to be £399k, rising to £826k in 2015...

A total of £133k implementation funding is required to cover 2013. The additional capital costs for 2014 total £108k.

Cost containment benefits from releasing capacity in JGH would total £1.5m in 2014 and £3.1m p.a. from 2015.

3.10.8 Verification procedures and assumptions

The End of Life OBC was produced in consultation with a Working Group.

The verification of bed day cost and equivalent bed day savings from implementation of the service model was agreed with the Head of Capacity, Madeline Simpson.

HSSD Management Accountants supported the financial modelling and costing of pathway, developing a set of detailed costs provided within Appendix 6.

3.11 Implementation Actions and Timescales

A high level timeline has been agreed by the Working Group. This is presented in detail at Appendix. 7, and summarised briefly below:

Action	2012			2013			2014			2015						
	Q 1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
HSSD Palliative Care Nurse in post																
Jersey End of Life care pathway developed and agreed																
Development of End of Life care training strategy																
Start to monitor the number of patients transferred into hospital shortly before dying																

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Action	2012				2013				2014				2015			
	Q 1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Liverpool Care Pathway	-															
Nurse to commence																
employment in Jersey																
Develop the FBC,																
implementation plan,																
timetable and required																
commitment with a wide																
group of stakeholders,																
including Third Sector,																
Parishes, Primary Care																
and private sector nursing																
homes																
Develop a service																
specification for medical																
outreach into nursing																
homes																
Pharmacy scoping																
Training Needs Analysis																
Produce uniformed																
DNAR/CPR paper																
Hold Advanced Care																
Planning Conference																
LCP implementation																
IT scoping																
Develop End of Life																
indicators for QIF																
Develop jointly agreed standards, policies and																
standards, policies and guidelines																
Scoping of																
Respite/Hospice provision																
for Children																
Development patient																
information and website																
Recruitment of Palliative																
Care Associate Specialist																
Appoint GP with Specialist																
Interest in Palliative Care																
to support GP training																
Advanced communication																
training roll out																
Cross sector training																

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Action		20	12			20	13			20	14			20	15	
	Q 1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Work with 3 rd sector																
stakeholders to roll out the																
Gold Standard Framework																
Implementation of																
Ambulance Command &																
Control IT System																
Implementation of IT EMIS																
'cloud computing' system																
Complete Specialist																
Palliative Care Team in																
post																
Intermediate Care																
Services fully operational																

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4 Stakeholders

4.1 Stakeholder involvement in service model development

The Working Group that assisted the development of this OBC and service model were:

- Andrew Luksza, Consultant Physician HSSD
- Lindy Taylor, Sister/Specialist Nurse, Renal Unit HSSD
- Angela Bradshaw, Palliative Care Nurse Specialist HSSD
- Rev Maureen Turner, Hospital Chaplain HSSD
- Ann Kelly, Lead Nurse, Paediatrics HSSD
- Nigel Minihane, GP
- Gari Purcell-Jones, Chair Jersey Hospice Care
- Nikki Bailhache, Hospice GP facilitator
- Pippa Knight, Palliative Care Nurse Specialist Jersey Hospice Care
- Pamela Massey, Director of Family Nursing & Home Care
- Pat MacFarlane, District Nursing Sister Family Nursing & Home Care
- Helen Hooper, Head of Nursing Older People HSSD
- Barbara Selvon, Head of Nursing, Ambulatory Care HSSD
- Craig Smith, Clinical Educator HSSD
- Patrick Le Coz, Finance Officer HSSD
- Tessa Cavey, Finance Officer HSSD
- Elsa Viera, HR Officer HSSD
- Anne Bertalli, Secretary to Rose Naylor
- Rose Naylor, Chief Nurse HSSD (SRO)
- Honor Blain, Senior Manager Workforce Planning (OBC Lead)
- Scott Maslin, KPMG
- Hugh Neylan, KPMG

Additional stakeholders will be involved as the FBC is developed:

	Are they			
Stakeholder Identified	Responsible (will work to deliver the OBC)	Accountable (answerable for the delivery of the OBC)	Consulted (opinions sought)	Informed (kept up-to- date on progress)
Social Security			√	√
States Members			√	√
SRO – Rose Naylor	√			
HSSD Corporate Directors		√	√	√
States Departments Social Security Treasury Housing Education + external			~	\
Law Society			√	√

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Stakeholder	Are they			
Identified	Responsible	Accountable	Consulted	Informed
Private Health /			√	√
Insurance				
Public Health	✓	√		
Inspection and registration				
Third Sector	√		√	→
Autism				
Parishes				
Care Homes				
Samaritans				
Public Health				
Diabetes Mind				
Alzheimer's				
Stroke Association				
Macmillan				
BHF				
Asthma				
Neurocare				
JKPA Jersey Cancer				
Hospice	√	√	√	√
-				
Pharmacy	√	√	√	✓
Ambulance	√	√	✓	√
Funeral Directors	√		√	√
Crematorium				
Viscount				
Chaplaincy	√		√	√
Psychologists	√		→	→
. cycliciogicto				
Community and	√	✓	✓	✓
Social Services				
All				
(Oakwell)				
GP and Primary	✓	√	√	√
Care Body Acute Hospital	√	→		√
(includes				
consultants)				
JETS				
Specialist Nurses	√	√	√	✓
FNHC	√	√	✓	✓
Resuscitation				
Committee,				
Ethics Committee,				
Drugs and				
Therapeutics				

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4.2 Communications to Internal Stakeholders

The SRO will meet with the Corporate Directors and Health Minister to inform them of progression and for high level decision making.

OBC leads will meet monthly to discuss developments/changes and interdependencies

The SRO and End of Life OBC Lead will meet on regular basis for discussion and planning for completion of FBC.

Members of the Working Group will update the SRO and OBC Lead on outcomes of further analysis.

The OBC Lead will consider outcomes of further analysis in context with the costs of the proposed service within the FBC.

4.3 Communications to External Stakeholders

Some external stakeholders will require communications at a particular point or stage in the programme; others will want or benefit from communications throughout.

The approach and mechanisms for regular and occasional communications with external stakeholders include:

- SRO and OBC Lead will meet with stakeholders representing other States of Jersey Departments to appraise and inform them on the development of the End of Life OBC.
- Updates with States of Jersey stakeholders will be monthly unless specific information and/or further analysis required.
- Jersey Hospice Care will hold a Palliative Care Conference towards the end of 2012. The draft End of Life care pathway will be presented and discussed at this conference.
- The OBC Working Group will need to agree an awareness raining strategy for the public. Use of the local media will be included in this.

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5 Conclusion and Next Steps

5.1 Conclusion

Current services for patients nearing End of Life are minimal and inconsistent in relation to standards and quality.

The numbers of patients who end their life within an acute hospital bed is an indication of a lack of choice and support to remain in their place of residence, in familiar surroundings and in privacy, comfort and dignity.

The acute model of End of Life care is unsustainable and inappropriate given the demographic changes anticipated as a result of the ageing population. More effective use of JGH beds could be achieved by development of a community-based model of care.

The new model will ensure accessibility and affordability for all patients in the last twelve months of life regardless of age or disease. Through the development of the hospice model option for all patients it is anticipated that, for those who prefer to move from their normal place of residence in the final stages of their life, there will be a more appropriate environment to meet their needs rather than a busy acute hospital ward.

The key benefits are an improvement in the quality and experience of patients and families, and improvement in choice and dignity. This is achieved through providing support and symptom management to enable living and dying well using a modern, measurable framework for care.

The single point of information and facilitation ensures effective coordination and streamlining of care, directing care where it is most needed to provide best value for money and empowering Islanders to understand more about the nature and trajectory of disease and what to expect at End of Life. It is anticipated that this will affect a culture change, where discussions relation to End of Life and subsequent death are undertaken in an open manner to enable adequate and appropriate planning to occur.

The reduction in demand for acute beds for End of Life care will reduce the pressure in acute beds and enable capacity to respond to the complex acute care needs of the ageing population.

The model will provide increased development and professional scope within nursing. It will also improve working relationships across the full range of sector provider agencies, and support common aims, consistent pathway standards, guidelines and tools.

5.2 Capacity and project management requirements

Changes to End of Life services will need to be delivered with current planning and project management capability and capacity.

Additional specialist skills for health and social care staff will be secured through a combination of recruitment, training and ongoing support.

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It is likely that a restructure of management will be required to ensure robust leadership and operational management capacity.

Support and discussion will be required across a range of Departments of the States including Treasury & Resources and Social Security

5.3 Next Steps

This OBC will be finalised in the Full Business Case (FBC). The FBC will aim to:

- Verify the continuing need for investment in the project
- Demonstrate that the preferred solution represents value for money
- Establish that the HSSD is capable of delivering the service change
- Confirm that the planned investment is affordable
- Demonstrate that HSSD is capable of managing a successful implementation and subsequently sustaining success
- Provide an essential audit trail for decisions taken
- Identify how benefits will be realised and monitored
- Confirm the investment decision
- Support and test the market

The FBC will need to be approved and provide sufficient assurance to senior management that the service developments can proceed and resources can be committed.

The FBC is used as a reference point in the event of any business changes during the project lifecycle and in the event of a post project review or equivalent major review following implementation of the project.

The timeframe for development of the FBC will be the end of 2012.

Sign	off by	Ministe	r

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Appendices

Appendix 1 - Benefits Log

What is the benefit	Туре	Short term or long term?	How will the benefit be measured	What is the baseline	Target
Privacy and dignity in death	Service users Patients Carers	Ongoing	 Patient satisfaction survey Preferred place of care documentation Pre-bereavement question Staff satisfaction survey Audit of preferred priorities & Advanced Care Planning 	No baseline	80% satisfaction achieved in patient and staff satisfaction surveys 50% preferred priorities achieved 50% advanced care plan compliance
Improved choice – on place to die, and on care during the end of life stage	Service users Carers Staff	Ongoing	 Patient satisfaction survey Preferred place of care documentation 	Some basic data available e.g. from FNHC, Residential and nursing care homes, and on deaths in hospitals	 80% patients /relatives satisfied with information and services. 50% achieved preferred place of death.
Increased patient and carer experience, with reduced distress	Service users Staff Carers	Ongoing	 Staff/patient satisfaction survey Pre-bereavement question 	Patient complaintsPicker survey	80% reduction in patient complaints

What is the benefit	Туре	Short term or long term?	How will the benefit be measured	What is the baseline	Target
Clarity, expectations managed, greater understanding of what might happen and the type and location of care that they will receive. More information available, in more accessible locations	Service users Staff Carers	Ongoing	Lack of information for services users, families/carers	2011 and 2012 audit data	80% directed to Single Point of Access for signposting for information and entry onto the End of Life Register
Reduction in wait for residential care	Service users Carers Staff Acute sustainability	Ongoing	Number of service users waiting for a home dying in acute care	JGH audit figures	50% reduction on patients within JGH awaiting long term care placement
Reduced hospital admissions and reduced hospital bed days	Service users Carers Staff Acute sustainability	Ongoing	Bed daysAdmission rates	228	 40% reduction in hospital admissions 40% reduction in acute bed days
Reduced repeated admissions	Users Patients Carers	Ongoing	 Admissions per head of population Register 	PARR No baseline	50% reduction on JGH acute admissions associated with EoL care
Reduction in ambulance journeys	Service users Carers Staff Service sustainability	Ongoing	Ambulance call outs	68 home to JGH transfers	50% reduction of ambulance call outs associated with EoL care
Improved access, regardless of age or disease/condition	Service users Carers Staff	Short and long term	Single point of access audit	2011 and 2012 audit data	40% achieved in user/patient/carer satisfaction survey

What is the benefit	Туре	Short term or long term?	How will the benefit be measured	What is the baseline	Target
More streamlined, seamless care	Service users Carers Staff	Ongoing	 Bereavement questionnaire Palliative care outcome score Satisfaction surveys Register 	No baseline	 50% carer satisfaction achieved from bereavement questionnaire 95% of patients on Register 50% of patients discussed at MDT 95% satisfaction achieved within patient surveys
Reduced crisis management	Patients Carers Users	Ongoing	 Audit LCP Advanced care Planned admissions Reduced Hospital Staff satisfaction Audit of register 	No baseline	 80% of patients provided with EoL services/specialist support. 95% staff referrals actioned 50% reduction in JGH admission 50% achieved preferred priorities of care
Increase in confidence and reduction in burden on informal carers	Carers Service users Voluntary Organisation sustainability	Short and long term	Relative/carers satisfaction survey	No baseline	50% reduction in Carers Association being contacted for information/support re EoL care
Improved co-ordination, which reduces duplication and improves quality of care	Patients Carers Service users Staff Service sustainability	Long term	Patient satisfactionCarer satisfactionStaff satisfactionReduced costs	2011 EoL audit data 2011 EoL drug costs	 80% of Palliative Care Team referrals 25% reduction in EoL drug costs 80% satisfaction achieved in patient/carer survey

What is the benefit	Туре	Short term or long term?	How will the benefit be measured	What is the baseline	Target
Improved efficiency in the future, through the use of modern technologies such as telecare	Patients Carers Service users Staff JGH Consultant and GP sustainability	Long term	 Patient satisfaction Carer satisfaction Staff satisfaction Reduced costs Contained ambulatory care activity 	 Annual audit of out patients activity Patient satisfaction Carer satisfaction survey Staff satisfaction survey 	 40% of patients avoiding JGH clinic appointments 40% cost containment from reduction in JGH clinic activity 80% satisfaction achieved in patient/carer survey
Standardisation use of equipment/contracts cost benefits	Service users. Carers Staff Tax payers	Ongoing (initially high)	 Patient safety Reduced procurement costs Reduced maintenance costs Staff satisfaction Improved access to equipment 	 Previous equipment register audit Datix incident records Previous audit of equipment costs 	80% compliance with equipment procurement 50% reduction in equipment related incidents 10% reduction in previous equipment costs 10% reduction in maintenance costs 80% satisfaction achieved in staff survey
Improved access to spiritual care.	Service users Carers Staff	Ongoing	Patient satisfactionCarer satisfactionStaff satisfaction	 Carer satisfaction survey Staff satisfaction survey 	80% achieved satisfaction in patients/ carers and staff satisfaction surveys

What is the benefit	Туре	Short term or long term?	How will the benefit be measured	What is the baseline	Target
Improved monitoring of costs	Tax payers	Short and long term	 Standardisation of drug formulary Reduction in EoL drug costs Reduced equipment costs 	Pharmacy auditProcuremen t audit	80% prescribing from standardised formulary 80% procurement compliance from standard equipment list
Reduced repatriation to UK	Service users Carers Staff Taxpayers	Ongoing	 Reduced repatriation costs Reduced staff time for transfer 	No baseline	 2012 audit of EoL repatriation costs 2012 staffing audit for EoL repatriations
Improved recruitment and retention, and improved staff morale:	Staff Patients Carers Users	Ongoing	 A more interesting and broader role, with enhanced roles and the introduction of specialist nurse roles More attractive career paths Improved specialist nurse succession planning Up-skilling of staff to support their further development Improved team working Increased job satisfactions, as staff are able to support more 	 2011 and 2012 vacancy data 2011 and 2012 Recruitment and retention data Staff survey 2011 & 2012 Sickness and absence data 	 Improved calibre of applicants to posts 80% satisfaction achieved in staff survey 20% reduction in sickness and absence

			service users and carers in their own homes Increased staffing in the community, which should reduce pressure and sickness absence		
Reduced prescribing	Patients Carers Users	Ongoing	 Audit of LCP Pain management score Nurse prescribing audit Complaints around pain 	No baseline	80% compliance achieved with drug formulary 20% reduction in prescribing costs
Increase number of transplants from increased organ donation	Patients Carers Users	Long term	 Extended life expectancy improved quality of life 	No baseline	Audit transplant data at point local transplant services implemented
Reducing high cost and / or unnecessary treatment	Patients Carers Users Service sustainability	Long term	 EoL Audit Pain management score Nurse prescribing audit Audit complaints around pain 	2011 & 2012 EoL audit data No baseline for nurse prescribing	 50% patient understanding achieved re EoL treatment options 80% compliance achieved with drug formulary 20% reduction in prescribing costs

APPENDIX 2 - Stakeholders Log

	Are they			
Stakeholder Identified	Responsible (will work to deliver the OBC)	Accountable (answerable for the delivery of the OBC)	Consulted (opinions sought)	Informed (kept up- to-date on progress)
Social Security			√	√
States Members			✓	✓
Corporate Boards		√	√	✓
SRO	√			
States Departments			✓	✓
Law Society			✓	√
Private Health / Insurance			✓	✓
Public Health Inspection and registration			√	
Third Sector Jersey Hospice Care Family Nursing & Home Care Autism Jersey Parishes Care Homes Samaritans Diabetes Mind Alzheimer's Society Stroke Association Macmillan BHF Asthma Neurocare JKPA Jersey Cancer				
Jersey Cancer Pharmacies			√	<u> </u>

Ambulanas Camias			_/
Ambulance Service		V	V
Funeral Directors		✓	✓
Crematorium			
Viscount			
Chaplaincy		√	✓
Psychologists		\checkmark	√
Community and Social Services		\checkmark	√
GPs and Primary Care Body		\checkmark	√
Acute Hospital		\checkmark	✓
JETS			
Specialist Nurses		\checkmark	✓
Resuscitation Committee		√	√
Ethics Committee			
Drugs and Therapeutics Committee			

APPENDIX 3 - Risk Log

Risk (description)	Likelihood (High / Medium / Low)	Impact	Controls (What has been done or will be done to work around the issue?)
Sustainability of Third Sector providers is undermined	L	Н	Joint working and consultation
Competitive tension is undermined if all specialist End of Life care was provided by one organisation	M	Н	Appointments and investment to be made across all existing providers
Lack of agreement for non medical prescribing	М	Н	Palliative Care Specialist working with GPs to achieve Gold Standard Framework and best practice
Non-achievement of bed day savings, as full savings dependent on full implementation (including intermediate care in 2014 and Rapid Response teams in 2016)	Н	Н	Clarity on benefits and timings – to take into account ramp- up to full implementation
Inconsistency of learning outcomes	L	Н	 EoL training strategy developed alongside OBC Third Sector provider has already commenced multi sector training Conference planned for late 2012 Training needs analysis in 2012 Funding for training included within OBC
Increased costs required to incentivise Primary Care activity	Н	Н	 Palliative Care Associate Specialist working with GP community. Discussions ongoing about logistics of multidisciplinary teams
Lack of coordination between professionals	M	Н	 Stakeholder involvement Continued engagement with GP community Introduction of Gold Standard Framework and Liverpool Care Pathway Support for patient pathway and best practice OBC investment for 2013 includes staffing to ensure standardised approach and coordination
Retention challenges from existing HSSD HCA workforce moving to community roles	Н	н	 Develop a mix of existing and new HCA staff Regular and sustained recruitment into JGH HCA bank to ensure availability of staff Partnership with Careers Service/ Education Sport and Culture to identify individuals for non-registered roles
Not selecting the appropriate education	L	Н	HSSD and Third Sector provider have identified and

programme			commissioned appropriate training programmes and providers
Lack of agreement regarding the vision and new model No change in culture - medical approach to End of Life continues	Н	Н	GP with Palliative Care Interest to commence in post, to maintain momentum across GP and wider community Multidisciplinary team and the EoL Register will trigger for discussion on each patient
Reticence from professionals to hold the 'difficult conversation'	М	Н	 Dependent on quality of training and learning outcomes relating to Advanced Communication training roll out. Training arranged and first cohort identified
Failure to recognise and refer patient "Patient Possession" professional refusal to "let go"	Dependant on education and culture	Н	 Role of Liverpool Care Pathway nurse will reduce risk Role of Specialist Practitioners for support and advice, with key workers delivering frontline care
Lack of integration and coordination of services	Н	Н	Success of scheme is dependent on development of Rapid Response Team and Intermediate Care services
Inability to collect data IT infrastructure does not link acute, community, Third Sector and Primary Care	Н	Н	OBC includes 2014 funding for IT EMIS 'cloud computing' to enable sharing and access to core data across sectors
Inadequate workforce capacity Inability to recruit to new roles Inability to train and support existing staff in new roles	Н	Н	 Training strategy developed Training Needs Analysis required for existing staff across all sectors
Reticence from patients / service users and carers to exercise choice	M	M	 End of Life Care team currently in place working with professionals and carers Improved cross sector agency working should improve awareness Multidisciplinary team to identify EoL patients, with professional discussion by GP and/or key worker Awareness and attitude to death and dying planned for later 2016 onwards
Social Security benefits and allowances do not support pathway	high	High	Chief Officer- level agreement required on development of appropriate financial support during end of life
Lack of co-ordination of equipment issues and returns Increased costs for home adaptation and equipment	High	High	 Standardisation of equipment and EoL Register Grab bags/Just in Case boxes already purchased and in use by a Third Sector provider The likelihood of co-morbidities in EoL patients suggests that adaptations to homes would be required due to a previous existing condition
Model of MDTs struggles in single handed practices	Н	Н	 Discussions already ongoing in relation to logistics of Multidisciplinary teams and GP workload GP attendance at team meetings

Rev Date Author

			GP with Palliative Care Interest post to act on behalf of GPs and liaise /advise in their absence
Security issues for access to citizen's portal Ownership, population and maintenance of	Н	Н	 Work with IT providers to ensure security Permissions and profile to be allocated to specialist staff.
information			• Fermissions and prome to be anocated to specialist stail.
Standards, policy, procedures not agreed,	Н	Н	Lack of compliance identified through audit
and/or not adhered to			Joint appointment across Third Sector and HSSD to
			facilitate change Shared ownership and development of policy should
			prevent non compliance
Cross boundary risks – understanding where and when boundaries exist	Н	Н	Work ongoing with joint Associate Specialist appointment across HSSD and Third Sector provider
Conflict between organisations and professions			Training programmes will be multi agency/professional to encourage shared vision and goals
			Consistent reinforcement of patient pathway and experience
			Regular stakeholder meetings to support change

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APPENDIX 4 - Issues Log

Description	Impact (High/Medium/Low)	Lead	Comments (What has been done or will be done to work around the issue?)
Maintaining clinical competency across all practitioners and professionals	M	Palliative Care Associate Specialist, Dr Nicola Bailhache Chief Nurse and Director of Governance, Rose Naylor	 Link into a strategic group/body for island Training strategy applied cross boundary Governance strategy Clarity and definition, expectations of roles Create robust communications Ensuring existing post holders are pivotal to developing training strategies and TNAs
Robust standardisation, policies and procedures, formulary	Н	Chief Pharmacist, Drugs and Therapeutics Committee, Paul McCabe,	
 Equipment: Lack of equipment, choice of equipment Defining liability and ownership Maintenance contracts Funding 	Н		 Improve data to identify needs Research/guidance from UK and Hospice at homes models Standardisations of McKindlay syringe drivers
Political and practitioner will to engage and support the pathway	Н	 Palliative Care , Associate Specialist, Dr Nicola Bailhache Senior Responsible Officer, Rose Naylor Health Minster, Deputy Anne Pryke 	 Review funding and incentivisation to GPs Introduce End of Life care onto QIF Base on UIK models to incentivise GP's to attend MDT's

APPENDIX 5 - Enablers and Dependencies Log

Description of Dependency	Dependency Lead	Dependency 'Strength' (High/Medium/Low)	Comments			
Intermediate Care OBC: • 24 hour Home Care • Rapid Response	Honor Blain John Cox (Intermediate Care Lead)	Н	Development of Rapid Response in particular and Intermediate care is pivotal to success of the EoL Care Pathway implementation and forms the clinical indicator for best practice			
Dementia OBC: • 24 hour Home Care • Rapid Response	Honor Blain Ian Dyer (Dementia Lead)	Н	Dependent on 24/7, Intermediate Care and Rapid Response teams			
Children's OBC – Need to ensure coordination from diagnosis to end of life for children	Ann Kelly Andrew Heaven (Children's Lead)	M	Ensure coordination of complex need for children at point of diagnosis			
COPD OBC: • 24 hour Home Care • Rapid Response	Honor Blain Linda Diggle (COPD Lead)	Н	Dependent on 24/7, Intermediate Care and Rapid Response teams			
Third Sector providers, including Family Nursing & Home Care and Jersey Hospice Care	Julie Gafoor (Director of FNHC) Dr Gari Purcell Jones (Jersey Hospice Care)	Н	Work is ongoing with both agencies in relation to activity, policy development and future services			
Ambulance command and control	Gari Purcell-Jones	Н				
GP funding and QIF	Nigel Minihane	Н	UK QOF includes End of Life care			
JGH	Andrew McLaughlin	Н				
Existing Community teams	HSSD Community and Social Services FNHC, Jersey Hospice Care	Н				
Other States Departments, particularly Housing and Social Security	Employment & Social Security, Housing Treasury Education Sport and Culture	Н	Long Term Care Benefit and access to timely benefits and allowances			
Changes in pharmacy drug list	Paul McCabe (Chief Pharmacist)	Н	Skilling up existing pharmacist to "specialise" in palliative care drugs and lists			

Policies development and implementation	Dr Nicola Baillache (Palliative Care Associate Specialist)	Н	Policy development is ongoing Implementation of Liverpool Care Pathway				
Long Term Care Benefit Other allowances and benefits	Mark Richardson	Н	Continued discussions with Social Security Department				
Central server and out of hours IT system	Karen Gray/ PCB	Н	Currently on hold due to elections				
Legal considerations:	lan Dyer	Н					

Appendix 6 – Financial Analysis

Note: the costs shown in the table below, and throughout the document, have been inflated to reflect the relevant prices for each year

Note: the costs shown in the table below, a Initiative total and resource requirements		Implemen tation Date	•	2014 Revenue	2015 Revenue £'000s	2013 Capital £'000s	2014 Capital £'000s	2015 Capital £'000s	2013 Revenue Implementation £'000s	2014 Revenue Implementation £'000s	2015 Revenue Implementation £'000s
A) Palliative Care Support									_		
Palliative Care Associate Specialist	0.5	Jan-14	-	41	42	-	-		-	-	
GP Palliative with Care Interest	1	Jul-13	58	119	122	-	-	-	-	-	
Palliative Care Associate Specialist Admin	0.5	Jan-14	-	19	19	-	-	-	-	-	
Liverpool Pathway Nurse	1.5	Jan 2013 / Jun 2013	68	82	84	-	-	-	_	-	
Consultant Nurse	1	Jan-13	65	66	68	-	-	-	-	-	
Childrens Palliative Care Nurse	1	Jul-13	30	61	63	-	-	-	-	-	
Fast Track Palliative Care Co-ordinator	1	Jul-13	19	39	40	-	-	-	-	-	
Liverpool Pathway Admin Support	1	Jan-13	32	33	33	-	-	-	-	-	
Off Island Consultant Palliative Care Support		Jul-13	13	27	28	-	-	-	-	-	
Admin Support		Jul-13	-	-	-		-	-		-	
GP Visits		Jul-13	12	25	25	-	-		-	-	
B) 'CPD & Consumables				L			•		•		
Non Medical Prescribing Backfill	1	Jan-13	45	14	14	-	-	-	-	-	
Training		Jan-14	36	46	48	-	-	-	. 57	-	
Grab Bag		Jan-14	-	37	38	-	-	-	-	-	
Just In Case Packs		Jan-14	-	88	90	-	-	-	-	-	
Telecare		Jan-14	-	9	9	-	-	-	-	-	
Ambulance		Jan-14	-	-	-	-	-	-	-	-	
IT EMIS		Jan-14	-	17	17	-	- 108	-	-	-	
Ambulance Command & Control		Jan-13	-	-	-		-	-	-	-	
Staff I Pads		Jan-14	-	7	7	-	-	-	-	-	
Transport		Jan-14	-	54	56	-	-	-	-	-	
Estates		Jan-14	-	-	-	-	-	-	-	-	
C) Administration Costs of New Posts		-	•		-	-	-	-	•	•	
Recurrent Costs		Jan-13	21	22	23	-	-	-	-	-	
Non-Recurrent Costs		Jan-13	-	-	-	-	-	-	. 76	-	_
Total Capital and Revenue Costs	8.50		399	806	826	-	108	-	133	-	-