Business models in health care: Accounting for the sustainability of palliative and end of life care provision by voluntary hospices' in England

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Abstract

This study evaluates the sustainability of palliative and end of life care provision by voluntary hospices in England. Using a mixed methods, inductive approach, we construct a *'descriptive business model'* for hospices which is grounded in analysis of relevant accounting information, and supported by narratives extracted from interviews with senior clinical and non clinical managers from four large and medium sized hospices. The study reveals the strengths and weaknesses of the hospice business model and evaluates its robustness against forthcoming challenges. Our findings highlight the gradual transition from a basic voluntary sector business model to a complex, highly sophisticated, and institutionalized care establishment, sharing many of the characteristics found in large private and public organizations. The sustainability however of the business model is threatened due to its exposure to a number of contradictory forces. Whilst demand for palliative and end of life care going forward is set to increase, due to both demographic and regulatory factors, hospices' voluntary income is highly volatile. Dependency on sustaining a complex network of stakeholder groups to underwrite income, challenges the hospice business model's ability to cope with the anticipated challenges.

Key words: Voluntary hospices, Charity accounting SORP, hospice business model

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1. Introduction

In its modern form the term hospice is connected with the provision of palliative care to terminally ill patients. World Health Organization (1990) defines palliative care as *"the active total care of patients and their families when the patient's disease is no longer responsive to curative treatment."* Such a care, including sufficient symptom relief of the illness and psychological support for both the patients and their families, can be obtained in hospices (Moore and Naierman, 2002).

Attempting to discover the roots of what is currently worldwide known as *"The Hospice movement"* one may come to the conclusion that in the ancient times *"hospice ideology"* appeared to share or be part of the general principles of care and hospitality of each culture. Milicevic (2002) suggests that the roots of the words hospice, hospital and hospitality are the same, dating as far back as the 4th century A.D. and connects this with the ancient Greek word "xenodochion" which is the place where hospitality is provided.

According to material published by the Hospice Information organisation in 2005, the term hospice was first associated with the care of dying patients in the 19th century in France by Madame Jeanne Garnier. Madame Jeanne Garnier founded the Dames de Calvaire in 1842 and opened the first hospice for the care of dying in Lyon in 1843. The Irish Sisters of Charity introduced the term hospice in Dublin by opening Our Lady's Hospice in 1879. St. Luke's Hospital 1893 and St. Joseph's Hospice in Hackney 1905 were the next units established for the care of dying patients.

Modern hospice movement was initiated by the efforts of Dr Cicely Saunders who established St. Christopher's Hospice in London in 1967. The book of Elisabeth Kubler-Ross "On death and dying", in 1969, brought death to public awareness in the USA causing much public reaction and facilitating the spread of hospices in USA. Due to the efforts of Cicely Saunders and others the hospice movement has spread out all over the world with various forms from country to country, promoting primarily a philosophy of care rather than a type of building or service (Milicevic, 2002).

Since the opening of St. Christopher's Hospice the hospice movement experienced rapid growth within Britain. The voluntary sector is still at the forefront of the developments in the country's palliative care field both at a service and research level. More than 70 per cent of the available palliative care units are managed by voluntary sector initiatives, providing

around 80 per cent of the available beds for adult in-patient care. The great majority of these hospices are independent, local charities, but large charities like Marie Curie Cancer Care and Sue Ryder as well as the National Health Service (NHS) also provide palliative care services (see The National Council for Palliative Care (NCPC) 2011, NCPC 2006, and Hospice Information 2005).

In their vast majority hospices are independent, service delivery voluntary organizations (Handy 1992), governed by trustees and regulated by The Charity Commission. Hence, palliative care services in England are mainly funded through charitable activities and fundraising, with the government covering, just around one third of the voluntary hospices' expenditure. However, as palliative care providers, they also have to comply with the relevant Health and Social Care Standards (Palliative Care Funding Review 2011, Help the Hospices 2009, DoH 2002, Care Standards Act 2000).

Palliative and end of life care services, provided by voluntary hospices mainly lay within one of the following categories: in-patient care, community care, day care, bereavement, and outpatients (see NCPC 2011, NCPC 2006, and Hospice Information 2005). Even though these categories provide a framework which facilitates broad understanding of the service type, when looking at individual hospices one finds diversity in meanings, definitions, processes, capacity, and length of service provision.

Despite their leading role in the country's palliative care field when viewed at sector level, individual hospices operate within a broad range of diverse standards. Those standards are largely influenced by the level of each hospice's financial autonomy, service provision capacity, the vision and priorities of its founders/trustees and the relationship – financial dependency/independency – with the local health authority PCT (Ellis 2012, Department of Health 2009, Help the Hospices 2006a, Kings Fund 2005, Finlay 2001). The combination of the above factors largely influences both the choices/options of services individual hospices opt/required to provide and their role and strategic direction within their local health establishment.

After almost fifty years of development and gaining substantial importance within the society, the British voluntary hospice sector appears to be in forefront of major challenges in terms of strategic orientation, choice and funding of provided services, income volatility and increased regulatory requirements. The ageing population, the requirement to provide palliative care services to a wider patient base, the competition for charitable fundraising, the

implementation of relevant regulatory requirements associated with their collaboration with the NHS, challenge the sector's status-quo. Within this changing context it is becoming a necessity to develop robust strategies in order to sustain its viability (Theodosopoulos 2011, Dent & Haslam 2006, Haslam & Marriott 2006, Pickles 2006, Help the Hospices 2006, Hospice information 2005, Kirk 2004, Finlay 2001). This paper adopts an accounting business models framework of analysis to reveal the strengths and weaknesses of the voluntary hospice sector and evaluate its robustness against the forthcoming challenges.

Despite the plethora of research in palliative and end of life care addressing its clinical, social, historical and political aspects which has been developed over the last decades (see for example Davison 2010, Association of Children's Hospices 2006, Milicevic 2002, Sauders 2001, Clark 1998, Denice & Walter 1996, Saunders 1993, Kubler-Ross 1969), the literature on voluntary hospices *'business elements'* is fragmented and scattered within academic and practitioner discourses. However, it can still collectively reveal some of the challenges facing this sector and assist in constructing and evaluating the sustainability of a relevant *'business model'* (Theodosopoulos 2011).

Haslam et al. (2013), Andersson et al. (2010) and Haslam and Andersson (2012) make a distinction between a *'productionist'* and a *'financialized'* scope to the term business model. Under the productionist approach the term is used for a broad range of informal and formal descriptions to represent core aspects of a business which can include purpose, offerings, strategies, infrastructure, organizational structures, trading practices, operational processes, and policies. On the other hand under the financialized approach one adopts a broader perspective, the aims are not so much process focused even though the core activities of a business are still taken into account.

Maximisation of shareholders' wealth is the primary objective within a commercial setting Pike and Neale (2008), whilst the maximisation of benefits to beneficiaries, on a broad sense, can be seen as the primary objective within a voluntary / charitable setting (see Nicholls 2009, Landsberg 2004, and Anheier 2000). Hence from an accountant's standpoint identification of strengths and weaknesses would take into account issues relevant to investment sustainability and risk, market requirements and perceptions, and relevant stakeholders' interests Haslam et al. (2013).

This paper accounts for the sustainability of the voluntary hospices' business model in England. Using a combination of numbers and narratives we construct a descriptive business

model, in line with the works of Haslam et al. (2013), Theodosopoulos (2011), Andersson et al. (2010), and Haslam and Andersson (2012) and then we ascertain its robustness, in the light of associated current and future challenges.

The literature review is used to define the core activities of hospices and to further our understanding on the socio-historic-economic-regulatory context within which they developed and operate. Interviews with 9 clinical and 9 non-clinical directors from four hospices across a range of regions, reveals both the gradual transition to a more complex and sophisticated business model, as well as the anticipated challenges for the future. Finally, analysis of financial information from the accounts of the largest 35 hospices in the country, covering the period from 2004 to 2011 and nearly 50 per cent of the sector's total income and expenditure, reveals both the volatility of their income as opposed to their steadily increasing expenses, as well as their dependency on sustaining a complex network of stakeholder groups to underwrite the diverse sources of this income. Both of these factors challenge the hospice business model's ability to cope with the anticipated challenges and threaten its sustainability on the mid to long term future.

2. The landscape of palliative and end of life care provision

Following to a rapid growth throughout the first three decades after the opening of St. Christopher's Hospice, the hospice sector appeared to enter the maturity stage of its life cycle - as the term maturity is explained by Bender and Ward (2009) - in terms of its service provision capacity, during the early 00's. This can be seen on charts one and two, which demonstrate the growth in palliative care services provision capacity in the form of units – palliative care settings – and beds, from late 70s to 2005. With more than 70 per cent of the available palliative care units and 80 per cent of the available beds for adult in-patient care being managed by voluntary sector initiatives, the voluntary sector is still at the forefront of the developments in the country's palliative care field.

Even though the development of hospice movement was initiated in the UK by the voluntary sector there is now a closer cooperation with the NHS which is managing about 29 percent of in-patient hospices (Palliative Care Funding Review 2011, Department of Health 2009, and Hospice Information 2005). This cooperation with the NHS, through contractual arrangements, had been anticipated by Cicely Saunders even before the opening of St. Christopher's hospice (Clark 1998). In 1987 palliative care was recognized as a service that

the state was responsible to provide. However, government funding has not always reflected the change on the service's status (Help the Hospices 2001).

Chart one: source data found through the Hospice Information centre during 2008

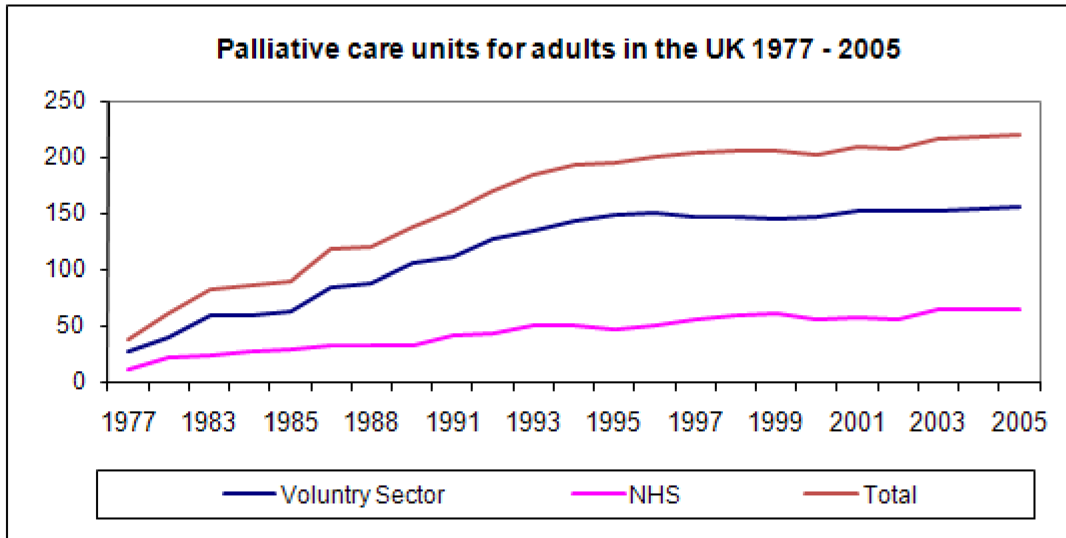
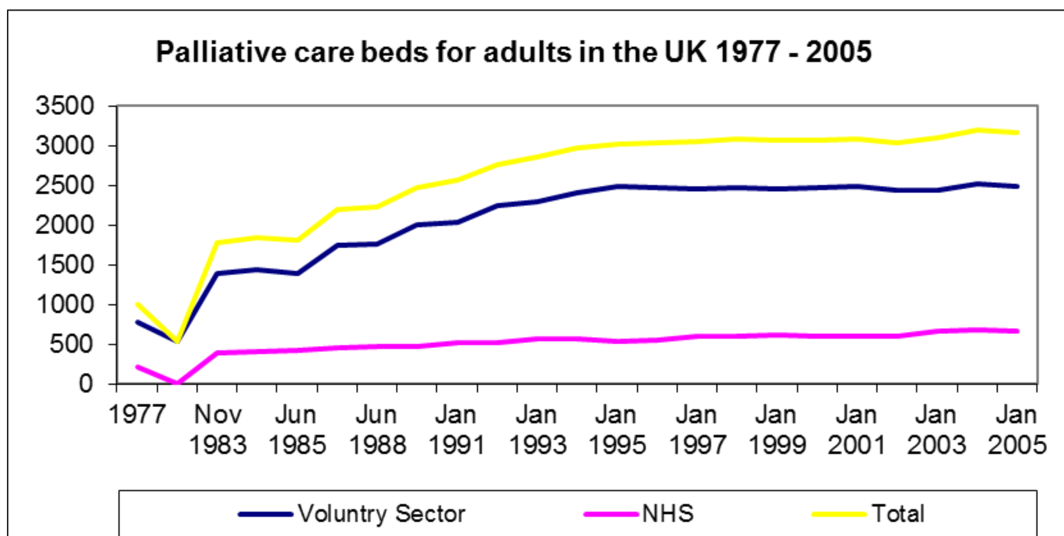


Chart two: source data found through the Hospice Information centre during 2008



Charitable status allowed hospices to develop independently and organize their services based on the needs of the communities within which they operate. Though, reliance on non-statutory sources and lack of central planning in terms of need for palliative care resulted to an ad hoc development of services, depending mainly on the vision of the founders and their anticipation of the specific needs of each hospice's locality. The initial emphasis on developing and providing palliative care services to adult cancer patients and the

comparatively belated development of services to other patient groups is seen as a consequence of this ad hoc development (see Finley 2001).

The initial focus on providing terminal care to cancer patients has been progressively shifted to a more holistic model adjusting to both the domestic and the international developments. The current approach anticipates the need of providing palliative care to diverse patient groups and considers diagnosis as the starting point of palliative care provision recognizing a complementary role for palliative care compared to the role of curative treatment. (Hospice Information 2005, Finlay 2001, Saunders 2001).

The role of the patient's family and their specific needs attract more attention and services to support the family both before the death and during the grief period have been developed. Additionally, social aspects related to palliative care provision by multidisciplinary teams of carers have been raised and the related research on various approaches of palliative care and end of life care grows continuously (NCPC 2011, Payne 2006, Seymour et al. 2005, Hospice Information 2005, Addington – Hall et al. 2004, Monroe & Oliviere 2003, Twycross 2003, World Health Organization 2002, Finlay 2001, Saunders 2001, National Council for Hospice and Specialist Palliative Care Services 2000, O'Neill & Fallon 1997, Higginson 1993, Saunders 1993).

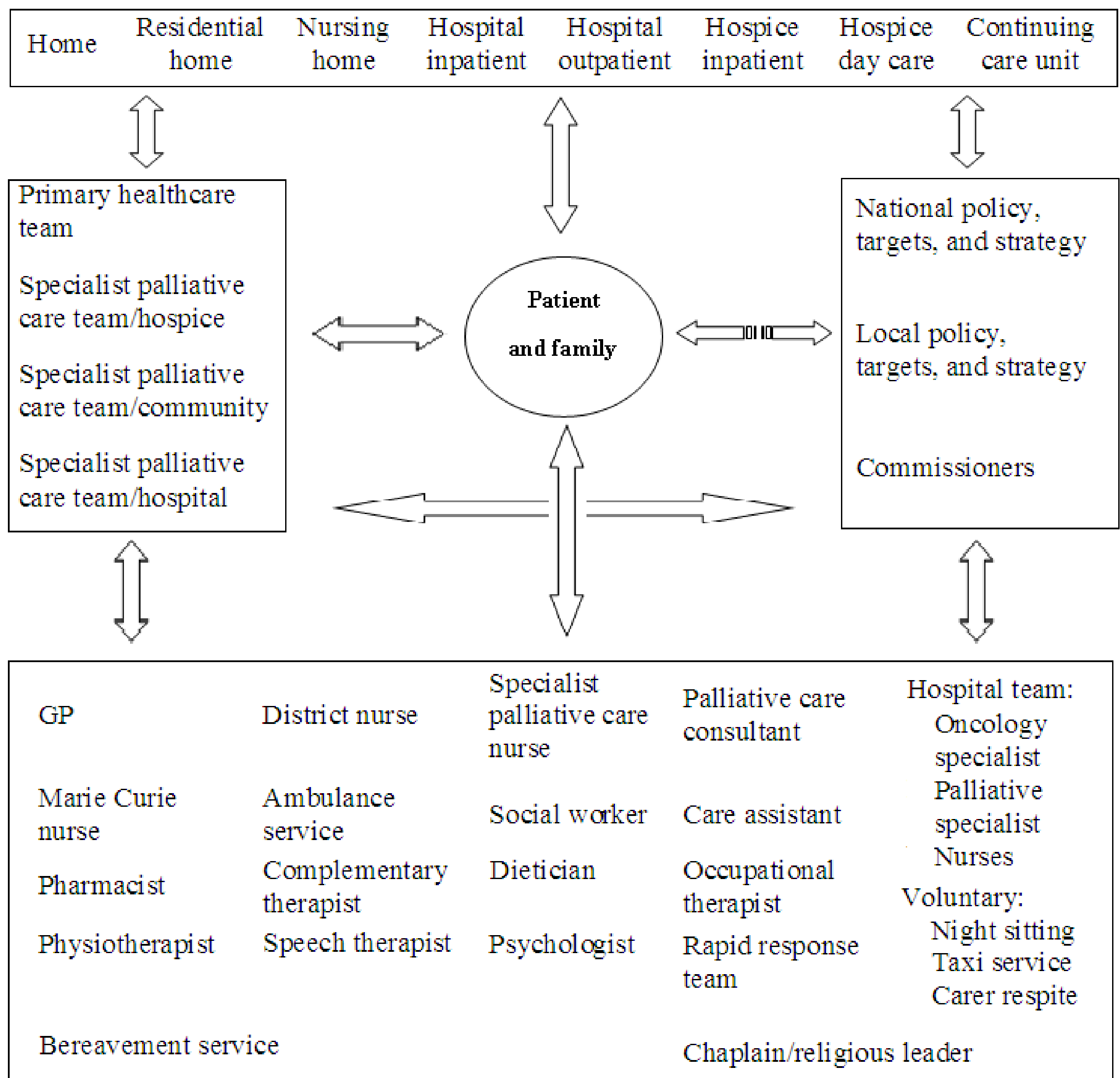
2.1 The environment of the voluntary hospice sector in England

Following to the development of the hospice voluntary sector, the recognition of palliative care as a service the state has to offer, and the involvement of the NHS, the service's provision evolved in to *"a complex whole system"* (Kings Fund 2005:4). Involving a large variety of professions across a range of very different sectors (figure 1), modern palliative and end of life care provision is largely commissioned by Primary Care Trusts (PCT) at a regional level. Alongside with PCTs, acute trusts, and other voluntary organisations, hospices are called to undertake an increasingly demanding role within the wider context of both local needs and national priorities and policies (NCPC 2012, Hospice Information 2005, Kings Fund 2006 and 2005).

Despite their leading role in the country's palliative care field when viewed at sector level, individual hospices operate within a broad range of diverse standards. Those standards are largely influenced by the level of each hospice's financial autonomy, service provision capacity, the vision and priorities of its founders/trustees and the relationship – financial

dependency/independency – with the local health authority PCT (Ellis 2012, Department of Health 2009, Help the Hospices 2006a, Kings Fund 2005, Finlay 2001). The combination of the above factors largely influences both the choices/options of services individual hospices opt/required to provide and their role and strategic direction within their local health establishment. This leads to a diversity of services provision by different hospices, both at type and length level, as well as to difficulties in defining the exact components on each service.

Figure one: Providing palliative care: a complex 'whole system' (Kings Fund 2005:4)



2.2 Government planning, policy framework, and funding

Even though hospice movement was introduced and developed primarily by the voluntary sector, the concept of palliative and end of life care service provision gradually attracted the interest and was recognised as a necessity by the government. "*Perhaps the greatest achievement of the modern hospice movement is that palliative care is now acknowledged by the state as essential. Indeed, since 1987 all health authorities have had an obligation to develop plans for palliative care in collaboration with the voluntary sector"* (Help the Hospices 2001:64). Consequently a series of issues started to arise regarding, policy targets at local and national level, the relationship between NHS and hospices, as well as the commissioning and funding of services (see Ellis 2012, Department of Health, 2012 and 2009, NCPC 2012, Help the Hospices 2008, Hospice Information 2005, Help the Hospices 2001, Finley 2001 and others). Looking into these developments helps lay the foundation of constructing the hospice business model and developing our understanding of the interdependencies and relationships amongst key stakeholders.

"Trustees cannot normally use a charity's funds to pay for services that a public body is legally required to provide at the public expense. However, trustees may use a charity's resources to supplement what the public body provides"(Charity commission 1998). During the development of hospice movement, voluntary hospices have gradually been moved from providing, a non-recognised as a responsibility of the state service, to supplementing a service which is a recognised responsibility of the state. However, there is an ongoing debate over whether government funding has been reflecting the theoretical change on the service's status and hospices have been consistently in need of covering, on average, around 70 per cent of their expenditure through various means of charitable fundraising (Ellis 2012, Palliative Care Funding Review 2011, Theodosopoulos 2011, Help the Hospices 2009, Help the Hospices 2001).

A policy framework for the commissioning of cancer services was set out through the Calman–Hine report in 1995, in response to much public discussion about the inequalities in cancer care around the country. The report highlighted the need for planning, in order to direct resources to areas of greatest need. The specialist nature of palliative care service provision was also recognised, as well as the need for further development of relevant skills

to maintain care quality. Although this report focused on services for cancer patients, the subsequent government executive letter revealed that its principals applied equally to those for patients with other life-threatening conditions. This was introducing a challenge for the cancer centred system of palliative care provision at the time (see Department of Health and Welsh Office 1995)

The aim to increase provision of palliative care to non cancer patients was further strengthened through *"The NHS Cancer Plan"* and the *"Manual of Cancer Services Assessment Standards"* in 2000. The later document recognized that the major contribution to palliative care services was coming from the voluntary sector and outlined the need for hospices to become more integrated with the NHS. The necessity for agreed national service standards was also included as a condition for government funding through the NHS.

The *"End of Life Care Strategy"* published by the Department of Health attempted to develop the strategic framework on both commissioning and delivery of palliative care services. Aiming to widen access, standardize quality, and coordinate provision, the document placed emphasis on the role of PCTs as central coordinating facilities for the commissioning of palliative care at locality level (see End of Life Care Strategy 2008). The government's strategy recognized that the demand for palliative care delivered to a wider base of patients would require additional resources. It also documented the difficulty of calculating the cost of end of life care in UK, even though presented as a challenge the country could not afford to ignore.

Help the Hospices in 2006 grouped hospices into four bands based on the size of their annual expenditure. Size and expenditure (availability of funds) directly influence hospices' service provision capacity. An example of the level of influence is the fact that 87 per cent of the hospices in the lower band do not provide in-patient care and focus mainly on day and/or home care. In 2009 this grouping was adjusted to better reflect the current picture of the sector Help the Hospices (2009). This paper uses the 2006 classification in conjunction with information on each hospices income for sampling purposes as the 2009 changes did not have a material impact on the sample selection.

Table one: Classification of hospices based on size of annual expenditure (Help the Hospices 2009 and 2006)

	Number of hospices	Percentage of total expenditure	Average expenditure million (£)
Hospices with expenditure more than £4m	23	47	5.8
Hospices with expenditure £3m to £4m	16	20	3.5
Hospices with expenditure £2m to £3m	24	20	2.2
Hospices with expenditure £1m to £2	18	10	1.6
Hospices with expenditure less than £1m	19	3	0.5

Acknowledging the importance of developing a sustainable system for end of life / palliative care funding, the coalition government initiated a review in July 2010 which aimed to provide recommendations towards developing a new per-patient funding system. The review was published in 2011 introducing a national payment structure which aimed to cut variations around the country in what the government pays for and what it does not. Integration of health and social care as well as patient choice has been placed at the heart of the review. Clinical commissioning groups comprising of General Practitioner (GP) practices and other health professionals will replace PCTs under a new structure of end of life care service commissioning (Palliative Care Funding Review 2011, King's Fund 2011).

The new initiative even though welcomed in principal by most involved parties is expected to face and bring providers and commissioners of palliative and end of life care services under a number of challenges.

> *"In order to satisfy the diverse need of individuals at the end of life, as well as those of their families, care can involve a wide range of services, spanning multiple sectors and settings. The significant variability in co-ordination between services can result in end-of-life care being disjointed and ineffective, which is often a cause of distress, and this fragmentation of care can make the transition from one provider to another particularly difficult"*
>
> (King's Fund 2011:2)

> *"The review makes a number of bold recommendations about the way care should be funded in the future and we urge the government to deliver on its promise to reform the patchy and inconsistent funding system for hospice and*

palliative care in England. However, with NHS funding already under pressure, it is vital that independent charitable hospices and other providers of palliative care are protected during the long transition to a new system. We cannot risk destabilizing the current provision of funding which would have serious implications for people facing the end of life and their friends and family."

(Praill 2011at: *http://www.helpthehospices.org.uk*)

Hospices are currently not only required to meet their own internally set governance practices and policies but are also subject to external assessments for example, hospices must meet the regulatory requirements of: the Care Quality Commission (CQC), and care professional regulators, the Charities Commission and complex obligations set into NHS commissioning contracts. In January 2011 the Healthcare Bill was introduced and this envisages a substantial restructuring of the regulatory framework within which healthcare will be commissioned, financed and regulated. The combination of regulatory and organization reforms which will place some GPs and not all PCT's in charge of NHS commissioning and the financial climate within which these changes are to take place heightens uncertainty for voluntary hospices (see Ellis 2012, Richardson 2012, King's Fund 2011, Praill 2011, Theodosopoulos and Haslam 2010).

2.3 Governance and reporting

The majority of hospices are independent, service delivery voluntary organizations (Handy 1992), governed by trustees who report to the Charity Commission and comply with the relevant Health and Social Care regulations (Palliative Care Funding Review 2011, Help the Hospices 2009, DoH 2002, Care Standards Act 2000). Charities in England and Wales are subject to the regulatory requirements of the Charities Act 1993 (as amended in 2006) which sets the criteria for an organization to be recognized as a charity and ensures the protection of charitable gifts. This is because being a charity secures for the organization a considerable reputational benefit as many people are inclined to offer time and money to a charity in ways that they would be very reluctant to do for a non-charitable institution. Hence regulation ensures that courts and the Charity Commission have recognized powers to intervene in cases where donors' funds have been diverted to non-charitable purposes (Morgan 2010).

Most charitable organizations in England and Wales are required by legislation to publish financial statements comprising in general by a trustees' annual report, and annual accounts to ensure the accountability of the sector. Charities above the income threshold of £250,000 have to prepare accounts on accruals basis in compliance with the charities Statement of Recommended Practice (SORP). These accounts must include a statement of financial activities (SOFA), a balance sheet, and extensive notes. The SOFA, (see table 11 for an abbreviated version) is practically an income and expenditure account. Running down the table charities are asked to report: incoming resources, expenditure, transfers and other gains and losses and running across categories income, expenses, gains and losses into unrestricted, restricted or endowment (capital) funds (see Morgan 2011, Theodosopoulos 2011, Morgan 2010, SORP 2005).

Table 11: SORP Statement of financial activity, Source: Theodosopoulos (2011:120)

	Unrestricted	Restricted	Endowment
Incoming resources:			
By type of income received			
Resources Expended			
By type of activity			
Transfers between funds			
Other gains and losses			
Asset revaluation			
Gains / loss on investments			
Fund balance brought forward			

"The classification of incoming resources and resources expended by activity is encouraged for all charities preparing accruals accounts. Smaller charities maybe excused from adopting this approach by legislation recognizing that such information is likely to be less relevant to the users of small charity accounts". (SORP, 2005 revised paragraph 93) Based on Help the Hospices' 2009 and 2006 analyses of hospices' accounts, the vast majority of voluntary hospices in England and Wales are within those charities that have to fully comply with the provisions of the Charities SORP whilst preparing their annual accounts. Those accounts have to then be publically available and to be filed with the charity commission, hence securing a source of sufficient data for both public scrutiny and - for the case of this study - research purposes.

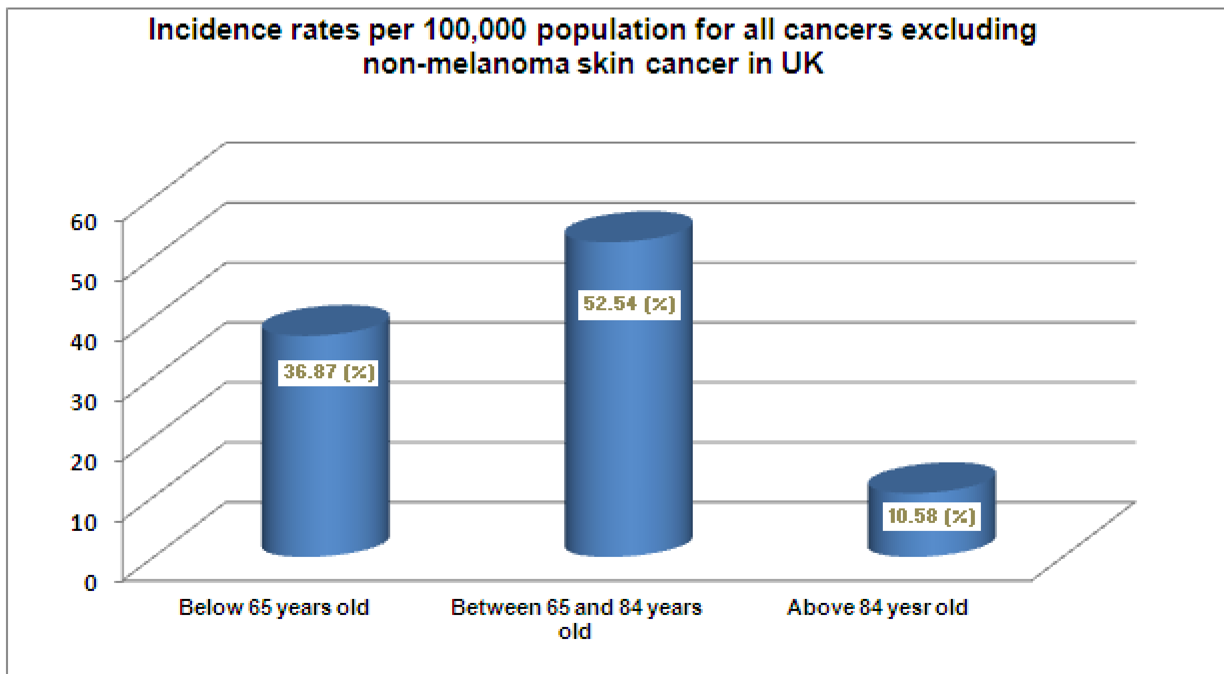
2.4 Increasing demand due to ageing of the country's population

During 1985-2010 there was an increase of 20 per cent in the number of people ageing 65 and above to 10.3 million or 17 per cent of the total population. Additionally, the number of people aged 85 and above, more than doubled during the same period of time (see UK National Statistics 2012). Given that cancer is a disease of the elderly, see chart six below, changes in population demographics add to the demand for palliative and end of life care services hence directly increasing the pressure on hospices.

> *Population ageing will continue for the next few decades. By 2035 the number of people aged 85 and over is projected to be almost 2.5 times larger than in 2010, reaching 3.5 million and accounting for 5 per cent of the total population. The population aged 65 and over will account for 23 per cent of the total population in 2035, while the proportion of the population aged between 16 and 64 is due to fall from 65 per cent to 59 per cent.*

(UK National Statistics 2010: http://www.statistics.gov.uk/hub/population/ageing/)

Chart six: Incidence rates per 100,000 of population for all cancers excluding non-melanoma skin cancer in UK Source: Data found through Cancer Research UK in 2012



Apart from issues related to the widening of patient base in need of palliative and end of life care services, which were explored in sections 2.1 and 2.2, demographic factors are imposing additional challenges on the voluntary hospice sector. Population projections show that by 2035 the population aged over 65 will have doubled and if we assume that the incidence in cancer rates per 100,000 of the population remains at current (or slightly lower) levels it is still the case that the demand for palliative and end of life care services from hospices and other providers will almost certainly double.

Within the next sections we draw on the expertise of 18 senior clinical and non clinical hospice managers to reveal the transition of the voluntary hospice business model into increasing levels of sophistication and complexity. We also identify and evaluate the challenges hospices are expected to face in the foreseeable future. Finally, we construct a descriptive hospice business model to reveal both the fragility and volatility of hospice income. This is based on the a analysis of financial accounts - covering the period from 2004 to 2011 - of the top 35 hospices ranked by their total income which accounts for approximately half of all hospice income in England.

3. Transition to a complex business model and identification/evaluation of future challenges

A wide range of indicators that the hospice business model has become increasingly complex, during the rapid development of the hospice movement between the late 1970's to middle 2000's, has been revealed on the literature review. The increasing level of sophistication and complexity of provided care services, in conjunction with the increasing demand for palliative and end of life care lead hospices to gradually rely more on highly qualified clinical personnel instead of volunteers. This has an impact on both the movement's ideals and orientation with a shift towards institutionalisation and professionalization.

Their voluntary foundations and reliance on charitable funding led hospices to gradually develop organisational characteristics beyond those found in typical care settings. The necessity to secure large portions of their funding through fundraising and relevant trading activities, requires skills found mainly in commercial settings. The initial reliance on volunteers to handle the administrative aspects of the business model became superseded due to the difficulty of managing the associated stakeholder groups and the increased competition

for funding. This also led to the recruitment of large numbers of commercially minded professionals which also influences the movement's ideals and orientation and increases the complexity of the business model.

A broad spectrum is revealed in terms of the clinical participants background, level of training, and duration of employment either within a hospice or within a relevant specialty The majority of medical directors joint the hospice movement after a considerable period of employment within the NHS or general practice and they have been employed within the hospice movement for periods ranging from four to 11 years. With one exemption their interest in palliative care was developed during their employment and was not their medical specialty at the start of their careers. On the other hand most nursing directors or senior nurses have been employed in relevant specialties for much longer periods of time and in most cases they have stayed within the hospice sector for periods ranging up to 25 years.

Diversity in terms of background, qualifications, and duration of employment within a hospice is a lot wider in the group of senior non-clinical professionals, compared to senior clinical personnel. Most fundraising directors moved to charity sector after a career in commercial organisations were they gained variable levels of experience in marketing, sales, advertisement, and management. Finance and accounting professionals joint hospices after substantial employment periods in the corporate sector.

3.1 The evolution of the hospice movement in England: towards a more complex business model

Wide spread consensus among the participants that the hospice business model is becoming increasingly complex has been revealed, when they were asked to comment on the evolution of the hospice movement and on any changes they have noticed on its ideals and orientation. The main areas of interest include: organisational change, institutionalisation through the involvement of the government in palliative and end of life care, a gradual shift towards professionalization and medicalization of palliative/end of life care, and increased complexity and spectrum of care provision. The participants’ views on each of these developments and their impact on hospices vary from scepticism for example on the collaboration with the NHS to acceptance of the necessity to become more “business-like”.

> *"..but perhaps it becomes a little bit more professionalized and a little bit more businesslike so there is some shift but what we don't want to do is to lose these qualities of this earlier model because it does bring important things to our service so people's commitment is important to us ..."*

Hospice A: Medical Director

The recognition of palliative care as a service the state has to offer and the involvement of the government through the development of relevant policies, the provision of a percentage of funding to hospices, and the setting of requirements for clinicians training, is an additional cause of transformation, leading the hospice sector towards institutionalisation. Hospices have moved away from their initial charitable organisational characteristics and are now positioned within a wider system of care. This is impacting on their independence through getting them to assume contractual responsibilities, negotiate on targets, and adjust their service provision in terms of both capacity and quality.

> *"I think it's having to become… I won't say more professional, I'd probably say more institutionalized, and NHS-ized ... And I don't think that's… it has some good features, but actually I think it's something that I'm very suspicious of"*

Hospice B: Medical Director

Changes in terms of new types of treatment, increased length of service provision, and the requirement to provide palliative care to non cancer patients has led to increased complexity and sophistication of care provision. This is increasing both the internal complexity of each focal organisation, as well as the expectations and demand for service provision at sector level.

> *"... I would say that the way in which the patients have changed and become more complex and their illnesses with co-morbidities, everything, actually it's not an easy option to work in a hospice anymore..."*

Hospice D: Nursing Director

The evolution/transformation to a more complex model of service provision leads to professionalization and medicalization of the hospice movement and shifts away from the

initial voluntary and predominantly nursing based approach to palliative care. Training of palliative care clinicians, as well as professional development through specialisation and relevant qualifications, is gradually becoming the norm on the sector.

> *"When I first started ten years ago, on the ward, there were very few treatments given on the ward. There was no, we weren't giving blood transfusions. It was much more low key. It wasn't medicalised as such ..."*

Hospice A: Community Nurse Specialist

Hence, the clinical culture within both individual hospices as well as the whole sector is changing towards more standardisation instead of diversity and inclusiveness. (Quote 36). This standardisation though does not lead to decreased operating costs. As a wider range of activities is now the responsibility of trained professionals, instead of volunteers, hospices have to incur additional costs for recruitment and staff development.

> *"Now medical training is very rigid, it follows the same pattern as specialist training in any other specialty, so then it's a very different group of people coming through, it's a little bit more like a sausage machine you get the predictable product at the end. Whilst in the early days we had a wide mixture of people, mostly with very strong personal motivations on this work ..."*

Hospice A: Medical Director

Additionally, cultural changes resulting from increased competition for funding among charities, the need to manage expectations of the public, the challenge of increasing their care provision capacity to accommodate the needs of more patients, and the requirement to recruit sufficient numbers of non-clinical professionals with commercial acumen, comprise the main categories of the participants' interests. Increased levels of business model complexity are easily observed, as the participants highlight the contrast between the way, hospices used to operate during their earlier stages of development and the way they have to operate in the present.

Structural changes became apparent as hospices started to become larger, incorporate additional services for patients, and recruiting more professionals to sustain their care provision capacity. This in addition to recruiting more clinicians led to the requirement of developing adequate management structures and administrative support teams. Hence shifting

the culture of individual organisations from purely voluntary and contribution based, to more structured, professional, and in terms of their non-clinical activities, more market like

> *"In fact, the day unit at the hospice I started at was just, you know, a conservatory; they didn't have a proper building. Now it's huge, the one at XXXX hospice and the same here: we started off with five patients and now, you know, 25 years later, we can take 25 each day"*

Hospice D: Voluntary Services Manager - Fundraising

Increased funding requirements, resulting from the necessity to sustain more sophisticated operating structures, lead to additional investment in fundraising and trading activities. These however are obstructed by the increasing competition with other charities. Consequently, to remain operational within a competitive market, hospices need to sustain a complex network of stakeholder groups to underwrite their varied range of income streams.

> *"And so we have to be a lot more professional, a lot more aware and a lot more able to present ourselves against other charities when, from my perspective, we're looking for money and we're actually sourcing funds"*

Hospice D: Appeals Coordinator - Fundraising

Effective management of public relationships and expectations within each hospice's locality is of vital importance for the sustainability of the above mentioned stakeholder network, as hospices have to appear more attractive to potential donors, volunteers and supporters compared to other charities. This however is challenging due to both out-dated public perceptions, on the way hospices operate, as well as public scrutiny in terms of allocation of funds between charitable activities and administration. Therefore as hospices inevitably become larger and more professional, continuous efforts through appropriate marketing activities are required to educate the public on their changing operating environment.

> *"...we have to be more businesslike, and that's not, I think, what the public actually want to see ... they want responses to their phone calls and their emails, and so on, but what they don't want is for charities to be spending money on the administration behind returning those emails and phone calls, and so on"*

Hospice A: Fundraising Director

3.2 Forthcoming challenges and their impact on the business model

Having identified the changes and the gradual transformation of the hospice movement from a simple voluntary sector business model into a new more complex form, the participants were asked to present their views on what they see as forthcoming challenges for the sustainability of palliative and end of life care provision by hospices in the foreseeable future. The areas attracting most of the participants' attention were related to the ageing of the country's population and the widening of the patient base, the shortage of relevant expertise associated to both the need for training and the difficulty to recruit key professionals, and the shortage of funding to sustain the expected level of service.

3.2.1 Funding of service provision

Securing funding from sustainable sources to enable hospices cope with the increasing demand for their services and to remain competitive within a demanding recruitment market was mentioned as a core challenge by all participants. Government funding through the NHS is seen by most as a potentially key factor for the business model's viability in the future. However, in many occasions the participants expressed their concerns over the requirements attached to this funding.

> *"The more the NHS funds you, the more they expect from you, but at the same time, they actually want it dirt cheap. So what the PCT would like is to have most palliative care delivered by generalists ... but the specialist units have to have a certain lower level of funding to enable them to provide the services that they do"*

Hospice B: Medical Director

The potential threat of becoming an extension of the NHS or having to reduce the standards of service quality in order to meet funding targets was a widespread cause of hesitation. Participants working for financially stronger hospices appear more reluctant to engage in negotiations for additional NHS funding as they expect it to impose limitations on their independence.

"... there might be a lot of reasons that we might not want to come under government funding because then we get involved in all the competition for funding with other specialties and we also get involved with huge bureaucracy which is the NHS and that's not very attractive, at the moment we have our independence we are self-determined to some extent ..."

Hospice A: Medical Director

On the other hand most hospices have to rely on NHS funding to cover major parts of their expenditure. Hence there is no homogenous approach on a potentially optimal funding scenario to meet the requirements of all hospices in the sector. The ability of individual hospices to raise sufficient funds determines their independence as well as their service provision capacity / quality.

"... one of our biggest challenges is getting money and sustaining an adequate amount of money to fund the hospice, because we are a voluntary provider ..."

Hospice B: Nursing Director

With a large portion of their expenses being inflexible, for example the salaries of specialist clinicians, hospices are in need of stable sources of funding, their funding model however is sensitive to a range of environmental conditions. The recent economic downturn for example exposed hospices to income uncertainty as government funding cuts on the NHS limited PCTs ability to provide adequate financial support.

"So, at the moment, of course, the problem is the hospice is in a crisis, the government has run out of money, they've got to make savings in the NHS, so the NHS passes on the financial cuts, if you like, through the PCT

Hospice D: Hospice Accountant

Charitable fundraising is significantly reliant on individual patterns of giving within various communities and also sensitive to uncertain environmental conditions. Existing donors and supporters, for example will rarely adjust their contribution to the percentage increase in hospices' annual expenditure required to sustain similar standards of service provision. Additionally, securing a sustainable group of donors is also challenging in a financial crisis as

individuals may not be in a position to continue their support to charities when the level of their own income is uncertain.

> *"They're used to donating £10. It's their level, if you like. They'll buy £5 worth of raffle tickets and those £5 of raffle tickets every year. They don't by £6 the year after and £7 the year after that because our costs are going up. They're contributing at the same level so we have to find more contributors, if you like"*

Hospice C: Finance Manager

Giving individuals' tendency to spread their donations across various charities from year to year makes investment in renewal and expansion of their potential donors base vital for hospices. This however is restricted by both the size of each hospice's region as well as from the existence of other charities aiming to increase their share of supporters.

> *"... people like to support a charity one year and do something different the next, because they like to feel that their money is being spread around, and that's one of our big challenges ... we need the money year in year out ..."*

Hospice A: Fundraising Director

> *"... there is a little fatigue coming in, particularly when things are hard and lots of people are asking for money"*

Hospice C: Fundraising Director

Diversification of their base of donors, through developing links with local businesses to strengthen corporate fundraising, is a way of securing a degree of income stability and a number of hospices are now starting to engage on this type of activity. Corporate fundraising however, is not yielding equally good results for all hospices as it is also reliant on the general economic conditions of deferent regions.

> *"... we need to start looking outside of that and really concentrate on the business sectors, and getting people involved and doing things like that, because people only have so much money to give"*

Hospice C: Fundraising Director

"With the present economic climate it's very difficult for us to attract money from corporate so, and that's something that's been in a sort of a decline at the moment"

Hospice D: Appeals Coordinator - Fundraising

With charitable fundraising enabling most hospices to maintain a certain degree of independence a mixture of government and charitable funding is seen as a probable development in the near future. Charitable funding is currently used to fund the vast majority of palliative and end of life care services. However, most participants would expect the Department of Health to decide which elements of palliative care are considered standard for all patients and provide adequate funding to cover them. This would allow hospices to use charitable funding for the provision of any additional services and consequently increase the overall quality of palliative care for their patients.

3.2.2 Recruitment and scarcity of relevant expertise

Recruitment, retention, and training of qualified clinical personnel is considered a major challenge which is already affecting hospices' capacity to provide the desired level of care. Scarcity of relevant skills at national level and variable levels of competition with NHS hospitals and neighbouring hospices at local level impacts adversely on both hospices' operating capacity and financial viability. Training targets set at national level, the wider spectrum of patients and the requirement for longer term provision of service, as well as compensation packages for clinicians, have been mentioned as contributing and / or interrelated factors to hospices' recruitment challenge.

"Okay. Seeing we're talking about staffing, I mean, great plans, the end-of-life care strategy, lots of good stuff in it. But they've starved the people to do it at a general level, let alone at the specialist level"

Hospice B: Medical Director

Their initial focus on providing palliative care to cancer patients helped hospices to develop adequate expertise at both generalist and specialist level. However, the requirement to widen their patient base challenges the capacity of their existing personnel in terms of available skills and imposes the need for retraining and recruitment of additional numbers of clinicians.

> *"I think we're finding them a challenge in terms of our knowledge* (referring to non-cancer patients). *Because although we're, sort of, at end stage, sort of, our skills should be applicable to anybody. It's still concerns, you know, we're not trained as respiratory nurses, we're not trained as, you know, renal nurses. So we're just concerned about that the, sort of, challenges of knowledge and being skilled enough to do it"*

Hospice A: Community Nurse Specialist

Internal training and development of skills has been an alternative used by many hospices but with no input at national level training for specialists, the competition for recruitment is only expected to increase. Setting of training targets at national level by the department of health, on the other hand, does not appear to alleviate the situation.

> *"So I think that's quite tricky ... There are… nationally there are over 100 consultant posts that are unfilled in palliative care. It's that there aren't the people ... So yes, there will be some competition for the specialist registrars that are finishing and ready to be consultants at that stage"*

Hospice B: Medical Director

> *"... workforce is obviously an issue in other areas and that's also not just in this specialty but nationally to do with how the Department of Health is determined to put training numbers in medicine or nursing and so on and of course they are always getting that wrong and we either got too many of one sort of doctor or too few of another sort of nurse…"*

Hospice A: Medical Director

Scarcity of adequately qualified and experienced professionals has already led to competition on developing attractive remuneration packages and poses the question of how to make working for a hospice an attractive career path. Matching NHS payment scales and providing

similar employee benefits is becoming a trend amongst hospices. This however has considerable implications on their expenditure and imposes the need for additional investment in fundraising.

> *"Our main competitors are the neighbouring hospices and the neighbouring hospitals but mainly the neighbouring hospices. I remember back two years ago we were fighting over one doctor where to work, we wanted the doctor, we also knew that two other hospices wanted that doctor, so we interviewed the same person, you know, for the three jobs and unfortunately we didn't get her"*

Hospice D: Medical Director

Competition on salary basis has also been acknowledged, by non-clinical directors, as a limiting factor on many hospices' ability to recruit clinical staff and certain categories of non-clinical professionals. This drives many hospices to follow the NHS pay scales to secure access to a competitive recruitment pool.

> *"We want to be able to, when we recruit, make sure we get the same talents and the same abilities that the NHS have and not take on a second tier of clinical staff"*

Hospice C: Finance Manager

In addition to the challenge of recruiting and retaining qualified clinical personnel, scarcity of relevant expertise in fundraising is a significant challenge for most hospices. Shortage of relevant training programmes and qualifications, competition with other charities to attract experienced professionals, and competition on salary basis with private sector organisations to attract professionals with potentially transferable skills, are challenging hospices ability to recruit fundraisers at senior level.

> *"I think just from a fundraising perspective, yes, I'm looking for people with sales and marketing skills. These people could be earning a lot more money elsewhere, so what are you ending up with in a recruitment pool?"*

Hospice A: Fundraising Director

At the same time the requirement to further develop their fundraising capacity forces hospices to invest in developing internally the required skills on the basis of an individual fitting the requirements in terms of interpersonal skills and commercial awareness. Recruitment on the basis of transferable, social, and interpersonal skills frequently becomes an act of necessity for hospices. This however requires considerable investment in time and training before individuals can take up the requirements of their new role.

> *"So the decision I made was to actually find people who've got that warmth and have got that quality, and who've got the business skill I mean, it's business, isn't it, really?"*

Hospice C: Fundraising Director

3.2.3 Increasing demand for service provision due to the widening of patient base to non-cancer patients and ageing of the country's population

Confirming the assumptions made through the analysis of relevant statistics in the literature review, the participants expect considerable increase in demand for palliative / end of life care services in the foreseeable future. Both the ageing of the country's population, as well as the widening of the patient base to non-cancer patients, drive the demand for palliative care services to substantially higher levels. This constitutes a significant challenge for the hospice business model which is already under financial stress and with limited capacity to expand through increasing its clinical workforce due to constrains mentioned on the previous two sections.

Initially hospice care has been positioned around the treatment of cancer patients at the end of their lives and this has influenced both the culture as well as the type of expertise developed within the sector. However over the latest period of their development and partly due to recent government initiatives hospices are increasingly required to provide end of life care to patients with non-malignant conditions. Most participants expressed their concern on hospices' ability to handle the complexity of the conditions new patients bring into the system.

> *"We're looking at doing non-malignant work, so that's putting a huge increase, that's, you know, doubling potentially the amount of patients that*

there are going to be, although I'm not convinced whether hospices should be prime movers in non-malignant palliative care, or whether they should just be advisory"

Hospice B: Medical Director

"And the other thing is, with the end of life care and the all the sort of proposals of what other patients we might taking other than cancer patients, we could be opening the floodgates, I would imagine, to lots of referrals"

Hospice D: Voluntary Services Manager - Fundraising

The ageing of the country's population in conjunction with the increased number of people living longer with chronic illnesses and hence requiring support for longer periods of time, is also increasing the demand and complicates the type of care provision. With a finite number of beds available and with restrictions in recruiting additional staff hospices will be in need of substantial capital investment to upgrade their capacity.

"The challenge would be on trying to make places available for those patients, but also to run our policies alongside them"

Hospice A: Day Hospice Leader

The combination of an ageing population, the widening of the patient base to include non-cancer patients, children and young adults, as well as the increase in numbers of people living longer with complex health conditions and co-morbidities is expected to double the demand for palliative / end of life care services in the future. This is seen as a major challenge for hospices and their ability to continue providing their services without being forced to compromise quality by either focusing on generalist level services or rely on alternative types of care which are currently perceived as cheaper such as care at home.

"Because the difficulty can sometimes be, particularly from myself in day hospice, that despite the fact that they've got on going chronic illnesses the length of their life may actually still be longer than a cancer patient, and therefore can we accommodate places for perhaps periods of years as opposed to periods months?" .

Hospice A: Day Hospice Leader

Hospices' service provision capacity has gradually reached a maturity stage where, to cope with additional demand, substantial investment in recruitment and development of new care premises will be required. Funding for this investment however, might not become available as many hospices are already financially stretched.

> *"And, you know, the biggest chunk of our cost is staffing as we've increased… and obviously we need the specialized staff. So it's not just about increasing the beds. You need extra nurses, you need extra doctors if the clinics get too big"*

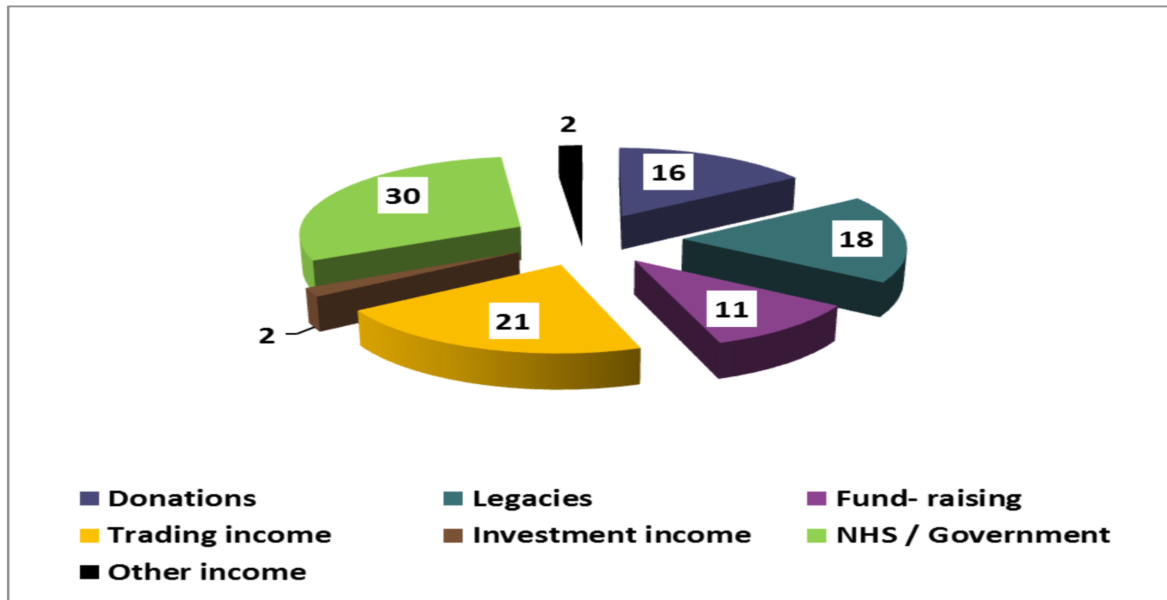
Hospice C: Fundraising Director

4. Evaluation of the hospice business model's financial sustainability

Considering hospices' transition into a mature and complex business model of care provision and the challenges to the business models' sustainability – increased demand for service provision, increased funding requirements due to increasing operating/recruitment costs, and scarcity of relevant expertise in the recruitment market – this section provides an analysis of relevant financial information focusing on the top 35 hospices ranked by their total income. Based on Help the hospices 2006 and 2009 classifications, we estimate that this group accounts for roughly half of all hospice income in England. At the top of our list, we have St. Christopher's hospice receiving £19.1 million of income in 2011, and at the bottom of our group, we have St Wilfrid's Hospice (Eastbourne) with an income of £3.5 million. The majority of hospices are thus operating with income levels below £3.5 million to provide high quality in-patient and day care facilities in addition to hospice at home visits and family support and bereavement within their localities.

The group of 35 hospices reviewed in this paper are therefore not physically representative of the hospice voluntary sector where there are many small regionally embedded hospices. However, they are a financially significant sample. Aggregating the financials for this group, we are able to describe the underlying characteristics of the hospice business model in terms of trajectory and composition of income and expenditure. Hospices generate their income from a range of sources all of which have varying properties (see chart four below).

Chart four: Top 35 UK Hospices Revenue Breakdown 2011, Source: Charity Commission for Hospice annual report and accounts



Hospices sources of income have varying characteristics and levels of volatility, for example legacy income can be volatile because it depends on both a specific set of conditions governing the pattern of giving as well as on capital market valuations. Hospice cost structures are such that a small fraction of income remains as a cash surplus each year. To deal with income volatility and growing expenses hospices' trustees tend to hold 10-12 months of reserves as cash and investments (see chart six). This aims to sustain the level of palliative care services they provide and also maintain their capacity to generate income through fundraising and their trading activities which incur additional expenses to keep it all going. However, as demonstrated in chart five, over the last few years expenses have moved ahead of growth in total income in many hospices. Hence, many hospices have needed to draw upon unrestricted balance sheet reserves and adjust their reserves policies.

Chart five: Top 35 Hospices Revenue and Surplus Operating Income £mill, Source: Charity Commission for Hospice annual report and accounts various years

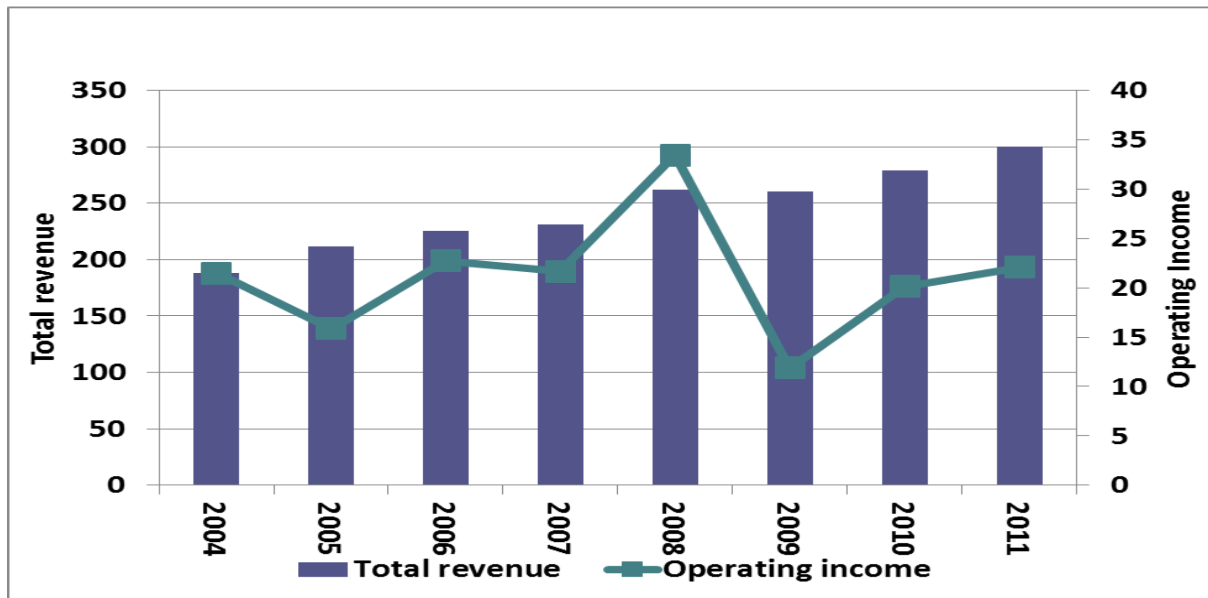
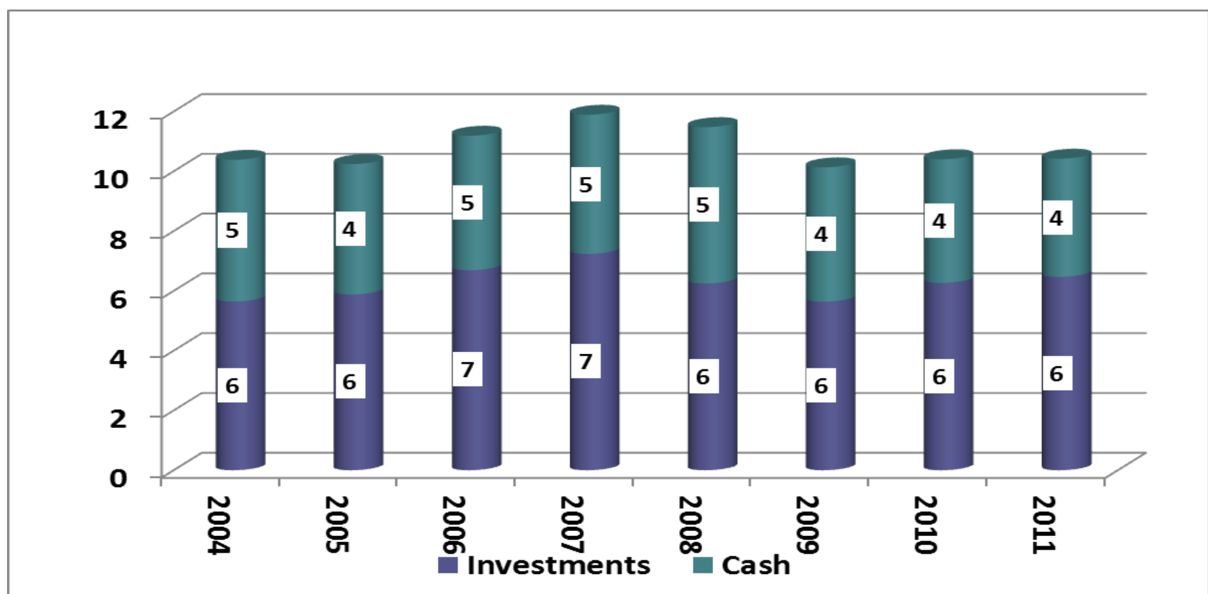


Chart six: Hospices Balance Sheet Cash and Investments (Months of total income), Source: Charity Commission for Hospice annual report and accounts various years



Despite the decline of revenue growth in relation to the increasing expenditure, our analysis above indicates an aggregate stability in terms of the share of hospice income from various sources when viewing the entire group. However, this conceals the vulnerability of individual hospices and their weaknesses to, sustain income and operating surpluses, maintain sufficient reserves on their balance sheet and manage their exposure to capital market risk. Below we

see two examples of individual hospices to highlight the risk exposure of palliative care provision at locality level.

Chart seven: Trinity Hospice, Income by source £ mill, Source: Charity Commission for Hospice annual report and accounts various years

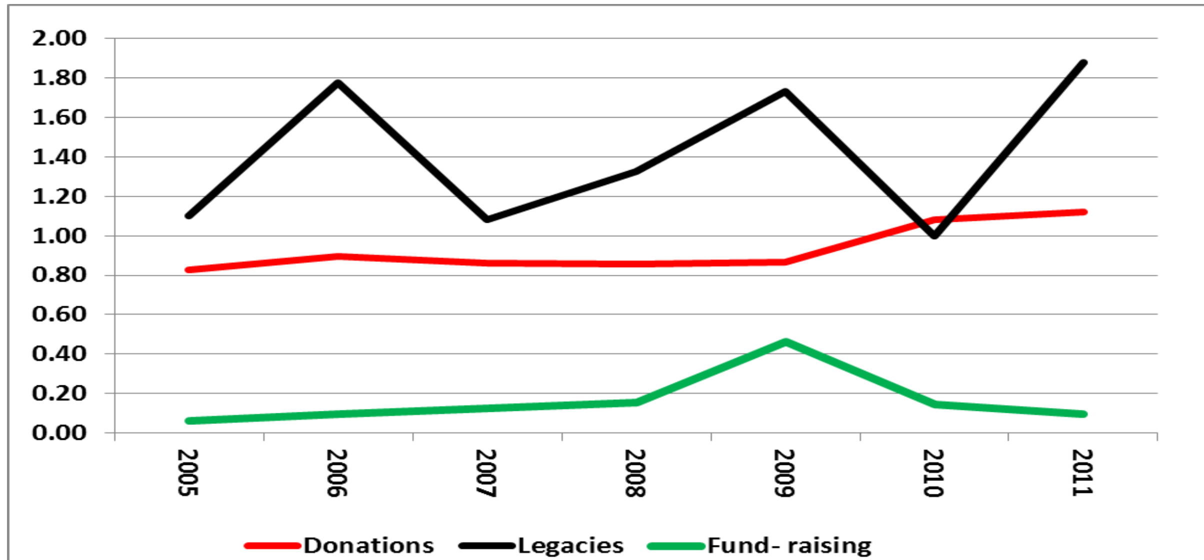
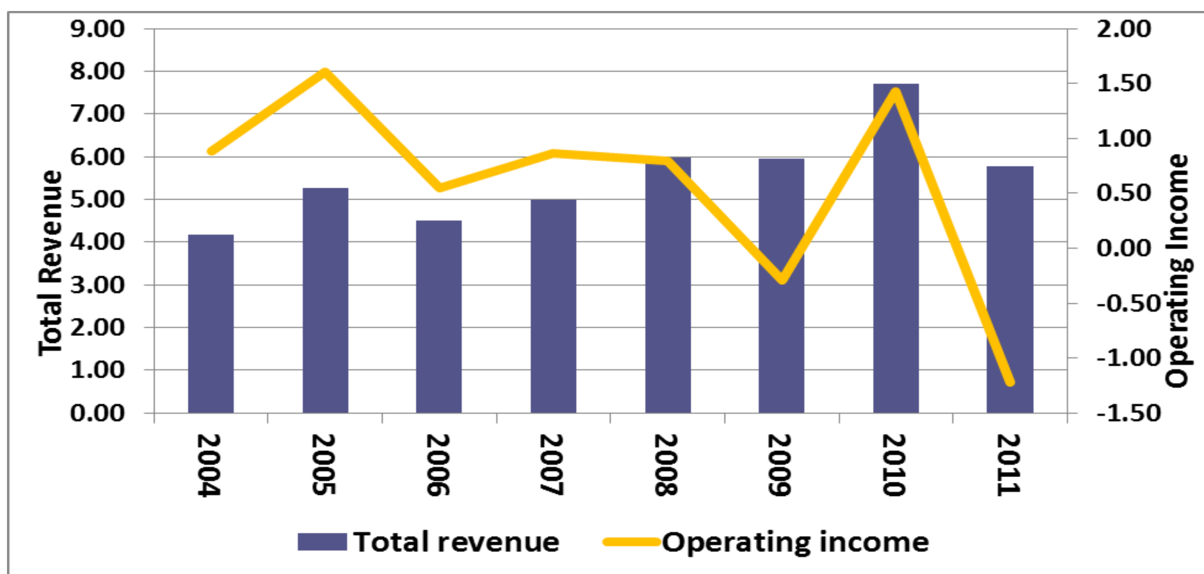
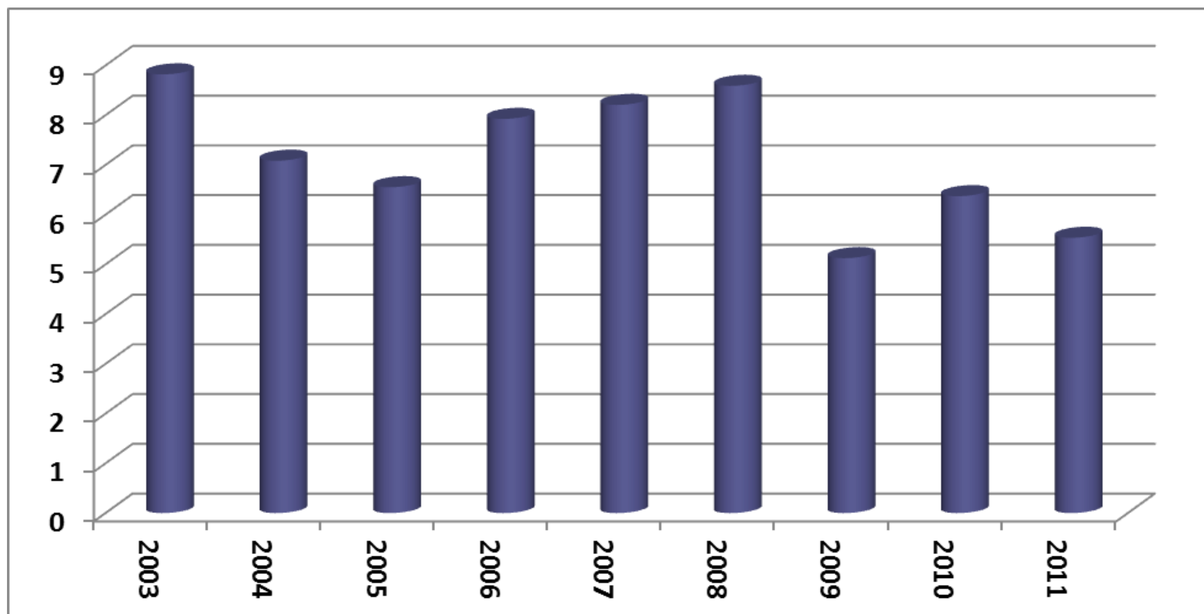


Chart eight: Trinity Hospice, Revenue and Operating Income £mill, Source: Charity Commission for Hospice annual report and accounts various years



In the case of Trinity Hospice charts seven and eight reveal the volatility of the hospice's various sources of income and the associated volatility of its operating margins. This volatility in conjunction with a situation where expenses persistently run ahead of growth in total income and force hospices' trustees to draw upon unrestricted balance sheet reserves leads to their gradual depletion. St. Francis Hospice for example (see chart nine) is running with around half the available reserves compared to the sector's average shown in chart six.

Chart nine: St. Francis Hospice, Investment and Cash Reserves in Months, Source: Charity Commission for Hospice annual report and accounts various years



Hospices are exposed to a variety of contradictory forces including revenue and income volatility, expenses running ahead of income to preserve care services, investment volatility from changes in capital market valuations. For example a hospice like St. Francis can find itself with a reducing operating surplus, a drain from cash reserves and losses on investments made in the capital market. Dependency on sustaining a complex network of stakeholder groups to underwrite income, challenges the hospice business model's ability to cope with the anticipated challenges.

5. Summary

The objective of this paper was to construct a descriptive business model for voluntary hospices in England and to evaluate their ability to maintain their current standards of palliative and end of life care provision in the face of forthcoming challenges. A review of relevant literature explored the evolution of the voluntary hospice movement from its commencement with the establishment of St. Christopher's Hospice to its current mature state. This helped to outline the landscape of palliative and end of life care provision by voluntary hospices in England as well as to find indicators of the business model's transition towards complexity and causes for potential challenges to its sustainability.

Interviews with 18clinical and non-clinical directors from four hospices revealed the transition into a more complex business model. It also helped to identify increased demand for service provision, increased funding requirements due to increasing operating/recruitment costs, and scarcity of relevant expertise in the recruitment market, as the main anticipated challenges for the business model's sustainability in the foreseeable future.

Organisational change in the form of transitioning from being, purely voluntary care settings to becoming, *" more business-like"* is evident through both the participants' mentioning of it, as well as through their descriptions of the range of activities comprising hospices' service provision and its sustainability. The wider range and the longer duration of the services provided by hospices, require the development of suitable organisational and management structures and recruitment of / reliance on, professional staff rather than volunteers. This consequently leads to the requirement of additional funding which however needs to be secured through a variety of sources with variable volatility and sustainability characteristics.

The increasing cost of service provision in conjunction with the increasing competition for charitable funding is seen as a major challenge for hospices by all participants, when asked to present their views on what they see as forthcoming challenges for the sustainability of the hospice business model in the future. Recruitment of suitably trained/qualified clinical personnel and fundraisers has been identified as a major challenge for hospices, as shortage of much needed relevant expertise directly affects hospices' capacity to provide the desired level of palliative and end of life care. It also often leads to competition on salary basis with neighbouring hospices, hospitals, and - in the case of fundraisers - private sector organisations, which adversely impacts on both hospices' operating capacity and financial viability.

Considerable increase in demand for palliative and end of life care services, due to the widening of the patient base to non-cancer patients and the ageing of the country's population, is also seen by the participants to threaten the sustainability of the current standards of care provision. This constitutes a significant challenge for the hospice business model which is already under financial stress and with limited capacity to expand through increasing its clinical workforce due to the aforementioned scarcity of suitable expertise.

The analysis of financial information from the accounts of the largest 35 hospices in the country, helped to construct the financial aspect of the business model. It also revealed both the volatility of hospices' income as opposed to their steadily increasing expenses. This highlights the vulnerability of hospices to income uncertainty from donations, legacies, and trading, in addition to the impact of fragile financial market conditions which cause fluctuations in holdings gains/losses on invested funds and pension deficits. Hence, hospices' dependency on sustaining a complex network of stakeholder groups, to underwrite their diverse income streams, is becoming apparent.

Therefore we argue that hospices share many of the financial characteristics of a private sector business model, especially their exposure to uncertain income streams. Managers and trustees are motivated to maintain their capacity to generate income and either maintain or increase palliative care provision in the community. However, this often drives internal and external expenses ahead of income forcing hospice managers and trustees to draw down and deplete free cash reserves.

The Government's end of life care strategy draws upon the capacity and additional choice provided by charitable voluntary hospices in England. However, the fate of this state-voluntary sector policy intersection depends on the stability of the hospice business model in the medium to long-term future. The sustainability though of the business model is threatened due to its exposure to a number of contradictory forces. Whilst demand for palliative and end of life care going forward is set to increase, due to both demographic and regulatory factors, hospices' voluntary income is highly volatile. This conjuncture threatens to restrict the growth in palliative and end of life care capacity, unless the government takes active steps to secure a strong partnership with voluntary hospices and consider how it can contribute to stabilising the underlying financial business model.

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