Policy Review in a Specialist Field
Service Evaluation and Leadership
Advanced Research Methods

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A thesis submitted for the Doctorate in Clinical Practice

THESIS PART TWO

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December 2014

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INTRODUCTION TO PART TWO OF THE THESIS

Part two of the thesis consists of the achievements gained from undertaking the taught elements of the Doctorate in Clinical Practice programme (DCP).

The three academic assignments from the policy analysis, advanced research methods and service evaluation and leadership modules are presented. This follows on from the review of the researcher’s learning and development (in part one; chapter 7) and concludes the thesis. These were instrumental in providing the platform from which to base the research study.
INTRODUCTION

Health policy is defined as “an agreement or consensus on the health issues, goals and objectives to be addressed, the priorities and the directions for achieving them” (WHO, 1999). It is afforded a central role in the government’s agenda due to accounting for one of the largest areas of expenditure and the increasing pressure on the economic climate.

The fundamental aim of health policy development is that it is able to be implemented, sustainable and useful in practice to the people who are in receipt of it. The translation of policy to practice is paramount for it to be worthy of attention (Buse, et al, 2005).

The National Health Service (NHS) was established to provide a comprehensive service with an egalitarian ideology: “We start with our values – the values of a health service funded by all of us, available to each of us, free at the point of treatment, with care based on our need and not our ability to pay. These values are non-negotiable” (The National Health Service Act 1946). These egalitarian values seem to be echoed by both major parties when they have been in power but within a competitive market which has given rise to numerous concerns regarding the ‘selling off’ of the NHS to the private sector; e.g. the use of private contractors (Arie, 2005) and privatisation plans (Carvel, 2006).

I am a Nurse Consultant working in a hospice (in the voluntary sector) in palliative care. For the past 20 years my nursing career has focused on caring for patients who are in need of palliative and end of life care. I am mindful that dying affects
everyone. I always strive to achieve the best quality care but realise that economic, political and social pressures dictate, to an extent, what it is possible to achieve within the available resources. Since becoming a Consultant I have had to negotiate at a higher level for allocation of resources and appreciate how competitive this can be.

**BACKGROUND**

Around 500,000 people die in England each year. This will rise to around 530,000 by 2030 due to our ageing population (Gomes & Higginson, 2006). Everyone has a right to expect and receive high quality care and dignity at the end of life (WHO, 2004). Shockingly 54% of complaints in acute hospitals relate to care of the dying and bereavement care (Commission for Healthcare, 2007). These figures give an indication of the scale and range of problems encountered at end of life.

The End of Life Care Strategy (DH, 2008b) was the first policy produced by the government to address end of life care issues in different settings. It was comprised of a pathway (Figure 1) consisting of six steps with three threads running as a theme throughout. The strategy was developed in response to Lord Darzi’s NHS Next Stage Review (2008a) which signalled the next round of NHS reforms under a labour government. End of life care (EoLC) was one of Lord Darzi’s work streams and, for the first time, resulted in palliative care explicitly being included as a fundamental element of health service provision.
The aims of the strategy were to:

- Bring about a change in access to high quality care at the end of life
- Raise the profile of end of life care and to ensure it was high on the government’s agenda
- Increase the public’s awareness of death and dying, thus acting as a driver for action with regard to resources, education and training.

In addition to Lord Darzi’s work, there had been several government documents which preceded the strategy and begun to highlight the importance of end of life care, namely:

- Building on the Best (DH, 2003)
- Supportive & Palliative Care for Adults with Cancer (NICE 2004)
- The Cancer Reform Strategy (DH, 2007a)

The strategy and supporting research shows that people would like to have a choice where they are cared for. Due to lack of resources and services available in the community, palliative patients are frequently admitted to hospital and die (Table 1) which may not be their preferred choice of setting.

Due to the size of the strategy and word limit for this assignment I intend to undertake a policy analysis on one part of the strategy: The coordination and delivery of out of hours services. This is of particular interest to me as, within my current role, my primary aim is to get patients to their preferred place of care as
soon as possible. However, that can be difficult to achieve and I am increasingly aware that my professional colleagues in the local community are struggling to develop and sustain services to support this.

Out of hours (OOH) care is care that is available 24 hours a day, 7 days a week. This includes direct care, telephone advice and support. When a patient is nearing the end of life their condition can change over a short period of time, therefore it is essential that a fast track specialist referral and home visit are expedited. Transparent partnership working and joint system planning between service sectors is essential (DH, 2009c). The strategy specifies a need for an increase in the availability of 24 hour district nursing (DN) services as well as access to specialist palliative care (SPC) support if required as being paramount to support patients who wish to die at home (DH, 2008a).

The difficulty is that patients often have changing multiple and complex needs, which require a rapid response from social and healthcare agencies. It is recognised that good, timely coordination is needed within teams and across organisational boundaries to meet the needs of these patients.

**POLICY ANALYSIS**

The purpose of policy analysis is to study the characteristics of the policy, how it came to be and what the consequences of that policy might be or are (Collins, 2005). It is concerned with outcomes and the effects on people, who are the main recipients of policy.
Health policy analysis is central to health reforms (Walt, et al, 2008). It is a means to inform future policies by considering the pros and cons of getting health policy issues high on the government’s agenda and to contextualise issues in time and place. This is a retrospective analysis of policy which involves looking at a policy already written within my field of work and using a method of considering its content, stakeholders, (those influential in devising the policy), how it was implemented and any evaluation as a result of it.

In order to conduct the analysis a policy analysis tool will be utilised. Eugene Bardach’s ‘eightfold path’ was a tool that was developed and could be used for policy analysis regardless of the specialist area of work. The tool has been refined over the years and published work has demonstrated it is generic and sensitive to health care policy analysis (Bardach, 2009).

For the purpose of this analysis I am using the Collins adaptation of the Bardach tool (Collins, 2005) because this version has more of an emphasis on linking the policy to health outcomes. It hones down in the relevant areas and provides a framework to examine the policy in a structured detailed way. The synthesis of the information and supporting research informs the policy at macro (national), meso (organisational) and micro (department / stakeholder) levels.

Both versions of the tool are stagist which means they are interrelated and it is possible to return to steps when new evidence appears. This iterative approach remains a thread throughout the analysis and allows for heuristic learning through new knowledge and past experience (See figure 2).
Step 1: Define the Context

It is important to contextualise health policy and consider mitigating and influencing factors in relation to its development and construction. Being aware of its history and surrounding circumstances can put meaning into the analysis.

Public policy usually reflects the values, interests and preferences of the government in power (Walt, et al, 2008). The labour government had been elected in 1997. They were undergoing a renaissance in their ideology and had begun to follow a path termed ‘The Third Way’ which was ‘in favour of growth and enterprise and in valuing social rights and equality’ (Adams, 2001). This showed a clear move away from socialism. The Third Way aimed to apply ‘left of centre’ values to the new world, thereby focusing on ‘respect for community, individual responsibility, accountability, autonomy and equality’. It was thought to be the way forward and in health care it would be instrumental in delivering high quality services at a reasonable cost to everyone (Adams, 2001).

There is growing awareness that England is a multi-cultural society with high rates of immigration. This results in a recognised need to acknowledge different practices in death and dying as families may prefer to keep the patient at home because that is traditional and important in their culture. This all contributes to considering responsibility and equality of services to meet individual needs.

In their election manifesto (The Labour Party, 2005) they stated that ‘in order to increase choice for patients with cancer we will double the investment going into palliative care services, giving more people the choice to be treated at home’. Historically end of life care has been given a low priority, possibly because people
preferred not to think about it. There has always been more of a focus on cancer and consequently other end stage conditions often get a poor deal and less of a slice of the funding (DH, 2008a). There has begun to be a growing interest in end of life care due to the publication of several palliative care documents (DH, 2001; DH, 2003; NICE, 2004) which received varied media attention (Andalo, 2004). In addition, as treatments improve, the ageing population is increasing, which has resulted in the government beginning to consider how they will care for the elderly in the future (Gomes & Higginson, 2006). End of life care has leverage of public opinion as it affects and benefits everyone, thus capturing hearts and minds. This angle of appeal was likely to have secured votes for the labour party and attained positive feedback that a government was addressing such a fundamental issue.

Before the release of the strategy, work had already started in producing initiatives in improving end of life care services, for example:

- The NHS Cancer Plan (DH, 2000) – specified commitment to increase expenditure on specialist palliative care services by £50 million as it was recognised that for too long it had been an ‘optional extra’ and there had been heavy reliance on the goodwill of the voluntary sector
- National Service Framework for Older People (DH, 2001)
- NICE Guidance on Supportive and Palliative Care (2004)
- National End of Life Care Programme (NEoLCP) (2004-2007) - which was influential in the rollout of end of life care tools e.g. Liverpool Care
Pathway (LCP), Gold Standard Framework (GSF) and Preferred Priorities of Care (PPC)

- The Marie Curie Delivering Choice Programme (MC DCP) (2004)
- The advent of community matrons whose roles & responsibilities included managing long term conditions (LTC)
- Good quality research to support the concept (e.g. Higginson & Gomes, 2006)

(Refer to Appendix 2 for glossary).

The strategy underwent several consultations and involved many stakeholders (some of whom were globally recognised), who exerted different levels of influence and power depending on their roles and expertise. These levels of power and influence in relation to the strategy are shown in Table 2. Professional groups such as doctors have the support of powerful agencies such as the British Medical Association (BMA). Doctor’s power is deemed to be ‘legitimate’ due to their expertise (Buse, et al, 2005) and, though there were several general consultations reaching a wide range of stakeholders, the overwhelming majority of authors of the strategy were doctors. Their dominance, tribalism and influence over health policy has been long standing and acknowledged as important for policy to become recognised, accepted and implemented (Ham, 2004).

In stark contrast, funeral directors had low levels of power as they only had an interest in the strategy and were not considered to be highly influential in its construction and implementation.
When considering health policy it is useful to review the drivers and resistors that influenced the strategy development (See tables 3 & 4). The strategy dovetailed in with the current political ideological stance because the labour party had continued to support the shift of money from hospitals to the community, initially instigated under Thatcher’s government. Closure of hospital beds meant there was additional pressure for early discharge and patients approaching end of life were seen as ‘bed blockers’ because of the uncertainty surrounding their prognosis (Cawston, 2010). Initiatives such as the personal health budget pilots, (where the patient was given greater choice and control over the care they receive) were an extension of community care. The main aim of the community care policy has always been to maintain individuals in their own homes wherever possible. It was thought to be the best option from a humanitarian and moral perspective and also believed to be cheaper (Means & Smith, 1998). Generally there is a dearth of research to demonstrate definitive cost effectiveness of home care compared to hospital / hospice care (Payne, et al, 2002) although the study by Hatziandreu, et al, (2008) demonstrated there could be a benefit.

From a professional viewpoint palliative care has always been slighted in favour of acute care which was lifesaving and worthy of discussion and attention. The strategy provided a platform for launching a positive stance.

Finally, it is possible for a driver to become a resistor and vice versa depending on circumstances and worldviews; e.g. the media regarding euthanasia could be either a driver or resistor of the strategy.
**Step 2: State the Problem**

Health policy analysis must be led by the issue under scrutiny. The statement of the problem must be clear in order to inform the gathering of evidence and the seeking of alternatives. It must be concise and not include a diagnosis (Collins, 2005).

The strategy provides clarity about the problem it addresses. It introduces the issue immediately and provides adequate and appropriate data to support the problem. The problem is acknowledged as a major mismatch between people’s preferences for where they should die and their actual place of death. The majority of people would specify a preference to die at home - between 56% and 74% (Gomes & Higginson, 2008) but most die elsewhere (see Table 1). One of the major obstacles to people dying where they want to is the lack of services available in the community which results in unnecessary hospital admissions (DH, 2008b; House of Commons, 2009). The sense of urgency is paramount as there is only one chance to get it right. “If a person is likely to live for only a matter of weeks, days matter. If the prognosis is measured in days, hours matter” (DH, 2008b).

**Step 3: Search for Evidence**

Once the problem has been identified then it is important to collect meaningful data to support and drive the policy construction.

The strategy refers to how it has connected up with other strategies and aligned policies relevant to this area. Innovative work had already been ongoing in relation to end of life care and the strategy was leading on and supporting findings and proposals from the NHS Next Stage Review (DH, 2008a), of which end of life care was
one of the eight pathways addressed. One of the main outcomes from this pathway group was the desire to have round the clock access to palliative services.

The strategy mentions learning from other areas and localities and the importance of sharing knowledge and experiences. The National End of Life Care Programme (NEoLCP) was established in 2004 and has been extremely beneficial in providing an arena for sharing experiences. It is excellent at using examples and showcasing pockets of good, and even outstanding, practice but access to care is not equitable. Geographical variations exist regarding resources and it tends to depend on where you live as to what you can potentially receive. It also highlights the need for provision of homecare in order to support carers as well as patients (Gomes & Higginson, 2006).

Uncommonly the strategy is supported by good quality research evidence (e.g. Thomas, 2003; Gomes & Higginson, 2006 & 2008) which included national and international research; e.g.

- study of Locum General Practitioner’s (GP) who were called to see end of life care patients had no awareness of the patient’s history and it was left to the carers to furnish the GP with relevant details. Carers talked about feeling very vulnerable at these times which were the primary reason they sought help from the GP (Worth, et al, 2006). ‘Knowing the patient’ is vital at this difficult time (Luker, et al, 2000).
• A study undertaken in Taiwan revealed that culturally both patients and caregivers preferred place of death was home but often patients were hospitalised near the end due to lack of resources (Tzuh Tang, et al, 2005).

• Similarly an Australian study identified 42 barriers to palliative patients receiving optimal care in the community and one of those was lack of after-hours care (Hardy, et al, 2008).

• OOH care also refers to care homes – 61-80% of care home residents could have died in their care home (which was considered their home as a permanent place of residence) if they had more support and advice from specialist services (The Balance of Care Group & NAO, 2008).

In addition there have also been baseline reviews of service provision conducted to inform the strategy of the gaps in existence. This enables the standards to be commensurable across the UK and allows the opportunity to benchmark care (DH, 2007b).

The strategy also included the involvement of patients and carers which was important to demonstrate user involvement.

**Step 4: Consider different Policy Alternatives**

No policy should be based on one option. There should be depth and breadth associated with considering the alternatives which may also include a compilation of one or more (Collins, 2005). The options should include cogitation of ethnicity, available research, expert opinion and international experience.
There were four policy options that were considered during the policy development. Each consequent option includes the one preceding it.

1. Take no central action & leave up to local agencies
2. Focus on improving community services which included establishing EoLC registers, rapid response and 24/7 services
3. Improving community services, education & training and the environments
4. Improving community services, education & training, environments and care after death by providing comprehensive information and access to bereavement services (DH, 2008d).

Each alternative had details of financial implications as well as specific actions that were required to implement it. The costs were predicted by including a projected increase in expenditure. There was no mention of a change in government which might adversely affect allocation of money but this was balanced by the strategy stating “the actual costs will depend on decisions taken about, and for the NHS” (DH, 2008d).

Each option addressed inequalities as detailed in the DH paper on Tackling Inequalities (Hunter & Killoran, 2004), reflecting on issues such as:

- The deprived, care homes and certain ethnic groups often do not know how to access services or what they are entitled to
- The frequent hierarchy of national-regional-local implementation which can create tensions and affect implementation as well as result in using scarce resources ineffectively (DH, 2008c).
The underlying principle should always be to aim for best practice and standard setting by benchmarking clinical decisions and resources to create equity of access.

Emphasis was placed on the development of the GSF locality-wide registers (DH, 2008b). The purpose of these registers were to enter the details of patients approaching end of life thus enabling them to access out of hours support services quickly. The registers were a theme throughout the options but need adequate resources for them to be operationalised.

In view of the research conducted (Gomes & Higginson, 2006 & 2008), which shows a dramatic rise in the numbers of people dying from 2012 onwards due to the ageing population, I wonder whether it was short sighted of the strategy not to consider as one option (to be included in the work related to community care), the need for hospitals to create more facilities for in-patients as a 20% increase in in-patient beds was predicted? Although patients may prefer to die at home it is essential to consider that even with adequate resources in the community and service redesign it may not be physically possible to cope with the predicted volume. In addition, research has shown that patients may change their mind about wishing to die at home as death nears (Townsend, et al, 1990; Hinton, 1994), though a recent small scale study has questioned these findings (Higginson, et al, 2010).

In addition, the use of technology was not fully explored. An option could have included utilising mobile phones as a means of supporting patients, especially in rural
areas where access to services (even if available) is difficult to achieve in a timely fashion (Addicott & Ashton, 2010).

**Step 5: Project the Outcomes**

The alternatives should be assessed for projected outcomes in order to consider their worth.

The strategy stated the intended effects:

- To ensure that care is well coordinated, and can be accessed rapidly 24/7 in order to avoid unnecessary hospital admissions (DH, 2008b; House of Commons, 2009).

- More joined up working between the Local Authority (LA) & Strategic Health Authority (SHA). There was no mandatory means of monitoring the spending so this would need to be clearly documented and both authorities would need to display coordinated thinking and agreement about priorities for coordinated and 24/7 care. Their role is to share a common responsibility and commitment to their local population to secure the best outcomes for health and addressing inequalities.

The four options needed to reflect these proposed outcomes. Many questions need to be considered regarding fairness in distribution of resources. It is the voluntary and community sector (VCO) who provide a vast majority of services and it was not clear if they would have an opportunity to engage with the local authorities to consider priorities and distribution of funds. They may not have the appropriate knowledge to understand the level of power each stakeholder possesses or how the...
partnership will work but they have plentiful user involvement and service provision experience and this would be useful in identifying cleavages and factions within certain areas. The options did not provide clarity regarding the role of the VCO.

The strategy was based on option 4 because it was thought to ‘deliver the most significant improvements for people at the end of life, their carers and loved ones and at the best value for money in terms of net benefits’ (DH, 2008d). Lobbying by palliative care interest groups also added their support to this option (Addicott & Dewar, 2010; House of Commons, 2009).

**Step 6: Apply Evaluative Criteria**

Collins (2005) identifies specific criteria for evaluation of all options:

- **Relevance** – is the policy consistent with the aims?

All options serve to address the policy to a greater or lesser extent. It is ensuring that monies invested in creating or remodelling the services also has the ability to deliver the care effectively. It is important to extend to all life threatening conditions but the policy does not specify how that might be done.

- **Progress** – how do actual results compare with projected results?

The strategy also considered the workforce that would be required to implement 24/7 and rapid response services which was based on Marie Curie (MC) data, who have extensive experience of establishing services. However the strategy was written for ‘organisation’ based services, the meaning of which isn’t clear, although presumed to be the population each organisation serves. This may definitely leave a
shortfall as it is recognised that there are existing gaps in services due to inequalities (e.g. the homeless, learning disabilities, ethnic minorities (NA0, 2010))

- Efficiency – results in relation to resource expenditure?

There is a large outlay in terms of staff wages due to OOH payments. Other outlay will include the Quality and Outcomes Framework (QOF) which is a voluntary reward and incentive scheme for GP practices which results in payment for involvement in certain initiatives including the GSF register, although there was identified money to support the strategy

- Effectiveness – does the intervention achieve its objectives?

Option chosen (4) supports policy and considers workforce and resources required to do it. Other alternatives do not consider all angles, e.g. option 2 – develop community services by employing more staff. If these staff do not possess the necessary skills and training to do the job they will not be effective.

- Impact – effect on overall workforce / development?

The biggest challenge identified is managing change. Resistors include people who believe change is forced on them and they have had no part in its construction. It is important to secure buy-in and local ownership and thus share a vision. There was mention of the need for joined up policy, organisation and management in order to succeed.

**Step 7: Weigh the Outcomes**

After applying the evaluative criteria the next step is to weigh up the outcomes. It was obvious that the options were heavily dependent on getting the commissioners on side who have their own competing priorities and incentives to consider. This
would determine the way it progressed and the benefits of engaging with them for joint working initiatives was a key vehicle for delivery.

In the strategy it was clear that option 4 provided the most comprehensive outcomes possible. The expenditure analysis showed value for money and option 4 demonstrated forward thinking by way of providing the training and education of the workforce to support the proposed initiatives.

**Step 8: Make the Decision**

Finally a decision would need to be made. Issues to consider were:

- Was the decision making transparent in final conclusion? Did it involve all participants?

The impact statement showed the process of decision making involving most stakeholders. Consultations regarding the final decision were conducted and patient’s views were sought which are considered vital for policy to be accepted (Ham, 2004).

- Evaluation – is there published evidence to suggest intended outcomes were achieved?

There has been progression in achieving targets but there remain problems relating to inequity of resources and provisions. The strategy came with £286 million investment for improving EoLC over the next three years. This indicated that there was endorsement from the government and a commitment to begin plans (NAO, 2008). However, the money was not ring fenced (House of Commons, 2009) and many PCT’s found it difficult to identify those additional funds. Though EoLC is
mentioned in the NHS operating frameworks for 2009-2010 (DH, 2007b) where the DH sets out priorities for services, it is not one of the key national objectives PCT’s are performance managed on. Therefore, although the strategy commented on the PCT’s monitoring expenditure of the monies for EoLC it is not mandatory to do so and monies could easily get diverted into other priorities. The NEoLCP was particularly concerned to support PCT’s to spend the money over the next three years in the areas most in need, as future public spending after that time was thought to be uncertain, which is now a reality of the new government (DH, 2010a).

In addition, annual reports have been produced in order to provide evidence of progress in all areas of care (DH, 2009e; DH, 2010b).

**IMPLEMENTATION AND EVALUATION**

Locally driven agreement and support is essential if a policy from the government is to be successfully implemented. The simpler a policy, the more chances it has of success (Ham, 2004). The strategy had no implementation plan which is often the main driver for achieving the aims and objectives specified. Implementation and evaluation are fundamental, as management of progress is difficult if it is not possible to accurately measure it; however the NEoLCP provided guidance on time scales and direction. The first annual report (DH, 2009e) referred to documentation of the number of patients being put on the registers as a means of evaluation.

The strategy identified that commissioners and organisations would need guidance on delivering improvements in end of life care which was supported by published
quality markers. Individual organisations and PCT’s would need to determine locally which of the markers to use in order to measure practice but this was not mandatory (DH, 2009a; Addicott & Ashton, 2010).

Many policies which require public support are covered by media (e.g. The Dementia Strategy; DH, 2009d) but the EoLC strategy did not receive that level of attention. There were no adverts on national television but there were radio broadcasts from lobbyists and service users, especially regarding carers who have experienced no choice over their loved ones place of death. In addition there was support from the major palliative care professional groups and charities; e.g. National Council for Palliative Care (NCPC), Help the Hospices (HtH), Marie Curie Cancer Care (MCCC) and Macmillan who all added weight because their branding ensures the public recognise them. It was interesting to note that Macmillan had previously been concentrating their efforts on survivorship from cancer which spotlighted on treatment and cure. The EoLC Strategy made them realise that monies would now follow EoLC and therefore they would need to adjust their focus and attention. It was clear that survivorship was much more appealing for the public to engage with.

From a political point of view the inception of the strategy was during a labour government but it was clear that the Third Way had created a certain tension between individuals taking responsibility for themselves and those who would not conform; e.g. the homeless and those living in deprived conditions. The recent change of government has demonstrated a commitment to EoLC but is driven by outcomes. There is no mandatory monitoring but it has recognised that there needs
to be a mechanism or feedback loop in order to prove processes are working and there are adequate outcomes in order to secure funding. In relation to the new White Paper (DH, 2010a), it has strong emphasis on patient choice for place of treatment and choice of GP and it also, for the first time, has embodied the phrase "No decision about me without me" which continues to promote people taking personal responsibility. However, the coalition government has specified savings within the NHS of up to 20 billion by 2013-2014 which will need to be recouped somehow and the areas where significant savings will need to be made remain uncertain.

In the UK, many patients’ access hospice care, either for in-patient, day or community care. Limited funding comes from the NHS which is extremely beneficial for them as the patient and family will receive high quality care with minimum outlay financially. It is a paradoxical situation for the voluntary sector as they would benefit from additional NHS funds in order to continue their work and the research links would be very useful, but they want to remain independent and not under the control of the NHS. The voluntary sector provides most of the support for the out of hours services through direct care and by offering 24/7 advice for patients, carers and professionals. This has had an impact on managing the in-patient services and many hospices have had to undergo their own service redesign to manage the additional pressures, especially medical staffing that is tightly governed by the European Working Time Directive (EWTD) rules. Reports have also shown that funding may have been agreed in some areas for out of hours care services but
resources in terms of manpower (skilled professionals) may not be available (O’Brien & Jack, 2010).

**POLICY IMPACT ON SERVICE CARE / PROVISION**

There is often a tension between long term development and quick answers regarding policy development and implementation. Changing the minds of people in England regarding seeing death and dying as a priority is challenging and not easy to do. To date the impact on service provision has been variable. The two annual reports of the strategy were positive (DH, 2009e, 20102b), listing the progress made and acknowledging there was much work left to be done. The ongoing work by the NEoLCP has been incredibly helpful and has ensured that promoting end of life care and patients’ wishing to die at home has remained firmly on the public agenda.

When things go right patient satisfaction is so pertinent, especially when they are given choice and access services as required, however there is still a lack of consistency in care which is dependent on where you live. It has been clear that options open to patients and carers do not necessarily equal patient choice about where they would like to be cared for, as there remains inequity of access to out of hours care. From a personal viewpoint the hospice where I work serves three separate boroughs for community care. These boroughs are very diverse in their service provision – only one of them can provide out of hours care whereas the other two woefully lack any level of care after 6pm. Patients within those boroughs depend on the goodwill of the hospice to offer advice or they call the out of hours GP who is usually not familiar with the patient or their situation unless the local GP practice is
part of the GSF programme. GP Cooperative working needs to be addressed as this does not provide continuity for patients and carers at a time when they are feeling so vulnerable. A lack of staff skill and knowledge results in inappropriate use of specialist PC provision which means some areas have to pick up the shortfall. Specialist palliative care services are overwhelmed with the demand for out of hour’s support. In conjunction with this there are difficulties marrying up the rotas to satisfy EWTD which culminates in less available resources to deliver OOH and in-patient care.

**CRITIQUE OF TOOL**

Whilst I was using the Collins version of the Bardach’s tool I wondered if it was too ‘formulated’ when, in reality, things are often blurred in practice. However, the tool felt organised and ordered which was useful for providing a structure as I was a novice analyst.

I reviewed the diagrammatical form of the tool (Figure 2) and realised that it appeared quite linear but in practice was actually quite cyclical which is usual for policy development (Buse, et al, 2005). I frequently returned to previous steps in order to check and refocus my thinking.

The major flaw of both versions of the model was that it did not include an implementation step which I believe to be a major criticism. Development of policy is important but if it is not transferrable into practice it is not useful and unlikely to be successful. The ability to embed in the everyday, both from a professional and public point of view is a vital component of policy construction and implementation.
Fortunately the NEoLCP provided implementation guidance for commissioners and organisations.

**CONCLUSION**

A recent comprehensive analysis of the number of emergency admissions in England reveals a 12 percent increase in admissions over the last 5 years. One conclusion from the report was that ‘better out of hours care was required in order to break the cycle’ (Blunt, et al, 2010). This shows that two years following the strategy there is still much to be done to provide adequate coordination and out of hour’s services to enable people to have a choice about where they would like to die.

The development of the strategy was a major breakthrough in raising the public’s and government’s awareness of choice and control and there have been measures put in place by national programmes and palliative care professional groups to support it. There have been identified areas of shortfall in considering out of hours care as well as a blinkered approach to some of the research which highlights the need for an alternative option related to in-patient care in order to cope with the massive increase in the number of people dying in the future.

From a personal viewpoint I am aware that the hospice is developing problems with being able to continue to deliver this extended service. We are experiencing a rise in telephone calls from patients who are not known to the hospice and who have no one else to ask for help out of hours. There is minimal flexibility in the rota to allow doctors to visit out of hours and because we do not offer a 24/7 Clinical Nurse
Specialist (CNS) visiting service at the present time we are mindful that it all falls to the junior doctors.

The Labour government provided a platform for the launch of end of life care which initially got off to a good and positive start. The uncertainty of the coalition government and the massive savings that are required will mean that we need to be cautious in our optimism. As professionals we will also need to find new ways of working under the QIPP (quality, innovation, productivity and prevention) agenda which may involve significant service redesign and utilising resources available to us in a completely new way.

This may involve thinking of more sophisticated ways of delivering home based care and therefore increasing capacity to do so. Using technology, e.g. mobile phones to support patients may be one mechanism of providing support and guidance (The Economist Intelligence Unit 2010) which was not addressed in the strategy.

Lack of available services, especially out of hours, remains a major barrier to patients preferring to be cared for and die at home (O’Brien & Jack, 2010). Lack of coordination of care and flexibility of community teams are key obstacles to implementing planned and organised care packages to assist a home death (Sines, et al, 2009). There is also diverse and varied inequity of access for patients.

As a policy document the strategy has many excellent ingredients and ticks most of the boxes for good quality care at end of life but much still needs to be done to ensure resources are available to support the choices patients are making and implement the fundamental principles of the document (Bracegirdle 2010).
REFERENCES


FIGURES

Figure 1: The End of life Care Pathway (DH, 2008b)

- Open, honest communication
- Identifying triggers for discussion
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

- Strategic coordination
- Coordination of individual patient care
- Rapid response services

- High quality care provision in all settings
- Hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Link for End of life Care Strategy (DH, 2008):

Figure 2: Tool for Policy Analysis

1. DEFINE THE CONTEXT
2. STATE THE PROBLEM
3. SEARCH FOR EVIDENCE
4. CONSIDER DIFFERENT POLICY OPTIONS
5. PROJECT THE OUTCOMES
6. APPLY EVALUATIVE CRITERIA
7. WEIGHT THE OUTCOMES
8. MAKE THE DECISION

Collins (2005): adapted from Bardach (2009)
### Table 1: Deaths in England

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>Percentage of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Hospital</td>
<td>58%</td>
</tr>
<tr>
<td>Home</td>
<td>18%</td>
</tr>
<tr>
<td>Care Home</td>
<td>17%</td>
</tr>
<tr>
<td>Hospice</td>
<td>4%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
</tbody>
</table>

### Table 2: Stakeholders / Key Players

<table>
<thead>
<tr>
<th>Actors / Stakeholders</th>
<th>Power</th>
<th>Level of Influence (factors – no of representatives, professional vs. lay people)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department of Health, inc Complaints Commission</td>
<td>High Manages funding</td>
<td>High Makes decisions re: priority for agenda</td>
</tr>
<tr>
<td>Health Care Professionals Inc doctors &amp; nurses, managers</td>
<td>High Need to get professionals on board in order to deliver services Expertise</td>
<td>High Doctors are seen as influential – important to get clinicians on board</td>
</tr>
<tr>
<td>Charities &amp; Voluntary Sector (e.g. Hospices, Macmillan, Marie Curie)</td>
<td>High Provide a high percentage of care with minimal cost to NHS Maybe seen as gatekeepers</td>
<td>High ‘Branding’ of the charities carries weight</td>
</tr>
<tr>
<td>Marginalised groups, inc BME, faith groups, non-malignant groups</td>
<td>Low to medium Not as recognised or embedded in practice and lose out in power stakes</td>
<td>Low</td>
</tr>
<tr>
<td>Cancer Networks</td>
<td>High Well embedded although future uncertain</td>
<td>High Disseminate and action policies</td>
</tr>
<tr>
<td>Lobbyists, inc national groups &amp; Parliamentary Select Groups</td>
<td>Medium to High Important professional status (high % of medical staff)</td>
<td>Medium to high</td>
</tr>
<tr>
<td>Commissioners (SHA’s &amp; LA’s)</td>
<td>High Money holders – part of decision making regarding priorities of care</td>
<td>Medium Have competing priorities from acute care</td>
</tr>
<tr>
<td>Care homes</td>
<td>Medium Managers with skills</td>
<td>Low to medium Strategy will provide increased access to education/training</td>
</tr>
<tr>
<td>Funeral Directors</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>Category of Drivers</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td><strong>GLOBAL</strong></td>
<td>Health care services are facing global and societal changes. Needs in the UK are more complex and diverse from the social, cultural, racial and geographical perspectives</td>
<td></td>
</tr>
<tr>
<td><strong>DEMOGRAPHY</strong></td>
<td>Ageing population Improved health care</td>
<td></td>
</tr>
<tr>
<td><strong>POLITICAL</strong></td>
<td>Promoting health equality Maintain values of NHS (Labour party original founders of NHS) National guidance from government committees (e.g. NICE) Shift of money - following patient into community – originally from conservative government but adopted by labour</td>
<td></td>
</tr>
<tr>
<td><strong>SOCIAL</strong></td>
<td>Shift towards community care Patients expecting more form the NHS and workforce – internet available for searching, increased knowledge &amp; awareness, more proactive Changing attitudes to death and dying - public debates e.g. euthanasia, LCP Increase in number of informal (unpaid) carers Better evidence demanded in order to demonstrate access to services and equity</td>
<td></td>
</tr>
<tr>
<td><strong>ECONOMICAL</strong></td>
<td>Rising cost of health means each government has to think of innovative ways of delivering high standards of care in a cost effective manner Local authorities under pressure and need to reduce / avoid unnecessary &amp; costly admissions to hospitals</td>
<td></td>
</tr>
</tbody>
</table>
Consider alternative ways of delivering care (using technology)
Commissioning & procurement considerations
Opening up to competition and market forces which may blur roles and boundaries and cause confusion when services are being taken on by private companies (e.g. some community services are out to tender and there is an need for quality monitoring)
Encouraging ‘localism’ – transferring decision making power to the local authority (LA) – including determining services delivery from DH policies. This will depend on who the LA asks to be part of the decision making process and the power distribution – the voluntary & charity organisations (VCO) could be sidelined although they are expected to provide the majority of the care and lead the way in excellence.

PROFESSIONALS
Health & social care
PC associations and committees (NCPC, APM)
Charities (e.g. MC DCP, Macmillan & voluntary sector)
Establishment of the National End of Life Care Programme
Community (generalist) staff who need help / support with complex cases / situations

MEDIA
Myriad of cases being brought to life, some adversely; e.g. Dignitas clinic in Switzerland.
Resulting pressure on PC to prove value of existence in managing LTC / people at the EoL. Celebrities such as Esther Rantzen’s documentary – ‘How to have a good death’ – all served to heighten awareness for the public.

Table 4: Resistors

<table>
<thead>
<tr>
<th>Category of Resistor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>POLITICAL</td>
<td>Competing with existing policies – monies allocation for OOH care</td>
</tr>
<tr>
<td>SOCIAL</td>
<td>Local CNS’ – not keen to take on additional OOH role – many come into CNS role to avoid unsocial hours due to family commitments Concerns re: lone working &amp; safety</td>
</tr>
<tr>
<td>PROFESSIONAL</td>
<td>Lack of staff Lack of monies Insufficient time / training – having to take on extended roles with no additional rewards Impact on institutions regarding increased responsibility around clock to provide a level of support / advice Processes need to be sorted - OOH medicine / equipment</td>
</tr>
<tr>
<td>ECONOMICAL</td>
<td>Commissioners need to redirect money / resources – competing priorities with acute care European Working Time Directive (EWTD) - organising rotas to provide sufficient medical cover 24/7 – concern that in hours care may be compromised due to non availability of doctors</td>
</tr>
</tbody>
</table>
APPENDIX 1:

Diagram to illustrate links with DH policies

DH Policy Documents on EoLC

DEO LC

Building on the Best Choice, Responsiveness
And Equity (2003)

Inequalities

NHS End of life Care Programme (2004)

NICE Guidance: Improving Supportive and
Palliative Care for Adults with Cancer (2004)

(2007)

NHS Next Stage Review (2008)

END OF LIFE CARE STRATEGY (2008)

Quality Markers (2008)

Transforming Community Services:
Ambition, Action, Achievement:
Transforming End of Life Care (2009)

DH Policy Documents influencing

Tackling Health

NSF for Older people (2002)

Tackling Health (2003)

NSF: Long term conditions (2005)


Cancer Reform Strategy

Carers at the heart of the 21st Century (2008)

Supporting people with long term conditions:
Commissioning personalised care plans (2009)

Dementia Strategy (2009)

Equity & Excellence: Liberating the NHS (2010)
APPENDIX 2:

Glossary of End of Life Terminology

End of life Care Register (EoLC Register):

The register enables service providers across care boundaries to share information about patients nearing the end of their life, helping to improve care delivery and coordination.

Information such as the patient’s carer’s name and contact details, main diagnosis, Care Pathway status and other relevant details can be viewed and maintained by health and social care professionals across a geographical area and service managers are able to define their own particular data sets.

Gold Standards Framework (GSF)

GSF was initially developed for use in primary care settings so that people approaching the end of life can be identified, their care needs assessed and a plan of care with relevant agencies put into place.

Liverpool Care Pathway (LCP)

The LCP provides an evidence-based framework to support those delivering care to the dying patient and their relatives in the last days and hours of life, in a variety of settings.

Marie Curie Developing Choice programme (MC DCP)

The DCP helps local providers and commissioners of care to develop the best possible local services for palliative care patients, regardless of diagnosis, so that they are cared for in the place of their choice

National End of Life Care Programme (NEoLCP)

The National End of Life Care Programme works with health and social care services across all sectors in England to improve end of life care for adults by implementing the Department of Health’s End of Life Care Strategy.

National Institute for Clinical Excellence (NICE)

NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

Preferred Priorities of Care (PPC)

The Preferred Priorities for Care (PPC) document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life.
ADVANCED RESEARCH METHODS

DIANE LAVERTY

17th December 2010
Scenario One

Challenges when researching into the ‘good death’

The aim of the research study is to understand the challenges involved in researching end of life issues within England. The research design, data collection methods, sampling and ethical issues will be explored. The End of Life Care Strategy (DH, 2008b) highlighted the importance of death and dying as a consideration for everyone.

Research design:

A literature search would be the initial step in conducting this research. Death and dying can be scrutinised from different viewpoints, depending on whether it is concerned with policy, practice or the views of the public. A clear definition for a ‘good death’ would be a useful starting point and something which could be built upon from the experiences and thoughts of the participants. Previous research has focused on the process of dying as opposed to the actual death (Payne, et al, 1996; McNamara, 2001).

There is an opportunity to consider different ways of approaching this study which would fit well with a mixed methods approach. This would enable quantitative and qualitative research to ‘mutually illuminate’ each other (Bryman, 2008) and provide additional information to give a fuller picture of the challenges involved in researching a good death, termed ‘completeness’ (Bryman, 2008). Some researchers comment that mixed methods causes confusion with the construction of a paradigm (Lincoln & Guba, 2000) whilst others state that this approach can combine the strengths of both methodologies (Johnson & Onwuegbuzie, 2004).
In order to gain an understanding of the patients, carers and researchers it would be necessary to design a qualitative element of the study which is exploratory in nature, allows an interpretative field of inquiry and locates the researcher in the world they are exploring (Denzin & Lincoln, 2000). The quantitative component would “add precision” to the words gained from the qualitative element (Johnson & Onwuegbuzie, 2004).

**Data Collection:**

In exploratory research a forum for allowing participants to freely express their opinions and views is essential as well as a need to consider all cultural and ethnical aspects. One method of data collection would be through focus groups which generate data by allowing open ended conversation, discussion and interaction, enabling everyone to have an equal and valued voice (Addington-Hall, et al, 2007). Focus groups should include the researcher, who sits apart from the group and observes attitudes, behaviour and conversation but does not participate, and an external facilitator who guides the session to ensure inclusion of all participants and promotes focused conversation (Bryman, 2008).

The quantitative part of the study would involve a survey which would reach a wider audience. Questionnaires have to be carefully designed to ensure the questions have clarity and are not ambiguous (Bryman, 2008). They can be cheaper to administer, as an interviewer is not required, and allow more time for the participant to respond (Bryman, 2008) though, conversely, inaccuracy of contact information and non-respondents can be among the problems with this type of data collection (Addington-Hall, et al, 2007).
**Sampling:**

Sampling for this study should involve a wide diverse (culturally and ethnically) group which should include patients and carers of patients with malignant and non-malignant conditions as previous research has been weighted towards patients with cancer (McCarthy, *et al*, 2000; Workman, 2007; Shinjo, *et al*, 2009).

In order to reach a large audience an online survey could be conducted by a professional research and consulting information technology (IT) company such as YouGov Plc which specialises in accessing stakeholders and the general public and seeking opinions and views. An e-mail invite would be sent to randomly selected panellists who fitted the sample definition and providing a link to it. Companies such as YouGov Plc ([www.yougov.co.uk](http://www.yougov.co.uk)) usually achieve a reasonable response rate and it is representative of the population being studied (Jacob Garber 2010, personal correspondence) although the IT format may limit the upper age range response.

There would be three focus groups (patients, carers and researchers) who are purposively selected to be congruent with the research question. Each group should have 6-8 participants and it may be necessary to have two or more of each category group to ensure a richness of data (Kreuger & Casey, 2000). They would be selected via patient and carer forums / support groups and academic institutes respectively across England. The researchers should be chosen for their work in end of life care and have a range of research experience to inform the study. Additional thought would need to be given to the locations of the focus groups due to the wide area to be covered. These may need to be centralised to large cities to enable this group of people to travel. Reimbursement of expenses and incentives to participate would need to be costed. Smaller focus groups may be needed for patients who may not be
physically able to make long journeys. If this proves difficult to facilitate, an alternative method may need to be adopted, such as semi structured interviews in the patients / carers homes (Bryman, 2008) or smaller focus groups in a geographical selection of institutions (e.g. hospices) which would provide ‘expert’ patients and carers.

**Inclusion criteria:**

- All patients, carers and researchers who self-select – this could include children/adolescents who are able to consent and with the parent’s permission. They may be classified as a vulnerable group but should not be excluded. Staff may be prone to ‘gatekeeping’ and being protective but research supports the involvement of patients, providing they understand the purpose of the study and are willing to participate (Lee, 2005; Alderson, 2007)
- Carers of, and patients with, a life threatening or life limiting condition.

**Exclusion criteria:**

- Self-choice – if participants prefer not to be included.

**Ethical Issues:**

The Good Clinical Practice (GCP) guidance should be embedded in this study (EMEA, 2002). Palliative patients should not be excluded from research opportunities but consideration should be given to their vulnerability (Addington-Hall, et al, 2007) and the consent process should be novel such as advance prospective consenting which requires checking with the participants that consent is still valid on an ongoing basis.
(Rees & Hardy, 2003). The researcher should be sensitive to the fact that these patients and carers are unlikely to benefit from any research and that their condition is rapidly changing so attrition may be high. There are concerns that these patients have a high degree of fatigue and the ethical soundness of asking them to participate (Janssens & Gordijn, 2000) but central to research is the ethics of autonomy and participants should be given the opportunity to make that decision (Addington-Hall, 2002).
Scenario Two

A comparison of hospital and telephone follow up after treatment for breast cancer

The aim of this research study is to compare the traditional outpatient (OP) follow up that patients receive after treatment for breast cancer with a new approach of telephone follow up by specialist nurses. The research design, data collection methods, sampling and ethical issues will be explored. As more emphasis is placed on community care, avoiding unnecessary hospital visits (DH, 2008a) and the skills of specialist nurses (Ball, 2005) this study is timely.

Research design:

Initially a literature search should be conducted to ascertain the current research and national guidance regarding:

- average time to recurrence for early stage breast cancer patients
- follow up for breast cancer patients by specialist nurses

A literature search should encompass as many different types and sources of research (as opposed to descriptive reviews) as possible in order to ensure the researcher has an up to date knowledge of what is already known about the subject (Harvard, 2007).

As this research study is looking at an alternative follow up option it would be appropriate to adopt a quantitative design using a randomised control trial (RCT) which is commonly used to test the efficacy or efficiency of a service (Beaver, et al, 2009; Gray, et al, 2010).
Quantitative research design requires a hypothesis for testing data and the null hypothesis would be that ‘there is no difference between traditional follow up and telephone call follow up for patients with breast cancer’. The aim of the research would be to accept or reject the null hypothesis.

The RCT would take the form of two arms – a ‘control arm’ which would be patients accessing the traditional approach of attending OP appointments at the hospital (receiving a mammogram, face to face consultation and physical examination) and the ‘intervention arm’ which would be the new approach of patients receiving a telephone call at regular scheduled times from the specialist nurse (receiving a mammogram and a telephone call). In order to fulfil recommended cancer follow up over a period of five years (NICE, 2002), this would be a longitudinal study which would require large sample sizes to cover possible attrition over time.

Each participant would be provided with an information leaflet about the study and relevant contact numbers.

**Data Collection:**

The specialist nurses would follow a semi structured proforma which would be designed in accordance with information needed by patients and required to make clinical decisions. They would access training in telephone interviewing and then the proformas and interviews would need to be piloted to ensure a consistency of approach (Tingle & Marsland, 2001). Measurement of the patients anxiety levels and satisfaction should be conducted using validated tools such as the distress thermometer (Ransom, *et al*, 2006) and a questionnaire designed to ascertain the patient’s satisfaction with the information.
they received and the time spent on their concerns. The value of satisfaction questionnaires can be viewed as dubious. Satisfaction is based on individual’s beliefs and values as well as differing views of what satisfaction is (Draper, et al, 2001). However, it is important to collect some form of data to depict the general overall satisfaction of the information delivered by the healthcare professionals. Further detailed research may need to be developed at a later date. The questionnaires should be posted soon after each telephone interview / OP appointment so that patients can complete whilst they are still able to recall the information.

Follow up of all patients (both study arms) would be routinely done by accessing the Electronic Patient’s Record system (EPR) to check for patients presenting with symptoms outside of appointments and any consequent investigations being ordered / recurrence being diagnosed.

**Sampling:**

Patients fitting the sample definition should be selected randomly via the hospital EPR. The study will not be blinded (patients will know what intervention they are receiving) and there will be no cross over to the other arm as this is not practical. The primary outcome of this study would be the time to recurrence. In order to ascertain the numbers of participants required to ensure the data collected is valid and reliable, the standard deviation would need to be calculated. This would be done using the data from research that looks at the average time to recurrence over a five year period. This would demonstrate the variation and ascertain the frequency distribution. In addition, using the statistical power of 0.8 would demonstrate the
probability that it will find an effect. These factors would be used by a statistician to conduct calculations which would determine numbers required. Insufficient sample numbers would provide results that were not representative of the population of breast cancer patients and make the trial invalid.

**Inclusion criteria:**

- 18 years and above (to give valid consent)
- A primary breast cancer diagnosis of stage 1 or 2 (patients would need to have a similar diagnostic stage of disease in order to ensure the risk of recurrence is equitable).
- No existing depression/mental health issues (this could adversely affect the results produced by the distress thermometer)
- Patient is able to speak & understand English (information to and from the patient may be lost or diminished in translation by interpreting services which are time consuming to arrange)
- Patient has minimal hearing impairments (in order to use telephone effectively) and access to a telephone

**Exclusion criteria:**

- Metastatic breast cancer

**Ethical issues:**

The study would be required to acknowledge and fulfil all Good Clinical Practice (GCP) guidance (EMEA, 2002).
Patients should receive detailed explanation and reassurance regarding the study. They may feel a level of uncertainty about receiving the intervention, although studies are beginning to demonstrate that nurse led follow up is an effective intervention for patients following cancer treatment (Moore, et al, 2002; Lewis, et al, 2009).

Reassurance will need to be given regarding the option of withdrawing from the study without reason or prejudice to continuing rights to treatment.

Careful thought must be given to the scheduling of the telephone calls so that the patient is offered appointments with the same frequency as the control group.

All existing policies and procedures relating to the hospital and cancer departments must be adhered to.

Clinical equipoise (genuine uncertainty over whether a treatment will be beneficial) should be present at all times. If this is not met the study should be discontinued as it would not be ethically sound (Weijer, et al, 2000).
Scenario Three

General practitioners’ (GPs) perceptions of effective health care

The aim of the study is to explore GPs’ perceptions and application of effective evidence based health care in south east (SE) England. The research design, data collection methods, sampling and ethical issues will be considered. This will be supported by the presentation slides (attached).

Research design (Slide 1):

To ascertain what is already known it is necessary to conduct a literature search and, if available, examine systematic reviews and meta analyses. These comprehensive reviews enable the management and analysis of vast amounts of literature regarding a specific topic area and ascertain if the results from numerous studies are consistent (Bettany-Saltikov, 2009).

When examining perceptions, values and behaviour, qualitative phenomenological research provides an opportunity to examine in depth the world of the participant and begin to understand it from their perspective (Van der Zalm & Bergum, 2000). Qualitative research has been criticised for not being generalisable to the entire population (Gubrium & Holstein, 2000) but the knowledge gained from this design can be generalised to similar specific populations and this adds value to overall knowledge (Myers, 2000).

Data Collection (Slide 2):

In order to reach a wide, diverse audience, focus groups are the ideal method, especially in creating spontaneity and a feeling of shared experiences. However, this
is a large area of England and logistically difficult to facilitate focus groups and GPs being able to attend, especially considering their workloads.

An alternative method of data collection is interviews which are loosely based on a semi-structured schedule, which encourage flexibility and free discussion between the interviewer and participant (Bryman, 2008). The interview would include a case study which describes a clinical situation that has supporting evidence based national guidance. The GP would be asked to discuss their decision making process regarding their chosen treatment/investigation(s) options. This will provide valuable insight into their use of available evidence.

**Sampling (Slide 3 & 4):**

Sampling such a vast area of England would prove challenging. One idea would be to divide SE England into urban, suburban and rural areas. Consideration also needs to be given to ensure a broad selection of different sizes and types of practice (e.g. training practice, situated in a polyclinic, small rural practice). This data would be available from each of the local Primary Care Trusts (PCTs).

A maximum of six GPs who have a range of experience (see inclusion / exclusion criteria) from each of these areas would be recruited as a reasonable cross section of the GP population. This should provide a rich breadth of data. If, during the analysis of the transcribed interviews new themes were emerging, it may be necessary to select and interview more GPs.
Ethical Issues (Slide 5):

This study should satisfy the Good Clinical Practice (GCP) guidelines (EMEA, 2002).

The GPs would need reassurance that they would retain anonymity during the reporting of data. In addition they may feel vulnerable, threatened or challenged in relation to their decision making skills. They should be encouraged to be open in the dialogue and feel supported. The GP should always have the opportunity to withdraw from the interview.
General Practitioners’ perceptions of effective health care

Diane Laverty
November 2010
Research Design (Slide 1)

- **Literature review / Systematic review**
  - What are GP’s perceptions views on evidence based medicine?
  - Is there a definition of ‘effective health care’

- **Primary outcome of study**
  - To ascertain if GP’s generally offer a gold standard service by assessing and treating patients according to the availability of evidence.

- **Qualitative research**
  - To explore and gain an understanding of GP’s perceptions and their application in clinical practice of evidence based health care (*words not numbers*)

- **Exploratory study - Phenomenology**
Data Collection (Slide 2)

- **FOCUS GROUPS**

- **INTERVIEWS:**
  - Choice of location away from practice
  - Taped, lasting approximately 1 – 1.5 hours
  - Semi-structured, using following prompts:
    1. What is the GP’s own definition & understanding of effective, evidence based health care?
    2. What are the challenges facing the GP to practice evidence based medicine in general practice?
    3. How and where do GP’s access clinical information?
    4. What might persuade a GP to alter their practice?
    5. Case study – ask the GP to discuss their decision making process related to treatment / investigation options for patients presenting with back pain.
Sampling (Slide 3)

- **SE England**
  - 9 counties with a population of 8,000,550 people & 7000 GP practices
  - Management of vast area – divide into ‘urban’, ‘suburban’ and ‘rural’ settings (might only be representative of ‘average’)

- **Range of experience**
  - Write to a selection of practices to request volunteers or attend practice meetings and ask for AOB agenda slot
  - Liaise with regional GOP deanery to provide incentive of CPD points to participate in study.

- **Recruit 5-6 GP’s from each setting**
Sampling (Slide 4)

**Purposive sampling**
- Participants known to be relevant to the research question(s)
- Data saturation

**Inclusion criteria:**
- NHS General Practitioner
- Range of experience:
  - 1-5 years of experience (junior GP being supervised)
  - 5-10 years of experience (GP)
  - 10+ years of experience (Senior GP)

**Exclusion criteria:**
- GP’s with less than 1 year of experience
- GP’s unwilling to participate

*Protocols should fit inclusion/exclusion criteria*
Ethical issues (Slide 5)

- Good clinical practice (GCP guidelines)
- Confronting difficult issues – challenging professional decisions
- Wide inclusion list representative of SE England using settings to demonstrate / include diversity and cultural significance
- Confidentiality and anonymity of presenting data
- Consent and information giving – benefits of study
- Researchers role – not intimidating or threatening when questioning decisions; integrity and accuracy
REFERENCES


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SERVICE EVALUATION:
CHANGE, RISK AND DEVELOPMENT

DIANE LAVERTY

23rd June 2011
**Introduction**

This essay aims to describe an evaluation of a newly established nurse led respite unit in a Hospice. The drive for change came from many angles (e.g. commissioners, referrers, local community) and therefore needs evaluating from different aspects in order to provide evidence and collaboration to satisfy all stakeholders involved (Springett, 2001; Green & South, 2006) but, due to word limitation, it will only critically examine what the organisation (as a major stakeholder) requires.

The questions posed by the Hospice are:

- What is the patient experience & benefit?
- What is the carer experience and benefit?
- Have we met the needs of the local population as determined by the Hospice Strategy? (Appendix 1)

(Appendix 2 is a complete list of all proposed evaluation methods).

No additional funds are available for the evaluation and it must be conducted within six months of the ward opening. Appendix 3 outlines the evaluation purpose /plan. An evaluation can be described as a means to provide information that can be used by those with an interest in the improvement and effectiveness of interventions (WHO, 1998).

**Setting**

The Hospice is situated in a deprived area of East London, serving people from diverse ethnic, cultural, religious, social and economic backgrounds.
The Hospice aims to provide services to the local community which best fit identified needs. The End of Life Care Strategy (DH, 2008) supports those living with long term conditions and aims to keep people at home for as long as possible, (if that is their preferred place of care), by providing timely relief from caregiving duties to the main informal caregiver. (See Appendix 4 for definitions of respite).

The nurse led unit will be opened with six beds which aim to provide a comprehensive programme of care to enable patients to reach their full potential (See Appendix 5 for an outline of the Respite Programme). Every effort was made to plan the evaluation at the same time as the service design (McDonnell, et al, 2006).

**Underpinning Framework**

A Realist Evaluation framework will be used as this recognizes and incorporates scientific and interpretivist approaches. It takes on the view that a programme (service) is an open system and needs to be examined and evaluated in a multifarious manner in order to include all essential elements (Kazi, 2003). It avoids rigid goal setting (Greenhalgh, et al, 2009) and does not set out to prove or disprove theory (Marchal, et al, 2010) but instead aims to customise theory in response to *what works, for whom and in what context* (Hansen, 2005). This approach is congruent with palliative respite care because patients are unpredictable in their disease trajectory and individual in their requirements (See Appendix 6 for the Hospice Respite programme demonstrated as a Realist Evaluation Cycle). It must be remembered during the design stage that a high number of variables can make a realist evaluation too complex to analyse (Hansen, 2005) and comparisons over time and context(s) are more difficult to conduct (Pawson 2006).
The outcomes of the service are to enable:

- patients to regain/maintain as much independence as possible by focusing on rehabilitation
- carers to have timeout so that they can maintain good health and continue in their caring roles (See Appendix 7 for the Respite Outcome Table).

The preceding historical, cultural and social contexts must be taken into account (Pawson & Tilley, 1997) and the outcomes should also be examined for intended and unintended consequences which contribute to unearthing all conditions and circumstances where change can occur (Greenhalgh, et al, 2009).

**Research Design**

A literature search to ascertain current knowledge and thinking around respite care and nurse led initiatives provides a useful starting point to explore the theories, concepts and opinions of other researchers (Bryman, 2008).

Realist evaluation is based on the use of methodological pluralism (Pommier, et al, 2010) which ensures breadth of data. There would be opportunity for the qualitative and quantitative data to ‘mutually illuminate’ each other (Bryman, 2008) and provide strength to both methodologies (Johnson & Onwuegbuzie, 2004), though Lincoln & Guba (2000) suggested this may lead to confusion by mixing paradigms.

The quantitative approach demonstrates the amount of service throughput and information such as ethnicity, borough usage and disease specifics which would provide details of service uptake. Pre and post unit opening data would also allow
exploration of appropriate use of resources as defined by the Hospice and local Primary Care Trusts (PCT’s). In addition, perceived benefits gained would be ascertained from patients completing an outcome measure. 

The qualitative approach would focus on the carers and allow them an opportunity to discuss their world and how they view it (Van der Zalm & Bergum, 2000). These two sets of data would complement each other and provide more comprehensive evidence for the realist cycle of mechanism-context-outcomes configuration (Appendix 6 – Realist Evaluation Cycle) which, in turn, will appraise the evaluation results.

An economic evaluation would not be appropriate at this stage as the emphasis is on patient and carer benefit. The Hospice and commissioners are keen to know that resources are being utilised appropriately but the Hospice is only part paid (60%) by the local PCT’s with the remainder coming from charitable donations. The focus is on referrals (and criteria for referrals) which should be suitable and timely, thus benefiting the community which the hospice belongs to and serves. The Hospice Mission and Core Values (See Appendix 8) are of upmost importance and therefore an economic evaluation is deemed unnecessary.

**Data Collection**

The mixed methods design will involve a heterogeneous approach to data collection. It can be time consuming so it is important to consider the usefulness of the data collected (Springett, 2001).
The validated outcome tool (SKIPP) is specifically designed for Hospice patients (Heal, 2010). This will be given to the patient to complete at day 3 after admission and then the day prior to discharge. The tool is short and succinct which is imperative in palliative care where patients may not be well enough to participate in lengthy questionnaires (Addington-Hall, et al, 2007) but are often still keen to participate in data collection for research and evaluation purposes (Addington-Hall, 2002). In one Hospice, patients have been assisted by staff in completing the outcome measures (Rosanna Heal 2011, personal communication) but care should be taken to avoid bias ( Bowling, 2002). Volunteers who do not provide care may be an unbiased means to assist the patient if required.

An audit was conducted prior to the unit opening to look at which patients had been accessing respite care at the Hospice, how appropriate these admissions were and any outcomes. The data collection would involve a follow up audit in order to provide a comparator which is essential in evaluation design (Ovretveit, 1998). The Hospice data collection system (PalCare) would provide demographics to monitor equity of access to the service.

The qualitative data collection will involve focus groups for the carers. This will provide a forum to openly express their views, encourage discussion and debate (Bryman, 2008). Focus groups are a means to access many recipients of the respite care programme who all share a commonality of having a relative with a long term condition who requires care at home. In addition to serving the purpose of collecting valuable data, it may also provide an unintended outcome of informal support for the carers.
**Sampling**

Purposive sampling would be used for this evaluation. This type of sampling is a means of focusing on participants who receive or benefit from the intervention (the respite programme) whether that is directly (patients) or indirectly (carers who can take a break from the caring role). Purposive sampling does not allow results to be applied to the general population (Bryman, 2008) but this adheres to the concept of realist evaluation where the context and circumstances should always be taken into account.

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient is accessing respite programme according to criteria (Appendix 5). NB: by being known to the Hospice they have a diagnosis of a life threatening/limiting condition &amp; are over 18 years of age</td>
<td>• Patient is mentally or physically disabled and unable to participate due to lack of cognition and/or understanding, particularly for consent purposes</td>
</tr>
<tr>
<td>• Participant is a carer of a patient accessing the respite programme.</td>
<td>• Patient or carer decline to participate.</td>
</tr>
<tr>
<td>• NB: An advocating service is available by appointment so inability to speak English is not an exclusion.</td>
<td></td>
</tr>
</tbody>
</table>

**Risks**

It is important to consider the risks involved, especially when a new service is designed. These need to be an integral part of the evaluation process (Health & Safety Executive, 2010). The risks identified need to be understood and should inform future decision making.
<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>POTENTIAL RISKS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Patient journey – (where are they) – their ability to self-manage. Risk assessment on referral and at admission</td>
</tr>
<tr>
<td>Emotional</td>
<td>Not meeting patients expectations (provide clarity to avoid unrealistic assumptions of respite programme)</td>
</tr>
<tr>
<td>Social</td>
<td>Not meeting patient expectations (adequate assessment to ensure awareness of limitations)</td>
</tr>
<tr>
<td>Economic</td>
<td>Sustainability of resources</td>
</tr>
<tr>
<td>Ethical</td>
<td>Patient consent / confidentiality</td>
</tr>
</tbody>
</table>

**Ethical Issues**

Any form of research or evaluation should always satisfy the Good Clinical Practice (GCP) guidelines (EMEA, 2002). Evaluation differs from research because, although similar methods are employed, the process is about judging the value or worth of the service (Springett, 2001), however ethical approval should be discussed with the Hospice board of directors.
Palliative care patients are vulnerable (Addington-Hall, et al, 2007) due to the fact that they can deteriorate unpredictably and rapidly. They have multiple needs and concerns and these should be taken into account when considering their ability to participate in, and complete, outcome measures.

Patient and carer consent should be gained and this should be supplemented with adequate and timely information related to the purpose of the evaluation.

Confidentiality and anonymity should always be assured and measures taken to ensure data collected is stored in a safe and secure manner with password protection.

Provision should be made to ensure that feedback to patients and carers from the valuation is conducted.

**Leadership Issues**

The second part of this essay will examine an aspect of leadership which has arisen due to this service development and this will be critically explored supported by relevant literature. The background will be explained in order to place the leadership challenge in context then the essay will focus on organisational culture and cross-cultural leadership which are considered influential when bringing about change in a traditional setting under transformational leadership. There is a wealth of knowledge about all of these areas but, due to word limitation, the essence of these concepts will be explored briefly.
**Background and Setting**

The Hospice was founded by the Sisters of Charity in 1905 in response to concerns for the sick amidst the deprivation of East London. It set out to give to the poor what the rich automatically had through possession of money and the Mission and Core Values remain of paramount importance to its everyday work (Appendix 8).

The Hospice is steeped in history and tradition. Longevity of service is common amongst nursing staff and they are extremely dedicated to the Hospice. They describe their work colleagues as ‘family’ and several staff live in the nursing home in the grounds of the Hospice.

Although the Sisters of Charity were a force within the organisation, it has traditionally been medically dominated. Over the last five years a shift in thinking has begun to occur with the appointment of new senior members of staff, including four newly qualified Medical Consultants, a Director of Care, Nurse Consultant and Lead Nurse. A new management structure was established and the Clinical Director (a nurse) took over the line management of the medical consultants.

**The Nurse Led Respite Unit**

The newly opened respite unit’s vision was to enable patients, considered to be in the last year of their life, to maximise their potential and live until they die, maintaining control and independence for as long as possible (Appendix 10). The multi-disciplinary team was led by a Nurse Consultant who had physical examination and prescribing skills. Nursing staff were used to a strict task related routine where the patients were usually ‘done to’ with little emphasis on rehabilitation (See Appendix 5 for details of the Respite programme).
Change Management

Establishing a nurse led unit proved to be a controversial and unwanted development. The nursing staff were unwilling to engage with the Nurse Consultant, not understanding what she represented or what her role within the organisation was. Repeated attempts to introduce the role and explain the initiative were largely unsuccessful. The staff have minimal exposure to external government documents and policies so remain unaware (and largely uninterested) in developments within the National Health Service (NHS) generally.

Adopting change can be challenging and requires collaboration. As a leader it is important to understand the barriers to change and how transition can be enabled. Rogers (1995) refers to change being adopted at different rates by different people as change ‘diffuses’ into the organisation which can be assisted by the leader devoting time and energy to each group of people. The Nurse Consultant, who considers herself to be a transformational leader, acknowledged the massive shift in thinking that the nurse led unit would require and endeavoured to initiate the fundamentals of change management, involving the staff from the beginning and enabling them to establish ownership of the project, through two dedicated days where the ward vision, design and activities were planned.

Organisational Culture

Organisational culture can be described as “the specific collection of values and norms that are shared by people and groups in an organisation and that control the way they interact with each other and with stakeholders outside the organisation” (Hill & Jones, 2006). Sackmann (1991, cited in Wallace, et al, 1999:551) used the
analogy of an iceberg to discuss how difficult it can be to truly recognise culture - some ‘observed regularities’ are visible (tip of the iceberg) but the values & beliefs will be invisible (below water level). The culture is usually strong in well-established organisations, especially if staff share deeply ingrained values and beliefs. The Hospice thrives on embedded stories, rituals and customs which are part of its history. This can lead to power which is described by Handy (1993) as one of his ‘varieties’ of culture, especially if smaller groups form ‘sub-cultures’, which may vie for the attention of newcomers and then merge to increase dominance (Schein, 1985). Culture can be a resilient phenomenon which becomes obvious when you attempt to introduce and lead change within it (Jackson & Parry, 2008).

Several researchers have put forward models of culture which inform our thinking today. Hofstede (1980) studied IBM employees looking for cultural differences which might affect business behaviour (Appendix 9). He initially identified four dimensions which he felt explained the connections between different cultures. The dimension of ‘collectivism’ particularly resonated with the Hospice culture as it was a strong cohesive group which protected each other and was hard to penetrate (Ewest, 2011).

Equally important is that certain types of leadership emerge more naturally out of particular dimensions; e.g. transformational leadership favours collectivistic culture (Hartog, et al, 1999) because the central focus of work life could promote followership if the concepts matched the group’s values and beliefs. Hofstede’s dimensions are frequently used in research studies though they are not necessarily generalisable to all organisations as the original data was collected from only one organisation (Dickson, et al, 2003).
Schein (1984) advocated a deeper understanding of the identity and impact of organisational culture. He referred to developing a strong organisational culture which encompassed achieving jointly reached goals and coordinating team work which contributed to effectiveness. This resonated with the principles of the respite programme and transformational leadership which could ‘transform’ people in order to capture hearts and minds so that the passion is there to succeed and move forward.

Conversely Smircich (1983) used a ‘root metaphor’ stating that culture was spontaneous and ‘as things are’. It doesn’t conform and it is not possible to direct it or control it by management. It can be seen as being a positive thing, the glue which holds the organisation together, and can provide a sense of identity and commitment. These are valuable attributes which can be highly influential in making an organisation successful. Smircich (1983) also said that culture is usually what drives the organisation and not the other way around. Similarly, Wallace, et al, (1999) suggests that culture is created from a diverse chain of both external and internal influences, which are mostly considered to be outside of managerial control. It is not linear but involves a complex set of challenges and solutions.

Trompenaars & Hampden-Turner (1998) culture model (Appendix 9) presented a comprehensive overview of seven identified dimensions, of which two closely reflect Hofstede’s individualism/collectivism aspect. The Hospice could be married up with these dimensional choices but the model does not recognise personal traits and the literature does not support any recommendations on how to work with these specific cultures (Ewest, 2011).
Another of Hofstede’s dimensions (Appendix 9) is the masculinity and femininity aspect. Handy (1993) proposes the importance of considering a power base due to male dominance but this is not considered the case at the Hospice. The chief executive is male but the vast majority of the senior management are female but with no overt gender influence. Handy also refers to recognising the current situation and where the organisation needs to go in order to identify gaps. He suggests change within organisational culture is a ‘long term project’ (Handy, 1993).

**Cross cultural leadership**

Another element from the literature is cross cultural leadership which endeavours to understand how individuals of different cultures interact with each other. This usually refers to global initiatives where people from vastly different cultures come together to work (Hickson & Pugh, 2001) but this also echoed some of the issues relating to the Hospice culture and the Nurse Consultant’s role.

In his work on transformational leadership, Bass (1985) referred to applying cultural lense in order to fully appreciate the nuances that make up the culture and adapt to suit it. Was the emphasis on the Nurse Consultant as a transformational leader to find ways to adapt the respite programme to suit the culture? Transformational, authentic leadership requires the building of respect, trust and partnerships, (Johansson, *et al*, 2010) as well as raising awareness of the importance of desired outcomes (Bass, 1985). Was enough time dedicated to this to gain much needed benefits?
Conclusion

The design and consequent evaluation of a nurse led initiative breaks new ground and will form part of the Hospice’s strategic plan to best suit the needs of the local community within a newly emerging health care service. It is essential that evaluation is part of service design as it can be influential in determining future directions.

Reflection is a valuable tool but can frequently “fail to do justice to the complexity, diversity and variability of human life” (Thompson & Thomson, 2008). During the process of reflecting about the service change and leadership issues, the Nurse Consultant realises that there had not been enough consideration given to how complex the culture was, how many sub-cultures had formed and how they meshed. Cultures evolve over time and the attributes of each one may not be generalisable to other contexts.

The Nurse Consultant’s understanding and adaptation to Hospice life was a challenge after a long career in the NHS, where change is much more a part of everyday thinking, especially with constant newly emerging government initiatives and targets. The proposed nurse led unit was introduced soon after the appointment of the Nurse Consultant. It is important to acknowledge that there may have been insufficient systems put in place by the senior management in order to modify the organisation and prepare the nursing staff for this radical change in pace and leadership.

The requirement of a leader is to orient, fully immerse & integrate into the culture in order to bring about change (Ewest, 2011). It is imperative to hear the people who are part of the culture, pick up their signals and understand their concerns, as well as
identify what are the rules and how the people see their world within their organisation (Smircich, 1983).
REFERENCES


charismatic/transformational leadership universally endorsed? Leadership Quarterly. 10(2), pp. 219-256.

Heal R. (2011) Personal communication. 23rd March.

Accessed: 23rd May 2011


APPENDICES

Appendix 1. The Hospice Strategic Plan 2007-2012

Appendix 2. Evaluation approaches for all stakeholders

Appendix 3. The Purpose of the Evaluation

Appendix 4. Definitions of Respite Care

Appendix 5. The Respite Referral Criteria and Respite Programme

Appendix 6. The Realist Evaluation Cycle: A Hospice Respite Programme

Appendix 7. Respite Outcomes Table

Appendix 8. The Hospice Mission and Core Values

Appendix 9. Examples of Culture Models

Appendix 10. The Vision for Respite Care
Key dimensions:

- Strengthen existing services
- Extend and enhance community services
- Develop new services for people with conditions other than cancer
- Provide additional support for carers
- Establish St Joseph’s as an easily accessible source of information, advice & expertise
- Engage with communities in our locality – improve responsiveness
APPENDIX 3

EVALUATION PURPOSE

Who is the evaluation for?

- The organisation – use of resources and patient experience
- The patients – respite availability and access / timing / benefits
- The carers – providing a timely break / patient safety
- The staff - new model of care / new nursing skills
- The referrers – are they receiving the service they had anticipated / needed?

What do I need to find out?

Is the service
- Meeting patients needs?
- Providing what the referrers expect?
- Providing what the carers want and is safe?

Demographics
- Who are we reaching?
- Malignant vs. non malignant?
- Carers informal vs. patients living alone?
- Diverse ethnicity

Why do I want to find it out?

- Increased bed numbers / staff
- Health policy agenda – End of life Care / keeping people at home in their preferred place of care
- Local community / diverse needs
- Baseline audit for comparison

When will the findings be required?

- Analysis six (6) months into project after ward opening (October 2011)
- Further analysis after one year of opening (April 2012)

Information to gather:

- Demographics, including ethnicity
- Diagnosis
- Carer details
- Outcome measures
APPENDIX 4

Definitions of Respite Care

“Respite care is the temporary physical, emotional, spiritual or social care of a dependent person in order to provide relief from care–giving to the primary provider” (Skilbeck et al, 2000)

"Respite care is a service intended to benefit a carer and the person he or she cares for by providing a short break from caring tasks".

http://www.scotland.gov.uk/Publications/2009/12/29123251/1
Accessed 23rd May 2011
APPENDIX 5: Respite Programme

In order to ensure equity of access to patients with any progressive and life threatening condition we have the following referral guidelines:

People eligible for this service are:
- Patients who are medically stable but still have palliative care needs
- Patients with a progressive and life threatening condition living at home
- Patients for whom the unpaid carers need a break from caring
- Patients living at home alone who wish to have a break from care in this context
- Their needs can best be met by the hospice as opposed to an alternative option

Priority will be given to:
- Patients who are thought to be in the last year of life. This can be determined by patient being on GSF register and asking other professionals caring for the patient their opinion
- Patients who are at risk of increasing levels of dependency due to functional deterioration that may be retrievable
- Any other mitigating factors that should be taken into consideration such as burden of illness, family & social factors

Programme of Care
Their care will follow a structured approach. The goal is to support patients and carers to enable them to remain at home. These admissions will be planned and the expected date of discharge agreed with an appropriate established care package to support the patient’s timely discharge. In addition,

- Admission will allow for comprehensive assessment of medical and nursing needs (e.g. review of medication where this needs to be done under supervision, assessment of incontinence, assessment of wound management)
- Admission will provide an opportunity for multi-disciplinary therapy input, in order to maintain or improve functional capacity. The goal is to prevent fatigue and maximise the patient’s quality of life and functional abilities
- Admission should take into account their usual routine which should be adhered to as much as possible. Patients should be encouraged to bring any pertinent items from home as desired.
- Programme of activities – DH, therapies, volunteers

Additional benefits include:
- Ongoing specialist palliative nursing
- Nurse Consultant who has extended skills in physical examination & non-medical prescribing
- A wide range of complementary therapies which are also available to the carers
- Specialist therapists – physiotherapists, occupational therapists, speech & language, dietetics
- Medical advice if required
- Psycho-social care
- Volunteers who are able to escort / assist patients who require to leave the Hospice for the purpose of a pleasure or personal activity
THE REALIST EVALUATION CYCLE: A HOSPICE RESPITE PROGRAMME

MECHANISM
- Aim to:
  - Maximise functionality
  - Promote independence
  - Offer opportunity for socialisation
  - Offer non-threatening introduction to hospice
  - Involve in activities
  - Offer review of current condition (MOF)
  - Provide informal care with a break
  - Ensure patient stays at home if that is their preferred place of care
  - Provide safe environment to deliver respite care from trained professionals

CONTEXT
- Patients and carers ability to understand respite programme
- Patients ability to engage in activities/programme
- Caregivers ability to have a break and pass care on to respite team
- Patients ability to read supplied information and cooperate e.g. bringing medication

OUTCOMES
- Patients to return home
- Carer to continue the caring role
- Patient and carer signposted to other activities/support
- Positive evaluation demonstrated through validated outcome measure
- Decreased fear of hospice

THEORY

PROGRAMME SPECIFICATION

WHAT WORKS FOR WHOM IN WHAT CIRCUMSTANCES AND REFINE THEORY [ON COMPLETION OF EVALUATION]

HYPOTHESIS

WHAT MIGHT WORK
- Respite planned programme
- Patient has own objectives and goals
- Individually tailored programme
- Menu of activities
- Keep to usual routine
- Pre-determined date of discharge
- Rehabilitation opportunities
- Access to full MDT
- Staff trained to focus on specialist palliative care needs in an enabling manner

OBSERVATIONS

MULTI-METHOD DATA COLLECTION & ANALYSIS
- Patients - validated outcome measure
- Caregivers - focus groups
- Staff - pre & post questionnaires & Reflections
- Referrers - Questionnaire
- Organisation - pre & post audit, occupancy figures
## APPENDIX 7

**Respite Outcome Table**

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>INTERVENTION</th>
<th>OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Informal carers</strong> are being left with minimal support to care for their loved ones and enable them to remain in the home setting.</td>
<td>Provide regular and timely respite care to allow an opportunity for carers to re-establish links with friends &amp; family &amp; get a break from the caring role.</td>
<td>Carers can continue in their caring role.</td>
</tr>
<tr>
<td><strong>Patients</strong> are wishing to choose their <strong>preferred place of care</strong> but are very dependent on their informal carers to allow that to happen.</td>
<td>A respite programme that ensures patients are maximising their functionality and their level of independence for as long as possible.</td>
<td>Patients are able to remain at home with a feeling of achievement by retaining and maintaining a level of control over their life.</td>
</tr>
<tr>
<td>Patients in the last year of life are slowly deteriorating and need a <strong>review of care</strong> as well as a programme of activities to maximise quality of life.</td>
<td>An individually tailored respite programme that allows for a comprehensive assessment of medical and nursing needs (e.g. review of medication, assessment of incontinence).</td>
<td>The patient is able to return home with their goals of care achieved and an understanding of how to manage their symptoms / issues.</td>
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APPENDIX 8

Hospice Mission & Core Values

MISSION

To treat every individual as unique, whom we value without distinction and whose culture and beliefs we respect.

To enable all to reach their full potential, valuing what they offer, respecting their autonomy and encouraging them to participate in their own care.

To confront the patient’s pain and distress whether mental, physical, social or spiritual.

To encourage openness and honesty when communicating with patients and their families, and to respect the patient’s confidentiality and wish to question or remain silent.

CORE VALUES

- Human Dignity
- Compassion
- Justice
- Quality
- Advocacy
APPENDIX 9

CULTURE MODELS

Hofstede’s Culture Dimensions (1980)

- Power distance – high score suggests some wield higher power than others; low score suggests all have equal power
- Uncertainty avoidance – extent to which an uncertainty and risk are accepted as natural occurrences
- Individualism vs. Collectivism – stand up for themselves (individualism) or act as a member of a group (collectivism)
- Masculinity vs. Femininity - competitiveness & ambition vs. caring & quality of life

Trompenaars and Hampden-Turner’s Seven Dimensions of Culture (1998)

- Universalism vs. Pluralism – the degree of importance the culture assigns to rules vs. relationships
- Individualism vs. Communitarianism – degree to which people see themselves as individuals or in communities
- Specific vs. Diffuse – degree to which responsibility is assigned
- Affectivity vs. Neutrality – degree to which emotions are displayed
- Inner directed vs. Outer directed – degree to which the environment controls or is controlled
- Achieved status vs. Ascribed status – degree to which people prove themselves or status is given to them

Sequential time vs. Synchronic time – do things one at a time or several things at one time
APPENDIX 10

The Vision for Respite Care

The ultimate purpose of respite for.................................

Patients
is to provide a safe, supportive, homely environment which enables patients to maximize and improve (if possible) their independence, maintain their usual routine (if desired) and act as equal partners in decision making

Carers
is to confidently handover care of their loved one to the team and have an opportunity to have quality time away from the caring situation and for staff to acknowledge their expertise and facilitate their involvement as a partner in care

Staff
is to have the necessary skills, including excellent communication, to work in an enabling way in a multi-disciplinary team. This will be achieved by being supportive and respectful of each other.

The factors / values that will help us to achieve this are.........................
- Listening carefully to what is being said
- Allowing time for patients, carers and staff
- Working well as a team
- Respecting different cultures and religions
- Ensuring clear, concise documentation & communication
- Being non-judgmental and respectful
- Accessing appropriate support and training to ensure we are fit for purpose
- Being professional and approachable
- Being trustworthy
- Being available to discuss any issues and providing adequate information and education
- Asking for feedback and acting on it

We can achieve this by......................
- Allowing people space and opportunity to make decisions
- Showing individual willingness and commitment
- Sharing goals
- Being open to inviting challenge & questions
- Valuing each other as individuals
  - Working together as a happy, whole & supportive team