



One to one support for cancer patients

A REPORT PREPARED FOR DH

December 2010

One to one support for cancer patients

Executive Summary	1
1 Introduction	7
2 One to one support model	9
2.1 <i>Description</i>	9
2.2 <i>One to one support along the cancer pathway</i>	12
2.3 <i>Expected benefits</i>	14
3 Estimating the gap in provision of one to one support services to breast cancer patients	19
3.1 <i>Our assumptions for breast cancer model</i>	20
3.2 <i>Our estimate of the gap for breast cancer</i>	23
4 The cost of closing the gap in breast cancer	27
5 Estimating the benefits of one to one support to breast cancer patients	33
5.1 <i>Unit (per patient) savings</i>	33
5.2 <i>Who do these savings apply to?</i>	38
5.3 <i>Aggregated savings</i>	40
6 Estimating the net savings of one to one support in breast cancer	43
7 Findings from other models	45
7.1 <i>Gap analysis - adult cancers</i>	45
7.2 <i>Costs and benefits - adult cancers</i>	47
7.3 <i>One to one support with metastatic cancer</i>	52
7.4 <i>Children and Young People (CYP) model</i>	58
8 Concluding remarks	71
Annexe	72
References	85

One to one support for cancer patients

Figure 1. Cancer care pathway	9
Figure 2. Levels of aftercare	14
Figure 3. Caseloads by stage	22
Figure 3. Breast cancer specialist nurse job titles	25
Figure 4. Annual cost of filling the gap in breast cancer	28
Figure 5. Annual savings in breast cancer	41
Figure 6. Net annual savings in breast cancer	43
Figure 8. Gap in one to one support – colorectal, head & neck, lung and prostate cancer	47
Figure 8. Annual costs of closing the gap in head & neck, colorectal, lung and prostate cancer	48
Figure 9. Annual savings in head & neck, colorectal, lung and prostate cancer	50
Figure 10. Net annual savings in head & neck, colorectal, lung and prostate cancer	52
Figure 12. Net annual savings in metastatic cancer	57
Figure 13. CYP cancer incidence by age group	59
Figure 14. Number of patients in diagnosis and treatment stage	60
Figure 15. CYP specialist nurse workforce (2008 data)	61
Figure 16. Estimate of gap in CYP cancers by age group	63
Figure 17. Annual cost of closing the gap in one to one support : CYP	65
Figure 18. Annual savings in CYP cancers (NHS)	67
Figure 19. Net savings in CYP cancers	68
Figure 20. Net annual savings of extending one to one support	78

Table 1. Annual cost of closing the gap in provision of one to one support, by cancer type (excluding activity classes)	3
Table 2. Annual NHS benefits (gross) associated with one to one support, by cancer type	4
Table 3. Annual net savings associated with provision of one to one support, by cancer type	5
Table 4. Number of breast cancer patients by stage in the care pathway	21
Table 5. Estimating the gap in breast cancer one to one support	24
Table 6. Annual cost of closing the gap- breast cancer 'high cost scenario'	29
Table 7. Annual cost of closing the gap- breast cancer 'central cost scenario'	30
Table 8. Annual cost of closing the gap- breast cancer 'low cost scenario'	31
Table 9. Annual savings arising from providing one to one support to breast cancer patients	34
Table 10. Savings scenarios in breast cancer: proportion of patients to whom savings apply	40
Table 11. Caseload assumptions for lung, prostate, head & neck and colorectal cancer	46
Table 12. Patient risk stratification lung, prostate, head & neck and colorectal cancer	46
Table 13. Value of annual savings from emergency bed day reductions relative to total savings	51
Table 14. Gap in one to one support to metastatic patients	54
Table 14. Total cost of closing the gap in provision of one to one support to metastatic patients	55
Table 15. Total benefits associated with provision of one to one support to metastatic patients	56
Table 16. Net savings associated with provision of one to one support to metastatic patients	57
Table 17. Caseload assumptions	62

Table 18. Estimate of gap in CYP cancers by stage in pathway	64
Table 19. Differences in educational attainment: childhood cancer survivors vs. the general population	69
Table 20. Total annual cost of employing specialist nurses	72
Table 21. Patient numbers* by stage in the pathway	73
Table 22. Annual savings arising from extending one to one support in colorectal cancer	74
Table 23. Annual savings arising from extending one to one support in head & neck cancer	75
Table 24. Annual savings arising from extending one to one support in lung cancer	76
Table 25. Annual savings arising from extending one to one support in prostate cancer	77
Table 26. Estimated patient numbers by stage in the pathway and age group: CYP	79
Table 27. Survival rates of CYP patients (0-15 years)	81
Table 28. CYP patients in diagnosis and treatment (0-15 years old)	82
Table 28. CYP cancer patients risk stratification: diagnosis & treatment stage	83
Table 29. CYP cancer patients risk stratification: aftercare year 1	83
Table 30. Assumed caseloads: CYP diagnosis & treatment stage	84
Table 31. Assumed caseloads: CYP aftercare year 1	84

Executive Summary

The Department of Health commissioned Frontier Economics to undertake modelling aimed at understanding the benefits and costs associated with one to one support for cancer patients. Current evidence from NAO (2005) and Picker Institute (2009) suggests that in some cancers only half of patients benefit from such support. While support is generally good during diagnosis and treatment stage, the gap appears to be in aftercare and metastatic disease.

One to one support to cancer patients is a broad concept and will be tailored to the needs of patients. One to one support is likely to include the following elements

- To ensure personalised holistic assessment and care planning which takes account of needs associated with the individual, the disease and the treatment.
- To undertake a major role in coordination and continuity of care, through supporting patients to navigate the system, to signpost to other sources of support and ensure that patients can re-enter the system if required.
- To ensure that patients and their carers get information, advice and support about diagnosis, treatment, aftercare, palliative and end of life care services.
- To enable supported self-management, where appropriate.
- To identify emerging problems around communication between patients and the healthcare system, symptom control and side effects of treatment, signposting to appropriate lifestyle interventions.
- To take a leading role in the provision of care and support, for example by providing specialist clinics as appropriate to the patients needs.

The one to one support function might best be understood as a team comprising of specialists (e.g. Clinical Nurse Specialists – grade 6 and 7) and generalists (e.g. band 4 Care Coordinator roles) who support the patient across the cancer pathway, based on the intensity of need of patients.

Costs

Providing one to one support to all cancer patients in England would require substantial investment in one to one support workers. The analysis we undertook focused on several adult cancers (breast, lung, prostate, colorectal, head and neck, metastatic) and all children and young people's cancers. Our estimates suggest that approximately 1,234 additional one to one support workers are needed to close the gap in provision.

The term 'one to one support worker' can refer to Clinical nurse specialists (CNS) but also care coordinators and nurses at lower grades. We model costs in three scenarios where we change the mix of one to one support workers (by grade). Our High cost scenario assumes that only CNSs are used to close the gap while at the other end of the spectrum, in our Low cost scenario staff at lower grades plays a very important role. In our Central case scenario, we assume that 12% of the work currently carried out by CNS can be done by lower grade staff. This assumption is based on research carried out by Leary et al. (2008) which shows that 12% of CNS work is administrative in nature and does not require clinical input. Our scenario assumptions are discussed in more detail in Chapter 4.

Expanding the workforce by 1,234 will cost in the region of £60m per annum (2011 money). On top of these staff costs, some additional expenditure may be required in order to achieve greater benefits for cancer patients. One such cost we model (in breast, prostate and colorectal cancer) is the provision of activity classes which have been shown to improve survival and lower recurrence. We estimate the total annual costs of activity classes to be between £4.5m and £14.8m with a central estimate of £9.8m. We consider activity classes in our modelling because their provision may be facilitated through better coordinated cancer care, leading to improved patient outcomes (modelled in our benefits sections). However, the provision of activity classes incurs costs over and above the costs of expanding the workforce.

Table 1. Annual cost of closing the gap in provision of one to one support, by cancer type (excluding activity classes)

	Gap (# of additional one to one support workers needed, WTE)	Low cost	Central estimate	High cost
Breast cancer	242	£8.5m	£11.5m	£13.3m
Lung cancer	179	£6.8m	£8.8m	£9.9m
Prostate cancer	209	£8.0m	£10.3m	£11.5m
Colorectal cancer	155	£5.5m	£7.3m	£8.6m
Head & neck	97	£3.8m	£4.8m	£5.3m
Metastatic (excl 5 cancers)	245	£8.9m	£11.6m	£13.5m
CYP cancers (all ages)	107	£5.3m	£5.4m	£5.9m
Total	1,234	£46.8m	£59.7m	£68.1m

Source: Frontier estimates

The gap estimates in Table 1 reflect shortages in both primary and metastatic disease. Therefore in order to avoid double counting, we present Metastatic estimates which exclude the cancers modelled in this study.

Benefits

The costs of closing the gap could be either partially or fully offset by a number of benefits arising from improvements in the quality and coordination of care. These include reductions in emergency bed days, reductions in routine follow-up appointments and GP visits.

We estimate the total benefits to range between £26m and £148m per annum, with the central estimate of £89m. Table 2 below provides the estimates by cancer type.

Benefits are the highest for prostate cancer in all scenarios. This is because of the relatively large number of patients in the aftercare stage who are suitable for self-management as well as the high number of emergency bed days which could be reduced.

Table 2. Annual NHS benefits (gross) associated with one to one support, by cancer type

	High benefits	Central estimate	Low benefits
Breast cancer	£20.7m	£14.2m	£7.3m
Lung cancer	£25.6m	£13.2m	£0.8m
Prostate cancer	£35.3m	£24.3m	£11.4m
Colorectal cancer	£26.8m	£16.0m	£5.1m
Head & neck	£4.2m	£2.5m	£0.7m
Metastatic (excl 5 cancers)	£26.5m	£14.3m	£0.0m
CYP cancers	£8.5m	£4.4m	£0.3m
Total	£147.5m	£88.8m	£25.7m

Source: Frontier estimates

For children and young people, we also estimate wider benefits to the patients, their families and society as a whole. These include (i) saving in transportation costs due to better coordinated ('shared') care and (ii) better educational attainment of young people with cancer (due to more support and better organised education process).

Net savings

Putting costs (including activity classes) and benefits together we expect the overall effect to be a net saving of £19m which is our central case estimate. Table 3 below breaks net savings down by cancer type. We expect to see net savings in all cancers except Head & Neck and CYP.

Table 3. Annual net savings associated with provision of one to one support, by cancer type

	Optimistic scenario	Central estimate	Conservative scenario
Breast cancer	£8.3m	£0.2m	-£7.3m
Lung cancer	£18.7m	£4.4m	-£9.1m
Prostate cancer	£19.4m	£8.7m	-£2.8m
Colorectal cancer	£17.8m	£6.4m	-£4.6m
Head & neck	£0.4m	-£2.3m	-£4.6m
Metastatic (excl 5 cancers)	£18.0m	£3.1m	-£12.9m
CYP cancers	£3.2m	-£1.0m	-£5.6m
Total	£85.9m	£19.3m	-£46.8m

Source: Frontier estimates¹

¹ Note that net savings are obtained by subtracting annual savings from the annual costs presented in **Table 1**. However, for breast, prostate and colorectal cancer we also add the costs of activity classes which are not accounted for in **Table 1**.

1 Introduction

The Department of Health commissioned Frontier Economics to undertake modelling aimed at understanding the benefits and costs associated with one to one support for cancer patients. Current evidence from NAO (2005) and Picker Institute (2009) suggests that in some cancers only half of patients benefit from such support. While support is generally good during diagnosis and treatment stage, the gap appears to be in aftercare and metastatic disease.

Specifically DH asked us to focus the analysis on the following tumour types:

- Breast cancer
- Lung cancer
- Prostate cancer
- Colorectal cancer
- Head and Neck cancers
- Metastatic cancer
- Children and young people's cancers

This report is structured as follows:

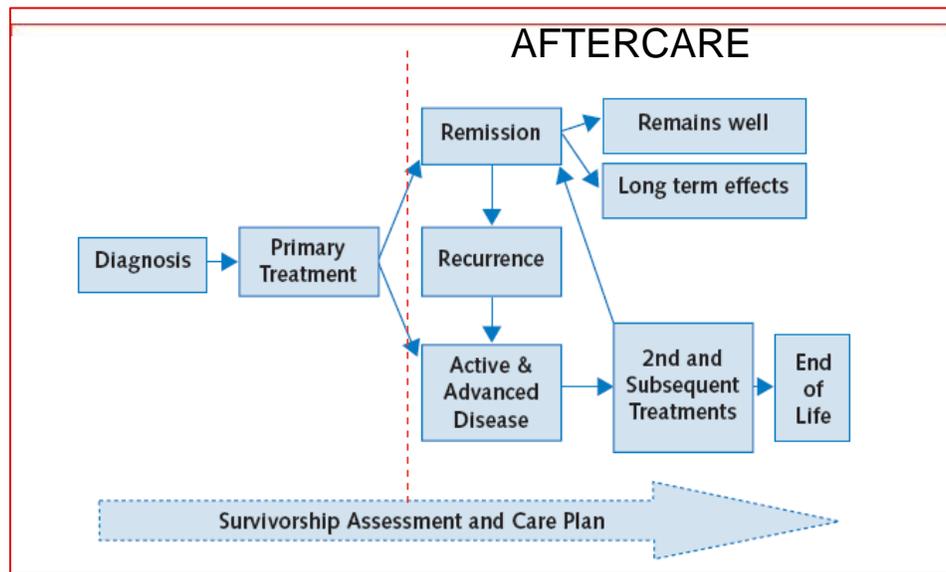
- Chapter 2 describes one to one support models and outlines the types of benefits associated with it.
- Chapter 3 focuses on breast cancer and estimates how many additional one to one support workers are needed in order to fill the gap in provision of one to one support to breast cancer patients.
- Chapter 4 shows our estimates of the annual costs of extending one to one support to all breast cancer patients
- Chapter 5 quantifies the savings associated with one to one support provision to all breast cancer patients.
- Chapter 6 outlines the findings from the other tumour types considered in this study: prostate, lung, colorectal, metastatic and Children and Young People.
- Chapter 7 presents our concluding remarks.

2 One to one support model

2.1 Description

One to one support to cancer patients is a broad concept and will be tailored to the needs of patients; - it will vary for individuals, by tumour type and by stage in the cancer pathway (shown in the Figure below).

Figure 1. Cancer care pathway



Source: National Cancer Survivorship Initiative (NCSI) vision, 2010

One to one support is likely to include the following elements:

- To ensure personalised holistic assessment and care planning which takes account of needs associated with the individual, the disease and the treatment.
- To undertake a major role in the management, coordination and continuity of care, through supporting patients to navigate the system, to signpost to other sources of support and ensure that patients can re-enter the system if required.
- To ensure that patients and their carers get personalised information, advice and support about diagnosis, treatment, aftercare, palliative and end of life care services.
- To enable self-management, where appropriate.

- To identify emerging problems around communication, symptom control and side effects of treatment, signposting to appropriate lifestyle interventions.
- To take a leading role in the management and provision of care and support, for example by providing specialist clinics as appropriate to the patients needs.

Better patient management and proactive discharge support could improve the quality of care for patients and reduce costs².

2.1.1 Current provision of one to one support

One to one support is currently delivered by Clinical Nurse Specialists (CNS), particularly in the early stages of clinical care including diagnosis and treatment. These are registered nurses at grade 6 or 7, who have graduate and specialist level nursing preparation.

While 84% of respondents to the 2010 Cancer Patient Experience Survey said that they were given the name of a CNS, there is inequitable distribution of access and patients with metastatic disease are likely to get less support than those with primary disease. Patient experience of support varies significantly by cancer type, stage of disease and phase in the pathway. For example there is evidence that prostate cancer patients have significantly worse experiences of their treatment and care than patients with other types of cancer³.

It appears that cancer patients are currently more likely to receive one to one support at the diagnosis and treatment stage than the aftercare stage. For example, The Picker Institute⁴ reports that only half of patients who are several years from diagnosis have a named one to one support worker who they can contact for support. This is clearly a problem, because this is the time when patients need advice on living ‘after cancer’, finding a quick way back to the system in case of recurrence and access to specialist services for managing post-treatment symptoms. Patients whose cancer has not been cured after the first treatment are likely to need more intensive support for living with cancer and managing symptoms.

² Scottish Executive (2006), Delivery for health

³ NAO “Tackling Cancer: Improving the Patient Journey” reports that only half of prostate cancer patients have a named nurse in charge of care compared with 61% of patients with other types of cancer

⁴ The Picker Institute “An Evaluation of the NCSI test community projects: Report of the baseline patient experience survey”

2.1.2 Who might provide one to one support in the future?

The key principle is that the level of one to one support is based on the needs of patients. It will vary for individuals and by tumour type and stage in the cancer pathway. The one to one support function might best be understood as a team which includes specialists (e.g. Clinical Nurse Specialists) and generalists (e.g. band 4 Care Coordinator roles) who support the patient across the cancer pathway, based on the intensity of need of patients.

Clinical Nurse Specialists

The National cancer Action Team defines CNS's role as follows:

“The high-level activities of CNSs can be separated into four main functions. In the context of cancer care these consist of:

- Using and applying technical knowledge of cancer and treatment to oversee and coordinate services, personalise ‘the cancer pathway’ for individual patients and to meet the complex information and support needs of patients and their families.
- Acting as the key accessible professional for the multidisciplinary team, undertaking proactive case management and using clinical acumen to reduce the risk to patients from disease or treatments.
- Using empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines as appropriate.
- Using technical knowledge and insight from patient experience to lead service redesign in order to implement improvements and make services responsive to patient need.”⁵

There is a considerable overlap between this description and the description of the one to one support, suggesting that CNSs are likely to play a critical role in delivering this support.

Care Coordinators

The National Cancer Survivorship Initiative (NCSI) is developing work to understand the contribution that a Care Coordinator role at Band 4 or equivalent

⁵ “Excellence in cancer care: the contribution of the clinical nurse specialist”, National Cancer Action Team,
<http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/ExcellenceinCancerCaretheContributionoftheClinicalNurseSpecialist.pdf>

might play in providing a care coordination service in the aftercare phase for people in remission.

The suggestion is that this role could be a day to day contact for general enquiries and with specialist nurses providing specialist advice and support where needed. The care coordination service could take a proactive role to ensure reviews (primary or secondary care based) take place, e.g. hormone therapy review at 3 years, a role to coordinate diagnostic and MDT referrals, to help patients with their appointments, and to signpost patients to further support when needed.

The role has parallels with the concept of a care tracker role developed by the Cancer Services Collaborative as part of the Integrated Cancer Care Pilot Project. “Care Tracker National workforce competences” recognises that this is “essentially a non-clinical role, but has the potential to include an optional clinical element”.

Core functions of care coordinator/care tracker include: gathering information about the patient, enabling the patient to understand how they can take advantage of the care coordinator role, co-ordinating with other services who contribute to the patient’s care, developing a personalised plan of care, making an effective referral to another professional or agency, supporting a patient’s family and carers.

2.2 One to one support along the cancer pathway

The levels of one-to one support may vary by stage in cancer care pathway. We reviewed the whole cancer care pathway in order to identify (i) those stages where one to one support is already provided for most patients and (ii) where it is currently lacking. We then reviewed existing research and policy documents and conducted interviews with experts to collect evidence on the type and magnitude of potential savings (per patient) that could be achieved through the provision of one to one support.

During the diagnosis and treatment stage, the level of support is high. Patients need information about their diagnosis and treatment options, emotional support, well coordinated care, and support with managing side-effects of treatment. The same applies to delivering support to patients with metastatic disease.

The National Cancer Survivorship Initiative Vision document summarises the evidence that current aftercare arrangements for cancer patients are not meeting the medical, psychological, social, spiritual, financial and information needs that people may have following cancer treatment.

Currently, patients at the aftercare stage are expected to attend a number of consultant-led follow up appointments. The main objective of these appointments is to monitor for recurrence. There is evidence to suggest that

One to one support model

these routine appointments might not adequately address patients' need for psychological support or to help them to adjust their life-style (e.g. to promote activity classes and healthy eating) Moreover, they may not be very effective at detecting recurrence early either – NICE Guidelines (2009) report that most breast cancer recurrences are detected by patients themselves between routine appointments. Indeed it has been suggested that having routine appointments may lead to delayed diagnosis of recurrence as patients may notice symptoms but wait to report them at their next routine appointment (de Bock et al. 2004).

The vision document describes how the aftercare stage can be potentially redesigned so that the number of routine consultant-led appointments is reduced and more tailored support is provided to patients based on their needs.

A risk stratified approach to aftercare will mean that the whole population of patients at the aftercare stage can be split into different groups based on the likelihood of recurrence and complexity of their needs. Naturally these will vary by cancer type. In common with the long term conditions model, personalised risk stratification is likely to lead to a small number of people with highly complex needs requiring intensive case management, slightly more people needing specialist disease management, and the vast majority able to cope through supported self-management with speedy access back to the system if required. As **Figure 2** illustrates, management of long term conditions may be stratified as follows:

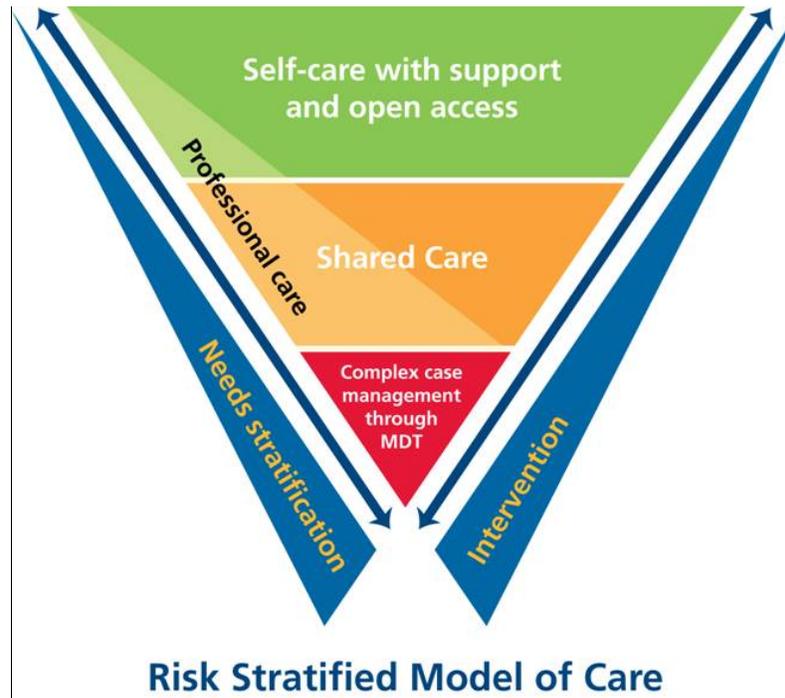
- 'Non-complex' cases – up to 70% of patients – may not need routine appointments at all (or only a small number in the first year after treatment). They, however, should have access to their CNS/care coordinator who they can contact with questions on symptoms of recurrence, life-style choices, going back to work, etc. One to one support workers should also be able to help their patients to re-enter the system quickly if they experience a recurrence or if their health deteriorates.
- 'Planned and coordinated care' – c. 20% of patients - these patients require greater input than 'non-complex' cases but not as intense as those with complex needs.
- 'Complex' cases – c. 5-10% of patients – these patients have more complex needs and would benefit from having access to a dedicated worker/CNS, who might provide case management or specialist care management.

These proportions will vary depending on the needs of patients, the cancer type and the treatment type.

Depending on patient needs at the aftercare stage, one to one support could be delivered by care coordinators/case trackers at level 4 or equivalent. This might

be most appropriate for patients in remission who are at low risk who have the appropriate support and information to empower them to self manage.

Figure 2. Levels of aftercare



Source: Department of Health

During the aftercare stage, one to one support may be less intensive for those in remission and may depend on time since treatment which is why we differentiate between year 1 post treatment and subsequent years. However, it should still be ‘tailored’ to patients’ needs.

“Self-management might include an individual engaging in activities which protect and promote their health and wellbeing, activities to monitor symptoms of further disease or the consequences of treatment, as well as monitoring the impact of the condition on functioning, emotions and relationships.”⁶

2.3 Expected benefits

There are a number of potential benefits that may arise from the provision of one to one support to all cancer patients. These are higher patients’ satisfaction,

⁶ “National cancer Survivorship Initiative: Vision”

One to one support model

improved equity and potential financial savings to the NHS. Although the scope of this project is limited to the latter type of benefits, we note that there are significant wider benefits that can result from effective one to one support. For example, the literature review we conducted as part of this study showed that patients are often more satisfied with CNS delivered care (which is part of the one to one support) than traditional care. Garvican et al. (1998) show that patients value highly the service provided by breast cancer nurses in diagnostic clinics. Faithful et. al. (2001) show that prostate cancer patients receiving nurse-led care during radiotherapy were significantly more satisfied with the care they received than patients receiving traditional care. James and McPhail (2008) show that patients with suspected prostate cancer valued highly the care received in a nurse-led diagnostic clinic.

Our focus is on estimating both the costs of provision and the financial benefits in order to assess whether this model of support is likely to generate net savings to the NHS (i.e. whether expected savings are higher than expected costs).

In this section, we describe the types of financial savings in broad terms. In Section 5 below, we will provide more details on how we aggregate these per-patient savings to build a comprehensive picture of potential benefits for the NHS arising from provision of one to one support for cancer patients.

Based on our review of existing research and policy documents and interviews with experts, we think the main benefits are expected at the aftercare stage, i.e. after diagnosis and treatment. These are:

- Reduction in the number of routine appointments - There is little evidence to suggest that routine follow-up for breast cancer leads to better outcomes for patients. A number of studies have shown that reducing the frequency of follow-up does not lead to deterioration in detection of recurrence. (Kokko et al. (2005))
- Some consultant-led appointments are replaced by nurse-led appointments
 - Baidam et al. (2004) show that there is no difference in the number of recurrences between patients followed up by a doctor and by a breast cancer nurse. Beaver et al. (2009) show that replacing routine hospital appointments with telephone follow-up does not lead to lower recurrence detection rates for patients at low risk of recurrence. Similarly, nurse-led on demand follow-up has also been shown to be no worse than traditional hospital follow-up at detecting local recurrence. Indeed Koinberg et al. (2004) find that on-demand follow-up may even

lead to more local recurrences being found relative to traditional follow-up⁷.

- Better coordinated care leading to a reduction in the number of GP visits and hospital emergency admissions.
 - Sridhar et al. (2007) show that COPD patients under the care of specialist nurses are less likely to visit their GP than the rest. Mutrie et al. (2007) demonstrate that patients taking physical exercise classes have fewer GP appointments and bed days than patients who do not. Molassiotis et al. (2009) also show reductions in hospital stays in patients receiving nurse-led care.
 - We also make an assumption about reductions in the number of emergency admissions to hospitals that could be achieved if one to one support is provided to all cancer patients.
- Potential reduction in recurrence for some cancers as a result of healthier life-style encouraged by CNSs/Care Coordinators.
 - Holmes et al. (2005) study the effect of physical activity following a breast cancer diagnosis on survival rates. They find that patients who are physically active have a lower risk of death and disease recurrence than patients who are not. The greatest benefits were found in women with hormone responsive tumours and women who performed the equivalent of 3-5 hours of walking at average pace. *“After adjusting for factors predictive of survival after breast cancer, the RRs of adverse outcomes including death, breast cancer death, and breast cancer recurrence were 26% to 40% lower comparing women with the highest to the lowest category of activity.”*
- Diagnosis performed by CNSs in nurse-led clinics (for some cancers)
 - When conducting our literature review we found several articles concluding that nurse-led diagnostic clinics have the potential to save money. In particular, James and McPhail (2008) find that one stop nurse-led diagnostic clinics for suspected prostate cancer patients improve the patient experience and are clinically no worse than conventional care. Savings can be realised because of the consultant/nurse wage differential.

⁷ *“Nurses detected 12 recurrences from 133 patients compared with eight local recurrences detected by physicians from 131 patients. Again, these numbers are too small for this to be significant, and there was no difference in the number of patients diagnosed with metastatic disease.”* in Montgomery et al. (2007)

- End-of-life care: more patients, who would prefer to die at home, may be able to do so
 - According to the National Care of the Dying Audit (Marie Curie Cancer Care 2007), 55% of cancer patients would prefer to die at home but in fact only around 25% actually achieve this wish. The National Audit Office (NAO) estimates that reducing admissions by 10% and length of stay by 3 days would lead to substantial savings to the NHS, over £100m. Further research by NAO and RAND Europe estimates that palliative care hospital bed days are much more expensive for the NHS than community care (including patient's own home). Moreover, NAO reports that 40% of patients who die in hospital have no medical need to be there.

In order to generate the benefits outlined above, one to one support needs to be provided throughout the cancer care pathway. Currently more support is provided at the diagnosis and treatment stage, but relatively few patients receive this support during the aftercare stage. This is primarily due to the insufficient number of staff (one to one support workers) but sub-optimal care planning and assessment are important factors too. In the following chapter we describe our methodology for estimating the gap in the number of one to one support workers needed to provide one to one support.

3 Estimating the gap in provision of one to one support services to breast cancer patients

There are three steps involved in estimating the gap in provision of one to one support to cancer patients:

- Step 1 – For each cancer type, we assess the number of patients at each stage of the care pathway, including diagnosis and treatment, aftercare (1st year and subsequent years) and palliative/end of life care. We use incidence figures and survival rates to estimate the number of patients at each stage.
- Step 2 – We make assumptions regarding typical caseloads, i.e. how many patients can be served by a one to one support worker. These caseloads vary by stage: e.g. at the diagnosis and treatment stage, these are typically 90-100 patients per one to one support worker, while at the aftercare stage (2-3 years since diagnosis), caseloads may be significantly higher – up to 500 patients per one to one support worker. These differences in caseloads reflect different tasks performed by a one to one support worker at each stage. While at the diagnosis and treatment stage, patients need a lot of support and care management, at the aftercare stage 2-3 years after diagnosis, patients may need to contact their one to one support worker only occasionally.

Where available, our caseload assumptions are underpinned by evidence from published sources⁸. However, evidence is particularly scarce regarding the aftercare stage. We relied on the interviews with experts from NCAT and other organisations and on case studies and CNS surveys⁹ to formulate some assumptions regarding appropriate caseloads at this stage.

- Stage 3 – We estimate the number of one to one support workers needed by dividing the number of patients at each stage by the appropriate caseload. We then estimate the gap by subtracting the current number of CNSs¹⁰ from the total number of one to one support workers needed.

⁸ Time to Care: Maintaining Access to Breast cancer nurses, Royal College of Nursing and Breast Cancer Care policy briefing. Caseloads for other tumour types from Thames Valley Cancer Network

⁹ Alison Leary has conducted interviews with lung cancer CNSs which reveal average ongoing caseloads as well as new referrals per annum

¹⁰ We also include other specialist nursing posts in our calculations as it appears that these are similar to CNS posts in terms of performed tasks.

Below we discuss in detail our estimate of the gap for breast cancer. Calculations for other cancers are carried out in a similar way and the results are reported in Section 7.1.

3.1 Our assumptions for breast cancer model

3.1.1 Number of breast cancer patients by stage

More than 38,000 people are diagnosed with breast cancer every year in England. 82% of them survive for 5 years or more and need one to one support both during treatment and during the aftercare stage. If we focus on newly diagnosed cases only, we will significantly underestimate the need for one to one support.

In **Table 4** below, we estimate the total number of breast cancer patients and survivors requiring one-to-one support to be c. 167,000. We note that prevalence data covering the tumours considered in this study is available from NCIN for numbers at the end of 2006. This is broken down by time since diagnosis and includes all people with a cancer diagnosis (both primary and metastatic patients). The main advantage of this data is that it represents actual counts of cancer survivors rather than estimates and as such is accurate. However, since we want to estimate the overall need for support for the most recent years, using prevalence data alone may lead to underestimates of the current gap. For this reason, we use incidence based estimates instead of prevalence data in our modelling. Note that as a sensitivity check we estimated two of our models using prevalence data. The results were not dissimilar to our incidence, survival and mortality based estimates. In general, using prevalence leads to lower gap estimates which translate into lower cost and benefits estimates¹¹

¹¹ Note that the prevalence data is for 2006 which is another reason why it may lead to underestimates of the gap (as incidence has been increasing year on year)

Table 4. Number of breast cancer patients by stage in the care pathway

Stage	Patients in a year	Method of calculation
Diagnosis and treatment (non-metastatic)	36,376	Equals 95% of incidence number (5% of patients are stage IV at diagnosis)
Aftercare year 1 (non-metastatic)	34,921	Equals 96% of patients in Diagnosis and treatment (96% 1 year survival rate)
Aftercare years 2-3 (non-metastatic, in remission)	66,023	Based on 82% 5 year survival rate (assuming deaths are equally distributed between years 2 to 5)
Metastatic patient care	20,488	Equals the mortality rate over two years (based on life expectancy of 3 years for metastatic patients, i.e. we only include the number of metastatic patients who are not in the final year of life)
End of life	10,244	Equals the mortality rate

Source: Incidence: ONS Cancer registrations 2007, Survival rates: CancerresearchUK, Mortality: NCIS 2006, Life expectancy of metastatic patients: Nice guidelines

These estimates are based on the following assumptions:

- Incidence: the number of newly diagnosed breast cancer cases in England (ONS, 2007).
- Survival rates: we use 1, 5 and 10 year survival rates in order to calculate the number of patients who are alive at various time intervals since diagnosis. These are applied to incidence figures.
- Mortality rates: we use mortality rates as a proxy for the number of patients at the 'end of life' stage in the care pathway. In addition, we use mortality to calculate the number of metastatic patients who are not in the final year of life.

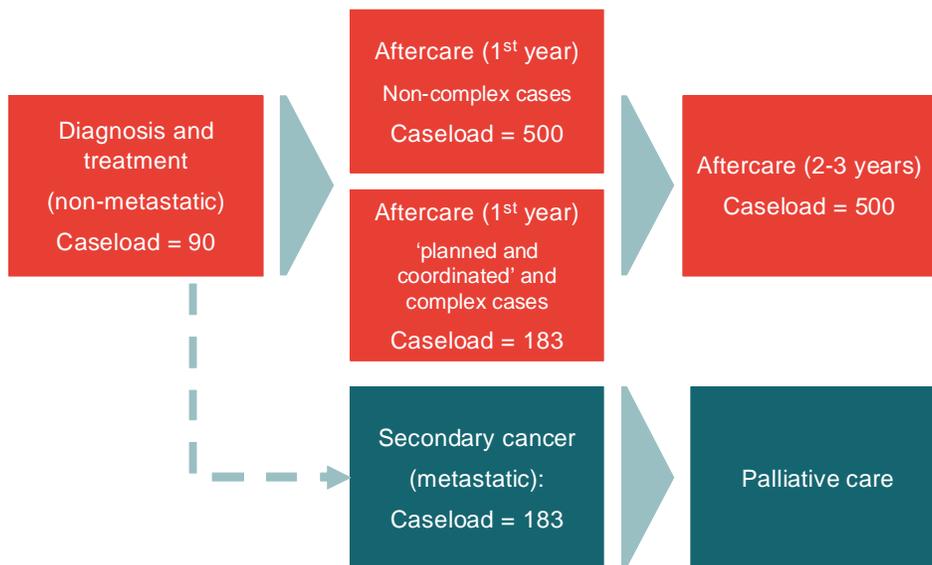
We estimate the number of patients by stage in their care pathway (or time elapsed since diagnoses). This is because the level and intensity of one to one support is likely to vary by stage in the care pathway: newly diagnosed cases may need more support, while those 2-3 years since diagnoses in remission may need less.

Our assumptions regarding caseloads at each stage are presented below.

3.1.2 Case loads

We calculate how many one to one workers are needed to cover all patients based on assumptions about what a realistic annual caseload may be. As we discussed above, patients who are undergoing treatment need more support than patients who are several years from diagnosis.

Figure 3. Caseloads by stage



Source: Frontier Economics

In order to reflect this difference in levels of need we use the following annual caseloads per one to one worker (illustrated by **Figure 3**):

- Diagnosis and treatment: 1 nurse supports 90 newly diagnosed patients. This assumption is based on work carried out by the Thames Valley Cancer Network.
- Aftercare year 1 (non-metastatic patients): 1 nurse supports 183 patients with complex needs OR 500 patients suitable for self-management. The former is based on the “Birmingham Own Health” pilot where 3 specialist nurses provide support to a cohort of 550 patients. The latter is an assumption based on conversations with experts. This is considered to be achievable with a move towards more patient self-management.

Estimating the gap in provision of one to one support services to breast cancer patients

- Aftercare years 2 & 3 (non-metastatic patients): 1 nurse supports 500 patients. As previously stated, this caseload is an assumption based on conversations with experts. Although it looks high in absolute terms it must be interpreted in the context of more patient self-managing, i.e. many of these patients will only contact their one to one support worker if the need arises. The duration of aftercare we model varies by tumour type and is typically longer (5 years). We base our assumptions on aftercare duration on evidence from a variety of sources including NICE, Consensus Workshop outputs and academic journals.
- Secondary breast cancer (metastatic patients): 1 nurse supports 183 patients. Assumption based on “Birmingham Own Health”.
- For palliative care, we do not estimate the gap in provision ourselves, but instead rely on the National Council for Palliative care estimate (discussed below).

Finally, it is worth noting that the caseloads used in our calculations of the gap in one to one support are not recommended caseloads but rather aim to reflect what should be possible if self-management was implemented more widely.

3.2 Our estimate of the gap for breast cancer

We estimate that 242 additional one to one support workers are needed to provide one to one support to all cancer patients and survivors.

We first estimate the number of one to one support workers needed in total – 754. The details of our calculations are presented in **Table 5**. We then subtract the existing number of one to one support workers to estimate the gap in provision.

Table 5. Estimating the gap in breast cancer one to one support

Stage	Patients in a year	Caseloads	Total number of one to one workers needed
Diagnosis and treatment	36,376	90	404
Aftercare year 1 (complex)	10,476	183	57
Aftercare year 1 (non-complex)	24,445	500	49
Aftercare years 2-3*	66,023	500	132
Metastatic patients	20,488	183	112
TOTAL (excl. palliative)			754

Source: Frontier calculations

* We assume that breast cancer patients are followed-up for 3 years based on NICE guidelines and conversations with experts. Risk stratification into complex/non-complex cases from Breast Cancer Consensus Workshop

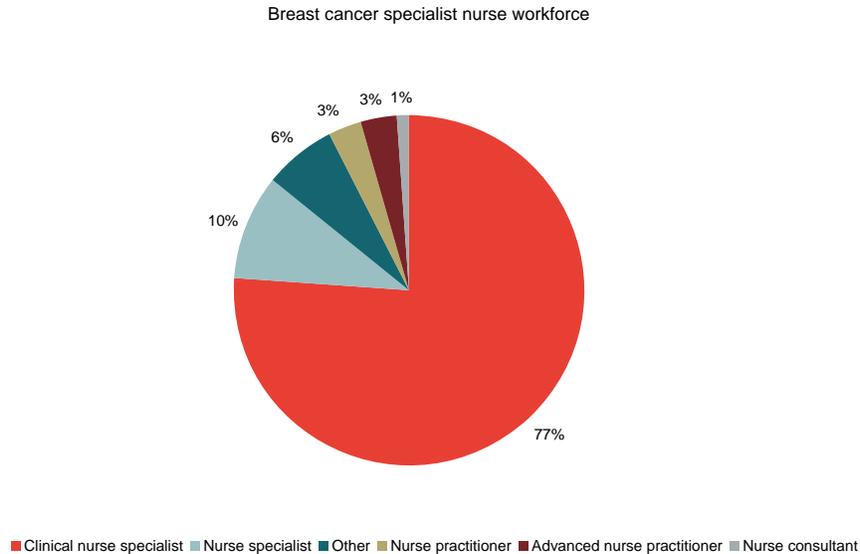
As **Table 5** demonstrates, we estimate the number of one to one support workers needed by dividing the number of patients at each stage in the care pathway by the appropriate annual caseloads. Note that the numbers in column 4 are not our estimates of the gap in provision. They simply show the total number of one to one support workers required to cover all patients at each stage of the pathway (the existing workforce is not accounted for in this table).

Existing workforce

There are currently 523 breast cancer specialist nurses in England (including those working with metastatic patients). The majority of specialist nurses are Clinical Nurse Specialists (77%) and Nurse Specialists (10%). There are also Nurse Consultants, Advanced Nurse Practitioners and other posts. We understand from our discussions with National Cancer Action Team that these posts are similar in terms of responsibilities involved. Therefore, we include all these posts in our count of the existing workforce.

According to experts we interviewed during the course of this study, there are 14 nurses working with metastatic patients.

Estimating the gap in provision of one to one support services to breast cancer patients

Figure 4. Breast cancer specialist nurse job titles

Source: 2010 English Cancer Networks Census Of Cancer Specialist Nurses

Therefore, the gap in provision (excluding palliative care) is 231 FTE posts (754 - 523).

For the 'end of life' care, we estimate the gap for all cancers first and then apportion it to different tumours. The total gap in palliative care for cancer patients is estimated to be 126. This is based on the following assumptions: the total palliative nurse workforce stands at 2,600 (NCPC) and 80% of that is dedicated to cancer patients. There are 126,000 people dying from cancer annually (NCIN), 70% of them need palliative care. A typical caseload for a palliative care nurse is 40 cases per annum.

We then apportion this figure to different tumours based on the share of people dying from that tumour, e.g. breast cancer represents 8% of all cancer deaths. Therefore, we apportion 8% of the total gap to breast cancer (11 nurses).

In total, the gap in provision of one to one support to breast cancer patients is 242 posts (231+11). This represents a 54% increase in the number of one to one support workers (given the current number of 523).

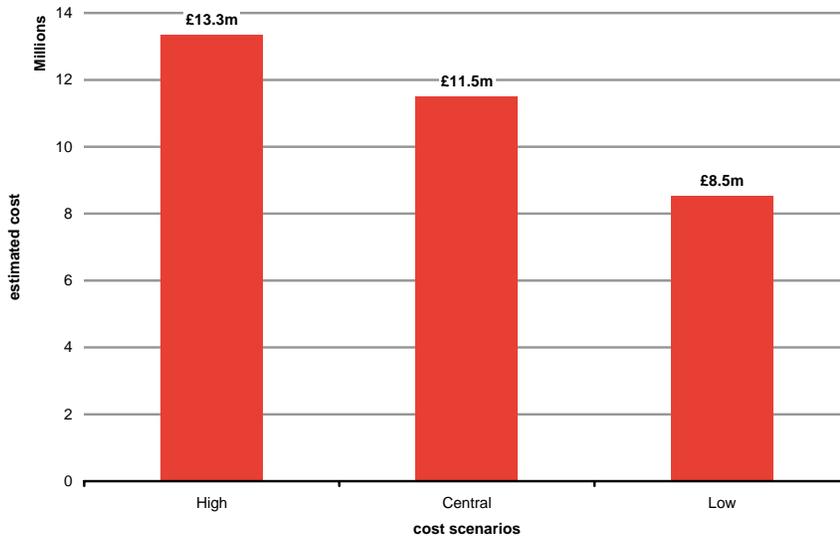
4 The cost of closing the gap in breast cancer

Our estimate of the gap for breast cancer in provision of one to one support to breast cancer patients shows that 242 additional (FTE) posts are needed in order to provide one to one support to all patients in England.

In this section, we estimate the annual costs of closing the gap in provision. These costs depend on the type of one to one support workers used to close the gap. One to one support is currently provided mainly by CNSs at grade 7 and 6 (with a small number of posts at grade 8) but there is evidence suggesting that at least some of the work specialist nurses currently do can be performed by staff at lower grades. An analysis of tasks carried out by CNSs (Leary et al. 2008) suggests that a proportion of these tasks (12%) are administrative in nature and can be carried out by administrative staff or by nurses at a lower grade. More fundamentally, there is a view that one to one support workers/ care coordinators need not be CNSs at grade 6 or 7. A significant proportion of tasks can be carried out by nurses at grade 4, with some supervision from senior staff.

We estimate that closing the gap in provision of one to one support to breast cancer patients would cost between £8.5m and £13.3m (**Table 6**), depending on the composition of one to one support workers (by grade).

- The ‘High cost’ scenario assumes that the whole gap is filled by CNSs at grade 6 and 7 (reflecting the current split - 30% grade 6 and 70% grade 7).
- The ‘Central case’ scenario assumes that most of the work is carried out by CNSs at grade 6 and 7 (30%/70% split), with 12% of all work being carried out by staff at grade 4.
- The ‘Low cost scenario’ assumes that a higher proportion of work (33%) can be carried out by staff at grade 4. This scenario effectively suggests that the existing staff (CNSs at grade 6 and 7) can be redeployed in such a way that one to one support to cancer patients is carried out more efficiently. CNSs would focus on more specialist tasks (e.g. providing information on different types of treatment and on management of side-effects), while less demanding tasks (writing letters, arranging appointments) would be carried out by staff at lower grade. At this stage, this scenario is purely hypothetical. It needs to be tested to understand whether one to one support to cancer patients can be delivered effectively by a combination of CNSs and other staff at lower grade.

Figure 5. Annual cost of filling the gap in breast cancer

Source: Frontier estimates

In each case, we estimate the annual cost of closing the gap by multiplying the number of staff required by the relevant wage. In addition to that we include on-costs and overheads. More specifically, the components included are as follows:

- basic salary: median full-time equivalent basic salary by grade (from ‘Agenda for change’ 2009);
- salary on-costs: employer National Insurance and superannuation contributions;
- overheads: indirect overheads and proportion of salary for direct revenue overheads;
- capital overheads: Based on the new-build and land requirements of community health facilities, and adjusted to reflect shared use of treatment and non-treatment space.

Hiring a Grade 7 specialist nurse is expected to cost £57,735 per annum in 2011 while the cost of hiring a Grade 4 nurse is significantly smaller - £35,258. Detailed calculations of the staff costs used in our modelling can be found in the **Annexe**. All of the above components are based on data from PSSRU Costs of Health and Social Care 2009.

The cost of closing the gap in breast cancer

4.1.1 High cost scenario: specialist nurses only

Assuming the gap in cancer care provision is filled by specialist nurses at grade 6 and 7, closing the gap will cost around £13.3m. This is our ‘High Cost’ scenario. It includes wages, on-costs and overheads associated with hiring 242 additional CNSs, but excludes costs of CNS training (as these are outside the scope of this project).

We assume that 70% of the 242 additional posts needed to close the gap are at Grade 7, which translates into 169 FTE posts, the remaining 72 posts being Grade 6. The 70%:30% split is similar the current CNS distribution (based on NCAT’s 2010 Cancer Specialist Nurses Census¹²).

Table 6. Annual cost of closing the gap- breast cancer ‘high cost scenario’

	GAP	Cost per worker	Total cost
Grade 7	169	£57,735	£9.8m
Grade 6	72	£49,179	£3.5m
Grade 4	-	-	-
Total	242	-	£13.3m

Source: Frontier estimates. Note GAP numbers do not add up to total due to rounding up

4.1.2 Central case scenario: specialist nurses and staff at grade 4 (12% of all posts)

The total annual cost of filling the gap in our central case scenario is £11.5m. This estimate is based on an overall gap estimate of 242 FTE posts, but a different mix of staff used to close it. As previously stated, there is evidence that some of the tasks currently performed by CNSs could be performed by staff at lower grade. In “Dimensions of clinical nurse specialist work in the UK” Leary et al. (2008) modelled the work of CNSs, recorded the tasks CNSs perform and how long these tasks take. They conclude that up to 12% of all CNSs’ time is spent on tasks that could be performed by staff at lower grade (possibly administrative staff).

If we assume that the CNSs’ work can be re-organised in such a way that 12% of their work is performed by staff at grade 4, the cost of closing the gap is lower

¹² According to the 2010 English Cancer Networks Cancer Specialist Nurses Census, 70% of specialist nurses are band 7. The remaining 30% are Grade 6 (20%) and other grades (10%). For the purposes of our modelling we have kept the ratio of grade 7 nurses constant at 70%, with the remaining 30% being grade 6.

than in our previous scenario. This is because fewer additional CNSs will be needed – 150 in total (105 Grade 7 and 45 Grade 6). The remaining 92 posts will be covered by staff at grade 4. A detailed breakdown of the costs and numbers of one to one support workers at different grades is provided below.

Table 7. Annual cost of closing the gap- breast cancer ‘central cost scenario’

	GAP	Cost per worker	Total cost
Grade 7	105	£57,735	£6.1m
Grade 6	45	£49,179	£2.2m
Grade 4	92	£35,258	£3.2m
Total	242	-	£11.5m

Source: Frontier estimates

4.1.3 Low cost scenario: specialist nurses and staff at grade 4 (33% of all posts)

Different models of cancer care support are still being discussed by various stakeholders. Some of the proposed models emphasise the role of a care coordinator. This role is somewhat different from the current CNS role and does not necessarily require the level of qualifications of specialist nurses.

Experts in the Breast Cancer Consensus group and other tumour type workshops¹³ have discussed the possibility that a higher proportion (up to 33% of ALL work, not just 33% of the gap) can be carried out by staff at grade 4.

¹³ A series of workshops with clinicians, which took place between June and August 2010

Table 8. Annual cost of closing the gap- breast cancer ‘low cost scenario’

	GAP	Cost per worker	Total cost
Grade 7	-	-	-
Grade 6	-	-	-
Grade 4	242	£35,258	£8.5m
Total	242	-	£8.5m

Source: Frontier estimates

This is a bold assumption that has not been fully tested yet. We use it to estimate out ‘Low Cost’ scenario. This leads to an annual cost estimate of £8.5m and means that all additional workers hired to close the gap are Grade 4. The implication of our low cost scenario is that specialist nurse time can be released by the deployment of lower grade nurses who can perform the administrative and coordination tasks that specialist nurses currently do as well as some of the simpler clinical interventions.

Having estimated the range of costs of providing one to one support to breast cancer patients, we now move on and estimate the benefits (financial savings to the NHS) associated with this support model.

5 Estimating the benefits of one to one support to breast cancer patients

In Section 2.3 above, we described broadly the types of financial benefits which can be expected to accrue to the NHS as the service delivered to breast cancer patients improves and becomes more coordinated, with more one to one workers coming in.

In this section, we examine in detail the type of savings that may arise at various stages of the cancer care pathway and assess what patient groups these savings can be applied to. We review the academic literature in order to identify the type of savings that are associated with one to one support. We base our benefit estimates on academic evidence where available and rely on reasonable assumptions where the evidence is lacking. Note that some of the papers we use as sources are not economic evaluations of nurse-led care (i.e. they do not estimate efficiency savings explicitly). In many cases these simply demonstrate that nurse-led care is no worse (or better) than standard care in terms of patient satisfaction and healthcare resource utilisation.

The evidence we collected during the course of this study tends to be specific to certain cancers and interventions. We build on the findings from these studies and apply them more generally in our modelling.

- For example, Beaver et al. (2009) demonstrate that nurse-led (telephone based) follow-up is no worse than conventional care. *“Participants in the telephone group were no more likely to consult with other health professionals between visits than those in the hospital group and so were not using additional healthcare resources.”* Although there is no specific cost information in this paper, the findings clearly indicate that increasing nurse-led aftercare has the potential to release resources and save money. This study is specific to breast cancer, but may be applicable to other cancer types.

In the absence of tumour specific evidence, we extrapolate findings from one cancer type to another, where such generalisations are reasonable to make.

Because cost information is often unavailable in the academic studies we have reviewed, we estimate savings separately using a variety of cost data sources, such as PSSRU Costs of Health and Social Care and the NHS Reference costs.

5.1 Unit (per patient) savings

Our unit savings (savings per patient) are presented in **Table 9**. Note that these are annual **gross** savings per patient (2011 money). For example, when assessing savings associated with a reduction in the number of routine consultant-led appointments, we calculate the cost of a consultant-led appointment rather than a

difference between this cost and the cost of an alternative service provided by a CNS (a nurse-led appointment or a phone call). This is because the costs of services provided by CNSs are taken into account in our estimate of the cost of provision of one to one support. The net benefits (i.e. benefits minus costs) are presented in the following section (Section 6).

Table 9. Annual savings arising from providing one to one support to breast cancer patients

Type of benefit	Monetary value per patient	Comment	Source	Stage in pathway
Increase in nurse-led diagnostic clinics	£58	Equals the cost of 2 consultant-led appointments, i.e. consultant/nurse substitution	Based on James and McPhail (2008), see References	Diagnosis & Treatment
Increase in nurse-led aftercare	£87	Equals the cost of 3 consultant-led appointments, i.e. consultant/nurse substitution	Based on Beaver et al. (2009), see References	Aftercare (year 1)
Reduction in hospital and GP visits	£29	Equals the cost of 0.1GP appointment and 0.1hospital bed day	Based on Mutrie et al. (2007), see References	Aftercare (years 2&3)
Reduction in recurrence rates	£10,906 ¹⁴	Equals the annual cost of recurrence to the NHS	Based on Thomas et al. (2009), see References	Aftercare (years 2&3)
Reduction in number of routine follow-up appointments	£130	Equals the cost of 1 clinic attendance	Adapted from Knowles et al, (2007)	Aftercare (years 2&3)
Reduction in number of patients dying in hospital	£700	Equals the cost of three bed days	Adapted from NAO & RAND Europe (2008)	End of life care

Source: Frontier estimates

Below we discuss each type of saving in more detail.

- **Some consultant-led appointments are replaced by nurse-led appointments** – There is evidence suggesting that supported self-management at the aftercare stage is no worse than traditional follow-up (i.e. routine consultant-led appointments) at detecting recurrence (see section 2.3

¹⁴ Note that although the saving per patient is high, this type of savings applies to a small number of patients – we estimate that between 66 and 198 recurrences could be saved per year

for details). Hence replacing routine consultant led hospital appointments with structured telephone nurse-led or even patient initiated follow up may release resources. Although there is variation in the way breast cancer patients are followed up around the country, there are commonalities too. Most patients are seen 3 monthly in their first 1-2 years after which the frequency of visits decreases to 6 monthly and then 12 monthly (Beaver et al. 2009). For patients in the first year of aftercare, we substitute three consultant led-appointments with nurse-led contacts- that is we assume that one of the four annual follow-up appointments remains consultant-led. The cost of a 10 minute consultant-led appointment (expressed in 2011 prices) is £29 (based on PSSRU Costs of Health and Social Care 2009, where the cost of 1 hour consultant patient related time is £166 or £174 in 2011 money).

- **Some consultant-led appointments are completely removed** - Routine follow-up may not be efficient at detecting breast cancer recurrence. Various studies have shown that changing the way in which patients are followed up does not lead to detrimental outcomes relative to conventional hospital follow-up. For example, Koinberg et al. (2004) demonstrate that a patient initiated follow-up is at least no worse than the conventional model at detecting recurrence. Similarly Kokko et al. (2005) show that reducing the frequency of follow-up appointments does not lead to worse patient outcomes. Some studies (de Bock et al. 2004) even suggest that having routine follow-up at regular time intervals may delay the detection of recurrence due to patients ignoring symptoms until their next scheduled hospital visit. We reflect the above in our models by removing 1 consultant clinic appointment (per patient per year) completely. Our savings estimate equals the cost of a clinical attendance of £130 and 10 minutes of consultant time cost of £29 (based on Knowles et al. 2007 and PSSRU Costs of Health and Social Care 2009 where the cost of 1 hour consultant patient related time is £166 or £174 in 2011 money).
- **Potential reduction in recurrence for some cancers as a result of healthier life-style encouraged by one to one support workers** – The NICE guidance states that it is **clinically and cost effective** for health professionals to assess physical activity levels and deliver a brief intervention (following a behaviour change methodology) signposting to local physical activity opportunities. The DH has developed Let's Get Moving resources including health professional training and patient resource to enable this. CNSs will be able to facilitate this if provided with the right top up training and resources. On average breast cancer survivors who are physically active reduce their risk of death by between 30 – 50% compared to women who

were less physically active¹⁵. Recurrence in breast cancer is not uncommon, around 1/3 of patients relapse at some point following treatment and this can happen many years after diagnosis. The cost of recurrence to the NHS is high - Thomas et al. (2009) show that the total cost of breast cancer relapse (per patient) is £25,186. This is equivalent to £10,906 (per annum expressed in 2011 terms). There is evidence that breast cancer recurrence rates can be reduced with the help of activity classes. Holmes et al. (2005) find that: *"After adjusting for factors predictive of survival after breast cancer ... breast cancer recurrence were 26% to 40% lower comparing women with the highest to the lowest category of activity."* Although one to one workers are not directly involved in the delivery of activity classes¹⁶, they can encourage more patients to participate, provide information on the benefits associated with exercise, hence playing a part in reducing recurrence rates. Based on the evidence we have examined, it appears that reductions in recurrence following lifestyle interventions are most likely in breast, colorectal and prostate cancer patients. Therefore we only use this unit saving in our breast, prostate and colorectal models.

- **Life-style interventions leading to reductions in the number of GP visits** - Reductions in the number of GP appointments may occur for a number of reasons: if care is better coordinated and patients have a named one to one support worker, they could contact their one to one support worker with questions. So there will be less need for them to contact their GP. In addition, if patients lead healthier lifestyle, they will be less likely to have the need to contact health professionals. Mutrie et al. (2007) demonstrate that patients participating in activity classes tend to have fewer GP appointments and hospital visits than those who do not. Specifically they show that patients taking activity classes are 10 percentage points less likely to visit their GP (72% vs. 82%) or have a hospital stay (10% vs. 20%). Using this information we calculate a unit saving of £29 which is equal to the cost of 0.1 GP appointments and 0.1 hospital bed days (based on £52 per GP appointment from PSSRU Unit Costs of Health and Social Care 2009 and bed day cost of £222 from NAO. Both uplifted to account for inflation).
- **Diagnosis performed by specialist nurses in nurse-led clinics** (for some cancers) – James and McPhail (2008) demonstrate that nurse-led diagnostic clinics for suspected prostate cancer patients are a good alternative to standard care. They cut waiting times and lead to high patient satisfaction

¹⁵ For example, see Patterson et al. (2010) or Irwin, ML et al (2008) but there are a number of other studies that are relevant here too.

¹⁶ The costs of activity classes are estimated separately (£192 per patient) because they are not delivered by specialist nurses.

due to continuity of care (the patient sees the same nurse throughout). In financial terms, assuming nurses and consultants see the same number of patients in a session; this could lead to savings due to the nurse/consultant wage differential. This study is specific to prostate cancer, but could be extended to breast cancer. Indeed, there is evidence (Garvican et al. 1998) that specialist breast cancer nurses can be substitutes for doctors in the diagnostic stage. The saving of £58 we calculate is equal to 20 minutes of consultant time which is reflective of the duration of a diagnostic appointment (based on PSSRU Costs of Health and Social Care 2009 where the cost of 1 hour consultant patient related time is £166 or £174 in 2011 money)

- **End-of-life care: more patients, who wish to die at home, may be able to do so** - According to the National Care of the Dying Audit (Marie Curie Cancer Care 2007)¹⁷, 55% of cancer patients would prefer to die at home, but in fact only around 25% actually achieve this wish. The National Audit Office (NAO) estimates that reducing admissions by 10% and length of stay by 3 days would lead to substantial savings to the NHS, over £100m. Further research by NAO and RAND Europe estimates that palliative care hospital bed days are much more expensive for the NHS than community care (including patient's own home). Moreover, NAO reports that 40% of patients who die in hospital have no medical need to be there. In our model the financial savings in the 'end of life' stage of the pathway are estimated to be £700¹⁸ (per patient), which is equal to the cost of 3 bed days, i.e. we model the cost of reducing length of stay by 3 days (based on a hospital bed day cost of £222; NAO and RAND Europe 2008).
- Finally, better coordinated care may lead to a **reduction in the number of hospital emergency admissions** – Robust quantitative evidence on the impact of one to one support on the number of hospital emergency admissions (or the number of emergency bed days) is scarce. However, there are several examples of small-scale interventions and initiatives demonstrating that emergency bed days can be reduced by up to 20%. For example unpublished data collected by Alison Leary (2010) shows that nurse-led interventions in lung cancer and thoracic oncology can reduce hospital bed days and inappropriate admissions. In our models, we make assumptions about what reductions in emergency bed days are achievable

¹⁷ In "Important Choices – where to die when the time comes"

¹⁸ We understand that these savings may be partially offset by the costs of providing home care. Given that these costs could be potentially significant, we include this type of savings only in two of our scenarios (see Table 10).

and apply them to the current total (emergency bed days in 2008/09 from HES). Note that we do not express these savings in per-patient terms because it is difficult to allocate emergency bed days to specific stages in the care pathway.

5.2 Who do these savings apply to?

The next step in our analysis is to establish who these savings apply to. Indeed, this is a crucial step as it effectively determines (together with the unit savings estimates) the overall savings estimates. Our analysis uses three scenarios in which we vary the proportion of patients to which the unit savings are applied:

- High benefit scenario

This includes 20% reduction in emergency bed days and all other unit savings identified in our review of the literature and conversations with experts. These are applied to a significant number of patients. For example, we noted earlier that if the correct level of support was in place more cancer patients who wish to die at home could do so. Potentially this could reduce NHS costs associated with end of life care significantly. We know that currently a quarter of cancer patients are able to die at home while 55% would like to. Therefore the maximum feasible increase in patients dying at home is 30 percentage points, which is the proportion of patients we apply this saving to¹⁹. Savings arising from activity classes are constrained by evidence on patient uptake.

At the diagnosis stage, we apply the savings associated with nurse-led diagnostic clinics to 20% of patients. We choose a low proportion here for two reasons: there is ongoing debate in the literature whether nurse-led clinics actually save money. It is claimed that if nurses order more diagnostic tests or take longer than consultants to diagnose patients, no savings would materialise. Because there is some degree of uncertainty around this type of benefit we only apply it in our High Benefit scenario and to a relatively small number of patients. Another reason for this is that diagnostic clinics may not be central to the one to one support model.

- Central benefit scenario

Includes most benefits identified in our review of the literature and conversations with experts. These are applied to a moderate number of patients and emergency bed days are cut by 10%. This is our central estimates of savings arising from one to one support to breast cancer patients and as such stands in the middle between our conservative and optimistic estimates. For example we assume that nurse-led aftercare is a suitable substitute for consultant follow-up for 70% of

¹⁹ Cost of 3 bed days=£700

breast cancer patients. We choose this number based on patient risk stratification by the Breast Cancer Consensus Group which asserts that ca. 70% of breast cancer patients are suitable for self-management. The same logic applies to removal of routine follow-up appointments for patients who are more than 2 years from diagnosis. There are no savings from nurse-led diagnostic clinics in this scenario for reasons outlined above.

- Low benefit scenario

Includes only some of the benefits identified in our review of the literature and conversations with experts. These are applied to a conservative number of patients and we assume no reduction in emergency bed days. We do not include any savings from nurse-led diagnostic clinics (for reasons outlined earlier) or more patients dying at home. Our reasoning for the latter is that moving patients in the end of life stage from hospital into the home may require some additional resources which may not be reflected in our gap estimates. In other words, if more patients dying at home results in even greater need for support (than reflected in our estimates), it is not clear that any savings can be made. Savings associated with healthy lifestyle interventions are applied to only a small number of patients in this scenario (10%) reflecting the possibility of very low take up rates.

Table 10. Savings scenarios in breast cancer: proportion of patients to whom savings apply

Type of benefit	Low benefit	Central case	High benefit	Comment
Increase in nurse-led diagnostic clinics	0%	0%	20%	Frontier assumption: low proportion chosen as diagnostic clinics may not be central to one to one support model
Increase in nurse-led aftercare	70%	70%	70%	Based on risk stratification results from Breast Cancer Consensus group
Reduction in hospital and GP visits	10%	20%	30%	Based on proportion of patients likely to take part in activity classes from Mutrie et al. (2007)
Reduction in recurrence rates	10%	20%	30%	Upper bound is based on the proportion of patients likely to take part in activity classes in Mutrie et al. (2007)
Reduction in number of routine follow-up appointments	50%	70%	80%	Frontier assumption: self management unlikely to completely remove follow-up appointments
Reduction in number of patients dying in hospital	0%	15%	30%	Based on difference between proportions of patients who currently die at home and who wish to die at home

Source: Frontier estimates

5.3 Aggregated savings

To obtain total annual savings in breast cancer, we multiply the unit savings presented in **Table 9** by the number of patients at the relevant stage taking into account the information in **Table 10**, i.e. the percentage of patients the savings can be applied to. We present an example of how the calculations are carried out for illustration purposes:

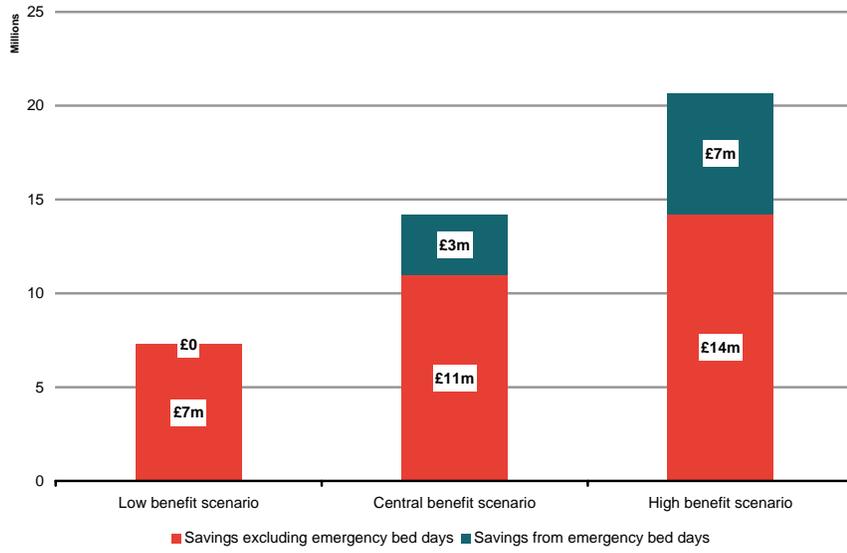
$$\text{Savings at end of life care (central case)} = (£,700) \times (10,244) \times (15\%)$$

$$\text{Savings at end of life care (central case)} = £,1,075m$$

Following the methodology outlined above we calculate the total annual savings at each stage of the care pathway and add them together. Finally, we add the savings associated with reductions in emergency bed days to this which give us total annual savings in the range £7.2m-£20.7m.

Estimating the benefits of one to one support to breast cancer patients

Figure 6. Annual savings in breast cancer



Source: Frontier estimates

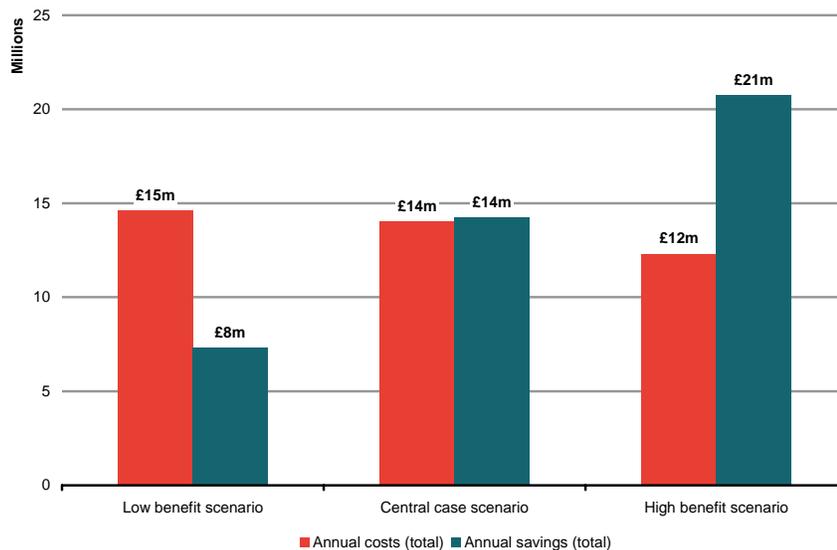
6 Estimating the net savings of one to one support in breast cancer

In section 4 of this study we estimated the costs of extending one to one support to all breast cancer patients, and in section 5, we calculated the benefits associated with that. In this section we put the costs and benefits together. As in previous sections we use 3 scenarios to analyse net savings:

- Optimistic scenario: we combine our low cost and high benefit estimates
- Central case: we combine our central cost and central benefit estimates
- Conservative scenario: we combine our high cost and low benefit estimates

It is worth noting that our costs scenarios are not explicitly linked to the benefits scenarios, i.e. low cost scenario does not necessarily lead to low benefits or high cost scenario – to high benefits. That means that the costs and benefits scenarios can be paired in a number of different ways. We present three combinations only as they give us the *lower bound* for net savings (low benefits and high costs), *upper bound* (high benefits and low costs) and the *central case* (central estimates for the costs and benefits).

Figure 7. Net annual savings in breast cancer



Source: Frontier estimates

We find that the net benefits associated with one to one support ranges between £8.4 million (net savings) and -£7.3m (net costs). In the central case scenario, the net savings are c. £0.2 million, i.e. the extension of on-to-one support model to all breast cancer patients is expected to result in savings for the NHS²⁰.

²⁰ Note that the cost of providing activity classes is entered separately in our total cost figures and added to the cost associated with closing the gap in one to one support. This is because in our model of support one to one support workers encourage participation in activity classes rather than provide them directly. Delivering better care to cancer patients may require additional expenditure on top of the staff costs associated with closing the gap in one to one support. We know that activity classes improve survival and reduce recurrence in breast cancer patients (Holmes et al. 2005). It has also been shown that the costs (to the NHS) of breast cancer recurrence are very high - Thomas et al. (2009) put the total cost at £25,186 per patient. Hence increasing patient participation in activity classes (through better service coordination and more information provision) may lead to better health and economic outcomes which are quantified in our model. The costs of activity classes (£192 per patient) are entered separately in our total cost estimates because they are not delivered directly by specialist nurses. Clearly total costs will depend on the number participating so for our calculations we rely on scenarios in which we vary patient numbers. In our low benefit scenario we assume that only 10% of aftercare patients partake. We increase this ratio to 30% in our high benefit scenario (in line with take-up rates from Mutrie et al. 2007). Overall, this results in additional annual costs in the range £1.3m-£3.8m with a central estimate of £2.5m.

7 Findings from other models

This section presents our findings for other cancer types considered in our study (lung, colorectal, prostate and head & neck). The general methodology used in these models is very similar to the one outlined above. Where differences exist, they are highlighted in this section.

Children and young people (CYP) cancer model and metastatic models are discussed in the following sections. These models are significantly different. More specifically, in the CYP model we consider wider economic benefits (benefits to patients and their families) alongside the NHS benefits. In the metastatic model, we aggregate the results for the metastatic patients from our other models (breast, lung, colorectal, etc.) and up-rate the costs and benefits to the total number of metastatic patients.

7.1 Gap analysis - adult cancers

Our methodology for estimating the gap in one to one support provision is identical to the one outlined in Section 3. In other words, we use incidence, survival rates and mortality to estimate the number of patients at each stage of the care pathway²¹.

We vary our caseload assumptions in order to capture the differences in the type and intensity of one to one support by cancer tumour and by stage in the care pathway. These are summarised in **Table 11**. Caseloads are assumed to be lower at all stages for head & neck cancer patients reflecting the greater complexity and time required to support these patients. Similarly, we assume lower caseloads in the aftercare stage for lung cancer patients (183 rather than 500).

We assume that the aftercare stage lasts 5 years for all cancers except prostate, where it is ongoing. The latter assumption is based on the NICE guidelines for prostate cancer patients. Patients are stratified into three groups according to the level of support they need: complex, planned and coordinated care and self management. **Table 12** shows the proportion of patients in each group (based on the outputs of the consensus workshops).

²¹ Patient numbers by tumour type and stage of the cancer care pathway are presented in **Table 22** in the Annexe

Table 11. Caseload assumptions for lung, prostate, head & neck and colorectal cancer

Cancer type	Diagnosis and treatment	Aftercare year 1 (complex)	Aftercare year 1 (non-complex)	Aftercare (subsequent)
Colorectal	100	183	500	500
Head & Neck	60	90	90	183
Lung	100	183	183	183
Prostate	100	183	700 ²²	700

Source: Caseloads in diagnosis and treatment for all cancers except head & neck from Thames Valley Cancer Network, the rest are Frontier assumptions based on expert interviews

Table 12. Patient risk stratification lung, prostate, head & neck and colorectal cancer

Cancer type	Self-management	Planned and coordinated care	Complex cases
Colorectal	40%	30%	30%
Head & Neck	0%	0%	100%
Lung*	25%	0%	75%
Prostate	70%	10%	20%

Source: Consensus workshops. Note that for prostate cancer we have assumed patient stratification possible with better support in place. Note that in lung cancer 75% of patients are in the Planned, coordinated and complex care pathway which we understand to mean complex cases

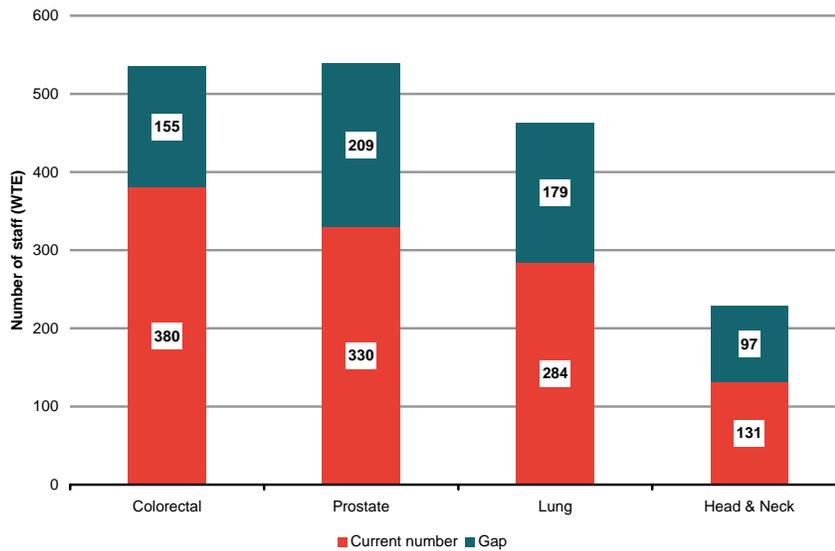
Figure 6 shows our estimates of the gap for each tumour type. In total, there are 640 additional one to one support workers needed to fill the gap in provision of one to one support to lung, colorectal, prostate and H&N cancer patients. This represents a 57% increase on the current number of CNSs working with these

²² Note that we combine this high caseload assumption with a conservative assumption that the aftercare is ongoing (as recommended in the NICE guidelines). However, if we change these two assumptions in line with those made in colorectal cancer model, that is 500 caseload and 5 year aftercare period, the difference in the gap estimate is relatively small – 175 (with 500 caseload and 5 year aftercare) versus 200 (700 caseload and ongoing aftercare).

Findings from other models

tumour groups (1125 in total). The biggest percentage increase is estimated in H&N (74%), the smallest – in colorectal (41%).

Figure 8. Gap in one to one support – colorectal, head & neck, lung and prostate cancer



Source: Frontier estimates

* Note that the data Census collects data for Urology nurses rather than Prostate nurses. We have assumed that the two are the same.

7.2 Costs and benefits - adult cancers

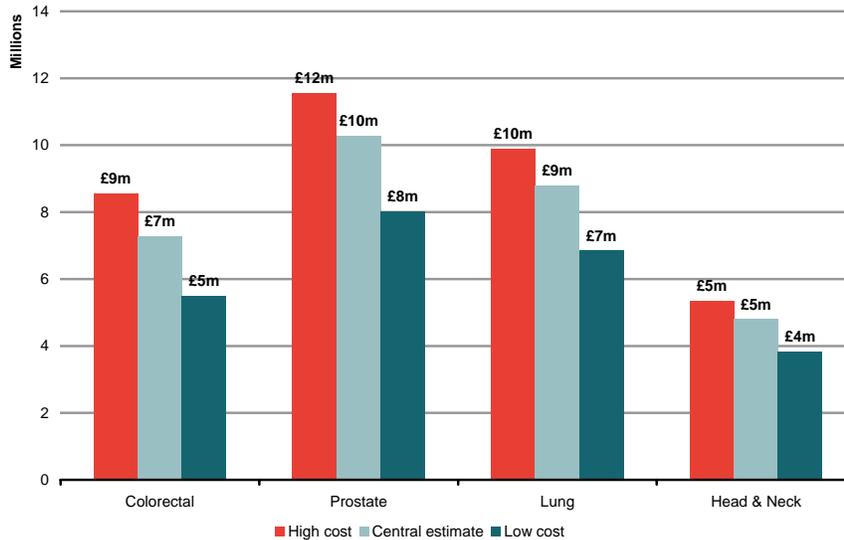
7.2.1 Costs

In the previous section of this report we estimated the gap to be 640 FTE posts. Our estimates of the annual costs of closing the gap are based on the methodology presented in detail in Section 4 - that is we model three cost scenarios depending on the mix of one to one support workers (different proportions of one to one support workers at level 4, level 6 and level 7).

Annual costs are obtained by multiplying the number of staff needed by the relevant wages and other employer expenses. Detailed calculations of staff costs are presented in the **Annexe**.

We estimate annual costs in the range of £24m-£35m for these four cancers. The costs are proportional to the number of CNSs needed. Therefore, the costs are highest in prostate cancer (where the gap is 209) and lowest in H&N (the gap is 97).

Figure 9. Annual costs of closing the gap in head & neck, colorectal, lung and prostate cancer



Source: Frontier estimates

As was the case in breast cancer we model the cost of activity classes in addition to the staff costs presented above. These are applicable in colorectal and prostate cancer where there is evidence that activity can improve recurrence and survival. We estimate the cost of activity classes to be between £3.8m and £11.4m with a central estimate of £7.6m.

7.2.2 Benefits

In this section we quantify the annual savings to the NHS from extending one to one support to all cancer patients. We outlined the type of benefits that can be expected to arise in this context in Section 5. Although the types of benefits we model in the four cancers presented in this chapter are broadly similar to those discussed earlier, there are differences in the extent to which they are applicable to the different patient populations. For example, there is evidence in the literature that activity classes may reduce both mortality and recurrence rates in colorectal cancer but it is not clear if they have the same effect in lung or head & neck cancer.

It may also be the case that the same types of savings apply to different cancer types but with varying degrees: whilst it may be feasible to remove or reduce the number of follow-up appointments with consultants in some cancers, this may not be the case for others. Our modelling captures the variation in both the level

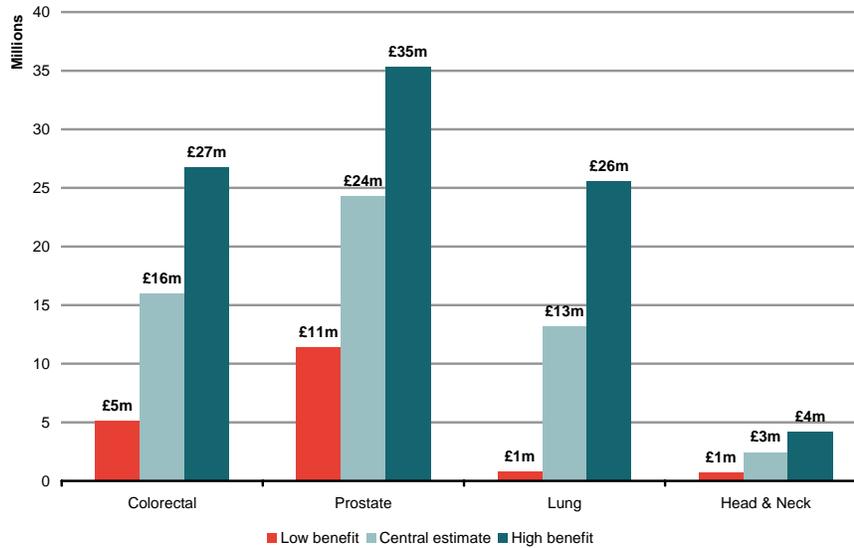
Findings from other models

and degree of applicability of the various benefits. Detailed tables explaining which savings are applied to the different cancers are available in the **Annexe**.

As in Section 5, we model three scenarios in which we vary the proportion of patients to which the benefits can be applied:

- High benefit scenario – includes all benefit types identified in our review of the literature and conversations with experts. Benefits are applied to a significant proportion of patients. Emergency bed days are cut by 20%.
- Central benefit scenario – includes most benefits identified in our review of the literature and conversations with experts. These are applied to a moderate number of patients. Emergency bed days are cut by 10%.
- Low benefit scenario – includes only some of the benefits identified in our review of the literature and conversations with experts. These are applied to a conservative number of patients. Emergency bed days are unchanged.

Figure 10 shows annual savings by cancer type. For example, total annual savings in colorectal cancer are expected to be in the range £5m-£27m, with the central estimate of £16 million. This is a wide range, which is largely driven by the relatively large value of the emergency bed day reductions considered possible in the High benefit scenario. This is particularly true for the tumour types where the numbers of emergency bed days are high (e.g. lung cancer).

Figure 10. Annual savings in head & neck, colorectal, lung and prostate cancer

Source: Frontier estimates

Below, we show how the monetary value of reducing emergency bed days relates to the other savings (**Table 13**). The top number in columns 2 to 4 gives the absolute value of savings due to a reduction in emergency bed days (0% in Low Benefit Scenario, 10% in Central case scenario and 20% in High Benefits Scenario). Percentages in brackets show how this relates to total savings.

Evidently reducing emergency bed days is a highly significant source of savings for all tumour types, but particularly so for lung cancer. HES data²³ shows a total of just over 400,000 emergency bed days in lung cancer in 2008/09 or 5 emergency bed days per patient²⁴. The ratio of emergency bed days per patient is significantly lower in other tumour types, averaging around 1 per annum.

In lung cancer, a 10% reduction in emergency bed days (ca 40,000 bed days) equates to a saving of £9.3m which represents more than 2/3rd of total annual savings (central estimate). **Table 13** below demonstrates the significance of reducing emergency bed days in the context of total savings for the different cancers we study. The data confirm that this source of savings drives between 1/5th and 2/3rd of the total.

²³ Data from HES queries is for 2008/09. The data was collected by DH and shared with Frontier.

²⁴ Based on a total number of lung cancer patients of 79,216 (NCIN) which equals prevalence plus mortality.

Findings from other models

Table 13. Value of annual savings from emergency bed day reductions relative to total savings

	Low benefit	Central estimate	High benefit
Colorectal	£0 (0%)	£6.7m (42%)	£13.3m (50%)
Head & Neck	£0 (0%)	£1.2m (48%)	£2.3m (56%)
Lung	£0 (0%)	£9.3m (71%)	£18.7m (73%)
Prostate	£0 (0%)	£5.2m (21%)	£10.3m (29%)

Source: Frontier estimates

7.2.3 Net Savings

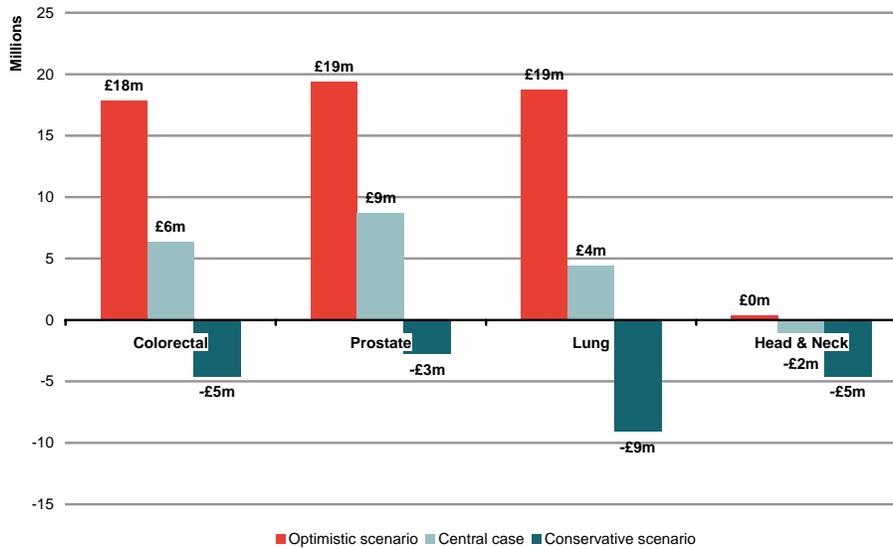
In this section we put the costs and benefits together in order to gain a better understanding of the overall impact of extending one to one support to all cancer patients. According to our central estimates, extending one to one support can lead to net annual savings in all adult cancers except head & neck.

We calculate net costs/savings by combining the estimates from sections 7.2.1 and 7.2.2. Once again we consider three scenarios:

- Optimistic scenario – constructed by combining the results from our low cost scenario and high benefit scenario.
- Central case scenario – constructed by combining the results from our central cost and central benefit estimates.
- Conservative scenario – constructed by combining the results from our high cost and low benefit estimates.

Net savings by tumour type are presented in **Figure 11**. Note that negative net savings are equivalent to net costs. Therefore, net savings are expected in colorectal, lung and prostate cancers, both in the central case and the optimistic scenario. In the conservative scenario, the model predicts net costs for all cancers. These are highest for lung cancer at £9m per annum.

For head & neck cancer, we estimate net benefits only in our optimistic scenario. The net costs are driven by high level of support needed by H&N patients and, therefore, by high gap estimate (relative to other cancers).

Figure 11. Net annual savings in head & neck, colorectal, lung and prostate cancer

Source: Frontier estimates

7.3 One to one support with metastatic cancer

So far we have presented estimates of the costs and benefits of extending one to one support in a selection of cancers not distinguishing between primary and metastatic patients. The aim of this section is to tease out the costs and benefits associated with one to one support for metastatic patients living with the cancers considered in this study. We present these findings separately because we believe that metastatic patients differ from primary patients fundamentally in the following respects:

- They have significantly lower survival rates
- They receive less support than primary patients
- They are disproportionately more likely to have emergency admissions

Note that these can not be added to the costs and benefits presented thus far as they have already been included in the individual cancer estimates. In this section we simply demonstrate how this group of patients stands relative to the whole patient population.

Closing the gap in metastatic cancer (only the tumours we consider) could cost in excess of £16m per annum but is likely to generate benefits in the region of £18m per annum. These estimates are based on a simple approach - we add together the results from our adult cancer models, separating primary and

Findings from other models

secondary patients out. The main difficulty is that we do not know what the baseline provision for metastatic patients is. Conversations with experts and evidence from Breast Cancer Care suggest that metastatic breast cancer patients receive significantly less support than primary breast cancer patients. We do not know if the same is true for all cancers but in the absence of other evidence we assume that this is the case. We reflect this in our models by allocating the existing workforce to primary cancer patients with any remaining posts going to metastatic patients. Once we have split our gap estimates into primary and metastatic we generalise our findings in the following way.

There are currently 1.6 million²⁵ people living with a cancer diagnosis in England. Just over 58% of these patients have one of the five cancers considered in this study (ca. 900,000 patients). We use this information in order to generalise the findings from our metastatic model to all cancers. This is done by scaling up our cost and benefit estimates by a factor of 1.72 (the same as dividing by 58%). Effectively this assumes that the costs and benefits estimated in our models (relating to metastatic disease only) apply to all cancers, including those not explicitly examined in the study, in exactly the same proportions. This is obviously a simplification. However, it gives us a useful approximation for the costs and benefits of extending one to one support to all metastatic patients.

Overall, extending one to one support to cover all metastatic patients is associated with an annual cost of £28m but is likely to produce benefits in the region of £32m (central estimate).

7.3.1 Costs

We note that it is not always possible to estimate the gap in provision at each stage of the cancer care pathway separately as information on the distribution of the current workforce by stage in the care pathway is very patchy. However, from our conversations with experts, we understand that metastatic patients, unlike primary cancer patients, receive little specialised support. Therefore, we assume the baseline in specialist nursing care for metastatic patients to be zero. This assumption, while strong, is not inconsistent with the opinions of experts we interviewed during the course of this project. Its impact is going to be reflected in the relatively high costs of closing the gap in metastatic cancers. We estimate that a total of 882 one to one support workers are needed in order to close the gap in the adult cancers we consider. 39% of this total is attributable to metastatic disease (344 FTE posts – see **Table 14**). Up rating this number to account for all cancers gives a total of 589 FTE posts.

²⁵ NCIN prevalence estimates for 2006 This figure is estimated back from 2008 (source: Maddams et al.) data using 3.2% rate of increase.

While on average 39%, the share of the gap attributable to metastatic disease varies by tumour type. In breast and colorectal cancer, the gap in provision for metastatic patients is particularly large, making up more than half of the total. This is caused by the following factors:

- There is a relatively high number of metastatic breast and colorectal cancer patients (Frontier estimates) relative to the primary cancer populations
- Median survival for metastatic breast and colorectal cancer patients is high (2-3 years) relative to patients with other cancers (e.g. lung)
- There are few or no specialised support available for metastatic patients (as discussed above)

We show how we split the gap into primary and secondary cancer by tumour type in the table below.

Table 14. Gap in one to one support to metastatic patients

	Current CNS number	Total GAP	Gap in metastatic	Gap in primary
Colorectal	380	155	119	36
Prostate	330	209	55	154
Lung	284	179	35	144
Head & Neck	131	97	13	84
Breast	523	242	122	120
TOTAL (5 cancers)	1648	882	344	538

Frontier estimates

The total costs associated with closing the gap in one to one support to metastatic patients are presented in **Table 15**.

Findings from other models

Table 15. Total cost of closing the gap in provision of one to one support to metastatic patients

	Low cost	Central estimate	High cost
Metastatic patients (5 cancers)	£12.5m	£16.3m	£19.0m
Other metastatic patients	£8.9m	£11.6m	£13.5m
All metastatic patients	£21.4m	£27.9m	£32.5m

Source: Frontier estimates

7.3.2 Benefits

We model two types of benefits which could be linked to extended provision of one to one support to metastatic patients:

- More patients will be able to die at home
- Some emergency admissions can be averted

We have information on emergency bed days attributable to metastatic patients as well as those attributable to the cancer sites we study. One complication is that the two categories overlap - that is a metastatic breast cancer bed day will be counted under both 'breast cancer' and 'metastatic' categories. In order to avoid double counting we need to separate the bed days attributable to metastatic patients from the cancer site totals. We do this in the following way:

We know that the total number of emergency bed days for metastatic patients is 897,164. We assume that the proportion of emergency bed days attributable to the adult cancers considered in this study is equal to their share of total cancer prevalence in England, which is 58%. This equates to 520,192 emergency bed days. Assuming the proportion of emergency bed days, which is attributable to metastatic patients, is constant across cancers we estimate that 47.5% of emergency bed days in the cancers we consider are attributable to metastatic patients.

As in the previous sections, we use scenarios to compare the costs and benefits of one to one support in metastatic patients. Overall, we find that for the five cancers considered in the study, the benefits of one to one support to metastatic patients range between £0 and £37.1 million, with the central estimate of £18.6 million. Scaling up these estimates to take into account all metastatic patients produces the range of £0 – £63.6 million, with the central estimate of £31.8 million (**Table 16**).

Table 16. Total benefits associated with provision of one to one support to metastatic patients

	Low benefit	Central estimate	High benefit
Metastatic patients (5 cancers)	£0	£18.6m	£37.1m
Other metastatic patients	£0	£13.2m	£26.5m
All metastatic patients	£0	£31.8m	£63.6m

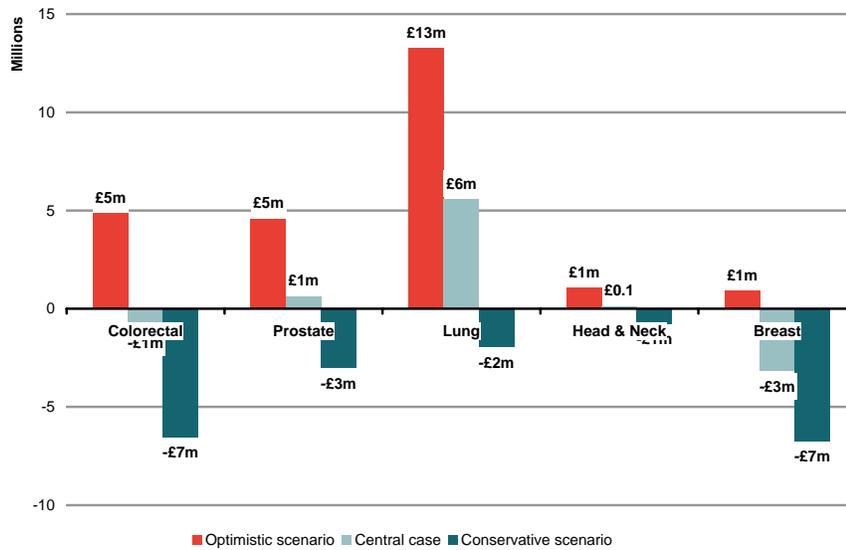
Source: Frontier estimates

7.3.3 Net savings

In this section we put the costs and benefits together in order to gain a better understanding of the overall impact of extending one to one support to all metastatic cancer patients. **Figure 12** below shows the net costs of extending one to one support to metastatic patients by tumour type.

Extending one to one support to all metastatic patients could generate net savings of around £3.8m per annum (central estimate).

Figure 12. Net annual savings in metastatic cancer



Source: Frontier estimates

Table 17. Net savings associated with provision of one to one support to metastatic patients

	Optimistic scenario	Central estimate	Conservative scenario
Metastatic patients (5 cancers)	£24.7m	£2.2m	-£19.0m
Other metastatic patients	£17.6m	£1.6m	-£13.5m
All metastatic patients	£42.3m	£3.8m	-£32.5m

Source: Frontier estimates

7.4 Children and Young People (CYP) model

We present the findings from our CYP model separately due to the very different nature of both patients and treatments relative to the adult cancers considered in this study. Our aim is to estimate the costs and benefits associated with the provision of one to one support to children and young people. Our CYP model covers a range of different cancers: the most common being leukaemia (18% of incidence), brain cancer (13%), Hodgkin's disease (11%) and cancer of the skin²⁶ (10%). We divide patients into three distinct age groups which are reflective of actual practice. These are 0-15, 16-18 and 19-24. We estimate the costs and benefits of providing one to one support for each of these age groups separately and then aggregate them up to produce a total estimate.

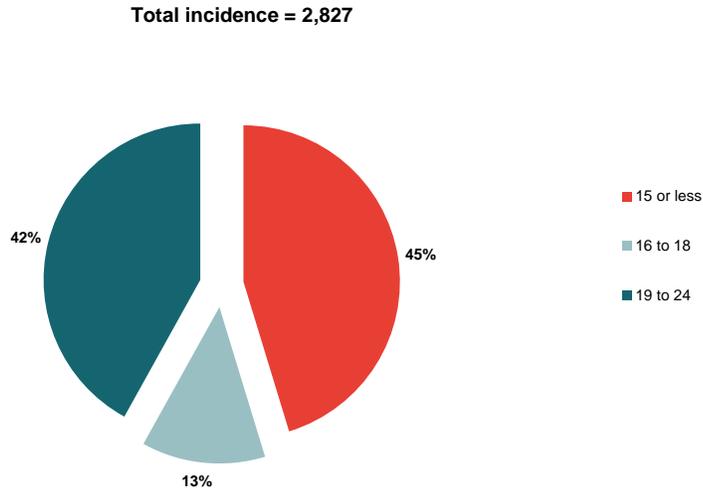
7.4.1 Gap

Currently almost three thousand²⁷ people aged under 24 are diagnosed with cancer in England each year. The age distribution of new CYP cancer cases is presented in **Figure 13**. This shows that 13% of new cases are in individuals aged between 16 and 18 the remaining 87% are equally split between the other two age groups.

²⁶ It should be noted that these figures 'include non-melanoma skin cancer' – as in general cancer statistics 'nmse' is generally excluded due to poor reporting of registrations

²⁷ ONS Cancer registrations (2007) shows incidence of 2,827 including non-melanoma skin cancer. We note that this number includes 145 individuals who also appear in the adult cancers covered in this study

Findings from other models

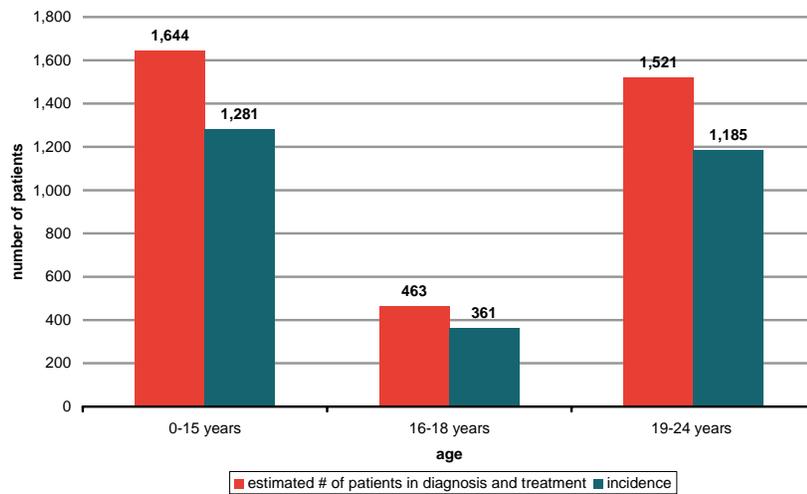
Figure 13. CYP cancer incidence by age group

Source: ONS Cancer Registrations 2007

As in adult cancers, survival rates in CYP patients have improved over time. This means that there are many more CYP survivors (not reflected in the incidence number) who need help and support with a range of problems, including long-term effects of treatment, going back to school, arranging benefit payments, etc. According to NCSI Vision the number of people (aged 17 or less) in England who have had a cancer diagnosis is 12,524. This indicates that total CYP prevalence (including individuals aged 18-24) is likely to be almost twice as high²⁸. Unlike adult cancers where treatment usually takes under a year, boys and girls with Acute Lymphoblastic Leukaemia (A.L.L.) are in treatment for 3 and 2 years respectively. Hence using incidence as a proxy for the number of patients in treatment will underestimate the need for support at this stage of the pathway. We solve this issue by splitting patients by gender and disease type. We then estimate patient numbers who are within 3, 2 or 1 years of diagnosis using incidence and survival rates²⁹ (**Figure 14**). In total we estimate that there are 3,627 CYP patients who are in the diagnosis and treatment stage of the pathway.

²⁸ We estimate this number using age specific incidence ratios, i.e. (incidence 0-17)/(incidence 18-24) is assumed to equal (prevalence 0-17)/(prevalence 18-24)

²⁹ There is a section in the Annexe which shows how we calculate patient numbers in each stage of the pathway in some detail

Figure 14. Number of patients in diagnosis and treatment stage

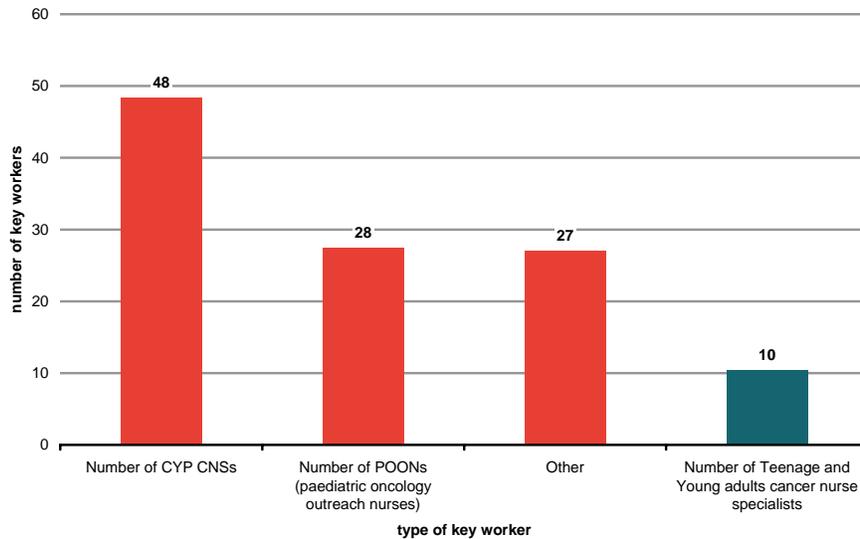
Source: Frontier calculations

According to Trevatt and Leary (2009) there are 113 specialist nurses currently providing support to children and teenagers with cancer (**Figure 15**). We do not have precise data on what age groups these nurses serve but conversations with experts indicate that the majority of support is focused on younger patients. It appears that the older age group (19-24 year olds) is very poorly covered.

We understand that there is often overlap between the age groups served by specialist nurses. Correspondence with stakeholders reveals that there are a number of nurses who provide support to patients aged 16-24 or in some cases 13-24. For the purposes of modelling we have allocated half of the Teenage and Young Adult cancer nurses (5 nurses) to the 19-24 age group³⁰.

³⁰ This is approximately equal to half the number of nurses funded by Teenage Cancer Trust who provide support to individuals aged up to 24 - due to overlap in age groups we allocate only half to the older age group.

Findings from other models

Figure 15. CYP specialist nurse workforce (2008 data)

Source: Trevatt et al. (2009)

We estimate the gap in one to one support for CYP patients using the same methodology as in the adult cancers. First we calculate the number of patients (in each age group) at each stage of the survivorship pathway (detailed information describing our calculations can be found in the Annexe). We then divide these numbers by the appropriate caseloads to obtain the total number of one to one support workers required. Finally, we subtract the current workforce from the total to obtain an estimate of the gap.

Although the methodology is similar in principle, there are differences in underlying assumptions:

- Treating CYP cancers takes much longer than adult cancers. As noted previously for some CYP patients treatment can take up to 3 years. Therefore we estimate the number of patients in the diagnosis and treatment stage on the basis of 1, 2 or 3 year treatment cycles (unlike adult cancers where we solely use the incidence rate as a proxy).
- CYP patients require more support than adult cancer patients which is reflected in the lower caseloads.
- Self management is only applicable to CYP patients in the older age groups (over 16 years old).

Based on conversations with CLIC Sargent and paediatric oncologists, we make assumptions regarding caseloads per one to one support worker (by age group and intensity of support needed). We understand that the need for support is

highest during the diagnosis and treatment stage of the pathway. Within that some patients will have greater needs for support than others. We stratify patients³¹ in each age group (diagnosis and treatment stage) into three groups according the level of support they need (reflective of our conversations with experts from CLIC Sargent and oncologists):

- High level of support needed: 30% of patients
- Medium level of support needed: 35% of patients
- Low level of support needed: 35% of patients

The complexity of patient need affects our gap estimates through the caseload assumptions we make, i.e. a one to one support worker is able to support 40 patients with low level of need but only around 20 with high need for support. We were advised (by CLIC Sargent) that the appropriate caseload for patients aged 19-24 who have a high need for support should be lower than the one for the other age groups. This is why we have assumed a lower caseload of 15. We further divide patients in the first year of aftercare into those with significant health problems (60%) and the rest (40%). As in the adult cancer models we do not risk-stratify patients who are in long-term aftercare.

Table 18. Caseload assumptions³²

Age group	Diagnosis & treatment	Aftercare 1 st year	Long term aftercare
0-15	20-40	40-80	200
16-18	20-40	40-80	200
19-24	15-40	40-80	200

Source: Frontier assumptions based on expert opinion

Combining the information on the number of CYP patients, appropriate caseloads and the current number of specialist nurses, we estimate that 107 additional one to one support workers are needed to fill the gap in provision of one to one support to CYP patients and survivors. The vast majority of this gap

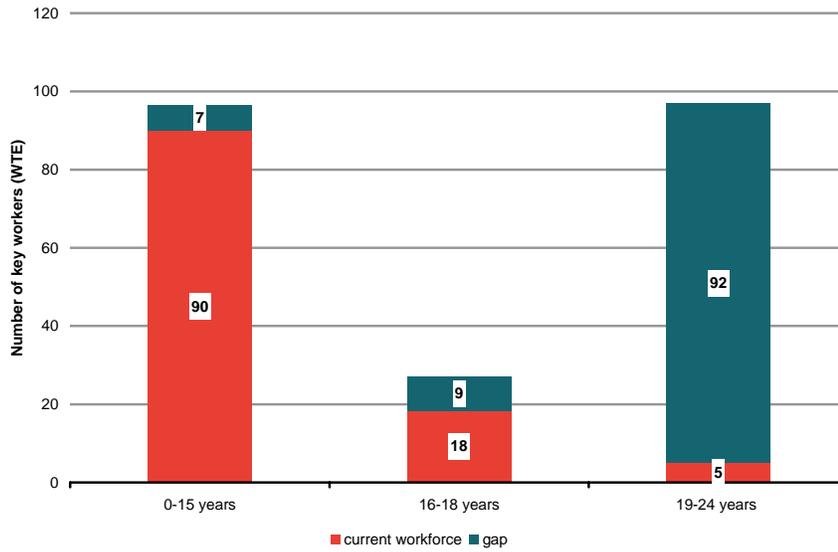
³¹ Patient risk stratification at all stages in the pathway is based on conversations with experts as no precise data is available.

³² We note that all paediatric and some Teenage and Young adult patients receive support from designated CYP cancer social workers based in the Principal Treatment Centres or shared care. This support is variable and has implications for the caseloads that specialist nurses can manage. If access to these support services were better, specialist nurses could in principle take on higher caseloads.

Findings from other models

is in provision of support to 19-24 year olds, the group which is currently under-resourced.

Figure 16. Estimate of gap in CYP cancers by age group



Source: Frontier estimates

Table 19. Estimate of gap in CYP cancers by stage in pathway

	Total # of one to one support workers needed	Total # of one to one support available	GAP
0-15 year olds	97	90	7
16-18 year olds	27	18	9
19-24 year olds	97	5	92
Total	211	113	107

Source: Frontier estimates. Note that numbers in row 4 do not add up due to rounding up

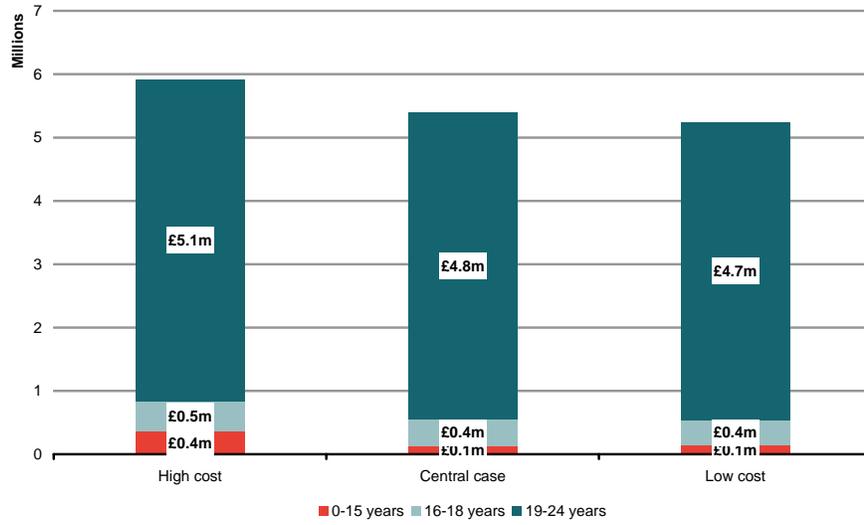
7.4.2 Costs

We estimate the annual cost of extending one to one support to all CYP patients and survivors in the range of £5.3m-£5.9m, with a central estimate of £5.4 million. These estimates are obtained by modelling the following three scenarios:

- The ‘High cost’ scenario assumes that the whole gap is filled by nurse specialists at grade 6 and 7 (reflecting the current split - 30% grade 6 and 70% grade 7).
- The ‘Central case’ scenario assumes that most of the work is carried out by specialist nurses at grade 6 and 7 (30%/70% split), with 12% of all work being carried out by staff at grade 4.
- The ‘Low cost scenario’ assumes the same proportion of grade 4 input as in the Central Case scenario, i.e. 12% of all work. However, the split between grade 6 and 7 posts is equal (50%/50% of the remaining gap). Note that this scenario differs from those used in the adult cancers’ modelling, where we assumed that 33% of all work could be carried out by grade 4 staff. This is because, according to paediatric oncology experts, one to one support required by children and young people is more intensive and requires more specialist/ qualified input.

Findings from other models

Figure 17. Annual cost of closing the gap in one to one support : CYP



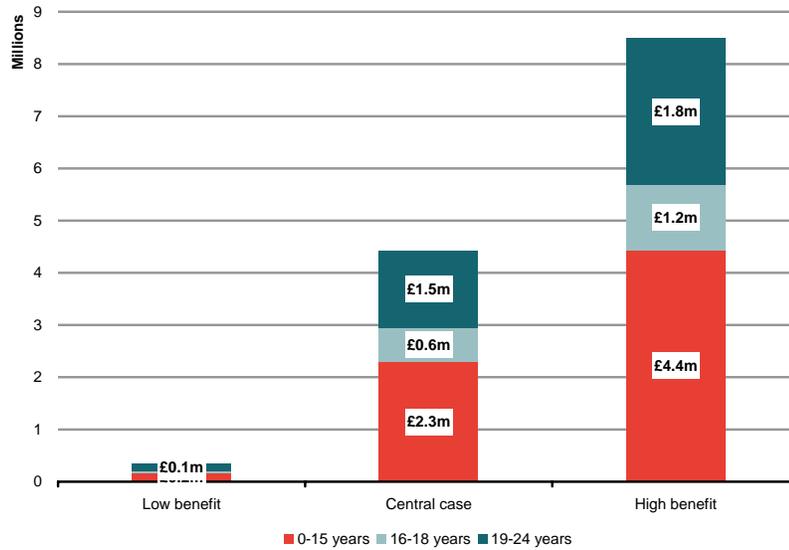
Source: Frontier estimates

7.4.3 Benefits

There are two types of savings we consider in this section:

- NHS savings -These are in line with the types of benefits we model in adult cancers. Here savings arise from reductions in hospital length of stay, consultant/nurse substitution in the aftercare stage and reductions in routine appointments for patients who can self-manage. We use only NHS savings in our scenario modelling.
- Wider benefits -There are many indirect benefits likely to arise from better one to one support for young cancer patients. Many of these will take years to materialise. For example, if better support leads to more CYP cancer patients enrolled in tertiary education, there will be wider economic and societal benefits realised through higher lifetime earnings and tax contributions. We quantify these benefits separately; they are not included in our overall NHS savings estimates.

We estimate annual NHS savings in the region of £0.3m - £8.5m with a central estimate of £4.4m. These are based on three scenarios in which the benefits we identify are applied to different numbers of patients.

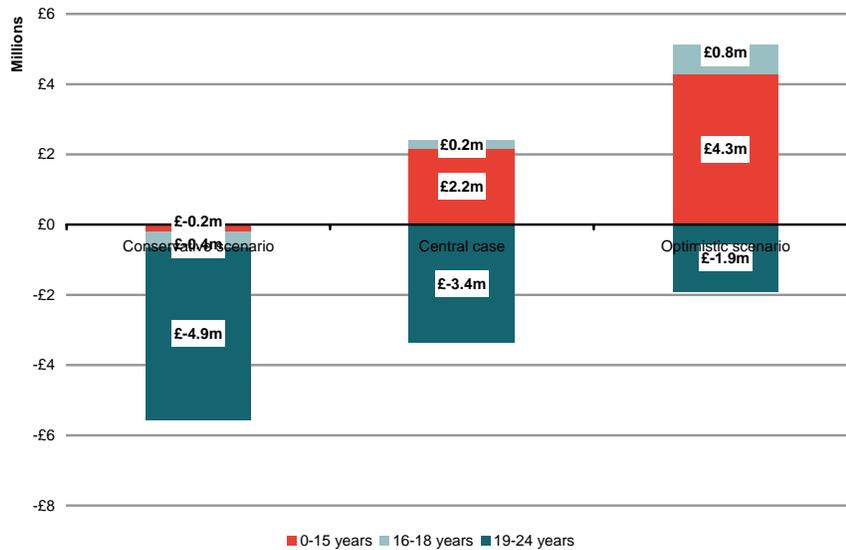
Figure 18. Annual savings in CYP cancers (NHS)

Source: Frontier estimates

7.4.4 Net savings

Combining our cost and benefit estimates we get annual net savings between -£5.6m and +£3.2m; our central estimate indicates net costs of £1m per annum. These are based on three scenarios (defined as in previous chapters):

- Optimistic scenario: combining low cost and high benefit estimates
- Central case: combining central cost and benefit estimates
- Conservative scenario: combining high costs and low benefit estimates

Figure 19. Net savings in CYP cancers

Frontier estimates

Wider benefits

In this section we present our estimations of the wider economic benefits associated with one to one support to children and young people with cancer.

● Educational attainment

It is expected that one to one support would help children and young people with cancer to return to education after treatment and to achieve their full potential. Lancashire et al (2009)³³ compare educational attainment for survivors of childhood cancers with that of the general population and find that childhood cancer survivors had lower educational attainment (illustrated by **Table 20**).

³³ Lancashire E., Frobisher C., Reulen R., Winter D., Glaser A. and Hawkins M. (2009) „Educational attainment among adult survivors of childhood cancer in Great Britain: a population-based cohort study”, JNCI, Vol. 102, Issue 4

Findings from other models

Table 20. Differences in educational attainment: childhood cancer survivors vs. the general population

	Childhood cancer survivors	General population	Odds ratio
Degree	17.9%	22%	0.77
Teaching quals (at least)	29.0%	32%	0.85
A-levels (at least one A-level)	46.6%	51%	0.85
O-levels (at least one O-level)	70.4%	75%	0.81

Source: based on Lancashire et al. (2009)

It appears that the biggest gap is in tertiary education, with the childhood cancer survivors being less likely to obtain a degree (17.9% vs. 22%)³⁴.

The Department of Education and Skills calculated the lifetime earnings differential of graduates over non-graduates to be as much as £400,000³⁵. Therefore, the childhood cancer survivors lose in the region of £9.3m annually, assuming 40-year average 'working life'.

If this gap in educational attainment is reduced by 25%-50%, the benefits to the survivors, their families and society as a whole would be between £2.3m-£4.7m.

● Travel costs

From an economic standpoint, patient follow-up delivered close to the patient's home maybe advantageous in certain populations. According to a report 'Panthames Shared Care Long Term Follow-up': *"The patients who would benefit from shared follow-up would be those deemed as level 1/2 patients and low and moderate risk of developing late sequelae in the follow-up period covered by the paediatric service."*

The report shows that for most patients the costs associated with travel to specialist centres can be several times higher than the cost of travel to local health service providers. It appears that the former costs in the region of £15 per patient (per visit) while the latter costs around £5 per patient (per visit). Although

³⁴ When the adjustment is made for the discrepancy in graduate education, the differences in other groups are minimal.

³⁵ Greenaway D. and Haynes M. (2003) Funding Universities to Meet National and International Challenges, Nottingham University School of Economics Policy.

these cost estimates are specific to the geographic area covered in the study, it gives an indication of the magnitude of the savings which could be realised if shared care was extended more widely.

8 Concluding remarks

One-to one support for all cancer patients in England would require substantial investment in specialist nurses and other one to one support workers. The analysis we undertook focused on several adult cancers (breast, lung, prostate, colorectal, head and neck, metastatic) and all children and young people's cancers. Our estimates suggest that approximately 1,234 one to one support workers are needed to close the gap in provision. Expanding the workforce by this number will cost in the region of £60m per annum (2011 money)³⁶.

However, the costs of closing the gap could be either partially or fully offset by a number of benefits arising from improvements in the quality and coordination of care. These include reductions in emergency bed days, reductions in routine follow-up appointments and GP visits. We estimate the total benefits (NHS) to range between £26m and £148m per annum, with a central estimate of £89m. Benefits are highest for prostate cancer in all scenarios. This is because of the relatively large number of patients in the aftercare stage who are suitable for self-management as well as the high number of emergency bed days which can be reduced.

The majority of our savings analysis focuses on NHS savings but in CYP cancers, we also estimate wider benefits to the patients, their families and society as a whole. The reason wider benefits are estimated in this model is because they are particularly relevant for this group. CYP patients are young and as survival rates improve can expect to live for a long time. So even relatively small changes in educational attainment (made possible by better organised care) for example can have a substantial effect on their labour market outcomes over a long period of time.

These include (i) saving in transportation costs due to better coordinated ('shared') care and (ii) better educational attainment of young people with cancer (due to more support and better organised education process).

Putting costs and benefits together we expect the overall effect to be a net saving of around £19m which is our central case estimate. We expect to see net savings all cancers except CYP and Head and Neck.

³⁶ In addition to the staff costs presented above, some additional expenditure may be required in order to achieve greater benefits for cancer patients. One such cost we model (in breast, prostate and colorectal cancer) is the provision of activity classes which have been shown to improve survival and lower recurrence. We estimate the total annual costs of activity classes to be between £4.5m and £14.8m with a central estimate of £9.8m.

Annexe

Annual costs associated with employing a nurse (by grade)

Table 21. Total annual cost of employing specialist nurses

	Grade 7	Grade 6	Grade 4
Basic salary	£35,900	£29,100	£19,600
Salary on-costs	£7,776	£7,173	£4,627
Overheads	£7,445	£6,704	£5,500
Capital overheads	£3,832	£3,832	£3,832
Total cost 2009	£54,953	£46,809	£33,559
Total cost 2011	£57,735	£49,179	£35,258

N.B. Grade 7 numbers are taken directly from PSSRU Costs of Health and Social Care 2009. Grades 4 & 6 basic salary from PSSRU Costs of Health and Social Care 2009. Remaining components have been calculated based on PSSRU methodology³⁷. Annual cost inflation is assumed to be 2.5%

³⁷ On-costs are calculated equal 14% of salary for superannuation plus 12.8% employer NI contributions (applied to earnings over £94 per week). Overheads equal 10% of basic salary with on-costs plus £3,077. Capital overheads equal £3,832

Number of patients by tumour and by stage

Table 22. Patient numbers* by stage in the pathway

	Colorectal	Head & Neck	Lung	Prostate
Diagnosis and treatment	21,546	5,403	31,805	22,819
Aftercare year 1 (complex)	11,820	4,241	6,870	6,709
Aftercare year 1 (non-complex)	7,880	-	-	15,654
Aftercare (subsequent)	60,335	14,047	14,678	137,946
Metastatic patients (not in final year of life)	19,365	2,086	-	8,513
End of life	12,910	2,318	27,468	8,513

Source: Frontier estimates based on incidence rates and survival rates

*The following 5 year survival rates were used in the calculations:

Colorectal stage A 83%, Stage B 64%, Stage C 38%

Head & Neck: 56.9%

Lung: 6%,

Prostate: 77%

Our general approach is to split patients in the diagnosis and treatment stage (incidence) into primary and metastatic³⁸ and then calculate patient numbers in the aftercare stage based on survival rates. We define metastatic patients as those diagnosed with Stage IV disease (we use Duke's stage D in colorectal cancer). The proportions of metastatic patients in each cancer type are as follows with sources in brackets:

- Colorectal: 29% (NICE)
- Head & Neck: 24% (estimated from NICE)
- Prostate: 25% (Cancer research)

³⁸ We do not follow the same approach here because metastatic lung cancer patients have very short life expectancy (less than 1 year) so we assume that they go directly from diagnosis and treatment into the end of life care stage

Savings (per patient) by tumour type

Table 23. Annual savings arising from extending one to one support in colorectal cancer

Type of benefit	Monetary value per patient	Comment	Source	Stage in pathway
Increase in nurse-led aftercare	£87	Equals the cost of 3 consultant-led appointments, i.e. consultant/nurse substitution	Based on Knowles et al. (2007), see References	Aftercare (year 1)
Reduction in GP visits	£57	Equals the cost of 1.1GP appointment	Based on Sridhar et al. (2007), see References	Aftercare (years 2&3)
Reduction in recurrence rates	£10,906	Equals the annual cost of recurrence to the NHS	Based on Thomas et al. (2009), see References	Aftercare (years 2&3)
Reduction in number of routine follow-up appointments	£188	Equals the cost of 1 clinic attendance and 2 consultant-led appointments	Adapted from Knowles et al. (2007)	Aftercare (years 2&3)
Reduction in number of patients dying in hospital	£700	Equals the cost of three bed days	Adapted from NAO & RAND Europe (2008)	End of life care

Source: Frontier estimates

Table 24. Annual savings arising from extending one to one support in head & neck cancer

Type of benefit	Monetary value per patient	Comment	Source	Stage in pathway
Increase in nurse-led diagnostic clinics	£58	Equals the cost of 2 consultant-led appointments, i.e. consultant/nurse substitution	Based on James and McPhail (2008), see References	Diagnosis & Treatment
Increase in nurse-led aftercare	£87	Equals the cost of 3 consultant-led appointments, i.e. consultant/nurse substitution	Based on Beaver et al. (2009), see References	Aftercare (year 1)
Reduction in GP visits	£57	Equals the cost of 1.1 GP appointment	Based on Sridhar et al. (2007), see References	Aftercare (years 2&3)
Reduction in number of routine follow-up appointments	£87	Equals the cost 3 consultant led appointments	Adapted from Knowles et al. (2007)	Aftercare (years 2&3)
Reduction in number of patients dying in hospital	£700	Equals the cost of three bed days	Adapted from NAO & RAND Europe (2008)	End of life care

Source: Frontier estimates

Table 25. Annual savings arising from extending one to one support in lung cancer

Type of benefit	Monetary value per patient	Comment	Source	Stage in pathway
Increase in nurse-led aftercare	£87	Equals the cost of 3 consultant-led appointments, i.e. consultant/nurse substitution	Based on Beaver et al. (2009), see References	Aftercare (year 1)
Reduction in hospital and GP visits	£57	Equals the cost of 1.1GP appointment	Based on Sridhar et al. (2007), see References	Aftercare (years 2&3)
Reduction in number of routine follow-up appointments	£130	Equals the cost of 1 clinic attendance and 1 consultant led appointment	Adapted from Knowles et al. (2007)	Aftercare (years 2&3)
Reduction in number of patients dying in hospital	£700	Equals the cost of three bed days	Adapted from NAO & RAND Europe (2008)	End of life care

Source: Frontier estimates

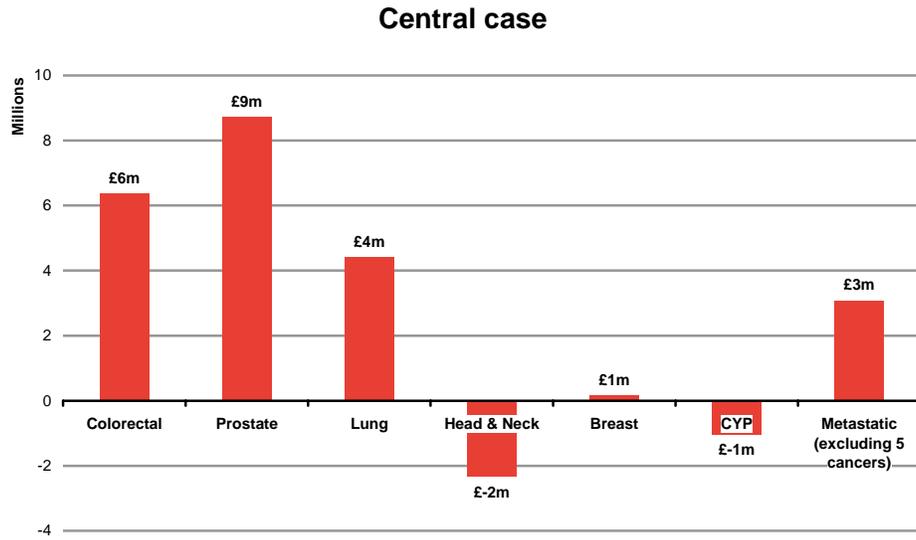
Table 26. Annual savings arising from extending one to one support in prostate cancer

Type of benefit	Monetary value per patient	Comment	Source	Stage in pathway
Increase in nurse-led diagnostic clinics	£58	Equals the cost of 2 consultant-led appointments, i.e. consultant/nurse substitution	Based on James and McPhail (2008), see References	Diagnosis & Treatment
Increase in nurse-led care during radiotherapy	£275	Cost of 1 clinical attendance and 5 consultant led appointments	Based on Faithful et al. (2001), see References	Diagnosis & Treatment
Reduction in hospital and GP visits	£57	Equals the cost of 1.1GP appointment	Based on Sridhar et al. (2007), see References	Aftercare (years 2&3)
Reduction in recurrence rates	£10,906	Equals the annual cost of recurrence to the NHS	Based on Thomas et al. (2009), see References	Aftercare (years 2&3)
Reduction in number of routine follow-up appointments	£130	Equals the cost of 1 clinic attendance	Adapted from Knowles et al. (2007)	Aftercare (years 2&3)
Reduction in number of patients dying in hospital	£700	Equals the cost of three bed days	Adapted from NAO & RAND Europe (2008)	End of life care

Source: Frontier estimates

Net Savings (central case) by tumour type

Figure 20. Net annual savings of extending one to one support



Source: Frontier estimates

Number of patients by stage: CYP

Table 27. Estimated patient numbers by stage in the pathway and age group: CYP

	0-15	16-18	19-24	Total
Diagnosis and treatment	1,644	463	1,521	3,627
Aftercare year 1 (complex)	695	196	643	1,534
Aftercare year 1 (non-complex)	464	130	429	1,023
Aftercare (subsequent)	3,807	1,072	3,522	8,401
End of life	269	80	198	546

Source: Frontier estimates based on incidence rates and survival rates

Calculating the number of CYP patients

We use incidence and survival rates to estimate the number of patients at each stage of the survivorship pathway. We do this separately for each of the distinct age groups we consider: 0-15, 16-18, 19-24. ONS incidence data splits patients into different age groups: 0-14, 15-19, 20-24. We make the assumption that incidence in the middle age group is equally distributed: 601 patients aged 15-19 are diagnosed with cancer each year. The number of patients who are 15 equals 120.2 which is the same those who are 16 etc (all equal 120.2). In total, we move 240 patients from the middle group to the other two age groups so that we have annual incidence:

- 0-15 years: 1,281
- 16-18 years: 361
- 19-24 years: 1,185

Diagnosis and treatment

The following section demonstrates how we calculate total need in this stage of the pathway for CYP patients aged 0-15. We use the same methodology for the other two age groups.

Length of treatment varies significantly by tumour type and also gender. For example, male patients with A.L.L. (Acute Lymphoblastic Leukaemia - ca. 10% of patients) are treated for 3 years while girls with the same condition (10% of patients) undergo 2 years of treatment. The average length of treatment for all other patients is approximately 1 year³⁹.

In order to estimate total need during diagnosis and treatment as accurately as possible we split patients by gender and tumour type. This means we have four patient groups:

- Boys with A.L.L. – ca. 10% of cases and 3 years of treatment
- Girls with A.L.L. - ca. 10% of cases and 2 years of treatment
- Boys/girls with other conditions – ca. 80% of cases and 1 year of treatment

The next step is to estimate the number of boys and girls within 3 or 2 years of diagnosis. We do this by applying 1 and 3 year survival rates to the number of boys diagnosed with A.L.L. in a year (all survival rates we use are shown in the table below). We then add the number of patients in years 1,2 and 3 (boys) and 1,2 (girls) to obtain a total number of A.L.L. patients during diagnosis and treatment. For patients with other conditions we simply use the incidence rate because for them treatment takes 1 year. Adding A.L.L. and non-A.L.L. patients together gives us the estimate of total need during diagnosis and treatment. We show our calculations in **Table 29**. Our estimates show that there are 1,644 CYP patients aged 0-15 who need support during diagnosis and treatment.

³⁹ Duration of treatment for CYP patients and proportions with A.L.L. based on input from clinicians

Table 28. Survival rates of CYP patients (0-15 years)

Diagnostic group	Number of registrations	1 year survival (%)	3 year survival (%)	5 year survival (%)
ALL	1620	95	91	88
Other leukaemia	462	82	69	67
Hodgkin lymphoma	316	98	96	95
Non-Hodgkin lymphoma	361	87	83	83
CNS tumours (incl. Germ-cell)	1748	84	75	72
Neuroblastoma	408	88	70	65
Retinoblastoma	176	99	99	98
Renal tumours	394	92	85	84
Liver tumours	81	79	67	65
Bone tumours	276	94	69	62
Soft tissue sarcomas	422	87	71	66
Non-CNS germ-cell tumours	136	96	94	93
All other (excl. skin carcinoma)	210	95	89	86
Average (non A.L.L)		90	81	78

Source: National Registry of Childhood Tumours

Table 29. CYP patients in diagnosis and treatment (0-15 years old)

	A.L.L.		Non A.L.L.
	Boys	Girls	
Incidence	128	128	1,025
Treatment length	3	2	1
1 year survival	95%	95%	90%
3 year survival	91%	91%	81%
Patients in year 0	128	128	1,025
Patients in year 1	122	122	923
Patients in year 2	119	119	-
Patients in year 3	117	117	-
Total (sum of numbers in bold)	369	250	1,025
Total need in diagnosis and treatment=1, 644			

Frontier estimates

Aftercare year 1

We calculate the number of patients in aftercare (year 1) by simply extending the estimates shown in the table above (our estimates are shaded in grey). That is, for A.L.L. patients we take the sum of the number of boys who are 4 years from diagnosis and girls 3 years from diagnosis shaded (estimated using 5 year survival rates). For patients with other conditions we use the 1 year survival rate.

Aftercare subsequent

We assume that patients are followed-up until they reach the age of 25. Therefore, we calculate the number of patients in the aftercare (subsequent) stage by subtracting the number of patients in diagnosis and treatment and first year of aftercare from the total registrations⁴⁰ figure. Our estimates are that in total 8,401 patients need support in this stage of the pathway.

End of life

⁴⁰ According to the National Registry of Childhood Tumours the total number of cancer registrations for age group 0-15 is 6,610. We estimate the respective numbers for the other age groups using incidence rates as ratios. Our estimates are: 16-18 years - 1,860 registrations and 19-24 - 6,115 registrations

The number of patients in this stage of the pathway equals the age specific mortality rate which is only available for England and Wales (ONS). We adjust the rates by multiplying by 90.5% which is the ratio of total number of deaths in England (NCIN 2006) over total number of deaths in England and Wales (ONS 2007). Although mortality in CYP is low relative to adult cancers, more work needs to be done in order to understand the need at this stage of the pathway.

Patient risk stratification

CYP patients in the diagnosis and treatment stage and first year of aftercare are stratified according to their need for support. Patients in long term aftercare are not divided in this way. The proportions of patients in each group are presented in the tables below and are based on conversations with experts from CLIC Sargent.

Table 30. CYP cancer patients risk stratification: diagnosis & treatment stage

	High need for support	Medium need for support	Low need for support
0-15	30%	35%	35%
16-18	30%	35%	35%
19-24	30%	35%	35%

Frontier assumption based on conversations with experts from Clc Sargent and oncologists

Table 31. CYP cancer patients risk stratification: aftercare year 1

	Significant health problems	Low need for support
0-15	60%	40%
16-18	60%	40%
19-24	60%	40%

Frontier assumption based on conversations with experts from Clc Sargent and oncologists

Caseload assumptions

Table 32. Assumed caseloads: CYP diagnosis & treatment stage

	High need for support	Medium need for support	Low need for support
0-15	20	30	40
16-18	20	30	40
19-24	15	30	40

Frontier assumption based on conversations with experts from Clic Sergent and oncologists

Table 33. Assumed caseloads: CYP aftercare year 1

	Significant health problems	Low need for support
0-15	40	80
16-18	40	80
19-24	40	80

Frontier assumption based on conversations with experts from Clic Sergent and oncologists

Long-term aftercare caseload: 200 patients per one to one support worker. Frontier assumption

References

- Baildam AD, Keeling F, Thompson L, Bundred N, Hopwood P (2004) Nurse-led surgical follow up clinics for women treated for breast cancer – a randomised controlled trial. *Breast Cancer Res Treat* 88: S136–S137
- Beaver et al. Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial. *BMJ* 2009; 338:a2753
- Brown L, Payne S, Royle G (2002) Patient initiated follow up of breast cancer. *Psychooncology* 11: 346–355
- de Bock GH, Bonnema J, van Der Hage J, Kievit J, van de Velde CJH (2004) Effectiveness of routine visits and routine tests in detecting isolated locoregional recurrences after treatment for early stage invasive breast cancer: a meta analysis and systematic review. *J Clin Oncol* 22: 4010–4018
- Faithful et al. Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy. *British Journal of Cancer* 2001; 85(12): 1853-1864
- Garvican L, E Grimsey, P Littlejohns, S Lowndes and N Sacks. Satisfaction with Clinical Nurse Specialists in a Breast Care Clinic: Questionnaire Survey. *British Medical Journal*, Vol. 316, No. 7136 (Mar. 28, 1998), pp. 976-977
- Greenaway D. and Haynes M. (2003) Funding Universities to Meet National and International Challenges, Nottingham University School of Economics Policy.
- Gulliford T, Magi Opomu, Elena Wilson, Iain Hanham, Richard Epstein Popularity of Less Frequent Follow up for Breast Cancer in Randomised Study: Initial Findings from the Hotline Study. *British Medical Journal*, Vol. 314, No. 7075 (Jan. 18, 1997), pp. 174-177
- Holmes M, Chen W, Feskanich D et al. Physical Activity and Survival after Breast Cancer Diagnosis, *JAMA* 2005; 293(20): 2479-2486
- James N, McPhail G. The success of a nurse-led, one-stop suspected prostate cancer clinic, *Cancer Nursing Practice*. 2008; 7(3): 28-32
- Knowles et al. Developing and piloting a nurse-led model of follow-up in the multidisciplinary management of colorectal cancer. *European Journal of Oncology Nursing* 2007; 11: 212-223
- Koinberg IL, Fridlund B, Engholm GB, Holmberg L (2004) Nurse-led follow-up on demand or by a physician after breast cancer surgery: a randomised study. *Eur J Oncol Nurs* 8: 109–117
- Kokko R, Hakama M, Holli K (2005) Follow-up cost of breast cancer patients with localized disease after primary treatment: a randomised trial. *Breast Cancer Res Treat* 93: 255–260
- Lancashire E., Frobisher C., Reulen R., Winter D., Glaser A. and Hawkins M. (2009) Educational attainment among adult survivors of childhood cancer in Great Britain: a population-based cohort study, *JNCI*, Vol. 102, Issue 4

- Leary A et al. Dimensions of clinical nurse specialist work in the UK. *Nursing Standard* 2008; 23, 15-17, 40-44
- McCorkle R, Benoliel JQ, Donaldson G, et al: A randomized clinical trial of home nursing for lung cancer patients. *Cancer* 64:1375-1382, 1989
- Molassiotis A, et al. Effectiveness of a Home Care Nursing Program in the Symptom Management of Patients With Colorectal and Breast Cancer Receiving Oral Chemotherapy: A Randomized, Controlled Trial. *Journal of Clinical Oncology* (2009) Volume 27 _ Number 36 _
- Montgomery et al. Alternative methods of follow up in breast cancer: a systematic review of the literature. *British Journal of Cancer* (2007) 96, 1625 – 1632
- Moore et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. *BMJ* 2002; 325(7377):1386
- Mutrie N et al. Benefits of supervised group exercise programme for women being treated for early stage breast cancer: pragmatic randomised controlled trial. *BMJ* 2007; 334:517-520B
- National Audit Office. *Tackling Cancer: Improving the Patient Journey*, 2005
- National Cancer Survivorship Initiative Vision, Department of Health, NHS Improvement, Macmillan 2010
- NICE *Improving Outcomes in Head and Neck Cancers*, 2004
- NICE. *Improving Outcomes in Urological Cancers*, 2002
- NICE. *Improving Outcomes in Urological Cancers*, 2002
- NICE. *Improving Outcomes in Colorectal Cancers*, 2004
- NICE. *Early and Locally Advanced Breast Cancer: diagnosis and treatment*, 2009
- NICE. *Prostate Cancer Diagnosis and Treatment*, 2008
- RAND Europe in conjunction with NAO. The potential cost savings of greater use of home- and hospice based end of life care in England. Cited in “Important Choices- where to die when the time comes”, NHS Institute
- Rehnan A, Matthias Egger, Mark P. Saunders, Sarah T. O'Dwyer. Impact On Survival Of Intensive Follow Up After Curative Resection For Colorectal Cancer: Systematic Review And Meta-Analysis Of Randomised Trials. *British Medical Journal*, Vol. 324, No. 7341 (Apr. 6, 2002), pp. 813-816
- Richardson G, A Maynard. *Fewer Doctors? More Nurses? A Review of the Knowledge Base of Doctor-Nurse Substitution*. CHE University of York (1995) Discussion Papers 135
- Sridhar et al. Intermediate care package in patients who have been hospitalised with an acute exacerbation of chronic obstructive pulmonary disease. *Respiratory Medicine: COPD Update* Volume 4, Issue 2, May 2008, Pages 85-86

References

- Sheldon H, S Sizmur. An evaluation of the National Cancer Survivorship Initiative test community projects Report of the baseline patient experience survey. PICKER INSTITUTE EUROPE (2009)
- The National Council for Palliative Care: Population based needs assessment for palliative and end of life care, May 2008
- Thomas et al. The total hospital and community UK costs of managing patients with relapsed breast cancer. *British Journal of Cancer* (2009) 100, 598 – 600
- Trevatt P, A Leary. A census of the advanced and specialist cancer nursing workforce in England, Northern Ireland and Wales. *European Journal of Oncology Nursing* (2009) 1–6
- Irwin, ML et al (2008) Influence of pre and post diagnosis physical activity on mortality in breast cancer survivors: the health, eating, activity and lifestyle study; *Journal of clinical oncology*, 26, 24, 3958-3964
- Patterson et al (2010) physical activity, diet, adiposity and female breast cancer prognosis: a review of the epidemiologic literatue. *Maturitas* in press, corrected proof
- Holick CN, Newcomb PA, Trentham-Dietz A, et al: Physical activity and survival after diagnosis of invasive breast cancer. *Cancer Epidemiol Biomarkers Prev* 17:379-386, 2008
- Pierce JP, Stefanick ML, Flatt SW, et al: Greater survival after breast cancer in physically active women with high vegetable-fruit intake regardless of obesity. *J Clin Oncol* 25:2345-2351, 2007
- Neilson HK, Friedenreich CM, Brockton NT, et al: Physical activity and postmenopausal breast cancer: Proposed biologic mechanisms and areas for future research. *Cancer Epidemiol Biomarkers Prev* 18:11-27, 2009.
- Abrahamson PE, Gammon MD, Lund MJ, et al: Recreational physical activity and survival among young women with breast cancer. *Cancer* 107:1777-1785, 2006.
- Irwin ML, Smith AW, McTiernan A, et al: Influence of pre- and postdiagnosis physical activity on mortality in breast cancer survivors: The health, eating, activity, and lifestyle study. *J Clin Oncol* 26:3958-3964, 2008.
- Sternfeld B, Weltzien E, Quesenberry CP, et al: Physical activity and risk of recurrence and mortality in breast cancer survivors: Findings from the LACE study. *Cancer Epidemiol Biomarkers Prev* 18:87-95, 2009.
- West-Wright CN, Henderson KD, Sullivan-Halley J, et al: Long-term and recent recreational physical activity and survival after breast cancer: The California Teachers Study. *Cancer Epidemiol Biomarkers Prev* 18:2851-2859, 2009.
- Friedenreich CM, Gregory J, Kopciuk KA, et al: Prospective cohort study of lifetime physicalactivity and breast cancer survival. *Int J Cancer* 124:1954-1962, 2009.

Saxton J (2010) Physical activity and cancer mortality. In physical activity and cancer survivorship, springer new York 189-210

Frontier Economics Limited in Europe is a member of the Frontier Economics network, which consists of separate companies based in Europe (Brussels, Cologne, London & Madrid) and Australia (Brisbane, Melbourne & Sydney). The companies are independently owned, and legal commitments entered into by any one company do not impose any obligations on other companies in the network. All views expressed in this document are the views of Frontier Economics Limited.

FRONTIER ECONOMICS EUROPE
BRUSSELS | COLOGNE | LONDON | MADRID

Frontier Economics Ltd 71 High Holborn London WC1V 6DA
Tel. +44 (0)20 7031 7000 Fax. +44 (0)20 7031 7001 www.frontier-economics.com