National Cancer Action Team
Part of the National Cancer Programme

NCRI
National Cancer Research Institute

NCIN
national cancer intelligence network
Using information to improve quality & choice

The Economics of Cancer

A workshop to explore opportunities for study

October 28th 2011

The Ambassadors Bloomsbury, London

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Introduction

Cancer care is a major element of all health systems, in England alone accounting for over £5billion of public expenditure annually. Yet a recent National Audit Office report indicated that we do not know enough about how that money is spent and whether it is spent wisely and for the benefit of patients. There is therefore a pressing need for more evidence about the costs and effectiveness of cancer care. However, the extent of economic analysis of cancer is relatively modest in the UK, with little sustained funding and few centres of expertise. Its impact on cancer research, clinical practice and government policy has therefore been limited.

Hitherto economic research has been hampered by a lack of data linking the processes, outcomes and costs of individual cancer care. However, richer datasets are now becoming available, opening up the potential for new types of economic analysis with which to inform practice and policy. The purpose of this workshop is to explore the extent of existing research into the economics of cancer, the barriers to greater involvement of economists, and the priorities for future collaborative work and research.

Dr Michael Peake
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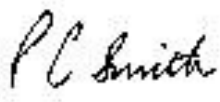

Professor Peter Smith
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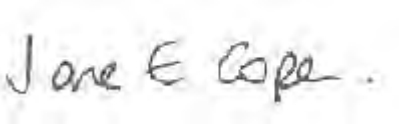

Dr Jane Cope
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THE ECONOMICS OF CANCER

A WORKSHOP TO EXPLORE OPPORTUNITIES FOR STUDY

October 28th 2011, 09:00 – 16:00

The Ambassadors Bloomsbury, Upper Woburn Place, London WC1H 0HX*

AGENDA

09:00-09:30	***Registration & Coffee***
09:30-09:45	***Chair: Stephen Parsons, Director, National Cancer Action Team*** **Welcome, Introductions, Context & Aims of the Day** *Professor Sir Mike Richards (National Cancer Director, England)*
09:45-10:15	**An Overview of Health Economics Data and Expertise in Cancer** *Peter Smith, (Professor of Health Policy, Imperial College London) & Mauro Laudicella (Research Fellow, Imperial College London)*
10:15-10:45	**Cancer Datasets Available in the UK** *Chris Carrigan, (Head of Co-ordinating Team, NCIN)*
10:45-11:00	**Discussion**
11:00-11:30	***Coffee Break***
11:30-13:00	***Chair: Peter Smith, Professor of Health Policy, Imperial College London*** **Examples of current models of Health Economic Analysis to Cancer** 1. **Costing the whole cancer pathway** *Marjorie Marshall (Economic Advisor, Scottish Government)* 2. **Economic burden of Skin Cancer** *Laura Vallejo-Torres (Principal Research Fellow in Health Economics, University College, London)* 3. **Economics of cancer from a patient perspective** *Linda Sharp (National Cancer Registry of Ireland)* 4. **Health economic evaluation in bowel cancer** *Paul Tappenden, (Senior Research Fellow, University of Sheffield)* 5. **Applying Health Economics in the Policy World** *Francis Dickinson (Department of Health HE Unit)* 6. **A pharmaceutical industry perspective & Value Based Pricing** *Gavin Lewis (Health Economics and Strategic Pricing Director, Roche Pharmaceuticals)* 7. **Health Economics of NICE Clinical Guidelines** *Sarah Willis (Research Fellow, London School of Hygiene & Tropical Medicine)*

13:00-13:45	**Lunch**
13:45-14:15	***Chair: Jane Cope, Director, National Cancer Research Institute*** **Bringing together health economics and clinical research** *Mark Sculpher (Professor of Health Economics, Centre for Health Economics, University of York)*
14:15-15:30	***Chair: Mick Peake, Clinical Lead, National Cancer Intelligence Network*** **Group Work - aims:** • **To identify the most important areas for future work** • **To clarify what the main gaps are in our knowledge of the economics of cancer are and consider how they may be addressed** • **To identify a few key areas where it might be feasible to start collaborative work sooner rather than later** • **To identify organisations and individuals from the Health Economics Community who may be interested in working collaboratively with the cancer intelligence and research communities** **Feedback from groups and discussion**
15:30-16.00	**Summary and way forward** *Professor Sir Mike Richards*

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A review of Health Economic Expertise in Cancer

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This paper describes some of the recent empirical findings and new methods of analysis in the health economic literature on cancer care. Particular attention is given to published academic studies that analyse the overall economic burden of cancer and geographical variations in cancer outcomes and costs. The review focus mainly on observational studies covering the total population of patients diagnosed with specific types of cancer and using administrative data sources. The main evidence comes from recent US and UK literature. The paper does not consider the many studies of the cost-effectiveness of individual treatments.

Main themes and conclusions of the published literature on health economic aspects of cancer care

The majority of studies on cancer costs can be grouped into two broad categories:

1. Evaluations of the aggregate economic burden of disease and illness, e.g. the net cost of care for the elderly cancer patients in the US[1]
2. Economic evaluations of specific health care interventions, e.g. the cost-effectiveness of patient mailings to promote colorectal cancer screening[2].

The first group typically uses data at population level and focuses on the overall burden of specific diseases including the effects on costs of health behaviour (e.g. drinking or smoking) and health conditions (e.g. obesity) that may affect the population health and health outcomes. The second group uses cost-benefit and cost-effectiveness analysis to assess the value for money of alternative health care interventions. The present work primarily reviews published applications falling in the first of these groups.

A number of different methods are available to estimate the cost of cancer care. Barlow[3] provides an overview of two general options available for estimating the direct costs of cancer: the prevalence and the incidence approach. The prevalence costs of a disease are usually reported for a specific calendar year and are based on the costs of medical care in that year for all the individuals diagnosed or living with that disease. Thus, prevalence costs include care delivered to all individuals across all cancer phases, i.e. newly diagnosed, long-term survivors and those at the end-of-life. Prevalence costs offer useful information for assessing the economic burden of specific cancer types and programming future expenditure. In contrast, the incidence approach considers only newly diagnosed patients and provides a representation of the costs of cancer from an individual perspective. This approach is typically used in longitudinal studies giving estimates of the medical costs following the diagnosis with the subsequent phases of care. Incidence costs are largely used in economic evaluation studies and provide useful inputs for policy decision about coverage and interventions to prevent or treat a disease.

Yabroff et al[4] examine the impact of using different data sources in evaluating the incidence costs of cancer care. They extract data on cancer incidence and survival from the US Surveillance

Epidemiology and End Results Program (SEER) and link them with costs information from Medicare enrolment data. The SEER dataset is maintained by the National Cancer Institute (NCI) and consists of data from population-based cancer registries covering 26% of the US population. This dataset includes every episode of primary incident cancer, time of diagnosis, cancer site, stage, histology, and vital status, and cause of death for patients in geographically defined areas. The Medicare dataset consist of fee-for-service longitudinal data including insured patients' claims for hospital, physician, home health, and hospice bills. The authors estimates incidence costs using similar patient population and methods but three alternative data sources: a SEER-Medicare cohort, a Medicare cohort, and a modelled phase of care approach. In a similar study, Yabroff et al[5] compare estimated prevalence costs from SEER-Medicare, Medicare alone, and Medical Expenditure Panel survey. Incidence cost estimates vary substantially depending on the strategy and data source for identifying newly diagnosed cancer patients and methods for estimating longitudinal costs. Prevalence costs also vary depending on the data sources, patient selection, and the proportion of long-term survivors included in the sample.

A recent report published by Lancet Oncology[6] describes how cancer has become a major economic expenditure for all high income countries with an estimated cost of US $895 billion in 2008. This cost is expected to increase due to acceleration in the rate of expenditure on cancer as well as an increase in the absolute numbers of patient diagnosed with cancer. The report identifies common drivers of costs across different countries and type of cancer, such as over use of services and drugs, shortening of life cycle of cancer technologies and lack of integrated health economic studies. The authors also highlights ethical and political factors that contribute to the rising costs, such us more defensive medical practice, a less informed regulatory system, a lack of evidence based political debate, and a declining degree of fairness for all patients with cancer.

Most of the evidence on the cost of cancer care comes from US studies. Cancer care accounted for $104 billion dollars in 2006 (about 5% of the total health care expenditure in US of $2 trillion) and this proportion is expected to accelerate as result of costly new treatments and growth in the number of cancer patients[7]. In a descriptive review of the US literature, Yabroff et al[8] identify 60 papers published between 1995 and 2006 on the cost of cancer. The studies are grouped in terms of settings, population studied, measurement of costs, and method of analysis. The review also identifies limitations of these studies in terms of the generealisability of the findings, misclassification of patients groups and costs, and concerns about the method of analysis (Table 1). In the "Limited generalisability" group are included studies with limited patient age distributions, studies conducted in a geographical limited area or in a single institution or with a single type of health insurance. "Potential misclassification" includes studies where the identification of patients or costs is not clearly described or controlled over the time period covered in the analysis. The methods of analysis include approaches to address common data limitation such as data censorship (e.g. complete sample, Kaplan-Maier sample average, phase of care approach, other or not reported) and the skewness of the cost distribution (e.g. log-transformation, two-part models, large sample size, other or not reported).

The same review reports five studies examining the cost of cancers for all tumour sites in prevalent cases of both newly diagnosed and existing cancer cases (Table 2). Also, costs estimates for each of the most common cancers (i.e. breast colorectal, lung and prostate cancers) and by phase of care are reported in Table 3-6.

The authors find that most of the studies reporting costs of cancer in multiple phases of care and for multiple tumour sites find evidence of a u-shape cost curve, i.e. costs are generally higher in the initial year following the diagnosis and the last year of life and lower in the continue phase. Also, costs for lung cancer and colorectal cancer are generally higher than costs for breast and prostate

cancer care within phase of care. However, costs for each type of cancer are more similar when the lifetime costs are considered. This is explained by the differences in survival and costs in each phase between different types.

A recent study by Mariotto and colleagues[9] reports projections of the medical cost of cancer care from 2010 to 2020 in US. Data on incidence and survival are extracted from the SEER database and linked to Medicare records in order to evaluate the cost of initial, continuing and final phases of cancer care for 13 types of cancers in man and 16 cancers in woman. Population projections are obtained from the National Interim Projection of the US population. The cost of care is estimated from Medicare claims. Assuming constant incidence, survival and costs of cancer in the population the study estimates a growth of 27% in the medical costs of cancer care over the 10 year period reflecting the change in the US population only. Moreover, if the cost of care increases annually by 2% in the initial and last year of life phases of care, the total cost is projected to increase by 39% in 2020. The largest increases are found in the continuing phase of care for prostate cancer (42%) and female breast cancer (32%). In contrast, projections of current declining trends in incidence and raising trends in survival have little effects on 2020 projections. Results from this study by cancer site are reported in Figure 1.

Evidence of substantial geographical variations in Medicare spending per beneficiary are reported in a large number of US based studies[10-17]. Large part of the observed variation has been linked to geographic variation in medical practice in the pattern of care, such as differences in the use of inpatient services, outpatient visits, diagnostic tests and specialist visits[11 12]. Some studies suggest that patients in high-spending areas do not receive better quality of care for some conditions, nor do they experience better health outcomes or satisfaction with care than patients in low-spending areas[13 14]. This seems to suggest that cost savings could be obtained, without negative consequences for the patient, if high-spending areas followed the practice of low-spending areas[15]. However, a recent study[16] finds evidence that not all the extra spending is wasteful in high-spending areas and similar outcomes across areas mask variation in both effective and ineffective care. In high-spending areas, positive outcomes generated by higher use of recommended care are offset by negative outcomes generated by higher use of non recommended care. The net effect results in similar outcomes across areas despite the differences in the level of spending. This study suggests that policies of cost containment should target specific services and practice patterns instead of specific geographical areas in order to be more effective.

Disentangling the relationship between health care spending and outcomes is of primary importance in assessing the performance of different health care organisations and alternative health care programs. By examining variations in cancer expenditures and outcomes across Primary Care Trusts (PCTs) in England, Martin et al[17] show that the effects on health outcomes is underestimated due to the endogeneity of the expenditure with respect to the health outcomes. In particular, current levels of health spending are likely to be influenced by past health outcomes so that PCTs with historical poorer outcomes tend to receive higher funding. This suggests a need to disentangle the positive effect of spending on health outcomes from the negative effect of health outcomes on spending. The authors address this 'endogeneity' problem by using an instrumental variables approach. They find that a 10% increase in cancer programme expenditure leads to a 4.9% reduction in deaths from cancer.

A number of contributions in the literature focus on the economic cost of cancer for society. These studies attempt to put a monetary value on the lives lost to cancer. Bradly et al[18] use the human capital approach and determine the cost of cancer in terms of lost of productivity as result of cancer mortality. They use earnings as a measure of the value of labour that people contribute to society and also include estimates of the value of nonwage labour, such as housekeeping and care giving. In

a similar study, Yabroff et al[19] adopt an alternative approach based on the willingness to pay (WTP) for a life year. The WTP approach includes aspects of the productivity and intangible benefits such as the value of avoiding the pain and suffering caused by cancer. Economists have developed a number of methods to estimate the monetary value of a life year in good health, which in contrast to other goods cannot typically be determined by transactions in the market.

The results produced by the Human capital and the WTP approach are different in magnitude and ranking. Lung cancer has the largest impact on both studies due to its incidence and mortality rate. Then, colorectal cancer has the greatest productivity impact, whereas breast and prostate cancer are larger than the former in terms of WTP. Such differences are mainly due to the age at which these cancers hit the population, their prevalence in men or women and their mortality rates. The WTP approach gives an equal amount of value to a life year regardless of age or sex, whereas the human capital approach reflects differences in wages across age and sex groups. The estimates of costs of cancer produced by the human capital approach ($116 billion in 2000) are dwarfed by the willingness to pay approach ($232 billion in 2000). In general, economists prefer the WTP approach arguing that the human capital approach is based on a narrow definition of the cost of illness that excludes the value of leisure and the individual preferences for health resulting in attributing more value to the rich than the poor in its evaluations.

Some studies incorporate the value of patients' time into estimates of the economic cost of cancer[20-22]. Patients' time typically includes the time associated with travelling, waiting and seeking medical treatment. Yabroff et al[21] provide estimates of the cost associated with patient time by cancer sites and phases. They convert time in monetary value by using the median hour wage in the US. Louise and Russell[20] argue that ignoring patients' time leads to underestimating the burden of disease and biases cost-effectiveness analysis in favour of interventions that use more patient's time.

A number of contributions from the health economic and econometrics literature tackle some of the issues involved in the estimation of cancer costs. Etzioni et al[23] develop a methodology to include future unrelated medical costs resulting from lifesaving interventions in the estimation of the lifetime costs for colorectal cancer patients. They identify future costs attributable to the disease as the difference between the projected lifetime costs for cancer patients and for a control group of individuals matched by age and gender without colorectal cancer. The inclusion of health care consumption in future years for patients whose cancer is prevented by screening scales down the estimates of the lifetime excess costs for colorectal cancer patients. Results including future costs are notably different from results without, especially in the advanced stage of the disease, and can have important implications in cost-effectiveness analyses of cancer screening programs.

Mitra and Indurkhya[24] propose a propensity score matching approach in cost effectiveness analysis of medical therapies using observational data. Observational studies are usually less expensive than experimental studies, such as clinical trials. However, the investigator has no control over the treatment assignment, hence treated and control groups are likely to be systematically different. The method proposed in this study adjusts for such differences and they perform a cost-effectiveness analysis without having to resort to more expensive clinical trial study designs. They show an application of their method using SEER-Medicare data for treatment of Stage II/III bladder cancer.

Often the analyst is able to observe the patient of interest only at the end of her treatment (or death), so the analysis is often characterised by what is known as 'right censoring'. Basu and Manning[25] extend the conventional methods[26] that tackle the problem of right censoring in estimating the lifetime and episode of illness costs. The new estimator is able to decompose the effects of patient characteristics and medical interventions on total costs into a part attributable to

survival effects and another attributable to intensity of health care utilisation. Their method does not assume discreteness in censoring of death times as in previous studies. An illustration is provided by estimating the lifetime cost trajectories of patients with prostate cancer using the linked SEER-Medicare dataset.

Finally, Basu et al[27] use a local instrumental variable approach to evaluate the average treatment effect and effect on the treated on 5-year direct costs of breast-conserving surgery and radiation therapy compared with mastectomy in breast cancer patients. Their method allows for heterogeneity in the effect of the treatment on different patients and for selection into the treatment program based on expected gains or losses. The authors illustrate an application using observational data from the OPTIONS dataset (Outcomes and Preferences in Older Women, Nationwide Survey).

Main areas of interest, expertise and current work in the UK

Large part of the UK literature on the costs of cancer focus on the cost-effectiveness analysis of alternative treatment interventions and care pathways[28-30]. Some of these studies contribute to providing evidence of best medical practice and shaping the National Institute Clinical Excellence (NICE) guidelines[31 32]. Tappenden et al[33] provide an illustration of the main methodological issues in the cost-effectiveness analysis of cancer treatments.

Only a small number of studies focus on the analysis of the direct costs of cancer. In contrast, a substantial number of works investigate the variation in the incidence and mortality rates of cancer across geographical areas and socioeconomic status.

Bending et al[34] estimate the direct costs of bowel cancer services in 2005. Their analysis is based on a service pathway model that includes the possible options for an individual at each stage of the disease: screening, diagnosis, primary treatment, follow-up, stoma care, palliative treatments, and management of individual at high risk. The model is populated using data from the NHS Reference Costs and the Hospital Episode Statistics. The cost of bowel cancer services is estimated to be in excess of £1 billion in 2005 with 35% of total costs attributable to investigating patients with suspected bowel cancer subsequently diagnosed as negative. This study represents the most comprehensive attempt to quantify the costs of bowel cancer across the entire NHS. However, the authors point out that the main limitation of the study is the absence of accurate data on current service pathways and poor quality of costing data.

Two studies compare the performance in the delivery of cancer services across European countries including the UK. Fourcade et al[35] calculate the direct cost of prostate cancer treatment in France, Germany, Italy, Spain, and the UK. They calculate costs per patient by stage of the disease in the first year after the diagnosis including diagnostic costs, first surgery, radio and chemotherapy, and hormonal therapy. Data in all five countries were obtained from the Information Management System (IMD) Oncology Analyser database, and the IMD Disease Analyser. The former dataset is based on a survey of a European panel of 1,200 specialists treating cancer patients in hospital inpatient or outpatient setting; the latter dataset consist of routinely collected data from participating primary care officers. The mean direct costs per patient for initial treatment are €3,256 in Spain, €3,682 in the UK, €3,698 in Germany, €5,226 in Italy, €5,851 in France. The authors highlight that cross country differences in the nature of their unit costs explain part of the differences in the estimated costs. While the UK costs can be considered an accurate measure of the average national cost, Germany Italy and Spain unit costs are based on predefined reimbursement fees that do not reflect true costs.

Flaming et al[36] Investigate the factors explaining hospital costs of lung cancer patients in Northern Ireland. They identify 724 cancer patients diagnosed in 2001 and estimate £5,956 the average cost per patient diagnosed with non-small cell lung cancer and £5,876 with small cell lung cancer. The main driver of costs is length of stay accounting for 62-84% of total costs depending on cell type. Other factors associated with costs are the stage of cancer, patient age, co-morbidities and deprivation. Patient profiles and treatment pathways were constructed by using the Northern Ireland Cancer Registry and a review of hospital case notes. Data on costs are constructed using a survey of local service providers, costs of chemotherapy are derived using the British National Formulary and the costs of radiotherapy are attributed on the basis of the fraction administered. As the authors point out, one of the limitations of their study is the low explanatory power of the models used in the analysis suggesting that further work needs to be carried out in this area in order to better understand cost variations.

Okello et al[37] examine the association between cancer spending reported by PCTs and the population characteristics, disease burden and service activity in South East England in 2005-2007. Lower per capita spending is associated with PCTs with smaller populations and higher prevalence of deprived areas. In contrast, higher expenditure is associated with higher proportions of radiotherapy treatments and higher per capita hospital bed days for cancer. The authors conclude that cancer spending is not associated to the burden of disease (i.e. the demand for care) but might be driven by treatments and service activity (i.e. the supply of care). The data used in the analysis come from a number of different sources: Department of Health Programme Budget data sets, the Office for National Statistics population and mortality data sets, the database of the TCR and Hospital Episode Statistics data.

A number of studies find evidence of socioeconomic inequalities and changes in inequalities over time in the incidence rates and mortalities rates of cancer[38-40], and participation in cancer screening programmes[41-44]. Lyratzopoulos[38] et al examine changes in socioeconomic inequalities for breast and rectal cancer survivals over a period of 32 years from 1973 to 2004. Data on cancer registrations are obtained from the Office for National Statistics for residents of England and Wales diagnosed with breast or rectal cancer during the 36-year period 1971–2006 and followed up to 31 December 2007. The authors apply a theoretical framework based on the Victoria's inverse equity law, i.e. survival inequalities could change with the advent of successive new treatments of varying effectiveness, which are disseminated with different speed among patients of different socioeconomic groups. Their results show a steady fall in the inequality in breast cancer survival (i.e., the gap between the most affluent and most deprived groups falls from -10% to -6%) and a rise of inequality in rectal cancer survival (form -5% to -11%). The authors suggest that inequalities in the introduction of new treatments may partly explain the reduction in inequality in breast cancer survival. Observed inequalities at a given point in time might be considered as the result of past inequalities in the successive phases of the cancer treatment. For example, the gradual introduction into clinical practice of adjuvant chemotherapy and endocrine therapy over the 70s and the 80s spreads the benefit of these treatments to a wider population narrowing the gap in survival rates from breast cancer in the following years. In contrast, trends in socioeconomic differences in tumour or patient factors are considered unlikely explanations of observed changes.

Rachet et al[39] examine trends in socioeconomic inequalities after the implementation of the NHS Cancer Plan (2000) aimed at reducing such inequalities. The authors examine relative survival among adults diagnosed with 1 of 21 common cancers in England during 1996-2006, followed up to 31 December 2007. The data are provided by the National Cancer Registry and linked with data on the patient's vital status (alive, emigrated, dead, not traced) at the National Health Service Central Register. Their results show that survival improved for most cancers, but inequalities in survival are still wide for many cancers in 2006. Also, a majority of the socioeconomic disparities in survival

occurred soon after a cancer diagnosis, regardless of the cancer prognosis. In an earlier study, Rachet et al[45] find a positive effect on cancer survival rates associated with the implementation of the NHS Cancer Plan[46].

Two studies report evidence of geographical inequalities across Health Authorities (HA) and Primary Care Trusts (PCT), i.e. the local commissioners of health care services in England[47 48]. Jack et al[48] investigate the management and survival of patients with lung cancer across 26 HAs in South East England using data from the Thames Cancer Registry from 1995 to 1999. They find a variation between 5 and 17% in the proportions of patients receiving active treatment for non-investigative surgery, 4 and 17% for any chemotherapy, 8 and 30% for any radiotherapy and 15 and 42% for any active treatment. One-year patient survival ranged from 11 to 34%. The authors suggest that these inequalities might be explained by variations in access to oncology services. In a similar study, Currin et al[47] investigate inequalities in the incidence of cervical cancer across PCTs in South East England in 2001-2005. They find that the age-standardised incidence rate for cervical cancer varies 3.1 fold across PCTs in South East England. Also, results show highly significant correlations between the age-standardised incidence rate and smoking prevalence, teenage conception rates, and deprivation at the PCT level. In contrast, screening coverage was not associated with the incidence of cervical cancer at the PCT level. The authors suggest that reducing exposure to the above risk factors is likely to result in significant public health gains.

A large number of studies on the incidence and the mortality rates of cancer in the UK are produced by the National Cancer Intelligence Network (NCIN). This institution coordinates data collection, analysis and publication of comparative national information on diagnosis, treatment and outcomes for types of cancers and types of patient. Some of the NCIN studies provide evidence of variation in incidence and survival rates across socioeconomic groups[49], and PCTs[50].

In November 2010, the National Audit Office (NAO) published a review[51] of the implementation of the Department of Health Cancer Reform Strategy[52] (2007). The report provides evidence of improvement and efficiency savings in key areas of cancer care, but also underlines that lack of appropriate information on costs of cancer services and their outcomes represent a substantial obstacle to further improvements. In particular, there is evidence of a large variation in outcomes, care pathways and costs of cancer services across the PCTs suggesting potential scope for substantial efficiency savings.

PCTs lack appropriate information on the drivers of services costs. Only 22% of PCTs had attempted to assess the value for money delivered by services providers. Most of the PCTs have reduced costs by avoiding unnecessary admissions and reducing length of stay for cancer patients. From 2006-7 to 2008-9, inpatient cancer care has been reduced from 9.9% to 9% of all impatient bed days despite an increase in the incidence of cancer. However, variation in length of stay across PCTs is substantial. In 2008-9, the average length of stay for inpatient cancer admissions varied from 5.1 to 10.1 days across PCTs. The NAO concludes that if all PCTs had the same length of stay as the average in the best performing quartile, then 566,000 bed days could be saved, i.e. the equivalent of £113 million per year.

One of the targets of the reform is the reduction of emergency admissions of cancer patients. However, the NAO reports that between 2006-07 and 2008-09, emergency admissions for cancer patients increased by 2%, though it slow down as compared with previous years (3.8% from 2000-01 to 2006-07). In 2008, inpatient admissions vary from 1.7% to 3.2% across PCTs. If all PCTs had the same patient admissions as the average in the best performing quartile, then 532,000 bed days could be saved, i.e. equivalent of £106 million per year.

Main sources of health economic data in the UK

The main source of data on cost of health care services is the Reference Costs[53]. This dataset provide a detailed picture on NHS expenditure used by over 400 NHS organisations including providers and commissioners of health care services. Reference costs provide unit costs at the level of treatments and procedures since 1997-98 reported by all NHS providers of health services in England. All NHS organisations allocate their total costs to service unit costs following a top down accounting procedure (rather than seeking to measure directly the costs incurred by individual patients). The calculation of unit costs is supported by detailed guidance in order to reduce variation arising from differences in costing methodologies. Reference costs use casemix adjusted measures, in which the care provided to a patient is classified according to its complexity. The casemix measures for acute care in England are the Healthcare Resource Groups (HRGs).

The Department of Health produces data on the allocation of health expenditure at commissioner (i.e. PCTs) and Cancer Network level. Commissioner level programme budgeting data are published annually from 2003-04 and enable commissioners to identify how they spend their allocated funds across 23 diseases and their subcategories and how their allocation compare nationally and over time. Programme Budgeting data is also presented at Cancer Network level from 2006-07 in the 2008-09 Cancer Networks workbook. The latter enables Cancer Networks to compare their expenditure on the Cancer and Tumours Programme Budgeting category against other Cancer Networks and previous years. Estimates of the gross expenditure for cancer service programmes and subcategories are reported in table 7.

Hospital Episode Statistics (HES) give data on the hospital care reported by NHS and non-NHS providers for each NHS patient. The dataset include all secondary care services provided under inpatient, outpatient and day cases admissions. Data are collected at the level of Finished Consultant Episode defined as the time the patient spends under the care of a consultant. The HES dataset contains detailed information on the patient diagnoses, performed procedures, and characteristics of the area of residence.

Eight regional cancer registries in England and one in each of Northern Ireland, Scotland and Wales collect information about every patient diagnosed with cancer. The NCIN organise these data into a National Cancer Data Repository for England and link them to additional data including surgery, radiotherapy and care in general practice. These data are made available to authorised researchers under the NCIN data access arrangements.

Conclusions

The present work has reviewed some of the most recent evidence and new empirical methods in the health economic literature on cancer care. The focus of the review is mainly on observational studies exploring the economic burden of cancer and covering the total population affected by specific types of cancer. The vast majority of empirical applications are from the US literature and are based on the US population. The availability of good quality data on the costs of providing cancer services at patient level and covering the full pathway of care is one of the main factors contributing to the success and abundance of US studies on this topic. In particular, the linkage between data on patient and treatment characteristics collected by the hospitals and data on service costs held by the insurance companies is a key instrument for a large part of the empirical work examined here.

In contrast, the empirical literature from the UK suffers from a lack of appropriate data on the costs of cancer. This is in part responsible for the small number of empirical analyses attempting to quantify the overall costs of cancer care. Many studies mention the lack of accurate data on costs of

key services, such as chemotherapy, and on relevant part of the care pathway, such as outpatient visits, as one of the main limits of the results of their empirical analysis. For this reasons, only a few studies have so far attempted to link data on utilisation of services with data on costs. However, the quality of data on costs is constantly improving, opening new opportunities for the next studies on the health economics of cancer care. In 2007-08, the Department of Health has adopted a new unit of casemix (the HRG version 4) that allows for a more disaggregated allocation of costs to specific service provided. In particular, new HRGs on chemotherapy and radiotherapy services are now available to cost hospital activity. Also, the quality of the data collected on outpatient visits is improving considerably over time, allowing a more accurate identification of the type of service provided.

A large number of UK studies offer evidence of a substantial unexplained variation in the outcomes and costs of cancer services commissioned by PCTs. This suggests that gains in health outcomes and cost savings might be achieved if all organisations adopt best practice. Therefore, one of the research questions that needs to be addressed by future studies is to identify the main drivers of such a variation in outcomes and costs. Modelling the relationship between inputs and outputs across the different organisations responsible for cancer services, such as GP practices, hospital providers, community services, cancer networks and NHS commissioners will be one of the key challenges of such an empirical analysis. Such studies will have to consider, *inter alia*, the complex interdependencies between screening programmes, GP referral practices, diagnostic testing, alternative therapies, hospital utilisation and community care, and will therefore necessarily entail a major research effort. The prize would be better use of limited NHS funds, and better outcomes for patients.

TABLE 1 Characteristics of studies examining the heath-care-related costs of cancer in the US

Source: Costs of cancer care in the USA: a descriptive review. K Robin Yabroff, Joan L Warren and Martin L Brown. Nature Clinical Practice Oncology (2007) 4, 643-656

Characteristics	Study categorisation	Number of studies	Percentage of studies
Study setting			
Delivery setting	Single institution or clinic	7	11.7
	Network of institutions or clinics	5	8.3
	Integrated system	13	21.7
	Insurance network	27	45
	Other	9	15
Health insurance type	Fee-for-service	21	35
	Managed care	11	18.3
	Multiple types	24	40
	Health insurance type not reported	5	8.3
Cancer patient characteristics			
Cancer patient identification	Medical record review	14	23.3
	Registry	26	43.3
	Claims	15	25
	Other	13	21.7
Tumour site	Breast	21	35
	Colorectal	14	23.3
	Lung	12	20
	Prostate	16	26.7
	Other	19	31.7
Characteristics of cost data			
Source of cost data	Claims	32	53.3
	Billing systems/cost accounting systems	18	30
	Other	14	23.3
Measurement of cost	Charges	11	18.3
	Payments	26	43.3
	Cost	17	28.3
	Expenditures	4	6.7
	Other	3	5
Study methods			
Phase of care	Prediagnosis	3	5
	Initial treatment of incident disease	18	30
	Continuing or monitoring	8	13.3
	Last year of life	19	31.7
	All phases together (prevalent cases)	21	35
	Long-term/lifetime costs	18	30
	Other	7	11.7
Comparison group	Noncancer controls	23	38.3
	Other comparison group	6	10
	No comparison group	32	53.3
Study limitations			
Study setting—limited generalizability	Limited patient age distribution in data source	39	65
	Geographically limited/single institution	32	53.3
	Single type of health insurance	31	51.7
Patient characteristics—potential misclassification	Patient identification not clearly specified	24	40
	Continuous enrolment in insurance plan not stated	30	50
Study methods—limited interpretability	Phase of care definitions unclear	13	21.7
	Analysis of cost data not clear	30	50
	Analysis of censored/missing data not addressed	27	45

Note: Studies may be included in more than one category

TABLE 2 Costs of cancer care among patients with prevalent cancer for all tumour sites.

Source: Costs of cancer care in the USA: a descriptive review. K Robin Yabroff, Joan L Warren and Martin L Brown. Nature Clinical Practice Oncology (2007) 4, 643-656

Study	Setting	Sample characteristics	Components of care after identification	Findings
Howard et al. (2004)[54]	MEPS	842 patients aged <65 years identified from encounters during 1996–1999	All care	Total cancer-related spending in the US was $20.08 billion in 2001 dollars during 1996–1999
Howard et al. (2004)[54]	Medstat MarketScan	41,756 patients aged <65 years identified from claims during 1999	All care	Total cancer-related payments in the US were $32.82 billion in 2001 dollars during 1999
Langa et al. (2004)[55]	AHEAD study	988 adults aged >70 years reporting a history of cancer in 1995	Out of pocket in 1 year	Cancer-related out-of-pocket spending for patients with cancer history and undergoing treatment were $240 and $670, respectively in 1995 dollars
Thorpe and Howard (2003)[56]	MEPS	1,383 adults of all ages identified from in-patient and out-patient records during 1996–1999	All care	Total spending was $6,115 over 6 months after identification. Spending for uninsured patients was lower in every category except out of pocket. All in 2001 dollars
Fishman et al. (1997)[57]	SEER–GHC	6,116 patients of all ages identified from registry who were treated during 1992	All care	Total mean costs were $8,992. Total mean costs for men and women were $9,264 and $8,782, respectively. All in 1992 dollars

Note: Total costs reflect all services received by patients with cancer. Cancer-related costs reflect either the cost of services presumed to be related to cancer treatment or the net cost of all services among patients with cancer compared with similar individuals without cancer. Abbreviations: AHEAD, Asset and Health Dynamics Survey; GHC, Group Health Cooperative; MEPS, Medical Expenditure Panel Survey; SEER, Surveillance Epidemiology and End Results.

TABLE 3 Costs of breast cancer care in the initial and last-year-of-life phases of care.

Source: Costs of cancer care in the USA: a descriptive review. K Robin Yabroff, Joan L Warren and Martin L Brown. Nature Clinical Practice Oncology (2007) 4, 643-656

Study	Setting	Sample characteristics	Findings
Initial phase of care			
Lamerato et al. (2006)[58]	Registry–HFHS	1,595 women aged >19 years, stage I/II diagnosed 1996–2002, charges 1996–2004	Mean total charges for women with and without recurrence were $38,165 and $41,345 in 2003 dollars
Oestreicher et al. (2005)[59]	SEER–Blue Shield	1,239 women aged <69 years, local or regional diagnosed 1996–2000, claims 1996–2000	Mean cancer related payments for women receiving and not receiving chemotherapy were $43,282 and $20,264 in 2003 dollars
Warren et al. (2001)[60]	SEER–Medicare	28,916 women aged >65 years, stage I/II diagnosed 1983–1996, claims 1990–1998	Mean cancer-related monthly payments for BCS + RT and MRM were $1,837 and $1,375 in 1998 dollars
Barlow et al. (2001)[61]	SEER–GHC	1,675 women aged >35 years, stage I/II diagnosed 1990–1997, cost data 1990–1998	Mean cancer-related costs for mastectomy, BCS + RT, and BCS + RT+adjuvant were $12,621, $13,031, and $17,106. All in 1998 dollars
Given et al. (2001)[62]	Registry–Medicare	205 women aged >65 years, all stages diagnosed 1993–1997, claims 1993–1997	Mean total charges for BCS, BCS plus mastectomy, and mastectomy were $5,237, $12,151, and $9,418 in 1997 dollars
Penberthy et al. (1999)[63]	Registry–Medicare	1,952 women aged >65 years, all stages diagnosed 1985–1988, claims 1985–1989	Mean total payments for surviving and not surviving the year were $6,781 and $14,771 in 1997 dollars
Fireman et al. (1997)[64]	SEER–KP Northern CA	3,824 women of all ages, all stages diagnosed 1987–1991, use 1987–1991	Mean total costs were $14,737 in 1992 dollars
Legorreta et al. (1996)[65]	US Health–PA	200 women aged >20 years, all stages diagnosed 1989, costs 1989–1993	Mean total payments with and without screening were $15,100; and $19,000 in 1993 dollars
Riley et al. (1995)[66]	SEER–Medicare	24,995 women aged >65 years, all stages diagnosed 1984–1989, claims 1984–1990	Mean total payments were $8,913 in 1990 dollars. Payments higher in younger age groups and higher stage
Taplin et al. (1995)[67]	SEER–GHC	645 women aged >35 years, all stages diagnosed 1990–1991, costs 1990–1991	Total and cancer related costs were $10,813 and $9,353 in 1992 dollars
Last year of life phase of care			
Lamerato et al. (2006)[58]	Registry–HFHS	92 women >19 years, stage I or II disease diagnosed 1996–2002, charges 1996–2004	Mean total charges for women with and without recurrence were $63,434 and $53,872 in 2003 dollars
Warren et al. (2001)[60]	SEER–Medicare	4,385 women >65years, stage I/II diagnosed 1983–1996, claims 1990–1998	Mean cancer-related monthly payments $2,561; and $2,754 and $2,666 for BCS with RT and MRM. All in 1998 dollars
Polednak and Shevchenko (1998)[68]	SEER–CHIME	274 patients <65 years and dying in 1992	Mean total charges for were $31,286 in 1992 dollars
Fireman et al. (1997)[64]	SEER–KP Northern CA	724 women of all ages, all stages diagnosed 1973–1991, use 1987–1991	Mean total costs were $18,406 in 1992 dollars
Riley et al. (1995)[66]	SEER–Medicare	15,369 women >65 years, all stages diagnosed 1973–1989, claims 1984–1990	Mean total payments were $11,129 in 1990 dollars. Costs were higher in younger age groups
Taplin et al. (1995)[67]	SEER–GHC	187 patients aged >35 years, all stages diagnosed 1974–1991, costs 1990–1991	Total costs were $17,686 in 1992 dollars. Total costs higher in younger age groups

Note: Total costs reflect all services received by cancer patients. Cancer-related costs reflect either the cost of services presumed to be related to cancer treatment or the net cost of all services among cancer patients compared with similar individuals without cancer.

Abbreviations: BCS, breast-conserving surgery; CHIME, Connecticut Health Information Management and Exchange, Inc.; GHC, Group Health Cooperative; HFHS; Henry Ford Health System; KP; Kaiser Permanente; MRM, modified radical mastectomy; RT, radiation therapy; SEER, Surveillance Epidemiology and End Results.

TABLE 4 Costs of colorectal cancer care in the initial and last-year-of-life phases of care.

Source: Costs of cancer care in the USA: a descriptive review. K Robin Yabroff, Joan L Warren and Martin L Brown. Nature Clinical Practice Oncology (2007) 4, 643-656

Study	Setting	Sample characteristics	Findings
Initial phase of care			
Ramsey et al. (2003)[69]	SEER–GHC	923 patients aged >50 years diagnosed 1993–1999, with costs 1993–2000	Total costs for screen- and symptom-detected were $23,344 and $29,384 in 2002 dollars
Brown et al. (1999)[70]	SEER–Medicare	16,527 patients aged >65 years, all stages diagnosed 1989–1993, claims 1990–1994	Mean cancer-related payments $18,100; and greater with higher stage ranging from $15,200 (stage I) to $21,200 (stage IV). All in 1994 dollars
Penberthy et al. (1999)[63]	Registry–Medicare	2,563 patients aged >65 years, all stages diagnosed 1985–1988, claims 1985–1989	Mean total payments for surviving and not surviving the year were $13,815 and $19,481 in 1997 dollars
Fireman et al. (1997)[64]	SEER–KP Northern CA	2,528 patients of all ages, all stages diagnosed 1973–1991, use 1987–1991	Mean total costs were $24,489 (colon) and $26,369 (rectum) in 1992 dollars
Riley et al. (1995)[66]	SEER–Medicare	27,788 patients aged >65 years, all stages diagnosed 1984–1989, claims 1984–1990	Mean total payments were $17,505. Costs were higher in higher stage. All in 1990 dollars
Taplin et al. (1995)[67]	SEER–GHC	290 patients aged >35 years, all stages diagnosed 1990–1991, cost data 1990–1991	Total and cancer related costs were $14,968 and $12,894 in 1992 dollars. Cancer-related costs were higher with higher stage, but similar by age groups
Last year of life phase of care			
Brown et al. (1999)[70]	SEER–Medicare	17,093 patients >65 years, all stages diagnosed 1983–1993, with claims 1990–1994	Mean cancer-related payments were $15,200; and were higher with higher stage ranging from $11,200 (stage I) to $21,600 (stage IV). All in 1994 dollars
Fireman et al. (1997)[64]	SEER–KP Northern CA	645 patients of all ages, all stages diagnosed 1973–1991, use 1987–1991	Mean total costs were $17,282 (colon) and $18,310 (rectum) in 1992 dollars
Riley et al. (1995)[66]	SEER–Medicare	21,829 patients >65years, all stages diagnosed 1973–1989 with claims 1984–1990	Mean total payments were $12,028 in 1990 dollars. Costs were higher in younger age groups
Taplin et al. (1995)[67]	SEER–GHC	157 patients aged >35 years, all stages diagnosed 1974–1991, costs 1990–1991	Total costs were $12,110 in 1992 dollars

Note: Total costs reflect all services received by cancer patients. Cancer-related costs reflect either the cost of services presumed to be related to cancer treatment or the net cost of all services among cancer patients compared with similar individuals without cancer.

Abbreviations: GHC, Group Health Cooperative; KP, Kaiser Permanente; SEER, Surveillance Epidemiology and End Results.

TABLE 5 Costs of lung cancer care in the initial and last-year-of-life phases of care.

Source: Costs of cancer care in the USA: a descriptive review. K Robin Yabroff, Joan L Warren and Martin L Brown. Nature Clinical Practice Oncology (2007) 4, 643-656

Study	Setting	Sample characteristics	Findings
Initial phase of care			
Penberthy et al. (1999)[63]	Registry–Medicare	3,331 patients aged >65 years with all stages diagnosed 1985–1988, claims 1985–1989	Mean total payments for surviving and not surviving the year were $13,450 and $16,096 in 1997 dollars
Fireman et al. (1997)[64]	SEER–KP Northern CA	2,505 patients of all ages, all stages diagnosed 1987–1991, use 1987–1991	Mean total costs were $17,583 in 1992 dollars
Riley et al. (1995)[66]	SEER–Medicare	11,575 patients aged >65 years, all stages diagnosed 1984–1989, claims 1984–1990	Mean total payments were $17,518. Costs were higher in younger age groups. All in 1990 dollars
Last year of life phase of care			
Au et al. (2006)[71]	VA Medical Centers	459 patients mean age >65 years, all stages dying in 1997–2001	Mean total cost of care were $26,118. Year of dollars not reported
Hillner et al. (1998)[72]	Registry–BCBS	349 NSCLC patients mean age <65 years, diagnosed 1989–1991, claims 1989–1993	Mean total costs of care were $32,411 in 1992 dollars
Polednak and Shevchenko (1998)[68]	SEER–CHIME	588 patients aged <65 years dying in 1992	Mean total charges for men and women were $34,702 and $35,943 in 1992 dollars
Fireman et al. (1997)[64]	SEER–KP Northern CA	1,834 patients of all ages, all stages diagnosed 1973–1991, use 1987–1991	Mean total costs were $13,851 in 1992 dollars
Riley et al. (1995)[66]	SEER–Medicare	11,394 patients >65 years, all stages diagnosed 1973–1989, claims 1984–1990	Mean total payments were $13,217 in 1990 dollars. Payments higher in younger age groups

Note: Total costs reflect all services received by cancer patients. Cancer-related costs reflect either the cost of services presumed to be related to cancer treatment or the net cost of all services among cancer patients compared with similar individuals without cancer.

Abbreviations: BCBS, Blue Cross Blue Shield; CHIME, Connecticut Health Information Management and Exchange, Inc; KP, Kaiser Permanente; NSCLC, non-small-cell lung cancer; SEER, Surveillance Epidemiology and End Results.

TABLE 6 Costs of prostate cancer care in the initial and last-year-of-life phases of care.

Source: Costs of cancer care in the USA: a descriptive review. K Robin Yabroff, Joan L Warren and Martin L Brown. Nature Clinical Practice Oncology (2007) 4, 643-656

Study	Setting	Sample characteristics	Findings
Initial phase of care			
Jayadevappa et al. (2005)[73]	Academic medical center	120 men with mean age >65 years, all stages diagnosed 1998–2001, billing 1998–2002	Mean cancer-related costs for African American and White men were $1,144 and $5,277. Year of dollars not stated
Penson et al. (2004)[74]	Registry–HFHS	1,956 men with mean age >65 years, all stages diagnosed 1995–2000, charges 1995–2000	Mean total charges with and without progression were $12,162 and $10,430. Year of dollars not stated
Burkhardt et al. (2002)[75]	SEER–Medicare	10,255 men aged >65 years, localized diagnosed 1992–1993, claims 1991–1994	Mean total payments for external-beam RT and RP were $14,048 and $17,226. Year of dollars not stated
Penson et al. (2001)[74]	CaPSURE	235 men aged >65 years, localized diagnosed 1990–1997, resource use 1990–1997	Mean cancer costs were $6,375 in 1996 dollars
Penberthy et al. (1999)[63]	Registry–Medicare	3,179 men aged >65 years, all stages diagnosed 1985–1988, claims 1985–1989	Mean total payments for surviving and not surviving the year were $8,186 and $14,512 in 1997 dollars
Fireman et al. (1997)[64]	SEER–KP Northern CA	2,159 men of all ages, all stages diagnosed 1987–1991, use 1987–1991	Mean total costs were $11,074 in 1992 dollars
Riley et al. (1995)[66]	SEER–Medicare	31,624 men aged >65 years, all stages diagnosed 1984–1989, claims 1984–1990	Mean total payments were $10,235 in 1990 dollars. Payments higher in younger age groups
Taplin et al. (1995)[67]	SEER–GHC	554 men aged >35 years, all stages diagnosed 1990–1991, cost data 1990–1991	Total and cancer related costs were $9,090 and $6,862 in 1992 dollars. Cancer-related costs higher with younger age
Last year of life phase of care			
Penson et al. (2004)[74]	Registry–HFHS	126 men with mean age >65 years, all stages diagnosed 1995–2000, charges 1995–2000	Mean total charges for patients with metastatic progression and without progression were $24,260 and $20,942. Year of dollars not stated
Fireman et al. (1997)[64]	SEER–KP Northern CA	487 men of all ages, all stages diagnosed 1973–1991, use 1987–1991	Mean total costs were $19,070 in 1992 dollars
Riley et al. (1995)[66]	SEER–Medicare	23,011 men 65+, all stages diagnosed 1973–1989, claims 1984–1990	Mean total payments were $12,061 in 1990 dollars. Payments higher in younger age groups
Taplin et al. (1995) ENREF 66[67]	SEER–GHC	178 patients aged >35 years, all stages diagnosed 1974–1991, costs 1990–1991	Total costs were $15,551 in 1992 dollars

Note: Total costs reflect all services received by cancer patients. Cancer-related costs reflect either the cost of services presumed to be related to cancer treatment or the net cost of all services among cancer patients compared with similar individuals without cancer.

Abbreviations: CaPSURE, cancer of the prostate strategic urologic research endeavor; GHC, Group Health Cooperative; HFHS, Henry Ford Health System; KP, Kaiser Permanente; RP, radical prostatectomy; RT, radiotherapy; SEER, Surveillance Epidemiology and End Results

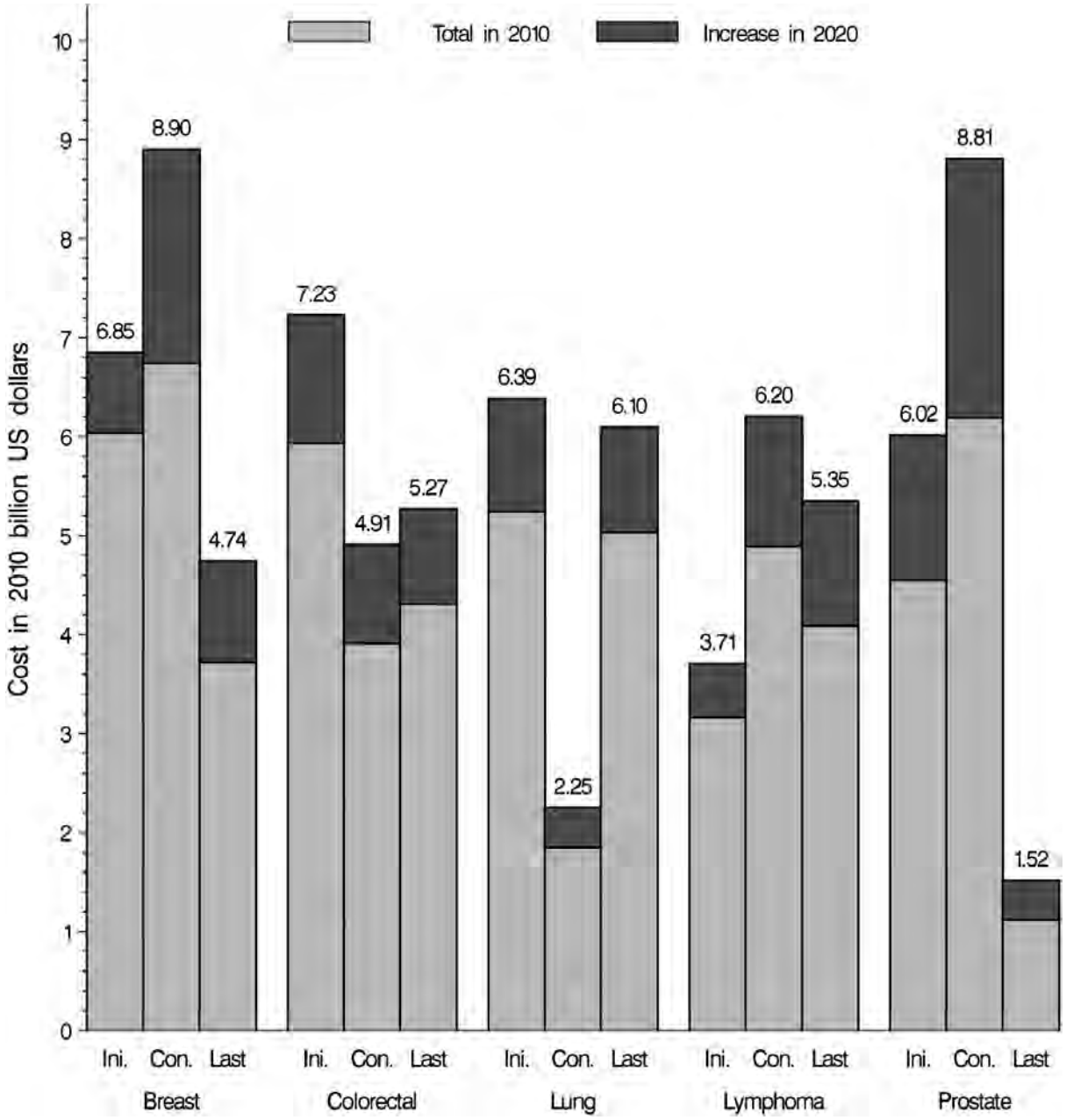
Table 7. Programme budgeting estimated England level gross expenditure for all cancer service programmes and subcategories for all years collected.

Programme budgeting category code	Programme Budgeting Category	Gross Expenditure (£billion)						
		2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10
2	**Cancers & Tumours**							
2A	Cancers & Tumours - Head and Neck	-	-	-	0.15	0.14	0.14	0.17
2B	Cancers & Tumours - Upper GI	-	-	-	0.21	0.23	0.24	0.28
2C	Cancers & Tumours - Lower GI	-	-	-	0.33	0.34	0.37	0.41
2D	Cancers & Tumours - Lung	-	-	-	0.20	0.23	0.24	0.28
2E	Cancers & Tumours - Skin	-	-	-	0.10	0.11	0.10	0.11
2F	Cancers & Tumours - Breast	-	-	-	0.40	0.45	0.50	0.57
2G	Cancers & Tumours - Gynaecological	-	-	-	0.16	0.16	0.16	0.18
2H	Cancers & Tumours - Urological	-	-	-	0.41	0.43	0.44	0.46
2I	Cancers & Tumours - Haematological	-	-	-	0.47	0.55	0.56	0.65
2X	Cancers & Tumours - Other	-	-	-	1.93	2.32	2.39	2.75
Total		**3.39**	**3.77**	**4.30**	**4.35**	**4.96**	**5.13**	**5.86**

Notes

1. Expenditure figures are from estimated England level programme budgeting data, which are calculated using PCT and SHA programme budgeting returns and Department of Health resource accounts data. Figures will include an estimation of special health authority expenditure.
2. In order to improve data quality, continual refinements have been made to the programme budgeting data calculation methodology since the first collection in 2003/04. The underlying data which support programme budgeting data are also subject to yearly changes. Caution is therefore advised when using programme budgeting data to draw conclusions on changes in PCT spending patterns between years.
3. Figures include expenditure across all sectors. Disease specific expenditure do not include expenditure on prevention, or GP expenditure, but do include prescribing expenditure.
4. When it is not possible to reasonably estimate a disease specific subcategory from existing data sets, expenditure is included within the other subcategory of the relevant programme. When it is not possible to reasonably estimate a main programme from existing data sets, expenditure is included within the other miscellaneous subcategory.

Figure 1. Estimates of the national expenditures for cancer care in 2010 (light gray areas) and the estimated increase in cost in 2020 (dark gray areas) because of the aging and growth of the US population under assumptions of constant incidence, survival and costs for the major cancer sites. Costs in 2010 billion US dollars by phase of care: initial year after diagnosis (Ini.) continuing care (Con.) and last year of life (Last).
Source: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010-2020. J Natl Cancer Inst 2011;103(2):117-28



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Costing the Cancer Pathway

It is estimated that more than 1 in 3 people in Scotland will develop some form of cancer during their lifetime, and that around 1 in 9 males and 1 in 7 females will develop some form of cancer before the age of 65.[1] There is increasing concern around the cost associated with diagnosing and treating cancer patients. Only last month the Lancet Oncology report stated that the incidence and prevalence of cancer is growing and the increasing cost of some treatments is a major financial issue. They called for more evaluation of the relative merits of different treatment options. In order to undertake such evaluation one of the first steps is to ascertain how much, as a health service, is currently being spent on cancer treatments and services. As the aim of this work is to ensure that NHS resources are used to maximise benefits for patients and to measure outcomes associated with that spend.

NHS Scotland benefits from comprehensive data gathering and analyses by the Information Services Division (ISD) which is part of National Services Scotland. However disaggregation of data by disease category, particularly regarding costs is limited. Discharge data by ICD 10 code is routinely published[2] but the source of NHS Scotland costs – the "Costs Book"[3] - whilst it provides a wealth of data, disaggregation of patient costs is primarily defined by the supply side of health care. For example we have both unit and aggregate cost data by health board, by hospital, by speciality – general surgery, general medicine, accident and emergency, oncology etc – but not by diagnosis**.**

Neither does NHS Scotland routinely disaggregate data by programme budgeting category in the same way as England . In 2002, the Department of Health in England initiated the National Programme Budget Project. The aim of the project is to develop a source of information, which can be used by all bodies, to give a greater understanding of where the money is going and the return on the investment in the NHS. The project aims to provide an answer to these questions by mapping all PCT and SHA expenditure, including that on primary care services, to 23 programmes of care. These programmes reflect ICD10 categories, plus two non clinical groups[4] and an 'other' category. The focus on clinical conditions is intended to forge a closer and more obvious link between the object of expenditure and the patient care it delivers.

There are three drivers of programme budgeting:

- a way of monitoring where NHS resources are currently invested
- a way of assisting in evaluating the effectiveness of the current pattern of resource deployment
- a tool to support and improve the process for identifying the most effective way of commissioning NHS services for the future.

[1] Cancer in Scotland (August 2011): Information Services Division, NHS National Services Scotland http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/
[2] http://www.isdscotland.org/Health-Topics/Hospital-Care/Diagnoses/
[3] http://www.isdscotland.org/Health-Topics/Finance/Costs/
[4] „Healthy individuals group" represents expenditure on disease prevention and „social care needs" reflects the cost of social support,

The Programme Budgeting project provides a retrospective appraisal of NHS resources broken down into 'programmes', with a view to influencing and tracking future expenditure in those same programmes to achieve the greatest health improvement per £ spent in the NHS.

Analysts within the Scottish Government and ISD tested the use of Programme Budgeting at national level in Scotland[5]. Two approaches to determining programme budgets were tested. A bottom up approach using activity and cost data obtained from information requests to the Information Services Division of NHS National Services Scotland (ISD) for conditions related to risk factors for long term conditions and a top down approach grouping expenditure and activity by 21 of the 23 programmes of care used in the NHS in England. These programmes reflect ICD10 categories, plus an 'other' category[6] . The two programmes that were excluded were 'healthy individuals' and 'social care needs' as these map specifically to National Service Framework activities, which do not apply in Scotland. Any activity and cost identified with these was included in the 'other' category. (A detailed report of the methodology used by ISD can be provided.) The second of these approaches is relevant for addressing questions around cancer spend.

Dues to the limitations of routine data, a previous piece of work undertaken by ISD used a "cost of illness" approach to estimate the cost of cancer services within NHS Scotland[7]. This was a comprehensive analysis of the costs of care across the cancer journey which included screening, hospice care, research, overheads and capital expenditure as well as treatment costs. The total costs for 2000/2001 were estimated at £425.4m, which was 7.5% of NHSScotland spend. Although the study was inclusive, SMR01 (episodes of care for inpatients and day cases in acute care) was the only data set from which the study could extract diagnosis coded information.

In the Programme Budgeting feasibility exercise, "cancer" is one of the 21 programme budgets identified. ISD analysts were able to map data for cancer related IDCD10 codes from SMR01 (inpatient activity), SMR01_E (geriatric long stay), SMR04 (mental health) and Prescribing Cost Analysis[8]. SMR00 (outpatients) has limited diagnosis information but it was possible to map, at specialty level, from SMR00 to the PB categories and to provide an estimate of GP consultations using Practice Team Information[9]. At the time of the initial analysis data from SMR02 (maternity services) had not been investigated. This has subsequently been carried out.

Community sector data and activity were unable to be accurately allocated to programme budgeting categories. Therefore all community expenditure reported in the Costs Book has been allocated to the 'Other' PBC category, except community dental (Report R820) which can be explicitly identified. The 'Other' PBC category will include Community Midwifery, Community Psychiatric teams, Learning Disabilities services and Community Nursing and Health Visiting teams.

[5] Twaddle S, Marshall M, Michael N (2010) Programme Budgeting – Testing the Approach in Scotland (unpublished)

[6] NHS Scotland: Programme Budgeting Methodology 2007/08 data ISD Scotland February 2010 (unpublished)

[7] Graham B (2003) The Cost of Cancer Care in Scotland 2002. ISD http://isd.scot.nhs.uk/isd/3401.html

[8] These are prescriptions that are dispensed within the community. Most will be written by GPs but they may include those written in hospital but dispensed in the community. They exclude those dispensed in hospital.

[9] Practice Team Information (PTI) collects information from a sample of Scottish general practices about face-to-face consultations between patients and a member of the practice team. http://www.isdscotland.org/Health-Topics/General-Practice/PTI-Statistics/

The results presented are for the financial years 2007/08 as at the inception of the project this was the most recent year with complete data sets. The high level (estimated) results are shown in Table 1 with proportions from the English PB exercise 07/08 included for comparison.

A few of the estimates presented are worthy of comment. At the time of analysis, as previously noted, it was not possible to map maternity spend and as a result the majority of the data is in the "other" category. This problem is being resolved. We are aware of data quality and completeness issues with Learning Disabilities data across both hospital and community care, so this category should be treated with caution and the low percentage will be one of the resulting effects. Conversely dental spend may seem high, in relative terms, because it was possible to map comprehensively from existing datasets to the programme budgeting category.

Table 1: Programme budgeting categories & associated spend NHS Scotland 2007/08

Programme Budgeting Category	All Services	Percentage	% from English PB exercise
All Other	£2,363,206,181	29.3%	31.4%
Problems of circulation	£756,720,451	9.4%	7.8%
Mental Health Disorders	£728,254,492	9.0%	11.0%
Problems of the respiratory system	£508,300,584	6.3%	4.0%
Problems of the gastro intestinal system	£481,524,197	6.0%	4.4%
Cancers and Tumours	**£475,299,004**	**5.9%**	**5.3%**
Neurological	£437,592,278	5.4%	3.7%
Dental problems	£374,083,410	4.6%	3.2%
Problems due to Trauma and Injuries	£357,432,705	4.4%	3.3%
Problems of Genito Urinary system	£314,612,189	3.9%	3.9%
Problems of the Musculo skeletal system	£290,808,712	3.6%	4.4%
Problems of the Skin	£203,331,806	2.5%	1.8%
Endocrine, Nutritional and Metabolic problems	£195,824,862	2.4%	2.6%
Problems of Vision	£185,093,353	2.3%	1.7%
Infectious diseases	£85,184,967	1.1%	1.4%
Adverse effects and poisoning	£89,540,357	1.1%	0.9%
Maternity and Reproductive Health*	£77,496,004	1.0%	3.2%
Disorders of Blood	£65,608,322	0.8%	1.3%
Problems of Learning Disability	£49,220,106	0.6%	3.0%
Problems of Hearing	£24,565,963	0.3%	0.5%
Conditions of neonates*	£1,989,574	0.0%	1.0%
Total expenditure	**£8,065,689,520**	**100%**	**100%**

* the majority of these data are currently included in the "other " category

Data source: ISD data request

As can be seen from the table, cancer services represent just under 6% of the identified spend at just over £475 million. The comparison suggests, that in percentage terms, the spend is slightly higher than England. For both the spend is consistent with the Lancet oncology report that stated that most developed countries spend between 4 and 7% of their healthcare budget on cancer[10].

[10] Sullivan, Peppercorn, Sikora et al . Delivering affordable cancer care in high –income countries. www.lancet.com/oncology Vol 12 September/October

It is possible to disaggregate the data in a number of different ways. In terms of both activity and cost it is possible to examine the distribution of cost across location of care – i.e. primary, secondary, prescribing – and across sub-programmes which represent major tumour sites.

Table 2: Cancer services: estimated activity and costs: Scotland 2007/08					
	Acute Services episodes	Geriatric long stay episodes	Out patient services	Pharmaceutical items dispensed	GMS visits
Activity	188,141	517	144,624	1,153,614	195,363
Cost	£389,749,741	£8,432,124	£25,056,598	£45,738,589	£6,321,952

Table 2 clearly shows that the majority of the spend is as would be expected, in the acute sector. Around 89% of the identified spend is in the hospital sector with the remainder (GMS and prescribing) in primary care. It is also possible to disaggregate by sub programmes. Table 3 identifies the costs associated with the main tumour sites.

Table 3: NHS Scotland 2007/08: programme budgeting : cancer costs

Code	Programme Budgeting Category	All Services	Percentage of total	*% of cancer spend*
02	**Cancers and Tumours**	**£475,299,004**	**5.9%**	
02A	Cancer, Head and Neck	£17,017,033	0.2%	*3.6%*
02B	Cancer, Upper GI	£36,483,102	0.5%	*7.7%*
02C	Cancer, Lower GI	£60,978,784	0.8%	*12.8%*
02D	Cancer, Lung	£47,939,226	0.6%	*10.1%*
02E	Cancer, Skin	£9,553,213	0.1%	*2.0%*
02F	Cancer, Breast	£47,632,653	0.6%	*10.0%*
02G	Cancer, Gynaecological	£18,996,935	0.2%	*4.0%*
02H	Cancer, Urological	£39,065,959	0.5%	*8.2%*
02I	Cancer, Haematological	£51,530,511	0.6%	*10.8%*
02X	Cancers and Tumours	£146,101,588	1.8%	*30.7%*

Colo-rectal, haematological, lung, and breast cancers make up more than 40% of the costs (43.7%).

Tables 4 and 5 disaggregate this further showing the distribution of spend for the individual cancer sites where is has been possible to map the data. Acute care remains the sector where the majority of cost is incurred: although where it has been possible to map prescribing against a specific cancer site it suggests that there may be substantial prescribing costs in the community for both breast and urological cancer.

Table 4 : distribution of spend in cancer types NHS Scotland 2007/08					
	Acute services	geriatric long stay	outpatients	Prescribing	GMS
Cancer, Head and Neck	£16,826,223	£102,169		-	£88,641
Cancer, Upper GI	£35,610,643	£552,797		-	£319,663
Cancer, Lower GI	£59,683,596	£1,010,581		£24,753	£259,853
Cancer, Lung	£46,216,400	£1,339,545		-	£383,282
Cancer, Skin	£9,337,406	£43,187		-	£172,620
Cancer, Breast	£34,210,952	£1,228,245		£11,856,203	£337,253
Cancer, Gynaecological	£18,704,807	£83,166		£123,667	£85,294
Cancer, Urological	£30,356,771	£1,205,788		£6,901,309	£602,092
Cancer, Haematological	£50,528,473	£815,869		-	£186,170
Cancers and Tumours	£88,274,471	£2,050,777	£25,056,598	£26,832,657	£3,887,085

Table 5 : distribution of spend (%) in cancer types NHS Scotland 2007/08					
	Acute services	geriatric long stay	outpatients	Prescribing	GMS
Cancer, Head and Neck	98.9%	0.6%		0.0%	0.5%
Cancer, Upper GI	97.6%	1.5%		0.0%	0.9%
Cancer, Lower GI	97.9%	1.7%		0.0%	0.4%
Cancer, Lung	96.4%	2.8%		0.0%	0.8%
Cancer, Skin	97.7%	0.5%		0.0%	1.8%
Cancer, Breast	71.8%	2.6%		24.9%	0.7%
Cancer, Gynaecological	98.5%	0.4%		0.7%	0.4%
Cancer, Urological	77.7%	3.1%		17.7%	1.5%
Cancer, Haematological	98.1%	1.6%		0.0%	0.4%
Cancers and Tumours	60.4%	1.4%	17.2%	18.4%	2.7%

There are some limitations to the data analysis. It excludes cancer screening programmes, which are included in the 'other' category. There are three cancer screening programmes in Scotland - bowel, breast, and cervical. The 2002 analysis estimated a cost of £7.5 million. This is now a gross underestimate. This is an area for further investigation although we know that for the Scottish Breast Screening Programme in 2009/10, which is a nationally commissioned screening programme with closely monitored costs, the full running cost was £13,715,669. The planning assumption for bowel screening, which is funded jointly by the Scottish Government and the Health Boards, was that in 2006 this would cost around £9 million. Cervical screening costs are met by individual Health Boards and it is therefore harder to estimate the national spend. The cost of cervical cytology laboratories alone in 2010 was nearly £6 million.

Another area that requires further investigation is the coding of radiotherapy treatment and the associated cost estimate. We suspect that radiotherapy treatment is not well captured by the SMR data collection processes. ISD colleagues advise that for in patients Radiotherapy treatments should be coded on SMR01 where the elective admission *is specifically for the radiotherapy procedure,* and thus mapped against the cancer programme budget, but is not mandatory if the admission is for other treatments as well, so the activity and costs may be spread through the PB categories. However the vast majority of radiotherapy will be delivered to patients as outpatients. Due to the limited information in outpatient data, that mapping excludes a number of specialties, including all allied health professional costs and activity[11]. As a consequence there is still a lack of radiotherapy data. This is a major issue as almost half of all patients with newly diagnosed cancers as well as recurrent disease will be treated with radiotherapy. Radiotherapy contributes to 40% of cases where

[11] The activity is simply included in the "other" category

a cancer is cured and adding radiotherapy to other treatments such as surgery or chemotherapy, improves five year survival by 16%.[12] A separate piece of work is required to determine the level of activity and cost associated with radiotherapy treatment across NHS Scotland.

Lastly the cost of palliative care is not well captured – not least because much of that is carried out in the Hospice setting. The National Audit Office in its 2008 report *End of Life Care*[13] found that Primary care trusts (PCTs) in England spent an estimated £245 million on specialist palliative care services in 2006/07. It also estimated that the annual cost to NHS and social care services overall of providing care to cancer patients in the 12 months prior to death (27 per cent of deaths) is £1.8 billion per annum. This is an area which we intend to explore and produce a Scottish estimate for the cost of palliative and terminal care.

We are very much at the beginning of the process in costing the entire cancer journey for patients. The programme budget work has however given us insights into the distribution of spend not previously available. In addition to exploring the costs that it excludes, or underestimates – screening, radiotherapy and palliative/terminal care in particular – to reach a more robust macro estimate we intend to carry out additional micro costing. We plan to begin by looking in more detail at a breakdown of costs across diagnosis and treatment for colorectal cancer.

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2. Information Services Division, NHS National Services Scotland *Cancer in Scotland (August 2011):* http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/
3. Mayor S, Expert group warns radiotherapy is still underused in England *BMJ* 2011;343:d4871
4. National Audit Office 2008 *End of Life Care* http://www.nao.org.uk/publications/0708/end_of_life_care.aspx
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[12] Mayor S, Expert group warns radiotherapy is still underused in England *BMJ* 2011;343:d4871
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Cost of skin cancer in England

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Background

The incidence of and mortality from skin cancer are increasing each year, with current estimates suggesting in excess of 8,000 new cases of malignant melanoma per annum and around 1,800 deaths from malignant melanoma per annum. With increasing awareness about the health impacts of skin cancer there is also a growing interest in its financial cost, to the health service, to patients, and to the wider economy. In previous work we used publicly available data to estimate the financial cost of skin cancer in England (Morris et al., 2009). In this study we undertake a detailed analysis of the cost of skin cancer in England and compare the results using two approaches to costing – a top down and bottom up approach. We begin by replicating the top down analysis previously undertaken by Morris et al., 2009 using more up-to-date figures. We compare the NHS costs estimates using this approach with the estimated cost using a bottom up approach.

Methods

The perspective for the analysis is societal, in that both NHS and wider costs are included. All costs are reported in 2008 UK pounds sterling (UK£).

The 'top down' approach to costing skin cancer involves assigning national all-cause expenditure data from administrative sources to skin cancer treatment. NHS costs using the top-down approach are based on data on the number of general practitioner (GP) consultations, inpatient stays, day cases, and outpatient visits due to skin cancer. Unit costs are taken from published national sources and applied to each category to give an overall estimate of the cost to the NHS of skin cancer. We use routinely available data sources that are commonly used in UK economic evaluations.

An alternative method to costing is a 'bottom up' approach based on the costs of care incurred by individual patients receiving skin cancer treatment, which are then aggregated up to the national level based on the numbers of patients receiving each type of treatment. For this, we identify care pathways for patients with skin cancer based on literature searches of case management patterns, the review of clinical guidelines on appropriate treatment pathways, and on input from expert clinicians on case treatment pathways used in practice. We then calculate the costs per patient associated with these pathways and multiply estimates of current number of cases of skin cancer by the calculated costs per patient to generate estimates of the cost of skin cancer based on current management patterns.

As a robustness check, we compare our estimates to other figures, generated from the National Programme Budgeting project, which allows analysis of total national and PCT expenditure on specific cancers, including skin cancer.

We also estimate non-NHS costs due to skin cancer. Costs incurred by patients in the receipt of treatment for skin cancer were computed by measuring travel costs and costs associated with lost earnings from time off work. These items were computed for each component of NHS costs. Indirect costs are based on lost working days due to skin cancer morbidity (called here indirect morbidity costs) and lost working life years due to deaths from skin cancer (indirect mortality costs). We do not explicitly consider indirect costs caused by reduced health related quality of life due to skin cancer, though this will be captured in part in the indirect morbidity costs.

Results

NHS costs

Appendix 1 describes the data we used for the top down analysis, and indicates which data we were able to update from our previous study. The annual GP consultation rate per new case was on average across all age groups 3.5 for malignant melanoma and 1.7 for other malignant neoplasms of the skin. Hence, the predicted number of GP consultations was 153,000, of which 30,000 were for melanoma and 123,000 were for non-malignant melanoma. The unit cost per GP consultation was £36, and therefore the total NHS cost of GP consultations was £5.5 million.

There were 1,000 non-elective inpatient admissions, 11,000 elective inpatient admissions and 77,000 days cases due to skin cancer, with mean unit costs of £2,650, £2,493 and £327, respectively. Hence, the total NHS costs of inpatient admissions and day cases were £32.4 million and £25.3 million, respectively.

The number of first and follow-up outpatient attendances due to skin cancer were estimated to be 136,000 and 498,000, respectively. The mean costs per attendance were £112 and £68, respectively, and hence the estimated costs were £9.5 million and £39.7 million, respectively, giving a total cost of outpatient attendances of £49.2 million.

The resulting costs of skin cancer borne by the NHS were estimated to be £112.4 million. The cost of each component and the proportion of total NHS costs attributable to each component are shown in Table 1. Fourteen percent of the total cost to the NHS is due to melanoma, and outpatient attendances account for the largest share of NHS costs (44%). By dividing the total cost by the number of adjusted registrations it is possible to estimate the mean cost per case. The mean cost to the NHS per case of melanoma and other malignant neoplasm is £2,560 and £1,226, respectively.

The bottom-up approach to costing is based on the simplified care pathway model presented in Figure 1. Data on probabilities and unit cost are presented in Appendix 2 and 3. Combining these data, the expected cost per case for malignant melanoma and non-melanoma skin cancer were calculated to be £2,607 and £889, respectively. The expected cost per case for benign cases was £181. Based on a total of 8,658 cases of malignant melanoma, 73,593 cases of non-melanoma skin cancer and 101,720 benign cases, the total financial cost to the NHS were calculated to be £106.4 million.

Non-NHS costs

Appendix 1 describes the data we used for the estimation of non-NHS costs. The mean cost incurred by a patient when attending a GP consultation was £8.29, and hence the private costs of GP consultations were £1.3 million. The mean cost per patient was £5.02 for inpatient admissions and £23.03 for day cases (the former include travel costs only, the latter also include economic inactivity costs) and hence the private costs were estimated to be £0.06 million and £1.8 million, respectively. The mean cost per patient for an outpatient attendance was £23.03 and hence the private costs were £14.6 million. The total patient costs were £17.7 million.

Claimant data for incapacity benefit rescaled to account for the changing incidence of skin cancer over time indicate that 313,000 working days were lost as a result of skin cancer in 2008. This resulted in total lost earnings of £20.5 million.

There were 1,746 deaths from melanoma in 2008 (55% in males, 63% in individuals older than the state retirement age) and 394 deaths from non-melanoma skin cancer (63%, 90%).
Deaths from skin cancer were estimated to result in the loss of an estimated £118.0 million.

Concluding remarks

Our total estimates of NHS costs due to skin cancer are closely comparable with those generated by the National Programme Budgeting project. According to programme budgeting data, total NHS spending on skin cancer in England in 2007/8 and 2008/9 was £104.0 million and £105.2 million respectively. In the update of Morris et al., 2009 NHS costs were estimated to be £112.4 million per annum. The estimate generated by the bottom up approach (£106.4 million) fall in between these two sets of figures. The expected costs per case malignant melanoma are very close using the bottom-up approach to those calculated by the update of Morris et al., 2009 (£2,607 versus £2,560), but the costs of other malignant neoplasms are lower (£889 versus £1,226).

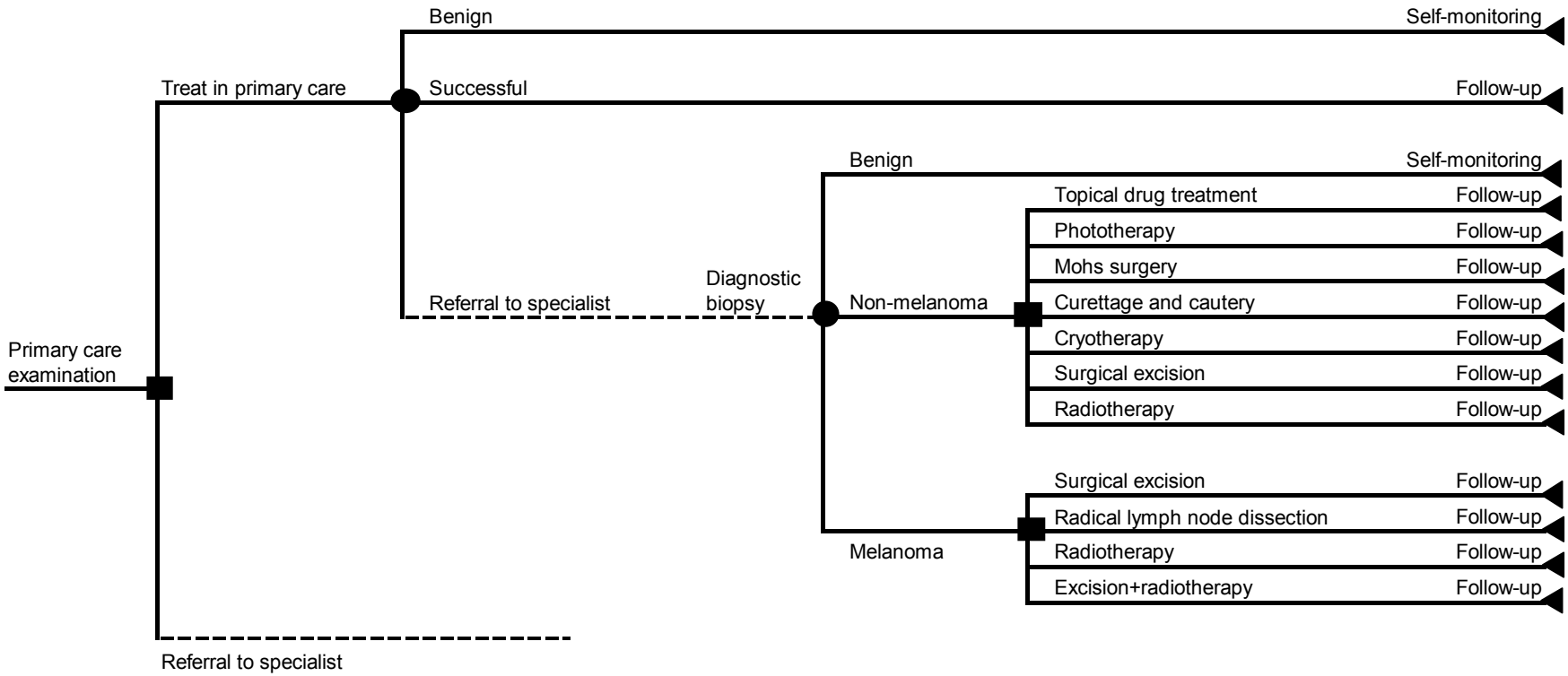
Since most skin cancers are caused by damage from ultraviolet rays in sunlight the majority of cases are thought to be preventable. If these cases were avoided then with the amount of money calculated in this study that is spent on skin cancer each year it would be possible to employ around an additional 500 hospital consultants for one year, or to employ an additional 3,100 Agenda for Change Band 5 nurses for one year. These NHS costs are in excess of those associated with multiple sclerosis and migraine, which have been calculated to cost £85 million and £45 million to the UK (in 1999 prices) in previous studies.

Table 1. Cost of skin cancer in England in 2008

	Malignant melanoma of skin			Other malignant neoplasms of skin			All skin cancers		
	£ 000	% NHS	% total	£ 000	% NHS	% total	£ 000	% NHS	% total
GP consultations	1,077	4.9	0.7	4,435	4.9	4.1	5,511	4.9	2.1
Inpatient stays	9,098	41.1	5.7	23,273	25.8	21.3	32,372	28.8	12.1
Day cases	2,465	11.1	1.5	22,849	25.3	20.9	25,314	22.5	9.4
Outpatient attendances	9,522	43.0	6.0	39,684	44.0	36.3	49,206	43.8	18.3
NHS costs	22,162	100.0	13.9	90,241	100.0	82.6	112,403	100.0	41.9
Patient costs	3,380		2.1	14,326		13.1	17,706		6.6
Indirect morbidity costs	20,489		12.9	-		0.0	20,489		7.6
Indirect mortality costs	113,278		71.1	4,706		4.3	117,983		43.9
Total cost	159,308		100.0	109,273		100.0	268,581		100.0

Numbers may not sum due to rounding.

Figure 1. Simplified care pathway



Appendix 1. Data

Cost component	Data	Data used in previous analysis	Year of data used in previous analysis	Updated?	Data used in current analysis	Year of data used in current analysis
NHS costs						
GP consultations	Ratio of GP consultations to incidence	OPCS. Morbidity statistics from general practice: fourth national study 1991-1992, series MB5 no. 3. London: HMSO, 1995.	1991-2	No	Same	1991-2
GP consultations	Skin cancer incidence	ONS. Cancer statistics: registrations, series MB1 no. 32. London: Office for National Statistics.	2001	Yes	ONS. Cancer statistics: registrations, series MB1 no. 37. London: Office for National Statistics.	2006
GP consultations	Adjustment factor for true incidence of non-melanoma skin cancer	Stefoski Mikeljevic J, Johnston C, Adamson PJ, Wright A, Bishop J, Newton A, Batman P, Neal RD, Forman, D . How complete has skin cancer registration been in the UK? A study from Yorkshire. European Journal of Cancer Prevention 2004; 12(2):125-133.	1994	Yes	SWPHO estimates	2004-6
GP consultations	Unit cost per GP consultation	Netten A, Curtis, L. Unit costs of health and social care 2003. PSSRU, 2003.	2003	Yes	Curtis, L. Unit costs of health and social care 2008. PSSRU, 2008.	2008
GP consultations	Patient costs	Netten A, Curtis, L. Unit costs of health and social care 2003. PSSRU, 2003.	2003	Partial; inflated to 2008 prices using inflation indices reported in Curtis, L. Unit costs of health and social care 2008. PSSRU, 2008.	Same	2008

Inpatient stays and day cases	Number of admissions	Department of Health. Hospital episodes statistics, England: financial year 2002-03. Primary diagnosis 3 character. London: Department of Health, 2003.	2002-3	Yes	Department of Health. Hospital episodes statistics, England: financial year 2007-08. Primary diagnosis 3 character, London: Department of Health, 2009.	2007-8
Inpatient stays and day cases	Cost per admission	Department of Health. NHS reference costs 2002. London: Department of Health, 2003.	2002	Yes	Department of Health. NHS reference costs 2005-06. London: Department of Health, 2007. Inflated to 2008 prices using inflation indices reported in Curtis, L. Unit costs of health and social care 2008. PSSRU, 2008.	2008
Inpatient stays and day cases	Patient costs	Kernick DP, Reinhold DM, Netten A. What does it cost the patient to see the doctor? British Journal of General Practice 2000; 50: 401-3.	2002	Partial; inflated to 2008 prices using inflation indices reported in Curtis, L. Unit costs of health and social care 2008. PSSRU, 2008	Same	2008
Outpatient visits	Number of visits	Department of Health. Hospital episodes statistics, Outpatient Statistics, England: financial year 2004-05. Primary diagnosis for first, subsequent and all attendances. London: Department of Health, 2006.	2004-5	Yes	Department of Health. Hospital episodes statistics, Outpatient Statistics, England: financial year 2007-08. Primary diagnosis for first, subsequent and all attendances. London: Department of Health, 2009.	2007-8
Outpatient visits	Cost per visits	Department of Health. NHS reference costs 2002. London: Department of	2002	Yes	Department of Health. NHS reference costs 2005-06. London: Department of	2008

		Health, 2003.			Health, 2007. Inflated to 2008 prices using inflation indices reported in Curtis, L. Unit costs of health and social care 2008. PSSRU, 2008.	
Outpatient visits	Patient costs	Kernick DP, Reinhold DM, Netten A. What does it cost the patient to see the doctor? British Journal of General Practice 2000; 50: 401-3.	2002	Partial; inflated to 2008 prices using inflation indices reported in Curtis, L. Unit costs of health and social care 2008. PSSRU, 2008	Same	2008
Indirect costs						
Morbidity costs	Days off work	Department of Work and Pensions. Days of registered incapacity. Table IB15(1), Annual, All Persons.	2001-2	Partial; updated based on ratio of malignant melanoma registrations diagnosed in 2006 to 2001.	Same	2006
Morbidity costs	Average earnings	ONS. Annual abstract of statistics No 140. London: The Stationery Office, 2004.	2002	Yes	ONS. Annual abstract of statistics No 145. London: The Stationery Office, 2009.	2008
Mortality costs	Mortality	ONS. Mortality statistics: cause, series DH2 no. 29. London: Office for National Statistics.	2002	Yes	ONS. Mortality statistics: Deaths registered in 2008. DR_08. London: Office for National Statistics.	2008
Mortality costs	Retirement age	Based on state retirement age of 65 years for males and 60 years for females	2002	Yes	ONS. Pension trends. Chapter 4: the labour market and retirement. 9 December 2009. London: Office for National Statistics.	2008
Mortality costs	Employment	ONS. Annual abstract of statistics No 140. London: The Stationery Office, 2004.	2002	Yes	ONS. Annual abstract of statistics No 145. London: The Stationery Office, 2009.	2008

Appendix 2. Probabilities used to populate the care pathway.

Event	Probability	Source	Notes
Treat in primary care	0.215	Murchie et al.2008; Malhomme de la Roche et al., 2008	Weighted mean probability of being treated in primary care from two studies, with weights given by sample size of each study.
Benign case after treatment in primary care	0.310	Jackson et al., 2000	
Referral after treatment in primary care	0.160	Hussain et al., 2008	
Diagnostic biopsy in secondary care	0.236	Gudi et al., 2006; Orr et al., 1993	Weighted mean probability of performing diagnostic biopsy from two studies, with weights given by sample size of each study.
Benign case after diagnostic biopsy	0.553	Jackson et al., 2000; Goulding et al., 2009	Weighted mean probability of case being benign from two studies, with weights given by sample size of each study.
Non-melanoma case after diagnostic biopsy	0.400	ONS (2009); SWPHO inflation adjustment for non-melanoma	Based on inflation estimates computed by SWPHO to model the incidence of non-melanoma skin cancer
Melanoma case after diagnostic biopsy	0.047		
Treating non-melanoma with surgical excision	0.860	Bachelor et al., 2006; Gudi et al., 2006; Goulding et al., 2009	Weighted mean probabilities based on treatment probabilities for SSC and BCC, with weights given by SSC and BCC prevalences
Treating non-melanoma with curettage and cautery	0.075		
Treating non-melanoma with cryotherapy	0.031		
Treating non-melanoma with radiotherapy	0.017		
Treating non-melanoma with phototherapy	0.008		
Treating non-melanoma with topical drug treatment	0.005		
Treating non-melanoma with Mohs surgery	0.004		
Treating melanoma with surgical excision	0.879	Orr et al, 1993	
Treating melanoma with radical lymph node dissection	0.088		
Treating melanoma with excision + radiotherapy	0.022		
Treating melanoma with radiotherapy	0.011		

SSC = squamous cell carcinoma; BCC = basal cell carcinoma.

Appendix 3. Unit costs used to populate the care pathway.

Cost component	Unit cost (£)*	Source(s)	Notes
GP visit	36	Curtis (2008)	Including direct care staff costs with qualification costs.
Treatment in primary care	85	NICE (2010)	Estimated excision costs for BCCs in primary care.
Specialist visit	112	Department of Health (2007)	Outpatient Adult First Attendance Face to Face: Dermatology 330F.
Diagnostic biopsy	112		Assume same as cost of specialist visit.
Topical treatment	200	British National Formulary (www.bnf.org); Curtis (2008)	Assume treatment with Imiquimod (Aldara®); application for 5 days each week for 6 weeks, assessing response 12 weeks after completing treatment. Drug cost is £51.32 for a 12 sachet pack, or £4.28 per pack. Require 30 packs at a cost of £128.30. Assume two GP visits; one at start of treatment and one 12 weeks after completing treatment.
Phototherapy	3,910	CancerHelp UK website (www.cancerhelp.org.uk); Department of Health (2010)	Assume 3 sessions a week for 8 weeks then one session every 2 weeks up to one year = 3*8+0.5*44 = 46 sessions in total, costed per session on the basis of Outpatient procedure cost: Phototherapy HRG JC29Z.
Mohs surgery	114	Department of Health (2007)	Outpatient procedure cost: Microscopically Controlled Excision of Lesion of Skin HRG J02op
Curettage and cautery	137	Department of Health (2007)	Outpatient procedure cost: Other Excision / Biopsy of Skin HRG J04op
Surgical excision	885	Department of Health (2010); Department of Health (2009)	Weighted average of inpatient procedure and day case procedure cost: Minor Skin Procedures category 1HRG JC07Z; weights given by proportion of inpatient and day cases episodes for Minor Skin Procedures category 1 in *Hospital Episode Statistics*
Radiotherapy	2,260	Department of Health (2007)	Teletherapy with technical support >12, <24 fractions HRG w22
Cryotherapy	204	Keogh-Brown et al. (2007)	Based on cost of GP-administered cryotherapy from cost-effectiveness analysis of wart treatment, in which cryotherapy involved three GP visits. Assume in a hospital setting this requires three specialist visits, costed on the basis of three outpatient attendances (Outpatient Adult Follow Up Attendance Face to Face: Dermatology 330F).
Radical lymph node dissection	16,808	Thomas et al. (2000)	
Surgical excision + Radiotherapy	3,145		Sum of surgical excision and radiotherapy costs
Follow-up in primary care	36	Curtis (2008)	Assume one GP surgery consultation
Follow-up in secondary care	68	Department of Health (2007)	Assume one Outpatient Adult Follow Up Attendance Face to Face: Dermatology 330F

* 2008 UK pounds sterling (UK£).

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Economics of cancer from the patient perspective

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Introduction

The data collected by cancer registries can be valuable in the estimation of the costs, to the health services, of diagnosing and treating cancer. The costs of cancer, however, do not fall only on the health services – there is increasing recognition that patients and their families may also experience a significant financial and economic burden. To date, however, this burden has not been extensively explored.

Cancer registries can be a valuable resource in enabling population-based studies of the financial and economic burden on patients and families. To illustrate the role that cancer registries may play in research in this area, this presentation will describe two studies exploring various aspects of the burden of cancer on patients and their families; these studies were conducted by the National Cancer Registry Ireland as part of a wider programmes of research on (a) the economic impact of cancer and (b) survivorship.

Methods

The studies are summarised in table 1.

Study	Cancer sites	Methods	Financial and economic outcomes considered*
1	Breast, prostate, lung	• In-depth interviews with key informants (oncology social workers) and survivors • Cross-sectional postal survey of survivors	• Out-of-pocket expenses (medical, medically-related, other) • Financial adjustments made as a result of cancer • Cancer-related financial stress and strain • Psychological costs (depression, anxiety, stress) • Workforce participation after cancer diagnosis • (Cost of lost productivity)*
2	Colorectal	• In-depth interviews with survivors +/- main family member involved in their care • Cross-sectional postal survey of survivors • Cross-sectional postal survey of carers	• Patient treatment-related time and travel costs • Patient out-of-pocket expenses • Patient health-related quality-of-life/utility • Costs of informal care • Caregiver quality-of-life • (Costs of lost productivity) • (Resource use/health service costs)

* Items shown in brackets represent costs incurred from other perspectives (i.e. health services, society or employers). They have been included to illustrate that these patient-focussed studies can be used to assess other economic outcomes.

Methods

Setting: Ireland has a mixed public-private health care system. All citizens are entitled to treatment within the public system. Within that system, those without a medical card (entitlement to which, at

the time of these studies, was means-tested in those under 70 and universal in those 70 and older), must pay a contribution for visiting primary care physicians and for hospital inpatient stays (approx €60 per visit/night) and the full costs of prescription medications. Most hospitals also offer private care. At any stage, patients can transfer from public to private care. Around 30% of the population have a medical card and half have private health insurance. There is no legal protection against dismissal from work because of extended absence for those with cancer, and sick leave and sick pay are at employers' discretion.

Development of instruments: There were no suitable "off-the-shelf" instruments available to assess out-of-pocket costs bourne by patients and family members, therefore qualitative research was undertaken to inform the development of the questionnaires. In study 1, this involved in-depth semi-structured interviews with key informants (hospital-based oncology social workers, who frequently advise patients on financial issues) and survivors with breast, prostate and lung cancer, who had incurred extra expenses or financial difficulties as a result of their diagnosis. In study 2, a focus group was held with members of a bowel cancer support group, followed by in-depth semi-structured interviews with patients and, where available, the main family member involved in helping to care for the patient. Patients were recruited with the assistance of health professionals (typically cancer nurse specialist) in collaborating hospitals. The interviews and focus group followed topic guides developed from literature review. Respondents were invited to discuss any extra costs incurred as a result of having cancer; the impact of cancer on work and household income; any financial adjustments made; and the impact of the financial/economic burden on the household.

The cost questionnaires developed from the interviews included questions on a range of potential out-of-pocket expenses (direct medical and medically-related), financial adjustments made (e.g. using savings, borrowing money), workforce participation before and following diagnosis, and socio-demographic factors. In study 2, respondents were asked to complete a care diary describing visits to the GP and hospital for diagnosis, surgery, chemotherapy and radiotherapy, modes of transport used and distance travelled, and waiting time and appointment length. In both studies, respondents were asked to rate cancer-related financial stress (impact of the cancer diagnosis on the household's ability to make ends meet) and cancer-related financial strain (how the respondent had felt about their household's financial situation since their cancer diagnosis). In study 1, psychological costs were assessed using the short-form of the Depression, Anxiety and Stress Scale (DASS). In study 2, health-related quality-of-life was assessed using the EORTC general questionnaire (QLQ-30) and colorectal cancer specific module (CR29) and the EuroQOL EQ-5D.

The carer questionnaire (study 2), included questions on time expended and out-of-pocket costs during the diagnosis and treatment phase and time dedicated to routine care and out-of pocket expenses in two periods - the 3-months post-diagnosis and the last 30 days before questionnaire completion. For routine care, respondents estimated the number of extra hours (as a result of caring for the individual with cancer) usually spent per week on housework; support with activities of daily living (e.g. moving around the house, going to the toilet); support with instrumental activities of daily living (e.g. visiting family or friends, health care contacts); and cancer- specific care (e.g. administering medicine, changing stoma bags). Caregiver quality-of-life was assessed using the SF12.

The draft questionnaires were pre-tested for ease of completion, face validity, etc. in small convenience samples of patients and carers.

Identification and recruitment of study subjects: The database of the National Cancer Registry was used as a sampling frame for the patient surveys. For study 1, the sample was selected in March 2008. Eligible individuals were diagnosed with primary breast or prostate cancer 6-24 months

previously, or primary lung cancer 3-21 months previously, and had been treated in 17 public or private hospitals across the country. For study 2, the sample was selected in March 2010 and included individuals with primary invasive colorectal cancer diagnosed 6-30 months previously, at any hospital which treated more than a few patients per year. The main treating clinician for each patient was identified from Registry records and contacted for their agreement to let the authors approach the individual to take part in the study. Individuals were excluded if the treating clinician indicated that they had died, were unaware they had cancer, or it would be inappropriate to contact them (e.g. they had dementia). For the carer survey, patients were asked to indicate whether someone in their family or a friend had been involved in helping care for them since they were diagnosed with cancer. If so, the patient was asked to provide the carer's contact details.

The surveys were administered by post. A range of strategies established as effective in maximising response rates were implemented, including pre-contact letters, reminder letters, enclosing a pen, and incentives (completed questionnaires entered into a prize draw).

Analysis: Statistical analysis is ongoing. In study 1, proportions of patients who had incurred each type of out-of-pocket expense were computed, with medians and ranges of amounts incurred. The percentages who had had to made financial adjustments were computed. Among those who were working at diagnosis, logistic regression analysis was used to identify (a) factors associated with continuing to work post-diagnosis and (b) among those who took a period of absence post-diagnosis, factors associated with resuming work. Using non-parametric tests, length of period of absence was compared between groups and average working hours pre-and post-diagnosis were compared. Respondents were defined dichotomously as having any or severe (a) depression, (b) anxiety, or (c) stress, according to whether they scored above or below recommended cut-offs on the DASS subscales. Frequencies with depression, anxiety and stress were compared with those from normative samples. Associations between financial stress and strain and psychological wellbeing were assessed using logistic regression models.

In study 2, time and travel costs associated with diagnosis and initial treatment were estimated. Costs were valued in €2008. Patient time was measured from the time they left home until the time they returned and was costed using a national survey on Earnings Hours and Employment Costs (gross national hourly average wage quarter 3, 2008: €21.21ph). With respect to inpatient stays, a per diem allocation of 16 hours was made (8 hours of lost productive time and 8 hours of lost leisure time) for each night spent in hospital. Travel costs were estimated based on transport type(s) used, using AA mileage rates and public transport and Taxi Regulator's standard fares. Where patients did not report travelling distance, this was estimated from Registry records. EQ5D responses were converted to utility values (maximum 1.0) using UK valuations. Mean utility values were compared between patient subgroups using anova tests.

For carers', imputed time costs for the diagnosis and treatment period included carer time spent: travelling to and from the hospital, visiting the patient in hospital, and waiting for chemotherapy/radiotherapy appointments. Extra time spent on caring activities due to the cancer diagnosis was estimated for the first 3-months post diagnosis and the last 30 days. Time was costed using the gross national average hourly wage for quarter 3 in 2008. Direct spending included all out-of-pocket costs associated with travelling to and parking at the hospital, eating out and accommodation expenses due to visiting or waiting for the patient, in addition to ongoing care-related medicine costs, household expenses and cancer-related items. As for the patient survey, valuation of travel costs (excluding time) was based on the mode of transport used. All costs were valued in €2008. The costs for the last 30 days were adjusted for inflation using the Irish CPI index.

Selected Results

Participation: In study 1, 1273 patients were invited to take part and 740 did so (response rate=54%). For study 2, 495 of 1,273 eligible patients took part (response rate=39%). Details of 228 carers were provided and 154 participated in the survey (response rate=68%).

Time and travel costs (study 2): The average total time and travel costs associated with diagnosis and initial treatment for colorectal cancer was €11,055. Time costs represented the vast majority of this total (96%). Patients with rectal cancer incurred slightly higher total costs than those with colon cancer (€11,860 vs €10,561). Average cost rose with increasing stage at diagnosis, peaking at stage III (stage I: €6719, stage II: €8,257, stage III: €11,677) before falling slightly for stage IV (€10,380). In terms of types of treatment, surgery costs were greatest (mean €7,104), with chemotherapy and radiotherapy somewhat lower (€3,629 and €5,301 respectively).

Out-of-pocket expenses, financial adjustments and cancer-related financial stress and strain (study 1): Almost half (45%) of patients with breast, prostate and lung cancer reported paying consultants fees, and just over one-third (36%) paid GP fees, in relation to their cancer. The median amounts spent were €465 and €250 for consultant and GP fees respectively. Less than one in ten paid for physiotherapy (9%), counselling (6%) or other therapies (2%). Almost 30% incurred costs in relation to prescribed supportive medications (typically pain killers, mouthwashes) and 40% paid for over-the-counter medicines. Costs for dietary supplements were incurred by 13%. Of women with breast cancer, 40% had out-of-pocket costs in relation to wigs or hairpieces (median amount: €400) and 5% paid for manual lymph drainage (median: €140). Those with medical cards and those with private health insurance reported having incurred cancer-related medical costs. Overall, almost 8 in every 10 patients incurred travel or parking costs associated with attending hospital appointments; the median amount spent was €425. Increased household bills were reported by 59%, with 44% reporting increased heating bills and 42% increased telephone bills following their cancer diagnosis. Financial adjustments were common. Of those who had savings, 57% had to use some of all of these to meet cancer-related costs; 11% reported borrowing money; and one in five patients cut-back spending on regular items (such as take-away meals, clothes and holidays) because of cost. 49% reported increased financial stress and 32% increased financial strain due to cancer.

Workforce participation (study 1): Of those patients with breast and prostate cancer who had been working at the time of diagnosis, 18% continued working during treatment while 82% took a period of absence. In multivariate models, the factors significantly associated with an increased likelihood of continuing to work were: having prostate cancer (OR=3.17, 95%CI 1.59-6.32); not having surgery (OR=2.69, 95%CI 1.27-5.66); being self-employed (OR=2.41, 95%CI 1.26-4.63); and having a lower pre-diagnosis household income (highest vs lowest tertile: OR=0.24, 95%CI 0.10-0.60). Of those who took time off, 18% had left the workforce, 66% had resumed working, and 16% planned to resume working. Factors significantly associated with having resumed work were: tertiary education, not having chemotherapy, receiving sick pay, and not having a medical card. Around half of those who took time off received any sick pay from their employer. Among those who resumed working, the median absence was 30.1 weeks (IQR=12.9-51.6). Length of absence varied significantly by socio-demographic, financial, medical, and job- and social welfare-related factors. The median absence for prostate cancer patients was less than half of that for breast cancer (17 vs 39 weeks) and for the self-employed was less than half of that for those working for an employer (17 vs 34 weeks). Those who did not have surgery, chemotherapy or radiotherapy were absent from work for half as long, or less, than those had these treatments. The median absence was shorter among older individuals. Median working hours pre- and post-diagnosis differed significantly (pre-diagnosis=38/week; post-diagnosis=30/week; $p<0.001$). Over half of those working at diagnosis reported that their income fell after diagnosis.

16% of all survey respondents indicated that a family member had had to make some change in their working pattern due to the cancer diagnosis (e.g. time off, changed hours, changed shifts). This rose to 30% among respondents with children under 18 living at home.

Quality of life (study 2) and psychological costs (study 1): The mean EQ5D utility value among colorectal cancer patients was 0.81, lower than reported utility among individuals in the general population (0.94). Utility was significantly lower in patients with rectal compared to colon cancer (0.76 vs 0.83) and those with a stoma compared to those without (0.73 vs 0.84). Utility did not vary by age, stage at diagnosis or time since diagnosis.

In terms of psychological costs, among patients with breast, prostate and lung cancer, the percentages who scored in the range of depression, anxiety or stress of any severity were 36%, 29% and 29%, respectively. The percentages scoring in the ranges for several depression, anxiety and stress were 14%, 13% and 13% respectively; in normative samples less than 5% score in these ranges. In adjusted analyses, risk of depression of any severity was raised three-fold in those reporting increased cancer-related financial stress (OR=2.79, 95%CI 1.87-4.17) and increased cancer-related financial strain (OR=3.56, 95%CI 2.23-5.67). For severe or worse depression, the risk estimates were more pronounced (increased stress: OR=4.36, 95%CI 2.35-8.10; increased strain: OR=8.21, 95%CI 3.79-17.77). Associations of a similar magnitude were found for anxiety and distress.

Caregiver costs (study 2): Average per person costs incurred by caregivers over the course of the initial diagnosis and treatment period were €5,227 (range: €0 - €19,169). Time costs represented over two-thirds of the total, with the remainder composed of direct non-medical costs. Time costs included waiting time (€2,414) and travel time (€1,467), both of which involve a sacrifice by the caregiver of time spent on other activities. Direct non-medical costs were made up of travel expenses (€768) and out-of-pocket costs (€999). The average cost of time spent on caring activities over the first 3 months following diagnosis was €7,339 (range: €0 – €24,179). 86% of carers incurred 3-month activities time costs. The breakdown of this was: household activities costs (€3,670); activities of daily living costs (€1,804); instrumental activities costs (€1,262); and cancer-specific care costs (€595). Per person out-of-pocket costs during the first 3 months of care were €830 (range: €0 to €5,172), with extra household expenses comprised two thirds of the total.

Conclusions

Cancer has a significant financial and economic burden on patients and their families. By providing a population-based sampling frame, cancer registries can facilitate the conduct of studies of the economic and financial impact of cancer on patients and their families. The data collected in these studies can also contribute to the estimation of cancer costs from other perspectives (e.g. health services, employers, society).

Reports and papers

Several papers are in preparation from these studies. A report and some of the papers in press and under review are listed below:

Sharp L, Timmons A. Financial impact of a cancer diagnosis on patients and their families. National Cancer Registry/Irish Cancer Society, Cork/Dublin, 2010.

Sharp L, Timmons A. Social welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland. *J Cancer Surviv* [Epub ahead of print]

Tilson L, Sharp L, Usher C, Walsh C, Whyte S, O'Ceilleachair A, Stuart C, Mehigan B, Kennedy J, Tappenden P, Chilcott J, Staines A, Comber H, Barry M. Cost of care for colorectal cancer in Ireland: A healthcare payer perspective. *Eur J Health Econ* [Epub ahead of print]

Sharp L, Carsin AE, Timmons A. Associations between cancer-related financial stress and strain and psychological wellbeing among individuals living with cancer. *Psycho-oncology* [in press]

Ó Céilleachair A, Costello L, Finn C, Timmons A, Staines A, Fitzpatrick P, Kapur K, Sharp L. Inter-relationships between the economic and emotional consequences of colorectal cancer for patients and their families: a qualitative study. [under review]

Hanly P, Timmons A, Walsh P, Sharp L. Breast and prostate cancer productivity costs: a comparison of the human capital approach and friction cost approach. *[under review]*

Timmons A, Gooberman-Hill R, Sharp L. Financial adjustments after cancer: what are the implications for patients and their families? *[under review]*

Timmons A, Gooberman-Hill R, Sharp L. The multi-dimensional nature of the financial and economic burden of a diagnosis of cancer on patients: findings from a country with a mixed public-private healthcare system. *[under review]*

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THE HEALTH ECONOMIC EVALUATION OF CANCER TECHNOLOGIES AND SERVICES – METHODOLOGICAL AND APPLIED RESEARCH

INTRODUCTION

Over the past fifteen years, the School of Health and Related Research at the University of Sheffield has undertaken a considerable body of methodological and applied research surrounding the economic evaluation of technologies for the prevention, detection, diagnosis, treatment and follow-up of cancer. This research includes a number of cancer sites including colorectal, breast, prostate, lung, cervical and haematological cancers. Our economic evaluation work has focussed on the main elements of the cancer service pathway from disease prevention and screening assessments through to the evaluation of end-of-life care. This research has been undertaken on behalf of a wide range of decision-making organisations including the National Institute for Health and Clinical Excellence (NICE), the NHS Research and Development Programme, NHS Cancer Screening Programmes, the Department of Health, as well as local and regional NHS decision-makers. Our expertise also extends to other elements of research to inform economic analyses of cancer interventions; these include the development of methods for the measurement and valuation health in cancer patients, costing studies, systematic reviewing, developing methods for survival analysis and modelling, and Bayesian evidence synthesis.

Below are some recent examples of research undertaken within ScHARR.

(A) RECENT APPLIED EXAMPLES OF ECONOMIC MODELLING IN CANCER

i) Options appraisal of population-based colorectal cancer screening programmes in England (Tappenden P, Chilcott J, Eggington S, Sakai H, Karnon J, Patnick J, Gut 2007;56:677-684)

The aim of this study was to estimate the effectiveness, cost-effectiveness and resource impact of faecal occult blood testing (FOBT) and flexible sigmoidoscopy (FSIG) screening options for colorectal cancer to inform the Department of Health's policy on bowel cancer screening in England. We developed a state transition model to simulate the life experience of a cohort of individuals without polyps or cancer through to the development of adenomatous polyps and malignant carcinoma and subsequent death in the general population of England. The costs, effects and resource impact of five screening options were evaluated: (a) FOBT for individuals aged 50–69 (biennial screening); (b) FOBT for individuals aged 60–69 (biennial screening); (c) once-only FSIG for individuals aged 55; (d) once-only FSIG for individuals aged 60; and (e) once-only FSIG for individuals aged 60, followed by FOBT for individuals aged 61–70 (biennial screening). The model suggests that screening using FSIG with or without FOBT may be cost-saving and may produce additional benefits compared with a policy of no screening. The marginal cost-effectiveness of FOBT options compared to a policy of no screening is estimated to be below £3,000 per quality adjusted life year gained. Screening using FOBT and/or FSIG is potentially a cost-effective strategy for the early detection of colorectal cancer. However, the practical feasibility of alternative screening programmes is inevitably limited by current pressures on endoscopy services.

ii) Cost-effectiveness of oxaliplatin and capecitabine in the adjuvant treatment of stage III colon cancer (Eggington S, Tappenden P, Pandor A, Paisley S, Saunders M, Seymour M, *et al*, Br J Cancer. 2006;6;95(9):1195-1220)

For many years, the standard treatment for stage III colon cancer has been surgical resection followed by 5-fluorouracil in combination with folinic acid (5-FU/LV). Ongoing clinical trial evidence suggests that capecitabine and oxaliplatin (in combination with 5-FU/LV) may improve disease-free survival and overall survival when compared against 5-FU/LV alone in the adjuvant setting. This study evaluates the cost-effectiveness profiles of these two regimens in comparison to standard chemotherapy, using evidence from two international randomised controlled trials. Survival modelling techniques were employed to extrapolate survival curves from the two trials in order to estimate the long-term benefits of alternative treatment options over the remaining lifetime of patients. The health economic analysis suggests that capecitabine is expected to produce greater health gains at a lower cost than 5-FU/LV. Oxaliplatin in combination with 5-FU/LV is estimated to cost £2,970 per additional QALY gained when compared to 5-FU/LV alone. Future research should attempt to elucidate uncertainties concerning the optimal roles of capecitabine and/or oxaliplatin in the adjuvant setting in order to achieve the maximum level of clinical benefit.

iii) The cost-effectiveness of bevacizumab for the treatment of metastatic colorectal cancer (Tappenden P, Jones R, Paisley S, Carroll C, Eur J Cancer 2007;43(17):2487-2494)

Bevacizumab is a humanised monoclonal antibody, which has demonstrated significant activity in metastatic colorectal cancer. The aim of this study is to estimate the cost-effectiveness of adding bevacizumab to chemotherapy for patients with untreated metastatic colorectal cancer. A decision-analytic model was developed to estimate the lifetime costs and benefits of adding bevacizumab to irinotecan plus FU/LV (IFL) or 5-FU/LV alone. Effectiveness outcomes, health utilities and resource use data were derived from recent bevacizumab RCTs and from the literature. Adding bevacizumab to IFL costs approximately £62,857 per QALY gained. Adding bevacizumab to 5-FU/LV costs approximately £88,436 per QALY gained. The acquisition cost of bevacizumab is a key determinant of its cost-effectiveness. The probability that bevacizumab has a cost-effectiveness ratio that is better than £30,000 per QALY gained is close to zero. Given high acquisition costs in relation to clinical benefits, bevacizumab is unlikely to represent a cost-effective use of NHS resources.

iv) Systematic review of economic evidence for the detection, diagnosis, treatment and follow-up of colorectal cancer in the UK (Tappenden P, Chilcott J, Brennan A, Pilgrim H, IJTAHC 2009, 25: 470-478)

The aim of this study was to examine the availability and consistency of economic evidence for the detection, diagnosis, treatment, and follow-up of colorectal cancer. A systematic review of UK economic evaluations of colorectal cancer interventions was undertaken. Searches were undertaken across ten electronic databases. Studies were critically appraised through reference to a conceptual model of UK colorectal cancer services. Forty-seven studies met the inclusion criteria. There is a substantial economic evidence base surrounding population-level colorectal screening, surgical procedures, and cytotoxic therapies for the adjuvant and palliative treatment of colorectal cancer. There is limited evidence concerning the diagnosis of suspected colorectal cancer, curative treatments for metastatic disease and follow-up regimens for non-metastatic disease. No studies were identified relating to the economics of radiotherapy, surveillance of increased-risk groups, end-of-life care, or the management of hereditary colorectal cancer. Where evidence is available, studies are subject to important differences concerning treatment options, decision criteria, and incongruent assumptions concerning the disease and its management. Across many aspects of the colorectal cancer service, current practice appears to have emerged without the consideration or support of economic evidence. There is a need to develop a common understanding how colorectal cancer models should be structured and implemented.

(B) RECENT EXAMPLES OF METHODOLOGICAL RESEARCH IN CANCER

i) Methodological issues in the economic evaluation of cancer (Tappenden P, Chilcott J, Ward S, Eggington S, Hind D, Hummel S, Eur J Cancer 2006;42(17): 2867-2875)

Cost-effectiveness analysis may be applied to the full range of interventions that make up a cancer service, including screening programmes and early treatments, diagnostic test and referral processes, surgery, radiotherapy, chemotherapy and palliative care. Numerous methodologies have been employed within existing models of cancer interventions. However, not all methodologies are equal; inappropriate modelling approaches may bias cost-effectiveness results. Generic guidelines for good practice in decision-analytic modelling provide a useful basis for critically appraising cost-effectiveness models, yet explicit consideration of a range of cancer-specific issues is required to avoid bias in cost-effectiveness results. These cancer-specific issues include the appropriate representation of relevant costs and health effects associated with unplanned treatments for metastatic disease administered beyond disease progression, the appropriate extrapolation of long-term outcomes and resources from clinical trials, assumptions concerning the nature of the event hazard function beyond the duration of the trial, and relationships between surrogate outcomes and final outcomes.

ii) A methodological framework for developing and using Whole Disease Models (Tappenden P, ISPOR, 2011 [forthcoming])

This paper presents a methodological framework for developing health economic models of whole systems of disease and treatment pathways to inform decisions concerning resource allocation – an approach referred to as "Whole Disease Modelling." Adopting this system-level approach can provide a consistent mathematical infrastructure for the economic evaluation of virtually any intervention across a disease pathway. The framework has been developed in cancer but is broadly generaliseable to other diseases. The framework has been informed by pilot work, a systematic review of economic analyses, a qualitative examination of model development processes, and other literature from the fields of operational research, statistics and health economics. The framework is built upon three principles: (1) the model boundary and breadth should capture all relevant aspects of the disease and its treatment, from preclinical disease through to death; (2) the model should be developed such that the decision node is conceptually transferable across the model; (3) the costs and consequences of service elements should be structurally related. A generalised process for developing Whole Disease Modelling is presented. Whilst this approach involves a non-trivial investment of time and resource, its value may be realised when: (1) multiple options for service change require economic analysis at a single timepoint; (2) a disease service changes rapidly and the Whole Disease Model can be re-used; (3) current services within a pathway have not been subjected to economic analysis; (4) upstream knock-on impacts are expected be important, or; (5) simple cost-utility decision rules fail to reflect the complexity of the decision-makers' objectives.

iii) Using Whole Disease Modelling to inform economic recommendations for the detection, diagnosis, treatment and follow-up of colorectal cancer (Tappenden P, ISPOR, 2011 [forthcoming])

Conventional economic evaluation typically involves piecewise comparisons of competing technologies at a single isolated point in a broader care pathway. This study assesses the value of simulating whole disease and treatment pathways to provide a common economic basis for informing resource allocation decisions across an entire disease service. This "Whole Disease Modelling" approach was applied to the evaluation of technologies for the detection, diagnosis, treatment and follow-up of colorectal cancer. A patient-level simulation model was developed with the intention of informing NICE's colorectal cancer clinical guideline. The model simulates disease and treatment pathways from preclinical disease through to detection, diagnosis, adjuvant treatment, follow-up, treatments for metastases and supportive care. The model was populated using randomised trials, observational studies, health utility studies, costing sources and expert

opinion. Unobservable natural history parameters were calibrated against external data using Bayesian Markov Chain Monte Carlo (MCMC) methods. Economic analysis was undertaken using 1) standard cost-utility decision rules within each topic, and 2) constrained optimisation across all modelled topics. The guideline included fifteen individual economic evaluation topics. Under usual processes, piecewise economic modelling would have been used to evaluate between one and three guideline topics. The Whole Disease Model provided a consistent platform for the economic evaluation of eleven of the fifteen guideline topics, ranging from alternative diagnostic technologies through to cytotoxic treatments for metastatic disease. The constrained optimisation analysis identified a configuration of colorectal services which was expected to maximise QALY gains without exceeding current expenditure levels. This study demonstrates that Whole Disease Modelling is feasible and can allow for the economic analysis of virtually any intervention across a disease service within a consistent conceptual and mathematical infrastructure. The approach may be especially valuable in instances whereby a substantial proportion of a disease service has not previously been subjected to economic evaluation.

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Applying Health Economics in the Policy World

This abstract and presentation are provided from a personal perspective, and do not represent official DH policy.

Presentation will aim to cover three aspects:

1. To sketch out recent and current policy questions in cancer:
    1. Cost of cancer
    2. Earlier Diagnosis
    3. Transforming Inpatient Care
    4. Proton Beam Therapy
    5. Survivorship baseline data
    6. End of Life care
2. Impact Assessment for the Cancer Strategy
3. Future Issues

Recent and Current Policy Questions

Cost of cancer

There is recurring interest in the total cost of cancer, and related questions such as the growth of cancer costs compared to other NHS costs. This is not readily answered from NHS routine data. One potential source is programme budgeting (PB) data, which provides an analysis of expenditure on cancer treatment in PB Chapter 2 (cancer).

However, there are limitations in the use of the PB data: (i) data are not expressed in annual costs per patient, but total costs, or costs per head of population; (ii) Chapter 2 does not include all cancer costs - screening costs and some primary care costs are in other chapters, and (iii) although the PB data have improved over recent years, there is still some concern about the reliability of the data, particularly for sub-national comparisons.

Earlier Diagnosis

A key policy question has been: "What is the likely impact of earlier diagnosis of cancer, in terms of costs and outcomes".

The specific questions addressed by this modelling[14] were:

- How would the costs to the NHS change if certain cancers (see below) were detected and diagnosed appreciably earlier than is currently the norm (ie according to current survival curves)?
- How would the benefits to individuals change if certain cancers (see below) were detected and diagnosed appreciably earlier than is currently the norm?

The work focussed on five cancers: breast, colo-rectal, lung, prostate and skin (melanoma). The modelling sought to examine the impact that earlier detection and diagnosis would have on survival

[14] Modelling carried out by Frontier Economics, and commissioned by DH

curves and on downstream costs and benefits. For example, what would be the impact on treatments costs and overall costs if more patients are diagnosed at stages I and II rather than III and IV. Does earlier diagnosis simply shift costs to earlier stages or does it avoid particular costs entirely?

The key feature of these models was that all inputs, activity and outcomes were modelled by stage of diagnosis.

For these cancers, the modelling found that earlier diagnosis is generally cost-effective, but not cost-saving. If people are diagnosed earlier, either through screening programmes or through their general practice, the main benefit is a substantial improvement in health outcomes. There is not a cost reduction, rather an increase in NHS costs (large increase in testing costs generally offset by a modest reduction in treatment costs). The modelling does not include the costs of the NAEDI interventions themselves, but these are expected to be very modest compared to testing and treatment costs.

Subsequently, these models were peer-reviewed, and some limitations and weaknesses were found. Suggestions have been made as to how the modelling could be improved.

Transforming Inpatient Care (TIC)

The National TIC programme is a joint initiative between NHS Improvement and the Department of Health to share good practice in the hospital treatment and management of patients, including cancer patients. Improvements have focussed on reductions in length of stay to provide inpatient savings and improved quality of care for patients. The programme started in about 2007, and has gone through several phases.

Our tasks have been to compare and contrast length of stay for the test Trusts with the NHS generally, and to estimate potential gains in inpatient savings.

Emergency episodes

All cancer emergency episodes continued to increase over the last five years, for both the 25 Test Trusts and the rest of the NHS, by around 1-6% per year. Average length of stay (ALoS) continued to decline over the same period, by around 3-7%. The net effect was that emergency bed days were fairly flat over 2007/08 to 2009/10. There is a suggestion that bed days might have fallen slightly in 2010/11, but this effect might disappear when we have final figures for the full year.

Non-emergency episodes

All cancer non-emergency episodes also increased over the same period, by around 1-6% per year. ALOS reduced more quickly than for emergencies, typically by around 5-10% per year. The net effect was a continuing reduction in non-emergency bed-days, by around 3-6% per year.

Breast surgery

More detailed analysis was also carried out for breast surgery. The number of procedures for relevant breast surgery has grown slightly over the last five years, from 52,371 in 2006/07 to 54,795 in 2010/11 (provisional). However, the composition by length of stay has changed considerably. Day case procedures have increased from 13,255 to 18,988, an increase of 43%.

The number of procedures for ordinary admissions with a length of stay of zero or one day has increased from 11,457 to 20,387, an increase of 78%; while procedures with a longer length of stay have decreased from 27,659 from 15,420, a fall of 44%. Day cases and short stays combined now

make up 72% of all procedures compared to 47% in 2006/07. ALoS for inpatients has fallen from 3.15 to 2.03 days over the same period, while overall ALoS for all patients, including day cases, has fallen steadily from 2.35 to 1.33 days.

The net effect on bed-days is that total bed-days have fallen from 123,038 to 72,709 over this period, despite the slight increase in the total number of procedures, a reduction of 41%. Most of the reduction has been due to shorter lengths of stay for episodes longer than one day, although the increase of short stays (zero or one day) has also contributed.

Another contributing factor has been the number of procedures where patients have not been admitted the day before an operation. The proportion of patients not admitted the day before (ie pre-Op length of episode is zero) has increased from 69.6% to 94.6%.

These improvements do not appear to have had an adverse impact on readmissions, as these have remained quite constant at 3.1-3.2% of procedures.

For the Cancer Strategy Impact Assessment, we needed to estimate the potential gain in inpatient savings. The basis used was the variation in length of stay for cancer patients. We estimated potential savings if all Trusts were able to meet the performance of the top 25th percentile.

Proton Beam Therapy

The policy question is whether the NHS should make the £150m - £450m investment to replace its one old PBT machine (which can only treat eye tumours) with 1, 2 or 3 larger modern machines.

There is a lack of statistically robust clinical trial data. The benefit is to a relatively small number of cancer patients (for eye, head & neck and spinal tumour sites). The assessment of the benefit has had to rely on a mixture of clinical judgment and simulation modelling.

Survivorship baseline data

The National Cancer Survivorship Initiative (NCSI) is looking at alternative models of post-treatment care for cancer patients, and needed a better understanding of the baseline. We need to know what happens to patients following their treatment – eg how many outpatient appointments, which scans, which staff mix etc. There were two parts of this work:

- A retrospective case note review of just under 600 patients, where nurses gathered structured data by looking through each patient's case notes. This aimed to estimate the cancer centre costs of follow-up over a 5-year period. Case note information was structured as individual 'events'; eg an event might consist of an inpatient admission, or an outpatient visit where a blood test is taken. Data were also gathered on other aspects (eg purpose, outcome), as well as further detail on the patients themselves.
- A survey of more than 1,000 patients in cancer follow-up clinics, based on a prospective audit of patients (adults and children & young people) attending relevant hospital outpatient clinics over an eight-week period. The questionnaire focused on the non-healthcare economic cost of attending follow-up clinics, covering transport costs, lost non-working time, and lost working time.

A summary of high-level results will be presented.

End of Life care

An important and difficult issue for patients receiving end-of-life care is the measurement of benefits, in particular the measurement of quality-of-life and changes in QoL for patients and their carers.

Impact Assessment (IA) for the Cancer Strategy

Improving Outcomes: A Strategy for Cancer (IOSC) was published in January 2011, accompanied by an Impact Assessment (IA). The analysis for the IA focussed on (i) increases in access to radiotherapy, (ii) implementation of existing cancer screening programmes, plus a new programme to implement bowel screening, using flexible sigmoidoscopy as a one-off screening, plus HPV triage; (iii) earlier diagnosis through raised awareness and increased access to diagnostic tests; and (iv) improved information collection.

The analysis required for the IA was challenging, generally due to the patchy evidence regarding benefits and cost-effectiveness.

Future Issues

Policy context

The main policy change is the emphasis now on outcomes, and the development of the three Outcomes Frameworks, particularly the NHS Outcomes Framework (NHS OF).

The first set of indicators in the NHS OF includes 1-year and 5-year survival rates for colorectal, breast and lung cancers. A number of other indicators are also relevant to cancer patients. We have some major analytical challenges in projecting these indicators forward on a counterfactual basis, and then looking at alternative levels of ambition.

Data

As mentioned above, evidence is often patchy. Typical problems include, eg:

- lack of comparators or control groups;
- difficult to link routine datasets, eg HES and registry data;
- not much evidence on benefits, especially Quality of Life changes for cancer patients, including End-of-Life care;
- lack of consensus about appropriate measurement and terminology for benefits, eg QALYs, or life-years saved, or “avoidable deaths”, or “lives saved”.

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(with thanks to analytical colleagues)

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A Pharmaceutical Industry Perspective & Value Based Pricing

1. Introduction

1.1 Important first principles of the Economics of Cancer in the UK

When considering that Economics is concerned with the allocation of scarce resources, the *Economics of Cancer* could be discussed from several different resourcing perspectives; overall government expenditure, the NHS budget, Cancer services expenditure, or even individual treatment strategies. A second fundamental principle of Economics is *opportunity cost;* the fact that any decision to spend finite resource on one activity displaces and removes the opportunity to spend upon another option. Currently Health Technology Appraisal (HTA) organisations, responsible for determining funding and access to new cancer medicines within the UK, such as NICE and the SMC, adopt the perspective of *NHS* resources and place the principle of opportunity cost at the heart of its decision making methods.

Consequently NICE firstly assume that healthcare interventions are displaced to fund new medicines and therefore generate a loss in health benefit. Therefore new cancer medicines in the UK must demonstrate that the health gained from adopting the new medicine exceeds the health lost from the displacement of existing healthcare expenditure. This opportunity cost of these marginal changes in NHS expenditure is represented by the cost effectiveness threshold. This threshold is not specific to cancer expenditure, but of the entire NHS budget. Please see Culyer et al (2007)[15] for a more elaborate description of these concepts.

These fundamental concepts are often misunderstood by many of the key stakeholders involved in the Economics of Cancer, including industry, the NHS and particularly the media. Understanding these concepts are a fundamental requirement in understanding the pragmatic challenges associated with access to cancer medicines in the UK and also identifying and prioritizing future evidence and research requirements.

This brief paper aims to provide a brief outline of the key challenges facing the appraisal of cancer medicines in the UK from an industry perspective. It serves only to highlight the key issues and should be supplemented with wider reading and discussion, as noted in the references, to achieve a more thorough understanding of the issues raised.

1.12 Oncology Medicine Expenditure

Currently cancer medicines account for £1.2bn or approximately 1% of annual NHS expenditure and approximately 12% of the £15.5bn NHS expenditure on drugs[16]. Expenditure on pharmaceuticals as a percentage of the NHS budget is actually reducing, between 1996 and 2008, the total NHS budget has increased twice as rapidly as the medicines bill[17]. Such issues of affordability and budget setting should be an integral part of the economics of cancer debate and not simply restricted to issues of technical efficiency as measured via cost effectiveness ratios.

[15] Culyer AJ, McCabe C, Briggs A, Claxton K, Buxton M, Akehurst R, et al. Searching for a threshold, not setting one: the role of the National Institute for Health and Clinical Excellence. J Health Serv Res Policy2007;12:56
[16] IMS data, 2011.
[17] ABPI, Did You Know? Facts and figures about the pharmaceutical industry in the UK, second edition, 2011. http://www.abpi.org.uk/our-work/library/industry/Pages/default.aspx

When evaluating the complex characteristics and volume of the oncology pharmaceutical pipeline, ensuring that both the appropriate methods of evaluation and evidence generation are in place will be key in ensuring that appropriate prices and patient access is achieved for potential significant advances in the future management of cancer within the UK.

1.13 Patient Access – the influence of HTA methods

Evidence exists that access to new cancer medicines in the UK is markedly lower compared to the rest of Europe and other developed nations[18]. A country's economic methodology for evaluating cancer medicines is clearly an explanatory variable in explaining variations in patient access but is also clearly not the only factor. However several examples exist where the majority of developed nations may grant access to a new cancer medicine after considering its economic characteristics, whilst the UK may not. As illustrated through the advent of the Cancer Drugs Fund, such inequalities in access to cancer medicines from an international perspective is politically unpopular. Therefore how the UK methods for evaluating cancer medicines and ultimate patient access performs relative to other developed nations is an important context to any debate on the role of HTA and cancer medicine access in the UK. How society is willing to trade-off the often conflicting goals of equity and efficiency (Wagstaff, 1991)[19] along with a formal understanding of societal preferences (Dolan, 2009)[20], is an important research area that frames the issue of patient access and HTA.

2. Clinical Development and Economics

2.1 Regulator and Payor requirements – can we keep both happy?

One of the practical challenges faced by those concerned with evaluating the cost effectiveness of cancer medicines within the UK are the differences in the key evidence requirements when comparing regulators and HTA organizations. Where the regulator may focus primarily upon safety, efficacy and tolerability, a HTA organistaion may also evaluate how much *more* effective a medicine is, or make comparisons to alternative treatment options, estimate longer term outcomes and focus on actual health outcomes not clinical or surrogate endpoints[21]. Consequently the clinical evidence base and clinical trial protocol to satisfy a regulator may be very different to that required by the HTA organisation.

Some encouraging steps are being taken by both industry and the relevant public authorities, such as scientific advice services now provided by HTA authorities or even joint advice between the EMA and various HTA groups across Europe are being piloted. However if the necessary evidence requirements remain divergent, for valid reasons, then this challenge of compromise will remain. Therefore more formal processes and strategies focused on how to best minimize the negative consequences of these inevitable compromises must be adopted. Below are some general examples observed within technology appraisals of cancer medicines that are impacted by the sometime divergent requirements of the regulator and HTA organisation.

2.2 Clinical Trial Endpoints

In order to demonstrate that a new cancer medicine is efficacious, very often the endpoint of interest considered acceptable by the EMA is "progression free survival". However the outcome of

[18] Richards M. Extent and causes of international variations in drug usage: a report for the Secretary of State for Health by Professor Sir Mike Richards CBE, 2010 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117962

[19] Wagsraff A, QALYs and the equity-efficiency trade-off, Journal Health Economics, 1991 May;10(1):21-41.

[20] Dolan P, Determining the parameters in social welfare function using stated preference data: an application to health, Applied economics, pp. 1466-4283, 2009

[21] D. Eddy: Can it work, does it work? Is it worth it? BMJ 319 (1999): 652-653

interest to NICE is the Quality Adjusted Life Year (QALY), measuring both the quality and quantity of life experienced by the patient. Neither of these endpoints are consistently measured as primary or often even secondary endpoints within a cancer clinical trial. Therefore the methodological challenges of translating surrogate measures of health within cancer to patient survival and quality of life is a large source of uncertainty affecting the decision making of HTA organisations. These methods are also not always consistent and are still evolving.

Patient reported outcomes, in particular health related quality of life is critical in demonstrating an improvement in generic health for a cancer patient and ultimately in estimating a QALY gain, utilizing instruments such as the Euroqol-5D. This is increased in importance where the benefit of a new cancer medicine is more in its impact upon patient quality of life, possibly through reduced toxicity and treatment related side-effects. Despite this, the evidence of PROs being systematically included in cancer trials is striking. Goznek et al[22] reported that less than 20% of industry sponsored studies included such instruments.

The other dimension here is the consistency of scientific advice and requirements between the FDA and EMA, adding further compromise to an international pivotal registration study in terms of endpoints, comparators and stopping rules.

2.3 Selection of Comparator

When evaluating the value for money of new medicines, the selection of the comparator treatment is critical and often a major point of discussion during NICE appraisals. Selecting the correct comparator can be challenging on 2 distinct levels. Firstly is the comparator of relevance for the specific country in question? It is unrealistic to expect a separate phase III study for each individual country; however the standard of care will undoubtedly vary across countries and regions. Secondly the relevant comparator is a moving target and there is always the risk of "selling yesterday's newspapers" if the treatment paradigm has moved on between agreeing a phase III protocol and the medicine being licensed. If one acknowledges having sub-optimal comparators will always be an inevitable consequence of variations in regulatory, HTA requirements and standard of care differences then developing methods for the indirect clinical comparison of medicines is important. Current acceptance of these methods by HTA groups is growing; however large parts of the clinical community and some academic quarters are still cautious in adopting such methods to inform treatment decisions.

2.4 Time Horizon of Clinical Outcomes

A further critical consideration that impacts the evidence base when evaluating cancer medicines at the time of marketing authorization is the length of follow up available from the clinical trial. As NICE is concerned with evaluating lifetime costs and health benefits, how long we have evidence of such costs and benefits can prove critical as to the certainty a NICE appraisal committee can place on the final estimates of cost effectiveness it is presented with. A specific issue often relating to cancer medicines is the duration of the treatment effect. The clinical trial may report a significant hazard ratio demonstrating a positive treatment effect from a new medicine, only for a defined period. A major compromise on the length of follow-up for the purposes of HTA may actually be the result of a decision by the regulatory authorities, that following a pre-specified interim analysis of a clinical trial, it may considered the endpoint is reached, recruitment is stopped and it may no longer be ethical to randomize patients. Even if longer follow-up and evidence for the treatment effect is produced, often this can be confounded by the existence of patient crossover due to this removal of randomization on ethical grounds.

[22] Gondenk K et al, Current status of patient reported outcomes in industry sponsored trials, Journal of Clinical Oncology, Vol 25, No 32 (November 10), 2007: pp. 5087-5093

2.5 Patient Crossover

Once a clinical trial results are un-blinded and there is evidence to support the efficacy of the new medicine, for ethical reasons it is difficult to continue randomization to the comparator treatment. Consequently the trial no longer becomes a controlled comparison of treatment A versus B, with any future overall survival results being confounded and any positive impact upon overall survival being diluted by the comparator population receiving the intervention medicine. Important new statistical methods are being developed to try and adjust for such crossover[23], further research and validation of such methods within oncology may prove a very practical tool for HTA decision making.

3. Health Economic challenges for Cancer Medicines

3.1 Heterogeneity in Cost Effectiveness

The *non-responding* patient is observed in almost all clinical trials and the ability to accurately predict such patients is constantly evolving and improving through major advancements in targeted therapies and companion diagnostics. However so long as there are variations in outcomes and cost, evaluating cost effectiveness at an average level of a clinical trial population may not always seem appropriate, if better or poorer performing patients can be reliably identified. Often referred to as *sub-group analysis* this often creates an opportunity to permit an endorsement for a cancer medicine by restricting the licensed population, which may not be cost effective on average, to a smaller group of patients who may have performed better within a clinical trial, or had improved cost effectiveness results for biologically plausible reasons e.g. disease staging. For many a counter-intuitive finding when performing economic evaluation within cancer medicines is when a specific population is identified that performs better, however the cost effectiveness ratio may worsen. This can often happen if there is a positive correlation between efficacy and duration of treatment, that is, the improved efficacy comes at the expense of longer time on therapy and increased drug cost.

A more controversial approach is that even when a medicine is cost effective on average within its licensed indication, heterogeneity may exist such that an identifiable patient group may lie above the cost effectiveness threshold, some may argue such patients should not be recommended or funded by the NHS. See Briggs et al 2007[24] for a practical application of such methods.

In general, the ability to adequately stratify and pre-specify such patient groups within clinical trial design based on anticipated prognostic or potential predictive factors can be of major importance for reasons of cost effectiveness and ultimately assisting patient access, if not on grounds of clinical efficacy or regulatory requirements.

3.2 Partnership therapies – can a new effective medicine be provided for free and still not be cost effective?

A specific economic challenge when looking at cancer medicines currently in development is that of combination therapies, where in future multiple biologic therapies may be used together to make new advances in efficacy. An interesting oncology case study is where the existing standard of care is very close or equivalent to the cost effectiveness threshold and considered value for money. A new medicine, for biological and pharmacological reasons may require that it is administered in combination with this existing standard of care. Consequently even with a major increase in patient survival as a result of the new combination therapy, extending the duration of treatment with the current standard of care will simply translate to a cost effectiveness ratio for the new combination equal to the threshold, even if the new treatment to be combined with the standard of care is

[23] Morden J et al, Assessing methods for dealing with treatment switching in randomised clinical trials, BMC Med Res Methodology. 2011; 11: 4.

[24] Briggs A. et al. Cost effectiveness of perindopril in reducing cardiovascular events in patients with stable coronary artery disease using data from the EUROPA study, Heart. 2007 September; 93(9): 1081–1086.

provided for free. Therefore any cost for the new medicine will result in it exceeding the cost effectiveness threshold.

For oncology research based upon developing combination therapies that extent existing standard of care treatment durations, this reality of economic evaluation and its impact upon incentivizing such innovations should be better understood and made more transparent to the relevant stakeholders.

4. Value Based Pricing

Will the proposed VBP system change the methods for evaluating the economics of cancer? In short the government VBP consultation still places the cost per QALY, a threshold and NICE at the heart of evaluating value and consequently an appropriate price[25]. Therefore compared to earlier speculation, the proposed system does not appear a radical re-design but more an evolution. Some important details however are contained within the consultation, namely the concept of a basic threshold and QALY weightings.

4.1 Cancer and QALY weightings

Criticisms of the Quality Adjusted Life Year (QALY) as a measurement of health gain are well documented[26]. To the credit of the government consultation on VBP, it sets out many of these issues and outlines genuine methodological intent to address these in the design of any new system. The consultation outlines several factors, currently not accounted for by the QALY that should in principle be incorporated into the future appraisal of all new medicines. These include the degree of severity and unmet need within the relevant population, plus the opportunity to evaluate the impact of the medicine from a broader societal perspective and account for its degree of innovation.

A significant challenge now lies not in identifying the limitations of the QALY in relation to cancer medicines, but how to implement and agree robust methods for refinements to the QALY, as outlined in the VBP consultation. A major point to note is that weightings may indeed be a "zero sum game", with certain characteristics and medicines not benefiting from such weightings. In such circumstances, the "basic cost effectiveness threshold", as described in the consultation will apply, which in fact could be lower than the existing threshold. Therefore the need for cancer medicines to demonstrate through robust evidence in how they may qualify for these QALY weightings could be a major factor in achieving future patient access in the UK.

4.2 Healthcare data systems

The advent of *patient access schemes* within the UK has highlighted a challenge for both industry and the NHS alike. Many Patient Access Schemes require the ability to track individual patients as they may be based on a payment or rebate for a non-responding patient or that the medicine may be supplied free of charge after a certain time period or number of doses. Such schemes can make perfect sense when the ability to predict non-responding patient may only exist retrospectively or where only a single price can be charged for various indications with varying levels of value.
From an NHS perspective this is administratively burdensome and the IT infrastructure or resource to perform this can vary drastically across trusts and regions. Examples have emerged in Italy for example of an explicit attempt to standardize the collection of clinical evidence at a national level for the specific purpose of supporting the reimbursement and economics of a cancer medicine. Given the large investment in cancer databases, such as ENCORE and SACT in England, the more explicit

[25] A new value-based approach to the pricing of branded medicines a consultation, December 2010. www.dh.gov.uk

[26] Garau, M., Shah, K.K., Mason, A., Wang, Q., Towse, A. and Drummond, M. (2010) Using QALYs in cancer: A review of the methodological limitations. OHE Research Paper 10/01. London: Office of Health Economics

integration of pricing and HTA implementation needs into such databases could provide significant benefits for only minor modifications to their design.

4.3 Pricing of multi-indication medicines

Currently in the UK the value of medicines are evaluated according to discrete indications. This is understandable as the clinical benefit, dosing requirements; comparator and cost profile will vary across these different indications for a single medicine. Cancer represents one of the most prevalent examples of this issue. One significant practical challenge that faces the future implementation of VBP in the UK is that to truly achieve a value based price, if value varies by indication, then one has to find a method to price multi-indication medicines accounting for this variation in cost and benefit. A practical suggestion outlined by Roche in response to the government consultation on VBP relied heavily upon the availability within the NHS of good quality, comprehensive and timely utilisation data. This would allow the NHS to as a minimum identify in which patients a medicine is being utilized and therefore on average, across its various indications what should the appropriate value based price for a medicine be. A method of ex-ante pricing or ex-post rebates could then help guarantee the appropriate value based price is achieved by the NHS, whilst rewarding industry innovation.

4.4 A Global VBP Perspective

How the UK compares to other developed nations in the price it demands of the pharmaceutical industry is an extremely important consideration in the design of any future VBP system. Considering that the EU is a single market with the freedom of movement of goods, the price set for a medicine may not necessarily reflect that demanded within a single country. Consequently if the price demanded by the UK, as a result of its cost effectiveness threshold or VBP judgement is an outlier compared to other major EU countries, then the ability for a pharmaceutical company to effectively price discriminate and satisfy the demands of the NHS faces real limitations. There is evidence to currently suggest that UK prices for medicines are among the lowest in Europe[27].

5. Conclusion

This paper does not aim to provide a detailed analysis of all the issues identified, but a very basic introduction to some of the key challenges observed from an industry perspective based upon over 10 years of engagement with UK HTA organisations in the appraisal of cancer medicines. These issues summarized here would benefit from further detailed discussion and consideration by relevant stakeholders within the health economic and cancer field.

Recommendations

1. Develop high quality evidence to support VBP QALY weightings for cancer medicines
2. Improve the UK/HTA country share of voice and influence in regulatory clinical trial design
3. Ensure a more formal integration of new UK cancer data systems with the needs of Value Based Pricing
4. Routine Health Economics representation and consultation in post registration trial design.
5. Research into evidence of NHS displacement and dis-investment policies to fund new cancer medicines.
6. Understand longer term impacts on access to medicines if variations in the willingness to pay for new medicines exists across the EU single market

[27] ABPI, Did You Know? Facts and figures about the pharmaceutical industry in the UK, second edition, 2011. http://www.abpi.org.uk/our-work/library/industry/Pages/default.aspx

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Health Economics in NICE Clinical Guidelines

NICE clinical guidelines provide advice on appropriate diagnosis and care for people with specific diseases and conditions in the NHS in England and Wales[1]. As of September 2011, 129 guidelines had been published covering a diverse range of patient groups and conditions and 52 guidelines were in development. Although compliance with NICE guidelines is not compulsory, they set standards for NHS organisations and professionals, and have a major impact on patient care.

Guidelines are developed for NICE by four National Collaborating Centres (NCCs) and an in-house 'short guidelines' team. As with technology appraisals and public health guidance, groups developing NICE guidelines are expected to take account of cost effectiveness. Instead of a standing committee, a new guideline developing group (GDG) is set up for each guideline, comprising of health professionals and patient/carer representatives with particular interest and expertise in that specific disease area.

Since 2006 the London School of Hygiene and Tropical Medicine have provided health economics support the National Collaborating Centre for Cancer. The special role of the guideline economist is to provide evidence on cost-effectiveness and advice on how this should be interpreted. However this is often difficult because of the size and complexity of NICE guidelines, which may cover up to 30 questions along a 'pathway' of care. Despite recent efforts aim to produce more focussed guidelines, NICE guidelines remain large and complex pieces of work.

The first methods guide for developing NICE clinical guidelines discusses "incorporating health economics into guidelines"[2], despite the fact that cost-effectiveness was supposed to be given an equal weighting in decision making, alongside clinical effectiveness. At that time, guideline economists had to juggle the demands of multiple guidelines and economic modelling was not always carried out. Although the economic content of guidelines has increased and the quality of economic modelling improved, guideline economists still have to decide which topics within the guideline will benefit most from their attention. Not every clinical question can be evaluated, so instead a selective approach is taken; relying on published economic evidence when this is of sufficient quality and relevance, conducting new analyses for questions which are anticipated to have the greatest economic impact on the NHS and encouraging the GDG to use judgement about the broad balance of benefits, harms and costs for the remaining issues[1]. This approach is pragmatic, and may be good enough, ensuring that the really important economic issues are identified and addressed.

The topics covered by clinical guidelines are diverse, with each posing different challenges. We have experienced logistical problems fitting the economics work into the guideline development process, methodological issues and challenges of how best to engage the process of model development and in presenting results.

Cancer guidelines are often thought of as more uniform than guidelines in other disease areas, typically including aspects of initial assessment, referral and diagnosis, curative treatment and follow-up, as well as treatment for supportive and palliative care. However the guidelines we have worked on have not been homogenous. Some guidelines were characterised by a wealth of evidence that required careful decisions about evidence synthesis [3,4]. Others were almost completely

'evidence-free zones' such as cancer of unknown primary and metastatic spinal cord compression [5,6]. In these situations, where in fact economic modelling can have the greatest impact on decision making, we used formal elicitation methods to populate an economic model with estimates from members of the guideline development group and carried out a value of information analysis to inform future research recommendations.

Several guidelines required de novo models to be developed to address diagnostic questions. Of course, upstream decisions such as which diagnostic tests to use at the beginning of the pathway are dependent on the cost-effectiveness of downstream treatments. Clinical review questions often pose questions with a focus on intermediate outcomes[7,8,9]. A model for the staging of patients with early breast cancer had to be re-evaluated using outcomes such as the cost per patient avoiding a secondary staging procedure as this was what members of the GDG felt was the most relevant outcome measure, yet a secondary analysis was also needed to allow a decision to be taken using NICE's cost per QALY threshold[9]. Diagnostic models also tend to have wider boundaries, which can be difficult when these extend beyond the scope of the guideline.

Guideline updates now account for almost 80% of NICE's clinical guideline programme. Outwardly, updating guidelines may appear easier since a diagnosis and treatment pathway from the old guideline serves as a good platform to start the economic work sooner. However these can raise tensions between revisiting an old decision and the new decision within a guideline context.

Despite the numerous challenges, NICE clinical guidelines provide a great opportunity for undertaking relevant economic analyses, which has yet to be fully exploited. Guidelines are tasked with trying to make sense of a complex clinical reality and demand economic models assess a multitude of different, relevant comparators in any analysis. In addition the guideline development group is made up of committed clinicians each with a different perspective on care for patients with a given disease, who can be invaluable when developing an economic model.

1. National Institute for Health and Clinical Excellence (2009) The guidelines manual. NICE, London. http://www.nice.org.uk/aboutnice/howwework/developingniceclinicalguidelines/clinicalguidelinedevelopmentmethods/GuidelinesManual2009
2. National Institute for Health and Clinical Excellence (2007) The guidelines manual. NICE, London.
3. National Institute for Health and Clinical Excellence (2009) Advanced breast cancer: diagnosis and treatment. NICE, London. http://www.nice.org.uk/cg81
4. National Institute for Health and Clinical Excellence (due November 2011) Colorectal cancer: diagnosis and treatment. http://guidance.nice.org.uk/CG/Wave16/2
5. National Institute for Health and Clinical Excellence (2010) Metastatic malignant disease of unknown primary origin. NICE, London. http://www.nice.org.uk/cg104
6. National Institute for Health and Clinical Excellence (2008) Metastatic Spinal Cord Compression: diagnosis and treatment. NICE, London. http://www.nice.org.uk/cg75
7. National Institute for Health and Clinical Excellence (2011) Ovarian cancer: diagnosis and treatment. NICE, London. http://www.nice.org.uk/cg122
8. National Institute for Health and Clinical Excellence (2011) Lung cancer: diagnosis and treatment. NICE, London. http://www.nice.org.uk/cg5121
9. National Institute for Health and Clinical Excellence (2009) Early and locally advanced breast cancer: diagnosis and treatment. NICE, London. http://www.nice.org.uk/cg80

The Economics of Cancer
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NHS

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