

“Getting to grips  
with the financial  
consequences of  
cancer...”

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## PAYING THE PRICE

Max Wind-Cowie  
Jo Salter



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All errors and omissions remain solely our own.

Max Wind-Cowie  
Jo Salter  
November 2013



# Executive summary

A cancer diagnosis can cost an individual an average of £570 a month. This places a huge financial burden on patients and their families. It is a growing issue that needs to be addressed.

This report builds on prior research undertaken by the University of Bristol and Macmillan Cancer Support – as well as extensive expert and stakeholder engagement – in order to lay out, and begin to address, the financial impact of cancer on individuals and families.

Our recommendations are not focused primarily on government investment. NHS and central government spending are important to resolving the financial pressures that a cancer diagnosis can create and exacerbate – but there is an important role for civil society, employers and financial services providers too. We have been led by the experts in devising specific interventions that would help to address and reduce the costs of cancer. But alongside these specific recommendations must be a better awareness, across stakeholders, that as more of us are diagnosed, treated and cured of cancer we need to understand and address the social and economic impact of cancer – not just the healthcare impacts.

## Recommendations

These are our recommendations to UK-wide and national governments, the NHS, the charity and voluntary sectors, and financial services.

The recommendations cover the whole of the UK – and so recommendations relating to health services will be the responsibility of the relevant devolved administration. References to ‘the NHS’ throughout the report refer to all four healthcare systems

in the UK (including NHS Scotland, NHS Wales and Health and Social Care in Northern Ireland).

## Government

- 1 The Department of Health (DH) in England – as well as the relevant agencies governing health in the devolved nations – in partnership with other government departments – should either update their existing national cancer strategies, or develop a complementary ‘social strategy for cancer’, which takes into account the wider social and financial implications of cancer, during illness and treatment, and following recovery.
- 2 Requests for *flexible working* from people experiencing a period of illness that is temporarily preventing them from working should be granted the same legal status as requests from parents and carers. Currently, anyone can apply to work flexibly, but only parents and carers have the *legal right* to request to do so. Demos has in the past called for flexible working to be extended to all employees, making the right to request universal.<sup>1</sup> For people with long-term conditions, this may require some adaptations to the request process, which can currently take up to 6 weeks. Local and national government could set the agenda, including leading by example, setting the benchmark for good, ‘cancer-friendly’ employers.
- 3 Introduce a system of *part-time sick leave*, similar to the model used in Finland since 2007. Regular conversations between employer and employee about working patterns could also be used as an opportunity to discuss any financial issues.
- 4 The UK Government should ensure that people who are off work because of a cancer diagnosis are eligible to apply for assistance from the new Health and Work Assessment and Advisory Service (HWAAS). The HWAAS should also routinely direct people to sources of financial advice and guidance.
- 5 The DH and Department for Work and Pensions (DWP) should *set up a joint working group on employment and health*, looking at opportunities for ‘shared saving’ between the two departments by improving employment outcomes for people with long-

term and chronic conditions. Opportunities for joint working, such as a single access point for both systems, should also be explored.

### The NHS

- 1 A financial health check should form part of the follow-up care after a diagnosis has been received (for any serious illness, not just cancer). The Welsh Government's 2012 Cancer Delivery Plan specifies that everyone diagnosed with cancer should be routinely referred to financial advice services – this should be replicated in other UK countries.
- 2 Free patient transport and local taxi services could be extended to meet the needs of a wider group of patients than are currently served by it, including those receiving treatment for short-term or episodic conditions such as cancer. These are currently generally only available to people who are on a low income or those with physical disabilities that make it difficult for them to use public transport (eg Dial-a-Ride services, the Taxicard scheme within London).
- 3 *Make chemotherapy and radiotherapy available in local treatment centres*, reducing the need for people to travel long distances to hospital. While this will not be suitable for all patients – and we should maintain awareness of the diverse needs of people undergoing treatment – national chemotherapy commissioners should attempt to treat patients locally wherever possible in order to mitigate transport costs for patients.
- 4 The NHS needs to do more to *promote and apply concessions and financial support schemes*, such as the Low Income Scheme in Wales, Scotland and England.
- 5 Continue and develop the National Cancer Information Prescriptions Programme – paid for in part by a contribution from financial services providers – in order to ensure that financial guidance is provided at natural contact points for patients.
- 6 There are more ways in which the *NHS can work creatively in partnership* with other organisations to tackle costs (eg linking up

with local car shares), and barriers to doing this need to be addressed. Health and wellbeing boards could act as facilitators in this process.

- 7 The NHS Mandate – which is currently out for consultation – should *renew its focus on increasing employment as a core role for the NHS in England*, including setting an outcomes indicator against which this can be measured.

### Civil society

- 1 Charities and voluntary services providing information and guidance on financial health should be *colocated, wherever possible*, with existing healthcare providers in order to make accessing advice easier for patients.
- 2 Financial information and literacy charities should push hard to be *included on local health and wellbeing boards*, given the important links that exist between financial health and public health.

### Financial services

- 1 *There should be better training for frontline staff in banks* to improve referral rates to specialist teams, encourage earlier intervention and deliver better customer experience and outcomes to people with cancer and other long-term conditions. The Financial Conduct Authority (FCA) should ensure that firms are providing appropriate levels of support to their customers with long-term conditions, including cancer. This training does not need to be cancer-specific, though special attention should be paid to cancer, given its prevalence.
- 2 Introduce better systems for people to *temporarily delegate payments* during illness or treatment. This would enable people living with cancer to take a step back from managing their finances – temporarily – while undergoing treatment and would reduce the overall stress of dealing with the impact of cancer.

- 3 Invest in advice around the risk of financial shock caused by short-term, temporary illness such as cancer. *Income protection and pension providers* should explain clearly to employees what their risk of income loss due to cancer is and what they can do to protect themselves and their families.
- 4 The Government should work with the insurance industry in order to develop a kitemarking scheme of minimum standards in the income protection industry, similar to the minimum standards that were introduced by the Pensions Act in 2008 for workplace pensions. Such a scheme would take place in partnership with the Treasury's Simplified Products Review and would set a standard model for income protection. In return for compliance, income protection could then be incorporated as an optional opt-in to the new National Employment Savings Trust (NEST) workplace pension scheme<sup>2</sup> – in order to boost the proportion of the workforce who are protected against the financial risk of ill-health and to maintain standards across the income protection sector.

Together, these interventions if implemented would constitute a concerted strategy to tackle the financial costs of cancer and help improve our systemic and individual preparedness for the risk of a diagnosis. The British workforce is living longer, but there is also an increase in cancer's prevalence and survival rates. That is all good news. The time has come to update our understanding, culture and systems so the modern reality of cancer is recognised and managed by our welfare, healthcare and private sector providers.



# Introduction

We are used to viewing cancer as a healthcare issue. Of course, this is the primary lens through which individuals and families – faced with a diagnosis – regard cancer. But for public policy makers and those tasked with organising public services and enacting regulation of private sector provision there are other, important and growing, concerns. The socio-economic impact of cancer is only just beginning to be fully understood. And, as diagnosis and treatment have improved (and continue to improve) these factors will become more and more important to individuals, families and society as a whole.

Research from Macmillan demonstrates that by 2030 4 million people will be living with or beyond cancer. That represents a doubling in the number of survivors in less than 20 years. This is obviously a cause for huge celebration – and is the result of breathtaking advances in diagnosis and treatment – but it also presents significant challenges for individuals who are surviving cancer and for policy makers.

One of these challenges is the extra financial burden faced by people affected by cancer – both during and after treatment and recovery. Research commissioned by Macmillan from the University of Bristol's Personal Finance Research Centre and the research agency TNS BMRB quantified the additional financial strains (through increased expenditure on things like travel, and loss of income from having to give up work or reduce hours) that are being placed on people with cancer. Their research revealed that following a cancer diagnosis, people are facing a financial shortfall of thousands of pounds in extreme cases, with an average loss of £570 a month.<sup>3</sup>

The sudden financial shock of a cancer diagnosis can be devastating for patients and their families – with repercussions that last well beyond when a patient receives the all-clear. This

obviously creates huge challenges and stress during the period in which a cancer patient is accessing treatment. But it also creates a hole in people's finances – one which can outlive the cancer itself and present a substantial gap in the long-term financial health of families and individuals. Furthermore, there is evidence that many areas of our lives – in particular insurance, banking and welfare services – have not caught up with the modern reality of cancer as a survivable rather than a terminal illness. The notion of cancer as a terminal condition persists, despite the medical advances mentioned above, so many services are not geared towards addressing the challenges common to cancer patients, and many former cancer patients continue to suffer financial penalties long after finishing treatment.

What is more, we need to see cancer patients as people going through periods of extreme distress and turmoil, who require our support in order to ensure that they recover emotionally as well as physically. The financial exclusion and sense of powerlessness that can accompany a diagnosis often contribute to the stress of treatment and to individuals' inability to cope financially. Referring to cancer patients as 'vulnerable customers' as some financial services – with good intentions – do is one example of institutions reinforcing the notion that a diagnosis undermines capacity. It does not have to and, wherever possible, solutions to financial problems faced by cancer patients should focus on empowering these patients to retain control over their lives.

This report explores some of the challenges facing cancer patients and survivors – the factors that contribute to 'cancer's hidden price-tag' – and looks at some potential solutions. It does not lambast the Government and demand fresh resources. In this period of austerity such fresh commitments are unlikely to be made and, as cancer rates and survivorship increase, related costs are likely to increase substantially over time. Rather, this report aims to make proposals around how public and private sectors might adapt to the new reality of cancer as an increasingly prevalent, but often treatable and increasingly survivable, illness. This reality is placing cancer on the radar of a far more wide-ranging group of players with whom people have a financial

relationship – including banks, insurers, employers, energy companies, housing providers and landlords. It will require a concerted effort from all of these and more to make a difference to the financial wellbeing of all people who are affected by cancer.

The report is based on extensive desk-based research – including a review of the academic evidence of the costs and drivers of costs of cancer – and on extensive engagement with stakeholders via a series of expert roundtables. Demos and Macmillan convened three expert roundtables in order to learn from frontline expertise about what best practice looks like and what might be done systemically to reduce the socio-economic impact of cancer. These were themed by sector, bringing together the financial services industry, representatives of patients and survivors, and leaders from the NHS and private healthcare providers. Together we have reviewed the evidence of impact and explored what measures might be pragmatic and purposeful in tackling the cost of cancer to individuals and society.



# 1 What are the costs of cancer?

In February 2012, the University of Bristol's Personal Finance Research Centre published new research, commissioned by Macmillan, quantifying the average financial burden faced by people with cancer, through loss of income and increased expenditure.<sup>4</sup>

The top-line finding from this research was that 83 per cent (four out of five) of people with cancer had incurred a financial burden, at an average financial loss of £570 a month. The biggest single loss in monetary terms came from lost earnings (for 30 per cent of people surveyed, at an average loss of £860 per month), while the most common additional cost incurred came from extra travel costs to and from outpatient appointments (71 per cent of those surveyed, at an average cost of £143 per month). Other sources of financial strain included additional day-to-day living costs (54 per cent of those surveyed), especially fuel costs and paying for help around the home and garden. These costs in turn have a direct impact on people's financial situation and wider sense of wellbeing and quality of life, with those with cancer disproportionately more likely than the population as a whole to have gone without essential items, such as heating their home adequately (28 per cent of those surveyed, compared with 11 per cent in the population as a whole) or replacing a major electrical item.

## **Case study 1: Laura<sup>5</sup> - the cumulative costs of cancer**

*Laura is single and in her early 30s. She was working when she was diagnosed with breast cancer in July 2011, however, her employer did not offer sick pay – she claimed statutory sick pay but at £320 per month, this was a £580 per month drop in income. Without her mother helping with her rent and a*

*Macmillan grant to help her cover her heating bills, Laura could not have managed.*

*On top of her reduced income, Laura found her living costs increased:*

- *Her electricity bill increased by £100 for the quarter when she was having chemo, as the treatment made her feel the cold.*
- *She spent an additional £400 on clothes and bras as the steroids and her inability to exercise caused her to gain weight. She also needed bras and swimsuits suitable for a prosthesis.*
- *She needed two wigs, and although she received a £100 voucher from the NHS, she still needed an additional £200 to cover the cost.*
- *Parking at Laura's local hospital cost £1.20 for each visit – a reduced rate, but the costs added up as she visited at least 40 times.*

*Unsurprisingly, Laura found herself in debt as she was using her credit card to meet her basic needs like food and petrol. She had already been in debt before she was diagnosed, but her debt more than doubled once she was unable to work. She paid £100 interest each month, causing her significant stress.*

*As a result of these financial pressures, Laura went back to work before she was ready; her health deteriorated and she had to stop working again. She is now planning to go back to work part-time, as she realises that she cannot manage full time, and has applied for benefits. She is due to have a breast reconstruction, but does not feel that she will be able to afford to take 2 months off work for this.*

*Our estimate is that her diagnosis has cost Laura £11,040 in lost income and increased living costs between July 2012 and May 2013. Laura explained:*

*I was diagnosed with breast cancer and treatment has been around 18 months due mainly to needing longer to recover from the surgeries. For me the length of treatment has been a big issue, due to being off work but also the disruption to my life and*

*putting any kind of career on hold. I have watched my friends around me buy their first house, get promoted, have children, go travelling, etc, whilst I have been stuck living [on] my overdraft feeling unable to do anything!*

### Key findings from the report *Cancer's Hidden Price Tag*

There are several key findings from *Cancer's Hidden Price Tag* that pose particular problems for policymakers. First, the financial burden of cancer is not evenly spread. The additional financial burden of cancer was less than £13 a month for one-quarter of people, with 17 per cent incurring no extra costs at all, and some even gaining financially. Yet, for another 25 per cent, the costs incurred were more than £489 a month, and the monthly financial impact (combined income loss and extra spending) of cancer for some individuals ran into the thousands. People who experienced a particularly high overall financial impact tended to be:

- those diagnosed with certain types of cancer (eg lymphoma, leukaemia, and testicular and brain cancers are particularly 'expensive')
- parents with dependent children (the overall financial burden was higher for single parents who incurred higher additional costs, though two-parent families had higher income loss)
- homeowners with mortgages
- those in work at the time they were diagnosed
- those on very low household incomes (of less than £100 a week) at the time of the survey (perhaps because they suffered substantial income loss between the time of diagnosis and the time of survey)<sup>6</sup>
- those in their 40s and 50s (pre-retirement age)
- those diagnosed recently (within the last 6 months)

These findings point to several key areas where financial interventions could be targeted:

- providing childcare support or free crèches in hospitals (which would particularly benefit single parents)
- increasing uptake of income protection among people in work and ensuring that income protection policies are appropriate for people with cancer
- making it easier for people with cancer to rearrange mortgage payments with their bank or building society
- extending compassionate leave for partners and carers of people who are ill or undergoing treatment
- providing specialist help for people with cancer to return to work when they are ready to do so, to improve their financial situation in the longer term, and alleviate their immediate financial worries

One challenge facing policymakers that was revealed by the Bristol research is the low use of specialist financial products as a way of coping with the extra costs incurred. However, 72 per cent of people surveyed had turned to one or more sources of funding to help pay their additional costs or cope with loss of income, most commonly through savings (39 per cent) and income (38 per cent) – with most coming from pensions or benefits rather than earnings – followed by commercial credit (21 per cent) and informal loans or gifts from family or friends (18 per cent). One in ten people said that they had sold possessions to help pay extra costs.

In contrast, it was extremely unusual for people to have drawn on any type of insurance policy (health insurance, income or payment protection insurance). Only 1 in 12 people had sought advice from a bank, building society or other financial services provider, and people were more likely to be unhappy with advice received from banks than that from any other source.

The most recent cancer patient experience survey for England<sup>7</sup> (2013) found substantial levels of unmet need for information and advice among people with cancer – almost half of patients (46 per cent) who would have liked information about accessing financial assistance or welfare on diagnosis did not receive any.<sup>8</sup>

People interviewed by the Bristol research team reported an element of chance involved in coming across information about

financial support – often it came from friends or other informal contacts, such as fellow patients, despite evidence that targeted intervention at the earliest possible opportunity can have the biggest impact on an individual’s financial outcomes.<sup>9</sup> Interviewees wanted to be able to access all of the help and information they required from one source (such as a leaflet or website). The idea of a financial health check soon after diagnosis also appealed to many people.

In the absence of financial assistance and advice, interviewees highlighted two key factors that currently help to mitigate the total financial impact of cancer – having an understanding employer and support from their family.

### Implications of these findings

The Bristol research throws up several dilemmas that will influence the type of response needed to tackle the extra costs that people with cancer are currently facing. What is the desired level of universality for financial support? Which organisations are best placed to provide this support: public or private sector organisations, or charities? And how do we ensure that support is marshalled effectively, rather than tackling different aspects of the problem?

### No single initiative will help all people who are financially affected by cancer

People are affected differently by cancer whether they are on high or low incomes, whether they are in work or out of work, whether they have children or not, and whether they rent or own their homes (either outright or with a mortgage). This makes it very difficult for a single policy to capture all people affected by cancer, and suggests that support either needs to be individually tailored or multi-pronged – reaching different groups of people through different channels. But each of these approaches has its own problems.

This presents some moral dilemmas. For example, the Bristol research showed that one of the most substantial costs

that people faced was travel to and from hospital appointments. The NHS Low Income Scheme reimburses travel costs in England, Wales and Scotland, but only to people on a low income or in receipt of certain benefits (such as Pensions Credit).<sup>10</sup> Although not all forms of financial assistance are means-tested in this way, in an era of straitened public funds, means-testing is likely to become more rather than less common, and there is a valid argument that financial support for people with cancer – like other financial resources – should be targeted at the most vulnerable. The people interviewed by the Bristol researchers felt that it was unfair to limit some forms of assistance (such as grants) to people on lower incomes, as people with higher incomes were incurring exactly the same costs, and should be equally entitled to help.

People whose income or savings disqualify them from such means-tested financial assistance can best be helped in different ways, such as by increasing awareness and uptake of financial products like income protection and critical illness cover. A possible downside of differentiating by income is the risk of developing a multi-tier system of financial support – with higher earners being encouraged to opt out of the welfare system, and to rely on the private sector for insurance against illness or disability, and those on lower incomes resorting to the benefits system, in the absence of private support through employers, for example. This is a tricky political issue – a blend of private and state support is probably desirable across the income spectrum.

Income is not the only factor that determines which types of support are available to different groups of people with cancer. Whether somebody is working or not when they are diagnosed – and the nature of their employment and employer – affects the channels through which people can be reached most effectively. In the Bristol survey sample, one-third of people were of working age (18–64 years old), while two-thirds were retired – likely to be a representative proportion of the age profile of those diagnosed with cancer. It is clear that employers – like means-tested state benefits – are only one of a number of parties that can help those financially affected by cancer.

This points to the need for a multi-sector response, spanning the public and private sectors, as well as dedicated charities such as Macmillan. Given the nature of cancer – an illness that cuts across the boundaries of age, income and social status – the benefits system will not be the only source of financial support for all people, and there is a need to recognise that other systems and services will be involved.

### There is a risk of a fragmented response

Because of the varied experience of financial loss among people with cancer, and the multiple agencies likely to be involved in addressing this, there is a risk of developing a fragmented response that tackles different aspects of the problem separately, rather than in a coordinated and joined-up way. We need to consider whether this is the best way to allocate resources, or whether some form of overarching structure or framework is necessary to unite the different activities.

There may be a case for strengthening the role of the junior health minister for public health (since the October 2013 reshuffle, this is Jane Ellison MP) to raise the profile of cancer within the ministerial portfolio. The DH published its strategy for cancer in 2011, but focused primarily on medical treatment for cancer, rather than social issues. An updated strategy, or a complementary social strategy for cancer, may be needed to address the ways that cancer impacts on a person's life beyond just their physical health. The Government has promised an integrated health and social care system by 2018, and the process of achieving this over the next five years may provide an opportunity to revisit the 2011 strategy to join up health and social care outcomes on the way to a fully integrated system.

### Many of the financial impacts are not specific to cancer

Some of the financial impacts on people with cancer are common to those with other health conditions and disabilities (eg travel costs to and from hospital, higher energy bills, specialist diets), so should we be calling for dedicated assistance and exemptions

for cancer patients, or for a more universal offer? One reason to offer help specifically for cancer is simply that it is by far the most prevalent long-term illness that people are likely to encounter during their lives – one in two of us are set to be diagnosed with the disease by 2020. A policy aimed specifically at the costs associated with cancer would thus help a significant proportion of the population. However, it is unlikely that commissioners, for example, would be interested in funding a service exclusively for cancer patients when a larger group of patients could benefit from it equally. These were some of the dilemmas that we put to the roundtable attendees – and their thoughts are presented in chapter 3.

## 2 The policy landscape

There is a range of support for cancer patients from public and private sector services, much of which is being reformed by the Coalition Government. A brief outline of the policy context in which cancer patients currently access services is laid out below.

### Welfare reform

The Coalition Government is committed to a root and branch reform of the welfare system, with no benefit or tax credit left untouched – in many cases resulting in benefits becoming less generous in real terms. The chancellor has outlined plans to reduce the benefits bill further – in the 2013 spending review, it was announced that the DWP would have to find savings of a further 9.5 per cent, including through implementing a cap on overall benefits entitlement, which came into force in October 2013.

The most important change for people with cancer is the time limit placed on claims for Employment and Support Allowance (ESA), which provides financial support to people who are unable to work because of illness or injury. Under the Welfare Reform Act, ESA claimants in the work-related activity group (WRAG) – who have been assessed as being capable of returning to work in the future – are only entitled to support for 12 months, after which point the benefit becomes means-tested.

Macmillan (among others) campaigned to change the process for claiming ESA for people with cancer, and last year won a victory, when the Government announced that people who are ‘awaiting, receiving or recovering from’ chemotherapy or radiotherapy will automatically be placed in the support group for people who are not currently able to work or undertake training or other work-related activity, with no time limit for financial support.<sup>11</sup>

The process of claiming ESA will also be simplified for people with cancer, allowing them to submit a report from their GP in support of their claim, rather than having to undergo a face-to-face assessment to determine their fitness to work. This ‘lighter touch’ process will, in theory, make it easier for people with cancer to claim the benefits support they are entitled to, without the stress of a back-to-work assessment, and the prospect of sanctions.

At the same time, the Government is gradually replacing the Disability Living Allowance (DLA) with a new Personal Independence Payment (PIP). The purpose of both benefits is to offset the extra cost of living with a long-term health condition or disability, but the qualifying rules and assessment criteria for PIP are stricter. For example, to qualify for PIP, an individual must have needed help for at least 3 months, and be likely to need it for the next 9 months – a particular problem for people with forms of cancer whose treatment regime is shorter than 12 months. Rather than being assessed on the needs arising from their condition, applicants are required to undergo an assessment of their ability to carry out day-to-day tasks, such as washing, dressing, cooking and budgeting, independently.<sup>12</sup> Government figures show that around 500,000 fewer people will be receiving PIP in 2015/16 compared with the number who would have been receiving DLA.<sup>13</sup> All in all, this raises the bar for accessing PIP, and leaves more people at risk of not being eligible. PIP is also less generous for those who are eligible to receive it – with the lower-rate care component of DLA (for people who needed some assistance around the house, eg preparing meals, housework) completely removed.

A raft of other welfare changes is squeezing the incomes of people with cancer who are receiving state benefits:

- The spare room subsidy – the ‘bedroom tax’ – docks the amount of housing benefit paid to people living in socially rented accommodation, if they are deemed to have more bedrooms than they need. This penalises people with cancer who may require a separate bedroom for their partner to sleep in, for example, or for a non-resident carer to stay overnight when necessary – or

people who are simply too ill to be able to move to a smaller property.

- In March 2013 the Government passed legislation to cap the up-rating of most benefits and tax credits at 1 per cent a year, so benefits rises will not keep pace with inflation, making it more difficult for people to stretch their benefits to cover the rising cost of living.
- Cuts to legal aid ensure that it will no longer help pay for appeals against welfare decisions or debt problems. The remaining pot is also now means-tested, restricting eligibility still further.
- The combination of multiple changes to the benefits system has resulted in increased demand for advice services, but the funds of many advice and legal aid charities have been cut, so they have to meet this demand with fewer resources. This leaves people with cancer with fewer places to turn to for advice and help in managing their financial situation.

Interviews carried out for the Bristol research showed that many people with cancer found the benefits system confusing and difficult to navigate – and they resented the conditionality attached to claims, particularly means-testing, feeling that this kind of financial support should be available to everyone.

### Return-to-work support

The reforms above paint a picture of a welfare system that is becoming increasingly less generous. At the same time, the Government has ramped up the penalty regimes and conditionality associated with out-of-work benefits. These are deliberate attempts to make life on benefits less attractive, and encourage more people to return to work.

The government-sponsored Work Programme is designed to assist people to do this – but has so far underperformed at helping people who are out of work because of illness or disability. Only 5 per cent of ESA claimants – 1 in 20 people – have been helped to find lasting employment since the scheme was launched, falling short of the original 16.5 per cent minimum

target for this group.<sup>14</sup> This presents a challenge for people with cancer getting the right support to get them back to work.

The Work Programme is aimed at the long-term unemployed, and so only captures people who were out of work before their diagnosis, and have slipped further from the labour market as a result of it. Employers play a key role in helping those in work when diagnosed with cancer to return to work after an episode of cancer, if they are able to. The Bristol interviews highlighted that having a sympathetic employer was one of two key factors that helped mitigate the cost of their treatment and illness. Conversely, divergence between employer and employee, during and after treatment, acts as a barrier to continuing in or returning to work, for people with cancer.<sup>15</sup>

Yet, support to help people with cancer return to or remain in work, including specialist vocational rehabilitation, remains poor. Macmillan research findings show that specialist return to work services are accessed by less than 2 per cent of people with cancer and over three-quarters do not access any kind of support to do with employment or work.<sup>16</sup> Although an effective model for work-related support and rehabilitation has been developed (such as the three-tier model of the National Cancer Survivorship Initiative<sup>17</sup>), which has proven to be effective in improving work and health outcomes, and cost-effective, little progress has been made to improve vocational rehabilitation since the 2008 review commissioned by DWP,<sup>18</sup> particularly for people with longer term health conditions.

Research by Oxford Economics for Maggie's and Unum calculated that 63,000 people currently living with cancer want to work but are prevented from doing so because they lack support.<sup>19</sup> This figure shows that there is significant demand for support to return to work. People who are affected by cancer stress the importance of work in providing a sense of normality, purpose and self-esteem – as well as financial security.<sup>20</sup>

There is also an economic case for assisting more people with cancer to return to work. Policy Exchange estimated that in 2010 some £5.3 billion in productivity was lost through people who had survived cancer not returning to work.<sup>21</sup>

In November 2012, the first mandate between the Government and the NHS Commissioning Board (now NHS England) was published. The Government highlighted, as a priority area, that it expected to see progress made in supporting people with health conditions to remain in or find work. In addition, there is an indicator on the employment of people with long-term conditions in the NHS Outcomes Framework, although not in any other key accountability framework (such as the Clinical Commissioning Group Outcomes Indicator Set), and there are still few incentives in the NHS that act to promote work as a positive health outcome.

Part of the problem is that in all UK nations, health and work policy is the responsibility of separate government departments, which tends to prevent more integrated policies on employment support for people with long-term health conditions. More joint working and joint ownership of this issue would help improve outcomes.<sup>22</sup>

One important step towards this kind of joint ownership was the announcement in January 2013 that the UK Government would introduce an independent health and work assessment and advisory service in 2014, based on the recommendations of the Black and Frost review of sickness absence, and building on the Fit for Work service pilots that ran between 2009 and 2013.<sup>23</sup> People will be referred to the scheme after they have been on sick leave for 4 weeks, unless they are already close to returning to work, or have an acute medical condition for which they are receiving treatment. The service aims to integrate back-to-work support into the recovery process, and ensure that employment is viewed as a key health outcome.

However, some concerns have been expressed that the new service will not suit the specific needs of cancer patients, and many of the details about how it will operate are still unclear. The Work Foundation has emphasised that the service must be accessible to people with ‘a long-term, chronic or fluctuating illness’ such as cancer.<sup>24</sup>

## Reforms to social care

Local authorities are experiencing unprecedented cuts to their budgets, and social care is no exception – £2.7 billion has been wiped off care funding since 2010, which has been met by restricting eligibility criteria for state-funded care for those with low or moderate needs and by closing services.<sup>25</sup> The effect of this is to increase the pressure on informal carers, who are increasingly becoming a safety net for those who are ineligible for state support, and unable to afford private care.

Though social care faces a grim future, not all of the news is bad, and many of the reforms currently under way offer new opportunities to expand the range of outcomes that social care and health services together can support. New social care legislation (the Care Bill, which is currently passing through parliament) contains encouraging signs of a move towards more holistic care – extending preventative care and support to people with lower levels of need, addressing the needs of carers and relatives, and shifting the emphasis away from a narrow clinical definition of care and support to a wider sense of wellbeing – within which there is more scope to address the financial aspects of wellbeing.

Alongside the wellbeing agenda, another policy lever is the drive towards personalisation in social care and, to a more limited extent, health care. Personalisation aims to offer individuals as much choice as possible over the type of care and support they receive, underpinned by better information and advice. Extending these principles to care for people with cancer could help to overcome one of the main problems driving financial difficulties for this group – the lack of information and advice available at the time of diagnosis, preventing people from being able to make informed choices about their finances.

## Reforms to the NHS

Within the health system, several new sets of statutory bodies became fully operational in April 2013. Prominent among these are clinical commissioning groups, clinically led groups of GP practices who are responsible for commissioning decisions in their local area, and health and wellbeing boards, responsible for

drawing up joint strategic needs assessments of their local population and developing joint health and wellbeing strategies based on these. Both were brought into being by the Health and Social Care Act 2012, shaping the way in which health services are delivered in England.

Together, these new structures for planning and commissioning health and care services should create opportunities for area-based strategies to support local people with cancer, and help to coordinate health and social care – something that will help allay the tendency to view cancer as a purely medical problem, rather than a responsibility to be shared between health and social care.

The UK Government has set itself a target to fully integrate health and social care in England by 2018 – with pioneer projects around the country announced before September 2013.<sup>26</sup> Voices across both sectors have been calling for this for years, though there is some scepticism over whether integration will be successful, given that no additional funding is to be provided to facilitate it.<sup>27</sup>

Meanwhile, the devolved regions are pursuing their own paths towards better integration of health and social care – through Transforming Your Care in Northern Ireland, the Integration of Health and Social Care Bill in Scotland and the Welsh Health, Social Care and Wellbeing Strategy.

Alongside moves towards integration, there have been significant reforms to the way cancer services are commissioned within the NHS in England. NHS England is now responsible for directly commissioning specialist cancer services such as chemotherapy and radiotherapy within hospitals, in order to ensure that national standards are met. Commissioning for other aspects of cancer treatment and support (eg screening, nursing care and surgery) rests with local clinical commissioning groups.

The cancer networks, which were established in 2000 and brought together representatives from different local NHS organisations to ensure quality, joined-up cancer services, have since 2013 been subsumed within new strategic clinical networks. The function of these networks is to support commissioning decisions and improved outcomes, within the remit of one of the

five domains of the NHS Outcomes Framework. There is a risk that individual networks will only look at one part of the cancer pathway, unlike their predecessors.<sup>28</sup>

Finally, financial challenges are ubiquitous across the health system, and have an impact on individuals with cancer and services supporting them. Nevertheless, the structural changes described above – mirroring reforms in social care – allow for a more holistic service offer that brings in issues of carer support, generic financial advice, housing and other aspects of support under the broad heading ‘wellbeing’.

### 3 What do the experts say?

Demos and Macmillan convened three expert roundtables – themed by sector – in order to better understand the evidence laid out above and to begin working towards addressing the problems raised. The purpose of these roundtables was to involve experts in this discussion and to ensure that our recommendations be targeted, pragmatic and purposeful. Attendees were presented with a summary of the evidence and asked to consider the following questions:

- 1 From your perspective, how could some of these costs be best addressed? What types of organisations are likely to be involved?
- 2 How will current policy changes affect the type of financial assistance?
- 3 Should financial support for cancer be universal or restricted (eg to people on the lowest incomes, groups vulnerable to higher costs such as single parents)?
- 4 How cancer-specific should this response be?
- 5 Which organisations are best placed to deliver this financial support:
  - a employers – statutory sick pay, occupational schemes, gateway to insurance products, return-to-work support
  - b insurers
  - c banks
  - d local authorities
  - e charity grants
  - f family and friends?
- 6 Will different organisations be better placed to help people who are retired (two-thirds of the Macmillan research sample)?

- 7 How do we avoid a piecemeal approach to the problem? What is needed to unify the different initiatives (eg a cross-departmental strategy, strengthened ministerial responsibilities)?

The discussions each lasted for an hour and a half and a summary of each one is presented below. These expert focus groups also came up with sector-specific recommendations and some general points that cut across sectors and speak to wider society and central government. These proposals form the basis of this report's recommendations – laid out in chapter 4.

### Roundtable 1 – financial services

Demos and Macmillan brought together representatives of the financial services industry to present them with the difficulties posed to individuals with a cancer diagnosis and to explore what best practice looks like and what might be done to improve experiences of financial services. A key theme that emerged during this session was awareness among customers and staff. Those receiving a cancer diagnosis are often unaware of the likely financial impact, as are their banks, which are unable to help them prepare and unsuited to mitigating financial risks.

#### The role of frontline staff

A recurring theme in this discussion – brought out very strongly in the evidence from patients themselves – was the difficulty that individuals can have in trying to deal with financial services following a diagnosis. It emerged during the conversation that this is as often a result of poor training as it is poor provision.

Financial services providers, including banks, are required to have procedures in place to help people who fall into financial difficulty – including because of cancer – but they rely on getting through to the right person. Sign-posting in banks – frontline staff recognising what the financial consequences of cancer may be and directing people with a diagnosis to the appropriate specialist teams – is often poor. Representatives of the financial services industry admitted that many frontline bank

staff are embarrassed or ‘panic’ when presented with a customer who reveals their diagnosis. As one contributor said –

*The service required is often basically the same as when someone tells you they’re likely to be made redundant... but staff in banks know how to deal with redundancy whereas a cancer diagnosis is a scary thing and the staff often don’t know what to say.*

The point was made that many of the problems occurring in referring cancer patients to the appropriate services – and recognising their financial vulnerability – are not unique to cancer. For example, very similar difficulties relating to lack of frontline understanding and preparedness have been identified in the Royal College of Psychiatrists’ work on mental health and customer experience.<sup>29</sup>

There is also a question about accessibility and the ease with which individual customers are able to access their financial services while undergoing treatment. For example, it is often difficult for people to access their banking services physically (eg because they are in hospital, or have a lowered resistance to infection) and even online banking can be difficult to manage for inpatients. Although the British Bankers’ Association (BBA) has recently produced guidance for how bank staff should deal with powers of attorney, as staff often lack awareness of how the system works it can be difficult for attorneys to actually take control of people’s finances. It can also be very difficult for the relatives or friends of a cancer patient to manage an account, so accounts can become overdrawn and incur charges, and direct debits and standing orders fail to be paid.

The existing rules for delegating payments and legal guardianship are outdated and generally geared towards people who are either at the end of life or lack mental capacity to manage their own affairs – this makes it very difficult for patients to take a step back from managing their money at a time of huge vulnerability and distraction.

What is required, then, is better training and more continuity of provision between financial services providers. The BBA has set up a new consumer panel and service improvement

group to address many of these issues – but it acknowledges that setting up and drafting new guidelines for staff takes a long time. Banks need to work together to ensure that there is a baseline of training and support for frontline workers in order to ensure that referrals to appropriate specialist services happen quickly when a customer reveals a cancer diagnosis.

These issues of frontline understanding – of their obligations and their bank's existing offer to financially vulnerable customers such as those with a diagnosis – is also an issue when it comes to managing arrears. Arrears management is often driven by bank IT systems – a missed payment automatically triggers a letter from the bank – and so people who approach their bank or provider for help are often told to wait until they are in arrears. This not only creates a false sense of security, but also misses an opportunity for earlier intervention – and reduces the range of options that people have available once they hit this point.

Many cancer patients who have tried proactively to manage their finances have faced a financial services industry that engages with people falling into financial trouble in an almost entirely retroactive way. This causes unnecessary stress and long-term damage to individuals' credit and borrowing records – what is required is a proactive engagement by financial services staff who recognise the likely long-term and short-term impacts of a cancer diagnosis and deal with customers appropriately. This is in the interests not only of individual patients but also of financial services providers: As more and more of us are diagnosed with cancer in our lifetimes – and suffer the associated costs and reduced earning potential for short periods of time – banks' responses to this increasingly common risk will impact on their relationship with a significant proportion of their customers.

### Looking to the long-term

One of the issues that faces a cancer patient's financial wellbeing is that their governing interactions are with healthcare providers – who often, with the best of intentions, urge patients to focus relentlessly on recovery. Of course, it is important that patients

are able to devote considerable emotional energy to their treatment and recovery – but the financial journey through cancer is also important and poor financial management can lead to the long-term financial impact of a diagnosis outliving the cancer itself.

It is important to remember that not all of the income shock is immediate – some factors (eg higher insurance premiums for things like travel insurance) are felt long into the future. In addition, missed payments due to job loss (as a result of a cancer diagnosis, or anything else) have a long-term impact on a person's credit score, and so can affect people applying for a credit card or loan (including a mortgage) in the future – in addition to the missed payment charges they may incur straightaway. As there is a significant lack of transparency around credit scoring, many people are not aware of this – or of potential ways to mitigate the impact of a cancer diagnosis in the longer term.

It is possible, for example, for a bank to add a note to a client's account explaining the reason for a missed payment, and there is evidence that this makes a real difference to the way banks and other companies deal with defaults. This is still a case of people explaining financial problems after the event, rather than preparing for them in advance, but more proactive provision of information by banks and financial services providers would encourage individuals to disclose their diagnosis and reduce the financial impact.

Difficulties around financial planning are also exacerbated by the jargon used by banks and insurers, for example, leaving people unclear about whether insurance products will cover them. Continuity of language – and an emphasis on using plain English when dealing with customers – would go a long way to explaining to customers what they are entitled to and what they are vulnerable to.

### Sources of information and advice

Many individuals experiencing a diagnosis of cancer lack information about what the financial risks of their condition are

likely to be. While some large employers have trained human resources staff in the range of issues likely to be faced by a colleague with cancer, most are not trained in this way. Many employees feel uncomfortable discussing their personal finances – and indeed their personal health – with their boss. This highlights the potential need for intermediary services – enabled by the employer but distinct from them. The pensions and insurance industries are well placed to offer such guidance – especially well in advance of a potential diagnosis. These financial services providers can be let into businesses by the employer in order to develop individual and discreet relationships with employees – engaging with them in long-term financial and risk planning, without employees feeling that there is an ulterior motive for being given such advice. There is an important role for such providers in helping individuals understand their risk of cancer – growing within the population as we live longer and experience more lifestyle illnesses – and in helping them plan for the financial consequences.

Similarly, trades unions – which are active in the workplace, but distinct from employers – could be a trusted source of information and advice for employees who receive a cancer diagnosis. Some of the big unions already provide financial advice. For example, members of Unite can benefit from a free financial review by an independent financial adviser,<sup>30</sup> as well as a range of other financial products and services. The union is planning to launch its own credit union by the end of 2013, which will offer low cost loans to members experiencing financial difficulty.<sup>31</sup>

The public and third sectors can also play a role. For example, the NHS runs an information prescription service (including a National Cancer Information Prescriptions Programme<sup>32</sup>), which is aimed at providing patients with more holistic information about support (including financial and social help) available but it is widely acknowledged that this has not been successful so far – partly because the public lacks awareness of the scheme, in the absence of a publicity campaign.

In partnership with Macmillan, Boots has been running a similar scheme in pharmacies, training pharmacists to provide

information and support to people with cancer. This has huge potential to expand the reach of advice at key points in a cancer journey – building, as it does, on the lived reality of individuals’ behaviour and priorities when receiving a cancer diagnosis.

It is unrealistic to expect most people to seek out specialist financial advice in order to help them plan as soon as they are diagnosed – as noted above the priority, rightly, is usually healthcare. But building on healthcare contact points – such as the relationship with pharmacists – can help to direct people to support, advice and information without inconveniencing them. However, such schemes are expensive, and third sector providers such as Macmillan and Citizens’ Advice are over-stretched. One way of addressing this – bearing in mind the acknowledged deficit in expertise and frontline training within the banking sector, which was flagged up in the roundtable – would be for financial services providers to contribute towards this training of healthcare providers, whether financially or by facilitating the training by sharing resources, or running training sessions, for example. This would be an investment in crucial social responsibilities as well as an upskilling of the banks’ customer base – helping to alleviate their staffing difficulties.

It is also important that wherever possible financial literacy and advice services are colocated with healthcare provision. This is important for two reasons – it reduces the burden on patients actively to seek out advice and guidance by making it available to them as they access treatment, and also serves to remind health providers of the holistic and financial impacts of illness.

### Conclusion

Although the financial services industry endeavours to cater to the needs of customers who are experiencing financial difficulty, a combination of poor training, poor communication of risk, and outdated regulations means that provision to cancer patients does not sufficiently help individuals and families to alleviate the financial risk of cancer. This needs to be tackled – not just because individuals and families are already suffering but because the rising prevalence of cancer (and of survivorship)

risks creating millions of people who experience real, long-term financial disadvantage as a result of diagnosis. This will drive customer dissatisfaction and undermine the financial independence and robustness of the British population.

There are a number of limited interventions that the financial services industry should enact in order to tackle the cost of cancer for their customers and improve their offer:

- *Train frontline staff in banks better* to improve referral rates to specialist teams, encourage earlier intervention and deliver better customer experience and outcomes to people with cancer and other long-term conditions. The FCA should ensure that firms are providing appropriate levels of support to their customers with long-term conditions, including cancer. This training does not need to be cancer-specific, though special attention should be paid to cancer, given its prevalence.
- Implement better systems for people *to delegate payments temporarily* during illness or treatment. This would enable people living with cancer to take a step back from managing their own finances – temporarily – while undergoing treatment, and would reduce the overall stress of dealing with the impact of cancer.
- Invest in advice around the risk of financial shock caused by short-term, temporary illness such as cancer. *Income protection and pension providers* should explain clearly to employees what their risk of income loss due to cancer is and what they can do to protect themselves and their families.
- Continue and develop the National Cancer Information Prescriptions Programme – paid for in part by a contribution from financial services providers – in order to ensure that financial guidance is provided at natural contact points for patients.

## Roundtable 2 - the charity sector

Demos and Macmillan brought together representatives of the charity and voluntary sectors and researchers working in this area to present them with the difficulties posed to individuals with a cancer diagnosis and to explore what best practice looks

like and what might be done to improve experiences. A key theme that emerged during this session was the availability of information, the relationship with employers and the role of the welfare state.

### Availability of information and advice

The charitable and voluntary sectors already provide advice and guidance to many thousands of individuals and families struggling with the impact of a cancer diagnosis. But there are things that could make a significant difference to their capacity and provision – many of which revolve around how public and private sector providers might work with the sector to improve access and sign-posting.

One effective measure, already trialled in some areas, would be colocating financial and health advice services, for example by placing financial advice services within GP surgeries and hospitals. This approach has worked particularly well when trialled in Wales – where Macmillan advisers (specialists in the financial impact of cancer and measures to mitigate and reduce risks) have been incorporated into multidisciplinary cancer teams. This allows a holistic approach to cancer – including the financial implications – to be built into treatment programmes from the offset. Colocation also offers patients access to advice and guidance without requiring them actively to seek out or make additional trips to find providers.

It is important, too, to recognise that different types of cancer require different kinds of intervention at different times. For example, for those with certain types of cancer (eg lung cancer), which generally have a very poor prognosis, it is particularly important that advice is offered at a point where it can still make a difference to quality of life.

The voluntary and charitable sector's ability to provide advice and guidance is experiencing considerable challenge following the withdrawal of public funds. The government – and many local authorities – is in the process of withdrawing funding from many advice services. This leaves a gap for the private sector (particularly employers and banks) to step in and fill, and

given the prevalence of the condition, this was felt in the roundtables to be an imperative that few businesses could choose to ignore. The recommendation above that financial services providers should invest in upskilling their customer base via funding for advice and training offers the potential to lessen this problem.

### Return to work

Several participants in this expert roundtable had direct experience of helping to facilitate the return to work of cancer survivors, either in their role as employers or as providers of support and guidance that helps facilitate return to work. This is a crucial area of concern for the long-term financial health of those cancer patients who are able to return to work following treatment.

Employees and their employers may feel uncertain about the process of returning to work after a period of illness. There is a need for more flexible models that allow both parties to 'test the water' before jumping straight back in to working their previous hours (whether full time or part time), recognising that recovery is an uncertain process. Too often, the pressure to return full time immediately after an all-clear ignores the psychological impact of having been treated for cancer and the ongoing occupational health needs that a cancer survivor may experience.

#### **Case study 2: Alex<sup>33</sup> - having an opportunity to 'test the water' when returning to work**

*Alex is in his late 30s, and lives with his girlfriend on the south coast of England. He recently returned to work after a six-month absence while he was undergoing chemotherapy:*

*Returning to work just before Christmas was a coincidence really. My last session of chemotherapy was at the end of November, and it had been tentatively agreed over the summer that I would aim to return to work at this point, once I had recovered from the last*

*dose. Christmas tends to be a quieter, more relaxed time at the company as well and this – coupled with the Christmas festivities – made it a pleasant time of year to return.*

*I had the best part of six months off work while I was having chemotherapy. I returned to work on a part-time basis, initially doing some afternoons, while still receiving radiotherapy in the mornings.*

*My company had been extremely supportive throughout my illness, ever since my diagnosis. As soon as I notified them of my illness they advised me I could take as much time off as I needed, while remaining on full pay. During a stressful and uncertain time, it was one less thing to worry about, knowing that my salary would continue to be paid, and I would have a job to return to once I was fit and ready.*

*During the course of my illness I maintained good contact with my employers, and a phased return to work was actively discussed with the human resources department. Their stance was always the same: it was up to me when I returned, but they would monitor the number of days and hours I worked to ensure I didn't try to take on too much. Upon returning, I gradually built the hours and days up, until I was back up to full time approximately six to eight weeks after recommencing.*

*I really valued being able to be in control of what hours I worked – psychologically as well as physically, it was difficult returning to an office environment after so long away. I was very grateful to my employers for being as understanding and supportive as they were.*

One way of reforming our working relationships with a cancer diagnosis and increased survivor rates is to look at international models that work well and flexibly with employers and employees. One lesson is that returning to work should not be dependent on a full recovery. In several Scandinavian countries (Finland, Norway, Denmark and Sweden) part-time sick leave is combined with partial sickness benefits, allowing people to work as many hours as they are capable of, and claim sick pay to make up remuneration for their normal hours.

This model accounted for up to a fifth of sickness benefit claims in Norway.<sup>34</sup>

Having the option to take part-time sick leave creates flexibility over employees' return to the workforce – allowing those with fluctuating capacity to start rebuilding their financial health as soon as possible and creating the space for an iterative understanding of recovery. An additional benefit is that, because of the flexible and negotiated frame in which return to work occurs, employers and employees naturally have to enter into holistic conversations about an employee's health and occupational needs – building understanding. Evaluations of Finland's model suggest that it has a variety of positive effects, for employees and employers. One study found that people with musculoskeletal disorders who took part-time as opposed to full-time sick leave (and were still working part-time hours) reported having better general health and health-related quality of life.<sup>35</sup> In another survey of Finnish employers and employees who had used the system, 76 per cent of employers and 87 per cent of employees felt that part-time sick leave had been beneficial to the return to work process, and 73 per cent and 81 per cent respectively felt that it helped to prevent people from becoming long-term ill or disabled.<sup>36</sup>

Flexible working combined with either part-time benefits or income protection would help to reduce significantly the income loss experienced by cancer patients and carers. Occupational health and pensions services are outsourced by many large employers, and there are some major providers in this field. This offers an alternative source of financial guidance after a diagnosis – because these companies are independent, where they are available, people may be more willing to talk to their representatives than directly to their employer.

Another area where reform to working lives would help mitigate and prevent the negative financial impacts of diagnosis is in the area of workplace flexibility more generally. Requests for flexible hours are currently only granted in certain situations (normally maternity or paternity leave), but not others – although anybody currently has the right to request flexible hours, there needs to be a change in working

culture so that requests are granted in a wider range of situations (eg from adult carers, or those in treatment or recovering from an illness). Promoting such an attitudinal shift may require legislative change – not to enforce flexibility for carers and people recovering from fluctuating or temporary ill-health but to grant their requests the same legal right of consideration currently afforded to parents. This would at least compel employers to consider carefully and properly such requests from employees who have either received a diagnosis themselves or are trying to balance caring for a relative with continuing in work.

### **Case study 3: Lindsay<sup>37</sup> – the struggle to fit work around caring responsibilities**

*Lindsay is a mother of two in her early 40s:*

*When dad was diagnosed with bowel cancer, it shook the family to the core... It was hard for us all, but at least he was alive. The whole family rallied round to care for him but it was my mum who was his full-time carer.*

*Family life carried on as normal as can be until mum was diagnosed with breast cancer. Now I was caring for two people and could only work part time because of the many hospital appointments they had between them.*

*When mum's cancer spread I made the decision to give up work completely. Caring for two people took its toll. I had lost full-time wages, child and working tax credits and child benefit; I was now on carer's allowance and income support top-up. But I still had bills to pay. I got help with my rent and council tax but I now have to pay bedroom tax or move to a smaller property or get a job. My gas bills and electric bills are the same and I sometimes struggle to pay them; I have even stopped using an electric fire to keep warm as I cannot afford to pay for it.*

*Carer's allowance at the moment is £59.75 per week with the condition that you spend 35 hours a week in your carer role. This works out to be £1.70 an hour! This is less than minimum wage! What a carer has to go through every hour of every day*

*emotionally and financially every day to help care for a loved one – does this seem fair?*

### Accessibility

Experts from the coal-face of the charitable and voluntary sectors strongly backed the notion of improved policies to facilitate the delegation of responsibility for financial services at key moments during cancer treatment. One contributor pointed out,

*People may have issues leaving the house or using the telephone (because of their illness or otherwise), which increases the risk of them losing control of their finances and entering a financial spiral.*

The point was also made that it is particularly difficult for people with cancer to deal with automated telephone services – whether of banks or utility companies. Such systems shoehorn customers into a very rigid and narrow set of options – there is unlikely to be a specific one for those wishing to discuss their illness and its impact on their finances, and so they may end up choosing the general option to ‘speak to an adviser’. Even where ‘social tariffs’ are in place to alleviate the financial pressure on cancer patients these tariffs can be difficult to access. Utility companies should identify easy routes for customers with complex issues (health related and non-health related) to contact advisers directly – by providing either specialist and clear advice lines or a quick, easy to understand option on their automated service lines. Similarly, banks should have systems in place to waive charges quickly in situations where such issues are identified.

### Welfare issues

The reforms to the welfare system – outlined briefly in chapter 2 – are also having an impact on cancer patients and their financial health. Together with historic and systemic problems, these risk exacerbating the financial impact on cancer patients and their families.

According to participants in our expert focus groups, an increasing number of private landlords are not accepting housing benefit, which leaves people in the private rental sector at risk if they are diagnosed with cancer, and need to claim housing benefit temporarily while they are out of work. At the same time, they may be hit by the withdrawal of the spare room subsidy. Moving to another property may not be a realistic option, and adds to their stress at a time when they are undergoing treatment or recovering from a serious illness. The lack of understanding in the welfare system of the difference between a circumstances-driven, short-term claim (as highlighted by the above example) and long-term engagement with the benefits system leaves cancer patients unnecessarily financially vulnerable and at risk of acute financial stress.

There is also a significant problem with the paperwork and bureaucracy involved in accessing benefits. Many – though not all – of the hold-ups in accessing disability benefits are due to delays in health professionals confirming a diagnosis and filling in the relevant paperwork (there are wider problems with benefit processing times – it is the responsibility of the DWP to deal with these). Medics tend to have a very narrow, health-related view of the impact of illness, so there is a case for expanding responsibility for signing people off ill to nurses and social workers. This would relieve some of the burden that currently falls exclusively on doctors, particularly given the shift from DLA to PIP and the new rules for claiming ESA, which are already increasing the number of cases doctors are dealing with. Nurses and social workers often have greater insight into a patient's health condition and how cancer affects their life than doctors, as they have more frequent contact with them. If nurses were given this responsibility, it would be necessary for a nurse or social worker's word to carry the same weight as a doctor within the welfare system.

Furthermore, there is an ongoing and non-cancer-specific problem with the number of hoops through which patients must, often unnecessarily, jump. The lack of information sharing between healthcare providers, the benefits system and within the welfare state between assessors for various benefits can create

huge delays in accessing funds and be a source of acute stress for cancer patients. Welfare and healthcare managers need to look at how their infrastructures can be more joined-up and work towards a single gateway for claimants.

### Key recommendations

- 1 Requests for *flexible working* from people experiencing a period of illness that is temporarily preventing them from working full time should be granted the same legal status as requests from parents and carers. Currently, anyone can apply to work flexibly, but only parents and carers have the *legal right* to request to do so. Local and national government could set the agenda, including leading by example, setting the benchmark for good, ‘cancer-friendly’ employers.
- 2 Charities and voluntary services providing information and guidance on financial health should be *colocated, wherever possible*, with existing healthcare providers in order to make accessing advice easier for patients.
- 3 Introduce a system of *part-time sick leave*, similar to the model used in Scandinavian countries (such as in Finland, since 2007). Regular conversations between employer and employee about working patterns could also be used as an opportunity to discuss any financial issues.
- 4 The UK Government should ensure that people who are off work because of a cancer diagnosis are eligible to apply for assistance from the new HWAAS. The HWAAS should routinely direct people to sources of financial advice and guidance.
- 5 The DH and DWP should *set up a joint working group on employment and health*, with the aim of looking at opportunities for ‘shared saving’ between the two departments by improving employment outcomes for people with long-term and chronic conditions. Opportunities for joint working, such as a single access point for both systems, should also be explored.
- 6 A *financial health check* should form part of the follow-up care after a diagnosis has been received (for any serious illness, not just cancer).

- 7 Utility companies should identify easy routes for customers with complex issues like cancer, by providing either specialist and well-directed advice lines or a quick, easily understandable option on their automated service lines.

### Roundtable 3 - NHS and government

Demos and Macmillan brought together representatives of the NHS and the Government to present them with the difficulties posed to individuals with a cancer diagnosis and to explore what best practice looks like and what might be done to improve experiences. A key theme that emerged during this session was the way in which costs impact on cancer patients and what role the Government and public services can play in mitigating them.

#### Transport costs

The cost of transport – and parking – is the single biggest additional expense faced by cancer patients and contributes significantly to the overall cost of cancer. But it varies hugely depending on what kind of diagnosis a person receives, what kind of treatment they undergo and on where in the country they live.

For example, London has its own public transport mechanisms, and so the costs of travel are not really comparable to other parts of the country. Within London, people over 60 are automatically entitled to a freedom pass granting them free travel in and around London. Individual local authorities also run their own schemes – for example, Southwark has a contract with a local taxi service to provide 108 free taxi journeys a year to people with long-term conditions or disabilities – similar to Dial-a-Ride schemes in other areas. Schemes such as this could potentially be extended to cover people with short-term conditions for which they are receiving treatment, like cancer.

Parking costs – a key expense for patients – also vary between local areas, and between the UK nations (eg hospital parking is free in almost all hospitals in Wales). In different local areas, some categories of patients are already entitled to free

hospital car parking (eg parents of children with critical illnesses, people claiming means-tested benefits), but the picture is mixed, disparate and difficult for individuals and families to understand. Better explanation of entitlements is needed in order to ensure that all those who should benefit from free parking can do so.

Hospital patient transport is available in some areas, but not always at the time that patients need to use it (such as out-of-hours), and so needs to be made more flexible. The Southwark model (108 free taxi journeys a year for those with long-term conditions or disabilities) is an example of how a more personalised and practical public transport scheme can assist patients. The idea behind all of these schemes is that they remove the need for people to incur costs in the first place – which is better than trying to reach them with financial support after the event.

Another way of reducing travel costs is to shift more care from acute settings into the community – or even the home – through the use of virtual wards, and phone or online clinics. This is possible for some cancer follow-on support but much less so for chemotherapy and radiotherapy.

### Universal versus restricted support

Entitlement to means-tested benefits (signalling low income) has always been the standard way of assessing financial pressure – and ensuring that funding is targeted at the most vulnerable. There was strong agreement among participants that this remains the most appropriate primary means of discerning need. However, contributors also recognised that means alone were a blunt measure of need – and that particular illnesses carry with them particular and exceptional levels of financial burden. Certain cancer diagnoses were recognised as falling into this category and there was widespread agreement that the system needs to be reformed in order to account for these factors.

Practitioners participating in these sessions agreed that there are two primary ways in which the NHS can improve its practice in this area – improving its role in information-giving, and improving its partnership working with the

third sector (with crèches in hospitals cited as a particularly good example).

The primary barriers to partnership working in the NHS are considered to be cultural – rather than technical, operational or regulatory challenges. One opportunity for improving joint working is the recent creation of local health and wellbeing boards, with responsibility for overseeing public health strategy and spending within localities. By their very nature, these boards bring together clinicians with managers, local councillors and charitable and voluntary organisations in order to share and plan resources. Local health and wellbeing boards should involve local financial advice bodies – in recognition of the crucial relationship between ill-health and financial vulnerability – in order to ensure that ‘every contact counts’ and that financial wellbeing is central to public health planning.

Most often what is needed at the time of diagnosis is generic financial advice, which could be offered through hospital InReach teams (eg Citizens Advice or Macmillan offices located within acute hospitals – offering drop-in sessions and bedside advice). Hospitals and GP surgeries should be encouraged to colocate with voluntary sector providers in order to ensure that patients in need of advice and guidance are able to access it easily and without having to make specific plans and trips.

### Key recommendations

- 1 Free *patient transport and local taxi services* could be extended to meet the needs of a wider group of patients, including those receiving treatment for short-term or episodic conditions such as cancer. These are currently generally only available to people who are either on a low income, or have physical disabilities that make it difficult for them to use public transport (eg Dial-a-Ride services and the Taxicard scheme within London).
- 2 Make *chemotherapy and radiotherapy available in local treatment centres*, reducing the need for people to travel long distances to hospital.

- 3 The NHS needs to do more to *promote and apply concessions and financial support schemes*, such as the Low Income Scheme.
- 4 The Government should help *incentivise employers* to offer good return-to-work support following an illness, as this ultimately saves the Treasury money.
- 5 There are more ways in which the *NHS can work creatively in partnership* with other organisations to tackle costs (eg linking up with local car shares), and barriers to doing this need to be addressed. Health and wellbeing boards could act as facilitators in this process.
- 6 The NHS Mandate – which is currently out for consultation – should *renew its focus on increasing employment as a core role for the NHS in England*, including setting an outcomes indicator against which this can be measured.
- 7 This group also echoed the previous group’s recommendation that the criteria for routinely granting *flexible working* should be extended to people experiencing illnesses such as cancer, which may temporarily prevent them from working.

## 4 What can be done?

There are already a number of schemes in place that can help to offset some of the extra costs imposed by cancer. These range from the NHS Low Income Scheme (which reimburses the cost of travel to and from appointments to people on a low income) to dedicated insurance policies for people who are diagnosed with long-term conditions. For example, Bupa's cancer cover includes access to a dedicated oncology support team and trained counsellors. Many financial services providers offer critical illness cover, which covers many forms of cancer. The problem is not necessarily that suitable products and services do not exist (with exceptions, such as insurance products for people who face high premiums, for example because of a previous illness) – but that people are not accessing them, and that even when they are, they are only helping some people some of the time (eg people on low incomes, younger people who are still in work), or are helping at the wrong time (too late).

This points to two things – the need to focus on gatekeepers (the people and organisations who are in the best position to direct those who need them to the range of financial assistance on offer) and the need, mentioned earlier, to unify the existing sources of support into one integrated system rather than a patchwork quilt of different measures.

These lessons were brought out during our expert roundtables. Above are three categories of key recommendations aimed at improving the financial security and robustness of individuals and families living with, and through, cancer. They can be defined by a series of key lessons that emerged throughout the process.

## Key lessons

- 1 In the same way as society needs to be preparing for an ageing population, at the same time we also need to be preparing for a situation where the number of people with cancer is increasing, but at the same time *more and more people are living with and beyond cancer*. Many services are still dealing with cancer as a short-term, terminal illness – which is increasingly not the case – but this affects the type of financial support that is being offered (short-term as opposed to long-term, for example).
- 2 *Low financial capability* across the whole population exacerbates this problem – linking up with those providing financial education will help to embed the idea that preparing for the costs of unexpected ill health is something that we should all be doing.
- 3 *Information and advice needs to go to people*, rather than expecting people to go to it (this links to lack of financial preparedness), so we should think more creatively about where and how it is offered (through employers, pensions providers and NHS partnerships).

## Sectoral recommendations

### Government

- 1 The DH in England – as well as the relevant agencies governing health in the devolved nations – in partnership with other government departments – should either update their existing national cancer strategies, or develop a complementary ‘social strategy for cancer’, which takes into account the wider social and financial implications of cancer, during illness and treatment, and following recovery.
- 2 Requests for *flexible working* from people experiencing a period of illness that is temporarily preventing them from working should be granted the same legal status as requests from parents and carers. Currently, anyone can apply to work flexibly, but only parents and carers have the *legal right* to request to do so. Demos has in the past called for flexible working to be extended to all employees, making the right to request universal.<sup>38</sup> For people

with long-term conditions, this may require some adaptations to the request process, which can currently take up to 6 weeks. Local and national government could set the agenda, including leading by example, setting the benchmark for good, ‘cancer-friendly’ employers.

- 3 Introduce a system of *part-time sick leave*, similar to the model used in Finland since 2007. Regular conversations between employer and employee about working patterns could also be used as an opportunity to discuss any financial issues.
- 4 The UK government should ensure that people who are off work because of a cancer diagnosis are eligible to apply for assistance from the new Health and Work Assessment and Advisory Service (HWAAS). The HWAAS should also routinely direct people to sources of financial advice and guidance.
- 5 The DH and DWP should *set up a joint working group on employment and health*, with the aim of looking at opportunities for ‘shared saving’ between the two departments by improving employment outcomes for people with long-term and chronic conditions. Opportunities for joint working, such as a single access point for both systems, should also be explored.

### The NHS

- 1 A financial health check should form part of the follow-up care after a diagnosis has been received (for any serious illness, not just cancer). The Welsh Government’s 2012 Cancer Delivery Plan specifies that everyone diagnosed with cancer should be routinely referred to financial advice services – this should be replicated in other UK countries.
- 2 Free patient transport and local taxi services could be extended to meet the needs of a wider group of patients than are currently served by it, including those receiving treatment for short-term or episodic conditions such as cancer. These are currently generally only available to people who are on a low income or those with physical disabilities that make it difficult for them to use public transport (eg Dial-a-Ride services, the Taxicard scheme within London).

## What can be done?

- 3 Make *chemotherapy and radiotherapy available in local treatment centres*, reducing the need for people to travel long distances to hospital. While this will not be suitable for all patients – and we should maintain awareness of the diverse needs of people undergoing treatment – national chemotherapy commissioners should attempt to treat patients locally wherever possible in order to mitigate transport costs for patients.
- 4 The NHS needs to do more to *promote and apply concessions and financial support schemes*, such as the Low Income Scheme.
- 5 *Continue and develop the National Cancer Information Prescriptions Programme* – paid for in part by a contribution from financial services providers – in order to ensure that financial guidance is provided at natural contact points for patients.
- 6 There are more ways in which the *NHS can work creatively in partnership* with other organisations to tackle costs (eg linking up with local car shares), and barriers to doing this need to be addressed. Health and wellbeing boards could act as facilitators in this process.
- 7 The NHS Mandate – which is currently out for consultation – should *renew its focus on increasing employment as a core role for the NHS in England*, including setting an outcomes indicator against which this can be measured.

### Civil society

- 1 Charities and voluntary services providing information and guidance on financial health should be *colocated, wherever possible*, with existing healthcare providers in order to make accessing advice easier for patients.
- 2 Financial information and literacy charities should push hard to be *included on local health and wellbeing boards* given the important links that exist between financial health and public health.

### Financial services

- 1 *There should be better training for frontline staff in banks* to improve referral rates to specialist teams, encourage earlier intervention

and deliver better customer experience and outcomes to people with cancer and other long-term conditions. The FCA should ensure that firms are providing appropriate levels of support to their customers with long-term conditions, including cancer. This training does not need to be cancer-specific, though special attention should be paid to cancer, given its prevalence.

- 2 Introduce better systems for people to *temporarily delegate payments* during illness or treatment. This would enable people living with cancer to take a step back from managing their finances – temporarily – while undergoing treatment and would reduce the overall stress of dealing with the impact of cancer.
- 3 Invest in advice around the risk of financial shock caused by short-term, temporary illness such as cancer. *Income protection and pension providers* should explain clearly to employees what their risk of income loss due to cancer is and what they can do to protect themselves and their families.
- 4 The Government should work with the insurance industry in order to develop a kitemarking scheme of minimum standards in the income protection industry, similar to the minimum standards that were introduced by the Pensions Act in 2008 for workplace pensions. Such a scheme would take place in partnership with the Treasury’s Simplified Products Review and would set a standard model for income protection. In return for compliance, income protection could then be incorporated as an optional opt-in to the new NEST workplace pension scheme<sup>39</sup> – in order to boost the proportion of the workforce who are protected against the financial risk of ill-health and to ensure standards across the income protection sector.

It is worth noting that the DWP is already informally reviewing the potential for broadening the income protection market – this is to be commended. But it should be acknowledged that any private provision entered into by individuals should be regarded as a ‘top-up’ to universal welfare entitlements, not an ‘opt-out’ from them. Living standards of those with a long-term illness are often low, as laid out in this report. The answer is to improve and broaden the financial protection available, not simply to shift all responsibility to the individual.

There is a role in meeting these challenges for all areas of society – from government itself to employers and financial services institutions to civil society. We all need to play a part in reducing the costs of cancer and taking forward strategies that will alleviate the problems faced by individuals and families in the longer term. None of the recommendations we make involve massive additional provision of costly services. Instead they focus on reforming and redesigning what is already there in order to protect people from risk, mitigate impact and ease the financial burden of sickness. There are benefits of such an approach for employers, financial services, government and individuals themselves – therefore, all must play their part in the journey to a less costly and less stressful experience of cancer for the 50 per cent of us who will receive a diagnosis.

## Notes

- 1 D Leighton and T Gregory, *Reinventing the Workplace*, London: Demos, 2011.
- 2 The Pensions Act 2008 placed new duties on employers to provide access to a workplace pension scheme for their workers to help them save for retirement, making pension enrolment opt-out rather than opt-in for most employees. The NEST was established as a public pensions provider for people whose employer does not offer an occupational pension, particularly smaller businesses. See [www.nestpensions.org.uk/](http://www.nestpensions.org.uk/).
- 3 Macmillan Cancer Support, *Cancer's Hidden Price Tag: Revealing the costs behind the illness*, London: Macmillan Cancer Support, 2006.
- 4 Ibid. Researchers carried out in-depth interviews with people who had been diagnosed with cancer about how their personal finances had been impacted by cancer, and what effect this had had on their wellbeing. These were then used to guide the design of a survey, which was distributed to 1,610 people.
- 5 Not her real name.
- 6 Although those with the lowest incomes experienced the highest income losses, people on mid to high incomes incurred higher additional costs – most likely because they had the financial means to spend money on things like food and clothing, which lower earners would have gone without.
- 7 Each of the devolved regions carry out their own cancer patient experience surveys.

- 8 DH, *National Cancer Patient Experience Survey*, London: Department of Health, 2013.
- 9 Oxford Economics, *Can Work, Will Work: Valuing the contribution and understanding the needs of people living with cancer in the workforce*, London: Oxford Economics, 2012.
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- 15 Oxford Economics, *Can Work, Will Work*.
- 16 Macmillan Cancer Support, *Making the Shift: Providing specialist work support to people with cancer*, London: Macmillan Cancer Support, 2013.

- 17 Ibid.
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Cancer is no longer as lethal as it once was. Improvements in diagnosis and treatment mean that the number of people living with or beyond cancer will have doubled by 2030. But these great steps forward in healthcare are only part of the story, as more and more patients find themselves confronted by the financial consequences of cancer.

A cancer diagnosis can cost an individual an average of £570 a month, through increased expenditure on things like travel and loss of income from having to give up work. This places a huge financial burden on patients and their families, and is a growing issue that needs to be addressed. This report builds on prior research undertaken by the University of Bristol and Macmillan Cancer Support – as well as extensive expert and stakeholder engagement – in order to lay out, and begin to address, the financial impact of cancer on individuals and families.

*Paying the Price* has recommendations for the NHS and central government in order to help ease the pressures, and identifies a key role for civil society, employers and financial service providers. It supports a right to flexible work for those experiencing long-term illness and suggests that the public sector lead the way towards a culture of ‘cancer-friendly’ employers. It recommends that the NHS perform a financial health check at the point of diagnosis. And it advocates training for frontline bank staff in how to support customers with long-term conditions. These measures would help those affected cope with the financial cost of cancer.

Max Wind-Cowie is a Demos Associate. Jo Salter is a Researcher at Demos.

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