

# **Economic Impact Case Study: Financial Advice for People Affected by Cancer in Lanarkshire**

How a dedicated financial advice and support service has generated over £13million worth of welfare benefits for clients; with every £1 spent on the service in 2009/10 generating £12.08 worth of benefits, grants or allowances for clients; freeing up the clinical capacity of specialist staff to perform core functions; and has shown a positive contribution to improving health and wellbeing outcomes for people affected by cancer in Lanarkshire.

## Service summary

The Macmillan and CAB Partnership (MacCAB) is a partnership between Macmillan Cancer Support, Lanarkshire Citizens Advice Bureaux, North and South Lanarkshire Councils and NHS Lanarkshire. It has been providing benefit, housing, employment, debt and consumer advice for people affected by cancer in Lanarkshire since 2003. The service is managed by and based in Airdrie CAB. The service was originally fully funded by Macmillan Cancer Support, with in-kind support from CAB. Its primary aim is to meet an identified unmet need in Lanarkshire for financial advice among those affected by cancer.

## Impact summary

- To date the service has had **8561** new clients referred and is now able to reach over two thirds of newly diagnosed patients in Lanarkshire each year.
- It has generated over **£13,442,854.81** in confirmed client financial gains in the form of benefits, grants and allowances, with **£2,179,640.74** worth of successful claims in 2009/10 alone

Every £1 spent on the service generated £12.08 of benefits, gains and allowances in 2009/10. In addition, users and stakeholders report that the MacCAB partnership has had a positive impact on outcomes for both patients and professionals. For example, it has:

- **Eased the levels of stress** experienced by those newly diagnosed with cancer, and their families / carers, by providing friendly, client-focused support and reducing the amount of time taken between diagnosis and successful benefit claim.
- **Led to a reduction in the burden on cancer support services** – before the MacCAB project was available the majority of benefit advice was provided by specialist cancer nurses

## 1) Background to the research

This case study is part of a wider programme of economic evaluation of Macmillan-funded services which will report in full in June 2011. An overarching report to be produced at a later date will set out, amongst other information, the aims and objectives of the overall economic evaluation; the methodology and rationale; key assumptions and caveats; and comparative analyses across services and also with relevant findings reported in the wider evidence base. The full implications of the findings reported in this case study will only be clear when the evaluation has reported in full, as there are a number of ongoing evaluation activities that will supplement the material included here or enhance the interpretation of the findings.

## 2) The Service

Research carried out by Macmillan Cancer Support, established that financial worries was second only to pain for those affected by cancer; additionally, a review of Macmillan's corporate strategy in 2003 identified financial advice for people affected by cancer as an enormous black hole into which a large number of cancer patients and their families unfortunately slide. The CAB Service recognises that people need advice in times of ill health; whether it is the patient or their carer, immediate answers on how the illness will affect day-to-day concerns such as employment, housing, benefits, and money are urgently needed. This was recognised as a growing area of need for people in Scotland and the Macmillan & CAB Partnership was set up in 2003 as a flagship project in order to bridge this gap for people in Lanarkshire.

### Project aims and purpose

The service is intended to meet the information needs of people affected by cancer on issues such as benefits, debt, employment and housing. The project involves collaboration with all nine Citizens Advice Bureaux in Lanarkshire and Macmillan Cancer Support, in a service managed by Airdrie CAB. Its original and ongoing aim and purpose is to provide an advice service to people affected by cancer, be they patient or carer, throughout Lanarkshire. The project also aims to raise awareness of professional and support staff to the effective support people who are affected by cancer can receive by being referred to recognised professionals in the benefits field such as Citizens Advice Bureaux.

### Staffing

The service is managed by Airdrie Citizens Advice Bureau on behalf of all nine Lanarkshire CABs. The service employs a total of 6 individuals: a full time co-ordinator to develop and maintain the service, three full time advisors, one part time advisor, and one full time administrator. All staff are appointed to work throughout Lanarkshire and have or are expected to develop specialisms in money advice, benefit appeal tribunal representation and employment tribunal representation. A Steering Group consisting of the Macmillan & CAB Partnership Co-ordinator, Managers from Airdrie and Clydesdale CABs and representatives from Citizens Advice Scotland and Macmillan Cancer Support, meet bi-monthly to review the progress of the service and set the agenda for further development. An Advisory Group made up of representatives from Macmillan Cancer Support, Citizens Advice Scotland, Health Professionals, Hospital and Community Social Work, Karen Whitefield MSP, Statutory agencies and Lanarkshire bureaux, exists to provide support and advice to the Macmillan & CAB Partnership in the development of its services. This group meets twice yearly.

### Data collection and monitoring

The project has had a new recording system since August 2009; this has really helped them to track clients and outputs. Ongoing data collection and monitoring takes place in accordance with Citizens Advice Scotland criteria. Data is also gathered in compliance with the professional evaluation established by Macmillan Cancer Support. For the purposes of this case study we have used the data collected since the new system has been in place.

### Services offered and intended outcomes

The services offered and intended outcomes that the MacCAB service seeks to achieve are illustrated in Figure 1.

### Referral process:

- The service has developed and sustains a system of referrals to come from across Lanarkshire, including special clinics at 3 hospitals, information provided on wards, additional information points and at GP/Primary Care Settings. The service has built strong links with health professionals working in these locations who are able to refer their patients directly to the service. These relationships have been significant to the service's success; they are now able to reach approximately **two thirds of all people diagnosed** with cancer in Lanarkshire. This relationship also helps to ensure the patient receives a **fast, efficient, and effective service**, and contributes to the minimal numbers of non-attendances

following referral, in the absence of the service the time taken to be referred and then access a similar service would be considerably longer, if accessed at all.

- Once MacCAB receives a referral the patient receives a phone call and letter from an advisor within 2 to 3 days. The time it takes for the patient to then receive benefits following this contact depends on when they can attend their first meeting and what benefits they need. If a client is then referred from the MacCAB to a partner e.g. The Pension Service; then the partner has to prioritise that client and work within the MacCAB timescales of between 5 and 7 days – ensuring that the patient is seen without delay.
- Nine out of ten people referred always attend the first meeting; non-attendance is almost always due to personal unforeseen circumstances and another appointment is made.

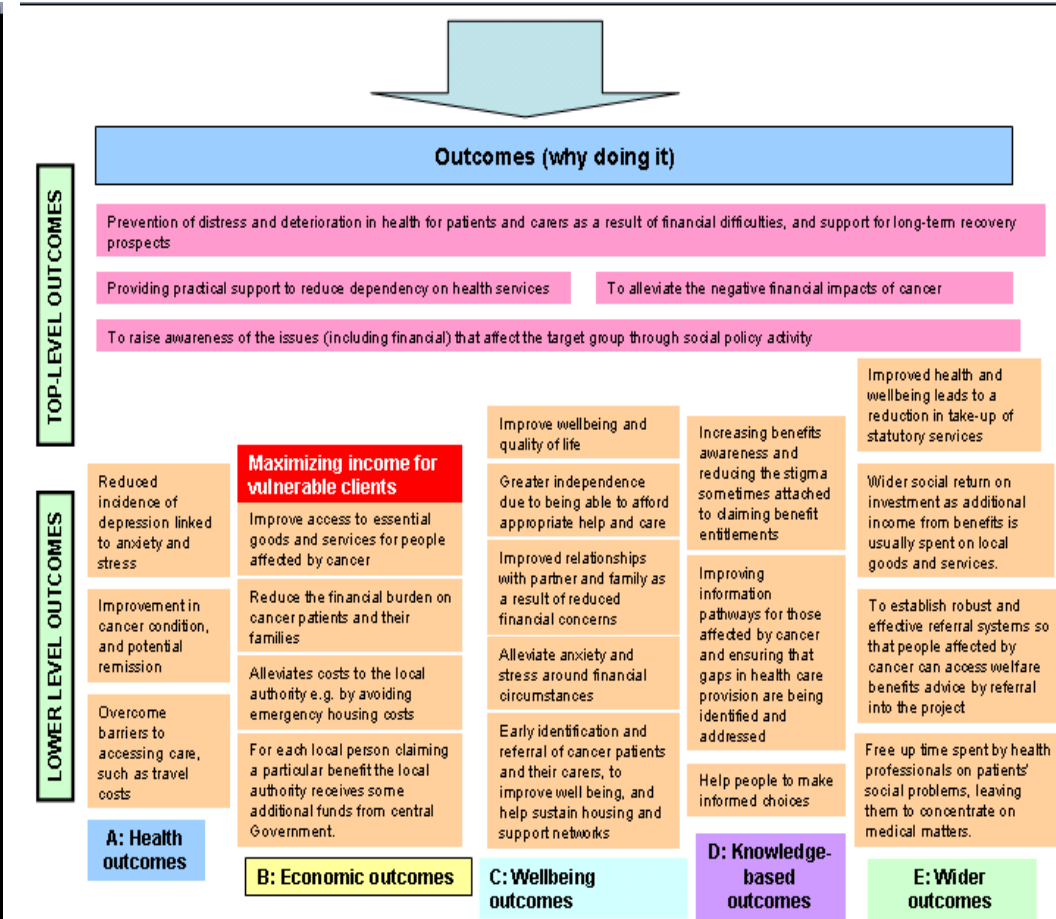
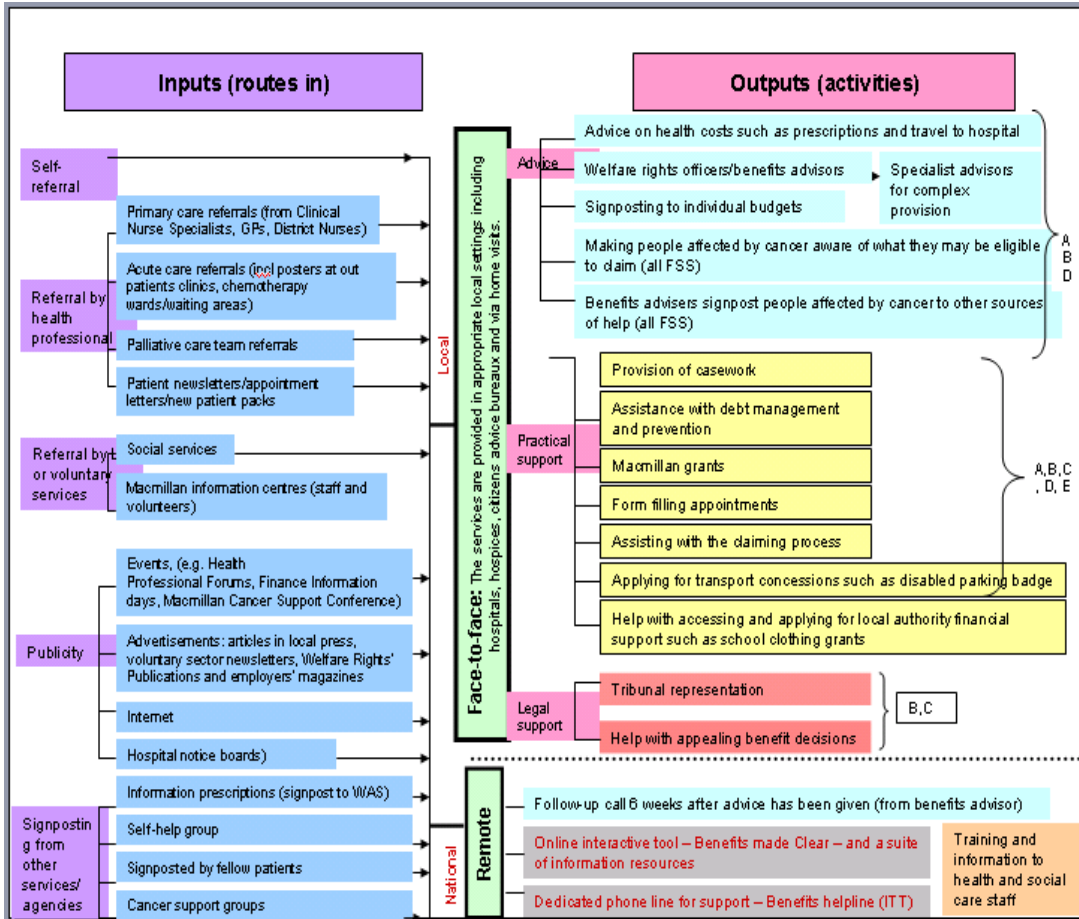
### Referral volume:

- To date the service has had **8561 new clients** referred. Over the last five years the largest number of referrals has come from health professionals working within a hospital setting. This means that in the majority of cases the project is being referred clients at or around the time of diagnosis, which is one of their key targets.
- In the period 1<sup>st</sup> September 2009 to 31<sup>st</sup> August 2010 **1258 new clients** were referred to the service and a total of **3607** enquiries for advice were made – this figure includes both enquiries made by new clients and by those clients already known to the service.
- The highest percentage of referrals (47%) came from specialist nurses, 19% were self-referral and 11% from palliative care specialist nurses.
- Each year the number of referrals coming from other sources such as those working in Primary Care, continues to increase. The second highest number of referrals (after those coming from the hospitals) are self referrals. These people often hear about the service while at hospital or just through word of mouth. These referrals continue to rise year on year. The number of self referrals is a positive aspect of the service and evidences the services' high profile in the community.

### Methods of delivery:

- The service takes a very **client-focused approach** to its delivery and improves and responds to the needs of the client on a year on year basis. The project now provides a direct outreach at Acute and Primary Care locations; Cancer Information Centres as well as home visits
- Research undertaken by the service has shown that clients prefer to be seen primarily in their own home; the service therefore provides a significant number of its services through its home visits. The service also undertakes a wide variety of outreach sessions each month with the potential to see over fifty clients. These weekly sessions take place at the three hospital sites in Lanarkshire and the Little Haven in Forth once a month. The advisers have all received cancer awareness training and have gained experience in dealing with people affected by the numerous different types of cancers and they take a holistic approach to advice giving.

Figure 1: Pathways to outcomes for Macmillan and CAB Partnership



### 3) Impact Evidence

The project has achieved over £13million in confirmed client financial gains in the form of benefits, grants and allowances, since its set up in 2003. The outcome of primary importance to MacCAB is to **'Maximise income for vulnerable clients'**, the project considers all other outcomes as outlined in Figure 1 are then achieved as a result of this. Evidence suggests that in addition to this the most common outcomes achieved by the project are that the service:

- **Eases the levels of stress** experienced by those newly diagnosed with cancer, and their families / carers, by providing friendly, client-focused support and reducing the amount of time taken between diagnosis and successful benefit claim.
- **Leads to a reduction in the burden on cancer support services** – before the MacCAB service was available the majority of benefit advice was provided by specialist nurses
- Has a **positive impact on local economy** due to money claimed being spent in the local economy.

#### Economic Outcomes

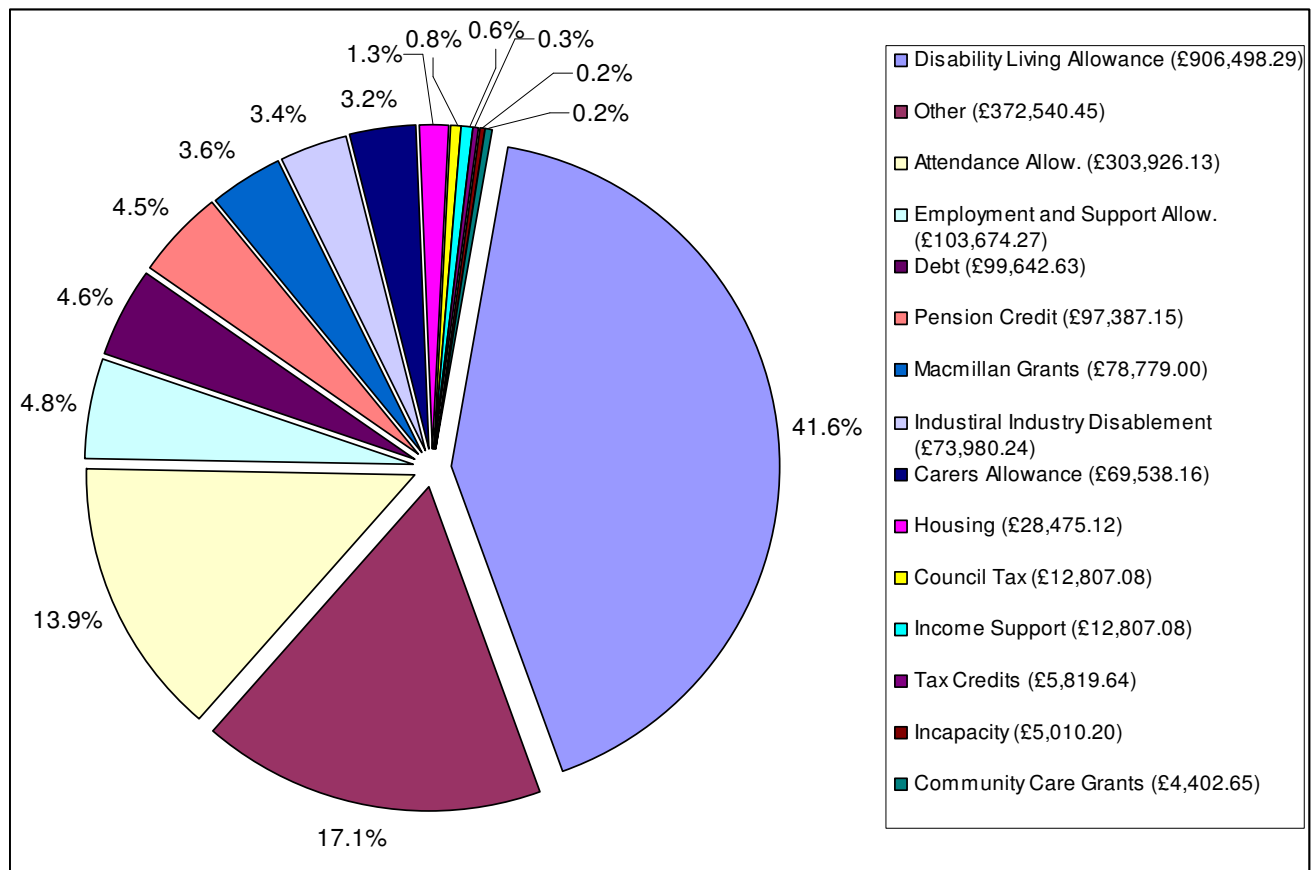
As means of providing evidence for how far the project has 'maximised income for vulnerable clients', the project collects data on Client Financial Gains (CFG), i.e. the amount of money that clients receive in benefits, grants and allowances as a result of support from the project.

- Since its start up in 2003 to August 2010, the MacCAB partnership's total financial gains for clients has been **£13,442,854.81**; this amount encompasses more than benefits (for example, it includes Macmillan Grants, allowances and debt relief).
- In the period September 2009 to August 2010 alone the project generated **£2,179,640.74** of financial gains for their clients. Included in this figure are only those claims that a member of the project team has had a direct involvement in i.e. they have supported the individual to complete the relevant forms; they *do not* count / include in this figure those successful claims made by individuals that have had contact with the service, but have then gone on to complete and finalise the forms themselves.
- despite figures relating to additionality (i.e. what benefits would be claimed in the absence of the service) being difficult to decipher, evidence from the client satisfaction surveys suggests that in the absence of the service a large number of the clients would not be accessing the benefits that they have done as a result of contact with MacCAB, therefore increasing the likelihood of benefits and other financial entitlements (such as Macmillan Grants) being unclaimed.

*"...the form I had would never have been filled in without her (Macmillan advisor) as I couldn't and didn't know how to answer the questions on benefits." (client)*

*"[I accessed] benefits I would never have know about otherwise" (client)<sup>1</sup>*

**Figure 2: Breakdown of revenue generation, by benefit type.**



### Health and Wellbeing Outcomes

The service's monitoring and recording systems does not collect data specific to the outcomes outlined in Figure 1, however, staff involved are confident that by providing support to their clients they do have a positive impact on the majority, if not all of the patient and service outcomes illustrated in Figure 1. More specifically evidence from clients suggests a positive impact on the following:

- **Alleviate anxiety and stress around financial circumstances**
- **Greater independence due to being able to afford appropriate help and care**
- **Improve wellbeing and quality of life**
- **Improvement in cancer condition, and potential remission**

### Knowledge Based Outcomes

**Improved patient pathways:** The MacCAB team are well aware that prior to the service being in place, people 'did not receive the holistic service now offered by the team, and invariably missed out on benefits to which they are entitled'. The lack of a joined up approach between health professionals and advice support services like those provided by MacCAB meant that patients slipped through the system, and were often 'bounced around' from service to service. Therefore in the absence of the service, although some support would still be received the generic pathway from diagnosis to successful claim would 'take considerably longer'. Due to the holistic and robust approach to referral and service provision developed and adopted by the project and its partners the impact on the patient pathway is that it has become less convoluted, more streamlined, and the time taken between diagnosis of cancer and successful benefit claim has been significantly reduced. It also means that patients are more likely to be aware and able to access the full range of benefits they are entitled to.

*"Service runs smoothly and proficiently" (professional)<sup>2</sup>*

*"Excellent, because a lot of people wouldn't claim these things, having them come out to your*

*house and doing it all for you makes all the difference.” (Client, taken from independent evaluation<sup>3</sup>)*

**Better informed professionals:** One of the main aims of the service since its initiation has been to raise awareness of healthcare professionals and support staff to the effective support those affected by cancer can receive from recognised benefit professionals, such as those at Citizens Advice Bureaux. The project uses various methods to publicise the service; they have leaflets for clients, service packs for referring professionals and do regular service talks. They also have posters within the hospitals where outreach posts are located. As a result of this, healthcare professionals across Lanarkshire are now increasingly aware of the services and support networks that are available to Cancer patients in the county. The 2008/9 MacCAB annual report includes views from professionals that have worked with the project:

*“I feel I could not do without this service it is a huge benefit to both me and patients” (professional)*

*“Excellent invaluable service for patients & Carers” (professional)*

### Wider outcomes

**Reduced pressure on the workload of cancer specialists:** There is some evidence to suggest that prior to the service being available a large amount of the benefit advice was being provided by the cancer nurse specialists seeing the patients. This evidence suggests that such advice could take up to an hour per session of specialist nurses’ time – this is therefore time taken away from treating other patients. Additionally, the nurses could not be expected to know the specific details of each benefit entitlement or the support services available to them therefore leading to patients losing out on possible benefit claims and wider services. The benefit of freeing up professional time can, potentially, be quantified and monetised through a more systematic study of time savings accrued to other agencies as a result of MacCAB’s work and the resource implications of such time savings – a crude calculation of this is shown in Table 4 on page 13.

## 4) Economic evidence and cost calculations

### Resources and funding sources

The service operates from Airdrie CAB who manage it on behalf of the Macmillan CAB partnership (i.e. process staff salaries, line manage the service coordinator, provide office space). The funding from Macmillan in 2001 and 2002/3 was for a scoping exercise and pilot project and totalled £81,939; this increased significantly in 2003/4 when the service was first fully operational and available to clients, and gradually increased to £175,000 in 2007/8. Since 2008/9 funding has further increased to include additional resources from the new partnership organisations. The NHS Lanarkshire and North and South Lanarkshire Councils now provide financial resources to fund the delivery of the service. In-kind support continues to be provided by CAB and The Pension Service. The income in 2009/10 totalled £180,000.00

**Table 1:** breakdown of sources of funding of the MacCAB project since 2001 (service was operational from 2003):

	2001	2002/3	2003/4	2004/5	2005/6	2006/7	2007/08	2008/9	2009/10	2010/11
Macmillan Cancer Support	£12,323	£69,616	£139,232	£139,236	£141,782	£190,125	£175,000	£50,000	£50,000	£50,000
NHS Lanarkshire								£50,000	£50,000	£50,000
South Lanarkshire Council								£50,000	£40,000	£40,000
North Lanarkshire Council								£40,000	£40,000	£40,000
	<b>£12,323</b>	<b>£69,616</b>	<b>£139,232</b>	<b>£139,236</b>	<b>£141,782</b>	<b>£190,125</b>	<b>£175,000</b>	<b>£180,000</b>	<b>£180,000</b>	<b>£180,000</b>



### Summated costs and benefits

Monetising costs and benefits at the highest-level shows that:

- Since 2003 the service has cost on average **£165,671.88** in total per annum (excluding set-up costs)
- The service has raised, between 2003 and 2010 a total of **£13,442,854.81** in financial gains via benefits claimed for clients.

### Effectiveness ratio

Analysing data at the activity level, we are able to make an approximated assessment of service cost effectiveness. Obtaining financial support is likely to have a positive impact on clients in terms of the 'lower-level outcomes' illustrated in Figure 1 on page 7. Given that we have only outcome data on revenue raised, the cost effectiveness analysis tabulated below relates only to the intermediate level income of 'maximising income for vulnerable clients'. The cost data included in Table 3 do not include set-up costs as the table provides a 'snapshot' of service costs and benefits in relation to revenue raised in one year (2009-10). It's also providing figures to show that the current performance of the service in terms of cost effectiveness is higher than the service average since 2003 – which would be expected and processes and systems improve and knowledge about the service is increased both with patients and professionals.

**Table 3 MacCAB cost effectiveness breakdown**

Benefit type	Total revenue raised	Total cost of service	Cost-effectiveness ratio*
All casework and claims since 2003	£13,442,854.81	£1,325,375.00	10.14
All casework and claims in 2009/10	£2,179,640.74	£180,387.00	12.08

\* = total revenue raised/total cost of claims

### Possible return on investment for maximising income for vulnerable people

Applying a ROI calculation to the total service costs and total revenue generated, we see that **every £1 spent generates £12.08** of financial gains for clients.

### Potential costs incurred in the absence of the service

#### Service related costs

There is a paucity of hard data on what a typical pathway might look like in the absence of the service. However, the MacCAB team explain that in the absence of the service in Lanarkshire benefit, grant and allowance advice would be provided through a number of different sources often in a non-holistic way. For example, a 'typical'<sup>4</sup> patient would receive advice in some form from a combination of the specialist nurses seeing them, by those working in the various benefit offices e.g. housing benefit office, council tax office, and / or by generic advisors working in the CAB who would not necessarily have the full knowledge of the benefit entitlements of cancer patients. A calculation based on this assumption is provided in Table 4.

In the absence of the service a 'simplistic' pathway may look like this:

- the initial benefit advice is likely to be provided by the patient's Cancer Clinical Nurse Specialist (CNS)<sup>5</sup>, such advice could take up to an hour of a CNS's time throughout the course of each patient's treatment (depending on need and how long the patient has contact with their CNS). The nurse would then signpost the patient to a local benefits advice office – or the local CAB

- then, depending on need, the patient would be likely to see a combination of a housing, council tax and employment benefit officers, and / or a CAB advisor depending on the needs of that particular patient.

Using the figure stated above of 2423 newly diagnosed cancer patients in Lanarkshire<sup>6</sup> you could complete the following crude calculation to work out the salary costs incurred:

**Table 4 – costs related to providing a ‘similar’ service in the absence of MacCAB. Figures based on 2432 newly diagnosed patients.**

<b>Cost/ benefit type Measure/s</b>	<b>Detail of costs</b>	<b>Total</b>
Salary costs over a 12 month period	<p><b>The following calculations based on 2432 patients following a similar pathway</b></p> <p>On average a CNS may spend up to an hour with patient talking through benefits on an average hourly rate of £17.71<sup>7</sup></p> <p>Following this the patient may spend an hour each with the housing, employment and council tax benefit officers – with an average hourly rate of £11.28<sup>8</sup> each</p> <p>additional involvement from the CAB advisor who may provide support with additional form filling and advice on where to source further benefits – with an average hourly rate of £13.01<sup>9</sup></p>	<p>£42, 911.33</p> <p>£81,994.32</p> <p>£31,523.23</p>
	<b>Total maximum Salary costs of providing service</b>	<b>£156,428.88</b> per annum
Salary costs over a 12 month period	<p>The following calculations are based on CNS seeing 100% of newly diagnosed patients, then only 50% taking the advice further.</p> <p>On average a CNS may spend up to an hour with patient talking through benefits on an average hourly rate of £17.71<sup>10</sup></p> <p><b>Assuming only 50%<sup>11</sup> (1216) then progress a claim:</b></p> <p>On average the patient may spend an hour each with the housing, employment and council tax benefit officers – with an average hourly rate of £11.28<sup>12</sup> each</p> <p>additional involvement from the CAB advisor who may provide support with additional form filling and advice on where to source benefits – with an average hourly rate of £13.01<sup>13</sup></p>	<p>£42, 911.33<sup>14</sup></p> <p>£40,997.16<sup>15</sup></p> <p>£15,761.62<sup>16</sup></p>
	<b>Total Salary costs of providing service</b>	<b>£99,670.11</b> per annum

The table above shows the total salary cost of other professionals providing financial advice and support in the absence of MacCAB.

- If 100% of all newly diagnosed patients completed the ‘typical’ patient pathway the total salary costs for advice provision would be **£156,428.88** per annum
- If only 50% of newly diagnosed patients completed the pathway – i.e. they got initial advice from their CNS but then failed to follow up any claim, the total salary costs for advice provision would be **£99,670.11** per annum – the cost per patient here is **£81.06**

- the total Salary costs of advice provision for the MacCAB project (i.e. of the individuals providing advice *not* those providing co-ordination or administration for the service) is **£94,084.00** per annum – the cost per patient for the service is: **£74.78**<sup>17</sup>

These figures do not take into consideration any additional operational costs relating to providing benefit advice and support such as premises costs, training, travel costs etc; neither do they take into consideration the additional costs incurred by the patient who would need to travel to each of the individual appointments.

In addition, the above assumes that the Cancer Clinical Nurse Specialists (CNS) are aware of the wide range of benefits that are available to the patient and how best to go about claiming such benefits; this is a huge responsibility required beyond the boundaries of a typical CNS's role with the cancer patient. Evidence shows that benefits advice services free up time spent by health professionals on patients' social problems, allowing them to focus on medical matters<sup>18</sup>. Additionally the stress of visiting all the different benefit offices and various individuals would likely lead to benefits being unclaimed and stress and anxiety levels being raised for the patient.

### Cost of not freeing up professional time

As mentioned previously in this report – it is not only the salary costs that need to be taken into consideration, in the absence of the service, there would potentially be an **additional 2432 hours of CNS time** that could be more appropriately spent on treating patients; this therefore incurs an additional cost of **£42, 911.33** for the additional 2432 hours needed for other CNSs' to provide the cancer support to patients.

### Patient related costs

The service reported that it is not possible to know the levels of benefits, grants and allowances that would be claimed in the absence of the service. However, research by Macmillan suggests that many cancer patients in need do not receive the benefits they are entitled to because they do not know what to claim or how to apply. In Scotland specifically it is known that each year up to £50 million in benefits, grants and allowances go unclaimed by cancer patients.<sup>19</sup> Such findings are supported by qualitative evidence gathered through MacCAB's client satisfaction surveys. In 2004, 'The Unclaimed Millions', estimated that £126.5 million in Disability Living and Attendance Allowance alone goes unclaimed by terminally ill patients;<sup>20</sup> the report goes on to say that Scotland has the lowest claim rate in the UK with 64% of cancer patients with a terminal illness. These benefits could be significant: a literature review by Adams *et al* found that, for welfare rights services delivered in a healthcare setting, there was a mean financial gain of £1036 per client in the year following advice being given<sup>21</sup>.

Using the above findings it is possible to make the following crude calculation:

- Over the last 12 months a total of 2423 people were diagnosed with cancer in Lanarkshire<sup>22</sup>;
- if 64% of these people do not claim the benefits they are entitled to, this means that 1550 individuals newly diagnosed with cancer in Lanarkshire may not make a claim;
- this could amount to a total financial loss in unclaimed benefits of **£1,606,545.90** for the cancer patients in question.

### Wider community costs

**Positive financial impact on the benefit recipient's local community:** Studies have shown that increasing benefit take-up can have a positive financial impact on the benefit recipient's local community, given that 'the higher incomes enjoyed by previously non-claiming recipients are spent on the purchase of goods and services'<sup>23</sup>. There are therefore wider services, community and economic costs to these people *not* taking-up their benefits in terms of lost economic gain for the local community. In this way, financial products 'such as tax credits and welfare benefits like Income support are not merely welfare for the individual, but can also be used as an effective part of local economic development'.<sup>24</sup>

## 5) Evidence to Support Quality and Productivity Effects

Evaluations of financial support and comparable support services have demonstrated that these services do indeed have a positive impact on a range of dimensions, again using outcomes set out in Figure 1. For example:

- **Reduced loss of economic output:** A study of a telephone debt advice service ('Debtline') found that 'the average cost to the National Health Service of 'difficult to solve' debt problems that led to physical or stress-related ill-health was around £50 (£20 per debt problem in general)' and 'the average cost per debt problem to the public and in lost economic output can be estimated at over £1000' or more, for more complex problems.<sup>25</sup> Debtline, however, provides advice at an estimated cost of around £25 per enquiry, on average, with more complex, face-to-face support involving higher costs. In relation to MacCAB, we are unable to categorically state that the service has helped all clients to avoid debt. However, given the likelihood that the service has contributed towards increased take-up of benefits, it is likely that MacCAB has potentially reduced the likelihood of beneficiaries being in debt or at least reduced the burden of debt.
- **Wider social return on investment:** Studies have shown that increasing benefit take-up can also have a positive financial impact on the benefit recipient's local community, given that 'the higher incomes enjoyed by previously non-claiming recipients are spent on the purchase of goods and services'.<sup>26</sup> In this way, financial products 'such as tax credits and welfare benefits like Income Support are not merely welfare for the individual, but can also be used as an effective part of local economic development'.<sup>27</sup> We also acknowledge, however, that there may be a counter-argument positing that, without benefits, there would be less taxation and people in the local community may also be more well-off. Economic evaluations need to balance considerations with efficiency with those of equity. In this instance, the re-distributional effect of the service targets those affected by cancer who are also, largely, less well-equipped financially to manage the complex implications of living with cancer. The ability to manage and handle these can demonstrably lead to other benefits, such as those described in the following bullet point.
- **Health/wellbeing gains:** There is evidence to suggest that providing people with support for, and advice about financial issues, particularly when they have other confounding difficulties such as ill-health, can lead to improvements in mental and/or physical wellbeing. These positive impacts are evident, most notably in respect of self-reported anxiety and depression, as well as quality of life.<sup>28</sup> Our ongoing review of the wider evidence base should provide more extensive illustrations of these benefits.

## 6) Conclusions

**Evidence** indicates that benefits related financial support and advice delivered in healthcare settings leads to worthwhile financial benefits for recipients.<sup>25</sup> The additional resources gained through such services can improve an individuals' ability to cope with health problems and enables them to afford necessities and additional items required as a result of a diagnosis of cancer<sup>26</sup>; this is supported by the evidence gathered from MacCAB and presented throughout this report.

The stress and anxiety caused by the financial implications of living with cancer can have a negative impact 'almost worse than the disease itself'<sup>27</sup>. Nearly 90 per cent of cancer patients' household incomes are negatively affected 'as a direct result of cancer.'<sup>28</sup> In spite of this, there is a wealth of evidence demonstrating significantly low awareness and/or take-up of financial support entitlement<sup>29</sup>. There is evidence to suggest that not being provided with advice and support on financial matters is a significant barrier to accessing information about entitlement, or benefits/grants themselves. Specifically, people are hindered or prevented from accessing financial support as a result of<sup>30</sup>

- the difficulty defining terminal illness and discussing prognosis;
- lack of knowledge and awareness of the benefits system (both among patients and staff)
- difficulties in accessing entitlement e.g. lengthy, repetitive and/or complex claims forms;
- lack of practical, expert support available to help navigate the system.

Services such as MacCAB, therefore, are invaluable to help build a much needed network of cancer-specific advisors who are trained to understand the impact of a cancer diagnosis on the need for financial support. Such services also help to embed these practices within clinical processes to ensure that financial status becomes a routine part of every patient's cancer journey.

The success of the MacCAB partnership in terms of positive impact on a range of patient and professional outcomes, combined with the data on client financial gains generated, show that the service is being delivered by people with expertise to effectively work with the benefit system to provide cancer patients with the financial reassurance that they need at times of high levels of stress. While the quantitative data are indeed limited to the financial gains received, these are still able to demonstrate that the service results in a net direct financial gain. Qualitative data from MacCAB clients and professionals working alongside the service help to demonstrate the additional positive outcomes achieved in relation to improved quality of life, health and wellbeing, knowledge and empowerment.

## Appendix 1: Evidence from case studies and qualitative data sources

In addition to collecting data on client financial gains the project also collects useful qualitative data through their client satisfaction surveys and the development of client case studies which help to illustrate the positive impact the project has on clients' lives. Although some basic assumptions have to be made in relation to outputs and their link to and impact on outcomes, the following provides a snapshot of how the MacCAB has helped its clients achieve positive outcomes; an independent evaluation of the project reported the following from clients<sup>31</sup>:

*"...D's illness came as such a shock and we were in quite a state, she made it easy for us to take it all in. She was much more accessible. It was like talking to a personal friend. When you get news like that, you're defensive, naïve and you have no clue how to go about it."*

*"... it's just excellent to have someone come to the house and sort these things out for us. I don't know whether I'm coming or going with running up and down to the hospital so I couldn't have done that on my own."*

*"Well, a few months ago a Social Worker had put in for this same benefit and we'd been turned down but when I told the Advisor, she couldn't believe it and she said she would try again for us so she got the form and filled it all in, I didn't need to do a thing which is just as well because my head is all over the place just now."*

### Client Case Study 1

Client aged 72 year old diagnosed with breast cancer last year. She has had surgery and just coming to the end of her course of chemotherapy. The project provides a benefit check. Following this a claim for Attendance Allowance is made and is awarded at the Lower Rate of **£47.80** a week. The client is widowed, lives alone and no-one is going to claim Carer's Allowance. This means the client can claim an additional premium onto her Pension Credit amount (SDP element - **£53.65**). A Macmillan grant was also award of £350. A **blue badge application** was made for the client. She was also given advice on her housing options as she was hoping to move to a more suitable house now that she was having difficulty managing the stairs. After contact with the service this lady saw her income increase by **£101.45 a week**. This allowed her **to keep her heating on** without worrying about being able to afford it.

### Client Case Study 2

Client aged 53 was referred to the service after a diagnosis of lung cancer by his lung specialist nurse. Prior to being ill the client had been self employed. His wife also 53 was employed full time and at time of referral had taken sick leave to look after her husband. Their only income at this time was client's wife's wage of £156.60 week. Following contact with the project the client was awarded Disability Living Allowance of **£113.75** a week. He was also awarded Industrial Injuries Disablement Benefit of **£136.80 a week**. A Macmillan grant of **£270** was awarded. Client received a lump sum payment for the Pneumoconiosis Etc (Workers Compensation) scheme of **£47,000**. The claim the client made of Incapacity Benefit was successful and he was awarded **£63.75** a week. This saw their income increase by **£250.55** a week, this was through the direct intervention of the Macmillan & CAB in Partnership. When the client passed away one the advisers visited the client's widow at home and helped her to make a claim for Bereavement Benefits. To date she has been awarded **£2,000** lump sum Bereavement Payment and is awaiting a decision on her entitlement to Bereavement Allowance.

## Appendix 2: monetisable costs and benefits of providing the service

The table below provides indicative figures for the monetisable costs and benefits of providing the service, based on 2009-10 data. This does not include the non-monetisable, categorical benefits summarised in the section 'Impact Evidence'.

### Available cost and benefit data for Macmillan and CAB in Partnership 2009-10<sup>11</sup>

Cost/benefit type	Measure/s	Costs	Total
<b>Direct Costs – one off set up</b>			
1. Set-up costs	£	Due to none of the current staff being in post at time of set up in 2003, it is not possible to provide a figure for set up costs.	n/a
<b>Direct costs – on-going</b>			
1. Staff Costs of MacCAB project	Staff time: wte x salary	<ul style="list-style-type: none"> <li>– 1 full time coordinator</li> <li>– 3 full time advisors</li> <li>– 1 part time advisor</li> <li>– 1 full time administrator</li> </ul> Plus: <ul style="list-style-type: none"> <li>– Employers Costs</li> <li>– Pension Scheme</li> <li>– Staff Training</li> <li>– Travel Costs</li> </ul>	£138,178.00  £13,836.00 £6,975.00 £1,500.00 £5,000.00  <b>Total = £166,791.00</b> per annum
2. Premises Costs	£	<ul style="list-style-type: none"> <li>– Rent and Electric</li> <li>– Insurance</li> <li>– Cleaning</li> </ul>	<b>£5038.00</b> per annum
3. Additional Operational Costs	£	<ul style="list-style-type: none"> <li>– Telephone, stationery, photocopying, postage, subscriptions, meetings &amp; conferences, petty cash, business consulting, adv/prom, equipment maintenance</li> </ul>	<b>£8,558.00</b> per annum
<b>Total costs of project</b>			<b>£180,387.00</b> per annum
<b>Direct benefits</b>			
4. Monetised patient outcomes - Client Financial Gains	Value in £	<ul style="list-style-type: none"> <li>– £2,179,640.74 client financial gains raised</li> </ul>	<b>£2,179,640.74</b>

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- <sup>1</sup> Quotes taken from MacCAB annual report 2008/9
- <sup>2</sup> Quotes taken from MacCAB annual report 2008/9
- <sup>3</sup> Quotes taken from independent evaluation undertaken by The Scottish Centre for Social Research incorporating Scottish Health Feedback, 2004
- <sup>4</sup> Note: a 'typical' patient is very hard to define in such circumstances
- <sup>5</sup> 47% of MacCAB's referrals in 2009/10 came from Specialist Nurses
- <sup>6</sup> Figure provided by MacCAB coordinator
- <sup>7</sup> Based on an average CNS being on pay band 7
- <sup>8</sup> Based on an average salary of £22000 per annum
- <sup>9</sup> Based on an average salary of £25,551 per annum
- <sup>10</sup> Based on an average CNS being on pay band 7
- <sup>11</sup> This year the service saw 1258 clients, just over 50% of the number of newly diagnosed patients (2423)
- <sup>12</sup> Based on an average salary of £22000 per annum
- <sup>13</sup> Based on an average salary of £25,551 per annum
- <sup>14</sup> Based on average hourly rate x 2432 patients
- <sup>15</sup> Based on average hourly rate x 3 x 1216 patients
- <sup>16</sup> Based on average hourly rate x 1216 patients
- <sup>17</sup> Based on the service successfully supporting 1258 clients in 2009/10
- <sup>18</sup> Jamieson, Teresa, (2010) Hampshire Income and Benefits Scoping Project 2007-8: Interim Report
- <sup>19</sup> Macmillan Cancer Support (2004) *The unclaimed millions* London: Macmillan
- <sup>20</sup> Ibid
- <sup>21</sup> Adams, J., White, M., Moffatt, S., Howel, D. and Mackintosh, J. (2006) A systematic review of the health, social and financial impacts of welfare rights advice delivered in healthcare settings *BMC Public Health*. 29 (6): 81
- <sup>22</sup> Figures provided by Airdrie CAB
- <sup>23</sup> Wiggan, J. & Talbot, C. (2006) The benefits of welfare rights advice: a review of the literature Commissioned by the National Association of Welfare Rights Advisors [online] Available at: <http://www.nawra.org.uk/Documents/Benefitsofwelrightrightsadvicelitreview.pdf> (Accessed: 26.09.10) p22
- <sup>24</sup> Sacks, 2002 cited in: Wiggan, J. & Talbot, C. (2006) The benefits of welfare rights advice: a review of the literature Commissioned by the National Association of Welfare Rights Advisors [online] Available at: <http://www.nawra.org.uk/Documents/Benefitsofwelrightrightsadvicelitreview.pdf> (Accessed: 26.09.10) p22
- <sup>25</sup> Adams, J., White, M., Moffatt, S., Howel, D. and Mackintosh, J. (2006) 'A systematic review of the health, social and financial impacts of welfare rights advice delivered in healthcare settings' *BMC Public Health* 29 (6): 81
- <sup>26</sup> Suzanne Moffatt, Emma Noble, Catherine Exley (2010) "Done more for me in a fortnight than anybody done in all me life." How welfare rights advice can help people cope with the practical demands of cancer' *BMC Health Services Research* 2010, 10:259
- <sup>27</sup> Soothill *et al.*, 2001, p602 cited in: Moffat, S., Noble, E. & Exley, C. (2010) "Done more for me in a fortnight than anybody done in all me life". How welfare rights advice can help people with cancer. *BMC Health Services Research*, 10:259 [online] Available at: <http://www.biomedcentral.com/1472-6963/10/259> [Accessed: 22.09.10]
- <sup>28</sup> Macmillan Cancer Support (2006) cited in: Durham County Council and Macmillan Cancer Support (2010) *Welfare Rights Service*. Annual Report 2009-2010 Durham: DCC & MCS, p2
- <sup>29</sup> For example: Chappell, A., Ziebland, S., McPherson, A., Summerton, N. (2004) Lung cancer patients' perceptions of access to financial benefits: A qualitative study. *British Journal of General Practice* 54 (505): 589 – 594; and, Macmillan Cancer Relief (2004) *The unclaimed millions* London: Macmillan Cancer Support
- <sup>30</sup> Social Security Agency & Macmillan Cancer Relief (2003) Benefits Access for People Affected by Cancer *in Northern Ireland - A joint report for Macmillan Cancer Relief and Social Security Agency*
- <sup>31</sup> Quotes taken from independent evaluation undertaken by The Scottish Centre for Social Research incorporating Scottish Health Feedback, 2004