WE ARE MACMILLAN. CANCER SUPPORT

Economic Impact Case Study: Durham Welfare Rights Service

How investing in a dedicated Macmillan Welfare Rights Service led to £3.6m revenue generation, with every £1 spent on the service generating £20.58 of benefits for clients, freed up the clinical capacity of specialist staff to perform core functions, and has significantly improved outcomes for people affected by cancer.

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Service summary

Established in May 2008, Durham's Macmillan Welfare Rights Service (WRS) is a partnership between Durham County Council (DCC) and Macmillan Cancer Support, supported by primary and acute trusts within County Durham, and linked to a network of voluntary and community sector organisations. The WRS sits within DCC's Social Inclusion Service and aims 'to provide those affected by cancer with comprehensive, free, confidential and impartial advice and information on their entitlement to social security and housing benefits, tax credits and grants at appropriate points in the patient pathway'.[1]

Impact summary

In the year 2009-10, the WRS reported:

- a 95% success rate in respect of benefit claims made.[2]
- that £3.6m revenue was generated for clients through casework and representation, including £122K compensation for mesothelioma victims and £71K in Macmillan Grant awards for vulnerable clients.[3]

Every £1 spent on the service generated £20.58 of benefits and, in addition, users and stakeholders report that the WRS had a considerable positive impact on outcomes[4]. It has, for example:

- enabled users 'to afford necessities and additional items that were required as a result of a diagnosis of cancer'[5]
- 'eased feelings of stress over financial issues at a time when participants were concerned about dealing with the impact of cancer'[6]

Further exploratory analyses also indicate that the service frees up the clinical capacity of specialist staff to perform their core functions.

1) Background to the economic evaluation

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 evaluation; its methodology, key assumptions and caveats; and comparative analyses across services as well as with relevant findings reported in the wider evidence base. This present series of case studies reports quantifiable, direct financial costs and benefits that can be monetised. Where case studies include complementary analysis of wider in-direct benefits that are amenable to monetisation, these are introduced conservatively and with necessary caveats. Ongoing scoping of the literature will further refine these estimates as well as provide comparable cost effectiveness ratios.

2) The Service

Aims

The WRS aims to ensure that:

- The income of people affected by cancer is maximised by providing casework and representation for those affected by cancer
- Tribunal representation is given to those who require it
- Support groups are offered information, guidance and advice on benefit and tax credit issues
- Social Care and Health staff and volunteers are provided with training and information
- Welfare Rights Staff campaign on and contribute to social policy issues on behalf of those affected by cancer, where these matters pertain to benefits and tax credits
- People in hard to reach groups are identified and offered a service by a welfare rights officer and referred on to other agencies who offer services to those affected by cancer.[7]

Staffing

The WRS is staffed by three full-time Welfare Rights Advisors funded through pump-priming from Macmillan. In addition, the Local Authority has also funded staff time to support deliver of the WRS, as follows:

- Administrative Support Officer (1 wte)
- Welfare Rights Service Team Manager (1 hour/ week)
- Principal Welfare Rights Officer (0.6 wte)

Set-up of the service involved approximately two hours per week of the Team Manager's time, and 0.2 wte Principal Welfare Rights Officer time, over the course of one year.

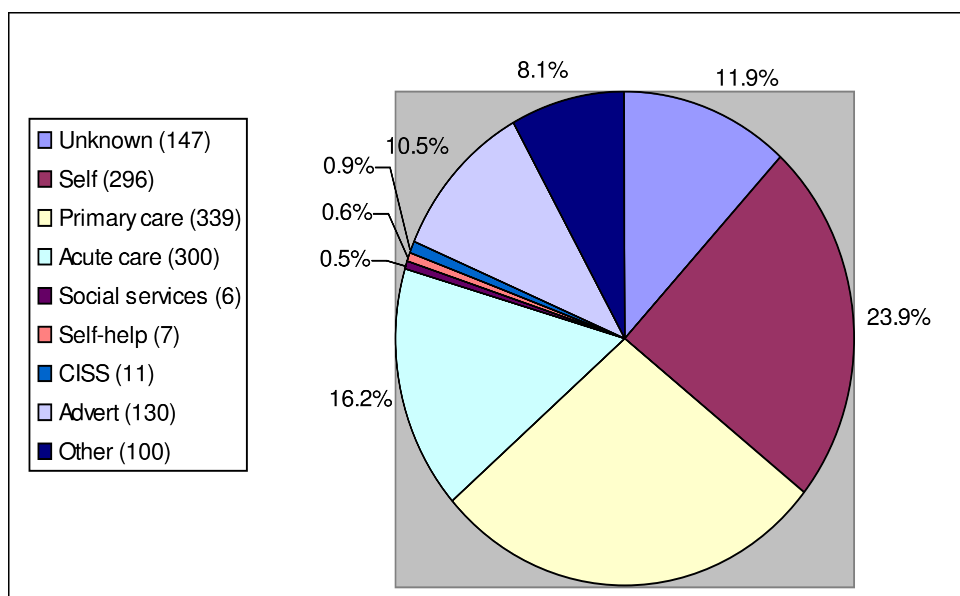
Services offered and intended outcomes

The services and outcomes that the Welfare Rights Officer seeks to achieve are outlined in Fig. 1.

Delivery volume

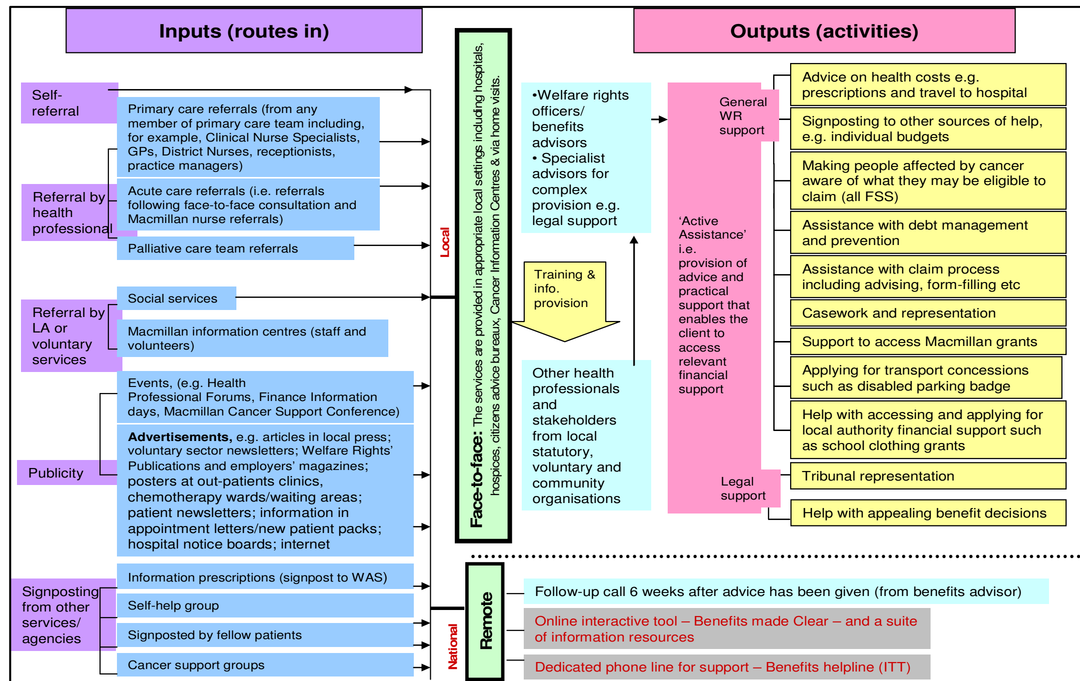
The referral routes and volume are illustrated in Figure 2.

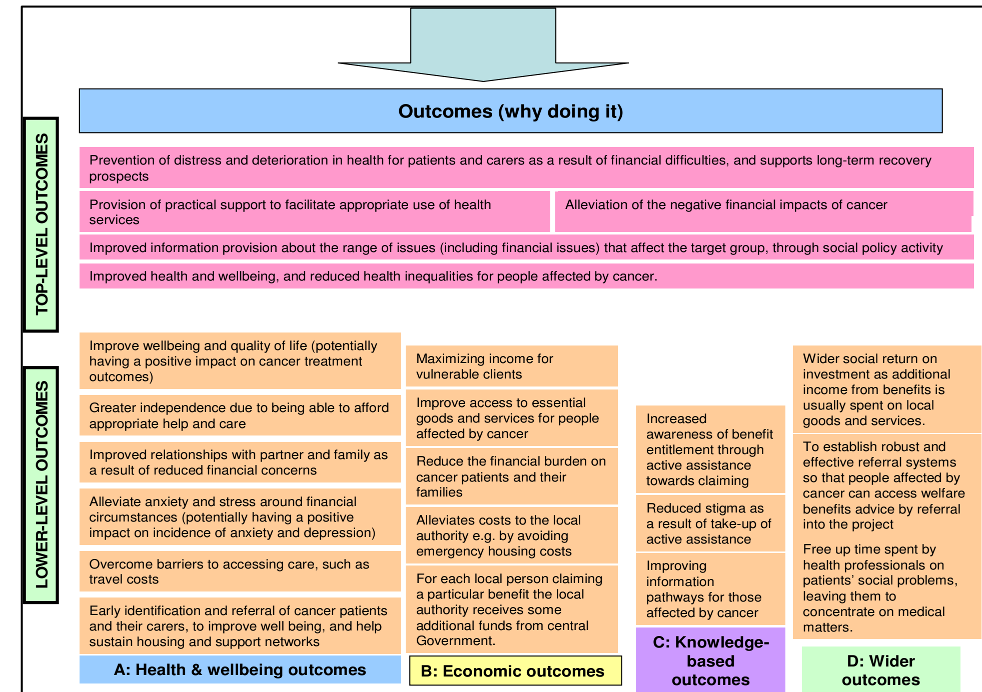
Figure 2: Durham Welfare Rights Service referral volume, by category[8]



'Other' includes: events (e.g. Health Professional Forums, Finance Information days, Macmillan Cancer Support Conference); the Department of Health's 'Information Prescriptions' project; or, signposting from other patients.

Figure 1: Pathway to outcomes for Durham Welfare Rights Service





Methods of delivery

Welfare Rights Officers deliver support to clients:

- face-to-face both from the service's base, as well as from a wide range of outreach posts. In 2009-10 the outreach services were provided from: Cancer Information Centres in Peterlee, University Hospital of North Durham, Shotley Bridge, Chester-le-Street and Sedgefield Community Hospitals; HealthWorks Easington; Newton Aycliffe Pioneering Care Centre and GPs' surgeries.
- over the telephone and online.

WRS staff also liaise with other stakeholders from local and national organisations on both informal and formal bases (e.g. through training and events) to help others understand what the service offers, to whom, when and how. In 2009-10, these included: Health Professional Forums, Finance Information days, Carers' Events as part of Carers' Week, Cancer Information Centres open days, Support Groups, GP practices, the 'World's Biggest Coffee Mornings' and a Macmillan Cancer Support Conference.

3) Impact evidence

Both locally gathered data from service users and the evaluation of the WRS being conducted by Newcastle University have illustrated that the WRS delivers a range of outcomes for those that use it. These are grouped as per Figure 1, with illustrative evidence from 2009-10 data provided.

1. Economic outcomes

- **'Maximising income for vulnerable clients', 'improving access to essential goods and services' & 'reducing the financial burden of cancer' -** There was a 95% success rate in financial claims made (1353 successful claims out of 1425 claim applications over a 12-month period) generating a total revenue of £3,635,399. There were 1236 cases opened by the service, meaning that some clients were entitled to claim for more than one type of benefit. A wide range of benefits were claimed, including for example, Housing Benefit, Disability Living Allowance, Income Support and Pension Credit and the service was highlighted as a model of good practice at the Citizens Advice Bureau Regional Managers meeting.

2. Health and wellbeing outcomes

- **Greater independence**
- **Overcoming barriers to care**

"It takes the pressure off ... you know it takes the worry away. You can concentrate on getting yourself better or making your life as comfortable as you can ... it's one less thing to worry about ..."[9]

3. Knowledge-based outcomes

- **Improved information pathways** i.e. helping people to see what they were entitled to, and why

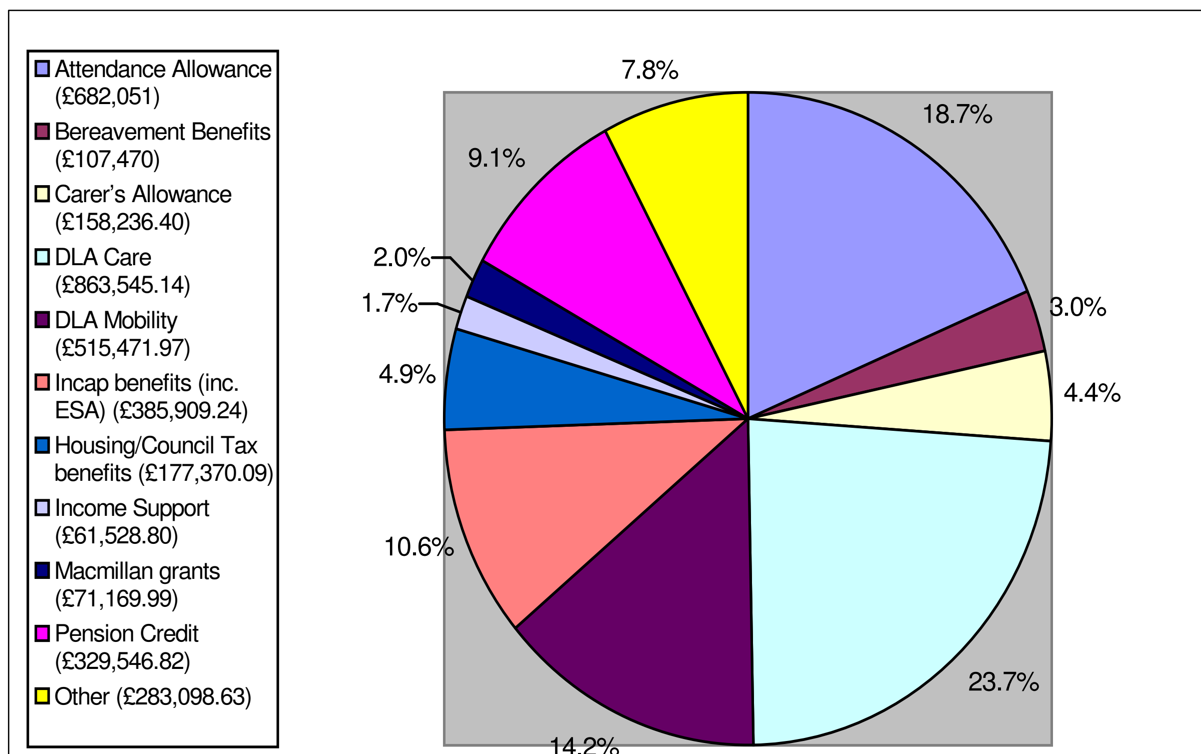
4. Wider outcomes

- **Robust and effective referral systems** i.e. strengthened two-way referral relationships between the Welfare Rights Service and the wide range of other cancer-related services
- **Freeing up the capacity of other health professionals** to undertake core functions

4) Economic Evidence and Cost Calculations

Appendix I 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 previous section 'Impact Evidence' and in more detail in 'Evidence to Support Quality and Productivity Effects' on page 9 of this document. Figure 3 overleaf provides a breakdown of revenue generated, by benefit type.

Fig. 3 Breakdown of revenue generation, by benefit type.[15]



1. **Summated costs and benefits**

   Monetising costs and benefits at the highest-level shows that the:
   - service costs **in total, £166,039 per annum,** on average (excluding set-up costs)
   - service raised in 2009-10, **£3,635,399** worth of patient benefits.

2. **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 5 of this document. Given that we have only outcome data on revenue raised, however, the cost effectiveness analysis tabulated below relates only to the high-level intended outcome: 'Alleviate the negative financial impacts of cancer'. The cost data included in Table 1 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).

Table 1: Welfare Rights Service cost effectiveness breakdown, by benefit type

Benefit type	Total revenue raised	Number of claims	Total cost of claims	Cost-effectiveness ratio *= total revenue raised/total cost of claims*
All casework and claims	**£3,635,399**	1425	£166,039	**21.9**

3. **Possible return on investment for improved financial wellbeing**

Applying a ROI calculation to the high-level data (total service costs, including set-up) and total revenue generated, we see that **every £1 spent generates £20.58** of benefits for clients.[16] This compares favourably to findings reported in the evaluation of the Macmillan Welfare Advice Project at Altnagelvin in Ireland where every £1 spent generated '…up to £16…claimed back in benefits or Macmillan grants'[24.] Our calculation includes set-up costs as the ROI provides a hypothetical scenario of possible returns from setting up a WRS 'from scratch'. This needs to be interpreted against the context that the service was only established in May 2008 which means that the set-up costs are set against, primarily, one year of full operation. As the service operates over a longer period of time henceforth, the set-up costs will be spread out over a longer duration of time. The money spent would therefore generate greater amounts of benefits. This trend, however, is not indefinite as it would be limited by the time it takes for the service to reach saturation in terms of the number of claims it is able to handle given current set up.

4. **Additional indirect benefits**

There is also evidence to indicate that the work of the WRS can free up the capacity of other staff to perform their core functions. This is an important wider benefit that warrants closer scrutiny. Evidence from the local evaluation (report available in Spring 2011) suggests that a wide range of professionals from other services are aware of the support and advice offered by the WRS and are able to refer service users to the WRS rather than spending time researching information or offering advice themselves. The work of WRS is therefore reducing the time spent by other agencies undertaking work that is not 'core' to their services (e.g. District Nurses completing Council Tax Benefit/Housing Benefit forms). If we apply a conservative estimate to these efficiency savings the return on investment increases further (see Appendix I for the conservative estimate):

Applying a ROI calculation to the high-level data (total service costs, including set-up) and total revenue generated and the cost of nursing capacity freed up as a result, we see that **every £1 spent generates £22** of benefits. These benefits are realised by both clients and the NHS.

5. **Potential costs incurred in the absence of the service**

There is a paucity of hard data on what a typical pathway might look like in the absence of the service. This requires establishing the 'additionality' effect of the service (i.e. how much extra benefit is being claimed as a result of WRS that would not have been claimed if it did not exist?). To do so would require, for instance, additional collation and analyses of other sources of secondary data such as claimant numbers in the area over a number of years in order to establish trends. Preliminary evidence suggests, however, that prior to the service being in place, people often 'fell through the gaps'. In some cases, people would be referred to the Citizens' Advice Bureaux (CAB) in the area. The Cancer Information Centre – which many people found, or were signposted to at a later stage in their pathway – reported that many of its clients had never made contact with the CAB.

The service reported that 'it has proved problematic to accurately establish the levels of unclaimed benefit for the target group within County Durham' but highlights '...a wealth of research which confirms that there is a trend for under-claiming benefit entitlement amongst those affected by cancer'.[17] A 2004 study commissioned by Macmillan – 'The Unclaimed Millions' – estimated that £126.5 million in Disability Living and Attendance Allowance alone goes unclaimed by terminally ill patients.[18] The Macmillan report goes on to say that this means that 55% of people dying from cancer in England do not claim these benefits. 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.[19] Research into barriers to claiming financial support experienced by people with enduring ill-health has identified the importance of having access to such advice; specialist expertise to help people navigate the welfare system.[20]

Rates of early death from cancer are higher in County Durham than in England: the age-standardised mortality rate is 130.8/100,000 population.[21] The current population of County Durham is approximately 500,700.[22] Taking current mortality and population figures together, therefore, we see that an estimated 655 people[23] will die each year from cancer. If 55% of these people do not claim benefits, in keeping with the finding in 'The Unclaimed Millions', this means that 354 people dying from cancer each year in County Durham may not claim benefits without some form of support or advice to enable them to do so. Based on the study by Adams *et al*, this could amount to a total financial loss of £366,744 for the cancer patients in question. There are wider costs to these people *not* taking-up their benefits in terms of lost economic gain for the local community (see: 'Evidence to Support Quality and Productivity Effects' for more detail).

5) Evidence to Support Quality and Productivity Effects

Evaluations of welfare rights services 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. [25] 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 WRS, we are unable to categorically state that the service has helped all clients to avoid debt. Nonetheless, given the likelihood that the service has contributed towards increased take-up of benefits, it is likely that WRS 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'.[26] 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'.[27] Nonetheless, we also acknowledge 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 redistributional 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.[28] Our ongoing review of the wider evidence base should provide more extensive illustrations of these benefits. There may even be a possibility that some of these benefits have been quantified and/or monetised in the wider literature.

6) Conclusions

The stress and anxiety caused by the financial implications of living with cancer can have a negative impact 'almost worse than the disease itself[29], in terms of living with the symptoms of the disease. Nearly 90 per cent of cancer patients' household incomes are negatively affected 'as a direct result of cancer'[30] In spite of this, there is a wealth of evidence demonstrating significantly low awareness and/or take-up of financial support entitlement.[31]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.[32] Specifically, people are hindered or prevented from accessing financial support as a result of[33]

- 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 Durham's Macmillan WRS, therefore, are invaluable. The significantly high success rate, combined with the data on revenue generated, bear out the fact that the service is being delivered by people with expertise to 'negotiate the welfare system'.[34] While the quantitative data are limited to the financial support received, these alone demonstrate that the service results in a net financial gain. Qualitative data from WRS clients serve to emphasise the supplementary gains in respect of quality of life, wellbeing, knowledge and empowerment.

References

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5. Ibid.
6. Ibid.
7. Durham County Council and Macmillan Cancer Support (2010) *Welfare Rights Service.* Annual Report 2009-2010 Durham: DCC & MCS, p3
8. Chart reproduced from Durham County Council and Macmillan Cancer Support (2010) *Welfare Rights Service.* Annual Report 2009-2010 Durham: DCC & MCS, p5
9. Moffatt, 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]
10. Ibid
11. Cost figures have been rounded to the nearest £
12. WTE = 37 hours; 2 hours per week = (2/37) = 0.054 WTE
    0.054 x £48,906 = £2641
13. WTE = 37 hours; 7 hours per week = (7/37) = 0.19 WTE
    0.19 x £42, 091 = £7997
14. WTE = 37 hours; 1 hour per week = (1/37) = 0.027 WTE
    0.027 x £48,906 = £1320
15. Chart reproduced from Durham County Council and Macmillan Cancer Support (2010) *Welfare Rights Service.* Annual Report 2009-2010 Durham: DCC & MCS, p6
16. ROI = total revenue raised/ total costs for one year including set-up
    = £3,635,399/ £176,677
    = 20.58
17. Guy, S. (2007) Durham Welfare Rights Service original bid document, Durham: DCC & Macmillan
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Appendix 1: Economic Evidence

Available cost and benefit data for Durham Welfare Rights Service 2009-10[11]

Cost/benefit type	Measure/s	Costs	Total
Direct costs – one-off set-up			
1. Set-up costs	Staff time: wte x salary (inclusive of on-costs)	• Welfare Rights Service Team Manager, TM = 2hr per week x £48,906pa for one year • Principal WRO 7hr per week x £42,091pa for one year • Incurred in 2007/08	• TM = £2641[12] • PWRO - £7997[13] **Total = £10,638**
Direct costs – recurrent			
2. Staff time	Staff time: wte x salary (inclusive of on-costs)	• Welfare Rights Service Team Manager, TM = 1hr per week x £48,906pa • Principal WRO = 0.6wte x £42,091 • Welfare Rights Officers, WRO = 3wte x £36,378 pa • Administrative Support Officer, ASO = 1wte x £21,330pa	• TM = £1320[14] • PWRO = £25,255 • WRO = £109,134 • ASO = £21,330 **Total = £157,039 per annum**
3. Mileage and office costs	£	• £3K per WRO per year	**£9000 per annum**
4. Promoting service to local stakeholders	Staff time: wte x salary (inclusive of on-costs)	• Cost neutral – included within '1. Staff time' above	£0
5. Training volunteers (7 sessions, training 40 people in total)	Staff time: wte x salary (inclusive of on-costs)	• Cost neutral – included within '1. Staff time' above	£0
Direct benefits			
6. Revenue raised for clients	Value in £	• £3,441,824 finance raised • £122,405 raised in Mesothelioma compensation awards • £71,170 raised in Macmillan grant awards	**£3,635,399**
Indirect benefits			
9. Freeing up the capacity of other health professionals	Number of hours x average hourly wage of health professional	• 1425 claims made in 2009-10 = 1425 ½ hours x £5.83 (this is based on a conservative estimate of the time nursing staff (on an average grade F pay band) would have spent contacting appropriate services and filling out forms for these patients)	**£8,308**