

A scoping exercise to identify the needs of people affected by cancer and key staff for a future welfare benefit service in Fife



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

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1. Executive Summary

1.1 This scoping exercise was undertaken to identify the current provision of welfare benefit advice services in Fife, any cancer-specific provision in Scotland and gather views on the needs of people affected by cancer, the public and key staff groups for a future welfare benefit service in Fife. It addresses 5 main questions:

- a. What is the current provision of welfare benefit advice services in Fife?
- b. What is the existing knowledge of welfare benefits among staff involved in the care of people affected by cancer, and how do they see their role in this issue?
- c. What is the existing knowledge and involvement of patients and carers in accessing advice and support in pursuit of benefits?
- d. What barriers exist to professionals and staff in helping people affected by cancer to take up the welfare benefits available?
- e. What type of welfare benefit service would recognise and meet the needs of people affected by cancer and key staff in Fife?

1.2 Data collection took place via a postal questionnaire survey with 106 staff; a focus group with 6 staff; patient and carer individual interviews; and face-to-face questionnaire survey with 13 members of the public conducted during an open stall event in a shopping centre in Fife. All data collection took place between January and May 2006.

1.3 The literature available suggests that good practice in providing welfare benefit advice to people affected by cancer would need to address issues of:

- a. Expertise (for example, advice staff being conversant with the complexity of cancer, and health/care staff having some knowledge

of welfare benefits but without too much detail)

- b. Timing (when and where in the often complex patient journey to introduce the issue of benefits)
- c. Awareness (how to ensure that health/care staff and patients are aware of the importance of benefits advice and appropriate pathways to getting advice)
- d. Psychosocial impact of any stigma attached to illness and claiming benefits

1.4 A mapping of cancer-specific project elsewhere in Scotland and their published reports was also conducted. A recent evaluation of benefits projects found that the themes raised above were validated at project level, but in addition, methods of raising awareness of the project were seen as a central difficulty right across the stakeholder groups and overlapped with concerns about quality and trust between potential referrers, patients and service providers.

1.5 There is no existing specialist provision for people affected by cancer in Fife, although the existing generic organisations do provide a case-by-case service.

1.6 A high proportion of staff responding to the survey could identify the major benefits applicable to patients and carers. Although not a state benefit, Macmillan grants featured as a benefit and had a strong brand name as provider of advice and support.

1.7 There was a clear division of roles and responsibilities identified for staff with most seeing clinical staff as those who should raise the issue with patients and refer on, and that detailed advice and support should be provided by those typically seen as providing this role, such as CAB/CARF, benefit staff and social services staff.

- 1.8 Most health/care staff would raise the question of benefits with patients and be happy to refer on if they had the relevant information and trusted the organisation to provide a good service. A smaller proportion of these staff helped patients access benefits either by directly assisting them with forms or through referring them to one of the existing agencies.
- 1.9 Respondents identified a number of practical factors which need to be addressed for a service to better meet the needs of people affected by cancer and key staff. These included:
- strategies for raising awareness of the benefit issue and following it up at every appropriate stage of the patient journey;
 - active consent should be sought so patients are in control of the access process;
 - the welfare benefits advisor role should be holistic taking a more in-depth look at all aspects of the financial “health” of the person affected by cancer;
 - benefit advice should be seen as part of the emergent practice of joined-up working between health and social care;
 - benefit staff should be conversant with the complex nature and range of possible patient journeys;
 - referrers should expect an initial feedback document confirming that the advice process is underway;
 - benefit staff should be accredited in their field, and
 - any new service should be subject to a service level agreement.
- 1.10 The Partnership Board deliberations are ongoing and it is recognised that there are changes within the NHS and Fife which will continue to require close monitoring to ensure that any new service is linked in with developments. It is recommended that decisions about funding be approached with two factors in mind:

- The extent to which the proposed service will compete or co-operate with existing providers
- The extent to which The Board wishes to take into account sustainability of service provision in Fife given the uncertainty of future funding.

1.11 In addition to the practical factors listed above recommendations from the scoping exercise include:

- The need to increase new cases through awareness raising with patients and staff from all relevant staff groups. This will be particularly important with the hard-to-reach patient groups.
- To ensure that feedback to referrers is built into the project to develop trust in the project and the support it offers patients. This is also something that could be improved in existing service providers.
- To ensure that all potential funders for continuation of the project are involved in its development so they feel engaged from the beginning of the pilot project.
- To ensure that staff views on the differences of their possible roles in the raising of the issue and the providing of support are taken into account.
- To provide appropriate training on benefit services or the cancer journey for each staff group based on their potential role as referrer, signposting, or provider of direct advice and support.
- To provide appropriate materials to staff groups to help them with their potential role such as information leaflets or cards or information about patient pathways.
- To ensure that mechanisms for recording impact of any new project is in place from the very beginning and that similar processes are

agreed with existing providers where recording is patchy.

- And most importantly, as this scoping exercise was only able to gather a very limited number of views from patients and carers, it is recommended that any proposed plan is discussed with a wider number of patients and carers through other mechanisms to ensure that it takes in to account their views and needs for any future service.

2. Background

Until recently, there has been very little published on welfare benefits advice (WBA) and cancer. The related issue of welfare benefits advice within primary care has featured strongly both within academic journals and at the level of reports and evaluations.

A review by Greasley and Small (2002) provides a very useful description of primary care based welfare benefit advice, highlighting that it is primarily “postcode” focused rather than concerned with a specific illness.

“Typically, the model these [WBA] projects adopt involves placing an advice worker within a GP surgery for one session per week. The rationale and impetus for locating advice workers in GP practices is to address the needs of a patient population who might not otherwise access services. Problems of access might be due to ill-health, lack of transport or simply a lack of knowledge about advice services and benefit entitlement.” (Greasley & Small, 2002, p1)

The focus of this model is on access difficulties affecting a particular population rather than trying to access patients with a specific illness. This point emerges clearly from the authors’ review of literature. While they cite over 100 references on the role of welfare benefits advice in GP surgeries and similar settings, they discuss only five studies looking at welfare benefits advice in the context of specific medical conditions, primarily the needs of people with long-term mental health problems. There are no references to cancer as the specific condition for the welfare benefit advice service in the primary care context.

The lack of published literature or reports could be attributed to at least two factors:

- It is only very recently that certain cancers have been re-cast as “chronic” conditions requiring the patient to deal with the medical and socio-economic impacts over a protracted period of time.
- Macmillan, among other agencies, has only recently managed to raise the

salient socio-economic issues associated with cancers into the public and political sphere. This has been achieved in part by commissioning research but also by running high-profile media campaigns and canvassing political support.

The rest of this background section of the report concentrates on issues surrounding the nuts and bolts of delivering a service. This includes issues that appear fundamental to making a service work, either as a specialised project or as a part of a wider framework of welfare benefits advice provision. Given the lack of published literature this section will:

- Review Wilson's (unpublished, 2005) presentation of "meta-recommendations" – features seen by different authors as key to running a advice service for people with cancer; and
- Review the evaluation report by Chalmers and Jones (2005) with the Wilson recommendations in mind, looking at issues that have arisen from the field, such as concerns raised by service providers, patients and professionals referring patients to the service.

Wilson (unpublished report, 2005) provides "a synthesis of qualitative research findings" on advice and support for people affected by cancer, and comments that very little appears to have been published on the topic before 1999 (p15). Wilson also remarks that much of the work produced subsequently has been sponsored by Macmillan and the strong role of Macmillan in taking both a policy and practice lead in this area is widely acknowledged.

The paper usefully draws together recommendations from the six sources reviewed¹. The recommendations are applicable to the day-to-day practice level of providing a welfare benefits service to people affected by cancer, and are presented here under thematic headings,. All quotes are taken from Wilson (pp41-42).

¹ The six papers synthesised are Thomas, C. et al. (2001); Quinn, A. (2002); Macmillan Cancer Relief & Social Security Agency, (2003); Chapple, A. et al. (2004); and Macmillan Cancer Relief, (2005a, 2005b).

Expertise

“Benefits advice for people with cancer needs to be delivered by specialist advisors or generic advisors who are knowledgeable about the physical, psychological and social impact of cancer.”

“Health and social care professionals need information, training and support to enable them to assess cancer patients’ eligibility for benefits and/or provide appropriate corroborating evidence.”

Timing benefits advice

“Benefits information and advice needs to be offered from the time of diagnosis, in order to prevent late applications that may result in loss of benefit and financial hardship.”

“Proactive benefits information and advice should be available in cancer hospitals/units and GP surgeries.”

“Issues relating to the definition of ‘terminal illness’ need to be resolved to ensure prompt receipt of benefit under Special Rules, but the issue of prognosis needs to be approached sensitively.”

Awareness

“There is a need for greater publicity/awareness about benefits and other help for people affected by cancer.”

“Health and social care professionals should not assume that someone else has already addressed patients’ financial needs.”

Psychosocial

“To maximise uptake of benefits, issues relating to stigma, moral entitlement and means-testing of benefits need to be addressed.”

Two of the recommendations cited in the review (p41-42), on educating Department of Work and Pensions (DWP) staff on cancer and redesigning benefits services, fall squarely within the remit of DWP policy and procedures, issues not immediately resolvable at the practice level.

Wilson's review provides a good summary of the main issues written about in a five year period. However, there have been developments during that time including Macmillan providing funds to put projects in place on the ground and arranging for the projects to be evaluated.

Chalmers and Jones (2005) reported on evaluations carried out on three specialist services supported by Macmillan.² Of the three projects in the evaluation, it is worth noting that:

- In terms of scale, the two Scottish projects are reasonably comparable in terms of cost and reach
- In terms of delivering the service, the national help line and the DIG project, are both telephone-based and have more in common than the predominantly "face-to-face" service offered in Lanarkshire
- In terms of being located within a clearly delineated administrative "space" analogous to Fife, the Lanarkshire project provides the closest, least problematic point of comparison.

Chalmers and Jones present a full report on the practical issues surrounding a specialist advice service seen from the perspectives of patients, referring staff and service providers. There is some difference of emphasis between the groups in deciding what an "issue" is, but the issue of publicity/ awareness of the service was the only common area of concern right across the three stakeholder groups.³

² The projects evaluated were: The National Helpline, Borders DIG project and CAB Lanarkshire, all funded by Macmillan Cancer Relief.

³ The reporting of "issues" across the stakeholder groups is not consistent in the evaluation so care needs to be taken in simply "reading across" between group views. But the issue of publicity/awareness emerges as an unambiguous, consistent theme.

From the service provider perspective:

“It is recognised by all that constant networking is necessary to maintain and form relationships with referring professionals. Lanarkshire CAB has not yet been able to promote the service to primary care” (p89)

From the referring health professional’s perspective:

“In both (Lanarkshire and Borders) areas publicity of the service was regarded as being inadequate and there were still non-cancer specific areas within Lanarkshire and the Borders health care environment where there was no knowledge of the service” (p77)

And finally, from the patient/carer, “client” perspective:

“Across all three services, many clients reported that they had been unaware of the availability of benefits advice before their contact. Many clients said they knew little of the benefits system itself.” (p65)

The issue of awareness is of course only the first part of the equation. There can conceivably be high awareness of a service but no subsequent use as being aware of a service and “buying into it” is a complex behavioural process influenced by skills, knowledge and attitudes.⁴

Chalmers and Jones make the point that securing referrals requires the service provider to meet referrer expectations on a number of levels:

“It is vital to the delivery of a high quality service that advisers have the right kinds of knowledge, skills and individual characteristics. Appropriate, timely training equips all staff to maintain high standards.”(p89)

This point is also expressed in reservations by potential professional referrers:

⁴ We borrow here from the “hierarchy of effects” model used widely in communication theory. In brief, the model posits that potential consumers can be moved from simple awareness to “purchase” of a service by addressing doubts or reservations they have about the service.

“There was concern among a very few professionals who had not yet referred clients to the services as to the level of cancer specific training the advisors had received.” (p77)

Where clients/patients had received help through referral (most clients/patients in the Scottish projects had been referred by professionals) they report:

“Clients across the services were generous with their praise for the individual advisors frequently citing approachability, expertise and willingness to help. Clients valued the advisors’ understanding of the effects of cancer on an individual” (p65)

Clearly, patients and carers, the ultimate beneficiaries of a welfare benefits advice service, reflect very positively both on the advisors’ technical skill and in exhibiting empathy enabling the patient/carer to develop trust, through experience, in the service. The issue being highlighted here however is not the subjective experiences of the patient/carer group, but the importance of feedback from the service to the referrers. In a system where referrals constitute the bulk of the advice service’s business⁵, building trust among professional referrers seems a paramount priority if the service is to achieve its objectives.

Chalmers and Jones go on to discuss the potential, sustainable scale of a service. Of the contacts resulting in claims being made, Chalmers and Jones note that the Lanarkshire Project assisted, on average, 38 new clients per month in the evaluation year, which is equivalent to 16% of monthly cancer registrations for Lanarkshire Health Board (p94). In the evaluation year, the Lanarkshire project cost £100,000 to run.

Chalmers and Jones comment that “the size of the clientele appears to be a small fraction of the total number that could potentially use the relevant service...there is likely to be scope for further expansion as awareness of the service expands” (p94).⁶ Since the Lanarkshire project was working flat out during the evaluation year (p99), it would

⁵ In the Lanarkshire case cited by Chalmers and Jones, the project received 81% of its case-load through professional referral, being 462 of the patients and carers in contact over the evaluation year. (p26).

⁶ Using the registration figure to arrive at the number of patients who could be helped appears to be the only base-line available but may understate the number of patients in a given area living with cancer.

require an expansion to the service to meet any expansion of awareness and increase in patient numbers using the service. This has a cost implication for the project, for example, if there was an increase of service uptake to 32% of all cancer registrations it would imply an investment of £200,000 per annum for the service, double their current cost.

This calculation points to a central issue in scoping for a service:

- If there is an unknown (and unknowable) number of patients living with cancer in any given geographical area, what is the likely cost incurred in reaching a majority to engage with them about welfare benefits?

Certainly the authors, in the context of all three services reviewed recognise the potential size of the client-base:

“There is no indication yet of what ultimate level of demand might be reached, but there is no ceiling yet in sight. While there was no way the evaluation could rigorously show that the services did not simply divert potential clients from other sources of advice, various indicators suggest that existing generic services - that is, benefits advice services not specifically geared to people affected by cancer - either do not reach, or do not adequately cater for the kinds of client who used these Macmillan-funded services.” (p100)

While the linkage of the special projects with existing generic providers is not explicitly explored in the evaluation the authors make a point relevant to the current scoping exercise:

“Where new services are being contemplated, it will be particularly important to document carefully what advice services are already in place, and how well they cater for people affected by cancer.” (p103)

The issue here is whether a specialist service is to supplant or supplement existing, generic provision.

3. Welfare benefits for people affected by cancer

The list below of welfare benefits is extracted from Martin (2006) and Cancerbackup.⁷

Disability Living Allowance (DLA)

DLA is a tax-free, non-means tested, non-contributory benefit for adults and children with disabilities. It is for people who need help looking after themselves and those who find it difficult to walk or get about.

DLA has two component parts:

- A care component- for help with personal care needs, paid at three different levels: a higher rate for supervision or personal attention during both the day and the night; a middle rate for supervision or attention during either the day or the night; a lower rate for those who need a limited amount of attention or who are unable to cook for themselves.
- A mobility component –for help with walking difficulties, paid at two levels: a higher rate for those who cannot walk or can only walk to a limited extent; a lower rate for those who can walk but need assistance to walk outside in unfamiliar settings.

Claimants can qualify for either the care component or the mobility component individually, or both components at the same time. Claimants must make a successful first claim before their 65th birthday, although once awarded DLA can remain in payment above that age.

There are currently 2.5 million people in receipt of DLA in the UK.

⁷<http://www.cancerbacup.org.uk/Resource/support/Practicalissues/Financiallegalissues/Financialissues>

Attendance Allowance (AA)

AA is for people who make a first claim after the age of 65. It has no mobility component. The disability tests for the lower and higher rates are exactly the same as for the middle and higher rate components of DLA. There are currently 1.3million people in receipt of AA.

You can claim DLA or AA even if you are working, and even if no one actually gives you the help you need. If you claim DLA or AA and someone is looking after you, they may be able to claim Carer's Allowance.

If you are claiming under 'special rules' (a fast-track claim for people who may not live longer than six months), your doctor needs to complete a form for either benefit. It is always difficult to tell exactly how long someone may live and many people with advanced cancer may be entitled to this benefit, so it can be helpful to check with your doctor. Claiming it does not mean that you will live less than six months.

If you are awarded the Mobility component of the Disability Living Allowance you will have an automatic entitlement to a Blue Badge parking concession and to exemption from road tax.

If your cancer was caused as a result of your employment you may qualify for Industrial Injuries Benefits. You can ask for details from the Department of Work and Pensions.

If you have a disability caused by your cancer or its treatment, you may be able to get further help such as special equipment put into your home (e.g. ramps or hand-rails), bus and train concessions and a special key to give you access to toilets for disabled people. You can get details of these schemes from your local Social Services office.

Incapacity Benefit (IB)

IB is a National Insurance-based benefit for those unable to work. For the first 28 weeks the claimant has to show that they are incapable of their "own occupation". Thereafter they need to show they are incapable of "all work". This involves scoring points on a

“personal capability assessment”, which tests functional ability over a range of everyday activities. There are various rules and exemptions relating to specific groups.

Means- tested benefits

These benefits consider the claimant’s income and capital when calculating entitlement. All ignore DLA and AA as income. All award higher amounts to those who receive those benefits, or who are accepted as being incapable of work in the long-term.

- Income support is for those who are not looking for work (for example, because they are sick or disabled, or are lone parents or carers)
- Pension Credit is basically a more generous form of Income Support for pensioners

People on very low incomes can claim Income Support or Pension Credit, if you are 60 or over, under certain circumstances. Income Support and Pension Credit can allow you to claim various other benefits (such as full Housing Benefit, or free school meals) so it is important to check whether you are entitled to claim these.

People on low incomes can get some financial help from their Local Authority, such as educational grants for children over 16 in full-time education, free school meals, Council Tax Benefit, or Housing Benefit.

Help with NHS Costs

If you are on a low income you may also be entitled to help with NHS costs, including travel for hospital treatment, dental treatment, prescriptions, wigs, glasses and sight tests. You can get information about these benefits from your local Social Security office, the Benefit Enquiry Line (0800 882200) or the Department for Work and Pensions website (www.dwp.gov.uk).

You are automatically entitled to free prescriptions, and do not have to pay other NHS costs if you:

- are over 60
- are under 16
- are aged 16–19 and still in full-time education
- claim Income Support or some other benefits
- are pregnant
- have had a baby in the last 12 months
- have a war or MoD Disablement Pension and need prescriptions for a war injury
- have particular long-term medical conditions – details of these are given in leaflet HC11 which you can get from the Social Security office. Unfortunately, cancer itself does not entitle you to free prescriptions, but you may be eligible for other reasons.

If you are not automatically entitled to free prescriptions, but are on a low income you can apply on form HC1 for a certificate for free services or reduced charges.

If you need a lot of prescriptions but cannot get them free, you can cut costs by buying a pre-payment certificate for 4 months or a year. You save money if you need more than 5 prescription items in 4 months or more than 14 items in a year. You can get a claim form (FP95) from your GP, your health authority or main post offices.

Grants

You may also be able to claim grants and benefits from other organisations or charities.

Macmillan Cancer Support (previously called Macmillan Cancer Relief) gives one-off grants to people with cancer and you can contact its information line (0808 808 2020) for information on how to claim. Applications must be made through a Macmillan nurse, social worker or advice organisation.

Sargent Cancer Care for Children gives grants to people under 21. The information line is 020 8752 2800. Again, applications need to be made by a health or social care professional.

A variety of charities will provide grants and financial help for particular situations or people with particular types of cancer.

The Association of Charity Officers is an organisation that tries to help individuals to find specific charities that may be able to offer some financial assistance. Using information about you such as your occupation, where you live, your religion and your type of cancer it is usually able to find relevant charities. It can be contacted on 01707 651 777, or via the website www.aco.uk.net.

A book that gives details of all the trusts and organisations that provide financial support to people in the UK is available from bookshops or local libraries.

4. Welfare benefit projects and support available in Scotland

Outside Fife, Macmillan Cancer Support (MCS) funds a number of projects elsewhere in Scotland to provide welfare benefits advice to people affected by cancer. Examples include:

MCS/Dumfries and Galloway Citizens Advice Service Project

This project is funded to January 2007. Service delivered by two full-time advisors and three trained volunteers covering the four districts that make up the region. Single largest route for advice is through self-referral possibly due to the fact that the project uses a mix of PR, press and radio ads to generate awareness of the service. The service is mainly delivered through home visits. Managers of the service note that establishing a continuing relationship with the patient is vital as their needs may change as the illness changes.

Citizens Advice Bureau/MCS Airdrie

Six staff work on this project with referrals coming from a mix of professional sources. The staff consist of three full-time advisors and one part-time advisor.

Disability Income Group (DIG)/ MCS Leith

This project offers advice and assistance on the whole range of welfare benefits and Macmillan Grants. Referrals come from leaflets and posters displayed in hospitals and surgeries and via health professionals. There are two full time and one part time staff members.

National Services provided by MCS

MCS run a national advice help line and an enquiry service which signposts callers to available local provision.

Summary

In terms of the type of service offered, only one provider (DIG) operates purely on a telephone based service, potentially allowing for geographical reach and unit-efficiencies.

In terms of accessing the service, all providers inform health professionals of the projects and encourage referrals as a matter of course. The Dumfries and Galloway project are the only project to add to this with periodic use of local media outlets. The Dumfries and Galloway project also reports high levels of self-referral.

5. Welfare benefit projects and support available in Fife

While there is no specialist welfare benefits advice service for people affected by cancer in Fife based in Fife, there are a number of organisations working in Fife that assist people with cancer to obtain benefits. Additionally, there is the DIG facility based at The Edinburgh Western General Hospital that receives some funding from Macmillan and counts a substantial number of Fife cancer patients as part of its case-load. DIG carried out an extensive awareness campaign in Fife last year on the general issue of disability and access to benefits. The Macmillan funding for this project ends in May 2007, but given the impact and importance of the scheme the team are hoping to secure continued funding from other sources.

DIG Project in Fife (partly funded by Lloyds/TSB foundation for Scotland)

In 2004, DIG applied to Lloyds TSB Foundation for Scotland, to partly fund a project which would encourage more disabled people and carers to use their Welfare Benefits Information and Advice service. A grant of £18,000 was awarded, over 3 years, from 2004 to 2007. The project aims to encourage more disabled people and carers in the Fife area to use the DIG Scotland Welfare Benefits Information and Advice service, with a view to maximisation of income for individuals, improved quality of life, and enhancement of independent living. A publicity campaign began in August 2004, issuing posters and leaflets to locations where disabled people and carers would be likely to see it. Additional publicity was done via the DIG Newsletter. Networking with a variety of disability and carers groups in Fife was also undertaken to heighten awareness of the DIG service. Additionally, benefits awareness training was given to health professionals.

Shortly after the start of the publicity campaign, enquiries started to increase in the Fife area. Over the 2 years since then, the project has handled 1374 Welfare Benefits enquiries, many of which have resulted in new or increased Benefits for clients who used the service. Advice was given on Benefits such as Attendance Allowance, Disability

Living Allowance, Carers Allowance, Pension Credit, Income Support, Incapacity Benefit, Housing and Council Tax benefits, the Motability scheme, free road tax, disabled parking badges. Clients were also signposted to other organisations for advice on other aspects of disability.

Citizens Advice and Rights Fife (CARF)

Citizens Advice and Rights Fife (CARF) provides a free, independent and confidential information and advice service throughout Fife. It is the citizens advice bureau in Fife, offering a full range of assistance and different ways to access help, including drop-in, telephone, outreach clinics and home visits. Specialist appointments can also be organised in a range of venues, including hospitals. Specialist services include tribunal representation, race discrimination and money advice.

CARF currently has five public access offices in Fife, with various opening times, and a telephone service from 9.30 – 4pm.

CARF is a recognised community partner of the local authority and is involved in a number of multi-agency initiatives within the statutory and voluntary sector, including training, referrals and project management. It is the recognised lead advice agency in Fife and plays a key role in Fife Rights Forum.

CARF also has experience of running health related projects and is currently in negotiations regarding provision of a Fife wide service, including administration of an independent complaints procedure.

The Pensions Service

Part of the Department of Work and Pensions is charged “to ensure that all customers who are 60 and over are receiving all their benefits and entitlements. These entitlements include State Pension, Pension Credit, Attendance Allowance, Disability Living Allowance and Carer’s Allowance.” The Kirkcaldy based unit is tasked to optimise local uptake of the Pension Credit benefit and the local team works through a variety of methods including

referrals from other agencies and outreach in the communities served. The service enjoys close links with NHS Fife, Fife Council and key voluntary sector agencies.

Princess Royal Trust- Fife Carers Centre

Part of the PRT Carers Network, The Carers Centre is a one stop shop for carers. The Centre provides: “accurate, up-to-date information on Carers’ issues, help and advice on resources and benefits, advocacy, or simply a listening ear. The Carers Centre works with Fife Council, NHS Fife and the Voluntary Sector to ensure Carers can access the services they need.”

As part of their remit to assist carers looking after someone with a disability, staff at The Centre will receive referrals from health professionals and, where required, assist in pursuing benefits on the behalf of people affected by cancer and their carers.

Cancer Network Fife

The Network was founded in 1999 and constituted to develop local access to information, support and advice for anyone in Fife affected by cancer, and to raise awareness within Fife’s communities about cancer and related issues. The network currently deal with benefit enquires and applications (for people affected by cancer) as a matter of course. The Centre has recently opened branch offices in Dunfermline and Levenmouth.

The Network has recently been conferred with ‘Alternative Office’ status by the DWP, meaning : “An Alternative Office can receive applications for Pension Credit and claims for other social security benefits from people who are aged 60 or over”. The relevant benefits are:

- Attendance Allowance;
- Bereavement Payment (claims from people aged 60–65 years)
- Carer’s Allowance
- Disability Living Allowance (claims from people aged under 65 years)

- Incapacity Benefit (claims from people aged under 65 years)
- State Pension
- Winter Fuel Payment"

(From the DWP website: http://www.dwp.gov.uk/publications/dwp/2004/linkage/alt_offices/alternative.asp)

Fife Rights Forum

This is the umbrella body for Fife's advice and rights agencies.

The remit of Fife Rights Forum includes helping to improve the quality of advice services, promoting co-operation between agencies and increasing community involvement across the sector. The Forum launched the Fife Online Referral Tracking system (FORT) in May 2006. The system allows a client to be referred from one advice agency (statutory or voluntary) to any other advice agency. The system is the first of its kind in the UK and is already being copied by other partnerships in Scotland. The system will be especially useful for any specialist agency where referral is a key part of the service. The Forum hopes to sign up primary care staff as users of the service.

Maggie's Centre, Victoria Hospital Kirkcaldy.

Maggie's is a place for people who have cancer, their families and friends.

The Maggie's centre in Fife is going to be located in the Victoria Hospital in Kirkcaldy. The building is under construction at present and should be completed by the end of July 2006.

The goal of the Maggie's Centre will be to keep people who have cancer as healthy in mind and body as possible by enabling them to participate actively in the treatment of their disease. Maggie's is not an alternative to regular medical treatment, but is an important supplement to that treatment. Maggie's is first and foremost a homely,

relaxing place for a patient to be in. It will be providing an environment where people can drop in at any time if they want to have a coffee and a chat. Maggie's will also be providing a structured programme of supportive activities, for example, relaxation sessions, Living with Cancer courses, and Nutrition workshops. People will also be able to have one-to-one sessions if they need more individualised support. Patients can just walk in, or it can help if the people who are supporting them in the NHS bring them over for the first time but they do not need to formally refer.

Authors comment

In the course of doing this research, the authors have consulted informally with a wide range of people working in the care professions, statutory and voluntary sectors in Fife. The referral figures that have been reported indicate that there is a system of referral and advice at work in Fife, and that many view the existing services as doing a good job in meeting much of the current demand, although improvements to patient awareness, additional support to these services and more joined-up working would be welcome.

6. Methods

6.1 Scope of the exercise

This scoping exercise reports on what has been identified as the current provision of welfare benefit advice services in Fife, with regard to generic services and any specific to cancer patients, the views of staff who are involved in the care of people affected by cancer about their role and issues of welfare benefit claiming, and the views of patients and carers. It also reports on possible scenarios for creating a dedicated, specialist service for these patients. The current welfare benefits advice provision in Fife has been reported in the previous sections. The following sections of the report will focus on four main questions:

1. What is the existing knowledge of welfare benefits among staff involved in the care of people affected by cancer, and how do they see their role in this issue?
2. What is the existing knowledge and involvement of patients accessing advice and support in pursuit of benefits?
3. What barriers exist to professionals and staff in helping people affected by cancer to take up the welfare benefits available to people affected by cancer?
4. What type of welfare benefit service would recognise and meet the needs of people affected by cancer and key staff in Fife?

6.2 Participant selection and recruitment

The respondents in the scoping exercise were (1) staff from professional groups with a role in caring for people affected by cancer and staff providing welfare benefit advice in Fife (2) cancer patients and their carers in Fife, and (3) the general public in Fife.

6.2.1 Staff questionnaire respondents

The staff respondents for the Fife-wide questionnaire were recruited in two ways:

- 1) A complete census of all cancer consultants and specialist nurses working in the acute sector in Fife.
- 2) A proportional sample of other acute staff, community, social work, voluntary and statutory sector staff with questionnaires cascaded down to staff through senior managers in each sector.

A breakdown of the 106 staff respondents is presented in Table 1.

Table 1. Respondents in the staff questionnaire

Sector	Staff set	Total staff in set in Fife	Total no. of staff sent questionnaires	No. of questionnaires returned
Acute	Consultants	12	12	6
Acute	Cancer nurse specialists	19	19	10
Acute	Surgical ward staff	120 (approx)	18	8
Acute	Medical ward staff	Not known	22	16
Community	Community nurses	375	74	34
Community	GPs	271	271	5
Community	Palliative care nurses	7	7	3
Social Care	Social workers	200	27	8
Statutory	Benefit staff	Not known	8	7
Voluntary	Advice agencies	Not known	9	9
Totals			467	106

6.2.2 Staff focus group respondents

Respondents of the questionnaire survey were asked to indicate if they would be willing to take part in a focus group. The original intention of the project was to conduct a two staff focus groups (one with social care and voluntary staff, the other with nursing and medical staff) in each of the 5 localities of Fife (n=10). However due to the lack of respondents being available or indicating an interest in taking part in a focus group

we held one focus group in a central location with six professionals that reflected the diversity of sectors involved, directly or indirectly, in cancer care.

6.2.3 Patient and carer interview sample

The original project plan was to conduct focus groups or individual interviews with patients and carers who had been through the benefits system, and with those who had not, to explore the differences of their experiences and their views on a future service for Fife. Despite extensively recruitment efforts it proved impossible to proceed with the focus groups due to very low recruitment of patients and carers.

Anecdotally, the feedback received suggests that patients perceived that the meetings would involve them in “talking about their private business” despite the recruitment flyer and verbal assurances which stressed that the groups would not be discussing personal finance issues, only the positive aspects and barriers to using the current advice service, and any views on how the services could be improved.

Due to the low recruitment individual interviews were conducted with three patients (two still receiving treatment) and one carer who was reflecting on events that took place some time ago.

6.2.4 Open stall event

In order to gather more information on patient and carer views on welfare benefit advice, the researchers conducted a one-day open stall event at the Kingdom Shopping Centre in Glenrothes in March 2006. During the day the researchers talked to approximately 33 people who had been affected by cancer in some way. Of the 33, 13 people chose to become respondents by completing a short questionnaire. Four of the respondents were current patients or had been treated in the past, and seven were currently or had been a carer in the past.

7. Measures

7.1 Questionnaire

The staff questionnaire was designed around the need to elicit levels of awareness of current welfare benefits, existing referral route, awareness of the advice community in Fife and their view on the most appropriate role of care staff in the advice process. (See Appendix A)

7.2 Staff focus group schedule

Respondents were asked to: Describe their involvement in the patient journey and experience with welfare benefit issues with patients, evaluate the strengths and weaknesses of existing advice provision and speculate on what needed to be done to improve the service in Fife.

7.3 Patient and carer interview schedule

Respondents were asked to reflect on their knowledge and experiences of welfare benefits as patients and carers, and to speculate on what was needed to improve the service in Fife.

7.4 Open stall questionnaire

The questionnaire was a shortened version of the staff questionnaire. (See Appendix B)

8. Ethical Approval

Ethical approval for the project was granted from the Fife and Forth Valley Research Ethic Committee and the Research and Development Office of NHS Fife.

9. Staff questionnaire

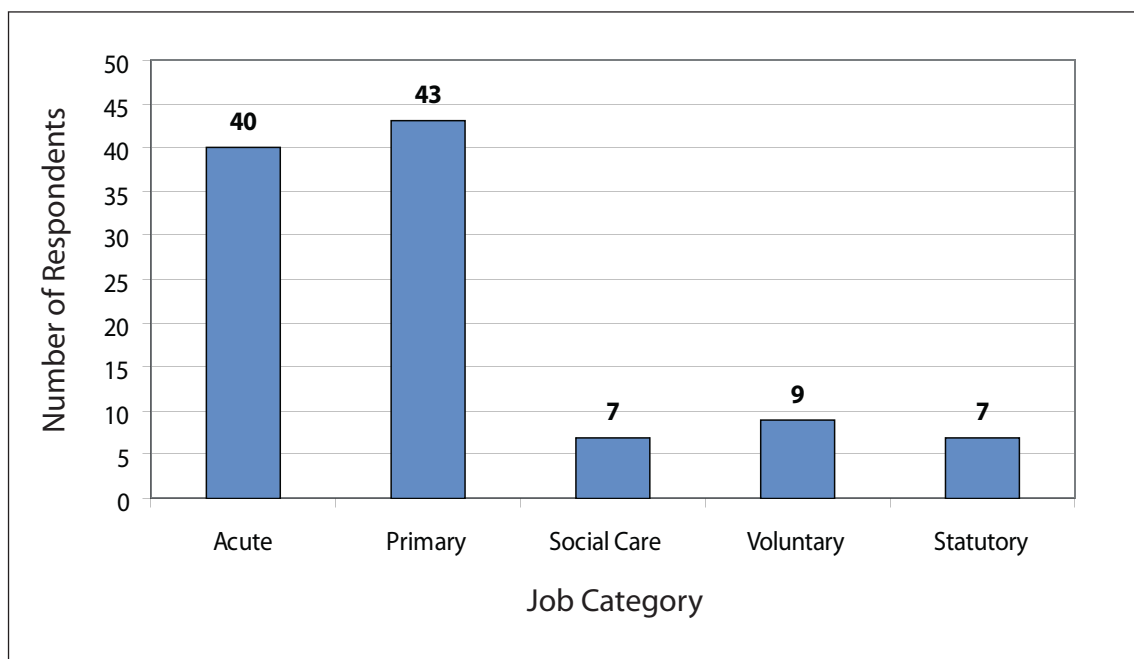
9.1 Section 1 - Respondents

The first section of the questionnaire was designed to gather information about the respondents in terms of their job, the area of Fife they worked in, and their role when working with people affected by cancer.

Q1: Job categories of respondents

This section began by asking the question 'What is your full job title?' Respondents wrote their job title and the responses were categorised into staff groups.

Figure 1. Job categories of respondents (n=106)



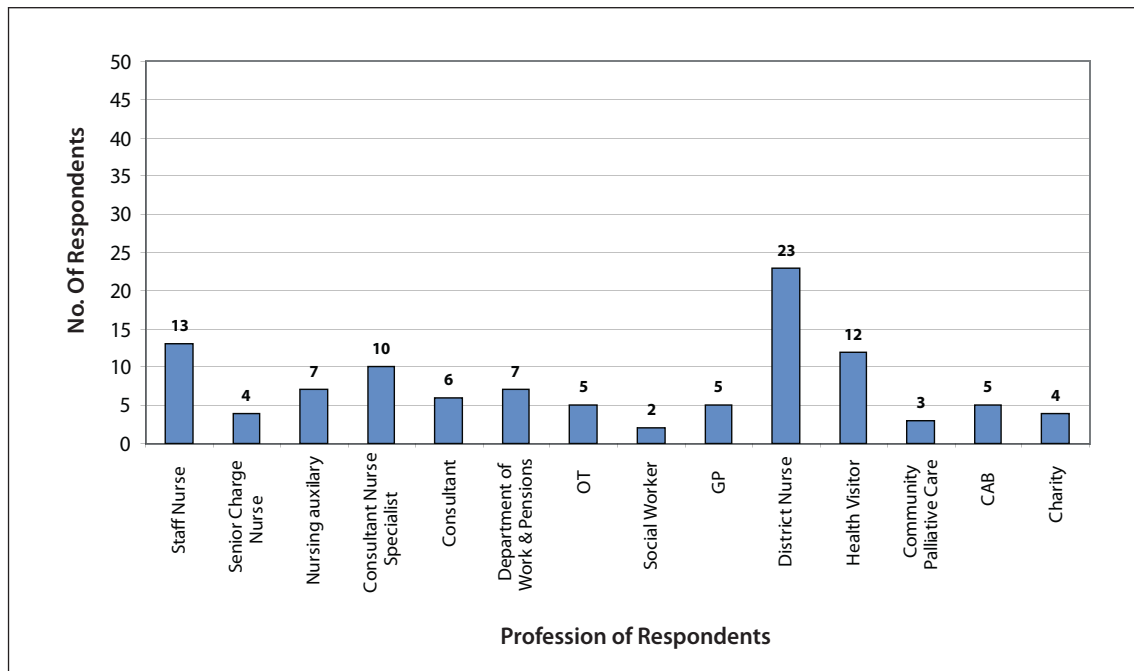
Q2: Geographic spread of respondents

Respondents were asked to provide the address of their work base. The respondents were from a geographical spread across Fife, with 54 from Central Fife, 30 from West Fife, and 20 from North East Fife (2 did not complete the question).

Q3: Roles of respondents within the job categories

Respondents were also asked “What is your role when working with people affected by cancer?” A range of staff were identified within the above categories.

Figure 2. Professional role of respondents when working with people affected by cancer (n=106)



9.2 Section 2 - Knowledge of welfare benefits

The second section of the questionnaire was designed to gather information from respondents about their knowledge of welfare benefits.

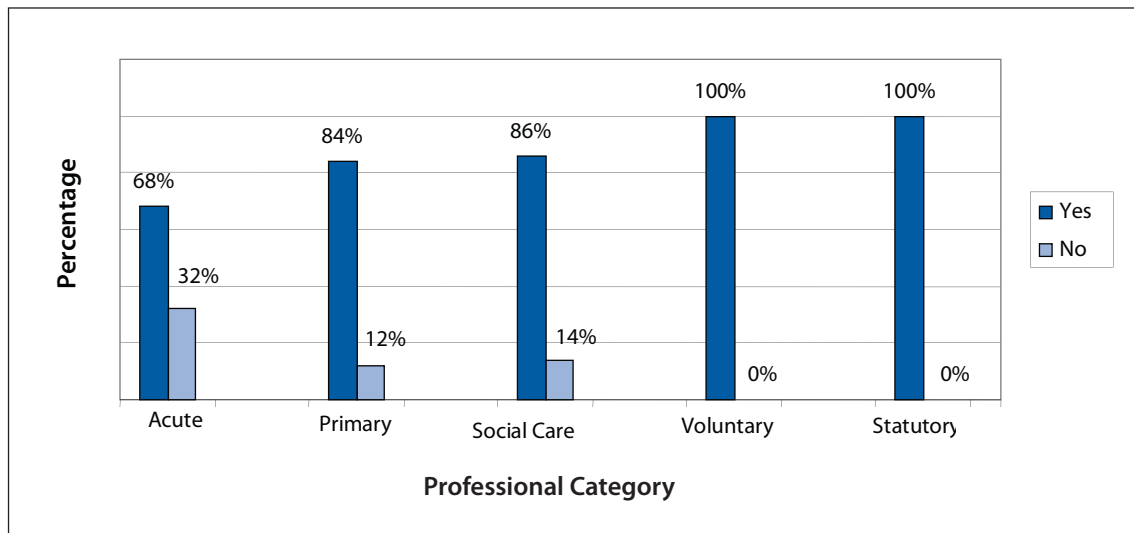
Q4a: Welfare benefits for people affected by cancer

It began by asking the question ‘Do you know of any welfare benefits that people affected by cancer can claim?’ and gave respondents the option of a ‘Yes’ or ‘No’ answer.

Of 106 respondents, 85 (80%) said they knew of welfare benefits that people affected by cancer can claim, while 19 (18%) said they did not, and 2 did not answer the question.

A breakdown of respondents who said 'Yes' and 'No' is given by professional category below.

Figure 3. Knowledge of welfare benefits by professional category (n=104, 2 missing)



Q4b: Welfare benefits for people affected by cancer

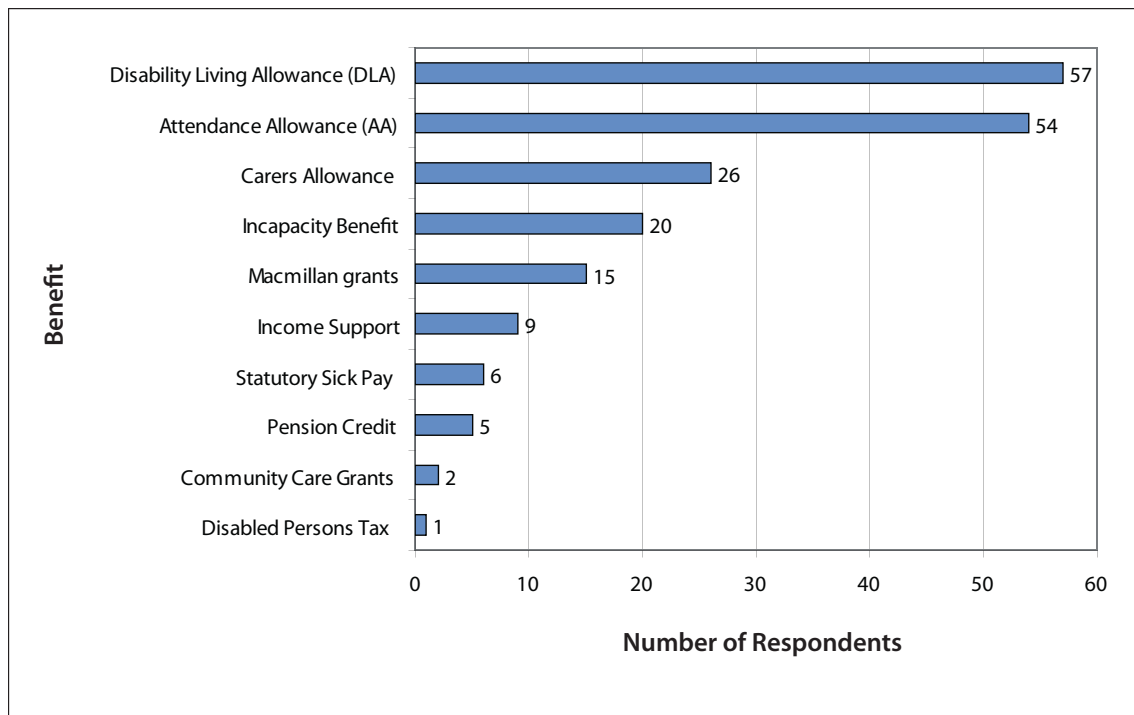
If respondents circled 'Yes' they were asked to list any welfare benefits they thought people affected by cancer can claim.

Disability Living Allowance (DLA) and Attendance Allowance (AA) were the most frequently listed.

Other benefits that a person affected by cancer may be eligible for due to other family or income reasons, but not associated with a diagnosis of cancer, were also listed by respondents. These included: Crisis loan, Working Tax Credit, Housing Benefit, Cold Weather Payment, Council Tax Benefit, Free prescriptions, Disabled parking badge, and Fife Mobility Bus.

There was some confusion evident around the DS1500, also called special rules for Disability Living Allowance, with some respondents listing it as a separate benefit rather than an additional form to be completed with the DLA form. In one case a respondent thought the special rules referred to an 'enhanced attendance allowance'.

Figure 4. Welfare benefits listed by respondents (n=85, 21 missing)

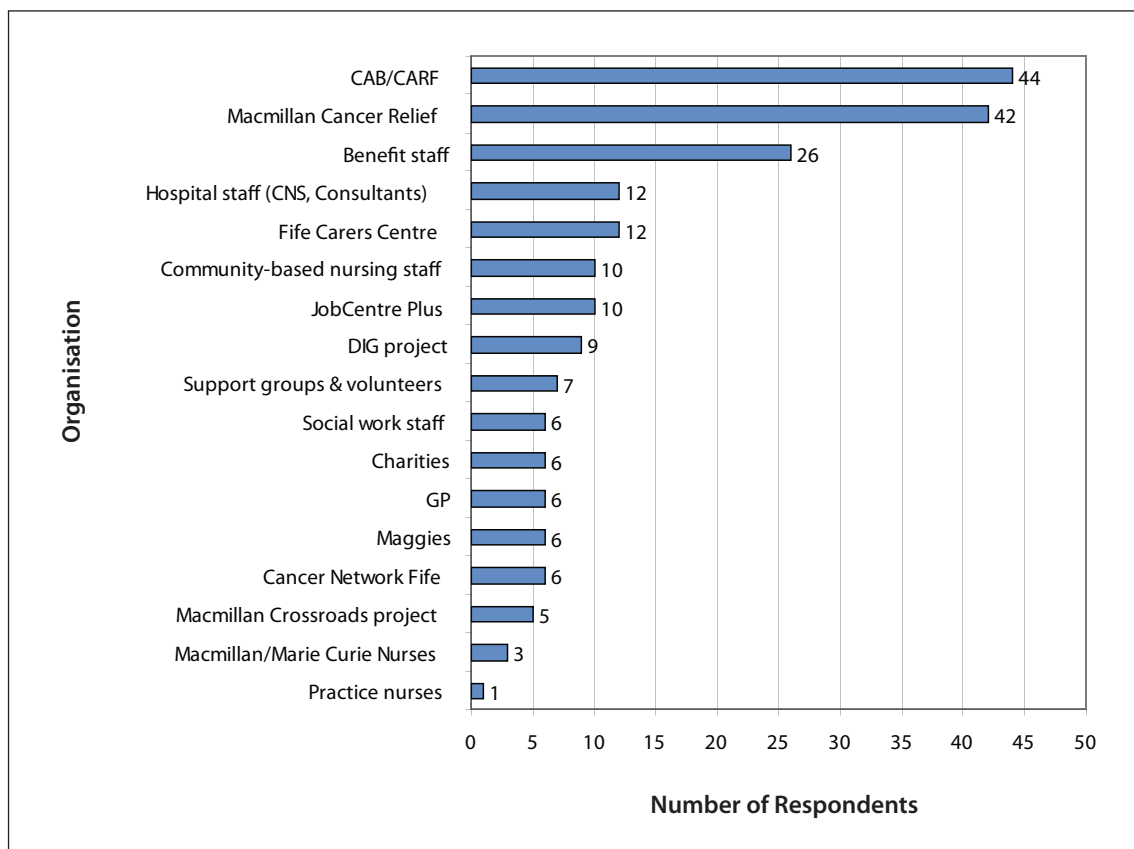


Q5: Organisations who offer advice and assistance

Respondents were also asked to list any organisations, or people, they thought offered advice and assistance about welfare benefits to people affected by cancer in Fife.

The Citizens Advice Bureau/CARF and Macmillan Cancer Support were the most frequently listed by respondents as organisations thought to offer advice and assistance about welfare benefits to people affected by cancer in Fife.

Figure 5. Organisations listed by respondents that offer advice and assistance on welfare benefits (n=95, 11 missing)

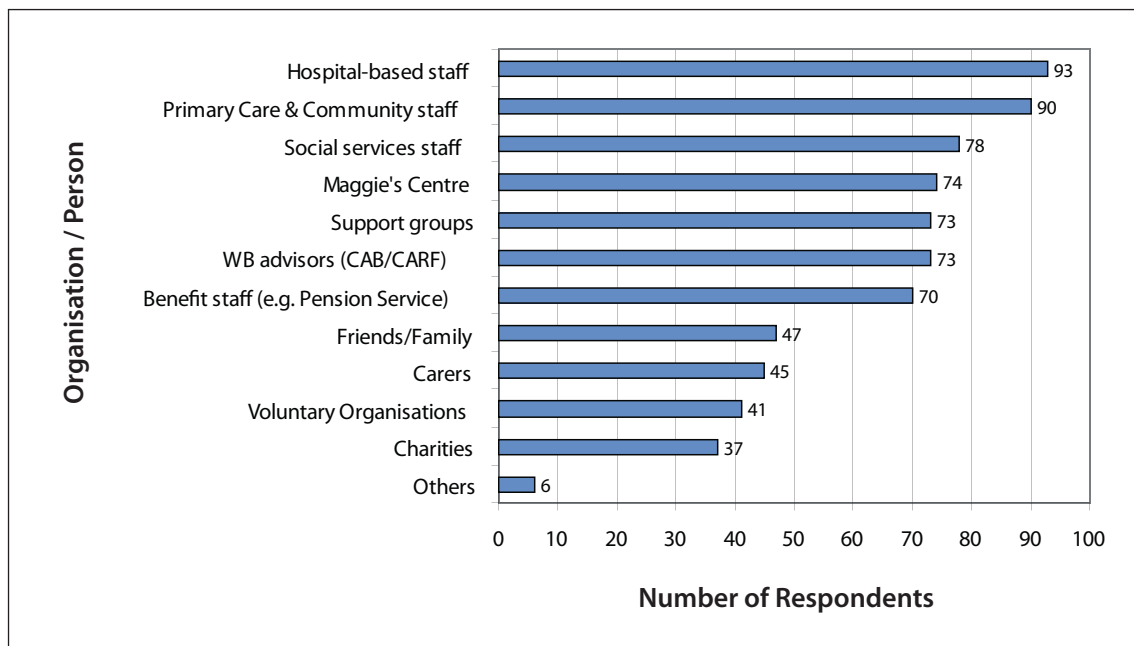


Q6: Raising the welfare benefits issues

Respondents were asked to tick on a list “Whose job do you think is it to raise the issue of welfare benefits with people affected by cancer?”

Clinical staff who may have the most contact with patients during their investigations and treatment are the staff group most frequently ticked by respondents as those who should raise the issue of welfare benefits with people affected by cancer (Hospital-based staff (Acute) and primary care/community staff), above the staff who would typically be providing the advice and support for applications such as social services staff, welfare benefit advisors, and benefits staff.

Figure 6. Organisations or people who should raise the issue of welfare benefits according to respondents (n=106)



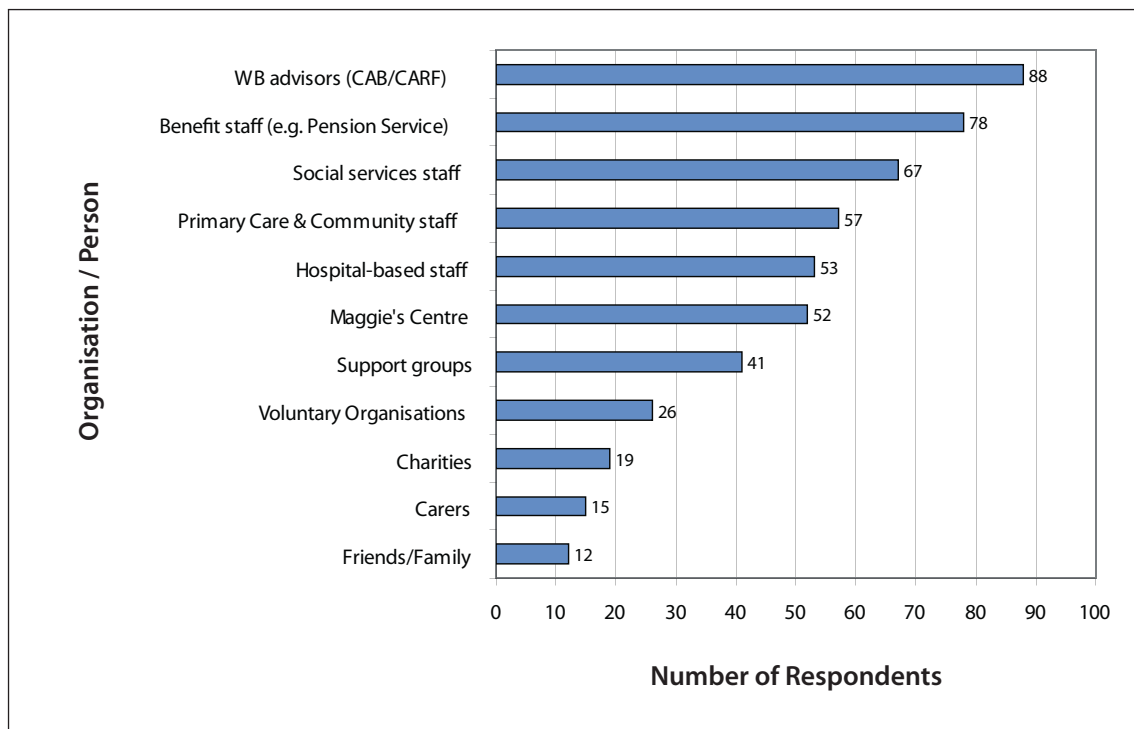
Three 'Others' were listed by respondents: "Cancer centres should have a resource available where patients can access this" (Primary Care, Ref.47); "Chaplain" (Primary Care, Ref.73); and "GP" (Primary Care, Ref.49).

Q7: Providing advice on welfare benefits issues

Respondents were asked to tick on a list "Whose job do you think is it to advise people affected by cancer on what welfare benefits they can apply for?"

Respondents most frequently ticked the staff groups who would typically provide support and advice on this issue. Over half of all respondents ticked CAB/CARF, benefit staff, social services staff, primary care and community staff, and hospital based staff, followed very closely by Maggie Centres.

Figure 7. Organisations or people who should advise on the issue of welfare benefits according to respondents (n=106)



Two 'Others' were listed by respondents: "Chaplain" (Primary Care, Ref.73); and "Carers Centre" (Voluntary, Ref.43).

9.3 Section 3 - Experience of welfare benefits

The third section of the questionnaire was designed to gather information from respondents about their experience of providing information or advice on welfare benefits or signposting to other organisations.

Q8: Current practice

Respondents were asked to circle an answer which fitted their typical action for the question "What do you currently do if a person affected by cancer asks YOU about welfare benefits?"

Table 2. Respondents typical action when asked about welfare benefits (n=104, 2 missing)

N	%	Item
38	(36%)	(a) I find out what benefits are available to the person and help them fill in the forms
30	(29%)	(b) I arrange for them to see a specialist in welfare benefits
15	(14%)	(c) I suggest they contact a welfare benefit specialist
8	(8%)	(d) I tell them that I'm not qualified to advise them and suggest they contact someone
13	(13%)	(e) If you do something not listed above, please tell us below.

The other options (e) listed by respondents tended to consist of staff referring the patient to their specialist nurse or a volunteer specifically available to help with benefit forms: "Clinical Nurse Specialist takes on this role" (Acute, Ref.2); "I contact specialist nurses involved. Breast cancer CNSs often help patients or contact welfare benefits office" (Acute, Ref.4); "Put in touch with colorectal CNS" (Acute, Ref.9); "Refer patient to our volunteer who helps them fill out the forms or refer to Princess Trust" (Acute, Ref.14); "Refer to the Palliative Care Nurse" (Primary Care, Ref.77).

Examining the responses to each item by staff category shows that the type of response varies within the health settings, probably dependent on the staff role, but demonstrates an awareness of the issue in respondents, which is not surprising given their self-selected involvement in the survey. The voluntary and statutory respondents who provide an advice/support service offer direct help primarily.

Table 3. Respondents typical action when asked about welfare benefits by staff category (n=104, 2 missing)

Staff category	Item A (Give direct help)	Item B (Make appointment)	Items C & D (Signpost)	Item E (Other)
Acute (n=40)	6	12	13	9
Primary (n=41, 2 missing)	17	13	7	4
Social care (n=7)	0	4	3	0
Voluntary (n=9)	9	0	0	0
Statutory (n=7)	6	1	0	0
Totals	38	30	23	13

Q9: Experience of raising the issue

Respondents were asked to circle the option that best described their typical action to the question "If the person affected by cancer has never raised the issue of welfare benefits, what would you do?"

Table 4. Respondents experience of raising the issue of welfare benefits (n=101, 5 missing)

N	%	Item
84	79%	(a) I would raise the issue if it was appropriate
17	16%	(b) I would never raise the issue

The missing respondents and those who ticked option (b) that they would never raise the issue were from the Acute staff (n=15 and 4 missing) and Primary Care staff (n=2 and 1 missing) job categories.

Q10: Feedback on assistance given

Respondents were asked "When you help a person access welfare benefits, how do you hear about the progress of the application?"

Table 5. Respondents experience of feedback (n=82, 24 missing)

N	%	Item
58	55%	(a) From the person
11	10%	(b) From the person and the welfare advisor
13	12%	(c) I never hear anything more about it

Examining the responses to each item by staff category identified that the most frequently reported response is that the staff member hears from the patient how their application is progressing.

Table 6. Respondents experience of feedback by staff category (n=82, 24 missing)

Staff category	Item A (From patient)	Item B (From patient and WB advisor)	Items C & D (Never hear)
Acute (n=21, 19 missing)	10	3	8
Primary (n=38, 5 missing)	29	6	3
Social care (n=7)	5	0	2
Voluntary (n=9)	8	1	0
Statutory (n=7)	6	1	0
Totals	58	11	13

9.4 Section 4 - Views on welfare benefit support

The fourth section of the questionnaire was designed to gather information from respondents about their views on raising the issue of welfare benefits with people affected by cancer, any problems they have heard of, and allowed space for respondents to write any other comments.

Q11 to 15: Statements about raising the welfare benefit issue

In order to gather respondents views a number of statements taken from a range of professionals in the same staff categories were listed and respondents were asked to circle whether they agreed or disagreed with them.

Statement 1:

“I’m so busy here attending to the immediate needs of the person that I just don’t have time to talk about things like welfare benefits.”

Table 7. Statement 1 responses by staff category (N=99, 7 missing)

	Acute	Primary Care	Social Care	Voluntary	Statutory	Total
Agreed	9	2	1	0	1	13 (13%)
Disagreed	28	38	6	8	6	86 (87%)
	3 missing	3 missing		1 missing		

Statement 2:

“Welfare benefits are such a complicated subject that I just wouldn’t feel comfortable raising the issue with people in case I misled them by mistake.”

Table 8. Statement 2 responses by staff category (N=100, 6 missing)

	Acute	Primary Care	Social Care	Voluntary	Statutory	Total
Agreed	19	8	2	1	2	32 (32%)
Disagreed	20	31	5	7	5	68 (68%)
	1 missing	4 missing		1 missing		

Statement 3:

“In my past experience, people affected with cancer have never been too keen to talk about personal financial matters.”

Table 9. Statement 3 responses by staff category (N=95, 11 missing)

	Acute	Primary Care	Social Care	Voluntary	Statutory	Total
Agreed	12	6	4	1	1	24 (25%)
Disagreed	25	30	3	8	5	71 (75%)
	3 missing	7 missing			1 missing	

Statement 4:

“I would suggest to a person affected by cancer that they should see someone about welfare benefit if I knew where to send them...”

Table 10. Statement 4 responses by staff category (N=95, 11 missing)

	Acute	Primary Care	Social Care	Voluntary	Statutory	Total
Agreed	29	25	5	6	5	70 (74%)
Disagreed	8	12	1	3	1	25 (26%)
	3 missing	6 missing	1 missing		1 missing	

Statement 5:

“I would help people affected by cancer fill in the welfare benefit form if I received appropriate training.”

Table 11. Statement 5 responses by staff category (N=100, 6 missing)

	Acute	Primary Care	Social Care	Voluntary	Statutory	Total
Agreed	27	28	6	9	5	75 (75%)
Disagreed	11	11	1	0	2	25 (25%)
	2 missing	4 missing				

Q16: Problems respondents have heard of

Respondents were asked to tick any problems they had heard of about the issue of welfare benefits from a list of common problems reported in the literature available.

Table 12. Typical problems ticked by respondents (N= 106)

N	Item
87	Lengthy claim packs
55	Inconsistency in outcome decisions for Attendance Allowance/ Disability Living Allowance resulting in many cases being turned down
46	Appeals process is long and complicated so many can't be bothered to fight the system
46	Lack of suitability of Attendance Allowance/Disability Living Allowance claim pack for people affected by cancer
45	Six month rule for terminally ill is too restrictive
27	Benefits authorities seeking corroborative evidence from GP when GP has not been dealing with patient as the patient is in hospital or attending hospital for treatment
15	Special Rules cases being turned down

Q17: Any other issues or views that responders wanted to share

There were 38 responders who provided additional comments that have been categorized into 5 themes: Effective use of staff time; Organising and providing advice for patients; Issues with the benefit system and rules; Raising the issue with patients; and Patient resistance to claiming benefit.

Theme 1: Effective Use of Time.

"Ideally we would prefer a local advisor be available who could take on this role for us. As a CNS I don't feel this is a good use of time (for me) although it is for patients. Having a service similar to DIG in Edinburgh would be good or an advisor

linked in with the new Maggie's Centre." (Acute, Ref.5)

"There is a definite shortfall in offering help and advice on benefits. the way forward would be social services input into the areas where cancer patients are treated. More and more pressures on nursing staff with lack of training in this area so best leave to experts. This is the way forward to help the financial hardship experienced by cancer patients." (Acute, Ref.10)

Theme 2: Organising and providing advice for patients.

"At present our department does not issue written information on [welfare benefits] to patients this is something we are looking at on discharge." (Acute, Ref.9)

"There is a definite shortfall in offering help and advice on benefits. The way forward would be social services input into the areas where cancer patients are treated. More and more pressures on nursing staff with lack of training in this area so best leave it to experts. This is the way forward to help the financial hardship experienced by cancer patients." (Acute, Ref.10)

"I tend to use the same agency to advise people on benefits and this seems to be successful. However, I never see how the applications develop as people are then home. I am hospital based however these people are always referred to the PCCT who would follow up financial concerns." (Acute, Ref.13)

"There should be more information in leaflet form in public buildings at doctors, chemists, supermarkets, libraries, hospitals as not everyone has computers." (Acute, Ref.22)

"As a staff nurse on a ward for elderly patients, we are frequently providing palliative care. I've only had the post for 1 year but in that time I've never helped a patient regarding welfare benefits but would be very keen to find out more in order to help patients and their families receive the benefits they are entitled to." (Acute, Ref.32)

"I feel strongly about benefits being approached with cancer patients and feel it should be approached as finance can be a huge underlying worry. Training days would be beneficial to ward based staff even basic training at least on how to approach and where to guide people to." (Acute, Ref.34)

"There should be an information pack given to clients when they are informed they have cancer. The pack should inform them in part what benefits they may be entitled to and who they should contact. There are too many people not getting the benefits they are entitled to because no one takes responsibility to inform them of help available." (Statutory, Ref.37)

"The Pension Service has been actively seeking to work alongside other organisations to provide a fuller service. We are still in relatively early days at developing joint teams and closer working can only benefit patients and fellow agencies alike." (Statutory, Ref.39)

"I work with children and young people affected by cancer and some of the issues are different. I feel, through experience, that in most cases I can advise families appropriately about a range of welfare benefits and will represent people at tribunals." (Voluntary, Ref.44)

"Cancer is a hard one re benefits. Long remission periods for cancers that will inevitably be terminal don't always determine whether individuals should apply, as many sufferers keep well for quite a few years and can still work. Six month rule for terminally ill patient-I've seen examples of lung cancer patients Refused AA because she could walk up the stairs –died 3 months later. It was granted and back dated to family. Her own GP had not completed 6 month rule. The pack is getting easier to complete" (Primary Care, Ref.57)

"Everyone who is working with people entitled to benefits should at least know how to Refer on to someone who knows more." (Primary Care, Ref.63)

"We do not have a specific support team for cancer sufferers. Perhaps we need to

look at joint working with NHS staff.” (Social Care, Ref.94)

Theme 3: Issues with the benefit system and rules.

“Many more patients are being turned down, particularly pts with haematological malignancies as most can walk a small distance, make a cup of tea , bathe and dress themselves. What about tiredness, psychological impact, fact they can’t work due to risk of infection. Many patients feel like they are begging.” (Acute, Ref.14)

“Although we have a high application rate the system seems to be prejudiced against the disabilities of patients with haematological cancer and I hear of many people being turned down.” (Acute, Ref.16)

“Unfortunately many cancer sufferers are under the impression that because they have “cancer” they can claim AA/DLA it is not the name of the illness that gets them the benefit it is how the illness affects their mobility or care needs. This can be difficult for patients to understand.” (Statutory, Ref.41)

“GPs are sometimes too slow to return DS1500s or forms costing patients time and money lost. Health Professionals passing the buck to others and delaying time.” (Primary Care, Ref.46)

“People automatically believe that DLA is means tested and don’t wish to apply on the grounds that their finances are adequate”.(Primary Care, Ref.48)

“For using special rules (DS1500) it is necessary to explain to patient their poor expected prognosis. Unable to stop application for DLA following death of applicant without involving the family during their bereavement . Ideally forms should be completed hospital staff on diagnosis to ensure benefit is received promptly.” (Primary Care, Ref.51)

“I have helped people claim benefits using DS1500 and found it satisfactory. In my experience I have found no difficulties. One issue that causes me great concern is the fact that cancer patients get no exemption certificate for their prescriptions.

If for example, we have a cancer patient who requires a dressing (for example a woman who does not work) all the dressings on prescription have to be paid for by the patient. She may not be housebound (collecting children) and not on income support but this seems an unfair expense considering people with a thyroid qualify for an exemption." (Primary Care, Ref.53)

"Clients often think that a diagnosis is enough to get them every benefit available. The law is not clear enough for sufferers." (Voluntary, Ref.80)

"Benefits eventually received tend to result in much lower income level for those people previously working, leaving people in poverty, especially those who are self-employed." (Voluntary, Ref.84)

"I have in the past assisted a patient or representative to complete the DLA/AA book but I cannot afford the time. I always remind them to phone the helpline for assistance. I also remind them when completing the form that they describe the worst day of their illness. As many decide to complete it when they feel better on the day. I find that by describing their worst days, which will vary in length in time, they will receive better payments." (Primary Care, Ref.90)

Theme 4: Raising the issue with patients

"Referring to Q9, in my current workplace, I am not as didactic as raising the issue as a matter of course nor would I never raise the issue. Financial concerns are sensitive issues and I would raise the issue as a result of observation and development of a trusting relationship with the patients and their families and act accordingly." (Acute, Ref.15)

"I feel anyone involved with the person should raise the issue of benefits to save from anyone slipping through the net. You do not need to have in-depth knowledge of benefits- just know who to refer on to." (Acute, Ref.35)

"I am happy to discuss allowances, telling patients and family I know little as they keep changing but I give telephone number of people who can help. If patient or

spouse has no one to help with phone calls, I will contact someone to help them. Never, ever ignore the subject." (Primary Care, Ref.74)

"It can be difficult to discuss claiming benefit under Special Rules if the patient's condition is stable but prognosis poor." (Primary Care, Ref.99)

Theme 5: Patient resistance to claiming benefits

"I have had a number of patients who have been unwilling to claim benefits in spite of being reassured they are entitled to benefit and not means tested." (Acute, Ref.17)

10. Staff focus group

A focus of 6 staff that has contact with people affected by cancer was held in April 2006. Respondents had been recruited through the questionnaire survey or by direct contact they had with the researchers.

10.1 Respondents

The respondents began by describing their role and how the issue of welfare benefit advice was typically involved in their contact with people affected by cancer.

- **A retired nurse who had previously cared for a terminally ill son**

"I'm involved with cancer patients through running a voluntary cancer support group and ...I become involved with patients when they attend and they've been recommended to come from, usually 'Cancerbackup' and the issue of benefits would only come up if they raised it, that this was a problem that they were experiencing."

- **A Day Hospice Co-ordinator**

"I'm a nurse and we have patients who have a disease that is going to limit their life. Sometimes they enter the hospice when they only have a few weeks to live but sometimes they can have a couple of years. At this stage the disease is impacting on their life and it will depend on which other services they have been linked in with, if we would address the benefit issues. But sometimes they were only diagnosed a few weeks and they're still emotionally unable to deal with information and mainly they come into our team and perhaps we would have to address issues especially if the family had financial problems that impacted on their ability to visit the patient and support the family at home. You know so we may have to, do it very soon after meeting the patient."

- **Retired social worker, co-ordinator of patient support at a day-unit**

"I'm a retired Senior Social Worker and have been doing volunteer counselling

for about 7 years now. I tend to become involved with the patient quite early on in their journey and they can be referred either by the nursing staff, by themselves even and by the consultants so I cover the Day Unit and the Ward. So the counselling bit can be quite involved as you would imagine but the problem of benefits certainly rears its head quite often early on and it depends on the patients needs and if perhaps the knowledge that they may have or may not have about benefits but if they don't mention it, I tend to mention it quite early on in the situation."

- **A district staff nurse**

"I'm a district staff nurse and we meet the patients really at different stages just depending on what their needs are...again it depends on the patient. Sometimes we will mention benefits, if we think that it's an issue. And other times, we don't. It depends at what stage they're at and what other people are involved with them. But it just varies really relating to the patient."

- **A senior children's social worker in the voluntary sector**

"I'm a Senior Social Worker funded by the largest children's cancer charities in the UK and [are based in]a regional treatment centre so it's quite a big catchment area and I'm very much part of the multi-disciplinary team on our Oncology ward and we meet, myself and my colleague, meet all the newly diagnosed families, within probably, 14 days of diagnosis and one of the areas that we would be assessing early on is about the whole financial status and so the issue of benefits will probably come up at that point."

- **Hospital based social worker employed by Fife Council**

"I'm a Social Worker in an early supported discharge team. We're predominantly a rehabilitation team. We work short term with people for 2 weeks to re-establish them back home. Mostly it's to do with fractures, breaks and all things like that. But occasionally we come across people who may have a diagnosis for cancer as well. The regard of benefits, it's because of the nature of the team. We've got Nurse, Physio, Occupational Therapist, Home-Care, Rehab Assistants, Social Worker. We

use a holistic approach, so it's actually seen as something that happens early to everybody, [looking at] benefits as well as diet and all the other aspects that we do."

10.2 Focus group schedule

The group were asked to comment on two main topics:

- What do you think are the strengths and weaknesses of the current welfare benefit advice services available to people affected by cancer in Fife?
- Building on the strengths of current services, what would the characteristics of a quality welfare benefit advice service for people affected by cancer in Fife look like?

The respondents all occupied distinctive niches within the care framework and admitted to only having partial knowledge of the WBA issue. Nevertheless, a number of themes emerged usefully highlighting what were seen as broadly positive or negative aspects of the current position.

10.3 Focus group analysis

Question 1: The current situation

Respondents raised both positive and negative aspects of the current situation. The positive aspects were:

- The developing practice of taking a holistic view of the patient which included how money issues impacted on patient well-being.
- Local DWP staff seen as partners.
- A range of professionals are willing to take the initiative through the patient's journey.
- A degree of inter-agency working is happening, including the acute sector.
- There is an appreciation of limited skill in face of complexity.
- There is an appreciation that welfare benefits are not limited to the central state

providers, and an often complex path must be taken between state, local authority and charity provided benefits.

- There is an appreciation that cancer journeys are complex, so what works for one patient in terms of timing the welfare benefit advice might not be appropriate for another patient.

The negative aspects were:

- There is a perception that there is a lack of information available.
- DWP procedures are seen as complex, opaque and often arbitrary.
- Patients are often in shock after diagnosis; leading to the problem of knowing when is the right time to raise welfare benefit issue on practical grounds when there may be clinical/care grounds for not raising the issue.

Question 2: Developing a service in Fife

The group were asked to think about key components in developing a WBA service in Fife. The group approached this issue as three dimensions⁸:

- The Service Dimension (the where, when and what);
- The Attribute dimension (what qualities, aptitudes and knowledge the welfare benefits advisor needed); and
- The Inter-agency dimension (the role of care workers in not only contributing to making the service work but the role of the service in improving the quality of care offered by the respondents' host agencies).

Theme 1: The Service Dimension

- **The Service needs to work within and across agencies boundaries**

"It's needing to deal with 3 different agencies, the Local Authority, the DHSS or benefit agency, Job Plus or what ever you want to call it, but also charities. A lot of the time you're actually going to charities as well and it does need a co-ordinated

⁸It should be noted, as with any list like this, that themes and categories overlap and that the respondents didn't always offer up neat, packaged solutions to problems.

approach because if it's different agencies, you've got the 3 different agencies involved, you go into charity, you can affect other payments and such like as well. And the income that can come into a family. "

- **The Service must work proactively**

"But it's actually to be offering this service to everybody and I think I agree with you that they need somebody to take that on for them, say 'Right, well look I've got this form now, can we make a time to do this, sor when are you next up in the hospital?' 'Do you want to take it away and have a look at it?' 'Cos some people are fine, you know can do it. But it's actually to, steering them there and knowing that they can come back to you."

"What must it feel like for a benefit person to actually ring you up and say, 'Look you know, I'd like to come and see you about benefits."

- **The Service should work to empower the patient**

"It's control, you know controlling your own life is also part of this as well. There's so much else going on that you haven't got control over. "

- **Types of visit available - Office, phone or home?**

"Flexibility. To cover everything [laughs]. Well, I mean I think it has to be something that's flexible because as I said you know you're dealing with people who have got lots of different needs, different strengths, different weaknesses."

"Yeah, and some people maybe wouldn't want them coming to their house or you know would rather do it over the phone so."

"I think sometimes I find, when you actually do it in the person's home, you're actually identifying other things...You know, this person, you know their carpets are all full of holes and trip hazards and you know. It is again about the whole thing."

- **A feedback system**

“What we need to know is that it’s been sorted.”

“Because do you not sometimes worry that things go off into the abyss and nothing happens. So it’s about communication.”

- **A “Service level agreement”**

“Can I also say that it needs some form of service level agreement in actually how it’s gonna be delivered because one of things, it needs timescales, it needs to be realistic timescales, that you know if a referral’s made, is it gonna be picked up within a week, two weeks, a month? Because all it does, if there’s no timescales that everybody knows about, there’s another profession going in you’re just gonna keep it being raised and raised and raised.”

Theme 2: The Attribute Dimension

- **More than just a welfare benefits advisor**

“you don’t need somebody who can just do benefits you need someone who can actually be a financial adviser to a family because that’s what they need. Because it needs to be kept up to date. As the income or as the money that you’ve got goes down it opens up other benefits you may be entitled to because most benefits are on a sliding scale.”

“It’s just, you know we’re talking about DLA and Attendance Allowance but there are others who go off sick when they’re working and don’t immediately get their Incapacity Benefit because of the system being so slow and they then have to fill up as well as the Incapacity Benefit form, they have to fill in a Income Support form, so that while they work through all the problems of looking through the Incapacity form, they can grant them Income Support until that’s through so there’s all these problems attached to people who are young and working when they’re diagnosed.”

“Basically one person is going to be able to answer their questions. You know if

we go in, they maybe ask us something and we really know very little about it so then we have to say 'Well I don't really know but I'll have to see if I can find out for you.' And then straight away that puts them off cos then there like 'Oh don't bother, it's too much effort don't bother.'"

- **An understanding of the variety and complexity of each patient's journey**

"initially when they're diagnosed there's so many people involved, you know with them that if they've been healthy before and have never had anything to do, with healthcare and suddenly there's like all of these people involved. It's quite daunting, you know and sometimes it's just not worth the hassle to them you know, to try."

"All different. All got different needs."

"You see you've got the treatment phase and the maintenance phase. Then quite often after the treatment they can have a good few years with good quality of life. And they might not actually qualify for all the benefits that they already have."

"But the other thing is, the longer timescale, cos as you said you know the person may not need, you know on, on diagnosis and they have their immediate treatments and then they're fine, they go back, so this financial person, [the patient would say] 'I don't need him at all. I don't need any help I'm gong back to my work.' And then 2 years down the line, it all kicks in. Then, that's when they need it, so at the initial onset of their illness, that could be far from necessary."

- **A trusted professional**

"To be able to say, you know the social worker does this and I do this and this person can help you with financial matters"

"And it's not about having a tick list, it's about the person goes out to talk to them about financial matters and then deal with what's appropriate for them."

"That would be amazing to have somebody like that at a time of stress wouldn't

it?”

Theme 3: The inter-agency dimension

- **An appreciation that the WBA service is seen as part of collaborative effort**

“Now we actually discuss each palliative person and there’s certain things that we have to complete. Which we probably did before but not so formally, you know, so now you know these things are not getting missed because, like the DS1500; there’s like a section, have they had, has that been completed?”

“it’s people like the CAB or CARF that surround us. Because they have the spectrum of knowledge.”

“But again if it’s an organised person, they would build up relationships with all the different agencies that are around, but it could also be acting as other professionals do in the game.”

“It still has to be collaborative, doesn’t it? Cos I often find that patients are unrealistic in actually defining their own needs. You know fear can make them over emphasise their problems and denial can make them under emphasise them.”

- **Practices to aid the WBA effort**

“Well we work in a multidisciplinary way I think.”

“But who’s going to take responsibility? Who’s going to do it? This is where again if we had the flowchart or something that person knows that they have done their job because you could think it’s your job, the GP could think its theirs, you could think...So somebody has to be responsible.”

“If you had a care pathway, a flowchart or something, that each bit’s ticked.”

“cos staff are required to raise issues so you’re gonna have this standard letter possibly that would be given to I don’t know what other things they might get on

discharge or whatever, or it sent, I don't know I mean, part of discharge planning or...? I don't know?"

"You know they're not always kept in, you know a lot of the patients we deal with, they go in for investigations might not have surgery, they might not have you know, they might not be In-Patients. They might go and see consultants; they may have chemotherapy, radiotherapy, all as day cases and never be an In-Patient. You know they might not be in the situation where they would be technically discharged from anywhere you know what I mean"

"Regardless of what the path is, the patient is going to go through their GP to whatever and if the primary care team are aware that this service is available, then they can decide within their own practice who should see the patient with regards to the form, you know..."

"We have 2 practices at our surgery. One is involved in Gold Standards and one is not. You know, so it's er, it's really down to the practice. I mean obviously if they were involved in Gold Standards, yes there would be the perfect opportunity to include it but that's not always gonna be the case"

Question 3: Bullet points

The respondents were asked to summarise their thinking in bullet point form at the end of the focus group.

- The service provider must develop strategies for raising awareness of the welfare benefits service with patients and carers at a time when they may be feeling distressed and confused.
- Both the service provider and clinical/care staff must work on the timing of information-giving, offering interventions at every appropriate stage of the patient journey.
- Active consent must be sought. The patient should always be in control of the access process so that a feeling of control is established and maintained
- The welfare benefits advisor role should be holistic. Not just giving welfare benefits

advice but taking a more in-depth look at all aspects of the financial “health” of the person affected by cancer.

- Clinical/care staff need to see WBA as part of the emergent practice of inter-disciplinary working.
- The welfare benefits advisor should be conversant with the complex nature of cancers and their differing effects on the lives of patients. Cancer journeys are complex, and any welfare benefit advice service serving this group of patients should be sensitive to that complexity.
- Clinical/care staff should expect an initial feedback document, confirming that the advice process is underway.

Welfare benefit advice staff should be professionally qualified, or accredited, in the field and the service as a whole should be subject to a service level agreement.

10.4 Summary of staff focus group

In the focus group discussion a central issue of trust emerged. Trust in the individual advisor, trust in the systems to achieve the best result for the patient and trust in the ability of the care agencies to establish a working relationship with the welfare benefit advice service. None of the respondents claimed to have the whole answer but all appreciated that a welfare benefit advice service to meet the needs of people affected by cancer and the key staff involved in their care would require a great deal of planning to grapple with the complexity of the patient experience and the difficulties in making the service patient-centred.

11. Patient and carer interviews

Three patients and one carer were interviewed for the project. Each interviewee had a complex and individual story to tell. Of the three patients, only one had formally applied for welfare benefits, while the carer applied for benefits on his partner's behalf. The patients' experiences with welfare benefits were:

- **One patient had applied for benefits and had real difficulty with the process of qualifying for DLA**
- **One patient had not applied for benefits through ignorance**
- **One patient had no need to apply for benefits**

With such diversity and low number of respondents, it was difficult to draw together common themes, but all the patients, with the benefit of hindsight reflected that:

- All had no prior knowledge of the benefits system or any real idea where one went to get advice:

"Um, from the doctor's surgery, em, region local press and the rights office which is CAB."

"Eh, no. The job centre has something like, I think they have leaflets in the job centre."

- In principle, all patients could see the benefit of advice on benefit, but felt there was no guarantee that applying for benefit would make any real difference:

"Yeah. So they helped me to put this together and still it came back, ah, that I didn't qualify. So, ah, it's just a nightmare. I've dreaded brown envelopes coming into the house... everything I have come across has been negative".

- Timing of active advice should be as close to diagnosis as possible although patients

were aware that their emotional state might mean that welfare benefit advice might not have been “taken in”:

“As a cancer sufferer I can only speak on my own experience but from the time of diagnosis you are in shock... After that you’re having to deal with the diagnosis and then wait for surgery which is always quick”.

- Awareness could be raised by display materials being seen in care-settings but again, the patients interviewed couldn’t attest that they would’ve taken much notice:

“Well when we were part of the support group we took on board signed posters, putting them all strategic places. Now I have to say it didn’t draw any more people into the support group. Cancer patients, em, are very hard people to get to...”

- The individual journeys through cancer are complex, with diverse patterns of formal treatment and periods of self-care, so patients also speculated that welfare advice and support might be best applied during hiatus periods:

“...at the first you know where you can get help and then it should be followed up are you getting the help that you need? ... Do you have enough information to know that you’ve got the help there if you want it. There should be a follow up and I think that should be once they’re in recovery after surgery, once they’re in recovery before they start the chemotherapy or the radiotherapy. Because that’s another set of things they have to deal with.”

- Illness is a stigmatising, isolating process in itself, accessing that psycho-social condition with respect to a person’s private, financial business presents a difficult challenge for the advice specialist.

“It was very stressful. I say you know I can fight the cancer but I can’t fight this lot. I just dreaded every envelope that come in. I thought I’m not a negative person but this, it made you feel as if I was telling porkie pies.”

The carer interviewed worked as a professional in occupational health and might be

thought atypical in some respects but drawing on his own professional as well as personal experience, said that :

- Stigma attached to the whole area of claiming for welfare benefits and required real sensitivity in designing interventions.

“...you could say that, you read the articles in the papers of people that are scroungers you know and yet on the other hand they don’t claim. Sometimes they wait until they’re stuck and in a corner and then somebody suggests and they come rather than come in to begin with.”

- In principle, welfare benefits advice should work irrespective of the immediate cultural setting, but admitted that deciding if there was a specific problem within Fife wasn’t an easy issue to resolve.

“And I don’t know whether it’s this sort of mining community idea in the hinterland that you know tough guy type of thing, community sticking together, I’m guessing, I’m guessing.”

11.1 Summary of patient and carer interviews

The patient views summarised here are not that different to other work that has been conducted on this topic. The patients who were interviewed are currently further along their patient journey than those who are given a diagnosis and fully acknowledge that they can “look back” with some degree of clarity about their situations which may not be the case with patients who are just receiving a diagnosis, especially if they have no prior contact with the benefits system. Although it was not in the topics for the interview a key issues throughout the interviews was the expressed trust in the cancer care patients received. Patients gave up autonomy because they trusted the care staff delivering their care. When dealing with an issue that can be sensitive such as personal finance perhaps a similar level of trust is also needed from patients and anyone who would refer a patient.

12. Open stall event

Of the 33 people spoken to during the open stall event in a shopping centre 13 chose to complete the short questionnaire.

12.1 Section 1 - Knowledge of welfare benefits

The first section of the questionnaire was designed to gather information from respondents about their knowledge of, and organisations who provide information and advice on, welfare benefits.

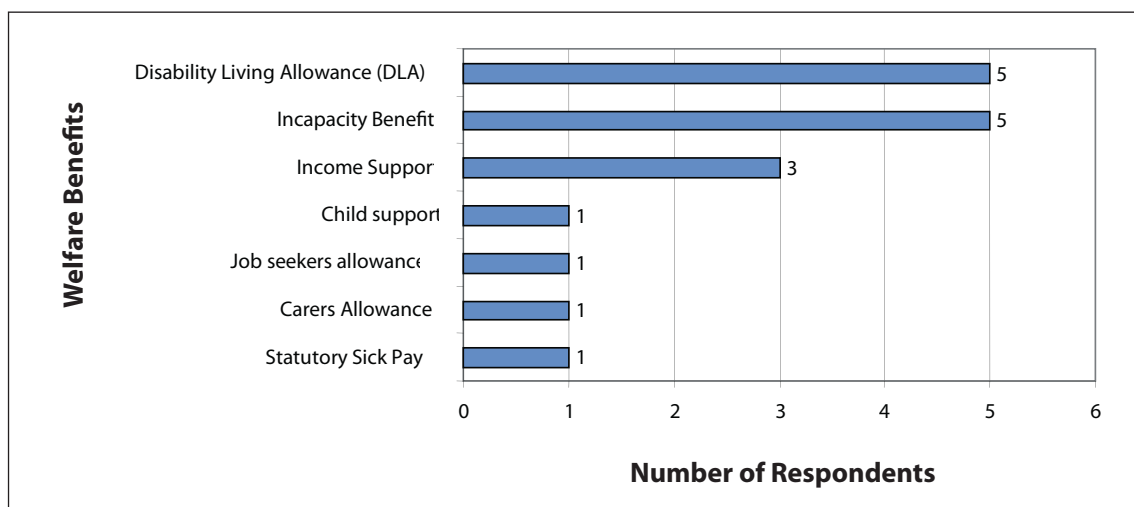
Q1a. Welfare benefits

Respondents were asked 'Do you know of any welfare benefits?' and gave the option of a 'Yes' or 'No' answer. Of the 13 respondents, 8 (62%) said they knew of welfare benefits that people affected by cancer can claim, while 5 (38%) said they did not.

Q1b. Welfare benefits

Respondents who said 'Yes' to the previous question they were asked to list any welfare benefits they knew. The most frequently reported benefits were Incapacity Benefit and Disability Living Allowance which were both cited by 5 respondents.

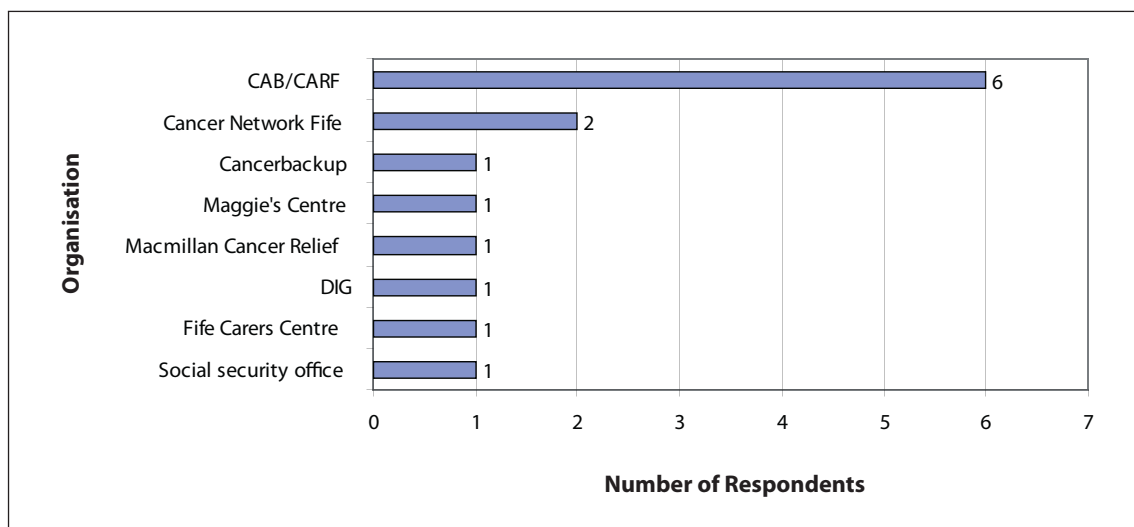
Figure 8. Welfare benefits listed by respondents (n=8)



Q2. Organisations who offer advice and assistance

Respondents were asked “Do you know of any organisations, or people, you think offer advice and assistance about welfare benefits in Fife?” Of the 13 respondents 8 mentioned at least one organisation. The organisation most frequently reported was the Citizens Advice Bureau which was cited by 6 respondents.

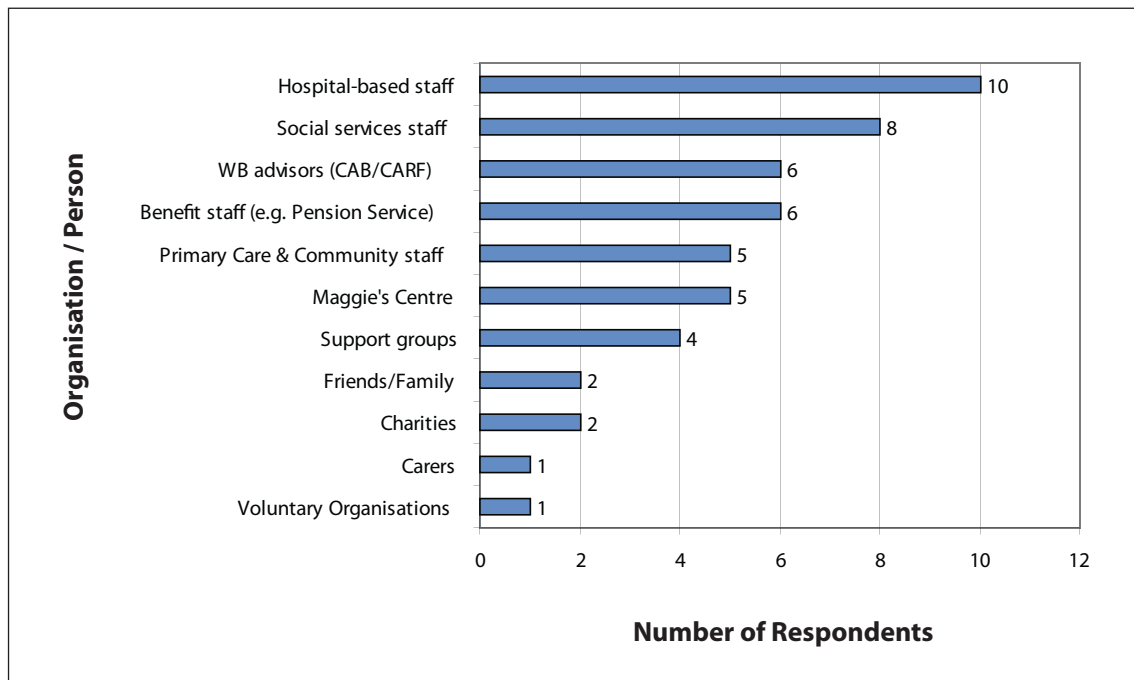
Figure 9. Organisations listed by respondents that offer advice and assistance on welfare benefits in Fife (n=8)



Q3. Raising the welfare benefit issues

Respondents were asked to tick on a list “Whose job do you think it is to raise the issue of welfare benefits with people affected by cancer?”

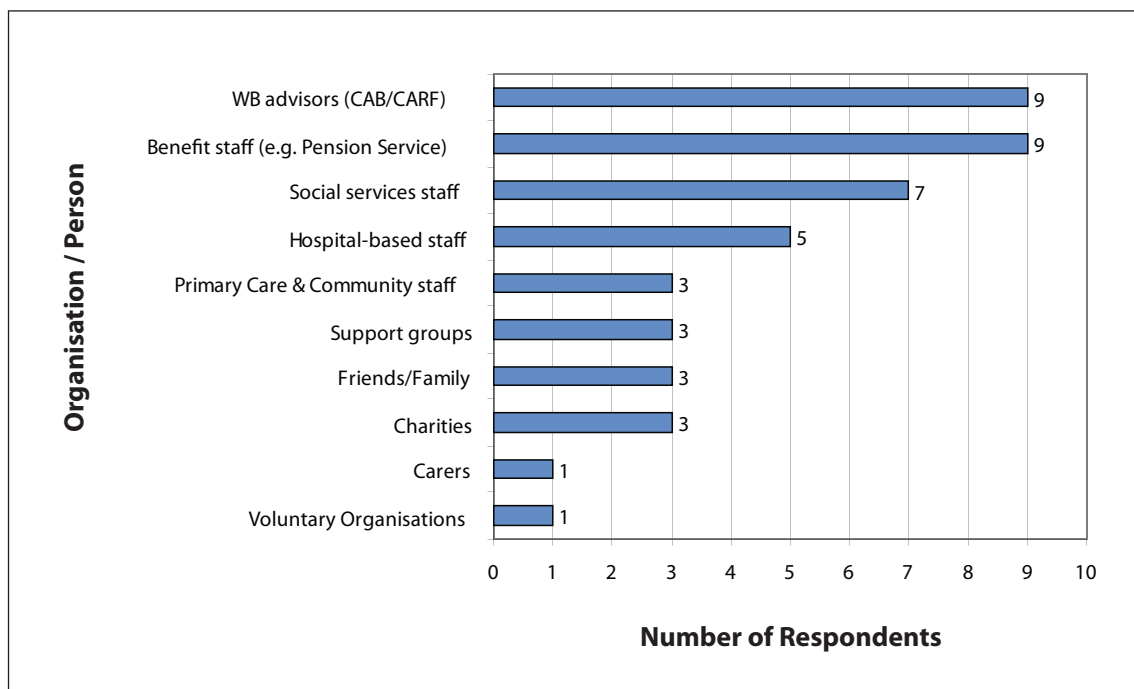
Figure 10. Organisations or people who should raise the issues of welfare benefits according to respondents (n=13)



Q4. Providing advice on welfare benefits issues

Respondents were asked to tick on a list "Whose job do you think it is to advise people affected by cancer on what welfare benefits they can apply for?"

Figure 11. Organisations or people who should advise on the issues of welfare benefits according to respondents (n=13)



Q5. Views on a future welfare benefit service

The final question on the questionnaire was an open question of “What do you think is important for a welfare benefit service aimed at people affected by cancer?” This question prompted lengthy discussions with some respondents about their views on a future welfare benefit service that would meet the needs of people affected by cancer and key staff in Fife. All 13 respondents answered this question citing key issues they felt were important for a future welfare benefit service.

- More support and information should exist for carers (n=6)
- Early access to advice is essential (n=5)
- Home visits should be a component of any service (n=4)
- The benefit system should be clearer to understand (n=3)
- NHS staff should not have to give advice and direct support (n=2)
- Help should be available with forms (n=2)
- There should be a simple referral system (n=1)
- Advice workers need good knowledge of cancer issues (n=1)

- Health workers need basic knowledge of benefits and to know where to refer or signpost patients (n=1)

As was mentioned in the method section of the report the project had difficulty recruiting patients and carers so held an open stall day to gather views from members of the public. The data reported here is limited as only 13 people completed the questionnaire but it is interesting to note that their responses and wishes for a future service do not differ greatly from those reported in the staff questionnaire.

One key finding of the day was the importance of the Macmillan logo for attracting people over to the stall. Patients, carers and the “general public” recognised Macmillan as a trusted “brand” which attracted them to come over to the stall to see what was being done. Although it was clear that these groups have different awareness of what Macmillan actually do their association with the brand name could be very important for any future service.

13. Discussion

13.1 Current welfare benefit advice provision

As outlined in section 4 of the report, there are a number of projects in Scotland funded by Macmillan Cancer Support which have different service models. These projects have used various methods to establish themselves with referrers and promote awareness of their services with the public, with varying outcomes in terms of costs and benefits of their provision.

In Fife, there is no existing specialist provision for people affected by cancer although the Edinburgh-based DIG project funded by Macmillan does have clients who are cancer patients living in Fife.

Existing generic service providers and organisations located in Fife do provide advice and support to cancer patients but this is done on an ad-hoc, case-by-case basis. As stated in section 5 of the report, the informal referral figures that have been reported to the authors indicate that there is a system of referral and advice at work in Fife using the generic service providers. The pervading view seems to suggest that the existing services are doing a good job to meet much of the current demand, although improvements to patient awareness, additional support to these services and more joined-up working would be welcome.

As expected, CAB/CARF was the most frequently cited organisation known to offer welfare benefit advice and support in both the staff and public questionnaire surveys. In the staff survey Macmillan Cancer Relief also featured strongly as either the first or second named source with CAB/CARF.

The development of the Fife Online Referral Tracking system (FORT), points to a very positive initiative in integrating the work of voluntary and statutory sectors in addressing the broad welfare rights agenda. At the time of writing this report NHS Fife had yet to sign up to FORT as a corporate , referring partner, which may be a constraining factor in the short term for the planning of a future service which integrates welfare benefit

advice or signposting into the care pathway of cancer patients in a systematic way.

13.2 Knowledge of welfare benefits

The data reported here supports previous findings that staff see Disability Living Allowance (DLA) and Attendance Allowance (AA) as the key benefits to apply for in the case of patients and carers. The public respondents at the open stall event also cited DLA as the key benefit.

There was some confusion reported by staff about the DS1500, also known as special rules, with some regarding it as a separate benefit rather than a second part of the application for Disability Living Allowance. Other issues or barriers to gaining this benefit highlighted were uncertainty of when to apply for it, the difficulty of discussing a patient's prognosis particularly when they appear to be doing well, and the need to contact the patient's family during their bereavement in order to stop the application if the patient should die.

The issue of suitability of these most often cited benefits for cancer patients and the reported difficulties in making applications are ultimately questions that intrudes into DWP policy and cannot be addressed at the local level of advice practice. However it was widely acknowledged by staff that completing the benefit application forms is a skill that requires technical knowledge and lots of practice in order to do it well.

It was interesting to note that Macmillan grants were listed as a welfare benefit that people affected by cancer could claim by staff completing the questionnaire. Although not a welfare benefit in the typical sense, it may be due to Macmillan's high profile as a source of help for people affected by cancer that even if staff don't feel knowledgeable about benefits they can still cite an organisation who they think can provide support.

Due to the low number of patients and carers involved in this project limited comment can be made about what their knowledge of welfare benefits. However, the report by Chalmers and Jones (2005) looking at projects elsewhere in Scotland concluded that the level of knowledge about benefits amongst patients is dependent on whether they were in receipt of benefits prior to diagnosis and it is unlikely that the Fife situation

would be markedly different.

13.3 How staff involved in the care of people affected by cancer see their role

The staff questionnaire and focus group respondents demonstrate that staff from a range of professional groups have an interest in the welfare benefit issue despite different levels of knowledge, and the reported difficulties or delays in securing these benefits for patients.

The staff questionnaire results suggest that the staff respondents see a clear role for clinical staff that are hospital-based, as well as in primary care and the community, for raising the issue or signposting the patient to the relevant services. They also reported the view that detailed advice and support should be offered by staff groups who would typically be seen as the experts who provide support and advice on this issue such as CAB/CARF, benefit staff, and social services staff. This suggests that staff respondents would generally see a clear division of skills and responsibilities between raising the issue and providing actual support and advice through the process.

The timing of raising the issue and appropriateness of training and awareness for staff was also raised by the staff focus group. Staff identified the need for each staff group who was involved in a patient's journey to have the appropriate knowledge and skill to be of use to the patient at each stage. For example, health care staff should develop strategies for information giving and follow up at the appropriate stages of the patient journey, whereas welfare benefit advice staff need to be knowledgeable about the complex nature of cancer journeys and develop strategies for providing feedback to referrers.

13.4 Future Services in Fife

The division identified above between who should raise the issue and who should provide the advice service was evident in the respondents' views on planning a future service in Fife that would meet the needs of people affected by cancer and the key

staff.

The questionnaire responses demonstrate a wish to provide a good service to patients and acknowledge that some kind of service should be in place. Many staff are happy to raise the issue and would refer patients on if they were unable to provide direct advice themselves. Some of the issues staff felt should be taken into account include considering the availability of staff time for this issue when balanced with their other roles and responsibilities, some clinical staff being unsure about their own expertise to advise on the issue so preferring to signpost patients rather than deliver an advice service, and the lack of feedback received from advice services when referrals are made from clinical staff.

Discussions in the staff focus group, made up of people with an expressed interest in the benefits issue, centred on the detail of provision such as how the service should be delivered; the need for staff to have the appropriate skills and knowledge for their role whether that is where to refer patients on to or an awareness of the complexities of the cancer journey; the importance of trust and feedback between referrers, service providers and service users; the need for patients to feel a measure of control in accessing the advice service; the need for service level agreements; and attention to the level of integration and joined-up working between an advice service and other care agencies.

Patient and carer views canvassed broadly support the findings of Chalmers and Jones on how future services should work. Overwhelmingly, existing patients stress that advice should be given as soon as possible after diagnosis while acknowledging that there is a potential problem with “taking it all in” and that the need for advice and support on money matters might vary widely between patients and during the individual patient’s journey. Staff should also be sensitive to the stigma which can be attached to being ill and claiming benefit among some patients.

In addition to some of the points noted above the open stall respondents also called for more support to be available for carers throughout the process; for NHS staff to refer or signpost patients rather than giving direct advice; and that home visits should be available for patients where necessary.

Taken together, these sources of opinion are complementary and demonstrate that the principle of welfare benefit advice provision is widely accepted. The findings support previous recommendations in the literature on the need for staff expertise (i.e. clinical and advice staff to have appropriate knowledge and training for their role in the process); appropriate timing of benefit advice and information (i.e. ensuring information is available from the beginning of the patient journey, avoiding late applications, and solving problems around special rules applications); increasing awareness of benefits; encouraging health and social care professionals to take an active role; and the need to consider the psychosocial impact of the patient of applying for benefits by making it an accepted part of the patient journey, reducing the stigma attached to claiming benefit and addressing issues of means-testing benefits.

14. Key questions and issues for the Partnership Board

As the project has progressed the evolving data has been discussed with the Partnership Board that oversees the project. Below are some key questions to be considered when planning a new service, some of which have been answered by the data gathered and some are new questions that have been raised by the scoping exercise.

- What elements of a good service are currently being delivered across Fife?
- What additional elements are needed to develop/support current services to increase uptake of benefits in Fife?
- Are there any novel aspects that a new service could provide?
- What training is needed for staff in health, social services and current welfare benefit advice services to improve the patient experience?
- How does any new service ensure it is sustainable and increases the uptake of benefit rather than just re-distributing the current population of potential claimants who would go through existing services?
- How to ensure that the cancer patients most in need, such as those with access problems or who have difficulty travelling, are able to access the service so all of Fife benefits from the new service/support?
- How does any new service fit with current developments such as FORT and the proposed changes of NHS service provision?

Some of the preliminary thoughts for a future service and support have included:

- Development of information packs to be given to patients at an early stage of their journey with details of services
- Development of training for staff working in generic benefit advice services on the cancer journey
- Development of a signposting business card for health staff to distribute to patients or refer to in order to encourage raising of the issue
- The use of out-reach support/advice workers to raise awareness across Fife,

particularly with hard-to-reach groups, and increase uptake of benefits through existing services such as CAB/CARF and the new Maggie's centre in Kirkcaldy

- The use of primary care settings to promote/provide a new service

The proposed shift in the balance of resources from the acute to the primary care sector, expressed through the new Community Health Partnership model, marks a change in NHS priorities with implications far into the future. In the longer term, such a shift in emphasis implies a more integrated, holistic approach to all aspects of health which should incorporate welfare benefit advice. As highlighted in the literature there is very little published evidence available on cancer-specific welfare benefit services in primary care settings. However, there are short-term operational issues that may have to be taken into account in planning the mooted project.

For example, The Herald reported on the 6th of June 2006 that two thirds of Scottish GPs canvassed did not consider their premises fit for purpose in the proposed shift in treatment from acute to primary care settings and cited pressure on space as a major, if short-term, limiting factor in delivering services. ("Need a Doctor? He's in the cupboard". Jennifer Veitch, The Herald, 06/06/06) It is not possible to judge at this stage if this concern over space will be a factor in other areas of primary care, but it may have implications in terms of locating any new outreach service in primary care facilities. Another consideration is that any NHS service change may take place after the Board initiate their new service so there may be some re-design or extension to the service at a later date. This evolving landscape will provide particular challenges impacting on the development issues for the Board. It may also be worth considering how the project will encourage GPs to give support any primary care based plans given the lack of response to this scoping exercise from GPs.

15. Conclusions and Recommendations

In the very short term the Board is faced with making decisions about project activities in the context of being able to guarantee funds for only one year. Therefore, the Board faces decisions on what the focus of the project should be in that year, with a given level of resource, and how to demonstrate impact if it wishes to attract more sustainable funding. There are many possible scenarios which could be considered. Two opposing service models are set out below with considerations of the case for and against each model.

Scenario 1:

- The project could concentrate exclusively on providing a direct service, generating new advice cases for the project by promoting the service to patients and canvassing sources of professional referral for support. The goal at year-end would be to site the new service, in a bid to potential funders, as a stand-alone, specialist WBA agency for cancer patients in Fife.

The case for: This approach should make an immediate impact on people affected by cancer in Fife by raising new cases and income levels over the year which could be recorded to provide evidence of impact. This would provide a strong case for continuance of funding.

The case against: This approach would not compliment existing services and might simply displace existing activity leading to a false picture of an increase in cases. Given the lack of recording of cases in some current providers it would not be possible to compare their previous numbers to any change of patients be referred to the new service. A serious concern would also be that this approach would leave the system in Fife dependent on one new supplier of welfare benefits advice to people affected by cancer which has limited funding if other existing providers could redeploy resources into other areas.

Scenario 2:

- Developing a system for increasing awareness and promoting current services to increase uptake across Fife, while providing support to current services and health care staff by providing training and education. The goal at year end is to site the project, in a bid to potential funders, as a WBA agency increasing the flow of advice cases while strengthening some aspects of the system as a whole in Fife.

The case for: claims referred to current services through the project alone are likely to be through new, previously under-exploited channels, such as patients in hard-to-reach groups, and existing providers and health staff benefit from training. This approach maximises the resources available to the advice network in Fife as a whole.

The case against: Potential funders could be less likely to re-invest where the project isn't solely responsible for increase in patients' income so it would be crucial to have some recording mechanisms in place that would enable the project to demonstrate its role in any uptake of benefits and referrals.

There are many service models which would fall in between these two opposing models, and the above examples are presented to encourage discussion of the possibilities. As seen in section 4 of the report specialised projects elsewhere in Scotland have tended to embrace the first scenario route because success has been judged primarily on their work-load levels, however, this would mean a new service would be acting in competition with existing services rather than complementing and widening access for patients through awareness and increasing the support available.

However, decisions about focus perhaps should be informed by thinking about the over-arching objective of the project. An important question for deciding on focus could be whether the chosen project focus will make sustainable improvements in the WBA system in Fife? For example, at a "system" level, will the project have made a sustainable difference which will be apparent even after the project is gone?

Clearly, a "sustainable difference" scenario, places the focus more on supporting existing service providers and less on directly competing with them for work-load.

This is essentially a conservative strategy that assumes that funding is finite and potential demand for service is likely to always outstrip funding as the number of people living with cancer is likely to grow.

The data gathered in the scoping exercise could support either course of strategic action, to develop a “stand alone” service or develop the project in a supporting role. The stand alone option would clearly involve building on existing referrals and perhaps using the Macmillan brand to open up new sources of professional referral. Equally, the strength of the Macmillan brand could be utilised in raising public awareness of the service, possibly “picking up” patients whose needs aren’t currently being addressed. To develop a new system sustainability, all of these resources would have to be employed but in addition the expertise, contacts and community involvement of the existing voluntary sector players would have to be integrated and developed both within and outside the project.

The following recommendations from the scoping exercise are presented for consideration of the Board:

- The need to increase new cases through awareness raising with patients and staff from all relevant staff groups. This will be particularly important with the hard-to-reach patient groups.
- To develop strategies for raising the issue with patients and following up progress throughout the patient journey.
- To ensure that feedback to referrers is built into the project to develop trust in the project and the support it offers patients. This is also something that could be improved in existing service providers.
- To ensure that all potential funders for continuation of the project are involved in its development so they feel engaged from the beginning of the pilot project.
- To ensure that staff views on the differences of their possible roles in the raising of the issue and the providing of support are taken into account.
- To provide appropriate training on benefit services or the cancer journey for each staff group based on their potential role as referrer, signposting, or provider of direct advice and support.
- To provide appropriate materials to staff groups to help them with their potential

role such as information leaflets or cards or information about patient pathways.

- To ensure that mechanisms for recording impact of any new project is in place from the very beginning and that similar processes are agreed with existing providers where recording is patchy.
- And most importantly, as this scoping exercise was only able to gather a very limited number of views from patients and carers, it is recommended that any proposed plan is discussed with a wider number of patients and carers through other mechanisms to ensure that it takes in to account their views and needs for any future service.

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References

Allirajah, D., Herbst, K., & Morgan, L. (2005) Free at the point of delivery?: exposing the hidden cost of hospital travel and parking for cancer patients. [online]. London: Macmillan Cancer Relief. Available from: <http://www.macmillan.org.uk/abetterdeal/FreeAtPointofDelivery.pdf> [Accessed 25 June 2006]

Cancerbackup (2006) Financial issues. [Internet]. Available from: <<http://www.cancerbackup.org.uk/Resourcessupport/Practicalissues/Financiallegalissues/Financialissues>> [Page last modified 15 June 2006].

Chalmers, T. & Jones, L. (2005) Final report of the evaluation of 3 different benefits advice services for people affected by cancer. Edinburgh: Scottish Centre for Social Research.

Chapple, 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, p598-594.

Greasley, P. & Small, N. (2002) Welfare advice in primary care. Bradford: University of Bradford. School of Health Studies.

Martin, C. (2006) Welfare rights advice in hospital and primary care settings. *Health Matters* 53 [online]. Available from: <<http://www.ferret.co.uk/main/index.asp?menu=1.51&page=1>> [Accessed 25 June 2006].

Macmillan Cancer Relief (2004) The unclaimed millions. [online] Available from: <http://www.macmillan.org.uk/Get_Involved/Campaigns/Better_Deal/Research_publications/Unclaimed_millions.aspx> [Accessed 25 June 2006].

Macmillan Cancer Relief (2004) Help with the cost of cancer: a guide to benefits and financial help for people affected by cancer. London: Macmillan Cancer Relief.

Macmillan Cancer Relief (2005a) Access Denied. Macmillan Cancer Relief, London.

Macmillan Cancer Relief (2005b) Free at the Point of Delivery? Exposing the hidden cost of hospital travel and parking for cancer patients. Macmillan Cancer Relief, London.

Macmillan Cancer Relief (2005c) DWP five year plan: Disability benefits consortium responds [online] London: Macmillan Cancer Relief. Available from: <http://www.macmillan.org.uk/About_Us/Newsroom/Cancer_Services_and_Campaigns/UK-wide/Press_release/DWP_five_year_plan_Disability_benefits_consortium_responds.aspx> [Accessed 25 June 2006].

Macmillan Cancer Relief and Social Security Agency (2003) Benefits access for people affected by cancer in Northern Ireland [online] London: Macmillan Cancer Relief. Available from: <<http://www.macmillan.org.uk/abetterdeal/images/materials/NI%20published%20report.pdf>> [Accessed 25 June 2006].

Miller S. (2005) Access denied: benefits advisers' perceptions of the problems cancer patients face when claiming Disability Living Allowance and Attendance Allowance. [online] London: Macmillan Cancer Relief. Available from: <http://www.macmillan.org.uk/abetterdeal/images/materials/Access%20Denied.pdf> [Accessed 25 June 2006].

Quinn, A. (2002) Macmillan cancer relief study into benefits advice for people with cancer. London: Macmillan Cancer Relief.

Roundup (2005). Roundup: weekly Macmillan news roundup. 14 October 2005. Macmillan Cancer Relief.

Thomas, C., Morris, S., Soothill, K., McIlmurray, M., Francis, B., & Harman, J. (2001) What are the psychosocial needs of cancer patients and their main carers?: report to the National Health Service Executive North West. Lancaster: Lancaster University. Institute for Health Research.

Veitch, J. (2006) Need a doctor?: he's in the cupboard. The Herald. June 6 Society suppl. p.2

Wilson, K. (unpublished report, 2005) Financial advice and support services for people

affected by cancer : a synthesis of qualitative research findings. Manchester: MRU.

Appendix A



Staff views on the welfare benefit services for people affected by cancer in Fife

Thank you for agreeing to take part in this survey. If you have any questions about this project please contact the researcher Alistair Richardson at the Cancer Care Research Centre, University of Stirling, on 01786 849260 or Alistair.Richardson@stir.ac.uk

You will see below that we ask for a few details about your job. We need this information to administer the survey correctly and **NOTHING** that could identify an individual will appear in our final report. *Anything written in bold italics in the text below tells you what we'd like you to do next.*

About Your Job

1. What is your full job title?.....
2. Please provide the address of your work base
.....
3. What is your role when working with people affected by cancer?
.....
.....

Knowledge of welfare benefits

4. Do you know of any welfare benefits that people affected by cancer can claim?
Yes/No

*If you circled "Yes" to the question above please list below the names of any benefits you know of and then proceed to item 5.
If you circled "No" to the question above please proceed directly to look at item 5.*

5. Please list any organisations, or people, you think offer advice and assistance about welfare benefits to people affected by cancer in Fife.

6. Whose job do you think it is to **raise the issue** of welfare benefits with people affected by cancer? **Please put a tick beside the organisations, or people, you think have a role in raising the issue.**

☐	Welfare benefits advisors (i.e. CAB/CARF)	☐	Primary care & community-based staff
☐	Benefits staff (i.e. Pension Service or Job Centre Plus)	☐	Friends/Family
☐	Social services staff	☐	Carers
☐	Hospital-based staff	☐	Charities
☐	Support groups	☐	Voluntary organisations
☐	Maggie's Centres	☐	Other: (please name)

7. Whose job do you think it is to **advise people** affected by cancer on what welfare benefits they can apply for? **Please put a tick beside the organisation or people you think have a role in advising people.**

☐	Welfare benefits advisors (i.e. CAB/CARF)	☐	Primary care & community-based staff
☐	Benefits staff (i.e. Pension Service or Job Centre Plus)	☐	Friends/Family
☐	Social services staff	☐	Carers
☐	Hospital-based staff	☐	Charities
☐	Support groups	☐	Voluntary organisations
☐	Maggie's Centres	☐	Other: (please name)

Experience of welfare benefits

8. What do you currently do if a person affected by cancer asks **YOU** about welfare benefits? **(Please circle the option that describes your typical action.)**
- (a) I find out what benefits are available to the person and help them fill in the forms
 - (b) I arrange for them to see a specialist in welfare benefits
 - (c) I suggest they contact a welfare benefit specialist
 - (d) I tell them that I'm not qualified to advise them and suggest they contact someone
 - (e) If you do something not listed above, **please tell us below.**
9. If the person affected by cancer has never raised the issue of welfare benefits, what would you do? **(Please circle the option that describes your typical action)**
- (a) I would raise the issue as a matter of course.
 - (b) I would never raise the issue

If you circled (a) please go to question 10.

If you circled (b) please go to the next section "Views on welfare benefit support".

10. When you help a person access welfare benefits, how do you hear about the progress of the application? ***(Please circle the option that describes your experience most closely).***

- (a) From the person
- (b) From the person and/or the welfare advisor
- (c) I never hear anything more about it

Views on welfare benefit support

Below are a number of statements professionals have made in the past about raising the welfare benefits issue with people affected by cancer. ***Please indicate whether you agree or disagree with the statements by circling your chosen option.***

11. *"I'm so busy here attending to the immediate needs of the person that I just don't have time to talk about things like welfare benefits."*

Agree/Disagree

12. *"Welfare benefits are such a complicated subject that I just wouldn't feel comfortable raising the issue with people in case I misled them by mistake."*

Agree/Disagree

13. *"In my past experience, people affected with cancer have never been too keen to talk about personal financial matters."*

Agree/Disagree

14. *"I would suggest to a person affected by cancer that they should see someone about welfare benefit if I knew where to send them."*

Agree/Disagree

15. *"I would help people affected by cancer fill in the welfare benefit form if I received appropriate training."*

Agree/Disagree

16. Below is a list of issues people sometimes have in claiming various welfare benefits. **Please tick the problems that you hear about through feedback either from the person directly or through someone advising them.**

☐	Lengthy claim packs
☐	Six month rule for terminally ill – too restrictive
☐	Inconsistency in outcome decisions for Attendance Allowance/ Disability Living Allowance resulting in many cases now turned down
☐	Appeals process long and complicated so many can't be bothered to fight the system
☐	More Special Rules cases being turned down
☐	Suitability of Attendance Allowance/Disability Living Allowance claim pack for people affected by cancer
☐	Benefits authorities seeking corroborative evidence from GP when GP has not been dealing with patient – patient attending hospital

17. Are there any other issues you've come across or other views that you would like to share with us? **If so, please use the space below to tell us about them.**

That was the last item in this survey. Thank you for your help with this project.

Appendix B



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OPEN STALL SHEETS – GLENROTHES 16TH MARCH 2006

1. Do you know of any welfare benefits?

YES NO

If Yes, what benefits? (List)

2. Do you know of any organisations, or people, you think offer advice and assistance about welfare benefits in Fife?

YES NO

If yes, what? (List)

3. Looking at this list, whose job do you think it is to raise the issue of welfare benefits with people affected by cancer?

☐	Welfare benefits advisors (e.g. CAB/CARF)	☐	Primary care & community-based staff
☐	Benefits staff (e.g. Pension Service or Job Centre Plus)	☐	Friends/Family
☐	Social services staff	☐	Carers
☐	Hospital-based staff	☐	Charities
☐	Support groups	☐	Voluntary organisations
☐	Maggie's Centres	☐	Other: (please name)

4. Looking at this list again, whose job do you think it is to provide support and information about welfare benefits to people affected by cancer?

☐	Welfare benefits advisors (e.g. CAB/CARF)	☐	Primary care & community-based staff
☐	Benefits staff (e.g. Pension Service or Job Centre Plus)	☐	Friends/Family
☐	Social services staff	☐	Carers
☐	Hospital-based staff	☐	Charities
☐	Support groups	☐	Voluntary organisations
☐	Maggie's Centres	☐	Other: (please name)

5. What do you think is important for a welfare benefit service aimed at people affected by cancer?

6. Anything else?

7. What town do you live in?.....

8. Are any members of your family, or friends, currently being treated for cancer?

☐ No ☐ Me ☐ Spouse/Partner ☐ Child ☐ Parent
☐ Sibling ☐ Grandparent ☐ Friend ☐ Other

9. Has any member of your family, or friends, been treated for cancer in the past?

☐ No ☐ Me ☐ Spouse/Partner ☐ Child ☐ Parent
☐ Sibling ☐ Grandparent ☐ Friend ☐ Other:.....

10. Are any members of your family, or friends, currently caring for someone who is being treated for cancer?

☐ No ☐ Me ☐ Spouse/Partner ☐ Child ☐ Parent
☐ Sibling ☐ Grandparent ☐ Friend ☐ Other:.....

11. Has any member of your family, or a friend, been a carer in the past for someone who was being treated for cancer?

☐ No ☐ Me ☐ Spouse/Partner ☐ Child ☐ Parent
☐ Sibling ☐ Grandparent ☐ Friend ☐ Other:.....

About the CCRC

The Cancer Care Research Centre was established in October 2003 so that people affected by cancer could help shape the future of cancer services in Scotland. Already we are working with patients and carers across Scotland from Stornoway to Dumfries and this number continues to grow. As well as working with patients and carers we also work closely with a range of cancer care professionals who advise us on what we do and work in partnership with us on our research projects.

The CCRC is the first of its kind in the UK as our research is informed directly by the views of people affected by cancer. Working jointly with people affected by cancer and cancer care professionals, we aim to improve future cancer services through linking scientific research with the reality of the experience of cancer and cancer treatment.

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