# Thinking positively about work

## Delivering work support and vocational rehabilitation for people with cancer

Evaluation of the National Cancer Survivorship Initiative (NCSI) Work and Finance Workstream Vocational Rehabilitation Project

## Final report

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This is the full and final report on the evaluation of the National Cancer Survivorship Initiative (NCSI) Work and Finance Workstream Vocational Rehabilitation Project.

A separate, stand-alone, short summary report containing the key project outputs, strategic framework and model diagrams, conclusions and recommendations is available from **www.ncsi.org.uk/what-we-are-doing/vocational-rehabilitation/** or **www.macmillan.org.uk/work/policyandresearch**. Alternatively, a printed copy can be requested by e-mailing **workandcancer@macmillan.org.uk**.

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# Executive summary

## Background

Many people who have had cancer want to go back to work when they feel ready and able. However, the evidence suggests that they can struggle to do so: people with cancer are 1.37 times more likely to be unemployed than people who have not had cancer. With an estimated 700,000 people of working age living with cancer in the UK, this represents a significant problem, economically, socially and personally.

Although there is a relatively strong scientific evidence base for many aspects of vocational rehabilitation in commonly occurring health conditions such as musculoskeletal disorders, mental health problems and cardio-respiratory illnesses, our understanding of how to support people with cancer to remain in or return to work is limited.

Recognising the need to improve the work support services available for people with cancer, the National Cancer Survivorship Initiative (NCSI) Work and Finance Workstream developed a four level model of cancer vocational rehabilitation which was implemented and tested in seven pilot sites located across England between April 2010 and July 2011. The project was evaluated by a research team based at UCL Institute of Neurology, led by Dr Diane Playford. The findings of the evaluation are presented in this report.

## Aim and objectives

The aim of the evaluation was to identify a model of vocational rehabilitation for people with cancer that is capable of being widely implemented and that has good outcomes.

There were three objectives:

1. To define the best elements of the models employed by the pilot sites – in terms of service structure and delivery, as well as the content of vocational rehabilitation interventions – as a guide to future service provision.
2. To identify patients' perspectives of vocational rehabilitation services with regard to both experience and outcome.
3. To estimate the cost of service delivery and assess cost-effectiveness.

## Method of investigation

Realistic Evaluation was used to examine the different ways in which the pilot sites structured and delivered their services, and to identify the outcomes that were achieved. Data on service structure and delivery were collected through four interviews and seven focus groups with 22 service providers, and also through the final reports prepared by the pilot sites. A Service Delivery Template was used to record data on service user characteristics, work outcomes and duration of intervention across the six pilot sites that had direct contact with patients (n = 330[1]). The content of vocational rehabilitation interventions was examined through two consensus development workshops using the Nominal Group Technique (n = 30). Twenty five service users were interviewed to gain an insight into their perspectives. Quantitative data were analysed using simple descriptive statistics. Qualitative data were organised using MAXQDA and analysed using the Framework approach.

The health economic elements of the project included work to estimate the costs incurred by the pilot sites. Additionally, self-report questionnaires were distributed, with a view to comparing levels of resource use (for NHS and personal social services, Jobcentre Plus schemes, patients and carers and benefits/work schemes) and quality of life in the six months before and after contact with the pilot sites. In the absence of a comparator group, it was however not possible to assess the cost-effectiveness of the service.[2]

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[1] This represents completed episodes of vocational rehabilitation interventions. The total number of referrals to the pilots was 597.

[2] Further research funded by the National Institute for Health Research (NIHR) is underway to assess the effectiveness and cost effectiveness of a specific cancer vocational rehabilitation intervention. A three year project, *The REJOIN study (REhabilitation for Job and Occupational INdependence) – a feasibility study of a randomised controlled trial to evaluate a vocational rehabilitation intervention for people with cancer*, will be completed in December 2014.

## Key Outputs

The NCSI Vocational Rehabilitation Project has delivered eight key outputs:

1. A strategic framework to underpin the planning and delivery of cancer work support services.
2. A new, robust model of the three levels of work support interventions required for people with cancer.
3. An indication of the costs associated with delivering specialist cancer vocational rehabilitation interventions.
4. A synthesis of the learning from the pilot sites' experiences of setting up and delivering services.
5. Guidance for health professionals, employers and patients on achieving positive work outcomes.
6. An outline of the content of specialist cancer vocational rehabilitation interventions.
7. A competency framework to underpin the delivery of specialist cancer vocational rehabilitation interventions.
8. Recommendations for service delivery and an indication of areas for further investigation and research.

Additionally, the work of the pilot sites and the four interim evaluation reports[3] have contributed to raising the profile of work support and vocational rehabilitation services for people with cancer.

Each of these outputs is briefly elaborated below.

### 1 Strategic framework to underpin the delivery of cancer work support

The key to enabling people with cancer to remain in or return to work is to embed work support into the patients' pathway from diagnosis, through treatment and on into life beyond cancer – or end of life care, where that is appropriate. It cannot be relegated to an add-on service, offered only when problems arise. Positive approaches towards work, tailored information delivered at the right times, access to specialist services, and effective liaison between patients, health professionals and employers are all crucial.

The Strategic Framework for Cancer Work Support[4] presents a blueprint for service configuration at a population level. *All* patients who are in work or who have the potential to work require attention to be paid to the impact of their illness on employment, with effective service provision relying on collaboration between patients, employers, health professionals, specialist vocational rehabilitation services and work support services.

The essential, core components required for providing effective work support for people with cancer are as follows:

**1** Health professionals should have the knowledge and skill to present the right messages about work in an acceptable and appropriate way, so that patients are encouraged to think positively about work from diagnosis onwards.

**2** Prompts to talk about work should be incorporated into national and local cancer guidelines, policies, assessment and treatment pathways, and information prescriptions.

**3** Tailored information and advice about patients' employment rights and responsibilities, and about the support services available, should be provided in order to facilitate patients' self-management.

**4** The statutory and voluntary services available locally to support people with cancer in employment should be identified, and pathways for effective liaison between these services and cancer treatment services should be created and used.

**5** Specialist vocational rehabilitation for people with complex problems should be provided.

**6** Treatment protocols and pathways should prompt effective liaison between patients, health professionals, employers, human resources departments and occupational health services.

**7** There should be engagement with employers and employers' organisations to raise employers' awareness of the needs of employees with cancer.

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[3] Available at www.ncsi.org.uk/what-we-are-doing/vocational-rehabilitation/

[4] See Figure 2, page 20

## 2 Three level model of work support interventions required for people with cancer

The Three Level Model of Work Support Interventions for People with Cancer[5] shows the structure of services required for individual patients across a spectrum of needs, from those which are straightforward to those which are highly complex. The model identifies the recipients of services, the service providers, and the interventions required at each of the three levels, as follows:

- **Level 1:** All patients who are in work or have the potential to work should be asked about their employment, and receive information and signposting.
- **Level 2:** People with specific concerns or worries should be provided with resources to support self-management.
- **Level 3:** The smaller subset of people who have complex needs should be referred to a vocational rehabilitation service for specialist support.

## 3 Indication of the costs associated with delivering specialist cancer vocational rehabilitation interventions

A total of 597 patients were referred across all of the pilot sites that provided direct interventions to patients. It was feasible to record work status outcomes for 320 of these patients. Over one third of patients (38%) went from 'not working to working' or from 'sick leave to full work or modified work'. A further 7.8% were supported to remain in work.

Expenditure levels for the pilot sites varied between £54,951.49 and £108,936.50. The average cost per patient contact (where 'contact' refers to the period of intervention) was thereby estimated to range between £384.86 and £1,590.02, with a weighted average cost per patient contact of £842.23 (£839.19 after excluding set-up costs).

The median gross annual earnings for full-time employees in the UK are £26,100 (Office for National Statistics 2012). With a personal allowance of £7475 (HM Revenue and Customs, no date), £18,625 taxed at 20% returns £3725 to the Exchequer per year. At approximately £850 per intervention, the tax returns outweigh the cost of the intervention within three months of employment. Consequently if patients return to work for an additional 12 weeks that they might not otherwise have worked, the intervention could be argued to have paid for itself.

## 4 Synthesis of the learning from the pilot sites

A number of learning points arose from the pilots' experiences of providing services, as follows:

1. It is feasible to incorporate vocational rehabilitation for people with cancer into work programmes that support people with other health conditions. However, these programmes are generally directed at people with significant health problems – those at Level 3. Work support at Levels 1 and 2 relies on interventions delivered within cancer centres, integrated into patients' treatment. This requires close contact between cancer treatment services and work support services. The pilots found that the physical location of specialist work support services within a cancer treatment centre could facilitate this interaction.
2. A wide range of services providing employment support will exist in any one geographical area, and an important function of a cancer work support service is to identify and co-ordinate these services, ensuring that they are accessible to people with cancer, and that they understand how to meet patients' cancer-specific needs.
3. Providing specialist vocational rehabilitation to people with cancer requires knowledge, skills and abilities in three main areas:
   - employment processes, practices, rights and responsibilities
   - cancer pathology, cancer treatment and the symptoms that impact on work
   - rehabilitation processes to support return to work

   Coming from either a health/rehabilitation background, or an employment background, the staff employed by the pilots had skills in one or two of these areas but not in all three. All of the pilot staff providing work support interventions identified learning needs in one or more areas.
4. A common feature of the two pilots that continued to operate after the pilot period had ended, was that both had support from senior management and clinical staff in their organisations who understood the need for work support for people with cancer and were committed to its provision.

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[5] See Figure 3, page 22

5. Patients might need encouragement to seek help and to re-engage with the service after an initial contact, and a pro-active approach to follow-up can be helpful.
6. Psychological interventions such as CBT and coaching were integral to rebuilding confidence and developing a sense of well-being and self-efficacy.
7. Some groups of patients, such as those with neurological cancers, have specific and complex problems and the ability to respond effectively requires specialised rehabilitation expertise.
8. Mapping existing services is a useful starting point in the provision of work support for people with cancer, but the availability of a directory of services is not enough to ensure that patients are appropriately signposted.

## 5 Guidance for health professionals, employers and people with cancer on achieving positive work outcomes

### Health professionals

Health professionals need to be alert to potential work problems, to understand that good work is an important component of well-being, and to enable patients to think positively about work. All of the pilot sites noted that work issues were not routinely raised with patients, particularly not in the early stages after diagnosis.

Patients may not recognise potential work problems, and there is a need for vigilance on the part of health professionals to be able to predict and pre-empt problems, so that patients can be nudged towards thinking positively about work. There are a number of risk factors that health professionals should to look out for, which could indicate future employment problems, including a lack of contact with the employer, impending organisational change, job inflexibility, self-employment and cancer-related disability.

Patients are not routinely given helpful advice about returning to work. In determining fitness for work, the physical, cognitive and psychological capacity of the patients should be assessed against the demands of the workplace, and cancer health professionals do not necessarily have the skills to do this.

### Employers

People with cancer identify their line managers as key to their successful reintegration into the workplace. Elements that facilitate a successful return to work include: effective channels of communication between employers, employees and health professionals; the employer’s understanding of cancer, its treatments and consequences; support for a phased return to work; willingness to make reasonable adjustments; and a good understanding of rights and responsibilities under the Equality Act.

In addition to one-to-one work with individual patients and their employers, several of the pilot sites worked with local businesses, offering education and support at an organisational level, with varying degrees of success. Employers are crucial to achieving good work outcomes, and any local initiatives that can support employers to help people with cancer to remain in or return to work are to be encouraged. However, the reach of an individual vocational rehabilitation service is limited.

### People with cancer

People with cancer have their own role to play in managing the disruption to work caused by their illness, and many patients are successfully able to negotiate changes to their work environment and schedules in order to remain in or return to work. Strategies and resources which support patients’ self management are valuable, for example, telephone advice lines and prompts to ask the right people the right questions.

## 6 Specialist cancer vocational rehabilitation

Vocational rehabilitation interventions used in other health conditions are equally applicable to people with cancer.

- Detailed assessment of work skills and capacity, job requirements and demands, work environment and social support systems.
- Prioritising key issues and setting short-term and long-term goals.
- Work preparedness and work readiness activities.
- Teaching strategies for managing particular health problems in the workplace.
- Negotiating a phased return to work and modifications to the work environment.
- Liaison with employers.
- Psychological interventions, for example coaching, counselling, motivational interviewing and/or cognitive behaviour therapy.
- Supported withdrawal from work, where that is appropriate.

- Information and advice on legal rights and responsibilities.
- Referral to other support services.
- Careers advice and guidance.

People with cancer have additional, specific needs relating to the disease and its treatment, which need to be taken into account. These include:

- Managing cancer-specific symptoms and impairments in the workplace, in particular, fatigue, functional difficulties, cognitive problems and pain.
- Building confidence after a traumatic diagnosis and what can be prolonged absence from work.
- Helping patients to manage employers' and colleagues' responses to the stigma of cancer.
- Helping patients and employers to understand the late effects of treatment.

## 7 Competency framework for cancer vocational rehabilitation

The delivery of vocational rehabilitation services that will meet the needs of people with cancer requires the following:

- Specialist knowledge of work and rehabilitation.
- An understanding of cancer and its treatments.
- An ability to support a person's adjustment to their illness, insofar as it impacts on work.
- A working knowledge of employees' and employers' legal rights and responsibilities.
- Communication skills – excellent listening skills, and the ability to manage uncertainty.
- Ability to provide education to patients and to professional colleagues.
- Ability to network, and to build and maintain effective links with a very wide range of individuals and other services.
- Insight into and awareness of the personal impact of working with people with life-threatening illness.
- Personal characteristics: optimistic, problem-solver, 'can-do' attitude, highly organised, flexible. A focus on health and well-being rather than illness.

It is unlikely that any single discipline or person would encompass all of these competencies, and input from a small multi-disciplinary team is likely to be needed.

## 8 Recommendations

**1** In order to ensure that people with cancer are well supported to remain in or return to work, each Cancer Network, or organisation responsible for cancer services, should nominate a lead person (or people) to take responsibility for:

**a** Ensuring that health professionals have adequate knowledge to provide early and on-going support.

**b** Embedding work support into cancer treatment protocols, pathways and guidelines.

**c** Identifying work support and specialist vocational rehabilitation services available to cancer patients in a locality, and noting gaps. Any development of new services should aim to integrate existing resources and avoid duplication.

**d** Ensuring that there are effective channels of communication and referral pathways between cancer services and external work support services.

**e** Ensuring that there are effective channels of communication between health professionals, employers and occupational health departments.

Commissioning contracts should include the requirement that cancer service providers ensure the availability of adequate work support and information for patients.

**2** Health professionals need the knowledge and skills to be able to facilitate patients remaining in or returning to work by following the 5 Rs:

**a** **Raise** work issues with patients early in the treatment pathway in a sensitive and acceptable manner.

**b** **Recognise** the risk factors for poor work outcomes.

**c** **Respond** effectively to the straightforward work problems that patients identify.

**d** **Refer** patients who have more complex difficulties to the appropriate specialist services.

**e** **Revisit** work issues at intervals during treatment.

Cancer health professionals do not necessarily have these skills, and training should be provided where required.

**3** There is a need for a national, strategic approach to employer engagement, education and support, to ensure that all employers understand the needs of employees who have cancer, and that they incorporate just, fair and informed practices into company policies and procedures.

**4** The provision of specialist vocational rehabilitation to people with complex work problems requires knowledge of employment practice, rights and responsibilities, cancer pathology, and rehabilitation. It is unlikely that any single discipline or person would encompass all of these competencies, and training is likely to be required. No cancer-specific vocational rehabilitation training programme currently exists, and the need for this should be considered.

**5** The following areas for further investigation and development in research and clinical practice have been identified:

- **a** The effectiveness and cost-effectiveness of specialist vocational rehabilitation programmes for cancer patients who have complex work problems.
- **b** Employers' perspectives on supporting people with cancer to remain in and return to work.
- **c** The impact of cancer on carers' employment.
- **d** The relevance of work support to palliative patients.
- **e** The use of communities of practice to share learning and improve cancer work support services.

# 1 Introduction and background to the NCSI Vocational Rehabilitation Project

## 1.1 Cancer and work

Work is important. It contributes to financial independence and material comfort. It provides a sense of purpose in life and has a strong influence on identity and self-esteem. It creates structure and order in daily routines and is an important source of social interaction and community engagement (Waddell and Burton 2006). 'Good work' (Coats and Lehki 2008) has both personal and societal value.

People with cancer emphasise the significance of work in regaining a sense of normality and control over their lives after (and sometimes during) diagnosis and treatment (Rasmussen and Elverdam 2008, Kennedy et al. 2007). Many people who have had cancer want to go back to work when they feel ready and able (Department of Health, Macmillan Cancer Support and NHS Improvement 2010). However, the evidence suggests that they can struggle to do so: people who have had cancer are 1.37 times more likely to be unemployed than those who have not (de Boer et al. 2009). With an estimated 700,000 people of working age living with cancer in the UK (Maddams et al. 2009),[6] this represents a significant problem, economically, socially and personally.

## 1.2 Factors impacting on work for people with cancer

A growing body of research evidence over the last two decades sets out the impact of cancer on work, and the factors that contribute to the ability of people with cancer to return to work (Feuerstein et al. 2010). In health terms, cancer site, stage and prognosis, treatment and the presence of co-morbidities are significant. Socio-demographic and psychological factors such as age, education level, mood and motivation to work are thought to contribute (Rasmussen and Elverdam 2008, Johnsson et al. 2007) although there are some discrepancies in this evidence (Short et al. 2005, Spelten et al. 2002). In addition to personal factors, work-related considerations are important. For example, a physically demanding job decreases the likelihood of returning to work, while an employer's willingness to be flexible about working terms and conditions during the recovery period enhances it.

The patient's direct healthcare team – clinical nurse specialists, GPs and oncologists – have a vitally important role to play in supporting people with cancer to return to work. However, research indicates that this is an area in need of attention. People living with cancer report that they receive little advice from health professionals about work issues (Johnsson et al. 2007, Main et al. 2005). Health professionals, in turn, do not feel equipped to deal with their patients' employment concerns (Bains et al. 2011). There is a need for health professionals to develop the skills required to respond to patients' straightforward problems, and also the knowledge of the availability of more specialist services to be able signpost people with more complex difficulties.

## 1.3 Interventions to support people with cancer to return to work

In contrast to the evidence base for many aspects of vocational rehabilitation in commonly occurring health conditions such as musculoskeletal disorders, mental health problems and cardio-respiratory illness, (Waddell et al. no date), our understanding of how to support people with cancer to remain in or return to work is limited (de Boer et al. 2011).

People who encounter significant problems with employment following a diagnosis of cancer may require specialist help from professionals with specific skills in employment support. The most striking feature of the research on specialist return to work interventions for people living with cancer is the lack of methodologically sound studies (de Boer et al. 2011, Hoving et al. 2009).

In their Cochrane Review of interventions to enhance return-to-work for people with cancer, de Boer and colleagues identified four categories of interventions that have been studied: psychological interventions (for example, education and/or counselling), interventions aimed at physical functioning (exercise), medical interventions (for example, chemotherapy and hormone therapy), and multidisciplinary interventions that incorporated physical, psychological, and vocational components. No trials of specific vocational interventions were found (de Boer et al. 2011).

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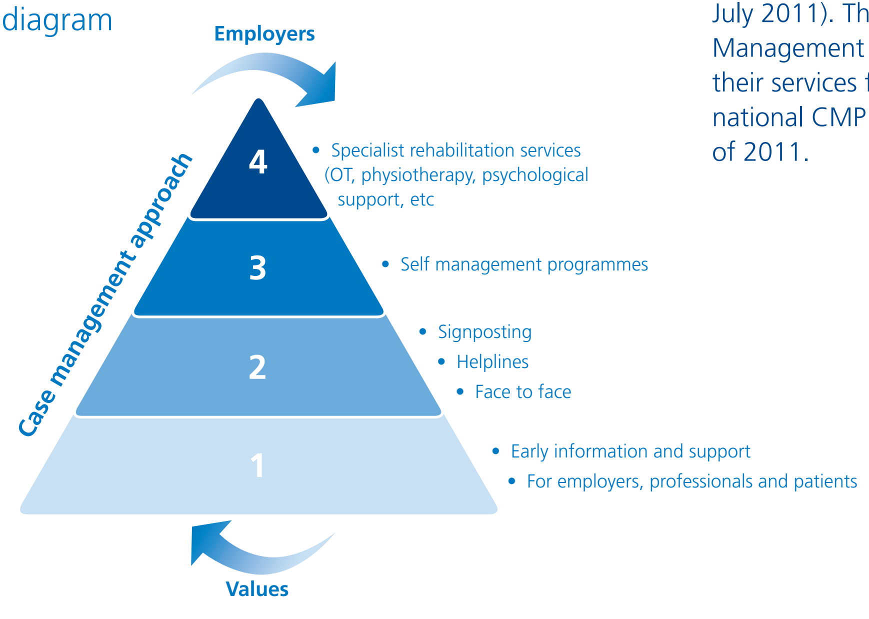
[6] This estimate is for 18-64 year olds at the end of 2008 and excludes non-melanoma skin cancer. It is based on taking the number of people aged 0-64(1) and subtracting an estimate of the proportion aged 0-17 i.e. 1% of the two million(2): www.ncin.org.uk/view.aspx?rid=70 accessed 19/06/2012.

Taking account of the factors that are associated with successful return-to-work for people with cancer, it is evident that effective interventions would need to incorporate a range of supportive, therapeutic and educational activities, including: attention to the consequences of specific symptoms in the workplace, physical fitness and conditioning, enhancing self-confidence, liaison between health services and employers, specific modifications to the work environment, and support with managing relationships with colleagues and managers. This multidisciplinary approach is supported by the Cochrane Review (de Boer et al. 2011), which found that support incorporating physical, psychological and vocational components was associated with more successful return to work than usual care.

## 1.4 Improving work support services for people with cancer: the NCSI Vocational Rehabilitation Project

Recognising the need to improve the work support available for people with cancer, the National Cancer Survivorship Initiative (NCSI) Work and Finance Workstream[7] set up a project subgroup to examine the provision of cancer vocational rehabilitation and to develop a service model that could be piloted. Following a wide-ranging consultation, a review of the evidence and an examination of existing good practice (NCSI Work and Finance Workstream 2009, Staley 2008), five principles were identified as key to improving services:

**Figure 1:** The prototype four level model diagram



- Early intervention to provide information and support, to encourage self-management, and to begin the conversation about remaining in or returning to work.
- A partnership approach between key services such as health, social care and employment organisations.
- Involvement of employers.
- The availability of specialist services to address barriers to work such as physical limitations, significant psychological distress, loss of self-esteem and confidence.
- An approach to providing services that supports self-management and instils confidence in rehabilitation among service users.

A four level model of cancer vocational rehabilitation was proposed.
The levels described in this model are:

- **Level 1:** Information and support provided through electronic and printed media.
- **Level 2:** One-to-one support and signposting through telephone helplines and digital media.
- **Level 3:** Self-management programmes accessed during or after treatment.
- **Level 4:** Specialist vocational rehabilitation services.

This model was subsequently tested in seven pilot sites located across England. The pilot sites were initially funded for 12 months (April 2010 – March 2011), with five receiving four month extension funding (to July 2011). The two pilots sited within the Condition Management Programme (CMP) were unable to extend their services for the additional four months, as the national CMP service was withdrawn at the beginning of 2011.

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[7] The National Survivorship Initiative (NCSI) is a partnership between Macmillan Cancer Support and the Department of Health, supported by NHS improvement. It was created in response to the 2007 Cancer Reform Strategy which recognised the need to improve support for people living with the longer-term consequences of cancer, and to address gaps in the available services.

## 1.5 The seven pilot sites

The pilot sites shared a common objective: to support people with cancer to remain in or return to work where that was their wish. The service configuration and methods used to achieve this objective varied significantly between pilots. Six of the sites developed and provided direct services to people with cancer; one used a workforce development model, seeking to identify and use existing services. Pilot site staff had a wide range of professional backgrounds: physiotherapy, life coaching, occupational therapy, social work, nursing, psychology, employment consultancy and human resources. There were shared skills (for example, an ability to separate complex problems into manageable components) as well as individual-specific or discipline-specific expertise (such as knowledge of employment law or management of particular cancer symptoms like fatigue). Each pilot was required to engage with employers to raise awareness of the needs of employees with cancer, and here again approaches differed.

This section gives a brief overview of each of the pilots in order to provide a context for the findings presented in Sections 3 – 8. In-depth case examples of the different approaches to providing services, drawing on the pilots' experiences, are provided in Section 4.7.

### 1.5.1 St John's Information and Support Centre, Doncaster Community Healthcare (Rotherham Doncaster and South Humber NHS Foundation Trust from April 2011), South Yorkshire

This service was based at St John's Information and Support Centre, which is co-located with St John's Hospice in Doncaster. A case manager, physiotherapist, occupational therapist, complementary therapist and support worker worked closely with the Information and Support Centre's information facilitator, the local Disability Information and Advice Line (DIAL) service, and counselling services.

The following services were offered:

- Information for employers, employees and health professionals on work and cancer.
- Brief one-to-one or telephone contacts, offering information and signposting to other services.
- Support for self-management through group programmes and/or individual sessions. Topics covered in group sessions included stress and anxiety management, building confidence, communication skills, health and lifestyle choices, fatigue management and exercise.
- Specialist one-to-one workplace assessments and advice, fatigue management in the workplace, goal-setting, counselling and complementary therapies.
- Education for employers on supporting individuals with cancer to return to work.

### 1.5.2 National Hospital for Neurology and Neurosurgery: London

The National Hospital for Neurology and Neurosurgery (NHNN) is a dedicated neurological and neurosurgical hospital with a large, highly specialist multi-disciplinary rehabilitation team. For the NCSI project, an established vocational rehabilitation service provided for people with multiple sclerosis was extended to patients with neurological cancers – primary and secondary brain tumours as well as spinal tumours. The pilot was led and provided by occupational therapy and neuropsychology staff. Assessment and interventions were delivered on an out-patient and in-patient basis, and considered mood, cognition and functional abilities in relation to work. Work-specific interventions included facilitating phased return to work and helping people to manage symptoms such as cognitive difficulties and fatigue in the workplace.

### 1.5.3 Shaw Trust with the Christie: Greater Manchester

The Christie NHS Foundation Trust, one of the largest cancer treatment centres in Europe, worked in partnership with Shaw Trust, a vocational rehabilitation charity, to provide work support services to patients across Greater Manchester. Two Shaw Trust case managers – who had previous experience with Shaw Trust's Pathways to Work and Workstep programmes – delivered a range of interventions, including:

- One-off advice and guidance to patients, with signposting to other services.
- Specialist one-to-one expert advice on specific return to work problems, legal and benefits advice, liaison with employers.
- Education and training for health professionals to embed work related issues into the holistic assessment process, and to enable them to provide straightforward advice and signposting.
- Education for employers on supporting individuals with cancer to return to work.

### 1.5.4 NHS Blackburn with Darwen: Lancashire

The Condition Management Programme (CMP) was set up in 2003 as part of the Choices Package provided by Jobcentre Plus together with the NHS. It was available to anyone claiming incapacity benefit or income support. CMP helped people to understand and manage their health conditions, with a view to being able to return to work. It was primarily aimed at supporting people with mental health, musculoskeletal and cardio-respiratory problems.

The NHS Blackburn with Darwen pilot project extended the Lancashire CMP service to offer an enhanced vocational rehabilitation service for people with cancer. The service was provided by two experienced CMP specialists, one a nurse and the other a physiotherapist, both of whom had received training in cognitive behavioural therapy approaches. The service included information, advice and signposting as well as individualised, specialist employment support where required. The team networked with health professionals and with employers to raise awareness of the work issues faced by people with cancer.

### 1.5.5 NHS South of Tyne and Wear: Gateshead

As with the NHS Blackburn with Darwen pilot project, the service based at NHS South of Tyne and Wear built on a well-established Condition Management Programme. It was delivered by professionals with nursing, social work and occupational therapy backgrounds and built on CMP's strong voluntary and third sector links, offering a range of information and support services for people with cancer, as well as an outreach programme to health care professionals to raise awareness of patients' employment-related needs.

### 1.5.6 Mount Vernon Cancer Network: Hertfordshire/South Bedfordshire

This pilot was led by a project manager/vocational rehabilitation champion, working closely with a variety of other professionals across the Network. Rather than setting up a new cancer vocational rehabilitation service, the pilot aimed to establish whether people's needs could be met through existing services by raising awareness and improving referral pathways to specialist psychological and rehabilitation services. There were two phases to the project. Firstly, a mapping exercise was undertaken to identify available resources and, secondly, education sessions were provided for cancer health professionals to improve their understanding of the issues affecting patients' return to work. These sessions were run together with a Human Resources Consultant who had first-hand experience of cancer.

### 1.5.7 Orbitals Ltd with the Olive Tree Cancer Support Centre: Crawley, East Sussex

This pilot was a partnership between the Olive Tree Cancer Support Centre based at Crawley Hospital, and Orbitals Ltd, a private consultancy specialising in business and career development and coaching. In addition to providing information, signposting and one-to-one coaching for individuals with cancer, the pilot had a strong focus on engaging and upskilling employers, supported by Cadia, the Gatwick Diamond Business Association. Work with employers aimed to:

- Raise employers' awareness of their legal and ethical responsibilities to staff affected by cancer.
- Provide employers with a toolkit of strategies to support staff affected by cancer in the workplace, and to aid communication – for example, practical tips for managing difficult conversations.

The specialised vocational rehabilitation/coaching interventions were provided together with a range of other services available at the Olive Tree, for example benefits advice, counselling, stress management and complementary therapies.

# 2 Evaluation and design

## 2.1 Aim and objectives

The aim of the evaluation was to identify a model of vocational rehabilitation for people with cancer that is capable of being widely implemented and that has good outcomes.

There were three objectives:

1. To define the best elements of the models employed by the pilot sites – in terms of service structure and delivery, as well as the content of vocational rehabilitation interventions – as a guide to future service provision.
2. To identify patients' perspectives of vocational rehabilitation services with regard to both experience and outcome.
3. To estimate the cost of service delivery and assess cost-effectiveness.

## 2.2 Method of investigation

### Objectives 1 and 2

Realistic Evaluation (Pawson and Tilley 1997) was used to examine the different ways in which the pilot sites structured and delivered their services, and to identify the outcomes that were achieved. Recognising that interventions are context-dependent – in other words, what works well in one area might not work as well in an area with different resources – this methodology enabled an examination of what was effective, for which groups of people, and in what circumstances.

The advantages of Realistic Evaluation in this project were that it maximised stakeholder and service-user involvement, it provided a framework for the synthesis of multiple sources and types of data, and it enabled us to understand the processes whereby outcomes were achieved.

### Objective 3

Pilot sites were asked to record expenditure and activity data which would be used to estimate service delivery costs. Questionnaires were also distributed to service users in order to compare levels of resource use (for NHS and personal social services, Jobcentre Plus schemes, patients and carers and benefits/work schemes) and quality of life in the six months before and after contact with the pilot sites.

## 2.3 Data collection and analysis

Data were collected from a variety of sources, as set out below:

### 2.3.1 Service structure and delivery

- Data on the service structure, staffing, mechanisms for service delivery, intended outcomes and learning from the pilot sites were collected longitudinally, in three phases:
  - **Phase 1:** Visits to the seven pilot sites to discuss and clarify proposed service delivery, early challenges, staffing and structure, and to negotiate how the overall project evaluation could dovetail most successfully with the pilots' individual evaluations. This included some observation of vocational rehabilitation interventions, i.e. visits with pilot site staff to two service users, and attendance at an education/support group. June 2010 – September 2010.
  - **Phase 2:** Three individual and three group interviews with service providers (n = 11) to examine pilot site context and operation, as well as interim achievements and challenges. November 2010 – February 2011.
  - **Phase 3:** Four focus groups and one individual interview with staff at pilot sites which had received extension funding (n = 17) to understand the changes in aims and service delivery over the life of the project, and examine the strengths and challenges of the different service delivery models. (Six of the 17 participants had also taken part in the interviews in Phase 2.) June and July 2011.
- Each pilot provided a different model of service, and carried out their own internal evaluations. In order to be able to make comparisons across the sites, pilots were asked to provide data on patients to whom they had provided a specialist intervention, where work status on referral and discharge was able to be recorded, using the following Service Delivery Template (n = 330):

| Patient identifier | Diagnosis | Age | Gender | Work status on referral | Work status on discharge | Number of hours spent | | | | Date referred | Date discharged |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | Direct contact | Indirect contact | Other | Total | | |

The following work status categories were used (columns five and six):

- Currently employed and working
- Currently working at your job, but in a modified role
- Employed, but not working at your job (for example, on sick leave)
- Not working due to cancer
- Not working due to other health problems
- Unemployed
- Doing unpaid (voluntary) work
- Other, please specify

Contact time (columns seven to ten) was split into the following categories:

- Direct contact – individual or group face-to-face contact.
- Indirect contact – telephone calls, e-mails.
- Other – for example, travel, writing reports, liaising with other services.

- The final reports received from each of the seven pilot sites. The five pilots that ran for the full sixteen months produced final report documents (St John's ISC, NHNN, Shaw Trust with Christie, Mount Vernon Cancer Network and Orbitals Ltd with Olive Tree CSC). The remaining two pilots (NHS South of Tyne and Wear and NHS Blackburn with Darwen) provided data spreadsheets.
- Quantitative data were analysed using simple descriptive statistics. All interviews and focus groups were audio recorded and transcribed verbatim. A qualitative data analysis software package (MAXQDA) was used to assist in organising data which was analysed using the Framework approach (Ritchie and Lewis 2003).

### 2.3.2 Definition, content and competencies for specialist vocational rehabilitation

- Two one-day consensus development workshops using the Nominal Group Technique (Gallagher et al. 1993, Van de Ven and Delbecq 1972) were held to explore definitions of vocational rehabilitation, to specify the content of a specialist cancer vocational rehabilitation intervention, and to identify the knowledge and skills required for its delivery.

Sixteen people participated in the first workshop – predominantly pilot site staff. The 25 participants in the second workshop (five weeks later) included the same group of specialists as well as service development managers, service users, vocational rehabilitation experts, and representatives from Macmillan Cancer Support and the Department of Health. Draft consultation documents were circulated after both events for comment and clarification.

### 2.3.3 Perspectives of service users

- In-depth interviews with 25 service users from four of the five pilots that received extension funding.

### 2.3.4 Health economic data

- Each of the pilot sites was asked to report expenditure across their period of operation (including any set-up and training costs, but excluding research related costs). This expenditure was categorised as either patient-related staff costs (for staff who had contact with patients) or as support costs (for example administration/management costs, training, computer equipment, marketing, travel and consumables). These two items were summed to estimate total expenditure across the seven sites.
- Patients referred to the pilots were invited to complete a questionnaire booklet containing:
  - Demographic information
  - Work status
  - EuroQOL EQ-5D-3L
  - Modified Client Services Receipt Inventory
  - Modified General Self Efficacy Scale

The questionnaire was given to participants by the pilot sites at baseline and sent to the participants again at six months for self-completion and return by post. 143 people returned the baseline questionnaire and 86 of these returned the subsequent six month follow-up questionnaire (60.1% response rate at six months). One participant had died; 85 respondents were therefore included in the final analysis.[8]

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[8] The characteristics of these respondents are shown in Table 4, page 26

Both baseline and follow-up questionnaires asked about participants' resource use over the previous six months, where these were categorised as either National Health Service (NHS) and personal social services (PSS), government (Jobcentre Plus, NHS and PSS), patient and carer, societal (NHS and PSS, government and patient and carer – calculated twice, with and without a value assigned to care from family and friends) and benefits/work schemes. Published unit costs (at 2010/11 cost levels) were used to value the reported levels resource use. Average hourly earnings were applied to the productivity and time costs of family and friends who provided informal care or child care, consistent with the human capital approach. However, since the methods used to calculate cost productivity and time costs are controversial (Sach and Whynes 2003), these costs were excluded from the base case and presented separately, and costs were not discounted as the time period was less than one year.

The EuroQOL EQ-5D-3L (Brooks 1996) was used to estimate patients' quality of life. Responses to the EQ-5D were used to estimate the mean utility score at baseline and six months, along with the change in utility for this period. Subsequently, the area under the curve technique (Manca et al. 2005), with adjustment for baseline values, was used to estimate the change in Quality Adjusted Life Years (QALYs) over the six month evaluation period (linear interpolation between the baseline and six month utility value was assumed).

- An initial aim of the health economic assessment had been to estimate the cost-effectiveness of the seven pilot sites compared to usual care (allocative efficiency). This was to be based on data collected by the seven pilots as well as two comparison sites, one at University College London Hospitals (UCLH) and one at University Hospital of South Manchester (UHSM) Wythenshawe, aiming to recruit 300 participants across both sites. The timescales for ethics, research and development, and local approvals made recruitment from UCLH unfeasible. Recruitment at UHSM Wythenshawe commenced in August 2012 and approximately 400 baseline questionnaires were distributed between August and November. Only 26 were returned. The six month follow up data is currently being collected with 19 questionnaires so far received. This data will be analysed and presented in future study publications.

### 2.3.5 Summary of data sets

Seven sets of data were generated for use in the evaluation, as set out in Table 1.

**Table 1:** NCSI Vocational Rehabilitation Project Evaluation data sets

| | |
|---|---|
| **Data set 1** | Focus groups and interviews with service providers<br>*(2.3.1 Service structure and delivery)* |
| **Data set 2** | Service Delivery Template<br>*(2.3.1 Service structure and delivery)* |
| **Data set 3** | Pilots' final reports and data spreadsheets<br>*(2.3.1 Service structure and delivery)* |
| **Data set 4** | Consensus development workshops<br>*(2.3.2 Definition, content and competencies for specialist vocational rehabilitation)* |
| **Data set 5** | Patient interviews<br>*(2.3.3 Perspectives of service users)* |
| **Data set 6** | Pilot sites' expenditure reports<br>*(2.3.4 Health economic data)* |
| **Data set 7** | Health economic evaluation questionnaires<br>*(2.3.4 Health economic data)* |

## 2.4 Ethical considerations and funding

This study was reviewed by an NHS Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans in accordance with the requirements of the Clinical Trials Regulations. In this case, the reviewing committee was the Central London REC 3, who gave a favourable opinion. REC Ref. No.: 11/H0716/5.

The study was funded by the National Cancer Survivorship Initiative.

## 2.5 Confidentiality and anonymity

The names of the service users who are quoted in the report have been changed, and identifying details such as geographical location and specific job titles have been anonymised. Pseudonyms have been used for individuals named by service users (such as family members, employers and health professionals). Pilot sites are identified in Section 4.7, but other than that, non-identifying descriptors and pseudonyms are used. This is to preserve the confidentiality of service users, as well as colleagues, other health professionals and employers who might be referred to, however indirectly.

## 2.6 Limitations of the data and consequences for analysis and interpretation

The way in which the pilots were commissioned and set up has consequences for data collection and interpretation and these should be borne in mind when reading the report.

Each one of the seven pilots was, essentially, developing a new service, even if not completely from scratch. While pilots drew on available expertise and incorporated aspects of existing services into their programmes, they were providing services, interventions and resources that had not been previously available in that particular configuration. Therefore, in the 12–16 months of their existence, they had to establish the service, publicise it, develop links and networks with other agencies, generate referrals, and then – in many cases, just as the momentum was starting to develop – negotiate the withdrawal of the service. This will have had an impact on referral rates and numbers, and also on the outcomes achieved and recorded.

The primary objective of the pilot sites was to set up and run a good service. Although all of the pilot sites were committed to evaluating the project, it was not set up as a research study. Services were provided to patients irrespective of whether they chose to participate in the evaluation or not. Despite intensive efforts to capture all appropriate information from the outset of the project, it proved challenging to get patients to complete and return questionnaires in both the intervention and comparison groups and to recruit comparison centres.

The health economic component of this report has identified, measured and valued the costs and health outcomes for those who received a vocational rehabilitation intervention, but it has not been possible to compare these to the costs and outcomes of usual care. Without a comparison group, it is not possible to assess the cost-effectiveness of the intervention.

A follow-on research study *The REJOIN study (REhabilitation for Job and Occupational INdependence) – a feasibility study of a randomised controlled trial to evaluate a vocational rehabilitation intervention for people with cancer* has been funded by the National Institute for Health Research (NIHR). This three year project, due for completion in December 2014, will build on the results of the NCSI Vocational Rehabilitation Project to test a cancer-specific vocational rehabilitation intervention, randomising participants to either an intervention or a control group in order to examine both clinical and cost-effectiveness.

# 3 Strategic framework for service design and delivery of work support and vocational rehabilitation in cancer

## 3.1 Overview

The key to enabling people with cancer to remain in or return to work is to embed work support into the patients' pathway from diagnosis, through treatment and on into life beyond cancer – or end of life care, where that is appropriate. It cannot be relegated to an add-on service, offered only when problems arise. Positive approaches towards work, tailored information delivered at the right times, access to specialist services, and effective liaison between patients, health professionals and employers are all crucial.

Two related areas need to be considered when setting up work support and vocational rehabilitation services for people with cancer. Firstly, do all of the components needed to provide an effective service exist in the particular locality or region? Secondly, are people with cancer able to access the support they require at a level appropriate to their needs? A framework for establishing the answers to these questions is presented in two models:

The first model (Figure 2, page 20) is a **Strategic Framework for Cancer Work Support**. It presents a blueprint for service configuration at a population level. All patients who are in work or who have the potential to work require attention to be paid to the impact of their illness on employment, with effective service provision relying on collaboration between patients, employers, health professionals, specialist vocational rehabilitation services and work support services.

The second model (Figure 3, page 22), a **Three Level Model of Work Support for People with Cancer**, shows the structure of services required for individual patients across a spectrum of needs, from those which are straightforward to those which are highly complex. This three level model emerged from the original NCSI Work and Finance Workstream Project Group four level model (Figure 1, page 12), and it is based on NHS Improvement's Model of Care for Living With and Beyond Cancer (NHS Improvement 2011).

The framework and model are explained in more detail in Section 4, and case studies of different ways in which this model has been implemented in practice, drawn from the experience of the pilot projects, can be found in Section 4.7.

## 3.2 Strategic Framework for Cancer Work Support

In order to provide effective work support services at a population level, it is necessary to take account of the needs, roles and responsibilities of:

- People affected by cancer and their carers.
- Employers.
- Health care professionals.
- Specialist vocational rehabilitation services.
- Organisations providing work support.
- Across these groups, two distinct strands of support are required:
- Strategies implemented across organisations to embed employment support into the cancer treatment pathway and into the post-treatment phase.
- Interventions at an individual level to provide tailored personalised support.

It is vitally important to pay attention to the interaction between people and services, and to the organisational environments in both employment and healthcare, because it is the interplay of factors as much as the requisite components and structures that supports or undermines successful employment.

The essential, core components required for providing effective work support for people with cancer are as follows:

1. Health professionals should have the knowledge and skill to present the right messages about work in an acceptable and appropriate way, so that patients are encouraged to think positively about work.
2. Prompts to talk about work should be incorporated into local and national cancer guidelines, policies, treatment pathways and information prescriptions.

**Figure 2:** Strategic model of cancer work support

## Strategic framework for Cancer Work Support

### Core Service Components

### Employers

**Working with employers at an organisational level**
Ensure that employers understand the needs of employees with cancer, and that they incorporate just, fair and informed practices into company policies and procedures.

**Working with employers and employees at an individual level**
Provide advocacy and support for individuals with cancer in liaising with employers.

Ensure effective channels of communication between health professionals, employers and occupational health departments.

### Cancer services

**Health professionals**
Ensure that health professionals have adequate knowledge to provide early and on-going support.

**Health service delivery**
Embed screening for work problems and provision of work support into assessment tools, treatment protocols, pathways and guidelines.

**Cancer information services**
Ensure that work support information, tailored to meet local needs, is available from cancer information and support centres.

### People with cancer and their families/carers

**Provide support at three levels:**

**Level 1**
Open access to information, support and signposting for all patients

**Level 2**
Active support for self management for those with straightforward problems and concerns

**Level 3**
Specialist vocational rehabilitation for people with complex problems

### Specialist vocational rehabilitation services

Ensure that specialist vocational rehabilitation services are available for people with complex problems, incorporating the following types of interventions:

- Assessment of individual capacity and workplace requirements.
- Rehabilitation to build work skills.
- Negotiation of phased return to work.
- Psychological interventions.
- Information on legal rights and responsibilities.
- Supported withdrawal from work, where appropriate.

### Organisations providing work support

Identify work support services available locally, such as:

- Benefits advisors
- Citizens Advice Bureau
- Jobcentre Plus
- Advisory, Conciliation and Arbitration Service (ACAS)
- Disability Law Service (DLS)
- Access to Work
- Other local services

Ensure effective referral pathways between cancer services and these organisations.

**Collaboration between employers, health professionals, service providers, patients and their families is needed for successful work outcomes.**

3. Tailored information and advice about patients' employment rights and responsibilities, and about the support services available, should be provided in order to facilitate patients' self-management.
4. The statutory and voluntary services available locally to support people with cancer in employment should be identified, and pathways for effective liaison between these services and cancer treatment services should be created and used.
5. Specialist vocational rehabilitation should be provided for people with complex problems.
6. Treatment protocols and pathways should prompt effective liaison between patients, health professionals, employers, human resources departments and occupational health services.
7. There should be engagement with employers and employers' organisations to raise employers' awareness of the needs of employees with cancer.

In order to ensure that people with cancer are well supported to remain in or return to work, each Cancer Network, or organisation responsible for cancer services, should nominate a lead person (or people) to take responsibility for:

1. Ensuring that health professionals have adequate knowledge to provide early and on-going support.
2. Embedding work support into cancer treatment protocols, pathways and guidelines.
3. Identifying work support and specialist vocational rehabilitation services available to cancer patients in a locality, and noting gaps. Any development of new services should aim to integrate existing resources and avoid duplication.
4. Ensuring that there are effective channels of communication and referral pathways between cancer services and external work support services.
5. Ensuring that there are effective channels of communication between health professionals, employers and occupational health departments.

## 3.3 Three Level Model of Work Support for People with Cancer

Patients' employment support needs can be divided across three levels, from straightforward to complex. The model identifies the recipients of services, the service providers, and the interventions required at each of the three levels, as follows:

- **Level 1:** All patients who are in work or have the potential to work should be asked about their employment, and receive information and signposting.
- **Level 2:** People with specific concerns or worries should be provided with resources to support self-management.
- **Level 3:** The smaller subset of people who have complex needs should be referred to a vocational rehabilitation service for specialist support.

## 3.4 Distinction between work support and vocational rehabilitation

It is important to understand the difference between 'work support for people with cancer' which takes place at Levels 1 and 2, and 'specialist vocational rehabilitation' at level 3.

### Work support for people with cancer: Levels 1 and 2

Everyone with a cancer diagnosis who is employed or who has the potential to be employed should receive support to remain in or return to work. This support should be provided from the time of diagnosis onwards, with positive messages about work (both implicit and explicit) incorporated into health professionals' interactions with patients throughout the treatment pathway.

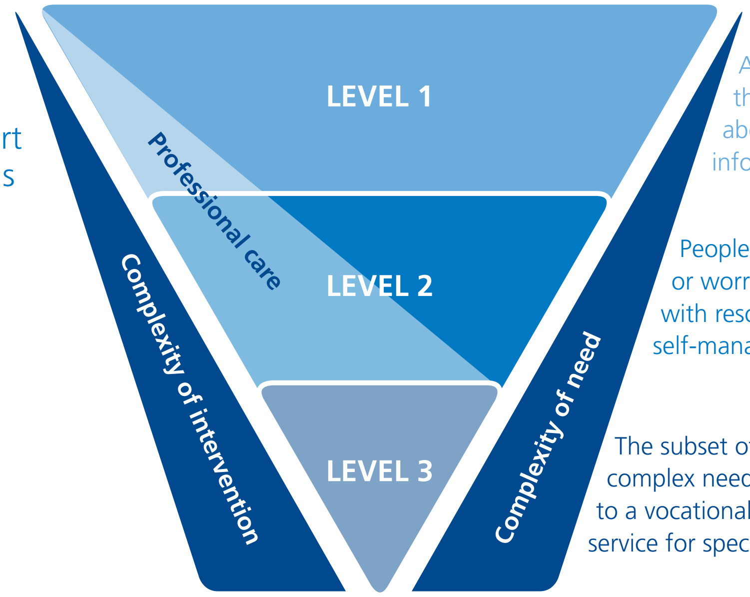
Sections 5 – 7 elaborate on the practical implications of this – providing tips and strategies for getting it right, and discussing some of the challenges that might be encountered.

### Specialist vocational rehabilitation: Level 3

A subset of people with cancer will have complex needs which are best met by a specialist vocational rehabilitation service where the interventions are provided by skilled vocational rehabilitation professionals.

Section 8 outlines the components of specialist vocational rehabilitation interventions for people with cancer, and the competencies that are required in order to deliver effective services.

**Figure 3:** Three level model of work support interventions for people with cancer



All patients who are in work or have the potential to work should be asked about their employment and receive information and signposting.

People with specific concerns or worries should be provided with resources to support self-management.

The subset of people who have complex needs should be referred to a vocational rehabilitation service for specialist support.

| | Recipients | Service providers | Interventions |
|---|---|---|---|
| **LEVEL 1 Open access to information and support** | Everyone with a cancer diagnosis who is employed or who has the potential to be employed. | All service providers and health professionals with whom the person with cancer comes into contact. | • Positive messages about work. Many people at this level will not identify any difficulties and might not think that they have problems – which may well be the case – but it is important to ensure that work remains on the agenda in a positive way.<br>• Signposting and information on (i) the impact of a cancer diagnosis on work, (ii) self management support programmes or other support available, and (iii) how to get in touch with professionals if problems arise in the future. |
| **LEVEL 2 Active support for self-management** | People who have specific questions, concerns or worries, and who, with the right information and support, will be able to resolve these issues themselves (i.e., who are able to self-manage). | Health professionals and other support staff with some specialist knowledge of the impact of cancer on work; for example, CNSs, oncologists, GPs, vocational rehabilitation specialists, Jobcentre Plus staff, benefits advisors, cancer information centre staff. | • Provision of specialised, tailored information, advice or support which people with cancer are able to take forward and implement themselves.<br>• Signposting to other specialist services and organisations.<br>• Support is typically of short duration and may be delivered face-to-face, or by phone or e-mail. |
| **LEVEL 3 Specialist vocational rehabilitation** | People who have complex problems, who require specialist help from qualified professionals. | Vocational rehabilitation specialists (with the knowledge and skills set out in the competency framework). | A process of specialist vocational rehabilitation including (but not limited to):<br>• Detailed assessment of individual capacity and workplace requirements.<br>• Rehabilitation interventions to build work skills.<br>• Education on managing specific symptoms.<br>• Liaison with employers, negotiating a phased return to work<br>• Psychological interventions.<br>• Information and advice on rights and responsibilities.<br>• Supported withdrawal from work where appropriate.<br>• Referral to other support services<br>• Careers advice and guidance. |

Based on their experiences of publicising their services, the pilot sites expressed concern that the term 'vocational rehabilitation' was not widely understood, and could be confusing for health professionals, and possibly for patients. It is, however, a useful term in describing the structured, problem-solving, goal-setting, biopsychosocial rehabilitation approach required for people at Level 3 who have complex needs. It also provides an important and clear connection to vocational rehabilitation services in other health conditions.

There is unlikely to be a perfect, universally acceptable term. The key is to find the most appropriate and comprehensible terminology for the audience being addressed, as one of the pilot site staff notes:

> *If I'm talking to OTs or physios, I'll probably talk about vocational rehabilitation because that's the language they'd understand. For nurses and doctors, I'd maybe say something like, 'These are the things we can do to help your patients to get back to work,' and give some examples, such as looking at work demands and talking to employers. With patients, it's more a matter of listening to what they're having problems with and then explaining how you can help them, responding to those specific issues. I wouldn't say to a patient, 'I'm here to give you vocational rehabilitation,' I'd say, 'Such-and-such sounds like it's a problem for you, here's how I can help.'*
>
> A (pilot site staff – pilot 2)

## 3.5 Priorities and drivers of different stakeholders

The effective provision of work support services for people with cancer relies on interaction and collaboration between a wide range of individuals and organisations including patients, health professionals, employers, service providers, funding bodies and policy makers. While there is broad agreement on the overall aim of work support services – i.e. to enable people with cancer to remain in or return to work where that is their wish – there are differences in emphasis and in the priorities of the various stakeholders.

In general terms, funding bodies, commissioners and policy-makers have an interest in ensuring that those who wish to work are able to do so, thereby reducing the cost of unemployment. Employers wish to maintain a skilful and productive workforce, and reduce sickness absence. People with cancer and their carers value being able to make informed choices and decisions about work, which might include returning to work as quickly as possible, or even remaining in work through treatment, but equally might be concerned with withdrawing from work with the best financial settlement possible. Health professionals and vocational rehabilitation practitioners may tend to consider the needs and preferences of their individual patients or clients over policy directives or institutional priorities. While the benefits of work are recognised and endorsed, practitioners are mindful that returning to or remaining in employment may not be ideal for all clients, and other occupations such as voluntary work can be meaningful and fulfilling.

It can be helpful for stakeholders to recognise and discuss areas of potential tension, in order to negotiate how expectations and outcomes can best be met.

## 3.6 Local considerations in service configuration

The Strategic Framework for Cancer Work Support (Figure 2, page 20) shows the essential components required for effective service provision. However, as with any initiative, it is necessary to take account of local circumstances, priorities, resources and constraints in order to build and deliver a responsive and effective service.

The seven pilot sites found that there was significant variability in the resources available across different regions, and also that services which work well in one area might not be available or might not be as effective in another. For example, the Shaw Trust with Christie pilot was able to make extensive use of the well developed, well structured employment support services provided by Shaw Trust across Manchester and the surrounding areas. For the London pilot based at the National Hospital for Neurology and Neurosurgery, identifying and liaising with much more disparate employment support services spread over many London boroughs and surrounding counties proved challenging.

There may also be discrepancies within services, as one of the pilot service providers noted:

> *I have found there is variability in what's available from Cancer Information Centres in this area. You can't assume that because there's a Cancer Information Centre, a particular level of advice will be available.*
>
> T (pilot site staff – pilot 1)

# 4 Findings from the seven pilot sites

This section presents the findings from the seven pilot sites. The quantitative and health economic data is presented in Sections 4.1 – 4.6. Section 4.7 describes five case studies illustrating a range of approaches to providing work support and specialist vocational rehabilitation services.

## 4.1 Referral numbers

A total of 597 patients were referred across all of the pilot sites that provided direct interventions to patients, i.e. all except Mount Vernon Cancer Network. This figure is calculated from patients seen at levels 2, 3 and 4 as defined by original prototype NCSI model[9] as this was the model used in setting up and delivering the pilots' services.

**Table 2:** Numbers of referrals[10] (shown across the four levels of the original prototype NCSI model)

| | **NHS SoTW** | **NHS BwD** | **Orbitals/ Olive Tree** | **NHNN** | **Shaw/ Christie** | **St John's ISC** | **Mt Vernon** |
|---|---|---|---|---|---|---|---|
| **Referral period** | 04/10 – 03/11 | 04/10 – 03/11 | 04/10 – 07/11 | 04/10 – 07/11 | 04/10 – 07/ 11 | 04/10 – 07/11 | 04/10 – 07/11 |
| **Level 1**[11] | 13 | 21 | No data | 13 | No data | 3431 | n/a |
| **Level 2** | 26 | 27 | No data | 33 | 260 | 69 | n/a |
| **Level 3** | 6 | 28 | 43 | 0 | | 13 | n/a |
| **Level 4** | 6 | 16 | | 48 | | 22 | n/a |
| **Levels 2, 3, 4** | 38 | 71 | - | 81 | 260 | 104 | - |
| **Levels 3, 4** | 12 | 44 | 43 | 48 | - | 35 | - |

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[9] See Figure 1, page 12

[10] The data is taken from the pilots' final reports (data set 3)

[11] Contact at Level 1 was indirect and difficult to count. For example, the figure given by St John's ISC (3431) refers to the number of work-related information booklets distributed through their local cancer information centres and information stands at promotional events.

Models of service delivery varied between pilots, as did the pilot sites' application of the levels to individual patients. All of the pilot sites found the four levels problematic to interpret, and there was a lack of consistency between pilots in the way that the levels were applied: a patient categorised as Level 3 in one pilot, for example, might have been categorised as Level 2 or Level 4 in another. As can be seen from Table 2, only three of the pilot sites separated out Levels 1, 2, 3 and 4 patients. Feedback from the pilots was used to develop the Three Level Model of Work Support presented in this report,[12] which provides a clearer, more straightforward system for classification. Table 3 shows the way in which the new three level model corresponds to the prototype NCSI four level model. Level 3 in the new model is approximately equivalent to Levels 3 and 4 in the prototype model.

**Table 3:** Comparison between the original prototype NCSI four level model and the revised Three Level Model of Work Support.

| **The original prototype NCSI model** | |
|---|---|
| **Level 1** | Information and support provided through electronic and printed media. |
| **Level 2** | One-to-one support and signposting through telephone helplines and digital media. |
| **Level 3** | Self-management programmes accessed during or after treatment. |
| **Level 4** | Specialist vocational rehabilitation services. |

| **The revised Three Level Model of Work Support** | |
|---|---|
| **Level 1** | All patients who are in work or have the potential to work should be asked about their employment, and receive information and signposting. |
| **Level 2** | People with specific concerns or worries should be provided with resources to support self-management. |
| **Level 3** | The smaller subset of people who have complex needs should be referred to a vocational rehabilitation service for specialist support |

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[12] See Figure 3, page 22

## 4.2 Patient characteristics

**Table 4:** Patient characteristics for the 85 respondents who completed the Health Economic Evaluation Questionnaire at both baseline and 6 months, compared with patient characteristics recorded in the Service Delivery Template

| | | **Data from the Health Economic Evaluation Questionnaire** n = 85 | **Data from Service Delivery Templates** n = 330 |
|---|---|---|---|
| **Gender** | Male | 34 (40.0%) | 127 (39.6%) |
| | Female | 51 (60.0%) | 193 (60.3%) |
| **Mean (SD) age in years** | | 51.2 (range 30 to 63) | 48.1 (range 18 – 82)<br>(n=320 – no data for NHS SoTW) |
| **Single** | | 9 (10.6%) | No data |
| **Separated** | | 4 (4.7%) | No data |
| **Married** | | 48 (56.5%) | No data |
| **Divorced** | | 13 (15.3%) | No data |
| **With partner** | | 11 (12.9%) | No data |
| **Education: n with a degree or higher qualification** | | 30 (35.3%) (missing=1) | No data |
| **Ethnic group: n white** | | 77 (90.6%) (missing=1) | No data |
| **Average date of cancer diagnosis** | | April 2009 (range Nov 2001 to May 2011) (missing=1) | No data |
| **Type of Cancer:** | Bowel | 5 (5.9%) | 27 (8.2%) |
| | Brain tumour | 9 (10.6%) | 53 (16.0%) |
| | Breast | 27 (31.8%) | 115 (34.8%) |
| | Head and Neck | 44 (51.8%) | 20 (6.1%) |
| | Leukaemia | | 18 (5.4%) |
| | Lymphoma | | 19 (5.7%) |
| | Gynaecological | | 16 (4.8%) |
| | Other | | 62 (18.8%) |

## 4.3 Work outcomes

Table 5 shows service users' change in employment status between referral and discharge for those who received an intervention from one of the vocational rehabilitation pilots. Of note is the fact that over one third (38%) went from 'not working to working' or from 'sick leave to full work or modified work'.

**Table 5:** Change in work status from referral to discharge[13,14]

| **Work outcomes** | **NHS BwD** | **Orbitals/ Olive Tree** | **NHNN** | **Shaw/ Christie** | **St John's ISC** | **Total** |
|---|---|---|---|---|---|---|
| | n = 43 | n = 32 | n = 53 | n = 158 | n = 34 | n = 320 |
| Remained in work or remained in a modified role (no change) | 4 (9.3%) | 1 (3.1%) | 11 (20.7%) | 2 (1.2%) | 7 (20.5%) | 25 (7.8%) |
| Modified work ➡ Full work | 0 (0%) | 1 (3.1%) | 1 (1.8%) | 0 (0%) | 0 (0%) | 2 (0.6%) |
| Not working (unemployed) ➡ Working | 0 (0%) | 2 (6.2%) | 0 (0%) | 18 (11.4) | 1 (2.9%) | 21 (6.5%) |
| On sick leave ➡ Full work or modified work | 16 (37.2%) | 14 (43.7%) | 13 (24.5%) | 50 (31.6%) | 8 (23.5%) | 101 (31.5%) |
| Full work ➡ Modified work | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (2.9%) | 1 (0.3%) |
| Working ➡ On sick leave | 1 (2.3%) | 0 (0%) | 1 (1.8%) | 0 (0%) | 0 (0%) | 2 (0.6%) |
| Working ➡ Not working | 0 (0%) | 0 (0%) | 2 (3.7%) | 0 (0%) | 0 (0%) | 2 (0.6%) |
| Remained on sick leave | 14 (32.5%) | 3 (9.3%) | 6 (11.3%) | 12 (7.6%) | 6 (17.6%) | 41 (12.8%) |
| On sick leave ➡ Not working (e.g. made redundant, retired, resigned) | 2 (4.6%) | 3 (9.3%) | 3 (5.6%) | 12 (7.6%) | 3 (8.8%) | 23 (7.2%) |
| Remained not working | 6 (13.9%) | 8 (25.0%) | 12 (22.6%) | 49 (31.0%) | 7 (20.5%) | 82 (25.6%) |
| On sick leave ➡ RIP | 0 (0%) | 0 (0%) | 4 (7.5%) | 15 (9.4%) | 1 (2.9%) | 20 (6.2%) |

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[13] This data is taken from the Service Delivery Templates provided by the pilot sites (Data Set 2).

[14] Data on work status changes for NHS South of Tyne and Wear is not available. The early closing of this pilot site due to the cessation of the CMP programme curtailed their ability to provide a full final report and complete a Service Delivery Template.

## 4.4 Cost of the intervention

### 4.4.1 Indication of the costs of providing specialist vocational rehabilitation services

Expenditure levels for each of the pilot sites, over their whole operational period, are shown in Table 6. Expenditure levels varied between £54,951.49 and £108,936.50, where patient-related staff costs far outweighed support costs. With regard to the number of patient contacts, one site did not undertake these as they made contact with employers/health care staff only. Across the other six sites, estimated numbers varied between 38 and 260. The average cost per patient contact (at each site) was thereby estimated to range between £384.86 and £1,590.02, with a weighted average cost per patient contact of £842.23 (£839.19 after excluding set-up costs). A 'contact' here refers to the whole intervention delivered to a patient, not to a single meeting.

### 4.4.2 Indication of cost savings

Taking the weighted average cost per patient contact of £842.23, it is possible to put the cost of delivering cancer vocational rehabilitation into some context as follows:

The median gross annual earnings for full-time employees in the UK are £26,100 (Office for National Statistics 2012). With a personal allowance of £7475 (HM Revenue and Customs, no date), £18,625 taxed at 20% returns £3725 to the Exchequer per year. At approximately £850 per intervention, the tax returns outweigh the cost of the intervention within three months of employment. Consequently if patients return to work for an additional 12 weeks that they might not otherwise have worked, the intervention could be argued to pay for itself.

**Table 6:** Expenditures across the seven pilots

| | NHS SoTW | NHS BwD | Orbitals/ Olive Tree | NHNN | SHAW/ Christie | St John's ISC | Mt Vernon |
|---|---|---|---|---|---|---|---|
| **Set up costs (1) e.g. training (£)** | | 1,300.00 | | | | 518.35 | 14,500 |
| **Patient related (staff) costs (2) (£)** | 49,356.68 | 65,064.00 | 62,648.50 | 80,013.96 | 72,107.00 | 70,524.88 | 41,625 |
| **Support costs[15] (3) (£)** | 5,594.81[16] | 42,572.50 | 5,722.40 | 14,843.57 | 27,957.17 | 4,588.43 | 3,625 |
| **Total cost (4)=(1)+(2)+(3) (£)** | 54,951.49 | 108,936.50 | 68,370.90 | 94,857.53 | 100,064.17 | 75,631.66 | 59,750 |
| **Number of patients in receipt of an intervention** | 38 | 71 | 43 | 81 | 260 | 104 | n/a |
| **Average cost per patient contact (£)** | 1,446.09 | 1,534.32 | 1,590.02 | 1,171.08 | 384.86 | 727.23 | n/a |
| **Average cost per patient contact, excluding set-up costs (£)** | 1,446.09 | 1,516.01 | 1,590.02 | 1,171.08 | 384.86 | 722.24 | n/a |
| **Period over which costs were incurred** | 04/10 – 03/11 | 04/10 – 03/11 | 04/10 – 07/11 | 04/10 – 07/11 | 04/10 – 07/11 | 04/10 – 07/11 | 04/10 – 07/11 |

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[15] This may include administration costs.

[16] Estimated from budget plans as administrative support was not itemised separately within expenditure figures.

**Table 7:** Patient contact time

| | NHS SoTW | Orbitals/ Olive Tree | NHNN | Shaw/Christie | St John's ISC |
|---|---|---|---|---|---|
| **Number of patient contacts** | 38 | 43 | 81 | 260 | 104 |
| **Number of timed contacts** | 10 (26.3%) | 32 (74.4%) | 53 (65.4%) | 158 (60.8%) | 34 (32.7%) |
| **Mean direct contact in hours (min – max)** | 2.6 (1.5 – 4) | 6.02 (1 – 21) | 3.36 (0 – 14) | 2.51 (1 – 11) | 16.8 (0 – 55) |
| **Mean indirect contact in hours (min – max)** | 0.93 (0.5 – 2) | 0.20 (0 – 1.5) | 1.02 (0 – 4) | 1.23 (0 – 4) | 1.88 (0 – 9.25) |
| **Mean other contact in hours (min – max)** | 1.35 (0.5 – 2) | 0.5 (0.5 – 0.5) | 4.04 (1 – 15) | 1.59 (0 – 7) | 8.74 (1 – 26.25) |
| **Mean total time in hours (min – max)** | 4.88 (3 – 7.75) | 6.72 (1.5 – 21.5) | 8.42 (2 – 28) | 5.33 (1 – 20) | 27.42 (2.5 – 82.5) |

NHS expenditure on cancer services in 2009/09 was estimated at between £5.1 billion and £6.3 billion (Department of Health 2011). In a recent report commissioned by BUPA, the total cost of cancer diagnosis and treatment in the UK, incorporating the NHS, the private sector and the voluntary sector, was estimated at £9.4 billion in 2010: the equivalent of an average of £30,000 per person diagnosed with cancer in the UK (Bupa 2011).

### 4.4.3 Duration of intervention

The time spent in contact with patients was recorded in five of the seven sites. (Data is not available for NHS Blackburn with Darwen, and Mount Vernon Cancer Network did not have direct contact with patients.) Data for the five remaining sites is presented in Table 7. Across these five sites, times were available for between 26.3% and 74.4% of all patient contacts. Times were recorded for direct contact with patients (face-to-face contact), indirect contact (telephone calls and e-mails), and other contact (for example, travel, writing reports, liaising with other services). Direct patient contact constituted between 40 and 90% of the total.

## 4.5 Resource use

Levels of resource use for NHS and PSS are given in Table 8, and for the job centre, patient and carer, society and benefits/work schemes in Table 9, with associated unit costs provided in Appendix I. It can be seen that the respondents tend to use a range of services, where oncology (cancer) out-patient visits and in-patient days tend to constitute the highest proportion of baseline overall NHS and PSS estimated costs. The mean NHS and PSS costs estimated from the six month questionnaire were nearly half that at baseline (see Table 7), where the costs associated with oncology (cancer) in-patient days showed a marked fall, but the cost of paid carers tended to increase. Indeed, the mean NHS and PSS costs in the six months after baseline, compared to that before, were still lower even after including the weight average vocational rehabilitation programme site cost of £842.23 (see Table 8). Contrastingly, the costs associated with Jobcentre Plus contacts, help from paid carers and some of the benefit/work schemes tended to be higher in the six months post-baseline compared to pre-baseline (see Table 9).

**Table 8:** Per patient mean six monthly levels of resource use and associated mean costs at baseline and six months.

| Item | Baseline resource use, mean value (n blank)[17] | Associated mean 6 month cost | 6 months resource use, mean value (n blank) | Associated mean 6 month cost | 6 month change in resource use | 6 month change in cost |
|---|---|---|---|---|---|---|
| **Oncology (cancer) out-patient visits** | 7.95 (10) | £1010.20 | 4.46 (42) | £590.88 | –3.49 | –£419.32 |
| **Other out-patient visits** | 4.26 (26) | £574.94 | 2.76 (24) | £373.24 | –1.49 | –£201.71 |
| **Oncology (cancer) in-patient days** | 4.66 (42) | £1383.67 | 0.36 (48) | £108.32 | –4.29 | –£1275.35 |
| **In-patient days (other)** | 2.08 (43) | £618.46 | 1.11 (46) | £328.45 | –0.98 | –£290.01 |
| **GP contacts**[18] | 3.73 (7) | £208.04 | 3.22 (9) | £144.87 | –0.51 | –£63.17 |
| **Practice nurse contacts**[18] | 1.13 (39) | £15.52 | 1.09 (52) | £11.21 | –0.04 | –£4.32 |
| **District nurse contacts**[18] | 2.60 (39) | £87.12 | 1.06 (61) | £14.77 | –1.54 | –£72.35 |
| **Cancer / Macmillan nurse contacts**[18] | 1.55 (34) | £24.82 | 1.26 (48) | £42.91 | –0.29 | £18.09 |
| **Physiotherapist contacts**[18] | 1.19 (42) | £22.32 | 0.89 (52) | £16.26 | –0.29 | –£6.06 |
| **Occupational therapist (OT) contacts**[18] | 0.34 (42) | £8.73 | 0.28 (62) | £9.29 | –0.06 | £0.56 |
| **NHS counselling session**[18] | 0.86 (47) | £25.62 | 0.73 (59) | £50.66 | –0.13 | £25.04 |
| **Other contacts**[18] | 0.79 (45) | £117.16 | 0.72 (58) | £32.44 | –0.07 | –£84.73 |
| **Help from paid carer (hours of care per week) (paid for by NHS or PSS)** | 0.01 (2) | £6.89 | 0.47 (0) | £269.18 | 0.46 | £262.28 |
| **Equipment/aids and adaptations (not paid for by respondent, assumed to be NHS or PSS)** | 0.29 (0) | £57.74 | 0.24 (1) | £65.70 | –0.06 | £7.96 |
| **Tests (total for specified tests)**[19] | 18.48 (28) | £587.08 | 4.96 (39) | £274.84 | –13.52 | –£312.24 |
| **Hospice** | 1.20 (49) | £43.20 | 0.65 (57) | £23.29 | –0.55 | –£19.91 |
| **Medication**[20] | 1.39 (3) | £12.71 | 0.71 (3) | £6.44 | –0.68 | –£6.28 |
| **Hospital transport services (number of journeys)** | 0.80 (0) | £202.40 | 0.92 (0) | £232.16 | 0.12 | £29.76 |
| **NHS and personal social services (PSS) – total** | | **£5,006.63** | | **£2,594.91** | | **–£2,411.72** |
| **Total NHS and (PSS) plus weighted site cost** | | **£5,006.63** | | **£3,437.14** | | **–£1,569.49** |

[17] Some of the questions in the 85 questionnaires included in the analysis were unfortunately left blank. Many of these blanks applied to questions where respondents were asked to report a zero if they had not used the service in the past six months. However, this request was noted in brackets, and it is possible that many of blanks were actually zeros that patients had not filled in. For example, only 43 respondents noted the number of oncology in-patient admissions, whereas all 85 respondents answered a subsequent (yes/no) question relating to hospital transportation. As a consequence, it was assumed that all blank responses to the question relating to the number of oncology in-patient admissions were actually zeros, though the number of blanks is reported. Similarly, some questions stated 'tick where applicable' and it has been assumed that all blanks equate to zero, rather than representing missing data.

[19] Specified tests were MRI scan, CT scan, X-ray, ultrasound and blood test. Totals for all tests are presented.

[18] Duration of visit was requested within the questionnaire and is available from the authors if required.

[20] Net change in the past six months. It was judged too onerous to ask about all medication. Consequently respondents were asked to state what had been started and stopped in the past six months and the latter was subtracted from the former.

**Table 9:** Non NHS and PSS per patient mean six monthly levels of resource use, and associated mean costs, at baseline and six months.

| Item | Baseline resource use, mean value (n blank) | Associated mean 6 month cost | 6 months resource use, mean value (n blank) | Associated mean 6 month cost | 6 month change in resource use | 6 month change in cost |
|---|---|---|---|---|---|---|
| **Jobcentre Plus contact** | 0.36 (49) | £2.64 | 0.60 (54) | £7.61 | 0.24 | £4.98 |
| **Government perspective – total** | | **£5,009.27** | | **£2,602.53** | | **–£2,406.74** |
| **Equipment/aids and adaptations (paid for by respondent)** | 0.20 (0) | £12.16 | 0.15 (1) | £7.32 | –0.05 | –£4.84 |
| **Help from paid carer (hours of care per week) (paid for by respondent)** | 0.08 (2) | £48.24 | 0.18 (0) | £104.31 | 0.10 | £56.06 |
| **Patient and carer perspective – total paid for** | | £60.40 | | £111.62 | | £51.22 |
| **Informal (unpaid) care from friends or relatives (hours per week)** | 9.92 (6) | £3766.97 | 7.86 (6) | £2985.44 | –2.06 | –£781.53 |
| **Help with child care from friends or relatives (hours of care per week) (assumed to be unpaid)** | 2.17 (2) | £823.96 | 0.82 (0) | £310.38 | –1.35 | –£513.58 |
| **Societal (excluding unpaid care)** | | **£5,069.67** | | **£2,714.15** | | **–£2,355.52** |
| **Societal (including unpaid care)** | | **£9,660.60** | | **£6,009.97** | | **–£3,650.63** |
| **Societal (excluding unpaid care) plus weighted site cost** | | **£5,069.67** | | **£3,556.38** | | **–£1,513.29** |
| **Disability Living Allowance: Care component**[21,22] | 0.12 (51) | £172.38 | 0.22 (55) | £230.25 | 0.11 | £57.87 |
| **Disability Living Allowance: Mobility component**[21,22] | 0.13 (51) | £97.20 | 0.14 (63) | £106.58 | 0.01 | £9.38 |
| **Housing Benefit**[22] | 0.06 (57) | £97.02 | 0.07 (67) | £107.80 | 0.01 | £10.78 |
| **Jobseeker's Allowance**[22] | 0.02 (60) | £24.64 | 0.07 (67) | £76.23 | 0.05 | £51.59 |
| **Income Support**[22] | 0.02 (60) | £18.48 | 0.01 (72) | £9.24 | –0.01 | –£9.24 |
| **Income-related Employment and Support Allowance (or Incapacity Benefit)**[22] | 0.31 (44) | £418.11 | 0.25 (62) | £264.88 | –0.06 | –£153.23 |
| **Working Tax Credits**[22] | 0.08 (57) | £62.55 | 0.12 (63) | £102.95 | 0.04 | £40.40 |
| **Access to Work grant**[23] | 0.02 (57) | £9.41 | 0.05 (69) | £8.19 | 0.02 | –£1.22 |
| **Pathways to Work (work focused interviews)** | 0.13 (51) | [24] | 0.07 (66) | [24] | –0.06 | [24] |
| **Condition Management Programme** | 0.00 (58) | [24] | 0.04 (69) | [24] | 0.04 | [24] |
| **Appointments with a disability employment advisor** | 0.06 (53) | [24] | 0.06 (68) | [24] | 0.00 | [24] |

21 The level of the allowance (e.g. low, medium, high) was requested. If missing, the mean level of other respondents was used.

22 The number of weeks over which the benefit had been received was requested. If missing, the mean level of other respondents was used.

23 The amount provided was requested. If missing, the mean level of other respondents was used.

24 For other schemes only information about participation was requested, and consequently a value has not been assigned to these schemes.

## 4.6 Health-related quality of life

Health-related quality of life scores, as measured by the EQ-5D are shown in Table 10. At baseline it can be seen that though many reported no problems with mobility (49.4%) and self-care (77.4%), approximately 70% of those sample reported having problems with regard to usual activities, pain/discomfort and anxiety/depression. The percentage with no problems had however increased across all dimensions by six months. As such, on average, the reported quality of life of respondents was estimated to improve over the six month period post-baseline.

**Table 10:** Health-related quality of life: Utility and QALY gains

| Item | Baseline, Mean value (n blank) | 6 months, Mean value (n blank) | 6 month change | Associated QALY gain, Mean value (n blank) |
|---|---|---|---|---|
| **Utility score** | 0.596 (3) | 0.627 (4) | 0.023 (8) | 0.006 |
| | **Baseline, % with no problems (n blank)** | **6 months, % with no problems (n blank)** | **6 month change** | |
| **Mobility** | 49.4% (2) | 51.8% (2) | 2.4% (3) | |
| **Self-care** | 77.4% (1) | 85.5% (2) | 2.4% (3) | |
| **Usual activities** | 26.2% (1) | 42.9% (1) | 15.7% (2) | |
| **Pain/discomfort** | 25.6% (3) | 31.8% (0) | 7.3% (3) | |
| **Anxiety/depression** | 31.0% (1) | 40.5% (1) | 8.4% (3) | |

## 4.7 Synthesis of learning from the pilot sites: illustrative case studies

Five case examples are presented here, drawn from the pilot sites' experiences. They illustrate a range of approaches to providing work support and specialist vocational rehabilitation services, highlighting the strengths of the different service configurations, and noting the challenges. The case studies are not comprehensive summaries of the activities of each of the pilot projects; these can be found in the pilots' final reports.[25]

### 4.7.1 Case study 1 – Integrating employment support for people with cancer into a work programme for people with other health conditions:

- Establishing links with cancer services
- Publicising the service and gaining referrals
- Geographical separation from potential referrers
- Drawing on existing skills and resources: expertise in return-to-work programmes and cognitive behavioural therapy
- Gaining the cancer-specific knowledge required

Two of the pilot sites, NHS Blackburn with Darwen and NHS South of Tyne and Wear, extended their local Condition Management Programmes (CMP) to offer an enhanced vocational rehabilitation service for people with cancer. The national CMP service (which

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[25] The pilot sites' final reports are available through the Macmillan Cancer Support Working through Cancer Team – e-mail: workandcancer@macmillan.org.uk.

closed early in 2011) was primarily aimed at supporting people with mental health, musculoskeletal and cardio-respiratory problems and used an educative, problem-solving, cognitive behavioural therapy (CBT) approach to help people to understand and manage their health conditions, with a view to being able to return to work.

In each of the two areas, a multi-professional group of staff including occupational therapists, physiotherapists, nurses and social workers with training in CBT and experience of delivering CMP, offered a specialist vocational rehabilitation service for people with cancer.

An immediate challenge for both teams was the lack of any pre-existing links with cancer services, and thus with potential referrers. A great deal of early effort was directed towards identifying the right contacts, publicising the service, educating health professionals about its importance and encouraging referrals.

> *We've taken a top-down and bottom-up approach – we've talked to health professionals, and we've also publicised the service directly to patients who pick up our leaflets and then self-refer.*
>
> Pilot site staff

Both pilots were situated on business parks, and both identified benefits and challenges in this arrangement. There was the obvious disadvantage of the lack of opportunity for 'passing conversations in corridors' to increase visibility and promote the service:

> *It has felt like we've been a bit remote. We've wondered at times whether it would have been an advantage to have been situated next to a Cancer Information Service, because that's often the first port of call for someone who has work problems.*
>
> Pilot site staff

On the other hand, cancer services are not centralised in one location, and staff commented that not being connected to any one service had facilitated contact with a very wide range of services, from cancer treatment centres, to hospice early diagnosis support groups, to Citizens Advice and Jobcentre Plus.

The clients accessing the CMP programme had different characteristics to the people with cancer to whom the service was extended, requiring that new skills were learned:

> *Not all of the knowledge we gained in CMP was applicable. Most of the people we saw before [this pilot] were unemployed whereas the majority of people we see now are in work. They need help with managing symptoms in the workplace, liaising with their employers, negotiating getting time off treatment, getting sick pay sorted out, that sort of thing. That's been a learning curve for us.*
>
> Pilot site staff

While there were new, cancer-specific skills that needed to be learned, staff found the training they had received for delivering CMP to be very valuable in working with the cancer population. CBT in particular was identified as a useful approach in helping people to test the assumptions they might make about working with cancer.

> *I've used my CBT training a lot. Patients can sometimes have fixed ideas about what they will manage and what they won't, or for example what will happen if they tell their manager they're having difficulty at work. Often they're basing their decisions on past experience – what work was like before they were ill. CBT can help people to think through their choices and their options.*
>
> Pilot site staff

### 4.7.2 Case study 2 – Case management approach within a cancer treatment centre:

- Located within a highly specialist cancer treatment centre
- Active support from senior executives, service managers and clinicians
- Embedding work support into treatment pathways
- Drawing on existing skills and resources: expertise in human resources and employment consultancy
- Gaining the cancer-specific knowledge required
- Focus on specific targets
- Active follow-up

The two case managers employed by the Shaw Trust with the Christie pilot had expertise in human resources and employment consultancy, and had previous experience of delivering Shaw Trust's Pathways to Work and Workstep programmes. Case management is a collaborative process of assessment, care coordination, problem solving and advocacy, making optimal use of existing services and maximising cost-effectiveness. The service provided one-off advice and guidance to patients with signposting to other services, as well as expert and on-going support with specific return to work problems, legal and benefits issues, and liaison with employers.

The pilot had strong support from senior executives, managers and clinicians who identified employment support as crucial to the well-being of patients, and saw it as their responsibility to ensure its provision.

A key component of the Shaw Trust with the Christie pilot was to raise clinical staff's awareness of the importance of supporting patients with regard to work, and to ensure that they had the knowledge to deal with straightforward employment queries. Over the course of the first year of the pilot, the team realised that health professionals' knowledge and skill were not sufficient, and that employment support needed to be written into clinical care pathways, with work being an integral part of the holistic assessment process and information prescriptions.

Their previous experience in work support meant that both case managers were well versed in employment practices, employer and employee rights and responsibilities, and they were confident in their ability to liaise with employers. They identified the need to develop their knowledge about cancer and its treatments, and to manage the emotional demands of working with this patient group:

> *I realised very quickly that 'cancer' is one label for many, many different diagnoses. People are at different stages of treatment, and they have so many different attitudes towards their diagnosis, and to their employers. I had to learn fast. […] I've also had to manage my own feelings about people who are palliative. One lady came to see me because she'd been told she had terminal illness and she wanted to know how it was going to affect her job. That knocked me for a six to be honest. I mean her questions about her work were straightforward to answer, but I did feel fairly upset afterwards. That's been new ground for me.*
>
> Pilot site staff

The team set very specific targets for their performance, which were closely monitored:

- To assist a minimum of 50% of patients back to work where employment is identified as a goal by the patient.
- Gain 80% satisfaction from service users, measured by a follow-up questionnaire.
- Provide a minimum of 24 education sessions to the community each 12 month cycle.
- Provide clinical staff with training on evidence-based vocational rehabilitation services, and support on integrating vocational rehabilitation into patients' care pathways.

Pilot staff recognised that patients might need encouragement to seek help and to re-engage with the service after an initial contact, and a pro-active approach was taken to following up queries and referrals. With patients' permission, follow-up telephone calls were made at one month, three months and six months (or other time-scales agreed with patients).

> *If I get a referral for someone who's only just started treatment, I wouldn't go in there saying, "You must do this, this and this to safeguard your job." It's more a case of, "This is our service, this is how we can help, these are the things it might help to be aware of for now." It's probably more reassurance than anything else, and letting them know that if they are worried they can call us at any time. We'd also say, "Would you like us to give you a call in a few weeks, see how things are going?" It's whatever works best for that person, but we want to make sure that they've got that information at the earliest possible stage, and that we're there to provide the support when they need it.*
>
> Pilot site staff

### 4.7.3 Case study 3 – Specialist rehabilitation:

- Highly specialist rehabilitation services
- Developing existing rehabilitation programmes to meet the employment needs of people with cancer
- Group work and peer support
- Interventions for a population of patients (neurological cancers) with highly specialist, complex work problems

The pilots based at the National Hospital for Neurology and Neurosurgery (NHNN) in London and St John's Information and Support Centre (ISC) in Doncaster both had their origins in existing, successful rehabilitation programmes – in different ways associated with, but not specific to, supporting people with cancer in work. The team St John's ISC had developed a fatigue management programme for people with cancer (Saarik and Hartley 2010), while the NHNN ran a well-regarded vocational rehabilitation service for people with multiple sclerosis (Sweetland 2012).

Cancer-related fatigue is known to be a particular risk factor in relation to successful return to work. The St John's pilot extended their successful fatigue management groups to cover a range of topics (including exercise and lifestyle choices) with a focus on supporting people back into work. The peer support element of the group work was highly valued by those who chose to attend.

> *There was always the opportunity to talk to the therapists individually, but the group was useful because we were at different stages and you could say, "Yes I've been there but I worked through it." Once one person starts talking, it encourages somebody else to say something, whereas it's not always easy to open up at first and talk about difficult things. Also, it wasn't clinical; getting dressed up and coming to the weekly groups felt like a step back towards normal life.*
>
> Service user

> *The key for me was hearing other people talking about their experiences, both personally and at work. It endorses and helps you to understand why you're feeling the way you are, and, importantly, that you're not alone, it's not just you. Because there is a tendency to question yourself as to why are you so tired, why you can't cope like you used to, and to think it's something you're doing wrong. Hearing that other people have the same struggles is a relief.*
>
> Service user

People with brain tumours have a number of specific and complex problems – for example, seizures, cognitive impairments, fatigue, hemiplegia, visual problems, headaches, balance problems – and the ability to respond effectively requires specific expertise. For example, the NHNN pilot noted that:

> *The most common barrier to work [for people with brain cancer] was cognitive rather than physical disability. We found that employers can find it more difficult to understand less visible disability. The severity of cognitive impairment is not the key thing, but rather the cognitive demands of the job itself. A chef with significant impairment whose work is repetitive might be able to manage his job well as it is not cognitively demanding. However, an accountant with mild cognitive problems struggles as the job is more demanding, requiring accuracy, prioritising and planning. It is important to understand both the cognitive impairment a person experiences and the cognitive demands of the role.*
>
> Pilot site final report

In both pilots, multi-professional rehabilitation teams with specialist experience and skills were able to respond to the specific needs of a particular population of patients.

### 4.7.4 Case study 4 – Vocational rehabilitation champion:

- Mapping existing services
- Raising awareness of patients' employment support needs
- Improving access to appropriate specialist services

The pilot based at Mount Vernon Cancer Network did not offer direct interventions to people with cancer, but rather aimed to establish whether needs could be met by raising awareness of the importance of work support and improving referral pathways to specialist psychological and rehabilitation services.

There were two phases to the project. Firstly, a mapping exercise was undertaken to identify available resources and, secondly, education sessions were provided for cancer health professionals to improve their understanding of the issues affecting patients' return to work.

The mapping process used a mixture of formal and informal approaches, including:

- Internet searching
- Word of mouth – informal discussions with clinical staff on their awareness of services.
- Contacting local cancer charity groups.
- Semi-structured interviews with staff to ascertain their understanding of vocational rehabilitation, the extent to which patients raised work problems and their confidence in responding to queries.
- Local service-user representatives.
- An on-line multi-professional survey of training needs.
- Contacting charities working in other long-term conditions (for example, diabetes, stroke, spinal injuries) and Fit For Work services to look at examples of work support in other conditions.

The mapping exercise highlighted the lack of resources available in the Network to support people with cancer to remain in or return to work, as well as poor awareness amongst staff to enable them to anticipate problems and refer appropriately. There was inconsistency in addressing employment – no elements of common practice could be identified and there appeared to be no standard practice. Time constraints in treatment consultations and staff's lack of knowledge meant that the subject of work was generally not raised beyond ascertaining whether or not a person was employed.

As a result of the work of the pilot project, a directory of resources was compiled, and recommendations for improving the support available were made – for example, the availability of 'one stop shop' clinics where patients could be seen by an employment expert who could facilitate the process of engaging with their employers earlier:

> *This model removes the reliance on staff to be experts in employment law as well as cancer, enables patients to seek advice at a time that suits them and enables an environment where information is accessible to all and not just following a referral.*
>
> Pilot site final report

### 4.7.5 Case study 5 – A coaching model:

- Establishing links with cancer services
- Publicising the service and gaining referrals
- Drawing on existing skills and resources: business coaching and training expertise

The Olive Tree Cancer Support Centre based at Crawley Hospital, and Orbitals Ltd, a private consultancy specialising in business and career development and coaching worked together to deliver work support services. There were two strands: providing information, signposting and one-to-one coaching for individuals with cancer, and also engaging and upskilling employers in order to improve their ability to support employees with cancer. The work with employers is discussed in more detail in Sections 6.2 and 6.3.

A significant issue for cancer patients returning to employment is the loss of confidence they can experience following what can be a lengthy absence from the workplace. Interventions to support return to work therefore need to incorporate strategies for building confidence and developing a sense of well-being and self-efficacy.

Life coaching is a process whereby people are helped (by a trained coach) to identify, prioritise and set clear goals to achieve desired objectives. Clients are encouraged to believe in their ability to achieve their goals: developing self-confidence and enhancing self-esteem are key outcomes of the coaching process. Specific practical tasks and strategies might be used, such as stress management or managing personal finances. Life coaching helps to break negative habits of thought and change unhelpful, habitual patterns of interactions with others. The coaching is typically delivered on a one-to-one basis, over a series of sessions, usually with actions and assignments to carry out between sessions. A relationship of trust and empathy between the coach and client is essential, as is the client's motivation to work through challenging issues and make changes.

The service users who received life coaching found it very beneficial, and were able to articulate how it had helped them, for example:

> *The coaching made a big difference – if I'm honest, much more than I thought it would. After the first session I come away feeling a lot brighter and a lot more at ease with things. I had been struggling with being so dependent on my family, not being able to be 'dad who goes out to work'. The coach helped me to see that they felt they needed to be involved and they wanted to help, and that by shutting them out I was making it worse for them. As I gained in confidence through the coaching, I could see things more from their side. Once you've got confidence, you can see the other person's point of view, and start to make plans, think about doing something. It helped to put me in a frame of mind to start thinking about work again.*
>
> Service user

> *The relationship with my manager has broken down since I've returned to work. There are nasty little put downs all the time – like one evening I was at work beyond five o'clock and she said, "Oh you better go, occupational health will see you and then we'll be in trouble." The coaching has really helped me to manage this. It's helped me to understand how my past ways of dealing with domineering people were making the situation worse. The coach turned it round for me, and I am now able to tackle it. I will say to her, "Can we just sit down and talk about this?" I'm calm and firm and respectful. I don't rise to it and I try not to let it get to me.*
>
> Service user

## 4.8 Summary of learning points from the case studies

**1** It is feasible to incorporate vocational rehabilitation for people with cancer into work programmes that support people with other health conditions. However, these programmes (such as CMP in this project) are generally directed at people with significant problems – those at Level 3. Work support at Levels 1 and 2 relies on interventions delivered within cancer centres, integrated into patients' treatment. This requires close contact between cancer treatment services and work support services. The pilots found that the physical location of specialist work support services within a cancer treatment centre could facilitate this interaction.

**2** A wide range of services providing employment support will exist in any one geographical area, and an important function of a cancer work support service is to identify and co-ordinate these services, ensuring that they are accessible to people with cancer, and that they understand how to meet patients' cancer-specific needs.

**3** Providing specialist vocational rehabilitation to people with cancer requires knowledge, skills and abilities in three areas (see Section 8):

- employment processes, practices, rights and responsibilities
- cancer pathology, cancer treatment and the symptoms that impact on work
- rehabilitation processes to support return to work

Coming from either a health/rehabilitation background, or an employment background, the staff employed by the pilots had skills in one or two of these areas but not in all three. All of the pilot staff providing work support interventions identified learning needs in one or more areas.

**4** A common feature of the two pilots that continued to operate after the pilot period had ended – the Shaw Trust with the Christie pilot and the NHNN pilot –was that both had support from senior management and clinical staff in their organisations who understood the need for work support for people with cancer and were committed to its provision.

**5** Patients might need encouragement to seek help and to re-engage with the service after an initial contact, and a pro-active approach to follow-up can be helpful.

**6** Psychological interventions such as CBT and coaching were integral to rebuilding confidence and developing a sense of well-being and self-efficacy.

**7** Some groups of patients, such as those with neurological cancers, have specific and complex problems, and the ability to respond effectively requires specialised rehabilitation expertise.

**8** Mapping existing services is a useful starting point in the provision of work support for people with cancer, but the availability of a directory of services is not enough to ensure that patients are appropriately signposted.

# 5 The role of health professionals in supporting positive work outcomes

## 5.1 The 5 Rs

Health professionals need the knowledge and skills to be able to facilitate patients remaining in or returning to work by following the **5 Rs**:

1. **Raise** work issues with patients early in the treatment pathway in a sensitive and acceptable manner.
2. **Recognise** the risk factors for poor work outcomes.
3. **Respond** effectively to the straightforward work problems that patients identify.
4. **Refer** patients who have more complex difficulties to the appropriate specialist services.
5. **Revisit** work issues at intervals during treatment.

In order to do this effectively:

- It is *not* necessary for health professionals to become experts in vocational rehabilitation and employment law.
- It *is* necessary for them to understand that good work is an important component of well-being, and to do all they can to enable patients to think positively about work.

## 5.2 Raising work issues early

There is some evidence in other health conditions that early attention to work, and early contact with employers, can reduce work disability duration (Bevan et al 2011, Franche et al 2005). All of the pilot sites noted that work issues were not routinely raised with patients, particularly not in the early stages after diagnosis. For example, in the survey that was carried out with health professionals in the Mount Vernon Cancer Network, it was found that:

> *Staff were unsure when to address the question of work for patients. Although evidence suggests outcomes are much better if the subject is addressed early in the patient's pathway, this does not happen in practice.*
>
> Pilot site final report

However, while talking about work early in the patient's pathway is important, it is not a straightforward matter. In essence, there is a tension between providing the support and 'permission' to be cared for that patients want and need – particularly in the first stages of illness – and encouraging them to think positively about life outside and beyond cancer treatment.

At the time of diagnosis, patients' concerns about the implications of diagnosis and treatment, and their – often unspoken – existential fears, can be overwhelming.

> *In the early days, I was passing blood both vaginally and anally and feeling really in shock: very, very tired, very weepy, and I found it very difficult to focus and concentrate. I'd go along for one lot of tests and then they'd refer me somewhere else, and then there'd be, "We need to check your lymph nodes so you'll have to have this done." I had no idea how drawn out the staging process would be. I thought when you got your diagnosis they'd work out your treatment and you'd get on with it and all the while I'm thinking, my God why don't they just do something? The whole time you know it's growing and it's getting worse.*
>
> Barbara (service user – administrator)

Also, the experience of diagnosis can be shocking and disorientating, leaving little space for any other concerns.

> *After about nine months of seeing one doctor after another with all of them saying different things, eventually I saw someone who said they'd found my condition and it was myeloma. I had no idea what that was so I came home and googled it, and the first page that came up was Macmillan. I thought, that's not right, maybe I've spelled it wrong. I typed it again, and again there was the Macmillan page. That doctor had described it in such a relaxed manner, he was so matter of fact, it didn't occur to me that it was serious. When I googled it, my world just came crashing down. The more I read, the more desperate I became: everything said it was incurable, it couldn't be contained. The next appointment was with a haematologist who said that I did not have myeloma, which was a relief. However, she explained that I had prostate cancer that had spread to my skeleton. She said it was unfortunate and unusual because of my age, but that it was very, very aggressive and very advanced. So that was quite a blow.*
>
> Fergus (service user – sales manager)

On the one hand we know that work is important, and that good work has clearly established health benefits. We also know that early attention to work facilitates successful reintegration into the workplace post-treatment. On the other hand, a diagnosis of cancer is traumatic and patients describe the need for a time of reflection on priorities and meaning in life, and an opportunity to focus their energies on healing and on the people closest to them. Health professionals find themselves juggling what can seem like inconsistent messages: encouraging patients to take time out and allow themselves to be taken care of, while at the same time emphasising the value of activity and a sense of normality.

Here is an example of this tension, observed during a support group for newly diagnosed cancer patients where work issues were being discussed.

> *Together with the two nurses facilitating the group, patients agreed on the importance of work in feeling normal, having a routine, giving structure to the day, gaining a sense of control over one's life. One patient described how her diagnosis had impacted on a course she was undertaking. "I was having chemo when everyone else was sitting their exams early in the summer, but I've been keeping up with studying during my chemo and I was able to take my exams with the others doing resits last week." The nurse beside her looked immediately concerned, and said, "Naughty! You need to look after yourself!"*
>
> Support group (observational data – pilot site 2)

In fact, 'taking care of yourself' and 'keeping active and engaged' are not mutually exclusive. Patients need to do both at the same time, and health professionals, in turn, need to support and facilitate this. It is legitimate for patients to feel ill and tired, and to want to be cared for. However, they also need to be encouraged and empowered to remain active, take an interest in life beyond cancer and its treatments, remain socially engaged, and hold onto a sense of themselves as 'normal'.

In other long-term conditions, such as stroke, or cardio-respiratory illness, or traumatic spinal injury, rehabilitation – in the sense of supporting a person's reintegration into society – is embedded into the treatment plan from diagnosis. From a very early stage, patients are encouraged to adapt to altered physical, emotional and cognitive capabilities. Although survival rates in cancer are improving, and it is well known that people are living longer with the disabling consequences of illness and treatment effects, cancer rehabilitation still tends to be seen as something that is useful post-treatment, rather than an approach that should be integrated into patients' pathways from the outset.

## 5.3 Recognising risk factors: 'work flags'

At diagnosis and on through the course of their treatment, patients' priorities tend to centre on the physical, emotional and logistical demands of illness and treatment. Work might be important, but it is not urgent, and patients are generally not minded to focus on work issues.

> *I was a workaholic before cancer, but while I was ill, I didn't want to know about work.*
>
> Celia (service user – nurse)

It is something that patients are quick to 'put on hold for the time being,' and if health professionals perceive work to be a worry or a burden, they feel they are being supportive by encouraging patients to do just that.

It is often only in retrospect that patients realise the consequences of sidelining work during treatment.

> **Celia:** *If somebody had brought up work at the stage of telling me my diagnosis, it would have been one thing too many. There were huge issues to be taking on board and I just didn't have the capacity to take anything else in. For someone to start talking about work, it would have felt totally insensitive. But then when I got to the point of going back to work, I struggled. I recognise that now.*
>
> **Interviewer:** *There is some research in other conditions which suggests that people should make early contact with their employers, and not to put work to one side until six months down the line, and then, when they think about going back, they feel overwhelmed, lacking in confidence, deskilled…*
>
> **Celia:** *I have to say I recognise all those things.*
>
> **Interviewer:** *So it seems like it's a bit tricky? You had some problems when the time came to go back to work with feeling anxious and unconfident, but you're also saying: I really needed to just shelve it at the beginning, and I didn't want to know about work while I was having treatment.*
>
> **Celia:** *And that's the truth as well. If I had been asked about work early on, I think I probably would have told a lie, not an intentional lie, but I would probably have said, "I'm keen to get back to work eventually" ... and I might have thought that was true, because I am deeply committed to my work, but at that stage I had no way of knowing how things were going to turn out and how the chemo would affect me.*
>
> Celia (service user – nurse)

Patients may well not recognise potential work problems, and there is a need for vigilance on the part of health professionals to able to predict and pre-empt problems, so that patients can be nudged towards thinking positively about work.

There are a number of risk factors that health professionals should to look out for, which could indicate future employment problems.

1 **Early contact**
Has the patient made contact with his/her employer? If not, is s/he intending to make contact?

2 **Communication and relationships**
What kind of a relationship does the patient have with his/her employer? Is there a history of poor communication?

3 **Impending change**
Is organisational change or workforce restructuring imminent?

4 **Job flexibility**
How flexible is the job? Might there be problems organising a phased return to work, or taking on lighter duties initially?

5 **Financial concerns**
Does the patient have any financial concerns?

6 **Self-employment**
Is the patient self-employed?

7 **Uncertainty in treatment or prognosis**
Is the treatment pathway particularly uncertain, or the prognosis unpredictable?

8 **Impairment and disability**
Is the illness or treatment likely to result in physical or cognitive impairment, excessive fatigue, disfigurement, or speech and communication difficulties?

This should not be viewed as a simple tick box check list. As Celia illustrates, asking a patient whether or not they have concerns about work might well elicit the response. "No I don't think so, thank you," because people can find it difficult to predict consequences when they are in unfamiliar territory. Rather, these topics need to be woven into consultations and conversations throughout the patient's treatment.

The way in which work issues are raised is important. One interview respondent suggested that asking, "What are the things that are important to you at the moment and how are you managing them?" was more helpful than, "Is work a problem?" The former question could lead on to further probing about work, whereas the latter might cause a patient to think, "That's more than I can deal with right now," and avoid the issue.

## 5.4 Responding, referring and revisiting

Where patients mention work concerns, or when risk factors are identified, health professionals should respond either by offering advice (where the question is within their area of expertise) or referring on for further specialist employment support (where it is not).

The vocational rehabilitation pilots raised concerns that health professionals inadvertently act as gate-keepers; that because staff are not sufficiently sensitive to work issues, patients' problems are not being recognised and responded to.

> *We're too reliant on health professionals to refer people. Services need to be accessible regardless of whether professionals think a patient needs it. All that CNSs and doctors should be doing is telling the patient that this and that support service exists, not making the judgement about whether to refer. For example, there's a chap I met who is self-employed, who looks relatively well-heeled, but he's living off a bunch of credit cards. Nobody's offering him financial advice because he doesn't look like he needs it.*
>
> T (pilot site staff – pilot 1)

There is more to putting people in contact with services than giving out a telephone number or leaflet. To access support, people need both to recognise that they have a problem and to believe that a solution is possible. Tailored health messages (Wanyonyi et al 2011) that address an individual's specific concerns are more likely to improve outcomes than simply providing information.

It is neither reasonable nor practical to expect the cancer multi-disciplinary team to have an extensive knowledge of the work support services available in a locality, or for there to be time in treatment consultations to delve into work problems in any depth. For this reason, there should be a designated person (or people) in each Cancer Network who has responsibility for ensuring that the appropriate pathways exist for connecting patients with the help and support they need. This could be an 'employment champion' (as in the Mount Vernon pilot), or case managers (such as the Shaw Trust / Christie pilot), or specialist vocational rehabilitation professionals (for example, St John's in Doncaster or NHNN in London) who have networks with cancer treatment centres, cancer information centres, benefits advisors, generic work support services (such as Jobcentre Plus) and specialist vocational rehabilitation services.

## 5.5 Fitness for returning to work

Findings of both this study and others show that patients are not routinely given helpful advice about returning to work (Bains et al 2012, Main et al 2005). Illness trajectories and treatment regimes in cancer can be more difficult to predict than in other health conditions; however the question "Can I return to work?" needs a more constructive answer than "Do you feel up to it?" A more helpful response lies in identifying the physical, cognitive and psychological demands of the workplace, and matching these to the patient's capacity. If the health professional who is asked the "When can I return to work?" question is unable to do this, the patient should be referred on to someone who can. The need for training for health professionals on assessing and advising cancer patients on returning to work should also be considered.

People with cancer find it difficult to make a judgement about when they are fit to return to work, and report that their doctors and nurses appear to find it difficult to give clear guidance.

> *No one said anything about work when they were telling me about my diagnosis and treatment. They told me the radiotherapy would make me tired and that I should rest. I would have liked someone to have sat me down and said, "Don't worry about work at all." But there's pressure on you, they [employers] wanted me to keep phoning them up to tell them how I was. And that was hard because every time I phoned and they said, "How are you?" I would say, "I'm fine." And I suppose I was – I was resting, at home, I was fine. And then I started to think, well, if I'm fine then why aren't I back at work? I felt under tremendous pressure to go back to work. No-one put direct pressure on me, but I'm part of a team and I had a friend at work who kept telling me how busy they were so I thought perhaps I'd better go back. I was still sleeping a lot during the day, but I thought oh I'll be all right when I'm back at work. But I wasn't, I was falling asleep at my desk.*
>
> Ingrid (service user – secretary)

This same patient contrasts her experience of returning to work after cancer with returning to work after a knee replacement:

> *I had a knee replacement a year before the cancer. They said, "You will be off work for three months, and then you will be fit enough to go back to work."*

> *After the three months, I felt ready to return; I didn't have any problems. But not with cancer. When I asked about when I'd be well enough to go to work, they said, "Everybody's different." How do I know when I should feel fit enough? The only problem I had was the tiredness and I thought maybe I just need to get up and get going.*
>
> Ingrid (service user – secretary)

Many patients would find it helpful to have more clearly defined expectations of and timescales for returning to work, but in practice a degree of indeterminacy is probably inevitable. It is likely to be difficult, if not impossible, to achieve the same level of certainty that is feasible in (for example) orthopaedic conditions, given the unpredictability of cancer illness trajectories and treatment outcomes. However, the possibility of providing more structured guidelines than are currently available would be worth investigating.

## 5.6 Educating health professionals

Three of the pilots carried out formal surveys of health professionals' (mainly nurses') knowledge and confidence with regard to supporting their patients' work needs. There was variation between sites but, in general terms, health professionals reported that they regarded work as important, and that they routinely asked patients about work. This is not supported by patients' accounts, which indicate that work is seldom mentioned. Health professionals might be over-estimating their ability to provide adequate work support. All of the pilot sites provided education and training to health professionals, and found that case study approaches, asking participants to think through what they would do in particular situations, were the most effective way of helping people to identify the gaps in their knowledge and be receptive to learning.

### Engaging doctors

Doctors (GPs and consultants) were found to be the most difficult group to engage. Information-giving sessions to groups of doctors during routine meetings generated polite interest but very little take-up of the services and resources being offered. Individual, tailored approaches to doctors who showed a particular interest and who could then act as 'champions' among their colleagues showed more promise.

> *We've sent countless number of letters and information packs to all the surgeries in [the area] but it feels like they've dropped into a void. We've done 15-20 minute presentations at surgery meetings and people seemed interested and they'd say, "We'll make sure your literature is available in the surgery," but we need them to do more than that – to actually be proactive in raising the issue with their patients. More recently we've had interest from a GP I know personally who has asked us to attend a practice meeting and I feel more confident about this one because the initiative has come from them. We need to find a way to encourage on-going interaction, not just a one-off event. That's going to have to be done on a step-by-step basis, building the relationship.*
>
> D (pilot site staff – pilot 3)

### Engaging nurses

Project staff found that the clinical nurse specialists they spoke to were in agreement that employment was an important issue, but were divided about the extent to which they saw providing work support as part of their role. Using case studies with a 'what would you do' approach was found to be an effective teaching strategy.

> *Case study presentation was vital to stimulating discussion. Without asking staff to talk through how they would manage specific patients – there was a tendency to say that work issues were anticipated, discussed and resolved.*
>
> Pilot 1 final report

> *I use specific case studies when I talk to nursing groups. I found that if I just talked about problems in general and the availability of this pilot, there was limited interest. But if I say: here's this patient, this is what happened, how would you handle the situation, people pay attention. They realise that they don't know what to do. So although some of the CNSs will say yes, we do the holistic assessment, yes we always ask about work, I find that when I present a particular problem and say OK, how would you help, where would you direct this person, they find themselves acknowledging that they don't know.*
>
> T (pilot site staff – pilot 1)

# 6 Working with employers

## 6.1 What patients want from employers

People with cancer identify their line managers as key to successfully reintegrating into the workplace. Patients identify a number of behaviours from line managers that facilitate a successful return to work, including:

- Keeping channels of communication open between the employee and the organisation, the management team, and work colleagues.
- Keeping the employee 'in the loop' while they are on sick leave, particularly about changes in the organisation, without exerting pressure to return to work.
- Understanding the illness and treatments, and the consequences of both, particularly in terms of longer-term effects such as fatigue.
- Not stigmatising cancer, and promoting positive, informed attitudes among colleagues.
- Negotiating the return to work procedures together with the employee, before they return.
- Making reasonable adjustments in the workplace to accommodate physical impairments, cognitive difficulties and fatigue.
- Being flexible about working hours, tasks and responsibilities in the first weeks and months of returning.
- Having a structured schedule with set meetings to talk about how the return to work process is going, in a way that does not cause the employee to feel that their progress is being monitored and negatively evaluated.
- Understanding the employee's rights and responsibilities under the Equality Act.
- Being willing to meet with health professionals who have been involved in the employee's vocational rehabilitation and take account of recommendations.

Patients report that there can be difficulties in communicating with line managers.

> *She's [line manager] taken on another hospital as well so we never see her. If I phone her up and ask, "Can I come and speak to you?" she would say, "I'll see if I can find some time … I'll give you a ring if I've got a minute." So, you know, it's difficult to get her attention.*
>
> Ingrid (service user – secretary)

> *If said to my boss, "I need to take some time off," she'd say, "Oh no, you've got to keep focused, keep yourself going, that's the way to get through this." She thought she knew what I was going through, but she really didn't understand. Well, how can you if you've not been there? I wouldn't have known."*
>
> Barbara (service user – administrator)

Some people are cautious about having a third party negotiating with their manager, as they fear it might create doubt about their fitness for work. People wish to present themselves to their employers as competent and capable, and worry about giving any indications to the contrary (particularly in the current climate of rising unemployment and job insecurity).

On the other hand, people with cancer tend not to be knowledgeable about their rights as employees, and this lack of knowledge, together with the erosion of confidence that can accompany lengthy ill-health and arduous treatment, can disadvantage patients in their return-to-work discussions with their employers. The support of a skilled vocational rehabilitation advisor can be extremely beneficial, and patients' fears may need to be explored and allayed.

> *I've been liaising with this patient's manager to look at how to help her to manage her job. I felt that the manager was being unrealistic in her expectations. This lady has still got on-going health problems, she's only just finished chemotherapy, she's waiting for reconstruction surgery and she's been told she's going to need a hysterectomy as well. To add to that, she's going through a divorce, and all sorts of other things at home. So I think if she's got a lot going on for her at work as well, she's just going to crumble. After we'd discussed it all, the manager agreed with me and also said the patient could go to her hospital appointments – which she has to go to two or three times a week – in work time without her pay being affected. So that was good.*
>
> P (pilot site staff – pilot 4)

## 6.2 Educating employers

In addition to one-to-one work with individual patients and their employers, several of the pilot sites worked with local businesses, offering education and support at an organisational level, with varying degrees of success. Employers are crucial to achieving good work outcomes, and any local initiatives that can support employers to help people with cancer to remain in or return to work are to be encouraged. However, the reach of an individual vocational rehabilitation service is limited, and there is a need for a national, strategic approach to employer engagement and education, to ensure that all employers understand the needs of employees who have cancer, and that they incorporate just, fair and informed practices into company policies and procedures.

## 6.3 Pilot sites' experiences of employer engagement and training

When approached by the pilot projects, employers and employers' organisations were generally interested in receiving information, and happy to distribute this through their networks. Employers were particularly receptive when they had had direct experience of supporting employees with cancer. However, it proved challenging to engage employers in participating in education and training sessions, as the pilots report:

> *At every event and contact with employers and managers, we offered to visit their organisation to provide education or awareness training in any cancer related areas, or one-to-one advice on sensitive issues. None of these offers were accepted and we were not contacted or given referrals from any areas outside of health or social areas.*
>
> Pilot 4 final report

> *Although initially the response to the proposed workshops had been very positive, in the event the number of confirmed responses was poor. Attendees at the one workshop that did run fed back that for SME employers HR services were often outsourced or not available. A more effective approach could have been to target the national HR consultancy bodies.*
>
> Pilot 1 final report

> *At the commencement of the project, it was assumed that the training would be popular in view of the subject matter and the fact that it was being offered free of charge. This proved to be an incorrect assumption. Some people were frightened of the subject matter. Employers who came forward for training tended to be those who were already affected by cancer in the workplace, either directly with staff or with staff acting as carers. Their objectives were to improve their conversations and their processes.*
>
> Pilot 3 final report

Despite the difficulties, many of the pilots did provide training sessions with local employers. The Orbitals Ltd with the Olive Tree pilot had around 200 people attended their training events, which were aimed at supervisors and managers. Their key areas of training were:

- Understanding cancer and how it affects people
- Workplace implications
- Communication skills
- Employers' and employees' rights
- The Equality Act 2010.

# 7 Enabling people with cancer to think positively about work

As has been described in Sections 5 and 6, the diagnosis of cancer is a shock and a disruption to a person's life. Each individual will have their own way of responding to that and managing it. Some people will choose to continue working through their cancer treatment where that is possible, while others will need and want to take time off. Some will welcome information and advice on employment at the time of diagnosis and early on in treatment; others might see this as intrusive, insensitive and irrelevant. Supporting patients to think positively about work, to make early contact with their employers, and to maintain an orientation towards life beyond cancer treatment requires skill and sensitivity.

## 7.1 Support for self management

People with cancer have their own role to play in managing the disruption to work caused by their illness, and many patients are successfully able to negotiate changes to their work environment and schedules in order to remain in or return to work (Maunsell et al. 2004, Bradley and Bednarek 2002). Strategies and resources to support patients' self management are valuable, for example, telephone advice lines and prompts to ask the right people the right questions (Bains et al. 2011, Macmillan Cancer Support – undated).

## 7.2 A positive outlook on work

As noted in Section 5.2, starting to think about work early in the treatment pathway can facilitate better employment outcomes. However, the experience of diagnosis can be shocking and disorientating, leaving little space for other concerns. It is often only in retrospect that patients can recognise that a more pro-active approach early on would have been helpful. Patients might need encouragement to:

- Make contact with their employers and keep them updated (bearing in mind that there is no requirement to disclose their diagnosis).
- Start to think about the adjustments that could be needed in order to return to work.
- Ask about the impact of treatment on work.
- Avoid making hasty decisions about withdrawing from work.
- Understand their legal rights and responsibilities.

# 8 Specialist vocational rehabilitation

## 8.1 Vocational rehabilitation interventions for people with cancer

Vocational rehabilitation interventions are well described and defined in numerous textbooks and documents (British Society of Rehabilitation Medicine 2012, Holmes 2007, Vocational Rehabilitation Association 2007) and are as applicable to people with cancer as they are to people with other health conditions. They include:

- Detailed assessment of work skills and capacity, job requirements and demands, work environment and social support systems.
- Prioritising key issues and setting short-term and long-term goals.
- Work preparedness and work readiness activities; building confidence.
- Teaching strategies for managing particular health problems in the workplace.
- Negotiating a phased return to work – not just in terms of hours, but also tasks and responsibilities.
- Liaison with employers, visiting work site if appropriate.
- Modifications to the work environment.
- Psychological interventions, for example coaching, counselling, motivational interviewing and/or cognitive behaviour therapy, to support adjustment to the consequences of illness and disability.
- Supported withdrawal from work, where that is appropriate.
- Information and advice on, for example, disclosing their diagnosis to managers and colleagues, and legal rights and responsibilities.
- Referral to other support services, for example Access to Work.
- Careers advice and guidance.

People with cancer have additional, specific needs relating to the disease and its treatment, which need to be taken into account. These include:

- Managing cancer-specific symptoms and impairments in the workplace, in particular, fatigue, functional difficulties, cognitive problems and pain.
- Building confidence after a traumatic diagnosis and what can be prolonged absence from work.
- Helping patients to manage employers' and colleagues' responses to the stigma of cancer.
- Helping patients and employers to understand the late effects of treatment.

## 8.2 Competency framework for cancer vocational rehabilitation

The delivery of vocational rehabilitation services that will meet the needs of people with cancer requires the following:

### Assessment

**1** Ability to undertake a thorough, comprehensive work assessment including client's work history, skills and attitudes; job requirements; task analysis; work environment (ergonomics, geography, relationships and culture); and workplace support.

### Work and employment

**2** Ability to encourage a positive attitude to work and to help clients to build confidence in their work skills.

**3** Knowledge of work and employment issues, such as the implications of cancer for people who are self-employed, and the local economy and job market.

**4** An ability to provide advice and guidance on careers, qualifications and skills, transferable skills, and on decisions about changing employment or re-training.

**5** Knowledge of employment legislation, policies, processes and practices, including the Equality Act 2010, the Fit Note, the benefits system, and work support schemes available.

### Cancer

**6** Knowledge of cancer pathology and cancer treatment procedures so that the medical language is sufficiently familiar to service providers, and that the clients' experience of illness and recovery is understood in general terms. Understanding of the implications of different cancer diagnoses with regard to likely treatment regimes and prognosis.

**7** Understanding of common symptoms and the ways in which these affect employment, work and work performance, in particular: fatigue, muscle weakness, anxiety, depression and cognitive difficulties. Ability to work with clients, their families and employers to manage these effectively.

8 Understanding of the psychological and emotional consequences of a diagnosis of cancer, and the coping strategies patients use. Ability to support patients to adjust to living well with cancer.

### Cancer vocational rehabilitation

**9** Knowledge and understanding of the process of cancer vocational rehabilitation.

**10** Ability to pace interventions in a way that is sensitive to the clients' needs while providing an effective and efficient service.

**11** Ability to use problem-solving and goal-setting strategies with clients.

### Communication skills

**12** Ability to listen carefully and non-judgementally. Willingness to hear and understand clients' agenda. Ability to respond with empathy.

**13** Ability to communicate effectively, confidently and knowledgeably with a wide range of people, for example: clients, their families, health professionals and employers.

**14** Advocacy and negotiation skills.

### Education

**15** Ability to identify learning / training needs, and to address these by planning and delivering education on work and employment, both formally and informally, to health care professionals and to employers.

### Networking

**16** An ability to establish a wide network of other specialists and agencies to whom clients can be referred when necessary, for example trade union representatives and solicitors specialising in employment law.

**17** Knowledge of, and contact with, locally available cancer support services.

### Service development

**18** Ability develop and publicise the vocational rehabilitation service, and to demonstrate its effectiveness in terms of both cost and patients' work status. Knowledge of the theoretical underpinnings and the evidence-base for cancer vocational rehabilitation.

### Self awareness

**19** Insight and awareness of the personal impact of working with people with life-threatening illness, and the ability to seek and use support systems effectively.

**20** An awareness of the limits to one's own expertise.

### Personal characteristics and attitudes

**21** Optimistic, motivated, enthusiastic, problem-solver, 'can-do' attitude, highly organised, flexible. A focus on health and well-being rather than illness.

It is unlikely that any single discipline or person would encompass all of these competencies, and input from a small multi-disciplinary team is likely to be needed.
No cancer-specific vocational rehabilitation training programme currently exists. The need for this should be considered.

# 9 Further investigation and research

A number of areas for further investigation – in terms of both research and service development – have emerged from this evaluation.

## 9.1 Effectiveness and cost-effectiveness of specialist vocational rehabilitation programmes

The logistical difficulties with setting up a comparison group in this evaluation meant that it was not possible to determine the effectiveness and cost-effectiveness of the vocational rehabilitation interventions offered. This is something that should be addressed in future studies.

## 9.2 Employers' perspectives

It was not within the scope of this project directly to examine employers' perspectives on managing employees with cancer, and it is clear that this is an important area for further study. Specific areas for investigation include:

- Employers' training needs with regard to supporting employees with cancer to remain in or return to work, and how these are best met.
- Employers' perspectives on effective strategies to facilitate the successful re-integration of employees with cancer into the workforce.
- The specific needs of small business where occupational health services are not available.

## 9.3 The impact of cancer on carers' employment

Concerns about carers' unmet needs were raised both by the patients who participated in interviews and by the vocational rehabilitation practitioners across all of the pilot sites. Taking time off to attend hospital appointments, to visit loved ones in hospital, and to care for them at home can have a significant impact on carers' ability to work. If patients' employment problems are not routinely addressed, carers' difficulties are even less well recognised. The financial, psychological and social consequences of cancer on carers' employment should be investigated.

## 9.4 The relevance of work support to palliative patients

A number of the patients who accessed the pilot sites' services had advanced disease. Work is not often a topic on the palliative care agenda, but patients identified a range of work support needs towards the end of life, for example:

- Support to continue in work, as it provided a sense of competence and normality, as well as a welcome distraction.
- Help with discussing their prognosis and reasonable adjustments with their employer.
- Information and advice on employment rights.

Advocacy related to financial settlements and packages. Patients reported that both they and their employers found these conversations upsetting and difficult, and that very little support or information had been available from their health care teams. There is a need to determine the employment support required by people with palliative disease and identify the best ways of providing this.

## 9.5 Community of practice

Opportunities for pilot staff to network with each other, the evaluation team and the project team were an important feature of the Vocational Rehabilitation Project. Monthly teleconferences were held, as were quarterly learn-and-share events where pilot site staff met with each other and with staff from Macmillan Cancer Support and the Department of Health. The learn-and-share programmes included sharing best practice, discussing challenges, and updates on significant policy developments. The events – particularly in the second half of the Project, once people had had an opportunity to get to know one another – were very well evaluated, and participants commented particularly on the benefits to practice of the shared learning.

Given that vocational rehabilitation for people with cancer is a new area, creating opportunities for shared learning and developing a community of practice should be considered.

# 10 Conclusions and recommendations

## 10.1 Conclusions

**1** The key to enabling people with cancer to remain in or return to work is to embed work support into the patients' pathway from diagnosis, through treatment and on into life beyond cancer – or end of life care, where that is appropriate. It cannot be relegated to an add-on service, offered only when problems arise.

**2** The essential, core components required for providing effective work support for people with cancer are as follows:

- **a** Health professionals should have the knowledge and skill to present the right messages about work in an acceptable and appropriate way, so that patients are encouraged to think positively about work.
- **b** Prompts to talk about work should be incorporated into local and national cancer guidelines, policies, treatment pathways and information prescriptions.
- **c** Tailored information and advice about patients' employment rights and responsibilities, and about the support services available, should be provided in order to facilitate patients' self-management.
- **d** The statutory and voluntary services available locally to support people with cancer in employment should be identified, and pathways for effective liaison between these services and cancer treatment services should be created and used.
- **e** Specialist vocational rehabilitation should be provided for people with complex problems.
- **f** Treatment protocols and pathways should prompt effective liaison between patients, health professionals, employers, human resources departments and occupational health services.
- **g** There should be engagement with employers and employers' organisations to raise employers' awareness of the needs of employees with cancer.

**3** For people affected by cancer, work support and vocational rehabilitation is required at three levels:

- **Level 1:** All patients who are in work or have the potential to work should be asked about their employment and receive information and signposting.
- **Level 2:** People with specific concerns or worries should be provided with resources to support self-management.
- **Level 3:** The smaller subset of people who have complex needs should be referred to a vocational rehabilitation service for specialist support.

**4** The average cost per patient contact (where 'contact' refers to the period of intervention) was estimated to range between £384.86 and £1,590.02, with a weighted average cost per patient contact of £842.23 (£839.19 after excluding set-up costs).

**5** It is feasible to incorporate vocational rehabilitation for people with cancer into work programmes that support people with other health conditions. However, careful attention needs to be paid to ensuring close liaison between work support programmes and cancer services.

**6** Psychological interventions such as CBT and coaching were integral to rebuilding confidence and developing a sense of well-being and self-efficacy.

**7** Some groups of patients, such as those with neurological cancers and people who are self-employed, have specific and complex problems and the ability to respond effectively is likely to require specialised rehabilitation expertise.

**8** Many patients are successfully able to negotiate changes to their work environment and schedules in order to remain in or return to work. However, patients might need encouragement to:

- Make contact with their employers and keep them updated (bearing in mind that there is no requirement to disclose their diagnosis).
- Start to think about the adjustments that could be needed in order to return to work.
- Ask about the impact of treatment on work.
- Avoid making hasty decisions about withdrawing from work.
- Understand legal rights and responsibilities.

## 10.2 Recommendations

**1** In order to ensure that people with cancer are well supported to remain in or return to work, each Cancer Network, or organisation responsible for cancer services, should nominate a lead person (or people) to take responsibility for:

  **a** Ensuring that health professionals have adequate knowledge to provide early and on-going support.

  **b** Embedding work support into cancer treatment protocols, pathways and guidelines.

  **c** Identifying work support and specialist vocational rehabilitation services available to cancer patients in a locality, and noting gaps. Any development of new services should aim to integrate existing resources and avoid duplication.

  **d** Ensuring that there are effective channels of communication and referral pathways between cancer services and external work support services.

  **e** Ensuring that there are effective channels of communication between health professionals, employers and occupational health departments.

Commissioning contracts should include the requirement that cancer service providers ensure the availability of adequate work support and information for patients.

**2** Health professionals need the knowledge and skills to be able to facilitate patients remaining in or returning to work by following the **5 Rs**:

  **a** **Raise** work issues with patients early in the treatment pathway in a sensitive and acceptable manner.

  **b** **Recognise** the risk factors for poor work outcomes.

  **c** **Respond** effectively to the straightforward work problems that patients identify.

  **d** **Refer** patients who have more complex difficulties to the appropriate specialist services.

  **e** **Revisit** work issues at intervals during treatment.

Cancer health professionals do not necessarily have these skills, and training should be provided where required.

**3** There is a need for a national, strategic approach to employer engagement, education and support, to ensure that all employers understand the needs of employees who have cancer, and that they incorporate just, fair and informed practices into company policies and procedures.

**4** The provision of specialist vocational rehabilitation to people with complex work problems requires knowledge of employment practice, rights and responsibilities, cancer pathology, and rehabilitation. It is unlikely that any single discipline or person would encompass all of these competencies, and training is likely to be required. No cancer-specific vocational rehabilitation training programme currently exists, and the need for this should be considered.

**5** The following areas for further investigation and development in research and clinical practice have been identified:

  **a** The effectiveness and cost-effectiveness of specialist vocational rehabilitation programmes for cancer patients who have complex work problems.

  **b** Employers' perspectives on supporting people with cancer to remain in and return to work.

  **c** The impact of cancer on carers' employment.

  **d** The relevance of work support to palliative patients.

  **e** The use of communities of practice to share learning and improve cancer work support services.

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# Appendix 1: Unit costs attached to different items of resource use, with associated source

| Item | Unit cost |
|---|---|
| Out-patient visit (Oncology) | £121.00[1] |
| Out-patient visit (Other) | £135.00[1] |
| Cost per in-patient day (Oncology) | £297.00[1] |
| Cost per in-patient day (Other) | £297.00[1] |
| GP contact (cost per minute) | £3.10[2] |
| Practice nurse contact (cost per minute) | £0.85[2] |
| District nurse contact (cost per minute) | £1.00[2] |
| Cancer / Macmillan nurse contact (cost per minute) | £0.42[3] |
| Physiotherapist contact (cost per minute) | £0.57[2] |
| Occupational therapist contact (cost per minute) | £0.57[2] |
| NHS counselling session (cost per minute) | £1.10[2] |
| Other healthcare contact (cost per minute)‡ | £1.72[2] |
| Test (average for specified tests*) | £130.40[1] |
| Hospice (cost per session) | £36.00[2] |
| Medication: Weighted average cost per prescription | £9.16[4] |
| Hospital transport services (assumed to equate to emergency transfer[2]) | £253.00[2] |
| Equipment/aids and adaptations | £511.97[#] |
| Paid carer | £0.37[2] |
| Jobcentre Plus contact (cost per minute) | £0.24[5]† |
| Informal (unpaid) care from friends or relatives (including child care) | £0.24[5]† |
| Disability Living Allowance: Care component – Lowest rate | £18.95[6] |
| Disability Living Allowance: Care component – Middle rate | £47.80[6] |
| Disability Living Allowance: Care component – Highest rate | £71.40[6] |
| Disability Living Allowance: Mobility component – Lower rate | £18.95[6] |
| Disability Living Allowance: Mobility component – Higher rate | £49.85[6] |
| Housing Benefit | £65.45[7] |
| Jobseeker's Allowance | £65.45[7] |
| Income Support | £65.45[7] |
| Income-related Employment and Support Allowance (or Incapacity Benefit) | £65.45[7] |
| Working Tax Credit ❖ | £36.92[8] |

* Specified tests were MRI scan, CT scan, X-ray, ultrasound and blood test. Totals for all tests are presented.

† Based on mean UK hourly gross pay for all employees in April 2010.

‡ Includes nurse, social worker, clinical psychologist, psychiatrist, psychotherapist, chiropractor, counselling, acupuncture, and A&E attendance.

# Includes bath seat, walking stick/frame, grab rail, crutches, stair lift, wheelchair, toilet frame, pressure cushion, hoist, CPAP (continuous positive airway pressure) machine, stool, concrete ramp and pressure mattress. Unit costs were requested from respondents but were taken from Curtis et al.[2] and other web-sites (information available from authors) if not reported.

❖ Based on the basic element of £1920 per annum (excludes Child Tax Credit, etc. as these are dependent on circumstances).

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