Thinking positively about work

A model of work support and vocational rehabilitation for people with cancer

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

Preliminary executive summary
March 2012

Lead author contact details:
Dr Gail Eva
Department of Brain Repair and Rehabilitation
UCL Institute of Neurology
Box 9
Queen Square
London WC1N 3BG
United Kingdom
g.eva@ucl.ac.uk

Gail Eva Research Fellow UCL Institute of Neurology
Diane Playford Reader UCL Institute of Neurology, and Consultant Neurologist National Hospital for Neurology and Neurosurgery, UCLH NHS Trust
Tracey Sach Senior Lecturer in Health Economics University of East Anglia
Kate Radford Senior Lecturer University of Central Lancashire
Chris Burton Senior Research Fellow University of Bangor
# Contents

1 **Introduction**  
1.1 Cancer and work  
1.2 The NCSI Vocational Rehabilitation Project  
1.3 The remit of this report  

2 **Evaluation aims and design**  
2.1 Aim and objectives  
2.2 Method of investigation  
2.3 Data collection  
2.4 Ethical considerations and funding  

3 **A model of work support and vocational rehabilitation in cancer**  
3.1 Strategic model of cancer work support  
3.2 Three level model of work support interventions for people with cancer  
3.3 Distinction between work support and vocational rehabilitation  
3.4 Configuration of services  
3.5 Outcomes  

4 **The role of health professionals in supporting positive work outcomes**  
4.1 The 5 Rs  
4.2 Raising work issues early  
4.3 Recognising risk factors: ‘work flags’  
4.4 Responding, referring and revisiting  
4.5 Fitness for returning to work  
4.6 Educating health professionals  

5 **Working with employers**  
5.1 How line managers can support people with cancer  
5.2 Educating employers  

6 **Enabling people with cancer to think positively about work**  
6.1 Support for self-management  
6.2 A positive outlook on work  

7 **Specialist vocational rehabilitation**  
7.1 Vocational rehabilitation interventions for people with cancer  
7.2 Competency framework for cancer vocational rehabilitation  

8 **Further considerations**  
8.1 The relevance of work support to palliative patients  
8.2 The impact of cancer on carers’ employment  
8.3 Community of practice  

9 **Recommendations**  

10 **References**
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.1 ‘Good work’2 has both personal and societal value.

Many people who have had cancer want to go back to work when they feel ready and able.3 However, the evidence suggests that they can struggle to do so: cancer survivors are 1.37 times more likely to be unemployed than people who have not had cancer.4

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,5 our understanding of how to support people with cancer to remain in or return to work is limited.6

1.2 The NCSI Vocational Rehabilitation Project

Recognising the need to improve the work support available for people with cancer, the Work and Finance Workstream of the National Cancer Survivorship Initiative (NCSI – a partnership between the Department of Health and Macmillan Cancer Support) undertook a wide-ranging consultation, evidence review and an examination of existing good practice. The resulting Strategy Paper7 identified five principles for improving cancer work support, and proposed a model of vocational rehabilitation which was subsequently tested in seven pilot sites located across England, with a view to replicating it nationally.

The pilot sites were initially funded for 12 months (April 2010 – March 2011), with five receiving four month extension funding (to July 2011). The sites were:

- St John’s Information and Support Centre, Doncaster Community Healthcare (Rotherham Doncaster and South Humber NHS Foundation Trust from April 2011), South Yorkshire
- National Hospital for Neurology and Neurosurgery, London
- Shaw Trust with the Christie, Greater Manchester
- NHS Blackburn with Darwen, Lancashire
- NHS South of Tyne and Wear, Gateshead
- Mount Vernon Cancer Network, Hertfordshire / South Bedfordshire
- Orbitals Ltd. with the Olive Tree Cancer Support Centre: Crawley, East Sussex

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 varied significantly between pilots.

The NCSI Vocational Rehabilitation Project has delivered five key outputs:

1. A new, robust model of work support interventions for people with cancer.
2. A strategic framework which can support the planning and delivery of cancer work support services.
3. An outline of the content of specialist vocational rehabilitation interventions for people with cancer.
4. A competency framework to underpin the delivery of specialist cancer vocational rehabilitation.
5. The work of the pilot sites and the three interim evaluation reports (available on the NCSI website: http://www.ncsi.org.uk/what-we-are-doing/vocational-rehabilitation/) have contributed to raising the profile of work support and vocational rehabilitation services for people with cancer.

1.3 The remit of this report

This preliminary executive summary sets out the key findings of the Realistic Evaluation component (see 2.2) of the NCSI Vocational Rehabilitation Project evaluation. It does not include the health economic data. Due to the four month extension of the pilot site activity, the six month follow-up data collection was not completed until December 2011, and it is currently being analysed.

The full executive summary and the final report, including the health economic analysis, will be available in April 2012.
2 Evaluation aims and design

2.1 Aim and objectives
The aim of the evaluation was to identify a model, or models, of vocational rehabilitation for people with cancer that have good outcomes with demonstrated cost effectiveness.

There were three objectives:
1. To define the best elements of the models employed in the pilot sites as a guide to future service provision.
2. To identify patients’ perspectives of vocational rehabilitation services in terms of both experience and outcome.
3. To demonstrate the cost of service delivery and demonstrate cost-utility.

2.2 Method of investigation

Objectives 1 and 2
Realistic Evaluation\(^8\) 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.

Objective 3
As noted earlier, this preliminary executive summary does not include the health economic data, which is currently being analysed and will be presented in the final report, available in April 2012.

2.3 Data collection

Data from a variety of sources were used in the evaluation.

Service structure and delivery
- Four interviews and seven focus groups with service providers between June 2010 and July 2011.
- Data collected by individual pilot sites on service user demographics, types of interventions offered, work status at referral and discharge, and duration of intervention.
- The final reports received from each of the seven pilot sites.

Definition, content and competencies for specialist vocational rehabilitation
- Two one-day consensus development workshops using a modified Nominal Group Technique to explore definitions, content and competencies for specialist vocational rehabilitation.

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

Health economic data
Patients referred to the pilots were invited to complete a questionnaire booklet containing:
- Demographic information
- Work status
- EQ5D
- Modified Client Services Receipt Inventory
- Modified General Self Efficacy Scale

Data were collected at baseline and again at six months. 143 baseline and 88 follow up questionnaires were returned.

2.4 Ethical considerations and funding
The evaluation was reviewed by an NHS Research Ethics Committee, Central London REC 3, who gave a favourable opinion. REC Ref. No.: 11/H0716/5. It was funded by the National Cancer Survivorship Initiative, a partnership between Macmillan Cancer Support and the Department of Health.
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 survivorship – 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.

3 A model of work support and vocational rehabilitation in cancer

3.1 Strategic model of cancer work support
(Figure 1)
In order to provide effective services, it is necessary to take account of the needs, roles and responsibilities of three intersecting groups:

• People affected by cancer and their carers.
• Health care professionals.
• Employers.

Across these groups, two distinct strands of support are required:

• Strategies implemented across populations to embed work support into the cancer treatment pathway and on into survivorship.
• Interventions at an individual level to provide tailored personalised support.

3.2 Three level model of work support interventions for people with cancer
(Figure 2)
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.

3.3 Distinction between work support and vocational rehabilitation

There is a distinction between ‘work support for people with cancer’, and ‘specialist vocational rehabilitation’. 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 incorporated into health professionals’ interactions with patients throughout the treatment pathway. 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.

3.4 Configuration of services

There is no universal prescription for setting up work support services for people with cancer. The evaluation of the pilot sites has shown that the exact configuration of services will depend on local circumstances and context. However, core components can be identified, as follows:

1 Incorporating prompts to talk about work into local cancer guidelines, policies, procedures, treatment pathways and information prescriptions.
2 Making sure that health professionals understand the need to present the right messages about work in an acceptable and appropriate way, from diagnosis onwards, to encourage patients to think positively about work.
3 Providing tailored information and advice to patients to support self management.
4 Ensuring that specialist vocational rehabilitation is available for people with complex problems.
5 Setting up cancer protocols and procedures to include prompts to ensure that there is effective liaison between patients, health professionals, employers, human resources departments and occupational health services.
6 Identifying the statutory and voluntary services available locally to support people with cancer, and ensuring that mechanisms exist for effective liaison between these services and cancer treatment services.
Cancer Work Support

Employers
- Engagement at an organisational level
  Increasing employers’ knowledge, awareness and ability to manage employees with cancer
- Engagement at an individual level
  Advocacy and support for person with cancer in liaising with employer

Health professionals
1. Raising awareness and understanding of the importance of work
2. Promoting health professionals’ understanding of their role in supporting people with cancer in employment
3. Improving confidence in listening for cues about problems, and the ability to respond effectively

People with cancer and their families/carers

LEVEL 1
Open access to information, support and signposting

LEVEL 2
Active support for self management

LEVEL 3
See below

Specialist vocational rehabilitation
- Detailed, skilled assessment of individual capacity and workplace requirements
- Rehabilitation interventions to build work skills
- Education on managing specific symptoms in the workplace, for example, fatigue, functional difficulties, cognitive problems and pain
- Liaison with employers, modification of work environment, negotiating a phased return to work
- Psychological interventions to support adjustment to the consequences of illness and disability.
- Information and advice on rights and responsibilities.
- Supported withdrawal from work, where that is appropriate.
- Referral to other support services, for example Access to Work.
- Careers advice and guidance.

Linking to other related areas
- Benefits advisors
- CAB
- Jobcentre Plus
- Access To Work
- ACAS
- Other local services
- Specialist Legal Support DLS
- Other local services

Figure 1: Strategic model of cancer work support
Thinking positively about work

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.

---

**Figure 2:** Three level model of work support interventions for people with cancer

<table>
<thead>
<tr>
<th>Recipients</th>
<th>Service providers</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEVEL 1</td>
<td>Open access to information and support</td>
<td>Everyone with a cancer diagnosis who is employed or who has the potential to be employed.</td>
</tr>
<tr>
<td>LEVEL 2</td>
<td>Active support for self-management</td>
<td>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).</td>
</tr>
<tr>
<td>LEVEL 3</td>
<td>Specialist vocational rehabilitation</td>
<td>People who have complex problems, who require specialist help from qualified professionals.</td>
</tr>
</tbody>
</table>

- 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.
- 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.

- Provision of specialised, tailored information, advice or support which people with cancer are able to take forward and implement themselves.
- Signposting to other specialist services and organisations.
- Support is typically of short duration and may be delivered face-to-face, or by phone or e-mail.

A process of specialist vocational rehabilitation including (but not limited to):
- Detailed assessment of individual capacity and workplace requirements.
- Rehabilitation interventions to build work skills.
- Education on managing specific symptoms.
- Liaison with employers, negotiating a phased return to work.
- Psychological interventions.
- Information and advice on rights and responsibilities.
- Supported withdrawal from work where appropriate.
- Referral to other support services
- Careers advice and guidance.
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 Embedding work support into cancer treatment protocols, pathways and guidelines.

2 Ensuring that health professionals have adequate knowledge to provide early support.

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 employment support services.

### 3.5 Outcomes

There is a wide spectrum of individuals and organisations with an interest in the work support and vocational rehabilitation needs of people with cancer. While there is broad agreement on the overall aim of work support services in cancer – 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.

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 skillful 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. Vocational rehabilitation practitioners tend to prioritise the needs and preferences of their individual patients or clients. 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.
4 The role of health professionals in supporting positive work outcomes

4.1 The 5 Rs

Health professionals need to be able to:

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.

4.2 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. All of the pilot sites noted that work issues were not routinely raised with patients, particularly not in the early stages after diagnosis.

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. It is important to understand that ‘taking care of yourself’ and ‘keeping active and engaged’ are not mutually exclusive messages. Patients need to do both at the same time, and health professionals, in turn, need to support and facilitate this.

In other long-term conditions, such as stroke and cardiac illness, rehabilitation tends to be 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 as an approach that should be integrated into patients’ pathways from the outset.

4.3 Recognising risk factors: ‘work flags’

Patients often do 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.
There are a number of risk factors that health professionals should 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. Simply asking a patient to identify concerns will not necessarily yield useful information as they might not recognise problems. Rather, these topics need to be woven into consultations and conversations throughout the patient’s treatment.

4.4 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).

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 that address an individual’s specific concerns are more likely to lead to improved 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. There is a need for a dedicated person (or people) to have responsibility for keeping up-to-date with available services, maintaining links between cancer treatment services and employment resources, and promoting the importance of providing patients with effective work support.

4.5 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. 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.

4.6 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.
5  Working with employers

5.1  How line managers can support people with cancer

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 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.

5.2  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.

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 Enabling people with cancer to think positively about work

6.1 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.\textsuperscript{14,15} 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.\textsuperscript{16,17}

6.2 A positive outlook on work
As noted in section 4.2, 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 proactive 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.
7 Specialist vocational rehabilitation

7.1 Vocational rehabilitation interventions for people with cancer
Vocational rehabilitation interventions are well described and defined in numerous textbooks and documents 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.

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

- 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. No cancer-specific vocational rehabilitation training programme currently exists. The need for this should be considered.
8 Further considerations

Three areas, not included in the original objectives for the evaluation, have emerged. They merit further attention, in terms of both research and service development.

8.1 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.

8.2 The impact of cancer on carers’ employment
It was not within the scope of this project to examine the consequences of a diagnosis of cancer on carers’ employment. However, 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.

8.3 Community of practice
Opportunities for pilot staff to network with each other 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.
9 Recommendations

1 Work support should be embedded into the patients’ pathway from diagnosis, through treatment and on into survivorship – 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 key ingredients required for the provision of effective support are: positive approaches towards work, tailored information delivered at the right times, access to specialist services, and effective liaison between patients, health professionals and employers.

3 Work support and vocational rehabilitation for people affected by cancer should be available 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 Each Cancer Network, or organisation responsible for cancer services, should nominate a lead person (or people) to take responsibility for:
   - Embedding work support into cancer treatment protocols, pathways and guidelines.
   - Ensuring that health professionals have adequate knowledge to provide early support.
   - 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.
   - Ensuring that there are effective channels of communication and referral pathways between cancer services and external employment support services.

5 Health professionals need to be able to:
   - Raise work issues with patients early in the treatment pathway in a sensitive and acceptable manner.
   - Recognise the risk factors for poor work outcomes.
   - Respond effectively to the straightforward work problems that patients identify.
   - Refer patients who have more complex difficulties to the appropriate specialist services.
   - Revisit work issues at intervals during treatment.

6 A national strategic approach should be taken 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.

7 People with cancer should be encouraged 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.

8 Delivery of vocational rehabilitation interventions for people with cancer should be based on a specific set of competencies. It is unlikely that any single discipline or person would encompass all of these competencies, and input from a small multidisciplinary team is likely to be needed. There is a need for a cancer-specific vocational rehabilitation training programme.

The full executive summary and the final report, including the health economic analysis, will be available in April 2012.
10 References


