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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

Summary of the final report

July 2012

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This is the short summary report for the evaluation of the National Cancer Survivorship Initiative (NCSI) Work and Finance Workstream Vocational Rehabilitation Project. It contains an overview of the project, the key project findings, conclusions and recommendations.

The detailed full report is available from **www.ncsi.org.uk/what-we-are-doing/vocational-rehabilitation/** or **www.macmillan.org.uk/work/policyandresearch**.

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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.

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),[1] 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 (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).

1.2 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[2] 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:

- 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.

1 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.

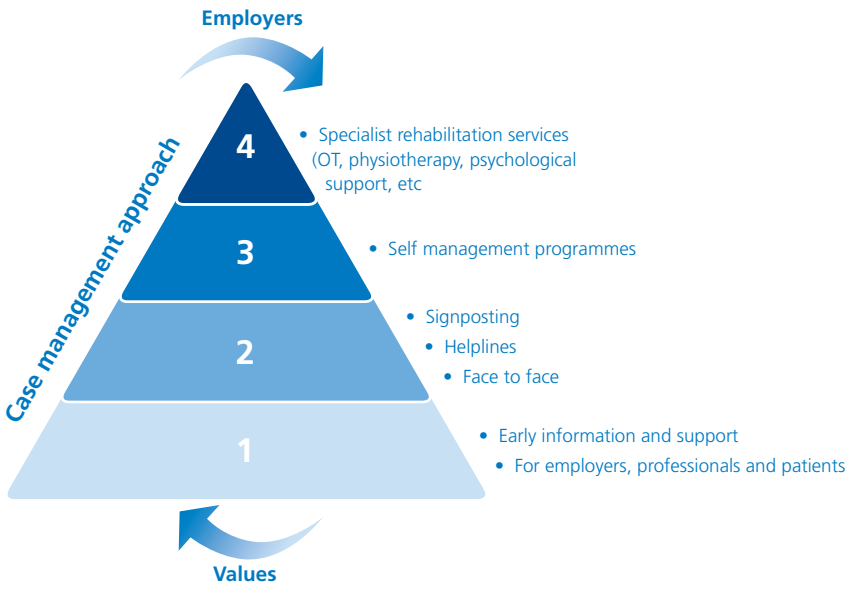
2 The National Survivorship Initiative (NCSI) is a partnership between Macmillan Cancer Support and the Department of Health, supported by NHS improvement. It was created in response to the 2007 Cancer Reform Strategy which recognised the need to improve support for people living with the longer-term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

This model 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 objective varied significantly between pilots.

Figure 1:
The prototype four level model diagram



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.

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

2 Evaluation aim 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.

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.

Service structure and delivery

- Four interviews and seven focus groups with 22 service providers between June 2010 and July 2011.
- 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).[4]
- The final reports received from each of the seven pilot sites.
- 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).

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) 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.

Perspectives of service users

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

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

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 and a modified General Self Efficacy Scale.

  Data were collected at baseline and again at six months. 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.
- An initial aim of the health economic assessment had been to estimate the cost-effectiveness of the seven pilot sites compared to usual care, however it proved difficult to set up comparison sites and also to recruit participants. One comparison site was successfully set up University Hospital of South Manchester (UHSM) Wythenshawe but of the approximately 400 baseline questionnaires distributed between August and November 2011, only 26 were returned. This data will be analysed and presented in future study publications.

  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.

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.

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

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:

- A Strategic Framework for Cancer Work Support (Figure 2).
- A Three Level Model of Work Support for People with Cancer (Figure 3).

3.1 Strategic Framework for Cancer Work Support (Figure 2)

The Strategic Framework for Cancer Work Support presents a blueprint for service configuration at a population level. It applies to all patients who are in work or who have the potential to work, not just to those with identified work problems.

In order to provide effective work support services, 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.

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.
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.

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.

3.2 Three level model of work support for people with cancer

The 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 NSCI Work and Finance Workstream Project Group four level model (Figure 1, page 4), and it is based on NHS Improvement's Model of Care for Living With and Beyond Cancer (NHS Improvement 2011).

- **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 as a distinction between 'work support for people with cancer' which takes place at Levels 1 and 2, and 'specialist vocational rehabilitation' at level 3. 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. 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 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.

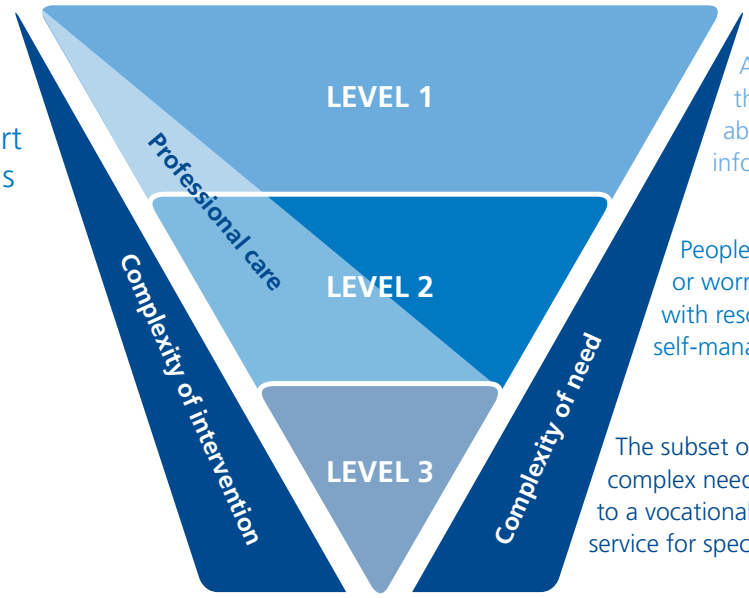
In general terms, funding bodies, commissioners and policy-makers have an interest in ensuring that those who wish to work are able to do so, thereby reducing the cost of unemployment. Employers wish to maintain a skillful and productive workforce, and reduce sickness absence. People with cancer and 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. 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.

3.5 Local considerations in service configuration

The Strategic Framework for Cancer Work Support (Figure 2, page 9) 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.

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. • 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. • 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.
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): • 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.

4 Findings from the seven pilot sites

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[5] as this was the model used in setting up and delivering the pilots' services.

Models of service delivery varied between pilots, as did the categorisation of patients across the different levels. 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. Feedback from the pilots was used to develop the Three Level Model of Work Support presented in this report,[6] which provides a clearer, more straightforward system for classification. Level 3 in the new model is approximately equivalent to Levels 3 and 4 in the prototype model.

Table 1: Numbers of referrals (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[7]	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	-

5 See Figure 1, page 4

6 See Figure 3, page 11

7 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.

4.2 Work outcomes

Table 2 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 that fact that over one third (38%) went from 'not working to working' or from 'sick leave to full work or modified work'.

Table 2: Change in work status from referral to discharge[8,9]

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%)

8 This data is taken from the Service Delivery Templates provided by the pilot sites.

9 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.

4.3 Cost of the intervention

4.3.1 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 3. 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.

4.3.2 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.

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).

Table 3: 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[10] (3) (£)	5,594.81[11]	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

10 This may include administration costs.

11 Estimated from budget plans as administrative support was not itemised separately within expenditure figures.

4.4 Synthesis of learning from the pilot sites

A number of learning points arose from the pilots sites' 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 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 cognitive behavioural therapy 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

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.

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.

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. 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, 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'

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.

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.

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).

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 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.

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.

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.

6 Working with employers

6.1 What people with cancer 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.

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.

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.

7 Enabling people with cancer to think positively about work

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, no date).

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:

- Ability to undertake a thorough, comprehensive work assessment including the person's work history, their skills and attitudes, the job requirements, and the work environment.
- 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.

9 Further investigations 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 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 cognitive behavioural therapy 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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