

Vocational Rehabilitation Strategy Paper

A proposed model of vocational rehabilitation in cancer

National Cancer Survivorship Initiative Work and Finance
Workstream

November 2009

This paper is a revised version of a discussion paper produced by a
sub-group of the Workstream

1.0 Executive Summary

- 1.1 The Cancer Reform Strategy, published in 2007, recognised the needs of, and lack of services for, people living with the side effects and long-term consequences of cancer treatment. As a result of this, the National Cancer Survivorship Initiative (NCSI) was established, led by the Department of Health and Macmillan Cancer Support.
- 1.2 The Work and Finance Workstream, one of seven NCSI workstreams, commissioned a project group to: review the provision of vocational rehabilitation; and develop a vocational rehabilitation service model that could be piloted. The group reviewed the policy context, the existing research literature and held a consultation workshop with people affected by cancer. It also looked at existing good practice. The review identified a number of principles key to improving vocational rehabilitation services for people affected by cancer. These are:
- early intervention to provide information and support, to encourage self-management, and begin the conversation about remaining at or returning to work
 - a partnership approach between key services such as health, social care and employment services
 - involvement of employers
 - specialist services that can address the various barriers to work such as physical limitations, significant psychological distress, and loss of self esteem and confidence
 - navigation of services in a way that supports self-management and helps instil confidence in rehabilitation services amongst users.
- 1.3 On the basis of this review a 4 tiered model of vocational rehabilitation has been proposed. The levels are:
- level 1 – information and support provided through electronic and printed mediums
 - level 2 – one-on-one support and signposting through telephone helplines and digital medium
 - level 3 – self management programmes accessed during or after treatment
 - level 4 – specialist vocational rehabilitation services.
- 1.4 The Work and Finance Workstream has agreed the proposed model of vocational rehabilitation. As a next step, Macmillan Cancer Support will seek proposals for projects to pilot this model of vocational rehabilitation.

2.0 Introduction

- 2.1 In November 2007, the Department of Health published the Cancer Reform Strategy.¹ This document outlined the direction of cancer services for the next five years and the objectives to be achieved by 2012.
- 2.2 Within this important document, the needs of people living with the long-term consequences of cancer were recognised. The Cancer Reform Strategy acknowledged that ‘survivors of cancer have a range of physical, psychological, social, spiritual, financial and information needs... services frequently do not meet these needs for patients or are poorly integrated’.² As a consequence of this the National Cancer Survivorship Initiative (NCSI) was launched, led by the Department of Health and Macmillan Cancer Support.

¹ *Cancer Reform Strategy*, Department of Health, November 2007.

² *Cancer Reform Strategy*, Department of Health, November 2007, Chapter 5, para 60.

- 2.3 In March 2008, Macmillan Cancer Support hosted a think tank event 'Making the Cancer Survivorship Agenda a Reality'. This enabled stakeholders to identify the key priorities that should be addressed by the NCSI. Work and financial problems were identified as important issues for people living with cancer.
- 2.4 In October 2008, a Work and Finance Workstream was established as part of the National Cancer Survivorship Initiative. This group's remit was to look at:
- how to ensure that people with cancer are given the information, advice and support they need to make informed decisions about their working lives
 - how to alleviate financial hardship caused by cancer, and ensure people with cancer are given the information and advice they need about benefits and financial issues.
- 2.5 In May 2009, a vocational rehabilitation project group (the Project Group) was established under the auspices of the Work and Finance Workstream. The aims of the Project Group were to:
- establish a model of vocational rehabilitation which supports the needs of people affected by cancer
 - provide specialist expertise on vocational rehabilitation to the Work and Finance Workstream (see Appendix A for the terms of reference and membership of the Project Group).
- 2.6 The Project Group consisted of a broad membership drawn from Macmillan Cancer Support, people diagnosed with cancer, the Department of Health (DH), academic and occupational health representatives, other interested charities and organisations, and Cancer Networks. The Group was chaired by Nicola Cook, Senior Macmillan Development Manager.
- 2.7 The definition of vocational rehabilitation agreed by the Project Group is deliberately broad and shadows that of the government's cross-departmental Health, Work and Well Being Strategy. Vocational rehabilitation is 'whatever helps someone with a health problem to stay at, return to or remain in work'.³
- 2.8 This strategy paper is a revised version of the discussion paper produced by the Project Group. It provides an overview of the work undertaken by that group and makes recommendations as to how this work can be taken forward by the Work and Finance Working Group.

3.0 Why vocational rehabilitation is important: the policy context

- 3.1 Vocational rehabilitation is increasingly being seen as a priority by the Government and is a key component of its employment and welfare reform agendas. The interaction between health and work is recognised as being the shared responsibility of Department of Work and Pensions (DWP) and DH. A major review of the health of the working age population by Dame Carol Black, *Working for a Healthier Tomorrow*, was published in 2008.⁴ There is a broad consensus view that work is good for health, and that intervention to support returning to work is cost effective.⁵
- 3.2 To date, the focus of Jobcentre Plus employment services has largely been on high volume conditions such as mild to moderate mental health problems, muscular skeletal and cardio respiratory conditions. These are responsible for the majority of sickness absences from employment.

³ Waddell G, Burton AK, and Kendall N, (July 2008), *Vocational Rehabilitation: What Works, for Whom, and When?*

⁴ Dame Carol Black, (March 2008), *Working for a Healthier Tomorrow*, Health, Work and Well Being Programme.

⁵ Waddell G, and Burton AK, (2006), *Is Work Good for Your Health and Wellbeing?*

- 3.3 The Black review identified the need to address the underlying health-related causes of unemployment/sickness absence, and to focus on ability, rather than inability to work. A number of initiatives were recommended, including the piloting of a 'Fit for Work' service, and changes to the process of medical absence certification from a focus on inability to work ('sick note') to ability to work ('fit note').
- 3.4 The 'Fit for Work' service pilots are intended to provide a personalised vocational rehabilitation service to enable employees who become sick or disabled to stay in or return to work.⁶ It is expected that these services will draw on both health services and the expertise of the employment sector. Pilot sites for these services have recently been announced.

4.0 What does the research show?

- 4.1 Research on the vocational rehabilitation needs of people diagnosed with cancer is limited. The research that is available shows two things. The first is the overriding importance that people attach to remaining in or returning to work after a cancer diagnosis.^{7,8} The second is that there is a relative lack of services available specifically to support individuals with a cancer diagnosis to remain in or return to work.⁹
- 4.2 This evidence suggests that if services were more focused on supporting people diagnosed with cancer, these services would have a positive effect on the ability of individuals to remain in or to return to work.
- 4.3 Further evidence suggests that these services should:¹⁰
- ensure integration between healthcare and employers
 - facilitate communication and coordination (i.e. a partnership) between the key players in health, social care and employment services
 - promote early intervention in order to prevent people with health problems going onto long term sickness absence.
- 4.4 On the issue of early intervention, evidence also suggests that it is helpful for people to start thinking about a return to work right from the beginning of their cancer journey, as this shapes people's attitudes and beliefs.¹¹ Early intervention of vocational rehabilitation also assists participants to manage their own condition.
- 4.5 Research on return to work issues more generally shows both medical professionals and employers have some difficulties advising people with cancer about returning to work. One study identified that one of the barriers to returning to work was the lack of medical advice from cancer specialists and general practitioners regarding the appropriate time to get back to work.¹²

⁶ Fit for Work Service: Programme of Piloting, Memorandum of Information - version 0.13, 2009.

⁷ Spelten E, Spragers M and Verbeek J, (2002), 'Factors reported to influence the return to work of cancer survivors: a literature review', *Psycho-Oncology* 11: 124-131.

⁸ Amir Z, Neary D and Luker KA, (2008) 'Cancer Survivors' views of work 3 years post diagnosis – A UK Perspective', *European Journal of Oncology Nursing*, 12(3): 190-197.

⁹ *Returning to work: Cancer and vocational rehabilitation*, Macmillan Cancer Support, (February 2008).

¹⁰ Waddell G, Burton AK and Kendall NAS, (2008), *Vocational Rehabilitation what works, for whom and when?* commissioned by the Vocational Rehabilitation Project Group in association with the Industrial Injuries Advisory Council.

¹¹ *Returning to work: Cancer and vocational rehabilitation*, Macmillan Cancer Support, (February 2008).

¹² Amir Z, Neary D and Luker KA, (2008) 'Cancer Survivors' views of work 3 years post diagnosis – A UK Perspective', *European Journal of Oncology Nursing*, 12(3): 190-197.

- 4.5 Another study explored the views of line-managers with regard to managing employees diagnosed with cancer. Managers reported emotional difficulties in dealing with employees diagnosed with cancer, lack of skills in relation to handling these emotional situations, and difficulties in striking a balance between the needs of the individual and those of the organisation. Managers felt that more information and guidance was needed to help them make appropriate adjustments for employees with cancer returning to work.¹³
- 4.6 This evidence suggests both employers and medical professionals could benefit from more information and advice about people with cancer returning to work.

5.0 The priorities for people affected by cancer

- 5.1 The Vocational Rehabilitation Project Group organised and facilitated a consultation event for people living with cancer to find out about their experiences of vocational rehabilitation services, and the type of return to work services they would ideally like to see. This event took place in May 2009 and involved 13 people who had been diagnosed with cancer. The participants were recruited via the Macmillan website.
- 5.2 The consultation revealed three main barriers to work caused by cancer. These were physiological, emotional and practical barriers. The physiological effects of cancer and its treatment, particularly fatigue, were those most directly associated with difficulty working. Emotional effects such as diminished confidence and guilt about a reduced ability to work, and practical difficulties such as needing to take time off for treatment, also affected ability to work. The participants identified that one, all, or a combination of the issues identified could make working life difficult.
- 5.3 The consultation also showed what services had been useful in providing support. Participants described useful support from health services, their employer, or another source. Notably, no attendees had experienced any services provided by DWP. Useful support from health and other services was largely associated with receiving information. However, while some people had almost more information than they needed, this was not the case for everyone. Some participants had also been referred into day therapy services, which they had found helpful.
- 5.4 The consultation event encouraged people to identify the services that they would have found useful to help them remain in or return to work. This discussion revealed support from employers as being important to people in enabling a successful return to work. Examples of support participants wanted from employers included highlighting of available changes to working arrangements such as flexible hours, altered duties and a phased return to work.
- 5.5 When participants discussed their experiences of poor support, employers again emerged as the main theme. A lack of knowledge of company policy, best practice, and employee rights under the Disability Discrimination Act; not providing flexible working arrangements; and underestimating the impact of fatigue were issues. This suggests that employer support is a key factor in determining return to work outcomes for people affected by cancer, backing up the existing evidence mentioned in the previous section.
- 5.6 These patient experiences are consistent with the existing research literature. A Cancerbackup study found that, despite 76 percent of employers agreeing that employees should be entitled to reasonable adjustments to duties on returning to work,¹⁴ only 50 percent of cancer patients are offered flexible working arrangements.¹⁵ Research by Macmillan Cancer Support showed a good relationship with an employer/manager was a major influence on returning to work.¹⁶

¹³ [Cancer and the workplace line manager survey](#), Macmillan Research Unit, March 2007-January 2009.

¹⁴ [Cancer and the workplace line manager survey](#), Macmillan Research Unit, March 2007-January 2009.

¹⁵ Cancerbackup, *Work and cancer*, (2005).

¹⁶ Amir Z, Neary D and Luker KA, (2008), [Cancer survivors' views of work 3 years post diagnosis: A UK perspective](#), *European Journal Of Oncology Nursing*, 12 (3), 190-197.

5.7 The user consultation also found that participants needed to have confidence in a service, and did not want to continually have to repeat the same information to different health, social care and employment professionals. Similarly people explained that it would be helpful to have the ability to contact the same person throughout their experience of a vocational rehabilitation service. The role of a navigator was therefore strongly supported. Participants also repeatedly emphasised the fact that one size does not fit all, and that support needs to respond to individual needs.

6.0 What do existing vocational rehabilitation services tell us?

- 6.1 Due to limited time, the Project Group were unable to undertake a detailed audit of existing services designed to assist people with a chronic condition remain in or return to work. However, the group were able to look at two pilots that incorporate the concepts of partnership, early intervention, and navigation of services. These pilots were: the Condition Management Programmes which are delivered by NHS providers working in partnership with Jobcentre Plus employment services; and the Scottish Healthy Working Lives Model, facilitated by the Dundee Community Health Partnership.
- 6.2 The Condition Management Programme is a cognitive educational intervention. It is aimed at empowering individuals to understand and to manage their health condition, with a view to returning to work. It is a voluntary initiative offered to people claiming Employment and Support Allowance (ESA) as part of the Pathways to Work programme.¹⁷
- 6.3 A distinguishing element of the Condition Management Programme is the partnership between the specialist ESA Personal Advisors and the Health Care Practitioner. Both of these roles focus on empowering individual claimants to manage their condition, and to help them to move towards returning to work. In order to foster this relationship there is joint training, joint working from the same premises, active communication and issues solving. The need for early intervention is also recognised as key.
- 6.4 The Scottish Healthy Working Lives Model (shown in Figure 1 below) provides a vocational rehabilitation service to employees of small and medium enterprises. The service provides access to a range of specialist health professionals, including a physiotherapist, occupational therapist, health nurse, physician and complementary therapist. The aim of the service is to help Dundee employees stay at work or get back to work sooner. The service is a joint project, funded by the Scottish Government, and delivered locally by the Dundee Community Health Partnership (NHS Tayside) and the Scottish Centre for Healthy Working Lives.
- 6.5 This Scottish Healthy Working Lives Model has only recently commenced and an evaluation process is currently underway. Early indicators show the importance of a case manager who provides continuity of service throughout use of the service. Early intervention has also been promoted so that participants are using resources to self-manage, with rapid access to more specialist support as and when required.
- 6.6 Both the Condition Management Programme and the Scottish Healthy Working Lives Model focus on the importance of navigation, as well as the need to support early intervention to promote self-empowerment and self-management. The Scottish Healthy Working Lives Model also indicates the needs for rapid access to specialist interventions such as physiotherapy or counselling, as and when the individual requires this support.

¹⁷ The DWP Green Paper, *Pathways to Work - helping people into employment*, was published in 2002, and launched in April 2003. It provided an opportunity for DH, DWP, JobcentrePlus, the NHS, and the Private and Voluntary Sectors to work together to deliver the Choices package of back-to-work programmes, one of which is the Condition Management Programme (CMP).

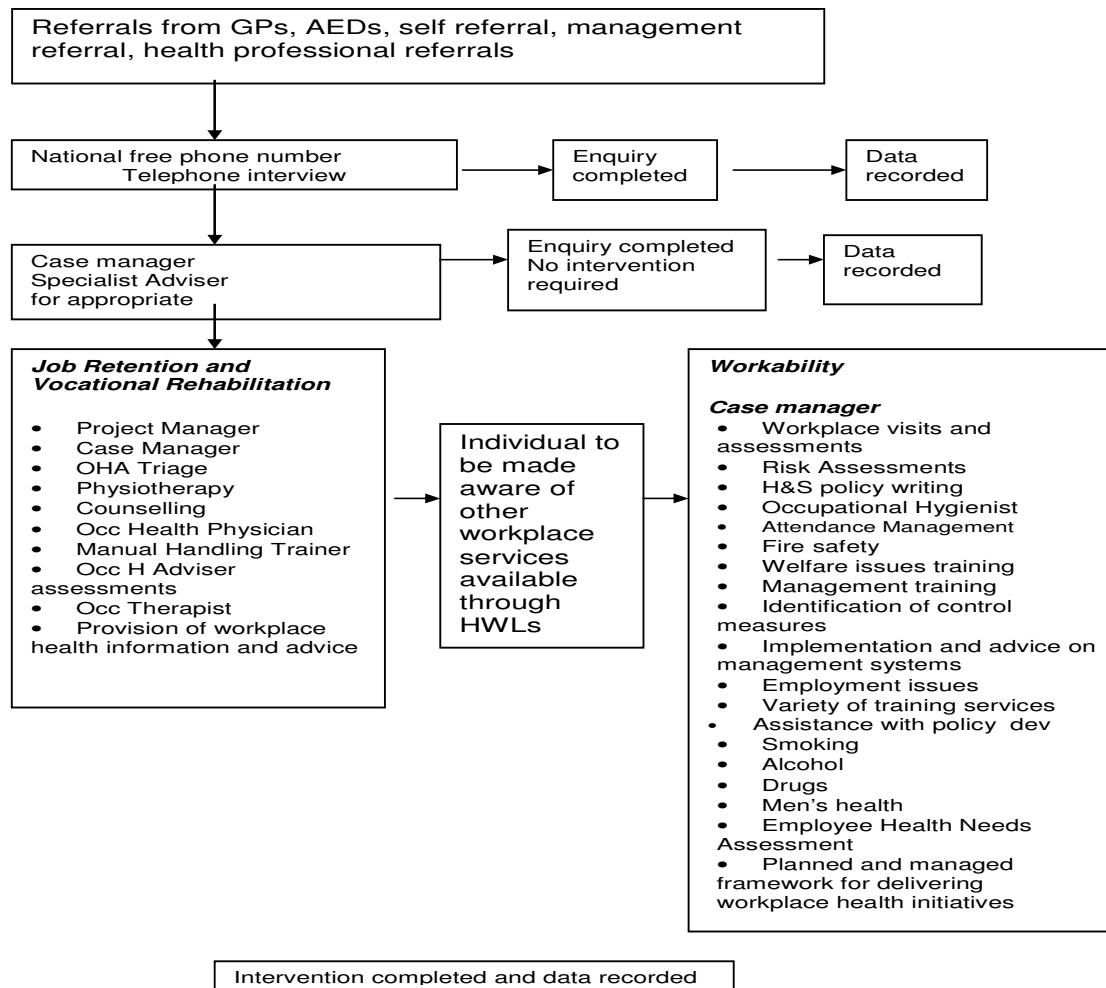


Figure 1 - Scottish Health Working Lives Model

7 Proposed Model of Vocational Rehabilitation

7.1 A review of the policy context, existing research, the views of people affected by cancer, and the success of current pilots, identifies a number of key principles that should underpin vocational rehabilitation services for people with cancer. These are:

- early intervention of information and support, to encourage self-management, and begin the conversation about remaining at or returning to work
- a partnership approach between key services such as health, social care and employment services
- involvement of employers
- specialist services that can address the various barriers to work such as physical limitations, significant psychological distress, and loss of self esteem and confidence
- navigation of services in a way that supports self-management, and helps users to develop confidence in services.

7.2 Bearing these principles in mind, the Project Group developed the following model of vocational rehabilitation.

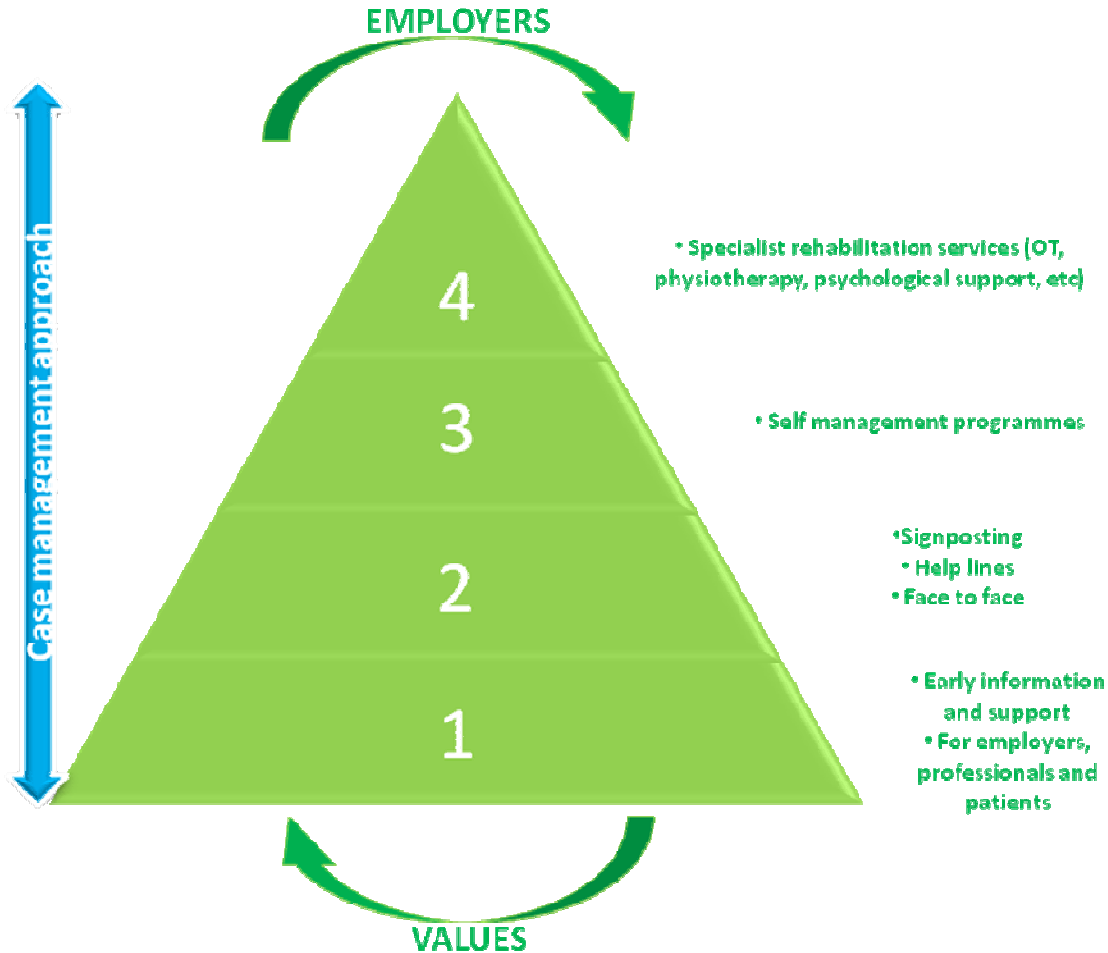


Figure 2 - Proposed Model for Vocational Rehabilitation.

- 7.3 Figure 2 displays the model's tiered approach to vocational rehabilitation. It shows that many people are likely to have their needs met at the lower levels of the model, while other people will have more extensive needs, and will need to access the more specialist services provided at the model's higher levels.

Level 1

- 7.4 Level 1 should provide participants with information on work and cancer issues, available services, and guidance on the type of issues which someone diagnosed with cancer may want to explore with their employer. It would be expected that this information would also be useful to employers to help them support someone diagnosed with cancer. This information might be provided through digital mediums such as websites, as well as information leaflets and other printed mediums.
- 7.5 Many organisations already provide support to people affected by cancer using these mediums. Macmillan Cancer Support, for example, provides a toolkit of resources on the Working Through Cancer page of its website. This includes information booklets for managers, employees, and carers; a DVD resource for employers; buddying guidelines; and an HR policy template.
- 7.6 For level 1, specific information on supporting people to remain in or return to work could be developed or promoted through existing channels.

Level 2

- 7.7 For those people who need more information and/or support than is provided at level 1, level 2 should provide guidance as to where to go next. This signposting service should put people directly in touch with organisations or services that can provide more specific support. The signposting might be provided via a telephone helpline or through web-based share/support services, for example. This contact is likely to be one-off.

Level 3

- 7.8 At level 3, people can access more specialist vocational rehabilitation support through self management programmes, following or during treatment. Programmes may be designed specifically to focus on vocational rehabilitation, or may be part of a wider cancer self-management programme. These programmes will not necessarily be run by a specialist, and are likely to be based locally. An individual is likely to make contact with this kind of service several times.

Level 4

- 7.9 Some individuals diagnosed with cancer will experience acute symptoms that may prevent them from remaining in or returning to work. Level 4 should provide specialist vocational rehabilitation support services that help to manage these acute symptoms. Services may include, for example, specialist psychological support services, specialist occupational health services, occupational therapy, physiotherapy, and specialist services that support the management of clinical symptoms such as fatigue. Contact at this level will be tailored to meet the acute needs of individuals, and may be with more than one specialist service.
- 7.10 The Project Group believes that services already exist at levels 1 and 2, which could be adapted to provide specific support to people diagnosed with cancer in the context of vocational rehabilitation. It was felt that specific pilots could be established to address levels 3 and 4.
- 7.11 The importance of the navigation role was felt to be valuable in supporting self management, but also to help users to develop confidence in an established service. The Project Group therefore felt that pilots could be encouraged to support models of navigation.
- 7.12 The consultation event and the patient representatives on the Project Group spoke very powerfully about their disheartening experiences as they either tried to remain or return to work by using existing services. The Project Group therefore felt that it was important to establish a set of values which underpinned a service model of vocational rehabilitation. The following values have therefore been suggested:
- Respect
 - Dignity
 - Empathy
 - Compassion
- The Group felt that any proposed pilots would need to demonstrate how they would incorporate these values within their service provision.
- 7.13 The critical role which employers play in supporting people to remain or return to work was a recurring theme in the consultation events and the research literature. It is therefore suggested that any proposed services need to address how support could be given both to the employer as well as the individual diagnosed with cancer.

8. Next Steps

- 8.1 Within this paper the Project Group have proposed a model of vocational rehabilitation together with ways in which these services could be piloted. In order to support the delivery of this proposal the following recommendations were made to the Workstream:
- to agree the model of vocational rehabilitation
 - to develop an implementation plan which may include:
 - a) a review of services at levels 1 and 2 and identification of the work which needs to be undertaken to support the development of a vocational rehabilitation service;
 - b) the issuing of a call for pilots to test the model of vocational rehabilitation with particular focus on levels 3 and 4, and address the need for navigation.
- 8.2 The Work and Finance Workstream agreed the proposed model of vocational rehabilitation at their July 2009 meeting. Since then, it has been decided that as a next step, Macmillan Cancer Support will seek proposals for a project or projects to pilot the model of vocational rehabilitation that can build on or integrate existing services across the four levels of the model.

Terms of reference
Macmillan Vocational Rehabilitation Project Group

1. Overall aims

- Develop, on behalf of the National Cancer Survivorship Initiative (NCSI) working group on work and finance (WFG), a written proposal for models of health-led vocational rehabilitation for people with cancer.
- To provide specialist expertise with regards to vocational rehabilitation to the Work and Finance Group of the National Cancer Survivorship Initiative.

2. Specific Objectives

- To define the principles of and establish models for vocational rehabilitation for people with cancer.
- To develop an implementation plan for the delivery of the project's aims.
- To review progress of the project in relation to the implementation plan.
- To agree communication and decision making processes with the Chair of Work and Finance Group.
- To share local and national information, knowledge and specialist expertise to ensure the development of an informed model.
- To review progress of the project in relation to how the needs of people affected by cancer are being met.
- Identify areas for improvement and development and assist with problem solving.
- To act as ambassadors for vocational rehabilitation encouraging the active participation and engagement of partner organisations to deliver the model.

3. Membership

Membership will consist of:-

Ziv Amir	Macmillan Manchester Research Unit
Sharon Cavanagh	AHP lead
Miranda Claremont	Macmillan Policy Analyst (WFG secretariat)
Nicola Cook*	Senior Macmillan Development Manager
Allan Cowie	Senior Macmillan Development Manager
Jane Fior	Cancer Counselling Trust]
Bec Hawkins	Macmillan Development Manager
Yvonne McKenna	Lead cancer nurse
Alison Morton	User representative
Ed Murphy	Senior Macmillan Development Manager
Jane Rudge	Senior Macmillan Development Manager
Phil Wynn	Occupational Health Practitioner
<i>Representative</i>	<i>Shaw Trust or other similar provider organisation</i>
<i>Representative</i>	<i>MS Society or other similar stakeholder organisation</i>

*Responsible for leading sub-group

4. Frequency of meetings

Meetings will be held on a monthly basis and will last for two hours. Meeting dates, times and venues will be agreed in advance

5. Project Duration

The project will need to be completed by 30th June 2009

6. Venue

The venue for the meetings will be London unless an alternative is agreed in advance.

7. Commitment from members

It is expected that there will be a commitment from group members with regard to the following.

- To actively contribute specialist knowledge and expertise
- To contribute or lead sub groups of the project group
- To attend meetings or send a deputy in their absence
- To notify the organisers of non-attendance in advance of the meeting
- To contribute to the agenda for each meeting.

8. Communications/Reporting mechanisms

Members of the group will receive minutes from the meetings via group e-mail or where requested as hard copies at least one week in advance of the meeting

The project group will report to the Work and Finance Group of the National Cancer Survivorship Initiative as agreed with the Chair of that group.

Date Drafted April 2009
Date Agreed To be determined
Review Date To be determined