

**NATIONAL CANCER SURVIVORSHIP INITIATIVE  
WORK AND FINANCE WORKSTREAM**

**EVALUATION OF THE VOCATIONAL REHABILITATION PROJECT:  
SECOND INTERIM REPORT – JUNE 2011**

**1 EXECUTIVE SUMMARY**

People with cancer can experience significant difficulties with regard to employment. The vocational rehabilitation support available to people with general health conditions (such as musculo-skeletal disorders) is neither accessible to, nor entirely appropriate for, people with a cancer diagnosis. To address this, the National Cancer Survivorship Initiative (NCSI) funded seven pilot services across England, running from April 2010 to July 2011, to test and refine a model of vocational rehabilitation for people with cancer. This is the second evaluation interim report (further background to the project and the pilot sites can be found in the first interim report – Early Findings, September 2010).

The key findings at this stage of the evaluation are as follows:

1. A three level model works better than the initially identified four level model. We propose adaptations to the NCSI Risk Stratification Model to distinguish (i) service providers, (ii) service recipients and (iii) interventions at each of three levels of need and complexity.
2. It is useful to distinguish between ‘work support’ for people with cancer, and ‘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. A subset of people with cancer will have complex needs which are best met by a specialist vocational rehabilitation service where the intervention is provided by skilled vocational rehabilitation professionals.
3. The term ‘vocational rehabilitation’ is not widely understood, and the needs and preferences of the particular audience being addressed should be considered when communicating about cancer work support and vocational rehabilitation.
4. We have identified a specific skill set required by individuals who provide specialist cancer vocational rehabilitation to people with complex employment needs. While there is some overlap with skills needed to deliver vocational rehabilitation in other health conditions, there are important elements that are highly specific to cancer.

5. Individuals providing specialist cancer vocational rehabilitation services are likely to need training to ensure that they have the requisite skills. No cancer-specific vocational rehabilitation training programme currently exists.
6. There is a very 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 and vocational rehabilitation 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.

## **2 INTRODUCTION**

This phase of the evaluation centres on examining and defining the contexts, processes and mechanisms of cancer work support and vocational rehabilitation. Outcomes data continues to be collected, and an interim analysis of this data will be presented in September 2011.

This interim evaluation report examines:

1. The conceptual model of work support and vocational rehabilitation in cancer: the range of work support and vocational rehabilitation needs experienced by people with cancer, and the services needed to respond effectively to these.
2. The significance of definitions and terminology in planning, delivering and communicating effectively about services.
3. The knowledge and skills required to deliver appropriate and acceptable vocational rehabilitation services.
4. The identification of desirable work support and vocational rehabilitation outcomes across a range of stakeholders.

## **3 METHODS**

Data was collected through:

1. In-depth interviews with the NSCI pilot site workers delivering hands-on vocational rehabilitation to people with cancer.
2. Consensus development using a modified Nominal Group Technique.

### **3.1 Interviews**

Six in-depth interviews were carried out (one at each of the pilot sites delivering vocational rehabilitation services to clients) between November 2010 and February 2011. Interviews lasted between 1 and 2½ hours and all were audio-recorded and transcribed verbatim to

ensure accuracy in analysis. All of the vocational rehabilitation specialists working with clients were interviewed – 11 people in total. At sites where there was more than one specialist, a group interview was carried out. See the Appendix for further information.

### **3.2 Consensus development**

A modified Nominal Group Technique<sup>1</sup> was used to explore definitions of vocational rehabilitation and to identify the knowledge and skills required by cancer vocational rehabilitation specialists. Two one-day consensus development workshops were held. Participants in the first workshop ( $n = 16$ ) were predominantly the vocational rehabilitation specialists from the seven pilot sites. The second workshop (five weeks later), included the same group of specialists as well as service development managers, service users, vocational rehabilitation experts, and representatives from Macmillan Cancer Support and the Department of Health ( $n = 25$ ). Draft consultation documents were circulated after both events for comment and clarification. See the Appendix for details.

## **4 A CONCEPTUAL MODEL OF WORK SUPPORT AND VOCATIONAL REHABILITATION FOR PEOPLE WITH CANCER**

In the development phase of the NCSI Vocational Rehabilitation Project, a four level model was proposed as a basis for setting up services (Figure I). While this model was a helpful starting point, one of the objectives of the evaluation was to test and refine the model further. Feedback from the pilot sites indicates that a three level model is clearer, less ambiguous, and better able to describe the (i) recipients of services, (ii) service providers and (iii) interventions across the range of problems that people with cancer encounter with regard to employment (Figure II and Table I). This three level model is an adaptation of the NCSI Needs Stratification Model,<sup>2</sup> which nicely defines three distinct levels, and shows the interface between self management and professional care.

### **4.1 The distinction between ‘work support’ and ‘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 employment. This ‘work support’ is delivered across the model at levels 1, and 2 and comprises any activity concerned with meeting the needs of people with cancer with regard to work. A subset of people (at level 3) will have complex needs which are best met by a specialist vocational rehabilitation service where the intervention is provided by skilled vocational rehabilitation professionals.

In other words, everyone with cancer for whom employment is relevant should receive work support. However there is a smaller group of people with complex problems who will benefit from specialist vocational rehabilitation. This distinction is discussed in more detail in Section 5.

Figure I: The original four-level Model of Vocational Rehabilitation used during the early stages of developing and setting up the vocational rehabilitation pilot sites

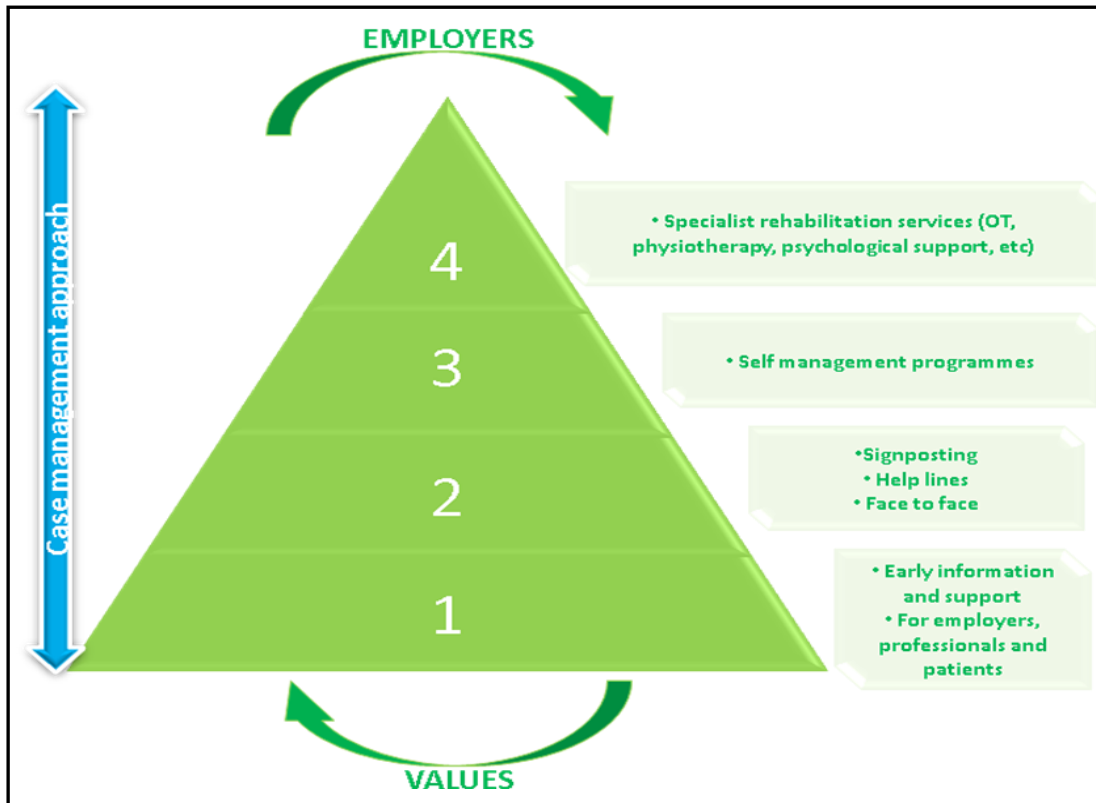


Figure II: The NCSI Risk Stratification Model, showing the proposed adaptation for a Model of Cancer Work Support and Vocational Rehabilitation

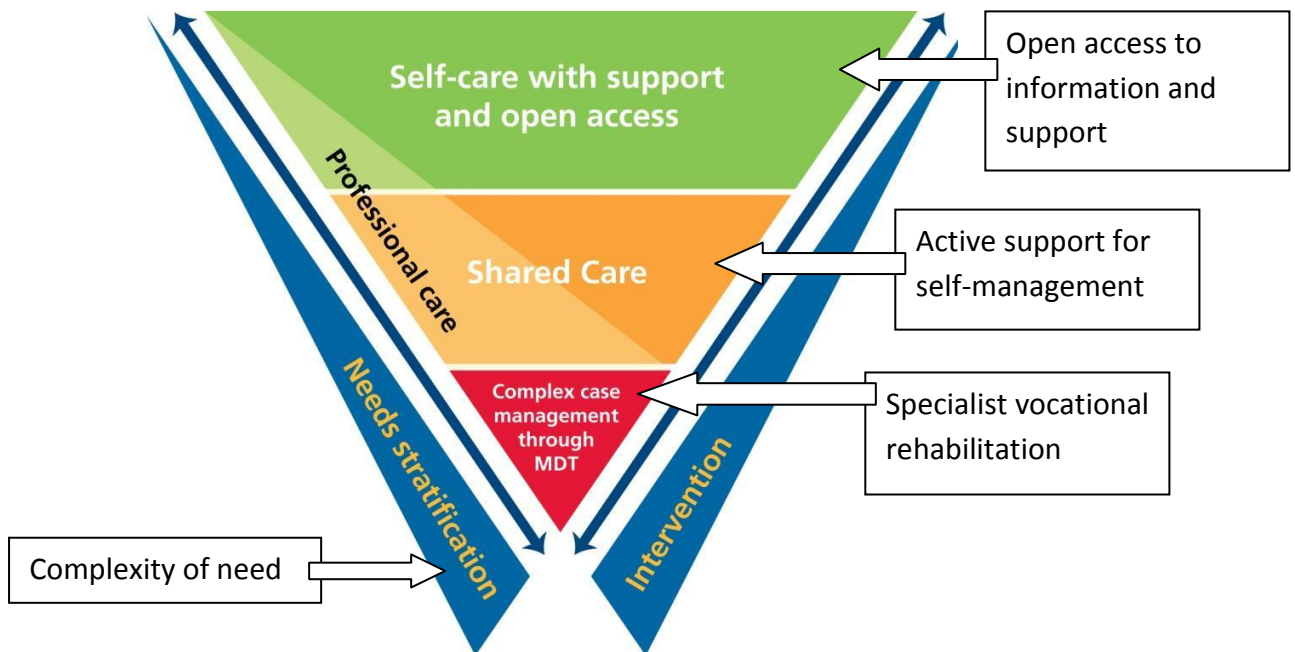


Table I: The recipients of services, service providers and interventions associated with the three levels of cancer work support and vocational rehabilitation.

	<b>Recipients</b>	<b>Service providers</b>	<b>Interventions</b>
<b>Level 1: Open access to information and support</b>	Everyone with a cancer diagnosis who is employed or who has the potential to be employed.	All healthcare professionals with whom the person with cancer comes into contact eg Clinical Nurse Specialists (CNSs), GPs, oncologists	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Signposting and information about (i) the impact of a cancer diagnosis on work, (ii) self management support programmes or other types of available support, and (iii) how to get in touch with other professionals if they have any concerns.</li> </ul>
<b>Level 2: Active support for self-management</b>	People who have specific questions, concerns or worries, who, with the right information and support, will be able to resolve these issues themselves (i.e., who are able to self-manage).	Allied Health Care (AHP) professionals and other professional groups with some specialist knowledge of the impact of cancer on work, e.g. Cancer information centre staff. Macmillan National Helpline, Welfare and benefits advisers, vocational rehabilitation specialists, Disability Employment Advisers. Jobcentre Plus staff,	<ul style="list-style-type: none"> <li>• Provision of specialised, tailored information, advice or support which service users are able to take forward and implement themselves.</li> <li>• Signposting to other specialist services and organisations.</li> <li>• Service users have face-to-face, phone or e-mail contact with professionals. Contact is typically of short duration.</li> </ul>
<b>Level 3: Specialist vocational rehabilitation</b>	People who have complex problems that require specialist help from qualified professionals.	Vocational rehabilitation specialists (with the knowledge and skills set out in the competency framework).	<p>Specialist vocational rehabilitation interventions, including (but not limited to):</p> <ul style="list-style-type: none"> <li>• Detailed assessment of the person and their work situation.</li> <li>• Ergonomic assessment.</li> <li>• Information and advice on legal rights and responsibilities.</li> <li>• Liaison with employers.</li> <li>• Modifications to the work environment.</li> <li>• Teaching strategies for managing fatigue, mobility problems, and cognitive problems.</li> </ul>

## 4.2 Positive messages

Giving people with cancer positive messages about work is a crucial aspect of work support. Positive messages are not the same thing as screening questions (such as, “Is your diagnosis likely to cause you any work-related problems?”) and information-giving (for example, “The Equality Act applies to people with cancer.”). Rather, a positive attitude to employment should be embedded in health professionals’ verbal and non-verbal interactions with patients. They should communicate the importance of work, while at the same time recognising that patients have competing priorities, for example, dealing with the physical and psychological impact of the diagnosis and treatment.

A balance needs to be struck between enabling adequate time and space for rest and recovery, and keeping work on the agenda in way that is encouraging and constructive. We know from other conditions, for example, that early contact with employers promotes successful return to work, and that health care professionals have a crucial role in facilitating this.<sup>3,4,5</sup> Interviews with the pilot sites’ vocational rehabilitation specialists suggests that this kind of support is not routinely provided to cancer patients.

We need to look at the messages that patients are getting. Their doctor is saying to them, “Just enjoy your time at home.” I was explaining to a lung CNS recently that she could refer patients to me and she said, “Oh no, my patients are still having treatment, it wouldn’t be suitable to talk about work.” So by the time some of the patients come to us, everything’s mounting up, they’re at risk of losing their job, and part of that is because they’ve been told, “Don’t worry about that now.”

– Vocational Rehabilitation Specialist, Pilot Site 3

Health professionals need to be trained to think differently. Patients are almost led into a sick role. One person I’m seeing has been off for about a year now. She finished all her treatment three months ago and she’s doing well but she’s still being told that they don’t feel that she’s ready to go back to work. Well why not? The trouble is the CNS sees it as all-or-nothing. They don’t know about phased returns and the support that can be offered.

– Vocational Rehabilitation Specialist, Pilot Site 6

## 5 TERMINOLOGY AND DEFINITIONS

### 5.1 Finding the most useful labels

The term vocational rehabilitation is not well understood, and is not widely used by employers or by the general public.<sup>6</sup> In setting up and promoting their services, the NCSI pilot sites encountered difficulties in finding the right language, commenting that vocational rehabilitation “means different things to different people”, is “easy to misinterpret”, and “sounds clinical and off-putting to clients”. However, the term does have advantages, particularly in health and social services contexts, where rehabilitation services are accepted, broadly understood and provided with funding.

The pilot site service providers found that a distinction needed to be made between specialist interventions for people with complex problems (vocational rehabilitation), and support for the more ordinary, fairly straightforward issues that people had (work support) eg. in understanding their rights and negotiating a phased return to work.

Several pilot sites introduced their service as ‘Macmillan Work Support’, finding the Macmillan badge to be a useful way of establishing early credibility, and that ‘Work Support’ was acceptable and comprehensible to both people with cancer and to health care professionals. The service providers noted that it was crucial to recognise the needs and preferences of the particular audience being addressed when communicating about cancer work support and vocational rehabilitation, tailoring the message to that audience using whatever terminology was likely to work best, rather than sticking rigidly to the label ‘vocational rehabilitation’.

## 5.2 Defining work support and vocational rehabilitation

Five commonly used definitions of vocational rehabilitation<sup>6,7</sup> were adapted to be specific to cancer, and formally reviewed during the first consensus development workshop. The aim was to develop a working definition of cancer work support and vocational rehabilitation. Workshop participants were asked to rate five definitions, and to suggest how the definitions might be improved.

Table II: Preferences for definitions of cancer work support and vocational rehabilitation

		<i>n</i> = 15		
		Like most	Neutral	Like least
1.	Whatever it takes to get people with cancer back into work.	1 (6%)	4 (27%)	10 (67%)
2.	A process whereby those disadvantaged by cancer – either by the illness, its treatment or ongoing disability – can be enabled to access, maintain, or return to employment or other useful occupation.	10 (67%)	3 (20%)	2 (13%)
3.	An approach whereby those who have cancer are helped to access, maintain or return to employment.	7 (47%)	0	8 (53%)
4.	A combination of the active approaches and interventions that are centred on individuals who encounter cancer related barriers to work, that enables them to fulfil their potential by achieving better work related outcomes.	7 (47%)	3 (20%)	5 (33%)
5.	A process of interventions whereby people with cancer can build up individual capacity to enable them to be the best they can be.	5 (33%)	5 (33%)	5 (33%)

The second definition attracted the most support, and was further revised to read as follows:

‘Cancer work support and vocational rehabilitation are services that enable people with cancer to access, maintain, or return to work or alternative meaningful occupation.’

## **6 A PROPOSED COMPETENCY FRAMEWORK FOR CANCER VOCATIONAL REHABILITATION**

The vocational rehabilitation interventions provided across the NCSI pilot sites at Level 3 (See Table I) are delivered by people with a wide range of professional backgrounds: physiotherapy, life coaching, occupational therapy, social work, nursing, psychology, and employment consultancy. A modified Nominal Group Technique (see Appendix) was used to identify and agree on the specific skill set required by individuals who provide specialist cancer vocational rehabilitation to people with complex employment needs. While there is some overlap with skills needed to deliver vocational rehabilitation in other health conditions, there are important elements that are highly specific to cancer.

No single discipline would encompass all of these competencies. Individuals providing specialist cancer vocational rehabilitation services are likely to need training to ensure that they have the requisite skills. No cancer-specific vocational rehabilitation training programme currently exists.

The following competency framework is proposed for consideration and feedback.

### ***Work and employment***

1. Ability to undertake a thorough, comprehensive work assessment including client’s work history, skills and attitudes; job requirements; task analysis; work environment (ergonomics, geography, relationships and culture); and workplace support.
2. Ability to encourage a positive attitude to work and to help clients to build confidence in their work skills.
3. Knowledge of work and employment issues, such as the implications of cancer for people who are self-employed, and the local economy and job market.
4. An ability to provide advice and guidance on careers, qualifications and skills, transferable skills, and on decisions about changing employment or re-training.
5. Knowledge of employment legislation, policies, processes and practices, including the Equality Act 2010, the Fit Note, the benefits system, and work support schemes available.

### ***Cancer***

6. Knowledge of cancer pathology and cancer treatment procedures so that: (1) the medical language is sufficiently familiar to service providers, and (2) the clients’ experience of illness and recovery is understood in general terms. Understanding of the implications of different cancer diagnoses with regard to likely treatment regimes and prognosis.

7. Understanding of common symptoms and the ways in which these affect employment, work and work performance, in particular: fatigue, muscle weakness, anxiety, depression and cognitive difficulties. Ability to work with clients, their families and employers to manage these effectively.
8. Understanding of the psychological and emotional consequences of a diagnosis of cancer, and the coping strategies patients use. Ability to support patients to adjust to living well with cancer.

#### ***Cancer vocational rehabilitation***

9. Knowledge and understanding of the process of cancer vocational rehabilitation.
10. Ability to pace interventions in a way that is both sensitive to the clients' needs and provides an effective and efficient service.
11. Ability to use problem-solving and goal-setting strategies with clients.

#### ***Communication skills***

12. Ability to listen carefully and non-judgementally. Willingness to hear and understand clients' agenda. Ability to respond with empathy.
13. Ability to communicate effectively, confidently and knowledgeably with a wide range of people, for example: clients, their families, health professionals and employers.
14. Advocacy and negotiation skills.

#### ***Education***

15. Ability to identify learning / training needs, and to plan and deliver education on work and employment, both formally and informally, to health care professionals and to employers.

#### ***Networking***

16. An ability to establish a wide network of other specialists and agencies to whom clients can be referred when necessary, for example trade union representatives and solicitors specialising in employment law.
17. Knowledge of, and contact with, locally available cancer support services.

#### ***Service development***

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

#### ***Self awareness***

19. Insight and awareness of the personal impact of working with people with life-threatening illness, and the ability to seek and use support systems effectively.
20. An awareness of the limits to one's own expertise.

#### ***Personal characteristics and attitudes***

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

## **7 RANGE OF STAKEHOLDERS AND OUTCOMES OF INTEREST**

There is a very 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.

### **7.1 Funding bodies, commissioners and policy-makers**

These include Government departments (the Department of Health and the Department of Work and Pensions), the third sector (Macmillan Cancer Support and the Shaw Trust) and employers' organisations. Their interest is in maximizing the health and well-being of the workforce, encouraging people with cancer to remain in or return to work, ensuring that those who wish to work are able to do so, and reducing the cost of unemployment to the state.

### **7.2 Employers**

Employers are interested in maintaining a skilful and productive workforce, and reducing sickness absence. Some employers (more often the larger companies and organisations) are keen to understand the general principles of supporting employees affected by cancer; others prefer to manage on a need-to-know basis, seeking information when they have an individual employee with cancer.

### **7.3 People with cancer and their carers**

Interviews with people with cancer are set up for the next phase of the evaluation, which will enable us more clearly to establish patients' priorities. Data collected for the first interim evaluation report in September 2010 suggested that patients' preferences are variable, ranging from those who want to attend to work issues early in their diagnosis, perhaps being supported to remain in work through treatment, to those who wish to take time out and re-evaluate their employment options for the future.

### **7.4 Providers of vocational rehabilitation services**

These include service managers, practitioners, and support staff. The interest of service providers is at the level of individual clients rather than at a population level. While the benefits of work are recognised and endorsed, service providers are mindful that returning to or remaining in employment may not be ideal for all clients, and see facilitating engagement in any meaningful occupation as a valuable and legitimate service objective.

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## **APPENDIX: DATA COLLECTION – INTERVIEWS AND CONSENSUS DEVELOPMENT**

### **Interviews with service providers**

1. The Shaw Trust with the Christie Hospital, Manchester: Richard Hunt (22<sup>nd</sup> November 2010).
2. Doncaster Community Healthcare, Doncaster: Julie Saarik, Judith Hartley, Nicola Edwards, Jo O'Marr (26<sup>th</sup> January 2011).
3. NHS Blackburn with Darwen, Lancashire: Pam Kay and Yasmin Patel (27<sup>th</sup> January 2011).
4. NHS South of Tyne and Wear, Gateshead: Lisa Ryan and Susan Thomas-Jones (8<sup>th</sup> February 2011).
5. Orbitals and the Olive Tree Cancer Support Centre, Crawley and the Gatwick Diamond: Mark Stevens (14<sup>th</sup> February 2011).
6. National Hospital for Neurology and Neurosurgery, London: Nicole Walmsley (24<sup>th</sup> February 2011).

### **Consensus development workshops**

The Nominal Group Technique enables a group to identify specific topics or issues (or, in this case, VR knowledge and skills), and then rank or prioritise them. It has five stages:

1. Generating ideas – for five to ten minutes delegates individually write down ideas based on the question/s posed.
2. "Round Robin" stage – each delegate reads out one of their ideas with their best one first and these are jotted down onto a larger piece of paper, blackboard or flipchart.
3. Clarification – each idea is discussed more widely and clarified; duplicate ideas are brought together and the individual ideas are numbered.
4. Voting – from the ideas which are numbered the delegates prioritise them based on an agreed voting system.
5. Actions and follow-up – if appropriate – the group discuss their plan of action and, based on the outcome of the vote, with the intent of reaching agreement on how they will deal with the original question.

*First workshop: Mary Ward House, London on 7<sup>th</sup> March 2011, 10:30am – 3:30pm.*

Vocational rehabilitation practitioners:

Mark Stevens – Olive Tree / Orbitals  
Richard Hunt – Christie  
Julie Saarik – St John's, Doncaster  
Judith Hartley – St John's, Doncaster

Nicola Edwards – St John’s, Doncaster  
Nicole Walmsley – NHNN, London  
Sarah Rusbridge  
Pam Kay – Blackburn with Darwen  
Yasmin Patel – Blackburn with Darwen

Other pilot project staff:

Paulina Slater – Olive Tree / Orbitals  
Anne Sabine – Olive Tree / Orbitals  
Anil Garcia – Mount Vernon Cancer Network  
Gary Johnston – Shaw Trust

Macmillan:

Lyn Bruce, NCSI Vocational Rehabilitation Project Manager  
Maartje de Laat, NCSI Work and Finance Project Coordinator

VR and research specialists:

John Paley, Cancer Care Research Unit, University of Stirling

Facilitator:

Gail Eva

*Second workshop: Mary Ward House, London on 5<sup>th</sup> April 2011, 10:30am – 3:30pm.*

Vocational rehabilitation practitioners:

Richard Hunt – Christie  
Julie Saarik – St John’s, Doncaster  
Judith Hartley – St John’s, Doncaster  
Nicola Edwards – St John’s, Doncaster  
Sarah Rusbridge – NHNN, London  
Stephen Wallwork - Christie

Other pilot project staff:

Paulina Slater – Olive Tree / Orbitals  
Anne Sabine – Olive Tree / Orbitals  
Anil Garcia – Mount Vernon Cancer Network  
Gary Johnston – Shaw Trust  
Pip Wilford – NHNN, London

Service user representative:

Alero Dabor

Macmillan:

Lyn Bruce – NCSI Vocational Rehabilitation Project Manager  
Maartje de Laat – NCSI Work and Finance Project Coordinator

Katharine McDonald – Policy Analyst

Maureen Dowling – National Cancer Survivorship Initiative Work & Finance Project  
Sponsor, AHP Lead

Linda Nixon – Macmillan Development Manager

Deepa Doshi – Macmillan Development Manager

Jez Such – Macmillan Development Manager

Julie Atkins – Macmillan Development Manager

Tom Noel – Macmillan Development Manager

Paul Foggitt – Macmillan Development Manager

Kristina Parkinson – Macmillan Development Manager

Steering group members:

Sue Davies – Lancashire Care Foundation Trust

Graeme Henderson – VR Steering group member

Facilitator:

Gail Eva