

**NATIONAL CANCER SURVIVORSHIP INITIATIVE
WORK AND FINANCE WORKSTREAM
EVALUATION OF THE VOCATIONAL REHABILITATION PILOT PROJECTS:
INTERIM REPORT – NOVEMBER 2011**

1 EXECUTIVE SUMMARY

This is the third interim report of the evaluation of the NCSI Vocational Rehabilitation Pilot Projects. It builds on and develops the findings presented in the reports of September 2010 and June 2011, both of which are available on the NCSI website.¹ The final report will be available in March 2012.

The key findings of this phase of the evaluation are as follows:

1. In order to provide effective services, it is necessary to take account of the needs, roles and responsibilities of three intersecting groups:

- People affected by cancer.
- Health care professionals.
- Employers.

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

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

We present a model for the delivery of work support services and vocational rehabilitation for people with cancer (Figure 1, page 5).

2. Support for people affected by cancer should be available at three levels (Figure 2, page 6):

- 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. Support for employers is required at an organisational level, and also for individual employees.
 - Information, resources, education and training on managing employees with cancer in the workplace should be available to organisations.
 - Individual employees may need support from cancer vocational rehabilitation specialists to facilitate a successful return to work.
4. Health professionals who support patients through their diagnosis and treatment need a clear understanding of the extent (and limitations) of their role in responding to patients' employment needs, and knowledge of the back-up and support services available.
5. There is significant regional variation in services available to provide employment support for people with cancer. A local scoping or mapping exercise undertaken prior to (or in the initial stages of) setting up cancer work support services would identify gaps and help to ensure the integration of existing resources to minimise duplication.
6. Factors which contribute to successful service delivery of work support services for people with cancer include: (i) local service integration and networking; (ii) careful consideration of the geographical location of the service; and (iii) ensuring effective strategies for publicising the service and generating referrals.
7. There are number of processes that need to be taken into account when scoping, planning and delivering services. Understanding these often quite subtle mechanisms is crucial in ensuring that people get the right help at the right time. They include: (i) the challenges of early intervention; (ii) understanding patients' short term needs against longer term consequences; (iii) asking the right questions; (iv) supporting interaction between people with cancer and their line managers; (v) providing proactive employment support; and (vi) the challenges of predicting fitness for return to work.
8. This phase of the evaluation has highlighted three areas that merit further investigation and development.
 - Development of a template against which existing services and resources could be mapped prior to – or in the early stages of – setting up cancer work support services.
 - Development of a structured guideline, or the identification of criteria that would contribute to decisions about fitness for return to work following (or during) treatment.
 - Identification of the knowledge, skills and attitudes required by front-line staff to support patients' employment needs from diagnosis onwards.

Work in all of these areas is in progress within projects currently being undertaken by the NCSI Work and Finance team.

2 INTRODUCTION

This report builds on and develops the interim findings presented in the NCSI Vocational Rehabilitation Pilot Projects evaluation reports of September 2010 and April 2011 – both of which are available on the NCSI website.¹

Data collection and analysis for the evaluation is in progress. Findings presented in this report are provisional. Baseline data collection was completed in June 2011 (the end of the pilot project funding period). The six month follow-up data collection will be completed at the end of December, and the health economic analysis is scheduled for January 2012. Data incorporated into this interim report includes:

- Final project reports received from each of the seven pilot sites.
- Monthly data received from the pilot sites on service user demographics, work status at referral and discharge and duration of intervention.
- In-depth interviews and focus groups carried out with the vocational rehabilitation service providers at each of the pilot sites.
- Focus groups with staff instrumental in delivering and developing the service at the four sites that received extension funding.
- Expert consensus development (modified Nominal Group Technique) on models of cancer work support and vocational rehabilitation, components of interventions and skills required for delivery of specialist cancer vocational rehabilitation.

The report is presented in two parts. Part one (sections 3 – 5) describes a model of cancer work support services and the infrastructure that is required to deliver these. Part Two (section 6) examines some of the processes that facilitate people with cancer being able to access and make the best use of available services. Understanding these often quite subtle mechanisms is crucial in ensuring that people get the right help at the right time.

3 A MODEL OF CANCER WORK SUPPORT AND VOCATIONAL REHABILITATION

The following four principles should underpin the planning and delivery of cancer work support services: ²

1. Support to enable people with cancer to remain in and return to work needs to be systematic and proactive.
2. There should be active support for self management: people with cancer should be provided with information and resources to take responsibility for their employment needs.
3. Service development should take a population-based approach, identifying those with the greatest need and ensuring that support is available to them at the right times.
4. Service integration is crucial to avoid duplication and waste of resources. Cancer work support services should be integrated with cancer treatment services as well as with the work support and vocational rehabilitation services available for people with other health conditions.

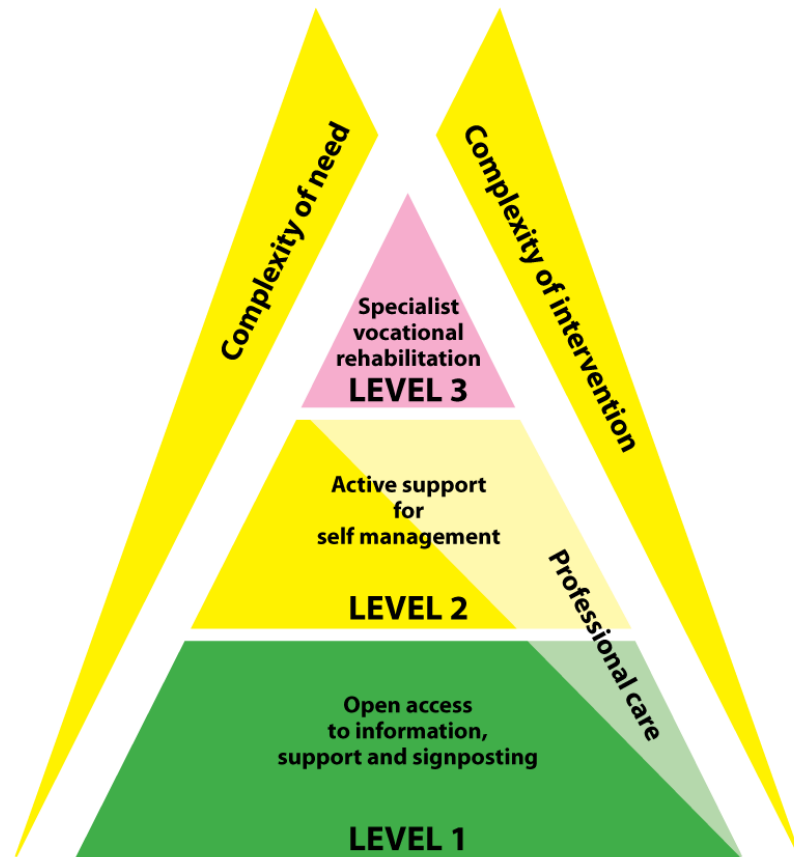
We present a model for the delivery of work support services and vocational rehabilitation for people with cancer (see Figure 1). In order to provide effective services, it is necessary to take account of the needs, roles and responsibilities of three intersecting groups:

- People affected by cancer.
- Health care professionals.
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Across these groups, two distinct strands of support are required:

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

Figure 2: Three level model of work support and vocational rehabilitation for people with cancer



	Recipients	Service providers	Interventions
Level 3: Specialist vocational rehabilitation	People who have complex problems that require specialist help from qualified professionals.	Vocational rehabilitation specialists with appropriate knowledge and skills.	Specialist vocational rehabilitation interventions, including (but not limited to): <ul style="list-style-type: none"> ● Detailed assessment of the person and their work situation. ● Ergonomic assessment and modifications to the work environment. ● Information and advice on legal rights and responsibilities. ● Liaison with employers. ● Teaching strategies for managing specific symptoms, for example fatigue, mobility problems, and cognitive problems.
Level 2: Active support for self-management	People who have concerns, who, with the right support, will be able to self-manage.	Health professionals 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"> ● Provision of specialised, tailored information, advice or support which service users are able to take forward and implement themselves. ● Signposting to other specialist services and organisations. ● Service users have face-to-face, phone or e-mail contact with professionals. Contact is typically of short duration.
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 healthcare professionals with whom the person with cancer comes into contact.	<ul style="list-style-type: none"> ● Positive messages about work. ● Information, for example on the impact of cancer on work, and on employees' rights and responsibilities. ● Signposting to other services.

3.1 Support for people affected by cancer

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 (see Figure 2). This support is required at three levels:

3.1.1 Level one: Open access to information, support and signposting

All patients should be asked about work, receive information and advice, and be signposted on to other support services where necessary. Health professionals should encourage a positive orientation to work.

3.1.2 Level two: Active support for self management

People who have specific questions, concerns or worries should be provided with more specialist support and resources. Most people at this level will be able to manage problems themselves, given accurate and appropriate information and advice.

3.1.3 Level three: Specialist vocational rehabilitation

A subset of people will have complex needs which are best met by a specialist vocational rehabilitation service where the intervention is provided by skilled vocational rehabilitation professionals with appropriate training.³

3.2 Support for employers

Employer support is required at two levels: organisational, and individual.

3.2.1 Organisational level

At an organisational level, information, resources, education and training should be available to employers to enable them to understand the general principles of providing pro-active, appropriate and effective support to employees affected by cancer.

3.2.2 Individual level

Support at an individual level is likely to be provided by cancer vocational rehabilitation specialists working with employees affected by cancer where concerns relating to returning to or remaining in work have been identified. Examples from the pilot projects of the types of individualised support provided to employers include:

- Supporting both employees and line-managers in negotiating a phased return to work.
- Discussing the feasibility and implementation of workplace adjustments to enable the employee to meet the requirements of the job.
- Providing information to employers on cancer pathology and treatment (taking due account of confidentiality).
- With the permission of the person affected by cancer, providing the employer with the results of assessments of work capacity.

3.3 The role of health professionals in supporting employment

It is important that front-line health care staff are aware of the importance of work and convey this to patients. Questions about work should be incorporated into the assessment process, and staff should know how to signpost patients who have concerns or queries to appropriate support services.

However, it is not feasible, practical or reasonable for front-line staff to have anything other than a supporting role. They do not have the time or expertise to provide more than the basics of encouragement and advice. Patients who have problems are likely to need the help of staff with specific knowledge and skills, ranging from support for self-management to specialist vocational rehabilitation (as set out in Figures 1 and 2). Also, patients report that they value the consultation time they are allocated, and are well aware that their doctors and nurses are busy. Their concerns about their illness, prognosis and treatment tend to be priorities for these consultations.

This is not to diminish the significance of the support role that oncologists, GPs and specialist nurses have with regard to patients' employment. Research in other long-term health conditions emphasises the need to pay attention to work issues early on in the patients' pathway. Timely contact with employers is advised in order to facilitate patients' return to work following sick leave.³ The health professionals with whom patients come into contact at diagnosis, and in the period when decisions are made about the likely course and duration of treatment, have a vital contribution to make in putting work on the agenda in a positive way. In this regard, the attitudes of health professionals towards work are important. Patients listen (often without being aware of it) to the cues that their doctors and nurses provide; the topics that are raised set an agenda and alert patients to issues that require attention.

Health professionals, in turn, need to attend to the cues that patients provide regarding a possible need for work support. A patient might not say, for example, "I am worried about work," but rather, "Money is a bit tight," which could indicate employment concerns. This is an area that is widely acknowledged – by staff and patients alike – to be in need of improvement.^{4,5} Health professionals do not have sufficient incentive to listen out for cues about work: they feel ill-equipped to respond to problems, and are reluctant to raise issues they feel unable to help with.⁶

4 SETTING UP CANCER WORK SUPPORT SERVICES: MAPPING EXISTING RESOURCES

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

There are also discrepancies in resources within individual localities, as one of the service providers described:

I have found there is variability in what's available from Cancer Information Centres in this area. I can think of one Information Centre manager who's brilliant, and another who is more of an administrator. You can't assume that because there's a Cancer Information Centre, a particular level of advice will be available.

T (pilot project staff – pilot 1)

This variability needs to be taken into account when planning services. The model presented in Fig. 1 shows the components and overall structure of the cancer work support services required across a given region, but the way in which services are configured and delivered will depend on locally available resources and identified gaps.

For this reason, it is recommended that a scoping or mapping exercise is undertaken either prior to, or in the initial stages of setting up cancer work support services. Mapping existing services against a template of an ideal service configuration would identify gaps and facilitate service development in a way that integrated existing resources and minimised duplication.

5 FACTORS WHICH CONTRIBUTE TO SUCCESSFUL SERVICE DELIVERY: LESSONS LEARNED FROM THE PILOT PROJECTS

5.1 Networking, integration and geographical location

Local service integration and networking are essential elements in the delivery of successful cancer work support and vocational rehabilitation services. All of the pilots emphasised the importance and value of finding and making contact with organisations and individuals that might wish to refer patients or clients, and also those which could provide supplementary services.

The geographical location of the pilot service is an important consideration. The pilot based at the Christie Hospital was co-located with the hospital's cancer information centre, and this facilitated networking with other staff and the provision of a drop-in service for patients. The staff at the pilot based in South of Tyne and Wear felt at a disadvantage being on a business park situated some distance away from the cancer services; specifically they felt that they missed the opportunity to take advantage of informal relationships and the 'chats in passing in the corridor' that were possible when working in close proximity to cancer service colleagues.

However, although geography is a factor, it is not a substitute for pro-active, energetic, enthusiastic marketing of the work support service offered, with perseverance in the face of any apparent indifference.

Raising the profile of the work support services so that there is good local awareness of the resources available can help to relieve the stress that patients experience in having to search for help on their own:

There were so many issues, like how I was going to manage financially. The practical things worried me most: I was in debt and I had family problems and I couldn't find information so eventually I went to the citizens advice bureau who tried their best. If there was a benefits advice service at the hospital where I was treated, I wasn't aware of it. I went on-line and googled 'cancer help' and found [a cancer information centre], and rang them. They put me in touch with the Macmillan service.

Celia (service user – nurse)

5.2 Publicising the service and generating referrals

The majority of the pilots found that the enormous effort they put in to publicising their services did not quickly translate into the numbers of referrals they had anticipated. It is likely that this is at least partly accounted for by the fact that the services were starting from scratch, and it takes time for any new initiative to build up momentum. However, there are some useful learning points.

5.2.1 Engaging doctors

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

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

D (pilot project staff – pilot 2)

5.2.2 Engaging nurses

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

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

T (pilot project staff – pilot 1)

5.2.3 Contact with benefits advice services

Patients do not routinely raise work problems with their doctors and nurses. From patient feedback, the pilot project staff identified that the agencies that patients most commonly turned to for help were cancer information centres, benefits advisors and citizens' advice bureau. Developing good working relationships with these organisations proved beneficial and facilitated referrals.

5.3 The Shaw Trust/Christie model

Using the uptake of the service as a measure, it is evident that the Shaw Trust / Christie Hospital pilot project was particularly successful in publicising their service and gaining referrals (see Table 2).

Table 2: Numbers of referrals at Levels 2 and 3 for each pilot project

	Orbitals / Olive Tree – Crawley	South of Tyne and Wear	Blackburn with Darwen	Shaw Trust / Christie Hospital - Manchester	NHNN – London	St John's Information Centre – Doncaster
Numbers of referrals	44	37*	92*	252	82	34

The pilot projects at South of Tyne and Wear and Blackburn with Darwen ran for 12 months. The other four projects ran for 16 months.

There are a number of possible factors which, in combination, might contribute to the Shaw Trust / Christie Hospital's higher referral numbers:

- The staff employed to deliver the service had extensive experience in vocational rehabilitation in other conditions.
- Establishing local networks and contacts was a priority.
- The service was energetically and enthusiastically marketed and any contacts made were followed up.
- A pro-active approach to contacting patients was taken – where a work support need was identified, project staff would initiate contact with the patient to let them know about the service and offer appropriate advice and support.
- Project staff quickly realised that cancer information centres and benefits advice services were picking up patients' work problems and developed close, collaborative working relationships with colleagues in these centres.
- The project was co-located with the cancer information centre at the Christie Hospital.
- There was very strong organisational support for the project, both within the Christie Hospital and the Shaw Trust, up to senior levels of management.
- A business model was applied to achieving project outcomes. Targets were very clearly set and regularly monitored.

PART 2

6 PROCESSES THAT FACILITATE OR HINDER THE PROVISION OF WORK SUPPORT

Service infrastructure, adequate resources and the requisite level of knowledge and skill – as detailed in Part 1 – are essential in providing effective work support services to people affected by cancer, their carers, and employers. However, the interviews with service users and service providers point to a number of processes that need to be taken into account when scoping, planning and delivering services. Understanding these often quite subtle mechanisms is crucial in ensuring that people get the right help at the right time.

6.1 The challenge of early intervention

It is widely accepted that employment should be on health professionals' and patients' agenda from an early point in the treatment pathway. In practice, this can be difficult to achieve. Recognising some of the barriers can help to overcome them.

In the early stages of illness, patients' concerns about the implications of diagnosis and treatment, and their – often unspoken – existential fears can be overwhelming.

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

Barbara (service user – administrator)

There is a perceived tension here. On one hand work is important, and has clearly established health benefits. We know that early attention to work facilitates successful reintegration into the workplace post-treatment. On the other hand, a diagnosis of cancer is traumatic and patients describe the need for a time of reflection on priorities and meaning in life, and to focus their energies on healing as well as on the people closest to them. Health professionals find themselves juggling what can seem like inconsistent messages: emphasising the value of activity and a sense of normality, while at the same time dissuading patients from 'overdoing things' and putting their health at risk.

Here is an example of this, observed during a visit to a support group for newly diagnosed cancer patients.

During a support group, patients discussed work issues. Together with the two nurses facilitating the group, they agreed about the importance of work in feeling normal, having a routine, giving structure to

the day, gaining a sense of control over one's life. One patient described how her diagnosis had impacted on a course she was undertaking. "I was having chemo when everyone else was sitting their exams early in the summer, but the uni was very supportive and I've been keeping up with studying and I was able to take my exams with the others doing resits last week." The nurse beside her looked immediately concerned, and said, "Naughty! You need to look after yourself!"

Support group (observational data – pilot 4)

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

6.2 Short term needs vs longer term consequences

At diagnosis and on through the course of their disease, patients' priorities tend to centre on the physical, emotional and logistical demands of illness and treatment. Work might be important, but it is not urgent. It is something that patients are quick to 'put on hold for the time being,' and if health professionals perceive work as a worry or a burden, they feel they are being supportive by encouraging patients to do just that.

I was a workaholic before cancer, but while I was ill, I didn't want to know about work.

Celia (service user – nurse)

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

Celia: If somebody had brought up work at the stage of telling me my diagnosis, it would have been one thing too many. There were huge things to be taking on board and I just didn't have the capacity to take anything else in. And for someone to start talking about work, it would have felt totally insensitive. But then when I got to the point of going back to work, I struggled. I recognise that now.

Interviewer: There is some research in other conditions which suggests that people should make early contact with their employers, and not to put work to one side until six months down the line, and then, when they think about going back, they feel overwhelmed, lacking in confidence, feeling deskilled...

Celia: I have to say I recognise all those things.

Interviewer: So it seems like it's a bit tricky? You had some problems when the time came to go back to work with feeling anxious and unconfident, but you're also saying: I really needed to just shelve it at the beginning, and I didn't want to know about work while I was having treatment.

Celia: And that's the truth as well. If I had been asked about work early on, I think I probably would have told a lie, not an intentional lie, but I would probably have said, "I'm keen to get back to work eventually" ... and I might have thought that was true, because I am deeply committed to my work, but at that stage I had no way of knowing how things were going to turn out and how the chemo would affect me.

Celia (service user – nurse)

Staff need to understand the consequences of not paying attention to work issues in the short term, so that they are able to help patients to anticipate and prevent problems.

6.3 Asking the right questions

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

Patients should be encouraged to ask questions about work, and prompts to do so should come from a variety of sources – the staff with whom they come into contact, but also leaflets, posters and information campaigns. An interesting Australian study on managing depression in primary care found that patients who were primed to ask their GPs three questions (in this case about their options for treatment and the likely benefits and harms) improved the information they were given, compared to a control group.⁷ Similarly, it may be helpful to identify a small number of key questions that health professionals should ask all patients who are employed in order to screen for potential problems. For example: Do you have any financial worries? How do you feel about work? Do you anticipate that your diagnosis will cause problems with regard to your work? Are you in contact with your employer? Do you have any concerns about your employment?

It is possible that the current system relies too heavily on clinical nurse specialists identifying problems and taking action:

We’re too reliant on the CNSs to refer people. Services need to be accessible regardless of whether the CNS thinks a patient needs it. All that CNS should be doing is telling the patient that this and that support service exists, not making the judgement about whether to refer. There’s a chap I met who is self-employed, who looks relatively well-heeled, and he’s living off a bunch of credit cards. Nobody’s offering him financial advice because he doesn’t look like he needs it.

T (pilot project staff – pilot 1)

It is likely to be useful to prime patients to ask questions that would cue useful responses.

6.4 Supporting interaction between people with cancer and their line managers

People with cancer identify their line managers as a key point of contact with their employers, and report that there can be difficulties in communicating with line managers.

She’s [line manager] taken on another hospital as well so we never see her. If I phone her up and ask, “Can I come and speak to you?” she would say, “I’ll see if I can find some time ... I’ll give you a ring if I’ve got a minute.” So, you know, it’s difficult to get her attention.

Ingrid (service user – secretary)

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

Barbara (service user – administrator)

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

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

6.5 Being proactive in providing support

People with cancer are glad to have the offer of someone to make contact with in the event that they are worried about something.

She [cancer nurse specialist] gave me her card and said I could phone her any time, and that was really reassuring. It was good to have that back up.

David (service user – bus driver)

However, it seems that the invitation from health professionals for patients to "Contact me when you need me" is reassuring but not entirely effective. Patients are very aware that health professionals are busy, and they are reluctant to raise what they might feel are trivial problems. Additionally, patients make judgements about the type of problem that it is relevant to take to the nurse who has been identified to them as their key worker; and they seldom feel that it is appropriate to raise work issues.

The two specialist nurses I saw were very good and I know that I can phone them any time. In fact, I did phone once to ask whether a drug my GP wanted me to have was okay with the chemotherapy and she was straight back with an answer, 'Yes, I've checked with the oncologist and it'll be absolutely fine etc etc.' So it's helpful to know I've got a shortcut, I've got a hotline. But I wouldn't ask them about work because that's not what they're there for.

Barbara (service user – administrator)

The Shaw Trust / Christie Hospital pilot took a proactive approach to maintaining contact with patients, building structured follow-up into their intervention plans and programming their client database to prompt telephone calls at six weeks, three months, six months and one year post-referral.

A pro-active approach is particularly helpful at the end of treatment, when people are making the transition from ‘cancer patient’ back to ‘normal’ life, adjusting to changed physical ability, relationships with others, and – crucially – returning to work. Patients report that this is a time when they can feel particularly vulnerable.

Successful return to work is not the end of the story. On-going support might be needed to help people to remain in work. Here a service user who has been back at work for six months describes her experience:

I find I’m struggling at the moment but I can’t keep saying I’m tired, I’m tired, I’m tired. And I’ve noticed that as the day goes on I tend to make more mistakes because I’m just so tired. It’s silly mistakes, and the team are good but I do think, oh God, I can’t go on much longer, at some point they will go and see my line manager and report me. Perhaps I ought to speak to her, but I’m really too scared to. She is nice, and she’s married to a doctor so she’s got a good understanding. I suppose I could talk to her actually, it’s just, I want her to see me as cheerful and well. I don’t want her to see me as a drain on the team.

Ingrid (service user – secretary)

A proactive approach to follow-up does not appear to imply a more costly service of longer duration. The mean intervention times of the Shaw Trust / Christie pilot are similar to the services at the National Hospital and the Olive Tree, and significantly shorter than the pilot based at the St John’s information centre (see Table 3).

Table 3: Total duration of intervention in hours (including both direct and indirect contact)

	Orbitals / Olive Tree – Crawley	Shaw Trust / Christie Hospital - Manchester	NHNN – London	St John’s Information Centre – Doncaster
Mean per client	7.5	5.4	8.3	29
Median	6	5	6	21

6.6 Predicting fitness for return to work

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

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

Ingrid (service user – secretary)

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

I had a knee replacement a year before the cancer. They said, "You will be off work for three months, and then you will be fit enough to go back to work." After the three months, I felt ready to return; I didn't have any problems. But not with cancer. When I asked about when I'd be well enough to go to work, they said, "Everybody's different." How do I know when I should feel fit enough? The only problem I had was the tiredness and I thought maybe I just need to get up and get going.

Ingrid (service user – secretary)

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

7 SUMMARY OF AREAS FOR FURTHER INVESTIGATION

This phase of the evaluation has highlighted three areas that merit further investigation and development.

1. Development of a template against which existing services and resources could be mapped prior to – or in the early stages of – setting up cancer work support services. Services should be mapped against the three domains identified in the Cancer Work Support Model (Fig. 1): (i) service providers, (ii) service recipients and (iii) interventions at each of three levels of need and complexity.
2. Development of a structured guideline, or the identification of criteria that would contribute to decisions about fitness for return to work following (or during) treatment.
3. Identification of the knowledge, skills and attitudes required by front-line staff to support patients' employment needs from diagnosis onwards. What are the messages that health professionals should be giving to patients early on in their illness, and how and when should these be followed up over the course of treatment? Is it possible to identify two or three simple questions that patients could be primed to ask that would initiate a discussion about employment needs?

Work in all of these areas is in progress within projects currently being undertaken by the NCSI Work and Finance team. The final evaluation report (March 2012) will revisit these.

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