

FINDING A CLEARER PATH

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Evaluation of the
Pathways to Work
Programme for people
living with cancer

March 2010

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This report was produced in association with Matrix, and is based on primary research carried out by them during 2009/10.

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Key implications for decision makers

- 1** The number of people who are living with and beyond cancer and want to return to work is rising. Returning to work is a fundamental step for cancer survivors; it restores normality and enhances well-being but the main benefit is that it alleviates the financial burden that people living with cancer face. The Government's Pathways to Work (PtW) programme will therefore need to respond to this growing customer group by targeting their specific needs.
- 2** People living with cancer have found the Condition Management Programme (CMP) helpful in that it has brought them into contact with other people in similar situations and has provided a form of social support. However, the programme has proved too generic to support people with cancer-specific needs. Additionally, customers felt that the CMP focused on claimants who were not job ready so the programme did not meet the needs of those with greater experience or skills. PtW should review how the CMP can meet the needs of specific customer groups such as cancer patients and should consider developing a cancer-specific programme within CMP.
- 3** Although many cancer survivors are successful in returning to work, they then often struggle to stay in work – often under-estimating the side effects of cancer treatment, such as fatigue and breathlessness, and finding it difficult to cope in the workplace. Extending the CMP so that ongoing support is provided to customers once they have moved into work would help to address these problems. Furthermore, advice for employers needs to be available to maximise the chances of sustaining cancer survivors in work.
- 4** The PtW programme needs to foster local and regional partnerships so that people living with cancer can be referred to appropriate wider psycho-social support or services offered by other organisations. For example, this might include services which address their broader emotional, practical or financial needs. Key to this success is communication.
- 5** Due to the generic nature of the PtW programme, personal advisers are not, nor can they be, experts in every condition, therefore appropriate induction and training will need to include information about this client group.
- 6** The core principles that underpin the PtW programme have allowed for regional flexibility and tailoring of support to local community needs. However, this has created great variation in the standards of service delivery across Great Britain. Minimum standards need to be embedded and an established framework is required to ensure PtW programme remains non-prescriptive, but also guarantees consistency. All customers must receive the support they require no matter where they are located.
- 7** Sharing best practice and good news stories gives organisations an opportunity to transfer knowledge and learning from real-life work experiences. A central forum should be established to allow for easy access across various organisations UK wide.



Executive Summary

Background and objectives

The number of people surviving cancer treatment is increasing¹ and for many, returning to work represents normality; it is a major milestone to recovery and a distraction from worries.² Employment is recognised as an important factor to enhance wellbeing and reduce health inequalities³ and the Department for Work and Pensions (DWP)⁴ has emphasised the importance of supporting people with chronic illness back into work.

In line with the Government's commitment to reform the welfare system, a central initiative is the PtW programme, which aims at supporting sick or disabled people back to work. This initiative was set up in 2003 in response to the DWP Green Paper, *Pathways to Work: helping people into employment*.⁵ In April 2008 the national roll-out of Pathways to Work was completed.

Research into return to work support and outcomes for cancer patients is scarce; however there have been a number of evaluations of the PtW programme from the perspective of customers with mental health, musculoskeletal and cardiovascular conditions.

The aim of this project is to evaluate whether the support provided by the PtW programme is effective in meeting return to work outcomes for cancer survivors.

Specific objectives were to:

- gain an understanding of the impact of the PtW programme on return to work outcomes for people living with cancer
- highlight areas of good practice
- identify development opportunities
- propose recommendations for future practice.

The project findings will inform the work of the National Cancer Survivorship Initiative, which is looking at how people with cancer can be better supported to return to, or stay in, employment.

Method

The evaluation was UK wide and focused on the delivery of the PtW programme from a Jobcentre Plus (JCP) and CMP perspective in supporting cancer survivors returning to work. The data collection took a qualitative approach.

Sixteen semi-structured telephone interviews were carried out with cancer survivors who were recruited via the Macmillan Cancer Support Exchanges programme. The interviews lasted approximately 45 minutes and explored their journey through the PtW programme and whether the programme had met their work related needs.

1 Macmillan Cancer Support, *Returning to work: Cancer and vocational rehabilitation*, February 2008.

2 Macmillan Cancer support. *Work after cancer*. Accessed on 16/01/10 at 11.48 from <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Lifeaftercancer/Workaftercancer.aspx>

3 Department for Work and Pensions. *Exploring how general practitioners work with patients on sick leave*, research report 257. Leeds: Corporate Document Services. 2005a.

4 Department for Work and Pensions, Department of Health, *Health and Safety Executive, Health, work and well-being – caring for our future*, October 2005.

5 Department for Work and Pensions, *Pathways to Work: helping people into employment*, 2002.

Two workshops (Glasgow and London) were also held with employees. All JCP and 90% of CMP regional managers were sent an invite letter to the workshops by their Department of Work and Pension (DWP) and Department of Health (DH) representative. In total 31 front-line staff and regional managers who deliver PtW support attended. Workshop activities identified areas of good practice, development opportunities and associated drivers for success as well as support strategies for sustainable employment.

Findings

Benefits of the PtW programme appear to be well established for a number of long term conditions. However, there are clear issues around meeting return to work outcomes of cancer survivors.

Analysis of the findings highlighted a number of areas requiring further development. These include:

- Greater partnership/collaboration with local cancer specific organisations as well as between JCP and CMP locally, to ensure a holistic approach to care and greater awareness of the value of the PtW programme.
- Incapacity Benefits Personal Advisor (IBPAs) lack of confidence in dealing with cancer specific issues effectively, and therefore the importance of the role of induction, training and partnership working to develop awareness of the customers' needs.

Initial entry to the PtW programme for people living with cancer was reported as problematic – for example, many are missing out on the PtW opportunities as entry is limited to those receiving Employment and Support Allowance (ESA). ESA is only eligible to those who pass the Work Capability Assessment (WCA) which was perceived to be insensitive to the needs of those with cancer. Furthermore, people

living with cancer who are not receiving ESA and are on long-term sick pay from their employment are not eligible to access the PtW programme.

Customers reported that the CMP courses support them to develop greater emotional well-being, increase their confidence and self-esteem and promote social interaction – however, due to the generic nature of CMP and the limited courses on offer, physical health needs are not met so successfully. In addition, customers felt that in-work support from CMP would have been beneficial in supporting them to sustain employment.

Interviews and workshops identified areas of good practice which are beneficial for all customers and these include:

- promotional events demonstrating the value of Condition Management
- employment of ex-customers who are able to offer advice to new/potential customers
- deployment of IBPAs to GP surgeries, supplemented by information leaflets to local services to increase engagement with the PtW programme.

Some JCP sites offer a three-way follow up interview between the customer, IBPA and CMP, and in other regions JCP and CMP operate services from the same site, which increases inter-service communication and also has a positive effect on shared learning and customer accessibility. A few JCP sites ensure customers are assigned to the same IBPA in order to build strong customer relations. Other examples of good practice include the provision of clinical psychology sessions and in-work support through CMP to enable people to remain in employment. Specifically for the benefit of people living with cancer, some IBPAs from local JCP services have identified a cancer specialist as a point of call to support them with more complex issues and this has supported knowledge development in this area.

Recommendations

A number of recommendations were made which cover areas identified as requiring further development.

- The changing needs of people living with cancer should be identified and appropriate courses offered before commencing the CMP. In addition, the DWP should consider whether specialist courses designed to target cancer specific issues could be offered through CMP.
- Induction and ongoing training should equip advisors with enough awareness to deal with this customer group.
- Services should be encouraged to further develop their partnership with the NHS, independent, and voluntary sectors.
- The CMP should offer ongoing support to customers once they have returned to work.
- Stronger working relationships between JCP and CMP should be fostered to ensure customers receive a holistic support package and experience a positive journey through the PtW programme.
- A central forum should be established to allow for sharing of best practice.
- Consideration should be given to the development of national and local benchmark criteria to ensure that there are consistent standards of service delivery UK wide whilst allowing flexibility to deal with local context.

Conclusion

The PtW programme was originally set up to deliver return-to-work support for incapacity claimants with mental health, musculoskeletal and cardiovascular condition specific issues. As a greater number of cancer survivors are engaging with the PtW programme, it is important to consider how it will evolve to successfully meet the needs of cancer survivors' return to work goals.



Background

Context

The need to support people living with cancer as they return to work is increasingly becoming a significant issue as more people are surviving cancer treatment; numbers are also expected to rise in the future.⁶ It is largely recognised that being employed can help improve a person's health and wellbeing and help reduce health inequalities,⁷ therefore it is essential that cancer survivors are supported into sustained employment.

The Department for Work and Pensions (DWP) released a green paper in 2005⁸ which stressed the importance of supporting people with chronic illness back to work, emphasising early intervention and flexible, tailored support. In the National Institute for Health and Clinical Excellence (NICE) guidelines on management of long-term sickness and incapacity for work, it is recommended that in planning interventions, the condition that leads to the sickness absence needs to be taken into account in the planning stage, as this may influence their speed of recovery and ability to return to work.⁹ The Welfare Reform Act, 2009, contains reforms to the welfare and benefit system to improve support and incentives for people to move from benefits into work, such as introducing work-focused interviews for over-60s. In the accompanying White Paper¹⁰ on future reform of employment, key principles of support are highlighted as:

- clarity of process and customer journey
- flexibility and tailoring of support to the needs of the individual
- the importance of placing rights and responsibilities at the heart of the relationship between customer and personal adviser.

There is a general lack of awareness of the need for vocational rehabilitation for people with cancer, and of their needs, which vary enormously depending on their individual circumstances. The evidence base on the effectiveness of return to work interventions for cancer survivors is currently very limited,¹¹ however there is more generic research evidence around support for the long term sick as a whole.

The Government has been committed to reforming the welfare system in order to encourage more people to return to work after a time of unemployment. One of the initiatives developed by central government is the Pathways to Work programme which aims to support people who are not in work due to sickness or disability return to work. In 2007 the Department of Health published the Cancer Reform Strategy (CRS) which outlined an updated plan for cancer services, treatment and care. The CRS recognised the profound effect a cancer diagnosis can have on a person's working life and recommended

6 Macmillan Cancer Support, *Returning to work: Cancer and vocational rehabilitation*, February 2008.

7 Department for Work and Pensions. *Exploring how general practitioners work with patients on sick leave*, research report 257. Leeds: Corporate Document Services. 2005a.

8 Department for Work and Pensions, Department of Health, Health and Safety Executive, *Health, work and well-being – caring for our future*, October 2005.

9 National Institute for Health and Clinical Excellence, *Management of long-term sickness and incapacity for work*, 2009.

10 Department for Work and Pensions, *Building Britain's Recovery: Achieving Full Employment*, December 2009.

11 Macmillan Cancer Support, *The Road to Recovery*, 2007

that patients be given information and advice on returning to work. Following this, the National Cancer Survivorship Initiative (NCSI) was established to develop new models of care for people who have completed cancer treatment. One of the NCSI workstreams is looking specifically at work and finance issues.

Pathways to Work Programme

The PtW programme was set up in 2003 in response to the DWP Green Paper, *Pathways to Work: helping people into employment*.¹² In April 2008 the national roll-out of PtW was completed.

The aim of PtW is to assist new and repeat incapacity benefit claimants into, and towards, paid work. In 2008 Employment and Support Allowance (ESA) was introduced to replace Income Support and Incapacity Benefit for those off work due to ill health or disability. The PtW programme now forms part of this benefit. Those claiming ESA must undergo an initial Work Capacity Assessment (WCA) by an external provider, Atos Healthcare, to determine whether they are entitled to Employment and Support Allowance (ESA). This assessment focuses on what a customer can do rather than what they are unable to do. Due to the nature of an illness, some customers would be exempt from this assessment and any further mandatory involvement.

There are two possible outcomes from the assessment:

- The claimant is not found to have limited capacity for work. The claimant is deemed too ill to work and is placed into a support group and excluded from any form of conditionality. This is a group of customers with the most severe health conditions and disabilities.

- The claimant is found to have limited capacity for work. The claimant is deemed capable of looking for work and is placed in the work related activity group.

Those in the work-related activity group are assigned an Incapacity Benefit Personal Advisor (IBPA) and are required to partake in the PtW programme. This includes Work Focused Interviews (WFI) with their IBPA to discuss work opportunities; identifying suitable goals for work (taking into consideration the specific health condition) and receiving an explanation of the support available to help move into work. A total of six mandatory WFIs are spaced, roughly, at monthly intervals. This non-health-related aspect of the PtW programme is delivered by Jobcentre Plus (JCP) in 40% of the UK and by independent providers in 60% of the UK.

Those who do not attend their WFIs face the possibility of sanctions such as a reduction in their benefits. Around a third of incapacity benefit customers attending an initial WFI who were not assessed to be WCA exempt would be screened out of the Pathways to Work programme.¹³ Those who are screened out can, however, request to access the support aspects of the PtW (WFIs and the Conditions Management Programme) voluntarily if they wish.

Claimants on the PtW programme have access to a package of voluntary provision known as 'Choices'. This includes the New Deal for Disabled People (NDDP), Financial Support (Advisors Discretionary Fund and Return to Work Credit), In Work Support (IWS) and the Condition Management Programme (CMP), a programme which runs in collaboration with local NHS providers to help individuals manage their health condition.

¹² Department for Work and Pensions, *Pathways to Work: helping people into employment*, 2002.

¹³ *Pathways to Work: the experiences of existing customers: Findings from a survey of existing incapacity benefit customers in the first seven pilot areas*. Jon Hales et al, DWP report 527, published 2nd October 08. Accessed from <http://research.dwp.gov.uk/asd/asd5/rports2007-2008/rrep527.pdf>

The CMP was developed in partnership between the Department of Health (DH) and the DWP and consists of a range of services provided by occupational therapists, physiotherapists, counsellors and other practitioners and is delivered through one-to-one or group modules that last between four and 16 sessions and are offered to each individual. Examples of support offered on the CMP are: stress and anxiety management; positive thinking about health and work; and advice and information on lifestyle.

Acute medical conditions such as mental health, musculoskeletal and cardiovascular conditions are amongst the most common causes of long term sickness¹⁴ and the CMP was originally developed to meet the needs of incapacity benefit claimants with these three specific conditions. However, more recently the CMP has extended its reach to support people with a range of other conditions, including cancer.

Research evidence

Cancer specific vocational rehabilitation

In 2008 Macmillan Cancer Support explored the vocational rehabilitation available for people with cancer and how it can be improved.¹⁵ It found that JCP services offer less support for people who want to remain with their current employer as they mainly focus on helping people on incapacity benefits get back into work. In addition, it was found that it would be helpful to start thinking about returning to work right from the beginning of an individual's cancer journey. Economic need and 'getting back to normal' are critical factors in decisions concerning return to work after a cancer diagnosis, and so support to return to work rather than coercion may be a more successful approach.¹⁶

From the Macmillan study it is evident that health professionals have neither the capacity nor the occupational health skills to support people with cancer in returning to work, and that cancer doctors rarely discuss returning to work with their patients.¹⁷ The findings highlight the uncertainty over how well vocational services meet the needs of people with cancer and how they are able to access these services. The report called for greater research in this area, specifically focusing on the experiences and needs of people with cancer using JCP employment services to determine whether their return to work outcomes are being met. This evaluation of the PtW programme from a cancer perspective takes forward this recommendation.

Long term conditions return to work evidence

Research into return to work support and outcomes for cancer patients is scarce; however there have been a number of evaluations of the PtW programme from the perspective of customers with mental health, musculoskeletal and cardiovascular conditions. Research in this area has typically found that continuity of care is considered to be central to developing a good relationship with the customer. Customers who had received help from more than one member of staff were left frustrated at having to cover the same ground on numerous occasions. The convenience of the location of courses and the option of privacy for people who wanted to discuss personal issues were considered critical by customers.

For customers who are not interested in working, IBPAs feel that after the initial WFI, subsequent WFIs achieve little. This is confirmed by the customers themselves. In practice, customers rarely manage to attend

¹⁴ Chartered Institute of Personnel and Development, *Annual Survey report 2008: absence management*, 2008, London.

¹⁵ Macmillan Cancer Support, *Returning to work: Cancer and vocational rehabilitation*, February 2008.

¹⁶ Macmillan Cancer Support, *The Road to Recovery*, 2007.

¹⁷ Macmillan Cancer Support, *Returning to work: Cancer and vocational rehabilitation*, February 2008.

all six¹⁸ and this is typically due to lack of interest in returning to work, or a legitimate reason, such as no longer receiving/requiring incapacity benefits or being WCA-exempt.

Although there is considerable positive feedback regarding the CMP, customers with physical health problems appear to be somewhat less positive about their experiences. Customers feel they are often not being offered any new ways to manage their condition/pain by the health related courses.¹⁹ However, the voluntary nature of attendance and an unpressured approach to work from CMP was particularly important in encouraging participation for those people who were initially unsure about CMP.²⁰

The CMP, being originally developed for people with mental health, musculoskeletal and cardiovascular conditions, seems to struggle with providing care for people with both mental and physical problems. People with cancer can fall into both categories but the original service model does not have the skill mix/staff profile to deal with this level of complexity, and therefore needs to offer better support.²¹

The focus of this evaluation is on access to the PtW programme, the WFI delivered by JCP, and the CMP which forms part of the Choices Programme. This decision was driven by a lack of evidence about whether the support available, and the CMP in particular, addresses the specific needs of people with cancer.

The aim of the project is to evaluate whether the support provided by the PtW programme is effective in meeting return to work outcomes for cancer survivors. Specific objectives were to:

- gain an understanding of the impact of the PtW programme on return to work outcomes for people living with cancer
- highlight areas of good practice
- identify development opportunities
- propose recommendations for future practice.

The project findings will inform the work of the National Cancer Survivorship Initiative, which is looking at how people with cancer can be better supported to return to, or stay in, employment.

18 Richard Dorsett, NIESR, *Pathways to Work for new and repeat incapacity benefits claimants: evaluation synthesis report*, DWP report 525, published 2nd October 2008. Accessed from <http://research.dwp.gov.uk/asd/asd5/rports2007-2008/rrep525.pdf>

19 *A qualitative study of the customer views and experiences of the Condition Management Programme in Jobcentre Plus Pathways to Work*, Warrener et al, Natcen, DWP RR582, published 16th June. Accessed from <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep582.pdf>

20 *A qualitative study of the customer views and experiences of the Condition Management Programme in Jobcentre Plus Pathways to Work*, Warrener et al, Natcen, DWP RR582, published 16th June. Accessed from <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep582.pdf>

21 *Pathways to Work: Qualitative research on the Condition Management Programme*, Policy Studies Institute, DWP Research Report no. 346, 2006. Accessed from <http://research.dwp.gov.uk/asd/asd5/rports2005-2006/rrep346.pdf>



Method

Approach

The evaluation was UK wide and focused on the delivery of the PtW programme from a JCP and CMP perspective in supporting cancer survivors to meet their return to work outcomes. The evaluation took a qualitative approach and Figure 1.0 identifies the three types of methods used. All data collected was thematically analysed to identify similarities and variation between the current research evidence, workshops and interview findings.

Phase 1:

Scoping – Literature Review

A scoping phase was carried out before the evaluation began to gain a thorough overview of the PtW programme. A rapid literature review helped to identify the structure, processes and support offered through JCP and CMP components of the PtW programme and how such interventions facilitate customers' return to work outcomes. The scoping phase identified what is currently working well and areas which are not as effective in meeting the needs of customers. The findings from the scoping phase supported the development of the scope and focus of the workshop and interviews.

Phase 2:

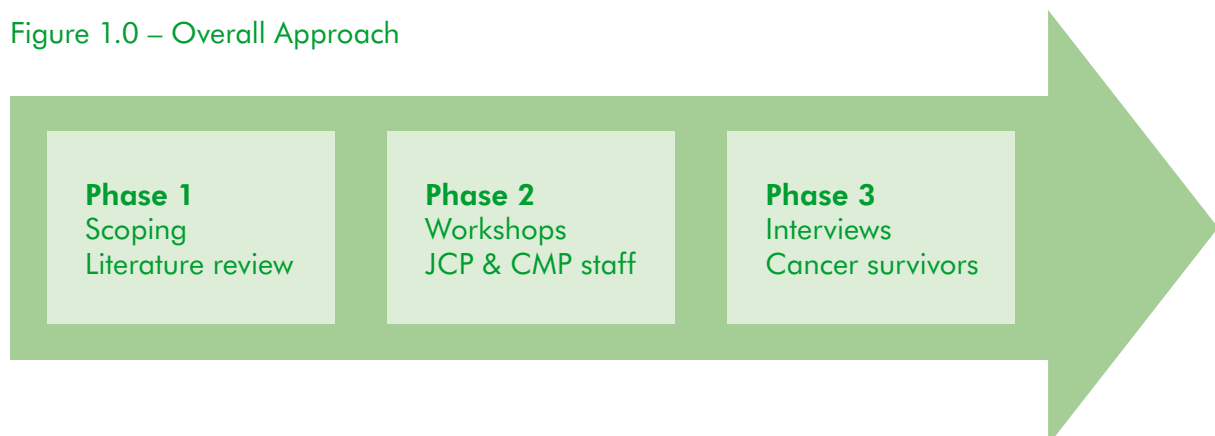
Workshops – JCP & CMP Staff

Two workshops were carried out to capture the experience of JCP and CMP front-line workers and regional managers in delivering support to people living with cancer to return to work (please refer to Table 1.0 for sample characteristics). Each workshop consisted of three engagement activities and staff were placed into groups with unfamiliar peers to promote shared learning.

Activity 1: Examples of good practice

Staff shared real life stories of partnership working, positive customer experiences and improved return to work outcomes within their groups and developed storyboards which highlighted the success factors that underpinned their examples of good practice. For example, they described people living with cancer, characteristics, needs and aspirations, types of interventions and support provided, stakeholder involvement and so on.

Figure 1.0 – Overall Approach



Activity 2: Development opportunities & drivers for success

Staff were asked to identify high priority development opportunities for the PtW programme with specific focus on:

- WFI
- access to the PtW programme
- referral from JCP to CMP
- CMP support.

They were asked to identify the critical factors in effectively addressing the high priority development opportunities and proposing suitable recommendations for how future improvements could be implemented and which stakeholders should be involved.

Activity 3: Support strategies for sustainable employment

Staff put together a mock campaign addressing how employers could support cancer survivors to effectively engage with and sustain long term employment. Groups worked creatively to design and present their return to work campaigns and drew on a range of mediums through which the campaigns could be disseminated.

Phase 3: Interviews – Cancer Survivors

Sixteen semi-structured telephone interviews were carried out with cancer survivors (please refer to Table 1.0 for sample characteristics). The interviews lasted approximately 45 minutes and explored their journey through the PtW programme and whether the programme had met their work related needs. The interviews specifically focused on their experiences of accessing JCP and CMP, the WCA, WFI and support offered by JCP and CMP.

Recruitment

Cancer survivors were recruited via Macmillan Cancer Support Exchanges programme. Information about the evaluation was provided through this recruitment route. Potential participants were asked to contact the research team at Matrix Insight if they wished to share their experiences of the Pathways to Work Programme.

All Jobcentre Plus and 90% of Condition Management Programme regional managers were sent an invite letter to the workshops by their DWP and DH representative. The research team then followed up over the phone with regional managers to see if they were interested in attending the workshops.

Sample characteristics

The table below shows the sample of characteristics of cancer survivors interviewed and staff who attended the workshops. The JCP and CMP staff who attended the workshops included front line workers (such as IBPA²² and CMP clinicians) as well as regional managers.

²² Note due to the change in benefits system, various names are used interchangeably, which include IBPA, ESA personal advisors and personal advisors. For the purpose of clarity, this report identifies them as IBPA.

Table 1.0 – Sample Characteristics

Data collection	Sample Characteristics		n	Total (N)	
Interviews	Gender	Female	10	16	
		Male	6		
	Age	30-39	1		
		40-49	7		
		50-59	5		
		60+	3		
	Employment status pre-PtW	Worked prior to PtW	14		
		Unemployed prior to PtW	2		
	Employment status post-PtW	Full-time	2		
		Part-time	3		
		Unemployed	9		
		Long term sickness	1		
		Re-training	1		
Location	South East	1			
	Scotland	1			
	Yorkshire & Humber	14			
Workshops	London	Gender	Female	12	17
			Male	5	
		Role	CMP	10	
			JCP	7	
	Glasgow	Gender	Female	13	14
			Male	1	
		Role	CMP	8	
			JCP	6	



Findings

What is working well for people living with cancer?

People living with cancer value the flexible appointment times offered by their IBPA, the choice about when to engage with the support on offer and are appreciative of the empathy and support the JCP and CMP offer. The opportunities for social engagement within the CMP courses were also praised.

Flexibility

“When I had to cancel an appointment she’d [IBPA] quite happily make another one.”

The flexibility of the WFI appointments is highlighted as a positive aspect of the JCP service. Customers feel that it is fundamental for these appointments to be at a time best suited to them, in light of attendance at numerous cancer-related appointments. Referral to CMP from JCP is purely voluntary and customers are not pressured to attend at a time that is not right for them. When customers feel ready to engage with support the referral process is also quick and efficient.

“It [CMP] was ready when I was ready...”

Empathy and support

“Brilliant, willing to listen and didn’t pre-judge...”

Customers appreciate the empathy and support offered by JCP and CMP staff. They feel that staff are approachable and willing to listen to concerns about the support they need as well as general issues. They also feel that CMP offers a positive opportunity to meet and interact with others going through both similar and dissimilar experiences.

“...makes you realise that when you are feeling a bit down, it’s not only you feeling down, other people have similar feelings.”

The social element of the CMP courses provides customers who are isolated or lacking in confidence an opportunity to engage with others and share their experiences, which boosts confidence and self-esteem.

“...just to go out for a day because I don’t go out very much.”

Development opportunities

Through the interviews and workshops, a range of development opportunities were identified. They broadly cover issues relating to partnership/collaborative working, lack of awareness about the PtW programme, skill and knowledge management within JCP and CMP and issues raised with regard to service delivery.

Partnership/collaborative working

Partnership working between JCP and CMP and with specific cancer organisations in the community could be further developed to ensure a holistic approach to care.

Missed opportunities for collaboration with cancer organisations

It is evident that the majority of JCP and CMP do not fully capitalise on forming partnerships with NHS and independent sector and voluntary/charitable organisations who work with the same cancer survivors and vice versa. Partnership working promotes shared learning and raises awareness of the services offered within the local community and in turn provides customers with a wider range of support to enable them to achieve their return to work goals. A critical example is that JCP and CMP staff at the workshops were not aware that Macmillan Cancer Support provides a network of benefits advisers throughout Great Britain. These advisers support people living with cancer and give benefit entitlement advice.

Lack of joined up working between JCP and CMP

It appears that in most PtW programme regions, JCP and CMP services work in isolation from each other. JCP and CMP staff express that there are limited opportunities to engage with each other and this is mainly due to capacity issues and that JCP have become more target driven. Limited opportunity for joint working has resulted in JCP and CMP staff being unable to recognise the full breadth of services each can offer and the benefits the interventions can provide to their customers.

Customers echo this concern and feel that the lack of communication between the two services is a contributing factor to the amount of times it is necessary for details related to their cancer diagnosis and treatment to be repeated to various professionals. This leaves the customer feeling apprehensive and also

that JCP and CMP staff are not efficiently prepared for their meeting.

Lack of awareness of services offered by the PtW programme

Underdeveloped working relationships between the PtW programme and other stakeholder groups appear to have contributed to a lack of public awareness about how the services are offered by the programme. In return this may have resulted in limited advertising of the programme from the DWP to their stakeholders and this is mirrored by customers who feel they did not receive adequate information about PtW.

Stakeholder organisational awareness

Many local cancer services, support groups and front line NHS staff delivering care and advice to people affected by cancer appear to have limited or no knowledge of the services offered by the PtW programme and how it can benefit this target group. This may be a consequence of a lack of partnership working across a range of cancer specific stakeholder groups within the local community and demonstrates the importance of creating opportunity for shared learning to promote awareness.

Public/customer awareness

Staff express concern that their local communities are not aware of the full range of services offered by the PtW programme. Customers have a lack of understanding of how PtW can benefit their return to work outcomes. It was found that there was inconsistency in the information provided to customers; some received a general letter or leaflet about PtW before entering the programme, however others had to undertake internet research to find out more.

Half of the customers interviewed felt that the information provided was not sufficient to enable them to make informed decisions about whether they wished to participate in CMP. The information is not clear enough

and some customers fail to understand exactly what is on offer and think that their benefits will be taken away if they refuse to engage with the programme. This causes them anxiety as they do not feel ready to embark on this type of support. Customers also have preconceived views:- they can feel intimidated by the clientele generally allied to JCP; they feel their condition and employment status is out of their control, whereas others at JCP make the conscious decision not to work.

“I almost turned around to go back home when got there...”

Customers feel they would prefer a phone call with someone before being contacted by the JCP staff so that any questions they have can be answered before attending their first appointment.

Limited opportunities to develop cancer specific knowledge

Throughout the PtW programme, and more specifically for JCP, it appears that there is limited knowledge about cancer-specific issues. JCP staff feel that they are not adequately equipped to deal with sensitive issues and this was also expressed by customers.

Limited cancer-specific knowledge

JCP staff, in particular, do not feel they have adequate cancer-specific knowledge and so feel less able to address the needs of people living with cancer compared to those with the conditions for which PtW was originally designed (mental health, musculoskeletal and cardiovascular). Staff report that recently there has been a rise of people living with cancer accessing the programme and hence the need for this knowledge and understanding has increased. This finding was mirrored by many of the customers interviewed who felt there was

a lack of understanding from staff around their condition-specific issues. An extreme example was given, in which an IBPA was unfamiliar with a customer’s condition and so the customer had to explain their diagnosis and what this meant.

Staff stated that others within JCP assume that customers who engage with talking therapies/psychological support outside of the PtW programme do not require CMP support and thus do not refer them onto the health related courses.

Lack of confidence in dealing with sensitive issues

Part of a professional’s role within PtW programme is the ability to deal with sensitive and complex health and financial issues.

Some JCP staff do not feel confident to address sensitive issues with customers living with cancer. This was less evident for CMP staff. Customers commented that they felt sorry for their IBPA as they appeared to be out of their depth at times.

“Actually felt a bit sorry for her [IBPA] as she wasn’t aware of my medical situation, I had to explain to her I’ve been diagnosed with cancer...”

Some IBPAs appear to lack the necessary skills to work with people enduring the stress of cancer and often fear the worst if a cancer patient returns to work. JCP staff find it hard to decide whether they should focus on the condition or the return to work issues and struggle to juggle the two. JCP staff feel that the boundaries of their roles are being slightly stretched, acting as therapists or counsellors when this is not within the scope of their job to offer this type of support.

Some customers feel that staff appear to lack sensitivity to their needs and situation and do not fully appreciate why they are not able to return to work or engage effectively in the PtW programme. JCP staff recognise that these issues may be partially due to limited capacity to equip new staff with skills to manage sensitive conversations.

Issues around service accessibility and delivery

Staff and customers raised issues relating to initial entry onto the PtW programme. Concerns were expressed around the WCA, which allows access to ESA and hence onto the PtW programme. In addition, CMP interventions are felt to be too basic for customers living with cancer and the interventions offered are not person centred. However, customers value the social element of the CMP courses and how it promoted their self confidence.

Initial entry onto the PtW programme

Many cancer survivors are missing out on the PtW opportunities as entry is limited to those receiving ESA, and ESA is only eligible to those who pass the WCA. Interviewees felt this posed a particular problem for cancer survivors who they believe are typically failing the WCA for reasons described below, although they might not be ready to return to work.

Customers and staff feel that the WCA does not adequately assess the needs of someone with cancer. The WCA is often carried out by a generic health professional who has no knowledge of the customer's history. Interviewees highlighted that the tick-box question format did not provide them with an opportunity to raise condition-specific issues and discuss how it affects their ability to return to work.

“The thing that didn't work for me with the whole PtW was the medical assessment ...it does not cater for people with cancer or on chemotherapy...”

People living with cancer who are not receiving ESA and are on long-term sickness absence from their employment, are unable to access the PtW programme. This includes those on statutory sick pay (SSP) who may benefit from the programme but are delayed from accessing it until their SSP ends and they can claim ESA. Customers who had experienced this mirrored the concern and felt their CMP introduction was delayed unnecessarily. Those who receive sick pay should not be excluded from PtW as they still have the same health needs. Furthermore, some JCP staff are under false impressions that cancer survivors who are on ESA and also receive substantial support through various health related cancer support may not require CMP support and thus do not refer the customer on.

Appropriateness of CMP interventions

People living with cancer feel that certain aspects of the CMP are inappropriate to meet their needs. For example, all those interviewed felt that the CMP was too generic (especially the introductory courses) and staff state that this is a result of the programme being designed to cater for a variety of conditions. Customers want to engage with health related courses that are appropriate to their needs. For example, many cancer survivors experience pain as a common side effect²³ and support could be targeted at addressing these problems in particular. Customers would value the opportunity to have a one-to-one with clinicians before

23 Stasi, R., Abriani, L., Beccaglia, P., Terzoli, E., & Amadori, S. (2003). Cancer-related fatigue: Evolving concepts in evaluation and treatment. *Cancer*, 98(9), 1786-1801

accessing the CMP course so that their needs can be assessed and matched to a suitable course. The consensus is that CMP is too basic and this might be a bi-product of customers not having the opportunity to have an initial assessment, which would identify their specific needs. Overall, customers feel that CMP courses are limited and a broader range of topics would allow courses to be tailored to specific needs, therefore improving overall return to work outcomes.

The PtW programme is focused on those who have been out of work for a long time, which might not necessarily be true for customers who have experienced a sudden acute episode of illness. Customers were frustrated with certain aspects of the programme that focused on basic skills such as CV writing. This was more aimed at those who have been out of work for a longer time.

In work support

CMP does not have funding to offer on-going support once customers have returned to work. However, some services are offering this as an extension to CMP. Customers and staff emphasised the positive effects of in-work support, however only a handful of regions have implemented this. Customers feel that in-work support will enable them to cope better with managing their condition more effectively while working. Staff also feel that this will prevent repeat ESA claims and, in addition, follow-up meetings after the customer has completed the PtW programme are beneficial in sustaining contact and monitoring the customer's progress.

Return to work outcomes

Overall, customers feel that CMP supports them to develop greater emotional well-being, increase their confidence and self-



esteem and promote social interaction. Physical needs are not met so successfully, however, and the pain management programme was not viewed as beneficial. Overall, the customers interviewed felt that the PtW programme is beneficial – although just a handful felt ready to return to work following its completion. Others expressed they were not yet ready, either because they were too ill or too old. Advice on phased return to work is greatly valued and alleviates the intimidation customers feel when returning to work. This intimidation stems from customers feeling uncertain whether employers will understand their condition and make reasonable work adjustments. This is a concern mirrored by the JCP and CMP staff.

Examples of good practice

A set of core principles underpins the PtW programme but it still allows regions the flexibility to design service delivery to meet the needs of their local community. There are clear benefits to this approach and the acknowledgement that one size does not fit all. However, there appears to be great variation in the standards of the services delivered across the UK as well as the type of support offered, which in turn impacts on return to work outcomes for customers.

JCP staff recognise there are fundamental differences between services and acknowledge this may be because just 40% of the services are run by the public sector; the remainder are delivered by independent organisations. While there are pockets of good practice across the UK, the majority of customers are not receiving the same opportunity and standard of support.

At the workshops, staff shared a range of good practice examples ranging from strategies to increase awareness of JCP and CMP support, partnership working across the PtW programme and with external

stakeholders, activities to promote shared learning, and a person centred approach to service delivery. The staff who attended the workshop acknowledged that there are limited opportunities to share good practice examples nationally and are keen to raise awareness of service innovation and success stories. The examples of good practice described below can add value to a range of customer's experiences of the PtW programme and return to work outcomes.

Raising awareness

CMP staff at one site hold promotional events to raise public awareness of the service. This has proven to be an effective method to recruit new attendees. These taster sessions show the benefits of CMP and what the programme has to offer; the events have recruited over 50% of attendees to the programme. Other sites have 'champions' (ex-customers) to promote CMP to new customers. This provides an opportunity for new and/or potential customers to speak with a peer about what the courses have to offer and the value it has provided for others in similar situations and/or with the same condition specific issues.

In one region, traditionally excluded groups are being targeted and incentives offered to encourage participation with CMP. For example, tailored work experience is incentivised for young people, which opens up opportunities for these groups to gain work experience, skills and knowledge specific to their personal interests.

Partnership working

A few JCP services have identified a contact who is a cancer specialist. This provides support to IBPAs around specific cancer related issues. This builds IBPA's knowledge and confidence to deal with more complex condition specific issues and in turn promotes customers' positive experience and faith in the service.

To encourage greater engagement with the PtW programme, some JCP sites have placed IBPAs into GP surgeries. This is a DWP initiative from the Pathways Advisory Service. This strategy promotes partnership working and helps customers to understand the broader benefits of both JCP and CMP. To supplement this, PtW have sent out information leaflets to GP surgeries and health providers to raise awareness about the services the programme offers.

To foster a joined-up approach to service delivery across the PtW programme, some sites conduct three-way follow up interviews between the customer, IBPA and CMP staff. This is an effective method to promote continuity of support and increase communication between the two types of services. In addition, some regions have JCP and CMP services operating from the same site. This fosters partnership working between the two services, facilitates shared learning and also increases accessibility for the customer.

“Everything was based in the same building so once agreed suitable, I walked into the next office for CMP referral.”

Shared learning

A few CMP services promote shared learning within their team through the use of ‘good news stories’ by writing positive customer stories in a communal book, which can be shared amongst the staff. This increases learning about what works well, supports staff to utilise their skills more effectively and also acts as a motivator for staff to aspire to achieve the same for their customers.

Person centred approach to service delivery

At some JCP sites customers are offered a follow-up interview once they have completed their CMP courses. This is carried out by a clinical psychologist to teach the customer coping mechanisms to manage their return to work more effectively. The aim is for customers to sustain employment and avoid returning to benefits. The interview takes a person-centred approach and is found to reduce the frequency of individuals failing to achieve their return to work outcomes, whilst providing an opportunity for the service to get an update on the customer’s progress.

Claimants do not necessarily see the same IBPA throughout their benefit spells. However, a number of JCP services do try to implement this so customers are assigned the same IBPA to support them through their PtW programme. This builds rapport and trust and customers report feeling more valued. In addition, a private interview room makes customers feel they are being respected and supports them to disclose personal information to IBPA’s. Some JCP have facilities to accommodate this, which helps the IBPA in identifying more sensitive concerns and thus they develop a more suitable support plan for the customer.

Recommendations

Specific to customers living with cancer

A monitoring process should be developed to ensure that changing needs of people living with cancer are identified and appropriate courses offered before commencing the CMP. This should help to ensure that customers do not attend the more generic or basic CMP elements, unless appropriate, and will ensure limited resources are allocated more efficiently. In addition, the DWP should consider whether specialist courses designed to target cancer specific issues could be offered through CMP.

Induction should be designed to equip the advisors with enough awareness to deal with this customer group. Moreover, an ongoing training programme should be made available for all staff to ensure they are kept up-to-date and able to address specific needs effectively.

Services should be encouraged to further develop their partnership with the NHS, independent, and voluntary sectors, to capitalise on the wealth of knowledge and support that currently exists within the field of cancer care. This should help customers to benefit from the full range of services on offer that might help them to better manage their condition and return to work. All partners should act to raise awareness of the benefits of the PTW programme among this target group.

Applicable to all customers

The CMP should offer ongoing support to customers once they have returned to work, as many will continue to struggle with ongoing problems. Carrying out follow-up assessments would also be beneficial in determining if further support is required. This could also include advice to the employer around facilitating improved return to work outcomes for the customer.

Stronger working relationships between JCP and CMP should be fostered to ensure customers receive a holistic support package and experience a positive journey through the PtW programme.

Sharing best practice and good news stories gives organisations an opportunity to transfer knowledge and learning from real-life work experiences. A central forum should be established to allow for easy access UK-wide across various organisations. One example of such good practice is the involvement of previous customers living with cancer as advocates for the PtW programme.

Consideration should be given to the development of national and local benchmark criteria to ensure that there are consistent standards of service delivery UK-wide whilst allowing flexibility to deal with local context. The benchmark criteria should be based on principles of good practice.

Conclusion

The Pathways to Work programme was originally set up to deliver return to work support for incapacity claimants with mental health, musculoskeletal and cardiovascular condition-specific issues. However, the need to support people with cancer to return to work is becoming of greater significance. More people are surviving cancer treatment and numbers are expected to rise in the future.²⁴

Engaging with employment can help improve a person's health and wellbeing and help reduce health inequalities.²⁵ As a greater number of cancer survivors are engaging with the Pathways to Work programme, the programme needs to consider how it will evolve to successfully meet the needs of cancer survivors' return to work goals.

²⁴ Macmillan Cancer Support, *Returning to work: Cancer and vocational rehabilitation*, February 2008.

²⁵ Department for Work and Pensions. *Exploring how general practitioners work with patients on sick leave*, research report 257. Leeds: Corporate Document Services. 2005a.

Glossary

Abbreviations

ADF	Advisors' Discretionary Fund
CMP	Condition Management Programme
DH	Department of Health
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
IBPA	Incapacity Benefits Personal Advisor
IWS	In-Work Support
JCP	Jobcentre Plus
NDDP	New Deal for Disabled People
PtW	Pathways to Work Programme
RTWC	Return to Work Credit
WCA	Work Capability Assessment
WFI	Work Focused Interviews
WRAG	Work Related Activity Group

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