

Cancer Journey Advisory Group

Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Environmental Scan

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This report was prepared by **Piceps Consultants, Inc.** for the National Survivorship Working Group, Cancer Journey Action Group.

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The views expressed herein represent the views of the authors.

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Executive Summary

The Cancer Journey's National Survivorship Working Group of the Canadian Partnership Against Cancer (the Partnership) requested that an environmental scan be conducted to determine existing support services, education, training programs, and online resources and practical tools available for people living with cancer and other chronic diseases that are designed to facilitate return to the workplace during or after treatment.

While research and cancer advocacy groups have acknowledged the need for return to work (RTW) supports to address these concerns, few programs or services have been implemented in Canada.

Two specific project goals were articulated:

1. Create a comprehensive list of support services and/or education and/or training programs and/or online resources and practical tools for employees returning to or managing at work that currently exist which address workplace issues for people living with cancer and other chronic diseases.
2. Establish contact with and interview key developers and providers of these support services and/or education and/or training programs and/or online resources and practical tools.

The environmental scan was conducted in two iterative phases:

1. A web-based review, assessment and synthesis of RTW programs and resources related to cancer and chronic disease in Canada and internationally for those programs and resources related to cancer specifically.
2. Up to 20 in-depth key informant interviews with representatives of relevant programs (i.e., developers, providers), cancer and chronic disease associations.

During the first phase, we scanned 8,385 websites for relevance (cancer, mental health and HIV organizations, and organizations identified by the expert consultation process), ending up with 90 resources that focused on supporting employees as they returned to work. The resources we identified included mainly programs, guides, information sheets, services, reports, publications and booklets. In terms of RTW resources in other chronic diseases, the field of mental health has produced the most work available on the Internet.

We then had a priority-setting meeting with the Partnership and determined that our focus would be to review RTW programs and services and contact those key informants that knew most about relevant programs and services and to focus on only HIV and mental health as examples of chronic diseases.

For the second phase of the environmental scan, 16 key informants were interviewed about 21 RTW programs. The following are key highlights from these interviews.

- Most RTW programs and services targeting cancer patients and people with other chronic diseases are comparatively recent, with most having been implemented between 2000 and 2010. It appears to be difficult to determine best practices. There is a broad range of program types, such as information or education, psycho-educational groups, and one-on-one coaching or counselling. There are various mechanisms for program delivery, such as by telephone (one-on-one and group), in person (one-on-one, group and workshop), videoconference and online (general information and one-on-one information).
- From the review of mainly English-language materials from five countries, including Canada, program and service content covers a similar range of topics, even across health concerns (cancer, mental health and HIV). For example, across countries and diseases, RTW content focuses on disclosure, stigma, job preparation, financial information, workplace accommodations, communicating with employers and coworkers, legal information, and dealing with stress and side effects.
- Most of the programs are offered to individuals who have completed their treatment. This was done in response to the programs' interpretation of individual readiness for RTW support. However, the evidence suggests employment issues can occur or help might be requested by an individual with cancer or other chronic disease from the point of diagnosis onward. As such, there is a gap in program offerings for people who require support to return to work during treatment.
- Most of the programs are about getting people back to work; few focus on what happens once they get there.

The following are recommendations for future research, programming and partnerships.

- Support the development and evaluation of pilot projects with an emphasis on programs involving the three intersecting groups: individuals with cancer, health care professionals and employers. The pilot projects should incorporate RTW support across the cancer trajectory, embrace multiple elements of RTW issues (including workplace reintegration and follow-up on the integration experience) and have a strong evaluation component.
- Support the creation of an expert panel of RTW professionals to inform and advise on best practices, inform the evaluation design and assist in identifying strategies to support long-term sustainability.
- Establish mechanisms for knowledge transfer among RTW program providers and agencies, and organizations supporting cancer patients and their caregivers, health professionals and employers.
- Evaluate the impact of knowledge transfer on the knowledge, attitudes and practices of RTW program providers and agencies and organizations supporting cancer patients and their caregivers, health professionals and employers

- Follow up with organizations both within and outside of the cancer community (i.e., HIV and mental health) to determine how to engage with and share information to help inform future opportunities.

Introduction

The Cancer Journey's National Survivorship Working Group of the Canadian Partnership Against Cancer (the Partnership) is investigating and identifying projects that address survivorship issues in Canada and supporting further development of resources and programs for those living beyond cancer treatment and their families. This project – an environmental scan of resources – focuses on return to work (RTW) challenges for people who have been diagnosed with cancer and other chronic diseases. Many cancer survivors face significant challenges when they return to work (including those who are self-employed¹). While research and cancer advocacy groups have acknowledged the need for RTW supports to address these concerns (including those needs identified in several resources and publications by the Partnership's Cancer Journey Advisory Group²), few programs have been implemented in Canada. The results of this national and international scan will provide the National Survivorship Working Group with an understanding of RTW programs available for people diagnosed with cancer and other chronic diseases.

Very recently Nitkin et al. (2011) produced a report for the Canadian Association of Psychosocial Oncology to “gain a broad understanding of the work-life experience, services and needs of persons with cancer in Canada in order to discuss the implications for clinical practice, policy and research” (p. 5). Until now, the issue of cancer and work has been inadequately addressed in Canada, but it is of critical importance because nearly half of all cancer survivors are of working age and the majority of survivors return to work a year following diagnosis (Spelten et al., 2002).

A recent Canadian Breast Cancer Network study showed that 16% of women with breast cancer reported having had their jobs terminated and 20% needed to quit their jobs because of work restrictions or difficulties associated with side effects and treatment. Nitkin et al. (2011) also reported that individuals with cancer in Europe and the United States are more likely to be unemployed than are healthy individuals.

¹ Those who are self-employed might work through treatment and so might find this an easier scenario with which to cope, however, they might also feel more pressure to work (Cancer.net).

² A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient (2009); Supportive Cancer Care Programs (2009); Environmental Scan of Cancer Survivorship in Canada (2008); National Invitational Workshop: Towards an Agenda for Cancer Survivorship (2008); National Psychosocial Oncology Education Framework (2007).

Nitkin et al. (2011) report that cancer survivors who more successfully negotiate their return to work cite the reason for successful reintegration as work accommodations provided by their employers, such as flexible work hours and duties, supportive colleagues, paid time for medical appointments and a gradual RTW schedule. Barriers typically included facing jobs with physical or cognitive tasks that survivors could no longer complete because of side effects and long-term effects of treatment such as fatigue; an unsupportive work environment; and job termination, demotion, perceived employer discrimination and lay-offs (Nitkin et al., 2011). Gould (2004) also found the following work concerns in a small qualitative study of the financial issues for lower-income women with breast cancer: single women without health insurance were unable to leave work during treatment; most endured long-term side effects (e.g., lymphedema, depression and fatigue) that prevented them from returning to previous employment; and some perceived employer discrimination.³

To focus on what exists to ameliorate these barriers Nitkin et al. (2011) reviewed international interventions, policies and programs associated with RTW. They discovered a shortfall of “well-designed outcome research on intervention-based work in psychosocial oncology” (p. 18). Those that did assist cancer survivors in returning to work included a variety of psychosocial, physical, vocational and psycho-educational interventions such as counselling, job training and placement, rehabilitation technologies, job search assistance, educational leaflets, maintenance services and occupational physicians who liaised with employers.⁴

Nitkin et al. (2011) also found that in Canada there were only a few workplace interventions developed in hospitals and in the community to facilitate RTW for patients with cancer. These programs included vocational rehabilitation counselling, assessment, case management, job search assistance, resource referral, psycho-educational and vocational weekly or weekend programs, support groups and support offered by occupational therapists to cancer survivors, health care team members and employers. The few interventions as part of government programs and insurance programs included some vocational rehabilitation support, assistance with self-employment, skills for employment, provision for assistive devices, retraining, medical and rehabilitation assessments, and compensation for returning to work; however, not all cancer survivors are eligible for these benefits (most programs are dependent on the survivor or employer having paid into these programs before becoming ill).

³ Other chronic disease groups/organizations have expressed concerns associated with returning to work. For example, 10% of those within the labour force, or 1.4 million working adults, have been diagnosed with depression (Gallson and Chenier, 2005). Interventions, policies and programs that support these individuals include flexible time, income or benefits whether or not they are working, meaningful work and a supportive work environment, but these remedies are often identified as barriers or gaps (Gallson and Chenier, 2005).

⁴ Occupational physicians diagnose and treat illnesses caused by the industrial environment.

The Scope of the Work

The Cancer Journey's National Survivorship Working Group requested that an environmental scan be conducted to determine existing support services and/or educational and/or training programs and/or online resources and practical tools available for people living with cancer and other chronic diseases as they return to the workplace during or after treatment.

Two specific project goals were articulated:

1. Create a comprehensive list of support services and/or education and/or training programs and/or online resources and practical tools for employees returning to or managing at work that currently exist which address workplace issues for people living with cancer and other chronic diseases.
2. Establish contact with and interview key developers and providers of these support services and/or education and/or training programs and/or online resources and practical tools.

The environmental scan was conducted in two iterative phases:

1. A web-based review, assessment and synthesis of RTW programs and resources related to cancer and chronic disease in Canada and internationally for those programs and resources related to cancer specifically.
2. Up to 20 in-depth key informant interviews with representatives of relevant programs (i.e., developers, providers), cancer and chronic disease associations.

Phase I: Web-Based Search for RTW Resources

Our first objective for the web-based review was to clearly define and articulate the criteria, search terms and framework for the web-based research. To accomplish this task, we consulted with experts in the RTW field and conducted a brief literature review to identify the specific search criteria and terms to use in the web-based research. We created a web-search framework that was then approved by the Partnership. A full description of the web-search methodology is available in Appendix A.

The second objective was to identify RTW resources and programs related to cancer and chronic diseases **in Canada** and to identify potential key informants that we could interview about their understanding of the objectives and components of these programs. Our third objective was to identify RTW resources and programs relevant to cancer only **outside of Canada** and to identify potential key informants that we could interview about the objectives and components of these programs. A collection of resources was created and is available in a separate Excel file (see Appendix B).

Our last objective was to review, synthesize and assess the resources that we collected in the web search. The following section provides a review and assessment of these resources.

Findings

We scanned 8,280 websites for relevance to RTW and an additional 105 websites were targeted and reviewed (cancer organizations and organizations identified by the expert consultation process). We collected 200 web-based English-language resources and 1 French-language resource in an Excel spreadsheet (Appendix B) and examined them more closely as RTW resources. At the end of our search we had 90 resources that focused on supporting employees as they returned to work. Additionally, we found the names of 39 potential key informants to interview (identified from resource reports, names offered by expert consultants, the Partnership working group and through snowball sampling as well as by calling the organization offering the program). A summary table captures the country of the intervention, host organization, health focus, website address, the search date, description of resource, type of resource and where the resource is now located (Appendix B). The following three tables outline a summary of the web-based resources identified. Tables 2 and 3 are a breakdown of Table 1.

Table 1. Web-Based Resources: Country

	# of Web Resources Searched
Canada	146
United States	21
United Kingdom	18
Netherlands	7
Australia	4

Table 2. Web-Based Resources: Health Focus

	# of Web Resources Searched
Cancer	84
Workplace*	50
Mental Health	19
General**	15
Disabilities	9
HIV	7
Lung	4
Arthritis	3
Diabetes	3
Heart	2

* Note that workplace refers to a targeted search of the top 50 companies in Canada as rated by the Globe and Mail.

** General indicates those resources dedicated to RTW and health and wellbeing.

Table 3. Web-Based Resources: Type of Resource

	# of Resources
Program	18
Guide	17
Information Sheet	17
Report	8
Publication	8
Service	7
Booklet	6
Workshop	4
Brochure	4
Discussion Paper	2
Guide for Employers	2
Resource List	2
Service for Employer	2
Video	2
Workbook	2
Resource for Health Care Professional	2
Association	1
Best Practices	1
FAQs	1
Information Session	1
Member Network	1
Online Course	1
Pilot	1
Presentation	1
Problem Cards	1
Program for Employer	1
Project	1
Resource Center	1
Screening Tool	1
Training Guide	1

Highlights from Phase I

- The majority of the online resources were cancer-related and most of the key informants were in the cancer field in Canada (note: our methods were focused on picking up cancer-related and Canadian-focused resources).
- The resources identified included mainly programs, guides, information sheets, services, reports, publications and booklets.

- In terms of RTW resources in other chronic diseases, the field of mental health has produced the most work available on the Internet.
- Some of the online resources focus on RTW following workplace injury (e.g., Ontario's Workplace Safety and Insurance Board).
- There are a number of resources that focus on employer management of RTW (e.g., policies, best practices) but resources for employers were not included in the scope of this project. Employer resources are the focus of a separate project funded by the Partnership.
- The targeted search of the top companies in Canada revealed almost no RTW information online for employees. Only three companies – Cisco Systems Inc. (Canada), Ivanhoé Cambridge and Nexen Inc. – have information on RTW available online for their employees. This RTW information focuses on general work and wellbeing information.
- Much information on the web focuses on the factors influencing RTW and statistics related to RTW. This is the scope of a separate Partnership-funded initiative and will be captured in that body of work.
- Although our scope of work and web-search strategy did not include online RTW resources directed toward health care professionals, we note there appears to be an absence of RTW resources for this group. This seems to be a glaring gap since some intervention-related literature points to the importance integrating the role of health care professionals, with employers and the individual to facilitate the RTW experience.

Phase II: Key Informant Interviews

The key informant interview phase allowed us to confirm and expand on the findings from the web-based research and obtain more detailed information and supporting documentation on relevant RTW programs and resources.

Methods

In preparation for this phase of the work, the Partnership and the consultants participated in a priority-setting exercise to determine which resources to analyze fully and which key informants to contact from the list of potential contacts that emerged from the web-based review in Phase I. It was decided that the consultants should:

- Focus on understanding more about *programs and services* and to contact those key informants who know most about the selected interventions.
- Contact key informants about programs and services in cancer and in the *HIV and mental health fields* where there appears to be more RTW activity.
- Submit the list of key informants to the Partnership for approval.

Twenty-six organizations were identified during the web-based review and from input from the project's working group as offering an RTW program and/or service. Of these organizations, 2 had no current RTW program, 2 did not have a core RTW component or focus to their program or service, 2 were involved as part of a partnership with other organizations included on the list, and 4 did not return requests for an interview. As a result, 16 key informants were interviewed about their organization's RTW programs and services. Of these, 3 organizations had more than one program or service (Wellspring, BCCA, and Cancer and Careers). In these instances, key informants were asked to speak about each program or service for a total of five programs and services, thus information was obtained about 21 different programs and services from 16 organizations.

In addition to using the web-based review and working group input to identify potential key informants, the open-ended responses to a concurrent Partnership national online survey of cancer survivors and caregivers were reviewed to identify other potential RTW programs and services and an email was sent to three experts in the field of RTW and cancer. These steps did not yield any RTW programs or services that we had not already identified, and we feel we have captured most of the English-language interventions⁵ in this field (noting that we are limited by what we found in the web review and by what key informants chose to share with us about their interventions).

The key informants represented a variety of organization and program/service types. Organizations were based in Canada or internationally, represented both not-for-profit and for-profit organizations and were focused on cancer, mental health or HIV/AIDS. Key informant interviews were conducted by telephone between September and December 2011 in two stages.

In Stage 1, the project team piloted the interview guide with three key informants of the first six programs to ascertain the completeness and suitability of questions. No additional questions were identified. In Stage 2, the project team completed the remaining interviews. All interviews were digitally recorded and transcribed verbatim. An information sheet about this project was disseminated via email to all key informants in advance of their interview. This material included a description of the purpose and background of the project and the interview protocol (see Appendices C and D). We asked key informants to talk about the program history, target audience, program components, program evaluation and any recommendations for future interventions. All participants were offered an honorarium of \$50. See Table 4 for a complete list of included programs.

⁵ Please note that after the web-based review the Partnership identified a French-language program (Cancer J'écoute) which is included as one of the 21 RTW interventions.

Table 4. Included Programs

Name of Program	Name of Host Organization	Location
Returning to Work	Wellspring	Toronto, Canada
Back at Work	Wellspring	Toronto, Canada
Money Matters	Wellspring	Toronto, Canada
Vocational Rehabilitation Counselling Service	British Columbia Cancer Agency (BCCA)	Vancouver, Canada
Return to Work Program	BCCA	Vancouver, Canada
Cancer Survivorship Transitions to Employment Project (STEP) <i>*inactive</i>	Princess Margaret Hospital (PMH)	Toronto, Canada
Return to Work Program <i>*inactive</i>	Northeast Cancer Centre	Sudbury, Canada
Navigation System™	CAREpath Incorporated	Toronto, Canada
Resources for Life after Cancer	Memorial Sloan-Kettering	New York, United States
Vocational Rehabilitation Pilot Project (VRPP)	Macmillan Cancer Centre	United Kingdom
One-to-one RTW coaching	Do Some Good	Sittard, Netherlands
Career coaching	Cancer and Careers	New York, United States
Educational presentations, etc.	Cancer and Careers	New York, United States
Support groups	Cancer and Careers	New York, United States
Working Beyond Cancer	Cancer Council	Sydney, Australia
Life After a Cancer Diagnosis <i>*inactive</i>	Cancer J'ecoute: Canadian Cancer Society (Quebec)	Montreal, Canada
National Telephone Assistance Line/ Educational Outreach	Cancer Legal Resources Centre	Los Angeles, United States
HIV and employment workshops <i>*inactive</i>	Canadian Working Group for HIV and Rehabilitation	Toronto, Canada
Employment Action	AIDS Committee of Toronto	Toronto, Canada
Mental Health Works	Canadian Mental Health Association	Toronto, Canada
Working Through It	Great West Life	Toronto, Canada

Analysis

Following each interview, the raw data from the interview was summarized in tables, mapping directly from the interview guide questions (see Appendix E). The transcript data were then read: 1) to ensure that all relevant information was captured in the summary feedback form and 2) to discover any other or emergent themes. The thematic data are presented below along with illustrative quotes (in italics) from different key informants.

The summarized raw data are categorized under the following headings:

- Background and Description of Program
- Target Audience

- Promotion
- Participation
- Content
- Program Materials
- Program Duration
- Where Offered
- Cost to Employee and/or Employer
- Program Evaluation
- Multi-pronged Programming
- Key Informant Recommendations

Findings

This section summarizes the findings from across the programs and services. See Appendix E for a program-specific summary and see Appendix F for a condensed summary by program or service. We also collected information about programs from the HIV and mental health communities, as directed by the Partnership. The information concerning these programs has been integrated into the summary below.

Background and Description of Program

All programs were developed between 1988 and 2012, with the majority of programs created between 2000 and 2010. All programs were created to deliver information, support, education, legal advice or options about RTW issues.

Programs include one-on-one vocational or emotional counselling or coaching or rehabilitation or case management about RTW issues (either in person, online or on the phone), group workshops or webinars or teleconferences, online forums or videos regarding these issues, and psycho-educational group sessions.

So the background was...based on the literature...that survival rate is going up, that people are facing all kinds of issues including (workplace) accommodation and difficulties with transitions. (Survivorship Transitions to Employment Project, or STEP)

It started probably around 2006, 2007, we started to hear from our members that we were doing great work with all of our supportive programs but there was this push for many to return to work for a variety of reasons, and that they felt as if there was a gap in knowledge, services, resources, in helping to address that. (Returning to Work)

Huge interest, huge turnout and a lot of people who I feel finally had someone where they could ask the questions, that money worries were put on the table, it wasn't a stigmatised topic and people just wanted to say hey, can I talk all about me. So we found that there was a large need for more individualized (programming). (Money Matters)

Many times (vocational counselling) is one-off, but sometimes it's not. For example, if I feel there isn't an available community resource and that they need the ongoing support, I do phone counselling sessions. (Vocational Counselling)

...we chose seven (Vocational Rehabilitation [VR] proposals) to go forward. Of those seven they all have a slightly different approach. Some were using staff who have experience as employment and health advisors from the government condition management program. Some were based within a hospital setting. Some were based around a particular location that was in partnership with (a cancer information centre)... at the end of it, we want to know that we've got the best model that will enable us to provide VR services. (VRPP)

(Cancer Legal Resource Centre) was actually a brainchild of a former Dean of Loyola Law School. His wife had been diagnosed with cancer, and he really saw a need for providing access to free legal information and resources. At the time nothing else existed, so it was really the first of its kind to be able to provide that type of information. (Cancer Legal Resource Centre)

We want to empower those that are looking to return to work to have the knowledge and the resources at their disposal to be able to do so. (HIV and Employment Workshops)

Most programs were provided by a non-profit health-focused organization like a treatment centre, a community-based organization or a national health service organization. Two programs – Navigation System and Do Some Good – are offered by for-profit organizations.

Target Audience

All programs we reviewed targeted individuals living with cancer (or HIV or mental health). Money Matters, Navigation System, VRPP, Working Beyond Cancer Workshop, Cancer Legal Resource Centre and Cancer J'ecoute also invite caregivers and family members to participate in their programs. Cancer and Careers' educational seminars and Cancer Legal Resource Centre's services are also offered to health care professionals. The Working Beyond Cancer Workshop, Cancer Legal Resource Centre, Mental Health Works, and HIV and Employment Workshops also invite employers, coworkers and human resource professionals into their programs.

Some programs have criteria for participation. The types of criteria for participation include: 1) must not have returned to work (e.g., Returning to Work), 2) returned to work only (Back at Work), 3) those who have finished treatment (e.g., Return to Work—Northeast Cancer Centre), and 4) those who are working on RTW issues with an insurance company or through their employer and therefore have a third-party payer (e.g., Navigation System, Do Some Good). Most programs have no criteria for participation and invite all participants in all circumstances: those on disability, unemployed and those who have already returned to work; some programs focus on both paid and unpaid work (e.g., VRPP, Return to Work—Northeast Cancer Centre, Resources for Life After Cancer, Working Beyond Cancer).

Work we defined not only paid work but we also defined it as volunteer or in the home because some of the topics that were discussed were very transferable to either work in the home sphere or in the paid work sphere. So we didn't limit that definition of work to be paid. (Return to Work—Northeast Cancer Centre)

Where age of participants was known, most participants were over the age of 40 years but all the programs and services are available to adults of all ages. Some organizations also recognize the unique work-related needs of young adults and offer RTW programming specific to this population (e.g., Careers and Cancer).

...we are always trying to provide services for (young adults)...because they do have their own unique set of career issues because they are early in their career, they don't have as much of a background, their resume might not be as filled out... (Cancer and Careers: Support Group)

Promotion

Participants find out about these programs or services through a number of mechanisms, including word of mouth from other participants or participants' family members and friends, community organization newsletters, websites, email, brochures to patients delivered via regular mail, health professionals, posters, through clinics in the cancer centre and/or survivorship programs, via Facebook, a universal telephone number or helpline, American Cancer Society, through the employer, or at conferences and training events. One informant spoke about the value of having champions promote the program.

One of the things we found...was that it really helps enormously to raise the profile if you can get one or two... senior health care, oncologists, doctors, medical directors. So you need your champions at a senior level. (VRPP)

Participation

Across the programs we interviewed the key informants about, participation is as low as three members per group or session to up to 30 members for group sessions and up

to 500 clients per year for one-on-one sessions (Resources for Life after Cancer) or 4,500 per year for the provision of telephone-based legal options (Cancer Legal Resource Centre). Some key informants noted that interest and participation in these programs is increasing over time (e.g., Money Matters, Return to Work Program, Cancer Legal Resource Centre). The majority of the programs are accessed through self-referral, although some cancer centres have their health professionals refer clients to their in-house RTW programming. Those who access one-on-one assistance receive the service for up to 10 times in the cancer community and once a week for up to 6 months in the HIV community.

Some programs may purposefully target a particular gender, but our research shows that predominantly women participate in the cancer-related programs or services. For online programs, the gender and cancer type of the user is typically not known. Primarily men access the HIV resources. It is unknown who primarily uses the mental health online resources.

And what has the response been (for Money Matters)... Oh, it's huge. We started with 8 hours of case managers (per week) and now we're up to ...46 hours (per week) in the span of 2 years... (Wellspring)

Content

The following components are featured across the various programs.

Personal Support

- Emotional support, coping with change and loss
- Coping with stress, self-care and work-life balance while coping with cancer and lifestyle changes
- Dealing with side effects or late effects such as fatigue, cognitive impairment, body image and anxiety about RTW
- Challenges at home during RTW
- Learning from the experience of peers from a variety of work settings who have returned to work
- Preparing a post-treatment survivor support plan

We...would have a guest peer speaker attend, somebody who came out the other side and they were now returned to work and how that happened to them. Sort of normalized and validated their concerns but also was a role model...despite the struggles and difficulties, they can fall into place and you can be back to work...and the changes they made as a result of having cancer, at work and at home. (Return to Work—Northeast Cancer Centre)

Employment Support

- Assessing readiness to return and preparing a vocational rehabilitation plan
- Communication, assertiveness, negotiating with employer, insurance representatives, health care team
- Disclosure of diagnosis in the workplace
- Preparing for meetings with colleagues in the workplace (concerns about stigma)
- Workplace accommodations
- Returning to the same job, making a career change, early retirement, vocational counselling, career coaching and career assessment
- Job search assistance, including handling gaps in resume, networking, mentoring, online personal branding (e.g., privacy issues when using social media)
- Workplace politics

...so gaps on the resume and how to address them in an interview is huge, especially when people are looking for jobs. Those are probably two of the biggest questions in terms of the job search piece. In terms of you're already employed but you just got diagnosed with cancer, those questions range from how do I tell my employer, do I have to tell my employer? (Cancer and Careers: Coaching)

Financial and Insurance Support

- Navigating insurance options: employment insurance (EI), long-term disability (LTD) or short-term disability (STD)
- Job-lock (inability to leave a job because employee benefits will be sacrificed) due to insurance
- Financial information (including income tax, estate planning, income replacement, information about government programs)

So we really try and deal with all the financial issues in a one-stop place, so everything from planning for today, planning for the next year, helping, advocating. (Money Matters)

Legal Support

- Legal information and advice: employment law, human rights, discrimination, health insurance, disability insurance and legal advocacy

Other Support

- Case management
- Resource referral, references about RTW issues

- The needs of caregivers in the workplace

Program Materials

Materials to support the programs include classroom and online workbooks, online videos, leaders' manuals, links to government forms, information handouts and summary care plans (e.g., details of diagnosis and treatment, recommendations for follow-up and to reduce late effects, resources for continuing care). Many key informants referred to resources that they provide to their participants (see Appendix G for more information).

Program Duration

Programs were offered either as a one-off (as offered in a Money Matters one-on-one appointment or one-off classroom session in the STEP program or Resource for Life After Cancer educational workshop) or as more lengthy psycho-educational and counselling sessions or courses (e.g., Returning to Work, Employment Action). If participants had already returned to work, the services tended to be offered during the evening or online. Course sessions are typically 1.5 to 2 hours in length and vary in terms of how often they are offered (e.g., once a week, once a month, twice a quarter, three or four times per year). The longest (one-time) session is a full day (one program only: Working Beyond Cancer Workshop). Two organizations arrange conferences concerning RTW issues (Cancer Legal Resource Centre, and Cancer and Careers) at least yearly.

A few resources are offered on the Internet and are therefore always accessible (e.g., Working Through It, STEP). Telephone sessions are used for one-on-one counselling (Cancer and Careers: Coaching, Cancer Legal Resource Centre, Navigation System) or for education purposes (e.g., Cancer and Careers: Educational Seminars).

One participant offered that the timing of offering the group was very important, stating that RTW programs should be offered to participants who were close to returning or who were nearing the two-year mark of being on LTD.

So it's interesting...if you tie (a program) into returning to work, (participants) sort of felt that they had to be really close to returning to work to even sign up for a returning-to-work group...and six months from attending the returning-to-work group, the vast majority return to work. (BCCA: Vocational Counselling)

Where Offered

Programs were offered over the telephone, by videoconference, online or in person at a treatment centre or a community-based organization and in several different countries.

Cost to the Employee or Employer

All reviewed programs were free for the clients and the costs were covered by either a third-party payer, such as the employer or insurance company (Navigation System, Do

Some Good), or by a non-profit national or community-based organization or treatment facility (e.g., Cancer Legal Resource Centre, HIV and Employment Workshops).

Program Evaluation

One-on-one interventions (e.g., vocational rehabilitation counselling or coaching, psychotherapy) were not typically evaluated. Evaluations were usually conducted for educational sessions or workshops and for group-based programming. However, these evaluation forms and/or reports were primarily not publicly available. The exception to this is the Macmillan Cancer Centre, National Cancer Survivorship Initiative, which evaluated its vocational rehabilitation pilot project. This evaluation, of which some interim reports have already been released, will provide detailed findings on seven different pilot sites and interventions. The final report will be available in the spring of 2012. The following are some of the interim findings (National Cancer Survivorship Initiative, 2011).

- Patients want assistance for RTW issues beginning early in the cancer trajectory and continuing through follow-up.
- Health professionals inadvertently give patients mixed messages about work.
- Managers are poised as a key stakeholder between patients and employers but need more knowledge and skills to manage RTW.
- Patients lack information about their employment rights and responsibilities.
- Vocational rehabilitation (a not-well understood term) services can prevent problems (especially for those with complex needs) and no training program for vocational rehabilitation services in cancer currently exists.
- Gaps exist in RTW support in terms of access to good-quality information.

The consultants were also provided with access to an evaluation report of the Working Beyond Cancer Workshop that indicated that among participants (which included cancer survivors, caregivers, employers and health care professionals): 83% were interested in practical and emotional issues, 71% financial issues (including superannuation), 70% exercise and nutrition, 68% communication, 60% issues related to caregivers and 57% managing employees.

In the absence of more available evaluation information, the following anecdotal comments were made during the key informant interviews.

- A two-hour group-based program is too short, a full day is too long. (BCCA: Return to Work)
- Programs whose participants are back at work are not well-attended. (Wellspring: Back at Work)
- The Canada Pension Plan has stated that patients that have received assistance completing LTD forms (e.g., within Wellspring's Money Matters program) are a third more likely to be approved for LTD.

- Memorial Sloan-Kettering’s Resources for Life after Cancer evaluation revealed that participants want peer panellists to represent a range of work experiences and organization types (e.g., non-profit, for-profit).

Multi-pronged Programming

The key informants for these organizations discussed how the RTW program or service can complement other programming offered in the same organization (e.g., group and one-on-one support or counselling, programs addressing side effects, psychosocial support):

- Money Matters, Returning to Work and Back at Work (Wellspring)
- STEP program participants and survivorship clinics (fatigue or lymphedema) at PMH.
- Return to Work program participants (BCCA) are informed about the cancer transitions program, relaxation program or one-on-one vocational rehabilitation counselling.
- Return to Work–Northeast Cancer Centre participants are invited to use one-on-one support following the program.
- Working Beyond Cancer Workshop participants have access to other services, such as legal advice, financial assistance and one-on-one counselling offered by the Cancer Council in New South Wales, Australia.

Key Informant Recommendations

When asked what else these key informants would recommend be included in RTW content, audience, availability and training they suggested the following, in no particular order.

- A focus on insurance and LTD processes
...an LTD insurance company 101 to teach people about how the system works, what are their obligations, what are a typical contract provisions. (BCCA)
- Assertiveness training or confidence-building
- RTW supports and education for small employers
One of the things that we didn’t talk about...is to make the employer as knowledgeable, welcoming, available...you have the vast majority of people who work for a smaller employer where there isn’t an HR professional, there isn’t someone who knows employment law and to just say well, you’re fired, I’m sorry, you’re away too much.... (Wellspring)
- Programs for young adults

- Expand the services that are working really well across the province or country
we're looking at other models that maybe we could look at how do we service more of the rural areas without having a presence there.
(Employment Action)
- Training in employment law for vocational professionals
...we've got a Macmillan help line which is a national number...HR and employment law, it's an area that it's frequently asked about but VR advisors and others don't have that area of skill or knowledge, (so) we've started training our help line advisors and they've undertaken some work on employment and HR issues. I think that probably that's something that we'll have to plan out in the future for some of the other Macmillan professionals. (VRPP)

Assessment Across Phases

The data collected from the web-based review and the key informant interviews was used to determine what was common in terms of structure, objectives and implementation strategies for the majority of the cancer-specific and HIV and mental health RTW interventions. An overview of what was identified from this environmental scan is presented in the statements that follow.

- Most RTW programs and services targeting cancer patients and people with other chronic diseases are comparatively recent, with most having been implemented between 2000 and 2010. There is a broad range of program types, such as information, education, psycho-educational groups, and one-on-one coaching or counselling. There are various mechanisms for program delivery, such as by telephone (one-on-one and group), in person (one-on-one, group and workshop), videoconference and online (general information or one-on-one information). The types of programs and services and the extent of implementation and evaluation of the impact of these interventions have varied considerably. It appears to be difficult to determine best practices.
- From the review of mainly English-language materials from five countries, including Canada, program and service content covers a similar range of topics, even across health concerns (cancer, mental health and HIV). For example, across countries and diseases, RTW content focuses on disclosure, stigma, job preparation, financial information, workplace accommodations, communicating with employers and coworkers, legal information, and dealing with stress and side effects. However, the depth of coverage of and resources provided for each of these topic areas varies depending on program focus.
- Most of the programs are offered to individuals who have completed their treatment. This was done in response to the programs' interpretation of individual readiness for RTW support. However, the evidence suggests employment

- issues can occur or help might be requested by an individual with cancer or other chronic disease from the point of diagnosis onward. As such, there is a gap in program offerings for people who require support at some time prior to completing treatment.
- Many programs offer both general information (through educational workshops) and one-on-one interventions that address individual concerns. Multi-pronged programming within an organization might be a valued resource to the provider and the consumer.
 - Individuals with cancer and those with other chronic diseases may require functional rehabilitation support as a result of the therapies (e.g., surgery) they have received. Our review suggests that the RTW programs and services currently available do not provide functional rehabilitation support. This appears to be an area of opportunity for further development in RTW program design.
 - Six of the 17 cancer-related RTW programs were offered within a cancer institution or cancer treatment centre. The remainder are community-based organizations, private organizations or foundations. It would be interesting to discover whether or not more resources for health professionals would be developed if RTW interventions were implemented more often in cancer centres.
 - All interventions are delivered at no cost to the individual with disease or health concerns. Any associated costs are covered by a third-party payer, for example, insurance or employer.
 - More women more than men attend RTW cancer programs. The programs and services are generally available to all ages; however, participants are often between the ages of 40 and 60 years.
 - Most one-on-one programs (counselling or coaching) are not evaluated.
 - The primary target audience for the majority of cancer programs and services included in the environmental scan was individuals diagnosed with cancer. Less frequently these programs or services were also available to caregivers, co-workers, employers and health care professionals working in the cancer field.
 - Most of the programs are about getting people back to work; few focus on what happens once they get there (e.g., Navigation System, Back at Work) to facilitate, monitor or evaluate reintegration into the workforce.
 - Duration of programs and services varied from as little as a few hours to a day or more. Our review, however, did not yield concrete evidence on the efficacy of different durations for outcomes. Only anecdotal remarks made by key informants suggested that day-long or longer programs appeared to be less effective. Therefore, more work on measuring the impact of length-of-program on outcomes would be warranted.
 - Programs are offered locally, provincially (state-wide) or nationally.

- Most key informants stated the great value of promoting their service widely. The programs or services are primarily not designed to assist the employee RTW by engaging directly with the employer and/or insurance company.
- Most key informants agree that programs offered in health care settings require champions from among senior managers and clinicians to support program implementation and sustainability.

Recommendations

Directions for Future RTW Research and Programming

The development and evaluation of pilot projects should be supported, with an emphasis on programs involving the three intersecting groups – individuals with cancer, health care professionals and employers. The pilot projects should incorporate RTW support across the cancer trajectory, be comprehensive (i.e., embrace multiple elements of RTW issues, including workplace reintegration and follow-up on the integration experience) and have a strong evaluation component. These pilots would generate interest and, if effective, strategies to facilitate long-term sustainability should be identified to provide a solid foundation for this emerging field in Canada.

Given that this field is relatively new, an expert panel of RTW professionals could help inform and advise on best practices, inform the evaluation design and assist in the identification of strategies to support long-term sustainability.

Mechanisms need to be established for knowledge transfer among RTW program providers and agencies and organizations supporting cancer patients and their caregivers, health professionals and employers. Knowledge transfer should include evidence to support program design, program implementation and evaluation.

The knowledge, skills and attitudes of health care professionals regarding supporting the employment needs of patients need to be investigated. Existing resources need to be explored and gaps for health care professionals need to be identified. Based on findings, educational interventions for health care professionals need to be created.

Potential Partnerships

To develop appropriate and beneficial partnerships, follow-up needs to be done with organizations both within and outside of the cancer community (i.e., HIV and mental health) to determine how to engage with and share information to help inform future opportunities.

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Appendix A: Web-Search Methodology

Scope of Review

To identify existing support services and/or educational and/or training programs and/or online resources and practical tools available for people living with cancer and other chronic diseases as they return to the workplace during or after treatment.

We did not include search results for commercial or sponsored sites, images, videos, news items or social media (e.g., Internet forums, blogs) or for resources that are directed at employers or health care professionals. Published literature is only included if it describes or reviews specific RTW programs, interventions or resources.

Overview

A list of possible search terms was developed through a number of steps.

- A review of the Nitkin et al. (2011) paper for relevant keywords
- An expert consultation process with Canadian and international representatives in the cancer, mental health, HIV and episodic disability (where cancer is considered to have episodic qualities when individuals RTW) fields to identify relevant keywords, existing programs and resources, and experts.
- An online search to determine how information in this field describes the “return to work” phenomenon
- Development of a list of relevant national cancer and chronic disease organizations in Canada and Canadian employers

Search Terms

The following is a list* of the *most frequently used terms* and those most likely to yield relevant results.

- | | |
|-----------------------------|-------------------------------|
| • return to work | • work resumption |
| • back to work | • work ability |
| • vocational rehabilitation | • re-employment |
| • vocational counselling | • labour force re-entry |
| • disability management | • occupational rehabilitation |
| • vocational integration | • workplace accommodation |

*The full list of terms considered was: RTW, return to work, returning to work, supported RTW, return to work, BTW, back to work, vocational rehabilitation, vocational counselling, disability management, work reintegration, reintegrate back to work, reintegration in workplace, work return, vocational integration, work rehabilitation, work resumption, workability, work ability, re-employment, workplace integration, workplace reintegration, labour force re-entry, labour force re-engagement, work trial, occupational rehabilitation, workplace accommodation, employment, occupational therapy, work.

Search Engines and Search Structure

We used a metasearch engine, Dogpile.com, to simultaneously access multiple search engines (Google, Yahoo, Bing, Kosmix, Fandango) and aggregate the most relevant searches. In addition, we used Google Chrome independently to ensure we identified the most relevant resources and programs. To increase our search effectiveness, we used available advanced search options to limit searches to English and combined phrase searching with full Boolean logic (AND, OR) as appropriate (see 1 and 3 below).

We used Google to conduct a targeted review of the websites for specific cancer and chronic disease-related organizations, cancer survivorship initiatives, links for resources/programs/organizations identified through the expert consultation process and a review of Canadian workplaces (see 2, 4, 5 and 6 below).

1. A review of cancer-related “return to work” programs and resources in Canada, the United States, the United Kingdom, the Netherlands, Germany, Australia, Norway and Finland
 - Using the metasearch engine Dogpile, a total of 64 different searches were run based on 1 of 8 possible key words⁶ AND cancer AND country. The top 60 hits for each of these searches was scanned for relevance for a total of 3,840 possible hits (64 searches x 60 hits per search).
 - Using Google Chrome, a total of 56 different searches were run based on one of 7 possible key words⁷ AND cancer AND country. The top 60 hits for each of these searches was scanned for relevance for a total of 3,360 possible hits (56 searches x 60 hits per search).
2. A targeted review of national cancer and chronic disease organizations in Canada for any “return to work” initiatives.

Arthritis

- The Arthritis Society: www.arthritis.ca

Asthma (and other pulmonary diseases)

- Asthma Society of Canada: www.asthma.ca
- Canadian Lung Association: www.lung.ca
- Canadian Allergy, Asthma and Immunology Foundation: www.allergyfoundation.ca

⁶ Return to work, back to work, vocational rehabilitation, work resumption, work ability, labour force re-entry, occupational rehabilitation, workplace accommodation

⁷ Return to work, back to work, vocational rehabilitation, vocational counselling, disability management, vocational integration, re-employment

- Canadian Network for Respiratory Care: www.cnrchome.net

Cancer

Canadian Cancer Organizations and Information by Cancer Site (Type) (n=25):
<http://people.ischool.utoronto.ca/marton/CancerOrganzationsCanada.pdf>

- Canadian Cancer Action Network: www.canceraction.ca
- Cancer Advocacy Coalition of Canada: www.canceradvocacy.ca
- Brain Tumour Foundation of Canada: www.btfc.org/braintumour.nsf/eng/home
- Breast Cancer Society of Canada: www.bcsc.ca
- Thyroid Foundation of Canada: www.thyroid.ca
- Lymphoma Foundation Canada: www.lymphoma.ca
- Leukemia and Lymphoma Society: www.leukemia-lymphoma.org
- Colorectal Cancer Association of Canada: www.ccac-accc.ca
- Lung Cancer Canada: www.lungcancercanada.ca
- Myeloma Canada: www.myelomacanada.ca
- National Ovarian Cancer Association: www.ovariancanada.org
- Ovarian Cancer Alliance Canada: www.ovariancancercanada.ca
- Canadian Cancer Society: www.cancer.ca
- Canadian Cancer Research Alliance: www.ccrca-acrc.ca
- Canadian Cancer Action Network: www.ccanceraction.ca
- Canadian Breast Cancer Network: www.cbcn.ca
- Canadian Breast Cancer Foundation: www.cbcf.org
- Prostate Cancer Canada: www.prostatecancer.ca

Diabetes

- Canadian Diabetes Association: www.diabetes.ca

Heart Disease

- Heart and Stroke Foundation of Canada: www.heartandstroke.ca
- Canadian Cardiovascular Society: www.ccs.ca

HIV/AIDS

- Canadian AIDS Society: www.cdnaids.ca
- Canadian AIDS Treatment Information Exchange: www.catie.ca

- Canadian Foundation for AIDS Research: www.canfar.com

Mental Health

- Canadian Mental Health Association: www.cmha.ca
 - Centre for Addiction and Mental Health: www.camh.net
 - Mental Health Works: www.mentalhealthworks.com
 - Presentations and websites from the 4th Annual Canadian Congress for Research on Mental Health and Addiction in the Workplace – We Can Do It – Evidence and Interventions for Transforming Mental Health in the Workplace
3. “Return to work” programs and resources in Canada for the following chronic diseases: arthritis, asthma, diabetes, heart disease, HIV and mental health
 - Using Google Chrome, a total of 18 different searches were run based on 1 of 3 possible key words AND chronic disease terms AND Canada. The top 60 hits for each of these searches was scanned for relevance for a total of 1,080 possible hits (18 searches x 60 hits per search).
 4. A review of the *Globe and Mail*'s 50 Best Workplaces in Canada (2010) and any “return to work” initiatives.

<http://www.lib.uwo.ca/news/business/2010/04/22/schoolsoutyouneedajob50bestplacetoworkincanada.html#2010>

Our search of these 50 companies revealed that information on programs available to employees (e.g., employee assistance programs and disability management programs) is typically not accessible to the general public through online sources.
 5. Review of International Survivorship Initiatives
 - United Kingdom: National Cancer Survivorship Initiative (NCSI)
 - United States: Office of Cancer Survivorship (OCS)
 - Australia: Survivorship Centre (ASC)
 6. Reviewed feedback provided by all participants of the expert consultation process and conducted a targeted search of information for all the relevant resources or programs they identified (n=44)

Appendix B: Web Search Resource Findings

Access the spreadsheet at the link below:

http://www.cancerview.ca/idc/groups/public/documents/webcontent/append_b_return_to_work_prog.pdf

Appendix C: Key Informant Interview Guide

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant Interview Guide

Key Informant Questions

Background or Description of Program

What is the history of how this program was developed? *Probes: How was it determined it was needed? What gap did it fill? When was it first implemented?*

Target Audience

Is this program currently active and available to consumers? If so, how long has it been available; if not, at what stage of development is it in?

Who is the intended audience for the program? *Probes: Age, sex, type of disease/cancer, stage of treatment? Who ends up coming to the program?*

How is the program profiled and how do potential participants hear about it? What has the response been to the program? *Probe: Waitlists?*

Program Components

What are the components of the program? *Probes: What specific work-related issues does it address (e.g., financial issues, legal issues, workplace accommodation)? How was it determined what to include in the resource? Are there any new components/issues that you are considering adding based on participant feedback/response? Program materials?*

How is the program offered? *Probes: How many sessions are there? What is the length of each session? How many times a year is it offered? Where is the program held? How many participants are able to participate? When is this program offered (day, night; times of year)? When should this program be offered (i.e., to reflect where participants are at in the cancer trajectory)?*

Who provides the program (e.g., community organization, benefits organization, workplace, government, union)?

Is there a cost associated with the program? If yes, what is the cost? Who pays for the program (e.g., individual, insurance, company)?

Are there any other resources in your centre or organization that also support individuals to return to work? If so, what are they (employment or financial issues, managing side effects)?

Program Evaluation

What evaluation/assessment has been conducted on the program? *Probes: How was/is the evaluation/assessment conducted? What were the findings and feedback from the evaluation? Is there a report available?*

Going Forward

If you were developing a new program to support people living with cancer return to work, what would you make sure that it included? What other RTW programs are you aware of that we should consider? Any additional comments?

Summary Feedback Form for Interviews

Interview Date _____

Descriptive Information

Organization _____

Country _____

Key Contacts (& Roles) _____

Contact Information _____

Specific Program(s)/ Resource(s) for Discussion	
Target Audience (cancer, mental health, heart disease, diabetes, asthma, HIV/AIDS, other)	
Content (e.g., psychosocial support, financial issues, legal issues, occupational issues, workplace accommodation, workplace integration, vocational rehab other)	
Program Duration (e.g., 1/2 day, 1 hour/week for 5 weeks, online)	
Where Offered (e.g., cancer centre, community organization, workplace)	
Cost (i.e., how much and who covers it: participant, benefits, employer, no cost to participant)	
Program Provider (e.g., community organization, benefits organization, government organization, workplace, unions)	
Evaluation (e.g., impact of program, program assessment if available, program evaluation if available)	
Program Materials	

Appendix D: Key Informant Information Sheet

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Information Sheet

Who is funding this project? The Canadian Partnership Against Cancer is funding the environmental scan and is an independent organization funded by the federal government to accelerate action on cancer control (www.partnershipagainstcancer.ca). The Partnership works with cancer experts, charitable organizations, governments, cancer agencies, national health organizations, patients, survivors and others to implement Canada's cancer control strategy.

What is purpose of this project? To conduct an environmental scan to determine existing support services and/or education and/or training programs and/or online resources and practical tools available for people living with cancer and other chronic disease as they return to the workplace during or after treatment. The results of this national and international scan will provide the National Survivorship Working Group with a more complete understanding of return-to-work programs and services available for persons diagnosed with cancer and other chronic diseases.

What does the project involve? The environmental scan is being conducted in two iterative steps: 1) a web-based review, assessment and synthesis of return to the work programs and resources related to cancer and chronic disease in Canada and internationally for those programs and resources related to cancer specifically; and 2) in-depth key informant interviews with representatives of relevant programs and services.

What would my involvement consist of? A telephone interview would be conducted with the Project Coordinator, at a time convenient to you, to discuss the program or service that your organization offers. We would be interested in learning about a number of aspects of the program or service that your organization offers, including the background leading to its development, program components, how and when it is/was offered and target audience. Interview notes will be taken during the discussion and if agreed, an audio-recording will also be made. A \$50 gift card will be provided in appreciation of your time.

Who do I contact for more information?

Cathy Cameron, Project Coordinator

Tel: (905) 326-6065

Email: cathy.cameron@rogers.com

Appendix E: Program Summaries from Key Informants

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date September 9, 2011

Descriptive Information

Organization Wellspring

Country Canada

Website Information <http://www.wellspring.ca>

Specific Program(s)/ Resource(s) for Discussion	Returning to Work (name recently changed from Return to Work)
Background and Description of Program	<ul style="list-style-type: none"> Developed in 2006/2007; first offered in 2008 Identified a gap in knowledge, services and resources related to RTW; members expressed need for this In 2007, conducted consultations to identify gaps Engaged program developers who focused on emotional issues related to RTW and a vocational rehabilitation counsellor provided practical component Gap existed in RTW programs, some information available online, disability groups were not addressing this issue either Developed pilot group program through this process (focus was always on a group format)
Target Audience	<ul style="list-style-type: none"> Cancer patients (not caregivers) Individuals thinking about returning to work in the next couple of months Typical participants: women (which is similar to participation in other Wellspring programs), individuals on LTD, 40-60 years of age, breast cancer, have completed treatment Group size is usually between 8–20 participants, would want at least 6 and no more than 20 per program Have had some interest from caregivers and from individuals who also have issues influencing work but not cancer; these individuals are not eligible to participate
Content	<p>2 individual sessions available to both program participants and other Wellspring members:</p> <ol style="list-style-type: none"> Government programs and services LTD and employment law presented by a lawyer

	<p>8-week core program:</p> <ol style="list-style-type: none"> 1. Group norms, confidentiality, story sharing, self-assessment survey 2. Grief and change, acknowledging change, adaptation 3. Skills from past transitions 4. Parameters of jobs, skills and abilities 5. Panel presentation of other Wellspring member's experiences (on videotape) 6. Communication skills (e.g., with colleagues, bosses, accommodations) 7. Self-care <p>Group wrap up, self-assessment and reflection</p>
Program Duration	<ul style="list-style-type: none"> • Each session is 2 hours for 8 weeks • Offered during the day; tried offering it at night but there was less interest • Runs 2 times per year in several locations
Where Offered	<ul style="list-style-type: none"> • Community organization • Was piloted in Greater Toronto Area Wellspring centres • Then trained staff at other Wellspring centres • Currently offered at all sites in the Wellspring Network (e.g., Niagara, London, Calgary, Toronto, Halton-Peel, Chinguacousy)
Cost	No cost to participants
Program Provider	Community organization
Promotion and Participation	<ul style="list-style-type: none"> • Maintain a list of individuals who want to participate • Promote program through newsletter, other program materials
Evaluation	<ul style="list-style-type: none"> • Participant self-assessment tool that is used at the start and end of the program • Conduct an in-depth evaluation that is used for quality improvement
Program Materials	<ul style="list-style-type: none"> • Leaders Training Manual • Workbook for participants (not well utilized)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date September 9, 2011

Descriptive Information

Organization Wellspring

Country Canada

Website Information <http://www.wellspring.ca>

Specific Program(s)/ Resource(s) for Discussion	Back at Work
Background and Description of Program	<ul style="list-style-type: none"> • Had been running the Return to Work program and felt that there was a programming gap in addressing issues that emerged when individuals went back to work • Developed program in 2009/2010 with a program developer and staff person • Has been offered 3 times since 2009/2010 • Always have had small attendance (< 7 people per program) • Offered it two times and it was not very successful; felt that the content was not meeting the needs of participants (e.g., too much focus on emotional versus practical needs) • Revised program and pilot tested second version in early 2011 • Program is still considered a pilot
Target Audience	<ul style="list-style-type: none"> • Cancer patients (not caregivers) • Individuals who are back at work and are experiencing work-related issues • Typical participants: unlike the RTW program, this program seems to have a broader range of participant characteristics (e.g., in terms of age, gender) though all have returned to work (mostly within the past year) • Group size is usually <7 (not all complete program) • Program is not for individuals who have returned to work and are not experiencing problems
Content	<p>8-week core program:</p> <ol style="list-style-type: none"> 1. Group norms, confidentiality, story sharing, self-assessment survey 2. Model of change 3. Demands, stresses, resources 4. Change: what stressors and challenges are being experienced and identifying solutions and action steps 5. Momentum of change, attitudes and communication 6. Reinvention 7. Employment law with a presentation and discussion by a lawyer 8. Self-care, group wrap up, self-assessment and reflection

Program Duration	<ul style="list-style-type: none"> • Each session is 2 hours for 8 weeks • Offered in the evening • Runs once per year
Where Offered	<ul style="list-style-type: none"> • Community organization • Was piloted in GTA Wellspring centres • Halton-Peel will be pilot testing it again
Cost	No cost to participants
Program Provider	Community organization
Promotion and Participation	<ul style="list-style-type: none"> • Maintain a list of individuals who want to participate • Promote program through newsletter, other program materials • Have not had sufficient interest to offer it again at Odette
Evaluation	<ul style="list-style-type: none"> • Participant self-assessment exercise at start and end of program • Good to have a leader with vocational experience as well as cancer experience for this program since the focus might be more practical • Conduct an evaluation of each program
Program Materials	<ul style="list-style-type: none"> • Leaders Training Manual • Workbook for participants (not well utilized)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date September 9, 2011

Descriptive Information

Organization Wellspring

Country Canada

Website Information http://www.wellspring.ca

Specific Program(s)/ Resource(s) for Discussion	Money Matters
<p>Background and Description of Program</p>	<p>2002–2005: Discussion series</p> <ul style="list-style-type: none"> • Offered as part of Wellspring’s discussion series; 2-hour, one-time session • Discussion series is available to members and caregivers • There was huge interest and excellent turnout; many expressed need for individual, one-on-one information <p>2005: One-on-one appointments</p> <ul style="list-style-type: none"> • Started offering one-on-one appointments (e.g., credit counseling, debt issues, income replacement options, help completing government/insurance forms) — conduct intake and assessment • Approximately 1.25-hour appointments <p>2008: Develop full Money Matters program</p> <ul style="list-style-type: none"> • Includes the two above components: one-on-one appointments and discussion series • Expanded to include: <ul style="list-style-type: none"> – Two case managers: search for relevant resources, advocate on client behalf, contact government programs for them – A resource centre at Women’s College Hospital – Training of social workers and other health care providers in Ontario cancer centres – Government liaison work (individuals come onsite to meet with members, specific case workers for Wellspring members) – Specialized clinics (e.g., wills and estate clinic, powers of attorney, income tax clinic, employment law and legal clinic)
<p>Target Audience</p>	<ul style="list-style-type: none"> • Cancer patients and caregivers • Men and women, across all income levels • Reflects Wellspring’s membership • Need to be < 65 since income programs change at 65 and over • Most individuals are over 45 years of age

Content	Includes but is not limited to <ul style="list-style-type: none"> • Employment insurance • Income replacement • Employment law • Income tax • All financial issues in one place
Program Duration	Varies depending on aspect of program
Where Offered	<ul style="list-style-type: none"> • Case management services is offered only at the Women's College Hospital resource centre (do not provide phone counselling) • Other centres are interested in offering this service
Cost	<ul style="list-style-type: none"> • No cost to participants • Some of the specialty clinics are means-tested: if you meet the income criteria, you can access the services; if not, you are not eligible
Program Provider	Community organization
Promotion and Participation	<ul style="list-style-type: none"> • High demand for services • Have increased the total time provided by the two Case Managers from 8 hours/week to 46 hours/week in 2 years • Money Matters has the highest number of new members attending compared to other Wellspring programs (approximately 50% are referred by social workers) • Promoted through newsletter
Evaluation	<ul style="list-style-type: none"> • CPP has indicated that individuals who have help completing the forms are 1/3 more likely to be approved
Program Materials	<ul style="list-style-type: none"> • Resource centre provides income and RTW resources (e.g., relevant government forms) • Money Matters Manual — available to members only (not publicly available) — not well used by members, but health care providers really like it (used for training)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date September 20, 2011

Descriptive Information

Organization British Columbia Cancer Agency (BCCA)

Country Canada

Website Information <http://www.bccancer.bc.ca/default.htm>

Specific Program(s)/ Resource(s) for Discussion	Vocational Rehabilitation Counselling Service
Background and Description of Program	<ul style="list-style-type: none"> • Service has been available since 1994 when the need was identified based on survey to examine needs of cancer survivors • Consultations offered in person at Vancouver Centre and Fraser Valley Cancer Centre, and by phone to cancer patients across the province • Individuals with disabilities often need an individual approach to address vocational rehabilitation concerns; there is a proportion of individuals who attend the RTW group program that also access one-on-one counselling • See description of service Content section below • Also public education forums (Partners in Care)
Target Audience	<ul style="list-style-type: none"> • Self-referral • No strict eligibility criteria, usually within 2 years post-treatment • Cancer patients (not caregivers) • Clients are working age, more breast cancer patients, head and neck cancers, some with pre-existing disabilities; slightly more women
Content	<p>Provides assistance for individuals with work-related issues or concerns including:</p> <ul style="list-style-type: none"> • Vocational counselling • Career assessment • Case management • Negotiating with employer • Rehabilitation counselling • Job search assistance • Education (individual and public) • Resource referral <p>Also provides support to colleagues (e.g., social workers, clinical counsellors) whose clients are experiencing RTW issues</p>
Program Duration	Number of times an individual is seen varies and depends on their challenges, but approximately 3 to 5 sessions
Where Offered	<ul style="list-style-type: none"> • Through cancer centre

	<ul style="list-style-type: none"> • By phone for individuals in other parts of British Columbia • Would like to offer it through Telehealth
Cost	No cost to participants
Program Provider	Cancer Centre
Promotion and Participation	<ul style="list-style-type: none"> • Self-referral • Referrals from other colleagues (e.g., clinical counsellors, social workers) • No waitlist • Interest and referrals to service seem to be increasing • Where appropriate, refer to other community resources
Evaluation	No evaluation of one-on-one counselling
Program Materials	<p>Have developed some information sheets:</p> <ol style="list-style-type: none"> 1. Disclosing your Cancer Experience at Work 2. Returning to Work and Long-Term Disability Forms (for brain tumour patients) 3. Things to Consider when Returning to Work 4. Return to Work Checklist 5. Tips for Working with a Vocational Rehabilitation Counsellor from an Insurance Company

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date September 20, 2011

Descriptive Information

Organization British Columbia Cancer Agency (BCCA)

Country Canada

Website Information <http://www.bccancer.bc.ca/default.htm>

Specific Program(s)/ Resource(s) for Discussion	Return to Work Program
Background and Description of Program	<ul style="list-style-type: none"> • Developed first pilot in late 2010 as a 1.5-hour presentation • Content of program based on experience and themes that have emerged through vocational rehabilitation counselling work • Developed the full pilot program as 3 half-day sessions run over 3 weeks, organized based on the 3 main components outlined in Content section below. This version ran 2 times. It was hard for participants to commit to all three half days. • Recently tried the session as one full day. Participants found this too long, too much information all at once. Will not offer it in this format again. • Runs 4 times per year • Next time going to offer 2 half-day (3-hour) sessions • Facilitated by the vocational rehabilitation counsellor and a Masters in vocational rehabilitation student • Content developed based on themes that had emerged through experience of vocational counsellor and based on a consideration of what would work well in a group format versus one-on-one
Target Audience	<ul style="list-style-type: none"> • Self-referral • No strict eligibility criteria • Cancer patients (not caregivers) • Working age, more breast cancer patients, nice mixture of participants • Intended for individuals who are considering returning to work (usually within the next 6 months) • Offers a job search session at the same time as this program for those individuals that are not returning to their same job • Conducts a pre-screening of interested participants to identify those individuals who might benefit more from the job search program or from one-on-one vocational rehabilitation counselling

Content	<p>1) Preparing rehabilitation plan</p> <ul style="list-style-type: none"> • Self-assessment • Existing resources • How to talk to your physician • Review of assessment <p>2) Workplace wellbeing</p> <ul style="list-style-type: none"> • Healthy lifestyle • Self-care • Self-esteem • Boundaries • Assertiveness <p>3) Preparing to return to work</p> <ul style="list-style-type: none"> • Preparing colleagues • Preparing employers • Negotiating return to work • Human rights • Workplace accommodations
Program Duration	Plan to offer program 4 times a year
Where Offered	Cancer centre
Cost	No cost to participants
Program Provider	Cancer Centre
Promotion and Participation	<ul style="list-style-type: none"> • Self-referral • Referrals from other colleagues (e.g., clinical counsellors, social workers) • No waitlist • Register approximately 15 participants per session and average about 12
Evaluation	<ul style="list-style-type: none"> • Evaluation is conducted each session • Workplace wellbeing session is the most well received (self-care, assertiveness, self-esteem)
Program Materials	Not mentioned during interview

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date September 21, 2011

Descriptive Information

Organization Princess Margaret Hospital

Country Canada

Website Information Program inactive – no website

Specific Program(s)/ Resource(s) for Discussion	Survivorship Transition to Employment Project (STEP)
Background and Description of Program	<ul style="list-style-type: none"> Created in 2007 and implemented 2007-2009 Designed to help transition survivors to better manage employment while living with cancer and to scaffold survivors back into the workforce by helping to build new skillsets Part of grant from the Canadian Council on Learning In-class intervention then online modules and resources
Target Audience	<ul style="list-style-type: none"> 28 participants for classroom component; 7 went on to register for the online course All were post-treatment breast cancer 75% were between 45 and 60 years 37.5% were receiving LTD
Content	<p>Classroom course: led by two clinicians and both classroom and online contained following modules:</p> <ul style="list-style-type: none"> Module 1: How ready am I to return to work? Module 2: What do we know about survivors' workplace experiences? Module 3: Learning about financial support Module 4: Creating a personal employment plan and preparing for: <ul style="list-style-type: none"> Returning to the same job Making a career change Early retirement Resources for information and support References and further reading
Program Duration	2 hours for a one-time workshop offered weekly over a 10-month period
Where Offered	Princess Margaret Hospital (with access to online resources)
Cost	No cost to participants
Program Provider	Princess Margaret Hospital

Promotion and Participation	<p>Promoted in the Breast Cancer Survivorship Program, the PMH Patient and Family Library, Oncology Social Workers at PMH and through the breast cancer clinics and breast imagine waiting area</p> <ul style="list-style-type: none"> • self-referred • most interest in classroom portion though
Evaluation	<p>Conducted as part of study for this pilot</p> <p>Participants wanted the following changes:</p> <ul style="list-style-type: none"> • Increase length of class (and modify class so not so ambitious to cover job search, new career search, career exploration) • Enable folks to participate in either online course or in-class intervention • Tailor the workbook and the online course to reflect the various streams patients are interested in exploring: returning to the same job, changing careers, early retirement and volunteering • Many planned to refer to the workbook after course • Include information to increase confidence/assertiveness
Program Materials	<ul style="list-style-type: none"> • Course workbook • Online version of workbook, including online resource links

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date October 7, 2011

Descriptive Information

Organization Northeast Cancer Centre

Country Canada

Website Information No website

Specific Program(s)/ Resource(s) for Discussion	Return to Work Program
Background and Description of Program	<ul style="list-style-type: none"> • First developed in 2008 as a result of a small group of women who were experiencing RTW challenges • Program was developed with 4 sessions, each 2 hours long, held over consecutive weeks, during the day • Since then the program has been offered approximately 3 times • Program has not been held in the past 2 years primarily due to lack of demand; individuals who have needed RTW support received it on a one-on-one basis
Target Audience	<ul style="list-style-type: none"> • Cancer patients who have completed treatment • Did not limit it to paid work; could include volunteer work, work in the home etc. • Not limited by cancer diagnosis but participants to date have been mainly breast cancer survivors • Men and women although to date participants have been women; would like to increase participation by men if offered again • Participants averaged roughly 50 years of age • Approximately 5 to 10 per program
Content	<p>Organized as 4 sessions:</p> <ol style="list-style-type: none"> 1. Overview of group processes, confidentiality, financial and systemic stressors of cancer 2. Coping with fatigue, changes in body image, cognitive functioning and memory 3. Emotional impact of cancer: multiple roles and healthy boundaries 4. Moving forward: peer guest speaker; was well received <p>Participants with ongoing concerns following the program can continue to see the social worker for one-on-one support</p>
Program Duration	<ul style="list-style-type: none"> • During the day • 2 hours a week for 4 weeks • Looking to expand this to 6 sessions over 6 weeks
Where Offered	Cancer centre; some participants joined the group via telemedicine
Cost	No cost to participants

Program Provider	Northeast Cancer Centre
Promotion and Participation	<ul style="list-style-type: none"> • Self-referral • Listed on the referral forms that the primary nurses and allied health professionals use • One-on-one RTW support is provided if no group is being run; have also received training through Wellspring's Money Matters professional training • Offered the program based on need and workload • Did try promoting the program with a poster and did not receive any referrals; most referrals come through the referral forms used by cancer centre health professionals • Was offered based on need
Evaluation	No evaluation has been conducted to date; plan for research project
Program Materials	Handed out materials that the Northeast Cancer Centre provides (e.g., ChemoBrain, Chemo Fog)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date October 20, 2011

Descriptive Information

Organization CAREpath Inc.

Country Canada

Website Information www.carepath.ca

Specific Program(s)/ Resource(s) for Discussion	Navigation System™: Individualized, one-on-one emotional support and medical advice
Background and Description of Program	<p>CAREpath Inc. delivers an advice, information and support program for clients with cancer. Canadian-owned and privately operated, CAREpath's specialized, evidence-based Navigation System is a complement to provincial health services.</p> <ul style="list-style-type: none"> • Provides informal RTW counselling while counselling clients • Most individuals want and/or need to return to work • Counselling and case management done by trained nurses; where possible matched with clients based on expertise with different cancers • Takes into consideration type of job when counselling about RTW (e.g., teaching environment higher potential for infections)
Target Audience	<ul style="list-style-type: none"> • Cancer patients across 200 different cancer types • Employees, spouses and children (eligibility for service would depend on the specific contract that a certain employer/insurance company had negotiated with CAREpath) • Service is not available to the general public even on a for-fee basis; it has to be through an employer or insurance company • Have contracts with a broad range of employers (e.g., teachers, health care professionals, lawyers) • The patient is their client until the end of active treatment (average 9 to 12 months) • They do a 6 and 12 month follow-up post-treatment
Content	<ul style="list-style-type: none"> • Not a formal dialogue about RTW but emerges as part of overall plan/counselling; talk also about lifestyle changes, regaining control, graduated RTW options, financial issues such as LTD, STD • Have a survivor support plan post-treatment for follow-up
Program Duration	Date and time for telephone meetings are prearranged
Where Offered	<ul style="list-style-type: none"> • All case management services are offered one-on-one by telephone • Office based in Toronto but provides national service by telephone

Cost	<ul style="list-style-type: none"> • No direct cost to participants • Not a billable OHIP service • Cost is paid by employer/insurance company
Program Provider	Private company
Promotion and Participation	Did not ask since vocational counselling is not a separate activity/ service/program but rather emerges throughout the overall support and counselling provided to clients
Evaluation	<ul style="list-style-type: none"> • Have a detailed electronic medical record that tracks RTW variables (e.g., work history, status at time of diagnosis, when they return to work) • Use this data to demonstrate return on investment (ROI) for employers/insurance companies, to show how it makes a difference in terms of employees returning to work, length of time off work • Have a lot of statistics about how long individuals will likely be off work based on type of cancer and treatment regimen; this information helps manage expectations and planning • Also have an exit survey that allows clients to provide feedback on overall service; done by an external reviewer
Program Materials	<p>At the end of treatment, the patient is given an individualized Summary Care Plan that contains the following types of information:</p> <ul style="list-style-type: none"> • Date of diagnosis • Cancer type, stage and markers • Summary of initial treatment • Toxicities resulting from initial treatment • Recommendations to reduce potential late effects of treatment • Recommendations for surveillance • Identification of providers who will coordinate specific aspects of continuing care

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date November 2, 2011

Descriptive Information

Organization Memorial Sloan-Kettering Cancer Center Survivorship Program
(LiveStrong Centre of Excellence)

Country United States

Website Information No website

Specific Program(s)/ Resource(s) for Discussion	Resources for Life after Cancer
Background and Description of Program	<ul style="list-style-type: none"> • Received a 5-year Centre of Excellence grant from the LiveStrong Foundation for capacity building for this survivorship initiative (one of 8 LiveStrong Survivorship Centres of Excellence) • 2 different components: workshop and one-on-one counselling • Have always had an awareness of work-related challenges following cancer diagnosis and recognized that work is part of the adjustment after cancer
Target Audience	<ul style="list-style-type: none"> • Self-referral • Participants of all services within the Resources for Life after Cancer represent all types of cancers, sex and age • Can be on disability, unemployed, have returned to work and are looking to make a change
Content	<p>Cancer Survivorship in the World of Work Workshop</p> <ul style="list-style-type: none"> • Been offering the workshop once a year for the past 5 years • Panel of volunteers (employees) from Goldman Sachs (8-10 panellists) • Panellists often have had cancer themselves or within their family • Questions and answers, breakout into smaller networking groups as well • Approximately 25-30 individuals usually participate • Address issues such as gaps in resume, networking, mentoring, insurance ('job-locked' can't leave because of insurance), disclosure of cancer in workplace • 2 social workers facilitate workshop • 1 hour in length <p>Smaller Workshop</p> <ul style="list-style-type: none"> • A smaller workshop was also held once with the 2 employment physicians that are on staff (role is to provide support to staff members) and a human resource person from Goldman Sachs • Similar to the other workshop but smaller (12-15 participants)

	<p>One-on-One Counselling</p> <ul style="list-style-type: none"> • Have provided counselling services since 1988 • 2 social workers but 1 developing expertise in employment and vocational counselling • Provide individual counselling • Most individuals have 8-10 sessions (approx. 45 mins each) • Based on a crisis intervention model, problem solving • Refer to other resources as required (e.g., psychotherapist, Cancer and Careers, legal help, discrimination)
Program Duration	<p>Workshop</p> <ul style="list-style-type: none"> • Offered once a year in the summer <p>One-on-one Counselling</p> <ul style="list-style-type: none"> • Ongoing on an as-needed basis
Where Offered	New York
Cost	No cost to participants
Program Provider	Hospital
Promotion and Participation	<ul style="list-style-type: none"> • Self-referral • Raise awareness through targeted outreach, including website, email and mail communication, included in a brochure that goes out two times a year, Facebook • Able to see anyone who contacts them, no waitlist • 500 individuals/year/counsellor; overall, not just work-related
Evaluation	<p>Workshop:</p> <ul style="list-style-type: none"> • Have evaluated the workshop with participant feedback • Participants have liked the workshop; however, they have noticed in the past few years that there has been a change of climate and participants are less receptive to the panel being made up exclusively of Goldman Sachs employees and from a banking perspective • Will modify the panel next year to include a broader representation of work (e.g., not-for-profit) <p>One-on-One Counselling:</p> <ul style="list-style-type: none"> • Has not been evaluated since it is a counselling service
Program Materials	None mentioned
Other Resources	Suggested contacting Cancer and Careers program (www.cancerandcareers.org), a not-for-profit organization in New York, and the NYLAG (www.nylag.org/legalhealth.htm), which provides legal support

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date October 24, 2011

Descriptive Information

Organization Macmillan Cancer Centre

Country England

Website Information <http://www.Macmillan.org.uk/Home.aspx>

Specific Program(s)/ Resource(s) for Discussion	Vocational Rehabilitation Pilot Project
Background and Description of Program	<ul style="list-style-type: none"> • Emerged in 2009 as part of the National Cancer Plan and Cancer Care Review of the National Cancer Survivorship Initiative and falls within the Work and Finance workstream • Conducted a national scan of RTW programs and services and identified a gap • Seven pilot sites were selected in April 2010 to test a four level model of vocational rehabilitation • Each pilot site implemented the pilot differently, most were led by a National Health System-based organization • All pilots will be completed by March 31, 2012
Target Audience	<ul style="list-style-type: none"> • Self-referral • Individuals diagnosed with cancer and of working age • Priority was for individuals with cancer who were already employed to support maintaining employment and then individuals diagnosed with cancer who were unemployed • Some caregivers • Work was defined as both paid and unpaid • All types of cancer, although some pilot sites focused on common cancers (e.g., breast) or on rarer cancers (e.g., brain)
Content	<p>Three levels of programming across sites:</p> <ol style="list-style-type: none"> 1. Hard copy early information and support for employers, professionals and patients 2. Help lines and face to face for one-on-one discussion 3. Self-management programs; case managers with employment expertise and specialist rehabilitation services (OT, PT, psychological services etc.) <p>7 pilot sites</p> <ol style="list-style-type: none"> 1. VR advisors work with cancer centre social worker to provide written and online resources 2. Self-management group program that includes fatigue, exercise focus 3. Adapted a clinical VR model from multiple sclerosis to focus on cognition, function and help with graded RTW

	<p>4. Rehabilitation program with 6-month follow-up</p> <p>5. VR project manager mapped existing services and sources of support across a region</p> <p>6. A private consultancy firm offering career development and coaching</p> <p>7. A skills and knowledge audit of clinical nurse specialists and identified training needs in work support/VR</p> <p>For more information see: http://www.ncsi.org.uk/what-we-are-doing/vocational-rehabilitation/vocational-rehabilitation-pilot-sites/vocational-rehabilitation-pilot-sites-continued/</p>
Program Duration	Throughout pilot period
Where Offered	Pilot sites throughout England
Cost	No cost to participants
Program Provider	National Health Service-based
Promotion and Participation	<ul style="list-style-type: none"> • Self-referral • Raised awareness through printed materials and referrals from clinical nurse specialists, outpatient clinics, information at cancer information centres, universal telephone number that provided triage service • 500 individuals have used the VR services to date (Sept/11 report); a smaller number of individuals require one-on-one support; approximately 100–150 individuals accessed the more complex case management level
Evaluation	<ul style="list-style-type: none"> • Formative and summative evaluation was conducted • 4 reports are currently publicly available (see PDFs): <ul style="list-style-type: none"> – Vocational Rehabilitation Strategy Paper — A proposed model of vocational rehabilitation in cancer – Evaluation of the Vocational Rehabilitation Pilot Projects — Early Findings (September 2010) – Evaluation of the Vocational Rehabilitation Pilot Projects — Second Interim Report (June 2011) – Evaluation of the Vocational Rehabilitation Pilot Projects (September 2011) • 5 learn and share events were held throughout 2010/2011 • A final evaluation report will be released in February 2012
Program Materials	<ul style="list-style-type: none"> • Booklet • Range of materials may be described more in the final report
Other Resources	<ul style="list-style-type: none"> • Macmillan Cancer Centre has a Learn Zone with online courses and resources for cancer patients • Cancer in the Workplace — Employee Perspective (also have an employer resource and one for trade unions) — online resource with 5 units: <ul style="list-style-type: none"> – Breaking the News – Confidentiality and Colleagues – Rights and Responsibilities – Carers and Treatment – Importance of Work

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date November 16, 2011

Descriptive Information

Organization Do Some Good

Country Netherlands

Website Information <http://www.dosomegood.nl>

Specific Program(s)/ Resource(s) for Discussion	Do Some Good Company
Background and Description of Program	<ul style="list-style-type: none"> • Information sessions and one-on-one coaching for individuals with cancer and other illnesses • Began in 2007 part-time and then 2010 full-time • In the Netherlands, the employer has a responsibility to the employee for the first 2 years following diagnosis; full pay for 1st year and 70% pay for 2nd year • After 2 years, the employee becomes the government's responsibility to support; employers can be fined by the government if it is deemed that they did not do enough to support patient's RTW, which sometimes causes problems between employer and employee because the employer might pressure employee to RTW to avoid fines.
Target Audience	<ul style="list-style-type: none"> • All cancer types • More women than men • Majority 40 years and older • Majority have completed treatment • Started with a cancer focus but is now expanding to include other illnesses — for example MS, colitis, heart disease — since impact on work and changes in life and relationships is similar although majority of client base is still cancer • Also provides support to employers (e.g., information sessions with HR professionals)
Content	<p>One-on-one Coaching</p> <ul style="list-style-type: none"> • Help both employee and employer • Issues discussed include how to return safely, help with fears they may have, how to prepare for meetings with colleagues, addressing challenges at home, recommendations for exercise • Each session 1.5-2 hours in length • Clients have approximately 8-10 sessions over 5-7 months • Issues and challenges are very different for each individual depending on their individual work and family situation although lack of energy is a big issue

	<p>Free Information Sessions — examples of topics:</p> <ul style="list-style-type: none"> • Challenges associated with RTW • Fatigue • Sessions are about 2 hours in length and held every 2-3 months • Hear about challenges, tips, what they need to know, how to interact with employer
Program Duration	Ongoing on an as-needed basis
Where Offered	Netherlands
Cost	<ul style="list-style-type: none"> • No cost to participants • Services paid for by employer or insurance company (2,000–4,000 Euros/client) • ROI for employer to get employees back to work
Program Provider	Private company
Promotion and participation	<ul style="list-style-type: none"> • People find out about service through employer, Internet, hospital (e.g., through nurses) • Promote service to hospital and employers
Evaluation	<ul style="list-style-type: none"> • Have implemented some monitoring and evaluation of service but too soon to make any statements on this • Most people are not aware of the difficulties associated with RTW; 2 problems: 1) either they return too fast and think they have the same capacity as before or 2) they are afraid to RTW because of lack of energy
Program Materials	None discussed
Other Resources	Other small companies in Netherlands offering similar coaching programs (see Appendix B)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date December 5, 2011

Descriptive Information

Organization Cancer and Careers/Cosmetic Executive Women (CEW) Foundation

Country United States

Website Information www.cancerandcareers.org

Specific Program(s)/ Resource(s) for Discussion	Career Coaching
Background and Description of Program	<ul style="list-style-type: none"> • In 2001, Cancer and Careers was developed as part of the Cosmetic Executive Women (CEW) Foundation (trade organization for women in the beauty industry) • The CEW Foundation is a New York-based non-profit trade organization of 4,000 executives in the beauty, cosmetics, fragrance and related industries • A number of women on the board had cancer and recognized a gap in the issue of work and cancer • At that time the CEW Foundation funded a couple of organizations but decided to make Cancer and Careers their sole initiative • Cancer and Careers is dedicated to empowering and educating people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events • Resources include a website, publications, career coaching, support groups and educational seminars for employees with cancer and their healthcare providers and coworkers • Website (www.cancerandcareers.org) has more than 180,000 visitors per year • The career coaching service was started about 4-5 years ago
Target Audience	<ul style="list-style-type: none"> • Online career coaching can be accessed by anyone, but the target audience is individuals diagnosed with cancer who are experiencing work issues • Majority of service users are 1–2 years from diagnosis; however, some are newly diagnosed or a number of years beyond the end of treatment • Initially the focus was on women diagnosed with cancer, but in 2010 the organization rebranded, revised its mission statement and now provides services to both genders
Content	<ul style="list-style-type: none"> • Currently have 6 active career coaches who provide pro bono services (most professional coaches, some HR experience, some cancer background) • Individuals submit questions that the Manager of Programs forwards onto the career coaches • Broad range of questions including how to address gaps during interviews and on resumes, what to ask for in terms of accommodation, if and what to tell their employer, what resources are available to address work-related issues

	<ul style="list-style-type: none"> • Questions and responses are publicly available and archived so that other individuals can benefit from the questions and answers — posts are organized by topic on the website: <ul style="list-style-type: none"> - Career change - Career management - Image and professionalism - Interviewing - Job search - Resume building and writing - Work, life and cancer balance - Workplace politics • Manager of Programs also reviews posts and makes referrals for the client in addition to forwarding to the career coaches
Program Duration	<ul style="list-style-type: none"> • Offered online • Available anytime via Internet access
Where Offered	Available online (office based in New York City)
Cost	No cost to participants
Program Provider	Community non-profit (funded by Cosmetic Executive Women Foundation)
Promotion and Participation	<ul style="list-style-type: none"> • This service is becoming more popular • Have had 52 posts to date for 2011
Evaluation	<ul style="list-style-type: none"> • No evaluation has been conducted to date of the online career coaching • Do not collect information about type of cancer or age
Program Materials	No program materials specific to the online career coaching, but numerous resources available online
Other Resources	<ul style="list-style-type: none"> • Online resources include a comprehensive publication entitled <i>Living and Working with Cancer</i> (see PDF) • On-the-Go guides that provide information about more specific issues (e.g., fitness, nutrition, make-up tips) • <i>Living with Cancer as a Chronic Illness</i> booklet (see PDF)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date December 5, 2011

Descriptive Information

Organization Cancer and Careers/Cosmetic Executive Women (CEW) Foundation

Country United States

Website Information www.cancerandcareers.org

Specific Program(s)/ Resource(s) for Discussion	Educational seminars, presentations and teleconferences
Background and Description of Program	<ul style="list-style-type: none"> • Developed in 2001 as part of the Cosmetic Executive Women (CEW) Foundation (beauty trade organization for women) • <i>See summary sheet for Cancer and Careers — Career Coaching for more background information on the organization</i> • Educational seminars, presentations and teleconferences (2008). Initially organized and conducted educational seminars, but now doing more partnering with other organizations to offer this service in conjunction with other events (e.g., Colon Cancer Alliance's National Conference on Work and Treatments; Cancer Legal Resource Centre conferences; Cancer Care podcasts; Association of Oncology Social Work annual conference)
Target Audience	Individuals with cancer, health care professionals, coworkers
Content	<p>Presentations</p> <ul style="list-style-type: none"> • Could include following topics/issues: <ul style="list-style-type: none"> - Communicating with health care team - Who, when and how to tell employers/coworkers - How much information to share - Modifying workspace, reasonable accommodations - Modifying work schedules (flex time, work from home, scheduling breaks) - Identifying a point person in the office - Networking and interviewing skills - Online branding (e.g., privacy settings on Facebook, LinkedIn) <p>Teleconference Series for Health Care Professionals</p> <ul style="list-style-type: none"> • In 2009, held a 3 part educational series for health care professionals (accredited series): <ul style="list-style-type: none"> - Legal issues - Practical tips to advise patients - Advising patient to re-enter workforce after treatment - Each session 1-hour long (45-min presentation, 15-min Q&A)

	<p>Teleconference Series for Patients, Survivors: Ask the Expert</p> <ul style="list-style-type: none"> • Started in 2011 • 2 calls were organized per quarter (one with career coach and one with legal expert) • Each call had a different focus (e.g., job search, legal issues) <p>1 hour in length (30-min presentation, 30-min Q&A or 60-min Q&A only) and participants register in advance</p>
Program Duration	<p>Teleconference Series for Health Care Professionals</p> <ul style="list-style-type: none"> • Runs twice a year <p>Teleconference Series for Patients, Survivors: Ask the Expert</p> <ul style="list-style-type: none"> • 2 calls quarterly, have held 9 calls this year • Tried different times 1:00, 6:30 and 9:00 p.m.; time does not seem to influence participation
Where Offered	<ul style="list-style-type: none"> • Presentations: in person at conferences, events etc. • Teleconference Series: register online
Cost	No cost to participants
Program Provider	Community non-profit (funded by Cosmetic Executive Women Foundation)
Promotion and Participation	<ul style="list-style-type: none"> • 30–50 individuals typically participate in each patient and survivor teleconference series • Most recent health care professional teleconference series had 143 participants
Evaluation	Have had very positive feedback to teleconference series
Program Materials	No specific program materials mentioned for the support group but extensive resources available on website
Other Resources	<ul style="list-style-type: none"> • National Conference on Working with Cancer; next on June 22, 2012 (will cover financial concerns, relevant laws, re-entering workforce, self-employed, young adult issues) for cancer survivors and accredited for health care professionals (oncology nurses and social workers) • Job Accommodation Network • Cancer Legal Resource Centre: 90% of referrals are for legal advice • Cancer Care: Cancer and Careers speaks at well-attended telephone workshops that Cancer Care holds • Manager's Toolkit (see PDF): something that individuals who have been diagnosed with cancer can print off and hand to their manager; helps facilitate discussion with employer

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date December 5, 2011

Descriptive Information

Organization Cancer and Careers/Cosmetic Executive Women (CEW) Foundation

Country United States

Website Information www.cancerandcareers.org

Specific Program(s)/ Resource(s) for Discussion	Support Groups
Background and Description of Program	<ul style="list-style-type: none"> In 2001, Cancer and Careers was developed as part of the Cosmetic Executive Women (CEW) Foundation (trade organization for women in the beauty industry) See <i>summary sheet for Cancer and Careers – Career Coaching</i> for more background information on the organization Two in-person support groups are available — one general group in 2009 and one for young adults in the Fall, 2010
Target Audience	<ul style="list-style-type: none"> Individuals working during or after treatment who are living in New York City When they realigned their mission statement last year they took out caregivers Target audience is now: cancer patients, survivors, health care professionals and coworkers of people working with cancer
Content	<ul style="list-style-type: none"> Monthly New York City-based support groups for people working during or after treatment In-person support group Held once a month at their office in New York City with a social work consultant 2 different groups: <ul style="list-style-type: none"> General group: Balancing Work and Cancer <ul style="list-style-type: none"> Focuses on balancing work and cancer For individuals that are either working through cancer treatment or are cancer survivors who have work issues (e.g., looking for a job) Same issues that come up in online career coaching Sometimes there is a guest speaker to address issues that are coming up in the group Group leads itself in terms of what is discussed each session Group facilitator contacts participants before each group since there is food provided so she knows how many to expect Majority of participants have finished treatment Approximately 15 individuals participate

	<p>Young Adults and Cancer group</p> <ul style="list-style-type: none"> - Target audience is for those 21-40 years of age - The work concerns in this age group can be unique because they are early in their career (not as much background or work experience) - This also reflects the general movement in the United States to provide services to the young adult (YA) community — survival rates for this population have not improved - Sometimes guest speakers
Program Duration	<ul style="list-style-type: none"> • Offered in person • Once a month
Where Offered	<ul style="list-style-type: none"> • New York City • Only program/service they offer that is in person and available only in New York City • All other programs/services are national
Cost	No cost to participants
Program Provider	Community non-profit (funded by Cosmetic Executive Women Foundation)
Promotion and Participation	<ul style="list-style-type: none"> • Approximately 15 individuals typically attend each of the general support group Balancing Work and Cancer • Approximately 7 individuals attend the young adult group support program • Promotion: word of mouth primarily (not posted on website yet), also referrals from local health care professionals, from American Cancer Society phone support line and people using the Internet • Cancer and Careers tries to be an integral part of cancer community (e.g., attending events, presentations, etc.)
Evaluation	No evaluation discussed
Program Materials	No specific program materials mentioned for the support group but extensive resources available on their website
Other Resources	<ul style="list-style-type: none"> • Cancer and Careers held their first national conference on Work and Cancer in June 2011; planning another one for 2012 • Mentioned Cancer Legal Resource Centre (see summary sheet)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date December 5, 2011

Descriptive Information

Organization Cancer Council, New South Wales

Country Australia

Website Information <http://www.cancercouncil.com.au/editorial.asp?pageid=1>

Specific Program(s)/ Resource(s) for Discussion	Working Beyond Cancer Workshop
Background and Description of Program	<ul style="list-style-type: none"> • Living Well After Cancer: people asking about workplace programs, questions about workplace challenges • An employee of a company called Mortgage Choice attended the Cancer Council's Living Well After Cancer and also noted a gap addressing RTW issues • Mortgage Choice then partnered with Cancer Council NSW to deliver the workshop • First held a few years ago • 3-4 per year; could hold more but are limited by resources • 1 day event to help educate individuals who want to RTW about rights and making this transition; addresses challenges working through and after treatment
Target Audience	<ul style="list-style-type: none"> • Cancer patients, survivors, caregivers, employers, human resource professionals, work colleagues • Anyone experiencing challenges associated with cancer and work, including the employer's perspective on having individuals with cancer in their workplace • Broad mix of participants works well; participants receive validation from each other and discuss diverse issues; employers develop a greater understanding of the challenges and complexities of the workplace issues faced by cancer survivors and caregivers
Content	<ul style="list-style-type: none"> • Preregistration required; agenda is reviewed with the individuals to ensure it is something they want to attend and they are asked what they hope to get out of the workshop • Workshop agenda: <ul style="list-style-type: none"> – Practical and emotional issues around returning to work or continuing to work – Legal and superannuation issues – Exercise at work and beyond – Human resources from both sides – Caregiver needs in the workplace – Financial and practical support

	<ul style="list-style-type: none"> The workshop serves as a doorway to other services (e.g., pro bono legal advice, financial assistance, one-on-one counselling) and if they have specific issues they can be dealt with following the workshop because they are given the information they need about where to go for additional support
Program Duration	<ul style="list-style-type: none"> Offered in person 1 day event Held on a Saturday
Where Offered	City of Sydney
Cost	<ul style="list-style-type: none"> No cost to participants Mortgage Choice provides volunteers and catering to host the event
Program Provider	Cancer Organization
Promotion and Participation	<ul style="list-style-type: none"> Approximately 30–45 participants per workshop Participants include those just diagnosed, still in treatment and finished treatment Promote the workshops through website; existing network of social workers, psychologists and oncologists; posters and flyers; Cancer Centre helpline Maintain a list of people who have expressed an interest when calling to inquire about the workshop and tell them when the next workshop is scheduled Do not currently have resources to go outside Sydney area, although demand is there
Evaluation	<ul style="list-style-type: none"> Conduct a pre/post evaluation Whether information presented can be applied to the participant's life, addressing concerns they may have had and feedback on program format and venue
Program Materials	Have handouts on a table during workshop that provide relevant resources
Other Resources	<ul style="list-style-type: none"> <i>Cancer, Work and You</i> is a new publication About to launch a new website Considering programming for young adults (18–45); noted that workplace challenges are going to be high on the list of priorities in the future as young adults are treated more successfully

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date December 13, 2011

Descriptive Information

Organization Cancer Legal Resource Centre (CLRC)

Country United States

Website Information www.CancerLegalResourceCenter.org

Specific Program(s)/ Resource(s) for Discussion	National Telephone Assistance Line and National Educational Outreach
Background and Description of Program	<ul style="list-style-type: none"> • The Cancer Legal Resource Centre was founded in 1997 to offer access to free legal information and resources • CLRC is a joint program of the Disability Rights Legal Center and Loyola Law School • Free information and resources on cancer-related legal issues include insurance coverage, taking time off work, access to health care and government benefits, and estate planning • Two main program/service streams: <ul style="list-style-type: none"> – National Telephone Assistance Line – National Educational and Outreach Program (e.g., webinars, seminars, conference presentations) • Do not provide legal advice or direct representation but inform people of their options, applicable laws and resources
Target Audience	<ul style="list-style-type: none"> • Cancer survivors, caregivers, health care professionals, employers, and others coping with issues related to cancer • All cancer types, majority 30–60 years of age, 60% women
Content	<p>National Toll-Free Telephone Assistance Line (866-THE-CLRC)</p> <ul style="list-style-type: none"> • Information about relevant laws and resources staffed by supervised law students • Members of the CLRC’s volunteer Professional Panel (n=300) of attorneys, insurance agents and accountants are also available to provide additional assistance if needed; only approximately 5% of calls are referred to this panel • Issues that are discussed fall into three main categories: <ul style="list-style-type: none"> – 20% employment-related (e.g., how to work through treatment, accommodations, employer policies, options if not able to work through treatment, disclosure and discrimination issues), – 30% related to health insurance issues and coverage, – 20% related to disability insurance, time off work and other issues (e.g., estate planning, family law) • Follow-up calls are made with any additional information

	<p>National Educational Outreach</p> <ul style="list-style-type: none"> • Conference presentations, seminars, workshops, education and outreach programs and training for health care professionals • Respond to requests for educational outreach • Webinars are held once a month on a specific topic (e.g., taking time off work, disability insurance, health insurance, health care reform, estate planning, insurance navigation and appeals, genetic discrimination) • Cancer Rights Conference; held in 2010, 2011. Planning 4 more in 2012 • Legal advocacy: such as writing to support a bill
Program Duration	<p>National Toll-Free Telephone Assistance Line</p> <ul style="list-style-type: none"> • 5 days a week (M-F), 9–5 p.m. (Pacific Time) • Individuals can also complete and submit online intake forms at any time and will be followed up with a call once reviewed <p>National Educational Outreach</p> <ul style="list-style-type: none"> • Monthly throughout the year and across the United States
Where Offered	Based in California but is a national service
Cost	<ul style="list-style-type: none"> • No cost to users • Organizations requesting educational outreach services are asked to pay for travel costs
Program Provider	Non-profit organization: funded by grants and donations
Promotion and Participation	<ul style="list-style-type: none"> • Receive approximately 4,500 calls/year • Educational outreach increases call volumes • Promoted through extensive outreach within the cancer community in the United States (e.g., American Cancer Society, LiveStrong) and through Internet
Evaluation	<p>National Toll-Free Telephone Assistance Line</p> <ul style="list-style-type: none"> • All individuals receive a follow-up questionnaire or can complete online survey; response is positive but low <p>National Educational Outreach</p> <ul style="list-style-type: none"> • Response has been very positive, meets a real need
Program Materials	<ul style="list-style-type: none"> • No specific program materials mentioned • Telephone assistance users receive tailored material by mail
Other Resources	<ul style="list-style-type: none"> • Legal aid organizations exist that also provide legal support but there are no other organizations they are aware of that provides the educational outreach that CLRC does related to legal issues and cancer • Some organizations and services provide information for specific cancer types (e.g., breast cancer)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date December 20, 2011

Descriptive Information

Organization Canadian Cancer Society (CCS) – Montreal

Country Canada

Contact Information cancerjecoute@quebec.cancer.ca

Specific Program(s)/ Resource(s) for Discussion	Life after a cancer diagnosis (official title for program still undecided)
Background of Program	<ul style="list-style-type: none"> • This program was developed based on a research initiative (2009) that included 50 participants looking at issues faced after a cancer diagnosis • Presentations and workshops were created based on the data from this research initiative • In January 2011, a group of 35 cancer patients, caregivers, employers, volunteers, psychologists and human resources professionals were invited to pilot the program. They attended the presentations and were asked to provide feedback and detailed evaluation, and to identify gaps. • The presentations have been reviewed; CCS expects to promote the program in early 2012
Target Audience	<ul style="list-style-type: none"> • Cancer patients, caregivers, couples • Participants will be recruited through CCS offices across the province, the web, services such as phone line (Cancer J'ecoute) • Planning to promote program in newspaper if enrolment is low
Content	<ul style="list-style-type: none"> • Psychosocial support, occupational issues, workplace integration, insurance, legal issues, vocational rehab, social perception of cancer • 8 PowerPoint presentations offered by trained professionals (e.g., sexologist, sociologist, psychologist, human resources professional) • 2 of the workshops will focus on issues related to returning to work during or after treatment
Program Duration	<ul style="list-style-type: none"> • 8 workshops on different topics (2 on RTW issues) offered over 2 full days split over 2 consecutive weekends (Wk #1: Workshops A,B,C,D; Wk#2: Workshops E,F,G,H) • Participants select the workshop they would like to attend based on the challenges they are facing; groups will be mixed • Planning to offer the program 8 times in 2012
Where Offered	<ul style="list-style-type: none"> • The workshops will be offered at CCS – Quebec Division in Montreal. CCS will make travel arrangements and cover the costs for those who need to travel to attend the workshop.

Cost	<ul style="list-style-type: none"> • No cost for the participants, CCS is covering all expenses • CCS is currently looking into possible funder to cover expenses related to the workshop
Program Provider	<ul style="list-style-type: none"> • CCS – Quebec Division • Workshops are offered by paid professionals
Evaluation	<ul style="list-style-type: none"> • Program evaluation will be conducted using an evaluation questionnaire for each of the workshops • Each participant will be followed up with a phone call after attending the program as an evaluation
Program Materials	<ul style="list-style-type: none"> • PowerPoint presentations have been created • Kit with info sheet on various subjects with common Q&A

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date November 16, 2011

Descriptive Information

Organization Canadian Working Group on HIV and Rehabilitation (CWGHR)

Country Canada

Website Information www.hivandrehab.ca

Specific Program(s)/ Resource(s) for Discussion	HIV and Employment Workshops
Background and Description of Program	<ul style="list-style-type: none"> Offered between July 2009 and March 2010 in 6 locations across Canada (Vancouver, Montreal, Toronto, Calgary, Winnipeg, St. John's) Some funding available during an 8-month window to develop and offer employment workshops for individuals living with HIV
Target Audience	<ul style="list-style-type: none"> Individuals living with HIV Other workshop participants included service providers and employers, although majority were individuals living with HIV Range of participants in terms of work experiences and current situations (e.g., some participants had been off work for years, some currently employed) More men than women, which is typical for HIV programming
Content	<p>One-day workshops</p> <ul style="list-style-type: none"> Organized as a series of presentations that ranged from 20 minutes to 1.5 hours each Started workshop with personal testimonials that identified challenges and solutions Speakers represented both not-for-profit and for-profit organizations of different sizes and types because this influences issues related to disclosure, resources and support All workshops had speakers that represented <ul style="list-style-type: none"> vocational rehabilitation employment law (issues related to duty to accommodate, disclosure, rights and responsibilities, living with an illness and being employed) human resource specialist (to present the employer's perspective regarding communication and maintaining relationships) Workshops were video recorded and edited versions are available on the Episodic Disabilities Employment Network (EDEN) website (www.edenCanada.ca) Employment journeys are so varied that they often require case management; provided referrals to participants if required for further support (through private practices, community-based organizations, government services, WSIB)

	<ul style="list-style-type: none"> • Had a literature table with local resources
Program Duration	<ul style="list-style-type: none"> • One-day workshops • Offered between July 2009 and March 2010 while funding was available
Where Offered	Canada; workshops that were held at local community organizations were more relaxed and participants more engaged than the workshops that were held in hotels
Cost	<ul style="list-style-type: none"> • No cost to participants; some participant mileage or child care covered if required • Workshop supported by funding CWGHR received
Program Provider	Community-based organization
Promotion and Participation	<ul style="list-style-type: none"> • Worked with local organizations and a point person to identify the best ways to promote the workshop (e.g., through membership lists, posted hard copy flyers) • 70 participants across 6 workshops (10–25 per workshop)
Evaluation	<ul style="list-style-type: none"> • Pre-post evaluation conducted • Positive feedback, modified some presentations, time for questions • Most participants indicated that they learned something from the workshop
Program Materials	None discussed
Other Resources	<ul style="list-style-type: none"> • Work experiences really vary (e.g., currently employed, contemplating returning to the workplace, long-term survivors who have been out of work for years), therefore case management is also important • Employment Action is the only employment support for individuals with HIV in Canada (included as key informant)

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date November 14, 2011

Descriptive Information

Organization AIDS Committee of Toronto (ACT)

Country Canada

Website Information www.actoronto.org

Specific Program(s)/ Resource(s) for Discussion	Employment Action
Background and Description of Program	<ul style="list-style-type: none"> • Vocational counselling and training programs for people living with HIV/AIDS (PHAs) • Employment Action works with PHAs to help them re-enter the workforce after periods of unemployment or long-term disability • Began in 1999 after treatment resulted in increased chronicity of HIV and increased demand for vocational support • 6 vocational rehabilitation specialists and 15 volunteers
Target Audience	<ul style="list-style-type: none"> • Self-referral • Individuals living with HIV in the Greater Toronto Area • Initially clients were white, gay men and clients now also include new Canadians, women, youth, long-term survivors, self-employed • Population served often has high educational backgrounds • Clients can be long-term survivors (e.g., 6–15 years out of work-force) or be experiencing shorter-term disability-related work interruptions • Also conducts employer education
Content	<p>One-on-one support:</p> <ul style="list-style-type: none"> • Intake process • Start with an employment consultant <ul style="list-style-type: none"> – Setting job goal, career planning and assessments • Then work with a job developer <ul style="list-style-type: none"> – Computer skills training – Resume development, cover letters, coaching – Using social networking and market research to identify job opportunities • Then have a 3-year retention follow-up <ul style="list-style-type: none"> – Contact individuals monthly (by email or phone) to provide ongoing support if needed and to monitor and evaluate success for quality-improvement purposes <p>Workshop topics include:</p> <ul style="list-style-type: none"> • Career assessment • Interview coaching • Social networking

	<ul style="list-style-type: none"> • Clients use employment consultant for approximately 4–6 months (once a week) and job developers for 1–6 months • Makes referrals as required to other community resources (e.g., for legal advice [HIV/AIDS Legal Clinic HALCO], income support) • It is a non-visual disability so concerns are related to stigma, discrimination and disclosure
Program Duration	Ongoing on an as-needed basis
Where Offered	Toronto
Cost	<ul style="list-style-type: none"> • No cost to participants • Clients are either funded through Ontario Disability Support Program (ODSP; approximately 2/3 qualify through this) or covered by ACT • ODSP funding model only allows individuals to be placed once; sometimes have to place clients 3–4 times (e.g., short-term contracts)
Program Provider	Community organization
Promotion and Participation	<ul style="list-style-type: none"> • Self-referral • 130–140 new intakes per year • No waitlist
Evaluation	<ul style="list-style-type: none"> • Do regular monitoring and evaluation of service • Considering expanding the service to outside the GTA; currently exploring different models for RTW programs and services
Program Materials	None discussed
Other Resources	<ul style="list-style-type: none"> • Mentioned the Job Opportunity Information Network (JOIN), which is a network of 22 community agencies that deliver ODSP employment supports in Toronto (www.joininfo.ca) • ACT is currently undertaking a literature review to identify models of return to work

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date November 28, 2011

Descriptive Information

Organization Mental Health Works (MHW)

Country Canada

Website Information www.mentalhealthworks.ca

Specific Program(s)/ Resource(s) for Discussion	Mental Health Works
Background and Description of Program	<ul style="list-style-type: none"> • Mental Health Works is a national initiative of the Canadian Mental Health Association • MHW began in 2001 as a partnership research project. In 2004, it began selling products and services to the business community, including offering corporate training solutions to workplaces • MHW is dedicated to advancing the field of workplace mental health through skills enhancement training, awareness education and stigma reduction efforts
Target Audience	<ul style="list-style-type: none"> • Primary target is employers so they reach employees through employer and online (fee-based corporate training) • Have an employee side of their website that includes online resources (e.g., <i>Working Through It</i> video series [see Great West Life interview summary]), option for individual support, contact and referral through website • Also provide employer-sponsored workshops • A workplace peer support program is being developed
Content	<p>Workshops for employees</p> <ul style="list-style-type: none"> • Awareness of Workplace Mental Health (target audience: general audience and employees) • Workplace Influence (target audience: general audience and employees) • Combined Awareness and Workplace Influence (target audience: general audience and employees) <p>One-on-one support</p> <ul style="list-style-type: none"> • If individual contacts them through their website • Mainly conducted through email or by phone • Not advertised well currently due to limited resources but will be part of the peer support program being developed • Issues that individuals deal with include legal advice, self-stigma • Needs vary by age of employee (e.g., older adults might be more reluctant to seek out workplace support) • Employers have employee assistance plans (EAPs), which often provide crisis management and are more referral based than

	treatment focused
Program Duration	<ul style="list-style-type: none"> • Online resources are available anytime and to anyone • Workshops for employees are approximately 2 hours in length
Where Offered	<ul style="list-style-type: none"> • Online resources • Workplace-based support if arranged by employer
Cost	<ul style="list-style-type: none"> • All services fee-based for employers • Free online resources
Program Provider	Canadian Mental Health Association
Promotion and Participation	Not discussed
Evaluation	Gaps exist in RTW support in access to good-quality information
Program Materials	<p>Resources for employees that are available online (www.mentalhealthworks.ca/employees) include:</p> <ul style="list-style-type: none"> • <i>Working Through It</i> video series • Employee Fundamentals 101 • What I Wish I knew • Steps to Employment • Hanging in There • External Resources • Currently developing a Human Rights at Work manual
Other Resources	<ul style="list-style-type: none"> • Did provide RTW intervention support for difficult cases, but no longer; instead refer employer to a group called Health Partners Inc., which has National Institute of Disability Management and Research (NIDMAR)-trained consultants, the designation for individuals doing RTW accommodations • Vital Workplaces workshop is a team-based intervention training specific to mental health and social support in the workplace and group communication

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or Other Chronic Diseases

Key Informant – Summary Feedback Form

Interview Date November 22, 2011

Descriptive Information

Organization Great West Life (GWL) Centre for Mental Health in the Workplace

Country Canada

Website Information www.workplacestrategiesformentalhealth.com
<http://www.gwlcenreformentalhealth.com>

Specific Program(s)/ Resource(s) for Discussion	Working Through It
Background and Description of Program	<ul style="list-style-type: none"> • Development began in 2003 when a woman diagnosed with cancer and depression wanted to give back to those experiencing mental health and work-related challenges • Developed online video series of 10 personal testimonials that identify challenges and solutions of RTW • Content and themes were determined by the individuals who participated in the video testimonials • Based on what worked for different individuals • Addresses fatigue, depression, brain fog, cognitive dysfunction • GWL put resources to help workplace mental health issues
Target Audience	<ul style="list-style-type: none"> • Current content and structure would apply across a lot of situations and diseases and are not limited to mental health (e.g., fatigue, depression) • Individuals off work, at work or returning to work and struggling with life issues; those issues could range from health concerns to relationship concerns to financial concerns
Content	<ul style="list-style-type: none"> • <i>Working Through It</i> is the premier employee resource on the GWL Centre for Mental Health in the Workplace website • 10 personal testimonials: share stories, insights and strategies • Practical focus (e.g., deep breathing, yoga, walks, art, changing attitudes, nutrition); range of examples <p>Video topics</p> <ul style="list-style-type: none"> • What is happening? Why is it such a struggle? • What can I do to feel better? • How can I cope better at work? • If I continue to struggle, what should I do? • Who can help me at work? • What should I say? • If I continue to struggle, should I stay at work? • How can I manage financially? • How can I begin to feel better?

	<ul style="list-style-type: none"> • What happens when I go back to work? • How do I stay well? • What if things go really wrong? • Never Give Up • Our insights <p>Additional video resources</p> <ul style="list-style-type: none"> • Help your supervisor support you • It was difficult to accept I needed help • Recognizing symptoms • Resources at work • Don't go it alone • Help your doctor help you • Getting the paperwork done • Navigating the disability supports system • Supports that may be available • Perceptions of mood disorders • Finding the right treatment • Concerns with medications • About cognitive behavioural therapy • My experience in a treatment centre • Be aware of triggers • Stay in the present <ul style="list-style-type: none"> • Handouts available online (e.g., wellness checklist, accommodations that work organized by challenge [e.g., accommodations that help if you are experiencing fatigue])
Program Duration	<ul style="list-style-type: none"> • Offered virtually through website so available anytime • No sign up required
Where Offered	Online so accessible everywhere
Cost	No cost to participants
Program Provider	Great West Life
Promotion and Participation	<ul style="list-style-type: none"> • Raise awareness about the site at conferences, events, management training • 15,000–20,000 hits per month; of those, approximately 50% go to the Working Through It resource, which is the most popular aspect of the GWL Centre for Mental Health
Evaluation	<ul style="list-style-type: none"> • Have a survey online but very few people complete it • Feedback that the site provides a sense of hope • Pleased by what exists there for employers and employees
Program Materials	See content above
Other Resources	Link individuals to other resources (e.g., Canadian Mental Health Association, mood disorders, debt counsellors)

Appendix F: Summary Table of Interventions Following Key Informant Interviews

RTW and Cancer Interventions (shaded programs are currently inactive)

Organization	Country	Resource	Description of Program/ Program Provider	Target Audience/ Promotion	Content/Participation/ Program Materials	Program Duration	Where Offered	Cost/ Refer	Evaluation
Wellspring	Canada	Returning to Work Program	8 facilitated sessions/ Community organization	Cancer – all types; mostly women. Not yet RTW. 40–60 years/ Promoted through newsletter	Two preliminary sessions on gov't programs and services, LTD and employment law. Program includes self-assessment, peer panellists on videotape, communication skills, self-care / 8–20 participants / Leaders manual and participant workbook.	2 hours/week for 8 weeks during the day; 2 times/year	At Wellspring	Free/ Self	Yes
Wellspring	Canada	Back at Work Program (pilot phase)	8 facilitated sessions/ Community organization	Cancer – all types; mostly women. Already RTW. 40–60 years/ Promoted through newsletter	Program includes self-assessment, stresses and challenges, communication, reinvention, employment law (lawyer), self-care / Less than 7 people/group / Leaders manual and participant workbook.	2 hours/week for 8 weeks at night; 1 time/year	At Wellspring	Free/ Self	Yes
Wellspring	Canada	Money Matters	Discussion Series, One-on-one Financial Legal Matters/ Community organization	Cancer – all types; Caregivers. Men and women aged 45–65 years/ Promoted through newsletter	All financial issues in one place. One-to-one appointments/case management. Information on credit counselling, debt issues, income replacement options, help completing forms, EI, income replacement, employment law and income tax. Some specialty clinics where participation is means-tested / Provides relevant forms. Money Matters manual.	2-hour, 1-time session. One-on-one appointments	At Women's College Hospital	Free/ Self	Yes
British Columbia Cancer Agency	Canada	Vocational Rehabilitation Counselling	One-on-one counselling, 3–5 times/ Cancer institution	Cancer – all types; Working age. More women/ Promoted through cancer centre HCPs*	Vocational counselling, career assessment, case management, negotiating with employer, rehabilitation counselling, job search assistance/ Program materials: information sheets	Not provided	Over telephone and in person	Free/ Self	No

Organization	Country	Resource	Description of Program/ Program Provider	Target Audience/ Promotion	Content/Participation/ Program Materials	Program Duration	Where Offered	Cost/ Refer	Evaluation
British Columbia Cancer Agency	Canada	Return to Work Program	2 facilitated sessions/ Cancer institution	Cancer – all types. Working age, more breast cancer/ Promoted through cancer HCPs	Three components include preparing rehabilitation plan, workplace wellbeing, preparing to RTW/ 12 participants/session	2, 3-hour days. 4 times/year	At BCCA	Free/ Self	Yes
Princess Margaret Hospital	Canada	Cancer Survivorship Transitions to Employment Project	In-class and online modules/ Cancer institution	Breast Cancer, women, 45–60 years. Many on LTD/ Promoted through clinics, other colleagues	Topics: RTW readiness, RTW research, financial support, creating a personal employment plan/ Eight classroom participants and 7 using online modules/ Workbook	2 hours for one workshop offered weekly for 10 months	At PMH, Online	Free/ Self	Yes
Northeast Cancer Centre	Canada	Return to Work Program	4 facilitated session program, one-on-one support/ Cancer institution	Post-treatment breast cancer. Mean age 50 years/ Promoted via colleagues at cancer centre	Topics: fatigue, body image, cognitive impairment, emotional impact, peer guest speaker. Also social worker for one-on-one support/ 5-10 participants/program/ Handouts.	2 hours/week during the day	At Northeast Cancer Centre and telemedicine	Free/ Self, HCPs at cancer centre	No
CAREpath Inc.	Canada	Navigation System™	One-on-one counselling and advice with nurse/ Private organization	Cancer – all types; spouses, children/ Promoted in insurance plan	Topics: lifestyle changes, regaining control, graduated RTW options, financial issues such as LTD, STD/ Give summary care plan at end	9–12 months counselling and then 6–12 month follow-up	Over telephone	Free (employer pays)/ Self	Yes. EMR and exit survey
LiveStrong – Memorial Sloan-Kettering	United States	Resources for Life after Cancer	Large and small workshops with peer panellists and one-on-one vocational counselling with social worker/ Cancer institution	Cancer – all types; men, women/ Promoted on website, email list, brochures, Facebook	Topics: gaps in the resume, networking, mentoring, changing careers, insurance and disability issues, 2000 people/year in groups. One-on-one counselling: RTW practical, physical, emotional issues. Problem-solving focus. Each counsellor sees 500/year	Workshops: 1 hour once/year. One-to-one sessions 8–10 times for 45 minutes	Workshops and one-on-one sessions are all done in person	Free/ Self	Workshop, yes. One-on-one, no.
Macmillan Cancer Centre	United Kingdom	Vocational Rehabilitation Pilot Project	Vocational Rehab services, RTW information, one-on-one counselling 7 pilot sites/ Cancer institution, private organization	Cancer – all types; working age, caregivers/ Promoted through relevant cancer clinics, helpline	Education and information; one-on-one counselling service/ 500 have used services; 150 have used specialized vocational rehabilitation service/ Booklet	Various and unspecified	Cancer care and support charity organization	Free/ Self	Yes

Organization	Country	Resource	Description of Program/ Program Provider	Target Audience/ Promotion	Content/Participation/ Program Materials	Program Duration	Where Offered	Cost/ Refer	Evaluation
Do Some Good	Netherlands	One-on-One Return to Work Coaching	Workshops and one-on-one support and advice (coaching)/ Private organization	Cancer – all types; 40 years and up, More women/ Promoted through employer, Internet, hospital	Information Session: RTW challenges, tips for talking to the employer. One-on-one: help with side effect and emotional and workplace problems, encourage exercise, dealing with problems at home, 8–10 sessions.	Info session: 2 hours, 6 times/year; One-on-one: 1.5-2 hours every 2 weeks	Do Some Good	Free (employer pays)/ Self	Yes
Cancer and Careers	United States	Coaching	Online coaching/ Foundation	Cancer – all types; Any age. Both genders/ Promoted by cancer HCPs	Any question an online user would have related to work (e.g., gap in resume, how to talk to employer)	Anytime	Over telephone	Free/ Self	No
Cancer and Careers	United States	Educational Seminars, Teleconferences	Presentations and Teleconferences, general audience and for young adults/ Foundation	Cancer – all types; employers, HCPs/ Promoted by HCPs, cancer organizations	Topics: Talking to your HCP, disclosure, work accommodations. Opportunity to talk to a career coach and legal expert/ 30–50 participants/call.	1 hour long; not more than once a month	Presentations in person; Teleconferences over the telephone.	Free/ Self	Yes
Cancer and Careers	United States	Support groups	Group for general work–life balance and group for young adults/ Foundation	Cancer – all types; + Young adults 21–40 years/ Promoted by cancer HCPs	Work–life balance/ 15 group members; Young adults group is newer and has 7 members.	Once a month	In person	Free/ Self	No
Cancer Council NSW	Australia	Working Beyond Cancer Workshop	Day-long workshop to educate individuals who want to RTW about rights and making the transition to work/ Community organization	Cancer – any type; Caregivers and employers/ Promoted through website, flyers, helpline	Emotional, practical, legal, financial, superannuation challenges, filling the gap in your resume, communicating with coworkers, caregiver needs/ 30-45 participants/ Legal advice, financial assistance	3-4 workshops per year; day-long program	Cancer Council	Free/ Self	Yes
Cancer Legal Resource Centre	United States	National Telephone Assistance Line and National Educational Outreach	Free information; resources on cancer-related legal/ Community organization	Cancer – any type; Caregivers, HCPs, employers. 60% women. 30–60 years/ Promoted through outreach and online	Telephone: legal information about insurance coverage, taking time off work, access to health care and government benefits and estate planning. Educational Outreach: conferences, webinars concerning similar topics.	Phone: 9–5pm, 5 days/week; Workshops: monthly throughout year	Cancer Legal Resource Centre/ Where asked to offer educational workshops etc.	Free/ Self	Yes
Cancer J'écoute for the Canadian Cancer Society in Quebec	Canada	Life After a Cancer Diagnosis	Workshops on RTW issues/ Community organization	Cancer – any type; Caregivers, men and women/ Not yet promoted.	Support, occupational issues, workplace integration, insurance, legal issues, vocational rehab, social perception of cancer	Offered 8 times/year; 2 hours/ workshop	Canadian Cancer Society, Quebec Division – Montreal	Free/ Self	Yes

*HCP: health care professionals

RTW and HIV and Mental Health Interventions (shaded programs are currently inactive)

Organization	Country	Resource	Description of Program/ Program Provider	Target Audience/ Promotion	Content/Participation/ Program Materials	Program Duration	Where Offered	Cost/ Refer	Evaluation
Canadian Working Group on HIV and Rehabilitation	Canada	HIV and Employment Workshops	Employment workshops offered in 6 locations across Canada over 8 months in only one year/ Community organization	HIV – mainly men; service providers, employers. People in 40s/ Promoted through membership lists, flyers and HIV case managers	Topics: peer panellists, experts in vocational rehabilitation, employment law, and human resource specialists (to present the employer's perspective) Workshops video recorded and available at www.edencanada.ca/ 70 people across six locations	Series of 20-minute to 1.5-hour presentations	Community-based organizations	Free/ Self	Yes
AIDS Committee of Toronto (ACT)	Canada	Employment Action	Vocational counselling and training programs for people living with HIV/AIDS (PHAs) to help PHAs re-enter workforce/ Community organization	HIV – white, gay men, new Canadians, women, youth, unemployed, self-employed/ Promoted at ACT	One-on-one support: career planning with employment consultant. Work with a <i>job developer</i> on job search and skill development. Workshops: topics include career assessment, interview coaching, legal referrals, income support/ 135 intakes/year. 50 get work.	Employment consultant: 4–6 months; Job developers: 1–6 months	Community-based organization	Free/ Self	Yes
Mental Health Works	Canada	Working Through It (details under Great West Life in the next row) One-on-one counselling	Can also help employee with RTW plan development and execution/ Community organization	Mental health – men and women/ Employees, employers	Workshops: coping with stress. One-to-one: legal advice, self-stigma, disclosure / Program material available on line; 15,000–20,000 hits/month	Workshop: 2 hours; One-on-one online	Workshop – in person at employers location; one-on-one by email	Free (workshops paid by employer)	Unknown
Great West Life Centre for Mental Health in the Workplace	Canada	Working Through It	Online video series of personal RTW testimonials of individuals diagnosed with mental illness/ Private organization	Individuals off work, at work, Premier resource/ Promotes at conferences, trainings/ 7,500–10,000 hits/month	10 personal testimonials about how to talk to coworker, deal with side effects of illness and treatment / Online supporting handouts	Anytime	Online	Free/ Self	Yes

Appendix G: List of Resources from Key Informants

1) British Columbia Cancer Agency (www.bccancer.bc.ca)

- Disclosing your cancer experience at work information sheet
- Things to consider when returning to work information sheet
- Return to work checklist
- Tips for working with a vocational rehabilitation counsellor from an insurance company

2) Canadian Mental Health Association – Mental Health Works (www.mentalhealthworks.ca)

- Hangin' in There publication
- Brochure of workshops

3) CancerCare (www.cancercare.org)

- Work-related podcasts (www.cancercare.org/tagged/workplace_issues)

4) Cancer and Careers (www.cancerandcareers.org)

- Brochure of resources
- Managers Kit
- Program Impact Sheet
- Information Sheet
- Living and Working with Cancer publication
- Survival Guide to Living with Cancer as a Chronic Disease

5) Cancer Council NSW (www.cancercouncil.com.au)

- Cancer, Work and You publication
- Working Beyond Cancer Workshop agenda
- Working Beyond Cancer evaluation form
- Working Beyond Cancer Evaluation report 2010

6) CAREpath (www.carepath.ca)

- CAREpath Navigation System overview
- Cancer in the workplace information sheet

7) Great West Life Mental Health Centre
(www.gwlcentreformentalhealth.com)

- Workplace Resource publication
- Working Through It video series
(www.gwlcentreformentalhealth.com/wti/HomeCaptionsFalsePage.aspx)

8) National Cancer Survivorship Initiative, Macmillan Cancer Support
(www.ncsi.org.uk)

- Vocational Rehabilitation Strategy Paper, November 2009
- Evaluation Report for Pathways to Work Program, March 2010
- Vocational Rehabilitation Early Findings, September 2010
- Vocational Rehabilitation Project, 2nd Interim Report, June 2011
- Vocational Rehabilitation Pilot overview, September 2011
- Evaluation of the Vocational Rehabilitation Project: Interim Report, November 2011

9) Wellspring (www.wellspring.ca)

- *Cancer Smart*, May 2010, Special Edition: Cancer and the Workplace