

The European Cancer and Work Network: CANWON

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Abstract *Purpose* The number of cancer survivors is rapidly growing due to improved treatment and ageing population. Almost half of cancer patients will experience a cancer diagnosis during working age when career and work-related issues play an important role. Many cancer survivors are at risk for unemployment which greatly affects their quality of life and financial situation. Research on cancer and work is therefore of great importance but scattered over Europe and lacking appropriate dissemination. Moreover, interventions supporting employment of cancer survivors are urgently required but scarcely developed. *Methods* The European Cancer and Work Network (CANWON) aims to combine knowledge on: (1) prognostic factors of unemployment in cancer survivors including gender- and country-specific differences; (2) work-related costs of survivorship for both patients and society; (3) the role of employers; and (4) development and evaluation of innovative, interdisciplinary interventions which effectively support employment. Furthermore, it aims at disseminating research knowledge and best practice worldwide. *Results* CANWON currently unites 23 teams from 15 countries across different stakeholders and research areas. The expected benefits are rapid exchange of research knowledge, standardised methods and techniques, innovative interventions, future guidelines on cancer and work and the improvement of quality of life of cancer patients. *Conclusions* Understanding prognostic factors,

work-related costs, role of the employer and innovative interventions in relation to work in cancer survivors might progress the understanding of other patients with long-term conditions therefore the knowledge resulting from CANWON will benefit a wide range of patient groups.

Keywords Neoplasms · Work · Employment

Introduction

Cancer is a major health problem in developed countries. The National Cancer Institute in the USA reports that it is estimated there are 14 million cancer survivors which is approximately 4 % of the total population in the USA [1]. Cancer is also a substantial social and public health problem in Europe. Each year, an estimated 3.2 million new cases of cancer are diagnosed in Europe with half of them of working age [2]. As cancer is predominantly a disease of older age, the ageing of the population in Western countries means that the number of survivors is predicted to continue to increase [3] and the number of people experiencing long-term and late effects by cancer is rising sharply [4]. A diagnosis of cancer has therefore for many people changed from a life threatening disease to a chronic condition.

Almost half of cancer patients will experience a cancer diagnosis during an age, when career and work-related issues play an important role in individual and family lives [5]. Most cancer survivors want to return to work after treatment but not all survivors are able to and find the process of return to work difficult as a result of the chronic physical, emotional and occupational problems [6–9]. Returning to work is important for cancer survivors, their families and society. Survivors often regard returning to work as a sign of complete recovery [10] and employment is associated with a

This study was carried out on behalf of CANWON members. Details given in Table 2.

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higher quality of life, self-esteem, social status, and personal identity [11]. In ageing Western societies, it is also an economic and social reality to encourage work participation whenever possible because of the decline of the labour force because of the costs involved [12, 13].

The number of research projects on cancer and work participation is currently increasing in many countries worldwide but they are performed in a relative isolated fashion. Further progress in this research area can be hugely achieved by integrating knowledge emerging from different fields. Therefore, the Cancer and Work Network (CANWON) was established in Europe.

The CANWON Network Funded by COST

The goal of CANWON is to form a network of a highly integrative Europe-wide team of experts and stakeholders involved in research and practice of cancer and work. Such a consortium is indispensable in this rapidly evolving field to progress the state-of-the-art by exchanging research knowledge, efficiently study complex participation processes and develop standard protocols to address the immediate problem of return to work after cancer. With an emerging group of international researchers highly skilled in (occupational) medicine, social and behavioural sciences, rehabilitation and economics directing their attention to cancer and work problems, there is an opportunity for an unprecedented synergism to respond to this public health and economical challenge.

CANWON is funded by the European Cooperation in Science and Technology (COST) [14] which is an inter-governmental framework allowing the coordination of nationally-funded research on a European level. Among COST key features are connecting high-quality scientific communities throughout Europe and worldwide, providing networking opportunities for early career investigators and increasing the impact of research on policy makers, regulatory bodies and national decision makers as well as the private sector. COST does not fund research itself, but provides support for networking activities during 4 years.

CANWON's Objectives and Envisaged Benefits

The formation of a permanent network of expert scientists, clinicians, economists and patient support groups and other stakeholders on cancer and work has the following objectives:

1. To assess significant prognostic factors in the work participation of cancer survivors in large and well characterised cohorts of cancer patients across Europe

in a standardised way including the impact of gender and country-specific differences which determine work participation in cancer survivors across Europe

2. To assess the work-related costs of cancer survivorship for both patients and society
3. To determine the impact of employers on work participation of cancer patients
4. To develop and evaluate innovative and multidisciplinary interventions which effectively enhance work participation of cancer patients.

CANWON is focussed on the social and economic need in Europe to support as many people as possible to maintain working. It is also focussed on the scientific advance of standardised measurement of prognostic factors, work-related costs, role of employers, and development of effective work participation interventions.

An immediate benefit is that joint efforts of, currently, 24 research teams from 15 countries will increase our understanding of employment issues in cancer survivors and provide for innovative, effective interventions. Second, CANWON will make earlier and quicker exchange of new information possible to target groups in different countries such as patient organisations, researchers and policy makers. As a third benefit, CANWON will raise public awareness about this important medical and societal problem. Finally, quality of life of cancer patients will significantly increase as it is strongly influenced by returning to work for those who want it.

CANWON's Working Groups

The scientific program of CANWON will be implemented in four working groups. Goals and chairs are shown in Table 1.

WG 1: Prognostic Factors of Work Participation of Cancer Patients

CANWON's first working group will focus on significant prognostic factors in the work participation of cancer survivors including the impact of gender and country-specific differences. This should be done in a standardised way because research results can only be compared when they have been measured with similar instruments. Better valid and reliable methods to assess prognostic factors of work participation, including country-specific or regional differences in cancer-related unemployment, will benefit the identification of the patients at risk who should be provided additional support.

This working group will take advantage of the availability of several large and registry-based patient cohorts

Table 1 CANWON's activities

	Goals	Chair
CANWON	Formation of network Rapid exchange of knowledge	Angela de Boer (chair) Tyna Taskila (co-chair)
WG1 prognostic factors	1. Establishment of large and well-defined disease cohorts 2. Identification of personal, environmental and country-specific prognostic factors 3. Risk assessment 4. Identification of novel targets for interventions	Linda Sharp
WG2 costs	1. A matrix of loss of job tenure due to cancer 2. Identification of temporality of return to work 3. Assessment of cost of all the detrimental effects of cancer upon work participation	Alain Paraponaris
WG3 employers	1. Identification of role of employers in work participation 2. Development of validated instruments 3. Identification of discrimination against cancer survivors	Ziv Amir
WG4 interventions	1. Development and evaluation of new evidence-based work participation interventions 2. Analysis of primary and secondary endpoints 3. Involvement of partners in translational activity	Anja Mehnert
Research and training schools	Educate early stage researchers in various fields of expertise	Ute Bültmann
Short term scientific missions	To learn research methods in other institutions	Joao Teixeira
Dissemination	Dissemination of results to policy makers, practitioners, patient communities, general public	–

WG working group

and the broad scientific expertise in handling large databases. A special focus shall be put on evaluating how gender, personal and disease-related factors interact with social factors influencing the duration of sick leave and employment status of cancer survivors.

WG 2: Work-Related Costs of Cancer Survivorship

The second working group will focus on quantitative methods to assess indirect costs of cancer survivorship caused by the diagnosis of cancer: reduced productivity, wage losses, altered careers, (unpaid) sick leave, unemployment, unsolicited and premature retirement, and labour market inactivity. Identifying the work-related costs of cancer survivorship will guide future research and policies across different countries regarding guidelines and interventions. The working group will also provide tools to evaluate cost-effectiveness of interventions aimed at preventing unemployment in cancer survivors.

WG 3: The Role of Employers in Work Participation

The role of employers, supervisors or line managers is often crucial for a successful return to work and work retention but knowledge and programmes on optimal management and workplace support are lacking. The third working group will integrate quantitative and qualitative data on the role of employers and supervisors in the work participation of cancer patients and how they can promote or hinder return to work. The role of the employer or supervisor will be studied regarding communication on work participation matters with the patient, the colleagues and the medical and occupational professionals. Common workplace factors affecting work participation of cancer patients such as workplace accommodations, the content of work, change of work times and—breaks, and travel arrangements will be considered. The valid and reliable assessment of these factors will be harmonised in order to establish results that can be generalised across (European) countries.

WG 4: Development of Innovative Interventions to Enhance Work Participation of Cancer Patients

Ultimately, the fourth working group will focus on the development of innovative and multidisciplinary interventions which effectively enhance work participation of cancer patients and evaluate their cost-effectiveness. Collaboration between countries on the development of evidence-based, validated interventions for work participation of cancer survivors to prevent unemployment will highly benefit the lives of millions of cancer patients, as well as of other stakeholders, including employers, colleagues and society as a whole. Knowledge from prognostic factors affecting work participation, the economic burden and the role of the employer can be used to develop effective interventions. These strategies will improve the psychosocial situation of cancer survivors by vocational counselling, education, rehabilitation, communication, and supporting work participation. The endpoints of these programmes (such as work participation, return to work rates and quality of work life) will be investigated by research groups with complementary expertise and facilities.

CANWON's Activities

CANWON will last 4 years from 2013 to 2017 and will be coordinated by the management committee (MC). The

kick-off meeting took place on May 24, 2013 in Brussels (see Table 2 for those MC members present at kick-off). The MC and working groups will meet twice a year to exchange knowledge, monitor progress and establish priorities. Meetings are, if possible, linked to important international conferences and/or public workshops organised by CANWON. Public workshops will be open to researchers and stakeholders outside the MC and working groups and from non-COST countries.

The network will provide a lot of training opportunities for early stage researchers such as Masters and PhD students in various fields of expertise. Of particular value will be the research and training schools aiming at different aspects such as the identification of personal, environmental and country-specific prognostic factors affecting employment in large (international) cohorts of cancer patients. Institutes involved in CANWON will use their infrastructure and resources to enable researchers involved in short-term scientific missions to learn research methods and/or participate in short training courses. One or two experts or support staff from each institute will be responsible for training of visiting researchers; visits supporting PhD theses and/or joint publications will be favoured.

An essential component of CANWON will be the maximum dissemination of objectives, results, recommendations for policy, and the development of novel interventions to empower cancer people for work participation. Classic and social media such as printed press and

Table 2 CANWON's management committee members

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Management committee members who were present at the kick-off meeting

internet will transmit these messages to scientific and health professionals, cancer patients, policy makers and the public.

The dissemination of CANWON results will be fuelled by the inclusion of the Association of European Cancer Leagues (ECL). Involvement of the ECL and its members ensures instant dissemination of the results and deliverables to 23 countries in Europe and to other European Institutions, WHO, UICC and patient organisations.

The CANWON website will be developed to present clearly the objectives and most recent achievements, as well as announcing public workshops. The integration of work participation needs of vulnerable people such as cancer patients into national plans, policies and strategies is high on the EU agenda as indicated by the EU Council and its endorsement recently by the WHO. Dissemination of the results of this project to policy makers, practitioners, patient communities as well as general public is therefore needed.

CANWON's Potential Impact

Quality of life of cancer patients can significantly increase as it is strongly influenced by returning to work and as such CANWON can have a substantial impact on cancer survivors' lives. For social impact, CANWON will provide more targeted prevention and intervention strategies thereby reducing the personal, social and economic burden resulting from cancer and its treatment. CANWON will furthermore raise much needed public awareness in Europe and worldwide about this important medical and societal problem.

There will be recommendations and toolkits for how to design guidelines and interventions to prevent unemployment of cancer survivors. Furthermore, there will be benefits to early stage researchers to be engaged in a gender-balanced network offering exchange programmes.

From a global perspective, CANWON can raise interest from a wide range of non-COST countries because cancer and employment is an important issue in many countries due to increasing survival rates of cancer, the ageing society and difficult economic situation. Emerging knowledge and new interventions will therefore have a positive global impact.

Impact on Other Patient Groups with Long-Term Conditions

The increase of people with long-term conditions and disabilities in the Western world's ageing society can undoubtedly be considered as a threat to the quality of life. One in every six persons in the European Union (EU) has a disability [15] that ranges from mild to severe.

Unfortunately, the employment situation for working-age adults with disabilities remains dismal. Disability and ill health are often associated negatively with poverty, social exclusion and, most importantly in terms of the social determinants, lower employment rates [16, 17].

In CANWON, we take the case of people living with the long-term disabling effects of cancer. We might assume that they represent a patient group with a comprehensive profile of disabilities, elements of which are found in many other groups of people with chronic conditions. They are generally faced with physical and psychosocial problems, stigma and discrimination like many other people with chronic conditions who want to participate in the labour market. Understanding prognostic factors, work-related costs, role of the employer and innovative interventions in relation to work in cancer survivors might progress the understanding of other patients with long-term conditions therefore the knowledge resulting from CANWON will benefit a wide range of patient groups.

Finally, the formation of a highly competent group of researchers and stakeholders in the field of cancer and work may hopefully inspire other similar "collaboratories" focusing on other chronic medical conditions that can influence return to work and job retention.

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References

1. Estimated US cancer prevalence counts: who are our cancer survivors in the US? <http://dcccps.nci.nih.gov/ocs/prevalence/> (2012). Accessed 27 June 2013.
2. Ferlay J, Autier P, Boniol M, Heanue M, Colombet M, Boyle P. Estimates of the cancer incidence and mortality in Europe in 2006. *Ann Oncol*. 2007;18:581–92.
3. La Vecchia C, Bosetti C, Lucchini F, Bertuccio P, Negri E, Boyle P, Levi F. Cancer mortality in Europe, 2000–2004, and an overview of trends since 1975. *Ann Oncol*. 2010;21:1323–60.
4. Harrington CB, Hansen JA, Moskowitz M, Todd BL, Feuerstein M. It's not over when it's over: long-term symptoms in cancer survivors—a systematic review. *Int J Psychiatry Med*. 2010;40:163–81.
5. Mehnert A. Employment and work-related issues in cancer survivors. *Crit Rev Oncol Hematol*. 2011;77:109–30.
6. de Boer AG, Taskila T, Ojajarvi A, van Dijk FJ, Verbeek JH. Cancer survivors and unemployment: a meta-analysis and meta-regression. *JAMA*. 2009;301:753–62.
7. Taskila T, Lindbohm ML. Factors affecting cancer survivors' employment and work ability. *Acta Oncol*. 2007;46:446–51.
8. Roelen CA, Koopmans PC, Groothoff JW, van der Klink JJ, Bültmann U. Return to work after cancer diagnosed 2002, 2005, and 2008. *J Occup Rehabil*. 2011;21:335–41.
9. Amir Z, Neary D, Luker K. Cancer survivors' views of work 3 years post diagnosis: a UK perspective. *Eur J Oncol Nurs*. 2008;12:190–7.
10. Spelten ER, Sprangers MA, Verbeek JH. Factors reported to influence the return-to-work of cancer survivors: a literature review. *Psychooncology*. 2002;11:124–31.

11. Tamminga SJ, de Boer AG, Verbeek JH, Frings-Dresen MH. Breast cancer survivors' views of factors that influence the return-to-work process—a qualitative study. *Scand J Work Environ Health*. 2012;38:144–54.
12. Paraponaris A, Teyssier LS, Ventelou B. Job tenure and self-reported workplace discrimination for cancer survivors 2 years after diagnosis: does employment legislation matter? *Health Policy*. 2010;98:144–55.
13. Sharp L, Timmons A. Social welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland. *J Cancer Surviv*. 2011;5:382–94.
14. Cost <http://www.cost.eu/>. Accessed 28 June 2013.
15. EU Labour Force Study ad hoc module on employment of disabled people. LFS, 2002.
16. Jans LH, Kaye HS, Jones EC. Getting hired: successfully employed people with disabilities offer advice on disclosure, interviewing, and job search. *J Occup Rehabil*. 2012;22:155–65.
17. Burstrom B, Holland P, Lindholm C. Winners and losers in flexible labor markets: the fate of women with chronic illness in contrasting policy environments—Sweden and Britain. *Int J Health Serv*. 2003;33:199–217.