Summary

This PhD thesis starts with an appeal to break the taboo of working with (a history of) cancer in the Netherlands, offered by L.F. Asscher, the Dutch Minister of Social Affairs and Employment, to the Chair of the House of Representatives of the Netherlands, on July 10th 2015. In Chapter one, the background of his appeal is discussed in light of current developments in cancer survivorship and the given state of knowledge on cancer survivors’ return to work in the Netherlands and worldwide. Specifically, the number of cancer survivors with job loss in developed countries is rising due to increases in both cancer incidence and cancer survival rates, the rising retirement age and the increasing proportion of flexible employment contracts. For cancer survivors who lose their job, the process of return to work may be particularly challenging because of a large distance to the labour market and a lack of support from an employer or colleagues. Further, the literature shows that supportive interventions to enhance return to work in cancer survivors do not show consistent effects. Also, current return to work interventions are not suitable for cancer survivors with job loss, as these programs are generally developed to support survivors who still have an employer. This thesis states that, considering the increase in the number of cancer survivors with job loss in the Netherlands, and the lack of appropriate interventions to support their return to work, it is necessary to study return to work in these cancer survivors. Therefore, three main objectives were formulated:

1. To explore barriers and facilitators for return to work for cancer survivors with job loss, to translate this knowledge into a tailored return to work intervention program for these survivors, and to evaluate process outcomes and the effectiveness of this program on sustainable return to work in cancer survivors with job loss;
2. To obtain a broader perspective on sustainable return to work in cancer survivors with job loss, by exploring therapeutic work as a potential facilitator for return to work;
3. To present an overview of physical and/or psychosocial health problems that cancer survivors may experience beyond their return to work.

Chapter two presents the results of a focus group study on barriers and facilitators for return to work of sick-listed cancer survivors with job loss, as perceived by these cancer survivors themselves and by insurance physicians from the Dutch Social Security Agency. In this qualitative study, two focus groups and one interview were conducted with cancer survivors (N = 17), and three focus groups with insurance physicians (N = 23). The discussed topics included, amongst others, cancer survivors’ experience of job loss and barriers and facilitators for return to work. Thematic analysis was used to analyse the data. The main finding of this study was that cancer survivors essentially had a double loss experience: loss of job on top of loss of health, both due to cancer. This was mainly explained by the fact that many of these cancer survivors were employed on a temporary basis (fixed-term contract). Cancer survivors reported that their employment contracts were not renewed by the employer. In their perception, this happened because of their cancer diagnosis and corresponding financial risk for the employer in case of sick leave. As a result of the double loss experience, cancer survivors reportedly feared for job applications, lacked opportunities to gradually increase work ability, and they faced reluctance from employers in hiring them.
Insurance physicians in this study expressed a need for more frequent and longer consultations with cancer survivors with job loss. The conclusion of this study was that cancer survivors who experience double loss encounter specific barriers for return to work, for which they may need tailored return to work support.

In Chapter three, the study protocol of a randomized controlled trial and the design of a tailored return to work intervention program for cancer survivors with job loss was presented. The study was designed as a two-armed (intervention/control) randomized controlled trial with a follow-up period of 12 months. From a national sample of cancer survivors in the working age (18-60 years), 164 persons were to be recruited, both retrospectively and prospectively, from the databases of the Dutch Social Security Agency. All participants in the study were to receive usual care as provided by the Dutch Social Security Agency. Participants in the intervention group would also receive a tailored return to work program alongside usual care. The intervention program was designed in cooperation with a re-integration agency, specialized in the return to work process of cancer survivors. The return to work program started with an introductory interview with a coach from the re-integration agency. During this interview, it was assessed how much, and which type of, support a participant needed for return to work. After the introductory interview, the participant would start with either the first or the second part of the program. The first part was ‘Preparation for return to work’, delivered by the re-integration agency. The second part was ‘Return to work’, delivered by two job hunting agencies. The re-integration agency would offer vocational rehabilitation and supportive psychosocial elements, and the job hunting agencies would offer (therapeutic) placement at work. Participants could immediately start with the ‘Return to work’ part, but they could also follow the ‘Preparation for return to work’ part if they needed time and support before starting with actual return to work. The maximum duration of the complete program was set at six to seven months.

The primary outcome measure of the study was determined to be ‘duration until sustainable return to work’. Data for the primary outcome measure was collected through the social security agency registries and by questionnaires from participants. Participants in the study would complete questionnaires at baseline, and after three, six and twelve months. These questionnaires contained questions regarding, e.g., sociodemographic characteristics, levels of fatigue, cognitive failure, quality of life, depression, readiness to return to work, attitude towards work, and participation in society. The data collected during the study were to be analyzed with descriptive analysis and Cox regression analysis. Alongside the trial, a process evaluation was conducted, for which data were collected with an additional questionnaire at six months of follow-up. The study protocol was published for the sake of good scientific practice, in order to enable comparison with the evaluation of the study’s results and procedures (Chapter six and seven).

Chapter four presents the results of a longitudinal study on the role of therapeutic work as a potential facilitator for return to work of cancer survivors. The rationale for this study was that the increase of flexible employment in European labour markets contributes to workers’ risk of job loss, in case of long-term sick leave due to cancer. Therapeutic work could be a potential facilitator for return to work in populations of cancer survivors with job loss, as it involves flexible working arrangements. Since we found in the focus group study (Chapter two), that unemployed workers generally have less access to therapeutic work, this study also examined the potential difference in participation in therapeutic work between workers with and without an employment contract. The study used data from a cohort of Dutch cancer survivors (N=192), who applied for disability benefits after two years of sick leave. The primary outcome measure was return to paid work after one year. Logistic regression analysis showed that cancer survivors without an employment contract participated significantly less in therapeutic work (p < 0.001) compared to those with an employment contract. Also, those without a contract were significant less likely to return to paid work after one year (p = 0.001). We also found that participation in therapeutic work significantly increased the odds of return to paid work after one year (OR 6.97; 95% CI 2.94-16.51). The main conclusion of this study was that participation in therapeutic work could be an important facilitator for return to paid work in sick-listed cancer survivors, and that therapeutic work should be studied as a potential intervention for return to work in these survivors.

In Chapter five, the findings of a cross-sectional study are described, in which factors and motives associated with (non-)participation of cancer survivors with job loss in the tailored return to work program were examined. The data for this study were gathered from the recruitment phase of the randomized controlled trial, as described in Chapter three. Cross-sectionally, information on socio-demographics, health-related, psychosocial, and work-related characteristics of participants in the tailored return to work program was collected. Similar data were collected from those who declined participation.
In total, data from 286 cancer survivors was used in this study. Descriptive and multivariable logistic regression analyses were conducted to obtain the results. We found that being married (odds ratio (OR) 0.23; 95% confidence interval (CI) 0.08-0.69) or living together (OR 0.25; 95% CI 0.07-0.96) decreased the likelihood of survivors’ participation in the return to work program. Further, having a temporary employment contract prior to unemployment (OR 2.60; 95% CI 1.20-5.63), reporting a clear intention to return to work (OR 2.65; 95% CI 1.20-5.82), and having higher scores on a readiness to return to work instrument, i.e., contemplation scale (OR 2.00; 95% CI 1.65-2.40) and prepared for action-self-evaluative scale (OR 1.27; 95% CI 1.04-1.54), significantly increased the likelihood of participation. Further, we found that physical (50%) and mental problems (36%) were leading motives for declining participation. The results of this study can be used to distinguish survivors most in need of return to work support, from those that may not need such support. Another conclusion of this study is that practitioners and researchers should tailor their return to work support to cancer survivors’ socio-demographic, health-related and work-related characteristics.

In Chapter six, a process evaluation of the randomized controlled trial procedures and the program procedures of the tailored return to work program, is presented. The process evaluation consisted of six components: Recruitment, Reach, Dosage, Implementation, Satisfaction, and Experienced Barriers. The data for this study were provided by intervention and study logbooks, as well as by questionnaires from participants in the intervention program, from occupational health care (OHC) professionals employed at the Dutch Social Security Agency, and from re-integration coaches and job hunting officers who delivered the return to work program. At the start of the randomized controlled trial, 85 cancer survivors were randomly allocated to the intervention group. The program reached 88% of the target population. Of the participants in the intervention group who had started the program, 52% received the adequate dosage. The overall program implementation score was 46%. Further, we found that the re-integration coaches reported higher scores of satisfaction, compared to the job hunting officers and OHC professionals. Likewise, participants reported higher levels of satisfaction with the program delivery by the re-integration coaches, compared to the delivery by the job hunting officers. Several barriers for program implementation and delivery were reported, including a lack of communication between the re-integration coaches, OHC professionals and job hunting officers, high program intensity and short program duration, and, specifically regarding the job hunting officers, a lack of experience with cancer-related return to work problems. The main conclusion of this study is that the participants, OHC professionals, re-integration coaches and job hunting officers generally reported positive experiences with the tailored return to work program, but that there were several barriers for implementation and delivery of the program. As a result, only less than half of the participants in the intervention group received the intervention as intended.

Chapter seven describes the most important results of this thesis, i.e., the results regarding the effectiveness of the tailored return to work program on duration until sustainable return to work for cancer survivors with job loss. These results were based on the data gathered within the randomized controlled trial, of which the study procedures are described in Chapter three. The study was carried out from April 2013 to March 2016, with the recruitment starting in April 2013 until January 2015. In total, 171 cancer survivors were included, which was more than the pre-estimated needed sample size of 164. The primary outcome measure was duration until sustainable return to work. Secondary outcome measures included rate of return to work, fatigue, quality of life, and participation in society. We used descriptive analyses, Kaplan-Meier estimators and Cox regression analyses to obtain the results. The population in the randomized controlled trial (N=171) had a mean age of 48.4 years (SD=8.6). The majority of participants was female (69%) and had survived breast cancer (40%). The crude Hazard Ratio (HR) for duration until sustainable return to work was 0.86 (95% CI 0.46-1.62, p=0.642) in the intervention group, compared to the control group. In the adjusted model, we found that the intervention group had a slight, but statistically non-significant, improvement in duration until sustainable return to work compared to the control group (HR 1.16; 95% CI 0.59-2.31; p=0.663). Further, the program did not have any significant effects on secondary outcome measures. The conclusion of this study is that the tailored return to work program did not demonstrate a statistically significant effect on duration until sustainable return to work in cancer survivors with job loss. The lack of effectiveness in this study could be explained to a certain extent by the outcomes of the process evaluation (Chapter six).
In Chapter eight, the results of a systematic review on physical and psychosocial problems experienced by cancer survivors beyond return to work, are presented. The rationale for this study was the gap in the literature regarding the period beyond return to work, and the fact that studies show that cancer survivors may quit working even after initially successfully returning to work. For this review, publications were identified through Medline, PsycINFO, Embase and CINAHL searches. We searched for qualitative and quantitative studies published in the period of January 2000 to March 2013. To be included in this review, studies had to be aimed at cancer survivors who were employed during the study period. Two reviewers independently extracted data from each publication and performed a methodological quality assessment of each publication. The initial search identified 8,979 articles, which were evaluated based on title and abstract, of which 64 publications were retrieved for full text screening. Of these, 30 met the inclusion criteria, of which 20 publications described quantitative studies and 10 publications described qualitative studies. Across studies, several psychosocial problems were reported to influence survivors’ work ability, including cognitive limitations, coping issues, fatigue, depression and anxiety. Functioning at work was also affected by physical problems, including problems with heavy tasks as lifting, and treatment-induced menopausal symptoms including hot flashes. The main conclusion of this review is that long-term or permanent physical and psychosocial problems are present in working cancer survivors, and that these problems may impair their work ability or functioning at work.

In Chapter nine, the main findings of this PhD thesis are discussed in the context of cancer survivorship and the changing labour market. One of the main finding of this thesis is that cancer survivors with job loss essentially experience a double loss: loss of employment on top of loss of health due to cancer. As a result, the return to work process of these cancer survivors is complicated by additional barriers related to job loss, which reduce the likelihood of participation in the labour market. Another main finding of this thesis is that the tailored return to work program developed for these survivors was not effective. These findings are discussed in light of the current societal and political context. Moreover, it was discussed how the findings of this thesis may apply to sick-listed workers with job loss in general, suffering from a different health condition than cancer. Finally, recommendations for future research and practice are offered. One key recommendation is that researchers and practitioners should not focus only on preparing cancer survivors, or other long-term sick-listed workers, for return to work. That is, methods for employer engagement in the return to work process of these workers should be developed as well. The increasing emphasis in Western societies on participation, the decay of the traditional welfare state, and the increase in the prevalence of cancer and other chronic illnesses, form the main arguments to construct a realistic model in which both the worker and the employer are committed and willing to invest in work participation, regardless of health problems.