ESRI SURVEY AND STATISTICAL REPORT SERIES NUMBER 103 February 2021

RETURNING TO EMPLOYMENT FOLLOWING A DIAGNOSIS OF CANCER

AN IRISH SURVEY SHEELAH CONNOLLY, HELEN RUSSELL AND EDWARD HENRY



RETURNING TO EMPLOYMENT FOLLOWING A DIAGNOSIS OF CANCER: AN IRISH SURVEY

Sheelah Connolly

Helen Russell

Edward Henry

February 2021

ESRI SURVEY AND STATISTICAL REPORT SERIES

NUMBER 103

Available to download from www.esri.ie

© The Economic and Social Research Institute Whitaker Square, Sir John Rogerson's Quay, Dublin 2

https://doi.org/10.26504/sustat103



This Open Access work is licensed under a Creative Commons Attribution 4.0 International License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly credited.

ABOUT THE ESRI

The mission of the Economic and Social Research Institute is to advance evidencebased policymaking that supports economic sustainability and social progress in Ireland. ESRI researchers apply the highest standards of academic excellence to challenges facing policymakers, focusing on 12 areas of critical importance to 21st Century Ireland.

The Institute was founded in 1960 by a group of senior civil servants led by Dr T. K. Whitaker, who identified the need for independent and in-depth research analysis to provide a robust evidence base for policymaking in Ireland.

Since then, the Institute has remained committed to independent research and its work is free of any expressed ideology or political position. The Institute publishes all research reaching the appropriate academic standard, irrespective of its findings or who funds the research.

The quality of its research output is guaranteed by a rigorous peer review process. ESRI researchers are experts in their fields and are committed to producing work that meets the highest academic standards and practices.

The work of the Institute is disseminated widely in books, journal articles and reports. ESRI publications are available to download, free of charge, from its website. Additionally, ESRI staff communicate research findings at regular conferences and seminars.

The ESRI is a company limited by guarantee, answerable to its members and governed by a Council, comprising 14 members who represent a cross-section of ESRI members from academia, civil services, state agencies, businesses and civil society. The Institute receives an annual grant-in-aid from the Department of Public Expenditure and Reform to support the scientific and public interest elements of the Institute's activities; the grant accounted for an average of 30 per cent of the Institute's income over the lifetime of the last Research Strategy. The remaining funding comes from research programmes supported by government departments and agencies, public bodies and competitive research programmes.

Further information is available at www.esri.ie

THE AUTHORS

Sheelah Connolly is a Senior Research Officer at the Economic and Social Research Institute (ESRI) and an Adjunct Associate Professor at Trinity College Dublin (TCD). Helen Russell is a Research Professor at the ESRI and an Adjunct Professor at TCD. Edward Henry was a Research Assistant at the ESRI when contributing to this research.

ACKNOWLEDGEMENTS

Financial support for this research was provided by the Irish Cancer Society. The authors would like to thank staff at the Irish Cancer Society and a patient representative for valuable comments on an earlier draft. We would also like to thank Anne Nolan and the internal ESRI reviewer for their insightful comments. We are particularly grateful to all those who completed the questionnaire and shared their experience of returning to work following their cancer diagnosis.

This report has been accepted for publication by the Institute, which does not itself take institutional policy positions. The report has been peer reviewed prior to publication. The authors are solely responsible for the content and the views expressed.

FOREWORD BY THE IRISH CANCER SOCIETY



For many people work gives their life purpose and fulfilment, not to mention paying the bills.

A cancer diagnosis can strip this away from patients. Along with the physical and psychological effects of cancer, leaving work as a result of it can have a severe financial impact and leaves people feeling lost, bereft of both the routine work brings and the sense of accomplishment we get from it.

At the Irish Cancer Society, we hear every day about the personal challenges a cancer diagnosis brings. Many are unprepared for the effect it can have on their livelihood and don't know how to talk about their cancer with their employer.

We know from research we published in 2019 on the 'Real Cost of Cancer', that cancer patients face a loss in income of over $\leq 1,500$ a month after their diagnosis, as a result of taking time off work or working reduced hours.

We also know that, to date, there is limited evidence in Ireland on the barriers cancer patients face in returning to work.

This is why we funded the ESRI to undertake this research. We want to begin to build a solid evidence base on the barriers and facilitators of a return to work, and use this to support positive change for patients to return to work, should they wish to do so.

The good news is that almost 7 in 10 patients and survivors reported that their organisation and manager were very supportive or supportive on their return to work. We're pleased that so many do feel supported, but there are a number of areas of this report that give cause for concern.

Almost half of respondents said their cancer diagnosis had a negative impact on their career prospects, with particularly negative impacts reported by women, younger workers, self-employed, and those working in the public sector.

Nearly 4 in 10 cancer patients said their time off work was shorter than they wanted, and almost half of this group reported that the main reason they returned was financial need.

As more people than ever are either surviving cancer or living well with cancer, we must ensure that greater practical and financial supports are available to patients as they navigate one of the most stressful times of their lives.

The Irish Cancer Society believes that all patients should feel supported in their return to work after a diagnosis, and their quality of life, finances and career prospects should not be affected by their illness.

The way we work has been fundamentally, and likely irreversibly, changed by the events of 2020. This has enforced changes upon employers and caused Government to take steps towards legislating for a statutory sick pay scheme, working from home and a right to disconnect.

To fully support cancer patients, before, during and after they return to work, whether they were employed, self-employed or unemployed at the time of their diagnosis, requires a similar step-change from a range of stakeholders, and the Irish Cancer Society wants to lead the way.

We want this report to act as a catalyst for change. As a complement to the ESRI's detailed work, we have published a set of recommendations for employers, trade unions and Government; along with a set of actions we will take as an organisation.

We believe this report and the recommendations we've published will act as blueprints for progressive change that drastically improve patients and survivors work, financial and career satisfaction and outcomes.

The Irish Cancer Society will demonstrate best practice, build broad public support for our recommendations, and work in a spirit of partnership with policymakers, politicians, trade unions and employers, all led by patients and survivors, to achieve this.

Conor King Acting CEO Irish Cancer Society

TABLE OF CONTENTS

EXECUTIVE S	UMMARY	VII
CHAPTER 1	INTRODUCTION	1
CHAPTER 2	WORK-RELATED FACTORS INFLUENCING THE RETURN TO EMPLOYMENT OF PEOPLE DIAGNOSED WITH CANCER – A BRIEF REVIEW OF THE LITERATURE	3
2.1	Support	3
2.2	Communication	3
2.3	Work environment	4
2.4	Financial need	4
2.5	Ability to work	5
CHAPTER 3	METHODS	7
3.1	Sampling	7
3.2	Questionnaire	9
3.3	Ethical approval	9
3.4	Analysis	10
CHAPTER 4	PROFILE OF QUESTIONNAIRE RESPONDENTS	11
4.1	Demographic and socio-economic characteristics of respondents	11
4.2	Health characteristics of respondents	13
4.3	Employment characteristics of respondents at the time of diagnosis	15
4.4	Employment situation of respondents at the time of completing the questionnaire	16
CHAPTER 5	THE EXPERIENCE OF RETURNING TO EMPLOYMENT FOLLOWING A CANCER DIAGNOSIS	19
5.1	The perceived impact of cancer diagnosis on career prospects	19
5.2	Returning to work following a cancer diagnosis	24
5.3	Level of support provided by organisation and manager	27
5.4	Factors which facilitated a return to employment	30
5.5	Factors which acted as barriers to return to work	31
5.6	Impact of COVID-19 pandemic on employment situation of respondents	34
5.7	Experience of those who have not yet returned to formal employment following a cancer diagnosis	36

CHAPTER 6	CONCLUSION AND POLICY RECOMMENDATIONS	. 39
6.1	Main findings	. 39
6.2	Policy and practice recommendations	.42
6.3	Limitations and further research	.45
REFERENCES		.47
APPENDIX 1	RETURNING TO WORK QUESTIONNAIRE	.51

LIST OF TABLES

Table 4.1	Demographic and socio-economic characteristics of respondents 12
Table 4.2	Health characteristics of respondents 14
Table 4.3	Employment characteristics of respondents at the time of diagnosis
Table 5.1	The percentage of respondents reporting a negative impact of cancer diagnosis on career prospects for a range of respondent characteristics
Table 5.2	Association between likelihood of reporting a negative impact on career prospects of cancer diagnosis and a range of respondent characteristics
Table 5.3	Median (minimum and maximum) lengh of leave from formal employment in weeks for a range of respondent characteristics
Table 5.4	The percentage of respondents reporting level of support provided by organisation on return to work for a range of respondent characteristics
Table 5.5	The percentage of respondents reporting level of support provided by manager on return to work for a range of respondent characteristics
Table 5.6	The percentage of respondents reporting negative work-related issue by sex
Table 5.7	The percentage of respondents reporting negative work-related issue by age- group
Table 5.8	The percentage of respondents reporting negative work-related issue by employment sector

LIST OF FIGURES

Figure 4.1	Employment situation of respondents at the time of completing the questionnaire	17
Figure 5.1	The percentage of respondents reporting appropriateness of period of leave	26
Figure 5.2	The percentage of respondents reporting the main reason for returning to work/staying in work	27
Figure 5.3	The percentage of respondents reporting level of support provided by organisation and manager on return to work	28
Figure 5.4	The percentage of respondents reporting work-related factors which facilitated return to work	31
Figure 5.5	Percentage of respondents reporting particular barriers to returning to work	32
Figure 5.6	Percentage of respondents reporting negative work-related issues on return to employment	33
Figure 5.7	The percentage of respondents reporting impact of COVID-19 pandemic on employment situation	35
Figure 5.8	The percentage of respondents reporting impact on employment due to cancer diagnosis	36
Figure 5.9	The percentage of respondents reporting main reason they have not returned to employment following cancer diagnosis	37
Figure 5.10	The percentage of respondents reporting that specific work-related factors would help their return to work	37
Figure 5.11	The percentage of respondents reporting that particular factors have acted or could act as barriers to return to work	38

EXECUTIVE SUMMARY

International and Irish research suggests that not all people of working age diagnosed with cancer return to formal employment and for those that do, many reduce working hours. For some, this is a personal decision as priorities shift and change. However, for others there are likely to be barriers and challenges which impede a return to employment. The aim of the research presented in this report is to explore the experience of returning to employment following a diagnosis of cancer in Ireland. A questionnaire was completed by 377 people diagnosed with cancer since 2010 (and aged between 18 and 65 and in formal employment at the time of diagnosis) about their experience of returning to employment after their diagnosis.

MAIN FINDINGS

- Nearly half (47 per cent) of all questionnaire respondents reported that their cancer diagnosis had a negative impact on their career prospects, with females, younger workers, the self-employed and those working in the public sector more likely to report a negative impact. The greater negative impact for women was related to their longer length of leave from formal employment. The reason underlying the higher proportion of public sector workers reporting a negative impact on career prospects is unclear and worthy of further exploration, in particular to identify if it is associated with particular occupations within the public sector.
- Of those that responded to the questionnaire, 38 per cent reported that the main reason they returned to work was financial need, while 28 per cent reported the main reason as maintaining or regaining a sense of normality. Asked about the appropriateness of the length of leave, 38 per cent reported that their period of leave was too short.
- In general, respondents reported high levels of support from their organisation and manager on returning to work, with 68 per cent reporting that their organisation and manager were very supportive or supportive. However, 11 per cent reported that their organisation was unsupportive or very unsupportive on their return, while 17 per cent reported that their manager was unsupportive or very unsupportive.
- The most commonly reported factors which facilitated a return to employment were a phased return, help and support from colleagues and employer/ manager, and time off for medical appointments.
- Asked about barriers to returning to work, almost half (46 per cent) reported at least one barrier, the most common of which were physical and psychological health issues. One-quarter of respondents noted that they had difficulty completing job requirements.

 Presented with a list of negative work-related experiences due to their cancer diagnosis, 32 per cent of respondents reported that they experienced at least one, while 15 per cent reported experiencing two or more. The most commonly reported issues were a reduction in salary or bonus (11 per cent), unsuitable workloads or tasks (8 per cent) and being made redundant or dismissed (4 per cent). The proportion of respondents reporting a negative issue differed somewhat by sex, age-group and employment sector.

IMPLICATIONS FOR PRACTICE AND POLICY

- For employers: Open communication and allowing a flexible return to work are key facilitators of a successful return to employment for those diagnosed with cancer. Employers should be aware of their obligations under the Employment Equality Acts to avoid less favourable treatment of those diagnosed with cancer and of their responsibility to make reasonable accommodations.
- For Government: There is a key role for Government in ensuring that there are adequate financial supports in place to allow those diagnosed with cancer to return to employment only when they are ready. Such supports should seek to facilitate the return to work on a phased and flexible basis. In addition, the Government should consider providing additional supports (such as training) to those who have lost their jobs due to their cancer diagnosis and those whose career has been negatively impact by their diagnosis. The Government also has a role to play in providing up-to-date information for employees and employers, ensuring that employees are aware of available supports and that employers are informed as to how they can facilitate a return to work. Employers should also be made aware of the details of anti-discrimination legislation as it relates to cancer and other illnesses.

CHAPTER 1

Introduction

In 2015, approximately 24,500 cases of cancer (excluding non-melanoma skin cancers) were diagnosed in Ireland, of which 44 per cent were diagnosed in those of working age (20-64) (National Cancer Registry Ireland, 2020). If trends in the rates of cancer diagnosis observed during the period 2011-2015 were to continue, the annual number of cases of cancers (excluding non-melanoma skin cancer) are projected to increase from 11,460 in 2015 to 24,160 in 2045 (+111 per cent) in males and from 10,240 in 2015 to 18,840 in 2045 (+84 per cent) in females (National Cancer Registry Ireland, 2019). Developments in early detection and treatment of cancer have resulted in improvements in prognosis and a general prolongation of survival (National Cancer Registry Ireland, 2018). Consequently, cancer survivors increasingly resume (or seek to resume) activities of everyday life including returning to work (Kennedy et al., 2007).

Returning to work following a cancer diagnosis is important for a number of reasons, not least of which are financial. A recent report by the Irish Cancer Society noted that the average fall in income of cancer patients was $\leq 1,527$ per month (Irish Cancer Society, 2019); in addition, there are a number of additional costs associated with cancer which individuals must bear. For example, O'Ceilleachair et al. (2017) identified a range of out-of-pocket costs incurred by colorectal cancer survivors in Ireland including payments for tests, procedures, drugs, travel, subsistence and home alterations, and estimated that the average out-of-pocket cost was $\leq 1,587$ over the course of the illness (2008 prices). Building on this work, Hanly et al. (2018) looked at financial hardship associated with colorectal cancer survivorship. They found that almost 41 per cent of colorectal cancer survivors experienced cancer-related financial stress post diagnosis; of those with savings at the time of diagnosis, almost half (45 per cent) used some or all of their saving, while 7 per cent reported borrowing from a financial institution and 16 per cent sought financial aid from a friend or family member.

While for some a return to work is motivated by necessity, for others incentives extend beyond monetary requirements. De Rijk et al. (2020), for example, note that motivations are based not only on financial need but also on psychological need, as work often provides meaning to people's lives. Similarly, Wells et al. (2013) note that in addition to providing financial security, studies consistently show that for people with cancer, employment forms a central basis for self-identity and self-esteem, helps form and maintain social relationships, and represents an outlet for an individual's abilities, talents and health.

Despite the potential benefits of returning to work, not all people of working age diagnosed with cancer can and do return and a significant proportion end up unemployed, retire early or change jobs more often than those without a cancer diagnosis (Taskila et al., 2006; de Boer et al., 2009; Rottenberg et al., 2016; Beesley et al., 2017). While for some this is a contemplative decision, for others, personal or work-related factors can act as a barrier to returning to work. The international literature has identified a number of factors that impact on the return to work of cancer survivors including socio-demographic characteristics including age and family status, disease and treatment characteristics, work-related factors and personal and subjective factors (Kiasuwa Mbengi et al., 2016).

Some work has been done for Ireland looking at the employment situation of cancer survivors. Hanly et al. (2012), for example, examined work absences and departures for a sample of Irish breast and prostate cancer survivors. They found that approximately 13 per cent of breast cancer survivors and 12 per cent of prostate cancer survivors permanently departed from the workforce following their diagnosis. Among a sample of colorectal cancer survivors, Hanly et al. (2013) found that almost one-fifth of survivors returned to work with reduced hours and more than one-third of survey respondents left the workforce permanently after diagnosis.

While the available evidence suggests that some cancer survivors leave formal employment entirely and others reduce their working hours, there is little evidence in the Irish context as to why this occurs and the factors which may facilitate or impede a return to work. Consequently, the *aim* of the research presented in this report is to explore the experience of returning to employment following a diagnosis of cancer in Ireland.

The specific objectives are:

Objective 1 - to identify the perceived impact of a cancer diagnosis on career prospects.

Objective 2 – to identify the work-related facilitators and barriers to returning to employment following a diagnosis of cancer.

Objective 3 – to draw out lessons for employment practices and policy.

The following chapter will provide a brief overview of the literature which has examined the work-related factors which facilitate and impede the return to employment of people diagnosed with cancer. Chapter 3 details the methods used in this analysis, including details of the 'Returning to Work' questionnaire on which the analysis presented in this report is based. Chapter 4 describes the characteristics of those who completed the 'Returning to Work' questionnaire. Chapter 5 describes the experience of returning to work of those who completed the questionnaire. Finally, Chapter 6 identifies lessons for employment practice and policy.

CHAPTER 2

Work-related factors influencing the return to employment of people diagnosed with cancer – a brief review of the literature

A range of factors influence the decision around, and experience of, returning to work following a diagnosis of cancer. These include work-related factors as well as demographic, socio-economic and health status (Islam et al., 2014; Greidanus et al., 2018). The aim of this short review was to identify some of the work-related factors which influence the return to employment of people diagnosed with cancer. The review provided an evidence base for the development of the 'Returning to Work' questionnaire.

Given that the focus of this report is largely on work-related factors, this review will examine employment-related barriers and facilitators in returning to work. These include support from employer/colleagues, communication, the work environment, financial supports and ability to work.

2.1 SUPPORT

A consistent finding across much of the literature is the positive association between colleague/employer support and return to work of cancer survivors (Bouknight et al., 2006; Ahn et al., 2009; Kiasuwa Mbengi et al., 2016; Greidanus et al., 2018; Tamminga et al., 2018). Reviewing the literature on barriers and facilitators for work participation of cancer survivors, Greidanus et al. (2018), for example, noted that cancer survivors perceived employer support during the duration of the illness and during return to work as a facilitator for their work participation. Such support could take a variety of formats including practical supports such as adjusting working tasks or hours, social/emotional supports such as consistent treatment of the cancer survivor before and after diagnosis, and financial support such as provision of sick pay. Correspondingly, not providing such support was perceived as a barrier for cancer survivors' work participation (Greidanus et al., 2018).

2.2 COMMUNICATION

In terms of communication, cancer survivors perceived regular contact as a facilitator, while a lack of communication or no communication at all was perceived as a barrier for cancer survivors' work participation (Greidanus et al., 2018). However, too much contact while on leave may also be problematic if employees perceive this as pressure to return. Discussing a survivors' work plan was perceived as facilitating their work participation (Frazier et al., 2009; Isaksson et al., 2016;

Stergiou-Kita et al., 2016a; Stergiou-Kita et al., 2016b), as were conversations about the survivors' limitations and the required work adjustments (Frazier et al., 2009; Mitchell, 2015; Isaksson et al., 2016). Kiasuwa Mbengi et al. (2016) note that keeping in touch with colleagues at work helped cancer survivors to return to work and also provided a better understanding among colleagues regarding the cancer survivors' limitations. It also helped them to tailor their work adequately so as to fit with their capacities for the demands of the job.

2.3 WORK ENVIRONMENT

Return to work of cancer survivors is facilitated by a positive work environment which may consist of a stable or caring environment. Conversely, a negative work environment is regarded as a barrier to returning to work (Greidanus et al., 2018); for example, a highly structured or competitive environment (Blinder et al., 2012; Tamminga et al., 2012; Nilsson et al., 2013). A qualitative study of breast cancer survivors' views of factors that influence the return-to-work process also found that a positive attitude in the work environment helped them return (Tamminga et al., 2012). This included having no expectations regarding productivity and giving the employee the freedom to plan a return to work as they want. Conversely, not having control over the working situation (for example, the job can only be performed full-time or it is not possible to have a flexible work arrangement) is also perceived as a barrier, as are negative terms of employment (including freelance work and lack of job security) (Tamminga et al., 2012).

A number of studies have noted the association between job type and return to work. Manual work, higher job demands and concern around ability to fulfil job requirements, in particular, were seen to act as barriers to returning to work (van Muijen et al., 2013; Knott et al., 2014; Kiasuwa Mbengi et al., 2016).

2.4 FINANCIAL NEED

A qualitative study examining the experience of 29 people returning to work following a cancer diagnosis found that many participants experienced financial pressure from being off work and almost half indicated that this was the primary reason for returning (Kennedy et al., 2007). Conversely, others spoke of how they felt fortunate in not having to return to work immediately or worry financially because they were paid throughout their treatment. While the prevalence of illness/sickness benefit will differ from person to person and job to job, social security systems may also have a role in influencing cancer survivors' return to work (Fantoni et al., 2010). In their review of return to work of breast cancer survivors, Islam et al. (2014) noted very high rates of return to work among cancer survivors with employment related health insurance in the US relative to other groups, which is likely related to the reliance of such groups on employment for their health insurance and consequently healthcare.

2.5 ABILITY TO WORK

A number of studies have identified fatigue among cancer survivors as a barrier to returning to work (Johnsson et al., 2007; Carlsen et al., 2013; Islam et al., 2014; Kiasuwa Mbengi et al., 2016). As well as having a physical impact on the ability to work, fatigue can also affect survivors psychologically (Islam et al., 2014). Carlsen et al. (2013), for example, examined whether the ability of long-term breast cancer survivors to work was different from that of a cancer-free control group. They found that health-related factors were most strongly associated with work ability, with fatigue increasing the risk of rating low work ability by almost 11 times. They also found that the significant association between depression and low work ability disappeared after adjustment for fatigue.

Several studies have identified the receipt of chemotherapy as a barrier to returning to work (Balak et al., 2008; van Muijen et al., 2013; Islam et al., 2014; Kiasuwa Mbengi et al., 2016). This is likely related to the many potential side-effects of chemotherapy including nausea, vomiting, depression, fatigue and cognitive dysfunction (Islam et al., 2014). Multi-modal treatment (for example, combination of cancer therapies) was also negatively associated with return to work (Balak et al., 2008; den Bakker et al., 2018). Similarly, Kiasuwa Mbengi et al. (2016) reported that that cancer survivors who had chemotherapy or a combination of therapies (for example, surgery, radiotherapy and chemotherapy) had a four-fold increased risk of not resuming work in the first (or even the three) following year(s) after treatment, compared to cancer survivors who had only surgery or one type of treatment.

CHAPTER 3

Methods

The analysis presented in this report is based on a questionnaire (Appendix 1) developed by the ESRI, in conjunction with the Irish Cancer Society, and administered by Ipsos MRBI. This section provides an overview of the methods used in the development, administration and analysis of the questionnaire.

3.1 SAMPLING

The focus of this project was on the experience of returning to work of those who had been in formal employment at the time of their cancer diagnosis. Consequently, the questionnaire was open to people who were diagnosed with cancer when aged between 18 and 65 and in formal employment at the time of diagnosis. The questionnaire was also restricted to those diagnosed with cancer since 2010, to ensure that the analysis captures the relatively recent experiences of returning to employment.

While approximately 25,000 people are diagnosed with cancer (excluding nonmelanoma skin cancer) each year in Ireland, of whom approximately 44 per cent are of working age, it is difficult to quantify the size of the target population for the questionnaire as there are no data on the number of people who are in employment at the time of diagnosis (and therefore eligible to complete the questionnaire), or of the number of people diagnosed with cancer in the target period (2010-2020) that would have survived to 2020. However, given the relatively small number of people in the population eligible to complete the questionnaire relative to the general population, a general probability sample of households to obtain a random sample of respondents was prohibitive; consequently, a pragmatic approach, led by the Irish Cancer Society, was used to identify potential respondents.

Founded in 1963, the Irish Cancer Society is a charity in the Republic of Ireland which is concerned with improving the lives of those affected by cancer, reducing the risk of cancer, influencing public policy on cancer and leading collaborative research. The society provides a range of services to people affected by cancer including information, advice and counselling as well as practical and financial supports. In addition, it has 13 cancer support centres, called Daffodil Centres, located in hospitals across Ireland. While it is not possible to determine the proportion of people diagnosed with cancer in any period of time that come into contact with the Irish Cancer Society, given the broad range of services and supports offered by society, it is envisaged that a substantial proportion of people diagnosed with cancer or their family members connect in some manner with the society. Details of the project and questionnaire were emailed by the Irish Cancer Society to all those who had previously subscribed to an Irish Cancer Society mailing list.

Those that were eligible to participate were requested to complete the questionnaire, while those that were not eligible were asked to the share the questionnaire with those who may be eligible. The Irish Cancer Society also published a series of Social Media posts (on Facebook, Twitter and LinkedIn) advertising the project and questionnaire.¹ Early analysis of questionnaire respondents found that there were relatively few male respondents. To increase the number of male respondents, details of the project and questionnaire were forwarded to and circulated by Men's Sheds Ireland and the Construction Industry Federation.

Those interested in participating in the project had the option of completing the questionnaire online or requesting a paper copy of the questionnaire. The questionnaire was formatted and administered for paper and online purposes by Ipsos MRBI. No paper copies of the questionnaire were returned. The questionnaire did not collect any personal identifying data (for example, name, address, date of birth). The questionnaire was open for responses for six weeks through July and August 2020. A data transfer agreement was signed between Ipsos MRBI and the ESRI to facilitate the transfer of data to the ESRI.

As the sample is a convenience sample rather than a random probability sample, it is not possible to generalise the results to all those diagnosed with cancer. Despite attempts to increase the number of male respondents (as described above), males (and subsequently male-related cancers) were significantly underrepresented among study respondents. Consequently, to increase the representativeness of the study findings, the data were reweighted using information from the National Cancer Registry of Ireland for those aged 15-64 years. The National Cancer Registry provides data on cancer incidence in Ireland by age, sex, cancer type, county and year. For the purpose of this analysis, the data were weighted for sex and cancer type of those aged 15 to 64 in 2015. The age distribution of respondents to the 'Returning to Work' questionnaire (including those aged between 18 and 65) was similar to the age distribution of those diagnosed with cancer in the general population (aged between 18 and 65) and initial analysis including age in the weighting factor did not change the study findings, consequently age was not included in the final weighting factor presented in this report. Throughout the

¹ The Society's email list consists of more than 90,000 individuals, while its Facebook, Twitter and LinkedIn accounts had 167,000, 41,000 and 7,800 followers respectively at the time of posting in July 2020.

report the percentages presented are based on the weighted survey data. The actual (unweighted) base number of cases is also reported for reference.

3.2 QUESTIONNAIRE

All questionnaire respondents were asked about working status at the time of diagnosis, working status at the time of completing the questionnaire, health status and demographic and socio-economic status. Subsequently, different questions about return to work were posed depending on whether the individual reported that they had:

- (i) returned to employment/self-employment with the same employer/selfemployment since their cancer diagnosis (or did not take time off work);
- (ii) had returned to employment/self-employment but to a different employer/self-employment following their cancer diagnosis; or
- (iii) not returned to employment.

Those that had returned to the same employment/self-employment were asked about factors which facilitated or impeded their return and the impact of their illness on their employment. Those that had returned to work but with a different employer/self-employment were asked, in addition to the questions on the factors that acted as facilitators and barriers to their return to work, about why they returned to a different employer. Given the prevalence of COVID-19 in Ireland at the time the questionnaire was open for responses (July and August 2020), and that those diagnosed with cancer are regarded as high risk and advised to stay at home as much as possible, additional questions on the impact of COVID-19 on employment status were included in the questionnaire. Finally, those that have not returned to work were asked the reason they had not returned and what factors could facilitate or hinder their return. Where possible, previously used and validated questions were included in the questionnaire. Both the online and paper version of the questionnaire were piloted by nine respondents identified by the Irish Cancer Society.

Respondents to the questionnaire were able to skip questions if they wished. In addition, not all questions were relevant to all individuals. In general, most questions were well answered (for example, less than ten non-responders). The exceptions are 'Number of people in organisation' which was not answered by 45 people and 'income band' which was not answered by 13 respondents.

3.3 ETHICAL APPROVAL

Ethical approval for the project was obtained from the ESRI research ethics committee in May 2020.

3.4 ANALYSIS

The analysis presented in this report is descriptive in nature, focusing in particular on the proportion of respondents reporting particular challenges, barriers and supports on returning or seeking to return to formal employment. Some results (where numbers permit) are broken down by demographic, socio-economic and work-related factors to identify if particular groups are more or less likely to report particular issues. To facilitate such an analysis, a range of statistical tests and techniques are employed. In general, as the variables of interest were not normally distributed, non-parametric tests were used. These include:

- *Mann-Whitney* test used to compare the median of two groups (for example, the number of weeks off from formal employment by sex).
- *Kruskal-Wallis* test used to compare the median of three or more groups (for example, the number of weeks off from formal employment by age-group).
- Pearson Chi-square test used to assess the relationship between two categorical variables (level of support offered by organisation and employment sector).

In addition, logistic regression analysis was used to examine the association between two variables while adjusting for other variables (for example, the association between likelihood of reporting a negative impact on career prospects of cancer diagnosis and employment sector while controlling for sex of respondents).

CHAPTER 4

Profile of questionnaire respondents

This chapter provides an overview of the demographic, socio-economic and health characteristics of those who completed the 'Returning to Work' questionnaire. All respondents were diagnosed with cancer between 2010 and 2020 and aged between 18 and 65 and in formal employment at the time of diagnosis.

As discussed in an earlier chapter, throughout the report the percentages presented are based on the weighted survey data; the actual (unweighted) base number of cases is also reported for reference. It is important to note that the unweighted raw numbers will not necessarily correspond to the weighted percentages.

4.1 DEMOGRAPHIC AND SOCIO-ECONOMIC CHARACTERISTICS OF RESPONDENTS

A total of 377 people completed the online questionnaire. No postal questionnaires were returned. Table 4.1 shows the demographic and socioeconomic characteristics of respondents. Using the weighted data, 65 per cent of respondents were female, 54 per cent were aged between 35 and 54, while 70 per cent were married or in a civil partnership. The vast majority (89 per cent) were born in the Republic of Ireland, while nearly half (46 per cent) had a third-level qualification.

As previously discussed, the data were weighted using sex and cancer site. The impact of the reweighting is particularly visible on the sex distribution of questionnaire respondents; before reweighting the data 18 per cent of respondents (n = 68) are males, relative to 35 per cent using the weighted data. Reweighting the data by sex and cancer site reduces the proportion of respondents with breast cancer from 51 per cent to 17 per cent, and increases the proportion of respondents whose primary diagnosis was prostate cancer from 6 per cent to 9 per cent. This reweighting will mean that responses on questions including those on types of treatment, length of leave etc. will be more reflective of cancer patients in general and less dominated by breast cancer.

Characteristic	Percentage	Number
Sex		
Male	35	68
Female	65	307
Age-group ¹		
<35	4	20
35-44	28	82
45-54	26	138
55-65	36	119
>65	6	17
Marital status		
Single	21	83
Married/civil partnership	70	253
Separated/Divorced	6	26
Widowed	3	14
Number in household	-	
Single person household	15	61
2	33	116
3	18	59
4	20	81
5 or more	14	57
Country of birth		•••
Republic of Ireland	89	331
Other	11	39
Highest level of education completed		
Primary/some secondary	3	10
Lower secondary	15	21
Upper secondary	15	62
PLC certificate or diploma	19	85
Third-level degree	18	87
Postgraduate degree	28	97
Other	2	12
Annual household income	2	12
€0 - €19,999	9	22
€20,000 - €39,999	26	82
€20,000 - €39,999	26	102
€40,000 - €39,999	13	60
€80,000 - €79,999	13	46
£80,000 - £99,999	14	40

TABLE 4.1 DEMOGRAPHIC AND SOCIO-ECONOMIC CHARACTERISTICS OF RESPONDENTS

Source:Authors' analysis of the 'Returning to Work' questionnaire.Note:The number of cases may sum to less than 377 due to missi

The number of cases may sum to less than 377 due to missing information. The percentages relate to the weighted data, while the numbers relate to the unweighted data, therefore they do not necessarily correspond.

¹ Age-group relates to age at the time of completing the questionnaire rather than at diagnosis – the questionnaire was restricted to those aged 65 or less at the time of diagnosis.

4.2 HEALTH CHARACTERISTICS OF RESPONDENTS

Table 4.2 provides detail on the health status of respondents, including selfreported cancer site, stage and treatment, years since diagnosis and current health issues. Reweighted to reflect the national cancer statistics, the most frequently reported cancers were cancer of the cervix (24 per cent), breast (17 per cent) and prostate (9 per cent). Reweighting the data by sex and cancer site means that the prevalence of particular cancers among questionnaire respondents is more in line with the national prevalence of such cancers. For example, for those aged 15-64, incidence data from the National Cancer Registry Ireland in 2015 show that cancer of the cervix (including in-situ cancer) accounted for 36 per cent of all reported cancers, breast accounted for 22 per cent of cancers and prostate accounted for 14 per cent of cancers. In terms of treatment, 59 per cent of respondents noted that they had surgery, 53 per cent noted they had chemotherapy, 48 per cent noted they had radiotherapy while 21 per cent had all three.

Approximately 7 per cent of respondents were diagnosed within the previous 12 months, while 37 per cent were diagnosed five or more years ago. A significant proportion of respondents reported ongoing health issues and symptoms. For example, 86 per cent reported currently experiencing tiredness, 71 per cent reported experiencing insomnia or disturbed sleep, 66 per cent reported anxiety, 62 per cent reported difficulty with remembering things, while 56 per cent reported that they were currently experiencing pain.

Characteristic	Percentage	Number
Site of cancer		
Breast	17	190
Colorectal	7	27
Cervix	24	27
Prostate	9	21
Lymphoma	3	15
Skin	6	8
Lung	5	10
Ovary	1	10
Other	28	62
Stage of cancer		
0	2	8
1	30	91
2	20	105
3	20	78
4	10	33
Don't know	18	54
Treatment (Respondents can report more than one	treatment)	
Radiotherapy	48	224
Chemotherapy	53	233
Surgery	59	254
Hormonal therapy	16	123
Immunotherapy	7	29
Active surveillance	5	10
Years since diagnosis		
<1	7	22
1-2	31	139
3-4	25	84
5+	37	126
Current issues (Respondents can report more than	one issue)	
Tiredness	86	298
Insomnia/disturbed sleep	71	238
Anxiety	66	194
Difficulty remembering things	62	194
Pain	56	173
Bowel problems	44	106
Shortness of breath	35	79
Nausea	22	55
Lack of appetite	20	46
Behavioural problems	20	35
Problem passing urine	19	25

TABLE 4.2 HEALTH CHARACTERISTICS OF RESPONDENTS

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: The number of cases may sum to less than 377 due to missing information. The percentages relate to the weighted data, while the numbers relate to the unweighted data, therefore they do not necessarily correspond. All data are based on self-report.

4.3 EMPLOYMENT CHARACTERISTICS OF RESPONDENTS AT THE TIME OF DIAGNOSIS

All respondents were in formal employment at the time of their diagnosis. Table 4.3 shows the employment characteristics of respondents at the time of their diagnosis. In terms of employment status, 86 per cent of respondents were employees, 13 per cent were self-employed, while the remaining 1 per cent were on a State training or employment scheme. In relation to the sector of employment, 37 per cent worked in the public sector and 57 per cent worked in the private sector. The remaining 6 per cent worked in the semi-state or the not-for-profit sector. Most questionnaire respondents (76 per cent) had a permanent contract at the time of their cancer diagnosis, though 12 per cent were employed on a temporary or casual basis with the remainder self-employed. Three-quarters of respondents reported working 35 hours or more per week, while 4 per cent worked less than 15 hours. Finally, 18 per cent of respondents worked in an organisation that employed less than ten people, while 51 per cent worked in an organisation with 250 or more employees.

TABLE 4.3 EMPLOYMENT CHARACTERISTICS OF RESPONDENTS AT THE TIME OF DIAGNOSIS	TABLE 4.3	EMPLOYMENT	CHARACTERISTICS O	F RESPONDENTS AT	THE TIME OF DIAGNOSIS
--	------------------	------------	--------------------------	-------------------------	-----------------------

Characteristic	Percentage	Number
Employment status		
Employee	86	336
Self-employed	13	33
On State training/employment scheme	1	3
Employment sector		
Public sector	37	146
Semi-state sector	2	13
Not-for-profit sector	4	20
Private sector	57	195
Contract type		
Permanent	76	302
Temporary/Fixed term contract/casual	12	38
Self-employed ¹	12	28
Hours worked (per week)		
<15	4	12
15-24	8	36
25-34	14	58
35-44	53	218
45+	22	58
Number of people in organisation		
1-9	18	57
10-19	8	25
20-49	11	33
50-99	6	22
100-249	7	31
250+	51	177

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note:

The number of cases may sum to less than 377 due to missing information. The percentages relate to the weighted data, while the numbers relate to the unweighted data, therefore they do not necessarily correspond.

¹ A small number of respondents reported that their 'employment status' was self-employed but that their 'contract type' was permanent.

4.4 EMPLOYMENT SITUATION OF RESPONDENTS AT THE TIME OF COMPLETING THE QUESTIONNAIRE

Figure 4.1 shows the employment situation of respondents at the time of completing the questionnaire. Over three-quarters (77 per cent) had returned to the same employer or self-employment following their cancer diagnosis, 7 per cent did not take any time off, 2 per cent returned to a different employer or self-employment while 14 per cent had not (at the time of completing the questionnaire) returned to employment.

FIGURE 4.1 EMPLOYMENT SITUATION OF RESPONDENTS AT THE TIME OF COMPLETING THE QUESTIONNAIRE



 $\begin{array}{lll} \textit{Source:} & \text{Authors' analysis of the 'Returning to Work' questionnaire.} \\ \textit{Note:} & \text{N} = 373. \ \text{The percentages relate to the weighted data.} \end{array}$

CHAPTER 5

The experience of returning to employment following a cancer diagnosis

Based on the 'Returning to Work' questionnaire, this chapter outlines the experience of returning to work following a diagnosis of cancer.

- Section 5.1 discusses the perceived impact of their cancer diagnosis on the career prospects of questionnaire respondents.
- Section 5.2 provides detail on the length of time that respondents were away from formal employment, the perceived appropriateness of the length of leave and the reasons for returning to employment.
- Section 5.3 examines the level of support provided by organisations and managers to respondents when returning to employment.
- Section 5.4 examines the factors which facilitated a return to employment.
- Section 5.5 discusses barriers to a return to work following a diagnosis of cancer and some of the challenges experienced on return.
- Section 5.6 examines the impact of the COVID-19 pandemic on the employment situation of cancer survivors.
- Section 5.7 examines the experience of those who have not yet returned to formal employment following their diagnosis.

As previously discussed, throughout the report all the percentages presented are based on the weighted survey data. The actual (unweighted) base number of cases is also reported for reference. It is important to note that the unweighted raw numbers will not necessarily correspond to the weighted percentages.

5.1 THE PERCEIVED IMPACT OF CANCER DIAGNOSIS ON CAREER PROSPECTS

Asked about the impact of their cancer diagnosis on their career prospects (n = 375), 51 per cent of respondents reported that it had no impact, 47 per cent said it had a negative impact and 3 per cent noted that it had a positive impact.

The association between the respondent reporting a negative impact on their career prospects and a range of demographic, socio-economic, health and work-related characteristics was examined. Table 5.1 shows the percentage of respondents reporting a negative impact on their career prospects for a range of characteristics (sex, age-group, employment status and employment sector) for

which a statistically significant relationship (at the 5 per cent level) was found.² The association between reporting a negative impact on career prospects and a range of other characteristics (including education and income) were also examined but were not found to be statistically significant.

A higher proportion of females (53 per cent) reported a negative impact of their cancer diagnosis on their career prospects than males (35 per cent). A significant relationship was also observed between reporting a negative impact on career prospects and age-group with, in general, younger age-groups more likely to report a negative impact. In terms of employment characteristics, employment status and sector were significantly associated with the proportion reporting a negative impact: for example, a higher proportion of the self-employed (61 per cent) reported a negative impact relative to employees (44 per cent); while those employed in the public sector were more likely to report a negative impact than those employed in the private sector at the time of diagnosis.

² This means that there is less than a 5 per cent chance that the observed differences within each characteristic occurred by chance alone.

TABLE 5.1THE PERCENTAGE OF RESPONDENTS REPORTING A NEGATIVE IMPACT OF CANCERDIAGNOSIS ON CAREER PROSPECTS FOR A RANGE OF RESPONDENT CHARACTERISTICS

Characteristic	Percentage reporting a negative impact
Sex	
Male	35%
Female	53%
P-value (based on Pearson chi-square)	0.001
Age-group ¹	
<35	69%
35-44	52%
45-54	56%
55-65	33%
>65+	46%
P-value (based on Pearson chi-square)	0.001
Employment status	
Employee	44%
Self-employed	61%
P-value (based on Pearson chi-square)	0.025
Employment sector	
Public sector	59%
Semi-state sector	50%
Not-for-profit sector	44%
Private sector	39%
P-value (based on Pearson chi-square)	0.007

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: N = 375. The percentages are based on the weighted data.

¹ Age-group relates to age at the time of completing the questionnaire rather than at diagnosis – the questionnaire was restricted to those aged 65 or less at the time of diagnosis.

Further analysis examined whether the associations detailed in Table 5.1 held after adjustment for the other characteristics included in the table. For example, given that women are more likely to be employed in the public sector (44 per cent of female questionnaire respondents were employed in the public sector relative to 22 per cent of males), does the relationship between sector and perceived negative impact on career hold once adjustment is made for the sex of respondents? The analysis also includes 'length of leave away from formal employment' as initial analysis found that the average number of weeks of leave was 51 for those that reported a negative impact on career prospects relative to 32 weeks for those that did not report a negative impact. Section 5.2 further examines the factors associated with length of leave.

Model 1 in Table 5.2 shows the results of a multi-variate logistic regression examining the association between the likelihood of reporting a negative impact on career prospects of cancer diagnosis and age-group, sex, employment status

and sector, while adjusting for the other characteristics included in the table.³ Model 2 also includes length of leave from formal employment. The table presents odds ratios, the 95 per cent confidence intervals and p-values. An odds ratio greater than one indicates a greater likelihood of reporting a negative impact of cancer diagnosis on career prospects, while an odds ratio lower than one indicates a lower likelihood, compared with the reference category. The 95 per cent confidence interval is a range of values where there is a 95 per cent chance that the range contains the true odds ratio. The p-value shows the likelihood that the observed result was due to chance; for example, a p-value of 0.01 indicates that there is a 1 per cent chance that the observed result is due to chance.

In Model 2 (which includes length of leave), males were more likely to report a negative impact on career prospects from their cancer diagnosis relative to females, though this was not significant at the 5 per cent level. Significant relationships were observed between the likelihood of reporting a negative impact on career prospects and employment status, employment sector and length of leave. For example, those in the public sector had over four times the odds of reporting a negative impact on career prospects from their cancer diagnosis relative to those employed in the private sector at the time of their diagnosis.

³ The effect of cancer site was tested but was not significant, did not change the other coefficients and so was not included in the final model.

TABLE 5.2ASSOCIATION BETWEEN LIKELIHOOD OF REPORTING A NEGATIVE IMPACT ON CAREER
PROSPECTS OF CANCER DIAGNOSIS AND A RANGE OF RESPONDENT CHARACTERISTICS

Characteristic	Odds ratio (95% confidence interval) p-value	Odds ratio (95% confidence interval) p-value
Age-group ¹	Model 1	Model 2
<35	Ref category	Ref category
	0.41	0.25
35-44	(0.11, 1.49)	(0.06, 1.09)
	0.174	0.065
	0.43	0.28
45-54	(0.12, 1.57)	(0.07, 1.23)
	0.199	0.091
	0.16	0.11
55-65	(0.04, 0.61) 0.007	(0.02, 0.49) 0.004
	0.34	0.004
>65	(0.07, 1.57)	(0.02, 0.84)
203	0.166	0.032
Sex	0.100	0.032
	0.76	1.11
Male	(0.46, 1.28)	(0.60, 2.07)
	0.306	0.732
Female	Ref category	Ref category
Employment status	,	6,
. ,	0.18	0.18
Employee	(0.08, 0.38)	(0.08, 0,42)
	0.001	0.001
Self-employed	Ref category	Ref category
Employment Sector		
	2.93	4.66
Public sector	(1.77, 4.84)	(2.61, 8.32)
	0.001	0.001
	3.14	4.21
Semi-state sector	(0.74, 13.35)	(0.94,18.87)
	0.121	0.061
	0.93	1.18
Not-for-profit sector	(0.25, 3.41)	(0.28, 5.00)
	0.914	0.820
Private sector	Ref category	Ref category
		1.01
Weeks away from formal employment		(1.00, 1.01)
		0.001

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: Results from a weighted multi-variate logistic regression. N = 361. The analysis is based on the weighted data.

 1 Age-group relates to age at the time of completing the questionnaire rather than at diagnosis – the questionnaire was restricted to those aged 65 or less at the time of diagnosis.
5.2 RETURNING TO WORK FOLLOWING A CANCER DIAGNOSIS

Of those that had returned to work (including those that did not take any time off) at the time of completing the questionnaire, the average length of time away from formal employment was 40 weeks (ranging from 0 to 260 weeks), while the median was 26 weeks.

In order to look at the factors associated with length of leave from formal employment, Table 5.3 shows the median length of leave for various demographic, health and work-related characteristics (the minimum and maximum are shown in brackets). Significant associations are observed between length of leave and cancer-related factors. In terms of cancer site, the median length of leave for those with breast cancer was 42 weeks, relative to six weeks for those with melanoma skin cancer. Significant differences were also observed across treatment types. For example, the median length of leave was 40 weeks for those who received radiotherapy, relative to 20 weeks for those that did not receive radiotherapy, while the median length of leave was 44 weeks for those who received chemotherapy relative to 15 weeks for those who did not receive chemotherapy. Those that were diagnosed as Stage 0 had a shorter length of leave relative to all other groups.

	Median leave in weeks (Minimum, maximum)
Sex	
Male	26 (0, 260)
Female	26 (0, 260)
P-value (based on Mann-Whitney test)	0.025
Age-group ¹	
<35	26 (0, 104)
35-44	26 (0, 208)
45-54	31 (0, 260)
55-65	26 (0, 26)
>65	17 (0, 82)
P-value (based on Kruskal-Wallis test)	0.011
Employment status	
Employee	26 (0, 260)
Self-employed	24 (0, 260)
P-value (based on Mann-Whitney test)	0.310
Employment sector	
Public sector	31 (0, 208)
Semi-state	18 (12, 103)
Not-for-profit sector	24 (0, 103)
Private sector	26 (0, 260)
P-value (based on Kruskal-Wallis test)	0.422

TABLE 5.3MEDIAN (MINIMUM AND MAXIMUM) LENGH OF LEAVE FROM FORMAL EMPLOYMENT
IN WEEKS FOR A RANGE OF RESPONDENT CHARACTERISTICS

|--|

	Median leave in weeks (Minimum, maximum)
Cancer site	
Breast	42 (0, 208)
Colorectal	31 (0, 132)
Lung	16 (0, 52)
Melanoma skin cancer	6 (2, 26)
Cervix	25 (0,208)
Ovary	63 (0, 104)
Other	30 (0, 260)
Lymphoma	29 (0, 56)
Prostate	7 (0, 30)
P-value (based on Kruskal-Wallis test)	0.001
Cancer stage at diagnosis	
0	7 (0, 44)
I	26 (0, 208)
II	30 (0, 156)
	27 (0, 260)
IV	32 (6, 26)
Don't know	25 (0, 162)
P-value (based on Kruskal-Wallis test)	0.191
Treatment	
Radiotherapy	40 (0, 260)
No radiotherapy	20 (0, 260)
P-value (based on Mann-Whitney test)	0.001
Chemotherapy	44 (0, 260)
No chemotherapy	15 (0, 208)
P-value (based on Mann-Whitney test)	0.001
Surgery	27 (0, 260)
No surgery	24 (0, 260)
P-value (based on Mann-Whitney test)	0.180

Source: Authors' analysis of the 'Returning to Work' questionnaire. Note:

N = 312. The analysis is based on the weighted data.

¹ Age-group relates to age at the time of completing the questionnaire rather than at diagnosis – the questionnaire was restricted to those aged 65 or less at the time of diagnosis.

Asked about the appropriateness of the length of leave, 38 per cent reported that their period of leave was shorter than they needed, 9 per cent that it was longer than they needed and 53 per cent that it was an appropriate period of leave (Figure 5.1).



FIGURE 5.1 THE PERCENTAGE OF RESPONDENTS REPORTING APPROPRIATENESS OF PERIOD OF LEAVE

Source:Authors' analysis of the 'Returning to Work' questionnaire.Note:N = 319. The percentages are based on the weighted data.

When asked about the main reason for returning to work, 38 per cent reported that the main reason they returned to work was financial need, while 28 per cent reported the main reason as maintaining or regaining a sense of normality. A small proportion (3 per cent) reported that they returned due to pressure from their employer (Figure 5.2). Separately, the main reason for returning to work was examined for those that reported that their period of leave was too short (Figure 5.2). A slightly different distribution was observed. For example, almost 50 per cent of this group reported that the main reason they returned was financial need, while 20 per cent reported that the main reason was to maintain or regain a sense of normality.



FIGURE 5.2 THE PERCENTAGE OF RESPONDENTS REPORTING THE MAIN REASON FOR RETURNING TO WORK/STAYING IN WORK

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: N = 319 for all respondents and n = 103 for those that report 'leave too short'. The percentages relate to the weighted data.

5.3 LEVEL OF SUPPORT PROVIDED BY ORGANISATION AND MANAGER

Those that had returned to work were asked how supportive their organisation was on return (number of respondents = 299); the same question was asked regarding the level of support received from their immediate manager or supervisor (number of respondents = 290).⁴ In general, high levels of support were reported with 68 per cent of respondents reporting that their organisation and manager were very supportive or supportive (Figure 5.3). However, 11 per cent of respondents reported that their organisation was unsupportive or very unsupportive, while 17 per cent of respondents noted that their manager was unsupportive or very unsupportive (Figure 5.3). There was a significant association between support at the organisation level and support at the manager level (Pearson chi-square p < 0.001). For example, 77 per cent of those that reported that their organisation was very supportive, while 42 per cent of those that reported that their organisation was very unsupportive, also reported that their organisation was very unsupportive, also reported that their organisation was very unsupportive, also reported that their organisation was very unsupportive.

⁴ These questions were not explicitly limited to employees, and approximately one-third of the self-employed answered these questions. It is possible that this group of self-employed are contractors or freelancers that work for one or more clients.





Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: N = 299 for organisation and n = 290 for Manager. Approximately two-thirds of the self-employed noted that this question was not relevant to them. The percentages relate to the weighted data.

Further analysis examined the level of support reported at the organisation and managerial level for various demographic, socio-economic and work-related characteristics. Table 5.4 shows the percentage of respondents reporting that their employment organisation was very supportive/supportive, neither supportive nor unsupportive and unsupportive/very unsupportive on their return to work by age-group, sex, employment sector and number of people employed in the organisation. It also shows the p-values from a statistical test (Pearson chi-square) which identifies if the observed differences are statistically different.

At the organisation level, no significant associations were found between reported level of organisation support and age-group or sex. However, significant differences were observed across employment sectors and number of people in the organisation. For example, 17 per cent of those employed in the public sector at the time of their diagnosis noted that the organisation was unsupportive or very unsupportive relative to 9 per cent in the private sector. Twenty per cent of those in organisations which employ less than ten people noted that the organisation was unsupportive or very unsupportive, relative to 8 per cent of those in organisations with more than 250 employees. Other personal characteristics including income and education were also examined but were not found to be statistically significantly associated with the level of reported support at the organisation level.

TABLE 5.4 THE PERCENTAGE OF RESPONDENTS REPORTING LEVEL OF SUPPORT PROVIDED BY ORGANISATION ON RETURN TO WORK FOR A RANGE OF RESPONDENT **CHARACTERISTICS**

	Very supportive/	Neither supportive	Unsupportive or
	supportive	nor unsupportive	very unsupportive
	%	%	%
Age-group ¹			
<35	75	0	25
35-44	68	20	12
45-54	60	27	12
55-65	70	22	8
>65	82	18	0
P-value (from Pearson Chi-square)		0.279	
Sex			
Male	76	17	7
Female	64	23	12
P-value (from Pearson Chi-square)		0.141	
Employment sector			
Public sector	68	16	17
Semi-state sector/not-for profit	86	14	0
Private sector	64	27	9
P-value (from Pearson Chi-square)		0.001	
Number in organisation			
<10	40	40	20
10-19	50	50	0
20-49	76	18	6
50-99	55	45	0
100-249	86	5	9
250+	76	16	8
P-value (from Pearson Chi-square)		0.001	

Source: Authors' analysis of the 'Returning to Work' questionnaire. Note:

N = 299. The percentages are based on the weighted data.

¹ Age-group relates to age at the time of completing the questionnaire rather than at diagnosis – the questionnaire was restricted to those aged 65 or less at the time of diagnosis.

Similar to Table 5.4, Table 5.5 shows the percentage of respondents reporting that their manager was very supportive/supportive, neither supportive nor unsupportive and unsupportive/very unsupportive on their return to work by agegroup, sex, employment sector and number of people employed in the organisation. Somewhat different results were found in relation to managerial support relative to organisational support. For example, a significant association was found between managerial support and age-group and sex, as well as for employment sector. In terms of age, a greater proportion of the younger agegroups (<35 and 35-44) reported that their manager was unsupportive or very unsupportive on return to work relative to the older age-groups. Males were also significantly more likely to report that their manager was unsupportive or very unsupportive relative to female respondents. Those in the public sector again were more likely to report that their manager was unsupportive or very unsupportive relative to those in the other sectors.

TABLE 5.5THE PERCENTAGE OF RESPONDENTS REPORTING LEVEL OF SUPPORT PROVIDED BYMANAGER ON RETURN TO WORK FOR A RANGE OF RESPONDENT CHARACTERISTICS

	Very supportive/ supportive	Neither supportive nor unsupportive	Unsupportive or very unsupportive
Age-group ¹			
<35	70%	0	30%
35-44	63%	11%	26%
45-54	63%	26%	11%
55-65	73%	12%	15%
>65	82%	18%	0
P-value (from Pearson Chi-square)		0.005	
Sex			
Male	64%	8%	27%
Female	70%	18%	12%
P-value (from Pearson Chi-square)		0.005	
Employment sector			
Public sector	73%	8%	20%
Semi-state sector/not-for profit	81%	19%	0
Private sector	64%	27%	9%
P-value (from Pearson Chi-square)		0.004	
Number in organisation			
<10	41%	38%	21%
10-19	50%	22%	28%
20-49	78%	9%	13%
50-99	62%	38%	0
100-249	75%	0	25%
250+	72%	11%	16%
P-value (from Pearson Chi-square)		0.001	

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note:

N = 290. The percentages are based on the weighted data.

¹ Age-group relates to age at the time of completing the questionnaire rather than at diagnosis – the questionnaire was restricted to those aged 65 or less at the time of diagnosis.

5.4 FACTORS WHICH FACILITATED A RETURN TO EMPLOYMENT

Respondents who had returned to employment (with the same employer or selfemployment) were asked about the work-related factors which helped them to return to work or stay in work following their cancer diagnosis (n = 312). A number of factors were identified including phased return to full-time work (reported by 44 per cent of respondents), help and support from colleagues (43 per cent), help and support from employer and manager (41 per cent) and time off for medical appointments (40 per cent) (Figure 5.4).

FIGURE 5.4 THE PERCENTAGE OF RESPONDENTS REPORTING WORK-RELATED FACTORS WHICH FACILITATED RETURN TO WORK



Source:Authors' analysis of the 'Returning to Work' questionnaire.Note:N = 312. The percentages are based on the weighted data.

5.5 FACTORS WHICH ACTED AS BARRIERS TO RETURN TO WORK

Respondents who had returned to work (with the same employer or selfemployment) were asked about any barriers they experienced on returning to formal employment following their cancer diagnosis. Of the 304 respondents, 46 per cent reported at least one barrier. Of those reporting at least one barrier, Figure 5.5 shows the proportion of respondents reporting that they encountered a particular barrier. The most commonly reported barrier was physical and psychological health issues, with 79 per cent and 62 per cent respectively reporting that this was an issue for them. One-in-four noted that they had difficulty completing job requirements, while 20 per cent mentioned that they experienced an unsupportive employer or manager. Given the opportunity to identify other barriers, a number of respondents noted that inflexibility with regard to taking time off was an issue, in particular taking time off for medical appointments.

FIGURE 5.5 PERCENTAGE OF RESPONDENTS REPORTING PARTICULAR BARRIERS TO RETURNING TO WORK (MULTIPLE RESPONSES PERMITTED)



Source:Authors' analysis of the 'Returning to Work' questionnaire.Note:N = 139. The percentages are based on the weighted data.

Respondents who had returned to work (either with the same employer or selfemployment or different employer/self-employment) were presented with a list of 11 negative work-related experiences and asked to tick any that they had experienced due to their cancer diagnosis (n = 321). Of those that responded to this question, 68 per cent reported that they did not experience any of the identified issues, 17 per cent reported experiencing one of the issues, 9 per cent reported experiencing two of the issues while 6 per cent reported that they experienced three or more.

Figure 5.6 shows the proportion of respondents reporting that they experienced a particular issue. The most commonly reported negative work-related experience was a reduction in salary or bonus (reported by 11 per cent of respondents). Other negative experiences included the respondent was given unsuitable workloads or tasks (8 per cent), didn't get a promotion that they felt they deserved (7 per cent) and received unpleasant comments from employer, manager or colleagues (6 per cent).

FIGURE 5.6 PERCENTAGE OF RESPONDENTS REPORTING NEGATIVE WORK-RELATED ISSUES ON RETURN TO EMPLOYMENT (MULTIPLE RESPONSES PERMITTED)



Source: Authors' analysis of the 'Returning to Work' questionnaire. Note: N = 321. The percentages are based on the weighted data.

The likelihood of reporting a negative work-related issue was further examined by sex, age-group and employment sector (Table 5.6, Table 5.7, Table 5.8). In terms of sex differences, some issues were more likely to be experienced by females, while others were more likely to be experienced by males (Table 5.6). For example, females were more likely to report a reduction in salary or bonus relative to males (15 per cent versus 1 per cent), while males were more likely to report that they were denied access to training relative to females (10 per cent versus 4 per cent).

TABLE 5.6 THE PERCENTAGE OF RESPONDENTS REPORTING NEGATIVE WORK-RELATED ISSUE BY SEX

	Male (n = 101)	Female (n = 219)	P-value (Pearson chi-square)
Reduction in salary or bonus	1	15	<0.001
Given unsuitable workload/tasks	12	6	0.066
Didn't get deserved promotion	5	9	0.240
Received unpleasant comments	5	7	0.429
Unfairly criticised or disciplined	4	7	0.319
Denied access to training	10	4	0.024
Made redundant or dismissed	4	5	0.805

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: The percentages are based on the weighted data.

A somewhat mixed picture is observed between reporting a negative work-related issue and age-group (Table 5.7). Some issues are more likely to be reported by younger age-groups (given unsuitable workloads or tasks, denied access to

training), but for other issues no obvious relationship with age is observed (received unpleasant comments, made redundant or dismissed).

TABLE 5.7 THE PERCENTAGE OF RESPONDENTS REPORTING NEGATIVE WORK-RELATED ISSUE BY AGE-GROUP

	<45 (n = 112)	45-54 (n = 83)	55+ (n = 126)	P-value (Pearson chi-square)
Reduction in salary or bonus	13	17	4	0.006
Given unsuitable workload/tasks	16	2	4	<0.001
Didn't get deserved promotion	5	17	3	<0.001
Received unpleasant comments	6	10	5	0.390
Unfairly criticised or disciplined	8	7	3	0.236
Denied access to training	9	6	2	0.037
Made redundant or dismissed	5	5	4	0.955

Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note:

Age-groups for this analysis were combined due to small numbers in some groups. The percentages are based on the weighted data. Age-group relates to age at the time of completing the questionnaire rather than at diagnosis – the questionnaire was restricted to those aged 65 or less at the time of diagnosis.

Table 5.8 shows the percentage reporting a negative work-related issue by employment sector. A number of issues were significantly more commonly reported by those employed in the public sector relative to the private sector, including being given unsuitable workload or tasks, receiving unpleasant comments and denied access to training.

TABLE 5.8 THE PERCENTAGE OF RESPONDENTS REPORTING NEGATIVE WORK-RELATED ISSUE BY EMPLOYMENT SECTOR EMPLOYMENT SECTOR

	Public sector (n = 116)	Private sector (n = 177)	P-value (Pearson chi-square)
Reduction in salary or bonus	15	10	0.187
Given unsuitable workload/tasks	14	2	<0.001
Didn't get deserved promotion	8	6	0.603
Received unpleasant comments	10	4	0.030
Unfairly criticised or disciplined	6	6	0.876
Denied access to training	10	2	0.001
Made redundant or dismissed	3	5	0.500

Source: Authors' analysis of the 'Returning to Work' questionnaire. Note: The percentages are based on the weighted data.

5.6 IMPACT OF COVID-19 PANDEMIC ON EMPLOYMENT SITUATION OF RESPONDENTS

Those in employment at the time of completing the questionnaire (n = 314), were asked about the impact of the COVID-19 pandemic on their employment situation. Nearly half (48 per cent) reported that the pandemic had in some way impacted

on their employment situation. The most commonly reported impact of the pandemic was a move to working from home, reported by 42 per cent of respondents (Figure 5.7). Other changes included being unable to work as job was not suitable for remote working (19 per cent), taking paid leave (7 per cent) and taking unpaid leave (5 per cent).

FIGURE 5.7 THE PERCENTAGE OF RESPONDENTS REPORTING IMPACT OF COVID-19 PANDEMIC ON EMPLOYMENT SITUATION



Source:Authors' analysis of the 'Returning to Work' questionnaire.Note:N = 152. The percentages are based on the weighted data.

Respondents who noted an impact on their employment situation were subsequently asked if the change was related to their previous cancer diagnosis, which might place them at greater risk of serious health effects from COVID-19. For each impact on employment, Figure 5.8 shows the percentage that reported that the change was related to their cancer diagnosis. It shows that 61 per cent of those who had to take paid leave did so due to their cancer diagnosis, while 28 per cent of those who experienced a temporary lay-off did so due to their previous cancer diagnosis.

FIGURE 5.8 THE PERCENTAGE OF RESPONDENTS REPORTING IMPACT ON EMPLOYMENT DUE TO CANCER DIAGNOSIS



Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: N = 11 for had to take paid leave; n = 18 for temporary lay-off; n = 63 for started working from home: n = 8 for had to take unpaid leave; n = 37 for increased number of hours working from home; n = 37 for change in work hours. The percentages are based on the weighted data.

Of those that made special arrangements regarding their employment situation during the pandemic due to their cancer diagnosis, almost all (98 per cent) reported that their employer was supportive in making these individual arrangements.

5.7 EXPERIENCE OF THOSE WHO HAVE NOT YET RETURNED TO FORMAL EMPLOYMENT FOLLOWING A CANCER DIAGNOSIS

At the time of completing the questionnaire, 52 respondents had not yet returned to formal employment. Figure 5.9 shows the main reason for not having returned; the most commonly reported was that the respondent 'was not physically able' (reported by 30 per cent), 23 per cent reported that they were still in receipt of treatment, while 11 per cent were currently on sick leave.

FIGURE 5.9 THE PERCENTAGE OF RESPONDENTS REPORTING MAIN REASON THEY HAVE NOT RETURNED TO EMPLOYMENT FOLLOWING CANCER DIAGNOSIS



Source: Authors' analysis of the 'Returning to Work' questionnaire.

Note: N = 52. The percentages are based on the weighted data.

Respondents were subsequently asked what work-related factors would help them to return to work (Figure 5.10). A phased return was commonly noted (reported by 47 per cent of respondents), as were flexible start and finish times (reported by 38 per cent), reduced hours (35 per cent) and time off for medical appointments (33 per cent).

FIGURE 5.10 THE PERCENTAGE OF RESPONDENTS REPORTING THAT SPECIFIC WORK-RELATED FACTORS WOULD HELP THEIR RETURN TO WORK



Source:Authors' analysis of the 'Returning to Work' questionnaire.Note:N = 52. The percentages are based on the weighted data.

Similar to those that had already returned to work, those that had not yet returned identified poor health as a barrier to returning to work (reported by 69 per cent of

respondents) (Figure 5.11). Other commonly reported barriers were inability to fulfil job requirements (28 per cent) and inflexible working arrangements (21 per cent).

FIGURE 5.11 THE PERCENTAGE OF RESPONDENTS REPORTING THAT PARTICULAR FACTORS HAVE ACTED OR COULD ACT AS BARRIERS TO RETURN TO WORK



Source:Authors' analysis of the 'Returning to Work' questionnaire.Note:N = 52. The percentages are based on the weighted data.

Asked if they planned on returning to the same employer/self-employment within the next 24 months, 50 per cent reported that they did plan on returning to the same employer/self-employment. For those not planning on returning to the same employment or self-employment, 11 per cent wanted a job with less pressure and/or responsibility; 17 per cent had taken early retirement; 4 per cent had taken long-term sickness leave. However, is caution is advised when interpreting these findings given the very small numbers involved.

CHAPTER 6

Conclusion and policy recommendations

International and Irish research suggests that not all those diagnosed with cancer of working age return to formal employment and, for those that do, many reduce working hours. For some, this is likely to be a personal decision as priorities shift and change. However, for others, there are barriers and challenges which impede a return to employment. The analysis presented in this report sought to document the experience of returning to work in Ireland following a cancer diagnosis. The following section provides a summary of the main findings and, where possible, compares the findings from this analysis to those of other studies. Section 6.2 discusses a range of recommendations for employers and Government. Section 6.3 discusses the limitations of the analysis and potential further research.

6.1 MAIN FINDINGS

6.1.1 Impact of cancer diagnosis on career prospects

Nearly half of all respondents to the 'Returning to Work' questionnaire reported that their cancer diagnosis had a negative impact on their career prospects, with females, younger workers, the self-employed and those working in the public sector more likely to report a negative impact. In addition, those with a longer length of leave from formal employment were more likely to report a negative impact on career prospects.

The observed association between age-group and negative impact on career prospects might be expected given that younger people may be more likely to be building their career and a period of leave or reduced working hours may have a more detrimental impact at this stage relative to older workers who may already be more established in their career. However, previous research shows that younger cancer survivors become as likely as healthy controls to achieve a successful career (Stone et al., 2017), suggesting that the negative impact on career prospects for younger people may lessen over time.

While females were more likely to report a negative impact on career relative to males, this relationship was no longer observed in the fully adjusted model once employment sector and length of leave from formal employment was included. The reason underlying the higher proportion of public sector workers reporting a negative impact on career prospects is unclear and worthy of further exploration, in particular to identify if it is associated with particular occupations within the public sector. Previous research has shown that people working in public

administration and the health sector are most at risk of job stress in Ireland (Russell et al., 2018), and while not all health sector workers are employed in the public sector, it could be that a cancer diagnosis might amplify stressors and have a particularly detrimental impact on career prospects in these sectors. For the self-employed, the potential loss of clients/customers while the individual is on leave could contribute to a negative impact on career prospects.

6.1.2 Return to work

In keeping with previous Irish research (Hanly et al., 2012; 2013; Pearce et al., 2015), the analysis found that length of time away from formal employment varied depending on cancer site and treatment. In general, significant differences were not observed across employment-related characteristics in length of leave and rather appear to be driven by health and treatment factors.

For some respondents, returning to work may be perceived as a positive development, with 28 per cent of respondents reporting that the main reason they returned to work was to gain a sense of normality, 12 per cent reporting that they returned as they felt able to work and 8 per cent reporting that the main reason they returned was because work was important to them. However, for others, financial need was the main reason for their return to work. While not directly comparable, a study in England, looking specifically at people who continued to work during treatment, found that almost half (49 per cent) said they worked to regain or maintain a normal life, while 23 per cent reported it was a financial necessity (Luker et al., 2013).

Asked about the appropriateness of the length of leave, 38 per cent reported that their period of leave was too short. Half of this group reported that their reason for returning to work was financially motivated, highlighting the need for access to appropriate financial supports for those diagnosed with cancer (further discussed in Section 6.2).

6.1.3 Level of support from organisation/manager

In general, respondents reported high levels of support from their organisation and manager on returning to work, with 68 per cent reporting that their organisation and manager were very supportive or supportive. However, 11 per cent reported that their organisation was unsupportive or very unsupportive on their return, while 17 per cent reported that their manager was unsupportive or very unsupportive or very unsupportive or very unsupportive or very unsupportive when they returned to work. These results were similar to an English study which found that 76 per cent of cancer survivors reported that their employer or line manager was supportive throughout their illness (Luker et al., 2013).

Public sector workers were more likely to report that their organisation and manager were unsupportive or very unsupportive relative to those working in the private sector. Those working in small organisations (less than ten staff) were more likely than those in larger organisations to report that their organisation was unsupportive or very unsupportive, while males and younger age-groups were more likely to report that their manager was unsupportive or very unsupportive. Again, it is not clear why those working in the public sector were more likely to report that the organisation and manager were unsupportive and would merit further investigation. The small number of respondents hampered attempts to examine whether the finding of higher levels of unsupportive organisations and managers reported by those in the public sector was driven by particular occupations.

The lower levels of support reported by those in small organisations is consistent with previous research (Tamminga et al., 2018). It is likely, in part, explained by small organisations being less likely to have occupational health services and by a lack of experience in the management of sickness absence (Braspenning et al., 2018).

6.1.4 Factors which facilitated return

In keeping with the international literature, the most commonly reported factors which facilitated return to work were a phased return, help and support from colleagues and employer/manager, and time off for medical appointments. Some respondents noted the importance of open and honest communication between the individual and employer/manager through treatment and, in particular, before returning to work. They noted that such communication should include discussion about what is feasible for the individual and the potential longer-term impacts of the condition. In terms of time off for medical appointments, a number of respondents noted the need for time off for medical appointments, which should be over and above annual leave, as annual leave may be required as a period to rest and recuperate.

6.1.5 Barriers to return

Asked about barriers to returning to work, almost half (46 per cent) reported at least one barrier, the most common of which were physical and psychological health issues. Tiredness appears to be a particular issue with 86 per cent of respondents reporting that they currently (at the time of completing the questionnaire) experienced fatigue. One-quarter of respondents noted that they had difficulty completing job requirements. These findings are largely in keeping with previous research which has shown that that most types of cancers result in decreased work ability compared to healthy controls or those with other chronic conditions (Munir et al., 2009). However, for many cancers, work ability improves over time irrespective of age (Munir et al., 2009).

Presented with a list of negative work-related experiences, 32 per cent of respondents reported that they experienced at least one of the mentioned issues, while 15 per cent reported experiencing two or more. The most commonly reported issues were a reduction in salary or bonus (11 per cent), given unsuitable workloads or tasks (8 per cent), made redundant or dismissed (4 per cent), threatened with redundancy or dismissal (3 per cent) and treated so poorly they felt they had to leave workplace (2 per cent). The proportion of respondents reporting a negative issue differed somewhat by sex, age-group and employment sector.

The information collected in the questionnaire relates to respondents' self-reports of whether they were treated unfairly at work because of their cancer. It cannot be said that these cases would constitute discrimination in the courts. However, it does highlight potential work-related discrimination against people diagnosed with cancer in Ireland, which contravenes discrimination legislation in which chronic disease or illness is a protected ground under the Employment Equality Acts 1998-2011.

6.1.6 Impact of COVID-19

Respondents completed the questionnaire in July/August 2020 at a time when there were significant changes and upheavals in the labour market due to the COVID-19 pandemic. Asked about the impact of the pandemic on their employment, 48 per cent reported that there was some impact. This included working from home, temporary lay-off and taking paid or unpaid leave.

For those respondents who indicated that the pandemic had an impact on their employment, they were subsequently asked if changes to their employment status were related to their cancer. Those with cancer are on the HSE list of those at high risk from COVID-19 and this question was included to pick up any additional disruption to employment that might arise for respondents. Among those who were laid off temporarily, 28 per cent said that this was due to cancer while 9 per cent of those that took unpaid leave did so due to cancer diagnosis.

6.2 POLICY AND PRACTICE RECOMMENDATIONS

For many respondents to the 'Returning to Work' questionnaire, returning to work was a relatively positive experience where the individual felt supported by their organisation and/or manager. However, for a minority, their return to work was a negative experience, with some subsequently leaving their employment. The following sections detail some recommendations to promote a more positive return to work for those previously diagnosed with cancer, who seek to return to

formal employment. These are divided into recommendations for the employer and recommendations for Government.

6.2.1 The role of the employer

Bringing together the evidence from the literature and the findings from the 'Returning to Work' questionnaire, there are several steps that an employer can take to facilitate the return to work of an employee that has been diagnosed with cancer. These include:

- Recognising that everyone's cancer experience is different and will depend on the individual's personal circumstances including cancer site, treatment, length of leave and ongoing health issues. Consequently, the process of returning to work will differ for everyone. In addition, there is a need to recognise that finishing treatment and returning to work does not necessarily mean that the individual is 'back to normal' and adjustments may be required in the short, medium and longer term.
- 2. Communicating with the individual throughout their cancer experience can facilitate their return to work and assist the employer in identifying what the individual is capable of and what adjustments may be required. Such communications should be treated confidentially and the decision about how much information and when to share this with their colleagues should rest with the employee (Irish Congress of Trade Unions, 2014). The Irish Cancer Society has produced a booklet which provides information and advice on life after cancer including returning to work (Irish Cancer Society, 2020). The booklet emphasises the importance of open communication between the employee and employer before returning to work.
- 3. Providing a flexible approach to the individual's return to work. This might include reduced working hours/days, lighter tasks, working from home and time off for medical appointments. Communication with the employee is key to identify what arrangements may be necessary for that individual's circumstances. While for some, such arrangements may be a temporary measure, for others a longer-term adjustment to their working conditions may be required.

The Employment Equality Acts 1998-2015 require employers to take reasonable steps to accommodate the needs of employees with illness and disabilities, including cancer. The law requires employers to make 'reasonable accommodation' which might include some modification to the way work is organised such as the tasks or structure of a job or workplace and working time arrangements (Irish Congress of Trade Unions, 2014).

Public sector employers are also bound by the Public Sector Duty to eliminate discrimination, promote equality of opportunity and protect the human rights of their staff when carrying out their daily work (Irish Human Rights and Equality Commission, 2019). This is particularly relevant in the light of more negative responses on organisational support and career impact of those working in the public sector.

- 4. Avoiding discriminatory behaviour. While not necessarily widespread, the 'Returning to Work' questionnaire did identify several examples of potentially discriminatory practices experienced by employees on their return to employment. A person diagnosed with cancer is regarded as having a disability for the purposes of the Employment Equality Acts 1998-2015 (Irish Human Rights and Equality Commission, 2019). Consequently, any less favourable treatment arising from the cancer diagnosis, for example being passed over for promotion, receiving less favourable terms and conditions, being selected for redundancy or not being given the same chances as other workers are all prohibited. This protection from discrimination continues even when there is no longer any evidence of the cancer (Irish Congress of Trade Unions, 2014).
- 5. Where possible providing financial supports to assist the individual if they need to take leave and to ensure that they do not need to return to work before they are physically and psychologically ready. There is a currently no statutory obligation for employers to provide sick leave pay. Consequently, current provision of sick leave pay varies across employers, and those in low paid, temporary, private sector employment are less likely to be covered. However, a bill proposing the introduction of a statutory sick leave pay scheme was introduced in response to the COVID-19 pandemic and is currently under consideration by the Oireachtas.⁵

6.2.2 The Government

There are also additional measures that the Government can take to ensure the successful return to employment of people diagnosed with cancer. These include:

 The provision of adequate financial supports to ensure that employees do not return to work before they are ready due to financial need. While those who have paid the requisite PRSI contributions are entitled to Illness Benefit (paid by the State), up to a maximum of two years, additional measures could include:

⁵ https://www.oireachtas.ie/en/debates/debate/dail/2020-09-23/2.

- Providing entitlement to employees to attend medical appointments, where necessary, during work time, without loss of pay.
- Ensuring flexibility regarding the provision of financial and other supports to facilitate the return to work on a phased and flexible basis.
- Progressing with the development of the statutory sick leave pay scheme.
- Targeting extra employment supports (such as training) for those who have lost their jobs due to their cancer diagnosis. In addition, such supports could be targeted towards those who feel their career prospects have been negatively impacted by their diagnosis, including younger people. Again, such supports should be provided in a flexible manner to accommodate those who may not be physically or mentally able to participate in a full-time capacity.
- Providing up-to-date information for employees and employers in relation to returning to work following a cancer diagnosis. It should include information such as employees' rights and available supports when diagnosed with cancer, as well as information for employers about facilitating the return to work and details of anti-discrimination legislation as it relates to cancer and other illnesses. This is particularly relevant for smaller organisations who may lack a designated human resource department.

6.3 LIMITATIONS AND FURTHER RESEARCH

The analysis presented in this report provided detail on the experience of returning to work following a cancer diagnosis in Ireland. There are some limitations to the analysis. First, the experience of returning to work following a cancer diagnosis of those who completed the questionnaire may differ from the experience of those who did not complete the questionnaire. It could be that those that had a more negative experience were more likely to respond than those who had a positive experience. Alternatively, it could be that those that completed the questionnaire were more advantaged in terms of socio-economic status than non-respondents and that therefore the results do not reflect the experience of the potentially most vulnerable employees. A comparison of education levels of respondents and the general population (from the 2016 Census) suggest higher levels of education in respondents to the questionnaire. However, this should be interpreted with a degree of caution as the distribution of socio-economic status of the general population does not necessarily reflect the distribution of the socio-economic status of the cohort of people diagnosed with cancer (Garcia-Gil et al., 2014); in addition, cancer survival can differ by socio-economic status (Walsh et al., 2014). Consequently, it is not necessarily appropriate to generalise the findings from the questionnaire to the general cohort of people diagnosed with cancer.

Second, the focus on the questionnaire and the project was, in the main, on the work-related factors associated with returning to work. However, other factors

such as personal circumstances including social support are also likely to be important. Third, the project only focused on the experience of the employee (and self-employed). Further work should include the perspective of the employer. Fourth, the 'Returning to Work' questionnaire was available for completion in July and August 2020 when the COVID-19 pandemic and associated restrictions were in place in Ireland. It is possible that the pandemic and the restrictions influenced some respondents' answers to some questions, for example current feelings of anxiety and issues with sleeping. The responses to these questions should be considered in this context. Finally, the analysis was restricted to those in formal employment at the time of their cancer diagnosis. It is possible that those not in employment at the time of their diagnosis (due to, for example, unemployment, sickness, in education or home duties) and therefore not attached to a particular employer may have a more negative employment-related experience, especially if they were not entitled to sickness benefit. Future work should examine this group in more detail.

- Ahn, E., J. Cho, D.W. Shin, B.W. Park, S.H. Ahn, D.Y. Noh, S.J. Nam, E.S. Lee and Y.H. Yun (2009). 'Impact of breast cancer diagnosis and treatment on work-related life and factors affecting them', *Breast Cancer Research and Treatment*, Vol. 116, No. 3, pp. 609-616.
- Balak, F., C.A. Roelen, P.C. Koopmans, E.E. Ten Berge and J.W. Groothoff (2008). 'Return to work after early-stage breast cancer: a cohort study into the effects of treatment and cancer-related symptoms', *Journal of Occupational Rehabilitation*, Vol. 18, No. 3, pp. 267-272.
- Beesley, V.L., J.K. Vallance, G. Mihala, B.M. Lynch and L.G. Gordon (2017). 'Association between change in employment participation and quality of life in middle-aged colorectal cancer survivors compared with general population controls', *Psycho-Oncology*, Vol. 26, No. 9, pp. 1354-1360.
- Blinder, V.S., M.M. Murphy, L.T. Vahdat, H.T. Gold, I. de Melo-Martin, M.K. Hayes, R.J. Scheff, E. Chuang, A. Moore and M. Mazumdar (2012). 'Employment after a breast cancer diagnosis: a qualitative study of ethnically diverse urban women', *Journal* of Community Health, Vol. 37, No. 4, pp. 763-772.
- Bouknight, R.R., C.J. Bradley and Z. Luo (2006). 'Correlates of return to work for breast cancer survivors', *Journal of Clinical Oncology*, Vol. 24, No. 3, pp. 345-353.
- Braspenning, I., S. Tamminga, M. Frings-Dresen, M. Leensen, A. De Boer, C. Tikka, J. Verbeek, F. Munir, S. Hemming, Z. Amir, L. Smith, L. Sharp and A. Haste (2018). *Rehabilitation and return to work after cancer – instruments and practices*, Luxembourg: European Agency for Safety and Health at Work.
- Carlsen, K., A.J. Jensen, R. Rugulies, J. Christensen, P.E. Bidstrup, C. Johansen, I.E. Huitfeldt Madsen and S.O. Dalton (2013). 'Self-reported work ability in long-term breast cancer survivors. A population-based questionnaire study in Denmark', Acta Oncologica, Vol. 52, No. 2, pp. 423-429.
- de Boer, A.G., T. Taskila, A. Ojajarvi, F.J. van Dijk and J.H. Verbeek (2009). 'Cancer survivors and unemployment: a meta-analysis and meta-regression', *The Journal of the American Medical Association*, Vol. 301, No. 7, pp. 753-762.
- de Rijk, A., Z. Amir, M. Cohen, T. Furlan, L. Godderis, B. Knezevic, M. Miglioretti, F. Munir, A.E. Popa, M. Sedlakova, S. Torp, D. Yagil, S. Tamminga and A. de Boer (2020). 'The challenge of return to work in workers with cancer: employer priorities despite variation in social policies related to work and health', *Journal of Cancer Survivorship*, Vol. 14, No. 2, pp. 188-199.
- den Bakker, C.M., J.R. Anema, A. Zaman, H.C.W. de Vet, L. Sharp, E. Angenete, M.E. Allaix, R.H.J. Otten, J.A.F. Huirne, H.J. Bonjer, A. de Boer and F.G. Schaafsma (2018).
 'Prognostic factors for return to work and work disability among colorectal cancer survivors; A systematic review', *PLoS One*, Vol. 13, No. 8, e0200720.
- Fantoni, S.Q., C. Peugniez, A. Duhamel, J. Skrzypczak, P. Frimat and A. Leroyer (2010). 'Factors related to return to work by women with breast cancer in northern France', *Journal of Occupational Rehabilitation*, Vol. 20, No. 1, pp. 49-58.

- Frazier, L.M., V.A. Miller, B.E. Miller, D.V. Horbelt, J.E. Delmore and C.R. Ahlers-Schmidt (2009). 'Cancer-related tasks involving employment: opportunities for clinical assistance', *The Journal of Supportive Oncology*, Vol. 7, No. 6, pp. 229-236.
- Garcia-Gil, M., J.M. Elorza, M. Banque, M. Comas-Cufí, J. Blanch, R. Ramos, et al. (2014). 'Linking of Primary Care Records to Census Data to Study the Association between Socioeconomic Status and Cancer Incidence in Southern Europe: A Nation-Wide Ecological Study', *PLoS ONE*, Vol. 9, No. 10, e109706.
- Greidanus, M.A., A. de Boer, A.E. de Rijk, C.M. Tiedtke, B. Dierckx de Casterle, M.H.W. Frings-Dresen and S.J. Tamminga (2018). 'Perceived employer-related barriers and facilitators for work participation of cancer survivors: A systematic review of employers' and survivors' perspectives', *Psycho-Oncology*, Vol. 27, No. 3, pp. 725-733.
- Hanly, P., A. Timmons, P.M. Walsh and L. Sharp (2012). 'Breast and prostate cancer productivity costs: a comparison of the human capital approach and the friction cost approach', *Value in Health*, Vol. 15, No. 3, pp. 429-436.
- Hanly, P., P.M. Walsh, A. O'Ceilleachair, M. Skally, A. Staines, K. Kapur, P. Fitzpatrick and L. Sharp (2013). 'Work-related productivity losses in an era of ageing populations: the case of colorectal cancer', *Journal of Occupational and Environmental Medicine*, Vol. 55, No. 2, pp. 128-134.
- Hanly, P., R. Maguire, A. O'Ceilleachair and L. Sharp (2018). 'Financial hardship associated with colorectal cancer survivorship: The role of asset depletion and debt accumulation', *Psycho-Oncology*, Vol. 27, No. 9, pp. 2165-2171.
- Irish Cancer Society (2019). The Real Cost of Cancer. Dublin, Ireland: Irish Cancer Society.
- Irish Cancer Society (2020). *Life after cancer: A guide to living well*. Dublin, Ireland: Irish Cancer Society.
- Irish Congress of Trade Unions (2014). *Policies to assist workers with breast cancer and other illnesses*. Dublin, Ireland: Irish Congress of Trade Unions.
- Irish Human Rights and Equality Commission (2019). *Implementing the Public Sector Equality and Human Rights Duty*. Dublin, Ireland: Irish Human Rights and Equality Commission.
- Isaksson, J., T. Wilms, G. Laurell, P. Fransson and Y.T. Ehrsson (2016). 'Meaning of work and the process of returning after head and neck cancer', *Supportive Care in Cancer* Vol. 24, No. 1, pp. 205-213.
- Islam, T., M. Dahlui, H.A. Majid, A.M. Nahar, N.A. Mohd Taib and T.T. Su (2014). 'Factors associated with return to work of breast cancer survivors: a systematic review', *BMC Public Health* Vol. 14, Suppl. 3, S8.
- Johnsson, A., T. Fornander, M. Olsson, M. Nystedt, H. Johansson and L.E. Rutqvist (2007). 'Factors associated with return to work after breast cancer treatment', *Acta Oncologica*, Vol. 46, No. 1, 90-96.
- Kennedy, F., C. Haslam, F. Munir and J. Pryce (2007). 'Returning to work following cancer: a qualitative exploratory study into the experience of returning to work following cancer', *European Journal of Cancer Care*, Vol. 16, No. 1, pp. 17-25.

- Kiasuwa Mbengi, R., R. Otter, K. Mortelmans, M. Arbyn, H. Van Oyen, C. Bouland and C. de Brouwer (2016). 'Barriers and opportunities for return-to-work of cancer survivors: time for action – rapid review and expert consultation', *Systematic Reviews*, Vol.5, No. 35.
- Knott, V., S. Zrim, E.M. Shanahan, P. Anastassiadis, S. Lawn, G. Kichenadasse, S. Sukumaran,
 C. Karapetis and B. Koczwara (2014). 'Returning to work following curative chemotherapy: a qualitative study of return to work barriers and preferences for intervention', *Supportive Care in Cancer*, Vol. 22, No. 12, pp. 3263-3273.
- Luker, K., M. Campbell, Z. Amir and L. Davies (2013). 'A UK survey of the impact of cancer on employment', *Occupational Medicine*, Vol. 63, No. 7, 494-500.
- Mitchell, T. (2015). 'Both sides of the couch: a qualitative exploration of the experiences of female healthcare professionals returning to work after treatment for cancer', *European Journal of Cancer Care*, Vol. 24, No. 6, pp. 840-853.
- Munir, F., J. Yarker and H. McDermott (2009). 'Employment and the common cancers: correlates of work ability during or following cancer treatment', *Occupational Medicine*, Vol. 59, No. 6, pp. 381-389.
- National Cancer Registry Ireland (2018). *Cancer in Ireland 1994-2016 with estimates for* 2016-2018: Annual report of the National Cancer Registry. Cork, Ireland: National Cancer Registry Ireland.
- National Cancer Registry Ireland (2019). *Cancer incidence projections for Ireland 2020-2045*. Cork, Ireland: National Cancer Registry Ireland.
- National Cancer Registry Ireland (2020). *Incidence Statistics*. Cork, Ireland: National Cancer Registry Ireland.
- Nilsson, M.I., M. Olsson, A. Wennman-Larsen, L.M. Petersson and K. Alexanderson (2013). 'Women's reflections and actions regarding working after breast cancer surgery – a focus group study', *Psycho-Oncology*, Vol. 22, No. 7, pp. 1639-1644.
- O'Ceilleachair, A., P. Hanly, M. Skally, E. O'Leary, C. O'Neill, P. Fitzpatrick, K. Kapur, A. Staines and L. Sharp (2017). 'Counting the cost of cancer: out-of-pocket payments made by colorectal cancer survivors', *Supportive Care in Cancer*, Vol. 25, No. 9, pp. 2733-2741.
- Pearce, A., A. Timmons, E. O'Sullivan, P. Gallagher, R. Gooberman-Hill, A.A. Thomas, M. Molcho, P. Butow and L. Sharp (2015). 'Long-term workforce participation patterns following head and neck cancer', *Journal of Cancer Survivorship*, Vol. 9, No. 1, pp. 30-39.
- Rottenberg, Y., N.Z. Ratzon, M. Cohen, A. Hubert, B. Uziely and A.G. de Boer (2016). 'Unemployment risk at 2 and 4 years following colorectal cancer diagnosis: a population based study', *European Journal of Cancer*, Vol. 69, pp. 70-76.
- Russell, H., B. Maître, D. Watson and E. Fahey (2018). *Job stress and working conditions: Ireland in comparative perspective.* Dublin, Ireland: ESRI Research Series Report Number 84.
- Stergiou-Kita, M., C. Pritlove and B. Kirsh (2016a). 'The "Big C"-stigma, cancer, and workplace discrimination', *Journal of Cancer Survivorship*, Vol. 10, No. 6, pp. 1035-1050.

- Stergiou-Kita, M., C. Pritlove, D. van Eerd, L.D. Holness, B. Kirsh, A. Duncan and J. Jones (2016b). 'The provision of workplace accommodations following cancer: survivor, provider, and employer perspectives', *Journal of Cancer Survivorship*, Vol. 10, No. 3, pp. 489-504.
- Stone, D.S., P.A. Ganz, C. Pavlish and W.A. Robbins (2017). 'Young adult cancer survivors and work: a systematic review', *Journal of Cancer Survivorship*, Vol. 11, No. 6, pp. 765-781.
- Tamminga, S.J., A.G. de Boer, J.H. Verbeek and M.H. Frings-Dresen (2012). 'Breast cancer survivors' views of factors that influence the return-to-work process-a qualitative study', *Scandinavian Journal of Work Environment and Health*, Vol. 38, No. 2, pp. 144-154.
- Tamminga, S.J., A.M. Braspenning, A. Haste, L. Sharp, M.H.W. Frings-Dresen and A. de Boer (2018). 'Barriers to and Facilitators of Implementing Programs for Return to Work (RTW) of Cancer Survivors in Four European Countries: A Qualitative Study', *Journal* of Occupational Rehabilitation, Vol. 29, No. 3, pp. 550-555.
- Taskila, T., M.L. Lindbohm, R. Martikainen, U.S. Lehto, J. Hakanen and P. Hietanen (2006). 'Cancer survivors' received and needed social support from their work place and the occupational health services', *Supportive Care in Cancer*, Vol. 14, No. 5, pp. 427-435.
- van Muijen, P., N L. Weevers, I.A. Snels, S.F. Duijts, D.J. Bruinvels, A.J. Schellart and A.J. van der Beek (2013). 'Predictors of return to work and employment in cancer survivors: a systematic review', *European Journal of Cancer Care* Vol. 22, No. 2, pp. 144-160.
- Walsh, P., J. Byrne, M. Kelly, J. McDevitt and H. Comber (2014). 'Socio-economic disparity in survival after breast cancer in Ireland: Observational study', *PLoS ONE*, Vol. 9, No. 11, e111729.
- Wells, M., B. Williams, D. Firnigl, H. Lang, J. Coyle, T. Kroll and S. MacGillivray (2013). 'Supporting 'work-related goals' rather than 'return to work' after cancer? A systematic review and meta-synthesis of 25 qualitative studies', *Psycho-Oncology*, Vol. 22, No. 6, pp. 1208-1219.

APPENDIX 1 RETURNING TO WORK QUESTIONNAIRE

	SECTION A:	FILTER QUESTIONS	
ASK ALI A1.	-	nosed with cancer in the last ten years?	
SINGLE			1
No			1
ASK ALI A2. SINGLE	Were you ageo	d between 18 and 65 at the time of your most recent cancer di	agnosis/episode?
			1
No			2 CLOSE
ASK ALI	_		
A3.	Were you in pa diagnosis/epis	aid employment (including self-employment) at the time of you ode?	ur most recent cancer
SINGLE	•		
Voc			1

Yes	T
No	2 CLOSE

SECTION B: WORKING STATUS AT THE TIME OF YOUR MOST RECENT CANCER DIAGNOSIS/ EPISODE

Please answer the following questions about the job you held at the time of your most recent cancer diagnosis/episode. You may still hold the same job. If you had more than one job at the time of your diagnosis, please think of the job that involved the most hours per week.

ASK ALL

B1. When did you begin work with that employer/start your business if you are self-employed? **DROP DOWN LIST FOR MONTH & YEAR.**

Month Year		Year	
------------	--	------	--

ASK ALL

B2. Which of the following best describes your employment situation at the time of your most recent cancer diagnosis/episode?

SINGLE CODE

Employee	1
Self-employed outside farming	2
Farmer	3
On state training/employment scheme	4

ASK ALL

B3. What was your job at the time of your most recent cancer diagnosis/episode? (*Please describe as fully as possible the exact nature of this job. For example, receptionist rather than office worker, assembly of computers rather than factory worker*)

OPEN END

B4.	In which of the following sectors did you work at the time of your most recent cancer
	diagnosis/episode?

SINGLE CODE

Public sector (e.g. civil service, public hospital,	
public school, public university, public agency, etc.)	1
Semi-state sector (e.g. ESB, VHI, An Post, etc.)	2
The not-for-profit sector, charity or an NGO	3
Private Sector (commercial, for-profit sector)	4

ASK ALL

B5. How many hours per week did you usually work in that job prior to your diagnosis? (incl. any regular paid or unpaid overtime)

SINGLE CODE	
	Hours per week

ASK ALL

B6.	Were you employed on a permanent basis, on a temporary/fixed term contract basis or a
	casual basis?

SINGLE CODE

Permanent	1
Temporary/fixed term contract	2
Casual	3
Self-employed	4

ASK ALL

B7. How many people work/worked in your organisation (i.e. in all branches, outlets, departments throughout the Republic of Ireland)?

SINGLE CODE

1
2
3
4
5
6
99

ASK ALL

B8.	Did your	employer	рау	any	illness	benefit	above	what	is	available	to	you	from	the
	Departme	ent of Emp	loym	ent A	Affairs a	nd Socia	l Prote	ction (DE	ASP)?				
SINGLE	CODE													

Yes 1 No 2 Not relevant as self-employed 3

B9.	What impact, if any, do you think your cancer diagnosis has had on your career prospe	ects?
SINGLE C	CODE. FLIP CODES 1 & 2.	
Positive	impact	1
Negative	e impact	2
No impa	ct	3

IF CODE 1 OR CODE 2 AT Q.B9 ASK

B.10	Please can you tell us the way(s) in which your diagnosis has had a positive (IF CODE 1 @
	B.9)/negative (IF CODE 2 @B9) impact on your career prospects?

SECTION C: CURRENT STATUS

ASK ALL

C1. Did you return to paid employment or self-employment after your most recent cancer diagnosis/episode?

SINGLE CODE

Yes, returned to same employer/self-employment	1	GO TO SECTION D
[Tick this box even if you subsequently changed employer]		

Did not take time off		GO TO SECTION D
Yes, returned to a different employer	3	GO TO SECTION E
No	4	GO TO SECTION F

SECTION D

IF CODE 1 AT C.1:

The following questions relate to your experience of employment after your most recent cancer diagnosis/ episode.

We are interested in your responses even if you subsequently left this job or changed employer.

IF CODE 2 AT C.1:

The following questions relate to your experience of employment after your most recent cancer diagnosis/episode.

We are interested in your responses even if you did not take time off.

ASK ALL

D1.	How long were you off work during your most recent cancer episode?
	CODE

Years		Weeks
Please write 0 if you did n	ot take any time off	

Please specify in both years and weeks.

ASK ALL

D2. Would you say this period of leave was? SINGLE CODE

Shorter than you wanted/needed	1
Longer than you wanted/needed (SHOW ONLY IF CODE 1 AT C.1)	
	2
What you wanted/needed	3

What were the main factors in your decision to return to work/stay at work after your D3. most recent cancer diagnosis? (Tick as many as apply)

ROTATE LIST. MULTI CODE

Illness benefit ended2To maintain career (didn't want gap in CV)3To maintain or regain a sense of normality4Felt physically and mentally able to work5Work is important to me6No one else available to do the work7Pressure from employer8Other (please specify)97	Financial need	1
To maintain or regain a sense of normality4Felt physically and mentally able to work5Work is important to me6No one else available to do the work7Pressure from employer8	Illness benefit ended	2
Felt physically and mentally able to work5Work is important to me6No one else available to do the work7Pressure from employer8	To maintain career (didn't want gap in CV)	3
Work is important to me6No one else available to do the work7Pressure from employer8	To maintain or regain a sense of normality	4
No one else available to do the work7Pressure from employer8	Felt physically and mentally able to work	5
Pressure from employer	Work is important to me	6
	No one else available to do the work	7
Other (please specify)	Pressure from employer	8
	Other (please specify))	97

ASK ALL WITH MORE THAN ONE RESPONSE AT Q.D3

QD3a. And which was the most important factor in your decision to return to work/stay at work after your most recent cancer diagnosis? (Tick one answer only)

SINGLE CODE. SHOW ONLY ANSWERS SELECTED AT D.3.

Illness benefit ended To maintain career (didn't want gap in CV)	3 4
	4
To maintain or regain a sense of normality	
Felt physically and mentally able to work	5
Work is important to me	6
No one else available to do the work	7
Pressure from employer	8
Other (please specify))	97

ASK ALL

D4. What work-related factors (if any) helped you to return to work/stay at work after your most recent cancer diagnosis? (*Tick as many as apply*)

ROTATE LIST. MULTI CODE

Phased return (e.g. Reduced hours per day, reduced days worked, non-consecutive	
day working, reduced total number of hours worked per week) to full-time work	1
Flexible start and finish times	2
Working from home (during normal working hours)	3
Part time/reduced working hours/days	4
Change in work tasks	5
Change to the work environment	6
Access to unpaid leave	7
Time off for medical appointments	8
Help and support from colleagues	9
Help and support from employer/manager	10
Other (please specify))	97
None of the above	98

ASK ALL

	work arising from your cancer diagnosis?	
SINGLE		

1

Yes No 2

ASK IF YES AT D.5.

D5a. What problems or challenges? (Tick as many as apply)	
MULTI CODE	
Inflexible working arrangements	1
Unsupportive colleagues	2
Unsupportive employer/manager	3
Difficulty in completing job requirements	4
Difficulty in getting to work	5
Physical health issues (e.g. tiredness, nausea, etc)	6
Psychological health issues (e.g. difficulty concentrating, etc).	7
Other (please specify))	97

ASK ALL

D6. How supportive was your organisation when you returned to work?	
SINGLE CODE. FLIP SCALE.	
Very supportive	1
Supportive	2
Neither supportive or unsupportive	3
Unsupportive	4
Very unsupportive	5
Not applicable	98

ASK ALL

D6a. How supportive was your immediate manager or supervisor when you returned to work? 'Immediate' is your direct line manager/the person to whom you report day-to-day.

SINGLE CODE. FLIP SCALE.

Very supportive	1
Supportive	2
Neither supportive or unsupportive	3
Unsupportive	4
Very unsupportive	5
Not applicable	98

ASK ALL

D7.	Did you experience any of the following due to your cancer diagnosis? (Tick as many as
	apply)

ROTATE LIST. MULTI CODE

I was given an unsuitable workload or unsuitable tasks	1
I was discouraged from attending medical appointments during work time	2
I received unpleasant comments from my employer/manager/colleagues	3
I was unfairly criticised or disciplined about my performance at work	4
I failed to gain a promotion I felt I deserved or was otherwise side-lined	5
I was denied access to training that I would otherwise have received	6
I had a reduction in my salary or bonus	7
I received a pay rise or bonus that was less than my peers at work	8
I was treated so poorly that I felt I had to leave	9
I was made redundant or dismissed	10
I was threatened with redundancy or dismissal	11
Other (please specify))	97
None of these	98

D8. Have you subsequently left the employer/self-employment you returned to following your most recent cancer diagnosis/episode?

SINGLE CODE

Yes	1
No	2

ASK IF YES AT D.8.

D8a. Why did you leave this employer/self employment? (<i>Tick as many as apply</i>)	
MULTI CODE	
My contract ended	1
My job was made redundant	2
I was dismissed	3
The hours were no longer suitable	4
The job was no longer suitable	5
The job was not flexible enough	6
I was treated unfairly	7
Issue within the work environment (bullying, unsupportive colleagues/boss)	8
The job was too far away from home/long commute	9
I wanted to pursue a better job	10
I wanted to pursue an alternative activity (e.g. education, training, volunteering, etc.)	11
To care for children/others	12
Other (please specify))	97

ASK ALL WHO GAVE MORE THAN ONE RESPONSE AT Q.D8a

D8b. And which was the most important factor in your decision to change or leave this employment?

SINGLE CODE. SHOW ONLY ANSWERS SELECTED FROM D8a.

1
2
3
4
5
6
7
8
9
10
11
12
97

D9.	Was your employment situation affected by COVID-19?	
SINGLE	CODE	
Yes		1
No		2

IF YES AT D.9 ASK:

D9a. How has your employment status or situation been affected by COVID-19? (Tick as many as apply)

ROTATE LIST. MULTI CODE

Lost my job	1
Temporary lay-off	2
Started new job	3
Change in work hours	4
Started remote working from home	5
Increased number of hours remote working from home	
Was unable to work as work was not suitable for remote working	
Had to take paid leave	8
Had to take unpaid leave	9
Changed business model to online/takeaway model	10
Unable to start new job	11
Other (please specify)	97

FOR EACH ANSWER (CODE 2, 4, 5, 6, 8, 9, 11, 97 ONLY) SELECTED AT QD.9a

D.9b And thinking about INSERT CODE FROM Q.D9a was this an individual arrangement specifically due to your previous cancer diagnosis/episode?

SINGLE CODE

Yes	1
No	2

ASK IF ANSWER AT D.9b.

D9c.	Did your employer support you in making these individual arrangements?	
SINGLE	CODE	
Yes		1
No		2
Not app	licable	3

ASK IF ANSWER AT D.9c.

D.9d

Please provide specific detail where possible.

SECTION E

These questions relate to your experience of employment after your most recent cancer diagnosis/episode when you returned to work with a different employer.

ASK ALL

E1. How long were you out of paid work during your most recent cancer episode? SINGLE CODE

	Years	Weeks
Please write 0 if you did not take any time off		

Please specify in both years and weeks.

E2.	Would you say this period of leave was?	
SINGLE	CODE	
Shorter	than you wanted/needed	1
Longer	than you wanted/needed	2
What yo	pu wanted/needed	3

ASK ALL

	recent cancer diagnosis/episode?
ROTATE	LIST. SINGLE CODE

My contract ended	1
My job was made redundant	2
I was previously self-employed and stopped trading	3
My employer did not want me to return/I was dismissed	4
The hours were no longer suitable	5
My previous job was not flexible enough	6
I want(ed) a better job	7
My previous job was too far from home/long commute	8
I want(ed) a job with less pressure/responsibility	9
Other (please specify))	97

ASK ALL

E4.	What were the main factors in your decision to return to work?	
	(Tick as many as apply)	
ROTATE	E LIST. MULTI CODE	
Financia	al need	1
Illness b	penefit ended	2
To main	ntain career (didn't want gap in CV)	3
To main	ntain or regain a sense of normality	4
Felt phy	vsical and mentally able to work	5
Work is	important to me	6
Other (p	olease specify))	97

ASK ALL WHO GAVE MORE THAN ONE RESPONSE AT Q.E4	
E5. And which was the most important factor in your decision to return to work?	
SINGLE CODE. SHOW ONLY ANSWERS SELECTED FROM E.4.	
Financial need	1
Illness benefit ended	2
To maintain career (didn't want gap in CV)	3
To maintain or regain a sense of normality	4
Felt physical and mentally able to work	5
Work is important to me	6
Other (please specify)	97

ASK ALL

E6.	Have you experienced any problems or issues related to your return to work?
SINGLE (CODE
Yes	

1 2

ASK IF YES AT E.6.

E6a. What problems or issues? (<i>Tick as many as apply</i>)	
MULTI CODE	
Physical health issues (e.g. tiredness, nausea, etc)	1
Psychological health issues (e.g. difficulty concentrating, etc).	2
Difficulty finding a new job because of time out of the labour market	3
Difficulty finding a new job because of cancer diagnosis	4
Inflexible working arrangements	5
Difficulty in completing job requirements	6
Difficulty in getting to work	7
Unsupportive colleagues	8
Unsupportive boss	9
Other (please specify))	97

ASK ALL

E7 How supportive was your organisation when you returned to work?	
SINGLE CODE. FLIP SCALE.	
Very supportive	1
Supportive	2
Neither supportive or unsupportive	3
Unsupportive	4
Very unsupportive	5
Not applicable	98

ASK ALL

ASK ALL		
E7a.	How supportive was your immediate manager or supervisor when you returned to v	vork?
	"Immediate' is your direct line manager/the person to whom you report day-to-day	' .
SINGLE	CODE. FLIP SCALE.	
Very sup	pportive	1
Support	ive	2
Neither	supportive or unsupportive	3
Unsupp	ortive	4
Very uns	supportive	5
Not app	licable	98

ASK ALL

E8.	Did you experience any of the following due to your cancer diagnosis? (Tick as many as
	apply)

ROTATE LIST. MULTI CODE

I was given an unsuitable workload or unsuitable tasks	1
I was discouraged from attending medical appointments during work time	2
I received unpleasant comments from my employer/manager/colleagues	3
I was unfairly criticised or disciplined about my performance at work	4
I failed to gain a promotion I felt I deserved or was otherwise side-lined	5
I was denied access to training that I would otherwise have received	6
I had a reduction in my salary or bonus	7
I received a pay rise or bonus that was less than my peers at work	8
I was treated so poorly that I felt I had to leave	9
I was made redundant or dismissed	10
I was threatened with redundancy or dismissal	11
Other (please specify))	97
None of these	98

E9.	Was your employment situation affected by COVID-19?	
SINGLE (CODE	
Yes		1
No		2

IF YES AT E.9 ASK:

E9a.	How has your employment status or situation been affected by COVID-19? (Tick as r	nany
	as apply)	
-	LIST. MULTI CODE	
Lost my	job	1
Tempor	ary lay-off	2
Started	new job	3
Change	in work hours	4
Started	remote working from home	5
Increase	ed number of hours remote working from home	6
Was una	able to work as work was not suitable for remote working	7
Had to t	ake paid leave	8
	ake unpaid leave	9
	d business model to online/takeaway model	10
Unable 1	to start new job	11
	please specify)	97

FOR EACH ANSWER (CODE 2, 4, 5, 6, 8, 9, 11, 97 ONLY) SELECTED AT QE.9a

E.9b And thinking about INSERT CODE FROM Q.E9a was this an individual arrangement specifically due to your previous cancer diagnosis/episode?

SINGLE CODE	
Yes	1
No	2

ASK IF ANSWER AT E.9b.

E9c. SINGLE (Did your employer support you in making these individual arrangements? CODE	
Yes		1
No		2
Not app	licable	3

ASK IF ANSWER AT E.9c.

E.9d

Please provide specific detail where possible.

SECTION F

These questions relate to your experience of employment after your most recent cancer diagnosis/episode.

ASK ALL

F1.	Please indicate the main reasons that you have not returned to employment. (Tig	ck as
	many as apply)	
ROTA	TE LIST. MULTI CODE	
I am i	n receipt of treatment	1
I am c	on sickness leave	2
I am r	not physically able to return to work	3
I am r	not psychologically able to return to work	4
l am u	inable to fulfil job requirements	5
l wou	ld have difficulty in getting to the workplace	6
I have	e decided to postpone my return to work due to concern about COVID-19	7
I am f	ollowing public health advice regarding COVID-19 which prevents me from working.	8
I cann	ot find a suitable job	9
My pr	iorities have changed	10
I do n	ot want to	11
I am p	pursuing other activities – e.g. education, training, volunteering, etc	12
I am c	aring for children/others	13
I have	e retired	14
Loss c	of benefits/medical card	15
Other	· (please specify))	97

ASK ALL WHO GIVE MORE THAN ONE RESPONSE AT Q.F1.

F1.b. And which is the most important factor in your decision not to have returned to worl	k?
SINGLE CODE. SHOW ONLY ANSWERS SELECTED FROM F.1.	
I am in receipt of treatment	1
I am on sickness leave	2
I am not physically able to return to work	3
I am not psychologically able to return to work	4
I am unable to fulfil job requirements	5
I would have difficulty in getting to the workplace	6
I have decided to postpone my return to work due to concern about COVID-19	7
I am following public health advice regarding COVID-19 which prevents me from working	8
I cannot find a suitable job	9
My priorities have changed	10
I do not want to	11
I am pursuing other activities – e.g. education, training, volunteering, etc	12
I am caring for children/others	13
I have retired	14
Loss of benefits/medical card	15
Other (please specify))	97

F2. What work-related factors (if any) would help you to return to work either now or in the future as someone who had/ has cancer? (*Tick as many as apply*).

MULTI CODE

Phased return	1
Flexible start and finish times	2
Working from home (during normal working hours)	3
Part time/reduced working hours	4
Change in work tasks	5
Change in work schedule	6
Change to the work environment	7
Access to unpaid leave	8
Time off for medical appointments	9
Other (please specify))	97
None of the above	98

ASK ALL

F3.	What factors (if any) have acted or could act as barriers to your return to work? (Tick as
	many as apply).

MULTI CODE

1
2
3
4
5
6
7
97
98

F4.	Do you plan on returning to the same employer/self-employment within the net	t 24
	months?	
SING	LE CODE	
Yes		1
No		2
IF NO) AT F4. ASK:	
F5.	What is the main reason you do not plan on returning to the job you had before your recent cancer diagnosis?	nost
ROTA	ITE LIST. SINGLE CODE	
Muca	antract and ad	1

My contract ended	1
My job was made redundant	2
My employer did not want me to return	3
The hours are no longer suitable	4
My previous job was not flexible enough	5
I want a better job	6
My previous job was too far from home/long commute	7
I want a job with less pressure/responsibility	8
I was previously self-employed and stopped trading	9
I have taken early retirement	10
I have taken long-term sickness leave	11
Other (specify))	97

SECTION G: HEALTH STATUS

Please answer the following questions in relation to your most recent cancer diagnosis/episode

ASK ALL

G1. On what date was your most recent cancer diagnosed?

SINGLE CODE. DROP DOWN LIST FOR MONTH & YEAR, YEAR RANGE FROM 2010 TO 2020.

	Month		Year	
--	-------	--	------	--

ASK ALL

G2.	What was your most recent cancer diagnosis? Please select the one which best applies to
	you.

SINGLE CODE

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
97

ASK ALL

G3. What stage of cancer were you diagnosed with?	
SINGLE CODE	
Stage O	1
Stage I	2
Stage II	3
Stage III	4
Stage IV	5
Don't know	99

G4.	Did you receive/are you receiving treatment?	
SINGLE	CODE	
Yes		1
No		2

Month	Year	
ASK IF YES AT G.4.		
	atment is ongoing, please select ongoing)?	
SINGLE CODE. DROP DOWN LIST FOR MO	ONTH & YEAR, YEAR RANGE FROM 2010 TO 2	:020.
Month	Year	
<u>_</u>		
Ongoing		9
G5. In relation to your most rece receive? (<i>Tick as many as apply</i>)	nt cancer diagnosis/episode, what treatme	nt did yo
receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy		1
 G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy 		1
 G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy Chemotherapy Surgery 		1 2 3
 G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy Chemotherapy Surgery Hormonal Therapy 		1 2 3 4
 G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy Chemotherapy Surgery Hormonal Therapy Immunotherapy 		1 2 3 4 5
G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy Chemotherapy Surgery Hormonal Therapy Immunotherapy Bone marrow transplant Stem cell treatment		1 2 3 4 5 6 7
G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy Chemotherapy Surgery Hormonal Therapy Immunotherapy Bone marrow transplant Stem cell treatment Other (please specify)	1 2 3 4 5 6 7 97
G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy Chemotherapy Surgery Hormonal Therapy Bone marrow transplant Stem cell treatment Other (please specify Active Surveillance		1 2 3 4 5 6 7 97 97
G5. In relation to your most rece receive? (<i>Tick as many as apply</i>) MULTI CODE Radiotherapy Chemotherapy Surgery Hormonal Therapy Immunotherapy Bone marrow transplant Stem cell treatment Other (please specify Active Surveillance No active treatment and follow-up care)	1 2 3 4 5 6 7 97 97 9

ASK ALL	
G6. At present, would you say your physical health is?	
FLIP SCALE. SINGLE CODE	
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

G7. In general, would you say your mental health is?	
FLIP SCALE. SINGLE CODE	
Excellent	1
Very good	2
Good	3
Fair	4
Poor	

G8. Do you currently experience any of the following symptoms?

ROTATE LIST. SINGLE CODE PER SYMPTOM.

	Yes	No
Tiredness	1	2
Nausea	1	2
Pain	1	2
Lack of appetite	1	2
Bowel problems	1	2
Problems passing urine	1	2
Difficulty remembering things	1	2
Shortness of breath	1	2
Anxiety	1	2
Insomnia/disturbed sleep	1	2
Behavioural problems	1	2

ASK ALL

G9. In addition to your cancer diagnosis, do you have any other longstanding health conditions?

SINGLE CODE

Yes	1
No	2

IF YES ASK:

G.10 Please specify the condition(s) in the box below.

SECTION H: DEMOGRAPHIC AND SOCIO-ECONOMIC QUESTIONS

And finally, some general questions about you and your family ...

ASK ALL

H2.	And what was your age at your last birthday?
SINGLE	CODE

НЗ.	What is your current legal marital status?	
SINGLE (CODE	
Single		1
Married	or living in a civil partnership	2
Separate	ed/Divorced	3
Widowe	d	4

H4. Including yourself, how many people are there in your household? (Please count people who use the same living room or share at least one meal per day) SINGLE CODE

ASK ALL WITH 2 OR MORE PEOPLE IN HOUSEHOLD:

H5. Of these, how many are aged under 18 years?

SINGLE CODE. VALIDATION - CAN NOT BE GREATER THAN ANSWER AT H.4.

None

99

1

2

3

4

5

2

ASK ALL WITH 2 OR MORE PEOPLE IN HOUSEHOLD:

H6. What is the age of your youngest child? SINGLE CODE Under 5 years 5 to 12 years 13 to 18 years Over 18 years Do not have any children

ASK ALL

	Do you provide regular unpaid personal help for a friend or family member with a l term illness, health problem or disability?	iong-
SINGLE	, , , ,	
Yes		1

No

ASK ALL

H8.	What is your country of birth?	
Republic	of Ireland	1
Other (S	pecify)	2

H9.	Do you have/would you have access to private transport (e.g. car, van, etc.) to g	get to
	work?	
SINGLE	CODE	
Yes		1
No		2
Not ap	plicable	3

H10.	Does your household own or rent your accommodation?
SINGLE	CODE
Own wi	th mortgage or loan
Own ou	tright
Rent	
Househ	old lives here rent free

IF CODE 3 AT H.10 ASK:

H10a.	If renting, which of the following best describes who you rent from?	
SINGLE	CODE	
Private	landlord	1
Local au	ithority	2
Volunta	ry/co-operative housing body	3

ASK ALL

H11.	Which of the following best describes the highest level of education which you have
	completed to date:

SINGLE CODE

Primary level/some secondary	1
Junior/Inter/Group certificate/lower second level	2
Leaving certificate/upper second level	3
PLC, Certificate or Diploma	4
Third-level degree	5
Postgraduate level qualification	6
Other (Please specify))	97

ASK ALL

H12. What is the total of your annual household income? This means the total income, after tax and PRSI, of ALL MEMBERS of the household. It includes all types of income: income from employment, social welfare payments, child benefit, rents, interest, pensions etc.

SINGLE CODE

€0 - €19,999	1
€20,000 - €39,999	2
€40,000 - €59,999	
€60,000 - €79,999	
€80,000 - €99,999	5
€100,000 or greater	

ASK ALL WITH 2 OR MORE PEOPLE IN HOUSEHOLD:

H13.	Are you currently living with a spouse/partner?	
SINGLE	CODE	
Yes		1
No		2

IF YES AT H.13 ASK.

<u>IF ILS AT II.15 ASK.</u>	
H13a What is your spouse's/partner's employment status?	
SINGLE CODE	
Self-employed (including farmer)	1
Employee	2
House person	3
Unemployed	4
Unable to work due to sickness/disability	5
Full-time study/training	6
Retired	7
Other (please specify)	8

H14. At the time of your diagnosis, were you the main income earner in your household? **SINGLE CODE**

Yes	1
Equal earners	2
No	3

SECTION I: CLOSING COMMENTS

Finally, if you would like to add anything else on your experience of returning to work following your cancer diagnosis, please do so below. Please note that given the anonymous nature of this questionnaire, it is not possible to respond to particular queries or questions raised in this section. If you have a particular question, please get in contact with one of the contacts mentioned in the information sheet.

I.1.

OPEN END.

Thank you very much for taking part.

If you would like to speak to someone about cancer information/supports or the completion of the questionnaire causes distress, please contact the Irish Cancer Society's Freephone Cancer Nurseline on 1800 200700.

Whitaker Square, Sir John Rogerson's Quay, Dublin 2 Telephone **+353 1 863 2000** Email **admin@esri.ie** Web **www.esri.ie** Twitter **@ESRIDublin**



