



JUNE 2018

/Summary

LIFE FIVE YEARS POST-CANCER DIAGNOSIS

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INTRODUCTION

Over 3 million people in France are currently living with or have recovered from cancer.

The prospects of recovery and survival are changing very favourably for many cancers, although the prognosis remains poor for some cancer sites. However, cancer remains a difficult ordeal, both physically and psychologically, with repercussions on the patient's personal, social and professional life.

For this reason, the French National Cancer Institute sought to repeat the survey on life two years post-cancer diagnosis (VICAN2) conducted in 2012. For most cancer sites, a period of two years post-diagnosis, while informative, is not enough to study long-term treatment side effects. This was the reasoning behind this new study on living conditions five years on (VICAN5).

The VICAN5 survey examines the various facets of life five years post-cancer diagnosis: health, after-effects and follow-up, problems encountered in day-to-day life, and also the impact of the disease and treatments on financial resources and employment. This is one of the areas in which inequalities may be particularly significant.

Led by the French National Cancer Institute in partnership with the main Health Insurance schemes, the National Health Insurance Fund¹ and the Central Agricultural Social Mutual Fund, the survey was conducted by the Inserm UMR 1252-SESSTIM research team who conducted the analyses in order to guarantee the quality and continuity required with the 2012 survey. Many experts from a range of disciplines also contributed to the research.

The findings highlight the needs of those affected by cancer with a view to guiding the action of public authorities and of all stakeholders involved in combating cancer.

1. As of 1 January 2018, the French National Health Insurance Fund for Employees (CNAMTS) has been replaced by the National Health Insurance Fund (CNAM) and the Social Scheme for Self-Employed Workers (RSI) has become the Social Security for Self-Employed workers and has been incorporated within the general scheme.

METHOD

The VICAN5 survey follows on from VICAN2, surveying health insurance beneficiaries residing in Metropolitan France, who were diagnosed with cancer approximately five years prior to the survey and who were 18 to 82 years of age at the time of diagnosis. Twelve cancer sites, including the most common, were chosen. In parallel with the telephone survey, medical file data and information on health care consumption² were compiled. In total, 4,174 people were surveyed, including 2,009 subjects who had previously taken part in the VICAN2 survey and an additional sample of 2,165 people.

2. Data retrieved from the French National Inter-Health Insurance Scheme Information System (SNIIRAM)

Life five years post-cancer diagnosis

HEALTH CONTINUES TO BE IMPACTED

33.1%

of respondents do not receive specific GP follow-up for their cancer

While 56.9% of respondents receive regular or occasional follow-up and 9.3% follow-up on an exceptional basis, one out of every three respondents states that they receive no GP follow-up for their cancer diagnosed five years previously. Respondents with no follow-up feel less well-informed about the symptoms that they are liable to encounter.

63.5%

of respondents suffer from cancer- or treatment-related after-effects.

The most frequently mentioned after-effects, disorders and dysfunctions particularly pertain to changes in body image, pain, fatigue, motor or vision disorders, and sexual dysfunction. In three out of every four cases, specific medical follow-up is not received for these after-effects.

48.8% of men
52.6% of women
are restricted in their physical activity.

These restrictions are less frequent than two years post-diagnosis. However, they mostly affect young people and people encountering financial and work-related problems.

48.7%

of respondents suffer from clinically significant fatigue.

This proportion is similar to that observed two years post-diagnosis. It is also more prevalent in women (56.5% *versus* 35.7% of men), younger people and those living in economically vulnerable circumstances.

73%

of respondents experienced pain in the previous two weeks.

In 35.3% of cases, this pain is neuropathic in nature. It has generally been experienced for many months. It disturbs sleep, affects all day-to-day activities and makes it more difficult to integrate into the world of work.

32.5%

of respondents report continual impairment of their mental quality of life.

This prevalence is very similar to that observed two years post-diagnosis. It is more common for some cancer sites: cervix, upper airways, thyroid. In addition, 46.1% of respondents report anxiety disorders and 16.8% depression disorders.

PROFESSIONAL LIFE AND FINANCIAL CIRCUMSTANCES ARE SUBJECT TO LONG-TERM CHANGES

26.3%

of respondents have seen a decline in their income.

Those most affected are those having lost their job since they were diagnosed, those previously in a blue-collar profession or who were self-employed, as well as those reporting substantial after-effects.

20%

of respondents between 18 and 54 years of age and in employment at the time of diagnosis are no longer working five years later.

Loss of the job held at the time of diagnosis is more likely to affect subjects deemed to be the most vulnerable on the job market: the under 40s and over 50s, those with the least qualifications, those lacking experience and without job security. Employees are more frequently affected than self-employed workers. Among the respondents in employment at the time of diagnosis, 54.5% stayed in the same job, 17.4% changed job, 5.9% are unemployed, 7.5% receive disability benefit, and 13% are retired.

24% of employees

in employment at the time of diagnosis have resumed work under the therapeutic part-time work scheme.

Among employees, the therapeutic part-time work scheme is availed of on average 17 months post-diagnosis, more often for women.

SUBSTANTIAL CHANGES TO LIFESTYLE

61.9% of women

with a cancer other than breast cancer report having had a mammogram within the last two years.

This proportion varies significantly according to age: 50.3% for those under 50, 78% for the 50-74 age group, 29.8% for those aged 75 years and over.

41.1%

of respondents have changed their diet since their cancer diagnosis.

28.6% have done so because their tastes have changed and 81.9% to have a healthier diet. This change is associated with the treatments administered (chemotherapy or radiotherapy), the presence of after-effects, and anxiety. It is more common in women and the younger population.

39.8%

of respondents who were smokers prior to their diagnosis have quit five years later.

Over the 5 years post-diagnosis, 51.9% of male smokers have quit smoking, as opposed to 33% of female smokers. Quitting is also more common in the younger populations, and those with lung or upper airway cancer.

INTIMACY AND PERSONAL LIFE ARE AFFECTED

29.1%

of respondents have been embarrassed by their appearance.

and 14.9% have avoided contact with others for this reason, over the last 7 days. In addition, 40% feel that the treatment has left their body less whole, and 17.8% are unhappy with the appearance of their scars. This feeling is more common in women and the younger population.

35.2%

of respondents feel less attractive due to their cancer or treatments.

This feeling is more common in women and the younger population. In addition, 56.8% of respondents report a loss of libido and 53.8% a decline in their ability to orgasm.

11.9% of women 17.6% of men

aged 40 years or under at the time of diagnosis were offered fertility testing.

50.1% are still menstruating, 34.3% are no longer menstruating, 15.7% don't know. In the case of men, while two out of every three men consider themselves to still be fertile, 7% have a fertility problem identified since their diagnosis.

42.3%

of respondents feel that they have found solace in their religious or spiritual beliefs since their cancer diagnosis.

This feeling is more common in women and the older population. While three-quarters of respondents are of the view that their illness has not had an impact on their religious or philosophical beliefs, 17.1% feel that it has strengthened their beliefs and 5.1% that it has weakened them.

Focus

HEALTH

Cancers and their treatments have major repercussions on the health of those affected and their effects continue to be felt five years on. Two out of every three respondents report that they suffer from after-effects, particularly fatigue and chronic pain. While the subjects' quality of life has changed for the better as their diagnosis moves further into the past for some cancer sites, it remains impaired for others.

Death, recurrences, metastases, second cancers: sharp contrasts between cancer sites.

Disease outcomes between two years and five years post-diagnosis are highly differentiated between different cancer sites.³ Between 2012 and 2015, approximately one out of every ten patients died, with significant differences between cancer sites (under 1% for thyroid and 38.6% for lung). Just under 10% of subjects are affected by metastases or recurrences, here again with significant variations between sites (for metastases: from 1% for thyroid to 23.5% for lung). The onset of second primary cancer affects less than one out of every ten patients, with the exception of those with cancer of the upper airways (19.1%), the bladder (13.6%), or colorectal cancer (12.1%).

Between two and five years, physical health remains impaired, especially for the younger population.

Two approaches were used to assess subjects' physical health: on one hand, a physical quality of life index, used to compare their health to that of the general population, of the same gender and same age; on the other, perceived restrictions in day-to-day activities that are attributed to a health problem. Quality of life is considered to be impaired for a patient if it is inferior to that observed for three-quarters of subjects of the same age and same gender in the general population.

Five years on from their diagnosis, 44.4% of patients have an impaired physical quality of life. This impairment is more common in women, respondents aged 50 years or under at the time of diagnosis, as well as those experiencing financial problems. It is

3. Disease outcomes over the first two years post-diagnosis were analysed in the VICAN2 survey.

also more common in subjects with lung cancer (66.5%), cervical cancer (60.8%) and upper airway cancer (55.0%), whereas the least impacted sites are the prostate (25.7%), bladder (28.6%) and the corpus uteri (29.9%). However, the impairment observed two years post-diagnosis did not increase over the subsequent three years. It even declined for some sites, particularly the lung (which nonetheless exhibits the highest rate of impairment, from 72.3% two years post-diagnosis to 66.5% five years on), bladder (from 46.8% to 28.6%), breast (from 55.8% to 50.9%) and prostate (from 30.6% to 25.7%).

As regards perceived restrictions, five years post-cancer diagnosis, 48.8% of men and 52.6% of women have felt restricted in their activity for at least 6 months. These proportions are markedly higher than those observed in the general population, particularly among those under 55 years of age. On the other hand, they are lower than those observed two years post-diagnosis. However, this subjective improvement is undoubtedly a reflection, at least in part, of adaptation to the restrictions experienced ("response shift"), rather than an objective improvement in health.

Fatigue, pain, cognitive or sexual dysfunction... Many common after-effects for which the care received is lacking.

Five years post-diagnosis, 63.5% of respondents report that they continue to have after-effects of their illness or treatments, which they regard as very severe (6.4%), severe (16.4%), moderate (26.2%) or very moderate (14.5%).

Pain and fatigue are those most frequently mentioned spontaneously and were the subject of specific investigations in the survey. However, other problems are also reported: 51.5% of men and 39.5% of women report genital or sexual dysfunction, whereas hearing problems (hearing loss), attention and memory disorders affect 39.7%, 35.9% and 67.7% of respondents, respectively. Also reported are perceived changes of body image, motor or vision disorders, as well as specific after-effects relating to a particular site. In three out of every four cases, specific medical follow-up is not received for these after-effects.

Fatigue: a major after-effect reported by one out of every two people, particularly women.

Fatigue represents the most common symptom post-cancer. It was measured using a scale specifically devised for persons diagnosed with cancer, helping identify subjects suffering from clinically significant fatigue.

Five years post-diagnosis, 48.7% of respondents report clinically significant fatigue, which is more prevalent in women than in men (56.5% *versus* 35.7%). This fatigue is also more common in those under 50 years of age (it affects 58.4% of the 41-50 age group and 61.0% of the 18-40 age group, at the time of diagnosis), and in those who consider the financial circumstances of their household to be difficult (70.1%). The frequency of fatigue is also linked with the cancer site, and is in excess of 50% for the cervix (64.3%), lung (59.4%), breast (57.2%), thyroid (55.8%) and upper airways (UA) (53.1%). This fatigue is also accompanied by the presence of after-effects, particularly pain, as well as an adverse development of the illness. Finally, these levels of fatigue are very similar to those reported two years post-diagnosis (VICAN2).

Three out of every four respondents suffer from chronic pain that disrupts their everyday life.

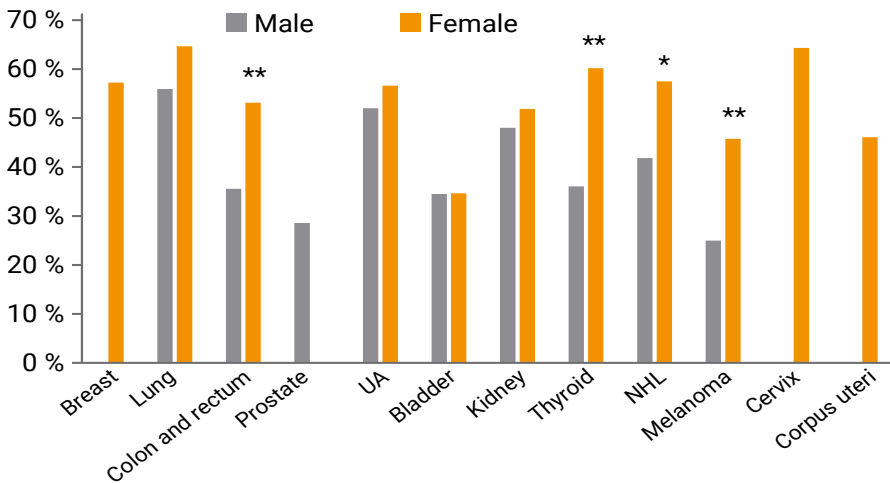
Pain also represents a very common symptom after a cancer diagnosis, even a considerable time after treatments. Often caused by these treatments, pain can occur very early on, subsequently becoming chronic. In this category, it is necessary to make a distinction between different types of pain, and neuropathic pain in particular, caused by nervous system damage, which requires specific treatments. Alongside questions on "generic" pain, the VICAN5 survey provides a more precise idea of this neuropathic pain using ad hoc indexes.

As such, five years post-diagnosis, 73% of respondents report having felt pain over the previous two weeks, women more often than men. Of these, 25.2% describe their pain as "quite", "very" or "extremely" severe, and 59.5% are of the opinion that it disrupts their sleep. Nine times out of ten, this pain is chronic (experienced for at least the previous three months). Three times out of four, subjects who experienced pain over the previous two weeks had

previously sought medical advice for their pain. These consultations generally give rise to the prescription of pain relief medication, with consultations for hypnosis or acupuncture remaining very rare. Among those reporting recent pain, our indexes indicate the potential presence of neuropathic pain in 35.3% of cases, i.e. for 25.8% of the total number of surveys. This neuropathic pain is also almost always chronic, and more common in women (particularly those with breast or cervical cancer) and the younger population.

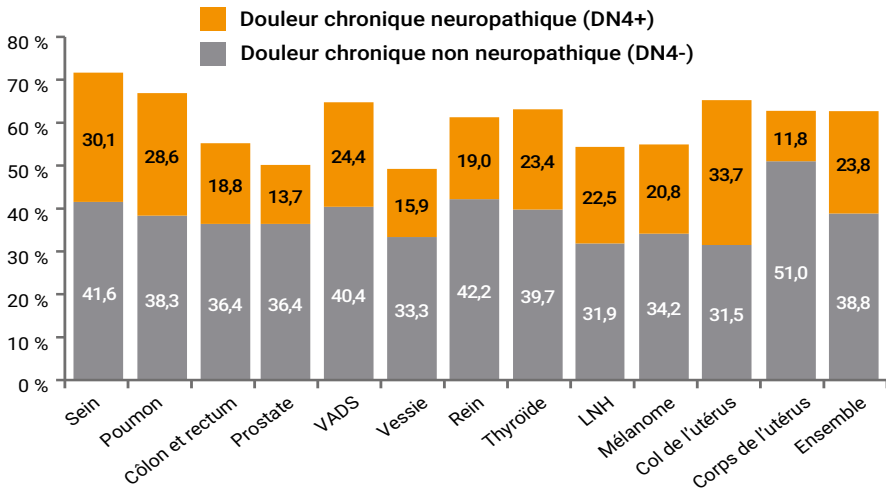
In the case of those aged 18 to 52 years at the time of diagnosis, 46.1% are of the opinion that the pain that they are experiencing has obliged them to restrict their work-related and non-work-related activities, as opposed to 32.8% of those who were 53 to 82 years of age at the time of diagnosis. For both age groups, this proportion is at its peak for subjects with lung cancer. Furthermore, subjects experiencing suspected chronic neuropathic pain are more likely to be unemployed or work on a part-time basis. Finally, beyond the world of work, these subjects have a less active social life and tend to feel more discriminated against.

PREVALENCE OF FATIGUE IN MEN AND WOMEN ACCORDING TO CANCER SITE (AS A %) (VICAN5 2016)



*: $p < 0.05$; **: $p < 0.01$; UA: upper airways; NHL: non-Hodgkin's lymphoma
 Scope: VICAN5 survey respondents excluding missing data on fatigue score
 (Weighted sample = 4,166).
 Analyses: weighted descriptive statistics.

REPORTED CHRONIC PAIN BY SITE (AS A %) (VICAN5 2016)



UA: upper airways; NHL: non-Hodgkin's lymphoma

Scope: male and female VICAN5 survey respondents (Weighted sample size = 4,174).

Note: each column represents the total proportion of respondents with chronic pain not neuropathic in nature (NP4-negative) with that of respondents with chronic neuropathic pain (NP4-positive).

Analyses: weighted descriptive statistics.

EMPLOYMENT

Two years post-cancer diagnosis, the VICAN2 survey had already demonstrated an impairment in the professional status of those affected, which is socially differentiated, the most vulnerable on the job market being more impacted by the disease. The VICAN5 survey extends the analysis to five years post-diagnosis, focusing on subjects aged from 18 to 54 years at the time of diagnosis, who, five years on, are therefore still below the statutory retirement age.

What is their professional status 5 years post-cancer diagnosis?

One out of five people have lost their job.

Five years post-cancer diagnosis, a concomitant decline in the labour force participation rate (from 94.2% to 83.9%) and the rate of employment (from 87.3% to 75.9%) is observed. Only one out of eight people was not working at the time of diagnosis, as opposed to one out of four people five years later. Meanwhile, the proportion of those unemployed increased by 2.2 points (9.5% of the workforce are unemployed in 2015 as opposed to 7.3% five years previously). However, over the same period, the rate of unemployment remained stable in the general population.⁴

The job separation observed five years on from diagnosis mostly occurred over the previous three years, highlighting a medium-term effect of the disease (which could not have been detected by the VICAN2 survey). For subjects with cancer, the decline in the rate of employment coincides with a significant increase in the disability rate (0.8% at the time of diagnosis, 9.3% five years later). Moreover, the proportion of those working part-time increased by 5 points since diagnosis, while it remained stable in the general population.

These losses of employment exacerbate social inequalities, since they tend to affect those most vulnerable.

Professional status five years post-diagnosis is dependent on the cancer site: the decline in the rate of employment and rise in unemployment are, as such, particularly substantial for those with lung cancer. However, sociodemographic and socioeconomic factors also have a strong impact. As such, as observed two years post-diagnosis (VICAN2), loss of employment five years on affects

4. The labour force participation rate is the ratio between the workforce (employed and unemployed workers) and the entire corresponding population (workers and non-workers). The rate of employment of a category of subjects is the ratio between the number of subjects in the category (generally age group) in employment and the total number of subjects in the same category. The rate of unemployment is the proportion of unemployed workers in the workforce (consisting of employed and unemployed workers).

those with the least qualifications, those under 40 and those under 50, those in a so-called blue collar profession (farmers), as well as those without job security.

Self-employed workers less affected than employees.

Respondents who were self-employed workers in employment at the time of diagnosis are more frequently in employment than employees five years on (86% versus 81.1%). Among self-employed workers, five years post-diagnosis, farmers are mostly still working while company directors are those most likely to have transitioned to disability. Those in professional practices are those most likely to have opted to work on a part-time basis.

Changing working arrangements becomes the norm.

In the case of those in employment at the time of diagnosis, 62.7% had availed of changes to their working arrangements over the subsequent five years, with changes to working time being the most common measure. Those who had availed of such changes to their arrangements reported that they were mostly satisfied with these changes. More women than men had availed of changes to their working arrangements, as well as those initially working full-time, public sector employees and those on permanent contracts. However, the self-employed are less likely to avail of such changes.

Use of sick leave and therapeutic part-time work scheme.

The detailed analysis of careers post-diagnosis illustrates the importance of two temporary measures for managing the impact of the disease on a person's career: sick leave and the therapeutic part-time work scheme.⁵

Higher frequency of sick leave, but which is also dependent on social status.

Among those in employment at the time of diagnosis, 77% had at least one period of sick leave of one month or more, over the subsequent five years. On average, this period of sick leave commenced 6 months post-diagnosis and lasted 10.2 months.

Sick leave is less common for sites regarded as involving a better prognosis, as well as for subjects not treated with chemotherapy. It is rarer among self-employed workers, senior executives, employees on fixed-term contracts and those working in very small businesses. Finally, it is more common for women (80.5% availed of

5. The therapeutic part-time work scheme refers to a scheme provided for by law (Article L323-3 of the French Social security regulations) set up to aid a subject's recovery following an illness or accident. It offers those affected the option to reduce their working time while guaranteeing compensation for the associated loss of income.

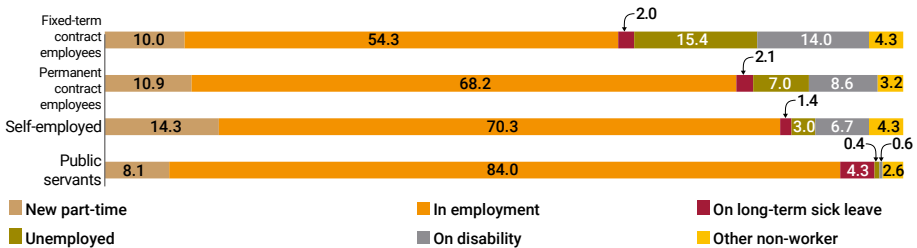
at least one period of sick leave, as opposed to 67% of men), as well as for the younger population, and those in low- or middle-income households.

Therapeutic part-time work scheme: a helping hand for employment.

Among those in employment at the time of diagnosis, 24.0% have availed of the therapeutic part-time work scheme. They availed of this scheme following a period of sick leave, on average a little over one year post-diagnosis, for a period of 4 months before resuming their job. Use of the therapeutic part-time work scheme also shows differences according to the subject's socioprofessional and medical characteristics, and women avail of this scheme more often than men (25.9% *versus* 18.2%).

Those who have availed of the therapeutic part-time work scheme following cancer are more frequently in employment five years post-diagnosis (84.6%, *versus* 68.0% for those who did not avail of the scheme). Use of this scheme is also associated with a quicker return to work.

PROFESSIONAL STATUS AT THE TIME OF THE SURVEY BASED ON EMPLOYMENT CONDITIONS AT THE TIME OF DIAGNOSIS (AS A %) (VICAN5 2016)



p < 0.001

Scope: VICAN5 survey respondents aged from 18 to 54 years at the time of diagnosis and in employment at the time of diagnosis, excluding missing data (Weighted sample size = 1,823).

Note: 92.1% of those in public service employment at the time of cancer diagnosis were still in employment five years post-diagnosis (8.1% on a part-time basis not reported at the time of diagnosis and 84.0% with the same working time as at the time of diagnosis), while 4.3% are on long-term sick leave, 0.6% are unemployed, 0.4% on disability benefit and 2.6% are non-workers.

Analyses: weighted descriptive statistics.

PREVENTION

Those suffering from cancer are faced with specific or higher health risks, compared to the general population, particularly an increased risk of developing a second primary cancer in the organ previously affected or in another organ. This increased risk may have multiple causes; it may be associated with side-effects of the initial cancer treatment, genetic predispositions, and also individual risk behaviours, with smoking or being overweight at the top of the list. Therefore, any post-cancer diagnosis prevention strategy will entail cancer screening and changes in everyday health behaviours.

Lower frequency of mammograms than in the general population.

The majority of women with a primary cancer other than breast cancer report having had a mammogram over the previous two years (61.9%, and 62.1% limited to those who have not had to deal with a second cancer or metastases). This proportion varies significantly according to the age at the time of the survey: 50.3% for those under 50, 78.0 % for the 50-74 age group, and merely 29.8% for the older population (75 years and over). It also varies according to the initial tumour site, and remains higher in women with a gynaecological cancer (cervix or corpus uteri). However, for the age group corresponding to the organised screening programme (50-74 years), the proportion measured in this study is lower than that observed in the general population.

Screening: smear test use highlights major social inequalities.

Among women with a primary cancer other than a uterine cancer, 73.4% had a cervical smear test carried out over the previous three years. This proportion varies according to the site, and the frequency is found to be higher for those with breast cancer. For patients falling within the recommended age group for this screening programme (25-65 years), this proportion reaches 86.5% for those with breast cancer and 75.7% for other sites (as opposed to 81.4% for the general population). Over the age of 65, this screening is much less frequent. Finally, women with less qualifications, as well as those living in an isolated municipality or in a socially deprived area, have a lower smear test participation rate.

Five years on, four out of every ten surviving smokers have quit smoking.

Five years post-cancer diagnosis, 16.7% of respondents smoke tobacco, generally on a daily basis. This prevalence is higher in women, negatively correlated with socioeconomic status, and declines with age. However, among those who were smokers prior to their diagnosis, 39.8% quit over the subsequent five years. Quitting smoking is more common in men, respondents living in a municipality characterised by a low social deprivation index, and those with lung or upper airway cancer. Due to these subjects quitting, the rates of tobacco use measured by age and by gender in our survey are lower than those observed in the general population.

Among those who smoked on a daily basis during the year prior to their diagnosis, 26.7% report having been offered tobacco cessation support: 11.7% accepted, 15% declined. For these smokers, the offer of support varies according to the cancer site: it was more common for those with cancer of the lung (39.3%) or upper airways (UA) (40.7%), as opposed to merely 8.2% for the kidney and 6.8% for the prostate. Paradoxically, the number of those who were offered support who continued to smoke five years post-diagnosis was greater than those who had not been offered support. This may be explained by the fact that the patients who were offered support had a higher dependency on smoking, for whom quitting is more difficult.

Overweight and obesity affect one out of two people.

Five years post-cancer diagnosis, 47% of subjects are of normal build, 33.4% are overweight, 16.4% are considered obese and 3.2% are underweight. Over these five years, 14.9% have gained weight, and 7% have lost weight.⁶ Weight gains or losses of over 10% vary according to the cancer site. Furthermore, weight gain is more common among women, the younger population, those suffering from after-effects, those who have quit smoking and those who have become less physically active.

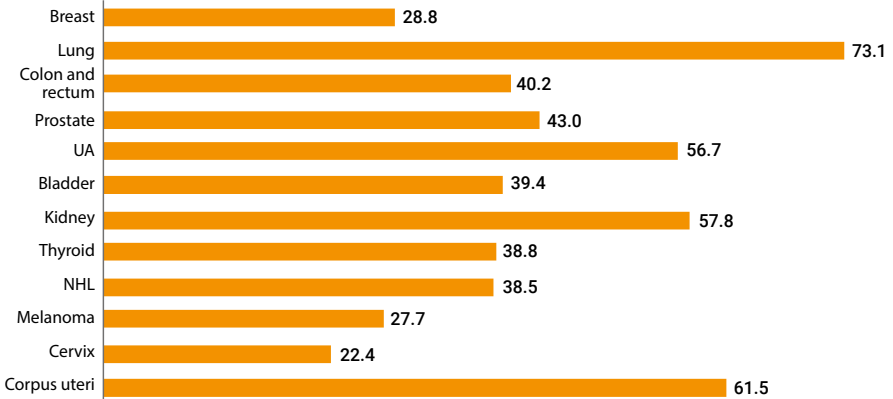
One out of two people has become less or no longer physically active.

Five years post-cancer diagnosis, 53% of respondents have reduced or completely given up their physical activity, 34.3% have not changed it and 12.7% have increased it. Reducing or giving up

6. Gains and loss of over 10% with respect to the initial weight are taken into account in this figure.

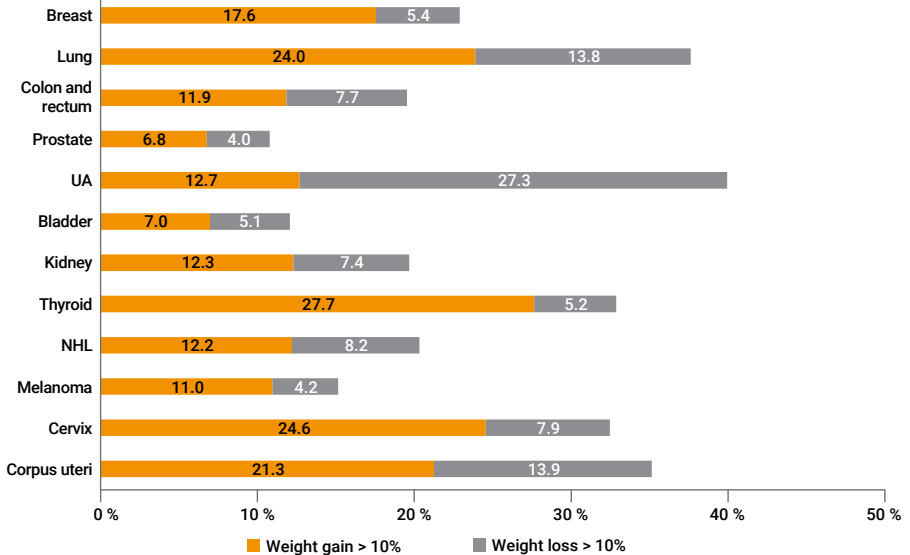
completely are more common among those suffering from after-effects (60.3%, versus 39.6% among other respondents), among those suffering from clinically significant fatigue (68.6% versus 38.1%), anxiety disorders (60.1% versus 46.7%) or depression disorders (78.8% versus 47.6%). Conversely, women and the younger population were more likely to have increased their physical activity post-diagnosis.

PREVALENCE OF SMOKING CESSATION FIVE YEARS POST-DIAGNOSIS ACCORDING TO CANCER SITE (AS A %) (VICAN5 2016)



Scope: VICAN5 respondents, who smoked in the year prior to cancer diagnosis (Weighted sample size = 1,009). Analyses: weighted descriptive statistics.

WEIGHT VARIATIONS > 10% SINCE DIAGNOSIS, BY CANCER SITE (AS A %) (VICAN5 2016)



UA: upper airways; NHL: non-Hodgkin's lymphoma

Scope: VICAN5 survey respondents excluding missing data (Weighted sample = 4,104). Analysis: weighted descriptive statistics.



The full "Life five years post-cancer diagnosis" report is available for download at e-cancer.fr.

Issued by the French National Cancer Institute (INCa)

Design: INCa

Printed by: CIA Graphic

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ISBN: 978-2-37219-402-0

ISBN net: 978-2-37219-403-7

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REF. ETUDVIEK5SYNT18