# Cancer Strategy of the Spanish National Health System

## Update approved by the National Health System Interterritorial Council on February 24, 2021

**SANIDAD 2024**
MINISTERIO DE SANIDAD

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GOBIERNO DE ESPAÑA MINISTERIO DE SANIDAD

**MONITORING AND EVALUATION COMMITTEE OF THE CANCER STRATEGY OF THE SPANISH NATIONAL HEALTH SYSTEM**

**Scientific Coordinator**

Josep María Borrás.

**Technical Coordination**

Pilar Soler Crespo.

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**Specific Technical Collaboration**

Beatriz Pérez-Gómez, Department of Chronic Diseases. National Center of Epidemiology. Carlos III Health Institute. Jaume Galcerán Padrós. Spanish Network of Cancer Registries (REDECAN).

**Ministry of Health**

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Secretariat General of Digital Health, Information and Innovation of the Spanish National Health System: Enrique Regidor Poyatos

Spanish Food Safety and Nutrition Agency: Marta García Solano.

Spanish Agency for Medicines and Health Products: Blanca García-Ochoa Martín.

**Carlos III Health Institute**

National Center of Epidemiology: Marina Pollán Santamaría.

Sub-Directorate General for Research Evaluation and Promotion: Cristóbal Belda Iniesta.

# Contents

# Prologue

Health is an essential human right and it is the responsibility of the public authorities to ensure and promote the effective exercise of this right. The Strategy against Cancer that I have the honour to present is one of the ways in which public administrations and private entities collaborate to ensure that people can receive the health response that is most appropriate to their characteristics and situation.

The Cancer Strategy of the Spanish National Health System was the first Health Strategy developed by the ministry, in 2006, with the aim of contributing to improving the quality of life of people with cancer and their families.

The Strategies of the Spanish National Health System (SNHS) are framed within the General Health Law 14/1986, of 25 April and Law 16/2003, on Cohesion and Quality of the Spanish National Health System, which establishes that comprehensive health plans be prepared for the most prevalent, relevant pathologies or those that represent a special socio-family burden for the population, guaranteeing comprehensive health care, which includes prevention, diagnosis, treatment and rehabilitation.

In addition, the SNHS Quality Plan defines within strategy 9 for "improving care for patients with certain pathologies", the objective of promoting implementation, promoting innovation and supporting the evaluation of the health strategies developed.

The first version of the Strategy, approved in March 2006 by the SNHS Interterritorial Council (SNHSIC), was evaluated by the Strategy Monitoring and Evaluation Committee and this Evaluation Report, approved by the SNHSIC in June 2008, led to the update of the Strategy in 2010.

The last evaluation took place in 2014 and this update of the Strategy has been prepared based on its conclusions and the review of available scientific evidence.

This current Strategy is the result of the cooperation among scientific societies, patient associations, expert professionals and representatives from all of the Autonomous Communities, the Carlos III Health Institute and the Ministry of Health.

The Strategy includes five key lines of action for tackling cancer: health promotion and cancer prevention, health care, specific health care for children and adolescents, cancer data and information, and research. The joint effect of all these lines of action will contribute decisively to reinforcing and expanding one of the essential capacities of the National Health System: care capacity.

Addressing cancer with precision requires a number of measures being taken to determine tested and proven criteria so as to achieve greater effectiveness and quality in dealing with this disease in all the health services that make up the Spanish health system. To this end, the document sets out a set of objectives and recommendations aiming to contribute to improving the quality of the interventions and results of the services and of the health care provided.

The objectives and actions of the SNHS Cancer Strategy are aligned with those of the European Plan against Cancer, approved on 3 February 2021, so that during the next few years both projects will work together on their implementation.

I would like to thank all those individuals and organizations who have taken part in preparing this document, especially Dr. Josep María Borrás Andrés, the scientific coordinator for this Strategy, given that without his dedication and effort, it would not have been possible to avail of a tool which will undoubtedly be contributing to improve the quality of the care provided to cancer patients and their families.

Carolina Darias San Sebastián
*Minister of Health*

# Introduction

The time elapsed since the second edition of the Cancer Strategy, a little over 10 years, allows a broad view of the changes observed in the prevention, diagnosis and treatment of cancer. A first observation is the improvement in the prognosis of the vast majority of cancers observed in the analysis of the Spanish epidemiological situation presented in this document. A second remark is the margin for improvement that we have in clinical results in relative terms with the countries with the best results in Europe, which indicates that we must continue our push to reinforce the effort to improve our health system in aspects such as organizational care, and rapid access to diagnosis and treatment, as well as cancer prevention and the reduction of socioeconomic inequality.

A key area in the coming years in the strategy against cancer is Europe. The European Union proposed carrying out four joint actions with the member states between 2009 and 2021. The European Partnership Action Against Cancer (EPAAC), Cancer Control (CANCON), the Joint Action on Rare Cancers (JARC) and aspects of innovation (iPAAC) have had the participation of members of the Strategy and different Autonomous Communities. All these activities have led to the European Strategy (Europe's Beating Cancer Plan) presented on 4 February, which will serve as a framework for the development of actions against cancer in the classic fields of primary prevention, screening, diagnosis and treatment. In parallel, the Mission on Cancer has been set up, whose objective is to support European research against cancer with a very significant endowment of resources. Together with these initiatives, the model of the European Reference Network of hospital centres for the diagnosis and treatment of rare diseases has been implemented, among which there are four networks directly focused on oncology (solid, hematological and pediatric rare tumors), with hospitals within our country included in all of them.

Of these activities carried out within the European framework, and in some of which the Strategy has played a leading role, various key aspects can be pointed out in the strategy against cancer in the coming years:

- The development of the European Code against Cancer has been reviewed and its use as an instrument to determine preventive priorities must be reinforced. There is still a lot of work to be done in our country in classic aspects such as smoking prevention, together with new forms of eating, diet and the important problem of obese and overweight children and adolescents, or insufficient physical

exercise. Furthermore, the prevention of exposure to radon is a new aspect that must be considered.

- The approval by the Interterritorial Council of population screening for cervical cancer, together with breast and colorectal cancer screening, sets an objective that must reach the entire candidate population according to age and gender, with a participation that allows the expected benefits to be achieved. The criteria remain to be established for assessing the suitability of approving new screenings with increasing evidence of their benefit with strict implementation criteria.
- The progressive extension of the multidisciplinary care model is very relevant in cancer care, partly as a consequence of the relevance attributed in the two previous editions of the Strategy. This model must be complemented with rapid access when there is a sign or symptom of risk of cancer diagnosis. Without this rapid access and a better connection between primary and hospital care, it will be difficult to see the expected progress in clinical results as a result of therapeutic advances.
- The diagnosis of cancer has changed remarkably in these years since the previous Strategy. The need to improve both access to quality imaging and pathology tests is most notable.
- Precision medicine is a new way of approaching the diagnosis and treatment of cancer, not only because of the biomarkers associated with the therapeutic decision, but also because of the possibility of better stratifying the disease and the prognosis, as well as evaluating the prediction of the response to treatment or toxicity. In this area, the work that must be carried out in our country is very notable and ranges from the standardization of tests and their interpretation to access and evaluation of their quality. The proposals of the scientific societies have been significant and should be the basis for defining a precision approach to oncology, together with the activities and programmes developed in some Autonomous Communities. The experience of countries like France is an example of how a policy can be conveyed that takes into account reference centres in the territory with access criteria, quality assessment and specific financing.
- The model of European centres of reference together with that of Centres of Reference of the National Health System (CSUR) in Spain show a key approach for improving clinical results in rare tumors. Accumulating clinical, diagnostic and therapeutic experience in these low-frequency cancers makes it possible to evaluate clinical results and have the necessary therapeutic technology for optimal clinical results.

- The decision of the Interterritorial Council of 2018 on the pediatric cancer care model, advocating a concentration of treatments in reference centres, agreed with scientific societies and patients, and in accordance with European recommendations marked a turning point in the model of care work. This allows greater access to European cooperative research studies and better evaluation of clinical results. Finally, it helps visualizing the usefulness of having cancer registries, such as the national registry of childhood tumors, to be visualized.
- The development of a cooperative model based on care networks between professionals and centres could be an institutional framework that allows optimizing care resources in our country. Undoubtedly, the development of shared electronic medical records, now widely extended, enables new forms of collaborative work that allow cooperation and specialization to grow, while minimizing the movement of patients.
- The quality of life, psychological care and assessment of the needs of patients who have survived cancer are unresolved challenges in our System, with patient and voluntary associations carrying out substitution tasks that should be part of the Spanish Health System. Probably this is the area in which we are furthest from those countries with the best resources for both psychological and social support for patients with cancer or other diseases. Along with improving rehabilitation and the feasibility of returning to work for patients who so wish, these are major challenges for the coming years; largely thanks to improved clinical outcomes. Good news never comes alone.
- Research into cancer is one of the recommendations that cannot be left out of a Strategy like this. Although progress in our country has been very notable both in both basic and clinical or epidemiological research, there is still a long way to go, especially in the financing of projects and the consolidation of researchers within the framework of research centres and hospitals.

An easily noticeable absence in this Strategy is any reference to the impact of the COVID-19 pandemic on our cancer care system. Parallel to this Strategy, and in compliance with an agreement by the Senate, a COVID-19 and Cancer Strategy has been drawn up which highlights the priorities for immediate action against COVID-19 and cancer. The pandemic has revealed the fragility of the health system during this type of high-impact epidemic and new episodes cannot be ruled out, so it is very important to propose a reinforcement of the cancer care system that allows cancer patients to be protected from the risks posed by the pandemic and its long-term consequences.

All these listed aspects are consistent with the European recommendations developed in the different joint actions mentioned and with the European Strategy. Continuing with the cooperative work model between European cancer plans, as well as between the cancer plans of the different Autonomous Communities, and patient and voluntary associations and scientific societies, has been key to continuing to advance over these years and it should continue to be this way in times to come.

Josep Maria Borrás Andrés
*Cancer Strategy Scientific Coordinator*

# Justification

Cancer is one of the most important diseases worldwide. It is estimated that throughout the year 2018 more than 18 million new cancers were diagnosed worldwide and that this disease was the cause of more than 9.5 million deaths that same year (Cancer Today. GLOBOCAN 2018. International Agency for Research on Cancer-World Health Organization) (https://gco.iarc.fr/today/data/factsheets/populations/900-world-fact-sheets.pdf). In the 27 countries of the European Union as a whole, the number of cancer cases estimated to be diagnosed in 2020 is almost 2.7 million and the number of deaths caused by cancer is more than 1.25 million (European Cancer Information System. Joint Research Centre, European Network of Cancer Registries, International Agency for Research on Cancer) (https://ec.europa.eu/jrc/en).

In Spain, cancer currently continues to be one of the most relevant groups of diseases in public health (https://www.who.int/nmh/countries/esp_es.pdf WHO, 2020). Thus, in the general population, cancer is the second cause of death after diseases of the circulatory system, although in men it has been, since the year 2000, the first cause of death. In 2018, one in three deaths in men and one in five in women were due to malignant tumors, which represents more than a quarter of the deaths in Spain in that year.

A high percentage of cancer cases are preventable, making it possible to reduce and control cancer by applying strategies based on scientific evidence aimed at preventing the disease. It is estimated that more than 30% of cancer deaths could be avoided by modifying or avoiding the main risk factors (WHO, 2015).

This data highlights the enormous challenge that an approach to this pathology entails, from the health point of view, causing the appearance of different action plans to fight cancer and a greater political commitment toward its prevention and control.

In this context, the Cancer Strategy of the Spanish National Health System was approved by the National Health System Interterritorial Council in March 2006, encouraged and supported by the Ministry of Health. This approval was the result of a fruitful coordination effort and consensus among the Autonomous Communities, the cancer-related scientific societies and the patients associations, headed by the Scientific Coordinator.

Within the framework of the Cancer Strategy, an updating process has been established that has arisen from the need to adapt to new challenges posed by this group of diseases and the incorporation of related technological, scientific and healthcare advances.

In accordance with this process, in 2009, the Cancer Strategy of the Spanish National Health System approved the update of the Strategy based on two points: on the one hand, the available scientific evidence on the effectiveness of various measures implemented in the approach to the disease and, on the other hand, the evaluation of the Strategy approved in June 2008 and which reviewed the progress achieved since its inception in 2006. The last evaluation of the Strategy was carried out in 2014, giving rise to this update.

This new update uses all the knowledge and data available to date, in order to establish a document that includes a review of the objectives based on the current state of affairs and the results achieved and which serves as a guide for the definition of lines of work for the coming years, with the aim of improving prevention and care for people with cancer throughout the national territory, in accordance with the principles of quality, equity and cohesion, as established in the Quality Plan for the Spanish National Health System.

# Technical organizational note

This document is comprised of five sections:

**Generalities:** This section deals with the methodology of this document, definition of concepts, current situation of cancer in Spain.

**Further details of the lines of strategy:** Detailing the objectives and the actions which are suggested for each one, agreed upon by the Monitoring and Evaluation Committee, to contribute to improving the quality of the interventions and results in cancer treatment.

The following lines of strategy were defined:

- Strategy Line 1: Health promotion and cancer prevention
  - Health promotion and primary prevention
  - Early Detection

- Strategy Line 2: Health care
  - Care model
  - Monitoring and quality of life
  - Palliative Care

- Strategy Line 3: Health care for children and adolescents
- Strategy Line 4: Cancer data and information
- Strategy Line 5: Research

**Evaluation:** This section includes the monitoring and evaluation indicators for the respective objectives set forth.

**List of Acronyms and Abbreviations**

**Bibliography**

# 1. Generalities

## 1.1. Methodology

The work of drafting the Cancer Strategy of the Spanish National Health System started off with the creation of two committees: the Technical Committee (TC) and the Institutional Committee (IC). The Technical Committee is comprised of representatives from scientific societies and other professionals of well-known prestige, as experts on the subject and by representatives of patient associations. The Institutional Committee is comprised of the 17 representatives appointed by the Autonomous Communities and INGESA (for the Autonomous Cities of Ceuta and Melilla). In addition, different departments of the Ministry of Health and the Carlos III Health Institute (ISCIII) participated. The coordination of the Work Strategy is carried out by a scientific coordinator, Dr Josep María Borrás, and by the Technical Secretariat of the Strategy that is in the Sub-Directorate General of Promotion, Prevention and Quality of the Directorate General of Public Health of the Ministry of Health.

The Cancer strategy was approved by the National Health System Interterritorial Council at the meeting held on 29 March 2006.

In 2007, the Strategy Monitoring and Evaluation Committee was formed for the purpose, as its name proper indicates, of establishing the system for monitoring and evaluating the Strategy. Said committee is made up of both the IC and the TC.

The first evaluation of the Cancer Strategy of the Spanish National Health System was undertaken in 2008 and consisted of assessing the degree to which the objectives set out were met by means of collecting data stipulated in the evaluation indicators and the proposal for updating the contents of the Strategy, as well as any possible actions for improvement. This evaluation led to the update of the Strategy in 2010, with the last evaluation being carried out in 2014.

The information necessary for the evaluation of the proposed objectives was obtained, both from the Autonomous Communities, as well as from the Ministry of Health, through the Institute of Health Information, the Network of Cancer Screening Programmes, the Spanish Network of Cancer Registries and the Carlos III Health Institute.

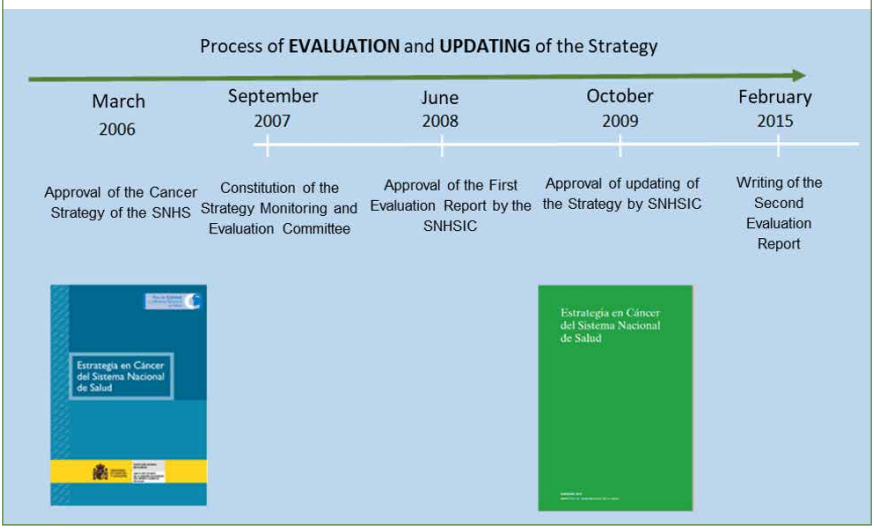
Following the conclusion of the evaluation process, the Strategy updating phase then began, the result of which is this document.

The updating of contents includes the modifications stemming from the final results of the evaluation process, in conjunction with the compiling

and updating of the information on cancer based on the scientific evidence available to date. In other words, the final updated Strategy document presented here is comprised of the changes and improvements related to objectives and indicators, as well as to its scientific and technical contents.

The Strategy update was reviewed and agreed upon by the Strategy Monitoring and Evaluation Committee in November 2020, when it was then forwarded to the National Health System Interterritorial Committee for their approval in December.

**Cancer Strategy of the Spanish National Health System Evaluation, Monitoring and Updating Schedule**




## 1.2. Definitions of concepts

The **objectives** are the goals to be achieved. All of these objectives have been included in the different recommendations of the scientific societies, patients associations and authorized institutional bodies. The objectives must be monitored, quantified and updated.

The **indicators** are measurements of processes or results which are essential for evaluating the effectiveness of the Cancer Strategy of the Spanish National Health System and which, in short, will provide clear, consistent, updated information.

The **actions** are the activities which need to be carried out according to the different organizational criteria of the various administrations. They contribute to guaranteeing that the objectives will be achieved.

## 1.3. Current situation of Cancer in Spain

It is estimated that throughout the year 2018 more than 18 million new cancers were diagnosed worldwide (excluding non-melanoma skin cancers) and that this disease was the cause of more than 9.5 million deaths that same year (Cancer Today. GLOBOCAN 2018. International Agency for Research on Cancer-World Health Organization) (https://gco.iarc.fr/today/data/factsheets/populations/900-world-fact-sheets.pdf). In the 27 countries of the European Union as a whole, the number of cancer cases estimated to be diagnosed in 2020 is almost 2.7 million (also excluding non-melanoma skin cancers) and the number of deaths caused by cancer is more than 1.25 million (European Cancer Information System. Joint Research Centre, European Network of Cancer Registries, International Agency for Research on Cancer) (https://ec.europa.eu/jrc/en).

In Spain, cancer currently continues to be one of the most relevant groups of diseases in public health (https://www.who.int/nmh/countries/esp_es.pdf WHO, 2020). Thus, in the general population, cancer is the second cause of death after diseases of the circulatory system, although in men it has been, since the year 2000, the first cause of death. In 2018, one in three deaths in men and one in five in women were due to malignant tumors, which represents more than a quarter of the deaths in Spain in that year.

The global incidence of cancer continues to increase due to ageing and the increasing trend of certain unhealthy habits and lifestyles. On the other hand, the maintenance or even decrease in the incidence and mortality of some types of cancer suggest a greater effectiveness of prevention policies, both primary and secondary, and of the new diagnostic and therapeutic alternatives available.

This section contains an update on the epidemiological situation of cancer in Spain, with the final objective of serving as support in prioritizing health policies and reducing the impact of this group of diseases in our population, as well as reducing inequalities between different geographic areas.

Incidence data provided and analysed by the Spanish Network of Cancer Registries (REDECAN) and survival data from Spanish cancer registries (Spanish Network of Cancer Registries. Cancer survival in Spain, 2002-2013) were used as data sources. The database of the Spanish Network of Cancer Registries (REDECAN) contains data from 14 population-based cancer registries: Albacete, Asturias, the Canary Islands, Castellón, Ciudad Real, Cuenca, Girona, Granade, La Rioja, Mallorca, Murcia, Navarre, the Basque Country, and Tarragona. REDECAN is the network of population-based registries made up of these registries and the Childhood Cancer Registry of the Valencian Community, in addition to the multi-institutional

Spanish Registry of Childhood Tumours (www.redecan.org). It should be stressed that REDECAN covers less than 30% of the Spanish population in the total of its records. Data from the European Cancer Information System (at European level) and GLOBOCAN (at world level) were used for international comparisons of incidence. Data from the EUROCARE-5 and CONCORD-3 projects (Allemani C., et al. 2018) were used for international comparisons of survival.

The mortality information was prepared by the Department of Chronic Disease Epidemiology of the National Center of Epidemiology (ISCIII) from the mortality data provided by the National Institute of Statistics.

Childhood cancer data was obtained and analysed by the Spanish Childhood Tumour Registry.

## 1.3.1. Incidence

### Cancer incidence in Spain

Based on the estimates of cancer incidence made by REDECAN, the total number of new cases/year for 2020 was estimated at 277,394, of which 160,198 were in men and 117,196 in women **(Table 1)**. With respect to the incidence of 2015, this would mean an increase of 8.7% in global figures (both sexes), an 8.6% increase in men and 8.9% in women.

**Table 1. Number of incident cases of cancer in Spain by age in 2015 and prediction for 2020.**

| Year | Males | Females | Both sexes |
|---|---|---|---|
| **2015** | 147,478 | 107,657 | 255,135 |
| **2020** | 160,198 | 117,196 | 277,394 |
| **Δ 2020-2015** | 12,720 (+8.63%) | 9,539 (+8.86%) | 22,259 (+8.72%) |

Source: Spanish Network of Cancer Registries (REDECAN)

**Tables 2 and 3** show the estimated cancer incidence in Spain for the year 2020. By tumor type and sex, we give the absolute number of incident cases, the crude rate and its confidence interval per 100,000 inhabitants per year, and the age-adjusted rate for the standard European population of 2013 per 100,000 inhabitants per year, and its confidence interval.

**Table 2. Projections of the number of incident cases of cancer, gross rate and rate adjusted to the new European standard population by type of cancer per 100,000 men per year. Spain, 2020.**

| Tumor type | N | CR | CI95% (CR) | ARne | CI95% (ARne) |
|---|---|---|---|---|---|
| **Buccal cavity and pharynx** | 6,049 | 26.2 | (20.3-33.1) | 26.6 | (20.5-33.6) |
| **Esophagus** | 1,908 | 8.3 | (7.3-9.3) | 8.4 | (7.5-9.5) |
| **Stomach** | 4,703 | 20.4 | (18.4-22.4) | 21.3 | (19.2-23.5) |
| **Colon** | 17,433 | 75.5 | (64.3-88.5) | 79.7 | (67.8-93.5) |
| **Rectum** | 8,611 | 37.3 | (32.6-42.4) | 38.5 | (33.6-43.9) |
| **Colorectal** | 26,044 | 112.8 | (100.6-126.8) | 118.2 | (105.3-133) |
| **Liver** | 4,971 | 21.5 | (18.5-24.8) | 22.1 | (19-25.5) |
| **Gallbladder and bile ducts** | 1,521 | 6.6 | (5.2-8.2) | 7.0 | (5.5-8.8) |
| **Pancreatic** | 4,384 | 19.0 | (16.9-21.3) | 19.9 | (17.6-22.3) |
| **Larynx** | 2,825 | 12.2 | (10.5-14.2) | 12.3 | (10.5-14.2) |
| **Lung** | 21,847 | 94.6 | (86.6-103) | 98.8 | (90.3-107.7) |
| **Skin melanoma** | 2,507 | 10.9 | (8.8-13.2) | 11.0 | (8.9-13.4) |
| **Prostate** | 35,126 | 152.1 | (123.1-184) | 163.3 | (131.7-198) |
| **Testicle** | 1,310 | 5.7 | (5.2-6.2) | 5.8 | (5.3-6.4) |
| **Kidney (without pelvis)** | 5,109 | 22.1 | (19.3-25.2) | 22.4 | (19.5-25.5) |
| **Bladder** | 18,071 | 78.2 | (69.7-87.5) | 82.2 | (73.1-92.1) |
| **Brain and nervous system** | 2,263 | 9.8 | (8.6-11.1) | 10.0 | (8.8-11.3) |
| **Thyroid** | 1,124 | 4.9 | (4.4-5.4) | 4.8 | (4.3-5.3) |
| **Hodgkin lymphoma** | 854 | 3.7 | (3.3-4.2) | 3.7 | (3.3-4.2) |
| **Non-Hodgkin lymphoma** | 4,932 | 21.4 | (18.5-24.5) | 21.7 | (18.8-25) |
| **Myeloma** | 1,861 | 8.1 | (6.7-9.6) | 8.5 | (7-10.1) |
| **Leukemias** | 3,575 | 15.5 | (13.1-18.2) | 16.2 | (13.7-19.2) |
| **Others** | 9,215 | 39.9 | (35.7-44.4) | 41.5 | (37.1-46.2) |
| **Total except non-melanoma skin cancers** | **160,198** | **693.7** | **(658.6-732.5)** | **725.5** | **(687.7-767.3)** |

**CR:** Crude rate. **ARne**: Rate adjusted to the new European standard population. **CI95%:** Confidence interval at 95%. All rates are expressed per 100,000 inhabitants per year.
Source: Spanish Network of Cancer Registries

**Table 3. Projections of the number of incident cases of cancer, gross rate and rate adjusted to the new European standard population by type of cancer per 100,000 women per year. Spain, 2020.**

| Tumor type | N | CR | CI95% (CR) | ARne | CI95% (ARne) |
|---|---|---|---|---|---|
| **Buccal cavity and pharynx** | 2,555 | 10.6 | (9.2-12.1) | 9.4 | (8.2-10.7) |
| **Esophagus** | 475 | 2.0 | (1.7-2.3) | 1.7 | (1.5-2.1) |
| **Stomach** | 2,874 | 11.9 | (10.9-13) | 10.2 | (9.3-11.1) |
| **Colon** | 12,635 | 52.4 | (43.4-63.2) | 45.4 | (37.6-54.6) |
| **Rectum** | 5,552 | 23.0 | (19.7-26.7) | 20.3 | (17.4-23.5) |
| **Colorectal** | 18,187 | 75.5 | (65.8-86.8) | 65.7 | (57.4-75.4) |
| **Liver** | 1,624 | 6.7 | (5.8-7.8) | 5.8 | (5-6.7) |
| **Gallbladder and bile ducts** | 1,454 | 6.0 | (5.2-7) | 5.0 | (4.3-5.7) |
| **Pancreatic** | 3,954 | 16.4 | (14.7-18.2) | 14.0 | (12.6-15.5) |
| **Larynx** | 386 | 1.6 | (1.3-1.9) | 1.5 | (1.2-1.8) |
| **Lung** | 7,791 | 32.3 | (29.7-35.2) | 29.5 | (27.1-32.2) |
| **Skin melanoma** | 3,672 | 15.2 | (12.5-18.3) | 13.9 | (11.5-16.7) |
| **Breast** | 32,953 | 136.8 | (115.8-160) | 123.5 | (104.5-144.5) |
| **Cervical cancer** | 1,972 | 8.2 | (6.7-9.9) | 7.6 | (6.2-9.1) |
| **Uterine cancer** | 6,804 | 28.2 | (23.7-33.2) | 25.9 | (21.7-30.6) |
| **Ovarian cancer** | 3,645 | 15.1 | (13.3-17.1) | 13.7 | (12-15.5) |
| **Kidney (without pelvis)** | 2,191 | 9.1 | (7.7-10.7) | 8.2 | (6.9-9.6) |
| **Bladder** | 4,279 | 17.8 | (13.2-23.8) | 15.5 | (11.6-20.8) |
| **Brain and nervous system** | 2,152 | 8.9 | (7.8-10.1) | 8.2 | (7.2-9.4) |
| **Thyroid** | 4,180 | 17.4 | (16.4-18.4) | 16.6 | (15.7-17.6) |
| **Hodgkin lymphoma** | 652 | 2.7 | (2.4-3.1) | 2.8 | (2.4-3.2) |
| **Non-Hodgkin lymphoma** | 4,256 | 17.7 | (15.9-19.6) | 15.9 | (14.2-17.6) |
| **Myeloma** | 1,337 | 5.6 | (4.5-6.7) | 4.8 | (4-5.8) |
| **Leukemias** | 2,667 | 11.1 | (9.1-13.3) | 9.8 | (8.1-11.7) |
| **Others** | 7,136 | 29.6 | (26.6-32.9) | 24.9 | (22.5-27.5) |
| **Total except non-melanoma skin cancers** | **117,196** | **486.5** | **(461.5-514.6)** | **434.0** | **(411.6-459.1)** |

**CR:** Crude rate. **ARne**: Rate adjusted to the new European standard population. **CI95%:** Confidence interval at 95%. All rates are expressed per 100,000 inhabitants per year.
Source: Spanish Network of Cancer Registries

In the group of both sexes, the most frequent cancer was colorectal with a total of 44,231 new cases (15.9% of the total). This is followed by prostate cancer with 35,126 (12.7%), female breast cancer with 32,953 (11.9%) and lung cancer with 29,638 (10.7%) new cases. Bladder cancer followed with 22,350 new cases (8.1%).

By sex, the most frequent cancers in men were prostate (21.9%), colorectal (16.3%), lung (13.6%), and bladder (11.3%). In women, the most frequent were breast (28.1%), colorectal (15.5%), lung (6.6%) and uterine (5.8%). It should be noted that lung cancer, with 7,791 new cases, rose to third position for the first time **(Table 4)**.

**Table 4. The five most common tumor types in Spain. Estimates 2020.**

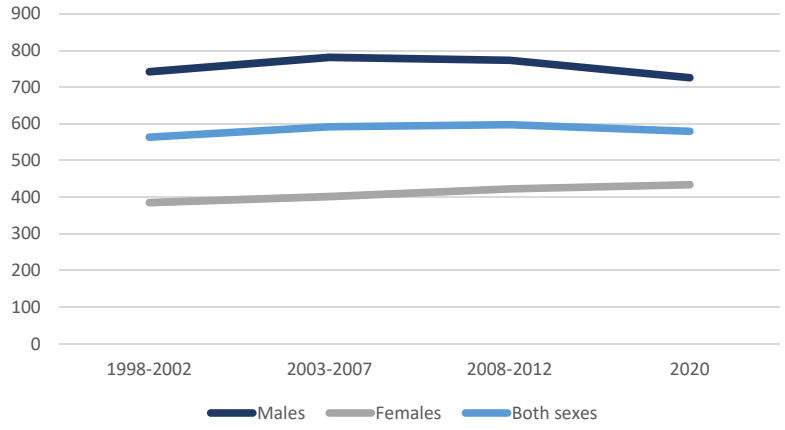
| | Males | Females | Both sexes |
|---|---|---|---|
| **1st** | Prostate **22%** | Breast **28%** | Colorectal **16%** |
| **2nd** | Colorectal **16%** | Colorectal **16%** | Prostate **13%** |
| **3rd** | Lung **14%** | Lung **7%** | Female breast **12%** |
| **4th** | Bladder **11%** | Uterine **6%** | Lung **11%** |
| **5th** | Buccal cavity and pharynx **4%** | Bladder **4%** | Bladder **8%** |

Source: Spanish Network of Cancer Registries (REDECAN). Estimates of the incidence of cancer in Spain, 2020.

## Cancer incidence trends in Spain

**Figure 1** shows the evolution of the cancer incidence rates adjusted by age to the standard European population of 2013 for three five-year periods 1998-2002, 2003-2007 and 2008-2012, global and by sex, as well as their estimate rates for 2020. In men, for all cancers as a whole (except non-melanoma skin cancers), after an increase of about 40 points (5.3%) between 1998-2002 and 2003-2007, the incidence rate fell by 1% between 2003-2007 and 2008-2012, and it is estimated that it will decrease by 6% between this last five-year period and the year 2020. In women, after an increase of about 16.5 points between 1998-2002 and 2003-2007 (4.3%), the rate continued to increase between 2003-2007 and 2008-2012 (20.7 points, 5.2%) and it is estimated that it will continue to increase between this last period of five years and the year 2020 (11.7 points, 6.2%).

**Fig. 1. Evolution of the cancer incidence rate per 100,000 adjusted by age to the new European standard population (2013) in the set of all tumor types, except non-melanoma skin cancer, in five-year periods and the projection for 2020. Men, women and both sexes.**




Source: Prepared by authors based on REDECAN data.

| | 1998-2002 | 2003-2007 | 2008-2012 | 2020 |
|---|---|---|---|---|
| **Males** | 741.8 | 781.1 | 773.1 | 725.5 |
| **Females** | 385.1 | 401.6 | 422.3 | 434.0 |
| **Both sexes** | 563.5 | 591.4 | 597.7 | 579.8 |

By type of tumor and centred between the years 2012 and 2020, it is estimated that, in men, the incidence decreased in cancers of the lip, buccal cavity and pharynx (-4%), esophagus (-10%), stomach (-21%), rectum (9%), larynx (-27%), lung (-11%) and bladder (-17%), and in myeloma (-3%) and leukemias (-5%). On the other hand, it is estimated that the incidence rates increased in cancers of the gallbladder and bile ducts (11%), pancreas (6%), skin melanoma (12%), testicle (16%), kidney (3%), thyroid (30%) and Hodgkin lymphoma (3%). Liver cancer and non-Hodgkin lymphomas remained stable (0%) **(Table 5)**.

In women, it is estimated that the incidence decreased in tumors of the stomach (-16%), rectum (-6%), liver (-9%), gallbladder and bile ducts (-6%), kidney (-13%), non-Hodgkin lymphomas (-7%), multiple myeloma (-6%), and leukemias (-9%). In contrast, it is estimated that cancers of the lip, buccal cavity and pharynx (22%), esophagus (30%), pancreas (11%), larynx (15%), lung (37%), skin melanoma (11%), cervix (6%), uterus (4%), bladder (5%), thyroid (18%), and Hodgkin lymphoma (17%) all increased

in their incidence rates. The increase experienced by cancers associated with tobacco use in women (lip, buccal cavity and pharynx, esophagus, pancreas, larynx, lung and bladder) is especially noteworthy **(Table 5)**.

For the calculation of the estimates of incidence of prostate cancer for the year 2020, the incidence rates were assumed to be stable since, due to the different use of the PSA test in the various geographical areas, there has been a great temporal variability in the observed incidence rates of the different geographical areas in recent years. A similar phenomenon occurred with breast cancer, in this case possibly due to the differences in the early detection programmes for this cancer in various territories and the phenomenon of screening saturation, so that a stable incidence rates were also assumed. Consequently, no change in the incidence rates between 2012 and 2020 is observed for these two cancers.

**Table 5. Incidence rates per 100,000 age-adjusted to the new European standard population (2013) by tumor type in 2012; projection for 2020 and percentage of variation between 2012 and 2020. Spain, Male and Female.**

| Cancer type | 2012 | 2020 projections | Variation | 2012 | 2020 projections | Variation |
|---|---|---|---|---|---|---|
| | Males | | | Females | | |
| **Lip, buccal cavity and pharynx** | 27.6 | 26.6 | **-4%** | 7.7 | 9.4 | **22%** |
| **Esophagus** | 9.3 | 8.4 | **-10%** | 1.3 | 1.7 | **30%** |
| **Stomach** | 27.1 | 21.3 | **-21%** | 12.2 | 10.2 | **-16%** |
| **Colorectal*** | 123.5 | 118.2 | **-4%** | 65.8 | 65.7 | **0%** |
| **- Colon** | 81.2 | 79.7 | **-2%** | 44.2 | 45.4 | **2%** |
| **- Rectum** | 42.3 | 38.5 | **-9%** | 21.6 | 20.3 | **-6%** |
| **Liver** | 22.0 | 22.1 | **0%** | 6.4 | 5.8 | **-9%** |
| **Gallbladder and bile ducts** | 6.2 | 7.0 | **11%** | 5.3 | 5.0 | **-6%** |
| **Pancreatic** | 18.8 | 19.9 | **6%** | 12.4 | 14.0 | **11%** |
| **Larynx** | 16.9 | 12.3 | **-27%** | 1.3 | 1.5 | **15%** |
| **Lung** | 111.4 | 98.8 | **-11%** | 21.6 | 29.5 | **37%** |
| **Skin melanoma** | 9.8 | 11.0 | **12%** | 12.5 | 13.9 | **11%** |
| **Breast**** | | | | 123.5 | 123.5 | **0%** |
| **Cervical cancer** | | | | 7.2 | 7.6 | **6%** |
| **Uterine cancer** | | | | 25.0 | 25.9 | **4%** |

**Table 5. Incidence rates per 100,000 age-adjusted to the new European standard population (2013) by tumor type in 2012; projection for 2020 and percentage of variation between 2012 and 2020. Spain, Male and Female. (Cont.)**

| Cancer type | 2012 | 2020 projections | Variation | 2012 | 2020 projections | Variation |
|---|---|---|---|---|---|---|
| | Males | | | Females | | |
| **Ovarian cancer** | | | | 13.8 | 13.7 | **-1%** |
| **Prostate**** | 163.3 | 163.3 | **0%** | | | |
| **Testicle** | 5.0 | 5.8 | **16%** | | | |
| **Kidney** | 21.6 | 22.4 | **3%** | 9.4 | 8.2 | **-13%** |
| **Bladder** | 99.5 | 82.2 | **-17%** | 14.7 | 15.5 | **5%** |
| **Brain and CNS** | 10.3 | 10.0 | **-3%** | 8.4 | 8.2 | **-2%** |
| **Thyroid** | 3.7 | 4.8 | **30%** | 14.1 | 16.6 | **18%** |
| **Hodgkin lymphoma** | 3.6 | 3.7 | **3%** | 2.4 | 2.8 | **17%** |
| **Non-Hodgkin lymphoma** | 21.7 | 21.7 | **0%** | 17.1 | 15.9 | **-7%** |
| **Myeloma** | 8.8 | 8.5 | **-3%** | 5.1 | 4.8 | **-6%** |
| **Leukemias** | 17.0 | 16.2 | **-5%** | 10.8 | 9.8 | **-9%** |
| **Others** | 43.7 | 41.5 | **-5%** | 26.8 | 24.9 | **-7%** |
| **Total** | **770.8** | **725.5** | **-5.9%** | **424.8** | **434.0** | **2.2%** |

* Sum of colon cancer and rectal cancer. ** See comment in the text.
Source: Prepared by REDECAN

The incidence data from the population registries with the longest operating period published in volumes IX, X and XI of the *Cancer Incidence in Five Continents* series, CIFC (Curado MP. et al., 2007; Forman D. et al., 2014; Bray F. et al, 2017) allow us to understand the trend of cancer incidence rates in recent years in territories where there are population-based cancer registries.

## International comparisons

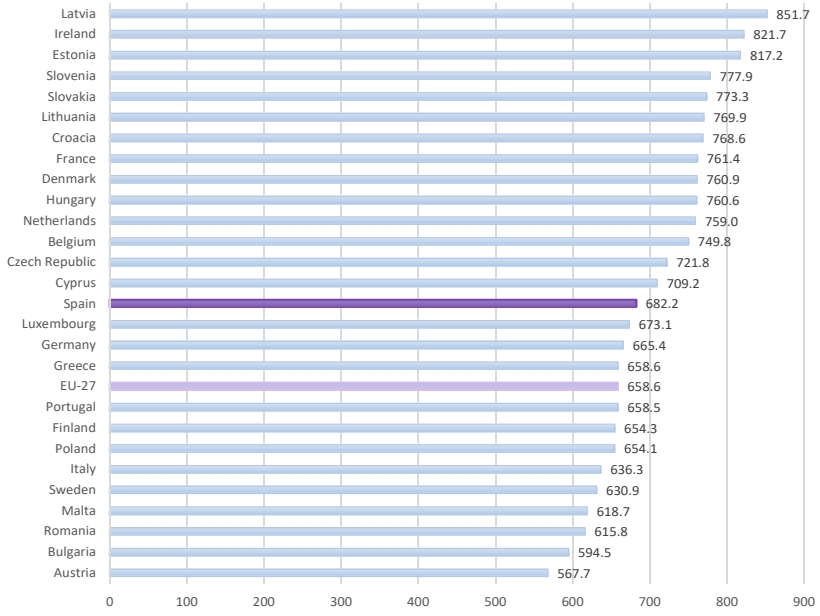
To obtain data at the international level, the main source of information of cancer incidence is the International Agency for Research on Cancer (IARC), an agency operating under the WHO which regularly publishes the incidence data of the population records which meet the quality criteria set out by the agency in the series Cancer Incidence in Five Continents. The last volume published in this series, volume XI, includes the incidence figures corresponding to the reference period 2008-2012 (Bray F. et al., 2017). Furthermore, the IARC also publishes, in digital format, the Global Cancer Ob-

servatory (https://gco.iarc.fr/) which provides worldwide national estimates of incidence, mortality and prevalence for 32 types of cancer. The latest incidence data published is that corresponding to 2018.

At European level, the Joint Research Centre (JRC) of the European Commission publishes in digital format, the European Cancer Information System —ECIS— a work carried out jointly with the European Network of Cancer Registries (ENCR) and the IARC (https://ec.europa.eu/jrc/en). The ECIS also provides the same national estimates of cancer incidence and mortality by cancer type in European countries. The latest incidence estimates published in the ECIS correspond to the year 2020. According to this data, it is estimated that in the year 2020, a total of 2,682,537 new cases of cancer will be diagnosed, in the whole of the 27 countries of the European Union (EU-27), 1,444,949 in men and 1,237,588 in women.

In men, Spain showed an age-adjusted incidence rate for the new standard European population slightly higher than the European Union average (682 new cases per 100,000 men per year in Spain vs 658 new cases per 100,000 men per year in the EU-27) **(Figure 2)**.

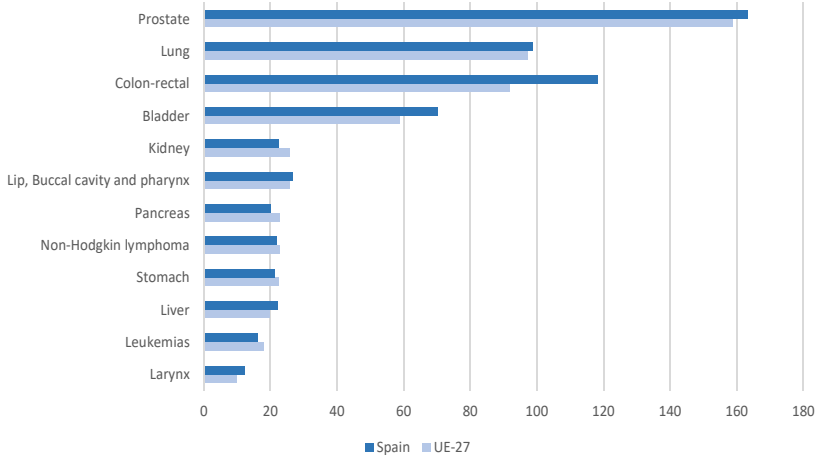
**Fig. 2. Cancer incidence rate per 100,000 adjusted by age to the new European standard population (2013) for European countries. All types of cancer except non-melanoma skin cancers, 2020 Male.**




Source: Prepared by authors based on REDECAN and European Cancer Information Service (ECIS) data

If we perform an exhaustive analysis of the 12 tumor types with higher incidence rates in men, Spain showed an incidence rate of prostate cancer (163.3 cases per 100,000 men per year) very slightly higher than the average of the EU-27 countries, although its comparison is less reliable than that of other tumor types due to the influence that improved diagnostic method has exercised in the incidence rates of the different countries **(Figure 3, Table 6)**. Lung cancer had an almost equal incidence in Spain (98.8) as in the EU-27 as a whole (97.2). Colorectal cancer should be highlighted, showing a clearly higher incidence in Spain than in the EU-27 (118.2 vs 91.6). Furthermore, higher incidence rates were also observed to a greater or lesser degree compared to the EU-27 average in cancers of the bladder (70.2 vs 58.9), lip, buccal cavity and pharynx (26.6 vs 25.7), liver (22.1 vs 19.8) and larynx (12.3 vs 9.8). In contrast, kidney cancer (22.4 vs 25.8), pancreatic cancer (19.9 vs 22.7), non-Hodgkin lymphomas (21.7 vs 22.6), stomach cancer (21.3 vs 22.4) and leukemias (16.2 vs 18.0) showed, to a greater or lesser degree, a lower incidence in Spain than in the EU-27.

**Fig. 3. Cancer incidence rates per 100,000 adjusted by age to the new European standard population of 2013 for 12 tumor types in 2020 in Spain and in all the countries of the European Union (EU-27). Males.**




Source: Prepared by authors based on REDECAN and European Cancer Information Service (ECIS) data

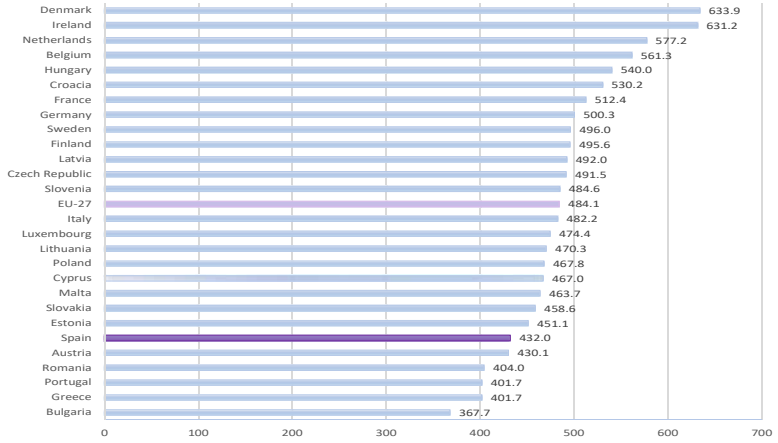
**Table 6. Cancer incidence rates per 100,000 adjusted by age to the new European standard population of 2013 for 12 tumor types in 2020 in Spain and in all the countries of the European Union (EU-27). Males.**

| Tumor type | Spain | UE-27 |
|---|---|---|
| Prostate | 163.3 | 158.8 |
| Lung | 98.8 | 97.2 |
| Colon-rectal | 118.2 | 91.6 |
| Bladder | 70.2 | 58.9 |
| Kidney | 22.4 | 25.8 |
| Lip, Buccal cavity and pharynx | 26.6 | 25.7 |
| Pancreas | 19.9 | 22.7 |
| Non-Hodgkin lymphoma | 21.7 | 22.6 |
| Stomach | 21.3 | 22.4 |
| Liver | 22.1 | 19.8 |
| Leukemias | 16.2 | 18.0 |
| Larynx | 12.3 | 9.8 |

Source: Prepared by authors based on REDECAN and European Cancer Information Service (ECIS) data

In women, Spain showed an age-adjusted cancer incidence rate lower than the European Union average (432 new cases per 100,000 women per year in Spain compared to 484 new cases per 100,000 women in the EU-27) **(Figure 4)**.

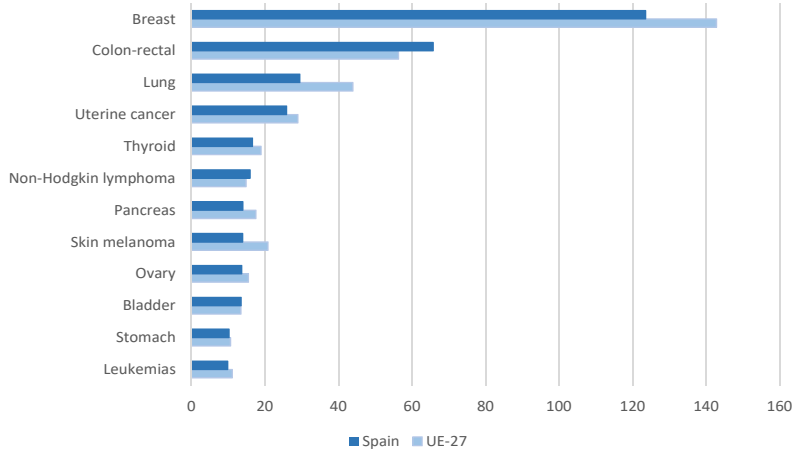
**Fig. 4. Cancer incidence rate per 100,000 adjusted by age to the new European standard population (2013) for European countries. All types of cancer except non-melanoma skin cancers, 2020. Females.**




Source: Prepared by authors based on REDECAN and European Cancer Information Service (ECIS) data

Among the 12 tumor types with the highest rates in women, Spain showed a lower rate than the EU-27 average in breast cancer (123.5 vs 142.8 cases per 100,000 women per year), lung cancer (29.5 vs 43.9), skin melanoma (13.9 vs 20.8) and, to a lesser extent, uterine cancer (25.9 vs 28.9), thyroid cancer (16.6 vs 18.9), pancreatic cancer (14.0 vs 17.5), ovarian cancer (13.7 vs 15.5), leukemia (9.8 vs 11.1) and stomach cancer (10.2 vs 10.6). Bladder cancer showed practically the same rate (13.5 vs 13.4) in Spain and in the EU-27. Non-Hodgkin lymphomas had a slightly higher rate (15.9 vs 14.8) in Spain and colorectal cancer (65.7 vs 56.3) had a rate clearly higher than the EU-27 average. **(Fig. 5, Table 7)**.

**Fig. 5. Cancer incidence rates per 100,000 adjusted by age to the new European standard population of 2013 for 12 tumor types in 2020 in Spain and in all the countries of the European Union (EU-27). Females.**




Source: Prepared by authors based on REDECAN and European Cancer Information Service (ECIS) data

**Table 7. Cancer incidence rates per 100,000 adjusted by age to the new European standard population of 2013 for 12 tumor types in 2020 in Spain and in all the countries of the European Union (EU-27). Females.**

| Tumor type | Spain | UE-27 |
|---|---|---|
| Breast | 123.5 | 142.8 |
| Colon-rectal | 65.7 | 56.3 |
| Lung | 29.5 | 43.9 |
| Uterine cancer | 25.9 | 28.9 |
| Skin melanoma | 13.9 | 20.8 |

**Table 7. Cancer incidence rates per 100,000 adjusted by age to the new European standard population of 2013 for 12 tumor types in 2020 in Spain and in all the countries of the European Union (EU-27). Females. (Cont.)**

| | | |
|---|---|---|
| **Thyroid** | 16.6 | 18.9 |
| **Pancreas** | 14.0 | 17.5 |
| **Ovary** | 13.7 | 15.5 |
| **Non-Hodgkin lymphoma** | 15.9 | 14.8 |
| **Bladder** | 13.5 | 13.4 |
| **Leukemias** | 9.8 | 11.1 |
| **Stomach** | 10.2 | 10.6 |

Source: Prepared by authors based on REDECAN and European Cancer Information Service (ECIS) data

## 1.3.2. Survival

The main factors that influence the survival of people with cancer are both the stage of the cancer at the time of diagnosis and the effectiveness of therapeutic procedures. For this reason, survival is considered the main indicator of the effectiveness of the healthcare system in cancer control.

The most up-to-date information on cancer survival in Spain is the report of the Spanish Network of Cancer Registries (REDECAN) published under the title *Cancer Survival in Spain, 2002-2013*. This report describes the survival of patients older than 14 years, diagnosed with cancer between 2002 and 2013, and residing in the Spanish geographic areas that have a population-based cancer registries and updated monitoring data. The report divides the results into two periods (2002-2007 and 2008-2013) in order to assess the evolution of survival in recent years. Thirteen population-based cancer registries covering 27% of the Spanish population (Asturias, the Canary Islands, Castellón, Ciudad Real, Cuenca, the Basque Country, Girona, Granade, La Rioja, Mallorca, Murcia, Navarre and Tarragona) participated in this study. The report shows the observed survival and the net survival (that is, the one that eliminates the effect of other causes of death) at 1, 3 and 5 years, and the trend over time, for the group of all cancers and separately for most specific types of cancer.

At the European level, the EUROCARE study (*Survival of cancer patients in Europe*) is a population-based study that provides estimates of cancer survival in Europe, for more than 25 years. Estimates of survival in Spain in the most recent period correspond to those of the EUROCARE-5 project (De Angelis R. et al. 2014), which included data from nearly 9 million adult cancer cases diagnosed in the period 2000-2007 in Europe.

Nine population-based cancer registries participated in Spain, providing data on 157,149 incident cases from the period 2000-2007. The registries

that participated were: Albacete, Castellón (breast cancer), Cuenca, the Basque Country, Girona, Grenada, Murcia, Navarre and Tarragona.

## Survival in Spain in the period 2002-2013

**Tables 8 and 9** show the net survival at 1, 3, and 5 years for all cancer patients, except those with non-melanoma skin cancer, by sex and age group. They also show the net survival at 1, 3 and 5 years for the set of all adult patients of 15-99 years old without age standardization and with age standardization.

In the period 2008-2013, the observed 5-year survival rate for all cancers except non-melanoma skin cancer (not shown) in men was 48.9%, while the net rate, that is, the rate that eliminates the effect of other causes of death, was 55.3%. In contrast, in women the values were higher. In the same period 2008-2013, the observed survival rate was 57.4% and the net survival was 61.7%. The main cause of the difference in survival between the sexes is the different distribution of cases by tumor type. For example, lung cancer, one of those with the worst prognosis, is much more frequent in men while breast cancer, with the highest incidence in women, has a much higher survival rate.

Survival rates decline with age in both men and women. Thus, the age-adjusted 5-year net survival in the age group 15-44 years old is 75% and 84% in men and women respectively, in the age group 55-64 years old it is 61% and 72%, and in the age group 75-99 years old it is 41% and 41%.

**Table 8. Net survival (%) at 1, 3 and 5 years of cancer patients (except non-melanoma skin cancer) by age group and diagnostic period in men. Spain.**

| AGE | TIME | 2002-2007 | | 2008-2013 | | p |
|---|---|---|---|---|---|---|
| | | CASES | NS | CASES | NS | |
| 15-44 | 1 | 9,904 | 82.8 | 8,842 | 86.9 | <0.000 |
| | 3 | 8,155 | 72.6 | 7,630 | 77.8 | <0.000 |
| | 5 | 7,113 | 69.2 | 5,974 | 74.6 | <0.000 |
| 45-54 | 1 | 17,831 | 72.1 | 17,335 | 75.9 | <0.000 |
| | 3 | 12,763 | 56.9 | 13,062 | 62.0 | <0.000 |
| | 5 | 9,952 | 52.0 | 9,237 | 57.1 | <0.000 |
| 55-64 | 1 | 37,409 | 74.3 | 41,389 | 77.7 | <0.000 |
| | 3 | 27,501 | 60.5 | 31,792 | 65.1 | <0.000 |
| | 5 | 21,899 | 55.6 | 22,817 | 60.7 | <0.000 |

**Table 8. Net survival (%) at 1, 3 and 5 years of cancer patients (except non-melanoma skin cancer) by age group and diagnostic period in men. Spain. (Cont.)**

| AGE | TIME | 2002-2007 | | 2008-2013 | | p |
|---|---|---|---|---|---|---|
| | | CASES | NS | CASES | NS | |
| 65-74 | 1 | 58,659 | 71.7 | 55,276 | 75.8 | <0.000 |
| | 3 | 41,069 | 59.2 | 41,002 | 64.2 | <0.000 |
| | 5 | 32,172 | 54.4 | 28,900 | 59.5 | <0.000 |
| 75-99 | 1 | 56,427 | 60.9 | 60,066 | 60.9 | 0.897 |
| | 3 | 31,944 | 47.7 | 34,200 | 47.0 | 0.092 |
| | 5 | 21,371 | 42.4 | 20,226 | 41.4 | 0.022 |
| 15-99 | 1 | 180,230 | 69.5 | 182,908 | 71.8 | <0.000 |
| | 3 | 121,432 | 56.4 | 127,686 | 59.2 | <0.000 |
| | 5 | 92,507 | 51.5 | 87,154 | 54.3 | <0.000 |
| 15-99* | 1 | 180,230 | 70.0 | 182,908 | 72.7 | <0.000 |
| | 3 | 121,432 | 56.8 | 127,686 | 60.1 | <0.000 |
| | 5 | 92,507 | 52.0 | 87,154 | 55.3 | <0.000 |

Time: years since diagnosis; NS: net survival. * Estimators standardized by age.
Source: Spanish Network of Cancer Registries

**Table 9. Net survival (%) at 1, 3 and 5 years of cancer patients (except non-melanoma skin cancer) by age group and diagnostic period in women. Spain.**

| AGE | TIME | 2002-2007 | | 2008-2013 | | p |
|---|---|---|---|---|---|---|
| | | CASES | NS | CASES | NS | |
| 15-44 | 1 | 13,908 | 92.5 | 13,366 | 94.0 | <0.000 |
| | 3 | 12,836 | 84.5 | 12,513 | 87.7 | <0.000 |
| | 5 | 11,705 | 80.5 | 10,160 | 84.0 | <0.000 |
| 45-54 | 1 | 17,454 | 88.9 | 19,977 | 89.9 | 0.002 |
| | 3 | 15,450 | 79.8 | 17,876 | 81.8 | <0.000 |
| | 5 | 13,803 | 75.4 | 14,015 | 77.9 | <0.000 |
| 55-64 | 1 | 20,618 | 85.6 | 23,449 | 86.3 | 0.043 |
| | 3 | 17,558 | 75.1 | 20,124 | 76.3 | 0.004 |
| | 5 | 15,271 | 70.2 | 15,242 | 71.9 | <0.000 |
| 65-74 | 1 | 26,019 | 75.1 | 24,444 | 79.2 | <0.000 |
| | 3 | 19,331 | 62.9 | 19,158 | 67.5 | <0.000 |
| | 5 | 15,807 | 57.6 | 13,861 | 62.1 | <0.000 |

**Table 9. Net survival (%) at 1, 3 and 5 years of cancer patients (except non-melanoma skin cancer) by age group and diagnostic period in women. Spain. (Cont.)**

| AGE | TIME | 2002-2007 | | 2008-2013 | | p |
|---|---|---|---|---|---|---|
| | | CASES | NS | CASES | NS | |
| 75-99 | 1 | 37,481 | 58.3 | 40,912 | 59.6 | <0.000 |
| | 3 | 20,615 | 45.4 | 23,184 | 46.6 | 0.007 |
| | 5 | 14,173 | 40.0 | 14,221 | 41.3 | 0.021 |
| 15-99 | 1 | 115,480 | 75.7 | 122,148 | 77.4 | <0.000 |
| | 3 | 85,790 | 64.6 | 92,855 | 66.7 | <0.000 |
| | 5 | 70,759 | 59.6 | 67,499 | 62.0 | <0.000 |
| 15-99* | 1 | 115,480 | 75.5 | 122,148 | 77.4 | <0.000 |
| | 3 | 85,790 | 64.2 | 92,855 | 66.6 | <0.000 |
| | 5 | 70,759 | 59.1 | 67,499 | 61.7 | <0.000 |

Time: years since diagnosis; NS: net survival. * Estimators standardized by age.
Source: Spanish Network of Cancer Registries

## Cancer survival trends in the period 2002-2013

**Tables 10 and 11** and **Figures 6 and 7** show the 5-year age-adjusted net survival for the two periods and the percentage variation between them.

In men, the observed 5-year survival rate for all cancers, except non-melanoma skin cancer, went from 44.9% in the 2002-2007 period to 48.9% in the 2008-2013 period. In parallel, the net survival rate increased from 52.0% to 55.3% between the same two periods. Thus, in men, net survival between the two periods increased by 3.3 percentage points.

In women, survival between the two six-year periods increased from 54.5% to 57.4% (observed survival) and from 59.1% to 61.7% (net survival), so the increase in net survival was 2.6% percentage points.

However, these percentages vary depending on the tumor type. Thus, in men there are two tumor types that presented a very slight decrease in survival rate, although neither of them presented a statistically significant decrease in survival rate. The rest showed non-significant increases to increases of variable significance.

In women, six tumor types showed a very slight decrease (none of them statistically significant), one tumor type remained stable and the rest of the tumor types showed increases of very different intensities.

Notable variations include an increase in survival in chronic myeloid leukemia due to the inclusion of a new effective drug in its therapy, imatinib, and an increase in survival in non-Hodgkin lymphoma probably due to the incorporation of rituximab (Sant M, et al; 2014). On the other hand, the maintenance of a high survival rate in prostate cancer is the result of the inclusion of numerous cases with a good prognosis due to the wide use of diagnosis by prostate specific antigen test (PSA) (Verdecchia A, et al., 2009).

**Table 10. Age-adjusted 5-year net cancer survival rates in Spain by type of cancer and period. Men (15-99 years).**

| Tumor type | NS 2002-2007 | NS 2008-2013 | % variation between periods |
|---|---|---|---|
| Buccal cavity and pharynx | 37.4 | 38.2 | 2.1 |
| Esophagus | 9.7 | 13.1 | 35.1 |
| Stomach | 24.6 | 26.0 | 5.7 |
| Colon | 57.5 | 63.1 | 9.7 |
| Rectum | 64.3 | 68.2 | 6.1 |
| Liver | 15.2 | 17.9 | 17.8 |
| Gallbladder and bile ducts | 18.5 | 21.8 | 17.8 |
| Pancreas | 5.7 | 7.2 | 26.3 |
| Larynx | 60.6 | 60.0 | -1.0 |
| Lung | 11.2 | 12.7 | 13.4 |
| Skin melanoma | 79.1 | 82.3 | 4.0 |
| Prostate | 87.9 | 89.8 | 2.2 |
| Testicle | 86.1 | 89.2 | 3.6 |
| Kidney | 59.8 | 64.8 | 8.4 |
| Bladder | 72.3 | 73.8 | 2.1 |
| Brain | 19.3 | 20.8 | 7.8 |
| Thyroid | 78.3 | 86.1 | 10.0 |
| Hodgkin lymphoma | 80.0 | 80.6 | 0.8 |
| Non-Hodgkin lymphoma | 57.2 | 62.4 | 9.1 |
| Myeloma | 40.1 | 44.8 | 11.7 |
| Chronic lymphocytic leukemia (CLL) | 78.8 | 77.7 | -1.4 |

**Table 10. Age-adjusted 5-year net cancer survival rates in Spain by type of cancer and period. Men (15-99 years). (Cont.)**

| Tumor type | NS 2002-2007 | NS 2008-2013 | % variation between periods |
|---|---|---|---|
| Acute lymphocytic leukemia (ALL) | 35.1 | 41.1 | 17.1 |
| Chronic myeloid leukemia (CML) | 59.2 | 68.8 | 16.2 |
| Acute myeloid leukemia (AML) | 17.0 | 19.2 | 12.9 |
| **All** | 52.0 | 55.3 | 6.3 |

Source: Prepared by authors based on REDECAN data. Guevara M et al. Cancer Survival in Spain, 2002-2013. Spanish Network of Cancer Registries, January 2020.

**Table 11. Age-adjusted 5-year net cancer survival rates in Spain by type of cancer and period. Women (15-99 years).**

| Tumor type | NS 2002-2007 | NS 2008-2013 | % variation between periods |
|---|---|---|---|
| Buccal cavity and pharynx | 51.6 | 57.2 | 10.9 |
| Esophagus | 17.3 | 15.7 | -9.2 |
| Stomach | 30.6 | 30.3 | -1.0 |
| Colon | 59.8 | 63.9 | 6.9 |
| Rectum | 58.1 | 62.7 | 7.9 |
| Liver | 16.4 | 16.2 | -1.2 |
| Gallbladder and bile ducts | 17.8 | 18.8 | 5.6 |
| Pancreas | 7.3 | 10.0 | 37.0 |
| Larynx | 68.5 | 66.1 | -3.5 |
| Lung | 16.2 | 17.6 | 8.6 |
| Skin melanoma | 88.6 | 88.9 | 0.3 |
| Breast | 83.2 | 85.5 | 2.8 |
| Cervical cancer | 64.4 | 65.5 | 1.7 |
| Uterine cancer | 74.6 | 74.0 | -0.8 |
| Ovary | 37.5 | 40.9 | 9.1 |
| Kidney | 61.4 | 65.8 | 7.2 |
| Bladder | 72.9 | 75.9 | 4.1 |
| Brain | 21.2 | 24.2 | 14.2 |
| Thyroid | 88.8 | 93.1 | 4.8 |

**Table 11. Age-adjusted 5-year net cancer survival rates in Spain by type of cancer and period. Women (15-99 years). (Cont.)**

| Tumor type | NS 2002-2007 | NS 2008-2013 | % variation between periods |
|---|---|---|---|
| Hodgkin lymphoma | 83.3 | 82.6 | -0.8 |
| Non-Hodgkin lymphoma | 63.0 | 68.4 | 8.6 |
| Myeloma | 42.5 | 51.2 | 20.5 |
| Chronic lymphocytic leukemia (CLL) | 80.7 | 80.7 | 0.0 |
| Acute lymphocytic leukemia (ALL) | 37.4 | 40.1 | 7.2 |
| Chronic myeloid leukemia (CML) | 67.5 | 73.0 | 8.1 |
| Acute myeloid leukemia (AML) | 19.8 | 24.9 | 25.8 |
| **All** | 59.1 | 61.7 | 4.4 |

Source: Prepared by authors based on REDECAN data. Guevara M et al. Cancer Survival in Spain, 2002-2013. Spanish Network of Cancer Registries, January 2020.

**Fig. 6. Net survival (%) standardized by age at 5 years from diagnosis by type of cancer and period in men. REDECAN, Spain.**

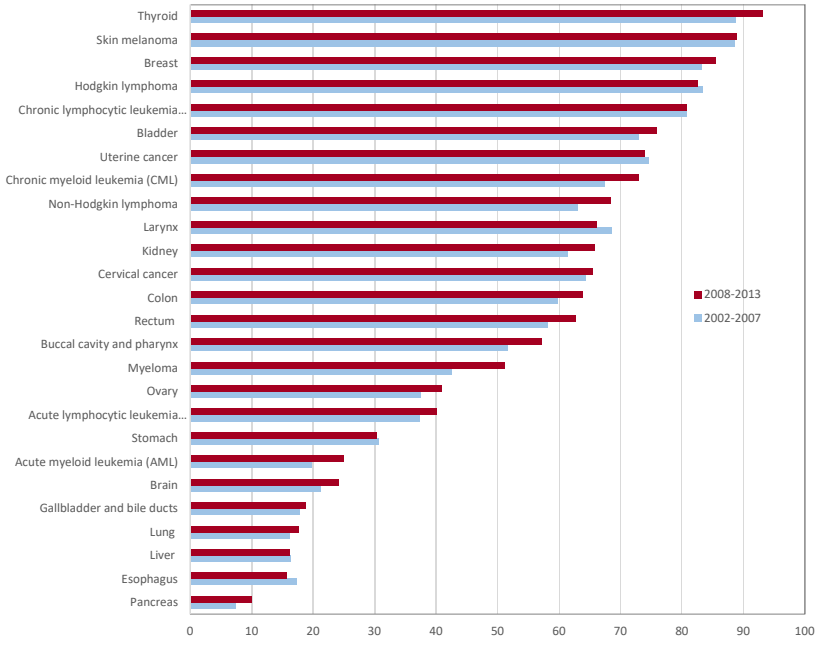
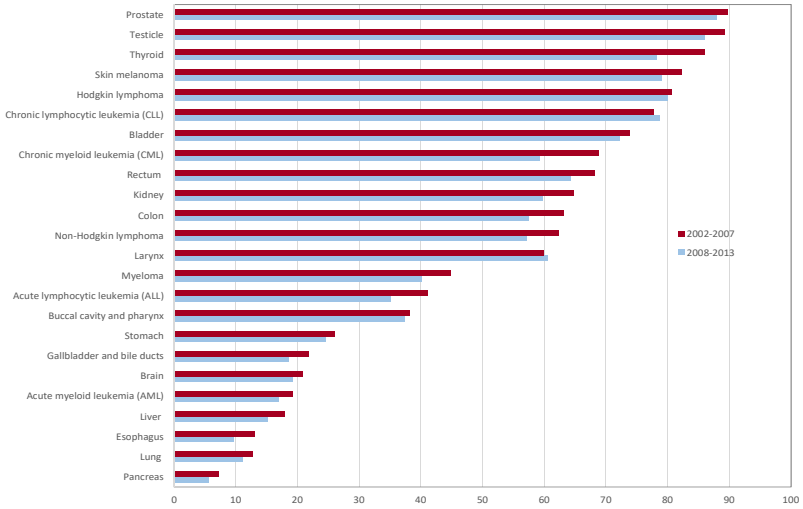


**Fig. 7. Net survival (%) standardized by age at 5 years from diagnosis by type of cancer and period in women. REDECAN, Spain.**




## Comparison of cancer survival in Spain in relation to Europe

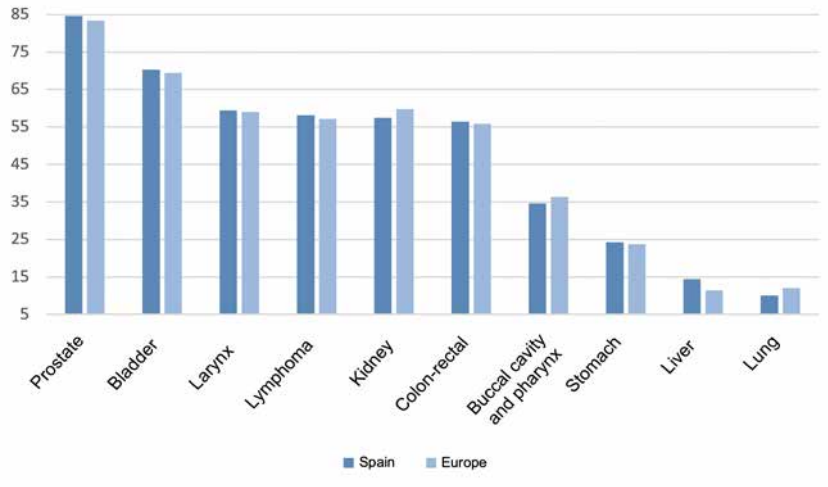
To compare the survival of cancer patients in Spain with those in Europe **(Figures 8 and 9)** and in order to cover the same period, the results of the EUROCARE-5 project that studied the survival of patients from cancer in multiple European countries diagnosed in the period 2000-2007, monitored until 2015, were used. In this case, age-adjusted 5-year relative survival rates are compared.

According to the latest data from EUROCARE, although there is a trend towards increased survival throughout the European Union, there are variations in survival between countries. The countries with the highest survival for most tumor types were the Nordic countries (except Denmark) and those of central Europe (Austria, Belgium, France, Germany, Switzerland and the Netherlands; except the United Kingdom) showing rates above the European average. Eastern European countries had lower survival rates, particularly in tumor types with better prognosis.

The differences found in survival rates in Eastern countries may be due to the scarcity of public funds for cancer control, the lack of national cancer plans, and lack of access to early diagnosis programmes and innovative therapies.

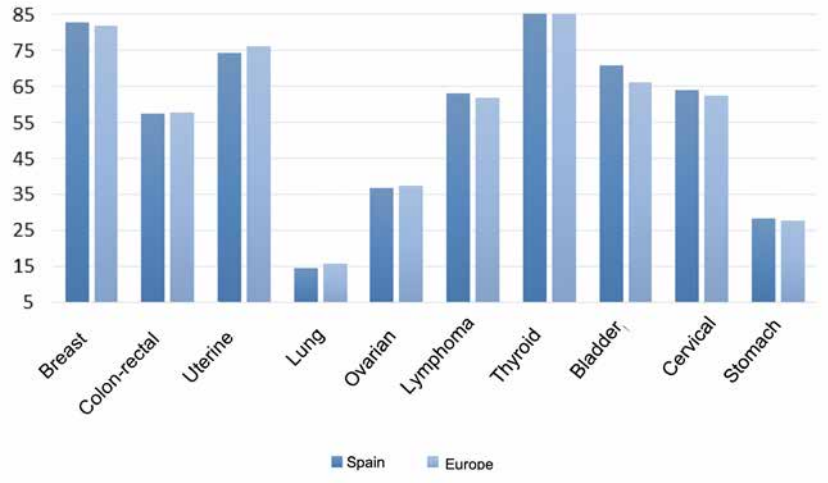
If we compare the survival data by sex between the European average and Spain: in men, Spain showed a 5-year survival rate one point below the European average (49% vs 50%) and in women the rate in Spain was equal to that of the European average (58%). By tumor type, all types of cancer showed survival rates very similar to those of the European average **(Figures 8 and 9)**.

**Fig. 8. Age-adjusted 5-year relative survival rates in adults. Cancer patients for 10 tumor types in the period 2000-2007 in Spain and in the countries of the European Union (EU-27). Males.**




Source: Prepared by authors based on REDECAN data. Galcerán J et al. *Estimates of cancer survival in Spain and its situation in Europe. Report 2014*.

**Fig. 9. Age-adjusted 5-year relative survival rates of cancer patients for 10 tumor types in 2000-2007 in Spain and in the countries of the European Union (EU-27). Females.**




Source: Prepared by authors based on REDECAN data. Galcerán J et al. *Estimates of cancer survival in Spain and its situation in Europe. Report 2014.*

For a comparison by European countries of the most recent data, **Tables 12 and 13** show the age-adjusted 5-year net survival of patients with 15 types of cancer diagnosed in the period 2010-2014 according to the results of the CONCORD-3 project.

Among the most frequent tumors, survival from colon cancer varies between 44.9% and 68.2%, while in Spain it is 63.2%. In breast cancer it varies between 70.8% and 89.1% with Spain showing a value of 85.2%. For prostate cancer, Spain shows a survival rate of 89.7% while the extreme values are 68.3% and 94.3%. In the latter cancer, survival can be greatly affected by the amount of use of the prostate specific antigen test (PSA) and, consequently, by the inclusion of many cancers with a very good prognosis in the case mix.

**Table 12. Age-standardized 5-year net survival (%) of adult patients (15-99) with 7 types of cancer diagnosed by country in the period 2010-2014.**

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Germany** | 36.8 | 20.8 | 33.5 | 64.8 | 62.3 | 13.0 | 10.7 | 18.3 |
| **Austria** | 100.0 | 18.6 | 35.4 | 63.7 | 64.2 | 14.8** | 10.5** | 19.7 |
| **Belgium** | 100.0 | 23.6 | 37.5 | 67.9 | 66.6 | 20.7 | 12.4 | 18.2 |
| **Bulgaria** | 100.0 | - | 16.0 | 52.4 | 45.9 | 6.5** | - | 7.7 |
| **Croatia** | 100.0 | 8.7 | 20.0 | 51.1 | 48.2 | 9.3** | 8.4** | 10.0 |
| **Denmark** | 100.0 | 13.7 | 19.9 | 61.6 | 64.8 | 7.5 | 8.0 | 16.6 |
| **Slovakia** | 100.0 | 6.4 | 21.1 | 51.8 | 48.6 | 7.6** | 6.4 | 11.2 |
| **Slovenia** | 100.0 | 8.6 | 28.8 | 61.9 | 60.3 | 7.4 | 6.6 | 14.8 |
| **Spain** | 20.3 | 13.0 | 27.6 | 63.2 | 59.5 | 17.3 | 7.7 | 13.5 |
| **Estonia** | 100.0 | 5.4 | 29.2 | 58.4 | 54.8 | 4.2 | 10.2 | 16.9 |
| **Finland** | 100.0 | 12.4 | 25.7 | 64.9 | 64.4 | 10.4** | 7.4** | 13.0 |
| **France** | 21.7 | 13.9 | 26.7 | 63.7 | 60.9 | 18.3 | 8.6 | 17.3 |
| **Ireland** | 100.0 | 20.3 | 27.6 | 60.5 | 61.7 | 14.2 | 9.6 | 17.5 |
| **Iceland** | 100.0 | 17.7 | 28.1 | 68.2 | 63.0 | 14.3 | 0.0* | 20.2 |
| **Italy** | 57.7 | 13.8 | 30.5 | 64.2 | 61.3 | 20.3 | 9.2 | 15.9 |
| **Latvia** | 100.0 | 6.1 | 28.0 | 56.5 | 53.3 | 12.9 | 13.7 | 20.4 |
| **Lithuania** | 100.0 | 5.6 | 27.0 | 56.9 | 52.7 | 8.0** | 7.0** | 9.9 |
| **Malta** | 100.0 | 11.2** | 23.8 | 57.5 | 56.1 | 0.0** | 5.5** | 14.9 |
| **Norway** | 100.0 | 16.5 | 26.5 | 66.7 | 69.2 | 18.7 | 9.5 | 19.0 |

**Table 12. Age-standardized 5-year net survival (%) of adult patients (15-99) with 7 types of cancer diagnosed by country in the period 2010-2014. (Cont.)**

| Country | %Pop | Esophagus | Stomach | Colon | Rectum | Liver | Pancreatic | Lung |
|---|---|---|---|---|---|---|---|---|
| Netherlands | 100.0 | 21.0 | 25.0 | 63.1 | 65.3 | 15.8 | 7.4 | 17.3 |
| Poland | 100.0 | 9.1 | 20.9 | 52.9 | 48.4 | 10.8 | 8.0 | 14.4 |
| Portugal | 100.0 | 16.1 | 32.2 | 60.9 | 59.6 | 18.7 | 10.7 | 15.7 |
| Czech Rep. | 100.0 | 9.8 | 20.6 | 56.1 | 52.3 | 6.7 | 6.1 | 10.6 |
| Russia | 5.6 | 8.6 | 21.0 | 44.9 | 41.9 | 6.3 | 4.4 | 13.7 |
| Sweden | 100.0 | 14.8 | 24.8 | 64.9 | 64.7 | 16.6 | 9.7 | 19.5 |
| Switzerland | 53.2 | 23.9 | 32.2 | 67.3 | 67.3 | 15.4 | 9.4 | 20.4 |
| Great Britain | 100.0 | 15.7 | 20.7 | 60.0 | 62.5 | 13.0 | 6.8 | 13.3 |

**Table 13. Age-standardized 5-year net survival (%) of adult patients (15-99) with 8 types of cancer diagnosed by country in the period 2010-2014.**

| Country | Skin melanoma | Breast | Cervical cancer | Ovarian | Prostate | Brain | Hemato Myeloid | Hemato Lymphoid |
|---|---|---|---|---|---|---|---|---|
| Germany | 93.1 | 86.0 | 65.2 | 41.2 | 91.6 | 29.6 | 54.9 | 67.9 |
| Austria | 87.8 | 84.8 | 63.9 | 41.0 | 90.2 | 26.3 | 32.0 | 63.3 |
| Belgium | 91.0 | 86.4 | 65.4 | 43.1 | 93.8 | 31.2 | 55.4 | 70.6 |
| Bulgaria | 61.2 | 78.3 | 54.8 | 37.3 | 68.3 | - | 41.6** | 43.5 |
| Croatia | 77.2 | 78.6 | 63.2 | 36.0 | 80.9 | 42.2 | 32.2 | 52.7 |
| Denmark | 91.1 | 86.1 | 69.5 | 39.7 | 85.6 | 38.9 | 47.6 | 70.9 |
| Slovakia | 78.2 | 75.5 | 60.5 | 33.4 | 74.7 | 28.5 | 37.5 | 51.6 |
| Slovenia | 85.1 | 83.5 | 65.5 | 37.0 | 85.0 | 24.8 | 37.5 | 59.0 |
| Spain | 86.8 | 85.2 | 64.5 | 39.8 | 89.7 | 27.4 | 50.0 | 62.0 |
| Estonia | 81.8 | 76.6 | 66.5 | 42.3 | 86.3 | 31.0 | 37.8 | 53.8 |
| Finland | 88.7 | 88.5 | 67.4 | 41.1 | 93.2 | 37.6 | 47.2** | 64.4 |
| France | 90.8 | 86.7 | 65.0 | 43.5 | 93.1 | 27.2 | 57.5 | 69.6 |
| Ireland | 89.2 | 82.0 | 63.6 | 21.8 | 91.1 | 34.5 | 53.1 | 66.9 |
| Iceland | 87.5 | 89.1 | 80.1* | 40.3 | 90.8 | 29.2 | 43.4 | 71.5 |
| Italy | 85.7 | 86.0 | 66.8 | 39.4 | 89.5 | 28.8 | 49.2 | 62.6 |
| Latvia | 72.1 | 82.2 | 56.0 | 45.5 | 90.4 | 26.1 | 21.4 | 71.6 |

**Table 13. Age-standardized 5-year net survival (%) of adult patients (15-99) with 8 types of cancer diagnosed by country in the period 2010-2014. (cont.)**

| Country | Skin melanoma | Breast | Cervical cancer | Ovarian | Prostate | Brain | Hemato Myeloid | Hemato Lymphoid |
|---|---|---|---|---|---|---|---|---|
| Lithuania | 75.3 | 73.5 | 59.2 | 35.0 | 94.3 | 23.4** | 52.8 | 56.7 |
| Malta | 81.9** | 86.9 | 57.4 | 28.0 | 88.2 | 28.0 | 46.3** | 61.9 |
| Norway | 89.3 | 87.7 | 73.3 | 45.5 | 92.9 | 36.8 | 52.7 | 68.4 |
| Netherlands | 91.0 | 86.6 | 67.5 | 37.5 | 88.5 | 28.2 | 52.2 | 66.4 |
| Poland | 69.8 | 76.5 | 55.1 | 37.5 | 78.1 | 28.2 | 27.3 | 52.1 |
| Portugal | 83.7 | 87.6 | 66.2 | 43.6 | 90.9 | 22.7 | 49.8 | 59.7 |
| Czech Rep. | 85.7 | 81.4 | 61.0 | 36.5 | 85.3 | 21.4 | 36.8 | 57.2 |
| Russia | 66.5 | 70.8 | 57.7 | 34.8 | 79.3 | 22.8 | 33.2 | 45.5 |
| Sweden | 91.5 | 88.8 | 68.3 | 46.5 | 90.7 | 31.6 | 57.5 | 66.7 |
| Switzerland | 93.6 | 86.2 | 71.4 | 44.1 | 89.2 | 29.7 | 49.7 | 72.0 |
| Great Britain | 90.9 | 85.6 | 63.8 | 36.2 | 88.7 | 26.3 | 48.7 | 64.9 |

% Pop: Percentage of the national population covered. * Survival not standardized by age. ** Survival estimate is considered less reliable because 15% or more of patients (1) were lost to monitoring or censored alive within 5 years of diagnosis or, if diagnosed in 2010 or later, before 31 December 2014; or (2) recorded only from a death certificate or at an autopsy; or (3) patients with unknown life status or registered with incomplete dates, i.e. unknown year of birth, unknown month or year of diagnosis, or unknown year of last known life status.

## 1.3.3. Prevalence

Cancer prevalence is the proportion of individuals in a population who at some point in their lives have been diagnosed with cancer. These individuals place greater demands on the health system than the general population. They require treatment, monitoring for cancer recurrence, independent secondary cancer screening, and may be permanently impaired or disabled as a result of their cancer. However, prevalent cancer cases are a very heterogeneous group in terms of health status, as they include patients undergoing clinical treatment and diagnosed many years previously, who can be considered to have had their cancer cured and require few or no additional medical resources. Thus, time since diagnosis is an essential qualifier of cancer prevalence data. For this reason, in addition to the total prevalence, it is of interest to know about the prevalent cases diagnosed at less than one, three and five years after diagnosis.

The prevalence of cancer in Spain as of 31 December 2020 has been recently estimated by the Spanish Network of Cancer Registries based on the most up-to-date information available on cancer incidence and survival in Spain.

**Tables 14 and 15** show, for men and women respectively and for selected tumor types, the estimated number of total prevalent cases as of 31 December 2020, the total prevalence rate per 100,000 men or women, and the number of prevalent cases diagnosed less than one, three and five years after diagnosis.

The estimated number of total prevalent cases in Spain as of 31 December 2020 is 2,265,152 (1,066,959 in men and 1,198,193 in women). This represents a total of 4,611 cases per 100,000 men and 4,961 cases per 100,000 women. Among men, 42.8% of cases (456,366) are prevalent less than 5 years after diagnosis. Among women this percentage is 32.1% (384,080 cases).

Since the main factors influencing the prevalence of cancer are incidence and survival, the most frequent tumors with a good prognosis are especially represented in the prevalence. The most prevalent cancers are female breast (516,827), prostate (259,788), colon (227,174), bladder (182,487) and rectum (112,915) and non-Hodgkin lymphomas (100,058).

It should be noted that some particular combinations of cancers (e.g. Lymphomas and Leukemias) include subtypes that show great heterogeneity in short- and long-term survival.

**Table 14. Total prevalence (number of cases and rate) and number of prevalent cases at 1, 3, and 5 years after diagnosis. Spain, 31 December 2020, men.**

| Tumor type | Total prevalencew | | Prevalence at 1, 3, and 5 years after diagnosis. | | |
|---|---|---|---|---|---|
| | Totals | Rate | < 1 year | < 3 years | < 5 years |
| Buccal cavity and pharynx | 40,087 | 173.3 | 5,176 | 12,992 | 18,266 |
| Esophagus | 3,298 | 14.3 | 1,203 | 2,276 | 2,699 |
| Stomach | 15,599 | 67.4 | 3,111 | 6,759 | 8,887 |
| Colon | 126,241 | 545.6 | 14,782 | 39,153 | 55,988 |
| Rectum | 65,643 | 283.7 | 7,549 | 19,625 | 28,776 |
| Liver | 11,347 | 49.0 | 3,220 | 6,513 | 8,151 |
| Gallbladder and bile ducts | 3,099 | 13.4 | 925 | 1,782 | 2,191 |
| Pancreas | 4,064 | 17.6 | 2,071 | 3,262 | 3,644 |
| Larynx | 28,542 | 123.4 | 2,563 | 7,061 | 10,548 |
| Lung | 35,815 | 154.8 | 12,902 | 24,082 | 28,617 |
| Skin melanoma | 38,873 | 168.0 | 2,370 | 6,637 | 9,735 |
| Prostate | 259,788 | 1,122.8 | 32,532 | 83,689 | 122,025 |

**Table 14. Total prevalence (number of cases and rate) and number of prevalent cases at 1, 3, and 5 years after diagnosis. Spain, 31 December 2020, men. (Cont).**

| Tumor type | Total prevalencew | | Prevalence at 1, 3, and 5 years after diagnosis. | | |
|---|---|---|---|---|---|
| | Totals | Rate | < 1 year | < 3 years | < 5 years |
| Kidney (without pelvis) | 44,137 | 190.8 | 4,432 | 11,685 | 17,256 |
| Bladder | 149,795 | 647.4 | 15,901 | 43,852 | 62,462 |
| Brain and nervous system | 6,290 | 27.2 | 1,365 | 2,670 | 3,431 |
| Thyroid | 17,857 | 77.2 | 1,066 | 2,998 | 4,742 |
| Hodgkin lymphoma | 16,182 | 69.9 | 791 | 2,202 | 3,481 |
| Non-Hodgkin lymphoma | 51,915 | 224.4 | 4,199 | 11,023 | 16,139 |
| Myeloma | 8,925 | 38.6 | 1,540 | 3,699 | 5,071 |
| Leukemias | 27,742 | 119.9 | 2,857 | 7,219 | 10,276 |
| Others | 111,720 | 482.8 | 8,800 | 21,995 | 33,982 |
| Total except non-melanoma skin cancers | 1,066,959 | 4,611.4 | 129,355 | 321,174 | 456,366 |

Source: Spanish Network of Cancer Registries

**Table 15. Total prevalence (number of cases and rate) and number of prevalent cases at 1, 3, and 5 years after diagnosis. Spain, 31 December 2020, women.**

| Tumor type | Total prevalence | | Prevalence at 1, 3, and 5 years after diagnosis. | | |
|---|---|---|---|---|---|
| | Totals | Rate | < 1 year | < 3 years | < 5 years |
| Buccal cavity and pharynx | 18,778 | 77.8 | 2,269 | 5,788 | 8,271 |
| Esophagus | 925 | 3.8 | 294 | 536 | 665 |
| Stomach | 12,900 | 53.4 | 1,908 | 4,292 | 5,741 |
| Colon | 100,933 | 417.9 | 10,684 | 28,012 | 40,923 |
| Rectum | 47,272 | 195.7 | 4,861 | 12,793 | 18,946 |
| Liver | 2,982 | 12.4 | 942 | 1,783 | 2,195 |
| Gallbladder and bile ducts | 2,629 | 10.9 | 796 | 1,483 | 1,833 |
| Pancreas | 3,775 | 15.6 | 1,873 | 2,962 | 3,325 |
| Larynx | 3,419 | 14.2 | 356 | 941 | 1,407 |
| Lung | 16,870 | 69.9 | 5,116 | 10,160 | 12,526 |

**Table 15. Total prevalence (number of cases and rate) and number of prevalent cases at 1, 3, and 5 years after diagnosis. Spain, 31 December 2020, women. (Cont.)**

| Tumor type | Total prevalence | | Prevalence at 1, 3, and 5 years after diagnosis. | | |
|---|---|---|---|---|---|
| | Totals | Rate | < 1 year | < 3 years | < 5 years |
| Skin melanoma | 58,673 | 242.9 | 3,573 | 10,243 | 15,562 |
| Breast | 516,827 | 2,139.9 | 32,128 | 91,122 | 144,233 |
| Cervical cancer | 39,758 | 164.6 | 1,805 | 5,011 | 7,605 |
| Uterine cancer | 83,099 | 344.1 | 6,351 | 17,321 | 26,748 |
| Ovary | 27,585 | 114.2 | 2,930 | 7,163 | 10,236 |
| Kidney (without pelvis) | 22,187 | 91.9 | 1,881 | 5,128 | 7,871 |
| Bladder | 32,692 | 135.4 | 3,691 | 9,719 | 14,134 |
| Brain and nervous system | 6,662 | 27.6 | 1,313 | 2,638 | 3,466 |
| Thyroid | 75,471 | 312.5 | 4,080 | 11,737 | 18,849 |
| Hodgkin lymphoma | 12,757 | 52.8 | 609 | 1,710 | 2,722 |
| Non-Hodgkin lymphoma | 48,143 | 199.3 | 3,668 | 9,847 | 14,913 |
| Myeloma | 7,382 | 30.6 | 1,130 | 2,786 | 3,883 |
| Leukemias | 25,461 | 105.4 | 2,085 | 5,349 | 7,627 |
| Others | 50,717 | 210.0 | 5,378 | 13,000 | 19,336 |
| Total except non-melanoma skin cancers | 1,198,193 | 4,961.0 | 97,158 | 255,200 | 384,080 |

Source: Spanish Network of Cancer Registries

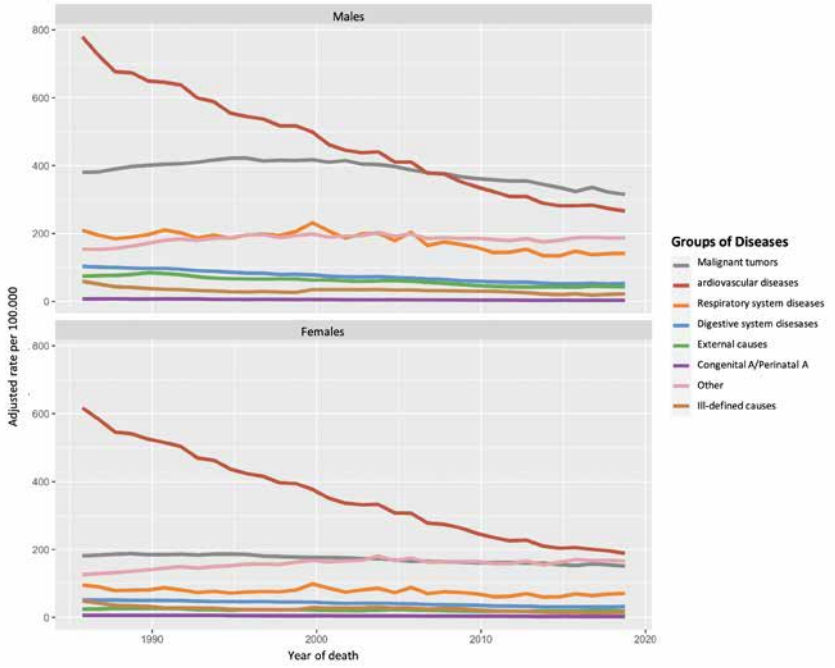
## 1.3.4. Mortality

Cancer continues to be one of the leading causes of mortality in Spain. In 2018, cancer caused a quarter of deaths in Spain, although its distribution is not homogeneous by sex. Of the 108,255 registered deaths, 65,851 (61%) were men and 42,404 (39%) women, that is, one in three deaths in men and one in five in women, were due to malignant tumors.

In total number of deaths, malignant tumors still rank second only to cardiovascular diseases, although age-adjusted cancer mortality rates, combining both sexes and using the European population as standard (for calculation of age-adjusted rates, throughout the entire document, the European standard populations have been used: Eurostat. Revision of

the European Standard Population. Report of Eurostat's task force: 2013 edition. European Commission 2013. https://ec.europa.eu/eurostat/web/products-manuals-and-guidelines/-/KS-RA-13-0280), are very close to those of diseases of the circulatory system. Once again, this comparison is somewhat different by sex: since 2006 tumors have been the leading cause of death in men, and in women the age-adjusted rates of cardiovascular diseases still exceed those of cancer, although they are getting closer and closer **(Figure 10)**.

**Fig. 10. Mortality trend in Spain by large disease groups (1986-2018).**




Source: Department of Epidemiology of Chronic Diseases. National Center of Epidemiology. ISCIII.

In terms of absolute mortality, again for 2018, the tumors with the highest number of deaths were, for men, lung, colorectal, prostate, and pancreatic cancer and, in the case of women, breast cancer, colorectal, lung and again pancreatic cancer. **(Table 16).** In Europe, for that same year, the four tumors causing the highest number of deaths for both sexes combined were also, in this order, lung cancer, colorectal cancer, breast cancer, and pancreatic cancer (IARC. Cancer Today. https://gco.iarc.fr).

**Table 16. No. of total deaths and those caused by the 5 tumor types with the highest mortality, in Spain in 2018**

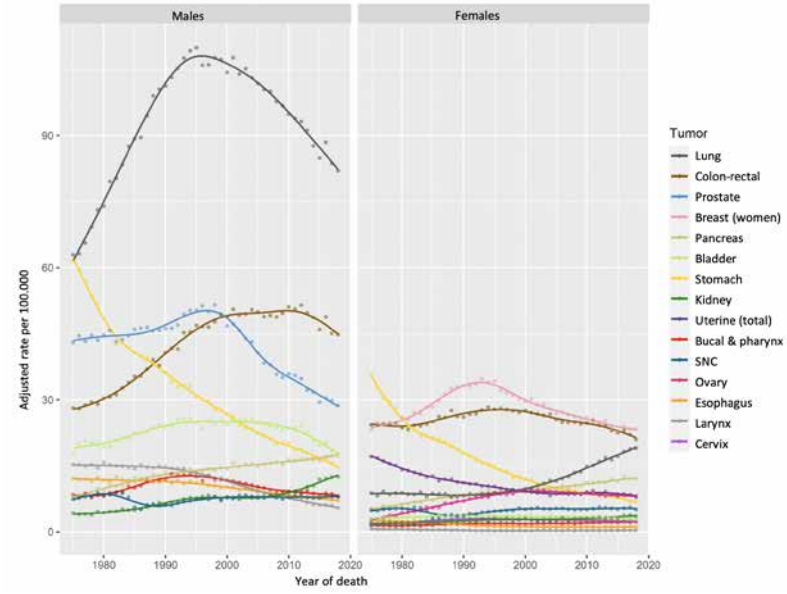
| | Males | Females | Both sexes |
|---|---|---|---|
| **1st** | Lung **17,159 (26%)** | Breast **6,519 (15%)** | Lung **22,104 (20%)** |
| **2nd** | Colorectal **9,200 (14%)** | Colorectal **6,048 (14%)** | Colorectal **15,248 (14%)** |
| **3rd** | Prostate **5,831 (9%)** | Lung **4,945 (12%)** | Pancreas **7,099 (6%)** |
| **4th** | Pancreas **3,739 (6%)** | Pancreas **3,360 (8%)** | Breast **6,606 (6%)** |
| **5th** | Bladder **3,509 (5%)** | Poorly-defined t. **2,282 5%)** | Prostate **5,831 (5%)** |
| **All** | **66,851** | **42,404** | **109,255** |

Source: Department of Epidemiology of Chronic Diseases. National Center of Epidemiology. ISCIII.

## Mortality trend

Although the number of deaths from cancer in Spain continues to be high, the mortality rate from this group of pathologies, studied globally, has decreased significantly **(Figure 11)**, although the evolution is not homogeneous according to type of tumor.

**Fig. 11. Cancer mortality trends in Spain (1975-2018) (European standard population)**




Source: Department of Epidemiology of Chronic Diseases. National Center of Epidemiology. ISCIII.

Figure 11 shows the evolution over time of the age-adjusted mortality rates of the main tumor locations in men and women, in order to have a global idea of how the relative weight between them has changed over time, and to be able to assess the differences in trends between tumors and by sex. This information is complemented by that provided in **Table 17**, which shows the recent mortality trend, providing the annual percentage change between 2009 and 2018 for each cancer, in addition to the rates for those years.

**Table 17. Cancer mortality in Spain: Adjusted rates in 2018 (deaths/100,000) and annual percentage change (%Δ) in the last 10 years (2009-2018) (European standard population).**

| Tumor type | Males | | | | |
|---|---|---|---|---|---|
| | Rate (deaths/100.000) | | | Annual %variation | |
| | 2009 | 2018 | %Δ | IC 95% | |
| Bucal & Pharynx | 9.1 | 8.1 | | -1.5 | (-2.0 ; -1.0) |
| Esophagus | 8.2 | 7.1 | | -1.8 | (-2.3 ; -1.2) |
| Stomach | 20.2 | 14.7 | | -3.4 | (-3.7 ; -3.0) |
| Small intestine | 0.6 | 0.7 | | 3.0 | (1.0 ; 5.0) |
| Colon-rectal | 49.6 | 44.8 | | -1.4 | (-1.7 ; -1.2) |
| Liver | 16.8 | 16.9 | | -0.3 | (-0.6 ; 0.1) |
| Gallbladder | 2.6 | 2.8 | | 1.1 | (0.1 ; 2.0) |
| Pancreas | 15.3 | 17.8 | | 1.1 | (0.7 ; 1.5) |
| Peritoneum | 0.5 | 0.5 | | -0.3 | (-2.4 ; 1.9) |
| Digestive (non spec.) | 1.7 | 1.4 | | -2.6 | (-3.9 ; -1.3) |
| Nasal cavity | 0.4 | 0.3 | | -3.1 | (-5.6 ; -0.4) |
| Larynx | 7.8 | 5.5 | | -4.2 | (-4.8 ; -3.6) |
| Lung | 96.8 | 82 | | -1.9 | (-2.1 ; -1.8) |
| Pleura | 1.0 | 1.0 | | -0.8 | (-2.3 ; 0.8) |
| Chest (others) | 0.6 | 0.4 | | -7.4 | (-9.4 ; -5.4) |
| Bone | 0.8 | 0.9 | | 0.2 | (-1.4 ; 1.9) |
| Connective tissue | 1.4 | 1.7 | | 2.1 | (0.8 ; 3.4) |
| Melanoma Skin | 2.6 | 2.5 | | -0.8 | (-1.7 ; 0.2) |

**Table 17. Cancer mortality in Spain: Adjusted rates in 2018 (deaths/100,000) and annual percentage change (%Δ) in the last 10 years (2009-2018) (European standard population) (Cont.)**

| Tumor type | Males | | | | |
|---|---|---|---|---|---|
| | Rate (deaths/100.000) | | | Annual %variation | |
| | 2009 | 2018 | %Δ | IC 95% | |
| Skin (non-melanoma) | 2.1 | 2.0 | | -0.8 | (-1.9 ; 0.4) |
| Breast | 0.4 | 0.4 | | -0.8 | (-3.1 ; 1.5) |
| Uterus | | | | | |
| Ovary | | | | | |
| Other female genital | | | | | |
| Prostate | 35.1 | 28.7 | | -2.7 | (-3.0 ; -2.4) |
| Testicle | 0.2 | 0.2 | | -1.1 | (-4.2 ; 2.1) |
| Other male genital | 0.6 | 0.7 | | 0.6 | (-1.3 ; 2.5) |
| Bladder | 23.3 | 17.1 | | -3.6 | (-3.9 ; -3.3) |
| Kidney | 8.4 | 12.5 | | 4.8 | (4.3 ; 5.3) |
| Eye | 0.2 | 0.1 | | -1.1 | (-4.6 ; 2.4) |
| SNC | 7.5 | 8.0 | | 0.3 | (-0.2 ; 0.9) |
| Thyrod | 0.5 | 0.6 | | 0.2 | (-1.7 ; 2.2) |
| Other endocrine | 0.5 | 0.3 | | -8.1 | (10.2 ; -6.0) |
| Poorly-defined | 23.4 | 12.7 | | -5.1 | (-5.5 ; -4.7) |
| Lnh | 7.1 | 7.3 | | -0.6 | (-1.1 ; 0.0) |
| Hodgkins | 0.7 | 0.6 | | -2.7 | (-4.5 ; -0.9) |
| Myeloma | 4.8 | 4.7 | | -0.2 | (-1.0 ; 0.5) |
| LLC | 2.5 | 1.9 | | -2.9 | (-4.0 ; -1.8) |
| Leukemia | 10.1 | 9.2 | | -1.0 | (-1.5 ; -0.5) |
| **Total** | **361.9** | **315.3** | | **-1.6** | **(-1.7 ; -1.5)** |

Source: Department of Epidemiology of Chronic Diseases. National Center of Epidemiology. ISCIII.

**Table 17. Cancer mortality in Spain: Adjusted rates in 2018 (deaths/100,000) and annual percentage change (%Δ) in the last 10 years (2009-2018) (European standard population). (Cont.)**

| Tumor type | Females | | | | |
|---|---|---|---|---|---|
| | Rate (deaths/100.000) | | | Annual %variation | |
| | 2009 | 2018 | %Δ | IC 95% | |
| Bucal & Pharynx | 2.0 | 2.3 | | 1.3 | (0.3 ; 2.2) |
| Esophagus | 1.1 | 1.1 | | -0.1 | (-1.4 ; 1.2) |
| Stomach | 8.8 | 6.8 | | -3.1 | (-3.5 ; -2.6) |
| Small intestine | 0.4 | 0.4 | | 2.7 | (0.4 ; 4.9) |
| Colon-rectal | 24.5 | 21.0 | | -1.7 | (-2.0 ; -1.4) |
| Liver | 6.6 | 5.5 | | -1.9 | (-2.5 ; -1.4) |
| Gallbladder | 2.9 | 2.5 | | -1.6 | (-2.3 ; -0.8) |
| Pancreas | 10.5 | 12.1 | | -1.5 | (1.1 ; 1.9) |
| Peritoneum | 0.5 | 0.5 | | -1.2 | (-3.0 ; 0.7) |
| Digestive (non spec.) | 0.9 | 0.8 | | -2.2 | (-3.6 ; -0.9) |
| Nasal cavity | 0.1 | 0.1 | | -0.2 | (-3.8 ; 3.7) |
| Larynx | 0.4 | 0.4 | | 1.4 | (-1.0 ; 3.8) |
| Lung | 13.6 | 19.0 | | 3.3 | (2.9 ; 3.6) |
| Pleura | 0.2 | 0.2 | | -1.8 | (-4.4 ; 0.8) |
| Chest (others) | 0.3 | 0.2 | | -2.2 | (-5.0 ; 0.7) |
| Bone | 0.5 | 0.5 | | 0.6 | (-1.3 ; 2.5) |
| Connective tissue | 1.0 | 1.1 | | 1.1 | (-0.3 ; 2.4) |
| Melanoma Skin | 1.6 | 1.5 | | -0.4 | (-1.4 ; 0.7) |
| Skin (non-melanoma) | 0.8 | 0.8 | | -0.9 | (-2.2 ; 0.4) |
| Breast | 25.9 | 23.4 | | -1.3 | (-1.5 ; -1.0) |
| Uterus | 8.6 | 8.2 | | -0.9 | (-1.4 ; -0.5) |
| Ovary | 8.6 | 7.9 | | -0.7 | (-1.2 ; -0.3) |
| Other female genital | 1.4 | 1.4 | | -0.2 | (-1.3 ; 0.9) |
| Prostate | | | | | |
| Testicle | | | | | |

**Table 17. Cancer mortality in Spain: Adjusted rates in 2018 (deaths/100,000) and annual percentage change (%Δ) in the last 10 years (2009-2018) (European standard population). (Cont.)**

| Tumor type | Females | | | | |
|---|---|---|---|---|---|
| | Rate (deaths/100.000) | | | Annual %variation | |
| | 2009 | 2018 | %Δ | IC 95% | |
| Other male genital | | | | | |
| Bladder | 3.5 | 2.8 | | -2.2 | (-2.9 ; -1.5) |
| Kidney | 3.0 | 3.6 | | 2.4 | (1.7 ; 3.2) |
| Eye | 0.1 | 0.1 | | -0.4 | (-3.9 ; 3.2) |
| SNC | 5.1 | 5.1 | | 0.3 | (-0.3 ; 0.9) |
| Thyrod | 0.7 | 0.7 | | -0.7 | (-2.2 ; 0.9) |
| Other endocrine | 0.4 | 0.2 | | -4.4 | (-6.7 ; -2.0) |
| Poorly-defined | 12.2 | 7.7 | | -4.1 | (-4.5 ; -3.7) |
| Lnh | 5.0 | 4.2 | | -0.7 | (-1.3 ; -0.1) |
| Hodgkins | 0.5 | 0.3 | | -4.7 | (-6.7 ; -2.6) |
| Myeloma | 3.4 | 3.1 | | -0.5 | (-1.2 ; 0.2) |
| LLC | 1.2 | 0.9 | | -3.0 | (-4.2 ; -1.8) |
| Leukemia | 5.4 | 5.1 | | -1.1 | (-1.6 ; -0.5) |
| **Total** | **160.8** | **151.4** | | **-0.7** | **(-0.8 ; -0.6)** |

Source: Department of Epidemiology of Chronic Diseases. National Center of Epidemiology. ISCIII.

As can be seen, in the last 10 years with available data (2009-2018), age-adjusted rates have fallen by 1.6% per year in men, while in women they have fallen by 0.7% per year. In men, the decrease in global mortality is mainly due to the fall in lung, prostate, bladder, larynx and digestive system (buccal cancer and pharynx, esophagus, stomach) cancer mortality rates; in women, it is due to a decrease in colorectal, stomach and breast cancer rates **(Figure 11 and Table 17)**. It is worth noting the significant decrease in mortality in the category of ill-defined tumors, which probably reflects the improvement both in diagnoses in clinical practice and in the quality of death certificates, and the rise in renal tumors in both sexes.

As specific comments for the main tumors, we would highlight the following:

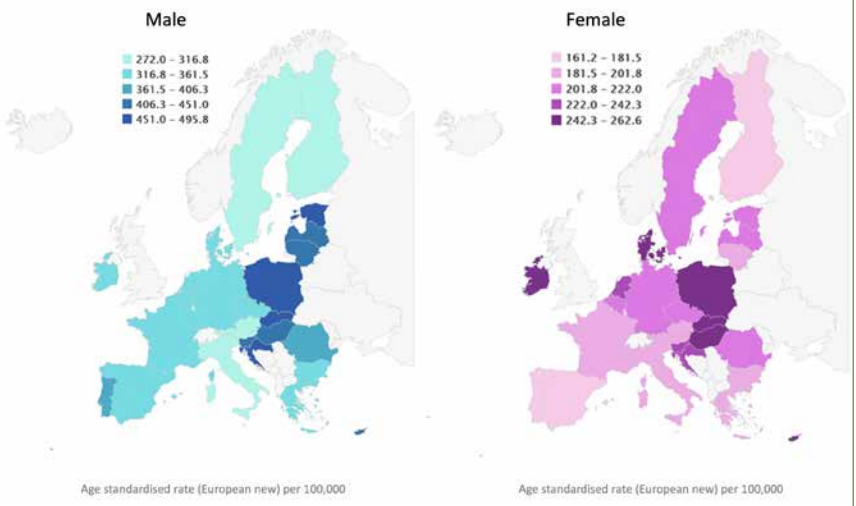
**In men:**

- **Lung cancer:** This continues to be the leading cause of death by cancer in men, although it maintains the downward trend that began in the 1990s. In the last decade, rates have continued to decline at 1.9% per year. This decrease is observed in all the Autonomous Communities, except in Castile-La Mancha and Aragon. In 2018, the highest mortality rates were detected in Asturias and Extremadura, with more than 100 deaths/100,000.
- **Colorectal cancer:** This ranks second in mortality rate. In the last decade, mortality has been decreasing by 1.4% per year in Spain. The highest rates are observed in Extremadura, Asturias, Cantabria, La Rioja and Aragon, with figures above 50 deaths/100,000. The evolution is not very homogeneous territorially: in most Communities mortality is decreasing, especially in the Basque Country, Madrid and the Balearic Islands, with falls of more than 2.5% per year; however, Extremadura, Castile-La Mancha, Aragon and Andalusia did not show decreases in mortality from this cancer.
- **Stomach cancer:** The trend in mortality from stomach cancer is decreasing, with an average decrease of 3.4% per year between 2009 and 2018. This fall is greater than 4% per year in Andalusia, with Asturias, Murcia, Extremadura, Catalonia and Castile and Leon above 3.5% per year, while in the Balearic Islands and Castile-La Mancha the fall is less than 2% and is not significant. Castile-La Mancha and the Basque Country were the communities with the highest rates in 2018.
- **Prostate cancer:** Third tumor location in terms of mortality rates. The highest rates are found in Asturias, followed by Navarre. In the last decade, mortality has decreased by an average of 2.7% per year in Spain, and fell in almost all communities, with decreases of more than 3.5% per year in Madrid, Aragon and Castile-La Mancha. In Melilla, Extremadura and Navarre, on the other hand, the rates rise or are practically stable.
- **Pancreatic cancer:** This is the type of cancer with the fourth highest mortality rate, but, in addition, it is one of the tumors with growing importance, since in the last decade mortality has grown at a rate of 1.1% per year. The highest mortality rates occur in La Rioja, Cantabria and Aragon, while the communities that have experienced the most marked rise are Castile-La Mancha (3.5%) and Cantabria (2.6%). Other regions, such as Extremadura, Navarre, Asturias or Ceuta and Melilla, have registered insignificant decreases in mortality in the last decade.

**In women:**

- **Breast cancer:** This is still the tumor that causes the highest mortality in women, with Asturias, Castile and Leon, and the Canary Islands as the communities with the highest mortality in 2018. However, it continues its downward trend since 1992, with an average annual drop of 1.3% between 2009-2018. This trend varies depending on the Autonomous Community, with the Canary Islands and Cantabria being the Communities with the most marked decrease, while Castile and Leon, Melilla, Extremadura, La Rioja and Castile-La Mancha have increases or minimum decreases in mortality rates, never significant.
- **Colorectal cancer:** Second type of cancer with the highest mortality rate in women, with a decrease of 1.7% per year in the last decade. The geographical distribution of mortality from this type of tumor is similar to that observed in men, with higher rates in La Rioja, Extremadura and Cantabria; in most communities, mortality is decreasing-more than 2% per year in the Canary Islands, Murcia, Castile and Leon, and Madrid, while La Rioja, Navarre and the Basque Country do not show appreciable decreases.
- **Lung cancer:** Mortality from lung cancer is rising by about 3% per year, and it is the one that has experienced the greatest growth in women of all the types of cancer analysed, reflecting the increase in general tobacco consumption in women compared to the cohorts of women of advanced ages. The highest mortality rates from lung cancer are concentrated in the north of the peninsula (Cantabria, Asturias and Navarre) and in the Canary Islands. The rates are growing in all the Autonomous Communities, with highest growth rates in Cantabria, La Rioja, and Melilla.
- **Pancreatic cancer:** As in men, this tumor ranks fourth in terms of the number of deaths and, between 2009 and 2018, its adjusted rates have risen by 1.5% per year. By region, in 2018 the highest rates were detected in Cantabria, the Basque Country and Aragon, and the largest annual increase in the decade studied was also observed in Aragon (4.3%) and Cantabria (3.1%). In contrast, Navarre and La Rioja show insignificant decreases in this period.

**Fig. 12. Age-adjusted cancer death rates in the European Union estimated for 2020 (European standard population).**




Source: ECIS-European Cancer Information System. https://ecis.jrc.ec.europa.eu/index.php.
© European Union, 2020

According to the latest available estimates (ECIS-European Cancer Information System. https://ecis.jrc.ec.europa.eu/index.php. © European Union, 2020), cancer mortality in Spain in 2020 is one of the lowest in the European Union, and only Finland and Malta have adjusted rates lower than those of our country. By sex, in men Spain occupies the 21st place and in women the last position of the 27 countries of the Union. By anatomical location, the distribution of cancers in Spain corresponds to that of most developed countries.

In men, Spain occupies an intermediate situation regarding mortality caused by two of the most important tumors (lung and colorectal), while it is the European country with the second lowest mortality from prostate cancer. In women, last position in breast cancer rates needs to be highlighted.

## 1.3.5. Comments on some specific tumors

The main changes and trends in relation to the epidemiology of the main types of cancer that have occurred in recent years are highlighted below.

### 1.3.5.1. Cancers related to tobacco use

There are at least 15 types of tobacco-related tumors. According to a Surgeon General report, published in 2014, since 1964 the association between tobacco and new types of cancer has been demonstrated. The report concludes that there is sufficient evidence to show that tobacco causes liver and colorectal cancer. Also included is a review of the available evidence on the relationship between smoking and cancer progression and outcomes, including mortality. It is concluded that there is a relationship between tobacco and cancer outcomes and it is therefore recommended that cancer patients quit smoking (U.S. Department of Health and Human Services, 2014).

**Lung**

Lung cancer continues to be one of the most significant tumors and constitutes a major public health problem in Spain. It is estimated that in 2020, a total of 29,638 new cases will have been diagnosed, 21,847 in men and 7,791 in women, occupying the third position in terms of incidence in both men and women.

In addition to its high incidence, its high lethality and low survival rate is noteworthy. In 2018, it was the leading cause of death from cancer in Spain, causing 22,153 deaths (INE. 2019).

Among the risk factors, the most important is tobacco consumption, responsible for 80-90% of cases. The risk of developing lung cancer in smokers is up to 9 times higher than the risk of non-smokers (Gandini S, et al. 2008). Indoor radon exposure, occupation and passive smoking are also proven risk factors (IARC, 2004). Changes in tobacco use may fundamentally determine the epidemiology of this neoplasm.

In recent decades there has been a significant drop in tobacco consumption in Spain in men and an increase in women, stabilizing in recent years (Ministry of Health, Consumption and Social Welfare. 2018).

These changes in tobacco use are beginning to be reflected in the incidence and mortality from lung cancer in both sexes. The incidence in men has been declining in recent years. In women, the incidence increased significantly between 2012 and 2020, going from an incidence rate of 21.6 new cases per 100,000 inhabitants in 2012, to a rate of 29.5 per 100,000 in 2020. This data shows a tendency towards a reduction in the differences in incidence rates between both sexes. This fact is also observed in other tobacco-related tumors.

Occupation, along with exposure to radon in the home, could be the second biggest risk factor for lung cancer (Lorenzo-Gonzalez M, et al. 2020).

According to Rushton et al. (Rushton L, et al. 2012), occupational exposure cause 21.1% of lung cancers in men and 5.3% in women. These include

exposure to arsenic, asbestos, beryllium and its compounds, cadmium and derivatives, hexavalent chromium and derivatives, nickel and its derivatives, soot, aluminum and its compounds, underground work with exposure to radon, crystalline silica, and ionizing radiation (occupational carcinogens classified as Group 1 or 2A by IARC, Monographs programme, 1972-present).

In conclusion, lung cancer continues to be a major public health problem in Spain. The evolution of the prevalence of smoking, together with the lack of effective therapy, show the need to improve the effectiveness of anti-tobacco control strategies and, especially, those aimed at the female population. At the same time, prevention and protection measures for workers against risks related to exposure to carcinogenic agents at work must be reinforced.

**Buccal cavity and pharynx**

As for lung cancer, for all cancers of the buccal cavity and pharynx, tobacco is the main risk factor. Smoking increases the risk of these types of cancer up to six times (Gandini S, et al. 2008). Another risk factor is alcohol consumption, which twice increases the risk, as a unit factor (Turati F, et al. 2013). Acting synergistically, tobacco and alcohol cause a risk 13 times greater than the population of non-drinkers-non-smokers (Hashibe M, et al. 2009). Infection by the human papilloma virus (HPV), especially in the tonsils, the base of the tongue and other locations in the oropharynx, also increases the risk of suffering from this pathology.

The differences in the degree of exposure to these risk factors are decisive and explain the great variability presented in the estimated incidence in the different Spanish registries.

As in other tobacco-related cancers, the ratio between the incidence of cancer in men and women has decreased from 6.8 in the period 1993-1997 to 4.0 in the period 2003-2007 and it is estimated that in the year 2020 it will be 2.8.

**Larynx**

The main risk factors for this cancer are smoking, alcohol consumption and HPV infection (although the latter with more limited evidence) (IARC, 2012a). Tobacco increases the risk 7 times compared to non-smokers (Gandini S, et al. 2008) and alcohol twice versus non-drinkers (Islami F, et al. 2010). Among occupational exposure, the evidence of a direct relationship between laryngeal cancer and work with asbestos, led to its inclusion in the Table of occupational diseases in force in 2015 (Royal Decree 1150/2015, of 18 December).

In relation to the incidence of laryngeal cancer, Spain occupied a medium-high position compared to the European average in 2020

in men, and an intermediate position in women (Ferlay J, et al. 2013). Within the framework of cancer registries in Spain, significant variability was observed between Autonomous Communities. In the period 2008-2012, the age-adjusted incidence rates for the world standard population of men varied between 6.5 per 100,000 in Girona and 10.6 per 100,000 in Ciudad Real. In women between 0.1 per 100,000 in Albacete and 1.08 per 100,000 in the Basque Country (Bray F, et al., 2017). This variability is highly influenced by the prevalence of the aforementioned risk factors.

**Bladder**

Spain shows high rates of incidence and mortality in this type of tumor compared to other EU countries, which makes it advisable to pay special attention to this pathology.

In Spain, it has been estimated that in the year 2020 some 22,350 new cases of bladder cancer will have been diagnosed, 10,071 in men and 4,279 in women. In men it is the fourth most frequent cancer and in women the fifth. In the European context, bladder cancer was the sixth most incident type of cancer in Europe. If we compare the incidence rates by sex, it is noteworthy that the incidence of this tumor in Spain was, in men, the fourth highest, only behind Greece, Italy and the Netherlands.

The most important risk factor for bladder cancer is smoking, to which more than 50% of cases are attributed. Smokers have about three times the risk of non-smokers (Gandini S, et al. 2008). Other risk factors are: occupational exposure to aromatic amines emitted, among others, by the textile industries (Vineis P, et al. 1997) and to polycyclic aromatic hydrocarbons, formaldehyde, asbestos and solvents (Bosetti C, et al. 2007), as well as exposure to other substances in occupations related to leather or aluminum manufacturing (Mannetje et al, 1999). Likewise, environmental exposure to arsenic increases the risk by more than three times in exposed persons, compared to those not exposed (IARC, 2012b).

The differences in the prevalence of smoking cause a high variability of the incidence in different geographical areas of Spain. For the period 2008-2012, the incidence rates adjusted by age to the standard world population varied between 25.2 new cases per 100,000 inhabitants in Cuenca and 43.4 per 100,000 in Navarre in men. In women, they ranged from 2.9 per 100,000 in Cuenca to 8.5 per 100,000 in Navarre (Bray F, et al., 2017).

In addition to the high incidence, in Spain there is a high prevalence of bladder cancer, especially in men, due to the combination of high incidence with survival rates slightly higher than the European average (De Angelis R, et al. 2014; EUROCARE database).

### 1.3.5.2. Cancers of the digestive system

**Esophagus**

At an epidemiological level, this type of tumor is characterized by its low incidence and high lethality, with 5-year relative survival rates of 11.9% in Europe and 9.0% in Spain in patients diagnosed between 2000 and 2007 (De Angelis et al. 2014; EUROCARE database).

Despite this data, in different European countries an improvement in the survival of patients diagnosed with esophageal cancer has been observed, which seems to be associated with an increase in the proportion of adenocarcinomas and with the use of surgery for their treatment (Karim-Kos HE, et al. 2008).

In Spain, this cancer is rare in men and very rare in women. It has been estimated that in 2020 there was an incidence of 2,383 new cases in total, 1,908 in men and 475 in women.

The main risk factor is alcohol consumption with a 50% increased risk in heavy drinkers. Tobacco use is another risk factor for this cancer. These two factors act synergistically, producing a risk increase of up to 100 times in heavy consumers of tobacco and alcohol compared to non-consumers (IARC. 1988). Another known risk factor is obesity, with an increased risk for adenocarcinoma of up to three times in obese people compared to non-obese people (World Cancer Research Fund/American Institute for Cancer Research. 2007). Barrett's esophagus (glandular metaplasia of the esophageal mucosa) also carries an increased risk for adenocarcinoma (Hvid-Jensen F, et al. 2011). Furthermore, the etiological factors vary depending on the histological type of this cancer.

**Stomach**

It is estimated that in 2020 in Spain a total of 7,577 new cases of stomach cancer were diagnosed, 4,703 in men and 2,874 in women. In men it occupied ninth position and in women twelfth. Its incidence has been decreasing in recent decades, going from first place in frequency of digestive cancers to fourth place.

This tumor stands out for its great geographical variability both internationally and in Spain.

Another notable factor is its poor prognosis. In Spain, the net survival standardized by age at 5 years in men diagnosed in the period 2008-2012 was 26.0% and in women 30.3%. In the period 2000-2007, in all the Spanish cancer registries, survival was very similar to the European average (De Angelis et al. 2014; EUROCARE database).

Factors that influence the risk of stomach cancer are listed below:

- Helicobacter pylori infection. The risk of developing gastric adenocarcinoma increases up to three times compared to uninfected people (Huang JQ, et al. 1998).
- Salt intake and salty foods. Salty foods exhibit synergy with Helicobacter pylori infection (World Cancer Research Fund/American Institute for Cancer Research, 2007).
- Tobacco. Up to 1.5 times the probability of developing cancer in smokers compared to non-smokers (Gandini S, et al. 2008)
- Occupational exposure to asbestos (Straif K, et al. 2009).
- Fruit and vegetable consumption as a protective factor (World Cancer Research Fund/American Institute for Cancer Research, 2007).

Exposure to these risk factors is highly influenced by socioeconomic level, this being an indirect variable in the incidence of this tumor.

Other risk factors for gastric cancer, independent of economic level, are pernicious anemia, blood group A, exposure to ionizing radiation, and a history of partial gastrectomy (Krejs GJ. 2010).

**Colorectal**

Currently, colorectal cancer ranks second in frequency in both men and women and first if cases in both sexes are considered. It is estimated that at a European level, the incidence of this cancer in Spain occupies a high position in 2020 and is found in ninth position (ECIS-2020). It is slightly more frequent in men both worldwide, in Europe and nationally.

The incidence of colorectal cancer still has a growing trend in Spain, especially in men and was more intense until the mid-1990s (López-Abente G, et al. 2010). This increase in incidence is basically due to the influence of risk factors and the progressive introduction of early detection strategies.

Known risk factors for this pathology can be classified as non-modifiable and modifiable. Within the non-modifiable risk factors we find age, with 90% of cases diagnosed in people over 50 years of age. Genetic predisposition and underlying diseases, such as inflammatory bowel disease, also increase the risk of suffering from this pathology.

Regarding modifiable risk factors for colorectal cancer, a series of dietary and nutritional habits are included, such as: consumption of red and processed meat, or meat well-done or cooked in direct contact with flame (IARC, 2018); obesity, especially abdominal obesity; alcohol consumption of more than 100 grams per week (Fedirko V, et al. 2011); fibre, fruit and vegetable consumption, as well as dairy or micronutrients such as folates, calcium and vitamin D, have been described as protective factors (World Cancer Research Fund/American Institute for Cancer Research. 2011); and exercise and physical activity act as protectors.

It is estimated that 70% of colorectal cancers are preventable through dietary and nutritional measures alone (Platz EA, et al. 2000). In addition to being able to reduce the burden of the disease based on exposure to different risk factors, screening has shown to be a good control measure for this pathology (Andreu García M, et al. 2009).

Colorectal cancer is an important and still growing health problem in Spain. The increased incidence and survival, as well as the high prevalence of its main known risk factors (inadequate diet, overweight, sedentary lifestyle) and the possibility of an effective early diagnosis, demonstrate the great need to expand the implementation of early detection population-based programmes until they cover 100% of the population between 50 and 69 years of age.

**Pancreatic**

Pancreatic cancer continues to have a low incidence rate but a high lethality. It is the cancer with the worst 5-year prognosis in both men and women, with a net survival rate in Spain of 7.2% and 10.0%, respectively. This high lethality means that mortality from this cancer is almost the same and follows the same temporal trend as the incidence (De Angelis R, et al. 2014; EUROCARE database).

The factors that influence the incidence of this cancer include:

- Tobacco, as the best-known risk factor, with twice the risk in smokers compared to non-smokers (Gandini S, et al. 2008).
- Alcohol consumption, especially in heavy drinkers (IARC, 2012c).
- Obesity and diabetes (Vigneri P, 2009).
- History of previous pancreatitis or gastric surgery (World Cancer Research Fund/American Institute for Cancer Research, 2007; Malka D, et al. 2002).

### 1.3.5.3. Cancers of the reproductive system

**Breast**

Breast cancer is the most frequent malignant tumor in women both worldwide and in Europe and in Western countries, with the risk of breast cancer presenting before the age of 75 being 8% in European women (Cabanes A, et al. 2009). In Spain, it has been estimated that in 2020 some 32,953 new cases of female breast cancer were diagnosed, which represents a rate adjusted to the new European standard population of 123.5 new cases per 100,000 women, which positions Spain in an intermediate place at the European level. Regarding the distribution of the incidence by Autonomous Community in Spain, a certain north-south gradient was observed (Bray et al, 2017).

There are numerous factors that influence the risk of breast cancer. As non-modifiable risk factors, age, endogenous hormonal factors (prolonged exposure to high concentrations of oestrogens, due to early onset of menarche or delayed menopause), as well as family history (Reeves GK, et al., 2009; Schottenfeld D, et al., 2006).

Among modifiable risk factors, hormone replacement therapy (HRT) carries a 20% increased risk compared with women who did not receive this type of treatment (Collaborative Group on Hormonal Factors in Breast Cancer, 1996). In the case of treatment with oral contraceptives, the association is currently more controversial and would depend on the hormonal combinations used (Mørch et al. 2017). Alcohol consumption has been shown to be another risk factor for this cancer, increasing the risk by up to 30% in women who drink compared to non-drinkers.

The evidence of tobacco as a risk factor is more limited and more studies are required to answer this point (U.S. Department of Health and Human Services, 2014). The results of a meta-analysis published in 2015 suggest consistent evidence of a moderately increased risk of breast cancer in women who smoke (Macacu A, et al. 2015).

Childbirth is a protective factor and reduces the risk by 10% compared to women who have not given birth, as does breastfeeding, which reduces the risk by 2% for every 5 months of breastfeeding (World Cancer Research Fund/American Institute for Cancer Research, 2007).

Physical activity has been linked as a protective factor for breast cancer in post-menopausal women, although the evidence is also limited (Monninkhof EM, et al., 2007).

The presence of a higher proportion of body fat increases the risk of breast cancer in post-menopausal women by up to 10% compared to non-obese women. Obese post-menopausal women are at increased risk of developing breast cancer because adipose tissue is a major source of oestrogen in women (World Cancer Research Fund/American Institute for Cancer Research, 2010). Exposure to ionizing radiation in medical diagnostic or therapeutic processes also increases the risk of breast cancer (Stewart et al, 2014).

In 2010, based on epidemiological and experimental studies, the IARC classified night work, which involves disturbances of the circadian rhythm, as probably carcinogenic. The circadian rhythm (the control of sleeping and waking) regulates numerous biological functions and is altered in people who work nights or shifts. Several hypotheses have been proposed to explain the observed associations between night work and breast cancer: exposure to light at night suppresses the nocturnal melatonin spike and its anti-cancer effects; the alteration of the function of the biological clock, which controls cell proliferation; or sleep disturbances, which can weaken the immune system.

The high incidence and survival rate of this tumor mean that the prevalence of breast cancer is the highest, by far, compared to that of the second tumor in women (colorectal cancer). Despite the good results in survival rates, and due to its high impact, both research and prevention, diagnosis and treatment of this cancer should be considered as priorities in cancer plans. The early diagnosis of this cancer, through screening programmes, must continue to be an important element along with other measures such as rapid diagnosis strategies and guaranteeing access to effective therapeutic measures. Finally, research must be continued, both etiological and therapeutic, since a good part of the improvements in the future depend on it.

**Cervical cancer**

Cancer of the cervix has a low incidence in Spain compared to other European countries. At a European level, it was ranked fourteenth (ECIS-2020), compared to seventeenth in Spain (REDECAN).

It has been shown that the main risk factor for this type of cancer is HPV infection (human papillomavirus). But despite being a necessary factor for cervical cancer, it is not a sufficient factor and the presence of risk cofactors is required for the development and progression of this cancer. As an example of risk cofactors we can highlight: a state of immunosuppression, multiple births, smoking and prolonged use of oral contraceptives. Specifically, smoking added to HPV infection causes an 80% increased risk compared to non-smoking women, while the use of oral contraceptives entails a 60% increased risk compared to women who do not undergo this treatment (International Collaboration of Epidemiological Studies of Cervical Cancer, 2007). Other possible cofactors to take into account are concomitant cervico-vaginal infections by Chlamydia and the herpes simplex virus.

In addition to its low incidence, cervical cancer has an intermediate-good prognosis. The age-standardized 5-year net survival of cervical cancer patients diagnosed during the period 2008-2012 was 65.5%. In women diagnosed in the period 2000-2007, age-adjusted 5-year relative survival was 63.9%, one point and a half above the average for European countries (62.4%) (De Angelis et al. 2014; EUROCARE database).

Due to the introduction of HPV vaccination, both incidence and mortality are expected to decrease in the long-term future.

**Uterine cancer**

Unlike that of cervical cancer, the incidence of uterine cancer in Spain is only slightly lower than the European average. In Spain, it ranked fourth among women, the same as at a European level.

As main risk factors we can highlight:

- The hormonal status of the woman, due to variation in oestrogen exposure. Nulliparous women and those older than menopause have a higher risk of endometrial cancer. Specifically, a delay in the onset of menopause is associated with a 120% increased risk.
- HRT at menopause, which causes a 70% increased risk in women who take HRT compared to those who do not.
- Tamoxifen, indicated in a significant proportion of breast cancer cases, increases the risk of endometrial cancer by having an oestrogen hyperstimulatory effect (IARC, 2012d).
- Polycystic ovarian syndrome and some hereditary syndromes such as Lynch syndrome (hereditary non-polyposis colorectal cancer, which increases the likelihood of various cancers) are also risk factors for this cancer (Vasen HF, et al. 2015).
- Obesity creates a 50% increased risk in obese women compared to non-obese women.
- Diabetes also increases the risk of developing this cancer, while physical activity is a likely protective factor (World Cancer Research Fund/American Institute for Cancer Research, 2007).

The trend of incidence rates shows a constant increase since 1993. This is possibly due to the increased prevalence of the main risk factors such as obesity or oestrogen exposure.

**Ovarian**

In 2020 this is the eleventh most frequent type of cancer in women in Spain, with 3,645 new cases (REDECAN). As in uterine cancer, the variability within the framework of cancer registries in Spain is not very high (Bray et al, 2017).

Ovarian cancer is related to hormonal and reproductive risk factors and family history:

- Not having given birth.
- HRT for menopause or ovarian hyperstimulation treatments for fertility also increase the risk.
- The use of oral contraceptives decreases the risk by 30% in women who take them (Collaborative Group on Epidemiological Studies of Ovarian Cancer, 2008).
- Hereditary breast and ovarian cancer syndrome with BRCA1 and BRCA2 mutations (Milne RL, et al., 2008).
- Lynch syndrome (Chen S, et al., 2007).
- Tobacco: increases the risk specifically for one of the histological types, mucinous adenocarcinoma, by 120% in women who smoke compared to non-smokers (Jordan SJ, et al. 2006).

- Obesity probably also increases the risk for this cancer in the same way as a high-fat diet.

Ovarian cancer has a poor prognosis. The 5-year net survival of women diagnosed between 2008 and 2012 was 40.9% (REDECAN). The 5-year relative survival standardized by age in Spain in patients diagnosed during the period 2000-2007 was 36.8%, similar to that of Europe as a whole (37.6%) (De Angelis et al. 2014; EUROCARE database)

**Prostate**

Prostate cancer, for a few years now, has ranked first in frequency of cancers in men both in Europe and in Spain.

Since the introduction and generalization, at the beginning of the 1990s, of the use of the PSA test, there has been a drastic increase in the incidence in developed countries (Larrañaga N et al, 2010).

Age is the main risk factor for this cancer, with an increase in incidence after the age of 50. On the other hand, it has been found that in 5-10% of cases this cancer has a genetic component. Mutations of the BRCA1/BRCA2 genes and the p53 and CHEK2 genes (Li-Fraumeni syndrome) have also been observed (Stanford JL, et al. 2001).

Just as the incidence has increased, survival rate for this cancer has also increased, largely due to the inclusion of a high proportion of tumors with a good prognosis in the case mix of incidence as a result of the use of the PSA test (Sant M, et al. 2009). However, it seems that in recent years survival has stabilized with values around 88-90%.

Due to this same reason, prostate cancer is the one with the highest prevalence in men, with an estimate for 2020 of cases diagnosed in recent years of 1,123 per 100,000 men (REDECAN).

The benefit-risk ratio of prostate cancer screening is not established. There is no evidence that cancers diagnosed from screening have better outcomes than cancers diagnosed from clinical symptoms. On the contrary, the risks associated with early detection and treatment are considered to be significant.

### 1.3.5.4. Haematological cancers

**Non-Hodgkin lymphoma**

It has been estimated that in 2020 a total of 9,188 new cases of non-Hodgkin lymphomas (NHL) were diagnosed in Spain. In men it occupied eighth position compared to other cancers and in women the seventh position.

During the period 2008-2012, a wide fluctuation was shown between the rates adjusted to the world population in both sexes in the cancer registries of Spain (Bray et al, 2017). The variability in Europe was even wider. (Ferlay J, et al. 2013). NHL were more frequent in men than in women.

There are a number of factors that influence the risk of developing NHL, including:

- Alterations in the immune system: immunosuppression present in AIDS (acquired immunodeficiency syndrome), immunosuppressive treatment as a risk factor.
- Infections: Epstein-Barr virus (EBV), HIV, human T-lymphotropic virus type 1 (HTLV-1), Helicobacter pylori, and gastric lymphoma. Furthermore, infection with the hepatitis C virus (HCV) increases the risk of suffering from some types of NHL, especially B-cell NHL (Plummer et al, 2016).
- Some autoimmune-based diseases increase the risk for this cancer: ulcerative colitis, systemic lupus erythematosus, rheumatoid arthritis, Sjögren's syndrome and Hashimoto's thyroiditis (Smedby KE, et al., 2008).
- Occupational exposures to pesticides, trichlorethylene and tetrachlorethylene (IARC Monographs Programme).
- Diagnostic or therapeutic exposure to ionizing radiation (Plummer et al; Stewart et al, 2014).

In Spain, the incidence of NHL increased until 1996, probably due to diagnostic improvements and its relationship with AIDS, among young adults (Marcos-Gragera R, et al., 2010). Since the mid-1990s the incidence rates have remained very similar.

In recent years there has been an increase in survival, probably due to the introduction of rituximab for the treatment of B-cell lymphomas (Sant M, et al., 2014).

**Leukemias**

In Spain, it was estimated that the incidence of leukemia in 2020 occupies twelfth position in men and the thirteenth in women. It is a more common cancer in men than in women.

Risk factors are only known for some specific subtypes of leukemia. Ionizing radiation, with diagnostic, therapeutic or occupational exposure, increases the risk of suffering from any of the subtypes of leukemia with the exception of chronic lymphocytic leukemia (CLL) (Stewart et al, 2014). Occupational exposure to benzene increases the risk of acute myeloid leukemia (AML), with twice the risk in the exposed relative to the unexposed. Another occupational exposure known to increase the risk of developing this cancer is formaldehyde, with twice the risk in the exposed compared to the unexposed, along with ethylene oxide (IARC, 2012e). Fanconi anemia conditions an increased risk of AML in affected people of

more than 400 times compared to unaffected people. Similarly, Down syndrome is also associated with an increased risk for a particular subtype, acute megakaryocytic leukemia (Rosenberg PS, et al., 2003) (Hasle H, et al. 2000). Treatments with the radioisotope Phosphorus-32 or with MOPP chemotherapy (mechlorethamine, vincristine, procarbazine, and prednisone) also increase the risk of AML (IARC, 2001; IARC, 2012d). Tobacco increases the probability of developing AML. There is also sufficient evidence of the relationship between prenatal exposure to tobacco and increased risk of childhood leukemia, especially acute lymphoid leukemia (IARC, 2004).

The prognosis is different depending on the subtype. Thus, the 5-year relative survival rate standardized by age for acute myeloid leukemia (AML) in patients diagnosed during the period 2000-2007 in Spain was 17.5% in men and 21.4% in women, this being the leukemia with the worst prognosis. In contrast, chronic lymphoid leukemia (CLL) had a survival of 73.4% in men and 75.6% in women (De Angelis et al. 2014). The most significant increase in survival between the periods 1995-1999 and 2000-2007 was for patients diagnosed with chronic myeloid leukemia (CML), an increase attributable to the introduction of imatinib (De Angelis et al. 2014; EUROCARE database).

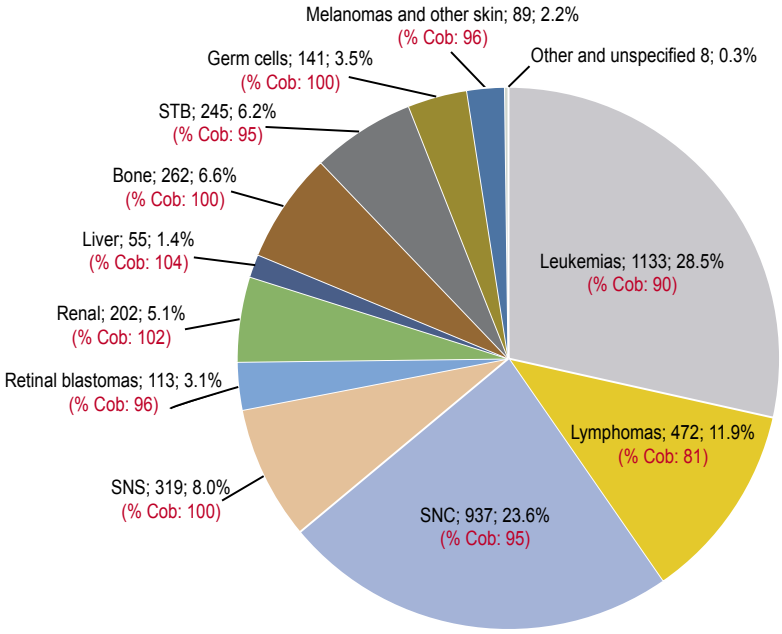
### 1.3.5.5. Childhood tumors

Cancer in childhood and adolescence presents histological, clinical and epidemiological characteristics different from those of adults, which makes it necessary to study it in a separate chapter. The incidence of childhood cancer in Spain is stable, and its mortality has decreased thanks to the success of therapeutic advances.

The predominant histological types in childhood are leukemias, brain tumors, lymphomas and sarcomas **(Figure 12)**, unlike adults, in whom carcinomas predominate. Approximately 158 cases per $10^6$ children aged 0-14 years are diagnosed with cancer per year in Spain **(Table 18)**. Considering the Spanish population of 2018, the annual number of new cases between 0-14 years of age is 1,096; and from 15-19 another 382 cases.

The Spanish Registry of Childhood Tumours (RETI) is the benchmark for knowing the epidemiological data of this disease in Spain. Currently, the RETI has registered 30,118 new cases for the whole of Spain since 1980. Of these, 28,564 (95%) are 0-14 years old and 1,554 (5%) are 15-19 years old; 57% are boys and 43% girls.

**Fig. 12. Percentage of cases registered in the RETI, by diagnostic group. Age: 0-14 years. Period: 2015-2018. Total tumors 3,976**




Source: RETI report, 1980-2018, May 2019

The incidence of childhood cancer in Spain is similar to that of Europe. **Table 18** shows the incidence (0-14 years) in Spain, based on the geographical areas of Aragon, Catalonia, Madrid, Navarre and the Basque Country, where the completeness of the RETI is around 100%, while **Figure 13** shows the incidence in Spain together with that of some European countries (IICC-3).

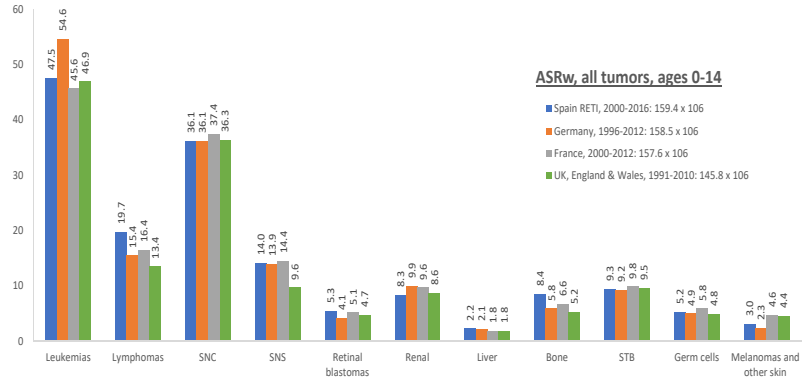
**Table 18: RETI-SEHOP. Registered incidence of childhood cancer in Spain. Areas with high coverage (Aragon, Catalonia, the Basque Country, Madrid and Navarre). Age 0-14, 2000-2017.**

| | % | Specific rates | | | | Crude | ASRw | M/F |
|---|---|---|---|---|---|---|---|---|
| | | 0 | 1-4 | 5-9 | 10-14 | 0-14 | | |
| **ALL TUMORS** | **100** | **257.1** | **196.9** | **129.4** | **130.8** | **157.8** | **160.6** | **1.3** |
| **Leukemias** | 29.5 | 38.5 | 74.0 | 39.9 | 31.1 | 46.5 | 47.8 | 1.3 |
| **Lymphomas** | 12.8 | 4.7 | 12.4 | 22.7 | 27.7 | 20.1 | 19.6 | 2.3 |

**Table 18: RETI-SEHOP. Registered incidence of childhood cancer in Spain. Areas with high coverage (Aragon, Catalonia, the Basque Country, Madrid and Navarre). Age 0-14, 2000-2017. (Cont.)**

| | % | Specific rates | | | | Crude | ASRw | M/F |
|---|---|---|---|---|---|---|---|---|
| | | 0 | 1-4 | 5-9 | 10-14 | 0-14 | | |
| HL | 36.9 | 0.3 | 1.2 | 6.2 | 15.8 | 7.4 | 7.0 | 1.9 |
| NHL (no BL) | 33.4 | 0.9 | 5.0 | 8.2 | 8.1 | 6.7 | 6.6 | 1.9 |
| BL | 26.6 | 0.3 | 5.0 | 8.2 | 3.8 | 5.3 | 5.3 | 4.5 |
| CNS | 22.9 | 40.3 | 43.9 | 35.5 | 28.9 | 36.1 | 36.6 | 1.1 |
| SNS | 8.3 | 84.7 | 19.9 | 3.6 | 1.2 | 13.1 | 14.2 | 1.1 |
| Retinal blastomas 319.4 | 3.1 | 28.2 | 9.7 | 0.5 | 0.1 | 4.9 | 5.4 | 1.0 |
| Renal | 4.9 | 18.9 | 16.5 | 4.5 | 0.9 | 7.7 | 8.3 | 1.0 |
| Liver | 1.3 | 6.2 | 3.8 | 0.9 | 1.0 | 2.1 | 2.2 | 2.0 |
| Bone | 5.6 | 0.9 | 2.4 | 8.1 | 17.2 | 8.9 | 8.4 | 1.4 |
| STS | 6.0 | 15.5 | 8.9 | 7.7 | 10.6 | 9.5 | 9.5 | 1.3 |
| Germ cells | 3.4 | 17.4 | 4.0 | 3.4 | 6.0 | 5.4 | 5.4 | 1.1 |
| Melanomas and other skin | 2.0 | 1.2 | 1.1 | 2.6 | 6.1 | 3.2 | 3.1 | 0.7 |
| Others and unspecified | 0.1 | 0.6 | 0.2 | 0.1 | 0.1 | 0.2 | 0.2 | 1.7 |

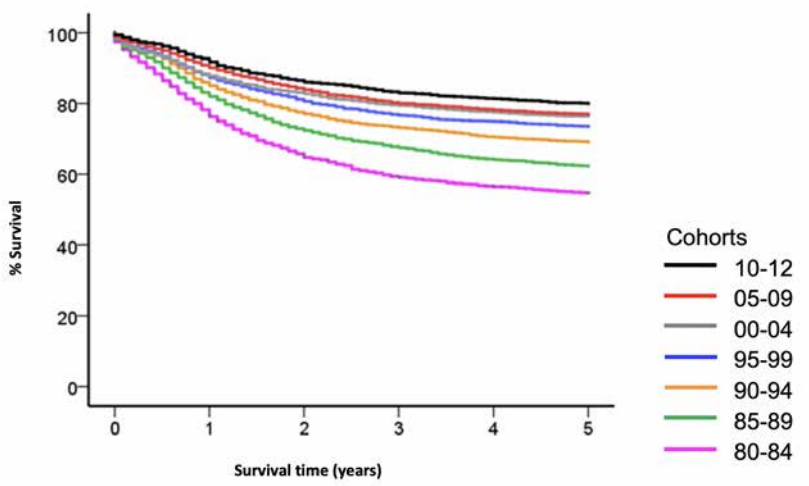
**Fig. 13. Incidence of childhood cancer in Spain (2000-2011) and European countries by types of tumors. World population standardized rate (ASRw), age: 0-14 years.**




Sources: RETI Spain, population base area: Aragon, Catalonia, the Basque Country, Madrid and Navarre. Germany, France and UK: International Incidence of Childhood Cancer Vol-III. Published by RETI

The overall survival of childhood cancer in Spain stands at 80% **(Figure 14)**.

**Fig. 14. RETI-SEHOP. All tumors. Survival at 5 years from diagnosis by cohorts of year of incidence. Age 0-14, 1980-2012.**




Source: RETI report, 1980-2018, May 2019

At present, the secondary effects derived from the treatment of childhood and adolescent cancer are cause for concern, so that in the design of new treatment protocols an attempt is made to modify or reduce the treatment for those children who have a good prognosis, while continuing to intensify treatment in those tumors which are still incurable. The sequelae of childhood cancer treatment are well known: early death, secondary tumors, organic sequelae (cardiac, pulmonary, endocrinological, neurological), psychological and social (difficulty finding a job or obtaining life or health insurance). In short, sequelae that can lead to a lower quality of life than their peers who were not ill (Robinson et al., 2009).

# 1.4. Situation analysis by strategic line

## 1.4.1. Health promotion and cancer prevention

### 1.4.1.1. Health promotion and primary prevention

On 18 December 2013, the National Health System Interterritorial Council approved the Strategy for the Promotion of Health and Prevention in the Spanish National Health System, with the general aim of fostering the

health and well-being of the population by promoting healthy environments and lifestyles and enhancing safety against injuries. In particular, it focuses on a series of factors that are more important from the point of view of addressing chronicity, and that in turn affect the pathology of cancer, such as:

- Healthy eating
- Physical activity
- Smoking
- Alcohol use

Health is influenced by the social, economic and cultural conditions of people's lives, which are known as social determinants of health. The pathology of cancer is related to factors that are part of one's lifestyle, living conditions, work, etc. In turn, the lifestyles that people adopt are influenced by the environment in which they live, work and interact, due to policies regarding urban planning, the environment, employment, and transport, among others. It is therefore necessary to promote living conditions and a physical and social environment in which healthy choices are the easiest to make.

In order to work on health promotion and disease prevention, an approach to the social determinants of health is required:

- It is necessary to work with an intersectoral approach, towards Health in All Policies, promoting coordination between sectors which have an influence on health.
- Have an approach taking into account equity, with the aim of the interventions reaching the entire population, adapting the actions in a proportional manner to the needs of the different population groups.
- It is important to reinforce citizen participation in the decision-making process and in the development of health promotion and prevention actions.

The current Cancer Strategy of the Spanish National Health System is aligned with the objectives, focus and lines of action of the National Strategy for Health Promotion and Prevention in the National Health System, especially with regard to the risk factors that have the greatest impact on the development of cancer. The Health Promotion and Prevention Strategy in the Spanish National Health System proposes a series of actions aimed at gaining health and preventing diseases, injuries and disability. It addresses the promotion of health and a healthy lifestyle in a comprehensive way, emphasizing intersectoral work and looking at settings, as well as equity. The

comprehensive approach that characterizes it refers to the joint consideration of the health determinants for the prevention of chronic diseases that this Strategy addresses (healthy eating, physical activity, alcohol use, smoking, emotional well-being), since these interact producing an effect greater than the sum of the individual parts and an action with greater impact, requiring a joint approach. For this reason, one of the lines of implementation is the development of comprehensive advice on healthy lifestyle in Primary Care, linked to the existing community health promoter resources. Within this framework, a nationwide website on the comprehensive promotion of a healthy lifestyle has been developed with information and training resources for the general population.

A summary of all cancer prevention priorities can be found in the fourth edition of the European Code against Cancer, published in 2014 by the EU, and which is based on an exhaustive review of scientific evidence (Schüz J, et al., 2015). It is presented in a double format, aimed at the public and healthcare professionals. These recommendations are the result of a project coordinated by the IARC of the WHO and co-funded by the European Commission. The recommendations in this fourth edition are the following:

1. Don't smoke. Do not us any type of tobacco or tobacco-related products.
2. Make your home smoke free. Support smoke-free policies in your workplace.
3. Keep your weight within healthy limits.
4. Exercise daily. Limit the time you spend sitting.
5. Eat healthily:

    - Eat plenty of whole grains, legumes, fruits, and vegetables.
    - Limit energy-dense foods (high in sugar or fat) and avoid sugary drinks.
    - Avoid processed meat; limit consumption of red meat and foods with a high salt content.

6. Limit alcohol intake, although avoiding alcoholic beverages altogether is best for cancer prevention.
7. Avoid excessive exposure to the sun, especially in children. Use sunscreen. Do not use UVA booths.
8. At work, protect yourself from carcinogenic substances by following regulations for the protection of health and safety at work.
9. Find out if you are exposed to radiation from naturally high levels of radon in your home and take steps to reduce it.

10. For women:

    - Breastfeeding reduces the mother's risk of cancer. If you can, breastfeed your baby.
    - Hormone replacement therapy (HRT) increases the risk of certain types of cancer. Limit HRT treatment.

11. Make sure your children participate in immunization programmes against:

    - Hepatitis B (newborns).
    - Human papillomavirus (HPV) (girls).

12. Participate in organized cancer screening programmes:
    - Colorectal (men and women).
    - Breast (women).
    - Cervical and uterine (women).

The European Code Against Cancer focuses on measures that every citizen can take to help prevent cancer. The success of cancer prevention requires that government policies and actions support these individual actions.

Along the same lines, the World Health Organization has established a set of nine goals for 2025, within the framework of the fight against chronic diseases (WHO, NCD Global Monitoring Framework, www.who.int). Due to their connection with the prevention of cancer, the following stand out:

1. A 0% increase in diabetes and obesity
2. A 30% reduction in smoking
3. A 10% reduction in physical inactivity
4. A 10% reduction in harmful use of alcohol

**Smoking**

Smoking continues to be the most relevant risk factor for cancer prevention. Both active and passive smoking cause at least 20 different types of cancer, being the main factor responsible for lung cancer, of which it is estimated that between 80-90% of cases are caused by tobacco (Hoffman RM, 2017; Leon ME, et al., 2015; U.S. Department of Health and Human Services. 2014). In addition to this high correlation between tobacco and lung cancer, smoking is also implicated in other types of cancer, such as cancer of the pancreas, esophagus and buccal cavity, larynx, and bladder (Konstantinou E, 2018), among others.

Quitting tobacco brings great health benefits, which begin to be noticed as soon as the person stops. It has been shown that stopping smoking in cancer patients has very significant positive effects, such as a reduction in the risk of the appearance of secondary tumors or metastases, an increase in survival time, a reduction in surgical or postoperative complications, a reduction in complications from radiotherapy and an improvement in the response to it, as well as to the toxicity profile of some drugs. In addition, it produces greater tolerance and resistance to exercise and a significant improvement in quality of life, increasing levels of activity and mobility.

According to the data collected in the National Health Survey of Spain (ENSE 2017), 22.08% of the population aged 15 and over state that they smoke daily, 2.34% are occasional smokers, 24.93% declared themselves ex-smokers and 50.65% have never smoked. Although the proportion of daily smokers continues to be higher in men (25.58%) than in women (18.76%), tobacco use in men compared to 2014 data is one point lower, while worryingly in women it is steady and has even increased slightly (from 18.56% in 2014 to 18.76% in 2017).

In adolescents, the latest data available from the 2018/2019 State Survey on Drug Use in Secondary Education (ESTUDES), show that in 2018, 41.3% of schoolchildren aged 14 to 18 have smoked tobacco at some time in their life, 35.0% in the last year and 9.8% smoke daily. This represents an increase, compared to the 2016 data, of 1 point in daily use, and 3 points in occasional use. By sex, the report indicates that 9.4% of girls smoke compared to 10.3% of boys, with use having increased for both sexes in the last two years. The starting age is equal at 14.1 years. Finally, in 2018, there were 41.4% of schoolchildren living in homes where there is daily smoking.

Looking at this data, we see the trend of smoking differs according to sex, with less of a decrease in the prevalence of daily smoking in women than in men. As such, the latest data indicates that the incidence of lung cancer has increased by 67% in women in the last decade and has decreased by 7% in men.

The number of cases of lung cancer, which has become the cancer with the third highest incidence in women, after breast and colorectal cancer, represents an increase of almost 1% with respect to 2019, compared to a decrease in incidence in men of more than half a point, according to the report *Cancer Statistics in Spain 2020* by SEOM: "Mortality from lung cancer in women is the only one with an upward trend, due to women having taken up smoking from the 70s and 80s onwards. Lung cancer in women born between 1950 and 1960 is becoming evident today, given that we are seeing the consequences of them taking up smoking, while in men the epidemic was earlier and has been declining slightly for years". According to INE data, from 2003 to 2018 mortality from lung cancer in Spanish women increased by 114%.

A recent study indicates that in 2016, there were 56,124 deaths attributed to tobacco use in Spain. Of these, half were attributed to deaths from cancer (65% of which were from lung cancer) (Pérez-Ríos M et al., 2020).

This data reflects the fact that smoking represents a considerable challenge for the current health system, in addition to the significant consequences it creates both economically and socially. It generates high associated costs, both direct due to its high mortality and morbidity, and indirect due to loss of productivity and suffering of victims and family members, among others (Eriksen M, et al., 2015. Jarvis A, et al., 2012).

Thus, reducing the incidence of cancer requires actions to reduce the consumption of tobacco and electronic cigarettes, and exposure to environmental tobacco smoke. To address this issue, the programmes for quitting used by the health system are cost-effective as demonstrated by different studies (Trapero-Bertran, et al., 2018). The planning and implementation of such programmes should contain differential characteristics when they are aimed at men or at women. Analysis of programmes to quit smoking shows that women make more attempts than men to stop, but they relapse more. Among the factors that make quitting difficult, weight gain is given as the main reason, especially relevant in women, as well as intense anxiety and other mental health problems. It is also important to take into account that pharmacological treatments to support quitting show differences by sex in terms of their effectiveness (bupropion, varenicline). These treatments have been included in the Spanish National Health System pharmaceutical service since January 2020.

At the regulatory level, two directives have been approved in the European framework to control smoking:

- Directive 2014/40/EU of the European Parliament and of the Council of 3 April 2014 on the manufacture, presentation and sale of tobacco products and related products, which repeals Directive 2001/37/EC.
- Directive 2003/33/EC of the European Parliament and of the Council, of 26 May 2003, on advertising, promotion and sponsorship of tobacco products.

In the national framework:

- Law 28/2005, of 26 December, which establishes health measures against smoking and regulates the sale, supply, use and advertising of tobacco. Consolidated text with the different modifications. The last modification of this law corresponds to Royal Decree-Law 17/2017, of 17 November, which modifies Law 28/2005, of 26 De-

cember, on health measures against smoking and regulating the sale, supply, use and advertising of tobacco products, to transpose Directive 2014/40/EU of the European Parliament and of the Council of 3 April, 2014, and

- Royal Decree 579/2017, of 9 June, which regulates certain aspects related to the manufacture, presentation and marketing of tobacco products and related products.

The implementation of these regulations, mainly Law 42/2010, of 30 December, which modified Law 28/2005, had a positive impact on smoking prevention policies, as highlighted by both.

*Reports to the General Courts of Evaluation of the Impact on Public Health of Law 42/2010*, of 2012 and 2014, mainly in relation to the reduction of exposure to environmental tobacco smoke (more than 90% in hospitality premises). There have also been decreases in exposure to environmental tobacco smoke in other contexts (Fernández E et al., 2017) and there has been a reduction in the prevalence of daily smokers, from 26.2% in 2009 to 23.1% in 2014 and 22.1% in 2017 (EESE 2014/2015 and ENSE 2017).

At a global level, during the 2010-15 five-year period, Spain led Europe with one of the most advanced regulations on smoking prevention and control, particularly in smoke-free environments. Since then, there has been a certain relaxation in compliance with the regulation, as well as the emergence of new forms of tobacco use and related products, meaning the downward trend observed in the number of smokers in the first years of the legislation is no longer followed. As such, the legislation still needs to be modified to expand the number of places where the use of these products is not allowed, as well as regulate the products that are emerging on the market. This measure must be accompanied by an increase in excise taxes on tobacco products, since it is a proven strategy that makes tobacco less accessible to minors and the most vulnerable of the population.

The WHO proposes the MPOWER initiative (WHO 2018) that establishes six measures to deal with the tobacco epidemic and reduce the number of fatalities from it: Monitor: monitor tobacco use and prevention policies; Protect: protect the population from tobacco smoke; Offer: offer help to quit smoking; Warn: warn of the dangers of tobacco; Enforce: enforce bans on tobacco advertising, promotion and sponsorship and; Raise: increase taxes on tobacco.

**Alcohol**

Alcohol is the psychoactive substance most used by the population in Spain. In 2017, 63% of the population aged 15 to 64 declared having consumed alcoholic beverages in the last 30 days (72% in men and 54% in women)

(EDADES, 1995-2017) and 36.5% had regularly consumed, at least once a week. This habitual consumption is double in men (49.0%) than in women (24.6%) (ENS, 2017).

Alcoholic beverages, as well as ethanol and acetaldehyde associated with the metabolism of alcoholic beverages, have been classified as carcinogenic to humans (Group 1) by the IARC, with a clear dose-dependent risk of developing cancer of the buccal cavity, pharynx, larynx, esophagus, colon-rectum, breast (woman) and hepatocellular carcinoma, without there being a safety limit for alcohol consumption below which it can be said that there is no excess risk (IARC. WHO. Research for Cancer Prevention-IARC. Wild CP, Weiderpass E, Stewart BW. 2020).

The risk does not depend on the type of alcoholic beverage (Scoccianti C, et al., 2015) and there is evidence of a synergistic effect of alcohol consumption together with tobacco use on the risk of suffering cancers of the buccal cavity, larynx, oropharynx and esophagus (Leon ME, et al., 2015).

According to the European Prospective Investigation into Cancer and Nutrition study (EPIC) and the 2017 mortality data from the Spanish Society of Medical Oncology (SEOM), a total of 1,343 deaths from alcohol and cancer in women (3%) and 6,850 in men (10%) were estimated, assuming a total of 8,192 deaths from cancer attributable to alcohol based on actual average consumption in Spain (Schütze M et al., 2011).

The health authorities advise reducing alcohol use using the concept of "low risk" consumption, which is that level of consumption from which mortality increases significantly. Low-risk consumption limits are established below 10 g/day for women or 20 g/day for men in our country (Ministry of Health. Límites de consumo de bajo riesgo de alcohol. Actualización del riesgo relacionado con los niveles de consumo de alcohol, el patrón de consumo y el tipo de bebida. Madrid; 2020). Bearing in mind that for certain gastrointestinal diseases, cancer and injuries there is no safe consumption level (IARC), the best preventive measure, as indicated by the European code against cancer, is to not consume alcohol at all and, in the event that it is consumed, limit the intake.

The WHO has proposed the SAFER initiative that focuses on five areas considered "best investments" for the reduction of alcohol consumption: Raise alcohol prices through excise duties and pricing policies, reduce availability, prohibit or restrict advertising, sponsorship and promotion of alcoholic beverages, measures against drink driving and facilitate the detection of risky alcohol use followed by brief intervention and treatment.

**Physical activity**

Physical activity plays an important role in reducing the incidence of certain cancers, such as colon, endometrial, and breast cancer (WCRF/AICR

2018). Getting 150 minutes of moderate physical activity each week may reduce the risk of breast cancer (Wu Y, et al., 2013; Fournier A, et al., 2014) or colon cancer (Wolin K, et al., 2009; Robsahm T.E, et al., 2013), according to global recommendations on physical activity and health published by the WHO in 2011. It is estimated that physical inactivity causes 9% of breast cancer cases and 10% of colon cancer in Europe (Leitzmann M, et al., 2015). Furthermore, physical activity in cancer survivors has shown positive effects on physical condition, quality of life, anxiety, and self-esteem (Leitzmann M, et al., 2015).

In 2015, the Ministry of Health, Social Services and Equality, within the framework of the Health Promotion and Prevention Strategy in the Spanish National Health System, published the Recommendations for the Population on Physical Activity for Health and Reduction of Sedentary Lifestyle (https://www.mscbs.gob.es/profesionales/saludPublica/prevPromocion/Estrategia/Recomendaciones_ActivFisica.htm). They were carried out jointly with the Ministry of Education, Culture and Sports, through the Higher Sports Council, and are based on existing international recommendations, adapted to the reality of the population in our environment.

According to the ENSE 2017, 36.0% of the population in Spain considers itself sedentary (does not perform any physical activity in their free time): one in three men (31.9%) and four in ten women (40.0%). Considering both main activity and free time, it is estimated that 35.3% of adults (15 to 69 years) do not meet physical activity recommendations, that is 33.5% of men and 37.0% of women.

**Excessive exposure to the sun**

Exposure to ultraviolet (UV) solar radiation has important implications for public health (Lucas R, et al., 2006). There is sufficient evidence on the causal relationship of overexposure to UV radiation and skin cancer, with it being the main preventable cause of both melanoma and non-melanoma skin cancer (Leiter U, et al., 2008; Cogliano VJ, et al., 2011). Skin cancer is the most common cancer in the light-skinned population and its incidence has skyrocketed in recent decades.

One aspect of the recommendations of the European Code that can be highlighted is avoiding the use of UVA ray cabins, when not used therapeutically, due to the clinical evidence of its causal effect on melanoma (eyes and skin) (Cogliano VJ, et al., 2011) with a 59% increased risk of melanoma if initially used before the age of 35, and 20-35% at any age (Boniol M, et al., 2012). In addition, a positive association has been observed between the use of UVA ray booths and squamous cell carcinoma (IARC. 2012).

Exposure during childhood appears to be especially harmful. This fact has been evidenced in some migratory epidemiological studies (Armstrong

BK, et al., 1984; Oliveria SA, et al., 2006). The underlying biological and molecular mechanism for the increased risk of the induction of melanoma at early ages may lie in the depth at which melanocytic stem cells are found in the hair follicle, that is more deeply (more protective) in adults than in pre-puberty (Greinert R, et al., 2015).

In Spain, Royal Decree 1002/2002 expressly prohibits in Article 7 the use of UV ray booths by people under 18 years of age.

**Obesity and excess weight**

Excess fat in the body is associated with various types of tumors, such as tumors of the esophagus, colorectum, gallbladder, pancreas, postmenopausal breast, endometrium, ovary, kidney, and prostate.

In Spain, according to data from the ENSE 2017, of every 100 adults aged 18 and over, 17 are obese and 37 are overweight. In the last 30 years, obesity in adults has multiplied by 2.4, from 7.4% in 1987 to 17.4% in 2017.

An emerging factor of concern is obesity and excess weight in children and adolescents. The data obtained in the ENSE 2017 show that, in children (2 to 17 years), the percentage of the population with obesity for both sexes is 10.3%. Up to 28.6% of this population suffers from obesity or being overweight. Based on this data, it is estimated that currently one in ten children is obese and two in ten are overweight. Regarding the trend according to sex, the prevalence of being overweight or being obese is similar in boys and girls. In order to curb the upward trend in obesity, the Strategy for Nutrition, Physical Activity and Obesity Prevention (NAOS) was drawn up in 2005 by the Ministry of Health, which paid special attention to children.

From a legislative point of view, in 2011, the Food Safety and Nutrition Law was enacted, with initiatives aimed at improving the nutritional status of children in Spain. Another national measure against childhood obesity has been the launch of the Nutrition and Obesity Study Observatory, with the aim of quantifying and periodically analysing the prevalence of obesity in the Spanish population and measuring the progress made in prevention of this disease.

**Food**

In addition to the determining role of diet in relation to body fat, which increases the risk of suffering from certain types of tumors as described above, experimental studies have indicated that diet can influence the process of suffering from cancer in different ways (Norat T, et al., 2015).

Prospective studies have shown that dietary patterns characterized by higher consumption of fruits, vegetables and whole foods, and lower intake of red and processed meats and salt, are associated with a lower risk of can-

cer; and that a healthy diet can improve overall survival after diagnosis of breast and colorectal cancer (Norat T, et al., 2015).

According to data from ENSE 2017, in Spain, 64.2% of the population (from one year of age) consume fresh fruit daily and 40.4% vegetables, salads or greens, daily. The daily consumption of both fruit and vegetables, salads or greens is higher in women than in men and in the more affluent social classes (daily fruit consumption: more affluent class: 72.8%, less affluent class: 59.4%; daily consumption of vegetables, salads or greens: more affluent class: 46.0%, less affluent class: 36.1%).

Furthermore, 9.1% of the population consume soft drinks with sugar on a daily basis (ENSE 2017), less than in the ENSE 2011/12 (12.5%) and than in the ENSE 2006 (17.2%). Some 1.4% declare that they consume fast food daily (ENSE 2017).

**Exposure at work**

According to the European Commission, cancer was the leading cause of occupational mortality in the European Union (EU) in 2015, with 53% of all occupational deaths, making it the greatest risk to the health of workers in the EU (EUROPEAN COMMISSION Brussels, 10.1.2017 COM (2017) 12 final. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. Safer and healthier work for all-Modernization of EU health and safety at work legislation and policies). According to the 2016 Carcinogens Roadmap, around 120,000 work-related cancers occur each year in the EU as a result of exposure to carcinogens at work, resulting in around 80,000 deaths per year.

Work-related cancers can be prevented and avoided by eliminating exposure to carcinogens. The significance of this statement lies in the magnitude of the exposed working population. The European Agency for Safety and Health at Work estimates that more than 32 million people are exposed to carcinogens in the European Union. The monitoring and estimation system of those exposed at work in Europe (CAREX, Carcinogen Exposure Database) indicates that 1 in 5 workers on the continent are exposed to occupational carcinogens (Takala J., 2015).

The tumors most frequently associated with work activity are cancer of the lung, bladder, nasal cavity and paranasal sinuses, liver (angiosarcoma), mesothelioma (involving the pleura, peritoneum, pericardium and tunica vaginalis of the testicle), larynx, colon, pancreas, prostate, kidney, brain, leukemia, lymphomas, skin, as well as soft tissue sarcoma, myeloma and others, and the evidence continues to accumulate.

Among the numerous carcinogens behind these tumors, there are naturally-occuring ones, such as arsenic, asbestos or silica, and artificial ones,

the product of human activities, such as vinyl chloride or pesticides. A great deal of this exposure is also found in other environments and not just in the workplace. Likewise, environmental exposure is also found in places of work. There are examples of miners exposed to radon decay products, health workers exposed to HBV or cytostatic drugs, outdoor workers exposed to ultraviolet radiation or exhaust gases from diesel engines, etc.

It has been calculated that 4% of cancers may be attributed to occupational exposure, with estimates ranging from 2% to 8%. These calculations are average figures for the entire population, including unexposed persons. Among people actually exposed to industrial carcinogens, the proportion of tumors is much higher. All of them can be avoided by taking appropriate measures, unlike cancers associated with lifestyle factors.

In general, preventive measures will depend more on legislative and regulatory actions than on changes in the individual behaviour of people; this normally requires coordination between different authorities and administrations. As such, in the EU, since 1 June 2007, the REACH system (Registration, Evaluation, Authorization and Restriction of Chemical Substances) obliges companies that manufacture and import chemical products to assess the risks derived from their use and to adopt necessary measures for managing any hazards and risks which have been identified. In addition, Royal Decree 665/1997, of 12 May, on the protection of workers against the risks related to exposure to carcinogenic agents at work, and its successive updates, seeks to guarantee that this protection is sufficient.

**Exposure to indoor radon**

Radon is a colourless, odourless and tasteless gas that comes from rocks in the Earth's crust. It is part of a radioactive decay series whose head element is Uranium 238. Radon and its short-lived daughters emit alpha radiation, which impacts the lung epithelium and can ultimately lead to lung cancer if there is prolonged exposure at high concentrations. Indoor radon exposure was declared a human carcinogen in 1988 by the IARC (IARC, 1988). In 2014, radon was included in the update of the European Code Against Cancer, which explicitly indicates "find out if you are exposed to radiation from high natural levels of radon in your home and take steps to reduce them" (IARC, 2020).

Radon exposure is measured in becquerels/$m^3$ and must be done by accredited laboratories. The most important scientific evidence comes from Darby et al., who carried out a study with 21,000 participants. This study concludes that there is a linear and statistically significant relationship between radon concentration and the risk of lung cancer in the general population (Darby S, et al., 2005), so that for every 100 Bq/$m^3$ increase in radon concentration, the risk of lung cancer increases by 16%. This result led the WHO to

establish a maximum concentration of 300 Bq/m$^3$ and a target concentration of 100 Bq/m$^3$ (WHO, 2009). Two recent studies with a large sample size have been published in Spain, finding statistically significant associations between radon and lung cancer. The first was performed on people who have never smoked (Lorenzo-González M, et al., 2019) and the second grouped all the studies carried out by the University of Santiago de Compostela, with more than 3,700 subjects between cases and controls. In addition to a significant association, an interaction was observed between exposure to radon and tobacco use in the risk of lung cancer (Lorenzo-González M, et al., 2020). A recent study by the Ministry of Health, within the National Radon Plan, commissioned the University of Santiago de Compostela to estimate the attributable mortality from lung cancer in Spain concluded that 3.8% of all deaths from lung cancer are due to exposure to radon, this percentage being 7% and 6.9% in Galicia and Extremadura, respectively (Pérez Rios M, Ministry of Health).

The distribution of radon is heterogeneous in Spain. The Nuclear Safety Council estimates in the Radon Map of Spain (with 12,000 measurements) that the most affected Autonomous Communities are Galicia, Extremadura and the Community of Madrid, with 70%, 47% and 36% of their territory with a radon potential higher than 300 Bq/m$^3$, respectively (National Security Council, 2018). The Radon Map of Galicia (www.radon.gal) from the University of Santiago de Compostela, with 4,330 measurements, indicates that 15.6% of Galician households exceed 300 Bq/m$^3$.

At the legislative level, there is a European directive that establishes a limit of 300 Bq/m$^3$ in homes and workplaces (9) together with the need to have a National Radon Plan. The new Technical Building Code of December 2019 establishes the mandatory protection measures against radon in new homes based on the estimated risk of the municipality of presenting high concentrations of radon (BOE, 2019).

**Infections and vaccines**

Of the 2,635,000 new cases of cancer diagnosed in Europe in 2012, approximately 185,000 were related to infection by human papillomavirus (HPV), hepatitis B and C (HBV and HCV) and *Helicobacter pylori* (*H. pylori*). Chronic infection by these agents can cause cancer of the uterus, liver, and stomach, respectively (Villain P, et al., 2015).

*I. Vaccination against infection by the Human Papillomavirus (HPV)*

One of the most notable changes achieved in the period since the approval of the 2009 Cancer Strategy has been the routine incorporation of HPV vaccination in all the Autonomous Communities. Together with vaccination against hepatitis B, it is expected to prevent a large number of cancers in the long term.

Although available nationally, the HPV vaccination coverage figures vary between Autonomous Communities, with coverage being higher in those that have established a school vaccination programme. Among the possible causes of this low coverage are: the loss of registration in transitions between primary and specialized care, the influence of the controversies raised in the benefit/risk ratio of the vaccine, and the existence of groups opposed to its implementation (HPV Working Group 2012, Ministry of Health). On the other hand, a high percentage of Spanish girls who are vaccinated start the regimen but do not complete it or do not receive it at the age established by the health authorities.

To evaluate the results of the implementation of this vaccine in Spain, the ministry prepared and published the *Review of the Vaccination Programme against Human Papilloma Virus* in 2013. According to this report, after tens of millions of doses of vaccines administered worldwide (approximately 3.5 million in Spain since its commercialization) and according to post-marketing surveillance systems, its safety and the absence of causally associated serious adverse effects have been confirmed.

Although the benefit/cost of vaccination has proven to be positive, in the not-too-distant future it is expected to be even better thanks to benefits such as: cross-protection against other oncogenic HPVs not included in the vaccines, community protection, protection against non-cervical cancers and the possibility of reducing the number of vaccine doses.

*II. Vaccination against hepatitis B*

Hepatitis B is a viral infection of the liver that can cause both an acute condition and a chronic disease. It can cause chronic liver disease and carries a high risk of death from cirrhosis and liver cancer. This infection is preventable with the currently available vaccine, which is safe and 95% effective in preventing infection (WHO, 2015).

The age of infection is critical for the infection to become chronic; Newborns diagnosed with HBV have a probability of between 80-90% of developing a chronic infection, while those infected in adulthood have a probability of less than 10% (Chen CJ, et al., 2014).

The CISNS, in 2017, recommended changing the vaccination regimen in the childhood vaccination calendar in Spain. This new guideline consists of the administration of the HBV vaccine to children at 2, 4 and 11 months. Except for the vaccination of children of HBsAg-positive mothers, who will be vaccinated with a 0, 2, 4 and 11-month regimen. The first dose will be administered in the first 24 hours of life together with the administration of anti-HB immunoglobulin.

**Hormonal therapy**

Scientific evidence currently shows that HRT is associated with an increased risk of breast, endometrial, and ovarian cancer. This increased risk

depends on the type of therapy administered, its duration, and the menopausal phase at the start of treatment (Million Women Study, 2003, Friis S, et al., 2015).

Since the year 2000, the consumption and prevalence of use of HRT in Spain have decreased exponentially after the publication of the Women's Health Initiative, the Million Women Study, and the safety communications published by the Spanish Agency for Medicines and Health Products in 2004 and 2008 that advised restrictions on the use of these drugs. Thus, in women ≥40 years old, a defined daily dose DDD/1000h of 33.12 in the year 2000 has changed to 5.32 in 2014 (Baladé L, et al., 2016).

Although HRT continues to be justified under certain medical conditions, the general population, and women and healthcare professionals in particular, should be informed about the risk of cancer and avoid the use of HRT outside of established indications (Friis S, et al., 2015). In order to minimize the possible associated risks, HRT treatment should be used at the lowest effective dose for the shortest possible treatment time for the treatment of climacteric symptoms that negatively affect quality of life (Baladé L, et al., 2016).

**Breastfeeding**

There is sufficient scientific evidence on the protective action of breastfeeding in breast cancer, with a reduction of 4.3% for every 12 months of breastfeeding (Collaborative Group on Hormonal Factors in Breast Cancer 2002) and 2% for 5 months (Norat T, et al., 2008). Protection against breast cancer increases with longer breastfeeding time (Norat T, et al., 2008).

Breastfeeding has also been related to ovarian and endometrial cancer prevention, although with less consistent data (Scoccianti C, et al., 2015; Parkin DM, et al., 2011).

Regarding breastfeeding data in Spain, according to the ENSE 2017, 73.9% of infants are exclusively breastfed with breast milk in the first 6 weeks of life, 63.9% at 3 months and 39.0% at 6 months. This data is variable according to social class based on the occupation of the person).

**Priorities for action**

As a priority for general action in line with promotion and primary prevention of the strategy, pushing forward with interventions and lines of implementation of the Strategy for Health Promotion and Prevention in the Spanish National Health System, of the Spanish Strategy for Safety and Health at Work, of the National Health and Environment Plan, and the measures described in the European Code Against Cancer, has been proposed.

### 1.4.1.2. Early detection

In accordance with Law 33/2011, of October 4, General Public Health screening is understood to be those activities aimed at the early detection of a disease, its diagnosis and early treatment, which are actively offered to the entire population susceptible to suffer from the disease, even if they do not have symptoms or have sought medical help.

Evidence-based cancer screening programmes are essential public health programmes that have great potential to improve health outcomes in the population. When organized effectively, they can prevent cancer, reduce its sequelae and the mortality it causes.

A screening test is not a diagnostic test; its function is to identify people at higher risk of suffering from the disease, who should undergo diagnostic tests to confirm or rule it out. This aspect is included in the *Framework Document on Population Screening*, approved in 2010 by the Public Health Commission of the SNHS Interterritorial Council (SNHSIC). This document establishes the criteria for decision-making with regards to population screening programmes (introduction, modification, etc.), as well as the key requirements for the implementation of these programmes in health services (Population Screening Report of the Commission on Public Health, 2010).

The success of a screening programme depends largely on the quality of each of its phases: identification of the target population, invitation, performance of the screening test, study of positive cases, and treatment of diagnosed cases. The quality of the entire programme depends on the organization. For this reason, the EU Council recommends that cancer screening programmes are implemented as organized, population-based programmes with a quality assurance system (Advisory Committee on Cancer Prevention, 2000), as opposed to the opportunistic screening model, in which participation depends on the initiative of the citizen or professional, and where there is no organization responsible for the different aspects of the screening nor is there an evaluation of the results.

At the European level, there is a consensus on the recommendation of the following screenings (Recommendation of the Council of the EU, 2003/878/CE):

- Screening for breast cancer. Through biennial mammography (50-69 years of age).
- Screening for cancer of the uterus or cervix. By cervical cytology every 3-5 years (25-65 years of age).
- Screening for colorectal cancer. Through biennial faecal occult blood detection in both sexes (50-69 years of age).

Since the formulation of these recommendations, the European Commission has updated them by introducing the possibility of using the detection of the human papillomavirus (HPV) every 5 years as a primary screening test in women from the age of 35 and never before the age of 30 years old (Von Karsa, et al., 2015).

The breast cancer and cervical cancer programmes have been part of the Spanish National Health System service portfolio since its publication in 2006. Colorectal cancer screening was included in the common portfolio of the Spanish National Health System services in 2014 and is currently in the deployment phase of the programmes (Order SSI/2065/2014, of 31 October, which modifies Annexes I, II and III of Royal Decree 1030/2006, of 15 September, which establishes the portfolio of common services of the National Health System and the procedure for updating it).

The main evidence supporting these recommendations is briefly described below.

**Screening for breast cancer**

The high burden of disease together with the benefits of screening and the feasibility of carrying out an early diagnosis programme in the population, has led to breast cancer screening programmes having been applied in most developed countries for several decades now. The participation rate in these programmes in 2017 was over 75%, although there are wide differences between Autonomous Communities. (Network of Cancer Screening Programmes, 2017). Breast cancer screening is carried out in all the Autonomous Communities and in the two autonomous cities of Ceuta and Melilla (through the National Institute of Health Management, INGESA) on a population basis with coverage of more than 90% of the population as its objective, and is included in the common portfolio of Spanish National Health System services with the biennial mammography test for women between 50 and 69 years of age. However, there is a differentiation in the age of the target population, with it also covering the screening of women between 45 and 49 years of age in five Autonomous Communities.

Despite the fact that breast cancer screening is one of the most well-evaluated public health activities, in recent years there has been an intense international debate about its benefits, its adverse effects and the balance between the two. After the review published by the Danish Cochrane Centre (Gøtzsche PC, et al., 2000), which questioned screening for breast cancer with mammography due to methodological problems in many of the reviewed trials, organizations and institutions from different countries have carried out several reviews and meta-analyses in which trials have been re-analysed, taking into account aspects of trial quality. In most recent reviews, there is a consensus on the results of trials in women aged 50-69 years, showing that

mammography screening reduces breast cancer mortality by 20% (Lancet, 2012) in the target population (WHO, 2014). If an analysis is made only of women who undergo mammography, it is estimated that the benefit comes to 25%-35%. A recent review conducted by the IARC in 2015 concluded that there is sufficient evidence that mammography screening is effective in reducing breast cancer mortality in women aged 50 to 69 years and that this benefit outweighs/exceeds the effects of overdiagnosis and other unwanted effects of screening (Lauby-Secretan B, et al., 2015). The European Commission Initiative on Breast Cancer also recommends screening women between the ages of 50 and 69 with biennial mammography (ECIBC. 2020).

**Screening for cancer of the uterus or cervix**

The discovery of the relationship between persistent infection by certain HPV genotypes as a cause of cervical cancer (Bosch FX, et al., 2002) opened the doors to the development of vaccines to prevent this tumor, but also to the possible use of detecting it as a screening test.

Randomized trials have shown that HPV detection has a higher sensitivity compared to cytology, although it has a lower specificity (Ronco G, et al., 2014). This increased sensitivity allows spacing of the intervals between rounds of screening, with a recommended interval of 5 years or more. The lower specificity makes it necessary to carry out a triage test, mainly cytology, in HPV-positive cases, to avoid unnecessary treatments. On the other hand, the data contraindicates the detection of HPV at under 30 years of age due to the considerable frequency of transient infections at these ages. Below this age, screening should continue to be performed using Papanicolaou cytology.

In 2018, the WHO issued a global call for the elimination of cervical cancer as a public health problem. The cervical cancer elimination strategy covers the period 2020-2030 and proposes three fundamental objectives:

- 90% of 15-year-old girls should be vaccinated against the HPV virus,
- 70% of women between the ages of 35 and 45 should be screened with a high-precision test,
- 90% of women diagnosed with cervical cancer should receive treatment and care.

Under these premises, the WHO proposes reducing the incidence to <4 cases/100,000 women. To be highlighted among its conclusions, are that:

- Although HPV vaccination is vital, models show that vaccination alone is insufficient. To achieve elimination in the shortest period of

time and with maximum impact, a combination of intensive vaccination, screening, and treatment should be performed.

- To achieve the goals set for 2030, focused action is required throughout the care continuum, including:
  - Increased HPV vaccination coverage;
  - Greater coverage of screening and treatment of precancerous lesions; and
  - Increased diagnosis and treatment of invasive cancer, as well as palliative treatments.

In Spain, the cervical cancer screening programme is included in the common portfolio of Spanish National Health System services. Historically, this screening has been offered opportunistically to women between the ages of 25 and 65, through cervical cytology every 3 to 5 years.

The introduction of vaccination against HPV, advances in virus detection techniques, the arrival of the screening age of the first cohorts of women vaccinated against HPV and advances in scientific knowledge, reflected in the updating of the European guidelines for quality assurance in cervical cancer screening, raised the need to review the way in which the Spanish National Health System was offering this screening, essential for the prevention of this type of cancer in Spain.

In 2019, and based on the proposal made by the Cervical Cancer Screening Working Group in the Spanish National Health System, the common portfolio of services (*Order SCB/480/2019*) was updated to include the cervical cancer screening programme as a population-based screening programme establishing the following criteria:

a) Target population: Women aged between 25 and 65 years.
b) Primary screening test and interval between scans:

1. Women aged between 25 and 34 years: Cytology every three years.
2. Women aged between 35 and 65 years: Determination of high-risk human papillomavirus (HR-HPV).

The implementation of population screening for cervical cancer will be done progressively so that within a period of five years from the entry into force of the order, all the Autonomous Communities and INGESA must have started this programme and in ten years the coverage, understood as an invitation to participate, will be close to one hundred percent.

The complexity of starting up population screening with adequate quality guarantees and the necessary reassessment of the programme due to the arrival of the screening age of the first cohorts of women vaccinated against

HPV, requires that its implementation be done gradually. In addition, it will be necessary to monitor the evidence regarding the screening guidelines in these women to establish the most appropriate strategy from this population and gradually adapt the programme to the available scientific evidence.

**Screening for colorectal cancer**

The normal evolution of colorectal cancer is characterized by a long preclinical phase of progression from the precursor lesion (adenoma) to invasive cancer, which means this tumor is suitable for screening and, furthermore, in addition to early detection of invasive cancer, reducing its incidence by removing the adenomas after they have been identified (Kuipers EJ, et al., 2013).

Several screening test options are currently available for the early detection of colorectal cancer. There is solid evidence since the late 1990s that screening, through faecal occult blood detection, reduces the incidence and mortality of this tumor, specifically a 15% reduction in biennial screening with a guaiac test in people invited to the screening (Kuipers EJ, et al., 2013; Lansdorp-Vogelaar I, et al., 2012), and that this reduction may be greater in people who actually participate in the programme. In addition, there is reasonable evidence that the detection of faecal occult blood using the most recent immunochemical tests is also effective (Lauby-Secretan B, et al., 2018), and there is solid evidence on its superiority in terms of the detection rate of cancer and adenomas compared to the guaiac test (Lansdorp-Vogelaar I, et al., 2012; Rabeneck L, et al., 2012).

Furthermore, there is data from randomized trials that shows reductions in the incidence (18%) and mortality (28%) of colorectal cancer through sigmoidoscopy screening, even if performed once in a lifetime (Kuipers EJ, et al., 2013; Elmunzer BJ, et al., 2012). A recent systematic review of trials and observational studies in Europe shows a positive effect of colorectal cancer screening by sigmodoscopy or detection of faecal occult blood on mortality from this tumor (Gini A, et al., 2020). Although colonoscopy is the gold standard for examination of the colon and rectum, there is no published evidence from randomized trials on its efficacy in screening. In addition to this lack of data, the greater complexity, invasiveness, and lower acceptance by the population mean that it is not universally accepted as a screening test. Results from ongoing trials will provide this evidence on the advantages and disadvantages compared to faecal occult blood detection (Quintero E, et al., 2012). A recent study showed a greater population detection of advanced neoplasms (including colorectal cancer) using screening rounds with fecal immunochemical tests compared to a round of sigmoidoscopy or colonoscopy and a lower need for colonoscopies (Grobbee EJ, et al., 2020).

Regardless of the screening method used, colorectal cancer screening is one of the most cost-effective forms of screening. This is due to its ability, not only to detect early cases of this pathology, but also to the savings derived from the reduction in incidence (Lansdorp-Vogelaar I, et al., 2011; Lansdorp-Vogelaar I, et al., 2012).

In Spain, population screening for colorectal cancer was incorporated into the common portfolio of Spanish National Health System services in 2014, establishing a period of 5 years for the Autonomous Communities to begin its implementation and 10 years to achieve coverage close to 100%.

Currently, all the Autonomous Communities have begun the implementation of this screening programme, with the performance of a faecal occult blood test in men and women between the ages of 50 and 69, every two years. The Autonomous Communities are in different phases of implementation of the early detection programme for colorectal cancer, with the Basque Country and Navarra being the ones that started it first and consequently have higher coverage. Average coverage in Spain in 2017 amounted to 44% of the eligible population (Network of Cancer Screening Programmes).

Regarding participation in the programme, the participation rate has not yet reached optimal levels; in some programmes it is less than 40% and only two exceed 70%. This data does not differ from the results of the latest National Health Survey (2017) where 71.1% of the population surveyed between 50 and 69 years old recognized that they had never had a faecal occult blood detection test.

**Other cancer screenings**

Prostate and lung cancer screening are two screenings for which there are randomized trials that are studying their efficacy but which still do not have sufficient evidence for recommending their implementation.

*I. Screening for prostate cancer*

Of the possible screening tests, PSA determination is the test that has been considered most appropriate for early detection. However, sensitivity to the commonly used values of 4ng/ml is low, slightly higher than 40%, and decreasing the cut-off point to increase sensitivity significantly decreases specificity, increasing the number of false positives that should be subjected to a biopsy (Holmström B, et al., 2009).

In 2009, the results of two randomized PSA screening trials were published. The publication of these results has not served to reduce the controversy, since although the European trial (Schröder FH, et al., 2009) showed a 21% reduction in mortality from this cancer in men aged 55 to 69 years, this was not seen in the American trial (Andriole GL, et al., 2009). The differences between the two trials and particularly the high percentage of contamination of the control part in the American trial could explain, according

to various authors, the differences between the two trials (Shoag JE, et al., 2020; de Koning, HJ, et al., 2018). Furthermore, these same two trials show considerable values of over-diagnosis (Schröder FH, et al., 2009; Andriole GL, et al., 2009). A recent update of the evidence (Ilic, D et al., 2018) concludes that this screening seems to increase the detection of prostate cancer of any stage, increases the detection of stages I and II and slightly decreases that of stages III and IV. Furthermore, it probably modestly reduces mortality from prostate cancer.

The adverse effects of the treatment of these tumors that penalize the balance between the benefits and the adverse effects of this screening (Moyer VA, et al., 2012; Albertsen PC, 2015) mean that routine screening is not universally recommended. However, in recent years, and in parallel with the appearance of stratified or personalized care in other cancer settings, some authors (Barry, MJ et al., 2018; Heijnsdijk EAM, et al., 2018; Heijnsdijk EAM, et al., 2020) have proposed carrying out studies of screening strategies that clearly reduce adverse effects and which can maintain a considerable part of the potential benefits.

*II. Screening for lung cancer*

The randomized lung cancer screening trials of the 1970s (Fontana RS, et al., 1986) and the most recent of the PLCO (Oken MM, et al., 2011) demonstrated the ineffectiveness of this screening using chest radiography as a screening test. In 2011, the results of the National Lung Screening Trial (NLST) were published, showing a 20% reduction in lung cancer mortality in the 3-year annual screening group with low-dose lung tomography compared with chest X-ray screening. (Aberle DR, et al., 2011). Overall mortality was also reduced by 6.7%.

Based on this trial, some organizations such as the United States Preventive Services Task Force (Moyer VA, 2014) or the Canadian Task Force on Preventive Health Care (Lewin G, et al., 2016) made recommendations in favour of screening for this tumor. In Europe, there have been no official recommendations to implement this screening due, in large part, to the high number of false positives from CT scans with the screening methodology used in the NLST. In our country, the Spanish Network of Agencies for the Evaluation of Spanish National Health System Technologies and Services published a report in 2016 (Sánchez González MC, et al., 2016) which concluded that the low statistical power and heterogeneity existing among the published randomized clinical trials (RCTs) (except the NLST), contributed to not detecting differences between screening and not screening the population at risk. Furthermore, the high rates of false positives and over-diagnosis, in addition to the costs of the diagnostic evaluation, made it advisable not to implement this screening.

The results of the NELSON trial (de Koning HJ, et al., 2020) were recently published. This trial, with a volumetric reading of the nodules and sufficient statistical power in men, showed a reduction in lung cancer mortality in low-dose CT screening of 24% in men and 33% in women, although in this case it is not statistically significant (it must be taken into account that the authors indicate that the study was not specifically designed to demonstrate the effectiveness of screening in women and that the median age of the participants was significantly lower than the median age at diagnosis of lung cancer (Ruano-Ravina et al.)). Other results to highlight are that over-diagnosis is estimated at a maximum of 10% and that the number of positives (cases to be studied) and false positives is much lower than in the NLST.

It should be noted that the Nelson study and the NLST use different screening intervals, as well as inclusion criteria in terms of age range and tobacco use of the participants, which adds uncertainty in the face of potential implementation.

In these two trials, as in the rest of those carried out, the population is a population at high risk of lung cancer: smokers or ex-smokers with a significant history of tobacco use, although with different criteria in the different trials.

The most recent (December 2020) and exhaustive systematic review to date, carried out by the European Network for Health Technology Assessment (EUnetHTA) and funded by the European Union (EUnetHTA OTCA28 Authoring Team, 2020), is not conclusive regarding the benefit/risk ratio of this screening and does not establish a recommendation for implementation at the European level. This review was carried out jointly by Technology Assessment Agencies in Austria, Germany and Spain.

Evidence of benefit and of a positive balance between benefits and adverse effects is an essential requirement, although not sufficient, to consider introducing screening. There are other aspects that it is convenient to know or analyse in order to make a decision about the introduction or not of lung cancer screening in our specific epidemiological and healthcare context. (Field JK, et al., 2019; van der Aalst CM, et al., 2016). Furthermore, the follow-up of indeterminate nodules may have different protocols and make it difficult to quickly confirm or rule out the disease (Ruano-Ravina, et al., Lancet Oncology, 2018). Some of these aspects are:

- Estimating the benefits and adverse effects, the population impact, its cost-effectiveness, the necessary resources and the feasibility of the possible screening strategies (criteria on which to base the inclusion, minimum risk level of lung cancer, ages, etc.) to apply.
- The possibility of a biennial periodicity instead of an annual periodicity in certain cases as suggested by the results of the NELSON

study, which have a significant impact on the costs, cost-effectiveness and feasibility of screening, provide experience on logistical and organizational aspects in our environment (Ruano-Ravina A, et al., 2016). This screening poses organizational and logistical challenges, some unique compared to other cancer screenings, such as the identification of the target population (based on the calculation of pack-years, which requires knowing at what age a person started smoking), about which more information or evidence is needed. Primary Care professionals play a fundamental role in this selection of people, in inclusion, in informed decisions, in integrating quitting smoking and in the coordination of the care process according to the organizational model of the programme.

- It is important to have some initial results of this screening in our specific context: participation, CT positive rate, detection rate, etc. which allow a better estimation and planning of the necessary resources.
- Finally, all the studies agree on the need for this hypothetical screening to include, inall cases, an effective and protocolized intervention for quitting smoking in all participants.

The evidence concerning this screening is continuously evolving and could be modified with the publication of new studies, the use of biomarkers combined with the results of the screening, introduction of the individual basal risk of lung cancer in the participants, or the use of radiomics in the interpretation of the images.

**Genetic counselling in syndromes of hereditary predisposition to cancer**

Another relevant aspect in the early detection of cancer, related to the incidence of hereditary cancer, is genetic counselling for patients. Genetic counselling is the procedure for informing a person about possible consequences for them or their offspring of the results of genetic analysis or screening and its advantages and risks and, where appropriate, advising them in relation to possible options derived from the analysis. This procedure takes place both before and after a genetic test or screening, and even without one taking place.

Approximately 5% to 10% of all diagnosed cancers are hereditary (Nagy R, et al., 2004). The most frequent hereditary cancer syndromes are Hereditary Breast and Ovarian Cancer Syndrome (HBCS) and Lynch Syndrome (LS), formerly known as hereditary non-polyposis colon cancer syndrome. Another less frequent syndrome, but in which the determination of the genetic alteration also directly influences the clinical management of the disease is Familial Adenomatous Polyposis (FAP).

In 2014, care for patients and family members in the area of genetics, which includes genetic counselling and genetic analysis, was included in the Spanish National Health System service portfolio. Genetic counselling will be indicated, among other things, for the diagnosis, diagnostic suspicion or family history of hereditary and familial cancers (Order SSI/2065/2014, of 31 October, which modifies Annexes I, II and III of Royal Decree 1030/2006, of 15 September, which establishes the portfolio of common services of the National Health System and the procedure for updating it. BOE 6 November 2014).

**Priorities for action**

The quality of any screening programme must be ensured based on a series of essential tools such as:

- Sustainable technical capacity to plan, coordinate, monitor and evaluate all the activities of the screening programmes, within the framework of continuous quality improvement, guaranteeing the follow-up of all detected lesions.
- The existence of an information system in the Spanish National Health System that makes it possible to evaluate the entire screening process, as well as its results.
- The application of screening and follow-up protocols that make it possible to maximize the impact on health (decrease in incidence/mortality) while minimizing the adverse effects that screening entails (false-positive results, over-diagnosis, etc.).
- Research into screening.
- Alliances between all those involved.
- Making progress in reducing inequalities in access to screening, guaranteeing equitable and rigorous access for the entire susceptible population.

**Priorities for action related to breast cancer screening**

Promote the performance of screening mammograms only within the population programmes established in the Autonomous Communities and with the bases included in the Spanish National Health System Service Portfolio, discouraging them happening outside these programmes (opportunistic screening or in parallel health screening systems, etc.).

**Priorities for action related to colorectal cancer screening**

Extension of the programmes in all the Autonomous Communities to the entire target population. The Ministerial Order of 2014, which modifies the portfolio of common services of the Spanish National Health System, estab-

lished that the implementation of population screening for colorectal cancer will be done progressively so that within five years from the entry into force of the order, all the Autonomous Communities, the INGESA and the official mutuals would have started this programme, and in ten years, the coverage, understood as an invitation to participate, would be close to 100%.

**Priorities for action related to cervical cancer screening**

- Transition from an opportunistic programme to a population programme, in accordance with the criteria established in the common portfolio of services and including quality control of the entire process.

**Priorities for action related to genetic counselling**

- It must be carried out by qualified personnel in centres accredited by the competent regional or state authority that meet the quality requirements established by law for this purpose.
- Guarantee equitable and rigorous access for the entire population susceptible to receiving genetic counselling, within the framework of multidisciplinary care, and to all the activities that entails.

## 1.4.2. Health care

### 1.4.2.1. Care model

The processes of diagnosis and treatment in oncology are of remarkable complexity given the number of specialties and levels of care that are involved in them, which makes the organization of cancer care a challenge for health systems. If we add to this the need to integrate advances from research, the results of which are a very relevant factor for progress in improving therapeutic results, as well as technological innovation, which is transforming entire areas of cancer diagnosis and treatment, the result is the need to establish shared criteria for care models that can meet the challenge of offering the best possible cancer care according to available resources and with the ability to integrate innovation into care practice (WHO Report on Cancer, 2020).

The multidisciplinary organization of cancer care is a key factor in the quality of care that is associated with better clinical results (Heuvelmans MA, et al., 2015). Together with this factor, the aspects of care coordination of the circulation of patients between levels of care (primary care and hospital, between hospitals in the care network and with social health care), as well as the type of care given to patients after treatment are aspects that have been consolidated at the European level as essential for high-quality

cancer care (WHO, 2020; Albreht T, et al., 2017; European Partnership Action Against Cancer consensus group, 2014). Finally, another aspect that has become more relevant in the last decade is attention to rare tumors, which make up 25% of all cancer incidence in Europe, when considered together (Gatta G, 2019).

Therefore, the years that have elapsed since the previous edition of the cancer strategy have consolidated the evidence on these issues and it is essential to consider them when establishing care priorities. They are analysed below in order to have a more complete vision of the main changes that have occurred, the challenges that arise and, based on them, to be able to establish priorities for action for the coming years:

**The ageing of the Spanish population will contribute to a greater impact of cancer in our society**

The ageing of the Spanish population will have a double consequence on the impact of cancer in our society. Firstly, an increase in cancer cases, given the direct relationship between age and the increase in the incidence of cancer. This fact will cause a clear increase in the resources needed to provide healthcare to these patients and, therefore, affects the financial sustainability of the healthcare system in the medium and long term and, in turn, may have an impact on access to therapeutic innovation in the country. The second factor has to do with the fact that cancer cases diagnosed in elderly patients have a very high prevalence of concomitant chronic pathologies and a tendency to increase (Aarts MJ, et al., 2015). The elderly with cancer (in the age groups over 75 years) is currently the age group with the highest percentage growth in relative terms. This group of elderly patients with comorbidities forces us to reconsider therapeutic strategies towards the personalization of therapeutic decisions in a multidisciplinary framework.

This personalization can be approached through systematized geriatric evaluations that make it possible to adapt the therapeutic decision to the specific clinical situation of each patient. In fact, oncogeriatrics is becoming established as a field of knowledge of its own in this type of patient (Brechot JM, et al., 2013; Antonio M, et al., 2018; Antonio M, et al., 2017). At the same time, this group of patients poses new follow-up challenges, given the need to address the greatest social problems.

In summary, these two factors combined will cause an increase in the number of patients and their complexity in the therapeutic decision, a fact that needs to be analysed in detail in the care organization to promote the best appropriate oncological care for each clinical situation according to existing resources.

Added to these two factors, the growing ageing of the population implies that diagnoses of cancer patients occur in older family contexts, with

a worrying increase in single-person households (the longer life expectancy of women feminizes this aspect of greater vulnerability and need for care), where there is no figure of the main caregiver, or, families made up of a married couple, where both members are elderly and neither of them can act as the other's main caregiver, once the illness is diagnosed.

This fact can generate serious situations of lack of protection and lack of support for the patient, problems that can directly affect adherence to treatments (Antonio M, et al., 2018) and/or their state of health.

According to the continuous home survey that the INE performs, in 2019, there were 4,793,700 single person homes in Spain. Of this figure, 41.9% corresponded to people aged 65 or over who lived alone. And, of these, 72.3% were made up of women. The report on Cancer and Loneliness of the AECC Cancer Observatory projects an estimate of 24,014 people with cancer over the age of 75 living alone in 2020 (Cáncer y Soledad. Observatorio AECC). We can highlight that this trend is growing, since it has been increasing in recent years.

It is essential, therefore, to take this factor into account when proposing a comprehensive intervention, due to the great risk and vulnerability generated in the patient and the family by not being able to have the non-formal care necessary during the disease process.

**Primary care and the cancer patient**

Accessibility, coordination, comprehensiveness and longitudinality are the basic attributes that mark the quality and efficiency of primary care. The primary care team facilitates adequate and timely patient access to specialized care, and sometimes, with the added value of protecting the patient against unnecessary or inappropriate interventions. In a context of growing need for health care, of necessary stabilization of health costs and adaptation of care to the care preferences of each patient in terms of proximity to their home, primary care is being promoted as a priority strategy for a large part of health care (Rubin G, et al., 2015).

One of the aspects little treated in the management of cancer care in our country is the coordination between the different levels of care (hospital and primary care) in the comprehensive care of cancer patients, that is to say, in prevention and diagnostic, therapy and follow-up phases. The role of the hospital in diagnostic confirmation and active treatment is not debatable, but it may be in the follow-up of all cancer cases.

From primary care, optimal care for patients with cancer includes prevention, detection of recurrences and possible secondary neoplasms, attention to comorbidity, and addressing the delayed and late effects of cancer treatment. In fact, the profile of cancer patients in our country is a user of primary care with a high degree of satisfaction for their other health prob-

lems (Ferro T, et al., 2014). In addition, many patients do not have health problems that require specific monitoring by the oncology unit. Given these premises, options related to the follow-up of patients with a low risk of recurrence in primary care which are common in other countries should be considered, modifying the role of primary care in follow-up.

The Lancet Oncology Commission (The Lancet Oncology Commission, 2015) has identified a series of aspects that show the benefits of the participation of primary care in the care process of cancer patients. Table 19 sets out as an indication the main challenges involved in caring for cancer patients that can be satisfactorily addressed with the participation of primary care in the care pathway (The Lancet Oncology Commission, 2015).

**Table 19. Challenges of health care in cancer and possible solutions with greater involvement of primary care**

| Care challenges | Possible solutions from primary care |
|---|---|
| The incidence of cancer is increasing and the number of surviving cancer patients is growing substantially. | Integrate primary care with specialized care, particularly in follow-up, while complying with standardized work guides/protocols that improve care practice. |
| Primary prevention is not fully consolidated, despite its potential ability to reduce the incidence of cancer. | Develop effective models to incorporate primary prevention into routine practice. |
| There are variations and inequalities in the use of cancer screening. | Implement good practices, especially in the contribution of primary care teams in the promotion of population screening programmes. |
| The symptoms that indicate a possible diagnosis of cancer in primary care are very common, which contrasts with the low predictive values of confirmed cases of cancer. These symptoms with low positive predictive values for cancer pose a great challenge. | Develop and systematically apply electronic support for clinical decisions in the selection of patients who require urgent evaluation, together with tools that allow cognitive error to be minimized.<br>Develop models that allow access to diagnosis based on risk levels. |
| Follow-up in these patients not only requires experience in cancer, but also in its physical and psychological sequelae. | Develop integrated models that include ongoing training programmes for primary care teams and work in networks or broad associations that allow the exchange of knowledge. |
| Those people who die from cancer want the process to be at home and with maximum comfort and well-being. | Integrate primary care with palliative care, through the ongoing training of professionals and the breaking of existing logistical barriers in primary care. |

Source: Adapted from The Lancet Oncology Commission. 2015

Patients followed exclusively by the primary care team are less likely to adhere to the recommended cancer follow-up plan, while those followed exclusively by the oncology service are less likely to receive good non-cancer care.

When the follow-up is carried out by both teams in a shared way, patients are most likely to receive adequate care (Meadows AT, et al., 2009).

In Spain, experiences in hospital-primary coordination have begun. There is an out-of-hospital oncology consultation within the specialty centres of Department 9 of the Valencian Community. In Catalonia, pilot experiences are being developed in the follow-up of patients with different types of cancer by primary care with a guarantee of immediate hospital return and in accordance with both the follow-up protocol and the risk of recurrence criteria. Castile and Leon has started a pilot project for a care plan for long-term cancer survivors, framed within the primary-hospital coordination programme, in which the creation of a Long-Term Survivors Unit in Oncology stands out, staffed by a coordinating medical oncologist (liaison oncologist) that constitutes the primary care contact point.

However, the challenge remains to define what should be the relationship model between primary and hospital care in the field of cancer care that includes aspects that are reviewed in the following paragraphs, such as rapid diagnosis of cancer in patients with symptoms of high suspicion, post-treatment follow-up or information about the disease to name but a few. This model should be defined with scientific partners, health service managers and patient associations.

**Multidisciplinary care in cancer care**

The complexity of the diagnosis and treatment of cancer derives from several factors, such as the involvement in it of different medical specialists, and nursing, pharmacy, psychology or social work professionals, and the need to make consensual decisions at each stage of care. For this reason, the model of care through a multidisciplinary team has been the subject of a European consensus among scientific societies, patient associations, and experts within the framework of the European Partnership Action Against Cancer (EPAAC) developed between the member states and the European Union (EPAAC, 2014). This model is also proposed within the framework of European reference centres for rare pathologies.

There is a very broad consensus on the evidence of the greater effectiveness both regarding the care process, as well as coordination between specialties and in the clinical results of the multidisciplinary model (Prades J, et al., 2015). Its implementation is extensive in countries such as the Netherlands or Belgium (Walraven JEW, et al., 2019; Dubois C, et al., 2018), although there is debate about aspects of its practical application. There is total agreement on the need to discuss complex cases and, possibly, those less complex cases in which the application of the care protocol is direct, can simply be communicated to optimize the care time being given.

In order to prevent or alleviate possible failures in the communication and/or coordination of the different professionals during the process, it is important to highlight the need to create the role of the health professional who acts as a case manager. Through this type of role, coordination between the different resources, both health and social, is guaranteed as they are thoroughly known, with the case manager being able to offer a response to the different information needs, health, care, psychological, family, work, relational, economic, etc., arising throughout the disease process, and mobilizing those existing resources that are necessary. This professional must be an integral part of the tumor committee or multidisciplinary unit, with this being the model in which it reaches its maximum effectiveness (Prades J, 2011).

**Centralization of complex treatments and/or low-incidence tumors**

There is sufficient scientific evidence to establish a relationship between mortality and/or morbidity and the volume of activity of hospitals and professionals for certain medical and surgical procedures (Birkmeyer JD, et al., 2002; Bassi C. Updates Surg., 2016; Gietelink L, et al., Ann Surg.2016; Hata T, et al., Ann Surg.2016; Hewitt M, et al., 2000; AHRQ. 2002; Gandjour A, et al., 2003; Smith TC, et al., 2003; Vonlanthen R, et al., 2018).

Despite this scientific consensus, there are numerous barriers to its practical application. In the first place, there would be the selection of the criteria to establish the clinical experience, the most used criterion being the minimum volume of cases. Although apparently easy to apply, in practice there are problems as to whether the volume should measure the activity of the surgeon, the multidisciplinary team, or the centre; in addition, the minimum thresholds differ depending on the study and, frequently, the volumes are selected arbitrarily or based on statistical criteria (quartiles or tertiles). Another added problem, in health systems with very low volumes of activity in numerous hospitals, is the possible interannual variability of data and the difficulty of categorizing centres when establishing a minimum threshold. Finally, the volume is only an indicator that can be associated with the quality of the clinical results, but this relationship is not necessarily linear, therefore, together with the aforementioned limitations, the difficulties in establishing the minimum volume are quite notable. Despite these difficulties, the experience of numerous European countries shows that it is feasible to apply concentration measures that are associated with an improvement in clinical results.

Experiences have been described in our country that have led to centralizing surgical treatments or rare tumors (Manchon-Walsh P, et al., 2011, Manchon 2017, Prades 2018), which demonstrates the feasibility of the proposal. In fact, patient groups for those affected by rare tumors have proposed moving in this direction, as is the case of patients with sarcomas. Similarly,

there are health organization models in other countries, such as the previously mentioned case of the INCa in France, which has carried out a centralization of care for patients with rare tumors and has established a minimum volume of cases for certain surgical procedures. Other models that go in the same direction with the involvement of scientific societies are the Netherlands, Germany, England and Wales (EJSO, 2012). However, there is no consensus on what the minimum level of cases should be for each procedure, due to the organizational differences between countries and the different methodologies used in the observational studies carried out. The volumes proposed in the document *Care Units in the Cancer Area: Standards and Recommendations for Quality and Safety in the Area of Cancer* (Informes, estudios e investigación 2013. Ministerio de Sanidad, Servicios Sociales e Igualdad), are the following:

- **Multidisciplinary esophageal-gastric cancer unit/team:** Requires a reference area of at least 1 million inhabitants and the performance of a minimum of 60 esophageal-gastric cancer procedures.
- **Colorectal cancer multidisciplinary unit/team (liver metastases):** The population scope for a unit that also performs resections of liver metastases must be greater than 2 million inhabitants.
- **Colorectal cancer multidisciplinary unit/team:** The multidisciplinary unit requires a minimum activity of 60 new cases of colorectal cancer per year and an experience for each surgeon of 20 surgeries per year with therapeutic intent. The population scope for a unit that also performs resections of liver metastases must be greater than 2 million inhabitants. If the unit is specialized in rectal cancer (multidisciplinary rectal cancer unit), it requires a minimum volume of activity of 50 procedures per year.
- **Multidisciplinary neuro-oncology unit:** The multidisciplinary unit requires a catchment area of at least 500,000 inhabitants and to perform a minimum of 50 procedures/year on CNS tumors.
- **Lung cancer multidisciplinary unit/team:** The multidisciplinary unit must have a minimum reference area of 500,000 inhabitants, if thoracic surgery is available. In reference areas with smaller populations, the participation of the thoracic surgeon in the tumor committee, as well as that of the radiation oncologist, is very relevant.
- **Surgical treatment of pancreatic cancer** with radical intent (in the English national system, a standard of 1 pancreatic cancer unit per 2 million inhabitants has been defined).

The 2019 Instruction for the Reorganization of Highly Specialized Oncology Care of the Catalan Health Service included the following minimum

volumes of cases for each procedure that must be carried out by reference hospital centres **(Table 20)**.

**Table 20. Surgical procedures to be carried out in highly specialized units integrated into reference hospital centres and minimum volume of cases with radical/curative intent for each procedure**

| Surgical procedures | Minimum number of annual procedures |
|---|---|
| Esophageal cancer | ≥ 11 |
| Stomach cancer | ≥ 11 |
| Pancreatic cancer | ≥ 11 |
| Surgical treatment of liver metastases | ≥ 25 |
| Rectal cancer | ≥ 18 |
| Surgical treatment of lung cancer | ≥ 50 |
| Surgical treatment of benign and malignant brain tumors | ≥ 50 |

Source: Instruction 01/2012 of 10 January 2012. Reorganization of highly specialized cancer care. Catalan Health Service.

These figures are located in the lower part of the range of minimum volumes of different countries and European scientific societies. For example, the German Cancer Society proposes the following minimum volumes to certify centres for each surgical procedure (www.krebsgesellschaft.de):

- Neuro-Oncology: 100 cases with diagnosis of primary tumor.
- Stomach: 30 patients with a diagnosis of primary tumor and 20 surgeries as a minimum.
- Rectum: 20 procedures annually.
- Pancreas: 20 surgical procedures for primary tumor of the pancreas.

In this context, the Centres, Services and Reference Units (CSUR) programme for the Spanish National Health System should be highlighted, where criteria for designation of centres are defined, agreed by the different professionals involved and the corresponding Scientific Societies (https://www.mscbs.gob.es/profesionales/CentrosDeReferencia/home.htm).

Likewise, a procedure was legislated for sending patients from other Autonomous Communities to the CSURs when they require highly specialized health care. This derived care is compensated through the Health Cohesion Fund.

The criteria applied for designating the CSUR-Spanish National Health Service respond to experience criteria (volume of activity; basic and continuous training of team members; training of other professionals, patients and families; research), multidisciplinary team care, continuity of care between ages and levels of care, specific resources (human, equipment), resources from other units or services necessary for adequate care provided in the CSUR, patient safety, patient registry, indicators of procedure and clinical results, and information system.

These criteria are verified through the accreditation procedure, through on-site audits, prior to designation. Every year, since 2009, the designation criteria referring to the activity are monitored, as well as the procedural indicators and results previously agreed with the CSUR professionals.

The Ministry of Health, at the proposal of the Interterritorial Council and prior to accreditation of the centres, has so far designated CSUR for the care of the following pathologies or oncological procedures:

- Childhood eye cavity tumors (3 CSUR)
- Childhood intraocular tumors (4 CSUR)
- Adult intraocular tumors (3 CSUR)
- Adult eye cavity tumors (3 CSUR)
- Total electron irradiation in mycosis fungoides (2 CSUR)
- Adult high and intermediate risk germ cell tumors which are resistant to first-line chemotherapy (4 CSUR)
- Pediatric allogeneic hematopoietic stem cell transplantation (9 CSUR)
- Complex pediatric neurosurgery (includes CNS tumors in children) (5 CSUR)
- Genetic neurocutaneous syndromes (phakomatoses) (2 CSUR)
- Neuroblastoma (3 CSUR)
- Childhood sarcomas (4 CSUR)
- Adult sarcomas and other musculoskeletal tumors (7 CSUR)
- Renal tumors with vascular involvement (4 CSUR)
- Complex hypothalamic-pituitary pathology (children and adults) (includes pituitary and hypothalamic tumors) (4 CSUR)

Likewise, it is planned to define CSUR for the care of adrenal cancer (adults and children), complex thyroid cancer (adults and children), pediatric kidney cancer, multiple endocrine neoplasms and complex neuroendocrine tumors (adults and children).

In summary, it would be relevant to combine the concentration of specific therapeutic procedures taking into account the pathology as a whole. It

would also be important to move towards pathology reference centres from a multidisciplinary approach, as an organizational instrument within each Autonomous Community, which allows clinical results to be improved and reduces their variability in our country.

**Networked cancer care**

The creation of networks fulfils a double objective, 1) promoting equity in access to quality care, achieved through coordination and improvements in cost-effectiveness and 2) exchange of information with the patient and with the centre (Borrás JM, et al., 2014). It is important to involve primary care professionals in this type of network if the aim is to cover the entire patient circuit (from prevention and detection to treatment and management of the disease). These types of networks are especially interesting in terms of care for rare tumors (Albreht T, et al., 2014; Sandrucci S, et al., 2015; Casali P, et al., 2019).

There are experiences in our country of oncology networks that allow therapeutic coordination between hospitals in the same region to be improved and ensure that the patient only travels to a hospital further away from their home, when medically necessary (Palm W, et al., 2013). These organizational models also allow the therapeutic decision to be made with the participation of the referral centre specialist in the tumor committee of the local hospital. Undoubtedly, ICTs and shared medical records greatly facilitate this type of activity. However, many collaborative experiences are based on informal agreements and it would be necessary to formalize cooperative networks, especially for rare tumors and complex treatments.

At the international level, in 2016, the European Commission designated the first 24 European Reference Networks. The participation of Spanish centres, as full members, in the three Networks most related to cancer is as follows:

- ERN for pediatric cancer (hemato-oncology) (ERN PaedCan): 4 centres.
- ERN for rare cancers in adults (ERN EURACAN): 3 centres.
- ERN for genetic syndromes with tumor risk (ERN GENTURIS): 2 centres.

**New information technologies**

Having a shared electronic medical record, which is progressively being implemented throughout the national territory, will make it possible to share the information and tests carried out between primary care doctors and those in specialized care practically instantly. This fact will undoubtedly make it possible to improve coordination between primary and hospital

care, and between the different centres of the care network, and represents one of the great health challenges in oncology in our country.

**Rare tumors**

There is no international agreement on the definition of rare tumors, although in the RARECARE project they have been defined as those with an incidence of ≤6 cases/100,000. However, according to the EU definition, rare tumors are considered those with a prevalence of <6 cases/10,000. There are more restrictive definitions, such as the one used by Gatta (2011), in which rare tumors are defined as those that are located in an infrequent part of the human body, of an infrequent histological type, and require complex treatments. Around 1 in 4 tumors can be considered rare (Gatta G, et al., 2011). The experience in diagnosis and treatment of this type of tumor is usually concentrated in a few experts and the clinical results vary considerably depending on the knowledge and experience of the care team. In fact, survival of this type of tumor is worse than that of the most frequent tumors (Gatta G, et al., 2011). Another problematic aspect of the dispersion of these patients is the difficulty of accessing clinical trials and new diagnostic strategies, which results in a lower possibility of clinical research, already complicated by the low volume of cases, and the need to have appropriate research methodologies (Casali P et al., 2015). Finally, the frequency of approved off-label treatments in this type of tumor is higher due to the difficulty of having adequate clinical studies to assess their efficacy.

In summary, rare tumors are characterized by a set of factors that suggest a specific organizational approach to improve both the quality of care and the possibility of developing clinical research. An initiative on rare tumors in Europe promoted by ESMO (European Society for Medical Oncology) and ECPC (European Cancer Patient Coalition) has been developed, in which a series of prioritization criteria are proposed to address the problems in this area (www.rarecancerseurope.org).

The different European cancer plans have so far insufficiently taken into account the singularities of these tumors and this is certainly a European challenge, with some exceptions, among which France stands out. The objectives included in this Strategy should be the starting point for implementing a specific care model for rare tumors in health services in our country.

**New role of patients**

The involvement of cancer patients has evolved a lot from the classic model of the patient who passively accepts medical indications and the family who tries to hide the seriousness of the diagnosis. Public acceptance of the diagnosis of cancer and their perception that aspects of it have advanced in

terms of improved survival and quality of life is being translated into a greater desire to get involved in the knowledge of therapeutic options, prognosis and in an increasing number of cases, in expressing their preferences for the type of treatment and that these wishes are heard. It should be made clear that delegating the decision to the doctor, once the therapeutic options are known in an understandable way, is also a preference. In fact, the clear consensus of the vast majority of patients, and what they clearly demand more of, is that the treatment and its prognosis be clearly explained and that the patient's preferences be explored and considered when establishing the therapeutic strategy, especially when the decision involves a balance of benefit and risk, differing between each available treatment.

Furthermore, a clear indicator of changes in the attitude of patients is shown in the growing demand for second opinions, especially when a recurrence of the primary tumor or a metastasis is diagnosed, or when the indicated therapy is especially aggressive with a high impact on future quality of life.

Another clear indicator of the change observed in cancer patients is the growth in the number of patient associations and volunteers. In many cases, these associations are focused on a type of tumor or a specific location, which significantly restricts the scope of action, although it increases its impact. The relationship between the associations and the administration goes through different stages over time, from collaboration to advocacy, and they are necessary collaborators to advance in the improvement of the quality of cancer care, participating in the defining of priorities for the strategy.

**Priorities for action**

- Multidisciplinary care is the care model proposed to face the challenge of care coordination between specialists, professionals and centres implicit in the diagnostic and therapeutic process. The tumor committees and/or the multidisciplinary units are the organizational instrument to apply it in the healthcare reality (EPAAC, 2014; Unidades asistenciales del área del cáncer. MS, 2013).
- A key aspect is the importance of the introduction into health centres of the role of the case manager, existing in other countries with similar names, which has demonstrated its usefulness and an increase in the effectiveness of medical work time, as well as patient satisfaction (Prades J, et al., 2015).
- The commitment to a model of care for cancer patients in a network, through the designation of reference centres (at the European, national, regional or local level) concentrates ample experience, guarantees the best health results and contributes to the equality

of access to quality care. The patient must have access to complex technology and procedures when needed during the course of their therapy while performing as many parts of the treatment as possible close to their residence, when clinically feasible, and with proper coordination of care.

- The evidence, together with the interests of patients with rare tumors, points to the need to order the flow of patients in certain rare cancer treatments or in highly complex processes so that they are treated in reference centres designated by the health authorities. Based on the analysis of clinical results and with case volume criteria, the establishment of care networks between reference centres and the rest of the hospitals in their geographical surroundings will undoubtedly contribute to improving the care process between hospitals and to carrying out those treatments that are not complex in hospitals close to the patient's residence.
- Develop a collaborative work model between primary and hospital care for cancer care that includes the various relevant care aspects together. Continue the preparation of care routes and coordination guides for primary care-hospital care with regard to the follow-up of different types of cancer.

**Diagnosis**

The relevant aspects of this area are speed and reliability in the cancer diagnosis and molecular diagnosis.

**Speed in the diagnostic process: quality and access**

Although it is difficult to establish what the impact is on the improvement in the prognosis of the times of access to the tests in the vast majority of cases, it is clear that patient satisfaction is closely linked to the fact that these times are minimal. On the other hand, an association has been shown between primary care physicians who systematically delay referral of patients and poorer survival outcomes (Moller H, et al., 2015). Probably, after six weeks of delay, the impact is very significant, although it cannot be deduced that shorter times are not significant (Khorana AA, et al., 2019). It is also important not to forget that the speed of access must be combined with the quality of the test and its interpretation.

There are various Autonomous Communities that have launched rapid diagnosis programmes in a similar way to other countries such as the United Kingdom or Denmark. Despite the fact that these programmes have varied aims and assessment mechanisms, all of them have been positively evaluated using a combination of qualitative and/or quantitative methods (Prades J, et al., 2011).

The Cancer Strategy has always set as its objective the existence of rapid access mechanisms when there is suspicion of cancer. This access can be measured with respect to the performance of the test and/or the start of the treatment, setting as the initial date the receipt of the request in the designated reference centre, in the different levels of the Spanish National Health Service. The problems of measuring these variables are significant and the cause of methodological debate, and an attempt has been made to establish an international consensus (Weller D, et al., 2012) with regard to these aspects.

This type of programme must be established in all the Autonomous Communities, based on the referral of patients with frequent tumors from primary care to a reference hospital designated at the different levels of the Spanish National Health Service. Symptoms of alarm must be previously agreed upon and the patient's referral circuit must be clear and prioritized.

In relation to cancer in childhood and adolescence, diagnosis in the initial stages could be improved by strengthening health programmes for healthy children, especially important in the case of retinoblastoma. The pediatrician should pay special attention to signs and symptoms such as prolonged fever, failure to thrive, weight loss, lymphadenopathy, irritability, paleness, ecchymosis, increased head circumference, headache, neurological focus, leucocoria, abdominal distension, hepatomegaly, splenomegaly, diarrhoea, constipation, skin lesions or persistent adenopathies among others. The severity of these signs and symptoms, their persistence or progression, or their unfavourable evolution despite initial treatment, are factors that should set off alarm bells for referral of the patient to a pediatric Onco-Hematology Unit.

**Molecular diagnosis of cancer**

In 2014, care for patients and family members in the area of genetics, which includes genetic counselling and genetic analysis, was included in the Spanish National Health System service portfolio (Order SSI/2065/2014. BOE 269, 6 November 2014; 91369-91382).

Among the genetic analysis services included in the 2014 update of the basic common portfolio of healthcare services of the Spanish National Health Service are:

- **Diagnostic genetic analysis:** These are performed on people with signs or symptoms of disease and are used to confirm or rule out a specific genetically based disease or disorder.
- **Pharmacogenetic and pharmacogenomic analysis:** These are carried out on people who need to be treated with certain drugs included in the pharmaceutical service of the Spanish National Health

Service and serve to determine the therapeutic strategy, assess the response to treatment or avoid possible adverse effects in a specific individual.

The diagnostic process in oncology is changing significantly after the consolidation of precision medicine that requires an evaluation of biomarkers both for prognosis and for predicting therapeutic response. These must be used in conjunction with the pathological diagnosis or when a recurrence or metastasis occurs, which increases the demand and complexity of the process. Furthermore, this set of markers is constantly expanding and poses new organizational problems such as the need for accessing its analysis when clinically necessary. For this objective to be met, access must be guaranteed in an equitable manner, as well as ensuring the quality of the test and the interpretation of the results, which leads to the need to analyse the advantages of concentrating them being carried out in centres that have suitable technology and expertise.

Another important aspect is the need to distinguish between useful biomarkers for medical decision-making, with proven efficacy, and those biomarkers whose analysis is associated with clinical research, useful in the framework of a clinical trial or preclinical studies. Clearly, the objective is to guarantee the performance of the biomarkers of clinical interest with appropriate quality, although it must be taken into account that it is not always easy to distinguish them and the evolution of research can change classification very quickly, so strategies should be implemented that facilitate rapid adaptation to new indications that may arise in the coming years. When biomarkers are related to the decision to administer a drug, they are determined upon approval of the indication by the Spanish Medicines Agency.

Due to the importance of molecular diagnosis, there are countries that have carried out unique initiatives to support the development of so-called precision medicine that has a fundamental focus on knowledge of these biomarkers, with the most interesting case being France. In this country, a programme funded by the National Cancer Institute (INCa) has been implemented, in which a network of 20 centres for the entire national territory was integrated. This concentration provides access with adequate quality and clinical experience for all patients who have an indication of a biomarker, in addition to enhancing the possibility of establishing clinical research programmes linked to this type of knowledge. Other countries such as the United States or the United Kingdom have launched initiatives with more interest in research than care, called precision medicine, which focuses on precisely adjusting the treatments of patients defined according to subcategories through genomic knowledge (National Research Council. Towards precision medicine: Building a knowledge network and a new taxonomy of

disease. Washington (DC): National Academy Press, 2011; Mosele F, et al., 2020; Benedikt C, et al., 2020; Institute of Medicine).

Currently, in our country there is no clear definition of how precision oncology should be implemented in health services, nor are there quality criteria to evaluate the results of these biomarkers or funding. The Senate approved a report that partially refers to this situation. Furthermore, the scientific societies of Medical Oncology, Pharmacy and Pathological Anatomy have prepared a proposal for its implementation (Garrido P, et al., 2017). Clearly, within the framework of the Strategy Against Cancer, a model for the implementation of precision oncology in the Spanish National Health Service must be defined that allows for an improvement in equity of access, quality and evaluation of its results.

**Priorities for action**

Within the general diagnostic process, the following stand out as priorities for action:

- Reduce the waiting time in diagnostic procedures, through the development of a rapid diagnostic programme where one is not already implemented.
- Promote quality control mechanisms in the anatomo-pathological diagnosis of tumors, promoting the participation of Anatomy Pathology services in the ISO standard, and participation in external quality controls that guarantee the reproducibility of the analysis and interpretation of tissue biomarkers of diagnostic, prognostic and predictive importance.
- Implement a double reading diagnostic test system for pathology in rare tumors, performed by an expert pathologist from a designated reference centre.
- Develop a molecular diagnostic programme that combines the criteria of equity of access and the quality of the test, along with scientific and health interest. The first step in implementing these programmes should be to ensure access to a set of quality biomarkers with therapeutic implications, based on the best clinical experience, making it possible to assess their quality and having up-to-date technology.

**Treatment**

The main challenges in treatment today are the following:

- **Consolidation of personalized approaches to cancer treatment:** In recent years, defining any new therapeutic strategy for cancer as an

advance towards personalized medicine has been a constant, both in terms of diagnosis and treatment. This so-called "4P" medicine (personalized, predictive, preventive and with a greater role for the patient) has been around for many years (Hood L, et al., 2011; Tursz T, et al., 2011; Tursz T, et al., 2015). There is no doubt that the development of new treatments and technologies such as the use of drugs based on certain biomarkers, the new radiotherapy oncology technologies that allow modulating the intensity of the dose, laparoscopy or robotic technology, and organ-preserving surgical strategies in surgery, mean that it is a consolidated strategy with a future. This conceptual change has clear implications for the therapeutic decision, which is much more multidisciplinary and based on new precision oncology technologies, with the clear objective of selecting only those patients who can benefit from treatment based on the data provided by genetic or molecular analysis.

- **New technologies in radiotherapy:** The main therapeutic strategies against cancer are chemotherapy, surgery and radiotherapy and more recently targeted treatments and immunotherapy. Between 40-50% of cancer patients are treated with RT, as monotherapy or combined with surgery and/or chemotherapy (Yaromina A, et al., 2012). The Spanish Society of Oncology and Radiotherapy (SEOR) estimates that approximately 60% of cancer patients should be treated with RT at some point in their pathological process (Herruzo I, et al., 2011) and globally it is considered that 50% of patients should receive an external radiotherapy treatment at least once in Europe (Borrás, 2015), although counted together only 70% of those that should receive this treatment in Europe actually do (ESTRO, 2018).

Radiation Oncology, in the same way as other technology-based medical specialties, is subject to continuous changes that depend on current technological advances. The main objective of incorporating new technologies in this area is to enable the optimal dose in tumor cells without increasing the harmful effects on healthy tissue (SEOR XXI White Paper, 2012 and White Paper in press 2020). In relation to the current situation of new technologies in Spain, there is no doubt that in our country the renewal of RT equipment and its greater availability in hospitals closest to the places of residence of patients has led to a very notable improvement in access to radiotherapy oncology treatments and have virtually eliminated the waiting lists common in the 1990s. Standards on recommended equipment and staffing are well established (MS. Unidades asistenciales del área de cáncer, 2013) (Rodriguez A, et al., 2018; Rodriguez A, et al., 2019).

However, the comparative data on radiotherapy oncology in Spain with that corresponding to the European countries with the best indicators show that we are still far from having all the current technology necessary to optimally define the volume of treatment, the guiding image of the tumor and modulated intensity when indicated. The recent subsidy from a private foundation to update technology in external radiotherapy in accordance with the priorities defined by each Autonomous Community has changed this situation and it will be necessary to assess whether up-to-date technology is currently available throughout the Spanish National Health Service.

**Proton therapy**

In some clinically defined cases, clinical studies suggest increased safety and efficacy by using proton therapy (PT) instead of conventional radiotherapy, for tumors such as uveal melanoma, chordomas, and chondrosarcomas of the base of the skull. The most relevant advantages of PT are more precise and concentrated radiation on the tumor and a lower irradiation of healthy tissues compared to conventional radiotherapy, reducing the probability of long-term adverse effects (Solans M, et al., 2014).

Regarding pediatric tumors, the indication for PT is justified by the lower radiation deposition in healthy tissue compared to photon radiotherapy and the consequent reduction in long-term adverse effects. However, the lack of studies with sufficiently long follow-up does not allow the long-term toxicity of PT to be evaluated in this type of patient (Solans M, et al., 2014).

Due to the commercial availability of proton therapy systems and the continuous increase in medical evidence of their results, there are 26 centres with proton therapy installed in the European Union (Particle Therapy Co-Operative Group, 2020), of which of which there are two in Spain operated in the private sector.

The provision of proton therapy has been included in the Spanish National Health Service treatment catalogue for very precise indications of pediatric and adult tumors since 2020.

**Equity of access to cancer treatment**

One of the aspects that has focused the debate on health policy in our country in recent years has been the presence of problems of accessing new cancer treatments. The existence of a delay in the effective access to new cancer treatments is due both to the negotiations between the manufacturing laboratories with the administration in establishing prices and indications, as well as to the inequalities in the inclusion of the medicine in the different Autonomous Communities, which conditions the accessibility of the medicine to the place of residence, although globally the differences are months. It should be noted that a recent study by SEOM, through a survey of different hospitals

in the country, shows that there is no clear territorial pattern either by Autonomous Community or by type of drug, which indicates that the reasons may be due to aspects in each hospital or each level of health decision in this area and that they do not depend on political decisions of a general nature or by the Autonomous Communities.

It should also be mentioned that there is unequal access to radiotherapy oncology treatment, with different availability of professionals, as documented by the SEOR (Rodriguez A, et al., 2018; Rodriguez A, et al., 2019), and a similar pattern can be observed for surgical oncology https://www.atlasvpm.org/atlas/. Given the principle of equal access according to equal need that the Spanish National Health Service should be subject to, it is clear that the analysis of the impact on clinical results of these differences in access and resources should be a priority reason for analysis in order to reduce the variability that is not due to the clinical situation of the patient.

**The evolution of the cost of cancer treatment**

The cost of cancer is annually growing above the global cost of treatment for most pathologies. Therefore, the volume of resources that will need to be dedicated to assume therapeutic innovation is significant and will represent a portion of the health budget (Nass S, et al., 2014). The concern for defining strategies to face this challenge is common to all countries. Thus, the main scientific societies in the field of cancer have proposed different strategies to define the value of innovations in response to the concern that the increase in cost is not in line with the increase in clinical benefit for the patient.

Along these lines, the ESMO has published a stratification model for the magnitude of the clinical benefit in relation to its cost, provided by new therapies for cancer treatment (Cherny, et al., 2015). The scale of magnitude of clinical benefit (ESMO-MCBS Magnitude of Clinical Benefit Scale) represents an important step for assessing the value of cancer care, to make an appropriate use of public resources and facilitate effective and affordable cancer care. The scale can be applied to compare results of studies evaluating the relative benefit of treatments using survival outcomes, quality of life, other outcomes (DFI= disease-free interval; DFS= disease-free survival; TTR= time to recurrence; PFS= progression free survival; TTP= time to progression) and toxicity of treatment in solid tumors. The scale is established at two levels for new curative therapeutic options (ABC scale, where A and B indicate a high clinical benefit) or non-curative (with a scale of 1 to 5, where 4 and 5 represent a high level of demonstrated clinical benefit).

A relevant aspect of this scale is that it allows the indications approved by the European and American regulatory agency to be evaluated. Some sci-

entific societies such as the Spanish Society of Hospital Pharmacy (SEFH) advocate this type of scale in the evaluation of the approval of therapeutic indications in our country (https://www.sefh.es/bibliotecavirtual/posicionamientos_institucionales/11-PosicionamientoSEFHaccesoNuevosAntineoplasicos.pdf).

It has been found that nearly two thirds of the drugs approved in recent years are not included in the healthcare system with survival improvement data, but rather with intermediate variables (Davis C, et al. 2017; Tibau A, et al., 2018). Furthermore, it has also been shown that there is no correlation between the price assigned to a drug and the magnitude of the clinical benefit, whether measured with the ESMO or ASCO scale, which implies that the cost for the health system is not related to clinical benefit (Vivot A, et al., 2017).

**The evaluation of the results of cancer treatments**

Many of the current health debates in oncology can only be resolved if it is possible to have data on relevant clinical results that make it possible to clarify whether concentrating certain treatments achieves an improvement or whether the lack of equity in effective access to a drug affects survival. Unfortunately, our sources of information through population cancer registries are limited to 27% of the country and these are the foundation of any quality cancer information system. In addition, the tradition of performing analyses based on the data available from the discharge report is modest, only partly explained by the difficulty of its use in such outpatient specialties as medical oncology and radiotherapy. It has only been useful in tumors with surgical treatment, in which we have relevant results, for example, from the atlas of variations in medical practice (http://www.atlasvpm.org/). Nor have there been any periodic analyses of data from tumor committees in centres or results from joint hospitals, beyond occasional publications. Finally, experiences of evaluation results based on clinical audits have been described that have shown the possibilities of improving them in practical terms in our health context (Manchon-Walsh P, et al., 2011, Manchon-Walsh P, et al., AQUAS. 2016, 2020).

Probably, the lack of a culture of evaluation of clinical results is a significant problem in our health system, and has been shown periodically. The improvement of cancer care can only take place rationally if it is based on clinical results linked to the health services of our country. For example, population registries have made it possible to comparatively objectify the situation in our country, within the European framework, even if it is only based on data collected in one part of the country (Allemani C, et al., 2018).

**Psychological care**

Cancer is a disease that affects the person as a whole and their immediate family and social environment (IOM, 2006; Grassi L, et al., 2007). Patients must face the health problems derived from their disease and also its psychosocial impact, which covers aspects such as a break with previous habitual life, feelings of vulnerability and the need to rethink their future. All of this generates significant psychological suffering that reaches levels of clinical emotional discomfort in half of people with cancer and is accompanied by psychopathological disorders in more than 30% of cases, a prevalence higher than that of the general population, which requires specialized psychological care (Hernández M, et al., 2013; Carlson LE, et al., 2004; Zabora J, et al., 2001; Canadian Partnership Against Cancer, 2009). In recent decades, the concept of emotional discomfort (distress) has been increasingly used, linked to other more clinical concepts such as depression and anxiety, and its clinical assessment, according to some authors, is fundamental (Bultz & Carlson, 2005). This concept of distress is supported by the National Comprehensive Cancer Network (NCCN, 1999). There are several instruments used to evaluate this discomfort, such as the K6 scale (Kessler RC, et al., 2005), the BSI-18 inventory (Derogatis LR, et al., 1983), the total score on the Hospital Anxiety and Depression Scale-HADS (Zigmond AS, et al., 1983), or the Distress Thermometer-DT (Roth et al., 1998), strongly supported by the NCCN (2004). Several studies have reported the existence of numerous barriers or difficulties in the detection of emotional distress.

This implicit distress in the whole pathological process can have an impact that must be measured, evaluated and which must receive psychological treatment when the impact is significant. In fact, it is estimated that one third of patients should receive specialized psychological support (Schaeffeler N, et al., 2015). Despite the great implications of psychological morbidity in cancer patients, it remains a frequently underestimated clinical area. In Europe in general and in Spain in particular, progress has been noted in this area of care and the need for it is recognized, although there is still a long way to go and inequalities in the care offer are very notable (Mehnert A, et al., 2005; Travado L, et al., 2013).

The study on psychological care for cancer in the Spanish National Health System prepared by the AECC Cancer Observatory (AECC. http://observatorio.aecc.es/sites/default/files/informes/2019_Informe_AtencionPsicologicaCancer_Hospitales.pdf) recommends: a) The inclusion of psychological care, both for the cancer patient and for the person who usually accompanies them as a care objective in all regional cancer plans/strategies, within a multidisciplinary and comprehensive cancer care model; b) The organization of cancer patient care processes in the hospital environment so as to integrate three levels of emotional support: basic (health profession-

als and trained volunteer service), medium (health professionals trained to identify and manage symptoms of non-complex emotional distress) and specialized; and c) The measurement of distress or emotional discomfort as the sixth vital sign after temperature, blood pressure, pulse, respiratory rate and pain, incorporating it into the clinical history.

In 2009, the International Psycho-Oncology Society (IPOS) together with 74 other international organizations and scientific societies, proposed a new standard in cancer care based on (Albreht T, et al., 2014):

- Care for patients with cancer and/or family members must integrate the psychosocial area into routine care.
- Distress should be measured, as the sixth vital sign, after body temperature, blood pressure, heart rate, respiratory rate, and pain (Bultz BD, et al., 2005; Holland JC, et al., 2007; Albreht T, et al., 2014).

The same International Psycho-Oncology Society (IPOS) formulated a statement saying that psychological and social care in cancer patients must be recognized as a universal human right, and must be integrated into regular health care (Travado et al., 2016).

In 2017, the Cancer Control Joint Action developed a guide consisting of 36 recommendations to improve the quality of cancer treatment, of which 11 are directly related to psychological care for people affected by cancer.

The need to standardize a way of rapid detection of emotional distress that facilitates orientation to the different levels of intervention has been recognized. This better detection must be accompanied by a greater presence and integration of the professional psychologist in the health teams that care for cancer patients. Following this path, the Joint European Action on Cancer Control, CANCON, which integrated the Commission together with the member countries of the Union, has recommended establishing systematic screening for emotional distress in cancer patients to assess who may need more specialized care (CANCON, 2017).

**Social care**

The negative psychological impact of the disease can be intensified by the presence of social and economic problems derived from or aggravated by it, affecting not only the patient, but also the entire family unit.

Among these problems we can highlight:

1) Reduction of economic income due to possible changes at work. Of note are adjustments due to job loss, impossibility of performing work that involves overexertion, temporary or permanent disabilities, or even non-existence of income in the case of patient

workers and self-employed workers with Social Security debts or unemployed people without access to social benefits and/or in a situation of social exclusion.

2) Assuming new expenses derived from the disease: hair prostheses, transfers to treatment, medication, etc. (Fernández B et al., 2020).
3) Difficulty in carrying out basic activities of daily living due to possible temporary or permanent loss of basic capacities of the patients, which directly influences their quality of life, need for care, as well as family structure and functioning.
4) Loss of social relationships, family support and reduction of leisure activities.
5) Sometimes, loss of work activity due to the cancer diagnosis itself, suffering from discrimination and rejection due to suffering from the disease.

Thus, it is important that the social worker be able to intervene from the first moments of diagnosis, and throughout the disease process, since in each phase they will be able to work on different aspects related to the specific moment of the disease and the particular situation of each patient and/or family member, from a care, preventive, educational, training and coordination point of view, working with other resources. This aspect has been indicated as an area of development within the framework of the priorities of patients who have completed cancer treatment in Europe (CANCON, 2017). It should be said that review of the European cancer plans revealed the limited scope of objectives in this area, although it also revealed its necessity.

**Priorities for action**

- Define the complex procedures and low-frequency tumors that should be proposed, in accordance with the available evidence and the specific characteristics of each Autonomous Community, in order to establish reference centres within the framework of cancer care networks.
- Maintain the process of updating and adapting to the future demand of cancer patients for technology and radiotherapy oncology professionals. Promote public facilities for proton therapy in accordance with the demand provided for in the resolution of the IC.
- Validate brief and simple methods to detect emotional discomfort (distress) early, make an assessment of it and establish the best approach to treating it.
- Provide psychological and social care to patients and family members who require it at any time during the disease, not limiting it to

the time of discharge and having the necessary resources, helping to reduce psychological distress and maintain the quality of life of patients and their families.

**Psychological care must aim to**

- Improve the adaptation of the cancer patient to oncological diagnosis, medical tests and treatments, check-ups and follow-ups, relapse and end of life; improve adherence to health prescriptions and treatments, as well as improve the quality of life during the disease process and survival.
- Improve the adaptation of the caregivers and direct relatives of the person with cancer to the disease process in order to improve their quality of life, promote communication and emotional and family support, and prevent and treat both overload and prolonged and complicated mourning.
- Prevent the appearance of psychopathological disorders among cancer patients and family members through specialized psychological care in cancer from the onset of the disease until survival or end of life.
- Train and improve the communication skills, emotional management and management of crisis and stressful situations of health professionals in the interaction with the person with cancer and their relatives, and between them and the health teams.
- Prevent and treat burnout syndrome and empathy exhaustion or compassion fatigue; as well as optimizing interdisciplinary teamwork.
- Research in: a) the behavioural and psychological aspects that are present in neoplastic diseases in their different stages; b) the efficacy, efficiency and effectiveness of the methods of evaluation and psychological treatment in the area of psychology applied to oncology; c) the factors that optimize the care system and the improvement of the relational climate in the health teams; d) grief processes in family members, their evaluation and treatment; and e) the psychological and social factors involved in improving the experience of cancer patients in the healthcare field.

**Social care must aim to**

- Counselling on guidelines for the organization and functioning of the patient's environment, burden-sharing, preventing co-dependence, etc.
- Informing patients and family members as to their rights and obligations, as well as counseling them concerning resources and differ-

ent types of aid affording the possibility of covering the care which the patient requires.
- Guarantee the minimum coverage of basic needs during the treatments and mobilize the internal and/or external resources that are necessary for its guarantee.
- Promoting volunteering to facilitate accompanying the patients during their stay in the hospital and at home.
- Promoting the organization of social support networks for patients and family members.
- Facilitate advice on labor reintegration, once a safeguard period has elapsed in the evolution of the cancer.

#### 1.4.2.2. Monitoring and quality of life

The main challenges in monitoring at present are the following, in accordance with the proposals developed within the framework of CANCON (CANCON, 2017):

- **Rehabilitation:** During and after treatment, some people may suffer physical sequelae, including the presence of lymphoedema, in the case of breast cancer, or a disability that may require the use of specialized rehabilitation services. In many cases, they also present fatigue and tiredness for a prolonged period of time after the treatments (Bower JE, 2005). Establishing guidelines for the prevention of the aforementioned sequelae and others through preventive rehabilitation programmes is relevant.
- **Nutrition:** Diet difficulties and nutritional problems are a common complication in cancer patients, often leading to weight loss and malnutrition. For this reason, systematic assessment of nutritional status and periodic weight control should be a regular practice in all cancer patients.

Due to the significant nutritional impact of the disease, the Nutritional Support in Cancer Patients Book (SEOM, 2006) recognizes the importance of providing adequate nutritional care to cancer patients.

In this regard, the guidelines published by the European Society for Clinical Nutrition and Metabolism (ESPEN) stand out, including recommendations on enteral and parenteral nutrition in cancer patients (Bozzetti F, et al., 2009; Arends J, el al. 2006). In our country, recommendations have also been drawn up from scientific societies that are relevant for the management of patients both during treatment and follow-up, once it has finished (SEOM: Guía de ejercicio físico y nutrición, 2018).

- **Psychological care:** After the completion of the treatments and during the follow-up phase, the appearance of psychological and emotional problems after the experience is very frequent. It is noteworthy that at present 50% of cancer cases are free of disease after primary treatment, that is, they are survivors and present psychological needs, worse quality of life and health habits (Martínez & Andreu, 2019). This situation is aggravated in those cases of adults who have suffered from cancer in childhood, adolescence and early youth. Approximately 70% of cancer patients present sleep disturbances, mainly insomnia with trouble falling asleep and staying asleep (Savard & Morin, 2001). Fatigue is, on the other hand, the most frequently reported cancer symptom among people with cancer and is identified as the one that causes the greatest interference with the patient's activities of daily living, with fatigue/asthenia rates being estimated in patients who have received chemotherapy and/or radiotherapy at close to 80% and in patients with metastatic disease at 75% (Weis, 2011), with these symptoms remaining even after the treatments have ended. Pain affects 50% of cancer patients throughout their disease, regardless of its stage; in the final phase of the disease, pain is present in 74% of cases (Syrjala et al., 2014). Pain is a key determinant of impaired quality of life as it decreases the patient's activity, interferes with appetite, sleep, and mood, and leads to loss of self-control.
- **Social care:** When the treatments finish, it is time for the beginning of the routine follow-ups with less frequent and continuous periodicities than during the treatment. At this point, a period begins that many patients and families describe as a sense of change and a new loss of control. It is not always possible to recover the life that was lived before the diagnosis, but the treatments have finished and it is necessary to resume everyday life in a normal way. At this time, the figure of the social worker can offer to:

    - Reinforce information regarding the disease and its evolution.
    - Inform and advise on the rights associated with cancer survivors and their families (acknowledgment of disability, dependency, etc.).
    - Offer family support for internal restructuring, readjustment of functions, etc.
    - Advise on resources and aid that allow the care that the patient requires to be covered.
    - Facilitate coordination with the Social Services system.
    - Promote support volunteers to facilitate the recovery of rou-

tines and/or offer support in situations where there is a possible lack of a social network or loneliness.
- Promote the organization of social support networks for sick people and family members.
- Facilitate advice on labor reintegration, once a safeguard period has elapsed in the evolution of the cancer, recognition of permanent disabilities, adaptation in the workplace, training, recycling, unemployment benefits, etc.

Specific studies that can evaluate the influence of psychological and social factors and factors related to treatment in the experience of cancer survivors who wish to continue their professional and work development are needed, especially in young populations (De Boer AG, 2009; Frazier et al., 2009).

- **Long-term survivors:** The improvements in cancer survival observed in the last three decades in our country, through population cancer registries, indicate two relevant facts: the continued improvement in survival percentages in practically all tumors and the spectacular gains seen only in rare tumors, such as chronic myeloid leukaemia. These advances are the result of the combination of improvements in diagnosis, that is earlier diagnosis, and improvements in cancer treatment, which will vary depending on the tumor. These improvements, together with the increase in new cases of cancer due to the ageing of the population, have caused an increase in the number of survivors in recent decades in Europe and Spain (Ferro T, et al., 2011). Faced with this situation, the SEOM has proposed joint actions with other scientific societies and groups of societies (SEOM, 2013; SEOM, 2017).

Despite the absence of a global consensus on what the initial reference point is for identifying a "survivor", it is more frequently associated with the period after the end of the primary treatment (Kline RM, et al., 2018; Surbone A, et al., 2016). If we talk about long-term survival, in general terms, the starting point is five years after having survived cancer and being disease-free. Although situations such as hormonal treatment in breast cancer are also included (Ferro T, et al., 2011).

For all these reasons, among the main challenges that health services must face in the coming years, it is worth highlighting that of cancer survivors in the following aspects:

- **Lack of specific data on long-term survivors:** In Spain, there is currently no exact specific epidemiological data on all cancer survivors,

which leads to a lack of knowledge of the current situation of these patients in the health system (Monográfico SEOM Largos supervivientes. 2012).

- **Limitations in the knowledge of health of long-term survivors:** Despite advances in treatment to reduce side effects and their intensity, they continue to occur, and although most have temporary effects, some can remain for a long time and even become chronic. On the other hand, late effects may also appear months or years after the end of treatment (Shahrokni A, et al., 2016; Aziz NM, et al., 2009; Haylock PJ, et al., 2007). Despite this, there is no availability of long-term data that allows us to know exactly the long-term effects of the therapies used, as well as the pathological process in most tumor types (Aziz NM, et al., 2009). Currently there are studies referring to survivors who have had cancer in childhood or their youth. In adults, most of the data corresponds to studies of surviving women in breast cancer (Ferro T, et al., 2011) and survivors of testicular cancer, prostate cancer, and non-Hodgkin lymphoma (Strumberg D, et al., 2002; Lilleby W, et al., 1999; Ng AK, et al., 2004).
- **Appearance of secondary neoplasms:** Beyond the problems caused by secondary neoplasms in children and adolescents, the aforementioned improvements in survival also have implications in adults, and among the most relevant is the increased risk of second neoplasms, which implies defining follow-up policies for long-term care of patients that are evidence-based and avoid saturation of outpatient care services. Some 16% of cancer survivors develop second primary neoplasms.
- **New needs of surviving patients:** The increase in life expectancy of patients has revealed the specific needs that these patients pose over the years after their treatment, beyond the risk of recurrence, such as psychological and social needs, challenges posed by returning to work, treatment of concomitant pathologies and adverse effects and sequelae derived from treatment (Bloom JR, et al., 2007; European Guide, CANCON, 2017).

Another relevant aspect is the impact of follow-up of cancer patients on hospital health services and the need to review the effectiveness of follow-up and the most appropriate level of care for each patient individually. With respect to this issue, it is possible to classify patients according to the most appropriate care framework for the clinical situation. Based on the fact that a patient after being diagnosed and treated may have been completely cured or present with an active disease throughout his life, these patients are classified into three categories (Ferro T, et al., 2011):

- **Patients free of disease.** No or low-severity sequelae related to their tumor episode. These patients will be candidates for follow-up from primary care.
- **Patients with active disease or severe sequelae.** These patients will be candidates for hospital follow-up. A classic example is the patient with lymphoedema.
- **Patients in special circumstances.** Patients whose follow-up will depend on circumstances other than the previous cases and which will influence the assessment of the appropriate healthcare framework. A classic example is the patient with problems accessing the health centre due to a disability.

Therefore, long-term survival is one more stage of the continuous care of the cancer patient and its implementation represents a great challenge for health systems. Beyond the diagnosis and treatment of cancer, care for long-term survivors should focus on the quality of life of patients, family members, and caregivers; so that it encompasses health, social, family, sexual and emotional aspects.

**Priorities for action**

Long-term survivors:

- Coordination between care levels. Standardized and coordinated circuits need to be developed between primary care and hospital care for these patients in order to optimize their care. Figure of the medical specialist coordinating care and organizational aspects, with clinical responsibility for patient treatment, existence of consultation circuits or preferential referral that allow the primary care physician to provide solutions to specific cases.
- Maintaining the quality of life of long-standing cancer survivors, as well as the maximum recovery of functional capacity, is critical for these patients. This requires that primary care health professionals participate effectively in the screening, diagnosis and monitoring of long-term side effects (Shahrokni A, et al., 2016).
- Promotion of adherence to treatment and a healthy lifestyle in patients with a long evolution (Beckjord EB, et al., 2008).
- Preparation of an individualized follow-up plan after finishing the treatment that collects information on the possible side effects derived from the cancer and the therapy used. As well as the management of other chronic health problems in the patient.
- Immediate re-entry into the system must be guaranteed in the case of secondary neoplasms. This implies the intervention of interloc-

utors in the hospital, or process managers, who are adequately informed about the clinical history of these patients, in order to avoid unnecessary interruptions (Jefford BR, et al., 2014).

- Need for research on chronic or delayed complications in cancer, with the aim of: increasing knowledge and understanding of the biological behaviour of the disease, leading to more effective treatments with fewer harmful implications, evaluating the psychological impact of care interventions and their results on quality of life and inform patients, favouring their collaboration in making decisions about their therapy (Aziz NM, et al., 2007).

**Palliative care**

The World Health Organization (WHO, 2002) defines palliative care as "an approach which improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable evaluation and treatment of the pain and other physical, psychological and spiritual problems".

Despite the therapeutic advances that have occurred in recent years, cancer continues to cause a need for health care in advanced and terminal stages in a large number of patients and should be an integral part of the strategy to improve cancer care (WHO, 2020). According to WHO data, the need for palliative care is currently greater than ever and is growing due to the ageing of the population and the increase in the incidence of cancer and other non-communicable diseases (WHO, Global Atlas of Palliative Care at the End of Life, 2014).

Dying is, without a doubt, one of the most difficult events to face and has the greatest impact, in which situations of great physical, emotional and spiritual intensity appear, both in the patient and in their family. The response that the health system offers to these multiple and complex needs is palliative care, which, from a global approach, seeks to alleviate suffering in order to achieve a good quality of life and die with dignity.

A care model for patients in advanced and terminal stages of cancer must encompass the following characteristics (Spanish National Health System Palliative Care Strategy, 2010-2014 update): promotion of a comprehensive and coordinated response from the health system to the needs of the patient and respecting their autonomy and values. With the objective of establishing appropriate, viable and measurable commitments by the Autonomous Communities to contribute to the homogeneity and improvement of Palliative Care in the Spanish National Health System.

In Spain, in 2005, during the Conference "Palliative Care in the Spanish National Health System: Present and Future" organized by the General

Directorate of the Quality Agency, the bases of the process were established by which the Palliative Care Strategy of the Spanish National Health System was prepared, approved by the CISNS in 2007. Since its publication, two updates to the strategy have been approved:

- The Palliative Care Strategy of the Spanish National Health System 2007-2010 is aimed at patients with cancer and progressive chronic diseases of any age who are in an advanced/terminal condition.
- The Palliative Care Strategy of the Spanish National Health System 2010-2014. Strategy currently in force.

Palliative Care should be generalized to the entire population that requires it. Pediatric Palliative Care, although closely related to adult Palliative Care, represents a special field, is unique and specific, and requires different skills, organization, and resources than adults.

With the aim of contributing to improving the quality of care provided to children in advanced and terminal situations and their families, the document Pediatric Palliative Care in the Spanish National Health System: Care Criteria, 2014 was prepared.

**Priorities for action**

The national strategy for Palliative Care includes the priorities for action that will be applicable to updating the cancer strategy:

- Palliative Care is an essential component of health care based on the concepts of dignity, autonomy and rights of patients. Although numerous programmes and activities have been developed, improving accessibility for all the people who need them and the quality of care received still remains a challenge today.
- Have in each Autonomous Community an organizational model for care for children with palliative needs.
- The specific level must habitually provide, in complex situations, continuous, expert and high-quality care. This means it is essential to integrate into interdisciplinary teams, bringing together medical and nursing professionals, and psychology and social work professionals.
- The continuity of care and the integration of levels still needs to be improved in patients with intense needs and frequent changes of location. As recommended by the Palliative Care Strategy of the Spanish National Health System, it is necessary to extend palliative teaching in undergraduate studies and seek ways to ensure advanced training of team members.

- The criteria for evaluation and funding of research projects in palliative care need to be reviewed, and their design and methodology should be proposed by professionals.

### 1.4.3. Health care for children and adolescents

Childhood tumors have been in recent decades a paradigm of progress in survival and in therapy with better control of adverse effects and sequelae. In Spain, this improvement in survival has been clearly observed and is an example of the best open therapeutic possibilities as a consequence of the orderly application of classical cancer treatments in agreed protocols. Furthermore, this success has resulted in the need to consider long-term follow-up of surviving patients to detect the early appearance of secondary neoplasms as well as control any adverse effects of treatment in the long-term. Childhood cancer survivors have a decreased probability of dying from recurrence over the years, but an increased probability related to secondary neoplasms and treatment-related cardiovascular effects (Ferro T, et al., 2011; Chao CH, et al., 2020).

Although most of the challenges that are seen in adult health care are applicable, we wanted to highlight a series of challenges that are specific to care in childhood and adolescence, which are described below.

- **Molecular diagnosis in all pediatric cases:** In relation to childhood cancer, the Personalized Medicine Group of the Spanish Society of Pediatric Hematology and Oncology (SEHOP) proposed at the beginning of 2019 to respond to a need of pediatric cancer patients: access to so-called Personalized Medicine or Precision Medicine. This group arose after various initiatives by SEHOP and its hospitals, such as participation in the Study Paper on Genomics presented to the Senate in 2019 or participation in the international clinical trial MAPPYACTS within the ITCC consortium. The objective is the creation of a national personalized medicine platform, coordinated, and open to all children and adolescents with cancer in our territory. National Personalized Medicine Strategies have been developed in other countries for pediatric oncology: in Germany (INFORM 2.0), in France (MAPPYACTS), and in the Netherlands (iTHER).
- **Side effects:** It is now clearly known that organ system damage in children caused by chemotherapy and radiotherapy may not become clinically apparent for many years (Oeffinger KC, et al., 2006). Approximately more than 70% of childhood cancer survivors will develop a chronic complication, and between 20% and 80% may

experience a severe, disabling, or life-long complication during adulthood (Armstrong GT, et al., 2014; Geenen MM, et al., 2007; Hudson MM, et al., 2013; Berbis J, et al., 2013, Chao CH, et al., 2020). Among the long-term effects in childhood cancer survivors we can highlight infertility, cardiotoxic effects, bone complications, cognitive effects, psychosocial effects, growth problems and thyroid alteration. Information on the evolution of survivors of cancer in childhood and adolescence is needed and dissemination among primary care health professionals of the long-term sequelae of cancer treatment in children and adolescents should be promoted for them to be recognized.

- **Secondary neoplasms:** Childhood cancer survivors are at high risk of developing secondary neoplasms (Metayer C, et al., 2000; Travis LB, et al., 2005). These secondary neoplasms are characterized by typical adult tumor types, such as gastrointestinal, head and neck, respiratory, and genitourinary cancers (Reulen RC, et al., 2011). The risk is higher for patients who have survived sarcomas, CNS tumors, Hodgkin lymphoma, or kidney cancer. The most common secondary tumor in childhood cancer survivors is non-melanoma skin cancer, probably related to exposure to radiotherapy (Friedman DL, et al., 2010). The factors that will influence the degree of risk are: the cancer therapy administered, factors to which they have been exposed, lifestyle factors and other factors (genetics, immune function, hormonal status) (SIGN 132, 2013). The risk of suffering a secondary neoplasm increases as the child cancer survivor progresses to adulthood (Olsen J, et al., 2009). Among childhood cancers, Hodgkin lymphoma presents the highest risk of secondary cancer (Friedman DL, et al., 2010). Furthermore, there is currently no evidence of risk reduction or benefit from the introduction of screening systems in surviving patients of childhood cancer (SIGN 132, 2013).
- **Cancer in adolescents and young adults (AYAS):** Although tumors at this age are very low in frequency, the effect on personal development and the high vulnerability of adolescents and young adults make cancer a pathology with a very high impact. The low incidence of cancer added to the transition between pediatric care and adult care at these ages makes the hospital environment where it should be treated a key point. These patients are out of place in pediatric oncology units just as they are in adult oncology units. For the good mental and physical development of a child, it is very important that they participate in an environment made up of children of the same age, who coincide with their stage of development.

- **Centralization of treatments:** Care for cancer patients is highly complex, a fact that is exacerbated in the case of care for patients with childhood cancer (Ouwens M, et al., 2010; JARC, 2019; Gatta G, et al., 2014; Gatta G, et al., 2017). All types of childhood cancer are recognized as rare diseases (Orphanet Report Series, 2012), and only 1% of all cancers are diagnosed in children (Kaatsch P, et al., 2010). Both the complexity and the low incidence are a challenge for the quality of care and, therefore, the survival of children with cancer (Knops RR, et al., 2013). Among the possible options for optimizing care for childhood cancer, the process of centralizing treatment is being considered. In general, there is a positive correlation between the hospitals with the highest volume of cases, or specialized hospitals, and survival. This volume effect is more evident for tumor types in which surgery is part of the therapy.

Currently, in Spain, there are 44 pediatric oncology and hematology units distributed throughout the Spanish territory. According to cases reported to RETI-SEHOP in the 2008-2012 period, it can be seen that there is a great disparity in the distribution of the average annual number of cases treated by these units, and that of the 44 units for childhood cancer care, only 12 comply with the activity criteria established in the recommendations of SIOP Europe, the International Society of Pediatric Oncology (i.e. a main treatment centre should receive at least 30 new patients per year).

- **Transition to adult services:** An important process to address in children and adolescents with cancer is the transition from the pediatric unit to adult care.

In order to address and optimize the appropriate environment for this group of patients in the Spanish National Health System, a series of recommendations have been made in the current report "Cancer Care Units in Childhood and Adolescence":

- The multidisciplinary team must guarantee continuous assistance to the patient throughout the treatment, taking into account the changes that the patient experiences due to their age.
- Guarantee the transition to adult care services adapting to the process of maturation and information concerning the child or adolescent.

In the CISNS plenary session, held on 15 November 2018, the agreement on the organization of care for childhood and adolescent cancer was approved, the objective of which was to agree on specific measures to be implement-

ed in the Autonomous Communities in order to improve survival results of childhood and adolescent cancer in the Spanish National Health System (Annex). The main measures agreed were:

- Creation of a regional care coordination committee for the management of care in all cases of childhood and adolescent cancer in each Autonomous Community.
- Concentration of care in pediatric onco-hematology units.
- Each Autonomous Community should adopt one of the following organizational models:

  - Network model based on one or several pediatric onco-hematology units. The care network is an organizational tool that contemplates the child or adolescent as the centre of the care process, guaranteeing optimal care.
  - Referral of all cases to another Autonomous Community. When the total volume of cases is not sufficient considering the reference population and territorial distribution, agreements will be adopted with other Autonomous Communities to provide optimal care.

**Priorities for action**

- Ensure equity in the national territory through the implementation of the resolution of the Interterritorial Council of the Spanish National Health System of November 2018 and its follow-up.
- Integrate the molecular diagnosis of pediatric cancers within the framework of the organizational proposals related to the implementation of precision medicine in our country.

## 1.4.4. Cancer data and information

Information as a whole is a useful tool for planning preventive, care and evaluation activities, as well as for establishing priority lines of research, helping to reduce the risk of cancer in the population and improving results. Cancer risk reduction requires information on both the causes of the disease and epidemiology in the general population. The generation of said information comes from different sources:

- Cancer risk factors: official statistics and population surveys.
- Cancer care services: cancer registries, prescription data, hospital administrative data, patient surveys and other sources.

The registry is the main pillar of cancer information systems. There are two different types of cancer registries:

- Population registries. This is the systematic collection of all new cases of cancer diagnosed among residents of a given geographic area and in a given period of time.
- Hospital registries. This constitutes a fundamental tool in monitoring the quality of care in hospitals.

Furthermore, the cancer data collection process requires very precise validation and quality control.

These norms are well defined internationally. On the one hand, there are basic principles that apply to all registries in the world and that are defined by the International Association of Cancer Registries (IACR) and, on the other, there are the standards and guidelines at the European level that are defined by the European Network of Cancer Registries (ENCR) in coordination with the IACR.

The situation of population-based cancer registries in Spain has changed since the strategy was last updated in 2009. On the one hand, new population registries have been developed in the Autonomous Communities and, on the other, part of these registries have been organized into a network constituting the Spanish Network of Cancer Registries (REDECAN).

Currently, there are 14 consolidated population-based cancer registries in Spain and together they cover a population of 12,581,900 inhabitants, which represents 27.05% of the total Spanish population. Furthermore, there are five unconsolidated population registries in different phases of consolidation and which cover a population of 12,113,700 inhabitants. Therefore, total coverage would represent 53% of the Spanish population **(Tables 21 and 22)**.

**Table 21. Consolidated global population records in Spain and percentage of the population covered.**

| Registry | Population | Percentage |
|---|---|---|
| Albacete | 396,684 | 0.85% |
| Asturias | 1,058,975 | 2.28% |
| Canary Islands: Gran Canaria | 1,014,131 | 2.18% |
| Canary Islands: Tenerife | 898,486 | 1.93% |
| Castellón | 578,213 | 1.24% |

**Table 21. Consolidated global population records in Spain and percentage of the population covered. (Cont.)**

| | | |
|---|---|---|
| Ciudad Real | 518,051 | 1.11% |
| Cuenca | 208,663 | 0.45% |
| The Basque Country | 2,167,166 | 4.66% |
| Girona | 743,124 | 1.60% |
| Granada | 920,484 | 1.98% |
| La Rioja | 315,223 | 0.68% |
| Mallorca | 869,111 | 1.87% |
| Madrid | 1,461,803 | 3.14% |
| Murcia | 636,450 | 1.37% |
| Tarragona | 795,328 | 1.71% |
| **Total** | **12,581,892** | **27.05%** |

Source: Registries report prepared by REDECAN

**Table 22. Unconsolidated global population records in Spain and percentage of the population covered.**

| Registry | Population | Percentage |
|---|---|---|
| Andalusia (except Granada) | 7,468,391 | 16.06% |
| Castile and Leon | 2,495,689 | 5.37% |
| Ceuta | 84,674 | 0.18% |
| Extremadura | 1,096,421 | 2.36% |
| Zaragoza | 968,552 | 2.08% |
| **Total** | **12,113,727** | **26.05%** |
| **TOTAL Spain** | **46,512,199** | **100.00%** |

Source: Registries report prepared by REDECAN

Although the current coverage of population cancer registries in Spain is 27%, if all the registries that have been created end up being consolidated, a coverage of 53% can be reached. This proportion is sufficient to make good estimates of the incidence of cancer in Spain; however, and due to the complexity of these types of registries, a great effort must still be made to ensure that this 53% corresponds to truly consolidated registries, with quality data recognized by the IARC and included in Cancer Incidence in Five Continents.

In addition to ensuring the maintenance of existing population registries and supporting the creation and consolidation of new registries, work must be done to define and develop a cancer information system that allows the incidence, prevalence and survival of cancer by Autonomous Community to be known.

Finally, it is also a priority that population registries include data on staging, multimorbidity, and follow-up (recurrences), as population registries in other European countries do. The availability of clinical data in the electronic medical record opens up the possibility of having accessible clinical data, although of variable quality (National Academies of Sciences, Engineering, and Medicine, 2019). Relevant research has been published using this data in areas such as therapeutic adherence combining real world data strategies with data from cancer registries that show the interest of this type of strategy and the benefits of the availability of computerized clinical data. (Font R, et al., 2019).

Since 1980, RETI has been a central registry specializing in childhood cancer, whose fundamental sources of information are all the pediatric oncology and hematology units in Spain. It has currently reached 94% coverage of childhood cancer in Spain and around 100% in five Autonomous Communities (Aragon, Catalonia, Madrid, Navarra and the Basque Country). There is also a population registry of childhood cancer that covers the entire pediatric population of the three provinces of the Valencian Community, as well as a registry of childhood tumors in Castile and Leon, covering the entire Autonomous Community.

Unlike the objective difficulties that exist in obtaining full coverage of adult cancer in Spain, in the case of childhood cancer it would be a possibility.

An effort to consolidate the five pending population registries will mean significant added value to cancer information, since they represent a large percentage of the national population. Strategic lines oriented towards the digitization of tools for greater agility seem fundamental to us in order to obtain more up-to-date information than is currently available. Exploring and strengthening other cancer information systems complementary to registries, taking advantage of the digitization of medical records, etc. seems to be one of the priority strategic lines.

REDECAN and RETI-SEHOP have been recognized as registries of interest for the National Health System by the Ministry of Health.

**Priorities for action**

Population registries:

- Define the geographic and administrative area that must be covered by population registries.

- Enrich the information collected in population registries with other sources of information both nationally and internationally.
- Favour the disaggregation of data by sociodemographic variables, as well as their disaggregation to the smallest possible territorial level.
- Evaluate the possibilities opened up by the availability of computerized clinical data through shared clinical history in order to evaluate clinical results and complement the information from population registries.

In population registries of adults:

- Ensure the maintenance of existing population cancer registries. Register the tumor stage systematically and exhaustively, as well as other variables of interest.
- Support the creation of new population registries and their consolidation after they are created.

In childhood cancer registries:

- Achieve complete coverage of the population.

## 1.4.5. Research

**Funding for cancer research**

Research funding in Spain comes from various sources, although the most relevant both from the point of view of the number of projects funded and the amount dedicated is that from the Carlos III Health Institute. This institute, in addition to funding competitive projects, also funds the National Cancer Research Centre (CNIO) and the National Center of Epidemiology.

The Autonomous Communities have various research funding programmes through health plans, calls and specific programmes and centres that prioritize cancer research.

In recent years, the AECC has been the main private entity that funds cancer research in our country. Other programmes with private funding from non-profit associations are also relevant in different territorial areas.

**Creation and consolidation of research groups**

Currently, there is an Oncology Network Biomedical Research Centre (CABER) with around 50 research groups in the traditional fields of basic, transnational and clinical research.

The SEAN Clinical Trials Platform (Spines Clinical Research Network) was created in 2013, within the framework of the Call for Strategic Action in Health 2013-2016, with the aim of supporting the undertaking of clinical trials. The Platform, is currently made up of 29 Clinical Research and Clinical Trials Units (UICEC) located in health centres. Their common objective is to facilitate excellent quality clinical research, by identifying relevant hypotheses, providing adequate support to turn them into projects carried out safely and efficiently, and disseminating and transferring the knowledge generated to the Health System and the productive system, albeit with very limited funding.

The BEST project (initiative for excellence in clinical research, led by Farmaindustria, which integrates the pharmaceutical industry, public and private hospitals, independent clinical researchers and Autonomous Communities on the same platform) periodically provides data on the clinical research carried out in our country. Of the total number of clinical trials followed in the BEST project, one third or more correspond to the therapeutic area of oncology, giving an idea of the significance of clinical research in our country. The number of clinical trials in the initial phases of the evaluation of efficacy in our country is noteworthy and has been increasing in recent years, with some highly specialized units in this type of research.

The Health Research Institutes (IIS) are entities dedicated to basic and applied research, created by an association of hospitals of the National Health System, universities, public research organizations and other public or private research centres, with the effect of establishing multidisciplinary research institutes.

The main mission of the IIS is, therefore, to carry out translational research of the highest quality, translating the results of basic, clinical, epidemiological, health services and public health research to the Spanish National Health System, the Spanish Science and Technology System, the patient and society in general.

Most of the IIS develops lines of research in cancer: Of the 29 accredited IIS, 27 have a specific research area in the field of oncology, under different denominations and orientations. All accredited IIS have some line or research group in the field of oncology.

**Scientific and Technological Results**

Scientific production in the field of oncology has increased significantly in recent decades in our country. Since 1996 there has been an increase of 2.5 times in the number of publications. The growth trend is also more marked than in other disciplines.

**European Union Mission on Cancer**

The development of the Mission on Cancer of the European Commission, an initiative that will serve as a guide for the approach to cancer during the coming years in the Horizon Europe 2021-2027 Framework Programme, continues on its course. The European Plan to Fight Cancer, through the EU4HEALTH programme, will also contribute to the aims and recommendations of the Mission on Cancer. Spain, with different agents and institutions among which the ISCIII has an outstanding position, continues to work through the formation of a national mirror group to collaborate in the tuning of the Mission, which hopes to be defined by mid 2021, when the first calls are expected to be made public.

As an integral part of the Horizon Europe Research Framework Programme (2021-2027), which replaces Horizon 2020 from next year, the European Union is proposing Missions to advance the search for solutions to some of the biggest societal challenges and achieve progress based on scientific knowledge, with cancer being one of them. Since September 2019, after the Steering Committees ('Mission Boards') were formed, the strategy and roadmap have been being created to prepare the missions, whose activity and development would begin as of 2021.

The Cancer Mission has as a global objective achieving progress in the next decade that will save at least 3 million lives in Europe. In general terms, it seeks to extend the life expectancy of cancer patients, achieve a better quality of life for survivors and families-and consolidate mechanisms that prevent or delay the onset of the disease.

Specifically, 13 actions are proposed that are grouped into five acting areas. The Mission on Cancer believes that in order to achieve effective interventions in the pillars of prevention, diagnosis and treatment, and to improve the quality of life of the population, a better comprehensive understanding of the disease is necessary. Finally, and as a transversal pillar, it is expected to achieve equitable/equal access to all interventions that are carried out in all EU countries. The recommendations are as follows:

- Launch of UNCAN.eu, a European platform to share data, resources, infrastructure, investment, samples and knowledge concerning cancer research.
- Development of a European research programme for the management of genomic information and the application of bioinformatics in the study of genetic variability against cancer.
- Promote the implementation of preventive policies shared between Member States with the creation of a specific European organization that facilitates their development.
- Optimize technologies and programmes for screening and early detection of cancer.

- Move forward with the development of personalized medicine which guarantees equal access to new treatments and advances.
- Create a shared European research programme focused on early diagnosis and the development of minimally invasive therapeutic technologies.
- Launch of a specific programme concerning the quality of life of patients and survivors, which includes care for families and people at special risk of developing the disease.
- Create a European Digital Centre for Cancer Patients that manages interoperable tools for shared and secure management of individual data on diagnostic tests, biomarkers, clinical advances and lifestyle.
- Create a specific initiative to guarantee equitable access to prevention, diagnosis, treatment and quality of life, regardless of Member State and demographic or social circumstances.
- Creation of a Network of Infrastructures shared between all Member States that homogeneously increases the quality of research and care in Europe.
- Create a specific care and management programme for childhood and adolescent cancer.
- Create a European network of Living Labs specialized in cancer that favour the shared boosting of scientific and socio-economic needs concerning cancer.
- Transform and promote communication in oncology and the social culture concerning cancer, with a programme focused on the participation of professionals and patients.

**Priorities for action**

In order to respond to the main challenges of cancer research in Spain described above, the following are proposed as priority lines of action:

- Promote the funding of cancer research as a priority area of research policy. The development of the European Union Mission on Cancer and the priority research areas defined in its initial programme should be considered as the way forward to also consolidate cancer research in the context of the Spanish National Health System.
- Move forward in the consolidation and coordination of integrated research units that allow an approach to lines of basic, clinical, epidemiological and translational research. Strengthen strategies for the incorporation of Spanish groups in projects of international scope.
- Promote integrated strategies between the different governmental entities and non-governmental non-profit foundations that manage

R&D calls at the state or regional level. Coordinate strategies with the framework offered by the EU Mission on Cancer and the European Beating Cancer Plan.

- Promote the funding and performance of academic clinical research by Spanish National Health System researchers/health professionals, as well as promote the research career of these professionals (PhD, MD, etc.) in the National Health System.
- Continue developing tissue biobank networks.
- Promote research that allows the generation of evidence for the correct application of tests with cancer biomarkers, target populations, validation and quality of tests, etc.
- Promote research on different screening strategies for which there is not yet enough evidence.
- Develop research in areas of growing interest such as early stages of the disease, immunotherapy and combined therapies, in the methodology of psychological intervention and nutritional assessment in patients.
- Boost clinical research into rare tumors.
- Boost research on socio-sanitary aspects that affect long-term survivors.
- Develop lines of research related to the evaluation of clinical results in oncology and health results in relation to quality of care, allowing comparison between hospitals and Autonomous Communities.
- Boost research into health promotion and cancer prevention.
- Promote basic, clinical and applied research into cancer immunotherapy focused on the search for new, more effective strategies, biomarkers and application of treatments in the earliest phases of different neoplastic diseases.
- Promote scientific research that addresses the differences between women and men in relation to the protection of their health, especially with regard to accessibility and diagnostic and therapeutic effort, reflected both in the field of clinical trials and care.

# 2. Strategy Execution

The European Beating Cancer Plan was approved on 3 February 2021 to ensure quality care for cancer patients in the European Union. It defines ten main initiatives and multiple supporting actions (https://ec.europa.eu/info/strategy/priorities-2019-2024/promoting-our-european-way-life/european-health-union/cancer-plan-europe_en). The Spanish National Health System Cancer Strategy will be aligned with the objectives of the European Beating Cancer Plan.

## 2.1. Health promotion and cancer prevention

### 2.1.1. Health promotion and primary prevention

The Cancer Strategy will be aligned with the objectives of the Health Promotion and Prevention Strategy of the National Health System, the Strategy for Nutrition, Physical Activity and Prevention of Obesity and with the National Strategy for Sexual and Reproductive Health, the Strategy for Addressing Chronicity in the National Health System, the National Health and Environment Plan and the Spanish Strategy for Safety and Health at Work in the areas of tobacco, alcohol, physical activity and nutrition, breastfeeding and work health.

**Objective 1.** Advance in Health and Equity in All Policies by collaborating with other sectors to make it easier for them to include actions that create healthy environments and policies among their priorities.

**Actions:**

- Promote intersectoral coordination work at the national level, in each community and at the local level, to advance Health and Equity in all actions.
- Promote structural and environmental measures in line with the best investments and other interventions for cancer prevention and control recommended by the WHO.

**Objective 2:** Promote healthy lifestyles and environments in the population, throughout the entire course of their life, by coordinating interventions with a population-based, comprehensive, and positive approach, in the areas of work, health, family, community, and education, mainly addressing the following health-related behaviour:

- Healthy eating from birth.
- Physical activity and sedentary lifestyle.
- Alcohol use.
- Use and exposure to environmental tobacco smoke and related products.
- Environmental pollution.
- Exposure to the sun.
- Exposure to occupational carcinogens.

**Actions:**

- The actions related to Objective 2 are framed within the actions prioritized in the Health Promotion and Prevention Strategy of the Spanish National Health System, the National Health and Environment Plan and in the Spanish Strategy for Safety and Health at Work.
- Disseminate the European Code against Cancer among healthcare professionals, patient associations, patients and the public.
- Disseminate the healthy lifestyles website within the framework of the Health Promotion and Prevention Strategy of the Spanish National Health System.
- Continue with online training for health professionals in Primary Care, Occupational Health and Hospital Care within the framework of the Health Promotion and Prevention Strategy of the Spanish National Health System.
- Strengthen institutional collaboration within the National Committee for Safety and Health at Work for the development of public policies for occupational risk prevention.
- Develop specific inspection actions aimed at promoting, facilitating and ensuring compliance with the regulations.

**Objective 3:** Improve the information and surveillance system for occupational cancer and carcinogens in the workplace.

**Actions:**

- Maintain and improve the Registry of Workers Exposed to Asbestos (RETEA).
- Guarantee the continuation of the post-occupational health surveillance of the cohorts included in the Comprehensive Health Surveillance Programme for Workers Exposed to Asbestos (PIVISTEA).
- Improve the identification and diagnosis of cancers derived from exposure to asbestos.
- Estimate the burden of cancer attributable to work and its healthcare cost in Spain.

- Strengthen, extend and harmonize the communication systems of suspicions of occupational disease identified by the medical staff of the National Health System and the prevention services, from the health administrations.

**Objective 4:** Promote medical-legal recognition of occupational cancer.

**Actions:**

Inform the managing and collaborating entities of the Social Security (mutual societies), for the purposes of qualification, of suspicions of occupational disease identified by the medical staff of the Spanish National Health System and prevention services.

**Objective 5:** Evaluate the health impact of exposure to radon in the Spanish population and develop actions aimed at reducing this impact.

**Actions:**

- Compile the scientific and technical evidence that serves as a basis for the preparation and implementation of a National Action Plan Against Radon.
- Establish a regulatory framework that protects the population with regards to new housing.
- Estimate the burden of cancer attributable to radon in Spain.

**Objective 6:** Achieve HBV vaccination coverage in boys and girls 12 months of age equal to or greater than 95% with three vaccination doses, in all Autonomous Communities and in accordance with the vaccination schedule agreed upon by the Spanish National Health System Interterritorial Council.
**Objective 7:** Achieve an HPV vaccination coverage in adolescents of 15 years of age equal to or greater than 80%, with the full vaccination schedule, in all the Autonomous Communities and in accordance with the vaccination schedule agreed upon by the Spanish National Health System Interterritorial Council.

## 2.1.2. Early detection

**Objective 8:** Early detection of breast cancer.

a) Carry out early detection of breast cancer always within the framework of organized population-based programmes and in accordance with the criteria contained in Royal Decree 1030/2006 (modified by Order SSI/2065/2014):

- Target population: women 50-69 years of age.
- Screening test: Mammogram.
- Time interval between examinations: 2 years.

b) Obtain a minimum of 70% participation in breast cancer screening programmes.

**Actions:**

- Promote actions to raise awareness and improve the accessibility of the target population in order to increase the rate of participation in the programme.
- Evaluate technological innovations in relation to screening programmes that appear on the market and their possible incorporation into the programme.

**Objective 9:** Early detection of cervical cancer.

a) Carry out early detection of cervical cancer always within the framework of organized population-based programmes and in accordance with the criteria contained in Royal Decree 1030/2006 (modified by Order SCB/480/2019):

- Target population: Women aged between 25 and 65 years.
- Primary screening test and interval between scans:
- Age 25-34 years: cytology every 3 years.
- Age 35-65 years: determination of high-risk human papillomavirus (HR-HPV):
  a. If HR-HPV is negative, repeat HR-HPV test at 5 years.
  b. If HR-HPV is positive, triage with cytology. If cytology is negative, repeat HR-HPV after one year.

b) Carry out the transition from opportunistic screening to organized population-based screening with the aim that all programmes have started before 2024 and full invitation coverage has been reached before 2029.

c) Obtain a minimum of 70% participation in cervical cancer screening programmes.

**Actions:**

- Promote actions to raise awareness and improve the accessibility of the target population in order to increase the rate of participation in the programme.
- Promote the transition from opportunistic screening to organized population-based screening.

- Establish recommendations, within the framework of the Spanish National Health System, concerning cervical cancer screening in women vaccinated against HPV.
- Assess for each Autonomous Community, and within its organizational model, the introduction of self-sampling for HPV, as a form of initial screening or to increase the participation of women who do not attend.

**Objective 10:** Early detection of colorectal cancer.

a) Undertake early detection of colorectal cancer always within the framework of an organized population-based programme and in accordance with the criteria contained in Royal Decree 1030/2006 (modified by Order SSI/2065/2014):

- Target population: 50-69 age range, in an initial stage.
- Screening test: fecal occult blood test.
- Time interval between examinations: 2 years.

b) Promote the implementation of these programmes with the aim of reaching full invitation coverage before the year 2024.

c) Obtain a minimum of 65% participation in colorectal cancer screening programmes.

**Actions:**

- Promote actions to raise awareness and improve the accessibility of the target population in order to increase the rate of participation in the programme.

**Objective 11:** Guarantee assessment, follow-up and access to appropriate care devices for people who have personal risk factors, and people who meet criteria for high risk of familial or hereditary cancer, in order for them to obtain advice (information and proposals for action) and follow-up appropriate to their risk, through specific action protocols.

**Actions:**

- Create multidisciplinary units for familial and hereditary cancer.
- Agree on the criteria for suspecting and including a person in a follow-up programme for familial and hereditary cancer.

**Objective 12:** Promote the development of information systems for cancer screening programmes in each Autonomous Community and City with Autonomy Statute that allow the application of the recommended screening

protocols, as well as the comprehensive management of the different programmes and evaluation of processes, results and their impacts both at the level of each Autonomous Community and for the whole of the National Health System.

**Objective 13:** Not carry out screening activities for other types of cancer, either on a population basis or on an opportunistic basis, until its efficacy and effectiveness can be demonstrated in terms of health impact, compensating for any adverse effects that derive from it being carried out.

**Actions:**

- Establish information plans among professionals about the inefficiency (and effects of overdiagnosis) of carrying out, in an asymptomatic population, tests for early detection of cancer when there is no evidence of it.
- Maintain, in coordination with the Population Screening Report and the Spanish Network of Agencies for Assessing National Health System Technologies and Performance, a line of periodic evaluation of the evidence of the screening of other types of cancer to find out if they are efficacious and effective in terms of health impact.

**Objective 14:** Not carry out screening programmes in the workplace, except those in relation to specific occupational risks. These programmes will be carried out in coordination with the population programmes if they are implemented.

**Objective 15:** Improve the early detection of cancer associated with exposure to occupational carcinogens through the development and application of guidelines and protocols for specific health surveillance in high-risk populations.

**Actions:**

- Development of guides and protocols for monitoring the health of workers exposed to occupational carcinogens.

## 2.2. Health care

### 2.2.1. Care model

**Objective 16:** Every hospital that cares for cancer patients will set up multidisciplinary units/tumour committees according to their needs and volume of care, which will have to:

- Define the make up and responsibility of its members.
- Have a professional nursing liaison figure or case management nurse in order to, from multidisciplinary oncology care, prevent or alleviate possible failures in communication and/or coordination between different professionals during the process and between the patient and the health system.
- Have a reference physician who will inform each patient of the committee's decisions and with whom they will discuss the different treatment options. Likewise, they will be the reference person in contact with the primary care physician.
- Establish the frequency of meetings.
- Have a clinical action protocol for each type of tumour.
- Have a work methodology for the presentation of cases and the formulation of therapeutic decisions.
- Have systematized the record of the therapeutic decision in the patient's clinical history.
- Establish the patient information process through standard operating procedures, although personalizing the information process is essential.
- Have protocols for referral and follow-up to other services, centres and/or autonomous communities.
- Have procedures and systems to include patients in clinical trials.
- Have a quality assessment procedure with specific indicators for this assessment.

**Objective 17:** Diagnostic confirmation, treatment planning, and follow-up of cancer patients (excluding non-melanoma skin tumours) should be performed in a multidisciplinary unit/tumour committee.
**Objective 18:** Centralize rare tumours and highly complex procedures in healthcare units of reference (the RARECARE definition and list of rare tumours are used). It is considered necessary for the units that treat cancer patients to attend to a minimum number of cases each year, which will be determined based on a certain type of cancer.

**Actions:**
- Establish the minimum threshold of people with rare tumours and highly complex oncological processes that must be performed annually for quality care.
- Establish regional reference centres for the care of rare tumours and highly complex oncological processes.
- Complete the CSUR designation for the care of rare tumours and highly complex procedures.

**Objective 19:** Establish a network care model for cancer patients that guarantees access to suitable resources and continuity of care for each patient (primary care, regional hospital care, regional reference centre, CSUR and European reference network); especially in the case of rare tumours and highly complex procedures.
**Actions:** Define the network care model in the Spanish National Health System that includes the tools to facilitate work at the different levels of the Health System.
**Objective 20:** Improve the diagnostic suspicion of cancer, both in adults and in children and adolescents.

**Actions:**

- Implement training courses aimed at primary care doctors and nurses to improve the identification of suspected cancer.
- Develop and disseminate evidence-based products for early detection in childhood and adolescence.

**Objective 21:** Establish rapid diagnostic channels between the primary care level and hospital care in the event of signs or symptoms of suspected oncological pathology of the most frequent tumour types (especially breast, colorectal, lung, prostate, ovarian, bladder, haematological cancer and melanoma).

- Maintain a median of seven days from the time the patient is referred from the primary care level to the first visit at the hospital care level.
- And a median of 15 days from the first visit at the hospital level of care to pathological diagnosis of cancer or absence thereof.
- If the diagnosis involves a molecular study, the median from the first visit at the hospital care level until the complete pathological diagnosis will be four weeks.

**Objective 22:** Reduce the time elapsed from the diagnosis of cancer (including the extension study and the complete pathological study) until the effective start of treatment.

- Surgical treatment: an average of two weeks is recommended.
- Systemic treatment: an average of one week is recommended.
- Radiotherapy: an average of four weeks is recommended (including the planning process).

**Objective 23:** Have radiotherapy equipment updated systematically by the Spanish National Health System throughout the period of action of this Strategy.

**Actions:**

- Prepare a map of radiotherapy resources in the Spanish National Health System, with the technological characteristics of the equipment and its age.
- Define obsolescence criteria to assess the renewal of radiotherapy oncology equipment.

**Objective 24:** Promote the development of agreed protocols between the medical oncology, clinical haematology and radiotherapy oncology service and the emergency service for the adequate and continuous care of cancer patients who come to the emergency room, in the emergency service itself or in/with cancer care resources.

**Objective 25:** Agree on the organizational model of precision oncology in the National Health System.

**Actions:**

- Define the organizational model of precision oncology agreed upon in the Spanish National Health System.
- Propose to the Benefits, Assurance and Financing Commission that molecular and genetic alterations in oncology, which should form part of the common basket of Spanish National Health System services, be assessed.
- Establish experience and quality criteria to evaluate the services that perform these analyses and which are a reference in each Autonomous Community.

**Objective 26:** Improve pathology diagnosis taking into account the precision oncology framework:

**Actions:**

- Promote quality control mechanisms in the anatomo-pathological diagnosis of tumors, promoting the participation of Anatomy Pathology services in the ISO standard, and participation in external quality controls that guarantee the reproducibility of the analysis and interpretation of tissue biomarkers of diagnostic, prognostic and predictive importance.
- Implement a double reading diagnostic test system for pathology in rare tumors, performed by an expert pathologist from a designated reference centre.

**Objective 27:** Promote knowledge and communication skills of care professionals with patients for shared decision-making using the best available

evidence. Information given to the patient should be communicated in a realistic, understandable, and empathic manner based on trust.

**Actions:**

- Launch training courses for professionals who care for people with cancer to improve relationship and communication skills. Collaboration between the different scientific societies and patient associations involved will be facilitated or encouraged.
- Provide patients, family members and caregivers with sources of information and training tools by making the best available evidence available through the Network of Health Schools for Citizens.
- Include courses in relationship and communication skills of healthcare professionals with patients in the transversal training plans of specialized health training.

**Objective 28:** Use a standardized tool in cancer care for the early detection of emotional distress validated in Spanish that makes it possible to identify, from the moment of initial diagnosis, those people with cancer, their relatives and caregivers who may need psychological care, establishing an early referral protocol for psychological intervention in these cases.

**Actions:**

- Select the most appropriate standardized tool/s for the early detection of emotional distress.
- Introduce the tool in the clinical history.
- Prepare referral protocols for specialized psychological care.
- Carry out a study of the psychological impact of cancer and its treatments within the framework of the Spanish National Health System.

**Objective 29:** Promote the referral protocols to the Human Reproduction Units for counselling in relation to the preservation of fertility in patients of childbearing age and who wish to have children.

## 2.2.2. Monitoring and quality of life

**Objective 30:** Provide social care for cancer patients and their families, according to their needs.

**Actions:**

- Carry out a study of the work, psychological and social impact of people with cancer and their families, within the framework of the Spanish National Health System.

- Establish together with the affected person/family member an individualized plan in which the intervention to be carried out is contemplated. The tools to be used for this will be detailed: the rights that correspond to them, the resources they can access, recognition (disability, permanent disability, dependency, etc.), reinforcing the information regarding the disease and its evolution, as well as tools for returning to everyday life.

**Objective 31:** Once the initial treatment and follow-up is finished, establish and deliver an individualized follow-up plan to each patient in writing.

**Actions:**

- Define an individualized follow-up plan model, which includes, at least, the treatments received, possible medium- and long-term side effects and toxicities that may have arisen during treatment, sequelae, care plan and psychological care.

**Objective 32:** Establish follow-up channels for patients without disease at present, who have completed their treatment and initial follow-up, between primary care and hospital in a coordinated and protocolized manner by mutual agreement. Under consideration are those patients without observable disease, who are no longer receiving treatment, with at least a period of five years having elapsed since diagnosis.

### 2.2.3. Palliative care

**Objective 33:** The Cancer Strategy will be aligned with the objectives contained in the Spanish National Health System Palliative Care Strategy and with the Paediatric Palliative Care Criteria in the Health Service, approved on 11 June 2014.

## 2.3. Health care for children and adolescents

**Objective 34:** Implement and evaluate the agreement on the organization of care for childhood and adolescent cancer approved by the Plenary of the Interterritorial Council of the Spanish National Health System on 15 November 2018.

The agreed measures to be implemented are the following:

1. Creation of a regional care coordination committee for the management of care in all cases of childhood and adolescent cancer

in each Autonomous Community. This committee must be created and defined through the relevant regulations. The constitution and functions of the committee are described in the annex.

2. Concentration of care in paediatric onco-haematology units. This model implies designating, through the relevant regional regulations, paediatric onco-haematology units in the Autonomous Communities, which will attend to the volume of patients necessary for optimum care. (SIOP Europe (The European Society for Paediatric Oncology) recommends treating at least 30 new cases per year in order to gain sufficient experience). Adolescent patients up to 18 years of age (18-year-old patients are not included) should be treated in paediatric units, unless there is the possibility of caring for them in specific units for their age group. Care for adolescents will be carried out jointly between paediatric onco-haematology professionals and adult oncology when the type of tumour requires it.

   The criteria that paediatric oncology units must meet are described in the annex.

3. Each Autonomous Community should adopt one of the following organizational models:

   a) Network model based on one or several paediatric onco-haematology units. The criteria and composition of the network are described in the annex.
   b) Referral of all cases to another Autonomous Community. When the total volume of cases is not sufficient considering the reference population and territorial distribution, agreements will be adopted with other Autonomous Communities to provide optimal care.

## 2.4. Cancer data and information

**Objective 35:** Define and develop a cancer information system that allows the incidence, prevalence and survival of cancer by Autonomous Community to be known.

**Objective 36:** Hospitals that treat patients with cancer will have an information system and will establish a methodology for evaluating clinical results in patients who have been totally or partially treated in said centre (survival according to stage at diagnosis, percentage of recurrences, surgical mortality at 30 days or within the same hospital admission). Feedback on the results will be provided to the professional teams and committees involved

in the treatment of tumours and the incorporation of measures to improve these results.

## 2.5. Research

**Objective 37:** Maintain and promote cancer research as a priority area in the main policies and funding instruments for biomedical research in our country. Possible areas to consider include: a) cancer screening strategies, early detection and early phases, health promotion and disease prevention, at the population level, applied to cancer risk factors; b) low-invasiveness and liquid biopsy diagnostic methods; c) dynamic biomarkers of recurrent, resistant or transforming disease; d) new therapies, advanced therapies and drug repositioning; e) radiobiology applied to oncology and radioresistance; f) precision surgery, robotics and reduction of amputations; g) rare tumours with high mortality and no therapeutic options; h) socio-labour rehabilitation and illness-work balance; i) incurable paediatric tumours; j) nutrition, psycho-oncology, palliative and continuing care; k) end-of-life care for cancer patients and freedom of decision; l) health services and health outcomes; m) results reported by the patient (Patient Report Outcomes-PRO).

**Objective 38:** Promote networks and groups of excellence in cancer research that are interconnected in a coordinated and cooperative manner within the framework of the CIBER and the health research institutes accredited by the ISCIII.

**Objective 39:** Promote clinical trials initiated by Spanish National Health System research staff to explore questions without commercial interest or consequences, as well as for the development of products generated from academic research of the National Health System.

**Objective 40:** Promote and value the training and research activity of health personnel belonging to the Spanish National Health System.

# 3. Strategy Evaluation

The evaluation, understood as a systematic, ongoing process which designs, obtains and provides scientifically valid, reliable and useful information for decision-making purposes, is an absolutely indispensable aspect of the Cancer Strategy of the Spanish National Health System and is understood as being an integral part thereof so as to be able to carry out continuing improvement in the approach for dealing with this illness.

The patients are the ones who clearly benefit from the evaluation, given that it contributes toward fostering, providing incentives for and improving integral cancer care by means of the control and optimization of the objectives put forth in the Strategy.

But the integral cancer care set out in the strategy, with the objectives which are taken into account ranging from health promotion to the quality of life of cancer patients, undoubtedly poses a challenge for the health system from the standpoint of its evaluation.

Hence, this strategy evaluation is conceived as the result of combining two main aspects:

- Indicators which can be extracted from the National Health System information system.
- Specific information gathered by means of designing a questionnaire for collecting information following an agreement with the monitoring Committee concerning the items and criteria for completing the questionnaire.

## 3.1. Indicator Table

**Indicators, by line of strategy and source of information**

**Cancer Strategy Evaluation Indicators of the Spanish National Health System and agencies or institutions responsible for collecting the information**

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| **1. Health promotion and cancer prevention.**<br>**1.1. Health promotion and primary prevention** | **Objective 1** | Intersectoral coordination board | Dichotomous (yes/no) | **MH**<br>**AC** |
| | **Objective 2** | Percentage of the population that consumes fruit or vegetables daily | Equation: (a/b) × 100<br>a= Number of people who state that they consume fruit or vegetables on a daily basis in the survey<br>b= Total population taking part in the survey | **MH** |
| | | Prevalence of obesity | Equation: (a/b) × 100<br>a= Number of people with obesity<br>b= Total population taking part in the survey | |
| | | Prevalence of a sedentary lifestyle | Equation: (a/b) × 100<br>a= Number of people who report being sedentary in their free time<br>b= Total population taking part in the survey | |
| | | Prevalence of alcohol consumption above the low risk limits in adults | Equation: (a/b) × 100<br>a= Number of individuals aged 15 or older who state that they drink alcohol in amounts considered to be above the low risk limits<br>b= Population aged 15 and over taking part in the survey | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Percentage of adults who use tobacco | Daily smokers:<br>• Equation: (a/b) × 100<br>a= Number of people aged 18 and over who declare themselves to be smokers in the survey<br>b= Number of people aged 18 and over taking part in the survey<br>Occasional smokers:<br>• Equation: (c/b) × 100<br>c= Number of people aged 18 and over who declare themselves to be occasional smokers in the survey<br>b= Number of people aged 18 and over taking part in the survey | |
| | **Objective 3** | Workers exposed to asbestos included in the Registry of Workers Exposed to Asbestos (RETEA) | Number of workers exposed to asbestos included in the RETEA | **RETEA** |
| | | Workers exposed to asbestos included in the RETEA monitored in the Health Surveillance Programme for Workers Exposed to Asbestos (PIVISTEA) | Equation: (a/b) × 100<br>a= Number of workers exposed to asbestos monitored in the PIVISTEA<br>b= Number of workers exposed to asbestos included in the RETEA | **PIVISTEA RETEA** |
| | | Burden of cancer attributable to work and its healthcare cost in Spain | Dichotomous (yes/no) | **MH** |
| | **Objective 4** | | | |
| | **Objective 5** | Burden of cancer attributable to radon in Spain | Dichotomous (yes/no) | **MH** |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | **Objective 6** | HBV vaccination coverage | Equation: (a/b) × 100<br>a= Number of 12-month-old boys and girls vaccinated with three doses against HBV<br>b= Total population of 12-month-old boys and girls | **MH** |
| | **Objective 7** | HPV vaccination coverage | Equation: (a/b) × 100<br>a= Number of 15-year-old adolescents vaccinated with two doses against HPV<br>b= Total population of 15-year-old adolescents | |
| **1. Health promotion and cancer prevention. 1.2. Early detection** | **Objective 8** | Coverage (annual) in the early breast cancer detection programme | Equation: (a/b) × 100<br>a= Number of women between the ages of 50 and 69, both inclusive, who have been offered the chance to participate in the breast cancer early detection programme<br>b= Number of women between 50 and 69 years of age and resident in the Autonomous Community on 31 December of the year being evaluated | **Spanish National Health System information system** |
| | | Participation in the early breast cancer detection programme | Equation: (a/b) × 100<br>a= Number of women between the ages of 50 and 69, both inclusive, who have participated in an organized, population-based early breast cancer detection programme<br>b= Number of women to whom this test has been offered | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Breast cancer detection rate | Equation: (a/b) × 100<br>a= Number of women who, after carrying out the necessary tests for the early diagnosis of breast cancer, are given confirmation of a diagnosis of cancer<br>b= Number of women who have had a screening mammogram | |
| | | Percentage of women who have had a mammogram | Equation: (a/b) × 100<br>a= Number of women within the 50-69 age range who state they have had a mammogram within the two-year period immediately prior to the survey<br>b= Total number of women within the 50-69 age range who were surveyed | **ENSE** |
| | **Objective 9** | Coverage in the early cervical cancer detection programme | Equation: (a/b) × 100<br>a= Number of women between the ages of 25 and 65, both inclusive, who have been offered the chance to participate in the cervical cancer early detection programme<br>b= Number of women between 25 and 65 years of age and resident in the Autonomous Community on 31 December of the year being evaluated | **Spanish National Health System information system** |
| | | Participation in the early cervical cancer detection programme | Equation: (a/b) × 100<br>a= Number of women between the ages of 25 and 65, both inclusive, who have participated in an organized, population-based early cervical cancer detection programme<br>b= Number of women to whom this test has been offered | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Cervical cancer detection rate | Equation: (a/b) × 100<br>a= Number of women who, after carrying out the necessary tests for the early diagnosis of cervical cancer, are given confirmation of a diagnosis of cancer<br>b= Number of women who have been screened for cervical cancer | |
| | | Percentage of women who have had cytology or HPV screening performed | Equation: (a1/b1) × 100<br>a1= Number of women within the 25-34 age range who state they have had cytology performed within the three-year period immediately prior to the survey<br>b1= Total number of women within the 25-34 age range who were surveyed<br>Equation: (a2/b2) × 100<br>a2= Number of women within the 35-65 age range who state they have had an HPV cytology test performed within the five-year period immediately prior to the survey<br>b2= Total number of women within the 35-65 age range who were surveyed | **ENSE** |
| | **Objective 10** | Coverage in the early colon cancer detection programme | Equation: (a/b) × 100<br>a= Number of people between the ages of 50 and 69, both inclusive, who have been offered the chance to participate in the colon cancer early detection programme<br>b= Number of people between 50 and 69 years of age, both inclusive, and resident in the Autonomous Community on 31 December of the year being evaluated | **Spanish National Health System information system** |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Percentage of people who state they have had a faecal occult blood test measurement carried out | Equation: (a/b) × 100<br>a= Number of people between the ages of 50 and 69 who have the faecal occult blood test done<br>b= Number of people between the ages of 50 and 69 who were given the possibility of having this test done | |
| | | Percentage of people who have had faecal occult blood tests done | Equation: (a/b) × 100<br>a= Number of people between the ages of 50 and 69 who state they have had a faecal occult blood test done<br>b= Total number of people within the 50-69 age range who were surveyed | **ENSE** |
| | | Percentage of faecal occult blood tests which tested positive | Equation: (a/b) × 100<br>a= Number of people between the ages of 50 and 69 who tested positive for the faecal occult blood test<br>b= Number of people who have been screened | **Spanish National Health System information system** |
| | | High-risk adenoma detection rate | Equation: (a/b) × 100<br>a= Number of people within the 50-69 age range in whom, after having taken the screening test and all of the other tests necessary for confirming a diagnosis, a high-risk adenoma is found to exist<br>b= Number of people who have been screened | |
| | | Invasive colorectal cancer detection rate | Equation: (a/b) × 100<br>a= Number of people within the 50-69 age range in whom, after having taken the screening test and all of the other tests necessary for confirming a diagnosis, invasive colorectal cancer is found to exist<br>b= Number of people who have been screened | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | **Objective 11** | Document agreeing on the criteria for suspecting and including a person in a follow-up programme for familial and hereditary cancer | Dichotomous (yes/no) | **MH** |
| | **Objective 12** | Information system for population cancer screening programmes | Equation: (a/b) × 100<br>a= Number of Autonomous Communities and Cities with an Autonomy Statute that have an information system that allows evaluation of the Programme<br>b= Total number of Autonomous Communities and Cities with Autonomy Statute | **AC** |
| | | Annual evaluation report of population cancer screening programmes | Equation: (a/b) × 100<br>a= Number of Autonomous Communities and Cities with an Autonomy Statute that have an annual report evaluating the Programme<br>b= Total number of Autonomous Communities and Cities with Autonomy Statute | |
| | **Objective 13** | | | |
| | **Objective 14** | | | |
| | **Objective 15** | | | |
| **2. Health care**<br>**2.1. Care model** | **Objective 16** | Multidisciplinary tumour units/tumour committee | Equation: (a/b) × 100<br>a= Number of hospitals caring for cancer patients with multidisciplinary tumour units/tumour committees set up<br>b= Number of hospitals evaluated that care for cancer patients | **Audit**<br>**MH** |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | **Objective 17** | Patients diagnosed with cancer assessed by a multidisciplinary unit/tumour committee | Equation: (a/b) × 100<br>a= Number of patients diagnosed with cancer (excluding non-melanoma skin tumours) who have been assessed by a multidisciplinary tumour unit/tumour committee<br>b= Number of patients diagnosed with cancer (excluding non-melanoma skin tumours) | |
| | **Objective 18** | Minimum threshold of patients with rare tumours and highly complex oncological processes that must be performed annually for quality care | Dichotomous (yes/no) | **MH** |
| | | Regional reference units designated for the health care of patients with rare tumours and for highly complex procedures | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with regional reference units designated for the health care of patients with rare tumours and for highly complex procedures<br>b= Total num. of Autonomous Communities | **AC** |
| | | CSUR of the Spanish National Health System for the care of rare tumours and highly complex procedures | Equation: (a/b) × 100<br>a= Number of rare tumours and highly complex procedures which have been designated by CSUR<br>b= Total number of rare tumours and highly complex procedures | **MH** |
| | **Objective 19** | Regional network care model for cancer care, especially in the case of rare tumours and highly complex procedures | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with a network care model defined for cancer care<br>b= Total num. of Autonomous Communities | **AC** |
| | **Objective 20** | Training courses for doctors and nurses in Primary Care on the diagnosis of suspected cancer | Number of training courses for doctors in Primary Care on the diagnosis of suspected cancer | **AC** |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Evidence-based products for early detection in childhood and adolescence | Number of evidence-based products for early detection in childhood and adolescence | **MH** |
| | **Objective 21** | Referral interval from primary care to hospital care | Equation: (a/b) × 100<br>a= Number of cancer patients whose interval between suspicion in primary care and the first visit to hospital care is equal to or less than seven calendar days<br>b= Total number of patients diagnosed with suspected cancer in primary care | **Audit MH** |
| | | Interval from the first visit to hospital care to pathological diagnosis of cancer or absence thereof | Equation: (a/b) × 100<br>a= Number of cancer patients whose interval between the first visit in hospital care and the pathological diagnosis of cancer or absence thereof is equal to or less than 15 calendar days<br>b= Total number of patients seen in the first hospital care consultation referred from primary care due to suspicion of cancer | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Interval from the first visit to hospital care to molecular diagnosis of cancer or absence thereof | Equation: (a/b) × 100<br>a= Number of cancer patients whose interval between the first visit in hospital care and the molecular diagnosis of cancer or absence thereof is equal to or less than 4 calendar days<br>b= Total number of patients seen in the first hospital care consultation referred from primary care due to suspicion of cancer | |
| | **Objective 22** | Histopathological diagnosis-treatment interval | Equation: (a/b) × 100<br>a= Number of cancer patients whose interval between histopathological diagnosis and treatment is equal to or less than 30 calendar days<br>b= Total number of patients diagnosed with suspected cancer in primary care | |
| | **Objective 23** | Map of radiotherapy resources in the Spanish National Health System | Dichotomous (yes/no) | **MH** |
| | **Objective 24** | Protocol agreed between the medical oncology, clinical haematology, radiotherapy oncology and emergency services | Equation: (a/b) × 100<br>a= Number of hospitals with a protocol agreed between the medical oncology, clinical hematology, radiotherapy oncology and emergency services<br>b= Number of hospitals with emergency services | **AC** |
| | **Objective 25** | Organizational model of precision oncology agreed upon in the Spanish National Health System | Dichotomous (yes/no) | **MH** |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | **Objective 26** | Percentage of Autonomous Communities that have implemented the double-reading diagnostic system of pathological anatomy diagnostic tests for the diagnosis of rare tumours | Equation: (a/b) × 100<br>a= Number of Autonomous Communities that have the double reading diagnostic system for the diagnosis of rare tumours<br>b= Total num. of Autonomous Communities | **AC** |
| | **Objective 27** | Courses for professionals who care for patients with cancer to improve relationship and communication skills | Number of courses for professionals who care for patients with cancer to improve relationship and communication skills | **AC** |
| | | Training aimed at cancer patients and caregivers disseminated through the Network of Health Schools for Citizens | Number of sources of information and training tools aimed at cancer patients, family members and caregivers disseminated through the Network of Health Schools for Citizens | **MH** |
| | | Transversal training for residents in relationship and communication skills with patients | Equation: (a/b) × 100<br>a= Number of Autonomous Communities that include training in relationship and communication skills with patients in their transversal training plans for residents<br>b= Total num. of Autonomous Communities | **AC** |
| | **Objective 28** | Hospitals with standardized tool/s for the early detection of emotional distress | Equation: (a/b) × 100<br>a= Number of hospitals that care for cancer patients that have standardized tools for the early detection of emotional distress integrated into the clinical history<br>b= Total number of hospitals that care for cancer patients | |
| | | Screening for early detection of emotional distress | Equation: (a/b) × 100<br>a= Number of cancer patients who have received screening for early detection of emotional distress<br>b= Number of cancer patients | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | **Objective 29** | Referral to Human Reproduction Units for advice regarding the preservation of fertility | Equation: (a/b) × 100<br>a= Number of patients diagnosed with cancer of childbearing age referred to the Human Reproduction Units for advice regarding the preservation of fertility<br>b= Number of cancer patients of childbearing age | **Audit MH** |
| **2. Health care 2.2. Monitoring and quality of life** | **Objective 30** | Study of the work, psychological and social impact of cancer on people and their families | Dichotomous (yes/no) | **MH** |
| | | Individualized social care plan | Equation: (a/b) × 100<br>a= Number of cancer patients treated in hospitals<br>with an individualized social care plan in their clinical history<br>b= Number of cancer patients treated | **Audit MH** |
| | **Objective 31** | Individualized long-survivor follow-up plan | Dichotomous (yes/no) | **MH** |
| | | Percentage of long-term survivors with an individualized follow-up plan | Equation: (a/b) × 100<br>a= Number of long-term cancer survivors who receive an individualized follow-up plan when discharged<br>b= Number of long-term cancer survivors evaluated | **Audit MH** |
| | **Objective 32** | Follow-up protocol/channel between primary care and hospital care for long-term survivors | Equation: (a/b) × 100<br>a= Number of Autonomous Communities that have a monitoring protocol/channel between primary care and hospitalized care for long-term survivors<br>b= Total number of Autonomous Communities | **AC** |
| **2. Health care 2.3. Palliative care** | **Objective 33** | The indicators are those agreed in the Spanish National Health System Palliative Care Strategy | | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| **3. Health care for children and adolescents** | **Objective 34** | Regulations for the constitution of the regional care coordination committee | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with regulations/instructions creating and defining the regional care coordination committee<br>b= Total number of Autonomous Communities | **AC** |
| | | Assessment by the regional care coordination committee | Equation: (a/b) × 100<br>a= Number of patients younger than 18 years old diagnosed with cancer during the year reviewed by the regional care coordination committee<br>b= Number of patients younger than 18 years old diagnosed with cancer during the year | |
| | | Protocol of the regional care coordination committee | Equation: (a/b) × 100<br>a= Number of Autonomous Communities that have a management protocol<br>b= Total number of Autonomous Communities | |
| | | Basket of care services | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with a publicly available healthcare offer<br>b= Total number of Autonomous Communities | |
| | | Designation of paediatric onco-haematology units | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with regulations/instructions by which paediatric onco-haematology units are designated in the Autonomous Community<br>b= Total number of Autonomous Communities | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Paediatric onco-haematology units with a high volume of patients | Equation: (a/b) × 100<br>a= Number of paediatric onco-haematology units that treat at least 30 new cases per year in the Autonomous Community<br>b= Number of paediatric onco-haematology units designated in the Autonomous Community | |
| | | Patient volume | Number of new patients younger than 18 years old attended in a paediatric onco-haematology unit in one year | |
| | | Paediatric Tumour Committee | Equation: (a/b) × 100<br>a= Number of paediatric onco-haematology units in each Autonomous Community with paediatric tumour committee<br>b= Number of paediatric onco-haematology units designated by the Autonomous Community | |
| | | Patients evaluated by the paediatric tumour committee | Equation: (a/b) × 100<br>a= Number of patients younger than 18 years old diagnosed with cancer during the year that have been assessed by a paediatric tumour committee<br>b= Number of patients younger than 18 years old diagnosed with cancer during the year | |
| | | Continuous care | Equation: (a/b) × 100<br>a= Number of paediatric onco-haematology units in each Autonomous Community with continuous care<br>b= Number of paediatric onco-haematology units designated by the Autonomous Community | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Research | Equation: (a/b) × 100<br>a= Number of paediatric onco-haematology units in each Autonomous Community who participate in research activities<br>b= Number of paediatric onco-haematology units designated by the Autonomous Community | |
| | | Direct accessibility for patients and relatives | Equation: (a/b) × 100<br>a= Number of paediatric onco-haematology units in each Autonomous Community with a direct accessibility procedure<br>b= Number of paediatric onco-haematology units designated by the Autonomous Community | |
| | | Record of activity of the Paediatric Onco-haematology Unit | Equation: (a/b) × 100<br>a= Number of paediatric onco-haematology units in each Autonomous Community with a registry of patients cared for by the paediatric onco-haematology unit<br>b= Number of paediatric onco-haematology units designated by the Autonomous Community | |
| | | Multidisciplinary team | Equation: (a/b) × 100<br>a= Number of paediatric onco-haematology units in each Autonomous Community with a multidisciplinary team<br>b= Number of paediatric onco-haematology units designated by the Autonomous Community | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Regulations that establish the network model | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with regulations/instructions describing the organizational model for childhood and adolescent cancer care in the Autonomous Community<br>b= Total number of Autonomous Communities | |
| | | Network evaluation procedure | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with a network organizational model that has a procedure in all the networks of its Autonomous Community<br>b= Total number of Autonomous Communities with a network organizational model | |
| | | Direct accessibility of health professionals to the network | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with a network organizational model that has direct accessibility to health professionals in all the networks of their Autonomous Community<br>b= Total number of Autonomous Communities with a network organizational model | |
| | | Unified care protocol in the Autonomous Community | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with a unified care protocol in the Autonomous Community<br>b= Total number of Autonomous Communities with a network organizational model | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Participation in clinical trials | Equation: (a/b) × 100<br>a= Number of Autonomous Communities with a network organizational model that participate in multi-centre studies and clinical trials<br>b= Total number of Autonomous Communities with a network organizational model | |
| | | Derivations between Autonomous Communities | Equation: (a/b) × 100<br>a= Number of patients younger than 18 years of age with cancer referred to an Autonomous Community other than their Autonomous Community of residence during the year<br>b= Number of patients younger than 18 years of age diagnosed with cancer during the year | |
| **4. Cancer data and information** | **Objective 35** | | | |
| | **Objective 36** | | | |
| **5. Research** | **Objective 37** | Cancer area present as a priority area in a strategic health action | Dichotomous (yes/no) | **ISCIII** |
| | | Annual funding granted in the field of Strategic Action on Health on cancer | Equation: (a/b) × 100<br>a= Annual funding granted by the Strategic Action on Health in the area of cancer<br>b= Total annual funding of the Strategic Action on Health | |
| | | Research projects in the area of cancer funded by the ISCIII calls | Equation: (a/b) × 100<br>a= Number of research projects funded in the area of cancer in the ISCIII calls<br>b= Total number of research projects in the ISCIII calls | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | | Average funding of research projects in the area of cancer funded in the ISCIII calls | Equation: (a/b) × 100<br>a= Sum of funding for research projects in the area of cancer in the ISCIII calls<br>b= Number of research projects funded in the area of cancer in the ISCIII calls | |
| | **Objective 38** | Health Research Institutes accredited with the thematic area of cancer as a priority area | Equation: (a/b) × 100<br>a= Number of Health Research Institutes accredited by the ISCIII with the thematic area of cancer as a priority area<br>b= Number of Health Research Institutes accredited by the ISCIII | |
| | | Funded coordinated and multi-centre cancer research projects presented by CIBER research groups and Health Research Institutes in the area of cancer over the total number of cancer projects in the ISCIII calls | Equation: (a/b) × 100<br>a= Number of funded coordinated and multi-centre research projects presented by CIBER research groups and Health Research Institutes in the area of cancer<br>b= Total number of research projects in the area of cancer in the ISCIII calls | |
| | | Number of Spanish publications on cancer in journals with an impact factor authored by CIBER research groups and Health Research Institutes in the area of cancer over the total number of Spanish publications on cancer in journals with an impact factor | Equation: (a/b) × 100<br>a= Number of Spanish publications on cancer in journals with an impact factor authored by CIBER research groups and Health Research Institutes in the area of cancer<br>b= Total number of Spanish publications on cancer with an impact factor | |

| STRATEGIC LINE | OBJECTIVE | INDICATOR | EQUATION | SOURCES |
|---|---|---|---|---|
| | **Objective 39** | Clinical trials in the non-commercial area of cancer | Equation: (a/b) × 100<br>a= Number of non-commercial clinical trials started in the area of cancer<br>b= Total number of clinical trials in cancer | **MH** |
| | **Objective 40** | Regional plan for postgraduate training in cancer research | Equation: (a/b) × 100<br>a= Number of Autonomous Communities including a postgraduate training plan in cancer research for healthcare professionals belonging to the Spanish National Health System<br>b= Total number of Autonomous Communities | **AC** |

| | | |
|---|---|---|
| **GLOBAL INDICATORS** | Cancer mortality rate | **MH** |
| | Premature deaths due to cancer | |
| | Potential years of life lost at age 75 | **MH** |
| | Potential number of years of life lost to life expectancy at the time of diagnosis | **MH** |
| | Cancer incidence rate | **Population cancer registries** |
| | Childhood cancer incidence | **Spanish Registry of Childhood Tumours** |
| | Observed population survival five years after cancer diagnosis in adults | **Population cancer registries** |
| | Net population survival five years after cancer diagnosis in adults | **Population cancer registries** |
| | Observed population survival and follow-up five years after cancer diagnosis in children (0-14 years old) | **Spanish Registry of Childhood Tumours** |
| | Percentage coverage of the incidence in Spain (complete), for childhood cancer (0-14 years) | **Spanish Registry of Childhood Tumours** |
| | Percentage of conservative surgery in breast cancer | **MH** |
| | Hospital mortality rate following surgery for:<br>a. Esophageal cancer<br>b. Pancreatic cancer<br>c. Lung cancer<br>d. Liver metastasis | |
| | Equity in the Cancer Strategy of the Spanish National Health System and regional cancer plans | **MH** |
| | Regional cancer plans | **AC** |

# 3.2. Indicator data by line of strategy

Organic Law 3/2007, of 22 March, for the effective equality of women and men establishes, through Article 27, the integration of the principle of equality in health policies and specifies that "the procurement and breakdown sex, whenever possible, of the data contained in registries, surveys, statistics or other medical and health information systems" should be undertaken.

In accordance with this requirement, the indicator sheets of this Cancer Strategy contemplate the procurement of the data broken down by sex, in those cases in which it is currently possible.

Sources of health information that do not yet allow the extraction of data broken down by sex should study the implementation of measures that facilitate this possibility, in compliance with current legal regulations.

## 3.2.1. Health promotion and cancer prevention

### 3.2.1.1. Health promotion and primary prevention

**Objective 1:**
Advance in Health and Equity in All Policies by collaborating with other sectors to make it easier for them to include actions that create healthy environments and policies among their priorities.

| **INDICATOR No. 1** | **Intersectoral coordination board.** |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | The activity of the intersectoral coordination board will be evaluated through the articles of incorporation and the work meetings of said board. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | At least one annual meeting. |
| Data sources | Ministry of Health. Autonomous Community. |

**Objective 2:**
Promote healthy lifestyles and environments in the population, throughout the entire course of life, by coordinating interventions with a population-based, comprehensive, and positive approach, in the areas of work, health, family, community, and education, mainly addressing the following health-related behaviour: healthy eating from birth; physical activity and sedentary lifestyle; alcohol consumption; consumption and exposure to environmental tobacco smoke and related products; environmental pollution; exposure to sun and; exposure to occupational carcinogens.

| **INDICATOR No. 2.1** | **Percentage of the population that consumes fruit or vegetables daily.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people who state that they consume fruit or vegetables on a daily basis in the survey.<br>b= Total population taking part in the survey. |

| | |
|---|---|
| Explanation of terms | |
| Level of breakdown | Autonomous Community and gender. |
| Guiding standard | |
| Data sources | |
| **INDICATOR No. 2.2** | **Prevalence of obesity.** |
| Formula or measurement system | Equation: (a/b) × 100 a= Number of obese people.<br>b= Total population taking part in the survey. |
| Explanation of terms | The body mass index is calculated based on the weight and height stated in the survey. A person is considered to be obese if their body mass index is 30 $kg/m^2$ or higher. |
| Level of breakdown | Autonomous Community, gender and age groups (2-17 and 18 or over). |
| Guiding standard | |
| Data sources | Spanish National Health Survey. Ministry of Health. National Institute of Statistics. |
| **INDICATOR No. 2.3** | **Prevalence of a sedentary lifestyle.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people who report being sedentary in their free time.<br>b= Total population taking part in the survey. |
| Explanation of terms | Sedentary lifestyle: declaration that physical exercise is not normally carried out. |
| Level of breakdown | Autonomous Community, gender and age groups (2-17 and 18 or over). |
| Guiding standard | |
| Data sources | Spanish National Health Survey. Ministry of Health. National Institute of Statistics. |
| **INDICATOR No. 2.4** | **Prevalence of alcohol consumption above the low risk limits in adults.** |
| Formula or measurement system | Equation: (a/b) × 100<br>a= Number of individuals aged 15 or older who state that they drink alcohol in amounts considered to be above the low risk limits. b= Total population that carries out the survey (15 years and over). |
| Explanation of terms | |
| Level of breakdown | Autonomous Community, gender, age and social class based on the occupation of the person. |
| Guiding standard | |
| Data sources | Spanish National Health Survey. European Health Survey in Spain Ministry of Health. National Institute of Statistics. |

| INDICATOR No. 2.5 | Percentage of adults who use tobacco. |
|---|---|
| Formula or measurement system | Daily smokers:<br>Equation: (a/b) × 100.<br>a= Number of adults (18 and over) who declare themselves to be smokers in the survey. b= Number of adults (18 or over) who take part in the survey.<br>Occasional smokers:<br>Equation: (c/b) × 100.<br>c= Number of adults (18 and over) who declare themselves to be occasional smokers in the survey.<br>b= Number of adults (18 and over) who take part in the survey. |
| Explanation of terms | Daily smoker: person who declares that they use tobacco on a daily basis, regardless of the type and amount of said use.<br>Occasional smoker: person who declares that they use tobacco but not on a daily basis, regardless of the type and amount of said use. |
| Level of breakdown | Autonomous Community and gender. |
| Guiding standard | |
| Data sources | Spanish National Health Survey. Ministry of Health. National Institute of Statistics. |

**Objective 3:**
Improve the information and surveillance system for occupational cancer and carcinogens in the workplace.

| INDICATOR No. 3.1 | Workers exposed to asbestos included in the Registry of Workers Exposed to Asbestos (RETEA). |
|---|---|
| Formula or measurement system | Absolute number of workers exposed to asbestos included in the RETEA. |
| Explanation of terms | |
| Level of breakdown | Autonomous Community and gender. |
| Guiding standard | |
| Data sources | RETEA. |
| **INDICATOR No. 3.2** | **Workers exposed to asbestos included in the RETEA monitored in the Health Surveillance Programme for Workers Exposed to Asbestos (PIVISTEA).** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of workers exposed to asbestos monitored in the PIVISTEA.<br>b= Number of workers exposed to asbestos included in the RETEA. |
| Explanation of terms | |
| Level of breakdown | Autonomous Community and gender. |
| Guiding standard | >90%. |
| Data sources | PIVISTEA. |

| INDICATOR No. 3.3 | Burden of cancer attributable to work and its healthcare cost in Spain. |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | Attributable burden: The proportion of a disease that can be attributed to a particular risk/prior exposure. |
| Level of breakdown | NA. |
| Guiding standard | Study carried out. |
| Data sources | Ministry of Health. |

**Objective 5:**
**Evaluate the exposure of the population to radon and know its impact on health.**

| INDICATOR No. 5.1 | Burden of cancer attributable to radon in Spain. |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | Attributable burden: The proportion of a disease that can be attributed to a particular risk/prior exposure. |
| Level of breakdown | NA. |
| Guiding standard | Study carried out. |
| Data sources | Ministry of Health. |

**Objective 6**
**Achieve HBV vaccination coverage in boys and girls 12 months of age equal to or greater than 95% with three vaccination doses, in all Autonomous Communities and in accordance with the vaccination schedule agreed upon by the Spanish National Health System Interterritorial Council.**

| INDICATOR No. 6 | HBV vaccination coverage. |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of 12-month-old boys and girls vaccinated with three doses against HBV.<br>b= Total population of 12-month-old boys and girls. |
| Explanation of terms | |
| Level of breakdown | Autonomous Community. |
| Guiding standard | >95%. |
| Data sources | Ministry of Health. |

**Objective 7**
**Achieve an HPV vaccination coverage in adolescents of 15 years of age equal to or greater than 80%, with the full vaccination schedule, in all the Autonomous Communities and in accordance with the vaccination schedule agreed upon by the Spanish National Health System Interterritorial Council.**

| **INDICATOR No. 7** | **HPV vaccination coverage.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of 15-year-old adolescents fully vaccinated against HPV.<br>b= Total population of 15-year-old adolescents. |
| Explanation of terms | Full vaccination against HPV requires the administration of a third dose of vaccine. |
| Level of breakdown | Autonomous Community. |
| Periodicity | Annual. |
| Guiding standard | >80%. |
| Data sources | Ministry of Health. |

## 3.2.1.2. Early detection

**Objective 8:**
**Early detection of breast cancer.**
**a) Carry out early detection of breast cancer always within the framework of organized population-based programmes and in accordance with the criteria contained in Royal Decree 1030/2006 (modified by Order SSI/2065/2014):**
**– Target population: women 50-69 years of age.**
**– Screening test: Mammogram.**
**– Time interval between examinations: 2 years.**
**b) Obtain a minimum of 70% participation in breast cancer screening programmes.**

| **INDICATOR No. 8.1** | **Coverage (annual) in the early breast cancer detection programme.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of women between the ages of 50 and 69, both inclusive, who have been offered the chance to participate in the breast cancer early detection programme.<br>b= Number of women between 50 and 69 years of age and resident in the Autonomous Community on 31 December of the year being evaluated.<br>This data corresponds to the target population to be studied in two years. It will be divided by two to obtain the annual target population. |
| Explanation of terms | This is the percentage of women (within the 50-69 age range) compared to the target total who have been offered the possibility of taking part in the programme.<br>Target population:<br>Population registered in the INE of women between the ages of 50 and 69 and resident in the Autonomous Community on 31 December of the year being evaluated.<br>This data corresponds to the target population to be studied in two years. It will be divided by two to obtain the annual target population. |
| Level of breakdown | Autonomous Community. |

| | |
|---|---|
| Guiding standard | >85%. |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 8.2** | **Participation in the early breast cancer detection programme.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of women between the ages of 50 and 69, both inclusive, who have participated in an organized, population-based early breast cancer detection programme,<br>b= Women who have been offered the test. |
| Explanation of terms | This is the percentage of women (within the 50-69 age range, compared to the total) who have been offered the possibility of taking part in the programme and who come in and have the mammogram taken (excluding the exceptions to having the mammogram done which are set out in the criteria for being included in the programme).<br>From the standpoint of accessibility and organization effectiveness of the systems, a person is understood as being included in the coverage when either she has taken the mammogram which was offered or she has explicitly refused having this test done.<br>A prior diagnosis of breast cancer or having previously had a mammogram taken for any reasons within a time period of less than two years, whether in the public or private system, is considered to be a criterion for exclusion. This refers to a period of evaluation time of the last two years.<br>In the case of offering the program to females of ages other than those stipulated for this indicator, the ages in question are to be recorded so as to distinguish them from the others. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | >70%. |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 8.3** | **Breast cancer detection rate.** |
| Formula or measurement system | Equation: (a/b) × 1000.<br>a= Number of women who, after carrying out the necessary tests for the early diagnosis of breast cancer, are given confirmation of a diagnosis of cancer.<br>b= Number of women between 50 and 69 years of age, both inclusive, with a mammogram performed as part of the breast cancer early detection programme. |
| Explanation of terms | All of the cancers detected are included, regardless of their stage. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 8.4** | **Percentage of women who state that they have had a screening mammogram.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of women within the 50-69 age range who state they have had a mammogram within the two-year period immediately prior to the survey.<br>b= Total number of surveyed women from 50 to 69 years old. |

| | |
|---|---|
| Explanation of terms | All those women who state they have had a mammogram are included, specifying the length of time which has elapsed (in years) since the mammogram was taken, independently of whether it was indicated or taken by the public or private health system.<br>An overall analysis will be provided at the point in time of the evaluation regarding the answers given on the survey related to mammograms being done, in regard, for example, of distinguishing the reason why they were taken as well as their relationship with sociodemographic variables which can be obtained from the Spanish National Health Survey affording the possibility of delving deeper into the analysis of this preventive practice.<br>Explicit refusal to have the test done must be put into writing, these cases not being counted for calculating the indicator. |
| Level of breakdown | By Autonomous Community and gender. An overall analysis will be provided at the point in time of the evaluation regarding the answers given on the survey in regard, for example, of distinguishing the reason why they were taken as well as their relationship with sociodemographic variables which can be obtained from the Spanish National Health Survey affording the possibility of delving deeper into the analysis of this preventive practice. |
| Guiding standard | Close to 80% of the target population. |
| Data sources | National Health Survey. Ministry of Health. |

**Objective 9:**
**Early detection of cervical cancer.**
**a) Carry out early detection of cervical cancer always within the framework of organized population-based programmes and in accordance with the criteria contained in Royal Decree 1030/2006 (modified by Order SCB/480/2019):**
**- Target population: Women aged between 25 and 65 years.**

**- Primary screening test and interval between examinations:**
**- Age 25-34 years: cytology every 3 years.**
**- Age 35-65 years: determination of high-risk human papillomavirus (HR-HPV):**
**If HR-HPV is negative, repeat HR-HPV test at 5 years.**
**If HR-HPV is positive, triage with cytology. If cytology is negative, repeat HR-HPV after one year.**

**b) Carry out the transition from opportunistic screening to organized population-based screening with the aim that all programmes have started before 2024 and full invitation coverage has been reached before 2029.**
**c) Obtain a minimum of 70% participation in cervical cancer screening programmes.**

| **INDICATOR No. 9.1** | **Coverage in the early cervical cancer detection programme.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of women between the ages of 25 and 65, both inclusive, who have been offered the chance to participate in the cervical cancer early detection programme.<br>b= Number of women between 25 and 65 years of age and resident in the Autonomous Community on 31 December of the year being evaluated.<br>This data corresponds to the target population to be studied in three or five years, depending on the interval between examinations according to age. It will be divided by three or five to obtain the annual target population. |

| | |
|---|---|
| Explanation of terms | This is the percentage of women (within the 25-65 age range) compared to the target total who have been offered the possibility of taking part in the programme.<br>Target population:<br>Population registered in the INE of women between the ages of 25 and 65 and resident in the Autonomous Community on 31 December of the year being evaluated.<br>This data corresponds to the target population to be studied in three or five years, depending on the interval between examinations according to age. It will be divided by three or five to obtain the annual target population. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | >85%. |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 9.2** | **Participation in the early cervical cancer detection programme.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of women between the ages of 25 and 65, both inclusive, who have participated in an organized, population-based early cervical cancer detection programme.<br>b= Number of women who have been offered the test. |
| Explanation of terms | This is the percentage of women (within the 25-65 age range, compared to the total) who have been offered the possibility of taking part in the programme and who come in and have the test done.<br>From the standpoint of accessibility and organization effectiveness of the systems, a person is understood as being included in the coverage when either she has taken the test which was offered or she has explicitly refused having this test done.<br>A prior diagnosis of cervical cancer or having previously had a test done for any reason within a time period of less than three years, whether in the public or private system, is considered to be a criterion for exclusion. This refers to a period of evaluation time of the last three years.<br>In the case of offering the program to females of ages other than those stipulated for this indicator, the ages in question are to be recorded so as to distinguish them from the others. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | >70%. |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 9.3** | **Cervical cancer detection rate.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of women who, after carrying out the necessary tests for the early diagnosis of cervical cancer, are given confirmation of a diagnosis of cancer.<br>b= Number of women who have been screened for cervical cancer. |
| Explanation of terms | All of the cancers detected are included, regardless of their stage. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | |
| Data sources | Spanish National Health System information system. |

| INDICATOR No. 9.4 | Percentage of women who have had cytology or HPV screening performed. |
|---|---|
| Formula or measurement system | Equation: (a1/b1) × 100.<br>a1= Number of women within the 25-34 age range who state they have had a cytology test within the three-year period immediately prior to the survey. b1= Total number of surveyed women from 25 to 34 years old.<br>Equation: (a2/b2) × 100.<br>a2= Number of women within the 35-65 age range who state they have had an HPV cytology test performed within the five-year period immediately prior to the survey. b2= Total number of surveyed women from 35 to 65 years old. |
| Explanation of terms | All those women who state they have had a cytology test or HPV detection test (according to age) are included, specifying the length of time which has elapsed (in years) since the test was taken, independently of whether it was indicated or taken by the public or private health system.<br>An overall analysis will be provided at the point in time of the evaluation regarding the answers given on the survey in regard, for example, of distinguishing the reason why they were taken as well as their relationship with sociodemographic variables which can be obtained from the Spanish National Health Survey affording the possibility of delving deeper into the analysis of this preventive practice.<br>Explicit refusal to have the test done must be put into writing, these cases not being counted for calculating the indicator.<br>This indicator may be modified depending on the situation of the programme in accordance with Order SCB/480/2019 and the information that the ENSE can provide. |
| Level of breakdown | By Autonomous Community and gender. An overall analysis will be provided at the point in time of the evaluation regarding the answers given on the survey in regard, for example, of distinguishing the reason why they were taken as well as their relationship with sociodemographic variables which can be obtained from the Spanish National Health Survey affording the possibility of delving deeper into the analysis of this preventive practice. |
| Guiding standard | >70%. |
| Data sources | National Health Survey. Ministry of Health. |

**Objective 10:**
**Early detection of colorectal cancer.**
**a) Undertake early detection of colorectal cancer always within the framework of an organized population-based programme and in accordance with the criteria contained in Royal Decree 1030/2006 (modified by Order SSI/2065/2014):**
**– Target population: 50-69 age range, in an initial stage.**
**– Screening test: fecal occult blood test.**
**– Time interval between examinations: 2 years.**
**b) Promote the implementation of these programmes with the aim of reaching full coverage before the year 2024.**
**c) Obtain a minimum of 65% participation in colorectal cancer screening programmes.**

| **INDICATOR No. 10.1** | **Coverage in the early colorectal cancer detection programme.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people (men and women) between the ages of 50 and 69, both inclusive, who have been offered the chance to participate in the colorectal cancer early detection programme.<br>b= Number of people between 50 and 69 years of age, both inclusive, and resident in the Autonomous Community on 31 December of the year being evaluated. |
| Explanation of terms | This is the percentage of people (within the 50-69 age range) compared to the target population who have been offered the possibility of taking part in the programme.<br>Target population:<br>Population registered in the INE of people between the ages of 50 and 69 and resident in the Autonomous Community on 31 December of the year being evaluated.<br>This data corresponds to the target population to be studied in two years. It will be divided by two to obtain the annual target population. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | >85%. |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 10.2** | **Participation in the early colorectal cancer detection programme.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people between the ages of 50 and 69 who have the faecal occult blood test done.<br>b= Number of people between the ages of 50 and 69 who were given the possibility of having this test done. |
| Explanation of terms | Having been diagnosed with colon cancer or having had a colonoscopy within the last three years are considered exceptions to having the screening test done.<br>Explicit refusal to have the test done must be put into writing, these cases not being counted for calculating the indicator. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | >65%. |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 10.3** | **Percentage of people who have had faecal occult blood tests done.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people between the ages of 50 and 69 who state they have had a faecal occult blood test done.<br>b= Number of people surveyed from 50 to 69 years old. |
| Explanation of terms | All those individuals who state having had a fecal occult blood test done by way of any of the available methods within the two-year period immediately prior to the survey are included. |

| | |
|---|---|
| Level of breakdown | Autonomous Community and gender. An overall analysis will be provided at the point in time of the evaluation regarding the answers given on the survey in regard, for example, of distinguishing the reason why they were taken as well as their relationship with sociodemographic variables which can be obtained from the Spanish National Health Survey affording the possibility of delving deeper into the analysis of this preventive practice. |
| Guiding standard | |
| Data sources | National Health Survey. Ministry of Health. National Institute of Statistics. |
| **INDICATOR No. 10.4** | **Percentage of faecal occult blood tests which tested positive.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people between the ages of 50 and 69 who tested positive for the faecal occult blood test.<br>b= Number of people who have undergone the screening test. |
| Explanation of terms | |
| Level of breakdown | Autonomous Community. |
| Guiding standard | |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 10.5** | **High-risk adenoma detection rate.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people within the 50-69 age range in whom, after having taken the screening test and all of the other tests necessary for confirming a diagnosis, a high-risk adenoma is found to exist.<br>b= Number of people who have undergone the screening test. |
| Explanation of terms | |
| Level of breakdown | Autonomous Community. |
| Guiding standard | |
| Data sources | Spanish National Health System information system. |
| **INDICATOR No. 10.6** | **Invasive colorectal cancer detection rate.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of people within the 50-69 age range in whom, after having taken the screening test and all of the other tests necessary for confirming a diagnosis, invasive colorectal cancer is found to exist.<br>b= Total number of people who have undergone the screening test. |
| Explanation of terms | |
| Level of breakdown | Autonomous Community. |
| Guiding standard | |
| Data sources | Spanish National Health System information system. |

**Objective 11**
**Guarantee assessment, follow-up and access to appropriate care devices for people who have personal risk factors, and people who meet criteria for high risk of familial or hereditary cancer, in order for them to obtain advice (information and proposals for action) and follow-up appropriate to their risk, through specific action protocols.**

| **INDICATOR No. 11** | **Document agreeing on the criteria for suspecting and including a person in a follow-up programme for familial and hereditary cancer.** |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | |
| Level of breakdown | NA. |
| Guiding standard | Prepared document. |
| Data sources | Ministry of Health. |

**Objective 12**
**Promote the development of information systems for cancer screening programmes in each Autonomous Community and City with Autonomy Statute that allow the application of the recommended screening protocols, as well as the comprehensive management of the different programmes and evaluation of processes, results and their impacts both at the level of each Autonomous Community and for the whole of the National Health System.**

| **INDICATOR No. 12.1** | **Information system for population cancer screening programmes.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities and Cities with an Autonomy Statute that have an information system that allows evaluation of the Programme.<br>b= Total number of Autonomous Communities and Cities with Autonomy Statute. |
| Explanation of terms | Individualized registration of people to invite, registration of screening results, follow-up in all cases of positive screening result, information system that allows the programme to be evaluated on an annual basis. |
| Level of breakdown | Breakdown for each screening programme: breast, colorectal and cervix. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |
| **INDICATOR No. 12.2** | **Annual evaluation report of population cancer screening programmes.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities and Cities with an Autonomy Statute that have an annual report evaluating the Programme.<br>b= Total number of Autonomous Communities and Cities with Autonomy Statute. |
| Explanation of terms | Coverage by screening rounds.<br>Indicators broken down by age groups and gender (in the case of colorectal cancer). |

| | |
|---|---|
| Level of breakdown | NA. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |

## 3.2.2. Health care

### 3.2.2.1. Care model

**Objective 16: Every hospital that cares for cancer patients will set up multidisciplinary units/ tumour committees according to their needs and volume of care.**

| **INDICATOR No. 16** | **Multidisciplinary tumour units/tumour committee.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of hospitals caring for cancer patients with multidisciplinary tumour units/tumour committees set up.<br>b= Number of hospitals evaluated that care for cancer patients. |
| Explanation of terms | Multidisciplinary units/tumour committee. Organizational entity of multidisciplinary cancer care that integrates professionals involved in decision-making on the therapeutic strategy and its application based on scientific evidence and expert knowledge.<br>The work of this committee consists of discussing and agreeing on the diagnosis and, based on the results, setting the treatment guidelines and deadlines.<br>The multidisciplinary unit/tumour committee will have to:<br>• Define the make up and responsibility of its members.<br>• Have a professional nursing liaison figure or case management nurse in order to, from multidisciplinary oncology care, prevent or alleviate possible failures in communication and/or coordination between different professionals during the process and between the patient and the health system.<br>• Have a reference physician who will inform each patient of the committee's decisions and with whom they will discuss the different treatment options. Likewise, they will be the reference person in contact with the primary care physician.<br>• Establish the frequency of meetings.<br>• Have a clinical action protocol for each type of tumour.<br>• Have a work methodology for the presentation of cases and the formulation of therapeutic decisions.<br>• Have systematized the record of the therapeutic decision in the patient's clinical history.<br>• Establish the patient information process through standard operating procedures, although personalizing the information process is essential.<br>• Have protocols for referral and follow-up to other services, centres and/or autonomous communities.<br>• Have procedures and systems to include patients in clinical trials.<br>• Have a quality assessment procedure with specific indicators for this assessment. |

| | |
|---|---|
| Level of breakdown | Autonomous Community. Type of tumour (breast, colorectal and others). Attributes described in the objective. |
| Guiding standard | 100% |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

**Objective 17: Diagnostic confirmation, treatment planning, and follow-up of all cancer patients (excluding non-melanoma skin tumours) should be performed in a multidisciplinary unit/tumour committee.**

| **INDICATOR No. 17** | **Patients diagnosed with cancer assessed by a multidisciplinary unit/ tumour committee.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of patients diagnosed with cancer (excluding non-melanoma skin tumours) who have been assessed by a multidisciplinary tumour unit/tumour committee.<br>b= Number of patients diagnosed with cancer (excluding non-melanoma skin tumours). |
| Explanation of terms | Evaluated patient: evidence in the clinical history or minutes of the committee of the evaluation of the patient and the agreements reached.<br>Multidisciplinary units/tumour committee. Organizational entity of multidisciplinary cancer care that integrates the professionals involved in decision-making on the therapeutic strategy and its application based on scientific evidence and expert knowledge.<br>The work of this committee consists of discussing and agreeing on the diagnosis and, based on the results, setting the treatment guidelines and deadlines. |
| Level of breakdown | Autonomous Community. Tumour type. |
| Guiding standard | 100%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

**Objective 18: Centralize rare tumours and highly complex procedures in healthcare units of reference.**

| **INDICATOR No. 18.1** | **Minimum threshold of patients with rare tumours and highly complex oncological processes that must be performed annually for quality care.** |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |

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|---|---|
| Explanation of terms | Rare tumours: the RARECARE definition and list of rare tumours are used.<br>Highly complex oncological processes: surgical procedures for cancer of the oesophagus, stomach, pancreas, ovary, primary tumours of the liver, and liver, rectal, and lung metastases; surgery for peritoneal carcinomatosis, and benign and malignant tumours of the central nervous system.<br>Consensus will be established in the Spanish National Health System Cancer Strategy based on reports from the Spanish Network of Agencies for Assessing National Health System Technologies and Performance. |
| Level of breakdown | NA. |
| Guiding standard | NA. |
| Data sources | |
| **INDICATOR No. 18.2** | **Regional reference units designated for the health care of patients with rare tumours and for highly complex procedures.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities with regional reference units designated for the health care of patients with rare tumours and for highly complex procedures.<br>b= Total number of Autonomous Communities. |
| Explanation of terms | Rare tumours: the RARECARE definition and list of rare tumours are used.<br>Highly complex oncological processes: surgical procedures for cancer of the oesophagus, stomach, pancreas, ovary, primary tumours of the liver, and liver, rectal, and lung metastases; surgery for peritoneal carcinomatosis, and benign and malignant tumours of the central nervous system.<br>A reference unit is considered to have been designated by the Autonomous Community when there is an official designation document for it (regulations). |
| Level of breakdown | Autonomous Community. Type of tumour and highly complex procedure. |
| Guiding standard | NA. |
| Data sources | Autonomous Community. |
| **INDICATOR No. 18.3** | **Centres, Services and Reference Units (CSUR) of the National Health System for the care of rare tumours and highly complex procedures.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of rare tumours and highly complex procedures which have been designated by CSUR.<br>b= Total number of rare tumours and highly complex procedures. |
| Explanation of terms | The CSUR designation project of the Spanish National Health System has as its objectives: Improve equity in access to highly specialized services for all citizens when they need it; concentrate the experience of a high level of specialization, guaranteeing quality, safe, efficient health care; improve care for low-prevalence pathologies and procedures.<br>In Royal Decree 1302/2006, of 10 November, the bases of the procedure for the designation and accreditation of the CSURs of the Spanish National Health System are established.<br>Rare tumours: the RARECARE definition and list of rare tumours are used.<br>Highly complex oncological processes: surgical procedures for cancer of the oesophagus, stomach, pancreas, ovary, primary tumours of the liver, and liver, rectal, and lung metastases; surgery for peritoneal carcinomatosis, and benign and malignant tumours of the central nervous system. |

| | |
|---|---|
| Level of breakdown | Type of tumour and highly complex procedure. |
| Guiding standard | 100%. |
| Data sources | Ministry of Health. |

| **Objective 19: Establish a network care model for cancer care, especially in the case of rare tumours and highly complex procedures.** | |
|---|---|
| **INDICATOR No. 19** | **Regional network care model for cancer care, especially in the case of rare tumours and highly complex procedures.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities with a network care model defined for cancer care.<br>b= Total num. of Autonomous Communities. |
| Explanation of terms | Assistance network: Integration of different resources (home, health centre, local hospital, reference services, etc.) providing assistance with the most appropriate service (home support, consultation, day hospitalization, conventional hospitalization, surgery, medium or long stay units, hospitalization at home, etc.), in such a way as to guarantee the quality, continuity and comprehensiveness of care in the most efficient way.<br>The network must be formally established and this must include the centres/services/institutions/units that comprise it, as well as its purposes and procedures.<br>Rare tumours: the RARECARE definition and list of rare tumours are used.<br>Highly complex oncological processes: surgical procedures for cancer of the oesophagus, stomach, pancreas, ovary, primary tumours of the liver, and liver, rectal, and lung metastases; surgery for peritoneal carcinomatosis, and benign and malignant tumours of the central nervous system. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 80%. |
| Data sources | Autonomous Community. |

| **Objective 20: Improve the diagnostic suspicion of cancer, both in adults and in children and adolescents.** | |
|---|---|
| **INDICATOR No. 20.1** | **Training courses for doctors and nurses in Primary Care on the diagnosis of suspected cancer.** |
| Formula or measurement system | Number of training courses for doctors in Primary Care on the diagnosis of suspected cancer. |
| Explanation of terms | Training courses: those training courses carried out within the continuing health training programmes of the Ministries of Health or Regional Health Service and whose duration exceeds 35 hours are considered. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | NA. |
| Data sources | Autonomous Community. |

| INDICATOR No. 20.2 | Evidence-based products for early detection in childhood and adolescence. |
|---|---|
| Formula or measurement system | Number of evidence-based products for early detection in childhood and adolescence. |
| Explanation of terms | Evidence-based products: products produced within the framework of the Spanish Network of Agencies for Assessing National Health System Technologies and Performance, and Care Processes, which meet the necessary inclusion criteria to be included in GuíaSalud. |
| Level of breakdown | NA. |
| Guiding standard | NA. |
| Data sources | Ministry of Health. |

**Objective 21: Establish rapid diagnostic channels between the primary care level and hospital care in the event of signs or symptoms of suspected oncological pathology of the most frequent tumour types (especially breast, colorectal, lung, prostate, ovarian, bladder, haematological cancer and melanoma).**

| INDICATOR No. 21.1 | Referral interval from primary care to hospital care. |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of cancer patients whose interval between suspicion in primary care and the first visit to hospital care is equal to or less than seven calendar days.<br>b= Total number of patients diagnosed with suspected cancer in primary care. |
| Explanation of terms | The time interval begins from the day the primary care professional refers the patient to hospital care until the patient is first seen in hospital care. |
| Level of breakdown | Autonomous Community. Tumour types: breast, colorectal, lung, prostate, ovarian, bladder, and haematological cancers. |
| Guiding standard | 90%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |
| **INDICATOR No. 21.2** | **Interval from the first visit to hospital care to pathological diagnosis of cancer or absence thereof.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of cancer patients whose interval between the first visit in hospital care and the pathological diagnosis of cancer or absence thereof is equal to or less than 15 calendar days.<br>b= Total number of patients seen in the first hospital care consultation referred from primary care due to suspicion of cancer. |
| Explanation of terms | The interval starts from the first visit to hospital care to pathological diagnosis of cancer or absence thereof. |
| Level of breakdown | Autonomous Community. Tumour types: breast, colorectal, lung, prostate, ovarian, bladder, and haematological cancers. |

| | |
|---|---|
| Guiding standard | 90%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |
| **INDICATOR No. 21.3** | **Interval from the first visit to hospital care to molecular diagnosis of cancer or absence thereof.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of cancer patients whose interval between the first visit in hospital care and the molecular diagnosis of cancer or absence thereof is equal to or less than four calendar days.<br>b= Total number of patients seen in the first hospital care consultation referred from primary care due to suspicion of cancer. |
| Explanation of terms | The interval starts from the first visit to hospital care to molecular diagnosis of cancer or absence thereof. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 90%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

**Objective 22: Reduce the time elapsed from the diagnosis of cancer (including the extension study and the complete pathological study) until the effective start of treatment.**
**- Surgical treatment: an average of two weeks is recommended.**
**- Systemic treatment: an average of one week is recommended.**
**- Radiotherapy: an average of four weeks is recommended (including the planning process).**

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|---|---|
| **INDICATOR No. 22.1** | **Referral interval from primary care to hospital care.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of cancer patients whose interval between diagnosis of cancer and surgical treatment is equal to or less than 15 calendar days.<br>b= Total number of patients diagnosed with cancer. |
| Explanation of terms | The time interval begins from the day the hospital care professional receives the diagnosis of cancer (including the extension study and the complete pathological study) until the patient starts treatment. |
| Level of breakdown | Autonomous Community. Tumour types: breast, colorectal, lung, prostate, ovarian, bladder, and haematological cancers. |
| Guiding standard | 90%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

| INDICATOR No. 22.2 | Interval from cancer diagnosis to systemic treatment. |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of cancer patients whose interval between diagnosis of cancer and systemic treatment is equal to or less than seven calendar days.<br>b= Total number of patients diagnosed with cancer. |
| Explanation of terms | The time interval begins from the day the hospital care professional receives the diagnosis of cancer (including the extension study and the complete pathological study) until the patient starts treatment. |
| Level of breakdown | Autonomous Community. Tumour types: breast, colorectal, lung, prostate, ovarian, bladder, and haematological cancers. |
| Guiding standard | 90%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |
| **INDICATOR No. 22.3** | **Interval from cancer diagnosis to radiotherapy treatment.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of cancer patients whose interval between diagnosis of cancer and radiotherapy treatment is equal to or less than 30 calendar days.<br>b= Total number of patients diagnosed with cancer. |
| Explanation of terms | The time interval begins from the day the hospital care professional receives the diagnosis of cancer (including the extension study and the complete pathological study) until the patient starts treatment. |
| Level of breakdown | Autonomous Community. Tumour types: breast, colorectal, lung, prostate, ovarian, bladder, and haematological cancers. |
| Guiding standard | 90%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

**Objective 23: Have radiotherapy equipment updated systematically by the Spanish National Health System throughout the period of action of this Strategy.**

| INDICATOR No. 23 | Map of radiotherapy resources in the Spanish National Health System. |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |

| | |
|---|---|
| Explanation of terms | • Radiotherapy resources will be based on high technology, which is as follows:<br>• Conventional radiotherapy.<br>• 3D conformal radiotherapy.<br>• Intensity Modulated Radiation Therapy (IMRT).<br>• Hypofractionated radiotherapy.<br>• Total body irradiation with photons.<br>• Total skin irradiation with electrons.<br>• Radiosurgery (intracranial stereotaxic radiotherapy).<br>• Fractionated stereotaxic radiotherapy.<br>• Extracranial fractionated stereotaxic radiotherapy (SBRT).<br>• Irradiation of blood products.<br>• Image Guided RT (IGRT).<br>• Adaptive RT (DART).<br>• Intraoperative radiotherapy (IORT) using electrons or brachytherapy.<br>• Brachytherapy.<br>• Proton therapy. |
| Level of breakdown | Autonomous Community. Team type. |
| Guiding standard | Developed map. |
| Data sources | Ministry of Health. |

**Objective 24**
**Promote the development of agreed protocols between the medical oncology, clinical haematology and radiotherapy oncology service and the emergency service for the adequate and continuous care of cancer patients who come to the emergency room, in the emergency service itself or in/with cancer care resources.**

| **INDICATOR No. 24** | **Protocol agreed between the medical oncology, clinical haematology, radiotherapy oncology and emergency services.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of hospitals who have a protocol agreed between the medical oncology, clinical haematology, radiotherapy oncology and emergency services.<br>b= Number of hospitals with emergency services. |
| Explanation of terms | Protocol: document that must include at least the points of contact for consultation, from the emergency unit, for the diagnostic and therapeutic assessment of cancer patients.<br>There should be a record of its joint development or consensus by the main participating disciplines: medical oncology, clinical haematology, radiotherapy oncology and the emergency department. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |

| **Objective 25**<br>**Agree on the organizational model of precision oncology in the National Health System.** | |
|---|---|
| **INDICATOR No. 28** | **Organizational model of precision oncology agreed upon in the Spanish National Health System.** |
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | |
| Level of breakdown | Ministry of Health. |
| Guiding standard | Existence of the model. |
| Data sources | Ministry of Health. |

| **Objective 26**<br>**Improve pathology diagnosis taking into account the precision oncology framework.** | |
|---|---|
| **INDICATOR No. 26** | **Percentage of Autonomous Communities that have implemented the double-reading diagnostic system of pathological anatomy diagnostic tests for the diagnosis of rare tumours.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities that have the double reading diagnostic system for the diagnosis of rare tumours.<br>b= Total number of Autonomous Communities. |
| Explanation of terms | Rare tumours: the RARECARE definition and list of rare tumours are used.<br>Double reading diagnostic system: the anatomopathological diagnosis of rare tumours will be carried out by the hospital that cares for the patient and by a regional reference unit or CSUR.<br>The autonomous community will have a double reading diagnostic protocol. |
| Level of breakdown | Autonomous Community. Tumour type. |
| Periodicity | Annual. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |

| **Objective 27**<br>**Promote knowledge and communication skills of care professionals with patients for shared decision-making using the best available evidence. Information given to the patient should be communicated in a realistic, understandable, and empathic manner based on trust.** | |
|---|---|
| **INDICATOR No. 27.1** | **Training courses for professionals who care for patients with cancer to improve relationship and communication skills.** |
| Formula or measurement system | Number of training courses for professionals who care for patients with cancer to improve relationship and communication skills. |
| Explanation of terms | Training courses: those training courses carried out within the continuing health training programmes of the Ministries of Health and whose duration exceeds 35 hours are considered. |

| | |
|---|---|
| Level of breakdown | Autonomous Community. |
| Guiding standard | NA. |
| Data sources | Autonomous Community. |
| **INDICATOR No. 27.2** | **Training aimed at cancer patients and caregivers disseminated through the Network of Health Schools for Citizens.** |
| Formula or measurement system | Number of sources of information and training tools aimed at cancer patients, family members and caregivers disseminated through the Network of Health Schools for Citizens. |
| Explanation of terms | Network of Health Schools for Citizens: platform of the Ministry of Health with the aim of providing patients, family members and caregivers with sources of information and training tools, based on a commitment to make the best evidence available to them. |
| Level of breakdown | Entire National Health System as a whole. |
| Guiding standard | NA. |
| Data sources | Ministry of Health. |
| **INDICATOR No. 27.3** | **Transversal training for residents in relationship and communication skills with patients.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities that include training in relationship and communication skills with patients in their transversal training plans for residents.<br>b= Total number of Autonomous Communities. |
| Explanation of terms | Specialized health training: internal training programme for residents on a Medicine, Pharmacy, Psychology, Biology, Physics, or Nursing specialty.<br>Transversal Training Plans: common training programmes for residents that cover the training activities that complement the specific programmes of each specialty. The transversal training plans are defined for each Autonomous Community by the Regional Health Services and/or Health Departments. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |

| **Objective 28: Use a standardized tool in cancer care for the early detection of emotional distress validated in Spanish that makes it possible to identify, from the moment of initial diagnosis, those people with cancer and caregivers who may need psychological care, establishing an early referral protocol for psychological intervention in these cases.** | |
|---|---|
| **INDICATOR No. 28.1** | **Hospitals with standardized tool/s for the early detection of emotional distress.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of hospitals that care for cancer patients that have standardized tools for the early detection of emotional distress integrated into the clinical history.<br>b= Total number of hospitals that care for cancer patients. |

| | |
|---|---|
| Explanation of terms | |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |
| **INDICATOR No. 28.2** | **Screening for early detection of emotional distress.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of patients, family members/caregivers for cancer patients who have received screening for early detection of emotional distress.<br>b= Number of patients, family members/caregivers for cancer patients. |
| Explanation of terms | Emotional distress: multi-factorial emotional experience of a psychological (cognitive, behavioural, emotional), social and spiritual nature that can interfere with the ability to adequately cope with the disease, its symptoms and its treatments.<br>The early detection of emotional distress must be screened at least once throughout the care process (diagnosis, treatment, discharge and final phase of the disease). |
| Level of breakdown | Patients and relatives/carers of patients and by Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

**Objective 29:**
**Promote the referral protocols to the Human Reproduction Units for counselling in relation to the preservation of fertility in patients of childbearing age and who wish to have children.**

| **INDICATOR No. 29** | **Referral to Human Reproduction Units for advice regarding the preservation of fertility.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of patients diagnosed with cancer of childbearing age referred to the Human Reproduction Units for advice regarding the preservation of fertility.<br>b= Number of cancer patients of childbearing age. |
| Explanation of terms | See the basket of services for details. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

## 3.2.2.2. Monitoring and quality of life

| **Objective 30**<br>**Provide social care for cancer patients and their families, according to their needs.** | |
|---|---|
| **INDICATOR No. 30.1** | **Study of the work, psychological and social impact of cancer on people and their families.** |
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | |
| Level of breakdown | NA. |
| Guiding standard | Study carried out. |
| Data sources | NA. |
| **INDICATOR No. 30.2** | **Individualized social care plan.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of cancer patients treated in hospitals with an individualized social care plan in their clinical history.<br>b= Number of cancer patients for whom care was provided. |
| Explanation of terms | Individualized follow-up plan for cancer that includes the assessment of social aspects carried out together with the affected person and/or family member and which takes into account the interventions to be carried out.<br>The rights that correspond to them, the resources they can access, recognition (disability, permanent disability, dependency, etc.), reinforcing the information regarding the disease and its evolution, as well as tools for returning to everyday life, will be detailed. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

| **Objective 31**<br>**Once the initial treatment and follow-up is finished, establish and deliver an individualized follow-up plan to the patient in writing.** | |
|---|---|
| **INDICATOR No. 31.1** | **Individualized follow-up plan for those patients without observable disease, who are no longer receiving treatment, with at least a period of five years having elapsed since diagnosis.** |
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | Individualized follow-up plan: it must include, at least, the type and clinical stage of the tumour, therapeutic intention (curative or palliative), the treatments received and the toxicities that may have arisen during the treatment, sequelae, care plan, psychological care. |

| | |
|---|---|
| Level of breakdown | NA. |
| Guiding standard | NA. |
| Data sources | Ministry of Health. |
| **INDICATOR No. 31.2** | **Percentage of patients without observable disease, who are no longer receiving treatment, with at least a period of five years having elapsed since diagnosis with an individualized follow-up plan.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of long-term cancer survivors who receive an individualized follow-up plan when discharged.<br>b= Number of long-term cancer survivors evaluated. |
| Explanation of terms | Individualized follow-up plan: it must include, at least, the type and clinical stage of the tumour, therapeutic intention (curative or palliative) and the treatments received and the toxicities that may have arisen during the treatment. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100% |
| Data sources | The evaluation of this objective will be carried out, on one hand, by means of conducting a study making it possible, by way of audits, to obtain quality information on the care-providing process. |

**Objective 32**
**Establish follow-up channels for patients without disease at present, who have completed their treatment and initial follow-up, between primary care and hospital in a coordinated and protocolized manner by mutual agreement. Under consideration are those patients without observable disease, who are no longer receiving treatment, with at least a period of five years having elapsed since diagnosis.**

| | |
|---|---|
| **INDICATOR No. 32** | **Follow-up protocol/channel between primary and hospital care for patients who have survived, without observable disease, who are no longer receiving treatment, with at least five years having elapsed since diagnosis.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities that have a monitoring protocol/ system between primary care and hospitalized care for long-term survivors.<br>b= Total number of Autonomous Communities. |
| Explanation of terms | Follow-up protocol/channel: document whose content brings together the guidelines, systematically developed, to help the professional and the patient in making decisions about the appropriate care to be provided in specific clinical circumstances, and which also serves as a guide for quality assessment in cases where the protocol is applicable. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |

## 3.2.3. Health care for children and adolescents

**Indicators for the evaluation of the implementation of the agreement on the organization of care for childhood and adolescent cancer.**

| Indicator area | Indicator name |
|---|---|
| **Regional care coordination committee** | 1. Regulations for the constitution of the regional care coordination committee. |
| | 2. Assessment by the regional care coordination committee. |
| | 3. Protocol of the regional care coordination committee. |
| | 4. Care offer. |
| **Concentration of care in paediatric onco-haematology units** | 5. Designation of paediatric onco-haematology units. |
| | 6. Paediatric onco-haematology units with a high volume of patients. |
| | 7. Patient volume. |
| | 8. Paediatric tumour committee. |
| | 9. Patients evaluated by the paediatric tumour committee. |
| | 10. Continuous care. |
| | 11. Research. |
| | 12. Direct accessibility for patients and relatives. |
| | 13. Record of activity of the paediatric onco-haematology unit. |
| | 14. Multidisciplinary team. |
| **Organization model** | 15. Regulations that establish the network model. |
| | 16. Network evaluation procedure. |
| | 17. Direct accessibility of health professionals to the network. |
| | 18. Unified care protocol in the Autonomous Community. |
| | 19. Participation in clinical trials. |
| **Others** | 20. Derivations between Autonomous Communities. |

## 1. Regional care coordination committee

| **Indicator No. 1 REGULATIONS FOR THE CONSTITUTION OF THE REGIONAL CARE COORDINATION COMMITTEE** | |
|---|---|
| **Indicator name** | **REGULATIONS FOR THE CONSTITUTION OF THE REGIONAL CARE COORDINATION COMMITTEE** |
| Justification | A regional care coordination committee will be created in each Autonomous Community to manage care for all cases of childhood and adolescent cancer. This committee must be created and defined through the relevant regulations (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Efficiency and effectiveness. |
| Equation | $\frac{\text{Number of Autonomous Communities with regulations/instructions which create and define the regional care coordination committee.}}{\text{Total number of Autonomous Communities.}} \times 100$ |
| Explanation of terms | • The committee will be constituted, at least, by a representative of each tumour committee of the centres with regional paediatric onco-haematology unit, those responsible for the paediatric onco-haematology unit, a head of the coordination of pediatric onco-haematology in the Autonomous Community, a person responsible for the management of the patients and the members determined by said committee for those situations that require it, as experts and of a permanent or non-permanent nature.<br>• In the case of Autonomous Communities that refer their cases to other Communities the committee will be constituted by a head of the coordination of pediatric onco-haematology in the Autonomous Community, a person responsible for the management of the patients and the members determined by said committee for those situations that require it, as experts and of a permanent or non-permanent nature.<br>• If the Autonomous Community has opted for a network organizational model, it would be advisable for the regional care coordination committee to coincide with the network coordinating committee. |
| Population | Autonomous Communities and INGESA. |
| Type | Framework. |
| Data sources | Departments of Health of the Autonomous Communities and INGESA. |
| Guiding Standard | 100%. |

| **Indicator No. 2 PATIENTS REVIEWED BY THE REGIONAL CARE COORDINATION COMMITTEE** | |
|---|---|
| **Indicator name** | **PATIENTS REVIEWED BY THE REGIONAL CARE COORDINATION COMMITTEE** |
| Justification | All patients under the age of 18 diagnosed with cancer must be assessed by the regional care coordination committee. (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |

| | |
|---|---|
| Dimension | Safety, adequacy, accessibility, effectiveness and efficiency. |
| Equation | $\frac{\text{Number of patients younger than 18 years old diagnosed with cancer during the year assessed by the regional care coordination committee}}{\text{Number of patients younger than 18 years old diagnosed with cancer during the year.}} \times 100$ |
| Explanation of terms | • Patient diagnosed with cancer per year: new patients diagnosed with cancer in one year.<br>• Reviewed patient: evidence in the clinical history and minutes of the patient review committee and the agreements reached.<br>• Regional care coordination committee: created to manage care for all cases of childhood and adolescent cancer. This committee must be created and defined through the relevant regulations.<br>• The indicator will be broken down into two age groups: 14 years and over and 15-17 years. |
| Population | All patients younger than 18 years old diagnosed with cancer during the year. |
| Type | Process. |
| Data sources | For the numerator, the minutes of the committee and clinical documentation of the patient will be used. For the denominator, data from the RETI and regional childhood cancer registries will be used. |
| Guiding Standard | 100%. |
| Comments | |

| **Indicator No. 3 PROTOCOL OF THE REGIONAL CARE COORDINATION COMMITTEE** | |
|---|---|
| **Indicator name** | **PROTOCOL OF THE REGIONAL CARE COORDINATION COMMITTEE** |
| Justification | Good clinical practice is favoured by the standardization of processes according to the best existing scientific evidence and the best care management. Protocols must be updated periodically. Its objective is to standardize the care provided in the Autonomous Community and serve as a tool that facilitates and speeds up decision-making.<br>(Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Safety, adequacy, accessibility, effectiveness and efficiency. |
| Equation | $\frac{\text{Number of Autonomous Communities that have a management protocol}}{\text{Total number of Autonomous Communities.}} \times 100$ |

| | |
|---|---|
| Explanation of terms | • Management protocol: document that must include at least:<br>- The Autonomous Community service portfolio defining where each resource is located.<br>- The criteria for referral to the POU for each pathology, for the entire disease process or part of the process.<br>- Patient management channels in order to establish agile, efficient systems that provide quick and effective solutions to each particular case.<br>- The possibility of requesting a second opinion from a CSUR of the Spanish National Health System.<br>- It will propose coordination protocols with the rest of the healthcare resources, including paediatric services both at the hospital and primary care level, paediatric palliative care and home care.<br>- The way of transitioning children and adolescents to adult services adapted to the individual maturation process of each patient.<br>• The protocol must express the date of approval and its period of validity. In general, a period of three years is recommended.<br>• The protocol will be drawn up and applied by the regional care coordination committee.<br>• Specific protocols will be created for at least the following tumour groups: leukemias, lymphomas, central nervous system, neuroblastoma, eye tumours, kidney tumours, liver tumours, bone tumours, soft tissue sarcomas, germ cell tumours, and melanomas. |
| Population | Autonomous Communities and INGESA. |
| Type | Framework. |
| Data sources | Regional care coordination committee. |
| Guiding Standard | 100%. |
| Comments | The standard will only be considered fulfilled when the protocol is available (in paper or electronic format), with the content and update characteristics described in the explanation of terms and whose last revision or update does not exceed three years at the time of the revision. |

| **Indicator no. 4 CARE OFFER OF THE AUTONOMOUS COMMUNITY** | |
|---|---|
| **Indicator name** | **CARE OFFER OF THE AUTONOMOUS COMMUNITY** |
| Justification | The Autonomous Community must have a detailed care offer for childhood and adolescent cancer and disseminate it (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Accessibility, effectiveness. |
| Equation | $\frac{\text{Number of Autonomous Communities with a publicly available healthcare offer.}}{\text{Total number of Autonomous Communities.}} \times 100$ |

| | |
|---|---|
| Explanation of terms | Care offer: the set of resources, means and actions of the public health administrations of the Autonomous Community or linked to them, aimed at satisfying the right to health protection through promotion, prevention and health care. The offer must include the designated POUs and their offer.<br>In relation to the offer of POU services, the following must be taken into account:<br>• Offer of services: the set of resources, means and actions of the POU or linked to it, aimed at satisfying the right to health protection through promotion, prevention and health care.<br>• The offer of services will include at least: paediatric radiology, paediatric hospitalization, paediatric day hospital, paediatric intensive care unit, paediatric outpatient clinic, paediatric emergencies, paediatric surgical area, child clinical psychiatry/psychology, radiotherapy oncology, and child oncology.<br>• In the event that the resource is not available, it will be made explicit where the patient is referred to for this resource. |
| Population | Autonomous Communities and INGESA. |
| Type | Framework. |
| Data sources | Departments of Health of the Autonomous Communities and INGESA. |
| Guiding Standard | 100%. |
| Comments | |

## 2. Concentration of care in paediatric onco-haematology units

| **Indicator no. 5 DESIGNATION OF PEDIATRIC ONCO-HAEMATOLOGY UNITS** | |
|---|---|
| **Indicator name** | **DESIGNATION OF PAEDIATRIC ONCO-HAEMATOLOGY UNITS** |
| Justification | The low incidence and the need for high specialization determine that care for childhood and adolescent cancer should be limited to those centres that guarantee, among other things, the experience (number of cases) required to maintain the training and periodic updating of their professionals. To guarantee this experience, it is necessary to concentrate health care in POU units in the AC. The designation of these units must be done through the relevant regulations (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Safety, suitability, effectiveness. |
| Equation | $\frac{\text{Number of Autonomous Communities with regulations/instructions by which paediatric onco-haematology units are designated in the Autonomous Community.}}{\text{Total number of Autonomous Communities.}} \times 100$ |

| | |
|---|---|
| Explanation of terms | • Criteria that POUs must meet:<br>• Accredit an activity with a volume of patients necessary so that, based on their experience, care is optimal.<br>• Have a paediatric tumour committee in the centre where they are located that will have defined operating standards.<br>• Explain the pathology or group of pathologies that are treated in the centre/unit.<br>• Include in the offer of services at least: paediatric radiology, paediatric hospitalization, paediatric day hospital, paediatric intensive care unit, paediatric outpatient clinic, paediatric emergencies, paediatric surgical area, child clinical psychiatry/psychology.<br>• Offer continuous cancer care 24 hours a day, 365 days a year.<br>• Have tools for working in a care network with other centres and units.<br>• Guarantee access to paediatric home care and paediatric palliative care.<br>• Participate in research activities related to the treatment of children with cancer.<br>• Guarantee the direct accessibility of the patients and their relatives in the centres where they usually treat the patient with the resources of the unit, by telephone, telematics, email or similar.<br>• Promote the participation of the patient and their parents in the decisions that are made throughout the process of caring for their children, when the minor cannot understand the scope of the interventions that are proposed.<br>• Have protocols, based on the best scientific evidence that will include diagnostic, therapeutic and patient follow-up procedures; have a registry of patients treated and participate in a childhood cancer registry.<br>• Ensure care by a multidisciplinary team made up of a care coordinator, paediatricians or oncologists dedicated to paediatric oncology, haematologist, paediatric surgeon, radiation oncologist, pathologist, hospital pharmacist, physician expert in infectious diseases, radiologist, nursing staff, social worker, teacher, rehabilitator, dietician, psychologist, physiotherapy and occupational therapy staff. |
| Population | Departments of Health of the Autonomous Communities and INGESA. |
| Type | Framework. |
| Data sources | Departments of Health of the Autonomous Communities and INGESA. |
| Guiding Standard | 100%. |
| Comments | |

| **Indicator No. 6 PAEDIATRIC ONCO-HAEMATOLOGY UNITS WITH A HIGH VOLUME OF PATIENTS** | |
|---|---|
| **Indicator name** | **PAEDIATRIC ONCO-HAEMATOLOGY UNITS WITH A HIGH VOLUME OF PATIENTS** |
| Justification | The POUs in the CA will attend to the volume of patients necessary for the care to be optimal. (SIOP Europe (The European Society for Paediatric Oncology) recommends treating at least 30 new cases per year in order to gain sufficient experience) (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |

| | |
|---|---|
| Dimension | Safety, adequacy, competence, efficiency and effectiveness. |
| Equation | $\frac{\text{Number of paediatric onco-haematology units that treat at least 30 new cases per year in the Autonomous Community}}{\text{Number of paediatric onco-haematology units designated in the Autonomous Community}} \times 100$ |
| Explanation of terms | New case treated in a POU: a POU is considered to be treating a new case when the case receives at least part of the treatment there, with second opinions not included. |
| Population | POU designated by the Autonomous Communities. |
| Type | Framework. |
| Data sources | Record of patients of the paediatric onco-haematology unit. |
| Guiding Standard | 100%. |
| Comments | |

| **Indicator No. 7 PATIENT VOLUME** | |
|---|---|
| **Indicator name** | **PATIENT VOLUME** |
| Justification | The POUs in the CA will attend to the volume of patients necessary for the care to be optimal. (SIOP Europe (The European Society for Paediatric Oncology) recommends treating at least 30 new cases per year in order to gain sufficient experience) (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Safety, adequacy, competence, efficiency and effectiveness. |
| Equation | Number of new patients younger than 18 years old seen in a paediatric onco-haematology unit in one year. |
| Explanation of terms | New case treated in a POU: a POU is considered to be treating a new case when the case receives at least part of the treatment there.<br>The indicator will be broken down into the following tumour groups: leukemias, lymphomas, central nervous system, neuroblastoma, eye tumours, kidney tumours, liver tumours, bone tumours, soft tissue sarcomas, germ cell tumours, and melanomas.<br>The indicator will be broken down into two age groups: 15 years and under and 15-17 years. |
| Population | POU designated by the Autonomous Communities. |
| Type | Framework. |
| Data sources | Record of patients of the paediatric onco-haematology unit. |
| Guiding Standard | More than 30 new cases a year. |
| Comments | |

| Indicator No. 8 PAEDIATRIC TUMOUR COMMITTEE | |
|---|---|
| **Indicator name** | **PAEDIATRIC TUMOUR COMMITTEE** |
| Justification | Every POU must have a paediatric tumour committee for assessment prior to any therapeutic process and in which all the professionals involved in the diagnostic and therapeutic process participate. (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Safety, adequacy, efficiency and effectiveness. |
| Equation | Number of paediatric onco-haematology units in each Autonomous Community with paediatric tumour committee<br>---------- x 100<br>Number of paediatric onco-haematology units designated by the Autonomous Community. |
| Explanation of terms | • Paediatric tumour committee: multidisciplinary group made up of a care coordinator, paediatricians or oncologists dedicated to paediatric oncology, haematologist, paediatric surgeon, radiation oncologist, pathologist, hospital pharmacist, physician expert in infectious diseases, radiologist, nursing staff, social worker, teacher, rehabilitator, dietician, psychologist, physiotherapy and occupational therapy staff.<br>• The committee will define the rules of operation. |
| Population | POU designated by the Autonomous Communities. |
| Type | Framework. |
| Data sources | POU designated by the Autonomous Communities. |
| Guiding Standard | 100%. |
| Comments | |

| Indicator No. 9 PATIENTS ASSESSED BY THE PAEDIATRIC TUMOUR COMMITTEE | |
|---|---|
| **Indicator name** | **PATIENTS EVALUATED BY THE PAEDIATRIC TUMOUR COMMITTEE** |
| Justification | All patients under the age of 18 diagnosed with cancer must be assessed by the paediatric tumour committee of the POU where they will be treated.<br>This assessment must be recorded in the clinical history and in the minute book.<br>(Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Safety, adequacy, efficiency and effectiveness. |
| Equation | Number of patients younger than 18 years old diagnosed with cancer during the year that have been assessed by a paediatric tumour committee<br>——————————————— x 100<br>Number of patients younger than 18 years old diagnosed with cancer during the year |

| | |
|---|---|
| Explanation of terms | • Evaluated patient: evidence in the clinical history and minutes of the committee of the evaluation of the patient and the agreements reached.<br>• Paediatric tumour committee: multidisciplinary group made up of a care coordinator, paediatricians or oncologists dedicated to paediatric oncology, haematologist, paediatric surgeon, radiation oncologist, pathologist, hospital pharmacist, physician expert in infectious diseases, radiologist, nursing staff, social worker, teacher, rehabilitator, dietician, psychologist, physiotherapy and occupational therapy staff.<br>• The indicator will be broken down into two age groups: 15 years and under and 15-17 years. |
| Population | All patients younger than 18 years old diagnosed with cancer in 2020. |
| Type | Process. |
| Data sources | The minutes of the committee and clinical documentation of the patient. |
| Guiding Standard | 100%. |
| Comments | |

| **Indicator No. 10 CONTINUED CARE** | |
|---|---|
| **Indicator name** | **CONTINUOUS CARE** |
| Justification | The POU should offer continuous cancer care 24 hours a day, 365 days a year.<br>(Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Accessibility, acceptability, adequacy, effectiveness. |
| Equation | $\frac{\text{Number of paediatric onco-haematology units in each Autonomous Community with continuous care}}{\text{Number of paediatric onco-haematology units designated by the Autonomous Community.}} \times 100$ |
| Explanation of terms | Continuous care: care provided by at least one paediatric oncologist 24 hours a day, 365 days a year.<br>Continuous care does not imply that the paediatric oncologist's care is face-to-face or that he has to belong to the POU. |
| Population | POU designated by the Autonomous Communities. |
| Type | |
| Data sources | POU designated by the Autonomous Communities. |
| Guiding Standard | |
| Comments | |

| Indicator No. 11 RESEARCH | |
|---|---|
| **Indicator name** | **RESEARCH** |
| Justification | The POU should participate in research activities related to childhood cancer.<br>(Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Continuity of care, adequacy, effectiveness. |
| Equation | $\frac{\text{Number of paediatric onco-haematology units in each Autonomous Community who participate in research activities}}{\text{Number of paediatric onco-haematology units designated by the Autonomous Community.}} \times 100$ |
| Explanation of terms | The participation of the POU in the SEHOP and SIOPE groups are considered to be research activities. |
| Population | POU designated by the Autonomous Communities. |
| Type | Framework. |
| Data sources | POU designated by the Autonomous Communities. |
| Guiding Standard | |
| Comments | |

| Indicator No. 12 DIRECT ACCESSIBILITY FOR PATIENTS AND FAMILIES | |
|---|---|
| **Indicator name** | **DIRECT ACCESSIBILITY FOR PATIENTS AND RELATIVES** |
| Justification | The POU should guarantee the direct accessibility of the patients and their relatives in the centres where they usually treat the patient with the resources of the unit, by telephone, telematics, email or similar.<br>(Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Continuity of care, adequacy, effectiveness. |
| Equation | $\frac{\text{Number of paediatric onco-haematology units in each Autonomous Community with a direct accessibility procedure}}{\text{Number of paediatric onco-haematology units designated by the Autonomous Community.}} \times 100$ |
| Explanation of terms | The direct accessibility procedure must include the contact method (telephone, telematics, email) and the accessibility hours.<br>The patient already has a diagnosis. |
| Population | POU designated by the Autonomous Communities. |
| Type | Framework. |

| | |
|---|---|
| Data sources | POU designated by the Autonomous Communities. |
| Guiding Standard | 100%. |
| Comments | |

| **Indicator No. 13 ACTIVITY RECORD OF THE POU** | |
|---|---|
| **Indicator name** | **RECORD OF ACTIVITY OF THE POU** |
| Justification | Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018. |
| Dimension | Suitability. |
| Equation | $\frac{\text{Number of paediatric onco-haematology units in each Autonomous Community with a registry of patients cared for by the paediatric onco-haematology unit}}{\text{Number of paediatric onco-haematology units designated by the Autonomous Community.}} \times 100$ |
| Explanation of terms | The POU patient registry must allow for the identification of patients who are being cared for in the POU.<br>The purpose of this registry is to assess the quality of care at the POU. |
| Population | POU designated by the Autonomous Communities. |
| Type | Framework. |
| Data sources | POU designated by the Autonomous Communities. |
| Guiding Standard | 100%. |
| Comments | |

| **Indicator No. 14 MULTIDISCIPLINARY TEAM** | |
|---|---|
| **Indicator name** | **MULTIDISCIPLINARY TEAM** |
| Justification | Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018. |
| Dimension | Suitability. |
| Equation | $\frac{\text{Number of paediatric onco-haematology units in each Autonomous Community with a multidisciplinary team}}{\text{Number of paediatric onco-haematology units designated by the Autonomous Community.}} \times 100$ |

| | |
|---|---|
| Explanation of terms | The multidisciplinary team will be made up of a care coordinator, paediatricians or oncologists dedicated to paediatric oncology, haematologist, paediatric surgeon, radiation oncologist, pathologist, hospital pharmacist, physician expert in infectious diseases, radiologist, nursing staff, social worker, teacher, rehabilitator, dietician, psychologist, physiotherapy and occupational therapy staff. |
| Population | All POUs of the Spanish National Health System. |
| Type | Framework. |
| Data sources | POU designated by the Autonomous Communities. |
| Guiding Standard | 100%. |
| Comments | |

## 3. Organization model

| **Indicator No. 15 REGULATIONS THAT ESTABLISH THE NETWORK MODEL** | |
|---|---|
| **Indicator name** | **REGULATIONS THAT ESTABLISH THE NETWORK MODEL** |
| Justification | The care network is an organizational tool that contemplates the child or adolescent as the centre of the care process, guaranteeing optimal care. This is created by the functional union of different health entities/organizations who consider that in order to guarantee adequate care for children and adolescents they must work as a team in an organized manner.<br>The network must be formally established and this must include the centres/services/institutions/units that comprise it, as well as its purposes and procedures (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Safety, adequacy, competence, efficiency and effectiveness. |
| Equation | $\frac{\text{Number of Autonomous Communities with regulations/instructions which describe the organizational care model for childhood and adolescent cancer care in the Autonomous Community}}{\text{Total number of Autonomous Communities.}} \times 100$ |

| | |
|---|---|
| Explanation of terms | The regulation/instruction must include the following criteria:<br>• Network criteria:<br>- Child oncology diagnoses and treatments will only be carried out within a healthcare network.<br>- It will have referral criteria, clinical sessions, clinical guidelines, training activities, registration and shared clinical information and monitoring of results.<br>- It will establish the diagnostic, therapeutic and patient follow-up protocols for each pathology. As well as a protocol, agreed upon by the Network and the Emergency Services for their coordinated action when one of these patients goes to the ER.<br>- It will have a procedure that evaluates the follow-up of clinical recommendations and networking agreements.<br>- It will promote continuity of care between the different levels through figures such as the head physician, case manager, etc.<br>• The network is composed of the following elements:<br>- Hospitals with POU.<br>- Hospitals without POU, primary care, palliative care and home care.<br>- Units that carry out highly complex procedures and processes that are included in the CSUR catalogue of the Spanish National Health System.<br>• The network will have a network coordinating committee which should coincide with the regional care coordination committee. |
| Population | Departments of Health of the Autonomous Communities and INGESA. |
| Type | Framework. |
| Data sources | Departments of Health of the Autonomous Communities and INGESA. |
| Guiding Standard | 90%. |
| Comments | |

| **Indicator No. 16 NETWORK EVALUATION PROCEDURE** | |
|---|---|
| **Indicator name** | **NETWORK EVALUATION PROCEDURE** |
| Justification | The care network will have a procedure that evaluates the follow-up of clinical recommendations and networking agreements. (Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Safety, adequacy, competence, efficiency and effectiveness. |
| Equation | $\frac{\text{Number of Autonomous Communities with a network organizational model that has a procedure in all the networks of its Autonomous Community}}{\text{Total number of Autonomous Communities with a network organizational model.}} \times 100$ |
| Explanation of terms | The care network will have a procedure that evaluates the follow-up of clinical recommendations and networking agreements. |
| Population | Departments of Health of the Autonomous Communities and INGESA. |

| | |
|---|---|
| Type | Framework. |
| Data sources | Network Coordinating Committee. |
| Guiding Standard | 100%. |
| Comments | |

| **Indicator No. 17 DIRECT ACCESSIBILITY OF HEALTHCARE PROFESSIONALS TO THE NETWORK** | |
|---|---|
| **Indicator name** | **DIRECT ACCESSIBILITY OF HEALTH PROFESSIONALS TO THE NETWORK** |
| Justification | Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018. |
| Dimension | Continuity of care, adequacy, effectiveness. |
| Equation | $\frac{\text{Number of Autonomous Communities with a network organizational model that has direct accessibility of health professionals in all the networks of their Autonomous Community}}{\text{Total number of Autonomous Communities with a network organizational model.}} \times 100$ |
| Explanation of terms | The direct accessibility procedure must include the contact method (telephone, telematics, email) and the accessibility hours.<br>The patient already has a diagnosis. |
| Population | POU designated by the Autonomous Communities. |
| Type | Framework. |
| Data sources | POU designated by the Autonomous Communities. |
| Guiding Standard | |
| Comments | |

| **Indicator No. 18 UNIFIED CARE PROTOCOL IN THE AUTONOMOUS COMMUNITY** | |
|---|---|
| **Indicator name** | **UNIFIED CARE PROTOCOL IN THE AUTONOMOUS COMMUNITY** |
| Justification | Good clinical practice is favoured by the standardization of processes according to the best existing scientific evidence. The protocols must be periodically updated and adapted to the characteristics and systems of each POU. Its objective is to standardize the care provided in the centre and serve as a tool that facilitates and speeds up decision-making.<br>(Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |

| | |
|---|---|
| Dimension | Suitability. |
| Equation | $\frac{\text{Number of Autonomous Communities with a unified care protocol}}{\text{Total number of Autonomous Communities with a network organizational model.}} \times 100$ |
| Explanation of terms | • Care protocol: document that must include at least the diagnostic, therapeutic and follow-up procedures for patients. The protocol must express the date of approval and its period of validity. In general, a period of three years is recommended. This is the protocol for the paediatric tumour committee. It will also include the patient's need for paediatric home care and paediatric palliative care.<br>• There must be a record of its joint preparation or by consensus of the multidisciplinary team of the POUs made up of a care coordinator, paediatricians or oncologists dedicated to paediatric oncology, haematologist, paediatric surgeon, radiation oncologist, pathologist, hospital pharmacist, physician expert in infectious diseases, radiologist, nursing staff, social worker, teacher, rehabilitator, dietician, psychologist, physiotherapy and occupational therapy staff. |
| Population | POUs designated by the Autonomous Communities. |
| Type | Framework. |
| Data sources | Regional care coordination committee or network coordinating committee. |
| Guiding Standard | 100%. |
| Comments | The standard will only be considered fulfilled when the protocol is available (in paper or electronic format), with the content and update characteristics described in the explanation of terms and whose last revision or update does not exceed three years at the time of the revision. |

| **Indicator No. 19 PARTICIPATION IN CLINICAL TRIALS** | |
|---|---|
| **Indicator name** | **PARTICIPATION IN CLINICAL TRIALS** |
| Justification | The regional care coordination committee will promote the participation of paediatric cancer patients in multi-centre studies and clinical trials, in which the tasks and responsibilities to be carried out by each centre are specified in accordance with current regulations.<br>(Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018). |
| Dimension | Suitability. |
| Equation | $\frac{\text{Number of Autonomous Communities with a network organizational model that participate in multi-centre studies and clinical trials}}{\text{Total number of Autonomous Communities with a network organizational model.}} \times 100$ |
| Explanation of terms | |

| | |
|---|---|
| Population | AC. |
| Type | Framework. |
| Data sources | Regional care coordination committee or network coordinating committee. |
| Guiding Standard | |
| Comments | |

## 4. Others

| **Indicator No. 20 REFERRALS BETWEEN AUTONOMOUS COMMUNITIES** | |
|---|---|
| **Indicator name** | **REFERRALS BETWEEN AUTONOMOUS COMMUNITIES** |
| Justification | Agreement on the organization of care for childhood and adolescent cancer approved by the Interterritorial Council of the Spanish National Health System on 15 November 2018. |
| Dimension | Adequacy, effectiveness. |
| Equation | $\frac{\text{Number of patients younger than 18 years of age with cancer referred to an Autonomous Community other than their Autonomous Community of residence in the year}}{\text{Number of patients younger than 18 years of age diagnosed with cancer during the year.}} \times 100$ |
| Explanation of terms | The indicator will be broken down into two age groups: 14 years and over and 15-17 years. |
| Population | |
| Type | Framework. |
| Data sources | SIFCO will be used as a source for the numerator and RETI for the denominator. |
| Guiding Standard | |
| Comments | |

## 3.2.4. Research

**Objective 37**
**Maintain and promote cancer research as a priority area in the main policies and funding instruments for biomedical research in our country. Possible areas to consider include: a) cancer screening strategies, early detection and early phases, health promotion and disease prevention, at the population level, applied to cancer risk factors; b) low-invasiveness and liquid biopsy diagnostic methods; c) dynamic biomarkers of recurrent, resistant or transforming disease; d) new therapies, advanced therapies and drug repositioning; e) radiobiology applied to oncology and radioresistance; f) precision surgery, robotics and reduction of amputations; g) rare tumours with high mortality and no therapeutic options; h) socio-labour rehabilitation and illness-work balance; i) incurable paediatric tumours; j) nutrition, psycho-oncology, palliative and continuing care; k) end-of-life care for cancer patients and freedom of decision; l) health services and health outcomes; m) results reported by the patient (Patient Report Outcomes-PRO).**

| **INDICATOR No. 37.1** | **Cancer area present as a priority area in a strategic health action.** |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | Strategic Health Action: is a strategy within the framework of the State Plan for Scientific and Technical Research and Innovation (2017-2020), aimed at researchers belonging to the National Health System for health research projects, managed by the Carlos III Health Institute. |
| Level of breakdown | NA. |
| Guiding standard | NA. |
| Data sources | ISCIII. |
| **INDICATOR No. 37.2** | **Annual funding granted in the field of Strategic Action on Health on cancer.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Annual funding granted by the Strategic Action on Health in the area of cancer.<br>b= Total annual funding of the Strategic Action on Health. |
| Explanation of terms | Strategic Health Action: is a strategy within the framework of the State Plan for Scientific and Technical Research and Innovation (2017-2020), aimed at researchers belonging to the National Health System for calls and grants managed by the Carlos III Health Institute.<br>The absolute funding and the percentage of growth with respect to previous years will be indicated. |
| Level of breakdown | Entire National Health System as a whole. |
| Guiding standard | |
| Data sources | ISCIII. |
| **INDICATOR No. 37.3** | **Percentage of research projects in the area of cancer funded by the ISCIII calls.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of research projects funded in the area of cancer in the ISCIII calls.<br>b= Total number of research projects in the ISCIII calls. |

| | |
|---|---|
| Explanation of terms | Calls and grants for research projects funded within the framework of the Strategic Health Action of the Carlos III Health Institute are considered. |
| Level of breakdown | NA. |
| Guiding standard | NA. |
| Data sources | ISCIII. |
| **INDICATOR No. 37.4** | **Average funding of research projects in the area of cancer funded in the ISCIII calls.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Sum of funding for research projects in the area of cancer in the ISCIII calls.<br>b= Number of research projects funded in the area of cancer in the ISCIII calls. |
| Explanation of terms | Calls and grants for research projects funded within the framework of the Strategic Health Action of the Carlos III Health Institute are considered. |
| Level of breakdown | NA. |
| Guiding standard | NA. |
| Data sources | ISCIII. |

| **Objective 38**<br>**Promote networks and groups of excellence in cancer research that are interconnected in a coordinated and cooperative manner within the framework of the CIBER and the health research institutes accredited by the ISCIII.** | |
|---|---|
| **INDICATOR No. 38.1** | **Health Research Institutes accredited with the thematic area of cancer as a priority area.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Health Research Institutes accredited by the ISCIII with the thematic area of cancer as a priority area.<br>b= Number of Health Research Institutes accredited by the ISCIII. |
| Explanation of terms | The Programme for the Evaluation, Accreditation and Monitoring of Health Research Institutes is a programme of the Carlos III Research Institute that is aimed at consolidating research centres, the core of which are the Spanish National Health System health centres, as knowledge generation and transfer centres to promote innovation, in response to health priorities at the state and European level. The accredited Health Research Institutes are oriented towards individual health needs and from the perspective of society. |
| Level of breakdown | NA. |
| Guiding standard | |
| Data sources | ISCIII. |

| **INDICATOR No. 38.2** | **Funded coordinated and multi-centre cancer research projects presented by CIBER research groups and Health Research Institutes in the area of cancer over the total number of cancer projects in the ISCIII calls.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of funded coordinated and multi-centre research projects presented by CIBER research groups and Health Research Institutes in the area of cancer.<br>b= Total number of research projects in the area of cancer in the ISCIII calls. |
| Explanation of terms | |
| Level of breakdown | CIBER. Health research institutes. |
| Guiding standard | |
| Data sources | ISCIII. |
| **INDICATOR No. 38.3** | **Number of Spanish publications on cancer in journals with an impact factor authored by CIBER research groups and Health Research Institutes in the area of cancer over the total number of Spanish publications on cancer in journals with an impact factor.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Spanish publications on cancer in journals with an impact factor authored by CIBER research groups and Health Research Institutes in the area of cancer.<br>b= Total number of Spanish publications on cancer with an impact factor. |
| Explanation of terms | |
| Level of breakdown | CIBER. Health research institutes. |
| Guiding standard | |
| Data sources | ISCIII. |

**Objective 39**
**Promote clinical trials initiated by Spanish National Health System research staff to explore questions without commercial interest or consequences, as well as for the development of products generated from academic research of the National Health System.**

| **INDICATOR No. 39** | **Clinical trials in the non-commercial area of cancer.** |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of non-commercial clinical trials started in the area of cancer.<br>b= Total number of clinical trials in cancer. |
| Explanation of terms | Non-commercial clinical trial: non-commercial academic clinical trial promoted by public/private (non-profit) entities that do not belong to the pharmaceutical industry. |
| Level of breakdown | NA. |
| Guiding standard | |
| Data sources | Ministry of Health. |

| **Objective 40**<br>**Promote and value the training and research activity of health personnel belonging to the Spanish National Health System.** | |
|---|---|
| **INDICATOR No. 40** | **Regional plan for postgraduate training in cancer research.** |
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of Autonomous Communities that include a postgraduate training plan in cancer research for healthcare professionals belonging to the Spanish National Health System.<br>b= Total number of Autonomous Communities. |
| Explanation of terms | Evaluated postgraduate training plan: Those postgraduate training plans recognized by the Health Departments of the Autonomous Communities are considered. |
| Level of breakdown | Autonomous Community. |
| Guiding standard | 100%. |
| Data sources | Autonomous Community. |

## 3.2.5. Overall indicators

| **Cancer mortality rate** | |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100,000.<br>a= Number of deaths caused by cancer within a one-year period.<br>b= Population in that year. |
| Explanation of terms | The codes for the causes of death from the International Classification of Diseases, 10th revision, are used for the selection of the main causes of death from cancer.<br>Crude mortality rates are obtained (see formula).<br>Age-adjusted rates are also obtained, using the new 2013 European standard population as the standard population.<br>The C00-C97 codes of the International Classification of Diseases, 10th Revision, are used. |
| Level of breakdown | Autonomous Community, gender, age and tumour type. |
| Limitations | Cancers in situ, benign tumours, and those of uncertain behaviour are not included. |
| Data sources | Ministry of Health. |

| **Premature deaths due to cancer** | |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100,000.<br>a= Number of deaths caused by cancer in individuals of less than 75 years of age within a one-year period. b= Population under 75 years of age in that year. |

| | |
|---|---|
| Explanation of terms | The deaths include the causes of death classified under the C00-C97 codes of the International Classification of Diseases, 10th Revision.<br>Age-adjusted rates are obtained, using the new 2013 European standard population as the standard population. |
| Level of breakdown | Autonomous Community, gender, age and tumour type. |
| Limitations | Cancers in situ, benign tumours, and those of uncertain behaviour are not included. |
| Data sources | Ministry of Health. |

| **Potential years of life lost at age 75** | |
|---|---|
| Formula or measurement system | Potential years of life lost before the age of 75: ∑(75-a) = Sum of the difference between 75 and the age of death of each cancer death prior to 75 years of age (a), during one year.<br>Rate of potential years of life lost before age 75: (∑(75-a)/b) x 100,000 = sum of the difference between 75 and the age of death of each death due to cancer before 75 years of age, divided by the population of the corresponding year multiplied by 100,000.<br>Where b= Population for that same year. |
| Explanation of terms | The years of potential life lost (YPLL) are a complementary indicator of mortality statistics whose usefulness is the approximation of premature mortality. There are several methods of calculating YPLL. One uses deaths prior to 75 years of age as avoidable mortality criteria. Although it is more complex to calculate, it is also interesting to know the potential years of life lost to life expectancy at the time of diagnosis.<br>The deaths include the causes of death classified under the C00-C97 codes of the International Classification of Diseases, 10th Revision (ICD10).<br>We get:<br>• The sum of the number of potential years of life lost before the age of 75 (∑(75-a)) of all those who died from cancer.<br>• The rate of potential years of life lost before age 75 of all cancer deaths per 100,000 people. |
| Level of breakdown | Autonomous Community, gender, and tumour type. |
| Limitations | Cancers in situ, benign tumours, and those of uncertain behaviour are not included. |
| Data sources | Ministry of Health. |

| **Potential number of years of life lost to life expectancy at the time of diagnosis** | |
|---|---|
| Formula or measurement system | Potential years of life lost: ∑(e-a) = Sum of the difference between life expectancy at the time of diagnosis (e) and the age of death of cancer deaths (a), during a one-year period.<br>Rate of potential years of life lost: (∑(e-a)/b) x 100,000<br>Where b= Population for that same year. |

| | |
|---|---|
| Explanation of terms | The years of potential life lost (YPLL) are a complementary indicator of mortality statistics whose usefulness is the approximation of premature mortality. There are several methods of calculating YPLL. One uses deaths prior to 75 years of age as avoidable mortality criteria. Although it is more complex to calculate, it is also interesting to know the potential years of life lost to life expectancy at the time of diagnosis.<br>The deaths include the causes of death classified under the C00-C97 codes of the International Classification of Diseases, 10th Revision (ICD10).<br>We get:<br>• The sum of the number of potential years of life lost before life expectancy at the time of diagnosis (∑(e-a)) of all those who died from cancer.<br>• The rate of potential years of life lost before life expectancy at the time of diagnosis of all those who died from cancer.<br>To know the age of life expectancy at the time of diagnosis of each death, the life table for the year of the corresponding diagnosis is used. |
| Level of breakdown | Autonomous Community, gender, and tumour type. |
| Limitations | Cancers in situ, benign tumours, and those of uncertain behaviour are not included. |
| Data sources | Ministry of Health. |

| **Cancer incidence rate.** | |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100,000.<br>a= Number of new cancer cases diagnosed within a one-year period.<br>b= Population for that year. |
| Explanation of terms | The types of cancer calculated by the Spanish Network of Cancer Registries according to the criteria of the International Agency Research of Cancer (IARC) are included.<br>Crude rates (formula) and age-adjusted rates are calculated, using the 2013 European standard population as the standard population.<br>The results obtained will be estimates based on incidence data from population-based cancer registries.<br>Population source: INE. |
| Level of breakdown | PHASE-1. Spain, gender, age and tumour type.<br>PHASE-2. In a second phase: Autonomous Community, gender, age and tumour type. |
| Limitations | Benign tumours are not included. Neither are cancers in situ, and those of uncertain behaviour except for bladder cancers. |
| Data sources | Population cancer registries of the Autonomous Communities and the Spanish Network of Cancer Registries (REDECAN). |

| **Childhood cancer incidence** | |
|---|---|
| Formula or measurement system | Equation: (a/b) × 1,000,000.<br>a= Number of new cases of childhood cancer (0-14 years), diagnosed in the last five years, of residents in Spain.<br>b= person-years 0-14 years old in that five-year period. |

| | |
|---|---|
| Explanation of terms | Tumour types from the International Classification of Childhood Cancers, Third edition, first revision (ICCC-3.1) accepted by the International Agency for Research of Cancer (IARC) are included.<br>Both crude (formula) rates and age-adjusted rates are calculated using two standard populations: the world standard population and the new 2013 European standard population.<br>Population source: INE. |
| Level of breakdown | Spain, gender, age and tumour group.<br>Age groups (0-4, 5-9, 10-14 and Global (0-14)). |
| Limitations | Benign tumours and those of uncertain behaviour of the central nervous system are included, but not benign tumours and those of uncertain behaviour of other locations.<br>Cancers in situ are not included. |
| Data sources | Spanish Registry of Childhood Tumours (RETI). |

| **Observed population survival five years after cancer diagnosis in adults** | |
|---|---|
| Formula or measurement system | Calculation method: Kaplan-Meier.<br>Survival time (in days) is counted from the first diagnosis until the end of follow-up due to death or loss to follow-up or until follow-up time reaches five years. |
| Explanation of terms | The survival observed five years after diagnosis is analysed by five-year cohorts from the date of diagnosis, for patients residing in Spain. This survival is only offered for complete five-year follow-up periods, that is, cases are followed up to their fifth anniversary from the date of diagnosis. The cases lost to follow-up at five years are those whose last follow-up date is a date prior to the fifth anniversary from the date of diagnosis and is not the date of death.<br>The accuracy of the survival estimate is based on follow-up, which should be as exhaustive as possible. It is accepted that follow-up should be around 95%. |
| Level of breakdown | PHASE-1. Set of provinces with population cancer registry, sex, age and tumour type.<br>PHASE-2. In a second phase (on demand): Each province with population registry for cancer, sex, age and tumour type. |
| Limitations | Benign tumours are not included. Neither are cancers in situ, and those of uncertain behaviour except for bladder cancers. |
| Data sources | Population cancer registries of the Autonomous Communities and the Spanish Network of Cancer Registries (REDECAN). |

| **Net population survival five years after cancer diagnosis in adults** | |
|---|---|
| Formula or measurement system | Calculation method: Pohar-Perme estimator. |
| Explanation of terms | This is the ratio between the observed survival at five years and the survival that would be expected in a cohort of the same sex and age structure as the general population in the same period of time.<br>Reference for the calculation method: ***Perme MP, Stare J, Estève J. On Estimation in Relative Survival. Biometrics. 2012;68(1):113-20.*** |

| | |
|---|---|
| Level of breakdown | PHASE-1. Set of provinces with population cancer registry, sex, age and tumour type.<br>PHASE-2. In a second phase (on demand): Each province with population registry for cancer, sex, age and tumour type. |
| Limitations | Benign tumours are not included. Neither are cancers in situ, and those of uncertain behaviour except for bladder cancers. |
| Data sources | Population cancer registries of the Autonomous Communities and the Spanish Network of Cancer Registries (REDECAN). |

| **Observed population survival and follow-up five years after cancer diagnosis in children (0-14 years old)** | |
|---|---|
| Formula or measurement system | Calculation method: Kaplan-Meier.<br>Survival: Time (in days) from the first diagnosis until the end of follow-up due to death or loss or until follow-up time reaches five years.<br>Follow-up percentage (complementary indicator): Percentage of cases that enter the study followed up until the fifth anniversary from the date of diagnosis or precise information is available on their date of death before the fifth anniversary. |
| Explanation of terms | The survival observed and the follow-up at five years after diagnosis is analysed by five-year cohorts from the date of diagnosis, for patients residing in Spain. This survival is only offered for complete five-year follow-up periods, that is, cases are followed up to their fifth anniversary from the date of diagnosis. The cases lost to follow-up at five years are those whose last follow-up date is a date prior to the fifth anniversary from the date of diagnosis and is not the date of death (Loss percentage = 100 - Complete follow-up percentage).<br>The accuracy of the survival estimate is based on follow-up, which should be as exhaustive as possible. It is accepted that follow-up should be around 95%.<br>No estimates are made for tumour groups with fewer than 15 cases. |
| Level of breakdown | PHASE-1: All of Spain, by five-year cohorts, tumour groups (ICCC-3.1), sex and age group.<br>PHASE-2: by Autonomous Communities, according to demand by the ministry and/or Autonomous Communities. |
| Limitations | Benign tumours and those of uncertain behaviour of the central nervous system are included, but not benign tumours and those of uncertain behaviour of other locations.<br>Cancers in situ are not included. |
| Data sources | Spanish Registry of Childhood Tumours (RETI). |

| **Percentage coverage of the incidence in Spain (complete), for childhood cancer (0-14 years)** | |
|---|---|
| Formula or measurement system | Equation: Observed/Expected × 100.<br>Calculation of Expected (complementary indicator): The reference rate (that of the Spanish Cancer Registries in IICC-3) and the population (INE person-years) are used. |

| | |
|---|---|
| Explanation of terms | Coverage: Proportion of new incident cases of childhood tumors (0-14 years) of patients residing in Spain registered in the Spanish Registry of Childhood Tumours (RETI) expressed as a percentage.<br>Observed number: This is the number of cases registered in the RETI and residing in Spain.<br>Expected number: This is an estimate of the incident cases calculated by the RETI, taking into account the Spanish population of children (INE person-years) and the reference incidence rates (that of the Spanish Cancer Registries in IICC-3).<br>Reference for the calculation method: ***Ross JA, et al. Childhood cancer in the United States. A geographical analysis of cases from the Pediatric Cooperative Clinical Trials Groups. Cancer 1996; 77:201-207.*** |
| Level of breakdown | For all of Spain, selection of tumor groups (ICCC-3.1) and age groups, for the recent five-year period. |
| Data sources | Spanish Registry of Childhood Tumours (RETI). |

| **Percentage of conservative surgery in breast cancer** | |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of discharges with conservative surgical procedure. b= Total number of discharges with any surgical procedure for removal of breast cancer. |
| Explanation of terms | An evaluation will be made of all those women whose main diagnosis is of a malignant breast neoplasia who have undergone surgery by means of a surgical procedure not entailing a radical or modified mastectomy (such as a segmentectomy, quadratectomy, tumorectomy), compared to the total number of females who have undergone any breast surgery procedure.<br>For the numerator, a segmentectomy, quadratectomy or tumorectomy are considered as being conservative surgery: ICD-9MC procedure codes: 85.20 to 85.23 and 85.25 and main diagnosis of malignant breast neoplasia (174.X).<br>For the denominator, all of the surgical procedures for removal of breast tissue and mastectomies (codes 85.2X, 85.34 to 85.36, 85.4X) and main diagnosis of breast cancer must be taken into account.<br>This includes the procedures performed with a hospital admission and those performed by means of outpatient surgery.<br>It is important to check that there are no reinterventions. |
| Level of breakdown | Autonomous Community. |
| Data sources | Ministry of Health. |

| **Hospital mortality rate following surgery for:**<br>**a. Esophageal cancer**<br>**b. Pancreatic cancer**<br>**c. Lung cancer**<br>**d. Liver metastasis** | |
|---|---|
| Formula or measurement system | Equation: (a/b) × 100.<br>a= Number of discharges with conservative surgical procedure. b= Total number of discharges with any surgical procedure for removal of breast cancer. |

| | |
|---|---|
| Explanation of terms | To calculate these indicators, an analysis is made of those cases in which, after having undergone surgery for the aforementioned problems, the person dies in the hospital within the 30-day period immediately following the surgical intervention.<br>All of the discharges including the following international classification of diseases (ICD) codes, version 9-MC, are included:<br>Esophageal cancer:<br>• diagnoses: 150; 150.0; 150.1; 150.2; 150.3; 150.4; 150.5; 150.8 and 150.9.<br>• procedures: 42.3; 42.31; 42.32; 42.33; 42.39; 42.4; 42.40; 42.41 and 42.42.<br>Pancreatic cancer:<br>• diagnoses: 157; 157.0; 157.1; 157.2; 157.3; 157.4; 157.8; 150.8 and 157.9.<br>• procedures: 52.2; 52.21; 52.22; 52.5; 52.51; 52.52; 52.53; 52.59; 52.6 and 52.7<br>Lung cancer:<br>• diagnoses: 162; 162.0; 162.2; 162.3; 162.4; 162.5; 162.8 and 162.9.<br>• procedures: 31.5; 32; 32.0; 32.01; 32.09; 32.1; 32.2; 32.21; 32.22; 32.28; 32.29; 32.3; 32.4; 32.5; 32.6 and 32.9.<br>Liver metastasis:<br>• diagnoses: 197.7.<br>• procedures: 50.2; 50.21; 50.22; 50.29; 50.3 and 50.4.<br>For the numerator, these same codes will be taken into account, to which the death criterion as a reason for release is added. |
| Level of breakdown | Autonomous Community and gender. |
| Data sources | Ministry of Health. |

| **Equity in the Cancer Strategy of the Spanish National Health System and regional cancer plans** | |
|---|---|
| Formula or measurement system | Dichotomous (yes/no). |
| Explanation of terms | The analysis of equity will be carried out through the tool ***Methodological Guide to Integrate Equity in Health Strategies, Programmes and Activities*** of the Spanish National Health System. |
| Level of breakdown | NA. |
| Guiding standard | Equity analysis performed. |
| Data sources | Ministry of Health. Autonomous Community. |

| **Regional cancer plans** | |
|---|---|
| Formula or measurement system | Number of Autonomous Communities with an oncology plan. |
| Data sources | Autonomous Communities. |

# 4. Annex. Agreement for the interterritorial council of the spanish national health system on the organization of care for childhood and adolescent cancer

24 September 2018

The Spanish National Health System (SNHS) has a National Health System Cancer Strategy that is the result of collaboration between the Ministry of Health, Social Services and Equality (MSSSI), Autonomous Communities (ACs), scientific societies and patient associations, with a strategic line on "Care for children and adolescents".

In order to provide health professionals, health administrations and their managers with an instrument that includes the quality criteria for the optimal organization and management of care units for the care of children and adolescents with cancer in Spain, the document "Cancer care units in childhood and adolescence. Quality and safety standards and recommendations", was prepared and later approved by the SNHS Interterritorial Council on 26 March 2015.

The low incidence and the need for high specialization determine that care for childhood and adolescent cancer should be limited to those centres that guarantee:

- The experience (number of cases) required to maintain the training and periodic refreshing of their professionals. The European Standards of Care for Children with Cancer propose that a minimum number of 30 new cases per year would be necessary to have sufficient clinical experience.
- Childhood and adolescent cancer care by a multidisciplinary team.
- The integration into a hospital that has those specialties (including diagnostic and treatment services) required to care for the complexity of childhood and adolescent cancer.
- Work in a healthcare network with other centres or units involved in the care of children and adolescents with cancer.

**Justification and objective of the agreement**

Analysis of the data from the Spanish Registry of Childhood Tumours shows that the survival results in childhood cancer (0-14 years) in Spain compared to other European countries in our environment can be improved, while differences in survival in Spain are also found.

Although the quality criteria for the organization and management of care units for the care of children and adolescents with cancer in Spain are defined in the document "Cancer care units in childhood and adolescence. Quality and safety standards and recommendations", its implementation is not homogeneous throughout the Spanish National Health System and could contribute to the differences in survival found.

The objective of this proposal is to agree on specific measures to be implemented in the Autonomous Communities in order to improve survival results of childhood and adolescent cancer in the Spanish National Health System.

**Measures to be implemented**

1. Creation of a **regional care coordination committee** for the management of care in all cases of childhood and adolescent cancer in each Autonomous Community. This committee must be created and defined through the relevant regulations.

The committee will be constituted, at least, by a representative of each tumor committee of the centres with regional paediatric onco-hematology unit, those responsible for the paediatric onco-hematology unit, a head of the coordination of pediatric onco-hematology in the Autonomous Community, a person responsible for the management of the patients and the members determined by said committee for those situations that require it, as experts and of a permanent or non-permanent nature.

In the case of Autonomous Communities that refer their cases to other Communities the committee will be constituted by a head of the coordination of pediatric onco-hematology in the Autonomous Community, a person responsible for the management of the patients and the members determined by said committee for those situations that require it, as experts and of a permanent or non-permanent nature.

The regional care coordination committee will have the following **functions**:

1) It will prepare the care offer of the AC for childhood and adolescent cancer.
2) It will analyse and define the clinical criteria for action, including follow-up in paediatric and adolescent oncological processes of the AC health service.

3) Prepare and apply patient management protocols that will include:

- The clinical criteria for referral to the paediatric onco-hematology unit for each pathology, for the entire disease process or part of the process.
- Patient management channels in order to establish agile, efficient systems that provide quick and effective solutions to each particular case.
- The possibility of requesting a second opinion from a CSUR of the Spanish National Health System.
- It will propose coordination protocols with the rest of the healthcare resources, including paediatric services both at the hospital and primary care level, paediatric palliative care and home care.
- It will guarantee the transitioning of children and adolescents to adult services adapted to the individual maturation process of each patient.

4) It will propose the professionals or centres designated to diagnose and treat each specific patient and will coordinate their network actions.
5) It will guarantee each patient their inclusion in the most effective, safe and updated therapeutic protocol according to the available evidence.
6) It will promote the participation of paediatric cancer patients in multi-centre studies and clinical trials, in which the tasks and responsibilities to be carried out by each centre are specified in accordance with current regulations.
   It will guarantee the continuous and joint training of medical and nursing professionals, as well as other professionals involved in the healthcare team, from the hospital itself, from other hospitals and from primary care.
8) Promote and monitor training/education programmes for patients and families.
9) Evaluate the results, identify problems and areas for improvement, and provide advice and adaptation in terms of care objectives.
10) Facilitate coordination with the competent institution in social support for patients and their families.
11) It will encourage long-term follow-up of survivors to control long-term sequelae, recurrences, etc.

2. **Concentration of care in paediatric onco-hematology units**

This model implies designating, through the relevant regional regulations, paediatric onco-hematology units in the Autonomous Communities, which will attend to the volume of patients necessary for optimum care. (SIOP Europe (The European Society for Paediatric Oncology) recommends treating at least 30 new cases per year in order to gain sufficient experience).

Adolescent patients up to 18 years of age (18-year-old patients are not included) should be treated in paediatric units, unless there is the possibility of caring for them in specific units.

Care for adolescents will be carried out jointly between paediatric onco-hematology professionals and adult oncology when the type of tumor requires it.

The requirements that these units must meet are described in Annex I of this agreement.

3. **Each Autonomous Community should adopt one of the following organizational models:**

**a) Network model based on one or several paediatric onco-hematology units.**

The care network is an organizational tool that contemplates the child or adolescent as the centre of the care process, guaranteeing optimal care.

This is created by the functional union of different health entities/organizations who consider that in order to guarantee adequate care for children and adolescents they must work as a team in an organized manner.

The network must be formally established and this must include the centres/services/institutions/units that comprise it, as well as its purposes and procedures.

Network criteria:

- Child oncology diagnoses and treatments will only be carried out within a healthcare network.
- The care network will have referral criteria, clinical sessions, clinical guidelines, training activities, registration and shared clinical information and monitoring of results.
- It will establish the diagnostic, therapeutic and patient follow-up protocols for each pathology. As well as a protocol, agreed upon by the Network and the Emergency Services for their coordinated action when one of these patients goes to the ER.
- The care network will have a procedure that evaluates the follow-up of clinical recommendations and networking agreements.

- The care network will promote continuity of care between the different levels through figures such as the head physician, case manager, etc.

The network is composed of the following elements:

- Hospitals with paediatric oncology and hematology units.
- Hospitals without paediatric oncology and hematology units, primary care, palliative care and home care.
- Units that carry out highly complex procedures that are included in the CSUR catalogue of the Spanish National Health System.

The network will have a network coordinating committee which should coincide with the regional care coordination committee.

**b) Referral of all cases to another Autonomous Community.**

When the total volume of cases is not sufficient considering the reference population and territorial distribution, agreements will be adopted with other Autonomous Communities to provide optimal care.

**Within one year after approval by the plenary session of the SNHS Interterritorial Council, the regulations/instructions will be available that will describe at least the regional care coordination committee and its model.**

*Criteria that paediatric onco-hematology units must meet*

- Accredit an activity with a volume of patients necessary so that, based on their experience, care is optimal.
- Have a paediatric tumor committee in the centre where they are located that will have defined operating standards.
- Specify the pathology or group of pathologies that are treated in the centre/unit.
- Include in the offer of services at least: paediatric radiology, paediatric hospitalization, paediatric day hospital, paediatric intensive care unit, paediatric outpatient clinic, paediatric emergencies, paediatric surgical area, child clinical psychiatry/psychology.
- Offer continuous cancer care 24 hours a day, 365 days a year.
- Have tools for working in a care network with other centres and units.
- Guarantee access to paediatric home care and paediatric palliative care.
- Participate in research activities related to the treatment of children with cancer.

- Guarantee the direct accessibility of the patients and their relatives in the centres where they usually treat the patient with the resources of the unit, by telephone, telematics, email or similar.
- Promote the participation of the patient and their parents in the decisions that are made throughout the process of caring for their children, when the minor cannot understand the scope of the interventions that are proposed.
- Have protocols, based on the best scientific evidence that will include diagnostic, therapeutic and patient follow-up procedures; have a registry of patients treated and participate in a childhood cancer registry.
- Ensure care by a multidisciplinary team made up of a care coordinator, paediatricians or oncologists dedicated to paediatric oncology, hematologist, paediatric surgeon, radiation oncologist, pathologist, hospital pharmacist, physician expert in infectious diseases, radiologist, nursing staff, social worker, teacher, rehabilitator, dietician, psychologist, physiotherapy and occupational therapy staff.

Source: synthesis of the book Childhood and Adolescent Cancer Care Units.

# 5. Index of Abbreviations and Acronyms

| | |
|---|---|
| **AC** | Autonomous Communities |
| **CAIBER** | Spanish Clinical Research Network [Consorcio de Apoyo a la Investigación Biomédica en Red] |
| **CIBER** | Clinical Research Network Centre [Centro de Investigación Biomédica en Red] |
| **CIFC** | Cancer Incidence in Five Continents |
| **CMBD** | National Health System General Hospital Discharge Registry |
| **COM** | European Commission [Comisión de las Comunidades Europeas] |
| **ECIS** | European Cancer Information System |
| **EDADES** | Spanish National Household Survey on Alcohol and Drugs [Encuesta Domiciliaria sobre Alcohol y Drogas en España] |
| **ENCR** | European Network of Cancer Registries |
| **ENSE** | Spanish National Health Survey [Encuesta Nacional de Salud en España] |
| **ERSPC** | European Randomized Study of Prostate Cancer |
| **ESMO** | European Society of Medical Oncology |
| **EU** | 27-member European Union |
| **GDP** | Gross Domestic Product [Producto Interior Bruto] |
| **HPV** | Human Papilomavirus |
| **IARC** | International Agency for Research on Cancer |
| **ICD** | International Classification of Diseases |
| **INE** | National Institute of Statistics [Instituto Nacional de Estadística] |
| **INGESA** | National Institute of Health Management [Instituto Nacional de Gestión Sanitaria] |
| **ISCIII** | Carlos III Health Institute [Instituto de Salud Carlos III] |
| **JRC** | Joint Research Centre of the European Commission |
| **MH** | Ministry of Health |
| **NAOS** | Strategy for Nutrition, Physical Activity and Prevention of Obesity [Estrategia para la Nutrición, Actividad Física y Prevención de la Obesidad] |
| **NCI** | National Cancer Institute |
| **NICE** | National Institute for Clinical Excellence |

| | |
|---|---|
| **OPI** | Public Research Organizations [Organismos Públicos de Investigación] |
| **PLCO** | Prostate, Lung, Colon, Ovary Trial |
| **R+D+i** | Research, Development and Innovation |
| **RD** | Royal Decree [Real Decreto] |
| **RETICs** | Theme-Based Cooperative Health Care Networks [Redes Temáticas de Investigación Cooperativa Sanitaria] |
| **RNTI** | Spanish National Registry of Childhood Tumours [Registro Nacional de Tumores Infantiles] |
| **RTICC** | Theme-Based Cooperative Cancer Research Centre Network [Red Temática de Investigación cooperativa de Centros de Cancer] |
| **SEHOP** | Spanish Paediatric Hematology and Oncology Society [Sociedad Española de Hematología y Oncología Pediátricas] |
| **SENC** | Spanish Society of Community Nutrition [Sociedad Española de Nutrición Comunitaria] |
| **SEOM** | Spanish Society of Medical Oncology [Sociedad Española de Oncología Médica] |
| **SEOR** | Spanish Radiotherapy Society [Sociedad Española de Oncología Radioterápica] |
| **SIOP** | International Society of Paediatric Oncology [Sociedad Internacional de Oncología Pediátrica] |
| **SMEC** | Strategy Monitoring and Evaluation Committee [Comité de Seguimiento y Evaluación de la Estrategia] |
| **SNHS** | Spanish National Health System [Sistema Nacional de Salud] |
| **SNHSIC** | Spanish National Health System Interterritorial Council [Consejo Interterritorial del Sistema Nacional de Salud] |
| **WCRF** | World Cancer Research Foundation |
| **WHO** | World Health Organization (OMS) |

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Based on the conclusions of the last evaluation of the Spanish National Health System Cancer Strategy Cancer Strategy that took place in 2014, and the review of the available scientific evidence, this update of the Spanish National Health System Cancer Strategy 2021 has been prepared. This new update uses all the knowledge and data available to date to establish a document that includes a review of the objectives based on the current situation and the results achieved, thus serving as a guide for defining the lines of work for the coming years, in accordance with the principles of quality, equity and cohesion. A rigorous approach to cancer requires a set of actions that establish contrasted and agreed criteria on the guidelines to be followed in any of the strategic lines included in the Strategy, in order to achieve better efficacy and quality in the approach to this pathology in all the health services that make up the Spanish health system. To this end, the document establishes a set of objectives and recommendations, which aim to contribute to improving the quality of interventions and outcomes of services and health care.

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