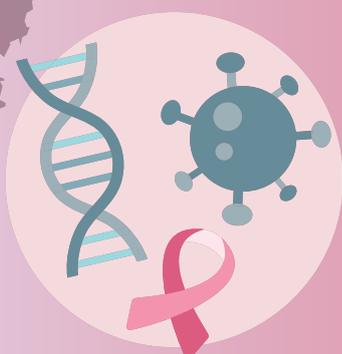


# Catalan Cancer Plan

## 2022-2026



## **By**

Catalan Cancer Plan  
Directorate General of Health Planning and Research.

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## **1. Introduction**

Since 2001, the Catalan Government's Department of Health has been developing five-year cancer plans, a sign of its active commitment to cancer prevention and control in Catalonia. The timeframe for the current Plan, delayed by the emergence of Covid-19 in March 2020 (the year when discussion of the new plan should have begun), is period 2022-2026. As in so many other areas of our healthcare system, Covid-19 has thus had an enormous impact and should lead us to rethink aspects of cancer diagnosis and treatment which, after the healthcare experience during Covid-19, will not be the same again.

This document presents an assessment of the impact of cancer in Catalonia up to 2025 (the year chosen to comply with the methodology and time periods of the International Agency for Research on Cancer, IARC). It is followed by an assessment of the progress made during period 2015-2020 and a discussion of the remaining challenges, especially in view of the goals introduced by Europe's Beating Cancer Plan published in February 2021 to mark the World Cancer Day. Finally, objectives for the next period are presented in a summary.

## **2. Impact of cancer in Catalonia: an assessment up to 2026**

In 2020, the continuum of cancer diagnosis and treatment was disrupted by the coronavirus disease 2019 (Covid-19) pandemic. Potential delays in diagnosis and treatment may lead to an underestimation of cancer incidence in the short term followed by an increase in advanced-stage disease and ultimately an increase in mortality (1). Nonetheless, it may take several years to quantify these possible consequences of the pandemic.

The results presented for cancer projections in 2020 and 2025 are based on robust models (2) which, in turn, are grounded on data from the Girona and Tarragona population-based cancer registries over a time period prior to the pandemic.

### **2.1 Projections of cancer incidence in Catalonia up to 2025**

The estimate of the burden (incidence) of cancer in Catalonia over the period examined shows features similar to those in other European countries in this period. The raw and age-standardised rates are at an intermediate-high level for men and below the European average for women. Table 1 shows the number of cases and the 10 most frequent tumours for both Catalan men and women in 2020. The five most frequent tumours in Catalonia and in Europe for men are as follows: prostate (N=4,396), colorectal (N=3,732), lung (N=3,055), bladder (N=1,865) and kidney (N=753), and they account for 65% of the total number of cases diagnosed in 2020 in men (N=21,026). For women, the top five most frequent tumours in Catalonia and Europe are: breast (N=4,626), colorectal (N=2,701), lung (N=975), corpus uteri (N=828) and pancreas (N=504), which represent 60% of the total number of cases diagnosed in 2020 (N=16,163) among Catalan women. 68.3% of cancer cases in men are diagnosed after age 64, while in women it is 57.6%.

The situation and trends observed in Catalonia (figures 1 and 2) in the period analysed show features similar to those in Europe:

1. Figure 1 shows the decline and stabilisation of the standardised rates of the main tumours and indicates that incidence in younger people is stabilising and/or falling in the majority of tumours, especially at ages between 35 and 64, given that these are the most influential age groups in the estimation of rates. However, the total number of cases continues to increase annually as shown by the crude rates, mainly due to the rise in cases in the population over 65 (2).
2. Prostate cancer is the most frequent tumour in men, while in women it is breast cancer. When women and men are considered jointly, colorectal cancer is the most common.
3. The incidence of prostate cancer had been increasing until the early 2000s, after which there was a decline. By 2025, 68.3% of cases are expected to be diagnosed in men over 64 (the majority, in men over 74, who account for more than 40% of cases) (2).
4. Colorectal cancer remains the most common cancer in both men and women, and more than 70% of cases are diagnosed after age 64.

5. The incidence of breast cancer in Catalonia has stabilised since the early 2000s. This is partly due to routine screening in women aged between 45 and 64 (2). However, the upward trend in crude rates is related to the expected increase in cases in women over 64, where 42% of cases are diagnosed.
6. The most important risk factor for lung cancer is smoking. The increase in the incidence of this tumour in women is associated with the rise in smoking rates, which began in the 1970s and peaked in the mid-1990s (2). This trend contrasts with men's, who have been quitting the habit since the mid-1980s. In men, 73.8% of cases are diagnosed after age 64, while in women that figure is 59.1%.

## **2.2 Variation in the number of diagnosed cases of cancer between 2015 and 2025**

Bearing in mind the demographic forecasts made by the Statistical Institute of Catalonia, the projections of incidence up to 2025 based on the incidence data from the Girona and Tarragona registries allow to estimate the number of foreseeable cases and to compare the variation between 2015 and 2025. The methodological details can be found in the referenced paper (2).

In men, it has been estimated that the number of cancer cases in Catalonia will rise from 21,436 cases in 2015 to 24,382 cases in 2025 (Table 2), while in women the number of incident cases will go up from 15,619 in 2015 to 18,288 in 2025 (Table 3). This represents growth between periods of 13.7% in men and 17.1% in women, respectively. In men, the rise in cases between periods is striking in prostate (718; 16.5%), colorectal (600; 15.7%), lung (433; 13.3%), kidney (210; 34.3%) and liver (191; 25.4%) cancers. Among women, the rise between periods is greatest in breast (787; 16.6%), colorectal (420; 19%), lung (280; 27.3%) and melanoma (181; 41%).

The variation between periods is the result of the sum of three percentage changes between the two periods: changes due to the risk of developing cancer, changes due to population ageing and changes due to population size. The growth in the number of cases in men is mainly down to an 13.8% increase which is accounted for by the demographic evolution of the Catalan population (6.9% attributable to ageing and 6.9% due to population rise), while the risk of developing cancer is expected to fall by 0.1%. For women, there is a 17.1% increase between time periods where ageing explains 4.8%, population rise 6.6%, while the risk of developing cancer increases by 5.7%. This increase is related to the rise in cases due to ageing for colorectal and breast cancer, and also to the rise in smoking-associated tumours, in particular lung, where the risk is up by 12.3% between periods, similar to the sum of the percentages due to ageing (7.8%) and population rise (7.8%).

## **2.3 Cancer survival in Catalonia**

As for the prognosis of patients diagnosed with cancer in Catalonia (Table 4), the most recent estimates of five-year cancer survival show that women have better cancer survival rates than men, at 62.7% and 53.9% respectively. Tumours with the best survival rates in women are breast (89.0%) and thyroid cancer (93.1%) while in men they are testicular (96.6%) and prostate cancers (91.8%). Overall, the most aggressive tumour is pancreatic cancer, with a survival rate of less than 10%. In women, survival rates for gallbladder and bile duct cancer (10.3%) and liver cancer (13.2%) show highly lethal, while in men lung cancer (14%) is the second most lethal, followed by oesophageal cancer (15.3%). Lung cancer survival in women (19.3%) is higher than in men. Finally, survival rate for colorectal cancer is close to 60% for both men and women.

## 2.4 Paediatric cancer

Paediatric cancer (PC) is considered a rare disease due to its low frequency. The most recent estimates in 2020 have shown that age-standardized incidence rates per 100,000 person-years are 17.2 in the USA and 15.6 in Europe. In Spain, incidence is 155 cases per million children (0.02%), with a prevalence similar to the European average. Table 5 shows the number of PC cases diagnosed in Catalonia during the period 2017-2021 by diagnostic group. A total of 800 cases were diagnosed in this period (160 cases per year over the period). Of the 12 diagnostic groups, the three most frequent were: i) leukaemia, myeloproliferative diseases and myelodysplasia, at 28.4%, followed by ii) tumours of the central nervous system and miscellaneous intracranial and intraspinal neoplasms, at 25.5%, and iii) lymphomas and reticuloendothelial neoplasms, at 12.6%.

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**Table 1.** Annual incident cases of cancer for the 10 most frequent tumours in Catalonia in 2020

Men Site	2020		Women Site	2020	
	N (%)	N > 64(%*)		N (%)	N > 64(%*)
Prostate	4,396 (20.9)	3,402 (77.4)	Breast	4,626 (28.6)	1,945 (42.0)
Colorectal	3,732 (17.7)	2,647 (70.9)	Colorectal	2,701 (16.7)	1,962 (72.7)
Trachea, bronchus and lung	3,055 (14.5)	2,256 (73.8)	Trachea, bronchus and lung	975 (6.0)	576 (59.1)
Bladder	1,865 (8.9)	1,408 (75.5)	Corpus uteri	828 (5.1)	512 (61.8)
Kidney	753 (3.6)	472 (62.7)	Pancreas	504 (3.1)	403 (80.0)
Lip, oral cavity and pharynx	726 (3.5)	357 (49.2)	Non-Hodgkin's lymphoma	501 (3.1)	290 (55.7)
Non-Hodgkin's lymphoma	719 (3.4)	378 (52.6)	Thyroid	494 (3.0)	105 (21.3)
Pancreas	642 (3.1)	435 (67.8)	Bladder	441 (2.7)	352 (79.8)
Liver	597 (2.8)	323 (54.1)	Melanoma	429 (2.6)	191 (44.5)
Stomach	582 (2.8)	410 (70.4)	Kidney	428 (2.6)	278 (65.0)
Total <sup>T</sup>	21,026 (100)	14,367 (68.3)	Total <sup>T</sup>	16,163 (100)	9,307 (57.6)

\*: percentage of total cases at the site; Total<sup>T</sup>: total cases excluding non-melanoma skin cancer.

**Table 2. Men:** differences in the number of incident cases of cancer in Catalonia between 2015 and 2025 associated with changes in the risk of developing cancer and changes in the demographics (ageing and size) of the Catalan population

Site	Change in the period				Percentage of change due to		
	2015 (N)	2025 (N)	Difference 2025- 2015	Variation (%)	Risk (%)	Ageing (%)	Size (%)
Lip, oral cavity and pharynx	717	832	115	16	1	7.9	7.1
Oesophagus	359	381	22	6.1	-8	7.7	6.4
Stomach	672	736	64	9.5	-3.9	6.7	6.7
Colon, rectum and anus	3,798	4,398	600	15.7	2.1	6.9	6.7
Gallbladder and bile duct	147	200	53	36.1	20.4	7.3	8.4
Liver	751	942	191	25.4	10	7.8	7.6
Pancreas	644	706	62	9.6	-4.2	7.2	6.6
Larynx	439	508	69	15.7	0.6	8.1	7
Trachea, bronchus and lung	3,249	3,682	433	13.3	1.6	6.4	5.3
Skin, melanoma	436	497	61	14	2.7	4.4	6.9
Prostate	4,344	5,062	718	16.5	1.5	7.9	7.1
Testicle	181	189	8	4.4	3.2	-5.1	6.3
Kidney and urinary tract	612	822	210	34.3	19.9	6.2	8.2
Bladder	1,441	1,443	2	0.1	-13.4	7.4	6.1
Central nervous system	340	419	79	23.2	10.5	5.2	7.5
Thyroid	143	134	-9	-6.3	-15.4	3.4	5.7
Hodgkin's lymphoma	131	174	43	32.8	25.3	-0.6	8.1
Non-Hodgkin's lymphoma	738	859	121	16.4	3.9	5.4	7.1
Multiple myeloma*	326	317	-9	-2.8	-16.2	7.5	5.9
Leukaemia	623	588	-35	-5.6	-17.3	6	5.7
Other and non-specific	1,345	1,493	148	11	-1.1	5.3	6.8
Skin, non-melanoma	7,694	9,503	1,809	23.5	9.6	7.6	6.3
Total <sup>†</sup>	21,436	24,382	2,946	13.7	-0.1	6.9	6.9

Multiple myeloma\*: includes multiple myeloma and immunoproliferative diseases; Total<sup>†</sup>: total number of cases excluding non-melanoma skin cancer.

**Variation (%):** Percentage change in the number of cases between 2015 (baseline) and 2025. This percentage change can be accounted for by the sum of three quantities: the percentage due to risk of developing cancer, **Risk (%)**, the percentage due to population structure/ageing, **Ageing (%)**, and the percentage due to population size, **Size (%)**, between the two periods. Ageing and size are considered demographic components in this variation.

**Table 3. Women:** differences in the number of incident cases of cancer in Catalonia between 2015 and 2025 associated with changes in the risk of developing cancer and changes in the demographics (ageing and size) of the Catalan population

Site	Change in the period				Percentage of change due to		
	2015 (N)	2025 (N)	Difference 2025-2015	Variation (%)	Risk (%)	Ageing (%)	Size (%)
Lip, oral cavity and pharynx	240	373	133	55.4	41	5.7	8.7
Oesophagus	41	80	39	95.1	78.5	5.7	10.9
Stomach	478	465	-13	-2.7	-12	3.8	5.5
Colon, rectum and anus	2,408	2,828	420	17.4	5.3	5.6	6.5
Gallbladder and bile duct	214	266	52	24.3	10.4	7	6.9
Liver	312	320	8	2.6	-8	4.8	5.8
Pancreas	513	620	107	20.9	9.7	4.4	6.8
Larynx	64	70	6	9.4	-5.7	9	6.1
Trachea, bronchus and lung	1,026	1,306	280	27.3	12.3	7.8	7.2
Skin, melanoma	442	623	181	41	29.7	3.3	8
Breast	4,728	5,515	787	16.6	5.9	4.2	6.5
Cervix	280	374	94	33.6	25.3	0.8	7.5
Corpus uteri	940	910	-30	-3.2	-14.9	6.3	5.4
Ovary and adnexa	442	545	103	23.3	10.3	6.1	6.9
Kidney and urinary tract	304	440	136	44.7	31.5	5.1	8.1
Bladder	262	367	105	40.1	26.5	5.7	7.9
Central nervous system	257	258	1	0.4	-9.5	4.3	5.6
Thyroid	386	482	96	24.9	16.5	1.4	7
Hodgkin's lymphoma	63	61	-2	-3.2	-10	1.4	5.4
Non-Hodgkin's lymphoma	592	609	17	2.9	-7.9	5	5.8
Multiple myeloma*	190	204	14	7.4	-4.1	5.5	6
Leukaemia	417	538	121	29	17.8	4	7.2
Other and non-specific	1,020	1,043	23	2.3	-7.7	4.2	5.8
Skin, non-melanoma	6,321	7,129	808	12.7	0.1	6.8	5.8
Total <sup>†</sup>	15,619	18,297	2,678	17.1	5.7	4.8	6.6

Multiple myeloma\*: includes multiple myeloma and immunoproliferative diseases; Total<sup>†</sup>: total number of cases excluding non-melanoma skin cancer.

**Variation (%):** Percentage change in the number of cases between 2015 (baseline) and 2025. This percentage change can be accounted for by the sum of three quantities: the percentage due to risk of developing cancer, **Risk (%)**, the percentage due to population structure/ageing, **Ageing (%)**, and the percentage due to population size, **Size (%)**, between the two periods. Ageing and size are considered demographic components in this variation.

**Table 4.** Estimated 5-year relative survival rate for the main malignant tumours diagnosed in Catalonia during the period 2010-2014 (Source: Girona and Tarragona Cancer Registries)

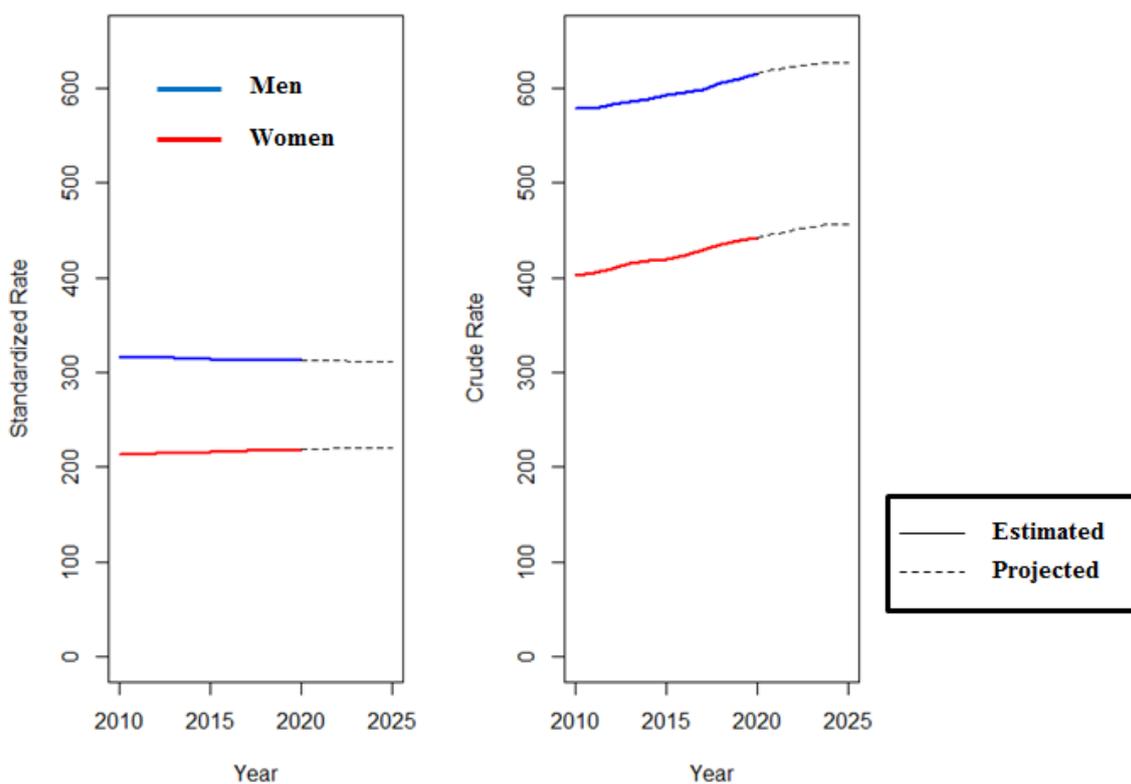
Site	Relative survival	
	Men	Women
Lip, oral cavity and pharynx	53.3	63.1
Oesophagus	15.3	23.9
Stomach	26.1	30.5
Colon, rectum and anus	60.1	60.3
Liver	21.0	13.2
Gallbladder and bile duct	21.6	10.3
Pancreas	8.8	9.6
Larynx	60.4	77.4
Trachea, bronchus and lung	14.0	19.3
Skin, melanoma	79.6	83.8
Breast	-	89.0
Cervix	-	67.9
Corpus uteri	-	74.7
Ovary and adnexa	-	47.4
Prostate	91.8	-
Testicle	96.6	-
Kidney and urinary tract	66.2	64.0
Bladder	57.6	47.5
Central nervous system	18.0	16.3
Thyroid	84.0	93.1
Hodgkin's lymphoma	79.0	74.2
Non-Hodgkin's lymphoma	64.9	59.4
Multiple myeloma	47.5	45.7
Leukaemia	56.1	59.4
Total†	53.9	62.7

†Total: total number of cases excluding non-melanoma skin cancer.

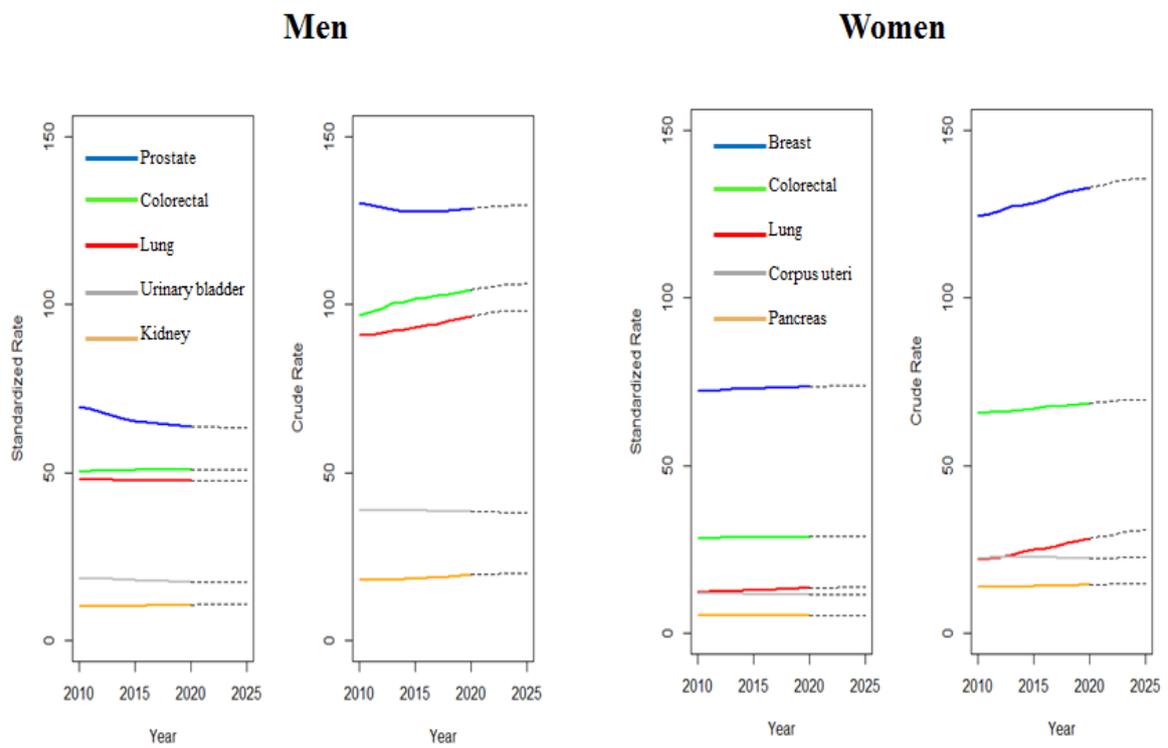
**Table 5.** Registered cases of paediatric cancer in Catalonia in period 2017-2021 by diagnostic group

Diagnostic groups	Period 2017-2021	
	(N)	(%)
I. Leukaemia, myeloproliferative diseases and myelodysplasias	227	28.4
II. Lymphomas and reticuloendothelial neoplasms	101	12.6
III. CNS and miscellaneous intracranial and intraspinal neoplasms	204	25.5
IV. Neuroblastoma and other peripheral nerve cell tumours	49	6.1
V. Retinoblastoma	19	2.4
VI. Kidney tumours	32	4.0
VII. Liver tumours	12	1.5
VIII. Bone tumours	49	6.1
IX. Soft-tissue and other extrasosseous sarcoma	50	6.3
X. Germ-cell tumours, trophoblastic tumours and gonadal neoplasms	22	2.8
XI. Malignant melanomas and other malignant epithelial neoplasms	33	4.1
XII. Other malignant and unspecified neoplasms	2	0.3
Total	800	100

**Figure 1.** Time trends in standardised rates (world population) and crude incidence rates of all cancers in Catalonia, excluding non-melanoma skin cancer, during the period 2010-2025 (Note: rates are calculated per 100,000 persons-year).



**Figure 2.** Time trends in standardised rates (world population) and crude cancer incidence rates in Catalonia for the top 5 tumour sites during period 2010-2025.



### **3. Overview of progress made in the Cancer Plan in previous periods and remaining challenges**

Innovations and actions which have changed the quality of and approach to cancer care as part of the Cancer Plan include the following by the periods in which they were implemented in the Catalan health system.

#### Period 2000-05:

- Rollout of psycho-oncological care in reference centres in Catalonia. This was a significant innovation in 2000 and has been a model for the rest of Spain.
- Evaluation of the quality of surgical care working with CatSalut and in partnership with the Catalan Healthcare Assessment and Quality Agency (AQuAS).
- Start-up of the first cancer genetic counselling units in selected reference centres.
- Planning cancer care by health regions.
- Pilot testing of colorectal cancer screening and completion of the implementation of breast cancer screening in Catalonia in the target population.

#### Period 2006-10:

- Start-up of the rapid cancer diagnosis programme for the three most important tumours (breast, lung and colorectal) linking primary and hospital care, successfully evaluated and extended to bladder and prostate.
- Setting up the network of hospital tumour banks in Catalonia.
- Establishment of the Harmonisation of Treatment with Drugs for Hospital Use and Outpatient Dispensing Programme, which during its timeframe and up to 2014 was aimed at cancer and AIDS drugs.
- Entrenchment of the nurse case manager model tied to rapid diagnosis and multidisciplinary care.
- Specification of the multidisciplinary care model as the cornerstone of quality cancer care.

#### Period 2011-15:

- Implementation of oncology tertiary care in complex cancer surgery (oesophagus, rectum, stomach, liver and pancreas coupled with chest surgery and neuro-oncology) and in rare tumours.
- Evaluation of rectal cancer outcomes.
- Participation of Catalan reference hospitals in the European Reference Network for rare adult and paediatric tumours and hereditary diseases.
- Pilot schemes for coordinating primary and hospital care in the follow-up of cancer patients after active treatment.

Period 2015-20:

- Evaluation of surgical tertiary care and confirmation of improved clinical outcomes associated with the Plan designated reference hospitals implementation. Addition of ovarian and head and neck cancer surgery to the tertiary care instruction.
- Completion of the rollout of colorectal cancer screening.
- Start of the shift in cervical cancer screening from opportunistic to population-based. Amendment of the early detection protocol with the HPV detection test as the primary screening test between 30 and 65 years of age.
- Collaboration with the shared medical record of Catalonia (HC3) and hospitals to implement SNOMED CT to build on an information systems model with staging and pathological anatomy information.
- Analysis of the results of the pilot test in geriatric oncology.

This brief description of some of the significant activities conducted by the Cancer Plan shows the priority afforded to enhancing clinical outcomes whether through screening tests, specifying the multidisciplinary care model or intervention in restructuring highly complex oncological processes. It has also been firmly committed to improving the quality of care in its decision to implement psycho-oncology and also in its relations with patient and voluntary associations over the years.

The challenge posed by cancer can be defined as a laboratory of innovation in healthcare services because oncology brings together aspects of innovation which are advanced in relation to other diseases, especially those with complex management, and which call for tailored responses. It is also a disease in which the challenge of the sustainability of the system, given the accelerated increase in the overall cost of innovative therapies, is initially and more acutely apparent.

Over the last decade, the Cancer Plan has engaged intensively in European cancer projects (the Joint Actions led by the European Commission and EU Countries) which has made it possible to gain early insight into the priorities on which all European cancer plans are working. These activities conducted by the European Union have resulted in the proposal for a European framework for the battle against cancer which combines an area focused on support for cutting-edge research at all levels whose goals are centred on organisational aspects of cancer care, prevention and screening, and also on the problems posed by patients who have survived cancer. The targets set for the Catalan health system need to be aligned with what has been put forward in Europe's Beating Cancer Plan (February 2021). Particularly relevant targets in this strategy include 90% of European patients being treated in Comprehensive Cancer Centres by 2030. This calls for a definition of what these types of centres are in our setting, priority in access to quality therapies for patients with rare or poor prognosis tumours and the importance attached to the quality of life of patients who have been successfully treated for their cancer.

Personalized treatment is another priority alongside preventive goals to reduce incidence and enhance the prognosis of the disease through effective early detection.

The main challenges for the coming years which can be drawn from these considerations are:

- Precision oncology: this was introduced in 2021 (Instruction 3/2021; [www.gencat.cat/catsalut](http://www.gencat.cat/catsalut)) and it would now be required to assess its implementation and dissemination across cancer patient.
- Introducing innovative diagnostic and therapeutic procedures into the healthcare system which will lead to a significant improvement in patient survival and quality of life.
- Care for long-term survivors and the relationship with primary care and the hospital.
- Return to work for patients treated for cancer once the active stage of therapy has been completed. These objectives are outside the remit of this Plan.
- Evaluating the clinical outcomes from real-world data generated by health services and their combination with data from population-based cancer registries and other registries such as the one for tertiary care to build a Catalan cancer information system which can be used for planning.
- Making cancer care sustainable in the public health system anchored in fairness and quality criteria.

Another challenge is to assess the impact of Covid-19 on cancer patients, both incident and those in treatment or follow-up, and on cancer care. Obviously, changes brought about by this epidemic have had an impact at several levels: on the number of diagnosed cases (discontinuation of breast and colorectal cancer screening, 12% reduction in the number of disease diagnoses in 2020 compared to 2019), under-treatment (7% reduction in external radiotherapy treatments), alterations in the therapeutic approach, emergence of telemedicine and changes in the organisation of cancer care and access to the healthcare system (3). The impact of these changes can only be quantified in the coming years and should be analysed in detail when population data become available.

### **References**

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## 4. Objectives of the Catalan Cancer Plan 2022-2026

The following sections describe the Catalan Cancer Plan's priority objectives which will be the core of the Plan's actions. To provide an operational presentation of the envisaged actions, each objective is presented with background information followed by a description of the objective, the actions, and the expected outcomes.

### 4.1 Primary prevention

#### Background:

Primary prevention of cancer is the key component in reducing the incidence of the disease. The potential reduction in new diagnoses which could be achieved by effective implementation of basic prevention measures, such as those in the European Code Against Cancer, has been estimated at around 40-50%. This Code, adopted by the European Union as a basic prevention instrument (including screening measures), has been developed on the strength of a review of the available evidence by the International Agency for Research on Cancer (IARC) and is currently under review for updating. Notwithstanding the potential impact of the strategy's preventive measures, its benefits will be perceived only over the medium and long term.

There is a significant tradition in Catalonia of implementing preventive measures including the struggle against smoking, improvements in diet, encouraging physical exercise and vaccination against hepatitis B and the human papillomavirus (HPV). These measures are supported and coordinated by the Secretariat for Public Health at the Ministry of Health, which means the measures put forward are part of its proposals and goals set for this period, which globally address health prevention and promotion.

#### Objective:

Reduce the incidence of cancer in the population by intervening on risk factors for the various types of cancer, or where possible, on protective factors, and on hepatitis B and HPV vaccination programmes.

#### Actions envisaged:

- Promote and publicise the European Code against Cancer as an instrument to add to knowledge of cancer risk factors and cancer prevention priorities. Awareness of these risk factors should be accompanied by measures, in many cases across sectors, to support compliance such as risk information labelling and encouraging physical exercise at school age.
- In the light of evolving cancer trends, preventive measures for skin cancer in general and melanoma in particular included in the European Code will need to be stepped up.
- Continue the hepatitis B and HPV vaccination programme while extending it to children.
- Smoking is the main risk factor for cancer, and healthcare professionals and institutions have a key exemplary role to play in prevention. Measures included in programmes such as smoke-free hospitals and primary care centres need to be more robustly enforced alongside anti-smoking counselling for healthcare professionals and activities such as peer support groups to prevent relapse.
- Implement measures in primary prevention strategies for chronic diseases relevant to cancer prevention.

#### Expected outcomes:

Reduction in the incidence of cancer, although quantifying this is tricky because the benefits will only be perceived in the long term.

## **4.2 Cancer screening**

#### Background:

Cancer screening is one of the strategies available in cancer control strategies. The current European-wide recommendation, set in 2003 (4), includes population-based screening programmes for cervical cancer, breast cancer and colorectal cancer. Since then, changes and additions have been made to these three screening programmes owing to scientific and technical advances such as the shift to immunochemical faecal occult blood testing, the introduction of digital mammography and the human papillomavirus test as a primary screening test between ages 30/35 and up to age 65. Similarly, like many others in our setting, our health system conducts a significant amount of opportunistic and unorganised screening for prostate cancer, mainly with PSA testing.

Importantly, these population-based programmes have increased knowledge of the effectiveness, benefits and adverse effects of screening through evaluation of these programmes. These evaluations have often shown the varying impact (balance of benefits and adverse effects) of screening programmes on subgroups in the target population and this has furnished the opportunity to offer more personalised screening to further optimise the positive balance. This opens the door to more bespoke, risk-stratified screening strategies and a better balance between the benefits and adverse effects of screening. There are several international trials such as WISDOM and MyPeBS, the latter with Catalan participation, which will deliver observed evidence of feasibility and benefits.

The publication and consolidation of the results of clinical trials of other screening tests (including prostate, lung and ovarian) has also provided fresh evidence of their efficacy.

Against this background, the new Europe's Beating Cancer Plan 2021 seeks to build on and improve existing cervical, breast and colorectal cancer screening programmes and update the Council Recommendation on cancer screening. In the specific case of breast cancer screening, the European Commission Initiative on Breast Cancer (5) is already in the process of making ongoing recommendations on various aspects of breast cancer screening and diagnosis and has additionally drawn up a voluntary quality assurance scheme for breast cancer care.

#### Objective:

Consolidate and assess proposed improvements and extensions to population-based screening programmes for breast cancer, colorectal cancer and cervical cancer.

Study and suggest interventions related to future new recommendations on other screenings, mainly for lung cancer and prostate cancer.

Continue regular evaluation of the activity, intermediate results and quality of population and cancer screening programmes and their impact on health.

Roll out artificial intelligence tools for screening optimisation.

#### Actions envisaged:

- Assess the benefits, impact and resources needed for age extensions in breast and colorectal cancer screening in our setting and improve the balance of benefits and adverse effects of these programmes.
- Complete the process of including HPV testing as a primary screening test in women aged 30 to 65 in the current screening model in order to achieve full population coverage in Catalonia.
- Complete the pilot study of cervical cancer screening with self-sampling in women aged 30 to 65 and assess its future role in population screening.
- Design and implement the shift from the opportunistic model of cervical cancer screening to an organised population-based programme.
- Fast-track digital transformation of programmes with widespread use of digital tools in communication with the population (My Health, texts, emails).
- Drive pilot studies of lung cancer screening with CT which provide additional information on relevant aspects of this screening (frequency, role of biomarkers, synergy with quitting smoking, etc.) and on key organisational aspects and resources needed in the potential future rollout of a population-based programme (optimal definition of the target population, identification of the target population, etc.) together with its benefit/risk ratio in our setting.
- Assess the situation of prostate cancer screening from the standpoint of the evidence of benefits and adverse effects and its practice in Catalonia and, if necessary, also design and implement a strategy to optimise current prostate cancer screening to improve its balance between benefits and adverse effects in line with future Council of Europe recommendations.
- Annually evaluate the activity, process indicators and early outcomes of screening programmes.
- Evaluate the impact of the breast cancer screening programme on breast cancer mortality.

#### Expected outcomes:

The results of the envisaged actions are intended to:

- o Step up the potential of early detection in reducing cancer mortality while maintaining an optimal balance with potential adverse effects in the screening currently delivered to the population (breast, colorectal, cervical and prostate).
- o Move forward on technical knowledge and key organisational drivers for the potential future lung cancer screening programme.

## 4.3 Diagnosis and treatment

### Diagnosis

#### 4.3.1 Precision oncology

##### Background:

Precision oncology has been defined as an approach to cancer diagnosis and treatment focused on identifying a subgroup of patients suffering from a particular cancer with specific molecular characteristics (usually genomic or genetic changes or protein expression patterns) which can usually be treated with targeted treatments that are more effective. CatSalut published Instruction 3/2021 which sets out the criteria for the deployment of the precision oncology programme in Catalonia. By the end of 2022, over 14,000 patients had benefitted from this programme.

Precision oncology application criteria are based on scientific evidence as established in conjunction with the Programme's scientific advisory board which has set out the alterations to be included in the mutation panels and the criteria for testing, preparation and presentation of the results. The Instruction also specified a limited number of reference centres which have analysed the results of the molecular alterations. The Programme has specific funding, and it is planned to draw up an evaluation of its results coupled with a joint database for all patients analysed.

##### Objective:

Consolidate the rollout of the Programme by setting up the central data repository under CatSalut and the criteria for evaluating clinical outcomes.

##### Actions envisaged:

- Set up the common central repository of tests and results and bioinformatics tools to allow access and interpretation by the person who made the request, the reference centre and the molecular tumour board at the reference centre. Evaluate the criteria for the use of these data for publicly funded research.
- Evaluate the benefits achieved in patients by the implementation of the Programme in terms of test coverage and outcomes (changes in treatment due to panel analysis and survival benefit).
- Analyse the activity of the reference centres on an annual basis to assess whether they achieve the expected targets in terms of activity, process, access for patients from centres for which they are reference facilities, and quality. This evaluation is to include the operations of the molecular tumour boards. Consideration should also be given as to whether new reference centres need to be set up based on the activity observed.
- Conduct cost-effectiveness analysis of the Programme and its budgetary impact in terms of both the Programme and the drugs administered.

##### Expected outcomes:

Rolling out precision oncology should enable individualised treatment of patients with molecular alterations, identifying those with the greatest likelihood of clinical benefit and reducing the likelihood of adverse effects.

#### 4.3.2 *Rapid diagnosis*

##### Background:

The rapid diagnosis programme was set up in 2006 and rolled out for lung, breast, colorectal, prostate and bladder tumours in the following years. It was designed to provide rapid access to diagnostic tests and treatment within 30 days as an overall average for patients, albeit not as a guaranteed timeframe for each individual case because there are clinical circumstances which may mean the diagnostic and treatment initiation process takes longer than 30 days. It has been highly rated by primary care professionals and patients, providing effective access for patients to hospitals to confirm or reject a suspected diagnosis. The relationship between primary care and the hospital has made it possible to build forms of relationships between care levels based on shared criteria and clinical pathways agreed between them. However, several factors now compel rethinking the pathway; Covid-19 and its disruptive consequences is undoubtedly the most recent and with the greatest impact, but there is also the fact that it is essential to capitalise on the availability of the electronic medical record and information technologies while improving the criteria for suspicion based on the experience gained in recent years.

##### Objective:

Revise existing protocols for clinical criteria for inclusion in the Rapid Diagnosis Programme while entering them in the electronic medical record system with the input of primary and hospital care experts. These clinical criteria should include all cancers where there are high-risk symptoms, and not be restricted to just the most frequent.

##### Actions envisaged:

- Set up a working group with experts from primary and hospital care to draw up criteria for the inclusion of patients with a high suspicion of cancer and criteria for implementation evaluation.
- Include the request for inclusion and follow-up of their procedure in the Integrated Public Healthcare System of Catalonia (SISCAT) electronic medical record. Use referral forms common to all of SISCAT which feature the inclusion criteria and the minimum additional clinical information relevant for referral.
- Regular updating of the Programme's evaluation parameters by CatSalut.
- Actively publicise the criteria established among primary care and hospital professionals and the general public.

##### Expected outcomes:

Achieve better access for patients with a high suspicion of cancer to the centre where accurate diagnostic confirmation can be made. Ensure that the majority of patients in whom cancer is confirmed are able to start first treatment within a median of 30 days for any high-suspected tumour.

#### 4.3.3 *Cancer diagnosis: pathology and imaging*

##### Background:

Appropriate cancer treatment is impossible without correct diagnosis. This in turn calls for multidisciplinary discussion between pathologists, radiologists and nuclear medicine specialists in a multidisciplinary setting with other therapeutic specialists. It is essential that anatomical pathology services have quality programmes in place and take part in the external quality controls furnished by scientific societies. The quality of the diagnostic process can be improved by harnessing the advantages of the information technologies

which are being rolled out in the Catalan healthcare system. Sharing images and performing double readings in anatomical pathology of tumours or radiological images will enable the quality of the diagnostic process to be improved and the diagnosis to be cross-checked between professionals. It will also allow the involvement of experts from the reference centres on the tumour boards at the centres in each centre's healthcare network. This technology will additionally support the learning process for professionals in training.

Objective:

Drive the use of digitalised databases with pathology or radiology images of patients diagnosed in SISCAT to enhance the diagnostic process and enable consultations with experts from reference centres. This objective is especially relevant in territorial care networks to leverage expert knowledge.

Set quality criteria for the performance of diagnostic tests in pathology and imaging so that patients can transition from one centre to another swiftly and efficiently.

Foster or enhance quality programmes in anatomical pathology, such as ISO 15189 accreditation, and taking part in external quality control of diagnostics and biomarkers delivered by scientific societies.

Actions envisaged:

- Consolidate the rollout of the common repository and the accessibility of radiological and pathological images of patients undergoing diagnostic confirmation or diagnosed with cancer in SISCAT.
- Set criteria for synoptic reporting according to standards such as SNOMED CT in pathology and diagnostic imaging for all reports.
- Set criteria for consultation between experts on tumour boards between centres that are part of a territorial cancer care network.
- Evaluate the use of quality criteria in the diagnostic process.
- Evaluate the use of databases and aspects which might improve quality of care.
- Progressively roll out diagnostic support systems (standardised set of questions and answers to indicate findings and support decision-making; inclusion of report templates as a structured data collection tool with exportable quantitative data).
- Roll out artificial intelligence tools for optimising diagnostic imaging (imaging, pathology and endoscopy).

Expected outcomes:

Enhance the quality of the diagnostic process and its efficiency in SISCAT by sharing expert knowledge and leveraging the availability of images and the application of the criteria for improving diagnostic process quality.

## Treatment

### 4.3.4 Care model based on multidisciplinary care, recognition of expertise and evaluation of outcomes

#### Background:

Cancer care in Catalonia has been based on a multidisciplinary work model which has been steadily put in place. Likewise, another key aspect of CatSalut's objectives and efforts in recent years has been evaluating clinical outcomes and designing complex procedures which call for centres with the capacity, expertise, resources and optimal outcomes to achieve the quality of care needed to be competitive in a European setting. This model is to be further consolidated over the course of this Plan and the inclusion of new aspects such as better coordination in the long-term follow-up of patients, and using information technologies in its activities has to be assessed. In this respect, Covid-19 has made it possible to analyse their potential, together with their advantages and drawbacks. Finally, the challenge of promoting long-term follow-up of patients by primary care should be met when clinically possible and the patient and their doctor need to have quick and priority access to hospital care for consultation or referral.

#### Objective:

Consolidate the multidisciplinary care model, set up the option of follow-up in primary care and evaluate its effectiveness in the healthcare system in both reference and local centres coupled with patients' perceptions.

Design, implement and evaluate a system for allocating the most appropriate inpatient resource for cancer patients.

#### Actions envisaged:

- Set up the model of care tailored to the therapeutic care needs of hospitalised cancer patients.
- Put in place a multidisciplinary electronic planner associated with the tumour board which brings together available clinical information and enables efficient review of each case, discussion where needed and the board's decision. The minutes of the board will also provide the basis for annual clinical assessment of the board's actions.
- Define cancer patients who are candidates for admission to intermediate care facilities according to their therapeutic needs, such as patients defined as sub-acute in the case of tertiary hospitals. Integrate the information and care coordination systems if these patients are in different healthcare institutions.
- Set criteria for follow-up of patients treated in the multidisciplinary setting to prevent duplication of visits and add the option of primary care-based follow-up where possible, including:
  - o Designing mechanisms in the electronic medical record to enable patient follow-up in primary care.
  - o Setting up a protocol for long-term survivors which specifies the risk threshold for the transition of patients to primary care. This protocol should be supported by appropriate training for professionals.
  - o Devising a flexible discharge report which brings together critical follow-up information (e.g., present, or likely side effects, follow-up tests) and provides guidance to primary care and patients.
  - o Remote consultation between care levels to enable communication in the event of suspicions of relapse or other incidents.

- Establishing the priority return pathway for the patient followed up in primary care when there is any suspicion of relapse or complication of the patient requiring specialised care. This return must be personalised for each patient and be included in the discharge report.
- Whenever possible, affording primary care nursing a leading role in health promotion in areas such as nutrition, sexuality and the psycho-emotional state of the person.
- Evaluate the results of multidisciplinary care, especially the patients' own perception.

Expected outcomes:

Continue the process of enhancing multidisciplinary care, evaluating its effectiveness, and fostering greater involvement of primary care in the long-term follow-up of cancer patients with appropriate clinical criteria. The percentage of stays in the emergency department awaiting a bed and stays outside cancer wards for cancer patients is expected to fall.

#### *4.3.5 The future of cancer care is specialised, in reference hospital comprehensive cancer centres*

##### Background:

One of the key features of the Cancer Plan adopted by the European Union in February 2021 was the target that 90% of patients should have access to Comprehensive Cancer Centres (CCCs) by 2030. This target makes it imperative to define what a CCC is and how to apply this organisational concept to Catalonia Public Health Care System (SISCAT). In the next two years, the European Union will decide which criteria these centres have to meet. In our case, these CCCs will be based on the reference centres treating cancer in Catalonia. This will entail their own governance structure and integrated organisation of the cancer diagnosis and treatment care process while coordinating care with their local hospital network. This governance is also to factor in the patients' vision and integrate them into their administration.

Accredited, quality centres based on multidisciplinary teams and externally evaluated in SISCAT will evidently be an aspect of enhanced care because they will be able to gain European approval by following models such as the European reference centres for rare or paediatric tumours. The challenge now will be to apply it to our setting.

##### Objective:

Arrange, designate and complete where needed the territorial network of comprehensive cancer diagnosis and treatment centres based on the SISCAT reference hospitals and bearing in mind the key health strands set out in the Catalan Health Plan.

##### Actions envisaged:

- Set the criteria for designating comprehensive cancer diagnosis and treatment centres in SISCAT, factoring in the criteria laid down by European organisations such as the OECl and the German Cancer Society and those drawn up in joint European actions such as CraNE.
- Put in place territorial networks or hubs which arrange the patient pathway under clinical criteria to coordinate the cancer care process in Catalonia. These territorial cancer care networks will have to draw up therapeutic protocols which ensure quality care with excellent clinical outcomes. Agreements between centres will have to be validated by CatSalut and include multidisciplinary and multi-institutional coordination mechanisms so that the therapeutic decision and service provision are delivered as close to the patient's residence as is reasonable.

- Foster vertical integration processes between comprehensive cancer centres and the levels of hospital complexity so that cancer care is structured cohesively and not only on the basis of specific interventions (e.g., complex surgery), such as care in sub-acute processes which require hospitalisation and can be treated at other hospital levels coordinated by the reference cancer centres.
- Underscore and specify the role of county hospitals in cancer care while assessing potential problems in geographical or service (e.g., nutrition, psycho-oncology) access for the patients they serve as a consequence of the shortage of specialised professionals.
- Evaluate the outcomes of using this model in SISCAT once it has been implemented, taking into account the perspective of the professionals at each level of care and patients together with the clinical outcomes achieved.

Expected outcomes:

SISCAT and cancer patients in Catalonia will have a network of reference centres which can be approved in the European framework for excellent cancer treatment. Setting up comprehensive cancer centres will be accompanied by regional integration processes designed to prevent problems in fairness between patients.

*4.3.6 Paediatric f paediatric tumours*

Background:

Paediatric cancer (PC), also called developmental cancer, is abnormally rapid and uncontrolled cell growth and spread originating from embryonic stem cells mainly in children and teenagers. PC has a higher replication rate than adult cancer, specific incidences according to age and maturational stages and blockage of cell differentiation due to genetic and epigenetic reasons, unlike adult cancer, which has a wide variety of cancers depending on the organ affected (although most are carcinomas): 50% of childhood cancers are of haematopoietic and nervous system origin. There are specific needs for further progress in this group of cancers such as early diagnosis once suspected, reducing the after-effects of cancer and treatment and scaling up clinical research specifically targeted at paediatric cancers.

One of the key organisational changes in recent years has been the centralisation of the treatment of childhood and adolescent cancer patients. This decision was based on the fact that 90% of new cases of children with this diagnosis were already being treated in the two reference centres with excellent clinical outcomes. This is reflected in the fact that both centres are accredited by the Ministry of Health as RCSUs and also the European Union as members of the European Reference Network for Paediatric Cancer. The Inter-territorial Council agreement of November 2018 adds to this approach. Finally, there are still clinical situations unresolved or with poor prognoses where research needs to be prioritised. Furthermore, the challenges of long-term follow-up and managing treatment complications are issues which have yet to be fully resolved. Psychosocial care is a key prerequisite in treating children and teenagers with cancer. Whether the purpose of treatment is curative or palliative, the patient and their family need to be supported by a group of professionals who combine what is happening at the physical/organic level with psychological/emotional facets. Only with a holistic and integrated approach can we deliver quality care which ensures the best quality of life. Aspects of social services, education and future working life, albeit of great significance for the quality of life of patients, are not dealt with here as they are outside the remit of this Plan. However, France and other European countries

have made outstanding progress in these fields and they should be targeted specifically in Catalonia across the various areas of government in addition to health.

Objective:

Consolidate the paediatric cancer treatment model in two reference centres by setting up shared clinical and research protocols, including long-term follow-up and treatment of therapy complications, tumour progression and prevention of the risk of a second malignancy.

Actions envisaged:

- Put in place treatment protocols agreed with the patients diagnosed and drawn up as part of SISCAT.
- Drive clinical research and clinical trials in paediatric patients, especially aimed at improving prognosis and reducing immediate and long-term adverse effects.
- Draw up the evidence-based clinical protocol for patients who are candidates for proton therapy in Catalonia along with the referral pathway once this facility is available in SISCAT.
- Develop specialised care resources to address the clinical aspects of the adverse effects of long-term treatment in the paediatric age group and specifically in adulthood in both reference centres, either with their own resources or in partnership with centres treating adult patients.
- Develop protocols of treatment and clinical indications in proton therapy for paediatric patients at the Proton Centre of Catalonia, which is being set up.
- Build care networks with primary care to enable rapid detection of second malignancies and long-term adverse effects.
- Evaluate the need to set up a unit for teenagers and young adults to enable better specialised treatment for this age subgroup as a transition between paediatric and adult services and which factors in their psychosocial needs.

Expected outcomes:

Consolidate the established model with two specialised European paediatric cancer treatment reference centres with resources for specialised treatment of the long-term physical, psychological and social needs of paediatric patients. These two centres should have shared therapeutic protocols for routine treatments.

#### *4.3.7 Rare tumours*

Background:

Rare tumours are low-incidence cancers which as a group can account for up to one in five cancers (including paediatric tumours) depending on the definition chosen. They obviously present a major diagnostic and treatment challenge which has led the European Union to set up a network of reference centres with hospitals evaluated to meet international quality standards, including six accredited centres in Catalonia for various rare diseases. This demonstrates the need to treat these patients in reference centres as is set out by Instruction 1/2011 and later ones which lay down the criteria for tertiary care in oncology in complex surgical procedures and in rare tumours (paediatric, sarcoma and neuroendocrine tumours as the most significant). The definition of comprehensive reference centres described in the previous objective is at the core of the accomplishment of this objective together with the rollout of the Precision Oncology Programme. Further progress along the

lines laid down by the European Union calls for consolidating the process underway and assessing its quality.

Objective:

Align the management of rare tumours with European targets and assess quality of care and clinical outcomes.

Actions envisaged:

- Define the rare tumours to be managed on the basis of the definition of rare haematological and solid cancers in adults set out by the European Reference Network.
- Draw up clinical practice guidelines agreed in Catalonia to ensure these cancers are diagnosed and treated with similar fairness, quality and outcome assessment criteria across SISCAT. These guidelines should be aligned with the ones developed in European Reference Networks.
- Ensure access to complementary molecular testing in diagnosis and treatment as part of the Precision Oncology Programme in rare tumours.
- Organise the care pathway to enable diagnostic confirmation and access to an expert multidisciplinary team in a reference centre.
- Devise an assessment of the clinical pathway and outcomes which reflects the views of the patients concerned along with proximity and quality criteria.

Expected outcomes:

Have a network of expert multidisciplinary teams in SISCAT in reference centres that ensure quality care with internationally comparable results. Promote highly specialised procedures in a limited number of centres based on expected demand and quality and expertise criteria.

#### *4.3.8 Innovation in organising cancer care*

Background:

Cancer care has always featured a high level of innovation in the organisation of care delivery in response to the challenge posed by such a complex disease. Examples of the new challenges emerging as priorities for the coming years are progress in treatment and the consequent improvement in survival; demographic changes in society and their translation into changes in cancer incidence with a significant increase in patients over 75; and the new needs for psychosocial support in cancer patients and the importance of diet and physical exercise in patients during and after treatment. These priorities are to be analysed for inclusion in SISCAT to ensure fair and quality access.

Objective:

Gradually roll out actions to support and improve cancer treatment in the psychosocial, geriatric oncology and nutritional counselling domains.  
Build telemedicine into cancer patient care and follow-up in SISCAT.

Actions envisaged:

- Geriatric oncology: set referral criteria for geriatric assessment agreed in SISCAT.
- Set up geriatric oncology support units in cancer care network reference centres to support multidisciplinary clinical decision-making for complex patients who need it.
- Psycho-oncology: systematically assess psychosocial distress in patients in order to ensure referral to multidisciplinary psycho-oncology units.

- Set criteria for the need for specialised support through dietary advice for all patients and in particular for those at risk of malnutrition during active cancer treatment or in follow-up.
- Encourage the promotion of physical exercise in cancer patients both during and after treatment consistent with the patients' condition.
- Foster training in breaking bad news for residents in radiation oncology, medical oncology and clinical haematology.
- Telemedicine: draw up a guide for SISCAT on how to use telemedicine in cancer patient follow-up.

Expected outcomes:

Achieve cancer care with a greater capacity to meet the global needs of cancer patients in Catalonia and which is delivered on the basis of fairness and quality criteria.

#### *4.3.9 Therapeutic innovation*

Background:

One of the features which have always been a hallmark of cancer care is its ability to innovate in surgical, medical and radiotherapy therapies. Coupled with advances in diagnosis, this has made a crucial contribution to improving patient prognoses. The number of innovations has also picked up speed in recent years especially in systemic therapy, albeit not all of them with the same impact. However, their cost has risen exponentially and poses challenges for the sustainability of the healthcare system because the percentage of resources earmarked for systemic therapy is getting steadily higher against a background of negligible growth in the overall health budget. All healthcare systems have to address this challenge which involves all actors in the healthcare system. A response other than those available in other European systems is not to be expected, although new treatments which entail significant changes in the prognosis of the disease or in the quality of life of patients' need to be supported. Furthermore, innovation uptake has to be matched with the system's resources and the input of each innovation examined on the basis of the value it brings, which means comparing the clinical benefits achieved with the cost borne by the system.

Objective:

Promote the uptake of therapeutic innovations in SISCAT on the basis of the value of their input in terms of health, quality of life and cost.

Actions envisaged:

- Change the funding system for radiation oncology treatments by bringing it into line with the new technologies available, complexity and estimated cost in order to foster and encourage using new techniques or treatment guidelines.
- Experience with the complexity-based funding system is a prerequisite for this shift because it was devised when the technology was less complex.
- Roll out the Proton Therapy Centre of Catalonia at Parc Sanitari Pere Virgili.
- Support emerging innovation by fostering funding with evidence-based assessment in complex surgery and radiation oncology whenever it is thought that the technologies can alter the prognosis of the disease.
- Assess the value-added contribution of new treatments by measuring their impact on survival, quality of life, adverse effects and cost using real-world data techniques.
- Support the Therapeutic Harmonisation Programme and especially the evidence-based agreements and the value of combined treatment of all drugs by tumour sites.

- Support the activities included in the Access to Drugs in Special Clinical Situations Programme.
- Draw up the evidence-based clinical protocol for patients who are candidates for proton therapy in Catalonia along with the referral pathway once this treatment is available in SISCAT.

Expected outcomes:

Ensure greater sustainability of the health system by achieving rapid uptake of new treatments based on their value-added contribution.

*4.3.9.1 Beyond cancer treatment*

Background:

Advances in cancer treatment have broadened the focus of care from survival as the central and virtually sole purpose to extending goals to enhancing quality of life, better enabling patients to cope with the adverse effects of treatment, tailoring follow-up of cases to the risk of recurrence and factoring in patients' preferences in decisions affecting their follow-up and type of care needed. The number of patients and improved knowledge of risk should also enable stratification of patient follow-up with greater involvement of primary care. The social support needs of patients in the long term and the possibilities of return to pre-disease life are one of the unresolved issues in any approach to cancer control in Catalonia, where the role of voluntary and patient associations is an essential building block in covering the necessary care. The engagement of civil society in cancer prevention and treatment is a key aspect to be ramped up.

Objective:

Enhance the quality of life of patients treated for cancer after the end of treatment and tailor follow-up and support for patients to their needs and preferences.

Actions envisaged:

- Set the parameters of the discharge report at the end of active cancer treatment with special emphasis on specifying any potential adverse effects the patient may experience in the long term and the actions to be taken if they emerge and the preventive strategies to be used with each patient. In short, empower patients to enhance the management of their disease and learn how the healthcare system will respond. The language used should be easy for the patient to understand.
- Gradually introduce this end-of-treatment report into cancer care.
- Agree on the criteria for patient follow-up after the end of active treatment in the multidisciplinary team to avoid duplication and in coordination with the primary care general practitioner whenever possible.
- Drive collaboration between professionals, health institutions and volunteer and patient associations in supporting patients in long-term follow-up.
- Evaluate the use of ICT such as mobile apps to help with identifying patients' care needs and perception of quality.

Expected outcomes:

Improve the quality of long-term follow-up of patients after cancer treatment with greater involvement of primary care and with patients better able to identify and cope with symptoms of recurrence and adverse effects of treatment.

#### 4.3.10 PROM and PREM as a component of post-treatment patient follow-up assessment

##### Background:

One of the aspects with the greatest potential for change in patient care is the need to measure quality of life during and after treatment coupled with follow-up anchored in parameters set by the patients themselves. There is also evaluation of the experience of the disease and treatment, together with patient-perceived quality of the care process. The introduction of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) has been made much easier by the development of digital technologies which allow the patient to measure these variables in a much more direct and accessible way. The challenge will be for clinicians to factor it into the care process, yet there is no doubt that it is valuable information which should be made available to clinicians and introduced into the clinical assessment of the patient's evolution. It is also a means of encouraging patient self-expression. Finally, the main advantage of these measures in a digital environment is the opportunity for systematic long-term follow-up of the quality and experience perceived by the patient and the changes which can be observed.

##### Objective:

Drive the inclusion of patients' assessments of clinical outcomes, quality of life and the care experience in the care process and in appraisal of quality of care.

##### Actions envisaged:

- Decide which measures are the most appropriate to introduce on a regular basis in the evaluation of quality and experience by cancer patients.
- Add these measures to the Catalan healthcare system's electronic medical record system to enable their systematic use by clinicians in their assessment of quality of life, side effects of treatments and therapeutic response.
- Include the patient-reported experience in the evaluation of the quality of the care process.
- Enable combined analysis of PROM and PREM results in the joint quality assessment of SISCAT for cancer.

##### Expected outcomes:

Systematically include PROM and PREM measures in the assessment of patients' clinical progress and in the evaluation of therapeutic outcomes and the experience with cancer health services by the end of the timeframe of this Cancer Plan.

#### 4.3.11 Genetic counselling: building up the care network

##### Background:

Cancer genetic counselling units are an example of the combined implementation of the rollout of reference and local units with a limited number of reference laboratories and drawing up a clinical practice guide which has enabled fairness in therapeutic indications. There is also a mechanism for SISCAT experts to discuss complex cases which results in a learning and alignment process in clinical indications and recommendations. The role of the genetic counsellor in the units, psycho-oncological support and systematic registration of cases has been steadily consolidated. Molecular panel testing of the analysis of potential hereditary genetic alterations has also been included as part of the Precision Oncology Programme.

Objective:

Harmonise the work of SISCAT genetic counselling units in line with the experts' recommendations and formally set up a network of genetic counselling units in the Catalan healthcare system.

Actions envisaged:

- Evaluate the activity of existing units once a year and identify future evidence-based needs.
- Support the process of drawing up and reviewing recommendations for managing patients and families with hereditary cancer syndromes following the best practices agreed on in the expert consensus on genetic counselling sponsored by AQuAS.
- Foster an agreement to set up a network of cancer genetic counselling units to cement a multidisciplinary working model.
- Set up a register of patients with hereditary cancer in Catalonia which will make it possible to analyse existing diseases and their clinical evolution and response to cancer treatments.

Expected outcomes:

Have in place a network of genetic counselling units integrated in the cancer reference centres in Catalonia which ensures fair and quality access together with a registry that makes it possible to learn from clinical experience in the system.

*4.3.12 Learning from the pandemic in cancer care*

Background:

The Covid-19 pandemic has been hugely disruptive in the healthcare system in general and in cancer care in particular. Indeed, in its first two months there was around a 40% drop in cancer diagnoses and in the first year there was a 12% reduction in diagnosis compared to the previous year. These figures give an idea of the scale of the impact and also underscore the system's weakness when confronted with unforeseen situations which have had such a profound impact on cancer care. On the upside, if it can be called that, there is the demonstration of the response capacity delivered in a very short time by hospitals and primary care centres in reordering care priorities, a response based on the close cooperation of healthcare professionals. Another learning aspect to consider has been the introduction and consolidation of telemedicine in healthcare. However, now that it has happened once, the healthcare system is bound to put in place measures to reorganise and get ready for potential new epidemics or other crises. A first step would be to compile and unpack the lessons learned over these two years.

Objective:

Rethink cancer care based on the lessons learned from the Covid-19 pandemic.

Actions envisaged:

- Put forward a protocol for monitoring cancer patients which sets out the instructions for follow-up with telemedicine.
- Learn from the prioritisation criteria in cancer care in the pandemic to agree on criteria applicable to future disruptive situations in health services which may impact the range of services, organisation and the patient-perceived risk of using the services. Draw up cancer care recommendations.

#### Expected outcomes:

Cancer care services which are better prepared to respond to the challenge of new pandemics or situations which suddenly disrupt the availability of health services.

## **4.4 Palliative care**

#### Background:

The healthcare system in Catalonia has been a pioneer in introducing palliative care for patients with advanced cancer. Since the 1990s, CatSalut has been a WHO-designated palliative care demonstration model with a programme combining a care model in primary care and acute and socio-healthcare hospitals with basic and advanced postgraduate training. It has also factored in medical, nursing, psychological, spiritual and social needs. This model, coming out of cancer care, has evolved towards advanced diseases in all the medical fields which need it at all levels of care. Hence, care resources now have a global vision and come under the Ministry of Health's socio-healthcare plan which also sets their targets.

#### Objective:

Consolidate the integration of palliative care in cancer care and improve pain management in patients with advanced cancer disease.

#### Actions envisaged:

- Help improve pain management in cancer patients through more effective diagnoses and ensuring the appropriate analgesic ladder is used in each clinical situation. Enable access to multidisciplinary pain units and make sure they are available in all cancer reference centres.
- Goals for improving the services specified in the long term and chronic care Plan for Palliative Care.

#### Expected outcomes:

Better pain management in patients with advanced cancer disease.

## **4.5 Cancer information systems**

### *4.5.1 Expand the coverage and quality of data available in population-based registries to build a comprehensive cancer information system*

#### Background:

The availability of population-based cancer registries has always been considered the backbone of the cancer information system because it allows reliable assessment of the impact of the disease in each population, its prognosis and evolution over time coupled with analysing the consequences of therapeutic advances and preventive activities. In Catalonia, we have had the Tarragona cancer registry since 1980 and its Girona counterpart since 1994. Both registries are accredited by the International Agency for Research on Cancer for their quality. The data they provide makes it possible to estimate the incidence of the disease in Catalonia and its foreseeable evolution together with mortality data. These registries need to be further consolidated by including more relevant clinical data, such as the stage for all tumours, and supplemented with care data available in the SISCAT health information system in order to move towards a genuine cancer information system in

Catalonia. It is also essential to evaluate the feasibility of having a paediatric registry based on SISCAT data and validated with data from population-based registries, while also setting up the Lleida population-based registry to enhance coverage of rural areas. Studies conducted in Catalonia show that data based on the SISCAT information system only allow for identifying around 80% of new cases, which demonstrates the need for continued availability of population data based on standard and internationally validated methods. The availability of hospital registry data in comprehensive cancer treatment centres also needs to be improved.

Objective:

Extend the population coverage of cancer registries and make clinical data such as staging available at diagnosis. Expand the number of hospital registries at comprehensive centres featuring clinical data on diagnosis and treatment as well as survival.

Actions envisaged:

- Have staging data for all tumours in Catalonia's population-based registries.
- Build up the Lleida population-based registry.
- Establish the SISCAT paediatric registry with available care data and the prognosis and validate coverage with the population-based registries.
- Support setting up hospital registries in cancer treatment reference centres including providing data on therapeutic and survival patterns.
- Validate the level of coverage achieved with SISCAT data using the Girona and Tarragona registries as a reference on a regular basis.

Expected outcomes:

Have better cancer registries and consequently better cancer information systems combined with care data on therapeutic and survival patterns.

*4.5.2 Evaluate cancer therapeutic patterns with real-world data: towards a cancer information system in Catalonia*

Background:

One of the key changes in the healthcare system has been the entrenchment of the electronic/digital medical record with huge data capital, much of it structured in analysable categories. However, most data are still only available in unstructured document form, which makes them hard to use for joint analyses. Notwithstanding these aspects, the current volume of data available in SISCAT is considerable and allows real-world data analyses to be performed, combining for each patient the use of the various health services over time, the cost and the outcomes achieved measured in terms of survival, second surgeries and other relevant variables. Given the continuous rollout of new therapies, it is imperative to examine how widely they are used in real clinical practice and their impact on clinical outcomes in order to analyse their actual value and compare them with the results of clinical trials.

More and more information systems are coming on stream which feature oncology data that would be worth exploring so as to include them in a genuine information system for cancer care which in turn would make it possible to evaluate its quality and outcomes in CatSalut. This system would be a key instrument for monitoring cancer aligned with the development criteria being drawn up by the European Commission under Europe's Beating Cancer Plan.

Objective:

Design an information system for cancer care which includes the existing registries and allows for regular monitoring of quality and outcomes in SISCAT.

Actions envisaged:

- Specify the care data from the databases and/or registries which should be integrated to build a SISCAT cancer care information system.
- Evaluate the cost of cancer treatment and its impact on clinical outcomes on a regular basis using data from the healthcare system. Specifically, the impact of therapeutic innovation in medical oncology, surgery and radiotherapy oncology needs to be evaluated both to publicise it and also in terms of its results in relation to budgetary impact.
- Implement DICOM® standards in non-radiological cancer diagnostic techniques: endoscopy, dermatoscopy, clinical imaging, 2D and 3D body imaging.

Expected outcomes:

To be able to systematically monitor cancer treatment care patterns, budgetary impact and clinical outcomes as a way of ensuring the quality of cancer care for people in the public healthcare system.