REPORT

Objectives & Priorities for the Coming Years by Cancer Type

A RECOMMENDATION PROJECT



Introduction

The Quebec Cancer Coalition was founded in 2001 to be a strong voice for people affected by cancer and to help improve Quebec's healthcare system. Made up of more than 70 non-profit organizations representing all types of cancer across every region of the province, the Coalition advocates for the rights and interests of patients, survivors, and caregivers. For over 20 years, its members have shared a common vision: to unite against cancer and work to improve public health through a healthcare system centred on the needs of those affected by the disease.

In 2025, the Coalition invited its Patient Association Members to participate in a key initiative: drafting cancer-specific recommendations that outline priorities and objectives for the next 10 years.

Following the États généraux de la lutte contre le cancer and the unanimous commitment of all political parties to a 10-year cancer plan, the Coalition set out to support this strategy with concrete, actionable proposals. The result is a set of detailed recommendations, organized by cancer type, to help guide the implementation of this plan.

The goal of this project is to provide a clear overview of the steps needed—cancer by cancer—to reduce incidence rates in Quebec, while offering decision—makers a practical tool to guide action within the healthcare system, for patients and their families.

This final report presents recommendations aimed at reducing cancer incidence, mortality, and morbidity, while also improving the quality of life of those living with cancer. It has been submitted to the government as a contribution to the development and implementation of Quebec's cancer action plan.

Project Objectives

- **01** Provide a comprehensive overview of the necessary measures, by cancer type, to reduce cancer incidence and mortality in Quebec.
- **02** Serve as a reference tool for decision-makers when implementing measures that involve the healthcare system and improving the lives of people affected by cancer.
- **03** Highlight the priorities and expertise of our member organizations, who work tirelessly to ensure that the voices and needs of those affected by cancer are heard and prioritized.

Our Participating Members

























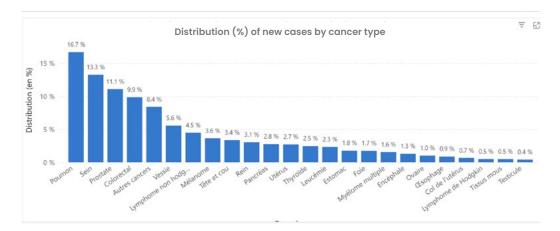


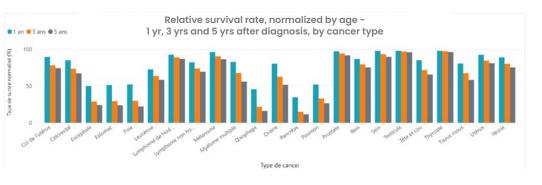
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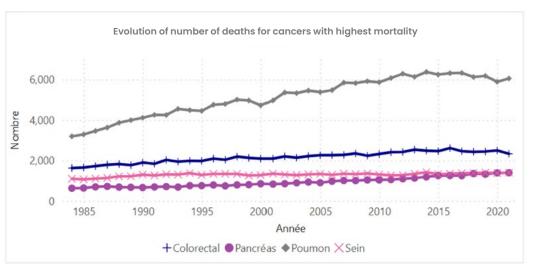
Cancer Statistics in Quebec

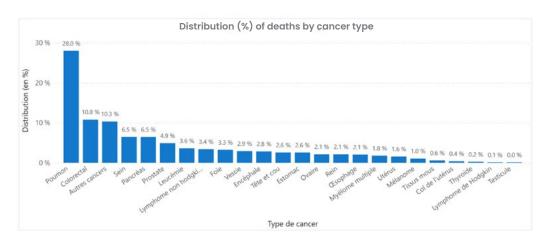
DATA FROM 2021

Cancer Type	New cases per year	Deaths by year
Lung	10,264	6,051
Breast	8,154	1,399
Prostate	6,813	1,057
Colorectal	6,064	2,331
Bladder	3,420	627
Non-Hodgkin's Lymphoma	2,759	729
Leukemia	1,435	782
Hodgkin's Lymphoma	306	28
Melanoma (skin)	2,237	223
Kidney	1,881	463
Pancreas	1,703	1,396
Multiple Myeloma	954	383
Brain	791	610
Ovarian	623	463
Cervical	406	81
Head and neck	2,067	553
Uterus	1,666	338
Thyroid	1,514	51
Stomach	1,089	552
Liver	1,070	703
Esophagus	537	444
Soft tissue (sarcoma)	299	127
Testicular	257	7
Other cancers	5,162	2,229
TOTAL	61,471	21,627









The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, availab The original data can be accessed here.

Skin Cancer — Melanoma

Recommendations by



Introduction

Types of Non-Melanoma Skin Cancer (NMSC)

Basal cell carcinoma (BCC): BCC represents about 80% of NMSC cases. It is correlated with sun exposure, and therefore most often manifests in sun-exposed areas, and primarily affects older Caucasian populations. Most BCCs appear as red, pink, or pearly white sores or elevated bumps on the skin.

Squamous cell carcinoma (SCC): is the second most common skin cancer, and develops in sun-exposed areas, burn, and wound sites. It develops in the squamous cells, which are thin, flat cells that appear in the skin's surface. SCC often appears as red sores, which may bleed, and large, red, scaly patches.

Merkel cell carcinoma (MCC): Merkel cell carcinoma develops in merkel cells, which are found in hair follicles and deep in the epidermis. MCC usually develops in sun-exposed areas, though it is able to develop anywhere on the body, and often spreads (or metastasizes). MCC generally appears in a firm, raised, and non-painful bump that may be red or purple in colour. If MCC spreads, more lumps may appear in the area or lymph nodes may swell.

Types of Melanoma

Melanoma is the most aggressive form of skin cancer. It starts in the melanocyte cells in the skin, which produce melanin (the polymer that causes the colour in hair, skin, and eyes. Melanoma is most often identified through the



manifestation of new moles (though not all moles are cancerous), or changes in the size, shape, or colour of an existing mole. The Canadian Cancer Society estimates that in 2024, 11,300 Canadians will be diagnosed with melanoma and 1,300 will die from the disease (Brenner et al.). Melanoma is prone to metastasis and is staged on the 1-4 scale, like most other cancers. There are four types of melanomas. 70% of melanomas are superficial spreading melanomas, which usually develop on the central areas of the body (legs, trunk, arms) and spread outward or downward into the skin. Nodular melanoma makes up approximately 15-20% of melanomas: it presents as a raised growth from the skin, always grows downward into the skin, and most often develops on the chest, back, or face. 10-15% of melanomas are lentigo maligna melanomas, which usually develops in older people; it often grows outward radially across the surface of the skin, taking the form of a flat patch with an uneven border that is tan, brown, or black in colour. Acral lentiginous melanoma, which comprises less than 5% of melanomas, is not related to sun exposure and is most common in people with darker skin. It often develops under the nails, on the soles of the feet, or the palms of the hands. There are also three types of melanoma that do not start in the skin: mucosal lentiginous melanoma (develops on the mucosa/mucous membrane or organ linings and is not related to sun exposure), desmoplastic melanoma (develops in the dermis (inner layer of skin), or the connective tissue surrounding the mucosa; a skin-coloured lump that often develops on the upper back, head, or neck, and grows down into the skin), and uveal/ocular melanoma (more below).

Ocular/Uveal Melanoma: ocular melanoma, often referred to as uveal melanoma, is an extremely rare form of melanoma that develops in the eye. The cause of ocular melanoma is unknown, however having fair skin and light eyes can increase the risk. This cancer does not cause vision problems as a symptom and can only be detected by an optometrist. Ocular melanoma has an extremely high rate of metastasis, usually to the liver. Please note that, while the terms ocular and uveal melanoma are often used interchangeably, they are not equivalent, as uveal melanoma technically only refers to melanoma occurring in the uvea (the middle layer of the eye).

Relevant Terms & Abbreviations:

NMSC: Non-melanoma skin cancer

CBC: Basal cell carcinoma

CSC: Squamous cell carcinoma

CCM: Merkel Cell Carcinoma

ABCDEs of melanoma: to use to identify suspicious moles to be checked by a dermatologist: asymmetry, borders (inconsistent), colour, diameter, evolution

Radial growth: spread of skin cancer outward, across the surface of the skin

Vertical growth: spread of skin cancer down into the skin

Melanocytes: The cell that produces melanin, which contributes colour to skin and hair.

Context — Reality & Impact on the Quebec Population

A Few Statistics

- Skin cancer accounts for at least 40% of all new cancer cases in Canada.
- Approximately 90% of non-melanoma skin cancers are associated with exposure to the sun's ultraviolet (UV) rays.²
- There are more new skin cancers each year than breast, prostate, lung and colon cancers COMBINED.³
- Among teenagers and young adults (aged 15 to 29), melanoma ranks fourth among newly diagnosed cancers.
- Skin cancer is on the rise in Quebec, with 138% increased chance of developing melanoma between 2009 and 2019.⁴
- Over the years, melanoma incidence rates have risen by 44% worldwide, and associated mortality rates by 32%.⁵
- 1 https://cancer.ca/fr/cancer-information/cancer-types/skin-non-melanoma/risks
- 2 Koh HK, Geller AC, Miller DR, Grossbart TA, Lew RA. Prevention and Early Detection Strategies for Melanoma and Skin Cancer. Current Status. Arch Dermatol. 1996;132(4):436 -443. https://jamanetwork.com/journals/jamadermatology/article-abstract/557666?redirect=true
- 3 "About Skin Cancer" Save Your Skin Foundation.https://saveyourskin.ca/thefacts-2/
- 4 "Tableau de bord Statistiques du Registre québécois du cancer." Gouvernement du Québec. 11 Novembre 2023. https://app.powerbi.com/view?r=eyJrljoiNjc2ZTAxNmMtMWFiMi00NDlwLTg0MzYtOTY2OTIzMDliYjA2liwidCl6ljA2ZTFmZTl4LTVmOGltN-DA3NS1izjZjLWFIMjRiZTFhNzk5MiJ9
- 5 https://www.mcgill.ca/channels/fr/channels/news/cancer-de-la-peau-lincidence-du-melanome-en-hausse-au-canada-339957

Non-Melanoma Skin Cancer

The Canadian Cancer Society (CCS) designates non-melanoma skin cancer as the most commonly diagnosed cancer among Canadians. NMSC is so common that statistics are not regularly kept for this type of cancer, as these are usually removed on site at provider offices.

Melanoma

A 2022 article published by McGill University cited cutaneous melanoma as the most deadly cancer, causing 1.9% of all cancer-related deaths in men and 1.2% in women (McGill University, "Melanoma map shows skin cancer is on the rise in Canada").

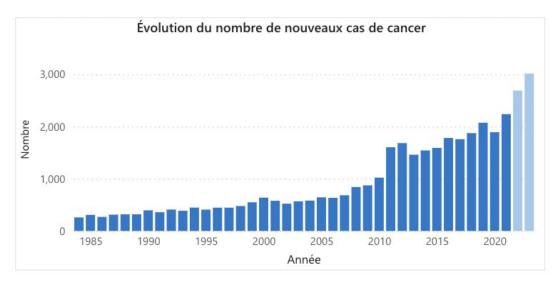
The Canadian Cancer Society (CCS) projects that in 2024, there will be 11, 300 new cases of melanoma and 1, 3000 deaths from melanoma in Canada (Brenner et al.). While specific statistics regarding cancer in Quebec

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are largely unavailable to CCS, Brenner et al. "used estimates derived from locally estimated scatterplot smoothing to the 2006–2017 reference period" to include Quebec in these estimates (par. 8).

In their 2023 cancer statistics publication, CCS further notes that cancer mortality rates are generally lower in the western provinces and Ontario, and higher in Quebec and the eastern provinces (2023, 54). CCS was also able to project age-standardized mortality rates for melanoma in 2024 in Quebec, which they calculated to be 3% in males and 1.8% in females (2023, 53).

The Registre québécois du cancer keeps cancer statistics in Quebec via dashboards. As per the figure below (Evolution in number of new cancer cases), they estimate that there has been a 1.5-2x increase in melanoma cases in the 2010s relative to the 2000s, with projections continuing to rise. They also noted that, while it has historically been the case that more men than women are diagnosed with melanoma yearly, a larger increase in diagnosis rates was seen in women.



The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French. The original data can be accessed <u>here</u>.

The last year of published data from the Registre québécois du cancer was 2021, in which they recorded 2, 237 new cases of melanoma, a remarkably high incidence rate relative to the rest of Canada. Their projected incidence for 2023 was 3, 016 (above).

Save Your Skin Foundation ran two patient reported experience measures surveys on the impacts of the COVID-19 pandemic which included a separate French language survey for the Quebec population (2020, 2021). The results of the 2020 survey indicate that Quebecois cancer patients generally experienced the same anxieties around contracting COVID, including from medical facilities, in their immunocompromised state and ambivalent feelings towards the transition to telehealth care. The most notable divergence between the English and French language surveys sent out across Canada in 2020 was that Quebec patients saw a much higher rate of postponed surgeries than in the rest of the country (5.88% in the English survey, 16.67% in French).

The second COVID-19 impact survey from 2021 had similar results, with consistency across both language groups other than reports of greater delays in medical imaging from the Quebec respondents (8.11% in English, 33.33% in French).

Although we were unable to find Quebec-specific incidence rates for ocular/uveal melanoma, the Canadian Cancer Society reports that in 2019 (the most recent update year), 325 Canadians were diagnosed with eye cancer ("Eye Cancer Statistics"). While it is not possible to accurately determine which percentage of these occurrences were in Quebec, Ghazawi et al. reported in their study of uveal melanoma incidence in Canada that British Columbia and Saskatchewan saw disproportionately high diagnosis rates relative to the rest of Canada, suggesting that Quebec is not in the highest contributors to incidence of ocular/uveal melanoma in Canada (The British journal of ophthalmology vol. 103,12 (2019), "Uveal melanoma incidence trends in Canada: a national comprehensive population-based study).



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Stakeholders to Consider & Priority Populations

Those above middle age: The highest priority population to consider in Quebec for melanoma diagnoses are those above middle age, with the Registre québécois du cancer reporting that in 2021, 42.2% of melanoma diagnoses were in people between 50 and 69 years of age and 32.1% were in people between 70 and 84 years of age. As previously noted, rates of melanoma diagnoses in Quebec women are also increasing faster than in men, which is likely related to the increasing age of demographics that were less aware of the risks of high UV exposure and therefore more likely to tan and/or not practice general sun safety.

Youth and teens are less likely to be sun safe without parental intervention; aggressive sun burns in youth are also associated with increased risk of skin cancer later in life. Teens especially are more likely to intentionally tan, further increasing risks of skin cancer.

Occupational workers and **outdoor athletes** are also at higher risk for developing skin cancer based on their increased UV exposure from being outside.

Fair-skinned people and those with a history of skin cancer in their families are genetically at increased risk of melanoma.

Other stakeholders to consider in terms of care option accessibility and reimbursement approval include providers, the pharmaceutical industry, and regulatory bodies such as the Institut national d'excellence en santé et services sociaux (INESSS). Government stakeholders are also able to assist in creating public awareness opportunities and financial grants.

Existing and Missing Supports for Patients and Their Families

bilingual informational content, patient and survivor support resources. Newsletters, which contain updates on the melanoma treatment landscape and news and upcoming events from Save Your Skin Foundation are available in French, as is all social media content. All patient-oriented resources created by SYSF are available in French, and every survey SYSF creates to gather patient-reported experience measures is also created in French to gather Quebec perspectives.

Quebec Cancer Foundation has a suite of resources for Quebecers facing all types of cancer. These include hotlines for patients to reach oncology consultants, support groups, information about cancers, and access to therapies such as art therapy, guided meditation, yoga, and massage therapy. They also offer a telephone peer matching service and online portal for teens and young adults.

Association du cancer de l'Est du Québec offers information guides and support to residents of Eastern Quebec who are fighting cancer.

Hope and Cope is a Quebec organization that offers resources for those at every stage of the cancer continuum, including survivors and caregivers. Services include peer mentors, support groups, rehabilitation and nutrition, and informational lectures and webinars.

Canadian Cancer Society has resources available for patients, caregivers, families, and health professionals. There is extensive information about all cancer types on their website and their Cancer Information Service is available in both English and French.

AIM at Melanoma is an American group that includes limited Canadian resources; this includes lists of melanoma specialists in Canada, including Quebec.

Melanoma Canada offers various informational and support resources to Canadians, with the educational resources available in both English and French.

Ocumel Canada is an initiative of SYSF that aims to provide information and support for Canadians with ocular melanoma. All information on this website is available in French and all webinars are translated.

Le Centre hospitalier de l'Université de Montréal (CHUM) offers a brief fact sheet about ocular melanoma on their website.

While Quebec has a substantial collective of cancer support resources, there is no Quebec-based foundation that specifically serves melanoma and skin cancer patients, or ocular/uveal melanoma patients, with SYSF offering the most resources for Quebec patients with these diseases. Given the increasing rates of melanoma survival, melanoma patients are also in need of increased resources related to survivorship. There are also significantly fewer support resources for caregivers than for patients. Ongoing gaps in cancer support also include individualized financial assistance and resources to support cancer patients applying for government disability benefits and navigating employment law-related situations and fertility/family planning-related resources. Finally, there is need for additional support for ocular/uveal melanoma patients, as the rareness of this cancer means there are limited resources available.

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Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

Short term objectives

- O1. Gathering of melanoma patient-related experience measures to gain an assessment of information and resource availability for melanoma, NMSC, ocular/uveal melanoma patients in Quebec
 One survey per population every two years
- **02.** Development of informational resources for patients on fertility issues, applying for government disability programs, and other resources related to taking time off work
- 03. Continued network-building of government stakeholders to proclaim May as melanoma month and endorse sun safe behaviours and melanoma awareness throughout Quebec
- **04.** Appeals to government and other donors (charitable, corporate) to sponsor sustainable sunscreen dispensers in public areas
- **05.** Media push of public safety announcements regarding melanoma awareness, sun safety, and skin checking, including network television, social media advertisements, and billboards

Medium term objectives

- **01.** Development of sun safety task forces in school boards, universities, athletic societies, and occupational worker unions
- 02. Increased awareness and implementation of precision medicine in melanoma care
- **03.** More reciprocal relationship between providers and patient groups: patient group/psychosocial support informational brochures being readily available in doctors' offices
- **04.** The unfolding of the pan-Canadian Health Data Strategy would increase access to health data for patients and ease of movement between providers; patient groups can support this work through ongoing endorsements and patient education
- **05.** Development of psychosocial support systems specifically for caregivers, young melanoma patients, and those with ocular/uveal melanoma

Long term objectives

- O1. Continued campaigning to the Institut national d'excellence en santé et services sociaux (INESSS) for reimbursement of a variety of innovative treatments that are equitably available and appropriate for a variety of different cases and medical histories
- **02.** Continued efforts towards sun safety awareness to decrease melanoma and NMSC diagnoses rates in the long term
- 03. Increased availability and options for care of ocular/uveal melanoma
- **04.** Sustainable financial support for patients who face geographical barriers to care, and/or care options being available in a broader range of geographic areas
- 05. Sustainable placement of sunscreen dispensers in public areas throughout Quebec



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Conclusion — Our Vision for the Future

We would love to see a future with meaningful changes for melanoma in the areas of prevention and education and across the cancer care continuum. As a highly preventable cancer, public education about melanoma is essential to lowering melanoma incidence rates and the burden of melanoma on the public health system. In the most ideal circumstance, the general public would be aware of the correlations between UV exposure and the development of skin cancers, and therefore practice sun safety (wearing sunscreen, UV protective clothing, seeking shade) when they are out in the world. In our vision of the future, the public would be supported in this endeavour with sunscreen dispensers being available in parks and other public areas, designated shade sites, and federal or provincial sun safety public awareness initiatives. Furthermore, public service announcements about self-checking your skin, and how to check others' skin, would also be shared in the media and in print form at doctors' offices; skin-checking would be as well-known as checking for breast or testicular lumps. While skin checks do not prevent melanoma, earlier discovery reduces mortality and healthcare burden, especially when paired with expedited access to dermatologists and general practitioners with mole identification training.

Public awareness information about melanoma, ideally, would highlight the increased risk of the disease in the elderly, outdoor athletes and occupational workers, and fair-skinned people, and highlight the dangers of unprotected sun exposure (either naturally or in tanning beds) as teens. These prevention and early diagnosis measures would also emphasized in Quebec and the Maritime/Atlantic provinces, which have higher melanoma incidence rates than the rest of Canada. In terms of ocular melanoma, greater awareness surrounding this rare cancer would influence the public to be vigilant regarding their annual eye exams and to ask their optometrists about ocular melanoma.

When patients are diagnosed with melanoma, non-melanoma skin cancer, and ocular melanoma, we hope for a future where they are offered timely and appropriate care, alongside adequate psychosocial and financial support. In the most ideal scenario, genetic testing for precision care would be covered by insurance, readily available to patients, and patients would be aware of this option. The diagnosis-to-care pipeline would be swift, and care would be available in a wider range of geographical areas and have increased reimbursement rates. From diagnosis to survivorship, patients with these diseases would have access to a holistic support network that would include nurse navigators, mental wellness and psychosocial supports, and increased data accessibility. Gaps in this area for melanoma patients currently include survivorship support, financial and legal resources, fertility and family planning support, resources for young melanoma patients, caregivers, and those living with ocular/uveal melanoma. In Quebec specifically, there is no designated support organization for melanoma, non-melanoma skin cancer, or ocular melanoma patients. This gap is currently being filled by Save Your Skin Foundation. Ideally, patient reported experience measures surveys would be conducted on a regular basis and categorized by the different areas of the cancer care continuum, with the results of these surveys being shared with government, industry, and medical care stakeholders.



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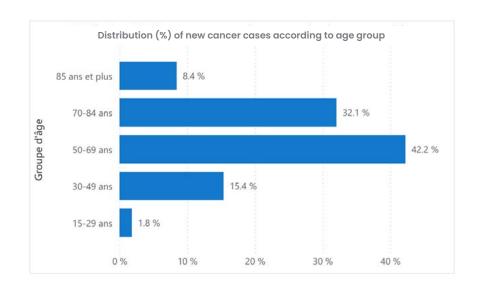
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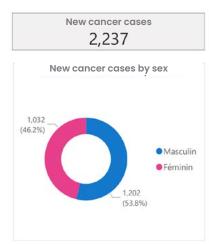
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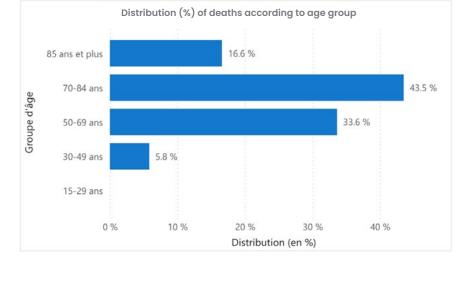
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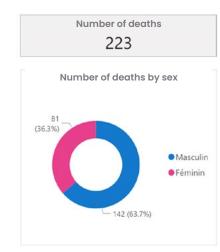
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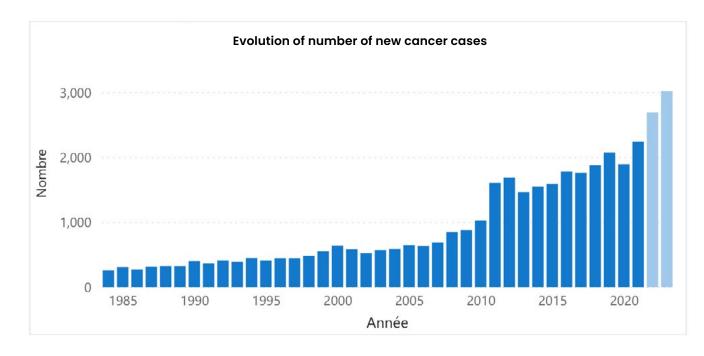
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