A ‘LAVENDER’ POLICY ENVIORNMENT FOR EARLY CANCER CARE

PROJECT REPORT

Centre for Research on Health and Social Care Management (CERGAS)
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INTRODUCTION

This report presents the evidence collected and the analyses conducted by the Center for Research on Health and Social Care Management (Cergas) of SDA Bocconi School of Management within the research project *“A 'Lavender' Policy Environment for Early Cancer Care”*. The project is the result of an unconditional grant from Brunswick (Brussels) to Cergas and was conducted within the framework of the global policy initiative “Mission Early”, whose objective is to enhance early cancer detection and treatment worldwide by bringing together organizations and individuals across sectors who share this goal. Initial funding for the initiative was provided by MSD and Sanofi.

This present document offers a comprehensive and detailed account of the research project’s steps, delving into the methodologies applied, the collected evidence, the solutions identified, and the potential conditions necessary to support effective and integrated early cancer care—from education and health literacy to early diagnosis and treatment.

A ‘Lavender Zone’ is defined as a national or regional context in which recommendations and calls to action in early cancer care are successfully transformed into effective policies, significantly improving patient outcomes. The research identified and ranked 32 OECD countries based on a composite index that measures the effectiveness of their early cancer care policies. Based on the index, we selected a set of countries—ranging from high-performing nations to those that have only recently begun investing in early cancer care—to conduct three in-depth case studies (Denmark, the Netherlands, and Italy) by drawing on scientific and grey literature as well as on interviews with key local informants. We also provide early cancer care profiles for Poland and Chile, two countries that have recently initiated efforts in this area. This analysis enabled us to identify the tools and conditions necessary to support effective early cancer care.

The Cergas team would like to thank Brunswick Brussels for support and guidance during the project and, in particular, F. Scassellati Sforzolini, A. Brandt, and C. Alexander. Our thank you also goes to the Advisory Board supporting Mission Early who provided suggestions and contributed to the creation of the early cancer care index: Dr. Cary Adams, Chief Executive Officer, Union for International Cancer Control; Dr. Nicoleta Antone, Head of Breast Cancer Center, Institute of Oncology “Ion Chiricuta”; Antonella Cardone, Chief Executive Officer, Cancer Patients Europe; Eduardo Pisani, Chief Executive Officer, All.Can International; Alexander Roediger, Associate Vice-President, Global Lead Oncology Policy, MSD.

BUILDING THE INDEX

The process of building an index consists of a series of steps some of which are outlined below:

- Defining the concept
- Select indicators
- Analyse and treat data, including deal with missing data or values
- Bring all indicators onto a common scale
- Weights the indicators and dimensions
- Aggregate the indicators (and dimensions)
- Assess the robustness of the index

DEFINING THE CONCEPT

Prior to defining the concept of early cancer care, the existing literature, indicator frameworks and definitions were mapped. In the process, stakeholders were involved to ensure the soundness of the concept. The definition of *early cancer care (ECC)* consists of two major components (WHO, 2004 and 2017; Dillner, 2019):

1. *Early cancer detection:*
    - Education to recognize symptoms and on screening
    - Screening programs
    - Early diagnosis
2. *Early treatment:*
    - Timely treatment
    - Early-stage treatment.

A pool of candidate indicators for each one of these phases and their components, representing the performance in early cance care, were assembled and analysed.

SELECTING INDICATORS

The process of selecting indicators that are meaningful and measurable included:

- scouting data powering indicators at international level (WHO, OECD, EU) and national level (early cancer detection / screening reports, minister of health / agencies websites, national documents).
- assessing whether data is accessible, and available at country level
- collecting experts' view about meaningfulness and relevance of a list of indicators.

Figure 1 summarizes the indicators suitable for building up a composite index covering early cancer care for three types of cancer. Since the reference period of analysis is 2017-2019, the sample of countries for assessment is based on the OECD members that joined the organisation prior to 2020.

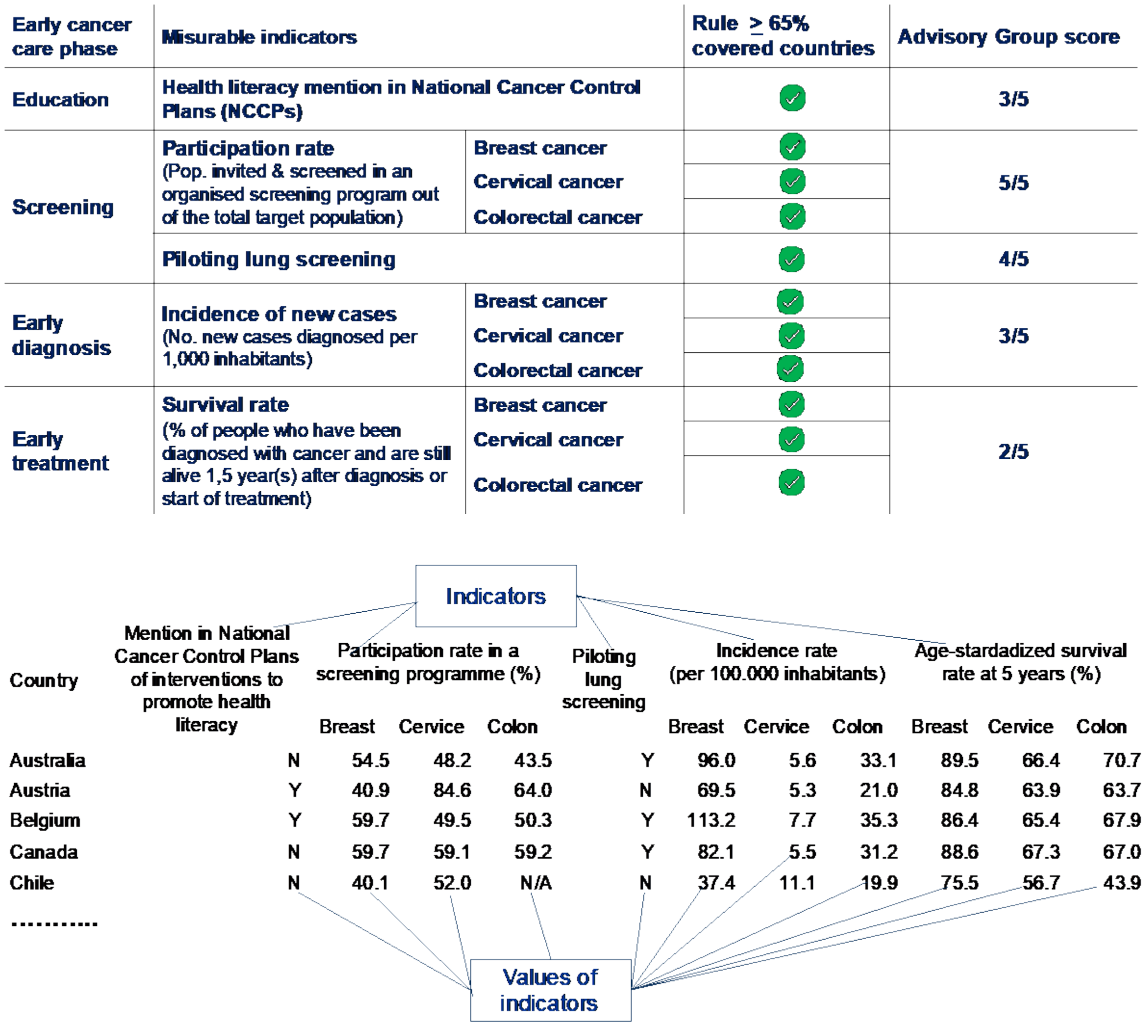
The next step in this phase consisted of checking the value of indicators. More specifically, two elements were examined: **source** and **availability** of values, country by country. These checks are relevant to ensure a balanced dataset that contains consistently the same values, applied to all considered countries. Next are reported the results of checking sources and availability for each indicator.

CANCER HEALTH LITERACY

Defined as: interventions mentioned in National Cancer Control Plans that promote health literacy (YES vs NO).

1. *Information source used*
    - ✓ First, information sources below were scouted, collecting information for less than 65% of countries (38% and 38% respectively):
        - International Report on the Methodology, Results, and Recommendations of the European Health Literacy Population Survey 2019 - 2021 (HLS19) of M-POL)

Figure 1. Relevant indicators for building up the index for early cancer care



Early cancer care phase	Misurable indicators		Rule ≥ 65% covered countries	Advisory Group score
Education	Health literacy mention in National Cancer Control Plans (NCCPs)		✓	3/5
Screening	**Participation rate** (Pop. invited & screened in an organised screening program out of the total target population)	Breast cancer	✓	5/5
		Cervical cancer	✓	
		Colorectal cancer	✓	
	Piloting lung screening		✓	4/5
Early diagnosis	**Incidence of new cases** (No. new cases diagnosed per 1,000 inhabitants)	Breast cancer	✓	3/5
		Cervical cancer	✓	
		Colorectal cancer	✓	
Early treatment	**Survival rate** (% of people who have been diagnosed with cancer and are still alive 1,5 year(s) after diagnosis or start of treatment)	Breast cancer	✓	2/5
		Cervical cancer	✓	
		Colorectal cancer	✓	

Country	Mention in National Cancer Control Plans of interventions to promote health literacy	Participation rate in a screening programme (%)			Piloting lung screening	Incidence rate (per 100.000 inhabitants)			Age-stardadized survival rate at 5 years (%)		
		Breast	Cervice	Colon		Breast	Cervice	Colon	Breast	Cervice	Colon
Australia	N	54.5	48.2	43.5	Y	96.0	5.6	33.1	89.5	66.4	70.7
Austria	Y	40.9	84.6	64.0	N	69.5	5.3	21.0	84.8	63.9	63.7
Belgium	Y	59.7	49.5	50.3	Y	113.2	7.7	35.3	86.4	65.4	67.9
Canada	N	59.7	59.1	59.2	Y	82.1	5.5	31.2	88.6	67.3	67.0
Chile	N	40.1	52.0	N/A	N	37.4	11.1	19.9	75.5	56.7	43.9
……….											

   - Countries profiles by ScreenCan5 surveying Data availability: 92% of countries

- ✓ Then, the National Cancer Control Plans (NCCPs) were scouted and value were imputed accordingly using NCCPs:
   - collected by the International Cancer Control Partnership (ICCP)
   - tracked by the OECD EU Cancer Country Profiles 2023

2. *Values availability by*
   - ✓ 92% of the 36 OECD countries

SCREENING PARTICIPATION RATE

Defined as: percentage of population invited and screened out of the total target population.

1. *Information source*
   - ✓ OECD Health Statistics 2023 >> category of "Healthcare utilization" >> subcategory of "Screening", using either administrative or survey data. Some countries provide data from both sources, while others provide data from just one source. We applied the following the decision-making process:
     - i. First best choice: administrative data
     - ii. Second best choice: survey data
2. *Values availability*
   - ✓ Matching the OECD information sources, we have the following data availability by country:
     - i. Breast cancer: 100% of the 36 OECD countries considered
     - ii. Cervical cancer: 100% of the 36 OECD countries considered
     - iii. Colorectal cancer: 72% of the 36 OECD countries considered

INCIDENCE RATE

Defined as: rate of new cases or events over a specified period per 100,000 inhabitants at risk for the event.

1. *Information source*
   - ✓ WHO International Agency for Research on Cancer (IARC) >> section “Cancer Today”.
   - ✓ Since the incidence rate varies greatly by age, it is usually age-adjusted. We used a “World Age-Adjusted rate.”
2. *Values availability*
   - ✓ 100% of the 36 OECD countries considered.

SURVIVAL RATE

Defined as: percentage of people in a treatment group alive five years after they were diagnosed with a disease, such as cancer.

1. *Information source*
   - ✓ From OECD Health Statistics 2023 >> area of “Healthcare Quality Indicators” >> item “Cancer Care” powered by the age-standardized survival rate at 5

years related to the period 2010 – 2014. By turn, these data are provided by the Concord – 3 Programme.

    - ✓ Considering the possible timing inconsistency of this information source, we identified a set of countries with updated 5-years survival rate data for the 3 cancer types. We compared the countries' rankings based on the 2010-2014 data with the updated 5-year period data consistent with our analysis timing. The countries' ranking did not change significantly.

2. *Values availability*
    - ✓ 92% of the 36 OECD countries considered

LUNG CANCER SCREENING PILOTS

Defined as: presence of lung cancer screening pilots in a country (Yes vs No).

1. *Information source*
    - ✓ The Lung Cancer Policy Network, a website promoting lung cancer screening and collecting information about the cost-effectiveness, feasibility analyses, and pilot programs for lung cancer screening at a global level.
    - ✓ NCCPs collected by the ICCP
2. *Values availability*
    - ✓ 100% of the 36 OECD countries considered.

ANALYSING AND TREATING DATA: DEALING WITH MISSING DATA

Although the selected indicators meet the rule of thumb of having at least 65% of countries with a value, we still need to address some missing data. As we have missing data at random, there are three general statistical methods to consider:

- ✓ Case deletion
- ✓ Single imputation (mean/mode/median, hot-and-cold-deck imputation)
- ✓ Multiple imputation (Markov chain Monte Carlo, etc. etc.).

According to the scientific literature, given our population size, we apply the single imputation and the case deletion approach in the following way. Considering each dimension:

- If one value out of the three in each dimension is missing, a single imputation approach is applied by imputing the median value of the entire set of values.

- If all three values included in a dimension are missing, the country is excluded from the analysis.

In the case of the survival rate indicator, the following countries are missing three values out of three, which leads to case deletion approach for:

- Greece
- Luxembourg
- Mexico

Consequently, the index can now be built considering a sample of 33 countries.

BRING ALL INDICATORS ONTO A COMMON SCALE

After ensuring there is a balanced dataset, the next step was to render the variables comparable. The selected method for the normalisation procedure was the ‘min-max’ approach which rescales indicators onto an identical range (0-1) by subtracting the minimum value and dividing by the range of the indicator values.

WEIGHT THE INDICATORS AND DIMENSIONS

There are different weighting methods used in the aggregation of indicators. As a first step in this phase, we used expert elicitation to understand the relative importance of indicators and dimensions. In Table 1, we report the results of the survey’s question about weights’ allocation amongst 4 dimensions / phases* of Early Cancer Care (ECC) Index according to the Advisory Group (AG) survey:

- If we look at the median value, the AG assigned the same weights to Detection, Early Diagnosis and Early Treatment. Moreover, one member of the AG suggested test a further scenario assigning a greater weight to Early Diagnosis and Early Treatment compared to detection (screening).
- As agreed, we include the possible presence of the lung cancer screening pilots in the composite index, assigning also a weight to it.

The Budget Allocation Process (BAP) was the method adopted in which experts on a given theme are asked to allocate a “budget” of one hundred points to a set of indicators, based on their experience and subjective judgment of the relative importance of the respective indicators.

Weights are calculated as average budgets. The main advantages of BAP are its transparency and relatively straightforward nature.

According to the results of BAP., equal weights are assigned (i.e. relevance) to each indicator for screening, early diagnosis and early treatment (see Assumption 1 in Table 2).

Table 1. Results of expert answers regarding weights

ECC dimension	Average	Median	Max	Min
Education	14%	10%	20%	10%
Detection (Screening)	18%	20%	20%	10%
Early diagnosis	22%	20%	30%	10%
Early treatment*	22%	20%	30%	20%

Table 2. Alternative scenarios for weight allocation

Assumption 1: Detection (screening), diagnosis and treatment have equal weights	Assumption 2: early diagnosis and early treatment hold greater relevance than screening, while the other 2 indicators have half weight of the screening
Health literacy: 12.50 Screening – participation rate: 25.00 Early diagnosis – incidence rate: 25.00 Early treatment – survival rate: 25.00 Lung cancer pilots: 12.50	Health literacy: 6.25 Screening – participation rate: 17.50 Early diagnosis – incidence rate: 35.00 Early treatment – survival rate: 35.00 Lung cancer pilots: 6.25

In a following analysis aimed at testing the robustness of our results («sensitivity analysis»), we are going to apply a further weights distribution, suggested by an AG’ member, assigning greater weight (i.e. relevance) to early diagnosis and early treatment than to the screening (see Assumption 2 in Table 2).

Given our observations' number and the type of indicators used, we apply the geometric aggregation method. This entails a product of the countries' weighted values of each indicator.

The advantage of this approach is preventing a sort of «compensation effect» amongst the indicators and it allows measuring the effective impact of each indicator on the final outcome of the early cancer care.

Figure 2 provides the ranking of countries based on the composite index, which aggregates indicators for all cancer types. The composite index indicates that **Denmark** and **The Netherlands** are the 2 top performers among 33 countries assessed for early cancer care.

Figure 3, Figure 4 and Figure 5 present the output of the general composite index per cancer type.

Figure 2. General ECC Index

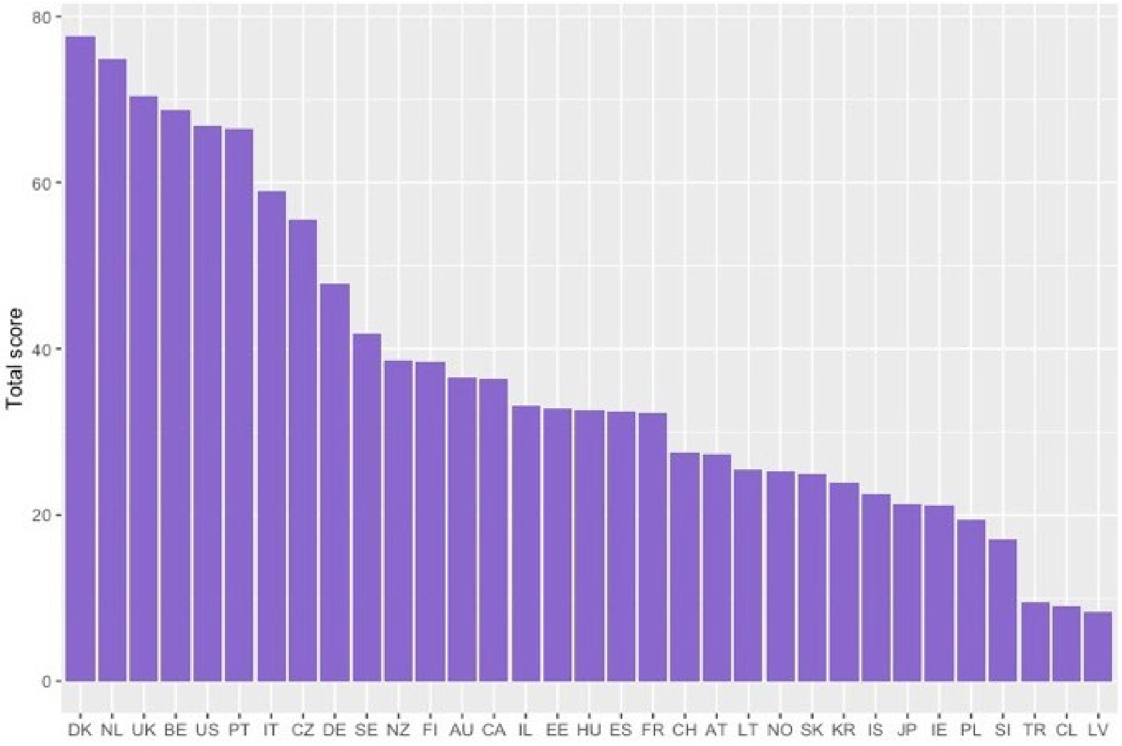


Figure 3. Breast cancer index

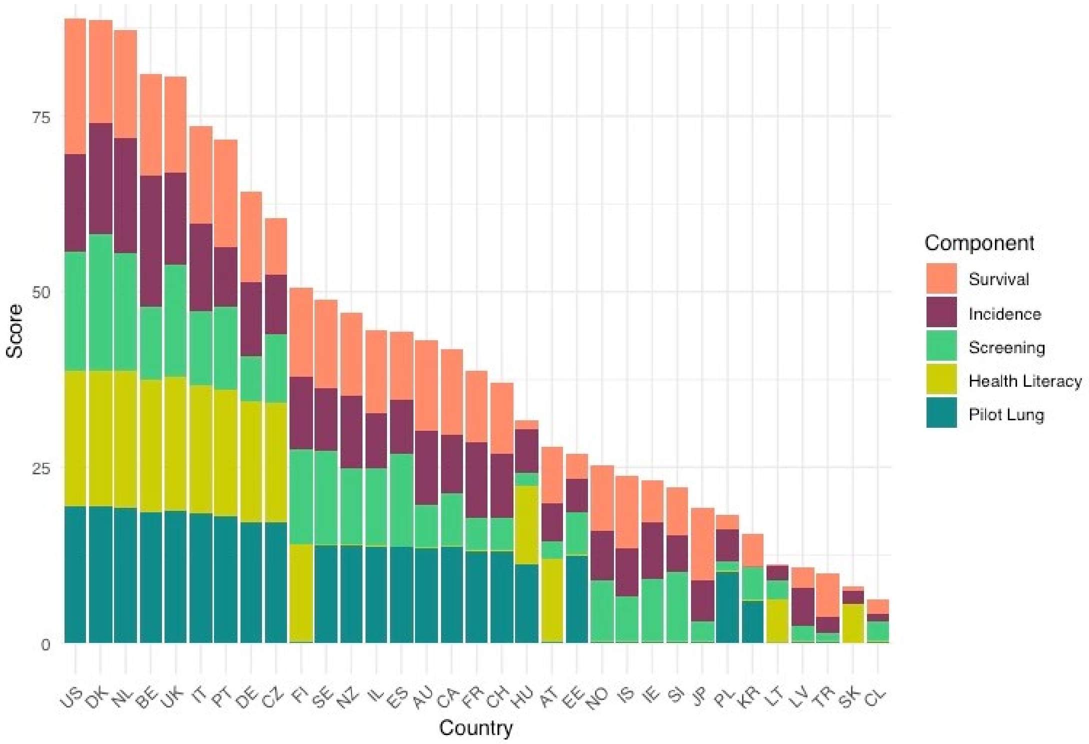


Figure 4. Cervical cancer index

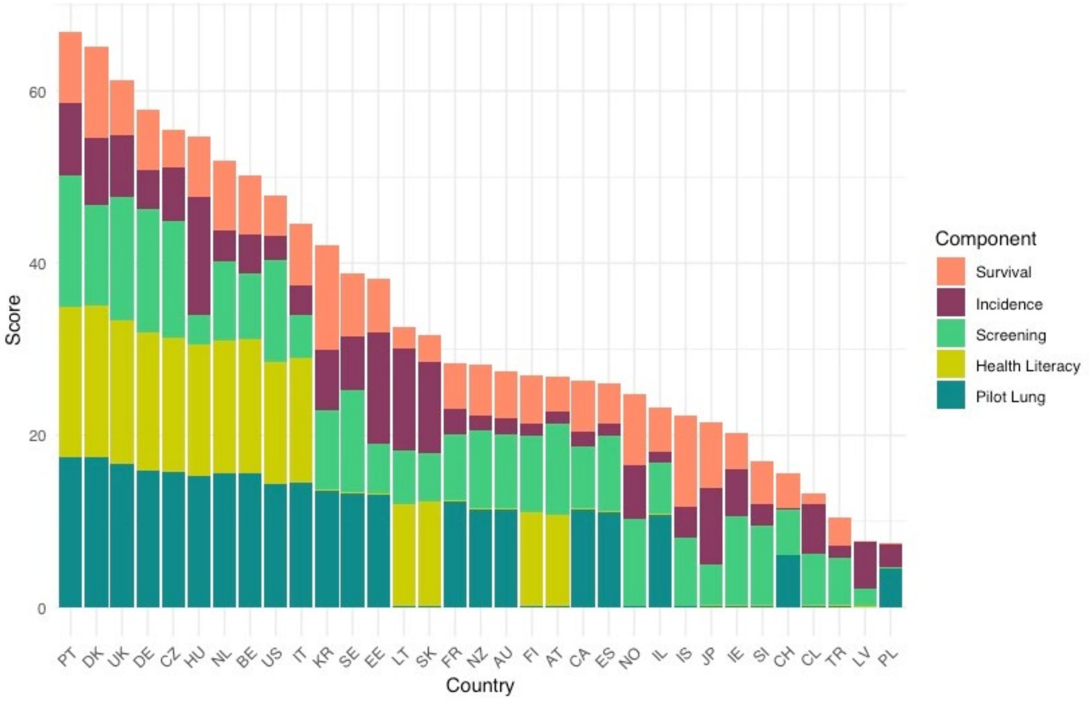
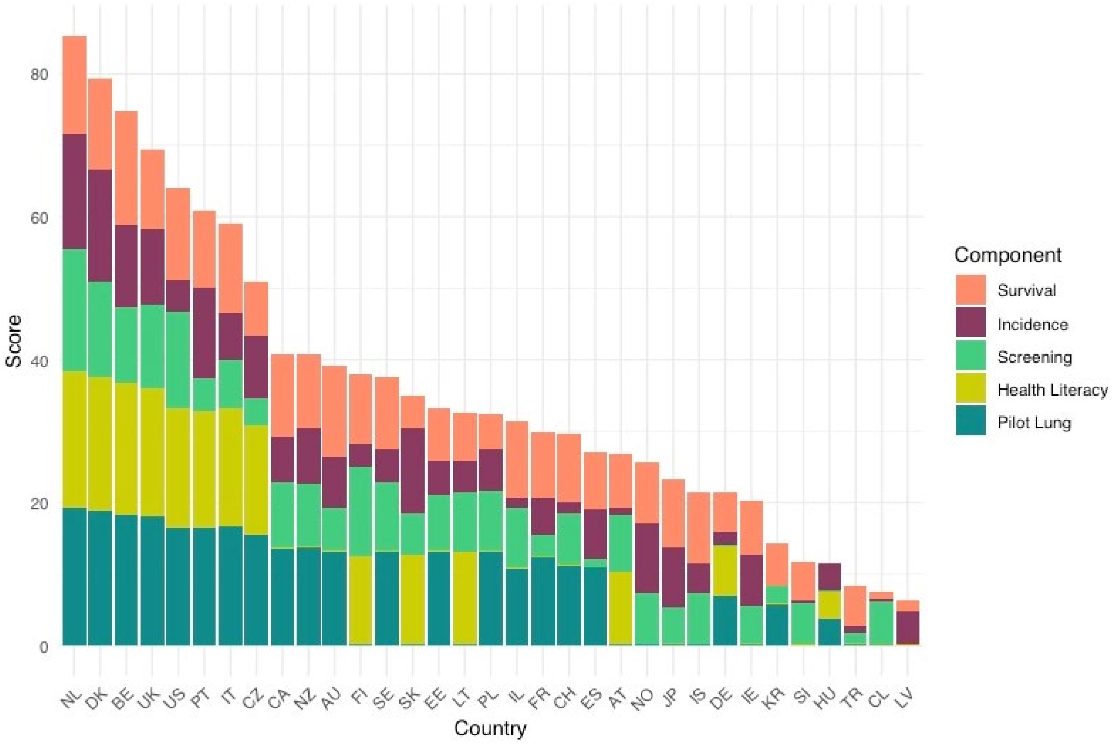


Figure 5. Colorectal cancer index



ASSESS THE ROBUSTNESS OF THE INDEX

To test the robustness of the countries' ranking, we carry out the following tests:

- We test how much the countries' rankings change if we apply a different weight distribution from the one previously used. Specifically, we test a second possible distribution proposed by an AG member.
    - General composite index whose weight distribution assigns greater weight to early diagnosis and early treatment than to screening and education, with lung cancer screening pilots given even less weight (see slide 20).
- We test how much the countries' rankings change if we use a different indicator representing the early diagnosis dimension. As the incidence rate is a very generic indicator of early diagnosis, we apply a more specific one, although only 60% of countries provide it, and it is only for breast cancer.

- Breast cancer composite index whose indicator for early diagnosis dimension is the rate of screening's participants with a breast cancer diagnosis of carcinoma in situ (i.e. I and II stadium).

As Figure 6 and Figure 7 show, Denmark and The Netherlands are still the 2 best performer countries once we have applied a different weights' distribution and we have used a more specific indicator (although on a smaller set of countries).

Figure 6. General ECC index with a different weights distribution

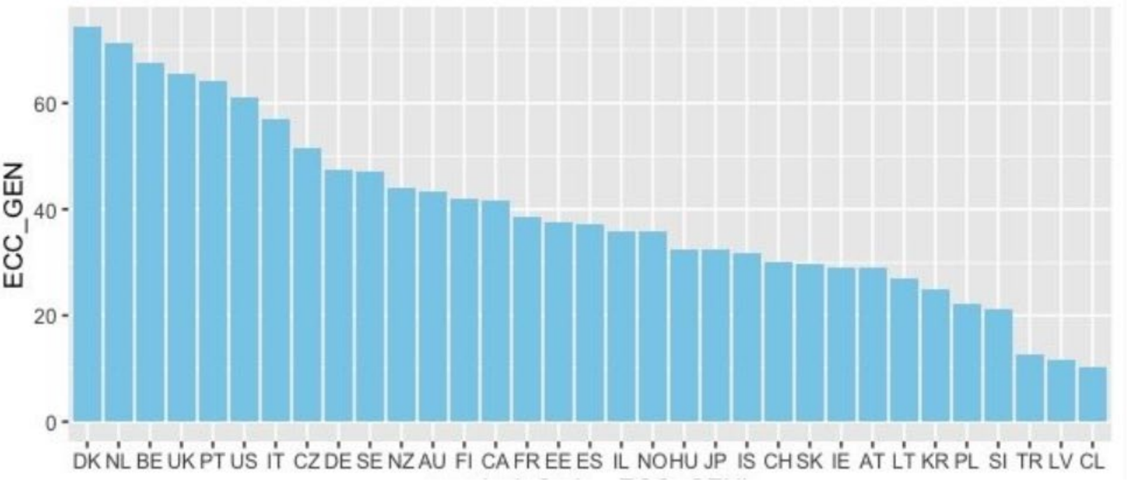
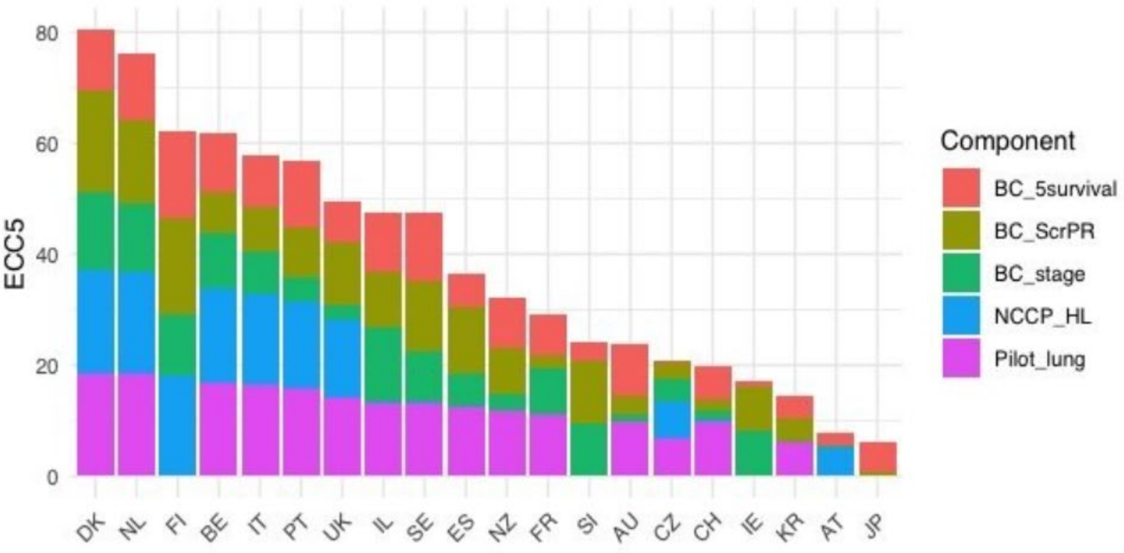


Figure 7. Breast cancer index with the rate of early stage diagnoses indicator



Caveats and possible developments

1. Data
    - Use of administrative and survey data
    - Use of different time points: when data for baseline year was unavailable, nearest data point was chosen. For survival, the nearest year available was 2014: the assumption is that between-countries trends hold in time, even if figures change
    - Missing data points: simple (hot-deck) imputation by the indicator median within a specified group (e.g. participation rate of countries with opportunistic screening programmes)
2. Indicators
    - Use of dichotomous variables display little variation and may not be sensitive enough at picking differential performance. In our case, they measure an important policy goal.
3. Weighting
    - Experts often give near-equal weights when asked, yet current number of experts could be increased to enhance decision legitimacy

THE CASE STUDIES: SELECTION AND METHODS

THE CASE STUDIES SELECTION

Case Study Selection Overview

As part of our research on early cancer care, we have selected a set of countries to serve as case studies. These countries were chosen based on their rankings in our Early Cancer Care Conduciveness Index, as well as their healthcare system models, policy environments, and the transferability of their strategies.

Selected Countries and Rationale

Denmark and The Netherlands

Ranked first and second respectively in our index, Denmark and the Netherlands represent leading examples of environments conducive to early cancer care. They function as "laboratories" where innovative strategies and tools have already been tested and implemented. Denmark operates under a Beveridge healthcare system, while the Netherlands follows a Bismarck model, allowing us to explore different system frameworks.

Italy

Italy is ranked seventh in our index and offers a unique case due to its large, decentralized, and complex healthcare system. It is considered a "country of two speeds," where regional disparities can highlight which policies or initiatives are more likely to succeed in challenging environments. Italy also allows for testing the effectiveness of our index in capturing nuanced realities in early cancer care across diverse conditions.

Poland

Positioned 29th in our ranking, Poland features a hybrid model that combines Bismarck and Beveridge elements. It is a large country where some innovative cancer care solutions have been implemented, although several critical components are still lacking, and results have been slow to materialize. Poland offers insights into partially developed but evolving care environments.

Chile

Ranked 32nd, Chile represents a non-EU case and features a predominantly Bismarckian system with Beveridge characteristics. Despite having issued a national cancer action plan, many initiatives are still pending implementation. Its inclusion provides a broader, global perspective and helps test the transferability of EU-centric approaches to other regions.

Selection Criteria

The countries were selected based on the following criteria:

- Their position in the Early Cancer Care Conduciveness Index
- The presence of policy components supportive of early cancer care
- The availability of evidence on policy transferability
- The opportunity to validate the effectiveness of the index across diverse healthcare systems

THE CASE STUDIES METHODS

Case Studies Methodology Overview

The methodology developed for the case studies aims to provide a structured and in-depth understanding of the factors shaping the early cancer care environment across selected countries. Each case study integrates background data, health system characteristics, and a detailed analysis of key dimensions and pillars of early cancer care.

Background Analysis

Each case study begins with background information that contextualizes the environment for early cancer care. Key factors include:

- Demographic Trends: Special attention is paid to the aging population, particularly individuals aged 40–74, who are the primary target for cancer detection and treatment.
- Socioeconomic Drivers: Factors such as risk of poverty, immigration, and education are analyzed due to their influence on the demand for healthcare services, including access to screening and treatment.
- Healthcare System Characteristics:
    - Degree of integration between funders and providers
    - Level of centralization or decentralization
    - Governance structures and institutional reforms
    - Funding models and reimbursement mechanisms
    - Roles of main actors in the cancer care ecosystem

Methodological Structure

The methodology is organized around three main components:

- **Population and Socioeconomic Context**

  - Demographic trends
  - Risk of poverty
  - Immigration
  - Education levels
- Cancer Epidemiology
  - Incidence
  - Mortality rate
  - Survival rate
- Healthcare System
  - Organizational structure
  - Funding and reimbursement
  - Characteristics of the cancer care environment

Analysis Framework

The core analysis is structured around four dimensions of early cancer care:

- Education
- Early Detection
- Early Diagnosis
- Early Treatment

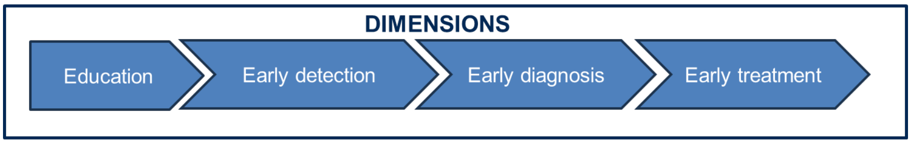
Each dimension is further broken down into the following pillars:

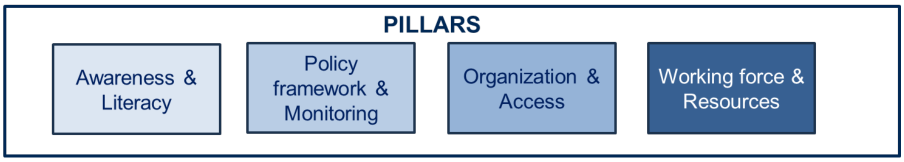
- Awareness and Health Literacy
- Policy Framework and Monitoring
- Organization and Access
- Workforce and Resources

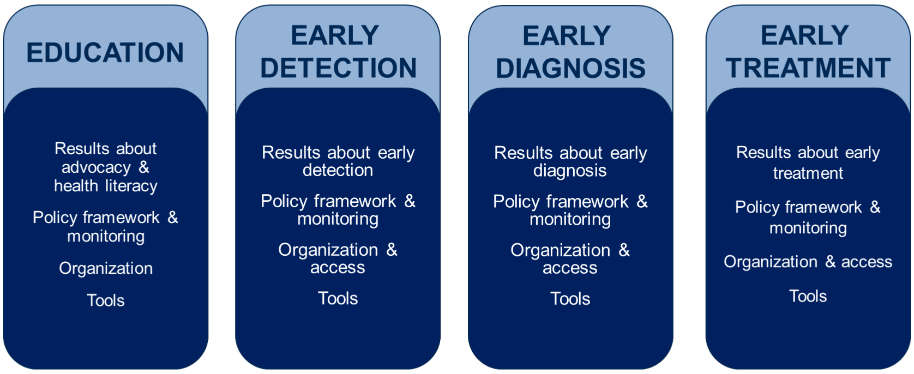
Within each dimension, the case studies examine:

- Key results and performance
- Existing policy frameworks, action plans, and monitoring systems
- Operational organization, including service provision processes
- Availability of tools, equipment, drugs, and human resources

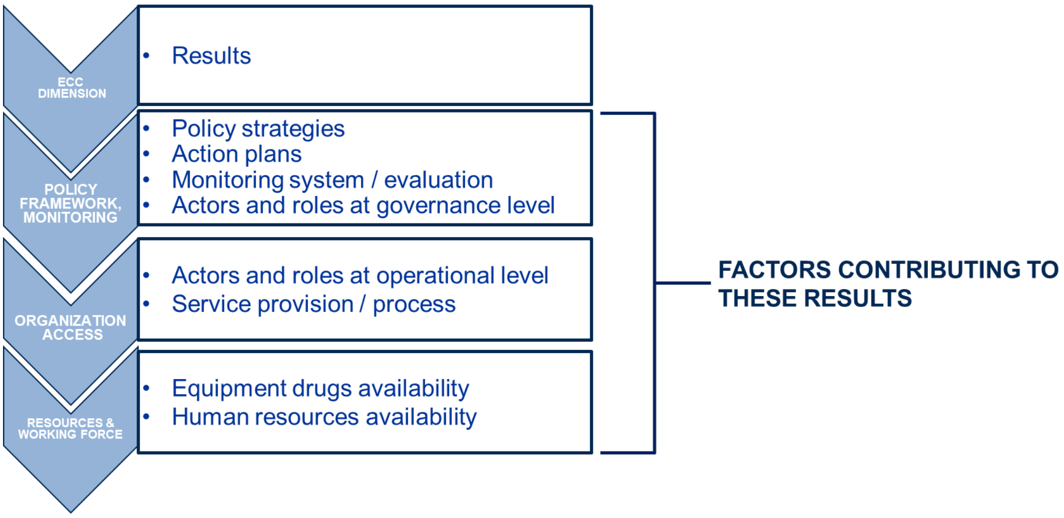
In summary, the following figures represent the analysis framework







The following figure summarizes the key items of the case studies structure.



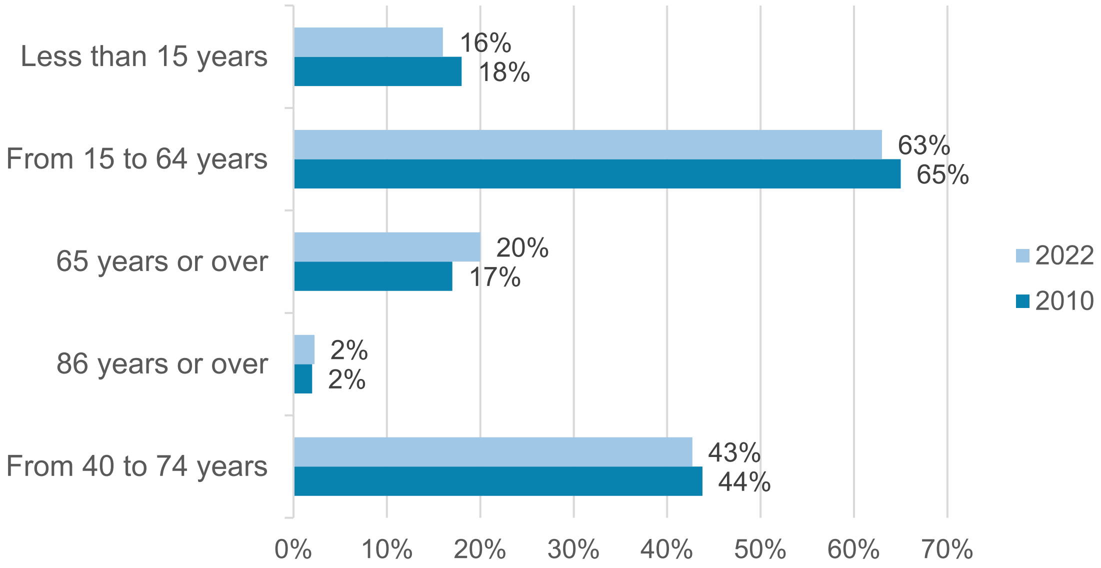
DENMARK

1.1 BACKGROUND

POPULATION

In 2022, Denmark had 5.91 million inhabitants, representing a 6% increase over the last 12 years. This growth was due to increasing immigration and a higher birth rate compared to the death rate up until 2023, when this trend has reversed.

Figure 8. Composition of population in 2010 and 2022 in Denmark

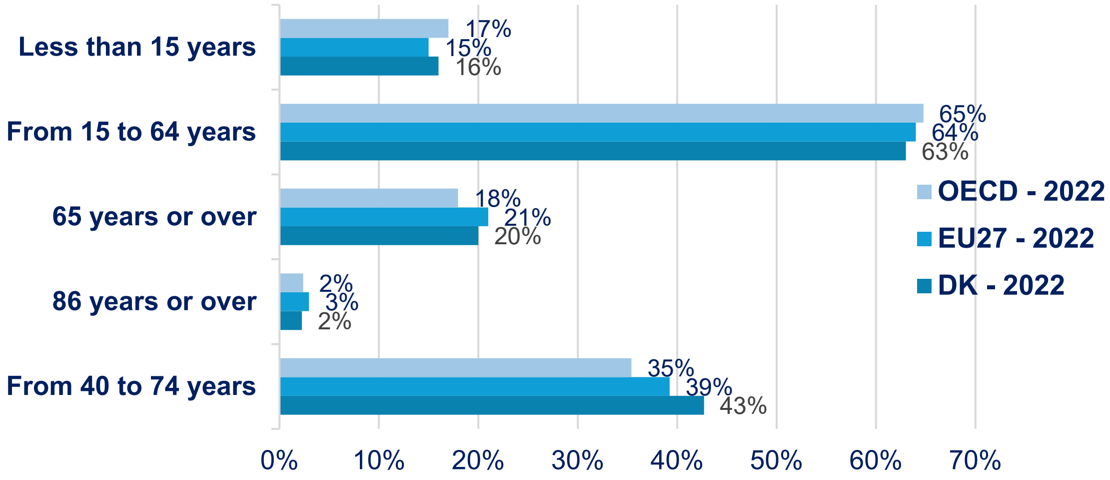


Source: Eurostat.

The above Figure 8 shows that in the last 12 years:

- The population between 0 and 15 has slightly decreased by 2% representing 22% of population in 2022;
- The population over 60 years old has switched from the 24% to 26%. Hence, Denmark is also experiencing an aging population;
- Although the largest population group is between 20 and 39 years (i.e. often referred to as a fertility age), the fertility rate is around 1.7;
- Population: a comparison between Denmark and the European average (EU27) and the OECD average.

Figure 9. Age distribution of the Danish population in 2022 compared to EU27 and OECD averages



Source: EuroStat.

Moreover, in 2022, Denmark had a population proportion between 40 and 70 years old greater than the OECD and the EU27 average.

Looking at the population from a **social perspective,** according to Eurostat data it can be observed that:

- Between 2019 and 2022, there was a decrease in the rate of recent immigrants over 20 years old out of total labour population;
- Nearly 25% of population – in line with EU27 data – has a low education level and possibly faces challenges in accessing healthcare.

Table 3. A set of social indicators of the Danish population in 2019 and 2022 compared to EU 27 average

Indicators		Denmark	EU 27 countries
Persons at risk of poverty* (% of total population)	**2019**	13.5	16.5
	2022	14.5	16.5
Active recent immigrants over 20 years old born in a foreign country (% out of total labour age population)	**2019**	1.3	2.0
	2022	2.5	2.1
Population by foreign citizenship (% of total population)	**2019**	1.5	2.2
	2022	3.0	2.6
At least upper secondary educational attainment (3 – 8) **– age group 25 – 64 years** (% of population 25 – 64 years)	**2019**	74.5	74.0
	2022	77.0	75.0

Source: Eurostat

°Cat-off point: 60% of median equalised income after social transfer.

Epidemiological outlook

Regarding cancer incidence in Denmark, the most common cancer-related causes of death in 2022 by sex (considering all cancer sites except non-melanoma skin cancer) were cancers of the trachea, bronchus, and lung for both men and women, followed by breast cancer in women and colorectal cancer in men. Finally, the absolute number of cancer deaths in Denmark in 2022 was 8,047 for women and 9,064 for men.

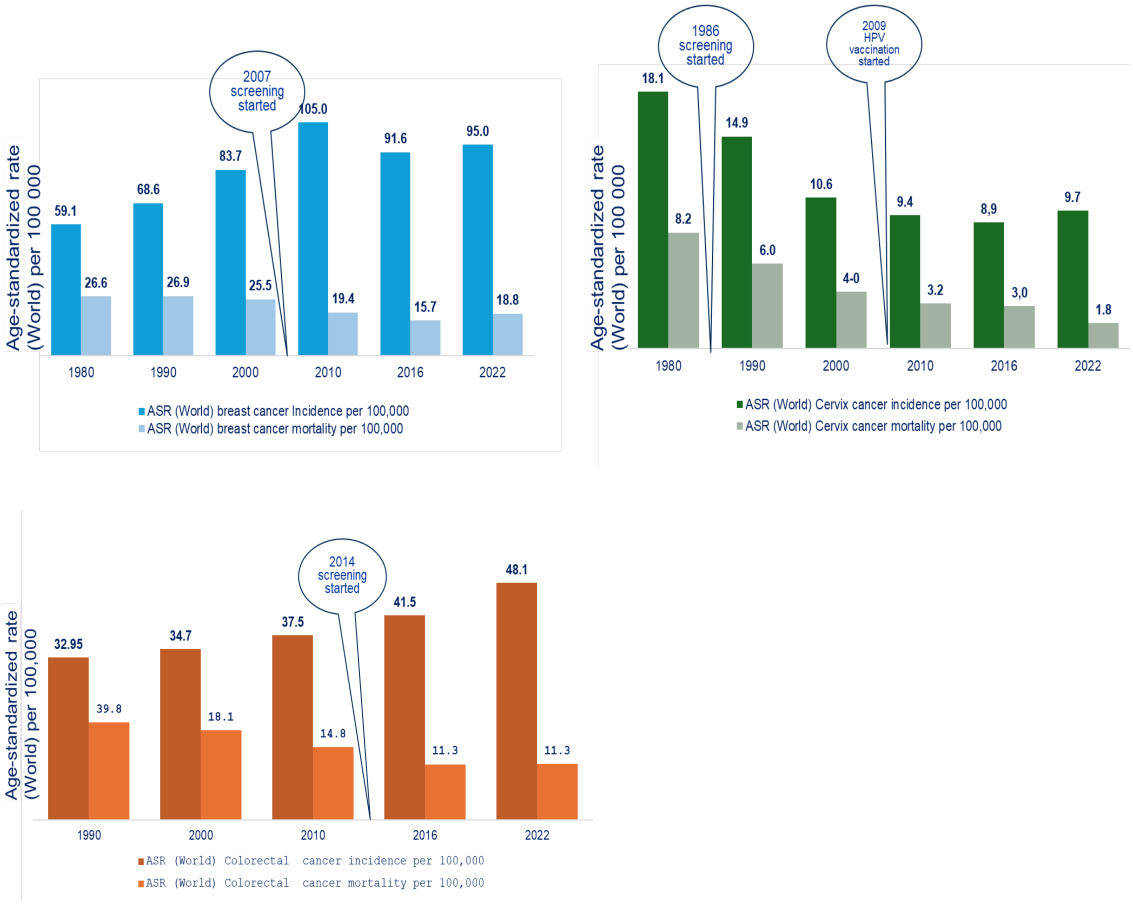
Considering the three cancers object of this analysis, we see that the breast cancer incidence's peak in 2010 might be explained by the screening implementation in 2007; while the cervix population-based screening introduced in 1986 did not impact incidence, instead the HPV vaccination, introduced in 2009, might have had some impact. In the case of the population based colorectal cancer screening, it seems this initiative might have had an impact on the incidence rate (see Figure 10).

Table 4. Incidence of the leading cancer causes of death by sex in Denmark, 2022. Five-year survival rates for the periods 2010-14 and 2017-21 for the main cancer types in Denmark

Type of cancer	Incidence of the leading cancer causes of death		Cancer Survival Rate at 5-years	
	Men	Women	CONCORD-3 report ASR 5-year 2010 - 2014	NORDCAN Registers Network ASR 5-year 2017 – 2021
Trachea bronchus and lung	21%	23%	16.6%	F 32..1% - M 25.2%
Breast cancer	n.a.	14%	86.1%	97.5%
Colorectum	15%	12%		
Prostate	12%	n.a.	85.6%	98.6%
Pancreas	8%	7%		
Ovary	n.a.	5%		
Liver	4%	n.a.		

Source: ECIS, European Cancer Information System ; Concord-3 Report[1]

Figure 10. Incidence and mortality trends for breast (1990–2022), cervical (1980–2022), and colorectal cancer (1990–2022) in relation to the year of introduction of population-based screening programmes



Source: WHO, Global Cancer Observatory, Cancer Today and Cancer Trend

Regarding cancer-specific survival rates, we can refer to an international study that provides the age-standardized five-year survival rate (ASR) for the period 2010–2014. Additionally, data from the Nordcan Registers Network – which includes the Scandinavian countries – allow these figures to be extended to the period 2017–2021.

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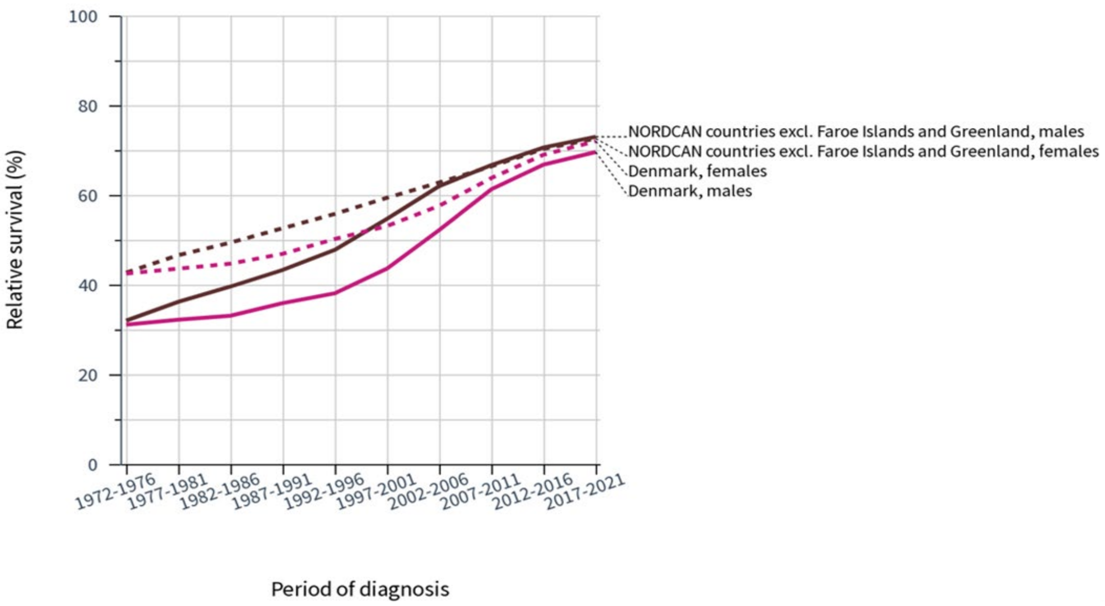
[1] https://worldpopulationreview.com/country-rankings/cancer-survival-rates-by-country; Nordcan – Association of the Nordic Cancer Registers, https://nordcan.iarc.fr/en/dataviz/survival?years_available=1943_2023

A comprehensive overview of the trends in survival rates for all cancers (excluding skin melanoma) since the 1970s helps to understand the rationale behind a series of Danish cancer-related policy initiatives launched from the 2000s onward and the resulting positive progress.

As scholars first and policymakers later stressed, Denmark had a lower survival rate compared to other Nordic countries up until the '90s. Then, in the early 2000s, a catch-up began, and Denmark reached the level of the other Nordic countries.

Figure 11. Cancer survival rate in Denmark and in the other NORDCAN countries between 1973 – 1976 and 2017-2021. ASR Survival rate 5-year % - Males and Females for all cancer sites but non melanoma skin cancer



Source: NordCan – IARC.

For instance, in the period 2000-2004, only one in ten Danish patients with lung cancer survived their disease for at least 5 years. For patients who were diagnosed in the years 2015-2019, the expected 5-year survival has increased to 25 per cent. (Kræftens Bekæmpelse, 2022).

HEALTHCARE SYSTEM

Denmark has a universal and tax-financed health system covering a wide range of medical services, excluding outpatient drugs and dental care which are the main causes of out-of-pocket spending, while prevention is free.

In general terms, the system is decentralized, as planning and regulation occur at three different levels:

State handling regulatory, supervisory, and financial functions:

- 5 regions tasked with overseeing hospitals and coordinating primary care services provided by independent healthcare providers;
- 98 municipalities responsible for rehabilitation, home and institutional long-term care, and public health.

The three levels operate in a collaborative rather than hierarchical manner, despite the state level having significantly greater financial and legislative resources compared to the other two levels:

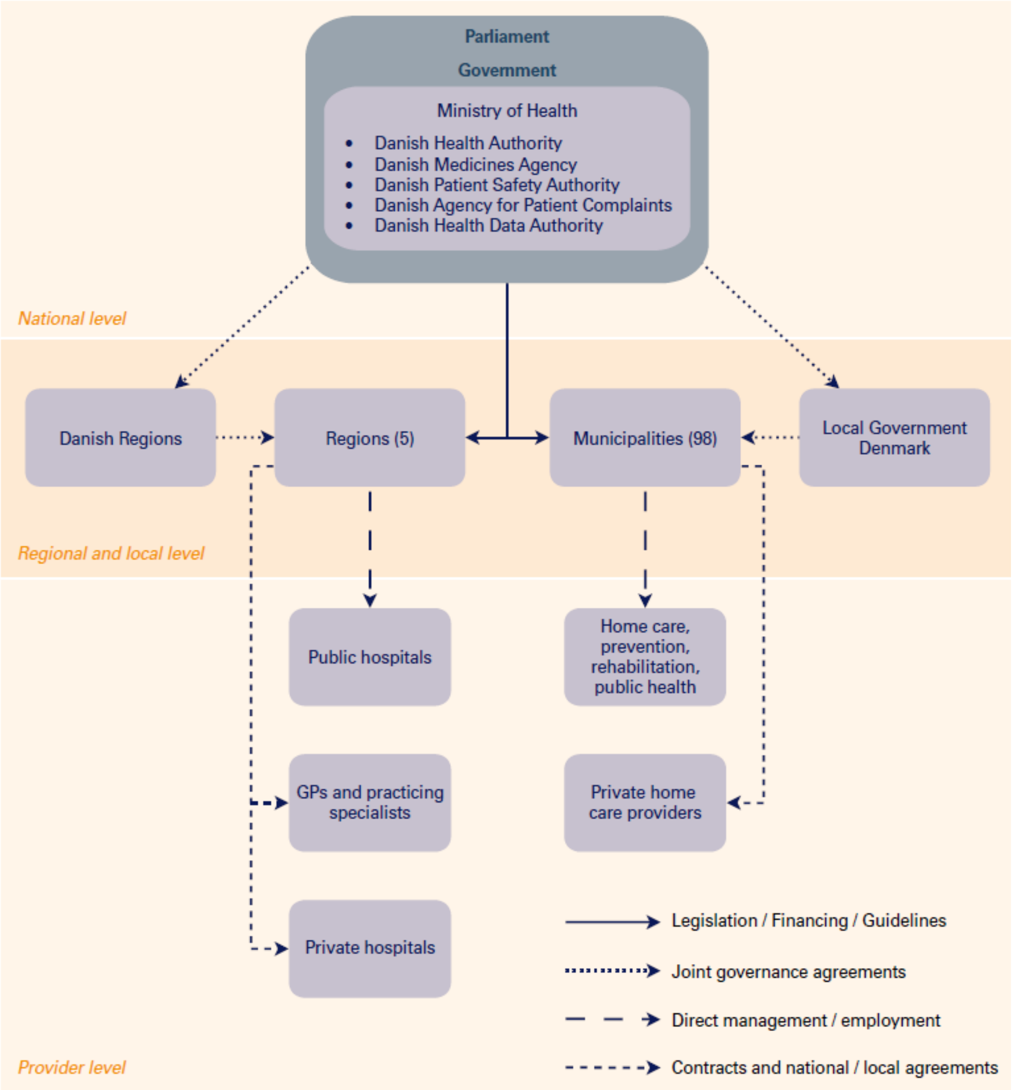
- The Danish Health Authority, under the Minister of Health, is the government agency in Denmark responsible for promoting public health and ensuring the quality and safety of healthcare services in the country. Its main tasks are:
  - ✓ Developing national health policies;
  - ✓ Providing guidelines and recommendations for healthcare providers;
  - ✓ Conducting health surveys and research;
  - ✓ Monitoring and inspecting healthcare facilities.
- The Danish Regions organization is the representative body for the five regions in discussions with both the government and private entities and facilitates policy coordination and development throughout the regions.
- The Local Government Denmark represents municipalities in negotiations with other government levels.

Most recent reforms

In 2005, the Danish Parliament approved a major administrative reform that significantly transformed the healthcare system, which was subsequently implemented in 2007. One of the key aspects of the reform was centralization. The number of regional authorities was reduced from 14 to 5, and municipalities from 275 to 98. Hospital functions were also consolidated, decreasing from 40 to 21 hospitals by 2022, accompanied by substantial investments in infrastructure and the creation of six super-regional hospitals.

The reform also redefined institutional relationships within the healthcare system. Regions were assigned primary responsibility for the provision of healthcare services, while municipalities took on tasks related to prevention, health promotion, and rehabilitation outside of hospital settings. To support coordination, mandatory health agreements were introduced, negotiated every four years between regions and their corresponding municipalities. These agreements clearly define patient pathways and outline the roles and responsibilities of hospitals, municipalities, and general practitioners (GPs). In 2022, health clusters were established around the 21 acute hospitals, functioning as operational hubs that promote collaboration among hospitals, GPs, and municipal health services.

Figure 12. An overview of the healthcare system



Source: Birk HO, Vrangbæk K, Rudkjøbing A, Krasnik A, Eriksen A, Richardson E, Smith Jervelund S. Denmark: Health system review. Health Systems in Transition, 2024; 26(1): FIG. 2.1 Overview of the health system p. 14.

In the area of pharmaceutical and health technology evaluation, the Danish Medicines Council was established to conduct pharmaceutical assessments, while the Danish Health Technology Council was introduced in 2021 to guide the prioritization of high-cost hospital drugs and broader health technologies.

Finally, the reform led to notable governance changes. Since 2007, governance has increasingly shifted toward stronger state control, characterized by tighter economic management through budget laws with automatic sanctions, as well as the implementation of specialty planning, clinical guidelines, and quality indicators, as noted by Vrangbæk (2010; 2021).

Financing of healthcare system

Over the past two decades, current health expenditure per capita has increased by 67%, with health spending since 2010 consistently accounting for 10% of the GDP. Private health expenditure has fluctuated between 15% and 17%, primarily funded through out-of-pocket expenses. These figures align with the trends observed in the leading OECD countries. Additionally, the proportion of GDP allocated to preventive care expenditure is approximately 0.23%. In Denmark, regions do not collect economic taxes; they depend on the Ministry of Health, while municipalities have taxation power. The Ministry of Finance plays a crucial role in defining the volume of resources allocated to regions, particularly in areas like early cancer care. The Ministry engages in negotiations with Danish Regions regarding the allocated budget and how these funds should be spent (see Figure 13).

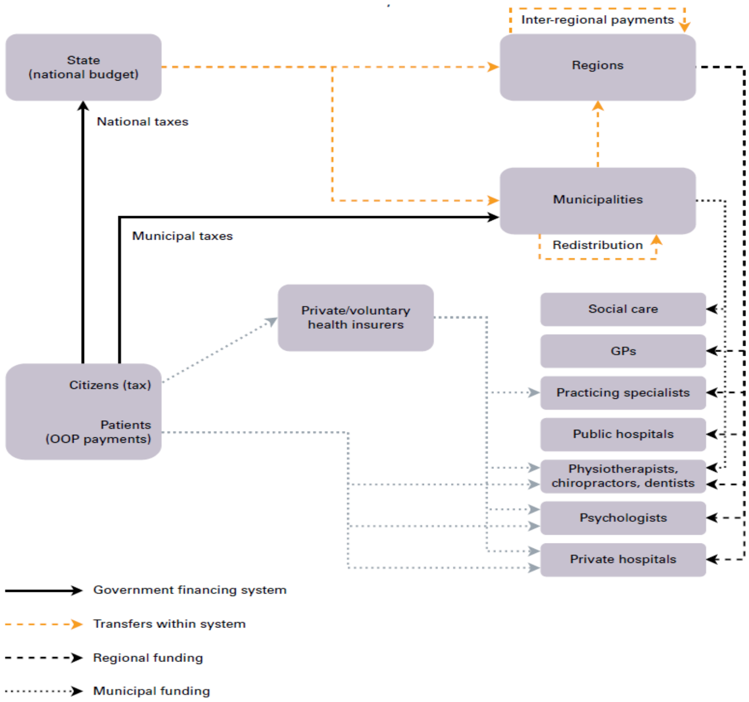
Once regions and the Ministry of Finance have agreed on the budget and its usage, the regions are responsible for making agreements on payments with practicing specialists, psychologists, general practitioners (GPs), and for funding both public and private hospitals. Meanwhile, municipalities collect their local taxes and partially redistribute them to the regions. They then fund services directly, including rehabilitation, social care, and primary prevention (Rudkjøbing et al 2014.).

Table 5. Trends of the main financial indicators in Denmark from 2000 to 2022

Indicators	2000	2010	2019	2020	2021
Current health expenditure per capita in International US$ (PPP)	2,327	4,572	5,950	6,351	7,140
Current health expenditure as % at GDP	8.1	10.6	10.1	10.5	10.8
Public expenditure on health as % of total expenditure in health	83.1	84.3	83.7	84.9	85.9
Public expenditure on health per capita in International US$ (PPP)	1,934	3,853	4,981	5,389	6,098
Private expenditure on health as % of total expenditure on health	16.9	15.7	16.3	15.1	14.6
Out of Pocket payments as % of total expenditure on health	15.4	13.7	13.8	12.8	12.4
Preventive care as % of GDP			0,23	0,34	0,97

Source: OECD Data Explorer

Figure 13. Financial flows in the Danish health system



Source: Birk HO, Vrangbæk K, Rudkjøbing A, Krasnik A, Eriksen A, Richardson E, Smith Jervelund S. Denmark: Health system review. Health Systems in Transition, 2024; 26(1): FIG. 3.5 Financial flows in the Danish health system p. 41.

KEY ACTORS IN CANCER CARE

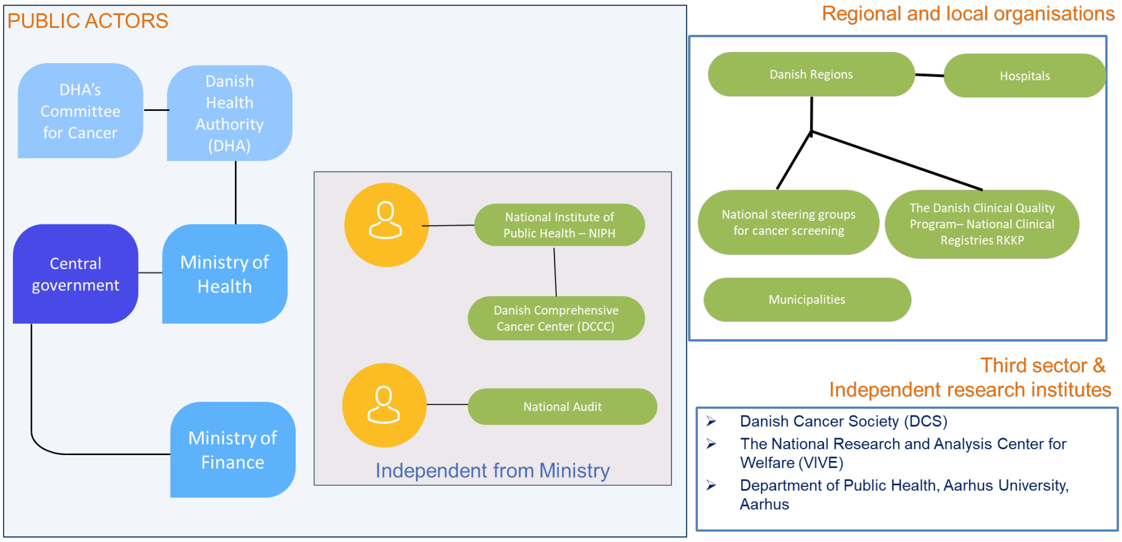
Figure 14 illustrates a multi-level, multi-actor governance model, where central authorities set strategy and policy, while regional and local bodies manage execution and delivery. Independent institutions support with oversight, data, and research, and the third sector adds civil society and academic perspectives. This interconnected and comprehensive structure underpins the coordinated approach Denmark has taken in enhancing cancer care.

The **Ministry of Health** is sometimes merged within the Ministry of Interior. The Ministry has the overall regulatory and supervisory functions in healthcare. The legislation covers the tasks of the regions, municipalities, and other authorities within the area of health.

Minister of Finance negotiates with Danish Regions about the budget and its spending, decides on funding for cancer care, outlines the tasks for Danish Regions, and monitors their implementation.

Danish Regions oversee all cancer-related screening, treatment, and rehabilitation services. They directly manage hospitals and agreements with GPs.

Figure 14. Overview of the key actors involved in the cancer care in Denmark



Danish Health Authority – DHA (Sundhedsstyrelsen) It is the operative arm of the Ministry of Health in all key public-health issues, included the improvement of cancer care. It has governed all reform processes and changes in cancer care.

Steering Group for Cancer from 1998 to 2015 with the purpose of improving cancer care treatment. This included: Minister of Health, Danish Regions, Danish Cancer Society, National Institute of Public Health, several medical specialist societies. The Steering Group was chaired by the DHA.

Since 2015, **DHA's Committee for Cancer** has replaced the Steering Group for Cancer and it is presented as an "advisory forum with the participation of the most important parties and actors within the field of cancer. The Committee is chaired by the DHA.

National Institute of Public Health – NIPH (Statens Institut for Folkesundhed, SIF). After 2007, NIPH is no longer part of the Minister of Health, and it merges with the University of Southern Denmark. A key research entity in the study of epidemiological trends and clinical outcomes also on cancer. It has been widely involved in working groups and commissions on cancer care initiatives.

The Danish Multidisciplinary Cancer Groups (DMCGs) coordinate collaboration among medical specialties and other professionals in cancer care, develops national clinical GLs, and improves cancer care quality through data analysis and feedback. The groups are chaired by the NIPH

Danish Comprehensive Cancer Centre (DCCC) is a binding collaboration established by the government, the public hospital owners, the clinical cancer departments, the universities and the DCS, gathering management and professional capacities within cancer and healthcare in Denmark.

Danish Clinical Quality Program – National Clinical Registries (RKKP) constitutes the infrastructure of the Danish clinical quality registries and the Danish Multidisciplinary Cancer Groups (DMCG).

National steering groups for cancer screening (Nationale styregrupper for kræftscreening) has the purpose to support uniform screening services across Denmark's five regions.

The National Research and Analysis Centre for Welfare (VIVE) is an independent state institution providing knowledge that contributes to developing the welfare society and the public sector.

Department of Public Health, Aarhus University, Aarhus along with other universities contribute to providing evidence through research.

The Main Steps of the Danish "Success" in Cancer Care

In the late 1990s, cancer care became a significant political concern in Denmark. Data comparisons with members of the NordCan network revealed to the public that Denmark's cancer care performance was lower than expected. Public opinion focused on several concerns, particularly the negative impact of waiting lists on the diagnosis and treatment of cancer patients.

The issue gained traction beyond the realm of epidemiologists. The Danish Cancer Society put pressure on policymakers and the government to improve cancer care, making it a prominent issue on the political agenda. While low survival rates were part of the discussion, the main driver for change was the growing concern over waiting lists.

Cancer care became a priority on the policymaking agenda with the introduction of *Cancer Plan I*[2] *in 2000 along with "waiting time guarantee" initiative* for patients with life-threatening cancer (Triantafillou et al. 2022), ensuring a maximum two-week wait from diagnosis to treatment in 2001 and *Cancer Plan II in 2005*[3] (Ministry of Interior and Health 2015). These plans aimed to address the real conditions of cancer care in Denmark. Key actions included updating guidelines, providing brush-up training to health care personnel to enhance their knowledge about cancer, and involving stakeholders in identifying solutions.

One of the main objectives was to initiate a process of concentration within hospital units involved in cancer care. This also extended to an administrative concentration process, enabling better integration between primary and secondary care. A quality assurance system and continuous monitoring were set up to ensure high standards in cancer care.

However, these initial cancer care plans in Denmark struggled with implementation and failed to produce significant improvements. It wasn't until the introduction of *Cancer Plan II update in 2007*—framed as an integrative document—that real progress began. This momentum continued

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[2] National Board of Health. The National Cancer Plan Summary and Recommendations 2000. http://www.epaac.eu/from_heidi_wiki/Denmark_National_Cancer_Plan_I_Summary_English.pdf

[3] National Board of Health, National Cancer Plan II • Denmark National Board of Health recommendations for improving cancer healthcare services. Published by: The National Board of Health, Copenhagen, Denmark, June 2005 http://www.epaac.eu/from_heidi_wiki/Denmark_National_Cancer_Plan_II_English.pdf

with *Cancer Plan III (2010)*[4] *and Cancer Plan IV 2017 – 2020 (2016)*[5]. Finally, in 2024, work was still ongoing on the finalisation of the *Cancer Plan V*[6] with a focus on improving cancer care and survival rates, including allocating resources for earlier cancer detection and addressing inequalities in treatment.

Crucially, broader systemic reforms between 2005 and 2007 played a significant role (Triantafillou et al. 2022). These reforms reorganized the administrative and financial structures across regional, municipal, and national levels, which helped streamline and rationalize cancer care services. Nonetheless, these changes triggered a continuing evolution, as evidenced by ongoing structural adjustments.

Moreover, a turning point came with mounting pressure from citizens, patient advocacy groups, and the media. The outcry over excessive waiting lists pushed policymakers to make cancer care a top priority in terms of policy focus and funding. While this emphasis led to measurable improvements, it also sparked criticism from other health sectors—particularly mental health advocates—who questioned the disproportionate allocation of resources.

Clinicians, although initially sceptical of the media campaigns around waiting lists, recognized the opportunity to secure more resources. They shifted their focus to optimizing cancer care processes, particularly through the development of clinical pathway tools, which gained international recognition for their effectiveness in standardizing and expediting patient treatment.

Ultimately, it was the combination of healthcare system reforms, social and political pressure, and professional engagement that enabled a sustained and progressive transformation of cancer care in Denmark. The tools and organizational changes implemented have had a significant and lasting impact, especially in the critical area of early cancer detection and treatment.

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[4] EPAAC – EU, Short summary of Cancer plan III, Denmark. http://www.epaac.eu/from_heidi_wiki/Denmark_Summary_of_National_Cancer_Plan_III_English.pdf

[5] PATIENTERNES KRÆFTPLAN KRÆFTPLAN IV https://www.iccp-portal.org/system/files/plans/Kraeftplan-IV-Patienternes-aug-2016.pdf

[6] Cecilie Iuul, senior advisor Danish National Authority Cancer Plan V Denmark. https://conferencemanager.events/nordiskenetvaerksmoedepakkeforloeb/download-zip?data=439213#:~:text=14.,health%20care%20system%20is%20coming

1.2 EDUCATION: LITERACY AND AWARENESS

Regarding the current level of health literacy and awareness in the field of oncology in Denmark, we rely on two different sources of information. The first is the M-POHL HL2019 Survey (HLS19), a European-level survey that explores general health literacy (HLS19 Consortium of the WHO Action Network M-POHL, 2021). The second consists of scientific reports and articles authored by Danish researchers, specifically focusing on health literacy within the context of cancer care."

Specifically, the M-POHL HL2019 Survey (HLS19) explored the level of health literacy among Danes, focusing on key competencies such as understanding screening information, evaluating treatment options, and using healthcare services effectively. Survey findings reveal that:

- 15.6% of Danish respondents found it difficult or very difficult to understand health information, slightly below the 17.8% average across the 17 participating countries.
- A significant 45% of Danish respondents struggled to evaluate the advantages and disadvantages of treatment options.

Overall health literacy regarding the use of healthcare services was moderate, with an average score of 77.4 on a scale from 0 to 100, where the 25th percentile was 66.7 and the 75th percentile 91.7.

Therefore, a research report and a scientific paper support the importance of health literacy in influencing cancer screening participation (Horshauge et al 2020). In particular, the SWIM study (Tatari et al., 2021) investigated the experiences of ethnic minority women from non-Western countries regarding cervical cancer screening. It found that non-participation was often driven by cultural beliefs, language barriers, and mistrust in the healthcare system. Some believed screening was only relevant for those already showing symptoms. According to Sundhedsstyrelsen (2022), both native Danes and ethnic minorities face challenges with screening programs, though for different reasons: native Danes may struggle with understanding how to participate, while minorities often need to understand why participation is important. Finally, Petersen et al. (2022) explored the relationship between health literacy and access to general practitioners (GPs) and the diagnostic process. Their study concluded that lower health literacy delayed primary care access, though it had no significant effect on entering the diagnostic pathway. Together, this data underscores the need to enhance health education and targeted communication strategies to improve cancer awareness, particularly among vulnerable populations.

POLICY FRAMEWORK

In Denmark, several strategies have been developed to enhance health literacy and, more specifically, cancer health literacy, within the healthcare system and among the general population.

The main strategies for general health literacy include initiatives by the Danish Health Authority (DHA) and various national networks. In 2009, the DHA published a report on health literacy, providing an overview of international knowledge and its relevance to municipal-level prevention efforts. Later, in 2016, the Danish Health Literacy Network was launched. This initiative culminated in 2019 when the Danish Society of Public Health and the Network established a national health literacy agenda, publishing a policy brief with eight recommendations for integrating health literacy into broader health strategies.

Regarding cancer health literacy, several targeted measures have been introduced. The Cancer Plan III (2010) was the first national policy document to explicitly address cancer health literacy. It emphasized patient education and empowerment to improve prevention, detection, treatment, and rehabilitation outcomes, aiming to enhance public access to reliable information and support informed health decisions.

Further developments occurred in 2022, when the DHA, in collaboration with Aarhus University, published a document titled “Health Literacy in Danish Health Care Organisations: A Path Towards Equity.” This report introduced the concept of organizational health literacy, promoting the idea that healthcare services, organizations, and systems should adapt to individuals’ health literacy strengths and limitations to ensure equitable access to information and care.

Additionally, a 2022 DHA report on cancer screening programs proposed new approaches to health literacy, such as involving ambassadors and facilitating face-to-face meetings. These strategies are tailored for specific population groups, particularly non-Western minorities and young people, to ensure more inclusive and effective communication.

RESOURCES AND WORKFORCE

The main actors currently providing general health literacy are::

- *Public Health Authorities,* including regional health departments, and the Danish Health Authority with also its National Public Health Board. For instance, The DHA incorporates academic research into national health promotion policies and recommendations in this area.
- *Medical schools* and the *Danish Medical Association* offer training programs for general practitioners (GPs) to enhance communication with cancer patients.
- *Hospitals and patient organizations* work together to form patient advisory boards, ensuring patient perspectives are considered in the development of educational materials and programs.
- *Academic institutions, universities* and *research* institutions
- *Municipal Health Services*
- *Danish Health Literacy Network* consisting of a variety of stakeholders, including health professionals, researchers, policymakers, and representatives from various organizations dedicated to improving health literacy in Denmark

Shifting focus to the field of oncology, improving cancer health literacy involves a range of initiatives led by individual stakeholders or through collaborative efforts. These initiatives form a supply chain where various actors work together to design and deliver effective cancer health literacy programs.

Several organizations and institutions contribute to these efforts:

- *The Danish Health Literacy Network* brings together professionals from policy, research, and practice to develop integrated health literacy strategies for cancer care and prevention.
- *The Danish Cancer Society (DCS)* plays a pivotal role by:
    - Commissioning and funding studies at *Aarhus University* to evaluate the effectiveness of educational programs for cancer patients.
    - Providing grants to support evidence collection for strategic planning.

    - Partnering with *regional health services* to jointly promote cancer-screening programs.
    - Offering educational materials, public awareness campaigns, and support services for *patients and families.*
    - Collaborating with healthcare professionals to improve communication and education.
- *Hospitals* and *their cancer treatment centres, GPs* and other healthcare providers

According to the DHA’s strategy of *organizational health literacy*, these collaborative interventions exemplify how all stakeholders—such as health authorities, patient associations, GPs, and hospital clinicians—contribute to enhancing cancer health literacy across care pathways.

1.3 EARLY DETECTION: SCREENING

The implementation of the cancer screening programmes for early detection has shown that in terms of invitations, the colorectal cancer-screening program had the highest number with 871,929 invitations, followed by breast cancer with 770,557, and cervical cancer with 366,947. However, participation rates varied significantly across programs. Breast cancer screening had the highest participation rate at 83.3%, while cervical and colorectal screenings were lower, at 61.6% and 61.0%, respectively. Among those who were advised to undergo further exams, 98% of breast cancer screening participants complied, compared to 90% in colorectal and 88% in cervical screenings. Timely response rates (i.e., results issued within 10 working days) were also high, particularly in colorectal screening (91.3%), followed by breast (86.6%) and cervical (83%) programs. Referral rates—the proportion of participants referred for further examination—were highest in the colorectal screening program at 8.2%, compared to 5.7% in cervical and 2.4% in breast cancer screening. When looking at screen-detected cancer rates (out of total invitations), colorectal cancer again reported the highest with 1.16%, followed by breast cancer at 0.6%, and cervical cancer at 0.07%.

For cancers detected at an early stage, cervical screening had the most favourable results with 74.4% of cases identified at stages Ia, Ib, IIa, and IIb. Colorectal cancer followed with 66.0% at stages I and II, and breast cancer with 56% of tumours measuring ≤20 mm. In terms of invasive cancers, breast cancer had the highest share at 44% (tumours >50 mm), while cervical cancer reported 24.8% at stages III and IV.

Table 6. Performance indicators of the 3 national population-based screening programmes: breast, cervical and colorectal cancer. Reference year: 2022

Indicators	Breast	Cervical	Colorectal
Invitations	770,557	366,947	871,929
Participation rate	**83.3%**	**61.6%**	**61.0%**
• Participation rate to further exams	98%	88%	90%
• Screening response issued in 10 working days	86.6%	83%	91,3%
Referral rate	**2.4%**	**5.7%**	**8.2%**
Screen-detected cancer out of invitations	0.6%	0.07%	1.16%
• Early-stage cancer	56% (tumor size ≤20 mm)	74.4% (stage Ia, Ib and Iia and IIb)	66.0% (stage I and II)
• Invasive cancer	44% (tumor size >50 mm)	24.8% (stage III and IV)	n.a,

* 130,000 HPV tests (35% of total invitations)

Source: Sundhedsstyrelsen, Statusrapport for de nationale screeningsprogrammer for kræft 2022, Sundhedsstyrelsen, 2022 .[The National Board of Health / Danish Health Authority, Status report for the national screening programs for cancer 2022a, The National Board of Health, 2022.] http://www.sst.dk/da/udgivelser/2022/Statusrapport-for-de-nationale-screeningsprogrammer-for-kraeft

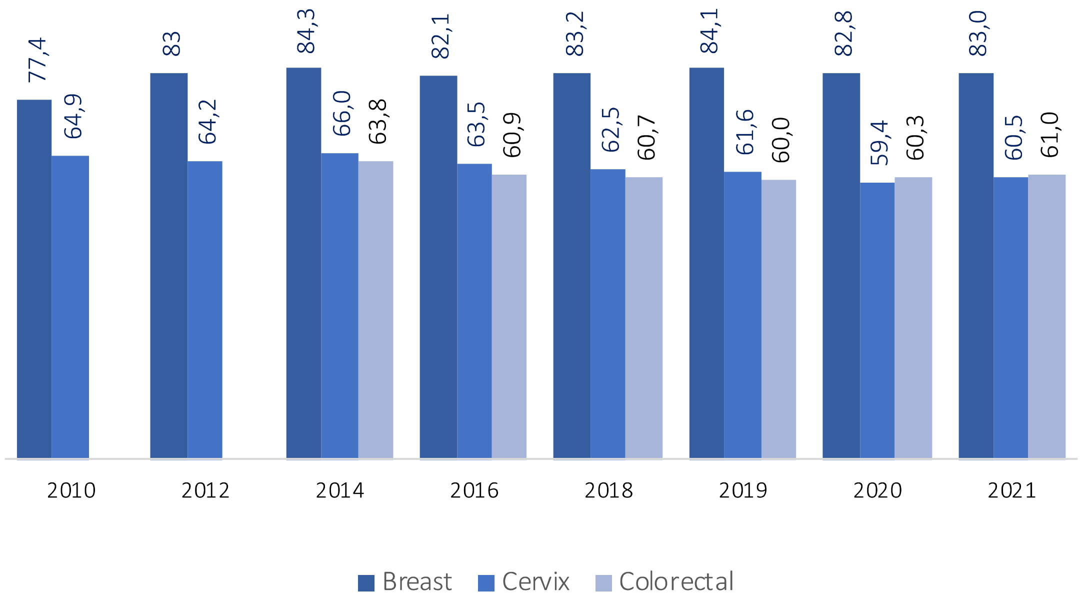
Looking at how effective screening programs are over time, the following figure presents the participation rates for breast, cervical, and colorectal cancer screening programs in Denmark from 2010 to 2021. Breast cancer screening consistently shows the highest participation, maintaining rates above 82% since 2014 and reaching 83.0% in 2021. Colorectal cancer screening has remained relatively stable around 60%, while cervical cancer screening shows a slight decline—from 64.9% in 2010 to 60.5% in 2021. According to the Danish Health Authority (DHA), Denmark's breast and colorectal screening programs perform above the EU27 average, while cervical cancer screening participation lags slightly behind (Sundhedsstyrelsen, Statusrapport for de nationale screeningsprogrammer for kræft 2022).

POLICY FRAMEWORK

The three national cancer-screening programs

Denmark's public healthcare system offers three national cancer-screening programs, all of which are free of charge for eligible citizens (Danish Health Authority 2014). These programs are legally mandated, regulated by the national government, and financed and managed by regional governments. Both access to the screenings and any required follow-up examinations are provided at no cost.

Figure 15. Participation rate of the three cancer screening programmes between 2010 and 2021



Source: OECD Data Explorer and RKKP, "Danish Quality Database for Mammography Screening, Annual Report 2021; Danish Quality Database for Cervical Cancer Screening, Annual Report 2022

The *national cervical cancer-screening* program was introduced in 1986 (Bigaard and Kvernrod 2020). It targets women aged 23 to 64 years, with screening intervals based on age:

- Every three years for women aged 23–49
- Every five years for women aged 60–64

For women aged 50–59, a randomized controlled trial is underway. This trial randomly assigns women, based on birth date, to receive screenings either every third or fifth year.

Implemented in 2007, the *breast cancer screening program* invites women aged 50 to 74 to undergo mammography every two years. Since 2015, women aged 70 to 79 with a previous diagnosis of breast cancer have also been offered follow-up screenings. To date, the program has completed seven screening rounds.

The *colorectal cancer screening program*, launched in 2014, targets both women and men aged 50 to 74 years. Screenings are conducted on a biennial basis (every two years). As of now, the program has completed four screening rounds.

In 2024, under the framework of the National Cancer Plan IV, Denmark launched a three-year pilot study focused on lung cancer screening. The pilot aims to assess feasibility, benefits, and potential for national implementation.

Planning and implementation strategy

The planning of cancer screening programs is a collaborative and systematic process led by the DHA involving the DMCGs and the Danish Regions. The features follow:

- The Cancer Plans, based on epidemiological and international data, guide the introduction of new screening programs.
- The DHA unit develops screening guidelines grounded in robust scientific evidence and monitoring results, reviewed by expert panels including DMCGs, scientific societies, and clinicians.
- The DHA, with DMCGs, issues recommendations and guidelines for screening, specifying target populations, methods, intervals, and follow-up procedures.
- The Regions and their hospitals handle implementation. Information systems manage the screening process, including invitation, tracking participation and results, and follow-up mechanisms.
- Quality assurance is managed at the regional level, with DHA and DMCGs evaluating and recommending program revisions.
- The Ministry of Finance defines in detail the funding allocations for the different health functions assigned to the Regions. This means that the Ministry determines the regional budget rate to be spent on cancer screening programs.

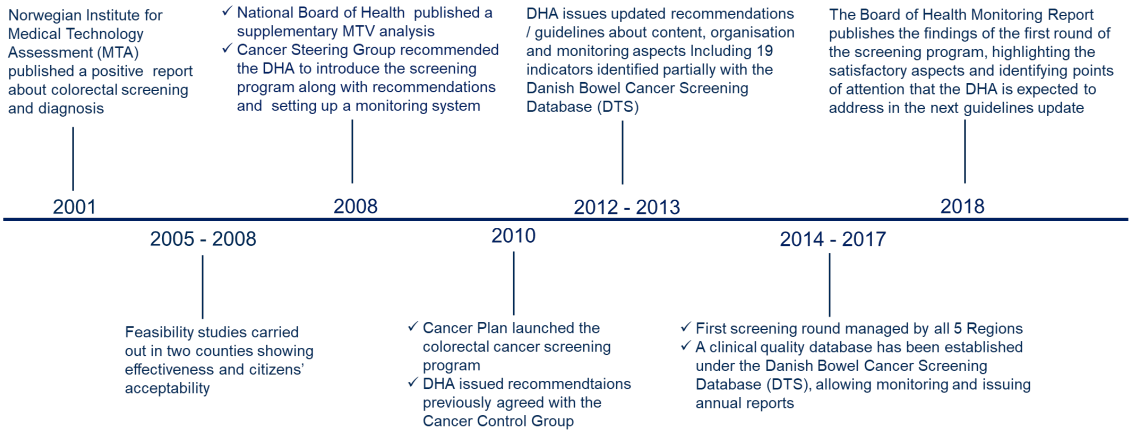
Figure 16 describes the phases of design, implementation and monitoring pathway put in place for the colorectal screening in Denmark from 2001 to 2018.

Next steps under consideration

The first Status Report by the Danish Health Authority (DHA, 2022) on cancer screening programs outlines key priorities and innovations for enhancing the effectiveness and equity of these initiatives. A central focus is placed on improving interventions targeted at specific population groups, including citizens with low levels of education, recent immigrants from non-Western countries, and younger individuals. The report notes that general practitioners, municipalities, and NGOs have traditionally concentrated efforts on older populations, resulting in lower engagement among youth, who are less likely to accept vaccinations or participate in diagnostic examinations.

In addition, the report emphasizes the importance of addressing regional variability by tailoring interventions to meet local needs. It also highlights the need for stronger coordination and integration between hospitals, which manage screening programs, and municipalities, which oversee community-level prevention efforts. This coordination is to be facilitated through the development of health clusters, as discussed in the background analysis.

Figure 16. From planning to implementing a cancer screening program: the case of colorectal cancer screening programme



Norwegian Institute for Medical Technology Assessment (MTA) published a positive report about colorectal screening and diagnosis

Feasibility studies carried out in two counties showing effectiveness and citizens' acceptability

- ✓ National Board of Health published a supplementary MTV analysis
- ✓ Cancer Steering Group recommended the DHA to introduce the screening program along with recommendations and setting up a monitoring system

- ✓ Cancer Plan launched the colorectal cancer screening program
- ✓ DHA issued recommendtaions previously agreed with the Cancer Control Group

DHA issues updated recommendations / guidelines about content, organisation and monitoring aspects Including 19 indicators identified partially with the Danish Bowel Cancer Screening Database (DTS)

- ✓ First screening round managed by all 5 Regions
- ✓ A clinical quality database has been established under the Danish Bowel Cancer Screening Database (DTS), allowing monitoring and issuing annual reports

The Board of Health Monitoring Report publishes the findings of the first round of the screening program, highlighting the satisfactory aspects and identifying points of attention that the DHA is expected to address in the next guidelines update

The report also references a series of innovations that should inform the design of future cancer screening programs. Recent Danish scientific studies provide emerging evidence to support these innovations. For example, Loft et al. (2024) recommend adjusting screening frequency based on individual risk profiles, particularly among women. Christiansen et al. (2022) highlight a decline in the effectiveness of breast cancer screening over time, citing that the Number Needed to Invite

(NNI) to prevent one breast cancer death has increased from 731 women in 1996 to 1,364 women in 2016. Moreover, the number of women over diagnosed per death prevented rose from 3.2 to 5.4 over the same period, signalling a need for more refined screening strategies. Technological advancements, such as the use of artificial intelligence in mammography, are also being explored. Lauritzen et al. (2023) report promising results from a trial conducted at Gentofte Hospital in Copenhagen, suggesting that AI could enhance diagnostic accuracy.

Together, these findings and recommendations provide a roadmap for evolving cancer screening efforts in Denmark, with a focus on equity, evidence-based personalization, and the integration of emerging technologies.

Actors and their roles

The two main actors that play a governance role in the field of cancer screening are the Danish Health Authority (DHA) and the National Steering Groups for Cancer Screening (NSGCS), respectively.

In particular, the DHA plays a central role in ensuring the uniform, systematic, and regular follow-up of cancer screening programs at the governance level. Its responsibilities include the development of professional recommendations and informational materials to support the implementation of screening initiatives. The DHA is also tasked with the overall quality assurance of these programs, ensuring that they meet national standards and deliver consistent results. Furthermore, the authority is responsible for evaluating the content and effectiveness of the screening programs, using data and feedback to assess outcomes. Lastly, it gathers and promotes improvement initiatives aimed at enhancing the design, delivery, and impact of cancer screening across the country.

The NSGCS are responsible for managing and coordinating Denmark's cancer screening programs, ensuring their effective implementation and ongoing quality assurance. Each screening program is overseen by a dedicated steering group specific to the type of cancer: the NSBS for breast cancer, the NSLS for cervical cancer, and the NSTS for colorectal cancer. These groups play a crucial role in maintaining high standards of care, driving continuous improvement in screening processes, and promoting equitable access to services. Through their work, the NSGCS contribute significantly to enhancing early detection and improving treatment outcomes for cancer patients across Denmark.

- The management and implementation of cancer screenings are primarily the responsibility of hospitals. In particular, hospitals manage the cancer screening programs through:
- The screening secretariat oversees administrative tasks coordinating the entire process from sending invitations to managing follow-up procedures
- The departments involved in providing screening (e.g. diagnostic, pathology). In the rural area, a network of 21 small hospitals supplies mammograms; however, possible follow-ups are managed by large and centralized hospitals
- Primary care units are often the first point of contact for patients and play a role in referring individuals to screening programs
- The public health departments overseeing the public health aspects of screening programs (e.g. outreach education programs, monitoring participation rates and analysing data from screening programs to assess their effectiveness and identifying areas for improvement)
- The Patient Support Services supply psychological support and counselling, and they help patients navigate the healthcare system.
- The IT and Data Management Units collects data on screening programs
- The Research Units conduct research on cancer screening methods, effectiveness, and outcomes to continuously improve the programs

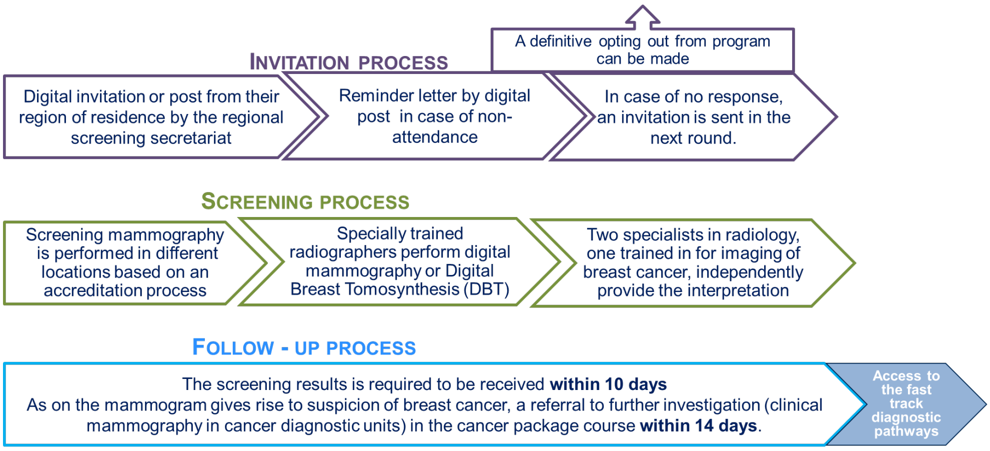
Moreover, Municipalities play a vital role in ensuring that cancer screenings are accessible to all individuals, particularly those facing barriers to care. Their responsibilities include facilitating appointments and follow-up care for individuals who require further examination or treatment after initial screenings. They also contribute by providing suitable venues for screening services and organizing transportation to ensure that logistical challenges do not hinder access. Additionally, municipalities offer home visits and follow-up care when needed, especially for vulnerable populations who may struggle to access traditional healthcare facilities. These efforts collectively help reduce disparities and promote equitable access to early cancer detection services.

General Practitioners (GPs), for their part, play a key role in the cancer screening process, fulfilling a variety of important functions. They are responsible for referring patients to appropriate screening programs and directly providing cervical cancer screening in primary care settings. GPs also help facilitate access to hospital-based screenings when needed. In cases where screening results are abnormal, they conduct initial assessments and follow-up consultations, offering guidance and coordinating further diagnostic steps. Additionally, GPs are tasked with maintaining comprehensive records of their patients' screening histories and outcomes, ensuring continuity of care and supporting informed clinical decision-making.

Finally, The Danish Cancer Society (DCS) plays a key role in advancing cancer screening efforts through its active involvement in public awareness campaigns, research, and support services. It provides counselling and assistance to individuals with positive screening results, helping them navigate next steps with clarity and support. DCS also works in close collaboration with healthcare providers to ensure the effective and smooth implementation of screening programs nationwide. A significant part of its mission involves community engagement, promoting participation in screening programs and specifically targeting populations with lower participation rates. Additionally, DCS supports healthcare professionals by offering training and educational resources to maintain high standards of practice in cancer screening.

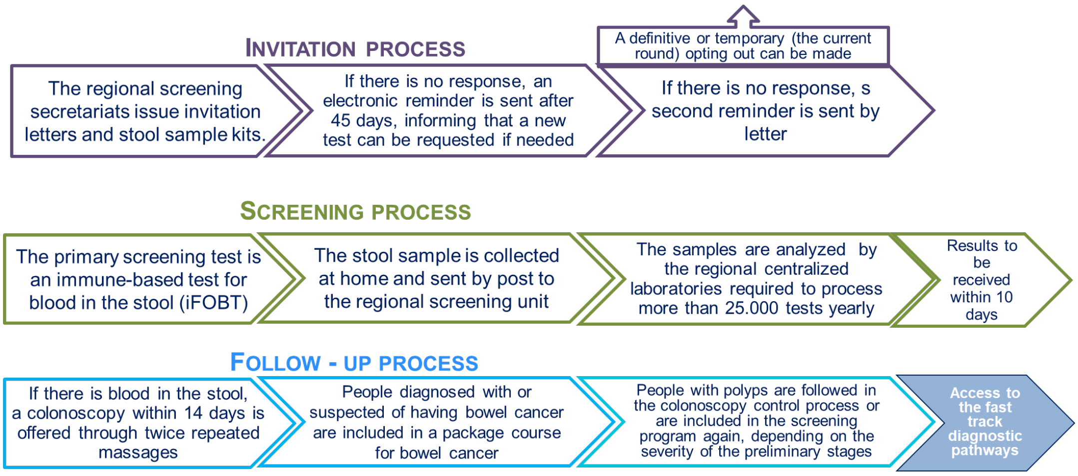
The process of conducting the three screening programs is described phase by phase in the following Figure 17, Figure 18 and Figure 19.

Figure 17. Organisation: service provision - breast cancer screening



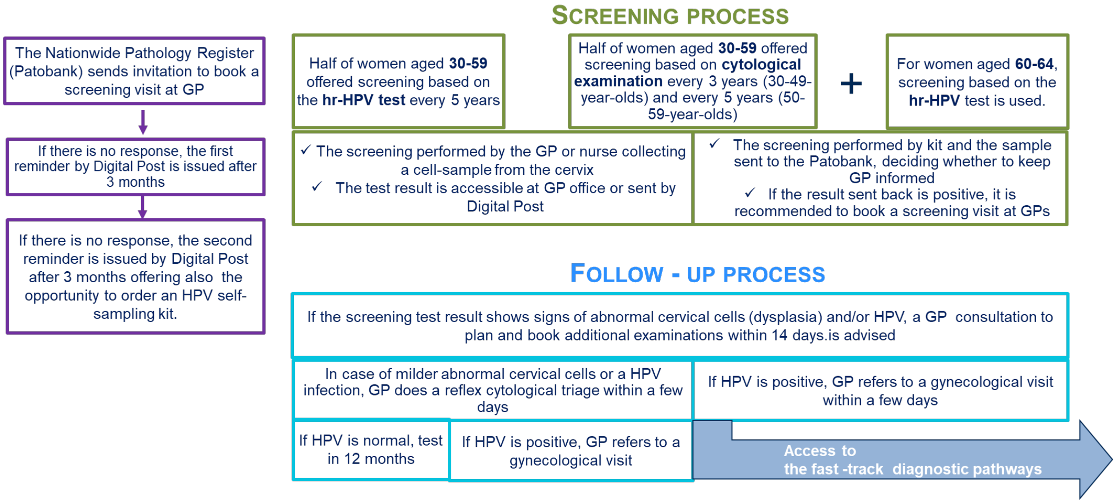
Source: https://www.sundhed.rm.dk/sundhedstilbud/kraftscreening/

Figure 18. Organisation: services provision - colorectal cancer screening



Source: https://www.sundhed.rm.dk/sundhedstilbud/kraftscreening/

Figure 19. Organisation: service provision - cervix cancer screening



Source Jørgensen et al. 2022

RESOURCES AND WORKFORCE

Operational Challenges and Innovations in Cancer Screening Programs

The breast cancer screening program in Denmark is currently facing a shortage of mammary radiologists, radiographers, and pathologists, particularly in hospitals located outside major urban areas. To address these challenges, a Danish Health Authority (DHA) report from 2022 recommends two key strategies, Firstly, a revision of the breast screening frequency based on individual risk profiles, potentially determined through genetic testing and the use of artificial intelligence (AI). This approach is currently being explored by a joint Dutch-Danish research group (Lauritzen et al., 2023). Therefore, a test of AI as a substitute for the second independent reading of mammogram images, leveraging promising trials already underway in the USA and EU.

The cervical cancer screening program is experiencing a shortage of colonoscopy exams, creating bottlenecks in diagnosis and follow-up care. In response, the DHA has implemented several strategies to improve efficiency and accessibility such as enhancing the capacity of existing facilities to manage increased demand; streamlining processes to reduce waiting times and improve appointment scheduling; exploring alternative screening methods to ease pressure on traditional colonoscopy services, including faecal immunochemical tests (FIT) and virtual colonoscopies.

Another cross-cutting issue affecting screening programs is the shortage of laboratory personnel, leading to delays in processing test results. As a solution, Denmark has centralized test analysis by concentrating these processes in three core laboratories, aiming to optimize efficiency and reduce turnaround times.

MONITORING

According to the National Board of Health, a fundamental requirement for implementing a population-based screening program is the establishment of a monitoring and quality assurance system. This system must include process and output indicators to assess performance and outcomes. This conviction has led Denmark to significantly develop a monitoring system based on two key components: an institutional monitoring system and a non-institutional monitoring system composed of independent bodies that act as external watchdogs.

The *institutional monitoring system* rely on two main tools:

- The *Quality Databases for Denmark's cancer screening programs*—DKMS (breast cancer), DTS (cervical cancer), and DKLS (colorectal cancer)—play a central role in monitoring performance and outcomes. These databases publish reports annually, or based on individual screening rounds, covering both screening activities and diagnostic follow-ups. Each report includes a comprehensive set of indicators aligned with the EU Quality

Assurance Guidelines, such as participation rates, detection rates, interval cancer rates, and follow-up rates. The data presented typically cover the current screening round along with the two previous rounds, allowing for trend analysis over time. Additionally, each report provides a detailed presentation and discussion of the results, followed by recommendations tailored to each indicator table to guide improvements in practice and policy.

- A biennial (two-year) report – that the Danish Health Authority (DHA) has recently decided to introduce - to ensure the uniform, systematic, and regular follow-up of national cancer screening programs. This initiative is designed to strengthen oversight and foster continuous improvement across the system. The report serves three primary objectives:
    - to evaluate the content and overall impact of the screening programs;
    - to provide a foundation for informed discussions with regional authorities, policymakers, and healthcare professionals regarding the potential need for specific actions or adjustments;
    - to present new insights and support professional development related to the ongoing delivery of screening services in Denmark.

Moreover, this monitoring system’s mission is to alert clinicians involved in cancer screening programs about non-compliance with guidelines. For example, it sends reminders to doctors about follow-up for cervical cancer screening if a patient has not been followed up as recommended, ensuring doctors remain responsible for proper follow-up even if patients are directly informed.

In Denmark, several independent entities contribute to the external monitoring and evaluation of national cancer screening programs. The Danish Cancer Society (DCS) plays a key role by publishing annual reports that assess the effectiveness, participation rates, and outcomes of these programs. Additionally, various independent research institutions and academic centres release spot reports and scientific publications analysing both the processes and impacts of screening initiatives. Oversight is further reinforced by the National Audit Office, which acts on behalf of the Danish Parliament to ensure government accountability. This includes monitoring the activities of the Danish Health Authority (DHA), which operates as an authority under the Ministry of Health.

1.4 EARLY DIAGNOSIS

In response to growing public concern over delays in early cancer diagnosis, particularly due to long waiting lists for diagnostic exams, Denmark began making significant investments in 2001 to better organize and standardize the pathway from symptom perception or risk detection (e.g., screening) to treatment access. This reform aimed to streamline the patient journey and improve timely intervention. Although no formal monitoring system has yet been established to track the performance or outcomes of this pathway, a study conducted by Danckert et al. (2021) analysed 144,635 cancer cases diagnosed in 139,023 patients between 2014 and 2017, identifying the most common routes through which patients were diagnosed:

- 45.9% followed a cancer patient pathway from primary care
- 20.0% entered via secondary care
- 15.8% were diagnosed following an unplanned hospital admission
- 7.5% were diagnosed through population-based screening

POLICY FRAMEWORK

Addressing Diagnostic Delays through Cancer Care Pathways in Denmark

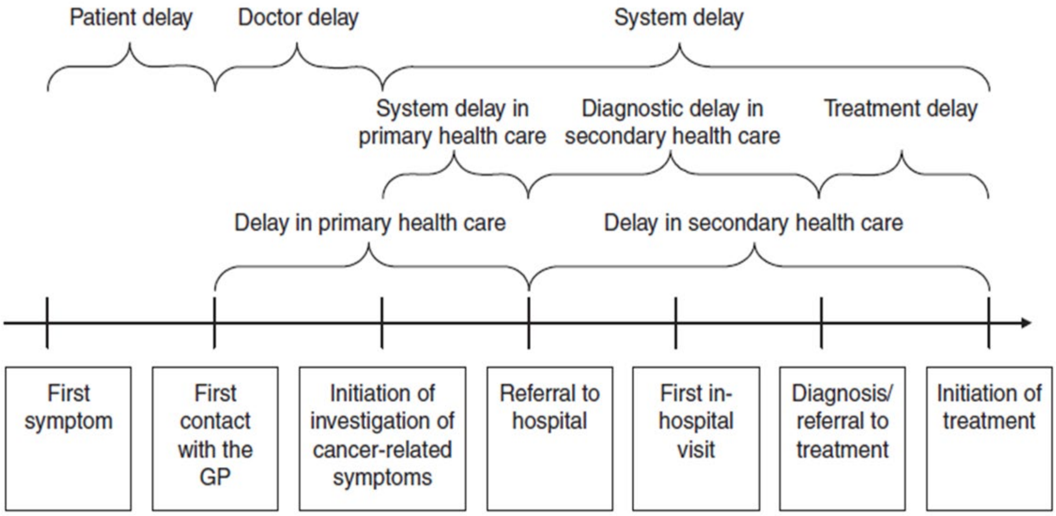
To reduce long waiting times for diagnostic exams and prevent patients from becoming "lost" in the healthcare system while seeking a definitive cancer diagnosis, Denmark has implemented a series of strategic reforms through successive Cancer Plans, resulting in the development of Cancer Care Pathways (CCPs).

The first step came with Cancer Plan I (2001), which introduced timing constraints for diagnostic procedures following a suspicion of cancer, whether based on symptoms or screening results. However, this guarantee did not apply to the waiting times for diagnostic tests such as X-rays ordered by general practitioners (GPs) or for specialist referrals made outside the hospital system. As a result, several unintended consequences emerged. First, a system of double gatekeeping was created, whereby GPs were required to refer patients to specialists, who then had to approve any further investigations—significantly increasing delays. Second, there were delays in GP-requested hospital investigations, as the system prioritized specialist referrals over direct investigation requests from GPs. Finally, hospital-related delays increased, particularly in the period between the first diagnostic test and the final diagnosis, due to the absence of guaranteed timelines from initial referral to treatment initiation.

Therefore, under pressure from the Danish Cancer Society and the Danish Multidisciplinary Cancer Groups (DMCGs), Cancer Plan II (2005) and its 2007 updates mandated the formal establishment of Cancer Care Pathways to be used in cases of suspected organ-specific cancers, based on referrals from general practitioners (GPs), specialists, or screening results (Høeg-Jensen & Worsøe Laursen, 2020). Figure 20, provided by the Danish Cancer Society, presents the categorization of delays supplied, making it clear to patients and citizens that 'cancer should be seen as an acute disease'. This awareness campaign shared by professionals led to the setting up of the patient cancer pathways.

A total of 32 CCPs were developed using a combined bottom-up and top-down approach, involving clinicians, administrative staff, patient organizations, and policymakers. This was supported by significant public investment, led by the Ministry of Finance, in radiology equipment and the centralization of diagnostic centres (Probst et al., 2012). Research by Jensen et al. (2014; 2015) demonstrated that these strategies were effective in significantly shortening the diagnostic interval, i.e., the time between the onset of symptoms or suspicion and the completion of diagnosis.

Figure 20. Categorisation of delays



Source: Olsen et al. 2009. Fig. 1, Categorisation of delay., p. 56

Recognizing that not all patients present with clear, organ-specific symptoms, Cancer Plan III (2010) introduced the NSSC-CPP—the Cancer Patient Pathway for Non-Specific Signs and Symptoms—to ensure timely referral and investigation for those with vague or unexplained health issues (Moseholm et al., 2017). Similar approaches have been adopted in Norway, the UK, and Spain.

This initiative was further reinforced by the Danish government's 2014 strategy, "The Sooner – The Better", which led to a 2015 agreement between the Regions and the Government. The agreement granted GPs extended access to refer patients directly to hospital examinations, without unnecessary administrative hurdles.

All these developments were underpinned by continued investment in dedicated diagnostic centres and units, both for organ-specific cases and for patients presenting with non-specific signs and symptoms, solidifying Denmark's commitment to early and equitable cancer diagnosis.

ORGANISATION: OPERATIONAL ACTORS AND SERVICE PROVISION

Operational actors

The key actors involved in the management of the early diagnosis implemented through the cancer care pathways are:

- *Diagnostic unit or centres* are small organizational hospital unit whose task is to coordinate the investigation process in the cancer care pathways. In 2018, 20 investigation units were established in the five regions with the following features:
    - The Multidisciplinary Team (MDT): reviews the initial diagnostic findings. This team may include oncologists, radiologists, pathologists, and other specialists as needed and they decide next steps (e.g. more specialized tests or referral to specific cancer treatment pathways if a malignancy is strongly suspected).
    - The units differ in key organizational characteristics, such as which specialty the units belong to, tasks and goals. There is thus a difference between where the investigation unit is organizationally located in the hospital and the competencies in the unit, including the specialist medical training the doctors responsible for treatment have.

    - There is also a difference in the purpose of the investigation, i.e. when an investigation process is considered completed. In some investigation units the goal is to confirm or deny whether the patient has cancer, while in other units the goal is to make a final diagnosis. The differences are seen both between the regions, but also within the regions.
- *GPs* represent a key stone in the whole diagnostic process as they are trained for acknowledge specific alarm symptoms, but also to investigate in case of non-specific symptoms or signs.
- *Task Force for Cancer Treatment* has the goal of facilitating coordination between different healthcare providers, including hospitals, general practitioners, and specialized cancer treatment centres, to ensure seamless patient care.
- *Danish Cancer Society* is monitoring the implementation and the quality level of the diagnostic processes. The DCS oversees the publication a three-month report about the timing compliance of diagnostic centres.

Resources

As far as equipment for breast cancer screening, Denmark ranks second in the EU for the number of radiation equipment per capita. This ranking is the result of significant investments planned and implemented by the Ministry of Finance, starting from the three-year period between 2007 and 2010 (Cancer Plan II and Additional Plan), amounting to approximately 21 million USD. Specifically, this investment was part of a broader initiative to enhance screening infrastructure, improve early detection rates, upgrade equipment, and ensure comprehensive coverage and quality of breast cancer screening services across the country. This process required time and the resolution of disagreements among clinicians and public providers; however, a determined stance taken by the Ministry of Finance over several years, DHA and a cross-regional working group established by the circle of health directors in the Danish Regions ultimately led to success. A crucial solution was to plan the equipment distribution according to the activity volumes planned instead of the expected capacity (Cancer Plan II Annex 6.2)

In the case of colorectal cancer screening, investments are being made in new and advanced colonoscopy equipment and updating current equipment to increase the number of screenings that can be performed.

Finally, these initiatives are part of a broader strategy to ensure timely and effective screening for colorectal cancer, aiming to reduce waiting times and improve early detection rates. Additionally, the DHA is considering the use of alternative screening methods, such as faecal immunochemical tests (FIT) and virtual colonoscopies, to alleviate the demand on traditional colonoscopy services.

Service provision

The service provision of early diagnosis in cancer care is managed through Cancer Patient Pathways (CPPs), specifically designed to cover the patient journey from the onset of suspicious cancer symptoms to the initiation of treatment. These pathways were developed and implemented between 2007 and 2010, aiming to structure and streamline patient care.

Cancer Patient Pathways differentiate between three types of initial symptom presentations managed by general practitioners:

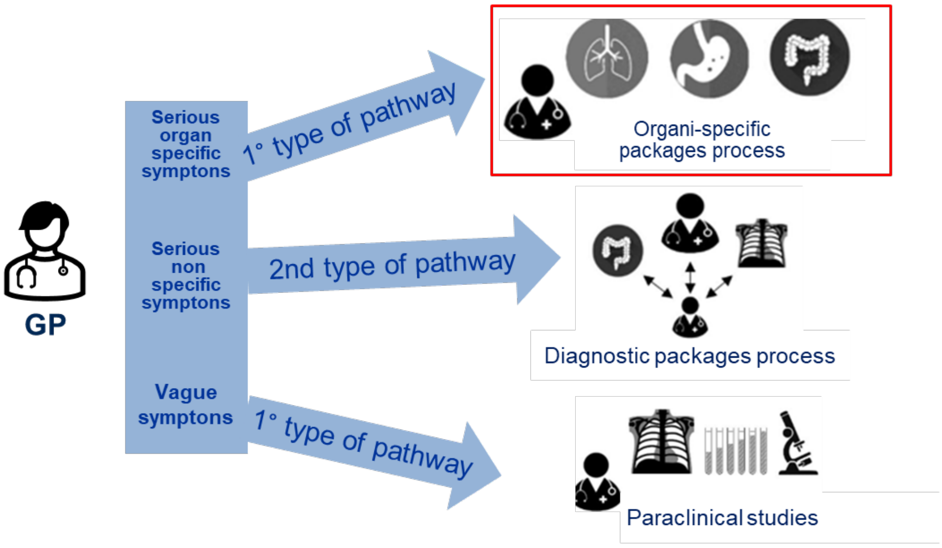
1. Serious organ-specific symptoms, which lead directly to organ-specific diagnostic package processes.
2. Serious non-specific symptoms, resulting in diagnostic package processes involving multiple diagnostic evaluations.
3. Vague symptoms, triggering initial paraclinical studies to further investigate and determine subsequent care pathways.

These structured pathways ensure effective management by defining clear stages—from the initial referral based on reasonable suspicion, through the patient’s first visit to an investigative department, until the conclusion of investigations or the offering of treatment options, and finally from the treatment proposal to the initiation of the actual treatment. Additionally, the pathways clearly outline necessary resources, including required equipment and professional roles, assign a coordinator responsible for monitoring patient progress, and specify exactly what information is communicated to patients, as well as the timing, to enhance patient engagement and understanding. A detailed description of each type of cancer care pathway follows.

32 Pathways for patients with cancer organ suspicious acknowledged through screening, GPs or specialists’ visits defined and implemented between 2007 and 2010 (see Figure 21). These pathways outline three distinct stages: first, from the moment a patient receives a referral due to reasonable suspicion of cancer to their initial appointment at the investigative department;

second, from this initial appointment to the completion of investigations or the offer of treatment; and finally, from the treatment offer until the commencement of initial treatment. Additionally, the pathways specify essential resources required, including equipment and necessary professional roles, designate a coordinator responsible for overseeing patient progression, and clearly define both the content of information to be shared with the patient and the appropriate timing for sharing it.

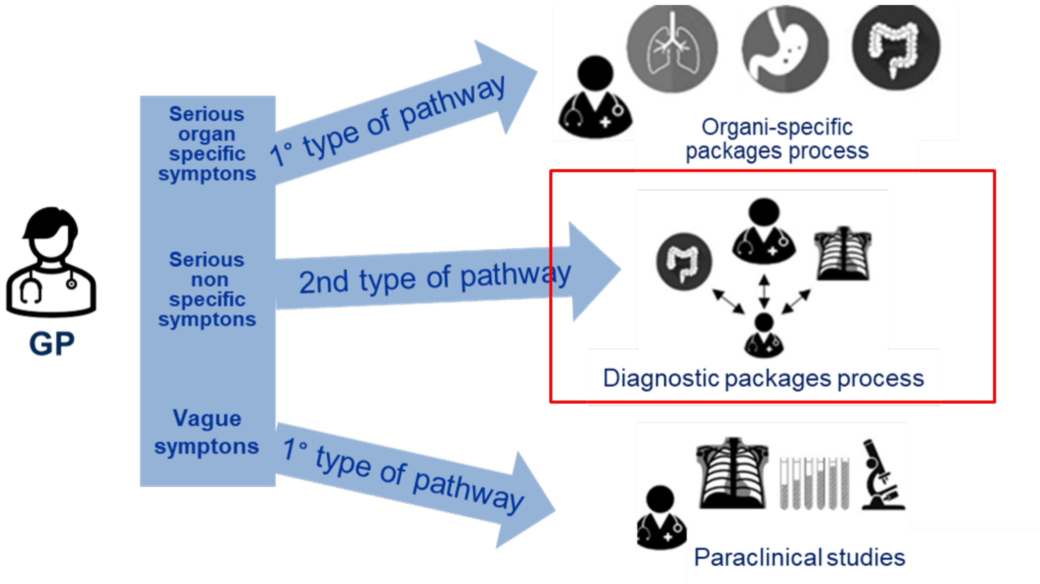
Figure 21. Cancer Patient Pathways) in case of serious organ specific symptoms



Source: The National Analysis and Research Institute for Municipalities and Regions [The National Analysis and Research Institute for Municipalities and Regions], Erfaringer Med Kraeftpakker [Experiences with cancer packages. From intentions to implementation in practice. August 2012. Auge et al. 2018. Høeg-Jensen and Worsøe Laursen. 2020.

The second type of **pathway for patients with serious non-specific symptoms** can start from the GP (see Figure 22), still representing a key stone of the cancer diagnostic process or accessing directly to the fast-track pathway in hospital (Damhus et al. 2023). So far, 10% of patients accessing this pathway has a definitive diagnosis of cancer (Danish Cancer Society, 2020). Moreover, an observational study tracked that there is no difference of diagnosis stage between patients accessed through GPs and those accessed directly to hospitals. This shows that this pathway is effective.

Figure 22. Cancer Patient Pathways in case of serious non- specific organ symptoms

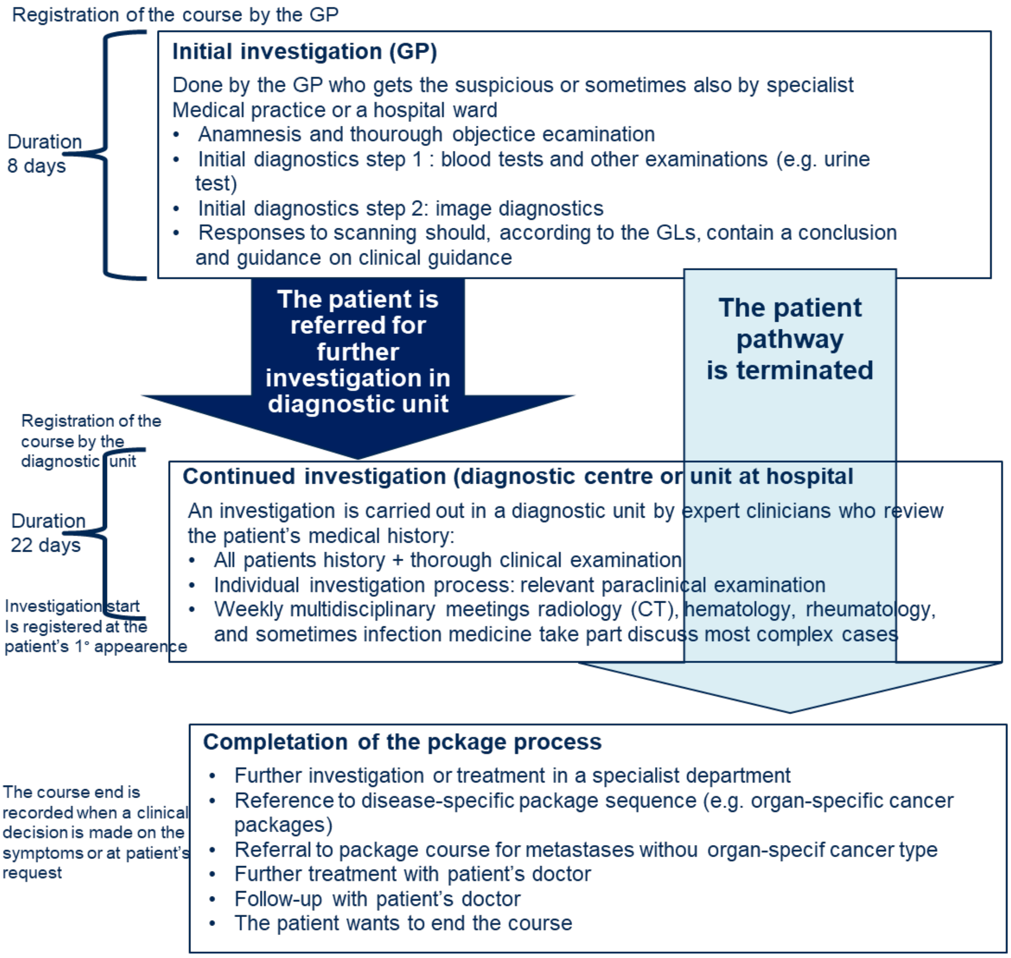


Source: Damhus et al 2022.

Figure 23 provides more detailed insights into the steps and the timing of this pathway. The VIVA Report (Auge et al., 2018) outlines several recommendations to improve the complex and often challenging cancer care pathway. One key area of focus is overview and communication, emphasizing the need to map out both local and regional diagnostic options available to patients presenting with symptoms of cancer or serious illness. This information should be systematically disseminated to ensure consistency and accessibility across the healthcare system.

Another crucial aspect is responsibility and cooperation. The report highlights the importance of clearly defining roles and responsibilities among general practitioners (GPs), imaging departments, and investigation units.

Figure 23. Steps of the cancer Patient Pathways in case of serious non- specific organ symptoms



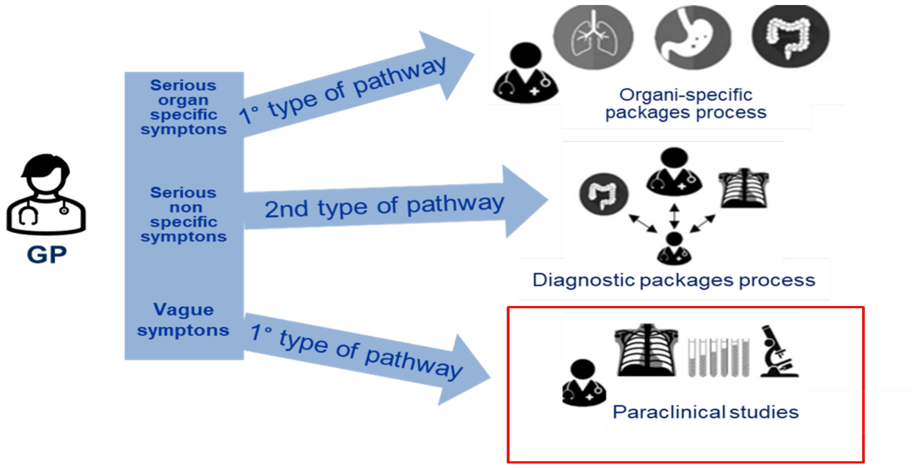
Source: Our translation of Figure 3.5 Diagnostic package sequence for patients with non-specific symptoms of serious illness that could be cancer (MAS). Auge et al. 2018. Høeg-Jensen and Worsøe Laursen. 2020.

Strengthening collaboration between GPs and radiology departments is essential to improve access to diagnostic imaging and ensure smoother patient pathways. Additionally, the report draws attention to the utilization of CT scans. It calls for a deeper understanding of the implications associated with different methods of using and regulating access to CT scans. This knowledge should inform national strategies and decisions regarding their role in cancer investigations, particularly in cases that fall outside standardized diagnostic procedures led by GPs.

Finally, The Government and Regions agreement planned to provide GPs with the following support to improve their capacity and the opportunity to investigate possible **cancer cases in patients with vague symptoms** (see Figure 24):

- extended access to refer patients directly to examinations at the hospital
- Initiation of a broad educational effort with the aim of strengthening general practice's professional skills and organizational knowledge of early detection of cancer
- strengthened telephone advice for general practice from hospital doctors
- expansion of hospitals' capacity to carry out investigations (e.g. scans).

Figure 24. Steps of the cancer Patient Pathways in case of serious non- specific organ symptoms



Source: The National Analysis and Research Institute for Municipalities and Regions [The National Analysis and Research Institute for Municipalities and Regions], Erfaringer Med Kraeftpakker [Experiences with cancer packages. From intentions to implementation in practice. August 2012. Auge et al. 2018. Høeg-Jensen and Worsøe Laursen. 2020.

MONITORING

The DHA is responsible for overseeing the implementation and monitoring of Cancer Patient Pathways (CPPs) and has established a comprehensive set of national indicators for this purpose. These indicators cover several crucial aspects of cancer care management, including:

- Timeliness indicators, which measure critical time intervals such as the Referral to Diagnosis Time (from initial GP referral to confirmed cancer diagnosis), the Diagnosis to Treatment Time (from confirmed diagnosis to treatment initiation), and the Overall Pathway Time (total duration from referral to completion of initial treatment).

- Process indicators focus on compliance with CPP guidelines, evaluating adherence to standardized diagnostic and treatment procedures, and the effectiveness of Multidisciplinary Team (MDT) meetings by tracking their frequency and quality.
- Quality of care indicators assess patient satisfaction through regular surveys and feedback, monitor adherence to prescribed follow-up protocols, and measure complication rates to evaluate the incidence of adverse events related to cancer treatments.
- Resource utilization indicators monitor the usage and appropriateness of diagnostic imaging procedures such as CT scans, MRIs, and PET scans, and track the availability and workload of healthcare professionals involved in cancer care.
- Equity indicators address disparities by measuring access to cancer care across various regions and demographic groups and assessing variability in treatment approaches and outcomes between different hospitals or regions.

According to independent research (Auge et al. 2018 and Høeg-Jensen and Worsøe Laursen 2020) and the interview done to Dr. Vejborg (May 2024), the organ-specific pathways are monitored effectively through the previous set of indicators, while the serious non-specific symptoms pathways still miss a proper monitoring system as it is difficult to identify a proper set of indicators and timing. However, this challenge required to be addressed.

1.5 EARLY TREATMENT

Denmark has implemented a comprehensive set of interventions aimed at improving early cancer treatment, leading the country to outperform the European average in most performance indicators. According to the 2023 OECD Policy Survey on Cancer Care Performance, Denmark ranks second in Europe for the number of radiotherapy machines per one million inhabitants. However, this advantage is partially offset by a shortage of radiotherapists.

Several distinctive features characterize the Danish healthcare system in the field of oncology:

- *Centralisation of cancer care:* Providers delivering cancer services have undergone a concentration process, with volume norms imposed to ensure quality and efficiency.
- *Light cancer care network*: A flexible national framework, such as the Danish Comprehensive Cancer Centre (DCCC), supports binding collaboration in cancer research and treatment.
- *Multidisciplinary teams*: These are widely used across the country for both diagnosis and treatment, ensuring comprehensive and coordinated care.
- *Accreditation*: An accreditation system is in place for cancer care services. Some centres have also received recognition from major European scientific societies, such as ESMO and ESGO.
- *Clinical guidelines and monitoring:* Clinical guidelines (GLs) are systematically developed and applied across all stages of the cancer care pathway. Denmark has also implemented an effective monitoring system that includes treatment processes.
- *Waiting time guarantees*: Maximum waiting time targets of 14 days have been established for key stages: (i) diagnostic examinations, (ii) surgery, and (iii) medical and radiotherapy treatments.

These measures have significantly contributed to timely cancer care delivery. For example, in breast, cervical, and colorectal cancers, the early treatment rate has been notably high. In breast cancer specifically, an estimated 78% of patients received early treatment between 2012 and 2017. However, this rate dropped to 69% in 2021, likely due to disruptions caused by the COVID-19 pandemic.

Cancer Drug Provision

Denmark also performs well in cancer drug access. Over 70% of new breast and lung cancer drugs are reimbursed and provided free of charge. Prior to 2017, drugs were automatically reimbursed upon market entry, with individual hospitals setting prices through a national procurement body. This changed with the establishment of the Danish Medicines Council in 2017, which centralized pricing negotiations and made decisions on which drugs are eligible for standard reimbursement.

Nevertheless, the reimbursement process has become more complex. A recent study (Samola et al., 2023) analysing 67 cancer drugs found that the average time from market authorization to reimbursement approval is 895 days.

POLICY FRAMEWORK

There is a general perception that policymakers in Denmark have placed greater emphasis on early detection and diagnosis than on early treatment, which has largely been managed by clinicians. To date, national Cancer Plans have addressed early treatment in only a limited way. However, recent insights suggest that this may change with the upcoming Cancer Plan V - still under discussion at the time this report was being written - which is anticipated to address early treatment more comprehensively.

In terms of clinical guidance, specific cancer treatment protocols in Denmark are primarily developed by the Danish Multidisciplinary Cancer Groups (DMCGs). While the Danish Health Authority is responsible for overarching healthcare policy and for issuing guidelines related to early detection and diagnosis, the DMCGs focus specifically on creating and updating treatment guidelines.

According to the DMCGs' websites, updates or new guidelines are typically issued in response to changes in international clinical guidelines, evidence-based modifications derived from national database analyses, and the introduction of new treatment options.

RESOURCES AND WORKFORCE

According to the Danish Health Authority (DHA), five hospitals in Denmark are equipped with advanced diagnostic technologies, treatment facilities, and multidisciplinary teams specifically dedicated to the early detection, diagnosis, and treatment of cancer. Two of these hospitals are in the Capital Region, another two in the Southern Region, and one in the Central Region. In these hospitals multidisciplinary teams — already widely employed during the diagnostic phase — continue to play a key role. In Denmark, the concept of the multidisciplinary team is focused not only on professionals, but also on patients: this means that clinical choices are never made by a single professional but are instead the result of collaborative decision-making. In line with this, current guidelines emphasize the importance of ensuring shared and informed decision-making with patients at the beginning of the treatment pathway. Clinicians are also expected to consider patients' individual needs and organize treatment plans accordingly.

Moreover, the DHA, in collaboration with the Danish Multidisciplinary Cancer Groups (DMCGs), is responsible for defining standards and timelines for early treatment steps through the issuance and regular updating of clinical guidelines. These guidelines are also used to support the introduction of innovative treatments.

Early-stage procedures

In the context of early-stage breast cancer, an observational study analysing data from 2012 to 2017 in Denmark and the Netherlands compared the implementation of various treatment options. The study highlighted the impact of updated guidelines and monitoring systems, as well as significant variations between and within the two countries (Heeg et al., 2020). In Denmark, for example, only 4% of breast contour preservation surgeries—the most performed type—were carried out in low-volume hospitals, supporting the Danish Health Authority's emphasis on centralising this type of intervention. Additionally, breast-conserving surgery followed by neoadjuvant chemotherapy (NAC) was less frequently applied in Denmark during the study period, as the relevant guidelines were updated in 2016, compared to 2012 in the Netherlands.

Regarding early-stage cervical cancer, the surgical approach has been a subject of debate in recent years. Since 2012, all Danish centres have implemented robot-assisted laparoscopic radical hysterectomy and pelvic lymph node removal for patients with early cervical cancer. However, a 2018 study (Jensen et al., 2018) reported reduced survival rates with minimally invasive surgery, prompting a nationwide review of recurrence and survival outcomes. The Danish data showed no excess mortality among patients treated with robot-assisted surgery. Based on discussions within the Danish Gynaecological Cancer Group (DGCG) and the Cervix Cancer Group, it was concluded that this approach could safely continue for Danish patients (Jensen et al., 2020).

In early-stage colorectal cancer, local excision (LE) has become an increasingly prominent treatment method. Initially used in more than two-thirds of cases, LE was employed in over three-quarters of patients by the final year of inclusion in a recent observational study (Ebbehøj et al., 2024). Despite its widespread adoption, Smith et al. (2024), analysing data from the DCCG database, argue that existing guidelines for stage 1 treatment may require revision.

Access and Reimbursement of Medicines in Denmark

In Denmark, medicines are primarily distributed through publicly funded hospitals, with procurement centrally managed by Amgros, a public company responsible for sourcing pharmaceuticals for the hospital sector. Since 2017, the Danish Medicines Council has assumed a central role in the healthcare system, particularly in the negotiation of pricing for new cancer medicines, ensuring both cost-effectiveness and timely access for patients.

A major shift in the reimbursement model accompanied the creation of the Council. Instead of relying on national health fund reimbursements, the Council now evaluates and approves medicines as standard treatments before they are introduced into hospital practice. Prior to this reform, most medicines were automatically reimbursed once launched on the Danish market.

Between 2010 and 2021, the total costs of prescription and cancer medicines increased significantly, with Denmark recording the highest overall cost increase (135%) among the Nordic countries. Despite efforts to regulate these costs, the reimbursement approval process remains challenging: on average, 895 days pass between marketing authorization and reimbursement for the 67 cancer medicines reviewed (Samola et al., 2023).

Nonetheless, recent data from IQVIA (June 2024) presents a more favourable picture. The report indicates that 75% of drugs approved by the European Medicines Agency (EMA) between 2019 and 2022 were available to Danish patients by mid-2024. However, only 36% of these drugs were fully accessible without restrictions. Denmark ranks third among EU countries for median time to availability, with an average of just 84 days between market authorization and patient access.

These results contrast with the findings of Samola et al. (2023), likely due to differences in the periods or datasets considered. Despite this variation, the issue of access to medicines and the timeliness of treatment remains a subject of ongoing debate in Denmark, as emphasized by key informants. In line with other Nordic countries, managed entry agreements are used in Denmark to support access to high-cost medicines, both for inpatient and outpatient care. These agreements have been in place since 2017 (Samola et al., 2023).

MONITORING

A monitoring activity is carried out through indicators tracking the early cancer cases and the related treatment. For instance, in the case of breast cancer, the DGBC report provides indicators differentiating between patients treated only with neoadjuvant therapy etc. etc. In the case of cervical cancer, in 2019, the DGCD updated the indicators applying the FIGO 2018 classification and according to new guidelines issued in 2022. This implied splitting the survival rate at 5 years of patients detected with a stage IA from those detected at stage IIA based on evidence showing the survival in the two stages is different. Last, as far colorectal cancer, the DCCG report provides the proportion of citizens operated on (incl. local res.) along with the diagnosis with screening detector.

Additionally, the Danish Cancer Society acts as an independent watchdog, monitoring compliance with the established timelines for early treatment and contributing to accountability across the healthcare system.

THE NETHERLANDS

2.1 BACKGROUND

POPULATION

Demographic trends. In 2022, The Netherlands registered 17,70 million inhabitants with a slight increase of 6% throughout the last 12 years (see Figure 25).

In the last 12 years:

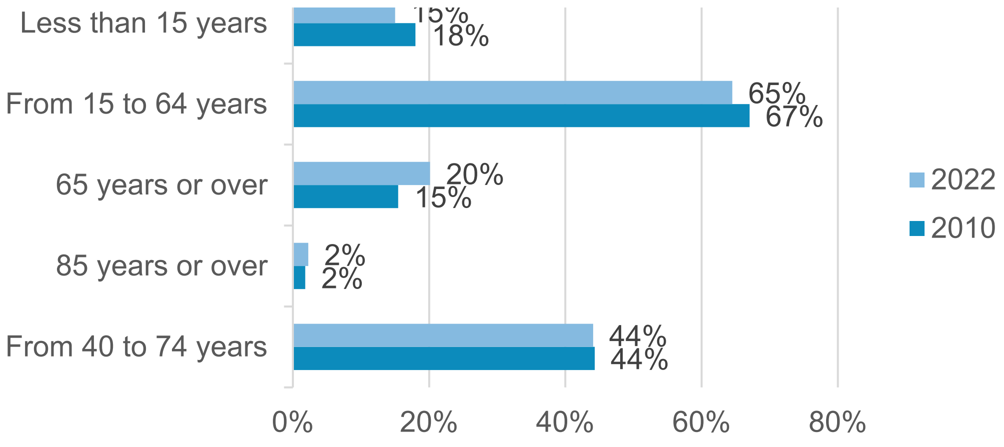
- the Dutch population over 65 years old has increased by 5%;
- the population under 15 years old has decreased by 3%;
- the population rate in the age range of 45 to 74 has remained the same.

The Netherlands needs to address slow population growth, characterized by an increase in the elderly population and a decrease in the young population.

Looking at the population from a **social perspective,** it can be observed that:

- The rate of population at *risk of poverty* is significantly lower than the EU 27 average, while the rate of population with at least upper secondary education attainment is close to the EU 27 average.
- The rate of recently *immigrated population*, based on birthplace and citizenship, has increased to 2.5% and 3%, respectively, surpassing the EU27 average.

Figure 25. Composition of Dutch population in 2010 and 2022



Source: Eurostat

As presented in Table 5, one fifth of the Dutch population has a foreign background. Studies also show that *inequalities in health* in general, and cancer specifically, regard less well educated and people with a lower socioeconomic status, who are also less likely to participate in population surveys and in the HPV vaccination programme (IKNL 2024[7]).

Epidemiological outlook.

In 2022, the registered number of new cancer cases was 55,379 among women, and 60,845 among men. Among the most common *cancer types* in The Netherlands (referred to all cancer sites but non-melanoma skin), for *women* were: breast (29%), colorectal (14%), trachea bronchus and lung (13%), while for *men* were: prostate (20%) colorectal (17%), trachea bronchus and lung (13%). In same year, the number of registered deaths due to cancer was 22,566 among women and 27,087 deaths among men. Table 6 reports the details on most common cancer causes of death in 2022.

A comprehensive overview of the trends in incidence and mortality rates for breast, cervical and colorectal since the 1990s helps to understand the impact of several policy measures, including national screening programmes introduced in these last three decades (see Figure 26).

Table 7. The social composition of the population in 2019 and 2022

Indicators		The Netherlands	EU 27 countries
Persons at risk of poverty* (% of total population)	**2019**	13.5	16.5
	2022	14.5	16.5
Active recent immigrants over 20 years old born in a foreign country (% out of total labour age population)	**2019**	1.3	2.0
	2022	2.5	2.1
Population by foreign citizenship (% of total population)	**2019**	1.5	2.2
	2022	3.0	2.6
At least upper secondary educational attainment (3 – 8) **– age group 25 – 64 years** (% of population 25 – 64 years)	**2019**	74.5	74.0
	2022	77.0	75.0

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[7] IKNL https://iknl.nl/kanker-in-nederland-ses-rapport-1

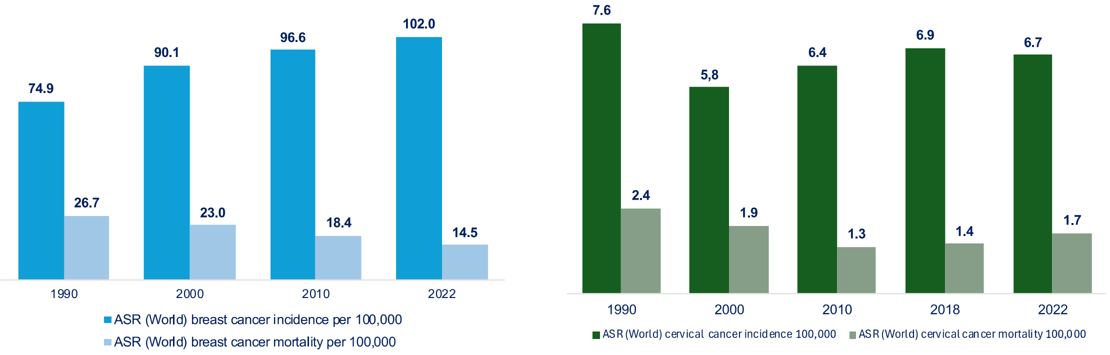
Source: Eurostat
*Cut-off point: 60% of median equivalised income after social transfer.

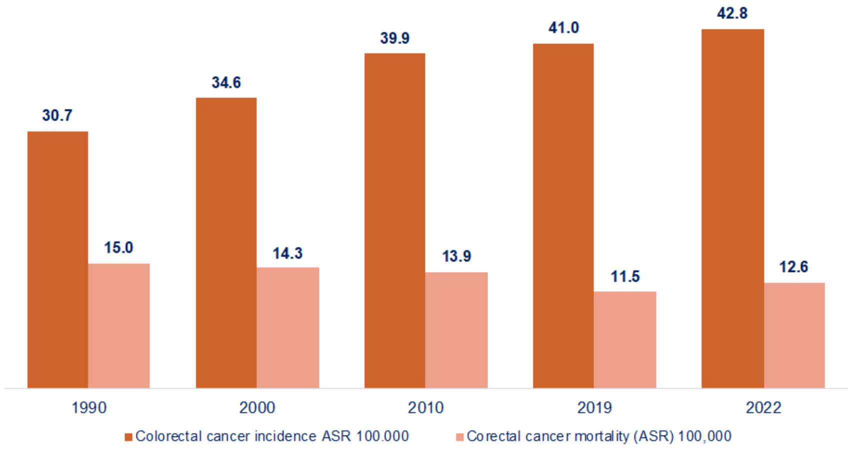
Table 8. Oncological situation in the Netherlands. Reference year 2022

	Most common cancer types (new cases)		Most common cancer causes of death		Cancer survival rate ASR at 5 year 2010-2014
	Women	Men	Women	Men	
Breast	29%	n.a	14,5%	n.a	86,6%
Colorectal	14%	17%	13,1%	13%	
Trachea bronchus and lung	13%	13%	21,3%	22,5%	17,3% (lung only)
Prostate	n.a	20%	n.a	12%	88,5%
Bladder	n.a	10%	n.a	n.a	
Cervical	4%	n.a	n.a	n.a	

Source: ECIS, European Cancer Information System and Concord-3 report for cancer survival at https://worldpopulationreview.com/country-rankings/cancer-survival-rates-by-country

Figure 26. Incidence and mortality of breast, cervical and colorectal cancers in the Netherlands





Source: WHO, Global Cancer Observatory, Cancer Today and Cancer Trend

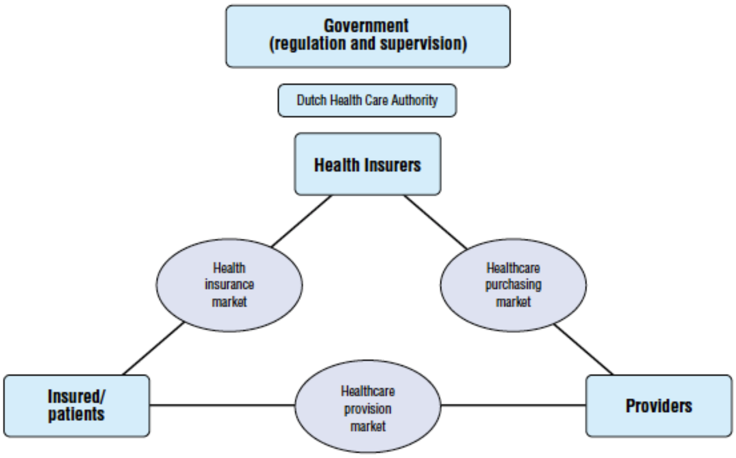
HEALTHCARE SYSTEM

Healthcare in the Netherlands is financed through compulsory health insurance contributions from citizens, with additional funds from general taxation (Kroneman et al., 2016). All citizens must choose a health insurance provider and health insurers are obliged to cover a basic package of healthcare.

The 4 main coverage schemes regard:

1. *Curative care*: directed towards successfully treating patients (Health Insurance Act). Financing is based on mandatory social health insurance and managed competition. Health insurance covers a standard basic benefits package: GP-care, maternity care, hospital care, home nursing, medications, and mental health.
2. *Long-term care:* intended for most vulnerable categories who need 24h supervision (Long-Term Care Act). Financed from income-dependent contributions anyone who pays income tax pays premiums under the Act. Municipalities oversee the organisation of care
3. *Social care*: for people who have difficulty participating in society or who cannot take care of themselves. Tax-funded social care implemented by municipalities
4. *Youth assistance and care.* Financed by central government and implemented by local authorities. Support, assistance and social care for children and adolescents encompassing general prevention and specialised care.
5. *Preventive care* in the Netherlands targets the whole population (Preventive Care Act) and is financed from general taxation. It comprises vaccination, cancer screening programmes and preventive care for children until age 18.

Figure 27. Scheme of Dutch healthcare system



Souurce: Kroneman et al 2016, p. 24

The healthcare system in the Netherlands is characterised by a tradition of social health insurance and shared governance among the government, professional organisations and health insurers. This collaborative framework ensures comprehensive coverage across different levels of care:

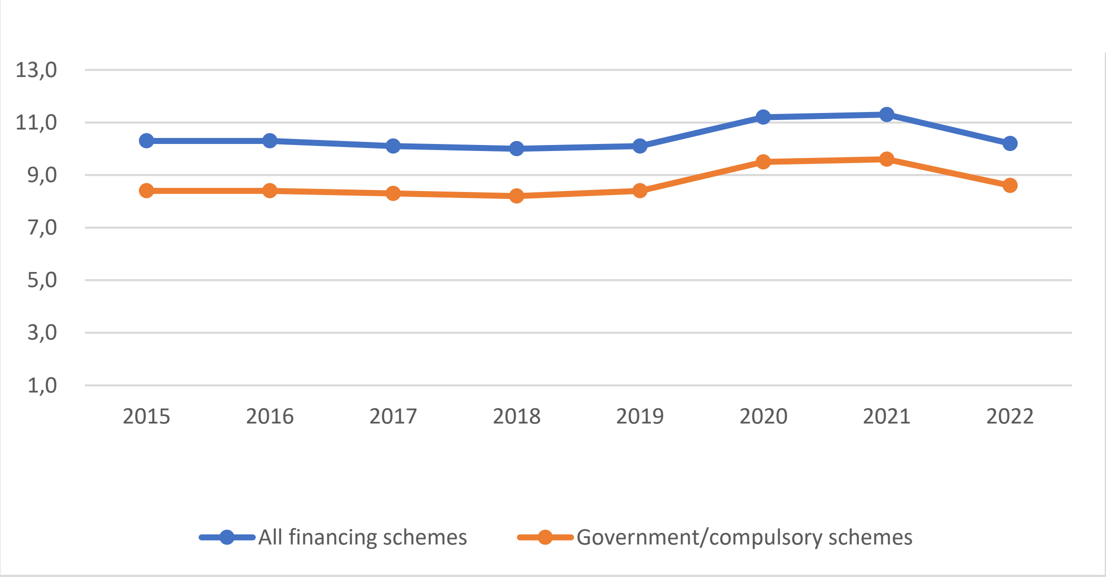
- Public health – provided by services for occupational medicine. Institutions for youth care and municipal health services
- General Practitioners (GPs) - act as gatekeepers of primary care that encompass personal curative and preventive services. All Dutch citizens are listed with a GP, and GP services are free as the costs for encounters are covered by basic insurance.
- General & university hospitals -- provide both inpatient and outpatient specialist care
- Long-term care -- delivered in nursing homes or community-based as home nursing care.

In the context of *cancer care*, the role of primary care in the Netherlands is particularly significant. GPs, who are the gatekeepers to secondary care, play a crucial role in the initial detection of cancer symptoms and the timely referral to specialist services.

Financing of healthcare system.

Adult citizens are subject to mandatory deductible of at least 385 Euro/year (not applied to general practice care, but pertains to medications and diagnostic tests in primary care). In 2022, the healthcare sector was mainly financed by government and compulsory contributions/

Figure 28. Health expenditure and financing. Share of GDP



Source: OECD Stats

premiums - 84.3%, followed by out-of-pocket expenditure – 15.7%. The increase in expenditure was mainly driven by long-term care, allocating almost 28% from the health budget.

In 2018, health expenditure for cancer care amounted to 5,309 million Euro, corresponding to 308 Euro per capita or 6.9% of the total health expenditure. While the expenditure on cancer drugs amounted to 62 Euro per capita (Hofmarcher et al. 2020).

Expenditure	2015	2017	2019	2021	2022
Total health expenditure in US$ PPP per capita	4 927.1	5 253.8	5 643.6	6 739.1	6 729.1
Government/compulsory schemes expenditure on health per capita in US$ (PPP)	4 009.7	4 291.7	4 673.0	5 721.8	5 672.1
Voluntary and out-of-pocket expenditure on health as % of total expenditure	18.6	18.3	17.2	15.1	15.7
Voluntary and out-of-pocket expenditure on health per capita in US$ (PPP)	917.3	962.0	970.6	1 017.4	1 057.0
Preventive care as % of GDP	0.36	0.34	0.33	0.96	

Source: OECD Stats

KEY ACTORS IN CANCER CARE

Public actors: central government

- *Ministry of Health, Welfare and Sport*: develops policies & measure to promote health & well-being; safeguard access to a high-quality system.
    - Dutch National Institute for Public Health (RIVM)
    - Centre for Population Screening (CvB)
- *Ministry of Finance*: levies social health insurance contributions via employers and pays 'health care allowance".
- *Ministry of Social Affairs*: responsible for health-related social security schemes covering sickness & disability benefits

Public actors: supervision role, independent from the Ministry

- Health Care Inspectorate
- Dutch Healthcare Authority
- Medicines Evaluation Board
- Dutch Institute of Clinical Auditing

Regional organisation

- *Dutch Comprehensive Cancer Organisation* – IKNL. Is the umbrella organisation comprising 7 national comprehensive cancer centres and is responsible for development and implementation of care guidelines (breast, cervical, colorectal), and supports administration of Cancer Registry, improving coordination of cancer care.

Third sector and independent research institutes

- Organisations of health professionals - e.g. Dutch College of General Practitioners (NHG), the Dutch Association for Prevention and Health Promotion (NVPG)
- Netherlands Institute for Health Services Research (NIVEL)
- Dutch Cancer Society (KWF) – NGO, has a Quality of Cancer Care Taskforce to advice the concentration of complex services in specialised settings with adequate resources, expertise & volume

Advisory boards

- The *Health Council* advises the government, both on request and on its own initiative, on the scientific state of the art in medicine, health care, public health and environmental protection.
- The *National Health Care Institute* is responsible for the quality, accessibility and affordability of the health care system; it advises the Minister on the basic health benefit package and executes regulation on non-payment of premiums and uninsured people.

Infrastructure for knowledge and research

- Netherlands Organisation for Health Research and Development (ZonMw), funds health research and promotes the application of knowledge for the benefit of health and health care.

NATIONAL PLANNING AND STRATEGIES

Since 2020, health care delivery in the Netherlands has followed the "**Appropriate care**" approach to ensure that everyone receives the care they need.

- The Appropriate Care Framework is the normative starting point for the realisation of appropriate care and offers tools to implement this transition.
- This Framework underpins many other plans and initiatives, including the Integrated Care Agreement (IZA) and the Netherlands Cancer Agenda.
- The tasks outlined in the Appropriate Care Framework should be reflected in all actions and requires the engagement of all parties across and beyond health care, including social parties and municipalities.

In November 2023, the Netherlands Cancer Collective (NKK) launched the **Netherlands Cancer Agenda.**

- Different from traditional national cancer plans, the Agenda is a living document implemented by a Collective uniting more than 100 parties, including patient associations, healthcare organisations, research centres, advocates.
- The Agenda serves as a comprehensive cancer plan with 20 goals aimed at reducing the impact of cancer on society: from prevention, early detection, treatment, follow up and palliative care to quality of life.

- The strategy is aligned with Europe’s Beating Cancer Plan, creating synergies between extant plans and initiatives.

The **Netherlands Cancer Collective** is an independent social movement, spearheading this effort. The Collective is independent of political actors but enjoys parliamentary support. The parties within the Collective work together as partners on concrete goals, each realising the Agenda from their own role and position.

2.2 EDUCATION: LITERACY AND AWARENESS

In 2021, 1 in 4 Dutch adults had insufficient or limited ability to find, understand and use information about health to make informed decisions about their healthcare (5% - insufficient;19.5% - limited) compared to 75,5% with sufficient health literacy (Willems et al. 2021).

Reforms introduced in recent years (e.g. Dutch Law of Agreement to Medical Treatment, Health Insurance Act) strengthened the position of citizens/patients in healthcare, underlying greater individual responsibility. To fulfil an active and responsible role in healthcare, people need competences such as skills, knowledge and mind-sets.

At the time of writing this report, there was no official policy of the Dutch government to improve the level of health literacy or to set targets for a more tailored care system (Sorensen et al. 2020). This responsibility is primarily delegated to non-governmental stakeholders and research organisations.

Actions and initiatives targeting population health literacy and awareness can be distinguished at:

- micro- and meso-level, spearheaded by non-governmental stakeholders, and
- macro-level, promoted by governmental and non-governmental actors.

The main organisations involved in different initiatives targeting **micro**-(citizens/patients-provider interaction) and **meso-level** (organisation) health literacy are:

1. *Health Literacy Alliance* is a network of 140 partners, including patient associations, who work together to ensure that knowledge on care and prevention is findable, understandable and acceptable for everyone. The Network is coordinated by Pharos. The Alliance has the objective to raise awareness of limited health literacy among organisations and professionals, and provide a platform in which partners exchange knowledge, experience and tools for mutual learning. It covers various areas, including cancer health education whereby it provides: checklists for healthcare practitioners to recognize low literacy and limited health skills; support organisations to become health literate organisations via materials and workshops; training courses and e-learning courses on effective communication with people with limited health literacy; talking cards for healthcare professionals about cancer.
2. *Dutch Cancer Society (KWF)* is an NGO that focuses on cancer prevention, research and patient support in general. The Society has a priority track for funding research projects on communication and shared decision-making (see next).

Macro-level initiatives targeting population health literacy and awareness are promoted both by the Ministry and a mix of civil society actors, professional organisations, research centres. The initiatives can be distinguished between (a) *general information* aimed to empower citizens and (b) *cancer-focused* general information.

a. General information to empower citizens.

Zorgkaart Nederland is an online platform for patients and healthcare professionals providing independent choice information to help patients choose a provider (information by disease and waiting times) promoted by the Dutch Patient Federation.

b. Cancer-focused, general information

Since 2013, the website «kanker.nl» has been the central online platform that provides reliable information about cancer and consequences related to the disease. The platform is an initiative and a partnership between KWF, IKNL and NFK. Similarly, the website «thuisarts.nl» provides reliable and accessible information about health and illness coming from 40 different associations of doctors to both patients and physicians.

To promote participation in national cancer screening programmes, the online page of the Dutch Institute for Public Health (RIVM) presents detailed information for citizens in 5 different languages (English, Turkish, Arabic, Ukrainian and Russian) besides Dutch.

The newly launched Netherlands Cancer Agenda contains a specific Action Plan for Early Detection (2024) to prepare activities around the organisation of Public Campaigns. A recent example of a national online campaign promoted by the Ministry of Health together with RIVM-CvB aims at incentivizing the participation of citizens in cervical cancer screening programme.

Shared decision-making[8]

The Dutch Law on Medical Treatment Agreement (2020) explicitly mentions shared decision-making as a prerequisite during doctor-patient encounters. Shared decision-making is set high on the agenda among policy makers, patient representative groups and professional bodies and educators. The Ministry of Health supports the integration of SDM in routine medical encounters using patient-reported outcome measures (PROMS) investing 70 mln over 2018-22, and grant extra time need for SDM during consultations.

Other initiatives regard:

- national campaigns to empower patients
- the development of patient decision aids in conjunction with clinical practice guidelines
- postgraduate training (update in the medical education curriculum of medical specialists, nurses)
- collaborative learning and system changes.

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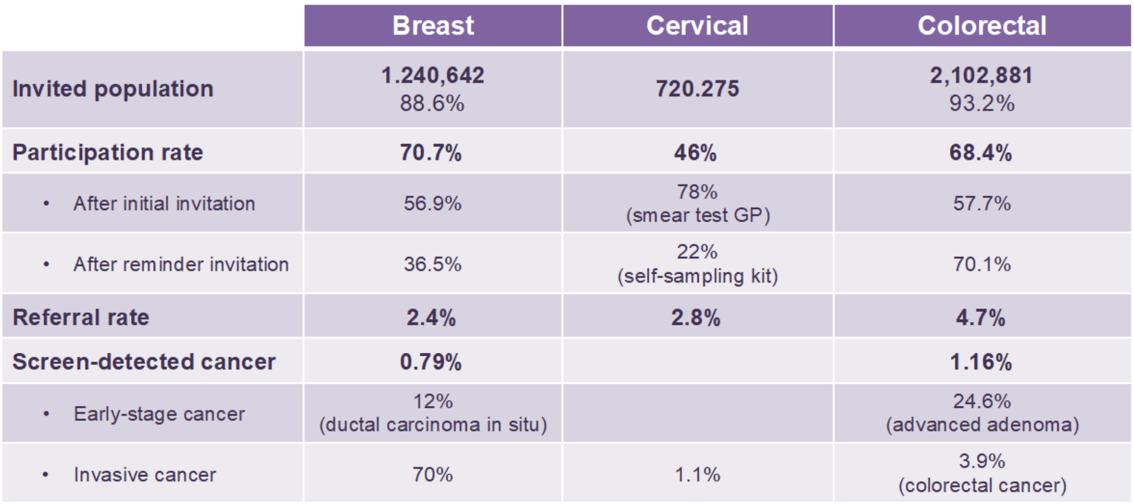
[8] Shared decision-making is an approach whereby information is shared with patients, who are supported to deliberate and express their preferences during the decision-making process.

2.3 EARLY DETECTION: SCREENING

The Netherlands performs high among OECD countries on several performance indicators for the 3 national population-based screening programmes for breast, cervical and colorectal cancer (see Table 7).

Table 9. Performance indicators for 3 national cancer screening programmes



	Breast	Cervical	Colorectal
Invited population	**1.240,642** 88.6%	**720.275**	**2,102,881** 93.2%
Participation rate	**70.7%**	**46%**	**68.4%**
• After initial invitation	56.9%	78% (smear test GP)	57.7%
• After reminder invitation	36.5%	22% (self-sampling kit)	70.1%
Referral rate	**2.4%**	**2.8%**	**4.7%**
Screen-detected cancer	**0.79%**		**1.16%**
• Early-stage cancer	12% (ductal carcinoma in situ)		24.6% (advanced adenoma)
• Invasive cancer	70%	1.1%	3.9% (colorectal cancer)

Source: Monitor Dutch Cervical Cancer Screening Programme 2022; Monitor Dutch Breast Cancer Screening Programme 2022; Monitor Dutch Colorectal Cancer Screening Programme 2022

POLICY FRAMEWORK

Key elements of the Dutch approach to early cancer detection:

1. Vision

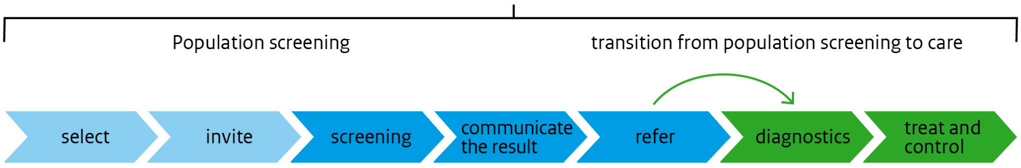
To ensure that all parts of the healthcare chain are aligned and there is a smooth transition from the screening stage to further diagnostics, all steps in the process for the Dutch population screening programmes are clearly delineated and integrated (see Figure 29).

2. Separate programmes supported by an execution framework

Each screening programme (for breast, cervical and colorectal cancer) is implemented via an execution framework under the responsibility of RIVM-CvB. These frameworks provide practical descriptions of execution in which principles, parties involved, as well as their roles and responsibilities are described. More specifically, the frameworks contain:

- Core principles of public value to accomplish in terms of quality, accessibility and affordability
- The primary process of screening
- The allocation of roles (parties and responsibilities)

Figure 29. Steps in the care chain



- Quality requirements
- Monitoring and evaluation
- Communication and information
- Risk management system

Actors and their roles

Several actors are responsible for the policy, implementation and monitoring of screening.

1. Policy
    a. The Ministry of Health, Welfare and Sport is responsible for national population screening programmes, deciding on the introduction & possible adjustments of programmes and their financing .
    b. Health Council advises the Minister on the target group, the screening test (nature, cut-off value), number of screening rounds, frequency and the quality requirements
    c. Netherlands Organisation for Health Research and Development (ZonMW) defines and monitors outlines of health research
2. Implementation
    a. The Centre for Population Screening (CvB) is a department of The Dutch National Institute for Public Health and the Environment (RIVM) responsible for the implementation of screening programmes in collaboration with General Practitioners (GPs) and hospitals. RIVM has the nationwide coordinating and supervisory role for prevention and screening programmes.

   b. Regional Screening Organisation (before 2022, there were 5 Population Screening Foundations for North, South, East, Mid-West, South-West), organises and coordinates the implementation in the regions (including sending invitations & communicating results), and provides data for the referral function.

3. Monitoring:
   a. Dutch Healthcare Inspectorate (IGZ) is part of the Ministry and monitors compliance with a number of quality-related healthcare laws.

Organisation and access

As mentioned earlier, the implementation of the three national screening programmes is regulated by a policy framework and an execution framework explicitly describing the various phases and the integration between screening, primary and secondary care. Table 8 gives an overview of the three national screening programmes organisation and transition between phases of services.

Table 10. Organisation of the three national screening programmes

Breast cancer	Cervical cancer	Colorectal cancer
Selection and invitation: ✓ Women aged 50 – 75 years invited every 2 years to participate in screening process ✓ Invited women can: i) accept to take part; ii) opt out for this round; iii) opt out permanently *Screening:* ✓ Examination takes place either in mobile or static screening centres by a radiographer *Informing & referral:* ✓ Written results & advice sent out within 10 working days after screening examination	*Selection and invitation:* ✓ Women aged 30 – 60 years invited every 5 years to have a smear test at GP or self-sampling kit ✓ Invited women can: i) accept to take part; ii) opt out for this round; iii) opt out permanently *Screening*: ✓ Examination takes place either at GP testing for the presence of hrHPV or a self-collected sample sent by regular post *Informing & referral:* ✓ Written results & advice sent out within 4 weeks after screening examination	*Selection and invitation:* ✓ Men & women aged 55 – 75 years receive a self-sampling test kit (FIT) every 2 years ✓ Invited people can: i) accept to take part; ii) opt out for this round; iii) opt out permanently *Screening*: ✓ Participant collects sample at home and sends it to laboratory by regular mail. *Informing & referral:* ✓ Written results & advice sent out within 5 working days after the screening organisation receives results from laboratory

✓ Written results & advice sent out to GPs if abnormal finding or insufficient information for assessment 2 days prior to sending to screened woman. Free of charge	✓ If positive, a cytological assessment is performed on the same smear. For HPV and abnormal cells results, referral to gynaecologist Free of charge	✓ Further testing & examination at a colonoscopy centre if blood value is greater than or equal to the cut-off value Free of charge

Source: authors' reconstruction

Impact of introducing innovation in screening

The Netherlands became the first nation in 2017 to introduce nationwide hrHPV-based cervical screening programme. HrHPV screening provides better protection against cervical cancer, due to higher sensitivity for CIN 2+ lesions, making it a suitable alternative to primary cytology-based screening.

The transition to HPV-based cervical cancer screening involved the following modifications to the test, triage parameters and referral of the screening program:

- Implementing hrHPV tests as the primary screening method.
- Introducing hrHPV self-sampling as an optional screening modality.
- Conducting cytology triage for individuals who test positive for hrHPV.
- Reducing the number of screening rounds by extending screening intervals to 10 years for women who test hrHPV-negative at ages 40 and 50.
- Sending all invitations in a standard manner by regional screening organisations, general practices or using a mixed approach to all women after their birthday in the year they were eligible for invitation

These changes might have affected the figures of turnout rate for women participating in the 2022 programme.

In the case of colorectal screening programme, the nation-wide adoption and implementation occurred after a piloting period which lasted 13 years. The process consisted of four phases:

- Phase 1: Pilot Studies (2006) - 2 pilot studies conducted to determine the best screening method, optimal screening intervals and population willingness to participate.
- Phase 2: Feasibility Study (2009) conducted to assess prerequisites for implementation (actors, financing, guidelines).

- Phase 3: Preparations (2011) implied the integration into existing infrastructure with clear roles & responsibilities for all stakeholders, services and products procurement 4 years prior to implementation; strategies developed for quality assurance systems.
- Phase 4: Phased Roll Out (2014) gradual increase in colonoscopy capacity, initial focus on older age groups to manage high referral rates.

Throughout the whole process, a rich network of policymakers, healthcare professionals, patient organisation, laboratories and participants were involved. Some key lessons learned from the entire implementation regard support and collaboration from political, professional & public stakeholders; a clear distribution of roles and responsibilities; and ensuring quality through monitoring and evaluation. Equally relevant, a well-structured communication strategy helped to manage public expectations and prevent opportunistic screening.

RESOURCES AND WORKFORCE

Technology supporting the process of early detection covers the laboratories responsible for sample analysis and a central information system.

The analysis of collected samples is carried out in specialised screening laboratories -- 4 for colorectal cancer and 5 for cervical cancer -- as part of the chain with whom regional screening organisations sign agreements. The specialised screening laboratories are responsible for processing samples using nationwide uniform tests and analytical equipment.

ScreenIT is an electronic central information system that supports the entire chain of the screening process, collecting essential data (select & invite participants, exchange information between labs etc.)

Workforce supporting the process of early detection.

In 2019, there were 90 GPs per 100 000 inhabitants, compared to the average of 81 GPs in EU 27. The role of GPs differs across the 3 population-based programmes, yet they keep their centrality in the process. For each programme, there are nationally defined NHG Practice Manuals that guide their tasks. Generally, the defined tasks of GPs for the cervical and colorectal screening programmes include:

- Screening: informing about population programme, taking a history and perform test (for cervical screening), pack and prepare collected materials

- Informing: receive authorised results from laboratory and enter in GP information system, contact the citizen to inform about the results if suspicion of cancer)
- Referral: refer to the hospital/clinic for further diagnostic testing and inform of the procedure to follow
- Treatment & surveillance: contact the citizen if no follow-up has occurred with hospital, supervise treatment at patient request, repeat test at a certain interval.

In the case of breast cancer screening programme, GP must inform and refer patients.

MONITORING

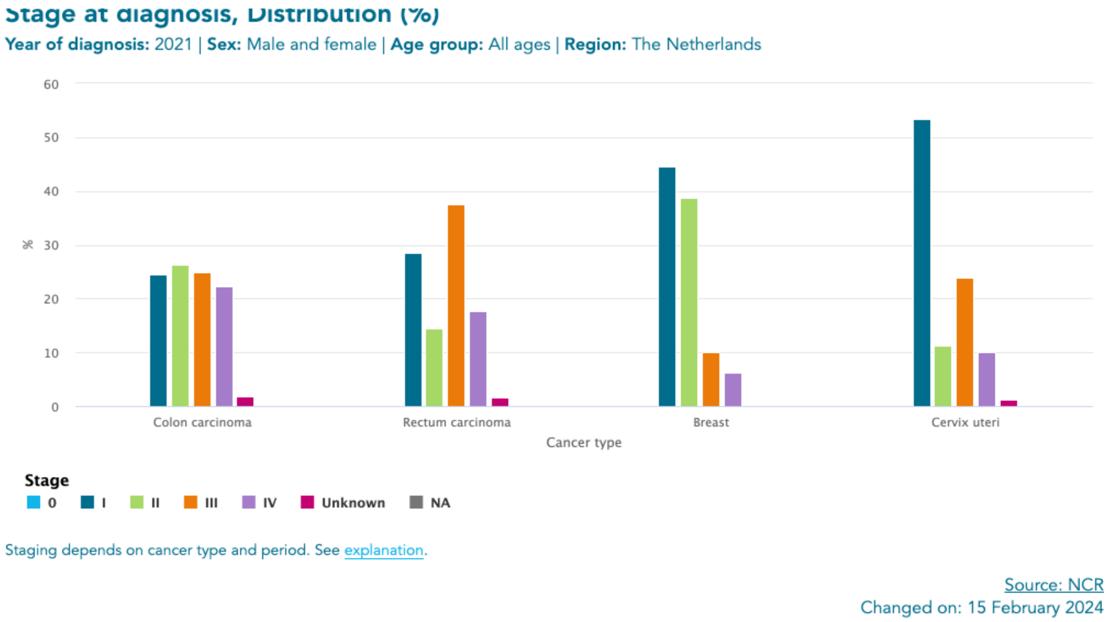
RIVM-CvB monitors the quality of all screening programmes and periodically evaluates standard or variable aspects (e.g. incidence/mortality reduction, cost-effectiveness). A set of indicators was developed to uniformly implement monitoring and evaluation of each of the three screening programmes. Each indicator is based on the European Core Health Indicators and is reviewed every five years. Indicators are applicable at national, regional, and local levels, covering the entire care chain from screening to treatment, and are categorized by the public values of quality, accessibility, and affordability (mentioned in the execution framework). National monitoring is carried out annually by an external party on behalf of RIVM-CvB: Erasmus University Medical Centre (Erasmus MC)/ Data registered and supplied to ScreenIT is used to evaluate screening programmes.

Evaluations are carried out either as event-driven or every 4 years. Periodic evaluations are always conducted by the National Evaluation Teams because they require a lot of (prior) knowledge, they are mainly epidemiological evaluations. The results of the evaluations are discussed in the relevant working groups, advisory groups and screening programme committees.

Dutch Healthcare Inspectorate (IGZ) - part of the Ministry, monitors compliance with a number of quality-related healthcare laws.

2.4 EARLY DIAGNOSIS

Figure 30. Stage at diagnosis for colon, rectum, breast and cervical cancer (%)



According to National Cancer Registry[9] data, in 2021, 84% of breast cancer diagnoses were at Stage I and Stage II, while 63% of cervical cancer diagnoses were at Stage I and Stage II (see Figure 30). Over nearly three decades of observation, the rate of early-stage breast cancer and cervical cancer diagnoses has steadily increased. More specifically, in 1995, 36% of diagnosed cases were at Stage I and 47% were at Stage II, while in 2021, these figures increased to 45% and 39% for Stage I and Stage II respectively. Similarly, 46% of cervical cancer diagnoses in 1995 were at Stage I and increased over the next 25 years to 57% in 2020 (see Figure 31).

ORGANISATION: OPERATIONAL ACTORS AND SERVICE PROVISION

The organisation of early diagnosis can follow either:

- the pathway designated by the national population-based screening programmes; or
- the pathway of screening outside the national screening programme as requested by GP (e.g. breast self-examination)

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[9] The Dutch Cancer Registry (NCR) provides the national data infrastructure to support early diagnosis: stage at diagnosis has been recorded nationally since 1989.

The General Practitioner is a key actor in early diagnosis, playing a gatekeeping role in the system as all the secondary care facilities are exclusively accessible through referral from primary care. Oncology care is delivered in institutions that are increasingly more part of a network (see Early treatment next), and which must comply with a series of requirements and meet the standards listed in Quality Framework for Organisation of Oncology care. The aim of Oncology Care Networks is to provide patient-centred care through the partnership of primary, secondary and third-line care providers. In 2019, the number of people diagnosed with cancer in the oncology networks/regions ranged from 5,000 to more than 21,000 diagnoses. This numbers are expected to rise, increasing the demand for care in the oncology networks.

Figure 31. Stage distribution for breast and cervical cancer in the Netherlands

The process of diagnosis and further referral and treatment is supported by tumour-specific, evidence-based Clinical Guidelines for breast, cervical and colorectal cancer (see Table 9).

The Clinical Guidelines are intended for all professionals involved in the diagnosis, treatment and management of patients with cervical, breast and colorectal cancer (GPs, medical oncologists, radiologists, pathologists, radiotherapists, gynaecologists, oncology nurses, psychologists).

- Tumour-specific guidelines are available on the Oncology Platform SONCOS which are regularly maintained and updated based on recent developments in oncological care.

Table 11. Overview of diagnosis process as prescribed by Clinical Guidelines

Breast cancer Clinical Guidelines (diagnosis part)	Cervical cancer Clinical Guidelines (diagnosis part)	Colorectal cancer Clinical Guidelines (diagnosis part)
The **GP** refers to a breast team or breast clinic if there are symptomatology objectified by clinical breast examination: ▪ Indications of malignancy ▪ Local palpable abnormality with suspicious mammogram o Persistent complaints (3 months) with non-suspicious mammogram: o Local palpable abnormality ▪ A lump felt by the woman ▪ Local pain or tenderness in one breast ▪ Brown or bloody nipple discharge Maximum **waiting time** for the clinic first appointment is **1 week**	The **GP** refers to a gynaecologist for colposcopy and/or treatment if: ▪ Abnormal cytology (Pap 2 and higher) is detected All women who are HR-HPV positive but cytologically normal are rescreened after 1 year with cytology only. ▪ Diagnosis is made after histological examination (cervical cytology), establishing clinical staging. ▪ Physical examination is performed by an oncological gynaecologist and radiotherapist together	The **GP** refers to an internist or gastroenterologist and/or treatment if: ▪ Blood is found in submitted samples Follow up tests are performed in a hospital/clinic (visual examinations). ▪ Diagnosis is made based on biopsies collected during examination (colonoscopy), establishing clinical staging ▪ Colonoscopy is important in detecting smaller abnormalities in particular that cannot be clearly localized on imaging and/or are difficult to localize during (laparoscopic) surgery

Once the GP issues the referral, patients need to make an appointment with a specialist to further investigate suspicions of disease through a series of diagnostics (blood tests, MRI, X-ray, CT-scan, mammography). In oncology care network institutions, care pathways are available for frequently treated conditions (i.e., 20 or more patients per year), with (i) a list of examinations to be performed, (ii) the minimum processing times, (iii) the indicators collected and (iv) who is responsible at what point for examination and treatment plan.

- The waiting time for a first visit to the outpatients clinic for a patient with a possible malignancy is maximum 1 week (Interval primary care IPC).
- Processing time for diagnostics is no more than 3 weeks (Interval referral IR)
- The time between the first visit to the outpatients clinic and the start of the therapy is no more than 6 weeks (Interval Therapy IT).

MONITORING

High quality, timely and accessible data is required to conduct monitoring & evaluation. There are three main sources of data:

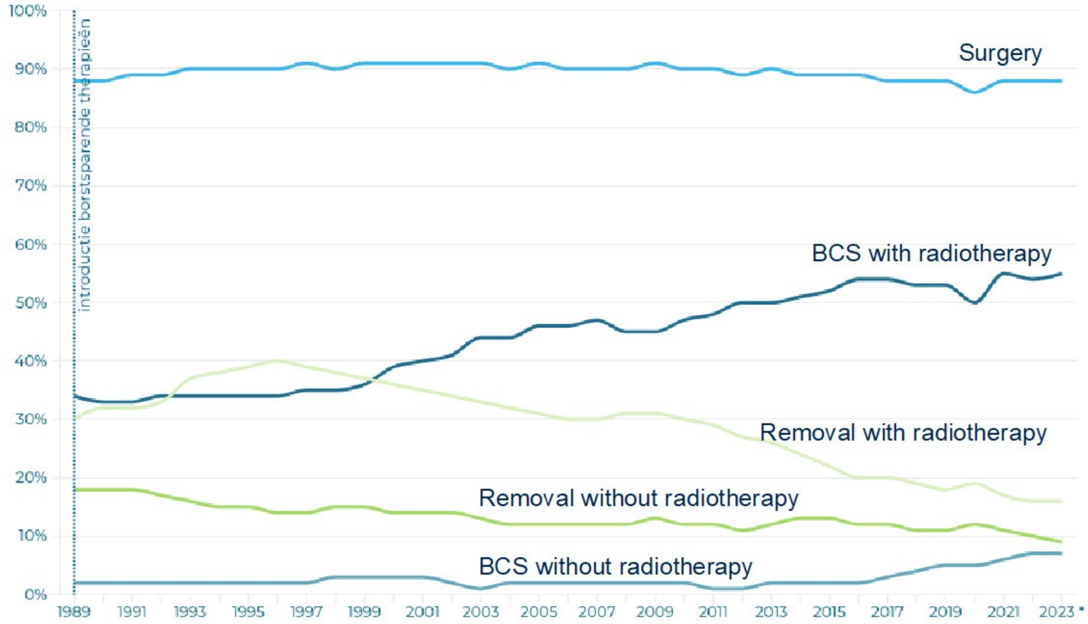
- The information about the diagnosis provided by the Pathological-Anatomical National Automated Archive (PALGA). PALGA is a nationwide network and registry of pathology laboratories that provides results of histological examination and stores them in a centralised databank
- ScreenIT provides data of performance for all screening programmes (invitations, reminders, participation, among other information).
- Data from the Dutch Cancer Registry (NKR) makes it possible to evaluate the extent to which guideline recommendations are followed.

2.5 EARLY TREATMENT

The prognosis for breast cancer has shown an impressive improvement over the past decades, thanks to earlier diagnoses and improved treatments. There is a trend of reduction in therapy. Surgical interventions are less invasive. Notably, although the percentage of patients with breast cancer undergoing surgery has remained the same between 1989 and 2023 (90%), this is usually a breast-conserving surgery (BCS). The number of breast-conserving operations has increased from 37% in 1989 to 62% in 2023. The percentage of patients having BCS with adjuvant radiotherapy has increased, while the percentage of patients treated with amputation without adjuvant radiotherapy has decreased. Systemic therapy is increasingly given prior to surgery (pre-operative) (see Figure 32). The advantage of this treatment is that patients can undergo breast-conserving surgery more often because the tumour has become smaller. BCS does not have to be as extensive, which means the cosmetic result of the breast-conserving surgery is better.

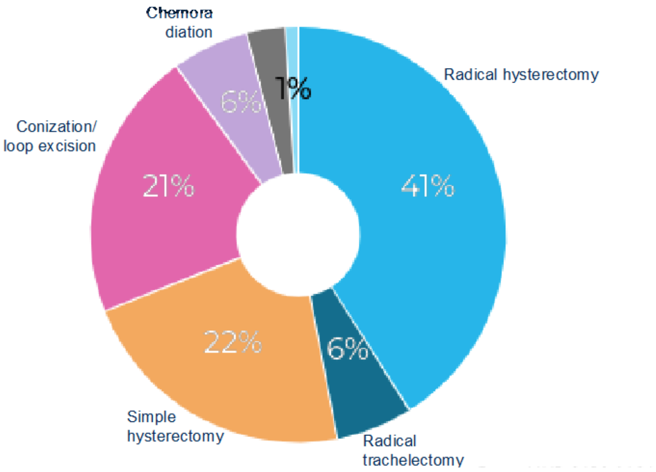
In the case of cervical cancer, surgery is the standard treatment for women with early-stage cervical cancer (FIGO IA1–IB1 and IIA1). In the 2016-20 period, 40% of Dutch women diagnosed with this stage underwent radical hysterectomy (see Figure 33). In general, the younger the patient is at the time of diagnosis, the more likely she is to be treated according to the guidelines.

Figure 32. Typologies of treatment for breast cancer over years



Source: Dutch Cancer Registry (NKR)

Figure 33. Type of treatment for cervical cancer from 2016-2020



Source: Dutch Cancer Registry (NKR)

In the sample of Dutch patients analysed for 2016-2020, the primary treatment of cervical cancer for early stage was 90% surgery for group 18-29 years and 96% surgery for group 30-44 years.

POLICY FRAMEWORK

Early cancer treatment is embedded in the general process of treatment, with a strong emphasis on detecting and treating the disease at early stages. The main strategy reforming healthcare, and early cancer treatment is the Cross-sectoral Care Agreement (Integraal ZorgAkoord, IZA). The Agreement is:

- Based on the proposed Appropriate Care Framework drawn up by the Dutch Healthcare Institute and Dutch Healthcare Authority
- Signed in 2022 between stakeholders from care and social sectors to keep health and social care accessible, affordable and of high quality.
- The Ministry of Health has allocated 2.8 billion EUR for 2023-26 to implement overarching innovative projects that contribute to “the right care in the right place”;
- IZA contains detailed agreements (around 400) on multiple aspects. Among covered themes, regional and cross-domain collaboration agreements provide significant input to the creation of networks in oncology care.

At the regional level, healthcare providers, patient associations, health insurers and municipalities can propose transformation initiatives by drafting a review of challenges and a plan, which undergo a two-step assessment. Once approved all health insurers must adopt the plan. As of April 2024, 102 transformation initiatives had been positively assessed and 12 had received a green light. Digitisation and data exchange are important preconditions in various components of IZA.

Within this policy framework, next to actors in the primary, secondary and tertiary-levels of care, two other actors must be highlighted for cancer care:

1. Oncology Task Force

The Task Force is a national administrative consultation (temporary) organisation created in 2014 in which all parties in cancer care participate: the Dutch Federation of University Medical Centres (NFU), the Dutch Association of Hospitals (NVZ), the Dutch Federation of Cancer Patient Organizations (NFK), the Dutch Society of General Practitioners (NHG), the Oncology platform - SONCOS of the Federation of Medical Specialists, Comprehensive Cancer Centre (IKNL), Nurses & Caregivers of the Netherlands (V&VN) and the Citrine Program. It advises the Ministry of Health on oncology and oncological care formation and coordinates healthcare providers and professionals in oncological care. Furthermore, the Task Force stimulates and advances oncological network formation to deliver optimal cancer care.

2. Oncology networks

The networks have been promoted, since 2014 through bottom-up projects, as an organisational form that enables integrated care to face the complexity and elevated costs of cancer care. In a regional oncology network, partners organise the network at the level of management, professionals (tumour-type networks) and facilities (IT, communication). A network connects in a partnership the healthcare providers from primary, secondary and tertiary levels to deliver high-quality care. They are constituted on care-related agreements at regional level signed between professionals that cover multidisciplinary observations, shared care pathways and protocols, research, information exchange and quality of care. RONs organise referrals, diagnostics, treatment and (after) care as a streamlined whole around the patient. IKNL supported network creation through tools, research, reports and advice relying on the Dutch Cancer Registry data.

Traditionally, oncological care has been based on multidisciplinary teamwork and collaboration. Regional oncology networks in the Netherlands aim to provide the necessary infrastructure to realise, maintain and innovate high-quality oncological care. In 2021, there were 11 regional oncology-wide networks & 153 tumour-specific oncological collaborations, established from 2015 to 2021. These networks include 3 to 9 general hospitals and 1 to 4 top clinical hospitals. Tumour-specific collaborations are built on the structure of Regional Tumour Working Groups

To provide optimal care by coordinating diagnosis and medical treatment, it is recommended that each cancer patient is discussed in multidisciplinary consultations (MDC) at the hospital level (SONCOS standard: at least 90% of patients):

- There are also tumour-specific regional MDC embedded in regional oncology networks which analyse more complex cases, and if necessary, require the expertise of a reference centre.
- All patient data from diagnostics and care must be available in preparation for an MDC
- The outcome of an MDC forms the basis for individual treatment plans. A patient care plan drawn up at an early stage can also involve the GP, informal caregivers and others in the integrated care, with a permanent point of contact
- Regional/transmural streamlined care pathways may include one or more hospitals: a patient can be referred and/or transferred to another healthcare provider and/or

location within the network, or to another network. Most patients with breast and colon cancer follow the entire treatment process in the hospital of first contact.

- Tumour-specific treatment guidelines play an important role in the referral lines within and between the oncology networks.
- To support specialists in implementing guidelines and the process of deciding the most appropriate treatment options for specific patient groups, decision trees are embedded in the clinical guidelines.

Access and Reimbursement of Medicines

Access to oncological drugs in the Netherlands is much lower compared to the European average. In 2024, patients had access to 21 (44%) out of 48 new EU approved oncological drugs (period of approval 2019-2022). These 21 medicines were fully available, without any restriction, to the patient population (get total reimbursement). In general, the average delay from marketing authorisation to patient access was 320 days (median 296 days), compared to 559 days in EU-27 (Newton et al. 2024).

Nevertheless, patient access to innovative drugs can be ensured through hospitals, mostly, in the context of Early Access Programmes or off-label use. Dutch hospitals generally reach faster patient access to selected innovative medicines before national reimbursement decisions (-1.9 years) (Vancoppenolle et al. 2023).

The Medicines Evaluation Board is responsible for the supervision and assessment of the efficacy, risks and quality of pharmaceutical drugs for humans and animals. However, authorization of a drug by the Board does not imply reimbursement by the health insurers. It is the Ministry of Health that decides the reimbursement based on the advice from the National Health Care Institute. Expensive drugs can be put temporarily on hold for reimbursement to negotiate an acceptable price with pharmaceutical companies.

The Dutch Federation of Cancer Patient Association (NFK) is committed to providing the right treatment for every cancer patient, both in terms of medicines and other treatments:

- Innovative cancer treatments include proton therapy, new diagnostics options using scans and MRI
- Innovative cancer drugs, which can be very costly.

Regarding the limited access to innovative medicines, the NFK has strongly criticised the situation: *"NFK believes that patients should have access to registered substances with (potential) added value. We find it shocking that less than half of the medicines approved by EMA become available to patients in the Netherlands. It should not be the case that resources with added value for patients do not become available or become available too late. (June 2024)."*

NFK participates in consultation bodies, providing patient perspectives on expensive medicines, new drug horizons, access to oncological drugs, data collection, and appropriate use of treatments. NFK also advocates for the inclusion of as many drugs as possible, including newly approved ones, in health insurance packages.

RESOURCES AND WORKFORCE

In the Netherlands, similar to other European countries, healthcare needs will increase, resulting in further demands for healthcare professions, especially the need for long-term care professions. In 2019, around 1.4 million people were employed in the healthcare & welfare sector (1 in 6 employees). According to recent estimates, in 2030 the additional demand for labour in health services will be around 6% (Schneider et al, 2022).

The challenge of workforce shortage, among GPs, specialists and in emergency departments, is duly acknowledged in the Integrated Care Agreement (IZA). One important task of IZA is to focus on retaining healthcare professionals and offer targeted support of (scarce) healthcare workers through technological applications (eHealth). On the other hand, the aim of oncology networks' formation is to concentrate care by organising work more efficiently and reduce costs where possible

On this backdrop, the Ministry of Health launched in 2022 the "Future-Proof Labour Market for Healthcare & Welfare" (TAZ) Programme giving impetus for a transition to appropriate and labour-saving care focusing on three themes:

- Innovative working methods: reorganising care process based on social and technological labour-saving innovation
- Employee retention: employment practices and job satisfaction
- Learning and development: continued attention to new developments

The Ministry allocated 80 million Euro in 2022, and from 2023 an amount of 130 million/year.

MONITORING

Monitoring and assessing the quality and outcomes of network cancer care has not been properly developed yet. On this backdrop, transparent data sharing is an important instrument for quality improvement in oncology networks. The collaborating hospitals in oncology networks/regions and tumour networks can mutually agree to discuss NKR data transparently and record this agreement in the IKNL 'Transparent NKR data sharing' form, with data available on NKR online tool for hospitals. In some networks, care processes such as MDCs, are periodically evaluated, goals set vs achieved are compared. In the future, all healthcare institutions will have to share their data via the National Basic Healthcare Register (LBZ) and the Dutch Hospital Database (DHD).

SONCOS issues verifiable qualitative and quantitative standards that a healthcare institution must meet in order to provide responsible oncological care in its standardization report published since 2012 Multidisciplinary standardization of oncological care in the Netherlands. In addition to standards for individual healthcare institutions, network standards are the next logical step in the continuous quality improvement of oncology. NFK and the cancer patient organizations are currently working towards a method for meaningful, objective and comparable transparency of network care for seven types of cancer. The aim is to further expand the number of cancer types over time.

ITALY

3.1 BACKGROUND

POPULATION

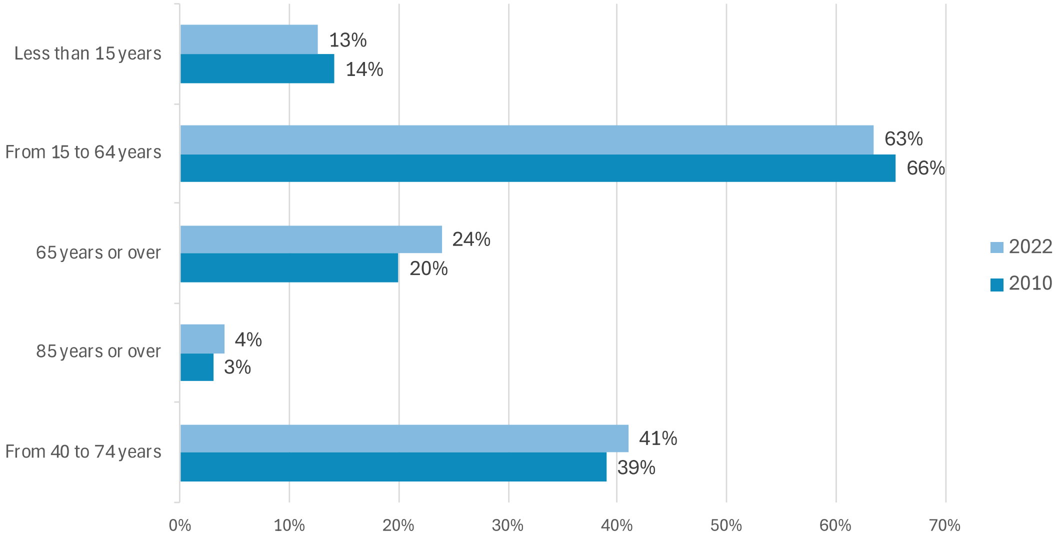
Demographic trends. In 2022, the Italian population was nearly 58.9 million. From 2010 to 2022 the population slightly increased from 59,8 to 60,3 million and then decreased again (see Figure 34). In this decade, Italy lost nearly 1 million inhabitants, and this trend is expected to continue under the same conditions.

In the last 12 years:

- The population under 15 years has slightly decreased;
- The population from 15 years to 65 years has decreased by 3%;
- The population with 65 years and over has instead increased by 4%;
- The population from 40 to 74 years, who are at greater risk of oncological diseases, has slightly increased.

These figures highlight the phenomenon known as 'demographic winter,' which is currently unfolding in Italy and is having a significant impact on the healthcare system. Moreover, compare to other EU27 and OECD countries' averages, Italy has a population rate under 15 years lower; while the population rate for those over 65 years old is greater.

Figure 34. Italian population trends



Source: Eurostat

Looking at the population from a **social perspective,** it can be observed that:

- The rate of population at risk of poverty is significantly lower than the EU 27 average, while the rate of population with at least upper secondary education attainment is lower than the EU27 average.
- The rate of recent immigrants over 20 y ears old born in foreign countries out of total labour population is low compared to the EU27 average.

As shown in Table 10, Italy has a higher rate of individuals at risk of poverty and with low education levels compared to EU-27 average.

Epidemiological outlook.

In 2022, the registered number of new cancer cases in Italy was 194,148 among women, and 213,802 among men. Regarding cancer incidence in Italy in 2022, the most common *cancer types* in Italy (referred to all cancer sites but non-melanoma skin), for *women* were: breast (29,6%), colorectal (13,2%), trachea bronchus and lung (7.9%), while for *men* were: prostate (17,9%) colorectal (13,7%), trachea bronchus and lung (13,3%). In same year, the number of registered deaths due to cancer was 89,198 among women and 103,029 deaths among men. Table 11 reports the details on most common cancer causes of death in 2022.

Table 12. A set of social indicators of the Italian population in 2019 and 2022 compared to EU 27 average

Indicators		Italy	EU 27 countries
Persons at risk of poverty* (% of total population)	**2019**	22.6	16.5
	2022	21.7	16.5
Active recent immigrants over 20 years old born in a foreign country (% out of total labour age population)	**2019**	0.2	2.0
	2022	0.1	2.1
At least upper secondary educational attainment (3 – 8) **– age group 25 – 64 years** (% of population 25 – 64 years)	**2019**	62.3	74.0
	2022	63.0	75.0

Source: Eurostat
*Cut-off point: 60% of median equivalised income after social transfer.

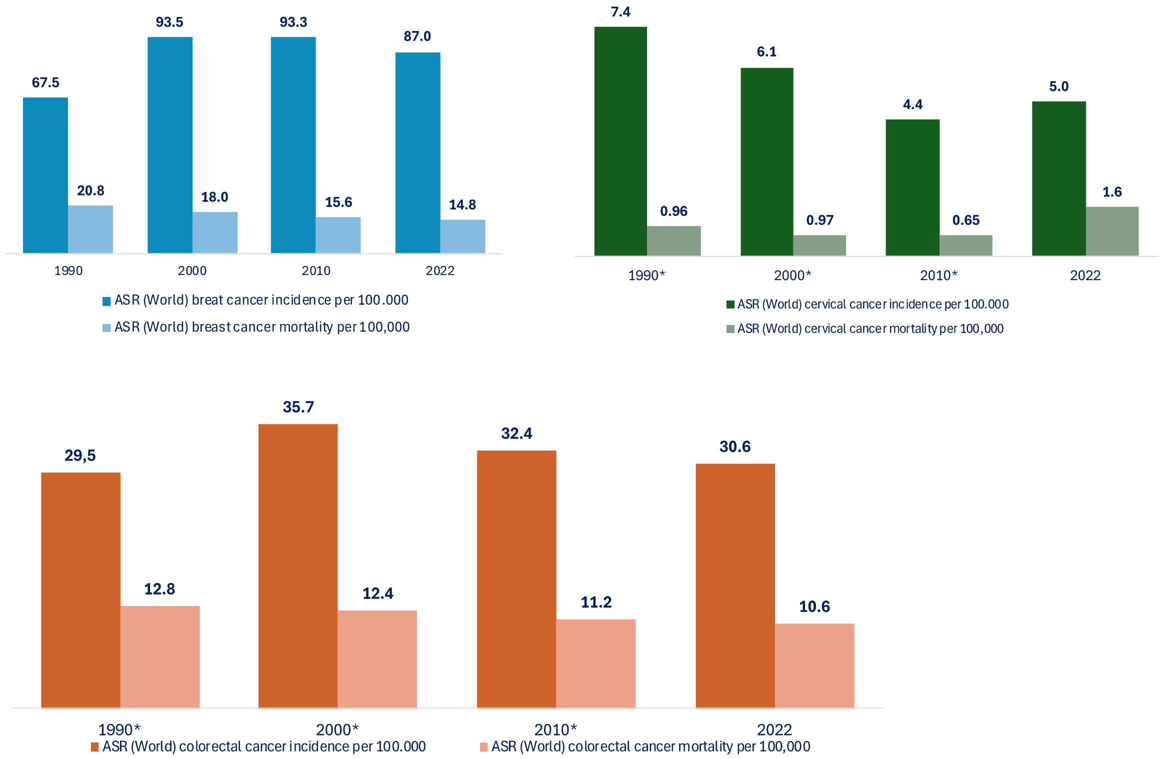
Table 13. Oncological situation in Italy. Reference year 2022

	Most common cancer types (new cases)		Most common cancer causes of death		Cancer survival rate ASR at 5 year 2010-2014
	Women	Men	Women	Men	
Breast	29,6%	n.a	17,3%	n.a	86%
Colorectal	13,2%	13,7%	12,6%	12,6%	
Trachea bronchus and lung	7,9%	13,3%	13,5%	22,9%	15,9% (lung only)
Prostate	n.a	17,9%	n.a	8%	89,5%
Bladder	n.a	12,8%	n.a	n.a	
Cervical	5,3%	n.a	n.a	n.a	

Source: ECIS, European Cancer Information System and Concord-3 report for cancer survival at https://worldpopulationreview.com/country-rankings/cancer-survival-rates-by-country

A comprehensive overview of the trends in incidence and mortality rates for breast, cervical and colorectal since the 1990s helps to understand the impact of several policy measures, including national screening programmes introduced in these last three decades (see Figure 35).

Figure 35. Cancer incidence and mortality of breast, cervical and colorectal cancers in Italy



Source: WHO, Global Cancer Observatory, Cancer Today and Cancer Trend

*Subnational data

HEALTHCARE SYSTEM

The **Italian National Healthcare Service**, known as Servizio Sanitario Nazionale - (SSN), is a taxpayer regionally based system that provides universal coverage to all Italian citizens and residents. It is organized into three levels: national, regional, and local.

The **national** level:

- sets general objectives
- defines the benefits package

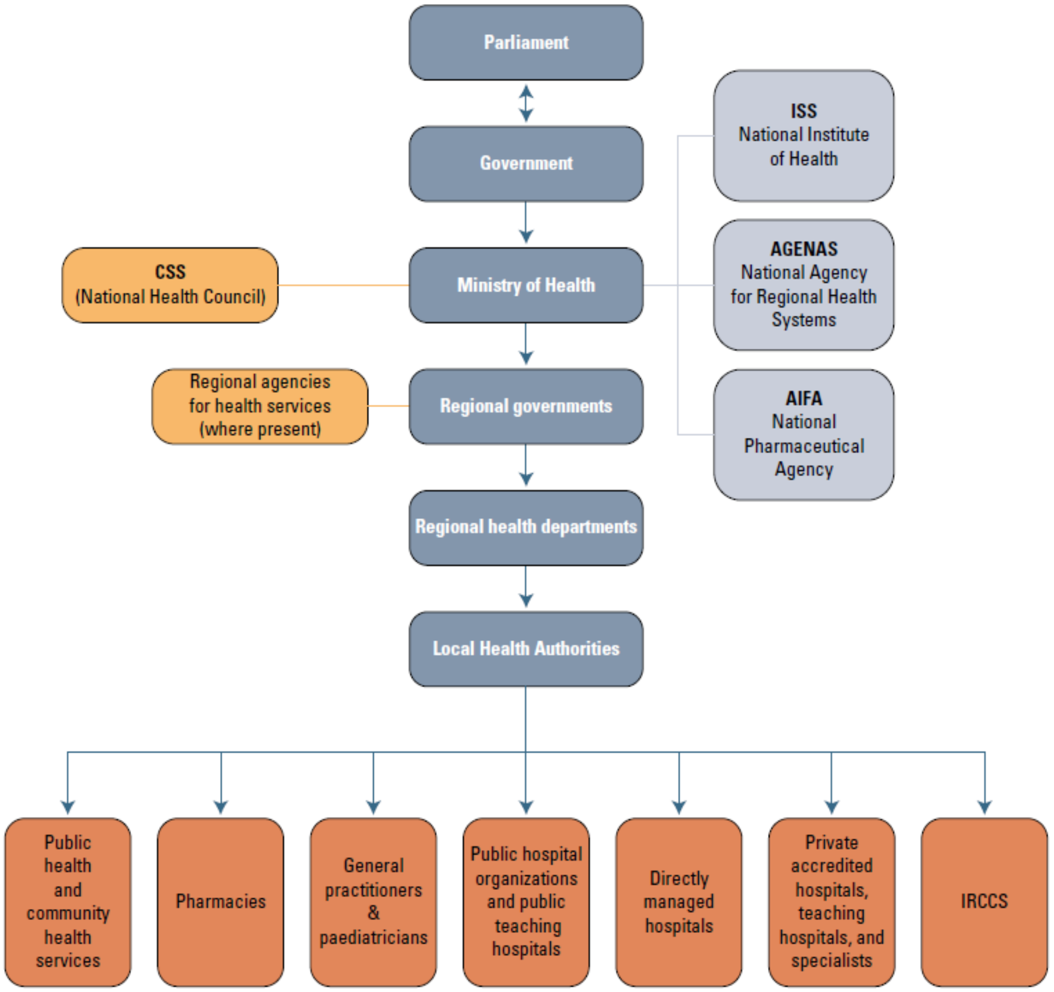
- determines funding
- establishes fundamental principles.

Through annual Budget Bills, the government and parliament decide on expenditures, revenues, and priority areas. The Ministry of Health leads healthcare planning, sets long-term goals, monitors the SSN, equalizes fund allocation, and co-governs with regions and research institutes. The **regional** level includes:

- Regional governments ensuring the delivery of the national benefits package by organizing networks of healthcare providers (i.e. local health authorities, hospital trusts, and private-accredited providers). Their responsibilities expanded significantly with reforms in 1999 and 2001, and now include setting general principles and organizing regional healthcare systems, defining financing criteria, providing technical and managerial guidelines, and conducting health needs assessments.
- Regional Departments of Health are responsible of the executive functions of the Regional Health Services (HRSs) such as: drafting 3-year regional health plans, defining authorization and accreditation criteria for providers, monitoring quality, coordinating health and social care, allocating resources, and appointing directors.

The **local level** is grounded on the **Local health authorities** in Italy providing preventive medicine, public health services, primary care (including mental health, family medicine, and community services), and secondary care.

Figure 36. Overview of healthcare governance in Italy



Note: IRCCS: Institutes for Care and Scientific Research.

Source. Overview of the Italian health system, in de Belvis et al. Italy: Health system review. Health Systems in Transition, 2022; 24(4): p. 16- Authors adapted from Ferr, 2014.

Their responsibilities include preventive medicine, community services, primary and secondary care, coordination with health districts, accredited private hospitals and specialists, and social care services in collaboration with municipal authorities. They can deliver services directly or through private-accredited providers and hospital trusts.

The SSN is highly decentralized healthcare system, with most legislative and executive powers assigned to the regional level of governance, while the central government takes on a stewardship role. This condition has substantially reconfigured the governance structure, effectively shifting the organization and management of health services to the regions.

Consequently, the regionalization process has created 21 different health systems. Therefore, a set of tools is used by the National Government to ensure uniform healthcare for all citizens, regardless of the region in which they live. The principal tools are:

1. **The "Livelli Essenziali di Assistenza**" (LEA), or **Essential Levels of Assistance**, referring to the set of services and treatments that the Italian SSN guarantees to all citizens (i.e. universal coverage), ensuring uniform health care across the entire country. Amongst the several specific functions played by LEA, let mention:
    - *Standardizing Care Across the Country*: By defining a national standard for essential health services, the LEA would ensure that the quality and types of healthcare provided do not vary significantly across different regions of Italy.
    - *Allocating Resources*: The Essential Levels of Assistance (LEA) help prioritizing healthcare spending by defining what treatments and services must be covered by public funding and ensuring that essential health needs are met first.
    - *Promoting Public Health:* Through inclusion of preventive services such as vaccinations and screenings, the LEA aim to improve overall public health outcomes.

Therefore, a set of tools is used by the National Government to ensure uniform healthcare for all citizens, regardless of the region in which they live. The principal tools are:

2. **The Italian Conference State-Regions** (Conferenza Stato-Regioni) facilitates cooperation between the central government and regional governments in Italy's healthcare system. Its key functions include:
    - Coordination: Ensuring healthcare policies are harmonized between central and regional levels
    - Policy Development: Contributing to national healthcare policymaking with regional input
    - Budget Allocation: Discussing and negotiating the distribution of national healthcare funding
    - Standards and Guidelines: Setting national standards for healthcare services
    - Conflict Resolution: Resolving conflicts between central and regional governments
    - Legislative Consultation: Providing regional perspectives on healthcare-related laws and decrees

    - Innovation and Best Practices: Promoting the exchange of best practices among regions

Overall, the Italian Conference State-Regions is a crucial mechanism for balancing regional autonomy with national cohesion in the healthcare sector, ensuring that the diverse healthcare needs of Italian regions are met within a coherent national framework.

3. A **monitoring system** of actual LEA provision, named **New Guarantee System** (Nuovo Sistema di Garanzia, NSG) to verify equity, effectiveness and appropriateness in the delivery of the national benefits packages, through 88 indicators (of which 22 are considered core) for prevention and public health, district (community) care, hospital care, care pathways, health needs assessment and social equity. As for incentives, an additional funding of 3% is granted to regions that fully comply with the benefits package indicators of the NGS. **Early cancer care** is covered by two indicators included in the core set:
    - The joint participation rate in breast, colorectal, and cervical cancer screenings
    - The proportion of interventions for breast cancer performed in wards with a volume of activity greater than 135 interventions per year

    Early cancer care is covered also by a set of indicators, so far not included in the core set, measuring the timing between diagnosis and treatment in the main cancer pathways including breast, cervical and colorectal cancers.

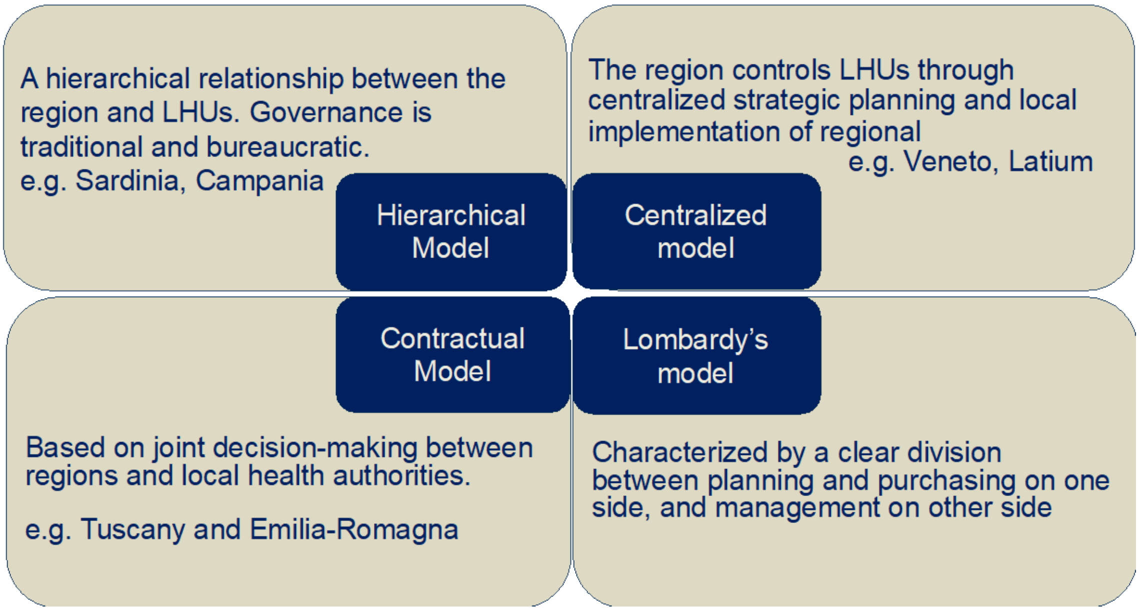
4. **Two legislative interventions** (Ministry of Health Decree no. 70/2015 and no. 77/2022) define the structural, process, and outcome standards that the Regional Health Services (RHSs) are required to implement for delivering secondary and primary care, respectively.
5. **National guidelines and recommendations**

A further driver of variability is depicted below. Figure 37 shows how each Region can apply a different model of governing their LHUs and all healthcare providers (e.g, hierarchical, centralized etc..). This impacts also on the Regions performance in implementing cancer screening or on Regional Cancer Network setting or on cancer patient pathway implementation.

Interregional mobility

Despite efforts to ensure as much uniformity as possible among the 21 regional health services, there is significant variability in the availability and often in the quality of services, which frequently leads citizens of these regions to 'vote with their feet' by seeking medical care primarily in the larger public and accredited private hospitals of Central and Northern Italy (Brenna, Spandonaro, 2015). Based on a recent analysis about the drivers of hospital admissions mobility, we see that the 2,686 billion value of hospital admissions of patients seeking treatments outside of their region of residence in 2022 was distributed amongst high complexity admissions (40.6%), middle complexity admissions (33%) and 17% because of casualty (Agenas, 2023).

Figure 37. Main types of health system governance arrangements adopted by the Regions



A hierarchical relationship between the region and LHUs. Governance is traditional and bureaucratic.
e.g. Sardinia, Campania

The region controls LHUs through centralized strategic planning and local implementation of regional
e.g. Veneto, Latium

Based on joint decision-making between regions and local health authorities.

e.g. Tuscany and Emilia-Romagna

Characterized by a clear division between planning and purchasing on one side, and management on other side

Source: Adapted from Mapelli, 2007 by de Belvis et al. Italy: Health system review. Health Systems in Transition, 2022; 24(4): p. 21. Fig.2.1

Financing of healthcare system.

Over the past two decades, public health expenditure in Italy grew first steadily and then very modestly in the following decade. The private health expenditure varied instead in a limited way. Currently, there is an ongoing debate about the underfunding of public healthcare expenditure.

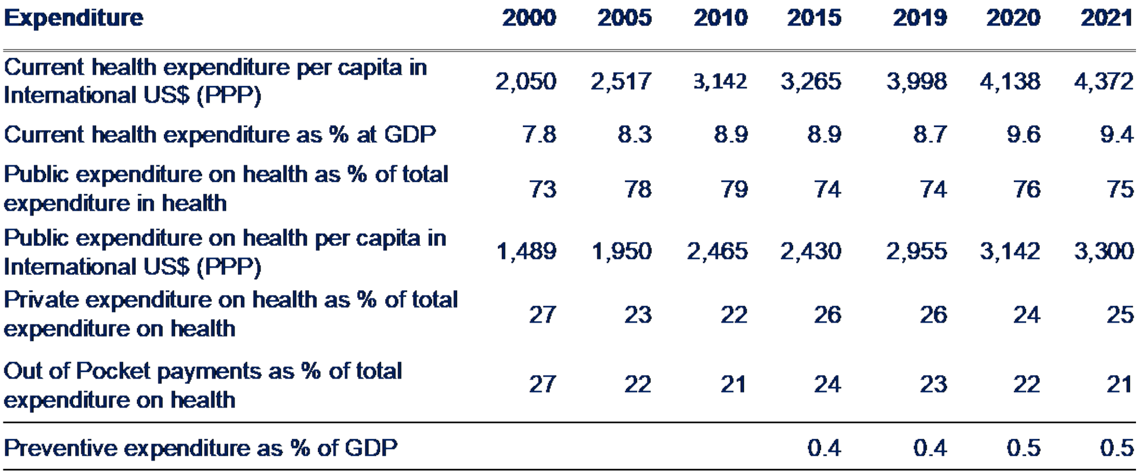
While hospital care is fully free, a cost sharing is applied to ambulatory care, except for:

- some specific types of services like diagnostic and laboratory exams included in early diagnosis and collective prevention programs organized by regions (e.g. HPV testing for cervical cancer screening)
- Some specific conditions included a cancer diagnosis.

KEY ACTORS IN CANCER CARE

Ministry of Health leads healthcare planning, sets long-term goals, monitors the SSN, equalizes fund allocation, and co-governs with regions and research institutes.

National Institute of Health (ISS, Istituto Superiore di Sanita') acts as a central authority for public health in Italy, conducts research across various public health areas, monitors and tracks the spread of infectious diseases in Italy, acts as a scientific advisor to the Italian government on public health matters, plays a role in ensuring the quality and safety of healthcare services in Italy.



Expenditure	2000	2005	2010	2015	2019	2020	2021
Current health expenditure per capita in International US$ (PPP)	2,050	2,517	3,142	3,265	3,998	4,138	4,372
Current health expenditure as % at GDP	7.8	8.3	8.9	8.9	8.7	9.6	9.4
Public expenditure on health as % of total expenditure in health	73	78	79	74	74	76	75
Public expenditure on health per capita in International US$ (PPP)	1,489	1,950	2,465	2,430	2,955	3,142	3,300
Private expenditure on health as % of total expenditure on health	27	23	22	26	26	24	25
Out of Pocket payments as % of total expenditure on health	27	22	21	24	23	22	21
Preventive expenditure as % of GDP				0.4	0.4	0.5	0.5

Source: WHO Global Health Expenditure Database and OECD Stats

Regional Governments play a crucial role in cancer care for their citizens, are responsible for organizing and delivering cancer care within their regions, managing public hospitals and clinics that provide cancer treatment, developing networks of care to ensure patients have access to specialists and necessary services, coordinating with private healthcare provider, they allocate and manage regional healthcare budgets, which funds cancer care services, develop and implement regional cancer plans.

Regional Health departments define priorities, allocate resources, and establish guidelines for cancer prevention, diagnosis, treatment, and follow-up care; provide equal access to high-quality cancer care services regardless of location or socioeconomic background.

National Centre for Disease, Prevention and Control (CCM, Centro Nazionale per il Controllo e la Cura delle malattie) is a network that liaises with the Ministry of Health and regional governments in surveillance, prevention and health emergency response measures: it also designs evidence-based strategies and programmes in prevention, health promotion and improving equity in access to care

National Screening Observatory (ONS Osservatorio Nazionale Screening). The ONS was set up by the LILT to monitor and analyse women's cancer pathways and was then chosen by the Ministry as the technical body to support screening programmes. Today, it manages monitoring and surveys at the national level, acts as a link between the national and regional levels, promotes screening programmes at the national level, gives advice on how to implement them with similar characteristics in the territory, in compliance with national and international guidelines.

Local Health Authorities (ASL, Azienda sanitaria locale). General medical and paediatric visits, vaccinations, health counselling, prescription of drugs, diagnostic tests, medical reports, maternal and child health protection, home care, rehabilitation; specialist services; prevention and Emergency healthcare.

Italian League for the Fight Against Cancer (LILT), it is a non-profit organization that was founded in 1922, its mission is to promote and support cancer prevention, raise awareness about cancer detection and diagnosis, provide support to cancer patients and their families, advocate for cancer research and treatment.

Federation of Italian Medical-Scientific Societies (FISM), is an umbrella organization that brings together over 200 Italian medical and scientific societies. It was founded in 1984 with the aim of promoting scientific research, education, and professional development in the medical field.

National Institute of Public Health (INSP), it is a public research institute that is responsible for conducting research on public health issues, founded in 2008.

Italian College of Medical Oncology Hospital Director (CIPOMO), it is a professional organization that represents the interests of medical oncologists in Italy founded in 1978. CIPOMO's main activities include: promoting the development of medical oncology in Italy and developing guidelines for clinical practice.

National Institute for Insurance against Accidents at Work (INAIL), it is a public non-economic, financially independent body that manages the compulsory insurance against accidents at work and occupational diseases in Italy.

Alliance Against Cancer (ACC), is an Italian non-profit organization that promotes scientific and technological innovation in cancer care and works to improve the quality of care for cancer patients in Italy.

Italian Association of Medical Oncology (AIOM), it is the leading professional organization for medical oncologists in Italy. it was founded in 1973. AIOM's mission is to: promote the scientific and professional development of medical oncology in Italy, improve the quality of care for cancer patients and promote research on new cancer therapies.

NATIONAL PLANNING AND STRATEGIES

The **National Cancer Plan 2023-2027** (Piano Oncologico Nazionale, PON) in Italy plays a crucial role in oncology screening through several key functions:

- *Setting Guidelines and Standards*: The National Cancer Plan outlines national guidelines and standards for organized screening programs. This ensures consistency across all regions of Italy, promoting a high level of quality and effectiveness in screening practices.
- *Prioritizing Populations*: The plan identifies target populations for different types of cancer screening. This helps to ensure that resources are directed towards those who will benefit most from early detection.
- *Promoting Participation*: The National Cancer Plan promotes public awareness and encourages participation in organized screening programs. This can involve educational campaigns, community outreach efforts, and collaboration with healthcare providers.
- *Resource Allocation:* The plan can influence the allocation of resources to support screening programs. This might involve funding for equipment, infrastructure, and personnel dedicated to screening activities.

- *Monitoring and Evaluation*: The National Cancer Plan plays a role in monitoring and evaluating the effectiveness of screening programs. This data is used to identify areas for improvement and ensure that programs remain efficient and up-to-date.
- *Alignment with European Strategies*: The plan also aims to align Italy's approach to oncology screening with broader European strategies like the "Europe's Beating Cancer Plan." This fosters collaboration and knowledge sharing across Europe

National and Regional Prevention Plans

Italy's "Piano Nazionale di Prevenzione Oncologica" (PON) it's a multi-faceted strategy focused on preventing and combating cancer. Here's a breakdown of its key aspects:

- *Focus on Early Detection*: The plan emphasizes the importance of early cancer detection through screening programs. This includes mammograms for breast cancer, Pap tests for cervical cancer, and tests for colorectal cancer.
- *Promoting Healthy Lifestyles*: It encourages healthy behaviors like maintaining a healthy weight, eating a balanced diet, and exercising regularly. These factors can significantly reduce the risk of developing cancer.
- *Vaccination*: The plan promotes vaccination against HPV (human papillomavirus), which can cause cervical cancer.
- *Surveillance and Research:* It prioritizes monitoring cancer trends and supporting research initiatives to develop new prevention, diagnosis, and treatment methods.
- *Improved Care and Support*: The plan aims to ensure high-quality cancer care and support services are accessible throughout Italy.

Guidelines for social reporting of screening programmes

The guidelines were defined within the project "Guidelines for social reporting of screening programmes", funded by the Ministry of Health - CCM, activated by ISPRO in the implementation of the DPCM of 12/01/2017, which provides for the "Promotion of informed participation and social reporting" for cancer screening. The study was carried out between 2020 and 2022. The study involved the Istituto per lo Studio, la Prevenzione e la Rete Oncologica (ISPRO), the ATS VALPADANA and the Azienda USL-IRCCS of Reggio Emilia, with their contact persons and screening programme coordinators. Social reporting (accountability) makes it possible to clearly explain vision, directions and policies, fostering strategic convergence on directions and priorities by the various actors in the health system and promoting informed adherence by citizens as well.

Project proposal for the urgent relaunch of oncological prevention throughout the country- LILT

The project was born from the awareness that the relaunch of oncological prevention at all levels is now a major priority for Italy, especially to ensure the sustainability of the National Health Service in the near future. LILT (Lega Italiana per La Lotta ai Tumori), which is made up of 106 provincial and regional associations and up to 400 outpatient clinics, with a capillary structural network represented by the provincial associations throughout Italy. This infrastructure would have enormous operational potential in the field of cancer prevention and screening campaigns, operating at all levels of society and almost exclusively on a voluntary basis. The project foresees the networking of the system with the creation of functional operational interfaces between the LILT Associations themselves and the public structures of the National Health Service and the private contract sector, as well as with the Provincial Medical Associations, the territorial pharmacies and all stakeholders in the oncological sector, including the third sector. The project could be taken up by all regions as a project proposal for the PNRR.

3.2 EDUCATION: LITERACY AND AWARENESS

Health literacy in general and cancer health literacy specifically has not been widely surveyed in Italy. However, Italy has actively joined the M-POHL Group and is participating in the 2024 survey. Italy partially participated in the previous rounds, and tested the tool in Florence, comparing the European Health Literacy Survey Questionnaire (HLSEU-Q16), used by the M-POHL Group, with the Newest Vital Sign (NVS).

The main results from this pilot study in Florence are as follows (Lorin et al., 2020):

- 22% of the sample had high HL skills (i.e. critical level of health literacy)
- 49.5% had partial HL skills (i.e. interactive level of health literacy)
- 28.3% had low HL skills (i.e. a functional level of health literacy)

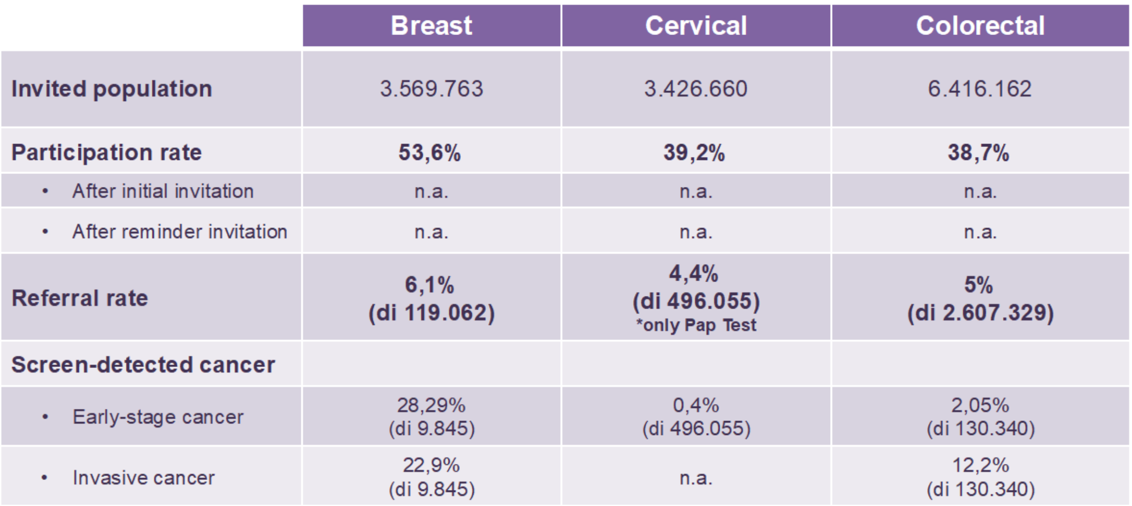
Educational level, age class and financial resources were significantly associated with HL skills.

To try to interpret these results, the analysis comprised the current **policy framework** and existing **actors and services** to support cancer health literacy. More specifically, up to this point, there are no policy documents or positions available on health literacy or cancer health literacy in Italy. Currently, both the Ministry of Health and the Ministry of Family, Childhood, and Equal Opportunities are actively addressing this issue. For example, a mapping initiative project is expected to identify what is already happening in Italy to design potential interventions and provide support. Before the institutional mapping project is completed, a preliminary investigation suggests that, for example, LILT (Italian League Against Cancer), the main cancer patients' association in Italy, is already implementing health literacy programs specifically targeting the foreign community. These programs provide meetings and workshops on cancer prevention, in partnership with local community stakeholders. There are also initiatives promoted by the academic world (e.g. University of Florence) implementing programs of health literacy organisations in hospitals.

3.3 EARLY DETECTION: SCREENING

Italy conducts population-based screening for breast, colorectal and cervical cancer. Performance indicators referred to year 2021 for the three national programmes are presented in Table 12. The results show large variations between the three regions of the country: North, Centre and South.

Table 14. Performance indicators for 3 national cancer screeening programmes



	Breast	Cervical	Colorectal
Invited population	3.569.763	3.426.660	6.416.162
Participation rate	**53,6%**	**39,2%**	**38,7%**
• After initial invitation	n.a.	n.a.	n.a.
• After reminder invitation	n.a.	n.a.	n.a.
Referral rate	**6,1%** **(di 119.062)**	**4,4%** **(di 496.055)** ***only Pap Test**	**5%** **(di 2.607.329)**
Screen-detected cancer			
• Early-stage cancer	28,29% (di 9.845)	0,4% (di 496.055)	2,05% (di 130.340)
• Invasive cancer	22,9% (di 9.845)	n.a.	12,2% (di 130.340)

Source: ONS-2021 Annual Report, some percentages calculated on available data

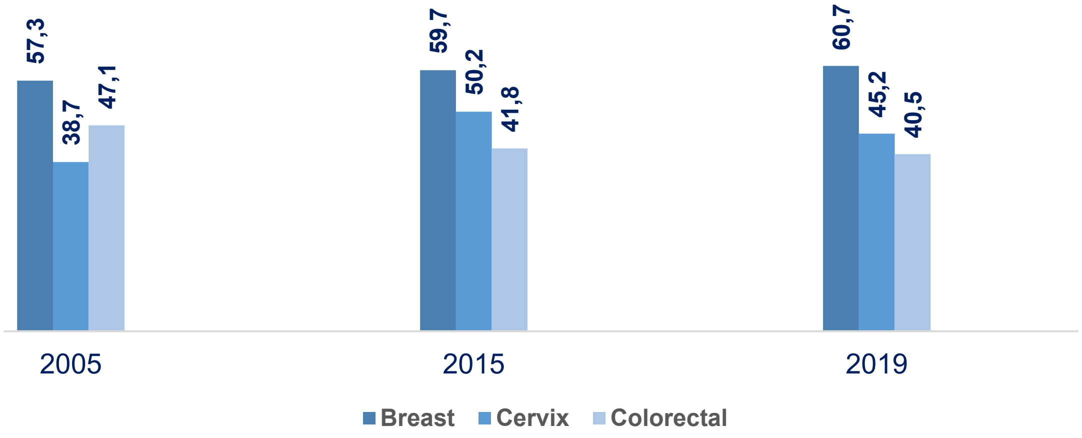
Figure 38 shows that the Italian breast cancer screening programs is close to the EU27 average, while participation in colorectal cancer screening is slightly lower. The data testify to the effectiveness of organised screening programmes, and the National Screening Observatory (ONS), on the activity carried out in the regions during 2018, highlighted continuous progress in the development of organised screening programmes, even if a gap between Centre-North and South-Islands remains, showing that between 80% and 90% of the Italian population of target age for mammography and cervical screening - and more than 75% for colorectal screening - was regularly invited (ONS annual report 2023).

POLICY FRAMEWORK

Cancer screening programmes in Italy did not begin simultaneously, but rather developed gradually over time across different regions.

- 1970s: Pilot programs for cervical and breast cancer screening emerged.
- 1980s: Existing programs expanded, and initial colorectal cancer screening programs started.
- 1996: Law 662/1996 mandated regional activation of screening programs for these three cancers.
- 2000: The National Screening Observatory (ONS) was established to monitor and coordinate national screening efforts.

Figure 38. The participation rate of the three cancer screening programmes in 2005, 2015, 2019



Source: ONS Annual report 2019, ONS Annual report 2017-2021

Since then, these programmes have been continuously improved and expanded to reach more people and be more effective. Currently, Italy offers free cervical, breast, and colorectal cancer screenings to women and men of the appropriate age in all regions. Oncology screening programmes, aimed at people belonging to the age groups considered at most risk, are offered as essential levels of assistance (LEA) since 2001 (DPCM 29 November 2001) and confirmed by the Prime Ministerial Decree of 12 January 2017. The three free national screening programmes provided by the Italian public healthcare system are mandated by national law and regulated by the national government, while the programs are financed and managed by regional governments.

The **national screening program for cervical cancer** was established in 1970. The target population is women aged 25-64 years, with screening conducted in three to five-year intervals:

- every third-year women aged 25-29 years (Pap test o HPV test)
- every fifth year for 30-64-year-olds. (HPV test)

The **national screening program for breast cancer** has been in effect since 1970 and women aged 50-74 years old is the target every other year. Mammography screening is offered every 2 years to women aged 59-68, while the same regions are piloting tests for a wider age group aged 45-74 (Ministero della salute 2021).

The **national screening program for colorectal cancer** has been in effect since 1980 (Launched as a pilot programme in some regions) involve women and men aged between 50 and 74 years every other year. It was established in 2008 in all Regions. The Piedmont and Veneto regions have adopted flexible sigmoidoscopy, once in a lifetime (or with a frequency of at list 10 years in patients aged 59 or 60 years).

Policy strategies and action plans

The First National Cancer Plan, published in 2023, representing the current iteration of Italy's national cancer prevention strategy. The planning of cancer screening programs is a collaborative and systematic process led by the Italian Ministry of Health and ISS involving FISM, ONS and the Italian Regions. The Cancer Plans and the National Prevention Plan (PON) based on epidemiological and international data, guide the introduction of new screening programs. The ONS unit develops screening guidelines grounded in robust scientific evidence and monitoring results, reviewed by expert panels including FISM, scientific societies, and clinicians. The ONS, with GISCOR, GISMA, GISCI issues recommendations and guidelines for screening, specifying target populations, methods, intervals, and follow-up procedures. The Regions and their ASL with public hospitals or private providers accredited by regional agreement handle implementation. Information systems manage the screening process, including invitation, tracking participation and results, and follow-up mechanisms. The national process is regulated by the Gelli Law (n 24/2017), which establishes a list of scientific societies and associations accredited to issue guidelines in the areas of competence. The law, also, standardizes the working and publication methods through the website of the National System for Guidelines (SNLG), managed by the ISS. Quality assurance is managed at the regional level, with ONS and GISMA, GISCOR, GISCI, scientific societies evaluating and recommending program revisions. Each region and each ASL is required to draw up a regional and company prevention plan that implements the guidelines of the national plan.

Actors and their roles

I. Governance

The *Italian Ministry of Health* has a crucial role in planning cancer care:

- Develops national guidelines and protocols for preventing, diagnosing, treating and following up cancer
- Stablishes minimum quality standard for various aspect of cancer care
- Play a role in ensuring equitable distribution of resource across different regions
- Monitoring and evaluation

- Allocates resources
- Evaluating the content and effectiveness of the programs
- Works with regional Health Authorities to ensure implementation of screening program at the local level

The *National Centre for Screening Monitoring (ONS)* has a liaison role between the ministry the regional levels and the ISS for the planning and governance of the three cancer screenings. The Observatory is a fluid organisation that activates a network of working groups that continuously exchange ideas to support and improve screening programmes.

- Each region has a regional observatory
- Each type of cancer (breast, cervix, colon, rectum) has its own non-profit group: GISCOR (colorectal cancer screening), GISMA (mammographic cancer screening), GISCi (Cervical cancer screening).

These groups work with the ONS to maintain high standards of care, continually improve processes and ensure accessibility, thereby improving the ease of diagnosis and treatment outcomes for cancer patients.

II. Monitoring

The *National Centre for Screening Monitoring*:

- Oversees the monitoring of screening processes and acts as a link with regional coordination and local health agencies
- Oversees adherence to guidelines at all stages of the pathway
- Provides common guidance on the target population and key tests
- Promotes communication to the population and facilitates communication between professionals
- Monitors and collects data with the support of three regional observatories (Veneto, Toscana and Piemonte), which send an annual survey to all regional observatories.

The three observatories send the annual survey to all regions to collect screening data through a series of indicators. The data, once analysed by the Observatory, are sent back to the regions to improve screening processes. This information flow is mandatory for all regions. It serves as a link between the data collected from screening (for these three cancers) and the cancer registry (RT).

The monitoring system, centralised in the National Screening Observatory, receives 21 streams of information from the 21 Italian regions, but the quality of the data is ensured by the fact that all regions use the same provider for data collection.

The *National Centre for Screening Monitoring and Tutorship:*

- Organises a monthly round table with professionals and regional observatory contacts to share and update progress on screening pathways
- Organises audits in regions that request them
- Encourages comparison and support between virtuous regions and less virtuous regions
- Organises on-site visits to monitor activities and disseminate good practice

III. Operational actors

Local Health Agencies (LHA) manage the cancer screening programs through:

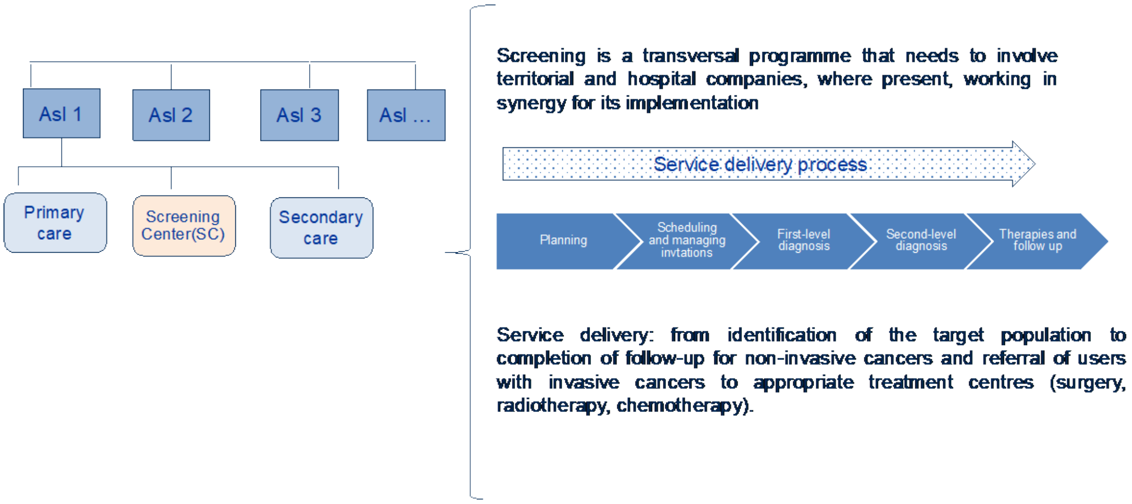
- The screening secretariat oversees administrative tasks coordinating the entire process from sending invitations to managing follow-up procedures
- The departments involved in providing the screening (e.g. diagnostic, pathology, radiology)
- The primary care units often the first point of contact for patients and playing a role in referring individuals to screening programs
- The public health departments overseeing the public health aspects of screening programs (e.g. outreach citizens education programs, monitoring participation rates and analysing data from screening programs to assess their effectiveness and identifying areas for improvement)
- The Patient Support Services supply psychological support and counselling, and they help patients navigate the healthcare system.
- The IT and Data Management Units collects data on screening programs
- The Research Units conduct research on cancer screening methods, effectiveness, and outcomes to continuously improve the programs

Figure 39 illustrates the process and operation actors involved in healthcare service delivery.

A *screening centre* is in charge with the organisation, management, administration and supervision. The main activities and responsibilities of the screening centre cover:

- Management software
- Promotional and information activities

Figure 39. Organisation and operational actors



Screening is a transversal programme that needs to involve territorial and hospital companies, where present, working in synergy for its implementation

Service delivery: from identification of the target population to completion of follow-up for non-invasive cancers and referral of users with invasive cancers to appropriate treatment centres (surgery, radiotherapy, chemotherapy).

Source: Authors illustration

- Mapping of services and locations
- Annual activity plan
- Periodic preparation of indicators and their analysis
- Clinical care and case management.

All the ingredients are in place to implement a quality assurance system at company and regional level.

RESOURCES AND WORKFORCE

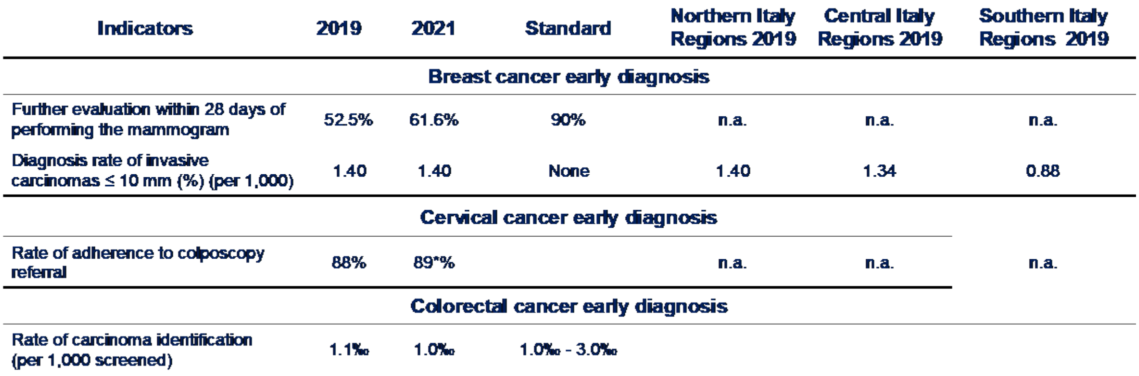
The last major funding to ensure adequate and specialised equipment for screening programmes dates back to 2006, more recently the 'National Equity and Health Programme' 21-27 provided new financial resources (650 million for health and dental care) to ensuring 'Increased cancer screening coverage. The intervention area aims to strengthen the capacity of screening services to increase programme adherence through the introduction of new organisational models - including the use of equipped motor homes to implement active and mobile provision, promoting effective communication methods and upgrading staff skills. Checkpoints will be affected by modernisation, infrastructure adaptation and technological upgrading.

To date, 14 projects have been activated in 7 regions to popularise the screening process and make it more accessible through the use of mobile homes equipped for mammography screening. There are regions that have always had an endemic problem of diagnostic imaging shortages. However, it is not yet clear whether this is due to a lack of equipment or a lack of specialised personnel.

3.4 EARLY DIAGNOSIS

According to National Screening Observatory data, the timing required for further evaluations is proper in average for the 60% of women. Although macro geographical data are not provided, the regional variability and the waiting lists are an issue (see Table 13).

Table 15. Main indicators for cancer diagnosis



Indicators	2019	2021	Standard	Northern Italy Regions 2019	Central Italy Regions 2019	Southern Italy Regions 2019
Breast cancer early diagnosis						
Further evaluation within 28 days of performing the mammogram	52.5%	61.6%	90%	n.a.	n.a.	n.a.
Diagnosis rate of invasive carcinomas ≤ 10 mm (%) (per 1,000)	1.40	1.40	None	1.40	1.34	0.88
Cervical cancer early diagnosis						
Rate of adherence to colposcopy referral	88%	89*%		n.a.	n.a.	n.a.
Colorectal cancer early diagnosis						
Rate of carcinoma identification (per 1,000 screened)	1.1‰	1.0‰	1.0‰ - 3.0‰			

Source: Osservatorio Nazionale Screening, 2021.

"If people see they have to wait for long time, they access privately, and we do not have any idea about their next steps". (Key informant coordinating a Regional Cancer Screening program in Region A).

"We have a nurse serving as a case manager who follows patients during further investigations and supports them until they receive a definitive diagnosis". (Key informant coordinating a Regional Cancer Screening program in Region B).

The issue of cancer early diagnosis in the national and regional governments documents is usually mentioned and addressed in relation to cancer screening programs and it is upon screening programs to manage patients through further diagnostic investigations towards the final diagnosis and referral to the dedicated treatment unit. However, there is a significant regional variability in addressing, governing and managing this intervention by the regional screening programs and their local screening centres.

Recently, some regions issued patient pathways, mainly addressing breast cancer care, planning also the management of asymptomatic women out the screening target or symptomatic women requiring further diagnostic investigations both referred by their GPs. Last, the recent mandating setting up of Regional Oncological Network (see further in the Early treatment part) are expected to provide an integrated and continuous pathway from cancer screening to treatment. This could be the right environment for implementing a supposed mix between patient pathway and clinical pathway Percorso Diagnostico Terapeutico Assistenziale (PDTA) applied to breast, cervical and colorectal cancer.

> "*The screening programs are a complex and long pathway going from the invitation sending to the diagnosis, and policymakers often struggle to understand it*". (Regional responsible of screening programs)

ORGANISATION: OPERATIONAL ACTORS AND SERVICE PROVISION

In Regions where there is not a single point of access:

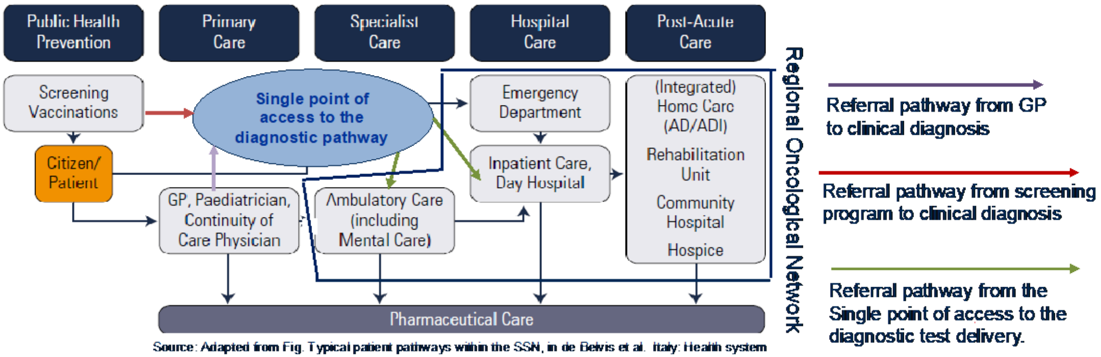
- *asymptomatic invitees* to a screening program in case of suspicious findings can be referred to clinical diagnostic exams at:
    - an ambulatory care
    - an inpatient care / DH

Usually, the screening centres book the exams; however, not all regions have a diagnostic fast-track pathway for all screening programs.

- *symptomatic patients* can be referred by their GP (or private consultant) to:
    - an ambulatory care
    - an inpatient care / DH

Figure 40 below shows how the diagnostic pathway of an asymptomatic or symptomatic person can change once a single point of access (SPA) to the diagnostic pathway has been set up. In both cases, this is responsible for the referred patients, arranging clinical diagnostic tests, and coordinating patient care and providing support. However, specific services provided can vary by region and sometimes also by Local Healthcare Unit.

Figure 40. Standard patient's pathway within the Italian NHS



Source: Adapted from Fig. Typical patient pathways within the SSN, in de Belvis et al. Italy: Health system review. Health Systems in Transition, 2022; 24(4): p. 118- Authors adapted from Ferré, 2014.

RESOURCES AND WORKFORCE

According to updated Eurostat indicators from 2018 on medical imaging technologies, including MRI ((Magnetic Resonance Imaging) and CT (Computerized Tomography) scanners, reveal that the use of medical imaging technologies is increasing in Italy's public healthcare sector. Italy now ranks among the top EU countries in terms of MRI, CT scanner, and PET unit density per capita. For example, Italy has 2.9 units per 100,000 inhabitants, which is significantly higher than the EU average of 1.5 (ECHI, 2018).

A survey conducted by the National Observatory on National Oncology Networks confirms the updated equipment availability, with digital mammography units being more available than analogue ones, and 40% of them being less than 5 years old. However, the data also indicate significant regional variability in terms of equipment availability and usage patterns across regions. (Agenas, 2023).

Regardless the equipment availability, an implicit issue of access to further diagnostic tests in case of cancer suspicious arises due to an increasing waiting lists pressure and the lack or weak prioritized access by these patients.

MONITORING

The limited attention paid to cancer diagnostic pathways outside of cancer screening programs is reflected in the monitoring system. Hence, there is no proper monitoring system dedicated to tracking the entire cancer diagnostic pathway regardless of the diagnostic route. Instead, national cancer screening guidelines require the National Observatory on Cancer Screening Programs to collect data and provide an indicator about the rate of further evaluation within 28 days of performing the mammogram.

The establishment of Regional Oncological Networks (see Early treatment section) and the implementation of single points of access to these networks may also lead to a broader perspective on monitoring. For instance, recently, the Agency for Regional Health Services (AGENAS) and its National Observatory on Regional Oncological Networks (RON) have set up a monitoring system that tracks two indicators related to patient referral routes, including those who were screened, seen by a general practitioner, or referred through emergency services. Specifically, it is asked whether:

- RONs collect information about the referral pathway taken by patients in their assessment forms (e.g., screening program, general practitioner, or emergency services)?
- RONs plan to systematically direct new breast cancer diagnoses resulting from mammography screening to network-affiliated breast units?"

3.5 EARLY TREATMENT

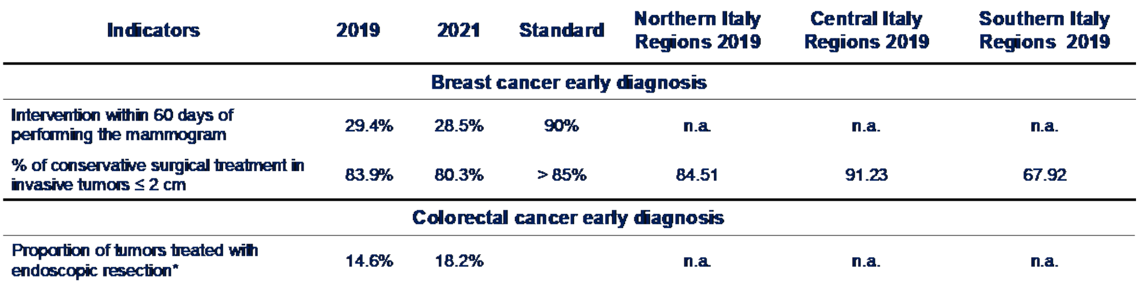
The results on early breast cancer treatment indicate that there are issues with managing the patient's pathway from screening mammography to surgical intervention. On a more positive note, the Northern and Central Regions meet EU standards for breast cancer early treatment. Table 14 shows some indicators on early treatment for breast and colorectal cancer.

POLICY FRAMEWORK

Existing Italian policy documents only mention early treatment in the context of screening programs; however the following factors can shift the perspective:

- recent publications by leading scientific societies on early treatment guidelines for breast and colon cancer
- the implementation of new diagnostic and treatment strategies
- changes to the oncological service network, may shift this perspective.

Table 16. Key indicators of early treatment for breast and colorectal cancer



Indicators	2019	2021	Standard	Northern Italy Regions 2019	Central Italy Regions 2019	Southern Italy Regions 2019
Breast cancer early diagnosis						
Intervention within 60 days of performing the mammogram	29.4%	28.5%	90%	n.a.	n.a.	n.a.
% of conservative surgical treatment in invasive tumors ≤ 2 cm	83.9%	80.3%	> 85%	84.51	91.23	67.92
Colorectal cancer early diagnosis						
Proportion of tumors treated with endoscopic resection*	14.6%	18.2%		n.a.	n.a.	n.a.

Source: Osservatorio Nazionale Screening, 2021

*Proportion of tumours treated with endoscopic resection is a key indicator of the utilization and effectiveness of endoscopic techniques in the treatment of tumours.

In a policy perspective, the driver of this change could be the already mentioned **Regional Oncological Networks** (RONs). Specifically, RONs are designed to manage and coordinate cancer care within specific regions in Italy and implementing different models such as Hub & Spoke and Comprehensive Networks. The purpose is to ensure that cancer patients receive well-coordinated, high-quality care by facilitating better access to services and improving the integration of various healthcare providers.

Considering the decentralized feature of the Italian NHS, the evolution leading to the RONs implementation can be summarised through the following steps:

1. *Early adopters design and test and local policy-makers support:*
    - Groups of oncologists in the Piedmont Region began to implement informally by in the early 1990s.
    - By 1998, these efforts were institutionalized with support from local policy-makers who set up organizational bodies to manage patient access and navigation
2. *National governments involvement*

- Between 2011 and 2014, the central government issued technical documents shared with regional governments, introducing the concept of RONs nationally and evaluating their feasibility and success.
- In 2015, the national government issued structural and operational standards for secondary care, which included the pathologies network for cancer care (Ministry of Health Decree no. 70/2015).

3. *Mandates, Coordination and Monitoring & Evaluation*
    - The 2019 Agreement between State and Regions mandated that regions implement the RONs.
    - Coordination of Cancer Networks body at national comprising representatives from AGENAS (RHSs Agency, National Institute of Health (ISS), national Medicine Agency (AIFA), Regions and patients association
    - In 2020, Agenas (the agency supporting regional health services) established a monitoring system to oversee the implementation and functioning of RONs.

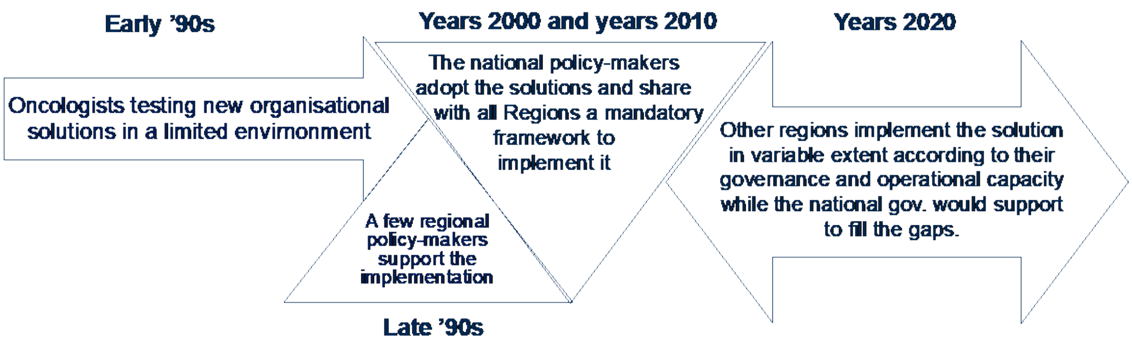
Figure 34 illustrates the long way to implementation of RONs.

«Consider that sometimes it is easier to implement a new organisation solution in a 'greenfield' rather than to remove early small pilots that continued their activity while the maturity cycle in a decentralised healthcare system took its time. This is also called the advantage of the late comers.» (Key informant involved in Cancer Care Networks)

ORGANISATION: ACTORS AND SERVICE DELIVERY

Literature and guidelines about oncological network provide several different organisation models. Based on the Agenas survey, currently in Italy RONs have applied respectively the Hub & Spoke and the Comprehensive Cancer Care Network (CCCN) models also widely promoted at the EU level (see Figure 42).

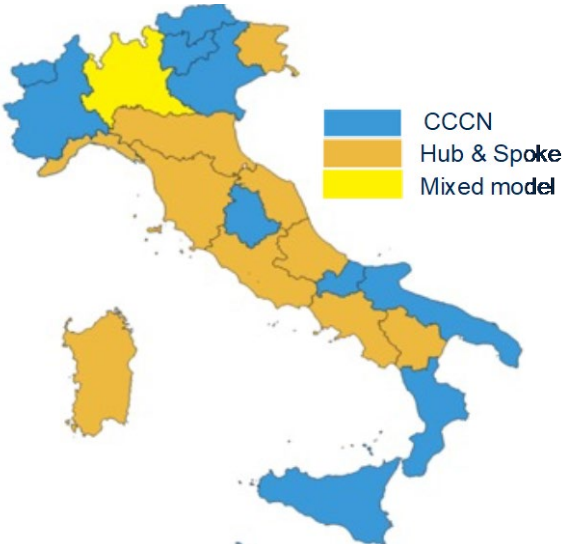
Figure 41. Timeline of experimentation with comprehensive cancer care



The case of the Regional Oncology Network in Campania Region ROC (Rete Oncologica Campana). The ROC is based on a Hub & Spoke model, where the Pascale Cancer Institute, a tertiary hospital specializing in cancer care, serves as the central Hub in context where due to limited providers and resources, patients prefer to be referred to other regions for care. The care tools are:

- A Multidisciplinary Oncology Group (MOG) in a condensed and expanded version, tailored to patients' needs, with an oncologist MD responsible for guiding the patient's treatment pathway
- Integrated care pathways drive the activities of the GOM and establish standards for care delivery

Figure 42. Organizational and Management Model representation adopted by the Regional Oncological Network 2022



The organizational tools are:

- A digital platform for sharing patients' documents and steps, keeping all network actors, directly or indirectly involved, including GPs, on the same page
- Monthly meetings among key network actors (e.g., responsible professionals from other regional hospitals' oncology units, palliative care services, etc.).
- Training for all GOM members.
- A monitoring system for integrated pathway management.

"The oncologists at Pascale are actively engaging and supporting all key stakeholders at the regional level, doing an excellent job. However, the issue remains that patients, once they receive a diagnosis, tend to prefer accessing cancer treatments from providers in the Northern region." (Key informant: a staff member of the General Direction of a Campania LHU)

Access and Reimbursement of Medicines

Regarding access to drugs indicated for early cancer treatment, they generally follow the same basic authorization and reimbursement process as other drugs, but there are specific nuances and considerations due to the critical nature of oncology treatments. A possible critical issue inherent in the Italian decentralized healthcare system is that while AIFA (National Medical Agency) sets the national framework, regional health authorities are responsible for implementing these decisions within their respective regions. This includes:

- Incorporating drugs into regional formularies, which may lead to a further delay in actual patient access to drugs
- Managing their distribution through local healthcare facilities, including prioritization, logistics, and specific protocols for their use in regional healthcare settings

According to the IQVIA Report (June 2024), the number of cancer medicines available by authorisation to patients in Italy between 2019 and 2029 was 40, ranking Italy 4th in the EU27. Moreover, two-thirds of them were authorized without any restrictions. Therefore, the median time to availability (i.e., the days between marketing authorization and the date of availability to patients as products gain access to the reimbursement list) is 358 days. This second indicator lowered Italy's ranking to the 13th position in the EU27.

MONITORING

Agenas is responsable of setting up and managing a monitoring system through a set of indicators shared with the Coordination of Oncology Network including a tight majority of regions representatives. Agenas has also provided a concise index including a qualitative and quantitative dimension. Specifically, the survey considers a set of indicators addressing:

a) The network basic structure
    - Organizational Model

    - Information System;
    - Economic Resources
    - Human Resources
    - Technological Resources
- b) Operational Mechanisms
    - Integrated Care Pathway
    - In-depth Radiation Therapy
    - In-depth Breast Unit
    - Clinical Research
    - In-depth Oncology Hospital Pharmacy and Pharmacology Services
    - Continuing Education and Training Activities
- c) Social Processes
    - Patients, Users, Citizens
    - Communication
    - Transparency
- d) Monitoring and Evaluation.
    - This area encompasses the requirements for monitoring and evaluation data related to Network Activities

Agenas publishes a two-year report providing the output of this motoring system and the related recommendations to each RONs. This initiative began in 2020, and its potential impact on the development and management of the networks remains to be determined.

POLAND

4.1 BACKGROUND

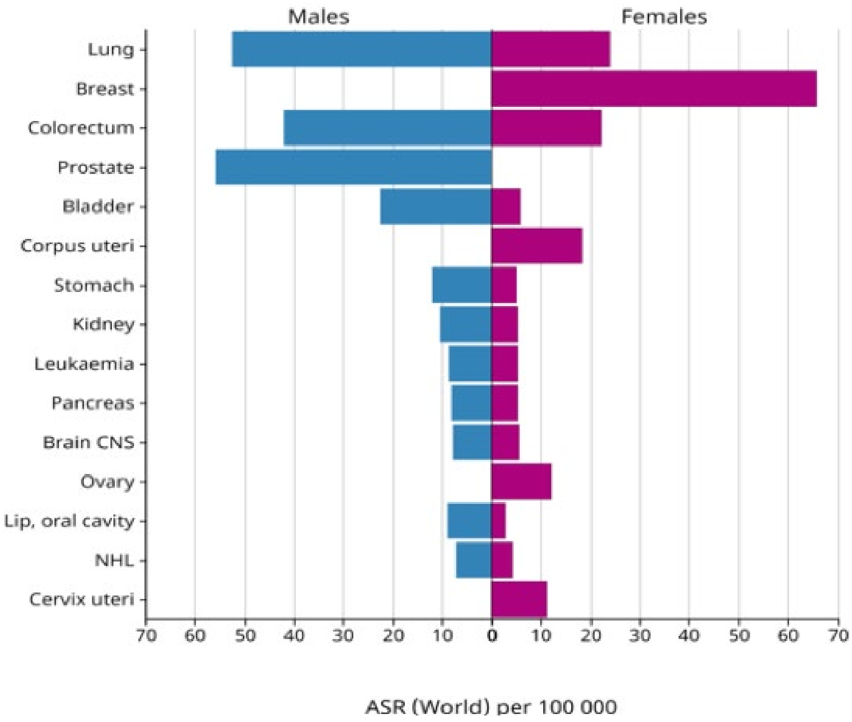
POPULATION

Epidemiological outlook.

In 2022, the age-adjusted incidence rate of breast cancer was 65.9 per 100,000 females, and the death rate was 17.3. The survival rate was 77%, compared to 83% in the EU24 from 2010 to 2014. The age-adjusted incidence rate of cervical cancer was 11.3 per 100,000 females and death rate was 5.2. Survival rate was 55% compared to 64% in the EU24 from 2010 to 2014. Finally, in the same year, the age-adjusted incidence rate of colorectal cancer was 30.85 and the death rate was 15.4. Survival rate was 53% compared to 60% in the EU24 from 2010 to 2014 (IARC, Poland Factsheet).

In Poland, breast (24.5%), lung (11.2%), and colorectal (11.3%) cancers are the most common among women. Prostate (24.5%), lung (17.6%), and colorectal (14.3%) cancers are the most common among men.

Figure 43. Age-Standardised Rate (World) per 100 000 , incidence, males and females in 2022. Poland



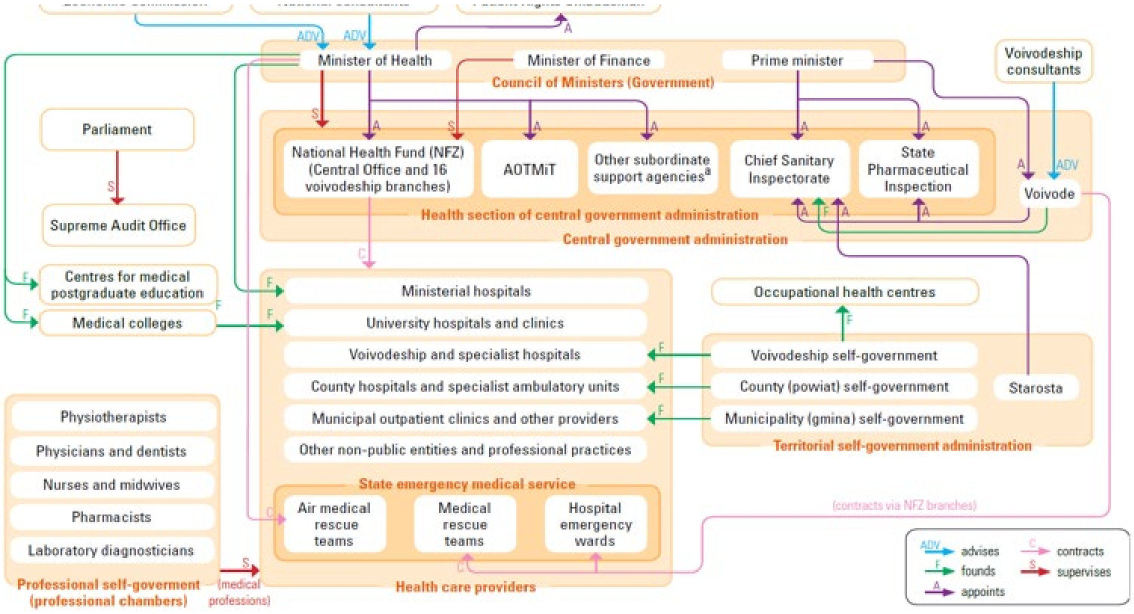
Since 1989, health system reforms followed Poland's rapid transition from a centrally planned economy to a market economy, along with administrative changes. Health care management and ownership were decentralized to lower territorial self-government levels, alongside the development of private medical practice.

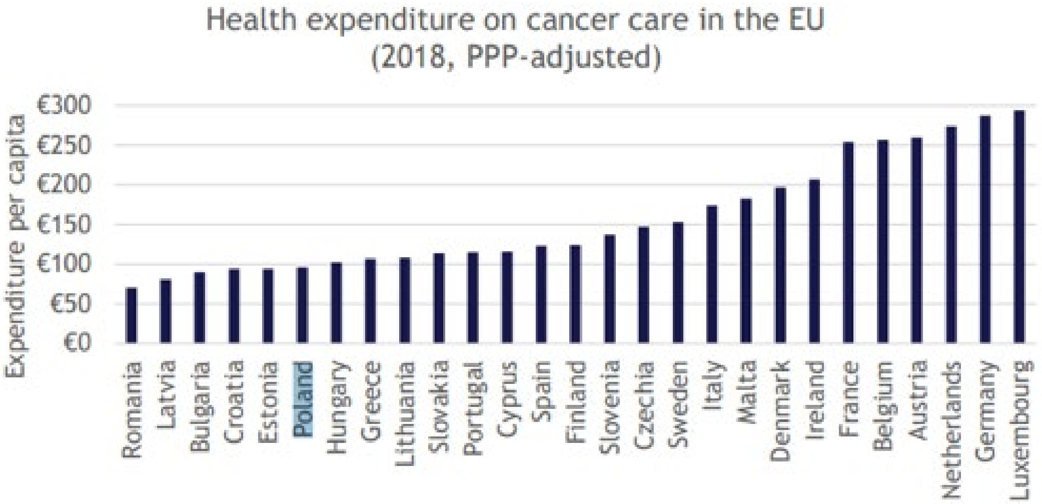
Initially, healthcare financing was decentralized in 1999 into 17 sickness funds and then recentralized in the **National Health Funds (NFZ)**. The NFZ contracting process with providers was decentralized to 16 voivodeship branches, and uniform contracting procedures ensuring equal healthcare access across all voivodeships. Municipalities manage primary healthcare, counties (powiats) manage smaller hospitals with basic specialties, and voivodeships manage larger hospitals providing complex procedures.

Financing of healthcare system

According to general statistics, Poland ranked at the bottom of EU countries in terms of per-capita health expenditure on cancer care in 2018. In 2023, the government planned to allocate more than PLN 5 billion for the National Oncology Strategy between 2020 and 2030. Nevertheless, barriers to accessing cancer care remain a topic of ongoing debate, with issues such as reimbursement for molecular testing still needing to be fully addressed.

Figure 44. Overview of the health system, 2018 in Sowada et al., 2019





Source: Per-capita health expenditure on cancer care (PPP adjusted) in EU member states in 2018 in Pousette et al., 2024.

NATIONAL PLANNING AND STRATEGIES

National planning for oncological diseases started in 2000s with different milestones achieved along the way. Worth emphasising is the introduction in 2015-2016 of the fast-track pathway for patients with suspicious symptoms of cancer. Equally important was the introduction in 2019-2021 of the experimentation with the pilot of cancer care networks

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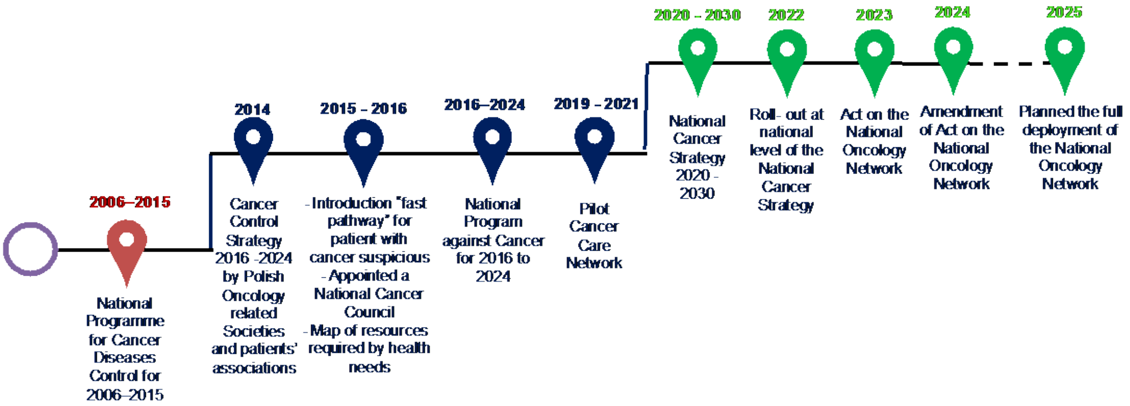
Figure 45. Timeline and milestones of cancer programmes in Poland



4.2 EARLY DETECTION: SCREENING

In 2019, the participation rate in the organised population-based screening programme for breast cancer was 54% (66% EU average). The participation rate in the organised population-based screening programme for cervical cancer was 63% (60% at EU average), and lastly, the participation rate in organised population-based and opportunistic screening programme for colorectal cancer was 8% (33% at EU average) (OECD CountryCancer Profie, 2023 and Andrzejczak et al., 2023).

In Poland, breast cancer and cervical cancer prevention programs are funded by the NFZ purchasing services from contracted healthcare providers.

The breast cancer prevention program started in 2007, provides mammography every 2 years to women aged 50–69, expanded to ages 45–74 in November 2023. Moreover:

- Women with a previous breast cancer diagnosis can participate annually after treatment completion and a 5-year monitoring period.

The cervical cancer prevention programme started 2007, offers cytology every 3 years to ages 25–59. Moreover:

- The NFZ covers traditional cytology, while the thin-layer cytology (LBC) is privately funded.

The colorectal cancer prevention program started in 2000 and offers free colonoscopy every 10 years to individuals aged 55–64 with personal invitation.

According to scholarly analyses, early cancer detection in Poland requires improvement. For instance, 40% of cervical cancer cases are detected too late for successful treatment (Sowada et al., 2019). Identified reasons include:

- Prolonged waiting times for diagnostic tests like MRI scans and colonoscopies (though colonoscopy access has improved).
- Ineffective screening programs, despite an increasing participation rate over the years for breast and cervical cancers, beginning with the National Programme Against Cancer Diseases (2006–2015), which increased mammography and cervical cytology rates and expanded colonoscopy access.

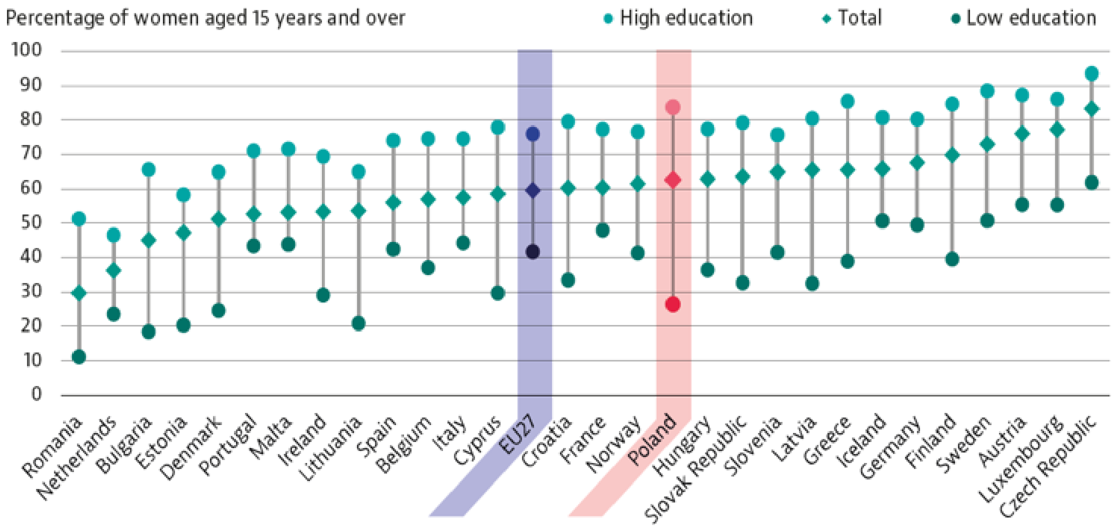
A recent survey among providers of breast and cervical cancer screening tests (Andrzejczak et al., 2023) highlights additional factors contributing to low participation rate in screening:

- Lack of personalised invitations
- Limited encouragement by general practitioners
- Inadequate public awareness campaigns - although other studies show a relatively high general knowledge about cancer screenings

Finally, the OECD Country Cancer Profile (2023) emphasizes the impact of low education level on the screening participation rate (see Figure 46). Considering EU countries, Poland has marked inequalities in cervical cancer screening by education level.

In Poland, the impact of education on cancer screening participation rates is higher than the EU average. The uptake of cervical screening is 58 percentage points higher among women with higher education levels (84%) compared to those with lower education levels (26%). Additionally, women in the first income quintile have a 28% points higher uptake (71%) compared to those in the fifth income quintile (42%).

Figure 46. Inequalities in cervical cancer screening by education level



Note: The EU average is weighted (calculated by Eurostat). The figure reports the percentage of women aged 15 years and over who reported having a cervical smear test in the past three years.
Source: Eurostat Database (EHIS). Data refer to 2019.

An analysis provided by a stakeholders group (Cancer Control Strategy by Polish Societies related to Oncology and patients' associations 2015–2024), although 10 years old, is still considered valid to our knowledge. It focuses on a sort of diarchy in the management of programs, involving the division of responsibilities between two groups of actors in the management of the programs:

- A first group consists of a Central Coordination Unit and 23 Regional Coordination Units, reporting to the Ministry of Health. This group is responsible for the administration and promotion of programs, as well as monitoring the quality tests.
- A second group operates under the auspices of the NFZ, handling contracts with public and private providers to finance the screening programs.

The latest National Oncology Strategy 2020–2030 plans the implementation of the following strategies to improve the cancer screening participation rate:

- Involve occupational health teams in primary and secondary prevention awareness campaigns.
- Introduce solutions that will enable Public Health Centres to actively invite citizens for screening tests.
- Improve screening quality by mandating the use of digital mammography and high-resolution endoscopes in colonoscopy examinations in the National Programs.
- Introduce mandatory certification of colposcopists and cyto-diagnosticians, implementing the "Cervical Cancer Prevention Program."

Policy interventions after 2014

Improving cancer care organization in Poland has been a public debate focal point involving external experts, patients, providers, and policymakers. These stakeholders shared the opinion that the two main challenges to be addressed were:

- Long waiting time for diagnostics and treatment
- Inefficient cancer care organization, emphasizing inpatient over outpatient care

This awareness led to the "Cancer Control Strategy 2016-2024" document publication by the Polish Oncology Association, scientific societies involved in cancer care, and a patients' association (PWC, 2014). Some of the several proposed interventions were implemented by the Government in the following years. On January 1, 2015, the Government introduced the so-called "oncological package" aimed at improving access to and streamlining cancer diagnostics and treatment, specifying patient pathway with the related maximum timing periods.

The goal of *comprehensive diagnosis and treatment* was pursued by mandating:

- Multidisciplinary consultations
- A care coordinator role

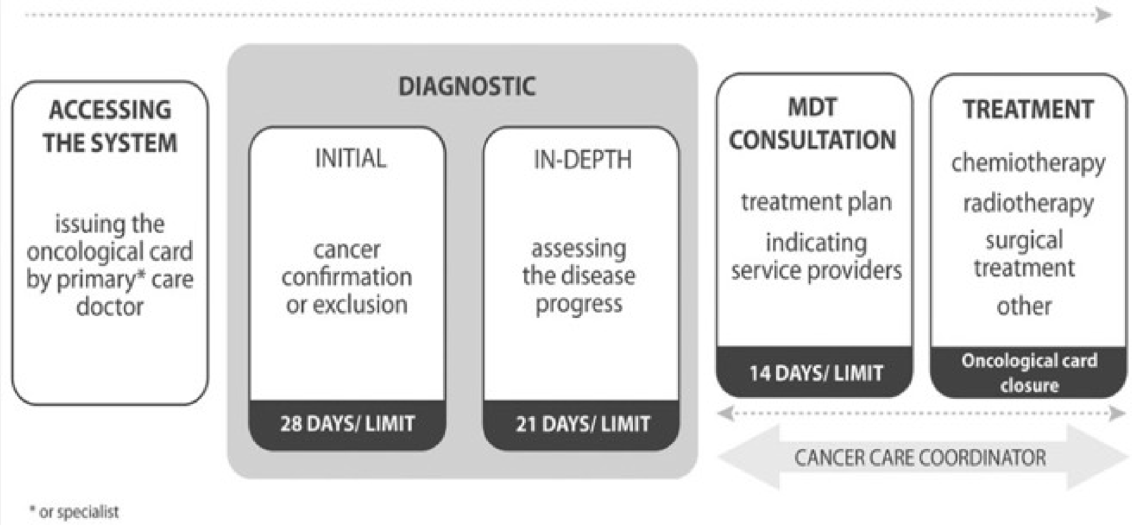
The package also established and appointed a National Oncology Council to monitor the Cancer Control Strategy and develop a national cancer action program. Finally, it defined five priority areas: (1) health promotion and primary prevention; (2) secondary prevention, including diagnostics and screening; (3) cancer treatment; (4) education for oncology professionals; and (5) a cancer register. For each priority, a set of tasks and outcome indicators were defined (Deal et al. 2018).

4.3 EARLY TREATMENT

In 2015, the so-called fast pathway for the cancer patient was implemented (see Figure 47). It includes the following steps:

1. A GP or primary care providers identify suspected cancer
2. Issuance of the Cancer Diagnostic and Treatment Card (DILO) grants access to the fast track involving public and private providers exempt from usual financial limitation
3. Initially, waiting time limits were 35 days for preliminary diagnostics and 28 days for in-depth diagnostic procedures, subsequently reduced t21 days (Amendments in July 2017) respectively and allowing specialist doctors (in addition to primary care physicians) issuing the oncological card (DILO).
4. The therapeutic process begins with a multidisciplinary team consultation. Hospitals designate a cancer care coordinator, responsible for coordination of the treatment process and providing information to the patient. The coordinator should assure the completeness of the patient's medical records, including those entered into the DILO card (Dela et al., 2018).

Figure 47. Oncological therapy fast-track



Source: Dela et al. 2018

The analysis of Dela et al. (2018) highlights the Supreme Audit Office's analysis indicating that:

- The reform was implemented without prior impact analysis or adequate preparation
- Medical associations' opinions were not considered in the initial regulation
- The public consultation process was too brief and focused on meeting formal legislative criteria rather than involving all relevant stakeholders
- The implementation stage faced significant protests from primary care doctors, who refused additional obligations without proper financial compensation

Sagan et al (2022), 4 years later, provides a most definitive assessment about the whole implementation process and the following outputs (see Table 15). Operational shortcomings became apparent soon after implementation, though some were addressed through legal amendments. For instance:

- Primary care doctors needed training and expanded competencies to order and interpret oncological diagnostic tests, which were previously limited to specialists.
- Initially, only primary care doctors could issue DiLO cards, causing delays as patients diagnosed by specialists still had to see their primary care doctors to access the new treatment pathway.

Table 17. Overview of the analysis on measures and key shortcomings of the oncological package

Measures	Key Shortcomings
Fast access to diagnostics and treatment	
Primary Health Care (PHC) doctors were assigned to issue DiLO cards to patients with suspected cancer, ensuring fast access to diagnostics and, if cancer is confirmed, to treatment.	• PHC doctors received no additional training or funding for cancer detection. • No extra financing was provided for basic diagnostic costs, which had to be covered within existing budgets. • Advanced diagnostics like CT or MRI scans could only be ordered by specialist doctors
Maximum waiting times for diagnostics and treatment were established, with financial incentives and penalties (up to 30% of the service value) for providers to ensure compliance.	• There are no maximum waiting times for the entire pathway • There are no standardized guidelines for diagnostics and treatment • No single provider is responsible for the entire pathway • There is no comprehensive, standardized evaluation of the quality of cancer care and health effects of applied treatments
A comprehensive diagnosis and treatment	
Establish a multidisciplinary council responsible for planning the treatment course	• Care fragmentation causes practical issues in organizing conciliums, • Since 2017, radiologist participation in conciliums has been optional.
Appoint a treatment coordinator to support patients throughout their treatment journey	• No coordination support is provided during the diagnostic phase. • There are no uniform guidelines or training for coordinators about their role and tasks
Abolish financing limits for services included in the treatment pathway	• The prices of some services within the pathway have been reduced • The pathway does not cover all cancers, all patient types, diagnostic settings, or services. • The pathway does not include post-treatment follow-up and prophylaxis [

Source: Table 1 in Sagan et a. 2022.

The authors also observe that:

- It is difficult to assess the real impact as providers can play system about the real moment of their patient management's beginning;
- It is yet difficult understanding in which extent the primary care role has improved in the cancer diagnosis;

- Insufficient training of PHC doctors in cancer detection;
- An unintended consequence has been an ever increasing of framgmentation: a very high number of providers were contracted although 18 of them provide the 50% of cancer services;
- 48% of patients who were referred to the pathway were found to have cancer;
- There is a lack of standardized diagnostic and treatment pathways in cancer care, leading to varying quality of care, particularly in facilities with low volumes of care.

The shortcomings in cancer care led to new proposals to improve it, resulting in the development of the **National Cancer Strategy 2020-30**. The strategy aims to improve the organization of cancer care through the **National Oncological Network**, while also increasing investment in primary and secondary prevention, human resources, science, and innovation. Drawing on experiences from other European countries, policymakers, the goal is to provide comprehensive and coordinated cancer services, covering prevention, diagnosis, treatment, monitoring, rehabilitation, palliative care, and hospice care through: (i) standardize care pathways; (ii) concentrate expertise in specialized procedures; (iii) monitor quality.

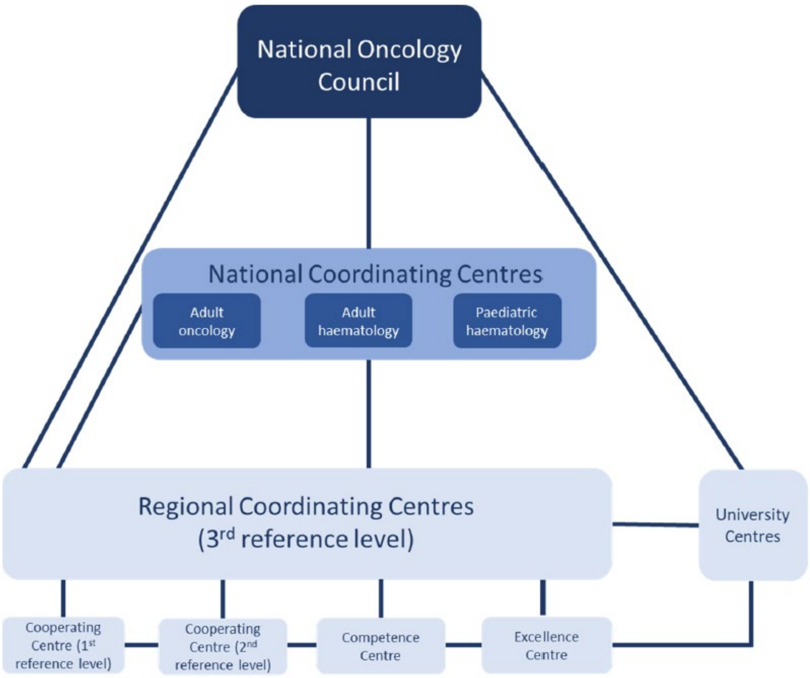
National Oncology Council

This organizational structure was described by Sagan et al. based on a 2018 Ministry of Health document and it appears to have given greater power to the National Oncology Council in terms of setting providers, accrediting providers, and monitoring the system's overall functioning. According to our understanding, the current 2023 Law revised this approach, assigning the National Oncology Council the role of providing opinions on these functions rather than managing them directly, as they are now the responsibility of the National Cancer Institute and the Polish Oncology Association (see Figure 48).

The National Oncological Network's model was piloted in four regions (2019 and 2020) to test the new model and collect clinical data. In particular:

- Specific patient pathways were developed and implemented through detailed protocols
- Diagnostic and therapeutic guidelines were established for the five most common cancers.
- A set of 35 quality indicators monitoring the timeliness of diagnostic tests and treatment, completeness of diagnostics was established

Figure 48. Structure of the national oncological network



Source: Proposed organization of the National Oncology Network, developed in 2018. in Sagan et al., 2022.

- Care coordinators were introduced from the start of a patient's cancer journey with defined responsibilities and procedures for working with medical staff
- Dedicated call centres provided cancer care information
- Patient satisfaction surveys evaluated timeliness, complexity, ease of access, and overall experience

The pilot project was initially planned to run from 2019 to 2020, but it was to 2021 due to the COVID-19 pandemic and challenges in interpreting the results. The official data published in 2021 showed mixed results across the four regions. While some centres, such as the Lower Silesia Oncology Centre, reported positive outcomes, these were mainly related to organizational changes and basic process measures, rather than quality indicators or patient outcomes. Moreover, due to limited baseline data and comparative information, a thorough evaluation remains challenging.

On World Cancer Day in 2021, Poland announced plans to expand the cancer care network nationwide by January 2022. The draft law was based on a preliminary assessment by the Polish

Cancer Society, which will launch pilots nationwide without a final assessment report. Polish Government issued a Law about the National Cancer Network in March 2023 ruling out:

- organization and principles of operation of the National Oncology Network defining three levels of cancer care provision and the related standards, and making the NFZ responsible to qualify and verify the compliance of cancer care provider with the expected level of care
- principles and method of monitoring the quality of oncological care by a National Monitoring Centre performed by the Maria Skłodowska-Curie National Institute of Oncology – State Research Institute in Warsaw and by the Polish Oncology Association
- principles of operation and tasks of the National Oncology Council, hereinafter referred to as the "Council" providing an advisory and consultative function for the minister responsible for health and the NZF.
- principles and mode of financing of the National Oncology Network in accordance with agreements on the provision of healthcare services
- principles of data sharing within the National Oncology Network;
- principles of oncological diagnosis and treatment based on the oncological diagnosis and treatment card already implemented

The 9th of March 2023 Act planned to deploy the National Cancer Network at national level in 2024. Political election changed the Government's majority, and the new Ministry of Health issued a new Act (on 22nd February 2024) amending the 2023 Act with postponing the qualification of cancer care providers joining the network from March 2024 to March 2025 that ensures proper timing for providers to prepare the necessary human and technological resources and establish rules for the flow of information among network members.

Although the paper by Segan et al. (2022) was published before the 2023 Law, it provides some helpful comments about the draft of the Law concerning the National Cancer Care Network and the Polish approach to enhancing cancer care in the country. Specifically, they observe that:

- The design of the network does not include the prevention and early detection steps (i.e. screening and addressing possible symptoms at primary care level). The definitive Law assigns the task of monitoring the screening programs and prevention initiatives to the Maria Skłodowska-Curie National Institute of Oncology – State Research Institute and the Polish Oncology Association. Moreover, the fast-track model, the only process addressing the link between primary and secondary care, is included in the 2023 Law without any changes addressing the shortcomings identified in the previous implementation.

- A rush to implement the National Cancer Care Network risks causing providers to lose the opportunity to redesign their internal organization of human and technological resources. However, the current government has postponed the deployment from 2024 to 2025. It remains to be seen whether this delay is sufficient to ensure the proper time for investment and reorganization by the providers.
- It is still difficult to implement an evidence-based decision-making process as the Polish healthcare system lacks reliable and detailed data to inform decision-making, particularly in the cancer care sector. So far, the National Cancer Registry collects some information, but coverage is limited and often delayed, and healthcare providers focus on collecting process data for financial settlements with the National Health Fund rather than gathering meaningful data to improve cancer care. This approach prioritizes hospital care, which may perpetuate an imbalance in the distribution of resources and services in favour of secondary care, continuing the neglect of primary care.
- The National Oncology Network's metrics and indicators are a step towards establishing a quality assessment system for cancer care in Poland, allowing for evaluations at the national, regional, and provider levels. This development is a positive change that could lead to real improvements and a shift away from the current status quo.
- The implementation of an innovative care model through a pilot project, which follows recent legislation approved in 2017, represents an important step forward in the process of designing organizational innovations in Polish healthcare.

CHILE

5.1 BACKGROUND

POPULATION

Epidemiological outlook

Breast cancer: the estimated incidence and death rate[10] based on two public anonymized databases provided by the Ministry of Health between 2007 and 2018:

- Age-adjusted incidence rates remained stable over time, with an average of 44.0 cases per 100,000 women (Madariaga et al. 2024);
- Age-adjusted mortality rate averages 10.5 cases per100,000 women (Madariaga et al. 2024).

Cervical cancer: the estimated incidence and death rate in 2020 from AIRC source:

- Age-adjusted incidence was 11.0 cases/100,000 women (the lowest in South America)
- Age-adjusted mortality rate was 5.15 cases/100,000 women (Bruni et al., 2023).

Colorectal cancer: the estimated incidence and death rate based on the national registry of all inpatient discharges from hospitals in Chile between 2001 and 2019:

- The 2018 age-adjusted incidence rate was 16.5 cases/100,000 women and 21.0 cases/100,000 men°
- The 2018 age-adjusted mortality was 7.9 cases/100,000 women and 11.1 cases/100,000 men (Mondschein al., 2022).

Chile has the highest stomach cancer rate among the large Latin American countries with 17.8 new cases per 100,000 in 2018. Moreover, Chile has the second highest incidence rate of prostate and colorectal cancer in Latin America (see Figure 48).

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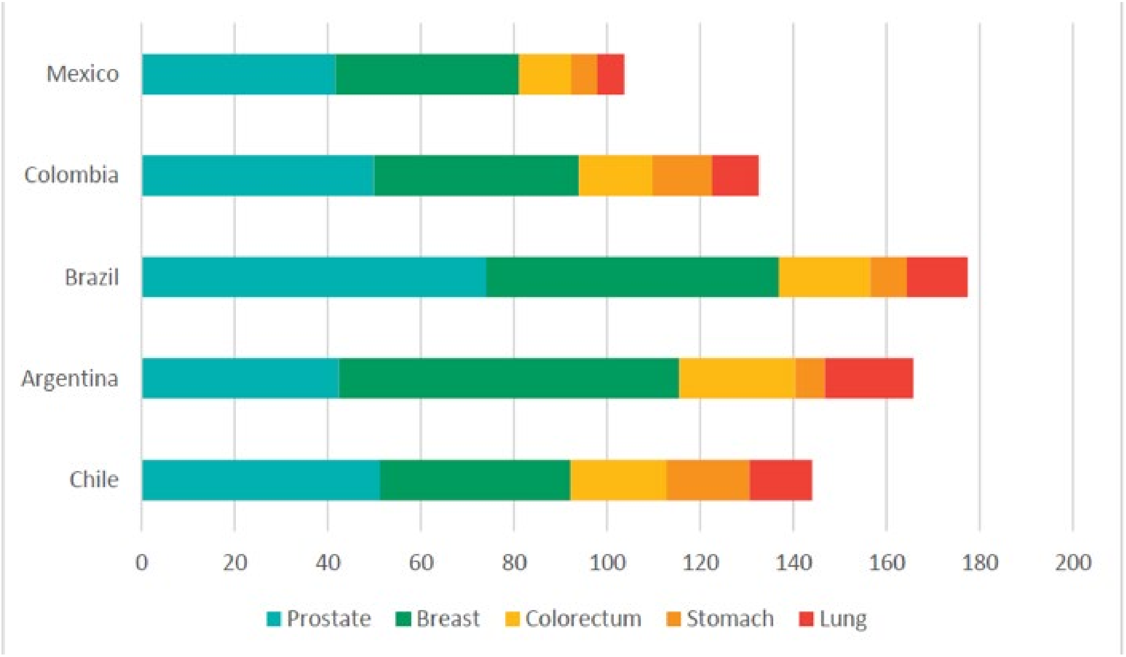
[10] Chile does not have a national cancer registry

Figure 49. Estimated age-standardized cancer incidence rate per 100,000 people in 2018, by cancer type



Source IARC Cancer Today

HEALTHCARE SYSTEM ACCESS

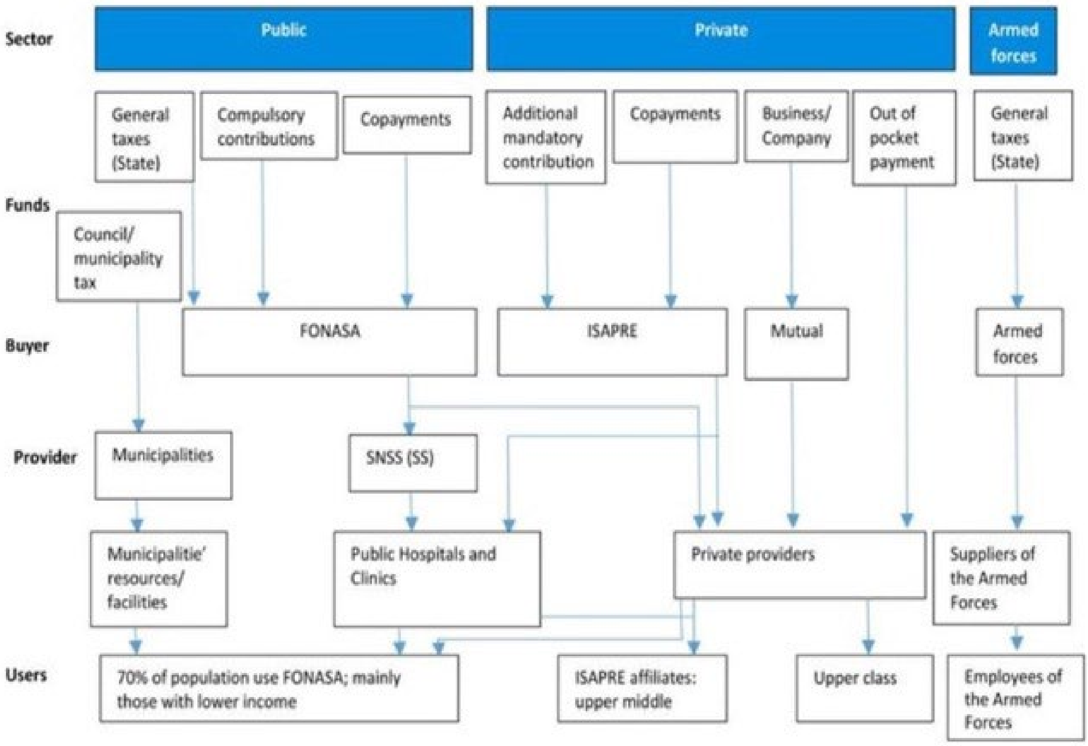
Despite recent reforms, Figure 50 offers a glimpse into the ongoing hybrid nature of Chile's healthcare system.

In 2005, a policy, known as *Explicit Health Guarantees (GES)* was launched with the goal of improving healthcare access, quality, timeliness, and financial protection for 80 specific health conditions. The program ensures coverage through two systems:

- FONASA, a public insurance system that covers 80% of the population
- ISAPRES, a private insurance system that covers 18% of the population.

GES also sets specific timelines for patient care, (e.g. a 30-day wait for diagnostic confirmation and specialist appointment for gastric cancer). Significant disparities exist between the benefits offered by FONASA and ISAPRES, particularly in access to cancer care and health outcomes.

Figure 50. Overview of Chile healthcare system



Source Justo et al., 2018. from Becerril-Montekio et al., 2011

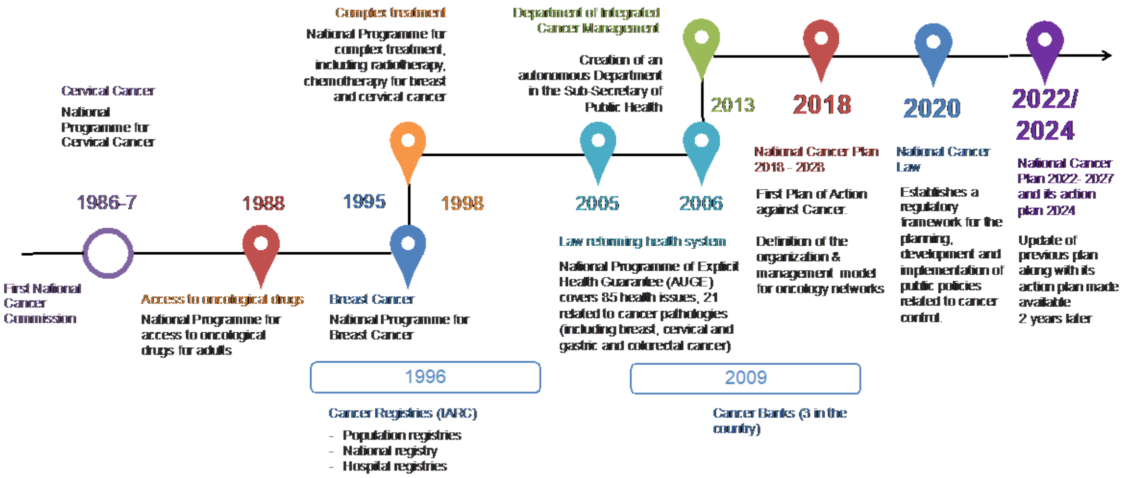
National planning and milestones

National planning for oncological diseases dates back to the 1980s with the creation of the first National Cancer Commission. The nineties were marked by the introduction of the national programme for breast cancer and the introduction of cancer registries promoted by WHO. The recent milestones worth mentioning are the introduction in 2018 of the National Cancer Plan and the adoption of the National Cancer Law in 2020. Figure 51 provides an overview of the progress in oncological planning in Chile.

5.2 EARLY DETECTION

In 2018, the participation rate in the organised screening programme in breast cancer was 40%, in the organised screening program for cervical cancer was 52%, and finally there is no organised national screening programme for colorectal cancer.

Figure 51. Timeline and milestones of cancer programmes in Chile



According to GLOBOCAN, Chile's age-standardized cancer incidence rate in 2018 was 195.5 new cases per 100,000 people, ranking between Mexico and Colombia, and below the rates in Brazil and Argentina. The cancer incidence is estimated to continue rising in Chile, with a 38.3% increase in cancer cases between 2020 and 2030, and an 74.9% increase between 2020 and 2040 (OECD Sta and Global Cancer Observatory).

Breast cancer: officially the breast cancer screening program was launched in the ’90s. However, there were several barriers to full access:

- There were few mammography facilities
- Insurance policies did not cover often the mammography exams
- Lack of trained professionals
- Cancer awareness campaigns were limited

In 2013 the Ministry of Health launched a new program to provide free mammography screenings to all women aged 40-69 years, regardless of their health insurance status.

National cervical cancer control actions started in 1966. In 1987 the National Cervical Cancer Programme was reformulated. Between 1993 – 1996 was created the National Cytopathology Referral Laboratory and investment in its computerization. In the year 2003-2006, the Clinical Guidelines on Cervical Cancer and program was published, ensuring compliance with maximum intervals for diagnosis, treatment and follow-up (2003 – 2006). In parallel, in 2005 was introduced the Universal Access with Explicit Health Guarantees (AUGE) health scheme. The HPV vaccine included in the annual immunization program was adopted in 2013 for: (i) girls aged between 9 and 13 years; and in 2015 for (ii) girls aged up to 13 years old.

5.3 EARLY TREATMENT

The National Programme of Explicit Health Guarantee (AUGE) covers 85 health issues, 21 of which are related to cancer pathologies (including breast, cervical, gastric, and colorectal cancer), where time constraints for access to oncological diagnostic and treatment services are defined.

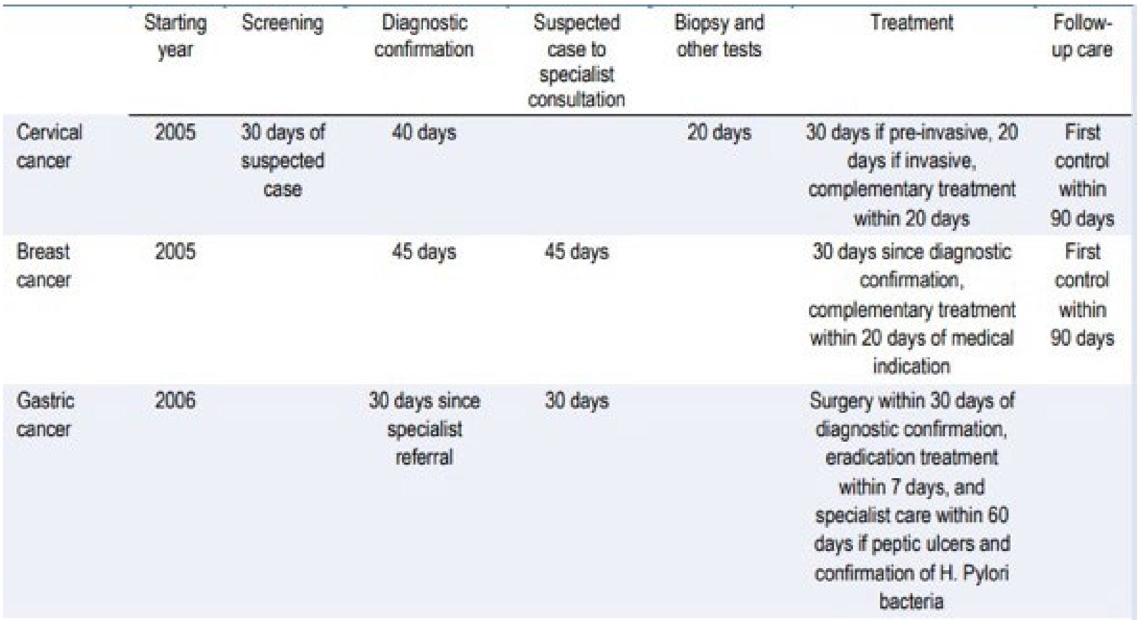
An assessment of cancer care in Chile

The goals of the 2023 ICCI-LA report «Addressing the Rising Burden of Cancer in Chile: Challenges & Opportunities» are: (i) to discuss the broader context of Chile's healthcare system regarding cancer; (ii) to identify major health system challenges as perceived by stakeholders; (iii) to examine policy options suggested by experts involved in the ICCI-LA study to address these challenges.

The challenges identified through a stakeholder survey and running virtual workshops include:

- Poor allocation of resources
- Poor financial organization
- Inefficiency in healthcare
- Fragmentation of the health system

Table 18. AUGE coverage and waiting time guarantees for cancer care



	Starting year	Screening	Diagnostic confirmation	Suspected case to specialist consultation	Biopsy and other tests	Treatment	Follow-up care
Cervical cancer	2005	30 days of suspected case	40 days		20 days	30 days if pre-invasive, 20 days if invasive, complementary treatment within 20 days	First control within 90 days
Breast cancer	2005		45 days	45 days		30 days since diagnostic confirmation, complementary treatment within 20 days of medical indication	First control within 90 days
Gastric cancer	2006		30 days since specialist referral	30 days		Surgery within 30 days of diagnostic confirmation, eradication treatment within 7 days, and specialist care within 60 days if peptic ulcers and confirmation of H. Pylori bacteria	

Source: OECD Cancer Screening and prevention in Chile

- Poor coordination and collaboration among different administrations and healthcare providers
- Lack of focus on prevention and primary care

The Report provides the following recommendations - coming from the summarised challenges identified through a stakeholder survey and virtual workshops - include:

Highest Priority

- Redesign cancer care delivery to eliminate fragmentation and ensure consistently high-quality, equitable, and patient-cantered
- Enhance access to cancer care across Chile by increasing regional capacity and improving services across all cancer treatment settings
- Conduct robust economic analysis to optimize resource allocation and ensure the efficient use of funds for cancer care and control

High Priority

- Strengthen regulatory frameworks to enhance the effectiveness of budget oversight, inspection, and surveillance at national and regional levels.

- Develop a comprehensive, population-based registry to track cancer incidence and prevalence nationwide.
- Establish an autonomous Cancer Authority responsible for devising cancer policies, providing training and technical assistance, evaluating cancer programs, and overseeing the implementation of the National Cancer Plan.

Medium Priority

- Enhance the focus on cancer prevention by making it a national priority.
- Develop and implement a strategic plan to incrementally increase the national budget allocation for cancer control, ensuring sustainable funding for programs and services.
- Strengthen primary healthcare in Chile by expanding its role in cancer prevention, early detection, and care coordination to improve patient outcomes and health system capacity.

National Cancer plan 2018 – 2028 (1° edition)

In April 2018, the Chilean Minister of Health at the time made an unprecedented call for civil society to contribute to the development of a 10-year National Cancer Plan. An "Advisory Council on Cancer Matters" was formed, comprising representatives from scientific organizations, universities, foundations, government ministries and civil society. The Council defined five strategic lines for the Action Plan to be issued (see next):

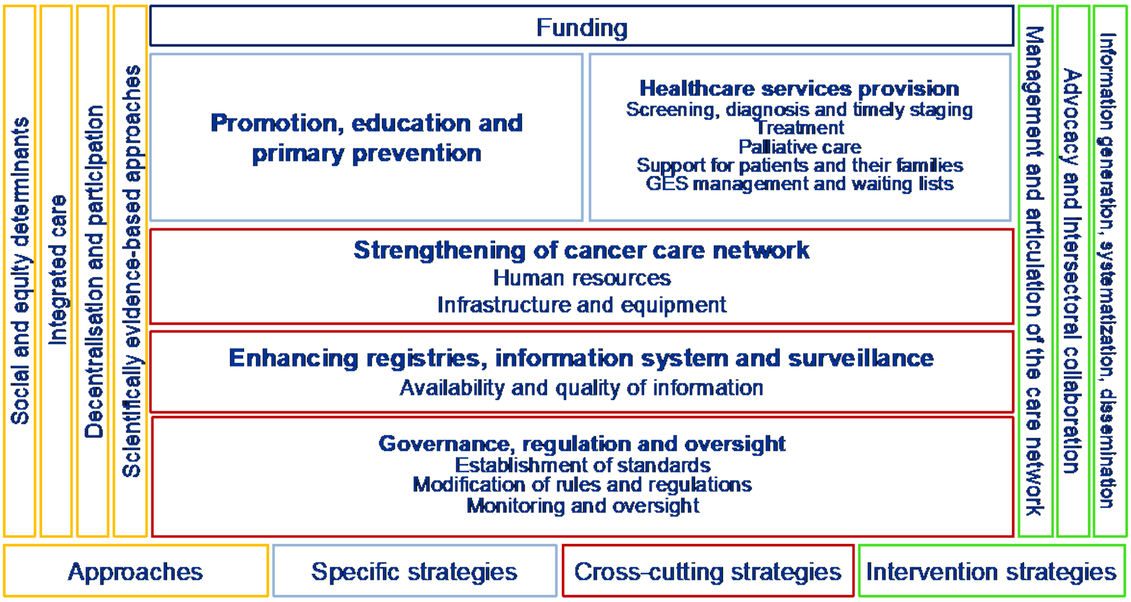
- Cancer promotion, education, and prevention
- Healthcare services provision
- Strengthening the oncology network
- Enhancing registration, research, and surveillance systems
- Stewardship, regulation, and oversight

Moreover, the National Cancer Plan defined 15 objectives to be attained by 2028:

1. Increase greater awareness
2. Strengthen healthy lifestyles and encourage self-care through health education

3. Generate a healthy environment
4. Improve immunization coverage against the human papilloma virus
5. Enhance screening coverage, ensuring timely and high-quality of confirmation of diagnoses and coordination with the pertinent referral centre
6. Ensure comprehensive, timely and quality treatment
7. Guarantee timely access to comprehensive palliative care
8. Integrate patient surroundings into their treatment & disease monitoring
9. Improve network management and GES compliance
10. Develop necessary human resources
11. Strengthen the National Oncology Network
12. Improve record keeping, information system and epidemiological surveillance & national registries by 2020
13. Promote cancer research
14. Ensure sustainable & incremental financing
15. Reinforce stewardship, regulation and oversight.

Figure 52. Presentation of the main approaches and strategies to be implemented by the National Cancer Plan 2018 - 2028



Source: Ministry of Health presentation of the National Cancer Plan 2018-2028 to the Chilean Parliament.

Building up the cancer care network 2018

A generative and collaborative process was undertaken to define the cancer care network model. In 2018, the Ministry of Health published a document collaboratively developed through a participatory and deliberative process, involving wide representation from the network's various levels of care, management, and citizen participation. The document, titled «Models for managing the cancer care network» provides:

- A snapshot of the public cancer care network in 2018 in terms of organisation and resources availability
- A detailed analysis of the critical issues to be addressed (e.g. capacity)
- A comprehensive proposal of redesigning the network's governance, organisation and standards

The management model provided is designed to integrate various levels of healthcare provision (primary and secondary care) across macro-regional levels to ensure a comprehensive and standardized care. Special emphasis is placed on the integration of services from prevention and early detection to treatment and palliative care. (i.e. a comprehensive cancer care network model). The document addresses operational details such as Organization of service provision, and roles of different healthcare facilities; governance structure of the network; geographic distribution of network services, identifying critical nodes and bottlenecks affecting service delivery. The model's implementation will be led by regional managers at the meso-regional level, working together with their teams, the network, and central support to ensure its effective functioning.

National Cancer Law 2020

Civil society, particularly non-governmental organisations (NGOs), played a key role in advocating for a National Cancer Law as the legal framework for the National Cancer Plan (Quijano et al. 2022). In 2020, a National Cancer Law was adopted to provide a systemic response to cancer care. More specifically, the Law:

- Establishes the guiding principles for all cancer policy initiatives in Chile
- Designates the Ministry of Health as responsible entity for the formulation of the National Cancer Plan
- Mandated the revision of the National Action Plan every five years

- Instructs the creation of a National Cancer Commission, whose mission is to advise the Ministry in the formulation of policies and strategy implementation, and together, as responsible for the revision and evaluation of the Plan
- Creates a National Cancer Fund to co-finance this policy with private contributions
- Regulates the establishment of a National Oncology Network, consisting of specialised centres as part of the Health Care Network, dedicated the diagnosis, treatment and follow-up of cancer patients. These centres will be categorised into High, Medium and Low Complexity of cases
- Delegates the authority to develop standards for existing and new centres.

The National Cancer Plan 2022–2027

The National Cancer Plan 2022–2027 is an update of the National Cancer Plan 2018-2028. It also contains the Action Plan for Adults. Bleow are summarised the actions regarding early detection, early diagnosis and early treatment.

1. *<u>Early detection and screening</u>*
    a. *Enhancing Cancer Screening Programmes and Early Diagnosis Interventions*

Basic actions to improve cancer screening coverage and early detection

- Integrate breast and cervical cancer screening into management commitments of primary and public and private secondary care
- Encourage the completion of screening exams, including follow-up exams in cases of suspected cancer, within the healthcare services network
- Expand gynaecological check-ups in community spaces through mobile gynaecological clinics
- Increase the availability of preventive gynaecological check-ups in primary care, with emphasis on cervical cancer and breast cancer screening

Basic actions to improve cancer screening information and monitoring system

- Merge and standardize information systems, monitoring, and surveillance for cancer screening

- Implement and monitor the application of the monitoring of Mammography Technical Quality Standard GLs based on the General Technical Standards issued by a Ministry of Health Decree

Expanded actions to improve cancer screening information and monitoring system

- Link computer systems that enable active searching for women and trans men for breast and cervical cancer screening.
- Improve connectivity in primacy care mammography machines allowing them to function as Spokes in a Digital Mammography System.

b. Early detection and screening programs: Improving coverage rates and detection processes leading to the early diagnosis:

Basic actions to introduce new screening programmes and early detection and screening techniques

- Conduct cost-effectiveness assessment for prostate, lung and colorectal cancer screening programs

Expanded actions to introduce new screening programs and early detection and screening techniques

- Expand primary cervical cancer screening by introducing HPV molecular determination tests in women and transgender men aged 35 to 45 years.
- Implement HPV self-testing techniques, in line with guidelines established at the central level

Basic actions to standardise of cancer screening procedures

- Develop training programs for healthcare teams on secondary cancer prevention topics, coordinated by SEREMIS (Secretarías Regionales Ministeriales de Salud - Regional Ministerial Secretariats of Health). This trainign will also address equity issues in access to screening programs

Expanded actions to implement standardization of cancer screening procedures

- Develop administrative clinical management algorithms in cancer screening.

- Update technical quality standards for mammography procedures

2. Early diagnosis and treatment
    a. *Strengthening the oncology network for early diagnosis and treatment*

Basic actions to consolidate the integration of providers in the oncology network

- Update the categorization of centres in the Oncological Network by high, medium, and low complexity, specifying the classification for each centre based on geographical location and complexity level
- Formalize medium - and – high-complexity centres in the National Oncological Network, defining the multidisciplinary health personnel and case management professionals that make up the team.

Expanded actions to consolidate the integration of providers in the oncology network

- Design a national referral network in anatomical pathology to centralize the diagnosis of specific cancers.
- Develop a referral plan for oncology support services, including pathology, transfusion medicine, clinical laboratory, imaging, nuclear medicine, and pharmacy

Desirable actions to consolidate the integration of providers in the oncology network

- Implement an integrated IT system for the traceability and management of drugs across the entire oncology network.
- Enable interoperability of consultation systems to access electronic records and test results for cancer patients.

b. *Improve early diagnosis and treatment by strengthening the providers relationships within the national oncology network*

Basic actions to define and implement protocols and guidelines for safe and effective cancer care

- Update the management model of the Oncology Network.
- Establish standards of human resources required in a comprehensive oncology care, considering levels of care, process, gender, territorial and intercultural relevance.
- Develop infrastructure and equipment standards for cancer care

Expanded actions to define and implement protocols and guidelines for safe and effective cancer care

- Develop training opportunities for the SEREMIS regarding health establishments providing oncology services to strengthen oversight
- Design a development plan for the national oncology network.
- Define the human resource training policy for cancer treatment, covering both medical specialists, health professionals, and researchers in the field.
- Prepare architectural design guidelines for units related to oncology according to the care model and defined standards.

Desirable action to define and implement protocols and guidelines for safe and effective cancer care

- Implement the development plan for the national oncology network

c. Enhancing citizen participation in oncology network development

Basic actions to involve citizens and associations in the oncology network design

- Design and implement through local councils and consultation a program aimed at involving citizens and association engage in the cancer care in the oncology network design.
- Develop a national cancer registry system

Basic actions to improve cancer registers through integrated information system

- Develop data collection processes to support for epidemiological analysis related to cancer

Expanded actions to improve cancer registers through integrated information system

- Strengthen the traceability system of user route milestones and alerts, encouraging widespread use of the monitoring platform for people with cancer
- Expand population-based cancer registries by increasing human resources, providing training and expanding the number of regions covered
- Implement mandatory notification of oncological health issues in the public and private systems
- Coordinate proposals to identify key factors contributing to non-GES waiting lists

Desirable action to improve cancer registries through integrated information system

- Implement integrated software for all pathology anatomy units in the public healthcare network, featuring computerized biopsy traceability to contribute to the national cancer registry

Cancer Action Plan monitoring indicators are summarised in Figure 53.

The design and the implementation of the cancer care network

The design and the implementation process of the cancer care network can be broken down into three key steps:

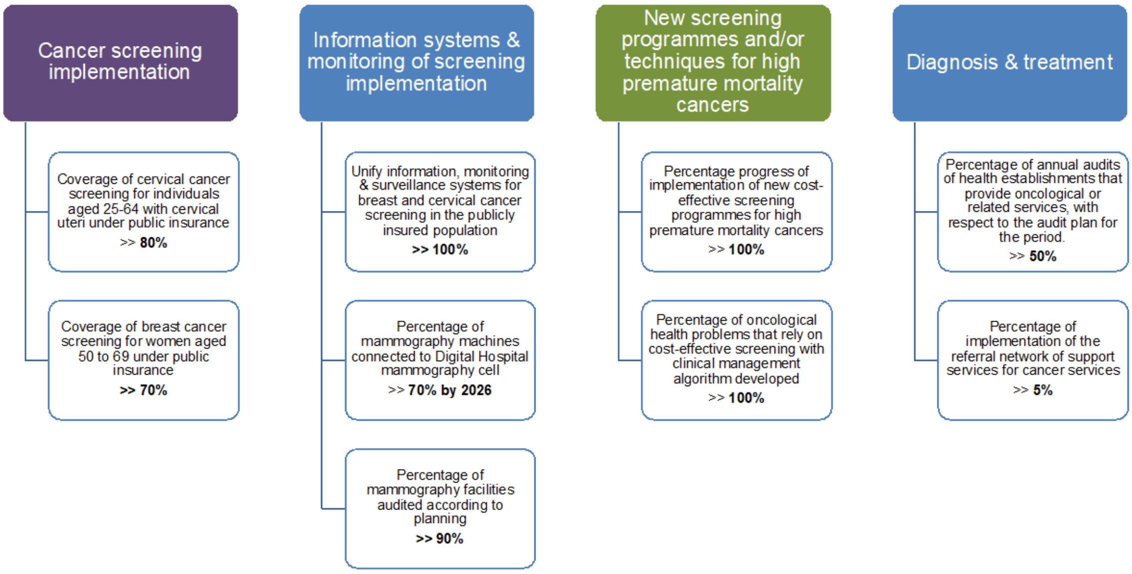
- A collaborative and generative process defined the initial stages of the oncology network, proposing a governance structure with macro-regional health authorities to ensure comprehensive and standardized care.
- The network was then shaped by various measures, including national cancer plans, an action plan, and a national law.
- The model under implementation follows a pyramidal structure, where the Ministry of Health provides the necessary tools (guidelines, standards, information flows etc.) to enable the 29 existing Health Services (SS) within the National System of Health Services (SNSS) to develop a cancer care network in their respective regional or sub-regional areas. These areas will integrate tertiary, secondary, and primary cancer care.

Notably, the National Cancer Commission's independent advisory role in overseeing Ministry of Health measures appears to be inactive at present. The Ministry of Health's current focus is on:

- Mandating guidelines and standards that determine which providers can join the network and the level of cancer care they provide.
- Implementing a mandatory notification process for cancer cases.
- Developing a shared platform to collect data on a sample size, which will be used to inform decision-making processes, and issuing an Act ensuring the interoperability among providers' information systems.

The Ministry of Health conducts regular visits to regional health secretariats, Health Services and local providers to monitor the implementation of required standards on a monthly basis.

Figure 53. Monitoring indicators of Cancer Action Plan



CONCLUSIONS

At the heart of a Lavender Zone we have identified three key dimensions: comprehensiveness, continuity, and timeliness. These zones are built on robust organizational tools, carefully crafted strategies, and integrated solutions that together form a responsive and efficient early cancer care system. They prioritize the involvement of citizens and patients, support multidisciplinary teamwork, and rely on structured, evidence-based decision-making processes.

Table 19. The essential items of a Lavender Zone

ESSENTIAL ITEMS OF A LAVENDER ZONE	STRATEGIES	SOLUTIONS (ORGANISATIONS & TOOLS)
COMPREHENSIVENESS	✓ The place and manner of governing and connecting all involved stakeholders ✓ The proper way to involve & support citizens, patients, and their families	✓ Cross-cutting bodies across multiple coordination and liaison areas, cancer control plans, shared action plans, evidence-based decision-making process ✓ Tailor-made health literacy intervention ✓ Informed patient / provider-patient shared decision-process
CONTINUITY	✓ Right balance of de/centralization and integration, depending on institutional structure and geographical features ✓ Down-up-down design process involving clinicians, managers and policymakers	✓ CCCNs based on pathways, care navigator, centralization of cross-cutting services, multi-disciplinary/multi-professional teams ✓ Process for accessing early treatment drugs ✓ Virtual platforms ✓ GLs, standards, procedures, evidence-based updating process
TIMELINESS	✓ Involving the entire healthcare system in cancer detection ✓ Develop patient-centered logistic solutions ✓ Use the information system and KPIs in powering a quality assurance system	✓ Virtual platforms ✓ Well-established referral procedures between primary and secondary care ✓ One access point to the diagnostic and treatment pathway ✓ Training / update on cancer symptoms and possible suspicion ✓ Training for civil servants, healthcare managers, and clinicians to feed and to use the monitoring system

Organizationally, Lavender Zones feature cancer care coordination networks (CCCNs), care navigators, and centralized services that ensure consistency and support throughout the patient journey. These structures are complemented by virtual platforms, clinical guidelines, and continual professional training — all of which are regularly updated through collaborative, bottom-up and top-down design processes that involve clinicians, managers, and policymakers.

In terms of strategy, Lavender Zones emphasize a balance between decentralization and integration, tailored to each country's institutional and geographical context. They promote shared decision-making, tailored health literacy efforts, and strong coordination across primary and secondary care. Crucially, these systems ensure that patients have timely access to diagnostic and treatment pathways through well-established referral mechanisms and the integration of digital tools.

However, creating such environments is not without challenges. Structural and institutional aspects—such as fragmented payer-provider systems or unclear governance between central and regional authorities—can obstruct continuity and coordination. A successful Lavender Zone must overcome these barriers by fostering trust, securing long-term political and organizational commitment, and establishing clear roles for all stakeholders involved.

Importantly, the presentation argues that policymakers often recognize the value of early cancer care in theory but fall short in practice. Early detection and intervention are frequently treated as secondary outcomes of broader cancer care strategies. In contrast, the Lavender Zone model proposes a reversal of this approach: early cancer care should be treated as the foundation of the entire cancer control strategy, demanding focused investment, cross-sector collaboration, and measurable goals.

Ultimately, the experience of Lavender Zones illustrates that turning words into action relies not only on structural solutions, but also on the intangible drivers of success: trust, sustained effort, effective communication, and a shared commitment to evidence-based policymaking.

REFERENCES

3. Andermann A., Blancquaert I, Beauchamp S., Déry V. (2008) Revisiting Wilson and Jungner in the genomic age: a review of screening criteria over the past 40 years. Bulletin of the World Health Organization, 86 (4). doi:10.2471/BLT.07.050112
4. Anttila M., Arbyn H., De Vuyst J., Dillner J., Dillner L. et al. (eds.) (2015) European guidelines for quality assurance in cervical cancer screening Second Edition Supplements. European Union. https://www.gisci.it/documenti/news/EW0115451ENN_002.pdf (accessed 15 November 2023).
5. Basu P, Lucas E, Carvalho AL, Sauvaget C, Muwonge R, Herrero R, Sankaranarayanan R (2019). Cancer Screening in Five Continents. Lyon, France: International Agency for Research on Cancer. Available from: https://canscreen5.iarc.fr (accessed 6 November 2023).
6. Dillner, J. (2019). Early detection and prevention. Molecular oncology, 13(3), 591-598.
7. Jacobsen KK, von Euler-Chelpin M. (2012) Performance indicators for participation in organized mammography screening. J Public Health; 34(2):272-8. doi: 10.1093/pubmed/fdr106.
8. Perry N., Broeders M., de Wolf C., Törnberg S., Holland R., von Karsa L (eds.) (2006), European guidelines for quality assurance in breast cancer screening and diagnosis. 4th Edition. European Communities. https://ec.europa.eu/health/ph_projects/2002/cancer/fp_cancer_2002_ext_guid_01.pdf (accessed 15 December 2023)
9. Ponti et al. (2017) Cancer Screening in the European Union. Report on the implementation of the Council Recommendation on cancer screening. https://health.ec.europa.eu/system/files/2017-05/2017_cancerscreening_2ndreportimplementation_en_0.pdf
10. WHO, (2017) Guide to cancer early diagnosis. Geneva: World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/254500/9789241511940-eng.pdf?sequence=1&isAllowed=y
11. WHO, (2020) Report on Cancer. Setting priorities, investing wisely and providing care for all. Geneva: World Health Organisation. https://www.who.int/publications-detail-redirect/9789240001299 (accessed 5 November 2023)
12. Wilson JMG, Jungner G. (1968) Principles and practice of screening for disease. Geneva: WHO. Available from: http://www.who.int/bulletin/volumes/86/4/07-050112BP.pdf

Denmark

1. Horshauge PM, Gabel P, Larsen MB, Kirkegaard P, Edwards A, Andersen B. The association between health literacy and colorectal cancer screening uptake in a publicly funded screening program in Denmark: Cross-sectional study. Prev Med Rep. 2020 May 29;19:101132. doi: 10.1016/j.pmedr.2020.101132
2. Sundhedsstyrelsen, Statusrapport for de nationale screeningsprogrammer for kræft 2022, Sundhedsstyrelsen, 2022 .[The National Board of Health / Danish Health Authority, Status report for the national screening programs for cancer 2022a, The National Board of Health, 2022.] http://www.sst.dk/da/udgivelser/2022/Statusrapport-for-de-nationale-screeningsprogrammer-for-kraeft
3. Tatari CR, Andersen B, Brogaard T, Badre-Esfahani S, Jaafar N, Kirkegaard P. The SWIM study: Ethnic minority women's ideas and preferences for a tailored intervention to promote national cancer screening programmes-A qualitative interview study. Health Expect. 2021 Oct;24(5):1692-1700. doi: 10.1111/hex.13309.
4. Dept of Public Health of Aarhus University and Danish Health Authority, ”Sundhedskompetence i det danske sundhedsvæsen. En vej til mere lighed” [Health Literacy in Danish Health Care Organisations A path towards equity]. 2022. https://www.sst.dk/da/Udgivelser/2022/ Sundhedskompetence-i-det-danske-sundhedsvaesen.
5. Regionernes Kliniske KvalitetsudviklingsProgram [Regions Clinical Quality Development Program] (RKKP), Dansk Kvalitetsdatabase for Livmoderhalskræftscreening. Årsrapport 2022 [Danish Quality Database for Cervical Cancer Screening. Annual report 2022].
6. Regionernes Kliniske KvalitetsudviklingsProgram [Regions Clinical Quality Development Program] (RKKP), Dansk Kvalitetsdatabase for Mammografiscreening. Årsrapport 2021 [Danish Quality Database for Breast Cancer Screening for Mammography]. Annual report 2021.
7. Sundhedsstyrelsen [Danish Health Authority], Kapacitetsudfordringer på brystkræftområdet. Faglig gennemgang af udfordringer og anbefalinger til løsninger [Capacity challenges in the field of breast cancer Professional review of challenges and recommendations for solutions]. 2022b
8. Dansk Kvalitetsdatabase for Mammografiscreening [Danish Quality Database for Mammography Screening] Mammografiscreening i Danmark Kliniske retningslinjer [Danish Clinical GLs for screening mammography]. Last update 29/1/2020.
9. Bigaard J, Kvernrød A. Screening for brystkræft. 2020; Available at: https://www.cancer.dk/forebyg/ screening/brystkraeft/.
10. Ministerium: Indenrigs- og Sundhedsministeriet (Minister of Interior and Health], Bekendtgørelse om maksimale ventetider ved behandling af kræft og visse tilstande ved iskæmiske hjertesygdomme [Proclamation on maximum waiting times for the treatment of cancer and

certain conditions for ischemic heart disease]. BEK no 584 of 28/04/2015. https://www.retsinformation.dk/eli/lta/2015/584

11. The HLS19 Consortium of the WHO Action Network M-POHL (2021): International Report on the Methodology, Results, and Recommendations of the European Health Literacy Population Survey 2019-2021 (HLS19) of M-POHL. Austrian National Public Health Institute, Vienna
12. Petersen GS, Laursen SGW, Jensen H, Maindal HT, Pedersen AF, Vedsted P, Virgilsen LF. Patients' health literacy is associated with timely diagnosis of cancer-A cross-sectional study in Denmark. Eur J Cancer Care (Engl). 2022 Jan;31(1):e13532. doi: 10.1111/ecc.13532. Epub 2021 Oct 27. PMID: 34704640.
13. Sundhedsstyrelsen, Statusrapport for de nationale screeningsprogrammer for kræft 2022, Sundhedsstyrelsen, 2022 .[The National Board of Health / Danish Health Authority, Status report for the national screening programs for cancer 2022a, The National Board of Health, 2022.] http://www.sst.dk/da/udgivelser/2022/Statusrapport-for-de-nationale-screeningsprogrammer-for-kraeft
14. Danish Health Authority, Sundhedsstyrelsens anbefalinger vedrørende nationale screeningsprogrammer [National Board of Health’s Raccomandations regarding national screening programmes], The Danish Health Authority, 2014.
15. Vrangbæk K (2021). Denmark. In: Immergut E et al. eds. Health politics in Europe: a handbook, 1st edition. Oxford: Oxford University Press
16. Vrangbæk, Karsten. (2010) "Structural reform in Denmark, 2007–09: Central reform processes in a decentralised environment." Local Government Studies 36: 205-221.
17. Sundhedsstyrelsen, Statusrapport for de nationale screeningsprogrammer for kræft 2022, Sundhedsstyrelsen, 2022 .[The National Board of Health / Danish Health Authority, Status report for the national screening programs for cancer 2022a, The National Board of Health, 2022.] http://www.sst.dk/da/udgivelser/2022/Statusrapport-for-de-nationale-screeningsprogrammer-for-kraeft
18. Regions' Clinical Quality Development Program (RKKP) - Danish Quality Database for Mammography Screening (DKMS) Annual report 2024 - 7th screening round. 27.05.2024 https://www.rkkp.dk/kvalitetsdatabaser/databaser/dansk-kvalitetsdatabase-for-mammografiscreening/nyheder-fra-dansk-kvalitetsdatabase-for-mammografiscreening-dkms/arsrapport-2024-fra-dansk-kvalitetsdatabase-for-mammografiscreening/
19. Regions' Clinical Quality Development Program (RKKP) - Danish Quality Database for Mammography Screening (DKMS) Annual report 2021 - 12/8/2022.
20. Regions' Clinical Quality Development Program (RKKP) - Danish Gynecological Cancer Database [Dansk Gyn√¶kologisk Cancer Database] . Nationwide clinical database for gynecological cancer

National Annual Report 2021/2022 1 July 2021 - 30 June 2022 [Landsd√kkende klinisk database for gyn√kologisk kr√ft National √Örsrapport 2021/2022 1. juli 2021 - 30. juni 2022].

21. Andreas D. Lauritzen AD, von Euler-Chelpin MC, Lynge E, Vejborg I, et al. Assessing Breast Cancer Risk by Combining AI for Lesion Detection and Mammographic Texture Radiology Vol. 308, No. 2 2023 Aug 29 2023https://doi.org/10.1148/radiol.230227
22. Olesen F, Hansen RP, Vedsted P. Delay in diagnosis: the experience in Denmark. British Journal of Cancer (2009) 101, S5 - S8
23. Jensen, H., T√∏rring, M.L., Olesen, F. et al. Diagnostic intervals before and after implementation of cancer patient pathways - a GP survey and registry based comparison of three cohorts of cancer patients. BMC Cancer 15, 308 (2015). https://doi.org/10.1186/s12885-015-1317-7
24. Jensen H, T√∏rring ML, Olesen F, Overgaard J, Vedsted P. Cancer suspicion in general practice, urgent referral and time to diagnosis: a population-based GP survey and registry study. BMC Cancer. 2014 Aug 30;14:636. doi: 10.1186/1471-2407-14-636.
25. Danish Health Authority, Sundhedsstyrelsens anbefalinger vedr√∏rende nationale screeningsprogrammer [National Board of Health's Raccomandations regarding national screening programmes], The Danish Health Authority, 2014.
26. The National Analysis and Research Institute for Municipalities and Regions [The National Analysis and Research Institute for Municipalities and Regions], Erfaringer Med Kraeftpakker [Experiences with cancer packages. From intentions to implementation in practice. August 2012.
27. Damhus, C.S., Siersma, V., Birkmose, A.R. et al. Use and diagnostic outcomes of cancer patient pathways in Denmark – is the place of initial diagnostic work-up an important factor?. BMC Health Serv Res 22, 130 (2022). https://doi.org/10.1186/s12913-022-07545-x
28. Christiansen SR, Autier P, Støvring H, Change in effectiveness of mammography screening with decreasing breast cancer mortality: a population-based study, European Journal of Public Health, Volume 32, Issue 4, August 2022, Pages 630- 635, https://doi.org/10.1093/eurpub/ckac047
29. Loft LH, Pedersen LH, Bigaard J, Bojesen SE. Attitudes towards risk-stratified breast cancer screening: a population-based survey among 5,001 Danish women. BMC Cancer. 2024 Mar 19;24(1):347. doi: 10.1186/s12885-024-12083-2.
30. Jørgensen SF, Andersen B, Petersen LK, Rebolj M, Njor SH. Adherence to follow-up after the exit cervical cancer screening test at age 60-64: A nationwide register-based study. Cancer Med. 2022 Jan;11(1):224-237. doi: 10.1002/cam4.4420
31. Danckert B, Falborg AZ, Christensen NL, Frederiksen H, Lyratzopoulos G, McPhai S.l, et al. Routes to diagnosis and the association with the prognosis in patients with cancer – A nationwide register-based cohort study in Denmark, Cancer Epidemiology, 74, 2021,101983, https://doi.org/10.1016/j.canep.2021.101983.
32. Lauritzen AD, Lillholm M., Lynge E., Nielsen M., Karssemeijer N., Vejborg I. Early Indicators of the Impact of Using AI in Mammography Screening for Breast Cancer. Radiology, 2024; 311 (3) DOI: 10.1148/radiol.232479

33. Høeg-Jensen L, Worsøe Laursen S. Viden om kvalitet i opsporing og diagnostik af kræft, [Knowledge of quality in detection and diagnostics of cancer], Kræftens Bekæmpelse Center for Kræftforskning og Patient- & Pårørendestøtte. 2020.
34. Moseholm E, Lindhardt BØ. Patient characteristics and cancer prevalence in the Danish cancer patient pathway for patients with serious non-specific symptoms and signs of cancer-A nationwide, population-based cohort study. Cancer Epidemiol. 2017 Oct;50(Pt A):166-172. doi: 10.1016/j.canep.2017.08.003
35. Auge AM, Vinge S, Kjellberg J, Højgaard B. Kræftudredning uden for kræftpakkerne Analyse: Hvordan fungerer udredningen i almen praksis og i diagnostisk pakkeforløb? [Cancer investigation outside the cancer packages – Analysis: How does the investigation work in general practice and in the diagnostic package process?]. VIVE - The National Research and Analysis Center for Welfare. 2018.
36. Heeg, E., Jensen, M.B., Mureau, M.A.M. et al. Breast-contour preserving procedures for early-stage breast cancer: a population-based study of the trends, variation in practice and predictive characteristics in Denmark and the Netherlands. Breast Cancer Res Treat 182, 709–718 (2020). https://doi.org/10.1007/s10549-020-05725-z
37. Ebbehøj AL, Jørgensen LN, Smith HG, Krarup PM. Current Management of T1 Colon Cancer in Denmark: A Nationwide Cohort Study. Ann Surg. 2024 May 27. doi: 10.1097/SLA.0000000000006355
38. Christiansen P, Ejlertsen B, Jensen MB, Mouridsen H. Danish Breast Cancer Cooperative Group. Clin Epidemiol. 2016 Oct 25;8:445-449. doi: 10.2147/CLEP.S99457.
39. Jensen MB, Laenkholm AV, Offersen BV, Christiansen P, Kroman N, Mouridsen HT, Ejlertsen B. The clinical database and implementation of treatment guidelines by the Danish Breast Cancer Cooperative Group in 2007-2016. Acta Oncol. 2018 Jan;57(1):13-18. doi: 10.1080/0284186X.2017.1404638
40. Sarnola K, Koskinen H, Klintrup K, Astrup C, Kurko T. Uptake and availability of new outpatient cancer medicines in 2010-2021 in Nordic countries - survey of competent authorities. BMC Health Serv Res. 2023 Dec 18;23(1):1437. doi: 10.1186/s12913-023-10421-x
41. Smith HG, Schlesinger NH, Krarup P-M, Nordholm-Carstensen A. Current treatment of pT1 rectal cancers in Denmark: A retrospective national cohort study. Colorectal Dis. 2024; 00: 1–9. https://doi.org/10.1111/codi.17049
42. Sundhedsstyrelsen [Danish Health Authority]. Diagnostic package course for serious illness analysis 1 January 2017-30. June 2018 AUGUST 2019 https://sundhedsdatastyrelsen.dk/-/media/sds/filer/find-tal-og-analyser/sygdomme-og-behandlinger/alvorlig-sygdom_diagnostisk-pakkeforlob/diagnostiske-pakkeforloeb-2017_2018.pdf

The Netherlands

1. Ministry of Public Health, Welfare and Sport, Healthcare in the Netherlands, “Healthcare in the Netherlands” 2016
2. Health Systems and Policy Monitor - OECD-WHO
3. OECD/European Observatory on Health Systems and Policies (2023), The Netherlands: Country Health Profile 2023, State of Health in the EU, OECD Publishing, Paris/European Observatory on Health Systems and Policies, Brussels.
4. Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E (2016). The Netherlands: health system review. Health Systems in Transition, 2016; 18(2):1–239
5. Netherlands Healthcare Institute (2022) “Appropriate Care Framework”, available at https://www.zorginstituutnederland.nl/werkagenda/publicaties/adviezen/2022/06/28/kader-passende-zorg
6. Comprehensive Cancer Organisation https://iknl.nl/over-iknl
7. Van der Heide I. (2015) “Health Literacy: as asset for public health” Doctoral thesis
8. Dutch Cancer Collective (2023) “Dutch Cancer Agenda: 20 goals to reduce the impact of cancer on society”
9. Sørensen, K., Maindal, H.T., Heijmans, M., Rademakers, J. Work in Progress: A Report on Health Literacy in Denmark and the Netherlands, 2020. In: Robert A. Logan, Elliot R. Siegel (Ed.). Studies in Health Technology and Informatics, vol. 269: Health Literacy in Clinical Practice and Public Health, 2020
10. Pharos web resources on low literacy and limited health skills https://www.pharos.nl/factsheets/laaggeletterdheid-en-beperkte-gezondheidsvaardigheden/
11. Health Literacy Alliance Steering Group (2023) “Multi-year plan of the Health Literacy Alliance 2023 – 2025” https://www.gezondheidsvaardigheden.nl/over-de-alliantie
12. van der Weijden, T., van der Kraan J., Brand P., van Veenendaal H., Drenthen T., Schoon Y., Tuyn E., van der Weele G., Stalmeier P., Dammani, O., Stiggelbout A., (2022) Shared decision-making in the Nehterlands: Progress is made, but not for all. Time to become inclusive to patients. Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ) 171 (2022) 98–104
13. Breast Cancer Practice Guidelines https://richtlijnendatabase.nl/richtlijn/borstkanker/startpagina_-_borstkanker.html
14. Cervical Cancer https://richtlijnendatabase.nl/richtlijn/cervixcarcinoom/startpagina_-_cervixcarcinoom.html
15. Colorectal Cancer https://richtlijnendatabase.nl/richtlijn/colorectaal_carcinoom_crc/startpagina_-_crc.html
16. Dutch Cancer Collective (2023) “Early detection Action Plan”
17. National Action Plan https://taskforcecancersurvivorshipcare.nl/nationaal-actieplan/

18. Klein & van Velzen (2018) Policy Framework for Population Screening for Cancer. National Institute for Public Health and the Environment. DOI 10.21945/RIVM-2018-0042
19. van de Schootbrugge-Vandermeer HJ, Lansdorp-Vogelaar I, de Jonge L, van Vuuren AJ, Dekker E, Spaander MCW, et al. Socio-demographic and cultural factors related to non-participation in the Dutch colorectal cancer screening programme. Eur J Cancer. 2023;190:112942.
20. de Klerk CM, van der Vlugt M, Smagge BA, Toes-Zoutendijk E, Lansdorp-Vogelaar I, Dekker E, et al. Urban density differences in colorectal cancer screening participation and screening yield in The Netherlands. Prev Med Rep. 2022;27:101791.
21. Monitor Dutch Cervical Cancer Screening Programme 2022, https://www.rivm.nl/en/documenten/monitor-cervival-cancer-screening-2022
22. Monitor Dutch Colorectal Cancer Screening Programme 2022
23. Monitor Dutch Breast Cancer Screening Programme 2022
24. Helsper, C. C., van Erp, N. N., Peeters, P. P., & de Wit, N. N. (2017). Time to diagnosis and treatment for cancer patients in the Netherlands: room for improvement?. European Journal of Cancer, 87, 113-121.
25. Dutch Cancer Registry (NKR), IKNL. Obtained via nkr-figures.iknl.nl , on 31-05-2024.
26. Oncology Task Force “Agenda Oncological Network Care 2019-2022. Accurate care for ever cancer patient” (2018) https://www.nfu.nl/sites/default/files/2021-04/20190220_Taskforce_Oncologie_Agenda_Oncologische_Netwerkzorg_2019_2022.pdf
27. ActiZ, De Nederlandse ggz, Federatie Medisch Specialisten, InEen, Nederlandse Federatie van Universitair Medische Centra, Nederlandse Vereniging van Ziekenhuizen, Nederlandse Zorgautoriteit, Patiëntenfederatie Nederland, Vereniging van Nederlandse Gemeenten, Verpleegkundigen & Verzorgenden Nederland, Zelfstandige Klinieken Nederland, Zorginstituut Nederland, Zorgthuisnl, Zorgverzekeraars Nederland, Ministerie van Volksgezondheid, Welzijn en Sport. Integraal Zorg Akkoord, Samen werken aan een gezonde zorg [Integral Care Agreement, Working together for healthy healthcare]. September 2002, https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2022/09/16/integraal-zorgakkoord-samen-werken-aan-gezonde-zorg/integraal-zorg-akkoord.pdf
28. Approved proposals and plans under the Integrated Care Agreement https://www.dejuistezorgopdejuisteplek.nl/programmas/integraal-zorgakkoord/transformatieplannen/goedgekeurde-voorstellen-en-plannen/?soort=transformatieplan,transformatievoorstel&weergave=lijst
29. IKNL, NFK, SONCOS and Citrin Programme (2022) Oncology Networks report in focus.
30. Schneider M., Krauss T, Kose A., Craig., Hofmann (2022) "Health workforce demand and supply. Netherlands".BASYS and European Institute of Health and Sustainalbe Development
31. Newton, M., Stoddart, K., Travaglio, M., and Troein E. (2024) EFPIA Patients W.A.I.T. Indicator 2023 Survey

Italy

1. Osservatorio Nazionale Screening, Rapporto sul 2021. https://www.osservatorionazionalescreening.it/sites/default/files/allegati/Rapporto%20ONS%202021.pdf
2. Osservatorio Nazionale Screening Rapporto del 2019 https://www.osservatorionazionalescreening.it/sites/default/files/allegati/Rapportosul2019.pdf
3. Osservatorio Nazionale Screening Rapporto del 2018 https://www.osservatorionazionalescreening.it/sites/default/files/allegati/ons%20rapporto%202018%20%281%29_compressed%20%281%29.pdf
4. Osservatorio Nazionale Screening, Programmi di Screening in Italia, 2008 https://www.osservatorionazionalescreening.it/sites/default/files/allegati/rapporti_brevi2008.pdf
5. Osservatorio Nazionale screening, , Documento per la gestione indicatori https://www.osservatorionazionalescreening.it/sites/default/files/allegati/Manuale%20Indicatori_def.docx_.pdf
6. Osservatorio Nazionale screening, Innovazione-un-commento-di-Nehludoff-Albano https://www.osservatorionazionalescreening.it/content/screening-digitalizzazione-e-
7. Ministero della salute, Piano oncologico nazionale https://www.salute.gov.it/portale/tumori/dettaglioContenutiTumori.jsp?lingua=italiano&id=6012&area=tumori&menu=vuoto
8. AGENAS Rapporto sulla ricognizione nazionale delle dotazioni tecnologiche in uso ANALISI SUI MAMMOGRAFI – ANNO 2019. Osservatorio per il monitoraggio e la valutazione delle reti oncologiche regionali, Gruppo di Lavoro (GdL) n.5 – Innovazione e Ricerca Agenas- https://www.agenas.gov.it/images/agenas/In%20primo%20piano/ONCOLOGIA/Rapporto_Mammografi.pdf
9. ECHI (2018). Indicators on medical technologies (MRI units and CT scanners) updated with most recent Eurostat statistics, 2018. Brussels: European Core Health Indicators https://webgate.ec.europa.eu/dyna/echi/
10. S. De Placido, The Patient's Journey: A Paradigm of Multidisciplinarity and Integrated Networks in Oncological Care, ESITI DELLA QUINTA INDAGINE NAZIONALE SULLO STATO DI ATTUAZIONE DELLE RETI ONCOLOGICHE REGIONALI, 23° Decembre 2023 https://www.agenas.gov.it/images/agenas/In%20primo%20piano/ONCOLOGIA/Rapporto_Mammografi.pdf

Poland

1. Ministerstwo Zdrovia, Program wieloletni pn. Narodowa Strategy Onkologiczna na can 2020 - 2030
2. Sowada C, Sagan A, Kowalska-Bobko I, Badora-Musiał K, Bochenek T, Domagała A, Dubas-Jakóbczyk K, Kocot E, Mrożek-Gąsiorowska M, Sitko S, Szetela A, Szetela P, Tambor M, Więckowska B, Zabdyr-Jamróz M, van Ginneken E. Poland: Health system review. Health Systems in Transition, 2019; 21(1): 1–235.
3. OECD, Country Cancer Profile 2023.
4. PWC for Polska Unia Onkologii, Polska Towarzystwo Onkologii Kliniczenej, Polske Towarzystwo Radioterapii Onkologiczneli, Polskie Towarzystwo Patologow, Polska Koalicjia Pacjentòw Onkologiznych, Cancer Control Strategy for Poland 2015 – 2024. https://www.iccp-portal.org/system/files/plans/Cancer%20Plan%20Poland.pdf
5. Andrzejczak A, Rucińska M, Żarłok E, Osowiecka K. Health care system and patient-related factors affecting low cancer screening participation in Poland. Prev Med Rep. 2023 Sep 26;36:102442. doi: 10.1016/j.pmedr.2023.102442.
6. Dela R, Dubas-Jakóbczyk K, Kocot E, Sowada C. Improving oncological care organization in Poland-The 2015 reform evaluation in the context of European experiences. Int J Health Plann Manage. 2019 Jan;34(1):e100-e110. doi: 10.1002/hpm.2635
7. Dubas-Jakóbczyk K, Sowada C, Domagała A, Więckowska B. Building hospital capacity planning mechanisms in Poland: The impact of 2016/2017 regulatory changes. Int J Health Plann Manage. 2018 Apr;33(2):e403-e415. doi: 10.1002/hpm.2493
8. Sagan, A.; Kowalska-Bobko, I.; Gałązka-Sobotka, M.; Holecki, T.; Maciejczyk, A.; McKee, M. Assessing Recent Efforts to Improve Organization of Cancer Care in Poland: What Does the Evidence Tell Us? Int. J. Environ. Res. Public Health 2022, 19, 9369. https://doi.org/10.3390/ijerph19159369
9. Act on the National Oncology Network Legal status as of: 24/07/2024 Journal of Laws 2023.0.650 - Act of March 9, 2023 on the National Oncology Network Follow the act https://lexlege.pl/ustawa-z-dnia-9-marca-2023-r-o-krajowej-sieci-onkologicznej/
10. Pousette A, Hofmarcher T. Tackling inequalities in cancer care in the European Union. IHE REPORT 2024:1. IHE: Lund, Sweden.
11. Dyba T, Randi G, Bray F, Martos C, Giusti F, Nicholson N, Gavin A, Flego M, Neamtiu L, Dimitrova N, Negrão Carvalho R, Ferlay J, Bettio M. The European cancer burden in 2020: Incidence and mortality estimates for 40 countries and 25 major cancers. Eur J Cancer. 2021 Nov;157:308-347. doi: 10.1016/j.ejca.2021.07.039. Epub 2021 Sep 21. PMID: 34560371

Chile

1. Madariaga B, Mondschein S, Torres S. Breast cancer trends in Chile: Incidence and mortality rates (2007-2018). PLOS Glob Public Health. 2024 Jun 27;4(6):e0001322. doi: 10.1371/journal.pgph.0001322
2. Bruni L, Albero G, Serrano B, Mena M, Collado JJ, Gómez D, Muñoz J, Bosch FX, de Sanjosé S. ICO/IARC Information Centre on HPV and Cancer (HPV Information Centre). Human Papillomavirus and Related Diseases in Chile. Summary Report 10 March 2023. (8° July 2024) https://hpvcentre.net/statistics/reports/CHL.pdf?t=1721054900323
3. Mondschein S, Subiabre F, Yankovic N, Estay C, Von Mühlenbrock C, et al. (2022) Colorectal cancer trends in Chile: A Latin-American country with marked socioeconomic inequities. PLOS ONE 17(11): e0271929. https://doi.org/10.1371/journal.pone.0271929
4. Integrated Cancer Control Initiative in Latin America – ICCI-LA, Addressing the rising burden of cancer in Chile: Challenges & opportunities An Analysis of Chile's Health System and Cancer Control Policies. 3 March 2023. https://www.uicc.org/resources/addressing-rising-burden-cancer-chile-challenges-opportunities
5. Justo N, Espinoza M, Ratto B, Rosselli D, Ovcinnikova O, García Martí S, Ferraz M, Langsam M, and Drummond M. 2018. "Real World Evidence in healthcare decision-making: Global trends and case studies from Latin America". White paper. Stockholm, Sweden. May 2018. file:///C:/Users/HP/Downloads/White-paper_RWE-in-Healthcare-decision-making_FINAL-21May2018.pdf
6. Ministerio de la Salud, Plan Nacional de Cancer 2018 – 2028. https://cdn.digital.gob.cl/filer_public/d3/0a/d30a1f5e-53d9-4a31-a4fe-e90d8d9a2348/documento_plan_nacional_de_cancer.pdf
7. Ministerio de la Salud, Labbé, T., Roje, D.D., Ciudad, A., Merino, G. F. López C.R., Becerra, S., Escobar-Oliva, P. Ríos R. (2021) Estrategias para el control del cáncer: Revisitando las directrices globales y mirando nuestro desarrollo local. Rev. Inst. Salud Pública Chile. 21, 5(1):15-21
8. Ministerio de la Salud, División de Gestión de la Red Asistencial, Departamento GES y Redes de Alta Complejidad.. Modelo de Gestión para el Funcionamiento de la Red Oncológica de Chile 2018.
9. Paula Escobar Oliva, Situación del Cáncer en Chile y su Marco Normativo, División de Prevención y Control de Enfermedades Subsecretaría de Salud Pública, Ministerio de Salud. 13° December 2021.
10. Quijano E., VillotaC., Jimenez de la Jara J., Corbeaux T., Goic C. et al. The Chilean experience with national cancer plan and law: a cooperative bridge between the civil society and the government. (2022). International Journal of Scientific Research and Management (IJSRM), 10(10), 698-705. https://doi.org/10.18535/ijsrm/v10i10.mp01

Appendix – List of key informants

Denmark

- Thomas Krogh, Head of Secretariat, Danish Cancer Society
- Kristine Sørensen, Global Health Literacy Academy
- Ilse Vejborg, MD, Chair of Danish Quality Database for Mammography Screening. Chair Danish Society of Breast Imaging. Head of Department and Head of Capital Mammography Screening Program. Department of Breast Examinations / Capital Mammography Screening Program. Copenhagen University Hospital Herlev Gentofte
- Janne Villemoes Bigaard, MD, PHD, Cancer Prevention and Information. Head of Screening, symptoms and vaccination, Danish Cancer Society

Italy

- Prof. Guglielmo Bonaccorsi MD, Department of Health Sciences, University of Florence Director of the Joint Laboratory for Epidemiologic Research and Training in Services and Healthcare (ERTSH), Laboratory on Health Literacy (HeLiLab)
- Prof. Gianpiero Fasola MD, Director of the Department for Clinical Governance and SSR Networks. Director of the Complex Structure "Coordination of the Regional Oncology Network"
- Paola Mantellini MD, Screening and Secondary Prevention Unit and Regional Reference Center for Oncological Prevention Unit at ISPRO – Tuscany Region and National Screening Observatory
- Alessandro M Minisini, MD PhD, Department of Oncology, University Health Authority Friuli Centrale
- Manuel Zorzi MD, Servizio Epidemiologico Regionale Azienda Zero [Regional Epidemiological Service of Veneto Region] and National Screening Observatory
- Sara Marino MD, General Direction Staff of Salerno Local Healthcare Unit
- President of a Breast cancer patients' association

The Netherlands

- Rianne de Heer, Project Manager at the Netherlands Cancer Collective
- Susan Potting, Ministry of Health, Welfare and Sport, Prevention Programmes and Public Health

- Dr. Chantal Lammens, Netherlands Comprehensive Cancer Organisation (IKNL), Senior oncological care advisor, expert on oncology care networks
- Dutch Federation of Cancer Patient Organisations

Chile

- Sung Hyuk Kim MD Jefe Agencia Nacional de Prevención y Control del Cáncer. División de Prevención y Control de Enfermedades. Subsecretaría de Salud Pública. Ministerio de Salud, República de Chile