# Estonian Cancer Control Plan

## 2021–2030

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# ESTONIAN CANCER CONTROL PLAN 2021–2030

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# Executive summary

## Estonian Cancer Control Plan 2021-2030

Cancer control as a term encompasses all actions against cancer from cancer prevention to either returning to normal life after recovering from cancer or having a dignified end of life. According to WHO's definition, a national cancer control plan is a public health programme designed to reduce the number of cancer cases and deaths and improve the quality of life of cancer patients.

There have been many advances in Estonia during the last decades. Premature mortality (before the age of 65) from cancer has declined, tobacco-related cancer incidence among men is decreasing and cancer survival continues to increase, having become equivalent to the survival rates of Northern countries for many cancer types. However, Estonia faces many challenges in cancer control. The number of cancer cases is expected to reach 11,000 by 2030, caused partly by an ageing population, but also by the impact of lifestyle-related risk factors (e.g. obesity). Many new cancer cases are still being detected in advanced stages. Moreover, until now, not enough attention has been paid to psychological and social support for patients and their families or their quality of life both during and after treatment. An evaluation of Estonia's only national cancer strategy (2007-2015) highlighted the lack of strategic planning as a major pitfall in Estonian cancer control.

Over a hundred experts in 16 working groups were involved in the development of a cancer control plan for 2021-2030, defining the challenges, objectives and required actions in their respective fields.

## Vision for cancer control

**Fewer people develop cancer**

**People live longer and healthier lives after a cancer diagnosis**

**People living with cancer have a better quality of life**

Priorities are set for the next 10 years to move towards this vision.

### Fewer people develop cancer

#### Priority 1. Lowering the risk of lifestyle-related cancers

Up to 40% of cancer cases can be prevented. The goal is to lower the prevalence of lifestyle-related risk factors among the population, primarily focusing on the use of tobacco and alcohol, obesity and the lack of physical activity. This will be achieved through raising public awareness and creating an environment that promotes healthier behaviours.

#### Priority 2. Protection of younger generations – vaccination against viruses that cause cancer

Future generations can be protected from cancers caused by the human papillomavirus (HPV) and the hepatitis B virus through vaccination. To this end, all newborns will continue to get vaccinations against hepatitis B and the national vaccination programme against HPV will be continued for girls. The goal is to ensure universal access to the HPV vaccination for both girls and boys. Efforts will be made to gain optimal coverage within all vaccination programmes.

#### Priority 3. Detection of pre-cancerous conditions through preventive screening (cervical and colorectal cancer)

Screening for cervical and colorectal cancer allows the detection and treatment of pre-cancerous conditions and thereby the prevention of these cancers. Screening is only effective if enough people participate and all steps of the process are carried out properly. Therefore, a central screening board will be established with a focus on increasing the coverage and quality of screenings.

### People live longer and healthier lives after a cancer diagnosis

#### Priority 1. Early cancer diagnosis for patients of all ages

The chances of recovery are several times higher when cancer is diagnosed at an early stage, and this applies both to children and adults. Unfortunately, cancer in Estonia is often diagnosed when it has already spread beyond the original tumour. There are two strategies for early detection. First, the coverage and quality of early detection screening (for breast and colorectal cancer) will be improved. Second, as a greater share of cancers are diagnosed only after symptoms emerge, the goal is to raise public awareness of the signs and symptoms of different types of cancer and ensure a smooth and fast pathway to diagnosis and cancer-specific treatment. Standard patient pathways will be implemented starting from the initial doctor's appointment up to the initiation of primary treatment.

#### Priority 2. Optimal care for every patient – centralisation of diagnostics and treatment in cancer centres

Whatever the stage of cancer at diagnosis, the key to best possible outcome is access to high-quality treatment for every patient regardless of their education, livelihood or place of residence. To ensure high-quality cancer diagnostics and treatment for all patients, cancer care will be centralised in cancer centres offering multimodal cancer treatment. This way, a uniform approach will be achieved across all treatment facilities, efforts will be made to quickly implement research results in everyday practice and treatment results will be constantly monitored. The crucial factor in diagnosing and treating rare tumours (including paediatric cancers) is cooperation with pan-European networks and centres of excellence.

### Priority 3. Availability of care according to patient needs, including treatment close to home coordinated by cancer centres

There are stages along cancer patients journeys when it is in their best interests to receive health services and cancer treatment as close to home as possible. A network, coordinated by cancer centres, will be established, integrating primary care, local hospitals, nursing care and support services into cancer treatment close to home while maintaining the optimal quality of care.

## People living with cancer have a better quality of life

### Priority 1. A patient-centred comprehensive cancer journey offering social and psychological support for patients and their families

A cancer journey starts before the diagnosis is confirmed and extends into the period after treatment. The goal is to offer each patient and their families help tailored to their individual needs throughout their cancer journey to cope with the side effects of treatment, smoothly undergo all treatment stages as well as solve psychological and social problems. A holistic needs assessment and care plan will be undertaken for each patient, and quality of life and patient satisfaction will be evaluated on a regular basis.

### Priority 2. Optimal follow-up of cancer survivors in collaboration between cancer centres and primary care

Thanks to early detection and improving treatment options, the number of long-term cancer survivors increases each year. Close cooperation between cancer specialists and primary care is required to create after-treatment follow-up pathways for adult and childhood cancer survivors and develop guidelines based on received treatment and possible late complications.

### Priority 3. Life beyond cancer – psychosocial support for returning to society

Cancer diagnosis and treatment often have physical and psychosocial consequences, some of which may last throughout the patient's lifetime. Both the patient and their families often need professional support to cope with these long-term consequences. To provide support for people living beyond cancer to adapt to the new situation, return to society and remain in employment, an integrated network of healthcare and social systems and municipalities will be established and patient organisations will be empowered.

## Key priority actions

- Central management, strategic planning and evaluation – a comprehensive view of cancer control measures, screening programmes, organisation of cancer care.
- Better communication with target groups – the population, patients, families and carers, primary care, specialist care.
- Uniform diagnostic, treatment and follow-up guidelines across healthcare institutions.
- Scientific research and quick implementation of research results in practice.
- Uniform high-quality structured data to plan actions and evaluate results.
- Competent and motivated workforce.

## Implementation

The cancer control plan will be implemented within the framework of the Estonian National Health Plan. The key role is played by the steering group and the Ministry of Social Affairs in cooperation with agencies who have the required mandate and decision-making powers. The first implementation plan, assigning responsibilities and deadlines for the period of 2021-2024, will be put in place during the first half of 2021.

# Introduction

Cancer, or malignant tumour, is a general term that encompasses over two hundred different diseases. Cancer is characterised by the uncontrolled growth of cells and the ability to invade surrounding organs and tissues and spread throughout the body through both the blood and lymphatic systems. The formation of cancer is based on changes in cells caused by various factors (e.g. genetic, lifestyle and environmental factors). It is estimated that up to 40% of all cancer cases can be prevented by reducing lifestyle and environmental risk factors and by vaccinating against cancer-causing viruses.

The formation and development of cancer in the body is usually a long-term process, which provides a good opportunity to prevent the development of the disease by detecting and treating precancerous conditions. In the case of cancer that has already developed, early diagnosis is crucial – the likelihood of recovery from cancer is several times higher if the cancer is diagnosed in its early stages.

Unfortunately, in Estonia, diagnosis is often only reached when the disease has already spread beyond the primary site. In 2017, over 40% of solid tumours[1] had spread locally, regionally, or distantly at the time of diagnosis.[2] Equally important is the availability of high-quality diagnostics and treatment regardless of a person's place of residence, education or social status.

In 2000, 1,200 people in Estonia died of cancer before reaching the age of 65. Thanks to the tobacco policy initiated in the 1990s, improvements in people's living conditions and health awareness, as well as sharply improved treatment options, this number has decreased significantly and is expected to be below 700 by 2030. However, even 700 lives lost prematurely to cancer are too many. The Public Health Development Plan 2020–2030 sets a goal of reducing this number to 550.

Each new cancer diagnosis means great concern for the patient and their loved ones, and a burden on the healthcare and social system. The number of new cancer cases is constantly increasing both in the world, in Europe and in Estonia, largely due to the increase in life expectancy and the growing share of elderly people in the population. However, the risk of cancer due to lifestyle is also increasing. In Europe, a 25% increase in cancer incidence is predicted by 2035. If current trends continue, the number of new cancer cases in Estonia will reach 11,000 in 2030 (Figure 1).

- 40% of cancer cases are preventable
- In 2017, there were over 62,000 people living in Estonia who had been diagnosed with cancer during their lifetime

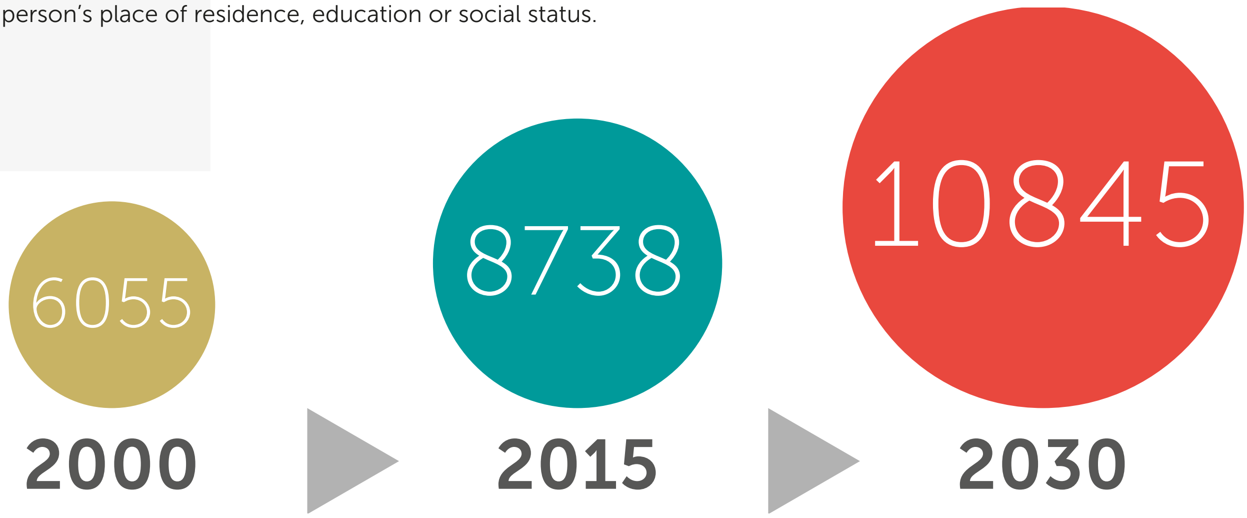

*Figure 1. Number of primary cancer cases and projections for 2000–2030.*

Among those diagnosed with cancer, there are more and more elderly people, 75 years of age and older – in 2017, already more than a third. This sets new challenges for doctors – how to treat cancer in a person who already has one or more chronic diseases, be it heart disease, high blood pressure or diabetes. At the same time, we must not forget that cancer is not only a disease of adults and the elderly. In Estonia, an average of 35 children under the age of 15 and 40 young people aged 15–24 are diagnosed with cancer every year. While in the case of children, the main difficulties arise from the lack of access to diagnostic and treatment options, in the case of young people, in addition to clinical problems, biological, psychological and social factors characteristic of age also play an important role.

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[1] A distinction is made between solid tumours, which form a tumourous mass in solid organs (e.g. lung, breast, intestine), and haematological, or lymphoid and haematopoietic tissue tumours, which occur in the blood and bone marrow.

[2] Locally advanced – the cancer has grown into neighbouring tissues; regionally advanced – the cancer has spread to regional lymph nodes; distantly advanced – the cancer has metastasised to other organs through the bloodstream.

People are living longer and longer after a cancer diagnosis – according to the latest data, more than 60% of people diagnosed with cancer in Estonia are alive five years after diagnosis. Thanks to this, the number of people living with cancer for many years is also increasing. While in 2000, 34,500 people living in Estonia were diagnosed with cancer during their lifetime, in 2017 this number increased to over 62,000. Our society needs a change in mindset. "A cancer diagnosis equals a death sentence" – such a belief can often be an obstacle to changing lifestyle, participating in screening, and agreeing to treatment. Cancer is nowadays considered more of a chronic disease, in which remission alternates with periodic episodes of exacerbation.

▸ From 2002–2006, 53% of cancer patients were alive five years after diagnosis; from 2012–2016, this rose to 63%

The well-being of patients and their loved ones during the cancer journey and the life with cancer and after cancer is increasingly at the centre of cancer control worldwide, and the focus is shifting from the disease to the person.

The Cancer Control Plan[3] for 2021–2030 describes Estonia's progress and shortcomings so far and sets priorities for the future – how to cope with the challenges cancer control and the healthcare system are facing, to ensure the best possible treatment results for every patient, and support patients and their loved ones on their cancer journey.

The Estonian Cancer Control Plan is being prepared in parallel with the European Commission's Beating Cancer Plan and the Mission on Cancer, which similarly focus on current cancer-related key issues with the aim of preventing three million cancer deaths by 2030, significantly extending the lifespan of cancer patients and improving their quality of life. The need to make evidence-based cancer prevention, modern cancer diagnostics and tumour-specific treatment, as well as rehabilitation and supportive care equally available in all Member States of the European Union is pointed out.

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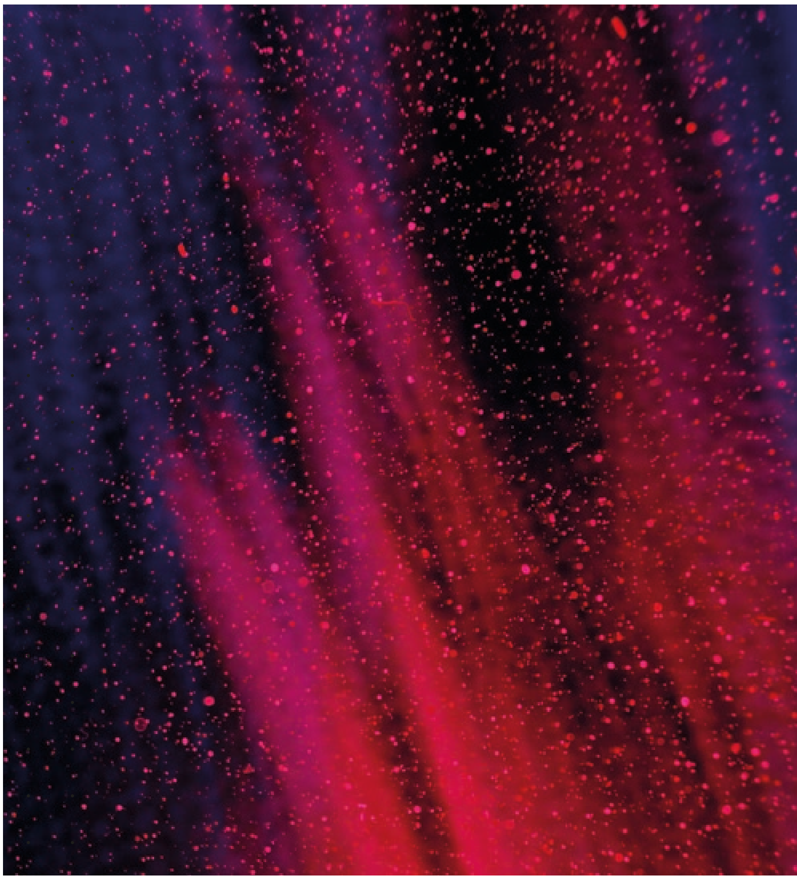
[3] Cancer control is understood as all cancer-related activities, from cancer prevention to returning to normal life after recovery or the end of life with dignity. According to the WHO definition, a national cancer control plan is a public health programme aimed at reducing the number of cancer cases and deaths and improving the quality of life of cancer patients.



# Overview of the current situation

## CANCER IN ESTONIA

### Cancer incidence

In 2018, 8,783 people in Estonia were diagnosed with cancer [1]. The most frequently diagnosed cancer sites in men and women are listed in Annex 1.

Estonian men develop cancer approximately 15% more often than European men on average, while for women the age-standardised4 total cancer incidence is approximately 10% below the European average (Figure 2). The largest difference occurs in cervical cancer, which Estonian women develop more than twice as often. Stomach, kidney, pancreatic cancers and leukaemia, plus prostate and lung cancers in men are more common in Estonia than the European average. However, Estonians are significantly less likely to develop thyroid cancer, Estonian women to develop lung and breast cancer, and Estonian men to develop testicular cancer than the European average.

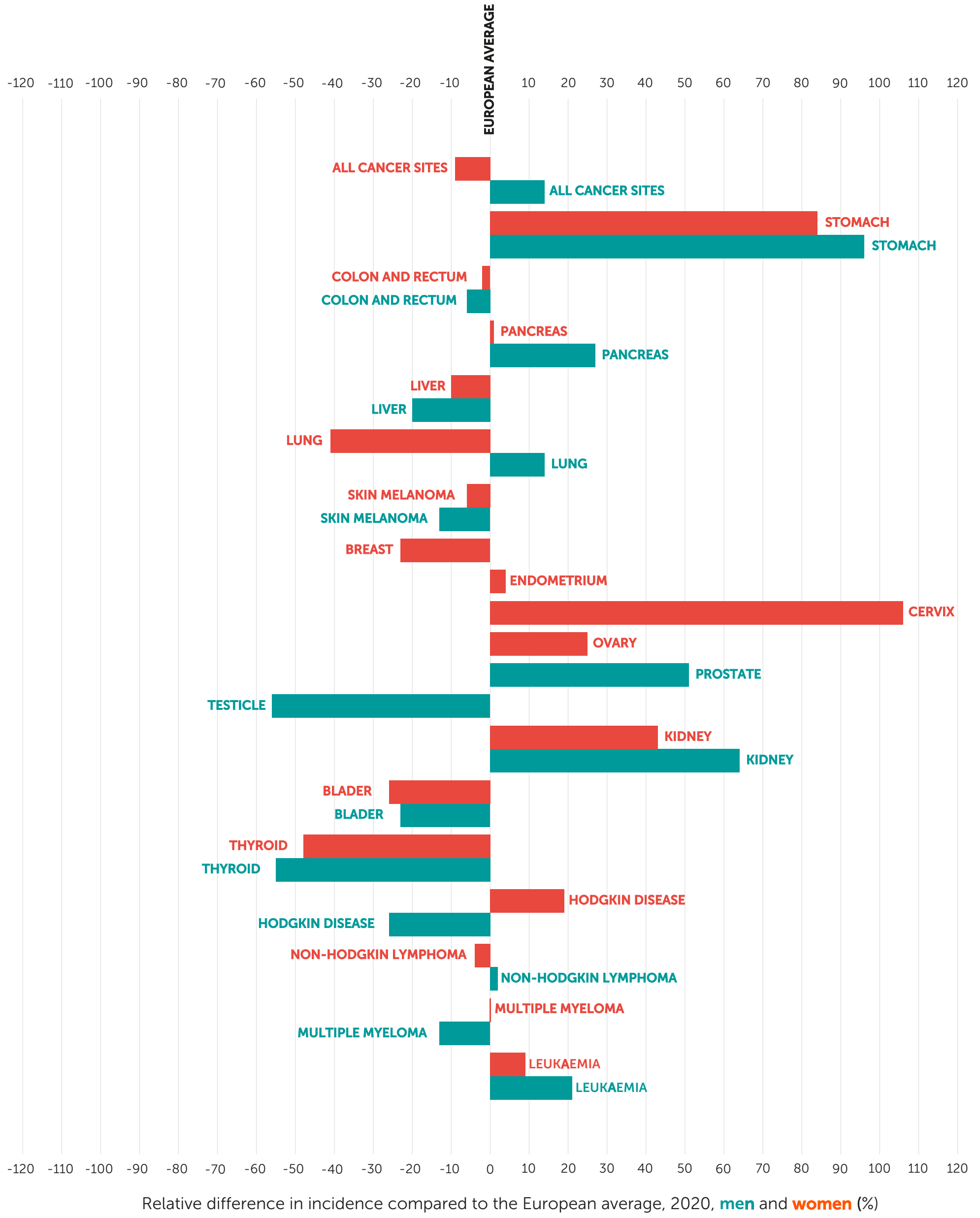


*Figure 2. Cancer incidence in Estonian men and women compared to the European average, 2020 [2].*

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[4] Age-standardised incidence – standardisation means adjustment to the age composition of the population and eliminates the effect of the age composition of different populations on incidence (including the effect of population ageing) when comparing different countries or time periods.

The incidence of frequently occurring stomach cancer and lung cancer in men shows a steady decrease in Estonia (Figure 3). On the other hand, although bowel cancer, skin melanoma and lung cancer in women are diagnosed less frequently in Estonia than on average in Europe, a trend of increasing incidence is noticed for these cancer sites. The incidence of bowel cancer and lung cancer in women increases by ca 1% each year [3,4], while the incidence of skin melanoma has increased by as much as 4% each year during the last decades [5]. The common feature of all these cancers is their connection with a person's lifestyle – the main risk factors are smoking, being overweight, and excessive UV radiation. Among the cancers related to health behaviour, endometrial cancer should also be highlighted, the main risk factor of which is obesity, and the incidence has increased by nearly 3% each year since 2008 [6]; also kidney cancer, which can be associated with both obesity and high blood pressure [7].

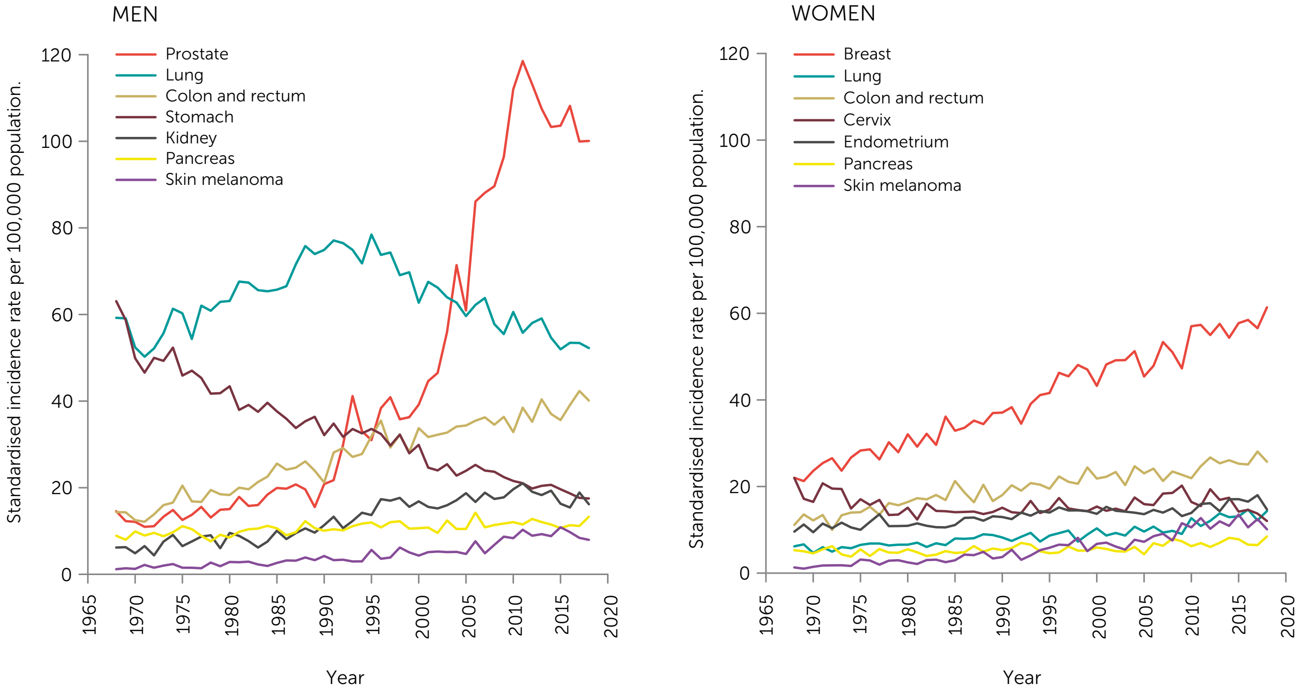

*Figure 3. Incidence trends of common cancer sites in Estonia 1968–2018.*

## Impact of screening on morbidity and mortality

Three population-based screenings are carried out in Estonia – cervical, breast and bowel cancer screening.

The aim of cervical cancer screening is to detect and treat precancerous conditions in order to prevent the development of cancer, so the screening can influence morbidity. While in most European countries, the number of new cases of cervical cancer began to decrease rapidly soon after the start of screening, this is unfortunately not the case in Estonia. Despite screening starting in 2006, the incidence has increased continuously since the 1980s (about 1% each year) [8,9]. Only in recent years has a downward trend been observed. The reasons for the ineffectiveness of screening can be attributed to low participation rates and lack of central management and quality control.

Screening aimed at early detection of breast cancer has been somewhat more successful. Breast cancer mortality has been steadily decreasing in women aged 50–64 who have had the opportunity to participate in biennial mammography screening for some time (Figure 4). However, it should be noted that the decrease in mortality had already begun several years before the screening programme started in 2004. Unfortunately, breast cancer mortality in women aged 65 and older is still increasing, which reflects the fact that screening for women aged 65–69 was only introduced in 2018. This also suggests that these women did not participate in screening at a younger age.

The impact of bowel cancer screening, started in 2016, on morbidity and mortality cannot yet be assessed. For more details, see the chapter "Screening".

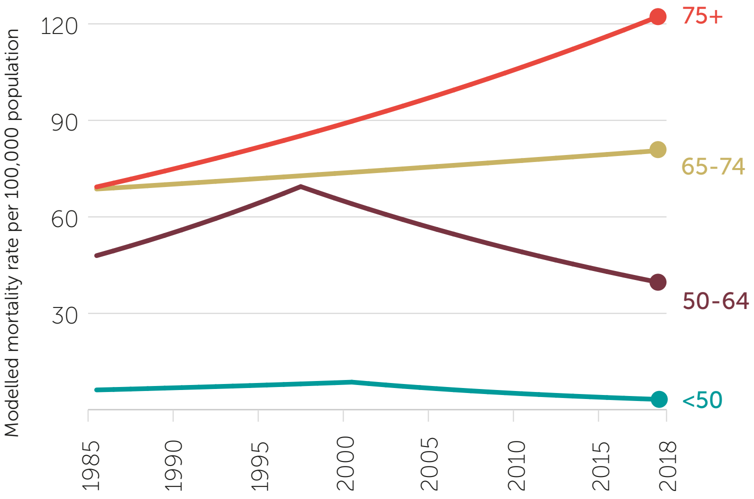

*Figure 4. Breast cancer mortality by age group, 1985–2017.*

## Cancer survival

The survival of cancer patients[5] is largely determined by the stage of the disease[6] at diagnosis, which indicates the size and spread of the tumour.
Breast cancer detection has shifted to an earlier stage in recent decades – while at the turn of the millennium, only 17% of all new breast cancer cases were diagnosed at a very early stage (stage 1), according to recent data, this figure is nearly 30%. However, this is significantly less than, for example, in Norway, where the corresponding figure exceeds 40% [10]. The share of women with breast cancer who are alive five years after diagnosis has increased in Estonia from 65% to 80% this century. Earlier detection, as well as improved diagnostics and treatment, have certainly contributed to this. Studies show that in Estonia, the survival rate of breast cancer diagnosed in stages 2 and 3 has improved the most, in which the combination of several treatment methods based on the characteristics of the tumour plays a decisive role [11] (Table 1).

Despite improvement, the survival rate of Estonian women with breast cancer still falls behind the results achieved in many developed countries (Figure 5).

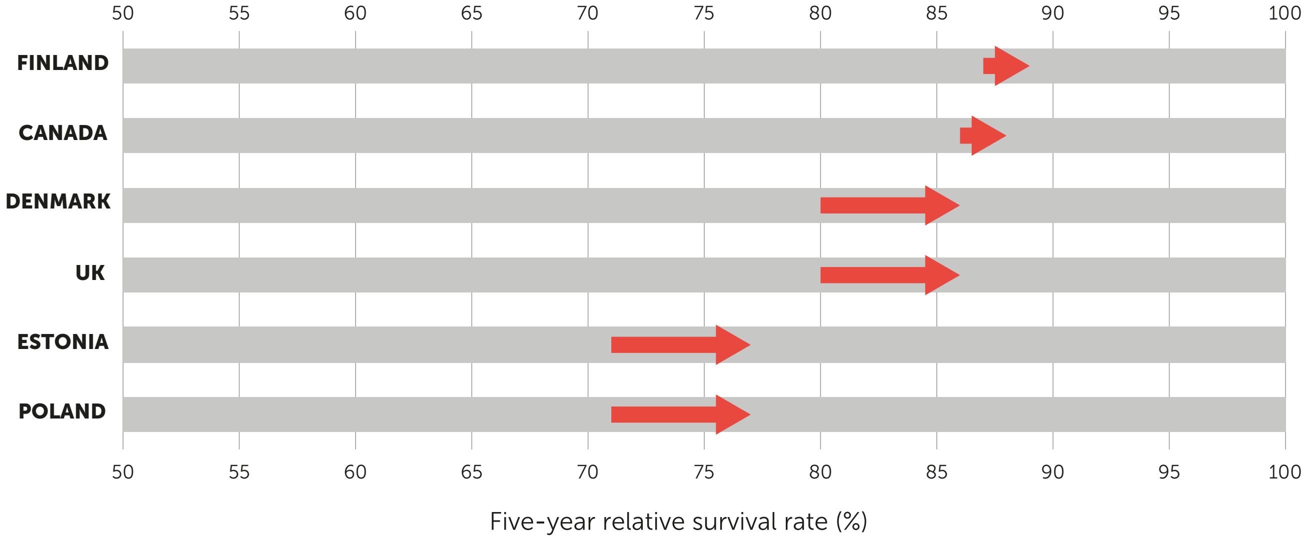

*Figure 5. Change in breast cancer survival, from 2000–2004 to 2010–2014 [12].*

The same can be said about bowel cancer, where the increase in survival has been one of the fastest, but the gap with others persists. (Figure 6).

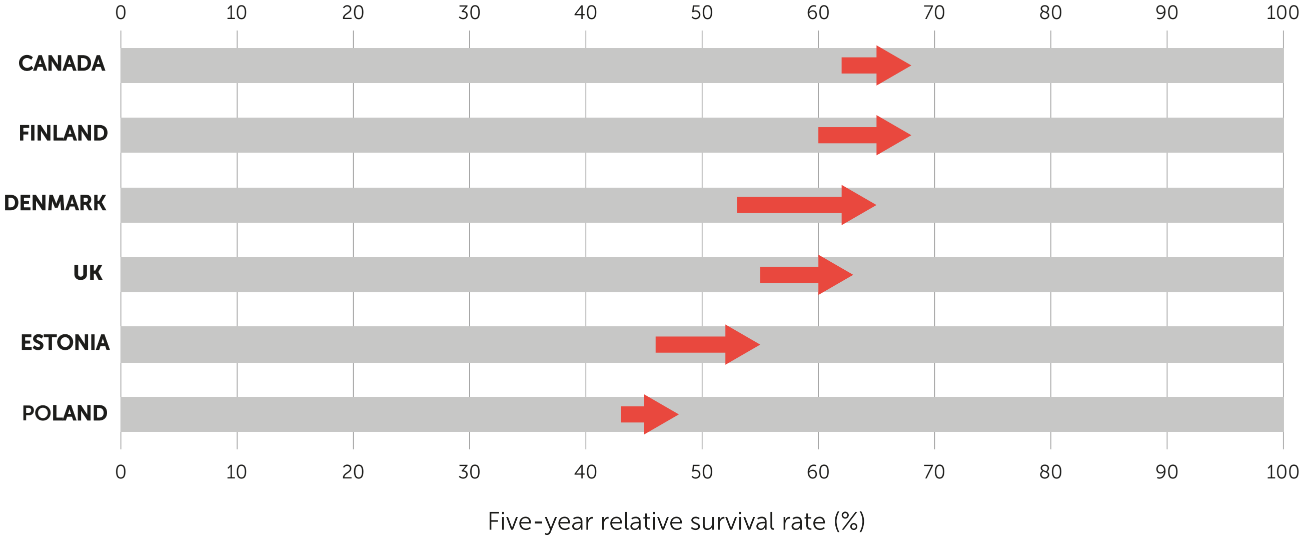

*Figure 6. Change in colorectal cancer survival from 2000–2004 to 2010–2014 [12].*

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[5] Survival – the probability of being alive a certain number of years after diagnosis. The most commonly used indicator is the five-year relative survival rate, which can be interpreted as the percentage of patients who are alive five years after diagnosis.

[6] Stages depend on the site of the cancer, but in most cases, TNM stages 1 and 2 are localised and small tumours, while stage 3 involves the spread to neighbouring organs or regional lymph nodes. In stage 4, the cancer has spread to other organs (distant metastases).

The main reason for the survival lag can be considered detection of cancer at a later stage – more than a quarter of bowel cancer cases in Estonia are still diagnosed only when the disease has already spread and distant metastases have formed [4]. Bowel cancer screening started in Estonia in 2016, so the of screening can only be expected in the coming years. The high share of bowel cancer patients who undergo emergency surgery is worrying [13], which indicates a lack of timely diagnosis and results in a worse prognosis for patients compared to elective surgery. However, the rapid improvement in survival is mainly due to improved diagnostics and treatment, which has significantly improved survival at all stages (Table 1) [4,13,14].

- People living in Ida-Viru County and Southern Estonia are diagnosed with stage 4 bowel cancer 20% more often than elsewhere in Estonia

According to the latest data, the five-year survival rate for prostate cancer in Estonian men is 92%, and the ten-year survival rate is 88%. About 60% of cases are diagnosed at an early stage, with a 100% five-year survival rate (Table 1). The rapid increase in prostate cancer incidence in the 2000s was due to intensive prostate-specific antigen (PSA) testing among middle-aged and older men. Studies have shown that the incidence increased only with early prostate cancer [15]. The incidence of advanced prostate cancer did not change, so there is no reason to talk about the increase in the risk of prostate cancer. The incidence and survival rates are in sharp contradiction with mortality statistics, according to which Estonia has one of the highest prostate cancer mortality rates in Europe. As one possible explanation, it is currently being investigated whether prostate cancer has been reported as the correctly (the results of the study will be available in 2021).

- Two-thirds of skin melanomas diagnosed in people under 50 are stage 1

An important change in early detection, and consequently, survival rates has occurred in recent years for skin melanoma. While in the early 2000s only 16% of melanomas in men and 28% in women were diagnosed at stage 1, according to the latest data, these rates are 44% in men and 52% in women. Simultaneously, five-year survival rates have also improved significantly – 81% in men and 87% in women – but still remain lower than the Nordic rates (over 85% in men and over 90% in women) [16].

However, late detection of cancer often does not explain the entire survival lag. It has been observed that treatment results are also poorer than those achieved in other countries. Thus, it has been found that survival at the same stage is shorter in Estonia, for example, in case of breast cancer, skin melanoma and bowel cancer [4,5,11,14]. A higher risk of cancer recurrence has also been noticed in Estonian patients [17].

On the other hand, there are examples where the survival of Estonian cancer patients over decades has been comparable to or even better than in other countries, for example, in the case of lung cancer (Figure 7).

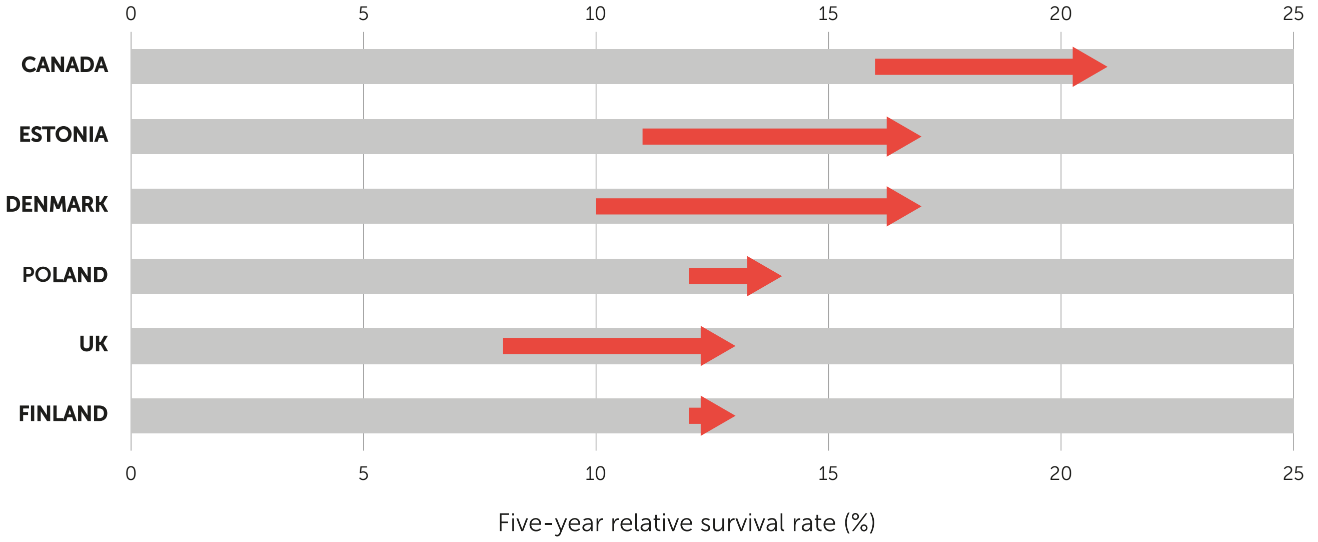

*Figure 7. Change in lung cancer survival from 2000–2004 to 2010–2014 [12].*

Lung cancer survival has improved largely due to the fact that more and more patients are treated surgically, and in the case of operated local tumours, the survival rate reaches almost 70% [18]. Good results can be attributed to the concentration of lung cancer surgery in two regional hospitals and the increasingly frequent use of minimally invasive (endoscopic) surgery, which also allows surgical treatment of frailer patients in poorer general condition and with comorbidities. However, overall survival remains below 20% for lung cancer, as nearly half of cases are diagnosed at an advanced stage – a problem that other countries in Europe and elsewhere face as well.

A pattern similar to lung cancer also characterises stomach cancer. In international comparison, Estonia's survival rates are good, outperforming many European countries. Although the survival rate for local-stage stomach cancer also reaches 70%, approximately 40% of cases are diagnosed with distant metastases [19]. Despite the steady downward trend, the incidence of stomach cancer in Estonia is one of the highest in Europe.

Ovarian cancer can also be highlighted as a cancer site where the latest survival rates in Estonia are comparable to those of other Nordic and European countries (the five-year survival in Estonia is 45%, and 44% in Finland) [16,20].

The results of several studies confirm the increased efficiency of cancer diagnostics and treatment – compared to the second half of the 1990s, standard treatment regimens are used much more often, more patients undergo the necessary diagnostic procedures to assess the spread of the disease or a sufficient number of lymph nodes are examined in the surgical material [14,21,22]. The enormous difference in diagnostics and treatment compared to other European countries observed a few decades ago has largely disappeared. Besides lung cancer, the impact of improved surgical treatment on survival has been demonstrated in endometrial cancer, where survival improved most in those patient groups where the share of patients who received surgical treatment increased [6].

*Table 1. Five-year relative survival for selected cancer sites by stage at diagnosis, 2012–2016*[1]

| | All stages (%) | Stage 1 (%) | Stage 2 (%) | Stage 3 (%) | Stage 4 (%) |
|---|---|---|---|---|---|
| **Mouth and oropharynx** | 36 | 76 | 65 | 57 | 27 |
| **Stomach** | 28 | 81 | 62 | 28 | 4 |
| **Colon** | 59 | 94 | 84 | 70 | 14 |
| **Rectum** | 59 | 95 | 79 | 70 | 12 |
| **Liver** | 9 | 36 | 30 | 2 | 1 |
| **Pancreas** | 8 | 42 | 22 | 7 | 2 |
| **Lung** | 16 | 60 | 41 | 14 | 3 |
| **Skin melanoma** | 85 | 99 | 81 | 64 | 15 |
| **Breast** | 80 | 97 | 93 | 65 | 15 |
| **Cervix** | 66 | 96 | 81 | 55 | 21 |
| **Endometrium** | 79 | 95 | 82 | 55 | 31 |
| **Ovary** | 45 | 98 | 89 | 38 | 21 |
| **Prostate** | 92 | 100 | 100 | 96 | 52 |
| **Kidney** | 66 | 94 | 82 | 76 | 11 |

*[1] Age-standardised five-year relative survival for 2012–2016, calculated using the period method, except for oropharynx, stomach, liver, pancreas, lung, prostate, for which the stage-specific survival for 2010–2016 has been calculated using the complete method. Unstandardised due to small numbers: liver, all stages; pancreas, stage 1; ovary, stages 1 and 2.*

## Gender and age differences in survival

One of the distinctive features of Estonia is the large difference in cancer survival between men and women (Figure 8). The gender difference is particularly significant in the case of oral and pharyngeal tumours, as well as skin melanoma, kidney and gastrointestinal tumours. The reasons may lie in detection, health behaviour before and after diagnosis, acceptance of treatment, as well as biological characteristics [23].

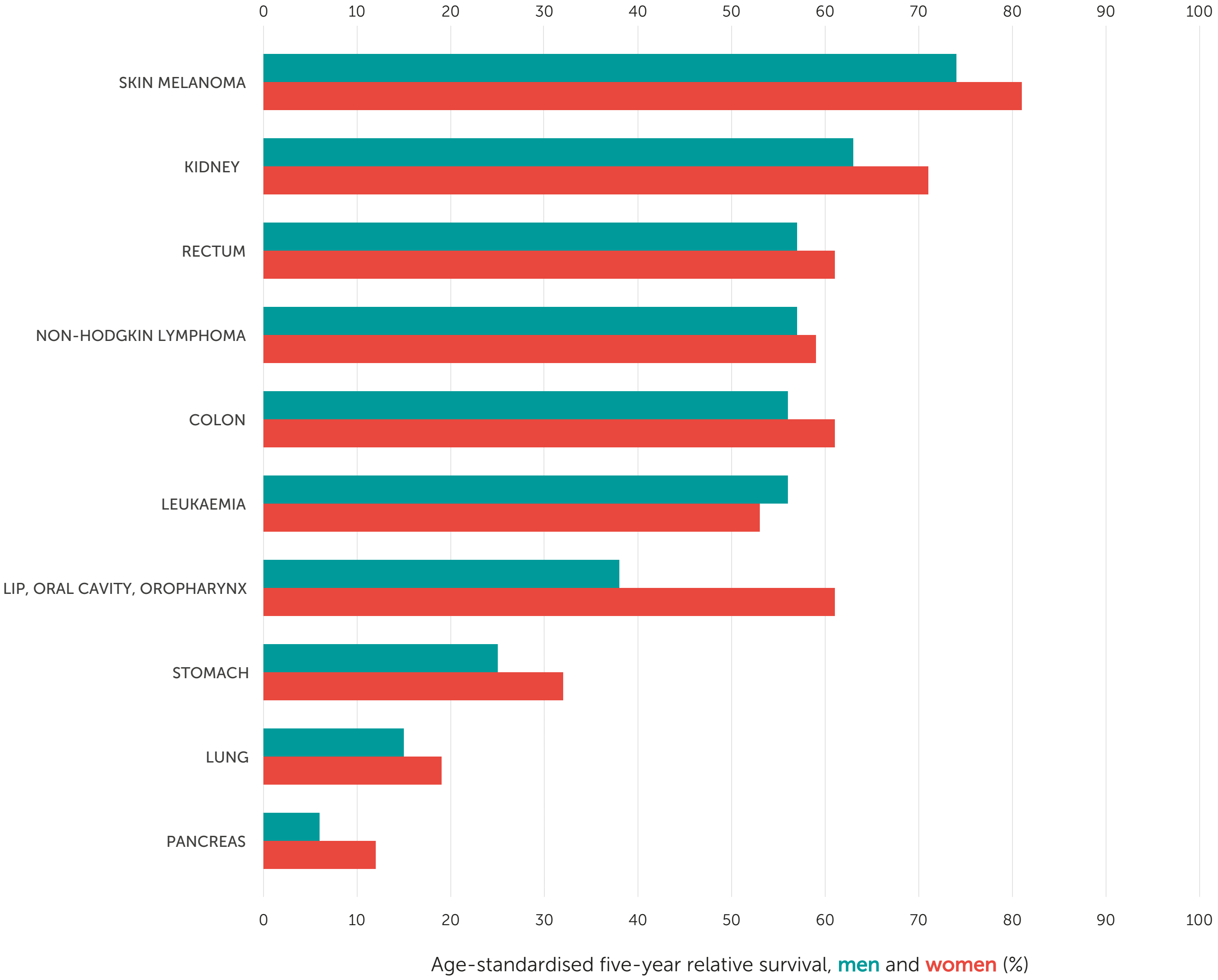

*Figure 8. Five-year cancer survival rates for men and women.*

Elderly cancer patients (aged 75 and over) have not benefited to the same extent as middle-aged patients from rapid advances in diagnostics and treatment, which is why the age gap in survival is widening for many cancers [4,6,11,20]. Survival in this age group can be significantly affected by comorbidities that prevent the implementation of sufficiently aggressive treatment – international studies have shown that Estonian cancer patients have more serious comorbidities than patients in other European countries [14,22].

▸ Almost a quarter of women with early breast cancer have two or more comorbidities

## Haematologic neoplasms

An average of 560 new cases of haematologic malignancies are diagnosed annually, with non-Hodgkin lymphoma and leukaemia being the most common (over 200 cases each). The average annual number of multiple myeloma cases is around 100 and of Hodgkin disease around 40. As can be seen in Figure 2, the incidence of leukaemia in Estonia is higher than the European average for both men and women, while the results for other haematologic neoplasms vary. The incidence of non-Hodgkin lymphoma and multiple myeloma has increased significantly since 2000, by around 3% each year (Table 2).

The average annual number of new cases of haematological neoplasms is projected to increase to 770 by 2030.

*Table 2. Annual change in the incidence of haematologic neoplasms, 2000–2017*

| | Annual increase of incidence (%) | |
|---|---|---|
| | **Men** | **Women** |
| **Hodgkin disease** | 1,2 | 1,1 |
| **Non-Hodgkin lymphoma** | 2,8* | 3,4* |
| **Multiple myeloma** | 3,3* | 2,8* |
| **Leukaemia** | 0,8 | 0,7 |

** Statistically significant change*

Of the haematologic neoplasms, Hodgkin disease has the best survival rate, with a five-year relative survival rate of 83% according to the latest data. The survival rate for non-Hodgkin lymphoma is 58%, with the survival rate of follicular subtype approaching 90%. The five-year survival rate for leukaemia is 55% and for multiple myeloma 40%.

## Children and adolescents

Children are very rarely diagnosed with cancer – in Estonia, an average of 35 primary cases of malignant tumours are diagnosed in children up to 15 years of age per year, and the incidence is 12% lower than the European average. Compared to the 1980s, the five-year survival rate has more than doubled (from 30% to over 70%) [24]. Changes in the survival rate can be attributed to specific developments in diagnostic and therapeutic methods – for example, the introduction of high-dose methotrexate and allogeneic bone marrow transplantation (from a related donor) in 1995 improved leukaemia survival from 52% to 65% from 1995–1999 to 2000–2004. The concentration of treatment into paediatric oncology departments had a significant impact. However, in recent years, the improvement in survival rates has slowed. Despite the progress, several groups of tumours still have poor survival (central nervous system tumours, neuroblastomas, malignant bone tumours, soft tissue and extraosseous sarcomas, and germ cell tumours) [24]. The fact that Estonian childhood cancer survival is lower than that achieved in other Europeancountries indicates continuing shortcomings in timely diagnosis, treatment, and supportive services.

- On average, 35 cancer cases are diagnosed in children up to 15 years of age per year, more than half of which are in children under 5 years of age

A separate group of patients are adolescents and young adults (15–24 years old), whose cancer incidence is increasing by nearly 2% each year. The increase in incidence is mainly due to the increased diagnosis of lymphoid leukaemia and non-Hodgkin lymphoma, central nervous system tumours, skin melanoma, thyroid cancer, and genital tumours. Across all cancer sites, according to the latest data, the five-year survival rate for this age group is over 80%, nearly 95% for lymphomas, nearly 70% for central nervous system malignancies, but less than 60% for leukaemia.

- On average, 40 cases of cancer are diagnosed in adolescents aged 15–24 per year

## ORGANISATION OF CANCER TREATMENT

According to the Regulation No 103 of the Minister of Social Affairs from August 19, 2004, "Requirements for Hospital Types", the right to provide full (surgical, systemic and radiotherapy) oncological and haematological treatment services has been given to regional hospitals in Estonia. These are the Tartu University Hospital (TÜK) and the North Estonia Medical Centre (PERH). Under a special permit, oncology treatment services (in the sense of chemotherapy) have also been provided by East Tallinn Central Hospital (ITK) since 2007, Pärnu Hospital (in cooperation with PERH) from 2014, Ida-Viru Central Hospital (in cooperation with TÜK) from 2018 and Kuressaare Hospital (in cooperation with ITK) from 2020.

Diagnostics and treatment of childhood cancer (solid tumours and malignant haematological diseases) are performed at TÜK and the Tallinn Children's Hospital, while treatment of eye tumours is concentrated in the ITK Eye Clinic.

While radiation therapy for tumours is performed only in cancer centres[7] of regional hospitals, systemic therapy in cancer centres and in departments outside cancer centres supervised by them, a significant portion of elective surgeries in some cancer sites are performed outside cancer centres. According to the Estonian Health Insurance Fund's 2018 data, the inpatient colorectal cancer operations were performed as follows: 45% in PERH, 26% in TÜK, 16% in ITK, 10% in West Tallinn Central Hospital (LTKH), 2% in other central hospitals and 1% in general hospitals [25]. In 2018, the radical prostatectomies were performed as follows: PERH 26%, TÜK 37%, ITK 19%, LTKH 16% and general hospitals 2%. According to the Cancer Registry, radical lung cancer operations were performed only in PERH (65%) and TÜK (35%). A more detailed overview of diagnostics and treatment by speciality is provided in the relevant chapters.

### Healthcare financing

In 2019, healthcare expenditure accounted for 6.8% of Estonia's GDP, which was one of the lowest in the European Union. [26]. According to the 2019 annual report of the Estonian Health Insurance Fund, cancer expenditure accounted for 12% of all specialist medical care funding, covering oncological or haematological treatment for 49,000 people, with an average of 2,100 euros spent on the treatment of each cancer patient. [27]. Oncology funding increased by 11% compared to 2018, up to 103 million euros.

## LESSONS FROM THE PREVIOUS CANCER STRATEGY

The previous and so far only National Cancer Strategy was prepared in Estonia for the years 2007–2015 [28]. However, even before its ending, starting in 2013, the strategies of different health areas were consolidated into one comprehensive Population Health Development Plan (RTA), into which the objectives and activities of the cancer strategy should have also been transferred. Unfortunately, only those related to prevention and screening were integrated into the RTA [29].

Of the objectives of the National Cancer Strategy 2007–2015 related to cancer morbidity and mortality, the only objectives met during the strategy period were the ones set for lung cancer in men. The objectives set for cervical cancer, which is preventable through screening, were far from being achieved [28]. The screening registry, which was intended to start in 2009, was only launched in 2015, and it still does not fulfil all its intended purposes when it comes to assessing the quality of screening. Although activities both in the framework of the Cancer Strategy and the RTA were driven by the goal of improving screening coverage, the participation rate in cancer screening in Estonia is still lower than the European average [30]. The achievement of the objectives related to the quality and accessibility of cancer diagnostics and treatment was largely impossible to measure due to the lack of indicators or their target levels [30].

The evaluation report of the Cancer Strategy published in 2017 stated that since 2013, Estonia has not set strategic objectives on a national level for cancer prevention, diagnosis and treatment, and the needs of cancer patients and the healthcare system have been neglected. For the future, it was recommended to define objectives, measures and indicators based on the cancer patient's treatment journey and to improve the availability of epidemiological, screening, clinical and quality of life data in order to better assess developments in the field of cancer Control and plan further activities [30].

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[7] Cancer centre – a medical institution offering the main methods of multimodal cancer treatment (surgery, radiation and systemic therapy) and palliative care, which, in addition to diagnostic and treatment work, is engaged in cancer prevention and early detection, training of medical professionals, support and education of cancer patients and their loved ones, and cancer research and development.

## SUMMARY OF THE CURRENT SITUATION

| WHAT IS POSITIVE |
|---|
| Premature (< 65 years) cancer mortality is decreasing |
| Age-standardised morbidity is stabilising |
| Smoking-related cancer morbidity (in men) is steadily decreasing |
| There has been a shift towards earlier detection for some cancers (e.g. breast, skin melanoma) |
| There are three screening tests[8], the impact of which has been internationally proven |
| Survival rates have increased over two decades and for several cancer sites have achieved the level of those in the Nordic countries |
| General access to cancer treatment does not depend on a person's social position |
| Treatment of some cancer sites has been concentrated in cancer centres and the effect of that is reflected in good treatment results (e.g. lung cancer) |
| High-quality data from the population-based Cancer Registry allows long-term assessment of cancer incidence, survival and changes in occurrence of different stages |

| MAIN PROBLEMS |
|---|
| The absolute number of cases is increasing |
| Cancer incidence related to health behaviour is increasing |
| The presence of risk factors is characterised by great social inequality |
| Many new cancer cases are still diagnosed at a late stage |
| Screening has not been sufficiently effective |
| Screening has not been available to people without health insurance |
| Cancer control is not seen as a whole and there is no strategic planning in the organisation of cancer treatment |
| All active cancer treatment is not concentrated into cancer centres offering multimodal[9] cancer treatment |
| The lack of structured clinical data does not allow to assess the patient's treatment journey, the availability and quality of diagnostics and treatment |
| The patient's cancer journey[10] is not seen as a whole and the quality of life or satisfaction of patients and their loved ones at different stages of the cancer journey is not measured |

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[8] Screening – a study performed on healthy people for the early detection of precancerous conditions or cancer.

[9] Multimodal cancer therapy – cancer treatment that combines surgical, radiation and drug treatment.

[10] The cancer journey begins with suspicion of cancer and extends to the post-treatment period.

# Preparation of the Cancer Control Plan 2021–2030

In September 2019, Estonia joined the World Cancer Declaration, which was signed by the Prime Minister of the Republic of Estonia, Jüri Ratas, the Chairman of the Council of the Estonian Cancer Society, Dr Vahur Valvere, and the CEO of the Union for International Cancer Control (UICC), Dr Cary Adams. The World Cancer Declaration sets the goal of reducing premature mortality from cancer, improving people's quality of life and extending survival, and to this end, the government decided to start preparing a Cancer Control Plan for Estonia for the years 2021–2030. At the beginning of 2020, consultations took place between the Ministry of Social Affairs, the National Institute for Health Development (TAI) and the Estonian Cancer Society. By a directive of the Minister of Social Affairs on May 19, 2020, a steering group for the Cancer Control Plan was formed (see "Members of the steering group"). TAI was given the authority to coordinate the preparation of the plan and convene working groups of specialist experts. The formation of working groups began after the first meeting of the steering group in July 2020, where the general structure of the Cancer Control Plan, as well as the topics for the working groups, were defined. Special doctors, family doctors, nurses, patient representatives, scientists, etc., were involved in the broad-based working groups (see "Members of the working groups"), with a total of over 100 experts. The coordinating working group at TAI prepared a description of the epidemiological situation of cancer. The working groups defined problems in their fields, the goals and the activities needed to achieve them. The first draft of the Cancer Control Plan was completed by the end of October. Broad-based feedback was collected from the steering group and other working groups. The vision and priorities were agreed upon at the steering group meeting. The second draft, completed in early December, was discussed by the steering group and working groups, resulting in a document ready to be presented to the public. From December 2020 to January 2021, public engagement took place, during which anyone interested could express their opinion and make suggestions. The final version was approved by the steering group on April 7, 2021.

# Vision for cancer control

Fewer people get cancer

People live longer and healthier after a cancer diagnosis

People living with cancer have a better quality of life

# Vision priorities 2021–2030

| | |
|---|---|
| **FEWER PEOPLE GET CANCER** | Reducing lifestyle-related cancer risk<br>Protecting new generations – vaccination against cancer-causing viruses<br>Detecting pre-cancerous conditions through preventive screening (cervical and bowel cancer) |
| **PEOPLE LIVE LONGER AND HEALTHIER AFTER A CANCER DIAGNOSIS** | Diagnosing cancer as early as possible in patients of all ages<br>The best possible treatment for each patient – centralising diagnostics and treatment under the management of cancer centres<br>Access to treatment based on patient needs, including home-based treatment coordinated by cancer centres |
| **PEOPLE LIVING WITH CANCER HAVE A BETTER QUALITY OF LIFE** | A patient-centred comprehensive cancer journey with social and psychological support for the patient and their loved ones<br>Optimal follow-up of cancer survivors in cooperation between cancer centres and primary care<br>Life after cancer – psychosocial support for returning to society |

## Continuous priority areas

- **Central management, strategic planning and evaluation – a holistic view on cancer control, screening, organisation of cancer treatment**
- **Diagnostic, treatment and monitoring guidelines across healthcare institutions**
- **More efficient communication to different target groups – population, patients, relatives, primary care[11], specialist care**
- **Research and rapid implementation of research results in practice**
- **Central structured and high-quality data for planning activities and evaluating results**
- **Qualified and motivated personnel**

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[11] Primary care – outpatient health services to solve a person's most common health problems, provided by a family doctor together with a family nurse and other supporting specialists.

# Primary cancer prevention

## Background

Primary prevention means activities aimed at preventing cancer. Since 30–50% of cancer cases are preventable [31], better awareness of the behavioural and environmental factors associated with cancer and personal preventive actions create the prerequisites for the development of effective interventions aimed at reducing health loss due to cancer.

## Health behaviour and health inequalities

### Tobacco use

A tobacco product is a product made entirely or partly from tobacco for smoking, chewing, sucking or sniffing [32]. Tobacco products contain nicotine, which easily causes both physical and psychological dependence and contain various chemicals, some of which are carcinogenic [33]. Tobacco use is one of the main preventable risk factors for chronic diseases, which causes seven million deaths (including cancer) worldwide each year [34]. Smoking is a risk factor for various cancer sites, such as the lung, oral cavity, pharynx, larynx, oesophagus, pancreas, bladder, and kidney [31,35]. In the first mentioned case, smoking increases the relative risk of developing the disease approximately seven times [36] regardless of gender.

In Estonia, daily smoking among the adult population has decreased from 48% to 23% in men and from 21% to 13% in women between 2004 and 2018, and from 33% to 17% in total [37,38]. It is significantly higher among men and women with lower education [39] (Figure 9).

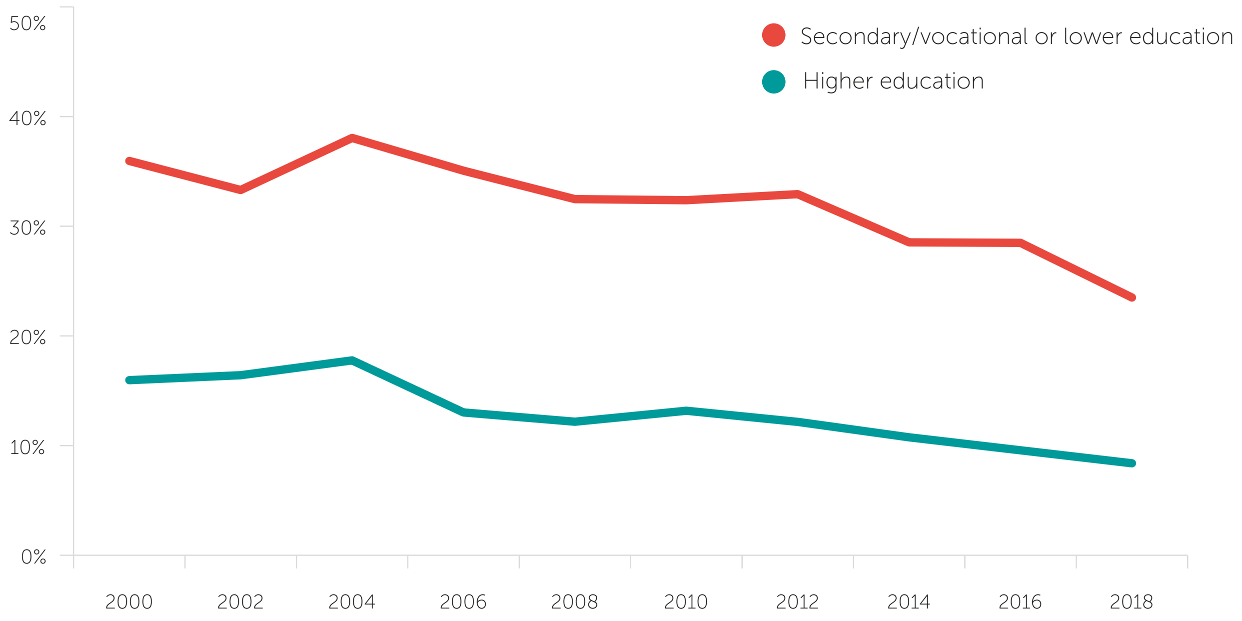

*Figure 9. Daily smoking prevalence among the adult population by education levels [39].*

In most EU countries, daily smoking among adults has been stable or decreasing in recent years, being higher among men and adults with lower education [40]. While the prevalence of daily smoking among Estonian women is comparable to the EU average, it is somewhat higher among men [40]. In recent years, the use of alternative tobacco products has emerged alongside cigarette smoking, the long-term health effects of which are unknown. While in 2012, 20% of men and 16% of women used water pipes, in 2018, this figure was 18% and 11%, respectively [37]. At the same time, e-cigarette use in Estonia increased by 2% among men and nearly 1% among women between 2012 and 2018 [41]. The use of snus in the month preceding the response increased from 10% to 17% among 15–16-year-old boys and from 3% to 9% among girls between 2015 and 2019.

### Alcohol consumption

Alcohol is the most dangerous carcinogen [43], which is known to be associated with the development of oral cavity, pharynx, oesophagus, larynx, breast, bowel and liver cancer [44]. Alcohol is estimated to cause 5.5% of all cancer cases and 5.8% of all cancer deaths worldwide [45]. In Estonia, approximately 6% of all deaths are related to the aforementioned cancers [46].

The amount and duration of alcohol consumption affect the risk of cancer [47], but an increased risk of cancer has been proven even with small amounts of alcohol consumption [48]. Total alcohol consumption[12] has remained below nine litres of absolute alcohol per capita in Estonia since 2015. For example, in 2019, 8.7 litres of pure alcohol were consumed per capita and 10.4 litres per person over 15 years of age [49]. However, there are noticeable demographic differences in consumption patterns: in 2018, 36% of men and 15% of women consumed alcohol a few times a week or more, and 22% of men and 9% of women consumed alcohol in amounts that were hazardous to health [50].

### Nutrition, physical activity and excess body weight

A third of cancer deaths are related to an unbalanced diet, low physical activity and excess body weight [51]. Certain dietary habits can affect cancer risk in one direction or another. While eating plenty of fruits and vegetables is associated with a reduced risk of many types of cancer, excessive consumption of processed and red meat is associated with an increased risk of developing various digestive system cancers, mainly colorectal cancer, stomach and pancreatic cancer, and lung cancer.

Epidemiological studies confirm that, compared to people who are less physically active, physically active people have a lower risk of developing various forms of cancer, such as bladder, breast, colorectal, endometrial, oesophageal, and kidney tumours [51,52]. In Estonia, physical activity is insufficient among both adults and children and adolescents – only 15% meet the recommended daily physical activity for their age [37,53].

Due to the combined effect of various factors, the body weight of Estonians has been on the rise since the beginning of the millennium: the share of overweight people among the working-age population has increased from 42% [54] to 51% [37] and among school-children from 7% [55] to 18% [53]. Approximately one-third of teenagers (aged 10–17) were overweight or obese in 2014 [1] and one in four first-grade children were overweight or obese in 2016 [56]. Excessive body weight is inversely related to education level: obesity is more common among adults with primary and secondary education than among men and women with higher education [57,58]. A similar relationship exists between parental education and overweight/obesity in children. Economic coping also highlights a clear difference. According to the latest study on the growth of Estonian children, among families that can easily cope, 24% of children were overweight and obese, but 45% of children were in poorer households (data published in 2021).

## Health-supporting environment

### Living and working environment

The main cancer-causing factors in the physical environment are ultraviolet radiation (UV radiation), radon, environmental tobacco smoke and fine particles in outdoor and indoor air, exposure to various carcinogens from products, as well as pollutants and additives related to the growing, handling and preparation of food products.

UV radiation causes melanoma when exposed to the skin intensively and/or for a long time. Over 200 new cases of melanoma are diagnosed in Estonia each year. Compared to 2000, the incidence of melanoma had approximately doubled by 2017 (8.5 vs. 17.1 cases per 100,000 population) [1]. This is considered to be due to the increased exposure of the population to UV radiation.

Radon is classified as a carcinogen [59] and is an odourless and colourless radioactive gas emitted from soil that may cause lung cancer if it enters living and working spaces. Worldwide, indoor radon is estimated to cause 70,000–170,000 new cases of lung cancer annually [60]. 3–14% of lung cancers are caused by radon in indoor air [61].

Environmental tobacco smoke is the exposure of non-smokers to tobacco carcinogens and other toxic substances due to the smoking of others. Exposure of non-smoking adults to environmental tobacco smoke has decreased nearly four times among Estonian men and five times among women between 1996 and 2016 [62].

Fine particles are airborne particles with a diameter of up to 10 μm that originate from exhaust gases (transport), combustion processes (oven heating, industrial plants) and chemical reactions in the atmosphere. These are able to penetrate deep into the lung alveoli and can cause lung cancer [63,64]. Various harmful chemical compounds, including carcinogens, can enter the body along with fine particles [62].

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[12] Total alcohol consumption – legal alcohol (excluding tourists' purchases and consumption in Estonia), illegal sale and purchase from abroad.

Cancer-causing risk factors in the work environment include exposure to toxic compounds (e.g. oil shale dust, wood dust, arsenic compounds, asbestos, vinyl chloride, etc.). Several of these compounds have been classified as definite or possible human carcinogens [65]. Exposure to carcinogenic compounds in the work environment is regulated by the Occupational Health and Safety Act and regulations have been established on its basis [66].

Contaminants related to food production that may cause cancer include mycotoxins (aflatoxins, fumonisins), dioxins, polycyclic aromatic hydrocarbons in smoked products, residues of veterinary drugs in animal products (antibiotic chloramphenicol), acrylamide in cereal and potato products and coffee, as well as plant toxins that are formed as metabolic products (pyrrolizidine alkaloids) in the plants themselves.

## Personal preventive actions

### Prevention of infections

Human papillomavirus (HPV) infection is one of the most common sexually transmitted infections. Approximately 12 high-risk HPV types are known, which can cause various cancers. Approximately 99% of cervical, 70% of vaginal, 50% of penile, 43% of vulvar, 88% of anal and 39% of oropharyngeal cancers in Europe are known to be caused by HPV [67]. The primary protection against HPV-related cancer is to prevent the infection through immunisation, as well as early detection of infection and treatment of precancerous changes. Vaccination against HPV for girls was added to the national immunisation schedule in 2018. Vaccination is most effective before infection with the papillomavirus (i.e. before sexual activity begins). The vaccine is approximately 90% effective against cervical cancer and over 95% effective against ***in situ*** adenocarcinoma [68]. Many countries are also considering HPV vaccination for boys, and several countries are already doing so [67,69].

In Estonia, more than 120 people are diagnosed with malignant liver tumours every year [1]. Most cases of hepatocellular carcinoma occur in patients with cirrhosis of the liver, one of the important causes of which is viral hepatitis [70]. Risk groups in Estonia have been vaccinated against hepatitis B since 1996, and from 2003 it has been included in the national immunisation schedule for all newborns [71]. The protective efficacy of the vaccine in clinical trials ranges from 95–100% [72]. To date, over 90% of Estonian residents aged up to 30 years have been vaccinated against hepatitis B.

Human immunodeficiency virus (HIV) infection is associated with a risk of certain cancers, such as Kaposi sarcoma and non-Hodgkin lymphoma. Early diagnosis and treatment of HIV reduce the risk of these cancers. In Estonia, 190 new HIV cases were diagnosed in 2018 (14.4 cases per 100,000 people) [73].

Over 300 cases of stomach cancer are diagnosed in Estonia annually [1]. ***Helicobacter pylori*** infection increases the risk of developing stomach cancer up to six times. ***H. pylori*** causes chronic gastritis, which affects 20–65% of adults and approximately 1% of patients with gastritis develop stomach cancer. So, ***H. pylori*** treatment at the same time reduces the risk of developing stomach cancer [67,70].

### Prevention based on genetic tests

All tumours arise as a result of mutations in different genes. In most cases, these are random changes in the genetic material in the tumour tissue, but a certain number of tumours emerge due to gene mutations that are passed down from generation to generation. Examples of well-known hereditary tumours include hereditary breast and ovarian cancer syndrome and Lynch syndrome [74].

Inherited mutations are identified in approximately 5% of all breast, ovarian, and colorectal cancers [74]. Inherited mutations can also be found in several other malignant tumours. Such hereditary syndromes are characterised by a higher-than-average risk of developing tumours. For example, in the case of hereditary breast and ovarian cancer syndrome caused by mutations in the BRCA1 gene, women have a lifetime risk of developing breast cancer over 70% and a risk of developing ovarian cancer up to 45% [74]. Several hereditary gene mutations are associated with a high risk of colorectal cancer, some of which (for example, familial adenomatous polyposis) can cause up to a 100% risk of developing colorectal cancer [75].

Diagnostics of hereditary tumour syndromes is important from several aspects: 1) monitoring of individuals at high risk of cancer is carried out differently from conventional screening; 2) certain malignant tumours can be prevented by prophylactic surgical methods;

3) the treatment strategy for the tumour depends on the gene mutation present in the patient.

In Estonia, there are modern opportunities for studying families with hereditary tumour syndromes as well as for genetic studies of tumour tissues. Patients are seen in various medical institutions in both Tallinn and Tartu, and all specialists and primary care doctors can refer individuals to a clinical geneticist.

# Problems

## Health behaviour and health inequalities

Despite the decrease in daily smoking, nearly one-fifth (17%) of Estonian adults are daily smokers [37], and this is more common among adults with lower education. In addition to smoking, the use of alternative tobacco products (water pipes, e-cigarettes, chewing tobacco) has emerged, and the use of the latter two has increased in recent years.

In the context of cancer risk, there is no safe amount of alcohol to consume, and international guidelines recommend not drinking alcohol or limiting it to two units of alcohol per day for men and one unit of alcohol per day for women [76]. In Estonia, a significant share of the population consumes alcohol in higher quantities and frequency than recommended, which is associated with an additional risk of cancer. There is little awareness of the risk of alcohol-related cancer. In the context of cancer risk, the frequent consumption of alcohol and tobacco together must also be taken into account; in addition, the energy content of alcoholic beverages is indirectly associated with excess weight gain. Estonia also stands out for its significantly higher overall alcohol-related mortality than the EU average [77].

The main problems with the dietary habits of the Estonian population are the low consumption of fruits and vegetables, whole grains, nuts and seeds, and the excessive consumption of energy-rich meat products and sweets. This is clearly reflected in the nutritional quality index based on Estonian dietary recommendations [78], which was only 52% in the 2014 population nutrition survey [79].

Besides unhealthy diet, low physical activity is also a risk factor for both children and adults [37,53]. Children's physical activity is modest even in primary school, where only a quarter of students meet the WHO physical activity recommendation (60 min of moderate to vigorous physical activity per day [80]). At the same time, sitting time accounts for a major part of the school day and free time [81]. Only a quarter to a third of students walk to school and play sports with their families, and about half of students do not have the opportunity to spend time outdoors during school day breaks or be physically active during the school day [82].

Lack of physical activity and unhealthy diet lead to excessive weight gain over time, which is the second leading preventable risk factor for cancer in developed countries after tobacco [83]. The age-standardised prevalence of obesity[13] in 2018 in Estonian adult men was 22% and in women 18%, which was significantly higher than in 2000 [58]. According to WHO data, a similar increase in obesity prevalence has also occurred in Estonia's neighbouring countries [84].

## Living and working environment

Skin cancer caused by UV radiation is almost completely (over 90%) preventable through conscious tanning behaviour and reasonable use of solarium. Preventive measures are especially necessary in younger age groups, as a person receives 40–50% of their lifetime UV radiation dose before the age of 20 [85]. In Estonia, the use of solariums by minors is not regulated, but its prohibition has been included in the new draft of the Public Health Act [86].

Estonia is among the countries with a higher-than-average radon risk in Europe. In general, buildings without radon protection measures located in areas with high radon levels have high radon concentrations in the indoor air. The main reason for this is the high radon risk in the soil beneath houses, caused by uranium-rich rocks in the bedrock. Nearly a third of the land area of Estonia is at high or extremely high radon risk [87,88].

4% of the Estonian working-age population spends more than an hour in a smoky workplace every day, and 12% are exposed to tobacco smoke at home [37]. At the same time, exposure to environmental tobacco smoke at home, at work or in the car is still relevant for both children and adults, despite the fact that the availability of tobacco products and smoking in public spaces is regulated in Estonia [32].

The capacity to measure chemical substances present in the working and living environment is low. The ability of employers to detect chemical substances present in the working environment, including carcinogens, is modest. The Labour Inspectorate's supervision does not reach all companies that use hazardous chemicals. There is no overview in Estonia of which chemical substances are used in the working environment and occupational diseases are rarely diagnosed [89].

The current priorities of the food safety supervisory authorities focus on immediate public health risks (e.g. food-borne infectious diseases), but risks with long-term effects (e.g. contaminants, additives) have so far been insufficiently addressed [90].

Information collected in different areas on risk factors arising from the living environment must be collated and used to assess total human exposure, develop interventions to reduce exposure, and design a health-supportive living and working environment.

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[13] Prevalence – an indicator that reflects the occurrence of a risk factor or health condition in a specified population at a specified point in time or period.

### Personal preventive activities

The problem in Estonia is the decline in vaccination coverage and its regional specifics. HPV vaccination coverage in 2018 was 18–51% of the target group [91]. Hepatitis B vaccination coverage among 2-year-old children in Estonia was 91% on average in 2019, while in 2015, it was over 93%, and in 2010, it was over 96%. There is a large variation in coverage by region; for example in Ida-Viru County and Jõgeva County, the vaccination coverage is over 97%, and in Tallinn and Harju County, it is under 90% [92]. There is no national HPV vaccination for boys.

Estonia has been one of the countries with the fastest HIV spread in the world for many years.

Estonia lacks solid and evidence-based guidelines for ***H. pylori*** detection at the population level.

A certain part of the population (approximately 5%) is at a significantly higher risk of developing malignant tumours than average because they have a corresponding hereditary predisposition [74]. Monitoring of these individuals should be carried out differently from conventional screening. In the case of hereditary tumours, treatment may also depend on the gene mutation present in the family [93–95]. In Estonia, not all cancer patients who have the corresponding indication get to a geneticist. There is a need for management guidelines and genetic testing targeted at hereditary tumour syndromes.

## Goals

### Goal 1. The incidence of cancer caused by health behavioural factors will decrease

#### Activities and recommendations

- The population will be informed about avoidable cancer risks, which will be reflected in increased awareness, creating the prerequisites for positive changes in health behaviour, reduction of environmental health risks, prevention of infections and consideration of hereditary predispositions.
- The use of tobacco products and socio-economic inequality will be prevented and reduced. A smoking cessation counselling service will be developed and made better accessible to all target groups. Compliance with restrictions on the availability of tobacco products will be monitored.
- The public will be informed more broadly and in a targeted manner (e.g., information campaigns, packaging labelling) about the cancer-causing effects of alcohol. Alcohol consumption will be reduced in risk groups and in the population as a whole through restrictions on alcohol availability and advertising, and through situation monitoring.
- A food reformulation plan will be developed and implemented in cooperation with the food industry with the aim of gradually reducing the average content of sugar, salt and saturated fatty acids in food products.
- A code for marketing to children will be created and implemented. Front-of-pack labelling (preferably assessive and colour-coded) will be introduced.
- Environments that support physical activity will be developed, and intervention programmes for children and young people (Schools that Inspire Movement) [96], workplaces and the elderly will be created. Local governments and community development activities will be supported in shaping a physically active lifestyle. Health protection requirements for educational institutions will be supplemented with requirements supporting physical activity. In cooperation with local governments, diverse sports opportunities will be ensured for children from low-income families, both in and out of school.

## Goal 2. All population groups are ensured a safe living and working environment that supports health and food safety

### Activities and recommendations

- The population will be informed about environmental health risks and ways to reduce them.
- A comprehensive environmental health information system will be created on environmental factors affecting health, which will be accessible to various stakeholders (including the population) to the necessary extent.
- To prevent skin cancer, the provision of solarium services to those under the age of 18 will be prohibited.
- A nationwide indoor radon survey will be carried out to obtain a complete overview. Determining the radon level in buildings must be mandatory in areas where radon is higher than normal.
- Biomonitoring will be carried out to assess exposure to various carcinogenic chemicals in both the living and working environment, and the measurement capacity for chemical substances will be increased. The awareness of employers and employees about the risks associated with chemical substances will be improved. An overview of the use of various chemicals will be compiled.
- The capacity to diagnose occupational diseases will be increased.
- The awareness of both consumers and food operators of the long-term risks of food safety to human health will be increased. The monitoring of long-term risks will be enhanced.
- A system (including communication) will be developed to assess the food safety situation and conduct scientific risk assessments and supportive studies.

## Goal 3. People are ensured protection against cancers caused by infections and, where necessary, prevention based on genetic testing

### Activities and recommendations

- National vaccination of all newborns against hepatitis B virus and girls against HPV will be continued and coverage will be improved.
- HPV vaccination of boys, with a priority for boys at high risk of cancer, will be initiated.
- Vaccination information will be recorded on a person-by-person basis to better implement screening strategies.
- Activities on prevention, testing, early diagnosis and treatment of HIV and other sexually transmitted infections will be implemented in the health system nationally.
- Evidence-based guidelines will be developed for H. pylori diagnosis and treatment.
- The availability of guideline-based genetic testing and related counselling, including the implementation of medicine options to reduce cancer risks, will be ensured for all whom it is indicated. International guidelines for hereditary tumour syndromes will be translated and adapted to Estonian circumstances. Guidelines for hereditary tumour syndromes will be used to conduct the treatment of cancer patients and the examination of their family members.

# Screening

## Background

Screening allows for the diagnosis of cancer at an early stage and reduces premature mortality. In certain cancer sites, it is possible to diagnose and treat precancerous conditions and reduce morbidity. Screening is the preclinical detection of disease in healthy individuals using the simplest possible test through regular repeated testing in the population, with the aim of reducing morbidity and/or mortality and improving quality of life. Cancer screening is a process that begins with an invitation to participate and ends with the treatment of those individuals who have been identified as having an abnormal finding.

An effective screening programme meets the following criteria: 1) systematic invitations to a defined target group; 2) mechanisms for follow-up monitoring of individuals identified as having an abnormal finding; 3) coverage of more than 70% of the target group to be screened; 4) infrastructure and resources for periodic invitation and screening of the target group and for the diagnosis and treatment of patients with cancer or precancerous changes; 5) a strong monitoring and evaluation framework to ensure quality – low participation rates and inconsistent screening do not reduce disease-specific mortality, but increase healthcare costs.

### International recommendations

The WHO already formulated the prerequisites for organising population-based screening in 1968 [97]. The European Union has developed quality requirements for screening programs in different locations [98–100]. According to the European Union recommendations, organised screening programmes require a central management body that operates under the authority of the ministry responsible for health, and coordinates the activities of screening programmes, making political decisions on expanding the target group, adding new cancer sites, initial testing, changing the examination interval, etc. [101]. As a member of the European Cancer Mission adopted in 2020, Estonia's task is to support the implementation of science-based innovative solutions in clinical practice, including in conducting population-based organised screening and the necessary research to ensure the fulfilment of the mission's objectives [102].

### Screening in Estonia

Three cancer screening programmes are currently implemented in Estonia based on the above WHO principles and taking into account EU quality requirements.

Breast cancer screening has been population-based since 2003, with mammography as the primary screening method, and the target group is women aged 50–69, who are invited to the study at 2-year intervals. Of the women in the target group for breast cancer screening, 55% participated in the screening in 2019 [1].

Cervical cancer screening has been population-based since 2006, with the PAP test as the primary screening method, and the target group is women aged 30–55, who are invited to the study at 5-year intervals. Cervical cancer incidence data show that the national screening programme has not yielded the desired results [9,103]. Starting in 2021, the HPV NAT test will be introduced as the primary test. Of the women in the target group for cervical cancer screening, 46.1% participated in screening in 2019 [1].

Colorectal cancer screening has been population-based in Estonia since 2016. By 2020, all planned age groups were included, with the initial screening method being a faecal occult blood test (FIT), and the target group includes women and men aged 60–68, who are invited to participate at 2-year intervals. Of the women and men in the target group for colorectal cancer screening, 52.9% participated in screening in 2019 [1].

The cost-effectiveness of all cancer screenings has been assessed in health technology assessment (HTA) reports. The existence of an HTA report is also a prerequisite for adding new or changing cancer screenings [104–106].

For site-based screening programmes, the working groups have prepared comprehensive organisational guidelines in Estonian [107–109], which are periodically reviewed and updated as needed and include, among other things, a list of site-based quality indicators. Screening in Estonia does not take into account personalised medicine and genetic data, and screening target groups are not specified using individual risk assessments.

Screening data has been collected by the Cancer Screening Registry (VSR) managed by NIHD since 2015 (see “Cancer data and research”).

### New screening programmes

Possible new screening programmes currently concern prostate and lung cancer.

Screening for prostate cancer, the most frequently diagnosed malignant tumour in Estonia, was not considered justified according to the HTA report published in 2017 [110]; the report is being updated.

Lung cancer caused 18% of all cancer deaths in Estonia in 2017. The results of two large international studies show that lung cancer screening improves both overall survival and cancer-specific survival. Low-dose computed tomography (LDCT) is used as a screening method. Radiography is not effective as a screening method [111,112]. Lung cancer screening has been recommended by several international organisations, including the European Respiratory Society (ERS) and the European Society of Radiology (ESR) in 2015 [113], as well as the European Union [114]. However, involving participants in lung cancer screening is more complicated compared to other screenings because, in addition to age, several risk factors (smoking history) must also be taken into account. A corresponding HTA report is being prepared at the University of Tartu.

### Applying personalised medicine in screening

In the case of personalised screening, various health data, including genetic data and behavioural and environmental data, are included in cancer screening and, if necessary, used for more accurate screening. The effectiveness of screening can be improved by implementing polygenic risk scores calculated from genomic data [115,116]. It has been shown that risk-based screening can be more cost-effective, improve the benefit-harm ratio for breast cancer screening and reduce overdiagnosis for prostate cancer screening [117,118]. The applicability of polygenic risk scores for breast cancer screening is being investigated in the estPerMed clinical pilot project.

### Problems

In Estonia, there is no overall screening coordination, including the procedure for initiating new screenings, auditing and management, and there is no regular analysis of quality indicators for site-based screenings.

Statistics on screening result indicators are incomplete due to data capture and quality problems in collecting data from the health information system (HIS). Incomplete data in the cancer screening registry does not allow for drawing conclusions about the effectiveness of screening or making recommendations for conducting, changing or supplementing screenings.

The participation rate of population-based screenings in Estonia remains below the recommended 70% threshold in all cancer sites.

The problem is also the poor adherence to screening guidelines by healthcare providers, which is reflected in the high share of opportunistic screening.

## Goals

**Goal 1. A screening management structure is in place to evaluate existing screenings and initiate new ones, taking into account scientific developments, including in the field of personalised medicine.**

### Activities and recommendations

- A broad-based, publicly funded management structure will be established to coordinate screening.
- The governing body/council will convene site-based working groups involving field experts. The task of the working groups is to make proposals to the council for improving screening on the basis of the results of the analysis of quality indicators.
- The quality indicators published in the screening guidelines [108,109,119] will be reviewed regularly.
- An analysis of the performance indicators of the first five years (2016–2020) of colorectal cancer screening will be carried out, based on which decisions will be made about necessary changes in the screening programme (including the age range of the target groups).
- The HPV test and the updated screening algorithm will be used as the primary screening for cervical cancer from 2021.

## Goal 2. Screening data is recorded in the registry in full and of high quality, which allows conclusions about the effectiveness and quality of screening to be drawn.

### Activities and recommendations

- In collaboration with partners (TEHIK, Ministry of Social Affairs, health institutions), IT solutions are being created to ensure the complete and high-quality receipt of screening data into the registry in order to get relevant information on screening performance indicators according to the current organisational guidelines.

## Goal 3. The participation rate for population-based screening will be at least 70% of the target group

### Activities and recommendations

- From 2021, screening will include people without health insurance.
- Different channels, such as family medicine centres, public media, and social media will be used to increase screening coverage. Here, cooperation with various associations, professional societies and the Health Insurance Fund is important for promoting healthy lifestyles among the population.
- The data structure and quality of databases and registries will be improved so that invitations reach the target group with the least possible loss, using traditional invitations sent by post, e-invitation and digital invitations-referral letters in the patient portal (or other digital solutions).
- The share of opportunistic tests performed on screening target groups outside of the screening programme will be reduced.

## Goal 4. The implementation of new screenings will be based on scientific justification, guided by the decisions of health technology assessment reports, and will consider the use of personalised risk scores and genetic data.

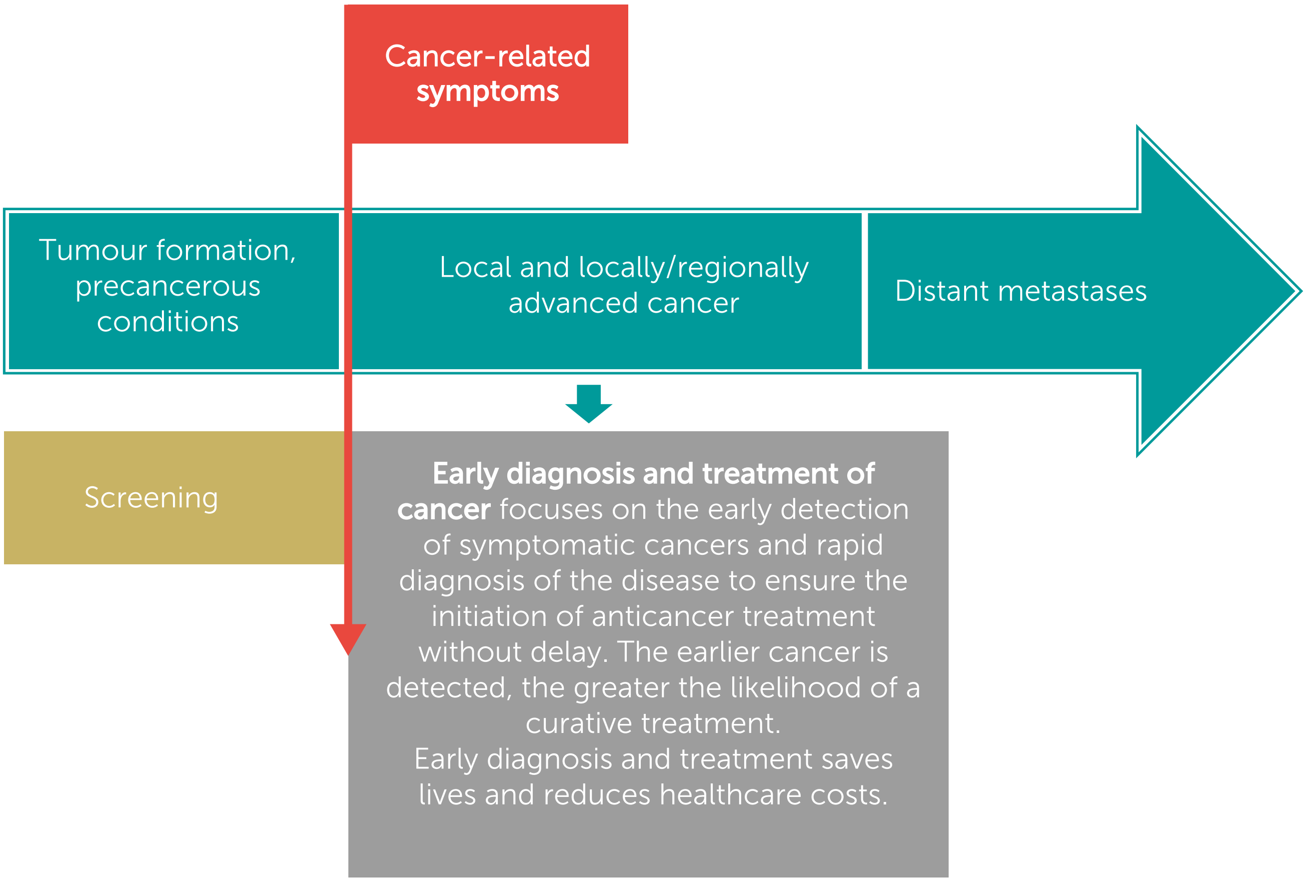
### Activities and recommendations

- The initiation of new screenings will be considered if the HTA reports, together with a feasibility study and a cost-effectiveness assessment, support the organisation of the corresponding screenings in Estonia.
- If the corresponding HTA report, together with a cost-effectiveness assessment, supports the organisation of lung cancer screening in Estonia, a lung cancer screening working group will be established. The task of the working group is to assess the feasibility of conducting lung cancer screening, which requires defining the target group of screened individuals, the inclusion methodology, the screening interval and the positive test result.
- The target groups for screening will be specified, using individual risk assessments and applying the principles of personalised medicine if there is a corresponding evidence base.
- The capacity will be created to implement personalised risk scoring in screening in Estonia, making it easier to use digital health records and add patient information (e.g. data about family predisposition and risk behaviour).
- A pilot project to supplement breast cancer screening with personalised risk scoring will be launched if the results of the estPerMed pilot project provide the necessary evidence.
- Prerequisite for the application of site-based risk scoring in the screening programme is a positive validation result and a supporting health service evaluation report.

# Early diagnosis and treatment

## Background

Both screening and timely diagnosis of malignant tumours play an important role in cancer control. Screening is performed on the asymptomatic population and can be used to diagnose cancer at an early stage, as well as to diagnose and treat precancerous conditions (see "Screening"). Early diagnosis differs from screening because it involves the early detection of cancer in patients who already have symptoms of the disease [120]. The aim of early diagnosis of cancer is the rapid diagnosis of patients with symptoms suggestive of cancer in order to ensure that cancer treatment can be started without delay (Figure 10). Early diagnosis is extremely important for this group of patients, because the earlier the cancer is detected, the greater the likelihood of curative treatment and a better quality of life for patients. In addition to the above, timely diagnosis and treatment of cancer helps to save costs for treatment, as the costs of cancer treatment increase with each subsequent stage of cancer [121].



**Early diagnosis and treatment of cancer** focuses on the early detection of symptomatic cancers and rapid diagnosis of the disease to ensure the initiation of anticancer treatment without delay. The earlier cancer is detected, the greater the likelihood of a curative treatment.
Early diagnosis and treatment saves lives and reduces healthcare costs.

*Figure 10. Early diagnosis and treatment of cancer.*

Early diagnosis of cancer involves three stages [120]: (1) public awareness of early symptoms of cancer and seeking medical care; (2) cancer diagnostics and determining the stage of the disease; (3) availability of cancer treatment. In cancer control programmes, it is therefore important to pay attention to measures to improve public awareness and ensure the prompt referral of patients with cancer symptoms to the healthcare system for timely diagnosis and treatment.

### Patient delay

For decades, it has been shown that the longer the time period between the onset of cancer symptoms and the start of treatment, the shorter the patient's survival [122]. Therefore, it is extremely important that people themselves understand the early symptoms of cancer and seek medical attention sooner. The importance of the latter time interval is also confirmed by several published studies, which have found that patient delay is an important factor affecting the effectiveness of cancer treatment [123,124].

### The role of the family doctor

Studies have shown that most patients seek medical attention before receiving a cancer diagnosis, but even symptoms of cancer with a high probability usually have a small positive predictive value because cancer is a rather rare condition for family doctors. On average, a family doctor sees about seven to nine new cancer patients per year and perhaps only one child with cancer during their entire career [125]. In Estonia, there are problems with the availability of family medicine in some regions (shortage of family doctors and family nurses), and, more generally, long waiting lists for examinations and specialist appointments are also an obstacle. A few years ago, guidelines were drawn up for different cancer sites [126], which are now outdated. All these factors can prevent a patient from accessing cancer treatment.

### Long waiting times in the diagnostic and treatment pipeline significantly affect the outcome of cancer treatment

Based on what was discussed in the previous chapter (see "Overview of the current situation"), it can be noted that many new cancer cases are diagnosed at a late stage. It has also been found that the risk of cancer death is higher in Eastern Europe, including Estonia, even after adjusting to age, sex and stage. [127]. The above suggests that poorer treatment outcomes cannot be explained solely by late detection of cancer and that there are probably also shortcomings in the diagnostic and treatment journey of patients. Unfortunately, these shortcomings also occur in the case of locally or locoregionally advanced disease, which should have the highest probability of cure.

In the case of curative treatment, long waiting times affect both local control of the cancer and the overall survival of patients [128,129]. In early breast, lung, kidney and pancreatic cancers, it has been shown that delay in the initiation of treatment increases mortality by 1.2–3.2% for each week of delay. Waiting times longer than six weeks have also been confirmed to affect survival in patients with all malignant tumours (except prostate cancer). For example, the five-year survival rate for stage 1 lung cancer is 56% if the waiting time is $\leq$ 6 weeks, and only 43% if the waiting time is > 6 weeks [128]. A recently published study involving seven cancer sites showed that starting treatment four weeks after diagnosis increased mortality by an average of 6–13% compared to patients who started treatment earlier [130].

### Standardising and thereby shortening waiting times is effective in cancer control

Most countries where cancer control has been effective have used standardising of waiting times, thereby shortening them. For example, the United Kingdom has set a limit of two weeks for suspicion of cancer to progress to an advanced phase and a 31-day waiting time for treatment when the cancer diagnosis is confirmed (after the time taken to diagnose). [131].

In Denmark, it has been determined that after a suspicion of cancer has reached an advanced phase, the waiting time for treatment (surgery, radiotherapy, radiochemotherapy, drug treatment) must not exceed 42 days [132], i.e. within 42 days, all necessary examinations (radiology, pathology, genetics) are performed, the diagnosis and stage of the disease are confirmed, and the treatment decision is made in a multidisciplinary council.[14] It is important to mention here that all these activities have received strong political support, the beginning of which can be considered the government press conference "Cancer is an acute disease" Aug 10, 2007). According to the Danish Lung Cancer Registry, rapid diagnosis and early treatment have improved lung cancer survival rates by 2016 compared to 2003 as follows: one-year survival has increased from 33% to 51%, two-year survival from 18% to 33%, and five-year survival from 8% to 15%. The rapid improvement in the five-year survival of cancer patients in Denmark between 2000 and 2014 has also been confirmed by the recently published CONCORD-3 study, which showed that Denmark is catching up with the Scandinavian countries (Iceland, Finland, Sweden, Norway) with the best results in Europe [12].

### For effective cancer control, it is necessary to standardise the entire patient journey from the onset of cancer symptoms to the start of anti-cancer treatment

The patient journey from suspected cancer to the start of anti-cancer treatment includes improving awareness among the population (recognition of symptoms and seeking medical care), primary care and specialists (recognition of symptoms, initial examinations in case of suspected cancer, referral to a cancer centre), and activities at the cancer centre (histological confirmation, radiological examinations, multidisciplinary council, treatment waiting times).
For effective cancer control, it is necessary to standardise the entire patient journey from suspected cancer to the start of anti-cancer treatment (Figure 10).

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[14] Multidisciplinary council – a cancer site based council consisting of specialists in three treatment modalities and specialists in tumour diagnostics.

### Standardisation and analysis of waiting times help to improve cancer treatment

Standardisation of waiting times for diagnostics and treatment makes it possible to detect cancer earlier, provide more effective treatment, increase the number of people who have recovered from cancer and improve survival.

Standardisation and analysis of waiting times also provide opportunities to optimise and improve cancer treatment:

- By monitoring indicators of timely diagnosis and treatment, it is possible to assess bottlenecks within the unit ( hospital) and plan resources accordingly (availability of diagnostic methods and treatment, lack of human resources and/or technical resources, etc.);
- By monitoring indicators of timely diagnosis and treatment, the health insurance fund has the opportunity to direct budget; resources to where there is a greater need. With each subsequent stage of cancer, the costs of cancer treatment increase [121]. Therefore, it is particularly important to optimise treatment waiting times for early-stage cancer (with local and locoregional spread), where the probability of recovery is highest
- At the national level, there is an opportunity to optimise human resources by monitoring indicators of timely diagnosis and treatment (e.g. the number of state-funded residency places opened).

In addition to the above, standardisation and analysis of waiting times have become increasingly important, as many countries have seen a trend of worsening waiting time indicators in recent years [128,133]. The reason for the latter is the increase in the incidence of malignant tumours, the increased number of indications, and the resulting significantly greater need for diagnostics and treatment.

## Problems

Several population-based studies confirm that early detection of cancer is a problem in Estonia because the share of primary cancer cases detected at an early stage is lower in Estonia than in other countries. For example, the share of local breast cancer cases in Estonia is 44%, but in Saarland, Germany and the USA, it is 50% and 63%, respectively [11,134]. The share of stage 1 and 2 kidney cancer is also lower in Estonia (61%) compared to the USA (70%) and the share of stage 1 cervical cancer (35%) compared to Norway (60%) [7,8,135]. See also "Overview of the current situation".

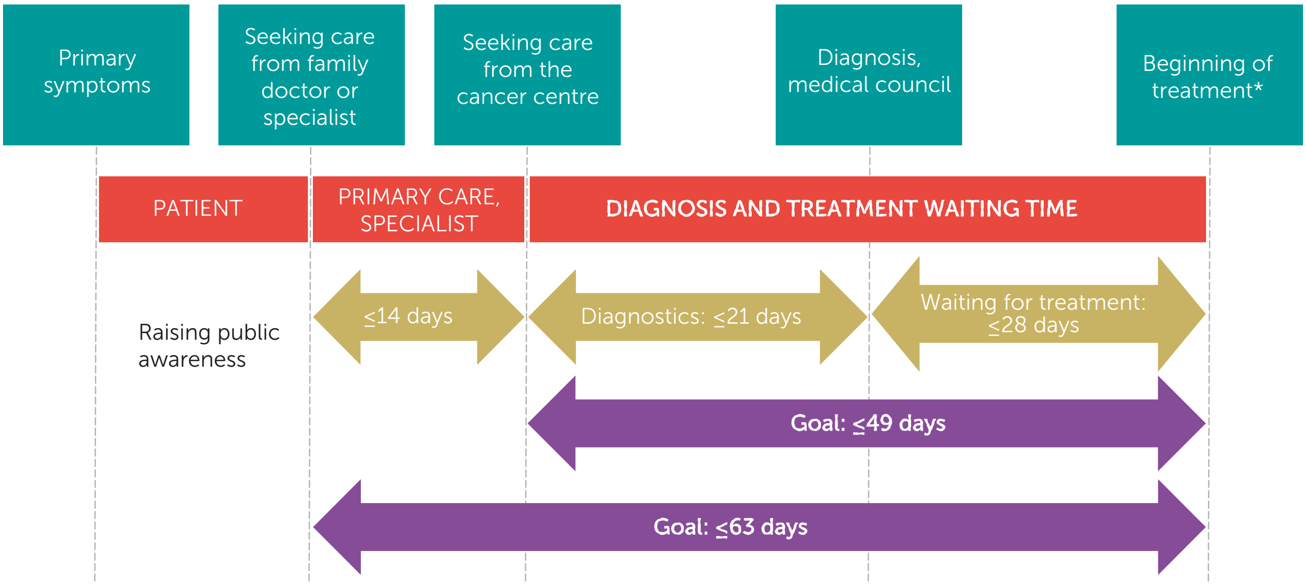
There has been no systematic analysis of waiting times in Estonia. Certain waiting times and corresponding indicators are set out in the 2011 document "Estonian cancer treatment quality assurance requirements" [136]. For example, according to the document, curative radiotherapy should begin within 28 days. Guidelines have also been prepared for several malignant tumours [126], which roughly define the treatment of patients until the medical council, but there is no clear data on waiting times for treatment.

In summary, it can be said that information on waiting times and their dynamics has not been systematically collected or evaluated in Estonia so far. Since there are also no clear indicators for monitoring the patient's journey from the primary care doctor and specialist to referral to a cancer centre and the start of the necessary anti-tumour treatment, standardisation of the entire process, collection of indicators, and analysis are extremely important for cancer control.

## Goals

The activities implemented to achieve goals and standardised waiting times are summarised in Figure 11.

In cooperation between primary care doctors, specialists and cancer centres, it is necessary to ensure that the maximum time from suspected cancer to initial cancer treatment does not exceed 63 days. In the cancer centre, it is necessary to standardise diagnostic and treatment processes and ensure that the maximum time spent on diagnostics and waiting for treatment does not exceed 49 days.



* surgery, radiotherapy, drug therapy

*Figure 11. Patient's journey from suspected cancer to the beginning of anti-tumour treatment.*

### Goal 1. Public awareness of cancer and cancer symptoms is higher

Activities and recommendations

- An action plan will be developed and implemented to increase public awareness. The action plan will include the recognition of symptoms of the most common malignant tumours and guidelines for seeking medical attention. The need to use multiple communication channels must be taken into account.
- An action plan team will be formed, including representatives of professional societies, hospitals, the University of Tartu,the Ministry of Social Affairs, the National Institute for Health Development and the Estonian Health Insurance Fund, as well as communication experts.

### Goal 2. Patients with suspected cancer will reach a cancer centre within a maximum of 14 days after being referred by a family doctor or specialist

Activities and recommendations

- A checklist will be compiled for family doctors and health centre teams of symptoms and results of simple tests that indicate suspicion of cancer in at least the five most common cancer sites. For other less common cancer sites, the list will be compiled later.
- A precise journey to the cancer centre for a patient with suspected cancer will be defined for family doctors and specialists, using existing and faster options (e.g. e-consulting).
- A patient with suspected cancer will be registered at the cancer centre, and further diagnostics will be organised.

## Goal 3. The entire patient journey until the beginning of anti-tumour treatment is standardised at the cancer centre

### Activities and recommendations

- The cancer centre will develop guidelines indicating which examinations and tests are necessary to confirm or rule out the diagnosis of a malignant tumour in a specific site. If possible and appropriate, previously developed guidelines for the management of patients with malignant tumours will be used. The guidelines for the five most common cancer sites will be created first, followed by other, less common cancer sites.
- Additional diagnostics are performed at the cancer centre and the patient is referred to the council within a maximum of 21 days.
- If the cancer diagnosis is not confirmed, the patient is referred back to primary care.
- The work at the cancer centre is organised in such a way that the primary treatment of a cancer patient begins within a maximum of 28 days, counting from the council.
- The work at the cancer centre is organised in such a way that the maximum time spent on diagnostics and waiting for treatment does not exceed 49 days.
- The cooperation between primary care doctors and specialists and the cancer centre is organised in such a way that the maximum duration of the entire journey from the patient's suspicion of cancer to primary treatment does not exceed 63 days.
- Cancer centres have organised continuous and repeated analyses of indicators of timely diagnosis and treatment journeys and, if necessary, measures are taken to shorten the period.
- Hospitals agree on the structure and inputs of a unified database that enables the collection of indicators for a timely diagnosis and treatment journey, allowing for comparison at the national level.
- It is important to ensure the exchange of information and data, especially between primary care and the cancer centre (confirmation or non-confirmation of cancer suspicion, epicrisis).

# Diagnostics and treatment

A cancer diagnosis is reached through an evidence-based process based on various methods, which includes the analysis of the clinical picture, diagnostic imaging, endoscopic and other examination procedures, and laboratory results. Accurate determination of the stage of cancer is the basis for the selection of treatment methods and the assessment of prognosis.

Currently, cancer treatment in Estonia is regulated by the document "Estonian Cancer Treatment Quality Assurance Requirements", published in 2011 [136]. Cancer-specific treatment is decided by a tumour site-based multimodality council, which includes specialists in three treatment modalities (surgeon of the corresponding site, radiotherapy and systemic therapy/chemotherapy) and specialists involved in tumour diagnostics. All three treatment methods are available in two regional hospitals – TÜK and PERH. Antitumour drug treatment options are available in central hospitals (ITK, Ida-Viru Central Hospital and Pärnu Hospital). General hospitals offer outpatient appointments/ consulting with oncologists and haematologists. Modern cancer treatment is not only multimodal but also interdisciplinary, so various specialties outside of oncology (cardiology, endocrinology, gastroenterology, etc.) are involved with the aim of preventing treatment-related side effects or ensuring their timely treatment. Cancer rehabilitation deals with the restoration of functions impaired as a result of cancer or cancer treatment. The goal of palliative care is to ensure the best possible quality of life for patients and to support patients and their loved ones. The treatment team also includes other specialists (speech therapists, pain management doctors and nurses, nutritionists, psychologists/peer support, social workers, pastoral counsellors, etc.) who help maintain the patient's quality of life during and after the treatment process.

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# DIAGNOSTIC IMAGING AND IMAGE-GUIDED THERAPY

## Background

Diagnostic imaging is a branch of clinical medicine that encompasses all aspects of medical imaging, which provides information about anatomy, pathology, histology, physiology, and the course of disease, and uses image-guided techniques to diagnose and treat diseases [137].

According to modern thinking, the core value of radiology is the receipt, transmission, and use of clinically relevant information to assess the patient's condition and the treatment of disease. This goal is achieved by the radiology team in collaboration with clinical partners. Radiological examinations for cancer diagnosis, treatment and monitoring are performed by a radiology team, which includes radiologists, procedural radiologists, nuclear medicine doctors and technicians, radiology technicians, ultrasound (US) specialists, medical physicists and biomedical engineers.

Compared to other European countries, Estonia has fewer devices used in cancer diagnostics, treatment and monitoring. There are 17 computed tomography (CT) scanners and 14 magnetic resonance imaging (MRI) scanners per million inhabitants in Estonia, which is about half the average number in European countries [138]. On the other hand, our equipment utilisation is much higher than elsewhere. For example, in 2017, 9,258 CT examinations and 3,797 MRI examinations were performed per device in Estonia, while the corresponding figures for Finland were 1,808 CT examinations and 1,592 MRI examinations [139]. This means that we use the equipment much more efficiently, but this is due to working more than eight hours a day and performing scheduled examinations on weekends in addition to weekdays.

The share of oncological examinations is higher in regional hospitals. According to the PERH and TÜK databases, one-third of all diagnostic imaging examinations are performed on cancer patients. According to the 2019 annual report of the TÜK radiology clinic, the share of large, time-consuming CT examinations of all radiological examinations has increased from 13% in 2009 to 42% in 2019. The growth has occurred primarily due to examinations performed for cancer diagnostics and monitoring of cancer patients.

The treatment of a cancer patient is discussed at multidisciplinary meetings and oncology councils. The councils usually include a radiologist and, in case of certain cancer cites, a nuclear medicine doctor and an interventional radiologist. Based on the work schedules of regional hospitals, approximately 20% of the working time of radiologists involved in cancer treatment is spent preparing for and participating in multidisciplinary meetings and councils. Similar data has been published for other countries [140].

Based on data from PERH information systems, 68% of primary cancer patients received a CT scan result within two weeks of their initial visit to a specialist. 55% of oncology patients received an MRI result within two weeks. Similar data is not available for other hospitals. It is important to consider that a primary cancer diagnosis can also be received when a patient with an acute pathology is hospitalised in the emergency department.

Interventional radiology plays an important role in the diagnosis and treatment of cancer, and the alleviation of cancer-related symptoms, i.e., in improving and maintaining the patient's quality of life. Image-guided minimally invasive cancer therapy (interventional oncology) is a rapidly developing subspecialty of interventional radiology, the advantage of which is the local effect on the tumour or organ and minimal systemic effect. The technological process of interventional radiology is based on the need for modern oncology to increasingly enable patient-centred precision cancer treatment. Interventional radiology treatment procedures are performed rarely for cancer patients – in 2019, 30 radiofrequency ablation (RFA) procedures were performed in Estonia, mainly for the treatment of liver and kidney tumours, ten (DEB)-TACE (drug-eluting beads transarterial chemoembolisation) liver tumour embolisations, and seven tumour embolisations (mainly closing the arteries feeding bleeding tumours in the pelvic region). One selective internal radiation therapy (SIRT) procedure was performed in collaboration with colleagues from Tampere University Hospital.

The use of nuclear medicine examinations in the diagnostics of oncological diseases increased after 2002 when positron emission tomography (PET) with 18F-FDG (fluorodeoxyglucose) was first introduced in Estonia. Currently, the PET/CT imaging method based on modern hybrid technology is available to oncological patients in the country's three largest cancer centres (PERH, TÜK, ITK). In 2018, a new generation marker, 18F-PSMA (prostate-specific membrane antigen), was introduced in all three centres with the aim to improve the diagnostics of the spread of prostate cancer.

Nuclear medicine treatment procedures allow the patient to receive personalised targeted therapy. While radioiodine therapy for thyroid cancer has been used in Estonia for decades, isotope therapy for both neuroendocrine tumours and advanced prostate cancer is available in Estonia. However, unlike in many other European countries, these treatment procedures are not sufficiently funded by the Estonian Health Insurance Fund at the time of preparing this document and are therefore underused.

Diagnostic imaging also plays an important role in planning radiotherapy – PERH and TÜK use MRI scans to plan radiotherapy for brain, head and neck and prostate tumours. Planning brachytherapy for cervical tumours is based on MRI; PET/CT scans are used in planning radiotherapy for oesophageal, cervical and lung tumours.

Two audits on the treatment quality of cancer patients have been conducted by the Estonian Health Insurance Fund, which also concern diagnostic imaging. The quality of treatment of rectal cancer was assessed in 2009, and pre-treatment diagnostics were rated as better in regional hospitals but weaker in central hospitals. The report "The quality of diagnostics and treatment of patients with cervical and ovarian cancer in 2012–2013" gave a very good result for diagnostic imaging – assessment of the extent of the disease was carried out using CT or MRI in almost all cases before the beginning of treatment [141].

Estonia is in a unique position with radiological examination images and results. All examinations are recorded and accessible to participants in a national image archive, and the results are stored in both the image bank and the health information system. An obstacle is the difference in the information systems of hospitals, due to which cross-use of data between them is usually not possible. The examinations archived in the image bank are in standardised DICOM format, but both referrals and examination results are usually stored in free text and have a very low level of structure. An exception here is the structured results of mammography screening.

## Problems

Compared to the European average, the resources for diagnostic imaging and image-guided treatment (both in terms of equipment and personnel) are more limited in Estonia, and therefore the rational use of this resource is very important.

The staff issues are particularly acute in smaller hospitals, where there are no necessary specialists. In the radiology departments of larger hospitals, the examination results are usually delivered by remote response. The parameters used for radiological examinations and the quality of examinations vary from hospital to hospital, as there are currently no agreed uniform examination protocols in Estonia. Simple diagnostics also suffer due to the lack of radiologists; for example, there are very long queues for ultrasound examinations. For more information, see the chapter "Qualified and motivated personnel".

Coverage with diagnostic equipment varies greatly between healthcare providers. Equipment located in regional and central hospitals is used 12/7 or 24/7, while equipment in smaller hospitals is underused. The use of equipment and ordering of examinations is not always optimal, therefore spending resources intended for performing justified examinations.

No unified quality indicators have been set. Current IT systems are not designed to analyse important quality indicators. For example, the existing information systems in hospitals do not enable the assessment of how long it takes for a cancer patient from the first visit to a specialist to receiving the diagnostic imaging results. It is estimated that this does not always fit within the limits set by the quality indicators, according to which a primary cancer patient should receive test results within two weeks of the first visit to a specialist [136].

The ordering of radiological examinations, crucial for a cancer patient, is within the competence of the specialist. To undergo examinations, the patient must travel several times to the cancer centre, where the availability of examination is poor due to lack of resources and devices being busy. There is no user-friendly IT solution for follow-up examinations that would support both the treating doctor's decisions and the patient on their treatment journey.

Interventional radiological procedures for cancer patients are underused in terms of both theranostic procedures and pain management [142]. Similarly, the problem of nuclear medicine units is the introduction of new technological solutions and disease-specific markers because completing clinical drug trials to obtain evidence-based data is too time-consuming. This complicates the introduction and financing of innovative diagnostic and treatment methods, and makes it more difficult for oncology patients to access diagnostic examinations and treatment [102].

The Health Insurance Fund does not pay for consulting with a radiologist as a specialist, second opinions for the evaluation of diagnostic imaging performed in other institutions, or advising a cancer patient. Thanks to the image bank, there is access to static examinations, but there is no information about referrals or a clinical view of the patient's treatment journey, and sometimes, the examination result is also not visible in the image bank.

There is no uniform terminology and classification of oncology examination referrals, and results entered into information systems. Both referrals and results are written in free text, which makes automatic dynamic comparison of radiological characteristics or numerical values of oncological findings impossible. Also, uniform radiological examination protocols and quality criteria are not available in digital form. The linking of an image in the image bank to the description of an important finding (the so-called key image link in the description) is largely unused.

## Goals

### Goal 1. A patient-centred, personalised approach is ensured in diagnostic imaging

Activities and recommendations

- Updating site-based imaging and monitoring guidelines and their personalised implementation.
- Performing examinations close to the patient's place of residence.
- Ensuring cost-based covered consultings by radiologists as specialists by the Health Insurance Fund.

Initial examinations of local and distant spread cancer, ordered with a referral from a specialist, will be concentrated in specialised centres. Less common cancer sites will be treated in site-based competence centres (neuroendocrine tumours and other rare diseases). If examinations are performed in an institution located in the patient's place of residence, they will be performed according to agreed standardised examination protocols and the results will be formalised as structured as possible with the aim of ensuring maximum machine readability of the data.

Interdisciplinary working groups in the competence centres prepare site-based guidelines for diagnostic imaging, description of findings and follow-up, according to which the examination methodology is harmonised and which are applied specifically and personalised depending on the symptoms. The follow-up guidelines take into account the nature of the disease, genetic diagnosis, cancer site, tumour prognosis, risk of recurrence, etc. Guidelines are available for both medical personnel and patients through a user-friendly IT solution.

The patient should be able to monitor the course of diagnostic imaging, including reservations for primary and follow-up examinations in the patient portal, and to choose the most comfortable location for examination.

It is recommended that the initial treatment of a cancer patient and the initial examinations assessing the treatment effect are performed in the competence centre, while follow-up examinations may take place in the hospital of the patient's residence or a place comfortable for the patient. The results of the examination should be interpreted by a field specialist in the cancer centre. Many studies have shown that secondary evaluation of oncological examinations by radiologists working in cancer treatment competence centres has added value in making treatment decisions for cancer patients [143–145]. If necessary, a second opinion from a radiologist must be provided for diagnostic imaging of cancer patients, which the health insurance fund will reimburse cost-based. The possibility of e-consultation with a specialist must also include radiology. Consultation by a radiologist and the preparation of a second opinion for radiological examinations will be included in the price list of Health Insurance funds as cost-based.

### Goal 2. Diagnostic imaging and image-guided treatment are performed in a way that ensures patients an optimal cancer

Activities and recommendations

- Cancer patients must be ensured timely ordering of appropriate radiological and nuclear medicine examinations via e-solutions.
- A patient with suspected cancer must receive initial diagnostic imaging and results within two weeks of the initial specialist appointment.
- The radiologist and, if necessary, the nuclear medicine doctor and the interventional radiologist will participate as full members in the team designing the patient's treatment journey.

Under conditions of limited resources, diagnostic and monitoring examinations must be performed according to agreed guidelines and the management of the waiting list of radiological examinations. Prioritisation of time-critical examinations must also be secured. The radiologist should have the right to change the examination protocol if necessary, replace the examination with another modality, or refuse the examination in the event of an uninformative or wrongly selected examination. In case of a change or refusal, the decision must be discussed with the attending doctor who ordered the examination. Disagreements are resolved in accordance with the operating procedures of the medical institution. Digital Clinical Decision Support has an important role in the treatment of a cancer patient – the introduction of e-solutions to ensure the ordering of appropriate examinations.

A patient with suspected cancer must receive initial diagnostic imaging and results within two weeks of the initial specialist appointment. To achieve this, resources of radiology personnel, biomedical engineers and physicists, support staff and equipment must be ensured.

A radiologist with the relevant subspecialty and, if necessary, a nuclear medicine doctor and an interventional radiologist must be present at all oncological multidisciplinary councils and treatment decision meetings [146].

## Goal 3. Patients are secured a high-quality diagnostic imaging and image-guided treatment

### Activities and recommendations

- Ensuring the number and competence of employees; see "Qualified and motivated personnel".
- Use of structured referrals, standardised examination protocols and structured results.
- Expanding the use of minimally invasive cancer treatment guided by diagnostic imaging.
- Increasing nuclear medicine diagnostics and treatment options in cancer treatment.
- Effective collaboration in planning of radiotherapy using MRI, CT and PET

It is important to expand collaboration with oncologists in research and clinical trials.

To ensure stable diagnostic and treatment quality and to maximise patient benefit, it is necessary to ensure resources for the sustainability of clinical audits.

Standardised protocols help to improve the reproducibility of examinations, comparisons over time and between modalities, and the quality of examinations. They enable diagnostic quality to be achieved with the lowest possible radiation dose (ALARA) and prevent unnecessary repetitive examinations. A structured referral letter is required to use standardised protocols, which reflects the patient's history, clinical data, diagnostic problem and results of the examination [147]. To improve the quality of examination results and patient management, it is necessary to introduce structured result forms that provide the most accurate assessment on the patient's condition and all relevant information that allows the clinical partner to choose the right treatment and management tactics. The introduction of structured referrals and responses requires the existence of nationwide terminology, classifiers and agreements. The use of structured result forms simplifies the dynamic comparison of examinations and enables the use of them together with clinical data in various research studies and cancer registers [148]. It is also the input for the development of computer programmes based on personalised medicine solutions and artificial intelligence. The structured result forms should include the examination protocol, clinical information, radiological findings and, in the case of a primary cancer diagnosis, the TNM classification[15], if possible. The assessment of the treatment effect must be formalised in a structured manner (complete, partial response, etc.) [148]. The creation of a structured referral, standardised examination protocols and structured result forms must be a priority of the Estonian Society of Radiology (ESR) and the Estonian Society of Nuclear Medicine (ESNM) in the coming years, which certainly requires additional resources.

Thanks to the continued rapid development of diagnostic imaging modalities (US, CT, MRI and PET), it is possible to precisely plan, perform and dynamically evaluate minimally invasive cancer treatment procedures. In recent decades, as a result of technological development, interventional radiology has become the so-called fourth pillar of cancer treatment in addition to surgery – systemic and radiotherapy. Therefore, we must take into account both the changes in workflows and the increase in the need for space, equipment and human resources [149].

In Estonia, the promotion of personalised isotope target therapy methods in cooperation with oncologists will be important in the coming years. The introduction of new innovative nuclear medicine methods in the diagnostics and treatment of oncological diseases will improve the availability of radiopharmaceuticals, which in turn is related to the development of radiopharmacy in nuclear medicine units. The Health Insurance Fund must find ways to finance innovative procedures from a separate fund until these are included in the list of health services.

To improve the quality of radiotherapy, it should be planned on the basis of MRI and CT/PET for more cancer sites. Planning of radiotherapy based solely on MRI for prostate, pelvic and central nervous system cancer patients will significantly increase the use of MRI. The MRI device used should include additional devices and specific programmes that enable image recording in the radiotherapy position. It is important to enhance cooperation with oncologists in radiotherapy planning on an adaptive radiotherapy journey and the application of artificial intelligence in organ at risk contouring.

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[15] TNM classification – classification of tumour stages prepared by the international cancer organisations American Joint Committee on Cancer (AJCC) and Union for International Cancer Control (UICC): T – tumour size and spread to neighbouring organs; N – spread to regional lymph nodes; M – distant metastases.

# PATHOLOGY, CYTOGENETICS AND MOLECULAR DIAGNOSTICS

## Background

### The role of molecular diagnostics and pathology in tumour diagnostics

Pathology and molecular diagnostics examine tissue or cell material taken during a diagnostic procedure or surgery using tissue processing, numerous histochemical and immunohistochemical stains, and studies at the molecular level. The aim of the studies is to identify the tumour and determine its subtype and pathological stage of the disease, along with various prognostic and predictive features. Specific studies also allow for the assessment of the drug sensitivity of the tumour. An internationally recognised synoptic or structured protocol is used for tumour assessment, along with standardised assessment of biomarkers, which requires the results of molecular and cytogenetic tests and thus allows for the collection and transmission of the aforementioned information in an unambiguous and understandable manner.

Thanks to technological developments, molecular and cytogenetic testing has become increasingly accurate, cheaper, and, therefore, more accessible. On the other hand, extending genetic information enables more accurate molecular pathological diagnosis and better assessment of disease prognosis, and thus more accurate personalised treatment.

The increasing complexity of the pathology has led to the need for site-based subspecialisation. This allows for the concentration of expertise and the provision of better and standardised services. Specialisation in Estonia, with a small population, leads to the centralisation of diagnostics of rare diseases and the need for close cooperation between different departments and specialties.

Multidisciplinary teams (councils) must ensure the necessary flow of information and feedback between radiologists, pathologists, surgeons, oncologists and other relevant specialists [101,150].

### Possibilities of digital pathohistological diagnostics

Digital pathohistological diagnostics (digital pathology), together with the development of whole slide imaging technology, image processing, machine and deep learning technologies, create additional possibilities for the conventional light microscopy method [151]. In Estonia, the pathology department of ITK has used digital pathology tools since 2020 [152]. The use of digital pathology helps create remote work opportunities, allows the showing of slides to in an interdisciplinary council, enables faster consulting of complex cases, and makes the department's workflow more efficient. The expansion of digital imaging diagnostics to the cytogenetics laboratory allows the integration of information from different laboratories, optimises workflows, and speeds up the resolution of more complex cases. In a situation where there are not enough specialists, the workload is growing, and expectations for shortening the examination time are high, the digital pathology method has the potential to select and prioritise specimens with quantitative evaluation, assist in determining the degree of tumour differentiation, and assess biomarkers [153]. Digital innovation allows the modernisation of workflows and diagnosis and reduce intra- and inter-observer variability, which in turn results in improved patient safety and collaboration with multidisciplinary and disease-specific councils [154].

### Data quality of response from the pathology department

The fastest possible diagnostics is very important in the treatment of tumours [150]. The speed of response in case of a malignant diagnosis is now outlined in the specialty quality indicator [25].

Currently, standardised responses are used only for certain cancer sites, and each pathology department uses its own response standards. Harmonisation of the standards across departments is ongoing. The information that needs to be reflected in the response is outlined in the WHO’s site-based classification and the latest published version of the TNM classification (currently, the 8th version of the TNM classification is agreed to be used in Estonia).

The use of standardised responses should streamline the handling of patients between different treatment and diagnostic units and ultimately enable better data analysis [150].

The basis for handling cytogenetic analyses is the common European guidelines on the handling of different materials, quality, requirements for responses and deadlines for responses [155].

### The need for further development

With the introduction of more complex examinations and the development of information technology, pathology is becoming increasingly data-centric and intensive, and the future development of the specialty directly depends on the available IT solutions [156]. In addition to collecting data within a single examination in the department's information

The implementation of digital pathology entails the need to integrate extensive artificial intelligence applications into daily work, including diagnostic decision support [154,156].

Developments also make it possible to automate and standardise subjective and manual work processes, which enables the pathologist to devote more time to their professional work.

### Accreditation

Accreditation of pathology and molecular diagnostics and cytogenetics laboratories is a guarantee to the patient and the doctor that the service complies with the agreed standards, the safety of the service, consistent quality, and accurate and reliable results. The existence of accreditation clearly shows which laboratories meet the requirements necessary to ensure quality. In Estonia, the ISO 15189:2012 medical laboratory quality and competence requirements are used for the accreditation of molecular diagnostics, cytogenetics, as well as pathology laboratory histology and cytology services [157–159].

## Problems

The volume of diagnostic work is increasing, and the requirements for the content and time of the response and additional studies are becoming more complex. The need for developments in IT and digital pathology is increasing year by year, but the reality does not meet the needs.

The movement of data and the harmonisation of information obtained from the response are increasingly important because patients move between different centres.

Meeting quality indicators in the pathology should be mandatory. If any indicator is difficult to meet, the reasons for the obstacles must be analysed.

Molecular and cytogenetic diagnostics in oncological and oncohaematological patients are not harmonised between different hospitals in Estonia. The possibility to analyse tumour tissue at the multigene molecular level have been available in Estonia since 2020, and somatic mutations have been analysed at the level of individual genes since 2010.

## Goals

### Goal 1. The continuity of the pathology as a specialty has been maintained, and effective interdisciplinary cooperation is ongoing

#### Activities and recommendations

- A sufficient number of employees and training must be ensured; see "Qualified and motivated personnel". Increasing the number of pathologists and specialists focused on molecular oncogenetics will help to keep waiting times for examination within the set limits [160].
- Both pathologists and molecular geneticists must be included in multidisciplinary councils [150,160]. Rare morphological diagnoses must be handled by pathological councils. Specialisation (subspecialties within pathology) increases the pathologist's expertise, which is necessary in diagnosing rare diseases.

### Goal 2. Pathology departments dealing with cancer diagnostics meet the quality indicators relevant to the specialty

#### Activities and recommendations

- Standardisation of responses will be implemented. The standardised content and unambiguous understanding of data obtained from histological and molecular examination of malignant tumours is necessary for both patient treatment planning and for collecting data in a digital register and processing them [160,161]. The standard set for the response will also mean more time spent by the pathologist and molecular oncogeneticists, which results in the need for more pathologists.
- IT developments will be implemented that are necessary for monitoring professional quality indicators [157] (use of SNOMED lists, standardised response times for malignant diagnoses). ISO accreditation will be ensured for basic pathology services, and digital pathology will be introduced. Clinical indicators for the specialty of pathology have been approved by the Estonian Health Insurance Fund [157]. The indicators can be assessed in the hospital's information system once the relevant IT developments have been carried out.
- The introduction of new diagnostic methods (e.g. immunohistochemistry) will be simplified. Diagnostic and treat-options must be secured simultaneously (the system for adding a health service to the list of health services of the Health Insurance Fund must be more flexible and faster).

## Goal 3. Molecular diagnostics for both germline mutation testing and tumour/metastasis testing are harmonised across Estonia in different hospitals for different cancer sites according to international diagnostic guidelines

### Activities and recommendations

- Pan-Estonian diagnostic guidelines for different cancer sites will be created based on international guidelines [162,163], or international diagnostic and treatment guidelines will be adopted and implemented [164].
- Somatic mutation studies will be concentrated in centralised laboratories to ensure cost-effectiveness, best use of field-specific knowledge and quality of analysis results, as testing for somatic mutations with multigene panels requires extensive experience and IT investments.
- It is recommended to convene a molecular tumour council [165] consisting of oncologists, clinical molecular geneticists, cytogeneticists and scientists, which provides recommendations for treatment choices in rare molecular alterations.

# SURGICAL TREATMENT

## Background

Surgical cancer treatment, or cancer surgery, involves the removal of malignant tumours and pre-tumour changes by surgical methods. Surgical treatment is an integral part of multimodal treatment, being one of the three main modalities of solid tumour treatment, and radical surgical treatment is usually a prerequisite for cure. The quality of surgical cancer treatment is one of the most important factors influencing the survival of cancer patients [136].

Surgical cancer treatment can be radical or palliative, planned or unavoidable by nature. Removal of the primary tumour site in accordance with oncological principles has curative potential in tumours without distant metastases. Surgical removal of distant metastases of some solid tumours may also be curative [166,167]. Partial removal of tumour tissue, or cytoreductive surgery, may be indicated for multiple cancer sites [168,169]. Palliative surgery for cancer-related complications is an important part of cancer surgery.

The evidence-based efficacy and wider use of radiation and systemic therapy [170–172] have sometimes led to changes in cancer surgery [173,174]. In the treatment of some cancer sites, surgical treatment has been partially replaced by a curative plan with radiation and systemic therapy [175–177]. However, surgical treatment remains necessary in cases of poor treatment response or cancer recurrence.

Provided that the basic principles of cancer surgery are followed and curative potential is sought, the general trend in modern cancer surgery supports an organ-preserving approach, the inclusion of reconstructive surgery, and consideration of quality of life in treatment planning [173,174,178].

The minimally invasive approach plays an important role in modern cancer surgery [174,179–181]. Minimally invasive surgery has generally proven to be equivalent to traditional access in oncological outcome measures. A prerequisite for the implementation of minimally invasive surgery is adherence to the basic principles of cancer surgery, i.e. the operation is performed in a volume that meets the requirements of cancer surgery. The advantages of minimally invasive surgery are manifested in faster postoperative recovery, reduced blood loss, and a lower probability of certain complications [179–183]. The learning curves for complex minimally invasive cancer surgeries are long, requiring specialised equipment and experience [184].

In Estonia, minimally invasive surgery has developed in line with the country's capabilities. There are sufficient resources in Estonia for the development of minimally invasive cancer surgery, as shown by the continuous increase in the share of minimally invasive surgeries in many surgical specialties [25]. The quality of minimally invasive surgery depends on the dedication to the given surgical activity and the experience of the centre and surgeons.

Globally, there is a trend towards centralisation and specialisation in cancer surgery [185]. Centralisation refers to the performance of complex and large-scale oncological surgeries in larger centres. Specialisation means that surgeries are performed only by surgeons who have received special training for this purpose.

In Estonia, the current organisation of cancer treatment, including cancer surgery, and the division of activities between hospitals are regulated within national legislation. Elective general and gynaecological cancer surgeries are permitted in regional hospitals (PERH and TÜK) or in central hospitals by the decision of the regional hospital council [186]. There are no legal restrictions on the performance of oncourological surgeries in central hospitals. Currently, cancer surgeries of central nervous system, head, neck and thoracic tumours are completely concentrated in regional hospitals, while urological and gynaecological cancer surgeries are somewhat more evenly distributed between regional and central hospitals [25].

15–30% of gastrointestinal and soft tissue cancer surgeries are performed in central hospitals. For example, 65 pancreaticoduodenal resections were performed in Estonia in 2019, of which 16% took place in central hospitals; 28% of the colorectal cancer surgeries performed in 2018 took place in central hospitals (16% in ITK and 10% in LTKH) and 2% in general hospitals [25].

More than 700 patients underwent breast tumour surgery, of which 20% took place in central hospitals [25].

According to professional societies, the number of oncological surgeries in Estonia is, on average, 1,500 per year, of which over 90% are performed in regional hospitals and two in central hospitals (ITK, LTKH) – the distribution between regional and central hospitals is approximately 60% vs. 40%.

According to professional societies, approximately 800 oncogynaecological surgeries are performed in Estonia per year, one-third of them in Tartu and two-thirds in Tallinn (PERH, ITK, LTKH); the distribution between regional and central hospitals is approximately 60% vs. 40%.

Representatives of many medical specialties are involved in the treatment of oncological patients. In the list of medical specialties valid in Estonia, an oncologist is defined as a specialist in the sense of radiotherapy and chemotherapy [187]. Specialists of various surgical specialties, mainly defined by the organs being dealt with, are engaged in cancer surgery, and cancer surgery is not defined as a specialty itself. Surgical residency programmes include limited theoretical and practical oncological training [188].

The rapid development of oncology and the increasing interconnectedness of the main modalities of cancer treatment have changed the role of the surgical specialist who deals with cancer treatment daily, both in Estonia and elsewhere in the world. Surgical cancer treatment requires thorough general oncological knowledge and specific cancer surgical knowledge specific to a particular surgical specialty.

The long-term results of cancer treatment, including surgical cancer treatment, can be assessed through cancer survival measured based on cancer register data. However, the purpose of the cancer register is not to assess the quality of treatment. The Health Insurance Fund's database, treatment quality indicators, audits and in-depth studies based on medical records have been used to assess the quality of treatment [13,14,22,141].

## Problems

The organisational structure of cancer surgery must be based on valid legislation. Any changes in the number and structure of cancer centres must only take place in accordance with the previous changes in legislation. There is no strategic planning by cancer sites in the organisation of cancer surgery in Estonia based on the need for surgical treatment and competence requirements, and there are no sufficient mechanisms to ensure compliance with legislation. International experience shows that in the case of low centralisation of surgical treatment, the lack of the necessary competence and experience to perform complex cancer operations and deal with post-operative complications may adversely affect treatment outcomes [185].

Additional competence in cancer surgery is not regulated within medical specialties in Estonia [187]. If a doctor is entered into the registry of healthcare professionals in a specific surgical specialty (e.g. general surgery, obstetrics and gynaecology, urology), they have the legal right to perform oncological operations within the scope of their specialty. Unfortunately, having a surgical specialty alone does not guarantee competence to perform cancer surgeries because the scope of cancer surgery training in surgical specialty residency programmes is insufficient. Thus, a situation may arise where doctors without the corresponding additional competence are engaged in surgical cancer treatment. For more information, see “Qualified and motivated personnel”.

There is no comprehensive overview of the current situation and quality of treatment in surgical cancer treatment in Estonia. There is no prospectively collected data as a comprehensive and structured dataset on the basis of which the quality and results of treatment in healthcare institutions could be analysed. This hinders decision-making regarding treatment management. The site-based audits and in-depth studies based on retrospective data that have been used so far are resource-intensive and do not provide the comprehensive and up-to-date information needed to improve the quality of treatment.

## Goals

### Goal 1. Surgical treatment of all cancer patients takes place in nationally recognised cancer centres that offer multimodal treatment and supportive services and are actively involved in scientific research

#### Activities and recommendations

Practice in several countries has shown that the number of cancer patients treated in a cancer centre directly affects the immediate perioperative course and long-term outcome of treatment [185]. Centralisation of surgical treatment in centres has reduced the number of complications and adverse treatment outcomes and significantly improved overall survival [189]. Some countries have, therefore, centralised the treatment of pancreatic, oesophageal, gastric, and liver tumours in national cancer centres, where there is a multidisciplinary team for the treatment of patients. In colorectal cancer surgery, it has been found that one of the independent prognostic factors for improving disease-free survival is the large number of operations performed by individual surgeons [190]. Similar recommendations for centralising surgical treatment to improve treatment outcomes are also made for lung, ovarian, bladder and soft tissue tumours [185,191,192]. The greater the competence and experience of both the surgeon and the centre, the more likely they will dare to perform surgeries on patients in poorer general condition and with comorbidities who would otherwise have no chance of recovering from cancer. The recent European Commission Cancer Mission document recommends concentrating cancer surgery in treatment centres, which allows for a minimally invasive approach to surgical treatment.

- A definition of a cancer centre and the principles of its national recognition will be developed, taking into account the requirements set out in the document "Estonian Cancer Care Quality Assurance Requirements" [136].
- The number of patients requiring surgical treatment will be analysed by cancer sites. Based on the results of the analysis and international evidence, the optimal number of medical institutions performing surgical treatment will be defined for each cancer site.
- Based on the above, a detailed plan for the centralisation of cancer surgery will be prepared, and the necessary national measures for its implementation will be developed.
- The centralisation of cancer surgery will be implemented gradually, ensuring continuous availability of treatment.

## Goal 2. Cancer surgeries will be performed by surgeons of the relevant specialty with additional competence in

### Activities and recommendations

Modern-day cancer treatment is complex by nature – in order to prepare the best treatment plan for the patient, all available options of surgery, radiotherapy and systemic therapy must be taken into account, as well as the order in which these will be implemented. Accordingly, there is a need for surgeons who, within their main specialty (general surgery, urology, obstetrics and gynaecology, etc.), have focused on the surgical treatment of malignant tumours or cancer surgery. The common thread connecting the fields of cancer surgery (based on the main specialty) is basic knowledge of the main principles of oncology.

- The additional competence of cancer surgery will be defined and added to the list of medical specialties. In Estonia, additional competences have already been implemented in many specialties [187]. There are various opportunities for acquiring additional competence; see "Qualified and motivated personnel".
- Cancer centres ensure the availability of surgeons with the necessary competence and maintain the competence of employees. Cancer centres also organise their work in such a way that only surgeons with the necessary additional competence perform surgeries on cancer patients.

## Goal 3. The quality and outcomes of treatment are measured in all medical institutions engaged in surgical cancer treatment, and changes in treatment management are made based on the results

### Activities and recommendations

The quality and outcomes of treatment must be assessed in different healthcare institutions on the basis of the same uniform methodology. Based on the results, conclusions should be drawn and changes made in treatment management to ensure optimal treatment outcomes for all patients. One option would be nationwide site-based databases, which have proven to be successful in many countries and have enabled significant improvements in treatment outcomes [185,193–195]. It is also important to ensure the availability of data from information systems and administrative databases used in everyday practice.

- A pilot project will be carried out in cooperation between professional societies, cancer centres and the state to collect site-based data to measure treatment quality and outcomes; see "Cancer data and research".
- The amount of structured data in hospital information systems and the health information system will be increased to ensure the availability of uniformly defined characteristics necessary for measuring treatment quality in different healthcare institutions.

# SYSTEMIC THERAPY

## Background

Systemic therapy includes drug treatment of cancer – chemotherapy, hormone, biological and targeted therapy.

Oncological systemic therapy is a rapidly developing branch of medicine. In recent decades, this specialty has undergone a qualitative change due to the development and introduction of new and effective drugs, which have contributed to improving the treatment outcomes and quality of life of cancer patients. Systemic therapy is used as the only treatment or in combination with other treatment methods, such as surgery or radiotherapy. Systemic cancer therapy is changing from non-specific chemotherapy to personalised targeted therapy, which can only affect the molecular characteristics of the cancer cell, which leads to the regression or destruction of the tumour in the body. Targeted therapy is less toxic compared to chemotherapy, as it affects fewer normal cells in the body. Personalised antitumour systemic therapy is based on tumour genomics. In many tumours, molecular profiling of tumour tissue may give clinically important diagnostic and prognostic information. Modern personalised therapy allows for the use of more effective antitumour systemic therapy drugs, which results in better treatment response, fewer side effects and better cost-effectiveness [196]. In recent decades, the use of innovative targeted or personalised drugs has steadily increased worldwide. While in 1999–2008, the European Medicines Agency registered 31 anticancer drugs, in 2009–2018 the corresponding number was 83 [197]. The process will be accelerated in the future by increasingly available DNA sequencing and molecular target identification, which, thanks to the collected data, will increase the use of targeted drugs both directly and indirectly, and this will promote the scientific development of innovative treatment methods. Therefore, it can be predicted that this trend will continue in the future, and the choice of new effective drugs will expand. The introduction of innovative cancer drugs has significantly affected the costs of drug-based cancer treatment. While in Europe, spending on cancer drugs accounted for an average of 12% of all cancer treatment costs in 2005, by 2018, the corresponding figure had increased to 31% [198]. The share in Estonia was 21% in 2019.

As a result, oncologists who provide systemic therapy need to keep up to date with developments in cancer treatment to ensure that the latest treatment options reach patients in a timely manner. This also sets requirements for training and the number of oncologists. According to a study conducted in Europe, there is also a site-based specialisation within systemic therapy – only 17% of systemic therapy doctors in Western Europe currently treat all types of cancer [199]. Since systemic therapy is often toxic, causing both acute side effects and late complications, the planning and preparation of systemic antitumour therapy must be done in accordance with all safety requirements associated with the handling of cytostatic drugs and be carried out under appropriate conditions. Currently, the conditions for providing cancer treatment in Estonia are regulated by the Regulation of the Minister of Social Affairs, "Requirements for the Quality Assurance of Cancer Treatment in Estonia", published in 2011.

A cancer-specific treatment plan is determined in tumour site-based councils, which include specialists in at least three cancer modalities (surgery, systemic therapy, radiotherapy) and additionally specialists involved in tumour diagnostics (radiologist, pathologist, etc.).

In Estonia, the necessary conditions for systemic tumour treatment are currently provided in two regional hospitals (PERH and TÜK) and ITK. In cooperation with regional hospitals, outpatient chemotherapy close to a patient's home is also provided in Pärnu Hospital, Ida-Viru Central Hospital and in cooperation with ITK and Kuressaare Hospital.

The best access to innovative treatment methods is available if the treatment is taking place within the framework of clinical and research studies. Clinical trials are science-based studies organised with the participation of medical personnel in order to find new effective drugs, treatment methods and opportunities to improve the quality of life for patients. According to the Organisation of European Cancer Institutes (OECI), clinical trials are part of the daily work of cancer centres.

## Problems

A major problem is the availability of systemic treatment, both in terms of the availability of medicines and social factors. Innovation in cancer treatment can only help patients if these new medicines reach everyday use. So far, the costs for new medicines have been partially compensated by the reduced share of inpatient treatment and a safer side effect profile, but these balancing mechanisms are not helpful in the long term. Taking these trends into account, it can be predicted that it will be increasingly difficult to finance new cancer medicines without increasing healthcare expenditures for cancer treatment [198]. Otherwise, not all effective medicines would become available to Estonian patients due to their high price and the small size of the Estonian market. In addition, even for newly registered medicines, the organisational side is outdated and needs an update. Professional associations do not have the resources to submit a separate request for each new indication of rare mutations or rare diseases, as well as for constantly changing treatment indications. Leaving the responsibility for requesting new drugs/treatments to professional associations is not sustainable.

In recent decades, there have been problems with the availability of commonly used anticancer drugs, due to which patients' treatment has been interrupted or switched to another preparation. The shortage of essential medicines can lead to treatment delays or poorer outcomes, forcing the use of alternative products with more side effects and less evidence-based. Between 2000 and 2018, supply disruptions in the European Union increased twentyfold [200]. The availability of these medicines, many of which are included in the WHO Model List of Essential Medicines for planning healthcare on a national level, has a potential impact on the quality of treatment and quality of life of all patients (morphine, dexamethasone, anti-nausea medicines, chemotherapy medicines). The WHO Model List of Essential Medicines also includes a separate list of cancer medicines that significantly improve survival. This list includes over 60 different cancer medicines, and 12 new ones were added in 2019, which have significantly affected treatment outcomes in several cancers [201,202]. Problems with the availability of essential medicines also take time and resources both from hospital staff (pharmacists, doctors, nurses) and patients (searching for points of sale, using more expensive alternatives) [203]. The seriousness of the problem is characterised by the fact that, based on a questionnaire for hospital pharmacies in 38 European countries, 91.8% of respondents consider supply disruptions or shortages of medicines to be a current concern that affects their daily work [204].

Systemic treatment is currently available in Tallinn, Tartu, Pärnu, Kohtla-Järve and Kuressaare. Access to regular treatment for patients living further away from centres may be limited due to transport issues, lack of time and financial resources.

The quality of systemic treatment may be affected by the high workload and intensity of systemic treatment oncologists and nurses due to the shortage of personnel; see "Qualified and motivated personnel".

A major problem in systemic treatment is the lack of resources for research. In Estonia, the number of clinical drug trials has decreased over the past decade [205] contrary to the general trend in Europe. Patient participation in oncology drug trials in Estonia is below the European average (4.16/100,000 and 5.5/100,000, respectively). While the share of early-phase trials has increased in Europe over the past decade, accounting for the vast majority of trials, in Estonia, it has remained at a level of only 25%.

From the perspective of clinical drug trials, Estonia's main problem is its small population, but its advantage is centralised cancer treatment (sufficient number of patients for opening a cancer centre). Organisers of drug trials are interested in the rapid inclusion of patients, an experienced and competent research team, the quick completion of the necessary trial documents, and good technical equipment in the research centre [206]. In the case of early-phase trials, the presence of a qualified centre and staff, a sufficient number of patients to be studied, and the capabilities of the research centre are important.

The rapid development of oncology has sharply highlighted the small number of oncological translational medicine projects in Estonia. Interpreting the results of molecular profiling of tumours and integrating them into patient treatment is already a real challenge. Close cooperation between scientists and oncologists in choosing the best personalised treatment for the patient is increasingly important.

In Estonia, data from the Estonian Cancer Registry, the Health Insurance Fund, and hospital health information databases are mainly used for research. Unfortunately, none contains sufficiently comprehensive, clear, and structured information to conduct specific research on cancer and cancer treatment. It is also not possible to analyse this data on the basis of the patient's treatment journey

## Goals

### Goal 1. Cancer patients have access to optimal and high-quality systemic treatment

#### Activities and recommendations

- Estonian patients will be secured access to new cancer drugs according to ESMO-MCBS score A or B (for curative purposes) and 4–5 (for palliative purposes), assessing the cost-effectiveness of the drugs in advance.
- New rules for requests of subsidised drugs and healthcare services containing drugs will be compiled in order to simplify and accelerate the reach of new effective drugs to patients. To ensure the availability of medicines, he period from the receipt of a marketing authorisation or approval of a new indication by the Health Insurance Fund to a reimbursement of the medicine should not be longer than the European Union average.

- When assessing medicines used to treat tumours defined as rare diseases for inclusion in the list of subsidised drugs or health services, different assessment criteria must be applied than in the case of medicines for common diseases. The procedures necessary for including medicines in the list of health services should be simplified and made faster.
- Measures will be taken to eliminate problems with the availability of widely used and important medicines. A strategic plan will be developed to reduce supply difficulties.
- A new type of multimodal council – molecular tumour council – will be established in cancer centres and its financing will be ensured.
- In-service training of oncology nurses in medical institutions and the availability of nurse-advisors will be ensured; see also "Qualified and motivated personnel".

## Goal 2. Patient-centred systemic treatment is ensured, including systemic treatment close to home, if necessary

### Activities and recommendations

- A structure will be created in cooperation with partners and networked hospitals for the implementation of systemic treatment outside cancer centres, integrating cooperation partners into the qualified provision of systemic treatment. Optimal conditions (including the presence of doctors/nurses) will be ensured to provide systemic treatment to patients as close to home as possible.
- The importance of recommendations from molecular tumour councils in making treatment choices will be increased.
- A nationwide electronic database of risk factors for cancer patients will be developed.

## Goal 3. Treatment outcomes will improve through the integration of cancer diagnostics, treatment and research

### Activities and recommendations

- In order to implement personalised cancer treatment in everyday practice, cooperation between oncologists, molecular geneticists and researchers will be intensified and will engage molecular tumour councils, with the aim of finding the best personalised treatment for the patient.
- A financing model will be developed for implementing personalised cancer treatment in clinical practice.
- Cancer centres will ensure optimal conditions for conducting clinical trials. Clinical trial departments will be established to organise (drug) trials in the hospital/centre, secure the competence and training of the research team, and manage trial documents.
- New opportunities will be found to bring more (drug) trials to Estonia: participation in pan-European research organisations and regional cooperation with neighbouring countries for involving patients in drug trials.
- Clinical trials that meet international standards and are planned and initiated by Estonian doctors will be promoted and supported, as well as fundraising for trials.
- In order to develop science-based oncology, nationwide tumour-specific databases (including biobanks) will be created in cooperation with hospitals, professional societies, the Health Insurance Fund, and the Ministry of Social Affairs. The existence of such databases would allow us to become a partner in various international studies, create a platform for planning studies and participate in the creation and operation of pan-European cancer databases [102].

# RADIOTHERAPY

## Background

Modern radiotherapy is a safe and effective treatment method that uses ionising radiation to destroy tumour cells. Radiotherapy has been one of the cornerstones of effective and high-quality anti-tumour treatment for the past hundred years. Radiotherapy saves lives. If all patients requiring radiotherapy had access to appropriate treatment throughout their treatment journey, it is estimated that by 2035, one million more cancer patients would be alive every year worldwide [207].

Radiotherapy provides the opportunity to cure cancer in multiple tumour sites [208,209]. 40% of cancer patients who have recovered, received radiotherapy as the sole treatment or in combination with other cancer treatments during their treatment journey [210]. Palliative radiotherapy reduces various symptoms caused by the tumour and improves quality of life [211–213].

Modern technology allows the dose of radiotherapy to be directed to the tumour according to a treatment plan individually prepared for each patient, thereby significantly reducing the side effects of the treatment and enhancing the effect [214,215].

Radiotherapy is a team effort in which the cooperation of various medical personnel (oncologists, medical physicists, radiotherapy technicians, engineers and nurses) is needed to ensure the success of the treatment [216].

Radiotherapy is a cost-effective treatment method. Although large-scale investments, infrastructure, trained staff, and prudent resource planning are needed in the beginning, the long-term costs are low [207].

Over 50% of all cancer patients could benefit from radiotherapy recovering from cancer, achieving a long-term disease-free period or alleviating symptoms caused by cancer. Unfortunately, this is not possible for a quarter of European cancer patients requiring radiotherapy due to insufficient availability of the treatment. In most countries, the ratio of actual to optimal use of radiotherapy was between 60–80%, with actual use below 60% in only four countries, including Estonia [217].

In the rapidly changing field of cancer care, reliable data on actual radiotherapy use, optimal evidence-based needs and future projections are essential as cancer treatment planning and addressing gaps in the availability of radiotherapy should be based on such data. [218]. Actual radiotherapy use can be assessed, and future needs predicted at a national level by cancer sites using evidence-based treatment indications and population-based data on cancer incidence and the share of different stages. [219].

The European Society for Radiotherapy and Oncology’s (ESTRO) vision for 2030, "Radiation Oncology. Optimal Health for All, Together“ aims to improve optimal access to radiotherapy for all patients within a multidisciplinary treatment approach and to raise awareness among both clinicians and health policymakers of the benefits of radiotherapy for patient survival and quality of life [220]. Currently, a quarter of European patients do not receive the necessary radiotherapy, but by 2025, the evidence-based need for the treatment method will increase by about 16% [221]. This requires additional investments and resource planning to ensure optimal access to treatment for patients.

### Situation in Estonia

As of 2020, two medical institutions provide external radiotherapy and brachytherapy in Estonia, PERH and TÜK (the brachytherapy for eye tumours is performed at ITK). Radiotherapy is performed at the radiotherapy centre at PERH and at the radiotherapy and oncotherapy department at TÜK. Both institutions providing radiotherapy services are staffed by oncologists (in the sense of radiotherapy and chemotherapy), medical physicists, radiotherapy technicians, engineers and oncology nurses.

Radiotherapy-specific training for all personnel categories, apart from hospitals, has been supported for a long time (since 1997) by the International Atomic Energy Agency (IAEA) within the framework of technical cooperation projects with both shorter and longer-term scholarships for studies in other hospitals and in specialty-specific courses (ESTRO, IAEA courses). From 2005 to 2020, the IAEA supported the development of radiotherapy in Estonia with 2.8 million euros (including technology).

In 2020, Estonia had a total of six linear accelerators for external radiotherapy (four of which were acquired partly with the assistance of the IAEA), thus 4.6 accelerators per million inhabitants. From 2016 to 2020, four linear accelerators were in use at PERH and two at TÜK. Both hospitals have one high-dose-rate (HDR) brachytherapy device and one software enabling low-dose-rate (LDR) prostate brachytherapy.

The linear accelerators in use allow the performing of 3D conformal, intensity-modulated, volume-modulated and breathing-adapted radiotherapy, and four accelerators are stereotactic or precision radiotherapy. HDR brachytherapy is mainly used for the treatment of gynaecological tumours.

In 2018, the median waiting times from the council to the first fraction of radiotherapy in PERH were 33 days for curative treatment, 8 days for palliative treatment, and 44 days for adjuvant treatment, while in TÜK, the same indicators were 38, 39 and 17 days respectively.

Radiotherapy services are included in the list of healthcare services of the Health Insurance Fund, and reimbursement is based on the fee-for-service principle [221]. The costs of radiotherapy investments are included in the cost of the corresponding healthcare service. The modernisation and investments in radiotherapy equipment are within the decision-making competence of the healthcare institutions.

## Problems

The poor survival rates of Estonian patients and possible shortcomings in quality of life can be partly attributed to the suboptimal availability of radiotherapy, based on experience from other countries.

The use of radiotherapy in Estonia is below the optimal level. Based on data from the Cancer Registry and the Health Statistics Department of the National Institute for Health Development, it can be roughly estimated that 33% of primary cancer patients (excluding non-melanoma skin cancer) received radiotherapy from 2013 to 2017 [1]. Based on international estimates, it would be optimal if at least 50% of patients diagnosed with cancer received radiotherapy during their lifetime (when comparing these two figures, it should be taken into account that the calculation methodology is different) [209].

Due to the increase in cancer incidence in the population, the need for radiotherapy is expected to grow during 2021–2030. Table 3 shows the use of radiotherapy from 2013 to 2017 and the need for radiotherapy in Estonia for the period 2028–2032, calculated according to the international methodology [209].

*Table 3. Radiotherapy – use and prognosis*

| | Average number of cancer cases per year (excluding non-melanoma skin cancer) | Optimal use of radiotherapy [209] | | Need for radiotherapy | | Actual average number of radiotherapy cycles per year | Difference between the minimal need and actual number of cycles |
|---|---|---|---|---|---|---|---|
| **2013–2017** | 7144 | 49,1 | 50,8 | 3508 | 3629 | 2292 | –1216 |
| **2028–2032** | 8540 | 49,1 | 50,8 | 4193 | 4338 | | |

### Reasons for suboptimal use of radiotherapy

The number of accelerators is insufficient. The IAEA has highlighted the need for radiotherapy equipment, where 450 patients per year are calculated per accelerator [222]. Using the data provided in Table 3 for the period 2013–2017 and also adding 10% for the patients requiring repeated radiotherapy, there should have been nine accelerators in Estonia in 2020 (3508 × 1.1): 450 = 9. There were six accelerators in Estonia in 2020.

The training of radiotherapy personnel is not optimal. Insufficient training opportunities for personnel in all categories and low awareness of radiotherapy options among personnel in related fields may be one reason for the underutilisation of radiotherapy in Estonia. This topic is discussed in the chapter "Qualified and motivated personnel".

Treatment decisions do not always take into account the possibility of radiotherapy. There is no systematic monitoring of the quality assurance of cancer treatment in Estonia that would observe whether the treatment is based on treatment guidelines and monitor decision-making in multidisciplinary councils. Reliable data on councils by cancer sites is difficult to get outside of audits. Audits are rarely conducted, and there is no overview of all tumour sites. A treatment quality audit conducted by the Health Insurance Fund on ovarian and cervical cancer cases treated from 2012 to 2013 found that in the case of cervical cancer, a multidisciplinary council was held before the first treatment in only 70% of cases [223].

Waiting times from the council to the beginning of radiotherapy are too long. Waiting times for radiotherapy are not systematically and centrally monitored in Estonia, and this data is not used for planning healthcare resources. The aforementioned audit found that waiting times for curative radiotherapy for cervical cancer exceeded four weeks in three-quarters of the patients requiring radiotherapy included in the audit sample [223].

Using existing databases, it is not possible to consistently assess the availability of radiotherapy by cancer sites and the evidence-based nature of treatment decisions to analyse the side effects of radiotherapy and to assess patients' quality of life or specific quality indicators of radiotherapy. The number of research studies related to radiotherapy in Estonia is low.

There is also a lack of awareness among the population, healthcare policymakers and medical professionals about the benefits of modern high-tech radiotherapy for patient survival and quality of life.

## Goals

### Goal 1. All cancer patients have timely access to optimal and safe radiotherapy

#### Activities and recommendations

Considering the incidence forecast for 2028–2032 and the number of patients receiving repeated radiotherapy (at least 10%), the number of accelerators in the period 2028–2032 should be 11, i.e. 8.4 accelerators per million inhabitants. For comparison, the average number of accelerators per million inhabitants in the Nordic countries (Finland, Sweden, Denmark) was 9.0 [224] in 2018.

The availability of maximally safe and effective radiotherapy for the patient (including precision radiotherapy, proton therapy, MRI-based adaptive radiotherapy, etc.) is related to the existence of up-to-date radiotherapy technologies in the country. Availability and continuous renewal of equipment are key factors here. The recommended technological lifecycle after which radiotherapy equipment should be renewed is seven years. According to the COCIR report, modern radiotherapy is enabled if the share of equipment under seven years old is at least 58% of all radiotherapy equipment and the share of equipment over ten years old is less than 17% [224].

The renewal of radiotherapy equipment began in 2007, and currently, 66% of equipment in Estonia is under seven years old, and 17% is over ten years old.

- A thorough analysis (if necessary, together with external expertise) of the actual use and need for radiotherapy will be carried out, taking into account the shares of cancer sites and stages.
- The number of accelerators will be increased to 11.
- Accelerators will be replaced consistently to ensure compliance with international requirements.
- In accordance with the development of radiotherapy technologies and methods, the Health Insurance Fund must ensure regular review of radiotherapy-related healthcare services and prices, preferably every 7–10 years (in case of new treatment methods, the list of healthcare services should be updated as necessary), in order to ensure that healthcare institutions may develop and provide patients with optimal, innovative and personalised treatment.
- Treatment decisions for patients diagnosed with cancer must be in line with international treatment guidelines and made in multidisciplinary consultations [225] [226]. We recommend regular centrally managed site-based audits of adherence to treatment guidelines [227]. It is recommended to centralise the assessment of the quality of cancer care in one institution, review existing indicators and create new ones, if necessary.
- Waiting times for access to radiotherapy from the council to the beginning of treatment must be optimal according to the treatment goal and site of the tumour.
- Raising radiotherapy awareness will be a priority. In cooperation with the University of Tartu, hospitals providing radiotherapy, professional societies and patient organisations, will pay greater attention to radiotherapy and its importance in curative cancer treatment. Regular campaigns, events and conferences will be organised for this purpose. In addition to the above, both popular science and scientific articles in the native language will be published.

### Goal 2. Qualified radiotherapy personnel are available to ensure optimal radiotherapy access for patients, and training is sustainable

This topic is discussed in the chapter "Qualified and motivated personnel".

## Goal 3. Systematic and consistent activities secure the quality of radiotherapy

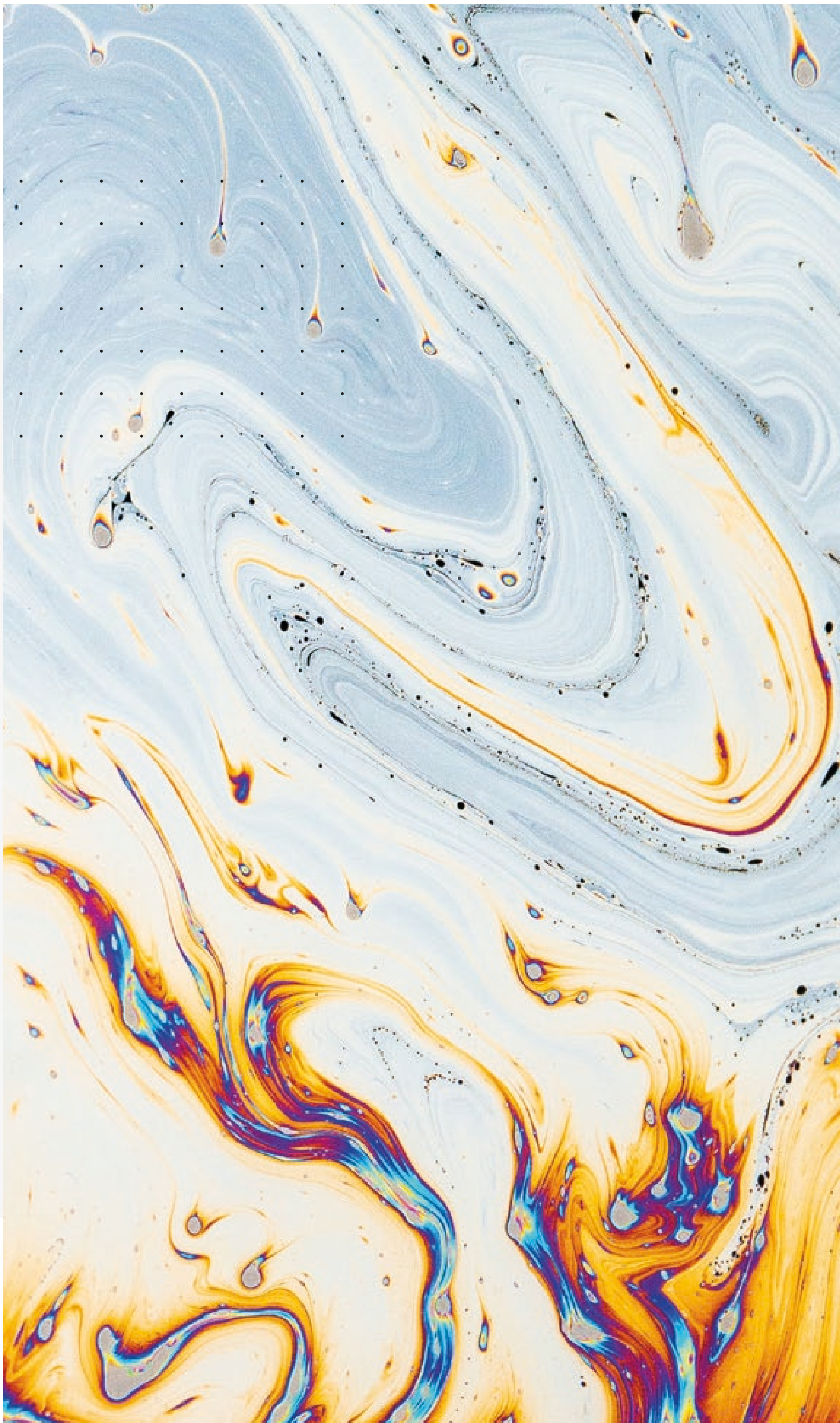
### Activities and recommendations

- A radiotherapy database structure that complies with international standards will be worked out, and systematic data collection will begin.

In order to obtain a comprehensive, up-to-date and reliable overview of radiotherapy and its quality, a radiotherapy database structure will be created which enables the assessment of the availability, use and quality of radiotherapy. One part of the database is the radiotherapy plans stored in the Estonian Image Bank in DICOM format.

- The volume of clinical and scientific research related to radiotherapy will be increased.

According to the EU Cancer Plan, it is expected to save three million lives in Europe. Radiotherapy is the second most important curative treatment method after surgery [228]. Therefore, it is not possible to increase the number of people cured of cancer without optimising the use of radiotherapy and finding innovative solutions and more effective treatment combinations. Based on the above, systematic scientific activities in cooperation with cancer centres and the University of Tartu are necessary at both the preclinical and clinical levels. In addition to national research, it is important to encourage and increase the volume of international clinical trials related to radiotherapy.



# PALLIATIVE AND END-OF-LIFE CARE

## Background

### Palliative care as part of cancer treatment and cancer control

Palliative care is an integral part of cancer treatment and cancer control. The palliative care needs of a cancer patient are individual and require early detection, assessment and addressing throughout the entire treatment journey.

Palliative care is aimed at alleviating the ailments caused by the disease or its treatment. The palliative care needs of a cancer patient are individual and require early detection, assessment and addressing throughout the entire treatment journey.

Palliative care is an interdisciplinary, comprehensive, active treatment aimed at improving the quality of life of patients with life-threatening and life-impairing health conditions, and their loved ones, from the moment of diagnosis until the end of life or recovery from cancer. According to modern principles, the continuity of palliative care must be ensured at every stage of treatment [232]. Palliative care provides medical, psychological, social and spiritual support and also includes end-of-life care and grief counselling.

A cancer patient needs an individual, complex approach that includes, besides noticing, assessing and alleviating physical ailments (pain, nausea and other symptoms), as well as dealing with psychosocial issues. This means that in addition to alleviating symptoms caused by the disease and the ailments caused by disease-specific treatment, the patient and their loved ones need counselling for spiritual, social and economic problems. A holistic and multidisciplinary approach to the patient and their loved ones ensures better consent to treatment, supports the treatment process and treatment results, overall coping, and ensures the best possible quality of life [232]. Early detection and alleviation of a patient's physical ailments and psychosocial problems is also vitally important in the future life of people who have recovered from cancer.

End-of-life care, or best supportive care, as a part of palliative care, is aimed at cancer patients at the end of their lives, and their loved ones. End-of-life care begins when cancer-specific treatment options have been exhausted. The main goal of end-of-life care is to alleviate ailments, provide nursing that respects human dignity, and enable the best possible quality of life until a peaceful and dignified death. It also aims to support families, helping them in dealing with grief work upon and after death. International studies show that the need for palliative care is greatest six months before a patient's death [233].

### Current situation

Due to the increase in cancer incidence and improved survival in Estonia, cancer has become a chronic disease that patients can live with for many years. As of 2017, 62,000 people were living in Estonia diagnosed with cancer. All people diagnosed with cancer may need palliative care at different stages of treatment. The need for palliative care is increasing with the ageing population, and the need for palliative care is also greater as more patients are diagnosed with metastatic tumours. In case of a life-threatening illness, the need for palliative care arises early [234]. The actual number of cancer patients in Estonia requiring palliative care is unknown. An estimated 8,569 adults and 51 children requiring palliative care died in Estonia in 2014 [235]. According to the World Bank, the need for palliative care in high-income countries is 1,042 people per 100,000 inhabitants [234].

It is important for patients and their loved ones that the patient can stay at home and cope for as long as possible. A functioning palliative care network ensures good accessibility of the service, especially at home, which reduces the burden on inpatient nursing care and active treatment (ER, intensive care).

The Foundation for Supportive Care for Cancer Patients, founded by the Estonian Cancer Society in 2002, provided home care to cancer patients over the years, with one team in each county. The teams included experienced nurses and doctors who specialised in palliative home care for cancer patients. The doctors and nurses made home visits. At the beginning of 2021, the organisation ceased its operations due to a lack of funding from the Health Insurance Fund. As of 2020, 48 different service providers offer home nursing services in Estonia.

In 2017, a palliative care centre was established at PERH with accreditation from the European Society for Medical Oncology (ESMO). It operates as a special interdisciplinary palliative care team. Among other things, the palliative care centre provides home nursing services to cancer patients in Tallinn and Harju County.

In 2019, an interdisciplinary working group for supportive care for cancer patients was established in TÜK. TÜK provides home nursing services to cancer patients in the city of Tartu and the surrounding area.

The first hospice department in Estonia, with 14 beds and a team with international professional training, is located in the Tallinn Diaconal Hospital of the Estonian Evangelical Lutheran Church (EELK). Currently, there are 12 hospice beds in ITK and six in TÜK. Since 2020, the Health Insurance Fund has been financing the bed-day costs in inpatient hospice care and is prepared to finance 40 hospice care beds.

Pallium, a professional society for palliative care, was established in 2010. The main goal of the society is to develop palliative care and hospice services in Estonia. The founders of the organisation have long been involved in palliative care and hospice work, trying to promote it within their institutions and in society at large and increasing awareness of palliative care and its need in society among decision-makers and healthcare professionals. Pallium has developed the principles of palliative care, including hospice care, and organises information days and conferences on the topic. Representatives of Pallium also participate in the development of regulations and Estonian terminology in the field of palliative care and in the preparation of the national guidelines for palliative care.

According to current understandings, proactive palliative care is the most efficient option. This means the entire treatment team will notice the patient's problems and needs in a timely manner and seek solutions. If a patient is diagnosed with a tumour, they are not physically or emotionally able to seek all the help options by themselves. Therefore, early detection by specialists is particulrly important.

### Provision of palliative care

The provision of palliative care must take place at every level of the healthcare system: in family medicine centres, in hospitals by palliative care teams, in active palliative care departments, in hospices and in day care. Services must be available both in homes and care institutions.

The composition of the palliative care team depends on the needs and ailments of the patient and their loved ones. The core palliative care team includes healthcare professionals (doctors, nurses), supporting specialists (social workers, pastoral counsellors, psychologists) and the patient’s loved ones. If necessary and possible, other specialists (nutritionist, stoma nurse, wound nurse, peer support, physiotherapist, occupational therapist, speech therapist, care workers, etc.), the supporting community and volunteers are involved. An interdisciplinary approach in palliative care ensures greater satisfaction and better quality of life for the patient and their loved ones and saves healthcare costs [236]. The number of specialised palliative care units in a country is one of the best indicators of the level of palliative care [235]. The European Association for Palliative Care (EAPC) recommends establishing two palliative care teams (one hospital team and one home care team) per 100,000 inhabitants and 80–100 palliative care and hospice beds per million people [234,237]. Palliative care should be available at all levels of healthcare, but the initial assessment of the patient should take place at the primary care level. It should be possible to refer complex cases to specialist centres [237].

The palliative care plan is drawn up at all levels of care by the doctor currently treating the patient or by the palliative care team. To achieve the best treatment results, effective communication between the patient, healthcare professionals and other specialists is necessary when drawing up the palliative care plan, as well as comprehensive consideration of the aspects associated with the illness and treatment, involvement of the patient and their loved ones and consideration of their wishes in palliative care decisions. The treatment plan is evaluated and modified according to the needs of the patient and their loved ones throughout the treatment journey until the end of life.

A palliative care plan may also be needed by a person who has recovered from cancer, as physical ailments (pain, sleep disorders, complications of cancer treatment, etc.) may remain, and psychological and social problems may persist. It is important to support the coping of a person who has recovered from cancer in maintaining their active attitude to life and returning to social life and work.

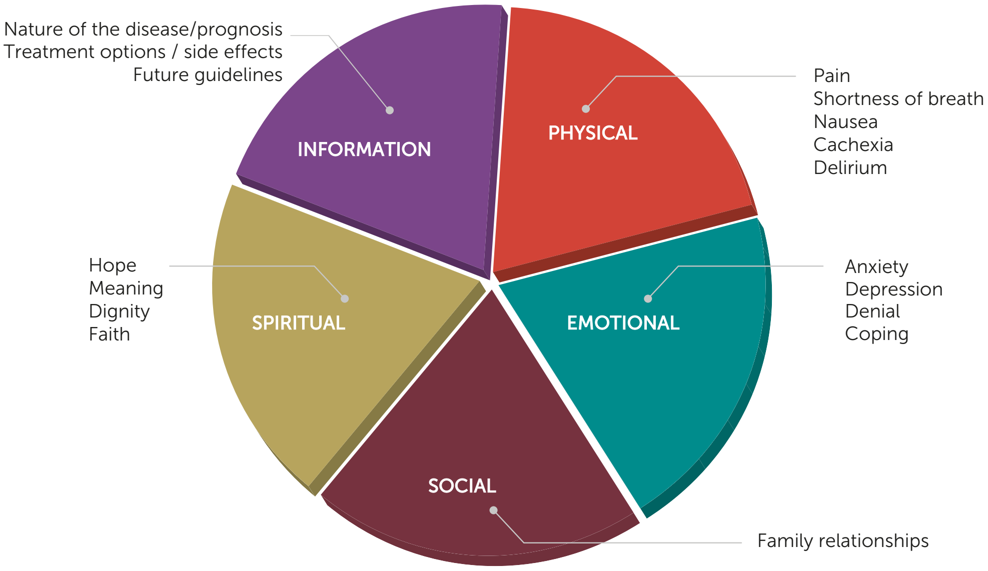


*Figure 12. Patient’s needs in palliative care.*

### The four pillars of palliative care: symptomatic treatment and psychological, social (psychosocial) and pastoral/spiritual support

Palliative care addresses the patient and their family as a whole.

#### Symptomatic treatment

The aim of symptomatic treatment is to prevent and relieve ailments caused by the disease or treatment as early as possible. The most common physical complaints are pain, nausea and vomiting, shortness of breath, diarrhoea and constipation, cachexia, fatigue, and sleep and mood disorders. Symptomatic treatment is important during cancer-specific treatment (for example, radiotherapy, systemic therapy, surgical treatment) and continues after the end of cancer-specific treatment or, if necessary, after recovery from cancer. Alleviating symptoms is particularly important in end-of-life care.

All healthcare professionals must have basic knowledge of symptomatic treatment.

#### Psychosocial support

Cancer affects the general coping, work and family life of patients and their loved ones, as well as psychological, cognitive and social behaviour and mental health as a whole. Cancer patients and their loved ones are psychosocially vulnerable, which in turn affects the entire treatment process. Even when cancer-specific treatment has ended and the person has recovered, residual symptoms, side effects of treatment and complications can significantly impair psychophysical coping ability. In addition, a significant share of people who have undergone cancer and cancer-specific treatment have had to give up jobs, can only work part-time or are even forced to stay away from working life at all. Difficulties in financial coping are likely to happen. In addition to physical ailments, mental health problems such as depression, post-traumatic stress and anxiety disorders prevent the fulfilment of work and social roles, including family roles.

The possible future needs of the patient and their loved ones must be taken into account upon receiving a cancer diagnosis so that problems can be prevented or treated in a timely manner. The psychological stress, fear, depression and anxiety of loved ones that emerge when caring for a person with cancer are also specific because cancer is accompanied by painful symptoms and ailments that are associated with the death of a loved one. By preventing or helping to resolve psychological and socio-economic problems that have already arisen, the effectiveness of treatment and the healing process in general can be positively influenced (Figure 13).

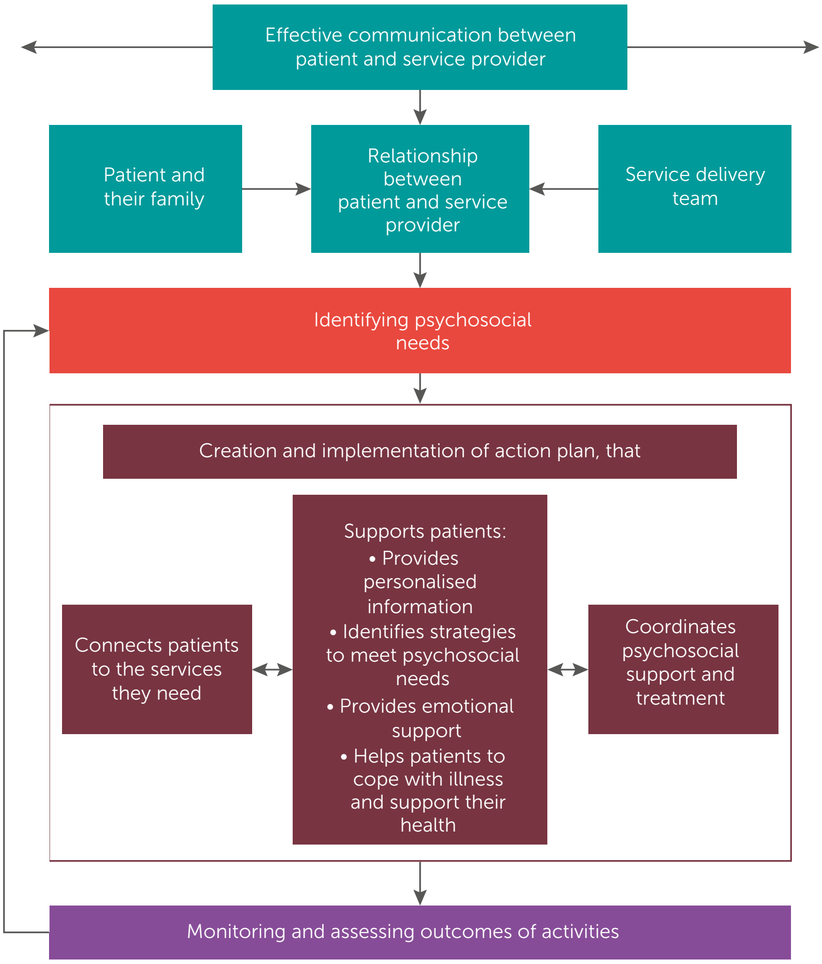


*Figure 13. Model for the provision of psychosocial services.*

### Pastoral counselling

Pastoral counselling provides support to a sick person throughout the entire treatment journey in case of a psychological crisis. It takes into account the individual's needs and beliefs, focusing on spiritual, existential and religious issues. Pastoral counselling can also be provided to members of the treatment team for coping with a crisis, and on the topics of death and grief.

In end-of-life care, an important addition to alleviating physical ailments is pastoral counselling and psychological support that respects the dignity, religious beliefs and cultural background of the dying person whilst supporting the grieving process of their loved ones. Most loved ones are not physically or mentally ready to care for a cancer patient at the end of life; they do not have sufficient knowledge and spiritual strength to cope with the complex tasks and such a situation. Therefore, it is important that relatives receive advice, encouragement and support from pastoral counselling specialists if caring for their dying family member at home.

## Problems

There is no national strategy or legislation for palliative care in Estonia. There are no national palliative care guidelines and patient guides in Estonia. The WHO's document "Global Atlas of Palliative Care at the End of Life" states that developing palliative care services in a country without an appropriate strategy is difficult [232]. In developed countries, the provision of palliative care services is regulated by the law, and palliative care guidelines or standards have been prepared. Currently, the Estonian palliative care guidelines are under preparation with funding by the Health Insurance Fund. Implementation of these guidelines will enable the improvement of the provision of palliative care services in Estonia. A relevant patient guide will also be prepared, along with the treatment guidelines.

The awareness of society and healthcare professionals about palliative care, its nature and possibilities is low. Palliative care is often equated with end-of-life care, which is why both patients and their loved ones may be reluctant to request such services.

The need for palliative care among patients diagnosed with cancer, receiving disease-specific treatment or the best supportive care is very high, but only a few patients reach the necessary specialists, and it is often too late. The reason is low awareness of palliative care among healthcare professionals, low awareness of patients about palliative care options, and the fear of cancer recurrence among recovered patients. There is a fear that cancer recurrence will stay unnoticed while relieving existing physical ailments. In the case of psychosocial issues, the unwillingness to admit to having psychological/emotional problems, the fear of appearing weak, giving up or not coping prevents people from asking for and receiving help. Based on a survey of cancer patients organised by the PERH Palliative Care Centre team in 2019, it was revealed that people are mostly unaware of the existence of palliative care and are, therefore, deprived of symptomatic treatment and psychosocial support.

Estonia lacks a palliative care network, and the availability of palliative care services is regionally uneven. Another problem is poor cooperation between the healthcare and social systems and the lack of coordination of services. There is no such palliative care that would allow cancer patients to stay at home for as long as possible. A large share of patients end up in hospital at the end of their lives because the care burden of relatives becomes too great. Also, medical professionals often lack knowledge about the possibilities of alleviating ailments.

The quality of home nursing services is uneven, and in many regions of Estonia, the experience of providing home nursing services to cancer patients is missing. Home nursing service providers also lack medical support. They often do not want to provide services to seriously ill cancer patients because doing so is resource-intensive, complicated and emotionally difficult.

The field is insufficiently funded. Palliative care is provided by a team, and the team should include support specialists whose work is not currently listed in the service list of the Estonian Health Insurance Fund. It is obviously necessary to define palliative care as a separate service (palliative care team work, active palliative care bed day).

There is no involvement of volunteers and no principles and strategy for their preparation.

## Goals

### Goal 1. Patients are secured access to palliative care at every level of the healthcare system

Activities and recommendations

- In order to provide regulated and systematic palliative care, the structure and service descriptions will be worked out The provision of palliative care services must take place at every level of the healthcare system and must be applicable to all patients in need of palliative care, regardless of pathology. The needs of patients who require palliative care can be very different (Figure 14). Based on this, the competence of healthcare professionals (and support specialists) and the provision of services at different levels in the healthcare system must be ensured (see levels 1–3 below). There must be a readiness to offer both contact consulting as well as telephone and video consulting based on the patient's condition and needs. The aim is to allow the patient to stay at home for as long as possible.

**Level 1 – palliative care in family medicine and nursing care**

- Family medicine is the most important factor for the patient's palliative care and supporting loved ones because the family doctor knows the patient's health condition and history and is familiar with their support network. Every family doctor and family nurse must have basic knowledge and skills to implement the principles of palliative care. The possibilities for involving support specialists (social worker, pastoral counsellor, psychologist, etc.) at the first level must be described, available and funded. The family doctor can consult with a level 2 or 3 palliative care team if necessary.
- Home nursing
- Independent inpatient nursing care

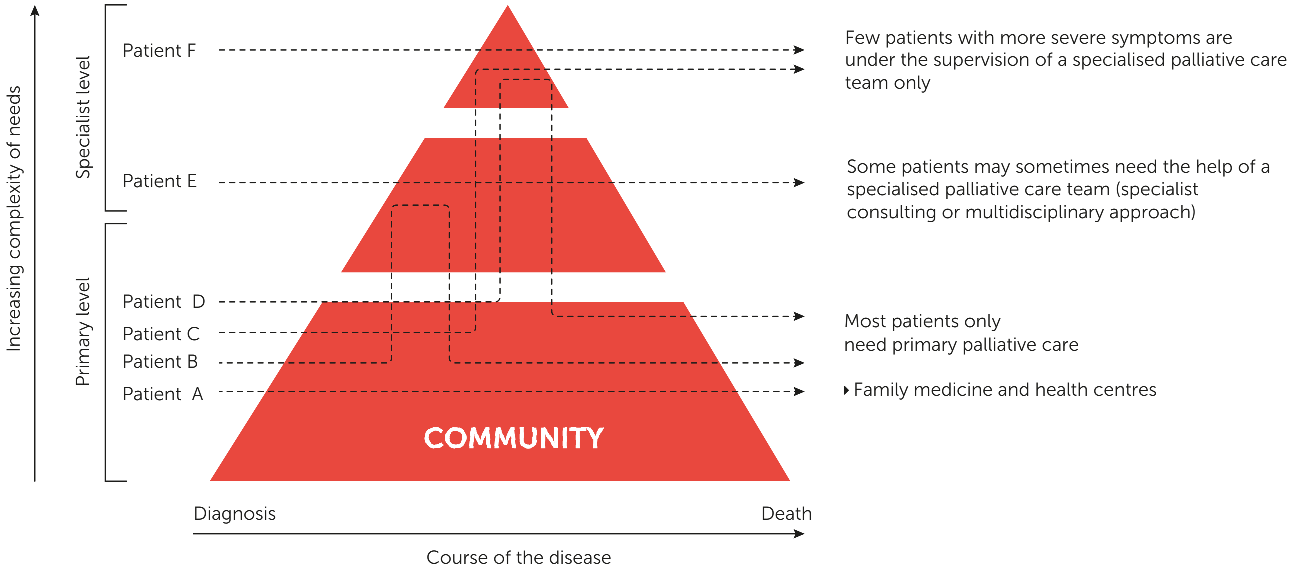


*Figure 14. Patients' needs and levels of the health system.*

**Level 2 – specialised palliative care provided at the county level**

- Palliative care support teams in central, general and local hospitals. The team includes a doctor, nurse and case manager who have completed advanced training in palliative care. There must be a readiness to provide psychosocial and spiritual care, and the possibility of involving a social worker, a pastoral counsellor and a psychologist. The team consults family medicine and health centres, independent inpatient nursing care departments, nursing homes, and, if necessary, other specialists in the given county for the provision of palliative care. Consulting on palliative care must be available 24 hours a day, seven days a week.

- Hospices and home hospices, where doctors and nurses with additional competence in palliative care work. The aim of the hospice is to ensure the most humane, ailment-free and safe life with pastoral/spiritual support until death, to enhance symptomatic treatment, to involve other members of the interdisciplinary team as necessary, and to initiate and continue grief counselling for the family after the patient's death. Patients who need enhanced symptomatic treatment or care for large, decomposing, ulcerated tumours are referred to the hospice, among others. The need for this service is constantly growing.
- Home support care teams for patients diagnosed with cancer in each county centre. The team consists of a doctor and nurses who make home visits and have in-depth knowledge and experience in palliative care for cancer patients.
- Inpatient palliative care beds in central and general hospitals.
- Palliative day care, where symptomatic treatment, counselling and minor procedures, e.g. ascites puncture, are carried out. Duration – max six hours per day.

**Level 3 – specialised palliative care provided at the regional level**

- A specialised interdisciplinary palliative care team, the core team includes specialised doctors, nurses, social workers, psychologists, and pastoral counsellors. Additional team members are included according to the needs of the patient and their loved ones: nutritionist, physiotherapist, occupational therapist, activity supervisor, peer support, wound nurse, stoma nurse, diabetic nurse, etc. The prerequisites for specialised palliative care are the existence of specialists who have completed a special training programme at inpatient palliative care departments. The presence of an interdisciplinary palliative care team is mandatory in all regional hospitals. Children's hospitals of the higher level must have the competence to provide palliative care to children (0–19 years).
- Outpatient visits by the palliative care team, consulting with colleagues working at levels 1 and 2 and inpatient treatment of patients with complicated conditions.
- Palliative day care, where symptomatic treatment, counselling, procedures and infusions are carried out. Duration – max six hours per day.
- Active inpatient palliative care. Improving symptomatic treatment so that the patient can return to previous levels.
- Training, providing the base for internships, developing standards and guidelines.

**Description and financing of the service**

- To finance the palliative care service, a complex price for palliative care will be determined, along with the description of the conditions for providing the service at different levels of the healthcare system.
- A system for financing the palliative care service will be created with the description and prices of services provided at different levels.
- Financing of the palliative care service will be ensured at all levels of the healthcare system.

### Goal 2. The training programmes for doctors, nurses, care workers and support specialists have been prepared and implemented in basic and advanced training

The topic is discussed in the chapter "Qualified and motivated personnel".

# REHABILITATION

## Background

Oncological rehabilitation is indicated if the patient has functional disorders that have arisen during the course of the disease or its treatment and that limit independent physical and/or psychosocial coping. Oncological rehabilitation focuses on restoring and compensating functional disorders. Various interventions in oncological rehabilitation are most often applied in cases of breast, bladder, prostate, colorectal, head and neck cancers.

It is important to assess the physical and psychosocial functional coping of each cancer patient. The results of the functional assessment help to distinguish the need for rehabilitation from the need for mainly supportive/palliative care. The recovery potential must also be taken into account. Oncological rehabilitation must not burden the patient or cause suffering. If functional improvement is not possible, the patient should be offered the best supportive care.

Oncological rehabilitation can be started during or after specific treatment, as needed. The need to continue oncological rehabilitation often persists for years after the end of cancer treatment.

### Summary of the patient's treatment journey

The referral of cancer patients to rehabilitation is currently quite random in Estonia. Patients with neurological complications are mainly referred to inpatient rehabilitation, and in ITK, cancer patients are also referred to rehabilitation by spine surgeons. Patients with thoracic and pelvic tumours, and to a lesser extent, head and neck tumours, are mainly referred to outpatient rehabilitation. Patients are generally provided individual treatment, such as physiotherapy, occupational therapy, psychotherapy, speech therapy, etc., but PERH also offers group counselling for patients with lymphedema. Regional and larger central hospitals offer specialised pelvic floor physiotherapy and lymphatic therapy. Home physiotherapy and primary physiotherapy services are not very common. In order to use the rehabilitation opportunities provided by the Unemployment Insurance Fund and the social system, loss of work capacity and/or disability must first be determined.

### International comparison

The European Cancer Mission [102] emphasises that in order to improve the quality of life, it is necessary to understand in depth the problems caused by cancer, from late side effects of the causal treatment, comorbidities and age-related functional problems to mental health and reproductive health problems. Many cancer patients find it difficult to return to work due to a persistent health disorder, but also due to the unsupportive attitude of employers. There may also be obstacles to adequate financing of the rehabilitation services needed. Special attention should be paid to the after-effects of childhood cancer, which may require both psychosocial and material support.

In 2017, oncological rehabilitation (excluding neurological tumours) accounted for 1–4% of the total volume of rehabilitation performed in different countries [229]. Oncological rehabilitation is provided by a multidisciplinary rehabilitation team trained to diagnose and treat physical, psychological and cognitive impairments with the aim of maintaining or restoring function, increasing functional independence and improving the quality of life of the cancer patient. Oncological rehabilitation should ideally be integrated into the oncospecific and supportive care phases throughout the cancer treatment. Unfortunately, it is currently underutilised. Based on international experience, the main obstacles to the development and availability of oncological rehabilitation programmes are the lack of funding, and human and spatial resources [230].

There is synergy between palliative care and rehabilitation. Specialists in both disciplines treat the patient as a whole – in addition to the diseased organ system, attention is also paid to their social environment. Cancer patients experience both disease- and treatment-related physical ailments, psychosocial stress, loss of function and a deterioration in quality of life before, during and after oncospecific treatment. Supportive care strategies and rehabilitation are both necessary to reduce the impact of the disease and its treatment's side effects [231].

In Germany, oncological rehabilitation is part of modern cancer treatment immediately following surgery, pharmacological or radiotherapy. It is also applied for years after treatment if functional impairment will remain after the cancer treatment. In Germany, oncological rehabilitation has historically been performed as an inpatient treatment, while in Northern Europe and Scandinavia, it is more often performed as an outpatient treatment and over a longer period of time. In both cases, it is important that the rehabilitation team is able to teach and train the patient to help themselves (help for self-help) [232].

A Cochrane review of 12 randomised clinical trials assessing physical and mental function, where functional capacity was assessed using the SF-36 questionnaire, showed a positive effect of oncological rehabilitation [233].

### In conclusion

Thanks to the increasing effectiveness of oncospecific treatment and improved survival, cancer is often considered a chronic disease or health condition in which the patient requires a multidisciplinary approach to the ailments resulting from the disease or its treatment for a longer period of time. To cope with these, supportive and restorative treatment is often needed.

In addition to supportive treatment, approximately 40% of cancer patients require rehabilitation due to the presence of functional impairment(s). The most common physical ailments are pain, fatigue/weakness, swelling, numbness of the hands and feet, paraesthesia, and balance disorders. Patients with pelvic cancer experience bladder and/or bowel incontinence and sexual dysfunction. In the case of head and neck tumours, speech and swallowing disorders may occur. Cancer patients also experience memory and concentration difficulties and mood disorders.

Rehabilitation focuses on restoring and compensating for functional impairment by teaching the patient to cope with their daily activities using an adapted activity pattern or assistive devices.

Patients need physiotherapy and psychotherapy the most. Depending on the cancer site, patients may need specific therapy for the functional impairment, such as speech and swallowing therapy, pelvic floor therapy, lymphatic therapy, scar and soft tissue therapy or temporomandibular physiotherapy. A significant part of therapy is teaching the patient how to adapt to the disease and its complications.

## Problems

There is no specific system and organisation for referral to oncological rehabilitation in Estonia. No indications and criteria are determined and no time limits are set for referring cancer patients to rehabilitation.

The assessment of the availability of oncological rehabilitation services is complicated due to the lack of a unified coding system for diagnoses and functional impairments. Both cancer diagnosis and functional impairment are used as the main diagnosis (e.g. breast cancer, ICD-10 code C50, vs. limb lymphedema, I97.2 or I89.0, etc.), which is why more precise analysis and evaluation of results is not possible.

The problem is the low awareness of specialist doctors/oncologists about oncological rehabilitation services. There are regional differences in the availability of rehabilitation. There is no information at the primary level about which institutions provide rehabilitation services in the region and who has a contract with the Health Insurance Fund for providing such services. The availability of home physiotherapy as a health insurance service is limited due to the lack of service providers. The implementation of new technologies (telemedicine, etc.) is not yet widespread.

Incomplete HIS data from the treating doctor (does not reflect functional impairment) may become an obstacle in getting rehabilitation services provided by the Unemployment Insurance Fund.

## Goals

### Goal 1. Patients are guaranteed access to comprehensive, high-quality and timely oncological rehabilitation services

#### Activities and recommendations

- Awareness of oncological rehabilitation options and the coherence of the treatment journey between specialties will be improved. Effective counselling of cancer patients and their relatives regarding services supporting functions and functional capacity will be established at all stages of the treatment journey.
- New technologies (tele- and e-consulting) will be applied to improve regional accessibility. Remote services (teleconsulting) will be provided. In the case of centre-based cancer treatment, rehabilitation specialists will be included in the team led by an oncologist. The patient will be referred to the oncological rehabilitation service in the place of their residence. In the case of network-based complex cancer treatment, a rehabilitation specialist is involved, depending on the location (outpatient consulting, e-consulting, teleconsulting).

- Cancer centres prepare a long-term treatment plan for the patient and, if necessary, refer the patient to oncological rehabilitation. To improve cooperation between specialties within the institution, oncologists are also informed about the possibility of referring the patient to physiotherapy or lymphatic therapy (if relevant). Need-based referral to complex rehabilitation (where the team is led by a rehabilitation doctor) and from rehabilitation to psychosocial and vocational rehabilitation is available. Functional capacity assessments, necessary for work capacity/disability documents and rehabilitation services close to home, are sent to the HIS by a cancer centre nurse/occupational therapist. The Ministry of Social Affairs supports the use of programme-based rehabilitation funding for cancer patients.

- Patient guidelines (e.g. for coping with lymphedema) are being developed with state funding.

- To assess the performance of the system as a whole, the share of patients who give up their work one year after diagnosis is measured. [234,235].

## Goal 2. Reliable measuring of oncological rehabilitation outcomes is ensured by standardisation of terminology, coding and the assessment system

### Activities and recommendations

- Unified terminology and coding principles for oncological rehabilitation (ICD-10, ICF) are introduced in official documents
- ICD and ICF based coding guidelines for oncological rehabilitation are worked out.
- A standard functional impairment assessment is used in epicrisis reports sent to HIS.
- For a comprehensive assessment of functional capacity of individuals, functional capacity and quality of life indicators based on the biopsychosocial model are introduced, which take into account the combined effects of physical illness, mental aspects and environment on functional capacity and quality of life. The WHO offers a classification of functions, which allows for the mapping of both structural and functional disability, activity capacity and limitations in participation in society as hindering environmental factors (b280 pain, b770 gait function, b152 emotions, b350 weight maintenance, d640 doing housework, etc.) [236]. There are also disease-specific short forms for the assessment of breast, head and neck cancer patients [237]; in other cases, a short form prepared for rehabilitation departments can be used.

# Haematology

## Background

Haematology is a medical specialty that deals with the diagnosis and treatment of diseases of the haematopoietic and lymphatic systems. Currently, malignant haematological diseases account for approximately 80% of outpatient and approximately 95% of inpatient haematology treatment cases.

The incidence of haematological malignant tumours is increasing year by year (see "Cancer in Estonia"). Modern diagnostics of haematological diseases is complex, including diagnostic imaging, pathomorphological and genetic diagnostics. Thanks to the development of pathological and especially genetic diagnostics, larger diagnosis groups have been divided into several subgroups, which often mean rare diseases, the treatment of which may differ significantly from other diseases belonging to the same diagnosis group.

There are three specialised haematology departments in Estonia – the Department of Haematology and Bone Marrow Transplantation in TÜK and the Department of Haematology in PERH. Tallinn Children's Hospital deals with haematological tumours in children (see "Haematology and Oncology of Children and Adolescents"). These departments have the capacity for up-to-date diagnostics of haematological diseases, that meet all requirements.

Both medical institutions offer outpatient, day care and inpatient haematological services. In addition to the aforementioned medical institutions, haematological outpatient treatment services (including chemotherapy) are provided at Pärnu Hospital (in cooperation with PERH) and Ida-Viru Central Hospital (in cooperation with TÜK).

A part of modern treatment of haematological malignancies is haematopoietic stem cell transplantation. Allogeneic, autologous and haploidentical peripheral haematopoietic stem cell and bone marrow transplantation are performed in TÜK, and autologous peripheral haematopoietic stem cell transplantation is performed in PERH.

## Problems

The path of patients with malignant haematological diseases to a specialised haematology department may be different: from the emergency department of the same health institution, from another department of the same health institution, from another health institution providing inpatient treatment, or by referral from a primary care doctor. Problems include delayed referral from the primary care system to a haematologist and long waiting lists for initial consulting. At the same time, patients who do not actually need a haematologist consultation may be referred to one.

Modern haematological diagnostics is complex and requires the cooperation of several specialists. Therefore, a diagnosis of haematological malignancy can only be made in a medical institution that has all modern diagnostic methods and is competent to use them. Diagnosing haematological tumours in medical institutions where these conditions are not met is problematic. This leads to the repetition of diagnostic procedures, which causes delays in getting the right diagnosis and starting treatment.

The number of both outpatient and inpatient treatment cases in haematology departments is growing faster than the ability of hospitals to increase their capacities, and limited infrastructure is a problem.

An important factor in ensuring the quality of cancer treatment is the existence of treatment protocols/treatment guidelines. In a country of the size of Estonia, it is only possible that two centres use similar treatment protocols/ treatment guidelines for all major diagnosis groups. To a large extent, this is the case, but it has turned out that way by itself rather than as a result of intentional collaboration. The problem is the lack of uniform treatment protocols/ treatment guidelines, largely due to insufficient human and financial resources.

Thanks to the cooperation between TÜK and PERH with Ida-Viru Central Hospital and Pärnu Hospital respectively, haematological outpatient care (including chemotherapy) is provided in Ahtme and Pärnu. This has improved the availability of chemotherapy in these regions to some extent. More than half of the cases of haematological inpatient care are not related to the administration of specific drugs, but to the treatment of complications arising from the disease and treatment (infections, blood component transfusions), which can also be performed in general internal medicine departments. The problem is the low integration of cooperation partners and networked hospitals into the provision of haematological inpatient care and the availability of outpatient haematological specialist care in only five Estonian cities. There is no systematic organisation of palliative, supportive and end-of-life care.

The treatment of haematological tumours is mostly based on drug treatment, and every year, more and more innovative drugs receive marketing authorisation from the European Medicines Agency. Many haematological malignant tumours are rare diseases. The period between obtaining a marketing authorisation for new medicines and their inclusion in the list of subsidised medicines or the list of health services of the Health Insurance Fund is, in Estonia, one of the longest among European Union countries. The pharmacoeconomic assessment of medicines used to treat rare haematological malignancies is based on the same criteria as the assessment of medicines used for common diseases. The procedure for including medicines in the list of health services is too long, and there are supply problems for several important and irreplaceable medicines.

The best opportunity for patients to obtain innovative medicines is to participate in clinical drug trials initiated by both sponsors and researchers. Due to the small number of patients, Estonia is usually not an interesting cooperation partner for the organisers of sponsor-initiated drug trials. All the more so, the opportunity to join study protocols initiated by international research groups (e.g. ALLTogether in acute lymphoblastic leukaemia) must be used. A small share of Estonian patients participate in clinical drug trials. Participation in trials is hindered by the equalisation of studies initiated by international research groups with studies initiated by sponsors, and the failure to exempt them from procedural fees of the ethics committee and the Medicines Agency and state fees.

High-quality data is essential for more accurate analysis of treatment outcomes and prediction of further activities. In Estonia, registration of primary cases in the cancer registry is ensured, but structured clinical data is not available from information systems and there are no diagnosis-based databases. The management of databases by medical institutions or professional societies is facing significant problems due to legislative requirements and a lack of financial resources.

## Goals

### Goal 1. A fast and smooth patient journey to haematological diagnosis and high-quality diagnostics are ensured

#### Activities and recommendations

- Referral to the initial haematology consultation is only done via e-consulting, which allows pre-selection for deciding how quickly the patient needs consulting. Primary healthcare professionals receive the relevant information and other specialists will be introduced to the guidelines for referral to a haematology specialist consultation. The technical solution for e-consulting will be further developed.
- Haematological diagnostics will be concentrated only in those healthcare institutions where the capacity for complex haematopathological diagnostics is secured (PERH and TÜK).
- A certification/accreditation system for diagnostic departments of healthcare institutions will be established.
- The diagnosis of malignant haematological disease must be based on the WHO classification, and diagnostic standards for haematological tumours will be established for that (minimum requirements for necessary examinations), as well as competence requirements for haematopathologists.
- Primary diagnostic imaging will be concentrated in specialised centres, and follow-up examinations may be performed in healthcare institutions in the patient’s place of residence.
- A system will be established for obtaining a second opinion from outside Estonia on morphological diagnostics of complex medical cases.

### Goal 2. Haematological treatment is organised under the management of specialised centres in cooperation with partners and networked hospitals, and optimal access to treatment is ensured for patients

#### Activities and recommendations

- The provision of haematological healthcare services and the organisation of specific treatment are concentrated under the management of two centres (PERH and TÜK), taking into account the limited number of qualified workforce. When planning new hospital infrastructure, the increasing number of patients and isolation requirements must be taken into account.
- Uniform treatment guidelines/protocols for more common diagnoses are developed; the necessary human and financial resources will be provided for this purpose..
- A systematic integrated network of various healthcare institutions will be created to better organise the treatment of haematological malignancies. Collaborative partners and networked hospitals will be better integrated into the provision of haematological inpatient healthcare services.

- In cooperation with PERH and the Estonian Centre for Haematology, the provision of outpatient haematological medical care will be expanded at central and local hospitals located outside Tallinn/Tartu (for example, Võru, Viljandi, Narva, Paide, Haapsalu, Kärdla, Kuressaare).
- A system of palliative, supportive and end-of-life care will be created, in which various medical institutions providing inpatient and outpatient healthcare services are involved in advising specialised centres.
- To ensure the availability of subsidised medicines, the period from the receipt of a marketing authorisation to reimbursement by the Health Insurance Fund will not be longer than the EU average.
- When assessing medicines used to treat haematological tumours that meet the criteria for rare diseases, the different assessment criteria must be applied than for medicines for common diseases, for inclusion of such medicines as subsidised medicines in the list of health services. The procedures for adding medicines to the list of health services should be simplified and made faster.
- Sufficient stocks of medicines will be ensured in cooperation with hospitals providing chemotherapy.
- The availability of qualified personnel will be ensured; see “Qualified and motivated personnel”.

## Goal 3. Achieving greater capacity for assessing treatment outcomes, participating in research and conducting international cooperation

### Activities and recommendations

- Participation in international clinical drug trials will be encouraged and the number of trials will be increased.
- Participation in trials will be facilitated by equating trials initiated by international research groups/organisations to trials initiated by the researcher, and exempting them from procedural fees of the ethics committee and the Medicines Agency, as well as finding financial resources to organise trials initiated by the researcher.
- For the further development of the specialty, cooperation with international professional organisations (European Association of Haematologists, EHA; European Society for Blood and Marrow Transplantation, EBMT) is important; it is necessary to encourage and intensify cooperation with these organisations and research groups.
- The availability of clinical data for analysing results is ensured; see “Cancer data and research”.

# Paediatric and adolescent oncology and haematology

## Background

Tumours in children (0–14 years) and young people (15–24 years) are very rare diseases, the frequency of which increases in Estonia by ~0.5% per year. These are the third cause of death at such an early age. Childhood tumours are rare diseases. In the European Union, rare diseases are defined as diseases with an incidence of < 5 cases per 10,000 people. According to this definition, all childhood malignant tumours are rare diseases because their incidence varies from 0.012 cases per 10,000 people (hepatoblastoma) to 0.35 cases per 10,000 people for the most common childhood malignancy – acute lymphoblastic leukaemia [238].

The incidence of tumours in children and adults by tumour sites varies significantly worldwide. Embryonic tumours are the leading cause of cancer in childhood, which decline with age, and carcinomas become more common (Table 4).

*Table 4. Number of cancer cases by tumour type and age group*

| **Malignant tumour (average number of cases per year)** | |
|---|---|
| **0–14 years (35 cases)** | **15–24 years (40 cases)** |
| Leukaemia (8) | Lymphoma (10) |
| Central nervous system tumours (6) | Carcinoma (6) |
| Lymphoma (4) | Leukaemia (4) |
| Kidney tumour (nephroblastoma) (2) | Central nervous system tumours (5) |
| Neuroblastoma (2) | Germ cell tumour (6) |

Based on the biological differences between childhood and adult tumours, paediatric tumours are treated differently from adult tumours. Treatment of childhood malignant tumours in Estonia is based on international treatment protocols, some of which are also research protocols. International research protocols are often the best-known treatment regimen [239], i.e. these are standard treatments. Accordingly, close cooperation with various competence centres and professional organisations (International Society of Paediatric Oncology, SIOP, Nordic Society of Paediatric Haematology and Oncology, NOPHO, ERN PedCan, etc.), and participation in pan-European research projects (ALLTogether, UMBRELLA, CHIP-AML 2021, etc.) are extremely important.

In Europe, it is customary for children with malignant tumours to be treated in centres designated for the treatment of children, where the environment taking into account the age needs of children and families, as well as support systems and specially trained personnel, are secured [239]. In Estonia, two paediatric haematology-oncology centres meet international standards [239], where all patients diagnosed with childhood malignant tumours are diagnosed and treated. These centres are the Department of Haematology and Bone Marrow Transplantation in TÜK and the Department of Haematology-Oncology in Tallinn Children's Hospital (TLH).

Approximately 2/3 of patients with childhood malignant tumours are diagnosed and treated in TLH, and approximately 1/3 in TÜK. In addition, the Department of Haematology and Bone Marrow Transplantation in TÜK is the only centre in Estonia where all allogeneic and autologous haematopoietic stem cell transplantation procedures are performed for children and adolescents up to 19 years of age.

To ensure high-quality and multidisciplinary treatment of all patients, there is regular and close cooperation between several hospitals and centres: besides TLH and TÜK, also ITK (ophthalmology, orthopaedic surgery, nuclear medicine) and PERH (pathology, laboratory, radiology, nuclear medicine, radiotherapy, oncosurgery, neurosurgery), etc.

In Estonia, the final diagnosis of a malignant haematological or oncological disease in the age group 0–18 years should be confirmed by a paediatric haematologist-oncologist.

### Cancer in adolescents

Cancers occurring in adolescents aged 15–24 are mostly similar to those occurring in childhood, although types of cancer characteristic to adults, such as carcinoma, also occur. International studies have shown that cancer survival in adolescents with the same diagnosis is shorter than in children. This may be due to the following factors: 1) the treatment of patients in this age group is divided between paediatric and adult oncologists and is therefore not standardised; 2) adolescents differ psychologically and physiologically from both children and adults; 3) adolescents reach a diagnosis too late because both the patients themselves and primary care professionals do not recognise the symptoms in indicating the disease; 4) patients in this age group do not participate sufficiently in clinical trials, which is why the development of new drugs is slower and less successful [240–242].

In Estonia, patients aged 19–24 are treated in adult departments corresponding to their diagnosis. Treatment protocols are selected based on histological findings – in the case of blastemic tumours, sarcomas and acute lymphoblastic leukaemia, the same treatment protocols are used for children and adolescents.

## Problems

### Prevention

There is no state-supported HPV vaccination of boys in Estonia, including vaccination of boys at increased risk of cancer.

According to the literature, 10% of children diagnosed with cancer have a disease-related change in the tumour predisposition gene [243,244], of which approximately 60% are directly related to the development of the tumour. People with tumour predisposition syndrome have a significantly increased risk of developing one or more tumours [243]. Therefore, it is important to regularly monitor the health of these patients (screening protocols) in order to improve tumour prevention and identify family members with asymptomatic tumours. Stress related to the tumour worsens the quality of life, reduces satisfaction with treatment and causes shorter overall survival. Therefore, in addition to screening, it is necessary to ensure regular psychological support for patients and families. In Estonia, there is no overview of patients and families with tumour predisposition syndromes (no registry), and the necessary screening for early detection of tumours does not exist. There is also no system for ensuring psychological support for such patients and families.

### Early diagnosis and treatment

There is no common awareness in Estonia that the diagnosis and treatment of malignant tumours in patients aged 0–18 years is managed by a paediatric haematologist-oncologist. Currently, the diagnosis of paediatric tumours can be delayed due to the incorrect referral of patients to centres specialising in adult treatment. Accordingly, all children with suspected malignant disease should be referred to a paediatric haematologist-oncologist until they graduate from high school, and not to other oncology specialists.

There is no well-functioning, state-supported histological material consulting system in the centres of competence.

The availability of systemic treatment is complicated by nationwide supply problems, the excessively long time between obtaining marketing authorisation for new drugs and reimbursement, restrictions on the availability of new treatment methods due to manufacturers' decisions and a lack of funding.

The availability of new medicines for children is also hindered by the current funding request system, where the effectiveness of cytostatic treatment for childhood cancer is assessed using cost-effectiveness as in the case of common diseases. This does not take into account that malignant diseases in children are rare or ultra-rare.

In Estonia, the availability of proton radiation is difficult due to a time-consuming requesting system. Proton radiation plays an important role in the treatment of childhood tumours as it allows radiation therapy to be performed, sparing healthy tissues more than conventional radiation therapy [245–248].

Currently, there is a lack of sufficient support for children and families to organise home palliative care and end-of-life care.

The care of a terminally ill child takes place mainly in specialised intensive care units in Tallinn and Tartu or at the parents' request, in a local hospital where trained medical personnel are constantly available [249]. The lack of child-specific home nursing services complicates the care of a terminally ill child at home.

## Life with and after cancer

Estonia lacks a well-functioning social support system for parents of children diagnosed with cancer.

There are currently insufficient conditions to support a child's development during long-term hospital treatment. There is a lack of state funding for children's creative activities and creative therapy, plus speech therapy and physiotherapy are not sufficiently available.

It is important to ensure the development support for preschool and school-age children in hospital because they are away from their peers for a long time, and the health condition caused by treatment does not allow for normal development. The efforts of parents are not enough to ensure a child's later success in school and life.

There is a similar problem with physiotherapy. However, considering the physical defects caused by tumours and treatment, which require long-term rehabilitation to normalise movement and motor abilities, rehabilitation during active treatment at hospital alone is not enough. Children often need long-term rehabilitation at home, which is not currently provided by the state.

The international organisation of parents of children with cancer, Childhood Cancer International, has formulated the goal:

"Every child with cancer can live their life with the best possible quality." Therefore, children diagnosed with cancer must be provided with the same development opportunities as healthy children who can attend kindergarten or school every day.

There is no specialist/team (so-called recovery specialist) who helps organise the child's return to kindergarten or school after treatment.

Currently, the problem is the lack of organisation of psychological support for children with cancer and their parents. Both parents of children diagnosed with cancer and the children themselves need constant support from a psychologist and psychiatrist during treatment. While in hospital, the availability of a psychologist's service is limited, as funding is only available to psychologists with a clinical psychologist qualification. Parents currently have to find psychological or psychiatric help outside the hospital themselves, as the state does not fund it. However, psychiatric care is not financially affordable for most people.

Disability determination for children diagnosed with cancer is currently not uniform and clear in Estonia.

In Estonia, a parent of a child over 12 years old does not have the opportunity to stay in the hospital or at home to care for a child with cancer without losing their job and/or income, which would lead to a decrease in their standard of living.

Only children with visual and mobility disabilities are eligible for transportation benefits, but in reality, all children with an oncological diagnosis whose disabled mobility is related to a serious general condition caused by both the disease and treatment would need it. In addition, there is a high risk of infection, which is why public transportation should not be used.

In Estonia, there is currently no overview of the health status and late complications of those who have recovered from childhood or adolescent tumours. There is also no regulated and agreed-upon monitoring system for secondary tumours and late complications when growing out of childhood. It is known that the treatment of every childhood tumour entails future health risks. Accordingly, it is necessary to ensure the continuous monitoring of young adults during the transition from a paediatrician to a family doctor or an adult specialist.

## Health data and research

Estonia does not have a population-based paediatric tumour registry, which would provide a better opportunity to analyse the reasons for the differences in survival/mortality of paediatric tumours compared to other countries.

Participation in international research studies focused on childhood and adolescent tumours, which would ensure access to the latest treatment methods for our patients, is complicated. This is hindered by the current legislation, which obliges Estonian researchers to pay the state fee of the Medicines Agency, professional evaluation fee, insurance, etc. when joining internationally initiated research projects. Another major obstacle is the lack of human resources in paediatric haematology-oncology in Estonia. Currently, the research team is made up of practicing doctors/nurses who do this work in their free time and without pay in addition to their main job.

# Goals

## Goal 1. A registration and monitoring system for patients and families with congenital tumour predisposition syndrome is established and psychological support provided

- Cooperation between geneticists, paediatric oncologists and oncologists will be enhanced.
- A pan-Estonian registry/database of patients with genetic tumour predisposition syndromes will be created.
- Guidelines for monitoring patients with genetic tumour predisposition syndromes/standards/screening will be developed (based on international standards).
- Means for organising psychological support for patients and families with congenital tumour risk will be found.

## Goal 2. Children and adolescents are guaranteed timely and accurate diagnosis of tumours and the best possible treatment

### Activities and recommendations

- Training is carried out for primary care teams (doctors, nurses, midwives, school healthcare specialists), and they will be introduced to the work and contacts of paediatric haematologists-oncologists through various channels.
- Diagnostics/consultation for ultra-rare pathologies are enabled in nationally agreed (contracts, logistics, funding) international competence centres, as well as cooperation in treatment (complex histological responses, etc.).
- The availability of new drugs is simplified and made faster. In order to obtain funding for new medicines and treatment methods, it is taken into account that these are rare diseases and that cost-effectiveness is not the only aspect to consider.
- Based on a national agreement and funding, proton therapy will be offered in a foreign competence centre in the event of an evidence-based indication, and the referral system for treatment there will be simplified.
- The creation of specific databases/registries will be supported.
- Legislation will be complemented to give children suffering from rare and ultra-rare diseases the opportunity to join studies initiated by foreign researchers in Estonia without additional fees.
- State and hospital support and funding for researchers to participate in international studies will be ensured.
- Regular analyses of mortality and survival rates of childhood tumours will be conducted.
- A registry of childhood tumours will be established and state financing for it will be ensured.
- Clinical databases in hospitals will be developed and financed.

## Goal 3. Children/youth with oncological diseases and their parents/youth are guaranteed adequate support services during treatment and follow-up monitoring in accordance with the diagnosis after recovery from cancer

- When a child arrives at the hospital and receives a diagnosis, in addition to doctors and nurses, a support group must also begin working with the family, including a social worker, psychologist, pastoral counsellor and peer support. The work of such a team is to provide support to the family to cope with drastically changed circumstances.
- A parent staying with a child who gets treatment will receive financial support.
- Better access to speech therapy and physiotherapy outside the hospital will be enabled.
- The organisation of psychological or psychiatric help for children/adolescents with an oncological diagnosis, as well as their parents and families, will be improved, and funding will be ensured. The requirement of a professional certificate of a clinical psychologist as a prerequisite for the funding of psychologist services will be cancelled.
- The system for disability determination will be complemented and improved, along with the expansion of transportation support for children with an oncological diagnosis.

- A home nursing system will be created, where specially trained family nurses or nurses working in paediatric haematology-oncology departments will support families and help to care for terminally ill children.
- A recovery specialist service will be introduced who will meet with the family in the hospital and, it if the child's health allows them to attend school/kindergarten, will organise visits to the child’s school/kindergarten and meet teachers, school management, medical staff and parents. They will inform everyone about the specific features of a child with cancer (risks of infection and other risks to the child's health).
- Quality of life studies are conducted to gain a better overview of childhood/adolescent tumours and later complications caused by treatment.
- Healthcare professionals working at the family medical centre are trained to organise the monitoring of a child/adolescent who has had an oncological disease.
- The European Union's SurPass platform is joined to better monitor the health of those who have recovered from childhood/adolescent malignant tumours, or the consistent and regular monitoring of young adults who have recovered from cancer is organised in the family doctor or specialist system for various health risks, taking into account the various tumour and treatment-related health effects.

# Life with and after cancer

## Background

### The patient and their loved ones in cancer treatment

A cancer diagnosis is a new and frightening situation for a patient, which affects many areas of a person's life for a long time. Consequently, psychological and social support is also needed in addition to medical care. The overall goal is to support the patient and their loved ones to cope with the changes in their lifestyle that accompany the diagnosis, treatment and monitoring of cancer. According to the literature, about a third of cancer patients and their loved ones experience emotional difficulties at some stage of the disease that impair coping and, if ignored, increase suffering, complicate cancer treatment and/or hinder recovery from the disease. Psychosocial support is understood as informational, emotional and practical support [250]. The patient and their loved ones face a heavy administrative burden, which means moving between different institutions and navigating a completely new information space in a situation where information is fragmented. They need help to reorganise their own or a loved one's life. The need for help may arise even before diagnosis, during treatment, or after the end of active treatment, and may affect overall coping and consent to treatment.

There are various studies confirming that current options for cancer survivors are insufficient and do not solve real problems. International experience shows that nearly 70% of patients experience physical, emotional, and practical life problems after the end of treatment [251]. The burden of cancer does not end for the patient with the end of the treatment, but in many cases, it goes on with long-lasting problems, which may include pain, fatigue, neuropathy, heart problems, sleep disorders, deterioration of cognitive functions, sexual disorders, mood and concentration difficulties, fear of the cancer returning, financial problems, etc. [252].

In Estonia, the possibilities of psychosocial support for cancer patients vary and are uneven. Regional, central and general hospitals have pastoral counsellors, psychologists and social workers. A separate palliative care centre has been established in PERH, where, in addition to pain treatment, the services of a palliative care nurse, home nurse, psychologist, physiotherapist, social worker, nutritionist, pastoral counsellor and peer support are offered. These services are often available to the patient to a limited extent, are not extended to the patient's relatives, are not specific to patients with an oncological diagnosis (especially in central hospitals) and are guaranteed only to persons receiving treatment in that particular clinic. The patient and their relatives need empowerment in dealing with the new situation, which is why it is necessary for different parties in the system to offer proactive assistance in solving all problems and in all areas of life. The Estonian Cancer Society has been operating since 1992, and 18 regional patient organisations have joined it, so there are approximately 2,000 members in total. The Estonian Cancer Society and regional patient associations offer limited peer support (including hotlines and virtual communication environments), support person services, adaptation courses and other activities aimed at different target groups.

### Information systems

e-Health portal and digital health services should support person-centred healthcare and help healthcare professionals to make the right treatment decisions. Corresponding services (e.g. electronic health records and referral letters) have been in use in Estonia for years, and the option of e-consulting was added later. Often, the shortcomings of digital services (there is no data in the person’s digital record, obtaining information is time-consuming, etc.) are an obstacle to the initial diagnosis of cancer or the provision of appropriate treatment. Social workers, physiotherapists, speech therapists and psychologists do not have access to the health information system and the necessary up-to-date data. Studies conducted in Estonia have shown that patients have also experienced a lack of information and problems in obtaining it [253].

## Problems

Regular visits to the treatment locations, which are often far from the place of residence, are time/resource-consuming. Regional transport between home and the cancer centre is not guaranteed. If the patient's condition does not allow the use of public transport, the patient or their loved ones must, in general, find transport options to get to the treatment themselves. There is no possibility of establishing patient hotels, which is why cancer centres are forced to use significantly more expensive inpatient hospital care only for social reasons.

Estonian cancer centres do not have sufficient access to palliative, supportive and rehabilitation care. Treatment plans often remain fragmented – there is no bridging between different stages of treatment, and consistent rehabilitation, psychosocial and other kinds of support are insufficient. The problem is the availability of other specialists (nutritionist, physiotherapist, sex therapist, psychologist, spiritual guide), as the Health Insurance Fund does not finance the services, and help is not provided proactively. In central, and especially in general hospitals, the possibilities for providing support services are even more limited.

In Estonia, there is no information on treatment outcomes and patient satisfaction with the treatment service, as well as on their quality of life during and after cancer treatment. In hospitals providing cancer treatment, there is no regular assessment of the quality of life during and after treatment and patient satisfaction with cancer treatment. There is also no comprehensive mapping of the patient's life situation and their needs (Holistic Needs Assessment) [254–260] before receiving the diagnosis and at the time of diagnosis and the preparation of an advanced care plan based on that [261–266]. In hospitals belonging to the Hospital Network Development Plan, satisfaction surveys on treatment services are conducted among inpatient and outpatient patients, but these surveys do not specifically assess the needs and satisfaction of cancer patients. Surveys assessing the quality of life of cancer patients are implemented only as part of clinical research (including treatment studies). Also, the satisfaction of specialists and staff involved in cancer treatment with their working conditions and environment is not assessed in order to ensure a better quality of treatment.

Patients do not have the opportunity/solutions to inform the treatment team 24/7 about the side effects of treatment as a routine part of the treatment process; Treatment aimed at side effects as early as possible improves patients' consent to treatment, quality of life and treatment outcomes and, and consequently, overall survival [267–270]. Staff working with cancer patients have not been given satisfaction surveys or are allowed to participate in supervision groups.

All aspects of a patient's cancer journey (treatment, side effects, nutrition, social, economic and psychological aspects) are not regularly assessed based on their need for support. The poor availability or absence of evidence-based information and health and lifestyle recommendations for patients causes ignorance, anxiety and emotional stress in patients and their loved ones. The patient's low involvement in treatment decision-making can be a problem.

Operational information exchange between doctors does not work; existing information systems do not support rapid information exchange. In addition, information systems in the health and social sectors are not compatible.

Patients lack the necessary support when returning to normal life after the end of oncological treatment; there is no assessment of post-treatment coping or need-based provision of support systems. There is no occupational health and labour market assessment (existing job, suitability for the job and field of activity, possible work environment problems, etc.). There is no support for employers that would enable them to retain and hire employees with chronic illnesses [271,272].

## Goals

### Goal 1. A patient-centred holistic cancer journey has been designed and implemented

#### Activities and recommendations

- A patient-centred holistic cancer journey is developed and implemented, starting before the final diagnosis of cancer and extending into the post-treatment period. Every cancer patient must have access to needs-based support for managing the treatment's side effects and rehabilitation, as well as for a healthy lifestyle and social, economic and psychological issues, which are regularly assessed throughout the journey. Regular assessment is the basis for preparing both a rehabilitation plan and, if necessary, a pre-care plan.
- To provide high-quality and safe treatment services, the stages of the patient's journey and their coherence are described – how the different levels work, how the smooth cooperation between them works, the timeline for receiving the next service, what is an acceptable waiting time, etc
- A site-based nurse-coordinator role is created in cancer centres, who is the contact person for the patient and their loved ones throughout the entire journey and helps to reduce the fragmentation of the treatment journey. Training for the nurse-coordinator is ensured.
- When managing and coordinating a multimodal cancer centre, part of the cancer treatment is directed as close to home as possible. A functioning information system is created between the various parties. The prerequisite for treatment as close to home as possible is operational information exchange and the functioning information system (IT platform) between all parties: patient – health specialist of the family medical centre – oncologist/oncology nurse of the partner hospital – coordinating cancer centre – local government.
- A list of anti-cancer medicines will be compiled for which treatment sessions can be carried out as close to the place of residence as possible. The position of oncology nurse will be created in the partner hospital with training in administering medicines and dealing with side effects. The oncology nurse will communicate with the nurse-advisor of the treatment centre and the oncologist, who will coordinate the treatment if problems arise. A system for providing blood tests and conducting examinations, if necessary, according to the place of residence will be developed and implemented, supporting treatment decision-making in the cancer centre coordinating the treatment.
- In all units dealing with cancer treatment, healthcare professionals must be guaranteed opportunities to provide patients and their loved ones with needs-based assistance. The need for help and applications depends on the stage of the disease (cancer suspicion, diagnosis, treatment, monitoring, disease recurrence, terminal care), the patient's comorbidities, age, life situation, and other factors. It is necessary to ensure the presence of a sufficient number of trained employees who can recognise psychosocial needs and have knowledge about assistance options, optimal team composition, supporting information systems, etc.

- A rehabilitation and supportive care plan form is developed and implemented as part of a multimodal council, including visits to support specialists (including rehabilitation and supportive care) in addition to the anti-tumour treatment plan. This ensures the inclusion of early palliative and psychosocial care, and makes the cancer journey more coherent. In addition to the treatment plan, the patient's needs are assessed, and a Holistic Needs Assessment Card is prepared, which is forwarded to the social support system and, if necessary, serves as the basis for the preparation of advance (Advance Care Plan) and end-of-life instructions. The holistic treatment plan is regularly assessed and, if necessary, adjusted throughout the cancer journey. The holistic treatment plan must be made available in the Health Information System.

## Goal 2. Patients are guaranteed social and psychological support throughout the cancer journey

### Activities and recommendations

- Psychosocial support and palliative care, in parallel with other cancer treatments, help to improve the quality of life of patients and prolong survival [273,274]. Regardless of where they live, all patients will be guaranteed access to psychosocial support throughout their treatment journey and after treatment.
- To reduce the administrative burden, local governments will work together to improve patient transportation options for cancer treatment at multimodal cancer centres. In cooperation with local governments, a functioning support system will be created to satisfy transport needs.
- Patient organisations will be empowered in their activities to ensure the necessary activities to support patients and their loved ones outside healthcare institutions for the entire treatment period, both at the national and county level (including continuous counselling of patients and their loved ones, training, information days, adaptation courses, etc.).

## Goal 3. Cancer patients' quality of life and satisfaction/experience will be assessed regularly

### Activities and recommendations

- Satisfaction surveys specifically targeted at cancer patients will be developed for regular assessment of treatment outcome (PROM) and service (PREM). These will be implemented in all healthcare institutions involved during the active treatment period and no less than one, three and five years after the end of treatment. Based on the analysis of the results, the necessary improvement measures will be implemented.
- To ensure the best treatment, satisfaction surveys of the cancer treatment team will be conducted at 2–3-year intervals. Employees will be allowed to participate in supervision groups.
- In order to maintain quality of life and consent to treatment, continuous monitoring of treatment complications platform with decision support will be developed.
- Patient awareness will be increased in a manner suitable to the target group.

## Goal 4. Life after cancer: patients are guaranteed optimal follow-up and comprehensive support for returning to society

### Activities and recommendations

- Post-treatment monitoring will be structured, and a system will be created for primary care and specialists.
- In cooperation with family doctors, post-treatment monitoring guidelines will be developed and implemented based on the treatment received and possible long-term complications, and immediate consultation between family doctors and specialists will occur if needed.
- Support will be provided for the reintegration of cancer patients and their loved ones and staying in the labour market. An exchange of information will be established between the medical system, the social system and the local government, which will help to consistently provide the necessary assistance and keep people active in society and the labour market. In cooperation with occupational health doctors, an occupational health and labour market assessment system will be developed (existing job, suitability for the job and field of activity, possible problems arising from the work environment, etc).
- The role of patient representative organisations will be enhanced to better cope with patients and their loved ones. Patient organisations are empowered in ensuring the necessary activities to support patients and their loved ones for resocialisation at both the national and county levels (including continuous counselling of patients and their loved ones, training, information days, adaptation courses, etc.).
- Comprehensive support for loved ones who have not received specific preparation for supporting cancer patients is necessary because they may become tired and suffer from emotional ailments themselves. Psychosocial support for both the patient and their loved ones is ensured for as long as it is needed [275–277].

# Qualified and motivated personnel

One of the key issues for the success of cancer control is the sufficient number of qualified and motivated personnel who contribute to the health and well-being of patients. The increasing number of patients, the expectations of patients and their loved ones towards the healthcare system, and the rapid development of diagnostic and treatment options are placing new demands on both the number of employees and their knowledge and skills. All of the above necessitates the need to regularly review the needs of employees, as well as their training and work organisation principles so that cancer patients are guaranteed high-quality, safe and viable healthcare services.

A patient comes into contact with a wide range of specialists during their cancer journey. The cancer journey usually begins with a family doctor. In the next stage, various specialists (e.g. gastroenterologists, pulmonologists, dermatologists, gynaecologists), radiologists and nuclear medicine doctors involved in cancer diagnostics, pathologists, cytogenetics and molecular diagnostics specialists, surgeons performing cancer treatment, radiation therapy and systemic therapy oncologists and haematologists may be involved. If necessary, specialists dealing with side effects of the treatment process (e.g. cardiologists, endocrinologists), rehabilitation doctors involved in restoring functions, and palliative care doctors ensuring quality of life (including pain medicine doctors) are involved in the treatment journey. In addition to doctors, nurses (including home nurses), radiology technicians, medical physicists, as well as speech therapists, physiotherapists, nutritionists, psychologists, pastoral counsellors etc. are involved. In cancer control in general, midwives play an important role in screening, geneticists in personalised prevention, and registry workers and researchers in evaluating the success of cancer control and developing new solutions.

Family medicine centres play an increasingly important role in cancer control, which requires additional manpower and the involvement of various specialists for preventive activities, timely diagnosis, treatment and research, and the provision of follow-up care. In certain regions, problems with the availability of family medicine care (shortage of family doctors and family nurses) may be an obstacle. There is also a need to increase the resources allocated to family doctors and family nurses who specifically and consistently deal with cancer prevention. It is important to strengthen teamwork between primary care and cancer centre specialists through training and joint seminars to ensure a smooth transition of patients from one stage to another.

When implementing screening programmes, it is necessary to strengthen cooperation between different specialists, increasing the role of midwives in both cervical cancer and breast cancer screening. The organisation of colorectal cancer screening is sometimes hindered by a lack of resources both at the primary care level (single practices with large lists, differences in the age group in the list, lack of a second nurse) and in specialised medical care (lack of specialists conducting examinations, such as gastroenterologists).

In order to ensure the best possible treatment for patients, it is important to secure a sufficient number of qualified medical, nursing and other personnel in the fields of oncology and haematology. Studies conducted in Europe and the USA have shown that, due to the nature and workload of the work of doctors and nurses who manage cancer care, 45–78% of oncologists and nearly 50% of oncology nurses experience burnout. In addition, nearly 60% of oncology nurses experience significant levels of compassion fatigue [278,279]. It is characterised by emotional exhaustion, depersonalisation, and decreased performance ability, which significantly reduces the ability of both doctors and nurses to perform high-level clinical work and poses a direct threat to the well-being of the patient and their family [278,279]. The level of psychological stress and burnout among people working with cancer patients has not been studied in Estonia, but this topic certainly requires attention. To prevent burnout, it is extremely important to provide psychological support to employees, conduct employee satisfaction surveys, and regularly assess employee turnover indicators.

The following is an overview of the main employee groups that support cancer prevention, diagnostics and treatment.

## Doctors

Doctors are trained in Estonia at the University of Tartu under the residency regulations [280].

### Family doctors

Family doctors, together with family nurses, deal with primary cancer prevention and advise patients on smoking, alcohol consumption, nutrition and exercise. The role of the family doctor in screening is direct (screening for colorectal and cervical cancer) or indirect (explanation of the need for screening and reminders). Family doctors could contribute more to the cancer treatment process and follow-up if the patient's cancer treatment plan included clear instructions for this (e.g. performing analyses or examinations and interpreting them, and if necessary, further actions). Family doctors can also deal with other possible health problems of the patient. Family doctors organise home nursing for patients and can also help to support family members of cancer patients, including being members of the support team for children with cancer. To this end, the primary level needs consistent training and more effective cooperation between primary care and specialist medical care.

### Diagnostic imaging and image-guided therapy

In Estonia, there are 11.4 radiologists per 100,000 inhabitants [281], while in Western Europe, this figure was an average of 12 in 2015 [282]. Based on current trends, it can be assumed that the number of primary and follow-up examinations will continue to increase, as will the need for complex and specific MRI and CT examinations, nuclear medicine and procedural radiological examinations and treatment procedures. The increase in the number of screenings and the possible introduction of new screenings based on personalised medicine must also be taken into account. This significantly increases the demand for qualified radiologists and creates a need to increase the admission of radiology residents. The expanding use of artificial intelligence in primary diagnostic imaging may be helpful in the future, but it certainly will not alleviate the need for additional labour force.

In Estonia, there are no subspecialties in radiology that are recognised elsewhere in the world. A radiologist achieves greater professionalism in a subspecialty through additional specialisation after residency, the organisation of which is in its early stages in Estonia. During the radiology residency, it is mandatory to complete a four-month oncoradiology cycle, a two-month breast radiology cycle, a five-month procedural radiology cycle, and a three-month nuclear medicine cycle. There is no possibility of specialising as a nuclear medicine doctor. To date, the International Atomic Energy Agency (IAEA) has ensured the sustainability of the nuclear medicine profession in Estonia within the framework of various cooperation projects and has made significant expenditures for the introduction of new diagnostic and treatment technologies, but given Estonia's good economic indicators, such a contribution may not continue in the future. The working group sees the need to encourage in-depth specialisation in a specific field of radiology based on clinical specialty (breast radiology, thoracic radiology, etc.) or modality (interventional radiology, nuclear medicine, etc.). To this end, it is necessary to continue and deepen field-based subspecialisation after completing a radiology residency [283].

### Pathology, cytogenetics and molecular diagnostics

In 2019, 44 pathologists worked in Estonia, i.e. 3.3 pathologists per 100,000 inhabitants [1]. According to 2015 data, 20% of 56 pathologists working in Estonia were over 65 years old [284]. Workload standardisation, taking into account the changed work requirements (increased number of immunohistochemical stains, the addition of molecular and cytogenetic methods, the introduction of multigene panels, participation in multidisciplinary councils, teaching, the longer time required to write responses), would help to better identify the need for pathologists.

In pathology residency, Estonia currently lacks training in molecular genetics and cytogenetics (residency cycle), which in other countries has been included in residency programmes and which would ensure an up-to-date approach to molecular pathology. At the same time, the number of molecular diagnostic tests for oncology patients has increased 20-fold in 10 years since 2009. The number of molecular genetics specialists in the laboratory has only increased 3-fold, which is why more specialists and doctors are needed who, in addition to pathology methods, would also be proficient in molecular and cytogenetic methods. The overload of such specialists significantly prolongs the time for responses of all pathology and oncogenetic-related studies, which in turn extends patients’ waiting times, worsens data quality, and complicates development activities. According to the Pathology and Molecular Diagnostics Working Group, molecular genetics and cytogenetics topics should be included in residency training in both oncology and pathology specialties. Specialists who have completed master's and doctoral studies in genetic engineering and biomedicine and who have already been employed in molecular diagnostics and cytogenetics specialties could also be involved in pathology laboratories.

### Surgical treatment

The teaching of surgical specialties in the residency programmes of the University of Tartu (general surgery, obstetrics and gynaecology, urology, otorhinolaryngology) is dominated by the principle of surgery based on the organ and anatomical region: in the case of an organ or anatomical region, one must be able to treat both benign and malignant pathology. Oncology training in general surgery, obstetrics and gynaecology, urology and otorhinolaryngology has decreased to a minimal level. There is also relatively little time left for familiarisation with multimodal cancer treatment. The thoracic surgery residency is in a better position based on the specificity of the specialty, where cancer patients are encountered every day. In obstetrics and gynaecology, the residency lasts 4 years, of which only 4 months are reserved for gynaecological oncology and only 1 month for breast cancer surgery. The general surgery residency lasts 5 years, of which only 6 months are dedicated to surgical oncology and only 2 ECTS credits for theoretical oncology training. Oncological training in urology and otorhinolaryngology is little [280]. Of the major fields of cancer surgery, breast surgery training is completely uncovered. Currently, residency graduates receive the necessary training for the surgical treatment of malignant tumours in the workplace, but this does not secure training of cancer surgeons on a uniform basis throughout the country.

The Surgical Treatment Working Group considers it necessary to define the additional competence of cancer surgery and add it to the list of medical specialties. Additional competencies have been applied in many specialties in Estonia (for example, paediatrics with additional competence in haematology-oncology, urology with additional competence in andrology and ophthalmology with additional competence in eye surgery) [187]. Cancer surgery is a term covering all surgical specialties, encompassing the prevention, diagnostics and surgical treatment of malignant tumours of organ systems and tissues within the scope of the main specialty. The common thread between the fields of cancer surgery (based on the main specialty) is basic knowledge of the main principles of oncology. The working group believes that additional competence in cancer surgery needs to be established for the following surgical specialties: general surgery, obstetrics and gynaecology, urology and otorhinolaryngology. The best option for acquiring additional competence in cancer surgery would be a 1–2-year post-residency fellowship in cancer centres, the funding of which could be arranged in cooperation between the state and cancer centres.

### Oncology (systemic and radiotherapy)

Since 2008, oncologists have been trained at the University of Tartu based on the clinical oncology study model, i.e. residents receive training in both radiotherapy and drug therapy [285]. In 2 Estonian regional hospitals that offer both systemic and radiotherapy, the work organisation of oncologists is different: The Oncology-Haematology Clinic of PERH has set up separate radiotherapy and chemotherapy centres, and the oncologists working there specialise in either radiotherapy or systemic therapy. In the Department of Radiotherapy and Oncotherapy of the Haematology-Oncology Clinic of TÜK, the majority of oncologists work in parallel with both types of treatment.

In order to acquire and maintain competence, an oncologist needs thorough preparation during residency and continuous further training during their medical practice. In recent years, the number of patients and treatment indications in oncology have increased, and new drugs and treatment methods have constantly been introduced. Due to this, the workload of the staff and the need for more employees have been increasing. Learning about new treatment methods and indications, their implementation in clinical practice, and participation in basic, translational and clinical research sets great demands on the oncologist for further training, which often has to be done outside of working hours due to the high clinical workload. Patients' expectations of oncologists have also increased significantly over time. To ensure the quality of treatment and the safety of employees, it is seen that there is a need to implement internationally recommended workload standards for oncologists in medical institutions based on an analysis of the predicted need for systemic and radiotherapy [286–288]. For example, the recommended workload for a systemic therapy doctor is estimated to be 150–175 primary patients per year [289], but the workload of PERH systemic therapy doctors is currently nearly 300 primary chemotherapy patients per year, which exceeds the recommendation of safe and optimal work standard [290]. According to the working groups, the current residency planning system has not taken into account all the circumstances for opening new residency positions and underestimates the need for specialists. One of the motivating factors for employees is optimal workload. To prevent oncologists from burning out and to keep them motivated, additional measures should be implemented (additional leave, psychological support, working time rationing, etc.).

*The systemic therapy* working group estimates that oncologists involved in systemic therapy need longer and more thorough training [291]. It is also considered necessary to continuously analyse training needs in changing circumstances, taking into account international recommendations [292].

***The radiation therapy*** working group considers it necessary that the training of oncology residents includes basic radiotherapy training within the framework of international courses. So far, the costs necessary for lifelong learning in radiotherapy and the introduction of new treatment technologies have been largely covered within the framework of cooperation projects with the International Atomic Energy Agency (IAEA), which may not continue in the future, given Estonia's good economic indicators. Limited access to training is one of the obstacles to the application of innovative treatment technologies. The importance of organising and financing specialist training to improve access to radiotherapy is emphasised internationally [207].

### Palliative and end-of-life care

In Europe, the lack of education and training opportunities in palliative care is considered to be an obstacle to the development of palliative care as a specialty [293]. The palliative care working group believes that addressing pain and palliative care in the basic and advanced training of doctors, nurses, support specialists and family caregivers is insufficient in Estonia. The shortage of specialists and the low appreciation of the field are also seen as obstacles. Based on international recommendations, the working group considers it necessary to address the principles of palliative care in the basic training of both doctors and nurses (basic knowledge of palliative care, treatment of pain and other symptoms, psychological and spiritual aspects, ethical and legal aspects, communication, self-reflection), as well as providing specialised advanced training programmes of palliative care for doctors and nurses, care workers and support specialists working in the field of palliative care [294]. Integration of palliative care into specialist nurse training (in master's studies) should be considered.

### Rehabilitation

The main problem in the rehabilitation of cancer patients is, according to the working group, the low volume of oncological rehabilitation in the training of rehabilitation doctors and rehabilitation specialists. In order to ensure the quality and safety of rehabilitation services for cancer patients, it is considered necessary to address oncological rehabilitation in training programmes for medical and support personnel in educational, informational and instructional materials, and in treatment guidelines with uniform terminology and in sufficient volume (including in the education of medical and rehabilitation specialists, as additional training for doctors and allied professions).

### Haematology

On the one hand, morbidity in haematology is increasing, but at the same time, many malignant haematological diseases have changed from fatal diseases to chronic diseases due to improved treatment options. The resulting increase in the number of patients has not been accompanied by a proportional increase in the number of qualified employees. The need for doctors in the field of haematology will be greater in the coming years than the number of doctors completing residency and obtaining qualifications in haematology. Due to the malignancy of the diseases and the higher mortality of patients compared to some other specialties, working in haematology is associated with greater psychological stress, which can lead to burnout. The main problems are, therefore, the shortage of qualified medical personnel and burnout of employees. To ensure a sufficient number of doctors, the working group recommends providing an adequate number of haematology residencies each year, funded according to international standards. To ensure the quality of treatment, it is necessary to bring the duration of a haematology residency into line with international requirements (5 years). In addition, there is a need to regularly assess the number of employees for outpatient and inpatient treatment cases.

### Paediatric and adolescent oncology and haematology

Paediatric haematology-oncology is a subspecialty of paediatrics in Estonia (since 2014). Specialist doctors are trained in the paediatric subspecialty residency of the Faculty of Medical Sciences of the University of Tartu. In Estonia, doctors working in paediatric haematology and oncology are united in the paediatric haematology-oncology working group of the Estonian Society of Haematologists. The workload of paediatric haematologists-oncologists is not measured, and the current financing of the service does not allow for the creation of new jobs.

### Nursing staff

Nurses in haematology-oncology departments are trained at Estonian healthcare colleges. Nurses are classified as general nurses or specialist nurses based on their training. There is no separate training for oncology in nursing. In Estonia, only 4 specialties are distinguished as specialist nursing: 1) intensive care nursing, 2) clinical nursing; 3) health nursing; 4) mental health nursing. Cancer treatment primarily involves nurses with a clinical nursing specialty. Working as a haematology and oncology nurse requires specific knowledge and skills (administration of cytostatic drugs, nursing care related to radiotherapy, blood component transfusions, nursing in haematopoietic stem cell transplantation etc.), which are not specifically covered within the general nurse and clinical nurse curriculum. Approximately 50% of the bed days in the inpatient haematology department are intensive care days on levels 1–3, which require a larger number of nurses than is needed in the general department (therefore, a clear definition of the nurse-patient ratio is necessary).

The work of nurses in the field of oncology has changed from year to year due to new tasks in the use of drugs and the introduction of rapidly changing treatment methods. Proactive monitoring of outpatient treatment has been added. Providing treatment and monitoring the patient's condition, as well as cooperation with the family and oncologists, requires specific professional training and continuous practice not only in clinical issues, but also in dealing with crises.

Estonia currently lacks a clear qualification system and differentiated salary scales for nursing personnel; the existing nursing standard does not meet actual needs because the nurse-patient ratio is undefined.

The workload of oncology nurses is not measured and the share of nurses in financing of the service does not allow for the creation of additional jobs. This can lead to burnout of oncology and haematology nurses, which results in a constantly high employee turnover, especially in inpatient departments.

Nurses working in haematology and oncology are united in the Estonian Oncology Nursing Society, a sub-organisation of the Estonian Nurses' Union. Estonian Oncology Nursing Society is a member of the European Oncology Nursing Society (EONS). EONS presents clear objectives and content for training programmes for nurses working in the field of oncology and also provides various recommendations on the work of oncology nurses, the aim of which is the safety of patients and their loved ones [295].

The profession of a midwife is acquired in health colleges where the curriculum includes basic knowledge of women's diseases, including the prevention of cervical and breast cancer. This allows midwives to be engaged in this field, thereby reducing the burden on nurses. Midwives acquire a holistic approach to women's health as basic knowledge (reproductive health, pregnancy, childbirth, the postpartum period and breastfeeding), but they definitely need to improve their specific knowledge and skills related to cancer.

### Radiology technicians

You can study to become a radiology technician at Tartu Health Care College. Radiology technicians have some degree of division of tasks, especially in nuclear medicine, MRI and mammography, but the advanced training of ultrasound specialists and nuclear medicine radiology technicians is insufficient. The small number of new radiology technicians is a major problem. The OSKA study conducted in 2017 assessing the need for radiology technicians does not provide an adequate picture of the current situation as this study does not sufficiently take into account the growing need for radiology technicians due to the increase in the number of devices and the number of examinations [296]. There is a shortage of radiology technicians, especially in general hospitals. The working group sees a need to increase the number of radiology technicians, encourage subspecialisation of radiology technicians and improve the training of nuclear medicine and ultrasound technicians at Tartu Health Care College.

### Radiation therapists

In Estonia, it is not possible to specialise as a radiation therapist, based on the national curriculum. Radiotherapy procedures are performed by radiology technicians whose basic education (applied higher education, EQF level 6) focuses mainly on performing diagnostic procedures. The share of radiotherapy-specific subjects in the entire programme is 3%, which does not meet international recommendations [297]. Of 32 radiation therapists working in Estonia in 2020, only 3 (9%) have completed a specialisation course within the RADEK project (2009–2012). In 2019, the first radiotherapy master's programme was opened at Tartu Health Care College as a continuation of the radiography curriculum, but this is not a permanent solution, as the programme is paid for by the student (3,300 euros per year) and is conducted in English. The working group sees a need to align the programme with the ESTRO basic curriculum [225], which ensures the minimum knowledge necessary for the work of a radiation therapist [298]. Part of the existing master's programme can be integrated as a basis for the course. The prerequisite for obtaining the profession of radiation therapist is specialisation in the field of radiotherapy.

### Medical physicists and other related specialties

In Estonia, there is no structured clinical residency of at least 2 years for medical physicists specialising in radiotherapy. In 2020, only 50% of medical physicists working in radiotherapy centres had a professional certificate in radiotherapy. TalTech organises a course in medical engineering and medical physics for physicists at the master's level with a volume of 6 ECTS credits. This does not allow participants to acquire knowledge in accordance with EU requirements [299].

There is a particularly large shortage of medical physics engineers and physicists in central and county hospitals, which is why there is a need to train significantly more biomedical engineers and physicists in order to ensure quality of treatment.

The development of radiopharmacy in nuclear medicine units is planned for the coming years, but there is no special training in radiopharmacy in Estonia. The development of radiopharmacy can take place through additional specialisation in the specialty of pharmacy or radiochemistry, where the preparation of radiopharmacists must include basic training in international courses based on EANM/ESMIT (European Association of Nuclear Medicine/European School of Multimodality Imaging & Therapy) programmes, together with continuous on-the-job training.

## Goal 1. A sufficient number of employees are engaged in cancer prevention

### Activities and recommendations

- The need for specialists by specialties is analysed and corresponding changes are made when opening residencies.
- The need for other specialists (nurses, radiology technicians, medical physicists, etc.) working with cancer patients is analysed and training is adjusted accordingly.
- Different solutions are considered to enhance prevention work at the primary level, including within the screening.
- The financing of registries takes into account the need for personnel, sufficient for ensuring the reliability of data.

## Goal 2. Training of employees meets the needs

### Activities and recommendations

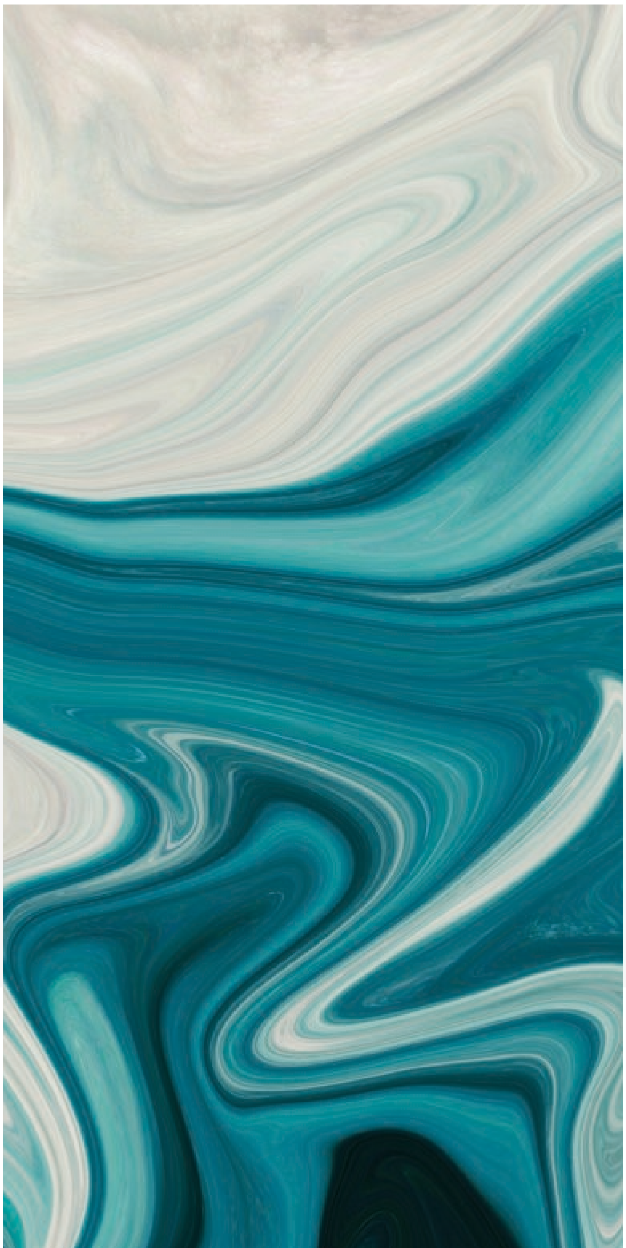
- The existing curricula (residency, training of radiology technicians, medical physicists, etc.) and their compliance with international requirements will be analysed, and updated as a result.
- The need for additional competencies in medical specialties and the changes necessary to define them in residency programmes or post-residency education will be analysed, and the corresponding changes will be made.
- Creation of opportunities for special training and specialisation of haematology-oncology nurses will be considered

## Goal 3. Employees are motivated

### Activities and recommendations

- The workload of doctors, nurses, and other specialists will be analysed, workload standards and competency requirements will be defined and established.
- Additional measures will be implemented to prevent employee burnout (including satisfaction surveys, psychological support, additional leave).
- The share of employee expense in the financing of oncology services will be reviewed.

To implement the activities, specialist working groups will be established involving representatives of relevant educational, healthcare and state institutions and professional associations.



# Cancer data and research

## CANCER DATA

### Background

Thanks to the long-term data set of the population-based cancer registry (since 1968), Estonia has a comprehensive overview of the occurrence of cancer over decades and good opportunities for conducting cancer research. Cancer mortality is estimated using data from the Cause of death registry, which contains data from death certificates since 1985. Since 2015, data on cancer screenings conducted in Estonia have been collected in the cancer screening registry.

#### Cancer Registry

The main objective of the population-based cancer registry is to consistently collect data on all cancer cases diagnosed in the population in order to ensure national cancer incidence and cancer survival statistics, and data for research. The registry collects data according to international rules and includes the minimum necessary data fields for diagnosis, stage, treatment and follow-up [300]. The Estonian Cancer Registry is a member of the International Association of Cancer Registries and the European Network of Cancer Registries.

The data is collected using 2 notification forms, one of which is completed by the healthcare institution that diagnosed the cancer or performed the cancer treatment, and the other is completed by a pathologist or forensic expert if the cancer diagnosis is confirmed on the basis of a tissue sample [301]. Currently, both notification forms are submitted on paper. Data exchange with the Population Registry and the Cause of Death Registry takes place via the data exchange channel X-Road [301]. The Cancer Registry has the ability to link other databases to supplement data (e.g. the Health Insurance Fund database, hospital information systems, Health Information System, etc.).

Based on data from any registry or database, reliable conclusions can only be drawn if data quality is ensured. Four important aspects are distinguished in the quality of the registry's data: completeness, validity, comparability and up-to-dateness [302]. The completeness of the registration of cancer cases depends primarily on the submission of data by healthcare institutions but also on the registry's activities in updating data [303]. The cancer registry regularly compares its data with the data from the registry of causes of death and data from three cancer centres – PERH, TÜK and TLH. For ensuring the validity of data (accuracy and truthfulness of data), the accuracy of the primary data of healthcare institutions and the data submitted to the registry, as well as the quality of cancer case registration based on the experience and skills of registry staff, are crucial [302]. To ensure the comparability of data over time and internationally, the cancer registry follows international rules, classification and coding guidelines [302]. The registry staff has undergone relevant training.

Cancer diagnostics and treatment are time-consuming processes, and it also takes time to insert data in the registry, check it, carry out the necessary actions to ensure completeness and validity, and prepare data for publication. Therefore, according to international practice, cancer data that is published with a delay of up to 2 years is considered up-to-date; according to a recent study, the median delay time for European cancer registries was 18 months [304]. The Estonian Cancer Registry currently publishes morbidity data with a 2-year delay (morbidity data for 2019 will be published in 2021).

#### Cause of Death Registry

The Cause of Death Registry operates on the basis of § 32 of the Establishment of Cause of Death Act [305]. The registry collects data on death notifications, cause of death notifications and cause of perinatal death notifications via the Health Information System. The underlying cause of death is established in accordance with WHO rules. The registry data is supplemented with data from the Population Registry and the pregnancy information system.

#### Cancer Screening Registry

The Cancer Screening Registry operates as an electronic registry which receives data presented by health service providers via the Health Information System. The registry receives data via queries over the data exchange channel X-Road. In addition, data from other national registries and databases are used (e.g. Population Registry, Cause of Death Registry, Cancer Registry, Health Insurance Fund) [306].

The registry collects data necessary for organising breast, cervical and colorectal cancer screening. The purpose of the registry is to analyse and regularly assess the effectiveness and quality of screening programmes and to enable the conduct of scientific research, including epidemiological research, on the basis of the registry's data. Another purpose is to participate in the organisation of screening, including creating digital invitation letters for target groups in the Health Information System before each screening year and sending individual invitations and reminders invitations by both e-mail and direct mail [306].

To evaluate screening programmes, it is necessary to measure quality indicators according to the recommendations of the European Commission [307], which are divided into process indicators (e.g. coverage by professions or studies, study results, number of inadequate tests) and result indicators (e.g. number of people referred to additional testing after a positive initial test, number of tumours and/or precancerous conditions detected, adequacy of treatment performed, occurrence of interval cancers, changes in cancer morbidity and mortality). In addition, site-specific indicators are used, such as complications arising during the study and the share of advanced breast cancer.

The Cancer Screening Registry is currently able to analyse and regularly publish the results of the main process indicators: coverage by screening, coverage by invitations and participation rate in screening. Data on cancer screening target groups, invitations and coverage by screenings, as well as on detected cancers, have been published in the Health Statistics and Health Research Database since 2015 [54].

The insufficient analysis of result indicators is caused by the insufficient receipt of screening responses through the Health Information System.

### Keeping of registries

The majority of population-based health registries have been consolidated in the National Institute of Health Development as it has the necessary competence and the registries operate on a single data platform. The work of registries is carried out on the basis of specific international rules. The training of registry staff is long-term and takes place mainly during their work in the registry.

## Problems

### Data quality in the Cancer Registry

Submitting data to the Cancer Registry is an obligation arising from the Public Health Act [308], but despite this, data on many cancer cases (about 20% of all cancer cases) are not submitted to the registry on time, and the burden of identifying and entering the corresponding cases falls on the registry staff.

There is no structured digital cancer notification form, and the data submitted to the Cancer Registry contains inaccuracies, is submitted only partially, or the instructions for completing the cancer notification form are not followed.

The heavy workload of the registry staff in supplementing and specifying data does not allow the publication of cancer data faster than with a 2-year delay. Due to budget constraints, the number of Cancer Registry staff is significantly lower than shown in a recent European-wide study, according to which, on average, one person works in the cancer registry for every 1,120 cancer cases (in the Estonian Cancer Registry, it is 1 person for every 4,500 cancer cases) [309].

In many ways, no dialogue between data providers and the registry would facilitate influencing and improving data quality through mutual feedback. Training on the registration of medical data and understanding the necessity and use of population-based disease data (e.g., in basic medical training, residency training, basic nursing and midwifery training) is insufficient, as is training on completing registry notification forms.

### Data quality in the Cause of Death Registry

Both under- and over-registration may happen in cause of death statistics. Under-registration may happen due to the lack of information on the actual cause of death from the data collected in the registry. Over-registration occurs when a past illness is noted on the cause of death notification form, which is later selected as the underlying cause of death. In the case of cancer, over-registration is more likely to happen because cancer is considered important both in completing the cause of death notification form and in selecting the underlying cause of death. To assess data quality, registry data are compared with other sources, e.g. medical records.

### Data quality in the Cancer Screening Registry

The main data quality problem of the Cancer Screening Registry is the receipt of incomplete data from the Health Information System. The test results required for the analysis of result indicators are not received from the health information system in the Cancer Screening registry; in 2017, the test results of 13% of those who underwent breast cancer screening were not received in the registry, and in the case of cervical cancer, as much as 50% of the data. The corresponding analysis of colorectal cancer in 2017 was published in December 2020 [1]. Another problem is the receipt of test results in the registry database as free text – in the description field or as part of the epicrisis. Data analysis in such a way is very labour-intensive and time-consuming, and errors due to different interpretations of data happen easily. Problems with insufficient data collection and data quality have led to the limited use of cancer screening registry data for assessing both cancer screening and health services.

### Lack of clinical data

Estonia lacks the data necessary for assessing the quality of cancer diagnostics and treatment in the form of a central, comprehensive and structured database that would allow for the assessment of the availability and quality of diagnostics and treatment on the basis of the patient's cancer journey and across treatment modalities. The information systems used by healthcare professionals have an inconvenient user interface and do not contribute to improving the organisation of the diagnostics and treatment journey. As a result, there is no overview of the availability, quality and outcomes of treatment that would facilitate better health policy decisions in planning and financing cancer treatment. The lack of a comprehensive and structured database also hinders participation in international research and pan-European cancer databases..

## Goal 1. The continuity of population-based registries and good data quality are ensured

### Activities

- Digitalisation of data submission to the Cancer Registry

A structured digital notification form must be created, which is integrated into the patient history, is user-friendly and has input controls. The notification form should be checked and approved by a healthcare professional before submission, and the Cancer Registry staff can send it back for correction or completion if necessary. The notification remains visible to specialists and healthcare institutions who will deal with the patient in the future. This also improves the completeness and accuracy of data, which in turn reduces the number of queries made by registry staff and helps speed up the routine tasks of the registry and the publication of cancer statistics.

- Reorganisation of the IT solution for data exchange between the Health Information System and the Cancer Screening Registry (data warehouse)

This helps to ensure receipt of more complete and high-quality screening data to the registry and enables, in accordance with the current organisational guidelines, the continuous receiving of information on screening performance indicators in order to draw conclusions about the effectiveness and quality of screening and if necessary, submit proposals for amendments.

- Activities aimed at data providers to improve data documentation, completion of registry notification forms and data submission

Training of doctors/residents, nurses and midwives, additional training, training on completing notification forms, including training for the establishment of cause of death, and more detailed feedback to healthcare institutions/doctors, see also Goal 3. Activities. In cooperation with data providers, it is ensured that the data needed by the cancer screening registry is entered into the Health Information System in a structured manner, implementing automatic quality checks before entry.

- Improvement of the quality of data comparison made according to the statutes of the registries and implementation of additional data comparison to supplement, check and correct registry data

Improvement of data exchange between registries (Cancer Screening Registry, Cancer Registry, Cause of Death Registry) and quality feedback. Additional data comparisons with other databases, such as the Health Insurance Fund database and Health Information System.

## Goal 2. Achieving a better ability to assess the success of cancer control, measure the quality of treatment, conduct research and participate in international projects

### Activities

- Supplementing the data in the Cancer Registry in accordance with international rules and recommendations

In cooperation with specialists and based on international recommendations [310], a new perfected dataset of the population-based Cancer Registry will be developed. The perfected dataset will be introduced together with a digital notification. The new data set will enable more efficient use of Cancer Registry data, a better understanding of shortcomings in cancer control activities and the expansion of international cooperation (via various projects and grants). The new dataset includes more detailed information on the following:

- Cancer stage – both clinical and pathological TNM for solid tumours; corresponding stage classifications for haematological and paediatric tumours (Ann Arbor, Toronto);
- Treatment – the purpose of surgical, systemic, and radiotherapy, radiotherapy method, bone marrow transplantation;
- Pathohistological features – lymph node examination, sentinel lymph node examination, tumour margins, hormone receptors, molecular and cytogenetic markers, etc.

- Collection of additional structured site-based data, which allows for the measurement of the quality of diagnostics and treatment outcomes across different cancer sites, and consequently drawing conclusions for making changes in healthcare organisation.

Based on international experience, the best option for this is to create site-based (including haematological and paediatric malignancies) databases in addition to the population-based Cancer Registry. That has helped to significantly improve the quality of treatment in many countries [185,193].

A pilot project will be initiated for one or more cancer sites in cooperation with professional societies, healthcare institutions and the state. An initiative group across institutions and organisations will be established, which will develop the concept, objectives, cooperation principles and quality assurance methods of data collection on the basis of national and international experience in accordance with data protection and other applicable laws. The terminology and data structure used by healthcare professionals will be agreed upon, and a suitable IT solution will be developed for data collection in healthcare institutions. The aim is to enter cancer data once during daily practice and use the entered, standardised and structured digital data for various purposes: by different healthcare professionals during the patient's treatment journey, by registries, for the planning of finances and research. The collection of digital data integrated into daily work does not increase the workload of healthcare professionals, but rather supports clinical decision-making. Standardised examination results, procedure codes, etc., are an important part of the data. Quality control is also essential during data creation, data entry, and later processing. Routine quality indicators that are regularly monitored will be worked out. An expert council will be selected to ensure the sustainability of data collection. Decisions for the future will be made based on the experience gained during the pilot project.

The introduction of an information system module that takes into account the cancer patient's journey would help to collect data into registries and databases more efficiently. Using modern methods of IT development, user involvement, and service design, an oncology module integrated with the Health Information System and hospital information systems could be developed or purchased, which would also support the use of uniform terminology across Estonia. Collection of optimally standardised and structured data in the information system should be based on the principles that the primary use, i.e. data entry at the workplace, would be intuitive and easy for the user and that the entered digital data would be transferred as automatically as possible to the registries and databases for secondary use (NIHD, EHIF, hospital databases).

- Purposeful cooperation will be established with universities (master's and doctoral students in public health and other disciplines) and health institutions, resulting in greater integration of epidemiological and clinical research

The activities will help increase participation in research, thereby improving the quality of registry data and helping assess the success of cancer control.

**Goal 3. Registry data as well as research results and conclusions based on it reach different target groups more efficiently (population, cancer patients, healthcare professionals, health promoters, policy makers, etc.)**

Activities

- Regular publication of interpreted registry data in a format suitable for different target groups; as detailed as possible feedback to healthcare institutions on the data submitted by them.
- Thoughtful scientific communication – communicating research results/conclusions to various target groups (including the population, cancer patients, family doctors and specialists, other healthcare professionals, policymakers), which, among other things, contributes to evidence-based policy in decision-making and to the efficiency of cancer control measures.

## Recommendations

- The achievement of the goals will be supported by increasing resources directed at collecting cancer data, which in turn increases the benefits obtained from the data.

Registries need additional resources to ensure the availability and training of necessary staff, update the database, and improve the receipt and quality of data, functioning of links, and publication of data and analyses based on them. Healthcare providers also need additional funding to collect data on a uniform basis and integrate IT solutions with other parties.

## RESEARCH

Cancer research helps to understand the causes of cancer and to develop effective measures for its prevention, diagnosis and treatment. Research plays a central role in the creation, implementation and evaluation of the cancer control plan. The rapid implementation of scientific findings and evidence-based best practices is in the interests of cancer patients but also of society as a whole.

Cancer research encompasses a wide range of research, including epidemiological and public health research, basic and applied research, clinical and translational research, and quality of life and health services research. The Cancer Control Plan emphasises the need to create a favourable environment for cancer research in Estonia:

- encouraging interdisciplinary cooperation between universities, other research and development institutions and healthcare institutions;
- creating opportunities in cancer centres and other healthcare institutions for their employees to participate and to use their infrastructure in research, including clinical drug trials;
- encouraging the next generation of researchers;
- accessibility of data and existence of information systems and biobanks;
- a national system for monitoring and supporting research ethics;
- involving patients and their relatives and raising their awareness of research;
- national support for knowledge transfer;
- national orders and targeted funding for priority research topics;
- supporting researchers for being successful in applying for competitive funding.

# Implementation of the Cancer Control Plan

The Cancer Control Plan is a framework that covers the entire spectrum of cancer control, from prevention, diagnosis and treatment to the post-cancer period in a person's life. The implementation of cancer control plans has been most successful in countries where they have a strong mandate and a well-thought-out management structure; implementation of the plan has been consistently evaluated, and recommendations for future improvements have been made. Sufficient financial resources are also the prerequisite for success. This goal is paved by Estonia's National Health Plan 2020–2030 (ENHP), which is approved by the government and for the implementation of which relevant programmes are prepared.[16] The first programmes will be prepared for the state budget strategy period 2021–2024. The financial resources for the Cancer Control Plan will be planned in the same programme.

A key role in the implementation of the Cancer Control Plan belongs to the steering group and the Ministry of Social Affairs, together with the institutions under the Ministry's administrative jurisdiction, which have the authority and decision-making power to implement the activities planned in the Cancer Control Plan, to organise and monitor health services, establish evidence-based guidelines and standards, direct resources, evaluate results and, based on this, reorganise health services. The steering group was formed by a directive of the Minister of Social Affairs and includes representatives of the Estonian Cancer Society, the Estonian Association of Parents of Children with Cancer, the Estonian Society of Oncologists, the Institute of Public Health and Family Medicine and Clinical Medicine of the University of Tartu, representatives of the Estonian Nurses' Union, the State Agency of Medicines, the Estonian Health Insurance Fund, the National Institute of Health Development and the Ministry of Social Affairs. The steering group will be supplemented according to the recommendations of experts. The task of the steering group is to approve the plan, assess the implementation, initiate the updating of the plan if necessary and formulate and introduce Estonia's positions in the field of cancer to international organisations.

A plan will be prepared to implement the Cancer Control Plan, which defines the activities, responsible parties, deadlines and assessment criteria. The general and specific indicators will help in assessing the implementation (see result indicators and process indicators). The achievement of the objectives of the Cancer Control Plan and the effectiveness of the measures will be assessed in 2025 as part of the mid-term evaluation. The first detailed implementation plan with responsible parties will be prepared in the first half of 2021 for the years 2021–2024.

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[16] Programme – According to the State Budget Act, a programme is a development document that determines the measures, indicators, activities and financing plan aimed at achieving the sub-goal of the performance area.

# Result indicators

| Vision | Result indicator | Target | Deadline |
|---|---|---|---|
| **Fewer people get cancer** | Age-standardised cancer incidence | Age-standardised total cancer incidence starts to decrease | 2030 |
| | | Incidence of preventable cancers starts to decrease: | |
| | | cervical cancer | 2022 |
| | | colon and rectal cancer | 2026 |
| **People live longer and healthier after a cancer diagnosis** | Relativecancersurvival | 1, 5 and 10-year survival by cancer sites will improve | continuous |
| | | Survival indicators are at the same level as in the Nordic countries | continuous |
| | | Gender differences in survival are decreasing | continuous |
| **People living with cancer have a better quality of life** | Quality of life | The experience of the cancer journey and the quality of life of patients and their loved ones is improving at various stages[1] | continuous |
| | Satisfaction | | |

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[1] requires the initiation of regular measurement of the quality of life

# Process indicators

| Objective/activity | Process indicator ***(key performance indicator)*** | Target | Timeline |
|---|---|---|---|
| **Objective: Prevention of preventable cancers** | | | |
| Reducing the spread of risk factors | Share of daily smokers among adults in the population | Men: 19%<br>Women: 10% | 2024 |
| | Absolute alcohol consumption per capita per year | < 8 litres | 2030 |
| | Share of overweight and obese adults | < 50% | 2030 |
| | Share of overweight and obese children aged 7–8 | < 25% | 2030 |
| | Share of people among the working-age population who ate an average of more than 300 g of vegetables per day in the last 7 days | ≥ 40% | 2030 |
| | Share of people among the population who ate an average of more than 200 g of fruits/berries per day in the last 7 days | ≥ 65% | 2030 |
| | Reduction in sugars, salt or saturated fats in food groups agreed in the reformulation plan | ≥ 10% | 2030 |
| | Share of adults engaging in moderate-intensity physical activity for half an hour or more four times a week or more | ≥ 15% | 2030 |
| | Share of 11-, 13- and 15-year-old schoolchildren engaging in at least 60 minutes of physical activity every day | ≥ 30% | 2030 |
| | Share of residents exposed to tobacco smoke at home | < 5% | 2030 |
| | Population awareness of food safety risks has increased | 5% | 2030 |
| | Food Safety Chemical Hazard Barometer Indicator | > 100 | 2030 |
| Vaccination | Target group coverage with HPV vaccine | ≥ 70% | 2030 |
| | Target group coverage with HBV vaccine | ≥ 95% | 2030 |
| **Objective: Early diagnosis and treatment of patients of all ages** | | | |
| Effective screening | Participation rate of the target group in population-based screening | ≥ 70% | 2025 |
| | Share of breast cancer cases diagnosed at stages 1 and 2 | ≥ 75% | 2025 |
| | Share of colorectal cancer cases diagnosed at stages 1 and 2 | ≥ 70% | 2025 |

| Objective/activity | Process indicator ***(key performance indicator)*** | Target | Deadline |
|---|---|---|---|
| Early diagnosis and treatment | Share of patients with suspected cancer referred to a cancer centre within 14 days | 90–95% | 2023 |
| | Share of patients with suspected cancer referred to a cancer centre via e-consulting | 90–95% | 2023 |
| | Share of patients with suspected cancer who have passed the necessary examinations to confirm the final diagnosis within 21 days | 90–95% | 2023 |
| | Share of patients whose primary cancer treatment has started within 28 days of the council | 90–95% | 2023 |
| | Share of patients referred to a cancer centre with suspected cancer, whose cancer diagnosis was confirmed | 90–95% | 2023 |
| | Share of cancer centre patients whose waiting time from the arrival at the cancer centre until diagnosis and the beginning of treatment was no more than 49 days | 90–95% | 2023 |
| | Share of cancer centre patients whose time from cancer suspicion to the beginning of primary cancer treatment was no more than 63 days | 90–95% | 2023 |
| | Share of patients whose treatment plan is prepared by a multidisciplinary council | ≥ 95% | 2023 |
| | Radiological examinations to assess the spread of the disease with a referral from a primary cancer specialist are performed and results received within two weeks of the initial visit to the specialist | ≥ 60% | 2023 |
| | | ≥ 75% | 2027 |
| | Share of examinations in case of which the time from registration of surgical or biopsy material in the laboratory to final confirmation of the examination result with a final pathomorphological diagnosis of a malignant tumour is within the prescribed period (biopsy 10 days, surgical materials 20 days) | ≥ 80% | 2021 |
| Early diagnosis of cancer in children and adolescents | Share of children with a genetically confirmed cancer risk who are under active surveillance | ≥ 75% | 2025 |
| | Share of childhood patients who reach an oncologist within 7 days after seeing a doctor first with initial symptoms | ≥ 90% | 2021 |
| **Objective: Ensuring the best possible diagnostics and treatment** | | | |
| Ensuring the quality of diagnosis service in Estonia | Laboratories providing the main pathology histology and cytology services – have a valid accreditation according to the international standard ISO 15189 | 100% | 2025 |
| | Use of SNOMED-CT nomenclature codings in all departments providing pathology services | 100% | 2021 |
| | Responding to histological surgical preparations of malignant tumours with a synoptic or structured response | ≥ 80% | 2021 |
| Assuring the quality of surgical treatment | Share of cancer patients on whom the surgery was performed in nationally recognised cancer centres | ≥ 95% | 2030 |
| Quality assurance of systemic treatment | Share of patients with primary stage 4 whose papalliative systemic treatment has been discussed in a site-based multidisciplinary council | 99% | 2030 |
| | Share of patients whose systemic treatment has been initiated within 14 days of the council | ≥ 90% | 2023 |

| Objective/activity | Process indicator ***(key performance indicator)*** | Target | Deadline |
|---|---|---|---|
| Access to radiotherapy | Share of patients receiving at least one radiotherapy cycle during their treatment journey | ≥ 39% | 2025 |
| | | ≥ 50% | 2030 |
| | Share of patients whose curative radiotherapy treatment has been initiated within 28 days of the council | ≥ 95% | 2022 |
| | Share of patients whose curative radiotherapy treatment has been initiated within 14 days of the council | ≥ 50% | 2025 |
| | | ≥ 75% | 2030 |
| | Share of patients whose palliative radiotherapy treatment has been initiated within 14 days of the council | ≥ 50% | 2025 |
| | Number of accelerators per million inhabitants | 8,4 | 2030 |
| | Share of radiotherapy equipment less than 7 years old | ≥ 58% | 2025 |
| | Share of radiotherapy equipment over 10 years old | < 17% | 2030 |
| Securing access to palliative care | Number of beds in palliative care | 100 | 2030 |
| | Number of hospice beds | 80 | 2025 |
| Securing access to rehabilitation | Share of cancer patients in rehabilitation | ≥ 40% | 2030 |
| | Share of patients returning to work one year after diagnosis | ≥ 60% | 2030 |
| Quality assurance of haematological cancer treatment | Share of patients diagnosed with haematological malignancy at a cancer centre | ≥ 95% | 2025 |
| | Share of patients referred to a haematologist consultation by a family doctor or specialist without a reason | < 5% | 2023 |
| | Number of treatment guidelines harmonised between two cancer centres | 10 | 2024 |
| Ensuring the quality of care for children and adolescents | Share of paediatric patients receiving proton therapy among all patients requiring proton therapy | ≥ 95% | 2025 |
| Ensuring the availability of medicines | The period from the receipt of marketing authorisation for innovative medicines to reimbursement by the Health Insurance Fund either in the list of health services or in the list of subsidised medicines (for medicines for which a request has been submitted) | ≤ EU average | 2025 |

| Objective/activity | Process indicator ***(key performance indicator)*** | Target | Deadline |
|---|---|---|---|
| **Objective: Ensuring quality of life** | | | |
| Life with and after cancer | Share of patients who are secured with a nurse-coordinator's service | ≥ 90% | 2030 |
| | Share of patients for whom a comprehensive treatment plan has been created | ≥ 95% | 2024 |
| | Share of patients who have received a rehabilitation and support treatment plan as part of their treatment plan | ≥ 90% | 2025 |
| | Share of patients for whom a comprehensive assessment card of needs has been prepared, the information of which is digitally available to the social welfare system | ≥ 90% | 2025 |
| | Share of patients who can, if they wish, do tests and pass examinations as close to their place of residence as possible | 100% | 2023 |
| | Share of patients who have been regularly completing satisfaction questionnaires | ≥ 95% | 2024 |
| | Share of patients who have access to an active and feedback-based adverse event reporting system | 100% | 2027 |
| | Share of children and adolescents included in quality-of-life research | ≥ 95% | 2025 |
| | Share of patients diagnosed with childhood cancer who are later under follow-up by a specialist or family doctor | ≥ 95% | 2025 |
| | Labour market participation of working-age patients who have completed cancer treatment | ≥ 80% | 2028 |
| **Objective: better and higher quality data** | | | |
| Ensuring availability and quality of data | Delay in publishing cancer registry data | ≤ 18 months | 2025 |
| | Screening quality indicators published by the Cancer Screening Registry | ≥ 80% | 2022 |
| | Completeness of person-based registration of HPV vaccination data | 100% | 2024 |

# Definitions

| Definition | Explanation |
|---|---|
| **Total alcohol consumption** | Legal alcohol (excluding tourists' purchases and consumption in Estonia), illegal sale and purchase from abroad. |
| **Survival** | The probability of being alive for a certain number of years after diagnosis. The most commonly used indicator is the five-year relative survival rate, which can be interpreted as the percentage of patients who are alive five years after diagnosis. |
| **Primary care** | Outpatient health services to solve a person's most common health problems, provided by a family doctor together with a family nurse and other supporting specialists. |
| **Rare disease** | In the case of malignant tumours, a cancer with an incidence of less than 6 cases per 100,000 people per year is considered a rare disease [311]. |
| **Distant or distantly metastatic cancer** | Cancer that has spread through the bloodstream to other organs. |
| **Prevalence** | An indicator that reflects the occurrence of a risk factor or health condition in a specified population at a specified time or period. |
| **Locally spread cancer** | Cancer that has grown into neighbouring tissues. |
| **Multidisciplinary council** | A cancer site-based council that includes specialists in three treatment modalities and specialists involved in tumour diagnostics. |
| **Multimodal cancer treatment** | Cancer treatment that combines surgical, radiation, and drug treatment. |
| **Programme** | According to the State Budget Act, a programme is a development document that determines measures, metrics, activities, and a financing plan aimed at achieving a sub-goal of a performance area. |
| **Regionally spread cancer** | Cancer that has spread to regional lymph nodes. |
| **Screening** | A study performed on healthy people for the early detection of precancerous conditions or cancer. |
| **Solid tumours** | A distinction is made between solid tumours, which form a tumour mass in solid organs (e.g. lung, breast, intestine), and haematological, or lymphoid and haematopoietic tissue tumours, which occur in the blood and bone marrow. |
| **Stage** | The stages depend on the location of the cancer, but in most cases, stages 1 and 2 by TNM classification are local and small tumours, stage 3 means spread to neighbouring organs or regional lymph nodes; in stage 4, the cancer has spread to other organs (distant metastases). |
| **TNM classification** | The classification of tumour stages compiled by the international cancer organisations American Joint Committee on Cancer (AJCC) and Union for International Cancer Control (UICC): T – tumour size and spread to neighbouring organs; N – spread to regional lymph nodes; M – distant metastases. |
| **Age-standardised** | Standardisation means adjusting to the age composition of the population and eliminates the effect of the age composition of different populations on morbidity (including the effect of population ageing) when comparing different countries or time periods. |
| **Cancer centre** | A medical institution that offers the main treatment methods of multimodal cancer treatment (surgery, radiation and systemic therapy) and palliative care, and, in addition to diagnosis and treatment, is engaged in cancer prevention and early detection of cancer, training of medical personnel, support and education of cancer patients and their loved ones, and cancer research and development work. |
| **Cancer journey** | The cancer journey begins with suspicion of cancer and extends to the post-treatment period. |
| **Cancer control** | Cancer control includes all anti-cancer activities from cancer prevention to returning to normal life after recovery from cancer or to a dignified end of life. According to the WHO definition, a national cancer control plan is a public health programme that aims to reduce the number of cancer cases and deaths and improve the quality of life of cancer patients. |

# Abbreviations

| Abbreviation | Meaning |
|---|---|
| **EU** | European Union |
| **ER** | Emergency Room |
| **ESMO** | European Society of Medical Oncology |
| **ESTRO** | European Society for Radiotherapy and Oncology |
| **HIV** | Human Immunodeficiency Virus |
| **HPV** | Human Papillomavirus |
| **IAEA** | International Atomic Energy Agency |
| **ITK** | East Tallinn Central Hospital |
| **CT** | Computer tomography |
| **LTKH** | West Tallinn Central Hospital |
| **MRI** | Magnetic resonance imaging |
| **PERH** | North Estonia Medical Centre |
| **PET** | Positron emission tomography |
| **PSA** | Prostate-specific antigen |
| **ICF** | International classification of functioning, disability and health |
| **ICD** | International classification of diseases |
| **RTA** | Public Health Development Plan |
| **NIHD** | National Institute of Health Development |
| **TEHIK** | Health and Welfare Information Systems Centre |
| **HIS** | Health Information System |
| **HTA** | Health Technology Assessment |
| **TÜ** | University of Tartu |
| **TÜK** | Tartu University Hospital |
| **US** | Ultrasound |
| **VSR** | Cancer Screening Registry |
| **WHO** | World Health Organisation |

# Working groups

## 1. Description of the clinical situation and organisation of cancer treatment in Estonia:

| Name | Institution | Position |
|---|---|---|
| Vahur Valvere<br>(Head of the working group) | North Estonia Medical Centre | Director of Research and Development, Oncology and Haematology Clinic, Oncologist/Chief Doctor |
| | Estonian Cancer Society | Chairman of the Board |
| Helis Pokker | North Estonia Medical Centre | Head of the Haematology-Oncology Clinic, Oncologist/Chief Doctor |
| Kristiina Ojamaa | East Tallinn Central Hospital | Head of the Oncology Department, Oncologist |
| Mariken Ross | North Estonia Medical Centre | Head of the Haematology Centre of the Haematology-Oncology Clinic, Haematologist/Chief Doctor |
| Margit Valgma | North Estonia Medical Centre | Oncologist/ Chief Doctor at the Radiotherapy Centre of the Oncology and Haematology Clinic |
| Lenne-Triin Kõrgvee | Tartu University Hospital | Acting Director of the Cancer Centre, Doctor-Lecturer |
| Toomas Veidebaum | National Institute of Health Development | Research Director, Principal Researcher |
| Kaire Innos | National Institute of Health Development | Head of the Epidemiology and Biostatistics Department, Senior Researcher |

## 2. Primary prevention:

| Name | Institution | Position |
|---|---|---|
| Kersti Pärna<br>(Head of the working group) | University of Tartu | Associate Professor at the Institute of Family Medicine and Public Health |
| Eha Nurk | National Institute of Health Development | Head of the Nutrition Research Department, Senior Researcher |
| Kadri Suija | University of Tartu | Associate Professor at the Institute of Family Medicine and Public Health |
| | Family Medicine Centre | Family Doctor |
| Rainer Reile | National Institute of Health Development | Researcher at the Epidemiology and Biostatistics Department |
| Eva-Maria Riso | University of Tartu | Researcher in Physical Education at the Institute of Sport Sciences and Physiotherapy |
| Piret Laidre | Tartu University Hospital | Paediatrician at the Centre for Clinical Genetics |
| Ene Indermitte | University of Tartu | Lecturer at the Institute of Family Medicine and Public Health |
| Aive Telling | Estonian Ministry of Social Affairs | Environmental Health and Chemical Safety Manager at the Department of Public Health |
| Sille Pihlak | Estonian Ministry of Social Affairs | Advisor at the Department of Public Health |

## 3. Screenings:

| Name | Institution | Position |
|---|---|---|
| Vahur Hollo<br>(Head of the working group) | National Institute of Health Development | Head of the Cancer Screening Registry |
| Thomas Zimmerer | East Tallinn Central Hospital | Gastroenterologist/Head Doctor at the Internal Medicine Clinic |
| Karin Kull | Tartu University Hospital | Head of the Endoscopy Centre of the Internal Medicine Clinic |
| Made Bambus | Estonian Health Insurance Fund | Chief Specialist of the Department of Primary Care Services |
| Irena Bartels | East Tallinn Central Hospital | Midwife at the Women's Clinic |
| Tanel Laisaar | Tartu University Hospital | Thoracic Surgeon at the Lung Clinic, Senior Doctor-Lecturer |
| Tiina Saks | Family Medicine Centre Sinu Arst | Family Doctor |
| Rein Raudsepp | North Estonia Medical Centre | Radiologist at the Radiology Centre of the Diagnostic Clinic |
| Tiina Kuum | Tartu University Hospital | Radiologist at the Radiology Clinic |
| Theo Raudsepp | Mammograaf AS | Radiologist |
| Mare Meldre | Mammograaf AS | Radiologist |
| Piret Kaarde | North Estonia Medical Centre | Gynaecologist-Senior Doctor at the Women's Disease Centre of the Surgery Clinic |
| Piret Veerus | National Institute of Health Development | Senior Researcher at the Department of Epidemiology and Biostatistics |
| Piret Viiklepp | National Institute of Health Development | Head of the Department of Registries |
| Helen Lepa | National Institute of Health Development | Advisor of Personal Medicine |
| Birgit Saare | National Institute of Health Development | Analyst at the Cancer Screening Registry |
| Kai Kabin | National Institute of Health Development | Senior Analyst at the Cancer Screening Registry |

## 4. Early diagnosis of cancer, diagnostic and treatment pathways until primary treatment:

| Name | Institution | Position |
|---|---|---|
| Jana Jaal<br>(Head of the working group) | University of Tartu | Associate Professor of Oncology |
| | Tartu University Hospital | Head of the Haematology-Oncology Clinic, Oncologist |
| Jarno Raid | Tartu University Hospital | Senior Analyst at the Development Department of IT centre |
| Gerli Kuusk | East Tallinn Central Hospital | Oncologist/Chief Doctor at the Oncology Centre |
| Maire Kuddu | North Estonia Medical Centre | Head of the Radiotherapy Centre of the Oncology and Haematology Clinic, Oncologist/Chief Doctor |
| Malle Avarsoo | Estonian Health Insurance Fund | Chief Specialist at the Department of Specialist Medicine Services |
| Vanda Kristjan | Mähe Familiy Medicine Centre | Family Doctor |

## 5. Pathology and Molecular Diagnostics:

| Name | Institution | Position |
|---|---|---|
| Liis Salumäe<br>(Head of the working group) | Tartu University Hospital | Head of Pathology Service |
| Eero Semjonov | East Tallinn Central Hospital | Pathologist-Consultant at the Pathology Centre |
| | Pärnu Hospital | Pathologist |
| Katrin Lepik | North Estonia Medical Centre | Pathologist/Senior Doctor at the Pathology Centre of the Diagnostic Clinic |
| Anu Planken | North Estonia Medical Centre | Oncologist at the Chemotherapy Centre of the Oncology and Haematology Clinic |
| Tiina Kahre | Tartu University Hospital | Head of the Molecular Diagnostics Laboratory of the Clinical Genetics Centre |
| Kadri Toome | Tartu University Hospital | Laboratory Specialist at the Clinical Genetics Centre |
| Pille Tammur | Tartu University Hospital | Head of the Cytogenetics Laboratory of the Clinical Genetics Centre |

## 6. Diagnostic Imaging:

| Name | Institution | Position |
|---|---|---|
| Äli Roose<br>(Head of the working group) | North Estonia Medical Centre | Head of the Diagnostics Clinic, Chief Radiologist |
| Liina Karusoo | North Estonia Medical Centre | Acting Head of the Nuclear Medicine Department of the Diagnostics Clinic, Chief Radiologist |
| Reet Otsus | North Estonia Medical Centre | Radiologist at the Diagnostics Clinic |
| Kaarel Kärmas | North Estonia Medical Centre | Radiologist at the Radiology Centre of the Diagnostic Clinic |
| Peeter Ross | East Tallinn Central Hospital | Radiologist |
| | TalTech | Professor of e-Health |
| Tõnis Loigom | East Tallinn Central Hospital | Head of the Radiology Centre of the Diagnostic Clinic |
| Anne Poksi | East Tallinn Central Hospital | Head of the Nuclear Medicine Centre |
| Gitana Kiudma | Tartu University Hospital | Radiologist at the Radiology Clinic |
| Triin Alter | Tartu University Hospital | Radiology Resident |
| Pilvi Ilves | Tartu University Hospital | Head of the Radiology Clinic |

## 7. Surgical treatment:

| Name | Institution | Position |
|---|---|---|
| Tiit Suuroja (<br>Head of the working group) | North Estonia Medical Centre | General Surgeon/Senior Doctor at the General and Oncosurgery Centre of the Surgery Clinic Oncologist at the Chemotherapy Centre of the Oncology and Haematology Clinic |
| Jaan Soplepmann | Tartu University Hospital | Senior Doctor-Lecturer at the Surgical Oncology Department of the Haematology-Oncology Clinic |
| Martin Kivi | East Tallinn Central Hospital | Head of the Urology Centre of the Surgery Clinic, Urologist |

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|---|---|---|
| Ingemar Almre | North Estonia Medical Centre | Thoracic Surgeon/Senior Doctor at the Cardio-thoracic Surgery Centre of the Surgery Clinic |
| Piret Kaarde | North Estonia Medical Centre | Gynaecologist/Senior Doctor at the Women's Diseases Centre of the Surgery Clinic |
| Jüri Teras | North Estonia Medical Centre | Head of the General and Oncosurgery Centre of the Surgery Clinic, General Surgeon/Chief Doctor |
| Taavi Põdramägi | Tartu University Hospital | Doctor-Lecturer in General Surgery at the Surgical Oncology Department |
| Priit Veskimäe | Tartu University Hospital | Urologist, Doctor-Lecturer at the Surgery Clinic |
| Lauri Maisvee | North Estonia Medical Centre | Head and Neck Surgeon at the Head and Neck Surgery Centre of the Surgery Clinic, Otorhinolaryngologist/Senior Doctor |
| Mihkel Mettis | East Tallinn Central Hospital | Head of the Centre for General and Oncological Surgery of the Surgery Clinic, General Surgeon |
| Jaak Lehtsaar | Tartu University Hospital | Doctor-Lecturer in Gynaecology at the Surgical Oncology Department of the Haematology-Oncology Clinic |
| Pille Kirjanen | North Estonia Medical Centre | Plastic Surgeon/Senior Doctor at the Orthopaedic Centre of the Surgery Clinic |

## 8. Systemic therapy:

| Name | Institution | Position |
|---|---|---|
| Anneli Elme<br>(Head of the working group) | North Estonia Medical Centre | Head of the Chemotherapy Centre of the Oncology and Haematology Clinic, Oncologist |
| Kristiina Ojamaa | East Tallinn Central Hospital | Head of the Oncology Centre, Oncologist |
| Andrus Mägi | Tartu University Hospital | Doctor-Lecturer at the Haematology-Oncology Clinic |
| Tõnis Metsaots | North Estonia Medical Centre | Oncologist at the Chemotherapy Department of the Oncology and Haematology Clinic |
| Elina Reva | North Estonia Medical Centre | Head of Nursing at the Chemotherapy Centre of the Oncology and Haematology Clinic |

## 9. Radiotherapy:

| Name | Institution | Position |
|---|---|---|
| Margit Valgma<br>(Head of the working group) | North Estonia Medical Centre | Oncologist/Chief Doctor at the Radiotherapy centre of the Oncology and Haematology Clinic |
| Jana Jaal | University of Tartu | Associate Professor of Oncology |
| | Tartu University Hospital | Head of the Haematology-Oncology Clinic, Oncologist |
| Maire Kuddu | North Estonia Medical Centre | Head of the Radiotherapy Centre of the Oncology and Haematology Clinic, Oncologist/Chief Doctor |
| Markus Vardja | Tartu University Hospital | Medical Physicist |
| Eduard Gerškevitš | North Estonia Medical Centre | Medical Physicist |
| Siret Kivistik | Tartu University Hospital | Radiation Therapist, Quality Manager |

## 10. Palliative and end-of-life care:

| Name | Institution | Position |
|---|---|---|
| Pille Sillaste<br>(Head of the working group) | North Estonia Medical Centre | Head of the Palliative Care Centre of the Rehabilitation and Palliative Care Clinic, Chief Doctor |
| Kaire Pakkonen | Pärnu Hospital | Pain Specialist/Anaesthetist |
| Ulvi Ragun | Tartu University Hospital | Internist at the Haematology-Oncology Clinic – supportive care of cancer patients |
| Jelena Leibur | Tallinn Diaconal Hospital | Head, Internist |
| Mari Lõhmus | North Estonia Medical Centre | Head of the Rehabilitation and Palliative Care Clinic, Oncologist |
| Katri Aaslav-Tepandi | North Estonia Medical Centre | Pastoral Counsellor at the Rehabilitation and Palliative Care Clinic |
|  | Estonian Ministry of Social Affairs | Senior Chaplain |
| Anna Vesper | Tallinn Diaconal Hospital | Head of Nursing at the Hospice Department |

## 11. Rehabilitation:

| Name | Institution | Position |
|---|---|---|
| Varje-Riin Tuulik<br>(Head of the working group) | West Tallinn Central Hospital | Head of the Rehabilitation Department |
| Annika Albert-Aksjonov | Tartu University Hospital | Doctor-Lecturer at the Sports Medicine and Rehabilitation Clinic |
| Annelii Jürgenson | North Estonia Medical Centre | Head of the Rehabilitation Centre of the Rehabilitation and Palliative Care Clinic |
| Ly Carlman | Tartu University Hospital | Doctor-Lecturer at the Sports Medicine and Rehabilitation Clinic |
| Meeli Mumma | East Tallinn Central Hospital | Head of the 2nd Rehabilitation Department of the Rehabilitation Clinic |

## 12. Haematology:

| Name | Institution | Position |
|---|---|---|
| Ain Kaare<br>(Head of the working group) | Tartu University Hospital | Head of the Department of Haematology and Bone Marrow Transplantation |
| Liina Karusoo | North Estonia Medical Centre | Acting Head of the Nuclear Medicine Department of the Radiology Centre of the Diagnostic Clinic |
| Kärt Tomberg | North Estonia Medical Centre | Pathologist/Senior Doctor at the Pathology Centre of the Diagnostic Clinic |
| Mariken Ross | North Estonia Medical Centre | Head of the Haematology Centre of the Haematology-Oncology Clinic, Haematologist/ Chief Doctor |
| Kreete Ilves |  | Resident doctor |
| Hele Everaus | Tartu University Hospital | Consultant, Professor Emeritus |

## 13. Paediatric and Adolescent Oncology and Haematology:

| Name | Institution | Position |
|---|---|---|
| Kadri Saks (Head of the working group) | Tallinn Children's Hospital | Head of the Department of Haematology-Oncology of the Paediatric Clinic |
| Kristi Lepik | Tallinn Children's Hospital | Paediatric Haematologist-Oncologist at the Department of Haematology-Oncology of the Paediatric Clinic |
| Sirje Mikkel | Tartu University Hospital | Paediatric Haematologist-Oncologist at the Haematology-Oncology Clinic |
| Maarja Karu | Tallinn Children's Hospital | Resident of Paediatric Haematology-Oncology |
| Kaili Semm | Estonian Association of Parents of Children with Cancer | Chairman of the Board |
| Laine Ütt | Estonian Association of Parents of Children with Cancer | Member of the Board |

## 14. Life with and after cancer

| Name | Institution | Position |
|---|---|---|
| Helis Pokker (Head of the working group) | North Estonia Regional Hospital | Head of the Haematology-Oncology Clinic, Oncologist/Chief Doctor |
| Kadri Putnik | North Estonia Regional Hospital | Oncologist/Senior Doctor at the Oncology and Haematology Clinic's Chemotherapy Centre |
| Mariken Ross | North Estonia Regional Hospital | Head of the Haematology Centre of the Oncology and Haematology Clinic, Haematologist/Chief Doctor |
| Tõnu Jõgi | Tartu University Hospital | Doctor-Lecturer at the Haematology-Oncology Clinic |
| Kadri Suija | University of Tartu | Associate Professor at the Institute of Family Medicine and Public Health |
|  | Family Medicine Centre | Family Doctor |
| Daniel Kotsjuba | Public Sector Innovation Team | Public Service Designer |
| Vanda Kristjan | Karulaugu Health Centre | Family Doctor |
| Siiri Rannama | Saaremaa Cancer Society | Representative of Patients and Their Relatives |

## 15. Health Data and research:

| Name | Institution | Position |
|---|---|---|
| Margit Mägi (Head of the working group) | National Institute of Health Development | Head of the Cancer Registry |
| Eleri Lapp | Estonian Ministry of Social Affairs | Chief Specialist at the Department of Health System Development |
| Katrin Lang | University of Tartu | Associate Professor of Epidemiology at the Chair of Epidemiology and Biostatistics |
| Toomas Veidebaum | National Institute of Health Development | Research Director, Principal Researcher |
| Kaire Innos | National Institute of Health Development | Head of the Epidemiology and Biostatistics Department, Senior Researcher |

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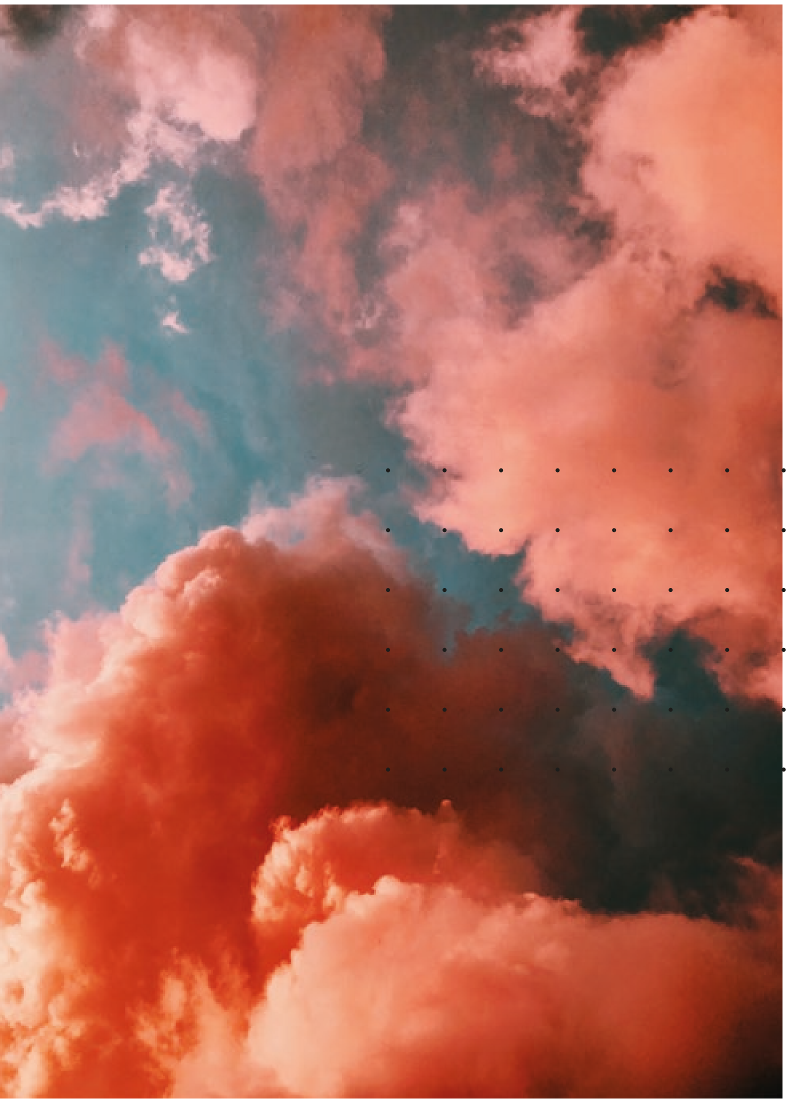
|---|---|---|
| Vahur Hollo | National Institute of Health Development | Head of the Cancer Screening Registry |
| Piret Viiklepp | National Institute of Health Development | Head of the Department of Registries |
| Gleb Denissov | National Institute of Health Development | Head of the Cause of Death Registry |
| Keiu Paapsi | National Institute of Health Development | Researcher at the Department of Epidemiology and Biostatistics |

## 16. Implementation of the Cancer Control Action Plan:

| Name | Institution | Position |
|---|---|---|
| Ulla Raid<br>(Head of the working group) | Estonian Ministry of Social Affairs | Advisor at the Department of Health System Development |
| Vahur Valvere | North Estonia Medical Centre | Head of the Research and Development of Oncology-Haematology, Chief Oncologist |
| Rainer Reile | National Institute of Health Development | Researcher at the Epidemiology and Biostatistics Department |
| Vahur Hollo | National Institute of Health Development | Head of the Cancer Screening Registry |
| Jana Jaal | University of Tartu | Associate Professor of Oncology |
| | Tartu University Hospital | Head of the Haematology-Oncology Clinic, Oncologist |
| Kristiina Ojamaa | East Tallinn Central Hospital | Head of the Oncology Centre, Oncologist |
| Tiina Kahre | Tartu University Hospital | Head of the Molecular Diagnostics Laboratory of the Clinical Genetics Centre |
| Äli Roose | North Estonia Medical Centre | Head of the Diagnostics Clinic, Chief Radiologist |
| Tiit Suuroja | North Estonia Medical Centre | Senior General Surgeon at the General and Oncosurgery Centre of the Surgery Clinic<br>Oncologist at the Chemotherapy Centre of the Oncology and Haematology Clinic |
| Anneli Elme | North Estonia Medical Centre | Head of the Chemotherapy Centre of the Oncology and Haematology Clinic, Oncologist |
| Margit Valgma | North Estonia Medical Centre | Oncologist/Chief Doctor at the Radiotherapy centre of the Oncology and Haematology Clinic |
| Pille Sillaste | North Estonia Medical Centre | Head of the Palliative Care Centre of the Rehabilitation and Palliative Care Clinic, Chief Doctor |
| Varje-Riin Tuulik | West Tallinn Central Hospital | Head of the Rehabilitation Department |
| Ain Kaare | Tartu University Hospital | Head of the Department of Haematology and Bone Marrow Transplantation |
| Kadri Saks | Tallinn Children's Hospital | Head of the Department of Haematology-Oncology of the Paediatric Clinic |
| Helis Pokker | North Estonia Medical Centre | Head of the Haematology-Oncology Clinic, Oncologist/Chief Doctor |
| Kaire Innos | National Institute of Health Development | Head of the Epidemiology and Biostatistics Department, Senior Researcher |
| Kaljo Poldov | Estonian Health Insurance Fund | Manager of the Partner Relations Department |
| Heli Paluste | Estonian Ministry of Social Affairs | Head of the Health Network at the Health System Development Department |

## Coordinating Working Group at the National Institute for Health Development:

| Name | Institution | Position |
|---|---|---|
| Kaire Innos | National Institute of Health Development | Head of the Epidemiology and Biostatistics Department, Senior Researcher |
| Keiu Paapsi | National Institute of Health Development | Researcher at the Epidemiology and Biostatistics Department |
| Maria Suurna | National Institute of Health Development | Project Manager at Cancer Control Plan Project Manager, Senior Analyst of the Department of Epidemiology and Biostatistics |



# Members of the steering group

| Institution or Organisation | Main Member | Substitute Member |
|---|---|---|
| Estonian Ministry of Social Affairs | Maris Jesse<br>(Chairman of the Steering Group) | - |
| Estonian Ministry of Social Affairs | Ulla Raid | Heli Laarmann |
| Estonian Health Insurance Fund | Maivi Parv | Rain Laane |
| Estonian Society of Oncologists | Jüri Teras | Tõnis Metsaots |
| Estonian Association of Parents of Children with Cancer | Kaili Semm (Lellep) | Luive Merilai |
| Estonian Cancer Society | Vahur Valvere | Maie Egipt |
| Estonian Nurses Union | Kristi Rannus | Kaire Jugar |
| Estonia State Agency of Medicines | Mihkel Arrak | - |
| Institute of Clinical Medicine, University of Tartu | Jana Jaal | Marju Kase |
| Institute of Public Health and Family Medicine, University of Tartu | Kadri Suija | Ruth Kalda |
| National Institute of Health Development | Annika Veimer | Kaire Innos |

# Annexes

## Annex 1. Most common cancer sites in Estonia 2018

| Men | | Women | |
|---|---|---|---|
| Cancer site (ICD-10 code) | Number of cases | Cancer site (ICD-code) | Number of cases |
| Prostate (C61) | 1145 | Breast (C50) | 836 |
| Lung (C33–34) | 615 | Colon and rectum  (C18–21) | 497 |
| Colon and rectum (C18–21) | 475 | Lung (C33–34) | 260 |
| Stomach (C16) | 200 | Endometrium (C54) | 212 |
| Kidney (C64–65) | 184 | Pancreas (C25) | 176 |
| Bladder (C67) | 157 | Stomach (C16) | 163 |
| Pancreas(C25) | 156 | Kidney (C64–65) | 146 |
| Lip, oral cavity, oropharynx (C00–14) | 152 | Skin melanoma (C43) | 139 |
| Leukaemia (C91–95) | 110 | Cervix (C53) | 127 |
| Non-Hodgkin lymphoma (C82–85/96) | 102 | Non-Hodgkin lymphoma (C82–85/96) | 125 |
| Liver (C22) | 93 | Ovary(C56) | 122 |
| Skin melanoma (C43) | 84 | Leukaemia (C91–95) | 90 |

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